Promoting Independence in Dementia – Changing Lifestyles & Improving Outcomes: RE-AIM Study of The PRIDE Self-Management App

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If there ever comes a day when we
can't be together, keep me in your
heart. I'll stay there forever.

A.A. Milne

If I could, I would always work in
silence and obscurity, and let my
efforts be known by their results.

Emily Brontë

Abstract

Introduction: The ever-increasing prevalence of dementia globally is placing significant demands on health and social care sectors and on families. Given the progressive nature of dementia, self-management can support people and their families to optimise the level of autonomy and independence they are capable of and reduce excess disability. Incorporating technology into self-management interventions could help remove geographical barriers and enable services to deliver to a wider-reaching audience.

Aims: To explore how the PRIDE-app online intervention could promote and support self-management in those living with mild dementia.

Methods: This study employed a mixed methods approach and incorporated the Reach, Effectiveness, Adoption, Implementation, and Maintenance framework. The app was subject to two development sprints to produce a version suitable for the main study. In the main study, we recruited 28 people diagnosed with dementia, although 17 completed the intervention. Participants completed the PRIDE-app intervention over 8 weeks with support from a dementia adviser facilitator. Measures exploring mood, physical well-being, and quality of life were collected at baseline and at follow-ups at 3 and 6 months. Eight post-intervention interviews were conducted with participants and facilitators. An additional online questionnaire was completed by 110 people living with dementia and supporters which explored attitudes to and use of computer technology, to better understand the low recruitment rate for the main study.

Results: Data collection began in June 2021 and ceased end of September 2022. Although the PRIDE-app appeared to have no significant improvements on participants' dementia symptoms or independence, interview data highlighted PRIDE's impact in encouraging people to carry out more activities. Although participants and facilitators identified areas for improvements to the app interface and delivery format, overall qualitative data showed that the PRIDE-app motivated people to reconnect socially and set individual goals.

Conclusions: This study evaluated the PRIDE-app's reach, effectiveness and adoptability in the independence and quality of life of those with lived experience of dementia, as well as how it could be implemented and maintained within services. Although pre- and post-intervention scores were inconclusive, the degenerative nature of dementia could have affected PRIDE's effect on the measured constructs. Interviews provided positive feedback on the influence of the app on peoples' activities and mood. Knowledge generated will help with any future developments to the app, with the aim of improving its uptake and implementation in services.

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Disclaimer

The views expressed are mine and those of the author(s) I collaborated with, and not necessarily those of the NIHR, the Department of Health and Social Care, the National Health Service (NHS), or the University of Nottingham.

Declaration

I declare that the thesis has been composed by myself and that no part of this work has been submitted in support of an application for any other academic degree or qualification at the University of Nottingham, or at any other academic institution.

The PRIDE-app study discussed in this thesis was a project based on the original PRIDE work from University College London. Members of the team who worked on developing the PRIDE handbook were Dr Emese Csipke, Dr Lauren Yates, Professor Esme Moniz-Cook, Dr Orii McDermott, Mr Daniel Kelleher, and Professor Martin Orrell. Mr Steven Taylor and Mr Mike Stephens at Ayup provided the PRIDE- app platform and maintenance. I was the lead researcher for all the work discussed in this thesis, except for Chapter 4, which details the development of the PRIDE-app from the original format to the one used in this study. The first half of development work was conducted by the team at University College London. I confirm that appropriate credit has been given within this thesis where reference has been made to the work of others.

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Presentations

University of Nottingham School of Medicine Research Forum (September 2021): Virtual poster with presentation – Promoting *Independence in Dementia: The PRIDE-app*

University of Nottingham Sue Watson Presentation Event (March 2022): Online presentation – *Promoting Independence in Dementia: RE-AIM study of the PRIDE self-management app*

East Midlands Applied Research Collaboration (May 2022): Virtual poster with presentation – *Promoting and Supporting Independence in People Living with Mild Dementia: The PRIDE-app*

Alzheimer Disease International (June 2022): Poster – *Promoting and Supporting Independence in People Living with Mild Dementia: The PRIDE-app*

Alzheimer Europe (October 2022): Virtual poster – *Promoting and Supporting Independence in People Living with Mild Dementia: The PRIDE-app*

Alzheimer Europe (October 2022): Virtual poster – *Computer Technology: What do people with lived experience of dementia think?* – Awarded 'Best Virtual Poster' prize

World Congress for Neurorehabilitation (December 2022): Virtual poster with presentation – *Promoting Independence in Dementia: A RE-AIM study of the PRIDE self-management app*

World Congress for Neurorehabilitation (December 2022): Virtual poster with presentation – *Development of the PRIDE self-management app*

World Congress for Neurorehabilitation (December 2022): Virtual poster with presentation – *Understanding barriers and facilitators to online and app activities for people living with dementia*

Co-author publications completed during this PhD

Kontou, E., Kettlewell, J., Condon, L., Thomas, S., Lee, A. R., Sprigg, N., ... & Shokraneh, F. (2021). A scoping review of psychoeducational interventions for people after transient ischemic attack and minor stroke. *Topics in Stroke Rehabilitation*, *28*(5), 390-400.

Gerritzen, E. V., Lee, A. R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Parkinson disease: narrative synthesis systematic review. *JMIR Aging*, *5*(3), e35425.

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Gerritzen, E. V., Lee, A. R., McDermott, O., Coulson, N., & Orrell, M. (2023). Online peer support for people with Amyotrophic Lateral Sclerosis (ALS): A narrative synthesis systematic review [Manuscript submitted for publication].

Kettlewell, J., Kontou, E., Lee, A., Thomas, S., Thorpe, N., & Wong, D. (2023). A Scoping Review of Remote Group-Based Psychoeducational Interventions for People After Transient Ischemic Attack and Stroke [Manuscript submitted for publication].

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List of Abbreviations

ARL – Abigail Rebecca Lee

CASP-19 – Control, Autonomy, Self-realization, and Pleasure Scale-19

CRF[s] – Case Report Form[s]

CRN – Clinical Research Network

DA[s] – Dementia Advisor[s]

DEEP – Dementia Empowerment Engagement Programme

EID-Q – Engagement and Independence in Dementia Questionnaire

EVG – Esther Vera Gerritzen

GDS – Geriatric Depression Scale

GHQ-12 – General Health Questionnaire-12

IADL – Lawton Instrumental Activities of Daily Living Scale

iCST – Individual Cognitive Stimulation Therapy

JDR – Join Dementia Research

MCI – Mild Cognitive Impairment

OM – Dr Orii McDermott

PRIDE – Promoting Independence in Dementia

PRIDE-app – Promoting Independence in Dementia App

Pt – Person/People Living with Dementia

ReACT – Rehabilitation in Alzheimer’s Disease Using Cognitive Support Technology

RE-AIM – Reach, Effectiveness, Adoption, Implementation and Maintenance

SMI – Self-management Interventions

Sup – Supporter [of someone living with dementia]

UoN – University of Nottingham

1. Introduction

1.1 Dementia and society

Dementia is an umbrella term for a collection of progressive neurological conditions, consisting of over 100 subtypes and causes, which currently affects an estimated 885,000 people in the UK, including 42,000 people under the age of 65 (Wittenberg, Hu, Barraza-Araiza & Rehill, 2019; Dementia UK, 2020). This number is only set to rise with the increasing ageing population, and it is estimated that 1.6 million people will have a dementia diagnosis by 2040 (Alzheimer's Society, 2020). Although severe dementia is the most prevalent, affecting over half a million people, the estimated numbers for mild and moderate dementia still total over a staggering 370,000 (Wittenberg et al., 2019). The most common types of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and mixed dementia (Dementia UK, 2020). Although symptoms vary between types, dementia causes impaired ability and performance across multiple cognitive domains, such as memory problems, cognitive ability, and communication, with these appearing even in the early stages (Dementia UK, 2020).

In the UK, the provision of care for people living with dementia, over the age of 65, currently costs the nation £34.7 billion a year and is expected to rise to £94.1 billion by 2040 (Alzheimer's Society, 2020). These figures include the costs to the NHS, social care, and unpaid care provided by families and friends. Social care costs alone amount to £15.7 billion of the overall total and are estimated to rise to almost 50% of the national cost by 2040 (Alzheimer's Society, 2020). In England, people living with dementia and their families contribute to more than 60% of the bill for social care. In addition, the hours of unpaid care by families equate to a value of £13.9 billion a year (Alzheimer's Society, 2020). Enabling people with dementia to manage this condition more effectively and remain living in their own homes benefits both the individual, through greater quality of life and wellbeing, and society, by reducing the cost and care burden on the health and social care sectors (Lord et al., 2020).

The idea of living well with dementia has been constructed around living with quality of life, choice, autonomy, dignity and as independently as possible (Lord et al., 2020). Interviews with relevant stakeholders, including people living with dementia, identified key priorities in how they quantify living well with dementia (Reilly et al., 2020). Participants agreed on a final 13 priorities, which fell under four domains: home and neighbourhood (which included the importance of relationships and communication); independence; self-management of dementia symptoms; and quality of life (Reilly et al., 2020). Interviewees felt that these should be considered as outcomes when developing and trialling non-pharmacological interventions for dementia, in order to increase their relevance and value (Reilly et al., 2020). Self-management, for example, encourages and enables people to adjust to living with dementia. As a large proportion of people with dementia in the UK continue to live within their own homes, non-pharmacological community-based interventions continue to be a source of support in enabling people to maintain their independence and a good quality of life (Reilly et al., 2020).

1.2 Impact of dementia on independence and quality of life

Mild dementia may present itself through subtle behaviour changes and episodes of forgetfulness, but the person has some insight into what is happening, and therefore attempt to hide these through coping mechanisms (Hobson, 2019). During these early stages of dementia, people with dementia are able to maintain an active and social life but quite often depression and diagnosis stigma cause them to become isolated (Hobson, 2019). Therefore, it is pivotal that people living with mild dementia feel supported and encouraged to maintain their normal activities and remain independent.

Evidence shows that dementia can often result in a poorer quality of life for the individual diagnosed (Kisvetrová et al., 2021). In a Czech study of 563 community-dwelling people with and without mild dementia, Kisvetrová et al. (2021) explored the potential predictors for quality of life. Participants completed measures looking at quality of life, depression, dignity, and attitudes towards aging. In people with dementia, the level of depression, feelings of dignity, and self-sufficiency in daily activities were highlighted as some on the key predictors to their quality of life. Isolation placed those with dementia at greater risk of negative predictors, therefore encouraging regular contact with their families and social networks appears an important step towards improving the quality of life for people with dementia. Interventions should prioritise enabling people with dementia to remain independent and capable of living within the community for as long as possible. This will help sustain their social inclusion and relationships, maintain personal dignity, and reduce feelings of depression (Kisvetrová et al., 2021).

Living with dementia can often have a significant impact on relationships with family and friends, and evidence suggests that these dynamics influence on health outcomes for both the person with dementia and their families (La Fontaine & Oyebode, 2014, as cited in Oh, Yu, Ryu, Kim & Lee, 2020). A meta-synthesis of qualitative studies exploring familial relationships in dementia in South Korea provided further understanding of the impact of dementia caregiving (Oh et al., 2020). Preliminary searches of title and abstracts found 371 potentially relevant studies, with 37 of these matching all the inclusion criteria and included in the final synthesis. Quality appraisal found that the 19 studies were of high quality, 13 as good, and five as acceptable (Oh et al., 2020). The meta-synthesis revealed that significant family-level adjustments are needed when living with a person with dementia, but how these adjustments are handled can have a positive or negative effect on the health of all involved. Concepts such as communication and understanding the dementia diagnosis were highlighted as important factors in determining whether outcomes were positive or negative. As only research conducted in South Korea was included, and that there are perceived differences in familial relationships between collectivist and individualist cultures, the potential generalisation of findings is reduced. However, they do provide insight into the wider impact a dementia diagnosis could have in the short and long-term for the person diagnosed and their family. Oh et al. (2020) suggested that future research should focus on developing interventions which promote family solidarity and support as an important factor in enabling people with dementia to accomplish difficult tasks. Worldwide, families continue to be a vital source of support for people living with dementia, and it is important that interventions which involve this are developed and implemented.

1.3 Self-management: Concepts and implementation

Self-management encompasses multiple components that can support an individual to improve their physical and mental well-being, either independently or in collaboration with their healthcare team (Taylor et al., 2014). These components include goal setting, decision-making, problem-solving, accessing and using resources, a strong collaboration between patient and health professional, and patient activation (Taylor et al., 2014; de Longh, Fagan, Fenner & Kidd, 2015; NHS England, 2020). The latter refers to the knowledge, skills and confidence an individual has in managing their long-term condition and overall health and has been linked to a lower number of medical appointments and hospital admissions (Hibbard & Gilburt, 2014).

Effective self-management requires the implementation of these components to encourage behaviour change. Education about the relevant condition(s) is crucial in promoting and sustaining this change (Taylor et al., 2014; Westland et al., 2017). Behavioural change frameworks, such as the Capability, Opportunity, Motivation, Behaviour (COM-B) model are often a starting point when developing self-management interventions (SMIs) as they help identify which intervention strategies are more likely to promote positive change (McDonagh et al., 2018). The COM-B model provides a comprehensive framework of the interactions required for positive behaviour change in self-management. Its three components are capability, the appropriate knowledge and skills; opportunity, the relevant social or environmental resources; and motivation, the emotional or behavioural goals set (Michie, Van Stralen & West, 2011; McDonagh, 2018).

Self-management is a pivotal part in the NHS Long Term Plan to enable more patients to manage their conditions successfully and reduce the economic burden on healthcare services (NHS England, 2020). Research, such as that conducted by Barker, Steventon, Williamson and Deeny (2018), has explored the association between patient activation, a central component of self-management, and the use of healthcare services. Barker et al. (2018) used an observational, retrospective study design, with longitudinal data from adults living with a range of long-term conditions, including dementia, in one area of London. Outcomes of interest were data from the Patient Activation Measure (PAM), collected at two time-points, and variables relating to healthcare use, such as the number of hospital admissions, which was collected over two, one-year periods. The authors analysed 12,270 PAM observations from 9348 adults, which was a response rate of 17.2% and 15.4% for the two time-periods respectively. Those who displayed the most activation had fewer hospital admissions and less GP contact, and those who experienced hospital stays had a significantly shorter stay than the least activated adults (Barker et al., 2018). The authors interpret these findings as higher activation equates to increased engagement in the ongoing management of their conditions. This leads to patients who are more equipped with the knowledge to coordinate their care, therefore requiring less input from healthcare services should their condition deteriorate. Although the generalisability of these findings is limited, due to the use of data from one geographical area and the low response rate, Barker et al. highlight the long-term relationship between self-management and healthcare utilisation. Their evidence suggests that encouraging and supporting self-management could lower patients’ use of services, therefore reducing the burden on the healthcare system, and is important in the provision of high-quality care.

Evidence supports the role of self-management across a range of long-term conditions. A comprehensive meta-review from Taylor et al. (2014) provided a summary of the findings from quantitative and qualitative systematic reviews into self-management support in long-term conditions, and from systematic reviews exploring the implementation of interventions. The authors were interested in several outcomes: use of healthcare services, health outcomes, symptoms, health behaviour, quality of life, or self-efficacy. The search strategies provided 102 quantitative reviews, 30 qualitative reviews and 61 implementation reviews. Analysis highlighted reoccurring themes that were key to providing and implementing effective self-management. These included the importance of healthcare services promoting and actively engaging with patient self-management; tailoring interventions to an individual, their beliefs, and the time point in their condition; and effective communication between patient and healthcare professional (Taylor et al., 2014). The meta-reviews also explored the components that were found to be imperative to successful SMIs, which included education and information, practical support to cope with day-to-day activities, social support, and the use of action plans. Taylor et al. (2014) concluded that, to be effective, SMIs should be tailored to individual needs and be actively encouraged and supported by a communicative collaboration between patients and healthcare services. There are many components required to make an intervention successful, and self-management should be viewed as a multidimensional concept when healthcare services are providing support for patients living with long-term conditions.

1.4 Self-management in dementia

Self-management can provide a beneficial strategy in responding to the increasing incidence and prevalence of dementia, and in helping people and their families to retain control over their lives. Psychosocial interventions are one approach to implementing successful self-management, as they have the potential to enable people living with dementia to have a better quality of life (Oyebode & Parveen, 2016). The experiences of people living with dementia vary, and it has been suggested that this may be due to the interaction between cognitive impairment and a range of psychological and social factors (Oyebode & Parveen, 2016). A review from Olazaran et al. (2010) found that multi-component, non-pharmacological interventions for people living with dementia had a positive effect on activities of daily living, cognitive functioning, and mood. Additionally, interventions targeted at dyads were found to have positive effects on the quality of life of people with dementia and their caregivers. Oyebode and Parveen (2016) provided an extension to Olazaran et al.'s work by updating the evidence base to consider randomised controlled trials, controlled studies and reviews from 2008 to 2015. The 61 studies and reviews included covered the whole dementia care pathway, from community-dwelling people to residential care and end-of-life care, and considered interventions aimed at caregivers (Oyebode & Parveen, 2016). Many of the publications included discussed residential care, with a particular focus on managing the behavioural symptoms of dementia. The authors concluded that more research was needed into care within the community-dwelling dementia population, and a greater focus on interventions that help enrich the overall quality of life.

Four systematic reviews included in Taylor et al. (2014) discussed self-management in dementia. These reviews agreed on the importance of considering perceptions of independence, identity and self-worth when providing self-management support. In particular, the reviews considered those in the early stages of dementia who require greater support to reach acceptance of their diagnosis, feel secure and valued (Taylor et al., 2014). It was noticeable to the authors that the term 'self-management' was not widely used in dementia, even though it was fundamental to the successful implementation of the interventions researched, and there was a shortfall in research exploring the role of self-management in dementia for people living in the community.

Half of the reviews that discussed dementia were classed as ‘poor’ on the quality appraisal measure. This was a reoccurring issue across the reviews on other long-term conditions and should be considered when discussing the findings from Taylor et al.’s meta-reviews. The quality of the findings was also restricted by the lack of long-term follow-up studies, which prevents conclusions being drawn as to the lasting impact or implementation of the self-management support interventions discussed. Additionally, the screening of included reviews and data extraction was conducted by one reviewer, which could have introduced bias into the reporting of the findings. The authors acknowledged this possibility and stated that the reviewer received training, and a second reviewer completed checks at random on the first reviewer’s work.

Despite these limitations, Taylor et al. analysed a large number of systematic reviews and considered self-management across multiple long-term conditions, potentially increasing the generalisability of the findings. The findings provide a consensus that self-management is a popular concept across multiple long-term conditions and that interventions that support self-management can be implemented effectively. The authors highlighted the need for further research into long-term self-management in relation to specific conditions, such as dementia.

Mountain (2006) highlighted the integral role that physical and mental wellbeing play in successful self-management. Mountain and Craig (2012) emphasised that an individual needs to acknowledge and understand their dementia and be equipped with skills and strategies to cope with their symptoms to maintain their independence for as long as possible.

Through a randomised controlled trial, Quinn et al. (2016) explored an eight-week self-management group intervention in people with mild dementia. Participants were recruited alongside their caregiver and allocated to either eight-weekly group sessions or treatment as usual. Of the 24 participants recruited, 13 were allocated to the intervention group and 11 to treatment as usual. One topic per week was covered in the group sessions, which included information about dementia, activities and interests, maintaining relationships, and planning for the future. Measures were collected from both groups at baseline, three and six months, with self-efficacy scores at three months being the primary outcome (Quinn et al., 2016).

The intervention had high adherence, with all participants attending at least six sessions, and satisfaction ratings were positive. Qualitative feedback from participants in the intervention group revealed that they felt the sessions promoted independence, encouraged social support among attendees and offered a space to gain more information on their dementia diagnosis. With regards to self-efficacy, a small improvement was shown in the intervention group, when compared to the usual group, at three months and sustained at six months (Quinn et al., 2016). Although the quantitative measure of self-efficacy showed only a small improvement and would possibly suggest that the intervention was not that successful, the qualitative feedback highlighted the value of the groups and the session content. The authors emphasise the need to develop and implement more cost-effective psychosocial interventions for people living with mild dementia to better support them to live well (Quinn et al., 2016).

Øksnebjerg et al. (2019) conducted a feasibility study of a SMI for people with early-stage Alzheimer's disease. Participants were recruited from three memory clinics in Denmark, with 19 included in the final analysis. The intervention comprised eight, two-hour long weekly group sessions for participants, which focused on elements such as psychoeducation, and three individual sessions, which focused on goal setting and attainment. For these individual sessions, dyads (participant and caregiver) completed pre-intervention sessions to identify one to three personalised goals for the participant, and a post-intervention evaluation of goals (Øksnebjerg et al., 2019). Caregivers attended an additional dedicated two-hour session. Baseline and post-intervention measures were obtained. Primary outcomes were the participants' and caregivers' evaluation of goal attainment, and the participants' satisfaction with goal attainment, both assessed through 10-point Likert scale ratings (Øksnebjerg et al., 2019). Secondary outcomes included health-related quality of life and capability-related wellbeing. The authors also conducted semi-structured interviews with participants and caregivers to explore their views on the feasibility and acceptability of the intervention. Baseline characteristic data showed that participants were mostly women, had a mean age of 67.5 years, and were on average 5.5 months post-diagnosis. Analysis revealed a significant change in participants' evaluation of goal attainment and satisfaction, but this was not repeated in the caregivers' evaluations or the secondary outcome measures. However, the authors emphasise that, as a feasibility study, it was not designed to find significant differences across outcome measures. Notes from the interviews revealed that most participants felt they had gained a greater knowledge of Alzheimer's and its symptoms and had become more confident and open about living with dementia and implementing the strategies for self-management (Øksnebjerg et al., 2019).

Although the participant characteristics and recruitment location limit the generalisability of findings, Øksnebjerg et al. demonstrated that an intervention which incorporates several self-management approaches, such as goal setting and education, was feasible and applicable to people living with early-stage Alzheimer's disease. While the study was not designed to detect significant differences, the qualitative data and participant goal-attainment evaluations suggest that SMIs in dementia have the potential to provide education and positive outcomes.

In the same study, Øksnebjerg et al. (2019) also explored the promotion and adoption of assistive technology. The authors had developed the ReACT (Rehabilitation in Alzheimer's disease using cognitive support technology) app, a compensatory tool to help support memory and provide structure in daily living. Participants and caregivers were introduced to the ReACT app in one of the pre-intervention sessions, where it was discussed as a possible solution to aid memory difficulties. They were reassured that use of the app was optional during the intervention period. Log data reporting app use was analysed, alongside results from a modified version of the USE (usefulness, satisfaction, and ease of use) Questionnaire (Øksnebjerg et al., 2019). Of the 19 participants, eight were classed as 'adopters', who continued to use the app post-intervention. There were no significant differences in characteristics between 'adopters' and 'non-adopters', but 'adopters' tended to be younger. Analysis of these participants' measures showed that they had a more significant change in goal attainment rating than 'non-adopters', and, understandably, rated the app considerably higher on the USE Questionnaire (Øksnebjerg et al., 2019). Although the feasibility study could not capture all the possible factors affecting the successful adoption of the ReACT app, the findings suggest that incorporating assistive technology into a wider self-management programme could promote the uptake of app-based interventions, and that they could be another potential method of intervention delivery in dementia.

1.5 Self-management in dementia: Role of technology

Øksnebjerg et al. (2020) further explored the applicability and usability of the ReACT app-based intervention in the self-management of dementia. The authors recruited 116 participants living with dementia and 98 caregivers from nine memory clinics in Denmark to trial the ReACT app over 90 days. The app was designed to assist with memory symptoms and daily life, and comprised of a calendar, diary, checklists, memos, and contacts. Participants had a personal user account on the app, which caregivers could access through a parallel login, and both were provided with materials to explain the app and support implementation (Øksnebjerg et al., 2020). Participant characteristics, log data and outcomes from a web-based survey were collected, and those who had activated the app completed an additional measure, a modified USE Questionnaire.

Data from 112 participants and 98 caregivers was included in the final analysis, with just over half of the participants having a diagnosis of Alzheimer's disease. A professional diagnosis was not required for participation and, as a result, 32 participants had an unspecified or unconfirmed dementia diagnosis (Øksnebjerg et al., 2020). For those with a confirmed diagnosis, the time since diagnosis varied between 0-73 months, with an overall mean of 12 months. The mean score for participants on the Mini-Mental State Examination was 25, indicating mild impairment. Log data revealed that 47 participants and 78 caregivers did not activate the app at all, and the app usage by the remaining participants and caregivers varied from one to over 90 days (Øksnebjerg et al., 2020). However, 18 participants and seven caregivers did become 'adopters' and continued to use ReACT beyond the 90-day intervention period. The survey, which was completed by 35 participants, showed that those who adopted the app were not significantly different to non-adopters in their skills, level of experience, and need for help when using a tablet (Øksnebjerg et al., 2020). The USE Questionnaire data revealed a moderately high level of satisfaction with the app among participants and caregivers, and echoed Øksnebjerg et al.'s earlier study as adopters provided higher ratings than non-adopters. For those who did not activate or continue to use ReACT, a number of reasons were given, including that it was not relevant for the stage of their condition, and a preference for using non-technology-based solutions (Øksnebjerg et al., 2020). Two key factors found, which significantly impacted whether participants adopted the app were caregiver activation of ReACT, and a shorter time post-diagnosis.

It must be acknowledged that the findings are compounded by several limitations. The recruitment method relied upon people having contact with the memory clinics and staff to raise awareness of the study, therefore the final sample of participants might be biased and not representative enough. Similarly, a number of participants were classed as having a non-specific dementia diagnosis. These factors could have biased the findings, as the needs of those recruited did not match the functionalities of the ReACT app. The low response rate to the surveys could also have biased the findings, as it is possible that only those less affected by their dementia responded, therefore not providing a representative view.

Øksnebjerg et al. do however contribute some valuable data surrounding the potential factors which influence the uptake of app-based interventions among people living with mild dementia and their caregivers. The use and adoption of ReACT among participants without caregiver involvement reemphasises the importance of addressing the person living with dementia as the primary user of any assistive technology, and a number of factors should be considered when creating and delivering SMIs in dementia. The introduction of these types of SMIs early on post-diagnosis may be instrumental in whether they adopt and use them.

DemPower, an app-based intervention, was developed to promote self-management and positive relations between couples (Bielsten et al., 2020). It promoted reflection on relationship strengths, on activities that they could still do or that could be achieved with adaptations and prompted the couple to store positive memories they would like to remember. Six couples piloted DemPower in their homes, before completing semi-structured interviews which, through thematic analysis, identified three key themes: relationship growth, not feeling alone, and embracing a positive approach to life (Bielsten et al., 2020):

- Relationship growth – a dementia diagnosis was reported as affecting all perspectives of couples' everyday lives and their relationship prior to their involvement in the study. Often, their focus was on supporting one another and adjusting to the challenges of living with dementia. DemPower gave couples the opportunity to engage with activities together and promoted positive reflection on their relationships.
- Not feeling alone – couples appreciated the effort that had gone into creating DemPower, and felt it provided them with additional support in their daily lives. The app was also a useful source of information and

advice which couples could apply in their current lives and help them prepare for the future.

- Positive approach – DemPower encouraged couples to live in the present and reflect on the positive things that improved their quality of life. Their participation contributed to positive feelings and couples felt that DemPower had helped to normalise living with dementia and embrace the future.

Couples reported positive experiences engaging with DemPower, with the app enabling a better transition to living well with dementia and supporting them to embrace a self-management approach to their dementia. As Bielsten et al. (2020) recruited only a small sample of couples and conducted dyadic interviews, which could either promote or prevent the person with dementia speaking, the potential validity of their findings is therefore limited. However, the study does suggest that an app-based intervention could positively support and promote self-management in people living with dementia, improve familial relationships and enable people to feel prepared to live well with their diagnosis.

1.6 Promoting Independence in Dementia study

The Promoting Independence in Dementia (PRIDE) programme was developed with the goal of supporting people living with mild dementia, who are likely to have minor difficulties with daily activities (Csipke et al., 2021). PRIDE was a five-year project, which began in 2014, and funded by the Economic and Social Research Council. The content is presented in a manual and incorporates several principles of self-management which promote positive lifestyle changes, encourage independence, and improve the quality of life for people living with dementia and their families. These include understanding a dementia diagnosis; decision-making; identifying and using relevant resources; and becoming more of an active voice in their care (Csipke et al., 2021). PRIDE promotes the importance of social inclusion and encourages people living with dementia to participant in cognitive, physical, and social activities to improve their self-management, independence, and quality of life.

Much like the intervention developed by Quinn et al. (2016), PRIDE was designed specifically for people living with dementia, with the opportunity for informal supporters to participate alongside. The programme incorporates mental, physical and emotional topics and activities, rather than just targeting one aspect such as memory or mood as many dementia-specific interventions often do (Bielsten et al., 2020).

PRIDE is delivered through three sessions with a Dementia Advisor (DA), a trained facilitator who supports people with mild dementia and their family throughout the program (Yates et al., 2019). DAs and people with dementia work collaboratively through the manual, identifying activity plans and social participation needs, and discuss resources available to support them. There is the opportunity for a supporter, such as a relative or friend, to be involved with PRIDE, but the program is primarily aimed at people living with mild dementia.

PRIDE comprises three core topics: *Finding a Balance; People and Connections; and Keeping Going.* There are seven additional topics provided, which people can choose which ones they would like to focus on. These topics are *Keeping Mentally Active; Keeping Physically Active; Keeping Socially Active; Making Decisions; Getting Your Message Across; What Does it Mean to be Told You Have Dementia; and Keeping Healthy* (Yates et al., 2019). Woven through the content are stories about the difficulties other people living with dementia have faced, which aims to help promote discussions during and between sessions.

To help guide the activity plans and promote positive behaviour change, PRIDE incorporates three steps: planning, doing, and reviewing (Yates et al., 2019). The first step selecting an activity or action, then to consider what would encourage that activity or action and any practical factors which would facilitate or prevent it. The last step is there to encourage reflection and the application of problem-solving strategies to alter, refine or strengthen the activity plan (Yates et al., 2019). Activity plans are recorded in the manual.

1.5.1 PRIDE session structure

The session outlines below are as described in Yates et al (2019).

Session 1: DAs run through the PRIDE program, cover the core topics, and encourage reflection on the person with dementia’s current activities, interests, and preferences. The person with dementia chooses three of the seven additional topics to particularly focus on, and plans are created.

Advisors introduce the plan, do, review steps, and show how progress can be recorded in between sessions.

Session 2: Discussions and reflections take place between the person with dementia, their supporter, and DAs about whether activity plans have been successfully enacted. Reviews of the plans are completed, and adjustments are made if required. Additional plans can be made, and DAs continue to encourage the person with dementia to carry out their plans in between sessions, and to record their progress.

Session 3: Further reviews of how well the plans are being implemented will take place. The final session will also cover how the person with dementia and their supporter might continue to use the resources and skills gained through PRIDE, such as the plan, do, review steps, in the future to maintain their independence and involvement in everyday activities.

1.5.2 PRIDE feasibility study

A feasibility trial was conducted with the paper version of the PRIDE program across six sites in England (Csipke et al., 2021). Adults living with mild dementia in the community were identified through Join Dementia Research (JDR) or self-referred to the study. Once recruited, they were assigned to either the PRIDE intervention or usual care, on a 1:1 ratio. They were able to participate individually or with a supporter. PRIDE facilitators had experience working in dementia care and attended a 1-day training session prior to becoming DAs. For participants in the intervention arm, they completed three sessions with their assigned facilitator, each approximately 4 weeks apart.

Sessions lasted 60-90 minutes. The majority of participants chose to conduct the sessions in their own home. Outcome measure data was collected from participants and their supporter at baseline, 3- and 6-months. Measures focused on quality of life, activities of daily living, wellbeing, and supporters' perceptions of the person with dementia's abilities.

Of the 53 sites initially approached, 6 eligible sites were chosen to cover different geographical and socioeconomic areas to attempt to recruit a diverse sample. Within these sites, 19 facilitators were trained to be DAs. A total of 402 people were approached, with a final sample of 92 participants included in the trial, with approximately two-thirds taking part with a supporter (Csipke et al., 2021). Those in the intervention arm were given the option to use the paper manual of PRIDE, or to explore a prototype of an online version which had the same content. However, only one participant selected to use this prototype. Completion rates for the PRIDE sessions for those in the intervention arm were positive, with 91% completing session 1, 74% session 2, and 72% for the final session. Both study arms lost participants to follow-up for reasons such as withdrawal of consent and ill health. Outcome measures were completed at 3-months by 80% in the intervention arm and 89% in usual care. At 6-months, this figure dropped slightly to 76% in the PRIDE group and 83% receiving their usual care, but the high completion rates for both arms suggested that the measures selected were feasible (Csipke et al., 2021).

Outcome measures included the Control, autonomy, pleasure, and self-realization (CASP-19), Positive Psychology Outcome Measure (PPOM) and Engagement and Independence in Dementia Questionnaire (EID-Q). Data from outcome measures indicated that PRIDE was well received by participants and could be a beneficial way to promote independence and a range of activities that improve the self-management and quality of life in people living with mild dementia (Csipke et al., 2021). Qualitative analysis from interviews with four dyads supported the quantitative findings and reinforced the positive effect of involving a facilitator in delivering the PRIDE intervention.

As the COVID-19 pandemic significantly impacted on the activities people could do, and community care services, online resources and use of video call technology gathered more attention and use. Although only one participant used the online version of PRIDE during the feasibility trial, the pandemic may have changed people’s perceptions towards technology, and could be a strategy for reaching those most isolated by COVID-19 (Csipke et al., 2021).

2. Exploring the Role of Web-Based Interventions in the Self-management of Dementia: Systematic Review and Narrative Synthesis

This chapter was adapted into to a journal publication:

Lee, A. R., Gerritzen, E. V., McDermott, O., & Orrell, M. (2021). Exploring the Role of Web-Based Interventions in the Self-management of Dementia: Systematic Review and Narrative Synthesis. *Journal of medical Internet research*, *23*(7), e26551.

2.1 Background

Technology-based interventions have the potential to provide practical and effective delivery of support to affected populations across a range of health conditions (Tighe et al., 2020). Their role in dementia care is still emerging, and more research is needed to explore their current use and potential impact and highlight gaps in the literature and knowledge (Neal et al., 2021).

The UK government highlighted the importance of enabling people with dementia to live well and independently in their dementia action plan (Department of Health, 2015). Self-management was identified as a potential strategy in response to the increasing incidence and prevalence of dementia and in helping people and their families to retain control over their lives. Self-management encompasses multiple components that can support an individual to improve their physical and mental well-being, either independently or in collaboration with their health care team (Taylor et al., 2014). These components include goal setting, decision making, problem solving, accessing and using resources, strong collaboration between patients and health professionals, and patient activation (Taylor et al., 2014; de Longh et al., 2015; NHS England, 2020). The latter refers to the knowledge, skills, and confidence an individual has in managing their long-term condition and overall health and has been linked to a lower number of medical appointments and hospital admissions (Hibbard & Gilburt, 2014).

With the ever-increasing aging population, it is estimated that 1.6 million people will have a dementia diagnosis by 2040 (Alzheimer's Society, 2019). Social care costs alone amount to £15.7 (US $21.6) billion, and the hours of unpaid care by families equate to £13.9 (US $19.2) billion a year (Alzheimer's Society, 2019). Enabling people living with dementia to manage their condition more effectively, improve their overall well-being, and maintain their independence for as long as possible may provide benefits for both the population living with dementia and the health and social care sectors (Whitlatch & Orsulic-Jeras, 2018). The role of technology-based interventions in dementia care is still emerging; however, they may offer the potential to provide practical and effective delivery of support for people living with dementia and their families (Whitlatch & Orsulic-Jeras, 2018).

The lived experiences of people with dementia vary considerably, and it has been suggested that this may be due to the interaction between cognitive impairment and a range of psychological and social factors (Oyebode & Parveen, 2019). One review found that multicomponent, nonpharmacological interventions for people living with dementia had a positive effect on the activities of daily living, cognitive functioning, and mood (Olazarán et al., 2010). In addition, interventions targeted at dyads were found to have positive effects on the quality of life of people with dementia and their caregivers. Oyebode and Parveen (2019) extended the previous evidence by updating the evidence base to consider randomized controlled trials (RCTs), controlled studies, and reviews from 2008 to 2015. The 61 studies and reviews included covered the entire dementia care pathway, from community-dwelling people to residential care and end-of-life care, and considered interventions aimed at caregivers (Oyebode & Parveen, 2019). Many of the publications included discussed residential care, with a focus on managing the behavioural symptoms of dementia. The authors concluded that more research was needed into care within the community-dwelling dementia population and a greater focus on interventions that help to enrich the overall quality of life.

A review of web-based interventions that targeted support and education to informal caregivers found that they have potential benefits for both the supporter and the person with dementia (Leng, Zhao, Xiqo, Li & Wang, 2020). A systematic search of the literature pertaining to RCTs of web-based interventions resulted in 17 studies. Interventions were found to be effective in decreasing symptoms of depression and anxiety in informal caregivers but failed to significantly reduce caregiver burden or improve quality of life. However, 6 studies demonstrated that caregiver interventions had the potential to positively improve the symptoms of depression and anxiety in caregivers and the quality of life of people with dementia. The review suggested that, when tailored to individuals and targeted at both caregivers and people with dementia, web-based interventions have the potential to improve the well-being and quality of life of all involved in informal dementia care.

Although the older population is generally perceived to have fewer technology skills, there is an emerging evidence base suggesting that technology plays a role in the self-management of dementia. In fact, it has been suggested that technology has five potential roles in dementia care (Wey, 2004): facilitating declining cognition, enabling better performance of daily activities, ensuring safety, helping maintain active social involvement, and providing support and reassurance for informal caregivers. All these roles aim to assist people living with dementia to maintain their independence, improve their quality of life, and contribute to their self-management.

Research focused specifically on app-based interventions targeted at people living with dementia has also supported their use in the self-management of the condition. A study exploring the use of tablet computers and apps by people with mild dementia demonstrated that people were quickly able to learn how to use new technology and engage positively with the content of the apps (Lim, Wallace, Luszcz & Reynolds, 2013). The findings highlighted the importance of motivational benefits for people to incorporate new technology into their daily lives, such as improving their self-management and quality of life. Access to informal technology support to aid adoption was shown to be valued by people living with dementia and their families. However, consideration should be given to individualizing interventions to encourage engagement (Lim et al., 2013). Several factors should be considered when creating and delivering self-management interventions (SMIs) in dementia to maximize their potential benefit and use.

Dementia is a chronic, progressive condition that affects multiple faculties in daily life (Dementia UK, 2020). The evidence base for self-management in dementia is limited, particularly regarding support for people living with mild dementia (Taylor et al., 2014; het Veld, Verkaik, van Meijel & Francke, 2020). Therefore, an in-depth review of the current knowledge and use of interventions, particularly regarding the role of technology, is needed.

2.2 Objectives

There are a range of nonpharmacological digital interventions that may be beneficial to people living with dementia, such as cognitive stimulation therapy (Rai, Griffiths, Yates, Schneider & Orrell, 2021). However, the aim of this review is to explore the existing use of web- or app-based interventions that facilitate or support self-management in dementia, the concepts they target, and their effectiveness.

The findings are likely to be useful to health services and policy makers when considering how to include self-management in dementia and to researchers to help design better studies on the effectiveness of web- and app-based SMIs. This review could provide useful insights into the role of web- and app-based interventions in the self-management of dementia, and the findings should be considered in clinical practice. A protocol was written for this review but was not registered with PROSPERO (Booth et al., 2012).

2.3 Methods

2.3.1 Overview

Narrative synthesis is one approach to the systematic review and synthesis of findings from multiple studies and different methodologies. Although it allows for the inclusion of statistical data, the distinguishing characteristic of narrative synthesis is the use of a textual approach to summarize and describe findings to form a story from the included studies.

2.3.2 Search strategy

A systematic search was conducted across five electronic databases in February 2020: Cochrane (Central Register of Controlled Trials), Web of Science, PubMed, Scopus, and ProQuest (Science Database, Technology Collection, PsycArticles, and Social Science Database). After scoping the literature, a trial-and-error process was applied to explore search term combinations. With each combination, every third title and abstract were screened on the first two pages of results to determine whether they were relevant to the review questions. The key terms found were combined to create the final search: (web* OR online* OR computer* OR internet* OR app* OR smartphone*) AND (intervention* OR support*) AND (self-manag* OR independ*) AND (dement*). Independence was found to be a term often used in discussions about self-management; therefore, it was included in the final search. Terms such as *tablet* were excluded from the search because of their connotations with pharmacological interventions found during the initial scope of the literature. The search included research, journal, and review or evaluation articles, as it was thought that these would encompass novel research and evaluation studies. The date limits of January 2010 to March 2020 were placed on the search to encompass any prospective publications.

2.3.3 Study selection

The search results were imported into EndNote (Clarivate Analytics), and duplicates were removed. Each title and abstract were read twice and vetted by the primary reviewer (ARL), with the inclusion criteria acting as a guide to identify possible papers. A second reviewer (EVG) independently examined 5% of the total results to provide a consensus on the quality of the search. Potentially relevant references were imported into Rayyan (Ouzzani, Hammady, Fedorowics & Elmagarmid, 2016), ready for a full-text review by the two reviewers (Abigail Rebecca Lee; ARL, and Esther Vera Gerritzen; EVG). Each reviewer independently read the full texts twice before deciding whether to include or exclude the review. Any conflicts regarding the inclusion or exclusion of papers at any stage of the process were discussed by the two reviewers. A manual search of the references from the included papers was conducted for any suitable additions.

2.3.4 Inclusion criteria

The inclusion criteria were as follows:

- Participant population included adults aged 18 years or above, with a confirmed diagnosis of dementia.
- Participant population was community dwelling.
- Included a web- or app-based intervention aimed at improving self-management or independence for people living with dementia.
- Intervention was for independent or dyadic use (involvement from an informal supporter).
- Included RCTs or quasi-experimental, observational, qualitative, or mixed methods studies.
- Publication dates were between January 2010 and March 2020. These years were selected based on the definition of web-based interventions by Barak, Klein and Proudfoot (2009).

2.3.5 Exclusion criteria

The exclusion criteria were as follows:

- Protocol papers, opinion pieces, conference abstracts, scoping reviews, or systematic reviews.
- Interventions that were exclusively for supporters.
- Studies with a focus on care management and community-delivered interventions where the planning and coordination of dementia care was the focus (Reilly et al., 2015).
- Published in a language other than English, and a translation was not available.

2.3.6 Data extraction

The principal reviewer (ARL) completed the data extraction using bespoke extraction forms based on the guidance of the Centre for Reviews and Dissemination for systematic reviews (Centre for Reviews and Dissemination, 2009). The data extraction forms were piloted before the review. A second independent review of the completed data extraction was provided by EVG. The following data items were extracted: (1) study information, (2) study characteristics, (3) population characteristics, (4) intervention, (5) outcome data, and (6) results.

2.3.7 Quality assessment and risk of bias in individual studies

The quality of studies assessed aspects such as the appropriateness of the study design, the potential risk of bias, and the quality of reporting. A total of 2 assessment tools were used: the modified Downs and Black (1998) checklist, as used in Trac et al (2016), to measure study quality for quantitative trials and the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (2018). Mixed methods studies were assessed using both checklists.

The scoring system used for the modified Downs and Black checklist followed that outlined in the study by O’Connor et al (2015), with 24-28 points regarded as *excellent*, 19-23 as *good*, 14-18 as *fair*, and less than 14 as *poor*. The 10-item CASP checklist had three response options: *meeting the criteria*, *unable to tell*, and *not meeting the criteria*. It was scored according to the method detailed in Stansfeld et al (2019), with *meeting the criteria* given a score of 1 and *unable to tell* or *not meeting the criteria* given a score of 0. For the tenth item, which asks how valuable the research is and does not provide the response options, the principal reviewer decided whether to award a score of 1. The principal reviewer administered a scoring system in which a score of 4 or less was defined as *poor*, 5-7 as *moderate*, and 8 or above as *high*. These tools were selected as they are suitable for randomized, nonrandomized, and qualitative studies. They have also been used in previous narrative synthesis systematic reviews (Stansfeld et al., 2019; McDermott, Crellin, Ridder & Orrell, 2013) and are recommended by the Centre for Reviews and Dissemination (2009).

2.3.8 Data synthesis

Narrative synthesis allows for the inclusion of qualitative, quantitative, and mixed methods studies and for a systematic yet transparent review of results. Therefore, owing to the diverse selection of studies and review transparency, narrative synthesis was viewed as the most suitable option for this review.

Unlike more analytical approaches to literature reviews, such as meta-analyses, narrative synthesis does not rely on a rigorously tested structured technique. Popay et al (2006) created guidance and a framework of four interconnecting elements to improve the transparency of narrative synthesis reviews. This review applied the following guidance and framework:

1. Developed a theory of how the intervention works, why, and for whom: a scoping of the relevant literature provided a greater understanding of the review topic, and the rationale for using web- or app-based interventions in dementia studies was considered.

Including the initial evidence, this stage guided the research questions, development of the search terms, and inclusion criteria for the review.

2. Developed a preliminary synthesis of findings of included studies: data were extracted from each of the studies and tabulated. Descriptive summaries of the same features from each study were extracted and tabulated to help with the initial comparison. Studies were clustered according to the methodology: quantitative, qualitative, and mixed methods.
3. Explored relationships within and between studies: concept mapping was used on the extracted data on study interventions to explore the similarities and differences between the studies and the factors that might have affected this.
4. Assessed the robustness of the synthesis: two validity assessment tools were used in this study. Quantitative studies were assessed using the modified Downs and Black checklist [(1998), and qualitative studies were assessed using the CASP checklist (2018). Studies with mixed methodologies were assessed using both tools.

2.4 Results

2.4.1 Reviewing process

A total of 2560 references were identified using the search strategy. After duplicates were removed, 1164 references remained, and their titles and abstracts were screened for inclusion criteria. Of these, 1130 were excluded as they did not focus on relevant interventions or include participants with dementia, leaving 34 papers for full-text screening. One additional paper was found through a manual search of the reference lists of the papers selected for full-text screening. After a full-text review conducted by the principal and secondary reviewers, 11 papers met the inclusion criteria and were accepted for this review. The main reasons for exclusion were that the app- or web-based interventions were not the primary focus of the study; they were not described in sufficient detail for analysis, for example, lacking description of the intervention and mode of delivery; and the outcome measures were not relevant to self-management in relation to independence. Figure 1 shows a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) diagram of the study selection process.

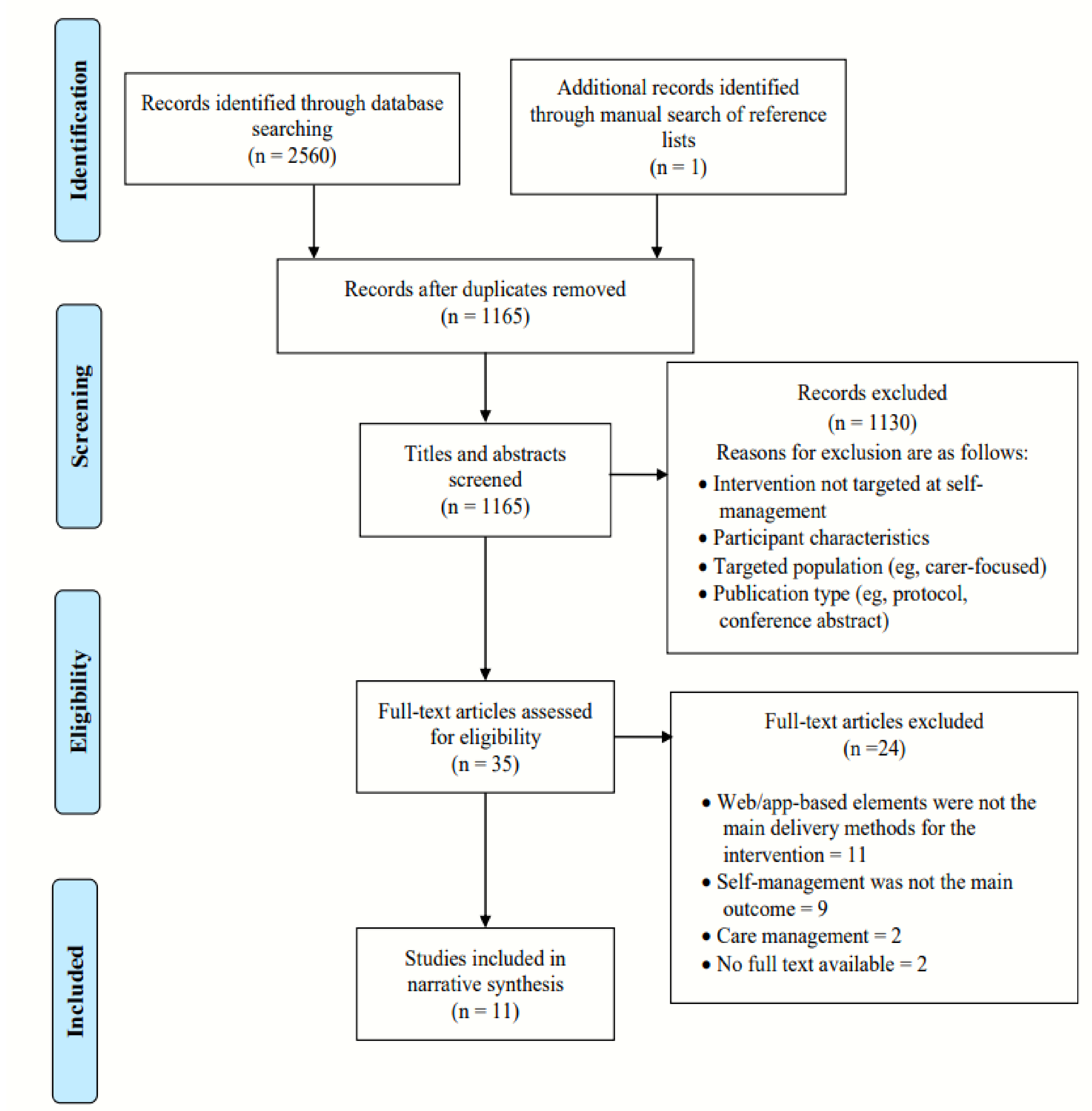

Figure 1. PRISMA diagram of the systematic review search process.

2.4.2 Preliminary synthesis of findings

Study characteristics:

The included articles varied in location (Denmark=2, Sweden=1, United Kingdom=1, Netherlands=1, and United States=1); however, several studies did not specify a country (n=5). For studies with an unspecified location, the primary reviewer contacted the corresponding author but received no reply. Day and activity centers were the most common locations for the interventions (n=6), with private homes being the second most popular (n=5). Almost all the articles had either quantitative (n=5) or mixed methodology (n=4), and a nonrandomized, nonconcurrent multiple baseline approach was the most common study design (n=6). This meant that data from multiple baseline and intervention sessions were not collected simultaneously for all participants. No control groups or blinding procedures were used in any of the included studies.

Participant characteristics:

A total of 189 people living with dementia participated across the included studies, with an age range of 59-92 years. All studies had small sample sizes of ≤11, except for one study, which had 116 participants (Øksnebjerg et al., 2020). Alzheimer disease was the most common diagnosis among study participants (n=7), and the Mini Mental State Exam score was the most common measure used to describe participants (n=8). Scores varied from <6 to 22, indicating that the participants had mild to severe dementia. Participants were recruited from day and activity centers for people living with dementia (n=6) or from memory clinics (n=3). Supporters were recruited in four studies, two as part of a dyad (Thorpe, Forchhammer & Maier, 2019; Kerssens et al., 2015), and two as supporters (Øksnebjerg et al., 2020; Kerkhof et al., 2019). Of the 121 supporters recruited, 119 (98.3%) were informal and 2 (1.7%) were formal (see Appendix 9.1 for further details of the study characteristics).

2.4.3 Exploring relationships within and among studies

Robustness of synthesis:

The quality of the included studies varied between fair and high. All the quantitative studies (Perilli et al., 2012; Perilli et al., 2013; Lancioni et al., 2017; Lancioni et al., 2018; Lancioni et al., 2019) were of fair quality, in accordance with the Downs and Black checklist scoring. These studies scored highly on reporting aims, intervention details, measuring outcome measures and providing a comprehensive summary of their findings. Mixed methods studies (Øksnebjerg et al., 2020; Thorpe et al., 2019; Kerssens et al., 2015; McGoldrick, Crawford & Evans, 2021) scored high or moderate on the qualitative CASP checklist but fair on the quantitative checklist. Qualitative commentary on participant recruitment and the summary of findings complemented the quantitative reporting of aims, outcome measures, intervention details, and participant numbers and characteristics. Both measures suggested that greater reporting of data analyses, ethical considerations, the acknowledgment of monitoring for adverse events, and the inclusion of blinding would strengthen the methodology and study reporting. Of the two qualitative studies, one (Kerkhof et al., 2019) scored highly on the CASP, whereas the other was moderate (Boman, Lundberg, Starkhammar & Nygård, 2014). The reporting of study aims, data collection, and findings was strong; however, more details on the data analysis techniques used, reasoning for the chosen research design, and the relationship between researchers and participants would have been preferred. In addition, wider contribution of the research could have been discussed more thoroughly in both papers. The content of the included studies was judged to be of sufficient quality and robust enough to be included in the narrative synthesis. Table 1 shows the quality assessment scores of each of the included studies.

Table 1. Quality assessment scores.

Study	**Methodology**	**Quality assessment score**		**Quality**
		Value, N (%)	Total, N	
Perilli et al (2012)	Quantitative	15 (54)	28	Fair
Perilli et al (2013)	Quantitative	15 (54)	28	Fair
Lancioni et al (2017)	Quantitative	16 (57)	28	Fair
Lancioni et al (2018)	Quantitative	14 (50)	28	Fair
Lancioni et al (2019)	Quantitative	14 (50)	28	Fair
Thorpe et al (2019)				
	Mixed methods (quantitative)	14 (50)	28	Fair
	Mixed methods (qualitative)	7 (70)	10	Moderate
Øksnebjerg et al (2020)				
	Mixed methods (quantitative)	14 (50)	28	Fair

	Mixed methods (qualitative)	9 (90)	10	High
Kerssens et al (2015)				
	Mixed methods (quantitative)	15 (54)	28	Fair
	Mixed methods (qualitative)	6 (60)	10	Moderate
McGoldrick et al (2019)				
	Mixed methods (quantitative)	17 (61)	28	Fair
	Mixed methods (qualitative)	9 (90)	10	High
Kerkhof et al (2019)	Qualitative	8 (80)	10	High
Boman et al (2014)	Qualitative	7 (70)	10	Moderate

Interventions:

Concept mapping enabled a clear comparison of the interventions among the included studies. All the studies described their interventions in detail. There was a range of web- and app-based technologies used to deliver SMIs: touch screen computers (n=1), smartphone apps (n=3), and multicomponent (n=7). Of the multicomponent interventions, smartphones or tablets were the most commonly used (n=4), followed by earpieces or headphones (n=3) and headsets (n=3), although apps (n=2), computers (n=1), and smartwatches (n=1) were also used. These findings suggest that apps are becoming more popular in the delivery of interventions, either alone or as part of a more complex, multicomponent method. A total of two studies examined the same intervention but with different participants (Perilli et al., 2012, Perilli et al., 2013), and three others focused on a similar alternative intervention in different participant groups (Lancioni et al., 2017; Lancioni et al., 2018; Lancioni et al., 2019).

There were similarities and differences among the aims of the studies with regard to the self-management concepts targeted by the interventions. In total, seven of the studies focused on interventions that targeted more than one self-management concept, although no intervention covered all domains or self-management concepts. One study targeted three concepts, six studies considered two concepts, and three studies focused on one self-management concept. Four overarching self-management concepts were widely assessed across the included studies: independence, activities of daily living, communication, and cognition.

Independence was the most commonly identified concept (n=8). A total of two studies focused on the effect of independence on the quality of life. Other popular concepts targeted by interventions in several studies were improving activities of daily living (n=5) and communication (n=5). Studies that explored communication could be divided into enhancing social relationships (n=3) and promoting social engagement (n=2). A total of two studies centered on improving cognitive functioning and memory enhancement. Figure 2 shows the intervention concept map. The numbers **refer to the study identities found in the study and outcome tables (Appendix** 9.1).

