TRACKING AND ANALYSING TRANSACTIONAL DATA TO SUPPORT THE PROVISION OF MENTAL HEALTHCARE IN COMMUNITY PHARMACIES: AN EVALUATION OF PUBLIC PERSPECTIVES

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Abstract

Background

Mental health conditions, such as depression and anxiety affect a large proportion of the population in England; it has been estimated that one-in-six adults show symptoms of common mental health disorders in any given week. Additionally, the outbreak of COVID-19 in March 2019 and the measures that have been implemented to curb the spread of the disease have negatively affected some individuals' mental health and wellbeing. Therefore, to tackle the ongoing mental health crisis, the development of support mechanisms that are easy to access and embedded in the primary care network, is required.

Community pharmacies are accessible without the need for an appointment and pharmacists are recognised as currently under-utilised, yet highly skilled primary healthcare providers. Thus, community pharmacy presents as an ideal candidate for establishing an alternative source of mental health support within the primary care network. Additionally, preliminary evidence suggests that pharmacy-recorded transactional data, as registered on loyalty cards, can be indicative of underlying health conditions, including mental health issues. Therefore, the tracking and analysing of these data could facilitate the identification of individuals at risk and, in turn, enable pharmacists to offer targeted support. However, currently there is limited evidence pertaining to public attitudes towards mental health support provided in pharmacies and the utilisation of transactional data to identify individuals at risk.

Aim

To evaluate public attitudes towards mental health support provided in community pharmacy using purchasing data as a tool to identify individuals at risk of developing mental health issues.

Methods

This study adopted an explanatory, sequential mixed methods research design, encapsulating two separate research streams. In research stream one, the views of pharmacy users towards mental health support provided in pharmacies were investigated. Research stream two evaluated the views of university students and pharmacy users towards utilising transactional data to identify individuals at risk of developing mental health conditions. Both research streams commenced with the development and subsequent distribution of surveys amongst the population of interest, in order to describe individuals' attitudes quantitatively. The obtained data were subjected to descriptive and inferential statistical analyses performed in Stata (Release 16). The results informed the subsequent qualitative research phases. Semi-structured interviews were conducted with some pharmacy users (n=9) and university students (n=17), to provide an in-depth understanding of individuals' stances towards both topics. The obtained narrative data were analysed thematically, utilising the software NVivo (Version 12) to aid with data management.

Results

Pharmacy users' attitudes towards mental health support provided in pharmacies ranged from scepticism to being moderately supportive in 2019 (n=3449) and 2020 (n=1474), respectively. Individuals who reported higher levels of trust in community pharmacists exhibited more positive attitudes; self-reporting a diagnosis of depression and/or anxiety was found to be predictive of more negative attitudes. Qualitatively, the importance of trust for public acceptance of mental health support provided in pharmacies was reiterated, and factors influencing individuals' stances were identified, such as facilitators, advantages and barriers for pharmacy provided mental health care.

In research stream two, university students as well as pharmacy users exhibited greater support for the utilisation of aggregate-level loyalty card data in health research than utilising these data to identify individuals specifically. Based on the student interviews, a preliminary framework of factors affecting individuals' stances was developed. First, aspects pertaining to the data provider, the prospective data user and the nature of the data itself were found influence students' attitudes. Secondly, university students performed a risk-benefit assessment, and in the instance that the expected benefits outweigh potential risks, students supported the utilisation of loyalty card data for the proposed purpose. Thirdly, greater understanding and trust in the prospective data user acted as facilitators in university students' thought-process. Pharmacy users' acceptance considerations appeared to be influenced by similar aspects.

Conclusions and recommendations

There is public support for establishing community pharmacy as an alternative source for mental health support within the primary care network; especially a role for pharmacists as an information hub and intermediary between pharmacy users and other healthcare professionals was endorsed. However, equipping pharmacists with the necessary toolkit to fulfil this role is crucial, e.g. by offering pharmacy-specific mental health first aid classes, or expanding existing services, such as the new medicines service and the community pharmacy consultation service. Secondly, trust between pharmacy users and pharmacists was found to be fundamental for public acceptance of new services in pharmacies. Therefore, pharmacy-practice research, which evaluates potential trust-enhancing mechanisms, is required; the results should guide future policy. Thirdly, there appears to be public support for the tracking and analysing of transactional data, especially if the benevolence of the approach is emphasised. Likewise, obtaining trust is fundamental for obtaining public acceptability. The importance of trust is widely recognised in the digital health landscape, and the implementation of trust-enhancing measures is a focal point of current policy. Pharmacy practice research and policymaking should draw lessons from these developments, if the tracking and analysing of transactional data in the realm of pharmacy-provided mental healthcare, is sought after.

Publications and conference publications

2021 93rd EGPRN (European general practice research network) meeting (Halle, Germany)

Poster presentation

F. Stoeckel, T. Thornley, M. J. Boyd. C. Anderson

Community pharmacy as an alternative source for mental health support within the primary care network – the views of pharmacy users.

2021 FIP - Pharmacy Practice Research Virtual Summer Meeting (online)

3-minute online presentation

F. Stoeckel, T. Thornley, M. J. Boyd, C. Anderson

Mental health service provision in community pharmacies: disentangling the impact of trust on public acceptability.

2021 PRIMM (Prescribing Research in Medicines Management) Annual Scientific Meeting (online)

Poster presentation (online):

F. Stoeckel, T. Thornley, M. J. Boyd, C. Anderson

Tracking and analysing medicine purchases registered on loyalty card – is that an acceptable use of data? – The views of students.

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2019 HSRUK (Health Research UK) conference (online)

Poster presentation (online):

<u>F. Stoeckel</u>, T. Thornley, C. Anderson, H. Boardman, M. J. Boyd

Community pharmacy customer attitudes towards mental health support from community pharmacies.

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List of Abbreviations

CATI	Computer-assisted telephone interviews
CDEI	Centre for Data Ethics and Innovation
CFIR	Consolidated Criteria for Implementation Research
CMD	Common mental health disorders
DMM	Double monotonicity model
COVID-19	Coronavirus disease 2019, caused by SARS-CoV-2
CP	Community pharmacist
CPCS	Community Pharmacy Consultation Service
CPS	Community pharmacy survey
CTT	Classical test theory
CR	Consultation room
CVD	Cardio-Vascular Disease
ESRC	Economic and Social Research Council
FA	Factor analysis
FIP	International Pharmaceutical Federation

GAD	Generalised Anxiety Disorders
GDP	Gross Domestic Product
GDPR	General Data Protection Regulation
GP	General practitioners
HANDS	Harvard Department of Psychiatry/NDSD scale
H&S	Hub and spoke (pharmacies)
ICD	International classification of disease
IIO	Invariant item ordering
IRT	Item response theory
ISRF	Item step response function
MHFA	Mental health first aid
NHS	National Health Service
NIHR	National Institute for Health research
NMS	New medicine service
OCD	Obsessive-compulsive disorders
OTC	Over-the-counter

PHQ	Patient Health Questionnaire
PTSD	Post-traumatic Stress Disorder
RPS	Royal Pharmaceutical Society
TFA	Theoretical Framework of Acceptance
TRA	Trusted research environment
UK	United Kingdom
US	United States
WHO	World Health Organization
VPC	Variance partition coefficient
YLD	Years lived with disability

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Chapter 1 Background

This chapter aims to provide an overview of the literature which influenced the design of this research project. I performed two structured reviews of the literature and consolidated the retrieved publications in a narrative synthesis. First, the current state of mental health support provided in community pharmacies is outlined (1.2). Second, different types of personal data, such as social media data, lifestyle data and transactional data are probed for their potential to advance health research in general and community pharmacy practice specifically (1.5). Third, I discuss the importance of obtaining public approval for successfully harnessing personal data for research endeavours and to inform policy. Therefore, a literature review that scrutinises public attitudes is provided (1.7).

This research project was conducted amidst the outbreak of COVID-19, hence, relevant developments (e.g. scientific advancements or policy changes) will be introduced.

1.1. The current picture of mental health

The World Health Organization[1] (WHO) defines *mental health* as:

> "[…] a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community."

Conversely, health conditions which cause mental ill health are summarised in the international classification of diseases (ICD, 10th Revision).[2] In the section pertaining to 'Mental health and behavioural disorders' mood disorders, such as depressive disorders are referenced, as well as neurotic, stress-related disorders, such as generalized anxiety disorders (GAD); other indexed mental health conditions include schizophrenia and obsessive-compulsive disorders (OCD). The term *common mental health disorders (CMD)* encompasses mental health conditions with high prevalence in the general population, this includes: depression, GAD, panic-disorder, OCD and post-traumatic stress disorder (PTSD).[3]

1.1.1. Mental health issues: prevalence, disease burden and societal impact

1.1.1.1. Prevalence and disease burden

Globally, almost 1 billion people are affected by mental disorders. Among these, one-quarter of a billion each comprises individuals with depressive disorders and individuals with anxiety disorders.[4] *Years lived with disability* (YLD) is a measure of disease burden; it depicts the number of healthy life years which are lost due to ill-health or disability.[5] Depressive disorders are currently the third leading cause for YLDs when combining both genders, while anxiety disorders are the 8th leading cause for female YLDs and rank 13th for males.[4] Thus, globally, depressive and anxiety disorders are highly prevalent and present a considerable source of disease burden.

The Adult Psychiatric Morbidity Survey[6] underpins estimations of the prevalence of CMD (i.e. Depression, Anxiety, OCD, PTSD) in England; the survey was distributed in 2014. Symptoms of CMD were found to be present in one-in-six adults (15.7%) examined at the time of the study and a one-week prevalence of 6.6% and 3.8% were reported for GAD and depressive disorders, respectively.[7] More than one-third of those with symptoms of CMD reported to have received some kind of mental health treatment (i.e. psychological therapy, medication or both) at the time of the survey, which reflects an increase from the years 2000 (23.1%) and 2007 (24.4%).[8] However, a significant proportion of individuals who showed symptoms of CMD reported not receiving support. Therefore, the authors conclude that a ‘treatment gap’ remains. The survey adopted a robust methodology, and a stratified probability sample of the adult population in England was acquired.[9] Thus, the findings are likely to be representative of the whole population.

Additionally, the outbreak of COVID-19 was found to have affected adults’ mental health and wellbeing in England. For example, individuals’ mental health and wellbeing reportedly deteriorated during periods of national lockdowns (i.e. April 2020 to May 2020 and October 2020 to February 2021) and adults with pre-existing mental health conditions reported higher levels of anxiety and depression compared to individuals without pre-existing mental health problems.[10] Although research concerning the impact of COVID-19 on mental health and wellbeing is still ongoing, it is expected that the pandemic might have long-term effects on individuals' mental health, as elaborated by England's Chief Medical Officer.[11] Therefore, it is plausible that the outbreak of COVID-19 and its aftermath, increase the demand for mental health support in the future.

1.1.1.2. Economic and societal impact

In addition to the individualised burden, mental health conditions carry a significant economic and societal impact. Mental health conditions were the fourth leading cause for sickness absence in the UK in 2020, accounting for 15.9 million absence days. In comparison, 20.1 million absence days due to mental health conditions were registered in 2019.[12] Thus, although the outbreak of COVID-19 may have affected individuals' mental health and wellbeing (see previous section) this did not translate in a higher number of registered absence days. It is plausible that the furlough scheme, as well as working from home, could be responsible for the reduction in registered absence days in 2020. Therefore, due to government policies (i.e. furlough programme and recommendations to work remotely) implemented to reduce the economic effects of the pandemic, the number of absence days pertaining to mental health conditions is likely to have been underestimated. Additionally, it has been estimated that mental health problems costed the UK economy approximately 106 billion Euro in 2015, accounting for 4.1% of the UK's GDP. Of these, 60 billion Euro were direct costs (i.e. health systems and social benefits) while the remaining amount represents indirect costs, such as lower workplace productivity.[13]

1.1.2. Current policies pertaining to mental health

In the previous section, it has been established that a large proportion of the population in England is affected by problems with their mental health and wellbeing, and some societal and economic consequences of mental health conditions have been outlined. As a result of these developments mental health and wellbeing has become a focal point of recent health policy. The Five Year Forward View for Mental Health, a policy paper published in 2016, emphasized three major aspects of England's strategy to tackle the mental health crisis.[14] First, improving access to mental health support, second, pursuing an integration of mental health and physical health care, as both domains are often interwoven but approached independently and third, promoting mental health and wellbeing and developing prevention strategies. The NHS Long Term Plan,[15] England's most recently published, all-encompassing health policy document, reiterates some of these points, such as, the necessity to improve accessibility to mental health services and decrease waiting times for appointments. Finally, in the Topol Review on mental health, digital health technologies were identified as a means to improve mental healthcare delivery.[16]

Thus, current healthcare policy in England places an emphasis on improving public mental health and wellbeing. A multitude of strategies were identified to support this goal and progressively implemented. However, the introduced policy papers were published before the outbreak of COVID-19, which required a sudden shift of health policy globally to be able to cope with the large number of infected individuals. Therefore, the current state of mental health policy in England is likely to be influenced by the pandemic, and a reassessment warranted as soon as the pandemic is under control and its consequences analysed.

1.2. Community pharmacy in England

Across England, 1.6 million people visit a community pharmacy every day[17] and 89% of the population in England lives within 20 minutes of walking distance from a community pharmacy.[18] As opposed to other primary healthcare providers, appointments are typically not required for community pharmacy visits and many operate outside regular working hours ('100-hour-pharmacies').[19] In order to practice pharmacy, the completion of a four-year university programme is required ('*MPharm*') followed by a one year foundation prgramme.[20] Moreover, after graduation and registration as a pharmacist, continuous education and revalidation is mandatory.[21]

Thus, community pharmacists are considered easily accessible and well- trained primary healthcare providers, qualities that could be invaluable for facilitating access to mental health support.

1.3. The role of community pharmacists in England

Community pharmacists’ role expanded considerably over the last decades. Historically, since the introduction of the NHS in 1948, community pharmacists’ role predominately revolved around the dispensing of prescriptions.[22] However, progressively it became apparent that, in order for the community pharmacy profession to withstand the test of time, a transformation of pharmacy practice had to occur.[22] Progressively, community pharmacists’ advisory role was expanded and clinical services were implemented. Some examples that highlight the continuous evolution of community pharmacy services are provided below.

Historically, community pharmacists had always been a source for health advice to the public.[22] Consequently, a role for pharmacists’ in public health was formally established in England in 2005, following the introduction of a new contractual framework.[23] Henceforth, the promotion of healthy lifestyle is an essential service delivered at community pharmacies. Pharmacies are required to participate in up to six public health campaigns per year and pharmacists are encouraged to initiate interventions in areas which are considered a public health concern, such as weight management.[24] A number of community pharmacy-based initiatives, such as smoking cessation and flu vaccinations were found to have positive effects on health outcomes.[25,26] Considering that lifestyle factors, such as alcohol consumption and physical activity are correlated with mental health outcomes, such as depression and anxiety,[27] it is plausible that there are links between pharmacy-based promotion of healthy lifestyles and improving public mental health.

Secondly, the new medicine service (NMS) is an advanced service provided in pharmacies where patients with long-term conditions who receive a new prescription are offered support in order to improve adherence.[28] As a result of improved adherence, the NMS has been found to improve health outcomes as well as to reduce healthcare expenses.[29] Initially, eligibility of patients in NMS was limited to four therapeutic areas (type 2 diabetes, hypertension, asthma and COPD and hypercholesterolemia). However, an extension of the NMS occurred in September 2021; health conditions, such as osteoporosis and Parkinson's disease are now covered. Currently, mental health conditions remain excluded from the NMS,[28] however, according to NHS England, a prospective expansion of the NMS to include mental health conditions is deliberated.[30]

Third, the community pharmacy consultation service (CPCS) is an advanced service, recently introduced in 2020. The CPCS aims to connect patients with minor ailments or individuals' in need of urgent medicine supplies with pharmacists, after referral from NHS 111 or general practice.[31] CPCS-trained pharmacists evaluate patients' medical history and perform clinical examinations, if necessary. Subsequently, pharmacists' signpost or offer advice, recommend suitable OTC-medicines or conduct referrals to primary- or secondary care. An evaluation of the CPCS pilot scheme suggested that almost

50% of referrals from NHS 111 could be resolved in community pharmacy; individuals' with acute pain and cough presented most frequently.[32] The benefits of CPCS for individuals with mental health concerns has not yet been a topic of discussion.

The previous paragraph introduced three community pharmacy-based initiatives, established over the last two decades, with different ties to public mental health. First, indirect effects on public mental health are plausible (i.e. promotion of healthy lifestyles). Second, opportunities to improve patients' adherence are missed (i.e. NMS).[33] Third, new services (i.e. CPCS) could present a promising area for increasing accessibility to mental health support.

1.3.1. Factors affecting uptake of pharmacy provided services

Two comprehensive reviews of literature pertaining to public and patients[34] as well as health professionals (i.e. pharmacists and GPs) views towards community pharmacy provided services[35] identified a multitude of factors that influence utilisation of new services in community pharmacy practice. Firstly, stakeholders' views (i.e. public and patients, as well as GPs) were mostly overshadowed by a lack of awareness of pharmacy provided services and questions concerning their value. Secondly, the perception of hierarchies within the healthcare system emerged as an influential factor. Public and patients considered GPs as superior in terms of training and knowledge as compared to pharmacists. Lastly, both reviews highlighted that uncertainties over pharmacists' role and low levels of trust affect stakeholders views towards pharmacy provided services beyond the dispensing of medicines and the provision of minor ailment advice. The significance of trust for public acceptance and uptake of services provided in pharmacies has been reiterated by Gidman, Ward and McGregor[36], as well as other studies investigating public perspectives on specific services provided in pharmacies, such as smoking cessation[37] or mental health support.[38]

However, public awareness of pharmacy provided services and understanding of pharmacists' role might have been positively influenced by the outbreak of COVID-19 and its consequences on pharmacy practice.[39,40] Community pharmacists remained open for face-to-face contact throughout the pandemic and were actively involved in mass vaccination campaigns and helped implementing new initiatives, such as a scheme to support victims of domestic abuse.[41]

Thus, new services have been implemented successfully in community pharmacy practice in the past, but service uptake appears to be influenced by a multitude of factors, including structural aspects, public awareness and stakeholders' understanding of pharmacists' role. However, public perspectives on community pharmacy might have undergone a shift, prompted by the effects of the COVID-19 pandemic on the healthcare landscape.

Therefore, the fundamental requirements for pharmacy provided mental health support are in place, but a more in-depth evaluation of the current state of pharmacy provided mental health support is warranted, to identify successful approaches as well as any potential pitfalls.

1.4. The current state of community pharmacy provided mental health support

1.4.1. Narrative synthesis

In the previous sections, I outlined two fundamental aspects that influenced this research project. First, the prevalence and societal impact of mental health conditions in England was emphasised. Second, the suitability of community pharmacy to provide additional services, beyond their traditional role as dispensers of medication was highlighted.

Hence, I propose that an involvement of community pharmacists is invaluable for tackling the ongoing mental health crisis and improving access to mental health support. Moreover, providing mental health support could present an opportunity for the pharmacy profession to develop their role beyond the dispensing of medication further and strengthen their position as members of the primary health care team.

To investigate the current state of community pharmacy provided mental health support, beyond medication and treatment-focused approaches, a literature review was conducted. The search methodology is outlined in section 2.3.4. For the purpose of this review I use the term *mental health issues* to summarise depressive- and anxiety disorders, as those are most common and typically treated in primary care;[3] other mental health conditions were excluded, unless stated otherwise.

In total, 45 publications were eligible for inclusion; 41 journal articles, three policy papers and one PhD thesis.

1.4.2. Community pharmacists' role in providing mental health support.

Five publications pertaining to potential roles for pharmacists in the provision of mental health support beyond treatment focused approaches were retrieved; this domain was dominated by literature reviews and policy papers. [42,43,44,45,46]

The International Pharmaceutical Federation (FIP) has proposed several roles for pharmacists in mental healthcare, some related to tasks beyond treatment-focused approaches.[42] First, pharmacists were thought to be in a position to assess the severity of a pharmacy user's mental health issues. Thus, the FIP advocated for pharmacy-provided triage, which could result in referrals to other health care professionals (HCP) or recommendations of OTC-medicines. Second, community pharmacy was identified as an ideal location for promoting public mental health and wellbeing, e.g. through the distribution of leaflets and brochures. Lastly, a role for pharmacists in supporting the detection of individuals at risk of having mental health issues by analysing OTC-medicine requests or implementing screening procedures was proposed. This aspect of pharmacists' role in mental healthcare was reiterated by the Royal Pharmaceutical Society[43](RPS); special emphasis was placed on detecting and offering support to pharmacy users presenting with known risk factors, such as recent diagnoses of long term health conditions. In the advent of the outbreak of COVID-19, the RPS renewed their commitment for pharmacy-provided mental health support.[44] It was suggested that pharmacists could facilitate access to available mental health support, such as GPs or mental health teams, by conducting referrals or signposting pharmacy users. In a review conducted by Rubio-Valera, Chen and O'Reilly[45] the narrative that pharmacists are well-positioned to assess the severity of individuals' mental health conditions and to conduct screenings, is maintained. However, the search methodology in that article was only vaguely addressed, and it remains unclear which type of pharmacy practice (i.e. hospital, community) their review intends to cover; as a result, roles for pharmacists in primary- as well as secondary care are incorporated and occasionally interchanged. A structured literature search performed by Silva, Lima and Ruas[46] unearthed similar roles for pharmacists in mental health care and identified no additional ones. However, their review highlighted the importance of establishing a relationship between pharmacist and pharmacy user, a topic that will be further discussed in section 1.4.4.2.

However, to successfully establish a role for pharmacists in mental healthcare, it is important, that stakeholders, such as pharmacists or members of the public support such developments. Therefore, the forthcoming section synthesises the views of stakeholders, besides policy makers, towards pharmacists' involvement in the provision of mental healthcare.

1.4.3. Stakeholders’ attitudes towards mental health support provided in pharmacies

The views of pharmacists were investigated in the majority of publications (n=13, Table 1-1). In one of these articles, the sample encompassed pharmacists as well as pharmacy support staff.[47] No publication exclusively pertaining to pharmacy support staff or other healthcare professionals, such as GPs or nurses were identified. Other studies (n=7) explored the attitudes of individuals with lived experiences of mental issues.[38,48,49,50,51,52,53] However, only one publication presents the views of the general public.[54]

1.4.3.1. Pharmacists’ attitudes towards mental health conditions and the provision of pharmaceutical services

Thirteen publications examining pharmacists’ attitudes towards mental health conditions and the provision of pharmaceutical services for individuals with mental health conditions were identified. Additionally, some researchers chose to examine relevant factors, such as which barriers, from the perspective of pharmacists, hinder the provision of pharmacy provided mental healthcare. The included studies were conducted in a multitude of countries, including, but not limited to, the US, UK, Malaysia, Belgium and Australia. Most of the studies (n=10) adopted a quantitative methodology (Table 1-1).

1.4.3.1.1. Pharmacists’ attitudes towards mental health conditions

A number of researchers examined pharmacists’ attitudes towards mental health conditions generally, by including questionnaire items that required participants to rate their agreement with statements pertaining to the nature of mental health conditions. To measure this concept consistently, a scale was validated by Scheerder, De Coster and Van Audenhove[55] and subsequently adopted by other researchers (Table 1-1). The developed scale included items such as: ‘anyone can suffer from depression’ or ‘depression is not a real disease’.

Studies that examined pharmacists’ attitudes using the scale developed by Scheerder, De Coster and Van Audenhove[55] (Table 1-1) reported that pharmacists exhibit predominately favourable attitudes towards mental health conditions. However, in some specific instances, pharmacists’ attitudes were less favourable. Exemplarily, 9% of British pharmacists who participated in a survey identified a lack of self-discipline and will-power as one of the main causes for mental health issues.[56] Two quantitative studies included scales to measure the extent to which pharmacists’ exhibit stigmatising views towards individuals with mental health issues.[57,58] Both studies reported low levels of stigma, however pharmacists displayed reluctance to support some statements, such as ‘I would be willing to have a person with mental illness as a baby sitter for children’.

These positive findings might be partly attributable to the introduction of a self-selection bias. Most studies reported pharmacists’ personal experiences with mental health issues (i.e. whether they or any of their family member had been personally affected). The percentage of individuals who reported personal experiences with mental health issues was consistently high; ranging from 23%[59] to 82%.[55]

Table 1-1 Overview of studies investigating pharmacists' attitudes towards mental illness and provision of services for individuals with mental health issues (PC= pharmaceutical care, CP= community pharmacist, CVD= cardiovascular disease, MH=mental health)

	Author, Title	*Country, Methods*	*Scale adapted from [in brackets]; Investigated topic*	*Population*
1	Al-Arifi[59]: Community pharmacists' attitudes towards mental illness and providing pharmaceutical care for mentally ill patients	Saudi Arabia QUAN	(8); Attitudes towards mental illness; Provision of PC, comparison to CVD; Barriers; Facilitators	CP in 9 private community pharmacies, who are allowed to dispense psychotropic meds
2	Giannetti, Caley et al[57]: Community pharmacists and mental illness: a survey of service provision, stigma, attitudes and beliefs	US QUAN	(11); Attitudes, beliefs, stigma towards mental illness; Provision of pharmacy services	Random sample of CP in the US (n=3,008)
3	Hagmair, Amering, Kaiser et al[60]: Counselling customers with psychotropic vs. cardiovascular prescriptions: A survey among Austrian community pharmacists	Austria QUAN	(8); Counselling activities mental health conditions vs. CVD; Privacy; Stigma; Adequacy of education	CP in Austria
4	Knox, Hattingh and Wheeler[47]: Community pharmacy staff motivations and barriers to working with mental health consumers	Australia QUAN	Attitudes; Knowledge and skills; Motivations and barriers	Pharmacists and support staff who self-selected in a mental health training programme
5	Liekens, Smits, Laekeman et al[61]: Pharmaceutical care for people with depression: Belgian pharmacists' attitudes and perceived barriers	Belgium QUAN	(10); Attitudes and current practice in depression care, comparison to other physical illnesses	CP working for a specific chain of pharmacies in Belgium
6	Morral and Morral[56]: A survey of community pharmacists' attitudes towards mental illness	UK (England, Wales) QUAN	(8); Pharmacists' attitudes towards PC for individuals' with mental illness; Provision of PC, comparison to CVD	Random sample of CPs in England and Wales, n=1000 pharmacies

7	Murphy, Phelan, Haslam et al[62]: Community pharmacists' experiences in mental illness and addictions care: A qualitative study	Canada QUAL	Exploratory study, CPs experiences in mental healthcare	Convenience sample of CPs (n=6) in Canada
8	Phokeo, Sproule and Raman-Wilms[63]: Community Pharmacists' Attitudes Toward and Professional Interactions With Users of Psychiatric Medication	Canada QUAN	Attitudes; Counselling activities and comfort; Provision of PC, comparison to CVD	Random sample of CPs in Canada, n=800
9	Rickles, Dube, McCarter et al[64]: Relationship between attitudes toward mental illness and provision of pharmacy services	US QUAN	Attitudes; Service provision (willingness, factors influencing service provision), comparison to Asthma	Random sample of community pharmacies in the north-eastern US (n=750)
10	Scheerder, De Coster and Van Audenhove[65]: Pharmacists' Role in Depression Care: A survey of Attitudes, Current Practices, and Barriers	Belgium QUAN	(8); Attitudes; Current practice, comparison to physical health conditions; Barriers	Random sample of CPs in Belgium (Bruges) (n=200)
11	Scheerder, De Coster and Van Audenhove[55]: Community pharmacists' attitude toward depression: A pilot study	Belgium QUAN	Attitudes towards depression	Random sample of CPs in Belgium (Bruges) (n=200)
12	Soliman[58]: Pharmaceutical Care in Depression: A survey of Stigma, Confidence, Attitudes, and Barriers	Egypt QUAN	(10); Attitudes towards PC for individuals with depression; barriers; Requirements; Stigma	Pharmacists in Egypt (not exclusively CP)
13	Wong, Khan, Wong et al[66]: Perception of Community Pharmacists in Malaysia About Mental Healthcare and Barriers to Providing Care Services to Patients with Mental Disorders	Malaysia QUAN	Attitudes; Knowledge of mental disorders; Provision of PC; Barriers	Random sample of CPs in Malaysia (n=300)

1.4.3.1.2. Attitudes towards the provision of pharmaceutical care for individuals with mental health conditions

Secondly, the work of Phokeo, Sproule and Raman-Wilms[63] and Scheerder, De Coster and Van Audenhove[65] spearheaded investigations of pharmacists' attitudes towards the provision of pharmaceutical care for individuals with mental health issues (or depression), and the extent to which these services are provided in practice.

Investigated elements of pharmaceutical care encompassed, amongst others, sustaining a trusting relationship, providing advice, condition monitoring and symptom detection. To increase the significance of the obtained findings, most researchers adopted a comparative approach. That is, pharmacists' attitudes and practice behaviour were investigated for both, mental health conditions and physical health conditions and differences tested for their statistical significance. Generally, pharmacists exhibited positive attitudes towards the provision of pharmaceutical services for individuals with mental health issues. Exemplarily, pharmacists in the US demonstrated high levels of willingness and interest to be involved in the provision of pharmaceutical services for individuals' with mental health issues.[57] Likewise, Liekens, Smits et al[61] reported that nine-in-ten pharmacists in their study (n=149), acknowledged that they should provide support and listen to individuals with mental health issues, and 75% agreed that maintaining a trusting relationship should be part of their role in mental healthcare. However, these findings were frequently contradicted by pharmacists' practice behaviour. Practice scores were universally lower than the scores pharmacists obtained on the attitude scales. As an example, less than two-thirds of pharmacists in the study conducted by Liekens, Smits et al[61] indicated that they actively provide support and listen to individuals with mental health issues, and only 16% reported to maintain a trusting relationship with individuals with mental health issues. Comparisons to pharmacists' practice behaviour with regards to physical health conditions further emphasise the magnitude of the issue, as 38% of pharmacists reported to maintain a trusting relationship with individuals with CVD. Likewise, significant differences were reported in the extent to which British pharmacists provided pharmaceutical care to individuals with CVD and mental health conditions.[56] However, the authors of this study speculate that their findings could be partly influenced by the exclusion of mental health conditions from advanced services, such as the NMS (1.3).

1.4.3.1.3. Barriers to mental health service provision

Barriers to mental health service provision by community pharmacists were explored using a multitude of methods, including closed-and open-ended questions, and focus groups and interviews (Table 1-1).

Quantitatively, irrespective of pharmacists' country of origin, similar barriers were consistently ranked high. Out of all barriers reported, most prevalently mentioned was a paucity of training and skills (e.g. in dealing with mental health issues) as well as a perceived lack of education in mental health, as considerable obstacles towards stronger pharmaceutical involvement in mental healthcare. Other reported barriers included time constraints, as well as the lack of privacy encountered in the pharmacy environment. However, it needs to be highlighted that response-options were pre-conceptualised, and relevant barriers could have been missed.[47,58,59,61,65,66] Consequently, a thematic analysis of open-ended questions included in a survey of Australian pharmacists and support staff members expanded the quantitative findings.[47] Participants in this study also indicated that a paucity of resources and professional incentives impede involvement as well as stigmatising attitudes held by pharmacy staff. It is important to highlight that participants were surveyed after they self-enrolled in a programme to aid the development and evaluation of a mental health training programme; thus, the results might be influenced by self-selection bias. Lastly, Canadian pharmacists who participated in a qualitative study highlighted that a lack of clarity concerning the role they are expected to fulfil may act as a potential barrier for the delivery of mental health services. Participants feared to act outside of their professional remit if clear guidelines were missing before the implementation of services. Additionally, the paucity of patient-specific information available to pharmacists, such as an individuals' medical history was considered to be a significant barrier. This cohort consisted of a small convenience sample of six Canadian pharmacists; thus, these findings might not be representative of the views of other pharmacists in Canada.[62]

1.4.3.1.4. Facilitators

Two studies explored facilitators for pharmacy-provided mental health support, as well as pharmacists' motivations for working with individuals with mental health issues.[47,59] Pharmacists in Saudi Arabia stated that participation in training and continuing education programmes may increase their confidence to provide pharmaceutical care for individuals with mental health issues. Moreover, stronger interdisciplinary collaborations across healthcare professions were identified as a crucial factor for pharmaceutical involvement and a strong facilitator for delivering these services.[59] Additionally, altruistic motives, such as the aspiration to improve individuals' quality of life and make a difference to one's community dominated the views of pharmacy staff members in Australia.[47]

1.4.3.2. Patients' and pharmacy users' attitudes towards mental health services provided in pharmacies

Seven publications evaluating the views of patients (i.e. mental health patients or their carers) were identified; whereas the public perspective was addressed in one study.[54] As opposed to studies investigating the perspectives of pharmacists, researchers predominately decided to investigate patients' perceptions qualitatively.[38,48,49,50,52] A cross-sectional survey was distributed in one study,[53] and Knox, Kelly et al[51] conducted computer-assisted telephone interviews (CATI) with 210 mental health patients or their carers. The retrieved studies were predominately conducted in Australia (n=2, resulting in five publications).[38,48,49,50,51] The remaining two studies were conducted in Canada.[52,53]

1.4.3.2.1. Patients' expectations and experiences of community pharmacy services

Both qualitatively,[48,52] and quantitatively[53] participants expressed high expectations of community pharmacy in the realm of mental healthcare. Due to participants' status as patients (i.e. individuals with a confirmed diagnosis of a mental health condition), many expectations revolved around medication-related needs, such as the provision of information about their medicine. However, expectations that are more general were also endorsed. Exemplarily, all participants (n=68, 100%) in a survey of Canadian mental health patients emphasised that they expected community pharmacists to show respect, and 41% of participants desired suggestions on how they could improve their mental health. At the same time, participants' responses indicated that their expectations were not always met satisfactorily. Only 22% of participants in the above mentioned study had received recommendations on how to improve their mental health from pharmacists.[53] However, the small sample size as well as a low number of participants above the age of 65 are important limitations of this study that could affect the reported findings adversely. Australian mental health patients and carers who participated in CATIs (n=210) after visiting a community pharmacy, predominately reported that their expectations were met (84%) and 93% rated their experience positively. Those individuals (n=12) who indicated to be dissatisfied attributed this to experiences with stigmatisation and changing staff. Although all participants in this study had experienced a mental health condition that required medical attention, not all pharmacy visits were related to individuals' mental health condition. Thus, it remains unclear to which extent satisfaction or dissatisfaction was linked to aspects related to mental health.[51]

1.4.3.2.2. Privacy and confidentiality

In several studies, privacy and confidentiality were reported as important factors, which affect patients' perception of pharmacy-provided mental health care.[49,51,52]

Oftentimes, the community pharmacy environment was found to be not conducive to individuals wish for privacy, as conversations can be easily overheard, which presents a significant challenge for the disclosure of mental health related information. Moreover, the practice of calling out names was criticised by participants in two studies.[49,52] In order to overcome privacy-related issues, a more frequent use of consultation rooms was suggested. Contrarily, patients who participated in CATIs predominately suggested that their privacy was maintained during their interaction with pharmacy staff members (84%), only 12 participants reported to be dissatisfied.[51]

1.4.3.2.3. Mental health stigma

Further, several studies reported findings that indicate that mental health stigma could affect patients' perception of pharmacy-provided mental healthcare. Importantly, as part of their considerations patients referred to both, the impact of public stigma (i.e. stigmatisation they had experienced from pharmacists and support staff members) as well as self-stigma (i.e. internalised reaction to stigma).[50,52,53]

Black, Murphy and Gardner[53] found that one-in-five of their participants had experienced some form of mental health stigma from a community pharmacist. Likewise, Canadian individuals with lived experiences of mental health conditions reported to have occasionally felt stigmatised by pharmacy staff members.[52] Self-stigma was reported to prevent individuals from accessing pharmacy services in two qualitative studies. Participants acknowledged that their own hesitation may prevent them from requesting support from pharmacy staff members.[50,52] Conversely, patients suggested that stigma may be mediated through established, positive relationships with pharmacy staff members. Focus group participants indicated that approachable, knowledgeable and compassionate staff members appear less stigmatising; as a consequence, educational initiatives to improve pharmacy staff expertise in mental health care were welcomed.[50]

1.4.3.2.4. Relationships with pharmacy staff and the establishment of trust

Participants in two studies emphasised rapport and relationships between pharmacists and patient as important for the establishment of trust.[38,52] However, two aspects were found to adversely affect the establishment of a relationship between pharmacists and patients. Firstly, pharmacy support staff members were perceived as a barrier to accessing the pharmacist and the advice of support staff appeared to be generally valued less. As a result, individuals decided to visit a different pharmacy if their first encounter with frontline staff did not meet their expectations, thereby removing opportunities for pharmacists to establish a relationship with a patient.[38,52] Secondly, pharmacists themselves were found to miss opportunities for establishing relationships with patients. Knox, Kelly et al[51] reported that 60% of participants (n=126) in their CATI-study were not queried about possible medicine or health-related problems when they collected their medicines. In 47 instances participants spoke to their pharmacist during medicine collection; however, most of these conversations were initiated by mental health consumers (n=28).

1.4.3.2.5. Pharmacy users' views towards mental health support provided in pharmacies

Only one publication addressing the views of the public emerged from the literature review; Hall, Kelly et al[54] aimed to quantify pharmacy users attitudes towards mental health promotion in pharmacies. 537 pharmacy users completed the survey, of those; a vast majority (86.4%) considered community pharmacy a suitable environment for the promotion of mental health and wellbeing. Importantly, a significant association between support for pharmacy-based mental health promotion and lived experiences with mental health issues was found; individuals with personal experiences were more likely to be supportive. However, fewer participants reported to have witnessed mental health promotion in pharmacies (n=125). Survey participants identified regular contact and relationships with pharmacy staff as facilitators, while the privacy-lacking pharmacy environment was suggested to be an important barrier by two-thirds of pharmacy users. More individuals who reported personal experiences with mental health issues participated in the survey, compared to the Australian population; thus, the result's generalisability could be limited.

1.4.3.3. Community pharmacy-based programmes for individuals with mental health issues

Sixteen publications pertaining to pharmacy-based programmes to support individuals with mental health issues were identified in the literature review. For example, the possibility to provide depression screenings in pharmacies was trialled in a several studies, as well as the implementation of a programme which aimed to promote men's mental health in pharmacies.

1.4.3.3.1. Headstrong

Headstrong is a community pharmacy-based programme focusing on men's mental health. It was implemented in 23 pharmacies in Canada in 2017 and aimed to offer support for men who struggle with their mental health and wellbeing, e.g. through the provision of literature or linking men who require support to community care. Pharmacists received training before the programme commenced.

In order to evaluate men's acceptability of the programme, a qualitative pilot study was conducted with five men.[67] Using the theoretical framework of acceptance (TFA), a number of elements that affected individuals' attitudes were identified. The TFA can be understood as a theoretical framework, which can be applied to theorise the extent to which individuals who are involved in the development, delivery or reception of a healthcare intervention consider the proposed intervention appropriate (or ‘acceptable’). These considerations are rooted in individuals’ responses to the intervention and constructed using the seven TFA- components (e.g. ethicality, perceived effectiveness).[68] With regards to Headstrong, pre-existing positive relationships with pharmacists were found to influence men’s willingness to participate positively and alleviate self-stigma, which was identified as a barrier to participation. However, the number of participating men was low, and all were diagnosed with a mental health condition, which limits the applicability of the findings to the population the programme served, i.e. the male population in general. Likewise, pharmacists’ (n=9) acceptability of the programme, after implementation, was investigated using the TFA.[69] The majority of interviewed pharmacists perceived the programme positively and training opportunities and mental health-related resources were a welcomed addition to their practice. However, pharmacists also reported that the programme’s uptake by men was lower than they had anticipated and they recognised time constraints as a considerable barrier for a widespread implementation of the programme. In some instances, the gendered nature of headstrong was found to collide with pharmacists’ professional values. In addition to low participation rates, most interviewed pharmacists identified as former students of the lead researcher, which may have introduced a bias. Lastly, headstrong was evaluated using a simulated patient experiment.[70] Unfortunately, only a small number of pharmacists agreed to participate (n=6/23) and the results of the experiment were ambiguous; on average, pharmacists' received moderate to low practice-scores (mean: 5.7, maximum: 13 points), but the simulated patients felt cared for and appreciated pharmacists' eagerness to help.

1.4.3.3.2. More than meds

'More than meds' is a Canadian community pharmacy-based programme, involving both, pharmacists and individuals with lived experiences of mental illness. 'More than meds' aimed to enhance pharmacy provided mental healthcare, through the development of partnerships between pharmacists and individuals with lived experiences of mental health issues.[71] The development and implementation of 'More than meds' was informed by theoretical considerations, the consolidated framework for implementation research (CFIR) and the behaviour change wheel were applied to inform the intervention components and to determine potential implementation barriers and enablers.[72] Again using a simulated patient experiment, the performance of pharmacists who were trained as part of 'More than meds' (i.e. intervention) was tested against untrained pharmacists (i.e. controls). On the telephone, a patient discussed having had sleeping problems for a prolonged period of time (as sleeping problems are known to co-occur with mental health issues).[73] Telephonic conversations conducted by intervention-pharmacists lasted significantly longer than those of the control cohort. Intervention pharmacists demonstrated more empathy, were perceived to be more confident and promoted non-medical resources, such as yoga or support groups, more frequently as compared to controls. However, case and controls were unmatched, thus, other influencing factors, such as pharmacy store size or prescription volume could not be accounted for. Additionally, interviews were conducted with community pharmacists (n=6) and community members (n=4) who participated in the More than Meds programme, to evaluate their experiences during participation.[74] Both stakeholders emphasised the value of the programme for establishing new relationships and intensifying existing linkages within their respective communities.

1.4.3.3.3. Depression screening in community pharmacies

In addition to the above mentioned standalone mental health programmes, 8 publications pertaining to depression screenings conducted in community pharmacies were identified. The publications comprise seven empirical research studies, conducted in the US (n=5), Australia (n=1) and Thailand (n=1) and one systematic review. Depression screenings were conducted using a multitude of screening instruments, which are validated for administration by non-specialists (e.g. PHQ-9[75] and HANDS[76]). One study also investigated pharmacy users' and health professionals' views towards pharmacy provided depression screenings.[77] Most researchers aimed to target community pharmacy users in general with the offered screenings, that is, pharmacy users were not pre-selected but randomly approached upon entering a community pharmacy.[78,79,80] On the other hand, O'Reilly, Wong and Chen[81] chose a more directed approach. In their study, pharmacy users who requested a mental health related OTC-medicine, such as sleeping aids, or appeared to be in distress, were offered to participate in a depression screening.

In a pilot study conducted in the US[78] researchers choose to utilise the 20 item ZUNG self-rating scale, a depression scale which can be self-administered.Every individual who visited a university campus pharmacy which served as the study site, was eligible to participate in the screening and verbally invited to complete the scale by the researchers. Intersted pharmacy users self-completed the questionnaire after agreeing to participate in the study. Two individuals were identified to be at risk of having depressive disorder; one had a (score>50) and the other had a score close to the cut off. Both were referred to a psychotherapist. Despite a 5-week study period, participation was low (n=25). The lack of involvement of pharmacists in the screening process might have attributed to low participation-rates. Likewise, only 18 individuals participated in a one-day screening service offered by four community pharmacies in the US, despite stark marketing efforts.[79] However, out of all participants (n=18), four individuals with symptoms of major depressive disorder were identified; one of which indicated suicidal tendencies and was immediately referred to emergency services. In this study, the 10-item Harvard Department of Psychiatry/National Depression Screening Day Scale (HANDS) was used; every pharmacy user was eligible for participation. Participants were followed-up after the intervention and all, but one reported to have followed pharmacists' recommendations.

A different approach was taken by Rosser, Frede, Conrad et al[82]. Embedded in a regular health screening pharmacy users in the US (n=3,726) were asked to complete the two-item patient health questionnaire (PHQ-2). Subsequently, those who screened positively (n=67) were then administered the nine-item version (PHQ-9). 17 individuals were found to have an elevated PHQ-9 score (>10); all of which were referred to their physicians. Five individuals with suicidal thoughts were identified and referred to urgent treatment. However, most participants were employees of one company who participated in the healthcare screening to lower the premium of their health benefits. Thus, concerns over company involvement might have driven individuals' response behaviour.

The feasibility of implementing depression screenings in pharmacy practice was further trialled by researchers in Australia.[81] Here, pharmacy users who presented with signs of mental distress, such as sudden changes in appearance, or requested OTC-products which may be indicative of any underlying mental health conditions, such as sleeping aids, were actively approached by pharmacists and depression screening was offered. Three screening tools were available to pharmacists, the PHQ-9, WHO-5 and the Beyondblue checklist. Pharmacists received training and an introduction to the screening tools. During the screening, pharmacists were able to choose the tool they considered most applicable, felt most comfortable with, or use more than one. Over the course of the eight-week study period pharmacists performed 41 depression screenings; of those, 29 resulted in a referral. Unfortunately, the number of positive screens has not been reported. However, the high number of referrals indicates that the more targeted approach of the intervention led to a higher success rate compared to previously introduced interventions.

The effectiveness of three different administration modes of a single screening tool was compared in a study conceptualised by Ballou, Chapman et al[80]. Irrespective of the mode of administration, the PHQ-9 was utilised and 50 screenings were conducted in each cohort. First, during the preparation of prescription bags, 50 screening questionnaires were added at random; instructions on questionnaire completion were included (‘bag stuffer method’). Only one individual returned the completed questionnaire. Second, individuals who collected medication were invited to participate in the screening (‘personal ask method’); pharmacists handed interested individuals the questionnaire but did not administer it. Fifty individuals were invited, of those, 36 completed the questionnaire. Lastly, pharmacists actively administered the questionnaire (‘interview method’); 40 individuals completed the questionnaire. In total, 18 participants were referred to other health professionals for further evaluation. However, taken into consideration both, the screening success rate and time spent, the researchers concluded, that the personal ask method may be best suited for successful implementation in a pharmacy context.

Several studies investigated pharmacy users’ satisfaction with pharmacy provided depression screenings.[78,79,80] Throughout, participants reported high levels of satisfaction, and attributed high value to the approach. However, qualitatively, pharmacy users (n=12) shared more diverging views.[77] Exemplarily, concerns over a lack of privacy in the pharmacy environment to perform depression screenings were raised. Moreover, participants felt that screenings should appear non-targeted, and they should be offered to all pharmacy users, to avoid the stigma of mental health conditions. Furthermore, participants highlighted the necessity to have a well-established personal relationship with a pharmacist, to be accepting of depression screening services.

Likewise, interviews with pharmacists who provided depression screenings identified a number of barriers that may impede the large-scale implementation of the approach.[81] Time constraints encountered in practice were found to be problematic, and a lack of public awareness concerning pharmacists' extended roles was believed to hinder the uptake of screening services. However, promotional activities, such as displaying mental health-related resources or involvement of pharmacies in awareness campaigns were thought to facilitate public acceptance.

1.4.3.3.4. Others

The community pharmacy mood intervention study (CHEMIST) constituted of an NIHR funded study which aimed to evaluate the effectiveness of enhanced support provided in community pharmacies to individuals with sub-threshold depression, in order to prevent progression to major depressive disorder.[83,84] The study commenced in January 2017 and was expected to end in December 2019. According to the study protocol, the intervention was intended to be delivered by pharmacy support staff in a number of community pharmacies in England. Unfortunately, presently no results have been reported.

A pilot study conducted in a community pharmacy in the United States trialled the provision of mindfulness meditation in a pharmacy setting.[85] Depression severity and anxiety levels were assessed at baseline and after the intervention, using the PHQ-9 and a questionnaire to determine anxiety levels (GAD-7), respectively. Twelve individuals attended a minimum of five weekly sessions; participants' PHQ-9 scores decreased significantly (p=0.005) as well as GAD-7 scores (p=0.003). However, the one-time intervention was expensive ($1840), to cover the cost for the meditation facilitator, which may prevent the widespread implementation of the approach.

1.4.4. Conclusion and research rationale

As a result of my review of the current state of mental health support provided in pharmacies, I conclude the following:

First, there is a lack of knowledge concerning the attitudes of the general public towards mental health support provided in pharmacies, especially in the context of pharmacy practice in England. Investigating the public perspective is important, as many of the prospective roles for pharmacists in mental healthcare focus on individuals who are not currently diagnosed with a mental health condition, such as initial screenings, the provision of advice or signposting to other health professionals. Thus, the factors influencing members of the public to approach community pharmacy for mental health support requires an in-depth exploration.

Two research objectives were developed:

1. *To evaluate community pharmacy users' attitudes towards mental health support provided in community pharmacies in England.*
2. *To explore requirements, barriers and facilitators for pharmacy users' acceptance of community pharmacy provided mental health support in England.*

Second, the identification of individuals at risk of developing mental health issues was recognised as a potential role for pharmacists by professional bodies nationally and globally. For that purpose, conducting depression screenings appears to be a promising approach. However, persisting barriers currently impede a widespread adoption of the approach. Therefore, an exploration of novel approaches that might support pharmacists to fulfil this role adequately is warranted. I attempt to examine alternative approaches to identify individuals at risk of developing mental health issues in the following sections.

1.5. Exploring alternative methods to identify individuals at risk of having mental health issues

The previous section demonstrated that depression screenings provided in community pharmacies are feasible, and generally accepted by pharmacy users. However, untargeted screening approaches suffered from low success rates, and pharmacists emphasised that time constraints interfere with their desire to provide such services. These aspects may rationalise why screenings have been rarely implemented in pharmacy practice. However, at the beginning of my PhD, I was confronted with alternative methods that may be used for the identification of individuals at risk of having mental health issues in community pharmacy practice. Researchers at the University of Nottingham were analysing transactional data, as recorded on loyalty cards, in order to identify patterns that may be indicative of underlying health conditions, including mental health conditions.[1] Thus, the following section provides an introduction to personal data and its utilisation in contemporary health research.

1.5.1. Personal data as a tool to identify individuals at risk

Personal data is defined in the General Data Protection Regulation (GDPR) as any information that relate to an identified or identifiable natural person. Data which permits the identification of individuals include location data, social media (SM) data or customer numbers (e.g. recorded on loyalty cards).[86]

Health research is increasingly turning towards using types of personal data, such as SM data, location data or lifestyle data (e.g. recorded using wearables, such as smartwatches) as substitutes or extensions to traditional data sources (e.g. surveys, activity diaries). The number of promising data sources is growing steadily, as is the body of literature

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[1] Notably, the N/Lab a University of Nottingham-based Data science lab, http://www.nlab.org.uk/

examining the potential value of these. For example, literature reviews summarising research utilising Twitter data,[87] data recorded on smartphones (e.g. accelerometer data, location data),[88] or smartwatches[89] to obtain health information and make inferences about public or individual health are available. Although these data types may be valuable in the wider context of health research, their suitability for use in pharmacy practice is more limited. Instead, I focused on a data source that registers pharmacy-specific data and allows inferences about the state of a pharmacy user's health; these sought-after characteristics may be provided by pharmacy-recorded purchasing data.

1.5.1.1. Loyalty cards

In the United Kingdom the majority of large retailers, including grocery store retailers, such as Tesco[90] or Sainsbury's[91] as well as Health and Beauty retailers, such as Boots UK[92] or Holland & Barrett[93] provide loyalty schemes for their customers. In essence, customers who subscribe to a loyalty card scheme permit a registration of their purchases, in exchange for receiving a benefit, such as money off. In terms of engagement with loyalty cards, a non-representative poll conducted in 2017 reported that 77% of adults in Great Britain subscribe to at least one loyalty card provider. Females reported to be more likely (85%) to subscribe to loyalty card schemes, compared to their male counterparts (70%).[94] Boots reports a customer base of approximately 10.2 million Advantage card users,[95] no authorised information about the customer base of Tesco's, Sainsbury's or Holland and Barrett's loyalty programmes could be retrieved.

Although empirical research on the number of individuals subscribing to loyalty programmes is scarce, the available data indicate that the purchasing habits of a considerable proportion of the adult population in the UK is recorded. Thus, loyalty card data may be a valuable source of information which enables the tracking of individuals' purchasing habits on a large scale.

1.5.1.2. Loyalty cards in health research

As highlighted in the previous paragraph, loyalty schemes are provided by a multitude of retailers, therefore, purchases of different categories of items are recorded, such as grocery items or OTC- medicines.

Thus, information stored on loyalty cards exhibits similarities with data traditionally collected for health research purposes, such as diet diaries or surveys about OTC-medicine purchases. Consequently, several scholars recognised the relevance of transactional data, which resulted in the conceptualisation of empirical research studies to examine its value. Nevalainen, Erkkola, Saarijarvi et al[96] argued that loyalty cards are currently underutilised in health research, as they provide unique insights into users' diets and require fewer resources than conventional data collection methods, such as surveys. However, their investigation of a sample of loyalty card users in Finland (n=14,595) identified important limitations, such as an uneven gender distribution and difficulties to allocate the recorded items to specific household members.

Likewise, loyalty schemes registering purchases of OTC-medicines have received considerable recognition from researchers. Davies, Green and Singleton[97] investigated OTC-medicine purchases across England, resulting in inferences about health-related behaviour in certain areas. Moreover, there is preliminary evidence that purchases of OTC-medication could mask symptoms of conditions as severe as cancer.[98,99] Extrapolation of factors which correlate with the purchase of anti-anxiety medication constitutes another growing field of inquiry. Dzogang, Goulding, Lightman et al[100] demonstrated that the expression of anxiety on Twitter and the purchase of anxiety-related OTC medication, are subjected to similar seasonal fluctuations. Ljevar, Goulding and Smith[101] reported a negative correlation between purchases of anti-anxiety medication and level of deprivation (the index of multiple deprivation underpinned the study), i.e. areas with lower levels of deprivation were found to be more likely to purchase greater amounts of anti-anxiety medications. Finally, grounded in a large-scale analysis of purchasing data from a health and beauty retailer (n= 12,968) Lavelle-Hill[102] proposes a number of predictors of purchases of anti-anxiety medication. Positive predictors of such purchases were: female gender and frequent shopping (at least once a week). On the other hand, residing in Northern Ireland and the North East of England were identified as negative predictors of purchases of anti-anxiety medicines, as well as being more present-focused (i.e. affirmative response to the question: ‘I would rather have £25 now than £75 in 3 months.’).

The previous paragraph aimed to highlight that loyalty cards capture rich information that can be exploited for health research. Consequently, the obtained results carry significance for several policy-relevant topics. For example, regional differences in purchases of sunblock[97] may attribute to different rates of skin cancer prospectively; thus, these findings could inform a targeted allocation of resources for preventative and diagnostic efforts. Likewise, better knowledge of early symptoms of conditions such as cancer[99] could support the development of awareness campaigns and encourage earlier diagnosis. Similarly, the preliminary insights obtained from the study conducted by Lavelle-Hill[102] indicate that certain demographic characteristics and socio-economic variables correlate with purchases of medicines, which are available to relieve stress and to mitigate sleeping difficulties. In turn, this knowledge could be a starting point for the implementation of screening approaches or the provision of information to a targeted audience. Moreover, a study mirroring the methodology adopted by Brewer, Hirst et al[98], that is, investigating the purchasing behaviours of individuals with a diagnosis of depression or anxiety retrospectively, may uncover shopping patterns which are unique for this cohort.

Thus, from a data-science perspective, loyalty card data has been recognised as a data source with great value for health research, and its potential to inform healthcare delivery and health policy has been unearthed. However, the singularity of the viewpoint from which loyalty card data has been examined to date constitutes a major limitation. In other words, current approaches exclusively focus on the outcome (i.e. *what* can we infer from loyalty card data), thereby neglecting the question of *how* and under *which* circumstances information derived from these data can be used in the context of healthcare, and specifically community pharmacy practice. Specifically, if researchers continue their attempt to utilise transactional data to retrieve information about the card user's health, careful consideration of public acceptability of such approaches is required. In the past, public disapproval of novel approaches to exploit personal and health-related data had detrimental effects on such schemes, as can be seen from the example of the care.data programme (for further discussion see section: 1.4.2.2)

Thus, members of the public constitute to be an important stakeholder if transactional data is to be added to the repertoire of data health researchers capitalise on. However, before delving into public attitudes towards the utilisation of personal data in a health context, a number of factors require consideration. First, I commence by briefly outlining the rise of digital health technologies as well as current policy pertaining to digital and data-driven approaches in health. Second, I highlight how the outbreak of COVID-19 has attributed to an accelerated distribution of digital health and data-driven technologies in healthcare. By introducing these aspects, I attempt to determine the contextual factors that may have influenced public attitudes towards the utilisation of personal data in a health research context. Lastly, contemporary literature pertaining to public attitudes towards using personal data, such as social media data, transactional data and location data in a health research context will be summarised.

1.6. The rise of digital health technologies and data-driven approaches

The previous section aimed to demonstrate that the tracking and analysing of personal data, including transactional data has the potential to augment and enrich current health research practices. The use of digital information to improve healthcare systems as well as individual and population health constitutes a facet of *digital health*, a field which arose on the grounds of the technological developments over the last decades. Digital health further encompasses aspects of remote healthcare delivery (*telehealth*).[103,104] Worldwide, technological developments digitalise society and each year growing amounts of data are generated. For example, it has been estimated that 2 zettabyte of data (1 zettabyte $= 10^{21}$) were produced globally in 2010, this increased to 79 zettabyte in 2021 and it is expected that in 2025, 181 zettabyte of data will be generated annually.[105]

Inevitably, a proportion of these data will be health-related, either directly (e.g. electronic health records (EHR)) or indirectly, e.g. through the collection of personal data, such as social media data or transactional data. Consequently, considerations pertaining to digital health and data-driven approaches are increasingly found in health policy documents.

1.6.1. Digital health in UK policy documents

The NHS Five Year Forward View lined out the strategy for the healthcare system over the next five years.[106] The strategy emphasised several focal points, including an emphasis on disease prevention and improving public health as well as the ability for individuals to exercise control over their own health. Amongst others, the “exploitation of the information revolution” was identified as a means to achieve the anticipated goals. Thus, the 5 Year Forward View promoted the development of NHS accredited apps, introduction of systems to request appointments and prescriptions online and establishment of a database which culminates hospital, care and administrative data. The majority of these objectives were met when its successor, the NHS Long Term Plan, was launched.[15] Shaped by the technological advancements over the last five years, the Long Term Plan placed an even greater emphasis on digital health and data-driven technologies. A central objective of the strategy documents was the provision of a “digital first” option by 2023/24. That is, individuals would be given the opportunity to access a healthcare professional virtually if desired. Moreover, the Long Term Plan set out the aim to progressively embed novel types of data, such as information collected by individuals themselves, in health records. Similarly, the Topol Review, published in February 2019, emphasised the profound effects the ongoing digitisation would have on the healthcare landscape and the delivery of healthcare.[107] In principle, the review aimed to evaluate the educational needs and skills required from the workforce in a digital healthcare environment. However, in addition to reviewing educational requirements, several principles that should underpin the digitisation of the NHS were outlined. Most importantly, it was emphasised that patients should be understood as partners in the process of digitisation and that, whenever possible, health technologies should allow health professionals to spend more time with their patients.

1.6.2. The state of digital health prior to COVID-19

The NHS Long Term Plan emphasised digital health and data-driven technologies as focal points that were foreseen to change the healthcare landscape permanently. However, this process was expected to be gradual; the plan was intended to inform health policy over the next decade.

1.6.2.1. Telehealth

At the time of publication of the Long Term Plan, less than one quarter of the English population was reportedly registered with NHS online services,[107] and the vast majority of appointments with health professionals occurred in person. For example, between January 2019 and June 2019 approximately 152,890,000 appointments occurred in general practices in England. Of these, four-in-five appointments were conducted in person, less than one-quarter via telephone, and less than 1% occurred virtually.[108] At the same time, 63% of the public reported to be willing to engage with a general practitioner virtually for advice concerning minor ailments, but fewer were inclined to accept video consultations for an ongoing medical problem. Importantly, more than one-quarter of those aged 65 or older opposed virtual appointments.[109] Additionally, HCP, such as GPs, appeared to be hesitant to adopt digital technologies in their practice.[110]

1.6.2.2. Data-driven approaches

Likewise, the NHS 5 Year Forward View and the NHS Long Term Plan emphasised the value of medical and personal data for healthcare delivery and highlighted opportunities to utilise the collected data for patient care. However, efforts to capitalise on existing data had occurred previously. Notably, in 2013 *care.data* was introduced by NHS England, a data sharing programme which aimed to link data from different healthcare providers, in order to improve healthcare delivery as well as support research.[111] However, the programme sparked public outrage across a number of mediums, such as newspapers, blogs and on social media platforms. Predominately, the perceived lack of transparency of the programme was criticised and concerns over its conceptualisation emerged, as individuals were required to actively choose to not participate (‘*opt-out*’), instead of providing consent to the use of their data (‘*opt-in*’).[112,113] As a consequence of failing to foster public trust,[114] the roll-out of care.data ceased in 2016. Additionally, several scandals concerning the misuse of personal data surfaced in subsequent years. For example, the utilisation of personal data for political purposes was widely discussed (i.e. Cambridge Analytica[2]).

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[2] Cambridge Analytica (a UK based consulting firm) was found to utilise social media data without user consent in order to target political advertisement, the scandal was first reported by newspapers, see:

Thus, prior to the outbreak of COVID-19, the significance of digital health technologies for the future of healthcare delivery had been recognised, and their implementation in the NHS had commenced. However, the uptake of digital technologies by HCP and patients was still in its infancy, but was expected to increase substantially over the course of the next decade. Public support was understood to be essential for the success of data-driven approaches, but due to publicly discussed data scandals it is plausible that the public grew to be more sensitive to the potential pitfalls of large-scale data collections throughout the outlined timeframe.

1.6.3. A changing context: the outbreak of COVID-19 and its impact on the healthcare landscape

As a consequence of the outbreak of COVID-19 and its declaration as a pandemic, a multitude of measures were implemented to slow the spread of the disease and prevent healthcare systems from being overwhelmed. Amongst others, these measures included instructions to practice social distancing and a stay-at-home order.

1.6.3.1. Digital health

Thus, virtual appointments with health professionals constituted a viable alternative to face-to-face consultations for non-urgent matters, such as

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115. Cadwalladr C, Graham-Harrison E. Revealed: 50 million Facebook profiles harvested for Cambridge Analytica in major data breach. *The Guardian* [online]. 17th March 2018. [Accessed 07th August 2021]; Available from: https://www.theguardian.com/news/2018/mar/17/cambridge-analytica-facebook-influence-us-election.

116. Confessore N. Cambridge Analytica and Facebook: The Scandal and the Fallout So Far. *The New York Times* [online]. 04th April 2018. [Accessed 08th August 2021]; Available from: https://www.nytimes.com/2018/04/04/us/politics/cambridge-analytica-scandal-fallout.html.

annual reviews or minor ailment advice, as physical contact between individuals is avoided. For example, it has been estimated that 125,120,000 appointments occurred in general practices in England between April and September 2020. Of these, less than 50% were conducted in person in April, June, and July 2020; the proportion of face-to-face appointments increased marginally in August 2020 (52%) and September 2020 (57%), as some COVID-19-related measures were temporarily eased. Simultaneously, more than 45% of appointments were facilitated telephonically over the same period, but the adoption of virtual approaches (i.e. online, video) did not increase significantly (less than 1% of appointments were conducted virtually between April and September 2020);[117] and adoption rates remained low in 2021.[118] However, other digital health technologies were taken up more rapidly. In June 2021 the NHS app reached 6 million users, which translated into 600,000 electronically requested prescriptions and 50,000 virtually booked appointments.[119] Moreover, only one month later, 10.2 million users were recorded, thereby requesting 1.2 million prescriptions and booking 100,000 appointments online.[120] Similarly, data provided by the NHS Business Services Authority indicates that the number of electronic prescriptions increased significantly at the start of the COVID-19 pandemic in March 2020; compared to February 2020, 22% more items were dispensed following an electronic prescription.[121]

1.6.3.2. Data-driven approaches

Prior to the outbreak of COVID-19 in 2020, data-driven approaches had been predominately recognised as an opportunity to improve healthcare delivery (e.g. by embedding information recorded through wearable technology into individuals' health records) or support research (e.g. by creating databases linking care data from a multitude of providers). However, the outbreak of COVID-19 incited a profound transformation of the scope of large-scale data collections. Originally understood as passively collected data, which are analysed retrospectively to improve healthcare delivery in the future, large-scale data collections metamorphosed into a means to obtain real-time information about disease spread and symptoms, as well as to track exposure patterns. Two examples shall elucidate the transformative power of these developments for society and healthcare.

Firstly, a phone application was developed by NHS test and trace, which tracked Bluetooth signals in order to trace chains of infection and issue exposure notifications to users who had been in close contact to an individual who tested positive for COVID-19. After receiving an exposure notification, users were expected to self-isolate for a certain number of days.[122] However, the development and implementation, of the test and trace system was overshadowed by a number of controversies pertaining to data security and user confidentiality. Most prevalently, differences between centralised (i.e. users' data are uploaded on a remote server) and decentralised (i.e. data remain on individuals' phones) models were discussed, as well as the implications of both methods for data privacy and confidentiality.[123] Eventually, the app was made available by NHS test and trace on 24 September 2020. Initially, its uptake by the public remained low, as measures to control the spread of the disease, such as the closure of venues were still imposed. However, concurrently to the gradual opening of society, app downloads and venue check-in increased. This process coincided with a raising number of individuals who tested positive for COVID-19 in June and July 2021; thus, exposure notifications with instructions to self-isolate were sent to large proportions of the population;[124] the coinage ‘pingdemic’ was born. App downloads and usage decreased drastically.[124] In the wake of the emergence of digital contact tracing to curb the spread of COVID-19, empirical research was conducted to understand public attitudes towards these methods. It has been suggested that supporting the ‘greater good’ acted as a facilitator for individuals to participate in digital contact tracing, whereas concerns over privacy and confidentiality where cited as reasons for disengagement with the NHS test and trace app.[125,126]

Secondly, real-time information about COVID-19 related disease patterns and the number of individuals who tested positively was obtained by developing phone applications that allowed individuals to self-record symptoms and document test results. A prominent example is the COVID-19 symptom study app (‘ZOE COVID Study’), developed by a health science company in conjunction with King’s College London.[127] Amongst others, the data provided by app users was then used to identify symptom clusters associated to COVID-19,[128] and to characterise ‘Long-COVID’,[129] a condition that emerged as a possible consequence of an infection with SARS-CoV-2. Thus, members of the public actively contributed information to large-scale data collections, which enhanced researchers understanding of a novel disease at almost real-time. The results were easily accessible and comprehensible, which may have increased public awareness of the value of personal data for health research. NHS test and trace and the COVID-19 symptom study app are only two examples of many examples of personal data utilisation during the COVID-19 crisis in England. Additionally, personal data was used to alleviate the impact of lockdowns, aid recovery and identify health priorities, as demonstrated by the examples compiled by the Centre for Data Ethics and Innovation and published in a comprehensive repository.[130]

1.6.4. The impact of COVID-19 on policy

The examples in the previous section highlighted the profound impact the outbreak of COVID-19 had on the landscape of digital health in England. Eventually, these developments permeated into health policy, as illustrated by ‘Data saves lives: reshaping health and social care with data’, a policy paper published by the Department of Health and Social Care[131]. Instead of outlining the anticipated impact of digital technologies on healthcare, the paper contains detailed suggestions pertaining to the implementation of digital- and data-driven technologies in the NHS. That is, ‘Data saves lives’ places an emphasis on fostering public trust, enabling transparency and facilitating understanding to obtain and maintain public support for the collection and utilisation of personal data in a health research context.

Thus, the outbreak of COVID-19 had a substantial impact on the digital health landscape, which permeated into policy. It is plausible, that these developments influenced public attitudes towards the utilisation of personal data in a health context, which has far-reaching implications for this thesis.

1.7. Public attitudes towards using personal data for health research

1.7.1. Introduction

The previous section aimed to illustrate the landscape of digital health technologies and data-driven approaches prior to the outbreak of COVID-19, and to outline the evolution the field has been subjected to. I chose to outline these aspects in detail, as it is plausible that the changing circumstances had a profound effect on individuals' awareness of data-driven approaches in a health research context, and the potential to influence their attitudes.

This is important, as the objective of the following literature review was to evaluate individuals' attitudes towards the utilisation of personal data, such as social media data, location data, data collected on wearables and transactional data in health research. An initial literature search concerning public attitudes towards the utilisation of transactional data for health research purposes yielded few results; thus, it was decided to extend the search and examine public attitudes towards other types of personal data, which had recently been evaluated for their value in a health research context (section 1.3).

1.7.2. Narrative synthesis

The search methodology, which was developed in conjunction with a librarian, is outlined in method section 2.3.5. Twenty-two publications that met the scope of the literature review were identified and included in this narrative synthesis. Of these, four publications were reports published by independent research organisations, sometimes on behalf of government-funded institutions, such as the Economic and Social Research Council (ESRC);[132] one study reviewed the existing literature.[133] The majority of the publications investigated the views of the general public, however some studies evaluated the perspective of more specific population groups, such as patients in the emergency department of a hospital or young adults. To account for the low number of publications, studies investigating those samples were included in the review. Publications examining the views of individuals with mental health issues were also included. Most publications (n=8) pertained to public attitudes towards social media (or specific types of social media, such as Twitter), fewer studies were found to be concerned with public attitudes towards the utilisation of location data, data collected on wearables and transactional data (Figure 1-1).

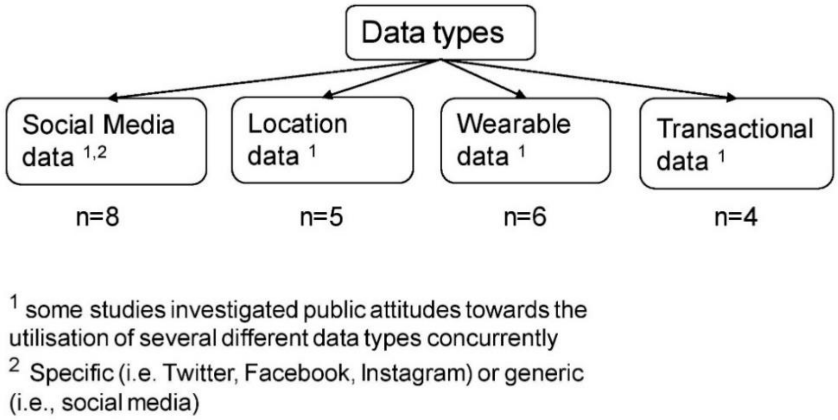

Figure 1-1 Overview of included studies

1.7.3. Social media data

The literature search retrieved eight publications pertaining to the utilisation of social media data for health research. Predominately, the views of the public were investigated (n=5). In few instances, the opinion of specific population samples, such as Twitter users[134] or young adults with mental health issues[135] were the topic of inquiry.

1.7.3.1. Use of social media and awareness of third party access

Typically, researchers commenced with an investigation of participants' use of social media. In general, high engagement rates were reported. Exemplarily, Ford, Curlewis, Wongkoblap et al[136] who sampled a cohort of social media users using a web-based survey distributed through mental health chaity websites and social media, found that 85% of their participants used Facebook, and 63% reported to have a Twitter account. All participants in a study conducted by Golder, Scantlebury and Christmas[137] reported to use some form of social media.

Individuals' awareness of the secondary use of social media data was evaluated in several instances. In a survey of 1,250 British adults (aged 16-75) participants displayed low awareness of the fact that their SM data can be accessed by third parties.[138] On the other hand, the majority of Twitter users in a qualitative study was aware that their data is publicly available and privacy was not expected, because Twitter is a free service. However, participants commonly endorsed the belief that their data is ephemeral and they occurred to underestimate the reach of their tweets.[134] Similarly, in a qualitative study conducted with members of the public, most participants reported to be unaware of their chosen privacy settings, and had little knowledge of the accessibility and utilisation of their data by third-parties.[137]

1.7.3.2. Attitudes towards the use of social media for health research

All studies investigated individuals' attitudes towards a potential utilisation of social media data for research; views were found to differ greatly and ranged from opposition to conditional acceptance. The large variety of views might be partly attributable to the various study designs adopted by researchers and the multitude of investigated population groups. Exemplary, 60% of adults in the UK reported to oppose the use of social media data for research purposes,[138] and patients who were approached in the emergency department of a hospital reported low willingness to donate their social media data (e.g. less than 40% were willing to share Facebook data, and less than 20% were willing to share Twitter data).[139] Opposition in this cohort was particularly prevalent in comparison to more apparent health-related data, such as electronic medical records and prescription history (e.g., more than 50% of participants were willing to share prescription history). However, participants in this survey were under the impression that the data sharing would occur subsequently to questionnaire completion, which might have affected acceptance rates. On the other hand, 60% of participants (n=183) in an online survey conducted in the UK with users of social media aged 16 years or older, supported the use of software to identify individuals at risk of having mental health issues based on Facebook postings, but fewer (n=69, 44%) stated that they would consent to their own Facebook data being used.[136] However, this survey was predominately distributed using mental health charity websites, and a majority of participants stated to have had mental health issues in the past, which might have influenced their responses.

The literature indicates that participants in qualitative research studies demonstrate greater acceptance. Exemplarily, Mikal, Hurst and Conway[134] reported that Twitter users in their study (n=26) were generally accepting of the use of their data for research purposes. Similarly, the majority of participants in a study conducted by Golder, Scantlebury and Christmas[137] (n=47) amongst members of the public in England, endorsed the use of social media data for research purposes. However, four individuals reported to be *completely against* the approach [italics in the original]. Two aspects could have attributed to the finding that individuals appear to express more positive views in qualitative research studies. Firstly, a self-selection bias could have been introduced. That is, individuals who held stronger views were more likely to participate. Second, the study design could have influenced individuals’ opinion. Both studies conducted focus groups with some[137] or all[134] of their participants. Consequently, the group discussions might have convinced some participants to alter their opinion, or individuals who held more positive views expressed those more vocally. Finally, members of the British public who participated in a qualitative research study conducted by Beninger, Fry, Jago et al[140] appeared to fall in one of three distinct categories with regards to their attitudes towards researchers using social media: Individuals who reported to be accepting, sceptical and ambiguous. However, no information about the magnitude of each category is provided.

1.7.3.3. Factors affecting acceptance

Several studies aimed to explore the factors that influenced individuals’ stances. Typically, in-depth understanding of a phenomenon is best achieved using qualitative methods, thus, influencing factors predominately emerged from the studies conducted by Mikal, Hurst and Conway[134], Beninger, Fry et al[140] and Golder, Scantlebury and Christmas[137] as well as in workshops which succeeded a large-scale survey in a study of British adults’ attitudes towards researchers using social media.[138] The reviewed literature indicates that three main categories of factors influence individuals’ opinion. First, most scholars reported that participants’ attitudes were susceptible to the research context. That is, individuals placed importance on who is conducting the research and the involvement of commercial entities was not appreciated. Similarly, researchers' affiliation was found to be an important aspect that influenced participants' thought-process as well as considerations pertaining to the types of data being collected. Participants were adamant to emphasise that the purpose for which the research would be conducted influenced their acceptance; altruistic motives were generally endorsed.

Secondly, the public and voluntary nature of social media was found to attribute to individuals' considerations. Participants recognised social media users as responsible for amending their privacy settings, to prevent the use of their data for research purposes. Thus, the use of voluntarily and publicly distributed data was often accepted. Finally, individuals who displayed ambiguity towards researchers using social media occurred to be disillusioned about their ability to oppose a possible utilisation. It was expected that the use of their data was inevitable, thus, some participants were neither apprehensive nor approving of researchers using social media.

1.7.3.4. Concerns and benefits

Lastly, irrespective of the study design, concerns and anticipated benefits emerging from utilisation of social media data in health research were a topic of investigation. Both categories were either independently raised by participants in qualitative research studies,[133,134,135,138,140] investigated by adding open-ended response questions to questionnaires[136] or addressed quantitatively.[139]

In terms of concerns, three aspects dominated individuals' considerations. First, individuals raised concerns about the accuracy and validity of the information obtained from social media sources and the quality of the data. In some instances traditional types of data collection were juxtaposed with social media research; in comparison, participants challenged the legitimacy of the latter.[140] Practices that occur on social media platforms, such as creating unreliable profiles, exaggerating views or commenting impulsively were found to be detrimental to data accuracy.[133,134,140] Moreover, social media users were thought to be non-representative of the general population, which may limit the validity of the information and biases the obtained results.[140] Second, participants concerns pertained to the data providers (i.e. social media users). That is, individuals expected negative consequences for individuals' privacy and confidentiality, and some were concerned over an undesired secondary use of the data. Exemplarily, 72% of participants in a survey (n=206) among visitors of an emergency department in the US reported to be concerned that information might be used for purposes beyond those stated in terms and condition policies.[139] Concerns over user privacy and an undesired secondary use of the data occurred to be influenced by the context in which the data were collected, as publicly discussed data leaks and scandals, such as Cambridge Analytica were found to shape participants responses in some instances.[136] Privacy concerns were particularly prevalent when the identification of individuals specifically was thought-after.[134] The identification of health conditions based on social media data was suspected to enable discrimination, and affect insurance plans negatively.[136] Lastly, three studies explicitly investigated the attitudes of individuals with mental health issues towards the use of social media in the context of mental healthcare.[134,135,136] Here, participants raised concerns specific to the area of mental health, such as the possibility for stigmatisation to occur. Young adults who had experienced mental health issues commented on the perceived lack of support mechanisms to aid individuals with mental health conditions.[135]

On the other hand, a number of potential benefits were highlighted in all studies. Most importantly, the use of the data to support the *greater good* was desired, that is, improve population and individual health. The use of social media in health research was expected to facilitate access to health services, and could be used to reach out to individuals who would otherwise be disregarded.[136]

Although quantitatively fewer benefits were mentioned, the argument to support 'the greater good' by permitting the utilisation of one's social media data occurred to be a convincing argument for research participants in most studies. Consequently, the benefits were expected to outweigh the anticipated risks, as illustrated by a research participant in a study conducted by Mikal, Hurst and Conway[134]:

> "It's like fluoride in the water to me. They put fluoride in our water. We don't really have a choice if we want to drink water, we're going to get fluoride. But the benefits outweigh the risk."

However, this opinion was not vocalised in all studies. Members of the public who participated in a study investigating attitudes towards analysing Facebook data to identify signs of depression indicated that they did not consider the benefits to society and to individuals to outweigh their risk to privacy.[136] However, views might have been influenced by the Cambridge Analytica Scandal which surfaced at the time the survey was distributed.

1.7.4. Wearables

Six studies investigating individuals' attitudes towards the utilisation of data collected on wearables were retrieved from the literature search. This included two publications mentioned in the previous section, as those addressed several types of data concurrently.[135,139] In terms of methodology, scholars chose to adopt both, qualitative and quantitative approaches. Surveys were distributed in three instances,[139,141,142] and three qualitative studies exploring individuals' views were identified.[135,143,144] The interview study conducted by Lehto and Lehto[144] occurred to be of substandard quality, as no information about participant recruitment, topic guide development and data analysis was provided.

1.7.4.1. Use of wearables

A number of studies investigated the uptake of wearable devices in their sample. Hyde, Omura et al[142] reported that 21.7% of adults in the US are currently using a wearable device. The study sample (n=1,020) was obtained through address-based probability sampling and weighted to mirror the demographic characteristics of the population in the US, which suggests that the obtained data are representative of the general population. Similarly, 18% of the participants of a web-based survey distributed at a University in the US to understand willingness to share health-related data collected through apps and wearable devices, reported to use a specific brand of fitness trackers ('Fitbit').[141] However, this cohort encompassed mostly staff and students of a university in the US and other types of fitness trackers were not included in the multiple-choice question. A qualitative study conducted by Lehto and Lehto[144] exclusively encompassed individuals using wearable devices. Other publications did not investigate or disclose the proportion of individuals who tracked certain lifestyle data using a wearable device.

1.7.4.2. Willingness to share data

Generally, study participants were moderately supportive of the use of wearables in a research context. For example, two-in-five participants of a survey distributed in the emergency department of a hospital in the US (n=206) reported to be willing to share data collected on wearables; wearable data ranked between social media data and more explicit health-related data, such as prescription history.[139] However, the impression that the data sharing would occur promptly constitutes as an influential factor. More than three-quarters of participants of a study amongst university staff and students in the US (n=101) were found to be accepting of the sharing of lifestyle data for research purposes.[141] However, in this study the term *lifestyle data* encompassed data collected on wearables as well as health-related data collected on mobile phones applications. The explicit health-relatedness of these data might have influenced participants' views; acceptance rates attributable to wearable data are not disclosed. Hyde, Omura et al[142] reported that two-fifths of their representative sample of American adults would be willing to share data collected on wearables with their local, state, or national public health agencies, while three-quarters were inclined to share these data with their healthcare provider. However, individuals' perspectives towards explicit research-related sharing purposes were not investigated. Finally, all participants in an interview study conducted by Lehto and Lehto[144] (n=10) reported to be willing to share data collected on wearables with research entities; however, this finding might be influenced by self-selection bias.

1.7.4.3. Factors affecting acceptance

Qualitative methods were selected by scholars to elucidate the factors for individuals' acceptance or disapproval of the use of wearable data for research purposes. However, the topic occurred to be addressed less comprehensively and the research of poorer quality than in the context of social media use for research, which reduces the ability to draw inferences for this narrative synthesis.

Lehto and Lehto[144] suggest that the sensitivity of the data affects individuals' acceptance considerations; data collected on wearables were found to be low in sensitivity, and participants did not consider the data to be particularly personal, especially in comparison to medical records. Participants in the same study suggested that trust in the entity using the data might facilitate acceptance. Lastly, early adopters of emerging health technologies indicated that controlling the utilisation of their own data might increase willingness to share personal data, including data collected on wearable devices. Control was thought to allow individuals to oversee the dissemination of their data and permits device users to self-analyse their data.[143]

1.7.4.4. Concerns and benefits

Similarly, emerging concerns and anticipated benefits of utilisation of wearable data in a health research context were predominately investigated using qualitative methodologies. A notable exemption constitutes the study conducted by Chen, Bauman and Allman-Farinelli[141], where 67% of participants (i.e. individuals affiliated to a University in the US, such as students and staff) reported that they required assurance about privacy to accept the utilisation of lifestyle data for research purposes, which indicates that concerns over privacy affected their decision-making process.

Qualitatively, individuals emphasised negative effects on wearable-user privacy and confidentiality as a considerable risk. More specifically, early adopters of emerging technologies and users of wearables raised concerns over an undesired secondary use of the obtained data, as the data could be sold for profit or leaked, leading to detrimental effects for individuals' privacy. Moreover, it was feared that the information could enable discrimination with regards to health insurance plans, long-term employment and loans.[143,144] On the other hand, similar benefits were expected to emerge from an utilisation of wearable data in a health research context to those outlined previously. That is, individuals envisioned utilisation of lifestyle data to advance scientific progress, which was in turn expected to benefit individual and population health.[143]

Exemplarily, early adopters of emerging technologies attempted to weigh between the potential disadvantages of sharing personal data and its utilisation to serve the *greater good*; generally, the benefits were thought to counterbalance potential risks, as illustrated by one participant in a study conducted by Cheung, Bietz et al[143].

> “That’s what would motivate me, would be to have [my data] used for the good, for the good of the communities or for the good of whatever it is they’re researching. I guess when data can be used to help make a difference, and hopefully a positive difference, then that would be motivating to me to share it.”

1.7.5. Location data

Few studies (n=4) investigating individuals’ opinions towards a possible utilisation of location data in the context of health research were retrieved from the literature search. Moreover, location data often constituted a subordinate aspect of the studies’ overall objectives. For example, Jones, Daniels, Heys et al[145] aimed to evaluate public perspectives on the use of records from mobile phone calls in health research, with location data being encapsulated in this conceptualisation, which impedes a clear demarcation of individuals’ opinions. Additionally, scholars chose to examine the views of a variety of population groups, such as millennials[3],[146] or patients who had been referred to a tertiary clinic for mood and anxiety disorders.[147] Two studies adopted a quantitative methodology, in order to fulfil their aim.[139,147] The two remaining studies were conceptualised to explore individuals' attitudes qualitatively, either by conducting focus groups[146] or workshops with members of the public.[145]

1.7.5.1. Use of mobile phones and awareness of third-party access

Information about the percentage of individuals who utilise a mobile phone, and therefore generate location data, was provided in three instances. 92% percent of members of the British public who participated in a workshop to evaluate their views towards utilisation of mobile phone details in health research (n=61) reported to own a mobile phone, the remaining participants utilised the phones of family members.[145] Similarly, 89% of survey participants in a tertiary clinic (n=82) were found to own a mobile phone and reported to use it daily.[147]

Some researchers further examined individuals' awareness of third party access to personal data. Exemplary, two-thirds of workshop participants (n=61) reported to be aware that mobile phone operators are accumulating their users' data; most prevalently, the collection of location data was expected. However, no participant had read the terms and conditions of their contracts with mobile phone operators,

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[3] The term 'millennials' encompasses those born between in the 1980s, 1990s and early 2000s

and only a minority (n=2/61) of individuals' demonstrated awareness of the use of mobile data for health research.[145]

1.7.5.2. Willingness to share data for research

Further, individuals' willingness to share location data for health research purposes was determined in several instances. Quantitatively, less than 30% of individuals in an emergency department of a hospital in the US were willing to share GPS data. Thus, willingness to share location was lower compared to health-related data (e.g. prescription history), data collected on wearables and Facebook data, but higher than individuals' willingness to share Twitter data.[139] Likewise, 35% of questionnaire respondents in a tertiary clinic reported to be willing to grant researchers' permission to access their location data.[147] However, this questionnaire was distributed to inform the development of a mobile phone application that enables researchers to analyse and detect symptoms of mental health disorders. Thus, survey participants responded to the questions under the impression that location data would only be collected after installation of the application on their phone. Additionally, the study participants exclusively consisted of individuals who were referred to a tertiary clinic for mood and anxiety disorders to aid with symptom management. Thus, the objective and cohort of the project might limit the applicability of the findings for the broader population.

Qualitatively, millennials suggested to be generally inclined to share mobile phone location data with health agencies, such as Public Health England, to improve healthcare delivery. However, research was not explicitly cited as a purpose to use the data, instead researchers highlighted the possibility to use location data to improve ambulance services or to monitor disease outbreaks.[146] Lastly, 60% of workshop participants (n=61) reported to be willing to share mobile phone data, including location data for research purposes before the workshop commenced. Subsequently, participants were introduced to studies utilising mobile phone data in the context of health research. Consequently, individuals' willingness to share mobile phone data increased (80% reported to be willing to share their data). However, in a few instances, individuals opposed the utilisation of their data after the workshops, as they became aware of the extent to which personal data is used.[145]

1.7.5.3. Factors impacting willingness to share data

Factors affecting individuals' stances were predominately explored in qualitative research studies. First, the previous section demonstrated that exposure to examples which illustrate the utilisation of location data in a health research context can affect individuals' attitudes, both positively and negatively. Thus, greater understanding may have a mediating effect on individuals' attitudes towards data sharing.[145] Heightened understanding as an important factor was further emphasised by millennials in a focus group study.[146] Secondly, trust in the entity utilising the data was found to facilitate acceptance. For example, millennials exhibited high levels of trust in well-known agencies, such as the NHS, and were accepting of those using their data. Moreover, workshop participants were more willing to share personal data with academic researchers than charities or government organisations.[145,146] Therefore, affiliation, reputation and trustworthiness of data users may affect individuals' willingness to share their personal data. Third, participants in both studies highlighted that control and the implementation of safeguards, such as the anonymization or aggregation of individuals' data could influence acceptance considerations positively.

Murphy, Keahey et al[146] further aimed to investigate the impact of the Cambridge Analytica scandal on individuals' attitudes. For that purpose, two focus groups that were conducted prior to the surfacing of the scandal in March 2018 were supplemented by two additional focus groups, conducted in May 2018. Focus groups participants suggested that the Cambridge Analytica scandal increased their desire for greater control over their data. Simultaneously, participants failed to implement any additional data safeguards; instead, they adopted a more fatalistic stance towards their ability to oversee its utilisation. However, different individuals participated in the two series of focus groups, and researchers failed to investigate baseline attitudes. Thus, the dimension of the impact the scandal had on individuals' attitudes remained undetermined.

1.7.5.4. Concerns and benefits

Individuals' concerns over utilisation of location data in the context of health research mirrored those introduced in the previous sections (1.4.7.4.4; 1.4.9.4). That is, a potential loss of privacy and breach of anonymity was feared, as well as an undesired secondary use and monetisation of the data.[141,145,146] On the other hand, individuals named a number of benefits they expected to emerge, if location data were to be used for health research purposes. Again, the use of the data to support the greater good, i.e. to improve individual and population health was found to be a convincing argument for participants of qualitative research studies.[145,146] Further, members of the public in the UK suggested that the use of location data could be beneficial to track and analyse the spread of diseases. They identified the use of location data as an inexpensive and straightforward approach to collect population data on a large scale, which can be exploited to investigate correlations between health-related data and demographic variables. However, prior exposure to recent research studies utilising location data, might have influenced individuals' thought-process.[145]

In some instances, the benefits were thought to outweigh potential risks:

> "Even if it's not a benefit to me personally, knowing it could help other people is a factor that makes me more happy for them to use my data."[145]

1.7.6. Transactional data

Three empirical research studies investigating individuals' attitudes towards the utilisation of purchasing data in the context of health research were retrieved from the literature[148,149,150] as well as one report published by an independent research organisation of behalf of a government institution. The report explored public perspectives on the adoption of private sector data (including loyalty cards) for social and health research purposes.[132] Two studies adopted a qualitative methodology;[132,149] the two remaining studies followed a quantitative approach.[148,150]

1.7.6.1. *Use of loyalty cards and awareness of third-party access*

None of the included studies provided an estimate of the number of people using loyalty cards. However, individuals' awareness of third-party access to and use of transactional data was examined in one instance. Participants of two rounds of public dialogues held in Glasgow (n=22), Colchester (n=19) and London (n=21) in 2015 reported to be surprised by the extent to which they share personal data with private sector companies on an everyday basis. Thus, for some participants the revelations during the public dialogues evoked concerns about the magnitude of data collections. [132] Negative associations with large-scale data collections occurred to be more prevalent in older age groups; digital natives were more prone to acknowledge their advantages. Public dialogue participants were recruited purposefully to represent individuals with diverse socio-demographic backgrounds and different levels of engagement with social sector data collections, such as loyalty cards.

1.7.6.2. *Willingness to share transactional data for research purposes*

In a large-scale, multinational survey (n=8,004) participants reported high willingness to share their purchasing data for health research purposes.[150] In particular, 78% individuals in Finland (n=2,000) were supportive of sharing their purchasing data, while more than two-thirds of German (n=2,004) and Dutch (n=2,000) participants' supported the approach. Fewer individuals (64%) in France (n=2,000) were willing to share purchasing data for research purposes. Unfortunately, the survey was not distributed in the UK and the method to track purchasing data was not specified (e.g. using loyalty cards), which might have made it difficult for participants to understand the concept. Skatova and Goulding[148] reported that 54% of their survey participants (n=1,300) were willing to donate transactional data, as recorded on loyalty cards, for research purposes, 31% reported unwillingness to donate data. Interestingly, individuals who were unwilling to donate their data were more likely to drop-out of the study before completion, which may have implications for the results obtained from an analysis of the factors which impact willingness to donate data (see next section). Students (69%), due to university mailing lists being the main distribution pathway, dominated the cohort. Moreover, the researchers chose to employ the term *data donation*, therefore implying the exchange of data for someone else's benefit, which may have affected individuals' response behaviour. Qualitatively, both focus group participants[149] and participants of a series of public dialogues[132] were found to be supportive of the use of loyalty card data for health research. However, the cohort of focus group participants solely encompassed individuals who were born in 1992 and part of a study that followed them since their birth (Children of the 90's); the sharing of transactional data was understood to occur in the context of the longitudinal study. Thus, the results from the focus groups represent a distinct perspective, which may not be transferable to other circumstances. On the other hand, public dialogue participants discussed research use of private sector data after seeing a movie that introduced them to the value of big data for social research, which might have affected perceptions.

1.7.6.3. Factors affecting individuals' stances towards the utilisation of transactional data for research purposes

In essence, Skatova and Goulding[148] aimed to evaluate factors impacting individuals' stances towards utilisation of loyalty card data for health research. For that purpose, they distributed a survey encompassing a number of pre-validated scales that were thought to correlate with individuals' attitudes, such as a prosocial tendencies scale and a personality trait measure. Additionally, a scale measuring individual reasoning to donate data was developed based on literature about blood donation. The reasons for data donation scale were subjected to exploratory and confirmatory factor analysis. Finally, all scales and the outcome measure (i.e. willingness to donate data) were included in a regression model, in order to determine predictors of the outcome measure. The reasons to donate data scale was found to explain 25% of the variance in individuals' willingness to donate data, it consisted of the subscales *social duty* (i.e. social responsibility to donate), *purpose/understanding* (i.e. desire to know the context in which the data will be used) and *self-interest* (i.e. guilt and concerns over one self's reputation as reasons to donate). Social duty was found to be a strong positive predictor of willingness to donate, while self-interest predicted willingness to donate negatively. Age was found to correlate with individuals' willingness to donate data, as well as the *anonymous* sub-scale of the prosocial tendencies measure (i.e. intentions to help others without them knowing). Finally, correlations between some personality traits (i.e. extraversion, agreeableness and openness) and willingness to donate data were identified. Thus, Skatova and Goulding's[146] work provides a detailed account of factors impacting individuals' intentions to donate data. However, by adopting a quantitative approach, the researchers were restricted to including predictors they had pre-conceptualised, predominately from literature pertaining to blood donation; a significant proportion of the variance in participants' responses remained unexplained. Skatova, Shiells and Boyd's[147] qualitative findings suggest that trust in the data user may contribute to individuals' willingness to share transactional data, as well as the level of control individuals are able to exercise. This notion is further supported by contributors to a public dialogue.[132] Moreover, by adopting an approach in which individuals are exposed to examples of how data can be used in a research context, both studies further manifested the finding that understanding attributed considerably to individuals' acceptance.

