A qualitative investigation of lay and professional perspectives of community pharmacy extended palliative care services

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A thesis submitted to the University of Nottingham for the degree of Doctor of Philosophy

December 2021

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

Dame Cicely Saunders

Acknowledgements

This research would not have been possible without my beloved parents' assistance, compassion, prayers and the support of my wife and children. I am indebted to my supervisors, Prof. Kristian Pollock and Dr Asam Latif, for their unparalleled support throughout my academic journey. They ensured an exemplary support system was available for me during the difficult period resulting from personal and family challenges. Equally effective were their subtle ways of encouragement, regular meetings, and astute knowledge of the research topic.

I feel honoured to have undertaken this project. The interactions with palliative patients, family caregivers, nurses, community pharmacists, and GPs fill me with an immense appreciation of the hard work they are already doing in the community with limited resources and under time constraints. Their generous contribution to this research will hopefully open new avenues into palliative care service provision.

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Glossary

Adherence: The extent to which a patient takes medication as intended by the healthcare professional who prescribed them

Anticipatory medicines: Medicines to control common symptoms occurring at the end-of-life that are prescribed in advance and kept in the home 'just in case' they are needed.

Comorbidity: The coexistence of two or more long-term health conditions (also known as multimorbidity).

Controlled drugs: Medicines that are subject to additional legal controls.

Dosette box: A box with small compartments that allow the medicines needed for a day or a week to be organised and set out in advance to assist with taking them as prescribed.

End-of-life care: A part of palliative care concerned with supporting patients identified as likely to be within their last year of life. In addition to providing excellent symptom control and emotional support, end-of-life care provides an opportunity for patients and family members to anticipate and express their preferences for future care.

Family caregiver: A family member, friend or neighbour providing care and/or support for the patient.

Life-limiting illness: An illness that may be treated but cannot be cured and is likely to result in death. Examples include advanced cancer and progressive neurological conditions, such as motor neuron disease and dementia.

Palliative and supportive care: Care takes a holistic approach to treatment and provides support to people affected by life-limiting illness, including family and friends, as well as individual patients. Palliative care aims to help support physical and emotional well-being and support excellent control of symptoms, including those that occur at the end-of-life.

Polypharmacy: When a patient takes two or more medicines.

Social care: Care that provides help, care and protection from harm for people with a range of requirements, including people at the end-of-life.

Abbreviations

General Medical Council	GMC
Royal Pharmaceutical Society of Great Britain	RPSGB
United Kingdom	UK
Medicine Use Review	MUR
New Medicine Service	NMS
World Health Organization	WHO
Health Care of Older People	HCOP
General practitioners	GPs

ABSTRACT

In the UK, an increasingly ageing population has expanded the patient population affected by multiple morbidities and palliative care needs. Patients report having complicated medicine regimens, a high incidence of problematic polypharmacy, and significant medication management problems. Growing numbers of patients opting for home-based palliative care, and in the absence of adequate support, they are faced with an increased burden of care. Furthermore, family caregivers accept this burden without formal training or regular outside support. As a result, patients and family caregivers have considerable unmet pharmaceutical needs. This environment presents an urgent need to explore the potential for community pharmacists, who traditionally have had limited involvement, to help support patients, family caregivers and existing palliative care services.

Aim: This research aims to explore patients, lay family caregivers, and health care professionals' views of current community palliative care and the role and scope for future expansion of community pharmacy in this domain.

Methods: Underpinned by a constructivist methodology, this was an exploratory qualitative study involving forty-four in-depth, semi-structured interviews. These included patients receiving palliative care (n=10), family caregivers (n=10), pharmacists (n=13), general physicians (GPs) (n=6), and community nurses (n=5). The qualitative software program NVivo 12 was used to facilitate a thematic analysis of the data.

Results: Most patients and family caregiver participants were unfamiliar with the holistic underpinnings of palliative care and understood this to be a "care package" focused solely on the "dying phase". There was a strong emotional feeling, a sense of helplessness and "giving in" considering the heightened challenges and difficulties in the coming days. The community pharmacist was perceived as an accessible and trustworthy healthcare professional. Most lay participants considered pharmacists presently have a minimal role in their palliative care needs. However, they would welcome additional support from community pharmacies around medicine management, a better understanding of treatment regimens in the palliative phase, and timely availability of medicines.

GPs and nurses reported increasing healthcare demands associated with community palliative care provision. They recognised the benefits of engaging community pharmacists and welcomed any load sharing with them. Importantly, however, GPs stressed that ultimate care responsibility should stay with GP practices. Pharmacists took a reserved approach towards increased participation. They pointed out the lack of funding arrangements, structure, and training needs as primary areas of concern. Nevertheless, there was an overarching willingness among community pharmacists to contribute further once suitable service specifications were laid out.

Discussion: Palliative and end-of-life care is often challenging and distressing for patients and family caregivers, combined with increased care needs. However, in the community, these needs are not consistently recognised in time and often remain unmet. Three main themes with important recommendations emerged from the study. Firstly, community pharmacists could do more to advance their involvement in palliative and end-of-life care needs. However, such expansion should be built upon a solid foundation of medicine supply obligations. Secondly, a carefully planned service specification is essential for greater community pharmacy inclusion in palliative services. Lastly, community pharmacy should be recognised as a specialisation. Rather than having limited specialist palliative care pharmacists in primary care networks, community pharmacists should be encouraged to take on extra palliative care services as part of their general repertoire. A greater community pharmacy involvement could help increase the availability of timely and responsive palliative care closer to the patient’s home. This study provides a strong justification for future research and a potential community pharmacy intervention to investigate additional services for patients receiving palliative care or their family caregivers. The study has important implications for future community pharmacy service development as the findings indicate areas of unmet need in community palliative care services, which are within the expertise of community pharmacists to support.

Conclusion: This study expands our knowledge of the community palliative care landscape. It explored the significant problems patients, and family caregivers face against the scope for greater community pharmacy participation. There was an overarching theme of willingness among community pharmacists to expand their current service repertoire to cater more for the unmet pharmaceutical needs in community palliative care, providing contractual issues that could be agreed upon and adequate workforce training in place. GPs welcomed such additional services to reduce their current workload pressures. Future studies should evaluate the scope and implementation of extended community pharmacy support for community palliative care services.

Chapter One

INTRODUCTION

This thesis contributes to a better understanding of the scope for community pharmacy to extend their contributions towards palliative care services by exploring the views and perceptions of lay (patients and family caregivers) and professional (pharmacists, GPs, and Nurses) participants. The study gathers analyses and presents key stakeholders' viewpoints on improving community palliative care services by better utilisation of community pharmacies. This chapter sets the scene and provides background to the many aspects of holistic palliative care and its comparison with non-palliative care. This is followed by an overview of the community pharmacy sector in England and its current involvement in palliative care service. Further on, a consideration is made to the scope of extension in the community pharmacist’s role given recently extended roles taken up by the community pharmacy sector. The chapter then concludes by providing a rationale for the literature review, detailed in Chapter two.

This introductory chapter details the definitions of palliative care and its realms. We then examine how palliative care differs from non-palliative medical care, what defines good palliative care and its distinct aspects. This is followed by a discussion on the current engagement and scope for further extension of community pharmacists’ role in palliative care services.

1.1 Palliative care: Defining a palliative care patient

Palliative care is often considered the symptomatic treatment offered to ease a dying patient’s pain and disease burden. These treatments are commonly introduced at later stages for progressive, non-curable, and life-threatening diseases (Van Mechelen et al., 2013). However, this approach identifies palliative care as care provided solely to terminally ill patients or as “care of the dying” (Pastrana et al., 2008). Recently, there have been fundamental changes in the patient population receiving palliative care. In practice, palliative care is often equated with end-of-life care, but that is not its original or professional remit (Boyd et al., 2019). Therefore, this abridged approach of considering palliative care as a care package for terminally ill patients near death limits palliative care's optimum outreach and application (Van Mechelen et al., 2013). Furthermore, clinical practices are moving forward from this historical view of palliative care and recognising the importance of providing palliative care support to patients other than cancers (Haun et al., 2017).

In 2002, WHO defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2002 pp xv). Importantly, besides the quality of life, the psychosocial and spiritual aspects of care are also acknowledged. The definition was widely adopted at the time and was further detailed and clarified in 2014 (Worldwide Palliative Care Alliance, 2014) with the following salient features as part of any palliative care program.

- Palliative care is needed in chronic as well as life-threatening/limiting conditions.
- There is no time or prognostic limit on the delivery of palliative care.
- The need for palliative care at all levels of care.
- Palliative care is not limited to any one care setting.
- Palliative care should in no way become a substitute for appropriate curative care.

Furthermore, palliative care is now desired as an early component in treatment plans for life-threatening health conditions (World Health Assembly, 2014). The WHO definition was further advanced by 'The International Association for Hospice and Palliative Care' in 2020 (Radbruch et al., 2020). They placed a greater emphasis on serious health-related sufferings, which allows a more person-centred approach to palliative care. Furthermore, palliative care should be delivered based on need rather than prognosis, applicable in all care settings and levels, and encompasses general and specialist care (Radbruch et al., 2020).

In the UK, general practices keep a register of all patients with supportive or palliative care needs (British Medical Association, 2006). Further, the policy directives encourage a comprehensive and earlier identification of patients with progressive life-threatening diseases at primary care (Department of Health, 2012). However, the suggested inclusion criteria for the palliative register include an ambiguous question on the part of a general practitioner (GP) "Would you be surprised if this patient died in the next 6-12 months?". While some argue that this surprise question improves the identification of palliative patients in an emergency setting (Zeng et al., 2020), others present this as a limiting factor for effective palliative care services roll-out (Harrison et al., 2012). Regardless, palliative care needs for non-cancer patients in primary care settings are increasing (Gadoud et al., 2020), and there is an urgent need to extend primary palliative care services (Mitchell et al., 2019).

1.2 History of palliative care in the United Kingdom

The origins of the current hospice movement in the UK can be attributed to the foundation of St Christopher's House in 1967 by Dame Cicely Saunders. Further, the Macmillan organisation, founded in 1911, expanded their services in the 1970s with an increased focus on palliative care. Similarly, the Marie Curie Memorial Foundation, established in 1948, transitioned to specialist palliative care centres in the 1980s (Clark, 2007). The term palliative was not widely adopted around that time, and there was limited promotion of this subject among healthcare professionals (Clark and Seymour). However, over the last five decades, palliative care has developed into a medical speciality in its own right and is actively promoted by government policies and health initiatives (Department of Health, 2012, National and End-of-life Care, 2015). Modern palliative care services expanded from pain control for cancer patients to a holistic approach for patients with other life-limiting illnesses (Tassinari et al., 2016, Murray et al., 2005a). However, there are challenges in planning, promoting, and delivering valued palliative care services to those with non-cancer diseases (Clark, 2007).

1.3 Palliative care as a holistic care concept

Multi-disciplinary holistic management is a key constituent of current palliative care programs. This means that the palliative care offered to a patient is not limited to physical aspects. The care package should recognise accompanying problems in psychosocial, spiritual, social, and emotional well-being for both patients and family caregivers. Furthermore, palliative care should be initiated earlier at the diagnosis of life-threatening illness (Murray et al., 2005a), and it has been reported that palliative patients have significant needs from diagnosis (Beernaert et al., 2016). This early palliative care improves the quality of life of patients and their families facing the problems associated with life-limiting illness at any stage from diagnosis; through timely identification and holistic needs assessment (Murray et al., 2017b). The early initiation of palliative care can improve the quality of life of people with cancer and other advanced life-limiting conditions (Temel et al., 2017, Tassinari et al., 2016, Higginson et al., 2014). It has been suggested that palliative care should be integrated alongside curative care to improve patient and family caregivers' experience and outcomes to allow comprehensive care throughout its life course (Gómez-Batiste et al., 2017).

1.4 Progressive phases of palliative care

Palliative care should be a holistic approach, and it could be offered alongside any curative treatment plans. People are living longer with multiple morbidities with a slow decline in health over time (Murray et al., 2005a). Early initiation of palliative care offers benefits to patients with chronic progressive illnesses over many years (Lynn and Adamson, 2003). Palliative care should be adjudged as a continuous care pathway which should be offered early in a disease trajectory alongside any other concurrent treatment plans (Vadivelu et al., 2013).

Holistic models of palliative care are considered to provide care from four different dimensions. These include the physical, social, psychological, and spiritual needs of persons and their families and carers (Murray et al., 2017b). This approach potentially provides scope for all allied health professionals to contribute to their capacity in a combined teamwork approach to accommodate the needs of patients and families. In the context of these integrated palliative care provisions, community pharmacists have traditionally been seen as having a marginal role. Their position in palliative care has yet to be fully explored. Integrated palliative care with successful coordination among different health care professionals helps in identifying and fulfilling the care needs of patients with advanced progressive illnesses other than cancer. Those identified are more likely to benefit from coordinated care and may be more likely to die at home (Harrison et al., 2012).

1.5 Palliative care and 'end-of-life' care

This section describes details "Palliative care" and "end-of-life care" are often discussed alongside each other, and at times, the terms are used interchangeably. Although the two terms are very closely related, they are not synonymous with each other. Palliative care aims to relieve suffering and to maximise the dignity and quality of both life and death of a patient, whereas end-of-life care aims to improve the quality of the death and dying process (Herndon et al., 2016). Palliative care covers a much longer disease trajectory and starts with the initiation of symptomatic treatment associated with progressive and life-threatening conditions. In contrast, end-of-life care typically refers specifically to care pathways from the diagnosis of a patient entering the process of dying. End-of-life care is therefore argued to be distinct, focused on symptom control of the dying process, and helps patients and family caregivers achieve what is often termed as a "good death".

It is intended that palliative care will be used as the primary focus of this study. End-of-life care, whilst having its own distinctive care needs, would be considered a part of the holistic palliative care spectrum. It is anticipated that care elements specific to end-of-life care would overlap within the current study investigation.

1.6 The growing need for palliative care in primary care

In line with most developed industrial countries, the UK population continues to age, bringing challenges to the way health services are delivered. In mid-2018, the population of the UK reached an estimated 66.4 million and is projected to surpass 70.1 million by mid-2029 (Office of National Statistics, 2019). Further, this continuous growth in population, along with people living longer and having fewer children, means that there has been a shift in the age structure towards later ages, which means that the UK have an ageing population (Office of National Statistics, 2019). The increase in the elderly population coupled with advancements in medical care is resulting in patients with life-limiting and frailty living longer. In most countries across the globe, the proportion of deaths that occur at ages 80 years or over has increased significantly (United Nations, 2013).

In the United Kingdom, increased life expectancy is resulting in an increasingly ageing population (Office of National Statistics, 2019). If the current trend continues, in England and Wales, there will be over half a million people who will need palliative care services by 2040 (Etkind et al., 2017b). In other estimates, there could be nearly 60% more people in need of palliative care by 2040 (Finucane et al., 2019), and therefore health and social care provisions in the community need to expand urgently. There could be a greater number of people suffering from advanced life-threatening conditions or other cancers. The primary care services need to evolve further as it would be far more challenging to provide care for people with these advanced diseases with a longer time frame and an uncertain disease course (Mitchell and Murray, 2021).

1.7 Implications of increased demand for palliative care services.

The increased cost and demands of caring for an older population put both financial and social pressure on the health care system. This is prompting a rethink of how the current division of health care labour is organised. In England, social care budgets for palliative care are constantly on a decline resulting in budgetary constraints and drive for efficiency across the health care sector. Palliative care provisions are therefore competing with other areas of health care for limited financial resources.

In the UK, the health care policy initiatives focused on increasing capacity at primacy palliative care sites (Department of Health 2008). This would encourage patients to be cared for at home, which is assumed to be the preference for the majority (Gomes et al., 2013a, Johnstone, 2017a). The consequences for patients and family caregivers are significant as they are often asked to take up important roles in medicine and health care management without any formal training and at short notice (Pollock et al., 2021).

Patients and family caregivers are widely acknowledged to require extra support in areas of pharmaceutical care, especially medicine management (Pollock et al., 2021). These needs provide an opportunity for community pharmacies to offer support and raise their professional profile. Community pharmacists are regarded as the most accessible primary care health professionals, especially out of hours but have so far seen a marginal role in palliative care service provision (Latif et al., 2021b).

1.8 The challenge of managing multiple morbidities and complex medicine regimens accompanying palliative care

People are living longer with life-limiting illnesses like cancer and are also dying of chronic rather than acute illnesses. With an ageing population, the prevalence of multiple chronic illnesses (multi-morbidity) is on the rise (Barnett et al., 2012). For example, since 2016, dementia and Alzheimer's disease have become the leading cause of death (Office for National Statistics, 2016a), and in 2019 they accounted for 12.5% of all deaths registered (Office for National, 2020). Inevitably medicine prescribing and use of medicines has progressively increased towards later stages of life to manage the increased prevalence of co-morbidities. This can be accompanied by patients experiencing medicines-related problems associated with managing multiple medicines for complex co-morbidity. Carers are often asked to manage their relatives' medicine(s) with little support or training. The initiation of palliative care further compounds this complexity.

1.9 Palliative care provisions in the community

At present, there are several different palliative and end-of-life care service models operational in the UK. These include care at home, care home, hospice, and hospital. It is reported that many people dying at home do not receive an acceptable level of pain management (Office for National Statistics, 2016b). In an audit, the general quality of care rating of outstanding is reported at 76% for hospice as opposed to the lowest figure of 26% when care was provided by urgent care services at hospitals (Royal College of Physicians, 2016). The above figures show a significant disparity in the quality of care among different care settings. Many factors are believed to contribute to the disparity in care provision. Among them is medicine mismanagement and/or lack of complete knowledge by patients and family caregivers about dosage regimens in home-based palliative care (Buck et al., 2020). With the progressive decline in physical abilities, the patients may become severely debilitated. This results in family caregivers taking on most of the complex roles involved in daily care and medicine management (Look and Stone, 2018). These tasks may be demanding, distressing and complex, for example, managing peritoneal dialysis, chest drains, and percutaneous endoscopic gastrostomy (Baillie and Lankshear, 2015).

There has been greater pressure and expectations on families to assume increasing responsibility for home care, including medicines management, without necessarily having the desire, confidence or professional support to do so (Pollock, 2015a). Health care professionals, particularly community, district and specialist community nurses, also play an increasingly significant role in administering medicines. However, even in these circumstances, they have reported they do not necessarily feel as confident as they would wish in this role (Wilson et al., 2015). In recent years, community pharmacists have been commissioned to offer extended services, and these have been shown to increase medication adherence and be effective and cost-effective (Elliott et al., 2020). This raises the question as to whether these services can potentially be extended to cover medicine-related problems that arise in palliative patient groups.

1.10 Pharmacists' extended role

Community pharmacies are a source for the provision of professional services which often complement those of other healthcare professionals. Community pharmacists are responsible for designing, implementing, and monitoring patient-specific pharmaceutical care plans aimed at optimum drug treatment for a specified therapeutic outcome (Mossialos et al., 2015a, van Mil and Schulz, 2006). Pharmacists are encouraged, in addition to their contributions, to recognise and expand the contributions of other team members (Cortis and Claire, 2013). Pharmacists provide valuable patient care, contribute to a growing literature base of medication knowledge, and participate in the education of patients, families, and fellow professionals.

In England, the recent expansions of the community pharmacist's role include.

- Non-medical prescribing (Independent pharmacist prescribers)
- Practice pharmacists (Pharmacists working in GP surgeries)
- Pharmacists with special interest (Pharmacists engaged in specialised roles, e.g., running warfarin clinic)
- Prescription Intervention Service (PIS)
- Influenza Vaccination Service
- NHS Urgent Medicine Supply Advanced Service (NUMSAS)

- Community Pharmacy Consultation Service (CPCS)

The list is not exhaustive, and in addition, there are local and private funded community pharmacy services like travel vaccination, malaria prevention, anticipatory prescribing, minor ailment scheme, and others. There is a growing onus on all healthcare bodies to better use their potential in the most cost-effective way possible. A recent analysis (PricewaterhoueCoopers, 2016) using conservative assumptions concluded a net contribution by the community pharmacy sector in England of £3.0 billion in value in 2015, with a further £1.9 billion expected over the next 20 years. NHS England is increasingly promoting pharmacists' inclusion in GP practice teams to ease GP workload in areas under the greatest pressure. The recent role extensions are considered important for the sustainability of the community pharmacy profession. The community pharmacy sector requires new innovative roles to support itself in an era of budgetary constraints.

Recently pharmacists have been encouraged to take up new roles in community health care. These include pharmacist positions in GP surgeries, CCGs, and out-of-hours services. However, community pharmacists often work in silos and are distant from participation in MDTs. But the new provisions of data sharing, i.e., community pharmacists' access to summary care records, are allowing them to increase their participation in clinical monitoring and the decision-making process.

1.11 The community pharmacy contract in England

Community pharmacies in England are primarily funded by the National Health Service (NHS) through a national community pharmacy contractual framework. This framework comprises three tiers, namely 'Essential services', 'Advanced services', and local contracts for 'Enhanced services' (PSNC, 2015). 'Essential services' are largely based on the supply of medicines (e.g., dispensing of prescriptions, disposal of unwanted medicines), whilst 'advanced services' are medicines optimisation interventions which are believed to be equally important (MURs, NMS). 'Enhanced services' are driven by the needs of the locally serviced population and consist of a mix of both public health and medicines optimisation interventions and may include services such as minor ailment, needle exchange, emergency hormonal contraception service, supervised consumption service etc. The payments to community pharmacy contractors are based on the above three tiers. Participation in all services covered under tier 1 is compulsory, and a set amount is paid for such participation. While payment to tier 2 services is optional, payments are predetermined on a national level. Meanwhile, tier 3 services are commissioned locally, and payments vary among different CCGs.

Since the introduction of the current contract in 2005, there has been a shift in focus from suppling medicines towards a more patient-focused and service-driven model. The uptake of clinically oriented services (NMS, minor ailment scheme, non-medical prescribing, CPCS etc.) has been structured to ease pressures in general practice (Elliott et al., 2017). However, community pharmacies' role in palliative care remains centred on the timely supply of essential medicines or ad hoc support when prescriptions are collected. It is not known to what extent pharmacists' role extension can develop into palliative care services.

1.12 Pharmacist involvement in palliative care

Apart from the physical supply of medicines, community pharmacists have now seen a marginal role in palliative care. This is despite being perceived as possessing pharmacological expertise. Potential areas where community pharmacists can play a more active role can include improving patients' pain control which is often regarded as the most significant factor in symptomatic treatment (Geum et al., 2019). Similarly, polypharmacy and associated medication burden lead to increased stress and confusion among patients and carers. By engaging in a community palliative care network, community pharmacists can help healthcare professionals, as well as patients and their family caregivers, in improving medicines management from early on in a palliative care plan.

1.13 The need for greater involvement of community pharmacists in palliative care

The current trends discussed above make it obvious that there is a need for greater collaborations among community health care professionals. This is important to ease the growing demands for palliative and supportive needs arising from an ageing population living longer with multiple morbidities. The NHS Long Term Plan (Alderwick and Dixon, 2019) recommends improved proactive, personalised, and well-coordinated care for all people in their final year of life. Care should be patient-centred and sensitive to the physical, psychological, social and spiritual needs of the patient and family. However, predicting such needs and when and how to initiate these discussions is challenging.

Palliative patients have complex care needs, the complexity of medicine use and polypharmacy (Latif et al., 2020a, NICE, 2015b). Policy initiatives are increasingly offering opportunities for community pharmacists to extend their current engagements, and they are well placed to advise patients and family caregivers (Latif et al., 2021b). Family caregivers often take on considerable responsibility, adopting caring roles that they may not be fully equipped or confident in the undertaking, and some may struggle to cope with the logistical and emotional work of organising and administering medicines for which the pharmacist can play a greater role (Wilson et al., 2020). Patients and family caregivers may find it hard to cope with rapidly changing symptoms and associated prescription changes. This may be particularly important in the last days of life/active dying phase where pharmaceutical care needs relating to timely supply, advice on anticipatory medicines and managing symptoms may become more common. The pharmacist has the potential to assume a key role in optimising medicine use in palliative care (Latif et al., 2020a). However, any greater role in medicine optimisation would require effective collaboration with a range of care providers.

Given the ease of public access and extended opening hours, community pharmacists are well-positioned to support palliative care in the community. However, at present most community pharmacists have marginal roles limited to medicine supply and have limited involvement as integrated members of the Multi-Disciplinary Team (MDT) (Elliott, 2014). Furthermore, there is little guidance for pharmacy teams about how and when medicine support may be required or the practical ways in which the pharmacy can contribute further to the supportive care of patients receiving palliative care from their family caregivers.

1.14 Opportunities for Pharmaceutical Care

Hepler and Strand (1990) defined pharmaceutical care as the responsible provision of drug therapy to achieve definite outcomes that improve a patient's quality of life. The definition received an update in 2013 by "pharmaceutical care network Europe". After reviewing different historical definitions, they called pharmaceutical care the pharmacist's contribution to the care of individuals to optimise medicine use and improve health outcomes (Allemann et al., 2014). Correspondingly, there are many ways in which pharmacists can contribute to advising family caregivers and other health professionals on a range of clinical interventions. Community pharmacists could have a greater input to advise in the use of anticipatory medicines (just in case medicines) and by ensuring that sufficient stocks of end-of-life medicines are available. (Wilcock, 2011, Wilson and Seymour, 2017), In accordance with NICE guidelines (NICE, 2015a), there are areas of medicine management where community pharmacists can contribute further. With a greater inclusion in community palliative care teams, the pharmacists could provide advice both to patients and health care professionals to monitor and manage the following (Latif et al., 2020a);

- Managing pain, e.g., limiting breakthrough pain episodes.
- Managing nausea and vomiting. Ideally, the cause should be determined and reviewed every 24 hours; if necessary, substitution or additional anti-emetic should be administered.

- Managing anxiety, delirium and agitation. The dose and frequency should be reviewed according to levels of patient distress and response.
- Managing troublesome respiratory secretions, e.g., “the death rattle”. If medicine is indicated, periodic review for efficacy and adverse effects is needed. Non-pharmacological advice may include repositioning.
- Awareness of other symptoms such as anorexia/cachexia, fatigue, constipation/diarrhoea, oral health issues, depression and difficulty sleeping.
- Rationale use of medicines/deprescribing where appropriate

1.15 Medicine Optimisation

Medicine optimisation is defined as a person-centred, evidence-based approach to safe and effective medicine use to ensure people obtain the best possible outcomes from their medicines and that they continue to provide benefit for the individual (De Simoni et al., 2012). Medicines optimisation ensures that there is a specific and justifiable reason for every medication the patient is taking and that this is as optimum as it can be based on evidence (Aggarwal et al., 2020). Community pharmacists are considered custodians of medicines (International Pharmaceutical Federation, 2014) and hold an advisory role for both patients and prescribers. As such, their contributions are paramount toward medicine optimisation goals. As experts on medicines, pharmacists have a crucial role in all aspects of medicines management to ensure a person is taking their medicines as intended and can support the management of long-term conditions, multi-morbidities and polypharmacy (Latif, 2019, NICE, 2015b). However, the care of patients at the end-of-life clinical decision-making may become more complex and even emotionally distressing, and adequate training is imperative for such integrative roles. With support from the pharmacist, patients could be empowered to make more informed decisions about their pharmaceutical care (Archer et al., 2017). However, the care of patients at the end-of-life clinical decision-making may become more complex and even emotionally distressing, and adequate training is imperative for such integrative roles. With support from the pharmacist, patients could be empowered to make more informed decisions about their pharmaceutical care (Archer et al., 2017).

1.16 Summary

This introductory section has 'set the scene' by providing contextual information about wider challenges in the delivery of community palliative care services and details the medicine management-related difficulties faced by patients and their family caregivers. It also explores the current marginal role of community pharmacists and the areas where they can have more significant contributions. The following literature review further examines the evolving concepts in palliative care and pharmacists' role expansion and how these are viewed by various stakeholders. It also answers what the pharmacist's current contributions are toward palliative care services and the evidence-based evaluation for these services. It finally seeks to understand the drivers and/or barriers toward greater community pharmacy integration into this emerging area.

The next section, chapter two, covers a literature review. Chapter three provides the methodological basis for the study along with the methods used. Chapters four, five, and six report the findings from the study. The findings are divided into three chapters in the following way.

Chapter four details the findings from professional (pharmacists, GPs, and Nurses) groups around the current involvement of community pharmacy. Chapter five provides the same findings from lay (patients and family caregivers) participants. Chapter six covers both lay and professional perspectives around potential future role extensions for community pharmacies in palliative care services. In Chapter seven, the findings from the study are discussed against the literature, and a discussion of these findings and their significance is considered. A reflection of the strengths and limitations of this study is also given as well as its practice implications. The chapter also details avenues for future research. Chapter eight then concludes the thesis.

Chapter Two

LITERATURE REVIEW

Research into palliative care and community pharmacy is an expanding field. Broadly, this literature review focused on exploring community pharmacies' current involvement and potential for further involvement in palliative care. The research inquiry of the current project was exploratory and planned to answer broad research questions. It involved contextualising the research questions within the published literature base.

2.1 Literature review approaches considered for the study

Three literature review approaches were considered to scour the published literature to clarify and map key concepts related to the research inquiry. These are detailed below.

2.1.1 comprehensive systematic reviews

A systematic review involves a review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant primary research, and to extract and analyse data from the studies that are included in the review (Pearson, 2004, Aromataris and Pearson, 2014). Such reviews are suited for a narrow line of inquiry and to answer focused questions to establish objective causality (Munn et al., 2018b).

2.1.2 Narrative synthesis

Narrative reviews involve discussing important topics from a theoretical point of view (Jahan et al., 2016). Narrative reviews take a less formal approach than systematic reviews and are more likely to include a literature base selected by the researcher and may carry the influence of personal bias. Furthermore, narrative reviews do not follow the strict guidelines generally set in systematic reviews, such as reporting methodology, search terms, databases used, inclusion and exclusion criteria, and critical appraisal. At its most basic, narrative reviews are most helpful in obtaining a broad perspective on a topic.

Both comprehensive systematic reviews and narrative synthesis are valuable approaches for evidence synthesis in health care research. However, considering the current research inquiry, scoping review approach was adopted for the literature review. The following text provides further details on scoping reviews.

2.1.3 scoping reviews

Scoping reviews are defined as a review process to construct an overview of a broad field (Moher et al., 2015) and are used to map the concepts underpinning a research area (Arksey and O'Malley, 2005). Scoping reviews are an ideal tool to determine the scope and extent of published literature on a given topic, provide a detailed overview of its focus and help examine emerging evidence when it is still unclear (Armstrong et al., 2011). Scoping reviews are generally indicated for the following purposes (Munn et al., 2018a).

- To identify the types of available evidence in a given field
- To clarify key concepts/ definitions in the literature
- To examine how research is conducted on a certain topic or field
- To identify key characteristics or factors related to a concept
- As a precursor to a systematic review
- To identify and analyse knowledge gaps

Scoping reviews are better suited for broad questions and are useful to clarify or map key concepts in a field. Considering the current research inquiry, community pharmacists' involvement in the palliative care field is limited, and patients' and stakeholders' perceptions on this topic are under-researched. To further explore key areas of this multi-faceted research topic, it was deemed appropriate to follow a scoping review approach for literature review.

The scoping review provided a comprehensive overview of community pharmacy involvement in palliative care and a framework to place this information into the perspective of a future role extension. The scoping review involved a broader search of the grey and peer-reviewed published papers, including searching the reference sources alongside supplementary resources relevant to the topic. The search followed a clear plan and included a review of the terms to create what Hart has termed a 'justifiable vocabulary '(Hart, 2018 ch1). McGrath et al. (2012) also provided helpful guidelines for necessary prerequisite work before commencing the literature search. The keywords and vocabulary used for this literature search were from previous topic knowledge. Further details of how the database search terms were created are provided in the next section.

2.2 Database search

The preliminary search of the literature was performed using "The Cochrane Library", "PUBMED", "CINAHL", and "EMBASE". These databases are considered sufficient for the current evidence base and hold a prominent reference status (McGrath et al., 2012). The University of Nottingham library online database portal was used to access these databases. Endnote version X9 was used to manage literature data. The search terms included "palliative care", "end-of-life", "symptom", "pharmaceutical care", "community pharmacy” "advance care planning” "medicine optimisation” "medicine management” "palliative medicine” "pharmacist". The articles that informed the initial research questions were published in English and were searched between 1 January 1980 and 30 May 2019.

After this initial search and taking account of the available evidence, the literature was constantly examined for relevant recent publications. This iterative search approach allowed the inclusion of recent publications and further development of the research topic. The scoping review scoured for published evidence in the following broad themes.

- Current and future projection trends in palliative care.
- Evidence for greater integrated primary care palliative services.
- Reported problems in home-based (primary care settings) palliative care services.
- Participation of community pharmacists in integrated palliative care.
- Pilot palliative care schemes with community pharmacy participation.
- Reviews examining benefits of extended community pharmacy roles.
- Barriers and enablers for greater community pharmacy participation.

The above iterative approach for scoping review resulted in the selection of 119 research articles. This selection comprised of systematic reviews (21), peer-reviewed published papers (87), editorials (2), and conference abstracts (9). In addition, the grey literature was also reviewed to access relevant policy papers and reports from the Department of Health and the UK government. This was achieved by a review of professional websites, print, and news media relating to organisations involved in palliative care and community pharmacy services were searched as well (Table 2-A)

Table 2-A Grey literature sources used in literature search

- Department of Health publications
- Royal Pharmaceutical Society of Great Britain publications
- Chemist and Druggist magazine articles
- Clinical Pharmacy Conference abstracts
- Office of National Statistics
- National Council for Palliative Care articles
- Association of Supportive and Palliative Care Pharmacy articles
- Palliative care Research Society publications
- Leadership Alliance for the Care of Dying People (LACDP) articles
- Dying Matters blogs

2.3 Evidence for greater integrated primary care palliative services.

Before we examine the potential greater participation by community pharmacies in palliative care services, it is important to acknowledge the trends in palliative care needs. Several authors (Finucane et al., 2021, Sleeman et al., 2019, Bone et al., 2018, Etkind et al., 2017a) provide useful insights into the future projections for palliative care needs. The overarching consensus is that most people dying in future would require palliative care support, and in later years of life, there would be an increase in care demands for an ageing UK population (Raleigh, 2021). When these care needs are not adequately addressed in primary care settings, these result in extra burden at hospitals due to frequent unscheduled visits (Mason et al., 2020).

The evidence that most people would prefer to die at home is extensive and consistent (Gomes et al., 2013b, Bone et al., 2018). Patients are increasingly shown a desire to receive care close to their place of living if available (Office for National Statistics, 2016b). Home-based care is preferable for patients with advanced chronic disease as an in-patient setting may accelerate functional decline (Lustbader et al., 2017, Gill et al., 2015). Patients and caregivers are reported to benefit from the early initiation of palliative care in their disease trajectories (Bakitas et al., 2015, Dionne-Odom et al., 2015). In one international review of palliative care in primary care, the failure to timely identify palliative care patients is reported as a major barrier (Murray et al., 2015). Initiation of palliative care can be started early in a primary care setting using a teamwork approach.

In a retrospective service evaluation study comparing the preferred and actual place of death, (Ali et al., 2015) report that the real choice for people approaching the end-of-life depends on the confidence they have that they will receive the right care in whatever place they choose. Etkind et al. (2018) argue that patients and their families can be considered as a single unit of care, and primary care services should be perceived as sites of quality palliative care by both patients and their families. In addition, the palliative care services should be flexible in their provisions to accommodate the health needs of diverse groups of recipients (Mitchell et al., 2013, van Kleffens et al., 2004). New models of integrated palliative care, therefore, will allow patients and families to consider their personal goals and quality of life when making choices about the direction of their medical care (Buss et al., 2017).

However, the evidence for the home being the preferred place of death is far from strong or consistent. For example, Hoare et al. (2015) question the number of people indicating home as their desired place of death. The authors point out that there are missing data where a significant number of respondents in various studies either do not reply or do not state any preference at all. They argue that most of these then chose a place of death away from home and, therefore, if accounted correctly, could have an impact on percentage figures stating home as the desired location. Nevertheless, it is vital to consider that in light of current policy directives, the number of people requiring home-based care is on the rise. This includes care for chronic illnesses, palliative and supportive care, and terminal end-of-life care. This presents a challenge for family caregivers as they have to take on this care burden of medicine management with a progressive decline in the patients' physical well-being (Noureldin and Plake, 2017). Further, failure to control symptoms, for example, pain, would result in anxiety and distress among patients and family caregivers (Notenboom et al., 2014).

Optimum pain control is considered one of the key objectives of palliative care and is given higher preference than the place of death (National Council for Palliative, 2016, Waghorn et al., 2011). However, pain is reported to be least managed for patients receiving home-based palliative care (Hackett et al., 2016, National Council for Palliative, 2016). This offers an opportunity for community pharmacists to extend their current contributions by providing medicine management support to patients receiving palliative care at home or their family caregivers.

2.4 Reported problems in home-based (primary care settings) palliative care services

In primary care settings, patients receiving palliative care and their family caregivers have reported many challenges when accessing healthcare services, with medicine management as one major area of concern. However, they are often unaware of the support available from most primary care providers. The following sections, therefore, examine the current evidence base for the challenges faced by patients and/or their family caregivers during the course of progressive palliative care phases.

2.4.1 Complex medication regimens in palliative care

A 2016 editorial in the Lancet draws attention to the worldwide challenge to provide dignified, compassionate, and quality care to the elderly population at a time when the ageing population exceeds economic growth (The Lancet, 2016). One estimate suggests that 75% of people nearing the end-of-life will benefit from some aspects of palliative care (Etkind et al., 2017b). There are strong policy priorities to support patients to die at home if they so wish (Department of Health, 2008, 2012). But this brings significant challenges for patients, families and the health care professionals that support them. One major concern is the management of complex medication regimens. Families are being expected to take on increasing responsibility for home care without necessarily having the desire or confidence to do so (Pollock et al., 2021). Health care professionals, particularly community, district and specialist community nurses, also play an increasingly significant role in administering anticipatory end-of-life care medicines but do not necessarily feel confident in this role (Wilson et al., 2015, Wilson et al., 2020).

2.4.2 Further challenges in community palliative care delivery

England has one of the highest rates of hospital death for older people in Europe. Despite stating a preference to die at home, older people are less likely to do so than other age groups (Gomes and Higginson, 2008). People often turn away from home care when faced with the extra burden of disease management in palliative care. Barriers to accessible quality palliative care are widely documented (Love and Liversage, 2014, McIlfatrick, 2007, Ahmed et al., 2004). The introduction of extra supportive medicines often needed during progressive palliative care regimens increases the health care burden for patients and their family caregivers. This can easily lead to confusion, medicine mismanagement, and inappropriate pain control (Herndon et al., 2016). Likewise, the past and existing palliative care services based on terminal illness come short of acknowledging the palliative care needs of patients with uncertain illness trajectories associated with chronic illnesses, frailty, and multiple morbidities (Seymour and Cassel, 2017).

There have been consistent calls to develop an integrated community-based palliative care service adapted to address care needs specific to palliative care patients (Cleary, 2016). Inadequate pain control in cancer patients is reported as a leading cause of contacting out-of-hours medical help in primary care, besides most of them already being prescribed strong relief medicines (Adam et al., 2014). There is a scope and value for increasing pharmacists 'involvement in supporting patients, carers and professionals in optimising medicine use associated with increased medication burden. However, there has been limited research into community pharmacist input in this area.

2.5 Participation of community pharmacists in integrated palliative care.

The section initially discusses developments in the pharmacist's role and then examples in the literature of community pharmacists 'participation in integrated care pathways for palliative patients or their family caregivers.

2.5.1 Developments in community palliative care and community pharmacy involvement

Current healthcare policies prioritise patients remaining at home during their final hours. Whereas some would argue that this is the patient's preference, others would argue this policy is also influenced by budgetary constraints and the need to relieve pressures in secondary care centres (Pollock, 2015a). The issue is that patients being cared for at home may not be receiving the support with medicines they need. There is, therefore, a gap in the literature to further understand and explore the patients 'perspective, specifically how they would feel about pharmacists 'greater involvement in their medication management and what this should look like in practice. Also, if services are reconfigured, what impact this would have on the operations of multi-disciplinary teams (MDTs). The following section describes the extent to which the pharmacist is currently involved in the MDT.

2.5.2 Pharmacist involvement in multi-disciplinary team participation

The participation of the pharmacist as an integral member of a multi-disciplinary team was historically overlooked across many developed nations with well-resourced healthcare systems. (Gilbar and Stefaniuk, 2002, O'Connor et al., 2011c). The ageing population has resulted in a modified healthcare need of the population. These changing dynamics are presenting new challenges for even the most advanced health care systems. There is an obligation for greater efficiencies resulting from budgetary constraints. In line with other primary health care bodies and professionals, there is an increased focus on the integration of community pharmacists into a more specialised role. American Society of Health-System Pharmacists (ASHP) has published its guidelines on the extended role of a pharmacist in palliative and hospice care (Herndon et al., 2016).

2.5.3 Expansion of community pharmacists ’role in palliative care

With NHS budgetary constraints on palliative care services as well as shortages of care staff, there are increasing pressures on both NHS and social care (Mitchell et al., 2019). Pharmacists have been identified as professionals with the scope to take on extended medicines management roles. Community pharmacists provide a well-placed avenue to relieve pressure from doctors and nurses due to the constant increases in demands. These may include medication reviews in the community, support for self-care and independent prescribing. Their involvement in end-of-life care is currently limited, and it is not known what the scope of their current involvement is or the readiness of the profession to take on more palliative care roles.

2.5.4 Current engagement of community pharmacy in palliative care

In the UK, the role of community pharmacy in relation to palliative care is mainly centred on the timely supply of essential medicines. There is a specialist service that is locally commissioned called the "NHS Community Pharmacy Palliative Care Drugs Stockist Scheme" (NHS England and NHS Improvement, 2020). This is an enhanced service which means it is locally funded, and participation is optional. Under this service, the participating pharmacies are required to maintain adequate stock of medicines required for symptom control towards the last days and hours of a dying patient. Another locally commissioned enhanced service built on this model is the "just in case box". It is adopted by many local commissioning bodies and involves dispensing a box containing important medicines needed to ease the symptoms, including pain, anxiety, nausea and vomiting, agitation, delirium, breathlessness, and noisy chest secretions during an imminent dying process (Johnstone, 2017b). The service greatly improves the availability of anticipatory medicines, especially out of hours. However, it utilises limited resources available at community pharmacies with very little active contributions by pharmacists. If community pharmacists are more involved, rather than just handing over the medicines, their clinical and pharmaceutical expertise could be better employed in advising patients, family caregivers and other healthcare professionals on adequate pain control and medicine management (Latif et al., 2020b).