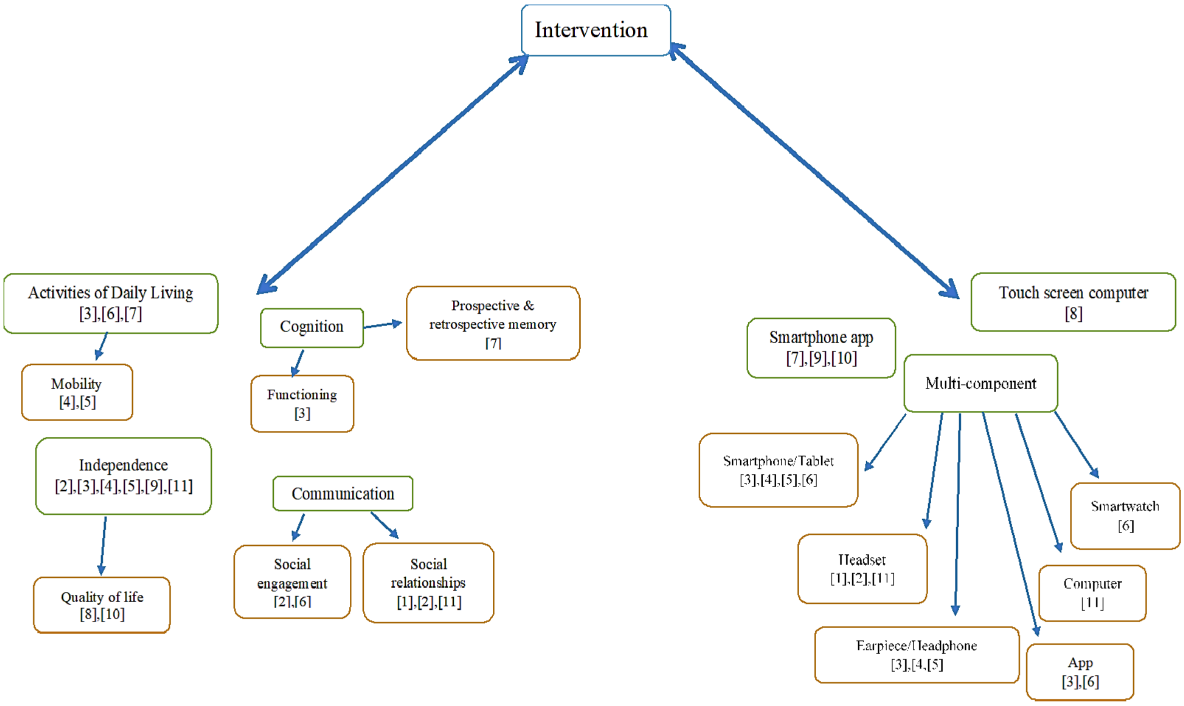

Figure 2. Concept mapping of the included interventions and the elements they targeted.

All interventions could be tailored or modified in their delivery to fit individual needs or goals. The study period was reported either through the number of intervention sessions or the number of days, with one exception where the duration of the session was provided. The number of intervention sessions varied between 20 and 119 sessions and the number of days from 24 days to nine months. Researchers or the research team was heavily involved in the intervention setup and provision across all 11 included studies.

Outcomes: Activities

A total of 6 studies focused on outcomes that measured or explored the completion of activity. In total, two studies measured the completion rate of independent phone calls to people who were relevant to the participants (Perilli et al., 2012; Perilli et al., 2013). The mean number of independent calls in the baseline of both studies was 0; however, this increased to around 4 during the respective interventions. A similar study explored the experiences of using a mock-up videophone (Boman et al., 2014). Observations and qualitative feedback from participants showed that they initially struggled with the new intervention but could use it independently following guidance from the research team. Participants reported that the intervention was enjoyable to use, but they would have preferred more options to individualize it. A total of three studies had outcomes that measured independent ambulation and object use (Lancioni et al., 2017; Lancioni et al., 2018; Lancioni et al., 2019). The interventions in these studies appeared to have a considerable impact on participants' ability to start and complete independent activities successfully, such as making a cup of coffee or preparing food. In particular, one study reported a significant improvement in all participants executing the correct steps to complete their activities (Lancioni et al., 2018).

Outcomes: Engagement

The outcomes of the other five studies (Øksnebjerg et al., 2020; Thorpe et al., 2019; Kerssens et al., 2015; Kerkhof et al., 2019; McGoldrick et al., 2021) explored the wider impact and experiences of app-based and wearable technology in dementia care. Interventions in two studies led to increased activity levels and a sense of independence in participants, which promoted positive engagement with daily activities (Thorpe et al., 2019; Kerssens et al., 2015). Several issues regarding the incorporation of web- and app-based interventions in dementia were highlighted in the qualitative outcomes. Contextual and personal factors, such as a lack of confidence in using technology, concerns about dealing with technical difficulties, and forgetting to use apps, were some of the issues raised by participants and their families. These factors were key to non-adoption in the respective studies and should be considered when designing and delivering future studies in dementia care.

Outcomes: Adoption and usability

The adoption and usability of apps were measured in two studies. One study (Øksnebjerg et al., 2020) trialed the Rehabilitation in Alzheimer Disease Using Cognitive Support Technology app-based intervention, designed to assist with memory symptoms and daily activities. The overall mean Usefulness, Satisfaction, and Ease of use Questionnaire for dementia scores in this study of 40 for participants and 34 for supporters out of a total of 60 indicated a moderately high-level satisfaction rating of the intervention regarding usefulness, satisfaction, and ease of use. The researchers divided participants into adopters and nonadopters, depending on their usage of the intervention. There were 18 participants and seven supporters who continued to use the app after the 90-day study period and were classed as *adopters*. However, 47 participants and 78 supporters did not activate the app. The survey, which was completed by 35 participants, showed that those who adopted the app were not significantly different from nonadopters in their skills, level of experience, and need for help when using a tablet. For those who did not activate or continue to use Rehabilitation in Alzheimer Disease Using Cognitive Support Technology, several reasons were given, including that it was not relevant for the stage of their condition and a preference for using nontechnology-based solutions (Øksnebjerg et al., 2020).

Another study (McGoldrick et al., 2021) used the Unified Theory of Acceptance and Use of Technology Questionnaire to assess changes in attitudes toward the use of their reminder app in eight domains. Unified Theory of Acceptance and Use of Technology Questionnaire scores were collected from two participants, with one showing a positive decrease in pre- and postscores but the other showed a negative increase in half of the domains. The adoption of web- and app-based interventions appears to be dependent upon individuals connecting with the intervention and feeling confident about using it and may or may not result in a positive research outcome.

2.5 Discussion

2.5.1 Principal findings

After reviewing the current evidence, web- and app-based interventions have the potential to benefit the lives and care of people living with dementia. This narrative synthesis review examined the literature discussing the use of web- and app-based technology in delivering SMIs in dementia care. From the 11 studies that met the inclusion criteria, it is apparent that a range of methodologies have been applied when researching this topic. All the included studies were generally of fair to good quality, and the results were consistent and coherent, which suggests that the synthesis was robust. However, the scores from the quality appraisal measures suggest that there is a lack of high-quality research on web- and app-based interventions. More details on participant recruitment methods and the acknowledgment of potential adverse events were needed, and the blinding of those conducting outcome measures would have strengthened the methodology. The interventions reviewed targeted independence, communication, and activities of daily living, and 7 studies focused on multiple concepts of self-management. However, there was inconsistency regarding the number of domains related to dementia self-management, such as daily living activities, which were targeted by each intervention.

Most studies had very small participant numbers, ranging from 3 to 11, except for Øksnebjerg et al. (2020), who recruited 116 participants living with dementia and 98 supporters. Owing to the small sample sizes, studies were unable to conduct comprehensive analyses on their results and often relied on reporting changes in the mean scores of outcome measures. Recruitment methods across studies were open to bias, as they usually relied on people who had contact with memory clinics or day centers. Therefore, the participants might not have been representative of the wider dementia population. There were no suitable RCTs, and none of the included studies reported blinding participants or researchers. This highlights the shortfall in comprehensive, large-scale RCTs of web- and app-based SMIs in dementia and identifies an area for future research.

Reflection was undertaken by the authors throughout the review process to identify any limitations or biases that could influence the review findings. As critical reflection is not a linear process, the authors acknowledge that there may be additional missed limitations. One strength of this review is that the search terms were created according to the scope of the relevant literature. This helped ensure that the final search would find the most relevant results and that the number of missed articles would be significantly reduced. Another strength is that the articles were differentiated and excluded using a standardized definition of care management. Having a definition meant a uniform exclusion of articles and a greater inclusion of self-management–focused results.

Although the search terms appear robust and the results were excluded in a uniform manner, this review has several limitations. First, the included articles were limited to those published in English or those that had an English translation available, which might have led to some relevant research being missed. It was decided to restrict participant populations to people living with dementia in the community, rather than those in residential homes or institutionalized care, which means the search strategy missed any web- or app-based SMIs in those settings. This could be a potential area for future reviews. Finally, owing to the small number of participants involved across the included studies, it is difficult for this review to provide a comprehensive evaluation of the effects of web- or app-based interventions on the self-management of dementia. There is a need for studies to explore these interventions in larger samples of people living with dementia and across a range of dementias and severities, for more significant conclusions to be drawn. As narrative synthesis takes a textual approach to analyzing evidence, the quality of methodological reporting could have biased the findings.

2.5.2 Critical reflection

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2.5.3 Comparison with previous work

To our knowledge, this is the first review to systematically synthesize evidence concerning web- and app-based SMIs for people living with dementia. However, previous reviews have identified digital interventions aimed at people living with noncommunicable diseases, such as cardiovascular diseases. One such review examined the potential role of digital interventions in promoting healthy behaviour change and improving self-management (Tighe et al., 2020). A search of 9 databases resulted in 29 publications meeting the inclusion criteria, with these studies covering 7 different interventions. All 7 interventions were identified as web-based, with 4 also having mobile-based delivery and targeted health behaviours such as physical activity and diet.

Clinical and psychosocial outcomes, such as quality of life, were reported in the included studies. Significant effects on psychosocial outcomes were reported only for one intervention. However, positive clinical outcomes on activity levels, disease-specific self-care, and self-monitoring behaviours were apparent across all interventions. These findings present a similar view to this review and indicate that evidence-based digital interventions, often provided through web- or app-based delivery, have the potential to promote positive behaviour change and better support the self-management of conditions when delivered with correct guidance and tailored to the individual.

2.5.4 Conclusion

This review explored and examined evidence concerning web- and app-based interventions targeted at self-management of dementia through a narrative synthesis methodology. Many of the interventions reviewed had a positive impact on the self-management concept they were targeting, which suggests that their use could prove beneficial in dementia care. The successful adoption of these interventions appears to be dependent on individuals' engagement and their confidence in using the technology. Common factors influencing non-adoption appear to be a lack of confidence or familiarity with using technology, apprehension about encountering and resolving technological difficulties, and forgetting to use the intervention.

The findings are beneficial to health services and policy makers in considering how to incorporate self-management in dementia care and to researchers to help design better studies on the effectiveness of web- and app-based interventions. Barriers to adoption and implementation should be considered when delivering these interventions digitally to maximize the potential reach and effect on people living with dementia and their families. Conclusions drawn from this review will provide a positive contribution to the growing evidence base and increase the understanding of the use of these types of interventions in the self-management of dementia and their role in service provision.

3. RE-AIM Study of the PRIDE Self-management App: Study Protocol

This chapter was adapted into a journal publication:

Lee, A. R., McDermott, O., Guo, B., Roe, J., & Orrell, M. (2022). A Self-management App for People Living With Mild Dementia (PRIDE): Protocol for a Pre-Post Feasibility Study. *JMIR Research Protocols*, *11*(7), e33881.

3.1 RE-AIM framework

The study will incorporate the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Glasgow, Vogt & Boles, 1999) to explore the effectiveness and impact of the PRIDE-app on people living with mild dementia. The RE-AIM framework was designed to assess and evaluate health behaviour interventions, better understand their impact, and improve the translation of research into broader health services (Glasgow et al., 1999). It has been successfully incorporated into the design, reporting, and reviewing of other self-management focused studies, trialling web or app-base interventions (Palermo, de la Vega, Dudeney, Murray & Law, 2018; Yoshida et al., 2020). One example was demonstrated by Yoshida et al. (2020) who incorporated RE-AIM to review of app- and text messaging-based self-management interventions in diabetes. The reporting of factors varied between the dimensions within the 20 included studies. Factors of reach (inclusion and exclusion criteria; sample size; and participation rate), effectiveness (results of follow-ups), adoption (description of intervention location) and Implementation (intervention duration and frequency) were reported in the included papers (Yoshida et al., 2020). However, there was a lack of reporting on some factors, including representativeness (reach); attrition rates (effectiveness); description of staff who delivered interventions and the method used to identify and recruit them (adoption); cost of implementation measures (implementation); and cost of maintenance measures (maintenance). Overall, many gaps identified in the reporting of RE-AIM criteria in mobile-based intervention studies need to be resolved through further research to improve the quality of reporting (Yoshida et al., 2020). The RE-AIM framework is constructed using five dimensions:

1. Reach – whether an intervention found the target population
2. Effectiveness (or Efficacy) – the short- and/or long-term impacts of an intervention
3. Adoption – whether the target staff, settings and individuals use the intervention
4. Implementation – if the intervention has been delivered and implemented as intended
5. Maintenance – the degree to which an intervention is sustained over time, and in the most cost-effective way.

3.2 Objectives

This protocol is written in accordance with the SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) checklist for reporting protocols (Chan et al., 2013). The overall aim of the study is to explore how the PRIDE-app can support the self-management of people living with mild dementia, using the RE-AIM framework: 1) the extent to which the PRIDE-app has the capacity to reach people with mild dementia, 2) the effectiveness of the intervention, and 3) the adoptability of the intervention. The findings will contribute to future developments of the PRIDE-app and inform a larger trial of its effectiveness.

3.3 Methods

3.3.1 Ethics approval

This study has been reviewed and approved by the Oxford Research Ethics Committee (21/SC/0066). All minor and substantial amendments will be reviewed by the University of Nottingham (UoN) and Oxford Research Ethics Committee. All participants, supporters, and interviewees will provide written informed consent. A copy of the ethical approval letter can be found in Appendix 9.2.

3.3.2 RE-AIM study design

We plan to conduct a pre-post feasibility study of the PRIDE-app in people living with mild dementia. The RE-AIM framework (Glasgow et al., 1999) will enable us to identify key components for effective adoption, successful implementation, and sustained use of the PRIDE-app, and identify potential barriers for the wider use of web-based psychosocial interventions for dementia.

The expected data collection period will be up to 12 months from enrolment of the first participant. Participant recruitment will be carried out for up to six months, and follow-up will continue for a maximum of six months following the end of recruitment. All five of the RE-AIM framework dimensions will be explored in this study. However, as the intervention is not being implemented into normal routine care, the implementation and maintenance dimensions will not be assessed in depth and will instead be explored as secondary objectives.

3.3.3 RE-AIM study setting

Research activities, including participant recruitment and intervention delivery, will be carried out within secondary care National Health Service (NHS) Trusts. The study will start as a single NHS Trust site, using relevant services within their region, and then proceed to recruit up to five additional research sites through the National Institute for Health Research's Clinical Research Network portfolio. To give sites more flexibility, the services they use are within their discretion. Any service with the capacity and where service users meet the inclusion criteria is eligible, and sites can use as many services as they have the capacity to. All intervention delivery and data collection activities will be conducted remotely, either on the web or via telephone or video call.

Two documents were made to provide any interested site with an overview of their responsibilities and the role of facilitators, and these were sent to sites following their initial interest. If the site had the capacity to complete their expected role, then the Local Information Pack was sent to the site and their local CRN. Within the Local Information Pack, there was the protocol, consent and information sheets, case report forms (CRFs), a study manual and other important study documents. A copy of the study manual can be found in Appendix 9.3.

If, after reading the Local Information Pack, sites maintained their interest in supporting the study, then a non-substantial ethical amendment was submitted to add a new research site. Once ethical approval was given, the UoN team worked in collaboration with the sites' research teams to support the study set-up.

3.3.4 Recruitment

There will be three possible pathways through which potential participants will be identified for recruitment in the study.

NHS pathway

Participants will be recruited from NHS Services for people with dementia within participatory care trusts by their research and delivery team. The initial approach will be from a member of the patient's usual care team, who will obtain patients' consent to pass their details onto the research and delivery teams, who will then complete a pre-screening telephone interview and the CRF.

Recruitment from this pathway will be divided into group targets, such as age and ethnicity, to increase the diversity and representativeness of the end participant sample. For example, recruiting participants will be divided into the following age groups: >65 years, 65 to 74 years, 75 to 84 years, and >85 years. The initial target will be to recruit 15 participants from each age group. Similarly, with ethnicity, the initial target will be to recruit a minimum of one Black, Asian, or Minority Ethnic individual for every three White participants. It is hoped that by using group targets, the recruited participants will represent the full spectrum of people living with mild dementia in England. If the ethnicity of participants is not as diverse as possible, then sites will be asked to oversample from Black, Asian and Minority Ethnic (BAME) groups to maximize their representativeness in the final participant group.

Join Dementia Research

Join Dementia is a web-based self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia, and healthy volunteers to register their interest in participating in research. We will register the study at the site and set inclusion and exclusion criteria. Volunteers who register their interest in the study will be contacted by the UoN team, who will then conduct the pre-screening telephone interview and complete the CRF.

Self-referral

Participants will also be able to self-refer directly to the UoN team. Potential participants may become aware of the study through relevant local and national charities, patient organizations, and through the general promotion of the study through relevant organizations’ newsletters, social media, mailing lists, and websites.

3.3.5 Participants

The minimum recruitment aim for the entire study is 60 participants living with dementia and a maximum of 90 participants. The recruitment target for individual NHS Trusts will be 10 to 15 people living with dementia. Each participant will have the option to participate with a supporter (a relative or close friend); however, this is not a criterion for inclusion. All participants will be assigned to the PRIDE app, and they will continue to receive their usual care outside of the study. The ability to provide informed consent is vital. As we are unable to collect this in-person, owing to COVID-19 restrictions, informed consent forms and information sheets will be provided electronically to interested participants. Members of the research or NHS site teams will go through the documents over telephone or video calls with everyone to ensure that they understand these documents before signing up for the study.

3.4 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria are presented in Textbox 1.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Aged ≥18 years
- Self-report a medically confirmed diagnosis of mild dementia
- Able to provide informed consent and engage with the intervention
- Have access to Wi-Fi, a computer or tablet computer, telephone number, and email address.

Exclusion criteria

- Living in a care home or other institutionalized setting

3.4.1 Facilitator recruitment

The capacity for sites to provide suitable facilitators to be trained as DAs and deliver the intervention was emphasised in all site guidance documentation. A recruitment guide of three to four facilitators per research site was given, although this could be tailored in relation to recruitment numbers at individual sites. Staff members, placement trainees, or work experience individuals (with an NHS contract) were eligible to volunteer. However, if they could not commit to deliver three sessions to at least one participant, they were excluded. Inclusion criteria for facilitators was:

- Aged 18 or over; there is no upper age limit.
- A staff member of a participating NHS Trust.
- Able and willing to deliver all three PRIDE-app intervention sessions to at least one participant.
- If taking part in interviews, then able and willing to discuss their experience as a facilitator.
- Able to give informed consent in the judgement of the recruiting researcher.
- Able to read and communicate verbally in English.

Consent forms, information sheets and the DA handbook were sent to facilitators prior to the first training session.

3.4.2 Facilitator training

The original PRIDE programme delivered training across a whole day, as an interactive workshop. Due to the restrictions in place at the time and the geographical spread of sites, all training was delivered remotely through Microsoft Teams. A meeting with Dr Phuong Leung, an honorary research fellow at University College London who developed and delivered the PRIDE training, was organised in December 2020. The meeting provided the opportunity to learn about the framework behind PRIDE and how facilitator training was delivered in the feasibility study.

Following the meeting, a new training presentation and DA handbook (Appendix 9.4) were created to support facilitator understanding of PRIDE and of the PRIDE-app itself. Training was divided into two sessions: the first lasted 30 – 45 minutes and provided background to PRIDE, an introduction to the PRIDE-app, role of DAs, session outline, and the plan, do, review steps; the second lasted approximately 20 minutes and gave attendees an opportunity to ask questions about training and their role in the study. Access to the development version of the PRIDE-app was provided to facilitators in-between training sessions. This enabled them to see the PRIDE-app from a participant viewpoint and trial the interactive activities they would be supporting participants through.

3.4.3 Fidelity checklists

Interventions are not always delivered as intended or in their full capacity. To record how the PRIDE-app was delivered and assess whether all aspects of the programme were able to be covered by facilitators within sessions, DAs and participants completed fidelity checklists following each of their PRIDE sessions. Checklists were completed independently and neither party saw the other's responses. These checklists would help us to better understand which components of the PRIDE-app programme were or were not delivered or understood and the possible reasons for this. Checklists were based on those produced by Dr Holly Walton for her PhD thesis on fidelity in the original PRIDE programme (Walton, 2018). Wording and design were adapted to suit the present study.

Facilitator checklists asked DAs to report whether items were 'Done', completed 'To some extent', or 'Not done'. If one of the latter two options were selected, then the 'Reason for not delivering' column would be filled in with reasons such as running out of time or simply forgetting to include that item. Participants were given a similar checklist to completed for session activities, with the response options of 'Happened', 'Possibly happened' and 'Did not happen'. For activities completed after the session or since the last session, the options were 'Yes', 'To some extent' and 'No. Following completion of checklists, they were emailed back to the study team for analysis. Copies of the checklists for participants and facilitators are in Appendix 9.5.

3.5 Intervention

3.5.1 Overview

The PRIDE app is a web-based handbook that provides information, case stories, and support for self-management across a range of topics often affected by a dementia diagnosis. The topics covered within the app are Keeping Mentally Active, Keeping Physically Active, Keeping Socially Active, Making Decisions, Getting Your Message Across, Receiving a Diagnosis, and Keeping Healthy.

This study will be delivered by facilitators called dementia advisers and the PhD student managing the study. The advisers will usually be NHS workers, ideally with some prior experience in dementia services, who volunteer to complete two mandatory training sessions and can commit to delivering the intervention to at least one participant. Training sessions, delivered by the PhD student, will last 20 to 45 minutes and introduce facilitators to the PRIDE program and the key sections of the PRIDE app. Following training, dementia advisers will be paired with the participants and will begin the PRIDE app intervention. There will be three one-to-one sessions, delivered remotely via video or telephone calls, which will last between 30 and 90 minutes each and will be spaced two-to-four weeks apart.

Session 1: Introduction

Lasting approximately 60 to 90 minutes, this session will provide participants with a brief overview of the aims of PRIDE, complete the core introductory session pages, encourage them to reflect on their daily activities, and introduce the PRIDE app. The general content of the Introduction session are presented in Textbox 2.

Textbox 2. General content of the introduction session.

Introduction session

- Aim of Promoting Independence in Dementia (PRIDE)
- Complete PRIDE profile
- Core topics
    - Finding a balance
    - People and connections
    - Keep going
- Personalize topics—participants will choose 3 main topics to focus on
- Familiarization with PRIDE app
    - Log-in process
    - Adding social contacts
    - Activity plans

Advisers will encourage participants to identify important aspects of their daily lives, discuss how to maintain or enhance the activities or routines they value and identify new activities they might benefit from. Participants will choose 3 topics and plan at least one activity they want to work on, which will be reviewed in later sessions.

Session 2: Review

The PRIDE app has a built-in review page for participants to complete alongside their advisers, and all key discussion points and progress will be recorded. Advisers will encourage participants to reflect on their progress and create or amend specific plans for activities or actions that will promote their independence. Choices and activities may be refined according to the participants' and supporters' experience of implementation and any needs that may have arisen since the first session. Barriers that may have prevented progress will be discussed, and the solutions will be explored. New activity options may also be set within the lifestyle domain topics. Emphasis will be placed on encouraging participants to continue implementing their plans between their sessions. Session discussions will include the following:

1. Progress since the last session and providing positive feedback
2. What worked or helped them achieve goals and what hindered
3. Overcoming barriers
4. Satisfaction with current plans and if any changes are wanted

Session 3: Final

In the final session, participant progress will be reviewed again, and a maintenance plan exploring how PRIDE could continue to support them after the study will be developed to encourage long-term change.

Session discussion will include the following:

1. Progress since the last session

2. How PRIDE could continue to help them in the future—PRIDE’s “Plan, do, review” steps are a practical approach to help them continue their everyday activities
3. Encouragement to maintain a normal routine and social contact and use the steps when planning new activities.

Plan, Do, Review

A principal technique of the PRIDE program is plan, do, review, and advisers will incorporate the technique to support participants in creating specific plans for activities or actions that will promote their independence. The participant and supporter will put their plans into practice between sessions and record their progress on the PRIDE app. To encourage participants, advisers will do the following:

1. Help them think about the action they would like to take or the activity they would like to do that would promote their independence
2. Support them in planning activities they would like to work on based on their topic choices, such as where their activity will take place, when they can begin their action plan or start making changes, and how they can do things in different ways
3. Explain how to record activities between sessions

3.6 Evaluation Outcomes

This study will record quantitative and qualitative data to collect all aspects of the RE-AIM framework that we will explore. Table 2 outlines how each RE-AIM concept will be explored through analyses of quantitative and qualitative data.

Table 2. How Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) dimensions will be addressed in the study.

RE-AIM dimension	Definition	How addressed in the study
Reach	The absolute number, proportion, and representativeness of individuals contacted and those who are willing to participate in the intervention and reasons given as to why or why not choose to participate in the study.	Recruitment and characteristic figures (identification): eligibility rate, characteristics of eligible people approached (age, gender, and ethnicity), participation rate, and representativeness of participants; app use data, participant characteristics, and interviews (engagement): Did participants engage regularly with the PRIDE[a]-app? What were the characteristics of those who used the app and why? The baseline to 6-month participation figures.

Effectiveness	Does the PRIDE app positively impact important individual outcomes, such as mood and quality of life and whether there are any potential negative effects?	Change of pre- and postintervention scores: CASP-19[b], IADL[c], EQ-5D-5L[d], GDS[e], EID-Q[f], and global change measure.
Adoption	The absolute number, proportion, and representativeness of settings and the target patient group and intervention facilitators who are willing to initiate a program and why.	Postintervention qualitative interviews with participants: How did participants feel they benefited from using the app and why or why not? How did the app affect their lives; for example, impact on daily activities and independence? Did they need additional help to use it? app use: How much did participants use the app and for how long? Which elements were most useful? participant retention rate: How many participants

		continued the study after baseline? How many completed the 3 intervention sessions? interviews with facilitators and clinical staff: How would the app fit into the existing services? How well was it delivered? Who is best to deliver it? How will the app be paid for?
Implementation	The extent to which an intervention may be delivered as intended and whether individuals would use the intervention.	Postintervention qualitative interviews with participants, facilitators, and clinical staff (information on delivery, barriers for delivery, and implementation): the ease of using the app, whether workarounds were needed, and if so, why? How would the app fit into the existing services? Who is best to

		deliver it? How will the app be paid for?
Maintenance	The long-term effects of a program on outcomes (usually 6 or more months) and the extent a program becomes part of routine practice.	Postintervention qualitative interviews with participants, facilitators, and clinical staff: How would the app fit into the existing services? Who is best to deliver it? How could the app be integrated into the existing care system?

[a]PRIDE: Promoting Independence in Dementia.

[b]CASP-19: Control, Autonomy, Self-realization, and Pleasure Scale-19.

[c]IADL: Lawton Instrumental Activities of Daily Living Scale.

[d]EQ-5D-5L: EuroQoL Quality of Life

[e]GDS: Geriatric Depression Scale.

[f]EID-Q: Engagement and Independence in Dementia Questionnaire.

3.6.1 Sample Size

For a pre-post comparison, 62 participants will be needed to detect a moderate effect size (Cohen *d*=0.4 and correlation=0.4) using 80% power at a 2-tailed .05 significance level. We will approach up to 200 people with mild dementia and aim to recruit a minimum of 60 and a maximum of 90 participants for the study, depending on the resources available, each with an optional supporter. These figures represent the total number of participants with dementia across all recruitment sites.

3.7 Quantitative Outcomes

3.7.1 Overview

Quantitative measures will be collected at baseline, 3 months, and 6 months from participants and supporters. For participants, the outcomes collected will help to evaluate the effectiveness of the PRIDE app and its impact on their quality of life. Measures completed by supporters will explore the impact of the PRIDE app on their mood, quality of life, and perceived change in their relatives or friends with dementia. Measures will be completed either on the web or on paper, with the final decision left to the participant or the supporter. All participants and supporters will have the option to complete their questionnaires with the help of a researcher, who will be either a PhD student or a member of their local research team, and this will be done remotely over telephone or video calls. As measures will be completed remotely, the researchers will be reliant on the participants or supporters communicating any difficulties encountered when completing them. All measures can be found in Appendix 9.6.

3.7.2 People Living with Dementia

Control, Autonomy, Self-realization, and Pleasure Scale-19: Baseline and 3 Months and 6 Months After the Intervention

The Control, Autonomy, Self-realization, and Pleasure Scale (Hyde, Wiggins, Higgs & Blane, 2003) has 19 items, each measured on a 4-point Likert scale

(0=never, 1=not often, 2=sometimes, and 3=often). Items will include “I feel left out of things” and “I enjoy the things that I do.” Scores range from 0 to 57, with higher scores indicating higher levels of well-being (Stoner, Orrell & Spector, 2019). The total and individual item scores will be recorded and used for the analysis.

EuroQoL Quality of Life Questionnaire-5 Domains, 5 Levels: Baseline and 3 Months and 6 Months After the Intervention

The EuroQoL Quality of Life Questionnaire-5 Domains, 5 Levels (EuroQol, 2020) measures 5 domains of quality of life: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Each domain has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The levels are scored from 1 to 5 to indicate increasing severity. The participant indicates which level is most appropriate for their situation and provides a self-rated health score on the vertical visual scale, which ranges from 0 to 100 (where 100 is the best health). Individual item and health scores will be recorded and used in the analysis.

Lawton Instrumental Activities of Daily Living Scale: Baseline and 3 Months and 6 Months After the Intervention

The Lawton Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) contains 8 domains that assess an individual’s ability to complete tasks necessary for independent living, such as preparing meals and maintaining a clean house. Each domain will be scored either 0 or 1, and a summary score of 0 (low functioning) to 8 (high functioning) will be used in the analysis. The measure is particularly good at identifying how a person is functioning at present and for identifying improvement or deterioration over time.

Geriatric Depression Scale: Baseline and 3 Months and 6 Months After the Intervention

The Geriatric Depression Scale (short form) is a 15-item measure that can be self-reported or read out to the participants if required. Each item has a "yes" or "no" answer, and the response indicating depression is scored as a point. A score of 0 to 5 is normal, a score >5 suggests depression, and a score of ≥10 indicates severe depression (Sheikh & Yesavage, 1986). The total score will be used in the analysis.

Engagement and Independence in Dementia Questionnaire: Baseline and 3 Months and 6 Months After the Intervention

The Engagement and Independence in Dementia Questionnaire has 26 items that assess the degree to which a person with dementia feels independent and engages socially with those around them. It reflects the multifaceted nature of independence in dementia and includes items related to remaining active, decision-making, reciprocity, and connectedness to others. Each item is measured on a 5-point Likert scale (0=not true at all, 4=true nearly all the time) and was developed for a sample of older adults with dementia (Stoner, Orrell & Spector, 2018). The total and individual item scores will be recorded and used for the analysis.

Global Change (Self-rated): 3 Months and 6 Months After the Intervention

The global change measure will ask participants about any change in their well-being and sense of independence since the baseline. The questions will be “Compared with 3/6 months ago when you started in the PRIDE study, how would you rate your general well-being now?” and “Compared with 3/6 months ago when you started in the PRIDE study, how independent do you feel now?” A 5-point ordinal scale (1=much better, 3=no change, and 5=much worse) and (1=much more independent, 3=no change, and 5=a bit less independent) will be used to measure change.

3.7.3 Supporters (Informal Carers)

General Health Questionnaire: Baseline and 3 Months and 6 Months After the Intervention

The General Health Questionnaire (Goldberg et al., 1997) has 12 items that assess an individual’s current state and asks whether it differs from their usual state. Each item is rated on a 4-point scale (less than usual, no more than usual, rather more than usual, or much more than usual). Two popular scoring methods are used: General Health Questionnaire (0-0-1-1) and Likert (0-1-2-3), each providing a total score for analysis. The total and individual item scores will be recorded for the analysis. For both methods, the wording of the items means that reverse scoring is not required. The severity level is indicated by how high the score is.

EuroQoL Quality of Life Questionnaire-5 Domains, 5 Levels: Baseline and 3 Months and 6 Months After the Intervention

As with the participants, individual item and health scores will be used in the analysis.

Global Change (Proxy-Rated): 3 Months and 6 Months After the Intervention

The global change measure asks supporters about their perceived change in participants' well-being and sense of independence since baseline. The questions will be "Compared with 3/6 months ago when you started in the PRIDE study, how would you rate the general well-being of your relative/friend now?" and "Compared with 3/6 months ago when you started in the PRIDE study, how independent do you feel your relative/friend is now?" A 5-point ordinal scale (1=much better, 3=no change, and 5=much worse) and (1=much more independent, 3=no change, and 5=a bit less independent) will be used to measure change.

3.8 Qualitative Outcomes

The experiences and perspectives of the study participants and facilitators will be explored through postintervention interviews. Up to 20 participants and dyads will be invited to discuss and reflect on their experience of using the PRIDE app. Additional interviews will be conducted with up to 10 facilitators and five senior NHS service staff to explore their experiences of delivering the intervention and how the PRIDE app could be implemented into existing services. Interviews and analysis will be conducted by the PhD student managing this study (ARL).

Participants and their supporters, if taking part, will be invited to attend an interview at eight to 10 weeks, shortly after the completion of the intervention. The final number of interviewees will be determined based on the data saturation. Participants will be asked at the point of obtaining consent and again, when invited, whether they are comfortable with being contacted to complete the interviews. Because of the COVID-19 pandemic, interviews are likely to be conducted remotely, via telephone or video calls. They will be audio recorded and will last for a maximum of 45 minutes.

Additional facilitator and service staff interviews will also be conducted remotely and audio recorded. An email to the research sites will ask volunteers to complete short interviews, which will discuss their facilitation experiences. Through snowball sampling, we aim to interview five additional service staff members who could provide feedback on the potential implementation and maintenance of the PRIDE app intervention. Both interviews will last for a maximum of 30 minutes.

For participant interviews, questions will explore their quality of life, experiences of using the intervention, and the impact of the lifestyle changes encouraged by the intervention. The themes covered will include the following:

1. Acceptability of the intervention and whether they enjoyed using the PRIDE app
2. Experience of using the intervention and its impact on daily life

3. Factors that may mediate or moderate the impact or effectiveness of the intervention
4. Likelihood of using the skills or behaviour changes in the future
5. Barriers to and facilitators for continued use of the behaviour changes encouraged through the intervention

For facilitator interviews, the themes covered will include the following:

1. Barriers to and facilitators for the delivery of the intervention
2. Skills and competencies required for delivery
3. Ease of delivery

For clinical staff, the themes covered will include the following:

1. How the PRIDE app intervention could fit into the existing care model
2. Would it be a financially viable intervention in the current health care system

3.8.1 Interview question development

Discussions between ARL and Dr Orii McDermott (OM) about the study aims, and drawing on their previous experience with dementia research, guided ARL in the development of the initial question guides. The questions created for people with dementia and their supporters explored whether they had completed all three sessions with Advisors; their views on the content of the PRIDE-app; its usability and how this could be improved; and whether they felt they had benefitted from their time using it. Prior to finalizing this interview schedule, an advert for people with lived experience to join a Patient and Public Involvement group was sent to local dementia groups. The intention was to establish a group which could meet regularly during the development of the interview materials, to maximize the dementia-friendliness of the wording. Due to the ongoing COVID-19 pandemic, recruitment was understandably impacted and only two people volunteered to join, with one attending the virtual meeting. The final semi-structured schedule developed with the involvement of a person with lived experience of dementia can be seen in Appendix 9.7. A similar schedule was developed for DAs, with questions more directed at the implementation and maintenance of the PRIDE-app, and the Advisor training provision. The DA schedule can be found in Appendix 9.7. The research team developed semi-structured interview schedules. This approach will be adopted to ensure that topics relevant to the study's aims are discussed. Consideration will be given as to how the order of questioning could improve the interview content and whether prompts will be needed to further expand the answers provided. However, the interview schedule will be flexible enough to allow for the discussion of any additional topics mentioned by the participants, which may be beneficial to the research aims if explored.

3.9 Data Analysis

Quantitative and qualitative data will be analyzed to provide insight into whether participants have adopted the intervention in their daily lives, whether they would be willing to continue to use the intervention, and whether it has had a positive effect on their quality of life and dementia self-management. Data will be analyzed anonymously using Stata 17 (StataCorp).

As patients will be recruited from various study sites and measured at baseline and follow-up, all measures will be summarized by site and across the measuring time. Outcome data will first be explored through descriptive analysis, with the mean (SD) for normally distributed variables, median (IQR) for skewed variables, and frequency (%) for each level of categorical variables. To evaluate the efficacy of the PRIDE app, multilevel linear regression modelling will be conducted to quantify the change estimates (95% CI) from baseline to the first and second follow-ups for normally distributed outcomes. The skewed outcome, if any, will be transformed for multilevel modelling. To understand the reach of the PRIDE app, analyses will be conducted on eligibility percentage—the number of potentially eligible participants approached, participation rate, and demographics—to understand who was approached and how representative the final participant sample is. Participant retention rate figures will show how well the intervention was adopted by participants and whether the PRIDE app could be a suitable long-term intervention for people with dementia. Analyses of pre- and post-intervention outcome measures will reveal whether the PRIDE app was effective in improving the respective dimensions measured.

From the PRIDE app use data, we will be able to analyse the number of times participants accessed the app, which topics were most popular, and the duration of app use (using log-in and log-off times). These figures will help us understand whether participants actively engaged with the PRIDE app and how well the app was adopted in their daily lives. Missing outcome information will be examined, and its influence on each change score estimate will be checked using data with missingness imputed using multiple imputations with an analytic model used to impute missingness, assuming the missingness mechanism is Missing-At-Random.

Qualitative interview data will be pseudonymized and transcribed verbatim by an NHS-approved transcription service. Participants' comments will be anonymized to maintain confidentiality. The data will be analysed through thematic analysis by ARL. Thematic analysis has been chosen because of its flexible application; appropriateness for the study's methodology and research aims; and ability to identify, examine, and report recurring and unexpected themes found within the interviews (Braun & Clarke, 2006).

A deductive approach to thematic analysis will be incorporated, thereby enabling more focused analysis, with the themes identified driven by the research aims and topics that need to be explored. The following analytical process will be applied (Braun & Clarke, 2006):

- Stage I—familiarization of data: the audio recordings will be transcribed and read multiple times to ensure familiarization. Initial ideas for codes are noted in the margin of the transcript.
- *Stage II—generating initial codes:* initial ideas will be coded and data extracts relevant to these codes collated.
- *Stage III—searching for themes:* ideas for themes will be developed in the initial coding and extraction stages. Additional data relevant to

these themes will be collected. The study's research aims will be kept in mind during the development of the themes.

- *Stage IV—reviewing themes:* a diagram will be created and reviewed, showing the relationship among themes, data extracts, and data as a whole.
- *Stage V—defining and naming themes:* a further thorough analysis of themes will be conducted, with clear definitions and names developed for each theme.
- *Stage VI—producing the report:* appropriate codes, themes, and data extracts will be finalized for analysis, with these suited to the research aims.

3.10 Monitoring

The occurrence of an adverse event as a result of participation in this study is not expected and therefore will not be routinely recorded by the UoN team. However, individual sites will be able to follow local procedures to monitor and record any events. The UoN team will be informed of any adverse events affecting the study participants.

3.11 Results

The analysis of measures will explore the impact of the PRIDE app on participants' independence, mood, and quality of life. Pre- and post- scores on outcome measures will show any statistical result of the potential effect of participation on individuals. Overall mean scores will help provide insight into the impact of app use across all participants and supporters, providing an indication of whether the PRIDE app could benefit people living with mild dementia and their supporters. With regard to the RE-AIM elements, reach will be understood through the participation rate and demographics, which will show the characteristics of the participants recruited and how well they have been retained. Pre- and post-outcome scores will support potential effectiveness. Adoption will be explored using the participant retention rate and use data gathered from the PRIDE app. This will help us understand whether the participants actively engaged with the app and how well it was adopted in their daily lives.

Interview data will discuss participants' experiences of taking part in the study, whether they enjoyed using the PRIDE app, and if they felt it had had a positive effect on their well-being and independence. The questions for the facilitator and service staff will focus on the ease of session delivery, barriers to successful delivery, and whether the PRIDE app could be implemented and maintained within the existing health care system. Themes that are generated through the thematic analysis process (Braun & Clarke, 2006) will complement the quantitative data in terms of the RE-AIM elements, in particular, the adoption, implementation, and maintenance of the PRIDE app by participants and dementia services. Data collection began in June 2021 and will finish in September 2022. The study has recruited four NHS sites, 28 participants with dementia, 14 supporters. Study findings are anticipated to be published in Spring 2023. All data will be analysed anonymously.

3.12 Discussion

3.12.1 Overview

This RE-AIM study will explore the PRIDE app psychosocial intervention to support self-management in people living with mild dementia. Through quantitative and qualitative data, we will evaluate its reach, effectiveness and adoptability in the independence and quality of life of the participants and their supporters before and after the intervention. Additional data collected from intervention facilitators and clinical staff will help us to better understand how the PRIDE app could be successfully implemented and maintained in existing dementia services.

In some cases, the process of seeking a diagnosis can be prolonged due to service delivery, diagnosis stigma, and more recently, the impact of the COVID-19 pandemic. Regarding the PRIDE app study, this might mean that by the time of diagnosis, some individuals would be ineligible to participate. Therefore, the inclusion criteria ask for mild dementia but place no exact assessment figures. All potential participants will complete a pre-screening interview where the relevant researcher will access their suitability and complete a CRF. We recognize that completing measures remotely may result in feelings of embarrassment or reluctance if participants experience issues and do not feel confident about asking for support. However, steps will be taken to provide as much support as possible to the participants throughout their involvement in the study. This will include follow-up contact if measures have not been completed within the timeframe to ensure that participants are not experiencing any issues. Further research on self-management interventions may benefit from including those with mild cognitive impairment and determining whether they have an effect on individuals' self-management of the condition and any reduction in the risk of developing dementia.

3.12.2 Limitations

Our study is small scale, with no control group, which reduces the generalizability and reliability of the findings. A small sample size also means that we are not able to demonstrate the individual needs of different dementias. However, if the results indicate potential feasibility and effectiveness, it will be important to conduct a larger trial with a greater number of participants and a control group to validate any initial findings and explore any differences among dementia diagnoses. A patient and public consultations group will be established to provide ongoing input from people and families living with dementia. Members will provide feedback on interview schedules, dissemination materials, and how best to disseminate the findings to relevant people. A paper discussing the development process of the PRIDE app is in progress and will include the original development and more recent modifications.

3.12.3 Conclusions

Dementia affects every aspect of an individual's life. Equipping them with relevant knowledge and support facilitates greater self-management and enables people living with dementia and their families to have a better quality of life. This study will be the first to explore whether the PRIDE app intervention can have a positive impact on the self-management of people living with mild dementia through a pre- and post-outcome study design. The knowledge generated from this RE-AIM study will help with the continuing development of the PRIDE app and other similar interventions and in the design of future studies. The data will also help us understand the potential clinical implications of the PRIDE app and how it might be best integrated into existing services.

4. Development of the PRIDE self-management app

This chapter was adapted into a journal publication:

Lee, A.R., Csipke, E., Yates, L., Moniz-Cook, E., McDermott, O., Taylor, S., Stephens, M., Kelleher, D., & Orrell, M. (2023). A Web-Based Self-management App for Living Well With Dementia: User-Centered Development Study. *JMIR Human Factors*, *10*, e40785.

4.1 Introduction

Living well with dementia has often been constructed around quality of life, choice, autonomy, dignity and staying as independent as possible (Lord et al., 2020). People with dementia have themselves identified how they quantify living well, which included involvement at home and in the neighborhood, independence, self-management of symptoms, and quality of life. They also recommend that these should be considered when developing dementia-specific interventions (Reilly et al., 2020). Many people with dementia have the ability to maintain an active and social life, but some of the negative effects of receiving a diagnosis, depression or diagnosis-stigma can result in social isolation and withdrawal from society (Hobson, 2019; Amano, Reynolds, Scher & Jia, 2021). It is important that people living with mild dementia are supported and encouraged to maintain their normal activities, remain independent and stay active within society for as long as they are able to.

Promoting Independence in Dementia (PRIDE) is a psychosocial program designed for people living with mild dementia, whose symptoms of dementia affect day-to-day activities but are able to live relatively independently, and promotes choice, autonomy and social inclusion. It encourages them to maintain and develop cognitive, physical, and social activities to improve their self-management, independence, and quality of life. The content is delivered in a manualized format, with interactive activities and discussion points throughout, such as creating activity plans. Users are paired with trained facilitators, who go through the PRIDE program and support the development and execution of personalized activity plans. Across three sessions, users and facilitators plan, carry out, and review users' individual plans and discuss how techniques learnt through PRIDE could support them in approaching activities in the future.

A multi-centre feasibility study of the PRIDE program provided participants with both a paper manual and an electronic version, so they were able to choose whether to use one or both formats (Csipke et al., 2021). The paper manual was the more popular, being used by all participants in the intervention arm, but one participant chose to use both the paper and electronic versions. Findings suggested that the PRIDE intervention was a useful and relevant program to promote independence and support people with dementia in their daily activities, and it was generally well-received by participants (Csipke et al., 2021). Although only one participant accessed the electronic version of PRIDE, the COVID-19 epidemic meant that more people have resorted to online resources and therefore further developments to refine the PRIDE web-based app would enable it to reach those who have become further isolated over the pandemic and beyond (Csipke et al., 2021).

This type of intervention delivery has the potential to be successfully adopted by people with dementia and their families (Lee, Gerritzen, McDermott & Orrell, 2021), but little is known about the technological processes required for developing high quality web-apps for people with dementia and their families. However, more high-quality research is needed in the area, and more consideration of the barriers and facilitators to use and how these impact adoptions.

4.1.1 Aim

As part of a large research program, a paper-based manualized psychosocial intervention of the Promoting Independence in Dementia (PRIDE) program was developed and feasibility tested (Csipke et al., 2021). Here we describe the processes associated with technological work and adaptation of the manualized PRIDE intervention into a usable web-based platform, the PRIDE-app. The aims of the web platform development were to; (1) design an innovative login system tailored to the needs and abilities of people with dementia; and (2) involve project stakeholders in the development of the website in order to ensure the intervention is tailored to their needs, preferences, and abilities. This involvement would help involve more consideration as to the barriers and facilitators to use of the PRIDE-app.

4.2 Methods

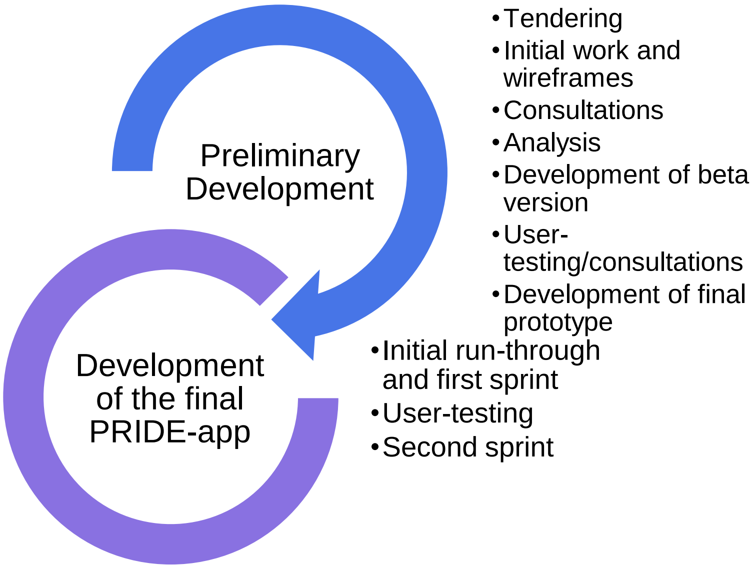


Figure 3. Outline of the process used in the development of the PRIDE-app.

Preliminary development

Work on the development of the PRIDE website began upon completion of the second draft of the PRIDE intervention (Yates et al., 2019) and ran concurrently with the feasibility testing of the paper-based version of the program. The development stages of the web-based platform were: (1) technological work, including project tendering and preliminary development: (2) consultations; (3) development of a beta version of the website and user testing/consultation; and (4) production of final web platform.

Tendering

An invitation to tender (ITT) was written with input from MindTech Healthcare Technology Co-operative, a National Institute for Healthcare Research (NIHR) funded national centre for the development, adoption, and evaluation of new technologies for mental healthcare and dementia. The standard university tendering procedure, managed by the procurement department, was followed. Developers accessed the brief which included details of the PRIDE intervention and requirements from the web-app (e.g. must be user-friendly, adhere to Dementia Empowerment Engagement Programme (DEEP) guidelines (2013), and bid for the work contact.

Twenty-six bids were received, and two members of the PRIDE team independently reviewed all bids, rating them according to standardised scoring criteria provided by procurement. Dimensions of the bids assessed included: service delivery, website development, implementation plan, and data security. Each dimension received a pass or fail, and notes were made to support these ratings. A total quality score was generated based on scores from each dimension, and bids were ranked, and a shortlist was made which was reviewed by a Digital Research Specialist (DRS). The final shortlist (7 bids) was further discussed, the outcome of which was the selection of four software companies to be interviewed. Ayup Digital Designs was commissioned to do the work on the basis of demonstration of an excellent understanding of the intervention, dementia-friendly design, and previous experience of health and social care-based projects.

Preliminary work and initial wireframes

Ayup followed a user-centred design approach broadly in-line with the Government Digital Service Standard Agile Delivery methodology. The first stage in the website development process was a ‘discover’ meeting attended by representatives from Ayup and the PRIDE team. The purpose of the meeting was to consolidate the company's understanding of the intervention and discuss ideas for how the paper-based manual content and processes of the intervention would be adopted for the website. Ayup carried out work on information architecture, user journeys, user experience and interface design. Alpha stage wireframe designs were created and reviewed by the project team. The work outputs facilitated further discussion on how the website would work in practise (e.g. how information would be navigated and presented by stakeholders).

Consultations on initial wireframes

Multiple consultations were arranged with various groups during the multiple iterations of the website. First, an opportunistic sample of key stakeholders was invited to discuss the initial drafts, including logins, font, colours and layout. Three consultations were held. The first of which was comprised of three members of a UoN Public and Patient Involvement (PPI) group with dementia. The PPI group was held regularly and typically attended by people with dementia, carers, researchers, representatives from local community organisations, and healthcare professionals. Participants were invited to be involved in the consultations following a presentation on the PRIDE project. They had not participated in any aspect of PRIDE. The second consultation involved a person with dementia, their supporter and memory nurses who had participated in the PRIDE feasibility study. These participants had insight into the experience of receiving or delivering the intervention in practice, therefore could comment in depth on the content of the intervention, intervention processes, and directly compare the paper-based and web-app version. The memory nurses invited dyads (people with dementia and their supporter) who had completed or were part way through the intervention to the session. A third consultation was conducted via teleconference with a researcher who had delivered several intervention sessions using the paper manual and materials at a PRIDE site. This researcher was contacted via email with an invitation to participate by the PRIDE team member who provided intervention training.

Consultations were planned to last a maximum of three hours. Examples of the website wireframes (blueprints that show the basic framework of a website) were shown on a projector screen, with pages adjusted for size as necessary. Before the close of the discussion, the web-developer summarised key points from the notes and asked the group to confirm these reflected their comments. Consultation two was shorter at around two hours in total. An online video conferencing program was used for consultation three so that the wireframes could be viewed.

Discussions topics

Discussions in consultation one focused on; (i) use of technology in order to identify which devices the intervention would most likely be accessed on (e.g. tablet, mobile, laptop), (ii) challenges with technology to highlight user experience, (iii) PRIDE login system to determine whether the innovative methods proposed were acceptable to stakeholders (easy to remember yet secure), and (iv) a limited selection of wireframes and examples of design features (e.g. font, color palettes, icons) were also shown to the group for feedback.

The same discussion points were covered by participants in consultation two. However, the group were also asked for their ideas about how best to adapt the paper-based version of the program for delivery via website. The group considered proposed ideas for the website presentation of activities featured in the paper-based materials (e.g. completion of profile), and how the website could be used to facilitate interaction between the person, supporter and the facilitator during the session compared to the paper-based manual and worksheets. Consultation three was focused on reviewing the wireframes and considering the functionality of the website from the perspective of an interventionist with experience of delivering PRIDE.

Analysis

Notes were taken at the consultations by the researcher facilitating the session and the website designer. These were circulated amongst the team and collated after the consultation. No formal analyses were performed on the data gathered; however, action points were generated for use by the website developer in creating further versions of the website wireframes.

Development of beta version

Findings from the user research activities were synthesised and assumptions around user stories / website features assumptions were tested and validated. A further round of design iterations was undertaken before a Beta version of the website was developed.

User-testing and consultations on beta version

The beta version was reviewed by the research team and checks (e.g. spelling, grammar, flow through intervention process) performed, before consultation sessions were arranged with stakeholders. The purpose of these consultations was to observe participants using the website and gather comments on usability issues such as ease of navigation. A key aspect of the user testing was to enter dummy data into the activity sections of the website and set up of the log in system.

Consultations on the beta version of the website included four people with dementia, four supporters, two PPI members and three intervention facilitators. Consultations took place at the homes of consultees or in NHS or university departments. Researchers were provided with a topic guide including questions, prompts, and a list of tasks for consultees to complete (e.g. log in and out of the website). Researchers implemented a ‘think aloud’ protocol, encouraging consultees to comment as they used the website to yield insight into their experience, particularly areas of difficulty (Olmsted-Hawala, Murphy, Hawala & Ashenfelter, 2010). Comments were noted and supplemented with written notes by the researcher.

Development of final web-based prototype

Feedback from user testing and consultations were fed back to the design team who subsequently made design tweaks to the Beta version to enhance usability. The full website was developed with special attention made to accessibility features to ensure the website was as accessible as possible.

Ethics

All consultations were informal, where no personal information about participants was collected and discussions were not recorded. All participants verbally consented to engage in the discussions. Consultations were specified in the PRIDE protocol on the basis of which the study received ethical approval from East Midlands Nottingham 1 Research Ethics Committee (REC) (16/EM/0044). All participants with dementia were in the early stages of the condition and were deemed able to provide verbal consent for their involvement by the recruiting researcher. Members of the PPI group with dementia were actively and regularly involved in PPI, community, and research activities associated with university and other organisations such as the NHS, therefore their participation in these consultations was not considered above and beyond their usual activities.

4.2.1 Development of the final PRIDE-app

Following on from the web-based app prototype which was developed during the PRIDE feasibility trial (Csipke et al., 2021), further work was carried out on the PRIDE-app by researchers at the UoN in collaboration with the development company Ayup.

Researchers and Ayup agreed on continuing an agile approach to app development, as it enabled dynamic collaboration between all relevant stakeholders, and was also the standard practice for Ayup. As part of this approach, intensive development periods called sprints were incorporated to ensure priority work was completed within a specific timeframe. For this stage of development, each sprint would last one week, and Ayup's workload would be aimed specifically at the PRIDE-app.

Initial run-through and first sprint

The work on further developing the PRIDE-app began in November 2019. An initial run through of the prototype was conducted by two researchers at the UoN (ARL and OM), with a list of issues regarding the design, functionality, and content of the web-app collated. One researcher viewed the app from a practical viewpoint, whereas the other utilized their knowledge and experience of working with people with dementia and viewed it from their perspective. Potential amendments were noted and then discussed among the study team. A specification document was compiled and sent to Ayup, the company responsible for app development for the study. Following the initial run through, two development sprints were scheduled for Spring and Summer 2020.

The focus for the first sprint was the highest priority issues identified with regards to the functionality, content, and overall design of the PRIDE-app. Specification and priority documents were supplied to Ayup prior to a sprint planning meeting between the study team and development company. This provided the chance to discuss the workload and clarify any last improvements before to the sprint start date.

Specification and priority documents

The specification document outlined the goals and key points for the first sprint:

- Navigation to and between sections – clearer signposting of the content, such as the addition of a contents page so users can see which section they are completing and making the sidebar menu items more evident.
- Larger font and better page layout (less empty white space) – reduction in the amount of text per page, to reduce the need to scroll down the screen, and increase of font size.
- Addition of identifiable icons – clear and consistent use of easily recognizable icons, with particular attention given to the navigation icons including ‘Home’, ‘Help’, and ‘Back’.
- Maintained access to introductory session content – prototype does not allow users to revisit session from first intervention session.

Priority tasks were identified as fundamental, high or low. The target was for all fundamental and high priority tasks to be completed within the first sprint. Fundamental tasks included: enabling continued access to introductory session content; increase font size; addition of show/hide tabs to reduce long sections of text; and improvements to navigation and signposting. High priority tasks included: addition of activity icons and instructions; inclusion of glossary link on user’s main dashboard; and the fixing of graphical glitches on images. The sprint was completed in April 2020, with all of the fundamental and high priority tasks completed. Those tasks which were of lower priority were held over to the second sprint. Please see Appendix 9.8 for copies of these sprint documents.

User-testing

Following the completion of the first sprint, it was important to get feedback from the target user group. Contact was made with established PPI groups at the UoN and in the local community, with the aim of recruiting volunteers to provide ‘expert-consultations’. Adverts for volunteers were posted on various social media feeds. The Alzheimer’s Society were also contacted but were unable to publicise the call for volunteers due to COVID-19. Two volunteers, a person living with young-onset dementia and their partner who were members of an established PPI group, were recruited for the user-testing stage. Written guidance on accessing and navigating the PRIDE-app was provided and they could contact the team if they encountered any problems. The volunteers explored the PRIDE-app in their own homes over the course of a week, before providing written feedback on their experiences.