1.7.6.4. Benefits and concerns

Lastly, potential benefits and concerns emerging from utilisation of loyalty card data in a health research context were reported rarely. Focus group participants raised concerns over consequences for insurance and loans if the data were accessed by third parties.[149] Public dialogue participants feared privacy intrusion and therefore preferred the use of aggregated as opposed to personally identifiable private sector data.[132] On the other hand, use of transactional data for public good was seen as a considerable benefit.[149] However, no information about the extent to which participants weighted between benefits and risks, as seen in previous sections, was provided.

1.7.6.5. The impact of COVID-19 on public attitudes

At the time this literature review was reiterated (August 2021) COVID-19 was still a prevalent topic and its implications not yet fully researched and understood. Thus, only few publications examining the impact the outbreak of COVID-19 had on public attitudes towards the utilisation of personal data in the context of health research were identified. A series of six surveys was distributed by the Centre for Data Ethics and Innovation[130] over a 6-month time period (June to December 2020); 2000 members of the British public participated in each survey and the results were weighted to be representative of the UK adult population. The survey was supplemented by a media analysis, which indicated that the media coverage of themes, such as data-driven technologies increased by 54% from pre-COVID (February 2019 to February 2020) to post-COVID (February 2020 to February 2021). Interestingly, public attitudes remained relatively consistent over the study period. However, the extent to which individuals would be willing to share their data was not investigated. Additionally, Romero and Young[151] aimed to explore the impact of COVID-19 on individuals' willingness to share personal data qualitatively. For that purpose, two cohorts of individuals were interviewed. One, individuals who had expressed willingness to share personal data, such as location data and social media data for research purposes, in a survey before the pandemic. Two, individuals who reported to be unwilling. Their findings suggest that COVID-19 had a moderating effect on participants' attitudes, as individuals who reported unwillingness to share data prior to the pandemic reported to be more inclined to support the utilisation of their data. However, the qualitative data was analysed using a quantitative approach, which reduced the depth of the analysis, and it was not further elaborated on participants reasoning for modifying their stances.

1.7.7. Conclusion and research rationales

Loyalty card data constitutes a promising data source for research, but to utilise these data in practice, obtaining public support is crucial. Therefore, I provided a narrative synthesis of the contemporary literature evaluating public attitudes towards utilisation of personal data, such as social media data, location data, wearable data and transactional data in health research. I included four different types of personal data, as only a limited number of publications pertaining to transactional data specifically could be identified. On the grounds of the results, I obtained from the analysis, I conclude the following.

First, from a methodological standpoint, most researchers commenced their investigations by determining the proportion of participants who produce the investigated type of personal data, to characterise the study sample and provide an overview of the cohort that could be subjected to analysis. However, to date, no empirical account of the proportion of individuals subscribing to a loyalty card scheme has been provided, and no information about the prevalence of loyalty card sharing is available, although the sharing of loyalty cards has been identified as a considerable problem for research endeavours (section 1.3.1.2). Thus, a third research objective was formulated:

3. To describe loyalty card use and non-use, frequency of use and related demographic data in different population groups.

Second, thus far, public attitudes towards loyalty card use in a research context have predominately been investigated in distinct cohorts and the positively connoted term *data donation* was typically employed. Moreover, little is known about the risks and benefits individuals anticipate to emerge from utilisation of loyalty card data in a health research context. No literature investigating these aspects in the context of mental health could be identified, despite evidence suggesting that loyalty card data could support an identification of individuals at risk of developing mental health issues (section 1.3.1.2). Thus, two final research objectives were developed.

4. To evaluate public acceptance towards loyalty card use for health research purposes, and specifically to identify individuals at risk of having mental health issues.

5. To explore factors impacting public acceptance towards the use of loyalty card data for the identification of individuals at risk of having mental health issues.

Hence, on the grounds of the current state of mental health service provision in pharmacies and the opportunities loyalty card data provides for identifying individuals at risk of developing mental health issues, this thesis aims:

To identify public attitudes towards mental health support provided in community pharmacy using purchasing data as a tool to identify individuals at risk of developing mental health issues.

In the next chapter, I am outlining the methodology and methods I adopted to address my research aim and objectives.

Chapter 2 Research methodology and methods

In the previous chapter I synthesised published literature pertaining to the two core topics of this thesis. Firstly, the current state of mental health service provision in community pharmacy was described. Secondly, the opportunities alternative types of data might provide for the identification of individuals at risk of having mental health issues were highlighted and an overview of public attitudes towards the use of these data in health research presented. Rooted in the findings from the literature synthesis, the aim and objectives of this research project were defined.

2.1 Research aim and objectives

Figure 2-1 provides a schematic overview of the research process. First, a purposefully broad literature search was conducted to refine the initial research question, which revolved around the opportunities novel technologies may present for improving community pharmacy practice. Three main areas of interest were identified: community pharmacy practice from a public perspective, mental health support available in community pharmacy, and the use of predictive analytics, in particular purchasing data, to identify individuals at risk. Second, two in depth-literature reviews were conducted, to identify gaps in the current literature and develop the specific research objectives.

Accordingly, this chapter introduces the methodology underlying this thesis and summarises the methods that have been adopted to fulfil the aims and objectives underpinning this research project.

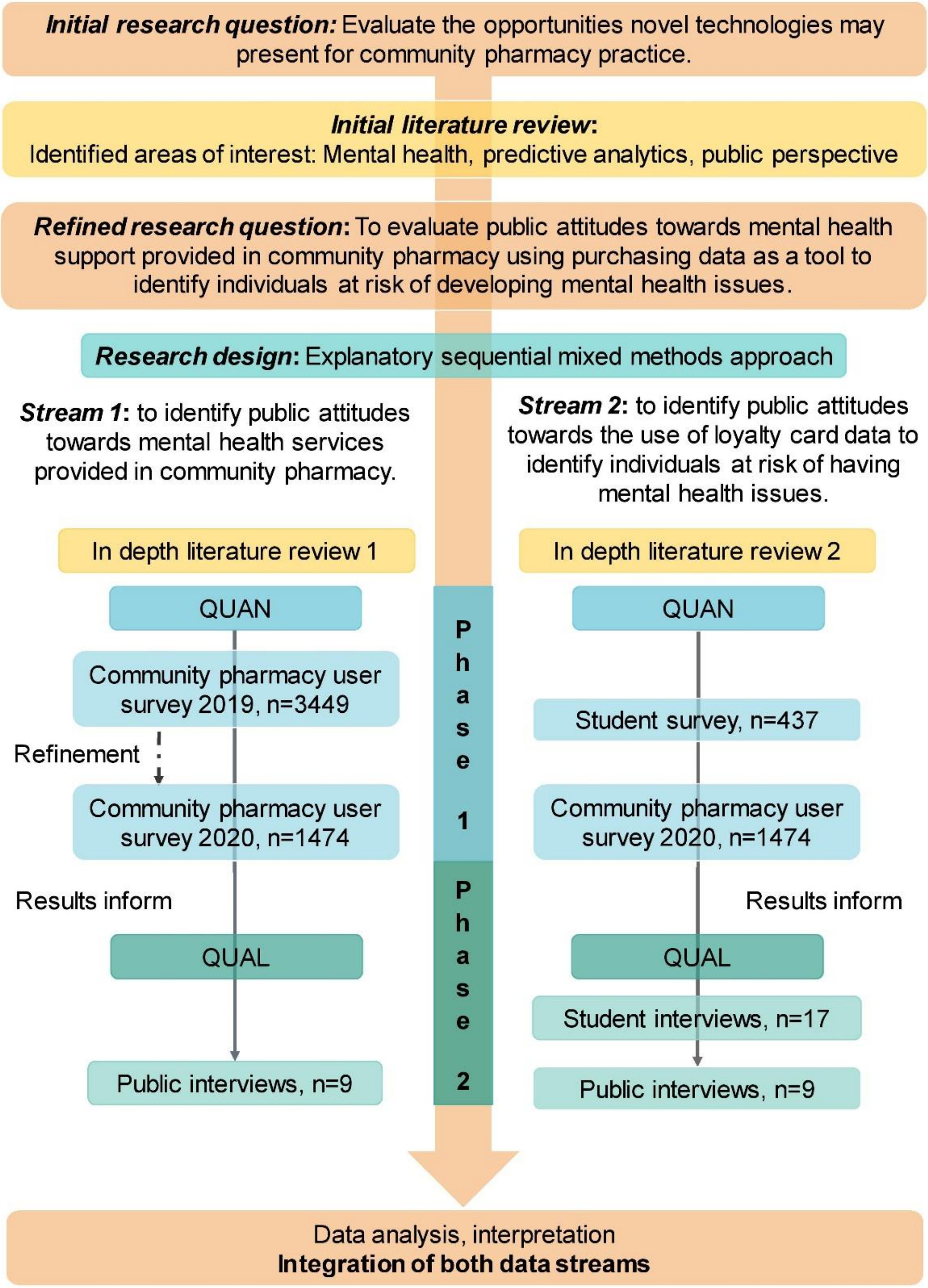

Figure 2- 1 Research process – schematically

2.2 Methodological approach

Two aspects were essential for the conceptualisation of the research process. Firstly, a paucity of literature pertaining to mental health support provided in pharmacies in England or the United Kingdom (UK) was identified; in particular the perspective of the public had not been investigated in detail. Thus, before moving towards exploring public attitudes towards more concrete ideas for improving mental healthcare provided in pharmacies, such as the use of loyalty card data to identify individuals at risk, it was necessary to map the views of the public more generally. At the time my involvement with the research project begun, a survey had been distributed in 12 community pharmacies in Nottinghamshire by third year MPharm students as part of a research project. The survey aimed to identify pharmacy users' views towards pharmacy provided mental health support. However, the survey had not been analysed comprehensively. Using this survey as foundation, I developed the first research stream, that is, *to identify public attitudes towards mental health support provided in community pharmacies*. On the other hand, research stream two was conceptualised *to identify public attitudes towards the use of purchasing data to identify individuals at risk of developing mental health issues*. The second consideration that influenced the conceptualisation of this research project pertained to its methodological approach. In order to address both core topics comprehensively, two separate research phases were designed. Phase one of both research streams was quantitative in nature, designed to address objectives 1, 3 and 4. The quantitative phase of both research streams was succeeded by a qualitative research phase which aimed to explore individuals' attitudes towards both core topics in more detail; conceptualised to address objectives 2 and 5. The findings from the preceding quantitative research phases influenced the conceptualisation of the qualitative phases of this research project; however, both phases were conducted *sequentially.* Thus, the research design can be described as an *explanatory sequential mixed methods approach*.

Finally, both research streams were synthesised to make recommendations concerning the suitability of loyalty card data as a tool to identify individuals at risk of having mental health issues within the wider realm of expanding mental health support provided in community pharmacy.

2.2.1 Methodology

In the previous section, I described the research design I chose as an *explanatory sequential mixed methods* approach. That is, the aim of this research project has been addressed using a combination of quantitative and qualitative methods. In order to justify why I considered a mixed approach to be most suitable for this research project, a more fundamental discussion of the synergy between research and knowledge and the believe systems that underpin them, is required.

2.2.1.1 Philosophical underpinnings

Epistemology/ Ontology

At its very core, research, irrespective of the nature of the research endeavour, is concerned with generating new *knowledge.*[152(p.4)]

However, questions pertaining to the nature of knowledge remain unanswered by this definition. The philosophical discipline *epistemology* or the '*theory of knowledge*'[153(p.3)] is concerned with studying the principles, origins and boundaries of human knowledge.[154] In a social science context the central issues concerning the theory of knowledge pertain to the principles that can be applied when studying, and thus aiming to generate new knowledge about the social world. This is especially relevant in comparison to the study of the natural world. Exemplarily, one could raise the question whether or not the same conventions we agreed upon to acquire and determine new knowledge in the natural sciences are applicable to the social world. Based on their stance towards this question, social scientists are divided between two diverging epistemological approaches. Advocates of a *positivist* approach may endorse this claim, while supporters of *interpretivism* are more likely to oppose it.[155(pp. 27-31)] That is, the natural sciences and social sciences are regarded as fundamentally different; domain-specific epistemological principles apply.[155(p.30)]

Another field of philosophy that needs consideration when aiming to acquire knowledge about the social world is *ontology*. Broadly, ontology is concerned with the nature of existence.[153(p.4)] Again, ontological debates in social research might be less fundamentally about existence or reality as such, but they address questions concerning the construction of *reality* or *truth* in a social context.[153(p.5),155(p.32)]

The characterising thought of a *constructivist* approach to reality is the refutation of the existence of a single reality.[153(p.68)] Instead, it is argued that individuals (i.e. '*social actors*') *construct* and *impact* social phenomena (i.e. reality) through interactions, and they are constantly being revised.[155(pp.32-33)] The opposing stance assumes a single reality, which is independent of the actors within the social world and cannot be altered by their actions (‘*Objectivism*’).[155(p.33)]

In short, epistemology is concerned with the nature and the origins of knowledge, while ontology is concerned with the nature of existence. Thus, by logic, both concepts are closely related, as our core understanding of existence is inherently influenced by the knowledge we acquire about it.[153(p.5)]

Hence, advocates of positivism typically take an objectivist ontological stance.[155(p.36)] The existence of a single reality is assumed, and the aim is to *measure* and *explain* said reality. In that, the positivist approach follows the epistemology of the natural sciences, i.e. the so-called ‘scientific-method’ should also be applied when studying the social world. That is, phenomena are measureable, hypothesis can be confirmed or disproven, and experiments can be controlled.[153(p.23)] Hence, positivism typically underpins a quantitative (i.e. number-and measurement-focused) research approach.[155(p.28)]

On the other hand, supporters of a constructivist approach towards reality typically endorse a clear demarcation of the social world from the epistemological traditions of the natural sciences (i.e. *interpretivism*).[155(p.36)] Thus, advocates of an interpretivist epistemology typically rely on qualitative social research methods, such as in-depth interviews or focus groups. The core objective is to enable the *understanding* of individuals’ perception of reality and subsequently interpret it.[155(p.30)]

The previous discussion indicates that research in the social world is affected by considerations pertaining to the *origins of knowledge* and the *construction of reality*. It has further been emphasised that these philosophical considerations have consequences for the types of data a researcher considers most applicable when aiming to investigate a social phenomenon. That is, advocates of positivism strive to describe the social world by adopting quantitative methods; interpretivists aim to understand individuals' perspectives by adopting qualitative methods. Consequently, the *dualism* between the diverging epistemological and ontological stances has resulted in the emergence of two distinctive social research paradigms.

2.2.1.2 The quantitative paradigm

Quantitative approaches are characterised by a reliance on numbers to *explain* and *make inferences* about a pre-conceptualised phenomenon (i.e. theory).[152(p.5)] Large databases (e.g. containing health records) or social surveys are typical sources for quantitative data.[156(p.53)]

The reliance on *a priori* formulated *hypotheses* also explains why quantitative research is often described to be *deductive* in nature; a phenomenon which is observable in the social world is thought to be explained in its particulars, hypotheses are intended to be confirmed or disproven.[155(p.25)] Rooted in the assumption that a single reality is being objectively depicted in quantitative inquiry, the obtained results are thought to be *generalizable* to a wider population under certain circumstances.[155(p.176)]

2.2.1.3 The qualitative paradigm

The quantitative paradigm is counterbalanced by the qualitative approach to social research. Narratives are the centrepiece of qualitative inquiry,[152(p.5)] thus a multitude of different data sources are used, including but not limited to individual and group interviews, observations or documents.[156(p.264)] Qualitative inquiry aims to gain an in-depth understanding of individuals' experiences (i.e. their 'reality') and often commences without an *a priori* formulated hypothesis. Instead, qualitative researchers strive to develop theories from the obtained data;[152(p.5)] hence qualitative inquiry is considered to be inductive in nature.[155(p.36)] Results obtained through qualitative inquiry are rarely generalizable to the wider population,[156(p.276)] however they may be transferable to other situations and circumstances.[155(p.392)]

In a nutshell, it is characteristic for quantitative approaches that theories precede the collection of data, they are predominately deductive in nature. The opposite is true for qualitative approaches, often theories are developed from the obtained data. Thus, qualitative approaches are considered to be inductive in nature.

However, the boundaries between both approaches are often less rigid than described above, quantitative approaches can contain elements of induction and theories can precede qualitative inquiry.[155(p26-27)] Thus, both approaches, despite often described as irreconcilable, bear more resemblance than anticipated from a purely theoretical standpoint.

2.2.1.4 Introducing the third research paradigm: mixed methods research

Thus far, I have introduced two paradigms of social research, qualitative and quantitative approaches, as well as their corresponding philosophical underpinnings, interpretivism and positivism, respectively. Historically, the opposing epistemological and ontological tenets in which both paradigms are grounded have caused a division of social scientists in two opposing factions; qualitative and quantitative purists.[157,158]

However, more recent developments have given rise to the emergence of a *third paradigm* in social research, mixed methods, which amalgamates the principles of qualitative and quantitative research.[158]

Philosophical underpinnings

Arguably, the epistemological and ontological stances of both qualitative and quantitative paradigms appear irreconcilable. Thus, instead of aiming to consolidate diverging stances, advocates of the mixed methods paradigm have opted to take a *practical-oriented* standpoint towards the philosophical foundations of mixed methods research.[156(p.45),157]

Pragmatism

At the centre of pragmatism sits the *Pragmatic Maxim*, as formulated by Charles Sanders Peirce. It states that, above all, the practical consequences of an '*object of our conception*' are to be considered, because the expected practical consequences determine the ‘*conception’* of said object.[159]

The applicability of the principles of pragmatism for the encountered dispute between the epistemological and ontological stances of quantitative and qualitative paradigms is further supported by William James’ conceptualisation of pragmatism:

> *“The pragmatic method is primarily a method of settling metaphysical disputes that otherwise might be interminable. The pragmatic method in such cases is to try to interpret each notion by tracing its respective practical consequences.”*[159]

Put simply, ideas or hypothesis should be evaluated based on their expected practical consequences.[157] The focus of the pragmatic maxim on the practical consequences to evaluate truth is understood by some scholars as a *philosophical justification* for mixing methods and approaches. That is, the practice of mixing is warranted because it supports the researcher’s aim to obtain valued results.[158(p23)]

Thus, instead of deepening the gulf between opposing philosophical stances, pragmatism aims to bridge between both by offering a practical solution. The epistemological and ontological standpoints of both paradigms are accepted and endorsed; the nature and hypothesised consequences of the encountered issue determine how to solve the problem.[158(p.23)] Thus, the pragmatic school of thought provides a valuable alternative to relinquish the dualism between two opposing philosophical stances, which might be too fundamental to be easily overcome. This *antidualistic* stance is sometimes referred to as *synechism.*[158(p.3)]

The mixed methods paradigm

In line with the philosophical standpoint of pragmatism, the mixed method paradigm offers the researcher a flexible approach to investigate multifaceted sociological queries. A combined application of qualitative and quantitative methods is advocated, depending on which methods offer the best solution for the encountered problem.[156(p.45)] Thus, the mixed methods researcher is able to exploit the advantages of both methodological approaches while reducing their respective disadvantages.[160(p.38)] Mixed method approaches are characterised by applying both, inductive and deductive logic; likewise, numerical and narrative types of data are typically combined. A prominent feature of mixed methods research is the attempted integration of both data types, that is, results from qualitative analysis can inform quantitative inquiry and vice versa. Similarly, results may be generalizable to a wider population and/or transferable to other situations and circumstances.[160(p.28)]

Lastly, due to its nature as a 'mixed paradigm' a number of different possibilities for combining and integrating both data streams are available to the researcher aiming to conduct a mixed methods study. Research design types should be selected on the grounds of the specific research question one is aiming to tackle. Creswell and Creswell identified three different types of mixed methods study design:

convergent design (one-phase design), explanatory sequential design and exploratory sequential design.[156(p.300)] Characteristic for a convergent research design is that quantitative and qualitative phase are conducted simultaneously (‘*single phase–design*’), data are analysed separately and the obtained results compared. This approach is advantageous to compare findings from both research streams.[156(p.300)] Two different versions of sequential research design exist. Firstly, the quantitative research phase can precede the qualitative research phase, known as an *explanatory sequential design*. Here, the findings from the quantitative phase inform the qualitative phase, which is added to *explain* the findings from the preceding quantitative stage.[156(p.304)] Secondly, if qualitative research precedes the quantitative phase of the study, this is referred to as an *exploratory sequential design*. A new topic is first explored and later tested quantitatively.[156(p.306)]

2.2.1.5 *My own philosophical stance*

Although, I, myself do take a positivist stance towards epistemology in the natural sciences and believe that there is an objectively measurable reality, I hesitate to adopt the same stance when evaluating the social world. I believe that each individual constructs their own reality of those social phenomena surrounding them, and I take the stance that it is exactly this ‘construction of individual realities’ that characterises the social world as such. Interactions with others, such as the exchange of thoughts and ideas culminate in a constant revision of our perceptions towards a certain topic or even society as a whole. Thus, in order to understand the social world, individuals' realties require attention. Exemplarily, my own perception of privacy and the use of personal data to monitor individuals has taken a tremendous turn throughout this research project. I grew up in a society that had experienced an unjustified monitoring of every aspect of their lives first-hand; the consequences are still prevalent today. Consequentially, I was raised to be naturally suspicious towards the use of data for population monitoring. However, this *'truth'* was challenged throughout the course of this research project. Still, I would refrain from calling myself an advocate of interpretivism, because I do believe that under certain circumstances the acceptance of 'one reality' (even if it is just a temporary truth) is necessary in order to make decisions which are of relevance to a wider population. The quantification of individuals' perceptions towards certain topics facilitates majority-focused and problem-based decision making, thus laying the ground for the development of services which are ought to improve individuals' lives (or less radically, their health or simply their experiences) which may in turn have an impact on people's experience of 'reality'. Arguably, this positivist stance towards epistemology can be attributed to my background as a pharmacist; the education I received revolved almost exclusively around quantitative data and its perceived value. Thus, I believe that neither a purely interpretivist nor a purely positivist viewpoint can provide an accurate depiction of social reality which is representative of the wider public.

The inapplicability of an ‘either/or’ perspective is further emphasised by the health science domain in which this research project operates. Health sciences combine aspects of the social world, such as interactions with HCP, with aspects of the natural world, such as objectively measurable health markers. In light of my own experiences and education as well as the health-focused topic of this research project, I oppose a dualistic stance towards epistemiologicalmiological and ontological issues. Instead, I support the practical approach mixed methods research underpinned by pragmatism offers, i.e. a focus on finding solutions tailored towards the problem.

2.2.1.6 Choice of methodology

After outlining the three research paradigms in social research, and emphasising my own philosophical standpoint that aligns with the principles of the mixed methods paradigm, I will summarise the practical and theoretical considerations that resulted in the choice to conceptualise this study using a *mixed method explanatory sequential design*.

From a theoretical perspective, opting to adopt the mixed methods paradigm was thought to be beneficial to cover the topic under investigation in depth and breath, which is argued to result in stronger overall inferences.[160(p.38)] Especially in the context of policy-making, inferences that are grounded in both qualitative and quantitative data may be particularly coercive.[157] Moreover, the first year of the research project was dominated by considerations pertaining to whether and how purchasing data of over-the-counter medicine could be used in a pharmacy practice context. For that purpose, multidisciplinary literature from a range of subjects, such as data science and computer science was reviewed. Owing to the nature of the subject, most of the published literature was purely quantitative in nature; ethical issues and individuals' attitudes towards the topic were rarely acknowledged. However, personal conversations revealed that individuals' stances towards the use of personal data differed greatly, as well as their reasoning for the expressed stances. Thus, I saw a necessity to address the underrepresentation of individuals' perspectives on the topic by conceptualising a qualitative research phase. This aligned with my own belief that understanding individuals' realties is crucial when investigating phenomena in the social world. Hence, theoretical considerations prior to the commencing of the research project indicated that adopting a mixed methods paradigm supports the fulfilment of the aim of this research project. From a practical perspective, the conceptualisation of the study was influenced by two aspects. As outlined in section 2.1, research stream one commenced with the analysis of a survey which had been distributed before my involvement with the project begun but had not yet been analysed. However, the obtained data were insufficient for understanding individuals reasoning behind their expressed stances. Thus, a qualitative research phase was conceptualised in order to aid with the explanation of the obtained results.

Secondly, research stream two was impacted by the fact that the initial literature review identified not only a paucity of literature concerned with individuals' attitudes towards the use of their data for health research purposes, but also a lack of literature pertaining to use or non-use of loyalty cards in the general population. However, in order to make recommendations concerning the use of purchasing data to identify individuals at risk of having mental health issues, understanding the cohort of people which might (or might not) be reached was deemed to be pivotal. Thus, an initial quantitative research phase was conceptualised, also to get preliminary insights into individuals' stances towards the use of these data for health research purposes. Subsequently, a qualitative approach was adopted, in order to explain the obtained results in more depth.

2.3 Reviewing the literature

For the purpose of this thesis, two separate structured literature searches were conducted. Literature review one aimed to synthesise any literature pertaining to mental health service provision in community pharmacy, while literature review two aimed to provide an overview of public attitudes towards the use of different types of personal data for health research. Thus, each literature review required individual inclusion and exclusion criteria and different types of databases in order to account for the objectives of each literature review.

2.3.1 Methods

The methods used for both literature reviews followed the steps outlined in Aveyard[161] and were adapted when necessary. That is, first the aim of each literature review was determined, as well as applicable inclusion and exclusion criteria. Next, key search terms covering the scope of the literature reviews were developed using an iterative process, i.e. search terms were selected, trialled and adapted when necessary, until the most suitable key words were established. All references were managed using Endnote X8.[162]

2.3.2 Database searches

After establishing aim, inclusion and exclusion criteria and the search terms, both structured searches were separately ran using a range of databases covering distinct core topics (Table 2-1). The obtained results were immediately subjected to preliminary screening. The remaining publications were considered for full-text evaluation.

2.3.3 Study selection

References considered for full-text evaluation were downloaded and imported into Endnote. Identified publications from all databases were collated and duplicates removed. For the remaining publications eligibility for inclusion was assessed using the full text (if available).

Table 2- 1 Included databases for structured literature search

Database	*Literature review (1;2; both)*	*Covered topics in the database*
Pubmed/Medline (OVID)	both	Life sciences, focus on biomedicine , including: delivery of healthcare, healthcare, social sciences
Web of Science[4]	1	Multidisciplinary, including: sciences, social sciences, arts, humanities
Scopus	both	Multidisciplinary, including: sciences, business, social sciences
EMbase	both	Biomedicine and pharmacy, including: health policy and management, public health
PsycInfo	2	Psychology, social sciences, health sciences
JSTOR	2	Social Sciences
IEEEXplore	2	Technology, computer science
ProQuest[5]	both	Dissertations and Theses
Google Scholar	both	Additional search tool, first 300 hits were searched for additional findings
Google	both	To identify Grey literature

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[4] Please note, both Scopus and Web of science cover a similar range of topics, however Scopus indexes a larger number of journal articles. Thus, Web of science was not separately searched for literature review 2.

[5] For literature review 2, ProQuests' advanced search yielded 185,992 results. The results were subsequently sorted by relevance and only the first 5000 results taken into consideration.

2.3.4 Literature review one

2.3.4.1 Aim

The aim of the first review was to synthesise literature pertaining to the state of community pharmacy provided mental health care beyond treatment-related interventions (e.g. adherence support, medication reviews). Treatment related articles were excluded, as I aimed to provide a more general account of mental health service provision in pharmacies, beyond the traditional, medication-focused role of pharmacists.

2.3.4.2 Search strategy

A structured search was conducted using the electronic databases outlined in Table 2-1. In order to identify literature relevant to the scope of this literature review, databases covering medical literature and general health topics were searched (e.g. PubMed, Embase) as well as multidisciplinary databases, indexing publications from both, science and social sciences journals. The search strategy used a combination of key words related to community pharmacy, mental health (including depression and anxiety) and available services and support mechanisms (Table 2-2). The final search string was developed iteratively; different combinations and the addition of related search terms were tested until the search string yielded results which were both precise (i.e. close to the topic under scrutiny) and wide-ranging (i.e. encompassing different countries, stakeholders and a variety of developed services).

Table 2- 2 Key words used for literature search one

Concept	*Key words/ search terms*	*Explanation*
1.	(Community pharmacy)	Only community pharmacy provided services/ support was taken into consideration
2. Type of health condition	(mental health or depress* or anxiety)	Covers both, the general term: mental health as well as depression and anxiety
3. Scope	(support* OR service* OR assist*)	Covers articles reporting additional mental health support offered in community pharmacy, as well as the implementation of specific services or provided assistance

2.3.4.3 Inclusion and Exclusion criteria:

Considered for inclusion were:

- peer-reviewed publications
- full-text and review articles, book chapters
- publications written in English or in German, and
- research conducted with humans.

Studies conducted using qualitative or quantitative methodology and mixed methods were included, as well as review articles (e.g. scoping, narrative, systematic reviews). Any studies aiming to assess the state of community pharmacy provided mental healthcare beyond treatment-related interventions were included. Thus, studies evaluating the preparedness of community pharmacy staff to provide mental health care were included as well as research evaluating a potential role for community pharmacists in the provision of mental health care. Studies focusing on the provision of treatment or medication-related interventions or support (e.g. adherence support) were excluded.

The identification of currently under-researched stakeholders was fostered by omitting any stakeholder-specific search terms (e.g. public, patients). Thus, the final literature review provides an overview of research pertaining to mental health support provided in community pharmacies from a range of perspectives, including: community pharmacists and support staff, patients, public and other healthcare professionals. Solely publications concerned with pharmacy education, such as the development or evaluation of educational interventions for pharmacy students were excluded.

Any additional inclusion and exclusion criteria are listed in Table 2-3.

Table 2- 3 Inclusion and exclusion criteria for study eligibility, CP=community pharmacist, MH=mental helath

Category	*Inclusion criteria*	*Exclusion criteria*
Population/ Sample	Public/ community pharmacy users, patients; community pharmacists; other stakeholders	Pharmacy students, children (<18 years), 'special-interest' population groups (e.g. farmers)
Study design	Qualitative, quantitative and mixed methods; controlled trials, reviews	Medication trials; non-empirical research (e.g. commentaries, opinion papers)
Type of health condition	Common mental health conditions, anxiety, depression	Severe mental health issues (e.g. schizophrenia); perinatal depression; mental health issues as a comorbidity
Service/ support provision	Mental health service/support provision in pharmacies (including: role of pharmacists in MH support provision, barriers, facilitators, advantages to	Medication and treatment related studies, e.g. medication optimisation, antidepressants use, etc.

	MH support provision in CP; newly developed services

2.3.5 Literature review two

2.3.5.1 *Aim*

The aim of literature review two was to identify and compare public attitudes towards the use of different types of personal data (i.e. non-traditional types of data), such as social media data, location data or lifestyle data, for health research purposes. During an initially conducted broad literature review few publications investigating public attitudes towards the use of loyalty card data for health research purposes were found. However, a number of studies scrutinising public willingness to share personal data as well as journal articles investigating public attitudes towards the use of other, non-traditional types of personal data in health research emerged. Based on these findings, it was then hypothesised that similar factors affect the perspective of members of the public towards an extended use of personal data in health research. Thus, literature review 2 was conducted to synthesise the core aspects, expected advantages and perceived risks attributed to an extended use of personal data in health research from a public perspective.

2.3.5.2 *Search strategy*

A plan for a structured search was developed in collaboration with a librarian. A search using a range of databases with different core topics was recommended to account for the multidisciplinary nature of the topic. Thus, in addition to interdisciplinary databases, such as Scopus, discipline-specific databases, such as PsycInfo, IEEEXplore, Pubmed and Embase were searched (Table 2-1). The search string adopted for literature review two is presented in Table 2-4.

2.3.5.3 *Inclusion and exclusion criteria*

Considered for inclusion were:

- peer-reviewed publications,
- full-text and review articles, and book chapters, conference proceedings
- publications written in English or in German, and
- research conducted with humans.

Empirical studies adopting a qualitative, quantitative or mixed-methods study design were considered for inclusion. Alternative types of study design, such as the analysis of Twitter data were accepted if the publication covered the topic under investigation. Narrative, scoping and systematic reviews were considered for inclusion. Excluded were non-empirical types of research, e.g. opinion papers, commentaries as well as literature theoretically discussing ethical issues, without providing any empirical evidence for the stance taken.

Table 2- 4 Keywords used for literature search two

Concept	*Search terms* [6]	*Justification*
Population /Sample	(public or people* or user* or patient* or population or citizen* or student*)	Synonyms and related search terms of the sample under investigation
Context	(opinion* or attitude* or perception* or view* or perspective* or accept* or concern* or survey* or questionnaire*)	Synonyms and related search terms of the aspect under investigation, i.e. attitudes. The term survey and questionnaire were included to account for/ not exclude quantitative research
	1 and 2	NA
Purpose	(healthcare or “health research” or “health care”)	Inclusion of literature with a health-related focus
	(health adj2 research)	
Data type	(“Social Media” or Twitter or Facebook or Instagram)	Personal data type: social media data
Data type	(“location data” or wearable* or fitbit or smartwatch or “activity tracker”)	Personal data types: location data[7] and lifestyle data
Data type	(“smart data” or “purchas* information” or “purchasing data” or “loyalty card*” or “advantage card*”)	Personal data type: purchasing data
Data type	(“personal data” or “personal information”)	Generic terms encompassing personal data
10	6 or 7 or 8 or 9	NA
11	3 and 10	NA
12	5 and 11	NA
13	4 and 11	NA

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[6] Please note, the order in which the search was conducted had to be adapted in the case of the searches conducted in GoogleScholar and IEEEXplore due to the specific conditions of use (i.e. limited number of wildcards or search terms). However, the wording of search terms was not modified.

[7] Please note, the inclusion of the search terms “GPS (global position system) data” was trialled, however due to the proximity of the term to GP (General practitioner) a large number of results was retrieved. In an attempt to keep the number of results manageable, the search term was omitted.

Studies outside the public perspective, studies investigating individuals' information needs and research investigating the secondary use of data types outside the realm of the literature review (e.g. genomic data, biobank data) were excluded. Studies considered for inclusion were required to have a focus on the use of data for health-research purposes in general, or mental health in particular (e.g. population monitoring, to identify health conditions). Publications covering specific patient populations (e.g. cancer patients) were excluded. Initially, no limit to the date of publication was applied; however, no articles published prior to the year 2000 were identified. The social science database 'JSTOR' was considered for inclusion, but yielded insufficient results, consequentially JSTOR was excluded. An overview of applied inclusion and exclusion criteria is provided in Table 2-5.

Table 2- 5 Inclusion and exclusion criteria for study eligibility

Category	*Inclusion criteria*	*Exclusion criteria*
Population /Sample	General public, and subgroups (e.g. students); patients[8]	Other stakeholders (e.g. policymakers), patients with specific diseases (e.g. cancer patients)
Study design	Qualitative, quantitative and mixed methods; controlled trials; reviews; alternative types of study design (e.g. use of Twitter data)	Non-empirical research (e.g. commentaries, opinion papers)
Health condition	Focus on health research in general, mental health (and related conditions)	Specific diseases (e.g. cancer)
Data types	Location data, transactional data, social media data, lifestyle data	Genomic data, biobank data

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[8] Included if term was used generically, e.g. patients in a hospital

2.4 Quantitative methods

As outlined in section 2.2, numerical data were a key component for the fulfilment of the aim of this research project, as it enabled a descriptive analysis of individuals' attitudes towards the core topics, inferences about factors affecting the expressed stances, as well as the quantification of loyalty card use and non-use in large population cohorts.

Quantitative data allows the researcher *to characterise* a population of interest based on the occurrence of certain demographic variables and *to measure* this populations' opinion towards a topic of interest. Quantitative approaches emphasise the value of numerical data in order *to seek explanations,* and, to *find correlations.*[152(p.5)]

In pharmacy practice research, surveys are frequently used to collect quantitative data.[163(p.113)] Surveys enable the collection of numerical data in a large population, are typically easy to administer and low in cost.[155(p.233)] The collected data can take many forms, but frequently included variables pertain to demographic information (e.g. gender, ethnicity) or investigate individuals' opinion towards a certain *concept* of interest. Bryman[155] refers to the term *concept* as phenomena or elements that are present in the social world. Consequentially, concepts are often the centrepiece of social research and surveys may be developed to investigate a (or several) concept(s) of interest in a target population.

However, attempting the measurement of complex social concepts often requires an indirect approach. That is, a number of questions pertaining to the same concept are included, in an attempt to cover the topic from different angles and therefore as comprehensively as possible. Exemplarily, measuring individuals' trust in healthcare providers using a single question (i.e. directly) may be difficult to achieve, due to the intangibility of the concept 'trust'. However, a combination of multiple measurement items may be used to measure the concept comprehensively. Subsequently, questions that are representative of the same concept may be combined to form a scale. Scales, and other variables included in the questionnaire, can then be subjected to inferential data analysis, depending on the objectives of the research. However, each step in survey research, from determining the concept to analysing the data, requires distinct methodological considerations. Thus, each decision inevitably affects the acquired data and obtained results, and in consequence the relevance of the findings for the overall research question. In order to transparently report on the decisions made during this research project, the following section is split in two parts. First, an overview of survey development is provided, sampling decisions are outlined and data collection methods introduced. Here, non-statistical methods to validate the content of surveys are discussed, and bias that can be introduced during the sampling and data collection phase of surveys outlined. The second part of this section is dedicated to the analytical methods; in line with this section's focus on mathematical concepts, a discussion of the statistical methods that were used to validate the survey content is provided.

2.4.1 Survey development, modes of data collection and sampling

Table 2-6 provides an overview of the three surveys that have been distributed during the course of this research project. All three surveys were cross-sectional in nature.[155(p.59)]

2.4.1.1 Survey development: from objective to final questionnaire

As illustrated in table 2-6, three survey instruments investigating two different topics were distributed during this research project. Survey 1 and 3 (part 1) investigated community pharmacy users' opinions towards mental health support provided in pharmacies. Survey 2 and 3 (part 2) were developed to investigate university students' as well as community pharmacy users' use of loyalty cards and attitudes towards the use of the recorded data for health research purposes. Therefore, during the survey development process it was vital to design questions which embody those topics accurately, i.e. to develop a questionnaire with high *validity* for the concepts under investigation.

Table 2- 6 Overview of survey instruments

	Survey 1: Community pharmacy survey 2019	*Survey 3: Community pharmacy survey 2020*		*Survey 2:Student survey 2020*
		Part 1	Part 2	
Objective	Topic 1: Investigate community pharmacy users' attitudes towards mental health support provided in community pharmacy.	Topic 1: Investigate community pharmacy users' attitudes towards mental health support provided in community pharmacy.	Topic 2: Investigate loyalty card use and attitudes towards the use of loyalty card data for health research in a pharmacy user population.	Topic 2: Investigate loyalty card use and attitudes towards the use of loyalty card data for health research in a university student population.
Collected demographic information	Age, gender, community pharmacy use	Age, gender, ethnicity, long term conditions, community pharmacy use		Age, gender, ethnicity, mental health and wellbeing, university related variables (e.g. degree type)
Population and inclusion criteria	Community pharmacy users in Nottinghamshire, age 18 or older	Community pharmacy users in Nottinghamshire, age 18 or older		Students enrolled at the University of Nottingham, age 18 or older
Expert review and piloting	Expert review, pilot with mock-pharmacy customers	Expert review, pilot with mock-pharmacy customers		Two pilots with n=14 and n=8 students
Timeframe	March 2019	March 2020		11 December 2019-01 March 2020

Survey distribution	12 Community pharmacies in Nottinghamshire	15 Community pharmacies in Nottinghamshire	Online
Recruitment	Pharmacy users were actively approached and asked to participate	Pharmacy users were actively approached and asked to participate	Distribution of leaflets with QR codes linking to the survey on campus, recruitment using social media, active approaching on campus and in lectures
Survey administration	Face-to-face by 24 third year pharmacy students	Face-to-face by 30 third year pharmacy students	Self-administered

Validity

The *validity* of a measurement instrument is concerned with the instruments' ability to capture and measure the concept under investigation. In turn, the extent to which a set of questions represents the concept under investigation has consequences for the understanding and interpretation of the questions by the target population. In other words, if the included questions fail to represent the concept accurately, survey participants might interpret the meaning differently, and respond according to their interpretation.[164]

Several different forms of validity exist, pertaining to different ways of assessing the questionnaire item's representativeness of a concept. *Face-and-content validity* are established using non-statistical methods, and will be elaborated on below. *Construct validity*, i.e. the relationship of a set of questionnaire items with a concept, can be investigated using statistical methods and will be outlined in section 2.4.2.2.3.[164]

Face-and-content validity

A meticulous survey development process and the subsequent piloting of surveys in the target population are methods to establish and assess the face validity, and the content validity of questionnaires. Both validity types are closely related and specify the relevance of the developed questionnaire items for the concept under investigation. *Face validity* refers to the intelligibility of the questionnaire by the prospective survey participants; face validity is established through questionnaire piloting with experts and prospective participants.[164] *Content validity* examines whether or not a questionnaire covers all relevant issues related to the content it is supposed to cover. This also means that irrelevant topics are excluded. The establishment of content validity is achieved through expert review and comparison with the literature.[164]

2.4.1.1.1 Investigation of attitudes towards mental health service provision in community pharmacy

My involvement with the community pharmacy survey 2019 begun after the survey had already been developed and distributed. The survey assessed pharmacy users' attitudes towards general healthcare topics and community pharmacy, and towards mental health support provided in pharmacies. Researchers with experience in survey research and a background in pharmacy practice developed the questions. It was further reviewed by an external expert panel (i.e. members of the research board of a large community pharmacy chain) and had been piloted with mock-pharmacy users.

I then analysed the obtained data. Simultaneously, a literature review that aimed to provide an overview of the state of mental health support provided in community pharmacies was conducted. Thus, the results from the survey analysis, and the information obtained from the literature review, informed the content of the survey in the succeeding year, i.e. the community pharmacy survey 2020. Additionally, to address the shortcomings of the survey conducted in 2019 (see 3.2.7.1), several newly developed questions were added. Throughout the development process, the survey content was discussed within the research team. After finalising the survey, an external expert panel (i.e.

members of the research board of a large community pharmacy chain) reviewed the questions. The reviewers suggested some minor changes in questionnaire wording and recommended the omission of some questions, which they considered to be too intrusive for the setting in which the survey was conducted (i.e. open community pharmacy environment). The final questionnaire was then piloted with a number of mock-pharmacy customers. The participants of the pilot recommended minor changes in questionnaire wording, which were subsequently implemented.

Ethical approval for both surveys was granted by the University of Nottingham School of Pharmacy Ethics committee (Ref-number: 023-2017er). This ethics documents covers the annual distribution of the community pharmacy survey, and has been written and submitted before my involvement with the project begun. Therefore, the ethics document is not included in this thesis. However, the later, qualitative phase of the research project (2.5) required an amendment to the initial ethics; the amendment has been written and submitted by me, and can be found in Appendix 6.

2.4.1.1.2 Investigation of loyalty card use and attitudes towards the use of loyalty card data in health research.

This survey was developed using a stepwise, iterative process. It was distributed to both a university student population and a sample of community pharmacy users, embedded in the community pharmacy survey 2020.

The decision to conduct a preliminary study with students was based on impressions from the literature review, which indicated that attitudes towards the use of personal data for health research are age-dependent and influenced by individuals' familiarity with the use of personal data for predictive analytics (e.g. personalised advertisement). Therefore, we decided to conduct the study in a clearly demarcated sample before turning to the larger population with greater differences in terms of knowledge about, and exposure to, novel technologies (i.e. the general population). Students provided an ideal starting point as they were thought to be in a similar age range and, as digital natives, accustomed to an extensive use of personal data.

An extensive literature review served as the starting point to establish core ideas for the survey. The initial steps were supported by discussions within the research team, as well as with external experts[9]. Both, the literature review and expert discussions further supported the identification of factors that were thought to correlate with the core concept of interest. Additionally, it became evident that there is a lack of empirical research concerned with the use of loyalty cards in the wider population. Thus, it was decided to cover both individuals use (or non-use) of loyalty cards and attitudes towards the use of loyalty card data in health research.

During ongoing discussions within the research team, the core constructs were progressively refined and a first draft of survey

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[9] Notably, the N/LAB https://www.nottingham.ac.uk/business/businesscentres/n-lab/index.aspx, a Nottingham-based data science group

questions developed. Throughout the process of developing the survey, a number of questions were omitted, while others were consecutively added. Following this iterative process ensured that the concept under scrutiny was sufficiently covered, before the survey was submitted for ethical approval.

Ethical review

Both questionnaires were independently submitted for ethical review. Ethical approval for the survey conducted in a student sample was granted by the University of Nottingham Ethics Committee (Reference number: 019-2019). The ethics documents can be found in Appendix 1. The survey investigating community pharmacy users' attitudes towards the use of loyalty card data for health research was embedded in the community pharmacy survey 2020. Ethical approval was granted by the University of Nottingham School of Pharmacy Ethics committee (Reference number: 023-2017er).

Survey piloting

Subsequently, questionnaires were piloted with prospective participants (university students or community pharmacy users). In the case of the student survey, the survey was piloted twice, due to students enrolled in pilot one (n=14) highlighting several issues they encountered. Students recommended to modify the wording of some questions, and highlighted two questions which they found difficult to understand. Thus, the survey was modified and a second pilot with a different cohort of university students was conducted (n=8). No further changes were recommended. The questionnaires intended for distribution in pharmacies were piloted with mock-pharmacy customers. Minor changes in wording were recommended and implemented in the final questionnaire.

2.4.1.2 Modes of data collection and consequences for the investigated sample

In the previous paragraph, I discussed the first steps of survey development, the art of developing the most applicable questions, phrased in the most comprehensible way to be able to measure the phenomenon of interest as accurately as possible. Thereafter, the conceptualised surveys are distributed within the *target population*; thus heralding the next step: the *collection of data.*

The term *mode of data collection* encapsulates aspects concerning the collection of the survey data, e.g. *how* and *where* participants were approached, *which* types of survey instruments were chosen and *how* the survey was eventually administered.[165] The chosen data collection methods can have a number of implications for the obtained dataset. Firstly, the choice of data collection method may pose a threat to the representativeness of the collected data for the target population, for example by leading to insufficient coverage of the population of interest (e.g. due to sampling issues) or low *response rates* (*Non-measurement errors*). Moreover, a number of biases may be introduced *(i.e. Measurement errors),* for example by creating an environment in which participants are more likely to give a socially acceptable response (*social desirability bias*) or in which the skills of the survey-administrator affect the obtained responses, both positively and negatively *(interviewer bias)*. Errors introduced during the data collection process lower the quality of the obtained data and, in consequence decrease the generalisability of the results for the target population.[165,166(pp. 275-289)]

2.4.1.2.1 Community pharmacy survey 2019/2020

Both surveys conducted in community pharmacies in Nottinghamshire in 2019 and 2020 took the form of interviewer-administered pen-and-paper surveys. Distributing the survey directly in community pharmacies provided best access to the target population and ensured that individuals in each age group were able to participate. Finally, the interviewer-assisted format was thought to increase participation rates[166] and provided 3rd year MPharm students with an opportunity to get involved in a research project. 12 and 15 community pharmacies in Nottinghamshire served as study sites in 2019 and 2020, respectively. Two students were assigned to each pharmacy, thus in 2019 and 2020 24 and 30 students assisted with data collection, respectively. The following eligibility criteria were applied:

- Pharmacy users were aged 18 years or older
- And visitors of the community pharmacy at the time of study

Participants were verbally invited to participate by the students who assisted with the data collection; no information about the upcoming survey was distributed in pharmacies prior to the start of data collection. No financial incentives were offered for participation. Equipped with the printed questionnaires, students approached participants they identified as eligible. After a participant was approached, students went on and first provided participants with some general information, such as length of the survey, ethical approval and credentials of the responsible organisation (i.e. the University of Nottingham, School of Pharmacy). Convincing participants of the legitimacy of a study is thought to have positive effects on data quality.[165]

Participants responded verbally to the questions posed by students while the interviewers filled out the corresponding questionnaire item. In 2019 it took approximately 10 minutes to complete the survey, while the questionnaire was marginally longer in 2020, completion took approximately 15 minutes.

The community pharmacies we chose as our study sites were located in Nottinghamshire, a county in the larger area of the English East Midlands. However, the included pharmacies were predominately situated in close proximity to the city of Nottingham, were the University of Nottingham is located. All included pharmacies were part of a larger chain of community pharmacies. However, the included study sites were purposefully chosen to represent a range of different types and locations of pharmacies. Pharmacies in affluent and less affluent areas were included as well as large, retail-focused, shopping centre affiliated pharmacies and smaller more health-focused pharmacies. The participating study sites had been part of the annual survey which is conducted in corporation with the University of Nottingham School of Pharmacy (i.e. community pharmacy survey) for a multitude of years.

2.4.1.2.2 Student survey

The survey was distributed across the student body of the University of Nottingham from 12 December 2019 to 01 March 2020 and took the form of a self-administered online survey. Students were invited to participate and were then able to complete the survey at a time and location convenient to them, using a mobile device or computer. The targeted population encompassed every student enrolled at the University of Nottingham at the time of data collection, irrespective of the status of enrolment. Thus, the following students were eligible to participate:

- Students currently enrolled at the University of Nottingha,
- students in full – and part time education
- undergraduate – and postgraduate students
- students aged 18 years or older

The most recent student statistics were used to estimate the size of the target population.[167] An online survey was thought to be beneficial for investigating the views of the student population for a number of reasons:

- The majority of students grew up as digital natives, thus being accustomed to the use of information and communication technology since their early childhood.
- Conceptualising the survey as an online survey opened up alternative ways to distribute the survey, such as social media or email distribution lists.

- It increased flexibility; there was no necessity for students to be present on campus to be able to complete the survey.

A variety of different distribution methods was selected to disseminate the survey as widely as possible across the student body (Figure 2-2). In terms of distributing the survey online, two approaches were used. Firstly, a multitude of University of Nottingham social media channels were used to promote the survey (e.g. Facebook groups). Secondly, owners of email distribution lists, the main researcher was familiar with, (e.g. postgraduate student network, mature students, pharmacy students) were asked for their permission to distribute the survey via these lists. In terms of distributing the survey in person, the main researcher approached students on campus and in lectures if gaining approval from the lecturer was otained.

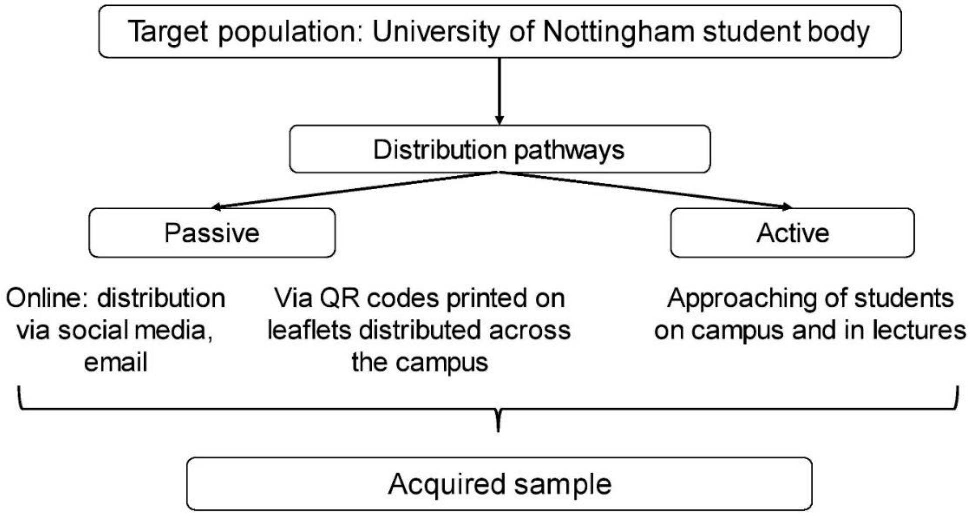


Figure 2- 2 Flowchart student survey distribution pathways

2.4.1.3 Sampling, sample size and response rate

Equally as important as decisions concerning the mode of questionnaire administration are choices pertaining to the prospective study participants themselves. That is, *which* type of sample has been chosen, *how* many participants were invited to participate, and *which proportion* of those who were invited to participate did eventually complete the survey? The answers to these questions have consequences for the representativeness of the sample for the target population and are therefore discussed below.

2.4.1.3.1 Sampling

To keep cost and time of survey research manageable, researchers typically rely on investigating a phenomenon of interest in a smaller sample of individuals drawn from the target population. Ideally, the study sample represents the target population perfectly, therefore results from the sample are *generalizable* to the population of interest.168(p.47)

Thus, methodological choices affecting the composition of the sample can have far-reaching consequences for the applicability of the obtained results for a wider population. Ideally, one aims to conduct a study using a *probability sample*, that is, a sample in which the chances of each individual of a target population to be included in the study sample are known.155(p.187)

The acquisition of a probability sample typically involves some form of randomisation. Frequently used approaches for probability sampling include: attributing each member of the target population a number and selecting prospective participants using a random number generator *(random sample)* or stratifying the sample based on a certain criteria (e.g. age) and selecting randomly from these subgroups (*stratified random sample*).[155(pp.190-192)] However, probability samples require knowledge of the total size as well as the contact details of the population of interest, which may be difficult to obtain. Thus, data collection methods leading to non-probability samples, such as *convenience samples* or *snowball samples* are frequently found in social research. The commonality between all methods leading to a non-probability sample is the high likelihood of acquiring a sample from a population in which not each member had equal chances to be selected. Thus, there is a high chance to introduce a sampling error, leading to low generalisability of the results for the target population. Convenience samples are the most common form of non-probability sampling and refer to the method of simply sampling those individuals a researcher has access to.[155(p.201)]

2.4.1.3.2 Sample size

Generally, the larger the size of a sample, the greater the precision of the obtained results. That is, a large sample size increases the chances that the predictions made from the sample data reflect the target population.[155(p.198)] However, increasing the sample size does not reduce the errors introduced through the chosen methods of data collection. Thus, even results from a large sample might not be representative of the target population if the sample composition deviates from the population.

Furthermore, sample size calculations are dependent on the *power* of a study to detect an effect.[169] Bowling[166] refers to '*statistical power'* as a measure to determine whether or not a study (or test, i.e. the statistical power of a test) is able to detect a statistically significant difference between two groups. Three factors are pivotal for the determination of the power of a test: the selected significance level, the sample size, *and the differences between the two groups*, which are being juxtaposed.

Ergo, to calculate the required sample size of a study, it is necessary to estimate the expected effect before the study commences. In situations where the aim of a study is to determine the effect of a single intervention (i.e. treatment vs. no treatment), sample size calculations are straightforward.[168(pp.64-65)] However, due to the multitude of outcomes measured in survey-based research (i.e. responses to each questionnaire item) it is theoretically necessary to calculate the required sample sizes to reach statistical significance for each questionnaire item separately.

To calculate required sample sizes, formula (1) is applicable.[170]

(1) $$n = \frac{p(100-p)z^2}{E^2}$$

Where:

n = required sample size
p = expected size of effect (%)/expected occurrence of an outcome
z = the z-value of the chosen level of confidence (for 95% CI, *z* = 1.96)

E = Margin of error (5%)

Using the student sample as an example, it can be demonstrated that a calculation of the recommended sample size for each questionnaire item can be avoided under certain circumstances. Exemplarily, we specify a 95% confidence interval and tolerate a 5% margin of error. The only variable term in equation (1) is now p, the expected size or occurrence of an outcome (e.g. the percentage of agreement to a questionnaire item). If p takes the hypothetical values of 10%, 50% and 90% one obtains the following results:

Table 2- 7 Sample size calculation

Expected size of effect (p)	90%	50%	10%
Required sample size (n)	138	384	138

Thus, the largest sample size to reach statistically significant results for the target population is needed if we expect the outcome to occur in 50% of cases. Therefore, using equation (1) and expecting a mixed outcome of the results provides a solid estimation for the maximum sample size necessary to reach statistical significance. However, a sample size calculation as demonstrated above, fails to take the analysis of sample sub-groups, such as age and gender into consideration. Thus, if a subgroup analysis is desired, this needs to be reflected by the size of the sample.[166(p.193)]

2.4.1.3.3 Response rate

The response rate delineates the number of individuals who decided to participate in a study from the total number of approached individuals.

Thus, the response rate provides evidence for the number of individuals who agreed to participate in a study.[155(p.199)] The lower the number of responders, the higher the chances that both groups differ significantly in their composition, which, again, reduces the generalisability of the obtained results for the target population.[165] The mode of questionnaire administration can have an effect on obtained response rates; surveys administered face-to-face may achieve higher response rates compared to other methods, such as postal questionnaires. However, response rates are on the decline, irrespective of the mode of questionnaire administration.[165] Thus, voices advocating a shift from a sole focus on response rates to probing the representativeness of an obtained sample to the target population are getting louder.[171]

2.4.1.3.4 The community pharmacy survey

In theory, every community pharmacy user in Nottinghamshire was eligible to participate in both surveys, 2019 and 2020 (i.e. population of interest). However, neither the total number of community pharmacy users per time variable (i.e. day, month) nor their contact details were known. Thus, participants were not selected at random; survey administrators invited those individuals to participate who visited the study sites at the time of data collection. The sample drawn from those surveys conducted in community pharmacies is therefore a convenience sample of pharmacy users of a specific chain of community pharmacies in Nottinghamshire.

Survey administrators were instructed to collect basic demographic information of non-responders, thus a total number of approached individuals is available and responders and non-responders demographic characteristics can be compared.

2.4.1.3.5 The student survey

Although the total number of students enrolled at the time of data collection was known, associated contact details were unavailable. Thus, randomisation did not occur. Instead, a multitude of methods was used to distribute the survey within the student population of the University of Nottingham (Figure 2-2). The passive distribution of the survey link (via social media and email distribution lists) impedes an estimation of the total number of approached individuals. A recommended sample size was calculated prior to the commencing of the study, in order to achieve a sufficiently large coverage of the population under investigation. Thus, this sample presents a convenience sample of students enrolled at the University of Nottingham at the time of data collection. No demographic information is available for non-responders. Thus, potential differences between individuals who decided to participate and those who did not cannot be assessed.

2.4.1.3.6 Summary of survey development, modes of data administration and sampling

In total, three surveys pertaining to two core topics were distributed during this research project. The content of the surveys was systematically developed to ensure that the topics of interest were sufficiently covered. The modes of data collection were selected to cover both distinct samples of interest as adequately as possible.

However, due to time and financial constraints as well as a lack of access to required information (such as contact details) the '*gold standards'* (e.g. random probability sampling) of survey research could not always be adopted. In consequence, it is possible that a number of biases, such as self-selection bias have been introduced during data collection. Potential sample bias and their impact on the generalisability of the obtained results will be discussed in the strength and weakness sections of each chapter reporting questionnaire results.

2.4.2 Quantitative data analysis

After distributing the developed cross-sectional surveys and collecting individuals' responses, the obtained numerical data were subjected to an in-depth data analysis phase. A strong emphasis was placed on the analysis of the quantitative data because the results were used to inform the subsequent qualitative data collection phases. Thus, data were first analysed descriptively, followed by an analysis of the data using inferential statistical methods.

2.4.2.1 *Introduction*

2.4.2.1.1 Data set

Although different concepts were explored in each survey, similar question types were used in all surveys, thereby generating similar types of variables. That is, questions pertaining to individuals' demographic information predominantly resulted in categorical data, ordinal data was acquired through a multitude of included Likert scale questions and questions which required open-ended responses provided participants with an opportunity to provide free-text answers. Thus, for each survey, similar analysis methods were applicable.

2.4.2.1.2 Data management

Data from paper-and-pen questionnaires were digitalised by those students who assisted with the data collection and uploaded on a dedicated platform (i.e. PharmOutcomes®[172]). The student survey was distributed online using the platform JISC surveys,[173] no digitalisation was necessary. All data sets were then downloaded and imported into Microsoft Excel;[174] duplicates were deleted. Missing data was coded as 'not answered'. Data were then imported into Stata Release 16 (StataCorp, Texas, USA). Research data management processes were devised to comply with University of Nottingham standards. That is, survey data will be stored securely for seven years after the final publication of the results. Email addresses and telephone numbers of survey participants were stored for six months following the distribution of the surveys. These requirements were embedded in the submitted research ethics documents and hence approved by the approving ethics committee (Appendix 1,6).

2.4.2.1.3 Missing data points

Missing data can present a considerable challenge for the analysis of survey data, if the number of missing data points is large and if individuals with missing data points differ considerably from those without.[175]

In survey research, missing data may be produced if an individual refuses to respond to a survey altogether (*non-response*) or refuses to respond to individual questionnaire items (*item non-response*). Additionally, the inability of the sampling method to reach every individual of the hypothetical population may lead to inaccurate population coverage and therefore missing data points.[176] The implications of non-response and inaccurate population sampling for the quality of the obtained results have been discussed previously (section 2.4.1). Likewise, item non-response poses a considerable challenge in survey research. Item non-response decreases the number of available complete scale score, which if the aim is to combine questionnaire items to form a scale, can impact the validity of the obtained results.[177]

2.4.2.1.4 Missing data analysis

For this research project, a systematic approach to missing data analysis was developed and applied to all datasets.

Firstly, the percentage of missing data per questionnaire items was calculated. This step provided some preliminary insights into the magnitude of data missing per questionnaire item. Secondly, all questionnaire items were dichotomised in order to create a binary variable, distinguishing between responders and non-responders. Two-way or more-way tables with measures of association (i.e. chi-square test) were then used to investigate correlations between responders (or non-responders) and the main demographic variables in the respective datasets (e.g. age, gender). Lastly, based on the results obtained from the analysis of missing data, the possible implications for the dataset and the validity of the results was determined (e.g., whether or not item-responders and non-responders differed significantly).

In the majority of cases, this research project adopted a complete case analysis approach. That is, participants without a response were omitted from the analysis, missing responses were not imputed.[175] However, if significant differences between item responders and item non-responders occurred, these are discussed in the strengths and weaknesses section of each respective chapter.

2.4.2.2 *Statistical analysis*

Descriptive and inferential statistical analyses were conducted using the software Stata, Release 16 (StataCorp, Texas USA). Throughout the analyses the significance level was determined as $p<0.05$.

2.4.2.2.1 *Descriptive statistical analysis*

Firstly, all data sets were analysed descriptively to obtain frequency counts and percentages. Descriptive results are presented using frequency tables or stacked bar graphs.

2.4.2.2.2 *Significance tests for categorical data (χ^2)*

In some instances, it can be worth investigating whether or not a relationship between two (or more) categorical variables exists. This case can be examined using contingency tables. Typically, one aims to investigate a possible association between two binary coded categorical variables (e.g. a hypothesised association between use of community pharmacy (yes/no) and individuals' gender (female/male)). If this is the case, one relies on 2x2 contingency tables, the associated test is known as a χ^2-*test*. Fundamentally, χ^2-tests determine the extent to which both variables are associated by comparing obtained and expected values (Equation (2)).

(2) $$\chi^2 = \sum \frac{[O_i - E_i]^2}{E_i}$$

Where O_i denotes the observed frequency and E_i denotes the expected frequencies. The statistical significance of the result is assessed by comparing the obtained value with a table containing the critical values for χ^2- tests. Similarly, associations between categorical variables with more than two response categories can be investigated. However, the increasing number of *degrees of freedom (df)* has to be taken into consideration.

(3) $$df = (r - 1)x\ (c - 1)$$

Where *r* denotes the number of rows and *c* the number of columns in hypothetical contingency table.[168(p.251-255)] Associations between categorical variables were investigated using Stata's “chi2” command.

2.4.2.2.3 Psychometrics

In section 2.4.1.1, I first introduced the concept of validity as well as non-statistical methods to determine the extent to which a set of questionnaire items represents a concept under investigation. The field of research which is concerned with the mathematical assessment of validity and reliability of a set of questionnaire items is known as *psychometrics.*[178(p.2)] In combination, both criteria are reflective of the *rigour* of the research process and outcomes.[156(p.215)]

Reliability

Reliability is defined as a scales' ability to be consistent in the measurement of the concept under investigation.[164] Specific aspects of reliability can be assessed using statistical methods, well-known and frequently used is Cronbach's α, a measure of inter-item reliability to evaluate the internal consistency of a set of measurement items. Cronbach's α can be calculated according to equation (4).

$$(4) \qquad \alpha = \frac{k}{k-1}\left(1 - \frac{\sum s_i^2}{s_T^2}\right)$$

Where k denotes the number of included items, s_i^2 describes the variance of individual questionnaire items, and s_T^2 represents the variance of the sum of all items. α can range from 0 to 1, where 1 denotes a perfect correlation between the items, and 0 describes an absence of correlation. For non-clinical applications, α values above 0.7 are considered satisfactory.[179]

Scalability and construct validity

The extent to which a set of questionnaire items pertains to the same latent trait and can therefore be summarised to form a scale, can be investigated using statistical methods, such as item response theory (IRT). This is sometimes referred to as the *scalability* of set of questionnaire items.[164]

In its attempt to identify those questionnaire items that are representative of the same latent trait, scalability demonstrates similarities with the investigation of construct validity. Construct validity is referred to as the extent to which a measurement scale is representative of the concept under investigation.[164] In order to investigate the construct validity of a set of measurement items, methods of classical test theory (CTT), such as factor analysis (FA) are typically chosen.

Consequently, IRT models are considered a valuable alternative to CTT, and sometimes even seen as complementary to CTT as both approaches attempt to answer similar analytical questions.[164] However, some scholars argue that data at the interval level is necessary for conducting a meaningful factor analysis.[164] This is grounded in the finding that CTT methods appear to be prone to over-dimensionalisation when applied to ordinal level data, i.e. truly one-dimensional scales, comprised of ordinal questionnaire items, were identified as multi-dimensional using CTT methods.[180]

For the majority of questionnaire items in my surveys I used a Likert-response scale, therefore ordinal data was generated. Thus, IRT models provided an ideal candidate for the statistical analysis of the latent structure of the questionnaire.

2.4.2.2.4 Mokken scaling

Similar to classical test theory, IRT is primarily an umbrella term to summarise a number of statistical models. Of the available methods to investigate the latent structures of this questionnaire, *Mokken scaling* was found to be most suitable. Mokken scaling is a non-parametric method to evaluate the correlation between questionnaire items and a latent trait and can be used for items with polytomous response categories.[181]

Background:

The foundations for Mokken scaling can be found in Guttman scaling,[182] and most of the general principles of Guttmann scaling remain applicable to later developed models, including what is known today as 'the Mokken model'.

The principles of the Guttman model are best exemplified using a theoretical set of questionnaire items with dichotomous response categories (Table 2-8).

Table 2- 8 Theoretical set of questionnaire items (Guttman scaling) taken and adapted from: Watson, van der Ark et al[181]

Question	*Response*
I like supporters of opposing football teams.	Yes/no
I would sit next to an opposing supporter on a bus.	Yes/no
I would speak to a supporter of an opposing team.	Yes/no
I would invite an opposing supporter to my house.	Yes/no
I would allow an opposing supporter to marry one of my children.	Yes/no

The questions in Table 2-8 are ordered purposefully. That is, the logic underlying the example implies that an individual, who is willing to accept the marriage of one of his children with a supporter on an opposing football team, would also accept sitting next to an opposing supporter on a bus. In other words, while the questionnaire items increase in *difficulty* (i.e. they are less likely to be endorsed), it is possible to make inferences about a respondents responses to previous 'less difficult' (i.e. more likely to be endorsed) items. If all questionnaire items pertain to the same underlying trait, scores on a hierarchical Guttman scale allow the researcher to categorise the extent to which a latent trait is present in a questionnaire respondent. Guttman scales are thought to be cumulative in nature.[181] In line with the example introduced above, one could categorise an individual who solely responded 'no' as generally intolerant towards supporters of opposing football teams, while an individual who endorsed all items is highly tolerant. This scope from low presence of a trait to high presence is sometimes called the latent trait continuum.[183(pp.5-14)]

Graphical representation

It is further possible to represent the Guttman model graphically. A graphical approach will further be valuable for the outlining the assumptions underlying the Mokken scaling procedure. I assume two questionnaire items (m,n) with dichotomous response categories which are said to measure the same underlying trait. No violations of the ideal Guttman scale were observed. Questionnaire item m is more likely to be endorsed by participants (i.e. it is less difficult) and questionnaire item n is less likely to be endorsed by questionnaire participants (i.e. it is more difficult). Figure 2-3 represents this scenario graphically, where (Θ) represents the latent trait and *p*(Θ) the probability of endorsement of n and m.

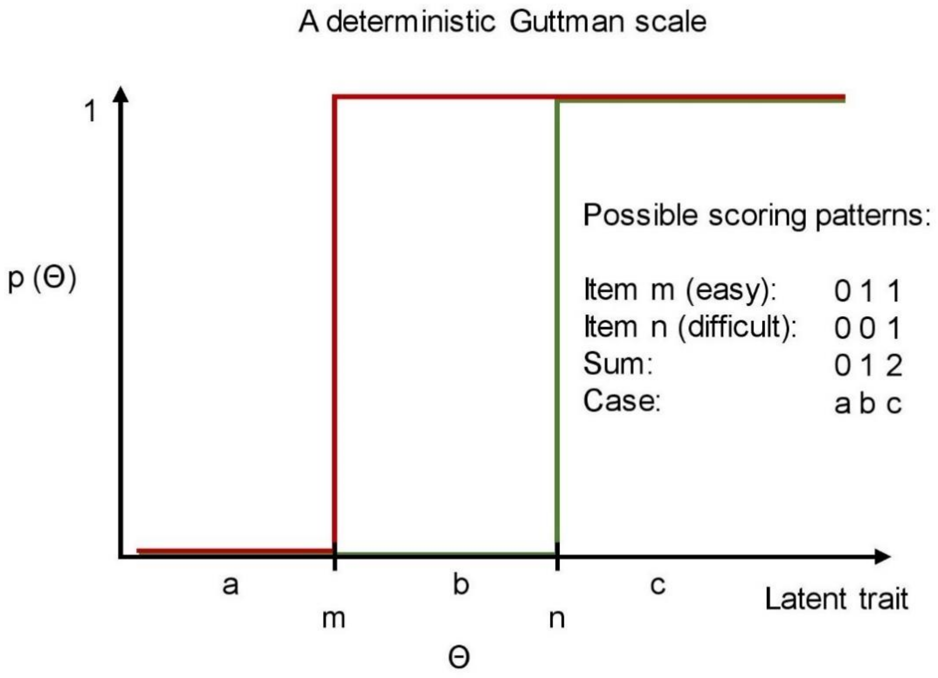


Figure 2- 3 Deterministic Guttman scale

In a hypothetical, ideal scenario with two questions, three scoring patterns can be observed. No endorsement of either item (a; 0,0), endorsement of the easier item but not the difficult item (b, 1,0) or endorsement of both items (c; 1,1). Under the assumption that Θ is continuously increasing, scenarios a,b and c, can be interpreted as follows.

a: low / no presence of the investigated trait

b: the trait is somewhat present (the easier item has been endorsed) c: the trait is more present (both, the difficult and easy item have been endorsed).

Figure 2-3 is sometimes referred to as a *deterministic* or *perfect* scale, because no deviations from the ideal pattern can be observed.[183(pp.5-14)] The term *deterministic* refers to the fact that the Guttman methods fails to take any stochastic elements into consideration, i.e. the relationship between questionnaire items (m,n) and Θ is not measured on the grounds of *probability*. In other words, the probability of the relationship between an individuals' level of trait and his or her score on an item being related is not taken into account; instead the relationship is strictly deterministic in that it only distinguishes between presence and absence based on whether or not an individual endorsed or rejected an item.[181]

Loevinger's H coefficient

So far, the principles of IRT models have been considered in an ideal scenario, that is, questionnaire respondents only endorse difficult items if preceding easier items have also been endorsed. However, in a real world scenario individuals' response patterns are likely to deviate from the ideal case. Exemplarily, an individual could endorse an item which is considered more difficult but reject an easier item; thus violating the cumulative scale. Therefore, the Guttman method takes observed deviations from the ideal (i.e. violations of the ideal pattern) into consideration ('Guttman error').[181,183pp. 15-32] Table 2-9 depicts a two-way contingency table of two questionnaire items (m,n) with dichotomous responses, a potential Guttman error is highlighted in red.

Table 2- 9 Contingency table

		Item m (‘easy’)	
		1 (Endorsement)	0 (No endorsement)
Item n (‘difficult’)	1 (Endorsement)	1,1	**0,1 (error)**
	0 (No endorsement)	1,0	0,0

Moreover, the number of committed errors lays the foundation for deciding which items have the desired properties to be included in a scale; it is therefore a criterion for *scalability.* In order to evaluate the number of violations committed in a data set, it has been proposed to compare the errors that have been observed in a dataset, with the number of expected errors, assuming *statistical independence*. Consequently, Loevinger’s *H* coefficient was introduced (also known as Loevinger’s coefficient of homogeneity); the coefficient is widely used as a criterion for scalability. For scales with two items, *H* is calculated using formula (5), where Err(obs) denotes the number of observed errors (i.e. how many respondents deviated from the ideal response pattern) and Err(exp) denotes the expected errors, assuming statistical independence.

(5) $$H = 1 - \frac{Err(obs)}{Err(exp)}$$

Further, equation (5) can be extended to be applicable for scales with more than two items, see equation (6).

$$(6) \qquad H = 1 - \frac{\sum_{i=1}^{k-1}\sum_{j=i+1}^{k} Err(obs)}{\sum_{i=1}^{k-1}\sum_{j=i+1}^{k} Err(exp)}$$

For both formulas (5) and (6), if $H=1$, perfect model fit can be assumed, i.e. the model does not contain any errors. On the other hand, if $H=0$ the model is characterised by a lack of fit. The agreed upon threshold to assume scalability is 0.3.[183(pp.15-32)]

In practice, H is a measure of homogeneity between two (or more) questionnaire items. In other words, $H=1$ equals perfect homogeneity, while $H=0$ represents a dataset where all responses are unrelated. That is, if two questionnaire items are homogenous at the $H>0.3$ level, they are thought to form an item pair. Importantly, H is always calculated for all item pairs in a scale, i.e. each individual item is required to reach $H>0.3$ with every other item one aims to include in a scale, irrespective of the number of items.[183(pp.15-32)]

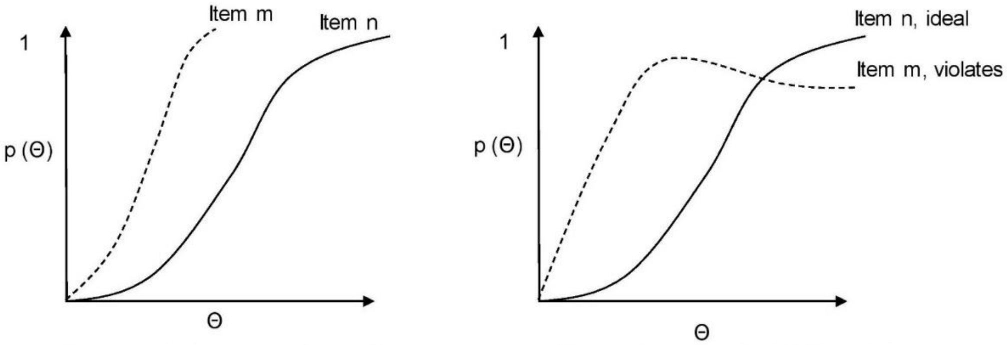
Beyond its use as a scalability coefficient, H can be used to indicate the strength of a scale. $H=0.3$-0.4 indicates a weak scale, a medium scale is characterised by $H=0.4$-0.5, and a strong scale is indicated by $H>0.5$.[181]

Mokken scaling

The foundations and general principles introduced above are applicable to the *Mokken method.* However, Mokken scaling provides a number of benefits compared to other IRT models. Firstly, it is non-parametric in nature and therefore less restrictive compared to its parametric alternatives such as the *Rasch model*.[184] Secondly, rather than being deterministic in nature, the Mokken model is probabilistic; stochastic elements are taken into account.[181] Thirdly, Mokken scaling is applicable even if the number of included questionnaire items is low.[184] Furthermore, the Mokken method is suitable for questionnaire items with polytomous response categories.[183(pp.70-87)] Therefore, the Mokken method is well suited to investigate the scalability of the underlying dataset.

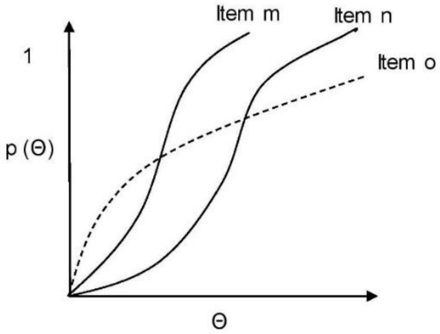
Assumptions of Mokken scaling

The Mokken model is underpinned by three fundamental assumptions. Unidimensionality, local stochastic independence and thirdly, the item response function is required to be monotonically non-decreasing.[184] Unidimensionality implies that all scale items measure and pertain to the same latent dominant trait. Secondly, the requirement that a respondent's score on a scale is solely influenced by the extent to which the latent trait is present in that participant is referred to as 'local stochastic independence'. Importantly, a respondent's score on one item is thought to be independent from scores on other items. Lastly, the Mokken methods requires the item response function to be monotonically non-decreasing. Monotone homogeneity is best described graphically (Figure 2-4, panel a.); both item curves m and n increase throughout the latent trait continuum (Θ).



a. Two monotonically non-decreasing ICC, where item n is more 'difficult' but less discriminating

b. Item n adheres to the MMH model, Item m violates MMH



c. Item m and n adhere to the DMM model, item o does not. (Dichotomous items)

Figure 2- 4 Graphical evaluation of the Mokken model

The graphs displayed in Figure 2-4 represent the relationship between item scores and the latent trait graphically; therefore, they are typically referred to as *item characteristic curves* (ICC). Monotonically non-decreasing ICC conform to the probabilistic nature of the Mokken model. That is, the probability of achieving a higher item score increases along the latent trait continuum. Similarly, ICC are representative of the nature of the questionnaire item (Figure 2-4, panel a). The ICC representing item m identifies questionnaire item m as less difficult to endorse (compared to item n), but more discriminating, as indicated by the steepness of the curve. In short, ICC are a visual representation of the monotonicity assumption and they additionally function as the unit of analysis in the Mokken model. It is distinguished between two different conceptual models, the model of monotone homogeneity (MMH) and the double monotonicity model (DMH).

MMH (model of monotone homogeneity)

Based on the assumption that all ICCs pertaining to the same latent trait are required to be monotonically increasing along the latent trait continuum, items that violate this assumption can be identified and excluded from a scale (i.e. they do not adhere to the MMH, Figure 2-4, panel b). Moreover, the item sum score is reflective of the magnitude of the latent trait[184] and enables the ordering of individuals along the investigated trait. These features of the MMH model are harnessed by statistical software packages to evaluate the properties of a set of questionnaire items.

DMM (double monotonicity model)

DMM can be interpreted as an additional assumption of the Mokken model, which is quintessential to evaluate whether or not the included questionnaire items can be ordered meaningfully. Figure 2-4, panel c, represents the DMM graphically. The ordering of individuals along the latent continuum based on their sum score is also referred to as invariant item ordering (IIO). In short, if no violations (i.e. no intersections) across all included items can be detected, IIO can be assumed and the scale is thought to have a hierarchical structure. However, fundamentally, the DMM as it is displayed in Figure 2-4, panel c, only applies to items with dichotomous response categories. If an investigation of the ordering of questionnaire items with polytomous response categories is attempted, it is necessary to investigate whether or not each item's *item step response functions* (ISRF) intersect.[181]

In short, polytomous response categories are divided to represent each 'step' along the response categories as one function; in the case of a five- point Likert-scale: four ISRF are generated. Finally, the same criteria which have been established, that is, H>0.3, monotone homogeneity and non-intersection in the DMM should also be met by polytomous items and their respective ISRF.

Stata procedure

In order to be able to investigate the scalability of the dataset, all Likert-scale items were coded (0-4), and if necessary reverse coded to generate a uniform data set. Stata does not contain a feature to perform the Mokken method by default. However, additional packages, such as the *msp* package, written by Hardouin, Bonnaud-Antignac and Sebille[185] are freely available and can be added to Stata. The initial search for scalable items was performed using the "msp*" command*; the threshold for item inclusion was set to H>0.3.

Questionnaire items which met the requirements for scalability were examined to assess whether or not a logical link can be established (*scale conceptualisation*). This included an investigation of excluded questionnaire items, especially if they were hypothesised *a priori* to relate to the concept under investigation.

Questionnaire items that were identified to pertain to the same trait statistically and logically were subjected to further analysis using Stata's "loevh" command (*scale properties*). Loevinger's *H* coefficients for the entire scale are reported, as well as the number of committed Guttman errors. A Stata command to investigate the properties of a scale reads as follows:

Loevh *variable list*, pairwise ppp pmm graph monotonicity (*) nipmatrix (*)

The monotonicity subcommand allows the investigation of the monotonicity assumption, a critical value (i.e. Crit < 80) has been defined as an indicator for whether or not the monotonicity assumption has been met. Monotonicity can further be evaluated graphically (i.e. *graph*). The subcommand "nipmatrix" was used to investigate non-intersection between the item characteristic curves, a critical value of Crit<80 is indicative of non-intersection. However, due to the special requirement necessary for the investigation of non-intersection of polytomous items (i.e. non-intersection of ISRF), P++ (i.e. *ppp*) and P-- (i.e. *pmm*) matrices were generated. Values in the p++ matrix are required to be consistently increasing, which implies adherence of the ISRFs to the IIO assumption. Consistently decreasing values in the P -- are an additional indicator for IIO. Finally, questionnaire items that were found to be representative of the same latent trait using the Mokken method, were summarised to form a scale.

2.4.2.2.5 Multilevel modelling

Introduction

In a nutshell, multilevel modelling is simply an extension of standard regression analyses. However, in contrast with traditional regression models, multilevel modelling approaches take the structure of the underlying data set into consideration. A data set has a multilevel structure when the individual sampling units (i.e. survey respondents) are nested within a bigger grouping unit (e.g. study sites). In the case of this research project, respondents (i.e. individual sampling units) were approached in a community pharmacy which was part of a bigger pool of study sites (*n*=12, *n*=15). Therefore, survey responses are nested within the sampling unit community pharmacy (Figure 2-5). Multilevel models take differences between the context in which the data were collected (e.g. the community pharmacy setting) into consideration and therefore provide a better depiction of the social world.[186(p.6)] Moreover, if a data set has a multilevel structure, the assumptions underlying standard regression models might not be met, in particular the assumption of *independence of observations.* That is, in a dataset with a multilevel structure, observations are indeed not independent from each other, and are instead likely to be influenced by the aspects of the setting in which the data were collected (e.g. the community pharmacist, the shop environment, size). Hence, the application of a multilevel model is recommended.[186(pp.1-21)]

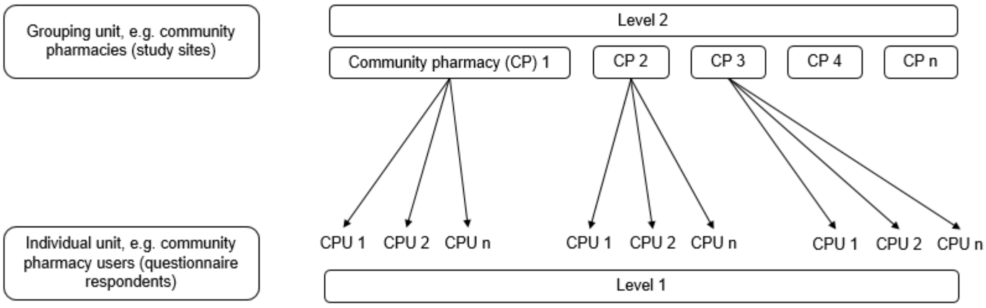


Figure 2- 5 Unit diagram of a two level clustered structure, CP=community pharmacy, CPU=community pharmacy user

Background

As stated above, multilevel regression models are an extension of standard regression models. A simple linear regression model without any independent variables (i.e. null-model) can be described using equation (8).

(8) $$y_i = \beta_0 + e_i$$

Where y_i denotes the value of y for the ith individual (i=1,…,n), β_0 represents the overall mean (or intercept) of y in given population, and e_i denotes the residual, that is, the difference between an individual's actual y -value (obtained value) and the population's mean (β_0). Formula (9) extends (8) for the purpose of a multilevel model:

(9) $$y_{ij} = \beta_0 + \mu_j + e_{ij}$$

Characteristic for multilevel models is that not one single population mean (intercept, β_0) is calculated, but that, in addition to the intercept, an overall group mean (i.e. group intercept) is calculated for each grouping unit independently. Thus, multilevel models are sometimes described as '*random intercept models*'; which refers to the approaches' characteristic of creating random intercepts for each included group individually. The equation term μ_j added in formula (9) describes this characteristic mathematically. μ_j denotes the group-level residual for the j^{th} group. That is, the value which denotes the distance between the overall mean β_0 and the mean of group j.[187]

Figure 2-6 depicts a multilevel model with two grouping units graphically. $\mathrm{CPU}_{11} - \mathrm{CPU}_{14}$ are hypothetical questionnaire respondents in community pharmacy one (CP 1) and $\mathrm{CPU}_{21} - \mathrm{CPU}_{24}$ are hypothetical questionnaire respondents in pharmacy two (CP 2). Responses of participants in CP1 equate to a mean slightly above the overall mean β_0. For each group (i.e. sampling unit) an individual group mean (or intercept) is calculated. The difference between the overall mean β_0 and the group mean is characterised using equation term μ_1. Respondents individual residuals between the group mean and the obtained value y are described using equation term e.

Sample size in multilevel modelling

Importantly, two different samples sizes are distinguished in multilevel modelling. The level 1 sample size (individual sampling units) and the sample size at level 2 of the model (grouping units). Due to the generally lower sample size at level 2, sample size issues are more likely to arise at the grouping level.

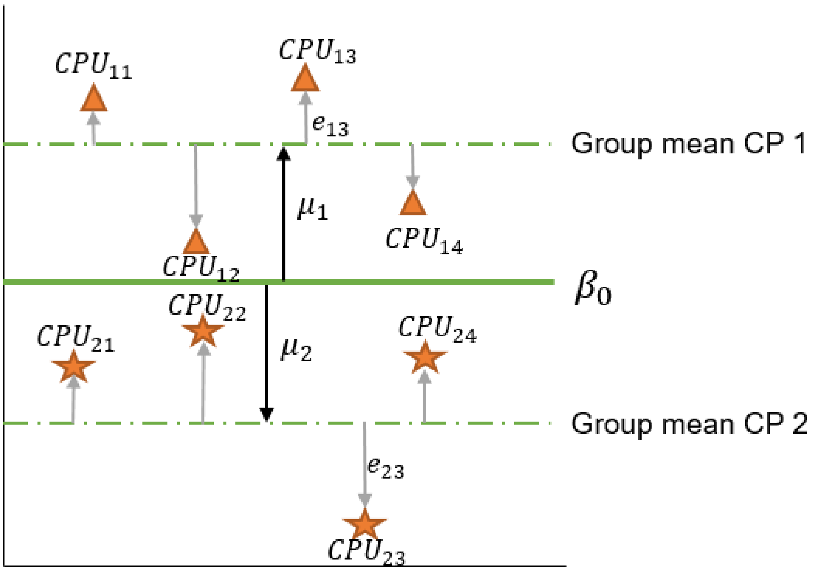


Figure 2- 6 Graphical depiction of a multilevel model with two grouping units adapted from Steele[187]

As a general rule of thumb, a minimum number of grouping units of n=20 (level 2) is recommended for multilevel models.[186(p.26)] Simulation studies have demonstrated that a low sample size at level 1 is unlikely to cause any severe issues, while a sample size of *n*<50 at level 2 can result in biased estimates of the standard error at this level.[188] However, some scholars advocate for the data structure as the decisive element, that is, if the data are organised in a multilevel structure, a multilevel model should be applied.[189] In our case, sample sizes at level two were n=12 and n=15, thus, it needs to be assessed whether an increasingly complex model (i.e. applying a multi-level model) is superior to a single-level model, despite a low sample size at level 2. For that purpose, a likelihood ratio test can be performed. A significant superiority of a multi-level model over a single-level model justifies the application of the former.

Likelihood ratio test

The log-likelihood values of a constructed model are a measure for the *fit* of the model. The term ‘model fit’ refers to the extent to which the constructed model is able to depict the original data, or, in other words, how accurately the model’s predicted values represent the obtained data. The discrepancy between predicted and obtained values is known as a model’s *residuals*; the sum of all residuals (i.e. errors) denotes the model’s overall lack of fit and is encompassed in the log-likelihood statistic. In short, the less errors (i.e. residuals) the better the performance of the model. Thus, an increase in model complexity (e.g. by constructing a multilevel model instead of a single-level model) should result in an improvement of the fit of the model, that is, the mismatch between obtained and predicted values should decrease significantly.[186(p.58)]

Consequently, the null-hypothesis (H_0) that constructing a multilevel model improves the fit of the model can be tested by comparing a single-level model to a multilevel model using a likelihood ratio test (10).

(10) $LR = -2\log L_1 - (-2\ logL_2)$

Where L_1 denotes the likelihood test statistic of the single-level model and L_2 denotes the likelihood test statistic of the multilevel model .[187] The obtained value follows a χ^2-distribution and can be interpreted accordingly. Stata provides a comparison of single-level model and multi-level model according to (10), including the corresponding p-value. H_0 is rejected when $p<0.05$.

The variance partition coefficient (VPC)

In order to assess which proportion of the total observed variance within a model can be attributed to differences between groups, one calculates the VPC according to:

$$VPC = \frac{\sigma_{\mu}^{2}}{\sigma_{\mu}^{2}+\sigma_{e}^{2}} \tag{11}$$

Where σ_{u}^{2} denotes the variance between groups (μ), and σ_{e}^{2} denotes the variance within a group (between individuals) e.

The VPC can range between 0 and 1. The value 0 describes that the total observed variance can be attributed to differences within individuals (meaning that there is no evidence for multilevel-effects in the data). A value of 1 means that the total observed variance can be attributed to differences between groups (which would mean that all individuals within one group scored exactly the same).[187] The VPC of a multilevel model can be calculated using Stata's *estat icc* command as a post-estimation command after a multilevel model was constructed.

Commonly a VPC of equal to or greater than 0.1 (meaning that 10% of the total variance can be attributed to differences between groups) is used as a threshold for considerable between-group effects. However, the applicability of this threshold is debated in the literature. Some scholars recommend the construction of a multilevel model irrespective of the size of the group effect; the structure of the underlying data is regarded as the decisive element.[189]

For the purpose of this research project, the data structure was the determining element for the construction of a multilevel model;

however, the VPC is reported throughout. Additionally, so called 'Caterpillar plots' (i.e. standard error bar charts of relative random intercept values) are reported. Caterpillar plots depict the relative intercept values for each individual grouping unit (i.e. the group mean) and the respective standard error. Thus, caterpillar plots provide information about the distribution of group means across the study cohort and aid the assessment of group effects.

Adding explanatory variables

After the multilevel-null-model is assessed for its significance over a single-level model and the distribution of group means across the study cohort has been determined using 'caterpillar plots', explanatory variables are added to the model. Results from the multilevel analysis with explanatory variables are interpreted akin to standard regression models. That is, coefficients to denote the effect each independent variable has on the overall group score (β_0) are calculated and assessed for their significance using the p-value. Thus, coefficients for each added explanatory variable are reported as well as their corresponding p-values.

Diagnostics

Lastly, the fit of the constructed model, and the extent to which the necessary assumptions for multilevel modelling were met have to be assessed.

Model fit

Earlier, the use of the log-likelihood statistic to compare single-level to multilevel models has been introduced. Similarly, the log-likelihood value can be used to assess model fit after explanatory variables have been added. A significant decrease in the model's likelihood test statistic, according to equation (10) is expected in order to conclude that the fit of the model has been improved.

In addition to the likelihood test statistic, two other measures of model fit are available in multilevel modelling: AIC (Akaike information criterion) and BIC (Bayesian information criterion). For both measures a reduction of the obtained value after increasing the complexity of the model indicates improved model fit.[186(p.58)]

Throughout I report, the likelihood test statistic and assess the changes for their significance using (10). Additionally AIC and BIC are reported.

Assumptions

Similar to traditional single-level models, multilevel models require a number of assumptions about the data to be fulfilled in order to obtain valid results; however multilevel models are considered more flexible than standard regression models.[190]

One important aspect pertaining to the assumptions of multilevel models compared to single-level models has been mentioned previously; the necessity for observations to be independent. Additional assumptions necessary for multilevel analyses, and their tests were outlined by Snijders and Bosker[190]and Robson and Pevalin[186] (Table 2-10).