2.6 Pilot palliative care schemes with community pharmacy participation.

In addition to the contractual services, a limited number of pilot initiatives have been trialled. These show the real potential to promote pharmacists' ability to help patients and allow them to integrate further into the multi-disciplinary palliative care team. Details of these are provided below.

2.6.1 Macmillan pharmacist project

Macmillan, a leading charitable organisation in cancer care, in collaboration with the University of Strathclyde and the chemist Boots, has piloted different projects extending the roles of pharmacists in the community. Macmillan Pharmacist Facilitator Project was a three-year project from 2009 to 2012 in Scotland. It was designed to address gaps in practice and explore a new service delivery model for community pharmacy palliative care services (Akram et al., 2012b). The project involved four participating community health and social care partnerships in diverse primary care settings. The project was particularly useful in two aspects. Firstly, in characterising baseline community pharmacy services and identifying the main challenges. Secondly, in listing the steps taken to improve community pharmacy capacity and skills for better integration within the multi-disciplinary team.

2.6.2 Macmillan pharmacy service

The Macmillan pharmacist facilitator project led to the development of the "Macmillan Pharmacy Service". It was a three-year project from 2013 to 2016 (Mccusker, 2016b). The service provided support to community pharmacy and health and social care partnership teams in advancing better pharmaceutical palliative care services as close to home as possible for patients with life-limiting illnesses.

2.6.3 The community Macmillan pharmacist project

Another such project is "the community Macmillan pharmacist project". This was a two-year project from April 2012 and was based in Hull, England. It involved two pharmacists working within a community end-of-life team in Hull and providing palliative care to patients with complex needs (Mellor, 2014). It was a small-scale project, and no systematic evaluations were published at the end. The project provided services to hospice and community healthcare teams. The two pharmacists worked in an advisory role to the multi-disciplinary team in more of a specialised role, and the self-evaluation concluded pharmacists' involvement was a valuable addition (Mellor, 2014). MacMillan Rural Palliative Care Pharmacist Practitioner (MRPP) project (Akram et al., 2017b) also reports pharmacists as a valuable addition to overall palliative care provisions. This pilot project also engaged pharmacists in an advanced specialised role capacity.

2.6.4 Critique of the pilot initiatives

Although all the above-mentioned projects used the term "palliative" in their description, the services provided were mostly within the domain of end-of-life care. Also, in all these projects, pharmacists were working in a special role outside of their community pharmacy premises. It was a pharmacist in the community rather than a community pharmacist. The pilots are reported as pioneer projects in extending pharmacists' role in palliative care. However, such development of a pharmacist's role is taking focus away from both the utilisation of community pharmacy and community pharmacist. Mossialos et al. (2013) and O'Connor et al. (2011c) report novel ideas for greater community pharmacy involvement and emphasise the expansion of already established pathways. Involving community pharmacy in palliative care services make them more accessible by expanding their reach further from traditional cancer and terminal care boundaries.

2.7 Examining the benefits of extended community pharmacy roles

This section provides details from studies examining potential benefits resulting from greater community pharmacy participation by pharmacists.

Need for greater pharmacist inclusion in the palliative care team

Community pharmacy has so far seen limited involvement in palliative care services. In England, pharmacy medicine management services have received significant focus and investment in recent years (Mossialos et al., 2015a). These are targeted to address patients 'problems around medicine adherence arising from their concerns of dependence, tolerance, and side effects (Pound et al., 2005b). The availability of trustworthy, skilled support from community health care professionals is a key factor shaping the choice of having palliative care at home (Aabom et al., 2006, Brazil et al., 2002, Cantwell et al., 2000). Community pharmacists are regarded as one of the most accessible primary care professionals, especially during out of hours when GPs are not available (Needham et al., 2002). In a community multi-disciplinary palliative care team, pharmacists may be well placed to provide expert medication advice and education for rational medication use (Walker, 2010).

Lessons can be learned from the contributions made by hospital pharmacists in cancer care. These have been highlighted in a review by Thoma et al. (2016). The benefits include palliative care, improved symptom control, enhanced patient and family's satisfaction, and improved quality of life. Several studies have mentioned a potential integrated role of the community pharmacy in cancer care and, by extension, in palliative care (Akai et al., 2009, Savage et al., 2013a, O'Connor et al., 2011c, Tait et al., 2013). The common assertion in these studies views community pharmacy as an underused healthcare resource. This, in part, is due to the lack of any established procedures for greater community pharmacy integration into palliative care services both nationally and internationally. Active involvement by community pharmacists is, therefore, not always visible in primary care interdisciplinary teams (O'Connor et al., 2011c). One converging point for most studies is to research further into effective pathways for greater community pharmacy inclusion in palliative care teams.

2.7.1 Pharmaceutical care

The term pharmaceutical care was first discussed by Hepler and Strand in 1990 and was defined as the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life (Hepler and Strand, 1990). Pharmaceutical care has placed a greater focus on a patient-centred holistic approach by collaborative treatment planning with a patient and other health care professionals in multi-disciplinary teams (Tang et al., 2020). However, Denham and Barnett (1998) reported that pharmaceutical care objectives were not adequately met for an older population. It can be argued that pharmaceutical problems such as polypharmacy, inappropriate prescribing, and adverse drug reactions still commonly exist for this group of patients and are also evident for palliative care patients (Chuang et al., 2017, van Nordennen et al., 2016, McNeil et al., 2016).

An earlier study (Remi et al., 2016) emphasises the importance of involving pharmacists in identifying and dealing with drug-related problems in palliative care patients. The involvement resulted in overall improved pharmaceutical care. Pharmacists 'involvement in prescribing anticipatory medicines resulted in improved end-of-life care in a study of nursing home patients (Owen et al., 2016). Despite this, in a community setting, most queries by patients for pain management associated with cancer are made to either GPs or nurses (Edwards et al., 2016). This may be down to the perceived view of patient groups where pharmaceutical care has not fulfilled its potential to allow community pharmacists to help as primary contact for medicine problem-solving. The following section further details the main barriers and facilitators.

2.8 Barriers and enablers for greater community pharmacy participation

This section details the silent factors acting as either barriers or facilitators towards greater integration of the community pharmacy sector in primary care setup. Initially, it will focus on stakeholder views and then broader barriers and enablers.

2.8.1 Stakeholders 'views about greater community pharmacy involvement in palliative care

Although new pharmacy services are making significant achievements in patient satisfaction and savings, the new roles are not always openly welcomed (Latif et al., 2013a, Latif et al., 2016, Wells et al., 2014, Pollock et al., 2021). There is a common perception that community pharmacists are not viewed as active or valued members of a multi-disciplinary team (Ise et al., 2010). The overarching role of community pharmacists is at times perceived by other healthcare professionals, patients, and colleagues as one crossing professional boundaries. There is a dynamic shift in power brought about by these extended roles in medicine management and patient education. Pharmacists can easily be perceived by patients as scrutinising agents or as Waring and Latif label as government allies where they keep close observations of patient routines (Waring and Latif, 2018). Similarly, pharmacists themselves are stepping into previously unaccustomed professional territories (Waring et al., 2016). Similarly, proper dissemination among healthcare professionals about any new initiative by community pharmacies is important. Latif et al. (2016) report that in the case of a recently developed pharmacy scheme supporting medicine management around newly prescribed medicines, “new medicine service” (NMS), a lack of proper engagement and communications with GPs and other health professionals led to its reduced implementation.

2.8.2 Crossing professional boundaries

The role expansion of community pharmacy is at times viewed as crossing into professional boundaries of other professions. This often leads to professional strain between different healthcare members. The role of community pharmacy in palliative care is not well documented, and at the same time, prescribers are not totally aware of community pharmacists ’abilities (Montgomery et al., 2007). Other barriers impeding greater community pharmacy collaboration within a multi-disciplinary healthcare team are reported as a lack of drive within the pharmacy sector itself, financial and workplace pressures, and the need for extra training. Previous efforts in community pharmacists’ role extensions have received mixed responses from other healthcare professionals, notably general practitioners (GPs). Even community pharmacists themselves have reservations about taking on extra professional responsibilities in addition to traditional dispensing duties.

2.8.3 Barriers to greater community pharmacy inclusion

Policy and professional bodies are keen to build on community pharmacy as an underutilised resource. The community pharmacist is valued as an important member of primary health care; however, traditionally, community pharmacist has seen limited involvement in palliative care. The healthcare expertise possessed by community pharmacists does not reflect any active palliative care initiatives (O'Connor et al., 2011a). This may be due to well-known barriers to implementing new services such as workplace issues (shortage of staffing, lack of professional motivation, costs), lack of support and awareness of the pharmacist's role from other healthcare professionals, and poor public awareness and acceptance of models of extending pharmacists 'role in health care. These may hinder the commissioning and adoption of any new services, and therefore, involvement of all stakeholders is a prerequisite in exploring how community pharmacies may better contribute to palliative care. The views of stakeholders and recipients of palliative care services commissioned by community pharmacies require careful and detailed exploration before any attempt at service development.

- Limited private funding and over-reliance by community pharmacies on local and national commissioning.
- Overworked pharmacists because of taking on many roles without an adequate number of trained pharmacy support staff.
- Limited access to medical records.
- Lack of integration in community MDTs.

The current study will build on these findings to provide an important perspective on the greater community pharmacy's inclusion in palliative care.

2.8.4 Facilitators toward greater community pharmacy inclusion

A palliative care approach that builds the capacity of local communities to support people living with chronic illnesses nearing the end of life is supported by Salau et al. (2007). They evaluated palliative health promotion projects through local community partnerships in Australia and found the partnerships between palliative care services and community organisations as helpful in increasing the outreach and capacity. This puts emphasis on community pharmacies which are recognized as stable delivery points for health care services in their local communities. Such an approach would provide an ideal context for community pharmacists to contribute to community-based palliative care. Furthermore, other factors supporting greater use of community pharmacy teams include,

- The limited number of GPs and community nurses who are available in primary care.
- The flexibility of pharmacists to take on new roles.
- Increased awareness of patients about extended services delivered by community pharmacies in addition to traditional medicine supply role.
- Better trained pharmacy support staff, e.g., Accuracy Checking Technicians (ACTs), freeing pharmacist time to take on extra duties.

More recently, the COVID-19 pandemic has shifted the healthcare landscape and has further stretched the already overwhelmed community healthcare systems. The healthcare systems had to quickly adapt and constantly evolve in light of fast-changing demand, supply, and preferences. Pharmacists have extended their roles as a consequence of new working practices, and patients have been expected to self-manage in these circumstances (Latif et al., 2021b). Further, it is observed that the undervalued access the general population have to community pharmacies acted as a treasured resource in the community. The adaptations brought in by community pharmacies during this time could be evaluated further for formal recognition and their potential to develop as future services. For example, remote consultations, distribution of lateral flow tests, and medicine delivery service.

2.9 Summary

There is currently little evidence about how community pharmacy could impact the delivery of palliative care services and what patients or carers could think of their greater involvement. It is also not well known whether other health care professionals working in the field would find extended involvement acceptable (Mossialos et al., 2013). It is therefore important to engage with all stakeholders involved. The opinions of all interested parties are equally important and should be explored in detail.

2.10 The rationale for the study

Recent advances in health care and health interventions mean that people live longer. In developed countries, life expectancy is rising; in the UK, it has almost doubled since 1941 (Raleigh, 2021). Further, due to better and advanced healthcare systems and considering policy directives (Imison et al., 2017), people can choose to receive care at home for chronic illnesses and multiple co-morbidities (Pollock and Seymour, 2018, Milligan, 2016). However, if cared for at home for a serious or life-limiting illness are dependent upon family caregivers for crucial extra support (Turner et al., 2016). This translates into patients gradually requiring extra support and care towards the latter part of their lives and possibly requiring palliative care support. There is also an increased policy shift to provide essential care packages in the community closer to patients' homes, and integrated community healthcare systems are advocated.

Community pharmacists in this regard have traditionally had a marginalised role, and their current and potential contribution to palliative and end-of-life care is rarely recognised by patients or health professionals (Latif et al., 2020a, Krzyżaniak et al., 2016, O'Connor et al., 2011b). Medicine management for palliative and end-of-life patients cared for at home is challenging and has been highlighted in recent studies (Pollock et al., 2021, Wilson et al., 2020). Recent studies have advocated the importance of community pharmacists in supporting medicine management roles for patients cared for at home (Wilson et al., 2020, Pollock et al., 2021). Expanding on these studies, the current project would further explore the participation of a vital but historically missing (Savage et al., 2013b) part of the community palliative care landscape, i.e., the community pharmacist. The current study is engaging with patients, lay family caregivers, and community health care professionals (pharmacists, GPs, and nurses) around community palliative care, current involvements by pharmacists, and the scope for future expansion of community pharmacy. The current project is novel and timely to establish a groundwork for potential future involvement of the community pharmacy sector in providing palliative and end-of-life care.

2.11 Project aim and objectives

This section details the study's, aim, objectives, and research questions.

2.11.1 Aim

The study aims to understand whether and how community pharmacies can contribute to palliative care services in the United Kingdom by using qualitative methods to engage with key stakeholders.

2.11.2 Objectives

The research objectives include,

1. To establish the current perception of community pharmacy discipline in relation to palliative care by lay (patients and family caregivers) and professionals (pharmacists, GPs and nurses) in England investigated by analysis of semi-structured interview data collected by March 2020.

2. To explore how these stakeholders view the expansion of palliative care services by community pharmacies in England examined by analysis of semi-structured interview data collected by March 2020.

2.11.3 Research questions

The proposed research is exploratory. The interaction with participants for information seeking in this study is essentially interpretive, leading to interpretivist epistemological positions. The philosophical underpinning for this study is social constructionism. This philosophical position is detailed and explained in the methodology section (section 3.3). With these viewpoints and methodological approaches, the project aims to answer the following questions:

1. What are the views of patients, carers, and healthcare professionals towards the current community pharmacy's role and involvement in palliative care in England?

2. What does an analysis of stakeholders' views indicate about the scope for community pharmacy to further contribute to existing palliative care services?

Chapter Three

METHODOLOGY AND METHODS

This chapter details the methodological approach employed in the current study. Firstly, a brief description is provided of common methodological approaches used in the social sciences. Secondly, details of the ontological and epistemological positions underpinning the study and a rationale for selecting a qualitative approach are presented. Thirdly, the research design and methods are detailed. One-to-one semi-structured interviews were the qualitative method chosen to explore the research aims and objectives. Following this, details of the data collection method and data analysis process are discussed. Finally, the ethical issues relating to the study are also considered.

3.1 Positioning the study

In the context of the current study, health services research can be defined as the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of health care, and ultimately our health and well-being (Lohr and Steinwachs, 2002). The goal of health services research is to provide information that will eventually lead to improvement in the health of the general population (Steinwachs and Hughes, 2008, Harris-Wehling and Morris, 1991). This study aims to investigate lay (patients and family caregivers) and healthcare professionals (pharmacists, GPs, and nurses) perspectives on palliative care services delivered by community pharmacies in England. The study, therefore, can be classed as health services research.

The current research inquiry deals with varied and multiple meanings. The study objective is to explore, understand, and conceptualize complex views within their context rather than following a narrow line of inquiry from the onset. The study was not targeted to establish the benefits or drawbacks of a predetermined integration pathway for community pharmacy in relation to the extended delivery of palliative care services. Instead, a deep understanding of participants 'views was desired to understand their opinions towards the expanding role of community pharmacy in palliative care.

3.2 Broad methodological approaches in social sciences

This section provides an overview of frequent methodological approaches used in health sciences research. These include "Quantitative", "qualitative", and "mixed methods". All three undertake research inquiry in their own specific way and differ in ways of approaching the same set of issues (Denzin and Lincoln, 2013 p17). Creswell (2014 ch 1) provided a helpful overview of these three research genres. Their broad definitions are given in Table 3-A.

Table 3-A Three research paradigms. Adapted from Cresswell (2014)

Qualitative	An approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem.
Quantitative	An approach for testing objective theories by examining the relationship among variables that can be measured and analysed using statistical procedures.
Mixed methods	An approach to an inquiry involves collecting both quantitative and qualitative data, providing a more complex understanding of a research problem than either approach alone.

3.3 Philosophical stance

Philosophical assumptions shape how the research question is formulated and influence how information is obtained to answer this question. There are various philosophical positions debated for a social inquiry requiring close interaction with participants. They all have their own salient features, and the choice is guided by the research aims and objectives. Positivist and interpretive are two common but contrasting approaches to health services research (Bowling, 2014, Smith, 2002). Positivistic and interpretive approaches hold specific epistemological positions with distinctive routes to knowledge (Blaikie and Priest, 2019).

3.3.1 Positivism and post positivism

Positivism in the social sciences can be seen as an approach to placing the study of human social life on a scientific footing by extending the methods and forms of explanations that have been successful in natural science. In brief, Positivist approaches focus on an external reality that can be studied, captured and in some way understood. Meanwhile, post-positivism allows room for an approximation of reality by acknowledging it can never be fully understood (Guba, 1990 pp22). Both positivist and post-positivist positions place emphasis on the discovery and verification of theories (Denzin and Lincoln, 2013). The positivist approach to a social inquiry is more centred on the development/identification of a causal relationship. This view of empirical science starts with a theory before the data collection phase. The analysis, therefore, either supports or refutes the parent theory.

In the current study, the views of lay participants (patients and family caregivers) are important as they are central to any future pharmacist role expansion. Equally important are the perceptions of health care professionals in an evolving and increasingly integrated primary care system. The idea of society as a structure beyond just the individuals and reality in its own right is proposed by Durkheim and Lukes (1982). Durkheim considered social facts as building blocks of a society and identified these social facts as ways of thinking, acting, and feeling (Durkheim and Lukes, 1982 pp 142). These social facts are considered external to individual constraints, independent of individual's control, and have the power of coercion by means of which they can control all the individuals in the society. These social norms are present in society even before an individual is born and are considered helpful for continuing the functioning of society (Durkheim and Lukes, 1982).

When exploring the social norms, the ontological differences between natural and social worlds lead to different relationships between respective researchers and their subjects (Benton and Craib, 2011). Positivist theory seeks causes, looks for explanations and emphasizes generality and universality (Charmaz, 2014). The aim is to establish causal relationships in health services research (Maxwell, 2013). Such naturalistic approaches, whether positivist or post-positivist, need to be conducted within known parameters (Kuhn, 1970). Henceforth such an approach will hinder an exploratory study like the current study. The focus of the study, therefore, is not on theory generation but rather on exploring the deep and varying perspectives of participants so they can be fully understood. An interpretive approach to knowledge-seeking aims to understand individual events in relation to the individuals involved and attempt to reconstruct the subjective experience of the participants without distorting the world around them (Denzin and Lincoln, 2013). In the next section, a discussion of the philosophical approach taken for the present study is presented.

3.3.2 Social constructivism

The exploration of the general principles according to which participants organize their experiences in a social world is generally a key element in any social and health services research (Schutz, 1967). An exploratory research question within a social construct ethos becomes broad and general so that the participants can construct the meanings of a situation. This also takes into account the social environment around an individual. A social constructivist viewpoint takes account of deep structures influencing the participants' actions but is dependent on the researcher's interpretation. A constructivist position, therefore, acknowledges that the resulting knowledge is an interpretation dependent upon the observer's involvement (Schutz, 1967).

According to Schutz (1967), a social constructivist epistemology carries the following assumptions and features.

- Individuals seek an understanding of the world in which they live and work.
- Individuals develop subjective meanings of their experiences (meanings derived toward certain objects or things)
- Varied and multiple meanings.
- The complexity of views.
- Rely mostly on participants 'views.
- Meanings are constructed by human beings as they engage with the world they are interpreting.

In general, studies employing social constructivist research designs use inductive strategies as a means to lead their enquiry and understand society. The current study deals with varied and multiple meanings, with the complexity of views rather than a narrow line of inquiry. A theory-neutral assumption with an inductive flow of knowledge can be argued as best suited for such socially complex models (Crotty, 1998).

Regarding pharmacy practice, Government and professional bodies are encouraging policies that better utilize the potential of a pharmacist. To understand the impact of these initiatives, it is important that the views of service-users, i.e., patients and carers, as well as health professionals, are acknowledged. To explore these views, it was considered that a social constructivist position should be taken. This would allow for the: understanding of the world in which participants live and work; subjective meanings of participants ' experiences; account of varied and multiple meanings; worldview to help uncover complex views by engaging with the world (Burr, 2015). These key features were most suited to explore the research questions.

3.3.3 Ontological and epistemological assumptions underpinning the study

Ontology deals with the nature of reality (Benton and Craib, 2011) and can be defined as the science or study of being (Blaikie and Priest, 2019). In contrast, epistemology deals with the nature and extent of knowledge along with the routes to the acquisition of that knowledge. It, therefore, can be argued that the social phenomenon around palliative care comprises multiple layers. This is further complicated by mixed appraisals from within the community pharmacy sector and other healthcare professionals in relation to the community pharmacist's role expansion resulting in participants having markedly varied perceptions. A relativist ontological position outlined by Creswell (2015) and Denzin and Lincoln (2013) is therefore considered appropriate for this research project.

The proposed research approaches participants in an exploratory manner without any expectations beforehand. Any research targeting this area cannot be narrowed down in advance into a few categories or ideas. An interpretivist strategy is, therefore, the best option for acquiring knowledge considering the current project's aims and objectives. In the context of the current research project, shared decision-making and patients' perspectives on key elements of any palliative care service is very vital for any future healthcare policy. Similarly, the view of service providers carries equal weight for the smooth running of any novel development in this field. The world around a person receiving end-of-life care is very different and cannot be compared with any other scenario or setting. The multiple factors influencing at that time lead to multiple realities, which vary in turn from person to person and one setting to another. As the goal of the research is to rely as much as possible on the participants 'views around palliative care, a social constructivist approach is justified.

To conclude, the interaction for information seeking in this study would be essential of an interpretivist nature. Therefore, the study is underpinned by relativist ontology and interpretivist epistemological positions and a social constructivist philosophical viewpoint.

3.4 Research design

It was considered that a qualitative approach would be appropriate to collect the rich data required for the study's aims and objectives. The approach was based on the principles of constant comparison. Constant comparison is an analytic process whereby data is interpreted and compared with existing findings as they emerge through the process of analysis (Charmaz 2014). In applying this to this study, the aim is not necessarily to formulate a theory around community pharmacy role extension; rather, this formed the basis for understating how people constructed their ideas about palliative medicines management and the potential role of the community pharmacist to help support this.

3.5 Methods

Once a qualitative approach was deemed appropriate, one-to-one semi-structured interviews were selected as a research method resulting in the collection of rich descriptive data. Table 3-B details distinctive features of the research methods selected.

The interviews allowed direct interaction with participants, flexibility, and open discussions. Individual interviews provided a relaxed environment to facilitate openness when discussing sensitivities surrounding palliative care. Further, there was an opportunity for follow-up questions to collect detailed insights, depth, and understanding of a participant's response to earlier questions. The analysis involved a constant comparison approach, and this allowed for the inclusion of follow-up questions in later interviews to explore additional meanings.

3.5.1 One-to-one interviews with participants

Semi-structured in-depth interviews are the most common method of qualitative data collection and are widely used in health and social care research. This research method is flexible and allows in-depth analysis by placing the focus of research on the views of participants. The interview is considered an act of active engagement of listening by providing an environment for participants to discuss their in-depth and complex experiences. Further, the interview relies on an interactive method in which mutual learning occurs between those involved in the interview process (Young et al., 2018). This interactive environment is useful in contextualizing accounts of participants (Josselson, 2014).

3.5.2 Topic guides

Specific topic guides were prepared for each of the different participant groups i.e., patients (Appendix 8), family caregivers (Appendix 9), pharmacists (Appendix 10), GPs (Appendix 11), and nurses (Appendix 12). The topic guides consisted of short documents containing initial information about the project, confidentiality commitments, and the interview process to be followed. In addition, the document had prompts for interview questions. The questions were laid out in plain simple English and, considering the sensitive nature of palliative care, were carefully ordered so they gradually move to potentially distressing questions. The interview flow was determined considering a participant's willingness to engage in potentially distressing discussions.

The initial question bank was drawn from a personal understanding of the topic and themes emerging from the literature review. The topic guides were constantly refined as I gained more experience of the interviews and the insights provided by the data collected in previous interviews. The initial interviews contained a greater proportion of broader questions, while the later interviews had more specific questions aimed at getting more deeper understanding of the emergent themes from data analysis at that stage.

Table 3-B Components of one-to-one interviews

• Participants	• Community Pharmacists • Practice pharmacists • Pharmacists involved in extended Roles • General Practitioners • District nurses • Patients • Family caregivers
• Structure	• Semi-structured interview aided with an interview guide • Audio recorded with field notes
• Duration	• 45-50 minutes
• Location	• Participant preferred place • University of Nottingham • Place of work
• Number of interview (Planned)	• 40
• Sampling	• Purposive

3.6 Sampling and recruitment of participants

A purposive sampling strategy was employed to recruit participants to the study. The research topic required interaction with as varied as possible sets of participants with an objective for diverse inclusion of views. The sample size was considered adequate considering the resources and time for a PhD study. The sample size was similar to other studies in this field (Latif et al., 2019). Table 3-C details the recruitment pathways for research participants. Demographic details captured for participants are outlined in Table 3-D.

The recruitment process was from 7 CCGs within the Nottinghamshire area. In addition, participants from different geographical regions and employed in distinct roles were approached to obtain a heterogeneous sample rich in diverse views. The parameters for variability considered for pharmacists' recruitment included community pharmacy division, experience in GP practice, independent prescriber role, independent owner, superintendent role, and internet (distance selling) pharmacy experience. The detailed recruitment characteristics achieved are detailed in table 4-A.

The initial approach for recruitment of healthcare professionals was from local contacts and from personal and professional networks. This purposive sample of research participants was requested to further disseminate information about the study to more participants. The participants were provided with a "participant information sheet" detailing all study aspects (Appendix 3). If a participant was interested, the plan would be that I would contact them and inform them of all aspects concerning participation in the study. Recruitment for patients and carers was expected to be mostly by indirect contacts with healthcare professionals. These indirect contacts were part of their usual medical care, e.g., GPs and nurses.

The recruitment of patients and family caregivers included indirect invitation through the healthcare professionals engaged in their direct care. Further, study details were advertised on a poster in (Appendix 5) displayed at community pharmacies, through patient and public involvement group (PPI), and U3A groups. The recruitment design was slightly modified for lay participants after recommendation from PPI group members. While initial plan was to invite general public for study participation however, PPI group members recommended that appropriate recruitment could be achieved from patients and family caregivers.

Table 3-C Recruitment of research participants

• Participant	• Recruitment path
• Patients and Family caregivers	• Indirect invitation via GP practices, community pharmacists, and specialist palliative care centre at Nottingham University Hospitals NHS Trust • Indirect invitation via community pharmacists • Advertisement by means of a poster at community pharmacies • Recruitment via patient and public involvement (PPI) and U3A groups • Snowballing
• Pharmacists	• Direct invitation • Snowballing
• GPs	• Direct invitation • Snowballing
• Community nurses	• Direct invitation • Snowballing

Table 3-D Demographic details captured for research participants

- **Healthcare professionals (Pharmacists, Doctors, Nurses)**
    - Age
    - Sex
    - Working full time/ part-time
    - Years of experience
    - Type of setting working
- **Patients and family caregivers**
    - Age
    - Sex
    - Frequency of use of community pharmacy
    - Clinical diagnosis (for patients only and not voluntary)
    - Caring for someone
    - Referral to palliative care

3.7 Inclusion and exclusion criteria

The inclusion and exclusion criteria for this study are detailed in Table 3-E. Palliative care patients for the study were defined as anyone who has received a referral to specialist palliative care services or on a GP register of palliative care patients.

Table 3-E Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Patients and carers	
• Aged 18 years and over • Willing to give consent • Ambulatory patients • In receipt of palliative care (patients) **or** Involved in care of palliative care patients (Family caregivers) • Nottinghamshire area	• Participants lacking capacity • In receipt of end-of-life care • Unable to communicate in the English language
Healthcare professionals	
• Registered with a professional body and practising for a minimum of one year • Nottinghamshire area	• Receiving or caring for a palliative care patient

3.8 Data analysis

Wertz et al. (2011) describe five broad approaches to qualitative analysis. These include Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry. Grounded theory, since its development in the 1960s, has been widely utilized in diverse professions, including healthcare research. It is a systematic yet flexible method that emphasizes data analysis, involves simultaneous data collection and analysis, uses constant comparative methods, and provides tools for constructing theories (Wertz et al., 2011 p165). Fundamentally, grounded theory is an iterative, comparative, interactive, and abductive method (Charmaz, 2006a).

Since its inception (Glaser and Strauss, 1967), grounded theory has evolved into various versions, notably Glaserian, Straussian and Charmaz's constructivist adaptation. These versions share common similarities and use an ongoing, systematic and iterative process of data analysis comprising of a cyclical method of data collection, coding, categorisation and theoretical sampling (Hood, 2007). The difference, according to (Devadas et al., 2011), rests in their ontological and epistemological differences. While the classic grounded theory model of Glaser and Strauss (1967), the Glaserian version is based on objectivity, while the Straussian version (Strauss and Corbin, 1997) operates under symbolic interactionism and pragmatism. Charmaz (2006a), however, proposed a grounded theory based on the relativist position and established in the constructivist worldview. This constructivist ground theory model, because of its relativism and subjectivity, was considered more aligned to the current project and was therefore adapted for the present study. The constructivist grounded theory views knowledge as located in time, space, and situation and considers the researcher's construction of emergent concepts.

3.9 Constant comparison method

The purpose of this research was to create a contextual understanding of palliative care from the participants' perspectives. The analysis took an interpretivist epistemology where the researcher interpreted data and acknowledged that this could never be entirely objective. For this study, an interpretivist epistemology was considered the most appropriate standpoint. Furthermore, the study was not designed to formulate a theory about a potential route for the greater community pharmacy sector's expansion in palliative care services. Therefore, theoretical sampling, a key component of grounded theory, was neither intended nor achieved.

The project used a thematic analysis approach using the principles of constant comparison. This involved comparing the codes and themes emerging from data analysis with other codes, themes, and more importantly, the data collected iteratively (Watling and Lingard, 2012). The insights and information gained through this process informed further data collection. For example, updating the topic guides in future interviews to gain a deeper understanding of emergent themes. The procedure outlined for comparative levels of analysis by Charmaz (2006b) is simplified in Table 3-F. The constant comparison method was adhered to throughout the analysis and data gathering process. The topic guides and interview processes were continuously revised and incorporated any emergent themes visible in the initial data analysis.

Table 3-F Comparative levels of analysis in constructivist grounded theory

Comparison between			Resulting in
Data	&	Data	Codes
Data	&	Codes	Codes
Codes	&	Codes	Tentative categories
Data and codes	&	Tentative Categories	Major categories
Major categories	&	Major categories	Concepts
Concepts	&	Concepts	Conception

3.10 Software to aid data analysis

A qualitative data analysis software programme was used for data management and to aid analysis during the course of the current project. (Jeanine et al., 2010) compared commonly available qualitative data analysis software (ATLAS.ti, Cassandre, MAXQDA, NVivo, Transana). They concluded that the impact of particular software in analysing the data was negligible, and therefore use of any particular qualitative software would be appropriate. NVivo version 12 was available through the University of Nottingham and was used for the current project. Bazeley and Jackson (2013) suggest that NVivo is particularly helpful in data organization, building a coding framework and grouping codes.

3.11 Ethical Considerations and Approvals

Research into palliative care and its proximity to end-of-life care issues frequently raises an ethical issue for patients, their families, carers, and the medical staff in attendance. However, ethical problems can arise as a result of the close direct contact between research participants and the researcher during fieldwork in qualitative research (de Raeve, 1994). Mount et al. (1995) considers such research areas as imperative to study unmet palliative care needs of patients or their family caregivers. Taking this into account, (Gysels et al., 2012) highlights the importance of effective communication and engaging patients and caregivers in healthcare research. A further informed discussion on ethical issues related to qualitative research is provided by (Seymour and Ingleton, 1999). They provide a checklist guide for ethically responsible conduct in qualitative research involving sensitive topics. Participants with serious physical illness or terminally ill are referred to as vulnerable, and their participation in the current study discussing sensitive topics of palliative care would require rigorous safeguarding (Sharkey et al., 2011). However, research participation from these groups should not be discouraged (Kipnis, 2001). The concerns around participation in research activity by vulnerable groups are evaluated in a systematic review (Alexander et al., 2018). They critically appraised 31 studies on this issue and concluded that research participation was an overwhelmingly positive experience. Participants would generally like to participate when offered an opportunity, and such participation was considered beneficial for the participants. Nevertheless, it was important to safeguard their well-being, and ethical guidelines were followed during the research processes, such as research design, informed consent, managing the researcher's role, and anonymity.

The study engaged with both lay and professional participants and thus had specific ethical considerations relating to these participant groups. The following sections further detail these ethical reflections. The ethical issues relating to patients and family caregivers (section 3.11.1), ethical issues relating to healthcare professionals (section 3.11.2), and ethical issues relating to governance (section 3.11.3).

Governance approvals

Research ethics and governance approvals were sought before the commencement of fieldwork. In the UK, this includes gaining NHS and ethical approval through Health Research Authority. Ethical approval was granted in December 2018 by West Midland – Black Country Research Ethics Committee. Ref: 18/WM/0339 (Appendix 1).

Patient and Public Involvement (PPI)

During the planning stage, the research proposal was presented at the "Dementia, Frail Older People and Palliative Care Public and Patient Involvement Advisory (Palliative Care) panel" meeting. The panel members highlighted the importance of integrating community pharmacies for a successful community health system. The panel was invited to give their views on the recruitment plan and potential pathways. Following their recommendations, a decision was taken to approach patients in receipt of palliative care and lay family caregivers instead of members of the general public to participate in the study. The proceedings of the meeting are provided in Appendix 2.

Participant recruitment was initiated after receipt of an approval letter from HRA. The individual research participants were provided with the project packs containing all necessary information. This included a participant information sheet (Appendix 3), consent form (Appendix 4), study poster (Appendix 5), and reply slip (Appendix 6). The participants were given as much time as they needed to read and consider if they wished to take part in the study. Written informed consent was obtained from all participants prior to the interviews. Participants were assured that their participation in the research was voluntary and that they could withdraw from this at any time and without giving a reason. It was not anticipated that taking part in the research would pose any risk to participants in the health care professionals 'group, who would be discussing issues and topics arising in their daily work. However, the research involved discussion of sensitive issues relating to personal experience of serious illness, which might aggravate distress in patients and family caregivers participants. To efficiently deal with such instances, a distress protocol was formulated as an interview aid. The protocol was based on guidelines by Draucker et al. (2009) for research on sensitive topics (Appendix 7). Briefly, it involves actively looking for any behaviour signs suggestive that the interview is too stressful. This would be followed by the stoppage of the interview, accessing the participant's well-being, and taking appropriate actions.

3.11.1 Ethical issues relating to patients and family caregivers

Patients and family caregivers received 24 hours or as long as they were required to decide on their participation in the study. Arrangements for interviews were sensitive to the preferences of the participants, and suitable interview locations were offered accordingly. Only patients and family caregivers who were able to understand the study information, were willing to consent and were able to participate in interviews were recruited. The study topic involves discussion around the sensitive topics of palliative care. This can elicit painful memories and distress among participants. A distress protocol for patients and caregivers was also developed (Appendix 7). This included prompts to assess any potential stress caused to participants during interviews and contained measures for timely administration of appropriate relief. Participants were assured that they could ask for an interruption at any time during the research activity, and their participation was entirely voluntary. Any concerns were to be raised by patients and/or their family caregivers or identified by the researcher (a registered pharmacist with ten years of experience) about the medications or health of a participant(s) during the research activity. Then the participants would be advised to speak to their GP or other HCP responsible for their regular care. However, no such incidents occurred during this project.

3.11.2 Ethical issues relating to healthcare professionals

The professional participants included in this study were GPs, nurses, and pharmacists. Most participants were commonly involved in palliative care, and therefore, it was anticipated that the study would not bring any possible extra burden for them. Any issues relating to malpractice or warranting concern would have been discussed with research supervisors. After this discussion, if necessary, the matter may have been reported to appropriate authorities. The project information sheet and consent forms made explicit reference to the responsibility and obligation the researcher had to report malpractice or potentially harmful situations. However, no such incidents were observed during the current study.

3.11.3 Ethical issues relating to governance

Assurance was provided to all participants that their participation was entirely voluntary. All study data adhered to the University of Nottingham research data management protocol. This meant that data were gathered on encrypted devices, kept on secure university servers, and kept confidential at all stages. The data was anonymised using a password-secured Microsoft Excel (office 365) file.

Fieldwork

The planned interview sites for this study were the University of Nottingham, the participant's home or place of work, GP surgery, or another preferred place, e.g., NHS trust meeting hubs. The University of Nottingham policy concerning lone fieldwork was adhered to whilst conducting any research away from the university. Verbal data were audio-recorded using an encrypted audio recording device (Zoom H6). Nonverbal data, including researcher reflections on interviews, were recorded both as encrypted audio notes and in a field notes diary.

Recorded interviews were securely transferred to the university server as soon as possible and deleted from the audio recorder after successful transfer. Data were anonymised in the process of transcription. Consent was requested from participants for the use of anonymous direct quotes from research data in reports and publications.

The project information sheets prepared for all participants followed UK General Data Protection Regulation (UK GDPR) regulation. The GDPR guidelines were revised by Data Protection Act 2018 (Information Commissioner's Office, 2018) and required an explicit mention of informed consent. Draft interview guides were developed to facilitate the fieldwork. These were constantly revised and updated, and initial drafts are provided in the appendices section (Appendix 8-12).

3.12 Reflexivity

Reflexivity is an essential feature of qualitative research. It is understood by some as a self-critical lens used to interrogate both the research process and the researcher's own interpretation of qualitative data (Finlay, 2017). As a tool, it acknowledges the complexities of a qualitative project. It, therefore, is important to identify and acknowledge my very own background and perspective in interviews and other interactions with the participants. A thoughtful self-reflection will lead to a critical appraisal of my stance. As suggested by (Mason, 2017 pp18), reflexive research requires the researcher to take account of their actions, role, and beliefs in the research process and then analyse them in conjunction with the data.

Reflexivity is most commonly regarded as an effort to acknowledge and therefore take into account the impact of the researcher on the study (Sin, 2010). Additionally, it is used to get as close as possible to subjective meanings (Gough, 2003). I am mindful of my previous exposure and personal perception about community pharmacy services influencing project design, data collection, data analysis, and presentation of the findings. By being reflexive, a researcher's subjectivity can be used as a tool to supplement the research process (Finlay, 2002). Furthermore, continuous self-reflection is vital to ascribing purposeful meanings to the researcher's actions and decisions throughout a research activity (Horsburgh, 2003).

This section describes my viewpoints concerning the topics researched and discussed in the current study. These viewpoints are the result of my personal and professional experiences.

3.12.1 Personal reflective account

Almost three decades ago, in 1994, my granddad passed away after a long period of illness in which the diagnosis was uncertain, and the best guess was "gastric cancer". My granddad was a farmer and lived in a rural village among fertile rice crops in Punjab province and close to a provisional capital, Lahore, Pakistan. My father was a professor at the esteemed University of Punjab in Lahore. I was in my teens and was studying towards GCSE around that time. My memories from around that time included that my grandad would periodically visit us in Lahore. My father would accompany my granddad to different clinics and set appointments with new consultants considering not many physical improvements. However, my granddad would be insisting or, somewhat more accurately, demanding to return to his home in the village as soon as possible, even if this means missing hospital appointments. Naturally, this would sometimes lead to arguments, and for me, this stance of my granddad was puzzling.

Soon after my GCSE exams, I spent time with my grandparents in their village. Unfortunately, my granddad passed away during that time but allowed me to spend two months in his company. The time allowed me to understand why he always said, "I do not want to die in Lahore". The unforgettable memories from those months include the daily routines of relatives and friends visiting him, and they would have some friendly chatter. Towards his last days, he would always have some familiar face around him. He was surrounded by numerous family members and close friends on his last day and passed away peacefully.

The events from this time are in my memories, but I struggled to explain the rationale behind his care choice as the rural village had far from ideal care services available. However, the more I researched holistic palliative care during my PhD studies, the more I started understanding the events from 1994. Now I can attribute his desire for a specific care location to what Prof. Murray calls social, spiritual and existential needs. The familiar surroundings and company of family and friends were a comfortable environment and a necessity. In his locality, he considered himself a king worthy of a king's burial.

The literature suggests that most patients with palliative care needs prefer home care (Pollock, 2015b). Also, recent health policy directives are inclined towards home-based care. However, I can now understand the place of care remains a personal choice and home-based palliative care is a choice made by many. Therefore, I can better acknowledge the care needs of patients receiving palliative care or their family relatives. The approach should not be "you could be better cared for at a hospital" but instead "how I can better assist you in your choice of care setting?". This is the question all community healthcare professionals should be asking. This approach of recognising and actively looking for unmet needs of patients receiving palliative care or of their family caregivers would allow community pharmacies an opportunity for their more significant contributions.

3.12.2 My professional account and perspective

I have a professional background as a registered pharmacist with 14 years of experience working as a community pharmacist. My professional background as a pharmacist would have shaped certain aspects of the current study, e.g., interpretations of interview transcripts. Therefore, it was critical to understand and importantly acknowledge how my familiarity influenced the design, conduct, and results. This was ensured through constant reflection on my viewpoints and feelings and regular discussion with my supervisors.

My dual identity as a researcher and pharmacist offered an easier route to professional engagements. Five research participants (three pharmacists and two GPs) were professional colleagues and acquaintances during my work at a community pharmacy. Although I was familiar with these participants, the interviews on reflection were broadly comparable to those of the other participants. These interviews were carried out in a relaxed environment, and the topic guides were developed before the interviews were followed. Efforts were also made to recruit representation from diverse community pharmacy organisations, thereby limiting reliance on a convenience sample.