Overall, feedback gathered was a mixture of positive and negative comments. The login process was perceived as easy to use and the activities prompted positive discussions between the users. However, they did think that some of the content was aimed more at older adults with dementia, rather than young-onset, and therefore might not be as relevant to those of all ages living with dementia. They also found that working slowly through each section and making notes helped the person with dementia to follow the content.

Feedback from this stage was actively implemented into the second sprint stage. Some comments from the user-testing are below:

> *Logging in was straightforward.*
>
> *The plan, do, review process made sense to [the person with dementia] when I worked through it with him and prompted ideas for things that would help/ hinder him in the activities he wanted to try doing.*
>
> *Impact of COVID on going out and socializing might need to be factored in.*
>
> *Generally, [the person with dementia] found it difficult to tackle more than a few sections in one sitting. When we started work the next day, he had forgotten what he had done previously. We found working through each section slowly and making notes or drawing something to reflect our conversations made things easier.*

Second sprint

A second sprint was originally planned for the summer, but due to the difficulties in finding user-testing volunteers and the impact of COVID-19, the sprint was delayed until September 2020. The focus was on making the improvements and amendments identified during the user-testing stage. Similar to the first sprint, a specification document was sent to Ayup with the development changes prior to the start date. For this sprint, the document highlighted the grammatical errors that needed resolving in the content; identified words and phrases which could be changed to increase clarity and make the content more dementia friendly; and the addition of a paragraph regarding the impact COVID-19 and how this could affect their activities. This information was also uploaded to Trello, a planning software, which enabled us to prioritise actions and estimate the time taken to complete these. This allowed for a more collaborative approach to the sprint work between the study team and Ayup, and the researchers were able to monitor the progress of tasks during the sprint. All high and medium priority changes were made, such as correcting typographical and grammatical errors and adding a statement about how COVID-19 could affect the ways in which people use the PRIDE-app, which vastly improved the usability and functionality of the PRIDE-app, bringing it up to a standard suitable for use by participants.

Prior to COVID-19, a field-testing stage was planned to follow the completion of the second sprint. Volunteers would have completed a remote run-through of the PRIDE-app with the study team and provided additional feedback on the app’s usability and functionality from the perspectives of the target population. However, due to the difficulties in recruitment experienced during the user-testing stage, and the additional constraints and impact of the pandemic, this stage was removed.

4.3 Results

4.3.1 Preliminary development

Based on discussions of previous research on how people with dementia may use technology and their specific needs, an initial draft of wireframes was developed. It was important for Ayup to understand the range of stakeholders' digital literacy and ability in order to best design an experience that meets their needs.

Keeping in mind the deterioration in cognitive skills characteristic of dementia, the team developed a log in system that would not require the user to remember a password, but that would uniquely identify their account and uphold security. Ayup proposed the intervention facilitator assigned to the person with dementia creates a PRIDE account for them in the first instance, which consists of basic data including name, date of birth, and contact details. This becomes their 'PRIDE profile'. Once an account is created, the person can log in to the PRIDE website by entering their initials and date of birth, then a unique, single-use, four-digit code is sent to a registered contact number via text message or automated telephone voice message.

Login process

The concept of the login system was discussed with consultees to determine its acceptability. Consultees with dementia in groups one and two acknowledged that dementia may affect their ability to remember passwords. They described 'fear' of having passwords, feeling the information was too important to lose if forgotten, and identified potential safety risks of strategies to remember passwords such as writing them down. The idea of a login system using initials, date of birth, and a single use code was well accepted. Although date of birth relies on memory, a consultee said that this information is a personal possession and something that never changes so they thought it would be difficult to forget. One consultee described feeling ‘lucid’ and able to solve problems using logic at the moment, for instance to navigate the login system, but that they didn't know how long they would be able to do this. Consistent with this concern, a consultee in group two suggested in order to use the proposed login system, there would have to be instructions on screen to remind the person of the sequence to follow.

By contrast intervention facilitators participating in consultation two and three suggested having login details saved in a browser might be a simple way to assist people to remember passwords without the need for a specific login system. However, people with dementia in consultations one and two were wary of saving passwords automatically through their web-browser or using auto-fill functions as they felt this was less secure and anyone could potentially access their personal information. When asked whether it would be preferable to receive the single use code via telephone call or text message, many consultees said the telephone call may be a problem as they have call screening devices to prohibit unknown or nuisance calls. Some said that as long as they knew they would be receiving the call, they could pick it up. The final login system used a combination of initials, date of birth and a single one-time code that is either sent via SMS message or via telephone using text-to-speech technology.

Paper-based versus web-based platform

Consultees in group one had not previously taken part in the PRIDE intervention but were asked if they would have a preference for paper-based or online materials if they were to take part in PRIDE. Two said it would be easier to use paper-based materials, adding this way they didn't have to think about things going wrong with technology. The person with dementia and supporter in consultation two who had used the paper-based materials in the feasibility study preferred the website format identifying the following benefits; (1) it would be easier for intervention facilitators to see necessary information (e.g plans) online rather than having to refer to several sheets of paper; (2) it would be a more effective way of delivering reminders instantly as you might forget to look at a calendar; (3) it might stimulate the person and lead to uptake of other activities like brain training which might be helpful; (4) it might be easier to read typed text and type text than to read and write for people with dementia.

Supporting the first point, intervention facilitators in consultation two added that they had experienced problems with people losing the manual and paperwork in between sessions and if the supporter was not present at sessions two and three it was difficult to determine what had actually been done without the accompanying paperwork. The intervention facilitator in consultation three felt the website wireframes seemed to relate to the paper-based manual quite well.

Concerns about use of technology

Intervention facilitators said that in their experience many older people with dementia didn't use or have computers, but many used mobile phones or had computer tablets. Intervention facilitators said use of computers would depend on the age group and raised the point that some people may feel embarrassed or reluctant to engage if they are not computer literate. Some intervention facilitators said they themselves were ‘scared’ of technology but have phones and computer tablets, although don’t use them in sessions with clients. The intervention facilitator from consultation three said there were participants they had delivered PRIDE to who benefitted from the paper-based version of the intervention, but who may not have agreed to take part if it were presented using an online platform as use of technology would be a barrier. However, they also reasoned that even if participants were not familiar with technology, they might be willing to try with the right advisor. Consultees with dementia highlighted the importance of social interactions in the delivery of interventions, stating that ‘people should not be replaced by computers’.

Intervention facilitators raised other considerations related to technology that may disrupt delivery of the intervention including practical issues such as the internet either not being available or working in people’s homes, paying for internet access, and the person forgetting to charge devices. However, all consultees with dementia reported using different types of technology in their daily lives to send and receive emails, search for information, watch videos, and play games in contrast to the expectations of the intervention facilitator of computer use amongst this client group.

Design and accessibility features

The designs presented included samples of text, proposed website page layouts, colors, and images. The intervention facilitators participating in consultation three said it was important for the design and layout of the website to be simple and felt the wireframes fulfilled this requirement well. The supporter participating in consultation two felt the colors needed to be brighter to make content more noticeable, commenting that ‘in older age eyesight isn’t as good’. They also suggested making all text, buttons, and icons that were supposed to be clicked the same color to differentiate between content without hyperlinks to other pages of the website. Some consultees with dementia had trouble identifying the meanings behind some of the images selected to represent themes, for example a running stick figure to represent ‘keeping physically active’.

Consultees said black text on a white or yellow background would be clearest to read and certain colors carried certain meanings. For example, red was seen as a danger. They felt the colors presented on the wireframes were clear enough. Consultees also expressed a preference for capital letters followed by small print in text, rather than text presented in block capitals. In terms of text size, consultees said text might be too small if viewed on a mobile and talked about the ability to change or set a particular text size on the website. Consultees felt it was a good idea to have audio recorded versions of the text presented on the website pages for those who did not or could not read the content.

Development of beta version

Following the initial consultations, Ayup iterated the website wireframes to incorporate a number of learnings. Specific developments to enhance user experience included:

- An option to download certain parts of the site/content for further reading offline or for printing
- An option to include a font size choice when setting up the users' profile
- Avoiding "pop ups" that are unclear
- Changing design styles too much to keep consistency
- Prioritising contact via a phone call when using the login system
- Removing block capitals and keeping all words in sentence case.
- Making clickable buttons more obvious
- Placing a title next to icons so there is less ambiguity

User-testing and consultations on beta version

The ability to skip through steps in the first PRIDE session was identified as something to be modified. A linear process by which users have to complete a sequence of 26 steps in the same order (before being able to freely navigate through the content of the website) had been chosen to standardise the first session of the intervention and ensure all compulsory activities were completed. However, consultees felt this made the process too lengthy and having so many steps was confusing. The intervention facilitators added that this structure also might impede their ability to tailor the information to the person, which they felt was an important aspect of delivering the intervention. According to a suggestion by a consultee, ‘Next’ buttons were added at the top of each page so that pages can be bypassed if required and ‘Back’ buttons were added so that users can move freely between the steps according to their preference. An overall action point was to review navigation across all aspects of the website to ensure all hyperlinks connect to the correct page, and refine the user journey through the ‘plan, do, review’ content as some of the consultees noted navigation through this information felt ‘circular’.

A point of frustration were the error messages displayed when data entered into the website had not been accepted or when boxes requiring data were left blank. It was not specified why the data had been rejected or which aspects of required data on the page were missing, so it was decided all error messages should specifically and clearly reference the issue and the location of the issue.

The PRIDE intervention manual includes a series of ‘case stories’ demonstrating ways people have overcome challenges associated with living with dementia. These are part of the tailored content of the intervention thus not all case stories will be relevant to every person receiving the intervention, rather the intervention facilitators select case stories they think will be helpful for the person. The intervention facilitators suggested instead of being embedded in the content of the website, which may make them difficult to locate, case stories should feature in a 'story index' intervention facilitators could refer to, to make the process of picking out examples more streamlined.

Consultees were able to easily use the log in system. However, it was suggested that to save time, intervention facilitators should be able to register the person with an account for the website before the first session, rather than as part of the first session.

4.3.2 Final development

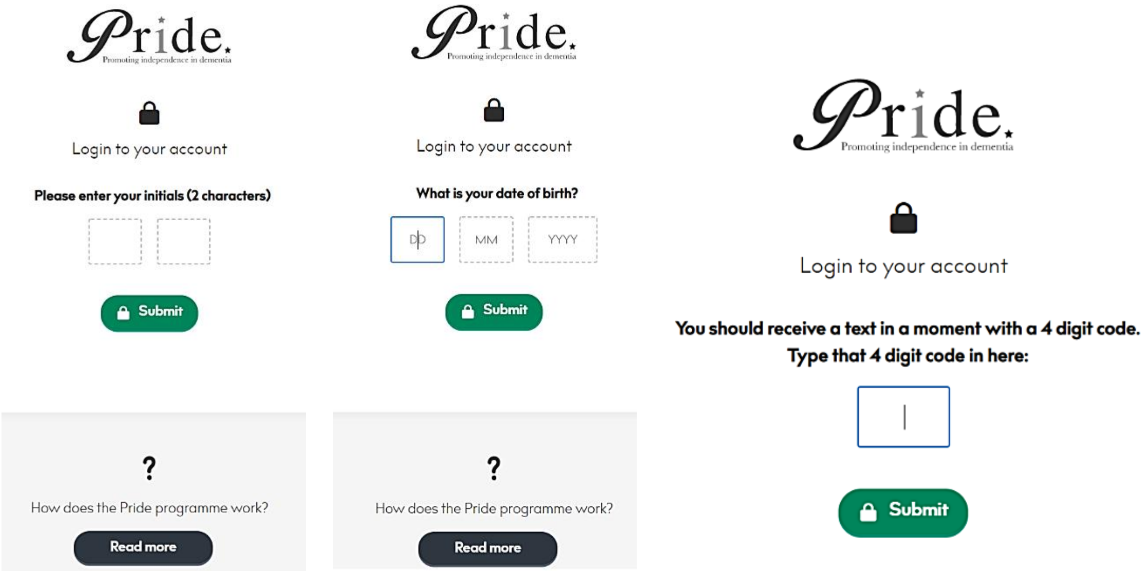
Researchers discussed their consultations and agreed on a series of action points, which were then provided to Ayup. The priority of amendments was negotiated using the MoSCoW prioritisation framework based on the assumed importance and estimated time they would take to complete.

The MoSCoW acronym stands for Must have, Should have, Could have and Won't have (this time). The MoSCoW method is a prioritization technique used in management, business analysis, project management, and software development to reach a common understanding with stakeholders on the importance they place on the delivery of each requirement; it is also known as MoSCoW prioritization or MoSCoW analysis.

Through the sprint work and user testing, the PRIDE-app was refined and made as relevant to its target users as possible. The PRIDE-app is a web-based app, accessed through a web link rather than an Appstore logo. After modification and refinement, the PRIDE-app became a functioning online interactive handbook.

Login process

Facilitators create an account for individual users, using two initials, a date of birth, and a four-digit code that is sent to a contact number. When users log into the app, the code is sent through either text or voice message, so is accessible to those without a mobile phone. Figure 4 shows the three-stage login process.



Login to your account

Please enter your initials (2 characters)

How does the Pride programme work?

Login to your account

What is your date of birth?

How does the Pride programme work?

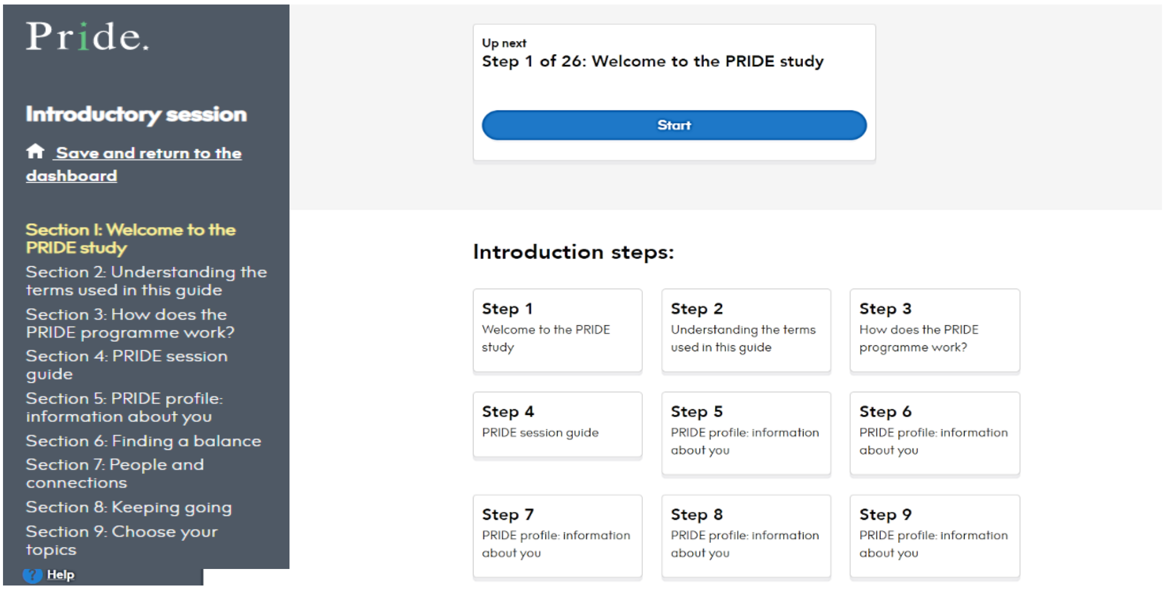
Login to your account

You should receive a text in a moment with a 4 digit code.
Type that 4 digit code in here:

Figure 4. The three-stage login process participants use to access the PRIDE-app.

Introductory session

The session structures are the same, with advisors and users completing the same introductory session as the paper version. After logging on for the first time, users are shown the 26 different steps which make up the session content. They can save their progress and exit the app at any time, with their next step highlighted at the top of the page when they log back in. A navigation bar on the left of the screen shows users which section they are currently in. Figures 5 and 6 show some of the introductory session content.



Pride.

Introductory session

Save and return to the dashboard

Section 1: Welcome to the PRIDE study
Section 2: Understanding the terms used in this guide
Section 3: How does the PRIDE programme work?
Section 4: PRIDE session guide
Section 5: PRIDE profile: information about you
Section 6: Finding a balance
Section 7: People and connections
Section 8: Keeping going
Section 9: Choose your topics

Help

Up next
Step 1 of 26: Welcome to the PRIDE study

Start

Introduction steps:

Step 1
Welcome to the PRIDE study

Step 2
Understanding the terms used in this guide

Step 3
How does the PRIDE programme work?

Step 4
PRIDE session guide

Step 5
PRIDE profile: information about you

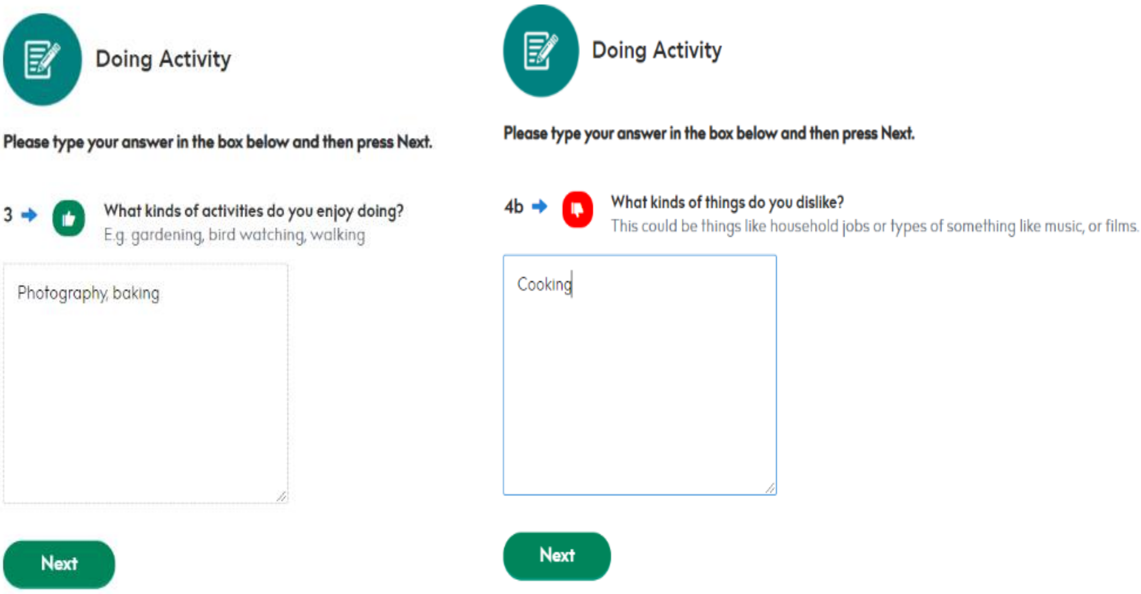
Step 6
PRIDE profile: information about you

Step 7
PRIDE profile: information about you

Step 8
PRIDE profile: information about you

Step 9
PRIDE profile: information about you

Figure 5. After logging on for the first time, users see the Introductory Session contents page.



Doing Activity

Please type your answer in the box below and then press Next.

3 → What kinds of activities do you enjoy doing?
E.g. gardening, bird watching, walking

Photography, baking

Next

Doing Activity

Please type your answer in the box below and then press Next.

4b → What kinds of things do you dislike?
This could be things like household jobs or types of something like music, or films.

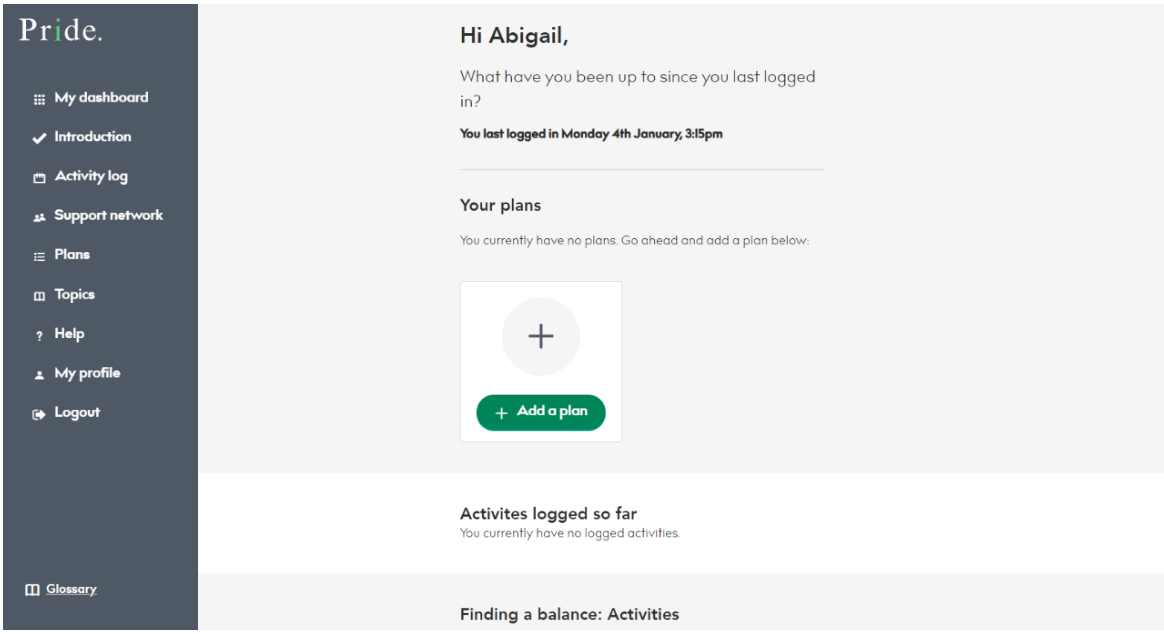
Cooking

Next

Figure 6. Examples of the interactive activities for users to complete. The instructions were added during the sprint development.

Main dashboard

Once the introductory steps are completed, users are taken to the PRIDE-app homepage interface (Figure 7). Here they can navigate back to the introductory session, access the individual topic areas, add members to their supporter network, create further action plans, and update their activity log (Figure 8).



Hi Abigail,

What have you been up to since you last logged in?

You last logged in Monday 4th January, 3:15pm

Your plans

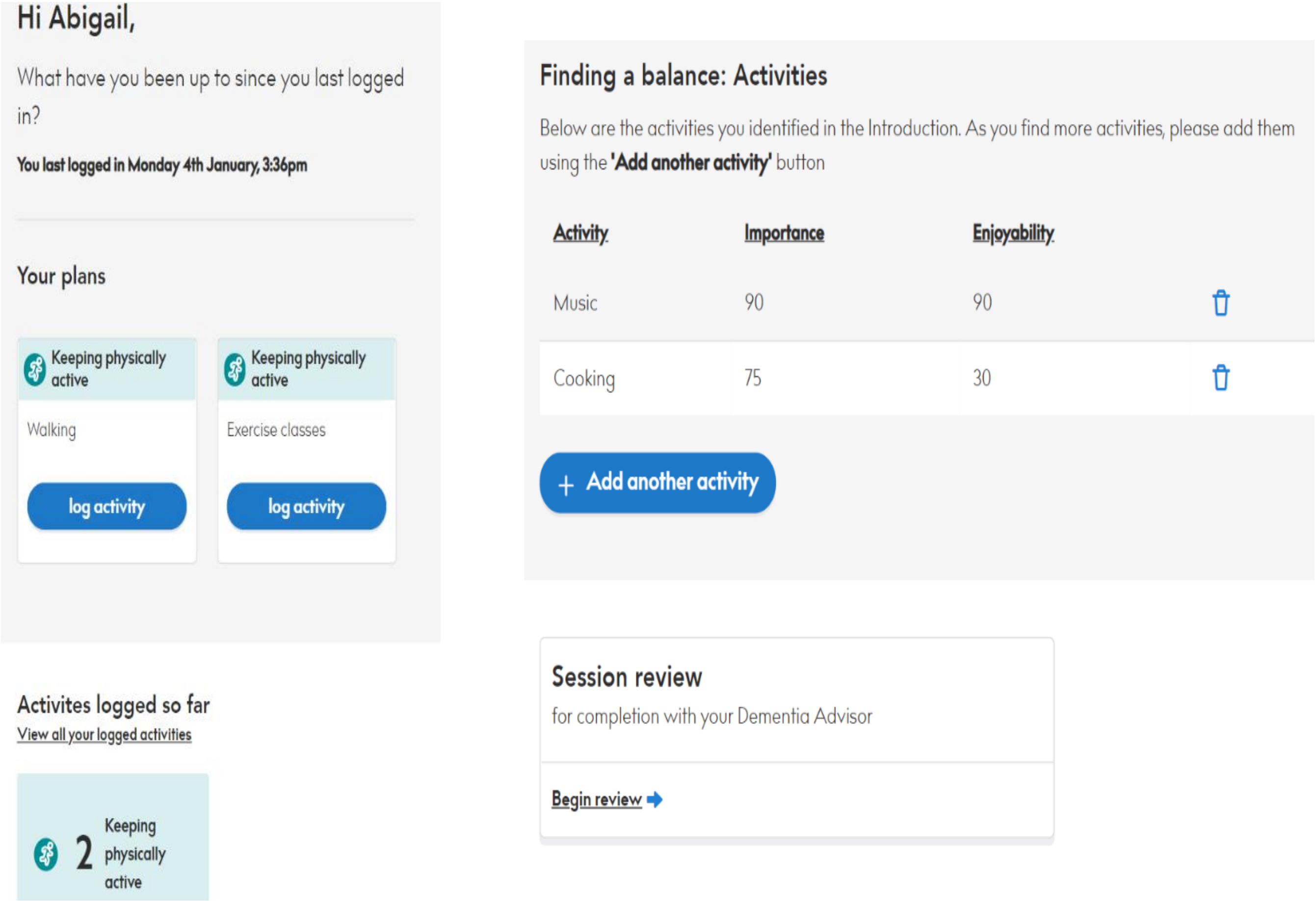
You currently have no plans. Go ahead and add a plan below:

Activites logged so far

You currently have no logged activities.

Finding a balance: Activities

Figure 7. PRIDE-app homepage where users can see their plans, activities and access topic information. This is what users will see the first time they access the main dashboard.



Hi Abigail,

What have you been up to since you last logged in?

You last logged in Monday 4th January, 3:36pm

Your plans

Activites logged so far

View all your logged activities

Finding a balance: Activities

Below are the activities you identified in the Introduction. As you find more activities, please add them using the **'Add another activity'** button

Activity	Importance	Enjoyability
Music	90	90
Cooking	75	30

Session review

for completion with your Dementia Advisor

Figure 8. The dashboard will show the last time a participant logged in; any plans they have set; where they can log an activity; their current activities and how to add more; and complete their review.

PRIDE-app topics

Participants can view information for the seven main topics included in the PRIDE-app at any time. During the introduction session, users are asked to select three topics they would like to primarily focus. This selection can be amended by users at any point through the topics section on the PRIDE-app (Figure 9).

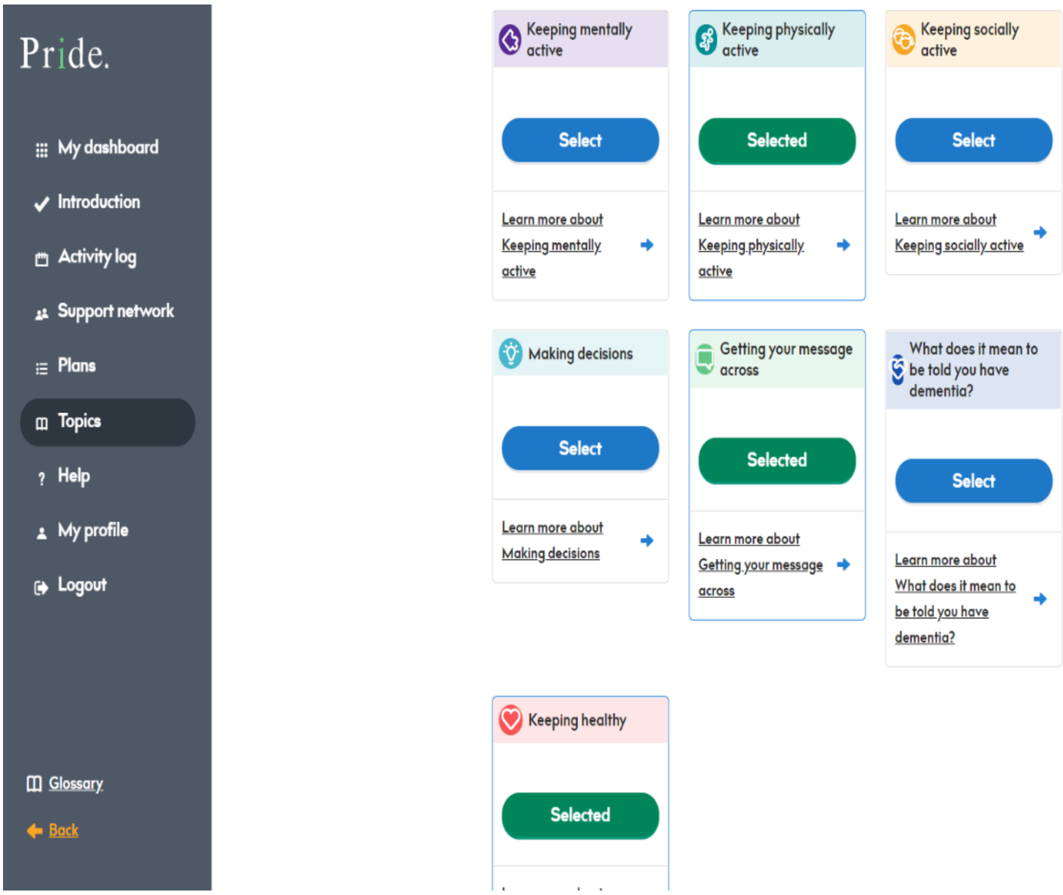
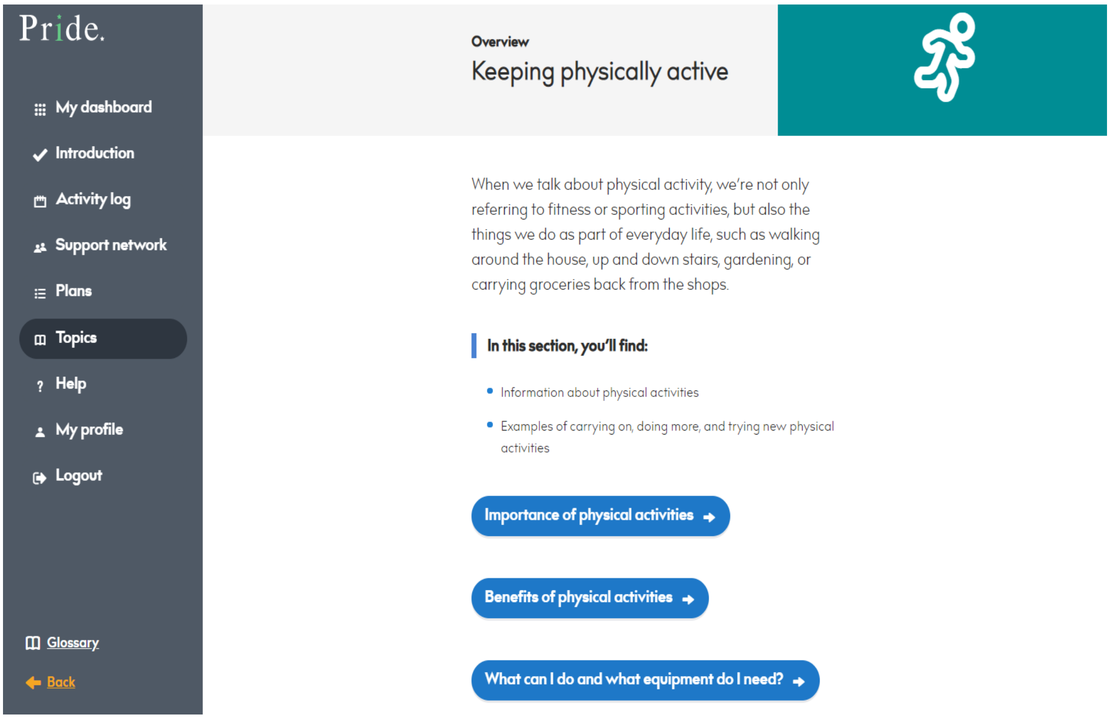


Figure 9. Topics section. Selecting and deselecting choices enable users to change their priorities.

Users can also use the section to learn more about each topic. There are personal stories intertwined throughout the content to provide users with insight and reassurance of how others with dementia have made positive changes across the topics. Figure 10 shows an example of one of the topic pages. Users can read all of the content or access specific subsections directly.



Overview

Keeping physically active

When we talk about physical activity, we're not only referring to fitness or sporting activities, but also the things we do as part of everyday life, such as walking around the house, up and down stairs, gardening, or carrying groceries back from the shops.

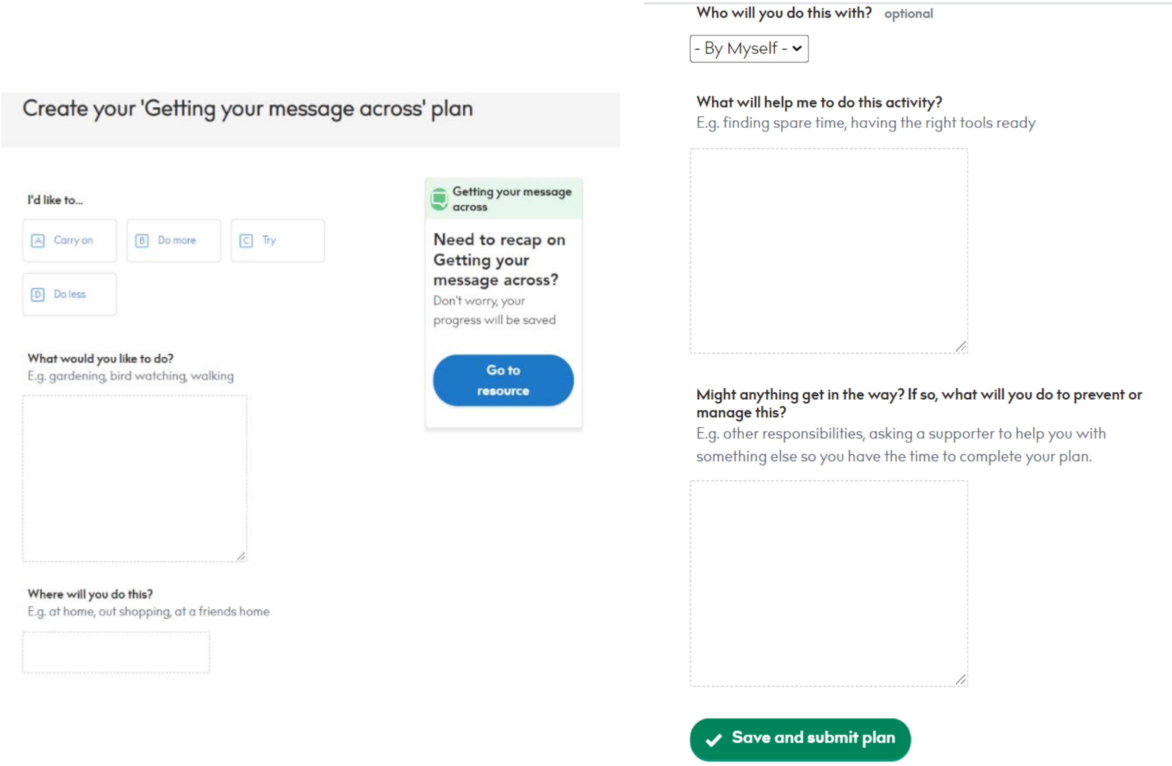
In this section, you'll find:

- Information about physical activities
- Examples of carrying on, doing more, and trying new physical activities

Figure 10. Example of a topic page.

Creating activity plans

From the Plans section, users click '+Add a plan' and select which topic they would like to create a plan for. The topic selection given on the screen are the three topic users have selected to focus on. After selecting a topic, a page will appear asking users whether they would like to learn more about the topic or create a plan. Participants fill in the plan, selecting whether they would like to carry on, try, do more or do less of an activity. They can write where they can execute this activity, the facilitators, and potential barriers. Once completed, they click on 'Save and submit plan' (Figure 11).



Create your 'Getting your message across' plan

I'd like to...

What would you like to do?
E.g. gardening, bird watching, walking

Where will you do this?
E.g. at home, out shopping, at a friends home

Need to recap on Getting your message across?
Don't worry, your progress will be saved

Who will you do this with? optional
- By Myself -

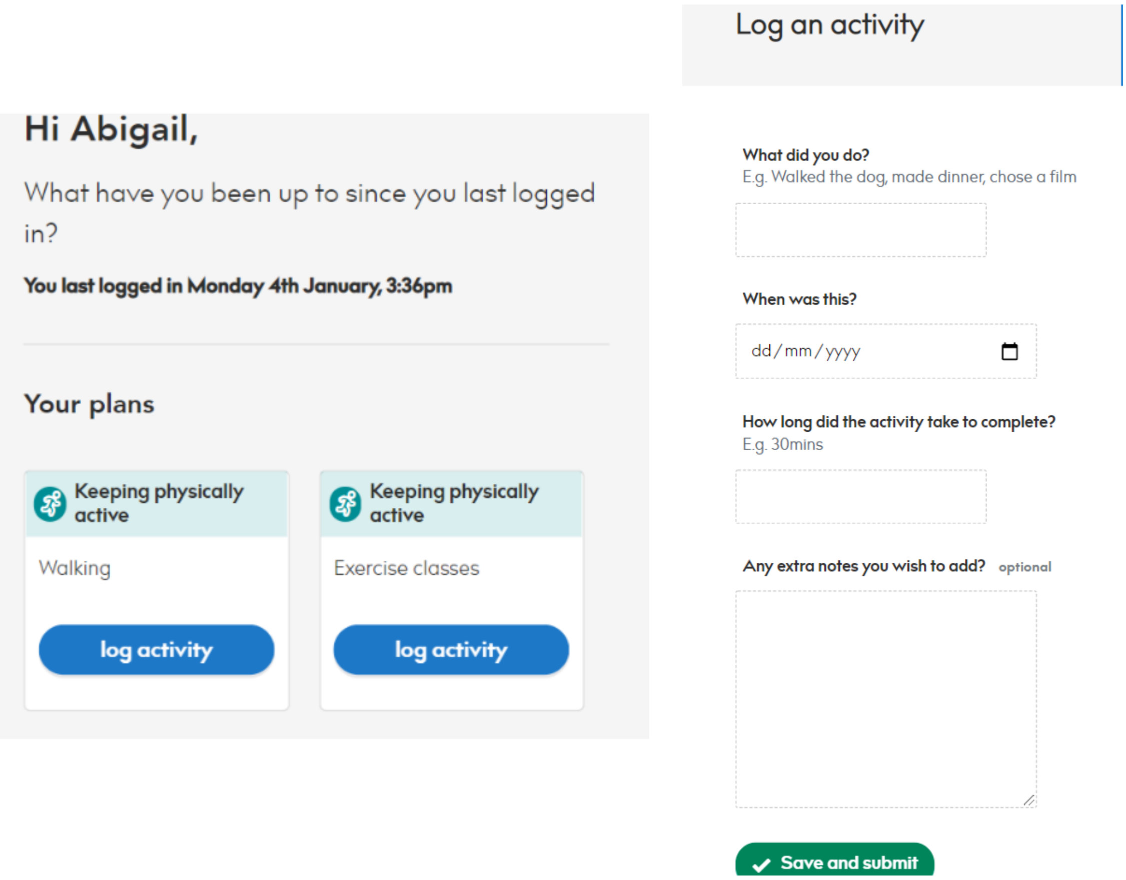
What will help me to do this activity?
E.g. finding spare time, having the right tools ready

Might anything get in the way? If so, what will you do to prevent or manage this?
E.g. other responsibilities, asking a supporter to help you with something else so you have the time to complete your plan.

Figure 11. Example of creating a plan.

Logging an activity

Once plans are created and saved, they appear on the user's home dashboard. They select the plan they would like to log an activity. On the next page, they fill in what activity they completed, when, and how long the activity took. Clicking 'Save and submit' will add that activity to their log on their dashboard (Figure 12).



Hi Abigail,

What have you been up to since you last logged in?

You last logged in Monday 4th January, 3:36pm

Your plans

Keeping physically active

Walking

Keeping physically active

Exercise classes

Log an activity

What did you do?

E.g. Walked the dog, made dinner, chose a film

When was this?

dd/mm/yyyy

How long did the activity take to complete?

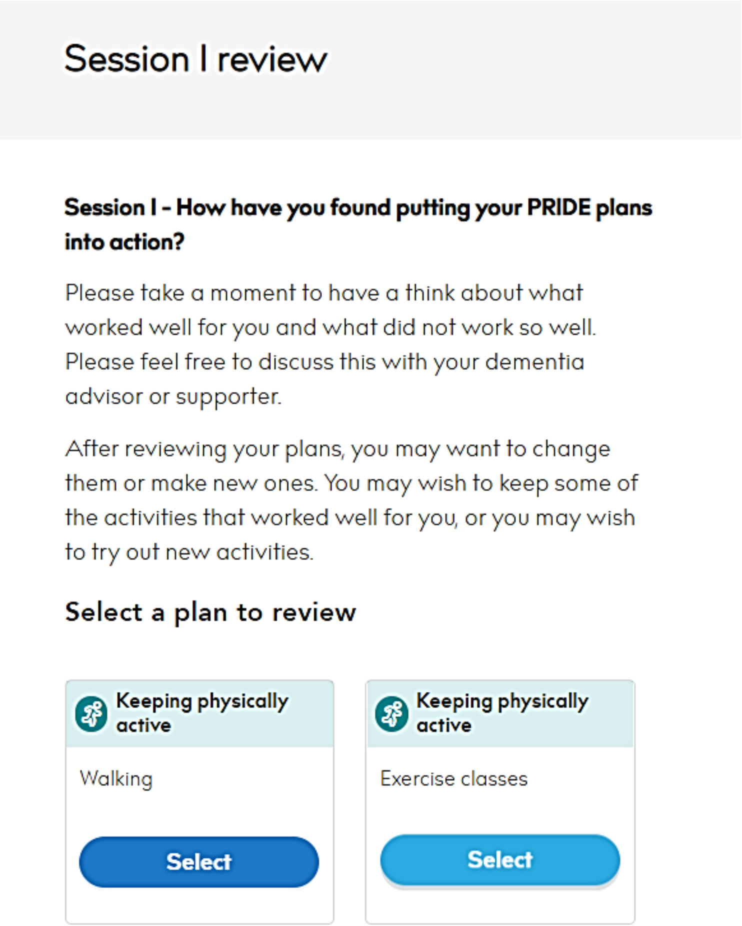
E.g. 30mins

Any extra notes you wish to add? optional

Figure 12. Example of logging an activity.

Review sessions

Following the introductory content, and after they have had time to use the PRIDE-app in their daily lives, users complete two review sessions with a facilitator. From the home dashboard, users click on the begin review link and confirm that a facilitator is present. Once confirmed, the app will ask which of their plans they would like to review (Figure 13). One plan can be reviewed at a time, but the review process can be completed for as many plans as they would like. The app asks users to complete boxes on how the activity went, whether anything helped or hindered them, and what are the next stages. At the bottom of the review page, participants will be asked whether they would like to leave the plan as it is, revise it, or archive it (if they are happy and feel like they've completed their plan).



Session I review

Session I - How have you found putting your PRIDE plans into action?

Please take a moment to have a think about what worked well for you and what did not work so well. Please feel free to discuss this with your dementia advisor or supporter.

After reviewing your plans, you may want to change them or make new ones. You may wish to keep some of the activities that worked well for you, or you may wish to try out new activities.

Select a plan to review

Figure 13. Example of selecting a plan to review.

4.4 Discussion

4.4.1 Principal results

This chapter presents the development of the PRIDE-app, a psychosocial intervention which targets multiple domains often affected following a dementia diagnosis. Developments to enhance the dementia-friendliness of the app were achieved through collaborative sprint work and through the involvement of people living with dementia. To our knowledge, the PRIDE-app is unique in its content, and this is the first paper to present such an intervention.

4.4.2 Comparison with prior work

A previous study about the individual Cognitive Stimulation Therapy (iCST) app helped inform our development process (Rai, Griffiths, Yates, Schneider & Orrell, 2021). They took an iterative approach to app development and involved people living with dementia and their carers throughout the process to improve the structured cognitive stimulation application. Through interviews and focus groups, the researchers were able to incorporate participant feedback into their three development sprints and explore the initial experiences of using the computerized cognitive stimulation program (Rai et al., 2021). The iCST app was similar to the PRIDE-app in that it was a one-to-one program delivered at home on a touchscreen tablet. However, the interventions differed as iCST was carer-led, only applicable to tablets, and purely focused on cognitive stimulation activities. Although there were differences, the iterative approach used was very similar to that in the PRIDE-app development as the feedback from people with dementia and their supporters also informed the sprint work (Rai et al., 2021). Additionally, the discussion guide for their interviews helped inform the questions asked when gathering feedback and for the interview that will be conducted with participants following their use of the PRIDE-app.

Over the last decade there has been a change in how health and quality of life are quantified. Some have proposed an update to the World Health Organization’s definition of health by altering the focus towards how well an individual can self-manage and adapt to physical, mental and social health challenges (Huber et al., 2011). The PRIDE-app aims to meet this evidence gap by providing an intervention which covers multiple domains relevant to the revised WHO definition and targets a range of self-management concepts.

A previous systematic review into web- and app-based interventions in dementia showed their potential to produce positive outcomes on self-management and can be successfully delivered through a range of methods (Lee et al., 2021). Existing interventions targeted several self-management concepts, such as independence and activities of daily living, but there was an inconsistency in which domains often affected by dementia were targeted by interventions and some purely focused on one concept. The review also revealed that there is a lack of high-quality evidence into these types of dementia interventions and no studies researching an intervention which encompasses physical, cognitive, social and emotional domains. The PRIDE-app aims to meet this evidence gap by providing an intervention which covers multiple domains and targets a range of self-management concepts.

4.4.3 Limitations

The low recruitment of user-testing volunteers was not foreseen, and this delay meant a wider impact on the study timelines. Despite the call for volunteers going out to local and national groups, there was very limited interest in user-testing. This was likely due to the COVID-19 pandemic and the change in people's priorities and lack of interest in research. However, the volunteers that were recruited were well experienced in dementia studies and provided useful feedback. Another limitation was the removal of the field-testing phase. Originally, this stage was to be incorporated following the second sprint to assess the PRIDE-app's usability and accessibility, with a third sprint proposed to resolve any urgent problems. A delayed field-testing phase was not a viable option for the study due to the time constraints and resources available for the study.

The COVID-19 pandemic meant that remote working was necessary for much of the PRIDE-app development. It also required community and PPI groups for people living with dementia and their families to either temporarily close or move online. These required measures unfortunately contributed to difficulties in finding user testing volunteers and removed an accessible source of feedback for during the ongoing app development. Delays caused by these difficulties led to the second sprint being delayed, which had a knock-on effect for the rest of the study timelines. As diagnoses were not recorded from those involved in the development of the app, conclusions about specific types of dementia were limited and this should be considered when conducting future research to understand any potential barriers specific dementias could cause.

Following the development work, the PRIDE-app will be the focus of a RE-AIM study (Lee, McDermott, Guo, Roe & Orrell, 2022). The app offers people living with dementia a central source for information and support on a range of domains commonly impacted by dementia, and this study will explore the potential reach, effectiveness and adoption of the intervention. Although a larger trial will be needed to assess the potential effectiveness more comprehensively, the RE-AIM study will provide initial insight into whether the PRIDE-app could be a feasible intervention, suitable for further research, and if it could have positive outcomes for people with dementia and their families.

4.4.4 Conclusions

Through the work discussed, the PRIDE-app has evolved from its initial prototype (Csipke et a., 2021) into a more dementia-friendly and usable program that is of a standard suitable for wider testing. It has the potential to advance the previous evidence into web- and app-based interventions, in addition to providing better support for self-management, improving individuals' level of independence, and enhancing the quality of life in people with dementia and their families. The finished version will be trialled in a RE-AIM study, with its potential reach, effectiveness and adoption explored. The study will contribute further to the evidence base, and our understanding of how web- and app-based interventions could be successfully implemented in dementia. Feedback gathered during the RE-AIM study will go towards any further developments to the app to increase its applicability to the target audience and usability, such as considering alternative login methods and identifying barriers for specific dementia types. It will also provide further understanding of the barriers and facilitators which have a significant impact on the adoption of these interventions, and how these could be overcome in future research.

5. Results of the RE-AIM Study of the PRIDE-app

The first section of the chapter presents the quantitative data collected in the RE-AIM study, including the recruitment of participants, fidelity checklists and outcome measures. Pre- and post-outcome scores were collected to provide insight into any potential benefit the PRIDE-app had on participants activity independence, mood, and quality of life, as well as supporter wellbeing. It was anticipated that the PRIDE-app would increase or sustain activity and have a positive effect on the wellbeing of participants and supporters. App data was also collected and analyzed to better understand the frequency of use, and which pages the users visited most. All of the measures and data analyzed are discussed in relation to the Reach, Effectiveness and Adoption elements of the framework, which explore how the PRIDE-app could benefit people living with mild dementia and their supporters.

In the second section, a description of the development and analysis of the interviews conducted with participants, supporters and facilitators, previously outlined in Chapter 3, is provided. The aim of the interviews was to explore the perspectives and experiences unable to be collected by the quantitative outcome measures. These insights are valuable in understanding the potential benefits of the PRIDE-app and the developments needed to improve this. Thematic analysis was conducted on the interview data by two reviewers, and the themes which developed from this are discussed. A summary of how the findings relate to the RE-AIM framework is also given.

Quantitative Results

5.1 Reach

5.1.1 Recruitment figures

An application was put in for the study to be accepted onto the Clinical Research Network (CRN) Portfolio. Once approved, the study was advertised through the Portfolio and local CRN teams were able to contact ARL to register their interest. A total of 19 sites requested more information about the study between February 2021 and January 2022, and five of these had the capacity and capability to support the study. This was reduced to four sites in the autumn of 2021, due to communication difficulties and slow setup with Nottinghamshire Healthcare NHS Trust. Participant recruitment opened at sites and on the Join Dementia Research (JDR) online platform in June 2021 and was planned to close at the end of November 2021. However, due to the unanticipated difficulties in finding recruits across the sites, this deadline was extended until the end of February 2022 to give sites more time to reach their new, lowered recruitment target of five to 10 participants with dementia. With regards to recruitment via JDR, the study received interest from 20 people living with a dementia diagnosis, who were not aligned with any other the included sites, and ARL provided them with the participant information sheet and answered any questions they had about the study. Two of the four sites utilised JDR, contacting 16 interested volunteers and enrolling three. Overall, 28 people completed the participant baseline. However, on review of the data, three of these were uncompleted duplicates. Therefore, 25 people with a diagnosis of mild dementia completed the baseline measures on REDcap, of which 15 were recruited with a supporter, although only 12 completed the full set of baseline measures.

5.1.2 Participant demographics

Gender, age and ethnicity was collected during completion of CRFs, and this was fed back to ARL after recruitment. Despite instructions to return them, only two CRFs were returned to ARL, and therefore data about age and gender were only provided for two participants: one male, aged 76 with mixed dementia; and one female, aged 66 with frontotemporal dementia. However, sites did inform the researcher of the ethnicity of participants. All participants and supporters were white British, and only one non-white person with dementia registered their interest via JDR. This individual did not respond to the email invite to learn more about the study. In addition to these figures, 22 (80%) participants said they would like to take part with a family member or friend. However, only 15 of these nominated supporters responded to the questionnaire link sent to them. Of these supporters, 10 (83.3%) were a spouse or partner of the participant, and 2 (16.7%) a son or daughter of them. Demographic data for participants and supporters is displayed in Table 3.

Table 3. Demographic characteristics of participants who completed baseline measures.

Demographic	Participant
Region	South West n=17(68%)

	West Midlands n=3(12%) South East n=2(8%) North West n=1(4%) Yorkshire n=1(4%) Scotland n=1(4%)
Marital Status	Married/Civil Partnership/Cohabiting n=20(80%) Widowed n=3(12%) Separated/Divorced n=1(4%) Single n=1(4%)
Living Arrangements	With a Spouse/Partner n=19(76%) With Family n=4(16%) Alone n=2(8%)
Taking Dementia Medication	Yes n=20(80%)
Current/Previous Smoker	Yes n=10(40%)
Weekly Alcohol Consumption	1 Day or Less n=13(52%) 5+ Days n=5(20%)
Weekly Exercise	2 Hours+ n=15(60%)
Prior Experience with Technology	None n=7(28%) Some n=11(44%) Quite a lot n=6(24%) Extensive n=1(4%)

5.1.3 Participant retention

Following the completion of baseline measures, invites were sent out by ARL and the sites to all those participants and supporters who had consented. The teams only received 19 responses to the invites, of which 17 completed one or more PRIDE-app sessions with their DA. With regards to the completion of outcome measures, the number of participants and supporters who responded at each stage can be seen in Table 4.

Table 4. Number of participants and supporters who completed the measures at each study timepoint.

Study timepoint	People with dementia	Supporters
Baseline	25 (n=2 incomplete)	15 (n=2 incomplete)
3 months	16	5 (n=1 incomplete)
6 months	15	7 (n=1 incomplete)

As Table 4 shows, completion rate dropped off between timepoints which is understandable due to the reduced number of participants who completed the intervention phase. Although the majority of responses at follow-ups were from participants and supporters who took part in the intervention phase, it was noted that a couple who did not still completed the follow-up measures, and this should be considered when interpreting the findings.

5.2 Effectiveness

5.2.1 Pre/post outcome measure performance

Due to the nature of the GDS, participants were divided into two groups depending on their total scores. A score of five or below was deemed as showing no signs of depression, where a score higher than 5 was. As Table 5 below shows, the majority of people with dementia reported no signs of depression at baseline or either of the follow-ups, and there was no significant difference across timepoints. Fisher Exact Test was conducted and reported a non-significant result (p = .811). Therefore, it is hard to conclude whether the PRIDE-app had any influence on mood and wellbeing of participants.

Table 5. Geriatric depression scale scores at baseline and follow-ups.

Month	<5 (no signs of depression)	>5 (signs of depression)
0	20	5
3	14	2
6	13	2

Table 6 details the modelled means and change in scores between baseline and follow-ups.

Table 6. Modelled mean scores and change significance across outcome measures.

Measure	Month	Modelled Mean (95%CI)	Change (95%CI)	*p*-value
IADL[a]	Baseline	8.00 (7.42, 8.58)		
	3	8.00 (7.42, 8.58)	Month 3 v Baseline 0	0 (no change)
	6	8.00 (7.42, 8.58)	Month 3 v Baseline 0	0 (no change)
EID-Q[b]	Baseline	74.67 (68.96, 80.37)		
	3	72.34 (66.06, 78.62)	Month 3 v Baseline -2.33 (-7.16, 2.51)	0.345
	6	74.20 (67.83, 80.57)	Month 6 v Baseline -0.47 (-5.42, 4.49)	0.853

CASP-19[c]	Baseline	42.46 (39.32, 45.60)		
	3	40.01 (36.40, 43.63)	Month 3 v Baseline -2.44 (-5.83, 0.94)	0.157
	6	40.89 (37.20, 44.58)	Month 6 v Baseline -1.57 (-5.04, 1.90)	0.376
EQ-5D-5L[d]	Baseline	70.74 (63.21,78.27)		
	3	65.79 (57.10, 74.48)	Month 3 v Baseline -4.95 (-13.78, 3.88)	0.272
	6	72.13 (63.23, 81.02)	Month 6 v Baseline 1.38 (-7.66, 10.43)	0.764
EQ-5D-5L	Baseline - Supporter	86.75 (82.18, 91.32)		

	3 - Supporter	77.66 (70.79, 84.52)	Month 3 v Baseline -9.09 (-15.75, -2.44)	0.007
	6 - Supporter	80.19 (74.31, 86.07)	Month 6 v Baseline -6.56 (-12.20, -0.92)	0.023
GHQ-12[e]	Baseline - Supporter	25.58 (23.03, 28.14)		
	3 - Supporter	19.17 (15.80, 22.54)	Month 3 v Baseline -6.41 (-9.50, -3.33)	0.000
	6 - Supporter	22.70 (19.68, 25.72)	Month 6 v Baseline -2.88 (-5.58, -0.19)	0.036

[a] IADL: Lawton Instrumental Activities of Daily Living Scale.

[b] EID-Q: Engagement and Independence in Dementia Questionnaire.

[c] CASP-19: Control, Autonomy, Self-realization, and Pleasure Scale-19.

[d] EQ-5D-5L: EuroQoL Quality of Life.

[e] GDS: Geriatric Depression Scale.

Lawton IADL, EID-Q and CASP-19

All participants reported a maximum score of eight on the Lawton IADL measure, which would indicate a good level of functioning and independence, at baseline and both follow-ups. This was anticipated at the baseline measures, as the participants had mild dementia where the symptoms would not have impacted their daily activities too considerably. The maximum score participants could achieve on the EID-Q measure was 104. The table shows that there was no significant variation in means between baseline and follow-ups, with a slight deterioration at 3 months compared to baseline, but this was stabilized by 6 months. No significant changes were found between the timeframes. On the CASP-19, a maximum score of 57 is achievable with the Likert scoring method, with a higher score indicating a better level of wellbeing. As shown in the outcome data, there was no significant difference in participants' wellbeing before and after using PRIDE-app, with slightly lower scores at both follow-ups when compared to the baseline, but not significant differences.