Table 2- 10 Assumptions of multilevel modelling, adapted from Robson and Pevalin[186] and Snijders and Bosker[190]

Assumptions	*Description*	*Test*
Hierarchical structure	Are levels classified accurately?; Are levels omitted in the analysis, despite being structurally present in the data?	Study design, model specification
Explanatory variables	Are explanatory variables categorised in accordance with the level they are affiliated with?	Study design, model specification
Level 1 residuals: Normal distribution, mean of zero (0)	Are level 1 residuals normally distributed with a mean of zero?	Histogram of level 1 residuals; Q-norm plot of level 1 residuals
Level 2 residuals: Normal distribution, mean of zero (0)	Are level 2 residuals normally distributed with a mean of zero?	Histogram of level 1 residuals; Q-norm plot of level 1 residuals

2.5 Qualitative methods

In order to elucidate the findings I obtained from the quantitative phase of this research project, qualitative data, in the form of semi-structured interviews was collected and subsequently analysed. However, before delving deeper into the steps which surrounded the acquisition and interpretation of the qualitative data I will introduce another data source which was used in the course of this research project and which might be best interpreted as an intermediate between qualitative-and quantitative data: open-ended questionnaire responses. This specific nature of open-ended questionnaire responses can pose unique analytical challenges, which will be elaborated on below.[191]

2.5.1 Open-ended questionnaire responses

As explained previously, the community pharmacy survey 2019 had already been circulated at the time my involvement with the research project begun, but not analysed. Two of the included open-ended questions aimed to explore pharmacy users views on how pharmacy could provide better assistance for individuals with mental health issues. However, it became apparent that participants had instead used the questions to discuss the state of mental health support provided in pharmacies more generally. Therefore, these open-ended questions provided an ideal opportunity for preliminary insights into the perspectives of a large cohort of pharmacy users towards the topic under investigation.

2.5.1.1 Analysis of open-ended questions

Firstly, open-ended responses were imported into NVivo[192] to aid with data management and analysis.

After combining the responses from both questions, a dataset with a quantitatively large number of often brief responses was obtained (n=2965, 2019). In order to analyse the data in a timely, yet sufficiently extensive manner, a flexible analysis approach, enabling a qualitatively informed, in-depth analysis of a quantitatively large number of responses was required. After discussion, content analysis was deemed to potentially yield insufficient results, due to the quantitative nature of the method. At this stage, the analysis-approach was curiosity-driven and exploratory, therefore the application of a pre-existing framework was not justified. Instead, an inductive thematic analysis of the responses was conducted, using the steps outlined by Braun and Clarke[193] as a guide. However, due to the briefness of the responses, these were not analysed beyond the semantic meaning of the data. A preliminary thematic map was developed after coding the first 100 responses and reviewed after coding 400 responses. The map was refined until every gathered response had been reviewed and codes attached. This approach resulted in the development of a preliminary framework, which was then, together with the results from the quantitative part of the questionnaire, used to inform the subsequent, qualitative phase.

2.5.2 Qualitative data: Data collection, sampling and recruitment

2.5.2.1 Introduction

In addition to the above mentioned open-ended questions, semi-structured interviews were used to explore students' and pharmacy users' perspectives on the two core topics of this research project, *attitudes towards mental health support provision* and *towards the use of loyalty card data to identify individuals at risk of developing mental health issues.* In line with the sequential explanatory methodology that underpinned the research project, interviews were conducted after the surveys had been distributed and subjected to a preliminary analysis. *Why* I chose to conduct semi-structured interviews, *how* the quantitative findings influenced the development of the interview guides, and *how* the data were analysed and interpreted will be outlined in the following paragraphs. The content of this section is guided by the consolidated criteria for reporting qualitative research (COREQ), which aim to support the systematic evaluation of the *quality* of qualitative inquiry.[194] Guidelines to evaluate the quality of qualitative research were synthesised following a longstanding (and ongoing) debate about the extent to which qualitative inquiry should be subjected to quality assessment and the criteria which should be adopted for its critical appraisal.[152(pp. 76-107),195,196,197(pp. 1373-1409)] In order to address those controversies, this section will be concluded with a brief discussion of the points of criticism qualitative inquiry is confronted with, and the quality criteria which have been adopted for this project.

2.5.2.2 Choice of qualitative data source

The quantitative data I collected for this research project provided a descriptive account of individuals' attitudes towards mental health support provision as well as towards the use of loyalty card data to identify individuals at risk of developing mental health issues. However, quantitative data fails to provide an in-depth explanation for individuals' attitudes, beyond those factors, for which a correlation was assumed a priori. For the purpose of understanding individuals reasoning behind their expressed views, the richness and depth qualitative data provides is ideal.[155(p.5)] Thus, qualitative research phases, following both questionnaires distributed in 2020, were devised.

2.5.2.3 The initial plan

Initially, I planned to conduct *focus groups*, a method to collect qualitative data which is frequently adopted in pharmacy practice research.[163(p.143)] Focus groups were thought to be superior to other qualitative research methods, such as interviews, for two reasons. Firstly, the group interaction can be beneficial for the generation of new ideas, which would have supported our objective of exploring new roles for pharmacists in the provision of mental healthcare. Secondly, focus groups enable participants to exchange knowledge about the investigated topic. This was thought to be beneficial for the intended discussion of the use of loyalty card data in healthcare; a topic which might have been rather abstract for some participants.[163(p. 143-144),198] Additionally, focus groups had successfully been used by a similar study which aimed to explore individuals' attitudes towards the use of

Twitter data for depression monitoring.[134] Thus, in line with this study's methodology, I intended to split prospective participants in groups of individuals with experiences with mental health issues and those without. Additionally, adopting this method was thought to create an atmosphere where participants feel comfortable discussing topics as sensitive as mental health issues and beneficial to explore whether or not individuals' views differ in both cohorts.

2.5.2.4 The impact of COVID-19

The first series (n=4, two with students with self-reported mental health issues and two without) of focus groups was scheduled to take place between 24 March 2020 and 02 April 2020. Unfortunately, these dates coincided with the announcement of the first lockdown in England due to COVID-19 on 23 March 2020; lockdown measures came legally into force three days later. Additionally, the University of Nottingham, which provided the location for the facilitation of the focus groups, closed on 20 March 2020. Therefore, focus groups could not be held as planned and a plan to mitigate the impact of COVID-19 on the research project had to be devised (Figure 2-7).

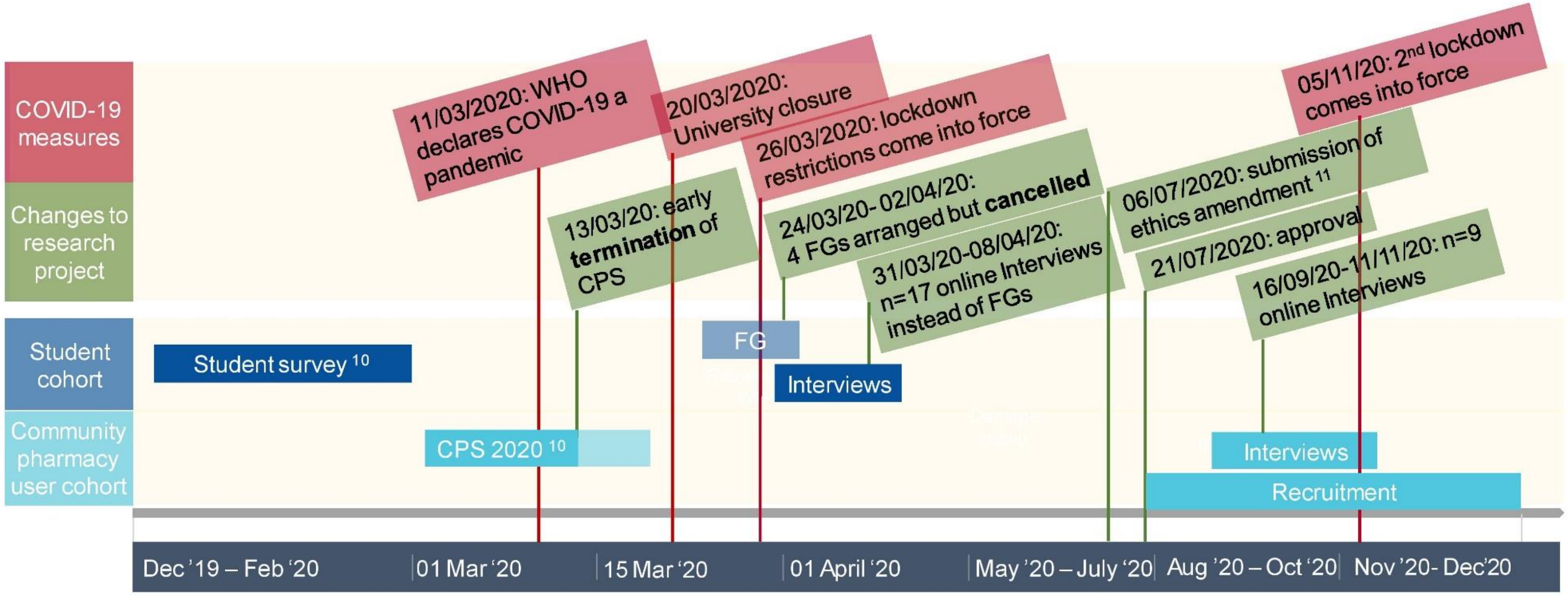


Figure 2- 7 The impact of COVID-19 and mitigating measures, CPS = Community pharmacy survey, WHO = World health organisation, FG=Focus groups

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[10] Both surveys also served as a recruitment tools for the qualitative research phase.

[11] The ethics amendment contained the semi-structured interview guide and introduced additional recruitment possibilities.

2.5.2.5 *Mitigating measures*

2.5.2.5.1 *Student interviews*

The general uncertainty of the situation, while trying to avoid losing participants due to time delay, made it necessary to rapidly reconceptualise the study. In the case of the focus groups we had planned to conduct with students, communication within the research team and with the approving ethics committee led to the decision to conduct online individual interviews with students instead. This was possible because the original ethics document included approval for conducting focus groups as well as for semi-structured interviews, as it was unclear at the time of writing, whether recruitment would be sufficient for the facilitation of focus groups. However, despite the ethics committee being supportive of the idea to conduct interviews online instead of face-to-face, it pointed out that the recoding of videos had not been approved and therefore the conversations should only be audio taped.

Interestingly, the prospect of conducting online interviews instead of groups affected individuals' willingness to participate positively. Retrospectively, the more intimate format of conducting face-to-face interviews might have helped some participants to talk more openly about previous mental health issues. Exemplarily, some student participants disclosed previous suicide attempts and how this experience influenced their stances. It can only be speculated to which extend participants would have been comfortable to disclose this information in group discussions, however it was felt that conducting semi-structured interviews instead of focus groups did not decrease the depth in which the subject was discussed.

Ethical approval for the interviews with the students cohort was granted by the University of Nottingham Ethics committee, reference number: Reference number: 019-2019 (Appendix 1).

2.5.2.5.2 Members of the public

In the case of the interviews I had planned to conduct with the wider public, ethical approval had not been sought at the time the impact of COVID-19 unravelled. Although this provided opportunities to develop strategies to mitigate the impact of COVID-19, two problems persisted. Firstly, the student focus groups were perceived as an opportunity to explore whether group discussions are suitable for the fulfilment of our study objectives. However, as described above, student focus groups could not be held as planned. Additionally, the pandemic resulted in the cancellation of all upcoming graduate school courses, including a course covering the facilitation of focus groups, which was scheduled for 01 April 2020. My lack of experience with the facilitation of focus groups, as well as the positive experiences I had gained during the interviews conducted with students, resulted in the decision to adopt a similar methodology with members of the public.

Secondly, the community pharmacy survey 2020, which preceded the qualitative phase, was intended to serve as the primary recruitment tool for follow up research participants. However, as Figure 2-7 illustrates, the survey was terminated prematurely due to the ongoing deterioration of the situation surrounding COVID-19. Hence, less survey participants declared interest in follow up research than anticipated. Thus, the ethics amendment I drafted for this phase of the research project stated that semi-interviews will be conducted (via telephone, online or face-to face, depending on the circumstances). Additionally, alternative recruitment strategies (e.g. via social media) were introduced, for which I designed a recruitment poster which was distributed digitally on social media and physically in community centres (Appendix 9).

Ethical approval for conducting interviews with survey participants and members of the public was granted by the University of Nottingham Ethics committee. For that purpose, an amendment to the original ethics documents (Ref-number: 023-2017er) was submitted for review. The ethics form can be found in Appendix 6.

2.5.2.6 Development of interview guides

Semi-structured interview guides were developed prior to the commencing of both qualitative stages of this research project. The use of semi-structured interview guides was considered to be beneficial for two reasons. The 'structured' aspect ensured that topics that were recognised to be crucial for the fulfilment of the study objectives were covered sufficiently and addressed in each respective interview. On the other hand, conceptualising the interview guides as 'semi-structured' introduced the necessary freedom for additional topics to emerge freely based on participants' responses.[155(p.471)]

Both interview guides were developed based on the literature reviews I conducted at the start of this research project, as well as the preliminary results I had obtained from analysing the survey data. Subsequently, the developed interview guides were piloted with both, students (n=3) and members of the public (n=4), respectively. Minor amendments to improve the flow of the interviews were recommended and implemented. Considerations pertaining to the two topic guides specifically are outlined below.

2.5.2.6.1 Student interviews

The objective of the student interviews was to investigate students' opinion towards the use of loyalty card data to identify individuals at risk of having mental health issues in more depth.

The topic guide and the preceding survey were submitted jointly for ethical approval. Thus, the topic guide was kept deliberately brief, in order to account for the quantitative results. (see Appendix 4). At the beginning of each interview participants were provided with a definition of personal data, according to the GDPR,[199] in order to avoid ambiguous interpretations of the concept. Additionally, participants were provided with examples of how personal data could be used in a health research context (e.g. social media data to monitor mood, or location data to track someone's activity level). Further into the interview, I introduced interviewees to summaries of recent publications using loyalty card data to identify physical or mental health conditions, in order to aid participants understanding of the topic and stimulate discussions.[99,102]

2.5.2.6.2 Public interviews

The interviews with the public covered the two core topics of this research project jointly. That is, participants were asked to share their opinion about mental health service provision in pharmacies and towards the use of loyalty card data to identify individuals at risk (see Appendix 8 for topic guide).

The preliminary results from the preceding survey with pharmacy users informed the content of the interview guide. However, experiences I had made during the student interviews also influenced its composition. A separate ethics document had to be submitted for this phase of the research project after all preceding research phases had been completed. Hence, the developed interview guide was more specific. After positive experiences with the student interviews, it was decided to introduce members of the public to recent publications pertaining to the use of loyalty card data in a health context to stipulate discussions.

The timeline in Figure 2-7 illustrates that the interviews with members of the public were conducted while measures to contain the spread of COVID-19 were still in place. In the literature review, I highlighted the impact COVID-19 had on public mental health and wellbeing. Additionally, the use of personal data, such as location data emerged as a key element in the fight against the pandemic (1.6.3). Thus, both key topics of the interviews were influenced by the external circumstances. Consequently, it became necessary to contextualise participants' experiences during the pandemic, such as the impact (of the pandemic) on mental health and wellbeing and awareness of the use of personal data in strategies to contain the spread of COVID-19. Hence, a number of questions investigating both topics were embedded in the interview guide.

2.5.2.7 *Qualitative sampling and recruitment*

The sample size required for qualitative research is often difficult to estimate before a research project commences.[155(p.425)] Statistical methods to calculate necessary sample sizes, as discussed for quantitative approaches (in section 2.4.1.3.2) are not applicable for qualitative inquiries. The primary focus of qualitative sampling strategies is not on acquiring a sample that is representative of the population of interest; instead the researcher aims to collect sufficiently rich data which enables an in-depth understanding of the topic under investigation. Consequentially, qualitative research results are rarely generalizable to the whole population.[200] Nevertheless, findings from qualitative studies may be transferable to other circumstances or settings.[155(p.392)] Thus, several strategies to ensure that the collected data are sufficiently rich were employed.

Firstly, qualitative researchers typically rely on purposeful sampling. That is, the selection of cases (e.g. participants) which are thought to be ‘information-rich’ and relevant to the topic under investigation are preferred over a random selection of cases with the aim of achieving population representation.[155(p.418),200] However, if it is not feasible for the researcher to adopt purposeful sampling methods, for example due to time constraints or due to difficulties with recruiting a sufficient number of participants, convenience sampling methods can provide an alternative.[201] Secondly, although strongly debated in the methodological literature,[202] the concept of *thematic saturation* is frequently applied in qualitative inquiry. The term refers to the idea that new participants are included in a study until no additional themes are thought to emerge from the narrative data. Thus, thematic saturation has been reached.[202] However, it is important to note that no concrete rules for the realisation of thematic saturation are agreed upon, and that the decision to cease additional sampling of participants depends on the researcher.[155(p.426)] In order to provide some guidance about sufficient sample sizes in qualitative research, Sandelowski[200] proposes to aim for sample sizes which are large enough to cover the topic adequately, but not too large, which might result in a superficial analysis of the collected bulk of data.

2.5.2.7.1 Student recruitment

The survey preceding the qualitative phase of this research served as the sole recruitment tool; the final question of the questionnaire allowed students to declare interest in follow-up research participation. As described above, the initial objective was to sample participants based on their previous experiences with mental health issues.

Although a large number (n=162) of participants reported to be interested to participate, only a minority of students responded to our repeated calls for further participation. Thus, owing to the low interest in participation and the change in methodology from conducting focus groups to semi-structured interviews, sampling criteria were discarded. All students who agreed to participate were interviewed; the sample can be described as a convenience sample. Despite the sampling and recruitment difficulties, an even distribution of participants with and without mental health issues was achieved.

2.5.2.7.2 Public recruitment

Similarly, the community pharmacy survey 2020, which preceded the qualitative phase of the research, was intended to be the main recruitment tool. However, less pharmacy users than anticipated declared interest in follow up research. The inconvenient timing of the survey, might have added to the low interest rate (Figure 2-7).

Therefore, in order to boost participation, additional recruitment methods were introduced during the ethical approval process for the interviews. Additional recruitment methods entailed recruitment via social media (such as Twitter, Facebook and Instagram), the opportunity to invite individuals directly (e.g. direct approaching) and snowballing methods (i.e. participants were encouraged to invite additional individuals[155(p.424)]). However, government measures implemented due to COVID-19 hindered the direct approaching of individuals. Thus, and due to low engagement rates on social media with the study, the additional recruitment strategies did not have the intended success and study participation remained low. All individuals who agreed to participate were interviewed, irrespective of whether or not they had previously received a diagnosis of a mental health issue; the sample can be described as a convenience sample. Additional sampling criteria were: participants had to be aged 18 years old or above and currently living in Nottinghamshire.

2.5.3 Data collection and analysis

2.5.3.1 Student data collection and data analysis

2.5.3.1.1 Interview scheduling

One main disadvantage of (physical) focus groups is the requirement for all participants to be present at the same point in time at a location ideally convenient to all. Thus, conducing semi-structured interviews instead, increased the flexibility with which interview appointments could be scheduled and participants were able to join from a location convenient to them. More flexibility about time and location might have added to students' willingness to participate, as indicated by higher interest rates after recirculating the call for participants with the information that we opted to conduct online semi-structured interviews instead of focus groups.

2.5.3.1.2 Interview process

Before the interviews commenced, each participant was send a participant information sheet as well as a consent form. However, due to the virtual setting in which the interviews were conducted, students were unable to sign the form. In line with the recommendations given by the approving ethics committee, consent was obtained by reading out the consent forms to each participant and asking for verbal confirmation. This process was audio recorded.

Next, participants were informed of the interview ground rules, such as the option to pause or interrupt the interview at any time, should the interviewee feel uncomfortable or distressed. All interviews were conducted by me, and I introduced myself as student, without specifying that I was studying for a PhD or my previous occupation as a pharmacist. This was thought to lessen possible power imbalances and increase participants comfort to talk about topic as sensitive as mental health issues. During the interview process, I engaged in an extensive note-taking process, in order to capture the atmosphere of each conversation. This proved to be valuable information during the analysis process. Lastly, participants were asked to verbally complete a short survey (see Appendix 3). The survey collected basic demographic information, such as age and gender and use of loyalty cards.

2.5.3.1.3 *Data management and analysis*

Demographic data collected from the short surveys were analysed descriptively and are presented in chapter 5.

The interviews were audio recorded, therefore, the obtained data had to be subjected to a processing stage before the analysis could commence.

First, the recorded audio data were transcribed verbatim and anonymised; the transcribing was done by the main researcher. This process was undertaken using the software NVivo (Version 12) [192], which allowed me to listen to the narrative data repeatedly and transcribe it. For that purpose, several NVivo features, such as decreasing the speed of the audio files, proved to be invaluable.The process of transcription commenced immediately after interview completion, thus, it was possible for me to reflect on the flow of the interview and its content, for example whether or not additional probing questions should be considered. Retrospectively, this process was especially valuable for my development as a qualitative researcher. It provided me with the opportunity to reflect on my facilitation of the interview and allowed me to progressively improve my interview skills. Additionally, the transcription process eased emergence into the data body. As outlined in section 1.7.6, a dearth of literature pertaining to public attitudes towards the use of loyalty card data in health research in general, and no literature concerned with public attitudes towards the use of these data to identify individuals at risk of having mental health issues were identified.

These findings, as well as the impressions I had gotten during the interview process, informed the subsequent analysis phase. The software NVivo was used to aid with the management and analysis of the narrative data. NVivo had already been used to transcribe the data, hence, no further data input was necessary.

After discussions within the research team, in which the benefits and disadvantages of a number of approaches to qualitative analysis were considered, I decided that *inductive thematic analysis* was the most suitable analysis method for the obtained data. The term inductive thematic analysis encompasses two different concepts, namely *inductive* and *thematic analysis*, which shall be elucidated separately first, before justifying the applicability of inductive thematic analysis for the underlying data.

Firstly, inductive approaches to analysis are characterized as data-driven, or ‘bottom-up’ approaches. That is, the data analysis is solely driven by the content of the collected data itself, without taking any pre-existing frameworks or otherwise published literature into consideration. Thus, following an inductive approach allows the researcher to generate general theories based on the collected data. In turn, inductive approaches may lead to the development of themes which are seemingly independent from the semi-structured interview questions.[193] The decision to follow an inductive approach to analysis was informed by the absence of a pre-existing framework which could have guided the analysis, and owed to the general dearth of literature pertaining to the topic of investigation. However, it has to be acknowledged that my preparatory engagement with the literature might have influenced my approach to analysis, despite making an effort to dissociate from assumptions I had previously developed based on the literature review. Secondly, thematic analysis broadly refers to the concept of trying to find patterns of meaning in data.[203] One main advantage of a thematic approach to data analysis is the flexibility of the method, which can be embedded across a variety of epistemological stances. Thematic analysis further provides the data analyst with the necessary freedom to make decisions about the analytical depth the data are being subjected to, depending on the objectives of the study and the collected data.[193]

Initially, students’ views appeared to be wide-ranging and diversified during the process of transcription and emergence into the data.

However, after having listened to the recordings repeatedly, it became apparent that students' stances, despite being expressed differently, revolved around similar core topics. Thus, inductive thematic analysis provided me with the tools to explore the data in sufficient depth, while also providing flexibility to account for the variety of views students had expressed. Consequently, the analysis was conducted following the steps outlined by Braun and Clarke[193].

First, I familiarised myself with the data by reading and re-reading the transcripts. This stage also entailed an extensive note-taking process; notes captured any impressions gotten from the data and built the foundation for the upcoming analysis steps.

Secondly, the interview data were subjected to a lengthy coding process. In short, the term *code* refers to a denotation assigned to a word, sentence or even whole paragraph of an excerpt, which embodies the essence and meaning of what has been expressed by a participant.[204(p.3)] Coding is by no means a straightforward process, instead it often requires several coding cycles in which codes are being assigned to the data, revised and rearranged.

Thirdly, the assigned codes were reviewed in order to identify those, which pertained to similar themes; subsequently codes were collated into identified thematic categories. This step was succeeded by an extensive review of the identified themes. The process from coding to theme development followed an iterative process, i.e. codes and subsequently developed themes and subthemes were repeatedly revised until a final thematic structure was developed and a framework established. This process was guided by ongoing discussions within the research team. Lastly, names were assigned to the developed themes and the findings written-up.

Data storage complies with University of Nottingham standards, that is, all qualitative data will be stored for seven years after the final publication (see researchethics form, Appendix 1.)

2.5.3.2 Public data collection and data analysis

2.5.3.2.1 Interview scheduling

Ethical approval for conducting interviews with the public was granted on 21 July 2020. Recruitment commenced promptly, starting with the pharmacy users who had declared interest in participation during the survey. At the time the ethics documented was drafted, it was unclear whether or not it would be feasible to arrange meetings in person. However, measures to limit contact between individuals remained more or less in place for the reminder of the year. Therefore, participants were given the option to be interviewed via telephone or virtually, using video software such as Microsoft Teams.[205] Interviews were scheduled at times convenient for the participants. Importantly, a number of participants encountered difficulties with the video software used, leading to the dropout of three prospective participants, despite offering telephone interviews as an alternative.

2.5.3.3 Interview process

The interview process followed the same protocol I outlined above. That is, consent forms and participant information sheets were sent to participants electronically; consent to participate was then verbally confirmed and audio recorded at the beginning at each interview. Notes were taken during each interview. At the end of the conversation participants were asked to complete a short survey; the survey collected basic demographic information as well as self-reported diagnoses of mental issues and use of loyalty cards (Appendix 7). All interviews were facilitated by me. I introduced myself as a research student, thus purposefully omitting my previous occupation as a pharmacist in order to limit the introduction of bias.

2.5.3.4 Data management and analysis

Before the analysis of the interviews commenced, the data were transcribed electronically, using a University of Nottingham provided transcription service. However, due to the incompleteness of the obtained transcriptions, the electronic transcriptions were subsequently subjected to a more traditional ‘manual’ transcription of the data. Again, this process was undertaken by the main research using the software NVivo (Version 12), and subsequently proved to be invaluable for my emergence with the data. Due to the transcription process predominantly taking place in NVivo, the analysis stage could commence promptly, futher data transfer was not needed.

As outlined above, the objective of the interviews with the public was to further explore public attitudes towards mental health support provision in community pharmacy and towards the use of loyalty card data for identification purposes. In order to explore both topics with sufficient depth, it was necessary to choose an analysis strategy that suited the nature of the data. At this stage, two independent frameworks had been developed:

a) The open-ended responses we obtained from the survey distributed in community pharmacies in 2019 resulted in a preliminary framework of community pharmacy users' attitudes towards mental health service provision in community pharmacy.

b) The inductive thematic analysis of the student interviews resulted in the development of a framework of students' attitudes towards the use of loyalty card data in a health research context.

Therefore, the interviews with the public were seen as an opportunity to:

a) Further refine and develop the existing frameworks and clarify encountered ambiguities.

b) Test the applicability of the framework and extend its content beyond a clearly demarcated, but somewhat narrow sample (i.e. students).

In order to address these challenges, I opted to conduct a deductive thematic analysis. As opposed to the earlier introduced inductive approach to analysis, deductive approaches are described as 'analyst-driven'. That is, the analysis is guided by specific aspects of the data which are of interest to the researcher, in my case a) and b). A pre-existing framework may be applied to the data, leading to the conceptualisation of deductive approaches as ‘top-down’.[193] Two further aspects were taken into consideration before opting to analyse the data thematically. Firstly, it was plausible that the briefness of the open-ended responses had resulted in an incomplete framework, that is, additional factors important for public acceptance of pharmacy provided mental health services had been omitted. Secondly, it was possible that the views expressed by students bore little resemblance with those of members of the public, for example due to low exposure to, and knowledge about the use of personal data for analytical purposes. These difficulties were mitigated by opting to conduct a thematic analysis as opposed to other framework driven analysis approaches (e.g. Framework analysis[206]). Thematic analysis provided me with the necessary analytical freedom and flexibility to take the emergence of additional themes into consideration.

The analytical steps follow those outlined in section 2.5.3.1.3. However, the coding process was more structured, due to the application of pre-existing framework to the data. In order to enhance the credibility of the obtained results, a number of transcripts were read by a second researcher, ambiguous results discussed within the research team, and emerging themes probed for their completeness.

Data storage procedures comply with University of Nottingham standards, that is, the obtained qualitative data will be stored for up to seven years, following the final publication from this data set.

2.5.4 Trustworthiness in qualitative research

In the beginning of this section I stated that qualitative inquiry has been the centre of debates concerning the extent to which it should be subjected to quality assessment and, if so, which measures should be adopted.

At its very core, these controversies mirror the dualism between the qualitative and quantitative research paradigm, which I introduced at the very beginning of this chapter. That is, it is disputed whether or not the same criteria which are adopted to evaluate the quality of quantitative inquiry (i.e. validity and reliability) should and can be applied to qualitative research.[152(pp. 76-83),155(pp. 389-397),156(pp. 274-276)]

Some scholars argue that qualitative inquiry should not be subjected to any quality assessment, as this defeats the purpose for conducting qualitative research, i.e. the depiction of individual experiences.[152(p.79)] On the other hand, it is postulated that the adoption of reliability and validity as quality criteria is legitimate in qualitative inquiry, however the criteria should be adapted to comply with the requirements of qualitative research.[195,196] Moreover, some scholars advocate for the adoption of quantitative methods to qualitative data, such as the assessment of 'inter-coder agreement'.[156(p.276)] However, this technique occurs more frequently within the positivist paradigm and its associated methods, as the assumption that the results from two or more independent coders are comparable is legitimised by a positivistic understanding of reality.[207]

During the introduction of this chapter, I described myself as an advocate of pragmatism. That is, the dualism between opposing philosophical stances is disputed, and instead solutions that are tailored to the question under scrutiny are embraced.

In my opinion, the pragmatic tenet can equally be employed to questions concerning the applicability of quality assessments in qualitative research. An underlying objective of qualitative inquiry is the accurate depiction and interpretation of the experiences of individuals who agreed to share those with the researcher. Although quantitative researchers conceptualise reality differently, the overall objective to do justice to the research participants remains prevalent. It follows then, that the extent to which the researcher captured and conveyed individuals' realities needs to be assessed, irrespective of the underlying epistemological and ontological assumptions. Exemplarily, in the section on quantitative methods I raised the question whether or not the conceptualised questions accurately represent the concept I intended to measure (i.e. have the questionnaire items face *validity*?). Thus, instead of regarding quality assessment criteria as a tool to evaluate the *outcome* of a research endeavour, they are the researcher's mechanism to evaluate aspects of the research *process* critically.[197(p.1384)]

I concede that qualitative inquiry is neither immune to quality assessment, nor should criteria that mimic the evaluation of rigour in quantitative research be applied. Instead, I support the *derivation* of quality assessment criteria for qualitative inquiry from existing quantitative criteria, if they are compatible with the adopted paradigm and have practical value. However, a clear demarcation between both approaches, by adopting subject-specific denominators, as proposed by Lincoln and Guba in the 1980s,[197(p.1379-1380)] may abate the constant comparison between both approaches. The umbrella term *trustworthiness* encapsulates criteria which are used to evaluate the quality of qualitative studies; the term can be understood as the qualitative analogue to rigour in quantitative research.[197(p.1379)]

2.5.4.1 Trustworthiness criteria

It is distinguished between four trustworthiness criteria: *credibility*, *transferability*, *dependability* and *confirmability*.[155(p.390)]

The *credibility* of the findings, i.e. the plausibility of the interpretation the researcher proposes based on the collected data is crucial for determining the quality of qualitative inquiry.[155(p.390)] *Member checking*, data *triangulation* [197(p.1380)] and *deviant case analyses* [156(p.275)] have been suggested as measures to increase credibility. Member checking, i.e. cross-validating interview transcripts or interpretations of obtained data with research participants, is not immune to critique from qualitative methodologists.[208] The technique has not been adopted for this project. Data triangulation means that two (or more) different data sources are used to compare or validate outcomes.[195] During this project data triangulation has occurred twice. Firstly, data from open-ended responses have been triangulated with interview data (research stream one). Secondly, the obtained results from the student interviews have been used to guide the analysis of the subsequent interviews with the public, which aimed to refine the preliminary framework and identify omitted factors (research stream two). Additionally, by highlighting disconfirming cases (i.e. deviant case analysis) the validity of the presented account is thought to be enhanced.[156(p.275)]

Transferability has been previously highlighted as the qualitative equivalent to generalisability in quantitative inquiry (section: 2.2.1.3). ‘Rich, thick descriptions’ are sometimes credited with increasing the transferability of findings.[155(p.392)] However, presenting narratives with sufficient depth may have a positive effect on the trustworthiness of qualitative research altogether.[156(p.274)] *Dependability* is seen as the qualitative equivalent to reliability in quantitative inquiry. Lincoln and Gubas’ suggestion[197(p.1380)] to use external audit trails as a method to evaluate dependability has not been adopted widely.[155(p.392)] Lastly, the term confirmability pertains to the extent to which a researcher’s personal stances are absent in the research;[155(p.392-393)] external audit is recommended to evaluate confirmability.[197(p.1381)]

Confirmability addresses a major point of criticism qualitative inquiry is frequently confronted with: the bias the researcher introduces at almost every stage of the research project. However, due to the researcher’s central role during data collection and interpretation, requesting the absence of a researcher’s personal values may bear little value for evaluating the quality of qualitative inquiry. Instead, a number of scholars advocate for a high level of reflexivity in order to address the bias the researcher will undoubtedly introduce.[156(p.274-275),209(p.60)] In other words, it is recommended for the researcher to reflect critically on his or her role during the process of knowledge production. In order to highlight my reflection on my own role, I have emphasised relevant aspects throughout the previous sections, such as how I introduced myself to research participants.

2.5.5 Summary

A qualitative research phase was designed to provide explanations for the results I had obtained during the preceding quantitative research phase. Initially, I planned to conduct focus groups with a cohort of students as well as pharmacy users, but the outbreak of COVID-19 required a rapid reconceptualization of the study. Thus, online, face-to-face interviews were conducted with both, students as well as pharmacy users and additionally sampled members of the public. Both obtained data sets were analysed thematically, however the student data required an inductive approach, whereas the interviews with the public were subjected to a deductive thematic analysis. Measures to increase the trustworthiness of the obtained data and results were implemented, and I made an effort to reflect critically on my own role during the collection of the data.

2.6 Reflection and implications for succeeding phases

This chapter provided an account of the methodology and methods I chose for of this research project. The methodology and methods are rooted in the experiences I gained during the first year of my PhD, which was characterised by ambivalences concerning the direction of this PhD. Almost throughout the entire year, I intended to utilise loyalty card data directly for this research project, in order to investigate its usefulness for the identification of underlying health conditions. However, two experiences resulted in a reconceptualization of my initial plan. Firstly, in August 2019 I attended a graduate summer school about ‘Big Data epidemiology’. I learned the foundations of machine learning technologies in a health context, and discussed possible applications. However, emerging ethical concerns and practical issues, such as how these data could be embedded in a ‘real-world-scenario’ were neglected.

Secondly, during ongoing discussion with experts in data science it became evident that my focus should not be on investigating the feasibility of making predictions about underlying health conditions based on loyalty card data. Instead, these information were already available, but an evaluation of how it can be embedded in and used to inform pharmacy practice was missing. In the same breath, it became apparent that a fundamental requirement for using these data in pharmacy practice, especially in the context of mental health service provision was missing. That is, the public opinion towards mental health service provision in pharmacies in England had not been investigated in-depth.

Equipped with the theoretical knowledge I had gained and influenced by the experiences I had, this study was conceptualised.

However, the outbreak of COVID-19 coincided with the start of my second year as a PhD student, meaning that the clarity I had obtained only recently was again challenged. Methods I had decided on could not be adopted anymore and recruitment strategies I had devised were unfruitful. More so, the use of data in a health context became a widely discussed topic in the media (e.g. ‘test-and-trace’), and we can reasonably state that public perceptions towards the utilisation of personal data were affected by these developments. Hence, the premises under which this research project had commenced were suddenly outdated.

The next chapters will provide an account of results I have obtained in this period of fluctuation. Therefore, throughout the next chapters, an effort was made to outline the context in which the data were collected.

Chapter 3

Mapping the terrain: Public attitudes towards mental health support provided in community pharmacy

3.1 Introduction

This phase of the research reports on findings from a survey distributed in 12 community pharmacies in Nottinghamshire in March 2019. The objective of the survey was to evaluate community pharmacy users' attitudes towards mental health support available in community pharmacy. I commence with a short overview and introduction to the data set, subsequently the results from both, closed- and open-ended questions are presented. This chapter will be concluded with an outline of how findings from this survey have been used to inform subsequent phases of this research project.

3.1.1 Data set

As introduced in section 2.4.1.2.1, the data set from which the results in this chapter originate, had been developed and distributed before my involvement with the research project begun. That is, the community pharmacy survey 2019 had been distributed by third year MPharm students as part of an annual research project of the University of Nottingham in partnership with a large chain of community pharmacies. The questions were developed by experienced pharmacy practice researchers, and aimed to investigate pharmacy users' attitudes towards mental health support provided in community pharmacies. Therefore, my involvement with the data set begun at the data preparation and analysis stage of the survey.

First, the obtained data were prepared and cleaned as described in section 2.4.2.1.2 (Data management). The analysis follows the steps outlined in section 2.4.2.2. Data points were collected at the individual level (i.e. the smallest sampling unit were community pharmacy users, level 1), and individual sampling units were clustered together in larger grouping units (i.e. community pharmacies which served as study sites, level 2). Therefore, the data is organised in a multilevel structure as described in methods section 2.4.2.2.5 and qualifies for a multilevel analysis.

3.2 Findings

Data analysis followed the steps described in methods section 2.4.2. Firstly, responders and non-responders were compared. Secondly, the data were analysed descriptively. Next, the psychometric properties of the questionnaire were assessed, followed by a multilevel regression analysis to identify factors affecting individuals' attitudes.

3.2.1 Participation, total non-response and item non-response

3.2.1.1 Total non-response

During the 3 weeks of data collection 6905 community pharmacy users were approached, of these 3449 agreed to participate (response rate= 49.95%). Survey administrators were instructed to record the gender of pharmacy users who declined to participate and estimate their age. The majority of non-responders was female (n=2427, 70.2%). Non-response was almost evenly distributed across all age groups (18-34: 20.5%, n= 707; 35-49: 27.4%, n=947; 50-64: 20.8%, n=927; 65-79: 20.8%, n=718). Less individuals aged 80 or above declined to participate (4.51%, n=156).

3.2.1.2 Item non-response

All Likert scale questions were dichotomised to delineate individuals who responded to given question (item responders) and those who choose not to respond (item non-responders). Although item non-response increased throughout the questionnaire (Figure 3-1), the response rate per item consistently exceeded the 95% mark.

Item responders and non-responders were compared across the main demographic variables, gender, age group, eligibility for free prescriptions, pharmacy use and frequency of pharmacy use, using contingency tables with measures of association. Up until question 15, the proportion of item non-responders was too small to obtain meaningful results. However, item non-response increased with the commencing of the mental health section of the questionnaire (Q17). No significant differences between item responders and non-responders were found for the variables age group, gender and eligibility for free prescriptions. However, differences between item responders and non-responders use of pharmacies, and frequency of pharmacy use were found. Non-responders were significantly more likely to report using different pharmacies than those who responded (Q17- Q20: p=0.043, p=0.034, p=0.039, p=0.013). Participants who did not respond occurred to use pharmacies less frequently than responders (Q18-Q31, p<0.05). Although these differences were found to be statically significant they were small in absolute magnitude. Thus, the significance of the obtained results could have been driven by the large sample size. Hence, the data set demonstrated suitable properties to perform a complete case analysis.

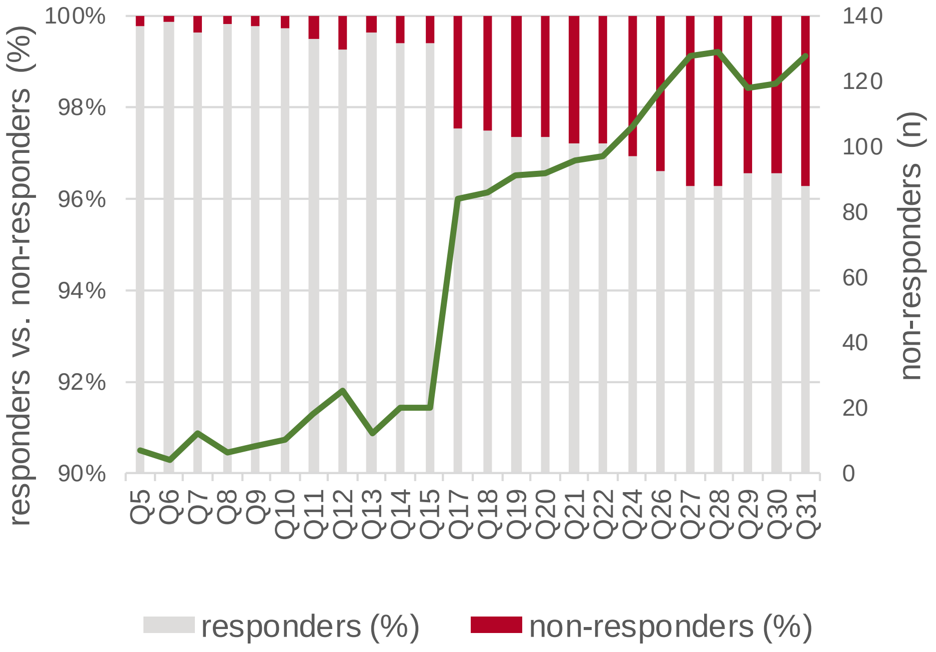

Figure 3- 1 Item response versus non-response (Likert scale-section of the questionnaire)

3.2.2 Sample characteristics

3.2.2.1 Demographic information and pharmacy use

The majority of participants were female (70%), and little more than half of participants reported to be aged 50 years or older (n=1849, 54%). Almost two-thirds (n=2544) of participants reported to use the same pharmacy every time, and of these, 1960 participants completed the questionnaire in the pharmacy they would normally use. Table 3-1 provides an overview of demographics and pharmacy use of the sample.

Table 3- 1 Participants' demographic information

Characteristics	*Frequency (n)*	*Percent (%)*
Sex		
Female	2416	70.0
Male	986	28.6
Other	2	0.1
Prefer not to say	3	0.1
Not answered	42	1.2
Age group		
18-34	852	24.7
35-49	702	20.4
50-64	812	23.5
65-79	859	24.9
80+	178	5.2
Prefer not to say	6	0.2
Not answered	40	1.2
Eligibility for free prescription[12]		
Yes	1891	54.8
No	1474	42.7
Not answered	33	1.0
Prefer not to say	51	1.5
Reasons for using the pharmacy at the day of data collection[13]		
Collect prescription	1649	47.8
Buy toiletries	1093	31.7
Buy medicines	440	12.8
Advice	130	3.8
For a specific service	26	0.8
Medicines review	22	0.6
Other[14]	254	7.4
Prefer not to say	17	0.5
Not answered	9	0.3
Use of the same pharmacy		
Yes	2544	73.8
No	896	26.0
Not answered	9	0.3
Frequency of pharmacy use		

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[12] Conditions for being eligible for free prescriptions include: > 60 years or over, >16 years, 16-18 and in full time education, Pregnancy or having had a baby in the last 12 months, any of the specified medical conditions, person (or their partner) receiving income support

[13] Multiple answers possible

[14] Frequently mentioned other: use weighting scale, accompany friend/family member, receive vaccination

At least once a week	331	9.6
Less than once a week but more than once a month	726	21.0
Once a month or less	2370	68.7
Not answered	22	0.6

3.2.2.2 Associations between demographic variables and pharmacy use

In accordance with the methods described in section 2.4.2.2.2 χ^2-tests were used to determine correlations between participants' demographics and their reported use of community pharmacy. Participants' gender was found to neither correlate with reported use of the same pharmacy, nor with reported frequency of pharmacy visits ($p=0.211$ and $p=0.212$, respectively). Participants gender was found to correlate with reported reasons for visiting community pharmacy, male participants were significantly more likely to report visiting to collect a prescription ($p<0.001$), while female participants reported visiting to buy toiletries more frequently ($p<0.001$). Participants were split into two almost evenly distributed age groups: participants <50 years old (46%) and participants aged 50 years and above. Again performing χ^2-tests, participants younger than 50 were found to report using the same pharmacy less frequently than their older counterparts ($p=0.002$). Participants aged 50 years and above were further found to visit community pharmacy more frequently ($p<0.001$) and reported more often that they were visiting community pharmacy to collect a prescription ($p<0.001$).

3.2.3 Descriptive overview

3.2.3.1 *Opinion towards general healthcare topics*

A large majority of participants reported to prefer managing their own health needs (Agreement: 88 %, n= 3021) and were strongly inclined to only visit their doctor when necessary (Agreement: 93%, n=3201). Almost 60% of participants (n=2019) reported having no difficulties to decide whom to consult in case of illness. Similarly, a majority of participants (n=1930) was unconcerned about the eventuality of approaching the wrong healthcare professional when seeking help (Figure 3-2).

3.2.3.2 *Trust in community pharmacists*

Throughout, high levels of trust in community pharmacists' abilities to give an accurate diagnosis, their advice regarding medicines and about general health were found. Only when asked about whether or not their local pharmacist cares about them, respondents reported less uniform agreement, 1000 participants (29.0%) responded neutrally (Figure 3-2).

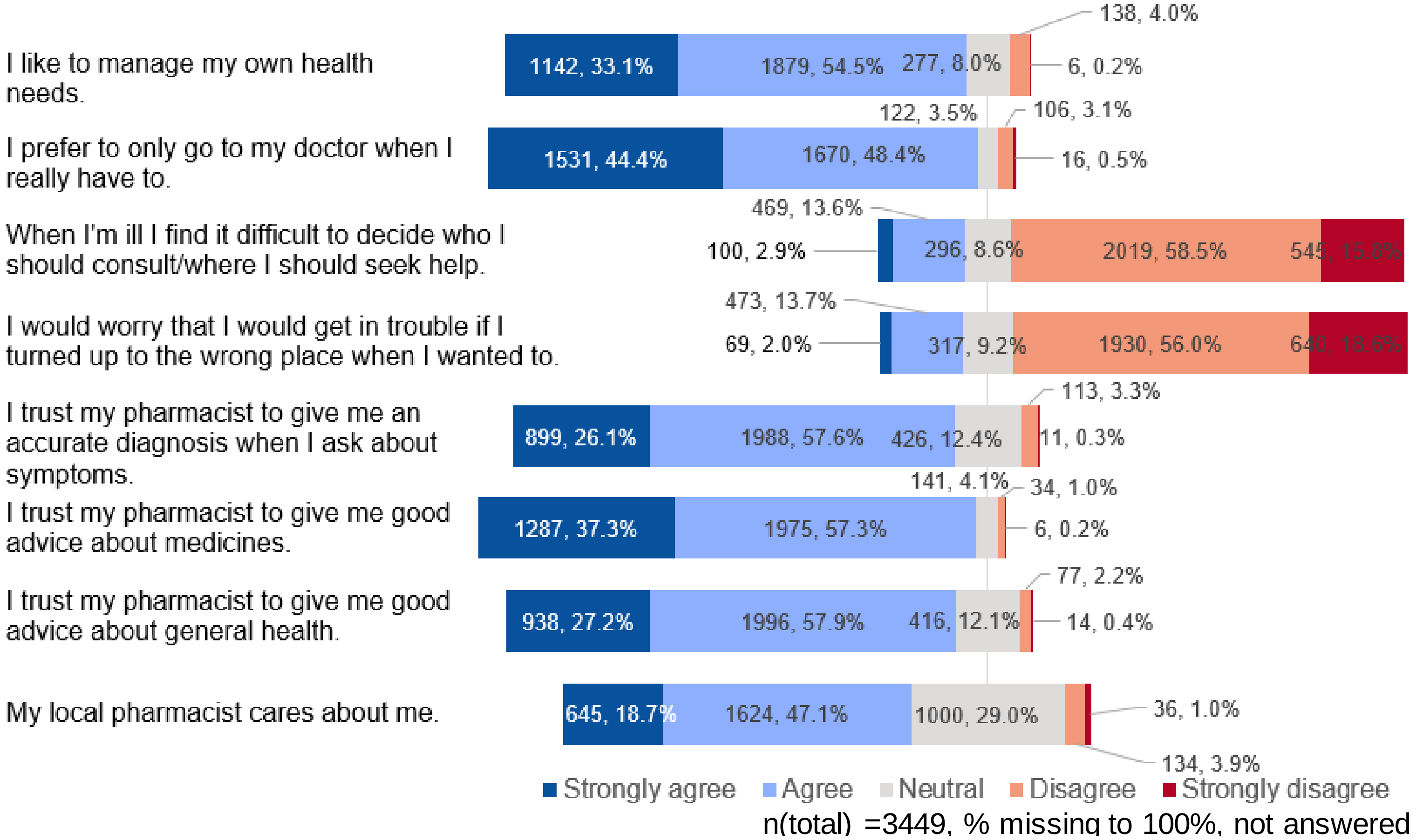


Figure 3- 2 Participants' opinions towards healthcare topics and community pharmacy

3.2.3.3 Opinions' towards mental health issues and mental health services in community pharmacy

Next, participants' perspectives on mental health in general and mental health support provision in community pharmacy were investigated.

90% of participants identified mental health as a significant problem in the UK (n=3101), only a minority (14%, n=493) of participants supported the statement that there is sufficient provision of mental health care in the NHS currently. Almost three-quarters of participants (73%, n=2531) were confident in their knowledge about which healthcare professional to consult when encountering a mental health issue.

Thereafter, community pharmacy users' attitudes towards community pharmacy as a setting for mental health support and advice were explored, focusing on scenarios where pharmacy users might get in contact with pharmacists due to a developing or already prevalent mental health issue. Participants' response patterns were found to be far less uniform compared to those found when assessing general health care topics. Only one-in-ten participants (n=344) reported to be inclined to use community pharmacy first when encountering a mental health issue. However, a joint consultation with a pharmacist as well as other healthcare professionals (such as a GP) when encountering a mental health issue, was met with more support (Agreement: 37%, n= 1275). Pharmacy users were mostly undecided when asked about the feasibility of community pharmacists identifying individuals at risk of having mental health issues (Neither agree nor disagree=46%, n=1573). Nevertheless, more than one in three participants (36%, n=1233) reported to trust community pharmacists’ advice about mental health issues. Lastly, participants exhibited modest support (37%, n=1279), for pharmacists providing greater assistance for individuals with mental health issues, however a majority of participants was undecided (39%, n=1341) (Figure 3-3).

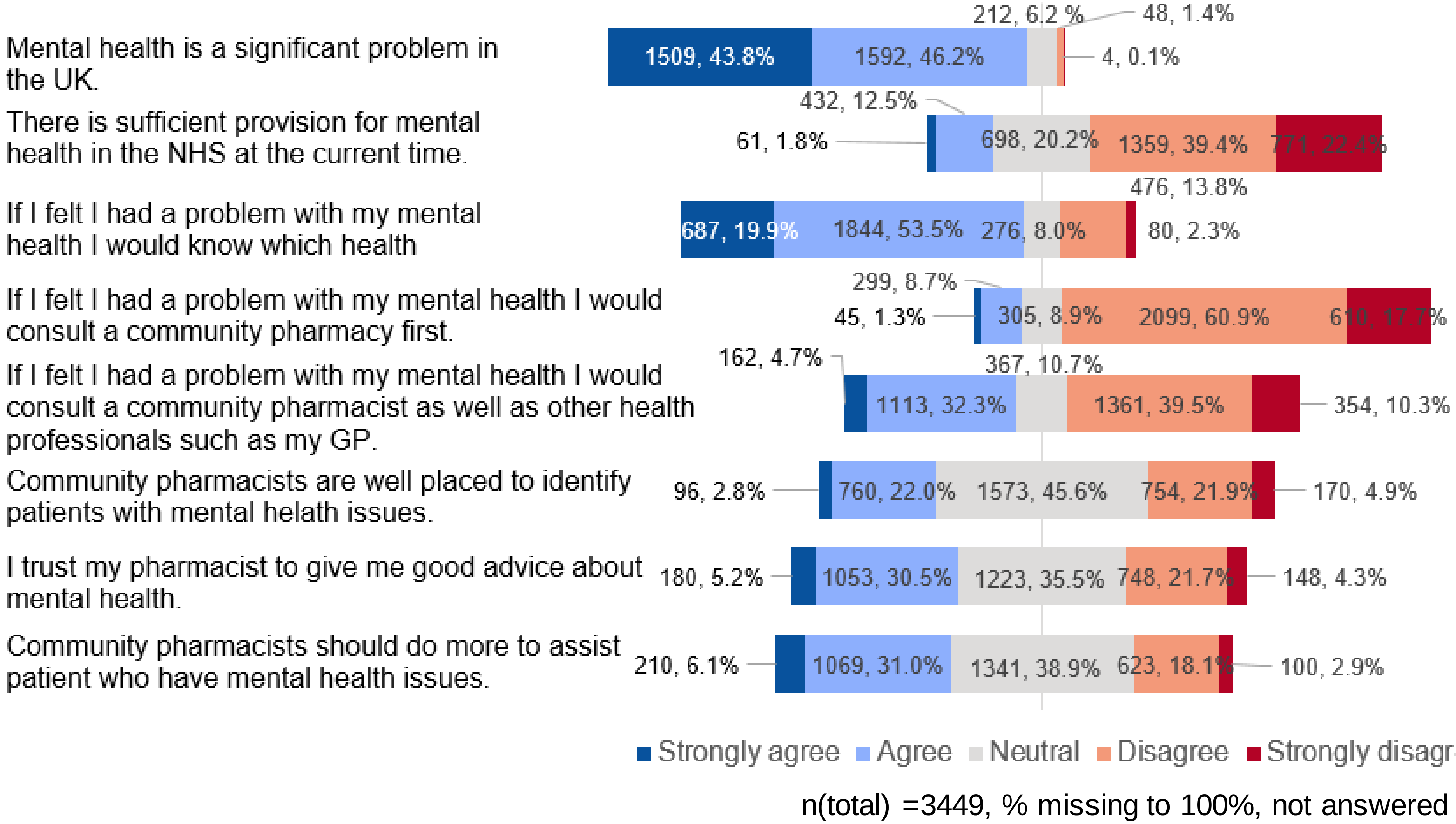
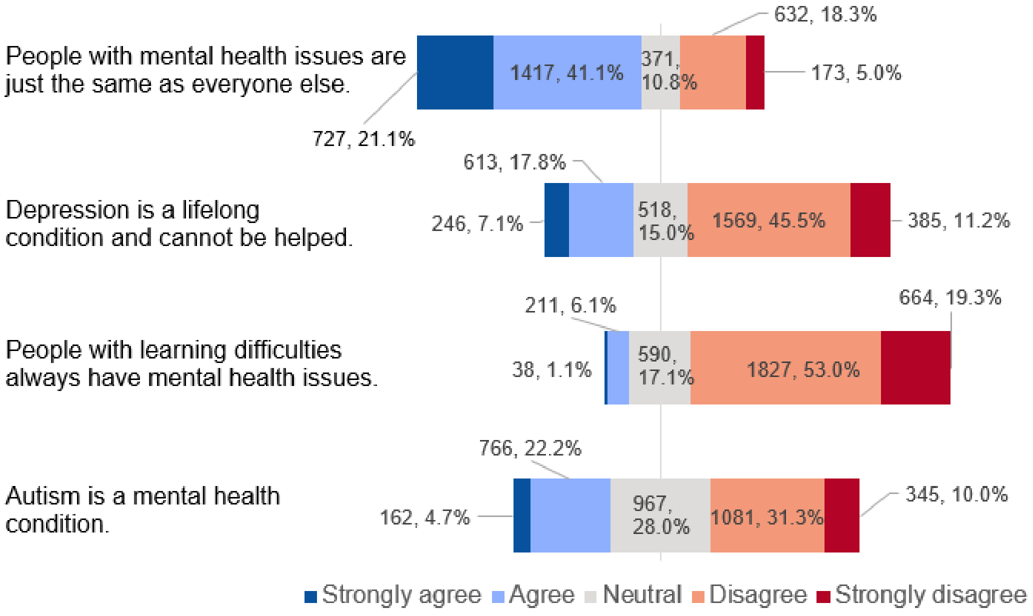


Figure 3- 3 Participants' opinions towards mental health in general and pharmacy-provided mental health support

3.2.3.4 Attitudes towards mental health topics

Lastly, in order to assess community pharmacy users' attitudes towards mental health related topics in general, they were confronted with four statements pertaining to the subject. A majority of participants did not distinguish between people with mental health issues and without (Agreement 62%, n=2144) and was aware that depression is not a lifelong condition (57%, n=1954). Similarly, only few participants believed that people with learning difficulties always have mental health issues (7%, n=249). However, autism was considered a mental health condition by more than one-quarter of participants (n=928) (Figure 3-4).



n(total) =3449, % missing to 100%, not answered

Figure 3- 4 Participants' attitudes towards mental health topic in general

3.2.4 Psychometric properties

Next, the extent to which certain statements pertained to the same underlying trait were investigated using an exploratory Mokken scaling procedure (section 2.4.2.2.4). All Likert-scale questions were included;

question 28 was reverse coded to align with the response patterns of other questionnaire items.

3.2.4.1 Results from the Mokken scaling procedure

The Mokken scaling procedure identified 10 questionnaire items pertaining to three different concepts (Table 3-2). The obtained results were then analysed as outlined in methods section 2.4.2.2.4.

Table 3- 2 Mokken scaling results

Concept/Latent trait	*Questionnaire item*
1. Trust in community pharmacists (section 4.2.4.2)	
	a. I trust my pharmacist to give me an accurate diagnosis when I ask about symptoms. b. I trust my pharmacist to give me good advice about medicines. c. I trust my pharmacist to give me good advice about general health. d. My local pharmacist cares about me.
2. Attitudes towards mental health service provision in community pharmacy (4.2.4.3)	
	a. If I felt I had a problem with my mental health I would consult a community pharmacist first. b. If I felt I had a problem with my mental health I would consult a community pharmacist as well as other health professional such as my GP. c. Community pharmacists are well placed to identify patients with mental health issues. d. I trust my pharmacist to give me good advice about my mental health.
3. Attitudes towards general mental health topics (4.2.4.4)	
	a. People with learning difficulties always have mental health issues. b. Autism is a mental health condition.

3.2.4.2 Trust in community pharmacists

3.2.4.2.1 Scale conceptualisation

Three questions revolving around trust in community pharmacists' competences and an additional question pertaining to the level of care individuals receive from their community pharmacist were found to be statistically related to the same concept. The questionnaire items encapsulate elements that are representative of the nature of trust.[15] That is, the pharmacy user is in a vulnerable situation and relies on the judgement of the pharmacist. Hence, the combination of the four questionnaire items can be conceptualised to be representative and scalable over the same underlying trait, namely trust in pharmacists.

3.2.4.2.2 Scale properties

Further investigation of the items using the loevh command returns the results presented in Table 3-3. The Loevinger H-coefficient of each included item exceeds the value of 0.3, thus it can be assumed that this set of items forms a so-called Mokken scale. The scale is considered a strong scale (H (scale) =0.57). These results are significant ($p<0.05$). No problems with the monotonicity assumption can be detected (Crit<80). Moreover, an investigation of the P++ and P-- matrix, reveals that the scale meets the criteria for invariant item ordering (IIO). That is, the P++ values consistently increase throughout the matrix and P--values consistently decrease (Crit <80). Matrices that have been used

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[15] Hardin R. *Trust and Trustworthiness*. New York: Russell Sage Foundation; 2002. McLeod C. Trust [online]. In: Zalta EN. (ed.) *The Stanford Encyclopedia of Philosophy (Fall 2020 Edition)*. [Accessed 16th June 2021]; Available from: https://plato.stanford.edu/archives/fall2020/entries/trust/.

to determine monotonicity and non-intersection can be found in Appendix 10 and 11).

Table 3- 3 Properties of the trust in community pharmacists scale, GE= Guttman error, coef= coefficient, Obs. = observations

Item	*Obs.*	*Mean score*	*Observed GE*	*Expected GE*	*Loevinger H-coef.*	*p-value*
1 a.	3437	0.94	1971	4759.7	0.59	<0.05
1 b.	3443	0.69	1487	3872.4	0.62	<0.05
1 c.	3441	0.91	1874	4662.7	0.60	<0.05
1 d.	3439	1.21	2432	4832.5	0.50	<0.05
Scale	3449	N/A	3882	9063.6	0.57	<0.05

Due to the scale adhering to the IIO assumption, it is possible to order the included questionnaire items by difficulty. Here, the difficulty of a scale item can be used synonymously to the level of endorsement the item has received from questionnaire participants. That is, higher difficulty values indicate stronger endorsement for this specific item, i.e. participants showed greater agreement with this statement. In our case, item 1b. achieved the lowest difficulty level, i.e. was easiest for participants to agree to, while 1d. demonstrated greatest difficulty for participants to agree to.

Therefore, the ordering of the item demonstrates that it was easiest for individuals to agree to a narrower definition of the role of community pharmacists (i.e. giving advice about medicines), while wider interpretations are less likely to be endorsed (e.g. giving a diagnosis). Survey participants were least likely to endorse being cared for by their community pharmacists. Subsequently, the four items were summarised to form a scale on which individuals could score high (indicating low levels of trust) or low (indicating high levels of trust). The developed scale ranges from 0 to 16.

3.2.4.2.3 Cronbach's α

Cronbach's α allows inferences about the internal consistency of a scale (section 2.4.2.2.3). Cronbach's α was found to be 0.78, which demonstrates satisfactory internal consistency.

3.2.4.3 Attitudes towards mental health support provided in community pharmacy

Four items pertaining to the concept of mental health support provision in community pharmacy were found to be statistically correlated and thus, scalable over the same latent trait.

Table 3- 4 Properties of the attitudes towards mental health support provided in community pharmacy scale, GE= Guttman error, coef= coefficient, Obs. = observations

Item	*Obs*	*Mean score*	*Observed GE*	*Expected GE*	*Loevinger H-coef.*	*p-value*
2 a.	3358	2.87	3148	6667.38	0.53	<0.05
2 b.	3357	2.19	4680	8591.72	0.46	<0.05
2 c.	3353	2.04	3850	7466.33	0.48	<0.05
2 d.	3352	1.89	4162	8099.43	0.49	<0.05
Scale	3449	N/A	7920	15412.43	0.49	<0.05

3.2.4.3.1 Scale conceptualisation

All four items found to correlate over the same latent trait were concerned with aspects of community pharmacy provided mental health support. Thus, the underlying trait was conceptualised as: individuals' attitudes towards community pharmacy provided mental health support. Interestingly, Questionnaire item 2d (I trust my pharmacist to give me good advice about my mental health) was found to be correlated, therefore implying that trust is crucial for understanding an individual's stance. Moreover the question 'pharmacists should do more to assist patients who have mental health issues', was found to be unrelated with the concept, potentially because it is phrased more generically instead of focusing on individuals attitudes specifically.

3.2.4.3.2 Scale properties

Again, the Loevinger H-coefficient of each included item exceeds the value of 0.3, thus it can be assumed that this set of items forms a Mokken scale. The overall H-coefficient of the scale is 0.49, therefore the scale can be considered to be medium in strength. These results are significant ($p<0.001$). No problems with the monotonicity assumption can be detected (Crit<80). Investigation of the P++ and P-- matrices reveal some problems with the IIO assumption, as indicated by intersections within the matrices. A critical value of 80 should not be surpassed in order to assume IIO for a newly developed scale. However, the critical values found for this scale are: 74, 56, 69 and 76 and therefore in close approximation of the upper value of 80. That, in addition to a visual inspection of the intersection within the P++ and P-- matrices leads to the conclusion that IIO should not be assumed. Therefore, no inferences about the level of difficulty of the included questionnaire items can be made.

3.2.4.3.3 Cronbach's α

A value of 0.73 was calculated for the scales' reliability coefficient thus implying satisfactory internal consistency.

3.2.4.4 Attitudes towards mental health topics in general

A correlation between two items intended to measure pharmacy users' attitudes towards mental health topics in general was found.

Table 3- 5 Properties of the attitudes towards mental health topics scale, GE= Guttman error, coef= coefficient, Obs. = observations

Item	*Obs*	*Mean score*	*Observed GE*	*Expected GE*	*Loevinger H-coef.*	*p-value*
3 a.	3330	2.86	1444	2580.81	0.44	<0.05
3 b.	3321	2.21	1444	2580.81	0.44	<0.05
Scale	3449	N/A	1444	2580.81	0.44	<0.05

3.2.4.4.1 Scale conceptualisation

The two items that were found to be statistically correlated are: 'People with learning difficulties always have mental health issues' and 'Autism is a mental health condition'. However, two other questionnaire items designed to measure individuals' attitudes towards mental health topics: 'Depression is a lifelong condition and cannot be helped' and 'People with mental health issues are just the same as everyone else' were found to be unrelated, i.e. not representative of the same latent trait. Thus, an exact demarcation of the trait that has been measured using item 3a. and 3b. is difficult to establish. It is plausible, that a specific aspect of individuals' attitudes towards mental health topics has been measured, however without the inclusion of further questionnaire items an exact definition cannot be found.

3.2.4.4.2 Scale properties

The combination of the two questionnaire items forms a scale of medium strength (Loevinger H coefficient: 0.44). The assumption of monotonicity has been met (Crit <80). Due to the fact that only two items were found to be correlated, no inferences about IIO can be made.

3.2.4.4.3 Cronbach's α

The level of internal consistency is low, Cronbach's α= 0.54.

3.2.5 Multilevel modelling

Methods section 3.4.2.2.5 introduced the fundamentals of multilevel modelling, while in the introduction to this chapter the two level structure of the underlying data set was highlighted. The analysis of the psychometric properties of the questionnaire led to the development of three separate scales, independently measuring

1) trust in community pharmacists
2) attitudes towards mental health support provided in community pharmacy and
3) attitudes towards general mental health topics.

Thus, all prerequisites to perform a multilevel (linear regression) analysis are met. However, due to the unsatisfying results we obtained from scale 3, no further analysis of the attitudes towards mental health scale will be conducted.

3.2.5.1 Trust in community pharmacists

The trust in community pharmacists' scale was introduced in section 4.2.4.2. After the four questions were combined, 3427 valid observations remained. Twelve pharmacies served as study sites, thus 12 grouping units (level 2 units) are included in the analysis.

3.2.5.1.1 Comparing a single-level model to a multilevel model in order to determine group effects

A single level null-model (i.e. a model without any explanatory variables) and a multilevel null-model were constructed and compared in order to determine the influence of the group structure (i.e. the pharmacy in which a participant was surveyed) on participants' level of trust.

Likelihood ratio test

The likelihood statistic provides information about whether or not an increase in model complexity has resulted in an improvement in model fit. Equation (10) has been introduced to test differences between the likelihood statistics of two models for significance (2.4.2.2.5).

Table 3- 6 Likelihood tests statistics single-level and multilevel model

	Single-level model	Multilevel model
Log-likelihood test statistic	*-7658.25*	*-7618.84*

The log likelihood statistic decreased from single-level to multi-level model; this change is significant ($\chi^2 = 78.82$ $p<0.05$) and indicates that estimations made using a multilevel model are less erroneous than those derived from a single-level model.

Variance partition coefficient (VPC)

In order to assess the proportion of the total observed variance that can be attributed to differences between groups, the VPC was calculated using formula (11) and Stata's *estat icc* post-estimation command. A VPC of 0.038 was found, thus implying that 3.8% of the variance in trust score can be attributed to differences between pharmacies (between group differences).

Distribution of trust scores across pharmacies

The results from the multilevel analysis without any explanatory variables (null-model) are presented in Table 3-7. Equation (7) describes a multilevel model mathematically.

(7) $$y_{ij} = \beta_0 + \mu_j + e_{ij}$$

For the trust in pharmacists scale, a mean trust score (intercept, β_0) of 3.69 was calculated. However, in order to determine differences in trust scores between pharmacies, equation term μ_j needs further assessment. This can be done graphically using a caterpillar plot (i.e. a standard error bar chart of each grouping unit's individual intercept) (Figure 3-5). The bar chart displays each grouping unit's (i.e. pharmacies) deviation (i.e. μ_j) from the average trust score. Therefore, the plot can be read as follows: participants in study site 511 scored significantly lower on the trust scale, meaning that higher levels of trust in community pharmacists were exhibited. Conversely, participants in study site 512 scored significantly above the mean average trust score, indicating that lower levels of trust were exhibited.

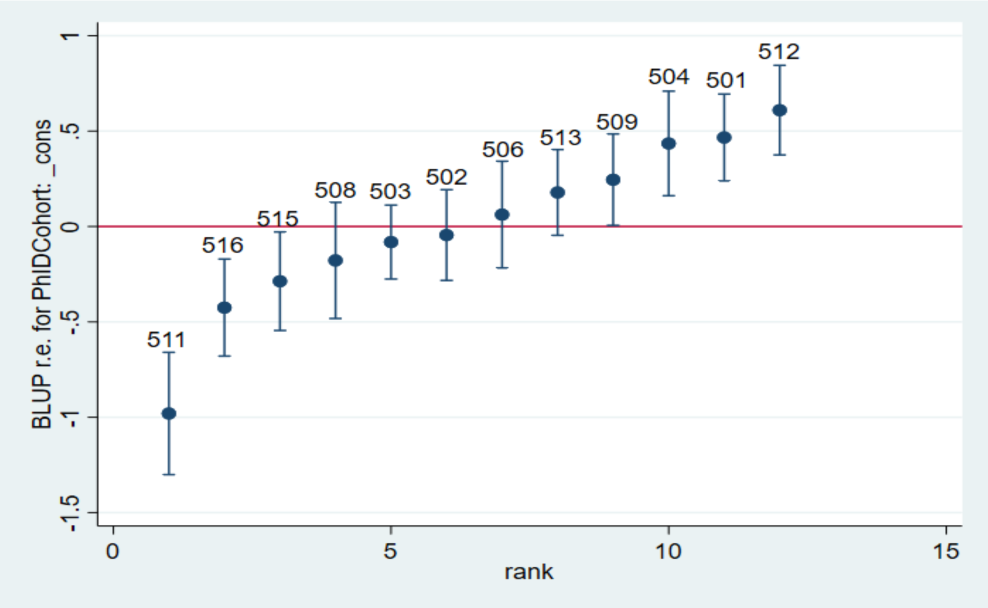

Figure 3- 5 Standard error bar chart of relative random intercept values for pharmacies (study sites) - null model

Summary

A two level model with community pharmacy users at level 1 and community pharmacies at level 2 has been successfully constructed.

Although the VPC remained below the recommended threshold of 0.1, indicating that at least 10% of the observed variances can be attributed to differences between pharmacies, we found preliminary evidence for the impact of the community pharmacy setting on individuals' level of trust in pharmacists. This is supported by the fact that a multilevel model provided significantly more accurate estimations than a single-level model as well as by the results from the analysis of the random intercepts of each pharmacy (Figure 3-5).

This, in conjunction with the fact that the data is organised in a hierarchical, two level data structure leads to the conclusion that a multi-level model should be retained. However, limitations due to the low number of included groups and the low VPC need to be taken into consideration.

3.2.5.1.2 Adding explanatory variables

Next, independent variables, such as gender, age and community pharmacy use were added to the model in order to identify factors influencing individuals' level of trust in community pharmacists (Model 1, Table 3-7).

After the inclusion of explanatory variables, the estimated population mean is 3.35 (β_0). The amount of variance in trust score that can be explained by differences between pharmacies (VPC) increased marginally, reaching 4.7%. The results of the multilevel analysis can be interpreted similarly to standard regression models. Therefore, in addition to the effect of the community pharmacy setting (level 2) on individuals' level of trust, the data suggests the following results at level 1 (individual level, within-pharmacies):

1. Participants who reported not using the same pharmacy were significantly more likely to report lower levels of trust ($p<0.001$).
2. Male pharmacy users were significantly more likely to report lower levels of trust in community pharmacists ($p=0.003$).
3. The frequency of pharmacy use has an effect on individual's level of trust: participants who reported using a community pharmacy at least once a week were significantly more likely to exhibit higher levels of trust ($p=0.003$).

4. Trust decreases with age, but this is only significant for the 65-79 year age group: Participants aged 65-79 reported the lowest levels of trust in community pharmacists (p=0.013).

*Table 3- 7 Multilevel modelling results- trust in community pharmacists- scale; Standard errors in parentheses; * p<0.05, ** p<0.01, *** p<0.001*

Independent variables	***Null-model***	***Model 1***
Use of same pharmacy		
Yes	Baseline	
No	Not included	0.46*** (0.09)
Sex		
Female	Baseline	
Male	Not included	0.26** (0.09)
Eligibility for free prescription		
Yes	Baseline	
No	Not included	-0.11 (0.10)
Frequency of pharmacy use		
Once a month or less	Baseline	
< once a week but > once a month	Not included	0.04 (0.10)
At least once a week	Not included	-0.40** (0.14)
Age group		
18-34	Baseline	
35-49	Not included	0.21 (0.12)
50-64	Not included	0.23 (0.12)
65-79	Not included	0.33* (0.13)
80+	Not included	0.31 (0.20)
Properties		
Cons (intercept, β_0)	3.69*** (0.13)	3.35*** (0.18)
Level 2 variance	0.20 (0.09)	0.24 (0.05)
Level 1 variance	4.95 (0.06)	4.85 (0.06)
VPC	0.038, 3.8%	0.0467, 4.7%
n	3427	3321
AIC [16]	14766.28	14724.56
BIC [16]	14784.6	14797.85
Log-likelihood statistic [16]	-7380.1	-7350.3
df	0	9

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[16] In order to be able to compare model fit statistics of both models, an equivalent sample size of n=3321 was assumed.

3.2.5.1.3 Diagnostics

Finally, the fit of the constructed models is investigated and the extent to which the necessary requirements (i.e. assumptions) for multilevel modelling are met, assessed. The procedure is outlined in methods section 2.4.2.2.5.

Model fit:

Model fit statistics for the constructed multilevel null-model and multilevel model with added explanatory variables are presented in Table 3-7. A likelihood ratio test indicates that the inclusion of explanatory variables improved the model fit significantly (χ^2=59.73, $p<0.05$). The reduction of the AIC further indicates improved model fit. However, the BIC has increased marginally from model null to model 1. The BIC value penalises the inclusion of redundant variables. Thus, there is evidence that some included independent variables did not add to the predictive ability of the model.

Assumptions:

The required assumptions to obtain valid results from multilevel models with added explanatory variables are outlined in methods section 2.4.2.2.5. No issues pertaining to the structure of the data were detected. Explanatory variables were only included on the individual level (level 1), no additional information at level two (community pharmacies) was collected or included in the model. Therefore, the categorisation of the added explanatory variables can be justified.

A histogram of level 1 residuals (Appendix 12) detects a slight deviation from the expected normal distribution. Especially negative residual values were more frequently found than expected from a Gaussian normal distribution. This indicates that the constructed model failed to fit values accurately at the lower end of the scale, i.e. it overestimated the score of participants with high levels of trust, resulting in larger negative residuals. The inverse normal plot of level 1 residuals confirms this observation, as the graph deviates from the desired (i.e. linear) shape at the lower and upper spectrum of the scale.

At level 2, severe problems concerning the normal distribution of the obtained residuals were detected. Both, a histogram and an inverse normal plot confirm this observation. The most plausible reason for the detected problems is the low number of included grouping units, which resulted in an incomplete histogram and a deviating inverse normal plot (Appendix 12).

3.2.5.1.4 Summary

A new scale to measure trust in pharmacists was developed and investigated using a multilevel modelling approach. Several variables that had a significant effect on individuals' level of trust were found, such as use of the same pharmacy, gender, frequency of pharmacy use, and, to some extent, participants' age. The setting in which individuals completed the survey was found to be a significant element when assessing pharmacy users' level of trust in pharmacists. However, despite the effect of the setting being significant in general, the magnitude of the effect was relatively small. A diagnostic investigation of the constructed model revealed problems concerning the normal distribution of residuals at level 2, most likely caused by the low number of included level 2 grouping units. Therefore, further investigation and conformation of the obtained results is necessary, preferably including a larger number of level 2 units.

3.2.5.2 *Attitudes towards mental health support provision in community pharmacy*

Next, the newly developed 'attitudes towards mental health support provision' scale was subjected to the same analysis. A null-model was developed to examine whether individuals' attitudes differ between community pharmacies. Secondly, the variable 'trust in community pharmacists' was included to examine the relationship between individuals level of trust and their attitudes towards mental health support provision (Model 1, Table 3-8). Third, other explanatory variables, such as participants' gender and age were added to the model (Model 2, Table 3-8).

3.2.5.2.1 *Comparing a single-level model to a multilevel model in order to determine group effects*

The likelihood ratio test suggests superiority of a two-level model over a single level model (χ^2=87.38, p<0.05). 4.1% of the variance in community pharmacy users' attitudes towards mental health support provision can be attributed to differences between pharmacies (VPC). The null-model calculated a mean average score on the attitude scale of 8.96 (β_0). (Table 3-8, Null-model) Again, a graphical depiction of each grouping units individual deviation from the mean score (μ_j) was created. The most positive attitudes towards mental health support provided in pharmacies (lowest score on scale) were found for participants surveyed in study site 511. The least positive attitudes were found for those participants surveyed in study site 516 (Figure 3-6).

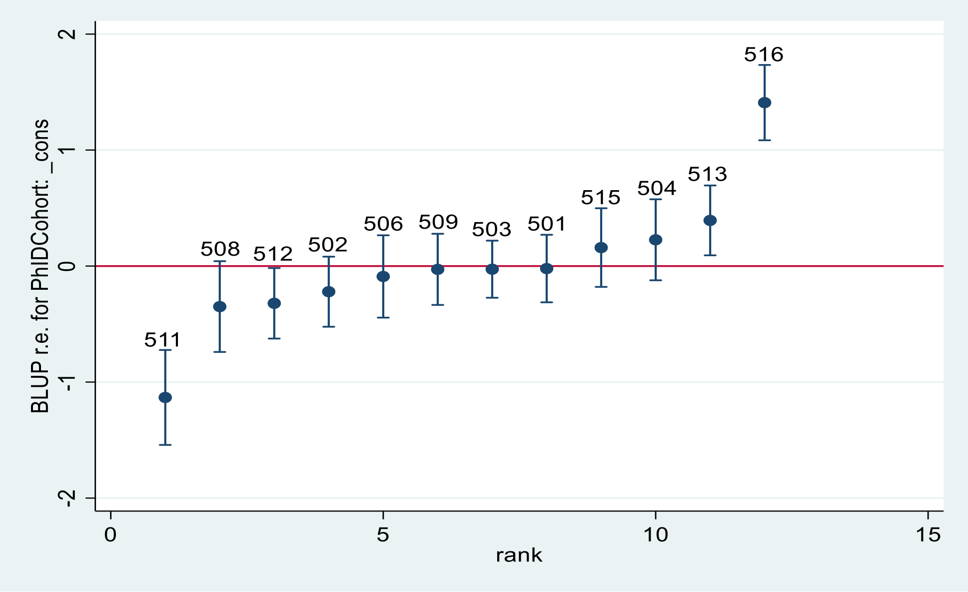

Figure 3- 6 Standard error bar chart of relative random intercept values for pharmacies (study sites) - null model

3.2.5.2.2 Adding explanatory variables

Trust in community pharmacists

First, the newly developed trust in community pharmacist scale was included as a single independent variable in the model (Model 1, Table 3-8). The data suggest that there is a relationship between individuals' level of trust in pharmacists and their attitudes towards mental health support provision. A one unit increase on the trust scale (i.e. a move towards more negative attitudes) leads to a 0.36 unit increase on the attitude scale, i.e., less trust in pharmacists negatively affects the attitudes of pharmacy users towards pharmacy provided mental health care.

*Table 3- 8 Multilevel modelling results - attitudes towards mental health service provision in community pharmacy; Standard errors in parentheses; * p<0.05, ** p<0.01, *** p<0.001*

Independent variables	***Null-model***	***Model 1***	***Model 2***
Trust in community pharmacists			
Linear	Not included	0.36*** (0.02)	0.36*** (0.02)
Use of same pharmacy			
Yes	Baseline		
No	Not included	Not included	0.37** (0.11)
Sex			
Female	Baseline		
Male	Not included	Not included	-0.37*** (0.11)
Eligibility for free prescription			
Yes	Baseline		
No	Not included	Not included	0.35** (0.12)
Frequency of pharmacy use			
Once a month or less	Baseline		
< once a week but > once a month	Not included	Not included	-0.01 (0.19)
At least once a week	Not included		-0.29 (0.17)
Age group			
18-34	Baseline		
35-49	Not included	Not included	0.12 (0.15)
50-64	Not included	Not included	0.14 (0.14)
65-79	Not included	Not included	-0.24 (0.16)
80+	Not included	Not included	-0.83*** (0.25)
Properties			
Cons (intercept)	8.96*** (0.18)	7.66*** (0.19)	7.62*** (0.23)
Level 2 variance	0.34 (0.08)	0.34 (0.08)	0.346 (0.08)
Level 1 variance	7.94 (0.10)	7.31 (0.09)	7.073 (0.09)
ICC	0.0415, 4.2%	0.0448, 4.5%	0.0466, 4.7%
n	3338	3324	3240
AIC[17]	15924.71	15661.53	15590.49
BIC[17]	15942.96	15685.86	15669.57
Log-likelihood statistic[17]	-7959.36	-7826.77	-7782.25
df	0	1	10

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[17] In order to be able to compare model fit statistics from all models, an equivalent sample size of n=3240 was assumed.

Trust in community pharmacists and other independent variables

In addition to the continuous independent variable 'trust in community pharmacists', other explanatory variables, such as age and use of community pharmacy were included in the model (Table 3-8, Model 2).

Figure 3-7 graphically depicts the relationship between the included independent variables and individuals score on the attitude scale. The variables trust in community pharmacists, gender, eligibility for free prescription and, to a lesser extent age, were found to affect individuals score on the scale significantly. Individuals who reported not using the same pharmacy were found to exhibit more negative attitudes ($p=0.001$). Male participants reported significantly more positive attitudes ($p<0.05$) as well as participants aged 80 or older ($p=0.001$). In general there was a trend towards more positive attitudes in older age groups, however this was not significant at the alpha<0.05 level. Individuals who received free prescriptions held more positive views compared to those who are not eligible to receive free prescriptions ($p=0.003$). Although there was a trend towards more positive attitudes in individuals using community pharmacy more frequently, this was not significant ($p=0.081$).

3.2.5.2.3 Diagnostics

Model fit:

The superiority of the multilevel model over a single-level model has previously been established. Log-likelihood tests indicate an increase in model fit from null-model to model 1 (χ^2=: 265.18, $p<0.05$) as well as model 1 to model 2 (χ^2=: 89.04, p<0.05). AIC and BIC decrease progressively from null-model to model 2, indicating improved model fit.

Assumptions:

Level 1 residuals demonstrate normal distribution with the mean centred on zero. The favourable properties of the scale at level 1 is supported by the observed linearity of the inverse normal plot. Similar to before, level 2 (i.e. study site) residuals show significant deviation from a Gaussian normal distribution. Again, this is mostly attributable to the low number of groups (i.e. community pharmacies) included in the analysis (Appendix 13).

3.2.5.2.4 Summary

A new scale to measure pharmacy users' attitudes towards mental health support provided in community pharmacy was developed. Several variables were found to affect individuals' attitudes significantly, namely: use of the same pharmacy, gender, eligibility for free prescriptions and, to a lesser extent, age; trust in community pharmacists was found to be the single-strongest predictor of participants' attitudes. The multilevel approach revealed that participants' attitudes differed significantly between study sites, thus providing evidence for the impact of the pharmacy setting on individuals' attitudes.

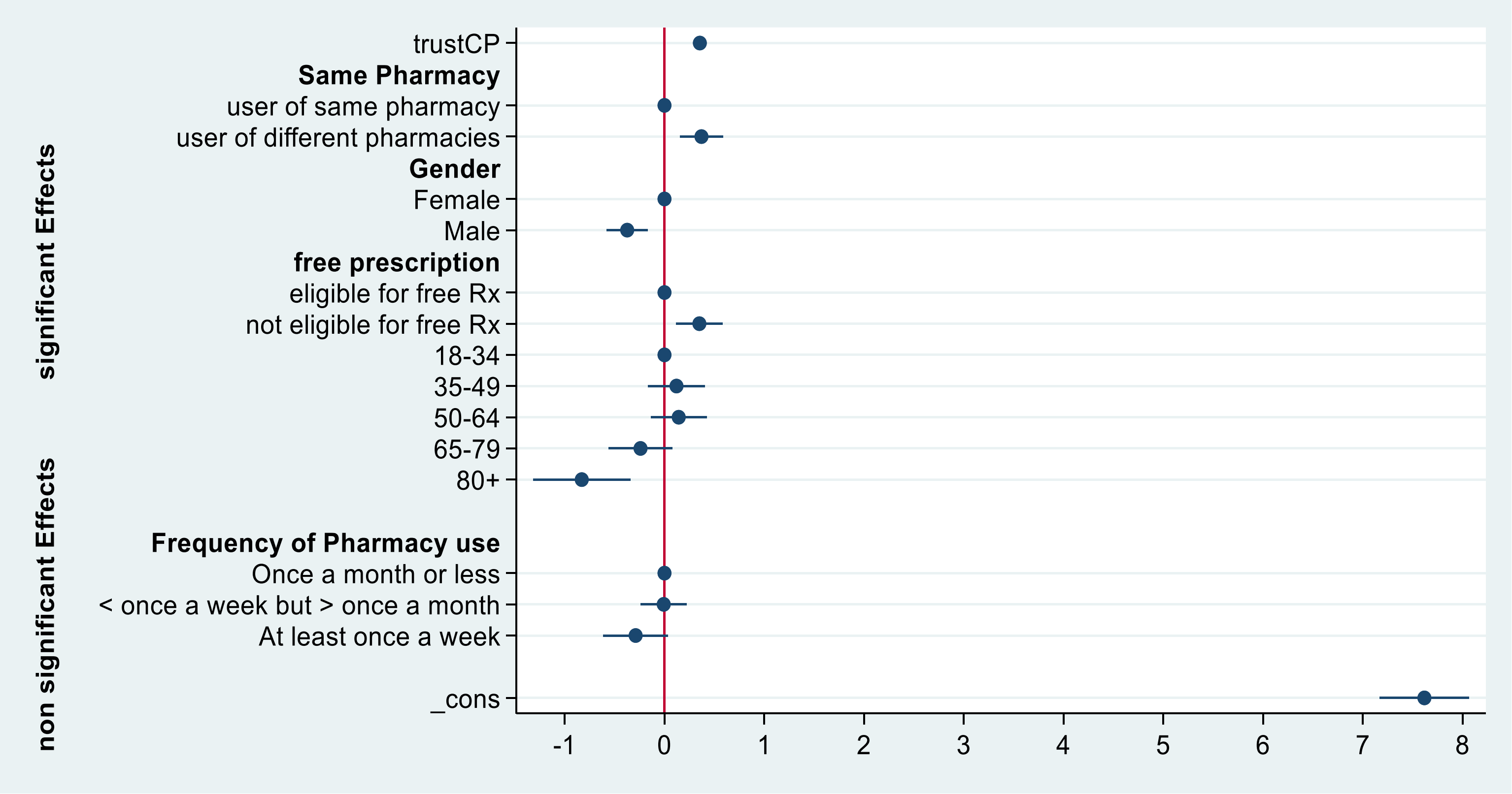

Figure 3- 7 Impact of included independent variables on attitude score - Relationship between independent variables and the dependent variable attitude score – model 2

3.2.6 Open-ended responses

3.2.6.1 Introduction

Three open-ended questions were included in the survey, two of which provided participants with an opportunity to share their opinion about mental health service provision in pharmacies.

A. How could pharmacists assist patients who have mental health issues?

B. How should pharmacists do more to assist patients who have mental health issues?

Question A yielded 2015 responses, of which 317 were excluded from the analysis because participants' response was not analysable (e.g. "Don't know").

Question B yielded less responses (n=950), because only participants who agreed to the preceding question ("Community pharmacists should do more to assist patients who have mental health issues") were encouraged to respond. Here, n=57 responses were excluded due to a lack of content (e.g. "don't know", "not sure"). Therefore a total of 2596 open-ended responses was included in the analysis, which was performed as described in methods section (2.5.1). Responses are coded using unique response IDs (e.g. A65), the letter codes for the respective question to which the response was given (A or B).

3.2.6.2 Findings

Individuals' open-ended responses were found to pertain to two broad topics, namely potential roles for community pharmacists in mental health and factors influencing pharmacy users' attitudes towards pharmacists' involvement in mental health care. Both themes are further divided in subcategories (Figure 3-8).

3.2.6.2.1 Potential roles for community pharmacists in mental health service provision

Participants used both questions to share their opinion about the role community pharmacists might be able to fulfil in the provision of mental health care. Moreover, participants' comments indicated a three-level structure of potential involvement, whereby the acceptable degree of involvement ranged from outright rejection to a positive reception of the idea.

a. Pharmacists have no or a limited role in mental health care

Several pharmacy users indicated scepticism about community pharmacists getting involved in providing mental health support or opposed the idea altogether. In many instances, this was rooted in the assumption that mental health issues operate outside pharmacists' professional remit and should be dealt with by different healthcare professionals (e.g. therapist, GP). Participants cited concerns over the professional qualification of pharmacists and the unsuitability of the pharmacy environment as the main reason for their hesitation. Those concerns will be discussed in more detail in section 3.2.6.2.2.

b. Intermediate role

Secondly, survey participants suggested an intermediate role for pharmacists in the provision of mental health care. Pharmacists would serve as a connector between different HCP as well as a gateway for accessing healthcare professionals, such as GPs. Participants indicted that a bridging role between different healthcare professionals would enable pharmacists to *provide information and advice* about mental health topics, *signpost* to the appropriate healthcare professionals or conduct *referrals* when necessary. In order to fulfil a bridging role, participants suggested the dissemination of leaflets, posters and signs in pharmacies with information about available support mechanisms or where to inquire for further advice.

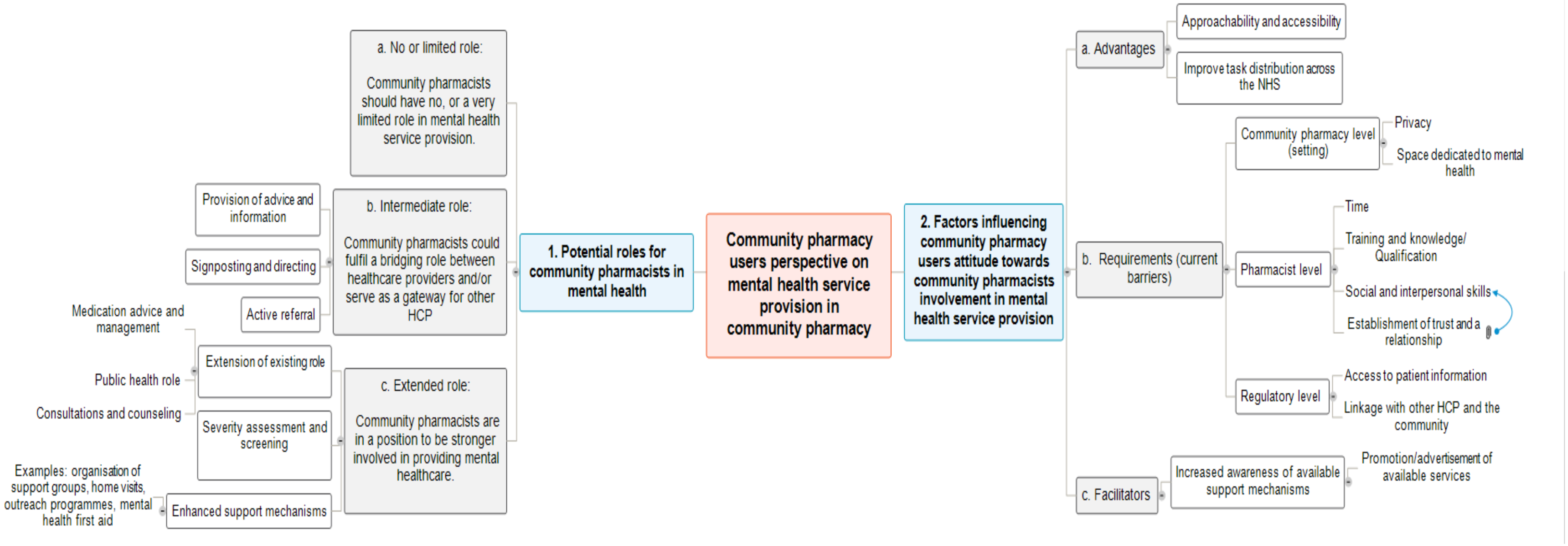

Figure 3- 8 Thematic map of open-ended responses

c. Extended roles

Thirdly, participants proposed an enhanced role for community pharmacists in the provision of mental healthvcare, which is independent from other HCPs and exploits the advantages of community pharmacy. Three broad categories of extended roles for community pharmacists were identified from participants' comments.