I intended to carry out no pharmacist role during research engagements with all participants. It was agreed during the planning stage that if any concern was identified, I would ask the respective participant to seek further help from the healthcare members of their usual care team. The exemptions were issues requiring urgent help or gross negligence by a healthcare professional. These details were included in the participant information pack. One incident involved an initially interested research participant from a healthcare professional group that required further explanations. The participant decided not to participate in the study as he was concerned that I might find something unusual to report if I visited him or during the research interview. There were no events where I identified any cause of concern requiring urgent reporting. Similarly, no events required using my pharmacist knowledge or experience to identify inadequate care.

3.12.3 Personal bias

Reflexivity takes into consideration the researcher's preconceptions while conducting a research activity. These inherent preferences result from the familiarities, beliefs, and opinions a researcher holds against a backdrop of personal and professional experiences (Malterud, 2001, Amin et al., 2020). The situated nature of knowledge construction in studies using qualitative methods, where the researcher and participants have a close interaction, further highlights the importance of acknowledging a researcher's preceding position (Daly, 2007). Malterud (2001) also suggests a systematic approach for the researcher to be attentive to their role during all phases of the research activity. According to Malterud (2001), this inherent bias resulting from the researcher's background would not be eliminated; however, the potential effect of a researcher's position can be considered before, during, and after a research activity. By upfront declaration, a researcher's sources of interest can act as strengths (Amin et al., 2020). As a result, the researcher is co-constructing knowledge, deeper insights and, thus, a potentially richer understanding of a given human experience (Amin et al., 2020).

3.12.3.1 Safeguarding against potential personal bias

The model described by Alvesson (2018) provides a helpful reference guide for applying reflexivity in research projects. The following approaches were employed to acknowledge, recognise, and safeguard the project findings against my personal bias.

- I was observant throughout the study towards any issues arising in the recruitment process because of gatekeeping and self-selection. My first two interviews were with community pharmacists who were previous colleagues. The interviews provided useful introductory insights. However, I purposefully did not recruit any more former colleagues.
- I maintained field notes and reflexive journals to avoid potential sway in participants' responses. These reflexive accounts were made on the same day the interview was conducted. For example, identifying me as a pharmacist, most GPs broadly welcomed extended role proposals for community pharmacists. However, on further exploration, GPs discussed interprofessional harmony, role limitations for pharmacists, and potential drawbacks resulting from greater community pharmacist inclusion in palliative care services.
- I developed and constantly revised topic guides as interview aids during the fieldwork. These topic guides helped to explore deeper understanding rather than broad discussions. Interviews were conducted in plain simple language and started with non-leading questions.

- I cared not to portray a leading question or impose a topic onto the participants. This way, efforts were made to gather a participant's valid contribution to the study rather than expecting them to concur with the emergent or pre-conceived findings.
- The emergent findings from the study were regularly discussed with the research team, including any issues relating to personal bias.

Despite these measures, it is impossible to claim that a researcher's personal bias was completely excluded from a qualitative study. However, I have explained in detail my unique position and the measures taken to limit their potential effect on study findings. Consequently, the outcomes of the current study could be considered more justifiable after accounting and reflecting on personal viewpoints.

Chapter Four

Perceptions of community health care professionals on current palliative care provisions and community pharmacy involvement

The findings of this study are presented in three chapters. This first finding chapter is centred on the data collected from interviews conducted with three different community health care professionals: pharmacists, general practitioners (GPs), and nurses. The second findings chapter (Chapter five) presents views from patients and family caregivers. The first two chapters explore participants' perceptions of palliative care services presently offered by community pharmacies. The final findings chapter (Chapter six) draws on both data sets and offers insights into potential routes for extended roles by community pharmacies in palliative care services.

This chapter covers professional perspectives, experiences, and views on the provision of palliative care services in the community setting. It also details the current participation of community pharmacists in palliative care roles and the pharmacy's scope of involvement. In total, twenty-four health care professionals were interviewed after a purposive recruitment approach. These included 13 community pharmacists (Table 4-A), six general practitioners (Table 4-B) and five community nurses (Table 4-C). The emergent themes within each group of health care professionals are detailed first. This is followed by themes overlapped across the palliative care field.

Table 4-A Participants' characteristics from the pharmacist group

Pharmacist	Experience (years)	Interview location	Recruitment pathway	Interview Duration	community pharmacy division	Experience in a GP practice	Independent Prescriber role	Independent owner	Internet pharmacy	Superintendent
PHM-1	12	Participant's home	Direct	30	Supermarket					
PHM-2	12	Participant's home	Direct	35	Supermarket	✓	✓			
PHM-3	6	Consultation room	Direct	25	Locum					
PHM-4	16	Consultation room	Direct	35	Independent			✓		✓
PHM-5	3	UoN	Direct	30	Multiple High Street					
PHM-6	8	Office in Pharmacy	Direct	45	Independent			✓		
PHM-7	10	UoN	Direct	35	Multiple High Street	✓				
PHM-8	7	Consultation room	Direct	40	Multiple High Street					
PHM-9	8	UoN	Direct	25	Supermarket					
PHM-10	4	Consultation room	Direct	25	Supermarket					
PHM-11	14	Office in Pharmacy	Direct	45	Independent	✓	✓	✓	✓	✓
PHM-12	15	Researcher's home	Direct	75	Locum					
PHM-13	7	Consultation room	Direct	35	Multiple High Street		✓			

Table 4-B Participants' characteristics from the general practitioner group (GPs)

General Practitioner	Experience	Interview Duration	Interview location	Recruitment pathway
GP-01	5	40	Participant's home	Direct
GP-02	7	45	Participant's home	Direct
GP-03	6	30	GP practice	Direct
GP-04	12	40	Participant's home	Direct
GP-05	4	35	GP practice	GP surgery
GP-06	7	30	GP practice	Direct

Table 4-C Participants' characteristics from the nurse group

Nurse	Experience	Interview Duration	Interview location	Recruitment pathway	Role - Nurses
Nurse-01	5	15	GP practice	GP surgery	Practice Nurse
Nurse-02	7	25	GP practice	GP surgery	District nurse
Nurse-03	12	30	GP practice	GP surgery	District nurse
Nurse-04	14	25	Community HCOP	Community HCOP	Community HCOP
Nurse-05	8	30	GP practice	GP surgery	District nurse

4.1 Pharmacist participants

This study draws on data collected from 13 community pharmacists. As mentioned in the methods chapter, a purposive recruitment strategy was employed. The aim was to capture views of community pharmacists working in various settings and include views of pharmacists working in diverse roles. Participants were identified as practising pharmacists in Nottinghamshire County. They were approached directly and were asked to circulate the study details further. Of the 13 pharmacists recruited, their experience as a pharmacist ranged from three to fifteen years. There were four recruitments from supermarket pharmacies (e.g. Asda, Tesco, Morrisons), four from high street multiples (e.g. Boots the Chemists, Lloyds Pharmacy, Wells), three from independent pharmacies, and two who considered themselves to be locums. Three of the thirteen pharmacists also had the experience of working in a GP practice. In addition, three pharmacists were qualified independent pharmacist prescribers, two were independent owners and superintendents, and one pharmacist was working for an internet-only pharmacy. The interviews were held at different locations at the convenience of the research participants. Of 13 interviews, five were held at consultation rooms in community pharmacies, two were in pharmacy office rooms, three in University of Nottingham meeting rooms, two at the participant's home, and one at the researcher's home. The interview duration ranged from 25 to 75 minutes.

The participants were invited for their personal experiences and perceptions about community palliative care provisions. The interviews were semi-structured, and the initial part was centred around the current shape of community palliative care services. Later, the interview discussions focused more on community pharmacies' current involvement and potential future role extensions. The conversations were held at an informal, relaxed pace and participants were encouraged to present their perceptions and examples from their experiences. The emergent themes from the analysis of these discussions are detailed in Table 4-D and described in this section.

Table 4-D Emergent themes from the analysis of interviews with community pharmacists (n=13)

- Community pharmacy services and accessibility for patients and family caregivers
- Community pharmacist's interaction and relationship with patients and family caregivers
- Pharmacists’ strategies to alleviate work pressure
- Pharmacists and community health care networks
    - Supporting the healthcare team
    - Pharmacists as part of the community health care network
    - Involvement with community nurses
- The changing perceptions of work associated with the pharmacy
- Involvement in palliative care services schemes
- Supply of essential end-of-life care medicines
- Limited palliative care engagement by community pharmacists
    - Pharmacists' reliance on other HCPs for palliative prescription queries
    - Pharmacist involvement in end-of-life care
    - Dosage aids for palliative care patients
    - Access to patients’ medical records
    - Communication of palliative care providers
    - Collaborations or advisory roles for community pharmacists
- Community pharmacy as a business enterprise

4.2 Community pharmacy services and accessibility for patients and family caregivers

The pharmacists were asked about how accessible they were to patients. Most perceived that they had an essential role in providing patient care, particularly dispensing prescribed medicines, managing minor ailments, and providing ad hoc health advice. They also thought the GPs were under significant work pressures that were ever-increasing. This perception influenced pharmacists' views of the time patients spent with their GP. This subsequently had an impact on patients' accessibility and ability to discuss in-depth health issues. Most pharmacists acknowledged that they were more accessible than the GP as a result of patients not being required to make an appointment with them. Because of the community pharmacy setting, which was considered open, they were more visible and so more approachable. There was also a perception that they were able to offer more time to patients and family caregivers.

> *Yes, we play a very vital role. Because like, these days GPs are so… (busy). Their target of 10 min to see a patient, and a lot of time, they don't have enough time to listen to the patient. But they (patients) can see a community pharmacist at any point. We can give them more time.*
>
> *(PHM-02)*

> *It is quite easy... yes. Because of the way we work in our pharmacy, it is quite open, and you can see the pharmacist behind, so it is not that we are hidden anywhere. We are there all the time so they can just ask for us.*
>
> *(PHM-09)*

Pharmacists in the study highlighted the relative ease with which patients could access a service delivered from a community pharmacy. Most pharmacists viewed their services as an alternative source of advice where patients, instead of going to GP surgeries, could be seen more conveniently by a pharmacist. For example, one pharmacist commented:

> *Rather than booking an appointment with the doctor, sometimes it isn't available. They can just come to the pharmacy, and they have seen the face (staff in pharmacy) many times before. They are familiar and confident that they are going to get what they want. Then there is a healthcare professional (pharmacist) who can provide them with medicines, advice or sometimes both.*
>
> *(PHM-08)*

As well as being approachable, their interactions with patients and other service users of the community pharmacy were then explored in more detail.

4.3 Community pharmacist's interaction and relationship with patients and family caregivers

When discussing pharmacists' direct interaction with service users, i.e., patients or their family caregivers, most pharmacists reported having routine face-to-face interactions with the service users. This was predominant during prescription handling and medicine supply issues. However, the pharmacists' perspective about their direct interaction with patients or family caregivers was reportedly varied. Several pharmacists mentioned the opportunity to have a consultation with a walk-in patient while dispensing a prescription. For example, one interviewee said:

> *If they need advice from a pharmacist, they ask for it, or sometimes, when we hand out prescriptions, we can go and ask the patients themselves if they need any advice or counselling about any medications*
>
> *(PHM-01)*

Pharmacists were unanimous in their views that most direct patient interactions were largely reactive, and this was part and parcel of their professional work. Several pharmacists indicated that medicine use review (MUR) and new medicine services (NMR) provided them with more structured consultations, which they welcomed. This was seen to be relevant because palliative care consultations would also be of a similar nature. They pointed out the significant role pharmacists can play in improving levels of face-to-face interactions and so enhancing patient care.

> *As a community pharmacist, I have been engaged with the patients in all those ten years. So, this is like my main job, and this is what I do every day… see patients. Deal with the patients directly…*
>
> *(PHM-07)*

> *I believe the two services which are at the heart of our profession are MURs and NMS. I would say… they are the services directly related to pharmacy. They directly connect the pharmacist and the patient.*
>
> *(PHM-06)*

An exception was a pharmacist (PHM-11) working in an internet pharmacy setting where the medicine supply interactions were online and not face-to-face. Because of the online nature, they did not provide any advanced services, which limited their opportunity for having a more planned consultation with patients.

4.4 Pharmacists' strategies to alleviate work pressure

Several pharmacists pointed toward the increasing workload that had resulted from taking on additional privately funded services that are outside the NHS-funded model (e.g., flu vaccinations, travel clinics). To manage these, pharmacists highlighted the importance of delegating certain aspects of administrative duties to other pharmacy support staff. Overall, pharmacists valued these supportive roles as these allowed responsible pharmacists to take on other responsibilities. To enable this, they suggested that support staff should receive additional, comprehensive training to improve their confidence. This would allow them to be assigned additional roles, for example, initial consultations with the patients or administration jobs. They also appreciated that delegation was an essential part of their workload management. One pharmacy owner and superintendent pharmacist were happy for his support staff, if permitted, to supervise P (pharmacy only) medicines sale.

> *Again, staff training is the key here… We have trained the staff so that most of the time, if it is a simple query, they can answer it as well. We have quite an extensive training program. So, the pharmacist time is not wasted a lot because the staff has taken over some roles. They do all the consultations, and they put all the data on the pharmoutcomes. And 90% can answer all the queries. So, that's how we are managing workload.*
>
> *(PHM-10)*

> *There's a lot of workload has come to the pharmacist and then pharmacist should be able to delegate that workload to his/her staff. The P medicines… I believe that all those things can be delegated to the pharmacy technicians. Obviously, there is a change in the law required for that.*
>
> *(PHM-04)*

The ability to delegate tasks was perceived to be essential and relevant. Pharmacy technicians were one option to allow pharmacists to take on an additional role, including assumed extended palliative care roles requiring any administrative duties or coordination with other healthcare professionals.

4.5 Pharmacists and community health care networks

4.5.1 Supporting the healthcare team

Pharmacists were then invited to discuss their experience of supporting other health care professionals and their interactions with them. Most pharmacists talked about their work pressures and resulting limitations on additional services they could offer. However, they perceived themselves as playing an important role in saving GPs time by taking on supportive roles and responsibilities for more minor health problems. They provided examples such as providing over-the-counter remedies for common problems that can be managed without seeing the GP (i.e. managing common colds, constipation). They recognised that this contribution might free up the GPs' time for them to focus on more complex health care issues.

> *We can't cater to everybody, but most of the time, we save GPs time. Patients, instead of going to GPs, can come to us for minor ailments.*
>
> *(PHM-03)*

> *It obviously saves their (GPs) time, and they can deal with other types of queries or they can fit in other appointments which need their time rather than somebody just going there and just asking… for example paracetamol for temperature. They can just come to us (pharmacy)*
>
> *(PHM-12)*

Several pharmacists also mentioned offering more extended roles such as providing NHS flu vaccination services, smoking cessation services, travel clinics etc. Some pharmacists, when offered incentives, created opportunities to develop more comprehensive services such as vaccination clinics. These clinics were considered to offer patients alternative access to vaccinations. Having been thoroughly trained in the role, the pharmacist felt comfortable and capable of expanding the range of services offered. This role was considered mutually beneficial for all parties. Primarily it offered convenient access for patients, reduced the GP practice workload, and increased the pharmacy's revenue. Consequently, pharmacists expressed positive feelings about the changing role and expectations of community pharmacy. They considered their current roles as not just limited to dispensing duties.

> *In this area there is a huge demand for private flu jab clinic… Sorry not flu jab private vaccination clinic, vaccination for everything. That's one area where I think pharmacy can fit in within NHS very easily. Like you know pharmacist, trained pharmacist… We can do one jab and we can do most of them. So, there is definitely room in this area and in general I believe this is a service which pharmacy can take over easily from GPs.*
>
> *(PHM-06)*

> *I personally think, in the pharmacy… it is changing now. It is moving away from counting pills and doing signatures.*
>
> *(PHM-13)*

4.5.2 Pharmacists as part of the community health care network

A range of perspectives was expressed by pharmacists about being part of the local community health care network, i.e., their interaction with GPs and community nurses. In most of their accounts of dealing with other HCPs, most pharmacists expressed having more frequent communications with GPs as compared to community nurses. As one participant commented:

> *We talk to GPs more than the nurses. Because nurses are usually like when there is handwritten prescription and they have not mentioned the right size of dressings or there is a problem with that.*
>
> *(PHM-01)*

In terms of the nature of communication with other HCPs, most pharmacists described having limited face-to-face conversations. Telephone conversations with the GP surgery team were the preferred way for many pharmacists. They also mentioned writing letters to the GP practice. This was viewed as not a common approach and occurred when necessitated following an MUR consultation. Most participants echoed the view of having received queries from other community healthcare professionals. The communications initiated by other HCPs were related to medicines availability or alternative recommendations for long-term out-of-stock medicines.

> *Usually telephone conversations or we sometimes… if we have identified any issues we write a letter or if we have done a private service then we write them a letter or if we have identified an issue after like medicine use review, sometimes we have to refer back if we think that the patient can do with an intervention from a GP*
>
> *(PHM-05)*

> *It can happen both ways. You know sometimes surgeries ring us as well if they need any certain type of query or certain type of medicine or they can't find, or they need to find an alternative. Same goes from us as well we obviously contact them for anything…, support we need.*
>
> *(PHM-08)*

4.5.3 Involvement with community nurses

In relation to community health care teams, the pharmacists were invited to describe their involvement and collaboration with nurses. On this topic, most pharmacists stated having very limited interaction with community nurses. This was besides many pharmacists being familiar with the roles of community nurses. Some participants, however, thought of hospital nurses when asked for examples of their involvement with nurses. These pharmacists provided examples of receiving telephone queries from hospital nurses before being prompted to their interaction with community nurses.

> *It's only if one of our patients goes to hospital for some reasons and then if nurses need to involve us with anything and then we go through with them.*
>
> *(PHM-07)*

When requested for their view and experiences of collaborations with community nurses, participants stated having limited interaction. Most pharmacists struggled to provide any detailed examples of such collaborative work. Their usual responses were:

> *It is very rarely that we actually have to ring nurses to find out anything.*
>
> *(PHM-09)*

> *Not really as far as I know. It is very rarely to be honest with nurses. At least not in our area.*
>
> *(PHM-12)*

Most pharmacists had limited awareness of how nurses worked in care settings. Only one pharmacist detailed the significance of having regular interactions with nurses and forming a collaborative arrangement. Their primary interaction was fielding stock inquiries from community nurses.

> *As a pharmacist, you do need to speak to a doctor if there is a query or different elements involved while dispensing prescription or other management issues like to run a pharmacy then you have to liaison with the surgery. And same is the case for nurses as well.*
>
> *(PHM-10)*

> *We normally receive a call from the Macmillan nurse or some of the patient's relatives that they are trying to find a particular medication. Have you got it in stock? I had couple of calls even this morning.*
>
> *(PHM-02)*

4.6 The changing perceptions of work associated with the pharmacy

When pharmacists were invited to discuss their place within the MDT, some felt that the perceptions about community pharmacy among other HCPs was variable and was dependent upon other HCPs' individual experience and views. One community pharmacist voiced how the views of other HCPs can be expanded. For him, the personal relationship between a community pharmacist and other HCPs was a vital contributor to raising the community pharmacy profile. He summarised this below:

> *Each individual is different… or it is just like what perception have they got about the pharmacy. This is what matters really. Sometimes you can even change their perception as well like you know there are certain GPs if they have any query any time, we will be their first call. They will always ring us asking for advice.*
>
> *(PHM-13)*

Others also expressed similar views, where they felt overlooked by other healthcare professionals, mainly GPs.

> *Some of them… I have come across in the past they will just ignore our advice completely. There could be a reason behind it because we may not have all clinical scenario in front of us, we may not understand it how the GP is perceiving something.*
>
> *(PHM-06)*

> *Most of the time they are quite approachable…it depends upon the surgery. The certain surgeries approach you more than other.*
>
> *(PHM-05)*

4.7 Involvement in palliative care services schemes

Pharmacists were invited to share their knowledge and experiences of participation in any locally commissioned palliative care schemes. No pharmacists described having any current involvement in these schemes, with most involved in a simple supply of prescribed palliative care medicines. However, most pharmacists were aware and knowledgeable about the need for more support for this vulnerable group. Some pharmacists were involved in such schemes in the past and explained that it involved keeping an up-to-date stock of certain medicines in a pharmacy. Nevertheless, in general, the pharmacists highlighted the usefulness of these schemes concerning the timely supply of medicines.

Despite not being formally part of commissioned schemes, some pharmacists strived to fulfil their obligations and kept in stock and made available most of the medicines. When asked about the funding arrangements, a few pharmacists criticised the reimbursement arrangements. This was because pharmacists only received a minimal upfront payment, and this did not offset the work to order, keep in stock and manage large quantities of controlled drugs. They, therefore, considered that they were offering this service 'free of charge', which caused a feeling of being operationally bound or obliged to continue with the scheme.

> *There were certain pharmacies which were registered there, and they were required to keep certain medications and then the nurses and the other staff who are involved in palliative care they know that where to go for those certain medications. We don't have that list anymore (not participating) but still we try to keep as many as we can.*
>
> *(PHM-02)*

> *Not much… and they only used to give us the cost of the expired medications which was not like… (much). So, we were doing basically service for nothing.*
>
> *(PHM-07)*

The participants generally considered the reimbursement arrangements insufficient. This was a strong reason for them not engaging in the schemes. They were subsequently asked to express their views on the importance of the timely availability of these medicines.

4.8 Supply of essential end-of-life care medicines

All pharmacists considered the supply of palliative care medicines that were frequently prescribed during end-of-life care as an important aspect of their day job. They did not associate this responsibility with one that would require any additional training or complexities. Also, the supply of medicines was not regarded as an extended service. One community pharmacist, when asked about stocking end-of-life care medicines without being formally part of any reimbursement scheme, replied:

> *Obviously, it is a part of our regular job. Although we are not part of scheme, but we still want to stock them.*

> *(PHM-08)*

Most participants voiced a sense of fulfilling an essential core duty by stocking and dispensing end-of-life care medicines. Several participants recognised the importance of the timely supply of medicines and felt comfortable carrying out these roles.

> *I have worked in pharmacies before where we were commissioned to keep the medicines. I mean this is a pretty simple thing.* *(PHM-12)*

One community pharmacist, also an independent owner, particularly elaborated on the role a community pharmacist undertakes while sourcing essential end-of-life care medicines in a timely manner. He emphasised that such duties should be delegated to a pharmacy team and must not be left to family caregivers.

> *Supply issues… absolutely. This is like you know… nobody wants to keep it and then the medicines expire… I really feel sorry like you know that the time, I think… That's not the time when patient should be struggling to find the medicines.*
>
> *(PHM-09)*

Expanding on this topic, another pharmacist provided further examples where the pharmacy team was in contact with family caregivers for the timely availability of medicines. The pharmacist perceived that the pharmacy team's liaison with the family caregiver contributes to sourcing specific medicines in time.

> *It is normally when carers take the medicines that sort of kind of like the end-of-the-line from us. But if somebody is on regular palliative care then we get involved with carers for example what sort of supplies they need and whenever they need medicine they can get in touch in advance.*

> *(PHM-03)*

4.9 Limited palliative care engagements by community pharmacists

The interviews with pharmacists revealed that there was limited involvement of community pharmacy teams concerning palliative care provisions. This section details different aspects of palliative care delivery by community pharmacies.

4.9.1 Pharmacists' reliance on other HCPs for palliative prescription queries

Pharmacists described having ad hoc and infrequent interactions with other community health care professionals. Their main engagement was via prescriptions which they dispensed. Periodically pharmacists would identify minor problems with medicines on prescriptions during the dispensing process. These were mainly related to dose, interaction and/or quantity prescribed on prescription. However, there was a sense among most participants that any clinical queries, e.g. dose adjustments to pain relief medications, were not fully discussed as part of a multi-disciplinary team. A small number of participants mentioned receiving an inquiry from a GP ahead of a prescription. These GP queries for palliative patients were limited to medicine availability inquiries.

> *The clinical queries regarding palliative care are usually initiated by the pharmacist. If like there is an interaction or like the dose is not right or the quantity is like more than normal. Then the pharmacist is usually like contact the GP rather than GP, or the nurses rather than they ringing us.*
>
> *(PHM-01)*

> *A lot of time when they ring us is regarding availability. if they are writing a prescription they want to know if that product is in stock, especially over the festive period.*
>
> *(PHM-05)*

4.9.2 Pharmacists' involvement in end-of-life care

Most community pharmacists in the study reported limited involvement in the overall palliative care phase. In some cases, pharmacists struggled to grasp the holistic palliative care approach. During the interviews, when the term 'palliative care' was introduced, their initial response was geared towards the supply of end-of-life care medicines. The following examples illustrate this view:

> *For palliative care… when you say for palliative care you mean these injections and stuff… or is it before that?*
>
> *I think that there are very few patients really… who are like this. We normally… in pharmacy when somebody tells us about palliative care we just simply go for morphine, midazolam, cyclizine… you know these sorts of things really. Anything before that we just call it normal dispensing really.*
>
> *(PHM-13)*

Subsequently, this theme about their limited involvement and potential for growth was discussed further with the participants. It was found that most community pharmacists were involved only in the latter stages of palliative care. Their interaction with patients, family caregivers, and HCPs was predominantly for the supply of end-of-life care medicines. For some pharmacists, stocking and dispensing end-of-life care medicines was a way of participating in palliative care services.

> *We stock some end-of-life medicines. So, from palliative care point of view they can be used as well.*

> *(PHM-10)*
>
> *We deal with palliative care but not as much. We are like end of the line when they need the medicines at the end.*
>
> *(PHM-02)*

4.9.3 Dosage aids for palliative care patients

During the interviews, pharmacists were asked about different ways in which they thought they were currently contributing to palliative care services. In this regard, some pharmacists asserted that the different dosage aids and delivery systems they were providing could be viewed as a form of palliative care service. Delivery of medicines in these dosage delivery systems (MDS) required extra dispensing time and resources. These, however, were provided free of charge to any patient deemed to benefit from their use and were not limited to palliative care patients only. Some pharmacists also pointed out the problems associated with the use of such dosette boxes. This included the difficulties arising when a dose adjustment was made, or a new medicine was introduced before a dosette box was finished. Nevertheless, the pharmacists overall felt the need and usefulness of dosage aids for palliative or frail elderly patients.

> *We do have… like a dosage system which is for, like MDS, which is to help and support the patients in taking their medications. Some patients who could be in palliative care they take dosage boxes from us as well.*
>
> *(PHM-12)*

> *Now a days more and more patients are asking for dosette dispensing. We are trying to accommodate as many as we can. Mostly district nurses or family members initiate this request and most of them are elderly frail patients. But 1doctors are now reluctant to issue weekly prescriptions*

> *and if there is a change midway there is a lot of confusion for patients and carers*
>
> *(PHM-09)*

4.9.4 Access to patients' medical records

A recurrent theme in the interviews was a sense amongst most pharmacists of limited availability of up-to-date patient information. Pharmacists repeatedly voiced their concern that they are usually the least informed health care professionals in terms of patient medical records. Consequently, most pharmacists viewed this lack of information as a contributory factor to their limited input into palliative care.

> *If someone goes onto palliative care, we really don't know until and unless they are one of our regulars and their relatives come and tell us that that patient is… dying… There is no clear-cut communication between the primary care and the secondary care.*
>
> *(PHM-04)*

> *Recently one of our regular patients was on palliative care. I only came to know about it while dispensing medicines for syringe driver setup. There was not much I could have contributed at that time.*
>
> *(PHM-01)*

This discussion was not explored with all pharmacist participants in the study, but the pharmacists who spoke on this topic considered that having a clear mechanism for information exchange between community pharmacies and other health care providers would encourage greater participation by the community pharmacy workforce. The pharmacists also emphasised that they already know, have a rapport with, and deal with patients regularly before they have been put on the palliative phase. However, they perceived that they were not kept informed when patients were started on the palliative care pathway. They considered this delay as a lost opportunity where they could have procured specific medicines in time, planned a structured consultation with patients, or had greater involvement in clinical care.

> *As a community pharmacist we don't know when the person is on the palliative care lines, we don't get that information. Obviously, it would be better if you can get involved in there as well.*
>
> *(PHM-03)*

> *Normally pharmacist don't get involved in palliative care. Not at least in the community level I don't know if in hospital they are involved. But not in community level which is a shame really because we deal with patients all the time and we obviously we see the patients go to that stage we often know them*
>
> *(PHM-07)*

4.9.5 Communication between palliative care providers

During the study, pharmacists routinely voiced their concern about not being involved in the development of GP palliative care plans. Because of a lack of general communication, all community pharmacists stated the absence of any formal channel about when the patient started receiving palliative care. This information was often relayed to them by family caregivers or when prescriptions specific to end-of-life care were presented for dispensing. Several pharmacists emphasised that their early involvement can be beneficial for patient care. One community pharmacist described medication reviews at the start of palliative care as an area where they can contribute. However, delays in engaging community pharmacists meant such reviews were never performed.

> *No… we do not find out really. Unless we have a discussion with the patient and unless there is… you know because of non-availability of certain medicines like… you know ondansetron… those like. So, that's the time patient tells us… Otherwise we have no communication channel with the GPs or Nurses. So, we just see the prescription…*
>
> *(PHM-04)*

> *as a community pharmacist we don't know when the person is on the palliative care lines so at that point, we can be more useful to see what medication they actually need because obviously it is end of the life, so you need to see like which medication are more important now for them. There could be some medicines which patient really does not need but because it is still going on as part of a regimen for example, they got cholesterol or anything like that going on*
>
> *(PHM-12)*

4.9.6 Collaborations or advisory roles for community pharmacists

The previous sections illustrated that there was a general sense of missed opportunity among pharmacists for their limited involvement in palliative care. This topic covers the discussions where pharmacists were invited for any collaborative work they had undertaken other than the supply of medicines. To such prompts during the interviews, some pharmacists provided examples of roles beyond the dispensing duties. However, they did not regard this as specifically related to palliative care and rather considered this as part of their usual work routines, which were extended for palliative care patients on an ad-hoc basis. Furthermore, pharmacists articulated that such instances were infrequent, unplanned, and limited in scope. Some pharmacists also believed that clinical decision-making was down to palliative care teams, and they saw themselves only as a supplier of medicines. The different examples pharmacists provided ranged from providing advice to community nurses, alternatives or dosage adjustments, and changes in medication regimens.

> *Sometimes we do have an advisory role. Like, when the nurses come to collect a prescription, we check with them about dose, etc and that they are comfortable with the revised prescription?*
>
> *(PHM-01)*

> *It is quite limited, to be honest. You know like obviously supply model and where really, they do need some information about some alternatives or dosage adjustments. But it is very rare because it is normally done by palliative care team, I believe.*
>
> *(PHM-07)*

> *Around suitability, or some time, if there are a lot of medicines need stopping because the person is on… for example like cholesterol medicines… you don't need it for the last months…But these discussions rarely happen…*
>
> *(PHM-07)*

4.10 Community pharmacy as a business enterprise

This was an interesting theme that emerged from interviews with pharmacy owners and superintendent pharmacists. They recognised the importance of community healthcare services delivered at a community pharmacy but emphasised the importance of operating their pharmacies as viable businesses. These participants reflected on the difficult choices they had to make when pausing or discontinuing a free service they used to offer in the past. In addition to the central NHS contract, the community pharmacies in an area receive a variable reimbursement package. This depends on local needs as decided by commissioning groups. The pharmacy owners discussed the need for appropriate services they offered, considering local commissioning arrangements. In addition, pharmacy owners also highlighted the importance they placed on customer loyalty. They used the term 'customer' instead of 'patient' when discussing their pharmacy business model. They were happy to offer certain services free of charge if they received a return in the form of customer retention. One pharmacy owner explained his reason for stocking end-of-life care medicines as:

> *The main reason for that is we are out of hours pharmacy… we are late opening pharmacy… 100-hour pharmacy. So, this suits with our business model.*
>
> *(PHM-04)*

Similarly, another pharmacy owner was content to provide additional services without any funding arrangements by NHS. According to them, this was suited to their customers' needs. For them, customer binding to their pharmacy was an important factor influencing their business decision-making.

> *this sort of funding is not available in this area, but we are the pharmacy… I mean…Three is a customer need for it.*
>
> *(PHM-04)*

> *We are still keeping most… because obviously as I explained to you that we don't want the customer to go back really.*
>
> *(PHM-06)*

This section covered the description of the emergent themes from the analysis of field data and interviews with pharmacist participants. The next section details the emergent themes from the analysis of data collected during interviews with general practitioners and nurses.

4.11 General practitioners and nurses

The previous sections described pharmacists' perceptions of holistic palliative care approaches. This section begins by presenting the main findings from general practitioners and community nurses concerning their involvement in palliative care in the community, including their interactions with other healthcare professionals, chiefly community pharmacists. Following purposive sampling, six GPs were recruited for the study. GPs had practice experience that ranged from four to 12 years. Three GPs were interviewed at their home, while the remaining three interviews were conducted at the GP practice where they worked. The interview duration ranged from 20 to 35 minutes. Five nurses were recruited for the study. This included three district nurses, one practice nurse and one nurse from the community health care of older people (HCOP) department of Nottingham University hospital NHS trust. Their experience ranged from five to 14 years. Four interviews were held at the GP practice, and one was conducted at the community HCOP meeting room. The interview duration ranged from 15 to 30 minutes.

The following sections summarise and discuss the main findings from these participant groups relating to current palliative care arrangements in the community. Emergent themes are listed in Table 4-E. Although, both GPs and nurses were engaged in the present study, during data analysis, it was observed that GPs' gave more detailed accounts about the current and potential future involvement of community pharmacies in palliative care services. Nurse participants had less to say on this matter. Consequently, the following sections mostly contain GPs perspectives and limited views and opinions from nurses.

Table 4-E Emergent themes from the analysis of interviews with GPs (n=6) and nurses (n=5)

- Holistic palliative care approach
- Early palliative care discussions
- GP day-to-day palliative care engagements
- The role of an assigned GP
- Automation in palliative care case management
- Importance of community palliative care services
- Challenges in community palliative care
- Collaborations and chain of care in community palliative care service delivery
- Increased pressures on GP practices
- Collaborations with community pharmacists in relation to palliative care services

4.12 Holistic palliative care approach

GPs had clear objectives for when a patient was transitioned to palliation. This involved keeping the patient comfortable and attending to their clinical needs as they arose. This was typically a slow process, and the GP was mindful of the impact on the wider family and FCG. They recognised that the well-being of the patient was closely linked to the well-being of the patient's social care network. They, therefore, saw palliative care as being part of a more comprehensive care pathway involving health and social care agencies:

> *the whole core idea of the palliative care is to keep the people comfortable in their family environment and that is a big thing. It is not just only clinical thing but social aspects as well. How is the care delivered? how is the family coping? So, the last thing you want is… family crying… or distressed or not getting enough support. It is whole*

> *holistic thing. Social aspects, family having support and different non-government organisations getting involved.*
>
> *(GP-04)*

GP participants were asked about how they managed palliative care in the community. In addition to attending to the physical symptoms experienced by palliative care patients, most GPs also discussed a wide range of other care needs that enabled them to provide holistic care. GPs were found to be generally conscious of family caregivers, and the stress caring for a person with palliative care could place. They also acknowledged family caregivers' difficulties in dealing with many different health care professionals in primary, secondary and tertiary care settings. Some GPs acknowledged the mental and emotional work undertaken by family caregivers. Moreover, some GPs used social aspects of palliative care to highlight the care needs of palliative patients and their family caregivers.

> *If you think from a perspective of a family member, family caregiver then it is quite a difficult time for them. It is quite demanding, challenging time because so many people involved. Somebody who is reaching their last days… it is not easy physically, mentally, emotionally… all aspects really*
>
> *(GP-02)*

Furthermore, it was found that GPs were aware of palliative care needs arising from conditions other than cancers. One GP provided an example of a patient who was not related to cancer care. In this way, the GP exhibited awareness of palliative care needs associated with non-cancer patients.

> *I remember a lady who was in her late 90s and she became palliative. She didn't have cancer but obviously…general frailty, declining health, cardiac failure.*
>
> *(GP-01)*

GPs also expressed views concerning the availability of adequate care for family caregivers and for family members. They repeatedly showed concerns about the care needs of family caregivers in addition to the physical and clinical health of the patient. Such discussions included adequate delivery of care packages, managing distress to family members, and support mechanisms available. In addition, GPs consistently discussed social aspects of palliative care in the context of holistic palliative care. They also expressed the need for a family support system during the palliative care phase.

> *The focus of the treatment is symptom control but on the other hand you… what is important or what is at the heart of the care is to keep patient's wishes. I think this is more like a social rather than a medical thing.*
>
> *(GP-05)*

> *When somebody reaches to the phase of palliative care or end-of-life care, which is obviously the advanced stage of palliative care, usually it is a slow process when they get to that point gradually. In a small of number of cases it might be a bit quicker but that's not a commonly seen thing.*
>
> *(GP-06)*

4.13 Early palliative care discussions

GPs recognised the importance of involving family members in early palliative care discussions. For example, they considered early communications with patients and family caregivers as an important aspect of developing and tailoring a palliative care plan. They also stressed having open and honest discussions. In doing so, GPs recounted how they were able to better implement patients, and family caregivers’ wishes into palliative care plans. Some GPs mentioned shared decision-making and included the appropriateness of certain treatment options in these early discussions. However, they also highlighted that any treatment decisions were made according to the wishes of patients and their family members. GPs also emphasised incorporating patients' preferences about the place of care during the palliative phase. Because of their relationship, GPs considered themselves to be better placed to facilitate patients, and family caregivers' need according to their wishes.

> *From medical point of view, it is important to explain and see what they like early on. Sometimes explain that we might not be able to actively resuscitate or do a particular treatment but if they have infection and it is appropriate, we will give you antibiotics.*
>
> *(GP-05)*

> *after the initial home visit, we try to identify with patients and their carers what are their expectations. What would they want to do? Also, there are things what we are trying as a healthcare system is to organise things more and more.*
>
> *(GP-01)*

GPs also expressed their views on recognising the wishes of patients for end-of-life care arrangements when they are started on palliative pathways. GPs were also pragmatic in their view when discussing such wishes and were more inclined to discuss the preferences around care sites rather than the general life events.

> *what would the patient want to do in the last few days of their life? Do they want to stay at home? or they prefer a hospice or…? So, all this kind of things. I think… I feel that you are more organised.*
>
> *(GP-04)*

4.14 GP day-to-day palliative care engagements

This section details GPs' experiences from their work in general practice surgeries to the provision of home care. During the interviews, GPs commented on the vital role they play in the primary care setting. In general, GPs emphasised the importance of the direct contact they have with their patients and family caregivers. One GP explained their relationship with palliative patients and their families at length. She considered GPs as the first primary contact for patients and families and expressed this below:

> *being a general practitioner or primary care physician or primary care team, we are usually the first contact… direct contact for the patients, their families, their carers… their loved ones.*
>
> *(GP-03)*

Another GP also highlighted the nature of their direct relationship with patients and their family caregivers. He expanded that their face-to-face contact is not limited to patients and often includes family caregivers as well. He was also mindful of the healthcare, social, and mental well-being of family caregivers.

> *Obviously we always engage in the palliative care and end-of-life care directly with the patients, looking after their families as well during the phase and period of palliative care or if somebody has actually died, then the families too… obviously to deal with the whole thing.*
>
> *(GP-02)*

Expanding on this subject, GPs were invited to discuss in more detail what these palliative care engagements were. This led to some interesting and surprising findings. GPs had previously mentioned many aspects of being part of a community palliative care plan. However, their accounts suggested that care was predominantly focused on the prescribing of medicines to ease symptoms and the process of medication reviews. Talking about this subject, one GP highlighted the two outcomes of medication reviews after the start of the palliative care phase. These included a review of the medicines currently being taken and a prescription of new medicines.

> *I would say two parts of prescribing. One is whatever they are taking whether they should be taking that medicine once they have reached that phase of the care so that needs a review or cancellation of any medicines. Secondly, prescribing of new medicines once they are started on palliative pathway, dose adjustments…etc*
>
> *(GP-06)*

Additionally, some other GPs reported prescription queries as the most common type of inquiries they received concerning palliative care patients and their family caregivers, with adequate availability of medicines for pain control as the most common concern. GPs also found themselves involved in reassuring patients about the continuity of treatment plans, especially around symptom control. They recognised this reassurance as a vital part of the palliative care plan in the community.

> *Mostly prescription. That's the most common thing we get involved. We do go and review them as well but usually it (the queries) is around the medication.*
>
> *(GP-03*

> *A lot of questions are around pain, especially with cancer patients and if they are boney met (bone metastasis). So, it is to re assure them that we will still treat all those symptoms.*
>
> *(GP-01)*

Time and work pressures meant that GPs, although mindful of their holistic palliative care, in practice described a limited role in reviewing prescribed medicines

4.15 The role of an assigned GP

During the interviews with general practitioners, one topic that was important to participants and frequently highlighted was the importance for palliative care patients to have an assigned GP. This was often done early on at the onset of the palliative phase. One GP explained that this usually was the first step they took once notified of a patient referred for palliative care. GPs considered such arrangements necessary for continuity of care during the palliative phase.

> *We get notified that they (patient) are palliative patients, what we tend to do among ourselves is that we try to keep a sort of regular GP for them.*
>
> *(GP-06)*

> *for palliative care patients we tend to keep this in mind and sort of try to adhere to this sort of a particular GP for continuity of care.*
>
> *(GP-02)*

Being assigned to one patient meant GPs could build up a rapport and special relationship, which could be built up over time. They reported that this connection with the patients was very helpful during the later stages of providing palliative and end-of-life care. According to these GPs, patients felt more at ease when they knew they could call upon someone whom they knew and that their GP would have a good understanding of their pre-agreed previous treatment plan. Where there were several practitioners in practice, GPs reported the importance of assigning a designated GP for the family caregivers as well. They felt that having an assigned GP as a central contact figure could alleviate some pressure on family members. Furthermore, such arrangements were valued as supportive, brought continuity of care, and eased communications.

> *There is bond between the patients and the doctors. And I think that helps, especially in the last few days or last few months of your life. If you know who your doctor is? What's happening?*
>
> *(GP-03)*

> *when you are seeing palliative patients, it is not just only the patients, you sort of tend to deal with relatives quite a lot. It's the carers, family so It is good if they have sort of one GP for continuity and sort of comfort and they are able to answer all the questions.*
>
> *(GP-05)*

The next section will explore GPs' use of technology and IT systems for carrying out services for patients in the palliative phase.