EQ-5D-5L (Participant and Supporter)

Following discussions with the statistician who ran the modeling for outcomes, it was decided to only use the vertical visual scale part of the EQ-5D-5L. This decision was taken as the other questions in the measure are generally used for health economics and so were deemed not suitable for this analysis. The mean visual health scores for participants and supporters, along with the modelled means, are shown in the table below. Modelled analysis on the change between baseline and follow-ups showed no significant improvements or deterioration in scores for participants living with dementia. However, significant change in score decline where found at 3 months ($p < 0.01$) and at 6 months ($p < 0.05$) when compared to the baseline in supporters.

GHQ-12

The Likert scoring method of 0-1-2-3 was chosen for analysis as it was felt this method would provide more insights into differences between supporters and timepoints, than the 0-0-1-1 scale. Better reported health was indicated by a lower score, with a maximum score of 36 possible. Supporters showed a significant positive change in scores between baseline and 3 months ($p<0.001$) and baseline to 6 months ($p<0.05$).

Global Change Measure

At three months, 75% (n=12) of participants reporter no change in their general wellbeing, with one identifying their wellbeing as much worse than in the time before the study. However, three participants felt that their wellbeing had improved slightly. Supporters provided the same perspective, although only three completed the measure at this stage. With regards to their independence, participants felt there tended to be no change (75%, n=12), although two felt they had become a bit more independent, and another two less independent. Each of the three supporters selected a different response from ‘A bit more independent’, ‘No change’, and ‘Much less independent’.

At the six-month follow-up, participants' perspectives of their general wellbeing were slightly worse than at the previous timepoint. Just over half (53.3%, n=8) reported no change since before starting the PRIDE-app study, with 26.7% (n=4) saying it was a bit worse, and one participant said theirs was much worse. Much like the three-month measure, a low number of supporters completed the questions (n=6), with one saying their relative had a much better general wellbeing, two reporting no change, two as a bit worse, and one as much worse. Similarly, to general wellbeing, many participants (73.3%, n=11) reported no change in their independence in the six months since the study start, with one participant feeling much more independent in contrast with three who felt less independent. Supporters reported similar views, with 66.7% (n=4) identifying no change and the other two supporters saying their relative had become less independent.

5.3 Adoption

5.3.1 Facilitator recruitment and training

Across the included sites 13 NHS and Memory Services staff volunteered to facilitate the PRIDE-app sessions. ARL and OM were available to deliver the PRIDE-app intervention sessions, should a site not be able to provide enough DAs.

5.3.2 Fidelity checklists

As planned in the protocol, each facilitator and participant were asked to complete a fidelity checklist after each of their PRIDE-app sessions to assess whether the PRIDE-app intervention was being delivered as intended.

However, the checklists were repeatedly missed by participants and DAs, and despite reminders, the final number received was significantly lower than intended. Across the four NHS sites, a total of three participant checklists and five facilitator checklists were completed. Two DAs completed a checklist for the first session and reported that all items on the checklist were either done or done to some extent. The discussion around how others can help people with dementia engage with activities was the topic that both Advisors completed to some extent. Feedback as to why this was done to some extent is given below:

> *[Pt] is very independent*
>
> *Already well engaged in a number of activities with good family support, covered to some extent, but in-depth discussion not had*
>
> *Ran out of time to cover in depth*

One also did not cover the finding a balance topic in full as the participant was already independent and engaging in activities:

> *[Pt] is already very active and has a busy schedule so didn't need much advice on this*

The other Advisor encountered difficulties with showing the participant how to navigate around the app due to the online delivery format. However, this difficulty was mitigated by the participant requesting a face-to-face visit:

> *Both participants and I found this difficult over [virtual platform], most content was covered but participants requested a home visit to complete the session in order this could be done more easily*

The two participants who completed the first session checklists felt that all items on their lists had been covered sufficiently. The topics chosen by them to focus on were ‘keeping mentally active’, ‘keeping physically active’, ‘keeping socially active’ and ‘getting your message across’.

Only one DA and no participants completed the checklist for the second session. The Advisor recorded all items as being done, and that the participant had worked on the three topics identified in the first session.

Two DAs and one participant returned the checklists for the final session. All items were recorded as being delivered properly from both perspectives, and the participant reported using the PRIDE-app between sessions two and three, a response that was supported by their Advisor’s checklist.

5.3.3 App usage

The app development company, Ayup, were able to link the PRIDE-app to Google Analytics software. This enabled ARL to download the site data and import it into Microsoft Excel. Each click onto a different page was documented, e.g. visits to the main dashboard did not count clicks on the review session button. Below, Table 7 displays the key figures from the analytics with regards to some of the main pages on the PRIDE-app.

Table 7. Key figures from the PRIDE-app usage data.

Page	Total number of page views (includes multiple visits from same user)	Bounce rate (the number of times a session started and ended on a page, without any other interaction)	Average time on page (seconds)
PRIDE-app login	548	71.79%	92.05
Main dashboard	226	6.67%	30.17
Log an activity	184	0%	8.45
Add details of a new plan	18	0%	358.87

Although the use of the app by DAs could not be separated from that of participants and supporters, the figures suggest that more visits were made to the app than just those made during the sessions and by facilitators adding new users. The bounce rate on the login page indicates that although it had a high number of visits, a significant proportion of users did not progress past this page when they visited the PRIDE-app. As there was no bounce rate on pages for logging an activity nor detailing plans, users only accessed these pages to add plans and log their activity levels, two main components of the PRIDE-app. In addition, the average time spent on creating plans demonstrates that, either during or outside of the facilitated sessions, users reflected on their goals and took time in building plans important to them.

Between 14th July 2021 and 20th July 2022, the average PRIDE-app session duration ranged from 6102 seconds to 0 seconds, when users immediately left the page. The data showed that up until the 14th June 2022, the app was receiving fairly regular views, with the most page views recorded between 22nd September 2021 to 5th November 2021. Overall, the PRIDE-app recorded a total of 3433 page views, which includes both Advisor and participant visits.

5.4 Summary

5.4.1 Key findings

This study looked at the reach, effectiveness, and adoption of the PRIDE-app intervention. Some of the challenges encountered, such as that with recruitment, were more difficult than expected. No significant effects were found with regards to participants' independence, wellbeing, and quality of life. However, there was an improvement in supporters' mental health and wellbeing, but an indication of possible adverse effect in their quality of life.

The reach of the PRIDE-app proved disappointing in terms of diversity, as all participants were of white British ethnicity. App usage data suggested that people living with dementia did use the app, and that there was interest in PRIDE, but an easier login and navigation would likely have reduced the bounce rate. The figures could mean users experienced difficulties logging in, found the process too challenging or confusing, or went on the app with the intention of using it and maybe were distracted or forgot what they had intended to do on it. However, as the bounce rate fell when users reached the main dashboard, it appears that once users negotiated the login process, they made an effort to explore the app. Although the page view figures were considerably lower on the topic pages and content not covered in the introductory session, it would appear that for the users who could navigate the login process and were motivated to use the app, they did utilize the PRIDE-app’s unique points of activity planning and logging and were interested in exploring the content past the main dashboard interface. The average duration of time spent on the dashboard too would suggest users spent time familiarising themselves with the navigation of the PRIDE-app and looking at the plans and activities they created.

Across the outcome measures, scores generally declined slightly for both participants with dementia and supporters between baseline and the respective follow-up, and these changes were significant for supporters. As the Lawton IADL scores did not differ during the study period, it is reasonable to assume that participants’ dementia might have naturally deteriorated within that time, and as the scores did not alter it could be suggested that the PRIDE-app achieved its goal in some participants to enable independence to be retained. Although the Global Change Measure figures do not show that the PRIDE-app significantly improved people with dementias’ general wellbeing and independence, the fact that the majority of participants were classified as no change in both questions at the two timepoints could suggest the app slowed down dementia progression. Likewise, the fact that dementia is a progressive condition, participants’ wellbeing and independence could have purely been down to the nature of their dementia and therefore deteriorate regardless of their involvement with the PRIDE-app.

In terms of adoption, the DAs who recorded their sessions delivered the intervention as intended and the content discussions were understood by participants. Although only a couple of participants completed the fidelity checklists, these indicated that they adopted the PRIDE-app in-between sessions and applied the content discussed into their everyday lives, and this could have been representative of more participants given the number of views the app received.

5.4.2 Methodological problems

The remote working enforced by the COVID-19 restrictions was problematic with regards to recruitment and collaborating with research teams. Prior to COVID-19, sites would have visited in-person outpatient services and recruited for studies from these. As this opportunity was removed for them, sites were reliant upon telephone calls and emails to potential participants who were registered on their research database or who they knew might be interested. This restricted the pool of potential participants and ways to recruit for the study, both bringing challenges that were not initially anticipated by the wider study team.

As the recruitment target for the study was 60 – 90 people living with dementia, the difficulties experienced in recruitment were not anticipated, and the 17 participants who completed the PRIDE-app sessions was significantly lower than intended. Reasons given for not wanting to take part largely mentioned the apprehension of using an online intervention and the lack of technology confidence. Similarly, the drop-off rate from baseline to 6 months outcomes completion means that the statistical tests originally planned were not as appropriate as intended, and the figures provide only a small reflection of participants' time in the study.

Fidelity checklists were provided to monitor whether the intervention was being implemented and understood as intended. It was organized so participants and facilitators would complete the forms shortly after the session, but data protection within sites meant that they were responsible for sending checklists out to participants. As a result, this along with facilitators forgetting to complete them themselves, meant that a significantly lower number of checklists were collected.

5.4.3 Limitations

Perhaps the most significant limitation was that the sample consisted wholly of white British participants and therefore does not provide any representation of minority ethnic groups, nor can any of the findings be interpreted outside of white British populations. In addition, the low number of participants initially recruited and the drop off before completing the intervention stage reduces the validity and potentially generalizability of the findings. The enforced social restrictions and isolation caused by COVID-19 meant that participants were unable to optimize their use of the app and some of the activities it promoted, such as attending community groups. As such, the outcome measures are unlikely to represent the app as a whole and may have had a more positive effect on participants if the study had not been conducted during the COVID-19 pandemic.

5.4.4 Findings in context other work

Similar research from Beentjes et al. (2020) explored the use of a digital intervention, FindMyApps, on dementia self-management, engagement in activities and quality of life. FindMyApps supports the use of a tablet computer and apps with the aim of encouraging dementia self-management and engagement in meaningful activities. Researchers had similar aims to the PRIDE-app study in exploring the benefit of the digital intervention on the quality of life and independence in people living with dementia and their caregivers. Participants were randomly allocated to either the intervention group, where they received a training session to introduce FindMyApps, or a control. Across the 3-month intervention phase, only half of participants actively used the app, with the outcomes showing no significant differences between intervention and control groups in terms of dementia self-management. However, their overall conclusion that FindMyApps had potential and required a larger trial to explore its effectiveness more is in line with the conclusion from the PRIDE-app study.

In their feasibility study of app-based iCST, Rai, Schneider and Orrell (2021) assessed similar outcomes to the PRIDE-app study. Their sample consisted of people living with mild to moderate dementia and their carers, with these dyads randomly allocated to either the iCST or treatment as normal control group. Although a small sample of 61 dyads were recruited, and therefore the figures should be interpreted with caution, there were no significant differences found between the iCST and control groups on any of the outcome measures. However, a positive significant difference in the quality of life of carers in the iCST group. These findings from Rai et al. (2021) contrast with those of the PRIDE-app, but the iCST app had a beneficial effect on carer wellbeing, which is in agreement with the PRIDE-app.

5.4.5 Considerations for future research

Future research should better understand the priorities of people living with dementia when considering developing new interventions. Exploration of the type of technology used to support dementia in the community is needed more, along with questioning whether people with lived experience would prefer new interventions or to use/repurpose existing familiar technologies and apps. More effort is needed to study those harder to reach communities living with dementia and understand their needs when it comes to technological support for dementia. These communities are also likely to be of underrepresented backgrounds and may have lees computer literacy than the sample in the PRIDE-app study. The role of stigma should also be considered more going forward, as there may be a reluctance from people to used technology which labels dementia in its name or target audience due to the negative connotations the condition has.

5.4.6 Conclusion

External factors, such as the isolation of COVID-19 social restrictions, and the nature of caring for someone with dementia should be taken into consideration when interpreting both participant and supporter scores across the timeframe. Although the fidelity checklists had a much lower completion rate than hoped, the information gathered from the handful completed identify how the online format affected delivery and Advisors' flexibility to work the content around their participants' interests and needs. They also demonstrated the capacity to cover the intended PRIDE content in the session timeframe and to the extent where participants feel that they have received sufficient information on said topic. Even though the outcome measures did not show the app had any significant effect on the constructs measured, or improve the general independence and wellbeing of participants, there were no significant deterioration in scores either. It could be suggested that the content and use of the PRIDE-app had a positive impact on slowing the progression of dementia symptoms in the small sample.

Qualitative Analysis of RE-AIM Elements

This section provides a description of the development and analysis of the interviews conducted with participants, supporters and facilitators, previously outlined in Chapter 3. The aim of the interviews was to explore the perspectives and experiences unable to be collected by the quantitative outcome measures. These insights are valuable in understanding the potential benefits of the PRIDE-app and the developments needed to improve this. Thematic analysis was conducted on the interview data by two reviewers, and the themes which developed from this are discussed. A summary of how the findings relate to the RE-AIM framework is also given.

5.5 Methods

5.5.1 Interview questions

Discussions between ARL and OM about the study aims, and drawing on their previous experience with dementia research, guided ARL in the development of the initial question guides. The questions created for people with dementia and their supporters explored whether they had completed all three sessions with Advisors; their views on the content of the PRIDE-app; its usability and how this could be improved; and whether they felt they had benefitted from their time using it. Prior to finalizing this interview schedule, an advert for people with lived experience to join a Patient and Public Involvement group was sent to local dementia groups. The intention was to establish a group which could meet regularly during the development of the interview materials, to maximize the dementia-friendliness of the wording. Due to the ongoing COVID-19 pandemic, recruitment was understandably impacted and only two people volunteered to join, with one attending the virtual meeting. The final semi-structured schedule developed with the involvement of a person with lived experience of dementia can be seen in Appendix 9.8. A similar schedule was developed for DAs, with questions more directed at the implementation and maintenance of the PRIDE-app, and the Advisor training provision. The DA schedule can be found in Appendix 9.7. All interviewees were given the freedom, and encouraged, to expand on any points they voiced, and the final question on each schedule allowed for them to add anything else that had not been discussed.

5.5.2 Interview participants

During the consent process, participants (people living with mild dementia), supporters (spouses) and facilitators (DAs) indicated whether they would be interested in taking part in post-intervention interviews. Invites were sent out via email between November 2021 and April 2022 to those you consented to being contacted. Of the 13 invites sent out, nine interviews were conducted with two participants, two supporters, one dyad, and three facilitators. All interviewees were of white British ethnicity, over the age of 18 years, and consisted of six females and three males. Interviews were conducted on a one-to-one basis by ARL over Microsoft Teams or by telephone and lasted between five and 50 minutes. Verbal consent was obtained on the day, prior to recording the interview. All interviewees were provided with a copy of their respective question schedule a week before their interview date. ARL initially intended to conduct all interviews but had to be replaced by OM for two, due to ill health.

5.5.3 Data analysis

ARL transferred the interviews into audio files before sending them to an independent transcription company, dictate2us, where they were transcribed verbatim. Any identifying material was removed to ensure anonymity and each transcription was given an individual identification code (e.g. PP1, PP2). Reflexive thematic analysis was chosen as an appropriate method of analysis as its flexibility suited the overall RE-AIM framework being used and would enable a better understanding of the thoughts and experiences within the qualitative data (Kiger & Varpio, 2020; Braun & Clarke, 2022). Due to the creation of interview schedules which intentionally explored certain topics, a deductive perspective was incorporated into the thematic analysis (Kiger & Varpio, 2020). ARL followed the phases of reflexive thematic analysis outlined in Braun and Clarke (2022):

1. Familiarization – ARL and OM independently read through the interview transcripts several times, and ARL listened to the audio recordings again. Both reviewers made initial notes about the individual data items and the dataset as a whole.
2. Coding – Once well familiarized with the data, ARL and OM worked through the transcripts independently to identify and code potentially relevant sections.
3. Generating initial themes – Shared meaningful ideas across the data set were identified. The coded data which made up these ideas were collated together to create initial themes. ARL and OM then met to discuss which sections they had identified and coded and why.
4. Developing and reviewing themes – Following the reviewers' discussions, ARL created documents for each transcript to check that the themes made sense in relation to the coded data and the overall dataset. Revisions were made to initial themes to either expand them, split them into new themes, or discard them if they were not deemed to highlight the most important points of the dataset.

5. Refining and defining themes – ARL and OM then reviewed the revised themes and added additional independent thoughts about the reflections and interview experience.

ARL acted as the lead reviewer for analysis and OM provided a second review. OM is an experienced qualitative researcher and could provide a professional insight during analysis.

5.6 Findings/recurring themes

Reflexive thematic analysis of the data led to the development of the following main themes: ‘positive support for PRIDE-app principle and concept’; ‘importance of facilitator’; and ‘recommendations to improve the PRIDE-app’. Each theme had several subthemes, and these, along with the main themes, often overlapped between the RE-AIM elements. These can be seen in Table 8. For the purpose of this thesis, participants living with dementia are labelled Pt, supporters as Sup, and facilitators as DA, each followed by their corresponding interviewee number.

Table 8. The four central themes, the sub-themes and the relation to the RE-AIM elements.

<table>
<tr><th>Themes</th><th colspan="4">Sub-themes and their relation to RE-AIM framework</th></tr>
<tr><td></td><td>Reach</td><td>Effectiveness</td><td>Adoption</td><td>Implementation and Maintenance</td></tr>
<tr><td rowspan="4">T1: Positive validation for PRIDE-app principle and concept</td><td colspan="3">❖ Motivation and engagement</td><td></td></tr>
<tr><td rowspan="2">❖ IT literacy and confidence</td><td rowspan="2"></td><td>❖ IT literacy and confidence</td><td></td></tr>
<tr><td colspan="2">❖ Continuation of techniques</td></tr>
<tr><td></td><td>❖ Reflection</td><td></td><td></td></tr>
<tr><td>T2: Readiness to face and attitudes towards dementia</td><td>❖ Reaction to and acceptance of diagnosis
❖ View of supporters</td><td></td><td>❖ Reaction to and acceptance of diagnosis
❖ View of supporters</td><td></td></tr>
</table>

<table>
<tr><td rowspan="3">T3: User engagement with and the importance of the facilitator role</td><td rowspan="3"></td><td colspan="3">❖ Source of encouragement and reassurance</td></tr>
<tr><td colspan="2">❖ Independent voice</td><td></td></tr>
<tr><td>❖ Necessity of Dementia Advisors</td><td></td><td>❖ Necessity of Dementia Advisors</td></tr>
<tr><td rowspan="4">T4: Recommendations for improving the accessibility, usability and delivery of the PRIDE-app</td><td colspan="4">❖ Dementia friendliness</td></tr>
<tr><td colspan="4">❖ Format and delivery</td></tr>
<tr><td colspan="4">❖ Ways to improve the app</td></tr>
<tr><td></td><td colspan="2">❖ Navigation and signposting</td><td></td></tr>
</table>

5.6.1 Theme One: Positive support for PRIDE-app principle and concept

Motivation and engagement

Across the three different groups of interviewees (people with dementia, supporters, and DAs), a positive view of the overall PRIDE-app intervention and what it aimed to achieve was presented:

> *First impressions, I think it's a really good idea* (DA 1)

> *For me, personally, I can see the advantage* (Pt 1)

Motivation appeared to be an important factor in participants' decision to take part in the study and apply the techniques the PRIDE-app encouraged, therefore identifying a potential characteristic in people with dementia or their families that would make them a suitable user of the app:

> *A lot of people wanted to do this because of the goal-setting and they wanted that aspect for their mum or partner or whatever. And I think there's a lot to be said for giving that motivation and that kind of focus for people who potentially would just sit in a chair* (DA 3)

> *If they've got lots of activities to look forward to, then that motivates them further on, and I think this whole thing can be quite useful because of that* (Pt 1)

DAs reported positively on the influence of the intervention in encouraging their participants, and supporters appreciated the additional support the PRIDE-app content provided in areas where they were uncertain how to help their loved ones:

> *He’s become so much more motivated just through those three sessions, and wanting to do things, and I thought that was a really nice worthwhile thing when you have those stories of people who are just doing things again* (DA 3)

> *I think keeping mentally active was the one that I was most concerned about, and wanted the most specific on because it’s possible for me to help on the physical side* (Sup 2)

IT literacy and confidence

Not all participants felt they were the target group for the PRIDE-app intervention, with computer literacy being a significant definer in whether people with dementia or their supporters would be motivated to engage with the app. Similarly, DAs felt that although participants engaged with the sessions and wanted to use the app in their own time, some were wary of using it by themselves due to the online format:

> *But looking at the app, it seemed fairly easy to follow, and I would suggest for those that were competent in a computer but it was, as I said, it was just for us, unfortunately, it was just a step too far* (Sup 3)

> *I felt that it was good whilst we were going through and getting to the goals. But I was very much aware that whilst there was an intention with some people, most of them didn’t actually go back in between* (DA 3)

Additionally, one participant was already using a number of techniques identified in the PRIDE-app to manage their dementia, and therefore felt less motivated to use it outside of the research environment:

> *I used it outside the sessions only as a help for you guys doing the PRIDE thing because, obviously, it was a duplication of what I was doing in my diary* (Pt 1)

Reflection and continuation of techniques

The PRIDE-app provided a useful stimulus for reflection, as well as motivation, and DAs worked with participants to tailor use of the app techniques to better fit their lifestyles and different dementias:

> *[They were] getting a little bit more of a way of learning how to manage what's happening to you in relation to what you can and can't do and hand[le] your expectations* (DA 3)

> *It can just be about confidence, not capability, so something like this [PRIDE-app] can really help that set of participants because it just builds on their autonomy and reminds them that they can do things and it sets them goals and all of that stuff that they can work towards* (DA 2)

A handful of participants were already focused on continuing the techniques that the PRIDE-app had encouraged, whether new or pre-existing, and a couple requested additional PRIDE sessions with their DA because they were enjoying the goal-setting process. DAs were very positive about the PRIDE-app and believed it had a place within services to support people on clinical waiting lists:

> *Some of [participants with dementia] quite kept going…somebody that came up with something for themselves* (DA 3)
>
> *And perhaps not so much lots of new ideas but making use of what we've already had* (Sup 2)
>
> *It could be really useful for things like cognitive stimulation groups, memory clinics…it would be useful to people on waiting lists for sure, setting goals, and things like that* (DA 2)

Facilitating the sessions prompted one DA to consider implementing the app's goal- setting technique into their services:

> *I mean, it's given me the idea that I'd like to do some face-to-face groups that are all about goal-setting because of the ideas of people [PRIDE-app participants] are coming up with* (DA 3)

5.6.2 Theme Two: Readiness to face dementia

Although the PRIDE-app intervention included a section on coming to terms with receiving a diagnosis, the readiness to accept being diagnosed and understanding the potential loss of social identity appeared important factors in whether the participants were able to engage as fully as intended with the app and have the level of insight required to make the behavioural changes PRIDE promoted. Participants displayed a mixed reaction to having a dementia diagnosis, with some acknowledging it and others distancing themselves. A sense of confusion about being diagnosed was evident in some:

> *It hit me at the beginning about being told that I've got dementia…I thought that was a bit odd* (Pt 2)
>
> *I think she felt that she doesn't really need any help* (Sup 2)

Despite the prerequisite criteria of having an official dementia diagnosis, one participant (Pt 1) wavered between acknowledging themselves as someone who was diagnosed and presenting people with dementia as different to him:

> *If somebody's got dementia, you know, and I'm not counting myself in that position at the moment*
>
> *I keep saying "they". I mean, maybe it's me as well, I don't know*

A different participant expressed frustration about the impact dementia has had on their independence, such as their ability to drive, and on their social role:

> *I just go into town or go to different places or, or…I am doing volunteer stuff as well…But it's just as …it's just very…well, a bit frustrating* (Pt 2)

It appears from the interview that the participant might not have been in the right frame of mind for the PRIDE-app study, as their reporting of the actual study is largely missing, and the focus was more about their current life situation:

> *[Person with dementia] been in denial for the last year or more, but the last few months, she had accepted having mild Alzheimer's…she has*

> *done, to some extent, fundamentally, but perhaps not emotionally* (Sup 2)

The views of supporters should also be considered when offering the PRIDE-app intervention, as their strong personal views on dementia and what people are capable of could potentially limit access to the app:

> *I'd like to think that [husband with dementia] could continue trying to do the things that we gave him as challenges if you like, but without something…reminding him, he just…I don't suppose he even remembers now* (Sup 1)

5.6.3 Theme Three: User engagement with and the importance of the facilitator role

The role of the DAs was identified as a pivotal factor in how well people with dementia engaged with the PRIDE-app. Several key behaviours and skills were identified as the core components of an effective facilitator. The DAs provided an independent voice within the dementia dyad, a relationship which could often be strained by dementia:

> *It is useful to have somebody like [Dementia Advisor] engaged with you, that third party is very, very valuable* (Sup 1)

From the perspectives of those living with dementia, they appreciated having the external voice of the DAs, who saw them as individuals and validated and respected them. This was in contrast to some supporters who unintentionally viewed their loved ones solely as someone with dementia:

> *Just the way she interacted and talked to me. It's good* (Pt 2)

DAs acted as an additional source of encouragement and reassurance for both those with dementia and their supporters, with regards to the PRIDE-app study and in their everyday lives. One supporter emphasised how the positive and inquiring attitude of their facilitator was more helpful in motivating his wife, who would otherwise have been reluctant to actively participate. There was a difference between simply reading through the content with participants and enabling positive open discussions with a person with dementia about their thoughts and goals:

> *The way that [Dementia Advisor], as it were, inquired and encouraged [Person with dementia] was more helpful than could be achieved simply by reading out questions or assuming that's good* (Sup 2)

The facilitators themselves felt that the PRIDE-app enabled discussions to happen between Advisors and those with dementia, but also within the dyads:

> *I think it's also a good communication tool for with the carer, for a carer to understand how that person's feeling* (DA 2)

> *And every time we did it, with [Dementia Advisor] guiding us, and [Person with dementia] wasn't achieving what we hoped he would achieve, but nevertheless we invigorated him to have another little go* (Sup 1)

Supporters sought reassurance regarding their role and whether they were 'doing the right thing' for their loved one with dementia. Advisors were seen as a source of knowledge who could provide this:

> *We were doing these things before, but I didn't realise perhaps until the PRIDE app and discussing with [Dementia Advisor], that this was the right thing to do, as it were, or that it was providing the sort of stimulus that I was seeking it provides* (Sup 2)

It was evident from the interviews how necessary the role of DAs was for the delivery of the PRIDE-app. Differing levels of computer literacy meant participants were reliant upon Advisors' guidance when using the app. As a result, few were able or confident enough to use it independently:

> *I think people are nervous about using an app…and this is using experience from other similar studies as well, is that they start off quite confident, and then…they press the wrong button or something…and then they won't revisit it at all…it feeds into their feelings of incompetency* (DA 2)

The remote delivery of the intervention caused some communication difficulties between participants and DAs, and Advisors were uncertain whether they were delivering the app as intended:

> *It's very difficult to know when you're giving a verbal instruction without any visual whether that's actually happening in the way that's intended or whether they're off on some other tangent because it's a misunderstanding* (DA 2)

5.6.4 Theme Four: Recommendations for improving the accessibility, usability and delivery of the PRIDE-app

All interviews discussed where the PRIDE-app fell short, mainly in terms of its usability and dementia friendliness. People living with dementia often found the navigation around the app difficult to understand and felt that the signposting could have been made clearer:

> *I think just frustration a little bit…it was like you going back and forwards a little bit* (Pt 1)
>
> *The navigation was the biggest issue…You're never quite sure where you were at any given time* (Sup 1)
>
> *The navigation, the finding your way around it is quite difficult to learn, so simplifying it, if you simplified it then yeah, it would be great* (DA 1)

Interviewees suggested how to improve the accessibility and ease of use of the PRIDE-app through a clearer mapping system of the content, adding reminders on pages to inform users which content section there are on, and revising the interface:

> *Maybe sort of more clear mapping system just so to return to this, to return to that might have been helpful* (DA 3)
>
> *Maybe changing the appearance of the app itself…not boxes for example, and more colours, and maybe pictures* (DA 2)
>
> *Maybe set it out just as a calendar and each…you know, just your log, you know, you go into that calendar date, you pick the date. Bang!*

> *That's my activity within the activity. You could put a future plan or a daily plan type of thing and something like that* (Pt 1)

Some felt that the app was not as dementia friendly as it could have been and believed that the end users were not considered enough in the development process:

> *It's more of a tool in some respect for you guys to analyse things rather than a tool for the user* (Pt 1)
>
> *It feels a little bit like homework…whereas if it had a sort of fun…a little bit of a game, brain train-y type of thing…that might help people engage with it and actually not feel like it's a chore to fill out on their own* (DA 2)
>
> *There was far too much reading and comprehension for the Alzheimer's person to really understand how to follow it* (Sup 1)

The perspective of dementia friendliness is pivotal in ensuring the PRIDE-app is useable and accessible for the target audience. The quotes gathered do portray some of the stigma which goes with dementia-specific technology, as individuals do not want to be seen using dementia-specific technology. Addressing and incorporating the different perspectives of key stakeholders would significantly improve the chances of the app being adopted and implemented by healthcare services and people living with dementia.

Delivery and format of the PRIDE-app were also identified by interviewees as areas for modification. Supporters and advisors shared the perspective that altering the angle of the PRIDE-app and including more ‘push’ technology, taking some of the responsibility away from the user to remember to use the app, would increase engagement in people with dementia:

> *I think instead of using pull technology, i.e., you’re requiring the patient to go online and do something, you should be using push technology…If you’re pushing them reminders, I think it would help significantly* (Sup 1)

Ideas relating to the format of the PRIDE-app were well discussed across the interviews. Supporters and advisors provided suggestions as to whether an online, smartphone or paper version, with in-person or virtual contact, would be best suited going forward. Although participants with dementia did not voice their views directly, they were reported:

> *I think it’s a personal preference as well I think because that lady probably would’ve preferred pen and paper whereas the first participant, he had an iPhone and he said he would prefer to actually have it as an app* (DA 1)

The idea of a smartphone version of the PRIDE-app appeared popular within the interview sample. This may be because the current online format requires users to make additional use of their computers rather than being able to access it via their mobile phones. Even those who were computer literate seemed to prefer a more accessible version. For those who were not altogether in favour of a smartphone app, having a paper version of PRIDE, combined with face-to-face sessions, would have suited them more.

DAs also proposed adaptations to their initial training and the delivery of the PRIDE-app sessions. With their initial training, Advisors would have preferred a longer gap between training and facilitating, and the opportunity to run dummy sessions with other facilitators training at their respective sites:

> *It would’ve been useful to just have that option set up a dummy person with one of my team and then be able to practice with them* (DA 2)

The remote delivery of the PRIDE-app posed difficulties for facilitating the sessions, as Advisors were unable to check what the person with dementia was doing on the app, and the support provided was restricted by the format:

> *I couldn’t see what see was doing, I couldn’t see what she was inputting. I think that’s the drawback actually* (DA 2)

Advisors used their experience from similar studies to provide recommendations on how the delivery of the PRIDE-app could be improved going forward and have a positive impact on its adoption and maintenance by services and users:

> *Before Covid…we’d have gone out and done a face-to-face visit with the person and maybe a carer. We would have taken them through the program, showing them what they have to do…okay, I’m going to call you next week, so, you can use it as much as you want in the time…and that would have raised their confidence…I might say let’s book in a weekly session where I call you and we go through the session together every time, not having them do it on their own in between because I’m pretty sure my lady didn’t do very much on her own* (DA 2)

5.7 Findings in relation to RE-AIM

5.7.1 Reach

From the interviews, the target population for the PRIDE-app was identified as motivated individuals who had begun to understand their dementia diagnosis and were at a good stage psychologically to engage with the intervention sessions. The level of computer and technology literacy required is an element that should be considered when enabling access to the PRIDE-app. However, the app may still be of use for people with dementia who are not as technologically confident and require additional support, as they could benefit from the content and techniques the intervention discusses.

5.7.2 Effectiveness

The engagement and reflection that the PRIDE-app encouraged and required appeared to play a key part in whether the app had a positive effect on participants and supporters. The independent voice and additional encouragement provided by the DAs was necessary in delivering the intervention and was a definite factor in whether users felt that the PRIDE-app was a positive addition to their lives. Future adaptations to the delivery and format of the app may improve the overall effectiveness, as participants and facilitators clearly struggled with the online and remote format, both of which influenced their use and understanding of the intervention.

5.7.3 Adoption

Participants and supporters did not adopt the PRIDE-app in their daily lives as originally intended, as the online format was divisive among users and deemed not very accessible. They did, however, adopt the techniques promoted and continued to apply these after the study, suggesting that the content was appropriate and relevant to the target population. Although the adoption was not wholly as intended, interviews demonstrated the importance of motivation, computer literacy, and encouragement in whether participants used the app. These factors should be considered to increase future adoption of the PRIDE-app. The recommendations put forward in the interviews would have likely increased adoption within this sample, as the modifications would have improved accessibility, usability and longer-term engagement with the PRIDE-app.

5.7.4 Implementation and Maintenance

There were reports of participants and facilitators continuing to use the PRIDE techniques and apply them further in other service areas after the study. This suggests that the PRIDE-app has a place within dementia services and that the content resonates with people living with dementia. Interviews demonstrated the necessity for a DA who could work collaboratively and positively with participants. This important factor should be considered if implementing the PRIDE-app in future services. Enabling long-term implementation and maintenance may require offering people with dementia alternative formats of the app, alongside the original online version, and involving face-to-face elements during the intervention delivery.

5.8 Discussion

Analysis of the interviews highlighted the importance of having a facilitator and direct engagement with the person living with dementia. The planning element of the PRIDE-app enabled dyads to have a record of their achievements and a source of reflection on how to incorporate the app techniques going forward.

DAs provided a positive perspective of the PRIDE principles and how users incorporated them into their lives, even if they were not using the app as originally intended. They identified ideas for improving real-world adoption of the app and engagement with users. The knowledge that users continued to have sessions post-intervention, and that the app had prompted ideas for other services, goes towards validating the principles and content. The positive components of the PRIDE-app that were identified required active, supportive input from the DA. This indicates that establishing a personalized, trusting relationship between facilitator and service user is crucial for the successful implementation of the intervention.

The acknowledgement of a diagnosis and readiness to face dementia was key in reaching and engaging participants. This highlights the need for users of the PRIDE-app to be in the right mindset when learning about and applying the techniques it encourages. Technological preference was key in who took part in the study and how well they engaged with it. One supporter spoke about how that, even though they used computers daily, they were still more used to using paper and this affected their use of the PRIDE-app. The dyad who were interviewed ended it with voicing an interest in participating in any future paper-based or face-to-face research, demonstrating their preference for these formats over online delivery. This was an ongoing underlying theme that was felt among most of the interviews with regards to the online component of PRIDE, even when not explicitly mentioned.

5.8.1 Methodological Issues and Limitations

The remote format meant that ARL was unable to fully grasp interviewee gestures or body language, especially with the interviews conducted over the telephone. This could have meant that some meaningful interpretation of the data was missed. However, as question schedules were provided prior to the interview itself, this gave people time to consider their answers and make notes of everything they wanted to say. As with all qualitative research, subjectivity and the interpretation of data are outstanding methodological limitations, as ARL created the interview schedules, conducted them and was lead on the analysis. The influence of any internal bias or views from ARL that could have affected the interpretation of data aimed to be limited by the inclusion of a second reviewer. As an experienced clinician and qualitative researcher, in particular dementia research, OM could provide an objective and professional insight across the data. The collaborative reflection during the thematic analysis process ensured that agreement was reached between both reviewers at the end of each stage.

5.8.2 Conclusion

Technological literacy appeared to be a barrier which prevented some participants and supporters from engaging fully with the PRIDE-app. Some felt that people with young onset dementia were more likely to adopt the PRIDE-app, as they would generally be more computer literate than older adults. As many interviewees thought the app was a good idea but was too complex to engage with fully, a choice of an online, smartphone app, or paper-based version of the PRIDE-app in the future would likely increase the reach and adoption of the intervention. Although most participants did not take full advantage of the PRIDE-app and incorporate it into their daily activities, the interviews demonstrate the largely beneficial effect it had across participants, supporters and facilitators.

6. Understanding barriers and facilitators to online and app activities for people living with dementia

This chapter was developed into a journal publication:

Lee, A. R., McDermott, O., & Orrell, M. (2023). Understanding Barriers and Facilitators to Online and App Activities for People Living With Dementia and Their Supporters. *Journal of Geriatric Psychiatry and Neurology*, 08919887221149139.

6.1 Rationale

In the past, people living with dementia have often been stigmatised as passive consumers of technology, who rely on their supporters to facilitate use (Savitch, Zaphiris, Clare & Freeman, 2004). However, technology can support people with dementia to stay engaged with meaningful activities, access resources, maintain independent relationships and achieve a decent quality of life (Good Things Foundation, 2020). Having a better understanding of the digital skills, confidence in and use of technology would help improve the guidance and inclusion for improving access to technology in people with dementia (Good Things Foundation, 2020). The increase in available technology, in particular computer technology such as smartphones and tablets, has raised questions as to how they could be used in dementia care services and in the community to support families and improve the wellbeing of those living with dementia (Astell et al., 2019). Little is known about how familiar people living with dementia are with technology and how often they use it. With the Covid-19 pandemic, many people living with dementia and their families have become more socially isolated and lost participation in meaningful activities (Quail, Bolton & Massey, 2021). Technology has enabled people to access services, resources and support during the social restrictions and closure of many healthcare services.

Existing literature shows a mixed reaction to and use of technology in people living with dementia. LaMonica et al. (2017) surveyed adults with subjective cognitive impairment, mild cognitive impairment (MCI) and dementia about their use of technology and interests in electronic health (eHealth). Most people were routinely using mobile phones and computers, had access to internet in their own homes, and experience in emails but were unfamiliar with social media. Although only a one in 10 of the sample had dementia, this study revealed that use of technology is prevalent in people with varying cognitive difficulties, raising the possibility that eHealth interventions could be of interest to some within this population, with the right support available. Guzman-Parra et al. (2020) surveyed older adults living with MCI or mild dementia. A quarter used smartphones almost daily, with many using specific applications to support their memory. Participants found to have higher enthusiasm for technology showed fewer depressive symptoms and a better health status score. Findings from this study revealed that attitudes to and daily use of technology varies among people with cognitive conditions and their supporters, but that there could be potential for it having a positive impact of depressive symptoms and health. However, only 27% had dementia so the findings are difficult to generalise.

Online interventions need to understand their target audience. In our PRIDE-app study (Lee, McDermott, Guo, Roe & Orrell, 2022), recruitment was slow compared to the study using the PRIDE paper-based manual which recruited over 90 people (Csipke et al., 2021). Although the evidence suggests that technology could play a role in dementia support, the adoption of such interventions is reliant upon people with dementia accepting it and feeling engaged. Technology acceptance relates to the attitudinal perception and behavioural intention to use technology and has a significant role in predicting whether technology will be adopted and used (Chen & Lou, 2020). However, to assess how far people with dementia are ready to use apps for self-management and independence, we need to know more about their internet use and approach to a variety of technologies. The aim of the questionnaire was to investigate attitudes and experience in relation to computer and smartphone technology use among those living with dementia and their readiness to use it to support self-management.

6.2 Development of the attitudes towards technology questionnaire

6.2.1 Participants

Any adult aged 18 years or over who either had dementia or lived with/supported someone with dementia were eligible to complete the questionnaire. A minimum target of 80 participants and a maximum of 250 was set, with these figures taking in both people with dementia and supporters. This target was set due to the short period of time the questionnaire was available for and considered that advertisement of the survey was reliant upon participants receiving notifications, as mentioned below.

To recruit participants, the link to the questionnaire was posted on the JDR website. This is an online self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia, and healthy volunteers to register their interest in taking part in research. The inclusion criteria were for participants with dementia to have a medically confirmed diagnosis of any form of dementia and live in the community were set. Inclusion for supporter/carers only required them to be an active supporter of someone with dementia who was living in the community. The volunteers signed up to JDR received an alert about the study if they meet the inclusion criteria. Then, eligible participants had the opportunity to access the questionnaire and contact the study team if they had any questions. A paper version of the questionnaire was available to request and could be posted to participants with a prepaid return envelope. The questionnaire link was live for six weeks from April to June 2022.

6.2.2 Development of the attitudes towards technology questionnaire

Following a scope of the research and defining the research questions, a 28-item self-report questionnaire was created using the JISC online platform (formally known as Bristol Online Surveys), an online tool designed for researchers which allowed participants to easily access the questionnaire. This platform enabled us to create questions, decide on the answer response (e.g., whether multiple answers could be selected), and select which were required and which were optional questions. There were also six demographic-based questions to record whether the participant was living with dementia or a carer/supporter, along with their age, gender etc. Questions were developed by scoping similar surveys published online (Anderberg, Eivazzadeh & Berglund, 2019; Anderberg, Abrahamsson & Berglund, 2021) and through several rounds of revisions following discussions within the research team prior to the final version going live. This was to try and maximize the relevance and cover of questions in terms of the study aim.

Questions explored how long the participants had been using computer technology; how regularly they used it; the popularity of common communication apps; and whether they were interested in using an app to support their independence. For this questionnaire, computer technology was identified as computers, laptops, tablet computers and smartphones. Most questions had a "Yes" or "No" answer, or a range such as "Very knowledgeable" to "Not at all knowledgeable". Several questions encouraged respondents to expand on their "Yes/No" answer by providing qualitative data. Many models and questionnaires have been created to predict technology acceptance, including the TechPH questionnaire (Anderberg et al., 2019), which was incorporated into the present survey. The six TechPH questions included were answered using a five-point Likert scale, with response options ranging from "Fully disagree" (1) to "Fully agree" (5). The final version of the questionnaire can be found in Appendix 9.9.

6.2.3 Ethics

This sub-study was reviewed and given ethical approval by Oxford Research Ethics Committee (21/SC/0066). All minor and substantial amendments were reviewed by the UoN before being approved by the Oxford Research Ethics Committee. Consent was gathered on the information page, where all participants had to tick the consent box to proceed.

6.2.4 Analysis

Data was imported into SPSS 28 for analysis and checked and cleaned. Although two respondents did not provide an answer, after reviewing the data during cleaning, one provided another answer which indicated that they were in the supporter role and was added to that group. The other respondent indicated that they were neither living with a dementia diagnosis nor were a supporter of someone who was. Therefore, their data was removed from the dataset prior to analysis. Qualitative data from all participants was reviewed and grouped together with the corresponding quantitative question, to enhance the understanding of the numerical figures.

6.3 Results

Data was imported into SPSS 28 for analysis and checked and cleaned. JISC also provided an option to explore responses.

6.3.2 Participant demographics

Table 9. Summary demographic details of questionnaire participants.

Demographics	**People with dementia (n=47)**	**Supporters (n=62)**
Time since diagnosis/Duration of informal caregiver	Six weeks – 23 years (M=4.5 years, SD=4.44)	Six weeks – 30 years (M=5.6 years, SD=4.85)
Age	45 – 64 years 14.9% (n=7) 65 – 74 years 31.9% (n=15) 75 – 84 years 48.9% (n=23) 85+ years 2.1% (n=1)	18 – 44 years 3.2% (n=2) 45 – 64 years 50% (n=31) 65 – 74 years 30.6% (n=19) 75 – 84 years 14.5% (n=9) 85+ years 1.6% (n=1)
Gender	Male 72.3% (n=34)	Male 14.5% (n=9)
Ethnicity	White 97.9% (n=46)	White 93.5% (n=58)
Highest education Level (high school or above)	Degree 46.8% (n=22)	Degree 50% (n=31)
Use(d) computer technology for work	Yes 76.6% (n=36)	Yes 79% (n=49)
Internet access from home	Yes 97.9% (n=46)	100%
Time of length using computer technology	2+ years 95.7% (n=45)	2+ years 96.8% (n=60)
Main use for technology	Email/communication 89.6% (n=42)	Email/communication 96.8% (n=60)

Table 9 presents the summary demographic data for the questionnaire respondents. Of 110 participants, 61 (55.5%) were supporters and 47 (42.7%) were people with a dementia diagnosis. In the 47 participants with dementia, time since diagnosis ranged from six weeks to 23 years. Most completed the questionnaire alone (n=40, 85.1%) and seven participants reported having assistance (14.9%). There were considerably more male respondents (n=34, 72.3%) than female (n=12, 25.5%). With regards to their ages, 80.8% of participants were between 65 and 84 years old (n=38), and 97.9% were of White ethnicity (n=46). 34% (n=16) had completed High School and 46.8% (n=22) held a degree. One participant did not provide an answer to the demographic questions.

The 62 supporters had been in their roles for vastly varying durations, from six weeks to 30 years. The majority were aged between 45 and 74 years old (n=50, 80.6%). As expected from experiences with the main study recruitment, almost all supporters were of white ethnicity. There were two from Asian/Asian British ethnicity (3.2%), and one from Black/African/Caribbean/Black British ethnicity (1.6%). The question about the highest level of education reached revealed that 33.9% (n=21) had completed High School and 50% (n=31) had completed a degree.

A vast majority were found to have been using computer technology for two or more years, which indicated most were regularly using it prior to the COVID-19 pandemic, rather than learning to use it during. Most supporters had also been using technology for two or more years. Much like the figures from people living with dementia, this shows that technology use among supporters was popular prior to the COVID-19 pandemic.

Email and communication were the most popular use for computer technology in both groups, with the news and weather (n=36, 76.6%) and shopping (n=29, 66%) also proving popular for people with dementia. As communication apps, such as WhatsApp and Zoom, were both used by almost 80% of this group (n=37, 78.7%), this would support the most common use of computer technology.

6.3.3 Internet use

Table 10. Summary of usage data reported by respondents.

Usage	**People with dementia (n=47)** (*Every day/Almost every day*)	**Supporters (n=62)** (*Every day/Almost every day*)
Internet use	89.4% (n=42)	96.8% (n=60)
Email use	76.6% (n=36)	92% (n=57)
Use of computer technology in past month	87.2% (n=41)	96.8% (n=60)

Table 10 details the internet, email, and general computer technology use amongst the participants. Use of the internet was daily or almost daily for 89.4% (n=42) of people with dementia, with emails being accessed either every day or almost every day for 36 (76.6%) respondents. When asked if they had used any computer technology in the month preceding the questionnaire, 61.7% (n=29) reported using it daily and a further 25.5% (n=12) almost every day. Use of the internet and time since diagnosis were not found to be related (X^2 (1, N = 45) = 1.6, p = .254). As the result was not significant, it revealed that those diagnosed more than two years ago were just as likely to use the internet daily as those diagnosed under 2 years ago.

6.3.4 Views on technology

Table 11. Summary of respondents' views on technology.

Views on Technology (statements)	**People with dementia (n=47)** (Fully agree/agree)	**Supporters (n=62)** (Fully agree/agree)
It's fun learning how to use new technological gadgets	62% (n=29)	61% (n=38)
Using technology makes life easier	89% (n=42)	89% (n=55)
I like to acquire the latest models or updates	47% (n=22)	24% (n=15)
Today, the technological progress is so fast that it's hard to keep up	72% (n=34)	82% (n=51)
	People with dementia (n=47) (Very/Quite knowledgeable)	Supporters (n=62) (Very/Quite knowledgeable)
How knowledgeable do you consider yourself to be when it comes to using a computer, tablet, or smartphone?	53.2% (n=25)	72.6% (n=45)

Table 11 presents the participants' views on technology and how knowledgeable they consider themselves. Over 60% of people with dementia said it was fun to learn how to use new technology, and most felt it made life easier, but there was also an agreement that the technological progress of today was hard to keep up with. The percentage of people with dementia who liked to acquire the latest technology indicated that this group presented as more innovative and interested in having new technology. People who felt more confident about their knowledge were more likely to seek the latest updates or models (X^2 (20, N = 62) = 65.6), p =.001). With regards to supporters, the enjoyment of learning how to use new technology was also over 60%. Parallels between groups were revealed with regards to their enjoyment of new technology, the positive impact it had on making lives easier and in agreement that the technological progress was hard to keep up with.

Table 12. Views of participants.

Views on Technology (statements)	**People with dementia (n=47)** Fully agree/agree	**Example quotes from people with dementia**	**Supporters (n=62)** Fully agree/agree	**Example quotes from supporters**
Sometimes I'm afraid of not being able to use the new technical things	66% (n=31)	*"Difficult to understand how to use."* *"Need lots of repeated support…to grasp the new tech."*	56% (n=35)	*"I struggle if new software/technology goes wrong."* *"They [computer technologies] can be quite complicated."*
I would have tried new technical gadgets to a greater extent if I had more support and help than I have today	38% (n=18)	*"Need lots of support to understand how a new gadget could be helpful."* *"My family lose patience when teaching me how to use technology."*	36% (n=22)	*"Don't know implications and how to rectify problems."*

Table 12 provides an overview of the qualitative feedback gathered from both group of participants. Figures and quotes demonstrate the lack of difference between groups, with people with dementia and supporters both experiencing apprehension when using new technology. Over half of both groups shared that they had apprehension for using new technology, with the sometimes-complex nature of technologies being identified as a main anxiety. For those with dementia who did not share this uncertainty, their reasoning showed determination and persistence to not allow their age or dementia to deter them from learning about new technology.

6.3.5 Technology for dementia

Table 13. Use of technology for supporting people with lived experience of dementia, in their daily lives.

Technology for dementia	**People with dementia (n=47)**	**Example quotes from people with dementia**	**Supporters (n=62)**	**Example quotes from supporters**
Knowledge level – very or quite knowledgeable	53.2% (n=25)		72.6% (n=45)	
Already accessing dementia-related resources	Yes 72.3% (n=34)	*“Medical information, diet advice. Lifestyle advice and academic studies.”* *“I use technology to do research on Alzheimer’s and to connect what Alzheimer’s groups and organizations.”*	Yes 79% (n=49)	*“Research info on symptom developments.”* *“Online forums for carers.”* *“Alzheimer’s Society, Alzheimer’s Research, browsing latest research etc.”*

Use for daily activities and independence	Yes 72.3% (n=34)	*"I depend on my computer, tablet, and smartphone for most things."* *"Researching my condition including any new symptoms."* *"Receiving counselling and support via teams/Zoom."*	Yes 53.2% (n=33)	*"Helps me stay in touch and manage my own life alongside the demands of being full time carer."* *"My smartphone is my link to my own life…I don't think I could do this caring role without the support I get via my phone."*
Highlighted concerns	• Data protection • Security • Lack of knowledge • Making mistakes	*"Lack of knowledge and fear of pressing the wrong button."* *"Data protection and identity theft."*	• Security • Fraud • Lack of knowledge	*"…worries around security, personal information being used."* *"Not knowing what I am doing. Feeling frustrated*

				when I can't get it to work."
Priorities for future technology	• Easily accessible • Simple to use • Secure	*"Data protection and minimizing scams is very important."* *"Simple to use, easy to understand."* *"Support with remembering all the passwords etc. in easy accessible way."*	• Accessible • Simplicity • Secure	*"Easily accessible, interesting to use, helpful to my situation."* *"User-friendly, safe, ethical."* *"Simplicity, works for person with dementia to use or can be remotely used to support them."*

One area of great interest to us was whether computer technology is already widely used by people living with dementia to access resources and support. Table 13 provides a quantitative and qualitative overview of the current uses of computer technology for dementia support among participants, as well as their concerns and priorities for technology. The majority accessed national and local dementia groups websites, such as the Alzheimer's Society; attended virtual support groups for those diagnosed; researched symptoms; and a number were receiving notifications of new research and journal publications. Existing use of computer technology to support their independence and daily activities included alarms and reminders; communication with family and friends; and electronic diaries to keep track of appointments and medication. Through their comments, it was clear to see that computer technology enabled the independence of people with dementia as a source of additional support. The four most common concerns were data protection and privacy; security and fraudulent activity; a lack of knowledge; and making mistakes, including deleting important information and accidentally sharing personal information. These concerns were reiterated to an extent when respondents were asked whether they had any priorities for future computer technology.

When asked about the use of an app to support their daily activities, the 72.3% (n=34) who were interested provided insightful reasoning as to why from the perspective of living with a diagnosis:

> *"Anything that helps myself and wife to deal with this [dementia]."* (Sup)
>
> *"Anything that could be of benefit to me of make my life easier."* (Pt)
>
> *"Help keep my mind active."* (Pt)
>
> *"I realize there is a lot of potential to be more self-sufficient."* (Pt)

Accessing dementia-related content was popular among most supporters, with similar resources accessed to people with dementia, such as charity website; support groups for informal carers; dementia-specific training courses; and as a source of symptom information. Through their comments, it was evident that computer technology provided a lifeline for supporters as a source of additional support and highlighted the benefits of online resources. As expected, supporters shared similar concerns about computer technology as those with dementia, with security, fraudulent activity and a lack of knowledge frequently reported. Supporters' priorities were very similar to people with dementia, with accessibility and ease of use reported by many.

As supporters reported many similar concerns and priorities for computer technology, it shows shared viewpoints among both groups. It perhaps reinforces the argument for including people with dementia in the development stages of relevant technology, as they are aware and have a good understanding of the potential benefits and pitfalls and are good at communicating what they want out of technology. Supporters were also asked whether they would be interested in using an app regularly on their computer, tablet, or phone to support their independence and daily activities. Understandably, and much like the responses from people with dementia, there were some supporters who did not feel that their situations would benefit from this, or that it would be easy to use regularly (n=28, 45.2%). However, for the small majority who did say ‘Yes’ (n=33, 53.2%), their reasoning centred around supporting their relatives and enabling their independence:

> *“Anything that can help my sister be as independent as possible but also safe.”* (Sup)
>
> *“Anything that helps me to manage my situation.”* (Sup)
>
> *“Anything to help independence is good.”* (Sup)
>
> *“If it was something that helped my husband maintain his independence I would be interested.”* (Sup)
>
> *“I’m always looking for resources that will help me provide a better quality of life for my wife.”* (Sup)

6.4 Discussion

6.4.1 Principal Findings

People with dementia and supporters actively used computer technology for a variety of needs and showed an interest in maximizing its use to support independence in those living with the condition. To our knowledge, this questionnaire provides the first comparison of attitudes towards the daily use of general computer technology in people living with dementia and supporters. There were no obvious differences found between groups in terms of their usage and range of computer technology use, but the majority of those with dementia were older males, whereas supporters tended to be younger females. Contrary to the common myth that older adults did not use computer technology, 51% of respondents with dementia were aged 75 and over. The broad ages of supporters, and the higher number of females, would suggest that there were more daughters and wives in this role. This is in accordance with what has been found globally with regards to informal care in dementia (Alzheimer’s Society, 2020). The survey figures question why there was a gender divide within the people with dementia group, and whether females with dementia were less willing to use computer technology, less interested in completing surveys, or if they simply did not have the time to answer the questionnaire. As the ages of participants include those of normal working age, it is reasonable to infer that some participants were likely to currently be using computer technology for work. When interpreting the findings, it should be considered that the participant population were predominately white British people.

Communication was identified as a primary use for computer technology, which demonstrates the importance of reducing social isolation and maintaining relationships for people living with dementia. Technology enjoyment level among supporters showed similarity to the attitudes of those with dementia, which was not expected due to the nature of the condition. As anticipated in a sample of older adults with cognitive difficulties, apprehension for using technology was shared by a number of respondents with dementia. Additionally, people with dementia voiced concerns about the use of computer technology, such as security and system issues, which could be indicative of why there is an apprehension to adopt new technology. As over half of supporters also reported apprehension, and a third felt they would have tried more with technology if they had more support, their hesitance or anxiety about using technology could have wider implications for its use among some people with dementia. People with dementia can use technology, but some may require additional support from family or friends in order to feel more confident. Therefore, supporters' attitudes could, for example, restrict the reach and use of technology within the population of those living with dementia. It was interesting that those who did not share this apprehension placed emphasis on not allowing their age or diagnosis to impede their usage. Knowledge levels in those with dementia appeared to support the apprehension found in using new technology, suggests a potential link between knowledge levels and adoption and that this is an important factor in the confidence and potential adoption of computer technology.

Accessing dementia-related resources was popular among the sample, and computer technology provided a majority assistance with daily activities, enabling their independence. Perhaps unexpectedly was the frequent use of computer technology amongst those with dementia and how long they had been using it. As a majority were familiar with computer technology prior to COVID-19, the restrictions and closures during the pandemic may have increased their frequency and range of use rather than prompt learning to use them.

As a tie into the RE-AIM Study of the PRIDE Self-management App (Lee et al., 2022), respondents were asked whether they would be interested in using an app regularly on their computer, tablet, or phone to support their independence and daily activities. Only 21.3% of people with dementia did not show any interest in using an app to support their activities. Those who were interested were enthusiastic to trial anything that could benefit their independence and help themselves and families come to terms with the diagnosis. With the difficulties experienced in recruitment for the Lee et al. study, the questionnaire results could suggest a gap between the attitudes towards technology in those with dementia, and their behaviour. It would appear that they believe computer technology could benefit their lives and have positive attitudes towards its inclusion and have been using it for dementia-related resources prior to the COVID-19 social restrictions. If this population do engage with technology, as the survey and previous evidence would suggest, then their access to dementia-related technology and research needs to be improved.