Extension of the exiting role

Some participants supported an extension of pharmacists existing roles into the area of mental health. In particular, pharmacists' competences as experts in medication were requested, e.g. by providing advice about prescribed medicines or by supporting the management of medicines. Frequently mentioned examples included checking for interactions between medications, adherence support and conducting medication reviews. Additionally, participants suggested that pharmacists could get involved in preventative and educational activities, such as the provision of lifestyle advice or raising awareness for mental health topics in general.

Severity assessment

A large number of pharmacy users indicated that pharmacists could support the recognition of signs of mental health issues and the assessment of the severity of someone's condition. In order to fulfil a role in the identification of individuals at risk, participants requested additional training for pharmacists or proposed alternative approaches, such as the analysis of individuals' purchases of readily available medicines.

Enhanced support mechanisms

Lastly, participants made numerous remarks about additional services pharmacists could offer, ranging from establishing outreach programmes to offering drop-in sessions or organising support groups. Some examples are highlighted in Table 3-9.

Table 3- 9 Example quotes: Potential roles for community pharmacists in mental health care

Role	*Example quotes*
a. No/limited role	
	"don't think it's their role personally" [A141]
	"Not pharmacists' job. They should just stick to providing medicines." [A1449]
	"I think mental health issues need to be dealt by doctors, not pharmacists." [A782]
b. Intermediate role	
Provision of advice and information	"You need to be more active, display stuff about mental health. Where to go when you need help, what help is available." [B3000]
Signposting and directing	"Point them to the right person and maybe facilitate the schedule of an appointment. Support the patient throughout the process of getting help at the right place." [A810]
	"Signpost to local help and services." [A1698]
Active referral	"refer to GP or mental health services" [A176]
	"They could listen sympathetically to the patient, provide them with any NHS booklets/leaflets and refer them to their GP" [A1333]
c. Extended role	
Extension of existing role	"Advice on drug interaction; Advice on how to stop medicines - and alternative medicines if patient does not like side effects" [B296]
	"Talk to patients more about MH, educate them." [A3013]
Severity assessment	"be able to identify regular patients showing signs of mental health illnesses and refer them

and identification	to the right people” [A108] “Observe patients from products they may be purchasing, whether they may be self-abusing etc.” [A1457] "Drop in counselling to assess their severity through an initial assessment.“ [B2091]
Alternative support mechanisms	“Host a support group” [A307]; “Be trained in mental health first aid” [A789]; “Have drop in sessions on a weekly basis” [B318]; Home visits - my brother in law committed suicide, was told by S.S. [social services] he was not at risk! [B2174]

3.2.6.2.2 Factors influencing pharmacy users’ attitudes towards pharmacy-provided mental health support

In addition to pharmacy users’ discussion of potential roles for community pharmacists in mental healthcare, participants used the open-ended questions to elaborate on the factors which impacted their stances. Three core elements were identified: advantages, barriers and facilitators.

a. Advantages

The benefits participants expected from stronger involvement of community pharmacists in mental health care were frequently discussed in contrast to the perceived drawbacks of other primary HCP, such as GPs. In this context, the approachability and accessibility of community pharmacy were persuasive arguments for pharmacy provided mental healthcare. Additionally, participants anticipated a better distribution of tasks within the NHS from pharmacists’ involvement in mental health care. Thus, the burden on other HCP might decrease, especially if pharmacists serve as an initial screening entity, which assesses the severity of individual' mental health issues and refers them according to their assessment.

b. Requirements/barriers

Most frequently discussed by participants were the prerequisites which would have to be fulfilled if community pharmacists were to get more involved in mental health service provision. However, depending on an individual's stance, that is, whether or not he or she supported the provision of mental health support in community pharmacy, those factors were seen either as reasons for individuals' refusal (barriers) or as necessary requirements for a successful implementation. Thus, implementing some of the ideas pharmacy users highlighted, might have a positive impact on individuals who deem community pharmacy unsuitable for the provision on mental health services. Prerequisites were found to pertain to three different categories: the structural level, the pharmacist level and the community pharmacy level (i.e. the setting).

Structural level

On a structural level, pharmacy users highlighted the need for better cooperation across HCPs as well as a better embedding of pharmacies within the wider community. Additionally, participants suggested that community pharmacists should be able to access to patients' background information, such as previously prescribed medication and patient history.

Community pharmacy level

Requirements pertaining to the community pharmacy environment mostly concerned the lack of privacy in community pharmacy, and the demand to make better use of the consultation room. Additionally, survey participants requested an area that is clearly dedicated to mental health in pharmacies, such as a separate departments [A237] or sections [A1014].

Pharmacist level

The level on which participants requested the most modifications concerned community pharmacists themselves. Questions over the level of training pharmacists had received were raised and doubts over the degree to which pharmacists are qualified to provide mental health advice were vocalised. Participants' scepticism seemed to originate from general unawareness of the contents of the pharmacy course, leading to demands for more communication about the training pharmacists had received. Moreover, participants raised concerns over pharmacists' ability to free time for in-depth conversations; in-depth conversations were deemed crucial for a successful provision of support for individuals with mental health issues. In turn, the perceived lack of time culminated in the refusal of some participants to acknowledge a role for pharmacist in mental healthcare.

Pharmacy users further commented on the need to establish a relationship and build trust in order to accept mental health support from pharmacists, and, related to these elements, the need for community pharmacists to improve their communication and interpersonal skills. The sensitive nature of mental health issues was found to require a more intimate relationship between pharmacy user and pharmacist in order to establish trust and eventually disclose difficulties with one’s mental health. However, efforts to establish a care-relationship with pharmacists are dependent on the ability to see the same pharmacist on a recurring basis, which participants found to be seldom the case. Encouraging open conversations as well as actively listening to individuals were found to be of great importance to respondents, with some comments indicating that these skills may not currently be in line with pharmacy users’ expectations. Participants’ remarks further highlighted the necessity for pharmacists to exhibit an understanding, supportive, reassuring and compassionate attitude, in particular when interacting with patients facing mental health issues.

c. Facilitators

In general, community pharmacy users’ comments indicated that they are lacking awareness of currently available mental health services and the role pharmacists might be able to play in the provision of these. Consequently, many participants demanded more information about available services and community pharmacists’ abilities to perform these. Visible advertisement in pharmacies were considered the most feasible option to reach large parts of the population, however some participants proposed more far-reaching campaigns, such as advertisement on TV.

Table 3- 10 Example quotes: Factors influencing community pharmacy users' attitudes

Factors influencing community pharmacy users' attitudes	*Example quotes*
a. Advantages	
Approachability and accessibility	"Support and talking to them. More accessible than GP." [A2226]
	"Available as GPs service is difficult to gain appointment." [B430]
Reduce burden on NHS	"Saves them from going to the doctors if the pharmacists talk to them and guide them in the right direction." [A945]
	"Long waiting list for mental health issues so pharmacists should be available to patients who are of lower level problems." [A2750]
b. Necessary requirements	
Regulatory level	"Pharmacist need access to medical health records." [A3187]
	"Reshaping whole context, placing a GP and mental health clinic alongside a pharmacy. Community driven is very important" [B1544]
Pharmacy level (environment)	*Privacy*
	"Make sure it's dealt in a private area, not over the counter. Protect patient's information, carefully develop a system." [A3375]
	Consultation room
	"consultation room with senior pharmacist...; flag services, private room with someone you feel is qualified. you don't want to chat with someone over the counter" [A96]
Pharmacist level	*Training:*
	"Don't think that's their role, haven't got the training." [A3007]
	"If they are trained to deal with mental health issues it needs to clear so patients know they can approach them to discuss their issues" [B3062]
	Time:
	"Spends time talking to patients, mental health is something very personal and sensitive and cannot be solved in short period of time" [A1455]
	"They could not. they are lacking knowledge and time" [A2786]
	Relationship/trust:

	“Don’t think they know people well enough to assess them, like doctors. I often see a different pharmacist. Don't think they should interfere in mental health, they should signpost”. [A148]
	"Maybe be more sympathetic, build a better rapport." [A3023]
	Communication and inter-personal skills:
	Be kinder to people, take in what someone is telling them. Need to be able to know customers/patients.” [B1094]
	“Listen to them. Many people who have [issues with their] MH have been lonely and no one to talk too. Doctors are busy, they want reassurances. They need kindness and assistance” [B1345]
c. Facilitators	
Increase awareness	“I wasn't aware this was something pharmacists dealt with, maybe giving the community more awareness of this would help” [A370]
	“I didn't know this was something pharmacists offered at all. Maybe making the community aware they could get advice on mental health at a pharmacy.” [A830]
How to increase awareness	“Make public aware this can be done. eg TV ad” [A736]
	"Showcase your services. So if there's like a support group put it on a poster, tell the patients." [A3027]

In summary, three main factors were found to be associated with pharmacy users’ attitudes towards mental health support provided in pharmacies. First, pharmacy users identified a numbers of potential advantages, influencing their views positiviely, such as the approachability of community pharmacists and the potential to reduce the burden on the NHS. Secondly, participants identified several prerequisites which were seen as essential for a successful introduction and uptake of pharmacy provided mental health support. For example, participants required more privacy in community pharmacies and identified a lack of training as a barrier to the provision of mental health support in pharmacies. Lastly,increasing pharmacy users’ awareness of available support mechanisms was identified as facilitators for influencing their attitudes towards mental health support provided in pharmacies positively; wide-reaching advertising campaigns were requested

3.3 Synthesis of information

3.2.7 Summary of key findings

This chapter reported the results of a large survey distributed in 12 community pharmacies across Nottinghamshire in March 2019. The survey data was analysed using both, qualitative and quantitative methods and provided information about English pharmacy users' attitudes towards mental health support provided in community pharmacies.

Quantitatively, a descriptive account of pharmacy users' attitudes towards mental health support provided in pharmacies was presented, and although most statements were met with scepticism or undecidedness, more than one-third of participants were supportive of greater involvement for pharmacists in the provision of mental healthcare. On the grounds of a Mokken scaling analysis, two scales, measuring both, pharmacy users' trust in pharmacists and their attitudes towards mental health support provided in pharmacies were developed. Higher levels of trust were found to be associated with female gender, recurrent use of the same pharmacy and more frequent use of pharmacies. Participants aged 65-79 years exhibited the lowest levels of trust. Positive attitudes towards mental health support provided in pharmacies were found to correlate with use of the same pharmacy, eligibility to receive free prescriptions and older age. A multilevel linear regression analysis further suggested that the community pharmacy setting impacts participants stances, as trust and attitudes scores fluctuated significantly across the 12 included study sites (i.e. community pharmacies.

The role community pharmacists might be able to play in the provision of mental healthcare was further explored by analysing the included open-ended responses thematically. Participants' suggestions covered a wide spectrum of possible roles, ranging from complete opposition, to acceptance of a bridging role between health care providers and approval of involvement beyond typical pharmaceutical tasks, such as the organisation of group therapies. Elements, such as facilitators, barriers and advantages, which impact individuals' stances towards mental health service provision in community pharmacy were identified. The approachability and accessibility of pharmacists as well as the prospect of decreasing the burden on the NHS were identified as advantages for pharmacists' involvement. Acceptance may be facilitated by increasing awareness about available services and pharmacists' qualification. Finally, participants determined a number of currently prevalent barriers to mental health service provision. Identified barriers concerned the community pharmacy environment (e.g. privacy and confidentiality), the regulatory level (e.g. access to patient information) and pharmacists themselves (e.g. concerns about qualification, necessity to establish a relationship/trust).

3.2.8 Informing the subsequent study phases

Addressing the limitations of the community pharmacy survey 2019.

The community pharmacy survey 2019 had been distributed before my involvement with the research project begun, and a number of limitations were encountered during the analysis phase. For example, the number of level two grouping units (i.e. pharmacies) was found to be too small to obtain significant results and some variables which were hypothesised a priori to correlate with individuals' attitudes were omitted. Therefore, a survey akin to this years' questionnaire was developed. This enabled the inclusion of previously omitted variables, such as participants' ethnicity and personal experiences with mental health issues, as well as the inclusion of additional questions which were thought to correlate with the concepts under investigation, such as the perceived suitability of the pharmacy environment for the provision of mental health support. Three additional study sites (i.e. pharmacies) were included in the sample. Lastly, a reiteration of the survey was thought to be beneficial to confirm the properties of both newly developed scales in a different sample of pharmacy users; results will be presented in Chapter 4.

Providing explanations for individuals' expressed stances

The open-ended responses included in this years' survey provided participants with an opportunity to share their views towards mental health support provided in pharmacies. However, the open-end responses were often brief, ambiguous and lacked context. Thus, they are of limited value for understanding individuals' reasoning behind their hesitation or support for pharmacy-provided mental healthcare. Therefore, a qualitative research phase was conceptualised to follow up from the community pharmacy survey 2020, in order to provide more in-depth explanations of individuals' expressed stances. This was seen as particularly important for the exploration of factors which impact individuals' stances towards mental health service provision in pharmacies, as some participants might have been reluctant to address topics such as the stigma surrounding mental health in the open pharmacy environment; results will be presented in chapter 4.

Disentangling the role of trust

This chapter presented preliminary statistical evidence for the existence of a correlation between individuals' level of trust and their attitudes towards mental health support provided in pharmacies. Moreover, the importance of establishing a trusted relationship was highlighted by participants in the open-ended responses. However, the nature and origins of this association remained unexplained. In order to address this topic, semi-structured interviews with pharmacy users were conceptualised (Chapter 4).

Identifying individuals at risk

A large number of open-ended responses indicated that pharmacy users are supportive of a role for pharmacists in contributing to the identification and assessment of individuals at risk of developing mental health issues. In order to support pharmacists with this task, alternative ways to recognise individuals at risk, such as through the analysis of purchasing behaviour, were identified and their acceptability in the wider population investigated (Chapter 5 and 6).

Chapter 4

Exploring public attitudes towards mental health support provided in community pharmacy

After pharmacy users' views about mental health support provided in pharmacies were mapped in the previous chapter, this chapter aims to provide a more in-depth analysis of several elements which were identified to be of interest (3.2.7.1).

A survey was distributed in community pharmacies in Nottinghamshire in March 2020 (i.e. the community pharmacy survey (CPS) 2020), and succeeded by semi-structured interviews with survey participants (and additionally sampled members of the public, 2.5.3.2). The replication of the survey allowed me to investigate the properties of the developed scales in an additional sample, and enabled the inclusion of variables, which were hypothesised to be of importance (e.g. diagnosis of depression and/ or anxiety). Two aspects were of particular interest for the qualitative research phase. First, to gain an understanding of the nature of trust in a pharmacy context and clarify the role of trust for individuals' acceptance considerations. Secondly, to explore participants' perception of the role pharmacists can fulfil in mental healthcare and to identify elements that affect individuals' stances. Thus, the preliminary framework developed from the open-ended responses in the previous chapter served as a guide to analyse and interpret the interview data (2.5.3.4).

The survey underpinning this chapter was distributed in March 2020; the succeeding interviews were conducted from September to November 2020. Thus, the data in this chapter have been collected amidst the outbreak of COVID-19 (2.5.2.4). Although measures to mitigate the impact had been implemented, it is likely that the presented data are interwoven with the external circumstances. The context in which the data were collected are highlighted in the relevant sections of this chapter.

4.1 The community pharmacy survey 2020

The CPS 2020 was distributed in 15 community pharmacies in Nottinghamshire, 30 3rd year MPharm students assisted with the data collection (2.4.1.2.1). The distribution of the survey commenced in early March 2020. However, data collection was terminated prematurely, following the announcement of the first national lockdown due to COVID-19 on 23 March 2020 in England.

4.1.1 Participation, total non-response and item non-response

During the two weeks of data collection, 1474 responses were collected; 1386 individuals refused to participate (response rate= 51.5 %). The majority of those who declined to participate was female (63.9%, n=885). Survey administrators were asked to estimate the age of those who declined participation; individuals who were estimated to be aged 35 to 49 and 50 to 64 most frequently refused to participate (Table 4-1).

Table 4- 1 Age distribution of non-responders

Age group	*Frequency (n)*	*Percent (%)*
18-34	267	19.3
35-49	394	28.4
50-64	380	27.4
65-79	275	19.8

80+	62	4.5
Not estimated	8	0.6

4.1.1.1Item non-response

To identify the percentage of non-responders per questionnaire item, all Likert-scale questions were binary coded, depending on whether or not the question had been answered (responder) or not (non-responder). Figure 4-1 depicts the delineation between item responders and item non-responders graphically.

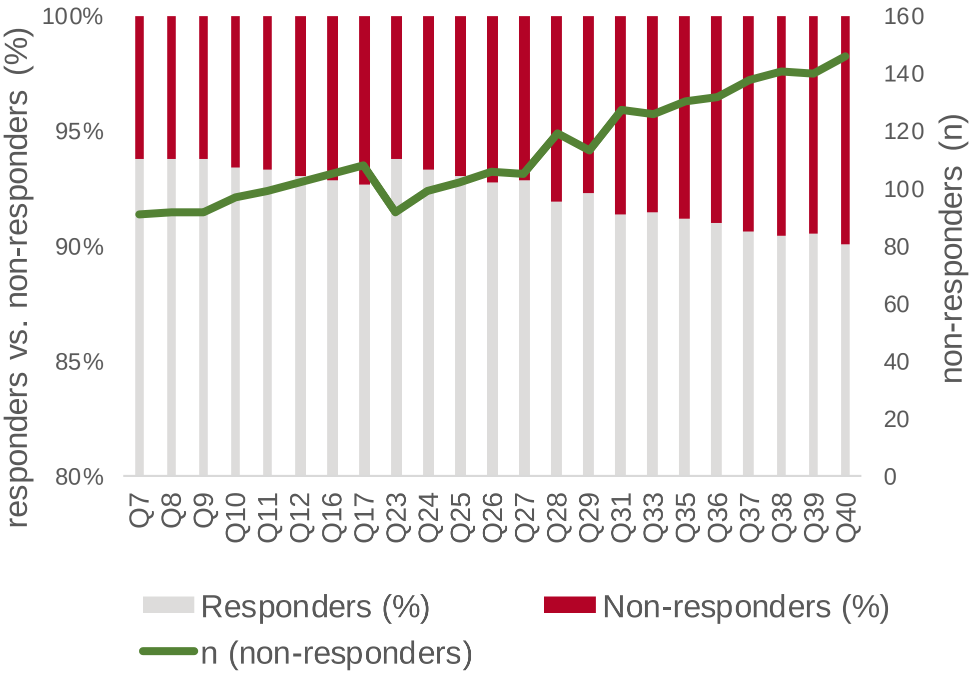

Figure 4- 1 Item response versus non-response (Likert scale section of the questionnaire)

Throughout, high rates of item response were achieved; none of the investigated Likert scale questions achieved response rates below 90%. However, the number of individuals who did not response to an item increased throughout the questionnaire. It is plausible that the increasing number of non-responders is attributable to the length of the questionnaire and thus, the time needed for completion. This effect might have been exacerbated by the circumstances under which the questionnaire was conducted, i.e. the worsening of the situation surrounding COVID-19, which may have decreased community pharmacy users' willingness to spend time to complete the entire questionnaire.

Item responders and non-responders were compared across the main demographic variables, sex, age, eligibility for free prescriptions, pharmacy use, frequency of pharmacy use and ethnicity and reported diagnosis of depression and/or anxiety. Few significant differences between both cohorts were identified. However, commencing with questionnaire item 16, participants who reported not being eligible to receive free prescriptions were found to be systematically more likely to decline response ($p<0.05$). Although statistically significant, this finding was small in absolute magnitude. A complete case analysis was performed.

4.1.2 Sample characteristics

4.1.2.1 Demographic characteristics

Two-thirds of participants were female (68.4%, n=975); and more than half reported to be aged 50 years or older (59.6%, n=879). More than four-fifths (n=1184) of participants reported their ethnicity as white, of those, an overwhelming majority (95.4%, n=1130) identified as white British. Consequently, the variable ethnicity was binary coded, delineating between those who reported their ethnicity as 'any white' (n=1184, 80.3%) and those who reported any other ethnicity (n=235, 16.0%). Almost one-fifth (n=283) of participants self-reported a previous or current diagnosis of depression or anxiety (Table 4-2).

Table 4- 2 Demographic characteristics of participants

Characteristics	***Frequency (n)***	***Percent (%)***[18]
Gender		
Female	975	66.2
Male	450	30.5
Other	1	0.1
Prefer not to say	1	0.1
Not answered	47	3.2
Age group		
18-34	281	19.1
35-49	268	18.2
50-64	366	24.8
65-79	411	27.9
80+	102	6.9
Prefer not to say	1	0.1
Not answered	45	3.1
Ethnicity		
White	1184	80.3
English/ Welsh/ Scottish/ Northern Irish/ British	1130	95.4
Irish	14	1.2
Gypsy or Irish Traveller	1	0.1
Any other White background	39	3.2
Asian / Asian British	143	9.7
Indian	33	23.1
Pakistani	65	45.5
Bangladeshi	5	3.5
Chinese	29	20.3
Any other Asian background	11	7.7
Mixed / Multiple ethnic groups	34	2.3
White and Black Caribbean	15	44.2
White and Black African	4	11.8
White and Asian	7	20.6
Any other Mixed/ Multiple ethnic background	8	23.5

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[18] % refers to percentage witin category

Black/African/Caribbean/Black British	46	3.1
African	22	47.8
Caribbean	20	43.5
Any other Black / African / Caribbean background	4	8.7
Other ethnic group	12	0.8
Arab	7	58.3
Any other ethnic group	5	41.7
Prefer not to say	10	0.7
Not answered	45	3.1
Health - Diagnosis of depression or anxiety (self-reported)		
Yes	283	19.2
No	1095	74.3
Not answered, prefer not to say	96	6.5

4.1.2.2Pharmacy use

Table 4-3 provides an overview of the samples' reported use of community pharmacies. This years' questionnaire included an additional question pertaining to participants' previous use of community pharmacy provided services. Unsurprisingly, almost 90% of participants (n=1287) reported having collected prescriptions in pharmacies in the past. Little more than one-third of participants (n=512) reported having used a pharmacy for advice about medicines in the past, while one-quarter of participants (n=388) had visited community pharmacies for advice about health. The use of more specific services, such as medicine reviews was reported less frequently (n=297, 20.2%).

Table 4- 3 Participants' use of community pharmacy

Characteristics	***Frequency (n)***	***Percent (%)***
Eligibility for free prescription[19]		
Yes	882	59.8
No	538	36.5
Prefer not to say	5	0.3
Not answered	49	3.3
Reasons for using the pharmacy at the day of data collection[20]		
Collect prescription	767	52.0
Buy toiletries	445	30.2
Buy medicines	155	10.5
Advice	39	2.7
For a specific service	8	0.5
Medicines review	3	0.2
Other	94	6.4
Prefer not to say	12	0.8
Not answered	72	4.9
Use of the same pharmacy		
Yes	1072	72.7
No	328	22.3
Not answered	74	5.0
Frequency of pharmacy use		
At least once a week	158	10.7
Less than once a week but more than once a month	338	22.9
Once a month or less	894	60.6
Not answered	84	5.7
Types of community pharmacy services used in the past[20]		
Collection of prescriptions	1287	87.3
Medicines review	297	20.2
For advice about medicines	512	34.7
For advice about health	388	26.3
Purchase of medicines	952	64.6
Purchase of non-medicinal products	814	55.2
For specific services	136	9.2
Other	34	2.3
Prefer not to say	2	0.1
Not answered	82	5.6

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[19] Conditions for being eligible for free prescriptions include: > 60 years or over, etc.

[20] Multiple answers possible

4.1.3 Scale validation and introduction of additional variables

Next, the Likert-scale questions pertaining to trust and attitudes towards mental health support provision were analysed descriptively, followed by a Mokken scaling procedure, in order to examine the validity of the newly developed scales in a different sample of pharmacy users. Subsequently, a multilevel regression analysis was performed.

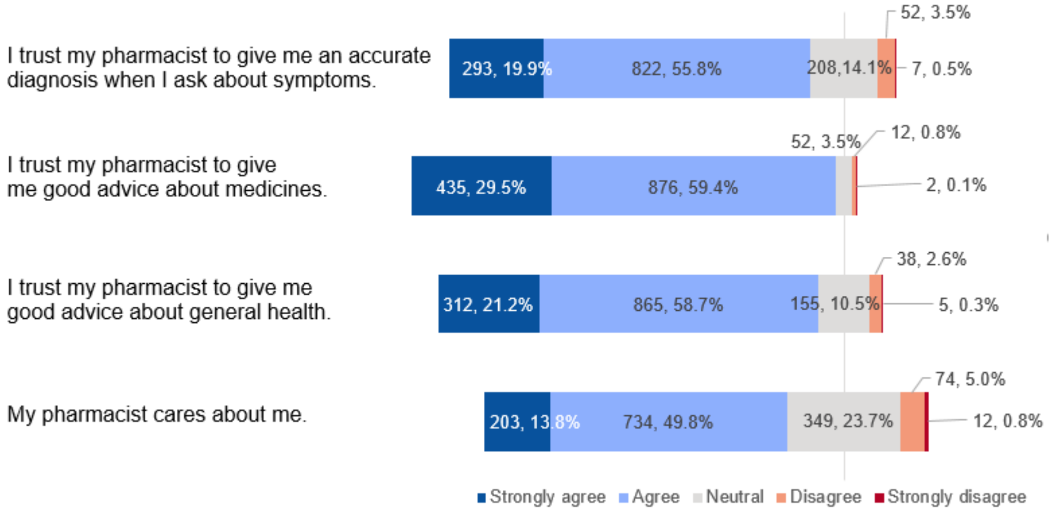
4.1.3.1 Trust in community pharmacists

4.1.3.1.1 Descriptive overview

Participants almost uniformly exhibited high levels of trust in pharmacists' ability to provide an accurate diagnosis, to provide advice about medicines and to give good advice about general health. However, the statement 'My pharmacist cares about me' evoked more diverse views (Figure 4-2).

4.1.3.2 Mokken scaling procedure

The four questions investigating pharmacy users' level of trust in pharmacists' abilities were subjected to a Mokken scaling procedure (2.4.2.2.4.). A Loevinger H- coefficient above the required threshold of 0.3 was established for each questionnaire item independently; the combined H-coefficient for the scale was estimated to be 0.52 (strong scale). Thus, the included questionnaire items are scalable across the same latent trait: trust in community pharmacists (Table 4-4). A scale on which individuals were able to score between 0 (highest level of trust) and 16 (lowest level of trust) was created.



n(total)=1474, % missing to 100%, not answered

Figure 4- 2 Participants' trust in community pharmacists

Table 4- 4 Mokken scaling results, GE= Guttman error, coef. = coefficient, Obs.=observations

Questionnaire item	*Obs.*	*Mean*	*Observed GE*	*Expected GE*	*Loev H-coef.*	*p-value*
I trust my pharmacist to give me an accurate diagnosis when I ask about symptoms.	1382	1.03	893	1843.8	0.52	<0.05
I trust my pharmacist to give me good advice about medicines.	1377	0.74	543	1399.8	0.61	<0.05
I trust my pharmacist to give me good advice about general health.	1375	0.95	786	1738.7	0.55	<0.05
My pharmacist cares about me.	1372	1.24	1006	1810.2	0.44	<0.05
Scale	1474	N/A	1614	3396.3	0.52	<0.05

No violations of the assumption of monotonicity were detected (Crit <80). The four questionnaire items adhered to invariant item ordering (IIO) (Crit<80). The scale demonstrated satisfactory internal consistency (Cronbach's α= 0.75).

Thus, the scale was found to exhibit properties similar to those found in the previous year, therefore confirming its desirable features for measuring pharmacy users' level of trust in pharmacists.

4.1.3.3 Multilevel model

Next, a multilevel linear regression model was built, in order to analyse pharmacy users' level of trust across the investigated study sites as well as to examine possible associations between trust and participants demographic characteristics. In 2020, 15 community pharmacies, situated in a variety of locations and representing different types of community pharmacies were included as study sites. Thus, 15 grouping units (i.e. level 2 units) were part of the analysis.

4.1.3.3.1 Comparing a single-level model to a multilevel model in order to determine group effects

A log-likelihood test according to equation (10) was performed. The multilevel model was found to significantly improve the accuracy of the model compared to a standard, single level regression model (χ^2 =21.2, p<0.05). The variance partition coefficient was estimated using Stata's *estat icc* post-estimation command. The results suggest that 2.7% of the total variance observed can be attributed to differences between groups (i.e. study sites).

The standard error bar chart (Figure 4-3) displays the distribution of trust scores across the investigated study sites graphically. Survey participants in pharmacy 509 and 503 displayed significantly higher levels of trust than those participants surveyed in study site 517. The results from other included study sites did not reach statistical significance. On the scale, which ranged from 0 to 16, the average mean trust score across pharmacies was estimated at 3.99 (Table 4-5, Null-model), which is indicative of high levels of trust

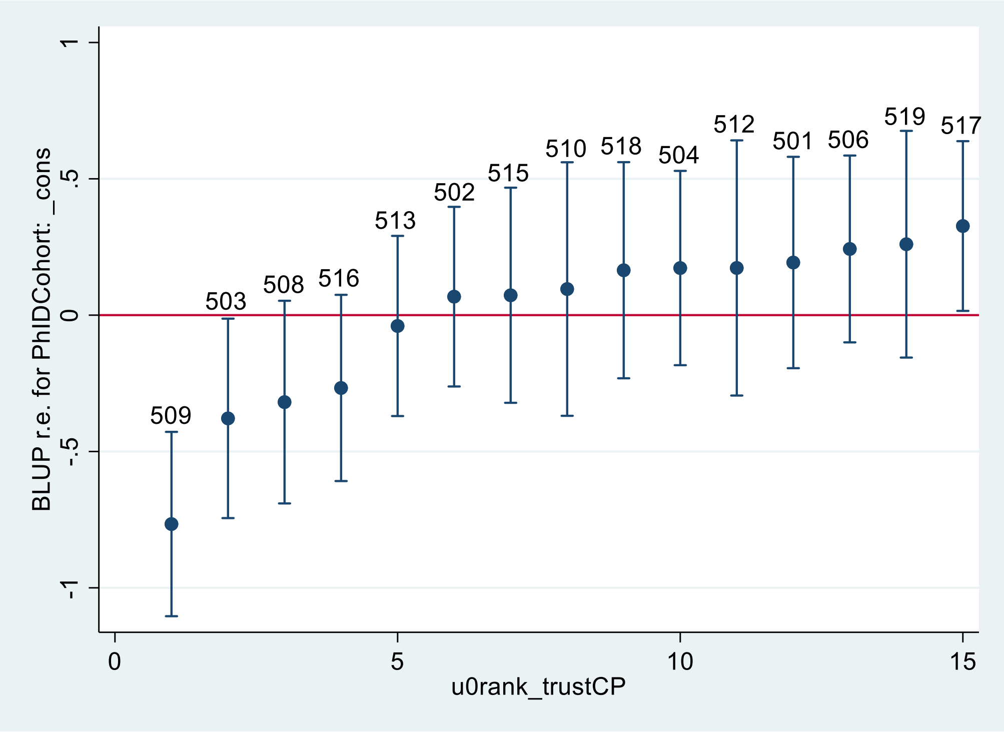


Figure 4- 3 Standard error bar chart ('Caterpillar plot') of trust scores across study sites

4.1.3.3.2 Adding explanatory variables

The results of the multilevel regression model with added explanatory variables can be found in Table 4-5 (Model 1). Male pharmacy users were found to be more likely to exhibit lower levels of trust (p=0.024), as were participants who reported not using the same pharmacy every time (p=0.017). Participants aged 65 to 79 exhibited lower levels of trust (p=0.041); no significant differences in terms of trust were found for other investigated age groups. However, the variable ‘ethnicity’ was found to have the strongest impact on the level of trust exhibited by participants. Individuals who reported their ethnicity as any other than white were significantly more likely to express lower levels of trust in pharmacists.

*Table 4- 5 Multilevel modelling results –trust in community pharmacists abilities; Standard errors in parentheses; * p<0.05, ** p<0.01, *** p<0.001*

Independent variables	***Null-model***	***Model 1***
Use of same pharmacy		
Yes	Baseline	
No	Not included	0.34* (0.14)
Gender		
Female	Baseline	
Male	Not included	0.29* (0.13)
Eligibility for free prescription		
Yes	Baseline	
No	Not included	0.12 (0.15)
Frequency of pharmacy use		
Once a month or less	Baseline	
< once a week but > once a month	Not included	-0.26 (0.14)
At least once a week	Not included	0.38* (0.19)
Age group		
18-34	Baseline	
35-49	Not included	-0.11 (0.19)
50-64	Not included	0.24 (0.19)
65-79	Not included	0.44* (0.21)
80+	Not included	0.46 (0.29)
Depression/Anxiety		
No	Baseline	
Yes	Not included	0.20 (0.15)
Ethnicity		
Any white	Baseline	
Any non-white	Not included	0.52** (0.18)
Properties		
Cons (intercept, β_0)	3.99*** (0.11)	3.52*** (0.21)
Level 2 variance	0.12 (0.03)	0.10 (0.03)
Level 1 variance	4.48 (0.09)	4.32 (0.09)
VPC	0.027, 2.7%	0.022, 2.2%
n	1371	1263
AIC [21]	5485.29	5476.3
BIC [16]	5500.71	5547.9
Log-likelihood statistic [16]	-2739.64	-2724.0
df	0	11

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[21] An equivalent sample size of n=1267 was assumed.

4.1.3.3.3 Diagnostics

Model fit

To compare the model fit statistics obtained from the null-model and the model with added explanatory variables, an equal sample size of n=1263 was assumed. The results from a log-likelihood test between null-model and model 1 indicate that the addition of explanatory variables significantly improved model fit (χ^2= 31.32, p=0.001). This is supported by an observed decrease of Akaike's information criterion (AIC) from null-model to model 1. However, the BIC did not decrease as would be expected from improved model fit, indicating that some variables are redundant.

Assumptions

A graphical examination of the obtained residuals at level 1 using a histogram and inverse normal plot ('QNorm') indicates some deviations from the ideal shape (Appendix 14). Deviations between the predicted and obtained values (as indicated by the residual value) were particularly prevalent at the upper and lower end of the scale. This indicates weaker predictive ability of the established model at both extreme ends of the scale. Deviations from the ideal were also found for the obtained residuals at level 2. This observation may be attributable to the low number of included grouping units as well as the comparably small effect of the grouping units on the proportion of total variance which could be explained (VPC). Further, no explanatory variables at the grouping level were included, further decreasing the predictive ability of the model at this level.

4.1.3.4 Attitudes towards mental health support provision in community pharmacy

4.1.3.4.1 Descriptive overview

Similar to the questionnaire distributed in the previous year, pharmacy users were asked to share their opinion about a range of topics pertaining to mental health support provided in community pharmacy; the results are presented graphically in Figure 4-4. In addition to these questions, pharmacy users' opinions about the suitability of the community pharmacy environment for the provision of mental health services were examined. The results suggest that pharmacy users were almost evenly split between those who considered the environment suitable (40.6%, n=599) and those who did not (35.5%, n=523).

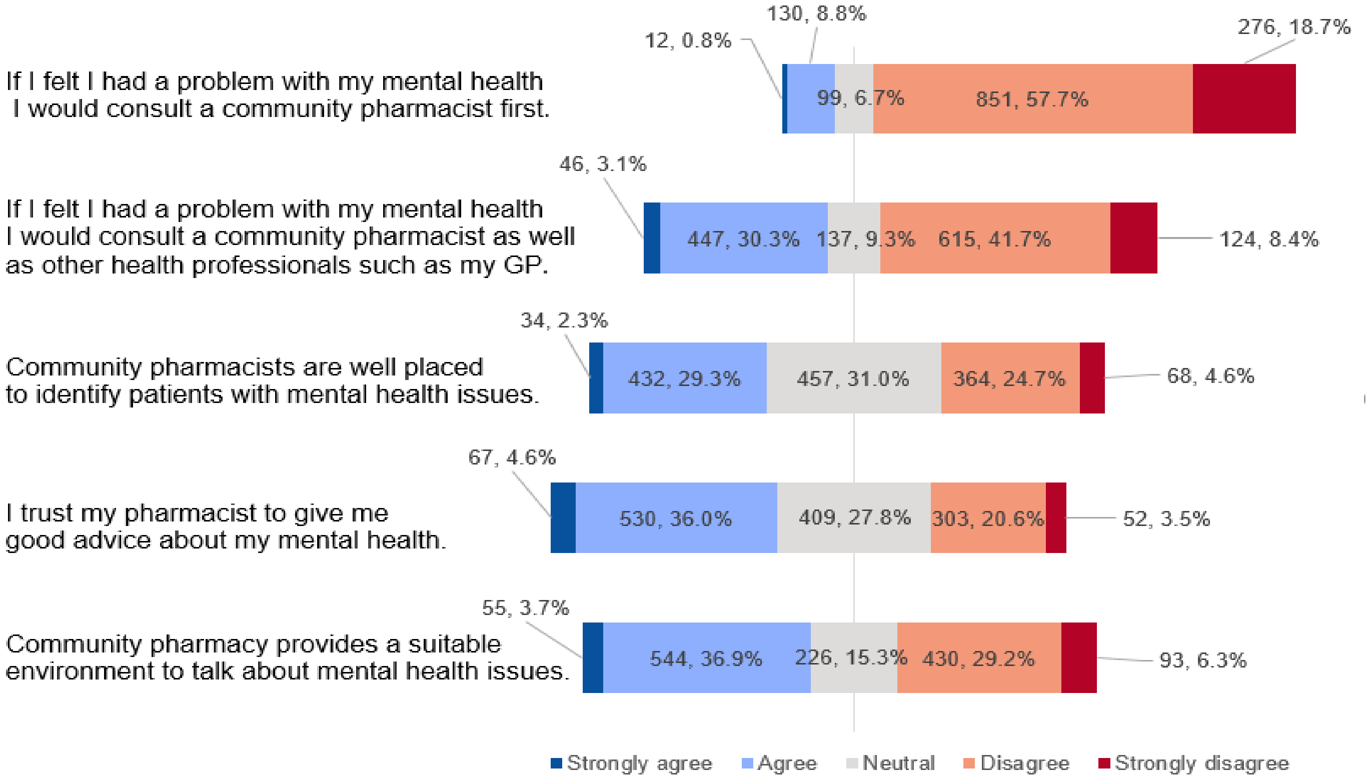

Figure 4- 4 Participants' attitudes towards mental health service provision in pharmacies

n(total)=1474, % missing to 100%, not answered

4.1.3.5 Mokken scaling procedure

In order to investigate the latent structure of the questionnaire items pertaining to mental health support provided in community pharmacy, a Mokken scaling procedure was run. The newly included item ‘Community pharmacy provides a suitable environment to talk about mental health issues’ was found to be related with those four questions we identified as a measure for individuals’ attitudes towards mental health service provision in the previous year. The following results were obtained:

Table 4- 6 Mokken scaling results, GE= Guttman error, coef= coefficient, Obs. = observations

Item	*Obs*	*Mean score*	*Observed GE*	*Expected GE*	*Loevinger H-coef*	*p-value*
If I felt I had a problem with my mental health I would consult a community pharmacist first.	1368	2.91	1625	3455.48	0.53	<0.05
If I felt had a problem with my mental health I would consult a community pharmacist as well as other health professionals.	1369	2.24	2766	4955.64	0.44	<0.05
Community pharmacists are well placed to identify patients with mental health issues.	1355	2.00	2375	4446.77	0.47	<0.05
I trust my pharmacist to give me good advice about my mental health.	1361	1.81	2285	4563.79	0.50	<0.05
Community pharmacy provides a suitable environment to talk about mental health issues.	1348	1.97	2899	4890.29	0.41	<0.05
Scale	1474	N/A	5975	11155.98	0.46	<0.05

Loevinger H- coefficients above the required threshold of 0.3 were established for each questionnaire item; the combined H-coefficient for the scale was estimated to be 0.46 (medium scale). Thus, the included questionnaire items are scalable across the same latent trait, which has been conceptualised as ‘attitudes towards mental health support provided in community pharmacy’. No violations of the assumption of monotonicity were detected (Crit <80). Although the critical threshold to assume IIO (Crit<80) has not been exceeded, IIO should not be assumed. That is, an investigation of the ISRFs using the P ++ and P -- matrices indicated a number of violations of the assumption of non-intersection (i.e. values in the P ++ matrix did not continuously increase and values in the P – matrix did not consistently decrease). Thus, no hierarchical order of the questionnaire items could be determined.

The scale demonstrated satisfactory internal consistency (Cronbach’s alpha= 0.76).

4.1.3.6 Multilevel model

Subsequently, the 5-item scale introduced above was subjected to an extended statistical analysis, using a multilevel modelling approach (2.4.2.2.5).

4.1.3.6.1 Comparing a single-level model to a multilevel model in order to determine group effects

Likelihood ratio test

The likelihood test statistic decreased from single-level null model to multi-level null model, this change was significant (χ^2= 12.46, p<0.001). Thus, the multilevel null-model was found to be significantly less erroneous than a single-level null model.

Variance partition coefficient

The proportion of observed variance in attitudes towards mental health service provision in community pharmacy which can be attributed to differences between study sites (i.e. level 2 units) was estimated to be 0.02 (2.0%).

Distribution of attitude scores across pharmacies

Lastly, the distribution of attitude scores across study sites was investigated. In two study sites (518, 502) participants exhibited significantly more positive attitudes towards mental health support provision; participants in study site 516 displayed significantly more negative attitudes. Results from other study sites did not differ significantly from the mean average score of all included study sites (β_0=10.92) (Figure 4-5).

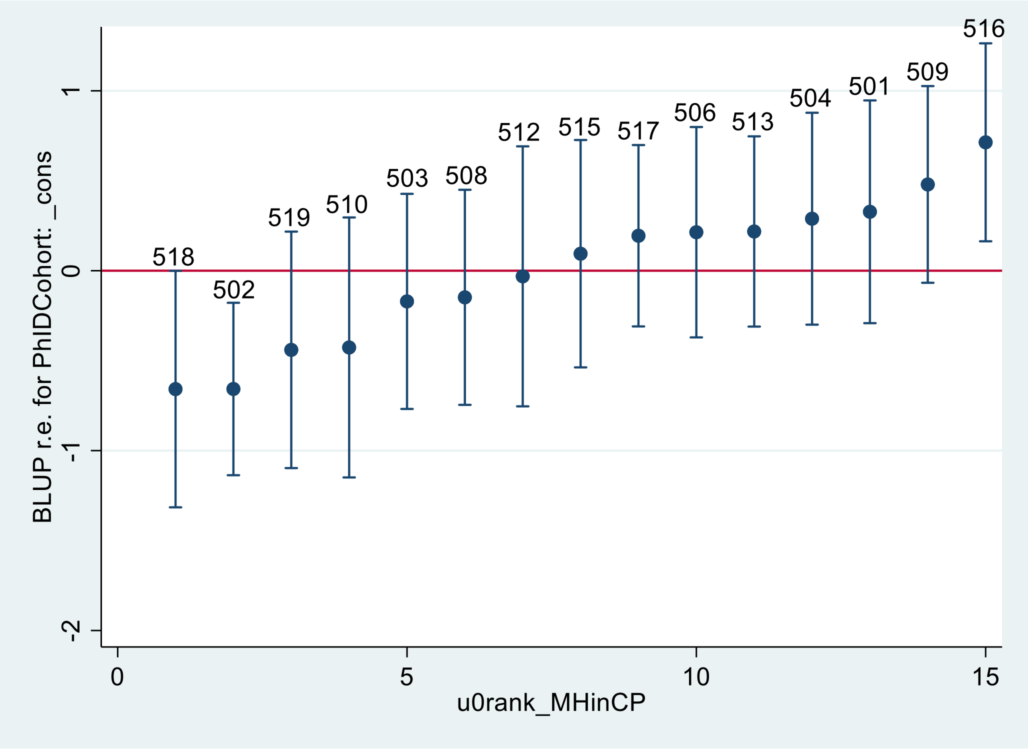

Figure 4- 5 Standard error bar chart ('Caterpillar plot')

4.1.3.6.2 Adding explanatory variables

Next, explanatory variables such as the above introduced trust scale and participants' demographic variables, were included in the multilevel regression model (Model 1, Table 4-7).

The frequency with which participants reported to use community pharmacy was found to have a significant effect on their attitudes; individuals who reported using a pharmacy less than once a week but more than once a month were more likely to exhibit positive attitudes (p=0.040) compared to those using a pharmacy once a month or less.

*Table 4- 7 Multilevel modelling results –attitudes towards mental health service provision; Standard errors in parentheses; * p<0.05, ** p<0.01, *** p<0.001*

Independent variables	***Null-model***	***Model 1***
Trust in community pharmacists		
Linear	Not included	0.48***(0.04)
Use of same pharmacy		
Yes	Baseline	
No	Not included	0.44 (0.25)
Gender		
Female	Baseline	
Male	Not included	0.06 (0.21)
Eligibility for free prescription		
Yes	Baseline	
No	Not included	0.43 (0.25)
Frequency of pharmacy use		
Once a month or less	Baseline	
< once a week but > once a month	Not included	-0.47* (0.23)
At least once a week	Not included	-0.52 (0.31)
Age group		
18-34	Baseline	
35-49	Not included	0.32 (0.31)
50-64	Not included	0.54 (0.30)
65-79	Not included	0.54 (0.35)
80+	Not included	-0.01 (0.46)
Depression/Anxiety		
No	Baseline	
Yes	Not included	0.61* (0.24)
Ethnicity		
Any white	Baseline	
Any non-white	Not included	-0.38 (0.29)
Properties		
Cons (intercept, β_0)	10.92***(0.16)	8.46*** (0.39)
Level 2 variance	0.25 (0.15)	0.39 (0.10)
Level 1 variance	12.38 (0.48)	10.69 (0.22)
VPC	0.020 (2.0%)	0.036 (3.6%)
n	1332	1208
AIC	6460.7	6340.3
BIC	6476.0	6416.7
Log-likelihood statistic	-3227.3	-3155.1
df	0	12

However, despite indicating a similar trend, this is effect was not significant for very frequent users of pharmacies (at least once a week, p=0.093). Participants who self-reported to have received a diagnosis of anxiety or depression were found to be significantly more likely to express negative attitudes towards mental health support provision in pharmacies (p=0.012). Lastly, the level of trust participants exhibited had a significant effect on their attitude score (p<0.001). With each unit increase on the trust scale (i.e. lower levels of trust), participants score on the attitude scale increased by a factor of 0.48. This suggests that lower levels of trust are associated with significantly more negative attitudes towards the provision of mental healthcare in pharmacies (Table 4-7, Model 1 and Figure 4-6).

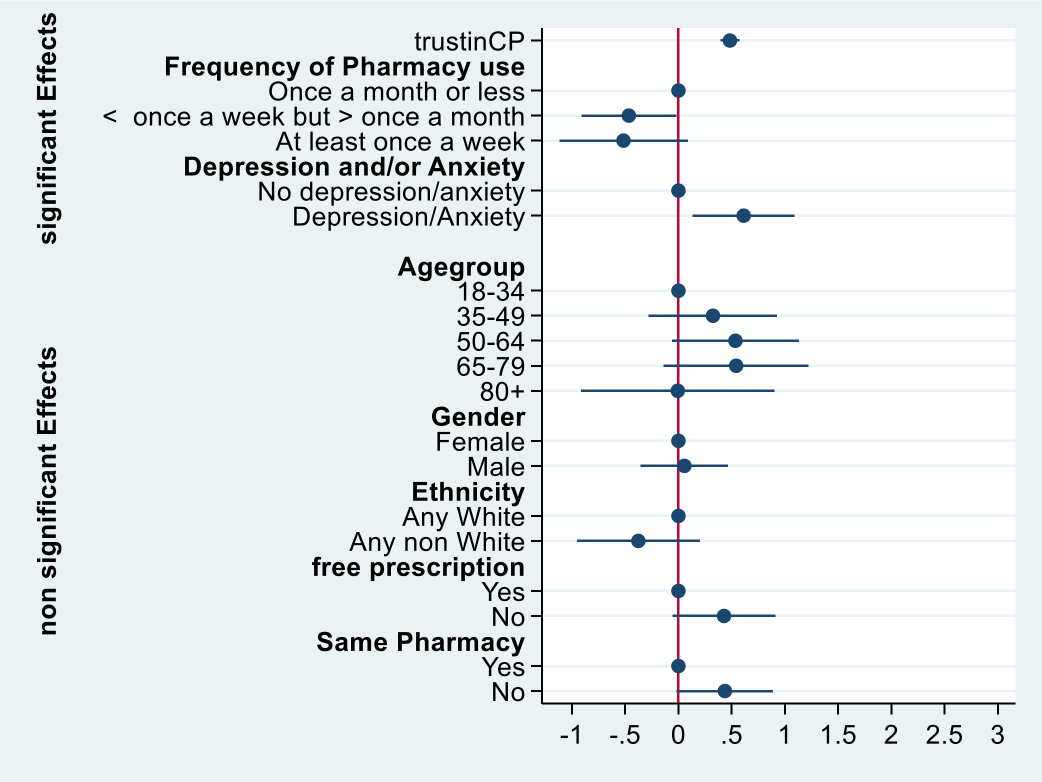

Figure 4- 6 The effect of included explanatory variables on attitude score.

4.1.3.6.3 Diagnostics

Model fit

In order to compare model fit values, an equal sample size of n=1208 was assumed for both models.The result from a log likelihood test comparing the log-likelihood values obtained from the null-model and the level with added explanatory variables was significant, indicating improved model fit (χ^2= 144.43, p<0.001). Both, the AIC and BIC decreased from null-model to model 1, thus indicating improved model fit.

Assumptions

Both, the histogram of residuals obtained at level 1 and the inverse normal (‘Qnorm’) plot of level 1 residuals do not show a noteworthy deviation from their intended shapes. Thus, level 1 residuals have been found to be normally distributed, therefore meeting the necessary assumptions (Appendix 15).

However, level 2 residuals deviate considerably from the intended normal distribution, as indicated by a histogram of level 2 residuals and an inverse normal plot of level 2 residuals. This might be attributable to the low number of included study sites, which, despite including 3 additional study sites in 2020 is still below the optimal minimum of n=20 level two units. Further, no explanatory variables at the grouping level were included, which may have further decreased the predictive ability of the model at this level.

4.2 Results from the semi-structured interviews

In line with the methodology outlined in Chapter 2, I then conducted semi-structured interviews with some of the survey participants and additionally sampled members of the public. Subsequently, the obtained narrative data were transcribed. The transcription process commenced with an automated transcription, however, due to dissatisfying results, the whole data set was additionally transcribed manually by the lead researcher (2.5.3.4). The main objective of the interviews was to aid with the understanding of the obtained quantitative results. Thus, trust and attitudes towards mental health service provision were at the centre of the developed interview guide. The analysis followed a deductive thematic approach (2.5.3.2) and was guided by the framework introduced in Chapter 3. That is, I first coded the qualitative data according to the previously introduced framework. However, after a number of coding cycles it became evident that the framework developed on the grounds of open-ended questionnaire responses did not sufficiently cover pharmacy users full range of attitudes towards mental health support provided in pharmacies and omitted an important factor, i.e. the origins of the expressed attitudes. Therefore, it was necessary to extend and amend the framework accordingly using thematic analysis.

4.2.1 Interview participants

Nine semi-structured interviews were conducted over the course of the data collection period. The demographic characteristics of study participants are outlined in Table 4-8.

Table 4- 8 Demographic characteristics of interview participants

Characteristics	Frequency (n)
Gender	
Female	4
Male	5
Age group	
18-34	5
35-49	2
50+	2
Ethnicity	
White British	7
Other ethnic group	2
Diagnosis of depression or anxiety (self-reported)	
Yes	3
No	6

4.2.2 Developing the context: the impact of COVID-19 on the interviews

All interviews were conducted between September and November 2020 via telephone or online using the software MS teams. Thus, the data were collected amidst the ongoing outbreak of COVID-19.

During the summer of 2020, the number of individuals testing positive for COVID-19 had seen a decrease, hence measures which aimed to slow the spread of the disease were gradually relaxed in England. The submitted ethics document stated that interviews could be conducted face-to-face, if in line with government recommendations and individuals could be verbally invited to participate. In order to boost participation, every community centre in the vicinity of the city of Nottingham was contacted with a request to distribute recruitment flyers and invite members of the public to participate in the study. However, these efforts were interrupted by a steady increase of individuals testing positive for COVID-19 from September 2020 onwards; gradually, measures to contain the spread of COVID-19 were reintroduced. The few community centres which had opened over summer, closed their doors again and study recruitment moved entirely online. As a result of continuously raising case numbers, a second national lockdown came into force on 5th November 2020.

Thus, despite being conducted within 3 months, the interviews fell into a period of fluctuation, measures to curb the spread of the disease were first eased, than tightened locally, and lastly a nation-wide lockdown was reintroduced. In consequence, it was plausible that interviewees' responses during the interview were impacted by the external circumstances. In order to understand respondents' individual perspectives, the interviews commenced with a number of questions pertaining to respondents' personal situation, their physical and mental health and wellbeing and their use of healthcare providers at the time.

Hence, before outlining the themes which were developed from the obtained data, I provide an account of individuals' perception of the impact of COVID-19 on their health and use of healthcare providers. In addition to that, some interviewees commented on the impact they perceived COVID-19 have had on community pharmacy practice; those comments will be highlighted in the relevant sections.

4.2.2.1 Personal experiences during COVID-19

No participant reported to have been directly affected by a COVID-19 infection at the time the interviews were conducted. Nevertheless, the measures which were in place to curb the spread of the disease impacted a multitude of aspects in participants’ life, such as being able to interact with others in everyday situations. Consequently, participants highlighted how feeling socially isolated and perturbed by concerns about the future influenced their mental health and wellbeing negatively.

> *“I'm naturally an optimistic person, but you know, there've been times when it's been quite tough really thinking about well, what future will, will I have? What future will my family have? […]. There's been no denying that I've been more gloomy in the last six months than I have been for a long time, really.” (MI3)*

Participants who had experienced issues with their mental health prior to the outbreak of the pandemic highlighted the importance of establishing a support network, to help them cope with the circumstances and prevent their mental health from deteriorating.

> *“I would, would say that there's been times where I've been cautious of my mental health because due to past experiences, I try and keep, um...kind of a vigilant eye on it, if that makes sense, and I have noticed in myself- times where I have been a bit more shaky when it comes to that, but I have worked quite hard to set myself up with a good emotional support network, so that definitely benefits me I think. (MI8)*

However, one participant who had been diagnosed with depression and anxiety prior to the start of the pandemic and was lacking a support network described how the circumstances surrounding COVID-19 had affected her mental health negatively which resulted in demand for assistance from external sources.

> *"Before I came to UK I was diagnosed [with] light depression, yeah so um actually from March to May [2020] that was fine but my flat mates they just went back like yeah one by one so, finally, I just like stayed in that flat by myself." (FI6)*

4.2.2.2 Access to healthcare

The majority of participants accessed some form of healthcare, other than pharmacy, amidst the ongoing pandemic, mostly due to long-term health conditions.

Experiences with healthcare providers were described as "*weird*" (FI2) or "*strange*" (MI3), as most consultations occurred over the telephone or because social distancing measures affected interactions with health professionals. More so, participants experienced delays in healthcare provision, which was suggested to have resulted in an increase in anxiety levels.

> *I think yeah- [I] was quite anxious at the beginning 'cause I yeah I have asthma and um also high blood pressure and some other stuff that was going on as well with regards to hospital tests... So I think the delays on that too did kind of - yeah all added up to a lot of, a lot of anxiety around that period of time." (FI2)*

Those participants who had received consultations over the telephone described how they understood the necessity for the shift in healthcare delivery, but simultaneously emphasised their preference for face-to-face consultations. This was mostly attributed to the belief that in-person consultations simplify the recognition of problems as well as a lack of trust in virtual decision-making.

> *[…] if we're talking about whether I think it was a nice way of accessing healthcare, then no... I'd much rather have gone because you still got that... Still, the level of uncertainty -you know- making an opinion from a picture is maybe not quite as […] accurate and you don't get the chance to discuss things a little bit." (MI9)*

On the other hand, rarely any changes had occurred in participants' use of community pharmacy, at the time the interviews were conducted.

> *I: And... Would you say that for all the reasons you've just mentioned, the way you access healthcare has changed in any way?*
>
> *F: Um...Probably no, I would say probably... from like a prescription point of view probably not. I still actually have still gone into pharmacy to collect mine. (FI2)*

4.2.2.3 Reflection of the impact of COVID-19

Despite all participants describing how the outbreak of Covid-19 had impacted aspects of their life negatively, most also made an effort to emphasise the positive facets of the situation. Thus, the chasm individuals had to endure were relativized in comparison to others who had been less fortunate, for example due to financial problems or being personally affected by Covid-19.

> *"We tend to like -I don't know- I- almost like make the most of our time more […]" (FI5)*

> *"I guess I've been one of the most fortunate ones insofar as um I wasn't working […] and financially it wasn't a problem, my partner is still teaching, so she was working and paid alright. So compared to a lot of people... um it wasn't so much of a problem." (MI1)*

Thus, the outbreak of COVID-19 transformed various aspects of participants' lives, several individuals experienced difficulties with their mental health and wellbeing amidst the circumstances. Participants' interaction with healthcare providers other than pharmacists saw a shift from in-person to tele-healthcare, which was accepted due to the circumstances but left some participants dissatisfied with the care they had received. On the other hand, individuals' access to pharmacy was only marginally affected by the changing healthcare landscape.

4.2.3 Attitudes towards mental health support provision in community pharmacy

After outlining the context in which the interviews were conducted, the specific objectives of the interviews will be addressed. Folloing an initial cycle of coding and attempting to apply the developed thematic map to the obtained data, two issues became evident. Firstly, trust and the community pharmacy environment seemed to play a more central role than depicted in the initial framework; a re-evaluation of the positioning of trust in relation to individuals' attitudes towards mental health support provision in pharmacies became pertinent. Secondly, the framework was found to be too rigid to accurately depict participants' conceptualisation of pharmacists' role in mental health and the factors that impact individuals' stances.

Rooted in these observations, two major themes were developed from subsequent coding cycles, supported by ongoing discussions within the research team. Both themes consisted of a number of subthemes.

1. The nature and origins of trust in a pharmacy context.

  1.a) Pharmacy- team related factors

  1.b) Community pharmacy setting related factors

2. *Individuals' attitudes towards mental health service provision are mediated by the established level of trust.*

  2.a) Pharmacists' role is conceptualised on a continuum

  2.b) Factors impacting individuals' stances are susceptible to the mediating effect of trust

Figure 4-7 depicts the extended and refined thematic map graphically.

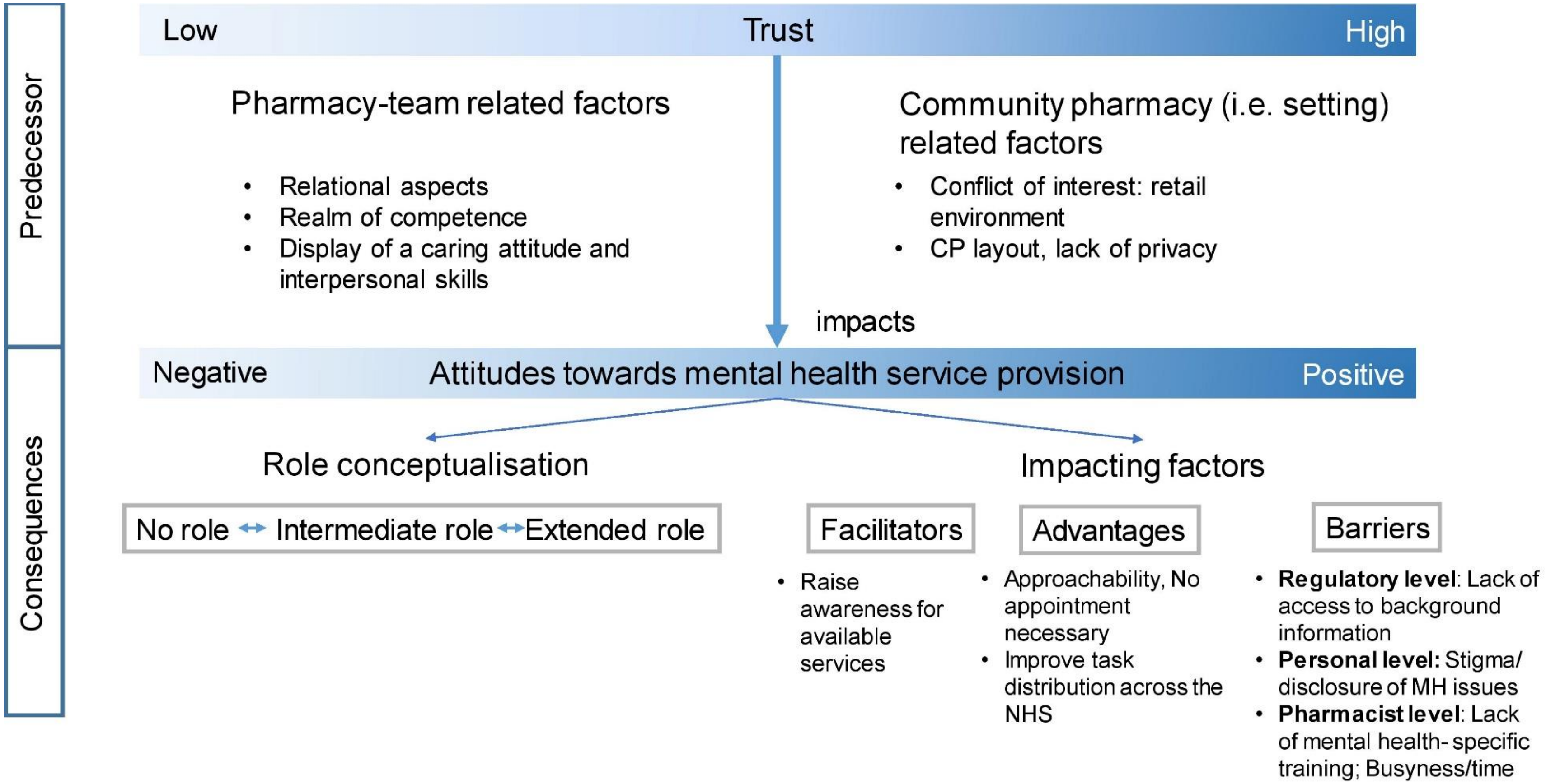

Figure 4- 7Mental health service provision in community pharmacy- framework, CP= community pharmacy

4.2.3.1 The nature and origins of trust in a pharmacy context

The topic trust was discussed extensively in all interviews, predominantly without the need for additional prompts. During the interviews, participants outlined elements they deemed essential for the establishment of trust and subsequently reflected on their perception of current community pharmacy practice and its effect on the development of trust. Thus, trust was identified as a pivotal element for understanding participants' perception of community pharmacy in general and towards the introduction of new services. In particular, two facets of community pharmacy practice were suggested to be important for the establishment of trust, namely, aspects concerning the pharmacy team and elements of the community pharmacy setting.

4.2.3.1.1 Pharmacy-team related factors

Three elements pertaining to the establishment of trust between pharmacy users and members of the pharmacy-team were emphasised by participants, namely: *relational aspects*, *pharmacy team-members' realm of competence* and *display of a caring attitude*.

However, the extent to which participants considered these requirements to be satisfied differed between pharmacists and support staff members. Participants' previous experiences with pharmacy influenced their perception; thus highlighting the complex set of elements which need to be taken into consideration when aiming to understand the nature of trust in a pharmacy context.

Relational aspects

Participants highlighted familiarity with staff members and interpersonal exchange as important elements for the initial establishment of trust.

> *[…] but the other bit which is much less definable, is almost like confidence and trust […] in an individual on a human level, empathic level. Um, which is....I don't know how you build that up, unless you are talking to people... (MI3)*

However, the fundamental nature of relational aspects for the establishment of trust between both parties stood in stark contrast to participants' description of their current interactions with pharmacists and support staff members. Most participants highlighted difficulties with obtaining access to pharmacists; instead interactions occurred more regularly between members of the support staff and the pharmacy user.

> *"I don't see them as... if I'm honest.... I don't see a pharmacist as necessarily an approachable person because it's always you, always deal with the, the people on the counter sort of thing." (MI9)*

Moreover, if interactions did occur, they were described as brief and transactional:

> *M: Yes... yeah, yeah, but that's- it's very transactional.*
> *I: Ok.*
> *M: Quick prescription online. I just go in and call out my name and they give me the medication, (basically) so....um, I'm in and*

> *out the pharmacy in a matter of seconds... basically, unless I have to queue yeah... (MI3)*

Thus, interviewees suggested that interactions with pharmacists are fundamental for the establishment of trust. However, the described lack of interactions, often due to being attended to by support staff members, hindered participants from developing a care relationship with their pharmacists. More so, arising opportunities for developing a care relationship were missed, for example during the collection of prescription medication, which were described as brief and transactional.

Realm of competence

In addition to relational aspects, participants acknowledged that awareness about pharmacists' competences can foster the establishment of trust.

> *"I think you have to show that you're competent as well so that they trust that you know what you're talking about" (FI5)*

However, participants perceived pharmacists' competences to be limited to the provision of medication which had been issued by other health care professionals and as a source of advice for minor ailments. Although most participants seemed to be aware of the expanded role of community pharmacists, available services had been rarely utilised.

> *"[…] it's really just providing me […] with my prescription, but I know sometimes I get nice advice about the cold, what to take*

> *for the cold… um and some facts and advice on that score.” (MI1)*

> *“I think there's been a big push,* ***not that I had to take it up****, towards saying: "but here is an alternative way of seeking help for some medical conditions that you may have or may be worried that you have." (MI3)*

Some participants drew unfavourable comparisons between pharmacists and general practitioners. GPs were regarded as a higher authority within the healthcare system, since they are able to prescribe medications.

> *“In my understanding is all they [pharmacists] would end up doing, would be refer- telling you to go and see the GP anyway, so I would just go straight to the GP.... It’s not that I've got anything against the pharmacist […] It's just.... I don't want to say it's a waste of time, but almost delaying the inevitable.” (MI9)*

On the other hand, support staff members were mostly recognised for their contribution to the business aspect of pharmacies. Interviewees seemed to be reluctant to acknowledge a role for members of the support staff beyond the provision of blanket advice for over-the-counter products and prescription medication.

> *“I think the staffs would be able to give like very general information about the products that they [customers] are trying to search for, the services that they are trying to get in the pharmacy, and especially in, in terms of the business aspect of*

> *the pharmacy I think those supporting staffs have really great contribution. (FI7)*

In summary, awareness of pharmacy team members' competences was suggested to foster the establishment of trust between pharmacy users and pharmacy employees. However, pharmacists' realm of competence was seen as limited to the supply of medication other health care providers had been issued and the provision of advice for low risk conditions, while GPs were viewed as the higher, 'prescribing' authority. Thus, individuals' level of trust may be limited to these aspects of the role of pharmacists, which might negatively influence individuals' perception of services outside this scope which are provided in pharmacies.

Display of a caring attitude and interpersonal skills

Although mentioned less frequently, some participants emphasised that the display of a caring and respectful attitude may help to instil trust in pharmacy users.

> *"I think one of the most important things is like showing an interest in your patients, so that way they then trust you and open up to you and they actually want to talk to you." (FI5)*

Remarks about pharmacists' demeanour indicated that individuals did not always feel as if they receive the desired attention from pharmacists.

> *“they've often got the back to you […] and they don't talk to you, they don't acknowledge you” (MI9)*

Whereas members of the support staff were more likely to exhibit a friendly attitude, in order to make individuals feel acknowledged.

> *“I mean sometimes the support staff […] greet you with a smile when you come in feeling like rubbish.” (MI9)*

Similarly, participants emphasised that pharmacists’ interpersonal skills might affect the establishment of trust.

> *“I: And can you think of factors that would help you to establish that kind of trust?*
>
> *F: [pause] I think.... In a way one of the most affecting is the way they speak to us or their, their speech and their gestures... I wouldn't want them to be so aggressive and so...um...so intimidating, you know I, I would prefer them to speak slowly and then patiently.” (FI7)*

In spite of the importance interpersonal skills may have for the establishment of trust, pharmacists’ attitude was occasionally described as discrepant to individuals’ desire for empathetic and compassionate conversations.

> *“With a pharmacist it's almost a case of... You're going in there and it's a direct: Okay, what you want? What, what would you like to do?” (MI1)*

Thus, demeanours that can be interpreted as lacking attentiveness and inadequate interpersonal skills may affect the establishment of trust between pharmacy users and pharmacists. However, participants also described how members of the support staff made them feel cared for, indicating that support staff members play a crucial role for instilling trust in pharmacy users.

Mediating effect of experiences

Thus far, participants' remarks indicated that there are discrepancies between the elements that have been identified as pivotal for the establishment of trust and individuals' first-hand experiences with pharmacy services.

However, participants who had been exposed to pharmacy services described the mediating effect those experiences can have on the establishment of trust.

> *"She [pharmacist] has been the one that's provided me advice through services such as the Medicines Use Review Service and the New Medicine Service. So she's built that trust with me through my past experiences with her 'cause she's demonstrated her knowledge and I've yeah- she's been really helpful in talking me through... like you know what to expect from side effects from, from medication that I've started on...um, yeah, so I think the, the trust that I've built up with her it's, it's because of those past, those past experiences."* (FI2)

4.2.3.1.2 Community pharmacy setting related factors

In addition to factors pertaining to the pharmacy team, the pharmacy environment was identified as an additional factor that was appeared to affect individuals' level of trust in pharmacy provided services.

> *"from my point of view, at the moment, I must say, I don't feel the need to interact with the pharmacy. However, if I did suddenly feel I needed help, I would need somewhere, that I would feel comfortable […] and at the moment I feel that our pharmacy isn't geared up for that." (MI1)*

Conflict of interest: the retail environment

Participants suggested that the retail environment in which community pharmacy operates might not be conducive for the provision of healthcare. Thus, a conflict of interest between business interests and healthcare provision ought to emerge.

> *"The way that everything's set out: the aisles, it does feel a lot like a supermarket, but for medical supplies instead. And I do feel maybe there's something, there's something psychological there that because it set out like a supermarket, there's a-, there's an emphasis on consumption or an emphasis on the power of the customer, which I think you could argue is dangerous because the whole idea of the pharmacy is meant to be that they're the experts, not you." (MI8)*

Community pharmacy setting is not conducive to individuals wish for privacy

Similarly, the acknowledgment of individuals wish for privacy was found to be an important factor for the establishment of trust.

> *"I think privacy and you kn- confidentiality and […] being really comfortable, about actually that conversation with the pharmacist is, is something that is between you and you and them..." (FI2)*

During the interviews, individuals commented on the openness of the community pharmacy layout, which permits others to overhear ongoing conversations. As a result, individuals highlighted that the pharmacy environment is lacking the necessary privacy for the discussion of sensitive topics.

> *"I guess the barrier that I see is often you go to a pharmacy and there's a row of people sat down and sat around you waiting...um... in the same- within earshot." (MI4)*

The outbreak of COVID-19 was suggested to have had an additional detrimental effect on privacy in pharmacies, due to implemented safety measures.

> *"[…] thinking of the pharmacist that I know, it's fairly small um and the discussion across the counter, which is obviously made more difficult now, that they're have to have a screen up." (MI1)*

Some established processes, such as reading out prescription details, need to be revaluated, as indicated by one participant who reminisced on an occasion where his wish for privacy had not been acknowledged.

> *"I think...there definitely is a lack of privacy. I mean, I've had my name, address and prescription details read out to me across a pharmacy with other people in it.... I mean, it's just inappropriate." (MI4)*

Interestingly, almost every participant independently mentioned the necessity to establish a separate privacy area in community pharmacy. However, when asked about consultations rooms directly, participants where either unaware of their existence, had never used them or described negative experiences.

> *"But, but certainly the only one I have been too, when I had a flu jab at the local [large pharmacy chain] -you know- we were almost rubbing knees, the space was so small." (MI3)*

The mediating effect of positive associations and experiences

However, positive associations and awareness of consultation rooms shifted participants' perspective, as consultations rooms were seen as a facilitator for privacy.

> *"I: Could you imagine that privacy might be a bit of a problem?*
> *F: Umm...Potentially, although I suppose most pharmacies have got consultation rooms and I think the pharmacist would take you*

> *into the consultation room if you did have, umm something that you wanted to speak privately about." (FI2)*

Summary

Participants emphasised elements pertaining to pharmacy employees and to the pharmacy environment as pivotal for the establishment of trust. Participants' remarks indicated a discrepancy between those elements they identified as essential for the establishment of trust and their personal perception of pharmacy practice currently. However, recurrent interactions with the same pharmacist and positive experiences with pharmacy services were found to converge both aspects, as they increase awareness of pharmacists' competences and instil a feeling of being cared for.

Hence, participants comments indicate that trust (or lack therefore) is a fundamental aspect to consider when aiming to understand individuals' perceptions towards the provision of additional services community pharmacy.

4.2.3.2 Individuals' attitudes towards mental health service provision are mediated by the established level of trust

Two aspects of individuals' attitudes towards pharmacy-provided mental health support were discussed during the interviews, the role of pharmacists in mental health support provision and factors impacting individuals' stances.

4.2.3.2.1 Pharmacists' role is conceptualised on a continuum

Participants comments about the role pharmacists may be able to fulfil in the provision of mental health care suggested that their conceptualisation aligns with the contents of the guiding framework. That is, some participants saw no, or a limited role for pharmacists in mental health support provision, others supported a bridging role for pharmacists between patients and other healthcare providers, and a number of participants advocated for an extended role of pharmacists. However, participants' role conceptualisations occurred to be influenced by their perception of community pharmacy in general and thus, were subject to fluctuation. Therefore, the rigid categorisation that had been proposed in the guiding framework may be misleading. Instead, individuals' attitudes towards pharmacists' role in mental health may be better conceptualised on a continuum, which ranges from complete opposition to endorsement for an extended role.

No/ limited role

Participants who opposed a role for pharmacy in the provision of mental health care, grounded their opinion in both, aspects pertaining to the pharmacy setting as well as in their perception that pharmacists are mainly responsible for low risk conditions.

> *"For me, you going to pharmacy- you can buy hairdresser sorry hair dryer, you can buy cat food, you can buy sweets, you can buy whatever you want.... Christmas cards probably. I mean, for me it's a shop. I wouldn't go to Tesco's for mental health*

> *concern, I wouldn't go to pharmacy equally for mental health concern." (MI4)*

Intermediate 'bridging' role

Several participants saw pharmacists in a position to fulfil a bridging role between visits of other healthcare providers, in order to provide ongoing support.

> *"just maybe check in as to how, how they are doing and -you know- see if so how, how they are finding the medication... if there is any side effects or...if, if there is any additional support they need, so it's not kind of to the last minute where they feel like they've got to go to the GP because things have got that bad" (FI2)*

However, some participants questioned pharmacists' ability to bridge between HCP and patients on the premise that the fundamental requirement for it, i.e. the establishment of a trusted relationship between both parties, was not met.

> *"I suppose if, if your pharmacist sees somebody regularly, and they […] notice a deterioration in their health um then they would... I don't know- who they would pass on, presumably to their GP, but um at the moment I don't, I don't see that." (MI1)*

Extended role

Frequently mentioned by participants was a role for pharmacists in providing more holistic approaches to mental health care, in particular as an alternative to other, ‘prescription-focused’ healthcare providers, such as GPs.

> *“I think GPs have gotten better at, at not thinking somebody's in here with depression I'll give him sertraline or whatever.... I think GPs have got better that way... but -you know- their instinct is much more towards the medical model, I think... then, […] the non-prescription side, I think increasingly we should be interested in.” (MI3)*

In the same breath it was highlighted that establishing pharmacists as a source for holistic advice about mental health requires a shift in individuals understanding of pharmacists’ role. That is, pharmacists should be acknowledged as complementary to GPs, instead of the hierarchical conceptualisation which is currently underpinning some individuals’ role understanding.

> *“[…] it needs to be for people like not necessarily coming into the pharmacy as well that they need to know that they can see a pharmacist ‘cause they might be completely against medication and seeing a doctor.” (FI5)*

4.2.3.2.2 Factors impacting individuals' stances are susceptible to the mediating effect of trust

The thematic map guiding this analysis encompassed three factors influencing individuals' stances towards mental health support provision. That is, advantages, barriers and facilitators; each of which comprised several subcategories. The majority of factors and subcategories included in the guiding framework were confirmed by interview participants.

In terms of advantages, participants almost uniformly highlighted the accessibility of community pharmacy, without the need for an appointment. This was of particular importance for the provision of mental health support, as the long waiting times expected from GP services were seen as unacceptable, especially for cases which require acute attention.

> *"I would think that mental health services or any service that is offered by the pharmacy would be much more accessible than the GP ones, because GP-, I would think […] we need to have an appointment first and then we need to wait long hours, especially because many other, um patients are perhaps more prioritised." (FI7)*

Secondly, participants suggested that raising awareness about available services could facilitate the uptake of those, in particular if advertisements were visible in community pharmacy or embedded in ongoing media campaigns about community pharmacy provided services.

> *“I suppose- it'd something that we need to raise awareness of it... So, so would there be something that's visible in that pharmacy that says, um that mental health support is available there.“ (FI2)*

The majority of barriers included in the guiding framework were confirmed by interviewees, especially barriers that are representative of underlying structural issues, such as pharmacists lacking time for additional services, due to an already high workload.

> *“I mean time, like but it's the same everywhere though... If, um if somebody's got a mental health problem and they come to speak to a pharmacist, and a pharmacist has got like you know, like 300 prescriptions to check […]” (FI5)*

Regulatory barriers, such as interconnectivity and data exchange between different healthcare providers may pose a challenge for mental health service provision in pharmacies. In particular difficulties with gaining access to individuals’ health records was suggested to be problematic, as it means that individuals are required to reiterate their medical history, which can result in distress.

> *“I mean they know- should know my basic information about my anxiety, also my depression problem because […] I found like if I need to talk to the NHS I need to explain all my problems again. […] Sometimes […] it's hard.” (FI6)*

However, interviewees’ responses also indicated, that some barriers to mental health service provision in community pharmacy are susceptible to the mediating effects of trust. This was particularly prevalent for an aspect of mental health service provision in pharmacies which had not been included in the guiding framework. That is, individuals personal struggle with seeking mental health support and the stigma which surrounds mental health.

> *"sometimes you feel that...maybe it's my problem to get that [mental health problems], or it's my fault to get that- so sometimes I feel like embarrassed to share that." (FI6)*

Trust between both involved parties may positively influence individuals' comfort and willingness to disclose problems as sensitive as mental health issues.

> *"If I trust that person. […] I believe that person won't judge my answers. […] If I trust them, I would be so- it would be so much easier for me to just spill everything out, and knowing that it is okay to spill everything out." (FI7)*

Thus, establishing a relationship with pharmacists is not only essential for the development of trust, it may be of particular importance in the realm of mental health service provision, as it decreases barriers which are specific for this type of service.

> *"There is less stigma attached to a physical ailment, most physical ailments I should say then there is to mental health one, and I think many people would probably find it more comforting to strike up a conversation with somebody they met, had some dealings with, and feel con-, confident, comfortable with them,*

> *then effectively asking to speak to a stranger about how they are feeling.“ (MI3)*

This stance was contradicted by some participants who suggested that the non-existence of relationships may act as an advantage for mental health service provision in pharmacies, as they preferred to remain anonymous.

> *“I: And that is not something that is important to you? [Establishing a relationship]*
> *I: Um... It's as important as getting... Um, buy my shopping at the same checkout with the same person, as in not important.*
> *I: Okay. Can you imagine, the establishment of a relationship being important if you were to access mental health support.*
> *M: No.*
> *I: Okay.*
> *M: I'm a very private person, so I would want, the anonymity of it.” (MI4)*

Thus, establishing a trusted relationship can have mediating effects on pharmacy users’ acceptance of mental health services provided in pharmacies, as it increases individuals’ willingness to seek help and reduces the stigma surrounding mental health issues. However, this might not be applicable to everyone, as some individuals appreciate the anonymity the community pharmacy environment is able to provide.

4.3 Synthesis of information

4.3.1 Summary of key findings

This chapter reported the results from a survey distributed in 15 community pharmacies in England in 2020. The survey was succeeded by a qualitative research phase; semi-structured interviews with some survey participants and additionally sampled members of the public were conducted.

Quantitatively two aspects are worth highlighting. Firstly, the survey results were able to confirm the favourable properties of a scale to measure pharmacy users' level of trust in pharmacists in a different sample of community pharmacy users. The obtained results further suggested that male participants, individuals who do not use the same pharmacy, and pharmacy users aged 65 to 79 were likely to exhibit lower levels of trust in pharmacists. Ethnicity was found to be the strongest predictor of participants' level of trust; individuals who reported their ethnicity as any other than white, exhibited significantly lower levels of trust in pharmacists compared to participants of white ethnicity.

Secondly, the previously developed scale to measure pharmacy users' attitudes towards mental health service provision was extended; an additional variable which investigates the suitability of the pharmacy environment for the provision of mental health support was successfully included. The new scale demonstrates favourable properties. Individuals who reported using the same pharmacy were more likely to exhibit positive attitudes towards mental health service provision, as were participants who reported higher levels of trust in pharmacists. Importantly, individuals who had self-reported a diagnosis of depression and/or anxiety exhibited higher levels of scepticism towards mental health support provided in pharmacies. This association had not been investigated previously.

Qualitatively, I explored the nature and role of trust in a pharmacy context and its impact on individuals’ stance towards mental health support provision in pharmacies. Familiarity with pharmacy team members, awareness of their competences and feeling cared for were found to contribute to the establishment of trust. However, these requirements were only insufficiently met in the eyes of most participants. In consequence, participants were hesitant to accept pharmacy services beyond the dispensing of medicines and the provision of advice for low risk conditions. Similarly, the pharmacy environment, as it is currently may have negative consequences for the establishment of trust. Both qualitative and quantitative results highlighted the importance of relational aspects for the establishment of trust. However, access to pharmacists occurred to be difficult to obtain and opportunities for interactions between pharmacy users and pharmacists remained unused.

Participants’ conceptualisation of the role pharmacists might be able to fulfil in the provision of mental health care resembled the results obtained from the open-ended responses in the previous year. However, a rigid categorisation may be misleading, as individuals’ level of trust and perception of pharmacy in general affected their expressed stances.

Likewise, most attitude impacting factors that were retrieved from survey responses in the previous year, were confirmed by interview participants, yet some additional aspects, such as the stigma surrounding mental health were introduced. Barriers to mental health service provision in pharmacies might be susceptible to the mediating effect of trust, e.g. by decreasing pharmacy users' fears to discuss topics as sensitive as mental health issues. Thus, both, individuals' conceptualisation of pharmacists' role in mental health and their perception of impacting factors were subject to fluctuations depending on the level of trust individuals had and wanted to establish with their pharmacist.

4.3.2 Informing the subsequent study phases

The previous two chapters provided detailed information concerning pharmacy users attitudes towards mental health support provided in pharmacies. In section 1.5.1. I argued that pharmacy-generated loyalty card data could support pharmacists' involvement in mental healthcare, as customers' purchasing patterns may be indicative of underlying health issues. However, it is currently unclear to which extent members of the public support the utilisation of personal data, such as loyalty card data in a health research context, and specifically as a tool to identify individuals at risk of developing certain health conditions. Thus, in the following chapters I attempt to explore this topic in more depth.

Chapter 5

Exploring new possibilities: Loyalty card use and attitudes towards the use of loyalty card data for health research purposes in a student population

In the previous two chapters, I evaluated pharmacy users' attitudes towards pharmacy provided mental health support in detail. Pharmacy users views were found to be diversified, but some agreed that pharmacists could be in position to identify individuals with mental health issues. Likewise, in the introduction, I outlined potential roles for pharmacists in mental health care; pharmacy professional bodies identified pharmacists to be in a position to assist with the early identification of pharmacy users who might be at risk of developing mental health issues (1.4.3). In section 1.5.1. I characterised purchasing data as a data source that could support such endeavours. However, I further argued that research efforts currently focus on the investigation of transactional data itself (i.e. *what* can be inferred from loyalty card data), while the question of *how* and under *which* circumstances information derived from these data can be used in the context of healthcare, and specifically community pharmacy practice, is largely unanswered. The second research stream that was conceptualised for this thesis, aims to address this question in detail (research objectives 3-5). In this chapter, I report the first set of results I obtained from this research stream; specifically, the information obtained from a survey and interviews conducted amongst the student population at the University of Nottingham will be outlined. Students were thought to provide an ideal starting point, as the literature review indicated that individuals' attitudes are age-dependent and influenced by one's familiarity with personal data and its use for predictive purposes (1.7). Thus, before turning my attention to the wider population with greater differences in terms of knowledge about and exposure to novel technologies I decided to investigate a student sample first, as students were thought to be in a similar age range and, as digital natives, accustomed to the concept ‘personal data’.

The chapter is split in two sections. First, I quantify loyalty card use in a student population and map students’ stances towards the use of transactional data in a health research context. Second, in order to add explanations to the obtained quantitative data, a qualitative research phase succeeded the survey. Throughout the study period 17 semi-structured interviews were conducted.

The data presented in this chapter were collected between December 2019 and April 2020, a time that was characterised by the outbreak of COVID-19, its dissemination around the globe and classification as a pandemic. Subsequently, measures to curb the spread of the disease were introduced. Thus, aspects that epitomise the context in which these data were obtained will be highlighted throughout this chapter.

5.1. Quantitative results

5.1.1. Introduction

A cross-sectional survey was distributed across the student body of the University of Nottingham from 12 December 2019 to 01 March 2020 using a multitude of dissemination pathways (2.4.1.2.2). The questionnaire was conceptualised as an online survey, hosted on the platform JISC. Thus, students were able to complete the survey at a time and location convenient to them, using a computer or mobile device. As a result of the chosen survey methodology, a response rate cannot be calculated (2.4.1.3.5).

The survey encompassed three components. Firstly, students' use (or non-use) of loyalty cards was investigated using seven closed-ended questions; therefore, predominately categorical data was generated. Second, respondents' attitudes towards the use of personal data and loyalty card data in the context of health research were measured using 13 five-point Likert scales and one ranking question. The last part of the questionnaire pertained to students' demographic characteristics, such as age, gender and field of study (n=6 questions). Throughout the questionnaire, high item response rates were obtained; a complete case analysis was performed.

5.1.2. Sample characteristics

During the two months of data collection, 438 students completed the questionnaire. One respondent withheld consent, thus the submission was excluded. Accordingly, 437 valid responses were considered for analysis.

The characteristics of the obtained sample are presented in Table 5-1. Subsequently, the demographic characteristics of the sample were compared to the student statistics at the University of Nottingham[22] Female students, participants aged 21 to 24 years and postgraduate research students were found to be overrepresented in the cohort. Additionally, more students studying science or medicine and health science subjects participated in the survey than what would have been expected from the overall student statistics (Table 5-1). However, the sample was found to be broadly representative of the student body with regards to students' ethnicity, registration and the degree programme students reported to be enrolled at. In order to facilitate an analysis of the obtained categorical data, a number of response categories were collapsed. Three age categories were created, namely students aged 18-20 years, 21-24 years and students aged 25 or older. A binary variable was generated based on participants reported ethnicity, delineating between individuals who reported their ethnicity as any white and those who reported any other ethnicity.

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[22] 167. The University of Nottingham. *Student Statistics 2018-19* [online]. 2018 [Accessed 13th April 2021]; Available from: https://www.nottingham.ac.uk/ppsc/spp/student-statistics/student-statistics-2018-19.aspx.

Table 5- 1 Participants' characteristics and comparison to university statistics

Characteristics	*Frequency (n)*	*Percent (%)*	*University (%)*
Gender			
Female	328	75.1	55.3
Male	103	23.6	46.2
Other	1	0.2	N/A
Prefer not to say	2	0.5	N/A
Not answered	3	0.7	N/A
Age group			
18-20	196	44.9	65.1
21-24	162	37.1	17.1
25-29	43	9.8	7.2
30-39	28	6.4	6.9
40-49	4	0.9	2.2
50+	3	0.7	0.8
Not answered	1	0.2	N/A
Registered as			
Home student (UK)	330	75.5	72.2
EU/EEA student	29	6.6	Combined: 27.8
Overseas student	77	17.6	
Not answered	1	0.2	N/A
Subject area[23]			
Science	145	33.2	21.9
Medicine and Health science	88	20.1	11.8
Social Sciences	77	17.6	30.8
Engineering	40	9.2	14.0
Art	43	9.8	14.5
Not applicable	26	5.9	N/A
Combined subject	16	3.7	N/A
Not answered	2	0.5	N/A
Degree programme			
Undergraduate	330	75.5	70.9
Postgraduate taught	37	8.5	18.7
Postgraduate research	68	15.6	8.4
I am not currently enrolled on a degree programme	1	0.2	0.2
Not answered	1	0.2	0.2

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[23] University student statistics do not add up to 100%, because subjects which are not allocated to schools are not included (e.g. Foundation Arts), and students studying joint honours are split equally between the schools they are enrolled at.

Ethnicity			
White (English/ Welsh/ Scottish/ Northern Irish/ British; Irish; Gypsy or Irish Traveller; Any other White background)	303	69.3	75
Asian / Asian British (Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background)	79	18.1	12
Mixed / Multiple ethnic groups (White and Black Caribbean; White and Black African; White and Asian; Any other Mixed/ Multiple ethnic background)	14	3.2	6
Black / African / Caribbean / Black British (African; Caribbean; Any other Black / African / Caribbean background)	16	3.7	5
Other ethnic group (Arab; Any other ethnic group)	23	5.3	1
Not answered	2	0.5	0.5
Current or previous struggles with mental health and wellbeing			
Yes	224	51.3	N/A
No	169	38.7	N/A
Prefer not to say	43	9.8	N/A
Not answered	1	0.2	N/A

5.1.3. Students' use of loyalty cards

Next, participants' use of loyalty cards was investigated to provide an overview of loyalty card use and non-use in the obtained sample. Subsequently, both cohorts were compared across the main characteristics, age, gender and ethnicity using significance tests with measures of association.

5.1.3.1. Loyalty card use versus non-use

Nine-in-ten students reported to own at least on loyalty card (n=394), while 42 (9.6%) students did not own any loyalty cards. Significantly more male students reported not using any loyalty cards, compared to their female counterparts ($\chi^2 = 15.3$, p<0.001). Participants' age was found to be unrelated to reported use of loyalty cards ($p < 0.571$). Significantly more students who reported their ethnicity as any other than white did not own any loyalty cards ($\chi^2 = 11.84$, p<0.001). It is noteworthy, that an overwhelming majority of international students (i.e. EU/EEA and overseas students) reported their ethnicity as any other than white, compared to UK students ($\chi^2 = 113.4$, p<0.001). Additionally, the association between loyalty card ownership and students registration (i.e. Home or international student) was found to be significant; home students were found to be more likely to be loyalty card owners ($\chi^2 = 6.5$, p<0.011). International students might spend a limited time in the UK, in order to pursue a degree and therefore refrain from acquiring a loyalty card, which might have driven the observed association between loyalty card ownership and individuals' ethnicity.

Students who reported not owning a loyalty card were asked to cite their reasons for not engaging with a loyalty scheme (multiple answers possible). Most frequently, students noted that they had not considered getting a loyalty card (n=21, 50.0%). Only two individuals cited concerns over privacy as a reason for deciding not to engage with a loyalty scheme.

5.1.3.2. Typology of loyalty card users

Next, the cohort of students who reported using at least one loyalty card was subjected to further analysis. Of the 394 students who identified as loyalty card users more than two-thirds (n=270) reported to use between one and four cards, one-third (n=124) owned five or more cards.

5.1.3.2.1. Frequency of use

Figure 5-1 illustrates the frequency with which students reported to use loyalty cards. The data suggest that in-store use of loyalty cards occurs more frequently than the use of loyalty cards online. However, it has to be taken into consideration that these data were collected before the impact COVID-19 were to have on society unravelled, which resulted in an increase in the number of individuals who decided to shop virtually instead of visiting a store physically.[24]

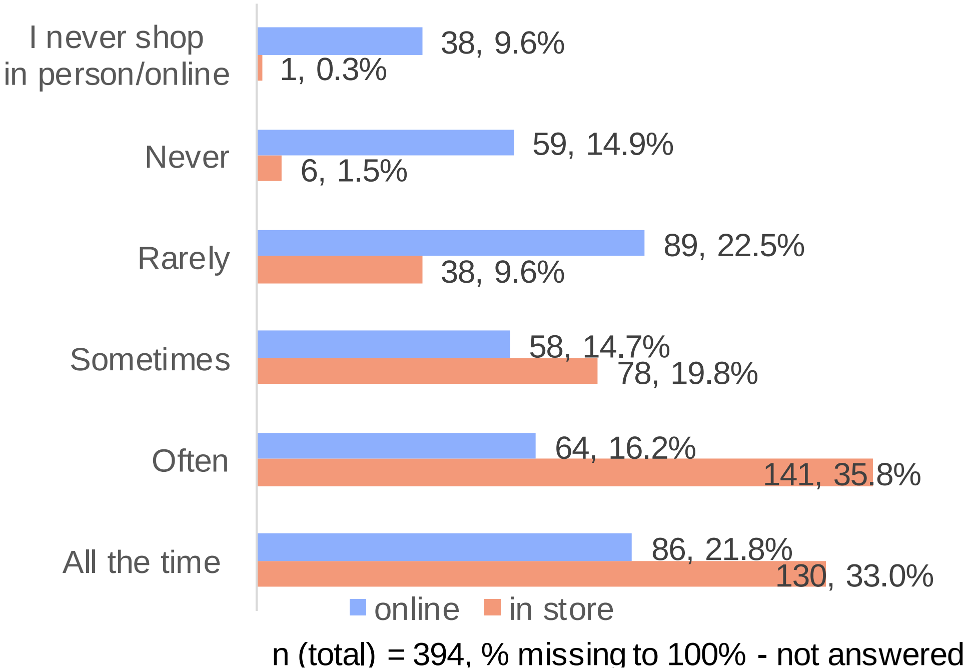

Figure 5- 1 Frequency of loyalty card use (in-store versus online)

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[24] 210. Dalgleish R, Office for National Statistics. *How the COVID-19 Pandemic has accelerated the shift to online spending* [online]. 2020 [Accessed 7th June 2021]; Available from: https://blog.ons.gov.uk/2020/09/18/how-the-covid-19-pandemic-has-accelerated-the-shift-to-online-spending/.