4.16 Automation in palliative care case management

This theme covers the use of computer systems in GP surgeries for the management of palliative caseload. GPs reported massive advancements in the use of computer systems in recent years. They highlighted different aspects of modern connected systems helping them in routine consultations. Most GPs also commented on the usefulness of their software during different phases of a patient's palliative care journey. Some GPs described how the system made it easier to facilitate their work with palliative patients. One such innovation was the use of Electronic Palliative Care Co-ordination Systems (EPaCCS). One

GP specifically elaborated on this concept and viewed the e-pack system as a valuable tool to have during early palliative care discussions. Likewise, another GP reported filling in details on the EPaCCS system as the first task he performed at the start of palliative care. Patients preferred priorities of care around the last stages of their life are documented on this system. This record then is widely shared with health and social care providers. This information sharing was considered useful, and the GP supported the access other palliative care teams have to this document.

> *They (software) have incorporated something called EPaCCS into the system. And we are encouraged to fill in e-packs. It is sort of a form but obviously in an electronic form that you fill in as a GP. These EPaCCS come in handy for early discussions*
>
> *(GP-01)*

> *Because once you are thinking that the patient is palliative, you start filling it in. Palliative care teams have access to system one. Sometimes they tend to fill in and most of the time we tend to fill in.*
>
> *(GP-03)*

Similarly, expanding on this topic, another GP highlighted the usefulness of a traffic light system now routinely used in GP surgeries for palliative patients. This is a colour-coded system that provides recommendations, including cautionary information on the prescribing for patients nearing the end of life. He recognised the difficulty of coordinating different aspects of palliative care during its different phases. He felt the use of a traffic light system had helped in offering better organisation of palliative care.

> *you got a traffic light system with red, yellow, and green and as GPs they want us to obviously sort of as an estimate, but they want us to say that red means that the life expectancy is last few weeks. Yellow a bit better, green… So, I think that is making things more organised as well.*
>
> *(GP-04)*

Overall, all GPs referred to greater use of aids and prompted from their software and automation and suggested this was a convenient way to manage a large workload of patients. The next theme is related to GPs' views about the importance of providing palliative care in a community setting.

4.17 Importance of community palliative care services

The theme explores how GPs perceived palliative care services delivered in a community setting. During the interviews, GPs were invited to discuss their experiences with home-based palliative care services. While GPs were unanimous in their approval of community-based palliative care, there were mixed views concerning the sustainability of such initiatives. Some GPs were very vocal about delivering palliative care closer to the patient's home and according to their wishes. One GP specifically outlined the community as the only suitable place for palliative and end-of-life care delivery. She also mentioned the need for effective collaboration among health care professionals as well as more resources. Once a patient had chosen home-based care, she was strongly in favour of continuing this for as long as possible.

> *I think it is to be delivered in the community. With availability of more resources… more hands put together to provide better care… It has to be in the community. I mean this is not something which can't be done because… there can't be anything worse than somebody who wants to*

> *stay at their home during last days of their life and we are sending them to hospital.*
>
> *(GP-04)*

GPs placed significant importance on community palliative care services but also mentioned limitations associated with such care plans. They highlighted certain treatments which were not possible in a community setting. They emphasised the need to have clear and detailed discussions with patients around such limitations and the potential need to change care plans in future. Nevertheless, they acknowledged that most palliative care patients preferred and found it comfortable to spend these days with their families and in their own homes.

> *In terms of caring palliative care in the community the idea behind that is obviously you are not going to do any aggressive treatment by sending them to hospital and most of those patients at that stage they want to be in their family environment along with their families and in their own home to be kept comfortable.*
>
> *(GP-05)*

4.18 Challenges in community palliative care

Whereas most GPs saw the advantages of having a single assigned GP for each palliative patient, this in practice did not always happen because of the lack of GPs in the workforce. This made managing care a challenging task, as summarised by one GP:

> *Keeping a regular GP for every patient is becoming harder in sort of today's general practice.*
>
> *(GP-04)*

Another GP highlighted the challenges of access to palliative care out of hours.

GPs also brought up the issues around timely access to essential palliative and end-of-life care medicines. They stated delayed availability of these vital medicines is a challenge for the delivery of home-based palliative care. Furthermore, some GPs also commented on the challenges they face in coordinating care for community palliative care patients. One of the problems stated was around responsive and efficient administration of medicines. It was reported that it is difficult to collaborate with different health care professionals involved in the administration of supportive medicines.

> *They need to have a professional advice and a professional coming to give them and that could be the middle of night or 4 o'clock in the morning. I think that is one of the main things we encounter as a problem and something they (patients) have not seen before.*
>
> *(GP-06)*

> *The medication is one of the most important things because these palliative medicines are not regular medications which people can administer themselves. Sometimes they struggle to get hold of medicines, even if they have got the medicines a nurse or someone else is required to properly administer them. So, its kind of challenging to coordinate with everyone involved.*
>
> *(GP-01)*

Another GP then further expanded on the concerns about the timely availability of medicines. In this case, the GP was involved in out-of-hours care and had to regularly visit patients receiving home-based palliative care. He reported frequently visiting palliative care patients who had been sent home without adequate medicine supplies. He found such situations particularly challenging, frustrating, and potentially avoidable. He also identified a lack of timely access to medicines as a major barrier in home-based palliative care.

> *I usually work in out of hours quite regularly and do home visits as well. So, the work which comes there is quite challenging because there is no service at that time and some people come and they get home without having any palliative care medication. You see them and they are really end-of-life, and that's a big gap there in the community. Because they have been sent home without any medications.*
>
> *(GP-02)*

District nurses were usually the primary healthcare professional in the community visiting patients ʼhomes. They discussed accounts of family caregivers overwhelmed by the tasks on hand. They emphasised a need for greater help for both the patients and their family caregivers.

> *I think more and more carers are taking it on and not getting the support they need and we do get people like that.*
>
> *(Nurse-03)*

This sentiment was also shared by another community nurse. She was worried and felt helpless to offer extra support to the struggling family members of patients receiving home-based palliative care.

> *when they come into see us… they break down and can’t cope any more when they haven’t got the support. So there is a big room for improvement for carer’s support.*
>
> *(Nurse-05)*

It is important to acknowledge that these are not isolated incidents and have been widely reported in related studies.

4.19 Collaborations and chain of care in community palliative care service delivery

During the interviews, GPs were asked about their interactions with other healthcare professionals while delivering palliative care. The GPs reported limited experiences of involvement with community pharmacists concerning palliative care. Regarding collaborations with other healthcare professionals in community settings, GPs reported having frequent collaborations with nurses for routine patient care. GPs considered nurses as the frontline health professional routinely visiting patients in their homes. They recognised the vital role nurses undertake, for example, visiting patients in their homes, accessing their pain relief and symptoms, and undertaking medication reviews. However, nurses later needed to relay their assessments to general practice and liaise with a GP for any action on their recommendations. These collaborations between GPs and nurses were frequent and were deemed necessary.

> *Macmillan team is good. If you involve them their holistic care is very good. They involve sort of visiting patients regularly. They are quite good with supporting carers.*
>
> *(GP-02)*

> *(Interaction with community nurses) Yes… it is quite frequent thing. When somebody is on a palliative care, nurses go and see them, they are in pain or they are having secretions. Medications need changes. They come back (nurses) they ask for some more doses or conversions to syringe drivers. So, that is sort of common thing*
>
> *(GP-06)*

Some GPs, whilst being appreciative of the task undertaken by the nurses, highlighted the limitations of palliative care nurses and their responsibilities concerning care in the community. These included the scenarios where nurses identified an intervention after visiting the patient's home but were unable to proceed with the recommendation because of professional boundaries. For example, GPs reported nurses had to rely on GPs to issue new prescriptions after recommending any change in medication regimen. One GP mentioned their collaborations with the hospital palliative team. Based on her experience, she felt the support she received reassuring and perceived the hospital team as an ad-hoc knowledge base.

> *most of the things and reviews… they can be done by the nurse, and they usually go and see the patient. Palliative nurses, Macmillan nurses or some others as well. But they are also quite limited in their roles. They can see that somebody is in pain but then if they need medicines, they can't do anything unless somebody prescribe it. So, I think their role is very important but to some extent it 's limited as well. That is where obviously they contact us. We prescribe, change medication or whatever is needed.*
>
> *(GP-03)*

> *If you need any support of help, the palliative care consultant… in fact I just spoke to one this week… last week. And they are quite good, they are approachable. You can get help; you can get guidance.*
>
> *(GP-04)*

4.20 Increased pressures on GP practices

During the interviews, several GPs expressed their concerns about the increased workload on GP practices. GPs also pointed out the extra care needs they cater for, specifically for ageing and palliative patients. One GP indicated that the increase in the ageing population was resulting in an extra workload for their practice.

> *I think with the increasing ageing population we are getting more and more elderly and palliative patients in with complex needs. So, definitely workload has increased.*
>
> *(GP-05)*

Likewise, other GPs shared similar experiences of dealing with increased demands for their services. Some GPs also acknowledged the challenges associated with increased workload and resulting difficulties in fulfilling all healthcare needs of patients. One GP, in particular, discussed the additional roles GPs had taken up now. He explained that GPs were required to actively participate in social care issues in addition to the usual medical need of patients and their families. These responsibilities had further contributed to their workload.

> *There is a continuous increase in demand for GP services and this demand is also creating some pressure. Work pressure, it is not always easy to meet the needs.*
>
> *(GP-02)*

> *It is not anymore that GPs are involved with just the healthcare, we are involved in a lot of other things, including active involvement in social issues So, I think... there is this element of work pressure.*
>
> *(GP-06)*

4.21 Collaborations with community pharmacists in relation to palliative care services

During the interviews, the general practitioners were invited to discuss their current involvement with community pharmacists concerning the care of palliative care patients or their family caregivers. Additionally, they were also asked for their opinions on possible future arrangements where they may consider increased involvement of community pharmacists. These views are further discussed in chapter six; this section summarises the perception of GPs concerning the present involvement of community pharmacists.

Most GPs struggled to provide any recent examples of their interactions with community pharmacists during the delivery of palliative care services. At the same time, several GPs listed other health care professionals (e.g. nurses, hospital consultants, hospices) as their routine contacts for delivery of palliative care services. GPs in the study shared a collective perception among themselves of having very limited engagements with community pharmacy teams when it comes to palliative care services. One GP provided examples of having routine interactions with community pharmacists to obtain advice on medications and their availability. However, she did not recall any examples of community pharmacy involvement in their palliative care services.

> ***[pharmacist involvement/interaction for delivery of palliative care services].*** *Not actively so far, I have not… I sort of… I have been in touch with a lot with the obviously the palliative care hospital team, with Macmillan team, with hospices, district nurses, community matrons… but not so far with pharmacists.*
>
> *(GP-01)*

> ***[when asked to provide any recent examples of community pharmacist's engagements for palliative care delivery].*** *We often speak with pharmacists to get advice about medications or to check on alternative availability…for palliative care… I can't think of much or any examples for palliative patients.*
>
> *(GP-05)*

Expanding on this topic, a nurse participant also highlighted the need for more collaborative engagements considering the current workload they were facing.

> *We need more staff and we need to work together as MDT approach… together as a team. Rather than people working separately and doing different things. You need to pool together to be able to cope with the amount we are going to get.*
>
> *Nurse-01*

This chapter presented the views of healthcare professionals concerning pharmacists' current engagement in community palliative care services. The next chapter provides an analysis of data from interviews with patients and family caregivers. The perceptions of patients and family caregivers in the following chapter are also around the current palliative care engagements by community pharmacists. The views about potential role extensions are covered in chapter six.

Chapter Five

Patients and family caregivers' experiences and perception of community palliative care provision and community pharmacy involvement

This second findings chapter is centred on the data collected from interviews conducted with patients and their family caregivers with palliative care needs. I will start by providing an overview of patients' and family caregivers' accounts of their illness, how they initially felt and coped with their diagnosis and the impact of this journey on their lives. Following this, I will present three themes that emerged from the data. The first emergent theme was patients' and caregivers' unawareness of the different types of support available for palliative care. The second theme centred on the variation in engagement with health care providers. The third explored participants' views on the current role of community pharmacy in palliative care services.

5.1 Patient and family caregiver participants

A total of twenty semi-structured interviews were conducted with a purposive sample of palliative care patients (n = 10, Table 5-A) and their family caregivers (n = 10, Table 5-B). Nine of the ten patients were recruited through their respective GP practices. One patient was recruited through a care home. For family caregivers, eight recruitments were made through GP surgeries and two from a care home. In total, six GP surgeries were engaged in this recruitment process. Most interviews were conducted at the GP surgery (fifteen interviews). Other places included care homes (three) and patient's homes (two). The interview lasted, on average, around 30 minutes. There was one instance where both the patient and a related family caregiver participated in the study. The interviews were audio-recorded and transcribed verbatim, following the process detailed in section 3.8.

The study's recruitment plan was designed to invite patients (or their lay family caregivers) affected by a range of serious or life-threatening illnesses (section 3.7). Palliative care is often perceived as a care package associated solely with cancer patients, and attempts were made to recruit patients (or their lay family caregivers) suffering from diseases other than cancer, for example, congestive heart failure, chronic obstructive pulmonary disease, end-stage renal failure, Alzheimer's or dementia, frail elderly. However, most responses to the invitation to take part in the study were from patients with a primary cancer diagnosis or their family caregivers (nine patients and eight family caregivers). The other three other participants were an elderly patient with a diagnosis of congestive heart failure, a lay family caregiver for the same patient, and a family caregiver for a patient with Alzheimer's disease.

Table 5-A Participants' characteristics of patients interviewed during the study (n=10)

Code	Recruitment pathway	Age Group	Gender	Palliative Diagnosis	Time since the palliative phase (months)	Demographic index	Interview location	Interview duration (min)
Pt-01	GP surgery	50-70	Female	Carcinoma	1		GP surgery	25
Pt-02	Care home	over 70	Male	Carcinoma	2		GP surgery	30
Pt-03	GP surgery	over 70	Female	End stage CHF	4		Care home	35
Pt-04	GP surgery	30-50	Male	Carcinoma	1		Patient's home	40
Pt-05	GP surgery	50-70	Female	Carcinoma	3		GP surgery	25
Pt-06	GP surgery	50-70	Female	Carcinoma	2		GP surgery	30
Pt-07	GP surgery	over 70	Female	Carcinoma	4		GP surgery	35
Pt-08	GP surgery	50-70	Male	Carcinoma	2		GP surgery	20
Pt-09	GP surgery	over 70	Male	Carcinoma	3		GP surgery	25
Pt-10	GP surgery	over 70	Female	Carcinoma	3		GP surgery	25

Table 5-B Participants' characteristics of family caregivers interviewed during the study (n=10)

Code	Recruitment pathway	Gender	Patient's Palliative Diagnosis	Time since the palliative phase (months)	Demographic index	Relationship to patient	Interview location	Interview duration (min)
CG-01	Care home	Female	Carcinoma	2		Spouse	Care home	30
CG-02	Care home	Female	End stage CHF	4		Sister	Care home	30
CG-03	GP surgery	Female	Carcinoma	2		Spouse	GP surgery	25
CG-04	GP surgery	Male	Carcinoma	2		Spouse	GP surgery	35
CG-05	GP surgery	Male	Carcinoma	3		Spouse	GP surgery	25
CG-06	GP surgery	Female	Carcinoma	1		Spouse	Patient's home	35
CG-07	GP surgery	Male	Carcinoma	3		Spouse	GP surgery	25
CG-08	GP surgery	Female	Carcinoma	2		Sister	GP surgery	20
CG-09	GP surgery	Female	Alzheimer	3		Spouse	GP surgery	25
CG-10	GP surgery	Female	Carcinoma	4		Spouse	GP surgery	30

Emergent themes

The analysis of interview data and field notes led to the generation of three major themes. These, along with their associated minor themes, are listed in Table 5-C. These minor and major themes from patients and their family caregivers ʾinterviews are discussed in detail in this chapter.

Table 5-C Major and minor themes from patients' and family caregivers' interviews

Major themes	**Minor themes**
Palliative care: The journey so far and holistic needs	• Patients' and family caregivers' accounts of their illness • "Nothing much a doctor can do" Palliative care as "surrendering to the disease." • Understanding the scope of palliative care • The burden of care over time • The shift in focus of care during the progressive phases of palliative care • Overall expectations from palliative care. • "End-of-life care" as a primary objective • Decisions about end-of-life care • Fear of being left alone • Managing medicines
Engagement with health care providers	• Continuity of care and integrated palliative care • Home visits by health care professionals • Expectations of healthcare professionals • Approachability of Healthcare professionals

	• Palliative care services from GPs & nurses • Palliative care services from a community pharmacy • Interaction with different health care professionals in the community • The continuous chain of care
Current community pharmacy involvement in palliative care services	• Community pharmacist among other health care professionals in the community • Current perceptions towards community pharmacy services • Involvement of community pharmacy in palliative care needs • Medicine management initiatives by community pharmacy • Knowledge of expanding role of community pharmacy teams • Remote consultations • Internet pharmacies

5.2 Palliative care: The journey so far and holistic needs

The first theme revealed the lack of understanding and limited approach to the holistic palliative care package. Patients and family caregivers were both observed to be more concerned with medical needs while staying reserved for physical, social, psychological, and spiritual needs. Furthermore, participants would often consider palliative care synonymous with end-of-life care. However, the first subsection below presents the accounts of patients and family caregivers during the palliative phase.

5.2.1 Patients' and family caregivers' accounts of their illness

Most patients and family caregivers described their health and care package since the start of the palliative phase as challenging. Overall, they detailed difficulties in managing their own or their loved one's health due to progressively increased illness and intensified health needs. An important aspect reported by many participants was their inability to understand the palliative care pathway and the new medication regimen. Furthermore, many family caregivers pointed out that suddenly they were now tasked with numerous duties that they were finding difficult to carry out.

> *I wasn't aware of this term [palliative care] before and to be honest I still doesn't know much about it. Initially I thought it would be like taking some additional medicines or extra hospital visits… that sort of thing. But now they are bringing many changes. Stop this, start that… Take this only when you need it, keep a diary…*
>
> *(Pt-08)*

> *Things are on a difficult path since we had the diagnosis. We never thought of it in this way and there was always hope. But, now we kind of manage it as it comes. Doctors, at hospital and then the GP have provided a lot of information about the changes and the days to come but it is difficult to deal with all that on a daily basis.*
>
> *(CG-07)*

Meanwhile, one patient was in a light mood and gleefully accepted the current challenges as ʻjust part of life. He was feeling content with the difficult daily routines and future prospects.

> *Ah… [little laughter] the coming days… I am grateful for the life I had. There's no point hanging about for ever, isn't? Right, there are some difficulties now, but I am at peace with the coming days. It is not something I planned for but now that it is coming, I have to take every day as a blessing.*
>
> *(Pt-09)*

The next section examines the limited understanding of the full scope of palliative care by service users (i.e. patients and family caregivers).

5.2.2 " Nothing much a doctor can do" Palliative care as "surrendering to the disease."

A very strong feeling among all the participants, both for patients and family caregivers group, was the sense of ʻgiving in ʼwhen the diagnosis was made. Most of the participants or their family members had a primary diagnosis of advanced-stage cancer for which palliative care had been started. Unfortunately, the prognostic trajectory leading to death was not a helpful topic during discussions with their doctor. Such discussions, although deemed necessary and very important, led to a sense of helplessness among the participants.

> *…I don't think there's much a doctor can do now…*
>
> *(PT-02)*

The inevitable consequence of their illness was found to take precedence in their overall approach to disease management and, in some cases, could be viewed as a coping mechanism. However, a strong focus on end-of-life care influenced their acceptability for care needed during the early palliative care phases. This approach was more visible among patients. The family caregivers expressed some resilience, but once the news of terminal illness was shared by the doctor, they also voiced a general sense of helplessness.

> *It's a waiting game…I'm taking it on a daily basis. It is a case of getting in terms with this whole scenario.*
>
> *(PT-09)*

> *First, we were hopeful… the doctor at the hospital was hopeful initially but then we were told it is very unlikely they will be able to control it. We were given different options and we decided to have one more cycle… unfortunately that wasn't successful. Now… we are just at the mercy… and doctors are not giving much time either.*
>
> *(CG-08)*

5.2.3 Understanding the scope of palliative care

At the onset of palliative care pathways, patients and their family caregivers were often faced with difficult decisions in deciding the place of care, i.e. hospice, specialized care home, hospital or home-based. Whilst it is widely documented that home-based care was the preferred place for many people, it was recognised that both patients and their family caregivers had limited understanding of what a complete community palliative care package should entail. Most participants understood palliative care to be a ‘care package’ that was only relevant towards end-of-life rather than care that began at diagnosis.

When asked for views on what could be part of a good palliative care plan, most participants responded with only medical-related needs. This suggested they had limited awareness of the importance of maintaining the overall health and well-being of both patients and their family caregivers. These low expectations of palliative care resulted in participants delaying the onset of important palliative care support. For example, there was a reluctance to accept the new regimen with more focus on “quality of life”. Similarly, some participants talked about perceived stigma toward palliative care having an influence on their decision-making. In this regard, a few patients considered the palliative pathway as a label of “not important” patients for NHS anymore.

> *At doctors they were talking about stopping medicines and putting me on some extra pain killers. But I do not feel much pain at the moment but they seemed only concerned with that. I do feel that since they started talking about palliative care there is not much on agenda for me anymore!*
>
> *(PT-07)*

Considering that palliative care is a sensitive subject and one that is not routinely discussed, publicised, or talked about in society, it was unsurprising that lay participants expressed a pattern of limited knowledge concerning the early initiation of palliative care. In cases where there was a recent diagnosis or where the death was not imminent, it was found that this lack of knowledge of palliative support influenced their focus of care. More importance was given to end-of-life care with an increased focus on terminal care rather than progressive phases of palliative care. This resulted in a lesser focus on early initiation of palliative support with more services geared towards the terminal care plan.

> *We are still discussing it… May be I will speak to my GP about it during our next appointment… I had some change in medicines, but that's about it so far.*
>
> *(PT-08)*

> *It is something we have not discussed in detail yet… to be honest… since the diagnosis we didn't think of this part much…*
>
> *(CG-04)*

> *We are not thinking that far yet [end-of-life care]*
>
> *(CG-07)*

5.2.4 The burden of care over time

Family caregivers of patients receiving palliative care are often reported to take on roles and responsibilities for which they have never received any formal training or much support. These responsibilities included medicine administration, nursing duties, and administrative roles. In addition, the family caregivers tended not to focus on the difficulties they had been facing. Rather, family caregivers showed a general sense of duty towards the patient and appeared content with providing care to those they loved. This often led to them having a decreased assessment of their own personal, social, and healthcare needs. After taking up the role of informal care providers, family caregivers were often overwhelmed by the demands this role kept piling on them.

> *I have taken a lot of things in my hands… like medicine times, food, drink, … that sort of stuff. We have carers visiting us but I feel it is an all day*

> *job now. I am happy that I am around to take care for [him] because he won't tell anybody and then this work keeps me busy all day.*
>
> *(CG-03)*

On many occasions during this study, the family caregivers revealed a constant increase in the number of tasks they had to perform themselves for the care of their loved ones. There was a continuous increase in responsibilities for family caregivers during the disease trajectory (CG010)

> *…I mean… I knew from the start… the doctor told us as well that it could be challenging but so far we been doing … I will say… we are doing… Ok*
>
> *(CG-02)*

> *…currently…, I just want to focus on his care. The best I can do.*
>
> *(CG-06)*

> *How do you think the care needs for Mr X changed over the last few months?* *(Interviewer)*
>
> *Well… they definitely have increased…and I am always worried whether he is comfortable of not. I am… kind of… constant on a run… chasing after GPs and Nurses… and all these tablets at different times…* *(CG-10)*

5.2.5 The shift in focus of care during the progressive phases of palliative care

As mentioned in the literature review, palliative care aims to extend over a period and is not limited only to end-of-life. The progressive phases of good palliative care are discussed in section 1.4. Both patients and their family caregivers demonstrated unfamiliarity with complete palliative care covering all the stages of palliative care. In addition, the participants highlighted an ever-increasing focus on end-of-life care throughout their palliative care journey.

It was notable that family caregiver discussions with healthcare providers kept shifting towards end-of-life care arrangements and disease progression. This focus of care was also present in the participants themselves. During palliative care, one of the main objectives for patients and their family caregivers was to draw up and put into place a detailed end-of-life care plan. There was a perception among both patients and family caregivers that palliative care was a synonym for end-of-life care planning.

> *… we had a few of these discussions with the GP and they were mostly around how best to make all necessary adjustments when its time…*
>
> *(CG-05)*

> *I have spoken to John (pseudonym for patient) about what he want. We haven't decided yet but have had some discussions. At the end of the day we want to do what is best for him. Where he thinks he will be more comfortable. We also thought of moving to a hospice near the time… but nothing decided yet*
>
> *(CG-01)*

The patient (PT-04) was on a palliative care register for a month at the time of the interview after a diagnosis of aggressive cancer. In this instance, palliative and end-of-life care planning were not higher up the agenda for him. The advanced care planning about a preferred place for receiving end-of-life care and arrangements necessary during palliative care were discussed, and understandably, such discussions were not the focus of care soon after diagnosis and on initiation of the palliative pathway.

> *There is a lot happening right now… and a lot on your mind. Everything happened so quickly. I wasn't expecting it but then that's life… The doctor asked me to consider my preferences but honestly… how can you plan for such event… may be when this all sinks in then I might sit down and decide about my last days here*
>
> *(PT-04)*

5.2.6 Overall expectations from palliative care.

The participants reported a decrease in their health expectations as the disease progression continued. This was also accompanied by increased uncertainties and worries. These were centred on the important and core issue of what was to follow in the coming days or weeks. Most participants had detailed discussions with their GP, but that did not remove the concerns around end-of-life arrangements.

> *The GP has gone through with me… there was a list and some details in it for what I would like or not… but to be honest, I wasn't much interested at all that.*
>
> *(PT-02)*

> *I'm not expecting myself to magically start improving now. The GP kept talking about different problems which we may face in coming days*
>
> *(PT-03)*

> *The nurse has visited us couple of times and has explained to me a lot about various aspects of his health and what to expect in coming days. It is a huge challenge and I don't think you can ever be ready for this…*

> *(CG-01)*

5.2.7 "End-of-life care" as a primary objective

It became clear that participants did not have a clear distinction between the care that should have been available during the palliative care stage and that of end-of-life. The predominant belief was that palliative care is only centred on preparations for good end-of-life care. During the initial stages of the interviews with palliative patients and their family caregivers, the palliative care period was often perceived as only relevant for terminal illness and end-of-life situations.

> *I discussed it [palliative care] with GP and other guys as well. They have put me on a plan as well and have given me some material to make my choices so that when the time comes everybody knows what to do.*
>
> *(Pt-10)*

Further discussions on the topic revealed that the participants themselves have limited expectations from the palliative phase. They revealed that the primary focus of their care package was increasingly geared towards end-of-life arrangements as the disease progressed. They noted that conversations with their GPs would quickly turn towards how they would wish for their end-of-life care arrangements to be made. Consequently, the palliative care phase leading to end-of-life care was often the case of missed opportunity. With too much emphasis on end-of-life care arrangements, it was felt that the care necessary early in the progressive palliative care was not addressed. Patients and, more importantly, family caregivers often perceived a peaceful death as the sole objective measure of palliative care.

> *There have been so many discussions lately with doctors and with friends and family members as well. All we need now it to have some sort of arrangements where [she] is at ease and not distressed when the time comes.*

> *(CG-07)*

5.2.8 Decisions about end-of-life care

Talking about palliative care planning, especially end-of-life care choices, was considered a challenging task by patients, family caregivers, and healthcare providers. A consistent theme observed during discussions with family caregivers in this study was the burden and accountability they experienced while making decisions on the part of their loved ones. The finding revealed that having these discussions with the healthcare providers was a tiring process for the family caregivers. Likewise, the palliative patients themselves also echoed a consistent difficulty while having to deal with the tough decisions ahead. Besides many factors, one dominant force in their decision-making process was their perception of the availability of adequate care programs in different palliative care settings.

> *You mentioned advanced care planning and there been some discussions around it. But I do not know where we will end up. We are going through different options now and have considered home care as well and costs and all that. He is comfortable here now but what will happen if he gets ill and I am the only one around. I am not saying that he needs to go to hospice, but I can't deal with everything.*
>
> *(CG-06)*

> *Going forward, I am not sure how things would be…. I mean no body knows that sort of things… I am happy where I am now [at home] and lets see how things go from here. We have discussed hospice plan in case we start struggling with no body available.*
>
> *(Pt-04)*

One of the main concerns expressed by family caregivers was about adequate symptom management and keeping their loved ones as comfortable as possible for the remainder of their time together. This was often the case once they had accepted the disease trajectory. Palliative patients themselves valued the support mechanism available through their family networks but were concerned with the extra burden they were putting upon them. Patients frequently voiced their opinion about the comfort of being able to stay at home. They were also quick to discuss uncertainties around the availability of round-the-clock care at home.

> *[out of hours care] you mentioned it and yes, it is often very difficult to get hold of anyone once the doctors [GP surgery] close. We have had couple of instances recently and going through out of hours was a nightmare. Seriously, if it keeps happening, we may have to re-consider our options [in terms of place of care]*
>
> *(CG-09)*

5.2.9 Fear of being left alone

One major fear voiced by the patient participants was being left alone without adequate physical help in the later stages of their disease. This belief formed an overarching question informing their decisions about advanced care planning.

> *I would love to stay here, with everybody around. Hospital… never like it. Now they are telling me I have to decide about it, and I am finding it difficult to choose. At hospital you have someone around all the time whereas here they visit and then forget. I or [Mrs] need to contact them again and again and arrange a visit.*
>
> *(Pt-09)*

A pattern was observed among participants of this study where they showed reluctance towards continued home care when faced with increasing demands and inadequate symptom control. When asked about advanced care planning for their palliative care (including end-of-life care) arrangements, there was a constant fear of limited help and support available. The uncertainties around the care package were even further for any emergency needs they perceived may be required. Even when both patients and their family caregivers were satisfied with the current arrangement, they still conveyed reservations about their health care needs in the coming days and weeks.

> *Overall, I would say that the situation is OK, fine for now at least. We have plenty of support around. But then they mention things can get bad quickly and we should be ready… how can one be ready? And we don't know what to expect and if it happens suddenly middle of night, then what?*
>
> *(Pt-06)*

> *We are receiving a good care at the moment and [HE] is doing fine and seems happy here. Plus, we get a chance to spend time together and children join us as well when they can. But frankly, the thought of what's coming and how to mange it at home does frighten me at times.*
>
> *(CG-10)*

5.2.10 Managing medicines

Participants experienced significant changes to their medicine regimens during different phases of the palliative care period, which became puzzling for research participants. Despite being informed about likely changes to their medical regimen from the onset of palliative care discussions and during advanced care planning, their personal understanding of the changing medical approaches was limited.

> *[medication routines] yes… there have been changes since the start of palliative programme, quite many of them, actually! They did mention that these are necessary changes and explained that some stuff is not needed anymore. But then these changes are still happening with very little details and explanations in between. Chemist keeps sending medicines every other day with little to no information.*
>
> *(Pt-05).*

Patients reported that they had a lesser degree of involvement in their use of medicines as their condition progressed. Where family members have taken up the role of informal caregivers, usually without any formal training, they tended to look for information from sources other than healthcare providers, chiefly from the internet, to resolve any issues that they had. They tended to ignore the medicine advice services available at their local pharmacy. Their decreased understanding and lack of information also resulted in non-adherence to the prescribed regimen.

> *There was too much to remember. I mean there were more than a dozen types of medicines and their timings. Now they come in a pre-packed [dosette box] from the chemist. It has made life easier but then last month doctor made some changes and we needed new packs and it was a bit of a hassle sorting it all out, and the extra pain medicines, we keep running short of them. Chemist said we are using too much but what to do when he's in pain. It's all a mess at times, really!*
>
> *(CG-07)*

This section covered details of the personal experiences and perceptions of patients and their family caregivers around the challenges, expectations, and areas of support in their palliative care journey so far. The next theme explores their engagements with healthcare providers.

5.3 Engagement with healthcare providers

In the UK, palliative and end-of-life care are mostly offered from three main sites, i.e., hospitals, hospices and residential care homes, and home-based care. The current study participants were recruited by intermediaries in primary care. The objective was to establish how service users interact with different healthcare professionals in primarily a community-based healthcare system. Therefore, the discussions with the participants were centred on their perceptions and experiences of primary care sites. This section covers the engagement between service users and providers from patients' and family caregivers' viewpoints.

A common finding was the absence of a universal process encompassing participants ' interaction with the health care providers. There was a great deal of variance in terms of how patients and family caregivers viewed and approached the health care providers. The themes which emerged in this regard are discussed further.

5.3.1 Continuity of care and integrated palliative care

Most participants routinely voiced their concerns about the reservations when their care moved from one place to another, such as from hospital to home-based care. Participants were worried about the timely transfer of their care setup when moving to home care with adequate arrangements made beforehand and continued throughout. Many family caregivers felt that they were the ones often chasing up and doing all the administration work required for coordinated care, such as prescription changes, timely supply of medicines, and arranging home visits.

During the palliative phase, many of the participants experienced unmanaged co-morbidities, e.g., diabetes, asthma, COPD, which meant changes to medication regimens were frequent. However, when medicines were initiated during an appointment in a hospital, the participants felt that the GP systems were late to update their medication records. This resulted in an increased burden on the part of family caregivers and a delay in obtaining further supplies of medicines started at the hospital.

> *Over the last couple of months, we have moved between hospital and home on quite many occasions. One thing really challenging for us was to make care arrangements when we come back home. At hospital they change your medications but when you come back home, they give you some supplies and by the time you run out of them there's no more supplies coming through GPs… they are not up to date, sometime chemist they said they haven't got a prescription or medicine is not available. If you're late chasing it up, you end up with a situation where there are no medicines available at all. So, it is quite distressing.*
>
> *(CG-10)*

> *I now have made a routine where the first thing when we come out of hospital is to let the doctors at the GP surgery know that there are some new medicine started and to chase it up with the chemist as well, letting them know that we're expecting some new medicines. So, yes really it is us who are coordinating that sort of stuff.*
>
> *(CG-10)*

> *[He's] got diabetes got this eczema which can flare up very easily but you end up at hospital because of a totally different thing like if he's not having enough pain relief or if the situation is deteriorating or if he's not eating a lot and they feel like they need to get him to hospital for a while and when he's back some of his other conditions worsen rapidly. At home it is kind of start from zero again.*

> *(CG-05)*

The participants with some experience in palliative care by the time they participated in this study had started to acquire a working knowledge of the administrative task involved and a familiarity with the different care agencies involved. It was felt that such understandings were dependent upon their experiences since the start of palliative care. The security of knowing that their care package would move swiftly between care sites and providers was an important factor for both patients and family caregivers.

> *So far, we have been able to manage it at home and it has been quite successful. [He] is comfortable at home and we all are comfortable around him and the situation is kind of under control however I do worry about what will happen when we have to go to hospital or to a Hospice all of a sudden. How quickly things will be switched over? if we like decide to go to Hospice at some stage so how quickly things will be in place there? that sort of time frame is like an unknown for us? How will his current care setup transfer across there? (CG-09)*

5.3.2 Home visits by health care professionals

Most participants overwhelmingly appreciated the home visits they received during their palliative care. Their opinions about home visits by GPs and nurses were filled with gratitude. They seldom view these as a health entitlement but as a personal favour. This perception would often dictate their decision to approach a healthcare professional in a time of need. For example, many would downplay what were significant palliative care needs in order not to cause trouble for a healthcare professional, especially where this was deemed for a home visit.

Within the context of this study, patients' and caregivers' views were invited around three community-based health care professionals, i.e. community pharmacists, GPs, and nurses (district and Macmillan nurses). Most participants viewed GP surgeries as a place for any previous or new health concerns. At the same time, community pharmacies were considered mainly suppliers of medicines. Similarly, most participants ʾperception of nurses' role was around medication administration and wound care duties.

None of the participants reported any home visits by community pharmacists in relation to palliative care. The home visits were made mostly by district nurses followed by GPs. The participants valued the contribution a home visit by a health professional had on the overall management of condition and preparation for the plans going forward. The informal home setting offered a better environment for most participants to engage in essential but potentially distressing conversations relating to end-of-life care plans.

> *Home visit… we hardly had any home visit by a pharmacist. They are at the pharmacy, and I can see them there or when occasionally pharmacist deliver medicine himself, but that's about it but nothing more than that. I never thought about it in that way about pharmacists so I'm not sure if they need to do a home visit for certain stuff… I'm not too sure about that.*
>
> *(Pt-03)*

> *We had some home visits by GPs they have visited us on few occasions and at times we requested them to visit us as I was too ill to go there and then we had a visit from them and some occasional visits by nurses before all this started. I must say that it's quite comforting if somebody visit us at home. Obviously, I know they are busy, but you do some relief when someone can arrange a visit here.*
>
> *(Pt-08)*

Family caregivers perceived home visits by GPs or nurses as a comforting act. This enabled them to contact the visiting healthcare professional in a time of need.

> *I mean knowing that you can call on someone to visit your home is quite comforting and the whole idea that someone is available for you to take care if needed. We really are trying to do our best and trying to do as much as work we can. I know they are busy people but knowing that we can call someone for a visit even if you don't need somebody right now, but you can fall upon someone's if you need it is reassuring.*
>
> *(CG-06)*

Patients appreciated when offered a home visit by a healthcare professional. The informal environment made it easier to discuss potentially distressing issues.

5.3.3 Expectations of healthcare professionals

During the interviews with patients and family caregivers, the participants demonstrated an overall limited knowledge of the complete palliative spectrum of care that was available. Consequently, their main focus was on good end-of-life care and "peaceful passing". For most participants, their expectations from health care professionals were not of a broad nature. However, many participants appreciated the extra help and support mechanisms being put in place for them.

Some participants, however, voiced their concerns about the adequacy of palliative care if they chose to stay at home. Some participants even did not regard home palliative care as their preferred route going forward and were deliberating plans for hospice care. Similarly, the preference for hospice-based palliative care was also voiced by family caregivers. In both circumstances, the primary expectation was to achieve satisfactory end-of-life care.

> *We had an initial meeting at the hospital and then another meeting with the doctors at the surgery they explained about things [to come by]. Like we have to make certain decisions about end-of-life care or about the last days of life going forward. So at that time that was a little shocking.*

> *I don't think anyone every be ready to think about or plan about such stuff. However so far we are here [home]. But we're thinking of moving to a hospice. Mainly on the reasons that we are not sure how tough the things can get and what sort of support will be available here. At least with the Hospice care you can think of a peaceful environment.*
>
> *(Pt-01)*

> *We are thinking about what sort of arrangements we have to make and the decisions we have to put in place. Doctors and other staff have provided a detailed view. we had a discussion with friends and relatives as well, like how and where I would like to be in when it gets worse. My prime concern, I mean what I'm thinking right now that it is not too much burden for everyone around here and to have adequate level of care available. We are still thinking about our options but it is what it is but as long as you make it comfortable for the family and not distressing for them with a little peaceful environment.*
>
> *(Pt-04)*

When they were asked about informed decision-making, patients and family caregivers were overall satisfied with the early discussion about their disease trajectory and death. This provided them with some time to reflect and plan for their future health care needs.

> *So far I would say we are in a way satisfied with the information provided to us at the hospital and then the surgery. They did tell us from the start that how the things will progress and when the things get serious who to call and what sort of expected in the coming days. Nobody knows how difficult it would be but at the moment we are satisfied in a way we knew*

> *what's coming and that's in a way has given a head start to plan accordingly.*
>
> *(CG-08)*

When family caregivers were asked about their own personal health care needs, they did not appear overly concerned, even when they had multiple morbidities of their own. They prioritised the care needs of their loved ones over their own needs. Their own health was therefore often overlooked. Furthermore, there were signs of stress and burden, which were rarely raised with health care professionals.

> *I'm not too concerned at the moment…. I'm doing alright. I obviously want to do the as much as you can because you don't know how many days you can cherish. So this is the kind of like, enjoy everyday and do whatever you can do.*
>
> *(CG-01)*

> *It is challenging and stressful but I'm happy to carry out these duties and I am around to carry out such stuff. It is a sort of time where you can't just simply runaway, the time to take up the responsibility and just focus on the care rather than bringing in my own issues and my own little problems. We got this big stressful situation going on and I don't see why I should be moaning about my problems at this time.*
>
> *(CG-03)*

5.3.4 Approachability of healthcare professionals

In the opinion of lay research participants, among all the healthcare professionals, pharmacists were the most approachable. Most participants were familiar with their community pharmacy staff, including the pharmacist. Generally, most patients and family caregivers described having somewhat personal relationships with the community pharmacy staff.

> *Yes, they are easily approachable I even know most of the staff personally. I give them a little wave when passing by. I would say they're quite approachable I don't have any difficulty discussing anytime and they all know my medicines and the situation I am so there's nothing kind of like hiding behind a wall or anything. I don't remember booking any appointment to see the pharmacist, just turn up and have a little chat.*
>
> *(Pt-06)*

> *It is quite easy for me to just turn up even like if you just need paracetamol tablets. You don't need an appointment to book for that… Even if you need advice or something bothering you about your condition or there's some medicine you're not sure about so I just turn up or pick up a phone and give them a ring. So, I do appreciate this aspect of the pharmacy.*
>
> *(Pt-09)*

They also valued the drop-in nature of a community pharmacy, particularly where they did not require to make an appointment. However, the participants pointed out an apparent lack of active involvement when it comes to palliative care needs. Despite the ease of access and availability of the pharmacist, most queries about palliative care or treatment that were asked of community pharmacists were for minor ailment issues.

> *If I think back, like I mean things where you just ask them for any stuff like got some itchy eyes or headache these sorts of stuff or like when to take a medicine. Sometimes you don't remember and what to do if*

> *missed a dose and not sure. Another time something was on my skin, that sorts of things. You just turn up and ask them and they just let you know there and then.*
>
> *(Pt-09)*

> *I have contacted pharmacy I would say mostly for things like headache or hayfever. You just turn up and tell them it is that time of the year again and they get you those medicines.*
>
> *(Pt-04)*

Many participants praised the work of community pharmacy teams, for instance, where they had adopted the administration work to align any changes in medication regimens. Without their help, they found communication about medicine changes between the hospital and GP to be problematic. Additionally, the timely availability of medicines for end-of-life care was another significant role the participants credited to the community pharmacists.

> *Yeah, I would like to mention that at times you are struggling to arrange a prescription from a doctor and you're going to-and-forth and our local guy at chemist he just took care of it. He said just leave it to me and so that was quite helpful and similarly previously on other times they [pharmacy] would just sort the prescription from the doctor surgery and then just get the medicines delivered to us. There's not much work we have to do in this aspect.*
>
> *(CG-02)*

Approachability toward other healthcare professionals (i.e. GPs and nurses) was not problematic either for most of the participants. Due to the sensitive nature of palliative care, participants were very early on counselled by their GPs for prioritised appointments.