Supporters showed similar computer technology use as those with dementia, with daily use reported amongst the majority of the sample, and communication appeared equally important to them. Just over half reported apprehension with innovative technology, although higher knowledge levels were recorded. This could be interpreted that although they may have the knowledge, supporters sometimes lack confidence in using computer technology, much like those living with dementia. Accessing dementia-related content was popular among many supporters, with similar resources accessed to people with dementia, such as charity website; support groups for informal carers; dementia-specific training courses; and as a source of symptom information. This suggests that some supporters actively seek dementia resources and are keen on improving the informal care they provide. Through their comments, it was evident that computer technology provided a lifeline for supporters as a source of additional support and highlighted the benefits of online resources. It would appear computer technology provides supporters with a valuable link to others in similar roles, resources to improve their support of the person with dementia, and a sense of their own lives outside of caring.

6.4.2 Methodological problems

Nearly all the survey questions were interpreted as intended, but during data cleaning one was found to have been ambiguous and their answers influenced by this. When asked if they were living with a dementia diagnosis, meant as having received a diagnosis themselves, several supporters answered ‘Yes’. As there was not the time available to trial the questionnaire beforehand, the study acted as the pilot and changes can be made to reduce the ambiguity of questions for future use from these findings. The majority of respondents being of white British ethnicity was perhaps expected from the researchers’ previous experiences, but the demographic data was still disappointing in terms of diversity. As JDR encourages those from all backgrounds to take part in research, it was hoped that the platform would have increased diversity in the sample. However, more consideration would need to be made for similar surveys in how to widen participation, such as targeting recruitment from charitable or community-based groups used by a diverse population or providing questionnaires in languages other than English.

6.4.3 Comparison with previous work

Previous evidence has suggested the potential positive impact of technology on people living with dementia and their network, a finding which our survey supports. The current study highlighted regular use of the internet and computer technology among those living with dementia and a generally positive attitude towards it. Previous evidence from Guzman-Parra et al. (2020) supports this, with their study suggesting technology could have a positive effect on people with mild dementia and interest was high in using technology to help the self-management of conditions. LaMonica et al. (2017) found that those with dementia were more likely to experience difficulties when using computer technology due to factors including their age. However, although use varied depending on the factors and diagnoses, most participants used technology routinely, regardless of these factors. Our findings that time since diagnosis did not negatively impact technology use among participants, nor was there a significant difference in internet use between respondent groups go well with LaMonica et al.'s conclusions in promoting a positive image of technology use among the dementia population. A systematic review from Kruse, Fohn, Umunnakwe, Patel & Patel (2020) of 48 studies explored the barriers and facilitators of assistive technology on older adults with dementia. Important facilitators identified included the potential to enable independence in dementia and the want from supporters to use the technology. Similarly, the present findings showed enabling independence was a key influence in what people with dementia look for and use technology for. As a contrast however, the study found that people with dementia showed similar enthusiasm for technology, and this would suggest that the role of supporters in wanting computer technology was not as prevalent or pivotal as it was in Kruse et al. (2020). Cost and the person with dementia not wanting to engage with technology were the top barriers reported in Kruse et al., contrary to our findings of security and anxiety around technical problems.

6.4.4 Limitations

Given that the questionnaire received 110 responses, of which the slight majority were supporters of those with dementia, the findings are limited in their generalizability to the dementia population in terms of figures and with regards to the use of JDR as the recruitment platform. Nevertheless, the priorities and concerns for computer technology that were identified are important and necessary considerations for the development of any dementia-specific technology or when widening accessibility to computer technology. Additionally, due to the recruitment platform used, all respondents would have had some previous use of computer technology and we were unable to reach those who did not have the online access of skills needed. As such, the survey could not unearth the barriers these individuals face when accessing online resources and technology. However, the broad range in the age and time since diagnosis suggest that the sample comprises people at different stages of dementia progression (and most likely levels of cognitive impairment), even if it is skewed in terms of prior technological experience. To improve adoption of technology to support dementia, research is needed within those communities who have minimal experience to understand their attitudes towards it. As the survey did not ask participants whether they were currently employed, we are unable to differentiate between those who previously used technology for work, and those who still do. However, as several participants were within the working age group, it is possible that some were still employed. The questionnaire did not differentiate between distinct types of dementia. Given the variety of types of dementia and the predominant symptoms of each, it would be valuable to understand differences in technology use across dementia type.

6.4.5 Recommendations for future research

To improve adoption of technology to support dementia, research is needed within those communities who have minimal experience to understand their attitudes towards it. Studies should consider the role of digital poverty within communities and how this currently, or will, affect dementia populations. Although researchers and policy makers were aware of the pre-existing digital divide between age groups, especially impacting those living with dementia

(Cunnah et al., 2021), the COVID-19 pandemic emphasized the barriers individuals have which prevent them from utilizing technology (Marston, Morgan, Wilson-Menzfeld & Gates, 2022). These included a restricted access to technology, limited knowledge, and a lack of dementia-friendly digital interventions (Cunnah et al., 2021). Future studies need to prioritize enabling digital skills and technology accessibility within these populations that are being prevented from accessing online resources and digital interventions. In addition, the questionnaire unearthed concerns with security, data privacy, and making significant errors from people living with dementia and supporters. These should be considered when developing digital dementia interventions and other technology, alongside the priorities identified such as easy access, simple to use and secure. Our sample were well educated, mainly White, and had previous experience with computer technology. As these factors are likely to have influenced our findings and do not give us a comparison to the wider dementia population, future surveys should include a diverse sample of people with dementia and their carers to give a more representative view. Additionally, detailing peoples' specific dementia diagnoses would help explore the differences in technology facilitators and barriers based on dementia type. A comparison between those with and without dementia (who are not informal supporters) would increase our understanding of how attitudes towards technology differ when compared to the general population. Increasing the diversity of the population, including those from under-represented communities and those with less technology experience, could be achieved through methods such as greater use of dementia support groups as a recruitment resource, or through an epidemiological and questionnaire study to gather views from a representative cross-section of society.

6.4.6 Conclusion

Contrary to the stigma associated with older adults being reluctant and unable to adopt technology, this study has contributed to raising awareness of the active use of computer technology among this population including those with dementia. Benefits of using computer technology were shown to include communication, increasing individuals' understanding of dementia diagnoses, and enabling independent activities for both those with dementia and supporters. There were no obvious differences between those with dementia and supporters when it came to regular technology usage and both groups showed positive attitudes to the use of it for independence in dementia. The accessing of dementia-related content helped respondents to better understand a diagnosis and educate themselves further on dementia and its symptoms, as well as connecting the wider dementia community. Although responses were mixed to the use of an app for independence and daily activities, there appeared to be interest in it and enthusiasm about its potential to enable independence among those with dementia. As there appeared to be no obvious differences between people with dementia and supporters in terms of internet use, the findings demonstrate that individuals with dementia are keen on using computer technology independently and do not usually rely on supporters to facilitate their use. Dispelling the myths around older adults, dementia and technology enables more opportunities to promote adoption and use of computer technology to benefit dementia and improve wellbeing and quality of life, as well as the social aspect which has been shown to be a priority for those diagnosed and their supporters.

7. Discussion

7.1 Key findings

7.1.1 Literature review

This research aimed to evaluate the Promoting Independence in Dementia App (PRIDE-app) in community-dwelling people with mild dementia and their supporters. The incorporation of Glasgow et al.'s (1999) RE-AIM framework enabled richer data to be collected from the smaller participant sample and include quantitative and qualitative data collection. The initial systematic review and narrative synthesis examined the existing evidence around web- and app-based interventions for self-management in dementia. Synthesis revealed the positive benefit these types of interventions could have on the lives of those living with dementia. The existing literature was of fair to good quality and included a range of self-management concepts, such as functional activities and independence. Adoption and engagement with interventions were linked to individuals' confidence in the use of technology and were negatively influenced by apprehension about technical difficulties and forgetting to use the interventions. Conducting the review provided a better understanding of the evidence on technology interventions involved in the self-management of dementia and provided an insight into how the PRIDE-app was a novel addition and where it placed within the wider dementia interventions.

7.1.2 Findings in relation to RE-AIM framework

Reach

The main study findings showed that the reach of the PRIDE-app intervention was limited regarding ethnicity, as all participants were white British. Although the data could not explain why this was, the inclusion of translated versions of PRIDE, and the involvement of more under-represented communities in the development and recruitment stages, may potentially bridge this gap. Qualitative data identified motivation, together with a sense of understanding and acceptance regarding their dementia diagnosis, as key components necessary for the target user to fully engage with the app. The people living with mild dementia involved in the study did access the app, demonstrating an interest in the intervention and confirming some of the findings from the systematic review and development work. The app data itself suggests that potential improvements to the PRIDE login system and navigation are needed, in order to widen the user audience to include both those confident with computer technology and those who need more support. The high bounce rate on the app indicated that users visited and exited on the same page without clicking on anything. This could suggest that the participants found the login process too complex or confusing, experienced technical difficulties with the text messaging component, were simply distracted or forgot to use the app. Users' level of computer/technology literacy appeared to be another key component in the success of the PRIDE-app in reaching people with dementia. Follow-up interviews with participants, supporters and facilitators indicates that this population of usually older adults were concerned about using an online intervention and often felt they were not the target audience. This was demonstrated by the low recruitment rate of older participants. In addition, the contrasting views of the key stakeholders gathered from the study suggest modifications are needed to improve the perception of the PRIDE-app. Dementia Advisors showed a positive opinion and believed the app could have a place in services, whereas supporters thought it was too complex for their relatives. People with dementia felt that the app could be beneficial to them, but its current interface and usability made it unappealing and appear more like homework, rather than an enjoyable resource. These perspectives should be considered when enabling access to the PRIDE-app, to ensure as wide-a reach as possible and encourage those less confident individuals to try the app with additional support. With improvement, the reach of the PRIDE-app could be increased to include a more diverse and representative sample of the dementia population, potentially enabling more people to benefit from the PRIDE-app content and techniques.

Effectiveness

It would be a fair point to raise that the potential 'effectiveness' of the PRIDE-app intervention was not fully measurable through this study due to the restrictions enforced by the COVID-19 pandemic lockdowns and their impact on the nature of the PRIDE interventions (e.g., promoting social health and psychological independence through expanding one's social network).

Quantitative Outcomes

Quantitative outcome data reported a decline in many of the measure scores at follow-ups for both those with dementia and their supporters, with the changes for supporters being statistically significant in terms of their quality of life. There was, however, a positive effect on supporters' mental wellbeing. As the data did not show any real improvements in participants' functional activities, independence, or general wellbeing, this provided no indication that the PRIDE-app was effective. However, given the nature of dementia as a progressive condition, it is realistic to presume that participants may have naturally deteriorated over the study timeframe, and this influenced their scores at follow-ups. As the Lawton IADL scores did not change between baseline and follow-ups, this could suggest that the PRIDE-app was able to support participants to retain their independence. Similarly, with the Global Change Measure, the majority of participants were categorized as having no change throughout the study. This could indicate that the PRIDE-app may have slowed down the dementia progression or helped participants to maintain their independence and wellbeing levels.

Qualitative Outcomes

Participants and supporters emphasized the engagement and reflection the PRIDE-app encouraged as crucial factors in whether they felt they had benefited from the intervention. Motivation was a key factor is whether participants applied the techniques from the PRIDE-app, and goal-setting was a popular concept with both participants and supporters. The PRIDE-app was effective in giving participants and supporters more information and guidance on adjusting to a diagnosis and providing techniques which were used effectively by some in their everyday lives. Supporters appreciated how the app contributed to their understanding of dementia and how they could best support their loved ones. The role of the Dementia Advisors was a vital factor in how users engaged with and perceived the PRIDE-app. Their role provided an independent perspective and encouragement which enabled positive discussions between themselves and participants, and within dyads.

Adoption

From the small number of fidelity checklists and interviews, it would appear that Dementia Advisors delivered the PRIDE-app intervention sessions as intended, and that participants were receptive to the session discussions. Participants attempted to adopt the PRIDE-app regularly in between their sessions and apply what had been discussed with their facilitator. Although the majority of the sample reported having some prior experience with technology, adoption of the PRIDE-app was lower than initially expected. The online format was not popular among all of the participants, as some showed a preference for a paper-based format, and confidence with computers varied within the sample. Participants and supporters modified their use of the PRIDE-app to fit in with their lifestyle by adopting the techniques promoted, rather than using the app itself to record goals and plans. This reaffirms that the content was relevant and applicable to those living with mild dementia, and that regular physical use of the online app is not necessarily required for the contents to be valuable. Even though the adoption of the PRIDE-app by participants was not as originally intended, the findings from fidelity checklists and interviews indicated the important role of motivation, encouragement, and a good level of computer literacy in determining adoption of the app. Interviewees put forward a number of recommendations for improving accessibility and engagement with the PRIDE-app, which should be considered to increase adoption of the app in the future.

Implementation and Maintenance

The fact that participants, supporters and facilitators continued to use the techniques promoted by PRIDE and aimed to incorporate them in other service areas would suggest the app has a place within dementia support services and the key stakeholders agree the content is relevant. The Dementia Advisors were imperative to participants engaging with the PRIDE-app, and a positive working relationship was identified as a key component to implementation. For future use of the PRIDE-app in dementia services, facilitators would need to work collaboratively with users over a longer duration of sessions, to monitor and motivate continued use of the app and its techniques. From the findings gathered, prolonged implementation and maintained use of the app by those living with dementia would likely be improved by offering a choice of formats for the intervention. For example, the PRIDE-app could be supported by a paper handbook, and face-to-face support and discussions could be encouraged during the intervention stage. These sessions could be moved to remote after the main intervention phase, but with the recommendation that Dementia Advisors continue checking in with users for as long as they request.

7.1.3 Attitudes towards technology questionnaire

People with dementia and their supporters actively sought the use of computer technology for communication and supporting their independence. As just over half of the participants with dementia were aged 75 and over, the questionnaire sample would suggest that some older adults with dementia do engage with technology, even if younger supporters were needed at times to aid engagement. As the majority of people with dementia and supporters were using computer technology before the COVID-19 pandemic, this pointed towards the social restrictions increasing uptake among the population rather than prompting them to learn how to use it. This was contrary to what the researchers initially thought they would find. Using technology to access dementia-related resources and for support networks was important to supporters, whereas communication was the top use for those with dementia. Both groups demonstrated similar computer technology and internet use, suggesting that both could use technology independently and were equally as keen on incorporating it into their daily lives.

7.2 Methodological difficulties

7.2.1 Patient and public involvement

The previous PRIDE feasibility study (Csipke et al., 2021) actively included involvement from patients and the public when creating the initial prototype of the PRIDE-app intervention. Views from PPI members, especially regarding the login process and wording of content, were taken into consideration when the app was being developed. The continuing involvement of PPI was vital to the further developments of the PRIDE-app and ensuring it was as accessible and relevant to the target population as possible. In December 2019, a presentation was given at the University of Nottingham's Centre for Dementia monthly meeting to inform its members of the original PRIDE study aims and design. The aim of the presentation was to gauge the potential reaction from the target patient population about the online intervention and to obtain their initial views on the study design and any potential problems they could foresee. Feedback from members was used to inform the design of the study and in discussions with Ayup about the development of the PRIDE-app. During the summer of 2020, a couple with lived experience of dementia provided feedback on usability by testing the PRIDE-app in their home between the development sprints. Their feedback provided a preparatory base for the suggested amendments to be made during the second app development sprint.

Following an invite from the organiser of a young-onset dementia group, the study was presented at Striving for Another Day (STAND) Fife's monthly online meeting in March 2021. This opportunity was used to publicise the study, act as a potential recruitment pathway for participants and PPI members and explore the group's thoughts on the PRIDE-app. Overall, the members had a positive reaction to the PRIDE-app and believed that it could help to motivate and encourage people living with dementia to become more independent and socially involved. However, they raised concerns over the login process being too complex and lengthy for people with dementia, and how this may prevent people using the app regularly or at all. It was a well-made point and, although any changes to the process could not have been made to the study version, it is a point to consider for any future studies into the PRIDE-app.

Throughout Spring and Summer 2021, the call for PPI members with lived experience of dementia to participate was promoted on social media, including relevant local and national support groups, and on the DEEP website. These methods were used to maximize the target audience who would see the study. Contact was also made with fellow researchers, who provided their PPI members with details of the study. Despite the active promotion of the study, PPI recruitment was disappointingly low. However, this was understandable considering the effects of COVID-19 on the public's priorities. There were two people who recorded their interest in joining the PRIDE-app PPI group, one via the STAND group and the other through DEEP. The first session was organised for September 2021 and was primarily focused on the question schedule for participants and supporters for post-intervention interviews. The draft interview schedule was emailed out to the two registered members a week prior to the session, with some questions that would prompt the desired feedback. One member attended the meeting and provided feedback on how to make the interview wording more dementia-friendly and concise. The suggested amendments were made before the final interview schedule was emailed out to the main study interviewees.

In May 2022, ARL gave a presentation to the Centre for Dementia PPI group at the University of Nottingham. The aim was to consult with those with lived experience of dementia on their use of technology and their initial thoughts on the concept of the PRIDE-app. As the group was held in person, and shortly after COVID-19 social restrictions were lifted, there were understandably only two members present. However, they did provide insight into what they would like when using new technology, such as easy-to-read instructions and delivery in a simple format suitable for use alone or with support from a carer. Mobile phones were viewed as not the easiest technology to use, and people often misplaced them, as opposed to larger screen options which were more suitable for those with dementia. Concerns about security, data privacy and scams were raised by PPI members, and also by respondents to the technology questionnaire in Chapter 6. Initial thoughts from the meeting suggested that the PRIDE-app would be a handy tool to motivate people with their interests and activities, and to work towards achieving their goals with their families. A suggestion was made that the app could have a function to send mobile/email reminders about plans, to compensate for users forgetting, and have different delivery formats to suit personal preferences. Both of these features were also discussed during interviews with participants and supporters in the main study.

7.2.2 COVID-19

The main study was originally planned to start in Spring 2020 and finish by Spring 2022. However, the first COVID-19 national lockdown began in March

2020, and this was followed by subsequent lockdowns in 2020 and 2021. Prior to the first lockdown period, it had been planned to conduct a larger-scale feasibility trial on the PRIDE-app, with in-person recruitment for multiple user-testing phases and regular PPI involvement. Face-to-face intervention support would have been given during these stages to enable users to provide a valuable insight into their experiences of using the app. Similarly, facilitator training was intended to be delivered at sites across a day of training with a practice run-through for staff. Once it became apparent that the lockdowns were not going to be temporary occurrences, and that COVID-19 numbers would continue to put significant pressure on NHS Trusts, core components to the study were changed. Through discussions within the research and funding teams, it was decided to change the research design to a completely remote format, with online training, intervention delivery and interviews, along with data collection via online or postal questionnaires. Moving to a remote approach overcame many of the barriers in recruiting participants with dementia, in regard to social distancing and minimising their contact with people. The changes in the study design considered the risk COVID-19 posed to the vulnerable and elderly, and provided a clear outline of how the safety of participants was to be maintained. As the pandemic and subsequent revisions delayed the study's original plan, the aim of the research was amended to better fit the revised timescale. The RE-AIM framework was implemented to help pinpoint the most important dimensions to evaluate in the outcome measures. The timings of the study stages were continually reviewed to cope with the changing circumstances, restrictions and delays resulting from the pandemic and university closure.

During the main study recruitment phase, the closure of community groups for people living with dementia and their families unfortunately contributed to difficulties in finding participants who were not under one of the four research sites involved. It also meant that the researchers at the sites were unable to visit memory clinics to promote the study, removing an accessible source of participants that was usually successful.

7.3 Findings in the context of existing work

The COVID-19 pandemic has led to an increased focus on digital formats of interventions for dementia. Although the initial systematic review for this study explored research conducted prior to the pandemic, the findings that app- and web-based self-management interventions could be beneficial, albeit with factors affecting adoption, continue to be supported by more recent reviews.

Neal et al. (2021) explored the use of digital technologies to facilitate self-management and social engagement in people with dementia or mild cognitive impairment. Three main technologies were identified across the nine included papers; virtual reality-based, wearable technology (in addition to virtual reality), and software applications. In agreement with the systematic review in Chapter 2, the authors found there to be limited evidence, and of what was included to be good or fair reporting quality. They concluded that digital interventions may benefit those with mild cognitive impairment more than those with dementia, with regards to their self-management and social engagement.

A similar review by Di Lorito et al. (2022) evaluated the evidence-base on digital interventions and their impact on cognitive, physical and psychological outcomes in people living with dementia or mild cognitive impairment. Meta-analyses of data from the 20 papers included showed digital interventions had a positive effect on cognition but a negative effect on physical abilities such as daily activities, when compared to non-digital interventions. However, the findings of individual studies on the effectiveness of digital interventions varied. The authors highlighted the need for more dementia-friendly digital interventions due to the concerns often raised about computer literacy and easy accessibility. The conclusions from this review were that digital interventions have the potential to have positive effects on cognitive, physical and psychological outcomes in dementia and mild cognitive impairment, and that hybrid delivery may be the best compromise for both patients and services. Further consideration needs to be given to the accessibility and acceptability of digital interventions in dementia.

The involvement of people with lived experience of dementia was an important part of both the preliminary development of the PRIDE-app and the secondary development stage. The Medical Research Council framework (Skivington et al., 2021) identifies the involvement of stakeholders as a core element in the development of any intervention. Meaningful engagement with stakeholders ensures that their views and experiences are given weight during the development stages. People with lived experience of dementia were actively involved throughout both stages of the PRIDE-app development in an attempt to increase the app's ease of use and dementia-friendliness. However, despite the aim to recruit more people for the user-testing and PPI groups in the second development stage, the remote meetings and impact of COVID-19 meant that stakeholder involvement was limited. To counter this, the interview feedback gathered should be given additional consideration in regard to the future developments to the PRIDE-app, as many of the suggested modifications may have already been identified earlier if more stakeholders had been able to be involved.

Studies of web- and app-based interventions, such as the PRIDE-app, have reported similar findings in terms of usability and adoption. The ReACT app (Øksnebjerg et al., 2020) had a number of features to help people with dementia to structure their days, including a calendar, dairy, checklists and personal contacts. Unlike the PRIDE-app, caregivers were given a parallel login so they could view and edit the primary user's account. Participant inclusion criteria were broad and recruited adults diagnosed with dementia who were motivated to use the app and had the means to run it on the correct operating software. In contrast to the PRIDE-app study, Øksneberg et al. found that the level of technological experience and support was a factor in whether or not participants adopted the ReACT app. However, similarities were found regarding caregiver involvement being a strong influence in whether participants adopted the ReACT app. This, along with the timing of introducing the app, were key components in whether participants adopted it, although there was adoption by those who took part independently too. Although the PRIDE-app covers a wider range of topics than the ReACT app, Øksneberg et al.'s work provides additional insight into technological interventions and the factors often affecting adoption in people living with dementia.

7.4 Limitations

7.4.1 Development of the PRIDE-app

Difficulties with recruitment of volunteers for the user-testing stage meant that the number involved was significantly lower than planned, and it caused delays within the overall study timeline. Although the two volunteers who did contribute were able to provide the perspectives of a person living with dementia and a supporter, they were unable to generate the comprehensive feedback that a larger sample would have. The involvement of more people with different dementias would have given better insight into how the PRIDE-app may have worked with the varied symptomology. A second limitation which may have had a significant influence on the final version of the PRIDE-app was the removal of the field-testing stage. As previously mentioned in Chapter 4, testing was originally intended to take place following the second sprint work, to note any urgent usability or accessibility issues with the app that could be resolved prior to the main study trial. Due to the effect of the COVID-19 problems, and the problems it caused for the user-testing recruitment, the field-testing had to be removed because of a lack of time and resources. This meant that some issues were missed during the earlier sprint work, and they first came to light during use in the main trial.

7.4.2 RE-AIM study of the PRIDE-app

With regards to the main study, the most significant limitation of the findings is that all participants were of white British ethnicity, and interest from non-white communities was non-existent except for one volunteer on JDR. The study was unable to demonstrate the reasons for this, but existing evidence has identified cultural and religious differences in understanding dementia and accessing dementia support (Parveen, Peltier & Oyebode, 2016; Hossain & Khan, 2020). Due to the study timeline being baseline to a six-month follow-up, implementation and maintenance were unable to be assessed as quantitative outcomes as these are ideally measured over a longer-term (Glasgow et al., 1999). Therefore, interviews were the sole source of data for these elements and could not be more comprehensively evaluated.

As the COVID-19 restrictions meant that all study activity had to be online, the interviews were conducted either via Microsoft Teams or over the telephone. There was a technical issue with one of the interviews which meant that not all of the audio was transcribed. However, this issue was mitigated by OM providing details of the content discussed and interviewee behaviour. Question schedules were worded with the help of people with experience of dementia, and they included scoring scales to aid interviewees in voicing their thoughts. Although some interviewees may have found the interview environment daunting, and which may therefore have affected their reporting of experiences, the fact that schedules were provided beforehand would hopefully have reduced the negative influence on the data collection.

7.4.3 Attitudes towards technology questionnaire

Findings from the questionnaire are restricted in their generalizability as there were only 110 responses, of which the slight majority were from supporters of those with dementia. Similarly, as with the main study, white British participants made up the majority of respondents. These figures, along with the use of an online platform for recruitment and completion of the survey, mean the findings are limited in being applicable to the wider dementia population. However, the data collected surrounding the priorities and concerns around new and existing technology were echoed by main study participants, therefore suggesting that some may be common points considered across the dementia population. If they are popular points among those with dementia and their supporters, then it is even more necessary to consider these in any developments or modifications of technology aimed at enhancing the lives of those with the condition. The choice of platform used to publicize the questionnaire, and recruit participants, meant that the sample size was being restricted from the beginning. Although alternative methods of recruitment were discussed, such as social media and advertising the link with local dementia groups, Join Dementia Research offered the quickest and most efficient route, given the time and resource constraints. Although it meant that all of the sample participants would have had some experience of computer technology, the inclusion of different ages and dementia progression helped to balance the representativeness and provided a more realistic sample. Reflecting on the demographic questions, it would have been worthwhile to ask respondents what their dementia diagnosis was. As each dementia has different symptomology, it would have been interesting to compare technology use and attitudes between these.

7.5 Considerations for future work

Moving forward, there appears to be a place for the PRIDE-app within dementia support services. The app offers a novel approach in combining many different topic areas and in its focus on goal-planning. One of the most beneficial areas for future development would be to incorporate the suggested modifications collected through the work discussed here. A number of strong, clear recommendations have been proposed by participants, supporters and facilitators. Priority should be given to simplifying the navigation and mapping of the PRIDE-app, streamlining the processes for goal-setting and activity logging, and reducing the multiple layers of text within each topic section. Any further development work should be structured with sprints and involve the engagement of key stakeholders throughout to ensure the work is relevant to end users' needs, and improve the reach, effectiveness, and adoption of the PRIDE-app.

Consideration should also be given to whether people living with dementia would rather engage with and adopt existing technology, which could be modified to their personal needs either structurally or with software applications, or whether they would prefer to use new specially developed dementia technology. The role of facilitators, such as the Dementia Advisors with the PRIDE-app, could also be explored further to determine who are most suited to support technology engagement and adoption among the dementia population, and what level of training they require.

Effort should be made to include a diverse range of dementia diagnoses and different levels of progression in future PRIDE-app studies, to assess the needs and uses across varied populations. The inclusion of the original paper-based PRIDE handbook would also be helpful to compare the ages and dementia diagnoses of the sample recruited. Widening the ethnic diversity of future samples would also provide more rich data on the reach and adoption of the PRIDE-app. Engaging more people living with dementia from under-represented communities would allow researchers to explore more personal preferences and needs within technology, as well as the barriers and facilitators specific to the PRIDE-app.

Future work should also be informed by the best practice guidance on technology in dementia, published by the Interdisciplinary Network for Dementia Utilizing Current Technology (INDUCT) (Dröes et al., 2022). The guidance identifies priority areas for consideration when designing technology-based interventions for people with dementia; provides recommendations to improve their usability, including those used for meaningful activities in daily life; and the barriers and facilitators often impacting access to and use of technology. Incorporating the guidance into future work on the PRIDE-app or similar interventions would better guide any further technical developments and implementation in peoples’ everyday lives.

7.6 Conclusions

The PRIDE-app is a novel intervention incorporating self-management concepts and encouraging independence through goal-setting objectives, both of which aim to improve quality of life in those living with dementia. The use of the RE-AIM framework enabled a mixed-methods study design, which provided insight into the PRIDE-app’s effect on quantitative and qualitative factors. Feedback from those with lived experience of dementia provided insight into how the usability and ease of use of the app could be improved, as well as highlighting the positive benefits of the techniques it promotes. Researchers and clinicians with relevant experience believe the app would be an effective resource for those on memory clinic waiting lists, as well as those with Mild Cognitive Impairment. Further development is needed on the PRIDE-app to maximize its reach, effectiveness and adoption, and a long-term study is required to properly assess its implementation and maintenance.

From the findings of the attitudes to technology questionnaire, adults with dementia and their supporters across the age range use computer technology to support their independence and social inclusion. Despite the common misconception that older adults are unable to use computer technology, the sample showed their use was equal to that of their supporters, and that they were keener on getting the latest technological updates. Taking both parts of this research into consideration, it may be more beneficial to design the

PRIDE-app for Android and iOS application, as well as tablet and computer use, due to the popularity of mobile phones. Future users would likely appreciate the choice of platforms and the option of the original paper handbook to go alongside. Overall, the RE-AIM study of the PRIDE-app demonstrated its potential in promoting autonomy and self-management in people living with mild dementia. It encouraged activity planning, social engagement, and better understanding of how all involved could better support the individual with dementia. The elements are among many which would enable more people to live well with dementia and achieve a better quality of life.

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9. Appendices

9.1 Tables detailing characteristics and outcomes from the included papers in the systematic review in Chapter 2.

Study [Identity number]	*Aims*	*Design*	*Duration*	*Setting*	*Participant demographics*	*Inclusion criteria*	*Exclusion criteria*	*Dropouts*
[1] Perilli et al., 2012	To assess the effectiveness of a computer-aided telephone system in people with AD to make calls independently.	Non-randomized multiple baseline design	2-5 baseline sessions and 3 familiarisation sessions. 50 intervention sessions. Intervention sessions lasted approximately 10mins.	Day centre. No country mentioned.	*Total* = 4 M/F = unknown *Age range* = 73-83 *Moderate AD* = 4 MMSE = 13-18 Hamilton Depression Rating = 4-15 Recruited from a day centre.	• Considered to have moderate AD • Unable to use a telephone device independent • Able to understand verbal and visual instructions	None mentioned	None
[2] Perilli et al., 2013	To carry out a social validation assessment of a computer-aided telephone system versus a conventional condition.	Non-randomized multiple baseline design	3 or 5 baseline sessions and 5 familiarisation sessions. First group completed 20 intervention sessions, second group 50 sessions. Intervention sessions lasted approximately 10mins.	Day centre. No country mentioned.	*Total* = 5 F = 5 *Mean age* = 80 (range 73-89) *Mild AD* = 2 *Moderate AD* = 3 MMSE = 14-22 Hamilton Depression Rating = 11-16 Recruited from day centre.	• Unable to use a telephone device independently • Able to understand verbal and visual instructions	None mentioned	None
[3] Lancioni et al., 2017	To assess a technology-aided program to help people with mild to moderate AD carry out daily activities independently.	Non-randomized multiple baseline design	3-5 baseline sessions and 3-4 familiarisation sessions. 34-78 intervention sessions.	Activity and care centres. No country mentioned.	*Total* = 8 M=1/F=7 *Age range* = 64-79 *Mild AD* = 4 MMSE = 21-25 *Moderate AD* = 4 MMSE = 15-22 Does not specify recruitment setting.	• Mild to moderate AD • Verbalise interest in using a device • Difficulties with daily activities	None mentioned	None
[4] Lancioni et al., 2018	To assess the effectiveness of interventions to promote (a) independent start and accurate performance of daily activities and	Non-randomized multiple baseline design	*Study 1* – 5-10 baseline sessions/37-82 intervention sessions. Each lasted 1.5-2hr. *Study 2* – 4-11 baseline sessions/73-119 intervention sessions.	Day centres. No country mentioned (ethics Italy).	*Study 1* *Total* = 8 M=5/F=3 *Age range* = 73-92 MMSE = 16-24 *Study 2*	*Study 1* – • Generally passive when left alone • Capable of following verbal activity reminders and instructions	None mentioned	*Study 1* – 2 due to lack of interest or poor health *Study 2* – 4 due to health or practical reasons (not included

	(b) supported ambulation.		Each lasted 3 minutes and occurred 3 to 7 times a day.		*Total* = 9 M=4/F=5 *Age range* = 70-92 MMSE = <6 - 14 Both groups recruited from centres attended by people with dementia.	• Verbalized interest in using a program such as the one in the study *Study 2 –* • Unable to ambulate independently • Enjoyed stimulation events (e.g. music) • Ambulated in response to verbal prompts • Staff/families considered ambulation intervention relevant to participant		in participant numbers)
[5] Lancioni et al., 2019	To assess a smartphone-based intervention to achieve goal-directed ambulation and object use in people with moderate AD.	Non-randomized multiple baseline design	6 baseline sessions and 51-107 intervention sessions.	Day centres. No country mentioned.	*Total* = 11 M=5/F=6 *Mean age* = 83 *Moderate AD* = 11 MMSE = 11-19 Recruited from day centres.	• Unable to ambulate independently • Known to enjoy stimulation events • Able to ambulate to specific destinations if verbally encouraged • Had verbalised their willingness to participate • Staff/families considered ambulation intervention relevant to participant	None mentioned	None
[6] Thorpe et al., 2019	To assess the feasibility of using smartphone and smartwatches to strengthen rehabilitation in early-stage dementia.	Mixed methods design	Participants used technology for at least 8 weeks.	Private homes. Denmark.	*Total* = 6 (each with caregiver) M=4/F=2 *Age range* = 65-78 *Diagnosis* = mild-to-moderate dementia MMSE = 23-27 Recruited from the dementia and memory clinic.	• Community dwelling with their primary caregiver • Early stage of dementia	• Any disability that affects use of devices or activity levels	*3* – enrolled but dropped out due to illness or feeling daunted about using the devices before start.

[7] Øksnebjerg et al., 2020	To assess the applicability and usability of the ReACT app.	Mixed methods design	Intervention period 90 consecutive days after activating the app, or 90 days from study inclusion for participants who did not activate the app.	Private homes. Denmark.	*Total* = 116 people with dementia and 98 supporters *Mean age* = 68 *AD* = 65 *Frontotemporal* = 3 *Vascular* = 2 *Lewy body* = 1 *MCI* = 9 *Other* = 27 *Unresolved* = 5 MMSE = 11-30 Recruited from 9 memory clinics.	• Patient at the memory clinics • Showed motivation to trial the app • Had access to a tablet computer	None mentioned	*4* - excluded from original sample number due to insufficient background information
[8] Kerssens et al., 2015	To assess the usability and adoption of a psychosocial touch screen interventions.	Mixed methods design	Baseline measures conducted at private homes. Intervention period was scheduled to last 3 weeks but ranged from 24-57 days. Follow-up interview/ assessments at end of intervention period.	Private homes. Georgia, USA.	*Total* = 7 dyads (people with dementia and supporter) MMSE = 11-27 Recruited from retirement communities, Alzheimer's Association, day centres and senior services centre	• Living independently in the community • Cohabitating couple or supporter dyads • Dementia diagnosis or assistive need in care recipients • Mild to moderate supporter distress • Aged 50+/supporter aged 21+	• MMSE <10 • Dementia diagnosis in supporters • Severe supporter distress • Comorbid conditions that would compromise participation	*5 dyads* – excluded (not included in the 7 final dyads) because the person with dementia died (n=2), was transferred to a nursing home (n=1), repeated hospital admissions (n=1), or the supporter could not agree on the focus of the intervention (n=1).
[9] McGoldrick et al., 2019	To assess the effectiveness and usability of a reminder tool on the MindMate app on prospective memory.	Mixed methods multiple baseline design	Baseline phase 5,6 or 7-weeks. Pre-intervention phase 1-3 weeks, then MindMate for a 5-week period. Clinical interviews conducted pre-and post-study.	Private homes. Scotland, UK.	*Total* = 3 M=2/F=1 *Age range* = 59-74 *Mild AD* = 3 Recruited from community mental health teams	• Mild dementia diagnosis • Memory difficulties confirmed by professional or family member • Owned a smartphone or tablet with internet access • Had a partner willing to support and monitor memory aid use	• Pre-existing neurological or severe psychiatric condition • Moderate or severe dementia • Visual or auditory difficulties	*1* – withdrew during intervention due to experiencing technical difficulties but continued using baseline phase. Follow-up interview was held, and partner continued to record prospective memory forgetting.

							• Developmental learning disability • First language other than English • Currently using online or electronic memory aids	
[10] Kerkhof et al., 2019	To develop an interactive web-based selection tool for self-management and meaningful activities in dementia.	Qualitative with user-participatory design	9 months	Day centres. The Netherlands.	*Total* = 8 (+ 8 informal/2 formal supporters) M=7/F=1 *Mean age* = 78.6 *AD* = 5 *Frontotemporal* = 2 *MCI* = 1 Recruited from two meeting centres and one day centre.	• Community-dwelling • Care dependent • Mild dementia (with/without confirmed diagnosis)	None mentioned	None
[11] Boman et al., 2014	To assess the usability of a videophone mock-up for people with dementia and their significant others.	Qualitative case study design with interviews and observations	Interviews and observations at private homes lasted 1.5-2hrs. Intervention sessions lasted 2-3hrs.	Private homes & Living laboratory. Sweden.	*Total* = 4 M=2/F=2 Recruited through an investigation memory unit.	• Dementia diagnosis • Able to participate in interviews and observations • Willing to test intervention in a living laboratory • Have a significant other willing to participate	None mentioned	None

Study [Identity number]	Components of intervention	How it's self-management	Who provided/set up the intervention	Intervention delivery and format	Individualisation & modifications
[1] Perilli et al., 2012	• Net-book computer, microswitch device to activate the computer, headset with microphone, and a software program • System presents identification names and photos of relevant people to call and responds to the microswitch activations to make calls	Ensuring people with dementia have an opportunity to communicate with others is instrumental in helping maintain their social relationships and reduce/slow down their social withdrawal	• Research assistant in baseline, familiarisation, and intervention sessions • Interrater reliability in 40% of intervention sessions (second RA)	• Baseline – participants provided with phones alone and told they could make phone calls • Familiarisation sessions – 3 • Intervention – 50 10-mins daily sessions, where the system was used independently. Computer presented 7-12 contacts and verbally gave the identification attributed to that photo. If they responded within 3-4mins, the computer activated a call. If not, it moved to the next photo	List of contacts and identification expressions were individualised
[2] Perilli et al., 2013	• Net-book computer, microswitch device to activate the computer, headset with microphone, and a software program • System presents identification names and photos of relevant people to call and responds to the microswitch activations to make calls	Ensuring people with dementia have an opportunity to communicate with other is instrumental in helping maintain their social relationships independently, which can raise self-determination and social engagement	• Research assistant in baseline, familiarisation, and intervention sessions • Interrater reliability in 30-50% of intervention sessions (second RA)	• Baseline – participants provided with phones and told they could make calls • Familiarisation sessions – 5 • Intervention – either 20 or 50 regular daily sessions, where the system was used independently. Computer presented 8-12 contacts and verbally gave the identification attributed to that photo	List of contacts and identification expressions were individualised
[3] Lancioni et al., 2017	• Tablet computer, with the Talking Alarm Clock app, and a Bluetooth earpiece • Earpiece provides instructions and encouragement during activities	Help people with dementia engage independently with daily living, by verbally scheduling activities. Possible benefits for their cognitive functioning, social image, and physical condition	• Research assistant in the baseline, familiarisation, and intervention sessions	• Baseline 1 – verbal and printed list of 6 or 7 activities executed and the times due • Baseline 2 – executed 6 or 7 activities, one at a time • Familiarisation – 3-4 sessions • Intervention – activities executed using	The activities scheduled were personalised.

				tablet/earpiece set-up	
[4] Lancioni et al., 2018	• Study 1 – Tablet or smartphone device with Android system and the Talking Alarm Clock app and a wireless Bluetooth earpiece • Study 2 – Tilt microswitch, notebook computer, and earpieces. Microswitch detected step responses, and the computer recorded these and provided stimulation events and verbal prompts	Both interventions promote completion of daily activities independently and support participants' ambulation	• Research assistants in baseline and intervention sessions	*Study 1 –* • Participant provided with the wireless earpiece linked to the tablet or smartphone, which promoted independent start and correct performance of the activities *Study 2 –* • Participants used walkers with the technology, which provided stimulation and prompts	Study 1 – The activities were adapted to participants' characteristics in terms of steps and complexity Study 2 - Stimulation events consisted of 5-s segments of old songs, religious hymns, and prayers, which were deemed preferred for the participants
[5] Lancioni et al., 2019	• Smartphone with a light sensor and a variety of audio instruction files; headphones; three battery-powered light sources	Help manage mobility difficulties to increase independence and quality of life	• Research assistant	• Familiarisation – 3-6 sessions • Intervention - sessions lasted 3-5 mins and carried out 2-4 times a day. Smartphone presented instructions to bring an object to a specific destination. Instructions repeated at 10-15s intervals until they reached the destination. Once completed, 15s of stimulation (song/hymn/ comic sketch) was played. This was repeated for second and third objects	The stimulation played once a goal was completed was tailored to individual preferences
[6] Thorpe et al., 2019	• Smartphone and/or smartwatch. The watch self-reports activity levels and a mobile app is used to get participants to evaluate their daily activity and mobility levels	Encourage people to remain active and socially engage through mobility and activity goals	• Research team	• Set-up support and manuals on device use were provided • Intervention - Participants set goals to follow and evaluated attainment in weekly phone calls. Mobile self-reports were issued daily to evaluate perceived activity and	Goals were individualised, and the calendar could be used for personal reminders and appointments

				mobility levels for that day • After, semi-structured interviews explored participants’ experiences	
[7] Oksnebjerg et al., 2020	• ReACT App - a calendar that interacts with the other features, diary notes, contacts, checklists, and memos	Provide support for various aspects of prospective and retrospective memory, and structuring daily activities	• Study team provided participants to access to app when recruited	• Participants accessed a personal user account, and carers could support them via a parallel login • Written materials supported the implementation of the app and detailed the support hotlines	Reminder systems and app preferences could be amended, and carers could view, edit and add information via parallel access
[8] Kerssens et al., 2015	• Companion - Touch screen computer that delivers audio-visual programs constructed of images, music and messages from individuals who are relevant to the user • Provides cues and primes for important tasks, reminders, and reminiscence therapy	Help people with dementia and carers manage common dementia symptoms, promote independence, improve behaviours and overall quality of life, without placing increased burden on carers	• Trained care specialist created a menu of relevant programs for each recipient • 2 researchers provided initial setup and guidance on use	• During a care needs interview, carers picked 1-4 goals • Intervention - carers given diaries to facilitate use of intervention and called weekly for updates • Post-intervention technology adoption questionnaire and semi-structured interview were completed. Carers also rated how the person with dementia was doing regarding the goals	Personalised to individual households and recipients through a life story and care needs interview
[9] McGoldrick et al., 2019	• Free to download dementia app for smartphones and tablets • Includes a ’’Reminder’’ tool which sends alerts about an event, prompting the user to remember it	Support people to improve their self-management skills and maintain their independence by enabling them to remember important activities, such as taking medication, to decrease reliance on carers	• Primary researcher conducted initial interview, baseline assessments and met with participants during intervention	• Initial interview identified target behaviours and aid use • Intervention - researcher met with participants weekly to decide upon targets, set reminders, and for further app training. Weekly form listing individual memory targets and completion times was	Personal tablets/smartphone used, and prospective memory targets personalised

				provided to partners. When no target could be identified, the researcher set a reminder for participants to text or phone the researcher. Form was used daily to record whether activities were remembered and completed	
[10] Kerkhof et al., 2019	• FindMyApps - User profile, ability to choose main and sub-categories of app interest, pages of recommended apps and specific app information	Help people with mild dementia to select relevant apps that meet their needs, encourage self-management and meaningful activities, and contribute to better quality of life	• Research team and development company	• Prototypes installed on tablets. Users were presented with scenarios which encouraged them to navigate the app. Research team observed use behaviour through videos and interviews	Ability to navigate preferred activity apps
[11] Boman et al., 2014	• Touch screen computer with camera, headset, and contact pictures	Support people with dementia to make calls independently, stay in contact with their social network and prevent isolation	• First and second authors responsible for leading intervention sessions and set-up	• Interviews and observations at participants' homes • Intervention – sessions conducted in a living laboratory, lasted 2-3hrs (including a break), and were filmed. Participants were shown the features of the videophone and asked to carry out 3 tasks: to make a call to their significant other, to answer a call from their significant other, and make a call to the mock-up emergency services. • After, participants were interviewed about the functions and usability of the videophone	The images of people to call could be personalised to relevant contacts

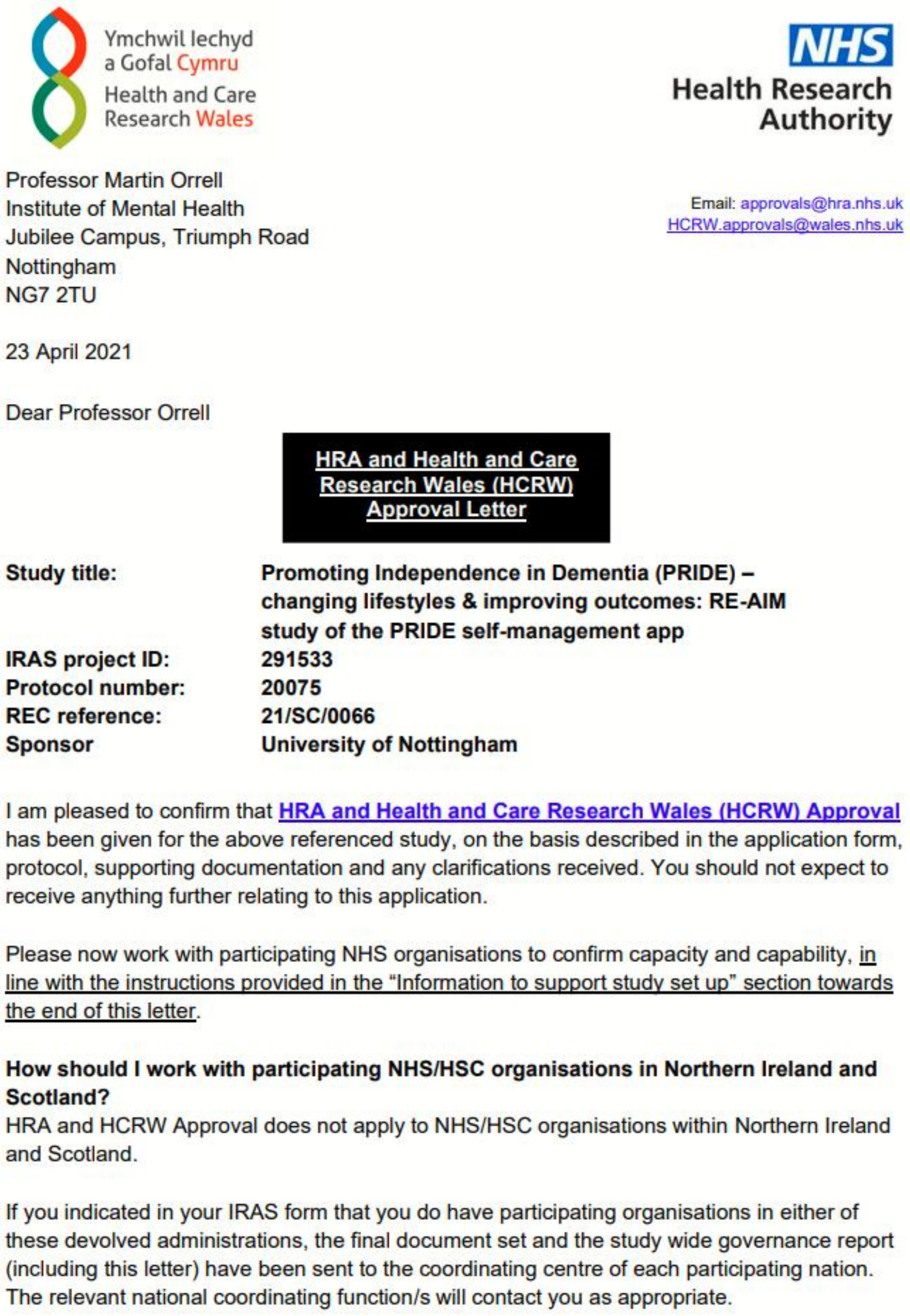
Study	*Outcome Measures*	*Key Findings*
[1] Perilli et al., 2012	*Quantitative – Mean number of independent phone calls:* In each session, the RA recorded the total number of phone calls and whether they were made independently. *Mean number of calls answered by the target partners:* In each session, the number of phone calls which were met with the answer of the target partner were recorded. *Mean call time:* RA recorded conversation time.	*Independent phone calls:* At baseline, no independent phone calls made. During intervention, 2 participants had a mean of 3 calls per session, and the other 2 had a mean of 4 per session. *Calls answered by partners:* 2 participants had a mean of 2 calls per session and 2 had a mean of 3 calls. *Call time:* 2 participants had a mean conversation time of about 5 mins per session, one was about 6 mins, and one was just over 5 mins. Suggests that the system was effective in helping people with AD make independent phone calls.
[2] Perilli et al., 2013	*Quantitative – Mean number of independent phone calls:* In each session, the RA recorded the total number of phone calls and whether they were made independently. *Mean number of calls answered by the target partners:* In each session, the number of phone calls which were met with the answer of the target partner were recorded. *Mean call time:* RA recorded conversation time. *Social validation assessment:* 35 healthcare professionals rated the performance of one of the five participants after watching two 3-min video recordings: one with a standard phone device, and one with the intervention. Rating was carried out through a five-item questionnaire, where 5 was the best rating.	*Independent phone calls:* At baseline, no independent phone calls made. During the intervention, there was an overall mean of nearly four independent phone calls per session. *Calls answered by partners:* Overall mean was between approximately two and a half and three. *Call time:* Overall mean conversation time per session was about 7 min. *Social validation assessment:* Mean scores for the five items of the questionnaire varied between 3.80 and 4.63. Extends the evidence available on the intervention used to enable people with AD to make phone calls independently and successfully. Social validation data was supportive of the computer-aided system and underlined its value in enhancing the independence, comfortableness, and social image of participants, and its overall practicality and usefulness in daily contexts.
[3] Lancioni et al., 2017	*Quantitative – Mean percentage of activities:* The number of activities the participant started as scheduled within first baseline and intervention phase. *Mean number of steps:* The number of steps participants performed correctly for the activities started in the second baseline and intervention phase.	*Mean percentage of activities:* During first baseline phase, participants' mean percentages were between 0-14. During the intervention, the participants' mean percentages of activities started independently were close to 100. The participants responded to al the technology-regulated reminders or missed only very few of them. *Mean number of steps:* During second baseline phase, participants' mean percentages were always below 35. In the intervention, the percentages of correct steps were near or above 90 for all participants. The use of a technology-aided program appears to be an effective resource with multiple practical implications. The program's components were suitable to positively engage participants.
[4] Lancioni et al., 2018	*Study 1* *Quantitative – Mean percentage of activities started independently:* At baseline, the RA read a list of 5 or 6 activities and the times at which they were due and placed the list on the table. The number of scheduled activities the participant started independently was noted. During intervention session, participants were provided with the technology, which promoted independent start of the activities. *Mean percentage of activity steps carried out correctly per session:* At baseline, the RA asked the participant to carry out 5 or 6 activities to determine how many steps were carried out correctly. For intervention session, the participant was provided with the technology, which promoted correct performance of the activities.	*Study 1* *Mean percentage of activities started independently* – At baseline, the participants' mean percentage was 0. During intervention this was (close to) 100. Participants responded to all reminders or missed a few. *Mean percentage of activity steps carried out correctly per session* – At baseline, the mean percentage of correct steps was always below 40. During intervention, the overall mean percentages were near or above 90. The differences between baseline and intervention data were statistically significant for all participants (*P*<.01 – *P*<.05). *Study 2* *Mean frequencies of step responses:* During baseline, participants head mean frequencies per session below 50. During intervention, the mean frequencies per session increased to between about 100 and over 150.

	Study 2 *Quantitative – Mean frequencies of step responses:* During baseline, participants were provided with the technology and walker, but received no prompts or stimulation. During intervention, prompts and stimulation were added. *Mean percentages of positive involvement per session:* Positive involvement was classed as singing, positive verbalisations and smiles etc. and recorded through observations.	*Mean percentages of positive involvement per session:* During baseline, the mean was between 0 and 8. During intervention, the mean percentages ranged from below 10 to near 80. The differences between baseline and intervention were statistically significant *(P* < .01) for all participants on step responses and for 6 participants on signs of positive involvement.
[5] Lancioni et al., 2019	*Quantitative – Mean frequencies of correct target responses:* 3 was the maximum frequency possible as each session provided the participant with the opportunity to bring 3 objects to 3 destinations. *Mean frequencies of intervals with indices of enjoyment/appreciation:* 4 was the maximum frequency possible as each session contained 4 observation intervals in which the presence or absence of the measure was recorded.	*Target responses:* At baseline, the mean frequencies of correct responses were between 0-1, over 4 sessions. During intervention, it was between 2.8-3 per session, and an overall mean across participants of 2.9 (3 was the maximum). *Intervals of enjoyment/appreciation:* Baseline mean frequencies of intervals with indices of enjoyment/appreciation ranged from 0-1. During the intervention, the mean ranged from 2.5-3.5 per session, and an overall mean across participants of 3 (4 was the maximum). The intervention was highly effective in improving overall performance in goal-directed walking in AD.
[6] Thorpe et al., 2019	*Quantitative – Activity levels:* Data from devices that calculated activity time *Self-reported activity, mobility and goal attainment:* Questionnaires completed pre-and post-study regarding mobility, activity, caregiver burden, functional performance and quality of life. Mobile self-reports were issued daily on a 5-point scale (much less than normal – much more than normal) *Qualitative – Interviews:* Semi-structured, at the end of the study, to explore experiences and outcomes.	*Activity levels:* Use of a smartphone and smartwatch were adequate in helping monitor activity levels. *Self-reported activity, mobility and goal attainment:* 2 participants who were satisfied with their current lifestyle followed goals to maintain their schedule. Participants also found it difficult to recall their goal over the duration of the study. *Interviews:* the support offered by smart technology addressed functional, memory, safety, leisure and psychosocial needs. 4 participants perceived this support to positively impact their health, mostly regarding motivation to be active, with one participant further describing considerable impact on anxiety, independence, activity and caregiver burden. The findings suggest the potential impact of smartphones and wearable devices to offer support for people with dementia in their everyday life.
[7] Øksnebjerg et al., 2020	*Quantitative – Log data:* App usage for all participants and caregivers for a maximum of 90 days. *Survey:* A web-based survey to collect additional background information and feedback on the app. It was distributed via email 3 to 4 months after inclusion in the study. In cases where email correspondence was unsuccessful, a printed version of the survey was sent out by mail. Two versions of the survey were distributed: one for participants and another by-proxy version for carers. *USEdem:* For participants who had activated the app, the questionnaire was included in the survey, and a by-proxy version was delivered to carers. This modified version contains 12 items and was adapted to be applied to people with dementia. Scores on each item range from 1 to 5 on a Likert scale, with a total score between 12 and 60, higher scores indicating higher ratings. *Qualitative - Survey:* Data from the survey feedback on reasons for not using the app, were processed and summarized in themes, as outlined in constant comparison analysis.	*Adoption:* Adoption of the app was defined as a minimum period of 90 days between the first and last use of the app. 18 participants and 7 of the carers became adopters. Overall, 47 participants and 78 carers never activated the app. Reasons for not using included needing to learn to use it and forgetting to use it. *USEdem:* An overall average score of 40 (range 21-55) for participants and 34 (range 18-51) for carers, which indicated a generally positive rating of the app with regard to usefulness, satisfaction, and ease of use, but with large variation. *Surveys:* Data revealed that there were no significant differences between adopters and nonadopters when it came to how much experience they had using a tablet, their skills when using it, and how much help they needed to use it. For participants who became adopters, the ReACT app and the methods for self-applied implementation were applicable. However, the results were also in accordance with the well-known challenges of non-adoption and nonadherence to digital health interventions. It underlined the personal and contextual factors that influence adoption. These factors need to be considered when designing and implementing digital interventions for people with dementia.