5.1.3.2.2. Categories of loyalty cards used by students

Those students who reported to own at least one loyalty card were asked which types of loyalty schemes they are engaging with (multiple answers possible, Figure 5-2). The majority of students (n=317, 80.5%) reported to own a loyalty card provided by a health and beauty retailer, such as Boots or Holland and Barrett. Significantly more females reported to engage with this type of loyalty scheme, compared to their male counterparts ($\chi^2 = 90.2$, p<0.001). Participants' age and ethnicity were found to be uncorrelated with use (or non-use) of health and beauty loyalty cards.

Students also reported high engagement rates with loyalty cards provided by grocery stores, such as Tesco or Sainsbury's (n=275, 69.8%). The data suggest that the use of these types of loyalty cards is more common in students aged 25 years or above, compared to younger age groups ($\chi^2 = 13.9$, p<0.001). Participants' gender and ethnicity were found to be unrelated to the use of grocery store provided loyalty cards (p=0.318, p=0.576, respectively).

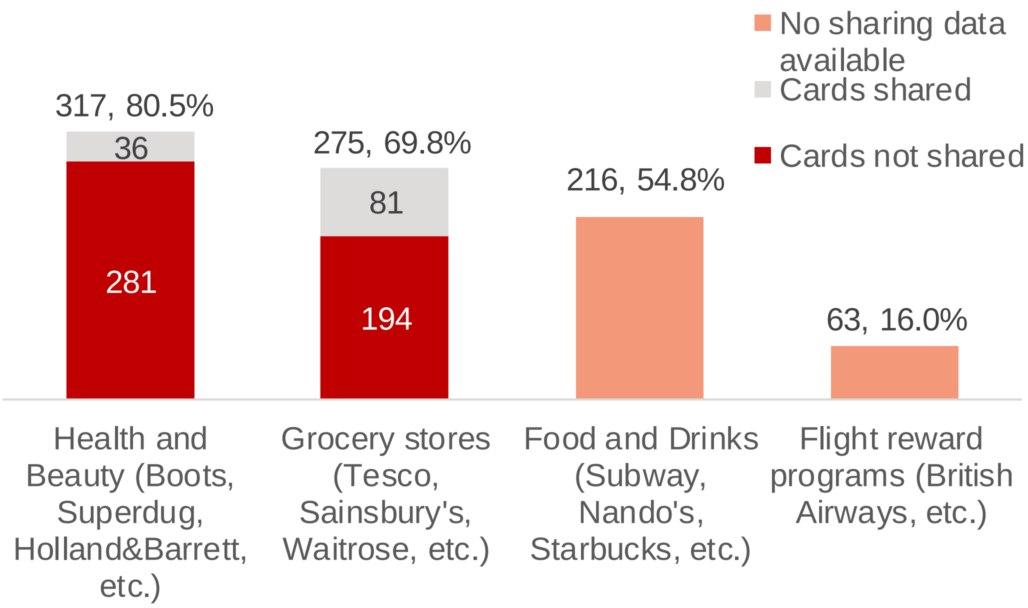

Figure 5- 2 Types of loyalty cards owned by students (n=394) and prevalence of loyalty card sharing

5.1.3.2.3. Sharing of loyalty cards

Students who reported the use of health and beauty loyalty cards and grocery store loyalty cards were asked whether or not they use their cards jointly, e.g. with other members of their household (Figure 5-2). Joint usage of loyalty cards was reported more frequently for grocery store loyalty schemes, health and beauty loyalty cards occurred to be shared less frequently. Irrespective of the type of loyalty card, no associations between joint usage and one of the main demographic characteristics, i.e. age, gender and ethnicity were found ($p > 0.05$)

5.1.4. Students' attitudes towards personal data

After providing a descriptive account of students' use of loyalty cards, their stances towards the value and sensitivity of personal data in general and its use for health research were investigated. At the beginning of this section of the questionnaire, participants were provided with a definition of personal data according to the GDPR[25].

5.1.4.1. Perception of the value and sensitivity of personal data

A majority of students reported to be careful about which companies they share their personal data with (n=251, 57.6%). Almost one-in-two students suggested that they trusted companies to treat their data confidentially (n=215, 49.3%). Additionally, participants were asked whether or not they would be willing to share personal data for benefits, such as store discounts. More than two-thirds of participants agreed or strongly agreed with the statement (n=300, Figure 5-3). Subsequently, the response categories of this question were collapsed, to delineate individuals who were willing to share personal data for benefit (n=300) and those who were not (n=51). Somewhat unsurprisingly, a χ^2-test suggested that participants who reported to use at least one loyalty card are significantly more likely to be willing to share personal data for benefit ($\chi^2 = 14.9$, p<0.001). However, 39 students reported to be unwilling to share personal data for benefit, although they had subscribed to a loyalty scheme.

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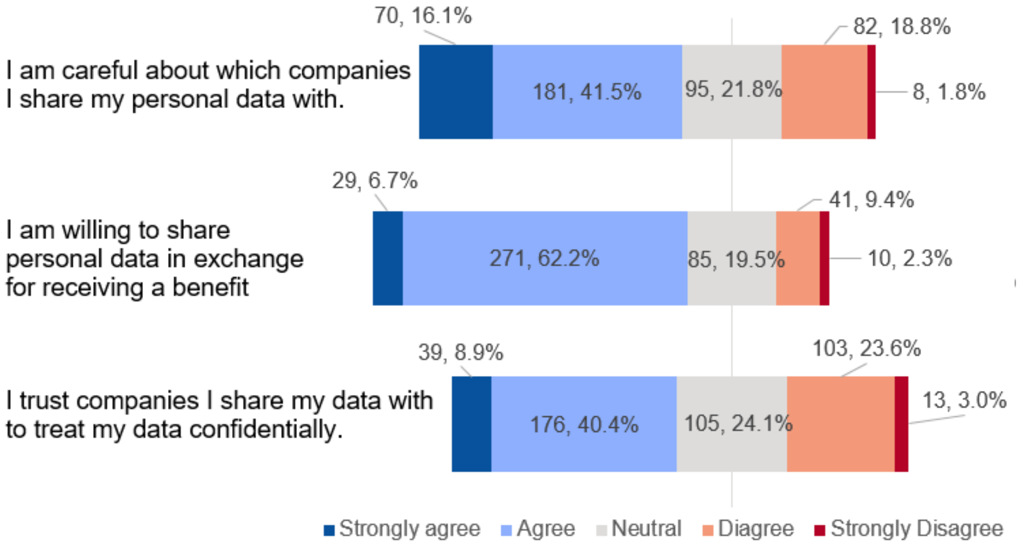
[25] 199. The General Data Protection Regulation (GDPR), Regulation (EU) 2016/679. Sect. Article 4 (Definitions) (2018).



% missing to 100% - not answered

Figure 5- 3 Students' attitudes towards sharing personal data

Lastly, student were asked to rank five different non-traditional types of personal data in order, based on how concerned they were if the data were to be misused (Figure 5-4). A possible misuse of location data and healthcare data evoked the greatest concerns in students, while a potential misuse of loyalty card data was met with less apprehension.

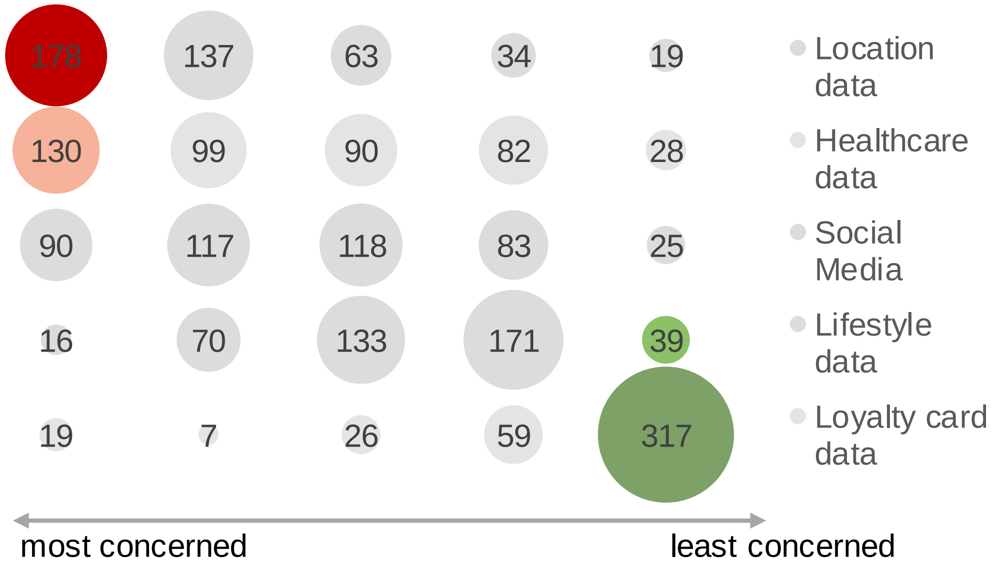


Figure 5- 4 Students' concerns about data misuse, ranked from 1 (most concerned) to 5 (least concerned)

5.1.4.2. *Use of personal data for health research*

Additionally, participants were asked to rate their agreement with the use of a number of different data sources, such as electronic healthcare data or social media data in the context of health research.

Students were most likely to endorse the statement that electronic healthcare data can be used for research, closely followed by a proposed utilisation of lifestyle data, such as data collected on wearables. The use of social media data was met with less unanimous support, and a possible application of location data and loyalty card in health research evoked hesitation in participants (Figure 5-5).

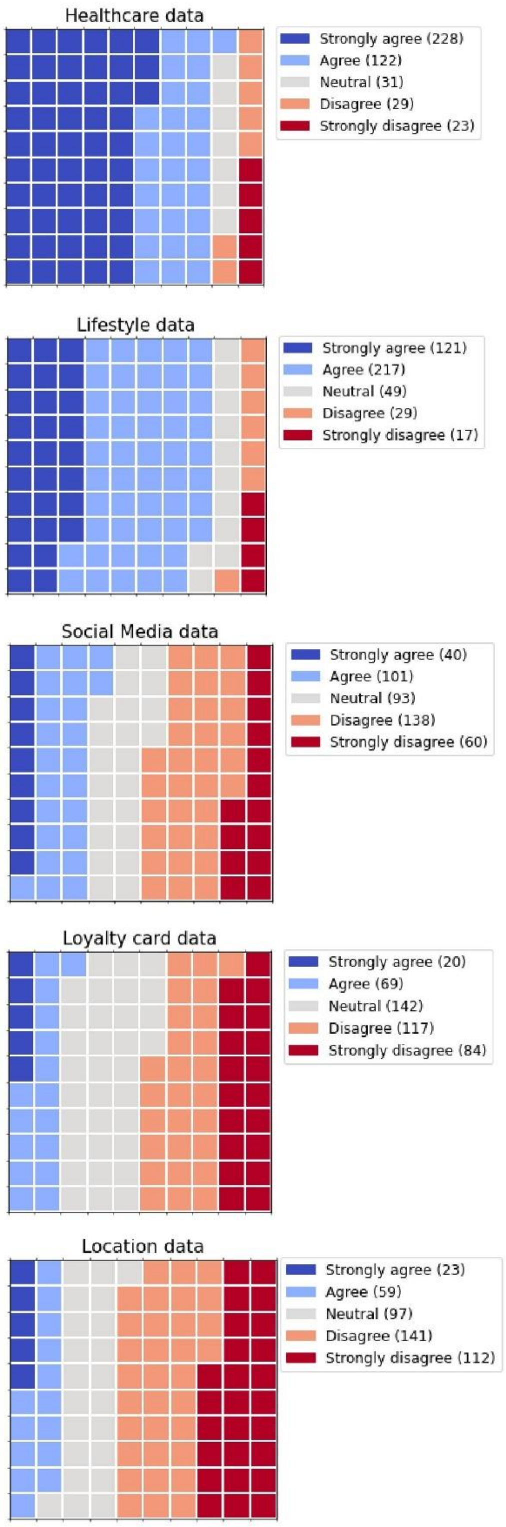
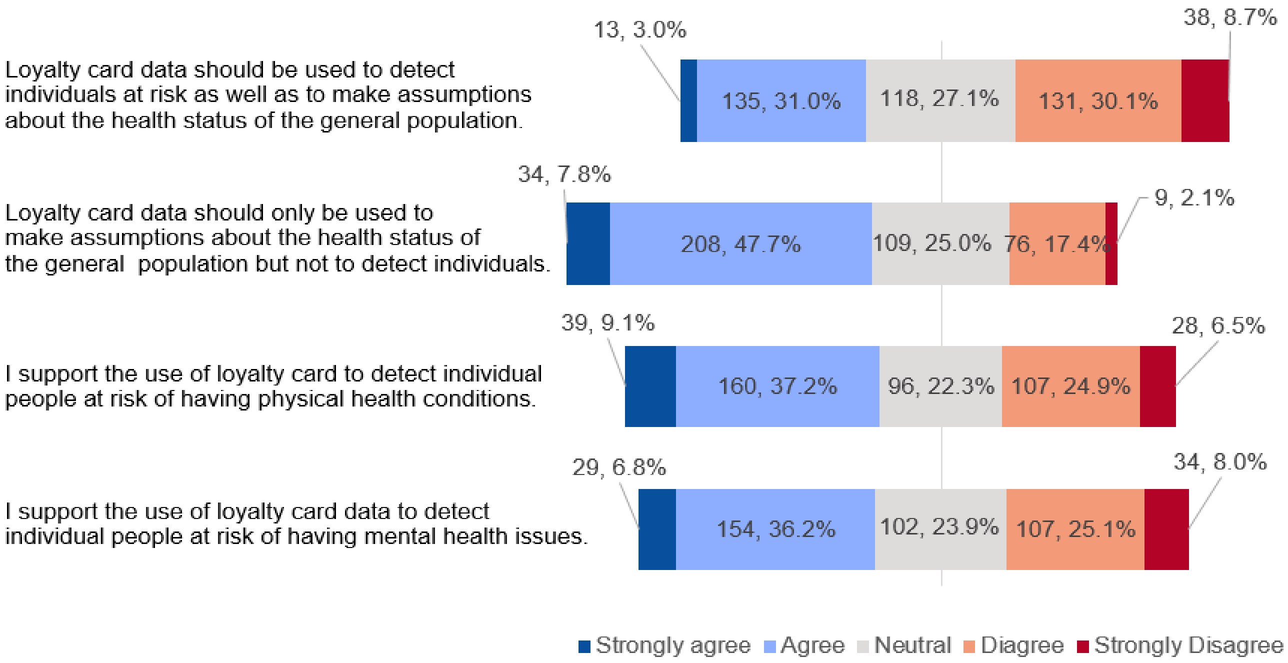


Figure 5- 5 Students' perspectives on using different types of personal data for health research (proportional)

The questionnaire further asked participants to respond to the statement “Sharing personal data should be mandatory if there is a clear benefit to the public (e.g. detection of disease epidemics).” This question was conceptualised prior to the outbreak of COVID-19 in December 2019. Overall, participants were almost evenly split between agreement (n=167, 38.5%) and disagreement (n=183, 42.2%). In order to investigate whether the evolving outbreak of COVID-19 during the collection of the data had an impact on individuals’ stances, the sample was divided in two cohorts. Cohort one encompassed all participants who completed the questionnaire between 12 December 2019 and 31 January 2020 (n=260), cohort two encompassed students who provided a response in February 2020 (n=174). Students in cohort one were marginally more likely to disagree with the statement (Disagreement=44.6%, n=116), while participants in cohort two exhibited more positive views towards mandatory data sharing to detect ongoing disease outbreaks (disagreement=38.5%, n=183).

5.1.5. Students’ attitudes towards the use of loyalty card data for health research

Lastly, students’ views towards the utilisation of loyalty card data in health research, and specifically to identify individuals at risk of developing mental or physical health conditions was investigated (Figure 5-6). A majority of students (55.5%, n= 242) was found to be supportive of the use of aggregated purchasing data in order to make assumptions about the health status of the general population. However, the use of loyalty card data to identify individuals specifically was met with more scepticism, almost 40% of students opposed this application (38.8%, n=169). No pronounced differences in students' attitudes about the identification of physical health conditions (agreement: 46.3%, n= 199) compared to mental health conditions could be found (agreement: 43.0%, n= 183).



% missing to 100% - not answered

Figure 5- 6 Students' attitudes towards the use of loyalty card data in health research

5.2. Qualitative results

In the previous section, I described loyalty card use (and non-use) in a student population and mapped students' views towards the use of personal data, including loyalty card data in a health research context. However, individuals' reasoning behind their stances remained unexplored. Thus, a qualitative research phase that aimed to explain the obtained findings was conceptualised.

5.2.1. Introduction

The preceding survey served as the sole recruitment tool for the qualitative research phase, student were asked to indicate interest in participation after they had completed the questionnaire. Interview guide development as well as data collection and analysis procedures are outlined in methods section 2.5. The interviews were held between 31 March 2020 and 8 April 2020. Thus, the interviews coincided with the beginning of the outbreak of COVID-19 in England; the first national lockdown came into force on 26 March 2020. Media coverage was high, but the magnitude of the long-term impact COVID-19 were to have on society not yet fully apparent. As a result, the stances students expressed might have been impacted by the external circumstances; the following results should be interpreted with this context in mind.

5.2.2. Sample characteristics

17 Semi-structured interviews were conducted online; interviews ranged from 28 minutes to 51 minutes in length. Interview participants were asked to complete a short survey at the end of the interviews that

included questions about students age, gender, mental health and wellbeing and loyalty card usage. The table below illustrates the main characteristics of the interview participants.

Table 5- 2 Demographic characteristics of interview participants

Characteristics	*Frequency (n) or range*
Gender	
Female	13
Male	4
Age	
	20-30 years, m=24 years
Degree programme	
Undergraduate	7
Postgraduate taught	2
Postgraduate research	5
Current/Previous struggles with mental health and wellbeing	
Yes	10
No	7
Registration	
Home	9
EU/EEA	1
International	7
Use of loyalty cards	
Yes	16
No	1

5.2.3. Findings

Four main themes related to students' attitudes towards the use of purchasing data for health research were developed from the interview data. These are: Students' perception of loyalty card data and its use in health research, risk-benefit considerations, individuals' need for control, and facilitators: trust and understanding. Figure 5-7 shows the relationship between the themes and the framework which was developed from the interview data.

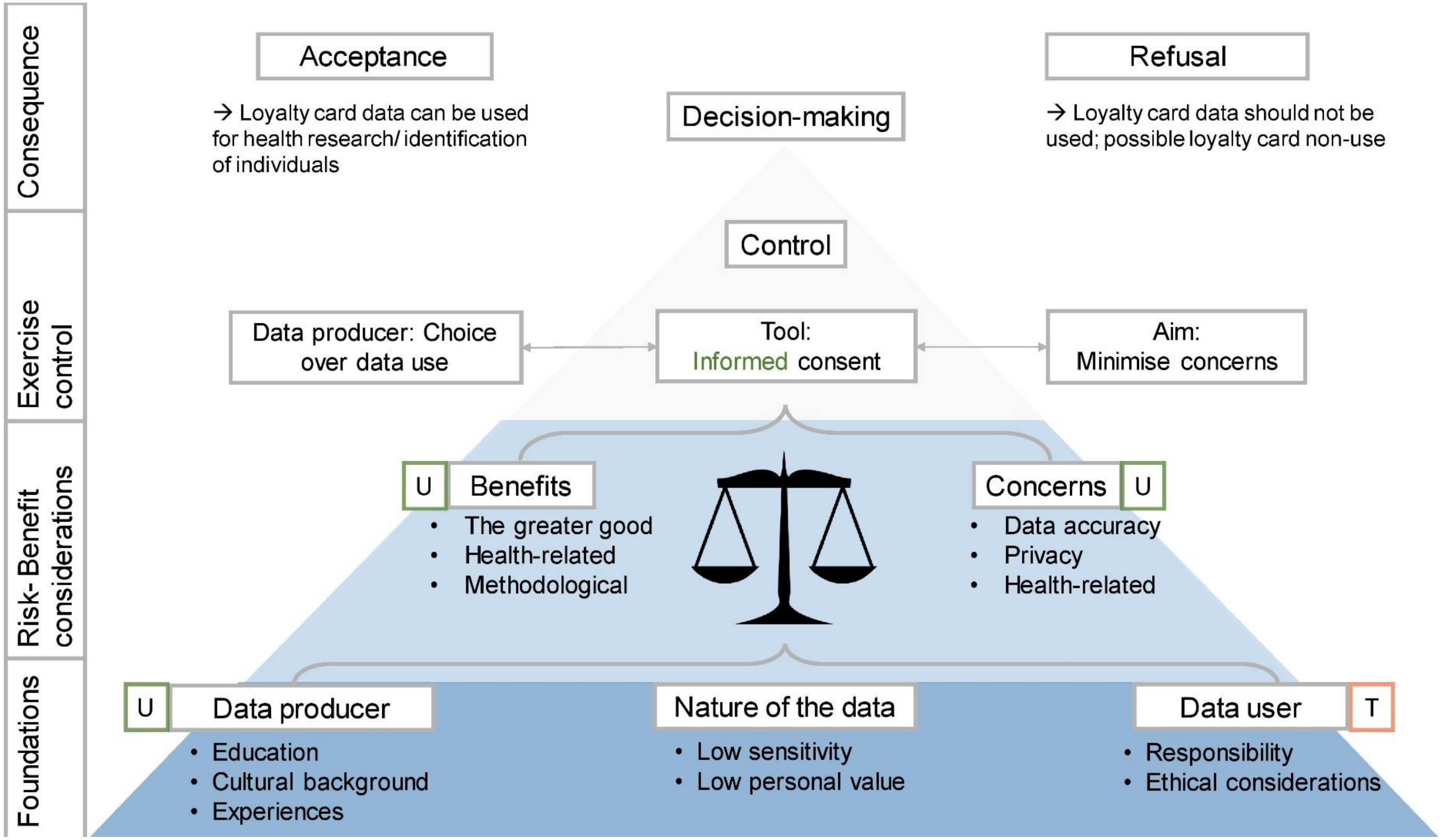


Figure 5- 7 Framework of acceptance, T= Trust, U=Understanding

5.2.3.1. Students' perception of loyalty card data and its use in health research

At the beginning of the interviews, students elaborated on their general perception of loyalty card data and its use in a health research context; comparisons to other types of personal data, such as location data occurred frequently. Three main aspects characterised these discussions. First, the nature of loyalty card data, that is, its perceived value and sensitivity. Second, aspects pertaining to the participants, i.e. the data-producers themselves were found to influence students' stances. Third, students attributed importance to the data owners, i.e. the companies providing loyalty card schemes, when outlining their perspectives on the proposed use of loyalty card data in a health research context.

5.2.3.1.1. The nature of loyalty card data

Students emphasised two facets of loyalty card data, namely, data sensitivity and its perceived value when describing their initial perspectives towards an extended use of these data in a health research context.

Data sensitivity was depicted as the degree to which data can be used to make inferences about the behaviour patterns of the data-producer. In other words, the sensitivity attributed to a type of personal data was suggested to correlate with the perceived intrusion of one's privacy.

Interviewees' comments suggested that they perceived loyalty card data to be generally low in sensitivity, especially in comparison to other types of personal data, such as location data. This notion was primarily attributed to the fact that the act of going shopping in itself is believed to be public. Thus, students were only little concerned about others having knowledge of their purchasing behaviours, their privacy was only intruded marginally.

> *"I think shopping is quite a public thing, I suppose, you go into a shop and people see what you're buying and it's not, it tends not be particularly private thing, for most items"-FI10*

However, participants suggested that there are different levels of sensitivity within the wider realm of purchasing data, personal items or medication were considered more sensitive in nature than typical grocery items.

> *"[…] there is some things with purchasing that I think are a bit more sensitive, maybe thinking more like pharmacies, certain over-the-counter stuff you can buy that people might be more sensitive to other knowing about." FI01*

Similarly, students attributed only little personal value to purchasing data; rather it was primarily seen as a commodity, which is deliberately exchanged for personal benefit, such as money off.

> *"with the loyalty cards I feel like it's, I mean, I've got- I get the money off, it's the payback for the shops taking my data on what my purchasing habits are, and I feel like that's fine and it can benefit the shops and I don't have a problem with it"-MI17*

5.2.3.1.2. Person-specific factors

In addition to the nature of loyalty card data, aspects pertaining to the data producers themselves were identified to impact students' perception of loyalty card data and its proposed use in a health research context.

Education

Several students underpinned their stances towards the utilisation of loyalty card data for health research with the nature of the education they are currently receiving. This rationale was particular common for students with a background in health sciences or data-heavy subjects, such as statistics.

> *"but maybe as a medical student, maybe I'm more willing for that sort of data to be used because I understand a bit more of the importance of, of kind of getting checked out and catching things early."-FI10*

Cultural background

Additionally, one's cultural background was suggested to have an impact on individuals' stances towards utilising loyalty card data.

> *"yeah, I think it's positive […] I can see why, why you feel, why, why some people might feel not because, because [...] I'm growing up in China so, I'm used to be moni- be controlled in some ways."-FI08*

Experiences

Personal experiences with data utilisation were found to have a profound impact on individuals’ perception, as emphasised by one participant who described how a childhood experience influenced her stance in the future.

> *“my dad had an issue where […] he didn’t know much first, ‘cause obviously internet banking wasn’t so much of a thing when he was growing up and they lost – I think it was £50000 or something, like they just went in and […] just completely wiped every single account that was connected to anything. So since then he’s been really careful and he’s passed that onto me and my brother.” FI09*

Interviewees emphasised that each individual may underpin their decision-making process with a different set of motivations, as most students were adamant to clarify that their rationales should not be generalised. This may indicate that a complex and diversified set of elements needs to be taken into consideration when aiming to understand individuals’ reasoning.

> *“I wouldn't mind if the companies had my data in regards to my purchasing habits too much- I feel like that, some people would feel differently about that, but I don't.”-MI17*

5.2.3.1.3. Data user specific aspects

Several participants opted to underpin their stances with considerations pertaining to the company that collects transactional data and is subsequently though to utilise the aggregated data.

Responsibility

Some interviewees regarded the companies tracking the data as responsible for its utilisation, in particular if explicitly health-related data are amassed.

> *“if they're [customers] buying a load of drugs that, like over-the counter, well, just whatever you can buy without a prescription-drugs, then maybe it should be looked into anyway, purely because if you're having to take loads of different on a regular basis to make you feel better, there's clearly something wrong anyway.”-FI16*

Ethical considerations

For other participants the involvement of companies as data users evoked ambiguity; the ethicality of following such approaches was questioned. In some instances, this resulted in open opposition towards the monitoring and tracking of purchases.

> *“I don't feel comfortable, thinking that companies are using my personal information to do any type of things...even if it is for research, I don't think is let's say –fair- for me... just don't like it, I prefer to, to keep information about what I do in the apps or in the way I shop for myself.”*-FI15

In summary, individuals’ initial stances towards loyalty card data and its proposed utilisation in health research were found to be rooted in three distinct factors, namely the nature of loyalty card data as well as person-specific factors and company-related aspects. Thus, the identified factors were embedded in the developed framework as the foundation for further considerations pertaining to more specific applications of loyalty card data in health research, such as the identification of individuals at risk based on their purchasing patterns (Figure 5-7).

5.2.3.2. Risk-benefit considerations

After students established their initial stances towards the use of loyalty card data in the context of health research and highlighted the origins of these stances, the discussion moved towards a practical application of loyalty card data in health research. That is, a possible identification of individuals at risk of developing a health condition. In the course of the ongoing discussion, all students were exposed to two recent examples of how loyalty card data could be used in health research, which stimulated the conversation additionally (2.5.2.6.1). Participants discussed the risks and benefits they anticipated to emerge at length and subsequently performed a mental assessment between both (Figure 5-8). In some instances, this resulted in an alteration of students initial stances.

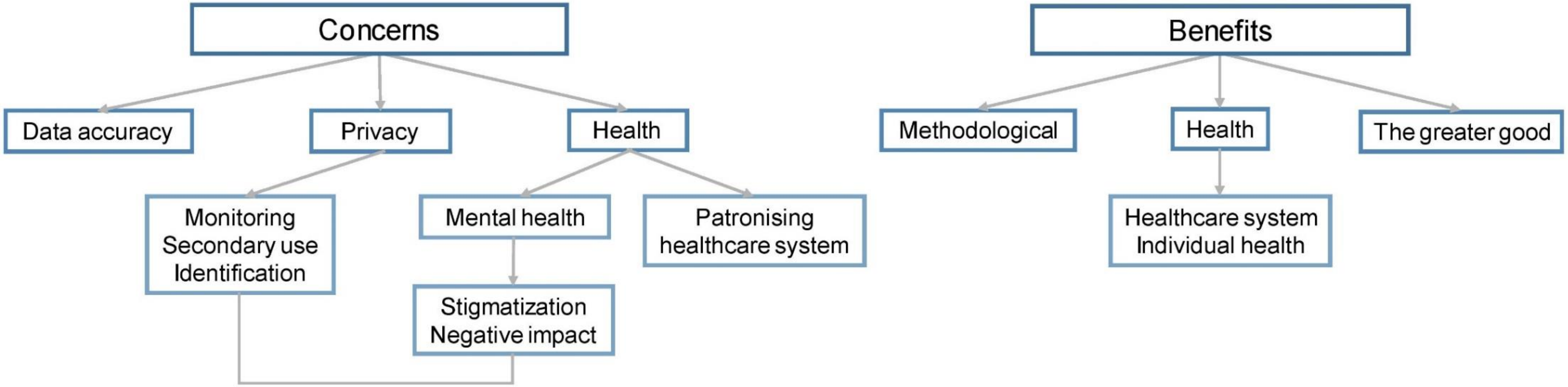


Figure 5- 8 Students' concerns and anticipated benefits pertaining to the use of loyalty cards in health research.

5.2.3.2.1. Concerns

Interviewees raised a range of concerns that were broadly categorised under three sub-headings, namely data accuracy, privacy concerns and health-related issues.

Most prevalently, participants indicated that they doubted the accuracy of loyalty card data for identifying an individual's health condition. The perceived lack of data accuracy was mostly attributed to the fact that sharing loyalty cards within a household seemed to be common practice, which was thought to reduce data precision. Moreover, missing information was considered to affect data accuracy negatively, either due to the use of loyalty cards from multiple providers or due to unawareness of a cardholder's medical history.

> *"When it comes to supermarket purchasing for example, I'd question just how useful it is, because unless you've got that full picture of what everybody's doing in every single supermarket, it's going throw up a lot of false positives"-FI09*

As a consequence of low data accuracy, participants raised concerns about the possibility of false positive results, or reminding individuals of existing diagnoses which in turn could lead to distress for the individual in question.

> *"people that have already been diagnosed […] they actually don't want to get help because they are already getting it, and they are kind of like- on track […] that might actually harm you in*

> *some way, I would say, because this kind of reminds you, that you're actually ill." – FI04*

Secondly, participants highlighted privacy-related concerns. This included concerns over an undesired secondary use of the obtained data, such as the sharing of data with other companies or the use of the obtained information to make profit or for political purposes.

> *"a lot of the reason people seem to gather this information is to sell it on, it's the same reasons why we get cold calls, it's the same reason why we get the targeted ads"- FI09*

Some international students raised concerns over an identification of individuals at risk in countries were premium-based health-insurance systems are in place, as this could result in inequalities or an increase of insurance fees.

> *"I would be uncomfortable with the idea of having the name of that person being disclosed, especially in countries where the insurance companies have more control over health care services than, than public health service"- MI08*

Moreover, knowledge about loyalty card data being tracked and analysed was though to create a feeling of being monitored.

> *"[…] it's not something you want to deal with when you're shopping, you just want to go, do your shopping and that's it, like you don't want to feel like you're being observed […]" –FI15*

These concerns were particularly prevalent in the realm of mental health, as the feeling of being monitored was suspected to affect an individual's mental health and wellbeing negatively.

> *"It could make you feel paranoid, if you're already like, suffering from poor mental health... because you would think about what you're buying in the supermarket whether that would raise any alarm bells, and it- yeah- it would make you paranoid."-FI11*

Therefore, students anticipated that some individuals may change their behaviour, or refuse to use loyalty cards altogether.

> *"I think if I'm prone to get mental health I won't allow people to know what I'm doing with my loyalty card. I wouldn't use it […] when I'm purchasing anything. So that they can't know. Let's say if I wanna buy a herbal remedy then I know: 'oh someone is tracking my loyalty card'- I wouldn't show them!" –FI07*

Additionally, some students emphasised that mental health issues are still subjected to stigmatisation, which should be taken into consideration. Importantly, this opinion was not shared by all participants, as many regarded the current student generation as equally acquainted to mental health and physical health issues; stigmatisation of mental health issues was thought to have been overcome.

> *"I think people would be more receptive to, ideas of promoting their physical health from this data, rather than, mental health, because it's still, a taboo."- MI12*

Lastly, participants displayed apprehension towards the establishment of a patronising health care system in which daily-life data were exceedingly used to interfere with one’s personal life.

> *“it's going back to the health care model which we're trying to get away from, it's very paternalistic, it's very much […] you should be doing this, you're doing this wrong, and I don't think it's necessarily helpful and we're trying to move into more of a thing of empowering the patient”-FI09*

Thus, students raised a multitude of concerns over the use of loyalty card data for identification purposes, especially in the realm of mental health. In some instances, privacy-related concerns were suggested to induce health-related issues, such as a deterioration of one’s mental health due to the feeling of being monitored, which highlights the necessity for a meticulous evaluation process to determine hidden consequences.

5.2.3.2.2. Benefits

Conversely, students outlined the benefits they anticipated to arise from an extended use of purchasing data. Again, benefits were found to be broadly organisable in three categories: methodological benefits, health-related benefits and the greater good (Figure 5-8).

Methodologically, participants identified the large number of people and data which could be accessed as a considerable benefit, as well as the convenience of the process, which would simply require participants to maintain their shopping habits.

> *"they don't require to do much more other than just agree and continue on with their purchases"-FI02*

Secondly, participants emphasised the use of purchasing data to support the greater good as a beneficial outcome. The use of transactional data to benefit either themselves or a larger population were persuasive arguments for being supportive of an extended utilisation of these data.

> *"I kind of think if it's benefiting other people by using my data or if it's then going to benefit me […] I would sign up or say yes to having my data being used like that"-FI03*

Lastly, students discussed the beneficial impact the utilisation of purchasing data could have on population health. The implementation of preventive measures based on results stemming from an analysis of the data was discussed as well as using purchasing data as an initial screening tool, allowing an earlier identification of risk groups.

> *"in hindsight it makes sense, maybe you don't necessarily think about it, but like, stuff like pain killers or, or symptomatic remedies for whatever is making this patient feel ill, it's definitely gonna show up on the loyalty card, I found that very, very interesting, so and that's, that can help earlier diagnosis if you find them and spot them properly, right?"-MI05*

Making recommendations based on loyalty card owners purchasing habits was seen as an efficient way to nudge individuals into receiving healthcare. Especially individuals who might not be aware of certain symptoms for health conditions, have difficulties navigating the health care system or missing a support network could benefit.

> *"it's a really nice thing, especially if it's more the mental health conditions, […], because a lot of people might not necessarily seek help, or know how to seek help for these kind of things."- FI05*

5.2.3.2.3. Weighing between benefit and concerns

After a scrutinization of both, concerns and benefits, most participants reflected on their arguments to reach a conclusion. The central argument from which benefits and concerns were assessed differed between participants, indicating that a 'one-size-fits-all' approach might not be sufficient for understanding acceptance or refusal towards sharing of purchasing data for health research. Some participants centred their argumentation on the perceived fairness of the approach, i.e. they weighted between the proportion of people who could be identified correctly compared to those who could be falsely identified to be at risk of a potentially life changing condition. Others focused their thought process on the type of health condition one is looking to identify; more severe conditions would warrant more profound measures than less severe conditions. Similar to before, the individuality of each situation was highlighted, by speculating where each person would be drawing the line between intrusiveness and potential benefits.

> *"Then it could be looking at people's food purchases, how healthy are they […] What kind of things that they're picking up from, things like pharmacies […] so I think it could definitely be useful but it's where it draws the line and how much people feel like they're being sort of trying to look after really rather than made to, made to feel a bit guilty about making your own personal decisions, I suppose…" FI01*

> *"I think that's, that's the grey area, that's why I don't really think it's ok, in general because, I personally wouldn't mind but I'm kind of relaxed about this kind of stuff, whereas, I don't know a lot of people probably wouldn't be. […] I think everyone's got a different point at which they would draw the line, and you have to cater for the person who is sort of least ok with, because ultimately it's about them, isn't it- it's their health." FI16*

In summary, students raised a multitude of concerns pertaining to the utilisation of loyalty card data for identification purposes, such as privacy-related issues. However, in the same breath, students emphasised the benefits they expected to emerge from said approach. Subsequently, participants performed a mental assessment between benefits and risks, in order to reach a conclusion.

Thus, the recognition of anticipated benefits and perceived risks as well as the subsequent weighting between both facets was included in the developed framework as the first step in individuals' decision-making process. Participants who perceived the anticipated benefits to outweigh potential risks were found to be more likely to be accepting of the use of purchasing data for identification purposes. However, students acknowledged that individuals may reach different conclusions with regards to their mental assessment between perceived risks and benefits Thus, a one-size-fits all approach may not be applicable and strategies to increase public awareness of potential benefits, such as exposure to recent research, are required (for a further discussion see section 5.2.3.4.1).

5.2.3.3. Individuals' need for control

In addition to finding a balance between emerging risks and perceived benefits, students discussed how exercising control over the use of their data could have a mediating effect on their attitudes towards an extended use of loyalty card data. Three different aspects of control were established: control means having a choice, consent as the tool to exercise control and control minimises concerns (Figure 5-9).

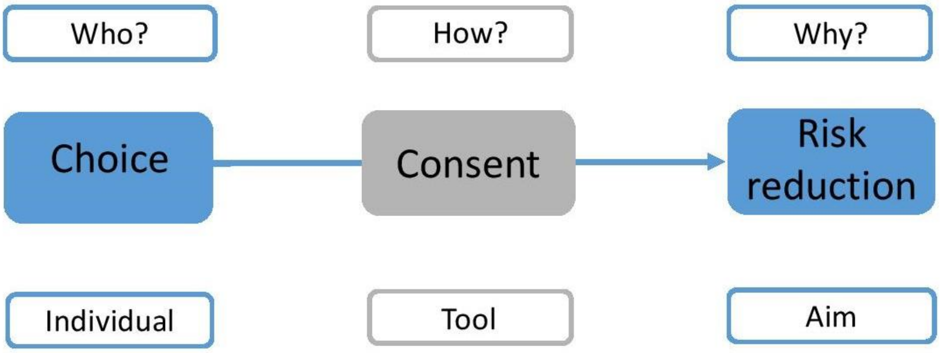


Figure 5- 9 Aspects of control

5.2.3.3.1. Control means having a choice

Students emphasised two aspects over which they desired control. First, the use of their data for identification purposes. Second, the decision on whether or not to act on the results of an analysis of the data. Consequently, in the majority of cases, voluntariness was seen as vital for obtaining public acceptance.

> *"I think fundamentally it's about, what people are saying: yes you can have this data for and yes you are allowed to analyse it in this matter."-FI09*

However, strictly voluntary approaches were not welcomed by all participants, few cited the publicly funded nature of the NHS as a reason for considering more radical approaches.

> *"It should be encouraged and that data should be shared with the NHS, because- let's say: your patient who is prescribed, pills for hypertension or something, as an example. If you're being funded by the NHS effectively they're giving you these pills on a free prescription, than you should follow the doctors order and the doctor should be alerted if you are doing stuff that would raise your blood pressure. Smoking being an example, because it's disingenuous for you to be funded by the NHS to help support and safe your life and then you go behind the doctors back and say you lie about your smoking habits it's-it- the doctor should know in my opinion."-MI17*

Voluntariness also characterised students discussions regarding the mode of result delivery, after the data had been analysed. Preferences for approaches that appear to be non-targeted, such as adverts and links to websites embedded in apps or emails or wider awareness campaigns dominated. These approaches were thought to present individuals with the opportunity to decide whether or not to follow a recommendation, without feeling pressured.

> *"maybe there could be some sort of, advert or some sort of support thing that's put in place, sort of subliminally almost, so that […] it doesn't have to be so forced, but can sort of show that there's support and stuff there if they want to then reach out, so it's kind of like extending the olive branch, rather than being like you've got, you know, you're spiralling do you need to come and get some help, it, it's more of an, it's a more sensitive way to approach it" –FI16*

However, the resulting lack of personal contact may be unsuitable in the case of mental health concerns, therefore prompting questions about optimal approaching pathways for the mental health domain.

> *"I don't know if, if somebody that is dealing with emotional issues, or mental issues is actually going to be open to receive feedback, like from an online website, or via online from a person who you don't even know." FI15*

5.2.3.3.2. Consent: tool to exercise control

Consent processes, such as mandatory terms and condition agreements were frequently mentioned as ideal tools for individuals to exercise choice. However, the current practice of signing a terms and condition form to acquire a loyalty card was deemed insufficient if the data were to be used for health research. Participants admitted to rarely take the time to read these lengthy documents and were therefore mostly uninformed about their contents.

> *“no one has the time to read three pages of fine print about your shopping data[…], if it were to become a thing, people should be informed about it in a different way.”-FI11*

Consequently, participants made explicit recommendations on how to effectively amend the current consent process. The process was expected to be person-centred and customizable according to one’s preferences. Exemplarily, some interviewees requested the option to decide which health conditions they might be monitored for as well as being asked about their consent recurrently, due to the possibility of preferences changing over time. Knowledge about the possibility of being approached was thought to prevent distress.

> *“I think… before you sign up to a loyalty card […], besides like all the terms and agreements […] I think you should also have a third tick, like would you like to receive email alerts, and the third one should be more like: ‛would you like to be alerted if one of your behaviours is identified as a potential risk factor towards –parentheses- these kind of diseases’ or some link were people would see the agreed diseases, that you could be contacted for.” MI05*

Secondly, participants highlighted the importance of the consent process being explicit and transparent. Documents should accentuate information about the types of data being used and for which purposes.

> *"I think it would have to be like: 'are you happy for this data to be used in this way', instead of just […] agreeing as a whole generalised thing, I think a lot of the time you don't know what you're agreeing to…"-MI06*

5.2.3.3.3. Control minimises concerns

As indicated in Figure 5-9, the main objective for participants request for more control was to mitigate concerns emerging from an extended use of personal data. Exemplarily, the implementation of controlling measures was found to curtail health-related concerns, such as the establishment of a patronising health care system or privacy-related concerns, such as undesirable secondary use of data.

> *"I think, you still want to think that you maintained your independence, that you're completely different to the person next door, but you probably aren't but, in-, in knowing that your data is protected, it's like your independence, you're not being, like breached, that you've managed to maintain one thing that is yours." -FI03*

In summary, control was illustrated as a cornerstone for individual's acceptance of the use of loyalty card data for identification purposes. Thus, handing loyalty card users control over the use of their purchasing data was identified as an additional element for obtaining individuals acceptance, as emphasised in Figure 5-7.

5.2.3.4. Facilitators: Trust and Understanding

Two facilitators, i.e. trust and understanding, were found to mediate students' acceptance considerations throughout the developed framework.

5.2.3.4.1. Understanding

First, understanding acted as a versatile facilitator affecting almost every aspect of the framework. Participants almost uniformly articulated a demand for being better informed about the types of data being used and for which purposes, by whom and, to a lesser extent, how these data are being collected and stored. Ideally, this information should be provided during the consent process, thus creating the foundation for the provision of informed consent.

> *"I think you've got to give people the information about what it's being used for, 'cause otherwise the consent isn't informed consent and that's the basics of healthcare and choices"-FI09*

Moreover, understanding was found to facilitate acceptance by addressing concerns and increasing awareness of the benefits purchasing data may yield for health research. In few instances, being exposed to ongoing research projects led to a shift in participants' attitudes towards the use of loyalty card data for health research from scepticism to tentative acceptance.

> *“I think its worth, I hate saying this- I, I think it's worth the possible invasion of privacy- because if, yeah- I don't know. I just think, putting [it] into [a] proper, real world, real world situation, it outlines to me why this would probably be acceptable.”-FI11*

Nevertheless, some participants also raised concerns about the implications greater understanding and awareness of the use of data may have, such as negative publicity and refusal to use loyalty cards altogether.

> *“I feel like have more awareness of how the data would be used, wouldn't help in that way, you would have more people they're going- oh you can't collect my data, I don't want you using my data, then people thinking: oh yes, this is a beneficial area.” MI17*

5.2.3.4.2. Trust

Trust was identified as a second facilitator, positively influencing participants’ opinion towards purchasing data being used in a health research context. However, while understanding was found to have mediating effects on a multitude of aspects across the framework, trust predominantly affected the relationship between data provider (i.e. loyalty card user) and the entity intending to utilise the produced data (i.e. data user). Especially concerns over an undesired secondary use of personal data were moderated by the level of trust students placed in the loyalty scheme provider. Interestingly, students cited a multitude of reasons as their justification for the trustworthiness of a data collector. First, some participants mentioned brand recognition and the fact that potential misuse could be detrimental for a company's reputation as their main motivators.

> *"I feel like, with the loyalty cards, it's if they're tracking where I purchase, which shops I purchase in, I feel like they're trustworthy enough to not publish that to anyone I wouldn't want to […] if that makes sense. It would be more disingenuous for the company to share that data and have negative publicity*"-MI17

Second, other students emphasised company ethics and ownership as their drivers for establishing trust.

> *"she [small shop owner with loyalty card scheme] puts a lot of it back into the community as well and I'm much happier having, people having my information if it is for that reasons, so she does a lot with the LGBT community, she does a lot with homelessness charity, she does a lot with soup kitchens, food banks, etcetera...when we look at big companies, like [large retailer] or [large retailer], it's a lot more uncomfortable almost, because it's like well, yes you're using this money, yes it's helpful for whatever reason, but... where is that money going?-FI09*

In summary, two factors, i.e. trust and understanding were identified to mediate students' acceptance of the use of loyalty card data in a health research context. Both facilitators were found to impact different stages of the developed framework. Understanding acted as a versatile facilitator, which influenced students' initial stances towards the use of purchasing data in health research (e.g. education) as well as later stages of their decision-making process, for example through enabling the provision of *informed* consent. Exposure to examples of how loyalty card data could be used in health research were persuasive arguments for some students to re-evaluate their initial opinion, as they increased awareness of potential benefits. Thus, consent processes that aim to increase individuals understanding may have a mediating effect on public acceptability.

Trust was found to predominantly affect the relationship between loyalty card user and the prospective data user. Trust was sought to reduce emerging concerns, such as an undesired secondary use of data. Thus, trust may positively influence individuals' willingness to engage with a loyalty card scheme initially, as well as their acceptance of the subsequent use of the obtained data in a health research context.

5.3. Synthesis of information

5.3.1. Summary of key findings

A cross-sectional survey was distributed at the University of Nottingham, to describe students' use of loyalty cards and investigate their attitudes towards the utilisation of personal data, including loyalty card data, for health research purposes. A large cohort of students completed the survey. However, the obtained sample differed from the student body at the University of Nottingham in several characteristics, such as gender distribution, age and subject area. Owing to the chosen mode of questionnaire administration, a response rate cannot be calculated.

A large proportion of the students who participated in the survey reported to subscribe to loyalty schemes. In particular, loyalty cards provided by health and beauty retailers, such as Boots or Superdrug, were frequently used and rarely shared between individuals. Students exhibited low levels of concern over a potential misuse of loyalty card data, but appeared to question the usefulness of these data for health research purposes. Further, the obtained data suggest that students are predominately supportive of the use of aggregate-level loyalty card data for health research, but more apprehensive towards an identification of individuals specifically. Students' opinion differed only marginally concerning a possible utilisation of loyalty card data in the realm of mental- or physical health care.

The main objective of the qualitative research phase was to add explanations to the results obtained from the quantitative research phase; in particular, I aimed to explore individuals' reasoning behind their expressed stances towards an utilisation of loyalty card data in health research. Four themes were developed from the interview data: students' perception of loyalty cards, risk-benefit considerations, individuals' need for control and facilitators: trust and understanding. Subsequently, the developed themes were consolidated into a framework that amalgamates important aspects in students' decision-making process.

5.3.2. Implications for the succeeding research phases

In the introduction of this chapter, I emphasised that I deliberately chose students as a study population, as considerations pertaining to the utilisation of alternative types of data in health research were thought to be influenced by age and one's familiarity with the topic. Therefore, students, due to their narrow age range and because they predominately grew up as digital natives, provided an ideal starting point for preliminary investigations. However, adopting this approach limits the applicability of the obtained results beyond this demarcated sample.

Therefore, a succeeding research phase was conceptualised to investigate this topic in a broader population (i.e. pharmacy users). A similar protocol was followed, that is, I first investigated loyalty card data use, and attitudes towards the use of transactional data in a sample of community pharmacy users and subsequently aimed to add explanations to the obtained qualitative data by adding a qualitative research phase. The framework presented in this chapter will guide the analysis.

Therefore, the results presented in this chapter will be discussed in conjunction with the results from the succeeding research phase (chapter 6), as well as the strengths and limitations of the chosen study methodology.

Chapter 6

Changing the perspective: Pharmacy user engagement with loyalty schemes and their attitudes towards the use of transactional data in a health research context

In the previous chapter, I evaluated students' use of loyalty cards as well as their attitudes towards utilising the data recorded on loyalty cards in health research. This research phase allowed me to map the views of a clearly demarcated sample towards a topic that is largely unexplored. However, it is plausible that age and familiarity with digital technologies influences individuals' views, and therefore a generalisation of the obtained results to the broader population should not be attempted. Consequently, a study phase that evaluates the views of the wider population was conceptualised. In particular, I chose to evaluate the views of pharmacy users, as a pharmacy user cohort was thought to be broad in terms of age and familiarity with digital technologies, but at the same time accustomed to the overarching context of this thesis (i.e. community pharmacy). Thus, this chapter aims to investigate pharmacy users' engagement with loyalty schemes as well as their attitudes towards the utilisation of loyalty card data in a health research context.

This chapter consists of two sections. First, the results from a questionnaire that was embedded in the community pharmacy survey (CPS) 2020 (see chapter 4) are presented. Pharmacy users' adoption of loyalty cards was quantified and their views towards personal data and the use of transactional data in a health research context mapped. The second section of this chapter reports the results from the qualitative phase of this research study; nine semi-structured interviews were conducted with some survey participants and additionally sampled members of the public. The analysis of the narrative data was guided by the framework established in the previous chapter.

Lastly, this study was conducted amidst the outbreak of COVID-19. Thus, the context in which the data were collected will be highlighted throughout this chapter.

6.1 Quantitative results

6.1.1 Introduction

The quantitative results presented in this chapter were obtained from the second part of the CPS 2020, which was distributed in 15 community pharmacies in Nottinghamshire for two weeks in March 2020. As outlined previously (4.1.1), the survey was terminated one week prematurely, due to the outbreak of COVID-19.

The survey consisted of three sections. First, pharmacy users' adoption of loyalty cards was quantified. For that purpose, participants were asked to respond to a number of closed-ended or multiple answer questions; the obtained data were predominantly categorical in nature. Second, participants' perspectives on personal data, i.e. its perceived sensitivity and value, and their attitudes towards the use of personal data in a healthcare context were examined. Third, pharmacy users were asked to express their stances towards the use of loyalty card data for health research, and specifically to identify individuals at risk of developing a health condition. In section two and three of the survey, Likert-scale questions were utilised, thus ordinal-level data were obtained.

6.1.2 Participation, total non-response and item non-response

The questionnaire items that underpin the results in this section were embedded in the CPS 2020, other components of the survey were reported in chapter 4. Thus, participation rate, total non-response rate, and characteristics of non-responders mirror those values reported in section 4.1.1.

6.1.2.1 Item non-response

To examine the characteristics of item non-responders, a binary variable was generated, delineating between individuals who reported a response to an item and those who did not.

As reported previously, throughout the mental health section of the survey, item response consistently exceeded the 90% mark (4.1.1.1.1). However, with the commencing of the loyalty card section of the questionnaire (Q55), item non-response increased sharply and persistently (Figure 6-1).

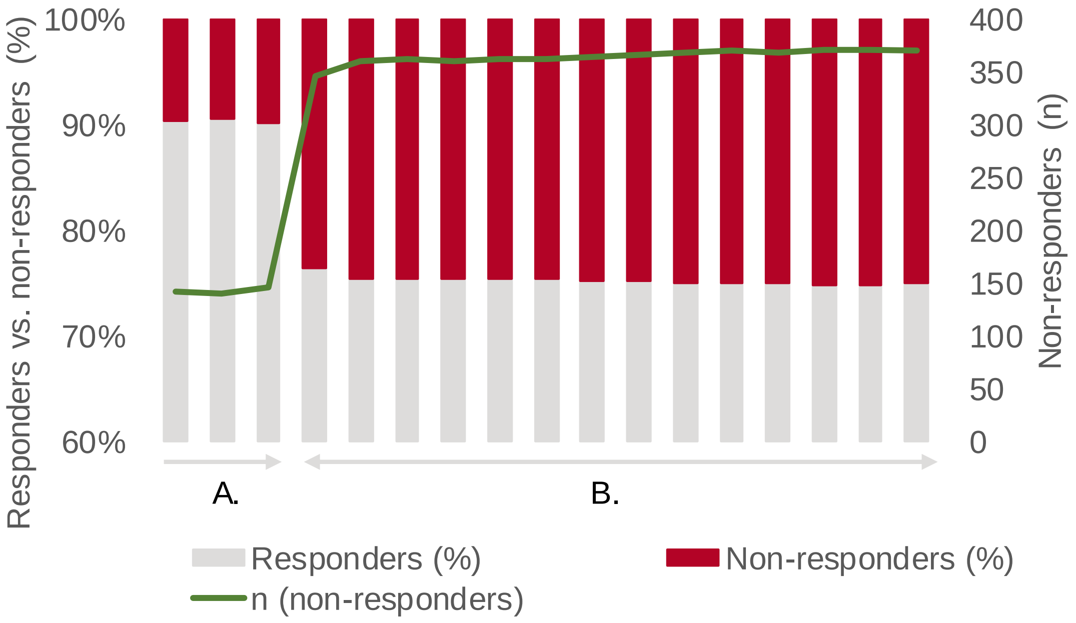


Figure 6- 1 Item response versus non-response; comparison between the end of survey part 1 (i.e. mental health section; A.) and part 2 (i.e. loyalty card section; B.).

Item responders and non-responders were compared across a number of core characteristics, such as age, gender and ethnicity. Item non-response and item response were distributed almost equally across genders (p>0.05). However, pharmacy users who reported their ethnicity as any white were significantly more likely to withhold response to the loyalty card section of the questionnaire (p<0.05). More so, a correlation between participants' age and their likelihood to provide a response was identified. Although item non-response increased across all age bands throughout the questionnaire, the phenomenon was particularly prevalent in older age groups (Figure 6-2). At the end of the questionnaire (Q75), more than one-quarter of pharmacy users aged 80 years or older withheld response. In order to account for the resulting low number of respondents in this age category, a new age band encompassing all participants aged 65 or older was created.

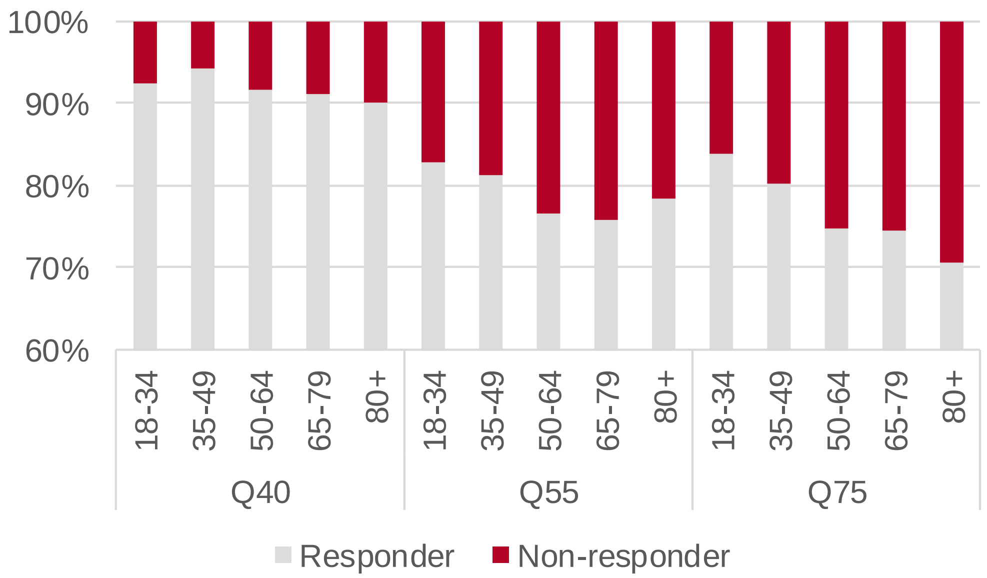


Figure 6- 2 Item non-response per age group, Q40= last question of CPS part 1, Q55=first loyalty card question, Q75= last loyalty card question

Pharmacy users in study site 502 were identified to be most likely to withhold response; almost three-quarters of participants in this pharmacy did not complete the loyalty card section of the questionnaire (Figure 6-3). Additionally, proportionally more individuals withheld response in the second week of data collection, compared to week one. Thus, the combination of questionnaire length and the worsening of the circumstances surrounding the outbreak of COVID-19 throughout March 2020, might have added to the high rates of item non-response.

As a consequence of low item response rates and the fluctuating response rates across study sites, the data underpinning this chapter were predominately analysed descriptively, obtained categorical data were subjected to significance tests with measures of association.

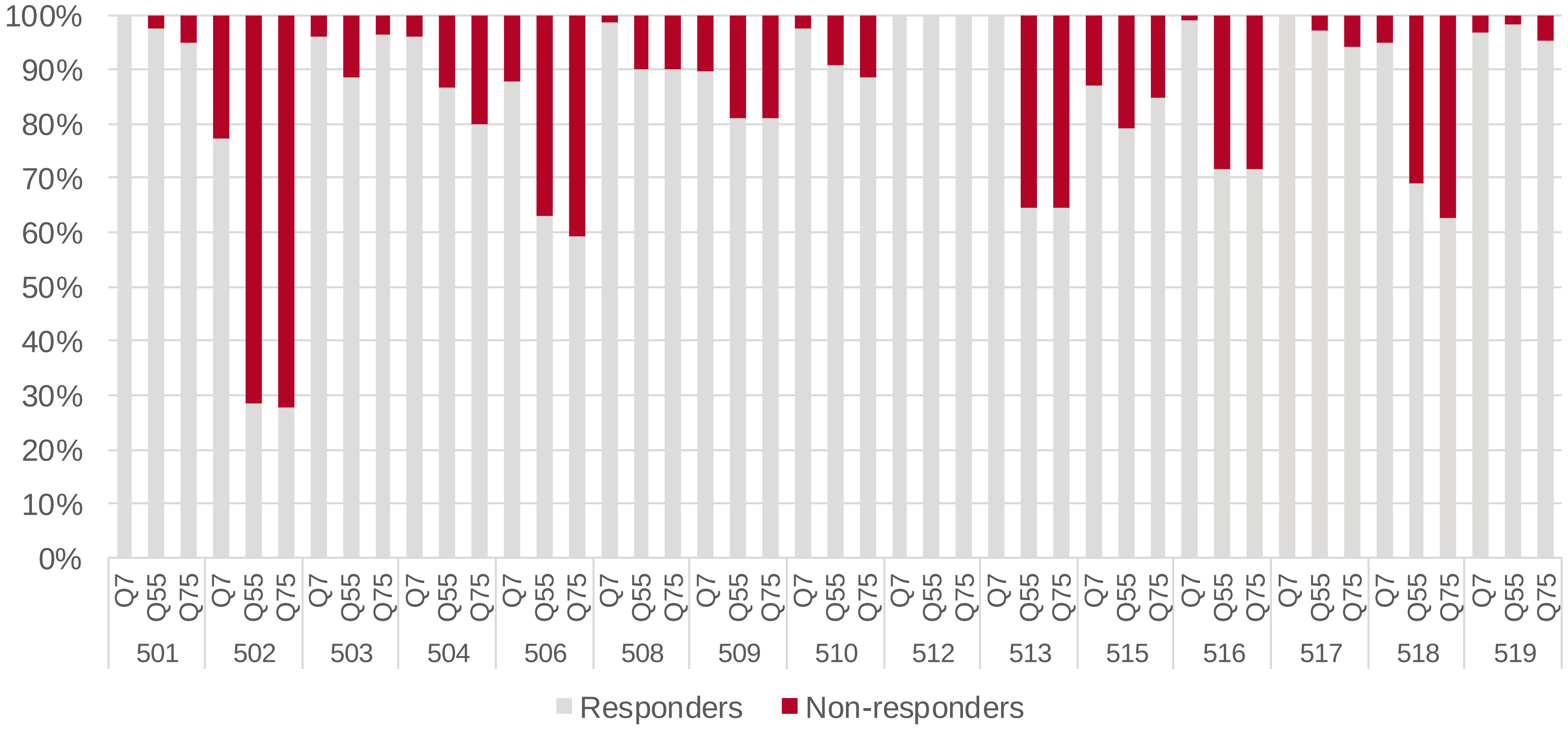


Figure 6- 3 Item response versus non-response per study site, Q7=first Likert-scale question of the questionnaire, Q55=first loyalty card-related question of the questionnaire, Q75=last loyalty card-related question of the questionnaire

6.1.3 Sample characteristics

The demographic characteristics of the cohort were reported previously, see section 4.1.2. Similar to before, the variable ‘ethnicity’ was collapsed. Thus, a binary variable, delineating between individuals who reported their ethnicity as any white (n=1184) and those who reported any other ethnicity (n=235), was generated.

6.1.4 Pharmacy users’ adoption of loyalty cards

6.1.4.1 Loyalty card use versus non-use

Next, survey respondents’ use and non-use of loyalty cards was investigated. In total, 895 (60.7%) of participants reported to use at least one loyalty card, while 15.7% of pharmacy users (n=232) did not engage with any loyalty schemes. Subsequently, loyalty card users and non-user were compared across the main demographic characteristics, i.e. age, gender and ethnicity.

Significantly more females reported using a loyalty card, compared to their male counterparts (χ^2 =103.7, p<0.001). No significant differences in terms of loyalty card use were found between individuals of different ethnicity and between age groups (p= 0.073, p=0.504, respectively). Individuals who reported not owning any loyalty cards (n=232) were asked to specify their reasons for not participating (multiple answers possible). A majority of participants stated not having considered getting a loyalty card as their main reason (52.2%, n=121). Only a minority reported unwillingness to share data (8.6%, n=20) or concerns over data privacy (7.3%, n=17) as their drivers for not owning any loyalty cards.

6.1.4.2 Typology of loyalty card users

Next, the cohort of pharmacy users who reported to use at least one loyalty card was subjected to further analysis. Of the 895 pharmacy users who reported to engage with loyalty schemes, more than three-quarters reported the use of one to four cards (n=685), 210 reportedly owned five or more cards.

6.1.4.2.1 Frequency of use

Figure 6-4 indicates that loyalty card use occurs more frequently in-store than the use of loyalty cards online. At the time the survey was conducted, one-third of participants reported not engaging in online shopping activities, however, shopping behaviours might have been altered since the outbreak of COVID-19[26].

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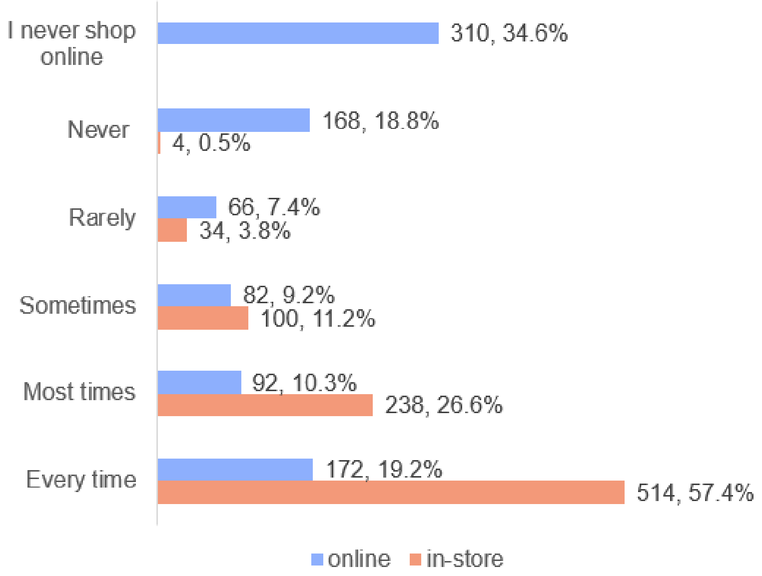
[26] 210. Dalgleish R, Office for National Statistics. *How the COVID-19 Pandemic has accelerated the shift to online spending* [online]. 2020 [Accessed 7th June 2021]; Available from: https://blog.ons.gov.uk/2020/09/18/how-the-covid-19-pandemic-has-accelerated-the-shift-to-online-spending/.



n (total) = 895, % missing to 100% - not answered

Figure 6- 4 Frequency of loyalty card use (in-store versus online)

6.1.4.2.2 Categories of loyalty cards used

The use of loyalty cards provided by health and beauty retailers was most frequently reported by survey participants (82.8%, n=741), and engagement with loyalty schemes provided by grocery stores was almost equally high (82.6%, n=739). Other types of loyalty cards were adopted less widespread (Multiple answers possible, Figure 6-5). The two main categories of loyalty card ownership, i.e. grocery store loyalty cards and health and beauty loyalty cards, were subjected to further analysis using significance tests with measures of association. No association between grocery store loyalty card ownership and participants' gender (χ^2=1.52, p=0.217) was found.

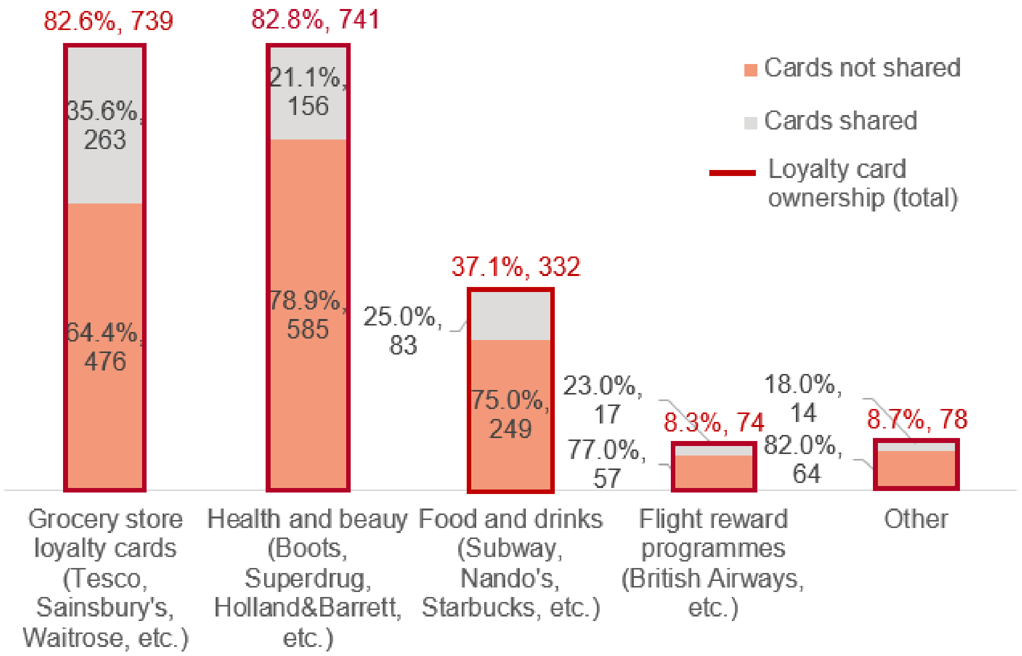


Figure 6- 5 Types of loyalty cards owned by loyalty card users (n=895) and sharing behaviour (multiple answers possible)

However, the data suggest that individuals who reported their ethnicity as any white were more likely to use grocery store provided loyalty schemes (χ^2=17.7, p<0.001) and that older individuals were more likely to use such cards (χ^2=21.2, p<0.001). Females were found to be more likely to engage with health and beauty loyalty schemes, compared to male participants (χ^2=72.9, p<0.001). Ownership of health and beauty loyalty cards was further found to correlate with age; younger participants were significantly more likely to report the use of this category of loyalty cards (χ^2 =8.90, p=0.031). No association between the use of health and beauty loyalty cards and ethnicity was found (χ^2=2.44, p=0.118).

6.1.4.2.3 Sharing of loyalty cards

As indicated in Figure 6-5, more than one-third of owners of grocery store loyalty cards reported to use their cards jointly (n=263). On the other hand, joint usage of loyalty cards was less frequently reported for health and beauty loyalty cards, one-fifth of pharmacy users reported to share those with other individuals, such as members of their household (n=156).

6.1.5 Pharmacy users' attitudes towards personal data

Next, pharmacy users' attitudes towards personal data and its use in a health research context were investigated. At the beginning of this section of the questionnaire, participants were provided with a brief definition of personal data[27].

6.1.5.1 Pharmacy users' attitudes towards personal data

Two-thirds of participants characterised themselves as careful about the type of companies they share their personal data with (n=982) (Figure 6-6). More than one-third (37.2%, n=549) of participants suggested that they trust companies to treat their data confidentially, but one-quarter of pharmacy users (n=382) described themselves as hesitant to trust companies in that regard. Almost half of participants self-identified as unwilling to share personal data in exchange for receiving a benefit, such as money off (43.4%, n=640). In order to investigate this cohort further, a binary variable, delineating between individuals who reported to be willing to share personal data for benefit and those who did not, was generated.

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[27] 199. The General Data Protection Regulation (GDPR), Regulation (EU) 2016/679. Sect. Article 4 (Definitions) (2018).

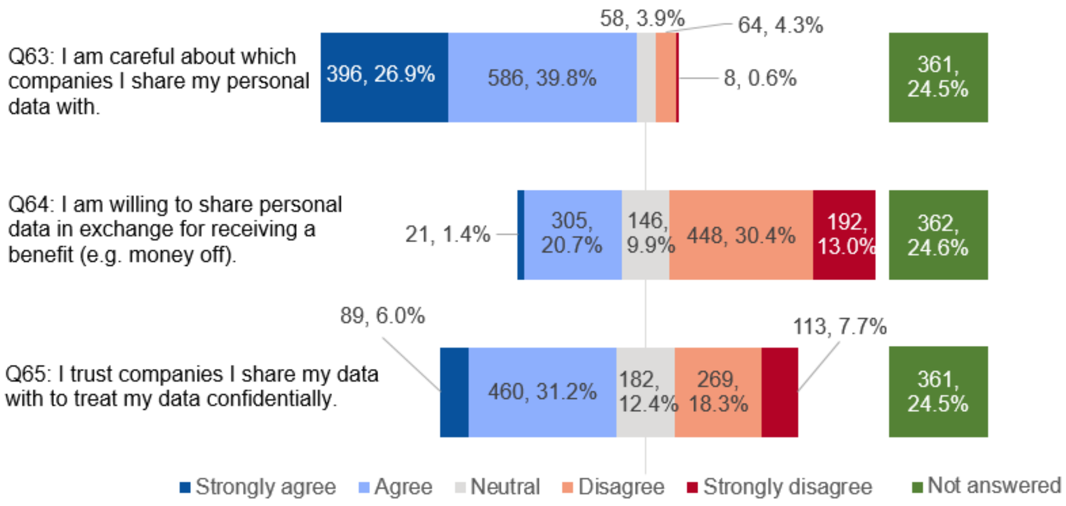


Figure 6- 6 Pharmacy users' attitudes towards personal data

Significantly more pharmacy users who reported the use of at least one loyalty card were found to be willing to share personal data for benefit (χ^2=9.7, p=0.002). However, the association was moderate in magnitude, and 484 pharmacy users who reportedly used at least one loyalty card stated that they were unwilling to share personal data for benefit. Further investigation revealed that individuals in older age groups (i.e. 50-64 and 65+) were significantly more likely to be unwilling to share personal data for benefit despite subscribing to a loyalty scheme, compared to participants in younger age bands (χ^2=84.6, p<0.001).

6.1.5.2 Use of personal data for health research

Next, pharmacy users' views towards the use of personal data in a health research context were investigated.

A majority of participants supported the statement that healthcare data can be used for health research, closely followed by a possible utilisation of lifestyle data, such as data collected on wearables. Pharmacy users were found to be divided over the extent to which loyalty card data can be used for health research. More so, participants predominately exhibited scepticism about a possible application of location data in health research (Figure 6-7).

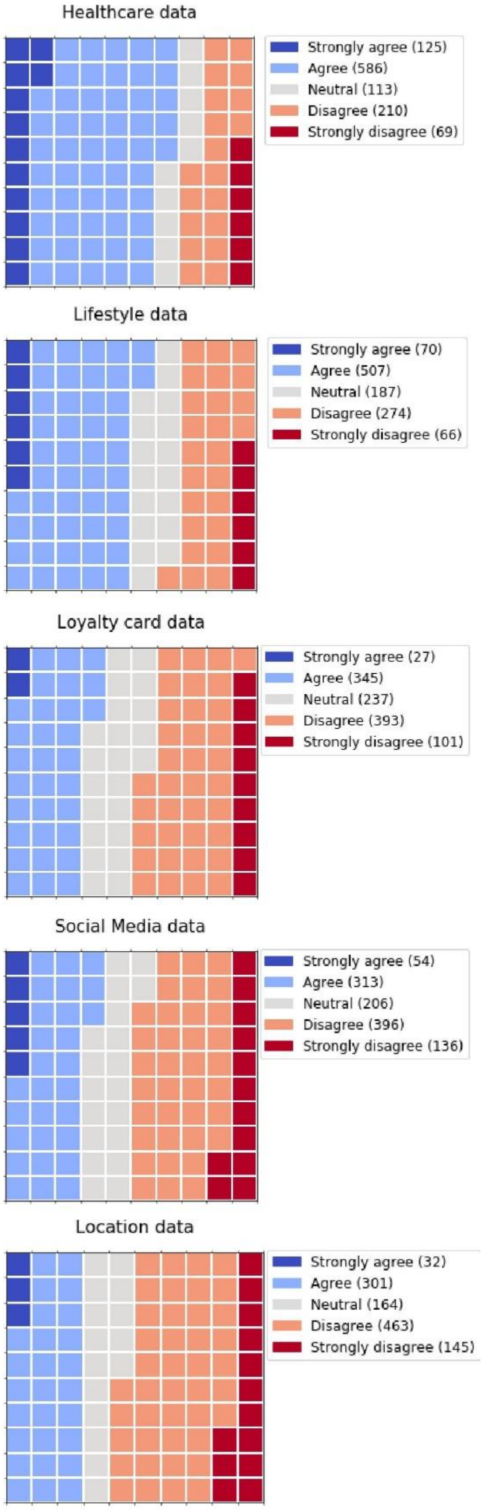


Figure 6- 7 Pharmacy users' perspectives on using different types of personal data for health research (proportional)

Additionally, participants' stances towards a hypothetical introduction of mandatory data sharing, in order to detect ongoing epidemics was investigated. Although more individuals in week two withheld response, the percentage of participants who supported or opposed the statement was found to be similar in both weeks of data collection (Figure 6-8).

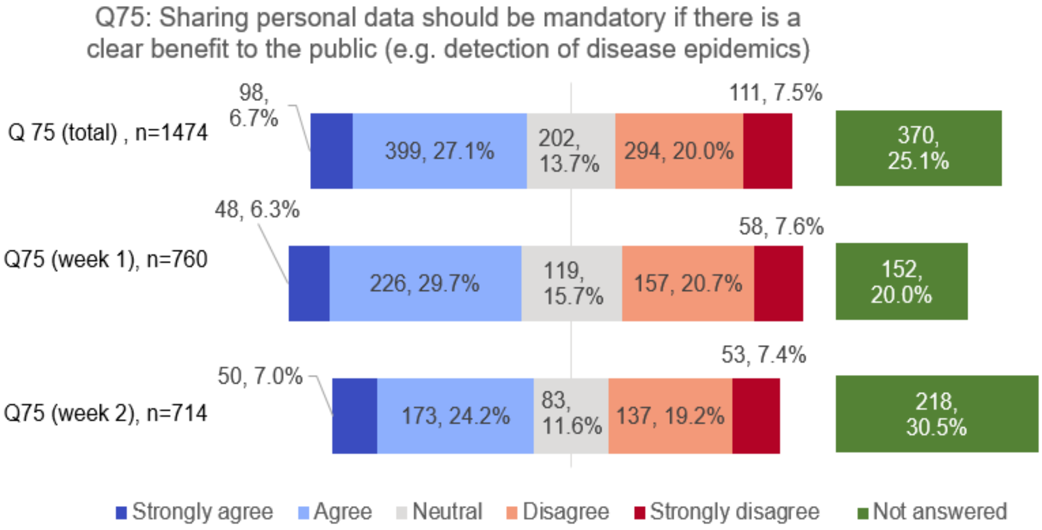


Figure 6- 8 Pharmacy users' attitudes towards mandatory data sharing

6.1.6 Pharmacy users' attitudes towards the use of loyalty card data for health research

Lastly, pharmacy users' attitudes towards the use of loyalty card data for health research, and to identify individuals at risk of having certain health conditions specifically, were mapped (Figure 6-9). A majority of pharmacy users (45.4%, n=669) supported the use of aggregate level loyalty card data, while fewer were supportive of the identification of individuals specifically (29.2%, n=430). No pronounced differences between participants support or opposition with regards to a possible identification of physical or mental health conditions were found.

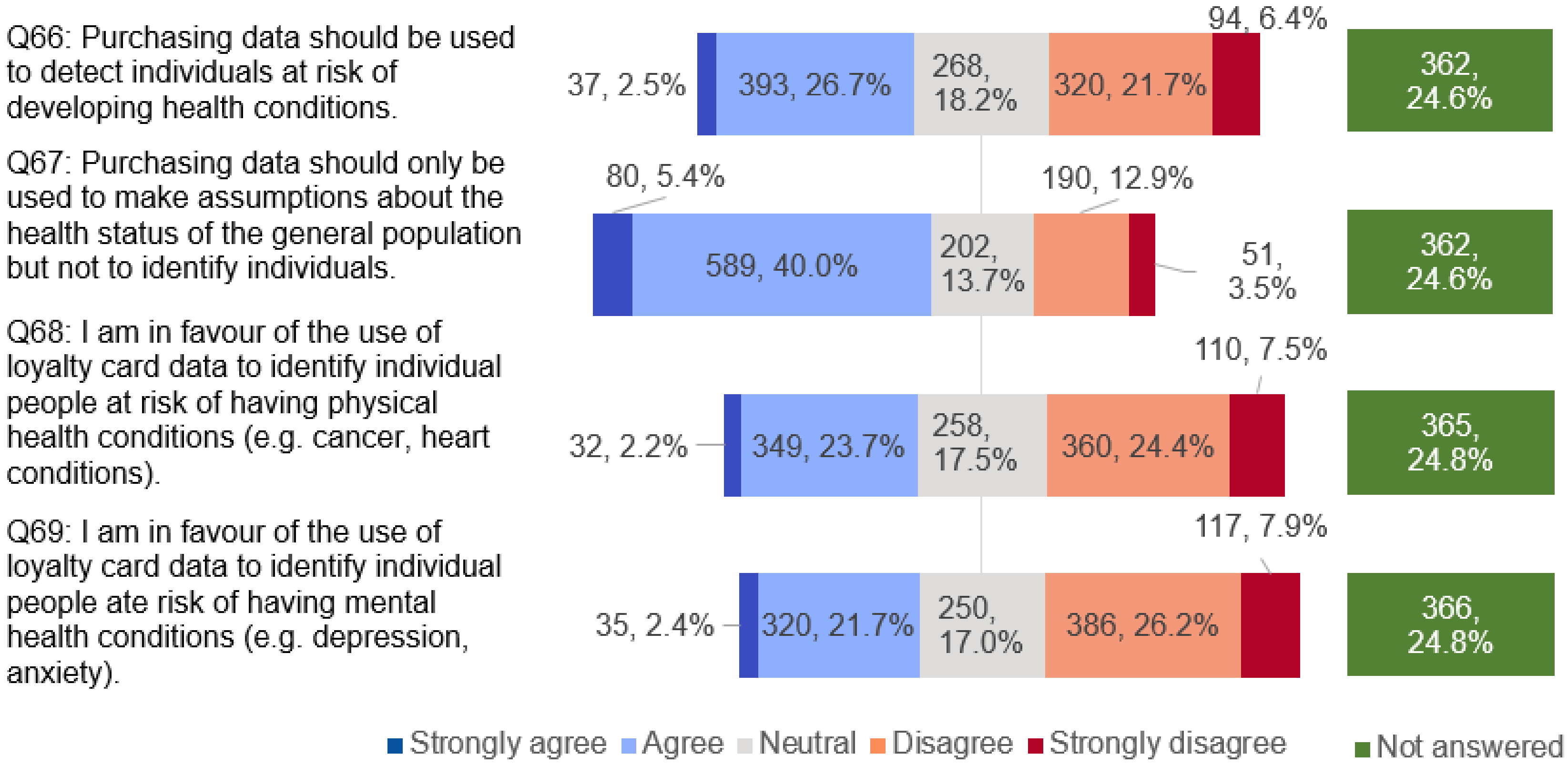


Figure 6- 9 Pharmacy users' attitudes towards the use of loyalty card in a health research context

6.2 Qualitative results

The previous chapter provided a descriptive account of pharmacy users' adoption of loyalty cards and mapped their views towards a possible application of loyalty card data in a health research context and to identify individuals at risk of developing certain health conditions. However, the reasoning behind the stances that individuals expressed remained unexplored. Thus, in line with the underlying explanatory sequential research design (section 2.2), the survey was succeeded by a qualitative research phase; the main objective was to add explanations to the obtained quantitative results.

6.2.1 Introduction

Discussions with individuals about the use of loyalty card data in a health research context were embedded in the same semi-structured interviews which were conducted to explore individuals' views towards mental health support provided in pharmacies. That is, during the semi-structured interviews participants first discussed the topic of mental health support provided in pharmacies, the results of which were reported in section 4.2. This was then followed by a conversation about loyalty card data and its use in health research. Both interview aspects were clearly demarcated, I initiated the interview section pertaining to loyalty card data with a definition of personal data, and provided participants with examples of how personal data could be used in a health research context. Later into the interviews, participants were provided with recently published examples of how loyalty card data could be used to identify individuals at risk (2.5.2.6).

Interviews were conducted with some survey participants and additionally sampled members of the public, as outlined in methods section 2.5.2.7. The obtained narrative data were analysed using a deductive approach to thematic analysis (2.5.3.4); the analysis was guided by the framework I established and outlined in the previous chapter.

6.2.2 Sample characteristics

Nine survey participants and additionally sampled members of the public participated in the interviews. The demographic characteristics of the interview participants mirror those reported in section 4.2.1, as both interview components were included in the same interview guide. In addition to that, the short survey included a question for participants to indicate their current use of loyalty cards. One participant reported not using any loyalty cards, the majority (n=6) of interviewees owned between one and four cards, and two participants reported the use of five or more cards.

6.2.3 Developing the context: the impact of COVID-19 on the interviews

The Interviews were held over the course of three months, from September 2020 to November 2020. During this period, COVID-19 was still dominating news outlets, and especially the use of personal data to contain the spread of COVID-19 was prominently discussed.

As a consequence, it was plausible that interviewees’ responses were impacted by the external circumstances. To understand respondents’ perspectives, the interviews commenced with a number of questions which investigated individuals' use of symptom and location tracking apps as well as their exposure to and perception of news covering the utilisation of personal data to contain the spread of COVID-19 (2.5.2.6.2).

Thus, before outlining the themes which were developed from the obtained data, I provide an account of individuals' responses to the topics highlighted above.

6.2.3.1 Participants adoption of data tracking apps

First, interviewees discussed their adoption of systems which were developed to track personal data in order to support the analysis of the spread of COVID-19, such as the ZOE symptom tracker or the NHS track and trace app.

Only one participant reported the use of a symptom tracking app, and their usefulness was questioned by some participants, mostly due to doubts concerning the honesty of their users.

> *"My mum uses a symptom tracker app but then she says to me that she doesn't put in some of her symptoms if she knows what's causing it....but how do you know what's causing it?" – FI05*

On the other hand, all participants reported the use of the NHS test and trace app at the time the interviews were conducted or planned on downloading the app as soon as it was available, if the interviews was conducted prior to the release of the application. In the majority of cases, participants were hopeful that a functioning test and trace system was going to help decrease the spread of COVID-19 and welcomed the opportunity to be informed about exposure to the virus. In order to achieve those expected benefits, most participants were accepting of the recording of some of their personal data.

> *"I've downloaded mine [test and trace app] and it does my background tracking of where I am and I'd rather I suppose give up that slight bit of data to potentially know if I've been at risk." – FI02*

> *"I have nothing to hide in terms of COVID my name, my date of birth, my location and I don't want to be in lockdown, so I'm, I'm not one of these people who are often a little bit paranoid -I feel- about sharing the smallest detail." – MI04*

Driven by the gravity of the ongoing pandemic, some interviewees stated that they were less worried about a potential misuse of their data, as the benefit of supporting the containment of COVID-19 was outweighing those concerns.

> *"I think that the way things are at the moment, if you start looking for little problems when they trying to sort out a big problem, I mean- I don't agree with everything that's been done at the moment, but yeah, there's a big problem at the moment and people having to make decisions on what they've got. So yeah,*

> *I'm not too concerned at the moment everyone was given a bit of a free pass and I'm not bothered.”* – MI09

Similarly, apparent high levels of trust in the provider of the test and trace app, i.e. the department of health and social care, were found to facilitate the uptake of such apps.

> *“I'd hope because it's like a NHS one that they're not going to be using it for advertising, or just like.... You know, like working out where I'm going. But at the same time, like I'm not 100% sure that that's actually gonna happen.”* – FI05

6.2.3.2 Engagement with the topic

Interestingly, only few interviewees reported to have actively engaged with the technical details of the test and trace system, such as the types of data being collected and data storage conditions, despite those topics being prominently discussed in media outlets for a few months.

> *“I feel like the one that they have developed that they've got at the moment seems quite OK, 'cause I think it's just your first your -post code, isn't it? And stuff.... So yeah, it's very minimal data that's being shared there I'm guessing...but yeah...I just download anything to be honest.”* – FI02

Moreover, some participants reported that they had actively chosen not to acquire any information concerning the utilisation of their data, in order to avoid dissatisfying results.

> *M: Yeah, I've got the NHS one on the phone. I will check in.*
>
> *I: And do you feel well informed how your data are used?*

> *M: I haven't got a clue.*
>
> *I: Okay- And would you like to have a clue?*
>
> *M: Not overly - I think I'd probably get quite a bit frustrated if I did. I think that there's going to be a downside too, but I think it's - as things are- it's a necessary evil. –MI09*

However, this approach was not followed by all participants, as some commented on the controversies which had tailgated the development of the test and trace system. Those interviewees emphasised that gathering information and an active engagement with the topic had eased their initial concerns and given them the confidence to install the application.

> *"My concern really is that you've got to have something in place which will still provide safeguards to people, but at the same time still helping to contain the pandemic. I wasn't happy at all with the first iteration of the world beating app, because we were going to find a whole load of data stored from the bits I read about it […], I'm happy with that now because... and I've downloaded it and I am using it because I think actually it isn't sharing my data....my data remains on my phone."- MI03*

6.2.3.3 The impact of the outbreak of COVID-19 on individuals' stances towards the use of personal data for health research

A small number of participants highlighted that the outbreak of COVID-19 and the subsequent discussion of the use of personal data to contain the spread of the virus had affected their stance towards the use of personal data in a health research context. Those who reported a transformation of their stance described a positive shift, rooted in heightened awareness of the potential benefits of personal data for health research.

> *“I've definitely seen like the actual positives of how it [personal data] can be used in like a way of like sort of, containing the spread of COVID-19 […] I never really thought about it before, but obviously this whole situation is like made me think about how it can be used in that way.” –FI05*

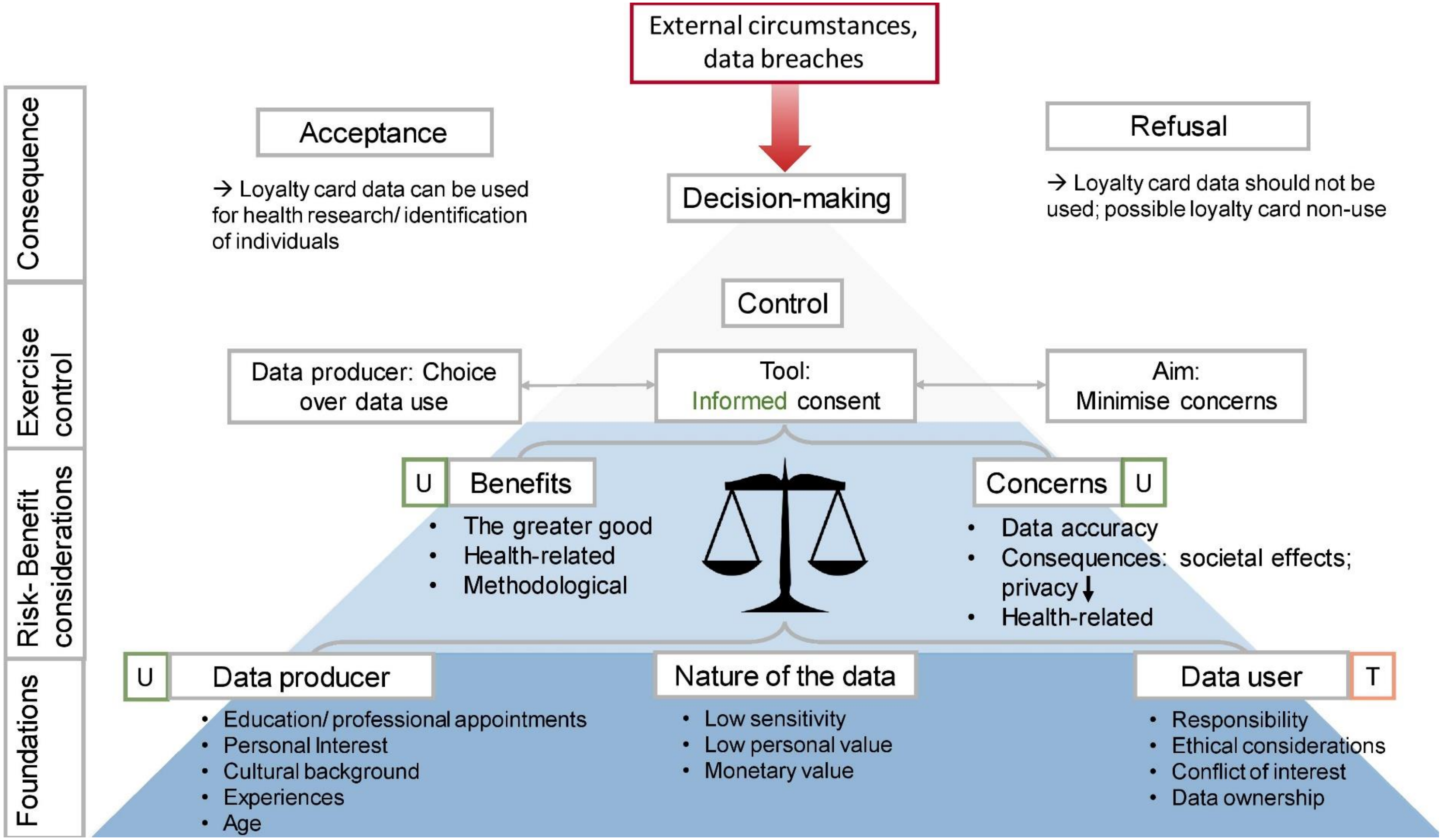


Figure 6- 10 Updated framework of acceptance, T= Trust, U=Understanding

6.2.4 Pharmacy users’ attitudes towards the use of loyalty card data for health research

The previous section provided some context to the societal circumstances under which the interview data was obtained. Next, the findings pertaining to individuals’ stances towards the use of personal data for health research purposes are outlined. The analysis of the obtained data was driven by the framework I established in the previous chapter; however, amendments to the guiding framework were made when necessary. Thus, the interview data was consolidated in four main themes, namely: pharmacy users’ perception of loyalty card data and its use in health research, risk-benefit considerations, individuals’ need for control and factors impacting individuals’ stances; Figure 6-10 shows the updated framework.