Similarly, district nurses' contact details were available to most research participants. However, participants voiced their reservations about contacting both GPs and district nurses for routine matters and for out-of-hours care needs.

> *I don't think I ever had any problem getting an appointment with the doctor. Obviously, you have to ring for it and arrange for it but having said that I don't find that why can't you plan it a little ahead… they absolutely have to fit you into their schedule but as long as you plan a little ahead it should be okay. I don't see a problem there.*
>
> *(Pt-06)*

5.3.5 Palliative care services from GPs & nurses

Patients and family caregivers viewed GPs and nurses as a primary source of help for their home-based palliative care needs. For example, a good relationship with a GP was perceived as necessary for achieving good palliative care. Regular interaction with either of these health care professionals also influenced the decision to receive further palliative care at home.

> *Luckily, the GP we have here is quite good and we know him for years. When we needed some extra support, it was little easy in a way. He has visited us on few occasions as well so that very helpful. I tend to just let the reception know that please book me with the [said] doctor.*
>
> *(Pt-07)*

> *We know our GP for a while now and then obviously she is the one visiting us now and it is quite helpful knowing the person beforehand. She's the one cared for her for some good years and when she's visiting us now*

> *after we had the diagnosis it's easy to communicate a little I will say. I will say a little more helpful considering we knew her before as well.*
>
> *(CG-08)*

GPs were also viewed as a source for answering most enquiries relating to palliative care. However, participants were anxious when questioned about out-of-hours care. Even when GP involvement was at hand and participants were satisfied with their care, they still did not view the general practice surgery as the sole provider for their palliative care needs.

> *Like what will happen if I need something urgently out of hours. At present it's challenging but I can still coordinate between GP and chemist and the medicines get to me but what will happen if you need somethings suddenly going forward. like some middle of night? I had a previous experience of out of hours and it is quite stressful going through the whole cycle.*
>
> *(Pt-07)*

In contrast, participants viewed the roles of district nurses as important in-house care providers. District nurses were often the primary source for their information on different matters. This included social care arrangements, local palliative groups, financial assistance and a liaison person organizing their whole palliative care package. Some participants also mentioned seeking advice from visiting nurses about medication dosage. Nurses were very much appreciated for their face-to-face front-line role. Family caregivers perceived them as the first point of call for end-of-life care arrangements. Additionally, palliative patients valued their informal discussions with district nurses during their home visits.

> *Nurses are marvellous being around, and they come in and they take care of everything, and they were really helpful in explaining different scenarios. Also, I think they have a little more time to talk to and that gives us a chance if you have any queries or if you're not certain about*

> *things you can ask them. They do tell you about how to manage and not to worry too much and they will be around.*
>
> *(CG-09)*

5.3.6 Palliative care services from a community pharmacy

The participants described limited involvement on the part of the community pharmacy team with regard to an overall palliative care package. Most participants viewed community pharmacists as medicine stockists. Family caregivers praised the work done by community pharmacists who routinely provided medicines on a consistent basis. After being informed that a patient was in receipt of palliative care, there was not much variation in terms of pharmacy services offered or changes or support from community pharmacy teams.

> *They [pharmacy] are still supplying us the medicines and yes I mean that's what they were doing before as well and we haven't had any problem in that sense. There been few changes since the start [of palliative care] but the medicines etc… they took care of it. We now get them delivered it was just getting a little difficult for us to pick it up so I spoke to them and they said yeah no problem will get it delivered.*
>
> *(CG-04).*

> *I think of pharmacy mostly like in terms of supplying medicines and to be honest I never had much problem. My interaction with community pharmacy… you could say that mostly in terms of having prescriptions filled.*
>
> *(Pt-01)*

> *They’ve been supplying my medicine for a long time now I don’t even know how many years. They could be late in certain instances but that’s about it.*
>
> *(Pt-10)*

The family caregivers were involved in the palliative care of their loved ones at the time of their participation. No bereaved family members were recruited for this study. Some participants were only familiar with the idea of anticipatory prescribing without any personal involvement or experience. They voiced their opinion about the timely supply of vital end-of-life medications, which was an important issue for them. They believed that community pharmacy teams would be able to provide such a service in a timely manner. They did not want to be chasing healthcare professionals just for the supply of medicines around that time. At the same time, the participants showed limited knowledge of laws around prescribing controlled drugs required for end-of-life care. Their perception, for the most part, was that their regular pharmacy should be able to take care of this matter.

> *Our local chemist they’ve been supplying our medicines for years and for the last few years you don't even have to see the doctor, they just sort it out themselves. However, a couple of weeks back there was some medicines and the chemist told us there's some sort of supply issue with it and they can't get it and we have to speak to the doctor to sort it out or we can try a different chemist. I was really surprised at that… that why can’t the pharmacist and the doctor sort it out between them. I mean end of the day we are the patients, and we don't know much around these problems.*
>
> *(Pt-03)*

> *Our pharmacy has generally been OK however we do have had some problems in the past where we struggled to get certain medicines. I do think going forward if that happens again and you need some medicines urgently… so who to call for at that time, the last thing I want to do is running around chasing.*
>
> *(CG-02)*

In addition, in instances where participants were struggling with medication issues and their treatment regimens, they still did not view community pharmacists as their primary source of help. The dosage queries relating to pain control medications were directed to GPs.

> *At times I do struggle with the pain relief I'm getting from the medicines and sometimes the medicines run out quickly… before the next prescription is around or before the next supplies are due so you end up calling doctor to find out what to do in these instances.*
>
> *(Pt-09)*

5.3.7 Interaction with different health care professionals in the community

Patients and family caregivers were invited to give their views on their experience of contacting different health care professionals while receiving home-based palliative care. These included their views on GPs, district nurses, and community pharmacists. Understandably the start of palliative care was a pivotal moment for the participants. Most participants in this study were either diagnosed or were caring for a family member who was diagnosed with non-curable cancer. Some of them have already received treatment cycles which, unfortunately, were not successful.

These participants had experienced a fundamental change in their treatment plan. For some, this was accompanied by an unwelcome change in approach towards this management plan by the hospital teams previously involved. They highlighted the importance of shared decision-making and wished to be provided with more control over their own treatment plan. Also, other participants within this sub-group accepted this transition from treatment to the palliative phase much more easily once they were taken on board and were provided with all the essential information about their disease progression. For them, the perception that they were in charge of the decision-making process rather than the hospital consultants were the desired route.

> *When we first had the diagnosis… it was quite tough at that time and then we went through treatment cycles as well. Then few months back they explained us about this palliative pathway and this new management plan and then afterwards it does leave you with a sense of like that's it… get ready! I was left quite frustrated because there was very little communication about the decisions, they have taken… or the decisions they were suggesting.*
>
> *(CG-05)*

> *The doctors kept me informed since the diagnosis and they did tell me… about… what are the chances. When they finally talked about this palliative plan, it wasn't like a big surprise. Obviously, I was taken aback… a bit! but in a way I knew what's coming.*
>
> *(Pt-05)*

During this shift in care from a treatment focus to symptom control management, the participants had regular interaction with their GP. They viewed GP surgery as a central point in integrating their care needs. However, they frequently felt that GP practices were overwhelmed with administrative tasks. This often resulted in both patients and their family caregivers chasing up the medication records. Consequently, this transition period was not smooth for most of the participants. There were frequent inquiries directed to GP surgeries around medication and dosage changes. Additionally, management of side effects was another major issue faced by most participants, which resulted in GP consultations. There was also a frequent approach to GP for ad-hoc needs concerning adequate pain relief, side effect management and medicine supplies. Participants also accepted the fact that they had limited prior knowledge of such instances. Their confidence in their palliative care management plan gradually improved with time.

> *When I was put on this palliative pathway there were some changes at the start and then there's been so many changes. At times you don't know what is happening and there's been many discussions as well. I have had many consultations with GP now and you do feel like they have been given too many tasks and got plenty on their plate. They put me on certain medicines and that didn't agree with me and then I have to go back and then there was another medicine and the pain relief was not adequate. Then they were reluctant to put me on these stronger medications so early on… there was a lot going on.*
>
> *(Pt-09)*

> *Initially I was explained that the focus will be more on like controlling my pain and which was worsening initially but it's kind of okay for the last few weeks. I think they figured it out it in the end.*
>
> *(Pt-06)*

The role of district nurses became apparent only after the start of the palliative phase. The participants highlighted the substantial contributions made by district nurses during their home visits. They regarded district nurses as their primary source of education for the palliative care plan. The informal home setting and lay language were easy for patients and their family caregivers to understand. Also, both patients and family caregivers were more comfortable having difficult conversations with the district nurses when compared with GPs or the hospital consultant team. District nurses were perceived as health advocates by patients and family caregivers and were often entrusted to speak to other health and social care providers on their behalf.

> *We have had a few visits by the nurses, and they have put in a care plan in place. Also, we had some discussions around what we need to do going forward and how to manage certain conditions or how the things will be in coming days. We also got their contact details in case we need to contact.*
>
> *(CG-08)*

> *We have had visits by GPs and nurses. I would say they were both quite useful but I think with the nurses… I think it is in a way a little more relaxed for us you. We were able to discuss something which you miss discussing with the doctor and certain stuff like plans going forward and obviously they are dealing with these scenarios on their daily basis. I even discussed with them about what could be the best place for care, what would they recommend in case we have to go to hospice or if you need to make certain adjustments in the house. They been quite a good information source.*
>
> *(Pt-03)*

Community pharmacists and other pharmacy team members were very frequently contacted by the participants. The delivery of services from a community pharmacy necessitated interactions at regular intervals. This involved picking up the prescription medications, ad hoc over-the-counter medicine supplies for minor illnesses, ordering repeat medications, inquiries over the phone, or medication delivery arrangements. The participants were generally pleased where they were offered a medicine delivery service by their pharmacy team.

> *I have contacted community pharmacy on numerous occasions. When you are picking up medicines or there sometimes doctors, they come and visit us and leave a prescription here or at surgery. I contacted them [pharmacy] to get that medicine delivered or if you need something just like for an odd box of paracetamol just to keep handy.*
>
> *(CG-01)*

5.3.8 The continuous chain of care

Both patients and family caregivers voiced their concerns about the continuity of care they received. They felt that there were inadequacies in the smooth transfer of their care between different care sites and organizations. This resulted in reduced confidence in the overall system of care which appeared at times disjointed. Family caregivers were often left searching for a central figure to coordinate their palliative care. At the time of diagnosis, they were often unfamiliar with the key roles and responsibilities of different health professionals that they encountered. The idea of the “who is who” style booklet was mentioned by one family caregiver. When this idea was discussed in subsequent interviews, the participants agreed that a booklet that clearly described the health professional team could be useful where the patient or family caregivers were unfamiliar with the role of healthcare professionals. Additionally, they also desired further health information or guidance for lay patients and their family caregivers. This was brought about by their own experience, where they felt they had a steep learning curve of palliative health literacy in a relatively short span of time. Participants demonstrated a concern about whom to approach and what to do in case of urgent needs.

> *The frustrating thing for us so far has been to find a person who holds the key to our care. At times we return from hospital and don’t know who*

> *to contact in community if it is a weekend. Even if it is a weekday and GPs are around still, they don't know what to do and you end up telling them what has happened at the hospital.*
>
> *(CG-10)*

> *One challenge I would like to highlight has been how to approach the different agencies and the people involved. I mean it is at times feet like a jigsaw puzzle.*
>
> *(CG-07)*

Both patients and family caregivers highlighted the value of having the same health professional over time. The instances where it happened brought a sense of security to participants and increased confidence in their treatment plan. Family caregivers reported many instances where they had to carry all the paperwork to an appointment with a health professional. They were surprised that they were chronologically more up-to-date than the health professionals. Both patients and caregivers preferred administrative work to be undertaken by professionals. These tasks were usually given to district nurses in case of prescription requests and less commonly to community pharmacists for medication supplies.

> *One thing useful would be if you deal with the same guy every time I know it could be difficult for the surgeries but if you need something on an urgent basis and you contact them often you go and you keep explaining them the previous history or sometimes somebody visit you and they haven't been to your house before so you keep telling them about different aspects and it does take a time for them to catch up as well. It would be useful if you know one person knows you and your care requirements.*
>
> *(Pt-07)*

This section explored topics under the major theme of patients' and family caregivers’ engagements with healthcare providers. The next section covers their experiences to date with palliative care services from community pharmacies.

5.4 Current community pharmacy involvement in palliative care services

This section details the views of patients and family caregivers about the current involvement of community pharmacy teams in palliative care services. The views in this section are based on participants' own experience as well as their general perceptions. The participant's opinions about future role extensions for community pharmacy teams in palliative care are discussed later in chapter six.

5.4.1 Community pharmacists, among other health care professionals in the community

The patients and family caregivers in this study regarded community pharmacists as valuable members of the health care set up close to their homes. Their experiences and perceptions of the services they received from community pharmacists were parallel to what they would expect from any member of community health care teams.

The overarching image of a community pharmacist was that of a person responsible for all medicine supply matters. Although this image did not portray the range of services currently offered by community pharmacies in the UK, the participants highly valued this unique role of community pharmacists.

> *I know my pharmacist quite well and know him for a while. About what could be his called his role… then it is like the person responsible for supplying my medicines… and that’s how I viewed him most of the time.*
>
> *(Pt-01)*

> *I consider community pharmacy as place where you get your medicines. I mean it is a bit like a medicine shop… (Pt-06)*

Getting the correct medicine in a timely manner was an important responsibility undertaken by the pharmacy team. When this expectation was breached, this quickly led to dissatisfaction among some participants in cases when they struggled to get hold of their medications in a timely and swift manner. For example, a few patients described problems obtaining medicines.

> *If there is any sort of issue or a problem sourcing a certain medicine, I would say it should be the responsibility of pharmacists, to sort this problem out rather asking me to sort it out. I don’t know where it is available or from where do you get your medicine? if you can’t get it then I certainly can’t get it… so if there’s any problem, I would like the community pharmacist to deal with it.*
>
> *(Pt-02)*

> *Obviously if there is a problem in getting hold of a medicine the thing what I would recommend it should be the responsibility of community pharmacy rather than the patient or anybody else.*
>
> *(CG-07)*

There were several instances where patients or their family caregivers had requested a community pharmacist to act on their behalf. This was often the case where prescriptions were not ready at the GP surgeries, or the GP records were not up to date. A family caregiver described an occasion where he left discharge letters from the hospital at the local community pharmacy to be chased up with the GP.

> *They have been quite helpful in the past at times you do hand them over certain tasks, like if there's a prescription need chasing up and you can just let the pharmacist know and they get it sorted with the doctors. I remember there was a time where I left discharge letter, I got from the hospital with them, and they sorted everything on that occasion. They been quite helpful.*
>
> *(CG-03)*

In terms of palliative care participation, most participants recalled the community pharmacist's role as being centred on the timely supply of medicines. The district nurses were their source for informal discussions and information about different palliative care services available. Furthermore, in the palliative phase, the participant did not describe any pro-active involvement by community pharmacists. Although they praised the service they received, the queries were initiated by patients or their family caregivers themselves. There was not a mechanism in operation where community pharmacists would routinely check up upon them as opposed to other health care professionals.

> *Personally, I did not see much change since the start of this palliative [pathway]. They [pharmacy] were supplying medicines before and they are still supplying medicines. There is not much change… obviously, medicines they have changed!*
>
> *(Pt-08)*

5.4.2 Current perceptions toward community pharmacy services

Patients' and family caregivers' views about community pharmacists can be divided into two distinct domains. Firstly, how they historically viewed community pharmacists in general. Secondly, their more recent experience of how they view community pharmacists in relation to the provision of palliative care. Participants were mostly aware of their local community pharmacy teams. They were accustomed to a specific community pharmacy for most of their needs. This relationship was also long-term for most participants; however, some reported changing their community pharmacy over time. Regardless frequent switches from one pharmacy to another were uncommon. This facilitated knowing the pharmacy team on a personal basis.

The community pharmacy setting was viewed as a site where they were able to obtain medicines and trustworthy information. Most patients and family caregivers felt satisfied by the services they received from their local pharmacies. The community pharmacists were perceived at par with other community health professionals regarding trustworthiness and professionalism. Participants valued the advice provided to them during consultations with pharmacists. The ad-hoc walk-in practice at community pharmacies was immensely appreciated by the participants. Free access to the pharmacist provided a sense of safety for both patients and family caregivers.

> *If you ask between pharmacist, GPs, and nurses. I'll say that they all kind of same… Pharmacist they are like GPs right! They all got different roles but in comparison with other professionals like GPs and nurses they [pharmacists] are also important.*
>
> *(Pt-02)*

> *They [pharmacists] are doing a great job and quite a responsible job. They are available quite easily; you can just turn up and just ask to speak to a pharmacist. They are available there and then. Obviously, you need pharmacist for other reasons than you need GP for but in terms of their profession and the work they are doing that they are no different to other guys [GPs and Nurses]*
>
> *(CG-10)*

In terms of different services offered by community pharmacies in the UK, most participants only credited them with the responsibility of dispensing and supplies of medicines. Several participants were receiving their medication in a metered dosage system (MDS), but there was an expectation that this was a normal part of the care they should receive. Nevertheless, they viewed having their medicines blistered as necessary to help them adhere to their medication regimens.

> *I am somewhat aware of different services now offered from pharmacy. I know they were advertising about flu jabs recently, but I have used them mostly about medicine supplies. The prescription need filling if you need any medicine over the counter.*
>
> *(CG-04)*

> *Mostly it is to do with dispensing of medicines. Also, that we were having problem with the timing of medicines, and someone suggested getting them in blister pack and probably what was needed. We spoke to pharmacy and now we do get them dispensed all in one single pack with the medication timings. It definitely has made our life a lot easy.*
>
> *(CG-09)*

One key point noted was that although participants viewed community pharmacy as a valuable health resource, their perception of services available from community pharmacy did not change on initiation of the palliative care phase. Their expectations from a community pharmacy team widely remained the same with or without any palliative care needs.

One participant (CG-04), a family caregiver for a patient suffering from cancer, liked the fact that there was not any material change from the approach in care at the community pharmacy. For him, this was a sense of comfort in its own way as he felt inundated by sympathetic but difficult conversations. By continuing services at the same level, community pharmacy in some way provided an escape route and a comfortable break.

> *I would say I am receiving the same set of services from my pharmacy. It is in a way the same what it was before and I like it that way. I still pick up medicines and there are dealing with me in the same way what they were dealing with me beforehand without keep reminding you that there are not many days left.*
>
> *(CG-04)*

5.4.3 Involvement of community pharmacy in palliative care needs

When it came to palliative care needs, participants did not distinguish any major change in services they received from the community pharmacy. The nature of their interaction with community pharmacists was very similar to what they were used to before the palliative care phase. The participants in this study did not have experiences with anticipatory prescribing, although some of them were familiar with the need for such arrangements in future. Their general perception was that the pharmacy team would be able to take care of their medication supplies. They did not view end-of-life care medications and other important controlled drugs such as morphine injections as any different to the medication supplies they were already receiving. One caregiver had such a discussion with their community pharmacist and was satisfied with the assurance the pharmacist provided about medicine supplies.

> *They [pharmacy] have been supplying me medicines all my life and I don't see why it would be difficult for them now. They are responsible for medication supplies right? I have a confidence in them to sort it out when they are needed.*
>
> *(Pt-04)*

> *There have been many medication changes recently and we've been able to get them from our pharmacy. I don't see any problem going forward. I even had a discussion with our chemist, and he said don't worry leave it to me.*
>
> *(Pt-08)*

There was a general perception that community pharmacists were medicine custodians. The participants did not view the supply of their palliative or end-of-life medications as any different from their regular medicine supplies. There was a sense of assurance that the supply of their essential medicines would be uninterrupted. There were instances when caregivers were informed by community pharmacists that their medicines could not be dispensed at the time because of the prescriber's error. At the same time, many patients and caregivers told of instances where a community pharmacy team member (pharmacist and pharmacy assistants) chased up the prescription inquiries from GPs on their behalf.

> *I have viewed our pharmacist as the person responsible for supplying all my medication needs. so when this [palliative phase] was started I did not see why it should change. However, Recently we had an incident where the prescription was not written correctly and the pharmacist was*

> *like I can't supply it at this time. I shouldn't be the person you're talking to why don't you sort it out with the doctor who's written it rather than explaining it to me. I don't even know what the problem was?*
>
> *(CG-05)*

> *The staff at our chemist they have helped us on a few occasions where we had to change the prescription from the surgery, and they said don't worry we will get it sorted. I think they got in contact with the doctor and later on we got the medicine delivered to us.*
>
> *(CG-3)*

The examples of participants' interactions with community pharmacists discussed above were centred around medicine supply matters. It was felt that lay participants perceive community pharmacy primarily as a medicine supply source even after initiating palliative care. The areas where participants would welcome future participation by community pharmacy teams are discussed in chapter six.

5.4.4 Medicine management initiatives by community pharmacy

Palliative treatment can still involve active treatment to reduce symptoms and improve quality of life, e.g. beta-blockers. However, there needs to be a distinction between medications that should not be started and medications that should be withdrawn in end-of-life situations. When offered, participants did welcome different medicine management initiatives by the community pharmacy sector, e.g., dosette pack dispensing or medicine use review (MURs).

Three participants (one patient and two-family caregivers) who had received an MUR service previously were satisfied with the purpose of such services. Having experienced the value of speaking to the pharmacist about medicines, they wished such services to be offered during the palliative care phase and preferably at-home setting. No participants have experience with a new medicine service (NMS). However, when explained the concept of having consultations with a pharmacist when a new medicine is prescribed. They generally liked this idea, especially around pain relief medications.

> *Oh yes, I have had an MUR before. This is the one where you sit down with the pharmacist and go through with your medicines. I did find it useful, it was a chance to sit down and discuss your medicines in detail rather than just picking up your prescription. It in a way gives you a sense like okay if there is an issue, the person is available to talk to, makes it easy to approach the pharmacist in future as well if needed.*
>
> *(Pt-02)*

> *I like this idea of a new medicine service as you describe it. So far I have not received this service but in principle it seems like a good idea. Recently we had a problem with pain [relief] medicines, these stronger painkillers when they were started. It would have been useful if I've been given some information from the start and how to manage some of the side effects.*
>
> *(Pt-07)*

5.4.5 Knowledge of expanding role of community pharmacy teams

Community pharmacies in the UK are increasingly encouraged to take part in primary care initiatives. This has resulted in an expansion in community pharmacy services in addition to traditional dispensing duties. Recent community pharmacy NHS contracts are designed to reward increased participation in extended roles. The research participants in this study were asked for their views and experience of services they received from community pharmacies other than common dispensing obligations.

Several respondents from both patients and family caregivers groups had some knowledge of additional community pharmacy services. They recalled occasions where they had been approached by a community pharmacist or a dispenser for MUR service and recently for seasonal flu vaccinations. They viewed these extra services as a useful addition. In the case of flu vaccination services, they were more flexible in making appointments. However, most participants were unaware of their community pharmacies' full range of services. According to them, the pharmacy sector should "shout out" more about these recent initiatives. The participant's views about any prospective engagement by community pharmacy in palliative care are discussed in chapter six.

> *Our local pharmacy where we normally get about medicines picked up they do now advertise a range of services like there was a some leaflet in the prescription bag about flu jabs and I think it is useful. It is another place where you can go to. Previously it was just one place the GP surgery, where you need to go for every single need and so if community pharmacy can expand on their services, I think there's no harm, it would be useful for us.*
>
> *(CG-02)*

5.4.6 Remote consultations

The participants viewed the community pharmacy as the most accessible health care team for telephone consultations. They appreciated how they have prompt and easy access to a community pharmacist. There was a feeling of security and comfort in accessing a community pharmacist, even for trivial and routine issues. They were also happy to talk to an actual person and valued the compassionate approach by the community pharmacy team.

Most telephone consultations were related to medicine supply issues. Additionally, the participants also approached their local pharmacies for dosage queries, running short on medications and prescription due dates. The salient feature in this theme was the relevant ease the participants felt in ringing community pharmacies. Remote interaction with pharmacy staff was only via phone call. This was not a common medium for most participants and was only needed to make medicine supply inquiries. Few participants, however, reported using the telephone for medication advice. One patient stated knowledge of skype calls with GP but was not keen on this idea during the interview. For them, the use of the telephone was easy and reliable.

> *We have called our pharmacy on few occasions I think it was mostly around when we were waiting on medicine, and we were not sure when it would be available. It was just a case of checking on its availability or delivery and on some occasions, it was around new prescription we were expecting from the doctors.*
>
> *(CG-10)*

> *I have contacted a pharmacy by making a phone call. It is useful in a sense that if you are worried about certain medicine and you don't know and you are not sure about things on the leaflet. You just pick up a phone and talk to the guy who probably knows much more than you rather than keep wondering about what this actually means.*
>
> *(CG-02)*

In relation to palliative care, one of the concerns where participants contacted community pharmacists was "prn" and" when required" dosage directions. This is often related to pain relief and other symptom relief medications. The participants were satisfied with the support provided over the telephone. During one interview, family care revealed that the pharmacist was not her first choice when faced with medicine dosage queries. They tried to contact their GP first and were directed to the community pharmacy by the reception team at GP surgery. Now due to easy accessibility and increased confidence, their local community pharmacist is their first point of call.

> *Recently we have contacted pharmacy and it was around these painkillers where we were not sure about the directions like … two spoons when needed and we were not sure about how many times we can take it like sometimes he would be in so much pain and can get through a small bottle like in a day, what would be safe? Doctor was busy and the lady at the reception told us to ring pharmacy. Now I just call pharmacy first.*
>
> *(CG-03)*

5.4.7 Internet pharmacies

When asked about the use of internet-based or internet-based pharmacies, none of the participants had used this for the dispensing of prescriptions. One participant viewed Boots online range of OTC medicines as an internet pharmacy. A few others recalled ordering some toiletries and some other common-use items from their local pharmacies at the time of their medicine deliveries.

At the same time, many participants were familiar with the idea of an internet-based / distance selling pharmacy. They had received some communications in the post or had seen their advertisements. However, in this study's select group of participants, the idea of the direct delivery of the medicines to patients' homes attracted ambivalent views. They were satisfied with the medicine delivery services from their current pharmacies. Additionally, they liked the fact that with local pharmacies, they were able to offload specific administrative tasks. Equally important was their ability to put a face to a role and the personalised care they have received over the years leading up to the palliative phase from their local pharmacies.

> *By Internet pharmacy do you mean ordering some medicine from tools website?*
>
> *(CG-01)*

> *I am a little bit aware of these online pharmacies. I think there was something through the post as well where I think they get in touch with your doctor and medicines just get delivered to you. I don't know how they operate. Personally, didn't have any experience of that but that is what was explained in that leaflet.*
>
> *(Pt-04)*

For urgent ad-hoc health care needs, the participants had reservations about the distance selling pharmacies. They liked the ability to pick up a phone and speak to a health professional (pharmacist) who could signpost them. For example, a participant recalled an incident where they lost important pain relief medications. Their local pharmacist was unable to supply the medicine because it was a controlled drug. However, the pharmacist could signpost them to the correct out-of-hours service. The participant, though, desired for such matters to be resolved by a community pharmacy. Such wishes originated from their beliefs of attributing all medicine supply matters to community pharmacy.

> *I don't mind online pharmacies there may be some out there who benefit from this idea but I get my medicines delivered from my local chemist, so don't see any need for a separate service. I do get a chance to see them and know the person responsible for taking care of my medicines and if there's a problem I can call them or get in touch with them. Like in the past if we had any problem obtaining a certain medicine and I was*

> *happy for our chemist to take care of it. I’m not sure how it will operate between my doctor and an online pharmacy.*
>
> *(Pt-05)*

In summary, the patients and family caregivers were often faced with stressful situations in the delivery of their care. This was particularly pertinent to families who found themselves providing home-based palliative care where the family caregivers were responsible for a substantial amount of the patient’s care. Problems with medicines were often reported, and it was found that they had little help from health professionals or from their community pharmacy.

Chapter Six

Participants' views and perceptions about community pharmacy role extensions

This final findings chapter builds on the previous two chapters to present the views of the research participants concerning the potential of community pharmacy involvement in palliative care and services. During the interviews, both lay and professional participants were encouraged to discuss what they felt could be future roles and responsibilities that the community pharmacy sector can undertake to better support patients or family caregivers. The expressed views covered both expansions of current roles and possible role extensions. This chapter draws together both lay (patients and family caregivers) and professional perceptions.

These findings are grouped into six themes and are listed in Table 6-A

Table 6-A Emergent themes from the analysis of data from all participants (lay and professionals) about potential role extensions in palliative care services by community pharmacies

- The importance of the timely supply of medicines
- Pharmacist participation in anticipatory medications and anticipatory prescribing
- Community pharmacists' contributions to medicine management during palliative care
- Home visits
- Remote consultations
- Community Pharmacy as care coordination centres

6.1 The importance of the timely supply of medicines

During the interviews, a key issue for both lay and professional participants concerned the timely supply of medicines. Patients and family caregivers recalled past instances where a delay in obtaining certain medicines was a cause of serious worry and frequently left them feeling anxious. A particular source of concern was when medicine was out of stock, and the patient was left to source the medicine elsewhere. While they appreciated the work undertaken by community pharmacy staff in sourcing medicines, they regarded this duty and associated workload as a core responsibility of a community pharmacy. For most of them, their community pharmacists were responsible for the timely supply of medicines, and that was how they always perceived the chemist. Patients and family caregivers reported struggling in these instances to obtain palliative care medicines and expressed their frustration when their regular community pharmacy was unable to dispense their prescriptions. In addition, some of them expressed displeasure on instances where a community pharmacist returned a prescription to them after being unable to dispense it.

Most lay participants highlighted that an essential role of the community pharmacy team is ensuring a timely supply of medicines. It was a significant concern for most of them, and they would like their regular community pharmacies to be responsible for sourcing and supplying medicines. Some participants also voiced that their local community pharmacy should be the sole link with other healthcare professionals in case of any problem with a prescription or with the supply of certain medicines. One family caregiver explicitly mentioned that the community pharmacy must not shy away from this duty of supplying medicines on time. He expected any future service development for community pharmacies in palliative care to have reserved some resources for sourcing and supplying medicines on time. Most patients and family caregivers also indicated a preference for palliative medicines to be delivered when needed.

> *… it is quite frustrating when you go to get a prescription dispensed and all they tell you is that it is not available. Sometimes they were able to*

> *deliver to our house but at certain times you have to wait a fair deal longer to get the medicine. I mean… chemists [community pharmacy] must brush up this aspect of their service and be on top of it in future.*
>
> *(Pt-05)*

A few patients discussed improvements to the delivery arrangements for medicines to be conveniently supplied in their homes. Although many of them were already receiving delivery of medicines from their local pharmacies, they would like this to be more formalised and organised. Some felt that medicine delivery was an ad hoc service where they could be chasing their medicines at certain times of urgent needs. Many patients and family caregivers participants preferred a delivery service to be formally integrated within a community pharmacy palliative care services.

> *It is a great help when medicines are delivered at home. It is not always possible for either of us to go and fetch them from a pharmacy. Definitely, any future plans should have this incorporated.*
>
> *(Pt-10)*

> *On occasions, our pharmacist has told us that he just can't get the medicine, and we need to get it changed by the doctor. I would like him to be speaking to doctors. Yeah… that would help a great deal if between them they decide what to do next rather than asking us to do the rounds…*
>
> *(Pt 08)*

All healthcare professionals highlighted the importance of the timely supply of medicines from a pharmacy or the delivery of medicines to the patient's place of living in a community setting if required. The views of service users about the timely supply of medicines contrasted with that of community pharmacists. While most pharmacists acknowledged already offering a delivery service to the patients, they expressed that this was more of a goodwill gesture as such delivery arrangements were not formally part of their core NHS contract, and so they were not remunerated for this. A few provided further details that such delivery arrangements were now embedded in current market competition, and providing such free services contributed towards stable patient share. Nevertheless, the pharmacy owners and managers, who were more concerned with the financial overview of the pharmacy, explained that any delivery services would be considered an "out-of-pocket" expense for their business.

One superintendent pharmacist and the owner of an independent pharmacy stated that they were happy to offer these services to keep the business, but no funding was available from the local or national NHS bodies. Unsurprisingly, he welcomed any future pharmacy palliative care service to make provisions for these delivery services.

> *We have always offered delivery service to anyone requesting it including palliative patients. But obviously we don't get any payments from NHS for supplying this service. It would be nice though if they [NHS] recognise this and offer a re-imbursements package. It in a way is a business need as well because everyone else is supplying it free of charge so you don't want to lose the customers for not supplying it and also I don't expect palliative patients to be visiting pharmacy just to collect medicines.*
>
> *(PHM-11)*

> *The sourcing and delivery of medicines is taking a good deal of our time at the moment. The NHS must think about it and some formal specifications should be brought it especially for elderly and palliative patients.*
>
> *(PHM-06)*

In the context of timely supply of medicines and delivering medicines to patients' homes, most GPs expressed limited views. However, some of them acknowledged and appreciated the work done by community pharmacists in this regard but were generally unaware of the formalities surrounding such services.

> *I always thought pharmacy is able to source medicines and [we, GPs] have not kept any list of medicines not available. The pharmacist usually rings the practice to let us know of any shortages asking for alternatives. However it is not possible to write a substitute prescription straight away and the process can take time but they [pharmacists] can deliver medicines [to] patients so patients do not need to wait in surgery.*
>
> *(GP-02)*

Like GPs, nurses also appreciated delivery services and assumed that all pharmacies offered this service as part of their contractual arrangements. Most of the nurses, who were more directly involved with the administration of palliative care medicines, discussed times when they relied on pharmacy staff for urgent supplies of medicines. Some of them also provided examples and appreciated where a community pharmacy team could deliver medicines at short notice.

> *… there was an instance when a patient required urgent medicines to setup the syringe driver. I remember the local pharmacy team was very helpful in getting the medicine to us quickly. For palliative patients, it is vital that their medicines are available in time and community pharmacies are doing an excellent job. I am not sure of current service specifications but would like this to be part of any palliative care services in future.*
>
> *(Nurse-03)*

Both GPs and nurses were generally supportive of such services being formally recognised and part of any future community pharmacy palliative care service specifications.

6.2 Pharmacist participation in anticipatory medications and anticipatory prescribing

This section describes service users' and service providers' views about the possible greater involvement of community pharmacy staff in relation to prescribing and use of anticipatory medications. Availability of necessary medicines during end-of-life care was described as an important contributor to satisfactory palliative care plans in a community setting. During the interviews, participants' views were invited about the availability of medicines during end-of-life care or during the last few days of a patient’s life. The availability of medicines during the end-of-life phase was often associated with anticipatory prescribing or often referred to as the “just in case box” scheme, which is operational in various parts of the country to facilitate the availability of medicines needed for end-of-life care. Participants were asked to give their views and opinions on how community pharmacies can improve the process around anticipatory prescribing and supply. Additionally how community pharmacies can facilitate better access to medicines during end-of-life care.

A variety of views and opinions were presented by lay participants concerning anticipatory prescribing and easy access to essential medicines during end-of-life care. Patients and family caregivers who participated in this study were not bereaved relatives. Therefore, most of them were unable to reflect on their personal experience. Their knowledge of this issue ranged from discussions with healthcare professionals, family members, and other support groups. Consequently, most lay participants were not familiar with the term ‘anticipatory prescribing’ and did not demonstrate how these medicines were any different from others. Nevertheless, a number of patients and family caregivers were able to make significant contributions to this important topic.

> *They mentioned that at the doctors … about some sort of arrangements later and then we discussed it with a nurse. She told us that if we were to stay at home and if [He] require extra support their specialised team will visit and sort it out.*
>
> *(CG-08)*

Most of these participants perceived anticipatory, and end-of-life care medicines just like other prescribed medicines and did not attach any particular significance to these. They also did not anticipate that community pharmacies should have any problem sourcing these compared with other medicines. They held strong beliefs that when the need arrived and a prescription was written, the medicine would be made available to them without delay. They did not distinguish the different legalities that classes of medicines hold. For instance, they were unaware of the legal restrictions, for example, controlled drugs (morphine etc.) that are often used to control symptoms during palliation and end-of-life care.

> *If you ask me, personally I don't know much difference about prescription requirements you mentioned. Sometimes they ask me to sign the prescription for controlled drugs but that's all the difference I can tell. Generally, they pharmacy] been very good in getting medicines here [home].*
>
> *(Pt-04)*

> *The pharmacy been very kind in delivering medicines now that we struggle to pick them up and they are very regular in supplying medicines on time. [Therefore] I do not see a reason to worry about medicine supplies in coming days.*
>
> *(CG-06)*

However, when asked, many community pharmacists pointed out the difficulties they often face when the prescriptions received from the GP/prescriber do not comply with current-controlled drugs regulation. This resulted in an extra administrative burden and an unwarranted but necessary delay in dispensing the medicine to the patient.

> *At times prescriptions for controlled drugs are not legal and then obviously we can't supply those medicines even when we are certain that the prescription is genuine. It is frustrating at times… especially when a prescription is brought by a patient or relative and needed urgently. This leads to extra work and arrange a delivery later, can't expect them [patient or relative] to wait while we sort it out which you know can take a long time.*
>
> *(PHM-03)*

The interviews during the later phases of the study also involved questions about when the patients and family caregivers would like to make sure of the availability of anticipatory medicines. This was around the issue of making sure essential medicines are always available to patients in their preferred place of living in a community and how exactly a patient or a family caregiver would feel such arrangements should be made.

Despite the issues with supplies, most patients and family caregivers reported they were satisfied with the community pharmacy as a central figure responsible for providing them with essential medicines as and when they would be needed. However, there were variations in views, and for a few lay participants, the best way to ensure adequate supplies of medicines was always to keep a reserve stock of such medicines with them, even before they were needed. However, others waited until the medicine was needed before obtaining the supply. It appeared that the decision to stockpile or only obtain supplies when needed was dependent upon the experience of how effective and efficient the pharmacy had been at dispensing medicines on time. Those who had poorer experience, who were more frequently told their medicines were unavailable or 'out of stock' and had been referred elsewhere, were more likely to order prescriptions early and to stockpile.

> *We had some problems in the past where [she] struggled to get medicines on time … and was in absolute agony! I now just order the next prescription early and have arranged to get it delivered at least a week before she runs out [of medicines].*
>
> *(CG-05)*

When anticipatory prescribing and supply were discussed with community pharmacists, they welcomed getting more involved in end-of-life care and being part of the community palliative care multi-disciplinary teams. However, they expressed having limited knowledge and skill set for such roles. For the majority, their understanding of the term palliative care was limited only to dispensing prescriptions for anticipatory medicines.

> *For palliative care… when you say for palliative care you mean these injections and stuff… or is it before that?*
>
> *(PHM-13)*

When they were asked about their potential extension of involvement within community palliative care programmes and anticipatory prescribing, the majority of pharmacists were happy to contribute further within this scope. However, when they were further asked for possible involvement routes, they described limited extended avenues. The majority of pharmacists perceived themselves as already playing a pivotal role in supplying prescribed anticipatory medicines. However, nearly all of them described their current role of a safe supply of potent medicines as an important one but limited on a broader scope. Besides the supply, they had limited roles in monitoring use after medicines had been dispensed, limited counselling roles as they do not see patients and limited input into the prescribing process. This was despite their expert knowledge of medicines.

> *… often we dispense medicine and once it is handed over or get delivered, there is very little interaction with patients after that… occasionally someone call to get some more details about the dispensed medicines. If there is any important counselling, that is usually done at the time of handing over prescriptions but generally nothing much after that.*
>
> *(PHM-10)*

Some pharmacists also described familiarity with 'just in case box' schemes operational in other parts of the country. 'Just in case box' scheme was not operational in Nottinghamshire at the time of this study (where all of the participants were recruited). The provisions for anticipatory medicines were through prescribers, usually GPs. Anticipatory medicines are medications used for symptom control to ease suffering during the dying process. The symptoms are not experienced by everyone but may be very distressing and include anxiety, pain, nausea, and bronchial secretions. The medicines include strong opioid pain killers, e.g., morphine injections.

'Just in case box' contains initial doses of anticipatory medicines. It is situated in the home and allows easier and immediate access to palliative end-of-life medicines well ahead of time when they would be needed. The few pharmacists who were familiar with this scheme expressed diverse views. One of them thought of it as a convenient way to make sure essential end-of-life care medicines were always available. However, the others voiced their concerns about the administration involved in running such a scheme. According to one pharmacist, such schemes were not utilising the potential available at a community pharmacy in the best possible way by only engaging them for supply assistance.

> *I was working in a pharmacy who participated in a pilot for 'just-in-case box' scheme a while back, but nothing recently. The scheme was useful and there was some good feedback from patients and carers but I think we [community pharmacists] can contribute much more than supplying boxes.* *(PHM-02)*

Furthermore, a number of pharmacists suggested that they were in favour of role extension and building on their current involvement. A few suggestions emerged on how to improve and become more actively involved in medicines management. One aspect which nearly all pharmacists voiced was to improve communications pathways and collaboration between themselves and other healthcare professionals. Most pharmacies thought that the main reason for suboptimal care was the lack of advanced information that was given to community pharmacy teams. Some pharmacists provided examples where they struggled to source and dispense end-of-life care medications in a timely manner because they only came to know about the requirement for such medicines upon presentation of a prescription. According to them, they could have made this whole process swifter if they had been provided with some advance notice, often requiring only a phone call by the prescriber. This would have enabled them to contact potential suppliers of the medicines to source and therefore dispense them promptly. Such pro-active collaboration would also allow them to adequately plan their workflow should delivery to a patient's home be required.

> *An important factor I would say is to improve the information we receive from GPs or hospitals. At times we know nothing and just chasing up prescriptions at the last minute. If they give us a little head start, that will make things a lot easier for us.*
>
> *(PHM-03)*

Another suggestion was that pharmacists should keep a designated dispensed prescription in the pharmacy for a specific patient. With community pharmacies opening till late, such prescriptions could be collected or delivered by a pharmacy team at short notice. The patient-specific dispensed bag of medicines may contain all necessary end-of-life care medicines but keeping it in the pharmacy near to the required time would decrease the administrative burden associated with 'just in case box' and other such schemes. Additionally, patients would not need to make safe storage provisions for controlled drugs in their homes, nor would unused medicines be wasted or cause the problem of subsequent disposal.