[8] Kerssens et al., 2015	*Qualitative – Goal and subjective attainment* *Quantitative – Technology implementation and feasibility, Goals and subjective attainment:* Carers asked to rate how the person with dementia was doing with goals with Better, Stable, Worse, N/A, and the level of functioning post-intervention with Much less than expected, Somewhat less than expected, As expected, Somewhat more than expected. **Technology adoption:** People with dementia answered Yes/No, carer answer options ranged from Very True to Very Untrue**.**	*Goals and subjective attainment:* 11 out of 25 goals were as expected or better than expected, whereas 8 goals were less than expected. Barriers to use included people with dementias' inability to use the intervention and ignoring the intervention even when they perceived them as positive. *Technology implementation and feasibility:* All participants accepted the intervention. 5 out of 7 couples kept the *Companion* post-intervention. *Technology Adoption:* People with dementia perceived many aspects of the intervention positively and helped them relax and enjoy life. Carers indicated that they valued the intervention. The intervention facilitated meaningful and positive engagement in the home and helped people with dementia and carers cope with symptoms and needs in daily life.
[9] McGoldrick et al., 2019	*Qualitative – Usefulness, strengths, limitations, and future use* *Quantitative – Unified Theory of Acceptance and Use of Technology Questionnaire:* Completed pre- and post-study by 2 participants in the interviews. Questionnaire concerned eight domains, such as attitudes towards the technology, and behavioural intentions, and each item was scored on a scale of 1-5. Items pooled to give overall domain score. *Target events remembered:* Frequencies calculated for the percentage of target events remembered out of all events for each week.	*Qualitative:* Positive overall impression of the app. Gave participants a sense of independence. Difficulties with the app and lack of insight contributed to the one participant withdrawing from intervention phase. *UTAUT:* Participant FD had an overall decrease in pre/post scores(positive), but the mean score for anxiety domain increased. Participant SI mean scores increased in 4 domains(negative). SI wanted to continue to use the app, but unsure about helpfulness of app, as they were learning to use it independently. *Target events remembered:* Participant FD completed 49% of tasks during baseline and 93% during intervention. Participant SI completed 69% during baseline and 95% during intervention. Participant CE completed 51% across 11-weeks of baseline. The evidence supports the effectiveness of MindMate in reducing prospective memory problems. Some concerns were raised about technical difficulties and frustration with use. 2 participants expressed intention for continued use.
[10] Kerkhof et al., 2019	*Qualitative – Behavioural observation in interviews and scenario testing of intervention*	User insight provided valuable knowledge to develop a workable app. Major insight was that the user-interface elements, such as pages and button, had to be simple and logically integrated to support users in operating and understanding the tool. FindMyApps selection tool makes a unique contribution to the field of dementia. It can support people with mild dementia in using the relevant apps that will contribute to a better quality of life.
[11] Boman et al., 2014	*Qualitative – Interviews and observations:* Conducted with participants and their significant others at their homes. Interview focused on participants' experiences of using phones, computer, and Skype, and how they responded to any difficulties. Participants then observed using their own technology, scored on a 3-point scale (3=no difficulty, 2=minor difficulty, 1=major difficulty). *Intervention sessions:* Observations and interviews were used to examine the usability of the mock-up. Questions were asked on satisfaction of design and how easy the features were to	*Interviews and observations:* Some participants were quite active with using a mobile or telephone, but some reported avoiding using the phone unless necessary and problems with remembering numbers. All participants could identify their phones and/or computers with no difficulty (one was minor when identifying computer). However, they struggled when performing the correct actions and choosing the correct buttons when calling or receiving a call.

	understand and use when carrying out 3 set tasks**.** Participants were observed when using the mock-up to carry out tasks.	*Intervention sessions:* Observations showed that initially most participants did not know how to make, or answer calls on the mock-up. However, after some feedback all could carry out the tasks independently. Participants perceived the mock-up as enjoyable to use and would have like to have it in their homes. However, they would have like to adjust the features of the video phone to their individual needs and wishes. The findings suggest that the videophone mock-up was enjoyable to use and effective in enabling people with dementia to make calls independently. The difficulties with phones and computers observed in participants' homes were not present when using the mock-up.

9.2 Ethics approval letter



Ymchwil Iechyd
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23 April 2021

Dear Professor Orrell

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

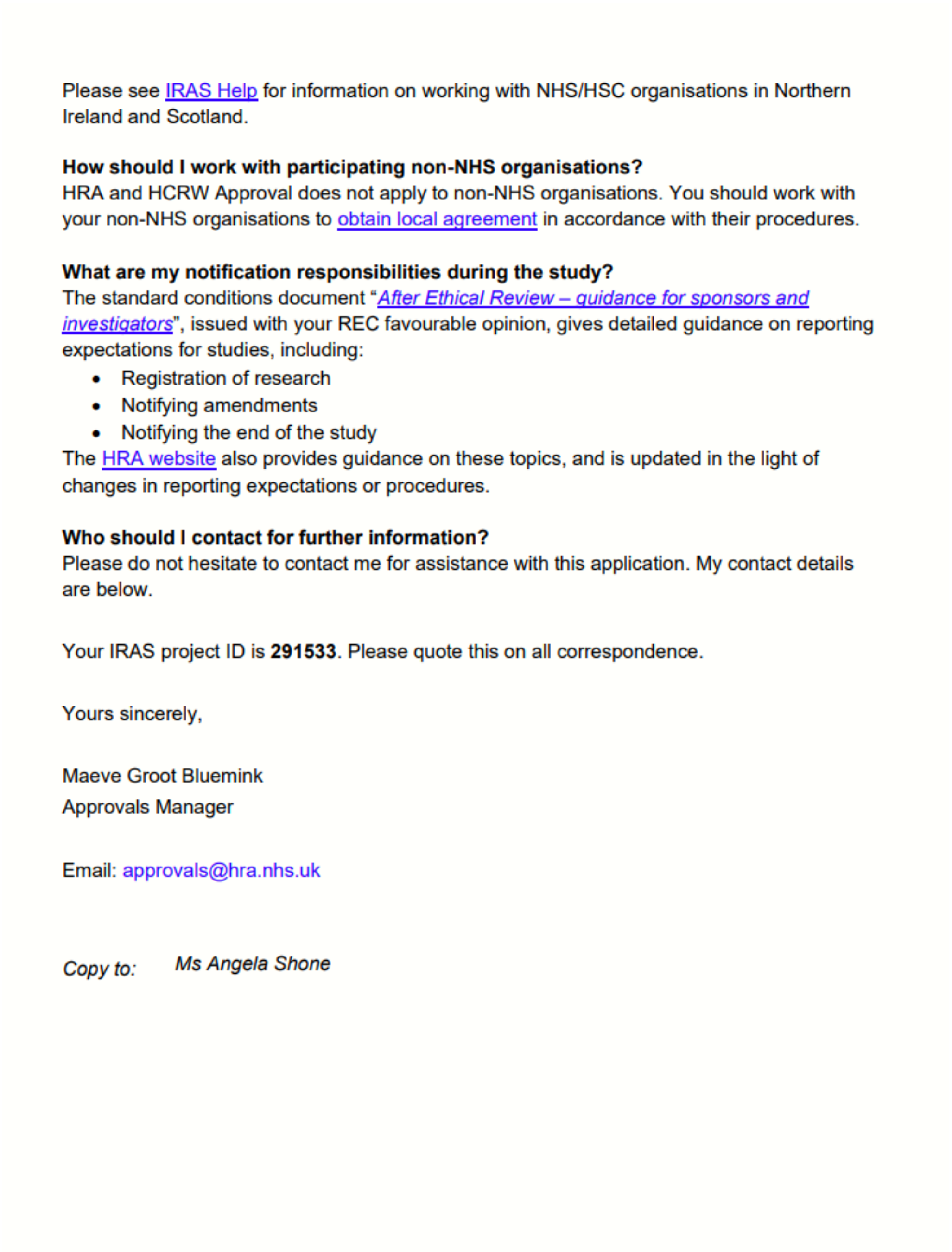
Study title:	**Promoting Independence in Dementia (PRIDE) – changing lifestyles & improving outcomes: RE-AIM study of the PRIDE self-management app**
IRAS project ID:	**291533**
Protocol number:	**20075**
REC reference:	**21/SC/0066**
Sponsor	**University of Nottingham**

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.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within 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) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



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?
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 standard conditions 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.

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

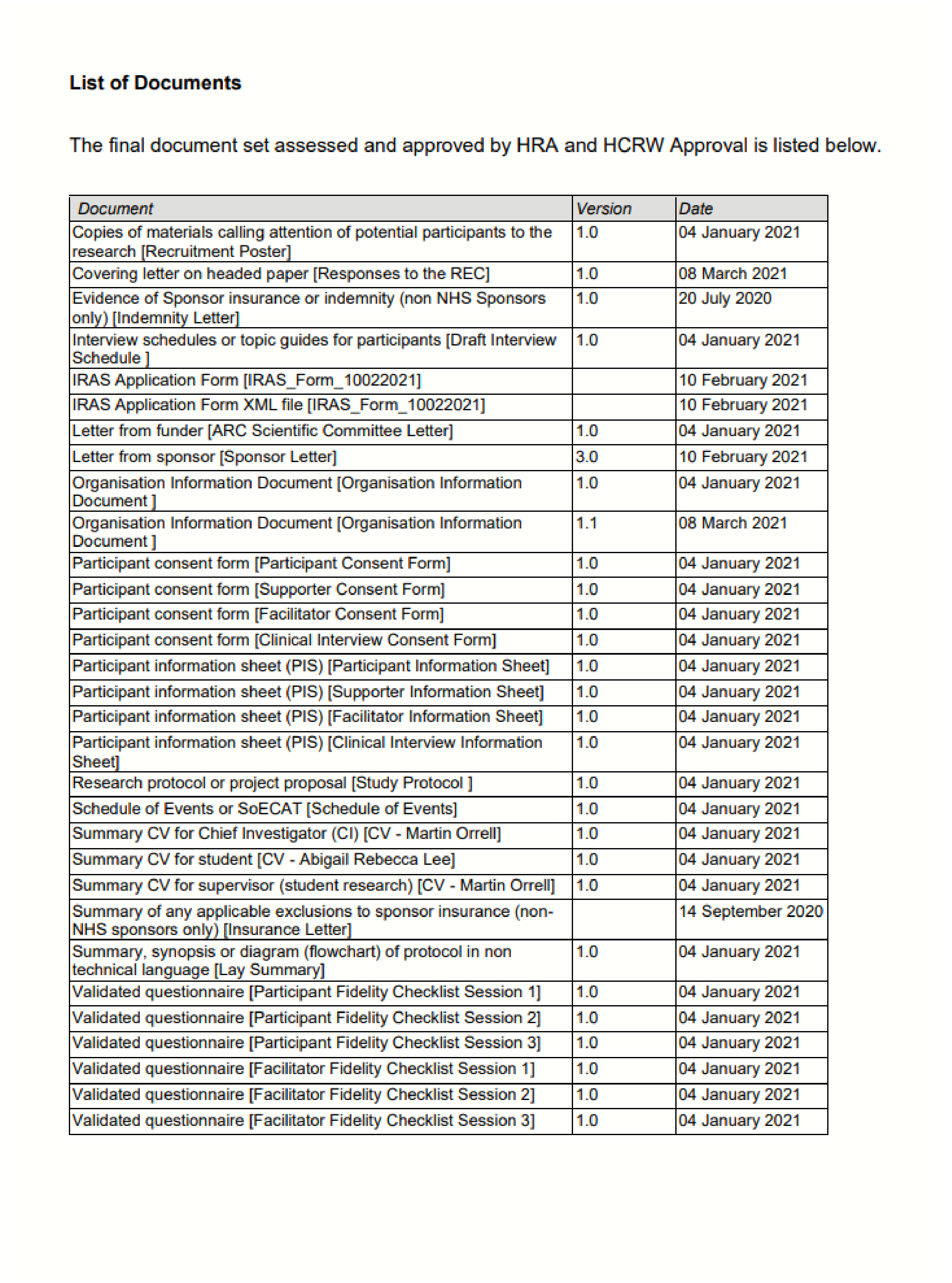
Your IRAS project ID is **291533**. Please quote this on all correspondence.

Yours sincerely,

Maeve Groot Bluemink
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Ms Angela Shone*



List of Documents

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

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Recruitment Poster]	1.0	04 January 2021
Covering letter on headed paper [Responses to the REC]	1.0	08 March 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Letter]	1.0	20 July 2020
Interview schedules or topic guides for participants [Draft Interview Schedule]	1.0	04 January 2021
IRAS Application Form [IRAS_Form_10022021]		10 February 2021
IRAS Application Form XML file [IRAS_Form_10022021]		10 February 2021
Letter from funder [ARC Scientific Committee Letter]	1.0	04 January 2021
Letter from sponsor [Sponsor Letter]	3.0	10 February 2021
Organisation Information Document [Organisation Information Document]	1.0	04 January 2021
Organisation Information Document [Organisation Information Document]	1.1	08 March 2021
Participant consent form [Participant Consent Form]	1.0	04 January 2021
Participant consent form [Supporter Consent Form]	1.0	04 January 2021
Participant consent form [Facilitator Consent Form]	1.0	04 January 2021
Participant consent form [Clinical Interview Consent Form]	1.0	04 January 2021
Participant information sheet (PIS) [Participant Information Sheet]	1.0	04 January 2021
Participant information sheet (PIS) [Supporter Information Sheet]	1.0	04 January 2021
Participant information sheet (PIS) [Facilitator Information Sheet]	1.0	04 January 2021
Participant information sheet (PIS) [Clinical Interview Information Sheet]	1.0	04 January 2021
Research protocol or project proposal [Study Protocol]	1.0	04 January 2021
Schedule of Events or SoECAT [Schedule of Events]	1.0	04 January 2021
Summary CV for Chief Investigator (CI) [CV - Martin Orrell]	1.0	04 January 2021
Summary CV for student [CV - Abigail Rebecca Lee]	1.0	04 January 2021
Summary CV for supervisor (student research) [CV - Martin Orrell]	1.0	04 January 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance Letter]		14 September 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay Summary]	1.0	04 January 2021
Validated questionnaire [Participant Fidelity Checklist Session 1]	1.0	04 January 2021
Validated questionnaire [Participant Fidelity Checklist Session 2]	1.0	04 January 2021
Validated questionnaire [Participant Fidelity Checklist Session 3]	1.0	04 January 2021
Validated questionnaire [Facilitator Fidelity Checklist Session 1]	1.0	04 January 2021
Validated questionnaire [Facilitator Fidelity Checklist Session 2]	1.0	04 January 2021
Validated questionnaire [Facilitator Fidelity Checklist Session 3]	1.0	04 January 2021

9.3 Study manual for research sites

University of Nottingham
UK | CHINA | MALAYSIA

Study Manual

Promoting Independence in Dementia – Changing Lifestyles & Improving Outcomes: Re-Aim Study of The PRIDE Self-Management App

Pride
Promoting independence in dementia

IRAS ID: 291533

V1.0 – 30th April 2021

This study is funded by the National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

General information

The Promoting Independence in Dementia (PRIDE) programme is aimed at promoting and supporting independence for people living with dementia. It provides a handbook to enhance independence and quality of life for people with mild dementia and their support network by enhancing decision making, reducing stigma, and encouraging participation in mental, physical, and social activities. As part of the feasibility study of the paper-based version of PRIDE, the research team developed the PRIDE-app. This web-based app holds the same information as the paper-based PRIDE but presents it through an interactive online handbook.

For the current study, researchers at the University of Nottingham have worked closely with a tech-for-good company, Ayup, to further develop the PRIDE-app. An initial prototype was evaluated by members of the research team and people living with dementia and their supporters, and feedback gathered contributed to changes made during two development sprints. The PRIDE-app is online and accessed through a web address (https://pridestudy.co.uk) rather than an Appstore icon. Each user has a personal login, using two initials, their date of birth, and a four-digit code sent to either a mobile or landline phone number.

The next step for the PRIDE-app is to have people with dementia and their supporters use the intervention in their daily lives and see whether an online version of PRIDE could be beneficial in improving independence, self-management, and quality of life for the person with dementia in addition to improving general wellbeing for the supporter.

We are conducting a RE-AIM study which will be managed from the University of Nottingham. The study will investigate: 1) the extent to which the PRIDE-app has the capacity to reach people with early-stage dementia, 2) the effectiveness of the intervention, and 3) the adoptability of the intervention. The entire project is part of Abigail Lee's (ARL) PhD study which is set to finish in September 2022.

As you have expressed your interest in being a site for this study, we have developed this manual to provide you with the necessary information to carry out the study activities. The manual includes the following information and more:

- Study and recruitment dates
- Inclusion of participants
- Assessments
- PRIDE-app intervention
- End of study process

Study preparation

1. Sites, targets, and recruitment dates

We are aiming to have up to 6 sites involved in this study.

Each site shall recruit **10-15** people with dementia (ideally each recruited with a supporter).

Recruitment shall start on the **1st June 2021** and cease by **28th February 2022** (last recruit in)**.**

The end date of the study is **31st August 2022.**

2. Research team requirements

The nature of the study means that there will be no blind and unblind researchers. All participants will receive the same intervention and complete identical baseline and outcome measures. The research team at sites will be responsible for identifying and recruiting participants, as well as identifying facilitation staff.

With regards to participant recruitment, figures will be divided into group targets, including age and ethnicity, to try and increase the diversity and representativeness of the sample. Participants will be divided up into the following age groups: less than 65 years, 65-74, 75-84, and over 85 years. The initial target will be to recruit 15 participants in each of these age groups across all sites. Similarly, with ethnicity, the initial target will be to recruit a minimum of one BAME individual for every 3 Caucasian participants. We ask that you keep track of recruitment figures and the number and characteristics of people seen, recruited and complete baseline. Please provide monthly figures to AL. If the ethnicity of participants is not as diverse as possible, then you will be asked to over sample BAME to try and maximise their representativeness in the final participant group.

3. Study documentation

Each site will be responsible for completing the consent process, keep a database of participants, and maintain storage of all study documents until end of the study. You will have received the Local Information Pack via email, but there is a list of study documentation at the end of this manual. Please check that you have all the required documentation prior to the start of recruitment. If you need any additional documents, please contact ARL. Contact details are provided at the end of the manual.

Study process

1. Participant identification and initial screening

The participants for this study will be adults with dementia and their supporters (relatives or close friends). They will be recruited individually or as dyads, depending on the person with dementia's preference. Potential participants are to be identified through NHS Memory Services and contacted by each site (e.g. through telephone etc.). People can also self-refer or register their interest through Join Dementia Research. Basic demographics: age, gender, ethnicity, are to be collected by screening staff. This will enable the University of Nottingham researchers to understand who was approached to participate in the study.

If people with dementia are interested in the study, please go through the following screening questions with them:

- Do you have access to a computer or touch-screen tablet? **If yes, next question. If no, exclude.**
- Do you have access to broadband in order to use the PRIDE-app? **If yes, next question. If no, exclude.**
- Do you have a mobile or landline telephone number that you are comfortable providing to us? **If yes, continue onto next section. If no, exclude.**

2. Inclusion of participants

While screening the participants, also check if they meet the formal inclusion criteria for the study. Both the person with dementia and supporter have their own inclusion/exclusion criteria:

Person with dementia:

- Aged 18 or over; there is no upper age limit.
- Self-report a confirmed medical diagnosis for dementia of any type, including Alzheimer’s, vascular, Lewy body type and mixed.
- Able to engage with and participate in the intervention in the judgement of the investigator or designee.
- Able to give informed consent in the judgement of the investigator or designee.
- Able to read and communicate verbally in English.
- Access to the internet and computer/tablet if they choose the PRIDE-app intervention

Supporter:

- Aged 18 or over; there is no upper age limit.
- Able to engage with and participate in the intervention.
- Able to provide informed consent.
- Able to read and communicate verbally in English.

Exclusion criteria person with dementia and supporter:

- Living in institutional care.

3. Participant Information Sheets (PIS)

This study has three PIS: one for the person with dementia, one for the supporter, and one for facilitators (please see the checklist at the end of manual to ensure you have the correct version). These will be sent to sites through email, but if you require postal versions, please notify ARL and she will organise this. After the participant has been identified, screened, and meets the inclusion criteria, please complete the PIS either over the phone, by email or post.

4. Informed Consent Forms (ICF)

All participants will provide written informed consent. The recruiting research member will explain the details of the study and provide a PIS, ensuring that the participant has sufficient time to consider participating or not. The Investigator will answer any questions that the participant has concerning study participation. It should be made clear to both participants and their families that no disadvantage will accrue if they choose not to participate.

The participant ICF will be signed and dated by the participant before they enter the study. A second supporter ICF will be signed and dated before they also enter the study. Informed consent must be collected from each participant before they undergo any interventions related to the study. One copy of ICFs will be kept by the participant/supporter, one will be kept by the Investigator, and a third will be retained in the participant's records, for those recruited through the memory service pathway. Please ensure **each copy** is signed/dated by the participants and by the person taking consent.

Depending on the COVID-19 restrictions in place during the study, participants will be offered options for providing informed consent:

- Online (electronic) consent – an identical ICF is provided via the REDcap online questionnaires, which will ask for an electronic signature. Once signed, participants will receive a copy of their electronic consent form.

- Video consent completed through either an online consent form (with tick box consent) or through observing the participant complete a paper form which is then posted to the appropriate research/staff member using a pre-paid envelope. The form will be counter signed on receipt and a brief explanatory note written on the form, explaining the difference in dates.
- Phone consent, with the participant completing a paper form during the call and confirming when done. This could be witnessed and confirmed by a supporter if present. The form will be posted to the appropriate research/staff member using a pre-paid envelope, counter signed on receipt, and a brief explanatory note written on the form to explain the difference in dates.

If eligible and willing, the following demographic data should be recorded on the participant CRF:

- Gender
- Date of birth
- Availability of computer / internet access for use of web-based manual
- Ethnicity
- Dementia diagnosis
- Postal or online questionnaires (if postal, please get consent to pass address onto UoN study team)
- Whether they will be participating with a Supporter

5. Identification of Facilitators

We would be grateful if you would help us identify and recruit volunteers to act as Dementia Advisors for this study. These should be NHS staff members, trainees or placement workers who have a good knowledge and experience of dementia care and are happy to help facilitate the intervention. Facilitators will have to complete two mandatory training sessions, which will be between 20-45 minutes in duration.

Inclusion criteria for facilitators

- Aged 18 or over; there is no upper age limit.
- A staff member, trainee or placement worker at a participating NHS Service.
- Able and willing to complete the mandatory training sessions.
- Able and willing to deliver all three PRIDE-app intervention sessions to at least one participant.
- Able to give informed consent in the judgement of the recruiting researcher.
- Able to read and communicate verbally in English.

Exclusion criteria

- Unable to deliver all three sessions to at least one participant.

6. Baseline Assessment

CRFs will be sent to each site by email. However, if they need to be sent by post, notify ARL and she will arrange for this. Following the end of recruitment, please return completed CRFs to ARL, either through secure email, post or organise an in-person collection. If your site requires an earlier collection, please contact the study team.

Participants who are eligible and willing to continue in the study will proceed to baseline assessment completion. The standard method for data completion will be through online measures using the REDCap software. However, baseline measures can also be completed over video call or over the phone with a member of the research/CRN team, if participants need further assistance. For video/phone remote collection, measures will be sent to participants along with a prepaid envelope to encourage questionnaire completion. See the list below for a summary for the baseline assessment:

Person with Dementia Baseline:

- Enrolment Questionnaire
- Lawton ADL Scale (IADL)
- EuroQoL Quality of Life (EQ-5D-5L)
- Geriatric Depression Scale – short form (GDS)
- Control, Autonomy, Self-realisation and Pleasure (CASP-19)
- Engagement and Independence in Dementia Questionnaire (EID-Q)

Supporter Baseline:

If the participant agrees to take part with a supporter, they will be asked to complete the following baseline questionnaires after providing written informed consent:

- Enrolment Questionnaire
- EuroQoL Quality of Life (EQ-5D-5L)

- General Health Questionnaire (GHQ-12)

7. PRIDE-app Intervention

The PRIDE-app is a web-based application that has information and resources on 7 key areas often affected by dementia. These are: *Keeping Mentally Active; Keeping Physically Active; Keeping Socially Active; Keeping Healthy; Making Decisions; Getting Your Message Across;* and *What Does It Mean To Be Told You Have Dementia*. Users are encouraged to reflect on their daily activities, social network, and what positive lifestyle changes could be made to improve their quality of life.

Once participants are assigned to the PRIDE-app intervention, a Dementia Advisor facilitator will contact them to set up their login details. The Dementia Advisor will deliver three sessions in partnership with participants within a 2-month window. Through these sessions, participants will be introduced to the PRIDE concepts, learn how to navigate the PRIDE-app, and create positive activity plans. Continued use of the resources and techniques introduced through PRIDE will be discussed in the final session to promote long-term positive lifestyle changes.

Usual Care

All participants will receive the services and interventions usually available to people with dementia and family at the participating sites. This will naturally vary between and within centres and may change over time.

8. Fidelity Checklists

Measuring fidelity is an important part of understanding whether an intervention works and how it is best delivered. Facilitators will complete a fidelity checklist for each of the 3 intervention sessions. Participants will complete a similar checklist following each session, to gain their perspective on what content was or was not covered.

9. Follow-ups

Like the baseline assessment, the main method of data collection will be online through REDCap, but participants will have the option to complete measures online, or over video call or the phone with research staff or ARL. The first follow-up will be 3 months after the participant started the PRIDE-app intervention. The second will be at 6 months.

Person with Dementia FU 1+2:

- Lawton ADL Scale (IADL)
- EuroQoL Quality of Life (EQ-5D-5L)
- Geriatric Depression Scale – short form (GDS)
- Control, Autonomy, Self-realisation and Pleasure (CASP-19)
- Engagement and Independence in Dementia Questionnaire (EID-Q)
- Global Change Measure (self-report version)

Supporter FU 1+2:

- EuroQoL Quality of Life (EQ-5D-5L)
- General Health Questionnaire (GHQ-12)
- Global Change Measure (proxy-rated version)

10. Interviews

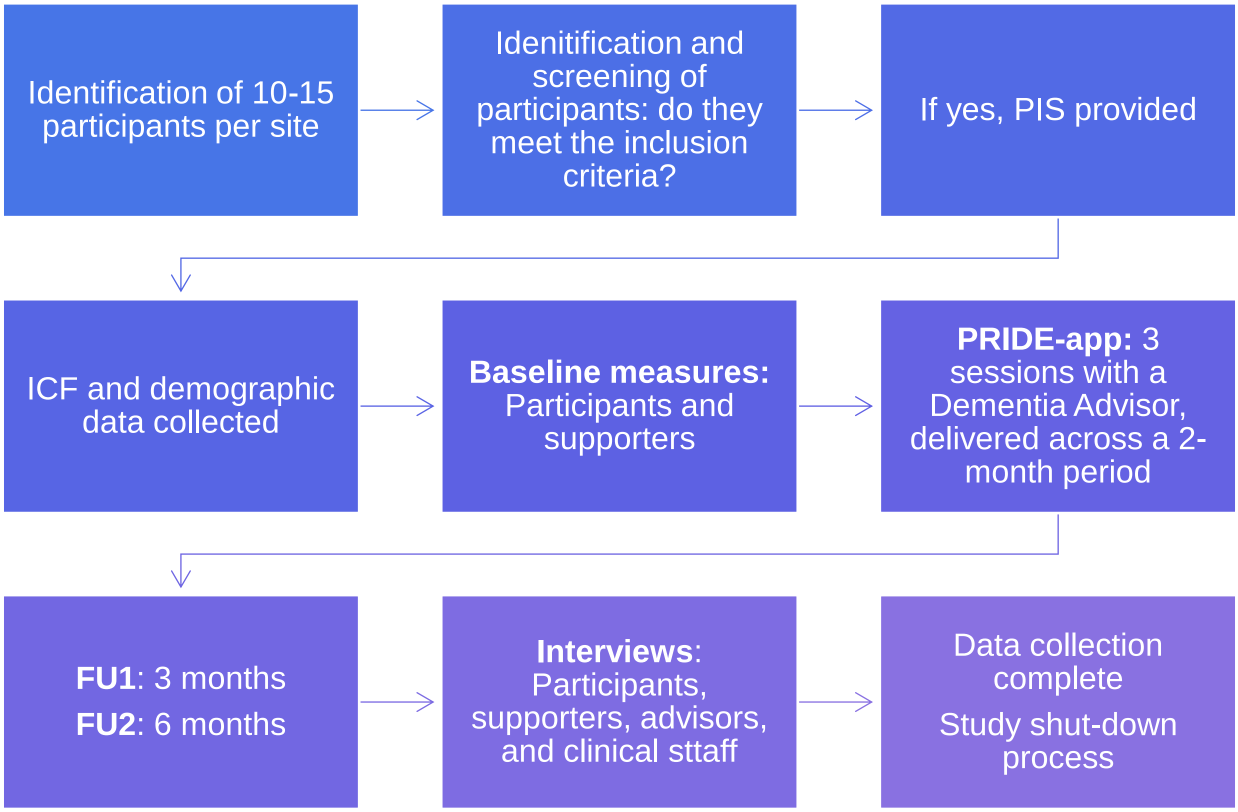
We would like to invite up to 20 individuals and dyads to participate in an interview shortly after they have completed the PRIDE-app intervention. This is to gather some qualitative feedback on the application and give people the opportunity to voice their thoughts/experiences. The interview is optional and when participants sign the study consent form there is a clause included re the interview. Only if individuals/dyads have explicitly expressed an interest in participating, will they be invited.

We are also interested in interviewing facilitators and senior clinical staff for their views on the PRIDE-app. Dementia Advisors will be contacted directly about this, but sites will receive an email when interviews start, and this will include an invitation to senior clinical staff who have not facilitated in the study. We would like senior staff to discuss their views on the positives and barriers to the potential implementation and long-term use of the PRIDE-app across wider services.

11. Study shut down

Once CRNs have completed their role in the study, any outstanding participant documents will be sent securely to ARL at the University of Nottingham. Dependent on the working restrictions placed on the University of Nottingham by COVID-19 at the time of data collection, documents will be either sent as scans over encrypted email or through the post. Prepaid envelopes will be supplied. Consent forms can remain at the site and can be included in the site file. As each site may have their own protocol for study shut down, please let ARL know your specific site details.

12. Study Flow chart



Contact

Contact information: pride-app@nottingham.ac.uk

Mobile: **07890 021703**

Document checklist

Please double check to ensure you have received/access to the following documents:

☐ This manual (v1.0)

☐ SoECAT (v)

☐ Latest protocol (v1.1)

☐ Participant Information Sheet (v1.0)

☐ Participant Consent Form (v1.0)

☐ Supporter Information Sheet (v1.0)

☐ Supporter Consent Form (v1.0)

☐ Facilitator Information Sheet (v1.0)

☐ Facilitator Consent Form (v1.0)

☐ Participant CRF (v1.0)

☐ PRIDE-app Study Recruitment Poster (v1.0)

☐ Facilitator Recruitment Poster (v1.0)

9.4 Dementia Advisor handbook

Dementia Advisor Handbook

Promoting Independence in Dementia – Changing Lifestyles & Improving Outcomes: RE-AIM Study of the PRIDE Self-Management App

Pride. Promoting independence in dementia

IRAS ID: 291533

V1.0 – 20/02/21

General information

Thank you for volunteering to be a Dementia Advisor (DA) for the PRIDE-app Study.

The Promoting Independence in Dementia (PRIDE) programme is aimed at promoting and supporting independence for people living with dementia. It is a social intervention to enhance independence and quality of life for people with mild dementia, that supports them by enhancing decision-making, reducing stigma, and encouraging participation in mental, physical, and social activities. As part of a feasibility study using the original paper-based PRIDE manual, the research team developed the PRIDE-app prototype.

For the current study, researchers at the University of Nottingham have worked closely with a tech-for-good company, Ayup, to further develop the PRIDE-app. An initial prototype was evaluated by members of the research team and people living with dementia and their supporters, and feedback gathered contributed to changes made during two development sprints. The PRIDE-app is online and accessed through a web address (https://pridestudy.co.uk) rather than an Appstore icon. Each user has a personal login, using two initials, their date of birth, and a four-digit code sent to either a mobile or landline phone number.

The next step for the PRIDE-app is for people with dementia and supporters to use the intervention in their daily lives to evaluate whether an online version of PRIDE could be beneficial in improving quality of life for the person with dementia, in addition to improving general wellbeing for the supporter.

We are conducting a RE-AIM study which will be managed from the University of Nottingham. The study will investigate: 1) the extent to which the PRIDE-app has the capacity to reach people with early-stage dementia, 2) the effectiveness of the intervention, and 3) the adoptability of the intervention. The PRIDE-app project is part of Abigail Lee's PhD, which is set to finish in September 2022.

As you have kindly volunteered your time to act as a DA and help facilitate the study intervention, we have developed this handbook to provide you with the necessary information. The handbook includes:

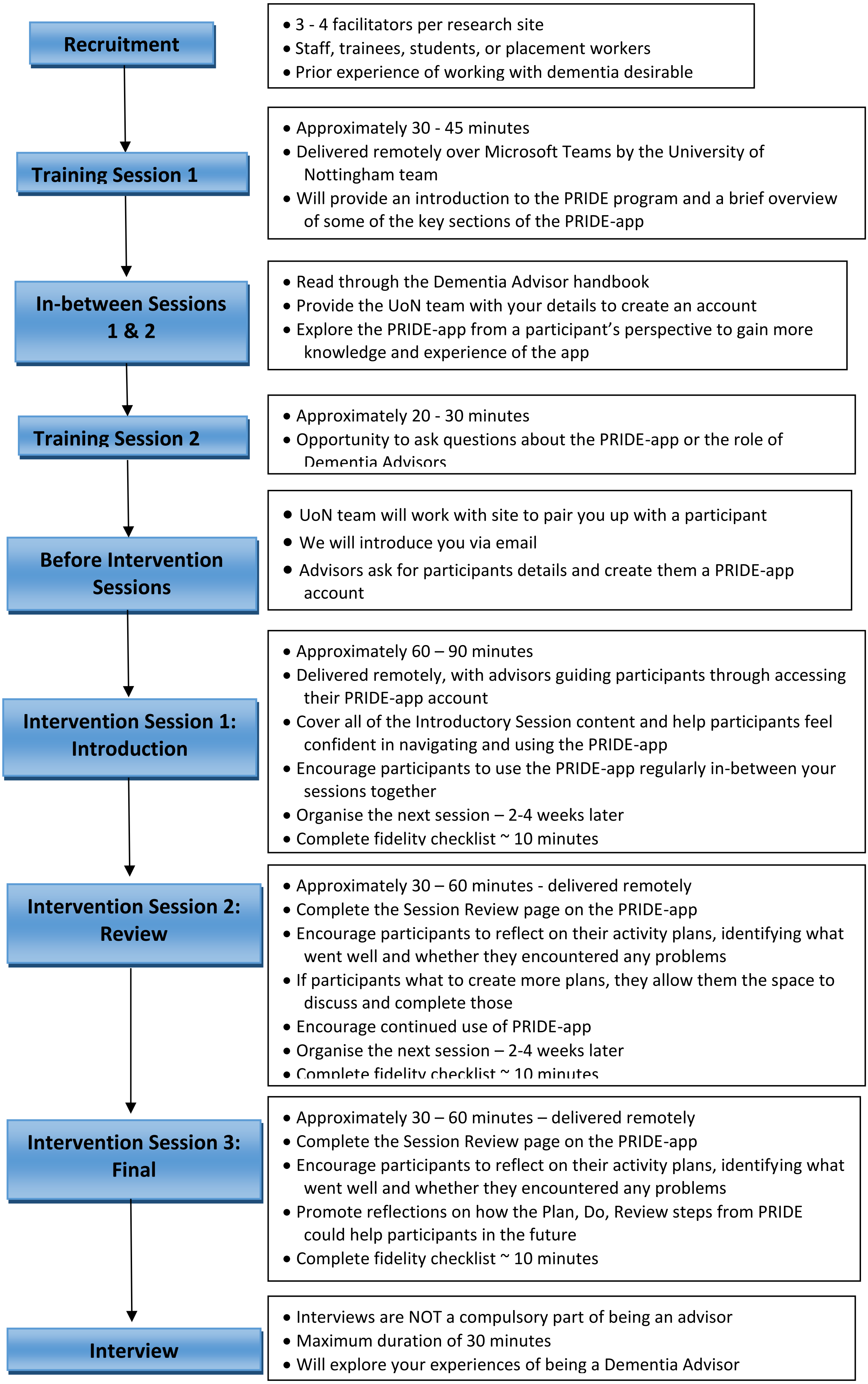
- Dementia Advisor Training
- PRIDE-app
- Intervention Session Content
- Fidelity Checklists and Interviews

Role of Dementia Advisors

DAs will play a vital role in the PRIDE-app Study. You will be key in ensuring participants understand the intervention and feel encouraged to actively use the PRIDE-app. The role of the DA will be to support participants living with dementia to:

1. Maintain or re-engage in activities in one or more of the three lifestyle topics of their choice.
2. Feel empowered to make independent decisions about activities and the use of resources such as the internet and their social networks.
3. Make choices to maintain or enhance their current social, mental, and physical activities and lifestyle, or try new activities / adopt new healthy living behaviours (e.g. smoking cessation).
4. Practice using resources such as telephone support (e.g. texting, help lines), web-based support, and peer support groups.
5. Reflect on how they might monitor and maintain their lifestyle activities in the future and devise a plan to consider future potential changes in personal and social circumstances.

Please see below a flowchart providing a brief outline of your involvement in the PRIDE-app Study.



Recruitment

- 3 - 4 facilitators per research site
- Staff, trainees, students, or placement workers
- Prior experience of working with dementia desirable

Training Session 1

- Approximately 30 - 45 minutes
- Delivered remotely over Microsoft Teams by the University of Nottingham team
- Will provide an introduction to the PRIDE program and a brief overview of some of the key sections of the PRIDE-app

In-between Sessions 1 & 2

- Read through the Dementia Advisor handbook
- Provide the UoN team with your details to create an account
- Explore the PRIDE-app from a participant's perspective to gain more knowledge and experience of the app

Training Session 2

- Approximately 20 - 30 minutes
- Opportunity to ask questions about the PRIDE-app or the role of Dementia Advisors

Before Intervention Sessions

- UoN team will work with site to pair you up with a participant
- We will introduce you via email
- Advisors ask for participants details and create them a PRIDE-app account

Intervention Session 1: Introduction

- Approximately 60 – 90 minutes
- Delivered remotely, with advisors guiding participants through accessing their PRIDE-app account
- Cover all of the Introductory Session content and help participants feel confident in navigating and using the PRIDE-app
- Encourage participants to use the PRIDE-app regularly in-between your sessions together
- Organise the next session – 2-4 weeks later
- Complete fidelity checklist ~ 10 minutes

Intervention Session 2: Review

- Approximately 30 – 60 minutes - delivered remotely
- Complete the Session Review page on the PRIDE-app
- Encourage participants to reflect on their activity plans, identifying what went well and whether they encountered any problems
- If participants what to create more plans, they allow them the space to discuss and complete those
- Encourage continued use of PRIDE-app
- Organise the next session – 2-4 weeks later
- Complete fidelity checklist ~ 10 minutes

Intervention Session 3: Final

- Approximately 30 – 60 minutes – delivered remotely
- Complete the Session Review page on the PRIDE-app
- Encourage participants to reflect on their activity plans, identifying what went well and whether they encountered any problems
- Promote reflections on how the Plan, Do, Review steps from PRIDE could help participants in the future
- Complete fidelity checklist ~ 10 minutes

Interview

- Interviews are NOT a compulsory part of being an advisor
- Maximum duration of 30 minutes
- Will explore your experiences of being a Dementia Advisor

Training

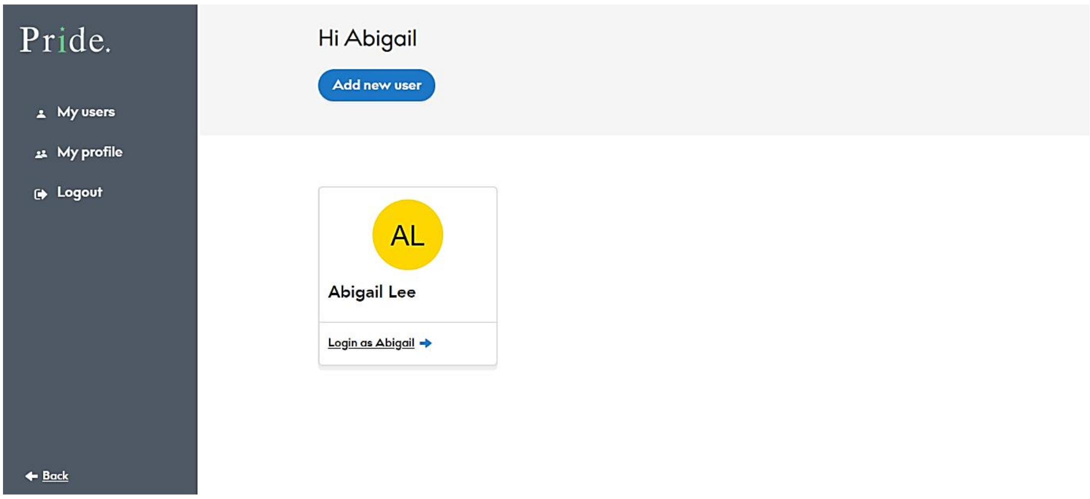
As DAs, you will be invited to complete two training sessions, organised and run by Abigail Lee. The sessions will provide you with the background to PRIDE, outline your role as a DA, and introduce the PRIDE-app. The sessions will be 20-45 minutes long, and completion of both sessions is a pre-requisite to providing the study intervention. In between the sessions, you will have the chance to explore the PRIDE-app.

Due to COVID-19 restrictions, training will be delivered remotely through Microsoft Teams. You will be contacted regarding suitable dates and times and sent the meeting link via email.

Getting Access

Once you have registered your interest in becoming a DA and signed the informed consent form, you will be asked to supply some personal details to set up your PRIDE-app login. These will be your name, date of birth, an email address, and a mobile number. The University of Nottingham will liaise with the app development company to create your logins, and you will receive an email notification when this is complete. Once you have a login, please check that you can access the site, and let the study team is you have any problems. All personal details will be confidential and stored securely.

As a DA, you will initially be given access to a user account, but this will change to a DA account after you have completed the training. When you have your DA account, your PRIDE-app home screen will look different to the participants' account. From here your profile and contact details can be amended, under ‘My profile’, and you will be able to add users and access their accounts in a ‘read only’ format. When delivering sessions, please click to login as the participant, and support them through the content via this ‘read only’ format.



This is what the DA homepage will look like. Each of your participants will appear here. Click on 'Login as...' when delivering the sessions.

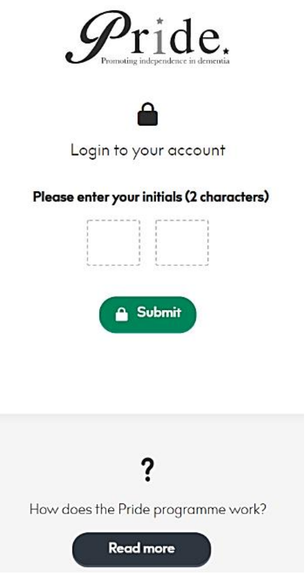
PRIDE-App

A brief overview of the App is provided below along with some screenshots.

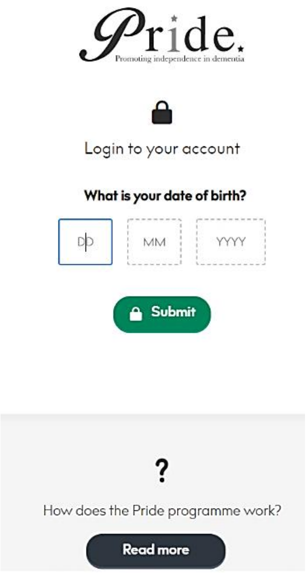
PRIDE-app Login

Type this link in the internet browser on a computer or tablet:

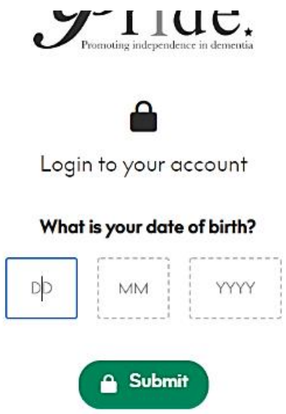
https://pridestudy.co.uk.



Enter your first and last name initials, then press submit.

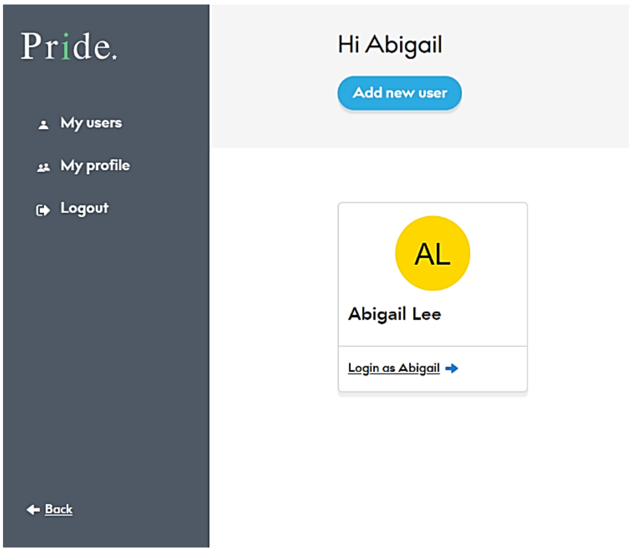


On the next screen, type in your date of birth – DD MM YYYY, and press submit.



After you have pressed submit, a 4-digit code will be sent to the phone number you provided for your account (either a text message to a mobile or a voice message to a landline). Type in the code and press submit.

Adding a New User

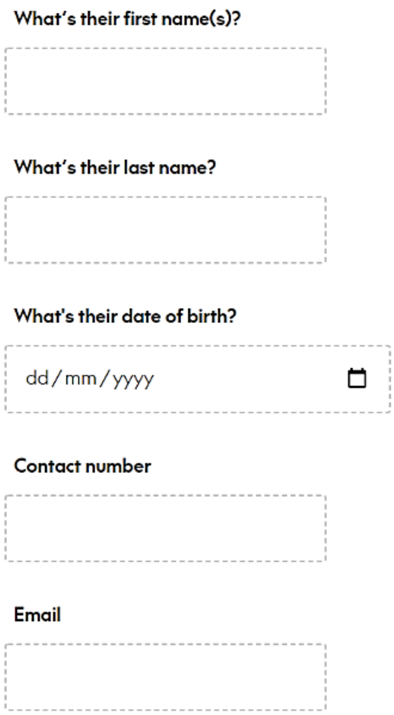


On the Home screen, click on the 'Add new user'.

Please fill in:

- their name
- date of birth
- contact number
- email
- how they would like to receive their 4-digit login code (text or phone call) and the number they would like this sent to
- notification settings (receiving notifications is not a requirement)
- preference for font size

Below are some screenshots of the ‘Add new user’ page.



What’s their first name(s)?

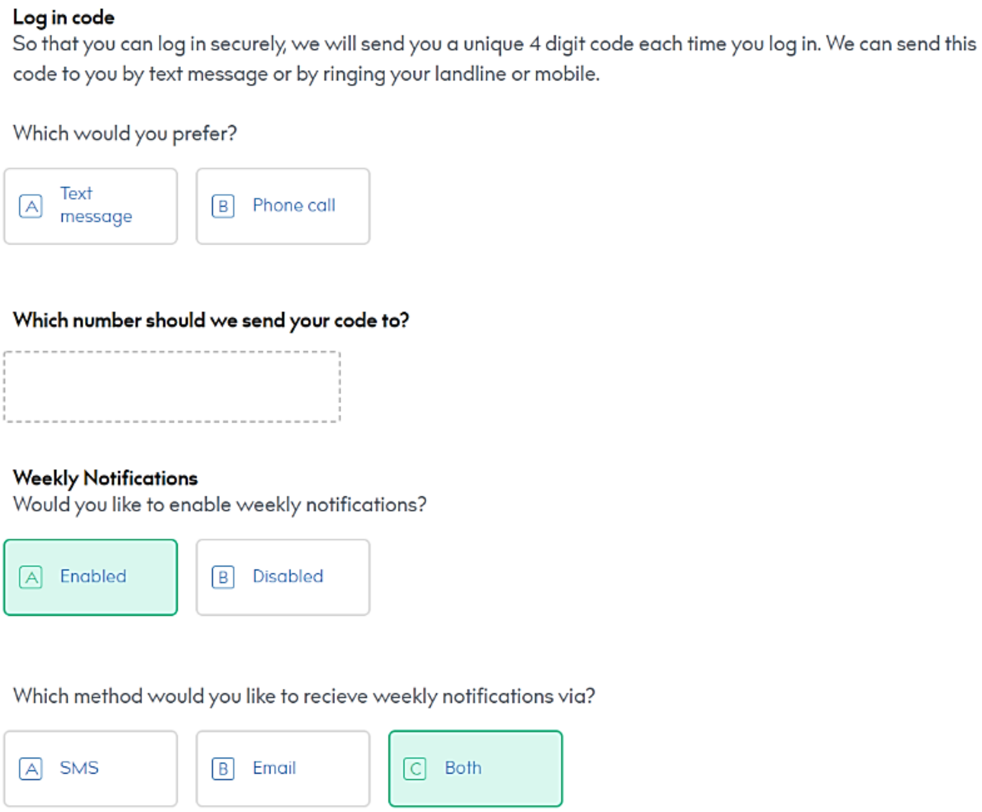
What’s their last name?

What's their date of birth?

dd / mm / yyyy

Contact number

Email



Log in code

So that you can log in securely, we will send you a unique 4 digit code each time you log in. We can send this code to you by text message or by ringing your landline or mobile.

Which would you prefer?

A Text message B Phone call

Which number should we send your code to?

Weekly Notifications

Would you like to enable weekly notifications?

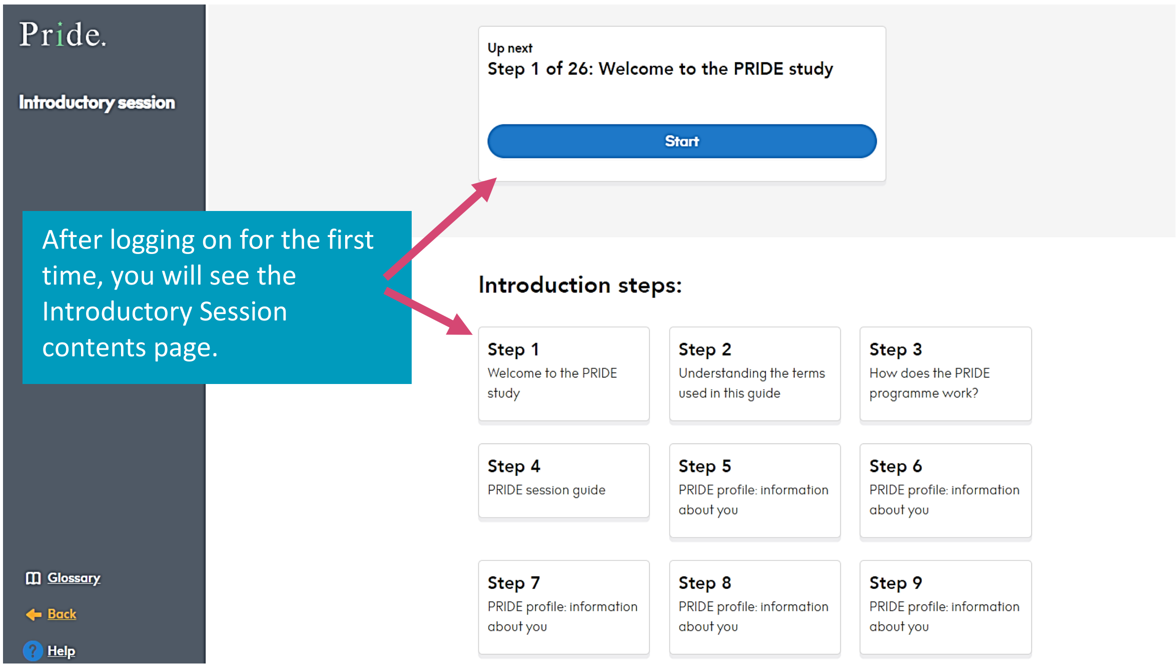
[✓ A Enabled] B Disabled

Which method would you like to recieve weekly notifications via?

A SMS B Email [✓ C Both]

Introductory Session Navigation

Below are some screen shots from the Introductory Session content. There are 26 steps in the session. When accessing the site for the first time, press ‘Start’. If continuing or revisiting the content, just select the step you wish to read.



Up next
Step 1 of 26: Welcome to the PRIDE study

Start

After logging on for the first time, you will see the Introductory Session contents page.

Introduction steps:

Step 1 Welcome to the PRIDE study

Step 2 Understanding the terms used in this guide

Step 3 How does the PRIDE programme work?

Step 4 PRIDE session guide

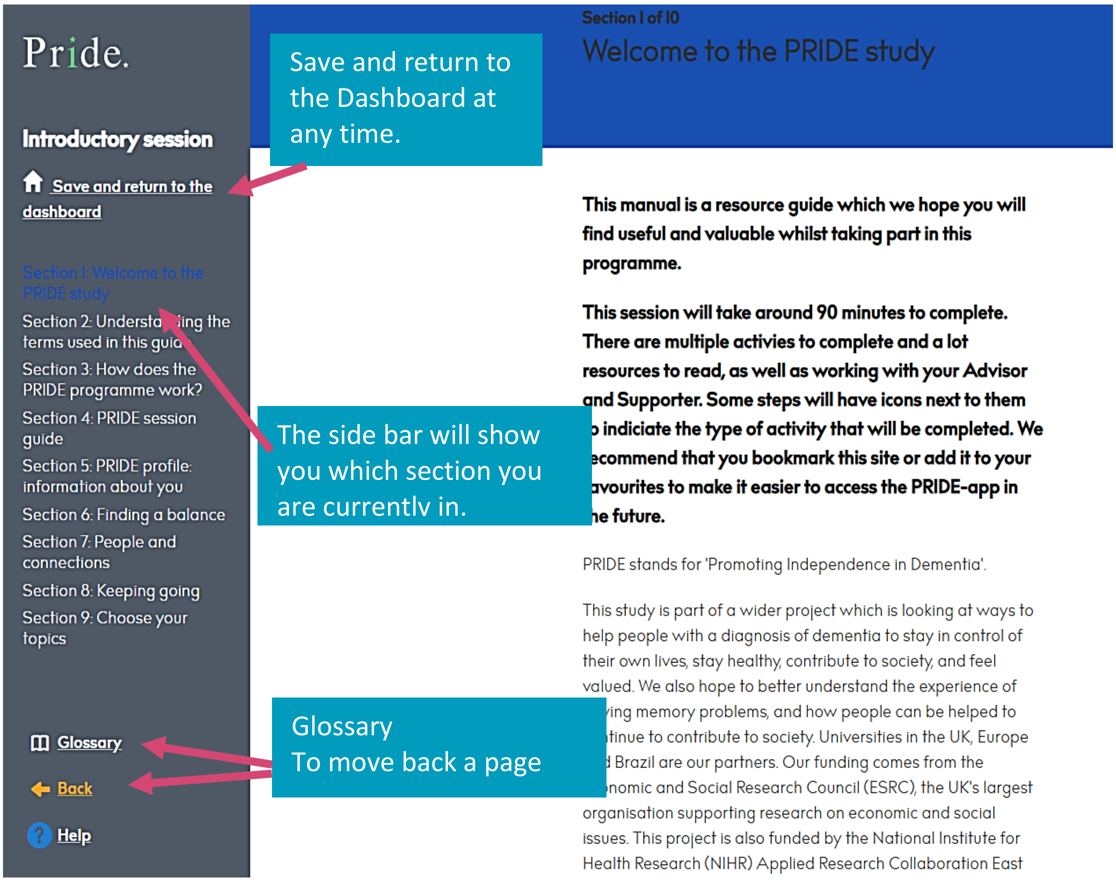
Step 5 PRIDE profile: information about you

Step 6 PRIDE profile: information about you

Step 7 PRIDE profile: information about you

Step 8 PRIDE profile: information about you

Step 9 PRIDE profile: information about you



Section 1: Welcome to the PRIDE study
Section 2: Understa ing the terms used in this guid
Section 3: How does the PRIDE programme work?
Section 4: PRIDE session guide
Section 5: PRIDE profile: information about you
Section 6: Finding a balance
Section 7: People and connections
Section 8: Keeping going
Section 9: Choose your topics

Section 1 of 10
Welcome to the PRIDE study

Save and return to the Dashboard at any time.

This manual is a resource guide which we hope you will find useful and valuable whilst taking part in this programme.

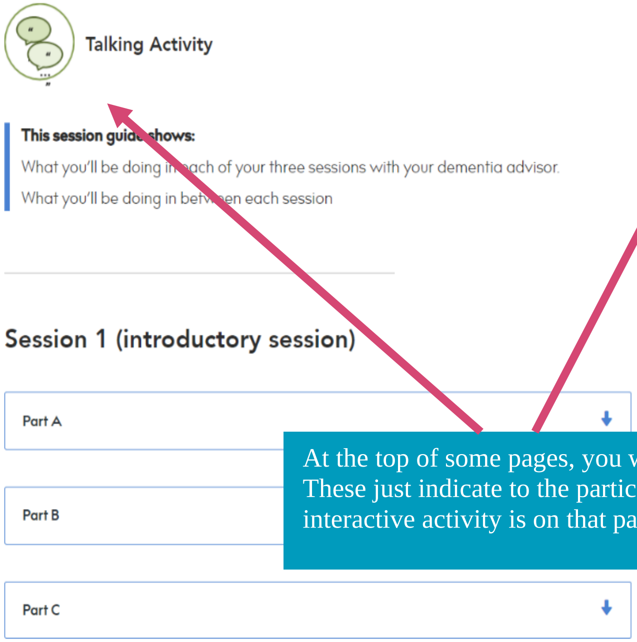
This session will take around 90 minutes to complete. There are multiple activies to complete and a lot resources to read, as well as working with your Advisor and Supporter. Some steps will have icons next to them o indiciate the type of activity that will be completed. We ecommend that you bookmark this site or add it to your avourites to make it easier to access the PRIDE-app in he future.