6.2.4.1 Pharmacy users’ perception of loyalty card data

Again, participants’ stances were predominately influenced by their perception of the nature of loyalty card data as well as factors concerning the data producer (i.e. the loyalty card user) and aspects pertaining to the data user (i.e. the loyalty card provider). However, pharmacy users’ categorisation appeared to be less distinct, as issues which accentuate the intricate synergies between the involved factors, such as data ownership, were prominently discussed.

The nature of loyalty card data

First, the nature of loyalty card data was found to influence individuals' stances towards a possible utilisation of loyalty card data for health research. Pharmacy users predominately commented on the perceived value of purchasing data, comparisons to other types of personal data occurred only rarely.

A number of interviewees described how they attributed only little personal value to loyalty card data; instead, the produced data were considered a commodity which is deliberately traded in exchange for a benefit, such as money off. Additionally it was acknowledged that loyalty cards incentivise customers to increase their spending, which in turn benefits the retailer providing the loyalty card scheme.

> *"I know like from a [large retailer] point of view […] people with loyalty cards are proven to spend more money than those that don't have a loyalty card. So from that point of view like it does mean that you get in more […] profit. But then I know I've got all of mine and it is quite nice too, if I'm just buying stuff to then get the reward from it. So if like for instance with [large retailer] if I'm just buying stuff that I would buy anyway and then I get to Christmas I actually had to treat myself […] It's good.... It's a present to me so…"-FI02*

However, a number of participants also highlighted the financial value of personal data, including loyalty card data, which they considered underappreciated.

> *“I don't think we've ever really appreciated the monetary value of the data we are supplying. Now whether that's around car insurance or... um... health needs or whatever else... It's got huge value within, within the wider world of commerce and, and beyond that, really.” – MI03*

The data user

The perception that the monetary value of personal data is currently underappreciated was further found to influence participants’ considerations pertaining to the companies which provide loyalty cards. That is, participants questioned whether the intentions behind those companies who provide loyalty schemes, and subsequently use the amassed data, can be entirely benevolent, due to the business model under which most companies operate.

> *“But loyalty cards... I want -you know- they're usually run by a company whose- whose sole purpose is to sell you more items. Find out what he liked- advertise it, sell him more items. And so I think there's a bit of a conflict of interest if you're talking about loyalty cards.” –MI01*

Eventually, issues concerning the monetary value of data and the perceived conflict of interest culminated in discussions about data ownership. Some participants demanded control over their personal data in order to prevent companies using the collected data for financial benefit.

> *“What is interesting is how essentially its companies making money out of people's property in the sense that you should own your data.”- MI08*

More so, demands for additional controlling mechanisms arose, in order to avoid potential power imbalances, should companies be allowed to use personal data for the proposed purpose.

> *“[…] once you give them [large companies] the power to do these things, there's, there's no- as far as I can tell...maybe I'm wrong. There's no real system to then put checks and balances on what these companies can do with our data.”-MI08*

However, some interviewees, similar to the previously interviewed students, saw retailers and particularly pharmacists in a position of responsibility to use the collected data, as the information may be indicative of an individual’s health.

> *I feel they [pharmacists] got more responsibility, and they take more responsibility on looking after their customers […] and so therefore if, if I went in there and started buying painkillers everyday […] they might mention it to me...talk to me about it and then recommend options, of course then there's [where the] loyalty card comes in. I understand I don't have to go there all the time there's quite a few pharmacists local to me which I can go in and nobody would know.”- MI01*

The data producer

Lastly, the interviews identified aspects pertaining to the data producer themselves as important for understanding participants' stances towards a possible utilisation of loyalty card data for health research.

Education and profession

A number of participants underpinned their stances towards the utilisation of loyalty card data for health research with the nature of education they had received or their professional appointments. This was particularly prevalent for individuals who were currently working or had previously worked in information governance roles or research.

> *"I worked for a large local authority- [anonymised] County Council for 35 years as a social worker and then... most recently I was the information governance officer for adult care, so I know-well, it's a little bit rusty now, but I know a fair amount about GDPR." –MI01*

Age

Interestingly, a number of participants, in particular those aged 50 years or older, referred to differences between generations as an important factor to consider when aiming to understand individuals' stances.

> *"I don't know whether that's a generation thing, obviously.... I'm not using social media, so I'm not out there. […] a lot of people....they don't mind and a lot of people are quite happy about it." –MI01*

A paucity of experience with social media as well as a lack of assimilation with a world driven by predictive technologies and artificial intelligence were found to influence older pharmacy users' viewpoints.

> *"I think for my wife, myself- and me and I think for many people our generation we're just a lot more cautious about well how's this data going to be used. […] We've all read 1984, whether my sons have.... I very much doubt it really, so I think they're just growing up in a different attitude to living in a world which is governed by algorithms, governed by IT, that's not a world I grew up in."-MI03*

The notion that generational differences and familiarity with digital technologies are important to recognise was further manifested by younger participants who appeared to be less cautious with regards to their personal data, often due to long-time engagement with social media.

> *"I figure I'm probably at the age that probably I've given my data away already many, many years ago, before GDPR came in." – FI02*

Personal experiences

Lastly, one participant described how experiences he had made in the past influenced his stance. Interestingly, the described experience bore similarities with the proposed application of loyalty card data in a health context, as data which had been collected for a different purpose was used to make inferences about the health of the individual producing the data.

> *"I used to use a bunch of a- kind of art sharing apps when I was younger. So I'm quite creatively inclined and when I was younger they were linked to my dad's email and they kept-, well not kept, a few times they flagged up that they thought I was having like mental health concerns just because of what I was drawing or writing or creating and that- it was really interesting to me when I first saw it 'cause I was like OK - either a person or an algorithm knows that this behaviour is linked to this stuff." –MI08*

In summary, akin to the contents of the framework guiding the analysis of the data, three fundamental elements influencing pharmacy users' perception of loyalty card data and its use in a health research were identified. These are: the nature of loyalty card data as well as aspects concerning the data producer and the prospective data user. In those subcategories, interviews with pharmacy users unearthended some additional aspects affecting individuals perception of loyalty card data, such as data ownership and a number of aspects pertaining to the data producer him- or herself. In addition to professional appointments, personal interest and experiences, pharmacy users identified age and generational differences as important factors to consider. Older participants considered themselves as more cautious about their personal data, due to a lack of familiarity and apparent fears over a creation of an *Orwellian society*.

Consequently, the earlier developed guiding framework was amended to account for the additional factors I found to influence individuals' fundamental stances towards loyalty card data and its use in health research.

6.2.4.2 Risk-benefit considerations

After pharmacy users established their initial stances towards the use of loyalty card data in the context of health research and highlighted the origins of these stances, the discussion moved towards a practical application of loyalty card data in health research. For that purpose, participants were exposed to two recent publications which examined associations between individuals' purchasing behaviour and their health (2.5.2.6.1); the utilised examples mirrored those students were exposed to.

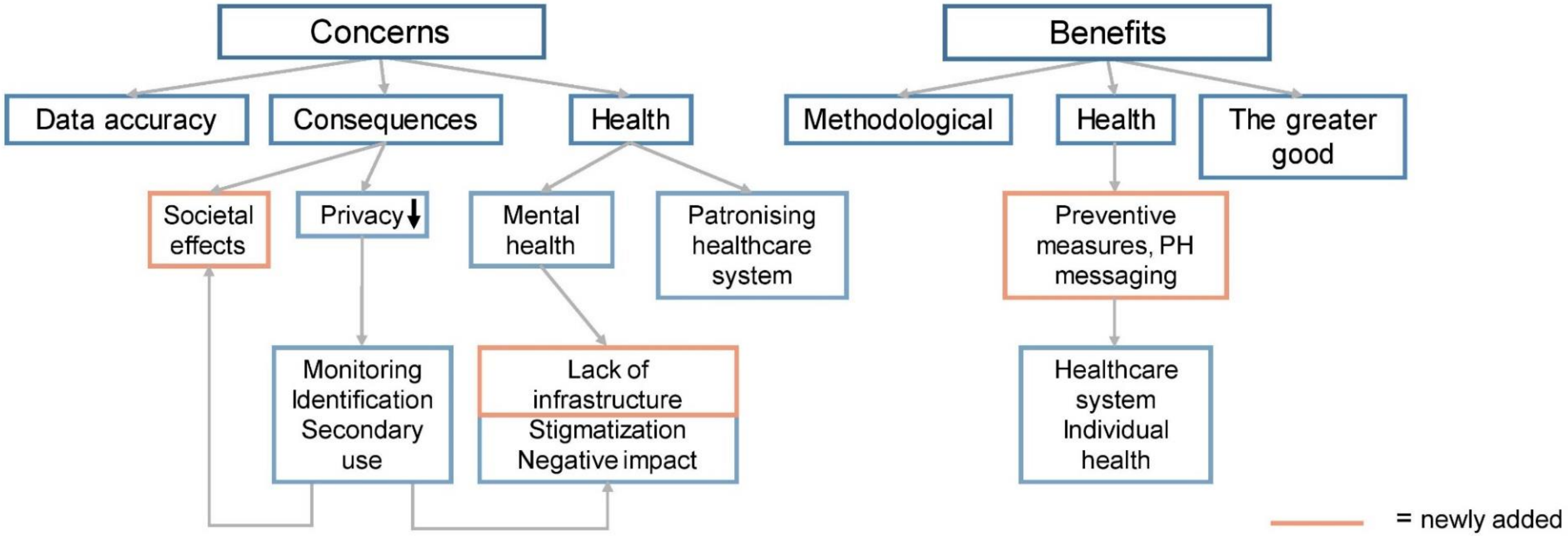


Figure 6- 11 Concerns about and benefits of loyalty card use in health research - updated.

Participants then discussed the benefits they anticipated to emerge from the proposed approach and elaborated on possible risks. Subsequently, some pharmacy users weighed between both categories, in order to reach a conclusion concerning a possible application of loyalty card data for health research, and to identify individuals specifically.

6.2.4.2.1 Concerns

In most instances, the concerns raised by pharmacy users mirrored those students had suggested previously. However, some additional concerns were highlighted (Figure 6-11).

Data accuracy

Almost all participants vocalised concerns over the accuracy of loyalty card data, and over the extent to which loyalty card data can be indicative of underlying health conditions. In the majority of cases, concerns over data accuracy seemed to originate from personal experiences, as sharing loyalty cards occurred to be common practice.

> *“When I go to [large retailer] I'll sometimes take my wife’s loyalty card with me. Well...Loyalty cards aren't particular to the person are they, -you know-, there, there's something that might be within a household or friendship group that might be passed around […].”-MI03*

As a consequence of low data accuracy and a lack of knowledge about an individual’s medical history, loyalty card users who are already diagnosed with certain health conditions may be contacted, which in turn was thought to cause distress.

> *"I suppose we -you know- somebody could potentially already have that diagnosis and we -you know-, contacting people yeah who it might be a sensitive subject for." –FI02*

In addition to concerns over the accuracy of loyalty card data, almost all participants raised concerns over the consequences an attempted tracking and analysing of loyalty card data may have. Particularly prevalent were fears over the diminishing of personal privacy and negative effects on community structures.

Privacy-related concern

Pharmacy users discussed potential effects on the privacy of the individual, which may deteriorate due to the feeling of being monitored or fears over being identified.

> *"I wouldn't be as keen on using the loyalty card 'cause you're almost like giving away how much you've been there, and I think I'd be a bit more sort of closed off to the idea if I knew that it was being used....not against me, but like you know, like somebody was actually looking at it and sort of saying: Oh- maybe you shouldn't be going there that often." – FI05*

Secondary use of data

Influenced by pharmacy users' perception that loyalty card data is of high financial value, concerns over an undesired secondary use of the obtained data dominated the discussions. In particular, participants raised fears over the repurposing of personal data, in order to increase company profits.

> *"[…] if it's, for example, a gym rang me up and says- 'oh why don't you join our gym because we can see that you're not doing anything, you've got all these unhealthy lifestyle choices and if you spend £50 a month with us it would be brilliant for you'-[…] It's very, very dodgy ground. I know there's a very fine line between supporting people and going into some sort of 1984 scenario and I'm not sure where that line is, 'cause I've not really thought about it to be honest." – FI09*

Societal consequences

Although students also raised concerns over an undesired secondary use of data, those fears were vocalised with particular emphasis by pharmacy users. In some instances, participants concerns culminated in more broad discussions over the societal consequences of an undesired secondary use of data. Particularly, the loss of civil liberties was feared by some participants and the influential power data can have on society was discussed.

> *"I don't wanna be overdramatic-, but I will use the word manipulated. […] I think [it's] hugely concerning really, because I*

> *think these things, these scenes are incremental aren't they and gradually...We will have, will be directed more and more. Um... And... I have to work harder and harder to resist being pushed in certain directions whether it's around musical choices, the way we vote, our views on -I don't know- the environment....whatever, I think we're in great danger of being manipulated frankly."* – MI03

Health-related concerns

Lastly, pharmacy users raised a number of health-related concerns which they expected to emerge from the tracking and analysing of loyalty card data.

Interference with patient empowerment

Participants mentioned concerns over the emergence of an increasingly patronising healthcare system. That is, the analysis of an individual's purchasing data was thought to contradict the current development towards self-empowering patients to take control of their own health.

> *"I was talking about we're a society that is very focused on protecting people, protecting patients and I think sometimes that can […] infantilize people and I think that's worrying because if you have a generation of grown children, then they're not going to know how to look after themselves […] across every dimension I*

Mental health

Most prevalently, pharmacy users discussed the effects and consequences the tracking and analysing of loyalty card data could have in the realm of mental health. Pharmacy users suggested that the stigma surrounding mental health issues could act as a barrier to obtaining public acceptance for the analysis of transactional data.

> *"And then also with mental health at the minute there's a lot of stigma around it still, and people feel like they have to hide if they knew that they were being tracked as well, I think that would be something else that they'd then be wanting to hide." – FI05*

Some participants feared that an attempted identification of mental health conditions may cause negative consequences for the individual in question. That is, distress could be experienced if the loyalty card user is unaware of a potential mental health problem or refuses to acknowledge it.

> *"[…] from a mental health point of view […] if someone comes back [to] you if you haven't identified it yourself or you're not confident enough to do anything about [it] […] being told 'look, we discovered that you're -you know- this, this and this.' I think that could have a detrimental effect. I can see that." – FI02*

The adverse effects of being told to be at risk of having mental health issues were profoundly illustrated by one participant who described how repeated questions concerning his mental health culminated in him challenging his own mental state.

> *“I remember quite a few times when I was younger and I struggled to manage it well I would feel fine until someone asked me if I was alright and I think that's because when you ask someone if they're alright, what you're really saying is...you're acting in a way which seems to me not OK, but -you know what I mean- like it's, is it a balance between how people perceive people should act and how people do act […]”-MI08*

Lastly, pharmacy users highlighted that developing a functioning infrastructure which is able to offer support to the majority of individuals with mental health issues is a prerequisite before the identification of individuals can be attempted. Most participants voiced dissatisfaction over the current infrastructure and consequently demanded improvements, such as an expansion and acceleration of the currently available mental health support.

> *“in teaching, there were plenty of children who needed the support [but] the mental health service provision wasn't there.... they were so overrun, that it didn't matter how...who was identified- getting them provision was six months, a year down the line, which was delayed too late. And so […] just saying that oh yeah, we know this people need help, if the provision for that help isn't there and I think that […] is the biggest issue not so much the identification without having the provision there.” –MI01*

6.2.4.2.2 Benefits

Similar to the earlier interviewed students, pharmacy users also elaborated on the benefits they anticipated to emerge from a potential utilisation of loyalty card data in a health research context.

Here, the possibility to utilise the amassed data to prevent the onset of health conditions, that is, to establish a proactive healthcare system with a focus on prevention instead of reaction, were seen as the most persuasive arguments for supporting the proposed approach.

> *“I think it's great, wouldn't it? I mean, it would help, it would be really helpful to encourage people to screen. It will, yeah, I think that's one and if we detect disease before it becomes worse than the […] I think the prognosis will become better if we...do something about it much earlier.”-FI07*

Along the same lines, some participants supported the utilisation of loyalty card data to detect trends in individual’s purchasing behaviour to improve our understanding of mental health conditions in general.

> *“I think the idea that you could look at someone’s purchasing history and see how likely they are to fall into different mental health categories is fascinating and very interesting. I think it could be extremely helpful for some people 'cause I could see quite a few trends that you could probably go through that would show you some forms of- not necessary, mental health decline, but cycles of mental health...”- MI08*

Consequently, the utilisation of loyalty card data was thought to be beneficial in order to ‘nudge’ individuals in need of mental health support into receiving healthcare.

> *If you if you not kind of thought about needing any additional support and it kind of just plodding on through and using stuff from pharmacy to support you and it might be a prompt, that you need to get some extra help.-FI02*

6.2.4.2.3 Weighing between benefits and risks

Lastly, pharmacy users attempted to weigh between the benefits they had identified from a potential use of loyalty card data and the risks they anticipated to emerge, in order to reach a conclusion concerning their personal stance towards the topic. Interestingly, contemplations over the use of personal data for research purposes where frequently accompanied by the question of ‘where to draw the line’ between intrusiveness and acceptability.

> *“It is a little bit of a- a bit of a slippery slope. There are plenty of benefits in […] that data being used... to then where you draw the line as you say. If someone is buying a lot of unhealthy food do you then step in and say -you know- I think there might be mental health issues. Some people who suddenly start buying alcohol for instance. So- it's a tricky one. Where do you draw the line? What is acceptable to be -sort of- monitored?” –MI01*

Eventually, most participants supported the tracking and analysing of transactional data. However, few participants opposed the proposed approach; outright rejection was oftentimes rooted in concerns over an undesired repurposing of the obtained data or scepticism about data accuracy.

> *"I know we do that all of the time.... It's completely hopeless. But yeah, we do all the time. […] I've been in research for 20 odd years. I can tell you this- the analysis of data like that is useless. " – MI05*

In summary, pharmacy users raised a number of risks, which they anticipated to emerge from an utilisation of loyalty card data beyond its original purpose. Interestingly, a number of pharmacy users discussed potential risks on a more global scale, that is, the societal effects of an extensive repurposing of personal data were considered. Additionally, participants placed an emphasis on the necessity to establish a working mental health support infrastructure, if an implementation of the proposed approach on a large scale is sought after. On the other hand, an utilisation of loyalty card data was thought to accelerate the desired shift from a health care system focused on reaction towards prevention-oriented healthcare provision, with beneficial effects on the health of individuals and entire communities. Accordingly, the framework was modified to include pharmacy users concerns and the benefits they expected to emerge.

Eventually, pharmacy users performed a mental assessment between the benefits and potential pitfalls associated with the tracking and analysing of transactional data.

6.2.4.3 Individuals' need for control

Besides the necessity to find a balance between potential risks and emerging benefits of using loyalty card data in a health research context, pharmacy users emphasised the importance of control and choice in their decision-making process.

Similar to the interviews with the students, three aspects of control were established from participants' comments. These are: control means having a choice, consent as the tool to exercise control and control minimises concerns.

Control means having a choice

Almost all participants emphasised choice over the use of their data as an important aspect in their decision-making process, as active involvement was thought to increase individuals' level of control. More specifically, participants demanded control over two aspects pertaining to the use of loyalty card data for health research. First, whether and to which extent their purchasing data can be used in a health research context.

> *"I would think- it would be nice to have the choice. I don't like things being done behind my back. And again, if you talk about trust I think that people would then trust it." –MI09*

Second, most participants preferred modes of result delivery which prioritise voluntariness and appear non-targeted; this was thought to enable individuals to decide whether or not they want to act based on the message they receive. In order to highlight the successfulness of voluntary approaches, some participants referenced previous public health campaigns in England.

> *"Because I can pick two little offers a week [from grocery store loyalty card] and they are normally related to beer, to be honest, now I don't- don't worry, I'm not- I've not got an alcohol problem that is huge. Then I think maybe that's quite clever if […] I was put on a list and maybe I've got a leaflet sent through saying "You know (um)- You know- I don't know whether they still do- […] NHS used to do something called 'Change for life' […]- and they used to have these little funny little cartoon characters and they used to tell you these […] healthy swaps and it was called 'Change for life' and it was really good." –M09*

This was seen as particularly beneficial in the area of mental health, where the receiving of non-targeted emails, which provide information about available support mechanisms, was seen as universally accepted.

> *"You get lots of emails already around things like wellness and mental wellbeing and stuff like that. It's kind of normal, […] normalised already to get that sort of information about the support that's available." – FI02*

Consent: tool to exercise control

The importance of choice further influenced participants' discussion of the ideal consent process. That is, pharmacy users, before outlining potential details of the consent process, emphasised that it was fundamental for the process to allow individuals' to opt-in or opt out, according to their preferences.

> *"Almost like sort of organ donor, if you could sign up to something if you got an opt-in or opt-out. […]- I think that would be fair." MI09*

Some pharmacy users mentioned the difficulties that are associated with the process of obtaining informed consent, and emphasised that this process, which is often rushed, can leave the consenter's need for information unsatisfied.

> *"[…] meaningful consent's a really tricky thing to obtain actually. I think-, I think we still pay lip service to it... Really, it's a hurry for whoever is trying to obtain it to go through the process, they have to go through. People can't always absorb what they're being asked to consent to... and it's often off the moment, isn't it... You'll have forgotten in nine months' time what you actually consented to and what you didn't."-MI03*

Therefore, some participants requested amendments to the current process, in order to facilitate the obtainment of informed consent. It was emphasised that the commercial use of transactional data should be strictly separated from a potential health-related application and that the purpose for which the obtained data will be used is explicitly stated.

> *"I think it would have to be like a clear split there between what is for your health and what is for sort of the store." –FI05*

Consent minimises concern

Finally, pharmacy users highlighted that their main reason for demanding control through opt-in was the hope to minimise possible risks emerging from a use of loyalty card data beyond its intended purpose, such as surprise over an unexpected secondary use of their data. Consequently, the implementation of processes that reinforce the obtainment of informed consent were thought to mitigate those concerns and facilitate public acceptance.

> *"I'd be happy to, to sign. I'd be happy to have my data used to pinpoint- to highlight to me if I was at risk of something like that, but I think I would want personally to, to opt in.[…] , I don't think I'd want it as like a surprise that I'm going to then have this information shared with me when it's not something I've asked for." –FI02*

In summary, pharmacy users suggested that the ability to exercise control over the use of one's personal data are a cornerstone for obtaining their acceptance for the tracking and analysing of transactional data. Control was understood as having the possibility to opt-in or out of the process, after receiving sufficient information to provide informed consent. The minimization of concerns, such as causing distress for the individual in question, occurred to be the main objective behind participants' demands for more control.

6.1.1.1.1 Factors affecting individuals' stances: facilitators and drawbacks

The interviews with students had identified trust and understanding as important facilitators for obtaining individuals' acceptance for an extended use of personal data in health research. This notion was partly supported by pharmacy users. Additionally, participants suggested that publicly discussed data breaches affected their stances negatively.

Trust

Pharmacy users indicated that higher levels of trust in the prospective data user could have a moderating effect on their attitudes towards the tracking and analysing of transactional data. Interestingly, most the participants in this study expected that community pharmacists would utilise the collected health-related loyalty card data, or the results from their analysis. During the interviews, participants exhibited high levels of trust in pharmacists to act with their patients' wellbeing in mind, which could occurred to influence acceptance positively.

> *"I think with a- with a community pharmacist, there is […] more trust in that community pharmacy to be operating on their customers wellbeing –[…] I do have more trust in them [community pharmacist] 'cause they pass the data, my GP passes my prescription data to them."-MI01*

More so, an association with the wider realm of the NHS was seen as beneficial, as some participants placed more trust in those institutions to act righteously.

> *M: […] all these cookies and things you go on anything and -you know- if you look on a clothes website then the next time I go on something different I get an advert for that clothes shop and*

> *things -you know- it's to a certain extent, I think you just got to put up with it a little bit.*
>
> *I: yeah*
>
> *M: But I could say hopefully the NHS's got more ethics then the retailer. –MI09*

Understanding

Despite also being exposed to recent examples of how loyalty card data could be used in a health research context, pharmacy users rarely emphasised understanding as a facilitator for their acceptance of an extended use of loyalty card data.

Instead, most participants were aware of the utilisation of personal data in a multitude of circumstances and normalised it. In some instances, personal data was seen as a powerful tool to actively promote behaviour change.

> *"Every week now I get a report saying- […] - I mean at the moment my screen times is through the roof cause of things like this- But it's important maybe to get that-, and I don't see the difference between you getting somebody saying you-you screen time went up 13% and you sort of-- if it's just letting you know then I think that's maybe quite clever."-MI09*

Drawbacks: knowledge of data breaches

Lastly, participants widely acknowledged that publicly communicated data breaches could have a detrimental effect on individuals' trust and subsequently their acceptance of the use of personal data beyond its intended purpose. A number of participants highlighted recent or past data breaches and explained how those had affected their stances negatively. Thus, it was acknowledged that obtaining public acceptance is often dependent on external circumstances, which may be difficult to control.

> *"I think there's a lot more about building up trust in the systems, and that is around communications, but rather sadly, it doesn't matter how good you are as an organisation that can be fundamentally undermined by what happens elsewhere in the world, really can't it. The NHS could spend millions of pounds around building up patient confidence in, in that system and then you just need Cambridge Analytica and Facebook to come along and suddenly everyone gets more wary about [it] again, which is nothing to do with what's happening in the NHS […]."-MI03*

In summary, trust in the data user was identified as an important facilitator for individuals' acceptance of the utilisation of loyalty card data in a health research context. Participants predominately determined pharmacists as the prospective users of their purchasing data. Pharmacists were characterised as trustworthy and as operating with their patients' wellbeing in mind. The interview data further indicated that the role of understanding as a facilitator for individuals' acceptance was marginal. Instead, participants were widely aware of the use of personal data in a multitude of circumstances, and normalised the approach. Lastly, publicly debated data breaches, despite often unrelated to the topic of discussion, occurred to influence individuals' attitudes. Therefore, the contemporary societal climate appears to have an effect on individuals stances, which needs to be taken into consideration when the utilisation of personal data beyond its intended purpose is proposed. Consequently, the framework was amended to include this aspect as an important element for understanding individuals acceptance considerations.

6.2 Synthesis of information

6.2.1 Summary of key findings

6.2.1.1 Quantitative data

A cross-sectional survey was distributed in 15 pharmacies in Nottinghamshire, in order to describe pharmacy users use of loyalty cards and map their attitudes towards the utilisation of personal data, including loyalty card data, for health research purposes.

In total, three-in-five pharmacy users reported to own of at least one loyalty card. The use of loyalty cards provided by health and beauty retailers was reported most frequently, closely followed by loyalty cards provided by grocery stores. Moreover, pharmacy users were found to be more likely to use grocery store loyalty cards jointly, compared to health and beauty loyalty cards. Demographically, users of health and beauty loyalty cards were identified to be more likely to be female and of younger age, while users of grocery store loyalty cards were more likely to be older and of white ethnicity.

Participants predominantly reported to be careful about the companies they share their personal data with, and a majority reported to be unwilling to share personal data for benefit. However, the data suggest a discrepancy between individuals' attitudes and their behaviour, as 484 pharmacy users who reportedly used at least one loyalty card stated that they were unwilling to share personal data for benefit. Quantitatively, participants appeared to support the utilisation of aggregate-level loyalty card data in a health research context, but expressed reluctance towards an identification of individuals specifically. No pronounced differences between participants support for the identification of mental health conditions compared to physical health conditions were found.

6.2.1.2 Qualitative data

Furthermore, nine interviews were conducted with survey participants and some additionally sampled members of the public. The framework established in the previous chapter guided the analysis, and the obtained data were consolidated in four themes. Those are: pharmacy users' perception of loyalty card data and its use in health research, risk-benefit considerations, individuals' need for control, and factors impacting individuals' stances.

Pharmacy users were found to attribute substantial financial value to personal data, including loyalty card data, although the data was still predominately seen as a commodity which is deliberately exchanged for benefit. More so, participants exhibited little trust in the benevolence of the prospective data user, and anticipated the emergence of a conflict of interest between business interests and the healthcare aspect. In some instances those considerations culminated in demands to re-evaluate aspects concerning ownership of the generated data.

In addition to already established concerns, pharmacy users discussed potential societal consequences which may emerge from a large-scale utilisation of routinely collected data, and questioned the adequacy of the current mental health infrastructure. On the other hand, it was thought that the utilisation of routine data, such as loyalty card data, in a health research context could stimulate a shift from a treatment-focused, reactive healthcare system towards a more proactive approach.

Pharmacy users emphasised the importance of control for their acceptance considerations, well-established consent processes leading to the provision of informed consent were preferred. Similarly, non-targeted public health campaigns received widespread support, as they emphasise voluntariness and allow the individual to remain in control.

Lastly, a number of factors occurred to mediate individuals' stances. First, trust in the data user was suggested to increase acceptance. Participants expected pharmaceutical involvement in the proposed approach, and appeared to trust pharmacists with their transactional data. Thus, a potential involvement of pharmacists in the utilisation of loyalty card data may increase individuals' support for the approach.

Secondly, it was suggested that acceptance considerations are susceptible to the effects of publicly discussed data breaches, such as Cambridge Analytica. Therefore, the current societal climate appears to have an effect on individuals stances, which needs to be taken into consideration when the utilisation of personal data beyond its intended purpose is proposed.

6.2.2 Implications for the succeeding phases

The previous four chapters presented the results I obtained from the data I collected in order to fulfil the objectives of this research project. The research aim and objectives were conceptualised on the grounds of the two extensive literature reviews, presented in chapter two. Consequently, in the following chapter I intend to evaluate to which extent the obtained results answer the initial research question. In other words, the key findings of this research project will be discussed. That is, I will evaluate how my findings relate to the existing knowledge in this field and what has been newly unearthed.

Chapter 7 Summary discussion and conclusions

The previous four chapters reported the results from both research streams conceptualised to fulfil the aim of this thesis (1.7.7). That is, to identify public attitudes towards mental health support provided in pharmacies and towards utilising purchasing data to identify individuals at risk of developing mental health issues. Two aspects influenced the development of this study. Firstly, there is a dearth of literature pertaining to public attitudes towards mental health support provided in pharmacies in England (1.4.5). Therefore, I argued, that the perspective of pharmacy users towards pharmacy-provided mental healthcare requires evaluation before novel approaches to identify individuals at risk can be advocated for. Consequently, two research objectives were developed.

1. To evaluate community pharmacy users' attitudes towards mental health support provided in pharmacies in England.

2. To explore requirements, barriers and facilitators for pharmacy users' acceptance of pharmacy provided mental health support in England.

Secondly, a paucity of literature investigating the attitudes of members of the public towards the utilisation of transactional data for research purposes was identified (1.7.6). However, loyalty card data materialised as a promising data source to inform community pharmacy practice (1.5). Therefore, three additional research objectives were developed.

3. To describe loyalty card use and non-use, frequency of use and related demographic data in different population groups.

4. To evaluate public acceptance towards loyalty card use for health research purposes, and specifically to identify individuals at risk of having mental health issues.

5. To explore factors affecting public acceptance towards the use of loyalty card data for the identification of individuals at risk of having mental health issues.

As both research streams addressed different aspects of the study's aim, a separate discussion is warranted. First, the key findings from chapter 4 and 5 of this thesis are discussed and interpreted in the context of the existing knowledge (7.1), followed by a discussion of the key findings from chapter 6 and 7 (7.2). However, to evaluate the fulfilment of the overall research aim, a synthesis of the data from both research streams follows (7.3). Finally, an overall conclusion is provided. In line with the mixed methodology underpinning this thesis. No distinction between qualitative and quantitative findings is made; instead, both are understood as complimentary components supporting the realisation of the overall research aim.

7.1. Public perspectives on pharmacy provided mental health support

First, the results I obtained concerning public attitudes towards mental health support provided in pharmacies, as well as factors affecting individuals' stances, are discussed in light of the existing knowledge. Secondly, recommendations for future research and policy are provided.

7.1.1. Pharmacy users' attitudes towards mental health support provided in pharmacies

Quantitative (i.e. CPS 2019 and 2020) and qualitative data (i.e. semi-structured interviews with pharmacy users) laid the foundation for evaluating pharmacy users' attitudes towards pharmacy provided mental health support.

On average, pharmacy users' views were found to fluctuate between scepticism and moderate support for pharmacists' involvement in the provision of mental health support. For example, members of the public predominately disagreed with using pharmacy first when encountering a mental health issue but exhibited greater support for consulting community pharmacists as well as other HCP. Quantitatively, a number of person-specific characteristics were found to affect individuals' attitudes. For example, higher levels of trust in pharmacists resulted in more positive attitudes; the importance of trust for understanding pharmacy users' attitudes is discussed in more depth in section 7.1.3.

In the community pharmacy survey 2020 a self-reported diagnosis of depression and/or anxiety was found to result in more negative attitudes towards mental health support provided in pharmacies. Qualitatively, participants suggested a three-tier structure of potential roles for pharmacists in mental healthcare, and opinions on their involvement ranged from opposition to support for an expanded role.

Pharmacists as a point of contact and intermediary between pharmacy users and other HCP

In our study, pharmacy users exhibited reluctance towards the idea to utilise pharmacists first when encountering a mental health issue but were supportive of approaches that combine the expertise of multiple healthcare providers. Additionally, pharmacists were identified to be in an advantageous position to signpost individuals and conduct referrals. Therefore, our findings suggest that pharmacy users in England are supportive of a bridging role for pharmacists. Pharmacists are encouraged to act as a point of contact within a tight-knit network of primary healthcare providers to forge connections between patients and other HCP and provide advice and informational material.

These findings underpin the recommendations made by the RPS in the wake of the COVID-19 pandemic; signposting and referrals by pharmacists were seen as important contributions to tackling the mental health crisis.[44] Likewise, pharmacy users in this study endorsed the distribution of leaflets and brochures in pharmacies to provide information and advice for individuals who encounter mental health issues. The FIP actively encourages the promotion of mental health and wellbeing in pharmacies,[42] and in an Australian context, it has been demonstrated that there is broad public support for the approach.[54] In order to establish a bridging role for pharmacists, participants in our study considered a better linkage between pharmacists, the community they serve and other HCP a necessity. In Canada, the ‘More than Meds’ programme has demonstrated that the establishment of community networks is attainable and worth pursuing. ‘More than Meds’ pharmacists appreciated the introduction of new resources in their practice and long-lasting relationships within their communities were forged. All involved parties drew positive conclusions from their participation in ‘More than Meds’, and pharmacists’ practice behaviour appears to have undergone a transformation.[72,73,74]

In the context of community pharmacy practice in England, the necessary cornerstones for introducing a bridging role appear to be underdeveloped. For example, the RPS emphasised that missing referral pathways impede efforts to involve pharmacists’ more actively in the provision of mental health support.[44] Moreover, current initiatives focus on small-scale, training-intensive support programmes,[83,84] which, although important for the patient group they aim to serve (i.e. individuals with sub-threshold depression), might not be feasible to implement on a larger-scale. Instead, our results suggest that initiatives, which aim to embed pharmacy team members more effectively into existing care structures and establish them as a reliable source for mental health support and advice nation-wide, are required.

One way to position pharmacists’ as a point of contact for mental health support, is to capitalise on existing structures. The newly introduced community pharmacy consultation service (CPCS) may provide an ideal starting point. The CPCS aims to connect individuals with minor ailments who contact NHS 111 with community pharmacists, where they receive a consultation. Subsequently, pharmacists recommend suitable OTC-medicines and signpost or refer patients to other HCP.[32] It is plausible that a large-scale rollout of the CPCS stimulates the establishment of community networks and functioning referral pathways, which can be capitalised on independently from the CPCS.

An expansion of the CPCS to include individuals with mild symptoms of mental health conditions is imaginable. Following a referral from NHS 111, pharmacists could serve as an initial screening entity, supplemented by an analysis of individuals' purchasing patterns. Untargeted pharmacy provided screening services have been found to be successful but suffered from low participation and positive-screening rates. This is potentially problematic, given the time pressures pharmacists' experience in their practice.[78,79,80,82] Therefore, the introduction of a structured referral pathway from NHS 111 to pharmacists as an initial screening entity could increase the extent to which the approach is targeted to individuals who require support. Following a positive screen, pharmacists could signpost to mental health support groups, recommend self-help resources, or conduct referrals to primary or secondary care, akin to the current structure of the CPCS. However, the introduction of new, clinical services in community pharmacy practice requires a re-evaluation of the current remuneration model. At present, the main source of income for community pharmacies is the reimbursement for dispensing services, dependent on the number of prescriptions filled.[211] Thus, the introduction of new services, which reduce pharmacists time to fulfil this task may ultimately result in financial disadvantages. Therefore, pharmacists require remuneration for the provision of clinical services. For example, the CPCS is commissioned by NHS England and pharmacists receive a £14 fee per completed consultation.[212] It is unclear whether or not this fee adequately remunerates pharmacists for the time spent, especially if more time consuming activities, such as administering and evaluating mental health screenings are to be added to the service. Therefore, an extension of the CPCS would necessitate a re-evaluation of the current funding structure, to ensure pharmacists are reimbursed proportionately to the time they invest.

In general, the CPCS provides an ideal foundation for developing initiatives to establish pharmacists as a point of contact and intermediary between different HCP, and it is plausible that screening services, supplemented by a large-scale analysis of transactional data, could support such endeavours effectively. However, even less ambitious initiatives, such as establishing pharmacists as an information hub, could benefit individuals who are lacking a support network or struggle navigating the healthcare system.

Expanding pharmacists' role further

Although participants in our study were found to be moderately supportive of an intermediary role for pharmacists in mental health, a further expansion of pharmacists' role was met with greater reluctance.

Amongst others, the impression that pharmacists are unable to prescribe appeared to impact participants' considerations. However, since 2006, pharmacists are able to train to become independent prescribers and the cohort of MPharm students commencing their course in 2021 will be able to prescribe independently after registering.[213] In Scotland, independent prescribers are already at the core of a new service, introduced in 2020: 'NHS Pharmacy First Plus'. The scheme encourages individuals to utilise pharmacies for the assessment and treatment of common conditions, such as urinary tract infections or respiratory infections; participating pharmacies receive monthly remunerations for the provision of the service.[214] Hence, in the future, what is currently an exemption (i.e. independent prescribers in community pharmacy) will become the status quo, and the widespread introduction of independent prescribing is likely to have a profound impact on pharmacy practice and the healthcare landscape. As a result, clear visions for the future of the pharmacy workforce in general, and their role in mental healthcare specifically, are required. Inspiration may be taken from previously implemented community pharmacy services. For example, pharmacy-provided flu vaccination services and travel clinics are widely accepted and utilised. Individuals are however required to pay for some of these privately, despite NHS-provided alternatives being available.[215,216] Likewise, the establishment of private mental health and wellbeing clinics in pharmacies could be considered; run by specialised mental health pharmacists who are qualified independent prescribers. Moreover, a more holistic role for pharmacists in mental health care is thinkable. For example, the facilitation of support groups in pharmacies was endorsed by participants in this study and the implementation of mindfulness meditation courses has been successfully trialled in the US.[85]

In summary, pharmacy users are currently supportive of an intermediary role for pharmacists in mental health care, but hesitant to endorse a more significant extension. However, the ongoing expansion of pharmacists' professional remit is expected to have profound impacts on pharmacy practice and the healthcare landscape, prospectively. Therefore, policy makers should not be reluctant to embrace bold visions for pharmacy provided mental health support.

7.1.2. Factors impacting individuals' stances towards mental health support provided in pharmacies

The open-ended responses included in the questionnaire together with the semi-structured interviews conducted with pharmacy users allowed for further exploration of pharmacy users reasoning behind their stances towards mental health support provided in pharmacies. The factor 'trust' was found to play a fundamental role in individual's acceptance considerations; thus, trust is discussed separately in section 8.1.3. Additionally, pharmacy users identified a number of elements influencing their stances; these were categorised in advantages, barriers and facilitators.

In terms of advantages for the provision of mental healthcare, pharmacy users highlighted similar aspects to those which pharmacy is typically recognised for, i.e. ease of access due to ubiquitous distribution[18] and operation on a non-appointment-based system. These features were suggested to be particularly important for the provision of mental healthcare, as long-waiting times to obtain an appointment with other HCP appear to be commonplace. Again, this finding supports widespread pleas for a role for pharmacists as an intermediary between different healthcare providers, where advice to support one's mental health can be obtained, until an appointment with a specialised HCP is available.[42,43,44] However, it appears to be crucial for pharmacies to retain their current, non-appointment-based system, as it differentiates pharmacists from other primary healthcare providers.

On the other hand, a number of barriers to mental health service provision emerged from this study's findings. Similar to individuals with lived experiences of mental health issues, interview participants suggested that mental health-related stigma might impede the successful involvement of pharmacists in the provision of mental healthcare.[50,52] Therefore, this study adds to the existing knowledge by demonstrating that stigma is not only perceived as a barrier by individuals who already experience mental health issues, but also members of the public without any diagnosis. There have been attempts to investigate the extent to which pharmacists and support staff members hold stigmatising attitudes towards individuals with mental health issues, and the results appear to be generally encouraging.[57,58] However, during the introduction (1.4.4.1.1) I argued that these positive results might be partly attributable to self-selection and social desirability bias. Thus, it is plausible that stigmatising attitudes are still prevalent in pharmacies and affect practice behaviour. This notion is underpinned by the negative experiences of individuals with lived experiences of mental health issues in pharmacies, which are described in the literature.[50,52] Educational programmes, specifically developed for pharmacists and support staff members, have been found to reduce stigmatising attitudes, and simultaneously increased participants' confidence and skills to work with individuals who present with mental health conditions in pharmacies.[217] This web-based intervention was developed by pharmacy practice researchers in conjuction with other health professionals, such as psychiatrists and individuals with lived experiences with mental health issues. Narratives about journeys of recovery from indivduals with lived experiences were incorporated into the intervention as well as real-life scenarios, to increase participants' awareness of the challenges individuals with mental health issues face in a community pharmacy environment. Moreover, educational material about mental health conditions was provided, through power-point presentations narrated by mental health professionals. However, comparable initiatives are currently missing in England. This might be problematic given that pharmacists' competence and knowledge regarding mental health emerged as an additional aspect influencing participants' stances in this study. Pharmacy users indicated in both, narrative questionnaire responses and interviews that they consider pharmacists inadequately equipped for an expansion of their professional remit. Pharmacy professionals globally seem to support this notion, as similar concerns were expressed in a number of studies.[47,58,59,61,65,66] Moreover, comparative assessments revealed that pharmacists' practice behaviour with regards to mental health differs significantly from the pharmaceutical care they provide for individuals with physical health conditions.[56,59,60,61,63,64,65] As a consequence, most scholars recognise the need to implement more training opportunities to enhance pharmacists' existing skill set to meet the demands of pharmacy users better. Our study adds to this knowledge by demonstrating that members of the public share this perception and, by extension, that concerns over pharmacists' level of competence may prevent members of the public from approaching pharmacists for mental health support.

Training pharmacists, and support staff members, to become mental health first aiders may present a solution to close this apparent training gap which can be implemented on a large-scale. Mental health first aid (MHFA) is a training programme, initially developed for members of the public, to increase mental health literacy.[218] In essence, the course equips participants with the necessary skillset to recognise symptoms of mental distress and provides information on how to approach the individual in question and help him or her access resources, such as self-help books, support groups or specialised care.[219] Moreover, MHF-aiders are organised in national networks, which could encourage the development of interdisciplinary support structures and referral pathways, prospectively. Studies demonstrated that participation in a MHFA course can have positive effects on pharmacy students' mental health literacy and their attitudes towards mental health[220] as well as stigmatising attitudes.[221] As a result, MHFA courses specifically for pharmacy staff were developed and some pharmacy professional bodies, such as the Pharmacy Guild of Australia encourage participation.[222] In the UK, professional bodies do not currently endorse MHFA training, but calls to consider the inclusion of MHFA-training into the undergraduate curriculum are intensifying.[223] Experiences with other training programmes demonstrate that a large-scale implementation of novel training programmes in pharmacy practice is attainable and worthwhile. In the past, British community pharmacies successfully implemented the 'dementia friend' programme; the programme was developed to increase understanding of dementia and improve support for individuals living with the condition.[224] Currently, 80% of community pharmacy staff in patient facing roles are required to be trained as dementia friends.[224] Following a similar approach for mental health may be an idea worth considering. In turn, several benefits could emerge from active promotion of the training pharmacists and support staff members receive. First, public concerns regarding pharmacists' competence in mental health may lessen. Second, the approach may increase public awareness of services available in pharmacies, which was suggested to be an important facilitator for service uptake.

7.1.3. The nature and origins of trust in a community pharmacy context

The empirical literature reviewed for this research project indicated that a trusted relationship between pharmacist and pharmacy user is a pivotal requirement for the successful implementation of new services in community pharmacy practice.[34,36,37] Accordingly, the results presented in chapter four and five of this thesis indicate that trust is also a fundamental facet of individuals' considerations pertaining to pharmacy-provided mental health support. Trust between pharmacy users and pharmacists was found to be the strongest predictor of positive attitudes towards pharmacy-provided mental health support and trust between both parties appeared to mediate some persisting barriers, such as stigma. Thus, the nature and origins of trust in a pharmacy context warranted further analysis. The introduction of a brief scale allowed me to investigate predictors of trust in a pharmacy context quantitatively, and semi-structured interviews unearthed further information concerning pharmacy users' reasoning for developing trust in pharmacists. Firstly, person-specific characteristics, such as ethnicity and use of community pharmacy were found to correlate with different levels of trust. Secondly, setting-related factors appear to affect the establishment of trust. Lastly, aspects pertaining to the pharmacy team were found to affect the establishment of trust, such as the relationship between pharmacy user and pharmacy team member.

The finding that a relationship between pharmacy user and pharmacy team member supports the establishment of trust, is not surprising, given that trust has been conceptualised as inherently relational.[225,226] Consequently, the relational aspect of trust occurs to affect the establishment of trust in both, medical and pharmacy contexts. For example, higher willingness to return to a pharmacy for care has been positively correlated with trust in pharmacists[227,228] and continuity of care (i.e. experiencing a continuous relationship with a HCP[229]) has been suggested to foster trust between doctors and patients.[230] Likewise, in our study, users of the same pharmacy consistently exhibited higher levels of trust than those individuals who fluctuated in their choice of pharmacy. It is plausible, that individuals who opt to use the same pharmacy are more likely to encounter the same pharmacist or support staff member, therefore build rapport and consequently develop trust. However, due to the system in which community pharmacy in England operates, continuity of care may be more difficult to achieve, compared to other primary health care providers. For example, in England, registrations with one GP surgery are customary. Although registration does not guarantee encountering the same GP at each visit, it is plausible that it increases the likelihood to familiarise oneself with the GP team. In contrast, registration with a specific community pharmacy is not required in England, thereby potentially decreasing the likelihood to encounter the same pharmacist and build rapport.

Since the study results support previous findings indicating that continuity of care fosters the establishment of trust between pharmacy users and pharmacists, the introduction of policies that facilitate continuity should be considered. For example, obligatory registration with one pharmacy could be recommended. However, advocating for such policies partially contradicts the stance taken in the previous section. It was argued that maintaining accessibility is important, as it is a major advantage of community pharmacy over other HCP. Therefore, recommendations concerning policies about registration with pharmacies need to be carefully weighed against potential consequences (i.e. affecting accessibility). There are countries, such as the Netherlands, where registration with one pharmacy is obligatory. However, it does not appear that the introduction of this measure was subjected to empirical evaluation. Therefore, the extent to which this policy influenced the establishment of trust between pharmacy user and pharmacist, or affected accessibility, is unknown. Thus, the findings from this study provide preliminary evidence for a relationship between trust, use of the same pharmacy, and eventual acceptance of services provided in pharmacies. These interrelating factors require further scrutiny and warrants supplementary empirical investigation.

In addition to the statistical link between trust and use of the same pharmacy, pharmacy users suggested that the establishment of trust can be impacted by pharmacy users' ability to obtain access to pharmacists. That is, despite the reputation of the institution of *pharmacy* as an easy to access primary health care provider, it has been suggested that obtaining access to *pharmacists* can be challenging. This observation reinforces Austin and Gregory's conceptualisation of *accessibility* as a trust-enhancing factor in the community pharmacy context.[231] Moreover, previous research indicates that pharmacists can appear inaccessible to pharmacy users, due to dispensing duties and high workload,[36] and that opportunities for interaction and to build rapport frequently remain unused.[51] As a consequence, it should be considered to decrease pharmacists' workload with regards to tasks which result in inaccessibility of the pharmacist, such as preparing medications for dispensing. Instead, increasing the time pharmacists can spend in patient-facing roles should be a focal point of future policy.

The introduction of the hub and spoke (H&S) model in pharmacies may offer a solution to increase the time pharmacists are able to spend in patient-facing roles. The department for health and social care refers to H&S as:

> 'arrangements where a retail pharmacy, notionally at the end of a spoke, receives prescriptions, and sends them electronically to a remotely located hub, which in turn takes in prescriptions from multiple spokes. At the hub, medicines are selected, packaged and labelled and then transported back to the spoke to be checked by the pharmacist and collected by the patient'.[232]

It is expected that an adoption of the model enables pharmacists to spend more time in patient-facing roles, as the dispensing process becomes less time-consuming.[233]

Although a number of pilot projects have been carried out, the legislative framework for a widespread adoption of the H&S model was only passed recently (i.e. in February 2021). Therefore, the evidence concerning the impact of the H&S model on pharmacy practice, and pharmacists' accessibility, is limited. Hence, future research should investigate the extent to which H&S models stimulate a redistribution of pharmacists' time, and whether positive effects on pharmacy users' levels of trust, due to better accessibility, can be observed.

Additionally, these findings suggest that some pharmacy user-specific characteristics, such as ethnicity, gender and, to a lesser extent, age correlate with individuals' level of trust in pharmacists. Especially the introduction of the 'ethnicity' variable added considerably to the explanatory power of the model constructed on the grounds of the CPS 2020. Individuals who reported to be of non-white ethnicity exhibited significantly lower levels of trust; similar associations have been proposed with regards to ethnicity and trust in GPs in the UK.[234] This finding is hugely concerning given that lower levels of trust may result in refusal to use available services, which can affect health outcomes negatively. For example, COVID-19 vaccine coverage was found to vary considerably between ethnic groups; members of ethnic minority groups appear to be more hesitant to receive the vaccine, which could result in adverse health outcomes.[235] Vaccine hesitancy may be driven by a lack of trust, caused by structural discrimination, underrepresentation of minority groups in health research and disregard for cultural differences.[236] In a community pharmacy context, the association between ethnic background and service uptake has not been investigated comprehensively, and the available evidence appears ambiguous.[26] Considering that our findings suggest the existence of a negative association between non-white ethnicity and trust in pharmacists, more research focused on the relationship between trust, ethnicity and outcomes (e.g. service uptake), is needed, in order to identify and prevent health inequalities.

The survey data further suggests that individuals in older age groups exhibit lower levels of trust in pharmacists, compared to their younger counterparts. This contradicts the available evidence from medical contexts, research almost unanimously suggests that older patients display higher levels of trust in their doctors.[237] However, this finding is unsurprising, given that older pharmacy users in a study conducted by Gidman, Ward and McGregor[36] were found to be more likely to endorse traditional hierarchical structures within the healthcare system where GPs were considered superior to other members of the healthcare team. As a result, some individuals placed less trust in pharmacy-driven interventions and support mechanisms and questioned their usefulness. Similar considerations may underpin the findings from the CPS 2019 and 2020. That is, pharmacy users aged 65 to 79 may have been more likely to draw comparisons between pharmacists and GPs and consider GP-driven interventions as superior to those provided in pharmacies. A lack of awareness and enthusiasm amongst GPs concerning the services available in pharmacies may reinforce this attitude, as well as inadequate collaboration between both healthcare providers.[35] Therefore, there is a need for the pharmacy profession to position itself as complimentary to other primary healthcare providers, in order to counter comparisons and dissipate hierarchical thinking. Promotional campaigns, comparable to those promoting pharmacy first for minor ailment advice,[238] and enhanced collaboration between primary healthcare professionals could support this development. However, it is encouraging that negative attitudes occur to be less prevalent in younger age groups.

Lastly, the results from this study suggest that the pharmacy setting can affect the extent to which pharmacy users place trust in pharmacists. Quantitatively, the multilevel regression model demonstrated that participants' level of trust fluctuated significantly across the included study sites; pharmacy users' trust in pharmacists appeared to be lower in larger, retail-focused pharmacies. Interview participants reinforced the impression that the pharmacy setting affects the establishment of trust.

Likewise, Gregory and Austin[231] conceptualised the retail environment in which community pharmacy operates as a trust-diminishing factor. Moreover, it has been suggested that the commercial context of community pharmacy can be perceived as a conflict of interest; stakeholders, such as pharmacy users[36] and GPs[35] raised concerns over discrepancies between pharmacy's standing as a healthcare provider and apparent business interests. These perceptions were reiterated by the pharmacy users in our study and affect the establishment of trust adversely. Similarly, the lack of privacy in the community pharmacy environment has previously been described as a barrier to service provision in pharmacies in general[34] as well as to pharmacists' involvement in mental healthcare specifically.[49,52] The findings from this study support this notion; privacy and confidentiality appear to be fundamental requirements for the establishment of trust, and consequently, the acceptance of mental health support provided in pharmacies. However, pharmacy's nature as a public space may contradict the establishment of privacy. Participants in this study recalled incidents where pharmacy users were able to overhear conversations or recognised other visitors; these experiences have previously been found to adversely affect pharmacy users' recognition of pharmacy as a (mental) healthcare setting.[49,52,239] Likewise, the practice to call out patients' names during medicine pick-up has been criticised by participants in this study as well as in previously published literature.[49,239] On the other hand, the accessible public nature of pharmacy has consistently been identified as one of the major advantages of community pharmacy, and it is plausible that the practice of calling out patients' names helps to build rapport between both parties, which, as argued earlier, is a fundamental requirement for the establishment of trust. Thus, amending the public nature of community pharmacy in exchange for an increase of privacy (e.g. by adopting an appointment-based system or operating 'behind closed doors') requires careful consideration, as to avoid a negative impact on accessibility.

A more frequent use of consultation rooms (CR) may provide a solution to enhancing privacy in community pharmacies, while retaining pharmacy's status as easily accessible primary healthcare providers. In the UK, the majority of pharmacies have a CR, as they are a requirement for several advanced services.[240] CR provide a space for confidential conversations, secluded from the pharmacy's public area. They are required to be clearly labelled as such and spacious enough to accommodate two individuals. Therefore, CR may provide an ideal space for the provision of mental health support in pharmacies.[240] However, in this study, participants recalled negative experiences with consultation rooms, predominately due to their small size or reported to be unaware of their existence. Research in Australia further indicates that an invitation to use a CR can cause pharmacy users to feel singled out, [239] which may be particularly problematic with regards to mental health conditions, due to the stigma surrounding them.[49] Although pharmacy users in our study did not display any overt reluctance to utilise a CR, they did not consider them an ideal space for the provision of mental health support. This might be attributable to the fact that CRs were primarily installed with legal requirements in mind, instead of aiming to create an inviting, confidence- and trust-instilling healthcare space.[241] In general, it appears that the pharmacy environment has not been subjected to the same innovative ambition which has induced the metamorphosis of pharmacists' role in England over the last decade. Therefore, the ongoing modernisation of pharmacists' role necessitates a reassessment of the traditional pharmacy environment, to create a trust-inspiring work environment. For example, prospective spoke pharmacies offer opportunities to develop models for repurposing the space previously needed for the dispensary. Overall, the impact of the pharmacy environment on the development of trust between pharmacist and pharmacy user needs to be subjected to closer scrutiny, as the relationship between both might affect service uptake prospectively.

The goal should be to create an environment that reflects and supports the ambitions of a modern, well-versed workforce.

7.1.4. Strengths and limitations

This study is the first of its kind to comprehensively describe and explore the attitudes of English community pharmacy users towards mental health support provided in pharmacies. Two surveys were distributed (i.e. the CPS 2019 and CPS 2020); large sample sizes were obtained in both years, n=3449 and n=1474, respectively. In 2020, a qualitative research phase succeeded the survey. Therefore, an in-depth evaluation of the views of a large cohort of community pharmacy users is provided, by combining numerical and narrative data, evidently, a strength of this research project. However, the limitations of this study require attention, to contextualise the obtained results.

Study sites

First, only pharmacies of one specific chain of pharmacies were included in this study and the study sites were exclusively located in the English region of the East Midlands. Thus, the results might not be generalizable to pharmacy users in England in general. To address this issue, a variety of pharmacy models were purposefully included (e.g. large retail-focused pharmacies, small health-focused pharmacies) in the sample, which was controlled for in terms of the effect of the setting on individuals' opinions by constructing a multilevel model. However, in both years, the number of included study sites was small (i.e. 12 and 15, respectively). Some scholars recommend a minimum of 20 study sites to perform a multilevel analysis,[186] others advocate for the data structure as the decisive element.[189] The advice of the latter was adopted for this study, guided by the exploratory nature of the survey and the fact that the hierarchical structure of the data restricted the application of traditional, linear regression models.[186] However, the validity of the findings would have benefitted greatly from an inclusion of additional study sites. Moreover, no level two variables, such as store size, prescription volume or pharmacist-to-customer ratio were included in the constructed model, although it is plausible that these variables affect pharmacy users' attitudes. Therefore, future research should consider the inclusion of more study sites as well as level two variables.

Response rates, item response vs. non-response

The surveys reached satisfactory response rates in both years, which is thought to have positive effects on the generalisability of the results to the target population.[165] Further, responders and non-responders were comparable in terms of gender and across the majority of age groups. However, middle-aged pharmacy users appeared to be more likely to decline response and the surveys were distributed exclusively during working days and hours (i.e. Monday to Friday, 9am to 5pm). Therefore, the sample appears to be broadly representative of the cohort of pharmacy users accessible to participate. However, working adults might be under-represented, due to the chosen time to administer the survey and a higher likelihood to decline response.

Statistically significant differences between item responders and non-responders were determined for several variables, such as use of pharmacies and frequency of pharmacy visits in 2019 and eligibility to receive free prescriptions in 2020. Although statistically significant, the differences might be attributable to the large sample size, as they were small in absolute magnitude. Thus, item responders and non-responders are broadly comparable; thereby further increasing the applicability of the obtained results for the accessible pharmacy user population.

Methodological biases

As outlined previously (2.4.1- 2.4.2), choices pertaining to data collection and analysis can affect the quality of the obtained narrative and numerical data; the introduction of biases, such as social-desirability bias or self-selection bias, is possible. The following section discusses possible biases and how they were mitigated.

First, the survey administrators approached pharmacies at random and interest in the topic did not determine participation. Therefore, the introduction of self-selection bias might have been mediated; it is unlikely that the sample encompassed a notably large number of individuals with strong opinions about the topic. On the other hand, conducting the survey in the pharmacy environment and adopting an interviewer-assisted format might have increased participants' tendency to provide socially acceptable responses (i.e. social desirability bias). Therefore, it is plausible that the obtained responses are marginally more positive than the responses we could have obtained through unassisted survey administration in a neutral environment. However, some statements captured unfavourable attitudes towards pharmacy provided mental health support. Thus, survey participants' inclination to provide socially acceptable responses appears to have been absent in some cases. Additionally, choosing to administer the survey in the open pharmacy environment might have decreased participants' likelihood to discuss sensitive issues in the open-ended response section of the questionnaires, such as mental health stigma. Generally, the open-ended responses were often brief and lacked context. Thus, responses were interpreted with caution and their ambiguity acknowledged. For the purpose of analysis, ambiguous responses were coded in every applicable category. Consequently, the vagueness of the obtained open-ended responses provided an additional rational for conceptualising a qualitative research phase, in order to provide an in-depth understanding of individuals' stances.

Lastly, the CPS 2019 failed to consider some relevant participant characteristics. For example, it has been suggested that a correlation between ethnic background and individuals' level of trust in healthcare providers exists, and personal history with mental health issues has been found to influence individuals' opinion towards pharmacy's involvement in mental healthcare. Hence, I decided to add these variables in the CPS 2020, indeed, they added significantly to the explanatory power of the constructed models. Therefore, the CPS 2019 provided some preliminary insights to pharmacy users' attitudes towards mental health support provided in pharmacies. The CPS 2020 confirmed and extended the obtained findings, and some of the limitations of the CPS 2019 were addressed, such as the omitting of important variables. However, some methodological problems, such as the introduction of bias due to the mode of questionnaire administration, persisted.

Qualitative research

A qualitative research phase was conceptualised to succeed the CPS 2020. The semi-structured interviews were conducted with a convenience sample of some survey participants and additionally sampled members of the public; convenience sampling might have introduced a recruitment bias towards individuals who were more motivated to share their opinion or held particularly strong views towards the topic under investigation. Furthermore, only few inclusion and exclusion criteria were adopted for the qualitative phase of this research project, in order to investigate the views of a diverse sample of pharmacy users and members of the public. As a result, only a limited number of participants in our study had been exposed to pharmacy-provided services beyond the provision of prescriptions and advice for minor ailments. Therefore, participants might have expressed more scepticism towards a role expansion for pharmacists in the area of mental health compared to individuals who are more familiar with pharmacy-provided services. Due to difficulties recruiting participants for the qualitative part of the study, the number of interview participants was lower than anticipated before the study commenced. As described in section 2.5.2.7, some scholars in qualitative research advocate for *data saturation* as a criterion for ceasing the recruitment of additional participants. However, in the case of this study, individuals' willingness to participate appeared to be the limiting factor for data acquisition, instead of reaching a point in the data collection process in which no new topics are being discussed. Therefore, it is unclear whether data saturation has been achieved. Instead it is plausible, that futher interviews would have unearthed additional themes. Hence, it should be taken into consideration to investigate the topic further using qualitative methods.

All interviews were conducted using the same semi-structured interview guide, to cover all topics of interest consistently. In order to minimise my own influence on the obtained data (i.e. interviewer bias) I opted to introduce myself as a research student, instead of disclosing my occupation as a pharmacist. To reflect on my own role during the data collection and analysis process, I took notes during the interviews and during the data analysis. Retrospectively, some interviews might have benefitted from a more courageous use of prompting questions, but apparent power imbalances prevented me from being more persistent in my quest for clarification.

Moreover, it is possible, that my education and occupation as a pharmacist inherently influenced the analysis and interpretation of the obtained narrative data. It cannot be assumed that I was able to detach myself entirely from this background knowledge, and the experiences I had made, to provide an unbiased interpretation of the data. Instead, my personal lens will have influenced my analysis. For example, more often than not did I view myself as the pharmacist in a situation that was described by interview participants and wondered how I would have reacted. Therefore, despite my efforts, the provision of a neutral and unbiased interpretation of the data was not attainable. Instead, the presented data should be understood with this backround in mind.

COVID-19

Lastly, the data are inherently influenced by the circumstances under which they were collected, i.e. the outbreak of COVID-19. The survey had to be terminated prematurely due to the commencing of the first lockdown in England and the interviews were conducted in times where measures to contain the spread of the disease were subject to immense fluctuations. Thus, the presented results and their subsequent discussion should be interpreted with this specific background in mind.

7.2. Public attitudes towards utilising loyalty card data to identify individuals at risk of developing certain health conditions

In the introduction, it was argued that loyalty card data could be a valuable data source for the provision of mental health support in pharmacies, as there is evidence that the collected data can be indicative of the health of the cardholder. However, there is a lack of empirical literature pertaining to loyalty card usage in the general population as well as individuals' attitudes towards the use of these data in the context of health research, and specifically, community pharmacy practice. To address this paucity of knowledge, three additional research objectives were conceptualised (1.7.7); chapter 5 and 6 reported the results that emerged from this research stream. In the following section, the key findings in relation to the existing knowledge in this field are discussed and highlight the contributions of this study to the growing field of scientific inquiry.

7.2.1. Practical considerations pertaining to the use of loyalty card data in health research

Two surveys were distributed in two different population groups, i.e. students and pharmacy users, in order to evaluate loyalty card use (or non-use) and related demographic characteristics.

In both cohorts, a significant number of individuals reported to subscribe to loyalty schemes; in particular, nine-in-ten students and six-in-ten pharmacy users reported to own at least one loyalty card. In comparison, in a non-representative poll conducted in the UK in 2017, 77% of participants reported to use at least one loyalty card.[94] It is plausible, that students are more likely to engage with loyalty schemes, because some loyalty card providers offer student specific discounts (e.g. Boots UK[242]). Contrarily, it appears that pharmacy users are less likely to engage with loyalty schemes compared to the general adult population in the UK. Age differences between both cohorts might have contributed to this observation. For example, a Finish study found older adults to be less likely to engage with loyalty schemes.[96] Our data does not support this finding; no significant differences in loyalty card ownership between age groups were identified. However, this might be attributable to the decision to create an age band that encompasses everyone aged 65 or older, due to low participation rates. Indeed, our sample encompassed more individuals over the age of 50 years compared to the general adult population in 2020,[243] but a conclusive determination of the importance of age differences on the observed discrepancies in loyalty card ownership is not attainable. Other factors, such as local differences need to be considered.

Irrespective of the population group, individuals reported to be most likely to subscribe to loyalty schemes provided by health and beauty retailers, closely followed by grocery store loyalty schemes. Two aspects might drive this observation. First, as indicated above, a UK-based health and beauty retailer provides student-specific discounts. Second, the survey was conducted in one chain of community pharmacies, which offers a health and beauty loyalty scheme. Therefore, regular customers of this chain, and in turn, loyalty card owners might have been more likely to participate in this survey. Both, female students and female pharmacy users reported to be more likely to subscribe to loyalty schemes. This aligns with findings reported by other scholars.[94,96] In this study, gender differences were particularly prevalent for health and beauty loyalty schemes. These findings might be driven by the nature of the products sold by those retailers, and gender-specific marketing.

Interestingly, we found that, compared to loyalty cards provided by grocery stores, individuals in both studies were less likely to use loyalty cards provided by health and beauty retailers jointly. The sharing of loyalty cards has, to date, not been investigated comprehensively in empirical studies. Our data suggest that purchases recorded on health and beauty loyalty cards are more likely to be person-specific, which could have important implications for the accuracy of the predictions made from loyalty card data. However, this quantitative finding was opposed by comments made by students and pharmacy users in the semi-structured interviews. In both cohorts, concerns over the accuracy of loyalty card data emerged, rooted in the expectation that the sharing of loyalty cards is common practice. Therefore, further research evaluating the prevalence of loyalty card sharing in the general population is needed. Moreover, mechanisms, which prevent individuals from using their cards jointly, should be developed and promoted. For example, it could be considered to actively advertise health and beauty loyalty cards as ‘well-being cards’, which track and analyse individuals’ health-related purchases, such as vitamins or OTC-medicines. Consequently, less loyalty card users could be inclined to share their cards. However, it is currently unclear whether this approach would have the desired effect.

In summary, loyalty card data, and especially health and beauty loyalty cards appear to contain valuable information for health research, as the purchasing habits of a large proportion of the general population are recorded. However, certain aspects, such as an uneven gender distribution and the possibility of joint usage need to be taken into consideration, if loyalty card data is to be added to the repertoire of information which health research capitalises on.

7.2.2. Individuals' perspectives on utilisation of transactional data in the context of health research

In addition to investigating loyalty card use and related aspects in different population groups, pharmacy users' and students' attitudes towards the use of loyalty card data for health research was also evaluated, as well as which factors influence acceptance considerations of both population groups.

7.2.2.1. Attitudes towards the use of loyalty card data for health research and factors affecting their stances

Initially, surveys which measured individuals' opinions quantitatively were distributed. Secondly, semi-structured interviews to explore students' and pharmacy users' reasoning behind their expressed stances were conducted.

55.5% of students supported the utilisation of aggregate-level loyalty card data in health research and 45.4% of pharmacy users endorsed the approach. In both cohorts, the application of aggregate-level loyalty card data to investigate the health status of the general population was preferred over the utilisation of loyalty card data to identify individuals specifically. Goulding and Skatova reported that 54% of their survey participants were willing to donate transactional data for research.[148] Given that their cohort predominately encompassed students, the results obtained in this cohort are comparable. However, Skatova and Goulding did not distinguish between aggregate-level and individual-level data. Thus, these results add to the existing knowledge that public acceptance towards the utilisation of transactional data is influenced by the level of abstraction of the data; the utilisation of more granular data appears to evoke scepticism more frequently. On the other hand, the different terminologies that were adopted (i.e. data *donation* versus data *sharing*) appear to have influenced individuals' attitudes only marginally. Additionally, only small differences between pharmacy users' and students' support for the use of loyalty card data to identify mental health conditions, compared to physical health conditions, were identified. Unfortunately, Skatova and Goulding did not differentiate between the utilisation of loyalty card data for different health conditions.[148] Therefore, these results are the first to indicate that public acceptance is generally independent from the type of health condition one is looking to investigate based on transactional data.

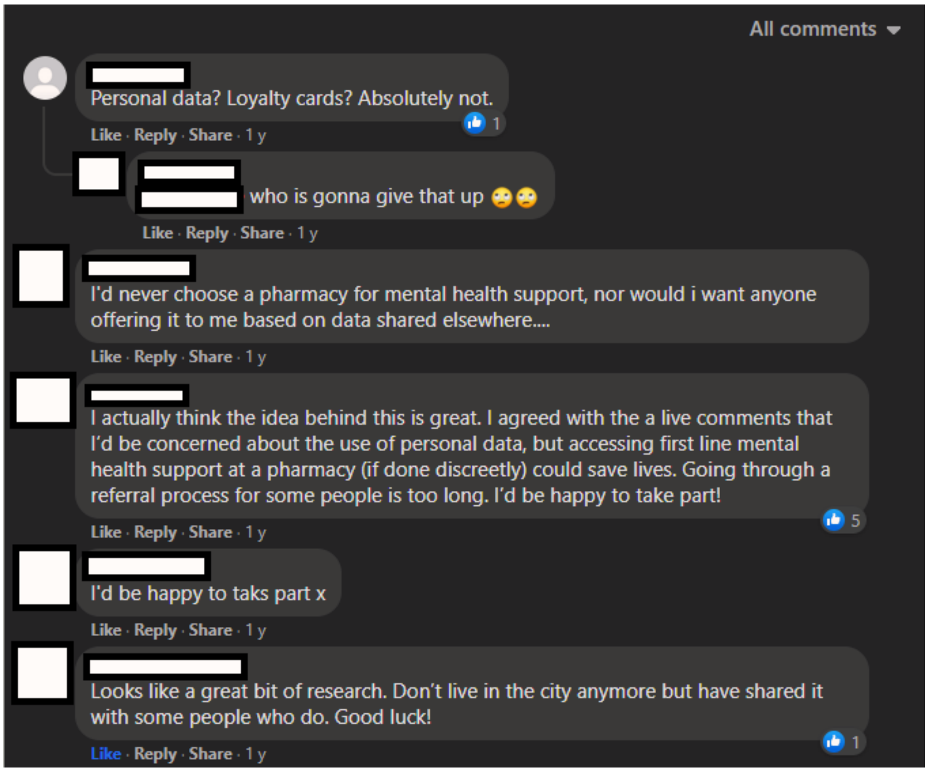
Transactional data in comparison to other types of personal data

Owing to the limited amount of empirical data pertaining to individuals' attitudes towards utilisation of purchasing data for health research purposes, acceptance rates for different types of personal data of interest for health research were compared. The majority of students and pharmacy users suggested that healthcare data and, to a lesser extent, lifestyle data, can be used for health research purposes. On the other hand, the use of location data was generally opposed in both cohorts. The hierarchy between data types established by participants in this study mirrors those reported by other scholars.[139] Differences in how sensitive data is perceived to be, could serve as an explanation for the observed hierarchical structure. That is, more accurate and detailed inferences about a person’s life carry a higher sensitivity for the data producer and are therefore less likely to be shared. For example, the participants suggested that the act of going shopping is considered to be public; therefore, the data is low in sensitivity, which positively influences their willingness to share. Likewise, it has been suggested that lifestyle data, as recorded on wearables, are low in sensitivity, which increased willingness to share these data.[144] However, this explanation does not hold for health-related data, which, despite carrying significant sensitivity,[144] ranks consistently high in comparative assessments.[139] It is plausible, that the explicit health-relatedness of these data influences individuals’ thought-process, that is, a clear association between the sharing of health-data and individual- or population health can be established. Consequently, individuals’ inclination to share these might be higher.

Thus, data sensitivity and straightforwardness of the association between data type and health might attribute to individuals’ acceptance-consideration. This should be considered in future research and policymaking, as the sharing and utilisation of data types with higher sensitivity, such as location data is less likely to be endorsed.

Methodological observations

Qualitatively, participants appeared to exhibit greater support for the use of transactional data for research purposes compared to what would have been expected from the quantitative results. Only one individual persisted to oppose the approach throughout the entire interviews. The observation that participants in qualitative studies exhibit higher acceptance rates also emerged as a key finding from my literature review (1.7.2). For example, the majority of participants in qualitative studies endorsed the use of social media data,[134,137] lifestyle data[144] and location data[145,146] for research purposes. The identified discrepancies between individuals' acceptance rates in qualitative and quantitative research studies, raises questions concerning the origins of these differences. First, it is plausible that individuals who held views that are more positive were more likely to agree to be interviewed (*self-selection bias*). In this case, it is likely, that self-selection bias has affected the results obtained. For example, recruitment for the interviews with pharmacy users proved to be difficult; therefore, the study was promoted on Facebook. Engagement rates were high, and a number of individuals commented on the postings (Figure 7-1). However, individuals who exhibited negative opinions towards the topic refused to be interviewed, despite several, personal invitations. Similar mechanisms could underpin the positive results obtained in other qualitative studies, i.e. individuals with strong negative views were not included in the study or deliberately refused to share their opinion. Consequently, techniques to mobilise those individuals with negative opinions to participate in research need to be developed. For example, the comments obtained indicate that conducting group discussions on social media platforms can present a fruitful alternative to face-to-face interviews.



[redacted]
Personal data? Loyalty cards? Absolutely not.

[redacted] [redacted] who is gonna give that up 😩😩

[redacted] [redacted]
I'd never choose a pharmacy for mental health support, nor would i want anyone offering it to me based on data shared elsewhere....

[redacted] [redacted]
I actually think the idea behind this is great. I agreed with the a live comments that I'd be concerned about the use of personal data, but accessing first line mental health support at a pharmacy (if done discreetly) could save lives. Going through a referral process for some people is too long. I'd be happy to take part!

[redacted] [redacted]
I'd be happy to taks part x

[redacted] [redacted]
Looks like a great bit of research. Don't live in the city anymore but have shared it with some people who do. Good luck!

Figure 7- 1 Facebook comments

Secondly, it is plausible that exposure to research utilising transactional data influenced individuals' opinion towards the topic. That is, their *understanding* of how loyalty card data could be used in the context of health research was enhanced, which had positive effects on the observed acceptance rates. This is particularly interesting given that understanding has been previously determined as a pivotal factor in individuals' thought-process, such as towards the utilisation of location data[145,146] and transactional data[148,149] in a health research context. Thus, exposing pharmacy users and students to recent research utilising loyalty card data might have had a positive effect on their expressed opinions. However, in this case, the baseline attitudes of interview participants were not measured, therefore, a quantification of the observed effect is not possible.

7.2.2.2. Factors impacting individuals' stances towards the use of loyalty card data in health research

The previous section discussed pharmacy users' and students' attitudes towards the use of transactional data in health research generally and in relation to other types of personal data, such as location- and social media data. Secondly, on the grounds of observed differences in acceptance rates between qualitative and quantitative research participants, 'understanding' was discussed as an important aspect for explaining individuals' stances towards the use of transactional data. Additionally, the narrative data collected for this thesis allowed the exploration of factors affecting individuals' stances in more depth; a detailed discussion is provided in the following section.

Person-specific factors

First, factors pertaining to the loyalty card user themselves appeared to influence individuals' viewpoints. Both, students and pharmacy users indicted that their education as well as professional appointments, and therefore, the level to which they understand the importance of utilising data, influenced their stances. This finding supports the notion that understanding is an important factor in individuals' acceptance considerations, as discussed previously in several other studies.[148,149] It is plausible that students, on average, are educated to a higher level and more familiar with data-rich environments than average pharmacy users, which might have attributed to the differences in willingness to share transactional data we observed in both cohorts. Additionally, Goulding and Skatova found age to be associated with individuals' willingness to donate data.[148] Likewise, pharmacy users in our study recognised age and, consequently, familiarity with novel technologies, as important aspects. Quantitatively, an investigation of the association between age and expressed attitudes was, due to the outlined problems with the data set (6.1.2), not possible. Further, the data suggest that both, previous positive and negative experiences can influence individuals' stances. Considering that experiences are accumulated with increasing age, it is possible that older individuals had a great wealth of negative experiences, which resulted in greater scepticism. However, in our study, some students recalled incidents that negatively affected their relationship with data; therefore, the link between experience and age does not appear to be linear.

Therefore, individuals' willingness to share transactional data was found to be influenced by a multitude of person-specific factors. Additionally, evidence for the influence of personality traits on willingness to donate data can be found in the published literature.[148] Consequently, '*a-one-size-fits-all*'-approach to understanding individuals' willingness to share transactional data appears to be difficult to achieve; instead, a multifactorial model, which includes personality, experiences, education and other demographic variables should underpin future quantitative inquiry.

The data user

Students and pharmacy users indicated that aspects pertaining to the prospective data user (i.e. loyalty scheme provider) influence their willingness to share personal data, e.g. responsibility and ethical considerations. Interestingly, responsibility has been discussed in several other studies, especially in relation to the use of social media for research purposes.[133,134] Most commonly, the data producers (i.e. social media users) were held responsible for amending their privacy settings, in order to restrict the use of their data for research purposes. In contrast, some participants in our study delegated the responsibility for the tracking and analysing of loyalty card data to pharmacists, especially if OTC-medicine purchases are under investigation. The motives for this contrasting understanding of responsibility might be rooted in the nature and origins of the data itself. That is, a link between purchases of OTC-medicines and vitamins and an individuals' health status is quick to establish, and pharmacists are regarded as experts of medication and responsible for the sale of OTC-medicines. Hence, delegating responsibility for the analysis of OTC-medicines to those who are experts in medication appears logical. This study is the first one to indicate, that, by virtue of the involvement of health professionals, individuals are inclined to forfeit responsibility for their data. In contrast, the utilisation of transactional data by large companies evoked greater scepticism. Likewise, in previous research, it has been suggested that greater willingness to share personal data is exhibited if prospective data users are driven by altruistic motives; the use of health-related personal data to generate company profit was rejected.[137,140] Therefore, the perceived motivation of the prospective data user appears to influence individuals' acceptance considerations.

Assuming that members of the public consider pharmacists actions to be underpinned by altruistic motives, this could explain pharmacy users' and students' willingness to entrust them with their data.

Further, our results suggest that concerns over company ethics can be mediated by trust in the prospective data user. This aligns with findings from the majority of studies I reviewed; the importance of a trusted relationship for obtaining public acceptance emerged consistently, and irrespective of the type of personal data under investigation.[144,145,146,149] Moreover, it has been hypothesised that a lack of public trust attributed to the failure of the care.data programme.[114] Consequently, these results have attracted the attention of policy-makers; mechanisms to support the development of trust between data provider and data user are a focal point of policy papers pertaining to the utilisation of data to support health systems and research.[131] For example, the establishment of trusted research environments (TRE) is recommended,[131] and a standard for algorithmic transparency is available.[244] The Opensafely project has demonstrated that the establishment of such environments is feasible,[245] and that it can facilitate the rapid analysis of large-scale data sets, which had important implications for acquiring knowledge about COVID-19.[235,246,247] Therefore, the potential utilisation of transactional data in a health research environment should be underpinned by efforts to increase public trust in such endeavours. Two approaches to fostering trust were identified. First, the presence of altruistic motives. Thus, the active involvement of HCP, such as pharmacists may convince data providers of the benevolence of digital- and data-driven technologies in healthcare. Second, establishing TRE should become the gold standard, if the analysis of personal data on a large scale is sought after.

7.2.2.3. Benefits and risks

The potential benefits and risks emerging from utilisation of transactional data in the realm of healthcare were an additional aspect discussed by students as well as pharmacy users in our study. Moreover, some participants attempted to weigh between both aspects, in order to reach a conclusion concerning their opinion about an extended use of these data. Likewise, a discussion of the potential benefits and risks of the utilisation of personal data in the realm of healthcare emerged in the majority of studies reviewed for this thesis, irrespective of the nature of the study or type of data under investigation (1.7.2).

Concerns

On the grounds of the literature reviewed for this thesis, it is posited that, irrespective of the type of data, their utilisation evokes similar concerns in individuals. The empirical data obtained for this study supports this notion; students and pharmacy users raised similar concerns over the use of transactional data for research purposes to those known from the literature (1.7.3-1.7.5).

Exemplarily, concerns over privacy intrusion and an undesired secondary use of data (e.g. to gain financial profit), have been voiced in the case of location data,[145,146] social media data,[133] and lifestyle data[144] as well as in this study. Likewise, the extent to which personal data is able to provide an accurate depiction of behaviour patterns or one's health status emerged as a concern in reviewed several studies.[134,137,140] Again, this concern was mirrored by participants in both study cohorts, in particular with regards to the multitude of loyalty schemes that are available and the possibility of joint card usage.

The knowledge that public concerns pertaining to utilisation of personal data in health are similar, irrespective of the data type under investigation could be crucial for both, researchers and policy makers. That is, it paves the way for the development of a universally applicable framework, which could ease the inevitable introduction of new types of personal data into the realm of healthcare, prospectively. Therefore, domain-overarching research, especially reviews are needed, to amalgamate the scattered knowledge and identify underlying patterns, akin to efforts in artificial intelligence.[248] Otherwise, it is possible that the rapidly evolving digital health landscape outpaces scientific inquiry.

Contrarily, the appropriateness of using personal data to monitor or identify mental health conditions has been less frequently a topic of inquiry. However, some studies focusing on utilisation of social media data, examined concerns related to mental health specifically. Most prevalently, concerns over stigmatisation[134,136] and a lack of established infrastructure to support individuals with mental health issues were raised.[135] The results from this study mirror these concerns, but some students were adamant to emphasise that the prevalence of stigmatising attitudes is negligible in their age group.

However, participants also anticipated additional negative consequences, caused by the monitoring and analysis of individuals' purchasing behaviour. Awareness of being observed or a subsequent confrontation with the results was feared to cause distress or trigger a deterioration of one's mental health, especially for individuals with an existing diagnosis or those who, until then, were oblivious to potential symptoms. A discussion of potential consequences of the analysis of personal data for individuals without a diagnosis is currently missing in the literature, due to the majority of research studies focusing on individuals with an existing diagnosis of depression or anxiety. Therefore, this study is the first one to introduce potential consequences for undiagnosed members of the public. Prospectively, studies related to mental health should pursue this path and include undiagnosed members of the public more actively, as their insights are a valuable addition to the existing knowledge and increases researchers and policy makers understanding of the risks attached to the tracking and analysing of personal data on a large scale.

Benefits

In the previous section, it was demonstrated that the results support the premise formulated on the grounds of the literature review. That is, irrespective of the type of data, individuals raise similar concerns about its utilisation. However, this study identified additional mental health-related concerns. This observation holds when examining the potential benefits individuals expect to emerge from an extended utilisation of personal data. That is, supporting the greater good (i.e. helping improve the health and wellbeing of others through data sharing) has been recognised as a persuasive argument for an extended utilisation of social media data,[134,136] lifestyle data,[143] and location data.[145,146] Likewise, Skatova and Goulding identified social duty as the strongest predictor for willingness to donate data, i.e. considering helping others a social responsibility increased willingness to do so.[148]

Similarly, pharmacy users' and students' willingness to share data was influenced by the possibility to support the greater good, that is, to aid the health of individuals and the population. Again, this finding can be understood as an incentive for more domain-overarching research, in order to identify data type-independent themes.

Additionally, participants were optimistic that the proposed approach could be useful to 'nudge' individuals into receiving healthcare, especially if they were struggling to navigate the healthcare system or missing a support network. This expected benefit is particularly interesting with respect to the background of this study, that is, to enhance mental health support provided by community pharmacies in England. It is plausible that the decision to purchase mental health-related medication in pharmacies is rooted in the absence of a support network, difficulty navigating the healthcare system or are unwillingness to engage with other available support. Therefore, through effective utilisation of the information recorded on loyalty cards, pharmacists could be in a unique position to offer support those pharmacy users. Therefore, future research aiming to link purchasing patterns and the onset of certain health conditions should be complemented by qualitative inquiry, in order to understand the origins of the observed patterns. Again, this calls for pharmacy practice researchers and policy makers to realise the opportunities loyalty card data have to offer for modernising and advancing the profession further.

7.2.3. The susceptibility of public attitudes to the social context

This study was conducted amidst the outbreak of COVID-19, therefore the change of the social context and its impact on individuals' opinion requires consideration. Quantitatively, individuals' attitudes towards sharing their personal data and mandatory data sharing to support the detection of disease epidemics remained largely consistent throughout the study period. However, qualitatively both, students and pharmacy users indicated that the outbreak of the disease convinced them to reflect on their attitudes and at times, alter their opinion.

Previous research, which coincided with events that have the ability to alter attitudes, support this premise. For example, the Cambridge Analytica Scandal has been found to increase scepticism towards data sharing and reinforce individuals desire to protect their data.[146]

In terms of the effect COVID-19 had on individuals' opinion towards sharing their personal data, evidence has only started to emerge. In a longitudinal study of a government institution, it appeared that individuals' attitudes remained largely consistent over the six-month study period, despite a 54% increase of media coverage concerning digital health from February 2019 to February 2020.[130] However, qualitatively it has been reported that COVID-19 had a moderating effect on individuals' attitudes.[151] Thus, similar to these results, there is evidence in the literature that the effect of the outbreak of COVID-19 on individuals' attitudes was more noticeable in qualitative inquiry; three possible explanations for these results shall be discussed here.

First, study methodology could attribute to the observed differences. That is, attempts to quantify fluctuations in individuals' attitudes were unsuccessful because baseline values were missing, or because the study period was too short to determine differences. In this case, the student survey was terminated shortly before the impact of COVID-19 on society unravelled, and the survey distributed in community pharmacies was terminated after a two-week study period, shortly before the first national lockdown in the UK. Secondly, it is plausible that individuals' attitudes did not change in their absolute magnitude, but that COVID-19 affected individuals' perception of the topic; subsequently, those were recognised in qualitative inquiry. Thirdly, it is possible that participants in qualitative studies were more inclined to inflate the extent to which their opinion changed, whereas, in absolute numbers, their attitudes had remained consistent.

Generally, without knowledge of individuals' baseline attitudes, it is difficult to put the quantitative results in context; therefore, it is difficult to justify the consistency of attitudes that have been observed in this study and the CDEI's survey.[130] Contrarily, qualitative inquiry provided insights into individuals' thought-process and COVID-19 has been vividly described as an event with significant effect on their stances.

Changes to the societal context are important to consider and require recognition when aiming to understand (un-)willingness to share data. Thus, careful observation and mapping of the current media landscape are important aspects of an evaluation of public attitudes towards data sharing. It is advisable to provide an overview of the societal circumstances, to contextualise the obtained findings. Moreover, a longitudinal study that investigates individuals' attitudes qualitatively and quantitatively, alongside a sociological assessment of the external circumstances, might be warranted, in order to acquire deeper knowledge of the fluctuations individuals' opinions are subjected to and why.

7.3. Strengths and limitations

In the previous section, the results obtained from the second data stream of this research project were discussed in light of the existing knowledge. Accordingly, a discussion of the strength and weaknesses of the methodological approach chosen to acquire the data is warranted. Two surveys were distributed and both were succeeded by a qualitative research phase. First, the views of students were evaluated through distribution of an online questionnaire; semi-structured interviews with some survey participants followed. Second, the views of pharmacy users were mapped. For that purpose, questions were included in the community pharmacy survey 2020. The narrative data were collected by means of semi-structured interviews; those were embedded in the conversations I had with pharmacy users about pharmacy provided mental health support.

7.3.1. Student cohort

The survey was distributed across the University using a multitude of dissemination pathways; the obtained sample size exceeded the recommended sample size. However, randomisation did not occur and the obtained sample was found to differ from the student body at the University of Nottingham in several characteristics, including gender- and age distribution. Thus, the generalizability of the results to the overall student body is limited. Further, the chosen mode of survey dissemination might have introduced a self-selection bias, as individuals who held particularly strong views or had an interest in the topic might have been more inclined to participate. I intended to decrease self-selection bias by approaching students randomly on campus on a number of occasions. Consequently, the introduction of a self-selection bias could also have permeated into the qualitative research phase, as the survey served as the sole recruitment tool. Next, in the survey, students were asked to report the number of loyalty cards they are currently using; this information might be subjected to recall bias. However, the online format of the survey allowed participants to complete the questionnaire at a time and location convenient to them. Thus, participants were given the opportunity to verify the requested information. Similarly, the online format facilitated anonymous survey participation, which might have increased students' willingness to disclose struggles with mental health and wellbeing and mitigated the desire to provide socially acceptable responses.

Qualitative data

Initially, focus groups were planned with qualitative research participants; section 2.5.2.3 outlines the rationale behind this approach. However, due to the outbreak of COVID-19, the focus groups could not be held as planned and interviews were conducted instead. The lack of group interaction might have affected the nature and richness of the obtained data. However, the more intimate format (i.e. face-to-face interviews) resulted in candid discussions about individuals' mental health and wellbeing and its impact on the expressed stances. Thus, the change in methods was thought to have affected data-richness only marginally. Additionally, the influence of the researcher on the obtained narrative data requires consideration (i.e. interviewer bias). As introduced in the beginning (section 2.2.1.5), I grew up in a society that had experienced a large-scale, government-mandated population surveillance first hand. As a result, I was raised to be naturally suspicious towards large-scale data collections. At the beginning, this background heavily influenced my own stance towards the topic I was investigating. However, with the help of memo-writing, I realised that I had, at times, projected my own scepticism onto my interview participants by phrasing or intonating questions a certain way. Prospectively, I actively tried to avoid suggestive questions and reassessed my own stance and its origins. However, it is plausible that I was not able to entirely detach myself from my upbringing and the belief system I inherited. Therefore, both the obtained narrative data and my subsequent analysis and interpretation might have been influenced by it.

The audio data were subjected to a meticulous transcription process, which commenced shortly after the interviews were conducted, this supported my development as a qualitative researcher, and helped to improve prospective interviews.

Lastly, the limitations of the cohort require attention. That is, the sample solely encompassed individuals within a narrow age range, with comparable familiarity with the use of personal data (i.e. digital natives) and a high level of education. Hence, the degree to which the obtained results are applicable to a broader population sample remains undetermined.

Lastly, initially I planned to conduct as many focus groups or interviews as necessary to reach data saturation (2.5.2.7). However, students' willingness to participate in the qualitative research phase was lower than anticipated, which meant that all individuals who declared interest to participate were interviewed. Therefore, the criterion for reaching data saturation, that is, to recruit and interview participants until no new themes emerge from the obtained data, could not be applied. However, I conducted 17 interviews with students, and despite exhibiting a large array of opinions towards the topic of investigation, students' views were found to pertain to similar core topics, such as concerns and potential benefits. Therefore, it is plausible that, despite being unable to interview more students to confirm that data saturation has been reached, I was able to collate enough voices to develop a comprehensive and thematically-exhaustive framework. This observation is supported by the fact that the interviews with pharmacy users confirmed the developed themes.

7.3.2. Pharmacy user cohort

As indicated in the previous section, the student cohort presented a demarcated sample with comparable characteristics, e.g. in terms of age, level of education and familiarity with digital technologies. Therefore, it was unclear to which extent the obtained results would be applicable to a population with greater demographic variability. To address this limitation, I opted to evaluate the attitudes of pharmacy users towards utilisation of transactional data in the realm of healthcare. First, pharmacy users' opinions were described quantitatively; questionnaire items were embedded in the community pharmacy survey 2020. Correspondingly, the strengths and limitations of the approach mirror those introduced in section 7.1.4. However, several additional aspects require consideration.

First, the loyalty card section of the CPS 2020 was characterised by a high percentage of item non-responders. Item responders and non-responders differed significantly in terms of their ethnicity and age, and response rates fluctuated considerably across the included study sites. Thus, the presented data could underrepresent or overestimate loyalty card use in the investigated population and should not be generalised.

Second, the loyalty card section of the community pharmacy survey included a number of questions that required participants to provide detailed information about the amount and types of loyalty cards they own. Thus, the introduction of recall bias is likely, as the chosen survey format limited participants' ability to verify the requested information.

The narrative data presented in this chapter were obtained from semi-structured interviews conducted with some survey participants and additionally sampled members of the public. A combined format was chosen for the interviews. That is, both individuals' opinion towards pharmacy provided mental health support and towards utilising transactional data were discussed subsequently. Thus, the limitations outlined previously (7.1.4) are equally applicable to this section.

Noteworthy is the high likelihood that the recruitment strategy introduced a self-selection bias, i.e. individuals with a stronger interest in the topic were more likely to participate. Several interview participants reported to work or have previously worked in information governance roles or medical research, which occurred to have influenced their stances. Moreover, as indicated in section 7.2.2.1 it was a struggle to recruit individuals who expressed negative opinions openly on social media, despite several invitations. Therefore, it is plausible, that contradicting voices and the opinions of those with less knowledge about personal data remained unheard; the transferability of the obtained results is limited (2.5.4.1).