A few pharmacists suggested the better utilising of the prescribing skills of suitably qualified pharmacists (independent pharmacist prescribers) who were qualified and working within community pharmacy settings. They thought that such involvement would significantly reduce the time required to dispense certain medicines, including controlled drugs. Moreover, such arrangements would also be beneficial if there happened to be a problem with a controlled drug prescription issued by a GP or other queries associated with prescriptions issued by a doctor's surgery or by a community nurse.

One pharmacist explained that the medicines which were often required for the end-of-life care phase of a palliative care plan were often potent controlled drugs. A visit by a suitably qualified healthcare professional was required to set them up properly in a syringe driver form or by other ways of administration. He presented his views that, in any case, a visit by a healthcare professional was required before such injectable medicines could be administered, irrespective of medicines availability. He proposed that the same healthcare professional could oversee the whole process of prescribing, supplying, and delivering medicines directly to the patient's home. He stated that presently, a GP prescribes, a pharmacist dispenses, and a community nurse or other healthcare professional visit a patient to set up adequate equipment for the proper administration of such medicines. This pharmacist felt that community pharmacies could play a much more significant role in addition to their dispensing and supply duties. The pharmacist acknowledged issues around professional boundaries. He further expressed any multi-tasking involvement from community pharmacists would require more interaction with other healthcare professionals and would be dependent on greater flexibility on the part of doctors and nurses.

General practitioners in the study welcomed the idea of greater involvement by community pharmacies. Many GPs appraised the idea of redistributing responsibility for anticipatory medicines to community pharmacies. They expressed that if future guidelines allow an adequately trained workforce to be available in a community pharmacy, then it would be beneficial for palliative patients if prescriptions and dispensing of medicines were accomplished from one place, i.e., community pharmacy with GPs providing an oversight.

> *If they are happy and comfortable, they are able to prescribe. So that was like a bit like a mini surgery really. So, I think obviously things are changing and I think for us if we embrace the change probably that would be the way forward.*
>
> *(GP-04)*

> *I think if they are trained and they feel confident, they have got the prescribing role. I think they can prescribe, they can get in touch with patients, carers.*
>
> *(GP-06)*

When asked, community nurses also welcomed the idea of more active involvement by pharmacy teams in anticipatory and end-of-life care medicines.

> *A lot of pharmacists… practice pharmacists are working in practices. They are all able to prescribe and they are going through the discharge letters, they are changing the medications, when they have got the appropriate qualifications obviously. They are amending the medications for the patients, they are doing the medication reviews for the patients*
>
> *(Nurse-01)*

Some nurses provided examples where they struggled to source essential medicines in a timely manner. In many instances, they were spending a lot of time obtaining end-of-life care medicines. They, therefore, felt that community pharmacy teams should be more hands-on in sourcing medicines. Most of them were happy for pharmacists to take on extra duties in the overall palliative care plan of the patient. However, one community nurse expressed a contrasting view, for her pharmacists were not adequately trained enough to be setting up syringe drivers or administering medicines via injections. These views were also echoed by some pharmacists who demonstrated clear reservations about becoming more actively involved in the administration and setting up syringe drivers or other end-of-life care medicines.

6.3 Community pharmacists' contributions to medicine management during palliative care

One important aspect of palliative care explored during the interviews was the need for medication management during palliative care. Views were invited by all participants about how the community pharmacists can further their contributions concerning any medicines management plans necessary in progressive phases of palliative care. On this subject, distinct and variable views were voiced by different healthcare professional groups. Community pharmacists mostly expressed views about possible role extensions toward end-of-life care but provided little insight into a comprehensive and complete palliative care plan. Community pharmacists discussed the possible inclusion in end-of-life care opportunities when asked about how they can increase their participation in palliative care.

> *I suppose probably you know like… obviously like reviewing the medicines and their use of medicines (medicine usage). There could be circumstances where pharmacist can actually go to the patient's house which is not obviously done. We don't do it at the minute but that might be helpful. The pharmacist can go to patient's house in the patient's environment. If they need any type of support which a pharmacist can offer.*
>
> *(PHM-04)*

For some, this involvement is related to their current activities, which are related only to medicine procurement and supplying end-of-life care medicines. Stemming from this position, one community pharmacist said that there was not much he himself or the community pharmacy sector could offer during the last few days of a person’s life other than sourcing and dispensing essential medicines. According to him, there were already many health professionals usually involved in a person’s care, and a pharmacist's inclusion at that critical time would not bring any advantage and rather could be a cause of concern for the service users, patients and their family caregivers.

Some other pharmacists, however, were able to demonstrate a grasp of the possibility of taking on more extended roles through progressive phases of a palliative care plan and how these would need accommodating differently over time. They mentioned certain phases where opportunities arose, and the community pharmacist could contribute further. These included dispensing medications in ‘blister packs’ or monitored dosage systems, providing information and medicine counselling to patients and caregivers about safe storage of controlled drugs, advising on symptom management, and possible deprescribing.

> *we can honestly help them with as we have a knowledge of the medicines. So you know like… we can be a part of the palliative care team but obviously it’s not been done before.*
>
> *(PHM-11)*

> *At that time we can actually try to help them to see if any medicine can be reduced any number of tablets can be reduced or like liquid form or like injectables. So, route can be changed for some.*
>
> *(PHM-03)*

In contrast to the views of community pharmacists, GPs demonstrated more knowledge of the palliative care pathway. Some of them were also able to describe the benefits of initiating an early palliative care plan. The majority of GPs interviewed welcomed greater contribution by the community pharmacy team towards medicine management plans. Some GPs advocated that community pharmacies should be actively involved in medicine management initiatives. They stated that palliative care in the community involves constantly changing the care plan in light of the patient’s needs. This often results in many medicines management-related queries directed towards GP practices like dose inquiries, side effects management, prescription and medicines availability. Nearly all GPs indicated that many of these queries could easily be addressed by the community pharmacy team. A couple of GPs provided an example where they had to consult a community pharmacist for an enquiry received by a palliative patient's family caregiver. According to them, they were acting as the middleman. This query could have been addressed in a timelier and more effective manner had the patient contacted the community pharmacist directly.

> *It will take a lot of pressure of… In terms of prescribing, any queries which nurses or families could have… because we do see some times that families are checking things up with the pharmacy then calling nurses, and they are calling us (GPs) then we are calling pharmacists. So, if that centre person pharmacist could be direct port of contact… for us, for nurses, or for the families. That will make things more swift.*
>
> *(GP-01)*

> *I think one thing which could be very handy is medication reviews. A general medication review not just four or five palliative medicines. A general review. I don’t know… may be somebody is epileptic and they are on what ever medications… does they need that or they need to be transferred from these to other… what could be done. Similarly somebody*

> *who is on… may be ranitidine or atorvastatin for 30 years, do they still need to be on them. So, these are things which could be done… picked up by pharmacist, can be done quite well.*
>
> *(GP-05)*

The views presented by nurses were similar to those expressed by GPs. A few of them provided examples where they contacted a community pharmacist for advice regarding a patient's palliative care plan. Such collaborations related to end-of-life care medicines where a community nurse identified a potential problem during a visit to a patient's home. In relation to the future potential for an expanded community pharmacist role, most nurses perceived it as a valuable addition to overall palliative care services.

When asked how the community pharmacist could support nurses, they mentioned that they would welcome advice on medicine dose adjustments, management of side effects, drug interactions and medicine compatibility while setting up syringe drivers. For example, one nurse reflected on a time when she received help from a community pharmacist about the appropriate dose of a potent end-of-life care medicine. In that instance, she felt there were ambiguities concerning establishing an appropriate dose for a patient. However, when she discussed the matter with the community pharmacist, the advice she received was sufficient and enabled her to resolve the query. She suggested that this arrangement could be more formalised as, at the moment, such contacts were initiated by the nurse, and she would prefer these to be made more regular rather than on an ad hoc basis.

Patients and family caregivers also made valuable additions to discussions around medicine management plans. Many patients commended the work community pharmacy was already doing and provided examples where they contacted their local community pharmacy for medicine-related problems. Both patients and family caregivers provided views supporting increased inclusion of community pharmacy in palliative care plans. Some family caregivers discussed their experiences where they were not sure and were confused about the appropriate use of certain medicines. There were a lot of changes during the palliative care plan, and they were finding it hard to keep on top of them. In this regard, they welcomed advice and support from community pharmacy teams to help them better understand their treatment plans. These perceptions are illustrative of the standard view that pharmacists are accessible professionals and can advise on medicine use. However, this expertise was not yet fully used or accessed when it came to managing medicines for patients who were seriously ill.

6.4 Home visits

The issue of home visits by healthcare professionals to patients receiving palliative care in the community was frequently discussed during the interviews. Several lay participants highlighted the importance, reassurance, and comfort they received when visited by a healthcare professional in their home setting. Most stated no specific preferences regarding which healthcare professional was visiting them. However, they did mention having not received such visits from community pharmacists except when a member of the community pharmacy team was delivering medicines. They thought that community pharmacists delivering more structured home visits would add value to their overall care. However, on this topic, a few patients and family caregivers put forward some reservations. These were around the suitability of services a community pharmacist would be offering them. But they were happy as long as the addition of a community pharmacist into the home visit team did not take anything away from what was being offered to them, i.e., their current ability to request a visit from a GP or nurse. So, not looking to pharmacy input as a substitute but rather as an addition to current care arrangements.

GPs and nurses also acknowledged the importance of visiting a patient in their own care setting. They thought of it as a vital element in an effective community palliative care plan. However, with the increasing demand, most GPs and nurses expressed difficulties in fulfilling such duties. Consequently, they supported the idea of including community pharmacists in providing such services. They listed specific tasks which community pharmacists could perform during a home visit. One nurse provided an example where she reviewed patient medication adherence during her home visits and felt that such tasks could be more effectively taken on by a community pharmacist. As per views presented by most GPs and nurses, community pharmacy inclusion of in-home visits would greatly help them in managing their own administrative workload.

> *…frequent home visits are required for palliative patients… as you know it is very difficult for them to be visiting us in the surgery. That puts a lot of pressure in term of scheduling your day. It would be nice to see if someone can help us in this area. I think it will be even greater if they [pharmacists] can do home visits. I think that would definitely ease some of the pressure surgeries are facing.*
>
> *(GP-03)*

> *I think there is a role for them to be going into reviews and supporting medications at home.*
>
> *(Nurse-04)*

> *I think they can visit patient and do medication reviews at home. Because you get a more realistic picture of what they are like at home. If they're getting any effects from the medication they are more likely to discuss it better at home than at surgery.*
>
> *(GP-05)*

The views presented by community pharmacists were varied and included contrasting expressions to those presented by GPs and nurses. Most community pharmacists expressed concerns about the substantial administrative burden that would be involved if they were to carry out regular home visits. This is also related to the inability of a community pharmacy to remain fully operational in the absence of a responsible pharmacist. The few community pharmacists who welcomed the idea also insisted that any arrangement would require an appropriate reimbursement package. An adequate service payment structure to cover the costs was integral for them to participate in any future palliative care scheme requiring community pharmacists to perform regular home visits.

> *I think doing a home visit would be an important part of getting involved in palliative care. Because a lot of palliative patients are really housebound. But it is very difficult with the current [funding] arrangement.*
>
> *(PHM-04)*

> *Because if pharmacists are out of the pharmacies, somebody else need to be in the pharmacy to run the pharmacy. So it is very important that the funding should be there because to support the whole process.*
>
> *(PHM-09)*

Most community pharmacists thought that they could add value to current palliative care services by visiting patients in their homes. According to them, such future inclusion will help patients and the family caregivers in medicine management, a better understanding of side effects, would provide a chance to better explain the medication regimen, and could engage patients and family caregivers in health discussions.

> *If this is something which is reflected in the funding model and the pharmacist… why not. If a doctor can go… come out of there office… clinics… and nurses can go and come out of their clinics and visit the patients… why not the pharmacists. I will be happy to do that.*
>
> *(PHM-11)*

> *… without a funding model… I mean I can probably what the maximum as a pharmacist we can do… you know we can deliver the medication free of charge but just going to somebody… but first… I am not equipped for something so I need that funding for training and other costs.*
>
> *(PHM-06)*

6.5 Remote consultations

Research participants were also invited to discuss their views on structured remote consultations in any future palliative care plans. Most participants in patients and family caregivers' groups highlighted the importance of having regular interaction with a healthcare professional. During the later interviews, the patients and family caregivers were asked what they thought about such interaction being carried out remotely rather than in face-to-face consultations. A variety of opinions was presented on this subject.

Most patients and family caregivers have experienced having received both a home visit and a telephone consultation with a healthcare professional. When asked about any future palliative care services, they were satisfied to consult a health provider by way of remote consultations as long as they were provided with the assurance of proper care. Additionally, some family caregivers stated their apparent dislike for a call centre approach. They would only welcome such a scheme if delivered by their known and regular healthcare professionals. Some patients were reserved concerning remote consultations and thought that such arrangements could restrict their abilities to discuss their healthcare needs with a healthcare professional. However, they considered teleconsultations valuable as long as the option of a home visit would still be available to them. Most patients and family caregivers were happy to receive any such future remote consultations by pharmacy team members. Some even stated a preference for such conversations to be held with their local community pharmacists as they had built a previous rapport there. They were content for a community pharmacist to act on their part as a local lead for their healthcare needs.

In relation to remote consultations, GPs and nurses engaging in palliative care reported having frequent telephone consultations with patients and family caregivers. Furthermore, they described such consultations to be both planned and on an ad-hoc basis. Some GPs explained their telephone triage service, where they were engaged in conducting telephone consultations with patients or their family caregivers throughout their clinic sessions. The majority of them also supported the idea of community pharmacy inclusion in helping with the triage services. Some GPs considered community pharmacies to be better placed to have regular consultations with patients or their family caregivers. They thought of medication dispensing and delivery times as an opportunity for community pharmacies to conduct some structured telephone consultations.

> *You can explain the rationale behind it as well. I think if a pharmacist can get involved a bit early for medication review at that stage. In the future few weeks or few months down the line, when they are actually on a palliative needs, then once again, when they contact you (pharmacist), so they will have some familiarity. It won't be anything new to the family as well, and that barrier of… you know, sense of un-familiarity won't be there.*
>
> *(GP-02)*

When community pharmacists were asked about remote consultations, most welcomed the idea and described it as a helpful alternative to home visits as they were not required to leave the pharmacy or operate a pharmacy with limited services for a certain amount of time. Some pharmacists provided examples of current operational schemes such as the 'New Medicine Service' where they were contacting patients remotely. They voiced that such services could easily be expanded into the domains of palliative care. One pharmacist explained that palliative patients would generally get their medicines delivered and therefore were missing necessary counselling by the pharmacy team for safe and effective use of medicines. According to her, structured telephone consultations would be a valuable alternative for such patient groups.

> *I think if you [community pharmacist] get involved early than obviously it would be much easier for everybody. I think we are already doing the reviews for medications, so definitely with the palliative care as well… there is plenty of scope.*
>
> *(PHM-03)*

> *Obviously like counselling the patient or the carer is a big thing. Specially like understanding their distress level as well. Community pharmacist can advise them about the clinical aspects or any interactions or at least like make them aware that there is a lot of support for the patient and carer available at the pharmacy as well.*
>
> *(PHM-11)*

6.6 Community Pharmacy as care coordination centres

During the earlier stages of the research, the proposition emerged that community pharmacies could be developed as an essential information hub in any future palliative care services. These ideas were subsequently discussed in a later interview. This idea centred on the majority of care needs for patients and family caregivers receiving palliative care being managed in a community setting and coordinated by a central hub which was the community pharmacy. A wide variety of opinions were received, ranging from supportive to sceptical.

From a lay perspective, the majority of patients and family caregivers were not concerned about who coordinated their care as long as adequate care levels for their chosen care pathway were available to them at all times. For most of them, community pharmacy would be a useful central position as they were already familiar with the community pharmacy staff. However, some of them were sceptical about the ability of community pharmacies to coordinate such a care package. The patients and family caregivers with this opinion perceived community pharmacy as a custodian over medicines and were considered the only suppliers. Moreover, they would describe their GP surgery as a health hub or when more chronic illness is present.

The few GPs who commented on this topic were happy to have greater contributions from the community pharmacy team but stated their reservations about arrangements where the community pharmacy would take the role of the central figure. One GP discussed professional hierarchy and explained that the responsibility for the care of patients rested with him, and he wanted to be ultimately responsible for any care received by his patients.

> *I think the one thing which is lacking in there… in community palliative care team is pharmacist. I don't know if it is in certain areas of the country where pharmacists are actually the part of palliative care team. I am personally not aware of it. I think that is one thing which is really lacking.*
>
> *(GP-01)*

Another GP commented on the substantial administrative changes necessary for such a plan to work and therefore only suggested a collaborative role for community pharmacy.

> *I personally think role of pharmacist would be really good for the patients, for the families, as well as for the clinicians, doctors and nurses as well. I think a good contact in the middle that would be really good.*
>
> *(GP-03)*

On the other hand, nurses were not concerned about who is ultimately responsible and for care coordination if it was performed in an effective manner.

> *I am sure putting in some extra funds and as you said pharmacists… Involving some sort of thinking a bit out of box and involving other HCPs more will definitely help improve the services. (Nurse-02)*

Community pharmacists presented mixed views on this topic. While some of them welcomed such an initiative, most community pharmacists perceived that such a move would lead to a huge administrative burden for them at a time when they were already struggling with decreased reimbursement packages from the NHS. Most community pharmacists expressed limited desires for any further administrative roles. Some stated the barriers involved in engaging with GPs within such a scheme. They provided examples of having little collaborative work in the past with their local GPs and did not perceive other healthcare professionals, namely general practitioners in the community and hospital consultants, would like the idea of community pharmacy holding the central hub position.

> *it all depends on the funding as well. because any extra resources with like all the funding cuts and everything. We are already like on a very tight budget. So, if NHS wants pharmacy to do more they have to bring in some sort of model.*
>
> *(PHM-05)*

> *I think so obviously with the evolving roles if we are willing to get involved in palliative care, I am sure that can be quite useful.*
>
> *(PHM-10)*

Community pharmacists supported extending their participation in a collaborative capacity. At the same time, two community pharmacy superintendents thought of experimenting with such an idea further. They provided examples of previously successful community pharmacy initiatives, like national flu jab schemes. They stated the current evolving nature of community pharmacy business models could benefit from further participation in different schemes. But they mentioned a need for adequate service specifications and reimbursements packages.

> *… unless it is a contractual requirement, any other additional service we would not be able to offer [without funding].*
>
> *(PHM-13)*

This concluding finding chapter provided the analysis of field and interview data from lay and professional participants concerning potential routes to expand palliative care services from community pharmacies. The next chapter will provide discussion and evaluate the emergent themes in these finding chapters against current evidence.

Chapter Seven

DISCUSSION

This in-depth qualitative study extends our current understanding of palliative care services delivered by UK community pharmacies. The data draw upon lay and professional views and seek to uncover areas where the community pharmacy's roles and services could be expanded. This chapter will initially summarise the key findings and then discuss these in light of the broader literature. The discussion is grouped into three overarching themes: the fundamental role of community pharmacists, the potential routes for extending community pharmacy services in palliative care, and the community pharmacist's role specialisation. This will be followed by discussing the salient implications, the research strengths and limitations, and future research avenues.

7.1 Summary of findings

The study revealed that the timely supply of medicines in the community is a key concern associated with adequate palliative care and community pharmacies' involvement in palliative care services. Many patients and family caregivers pointed to the unnecessary extra burden of care they faced when struggling to source medicines. Similarly, community pharmacists considered the timely supply of medicines as their primary and crucial role in community health care, so their participation in community palliative care services focused on medicine sourcing and supply roles.

Most patients and family caregivers had limited knowledge of health care and social support packages available in the early phases of their palliative care journey. Subsequently, their expectations were found to consist of receiving satisfactory care towards the end-of-life stage. However, patients and family caregivers valued their interactions with healthcare professionals and found these meetings helpful in improving their understanding of the early initiation of palliative care plans.

There was a lack of coordination of care between community care providers. Variations in patients' and family caregivers' interactions with health care providers resulted in different experiences. They had faced difficulties around continuity and adequacy of care packages when a change in care setting was necessary. Consequently, some were sceptical when choosing or moving to a home care setting for palliative care. Such situations often created challenging environments for the family caregivers when they were suddenly tasked with essential healthcare duties with little to no prior knowledge, experience, or training on medicines management (e.g., sourcing medicines and their safe storage, administration of controlled drugs).

Similarly, there was no established communication pathway between community pharmacists, GPs, and nurses. As a result, most participants considered community pharmacists to have limited involvement in palliative care. Conversely, GPs and nurses were reported as the leading community healthcare professionals engaged in palliative care provisions.

7.2 Community pharmacy and challenges faced by community-based palliative care services

Several studies have described areas where palliative patients and family caregivers struggle to cope with the increasing demands of the care regimens (Dew et al., 2014, Sheehy-Skeffington et al., 2014, Ullgren et al., 2018). Palliative patients and their family caregivers are often faced with many challenges ranging from the sudden increase in care burden to taking on many nursing tasks without any prior training and regular support (Given and Reinhard, 2017). Many of these challenges are described in related studies, and overall, managing serious illness at home is considered difficult at best (Reinhard and Choula, 2012, Rosenberg et al., 2018, Ullgren et al., 2018). The current study expanded on these difficulties and explored them in the context of the community pharmacists' involvement. It is felt that there are many avenues where structured integration of community pharmacy can be beneficial. Lay and professional participants highlighted medicine management as an area of concern, which is also widely reported elsewhere (Latif et al., 2021b, Wilson et al., 2018). These range from managing complex medicine regimens often common in palliative care, understanding frequent changes in medicines, management of side effects, dose adjustments for optimum pain relief, etc. The same was established in this study, and the current project further explored the role of the community pharmacy sector in easing these burdens.

Even where pharmacists expressed openness to greater involvement, palliative patients and family caregivers did not readily consider community pharmacy as a care site for holistic palliative care services. Patients and family caregivers associated community pharmacies' role limited only their medicine supply needs. While they appreciated the work community pharmacies carry out to ensure a timely supply of medicines, they were very reserved in associating community pharmacies for their additional medicine-related needs, e.g., dosage queries, side effects management, and optimum dosage for pain relief. Patients and family caregivers perceived that community pharmacists' role stopped after the supply of medicines, and there was limited involvement in further palliative care services. This absence of community pharmacists in home-based palliative care programs has also been reported elsewhere (O'Connor et al., 2011b, Ogi et al., 2021). Likewise, community pharmacists considered their roles in fulfilling medicine-related needs as their primary area of expertise. However, it can be argued that such expertise was not translating into practice beyond medicine supply roles for patients receiving palliative care or their family caregivers.

Although the timely supply of medicines is a vital duty of its own accord, the medicine management needs of patients receiving palliative care or their family caregivers go further than the supply of medicines. The absence of community pharmacies in these roles in home-based palliative care could be because these roles were not perceived as part of services that could be accessed through community pharmacies. The "local chemist" was considered a medicine expert and an easily accessible health professional in the community (Todd et al., 2015, Eades et al., 2011). However, this accessible site is not perceived for the expertise it can offer in addition to medicine supply roles by patients or their family caregivers (Eades et al., 2011, Anderson et al., 2004). This creates a scenario where healthcare expertise was present in the community to cater to the unmet medicine management needs in the palliative care spectrum but was not developed as a detailed structured service. It can be argued that the reasons for this limited involvement by community pharmacies in palliative services are the bonded perceptions among patients and family caregivers.

The following sections will discuss the three overarching themes that emerged from the findings. These include a fundamental role associated with community pharmacists, Potential routes for extending community pharmacy services in palliative care, and community pharmacist's role specialisation.

7.3 Fundamental role associated with community pharmacists

The first theme details what lay and other health care professionals perceive as a fundamental role associated with community pharmacists. This centres around community pharmacists' obligations towards the timely supply of medicines. Health professionals and the general population recognise this fundamental medicine supply role, but patients and family caregivers perceived that community pharmacies were not always successful in fulfilling their medicine supply needs. It can be argued that there is scope for community pharmacists to strengthen their medicine supply role further. However, this would require assistance from other healthcare professionals, a better supply chain, and improved access to medical records.

7.3.1 Medicine supply role of community pharmacists

Community pharmacists associated their involvement in palliative care with dispensing medicines usually required for end-of-life care arrangements. For some community pharmacists, presenting a prescription for these medicines is the first time they would notice a person is on palliative care. However, the medicine management needs of a patient receiving palliative care start much earlier. This limited involvement of community pharmacists can be argued to stem from their current routine engagement, predominantly reserved for the medicine supply role (Saramunee et al., 2014). Such engagements may seem limited but are vital for satisfactory delivery of community palliative care as patients, and family caregivers expressed their nervousness originating from medicine supply uncertainties. Many previous studies have detailed the distress caused to community palliative patients or their family caregivers when sourcing medicines (Joyce et al., 2014, Payne et al., 2014, Miller et al., 2019). As a result, schemes have been devised to eliminate or reduce such burden on palliative patients or their family caregivers, and one widely adopted scheme is the "just in case" box (Bowers et al., 2019a, Amass and Allen, 2005). The "Just-in-case" box scheme facilitates medicine supply only concerning anticipatory medicines, but the access problems relate to ongoing prescriptions of medicines during a more extended period along with progressive palliative care phases. In another palliative care scheme, community pharmacies are incentivised to stock-specific medicines at all times. The scheme is locally commissioned as an enhanced service and is called the "NHS Community Pharmacy Palliative Care Drugs Stockist Scheme" (NHS England and NHS Improvement, 2020). Although the scheme is locally funded, it is widely adopted across many regions of England.

The scheme aims to address the problems arising from the non-availability of medicines required in terminal illness but not commonly prescribed and therefore readily stocked by community pharmacies. Under the service specifications, the participating pharmacies receive £262.66 annually and are required to maintain specified stock of palliative care drugs included in the "palliative care drugs stockist scheme formulary". Additionally, if needed, the pharmacist would advise the health care professionals regarding the prescribing or dosage of palliative care drugs that should be administered. They would also provide information and advice on palliative care medicines to patients and caregivers (NHS England and NHS Improvement, 2020). To facilitate access, the pharmacies involved are geographically evenly distributed, and the list of participating pharmacies is then disseminated to community palliative care teams. The idea is to reduce the time required to source certain medicines specific to palliative care needs as some of these medicines are not otherwise prescribed and therefore not commonly stocked by all community pharmacies.

Among study participants, few community pharmacists had the experience of participation in this scheme. Although they acknowledged the extra funding payment their pharmacies received, they were overall dissatisfied with the amount. These schemes are currently not available nationally. However, their usefulness for service users cannot be ignored in areas where they are commissioned. It can be argued that these schemes had limited scope and that the community pharmacists ʼrole could be expanded further. A discussion of the areas where pharmacists could be deployed more readily is presented below.

7.3.2 Medicine sourcing and supply as a professional identity.

The study's findings reinforced a strong perception among patients and family caregivers of associating community pharmacy with their medicine supply-related needs. From the service user's perspective, a community pharmacy is a place and establishment responsible for any of their medicine concerns. These perceptions reflect the historic professional position held by the community pharmacy sector as primarily a medicine supply profession (Latif et al., 2018, Mossialos et al., 2015b).

Patients and family caregivers appreciated the usefulness of the current dispensing services. However, the current arrangements can fail at times of most significant need. Moreover, no one is accountable in such circumstances because of a lack of service specifications. Whereas from the patients' and family caregivers' perspective, the task of sourcing a medicine must not be passed on to them when a community pharmacy cannot dispense a particular prescription. This finding supports the work of Wilson and colleagues, who reported that patients and family caregivers assume a significant extra physical and emotional workload in their medicines management (Wilson et al., 2018).

It appeared that the decision to stockpile or only obtain supplies when needed was dependent upon the experience of how effective and efficient the pharmacy had been at dispensing medicines on time. Those with poorer experience, who were more frequently told their medicines were unavailable or ‘out of stock’ and had been referred elsewhere, were more likely to order prescriptions early and stockpile (Pollock et al., 2021).

In light of the medicine management challenges faced by patients receiving palliative care and their family caregivers (Langstrup, 2013, McCoy, 2009, McDonald et al., 2016a), the community pharmacy could play a much more significant role in overall support for medicine management initiatives throughout the illness trajectory of a serious and life-limiting illness (Latif et al., 2020b). This compared with study findings where community pharmacists described their willingness to extend their current contributions in palliative care provided the contractual and financial issues could be addressed. Similarly, upon reflection, pharmacists also emphasised that their existing services could be improved further by formalising the community pharmacists ʾroles in areas like dispensing aids, monitored dosage systems, information to patients and family caregivers, safe handling of controlled drugs, improved symptom management, review of medicines, etc. They believed that most community pharmacies were delivering different services associated with palliative care, but this was carried out on an ad-hoc basis. In line with others who have researched community pharmacy’s role in palliative care (Tait et al., 2020, Akram et al., 2012a, Wilson, 2021), a national palliative care service framework could improve patients' and family caregivers' access to medicine management services from their local pharmacies.

7.3.3 Community Pharmacy's limited involvement

Pharmacists generally had a limited understanding of the principles behind holistic palliative care. This mainly was reasoned due to the absence of such schemes and restricted involvement in community palliative care initiatives. The current study identified community pharmacists to be least informed about initiating a palliative care plan for any patient with family caregivers as their common source of information in this regard. It can be argued that the absence of any structured involvement of community pharmacists and delayed information potentially restricted their participation in palliative care plans. On the other hand, it can be argued that with the right incentives and circumstances, the community pharmacist could contribute further to ease the extra burden patients face during this challenging period. As others have also suggested (Hussainy et al., 2011a, Tait and Swetenham, 2014), this is one important area where pharmacists have enormous potential to increase their current contributions.

For example, two scoping reviews (Jordan et al., 2021, Mishriky et al., 2019) evaluated medicine management initiatives for patients with chronic pain. It was found that pharmacist's intervention decreased polypharmacy, improved symptom control, and improved adherence. Similarly, patients receiving palliative and end-of-life care could be better integrated with community pharmacists' direct input. However, in another review (Ogi et al., 2021) of access to palliative care medicines in the community, the community pharmacies were associated with access delays. This was primarily due to a lack of availability of medicine stock and communication difficulties between the pharmacy and other healthcare professionals (Ogi et al., 2021).

Alongside being willing to undertake role extensions, community pharmacists also had some reservations. Community pharmacists were reserved about potential roles in administering medicines and setting up syringe drivers during end-of-life care. Besides an increased focus on holistic palliative care among GPs and nurses, it was felt that community pharmacists associate palliative care only with the last days of end-of-life care.

This narrow focus limits their perceptions about role expansions. However, there has been some effort to enhance training in this area.

Latif et al. 2020 (Latif et al., 2020b) provide helpful guidelines and prompts for community pharmacists to look for unmet medicine management needs and better support patients receiving palliative care at home and their family caregivers. In addition, they encourage community pharmacists to actively look for medicine optimisation opportunities and how these can be applied in practice for patients receiving home-based palliative care from their family caregivers. The article outlines valuable insights; however, more work is needed.

Furthermore, community nurses had reservations about community pharmacists' role in medicine administration. From the study, nurses and pharmacists perceived that community pharmacists were not adequately equipped, experienced, or trained to carry out medicine administration duties or set up syringe drivers. Although the administration of anticipatory medicines is facing workforce challenges (Buchan et al., 2019) and often family caregivers have to take on extra responsibility during this challenging time (Lee et al., 2016, Rosenberg et al., 2015), it can be argued that community pharmacists are not at present considering such role extensions into the administration of injectables. However, community pharmacists could assist family caregivers trained to give injections, set up, and manage syringe drivers.

7.3.4 Challenges around the supply of anticipatory medicines

The study found a perception among patients and family caregivers concerning frequent changes in medication regimens after referral for palliative care. Potent controlled drugs, e.g., opioid pain killers, are often necessary and introduced during the progressive palliative phases by GPs (Bowers et al., 2020, Latter et al., 2020, Lucey et al., 2008). However, the study suggested that little information was relayed to patients or family caregivers at the onset of supportive care. Further, anticipatory medicines are meant to be prescribed well ahead of their intended use time, and the essential advice does not usually accompany prescriptions for these medicines. Community pharmacists could have a valuable role in advising patients and their family caregivers about the nature and purpose of anticipatory medicines once they have been prescribed.

Most of these anticipatory medicines are covered under the legal framework for controlled drugs and have a specific prescription, dispensing, delivery, storage, and disposal requirements (Bowers et al., 2019b, Faull et al., 2012). As these are legal requirements that pharmacists must adhere to, this sometimes causes delays in the supply of medicines to the patients or family caregivers. Patients and family caregivers are usually unaware of legal boundaries around the supply of medicines. Such perception could easily lead to expectations that there would be no difficulties in sourcing any of their essential medicines when the need arises. This includes potent opioid pain killers and anticipatory medicines for end-of-life care. Community pharmacists could play a broader role even within their current setup. This could involve having regular consultations, including remote consultations, with patients, their family caregivers, and their GP. The pharmacist can arrange such prescriptions when a GP prescribes anticipatory medicines and verify against legal compliance. Also, the pharmacist can pre-emptively arrange prescriptions for regular pain killers before the supply runs out. Scenarios where a patient had to take more than the prescribed amount and ran out of supply earlier presents pharmacist with an opportunity for medicine optimisation.

7.3.5 A role beyond participation in the ‘just in case ’box scheme

The ‘just in case ’box scheme helps facilitate medication supplies of anticipatory medicines. Similarly, local palliative care stock schemes also focus on the availability of anticipatory end-of-life medicines. Although in the present study, patients and family caregivers stressed the importance of having an adequate supply of medicines at home, it must be acknowledged that their medicine supply needs are not limited to end-of-life care anticipatory medicines. Continuous availability of supportive medicines initiated at the start of the palliative care plan is equally essential. Some patients and family caregivers also start stockpiling medicines after an unpleasant experience with medicine supply. They could frequently have occasions where they had to chase their medicines repeatedly. In a research report, Pollock and colleagues (Pollock et al., 2021) detail accounts from patients and family caregivers about the challenges they often face in obtaining medicines and the associated distress in this process.

Family caregivers explained that any difficulty in sourcing medicines during an already stressful phase of end-of-life care would undermine their confidence in home-based palliative care. Moreover, it should be noted that the palliative care support measures should start with the diagnosis of a life-limiting illness well before the terminal stage (Murray et al., 2017a) and continue after death for bereaved family caregivers (Murray et al., 2005b). Patients and family caregivers require extra support throughout the progressive palliative care phases and after death (Aoun et al., 2017), e.g., disposal of medicines. The distress caused by an inability to secure a timely supply of essential medicines is not limited to end-of-life care but is spanned throughout the palliative care trajectory (Wilson et al., 2021, Latif et al., 2021a). Therefore, medicine management initiatives by community pharmacies should be actively promoted to palliative care service users early in their palliative care journey.

There are locally funded schemes incentivising community pharmacies to keep a running stock of specified anticipatory medicines (NHS England and NHS Improvement, 2020). However, it was found in the current study that based on local needs, some pharmacies were taking all measures to stock anticipatory medicines without any extra reimbursement arrangements. Considering these ad-hoc stock arrangements, the community pharmacies with extra policy support and recognition could play a broader involvement in the availability of anticipatory prescribing within their current setup.

The study findings suggest that if local needs are consistent, some pharmacy owners are content to stock palliative care medicines and would take extra measures always to keep a running stock without any extra funding. Nevertheless, such practices are not universal across all community pharmacies. Further, measures to keep a running stock without formal participation do not give patients or family caregivers a sense of entitlement. This means an unnecessary delay in medicine supply can still happen, as illustrated in current study findings and reported in a recent broader managing medicine study by Pollock and colleagues (Pollock et al., 2021), in which family caregivers often feel distressed and anxious when asked to source medicine supplies themselves.

This issue of ad-hoc arrangements is reported in other areas of pharmacy practice. For example, Aziz and colleagues (Abdul Aziz et al., 2021) investigated the provision of unfunded pharmacy services in community pharmacies. They found that pharmacists offered many professional services without remuneration and that these services make up a substantial part of the pharmacist's time. Therefore, it can be argued that formal recognition of these currently voluntary stocking tasks is essential. This would help towards broader uptake of this practice across the community pharmacy sector. A national rollover can be incentivised by offering an extra dispensing fee for certain medicines commonly used in anticipatory medication. Pharmacists are already offered extra funding for dispensing controlled drugs or providing supervised methadone dispensing services (Pharmaceutical Services Negotiating Committee, 2021). A similar structure can accommodate extra resources required to source and always make palliative medicines available.

7.4 Potential routes for extending community pharmacy services in palliative care

The second theme considers the potential routes for extending community pharmacy services in palliative care. It will examine how the community pharmacy sector can expand its current palliative care contributions.

7.4.1 Limited understanding among patients and family caregivers of holistic palliative care

A robust emerging theme throughout the study was an apparent lack of acknowledgement, understanding or comprehension of holistic palliative care by patients, their family caregivers, and community pharmacists. Good palliative care should consistently incorporate social, psychological, and spiritual aspects of life and physical and medical wellbeing (Rego et al., 2018, Murray et al., 2007). National Institute for Health and Care Excellence (NICE) prioritises holistic palliative care (NICE, 2015a). However, it is widely reported that a palliative patient's needs are not solely centred around medical wellbeing, and other aspects of life, e.g., spiritual, are believed to be equally important (Grant et al., 2004) and considered to contribute to overall satisfaction with care and quality of life (Naoki et al., 2018, Ullrich et al., 2017). Besides this widely reported link between the fulfilment of non-medical needs with overall well-being during palliative care, in the current study, patients and family caregivers made limited contributions while discussing their general well-being. This approach could result from a lack of comprehension, knowledge, and understanding of all aspects of palliative care (Lin et al., 2019, Ranallo, 2017).

Holistic palliative care must encompass psychological, spiritual, and sociocultural domains and physical needs (Murray et al., 2005b). Importantly, non-physical care needs can be crucial in dictating patients 'or their family caregivers 'choices about palliative and end-of-life care arrangements (Mason et al., 2020). For example, the emotional distress family caregivers experience while undertaking demanding tasks of managing medicines during end-of-life care (Pound et al., 2005a). It is important to acknowledge their role, and there is a need for greater professional support.

7.4.2 Improved health literacy through better engagement with community pharmacists

Health literacy relates to a person's ability to understand and use the information to make informed, appropriate, and beneficial decisions about their health (Liu et al., 2020). Increased health literacy is often associated with a better understanding of underlying disease and treatment plans (McFadden et al., 2018), and concerning palliative care, most people have limited prior knowledge (Hassankhani et al., 2020). However, they can be upskilled by the increased community involvement of health care teams. All palliative care patients and their family caregivers regularly interacted with their local community pharmacist. However, these interactions were mostly for needs other than those associated with palliative care. There is tentative evidence to suggest that patients and family caregivers understanding of palliative care can be improved by better engagement of community pharmacy resulting in better management of medicines (Tait et al., 2020, Akram et al., 2017a). Information about palliative care could be added to the list of health promotion initiatives delivered by community pharmacies, e.g., weight loss, smoking cessation, and travel advice. Like other health promotion initiatives, a weeklong health campaign can be reserved to improve general awareness about palliative care in the community.

Presently, many campaigns discuss and advertise “good dying”, and although death is inevitable, the process is undeniably difficult, stressful, and challenging for most (Pollock and Seymour, 2018, Cox et al., 2013). Community pharmacy involvement may help improve public understanding of palliative care expectations without trivialising them. Improved health literacy was associated with a better understanding and acceptance of supportive and palliative care (Lloyd et al., 2016). Further, limited engagements between patients and healthcare professionals could lead to frustration and an unpleasant experience of care services (Caswell et al., 2015). The current study highlighted the challenges associated with progressive palliative care phases, and as reported elsewhere

(Archer et al., 2017), little support is available to understand the complexities of palliative care. Pharmacists were traditionally absent in this advisory role (O’Connor et al., 2011, Savage et al., 2013b), but their successful involvement in such roles has been demonstrated by recent McMillan pharmacist projects (Macmillan Cancer, 2012, McCusker, 2016a, Macmillan Cancer, 2016). Pharmacists effectively collaborated with other palliative care teams in training and educational roles in these projects. Pharmacist integration in these roles was well received and widely acknowledged, especially in rural settings where timely access to trained health care professionals was limited (Akram et al., 2017a, Akram et al., 2012a, Latif et al., 2021b).

7.4.3 Patients' and family caregivers' reservations towards initiation of palliative care

The current study findings also established the fear and avoidance among patients and family caregivers towards accepting palliative care. This would lead to a delay in engaging with the palliative team resulting in later initiation of palliative care, especially in chronic illnesses where physical decline is gradual (Tavares et al., 2020). There is understandable reluctance to accept and difficulty coming to terms with dying. Also, limited understanding of patients and family caregivers contributes to the delayed start of essential supportive care. Further, early initiation of palliative care is often not adequately handled, and its importance is not sufficiently conveyed to the service recipients (Tjia et al., 2015, Oliver et al., 2013). When patients and family caregivers recognise the future challenges, they are more likely to look for external help and support beforehand (Greer et al., 2018). Such initiative-taking measures contribute towards better management of care burden for both patients and family caregivers. It could be considered that community pharmacies can act as dissemination sites for explaining different aspects of the palliative care to patients and family caregivers.

7.4.4 Community pharmacy as a site for palliative care promotion and education

The study findings reaffirmed the need to improve the health literacy of patients and family caregivers to improve understanding, acceptability, and adherence to palliative care (Roodbeen et al., 2020, Collins et al., 2020). Similarly, improved health literacy could alleviate disparities in palliative care accessibility (Nelson et al., 2021, Crossan, 2021). While GPs and nurses were well versed in their understanding of palliative care, pharmacists showed limited knowledge of palliative care trajectories and associated holistic approaches. Community pharmacists are often identified as the most accessible health professionals in the community (Todd et al., 2015, Anderson and Thornley, 2014). Furthermore, patients and family caregivers value more than the basic level of service from the pharmacy and appreciate the pharmacy staff for support with medicine and symptom management (Lindsey et al., 2017, Steed et al., 2019). However, in the current study findings, community pharmacists 'understanding of palliative care was limited. This correlates with other studies identifying a reserved role by community pharmacists in palliative care services (Miller, 2019, O'Connor et al., 2011b). Therefore, it is imperative that adequate training and upskilling of pharmacists is planned before community pharmacies can be used as educational hubs for palliative patients and their family caregivers. Community pharmacies can be the primary contact for information on medicine management concerns and, in addition, can also signpost to other community palliative care services. A recent publication in "the pharmaceutical journal" (Latif et al., 2020b) has highlighted the importance of integrating community pharmacists in palliative care services and the need for extra training in this area.