The side bar will show you which section you are currently in.

PRIDE stands for 'Promoting Independence in Dementia'.

This study is part of a wider project which is looking at ways to help people with a diagnosis of dementia to stay in control of their own lives, stay healthy, contribute to society, and feel valued. We also hope to better understand the experience of ving memory problems, and how people can be helped to tinue to contribute to society. Universities in the UK, Europe d Brazil are our partners. Our funding comes from the nomic and Social Research Council (ESRC), the UK's largest organisation supporting research on economic and social issues. This project is also funded by the National Institute for Health Research (NIHR) Applied Research Collaboration East

Glossary
To move back a page



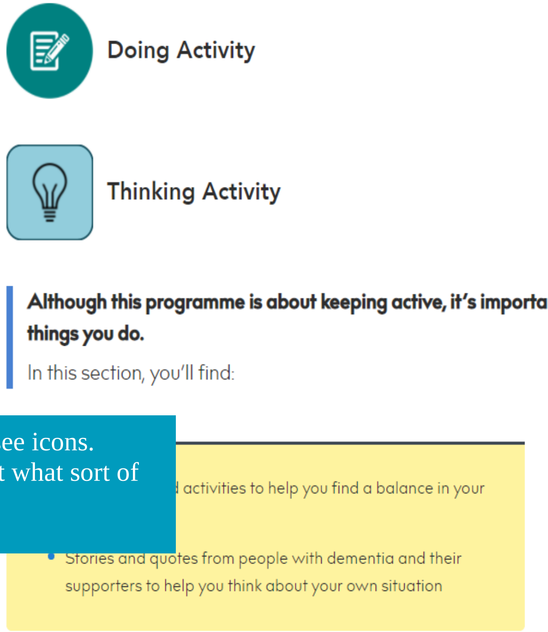
Talking Activity

This session guide shows:

What you'll be doing in each of your three sessions with your dementia advisor.

What you'll be doing in between each session

Session 1 (introductory session)



Doing Activity

Thinking Activity

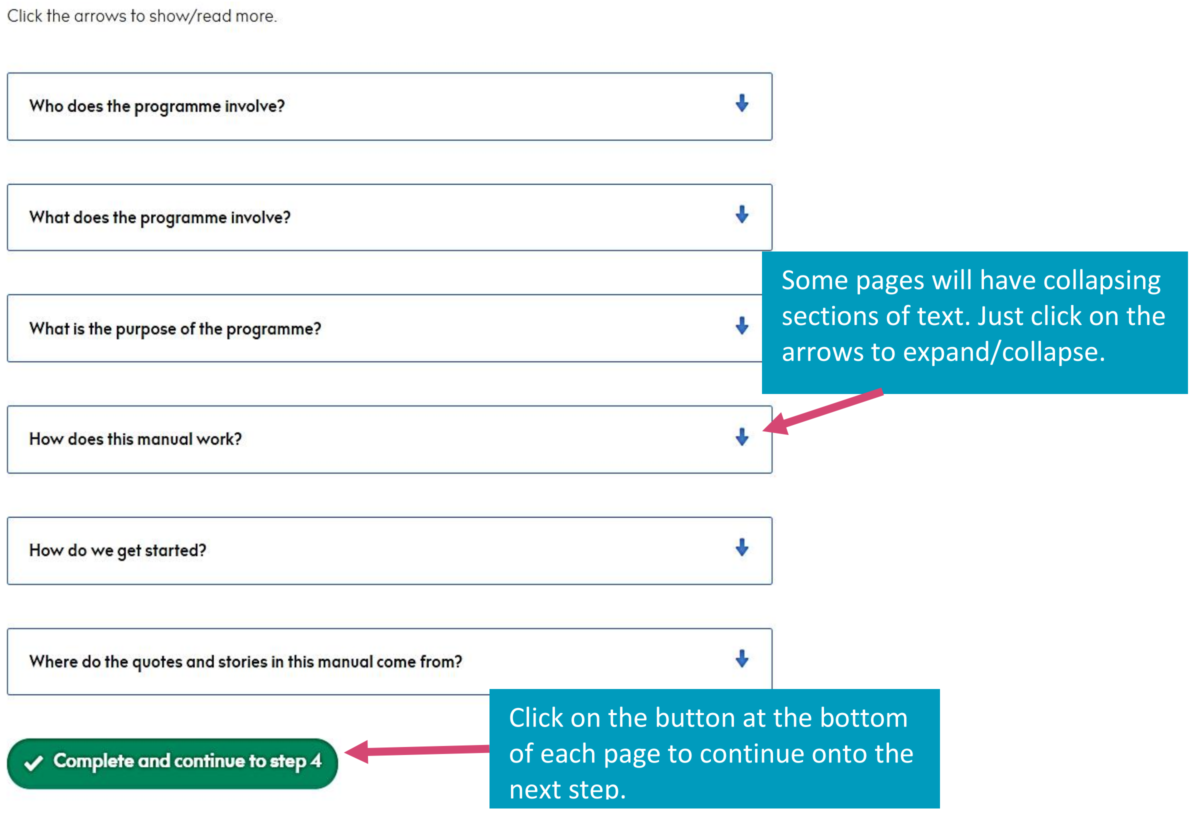
Although this programme is about keeping active, it's important to find a balance in the things you do.

In this section, you'll find:

activities to help you find a balance in your

- Stories and quotes from people with dementia and their supporters to help you think about your own situation

At the top of some pages, you will see icons. These just indicate to the participant what sort of interactive activity is on that page.



Click the arrows to show/read more.

Who does the programme involve? ↓

What does the programme involve? ↓

What is the purpose of the programme? ↓

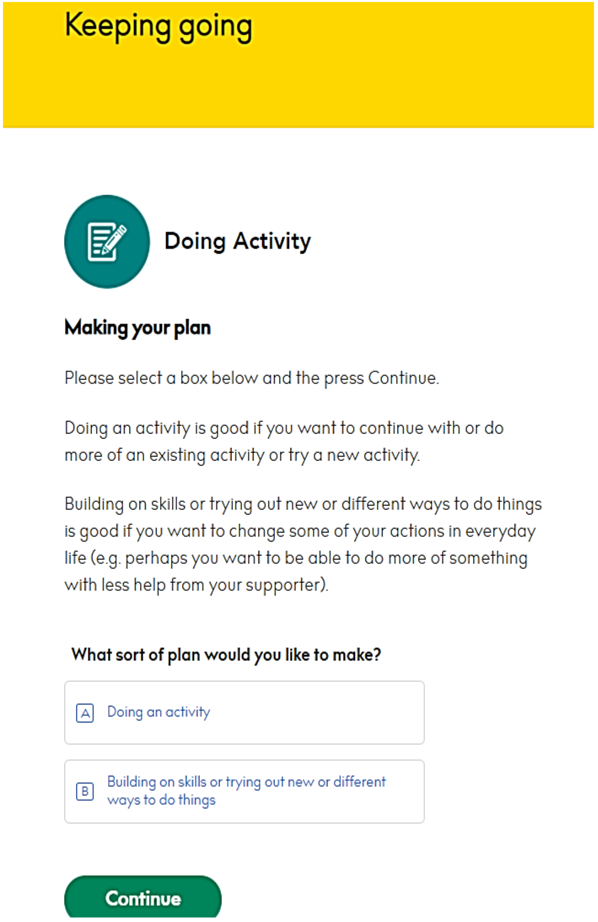
How does this manual work? ↓

How do we get started? ↓

Where do the quotes and stories in this manual come from? ↓

Some pages will have collapsing sections of text. Just click on the arrows to expand/collapse.

Click on the button at the bottom of each page to continue onto the next step.



Keeping going

Doing Activity

Making your plan

Please select a box below and the press Continue.

Doing an activity is good if you want to continue with or do more of an existing activity or try a new activity.

Building on skills or trying out new or different ways to do things is good if you want to change some of your actions in everyday life (e.g. perhaps you want to be able to do more of something with less help from your supporter).

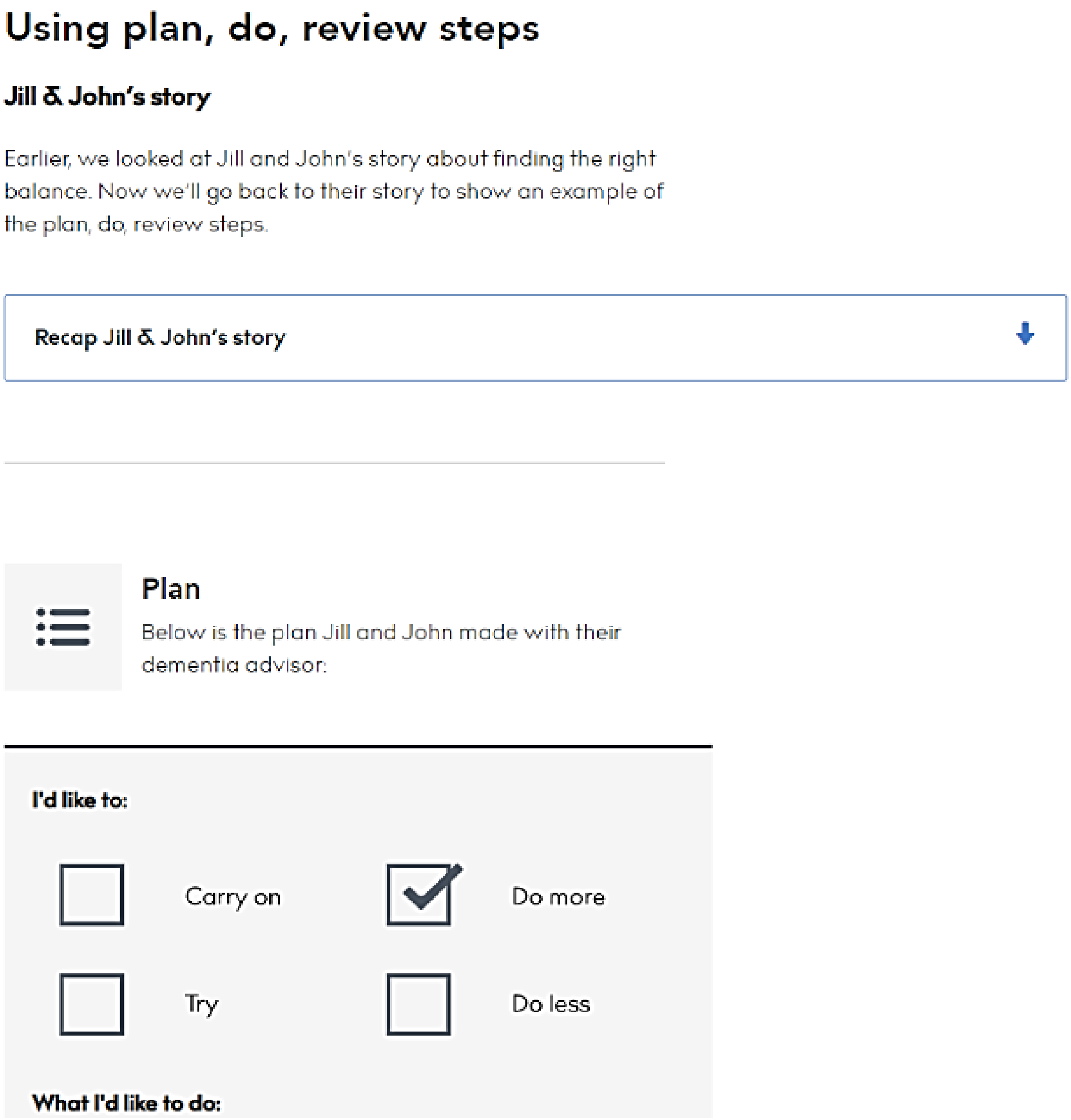
What sort of plan would you like to make?

A Doing an activity

B Building on skills or trying out new or different ways to do things

For some interactive activities, the following pages will provide specific information dependent on participants’ answer.

The Plan, Do, Review technique is discussed through a step-by-step guide. Please familiarize yourself with this technique in order to best support participants in creating their plans.



Using plan, do, review steps

Jill & John's story

Earlier, we looked at Jill and John's story about finding the right balance. Now we'll go back to their story to show an example of the plan, do, review steps.

Plan

Below is the plan Jill and John made with their dementia advisor:

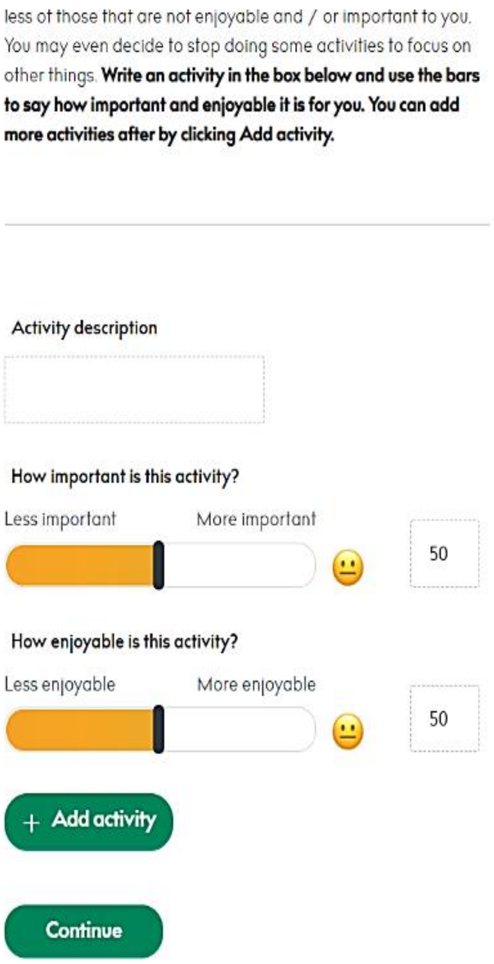
I'd like to:

☐ Carry on ☑ Do more

☐ Try ☐ Do less

What I'd like to do:

Adding an Activity



less of those that are not enjoyable and / or important to you. You may even decide to stop doing some activities to focus on other things. **Write an activity in the box below and use the bars to say how important and enjoyable it is for you. You can add more activities after by clicking Add activity.**

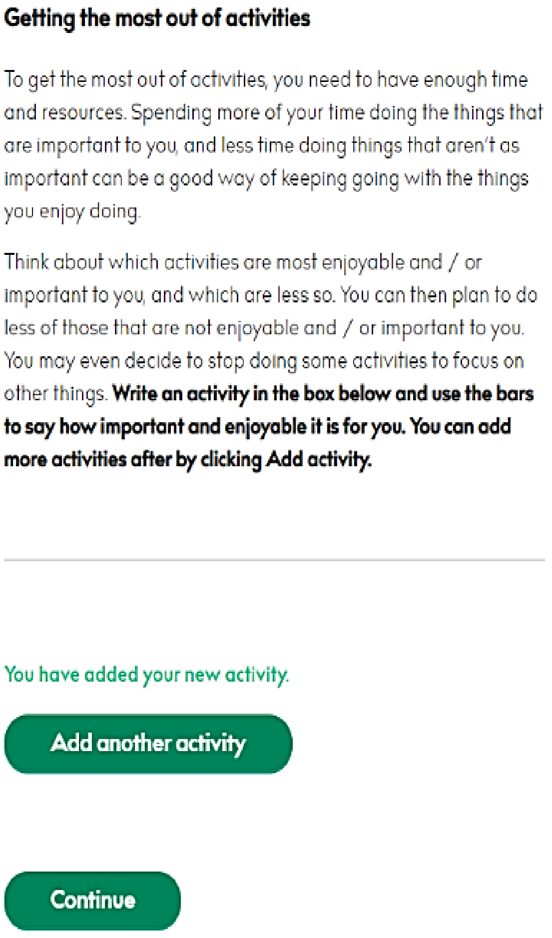
Activity description

How important is this activity?

50

How enjoyable is this activity?

50



Getting the most out of activities

To get the most out of activities, you need to have enough time and resources. Spending more of your time doing the things that are important to you, and less time doing things that aren't as important can be a good way of keeping going with the things you enjoy doing.

Think about which activities are most enjoyable and / or important to you, and which are less so. You can then plan to do less of those that are not enjoyable and / or important to you. You may even decide to stop doing some activities to focus on other things. **Write an activity in the box below and use the bars to say how important and enjoyable it is for you. You can add more activities after by clicking Add activity.**

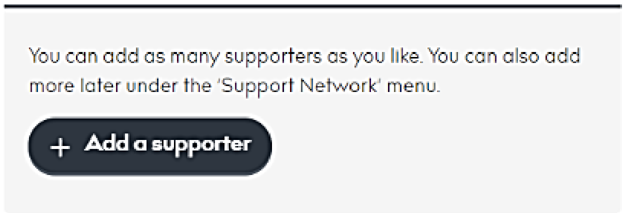
You have added your new activity.

When you reach Step 11 of 26, *Finding a Balance*, please encourage participants to reflect on the activities you have discussed in the previous sections. These will be activities which are important to participants or that will improve their quality of life. However, these should be activities that participants actively want to include in their plans. A mix of more enjoyable and less enjoyable activities, especially if these are important to maintaining independence and a good quality of life, would be ideal.

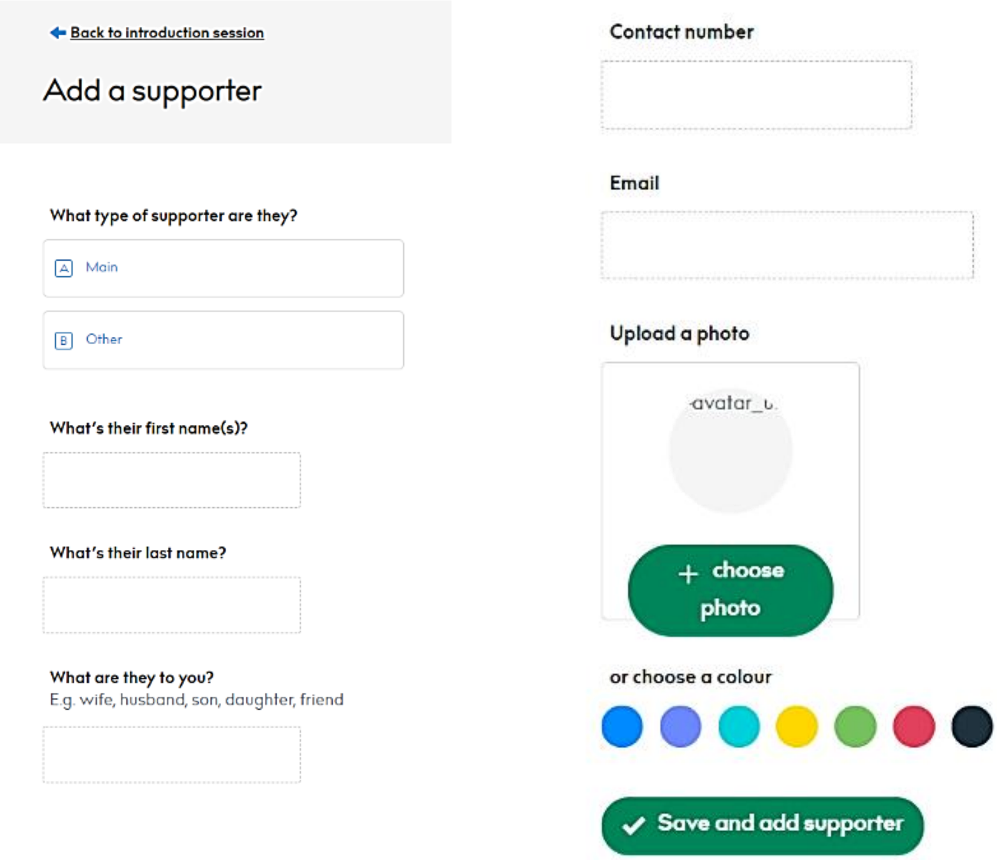
Participants use the bars to show how important/enjoyable the activity is to them. Clicking on ‘Add activity’ will save the activity to their PRIDE-app dashboard. They can add multiple activities at this stage, or add them later through their dashboard.

Adding a Supporter

When you reach Step 14, *People and Connections,* there is an activity which asks participants to add members of their support network. Encourage participants to reflect on their current support system. If there is no support system in place, could participants reach out to family and friends?

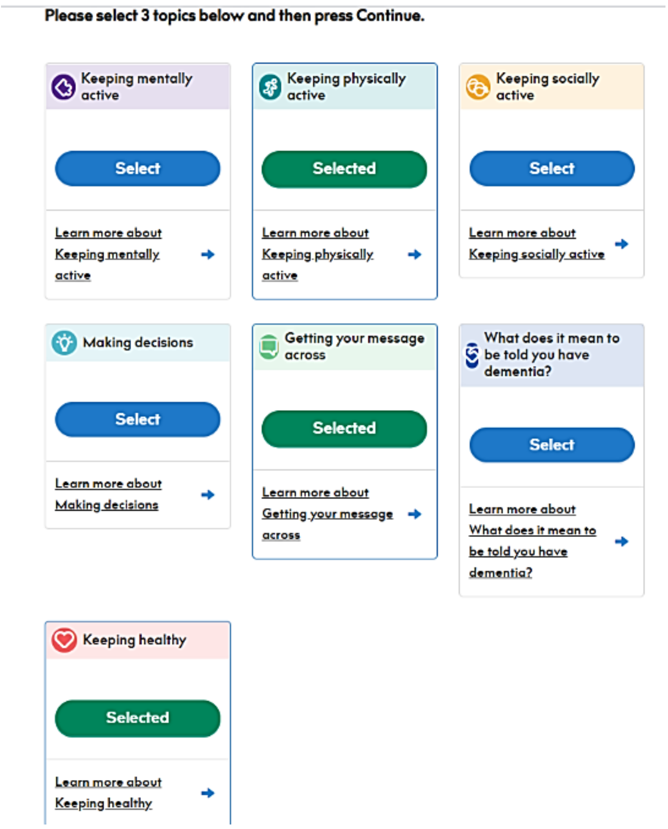


You can add as many supporters as you like. You can also add more later under the ‘Support Network’ menu.



Choosing Topics

At the final stage of the Introduction Session, participants' need to choose three main topics they would like to focus on with their plans. If participants would like to read about each topic, they can do so by clicking on the 'Learn more…' link. Topic choices can be amended later through the Dashboard.



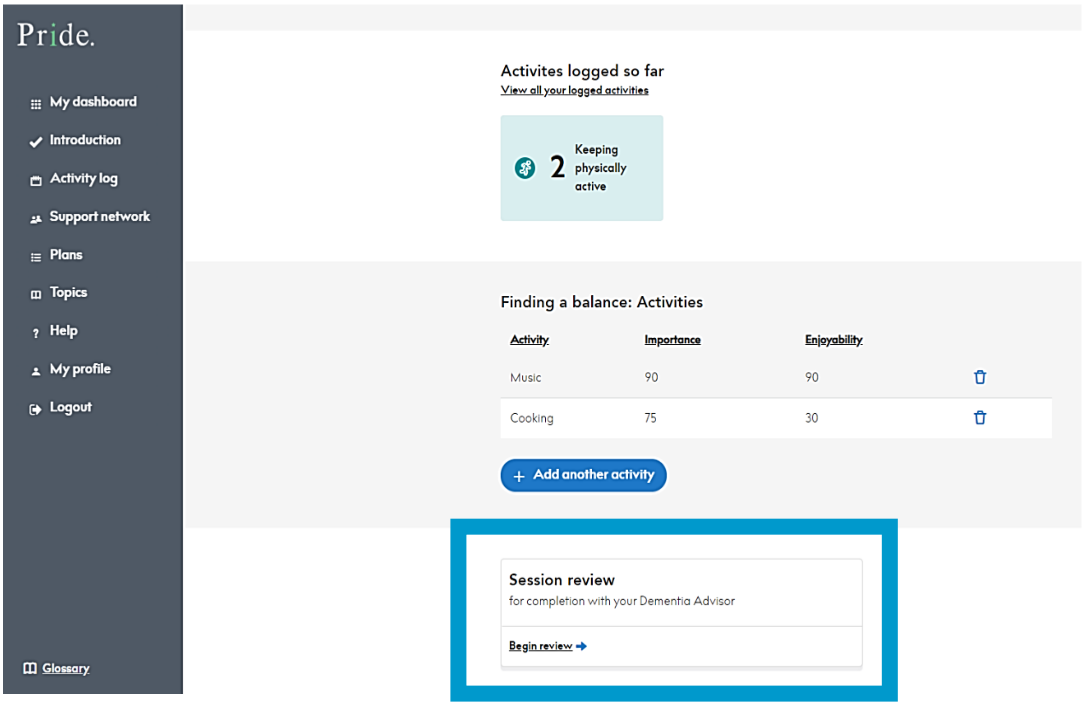
Please select 3 topics below and then press Continue.

Once the topics have been selected, participants will be able to visit their Dashboards.

PLEASE NOTE: If participants revisit the Introduction Session, they will need to go to Step 25 and press continue to get to this page again. Click ‘Go to dashboard’ and this will give them quick access to return to their Dashboard.

Session 2: Review

We would like you to encourage participants to reflect on their progress since the first session. For example, have they done more of an activity, started a new activity, or struggled with an activity?



Activites logged so far

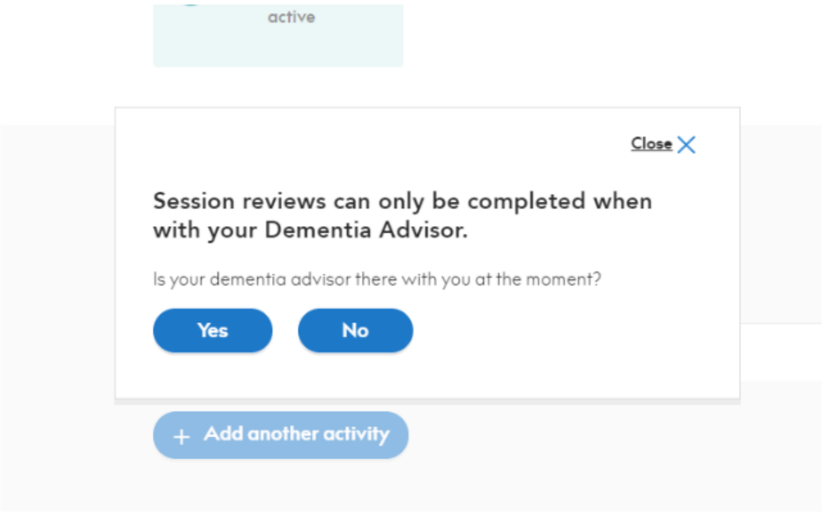
2 Keeping physically active

Finding a balance: Activities

Activity	Importance	Enjoyability
Music	90	90
Cooking	75	30

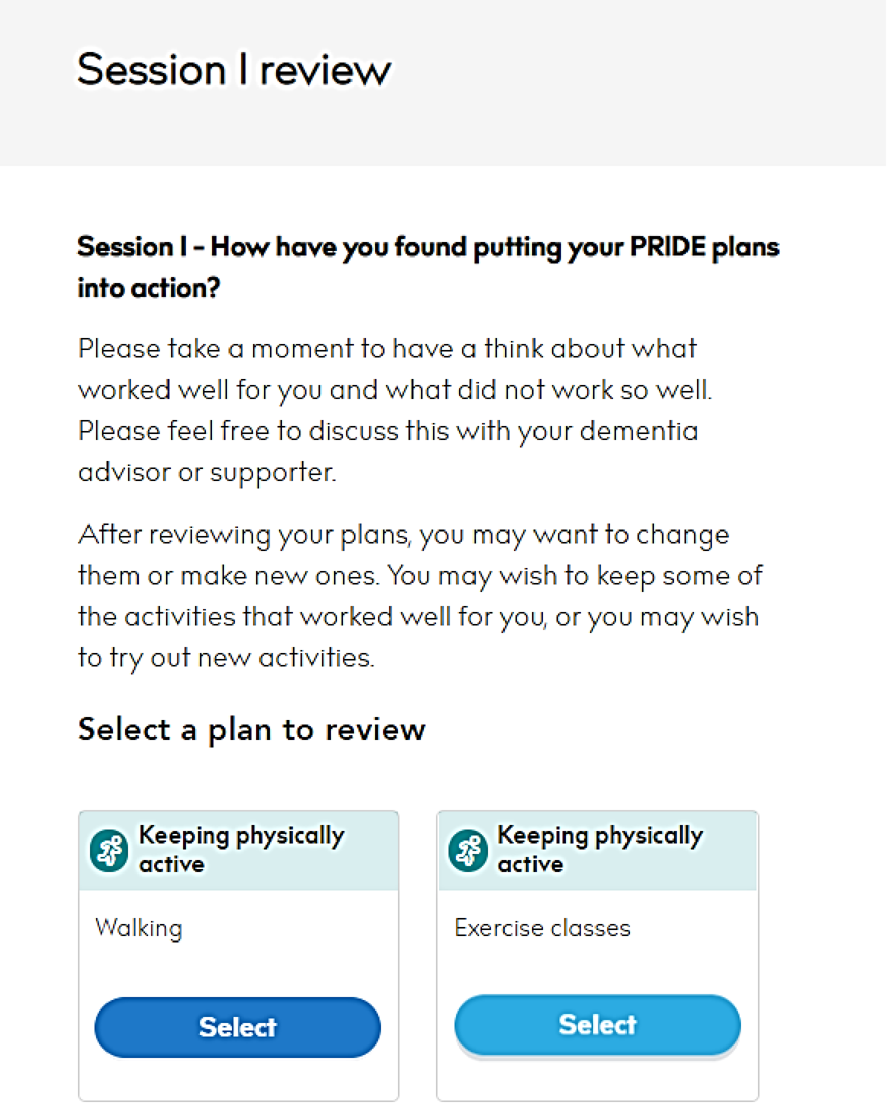
Session review
for completion with your Dementia Advisor

To start the Session 2 Review, participants need to click ‘Begin review’, which is found at the bottom of their Dashboard. They will then have to confirm that you, as their DA, are present.



Session reviews can only be completed when with your Dementia Advisor.

Is your dementia advisor there with you at the moment?



Session I review

Session I - How have you found putting your PRIDE plans into action?

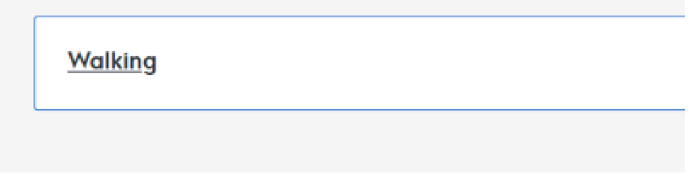
Please take a moment to have a think about what worked well for you and what did not work so well. Please feel free to discuss this with your dementia advisor or supporter.

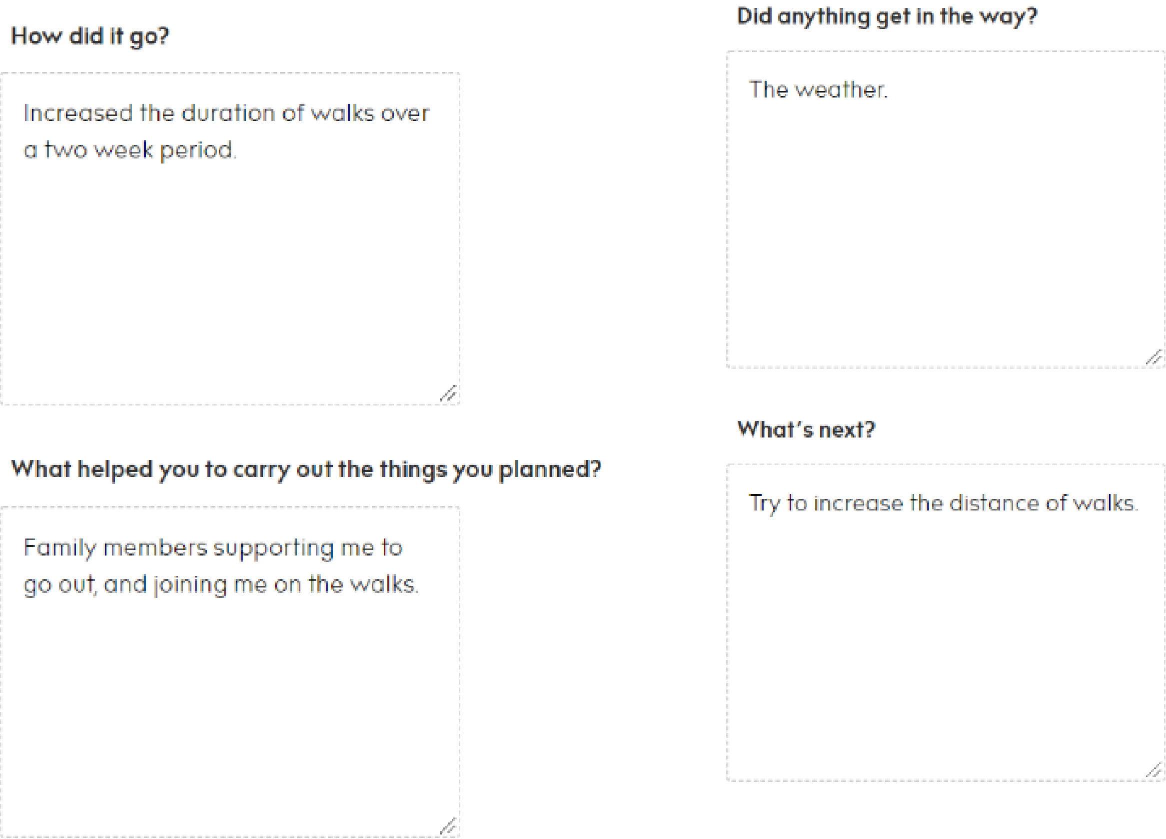
After reviewing your plans, you may want to change them or make new ones. You may wish to keep some of the activities that worked well for you, or you may wish to try out new activities.

Select a plan to review

Participants can then select which plan they would like to review. Please try and review as many plans as possible within Session 2.

Encourage participants to reflect on their progress since the first session and help them complete the boxes.


Walking


How did it go?

Increased the duration of walks over a two week period.

What helped you to carry out the things you planned?

Family members supporting me to go out, and joining me on the walks.

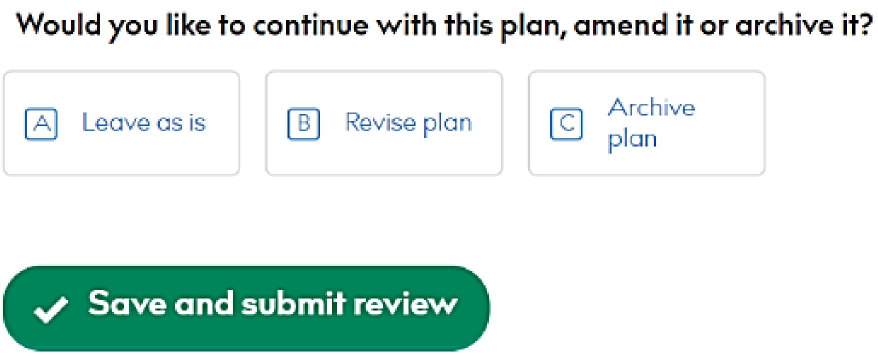
Did anything get in the way?

The weather.

What's next?

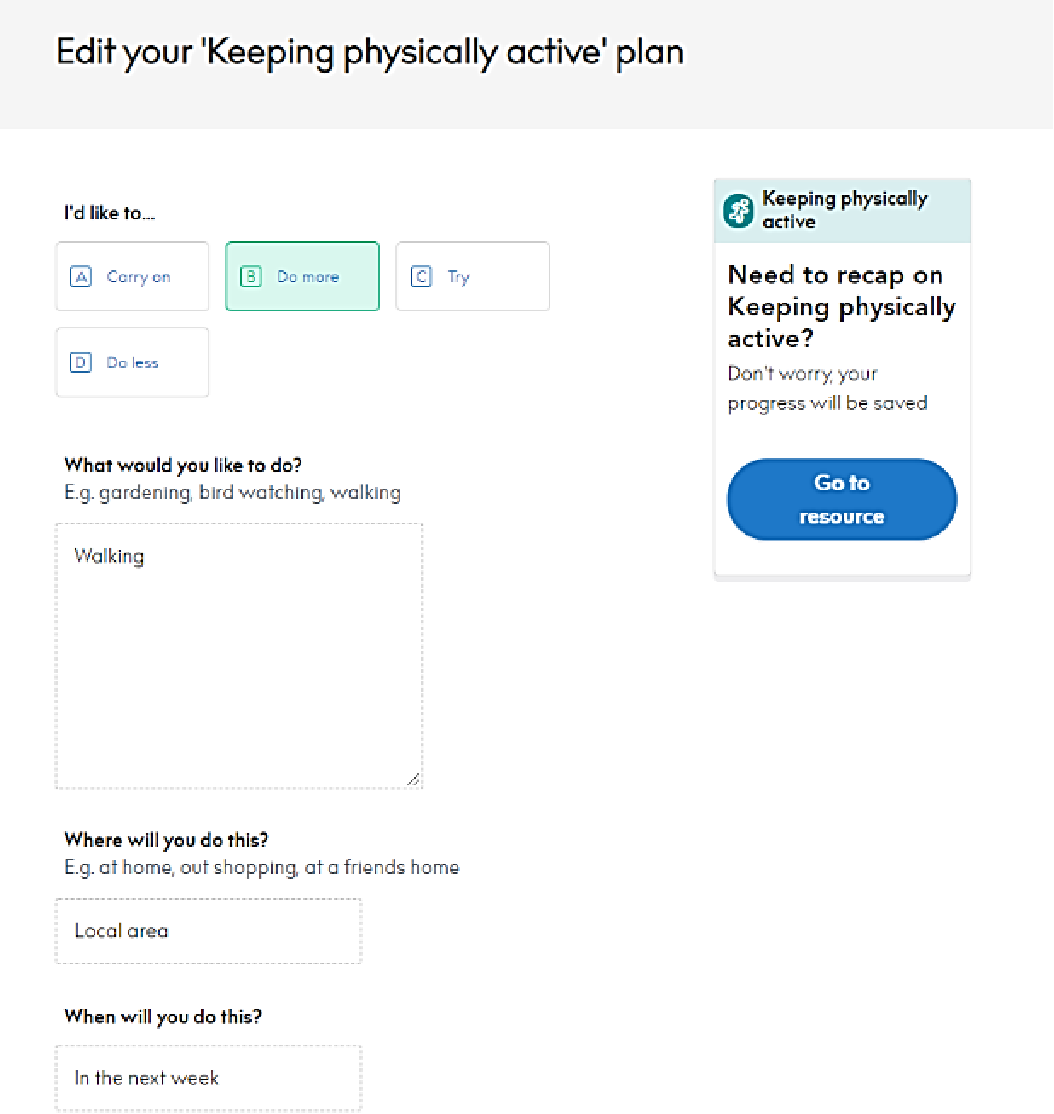
Try to increase the distance of walks.

At the bottom of the review page, participants will be asked whether they would like to leave the plan as it is, revise it, or archive it (if they are happy and feel like they've completed their plan).


Would you like to continue with this plan, amend it or archive it?

If they would like to revise their plans, participants will be shown their original plan and will be able to amend any section.

When they are happy with their revisions, they need to ‘Save and update plan’.



Edit your 'Keeping physically active' plan

I'd like to...

☐ A Carry on
☑ B Do more
☐ C Try
☐ D Do less

What would you like to do?
E.g. gardening, bird watching, walking

Walking

Where will you do this?
E.g. at home, out shopping, at a friends home

Local area

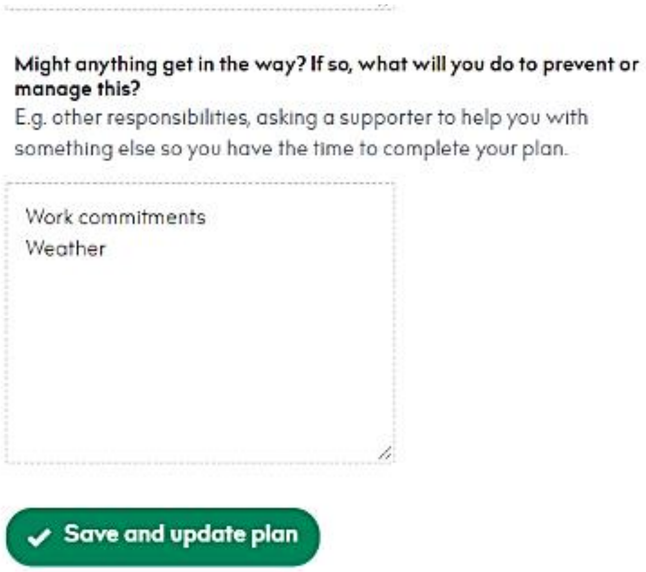
When will you do this?

In the next week

Keeping physically active

Need to recap on Keeping physically active?

Don't worry, your progress will be saved

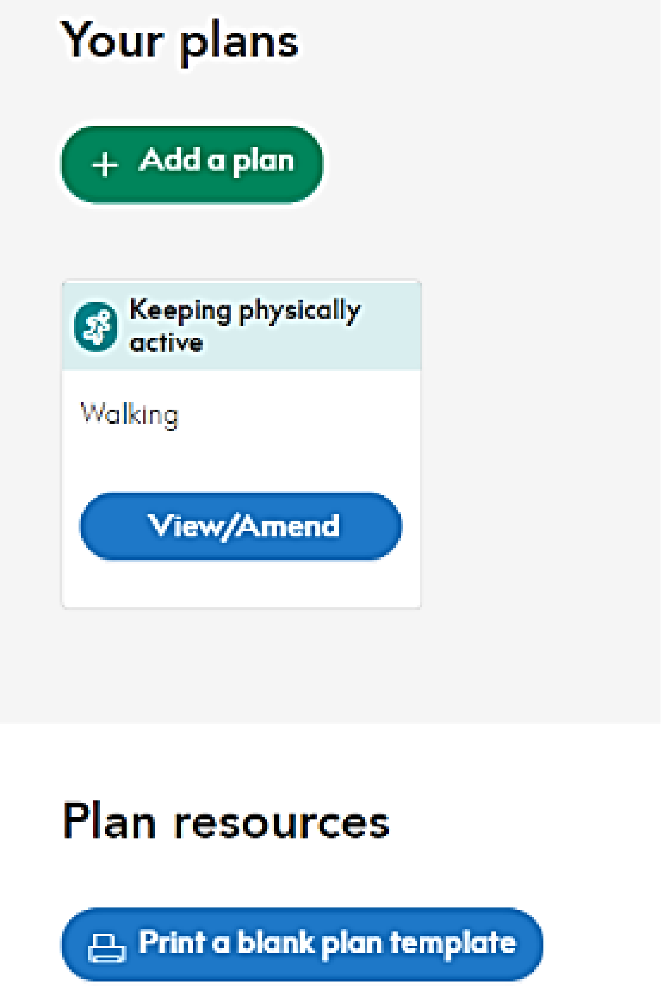


Might anything get in the way? If so, what will you do to prevent or manage this?
E.g. other responsibilities, asking a supporter to help you with something else so you have the time to complete your plan.

Work commitments
Weather

If participants want to change plans outside of the DA review, they can go to Plans and select 'View/Amend' on the plan they want to change.

Participants can also print a weekly activity plan to fill in by hand.



Session 3: Final

The final session will follow a similar structure to the second, using the same ‘Begin review’ link. Follow the same review process, encouraging participants to reflect on their progress and whether they are happy with their plans, want to revise them, or archive them.

As this is your final session together, we would like you to discuss with participants how the Plan, Do, Review technique could continue to help them after the PRIDE-app intervention. You could ask them what has helped them execute their activities, who has supported them, or what barriers have affected their goals. Also, please ensure that participants have a paper copy of any plans they would like to continue to use, as they will only have access to the PRIDE-app for a limited amount of time.

Intervention Session Outline

Session 1: Introduction

Your first session with participants, and supporters if present, will last between 60-90 minutes. This session will provide participants with a brief overview of the aims of PRIDE, complete the core introductory session pages, encourage them to reflect on their daily activities, and introduce the PRIDE-app. We also ask that you explore whether participants feel they have agency in everyday decision-making, and how to create more opportunities for supported but independent decision-making.

If possible, please contact your participants prior to the session to introduce yourself and collect their details in order to create their PRIDE-app accounts. However, if this is not possible, please complete this stage at the beginning of your first session.

The general content of the Introduction Session will run as follows:

- Aim of PRIDE
- Complete PRIDE profile
- Core topics
    - *Finding a Balance*
    - *People and Connections*
    - *Keeping Going*
- Personalise topics – Participants will choose three main topics to focus on
- Familiarisation with PRIDE-app

- Login process
- Adding social contacts
- Activity plans

During the first session, DAs provide an overview of the PRIDE intervention and information on ‘Finding a Balance’, ‘Social Connections’ and ‘Keeping Going’. We ask you to encourage participants to identify important aspects of their current daily lives and discuss how to maintain or enhance the activities/routines they value, as well as identifying new activities they might benefit from. Participants will need to choose three topics and plan at least one activity they want to work on, which will be reviewed in the later sessions. Topics covered within the app are *Keeping Mentally Active; Keeping Physically Active; Keeping Socially Active; Making Decisions; Getting Your Message Across; Receiving a Diagnosis;* and *Keeping Healthy*.

Finding a Balance

Encourage the participant to think about the resources and time they have available when planning activities:

- Finding different ways to take part in activities
- Rest and relaxation
- Having a routine; plan a “to do” list, plan day or week ahead
- Setting reminders; keep diaries, notepads or sticky notes
- Getting the most out of activities

People and Connections

Encourage participants to map their current social network to identify the strengths and the areas where they may need extra support:

- What is a support network?
- Why is it important to have a support network?
- Who is/might be in their support network?
- How can people in a support network help you?
- Complete support network activity

Keeping Going

Encourage them to consider ways to keep active, or be more active and involved in activities:

- Discuss ways to remain active and introduce the types of activities
- Encourage them to think about what they can do independently
- Provide examples of how other people keep going

Please provide your contact details, should participants need to contact you. Also remind them that they can contact the University of Nottingham team. This team will also contact participants in between sessions to encourage continued use of the intervention.

Session 2: Review

In the second intervention session, 2-4 weeks following the first, progress will be reviewed. You will continue to encourage participants to reflect on their progress and create/amend specific plans for activities or actions that will promote their independence. Choices and activities may be refined according to the participant and supporters’ experience of implementation and any needs which may have arisen since the first session. Barriers that prevented implementation of plans made in the first session should also be discussed, and solutions explored. New options may also be set within the lifestyle domain topics.

Content for Session 2 will comprise of:

- Progress since last session and provide positive feedback
- What worked/helped them achieve goals, and what hindered
- How could barriers be overcome
- Discuss satisfaction with plan and if it needs changing
- Record on review page

It's important to encourage participants and supporters to continue to put their plans into practice in between sessions.

Session 3: Final

For the final session, held 2-4 weeks after the second, participant progress will be reviewed again, and a maintenance plan exploring how PRIDE could continue to support them after the study will be developed to encourage long-term change.

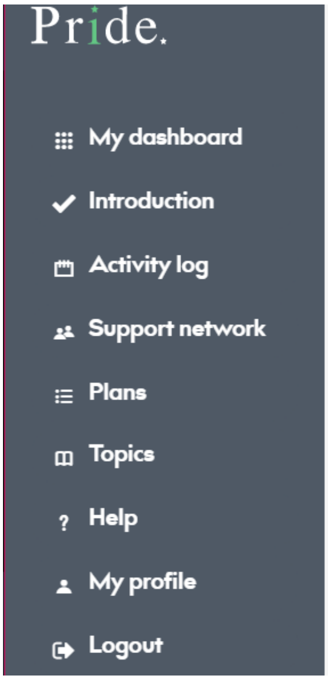
- Progress since last session
- Discuss how PRIDE could continue to help them in the future - PRIDE's ''Plan, do, review'' steps are a practical approach to help continue their everyday activities
- Encourage them to maintain a normal routine, social contacts, and use the steps when planning new activities

Plan, Do, Review

The most important technique to cover with your participants across all sessions is Plan, Do, Review. Work with participants to create specific plans for activities or actions that will promote their independence. The participant and supporter will put their plans into practice in between sessions. Ask them to record their activities in the ‘Log an activity’ section of the PRIDE-app. Some ideas of what you could cover in the sessions:

- Help participants think about the action they would like to take or the activity they would like to do that would promote their independence.
- Plan activities participants would like to work on based on their topic choices
  - Where their activity will take place
  - When they can get going with their action plan or start making changes
  - How they can do things in different ways
- Explain to participants and supporters how to record activities between sessions

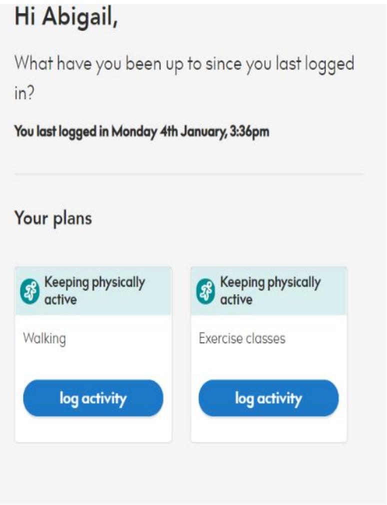
PRIDE-app Dashboard



PRIDE-app Dashboard navigation bar

This will always be found on the left-hand side of the screen, and can be used to move between sections, revisit the Introductory content, access the seven topics, or to logout.

If participants want to return to the Dashboard at any point, they can click on ‘My dashboard’.



Hi Abigail,

What have you been up to since you last logged in?

You last logged in Monday 4th January, 3:36pm

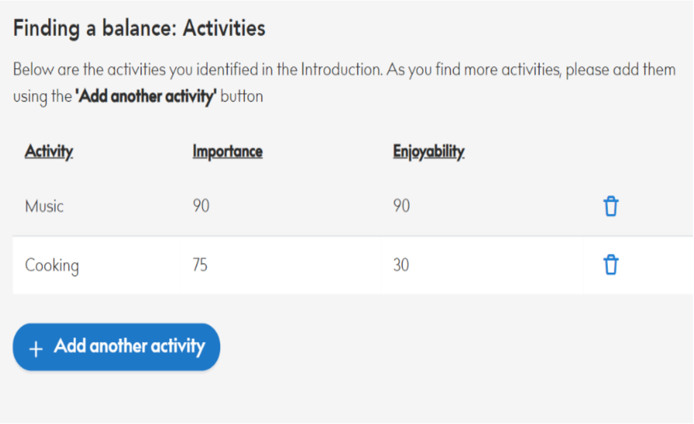
Your plans

Keeping physically active	Keeping physically active
Walking	Exercise classes

Activites logged so far

View all your logged activities

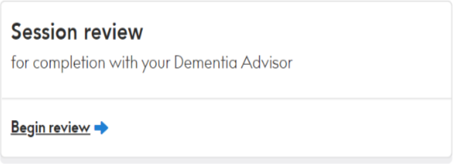
2	Keeping physically active



Finding a balance: Activities

Below are the activities you identified in the Introduction. As you find more activities, please add them using the **'Add another activity'** button

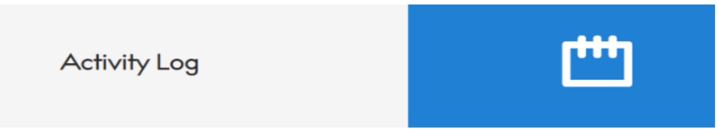
Activity	Importance	Enjoyability
Music	90	90
Cooking	75	30

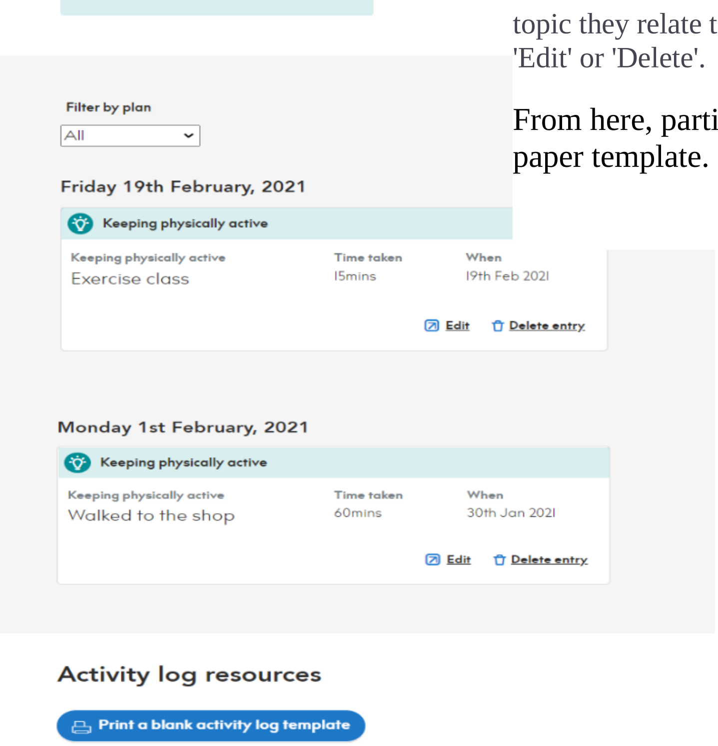


Session review

for completion with your Dementia Advisor

The Dashboard will show the last time a participant logged in; any plans they have set; where they can log an activity; their current activities and how to add more; and complete their review.




2 Keeping physically active

Filter by plan
All

Friday 19th February, 2021

Keeping physically active

Keeping physically active	Time taken	When
Exercise class	15mins	19th Feb 2021

Monday 1st February, 2021

Keeping physically active

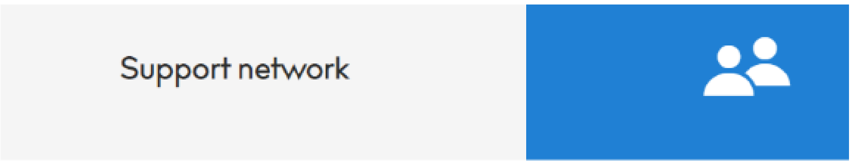
Keeping physically active	Time taken	When
Walked to the shop	60mins	30th Jan 2021

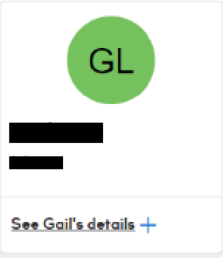
Activity log resources

Activity Log

This will show the events logged so far and the topic they relate to. Each will have the option to 'Edit' or 'Delete'.

From here, participants can also print a blank paper template.




GL

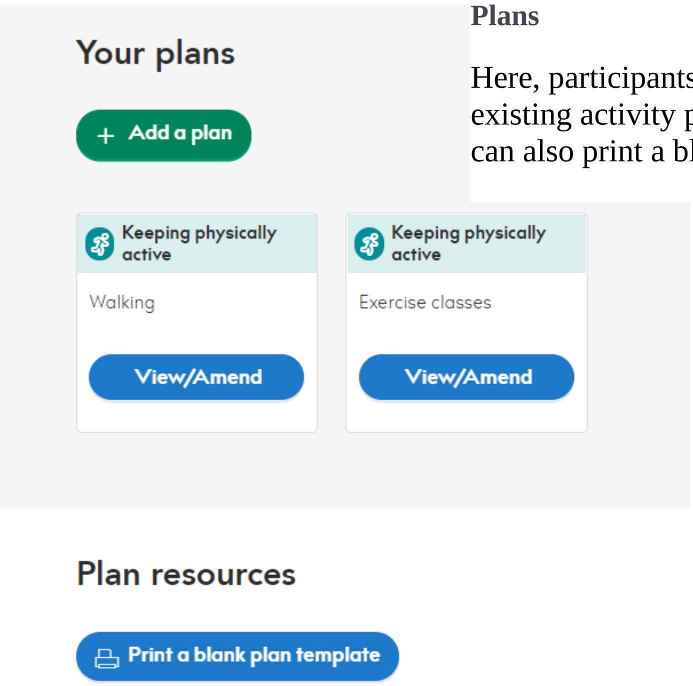
[redacted]

Support Network

This page will show the details of the supporter added during the Introductory Session.
More supporters can be added through Step 14 of the Introductory Session at any time.