Further, it is noteworthy that the strategy of embedding both interview aspects in a single conversation might present a limitation of its own. The loyalty card section of the interviews was often shorter than anticipated and yielded insufficient data in some instances, as participants chose to provide brief, one-dimensional responses. More so, at times, the previously discussed topic, i.e. mental health support provision in pharmacies appeared to intrinsically influence the subsequent part of the interview. For example, participants discussed trust in pharmacists as an imperative aspect of their considerations regarding the use of transactional data in a health research context. Retrospectively, it is possible that some methodological amendments could have yielded richer narrative data. First, a separate discussion of both topics could have been considered. Secondly, a more active amalgamation of both aspects could have been considered; however, this could have resulted in an inadequate fulfilment of the objectives of this research study. Thirdly, study recruitment could have been intensified; however, social distancing measures impeded such efforts. Lastly, given the circumstances, it could have been considered to adopt a different approach to data collection, e.g. facilitating discussions on social media platforms (7.2.2.1).

Likewise, following a deductive approach to thematic analysis might have decreased the depth of the analysis altogether. However, the framework developed on the grounds of the student data occurred to be applicable to the pharmacy user data which suggests that the chosen approach was appropriate. More so, the applicability of the framework developed from data collected with students to a broader population sample indicates that the perceptions of different population groups are comparable, which can be considered a strength of this research study.

Finally, this study was conducted amidst the outbreak of COVID-19. As a means to control the spread of the virus, the use of personal data for health research was proposed and subsequently prominently discussed in news outlets and on social media. This may have influenced participants' stances, both explicitly and implicitly. I attempted to contextualise this bias by asking participants about their experiences with and awareness of methods that were developed to contain and study COVID-19. However, the full extent of the impact COVID-19 had on participants' stances might have remained unexplored.

7.4. Synthesis of both data streams and policy recommendations

In the previous section, the results obtained from both research streams are discussed in light of the existing knowledge in this field and contributions made based on this research are highlighted. However, I discussed both research streams separately.

Therefore, a synthesis of the key points from both research streams and joint recommendations for policy and future research are required. In a final step, a summary conclusion is provided.

7.4.1. Data synthesis

Although this thesis consisted of two separate research streams, they both supported the fulfilment of the overall research aim, that is, to *identify public attitudes towards mental health support provided in community pharmacy using purchasing data as a tool to identify individuals at risk of developing mental health issues.*

First, it appeared that both aspects, i.e. developing pharmacists' roles in mental health and implementation of data-driven technologies in health, could benefit from each other; a synergy between both was established. Secondly, similar patterns identified in the data from both research streams, indicate that the fundamental requirements for public acceptability are applicable to both topics of inquiry alike. Thirdly, both research streams appeared to be sensitive to the societal context (i.e. the outbreak of COVID-19). Consequently, research and policy recommendations pertaining to the potential utilisation of transactional data to identify individuals at risk of developing mental health conditions in pharmacies are provided.

7.4.1.1. Synergy between both aspects

An intermediary role for pharmacists in mental healthcare found greatest support from pharmacy users; they proposed that the pharmacy team could serve as an information hub, which advises, signposts and refers individuals according to the severity of their condition. A large-scale analysis of loyalty card data could support such endeavours, as it enables the identification of individuals at risk. This data suggests that the involvement of pharmacists increases individuals support for the tracking and analysing of their transactional data. Furthermore, it was hypothesised that especially individuals who are missing a support network or have difficulties navigating the healthcare system would benefit from pharmacy provided mental health support. Consequently, the analysis of transactional data could enable a targeted approaching of individuals in need. Thus, a synergy between both data streams appears to exist. In other words, an extension of pharmacists' role in mental health could be supported by an effective use of data; contrarily, the recognition of pharmacies as an information hub could be beneficial for obtaining public support for the use of transactional data.

Future research and policy recommendations

There is an urgent need to acknowledge the synergistic effects between developing pharmacy practice and the evolving digital health landscape. Therefore, innovative pharmacy practice research is needed to evaluate how transactional data can be effectively applied in practice, keeping the uttermost goal in mind, that is, to improve patient-wellbeing. In turn, data-driven approaches could underpin an expansion of pharmacists' role and help making the profession future-proof. On the other hand, researchers and policy makers in digital health need to acknowledge the competences of health professionals and their contributions to a successful implementation of digital health technologies in practice. Thus, researchers and policy makers in digital health should capitalise on and draw lessons from pharmacists' wealth of professional experiences and knowledge. Therefore, in order to obtain public support for data-driven approaches in the healthcare context, multidisciplinary research and policy teams that amalgamate experiences and knowledge from a range of subjects are required.

7.4.1.2. Trust is fundamental for obtaining public acceptance

Irrespective of the data stream, trust between the involved parties (i.e. pharmacy user and pharmacists as well as data provider and data user) emerged as an acceptance-enhancing factor. As discussed previously (7.1.3; 7.2.2), this underpins the results obtained by other scholars in both, pharmacy practice and data-driven technology. However, the extent to which this realisation has permeated into policy appears to differ between both aspects. For example, recent policy pertaining to digital health and data-driven approaches contains detailed guidance on how public trust is fostered and maintained.[131] Contrarily, the development of guidance that could stimulate the development of trust in a pharmacy practice context does not attract the same attention. Instead, the development of new services to improve patient wellbeing has been at the heart of pharmacy practice research and policymaking. In principle, this path should be pursued. However, the current disregard for establishing the fundamentals for facilitating public uptake of such services may culminate in well- conceptualised, yet disregarded programmes.

Future research and policy recommendations

Thus, to facilitate public uptake of new services implemented in community pharmacy more fundamental research that investigates the development of trust between pharmacy team members and pharmacy users, is needed. Here, pharmacy practice researchers and policy makers could draw lessons from the experiences and knowledge researchers in digital health have acquired in recent years. The development of guidelines that accumulate trust-enhancing measures, akin to those developed for the digital health landscape, should be prioritised. The implementation of measures that, according to our study, could have a beneficial effect on the development of trust between pharmacy users and pharmacists should be trialled (7.1.3). Currently, the pharmacy profession is undergoing much change, revisions of supervision regulation in pharmacies are being discussed[249] and major online retailers, such as Amazon thrive to conquer the pharmaceutical market.[250] Therefore, the provision of clinical services is likely to be essential for the future of community pharmacy. Hence, the development and implementation of policies to foster public trust in the provision of clinical services provided in pharmacies is needed urgently, to avoid sinking into insignificance.

7.4.1.3. The importance of the societal context

This research was conducted amidst the COVID-19 pandemic, which prompted both, ephemeral and permanent societal changes. Naturally, the effect these changes had on the fulfilling of the aim of this thesis warrants consideration.

First, as described elsewhere (1.1.1), public mental health and wellbeing fluctuated throughout the course of the pandemic. Moreover, there is growing evidence that the aftermaths of a COVID-19 infection (i.e. long COVID) could affect individuals' mental health and wellbeing.[251] Second, numerous ideas that utilise personal data in the context of COVID-19 have been publicly discussed, e.g. to contain the disease or to deal with its consequences.[130] Consequently, public awareness of the utilisation of personal data in health research might have increased and attitudes might have undergone a transformation.

Therefore, both main aspects of this research project were impacted greatly throughout the study period. However, these developments were not foreseeable when this project commenced; a quantification of individuals' attitudes prior to the outbreak was not attempted. Thus, the obtained results are a snapshot taken at a time of turmoil and need to be understood in this unique context. A definite answer, as to whether the societal context impacted individuals' attitudes towards mental health support provided in pharmacies, using loyalty card data as a tool to identify cannot be provided. However, two aspects shall be pointed out. First, in the semi-structured interviews participants in both cohorts referred to COVID-19 when elucidating their opinions towards using personal data in a health research context. This applies to students, who were interviewed at the beginning of the pandemic, as well as pharmacy users, who were interviewed 6-months into the pandemic. Second, some pharmacy users pointed out that COVID-19 affected their perception of community pharmacy, which might have made them more likely to accept the introduction of new services.

Future research and policy recommendations

Primarily, the wealth of experiences that have been made during the pandemic need to permeate into the post-pandemic research landscape. It appears that public attitudes towards data utilisation are volatile and susceptible to external events. Therefore, future research pertaining to public attitudes towards utilisation of personal data in a health research context should always include a thorough evaluation of the societal context in which the data were collected.

Secondly, research evaluating the impact COVID-19 had on public perception of community pharmacy is urgently needed; pre-pandemic research is available and could be used for comparison. The obtained results can have implications for pharmacy policy prospectively. That is, a shift towards more positive attitudes should be understood as an opportunity to push for an extension of pharmacists' role. Likewise, policymakers in digital health should embrace the attention the pandemic brought to their subject and communicate the benefits greater data use could have for patient wellbeing more openly.

In summary, COVID-19 has shed light on the weaknesses, but also the benefits of the NHS on an unprecedented scale. The situation required quick decision-making, to cope with the fast-developing situation; new viewpoints on how problems could be addressed were offered. This forward thinking is required to prepare the healthcare system for the great challenges that lie ahead, such as an aging population. Greater use of already existing data to support public mental health is only one example but amalgamates visions for a digital future with the trustworthiness of a profession that carries its main mission in its key feature: being at the heart of their communities.

7.5. Conclusion

In summary, this study evaluated public attitudes towards mental health support provided in pharmacies, utilising transactional data as a tool to identify individuals at risk of developing mental health conditions. There appears to be public support for establishing community pharmacy as an alternative source for mental health support within the primary care network; especially a role for pharmacists as an intermediary between pharmacy users and other HCP and as an information hub was supported. By virtue of pharmacists' major advantage over other primary HCP—accessibility, pharmacy could provide a viable alternative for individuals who require support urgently, have difficulties navigating the healthcare system or miss a support network. However, contradictory opinions were also raised, indicating that the development of an approach suitable to everyone is difficult to attain. Prospectively, a large-scale analysis of loyalty card data, recorded in pharmacies, could support the targeted identification of individuals at risk of developing mental health conditions. Although there appears to be public support for following this approach, there remains a need to increase public understanding of its benevolence. Ultimately, this study established, that fostering public trust is fundamental for the success of both, i.e. expanding pharmacists' role in mental healthcare, as well as utilising personal data to identify individuals at risk. Policymakers in pharmacy practice appear to underestimate the importance of trust for public uptake of new services. Therefore, the development of trust-enhancing guidelines should be a focal point of future policies, lessons can be drawn from the digital health landscape. Conversely, developments in digital health can benefit from the involvement of HCP, such as pharmacists, as members of the public appear to value their competence, especially if a large-scale analysis of OTC-medicines is sought after.

Lastly, pharmacists, their professional bodies and researchers need to understand the value of digital technologies for modernising the profession and making it future proof. Pharmacists appear as a profession that is hunted by digital developments but currently too afraid to participate. A bold vision for the future of pharmacy practice is required, and if the benefits are communicated clearly to members of the public, widespread support can be obtained.

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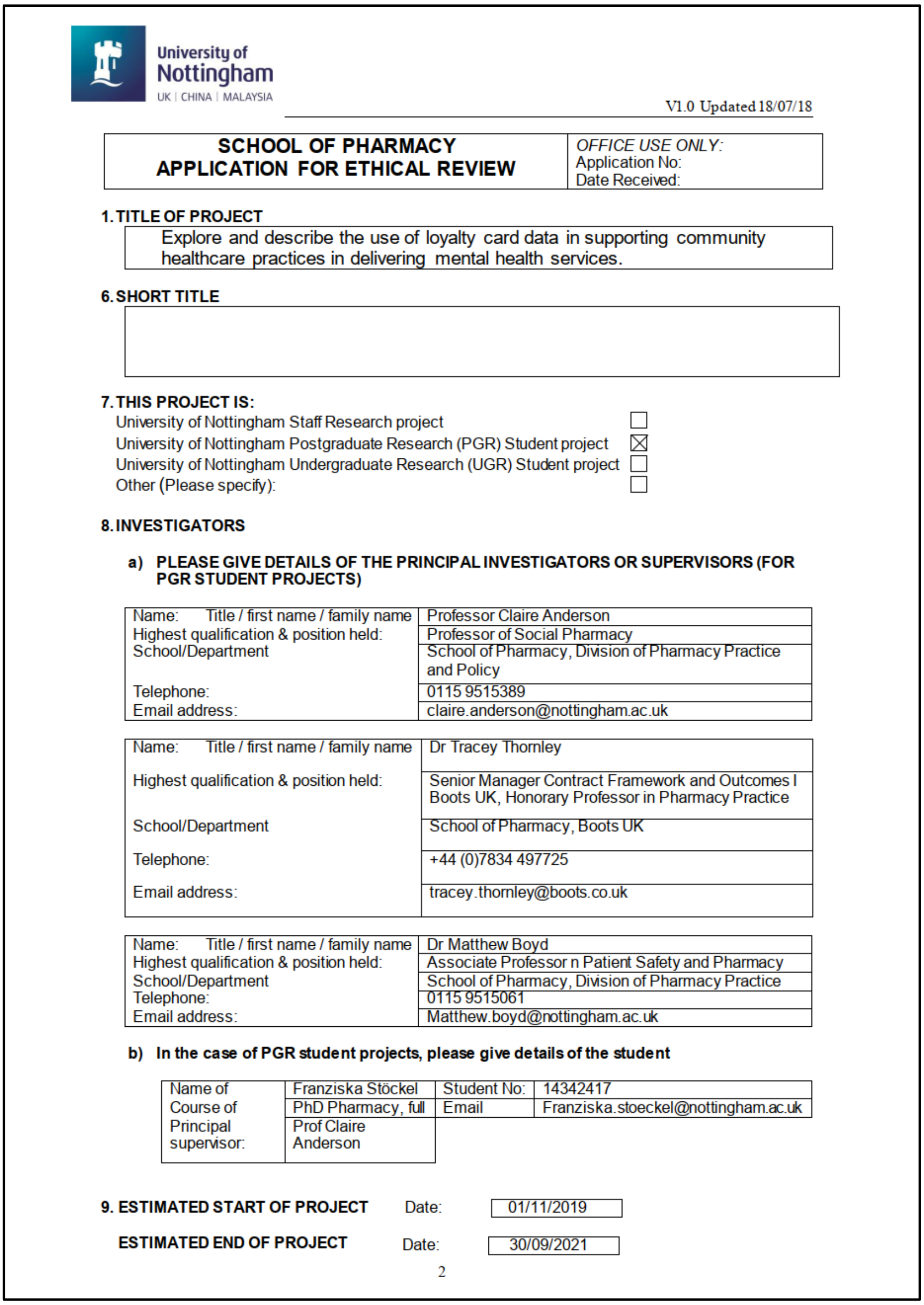
Appendices

Appendix 1: Research ethics form (019-2019)



University of Nottingham
UK | CHINA | MALAYSIA

V1.0 Updated 18/07/18

SCHOOL OF PHARMACY **APPLICATION FOR ETHICAL REVIEW**	*OFFICE USE ONLY:* Application No: Date Received:

1. TITLE OF PROJECT

Explore and describe the use of loyalty card data in supporting community healthcare practices in delivering mental health services.

6. SHORT TITLE

7. THIS PROJECT IS:

University of Nottingham Staff Research project ☐
University of Nottingham Postgraduate Research (PGR) Student project ☒
University of Nottingham Undergraduate Research (UGR) Student project ☐
Other (Please specify): ☐

8. INVESTIGATORS

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Professor Claire Anderson
Highest qualification & position held:	Professor of Social Pharmacy
School/Department	School of Pharmacy, Division of Pharmacy Practice and Policy
Telephone:	0115 9515389
Email address:	claire.anderson@nottingham.ac.uk

Name: Title / first name / family name	Dr Tracey Thornley
Highest qualification & position held:	Senior Manager Contract Framework and Outcomes I Boots UK, Honorary Professor in Pharmacy Practice
School/Department	School of Pharmacy, Boots UK
Telephone:	+44 (0)7834 497725
Email address:	tracey.thornley@boots.co.uk

Name: Title / first name / family name	Dr Matthew Boyd
Highest qualification & position held:	Associate Professor n Patient Safety and Pharmacy
School/Department	School of Pharmacy, Division of Pharmacy Practice
Telephone:	0115 9515061
Email address:	Matthew.boyd@nottingham.ac.uk

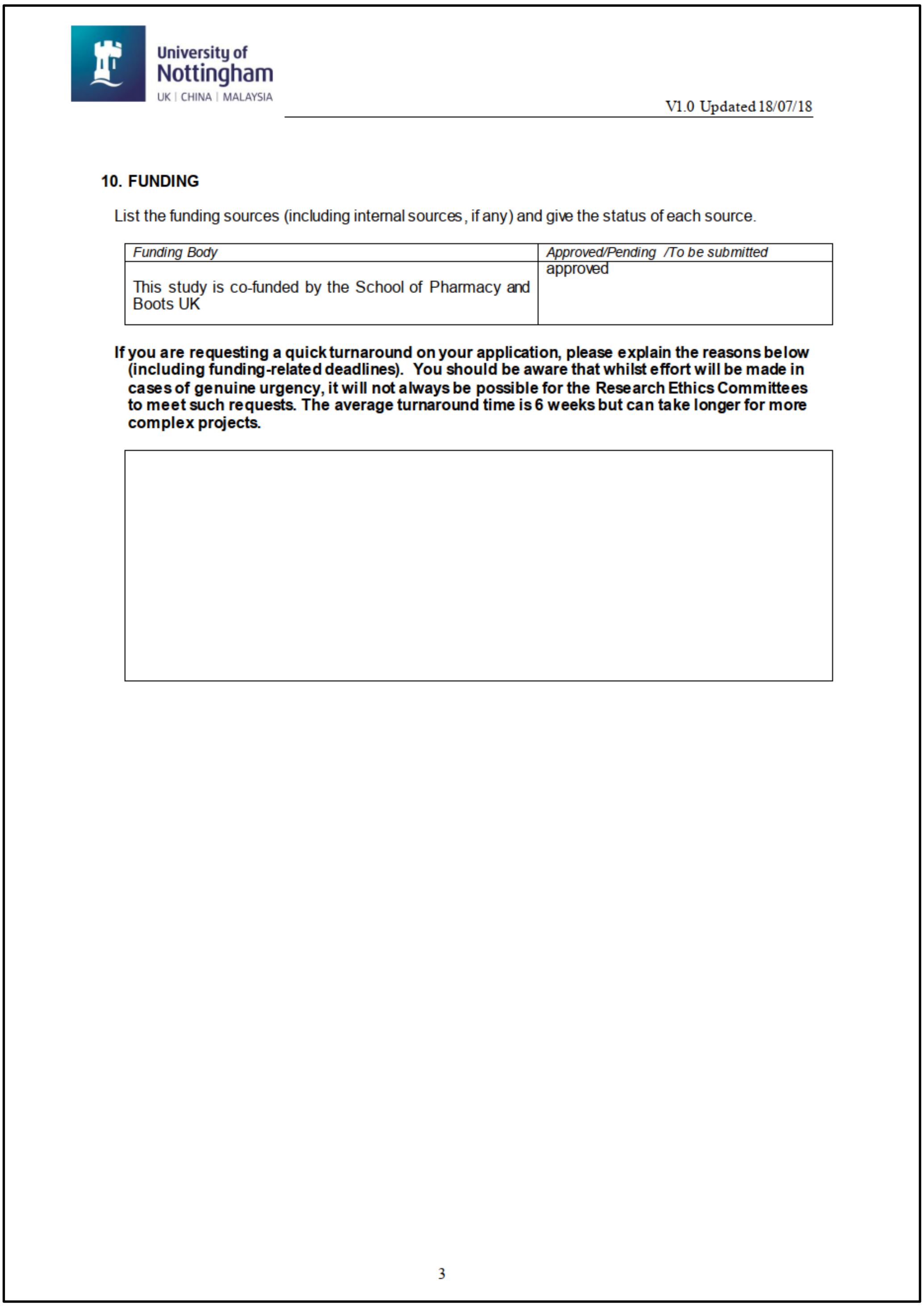
b) In the case of PGR student projects, please give details of the student

Name of	Franziska Stöckel	Student No:	14342417
Course of	PhD Pharmacy, full	Email	Franziska.stoeckel@nottingham.ac.uk
Principal supervisor:	Prof Claire Anderson		

9. ESTIMATED START OF PROJECT Date: 01/11/2019

ESTIMATED END OF PROJECT Date: 30/09/2021

2

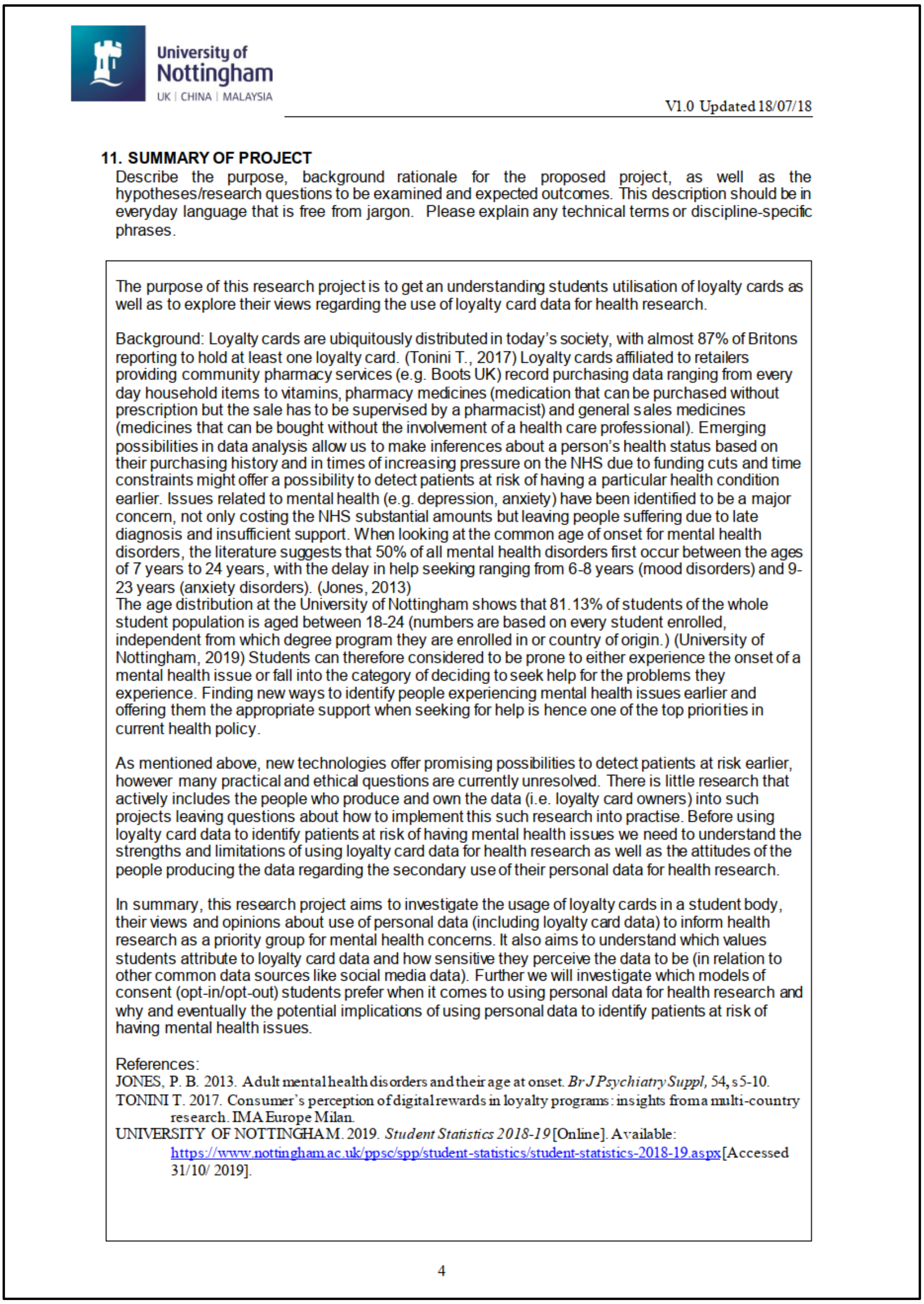


10. FUNDING

List the funding sources (including internal sources, if any) and give the status of each source.

Funding Body	*Approved/Pending /To be submitted*
This study is co-funded by the School of Pharmacy and Boots UK	approved

If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Research Ethics Committees to meet such requests. The average turnaround time is 6 weeks but can take longer for more complex projects.



11. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

The purpose of this research project is to get an understanding students utilisation of loyalty cards as well as to explore their views regarding the use of loyalty card data for health research.

Background: Loyalty cards are ubiquitously distributed in today's society, with almost 87% of Britons reporting to hold at least one loyalty card. (Tonini T., 2017) Loyalty cards affiliated to retailers providing community pharmacy services (e.g. Boots UK) record purchasing data ranging from every day household items to vitamins, pharmacy medicines (medication that can be purchased without prescription but the sale has to be supervised by a pharmacist) and general sales medicines (medicines that can be bought without the involvement of a health care professional). Emerging possibilities in data analysis allow us to make inferences about a person's health status based on their purchasing history and in times of increasing pressure on the NHS due to funding cuts and time constraints might offer a possibility to detect patients at risk of having a particular health condition earlier. Issues related to mental health (e.g. depression, anxiety) have been identified to be a major concern, not only costing the NHS substantial amounts but leaving people suffering due to late diagnosis and insufficient support. When looking at the common age of onset for mental health disorders, the literature suggests that 50% of all mental health disorders first occur between the ages of 7 years to 24 years, with the delay in help seeking ranging from 6-8 years (mood disorders) and 9-23 years (anxiety disorders). (Jones, 2013)
The age distribution at the University of Nottingham shows that 81.13% of students of the whole student population is aged between 18-24 (numbers are based on every student enrolled, independent from which degree program they are enrolled in or country of origin.) (University of Nottingham, 2019) Students can therefore considered to be prone to either experience the onset of a mental health issue or fall into the category of deciding to seek help for the problems they experience. Finding new ways to identify people experiencing mental health issues earlier and offering them the appropriate support when seeking for help is hence one of the top priorities in current health policy.

As mentioned above, new technologies offer promising possibilities to detect patients at risk earlier, however many practical and ethical questions are currently unresolved. There is little research that actively includes the people who produce and own the data (i.e. loyalty card owners) into such projects leaving questions about how to implement this such research into practise. Before using loyalty card data to identify patients at risk of having mental health issues we need to understand the strengths and limitations of using loyalty card data for health research as well as the attitudes of the people producing the data regarding the secondary use of their personal data for health research.

In summary, this research project aims to investigate the usage of loyalty cards in a student body, their views and opinions about use of personal data (including loyalty card data) to inform health research as a priority group for mental health concerns. It also aims to understand which values students attribute to loyalty card data and how sensitive they perceive the data to be (in relation to other common data sources like social media data). Further we will investigate which models of consent (opt-in/opt-out) students prefer when it comes to using personal data for health research and why and eventually the potential implications of using personal data to identify patients at risk of having mental health issues.

References:

JONES, P. B. 2013. Adult mental health disorders and their age at onset. *Br J Psychiatry Suppl,* 54, s5-10.
TONINI T. 2017. Consumer's perception of digital rewards in loyalty programs: insights from a multi-country research. IMA Europe Milan.
UNIVERSITY OF NOTTINGHAM. 2019. *Student Statistics 2018-19* [Online]. Available: https://www.nottingham.ac.uk/ppsc/spp/student-statistics/student-statistics-2018-19.aspx [Accessed 31/10/ 2019].

Our research questions are:

1) In general, what are the strengths and limitations of using loyalty card data for health research? Specifically is loyalty card data impacted by under- or over-representation of specific groups of individuals.

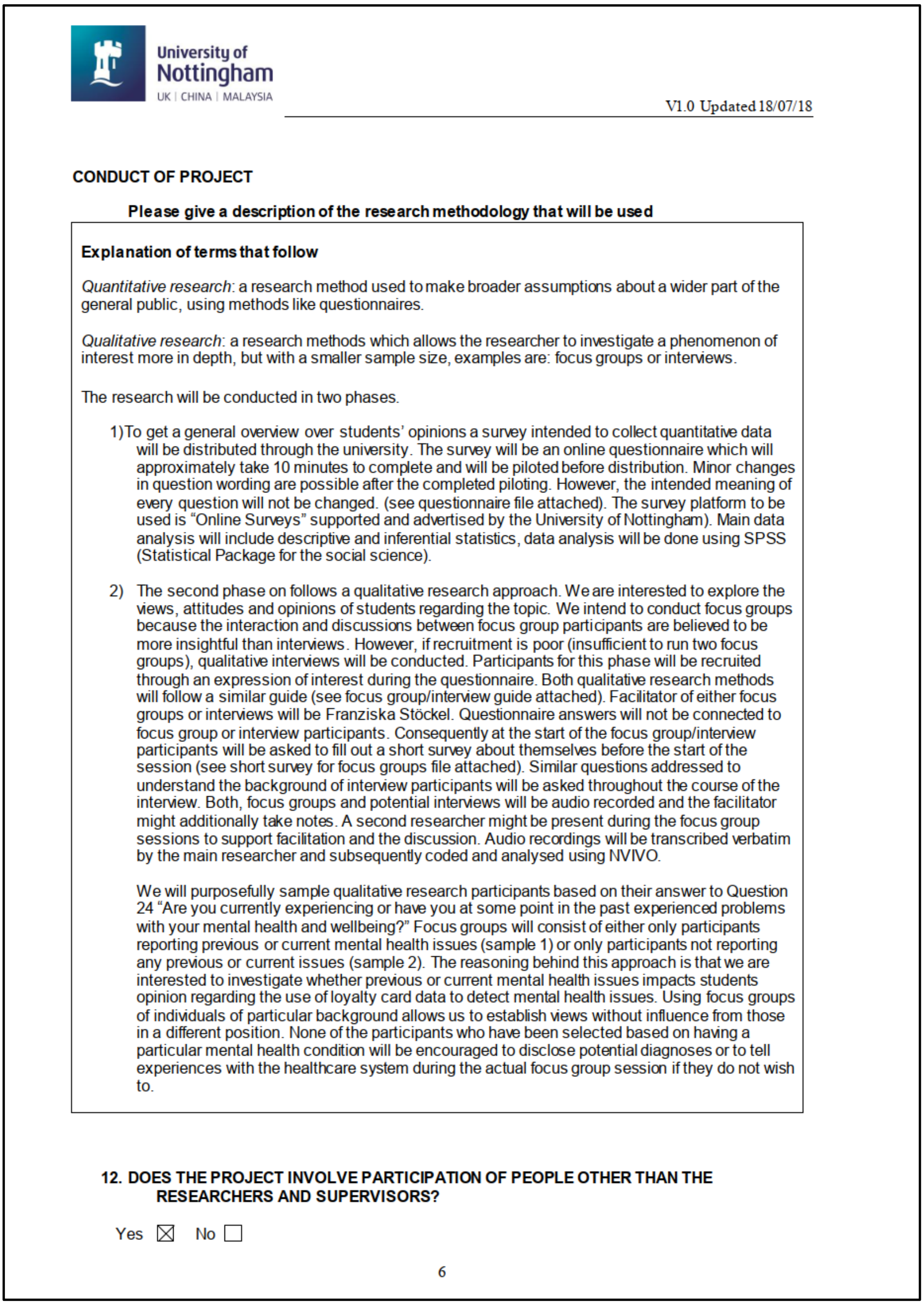
a) Demographics of loyalty card users
b) Usage of loyalty cards (e.g. ownership; frequency of usage, individual use or use by more than one household member?)

Expectations: Demographics of the user base may be impacted depending on which retailer type is offering it. For example, the Boots loyalty card may be skewed towards females; general tendency to own loyalty cards for more than one shop with an overlapping product range; members of one household or relatives might share one loyalty card

- ➔ Based on general demographic information we will investigate whether there are population groups that could be left behind when implementing a service that identifies patients at risk based on their purchasing behaviour (e.g. females vs. males, different age groups, etc.)
- ➔ Based on loyalty card usage we will investigate whether it is possible to make valid predictions about one single person or whether due to multiple store usage, forgetting the loyalty card and multiple people using the same card predictions might eventually lack clarity.

2) What are students' views on the use of purchasing data (as recorded through loyalty cards) to identify patients at risk of having mental health issues?

Expectations: Lack of awareness that purchasing data can be used for health research, concerns regarding data privacy, however if the purpose is seen as serving "the greater good" loyalty card users might be more prone to share their data voluntarily, interest in transparency regarding the usage of personal data for research purposes



CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

Explanation of terms that follow

Quantitative research: a research method used to make broader assumptions about a wider part of the general public, using methods like questionnaires.

Qualitative research: a research methods which allows the researcher to investigate a phenomenon of interest more in depth, but with a smaller sample size, examples are: focus groups or interviews.

The research will be conducted in two phases.

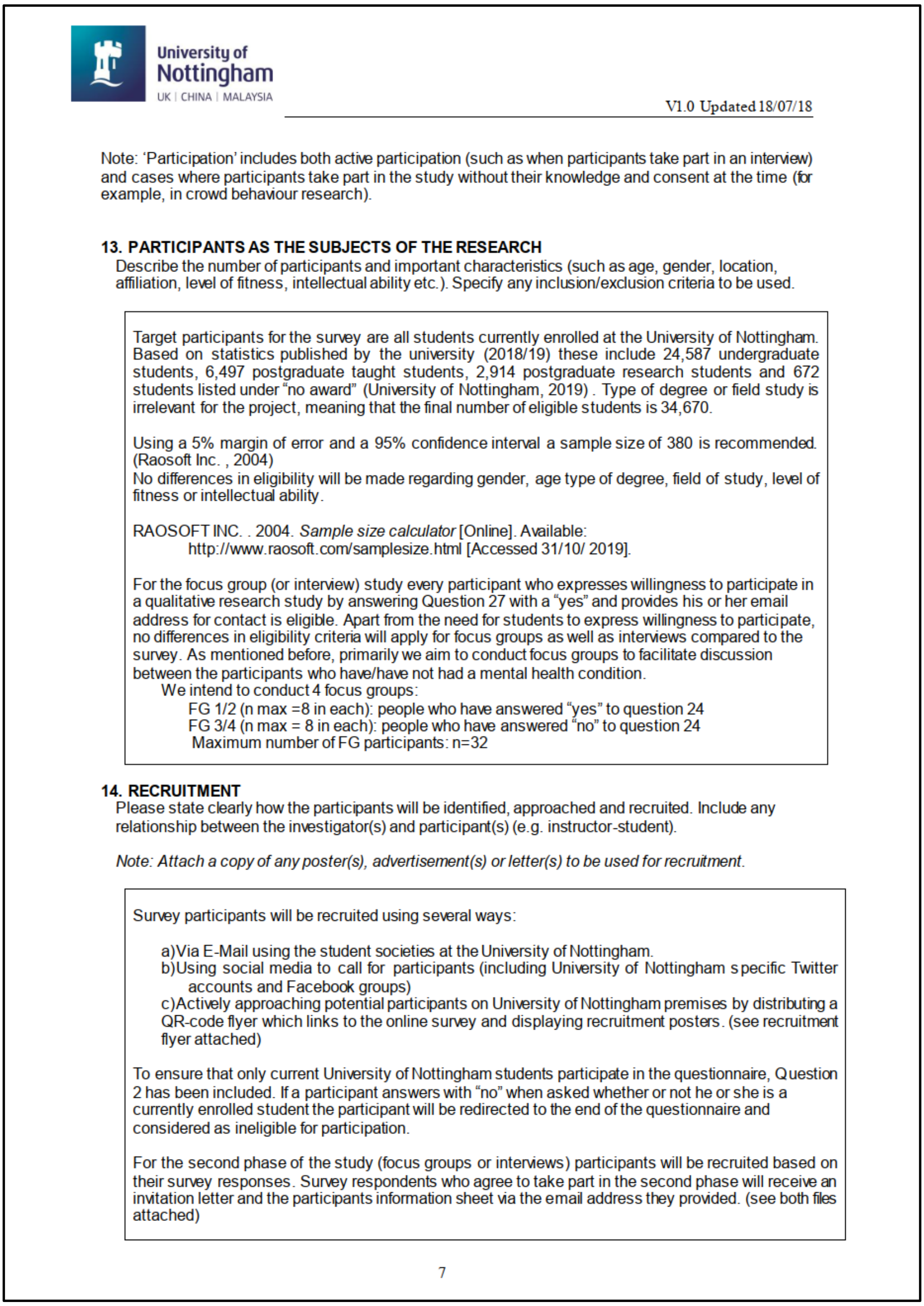
1) To get a general overview over students' opinions a survey intended to collect quantitative data will be distributed through the university. The survey will be an online questionnaire which will approximately take 10 minutes to complete and will be piloted before distribution. Minor changes in question wording are possible after the completed piloting. However, the intended meaning of every question will not be changed. (see questionnaire file attached). The survey platform to be used is "Online Surveys" supported and advertised by the University of Nottingham). Main data analysis will include descriptive and inferential statistics, data analysis will be done using SPSS (Statistical Package for the social science).

2) The second phase on follows a qualitative research approach. We are interested to explore the views, attitudes and opinions of students regarding the topic. We intend to conduct focus groups because the interaction and discussions between focus group participants are believed to be more insightful than interviews. However, if recruitment is poor (insufficient to run two focus groups), qualitative interviews will be conducted. Participants for this phase will be recruited through an expression of interest during the questionnaire. Both qualitative research methods will follow a similar guide (see focus group/interview guide attached). Facilitator of either focus groups or interviews will be Franziska Stöckel. Questionnaire answers will not be connected to focus group or interview participants. Consequently at the start of the focus group/interview participants will be asked to fill out a short survey about themselves before the start of the session (see short survey for focus groups file attached). Similar questions addressed to understand the background of interview participants will be asked throughout the course of the interview. Both, focus groups and potential interviews will be audio recorded and the facilitator might additionally take notes. A second researcher might be present during the focus group sessions to support facilitation and the discussion. Audio recordings will be transcribed verbatim by the main researcher and subsequently coded and analysed using NVIVO.

   We will purposefully sample qualitative research participants based on their answer to Question 24 "Are you currently experiencing or have you at some point in the past experienced problems with your mental health and wellbeing?" Focus groups will consist of either only participants reporting previous or current mental health issues (sample 1) or only participants not reporting any previous or current issues (sample 2). The reasoning behind this approach is that we are interested to investigate whether previous or current mental health issues impacts students opinion regarding the use of loyalty card data to detect mental health issues. Using focus groups of individuals of particular background allows us to establish views without influence from those in a different position. None of the participants who have been selected based on having a particular mental health condition will be encouraged to disclose potential diagnoses or to tell experiences with the healthcare system during the actual focus group session if they do not wish to.

12. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐



Note: ‘Participation’ includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

13. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

Target participants for the survey are all students currently enrolled at the University of Nottingham. Based on statistics published by the university (2018/19) these include 24,587 undergraduate students, 6,497 postgraduate taught students, 2,914 postgraduate research students and 672 students listed under “no award” (University of Nottingham, 2019). Type of degree or field study is irrelevant for the project, meaning that the final number of eligible students is 34,670.

Using a 5% margin of error and a 95% confidence interval a sample size of 380 is recommended. (Raosoft Inc. , 2004)
No differences in eligibility will be made regarding gender, age type of degree, field of study, level of fitness or intellectual ability.

RAOSOFT INC. . 2004. *Sample size calculator* [Online]. Available:
http://www.raosoft.com/samplesize.html [Accessed 31/10/ 2019].

For the focus group (or interview) study every participant who expresses willingness to participate in a qualitative research study by answering Question 27 with a “yes” and provides his or her email address for contact is eligible. Apart from the need for students to express willingness to participate, no differences in eligibility criteria will apply for focus groups as well as interviews compared to the survey. As mentioned before, primarily we aim to conduct focus groups to facilitate discussion between the participants who have/have not had a mental health condition.
We intend to conduct 4 focus groups:
FG 1/2 (n max =8 in each): people who have answered “yes” to question 24
FG 3/4 (n max = 8 in each): people who have answered “no” to question 24
Maximum number of FG participants: n=32

14. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

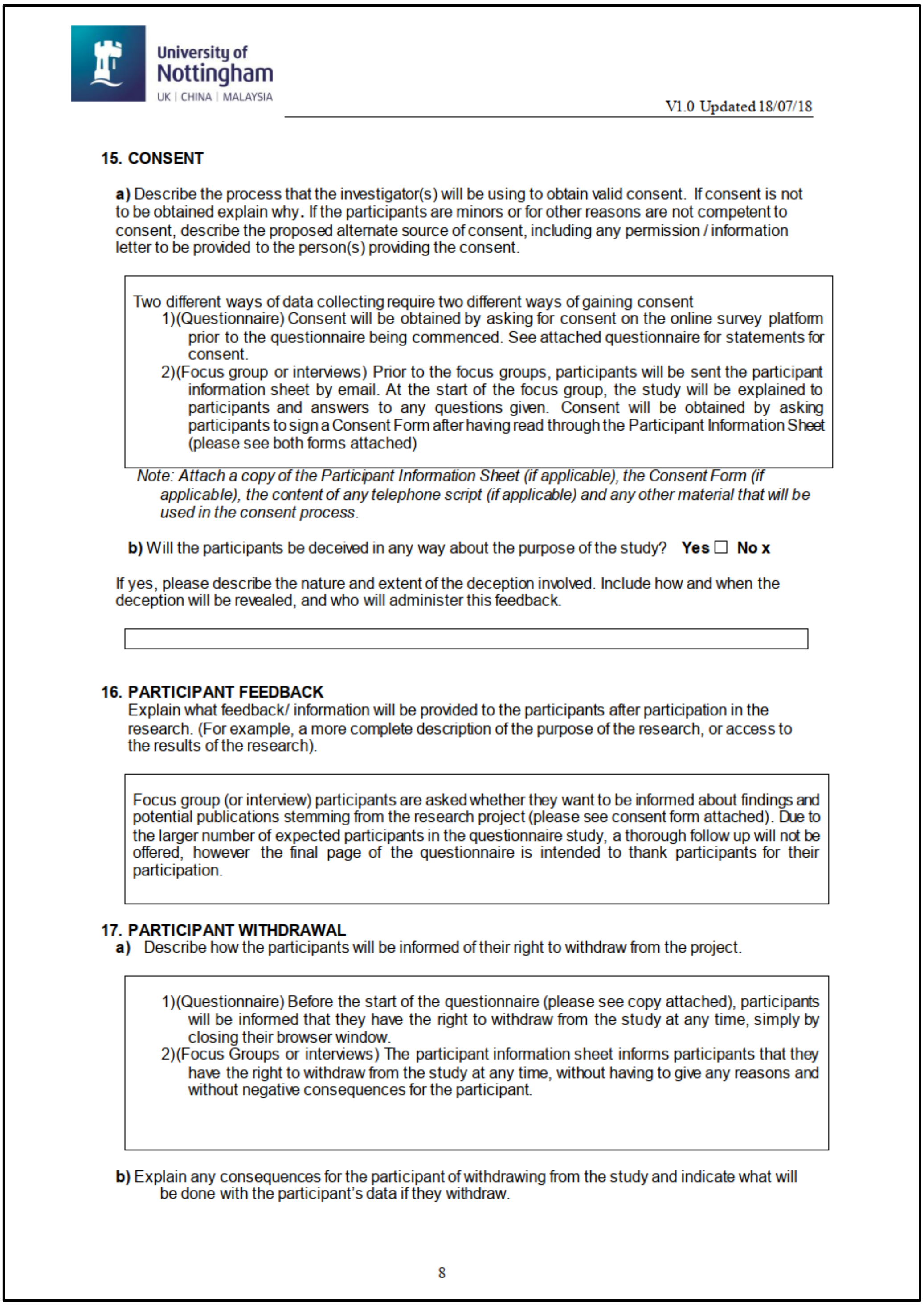
Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

Survey participants will be recruited using several ways:

a) Via E-Mail using the student societies at the University of Nottingham.
b) Using social media to call for participants (including University of Nottingham specific Twitter accounts and Facebook groups)
c) Actively approaching potential participants on University of Nottingham premises by distributing a QR-code flyer which links to the online survey and displaying recruitment posters. (see recruitment flyer attached)

To ensure that only current University of Nottingham students participate in the questionnaire, Question 2 has been included. If a participant answers with “no” when asked whether or not he or she is a currently enrolled student the participant will be redirected to the end of the questionnaire and considered as ineligible for participation.

For the second phase of the study (focus groups or interviews) participants will be recruited based on their survey responses. Survey respondents who agree to take part in the second phase will receive an invitation letter and the participants information sheet via the email address they provided. (see both files attached)



15. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Two different ways of data collecting require two different ways of gaining consent

1) (Questionnaire) Consent will be obtained by asking for consent on the online survey platform prior to the questionnaire being commenced. See attached questionnaire for statements for consent.
2) (Focus group or interviews) Prior to the focus groups, participants will be sent the participant information sheet by email. At the start of the focus group, the study will be explained to participants and answers to any questions given. Consent will be obtained by asking participants to sign a Consent Form after having read through the Participant Information Sheet (please see both forms attached)

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? **Yes** ☐ **No x**

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

16. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

Focus group (or interview) participants are asked whether they want to be informed about findings and potential publications stemming from the research project (please see consent form attached). Due to the larger number of expected participants in the questionnaire study, a thorough follow up will not be offered, however the final page of the questionnaire is intended to thank participants for their participation.

17. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

1) (Questionnaire) Before the start of the questionnaire (please see copy attached), participants will be informed that they have the right to withdraw from the study at any time, simply by closing their browser window.
2) (Focus Groups or interviews) The participant information sheet informs participants that they have the right to withdraw from the study at any time, without having to give any reasons and without negative consequences for the participant.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

1) There are no consequences if a participant withdraws from study participation before the end of the questionnaire, questionnaire that have not been completed will not be used for final analysis.
2) If a participant withdraws from participation **before** the start of the focus groups or interviews, there are no consequences and no data about the participant will be collected or used for analysis. If a participant withdraws during a focus group session or interview, there are no consequences, but data collected until point of withdrawal will still be included in the data analysis. (as mentioned in the participant information sheet)

18. COMPENSATION

Will participants receive any compenation for participation?

i) Financial	**Yes** ☒ **No** ☐
ii) Non-financial	**Yes** ☒ **No** ☐

If **Yes** to **either** i) or ii) above, please provide details.

1) A £50 gift voucher will be given away to **one** questionnaire participant. The winner will be chosen by using a random number generator. (financial)
2) Focus group participants will receive refreshments and snacks during the focus group session. (non-financial) (No compensation will be offered in case of interviews)

If participants choose to withdraw, how will you deal with compensation?

1) Survey participants who withdraw from participation and don't complete the questionnaire won't participate in the price raffle.

CONFIDENTIALITY

a)	Will all participants be anonymous?	**Yes** ☐ **No** ☒
b)	Will all data be treated as confidential?	**Yes** ☒ **No** ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

All information collected during the course of the research will be kept strictly confidential.
Quantitative research: Survey data will be collected using a University of Nottingham supported third party programme "Online surveys" which automatically allocates every completed questionnaire a random "response ID number" At no time will anything else except for the response ID number be used to refer back to a questionnaire answer.
Survey participant's names will only be collected where they are happy to be invited to take part in the second phase of the research. Email addresses will be collected for two purposes (both optional), to contact the winner of the price raffle and to contact potential participants of the qualitative study. However, provision of the email address is entirely voluntary and non-provision will not have negative consequences. Email addresses will be deleted as soon as the winner of the raffle is found and the recruitment process of the second phase of the study is completed. The questionnaire includes space for open text. If direct quotes are used we will assign the originator of the quote a random number, making tracing back personal identification impossible. No connection will be made between questionnaire answers and focus group or interview participants except for Question 25, which is used as a sampling question for the qualitative research.

Qualitative research: Names and other identifiable information that might come up during the focus group or interview sessions will be replaced by randomly chosen participant IDs when transcribing the audio recordings. When direct quotations of a participants are used in publications these will only include the participants ID. Example: Participant 4 of focus group one will be referred to as: Part4/FG1.
Keys to participant IDs (questionnaire and focus groups) will only be known to the main researchers and supervisors and will be stored securely in locked offices or behind a password protected database.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

n/a

19. STORAGE, ACCESS AND DISPOSAL OF DATA
Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Research data management processes comply with University of Nottingham standards. The platform used to collect survey answers is a University of Nottingham supported third party company ("online surveys") Data stored on this platform is password protect, with only the research team having access. To be able to do the main analysis in SPSS, the data will be transferred on the researcher's personal computer and from then on securely stored using password protected University of Nottingham Office 365 storage. Surveys will be stored for 7 years after the final publication of the results. The email addresses of survey participants will be stored for a maximum of 6 months or until the winner of the raffle has been chosen and participants for the focus group sampled. Focus group data (original audio files, transcripts and short surveys) will also be securely stored on a password protected University of Nottingham provided Office 365 database for 7 years after the final publication of the results or in a locked office respectively. Personal data connected to the focus groups (i.e. email addresses of people who want to be informed about study outcomes) will be stored for a maximum of one year after completing data collection. After this time data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain confidentiality, only members of the research team will have access to personal data.

20. OTHER APPROVALS REQUIRED? e.g. Disclosure and Barring Service (DBS) checks or NHS R&D approvals.

☐ YES ☒ NO ☐ NOT APPLICABLE

If yes, please specify.

The research team have contacted the Student Union for advice about contacting students. We have been advised to approach heads of individual societies to assist with distribution as the Student Union does not send out surveys that are not their own. .

21. SIGNIFICANCE/BENEFITS
Outline the potential significance and/or benefits of the research

Active contribution to a research project that is aiming to get an understanding of the possible limitations and strengths of using loyalty card data for health research. These include practicality issues as well as ethical considerations and questions around consenting to the use of personal data for health research. On a wider scale, the information we get from this study may help to develop new services for community pharmacy and eventually improve the mental health support that is currently available to all members of public.

22. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

There are no major risks of taking part in this study. The main disadvantage is the time that will be asked to contribute, which will be approximately ten minutes for the questionnaire and (if participating) one hour for the focus group, plus a small amount of time beforehand to sign and return the consent form.
Furthermore, one part of the discussion will be sharing ideas regarding the possibility to use loyalty card data to identify patients at risk of having mental health issues. We are aware that mental health can be a sensitive issue to talk about. To lower the risk of causing distress we will remind participants that there disclosure of any potential diagnoses related to mental health issues is entirely up to them and is not required.

Research staff will follow the lone-worker and field work policies when conducting the research.

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

The research in itself intends to find out which ethical issues and consequences might arise from loyalty card data being used to identify patients at risk of having certain conditions. Hence, instead of being a risk it is more likely that the research project benefits the society.

In terms of the student society we conduct the research in, it will be ensured that no one else except for the main researchers will have access to research data to ensure that the data will not be distributed or accessed by unauthorised personal. However, to minimise the risk of someone unauthorised accessing the database constant password protecting will be ensured. The data will never be stored on only a single device to prevent data loss, moreover, as advised by the University of Nottingham, research data will be stored on three different devices, on two different media, with one of them on a different site.

By choosing to conduct the survey as an online questionnaire, we avoid printing unreasonable amounts of questionnares.

23. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ **No** ☒

If yes, please specify

EXPERT REVIEWER/OPINION

You may be asked to nominate an expert reviewer for certain types of project, including those of an interventional nature or those involving significant risks. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Name
Contact details (including email address)
Brief explanation of reasons for nominating and/or nominee's suitability

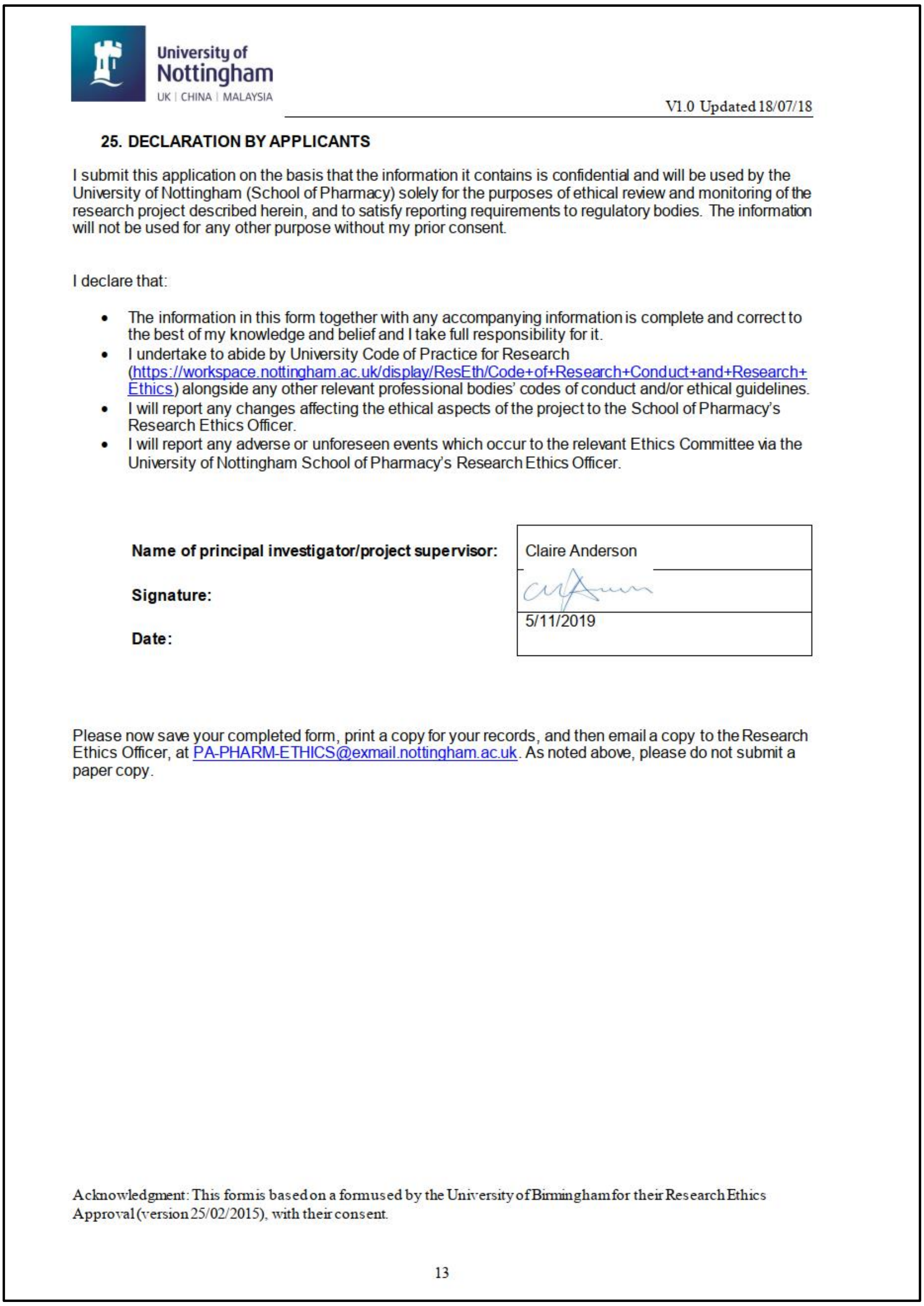
24. CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☐
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☒
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

Please check that the following documents are attached to your application.

	ATTACHED	**NOT APPLICABLE**
Recruitment advertisement	☒	☐
Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☒	☐
Interview Schedule	☒	☐



25. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Nottingham (School of Pharmacy) solely for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

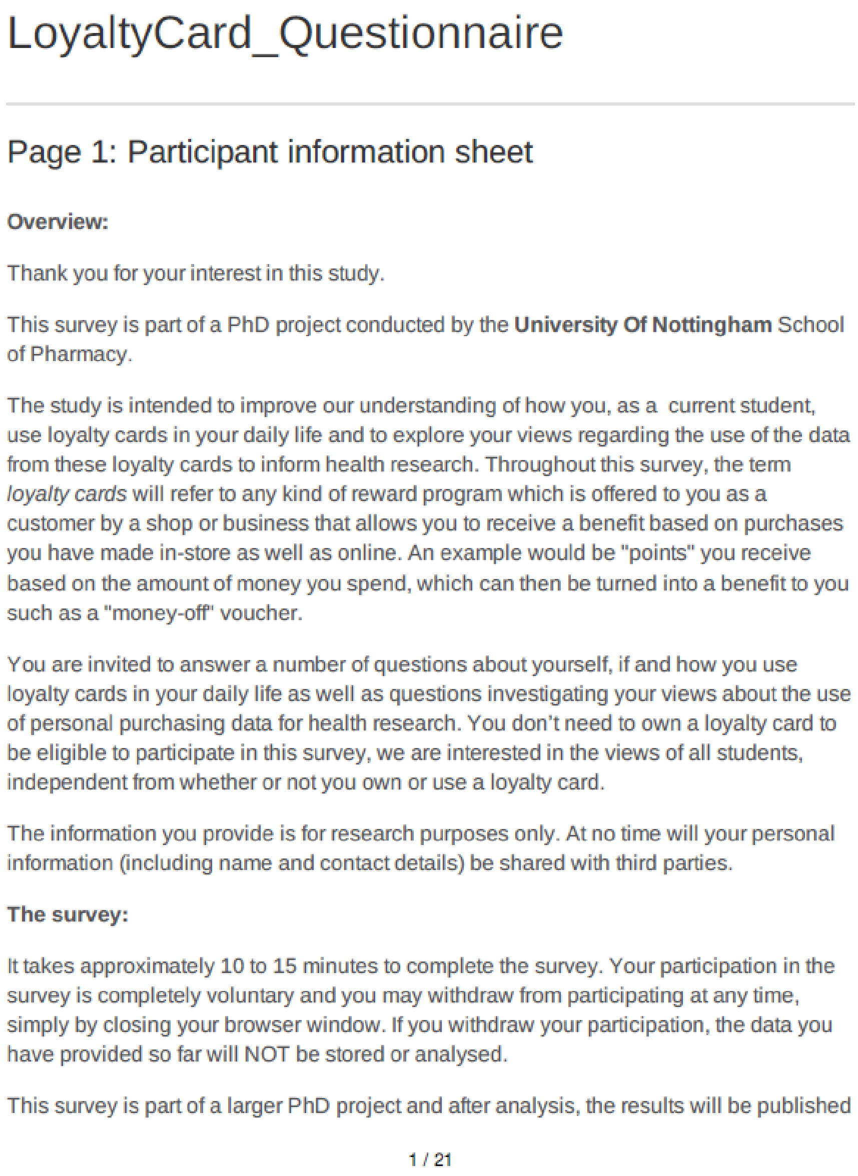
- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (https://workspace.nottingham.ac.uk/display/ResEth/Code+of+Research+Conduct+and+Research+Ethics) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the School of Pharmacy's Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Nottingham School of Pharmacy's Research Ethics Officer.

Name of principal investigator/project supervisor:	Claire Anderson
Signature:	
Date:	5/11/2019

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at PA-PHARM-ETHICS@exmail.nottingham.ac.uk. As noted above, please do not submit a paper copy.

Acknowledgment: This form is based on a form used by the University of Birmingham for their Research Ethics Approval (version 25/02/2015), with their consent.

Appendix 2: Student questionnaire



LoyaltyCard_Questionnaire

Page 1: Participant information sheet

Overview:

Thank you for your interest in this study.

This survey is part of a PhD project conducted by the **University Of Nottingham** School of Pharmacy.

The study is intended to improve our understanding of how you, as a current student, use loyalty cards in your daily life and to explore your views regarding the use of the data from these loyalty cards to inform health research. Throughout this survey, the term *loyalty cards* will refer to any kind of reward program which is offered to you as a customer by a shop or business that allows you to receive a benefit based on purchases you have made in-store as well as online. An example would be "points" you receive based on the amount of money you spend, which can then be turned into a benefit to you such as a "money-off" voucher.

You are invited to answer a number of questions about yourself, if and how you use loyalty cards in your daily life as well as questions investigating your views about the use of personal purchasing data for health research. You don't need to own a loyalty card to be eligible to participate in this survey, we are interested in the views of all students, independent from whether or not you own or use a loyalty card.

The information you provide is for research purposes only. At no time will your personal information (including name and contact details) be shared with third parties.

The survey:

It takes approximately 10 to 15 minutes to complete the survey. Your participation in the survey is completely voluntary and you may withdraw from participating at any time, simply by closing your browser window. If you withdraw your participation, the data you have provided so far will NOT be stored or analysed.

This survey is part of a larger PhD project and after analysis, the results will be published

1 / 21

as part of a PhD thesis and disseminated in scientific journals and at conferences with an emphasis on the topic we are investigating. No identifiable personal information will be used in any publication.

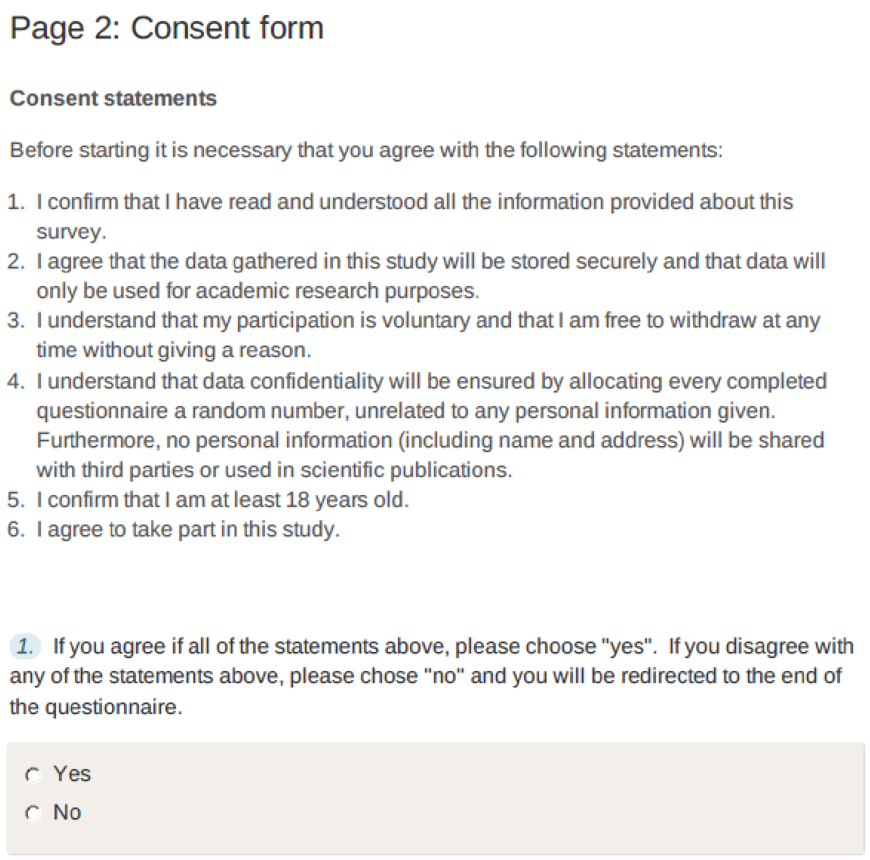
From every participant completing the questionnaire we will randomly choose one winning a £50 gift voucher. Only for the purpose of contacting the lucky winner, we will be asking you to provide your email address.

Finally, the data will be securely stored for 7 years after the final publication of the results on a password-protected database.

Thank you

Franziska Stoeckel - Ph.D.student (Franziska.stoeckel@nottingham.ac.uk)

Claire Anderson - Principal investigator (Claire.Anderson@nottingham.ac.uk)



Page 2: Consent form

Consent statements

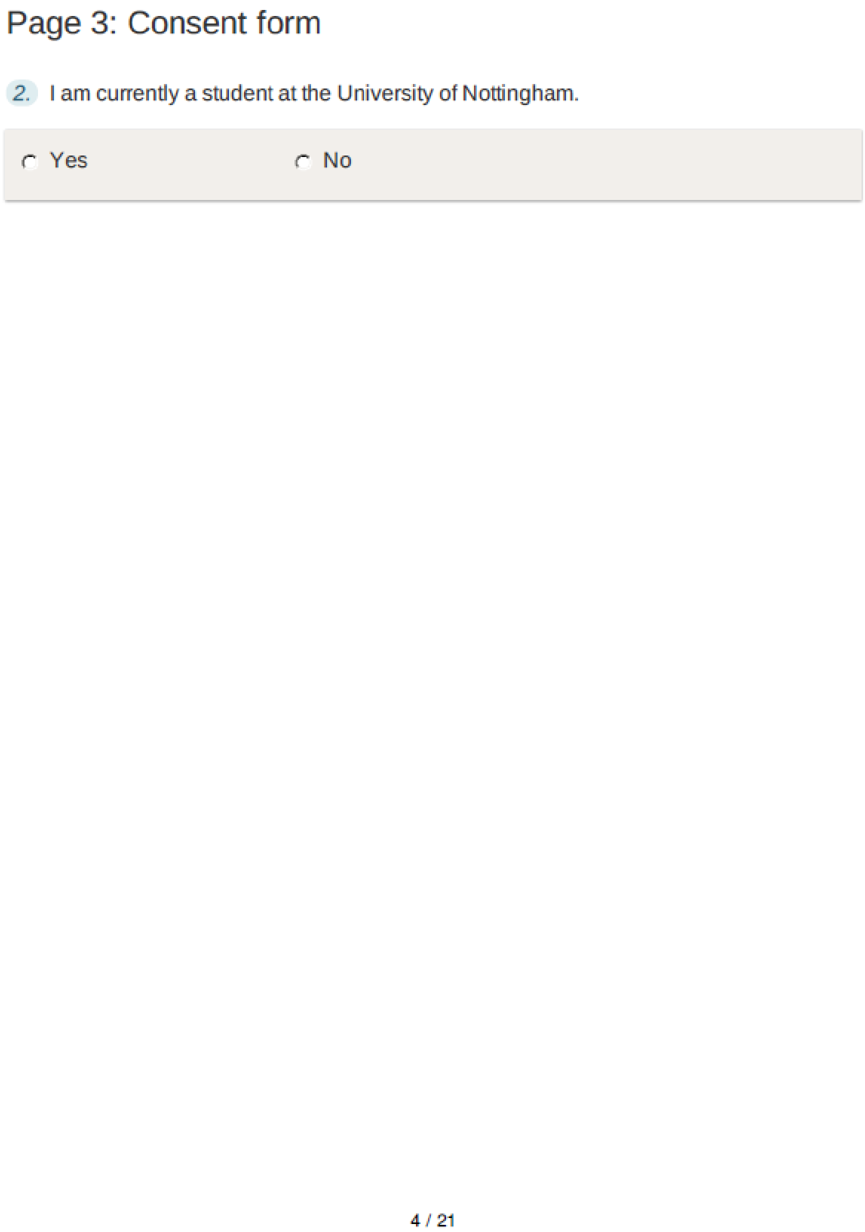
Before starting it is necessary that you agree with the following statements:

1. I confirm that I have read and understood all the information provided about this survey.
2. I agree that the data gathered in this study will be stored securely and that data will only be used for academic research purposes.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.
4. I understand that data confidentiality will be ensured by allocating every completed questionnaire a random number, unrelated to any personal information given. Furthermore, no personal information (including name and address) will be shared with third parties or used in scientific publications.
5. I confirm that I am at least 18 years old.
6. I agree to take part in this study.

1. If you agree if all of the statements above, please choose "yes". If you disagree with any of the statements above, please chose "no" and you will be redirected to the end of the questionnaire.

○ Yes

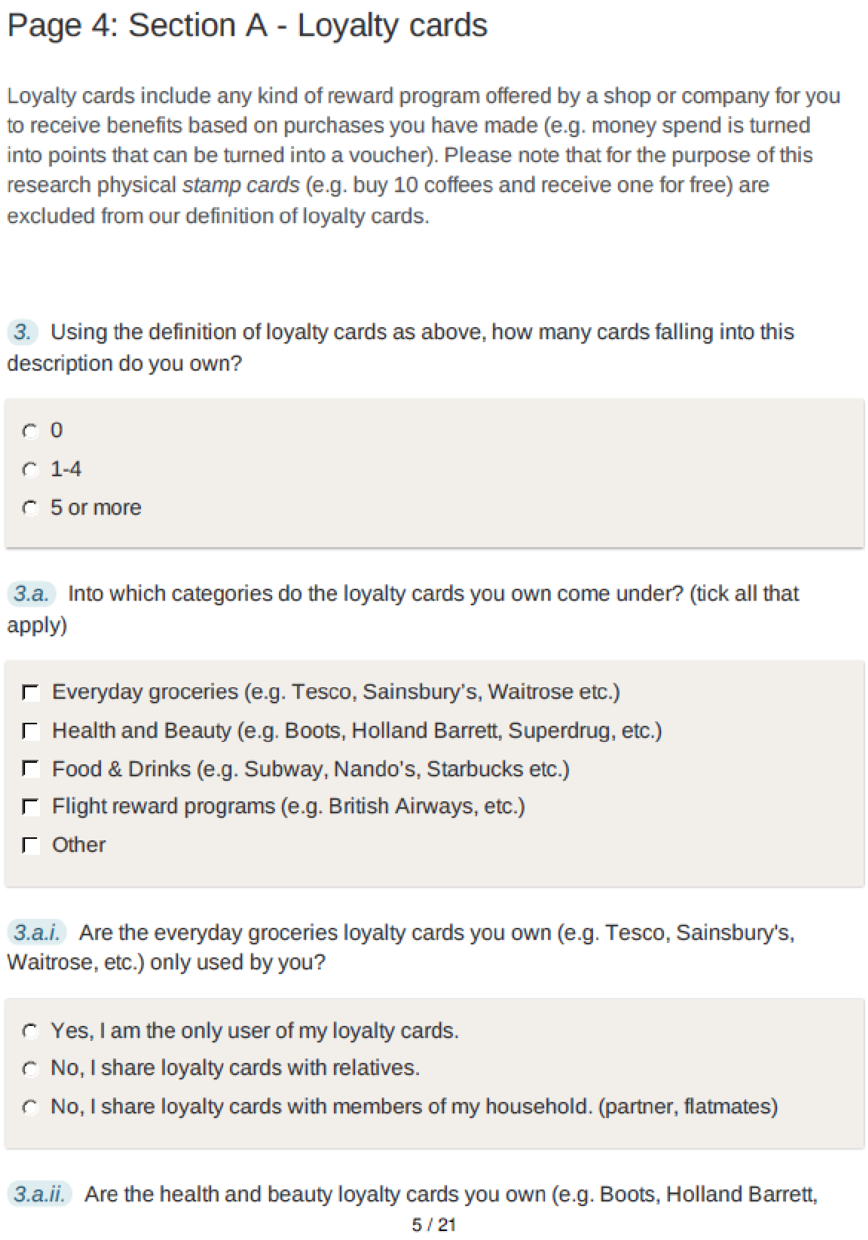
○ No



Page 3: Consent form

2. I am currently a student at the University of Nottingham.

○ Yes ○ No



Page 4: Section A - Loyalty cards

Loyalty cards include any kind of reward program offered by a shop or company for you to receive benefits based on purchases you have made (e.g. money spend is turned into points that can be turned into a voucher). Please note that for the purpose of this research physical *stamp cards* (e.g. buy 10 coffees and receive one for free) are excluded from our definition of loyalty cards.

3. Using the definition of loyalty cards as above, how many cards falling into this description do you own?

○ 0
○ 1-4
○ 5 or more

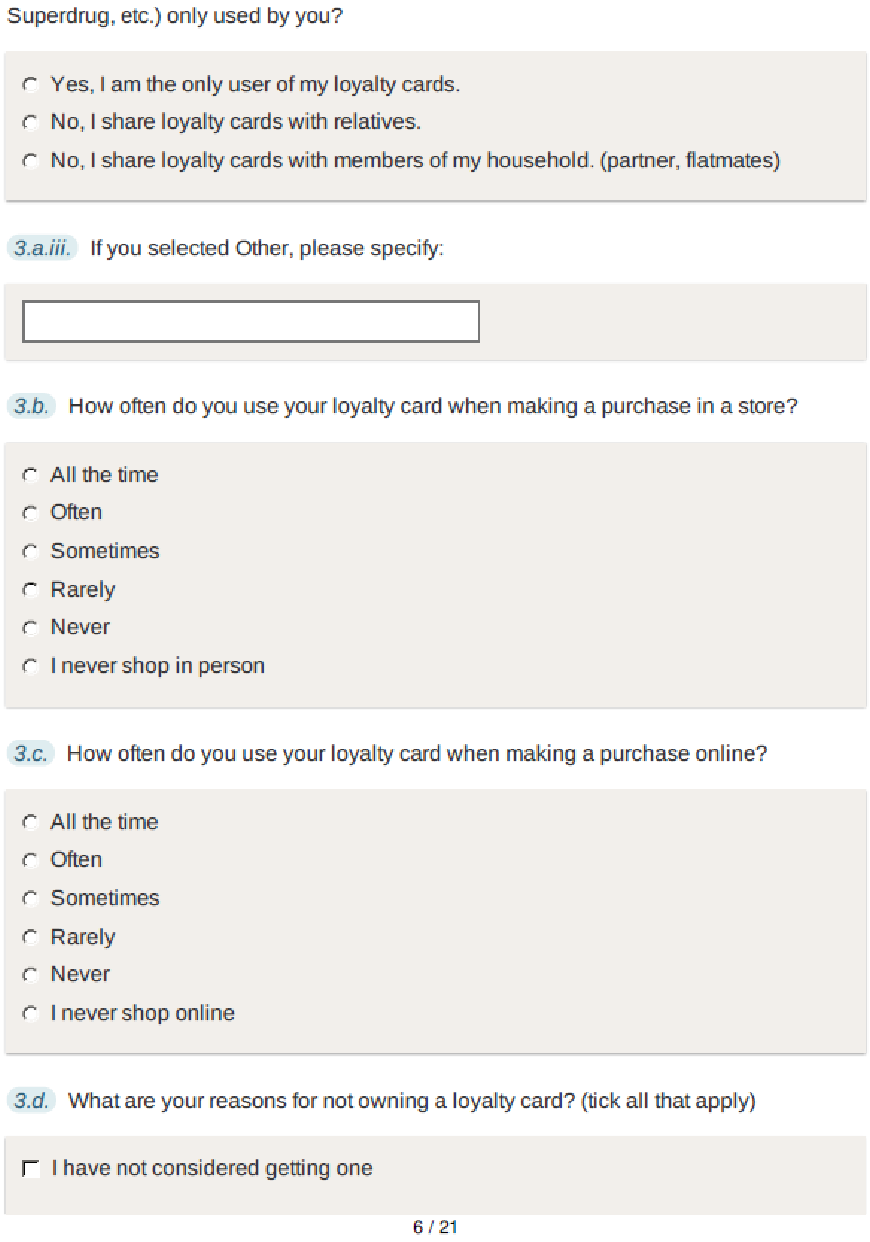
3.a. Into which categories do the loyalty cards you own come under? (tick all that apply)

☐ Everyday groceries (e.g. Tesco, Sainsbury's, Waitrose etc.)
☐ Health and Beauty (e.g. Boots, Holland Barrett, Superdrug, etc.)
☐ Food & Drinks (e.g. Subway, Nando's, Starbucks etc.)
☐ Flight reward programs (e.g. British Airways, etc.)
☐ Other

3.a.i. Are the everyday groceries loyalty cards you own (e.g. Tesco, Sainsbury's, Waitrose, etc.) only used by you?

○ Yes, I am the only user of my loyalty cards.
○ No, I share loyalty cards with relatives.
○ No, I share loyalty cards with members of my household. (partner, flatmates)

3.a.ii. Are the health and beauty loyalty cards you own (e.g. Boots, Holland Barrett,



Superdrug, etc.) only used by you?

○ Yes, I am the only user of my loyalty cards.
○ No, I share loyalty cards with relatives.
○ No, I share loyalty cards with members of my household. (partner, flatmates)

3.a.iii. If you selected Other, please specify:

3.b. How often do you use your loyalty card when making a purchase in a store?

○ All the time
○ Often
○ Sometimes
○ Rarely
○ Never
○ I never shop in person

3.c. How often do you use your loyalty card when making a purchase online?

○ All the time
○ Often
○ Sometimes
○ Rarely
○ Never
○ I never shop online

3.d. What are your reasons for not owning a loyalty card? (tick all that apply)

☐ I have not considered getting one

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- ☐ I don't see any benefits in having a loyalty card
- ☐ I don't use any shops offering a loyalty card scheme
- ☐ I have never been actively asked whether I want to participate
- ☐ I am concerned about data privacy
- ☐ I don't want to share my purchasing data with private companies
- ☐ Carrying physical loyalty cards is inconvenient
- ☐ Other

3.d.i. If you selected Other, please specify:

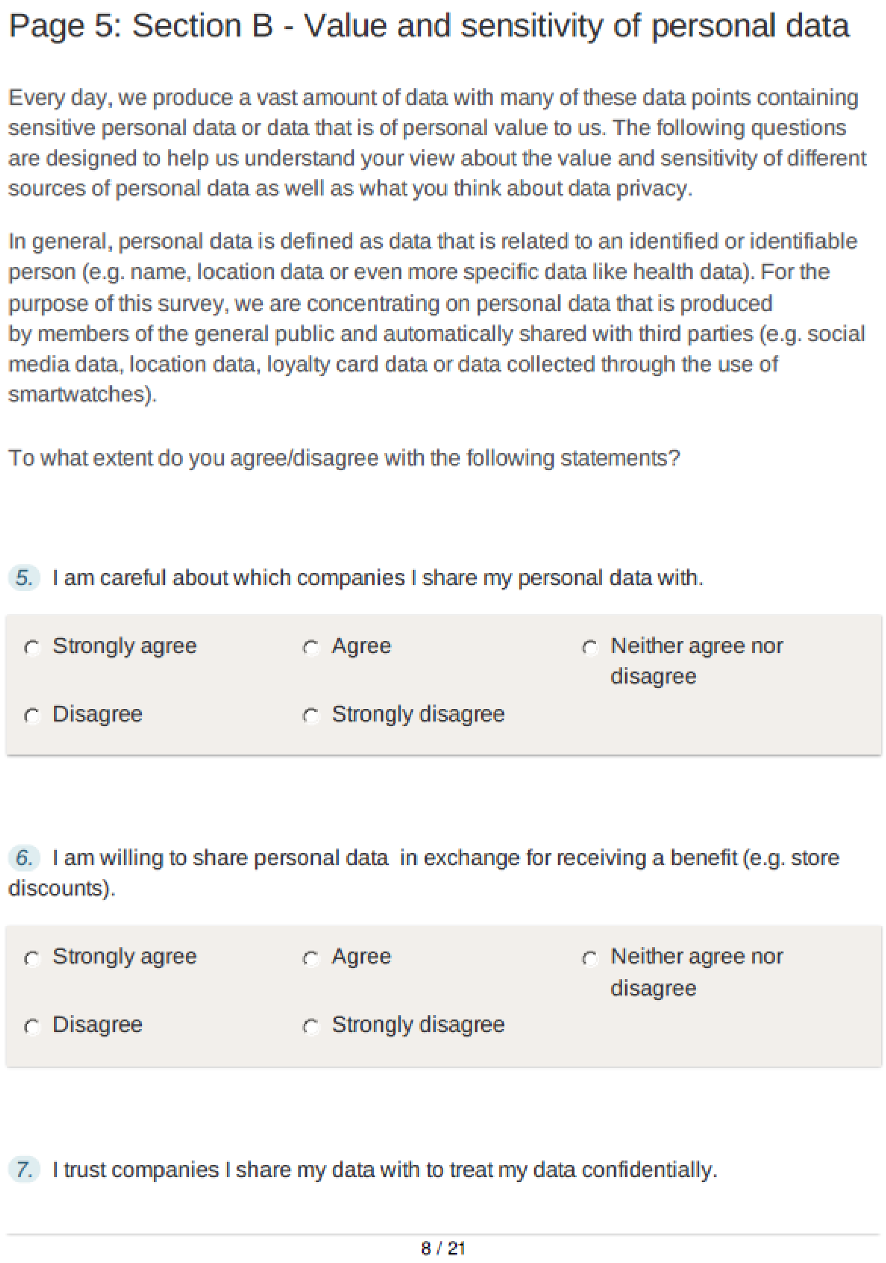
☐

4. What do you think companies running loyalty schemes use the data for? (tick all that apply)

- ☐ To personalise advertisement
- ☐ To provide the store with information about customer purchasing habits
- ☐ For individualised promotions
- ☐ To offer discounts to their customers
- ☐ To increase customer's store loyalty
- ☐ To make the store more attractive to customers
- ☐ Other

4.a. If you selected Other, please specify:

☐



Page 5: Section B - Value and sensitivity of personal data

Every day, we produce a vast amount of data with many of these data points containing sensitive personal data or data that is of personal value to us. The following questions are designed to help us understand your view about the value and sensitivity of different sources of personal data as well as what you think about data privacy.

In general, personal data is defined as data that is related to an identified or identifiable person (e.g. name, location data or even more specific data like health data). For the purpose of this survey, we are concentrating on personal data that is produced by members of the general public and automatically shared with third parties (e.g. social media data, location data, loyalty card data or data collected through the use of smartwatches).

To what extent do you agree/disagree with the following statements?

5. I am careful about which companies I share my personal data with.

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

6. I am willing to share personal data in exchange for receiving a benefit (e.g. store discounts).

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

7. I trust companies I share my data with to treat my data confidentially.

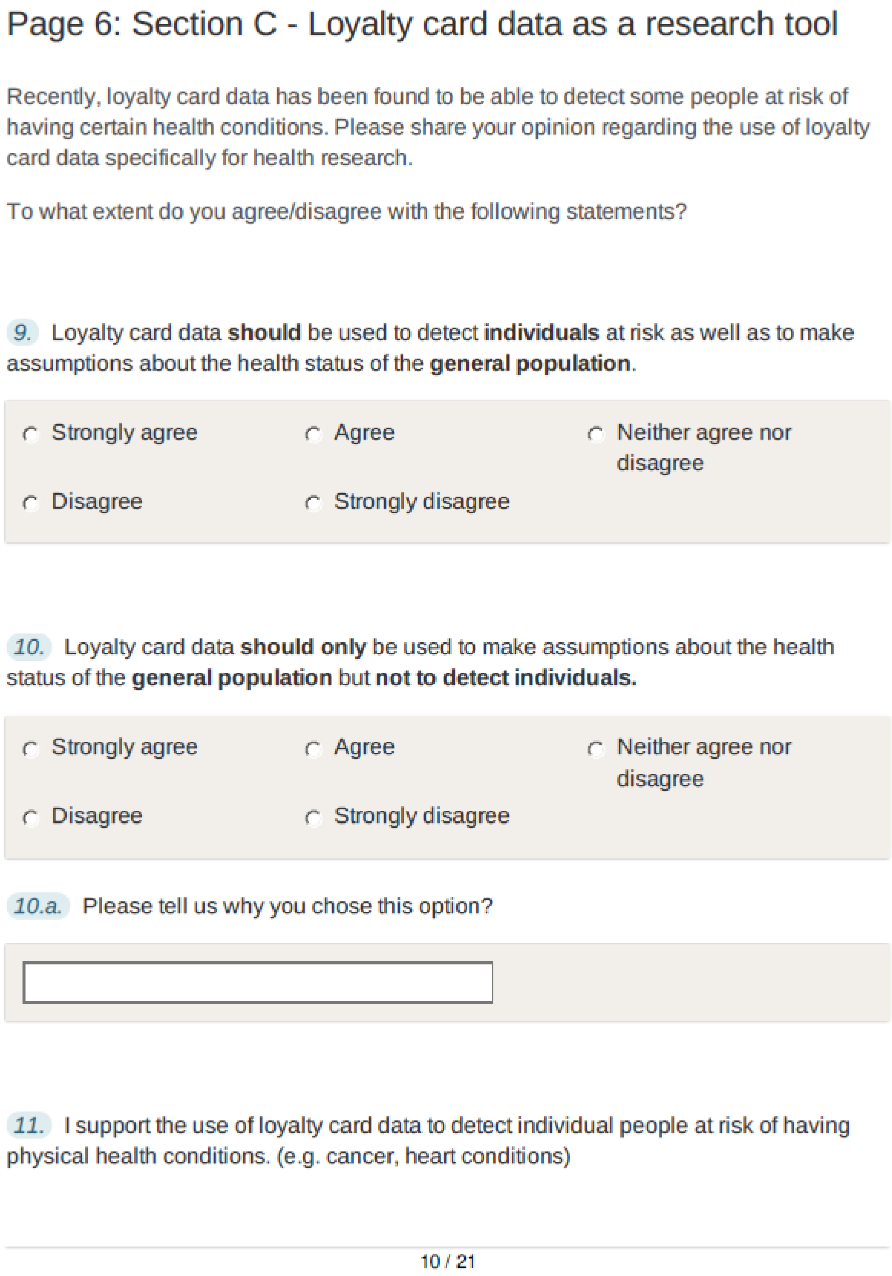
○ Strongly agree	○ Agree	○ Neither agree nor disagree
○ Disagree	○ Strongly disagree	

8. Please rank the following sources of personal data **in order** based on how concerned you would be if the data was misused. 1 represents the data source whose misuse would concern you most and 5 represents the data source whose misuse would concern you the least. (Please note, it is not necessary for you to own a smartwatch or have a social media account to answer this question, just think about the data that is produced in general and how concerning you would find the possibility of misuse.)

Please don't select more than 1 answer(s) per row.

Please don't select more than 1 answer(s) in any single column.

	1	2	3	4	5
Social Media data (e.g. Facebook or Twitter posts)	☐	☐	☐	☐	☐
Lifestyle data (e.g. data collected through wearables like smartwatches)	☐	☐	☐	☐	☐
Location data	☐	☐	☐	☐	☐
Healthcare data (e.g. electronic health records)	☐	☐	☐	☐	☐
Loyalty card data	☐	☐	☐	☐	☐



Page 6: Section C - Loyalty card data as a research tool

Recently, loyalty card data has been found to be able to detect some people at risk of having certain health conditions. Please share your opinion regarding the use of loyalty card data specifically for health research.

To what extent do you agree/disagree with the following statements?

9. Loyalty card data **should** be used to detect **individuals** at risk as well as to make assumptions about the health status of the **general population**.

○ Strongly agree	○ Agree	○ Neither agree nor disagree
○ Disagree	○ Strongly disagree	

10. Loyalty card data **should only** be used to make assumptions about the health status of the **general population** but **not to detect individuals.**

○ Strongly agree	○ Agree	○ Neither agree nor disagree
○ Disagree	○ Strongly disagree	

10.a. Please tell us why you chose this option?

11. I support the use of loyalty card data to detect individual people at risk of having physical health conditions. (e.g. cancer, heart conditions)

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

11.a. Please tell us why you chose this option?

12. I support the use of loyalty card data to detect individual people at risk of having mental health issues. (e.g. depression, anxiety)

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

12.a. Please tell us why you chose this option?

Page 7: Section D - Use of personal data

This section aims to help us understand the extent to which you would want to be informed about what is happening with your personal data and loyalty card data specifically.

13. To what extent do you agree that the following forms of personal data can be used for health research?

Please don't select more than 1 answer(s) per row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Social Media data (Facebook or Twitter posts)	☐	☐	☐	☐	☐
Lifestyle data (e.g. data collected through wearables like smartwatches)	☐	☐	☐	☐	☐
Location data	☐	☐	☐	☐	☐
Healthcare data (e.g. electronic health records)	☐	☐	☐	☐	☐
Loyalty card data	☐	☐	☐	☐	☐

14. Sharing personal data should be mandatory if there is a clear benefit to the public. (e.g. detection of disease epidemics)

○ Strongly agree
○ Agree
○ Neither agree nor disagree
○ Disagree
○ Strongly disagree

15. I would want to be informed every time my loyalty card data is being used for a new research project.

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

16. I want to be asked once before my data is being used for health research purposes, but from then on there is no need to inform me about every ongoing project.

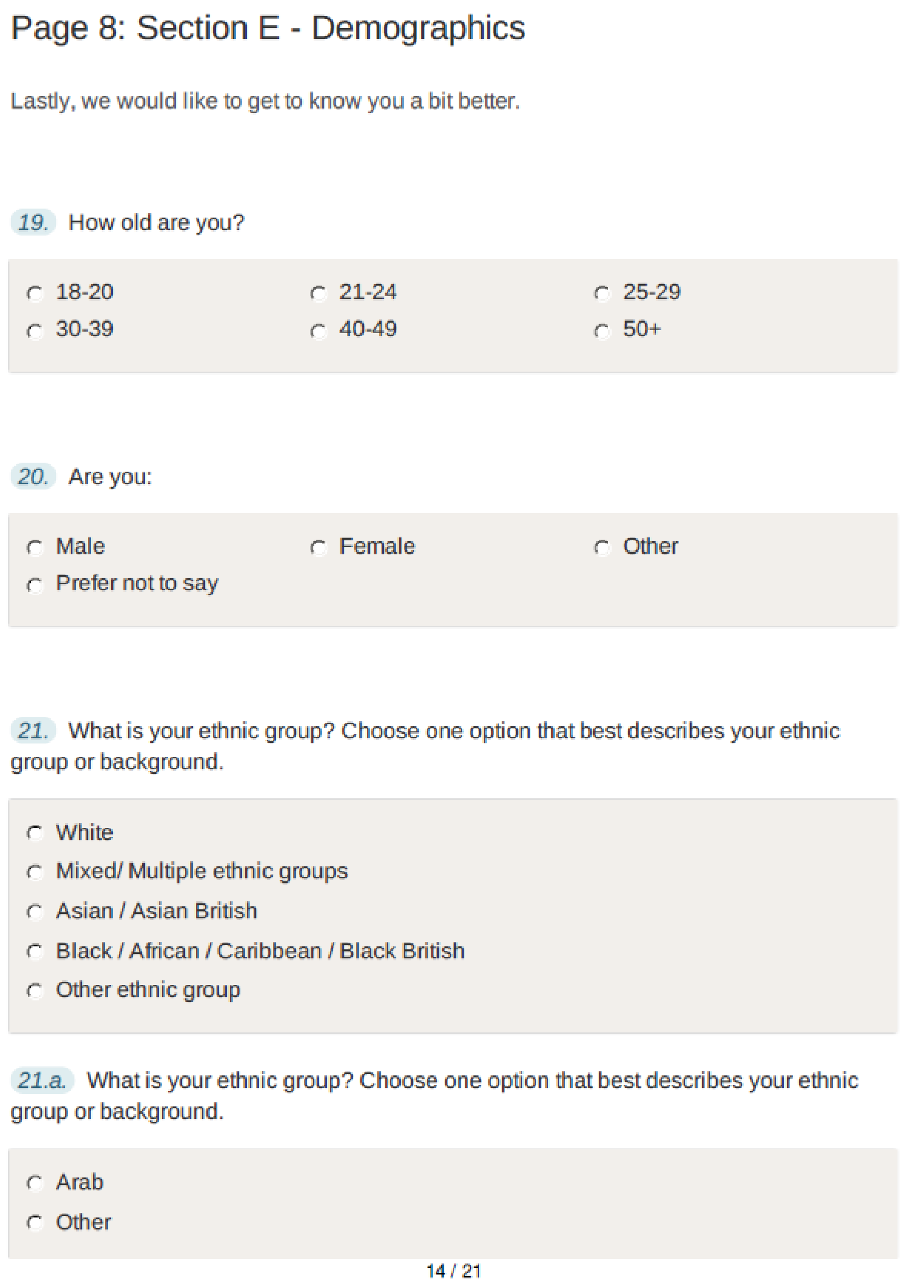
○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

17. There is no need to ask me for my permission to use purchasing data for research purposes but I want to have the possibility to withdraw my pre-given consent at any time.

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree

18. There is no need to get my consent whether it's once before or every time a research project uses my data, as long as the data is used anonymously and the project follows industry standard data protection practices.

○ Strongly agree ○ Agree ○ Neither agree nor disagree
○ Disagree ○ Strongly disagree



Page 8: Section E - Demographics

Lastly, we would like to get to know you a bit better.

19. How old are you?

○ 18-20 ○ 21-24 ○ 25-29
○ 30-39 ○ 40-49 ○ 50+

20. Are you:

○ Male ○ Female ○ Other
○ Prefer not to say

21. What is your ethnic group? Choose one option that best describes your ethnic group or background.

○ White
○ Mixed/ Multiple ethnic groups
○ Asian / Asian British
○ Black / African / Caribbean / Black British
○ Other ethnic group

21.a. What is your ethnic group? Choose one option that best describes your ethnic group or background.