There is little evidence to suggest that there has been a concerted effort to use community pharmacies as places to improve palliative care health literacy. However, many public health campaigns have recently been successfully delivered through extended community pharmacy services. These include weight management, smoking cessation, alcohol reduction (Brown et al., 2016), and flu vaccination (Kirkdale et al., 2017). The involvement of community pharmacies in such schemes was both effective and practical. There are 11,699 community pharmacies operating in England, providing NHS services to around 1.6 million people a day and in 2020/21 dispensed over 1 billion prescriptions in England (NHS Business Services Authority, 2021c). Around 90% of the population have access within a 20-minute walk from home, approaching 100% in areas of highest deprivation, suggesting a ‘positive ’rather than inverse care law (Todd et al., 2014). Also important is the prompt availability of healthcare counter staff who could offer health promotion and advice on managing minor ailments.

Building on the ease of access and professional expertise, community pharmacists could have the potential to play more active roles in palliative care. These can include explaining health information relating to progressive palliative care phases, medicine management problems, side effects anticipation and management, safe storage and disposal of medicines, etc.

7.4.5 Extension of ‘just in case ’box scheme involving greater use of community pharmacy

The current community pharmacists’ involvement in the supply of anticipatory medicines, including the "just in case" box scheme (Bowers et al., 2019a), can be argued as limited, ad-hoc and passive as such schemes were engaging community pharmacists as supply and hand-over assistants and thus not utilising their full potential. A useful expansion on current arrangements could be to keep an assigned prescription in a pharmacy rather than a patient’s home and when required, can be delivered in a timely manner. Another option, pointed out in the current study by a pharmacist, suggests that the healthcare professional, usually a community nurse tasked with administering anticipatory medicines, could collect such medicines from a local chemist when visiting a patient’s home. Such arrangements could give family caregivers another chance to consult a healthcare professional.

This facility of extra interaction could provide a necessary reassurance to family caregivers that they are not left alone in the community during this challenging time. The importance of opportunities to consult a healthcare professional has also been highlighted elsewhere (Aghaei et al., 2020, Brighton and Bristowe, 2016). Furthermore, there would be fewer concerns around safe storage and disposal of unused returns. On this subject, some other pharmacists suggested better utilising the prescribing skill of independent pharmacist prescribers working in community pharmacies. They believed such involvement could reduce the time required to obtain a legal prescription from a GP surgery or nurse prescriber. In addition, such role extension would be even more beneficial during out-of-hours care. However, non-medical prescribing is still a developing area for community pharmacists. Further, currently qualified independent prescribers have undertaken limited prescribing duties. (Robinson, 2018, Ziegler et al., 2017). Nevertheless, it can be argued that the limited participation by community pharmacists in prescribing duties could be related to the currently limited opportunities for such role extensions.

In the current study GPs positively appraised the idea of designating anticipatory prescribing duties to community pharmacists. They considered that if future service specifications permit, it would be beneficial for the patients and their families to reduce the number of trips they have to make to GP surgeries or pharmacies. However, such role enhancements of community pharmacies require further exploration to avoid professional conflicts with GPs or nurses.

7.4.6 Facilitators for community pharmacy role extension

This section describes the areas that could be considered facilitating factors towards expansion and better engagement of community pharmacies in providing palliative care services.

7.4.6.1 Increased GP workload and a desire for collaborative support

Even before the extra pressures caused by the COVID-19 pandemic, there were growing concerns about the increasing workload on GP practices (Fisher et al., 2017, Hobbs et al., 2016). There are expectations that GPs will assume the extra responsibility for care services as the population ages and more people live longer with chronic illnesses (Bone et al., 2018). Furthermore, there is a constant increase in demand for GP services (Croxson et al., 2017), and they also have to contribute to social care issues alongside daily medical duties actively. Such an environment is overstretching the GP resources, especially in the policy drive to increase capacity in the uptake of community palliative care. The study findings mirror these GP sentiments. This study adds to the literature as it expands on this issue and calls for more collaboration and support from community pharmacists. Similarly, there are areas of palliative care where community pharmacists can take some workload away from GP practices, for example, prescription ordering, dosage queries, side effects management, optimum pain control, and dosage routes.

7.4.6.2 Medicine management needs of patients and family caregivers.

The current study indicates that patients and family caregivers highly rated the medicine management services they received from a community pharmacy. These, among others, included dosage queries, structured medication reviews, administration and dosage aids. This is in line with other reported studies showcasing the usefulness of medicine management initiatives (Pollock et al., 2021). The current study further establishes the extended support for medicine management after the start of palliative care. However, a proportional increase in support is often neglected during this time when frequent medication changes are expected. With the constant physical decline in progressive illness trajectory, most aspects of managing the medicine regimen routine are undertaken primarily by family caregivers. The concerns faced by family caregivers in carrying out medicine administration duties are widely reported (Lau et al., 2010, Duerden et al., 2013), often without any formal support (Joyce et al., 2014, Payne et al., 2014).

Patients and family caregivers should be encouraged to contact their local pharmacy teams if in any doubt regarding medicine management issues. This could range from dose inquiries, palatability, dosage reminders, medication charts, missed dose, management of symptoms, inquiries about side effects, safe disposal, and sourcing of medicines. Better structure and promotion of such services among palliative patients or family caregivers could free up resources at GP practices.

7.4.6.3 Willingness among the community pharmacists for further training

Palliative care often presents complex and worrying care scenarios that could cause significant distress to healthcare professionals (Maffoni et al., 2020, Rego et al., 2020). Before community pharmacists can improve their participation in palliative services, a detailed training and upskilling route would be required. Community pharmacists have routinely been asked to complete training endorsements. Registration authorities also ask the pharmacist to have an up-to-date training portfolio (General Pharmaceutical Council, 2018). Local and nationally commissioned services also require training accreditation, e.g., flu vaccination and healthy living pharmacy. It was found that community pharmacists would readily complete these training initiatives and consider them valuable and part of their practice. It can be argued that, where necessary, the community pharmacists would be willing to take up any structured training courses required for a palliative care service.

Over the years, professional education institutes for pharmacists like the centre for pharmacy postgraduate education (CPPE) have developed many training materials and have recently rolled out its palliative care gateway (CPPE, 2021). Such initiatives could help alleviate some reluctance among community pharmacists when discussing palliative care. Similarly, Latif et al. (2020b) provide useful directions for community pharmacists to consider concerning palliative care provisions of their patients and family caregivers during routine practice.

7.4.6.4 Inclusion of pharmacy support staff in palliative care

Community pharmacists recommended that palliative care training initiatives should not be limited to pharmacists, and community pharmacy support staff should also be included in potential future roles. Pharmacy support staff, i.e., medicine counter assistants, dispensers, and accuracy checking technicians, are pivotal to the efficient delivery of pharmacy services. Saramunee et al. (2014) Identify pharmacy support staff as affecting the public’s overall utilization of a pharmacy. Further, Aly et al. (2020) concur that pharmacy support staff should be part of structured training and assessment process for advanced services.

In the current study, community pharmacists explained that appropriate delegation of tasks to support staff is helpful considering their current workload. For example, a task like coordination with a GP or clerical jobs could be conducted by support staff. Where there were no safety issues, this would allow greater flexibility on the part of community pharmacy teams and, therefore, can lead to the better rollout of services. Considering the pharmacy support staff participation in recent services, e.g., smoking cessation, it is felt that their upskilling required for greater participation in palliative care services can be achieved.

7.4.7 Barriers to community pharmacy role expansions

This section covers topics which could be considered as potential barriers toward expansion and better engagements of community pharmacies in providing palliative care services.

7.4.7.1 The increased workload at community pharmacies

Considering the increasing workload pressures on GP surgeries, it is proposed that community pharmacies could potentially provide shared services for specific tasks currently managed by GPs (Babar et al., 2018). However, there are ever-increasing workload pressures on community pharmacy teams resulting from increased dispensing work and additional services. In addition, there is limited empirical evidence that community pharmacies have unused capacity to take on further roles (Karia et al., 2020) in addition to recent services, e.g., flu vaccinations, PGD supply of medicines, travel advice, smoking cessation, etc. Further, work-related stress has been reported to have a personal impact on pharmacy staff (Yong et al., 2020, Jacobs et al., 2014).

In a systematic review of an extended role for community pharmacists in optimising opioid therapy (Iqbal et al., 2020), the participants in reviewed studies were found to perceive that their participation in opioid optimisation services could lead to an increased workload. Similarly, expanding community pharmacists' role in palliative care could increase their overall workload. However, this should not be considered critical to extended participation in palliative services. Rather, the extra administrative work involved should be recognised in future policy directives and service specifications. Further, some administrative tasks could be delegated to community pharmacy support staff. This could be built on the examples of services like smoking cessation, weight management, and healthy living pharmacy in which pharmacy support staff carry out many face-to-face consultations and administrative duties, thereby not limiting community pharmacist time.

7.4.7.2 Access to up-to-date medical records

The ease and efficiency with which different healthcare professionals can communicate are deemed vital for an effective palliative care system in the community (Pollock et al., 2021). however, pharmacists expressed frustration about not having up-to-date access to palliative patients' records. As a result, they considered themselves the least informed health care professionals regarding any forthcoming changes in a patient's medication regimen. This lack of access to up-to-date information has been considered a limiting factor for effective collaborations and more comprehensive engagements by community pharmacists in medicines management initiatives (Cortis et al., 2013a, Hussainy et al., 2011b).

Community pharmacies in the UK are now provided access to patients' "summary care records", allowing them to check for allergies, currently prescribed medications, and eligibility for a free flu jab (NHS Digital, 2021). This access to summary care has been cited as beneficial and widened the scope of services delivered by community pharmacies (Goundrey-Smith, 2018). Similarly, in a local scheme, "Dorset care records", community pharmacies are provided with access to shared health and social care records for Dorset England (PSNC, 2020). Dorset care records contain information in addition to summary care records which is considered helpful in medicine optimisation consultations, care after discharge from hospital, blood results to assist medicine discussions, support emergency supply options, the rationale behind a new medicine, and provide information if the medicine is changed or stopped (PSNC, 2020).

Building on these initiatives, there is an urgent need to design a national system connecting community pharmacies with the latest information on palliative patients. In addition, community pharmacies should be evaluated for shared access to "Electronic Palliative Care Co-ordination Systems" (EPaCCS) (Public Health England, 2014).

7.4.7.3 Sensitivities around palliative care discussions

Discussing palliative care and end-of-life care preferences is difficult, distressing, and complex. It is common for patients, family caregivers, and healthcare professionals to show reluctance when introducing these topics (Almack et al., 2012). In the current study, pharmacists were cautious when discussing their role extensions involving sensitive, distressing, and challenging discussions with patients receiving palliative care or their family caregivers. Pharmacists identified such roles as challenging and the ones they perceived as not fully prepared. However, Brighton and Bristowe (2016) express that the ability to carry out these discussions should be considered an opportunity to support patients. Further, it is important to timely convey the important details about future challenges (Fallowfield et al., 2002). This perceived barrier among community pharmacists could be alleviated by appropriate training.

7.4.7.4 Competition for a common pool of funding

Pharmacy services competition for resources from the funding pool available from the NHS can be reasoned as another barrier to role expansion. Further, some view it as contributing to professional disharmony (Latif et al., 2013b). Pharmacists considered there could be professional conflicts if community pharmacies start competing for funding presently allocated to GP surgeries or other community palliative care initiatives. Therefore, it is essential to recognise and address any potential overlap of future community pharmacy role extensions into palliative care services with other healthcare providers. The community pharmacy role extensions would require evaluations as an added value service and operational within defined boundaries.

7.4.7.5 Lack of coherence among health care professionals

One prominent finding from the study was related to the level of community pharmacists' interaction with other health care professionals. While most pharmacists described having only limited contact with GPs, their active involvement with community nurses was seen to be even more reserved. Additionally, these interactions were seldom initiated by GPs and were rarely face-to-face. In the study, pharmacists struggled to provide examples of their collaborative engagements with either GPs or nurses.

The wider literature also alludes to the lack of interaction of pharmacists with other healthcare professionals, and GPs rarely contact community pharmacists for advice about medicine choices or prescribing support (Pollock et al., 2021). The most typical queries received by community pharmacists from other healthcare professionals were around the availability of medicines. However, one superintendent pharmacist described having frequent conversations with local GPs and nurses. According to him, these regular contacts were particularly useful in completing tasks on hand, and each community pharmacy should establish active collaborative arrangements with their local GPs and nurses. Similarly, some other pharmacists expressed that the views of other healthcare professionals towards community pharmacy can be expanded. They valued that the personal relationship between a pharmacist and other health care professionals was crucial in raising a community pharmacy profile.

Many community pharmacists routinely requested timely communications from other health care professionals. No universal approach existed, and they explained that early notifications about medication changes were imperative for community pharmacy teams to source medicines in a timely manner. They pushed for some developments in their dispensing system enabling access to any changes made by GPs or other health care staff. Most pharmacists also anticipated that any change enabling a greater role for community pharmacies would be dependent upon greater flexibility on the part of doctors and nurses.

7.5 Community pharmacist's role specialisation

The final theme discusses the unique nature of community pharmacists' roles and the limited opportunities available to community pharmacists to develop their roles further.

7.5.1 Community pharmacy business viability approach

Another striking finding during the study was the emphasis placed by pharmacy owners and superintendent pharmacists on the business viability of their pharmacies. Pharmacy managers and business owners had to make difficult choices when initiating or stopping a service, reinforcing the ‘patients ’as “customers” approach. These services are offered considering customer loyalty and retention but can create an impression that certain services would always be free to access from community pharmacies (Abdul Aziz et al., 2021). Such approaches can extend into anticipatory medicines supply, where pharmacists were content to keep running stock of certain medicines without extra funding due to local demand and associated extra business. However, such an approach carries a severe drawback as there is no associated responsibility and accountability when these extra services are stopped.

The business nature and competitive environment often result in discontinuing previously free services, e.g., blood pressure checks. Whereas many service users then start viewing these services as contractual obligations. This mismatch in understanding can easily lead to confusion when a pharmacy unexpectedly fails to fulfil a patient’s needs. The situation is then complicated further if patients or their family caregivers are asked to take on extra responsibilities at short notice, for example, delivery of medicines. The current study explored these scenarios and considered discussions with both service users and service providers, and identified an urgent need to detail the services available from community pharmacies. The current project established the importance and usefulness of these ad-hoc services. Medicine delivery service is one example where patients felt entitled, but pharmacy contractors were not receiving any extra fee. During the Covid-19 pandemic, many community pharmacy contractors could not continue with the free medicine delivery service leading to distressed patients and family caregivers. The importance of this service was quickly realised nationally, and a service specification was drawn up (NHS Business Services Authority, 2021b). This gave pharmacy contractors an extra fee when carrying out a delivery service.

Potential palliative service extensions for community pharmacies should recognise the current ad-hoc arrangements, e.g., delivery services and consider ways to bring these services under detailed and formal service specifications. This would provide a feeling of entitlement among service users while providing pharmacy contractors with a service framework to follow instead of offering services scheduled around their workload.

7.5.2 Evolution in community pharmacist's role

As stated previously (Lindsey et al., 2017, Todd et al., 2015), community pharmacists in the current study were pleased to recognise themselves as easily and readily accessible health professionals engaged in important patient-centred roles. They also considered community pharmacy settings more visible, open, and approachable than GP surgeries. Some had also spoken about providing more time to patients and their family caregivers than GPs and lending a helping hand in easing current pressures on other health care services in the community. Pharmacists perceived that their contributions in dealing with issues like minor illness queries contribute to freeing up GPs' time which GPs can use to focus on more complex health care issues. Pharmacists expressed a general feeling of changing perceptions about the services offered by community pharmacies. They felt that now many visitors to a community pharmacy do not use it solely as a dispensing hub.

Though community pharmacists are content to develop the services like vaccinations or smoking cessation, they tend not to be so keen on extending their involvement in administration roles for injectable anticipatory medicines. They proposed that community pharmacy could play a much more significant role in overall medicine management initiatives from the start of palliative care and throughout its progressive phases. Community pharmacies currently offer certain services that can be considered to fall under the remit of palliative care needs. These include services like dispensing aids, monitored dosage systems, information to patients and family caregivers, safe handling of control drugs, improved symptom management, disposal of unused medicines, delivery of medicines etc. However, most of these are offered on an ad-hoc basis, and service structure varies among community pharmacy establishments.

GPs preferred for the pharmacist to have greater engagement in palliative care but emphasised that the ultimate responsibility of a patient lies with them, and therefore GP surgeries should remain the central point for delivery of any care packages. This professional territorialism (Dey et al., 2011) is important for future role extensions. GPs suggested a collaborative role for community pharmacists and considered administration duties by the pharmacist will require significant modifications in the current healthcare system. Interestingly, pharmacists expressed limited desire to take up extra administrative roles. Community pharmacists were inclined towards participation in palliative programmes in collaborative capacities.

In a collaborative capacity, a community pharmacist could act as a contact person for patients receiving palliative care or their family caregivers. However, previous services like MUR and NMS were described as causing professional disharmony among some GPs (Latif, 2017). Therefore, potential future collaborative roles between community pharmacists and other healthcare professionals would require detailed exploration.

7.5.3 Non-medical prescribing

“non-medical prescribing” refers to prescribing roles undertaken by allied health care professionals other than doctors, primarily nurses and pharmacists. In the UK, the prescribing route for pharmacists was first announced in 2006 (Cooper et al., 2008). However, this postgraduate qualification had a limited uptake until recently. In the UK, the number of qualified independent pharmacist prescribers has tripled since 2016, increasing from 2,781 registered on 1 May 2016 to 8,806 on 1 May 2020 (Wickware, 2021a). This was accompanied by a five-fold increase in the medicines prescribed by pharmacists outside of hospitals in England from 2016 to 2020 (over 32 million) (Wickware, 2021b). While these figures demonstrate broader participation by pharmacists, the participation by community pharmacists in prescribing roles was limited. Most independent pharmacist prescribers worked for primary care networks, GP practices, or care home pharmacists (Wickware, 2021a).

Pharmacists working in community pharmacies can rarely use their independent prescribing qualifications. This frustration is stated in a recent publication where one community pharmacist expressed that the NHS had never commissioned him to use his prescribing skills besides being qualified for 14 years (Wickware, 2021a). However, community pharmacy role extensions into shared prescribing duties with GPs present an exciting opportunity for this underutilised expertise.

In the current study, GPs were generally keen on designating prescribing duties for anticipatory medicines. With this in view, it can be argued that community pharmacists with independent prescriber qualifications can have extended roles as members of palliative MDTs. Therefore, exploring further role extensions for community pharmacists in anticipatory medicine prescribing and supply is logical.

7.6 IMPLICATIONS

The study findings provide useful insights that expand our understanding of the challenges patients face receiving palliative care and their family caregivers face. In addition, the study explored the contributions made by community pharmacies and investigated the potential areas where these could be expanded. The following section draws on the findings of this study and presents the implications for patients and family caregivers, health professionals, and policymakers.

7.6.1 Implications for patients and family caregivers (service user's groups)

7.6.1.1 Community palliative care 'who is who'

The study findings exposed the difficulties patients and family caregivers face in identifying health care professionals' different roles and responsibilities and the community palliative care team. There was a steep learning process about whom to approach for advice in case of minor or urgent care needs or concerns. This has been shown in other studies, for example, McDonald et al. (2016b) found that family caregivers continuously look for learning sources throughout an illness trajectory and recommended better support for patients and family caregivers for their learning needs. A "who is who" style booklet covering local palliative care services and key contact details of personnel available in a community setting could help people navigate the healthcare system more effectively.

7.6.1.2 Medicine management challenges and community pharmacies

The study explored the medicine management challenges faced by patients receiving home-based palliative care and their family caregivers. Often this patient group do not consider community pharmacy as a source of help for their unmet medicine related needs. However, community pharmacy teams could offer consistent, necessary, and easily accessible advice on medicine management concerns. Macmillan community pharmacist project (Akram et al., 2017a, McCusker, 2016a) involved increased involvement of community pharmacists in collaborative roles to advise patients and other healthcare professionals. Considering the many challenges patients receiving palliative care at home and their family caregivers face in managing their medicines regimens, there must be greater awareness of the pharmacist's role so people can better engage with these professionals to seek the much-needed support in times of need.

7.6.2 Implications for healthcare professionals

7.6.2.1 Improved medicine supply role for community pharmacies

Community pharmacists have taken up new roles, particularly since 2005, where Advanced services were introduced. However, their fundamental role remains centred around sourcing and the timely supply of medicines. Community pharmacists are contractually bound to make reasonable efforts to source and supply prescription medicines. However, it is felt that community pharmacies could do more to stock essential medicines often required for palliative and end-of-life care delivery. Difficulties or unnecessary delays in accessing medicines during palliative care have long been cited as a cause of distress for patients and family caregivers (Payne et al., 2014, Lucey et al., 2008) and recently (Sluggett et al., 2018, Wilson et al., 2021). Community pharmacies should consider stocking these medicines on a routine basis even when not associated with extra funding arrangements. Some pharmacies already undertake such measures considering their local needs; however, these arrangements should be widely adopted.

Nevertheless, this would require evaluations of extra costs against goodwill gestures and contractual obligations. Further, in addition to stocking issues, Pollock et al. (2021) report that lack of communication and timely information exchange between healthcare professionals often results in delayed access to medicines. Therefore, it would be helpful if future service specifications look at ways to improve communication between community pharmacies and other healthcare providers.

7.6.2.2 Local social platforms to increase awareness of community pharmacy palliative care services.

The study findings highlight the importance of end-of-life care within community palliative care services. This leads to the earlier and progressive phases of a life-limiting illness trajectory (Murray et al., 2005b, Boyd et al., 2019) being overlooked. Community pharmacies can significantly improve awareness about delivering holistic palliative care, which can be initiated from diagnosis. Currently, there are limited professional discussions or health promotion activities about this. Nevertheless, there is a scope for greater community pharmacists' participation to improve early engagement and outreach to enhance the care from current palliative care services.

Delivering palliative care is a sensitive topic. To build professional confidence and competence, community pharmacists could be encouraged to participate in local health club meetings about the scope, usefulness, and availability of palliative care and what community pharmacies could offer. In addition, participation of community pharmacists in local "death café" meetings could be one avenue where pharmacists can seek to better understand lay perspectives and patient priorities. A death café is an event where people drink tea, eat and discuss death and aim to increase awareness of death to help people make informed choices and make the most of their lives (Miles and Corr, 2017, Death Café, 2017).

"Death café" should not be viewed as a place for formal education, and they are not intended for serious discussions. However, community pharmacists can familiarise themselves with such community platforms to increase their awareness. In addition, their informal participation in these gatherings would improve the perception of services offered by a community pharmacy and its accessibility. Finally, as part of their continued professional development (CPD), they could think about how better to accommodate the needs of patients and their family caregivers.

7.6.2.3 Named prescription for anticipatory medicines

To facilitate more timely access to anticipatory medicines, assigned and pre-dispensed prescriptions can be kept in the pharmacy for a specific patient. When needed, these prescriptions could be collected by a family caregiver from a pharmacy or delivered by them at short notice. Such an initiative could improve accessibility to medicines and reduce the administrative burden for patients and the pharmacy team. Furthermore, when prescribed by GPs, anticipatory medicines are prescribed early and stored in patients' houses for an extended time. These are often wasted and can be distressing to some patients and families when disposing of medicines after death (Bowers et al., 2019a, Faull et al., 2012, Wilson et al., 2016). If it is more convenient for the patient, such prescription medicines could be held at the pharmacy. In such scenarios, a community pharmacist could be more integrated with the patient's care and act as a central figure linking prescribers with the patient and their family caregivers. There have been ongoing calls for more joined-up care between care providers (Savage et al., 2013b, Mason et al., 2013). This arrangement could extend to requests for prescriptions when needed so these could be delivered to the patient's home when requested.

7.6.3 Implications for policymakers and administrators

7.6.3.1 Medicines management in the continuity of care

In the UK, palliative and end-of-life care are delivered from four main sites, i.e., Hospitals, hospices, residential care homes, and home care. This requires an efficient collaboration between primary care settings in the community and specialized palliative care centres based in hospitals. It is common for patients receiving palliative care at home to move to a specialist palliative care unit at a hospital and vice versa. The study findings highlighted the challenges of patients and family caregivers during this transfer of care. This poor experience of care and dissatisfaction resulting from delays in communication between healthcare professionals operating at various care sites has also been reported in earlier studies (Parliamentary and Health Service, 2015, Caswell et al., 2015).

Many of these challenges originated from difficulties in medicine management, and the study findings have highlighted unmet needs in this area. However, the current study expanded on these issues and highlighted the potential scope for community pharmacists. Presently community pharmacists are primarily absent from MDT teams responsible for adequate transfer of care and have limited access to medical records (Royal Pharmaceutical Society, 2015). To promote the community pharmacist's role in ensuring adequate supplies of medicines are available, policymakers could review the governance to make the process more efficient. Additionally, policymakers and professional bodies should promote community pharmacists as a 'first point of call' for medicine management related enquires from patients receiving palliative care from their family caregivers.

7.6.3.2 Separate payment tier for palliative medicines

Withing their NHS contractual obligations, community pharmacies receive certain payments as fees for supplying services. These payments are grouped into different tiers depending on the usual work involved in the specific service. One example is dispensing controlled drugs, for which community pharmacies receive extra payments in addition to the usual dispensing fee. Similarly, there are extra fees for supervised methadone dispensing to substance users. All fees paid by pharmacy contractors are laid out in the monthly edition of drug tariff (NHS Business Services Authority, 2021a).

It is worth considering the possibility of creating a section in the drug tariff consisting of medicines commonly used for palliative and end-of-life care. Dispensing these medicines could attract a higher fee because of the extra financial implications, storage costs, and administration work involved. This would provide an incentive across all the national pharmacies to make extra efforts in stocking these medicines. Compared to local palliative medicines stockist schemes, this additional payment tier can be argued to have broader outreach.

7.6.3.3 Information sharing

There have been calls for computer software providers to increase the community pharmacy integrations and access to their systems (Tait and Swetenham, 2014). Community pharmacists have repeatedly expressed their frustration when unable to access up-to-date patient information (Royal Pharmaceutical Society, 2015) and considered a barrier to active and broader participation by pharmacists (Cortis et al., 2013b). However, many software systems are currently in operation at GP surgeries and pharmacies. Within a GP practice, a common channel for communication among practice staff is to generate a task within their IT system. The task would flag the intended recipient’s computer and carry out an audit trail.

A similar link between the GP practice and community pharmacies would help relay information when a person is added to the GP practice palliative register. This would allow more significant interaction and communication between community pharmacists, healthcare professionals, and services. However, there are policy implications as different companies supply the current computer systems. Currently, these are not obligated to develop instant communication links between GP surgeries and community pharmacies. However, given the recent technological advances, it can be argued that such communication links can be established if there is a strong policy directive. Community pharmacists would recognise the patient’s status, respond accordingly, and offer support.

7.6.4 Future research

The current study provides a firm foundation on which future research can be built. For example, future research could investigate the feasibility of extended community pharmacy involvement in palliative care and to what extent this is acceptable to patients or family caregivers. This includes exploring how well community pharmacists can conduct and manage discussions with patients receiving palliative care and their family caregivers about using anticipatory medicines.

Others have argued that community pharmacies should provide better access to care for disadvantaged patient groups, including ethnic minority groups, the homeless, those with serious mental illness, and substance dependents (Latif et al., 2021b). Although the current study did not specifically recruit participants from these groups, it is considered that they require extra support for medicine management challenges during progressive palliative care phases (McNamara et al., 2018, Ebenau et al., 2018, Calanzani et al., 2013). There is a scope for a more significant role for community pharmacies to better engage with these in-need groups early on. Future studies should recruit representatives from these participant groups.

Future studies could also evaluate the potential for community pharmacies to act as a communication hub in coordinating care needs and acting as care mediators for patients receiving palliative care or their family caregivers. Furthermore, studies should evaluate the feasibility of collating and publishing stock availability at local pharmacies. Currently, most retailers have a system to display up-to-date stock information. Community pharmacies could adapt the same system. Community pharmacies can develop such systems further to display the availability of specific medicines commonly required for palliative and end-of-life care across local pharmacies operated by different organizations. In the current study, patients and family caregivers described their frustration when having to ring or visit several pharmacies to ascertain essential medicine's availability. The shared stock availability system would reduce the time required to establish stock availabilities.

The current study engaged with diverse stakeholders, encapsulating rich data about the community palliative care landscape. This included patient, family caregiver and professional perspectives on both ideal and real-world scenarios about the development and operations of a successful community palliative care service. A further development of the research findings will be the development of a model to support palliative care services development and policy. This model could include tiered approaches adaptable in varying healthcare resource environments.

The community healthcare landscape had an impact on the current Covid-19 pandemic. The pandemic presented significant challenges for patients or their family caregivers receiving home-based palliative care. In the UK, community pharmacies swiftly brought in extra measures to deal with the fast-paced shift in community healthcare needs. In addition, the Covid-19 pandemic resulted in more collaborations between community pharmacies and GP surgeries, enabling a continuous supply of medicines. Future studies should build on studies investigating the impact of this pandemic on community pharmacy practice and the implications for the increasing scope of community pharmacists (Greenhalgh et al., 2020).

The current study did not evaluate the economic impact of greater community pharmacy involvement in palliative care services. Lastly, such studies are needed to ensure recommendations are cost-effective and that any proposed potential new roles or services are sustainable.

7.7 Strengths of the study

The study involved 44 semi-structured individual interviews resulting in a significant amount of rich qualitative data collection. This allowed a detailed exploration and comparison of the perspectives of patients, their family caregivers, and health care professionals.

The study design allowed engagement with a diverse group of participants. There was significant participation from service users (patients n=10, family caregivers n=10) and service providers (pharmacists n=13, GPs n=6, nurses n=5). In addition, the constant comparison method supported the inclusion of issues raised by patients and family caregivers into the revised topic guides and later interviews. This methodological approach allowed to examine the challenging areas for patients and family caregivers and then explore these concerns during interviews with healthcare professionals and how they can better align their services to cater for the unmet needs of patients receiving palliative care or their family caregivers.

7.8 Limitations of the study

The current study is exploratory qualitative research and does not aim to generalise findings. Furthermore, all study participants were recruited from the Nottinghamshire area. Therefore, there was limited scope to evaluate regional variations, and further, the two locally funded services in some other areas of England were not offered across the recruitment area. These include "just-in-case box" and "palliative care drugs stockist scheme". However, the sampling and recruitment approach allowed for engagement with participants who had previously participated in these two schemes and added valuable insight during the interviews. Moreover, the participants were specifically asked about their views on prescriptions for anticipatory medicines issued by GPs.

Most participants in service users' group were the patients receiving palliative care after a cancer diagnosis or their family caregivers (n=17). There were three participants from non-cancer pathways. This limited diversity of diagnosis was in part due to the recruitment pathway where most patients and family caregivers were recruited through GP surgeries and the restricted period of the doctoral study. Future studies should seek greater participation from other patient groups, e.g., old age frailty, dementia and Alzheimer's disease, and advanced renal or heart failure.

The study did not recruit patients or family caregivers who identify as vulnerable or BAME groups. Therefore, it was impossible to explore any variations between ethnic groups about the access, understanding, and quality of palliative care they received.

Chapter Eight

Conclusion

Advances in healthcare systems and health policy directives have enabled patients to receive palliative care at home, but they remain dependent upon family caregivers for extra support. However, community pharmacists have had a marginalised role, and their current and potential contributions to palliative care are rarely recognized by patients or health professionals. The community pharmacy sector in England is encouraged to take up extra roles and responsibilities, with roles in addition to medicine supply now included in national pharmacy contracts.

The current study expanded on existing understandings of the community palliative care landscape. The study engaged diverse stakeholders and contextualised diverse views on greater community pharmacy integration. Lay participants considered the timely supply of medicines as the fundamental role associated with community pharmacies, and the sector must keep a clear focus on its core identity when considering extra responsibilities.

GPs considered delegating specific tasks to pharmacists, e.g., shared roles in anticipatory prescribing, home visits, and prescription changes but would like to maintain their central position and overarching responsibility in community health care. However, community pharmacists were reluctant to extend their role in supporting community palliative care, e.g., by undertaking home visits or providing information about anticipatory medicines without additional training and funding agreements.

Community pharmacists routinely advise on medicine management queries, but this practice seldom extends to patients receiving palliative care or family caregivers. Palliative services, including medicine management support from community pharmacies, could be better publicized to help identify community pharmacies as relevant and accessible health resources for palliative care. In addition, community pharmacists have the potential to expand their advisory role in supporting patients to achieve adequate pain management, symptom control, or side effects monitoring. Delivery of palliative services through community pharmacies would enable patients and family caregivers to benefit from extended community support while relieving the pressure on GPs and community and specialist palliative care services. Furthermore, community pharmacies have the potential to act as centres of care coordination, health promotion, and education.

Increased workload pressures on GP practices further reinforce the need for greater involvement by community pharmacies, which can address the unmet medicine management needs of patients receiving palliative care at home. To limit the increased workload resulting from new services on community pharmacists, it would be useful to involve pharmacy support staff to deliver specific tasks, e.g., administrative duties. Pharmacists' lack of access to up-to-date medical records was considered a significant barrier to their participation in palliative care initiatives. Other barriers included competition for a common funding pool and training in undertaking sensitive palliative care discussions. The potential role expansions would require clearly defined operational boundaries promoting interprofessional harmony between community pharmacists and GPs.

The study has significant implications for future community-integrated services by expanding the current understanding of difficulties faced by patients receiving palliative care and their family caregivers. These include challenges in accessing medicines, understanding medicines and their side effects, red flag symptoms, safe handling and disposal of controlled drugs, and general well-being. Many unmet needs of community palliative care fall within the potential remit of community pharmacists, and with adequate support mechanisms and structured integration, a community pharmacist can successfully engage in extra roles and responsibilities. However, local commissioning of such services often leads to inconsistencies in delivery. The expansion of community pharmacist support for palliative care should be included in national contracts and recognised in future funding arrangements. The current study also provides a valuable backdrop for future research into how an extended role for pharmacists can develop, the scope for providing benefits for patients and family caregivers as a higher priority, and what this role may look like in practice.

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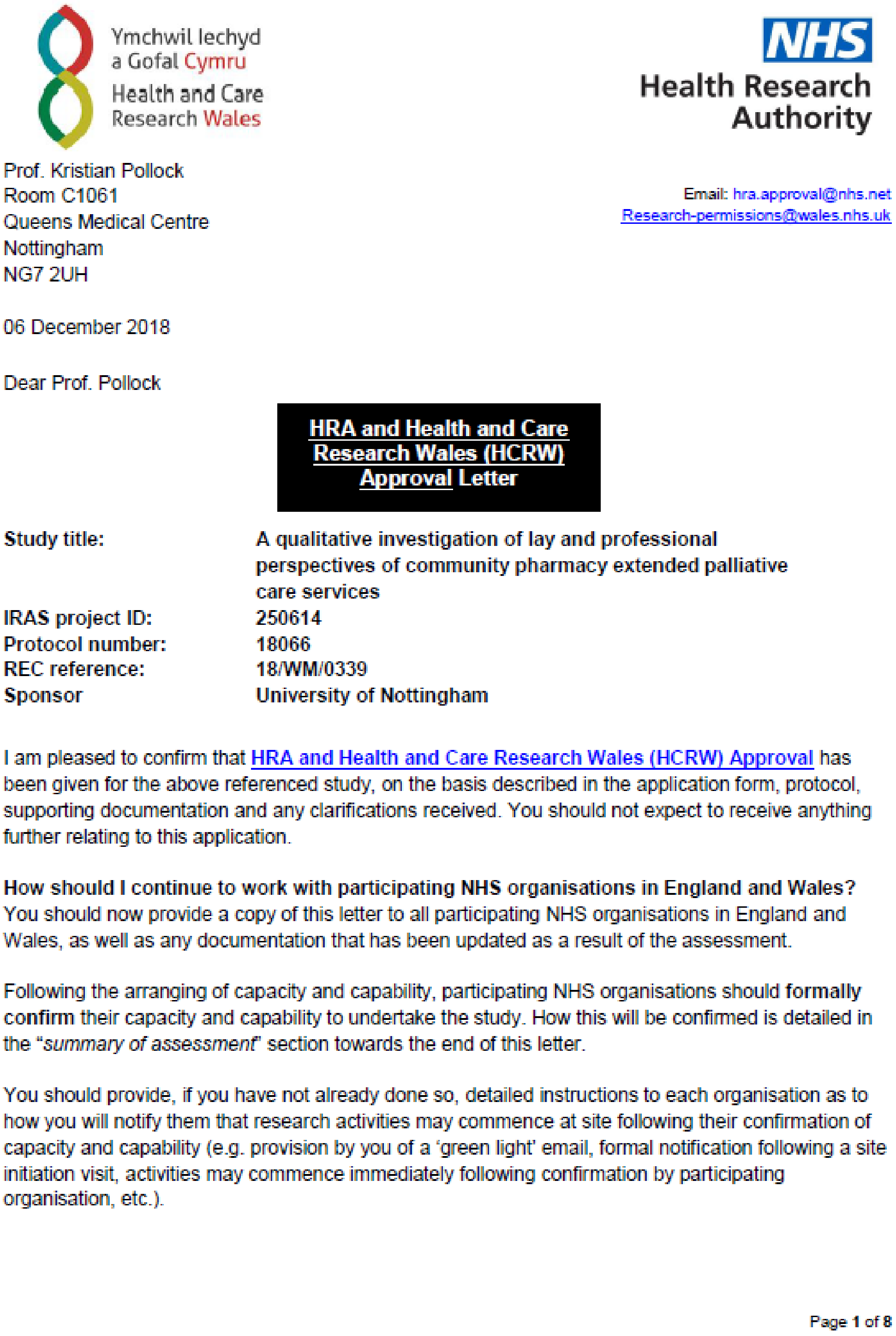
Appendices

Appendix 1 IRAS Approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

Prof. Kristian Pollock
Room C1061
Queens Medical Centre
Nottingham
NG7 2UH

06 December 2018

Dear Prof. Pollock

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**A qualitative investigation of lay and professional perspectives of community pharmacy extended palliative care services**
IRAS project ID:	**250614**
Protocol number:	**18066**
REC reference:	**18/WM/0339**
Sponsor	**University of Nottingham**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland? (if applicable)

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations? (if applicable)

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Angela Shone
Tel: 0115 8467906
Email: sponsor@nottingham.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **250614.** Please quote this on all correspondence.