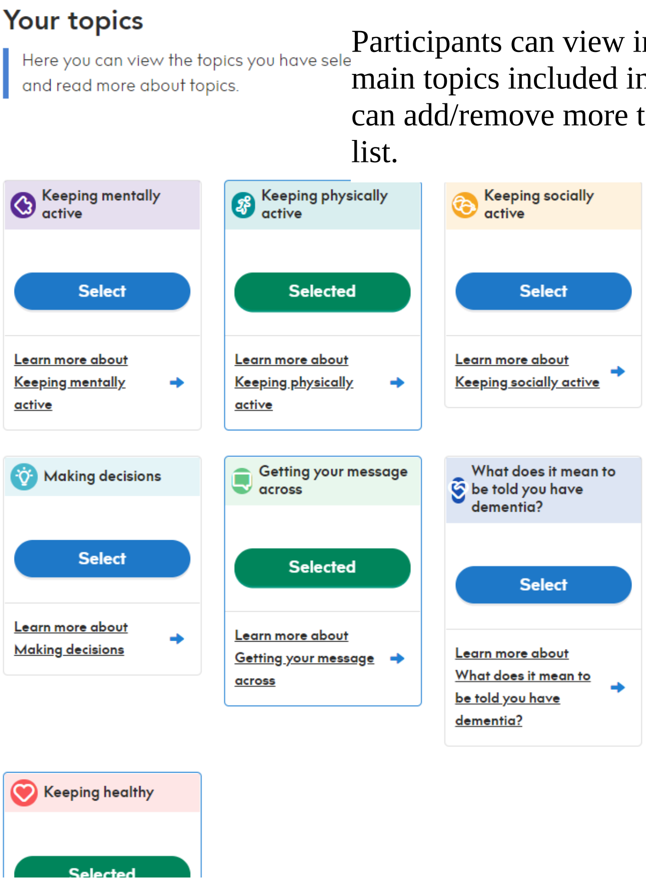
Plans

Here, participants can view and amend existing activity plans or add a new one. They can also print a blank paper template.

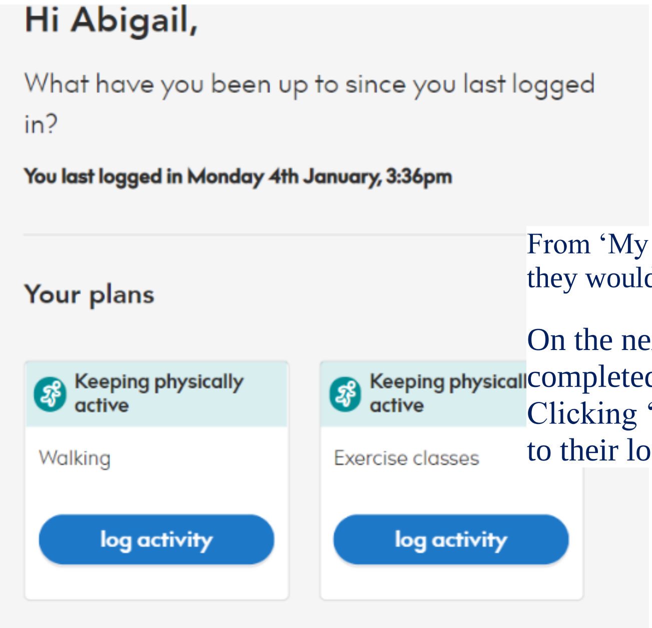


Topics

Participants can view information for the seven main topics included in the PRIDE-app. They can add/remove more topics to their selected list.


Here you can view the topics you have sele
and read more about topics.

Logging an Activity



Hi Abigail,

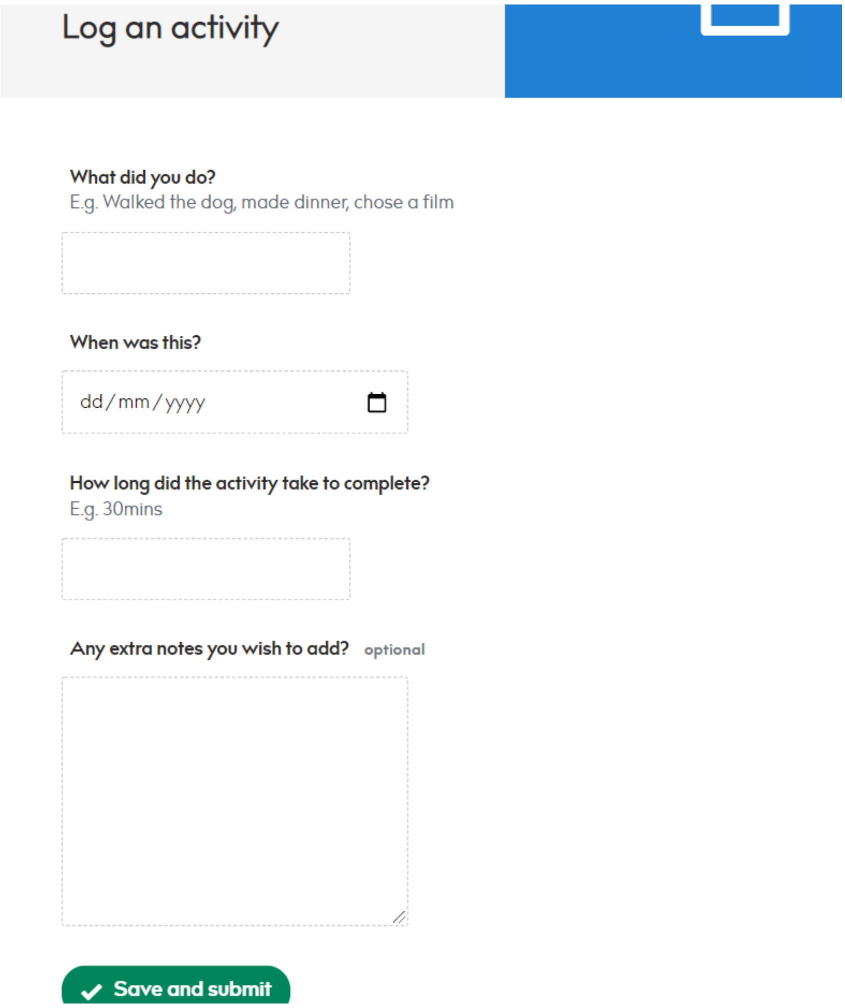
What have you been up to since you last logged in?

You last logged in Monday 4th January, 3:36pm

Your plans

From ‘My dashboard’, participants select the plan they would like to log an activity for.

On the next page, they fill in what activity they completed, when, and how long the activity took. Clicking ‘Save and submit’ will add that activity to their log.



Log an activity

What did you do?
E.g. Walked the dog, made dinner, chose a film

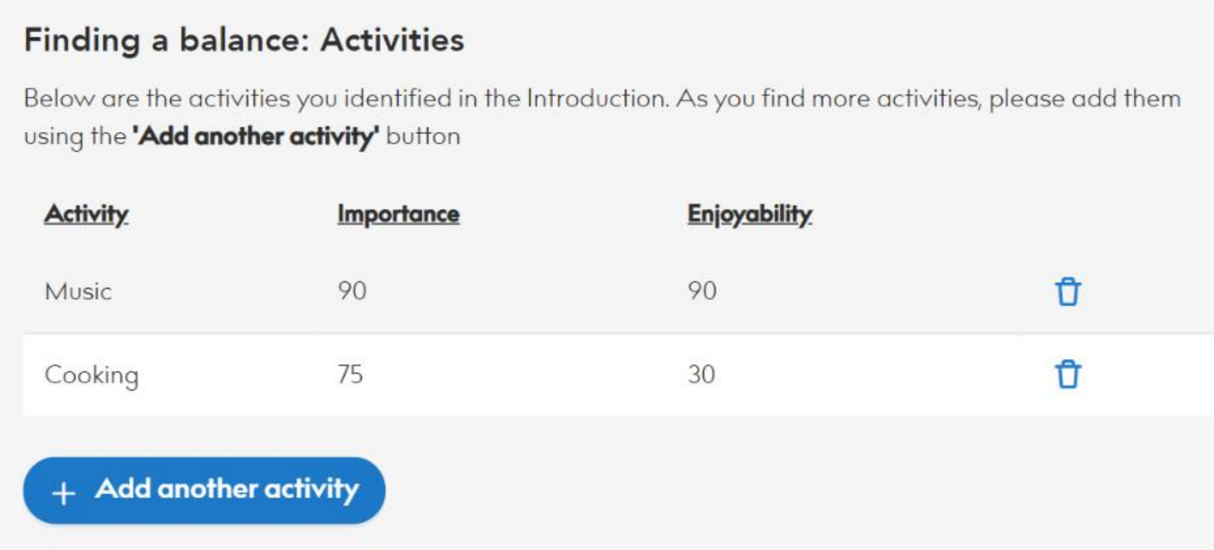
When was this?

dd/mm/yyyy

How long did the activity take to complete?
E.g. 30mins

Any extra notes you wish to add? optional

Adding Another Activity



Finding a balance: Activities

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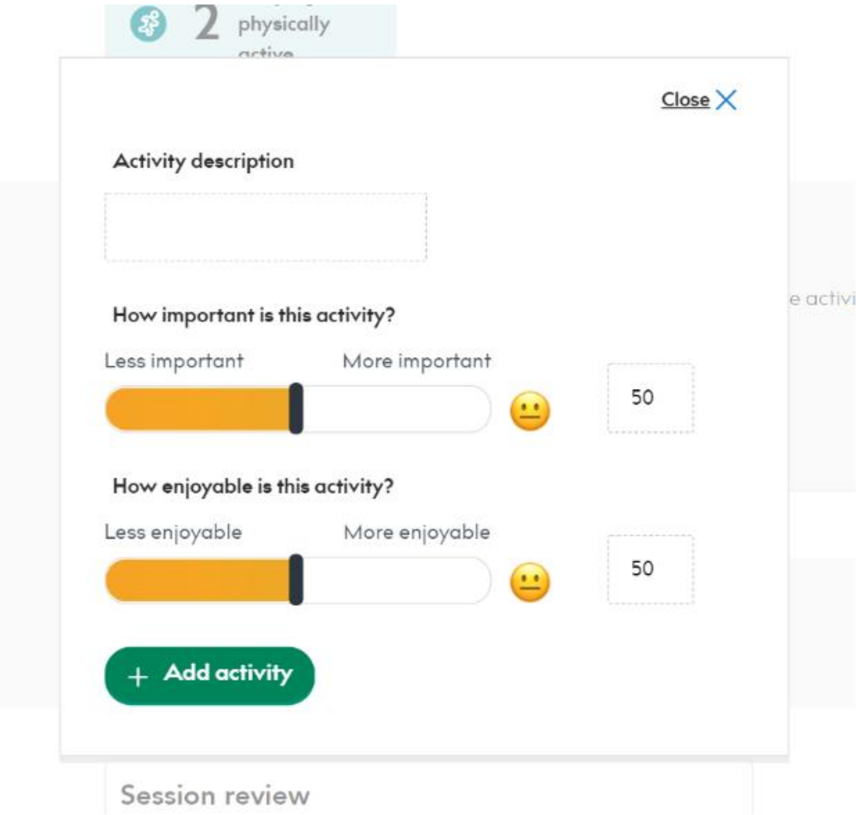
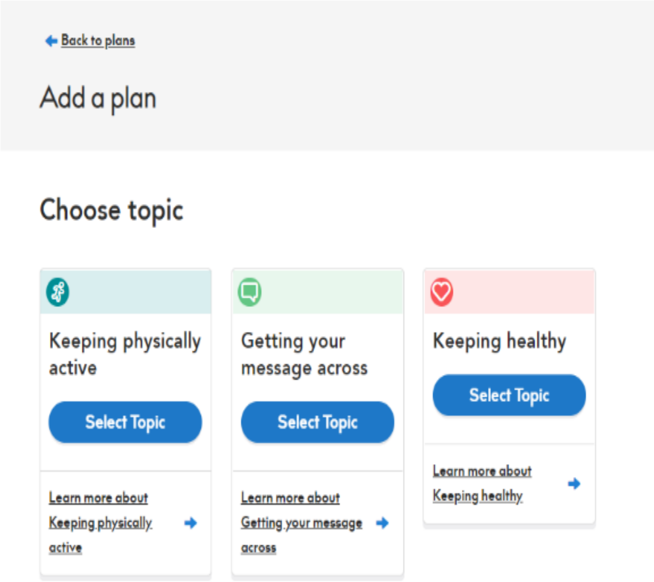
Activity	Importance	Enjoyability
Music	90	90
Cooking	75	30

Clicking on '+Add another activity' will bring up a box. Participants type in the activity and use the sliding bars to increase/decrease the importance and level of enjoyment. Clicking on 'Add activity' will add it to the Dashboard list.

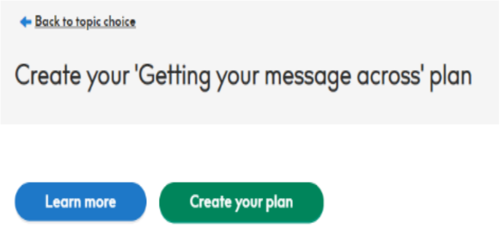


Adding a Plan



Add a plan

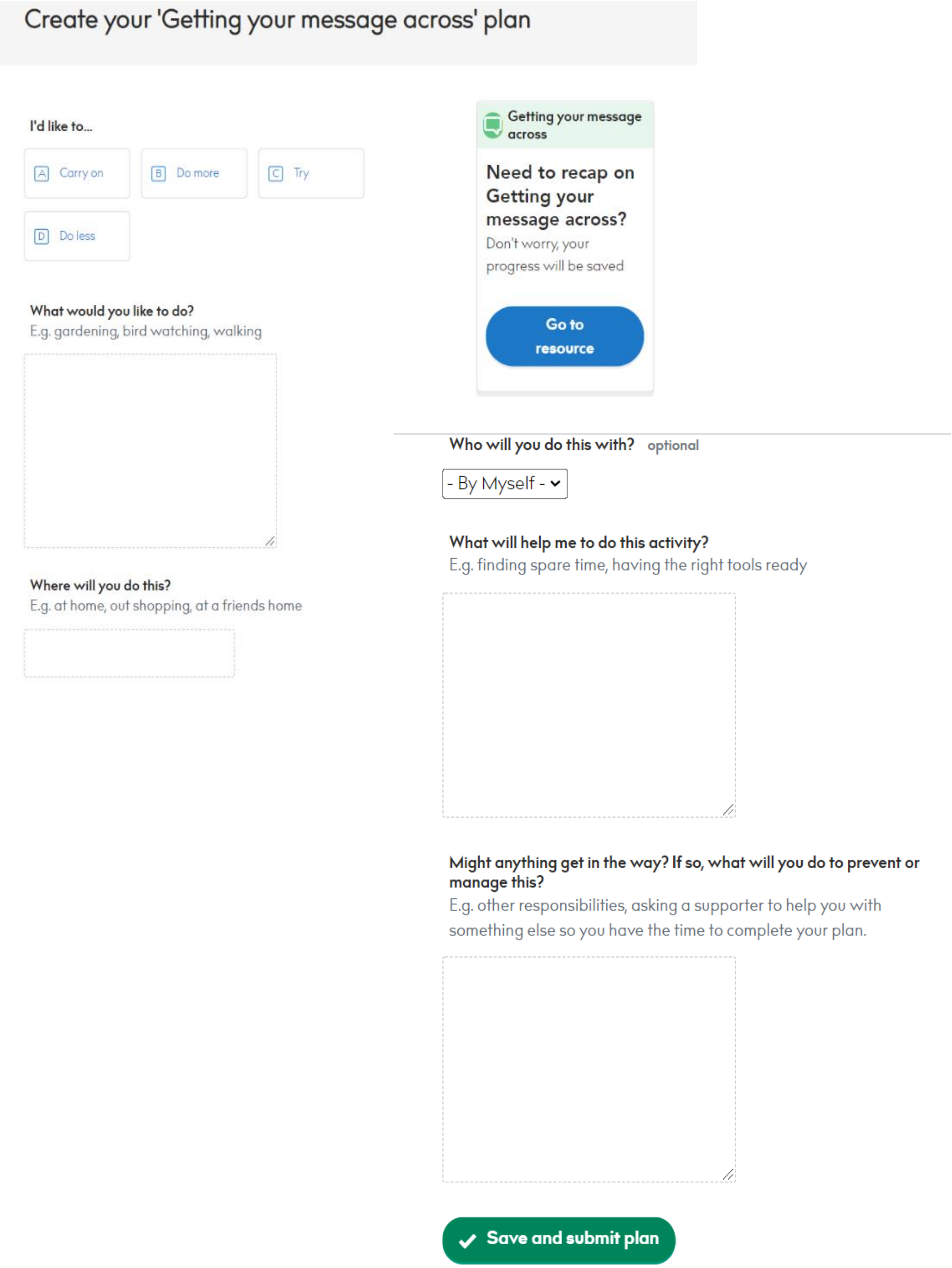
Choose topic



Create your 'Getting your message across' plan

From the Plans page, click '+Add a plan'. Participants then select which topic they would like to create a plan for.

Participants fill in the plan, selecting whether they would like to carry on, try, do more or do less of an activity. They can write where they can execute this activity, the facilitators, and potential barriers. Once completed, click on 'Save and submit plan'.



Create your 'Getting your message across' plan

I'd like to...

- ☐ A Carry on
- ☐ B Do more
- ☐ C Try
- ☐ D Do less

What would you like to do?
E.g. gardening, bird watching, walking

Where will you do this?
E.g. at home, out shopping, at a friends home

Getting your message across

Need to recap on Getting your message across?
Don't worry, your progress will be saved

Go to resource

Who will you do this with? optional
- By Myself -

What will help me to do this activity?
E.g. finding spare time, having the right tools ready

Might anything get in the way? If so, what will you do to prevent or manage this?
E.g. other responsibilities, asking a supporter to help you with something else so you have the time to complete your plan.

✓ Save and submit plan

Fidelity Checklists

Measuring fidelity is an important part of understanding whether an intervention works and how it is best delivered. You will be asked to complete one fidelity checklist per intervention session per participant. These can be completed when, or just after, delivering the session. The checklist will list core content identified for intervention training and have three response levels for each stage of delivery: 'completed', 'partially completed', and 'not completed'. DAs will have the option to provide more detail as to why a stage may or may not have been completed. These can be emailed back to pride-app@nottingham.ac.uk.

You will also be asked to provide participants with their checklists. We recommend emailing the relevant session checklist before your session, so participants have immediate access to the checklist. These are completed after each session, and participants can either send them to you to forward on or send directly to pride-app@nottingham.ac.uk. Please remember to remind participants to complete their checklists as soon as possible after your sessions. We also ask that if participants send their checklists to you to forward to us, you do not look at their responses. Please respect participants' confidentiality.

Interviews

We would like to invite up to 10 DAs to complete an interview following their role in the study. This is to gather qualitative feedback on the delivery of the PRIDE-app and give people the opportunity to voice their thoughts/experiences. The interview is optional and when you sign the study consent form, there is a clause included re the interview. If you register your interest, it does not mean you have to participate with an interview, only that you will be invited nearer the time. We are keen to hear your experiences and use your feedback to inform and improve future research. Please know that your participation is entirely voluntary, and any interview data used in publications will be completely anonymous.

Contact

- Contact information: pride-app@nottingham.ac.uk
- Mobile: **07890 021703**

Document checklist

Please double check to ensure you have received/access to the following documents:

☐ This handbook (v1.0)

☐ Facilitator Information Sheet (v1.0)

☐ Facilitator Consent Form (v1.0)

☐ Fidelity Checklist - Session 1 (v1.0)

☐ Fidelity Checklist - Session 2 (v1.0)

☐ Fidelity Checklist - Session 3 (v1.0)

☐ Participant Checklist - Session 1 (v1.0)

☐ Participant Checklist - Session 2 (v1.0)

☐ Participant Checklist - Session 3 (v1.0)

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9.5 Fidelity checklists

The Dementia Advisor checklist guidelines

What are the checklists for?

Nobody ever delivers all of a program. By completing the checklists, you help us better understand what components of PRIDE-app have and have not been delivered and the reasons for this.

Please complete a checklist immediately or as soon as possible after each session and email it to Abigail Lee at the University of Nottingham (abigail.lee1@nottingham.ac.uk).

How do I fill out the checklists?

- There are three checklists, one for each session.
- Please record the site and participant ID and date on the top of the checklist.
- For every item on the checklist, please tick whether it was:
  - Done
  - To some extent
  - Not done
- If ‘not done’ or ‘to some extent’, it would be helpful to let us know why in the ‘reason for not delivering’ column. For example: running out of time or forgetting.

Please complete this form as soon as possible after delivering the session. The responses are for research purposes and will not be seen by participants. Thank you.

<table>
<tr><td colspan="6">PRIDE-app: First Session (Introduction)</td></tr>
<tr><td colspan="6">Site ID: DA ID: Participant ID: Date:</td></tr>
<tr><td colspan="2" rowspan="2">SESSION ACTIVITIES</td><td colspan="3">Please tick</td><td rowspan="2">If not done or done to some extent, please give a brief reason for not delivering (e.g. ran out of time, forgot)</td></tr>
<tr><td>Done</td><td>To some extent</td><td>Not done</td></tr>
<tr><td></td><td>1. Explained what the PRIDE programme is and what it will involve.</td><td></td><td></td><td></td><td></td></tr>
</table>

Initial PRIDE activities	2. Showed the participant how to access and navigate the PRIDE-app					
	3. Helped complete the PRIDE profile.					
	4. Finding a balance	a. Provided information on how to find a balance with activities.				
		b. Helped the participant to think about which activities they find important and enjoyable using the interactive boxes.				
	5. How others	a. Provided information on how other people could help.				

	can help	b. Encouraged the participant to describe their current social connections.				
		c. Provided examples of how other people can.				
	6. Keeping going	a. Provided information on how to choose activities to keep going.				
		b. Provided examples of how others keep going.				
	7. Asked the participant to choose three topics to work on.					

Plan	8. Helped the participant to set an activity goal.					
	9. Chosen topics	a. Provided relevant resources for topic(s) chosen from PRIDE-app and own sources.				
		b. Discussed in relation to the participant (*Please turn over and provide details*).				
	10. Made at least one plan (including where, when, and how, and who could help).					

	11. Encouraged the participant to think about things that might help their plan(s), identified potential problems, and ways to solve them.				
Do	12. Showed the participant how to log their activity plan and record progress on the PRIDE-app between sessions.				
Support	13. Gave positive feedback.				
	14. Gave the opportunity to ask questions.				
	15. Provided contact details and ways to seek support.				
Next Step	16. Set a time and date for the next session.				

Session 1: Please complete for session activity 8 only.

For the topic that your participant chose to work on, please tick what was done.

If anything else was done, please provide details in the space below.

Provided information, assessed situation, and identified challenges					
Topic	Provided information on the benefits associated with it	Provided information on how dementia can affect it	Assessed participant's current style (decision making/ communication)	Identified potential challenges	Provided information on resources
1.Keeping mentally active					
2. Keeping physically active					
3. Keeping socially active					
4. Making decisions					

5. Getting your message across					
6. Receiving a diagnosis					
7. Keeping healthy					

Provided examples and tips						
Topic	Provided instructions on how to do it	Provided example activities for this topic	Provided examples of how others do it	Provided tips on how others can provide support	Provided example of how others overcome challenges	Provided tips to overcome challenges
1.Keeping mentally active						
2. Keeping physically active						
3. Keeping socially active						
4. Making decisions						

5. Getting your message across						
6. Receiving a diagnosis						
7. Keeping healthy						

Anything else:

The Dementia Advice Worker checklist guidelines

What are the checklists for?

Nobody ever delivers all of a program. By completing the checklists, you help us better understand what components of PRIDE-app have and have not been delivered and the reasons for this.

Please complete a checklist immediately or as soon as possible after each session and email it to Abigail Lee at the University of Nottingham (abigail.lee1@nottingham.ac.uk).

How do I fill out the checklists?

- There are three checklists, one for each session.
- Please record the site and participant ID and date on the top of the checklist.
- For every item on the checklist, please tick whether it was:
  - Done
  - To some extent
  - Not done
- If ‘not done’ or ‘to some extent’, it would be helpful to let us know why in the ‘reason for not delivering’ column. For example: running out of time or forgetting.

Please complete this form as soon as possible after delivering the session. The responses are for research purposes and will not be seen by participants.

Thank you.

PRIDE-app: Second Session					
Site ID: DA ID: Participant ID: Date:					
SESSION ACTIVITIES		**Please tick**			**If not done or done to some extent, please give a brief reason for not delivering (e.g. ran out of time, forgot)**
		Done	To some extent	Not done	
Review	1. Asked the participant about their progress since the last session.				
	2. Discussed what helped and what got in the way of participant's progress.				

	3. If problems were identified, discussed ways to overcome them.					
	4. Discussed and changed plan if needed.					
	5. Recorded review using the PRIDE-app.					
	6. Assessed participant’s satisfaction with their plan(s).					
Plan	7. Helped the participant to set an activity goal.					
	8. Chosen topic	a. Provided relevant resources for topic(s) chosen from PRIDE-app and own sources				

		b. Discussed in relation to the participant (*Please turn over and provide details*).				
	9. Made at least one plan with the participant (including where, when, and how, and who could help me).					
	10. Encourage the participant to think about what might help and what might get in the way of completing their plan(s).					
	11. Encouraged the participant to think of ways to overcome problems.					

Do	12. Showed the participant how to log their activity plan and record progress on the PRIDE-app between sessions.				
Support	13. Gave positive feedback.				
	14. Gave the opportunity to ask questions.				
	15. Provided contact details and ways to seek support.				
Next Step	16. Set a time and date for the next session.				

Session 2: Please complete for session activity 8 only.

For the topic that your participant chose to work on, please tick what was done.

If anything else was done, please provide details in the space below.

	Provided information, assessed situation, and identified challenges				
Topic	Provided information on the benefits associated with it	Provided information on how dementia can affect it	Assessed participant's current style (decision making/ communication)	Identified potential challenges	Provided information on resources
1.Keeping mentally active					
2. Keeping physically active					
3. Keeping socially active					
4. Making decisions					

5. Getting your message across					
6. Receiving a diagnosis					
7. Keeping healthy					

Provided examples and tips						
Topic	Provided instructions on how to do it	Provided example activities for this topic	Provided examples of how others do it	Provided tips on how others can provide support	Provided example of how others overcome challenges	Provided tips to overcome challenges
1.Keeping mentally active						
2. Keeping physically active						
3. Keeping socially active						

4. Making decisions						
5. Getting your message across						
6. Receiving a diagnosis						
7. Keeping healthy						

Anything else:

The Dementia Advice Worker checklist guidelines

What are the checklists for?

Nobody ever delivers all of a program. By completing the checklists, you help us better understand what components of PRIDE-app have and have not been delivered and the reasons for this.

Please complete a checklist immediately or as soon as possible after each session and email it to Abigail Lee at the University of Nottingham (abigail.lee1@nottingham.ac.uk).

How do I fill out the checklists?

- There are three checklists, one for each session.
- Please record the site and participant ID and date on the top of the checklist.
- For every item on the checklist, please tick whether it was:
    - Done
    - To some extent
    - Not done
- If ‘not done’ or ‘to some extent’, it would be helpful to let us know why in the ‘reason for not delivering’ column. For example: running out of time or forgetting.

Please complete this form as soon as possible after delivering the session. The responses are for research purposes and will not be seen by participants. Thank you.

PRIDE-app: Final Session					
Site ID:	DA ID:	Participant ID:	Date:		
SESSION ACTIVITIES		**Please tick**			**If not done or done to some extent, please give a brief reason for not delivering (e.g. ran out of time, forgot)**
		Done	To some extent	Not done	
Review	1. Asked the participant about their progress since the last session.				
	2. Discussed what helped and what got in the way of participant’s progress.				

	3. If problems were identified, discussed ways to overcome them.				
	4. Discussed and changed plan(s) if needed.				
	5. Recorded review using the PRIDE-app.				
	6. Assessed participant’s satisfaction with their plan(s).				
Plan: Going forward	7. Helped the participant to set an activity goal to work on after the programme.				
	8. Encouraged the participant to think about what might help and what might get in the way of completing their plan(s).				
	9. Encouraged the participant to think of ways to overcome problems.				

	10. Discussed and recorded plan(s) going forward.				
Support	11. Gave positive feedback.				
	12. Gave the opportunity for any questions.				

Participant checklist guidelines

PRIDE-app: Your experiences

We are interested in your experiences of being part of the Promoting Independence in Dementia app (PRIDE-app) study. We would be very grateful if you could fill out this form to help us know what happened in the sessions with your dementia advisor. This will help us improve PRIDE in the future. Please email this form back to your dementia advisor (who will pass it onto the study team) or directly to pride-app@nottingham.ac.uk.

Completing the forms

- Please complete the form immediately or as soon as possible after each session.
- Each form lists a number of activities that may or may not have happened in your PRIDE sessions.
- There are three forms, one for each session.
- Please put the date on the top of each form.
- For every session activity on the form, please tick whether it:
  - Happened
  - Possibly happened
  - Did not happen
- For activities 'after the session' or 'since the last session', please tick:
  - Yes
  - To some extent
  - No

Please complete this form as soon as possible after your session. The responses are for research purposes and will not be seen by your dementia advisor. Thank you.

PRIDE-app: First Session (Introduction)					
Date:					
SESSION ACTIVITIES			**Please tick**		
			Happened	Possibly happened	Did not happen
Initial PRIDE activities	1. The dementia advice worker explained what the PRIDE programme is and what it will involve.				
	2. The dementia advisor showed me how to access and navigate the PRIDE-app				
	3. We completed my PRIDE profile.				
	4. Finding a balance	a. The dementia advisor gave me information on how to find a balance with activities.			
		b. I described which activities I find important and enjoyable using the interactive boxes.			
	5. How other people can help	a. The dementia advisor gave me information on how other people could help me.			

		b. I described my current relationships.			
		c. We talked about examples of how other people’s support network helps them.			
	6. Keeping going with activities	a. The dementia advisor gave me information on how to choose activities to keep going.			
		b. We talked about examples of how others keep going.			
	7. I chose three topics to work on.				
Plan	8. I set an activity goal.				
	9. Chosen topics	a. The dementia advisor gave me information for my chosen topic.			
		b. We talked about my chosen topic in relation to me.			
	10. We talked about and made at least one plan (including where, when, and how, and who could help me).				
	11. We talked about things that will help my plan(s), identified potential problems, and ways to solve them.				

Do	12. The dementia advisor showed me how to log my activity plan on the PRIDE-app.			
Support	13. The dementia advisor gave me positive feedback.			
	14. I had the opportunity to ask questions.			
	15. The dementia advisor gave me their contact details and ways to seek support.			
Next Step	16. We set a time and date for the next session.			
AFTER THE SESSION		**Please tick**		
		Yes	To some extent	No
	17. The information given to me in the session was clear and easy to understand.			
	18. I understand how to use the PRIDE-app.			
	19. I understand how to put my plans into action.			

Participant checklist guidelines

PRIDE-app: Your experiences

We are interested in your experiences of being part of the Promoting Independence in Dementia app (PRIDE-app) study. We would be very grateful if you could fill out this form to help us know what happened in the sessions with your dementia advisor. This will help us improve PRIDE in the future. Please email this form back to your dementia advisor (who will pass it onto the study team) or directly to pride-app@nottingham.ac.uk.

Completing the forms

- Please complete the form immediately or as soon as possible after each session.
- Each form lists a number of activities that may or may not have happened in your PRIDE sessions.
- There are three forms, one for each session.
- Please put the date on the top of each form.
- For every session activity on the form, please tick whether it:
    - Happened
    - Possibly happened
    - Did not happen
- For activities 'after the session' or 'since the last session', please tick:
    - Yes
    - To some extent
    - No

Please complete this form as soon as possible after your session. The responses are for research purposes and will not be seen by your dementia advisor. Thank you.

PRIDE-app: Second Session				
Date:				
Activities since the last session		**Please tick**		
		Yes	To some extent	No
	1.Since the last session, I have used the PRIDE-app and logged my activities.			
	2. Since the last session, I have practiced and used the information and skills I learnt.			
Session activities		**Please tick**		
		Happened	Possibly happened	Did not happen

Review	3. We talked about how I have got on with my plan(s) since the last session.				
	4. We talked about things that helped and got in the way of me making progress.				
	5. If we identified problems, we talked about ways to solve them.				
	6. We reviewed my plan(s) and made changes if needed.				
	7. We talked about if I was satisfied with my plan(s)				
Plan	8. I set an activity goal.				
	9. Chosen topics	a. The dementia advisor gave me information for my chosen topic.			

		b. We talked about my chosen topic in relation to me.			
	10. We talked about and made at least one plan (including where, when, and how, and who could help me).				
	11. We talked about things that will help, identified potential problems, and ways to solve them.				
Do	12. The dementia advisor showed me how to log my activity plan on the PRIDE-app.				
Support	13. The dementia advisor gave me positive feedback.				
	14. I had the opportunity to ask questions.				
	15. The dementia advisor gave me their contact details and ways to seek support.				

Next Step	16. We set a time and date for the next session.			
AFTER THE SESSION		**Please tick**		
		Yes	To some extent	No
	17. The information given to me in the session was clear and easy to understand.			
	18. I understand how to use the PRIDE-app.			
	19. I understand how to put my plans into action.			

Participant checklist guidelines

PRIDE-app: Your experiences

We are interested in your experiences of being part of the Promoting Independence in Dementia app (PRIDE-app) study. We would be very grateful if you could fill out this form to help us know what happened in the sessions with your dementia advisor. This will help us improve PRIDE in the future. Please email this form back to your dementia advisor (who will pass it onto the study team) or directly to pride-app@nottingham.ac.uk.

Completing the forms

- Please complete the form immediately or as soon as possible after each session.
- Each form lists a number of activities that may or may not have happened in your PRIDE sessions.
- There are three forms, one for each session.
- Please put the date on the top of each form.
- For every session activity on the form, please tick whether it:
    - Happened
    - Possibly happened
    - Did not happen
- For activities ‘after the session’ or ‘since the last session’, please tick:
    - Yes
    - To some extent
    - No

Please complete this form as soon as possible after your session. The responses are for research purposes and will not be seen by your dementia advisor. Thank you.

PRIDE-app: Final Session				
Date:				
Activities since the last session		**Please tick**		
		Yes	To some extent	No
	1.Since the last session, I have used the PRIDE-app and logged my activities.			
	2. Since the last session, I have practiced and used the information and skills I learnt.			
Session activities		**Please tick**		
		Happened	Possibly happened	Did not happen

Review	3. We talked about how I have got on with my plan(s) since the last session.			
	4. We talked about things that helped and got in the way of me making progress.			
	5. If we identified problems, we talked about ways to solve them.			
	6. We reviewed my plan(s) and made changes if needed.			
	7. We talked about if I was satisfied with my plan(s)			
Plan: Going forward	8. We set a goal that I would like to continue working on.			
	9. We talked about things that will help me, potential problems, and how to solve these.			

	10. We discussed and wrote down my plan(s) going forward.			
Support	11. The dementia advisor gave me positive feedback.			
	12. I had the opportunity to ask questions.			
AFTER THE SESSION		**Please tick**		
		Yes	To some extent	No
	13. The information given to me in the session was clear and easy to understand.			
	14. I understand how to put my plans into action.			

9.6 Outcome measures

9.6.1 CASP-19

	Often	Sometimes	Not Often	Never
My age prevents me from doing the things I would like to				
I feel that what happens to me is out of my control				
I feel free to plan for the future				
I feel left out of things				
I can do the things I want to do				
Family responsibilities prevent me from doing what I want to do				
I feel that I can please myself what I do				
My health stops me from doing things I want to				
Shortage of money stops me from doing the things I want to do				
I look forward to each day				
I feel that my life has meaning				
I enjoy the things that I do				
I enjoy being in the company of others				
On balance, I look back on my life with a sense of happiness				
I feel full of energy these days				
I choose to do things that I have never done before				
I am satisfied with the way my life has turned out				
I feel that life is full of opportunities				
I feel that the future looks good for me				

9.6.2 IADL

Please Select the most appropriate response

A. Ability to Use Telephone	[Score]	**E. Laundry**	[Score]
1. Operates telephone on own initiative-looks up and dials numbers, etc.	1	1. Does personal laundry completely	1
2. Dials a few well-known numbers	1	2. Launders small items – rinses stockings etc	1
3. Answers telephone but does not dial	1	3. All laundry must be done by others	0
4. Does not use telephone at all	0	**F. Mode of Transportation**	
B. Shopping		1. Travels independently on public transportation or drives own car	1
1. Takes care of all shopping needs independently	1	2. Arranges own travel via taxi, but does not otherwise use public transportation	1
2. Shops independently for small purchases	0	3. Travels on public transportation when accompanied by another	1
3. Needs to be accompanied on any shopping trip	0	4. Travel limited to taxi or automobile with assistance of another	0
4. Completely unable to shop	0	5. Does not travel at all	0
C. Food Preparation		**G. Responsibility for Own Medications**	
1. Plans, prepares and serves adequate meals independently	1	1. Is responsible for taking medication in correct dosages at correct time	1
2. Prepares adequate meals if supplied with ingredients	0	2. Takes responsibility if medication is prepared in	0

		advance in separate dosage	
3. Heats, serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet	0	3. Is not capable of dispensing own medication	0
4. Needs to have meals prepared and served	0	**H. Ability to Handle Finances**	
D. Housekeeping		1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income	1
1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")	1	2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
2. Performs light daily tasks such as dish washing, bed making	1	3. Incapable of handling money	0
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness	1		
4. Needs help with all home maintenance tasks	1		
5. Does not participate in any housekeeping tasks	0		

9.6.3 GDS

Please select the response that most represents how you have felt over the past week.

Are you basically satisfied with your life?	No	Yes
Have you dropped many of your activities or interests?	Yes	No
Do you feel that your life is empty?	Yes	No
Do you often feel bored?	Yes	No
Are you in good spirits most of the time?	No	Yes
Are you afraid that something bad is going to happen to you?	Yes	No
Do you feel happy most of the time?	No	Yes
Do you often feel helpless?	Yes	No
Do you prefer to stay at home, rather than going out and doing new things?	Yes	No
Do you feel you have more problems with your memory than most?	Yes	No
Do you think it is wonderful to be alive?	No	Yes
Do you feel pretty worthless the way you are now	Yes	No
Do you feel full of energy?	No	Yes
Do you feel that your situation is hopeless?	Yes	No
Do you think that most people are better off than you are?	Yes	No

9.6.4 Engagement and Independence in Dementia Questionnaire (EID-Q)

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

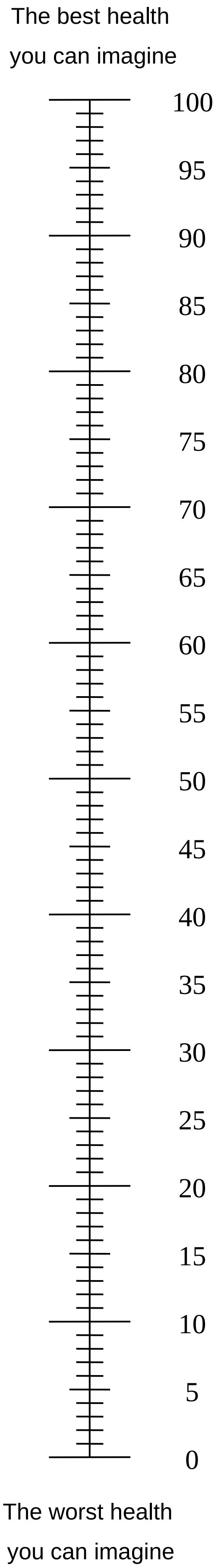
EID-Q					
	Not true at all	**Rarely true**	**Sometimes true**	**Often true**	**True nearly all the time**
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. I am a burden to others	0	1	2	3	4
6. I enjoy conversations with others	0	1	2	3	4
7. I can make my own decisions as much as I'd like to	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I'm confident in making decisions	0	1	2	3	4
10. I am often ignored by those around me	0	1	2	3	4
11. I can do activities that are important to me	0	1	2	3	4
12. I can get in touch with friends/ family if I need to	0	1	2	3	4
13. People take decisions away from me	0	1	2	3	4
14. My friends/ family care about me	0	1	2	3	4
15. I can arrange my life in a way that suits me best	0	1	2	3	4
16. I can help the people I care about	0	1	2	3	4
17. I feel I am active in everyday life	0	1	2	3	4
18. I can take part in groups/ activities with others	0	1	2	3	4
19. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
20. I feel that my friends/ family want to spend time with me	0	1	2	3	4
21. I can make changes to my life to match my abilities	0	1	2	3	4
22. I can confide in my friends/ family	0	1	2	3	4
23. I can get myself food if I need to	0	1	2	3	4
24. I can help my friends/ family as much as I would like	0	1	2	3	4
25. I keep myself busy with activities/ hobbies	0	1	2	3	4
26. I feel connected to others	0	1	2	3	4

9.6.5 EQ-5D-5L

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.

  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR OWN HEALTH TODAY = ☐



9.6.6 GHQ-12

Have you recently?

Been able to concentrate on what you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
Felt you were playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
Been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
Been feeling reasonably happy, all things considered	More so than usual	About same as usual	Less so than usual	Much less than usual

9.6.7 Global Change Measure

Participant

3 months

1. Compared to 3 months ago when you started in the PRIDE study, how would you rate your general wellbeing now?
    - much better
    - a bit better
    - no change
    - a bit worse
    - much worse
2. Compared to 3 months ago when you started in the PRIDE study, how independent do you feel now?
    - much more independent
    - a bit more independent
    - no change
    - a bit less independent
    - much more independent

6 months

1. Compared to 6 months ago when you started in the PRIDE study, how would you rate your general wellbeing now?
    - much better
    - a bit better
    - no change
    - a bit worse

- much worse

2. Compared to 6 months ago when you started in the PRIDE study, how independent do you feel now?
    - much more independent
    - a bit more independent
    - no change
    - a bit less independent
    - much more independent

Supporter

3 months

1. Compared to 3 when your friend/relative started in the study, how would you rate their general wellbeing now?
    - much better
    - a bit better
    - no change
    - a bit worse
    - much worse
2. Compared to 3 months ago when your friend/relative started in the study, how independent do you feel they are now?
    - much more independent
    - a bit more independent
    - no change

- ○ a bit less independent
- ○ much more independent

6 months

1. Compared to 6 months ago when your friend/relative started in the study, how would you rate their general wellbeing now?
    - ○ much better
    - ○ a bit better
    - ○ no change
    - ○ a bit worse
    - ○ much worse

2. Compared to 6 months ago when your friend/relative started in the study, how independent do you feel they are now?
    - ○ much more independent
    - ○ a bit more independent
    - ○ no change
    - ○ a bit less independent
    - ○ much more independent

9.7 Interview schedules

9.7.1 Participant/Supporter Interviews

Thank you for taking the time to talk to me today. This interview will ask about your experience of using the PRIDE-app and get your thoughts on how it could be improved to help more people living with mild dementia.

1) Firstly, do you give your consent to take part in this interview and for your answers to be recorded?
2) Did you complete any sessions with your Dementia Advisor?
    - Did you enjoy these sessions?
    - Did you find them helpful?
3) Did you enjoy using the PRIDE-app?
    - On a scale of 1 to 10, with 10 being very easy, how easy did you find the PRIDE-app to use?
    - Did you feel comfortable using it?
    - Did you have any favourite topics?
4) How often did you use the PRIDE-app?
        - Every day
        - Once a week
        - Only during Dementia Advisor sessions
    - How did it fit in with your daily life?
    - Would anything make it easier to use every day?
5) During the study, did you feel encouraged to use the app?

- Do you feel that the level of encouragement affected your motivation to use the app?

6) On a scale of 1 to 10, with 10 being a very positive impact, how much of an impact has the PRIDE-app had on your daily life and/or general wellbeing?
    - Can you give me any examples of how the app has helped you in your daily lives?
7) Did you find any difficulties when using the app?
    - If so, please could you expand on these?
8) Have you, or will you, continue to use the skills or tips you have learnt about through the PRIDE-app?
9) If so, which ones do you think you will keep using and why?
    - What would help you to continue using these in your daily lives?
    - Is there anything that might prevent you from continuing to use them?
10) If not, please could you expand on why not?
    - Are there any factors which could change your mind, or support you to continue to use them?
11) In your opinion, how could the PRIDE-app be improved?
12) If given the option, would you use the PRIDE-app again?
    - If so, please could you expand on your reasons why?
    - If so, please could you expand on your reasons why not?

13) Are there any other comments or thoughts you would like to share regarding the PRIDE-app or your experience in the study?

9.7.2 Dementia Advisor Interviews

Thank you for taking the time to talk to me today. This interview will ask about your experience of delivering the PRIDE-app and get your thoughts on how it could be improved to help more people living with mild dementia.

1) Firstly, do you give consent to take part in this interview and for your answers to be recorded?
2) What were your impressions of the PRIDE-app?
3) Do you feel you received enough training prior to delivering the intervention?
    a. Is there anything you would have liked included that wasn't?
4) On a scale of 1 to 10, with 10 being the most confident, how confident were you feeling about delivering the PRIDE-app sessions after the training?
5) Did you encounter any problems or barriers when delivering the intervention to participants?
6) Do you feel that participants actively engaged with the sessions and enjoyed using the PRIDE-app?
7) Do you have any views on how the delivery or app itself could be improved?

8) Do you think that the PRIDE-app could be easily incorporated into existing services?
    - If yes, how do you think this would work?
    - If no, please expand on your concerns?
9) Are there any additional thoughts or comments you would like to mention?

9.8 Specification and priority documents for app development

9.8.1 PRIDE-app Amendments – First Sprint

Show/hide tabs needed:

Introductory session:

- Step 3
- Step 4
- Step 6 (page 2 - starts with 'Having trouble with things you usually do')
- Step 7 (page 2 - starts with 'What is a support network)
- Step 8
    - 'Planning an activity'
    - 'Planning to build skills or trying new or different ways to do things'
    - 'Getting around'

Topics:

- Making decisions - 'Ways others can support decision making'
- Getting your message across
    - 'Talking about support'
    - 'Keeping involved in conversations'
    - 'Confidence'
    - 'Health issues that can make it difficult to get your message across'
- Keeping health
    - 'General health'

  - 'Lifestyle' - there is also an extra 'continue reading' that needs removing from the bottom of the page
  - 'Smoking and drinking alcohol'

Instructions need to be added to the following in the Introductory Session:

- Step 5 Q1 - Please select the box below that sounds most like your situation and then press Next.
- Step 5 Q3, 4a & 4b - Please type your answer in the box below and then press Next.
- Step 7 page 2 - Select Add a supporter to start.
- Step 8 'Making your plan' - Please select a box below and the press Continue.

Instructions need to be amended to the following:

Introductory Session:

- Step 5 Q2 – Please select the box below that sounds most like your situation and then press Next.
- Step 6 under ‘Getting the most out of activities’ – move ‘Write these activities below’ to the end of the paragraph and change to – Write an activity in the box below and use the bars to say how important and enjoyable it is for you. You can add more activities after by clicking Add activity.
- Step 9 – Please select 3 topics below and then press Continue.

Topics:

- Making decisions
    - ‘Overcoming challenges with making decisions’ – change ‘go straight to a story or continue reading’ to a new sentence – You can select a specific story or read through all of them.

Instructions need to be in bold in the sections mentioned above and in the following:

Introductory Session:

- Step 7 page 1 - Choose the option below which sounds most like your situation
- Step 7 page 2 - Talk about your support network with your dementia advisor, and fill in the boxes below to show who supports you.
- Step 8 'Plan, do, review' - In between your sessions, we would like you to carry out your plans.

Topics:

- Making decisions
    - 'How do you make decisions' - For each of the comments below, choose 'yes' if this sounds like your situation or 'no' if it doesn't.
- Getting your message across
    - 'Supportive relationship' - For each of the comments below, choose 'yes' if this sounds like your situation or 'no' if it doesn't.

General queries:

- What does it mean to have dementia?
    - 'Worries about dementia' - there are two + in the top paragraph. Are these here for a reason?
- Keeping healthy
    - 'Lifestyle' - there is an extra 'continue reading' that needs removing from the bottom of the page
- **The audio versions of the topic pages on the dashboard do not appear to work.**

9.8.2 PRIDE-app Priorities – First Sprint

Fundamental issues:

- Access to the Introductory Session content - without interactive content or answers saved
- Font size currently 18 pixels (13.5pt) - increase to 22 pixels (16.5pt)
- Show/hide tabs needed on some pages to limit scrolling and reduce long sections of text
- Navigation menu/bar in Introductory Session and clearer navigation icons
- Query audio recordings on all pages - Topic pages on dashboard not working
- Adding statement about ARC funding - This project is also funded by the National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM). The views expressed are those

of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care – awaiting confirmation of statement

- Data for research team – more information to follow regarding specific data collection

High priority:

- Activity icons
- Adding specific glossary link in Introductory Session menu and on dashboard menu
- Adding an introductory paragraph highlighting that the first session is quite long (1hr -1hr30mins) and requires a lot of reading, activities, working with the advisor and supporter etc.
- Adding/amending instructions for activities
- Fixing the photographs that do not show - Susannah's story ('I don't feel confident speaking to people since my diagnosis'), Hal's story or Phillip and June's story (both 'Making sure people understand'

Smaller issues:

- Adding a sentence to explain what each option means in Step 8 (Introductory Session):
    - Doing an activity is good if you want to continue with or do more of an existing activity or try a new activity.

    - Building on skills or trying out new or different ways to do things is good if you want to change some of your actions in everyday life (e.g. perhaps you want to be able to do more of something with less help from your supporter).

- In the ‘How can I make sure I get my message across?’ section, removing Elizabeth’s story in ‘Confidence’ and put in a separate story section titled ‘Talking to people about feeling low or unhappy’.
- Not having the stories following on from one another after the participant has read the relevant one that relates to their current situation.
- Colour coding section banners in Introductory Session
- Highlighting main points in coloured text boxes
- Putting instructions in bold

9.8.3 PRIDE-app Content Changes – Second Sprint

Introductory Session

Section 6: Finding a balance Having a routine – Diaries & notepads

- Change ‘Jot important things down in a diaries’ to ‘Jot important things down in a diary’.

Keeping Mentally Active

What can I do to be mentally active?

- Remove comma after ‘The good news’

Simon’s story: Carrying on with a mental activity

- Add full stop to the last bullet point (ends in ‘try audio versions of books)

Making Decisions

- Remove comma after second bullet point in top box. Add full stops to second and third bullet points.

How can dementia affect decision-making?

- In the last paragraph, remove comma after ‘two supporters’.

Making decisions stories - Bill & Lucy

- Change ‘We talk about things, but tend to have the final say’ to ‘We talk about things, but I tend to have the final say’.

Making decisions stories – Samuel & Rose

- Remove comma in ‘His wife, Rose takes care of a lot of things around the house’.

Shared decision-making

- Remove comma after for instance in ‘If someone else will be making an important decision about something that will affect you, for instance, receiving care, you..’

Ways others can support you to make decisions

- Change ‘thing’ to ‘things’ in the sentence ‘Likewise, not being able to even try to do thing can be frustrating’.
- In Gloria’s quote, a single quotation mark is needed after ‘Why don’t you try this?’

Getting Your Message Across

Supportive relationships

- Change ‘This will help guide you to you the resources…’ to ‘This will help guide you to the resources...’

Talking about support

- In Jenny’s quote, an apostrophe is needed in ‘well’ in ‘Right we’ll do this, well do that’.

How can I make sure I get my message across

- In the last box, ‘page’ needs to be changed to ‘pages’.
- Change ‘Brenda and Winston & Hal’ to ‘Brenda & Winston, & Hal’

Keeping Involved in Conversations

- First bullet point of Raj’s story - change ‘Contact a local health professional, such as a dementia advisor, or admiral nurse and arrange a visit to help him have a conversation with his family about how you feel’ to ‘Contact a local health professional, such as a dementia advisor or admiral nurse, and arrange a visit to help you have a conversation with your family about how you feel’

Health issues that can make it difficult to get your message across

- Last bullet point under Tips for meeting with healthcare professionals – remove ‘feel’ from ‘ask someone you feel trust to be there with you’

What does it mean to be told you have dementia?

- Remove comma after second bullet point in top box.

- In Claudia's quote, change 'but on the hand' to 'but on the other hand'

What can you do if you have worries about dementia?

- Get support – change 'can help you learn more about how others are successfully manage living with dementia' to 'can help you learn more about how others are successfully managing their dementia'.

Sharing your diagnosis

- Change 'The decision to tell others that you have problems..' to 'The decision to tell others that you are living with dementia…'
- A comma is needed after 'if at all' in 'In the early stages of dementia, symptoms may only interfere a little, if at all with everyday life…'
- In Rosa's quote, remove 'and things' from 'Neighbours and things just come up to me..'

Keeping Healthy

- Change all 'Recommended Page' to 'Recommended Pages'

Diabetes

- Add '**Recommended pages:** Type 1 diabetes, Type 2 diabetes' under NHS Choices website.

9.9 Attitudes towards technology questionnaire

Thank you for your interest in this survey, which explores attitudes towards technology in people living with dementia and their supporters. Over the last 2 years, during the Covid-19 pandemic, the rate of technology use has accelerated as social contact has become much more restricted at times particularly for many people with dementia. To better understand how technology may continue to be useful to people with dementia and their families, we need to know more about how often they use technology, what types and what they are using it for, plus their attitudes to it. For this questionnaire, the term ‘technology’ refers to computer technology including computers, laptops, tablets and smartphones.

The PRIDE-app Study is exploring whether an online handbook could support people living with dementia with their independence, making choices and daily activities. PRIDE-app covers information on physical, mental, and social health. Topics include keeping healthy, decision-making, and communication. It encourages the user to set activity plans and make positive changes, both of which can help the user to live well with dementia. At the end of the questionnaire, you will be given a link to further information on the PRIDE-app study.

All of the information collected through this questionnaire will be kept strictly confidential, anonymised and stored securely, and you can exit it at any time by closing down the window. If you would like to complete the questionnaire, please continue onto the consent page. If not, please just close the window.

Thank you.

With thanks,

PRIDE-app Study Team

Attitudes towards technology questionnaire

Are you living with a diagnosis of dementia?

☐ Yes

☐ No

[If yes] How long has it been since you received your diagnosis?

[If yes] Are you completing this questionnaire by yourself?

Are you currently a carer/supporter of someone living with dementia?

☐ Yes

☐ No

[If yes] How long have you been in this role?

What is your age?

☐ 18 – 44

☐ 45 –64

☐ 65-74

☐ 75 – 86

☐ 85+

☐ 95+

☐ Prefer not to say

What gender do you identify as?

☐ Female

☐ Male

☐ Non-binary

☐ Other (please specify)

☐ Prefer not to say

Please specify your ethnicity

- ☐ White
- ☐ Mixed/Multiple Ethnic Groups
- ☐ Asian/Asian British
- ☐ Black/African/Caribbean/Black British
- ☐ Other (please specify)

What is the highest level of education you have completed?

- ☐ Some school
- ☐ High School
- ☐ Bachelor’s Degree
- ☐ Master’s Degree
- ☐ PhD or higher
- ☐ Prefer not to say

Attitudes towards technology questionnaire – JDR Survey

1. Do you have access to the internet from home?

Yes

No

2. How often do you use the Internet?

Every day

Almost every day

At least once a week, but not every day

Less than once a week

I never use the Internet

3. How often do you use email?

Every day

Almost every day

At least once a week, but not every day

Less than once a week

I never use email

4. On average, how often would you say you have used a computer, tablet or smartphone during the last month?

Every day

Almost every day

At least once a week, but not every day

Less than once a week

Never

5. How long have you been using computer technology, tablets or smartphones?

Less than 6 months

6 months to 2 years

2 + years

I do not use them

6. Do you, or did you, regularly use technology for your work?

Yes

If Yes, then on average how often did you use this technology?

No

7. Do you use any of the following apps?

- ☐ Twitter
- ☐ Facebook
- ☐ Instagram
- ☐ WhatsApp
- ☐ Skype
- ☐ Zoom
- ☐ Microsoft Teams

8. Which of these things do you use technology for?

- ☐ Work
- ☐ Email/Communication
- ☐ Shopping
- ☐ Health
- ☐ News/Weather

☐ Games

9. I think it’s fun with new technological gadgets

Fully agree

Agree

Don’t know

Disagree

Fully disagree

10. Using technology makes life easier for me

Fully agree

Agree

Don’t know

Disagree

Fully disagree

11. I like to acquire the latest models or updates

Fully agree

Agree

Don’t know

Disagree

Fully disagree

12. I am sometimes afraid of not being able to use the new technical things

Fully agree

Agree

Don’t know

Disagree

Fully disagree

Please could you say a little more why you chose this answer?

13. Today, the technological progress is so fast that it’s hard to keep up

    Fully agree

    Agree

    Don’t know

    Disagree

    Fully disagree

14. I would have dared to try new technical gadgets to a greater extent if I had had more support and help than I have today

    Fully agree

    Agree

    Don’t know

    Disagree

    Fully disagree

    Please could you say a little more why you chose this answer?

15. Do you already use technology to access dementia-related content, resources or support?

    Yes

    No

    If Yes, please could you expand on this?

16. How knowledgeable do you consider yourself to be when it comes to using a computer, tablet or smartphone?

    Very knowledgeable

    Quite knowledgeable

    Not very knowledgeable

    Not at all knowledgeable

17. Are you currently using a computer, tablet or smartphone in a way to support your independence or daily activities?

    Yes

    No

    If Yes, please could you expand on this?

18. Would you be interested in using an app regularly on the computer, tablet or smartphone to support your independence and daily activities?

    Yes

    No

    Please could you expand on your reasons for this?

19. Do you have any concerns about using technology?

    [Comment box]

20. Do you have any priorities for new technology?

    [Comment box]

21. Are you interested in knowing more about technology around the house to help you manage with things such as daily tasks and safety?

    [Comment box]