○ Arab
○ Other

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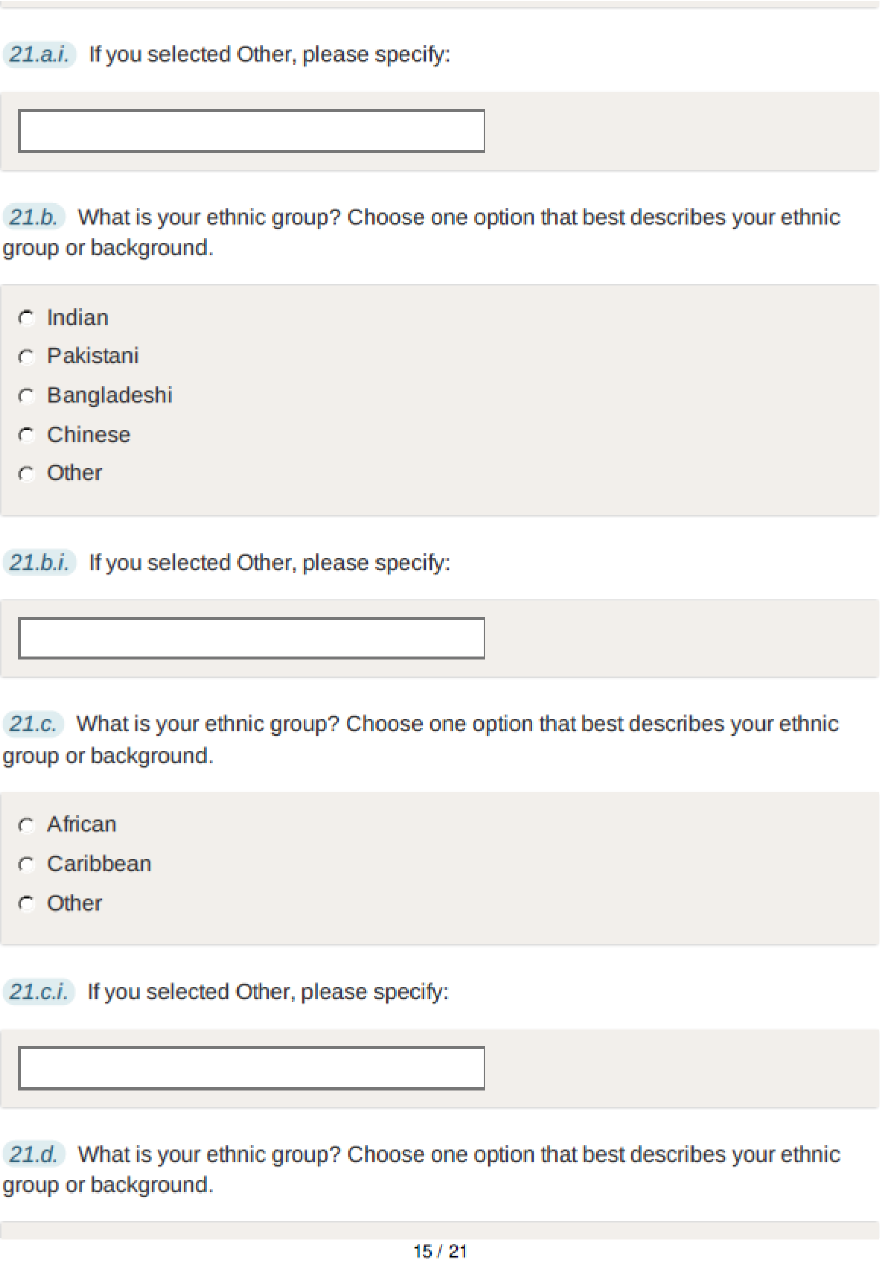


21.a.i. If you selected Other, please specify:

21.b. What is your ethnic group? Choose one option that best describes your ethnic group or background.

- ○ Indian
- ○ Pakistani
- ○ Bangladeshi
- ○ Chinese
- ○ Other

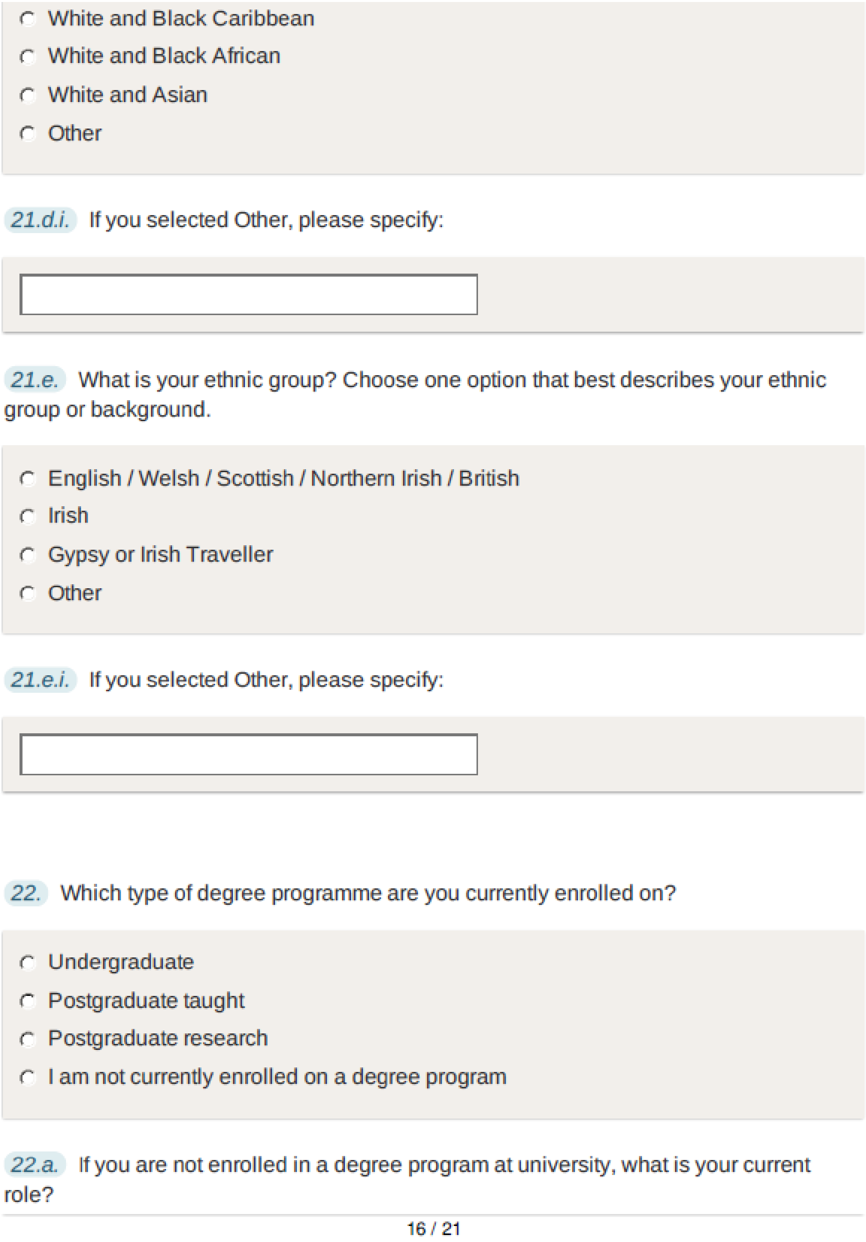
21.b.i. If you selected Other, please specify:

21.c. What is your ethnic group? Choose one option that best describes your ethnic group or background.

- ○ African
- ○ Caribbean
- ○ Other

21.c.i. If you selected Other, please specify:

21.d. What is your ethnic group? Choose one option that best describes your ethnic group or background.



○ White and Black Caribbean
○ White and Black African
○ White and Asian
○ Other

21.d.i. If you selected Other, please specify:

21.e. What is your ethnic group? Choose one option that best describes your ethnic group or background.

○ English / Welsh / Scottish / Northern Irish / British
○ Irish
○ Gypsy or Irish Traveller
○ Other

21.e.i. If you selected Other, please specify:

22. Which type of degree programme are you currently enrolled on?

○ Undergraduate
○ Postgraduate taught
○ Postgraduate research
○ I am not currently enrolled on a degree program

22.a. If you are not enrolled in a degree program at university, what is your current role?

23. Which subject are you studying? (Tick all that apply.)

☐ Art
☐ Engineering
☐ Medicine and Health Sciences
☐ Science
☐ Social Sciences
☐ Not applicable

23.a. Which subject area are you studying? (Tick all that apply.)

☐ Economics
☐ Education
☐ Geography
☐ Law
☐ Politics and International Relations
☐ Sociology and Social Policy
☐ Business

23.b. Which subject area are you studying? (Tick all that apply.)

☐ Biosciences
☐ Chemistry
☐ Computer Science
☐ Mathematical Sciences
☐ Pharmacy
☐ Physics and Astronomy

☐ Psychology

23.c. Which subject area are you studying? (Tick all that apply.)

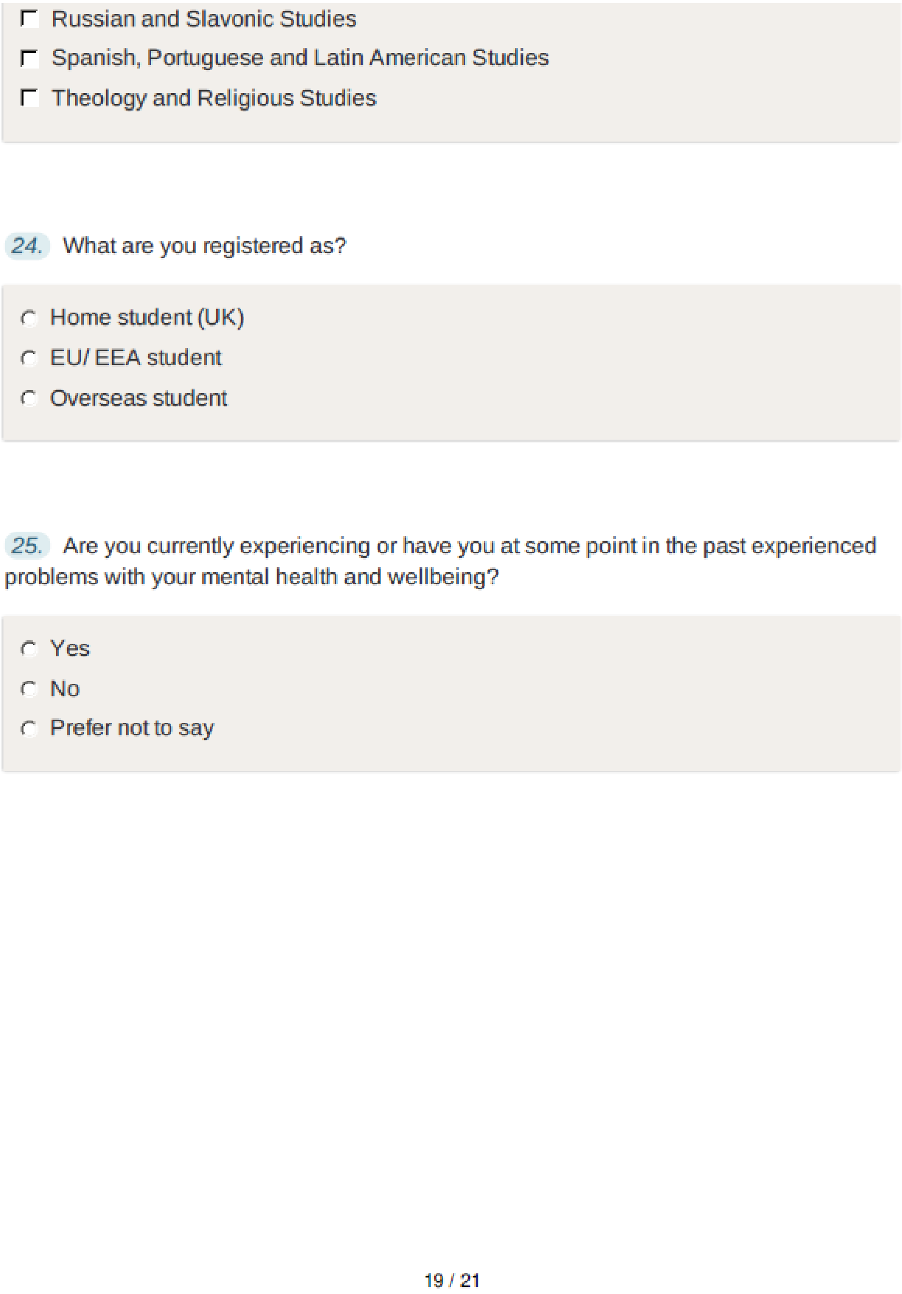
☐ Health Sciences
☐ Life Sciences
☐ Medicine
☐ Veterinary Medicine and Science

23.d. Which subject area are you studying? (Tick all that apply.)

☐ Architecture and Built Environment
☐ Chemical and Environmental Engineering
☐ Civil Engineering
☐ Electrical and Electronic Engineering
☐ Mechanical, Materials and Manufacturing Engineering

23.e. Which subject area are you studying? (Tick all that apply.)

☐ American and Canadian Studies
☐ Classics and Archaeology
☐ Cultural, Media and Visual Studies
☐ Cultures, Languages and Area Studies
☐ English
☐ French and Francophone Studies
☐ German Studies
☐ History
☐ Humanities
☐ Modern Languages and Cultures
☐ Music
☐ Philosophy



☐ Russian and Slavonic Studies
☐ Spanish, Portuguese and Latin American Studies
☐ Theology and Religious Studies

24. What are you registered as?

○ Home student (UK)
○ EU/ EEA student
○ Overseas student

25. Are you currently experiencing or have you at some point in the past experienced problems with your mental health and wellbeing?

○ Yes
○ No
○ Prefer not to say

Page 9: Future research

26. Before the end of this questionnaire, we would like to know if there is something you would want to add in regard to the questions we have asked you?

27. One person completing the questionnaire will be randomly chosen and win a £50 gift voucher. In order to contact the winner, we ask you to provide your email address below.

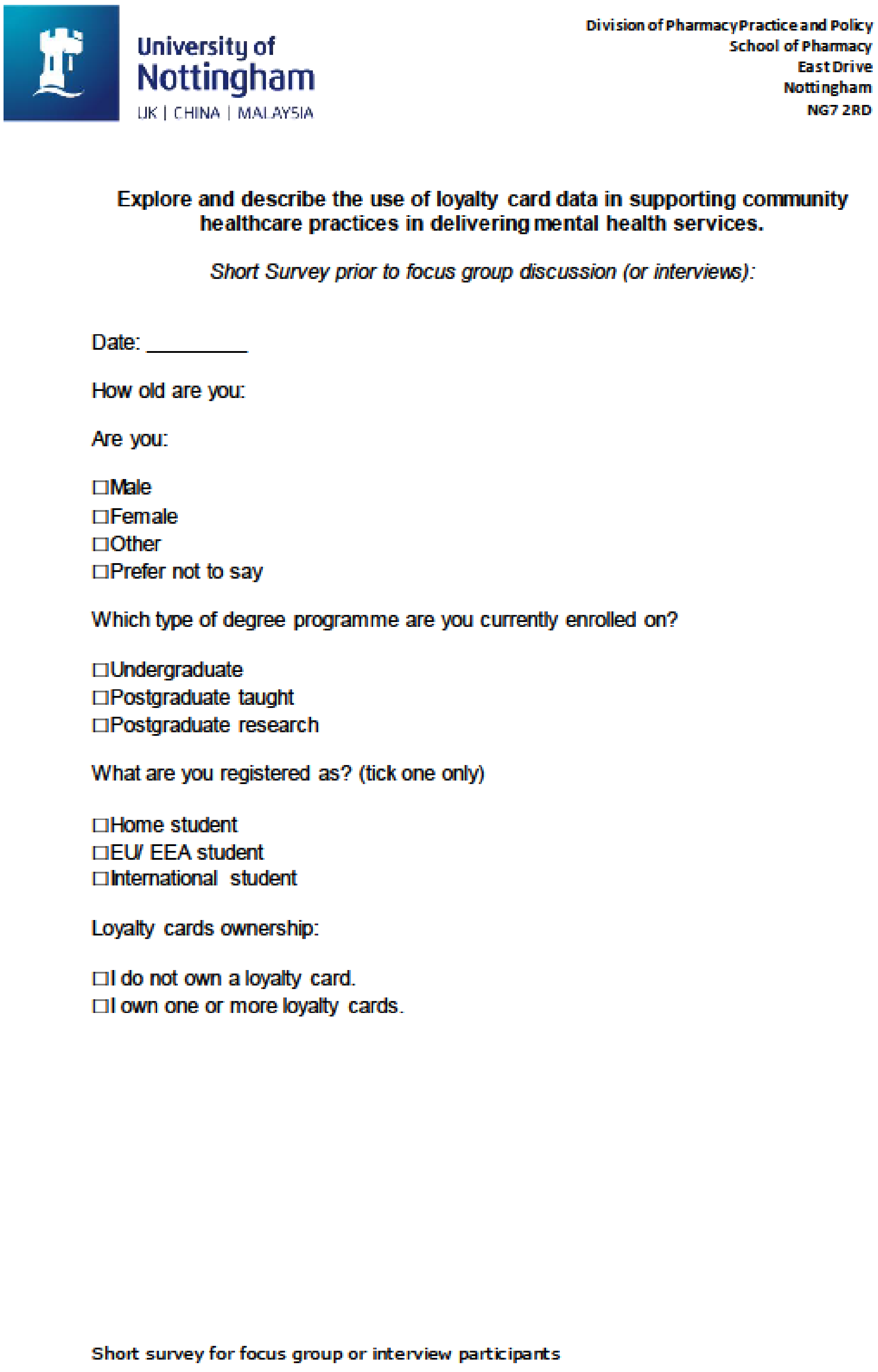
28. Finally, this questionnaire is part of a larger project and based on its results we plan to conduct focus groups and interviews, to assist our understanding in this area. Would you be interested in participating in our further research?

○ I am interest to participate in future research projects exploring the topic and you can use the email address provided to contact me.

○ I don't want to participate and don't wish to be contacted.

28.a. Please provide your name below:

Appendix 3: Short survey student interviews



University of Nottingham
UK | CHINA | MALAYSIA

Division of Pharmacy Practice and Policy
School of Pharmacy
East Drive
Nottingham
NG7 2RD

Explore and describe the use of loyalty card data in supporting community healthcare practices in delivering mental health services.

Short Survey prior to focus group discussion (or interviews):

Date: _________

How old are you:

Are you:

☐Male
☐Female
☐Other
☐Prefer not to say

Which type of degree programme are you currently enrolled on?

☐Undergraduate
☐Postgraduate taught
☐Postgraduate research

What are you registered as? (tick one only)

☐Home student
☐EU/ EEA student
☐International student

Loyalty cards ownership:

☐I do not own a loyalty card.
☐I own one or more loyalty cards.

Short survey for focus group or interview participants

Appendix 4: Interview guide students

Semi-structured topic guide for focus groups (or individual interviews)

1. Introduction
    a) Focus groups: explanation of the focus group process, introduction to the research and researcher, possibility to ask questions, signing of consent forms; introduction of every participant, completing of short focus group surveys
    b) Interviews: Explanation of the interview process, introduction of researcher and interviewee, Introduction to the research and handing out participant information sheets, signing of consent form

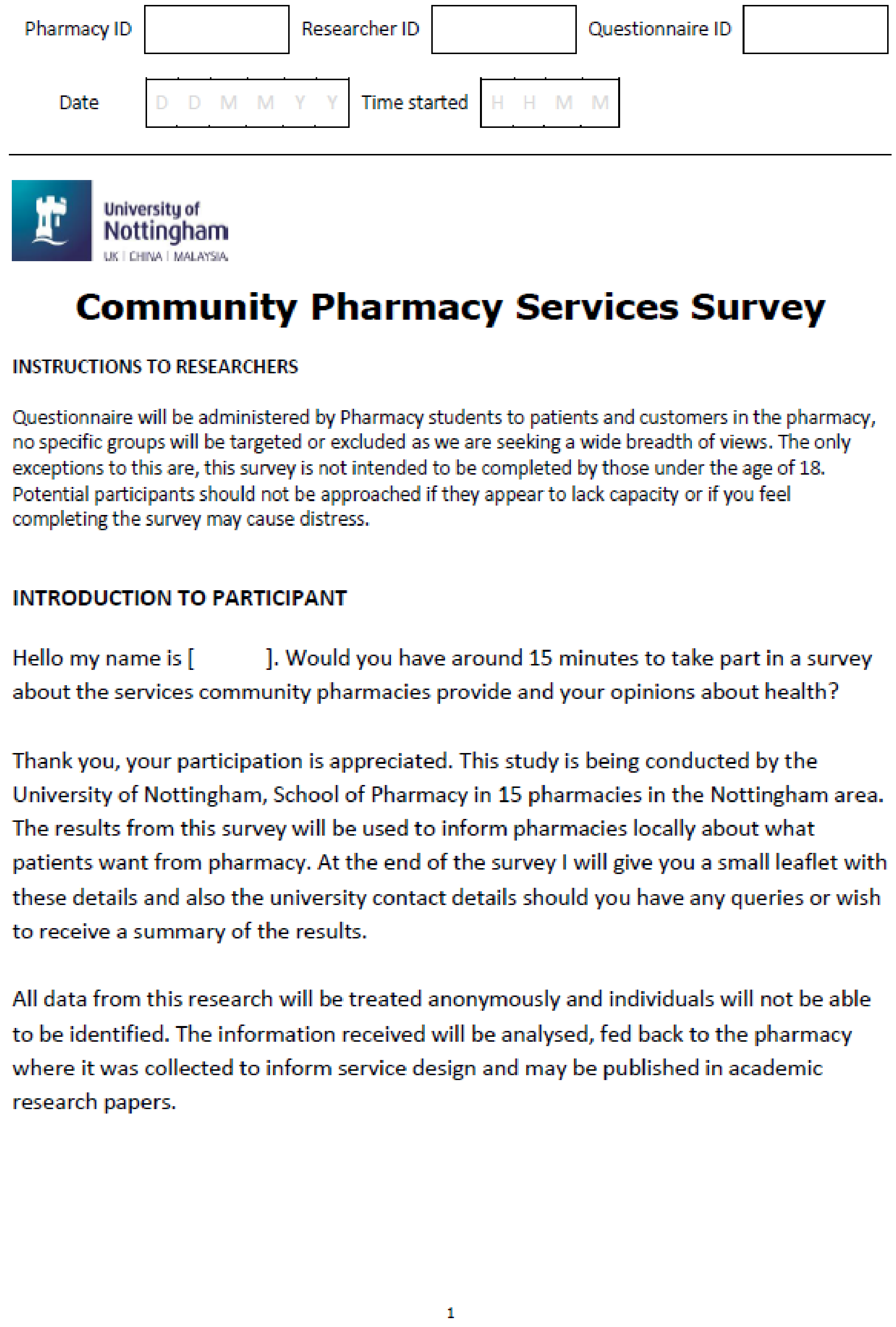
Before the start of the conversation (Focus groups or interviews) a definition of loyalty cards will be given to the participants. Reminder that disclosure of any diagnoses related to mental health is entirely voluntary..

2. Monitoring health using loyalty cards
    - Introduction to the concept that data analysis opens possibilities to detect/identify patients at risk of having certain health conditions (e.g. mental health issues) based on different sources of personal data (social media, loyalty cards, wearables) (reactions, thoughts?)
    - The concept of "Monitoring" → what are the opinions regarding investigating health issues through purchasing data, (prompts: surveillance, intrusion in private space?; change in opinion when talking about mental health issues being detected?)
    - Willingness/ approval to share personal data for health research (prompts: change in opinion when talking about mental health issues being detected?)
    - Monitoring individuals vs. the general population (prompts: change in opinion when talking about mental health issues being detected?)

3. Discussion of questionnaire findings

4. Consent/transparency/active involvement
    - Discussion of consent options (opt-in/opt/out), understanding of terms and conditions (prompts: preferences in consent options for loyalty card data?)
    - Transparency about ongoing research using personal data (How much transparency is wanted, trust in research using personal data)
    - Students interest to be informed about potential results stemming from loyalty card research

Appendix 5: Survey pharmacy users



Pharmacy ID ☐ Researcher ID ☐ Questionnaire ID ☐

Date D D M M Y Y Time started H H M M

University of Nottingham
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Community Pharmacy Services Survey

INSTRUCTIONS TO RESEARCHERS

Questionnaire will be administered by Pharmacy students to patients and customers in the pharmacy, no specific groups will be targeted or excluded as we are seeking a wide breadth of views. The only exceptions to this are, this survey is not intended to be completed by those under the age of 18. Potential participants should not be approached if they appear to lack capacity or if you feel completing the survey may cause distress.

INTRODUCTION TO PARTICIPANT

Hello my name is [ ]. Would you have around 15 minutes to take part in a survey about the services community pharmacies provide and your opinions about health?

Thank you, your participation is appreciated. This study is being conducted by the University of Nottingham, School of Pharmacy in 15 pharmacies in the Nottingham area. The results from this survey will be used to inform pharmacies locally about what patients want from pharmacy. At the end of the survey I will give you a small leaflet with these details and also the university contact details should you have any queries or wish to receive a summary of the results.

All data from this research will be treated anonymously and individuals will not be able to be identified. The information received will be analysed, fed back to the pharmacy where it was collected to inform service design and may be published in academic research papers.

VISITING PHARMACIES

1. Why did you visit this pharmacy today? (Tick ALL that apply)

☐ To collect prescription medicines
☐ Medicines review
☐ For advice
☐ Other (specify)
☐ Purchase medicines
☐ Purchase non medicinal products (e.g. toiletries)
☐ For a specific service (e.g. smoking cessation clinic)
☐ Prefer not to say

2. Do you normally use the same pharmacy?

☐ Yes ☐ No

3. Is this the pharmacy you normally use?

☐ Yes ☐ No

4. How often do you use a pharmacy?

☐ At least once a week
☐ Less than once a week but more than once a month
☐ Once a month or less

5. What services have you used pharmacies for in the past? (Tick ALL that apply)

☐ To collect prescription medicines
☐ Medicines review
☐ For advice about your medicines
☐ For advice about your health
☐ Other (specify)
☐ Purchase medicines
☐ Purchase non medicinal products (e.g. toiletries)
☐ For a specific service (e.g. smoking cessation clinic)
☐ Prefer not to say

MY OPINIONS OF HEALTH CARE AND PHARMACIES

6. Which of the following do you think community pharmacists and their teams can help you with? (Tick ALL that apply)

☐ Advice and support about medicines
☐ Repeat prescriptions
☐ Advice about mental health issues
☐ Healthy living advice
☐ Other (specify)
☐ Managing common conditions such as flu, colds etc.
☐ Advice about vitamins and herbal medicines
☐ Managing long term conditions (e.g. diabetes).
☐ None of the above

To what extent do you agree or disagree with the following statements:

7. I like to manage my own health needs

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

8. I prefer to only go to my doctor when I really have to

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

9. I trust my pharmacist to give me an accurate diagnosis when I ask about symptoms

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

10. I trust my pharmacist to give me good advice about medicines

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

11. I trust my pharmacist to give me good advice about general health

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

12. My pharmacist cares about me

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

13. For people who take medicines regularly, it is normal to miss an occasional dose

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

14. For people who take medicines regularly, missing an occasional dose cannot be helped

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

15. I would know where to get advice if I missed a dose of my medicine

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

16. When I'm ill, I find it difficult to decide who I should consult/where I should seek help

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

17. I worry that I would get in trouble if I turned up to the wrong place when I wanted to seek help

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

18. I am comfortable buying medicines from an online pharmacy to be delivered directly to my home

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

19. Public health campaigns for example on TV, radio, billboards and bus adverts have helped increase my awareness of health issues.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

Screening is where a professional provides a test to see if a patient has a particular condition. Anyone can receive the test, it is not dependent on having specific symptoms.

20. Community pharmacies are a suitable place for chlamydia screening (sexually transmitted infection).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

21. Community pharmacies are a suitable place for HIV screening.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

22. Community pharmacies are a suitable place for Hepatitis C screening (blood infection).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

23. Community pharmacies are a suitable place for mental health screening (e.g. depression).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

Those were some general questions about pharmacies and health. I would now like to move on to understanding more about your opinions about mental health issues

24. Mental health is a significant problem in the UK
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

25. If I felt I had a problem with my mental health I would know which health professional I would consult
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

26. If I felt I had a problem with my mental health I would consult a community pharmacist first
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

27. If I felt I had a problem with my mental health I would consult a community pharmacist as well as other health professionals such as my GP
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

28. Community pharmacists are well placed to identify patients with mental health issues
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

29. I trust my pharmacist to give me good advice about my mental health
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

30. How **could** community pharmacists assist patients who have mental health issues?

31. Community pharmacists **should** do more to assist patients who have mental health issues
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

32. If you said agree or strongly agree, how **should** community pharmacists do more to assist patients who have mental health issues?

33. Community pharmacy provides a suitable environment to talk about mental health issues.
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

34. Please tell us why you think community pharmacy would be suitable/ would not be a suitable environment?

35. People with mental health problems are more likely to miss doses of their medicines
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

36. There is sufficient provision for mental health in the NHS at the present time
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

37. People with mental health problems are just the same as anyone else
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

38. Depression is a lifelong condition that cannot be helped
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

39. People with learning difficulties always have mental health problems
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

40. Autism is a mental health condition
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

This last part of our questionnaire seeks to understand more about loyalty cards and personal data.

Loyalty Cards

Loyalty cards include any kind of reward programme offered by a shop or company for you to receive benefits based on purchases you have made (e.g. money spend is turned into points that can be redeemed for a voucher). Please note that for the purpose of this survey physical stamp cards (e.g. buy 10 coffees and receive one for free) are excluded from our definition of loyalty cards.

55. Using this definition of loyalty cards; how many cards do you have?

☐ 0 *(go to Q56)* ☐1-4 *(go to Q57)* ☐ 5 or more *(go to Q57)*

56. What are your reasons for NOT having a loyalty card? (tick ALL that apply)

☐ I have not considered getting one
☐ I don't see any benefits in having a loyalty card
☐ I don't use any shops offering a loyalty card scheme
☐ I have never been asked whether I want to participate
☐ I am concerned about data privacy
☐ I don't want to share my purchasing data with private companies
☐ Carrying physical loyalty cards is inconvenient
☐ I do not make purchases frequent enough in one store
☐ Other (please specify)

(Go to Q62)

57. Into which categories do the loyalty cards you have come under? (tick ALL that apply)

☐ Everyday groceries *(e.g. Tesco, Sainsbury's, Waitrose etc.)*
☐ Health and Beauty *(e.g. Boots, Holland Barrett, Superdrug, etc.)*
☐ Food & Drinks *(e.g. Subway, Nando's, Starbucks etc.)*
☐ Flight reward programs *(e.g. British Airways, etc.)*
☐ Other (please specify)

58. Are the loyalty cards you own used ONLY by you?

☐ Yes, I am the ONLY USER of ALL of my loyalty cards. *(go to 60)*
☐ No, we SHARE our loyalty cards. (e.g. together with relatives, partner, flatmates) *(go to 59)*

59. Which categories do your jointly used loyalty cards fall under? (tick ALL that apply)

☐ Everyday groceries *(e.g. Tesco, Sainsbury's, Waitrose etc.)*
☐ Health and Beauty *(e.g. Boots, Holland Barrett, Superdrug, etc.)*
☐ Food & Drinks *(e.g. Subway, Nando's, Starbucks etc.)*
☐ Flight reward programs *(e.g. British Airways, etc.)*
☐ Other (please specify)

60. How often do you use your loyalty cards when making a purchase in a store for which you have a card?

☐ Every time ☐ Most times ☐ Sometimes ☐ Rarely ☐ Never

61. When you are making a purchase online using a store for which you have a card; how often do you use your loyalty card?

☐ Every time ☐ Most times ☐ Sometimes ☐ Rarely ☐ Never
☐ I do not shop online

62. How do you think companies running loyalty schemes use your data? (tick ALL that apply)

☐ To offer individualised discounts to me
☐ To personalise adverts to me
☐ To provide the store with information about my purchasing habits
☐ To increase my loyalty to the store
☐ To make me more likely to shop in the store
☐ Other (please specify)

MY OPINION ABOUT DATA SHARING

For the purpose of this questionnaire personal data is defined as any data we actively or unknowingly produce in our daily lives, including social media data, location data, lifestyle data (e.g. through the use of wearables like Fitbits or Smartwatches), loyalty card data and data in electronic health records. The next questions ask how you feel about this.

63. I am careful about which companies I share my personal data with.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

64. I am willing to share personal data in exchange for receiving a benefit (e.g. money off).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

65. I trust companies I share my data with to treat my data confidentially.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

It has been found that purchasing data can detect people at risk of having some health conditions. The next questions ask how you feel about this.

66. Purchasing data should be used to detect individuals at risk of developing health conditions.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

67. Purchasing data should only be used to make assumptions about the health status of the general population but not to identify individuals.

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

68. I am in favour of the use of loyalty card data to identify individual people at risk of having physical health conditions (e.g. cancer, heart conditions).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

69. I am in favour of the use of loyalty card data to identify individual people at risk of having mental health issues (e.g. depression, anxiety).

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

To what extent do you agree that the following forms of personal data can be used for health research?

70. Social media data (e.g. Facebook or Twitter posts)

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

71. Lifestyle data (e.g. data collected through wearables like smartwatches)

☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

72. Location data (e.g. from your mobile phone)
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

73. Healthcare data (e.g. electronic GP records)
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

74. Loyalty card data
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

75. Sharing personal data should be mandatory if there is a clear benefit to the public (e.g. detection of disease epidemics).
☐ Strongly agree ☐ Agree ☐ Neither agree nor disagree ☐ Disagree ☐ Strongly disagree

ABOUT YOU

76. Are you:
☐ Male ☐ Female ☐ Other ☐ Prefer not to say

77. What age group are you in?
☐ 18-34 ☐ 35-49 ☐ 50-64 ☐ 65-79 ☐ 80+ ☐ Prefer not to say

78. Are you eligible for free prescriptions?
☐ Yes ☐ No ☐ Prefer not to say

79. Which ethnic group do you see yourself as being a member of? Choose ONE option that best describes your ethnic group or background.

White
☐ English / Welsh / Scottish / Northern Irish / British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Any other White background, please describe

Mixed / Multiple ethnic groups
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed / Multiple ethnic background, please describe

☐ Prefer not to say

Asian / Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, please describe

Black / African / Caribbean / Black British
☐ African
☐ Caribbean
☐ Any other Black / African / Caribbean background, please describe

Other ethnic group
☐ Arab
☐ Any other ethnic group, please describe

80. Have you previously been, or are you currently, affected by any of following conditions? (Tick ALL that apply)
☐ Heart conditions (e.g. Coronary heart disease, Angina, Heart failure, Arrhythmia)
☐ Diabetes
☐ High cholesterol
☐ High blood pressure
☐ Other long term condition
☐ Prefer not to say
☐ Respiratory conditions (Asthma/COPD)
☐ Depression and/or Anxiety disorder
☐ Long term pain
☐ Never suffered from any long term condition

Thank you very much for participating in this survey (*Give participant study and recruitment leaflets*)

Appendix 6: Amendment to research ethics form 023-2017-er

29/06/2020

Application for amendment to ethical approval for application ref. 023-2017er

Summary:

The community pharmacy survey 2020 has been distributed in 16 community pharmacies in Nottingham between 2nd and 15th March 2020. Due to the outbreak of COVID-19 data collection had to be terminated prematurely, with 1474 responses collected at the close of data collection. However, as stated in the initial ethics application, the survey served as a way to recruit participants for further qualitative research. Fourteen survey respondents agreed to participate in follow up research. Qualitative research projects often refrain from pre-determining a sample size. Instead, one aims to conduct interviews until thematic data saturation is achieved (i.e. no new themes emerge from the interviews). It is therefore impossible to estimate whether 14 participants will be adequate for, and continue to consent to, answering our research question sufficiently, however experience from previous research projects indicate that more participants may be necessary.

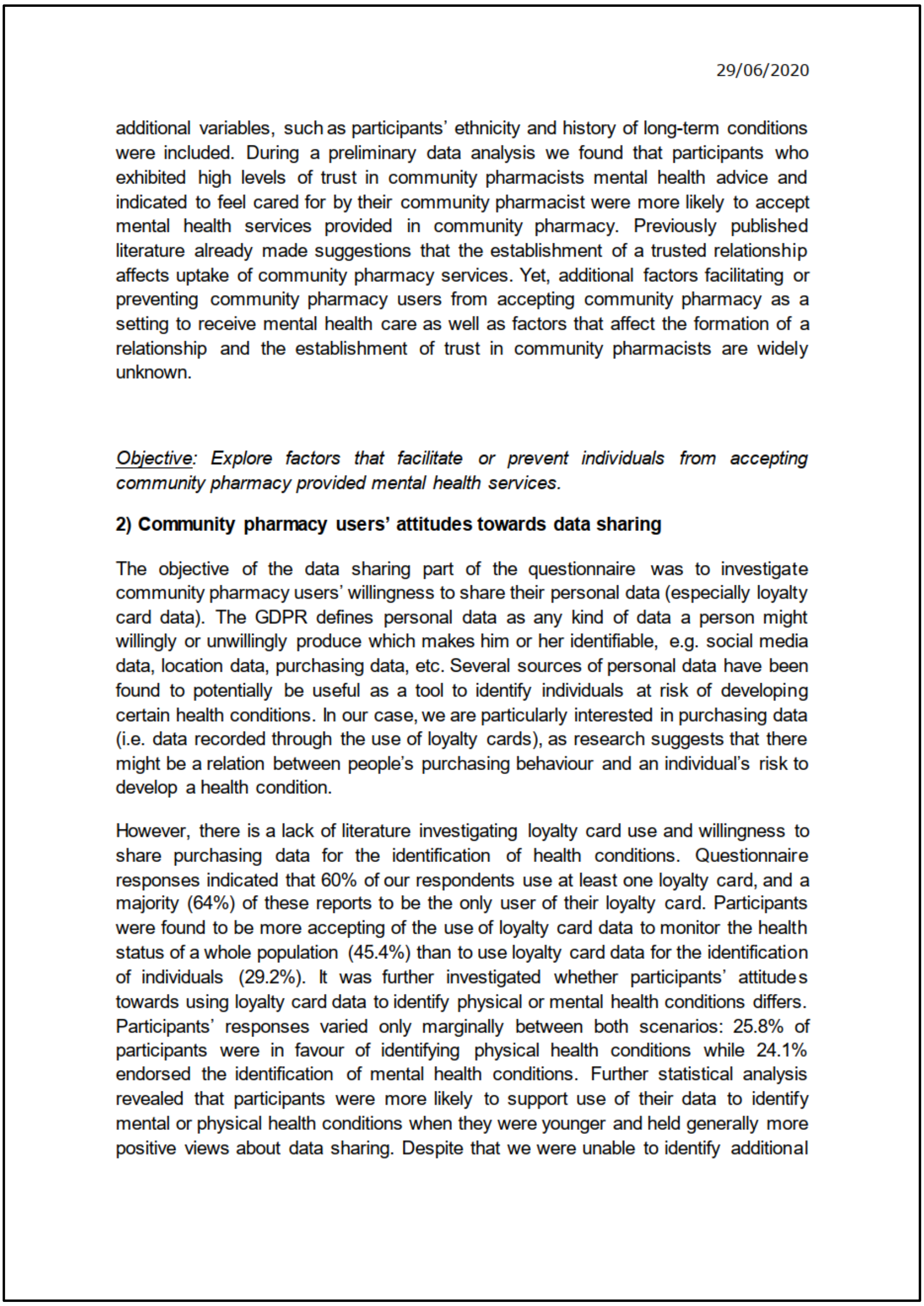
The purpose of this amendment is to introduce additional opportunities for participant recruitment into the research project and to get approval for the semi-structured interview guide. Two parts of the questionnaire are of interest for the follow up research: participants' attitudes towards the provision of mental health services in community pharmacy and their attitudes towards data sharing (with a focus on using loyalty card to identify individuals at risk of having certain health conditions.)

However, since the initial administration of the questionnaire in March both, the health care landscape as well as the way personal information is used in a health care context (e.g. through the emergence of symptom tracking apps, or track-and-tracing strategies) have changed tremendously. It is almost inevitable that the outbreak of COVID-19 will have also impacted the views of our participants. It is therefore necessary to contextualise *how* the outbreak of COVID-19 has shaped participants' attitudes towards both our objectives. The interview guide will therefore not only include questions helping us to understand topics that arose from the preliminary data analysis, but will also ask participants to provide insights about changes concerning their use of community pharmacy and concerning their view towards data sharing.

Overview of study objectives:

1) Provision of mental health services in community pharmacy:

The objective of this section of the questionnaire was to investigate community pharmacy users' acceptance of mental health services provided in community pharmacy. Questions were phrased similarly to last year's questionnaire, however



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additional variables, such as participants' ethnicity and history of long-term conditions were included. During a preliminary data analysis we found that participants who exhibited high levels of trust in community pharmacists mental health advice and indicated to feel cared for by their community pharmacist were more likely to accept mental health services provided in community pharmacy. Previously published literature already made suggestions that the establishment of a trusted relationship affects uptake of community pharmacy services. Yet, additional factors facilitating or preventing community pharmacy users from accepting community pharmacy as a setting to receive mental health care as well as factors that affect the formation of a relationship and the establishment of trust in community pharmacists are widely unknown.

Objective: Explore factors that facilitate or prevent individuals from accepting community pharmacy provided mental health services.

2) Community pharmacy users' attitudes towards data sharing

The objective of the data sharing part of the questionnaire was to investigate community pharmacy users' willingness to share their personal data (especially loyalty card data). The GDPR defines personal data as any kind of data a person might willingly or unwillingly produce which makes him or her identifiable, e.g. social media data, location data, purchasing data, etc. Several sources of personal data have been found to potentially be useful as a tool to identify individuals at risk of developing certain health conditions. In our case, we are particularly interested in purchasing data (i.e. data recorded through the use of loyalty cards), as research suggests that there might be a relation between people's purchasing behaviour and an individual's risk to develop a health condition.

However, there is a lack of literature investigating loyalty card use and willingness to share purchasing data for the identification of health conditions. Questionnaire responses indicated that 60% of our respondents use at least one loyalty card, and a majority (64%) of these reports to be the only user of their loyalty card. Participants were found to be more accepting of the use of loyalty card data to monitor the health status of a whole population (45.4%) than to use loyalty card data for the identification of individuals (29.2%). It was further investigated whether participants' attitudes towards using loyalty card data to identify physical or mental health conditions differs. Participants' responses varied only marginally between both scenarios: 25.8% of participants were in favour of identifying physical health conditions while 24.1% endorsed the identification of mental health conditions. Further statistical analysis revealed that participants were more likely to support use of their data to identify mental or physical health conditions when they were younger and held generally more positive views about data sharing. Despite that we were unable to identify additional

factors that correlate with participants acceptance to share data, thus further qualitative research is necessary.

Objective: Explore participants' attitude towards sharing personal data (with a focus on loyalty card data) to identify individuals at risk of having physical and/ or mental health conditions.

Methods:

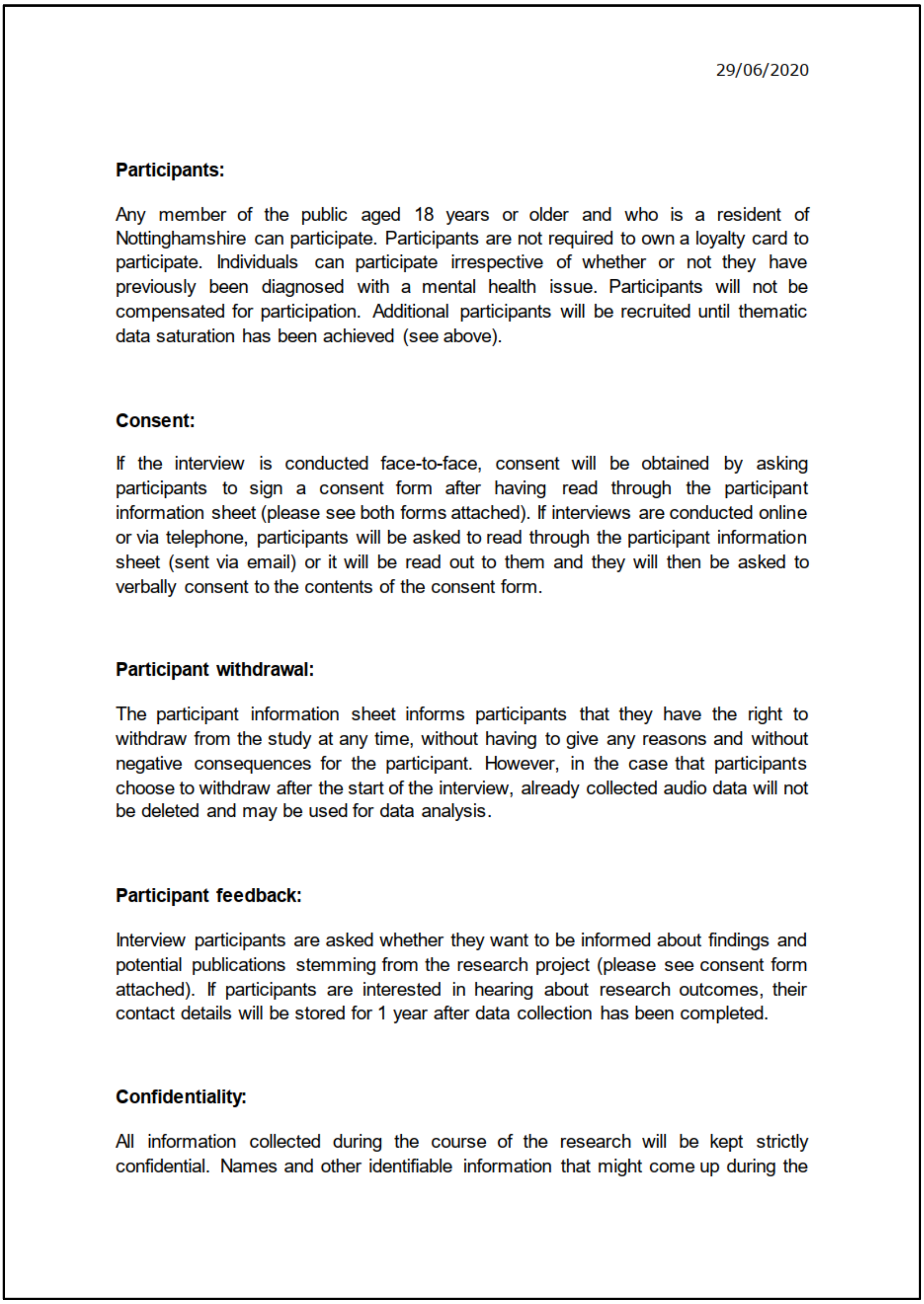
We intend to conduct qualitative semi-structured interviews. As initially stated, a sample size cannot be calculated in beforehand, however we estimate to interview between 20-30 individuals but may be up to 50, depending on the success of the recruitment methods and at which point thematic saturation has been reached. The interview guide is loosely informed by the results from our preliminary data analysis, previously undertaken research projects and a literature review. It also contains sections were participants are asked to provide insights into how the current circumstances have shaped the way they access health care and have impacted their view regarding sharing personal data for health purposes. The interview guide will be piloted to hone wording as required. Before the start of the interview, participants will be asked to sign or verbally agree to the consent form. Interviews will be conducted by the researcher responsible for the project and will be audio recorded. Participants will further be asked to fill out a short demographic survey at the end of the interview (also attached). After data collection, interviews will be transcribed verbatim, and subsequently analysed. The software Nvivo will be used to support data management and analysis.

Setting:

Due to the unpredictability of the situation, interviews could take place face-to-face (if in line with government advice at the time of the interview), online (using Skype or Microsoft teams, based on the participant's preference) or via telephone (if neither of the previous options is possible).

Recruitment:

Additional participants will be recruited using social media (e.g. Facebook, Twitter), through distribution of leaflets, face-to-face (verbal invitation), using the professional network of the researchers involved and using snowballing techniques (i.e. confirmed participants are encouraged to propose additional prospective participants)



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Participants:

Any member of the public aged 18 years or older and who is a resident of Nottinghamshire can participate. Participants are not required to own a loyalty card to participate. Individuals can participate irrespective of whether or not they have previously been diagnosed with a mental health issue. Participants will not be compensated for participation. Additional participants will be recruited until thematic data saturation has been achieved (see above).

Consent:

If the interview is conducted face-to-face, consent will be obtained by asking participants to sign a consent form after having read through the participant information sheet (please see both forms attached). If interviews are conducted online or via telephone, participants will be asked to read through the participant information sheet (sent via email) or it will be read out to them and they will then be asked to verbally consent to the contents of the consent form.

Participant withdrawal:

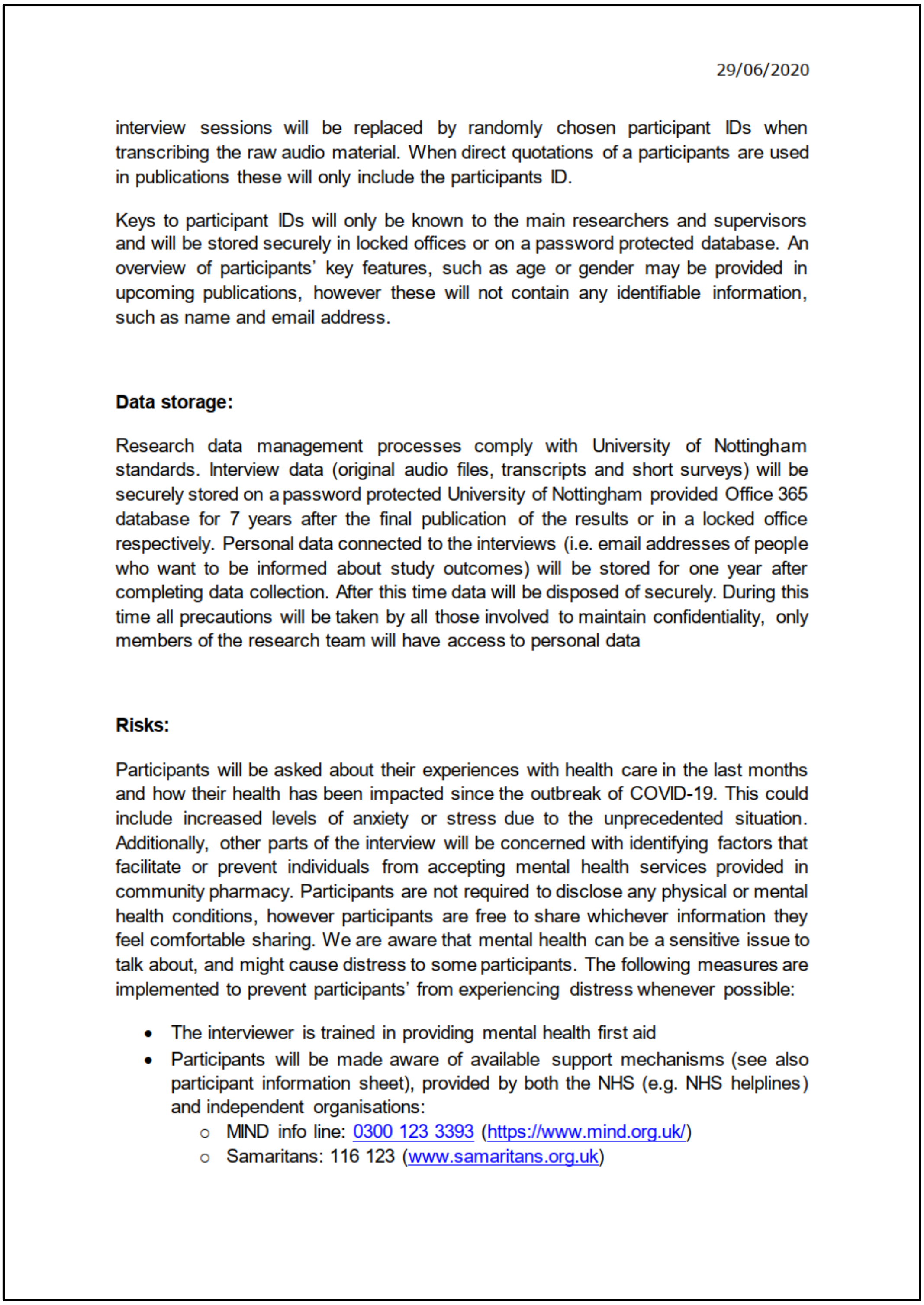
The participant information sheet informs participants that they have the right to withdraw from the study at any time, without having to give any reasons and without negative consequences for the participant. However, in the case that participants choose to withdraw after the start of the interview, already collected audio data will not be deleted and may be used for data analysis.

Participant feedback:

Interview participants are asked whether they want to be informed about findings and potential publications stemming from the research project (please see consent form attached). If participants are interested in hearing about research outcomes, their contact details will be stored for 1 year after data collection has been completed.

Confidentiality:

All information collected during the course of the research will be kept strictly confidential. Names and other identifiable information that might come up during the



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interview sessions will be replaced by randomly chosen participant IDs when transcribing the raw audio material. When direct quotations of a participants are used in publications these will only include the participants ID.

Keys to participant IDs will only be known to the main researchers and supervisors and will be stored securely in locked offices or on a password protected database. An overview of participants' key features, such as age or gender may be provided in upcoming publications, however these will not contain any identifiable information, such as name and email address.

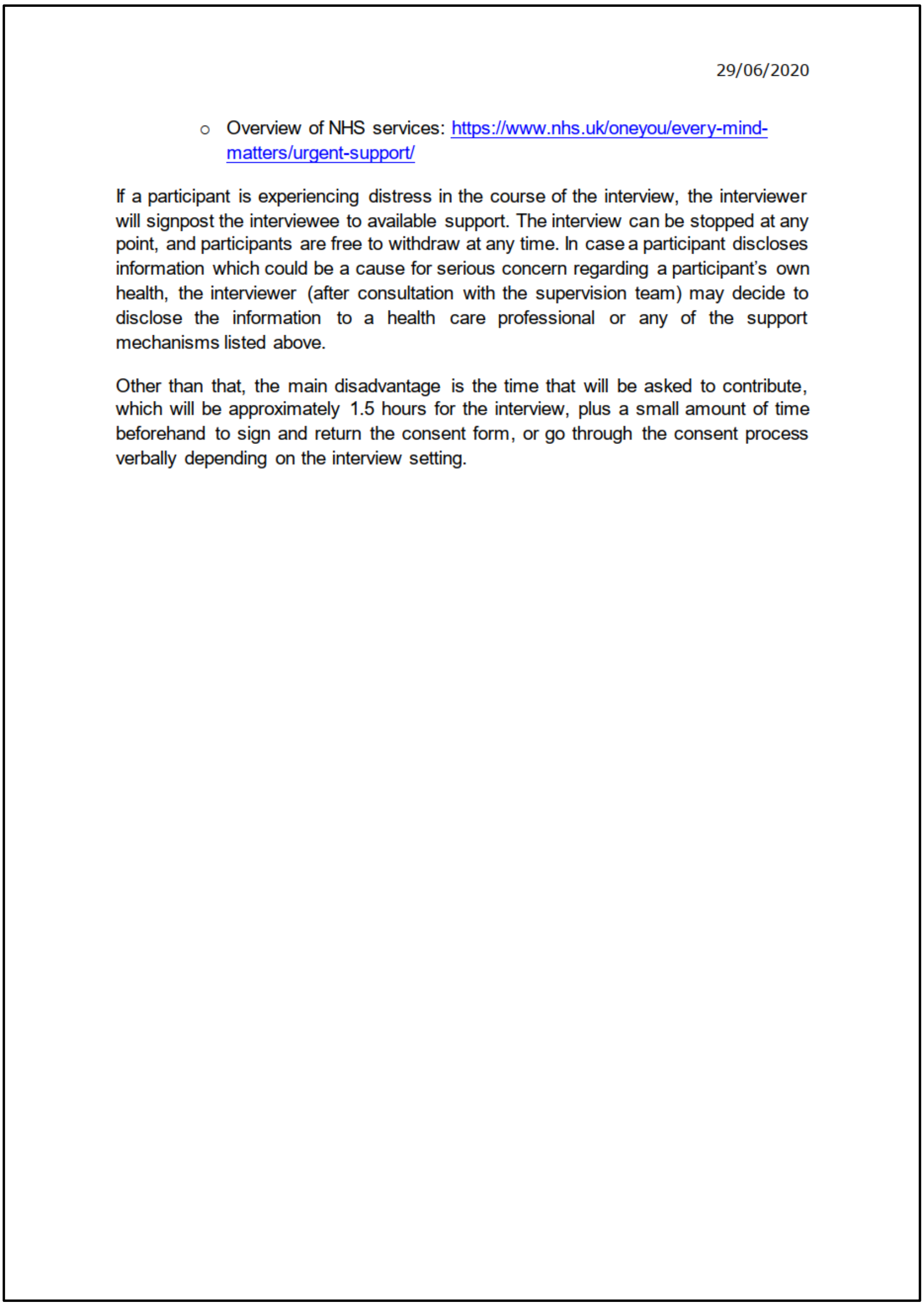
Data storage:

Research data management processes comply with University of Nottingham standards. Interview data (original audio files, transcripts and short surveys) will be securely stored on a password protected University of Nottingham provided Office 365 database for 7 years after the final publication of the results or in a locked office respectively. Personal data connected to the interviews (i.e. email addresses of people who want to be informed about study outcomes) will be stored for one year after completing data collection. After this time data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain confidentiality, only members of the research team will have access to personal data

Risks:

Participants will be asked about their experiences with health care in the last months and how their health has been impacted since the outbreak of COVID-19. This could include increased levels of anxiety or stress due to the unprecedented situation. Additionally, other parts of the interview will be concerned with identifying factors that facilitate or prevent individuals from accepting mental health services provided in community pharmacy. Participants are not required to disclose any physical or mental health conditions, however participants are free to share whichever information they feel comfortable sharing. We are aware that mental health can be a sensitive issue to talk about, and might cause distress to some participants. The following measures are implemented to prevent participants' from experiencing distress whenever possible:

- The interviewer is trained in providing mental health first aid
- Participants will be made aware of available support mechanisms (see also participant information sheet), provided by both the NHS (e.g. NHS helplines) and independent organisations:
    - MIND info line: 0300 123 3393 (https://www.mind.org.uk/)
    - Samaritans: 116 123 (www.samaritans.org.uk)



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- Overview of NHS services: https://www.nhs.uk/oneyou/every-mind-matters/urgent-support/

If a participant is experiencing distress in the course of the interview, the interviewer will signpost the interviewee to available support. The interview can be stopped at any point, and participants are free to withdraw at any time. In case a participant discloses information which could be a cause for serious concern regarding a participant's own health, the interviewer (after consultation with the supervision team) may decide to disclose the information to a health care professional or any of the support mechanisms listed above.

Other than that, the main disadvantage is the time that will be asked to contribute, which will be approximately 1.5 hours for the interview, plus a small amount of time beforehand to sign and return the consent form, or go through the consent process verbally depending on the interview setting.

Appendix 7: Short survey pharmacy users

Short survey – to be administered **after** the interview. Interview 1

1. Gender

How would you describe yourself as?:
☐Male ☐Female ☐Other ☐Prefer not to say

2. Age

How old are you?: ☐Prefer not to say

3. Ethnicity:
   - **White**
     - English / Welsh / Scottish / Northern Irish / British
     - Irish
     - Gypsy or Irish Traveller
     - Any other White background
   - **Mixed / Multiple ethnic groups**
     - White and Black Caribbean
     - White and Black African
     - White and Asian
     - Any other Mixed / Multiple ethnic background
   - **Asian / Asian British**
     - Indian
     - Pakistani
     - Bangladeshi
     - Chinese
     - Any other Asian background
   - **Black / African / Caribbean / Black British**
     - African
     - Caribbean
     - Any other Black / African / Caribbean background
   - **Other ethnic group**
     - Arab
     - Any other ethnic group

4. In which area of Nottinghamshire do you live?

☐Prefer not to say

5. Have you been diagnosed with a mental health issues in the past or do you have a current diagnosis of a mental health issue? (No response required)

☐ Yes ☐ No ☐Prefer not to say
If you are comfortable to disclose: Which mental health issue(s) have you been diagnosed with?

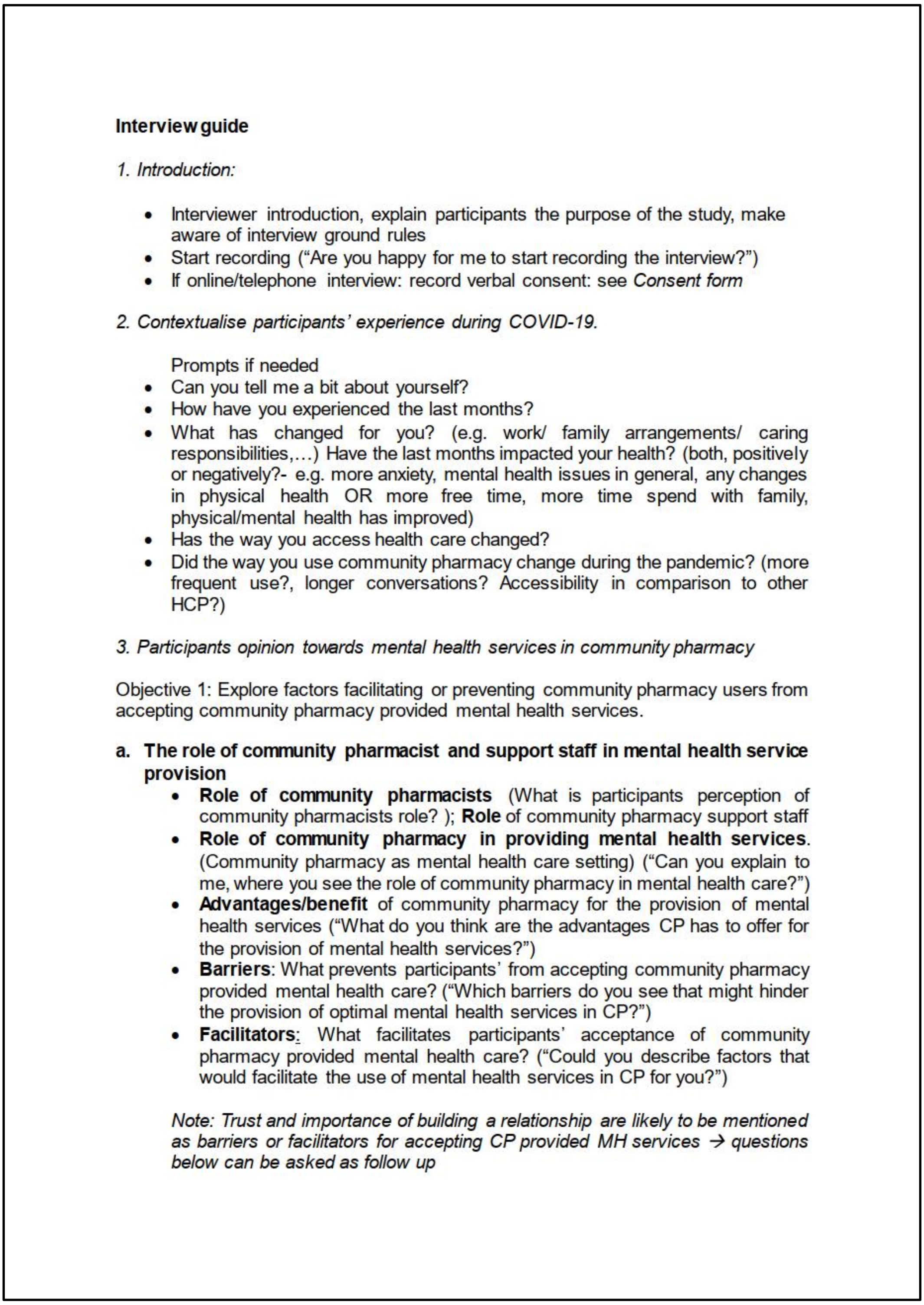
6. Have you or any of your family members been diagnosed with COVID-19?

☐ Yes ☐ No ☐Prefer not to say

7. How many loyalty cards do you own?

☐ 0 ☐ 1-4 ☐ 5 or more

Appendix 8: Interview guide pharmacy users



Interview guide

1. Introduction:

- Interviewer introduction, explain participants the purpose of the study, make aware of interview ground rules
- Start recording ("Are you happy for me to start recording the interview?")
- If online/telephone interview: record verbal consent: see *Consent form*

2. Contextualise participants' experience during COVID-19.

Prompts if needed

- Can you tell me a bit about yourself?
- How have you experienced the last months?
- What has changed for you? (e.g. work/ family arrangements/ caring responsibilities,…) Have the last months impacted your health? (both, positively or negatively?- e.g. more anxiety, mental health issues in general, any changes in physical health OR more free time, more time spend with family, physical/mental health has improved)
- Has the way you access health care changed?
- Did the way you use community pharmacy change during the pandemic? (more frequent use?, longer conversations? Accessibility in comparison to other HCP?)

3. Participants opinion towards mental health services in community pharmacy

Objective 1: Explore factors facilitating or preventing community pharmacy users from accepting community pharmacy provided mental health services.

a. The role of community pharmacist and support staff in mental health service provision

- **Role of community pharmacists** (What is participants perception of community pharmacists role?); **Role** of community pharmacy support staff
- **Role of community pharmacy in providing mental health services**. (Community pharmacy as mental health care setting) ("Can you explain to me, where you see the role of community pharmacy in mental health care?")
- **Advantages/benefit** of community pharmacy for the provision of mental health services ("What do you think are the advantages CP has to offer for the provision of mental health services?")
- **Barriers**: What prevents participants' from accepting community pharmacy provided mental health care? ("Which barriers do you see that might hinder the provision of optimal mental health services in CP?")
- **Facilitators**: What facilitates participants' acceptance of community pharmacy provided mental health care? ("Could you describe factors that would facilitate the use of mental health services in CP for you?")

Note: Trust and importance of building a relationship are likely to be mentioned as barriers or facilitators for accepting CP provided MH services → questions below can be asked as follow up

b. **The importance of trust and establishing a relationship for accepting mental health services provided in CP**
  - **Current relationship with CP:** "Could you describe me the relationship you are currently having with your community pharmacist" (if frequently the same pharmacy)/ Could you explain to me why you are not frequently using the same pharmacy (if not using same pharmacy)
  - Important aspects of CP- user relationship: What is important for you in your relationship with your CP/ What would be important for you, if you were to establish a relationship with a CP?
  - **Relationship with CP in the context of MH:** Would you emphasise something about what you previously mentioned as especially important in the context of mental health/ Would you add something about what is important for you in a relationship with a/your CP when it comes to mental health services?
  - **Trust in community pharmacists:** "Could you describe to me what trusting a/your community pharmacist means to you?"
  - **Importance:** "Could you describe elements which (characteristics/behaviours/environment etc.) are important for you to establish trust in your CP?"
  - **Trust in the context of MH:** Would you emphasise something about what you previously mentioned as especially important in the context of mental health/ Would you add something about what is important for you to establish trust in a/your CP when it comes to mental health services?

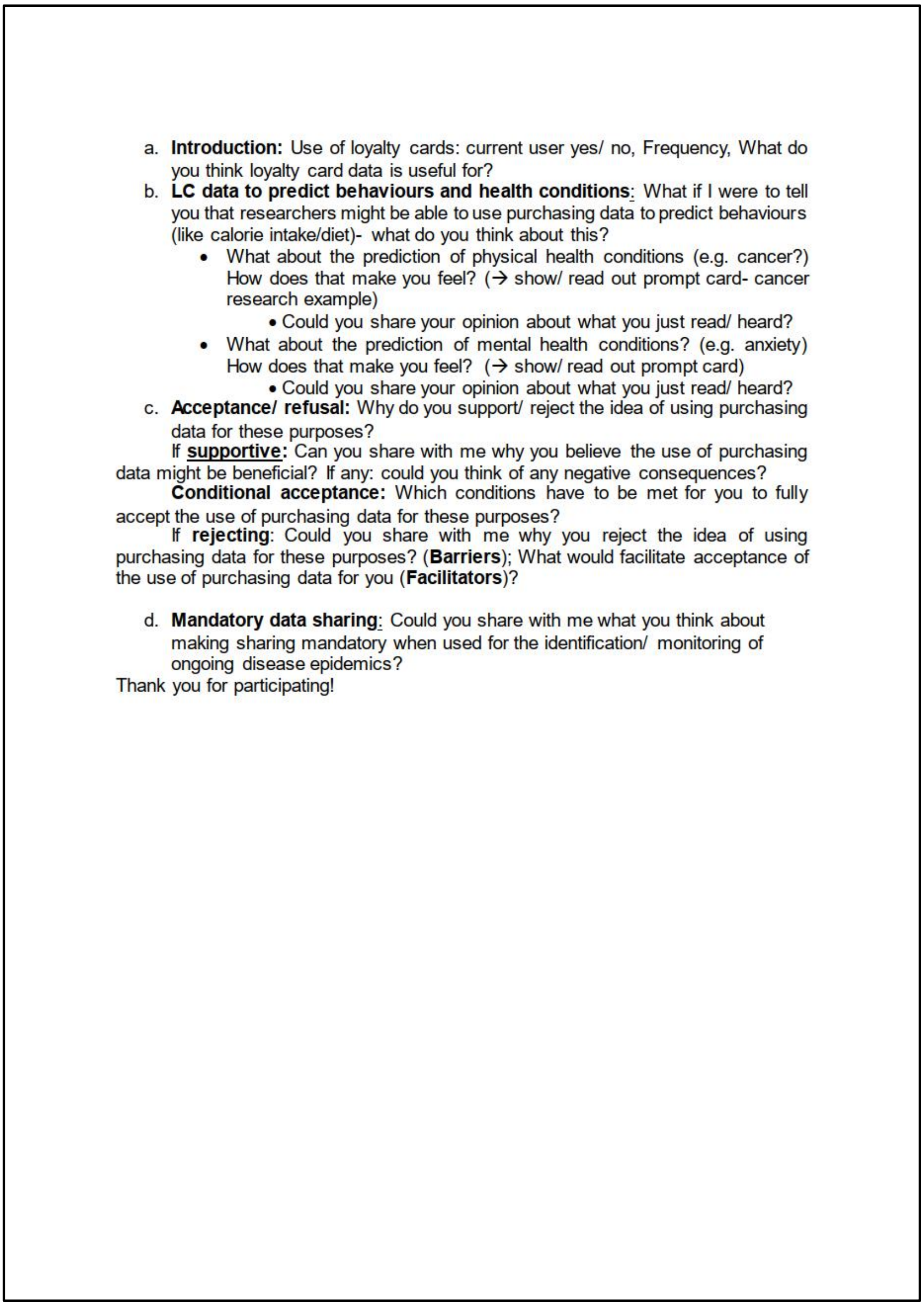
4. Contextualise how participants' view towards data sharing has been impacted by the outbreak of Covid-19.

An extended use of personal data (e.g. location data/ health data) to support the containment of Covid-19 has been widely discussed in the media/ by the government in the last months (e.g. track and tracing strategy, development of symptom tracing apps, etc.).

Prompts if needed

- What do you think about these methods? (**Opinion**)
- Have you used any of these? (e.g. Zoe app/ Symptom tracker?) (**Use yes/no**); If yes/no: Why?
- Do you feel well informed about how your data may be used/ may be helpful to control the spread of the ongoing pandemic? → **If well informed**: where did you get this information from? **If not**: Why would you say could you be better informed? What prevents you from getting more information about the use of personal data in the current situation? (**Barriers**, e.g. accessibility, understanding, time, etc.)
- Has your understanding of how personal data (e.g. location data/ health data) may be useful in a health context changed in the last months? (**Impact of Covid-19 on opinion**)

Objective 2: Explore participants' attitude towards sharing personal data (with a focus on loyalty card data) to identify individuals at risk of having physical and/ or mental health conditions.



a. **Introduction:** Use of loyalty cards: current user yes/ no, Frequency, What do you think loyalty card data is useful for?

b. **LC data to predict behaviours and health conditions**: What if I were to tell you that researchers might be able to use purchasing data to predict behaviours (like calorie intake/diet)- what do you think about this?
   - What about the prediction of physical health conditions (e.g. cancer?) How does that make you feel? (→ show/ read out prompt card- cancer research example)
     - Could you share your opinion about what you just read/ heard?
   - What about the prediction of mental health conditions? (e.g. anxiety) How does that make you feel? (→ show/ read out prompt card)
     - Could you share your opinion about what you just read/ heard?

c. **Acceptance/ refusal:** Why do you support/ reject the idea of using purchasing data for these purposes?

If **supportive:** Can you share with me why you believe the use of purchasing data might be beneficial? If any: could you think of any negative consequences?

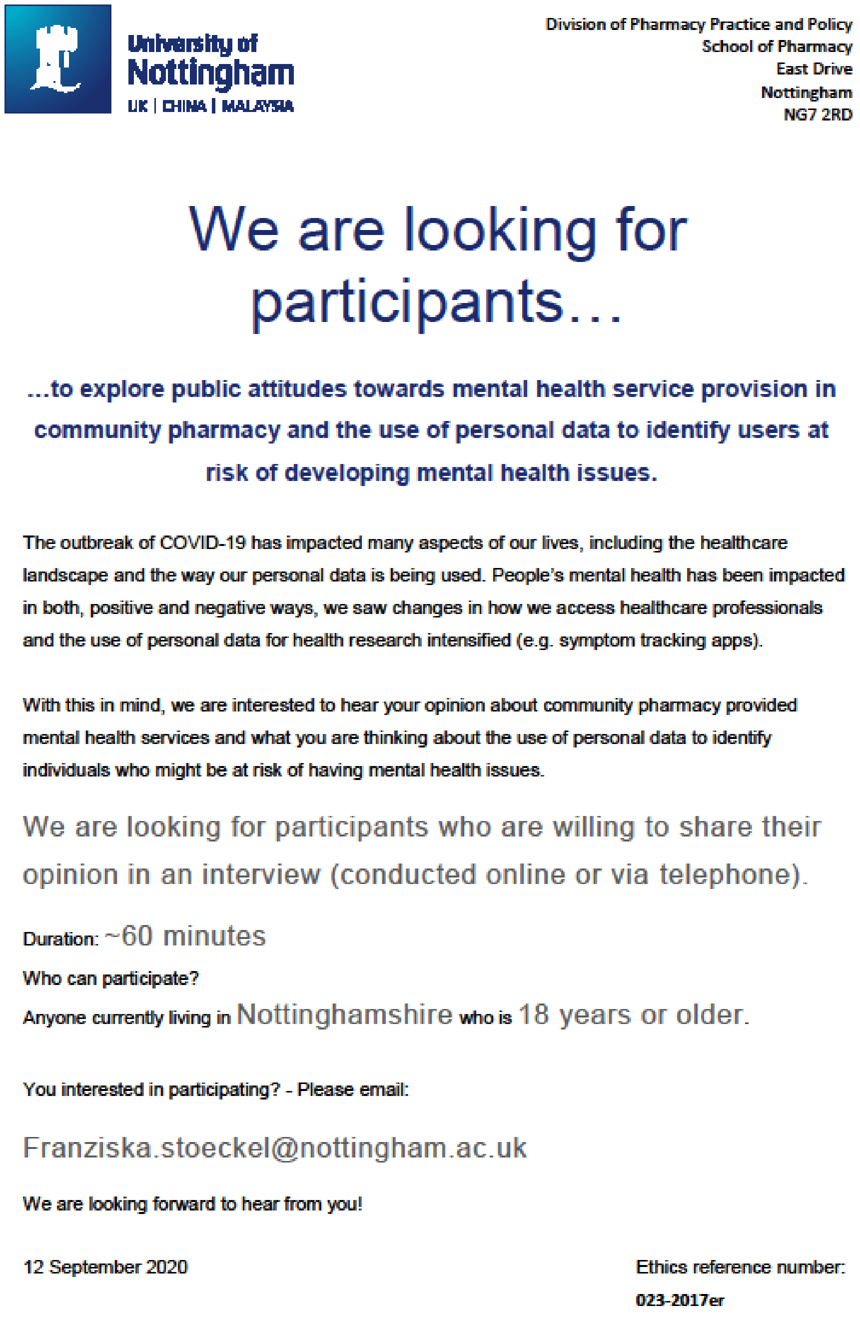
Conditional acceptance: Which conditions have to be met for you to fully accept the use of purchasing data for these purposes?

If **rejecting**: Could you share with me why you reject the idea of using purchasing data for these purposes? (**Barriers**); What would facilitate acceptance of the use of purchasing data for you (**Facilitators**)?

d. **Mandatory data sharing**: Could you share with me what you think about making sharing mandatory when used for the identification/ monitoring of ongoing disease epidemics?

Thank you for participating!

Appendix 9: Recruitment poster



University of Nottingham
UK | CHINA | MALAYSIA

Division of Pharmacy Practice and Policy
School of Pharmacy
East Drive
Nottingham
NG7 2RD

We are looking for participants…

…to explore public attitudes towards mental health service provision in community pharmacy and the use of personal data to identify users at risk of developing mental health issues.

The outbreak of COVID-19 has impacted many aspects of our lives, including the healthcare landscape and the way our personal data is being used. People's mental health has been impacted in both, positive and negative ways, we saw changes in how we access healthcare professionals and the use of personal data for health research intensified (e.g. symptom tracking apps).

With this in mind, we are interested to hear your opinion about community pharmacy provided mental health services and what you are thinking about the use of personal data to identify individuals who might be at risk of having mental health issues.

We are looking for participants who are willing to share their opinion in an interview (conducted online or via telephone).

Duration: ~60 minutes

Who can participate?

Anyone currently living in Nottinghamshire who is 18 years or older.

You interested in participating? - Please email:

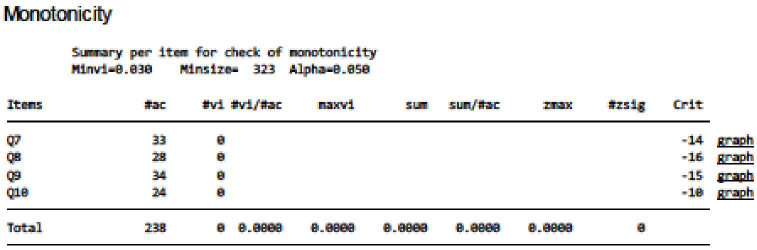
Franziska.stoeckel@nottingham.ac.uk

We are looking forward to hear from you!

12 September 2020

Ethics reference number:
023-2017er

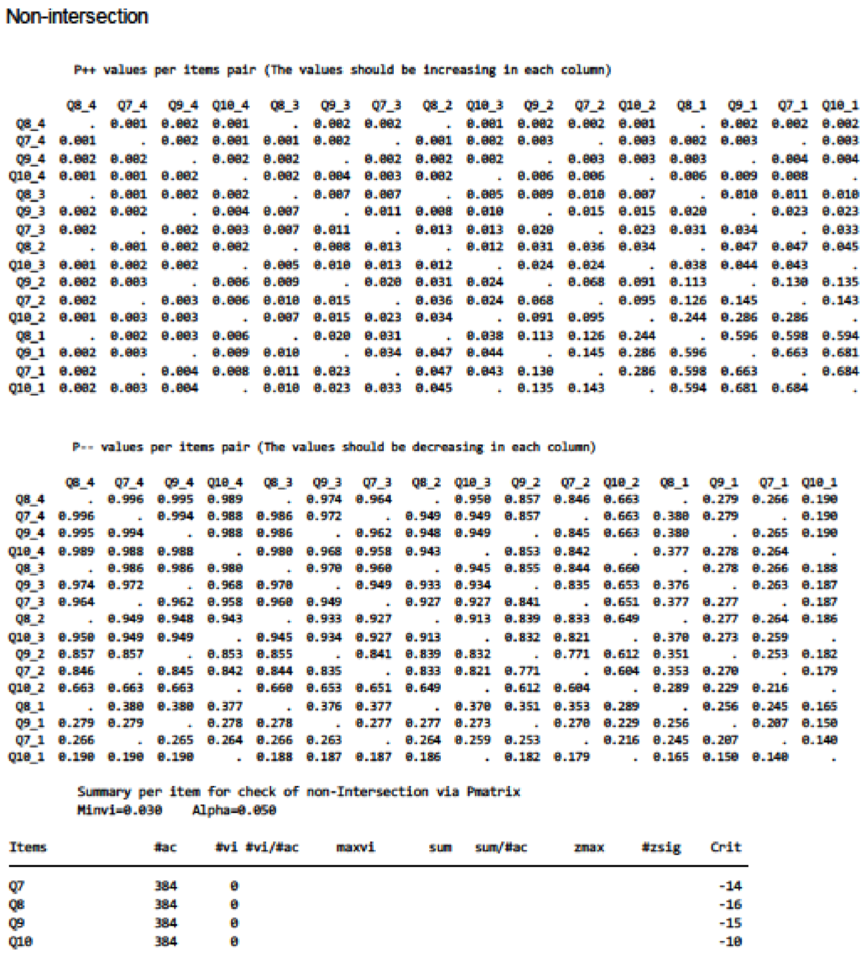
Appendix 10: Investigation of assumption of monotonicity – Trust in pharmacists scale (2019)



Monotonicity

```
        Summary per item for check of monotonicity
        Minvi=0.030    Minsize=  323  Alpha=0.050

Items              #ac     #vi #vi/#ac     maxvi       sum   sum/#ac      zmax     #zsig    Crit
------------------------------------------------------------------------------------------------

Q7                  33       0                                                              -14  graph
Q8                  28       0                                                              -16  graph
Q9                  34       0                                                              -15  graph
Q10                 24       0                                                              -10  graph
------------------------------------------------------------------------------------------------

Total              238       0  0.0000    0.0000    0.0000    0.0000    0.0000         0
------------------------------------------------------------------------------------------------
```

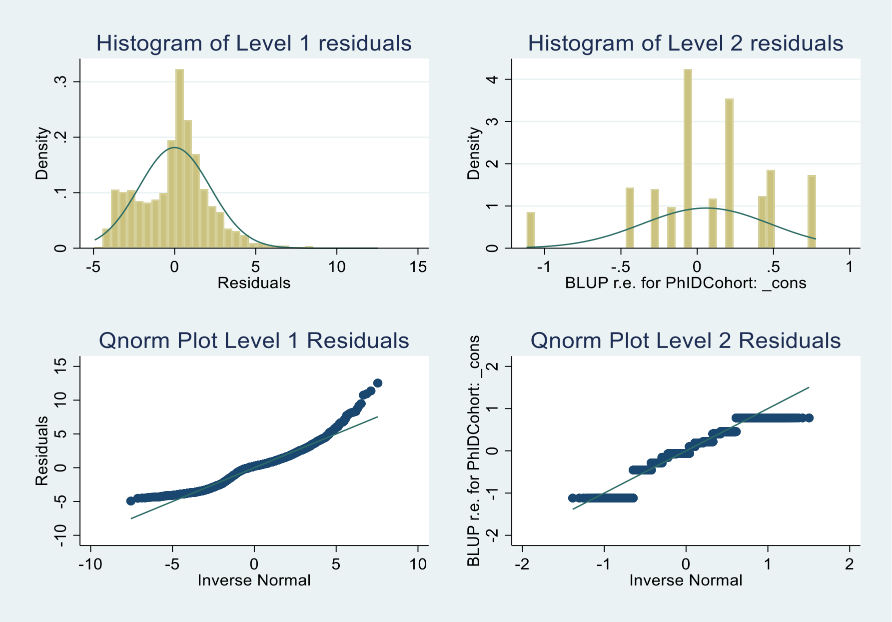
Appendix 11: Investigation of non-intersection – Trust in pharmacists scale (2019)



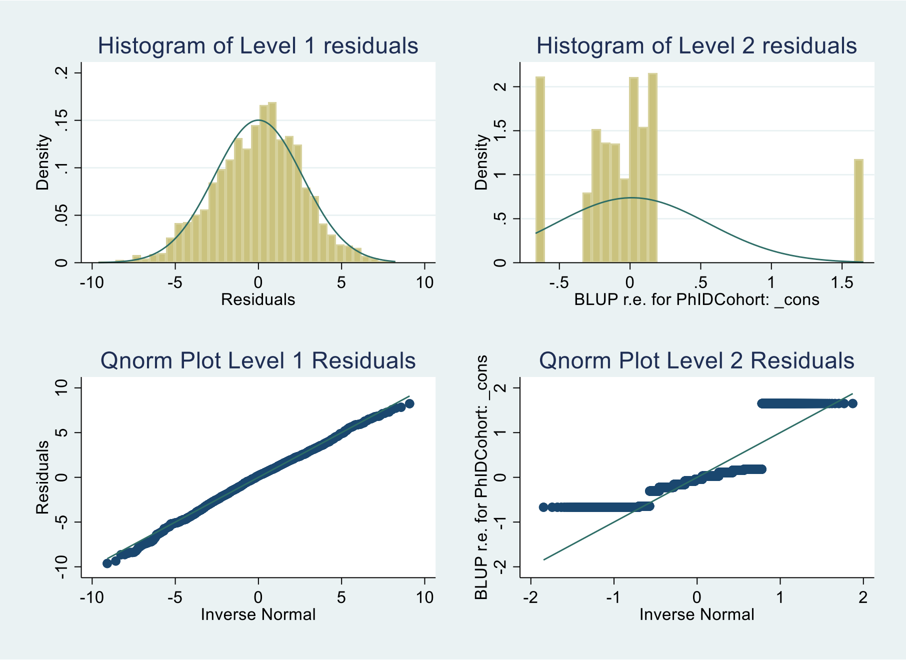
Non-intersection

```
        P++ values per items pair (The values should be increasing in each column)

         Q8_4   Q7_4   Q9_4  Q10_4   Q8_3   Q9_3   Q7_3   Q8_2  Q10_3   Q9_2   Q7_2  Q10_2   Q8_1   Q9_1   Q7_1  Q10_1
  Q8_4      .  0.001  0.002  0.001      .  0.002  0.002      .  0.001  0.002  0.002  0.001      .  0.002  0.002  0.002
  Q7_4  0.001      .  0.002  0.001  0.001  0.002      .  0.001  0.002  0.003      .  0.003  0.002  0.003      .  0.003
  Q9_4  0.002  0.002      .  0.002  0.002      .  0.002  0.002  0.002      .  0.003  0.003  0.003      .  0.004  0.004
 Q10_4  0.001  0.001  0.002      .  0.002  0.004  0.003  0.002      .  0.006  0.006      .  0.006  0.009  0.008      .
  Q8_3      .  0.001  0.002  0.002      .  0.007  0.007      .  0.005  0.009  0.010  0.007      .  0.010  0.011  0.010
  Q9_3  0.002  0.002      .  0.004  0.007      .  0.011  0.008  0.010      .  0.015  0.015  0.020      .  0.023  0.023
  Q7_3  0.002      .  0.002  0.003  0.007  0.011      .  0.013  0.013  0.020      .  0.023  0.031  0.034      .  0.033
  Q8_2      .  0.001  0.002  0.002      .  0.008  0.013      .  0.012  0.031  0.036  0.034      .  0.047  0.047  0.045
 Q10_3  0.001  0.002  0.002      .  0.005  0.010  0.013  0.012      .  0.024  0.024      .  0.038  0.044  0.043      .
  Q9_2  0.002  0.003      .  0.006  0.009      .  0.020  0.031  0.024      .  0.068  0.091  0.113      .  0.130  0.135
  Q7_2  0.002      .  0.003  0.006  0.010  0.015      .  0.036  0.024  0.068      .  0.095  0.126  0.145      .  0.143
 Q10_2  0.001  0.003  0.003      .  0.007  0.015  0.023  0.034      .  0.091  0.095      .  0.244  0.286  0.286      .
  Q8_1      .  0.002  0.003  0.006      .  0.020  0.031      .  0.038  0.113  0.126  0.244      .  0.596  0.598  0.594
  Q9_1  0.002  0.003      .  0.009  0.010      .  0.034  0.047  0.044      .  0.145  0.286  0.596      .  0.663  0.681
  Q7_1  0.002      .  0.004  0.008  0.011  0.023      .  0.047  0.043  0.130      .  0.286  0.598  0.663      .  0.684
 Q10_1  0.002  0.003  0.004      .  0.010  0.023  0.033  0.045      .  0.135  0.143      .  0.594  0.681  0.684      .


        P-- values per items pair (The values should be decreasing in each column)

         Q8_4   Q7_4   Q9_4  Q10_4   Q8_3   Q9_3   Q7_3   Q8_2  Q10_3   Q9_2   Q7_2  Q10_2   Q8_1   Q9_1   Q7_1  Q10_1
  Q8_4      .  0.996  0.995  0.989      .  0.974  0.964      .  0.950  0.857  0.846  0.663      .  0.279  0.266  0.190
  Q7_4  0.996      .  0.994  0.988  0.986  0.972      .  0.949  0.949  0.857      .  0.663  0.380  0.279      .  0.190
  Q9_4  0.995  0.994      .  0.988  0.986      .  0.962  0.948  0.949      .  0.845  0.663  0.380      .  0.265  0.190
 Q10_4  0.989  0.988  0.988      .  0.980  0.968  0.958  0.943      .  0.853  0.842      .  0.377  0.278  0.264      .
  Q8_3      .  0.986  0.986  0.980      .  0.970  0.960      .  0.945  0.855  0.844  0.660      .  0.278  0.266  0.188
  Q9_3  0.974  0.972      .  0.968  0.970      .  0.949  0.933  0.934      .  0.835  0.653  0.376      .  0.263  0.187
  Q7_3  0.964      .  0.962  0.958  0.960  0.949      .  0.927  0.927  0.841      .  0.651  0.377  0.277      .  0.187
  Q8_2      .  0.949  0.948  0.943      .  0.933  0.927      .  0.913  0.839  0.833  0.649      .  0.277  0.264  0.186
 Q10_3  0.950  0.949  0.949      .  0.945  0.934  0.927  0.913      .  0.832  0.821      .  0.370  0.273  0.259      .
  Q9_2  0.857  0.857      .  0.853  0.855      .  0.841  0.839  0.832      .  0.771  0.612  0.351      .  0.253  0.182
  Q7_2  0.846      .  0.845  0.842  0.844  0.835      .  0.833  0.821  0.771      .  0.604  0.353  0.270      .  0.179
 Q10_2  0.663  0.663  0.663      .  0.660  0.653  0.651  0.649      .  0.612  0.604      .  0.289  0.229  0.216      .
  Q8_1      .  0.380  0.380  0.377      .  0.376  0.377      .  0.370  0.351  0.353  0.289      .  0.256  0.245  0.165
  Q9_1  0.279  0.279      .  0.278  0.278      .  0.277  0.277  0.273      .  0.270  0.229  0.256      .  0.207  0.150
  Q7_1  0.266      .  0.265  0.264  0.266  0.263      .  0.264  0.259  0.253      .  0.216  0.245  0.207      .  0.140
 Q10_1  0.190  0.190  0.190      .  0.188  0.187  0.187  0.186      .  0.182  0.179      .  0.165  0.150  0.140      .

        Summary per item for check of non-Intersection via Pmatrix
        Minvi=0.030    Alpha=0.050

Items                #ac     #vi #vi/#ac     maxvi        sum   sum/#ac       zmax      #zsig    Crit
-----------------------------------------------------------------------------------------------------

Q7                   384       0                                                                  -14
Q8                   384       0                                                                  -16
Q9                   384       0                                                                  -15
Q10                  384       0                                                                  -10
```

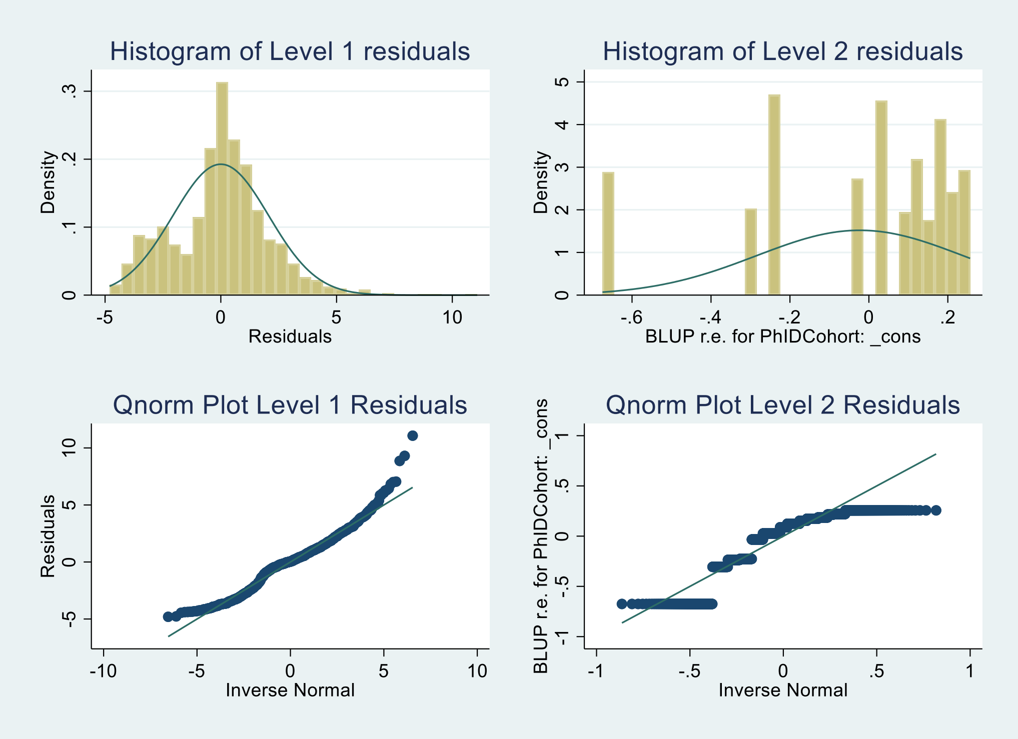
Appendix 12: Diagnostics – Trust scale (2019)



Appendix 13: Diagnostics – Attitudes towards mental health support provided in pharmacies- scale (2019)



Appendix 14: Diagnostics - Trust in parmacists-scale (2020)



Appendix 15: Diagnostics - Mental health in support provison in pharmacies- scale (2020)