Yours sincerely

Isobel Lyle | Senior Assessor
Health Research Authority
T: 0207 972 2496
HRA, Holland Dr, Newcastle upon Tyne NE2 4NQ
Hra.approval@nhs.net or Isobel.lyle@nhs.net
www.hra.nhs.uk

Copy to: *Ms Angela Shone, University of Nottingham*
Dr Maria Koufali, Lead R&D, Nottingham University Hospitals NHS Trust
Mr Abid Ali, Student

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

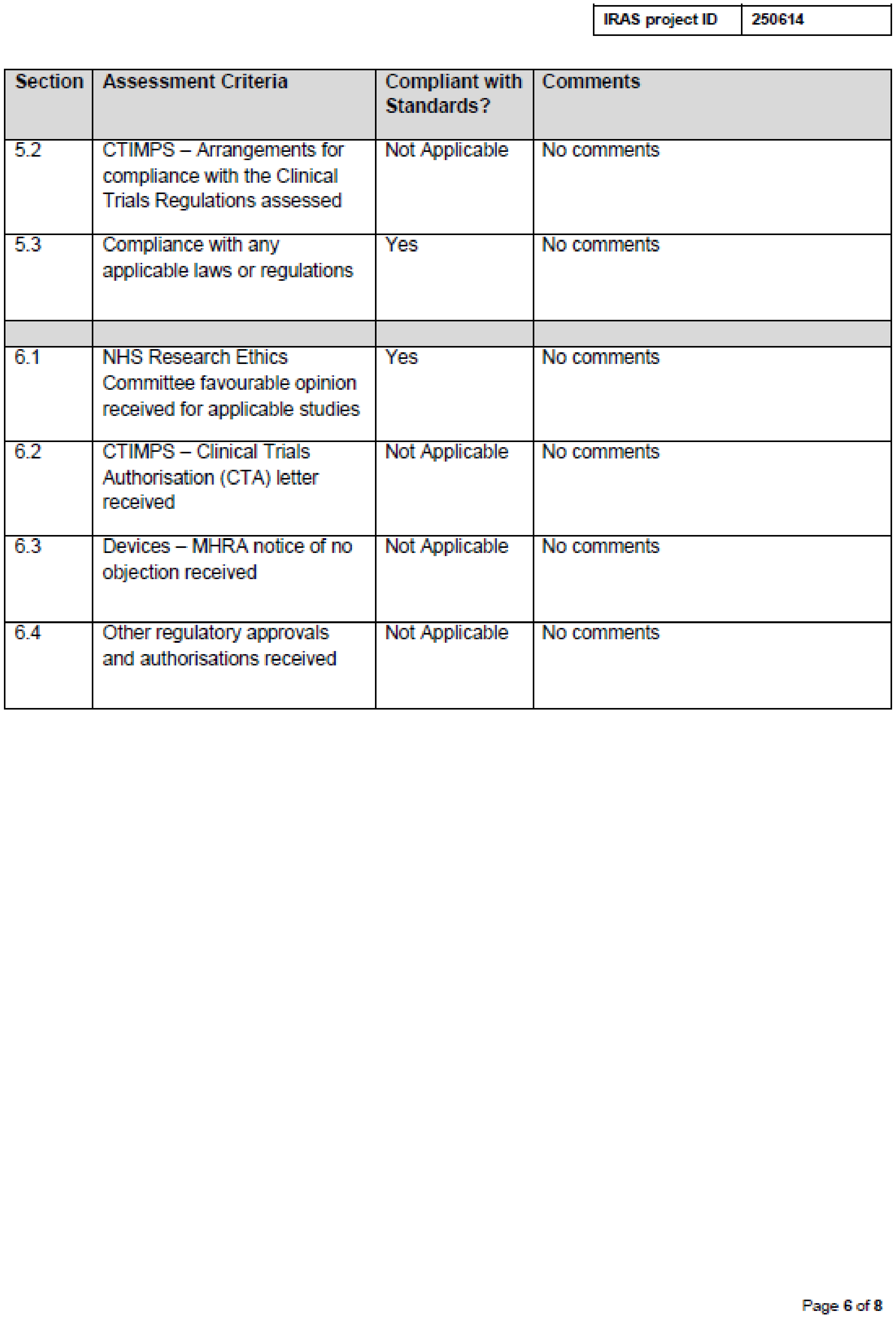
Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster IRAS 250614]	v1.0	18 October 2018
Covering letter on headed paper [Cover letter]		16 November 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		31 July 2018
HRA Schedule of Events [HRA assessed]	V2.0	21 November 2018
HRA Statement of Activities [HRA assessed]	V2.0	21 November 2018
Interview schedules or topic guides for participants [Topic guide patients]	v1.0	09 October 2018
Interview schedules or topic guides for participants [Topic guide carers]	v1.0	09 October 2018
Interview schedules or topic guides for participants [Topic guide GPs]	v1.0	09 October 2018
Interview schedules or topic guides for participants [Topic guide nurses]	v1.0	09 October 2018
Interview schedules or topic guides for participants [Topic guide pharmacists]	v1.0	09 October 2018
Interview schedules or topic guides for participants [Topic guide commissioners]	v1.0	09 October 2018
IRAS Application Form [IRAS_Form_10102018]		10 October 2018
Letter from sponsor [Letter from sponsor]		08 October 2018
Letters of invitation to participant [Reply slip with information pack]	v2.0	16 November 2018
Other [Poster IRAS 250614]	v1.0	18 October 2018
Other [Response letter to REC's provisional opinion and request for clarifications]		16 November 2018
Other [Distress protocol]	v1.0	09 October 2018
Other [Lone working policy]	v1.0	09 October 2018
Other [GCP training certificate]	v1.0	09 October 2018
Participant consent form [Consent form patients]	v2.0	16 November 2018
Participant consent form [Consent form carers and healthcare professionals]	v2.0	16 November 2018
Participant information sheet (PIS) [PIS - Patients and Carers]	v2.0	16 November 2018
Participant information sheet (PIS) [PIS - Healthcare Professionals]	v2.0	16 November 2018
Research protocol or project proposal [Project protocol]	v1.0	09 October 2018
Summary CV for Chief Investigator (CI) [CV Chief Investigator - Prof. Kristian Pollock]	Final 1.0	
Summary CV for student [CV research student - Abid Ali]		
Summary CV for supervisor (student research) [CV academic supervisor - Prof. Kristian Pollock]		
Summary CV for supervisor (student research) [CV Academic Supervisor - Dr. Asam Latif]		

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards?	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities will act as agreement of an NHS organisation to participate. The sponsor is not requesting and does not expect any other site agreement.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding is being made available to participating NHS organisations
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments



IRAS project ID	250614

Section	Assessment Criteria	Compliant with Standards?	Comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

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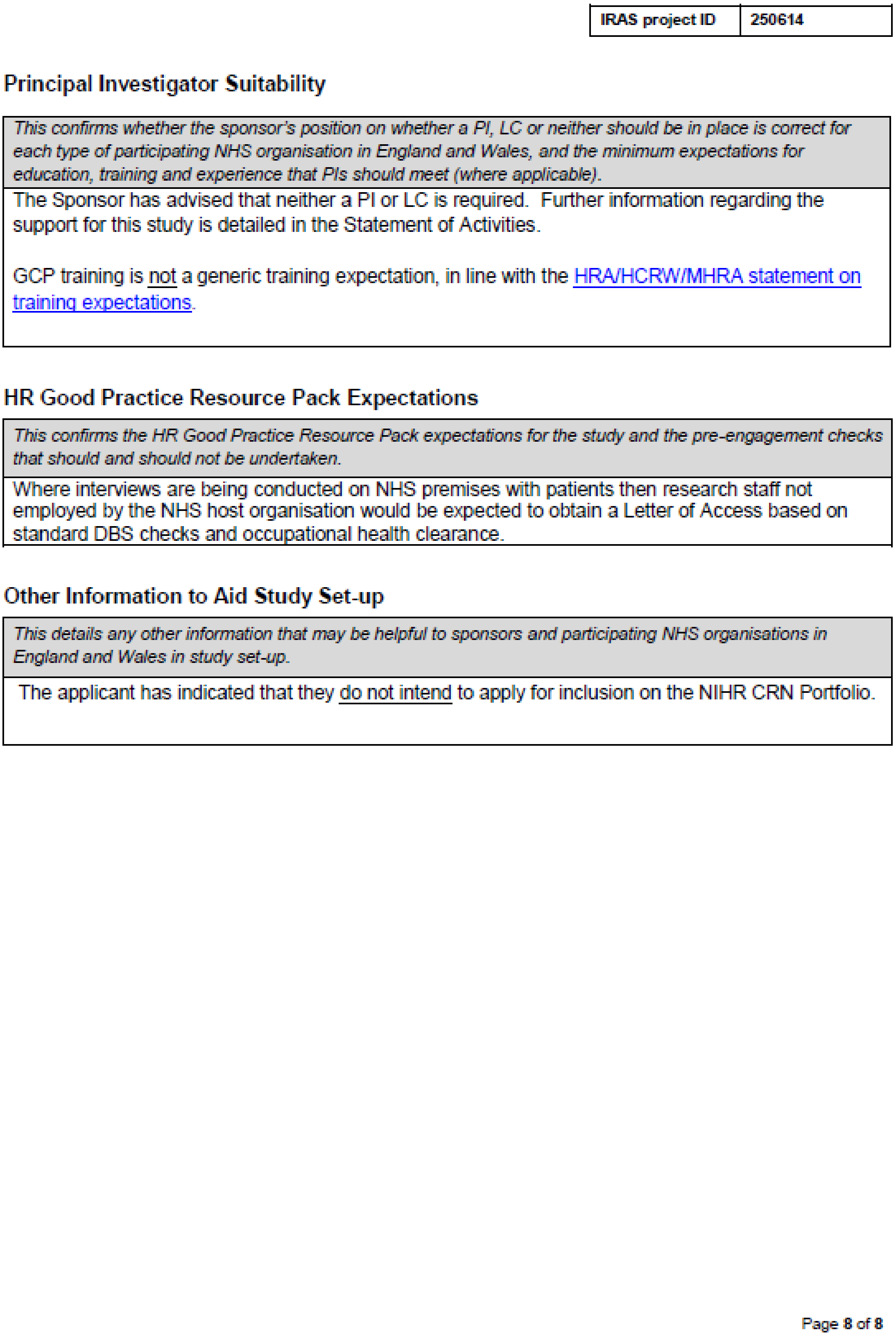
IRAS project ID	250614

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
All organisations will be undertaking the same activity, therefore, there is only one 'site-type' which is PIC activity.as outlined in the Statement of Activities The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS or on the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net, or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.



IRAS project ID	250614

Principal Investigator Suitability

This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).
The Sponsor has advised that neither a PI or LC is required. Further information regarding the support for this study is detailed in the Statement of Activities. GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.
Where interviews are being conducted on NHS premises with patients then research staff not employed by the NHS host organisation would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 2 Minutes of PPI meeting

Dementia, Frail Older People and Palliative Care Public and Patient Involvement Advisory panel Meeting (Palliative Care) Meeting Minutes June 2017

1. 16th June 2017, 10.30-13.00, B75 Medical School QMC

Attendees: Alan Caswell (AC), Marianne Dunlop (MD), Maureen Godfrey (MG), Kate Hodgett (KH), Margaret Kerr (MK), Janet Norris (JN), Kate Sartain (KS), George Wood (GW).

Meeting facilitator: Chair, Clare Burgon (CB), Minutes, Juliette Lock (JL)

Introductions: CB welcomed and thanked everyone for attending the meeting. Everyone in the meeting introduced themselves.

2. Researcher 1: Helen Ross

Helen presented her work supported by a power point presentation, this gave a background on Dementia and what the Nottingham City Council framework for Dementia will set out to achieve. The Well Pathway for Dementia aims to commission and provide services which will work together better to support individuals with dementia and their carers. Helen is from Nottingham City Council.

KS asked if HR had presented elsewhere regarding the framework? And how long the “well pathway” had been about? As she has a copy of a previous version.

MK asked where the CCG and City Care fit in to the joined up thinking? HR responded tha the idea of the frame work was joined up thinking. The facts are there are people with dementia, so whatever the latest fad, we need to work together.

MG asked how it is being operated and funded? Is it being implemented? HR replied it is being promoted and funded nationally. The purpose of presenting today was to ask for help in Nottingham with the implementation. CDG3 = Aspley/Bilborough/Leen Valley = 19% of dementia patients are in those areas.

MK asked who will be involved in designing the frame work? HR described it will be a collaboration, a list has been generated of people to approach to ask their views on who should be involved.

JN stated that the research has already been done, this is preaching to the converted.

MK asked if the money was there to implement it? Adding the Jack Dawe homecare scheme worked well. It was what people wanted, what we felt worked, if you implemented that we would be happy. The Jack Dawe scheme has been reduced. It was created by professional academics under Professor Rowan Harwood? MK described the scheme. Suggesting it saves money in the long run using well trained staff, adding the best thing was it was flexible. It looked after carers and the wider family unit. MK gave a personal example of using Jack Dawe. Expressing frustration over knowing what to do, but now having to go through it again.

MD said not a lot is measurable. All statistics are really good, but mean nothing if you can use the people.

MG gave a personal account of her mother highlighting consistency of care from the local services rather than agency care.

MK described attending a council meeting and stating her view that we have people making decisions about caring for people with dementia but don't know what they are doing.

KS praised the Jack Dawe system but was told it was too expensive after a pilot project and said being a 'compass worker' was not enough. Describing the 'IDEA' scheme that has been done by the same people that created Jack Dawe, and the AT guide (Trent guide).

MK said there is a "Healthcare for older People research guide"

JN suggested HR look at the notes from the Dementia day run by City Hospital.

MG raised the issue of this is a good time. Dementia is currently what people are worrying about. HR described having personal experience with her father, and can appreciate all the frustrations expressed. Saying she has been in touch with researchers, working to find out what research there is. And is aware of the Jack Dawe scheme. MK suggested getting the details of the scheme from the very beginning as it became more diminished as it went on. Have you a timeframe?

HR said they would like to populate the framework by August 2017, then implement it. Bringing all the bodies together to sign up for that. We are in as situation of cuts, we know how to achieve good practice, but we need to know how it can be delivered.

JN asked HR if people with experiences of dementia care are going to input information? HR confirmed they would.

KR said she has attended lots of meetings and has many documents she can hand over to HR.

AS suggested getting access to memory café for getting people involved.

HR stated she is looking for volunteers across the city and county to contribute and to contact her if interested in being involved in joining the group. KS, JN and MK expressed an interest. HR thanked the group for their time and trouble and all their comments.

Contact Helen Ross: Helen.ross@nottinghamcity.gov.uk

T: 0115 876 5759

Announcements:

CB asked if anyone had any announcements or news items to share.

MK suggested when sending out an email asking for responses. Can people cc it not bcc it, so all can see who else has replied. Are people happy to share email addresses? CB ACTION: to send round an email asking if all in the group are happy to share email addresses in the future.

MK asked if everyone has seen the results of the STP?

MK has been contacted by Alison Cowley re her Comprehensive Geriatric Assessment (CGA), to say she has funding to research this area.

AC has attended two meetings managing medicines, which includes looking at medications for end of life.

KS has been working with the VOICE study with Rebecca O'Brien. A discussion about PPI funding? Reena attended a meeting about involvement and there is a conference in July across all disciplines about PPI. It was suggested this needed the voice of someone involved for example MG. Reena may be in touch with the date of the conference so the voice of PPI can be represented at Uni level.

KS said there is an Alzheimer's conference in London in July asking for lay representatives.

JN said of the new GP contract, there is a focus on frailty as part of that contract and what does that mean? Where is the pathway? Then described the "social toe nail contract" which is trying to get established. GW said York set up a social toe nail contract.

MG described being involved on different studies. How she was very involved in the PrAISED implementation and now it is up and running, we (PPI) suddenly seem to be at a stage where we are not really involved. We do feel we will be back in it when dissemination happens. But MG wanted to make others aware of this, also describing another study and writing up a process evaluation which was a different strand of PPI, she had not previously been involved in or had any training for? AC described having had similar experiences observing studies.

MD described her PrAISED involvement and has been asked to be a CO-APP on the "Death Rattle" study.

KP is waiting to hear about an HTA funded study.

GW Described a PPI involvement study that is being written up.

KH described her involvement helping to run various groups and will be taking some away on holiday to the Isle of Wight soon.

KS has had a poster accepted for a conference in Berlin. RO'B will be attending.

3. Researcher 2: Rebecca O'Brien

Rebecca gave a brief overview of the VOICE study and said she is looking for volunteers for a specific task. However, these must be people who have not been previously involved in the VOICE study in any way. There will be a dissemination conference on 17th October 2017 at IMH.

So far there have been 45 health professionals trained using actors as patients. These were filmed and are being rated by speech therapists. Now Rebecca is looking for PPI members to rate the films. There is 2mins of video to be watched a couple of time. People will be needed for x3 separate days. Rebecca played a short video clip to show the filming to be rated.

Please contact Rebecca O'Brien if interested: Rebecca.Obrien@nottingham.ac.uk

4. Researcher 3: Glenys Caswell

Glenys presented her research. What does support and companionship for dying people and their families in the UK look like? Glenys discussed that some people need support in the transition from life to death. There are various sources of support available. Support can be provided by nonmedical, holistic companions such as end of life doulas or soul midwives. It is unclear what roles the individuals undertake and what proportion do so as volunteers or paid workers. It is also unclear how dying people and their families find out about the services. Glenys's proposal focuses on mapping services available in the UK and investigating end of life options for people not attached to a hospice or hospital, in terms of geographic spread and what different services offer. Plans include setting up an advisory panel with PPI representation. Conducting a literature review. A survey. Qualitative interviews with Doulas and health practitioners. Searching grey literature.

MK asked for clarification of grey literature. GC explained. Have they identified a demand for this type of service? GC responded that people don't necessarily ask for it, because they don't know about it.

KS suggested contacting funeral services as people are now arranging them before they die, or when making a 'lasting power of attorney' document.

MD commented she did 9 years as a volunteer sitter for palliative care, there could be a debriefing system for lay people.

A discussion took place about examples and roles of Doulas. KH described a case where Macmillan hospital nurse told a dying husband directly, commented about the delivery of bad news.

GW asked about demand? GC said that people may not be aware of what services are out there or feel they don't need to access services.

MG asked what length of time are the Doulas involved. GC replied an End of Life Doula is a negotiation between the person/family of what they want. Could be a week before dying could be a lot longer, they are usually an independent charitable organisation, and they can make their own rules.

KS offered to distribute information if you need to get information out there.

GW said there is an 'Ageing without Children' group in York, he will ask this group if this topic has ever come up?

GC thanked the group for their contributions and thinking ahead will be looking for volunteers. MD and JN stated they would like to be involved.

If interested please contact Glenys Caswell: Glenys.caswell@nottingham.ac.uk

5. Research 4: Abid Ali

AA presented his proposed doctoral research. A qualitative investigation of public and professionals perspectives of community pharmacy palliative care services. To understand whether and how community pharmacy can contribute towards palliative care services in the United Kingdom. AA wanted to ask if what he was planning made sense at this stage to the group. Do the group think it would be acceptable to extend the proposal to include people who have used/are using such support services as research participants? Would people be interested in being part of an advisory group?

MK stated she was a retired community pharmacist, saying that time was an issue. Do pharmacists have time to spend building up a rapport? Pharmacies are being cut financially, they had more time years ago, the close liaison has gone. AA said he wants to approach many different pharmacies to get their perceptions about is it worth spending the time at the moment to supply extra services with information exchanges and medicine management if on a palliative care pathway.

MK said if you had x2 pharmacists at each pharmacy allows more time but it's the cost. KS said in practice community is being destroyed, need pharmacies in the community working with GPs and district nurses. There is a lot of confusion, community pharmacists need to know who they are working with.

GW described that all health and well-being boards have to produce a pharmaceutical plan in York. He will investigate what that is.

AA said there is a tradition when they put up their plan, they have to include a palliative care list.

MG Has been accessing pharmacists for many years. They are always willing to speak to you in a pharmacy. You get a totally different response. A lot good will from the community from what you (pharmacists) do and people would value an extra role.

Discussion about taking pharmacies away from the doctor's surgeries would promote different questions. MD commented the community pharmacist would ring to check up on my controlled drugs. JN said if providing it onto a counselling role would that be separately funded? End of life is palliative care? Maybe an appointment system to come in and discuss directly with pharmacies? MK suggested it was a more positive point not to have an appointment system. The fact you can speak to a pharmacist when you want to. AA responded that people are already going through palliative pathways in pharmacies they already have that option. We are trying to get through to people who have not engaged in services.

AC said it would be interesting to see both sides public and patients. NG magazine could be a suggestion?

KS asked if AA had approached CCG's? AA, not yet. JN suggested U3A? MG suggested to approach Alzheimer's Society groups through KS?

KS asked if it was hoping to be funded to complete the work. AA said hopefully asking for pilot funding as an extension (not part of the PhD).

Abid Ali thanked the group for their contribution, if interested to take part contact: Abid.Ali@nottingham.ac.uk

The meeting then closed, CB thanked everyone for attending, gave people travel expense forms, and reminded the panel of the date of the next meeting (Friday 21st July at the Institute of Mental Health, Jubilee Campus, B27).

Appendix 3 participant information sheet

Participant Information Sheet **(Patients and Carers)**
(final version 1.0: 09-10-2018)

IRAS Project ID: 250614

Title of Study: A qualitative investigation of lay and professional perspectives of community pharmacy extended palliative care services

Name of researcher:	Prof. Kristian Pollock Dr. Asam Latif Abid Ali

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

6. What is the purpose of the study?

It is becoming increasingly common for people to live with one or more serious illnesses as they get older, and particularly when they are receiving palliative care (treatment focused on control of symptoms rather than cure). This can result in patients and family carers having to manage a lot of different medicines at home. We are interested in findings out about the problems managing medicines may cause patients and family carers, and the kinds of support and information they receive from health care professionals. In particular, we want to talk to patients, family carers and health care professionals to find out their views about the contribution community pharmacists currently make to supporting patients with their medicines use, and how this could be increased in future.

7. Why am I being invited?

You are being invited to take part because you are or a patient or family member caring for a person in receipt of palliative care. We are inviting 12-16 participants like you to take part.

8. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your medical care or legal rights.

9. What will happen to me if I take part?

You are being invited to take part in an informal discussion by either one or both of the following ways,

10. A one to one interview of about 30-45 minutes duration.
11. A focus group discussion with other patients and family carers of about 60-90 minutes duration.

Interviews will be arranged at a time and location that is convenient to you, either face-to-face or by telephone or skype if you wish. The focus group will involve discussions in a group of approx. 6 participants and will be held at a time and location that is convenient to you. The interview or focus group will involve informal discussions with no right or wrong answers. We are simply interested in finding out your views about extending community pharmacy involvement in palliative care services.

We will, with your permission, audio-record the discussion. We may use anonymous quotations from the interviews and focus group discussions in study reports, training materials and publications arising from this study, but you will not be identified from these.

12. Expenses and payments

You will not be paid for taking part in the study interview. However, reasonable travel expenses will be offered for any visits incurred as a result of participation in this study. Please retain your ticket/receipt so what we can reimburse you.

13. What are the possible disadvantages and risks of taking part?

The study topic involves discussion of the experience and treatment of serious illness. We hope that you will find taking part in the study to be an interesting experience, but it is possible that discussing these issues could arouse painful memories and distress. We ask you to consider how you would feel about discussing these issues in deciding if you would like to take part. You will never be under pressure to give information or consider topics that you do not wish to discuss. You can stop the interview or withdraw from the focus group at any time.

14. What are the possible benefits of taking part?

We cannot promise the study will help you directly but the information we get from your participation will help us understand how community pharmacists could better support patients in future.

15. What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the chief investigator Abid Ali (contact details can be found at the end of this information sheet). He will do his best to answer your questions. If you are still not satisfied, please feel free to speak to Dr. Asam Latif (Tel: 0115 823 0495; email: Asam.Latif@nottingham.ac.uk) or Dr. Kristian Pollock (Tel: 0115 823 0810; email: Kristian.Pollock@nottingham.ac.uk). If you are a patient and remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints through the Patients Advice & Liaison Service (PALS). You can contact your PALS by either calling 0800 028 3693 or e-mail: pals@nottspct.nhs.uk.
The normal National Health Service complaints mechanisms will still be available to you.

16. Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study is the Data Custodian (who manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx

Any information about you will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality. Only members of the research team will have access to your personal data.

Although what you report in the focus group is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

17. What will happen if I don’t want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

18. What will happen to the results of the research study?

The result of the study will be written up as a thesis to fulfil the requirements of Abid Ali’s doctoral thesis. The study findings will also be published in professional and academic journals.

19. Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham.

20. Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NHS Research Ethics Committee.

21. Further information and contact details

The results of this study will be available in April 2020. If you would like to receive a summary of study findings, have any questions or comments please feel free to contact Mr. Abid Ali. His details are given below:

Researchers: Prof. Kristian Pollock (Chief Investigator)
Professor of Medical Sociology
School of Health Sciences
Queen's Medical Centre
University of Nottingham
Derby Road
Nottingham
NG7 2HA
Phone: 0115 823 0810
Email: Kristian.Pollock@nottingham.ac.uk

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Email: Asam.Latif@nottingham.ac.uk

Abid Ali
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Room B316, B-floor, School of Health Sciences
Queen's Medical Centre,
Nottingham,
NG7 2HA
Phone: 0115 8230495, 07921720474
Email: Abid.Ali@nottingham.ac.uk

Thank you for reading this information sheet.
Please to not hesitate to ask us any questions if you need to.

Appendix 4 Consent form

CONSENT FORM (patients)
(interview / focus group)
(final version 1.0: 09-10-2018)

Title of Study: A qualitative investigation of lay and professional perspectives of community pharmacy extended palliative care services

IRAS Project ID: 250614

Name of Researcher: **Abid Ali**

Name of Participant: ______________________________

Please initial

1.I confirm that I have read and understand the information sheet, final version number 1.0 dated 09-10-2018 for the above study and have had the opportunity to ask questions. ☐

2.I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3.I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group, and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4.I understand that the interview / focus group will be recorded and that anonymous direct quotes from the interview / focus group may be used in the study reports. ☐

5.I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

6. I agree to take part in the above study. ☐

______________________	______________	______________________
Name of Participant	Date	Signature
______________________	______________	______________________
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix 5 Study poster

Participate in Research Study

A Qualitative Investigation of Lay and Professional Perspectives of Community Pharmacy Extended Palliative Care Services

In line with most developed countries, the population in England is getting older and there are more people needing palliative care services. Patients and carers are often asked to manage more and more complex medicine regimes with little support or training in medicines management. Healthcare policies are increasingly encouraging patients to be cared for at home which compound the issue. Community pharmacies are taking up more clinical duties encouraged by health policies both in the UK and around the world. With increasing demands on General Practice, pharmacists are seen to help support patients and carers with their medicines. However, successful policies for integration of community pharmacy in the palliative care field requires engagement with all stakeholders.

We invite patients in receipt of palliative care and their family caregivers to participate in this research study.

Research Study's Objectives

1. To explore the views of patients and, carers towards extending community pharmacy's role and involvement in palliative care in England?
2. To explore the views of healthcare professionals (e.g. pharmacists, GPs and nurses, commissioners) towards extending community pharmacy's role and involvement in palliative care in England?
3. To investigate the scope, barriers, and facilitators for community pharmacy to further contribute to existing palliative care services?

What does the study involve?

The participation in research study will involves an informal discussion by either one or both of the following ways,

1. A one to one interview of about 45 minutes duration.
2. A focus group discussion with other patients and family carers of about 90 minutes duration.

Interviews will be arranged at a time and location that is convenient to you, either face-to-face or by telephone or skype if you wish. The focus group will involve discussions in a group of approx. 6 participants and will be held at a time and location that is convenient to you.

The information from these discussions will be anonymised with strict confidentially guidelines followed at all times.

University of Nottingham
UK | CHINA | MALAYSIA

Further Information

If you would like more information about the study, or would be interested in taking part, please contact the researcher below

Abid Ali, Abid.Ali@nottingham.ac.uk, Phone: 07921720474
Room 312, B-Floor, School of Health Sciences, QMC Campus, Nottingham. NG7 2HA

A qualitative investigation of lay and professional perspectives of community pharmacy extended palliative care services – POSTER Pt + Carers – final version 1.0 - 18-10-2018

Appendix 6 Reply slip

Research project

A QUALITATIVE INVESTIGATION OF LAY AND PROFESSIONAL PERSPECTIVES OF COMMUNITY PHARMACY EXTENDED PALLIATIVE CARE SERVICES

Final Version 1.0

09 October 2018

We are thankful for your initial interest in this research project. Your participation will involve either a one to one interview and/or a focus group discussion with a member of our research team. The study details are enclosed in this information pack. Please leave you contact details in the reply slip below so we can discuss it further and answer any questions you may have.

Yours sincerely,

Abid Ali (Doctoral Research Student)
School of Health Sciences,
University of Nottingham

- -

A QUALITATIVE INVESTIGATION OF LAY AND PROFESSIONAL PERSPECTIVES OF COMMUNITY PHARMACY EXTENDED PALLIATIVE CARE SERVICES

I have received an information pack relating to this research study conducted by University of Nottingham. I am happy to be contacted at following contact details for further discussion around my participation.

Name: ______________________________________

Signature: ___________________________________

Date: _______________________________________

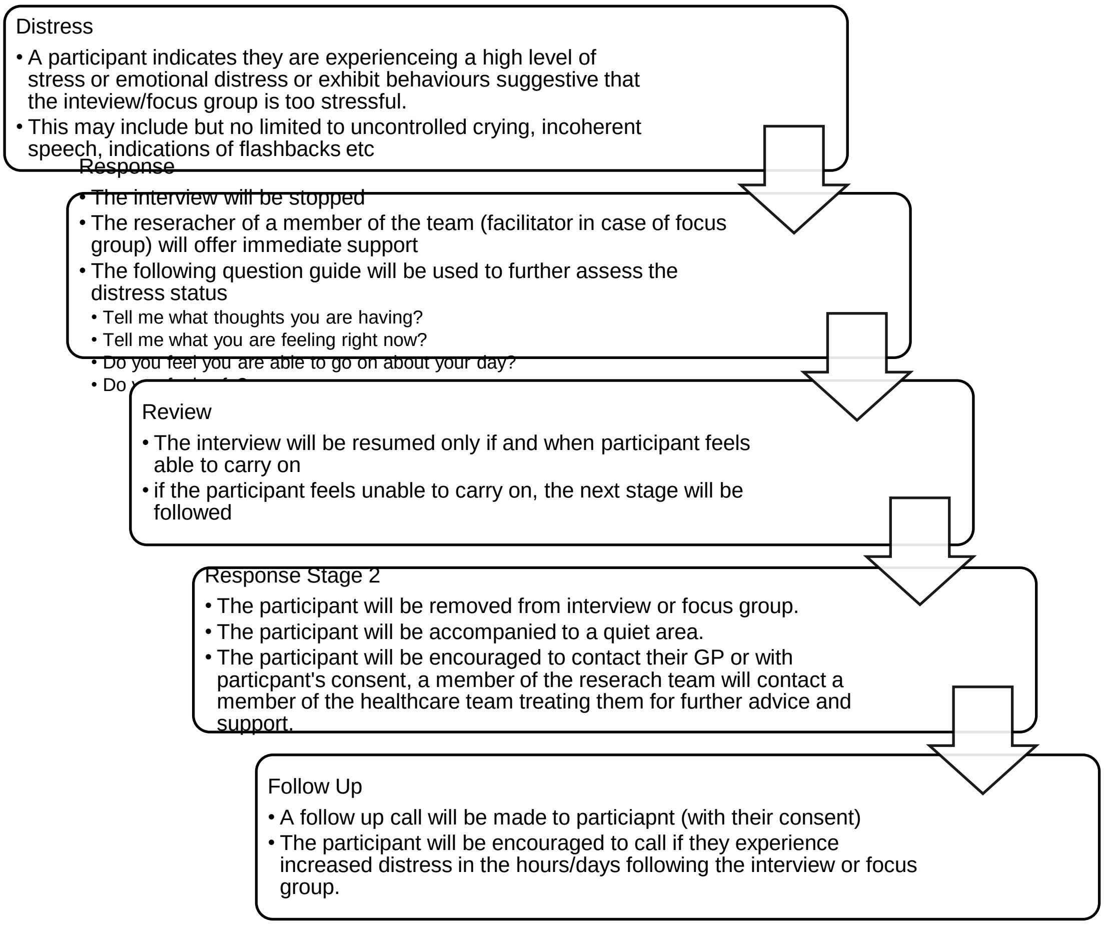
Contact details: _______________________________

Appendix 7 Distress protocol

A QUALITATIVE INVESTIGATION OF LAY AND PROFESSIONAL PERSPECTIVES OF COMMUNITY PHARMACY EXTENDED PALLIATIVE CARE SERVICES

Distress protocol Final Version 1.0 – 09 October 2018

The following distress protocol is developed as an interview aid for one to one interviews and focus groups with patients and carers. The distress protocol is developed taking account of guidelines by Draucker et al. (2009) who has developed this protocol for research on sensitive topics.



Distress

- A participant indicates they are experienceing a high level of stress or emotional distress or exhibit behaviours suggestive that the inteview/focus group is too stressful.
- This may include but no limited to uncontrolled crying, incoherent speech, indications of flashbacks etc

Response

- The interview will be stopped
- The reseracher of a member of the team (facilitator in case of focus group) will offer immediate support
- The following question guide will be used to further assess the distress status
  - Tell me what thoughts you are having?
  - Tell me what you are feeling right now?
  - Do you feel you are able to go on about your day?
  - Do

Review

- The interview will be resumed only if and when participant feels able to carry on
- if the participant feels unable to carry on, the next stage will be followed

Response Stage 2

- The participant will be removed from interview or focus group.
- The participant will be accompanied to a quiet area.
- The participant will be encouraged to contact their GP or with particpant's consent, a member of the reserach team will contact a member of the healthcare team treating them for further advice and support.

Follow Up

- A follow up call will be made to particiapnt (with their consent)
- The participant will be encouraged to call if they experience increased distress in the hours/days following the interview or focus group.

Appendix 8 Topic guide – Patients

Title of Study: **A Qualitative Investigation of Lay and Professional Perspectives of community Pharmacy Extended Palliative Care Services**

Patients interview topic guide Final Version 1.0 09.10.18

Thanks very much for taking part in this study. The study aims to explore your views about the involvement of community pharmacy in palliative care services. This interview will be an informal discussion about your views and experience. I'd just like to reiterate that everything you say in the interview is. If anything, you say is used in a publication then it will be anonymous. The interview itself will be open ended and the questions themselves are usually broad. There aren't any right or wrong answers - I'm simply interested in your experience and your views. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview, or if you want to stop the interview, please let me know. You do not need to give any explanation for doing so. Is there anything you'd like to ask me?

Patients interview topic guide

Demographic capture

Background

- Tell me a little about yourself? For example, living arrangements / family / hobbies and interests
- Can you describe what a typical day involves for you?
- If comfortable, tell me little about your illness?
-
- Tell me about your engagement with different healthcare professionals involved in your care e.g. GPs, pharmacists, practice & district nurses?
- How accessible are the different healthcare services?
- Can you think of important aspects for you while managing your condition? e.g. pain management, managing medicine supply, medicine reminders, etc.
- Can you identify a particular health care professional or service that you consider is most important to you?
- Can you think of any health-related problems you are facing at home because of your illness? e.g. pain management, medicine burden, managing medicines, medicine reminders, advice, accessibility to HCPs, etc.

- What about medicines? Is there someone who you feel you can go to for advice and information?
- While at home, which healthcare professional (GP, Nurses, Pharmacists) is usually your first point of contact? Can you provide some examples?

Community Pharmacy and palliative care services

- (If not already clear) What role does the pharmacist play in helping you manage medicines?
- Are there any times you have sought advice from a pharmacist?
- Can you give me some examples?
- Do you feel you could ask a pharmacist for help and advice about medicines prescribed for you? For example, the reasons for them being prescribed, how they work, how they should be taken, any risks of side effects?
- Have you ever done this? Give me some examples. Would you be willing to do this?
- Have you ever used any of the other services which pharmacists provide now a days? For example, flu vaccinations, travel health, medicine management, dispensing medicines in blister packs, medication reminder checks, medicine use reviews etc.
- Do you think there are ways in which pharmacists could play a more active role in supporting patients and carers in managing their medicines at home?
- Who would you feel most comfortable asking for advice about a medicine that had been prescribed for you? Why is that? Do you think a pharmacist would be a good person to ask for advice or information about medicines?
- How would you feel about a pharmacist undertaking a review of all your medicines and giving you advice and information about these?
- At the pharmacy? At your home? After patient was discharged from hospital?
- Are there any other ways you feel that a pharmacist could help you with medicines just now?
- How do you feel about community pharmacists' taking up prescribing duties?
- Do you think that community pharmacists could help other healthcare professionals in delivery of palliative care services?
- How? Are there any barriers to community pharmacists playing a more active role in supporting patients and family carers at home?
- Any final comments?

Appendix 9 Topic guide – Family caregivers

Title of Study: **A Qualitative Investigation of Lay and Professional Perspectives of community Pharmacy Extended Palliative Care Services**

Carers interview topic guide Final Version 1.0 09.10.18

Thanks very much for taking part in this study. The study aims to explore your views about the involvement of community pharmacy in palliative care services. This interview will be an informal discussion about your views and experience. I'd just like to reiterate that everything you say in the interview is. If anything, you say is used in a publication then it will be anonymous. The interview itself will be open ended and the questions themselves are usually broad. There aren't any right or wrong answers - I'm simply interested in your experience and your views. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview, or if you want to stop the interview, please let me know. You do not need to give any explanation for doing so. Is there anything you'd like to ask me?

Carers interview topic guide

Demographic capture

Background

- Tell me a little about yourself? For example, living arrangements / family / hobbies and interests
- Can you tell me a little about the illness of person you are caring or cared for?
- Tell me about your involvement in caring for the person.
- What a typical day involves in term of care for this person
- Do you have any concerns about the role you are taking on in providing care for this person? Particularly in relation to managing medicines?
- What medicines the person is taking? And for what conditions?
- Patients and your (carer's) understanding of medicines?
- Tell me about your engagement with different healthcare professionals involved in providing care for the patient e.g. GPs, pharmacists, practice & district nurses?
- How accessible are/were the different healthcare services?
- Can you think of important aspects for you in care for the patient.? e.g. pain management, managing medicine supply, medicine reminders, etc.

- Can you think of most important aspects for you yourself while involved in patient's care? Supply of medicines, accessibility to HCP, advice etc.
- Can you identify a particular health care professional or service that is most important to you and the patient?
- What about medicines? Is there someone who you feel you can go to for advice and information?

Community Pharmacy and palliative care services

- (If not already clear) What role does the pharmacist play in helping you manage medicines for the patient?
- Are there any times you have sought advice from a pharmacist?
- Generally? Re patient's illness?
- Can you give me some examples?
- Do you feel you could ask a pharmacist for help and advice about medicines prescribed for patient? For example, the reasons for them being prescribed, how they work, how they should be taken, any risks of side effects?
- Have you ever done this? Give me some examples. Would you be willing to do this?
- Have you ever used any of the other services which pharmacists provide now a days? For example, flu vaccinations, travel health, medicine management, dispensing medicines in blister packs, medication reminder checks, medicine use reviews etc.
- Do you think there are ways in which pharmacists could play a more active role in supporting patients and carers in managing their medicines at home?
- Who would you feel most comfortable asking for advice about a medicine that had been prescribed for the patient? Why is that? Do you think a pharmacist would be a good person to ask for advice or information about P's medicines?
- How would you feel about a pharmacist undertaking a review of all patient's medicines and giving you advice and information about these?
- At the pharmacy? At your home? After patient was discharged from hospital?
- How do you feel about community pharmacists' taking up prescribing duties?
- Are there any other ways you feel that a pharmacist could help you and the patient with medicines just now?
- Do you think that community pharmacists could help other healthcare professionals in delivery of palliative care services?
- How? Are there any barriers to community pharmacists playing a more active role in supporting patients and family carers at home?

Any final comments?

Appendix 10 Topic guide – Pharmacists

Title of Study: **A Qualitative Investigation of Lay and Professional Perspectives of community Pharmacy Extended Palliative Care Services**

Pharmacists interview topic guide Final Version 1.0 09.10.18

Thanks very much for taking part in this study. The study aims to explore your views about the involvement of community pharmacy in palliative care services. This interview will be an informal discussion about your views and experience. I'd just like to reiterate that everything you say in the interview is. If anything, you say is used in a publication then it will be anonymous. The interview itself will be open ended and the questions themselves are usually broad. There aren't any right or wrong answers - I'm simply interested in your experience and your views. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview, or if you want to stop the interview, please let me know. You do not need to give any explanation for doing so. Is there anything you'd like to ask me?

Pharmacist topic guide

Demographic capture

Background

- Tell me a little about your work?
- Tell me about your direct engagement with patients?
- Tell me about your direct engagement with GPs and nurses?
- What, if any, services in addition to core contractual essential services you offer?
- How do you manage your workload for these extra services?
- What do you achieve from undertaking these services?

Awareness of Palliative care services

- What are the arrangements for palliative care services in your pharmacy?
- What is your engagement with palliative care services?
- How do you liaise with other healthcare professionals and patients and carers for delivery of palliative care services?
- Are there any established protocols around supply of palliative care services?
- What are the funding arrangements for supply of palliative care services?
- How often you engage with supply of palliative care services in any capacity?

- Can you provide some examples?

Professional harmony

- How often you get approached by other healthcare professionals (GPs, Nurses) for issues relating to palliative care and end of life care services?
- Can you provide some examples?
- In which way you think a community pharmacist can help other healthcare professionals in delivery of palliative care services?

Community Pharmacy and palliative care services

- How community pharmacy can help patients in their palliative care needs?
- What do you think community pharmacy’s role should be when offering palliative care services?
- What sort of funding arrangements will facilitate delivery of palliative care services?
- What do you think about community pharmacist’s role expansion into palliative care area?
- What are the potential barriers in your view?
- Who do you think will benefit the most by community pharmacy palliative care services?

Any final comments?

Appendix 11 Topic guide – GPs

Title of Study: **A Qualitative Investigation of Lay and Professional Perspectives of community Pharmacy Extended Palliative Care Services**

General Practitioners (GPs) interview topic guide Final Version 1.0 09.10.18

Thanks very much for taking part in this study. The study aims to explore your views about the involvement of community pharmacy in palliative care services. This interview will be an informal discussion about your views and experience. I'd just like to reiterate that everything you say in the interview is. If anything, you say is used in a publication then it will be anonymous. The interview itself will be open ended and the questions themselves are usually broad. There aren't any right or wrong answers - I'm simply interested in your experience and your views. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview, or if you want to stop the interview, please let me know. You do not need to give any explanation for doing so. Is there anything you'd like to ask me?

General Practitioners (GPs) interview topic guide

Demographic capture

Background

- Tell me a little about your work?
- Tell me about your engagement with palliative care patients and their carers?
- Tell me about your engagement with community pharmacists and district nurses?
- What palliative care services you are requested to supply?
- How do you manage your workload for these services?
- How do you perceive future demands on GPs resulting from increased palliative care service users in primary care?

Delivery of Palliative care services

- How do you liaise with other healthcare professionals for delivery of palliative care services?
- Can you provide some examples?
- What are the funding arrangements for supply of palliative care services?
- How often you engage with supply of palliative care services in any capacity?
- Can you provide some examples?

Professional harmony

- How often you get approached by other healthcare professionals (Pharmacists, Nurses) for issues relating to palliative care and end of life care services?
- Can you provide some examples?
- What is your opinion about community pharmacists' current involvement in delivery of palliative care services?
- In which way you think a community pharmacist can help other healthcare professionals in delivery of palliative care services?
- What is the best way for community pharmacy to offer palliative care services without causing concern for GPs, patients, and carers?

Community Pharmacy and palliative care services

- What do you think community pharmacy's role should be when offering palliative care services?
- What do you think about community pharmacist's role expansion into palliative care area?
- What are the potential barriers in your view?
- Who do you think will benefit the most by community pharmacy palliative care services?

Any final comments?

Appendix 12 Topic guide – Nurses

Title of Study: **A Qualitative Investigation of Lay and Professional Perspectives of community Pharmacy Extended Palliative Care Services**

Nurses interview topic guide Final Version 1.0 09.10.18

Thanks very much for taking part in this study. The study aims to explore your views about the involvement of community pharmacy in palliative care services. This interview will be an informal discussion about your views and experience. I'd just like to reiterate that everything you say in the interview is. If anything, you say is used in a publication then it will be anonymous. The interview itself will be open ended and the questions themselves are usually broad. There aren't any right or wrong answers - I'm simply interested in your experience and your views. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview, or if you want to stop the interview, please let me know. You do not need to give any explanation for doing so. Is there anything you'd like to ask me?

Nurses interview topic guide

Demographic capture

Background

- Tell me a little about your work?
- Tell me about your engagement with palliative care patients and their carers?
- Tell me about your engagement with community pharmacists and district nurses?
- What palliative care services you are requested to supply?
- How do you manage your workload for these services?
- How do you perceive demands on nurses resulting from increased palliative care service users in primary care?

Delivery of Palliative care services

- How do you liaise with other healthcare professionals for delivery of palliative care services?
- Can you provide some examples?
- What are the funding arrangements for supply of palliative care services?
- How often you engage with supply of palliative care services in any capacity?
- Can you provide some examples?

Professional harmony

- How often you get approached by other healthcare professionals (Pharmacists, GPs) for issues relating to palliative care and end of life care services?
- Can you provide some examples?
- What is your opinion about community pharmacists' current involvement in delivery of palliative care services?
- In which way you think a community pharmacist can help other healthcare professionals in delivery of palliative care services?
- What is the best way for community pharmacy to offer palliative care services without causing concern for nurses, GPs, patients, and carers?

Community Pharmacy and palliative care services

- What do you think community pharmacy's role should be when offering palliative care services?
- What do you think about community pharmacist's role expansion into palliative care area?
- What are the potential barriers in your view?
- Who do you think will benefit the most by community pharmacy palliative care services?

Any final comments?