Designing and Evaluating Digital Mindfulness-based Interventions for Older Informal Carers

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Declaration by Author & Supervisor

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PwD – Person with dementia
MBI – Mindfulness-based intervention
MBSR - Mindfulness-based stress reduction
MBCT – Mindfulness-based cognitive therapy
HCI – Human computer interaction
TILDA – The Irish Longitudinal Study on Ageing
AD – Alzheimer’s disease
PD – Parkinson’s disease
QoL – Quality of life
RCT – Randomized control trial
PAC – positive aspects of caregiving
CBT – Cognitive behavioural therapy
PMOF-SF - Prolife of Mood States Short Form
SHE – sleep hygiene education
BP – Blood pressure
RRP - reading and relaxation program
ESM - Experience Sampling Method
iCBT - internet-delivered CBT
COPD - Chronic Obstructive Pulmonary Disease
TB-CBT - Technology-based CBT
ISO – International Standards Organization
Mt4C - My Tools 4 Care
TAM – Technology acceptance model
UTAUT - Unified Theory of Acceptance and Use of Technology
STAM - Senior Technology Acceptance & Adoption Model
PwM - People with multimorbidity
UCD - User-centered design
UI - user interface
ML - Multi-layered
HSE – Health Service Executive
NHS – National Health Service

CABIE - Context Aware Brokering and Inferencing Engine
SIMS - Subject Information Management System
RAPA - Rapid Assessment of Physical Activity
PSQI - Pittsburgh Sleep Quality Index
MAAS - Mindful Attention Awareness Scale
ZBI-12 - Zarit Caregiver Burden Interview Short Form
PSS - Perceived Stress Scale
SUS - System Usability Scale
pRCT - pragmatic randomised control trial

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Abstract

Across the world a change in demographics is occurring, with the average age of populations increasing alongside longer life expectancy. Increases in demand for health care alongside fewer staff and resources available are resulting in policy shifts towards ageing in place. The number of older informal carers, often caring for an older family member or friend, will therefore continue to grow. A significant issue facing this cohort is stress, which can negatively affect other areas of health wellbeing such as sleep quality, physical health and psychological wellbeing. Mobile technologies delivering interventions offer an important alternative to traditional, face-to-face support which may not be accessible for those unable to leave a care recipient unattended for significant periods of time, or for those living in rural areas. Moreover, mindfulness-based interventions (MBIs) have been used to increase awareness and support coping strategies by providing carers with tools to manage their emotional and physical health and wellbeing.

This thesis investigates the problem of chronic stress among older informal carers of persons with dementia and its negative impact on health and wellbeing, as well as the potential for mindfulness training, education, feedback and health self-management to address this phenomenon. The study focussed on the design and delivery of a digital application, Mind Yourself, delivering an MBI to manage stress alongside blood pressure, activity and sleep management through tracking, data visualizations and educational advice. An eight-week home-based trial was conducted to evaluate experiences and usage of the application with eight older informal carers of persons with dementia.

The work presented extends current research by focussing on the user-centred design of a digital mindfulness-based intervention specifically for older informal carers of persons with dementia. The study demonstrates that a viable and potentially effective means to support stress management is through the integration of a digital MBI into a digital health and wellbeing application. Findings from the trial suggest that this approach and design is acceptable, feasible, usable and engaging for older informal carers. Results from both the trial and the study overall would suggest that further research in the area of digital MBIs and connected health for older informal carers is warranted. Reaching this cohort and providing them with the tools and strategies to more effectively look after health and wellbeing could result in both the carer and care recipient remaining at home for as long as possible.

Chapter One: INTRODUCTION

Across the world a change in demographics is occurring. The average age of populations is increasing, which is happening in tandem with an increase in life expectancy. While such changes are clearly positive and to be celebrated, they bring with them some unique and pressing challenges. As people get older and continue to live longer, the number of diagnoses of dementia and other age-related illnesses continues to grow. With these changes further burden is likely to be placed on health systems, with increases in demand for care coming alongside decreases in available staff and resources (Hanly and Sheerin, 2017). It will become more common, therefore, for policy to shift towards a preference for ageing in place as much as possible, thereby leading to an increase in the number of informal carers, who will quite often also be older adults themselves (O'Sullivan, 2019). A 2011 census in Ireland revealed that 4.1% of the total population (187,112) were considered informal carers, providing unpaid assistance to family members or friends. Furthermore, from 2006 to 2011 there was an increase of 33.6% in the number of informal carers in the 60-74 age group; this increase was even more pronounced among those aged 75 years and over (39%) and it was the largest increase observed across all age groups (CSO, 2012). This underlines the growing importance of the role older adults play in relation to informal care. Indeed, in the period from 2006 to 2012 the economic value of such care in Ireland increased from €2.5 to €4 billion per year (Care Alliance Ireland, 2015). It is predicted that these numbers will continue to grow as populations get older, suggesting solutions must be found outside of standard and traditional health care models. There is considerable potential for technology to support both the carer and the care recipient in a wide range of areas, including provision of government services, information and support, news and entertainment, appointments and schedules, social participation, and health and wellbeing self-management.

The demands associated with providing full-time and unpaid care are considerable and varied, frequently resulting in feelings of isolation, psychological distress (anxiety, depression, stress), loss of self-esteem, and a tendency to neglect one's own health and wellbeing due to time constraints and feelings of exhaustion (Hoffman and Rodrigues, 2010). These issues can then negatively affect the carer's capacity to provide adequate care, increasing the likelihood of negative health outcomes for both the carer and the care recipient (Grady and Rosenbaum, 2015). In recent years, there has been an increase in the development and uptake of self-management technologies, primarily focussing on chronic disease management, with less attention being paid to older informal carers and stress management specifically. Nonetheless, the use of mobile and Internet technologies to deliver programmes which aim to increase carer competence and knowledge, delay institutionalization, and enable better care provision has grown somewhat in popularity in recent years (Parra-Vidales *et al.*, 2017); (Yamashita *et al.*, 2017). Such interventions are particularly important for people who may find it more difficult to access traditional, face-to-face support, such as those who are living in rural areas or in a position where a care recipient cannot be left unattended for significant periods of time. Reaching these groups and equipping them with the tools and strategies to better look after their own health and wellbeing could in turn allow for both the carer and care recipient to remain at home for as long as possible (Boots *et al.*, 2014).

There is an opportunity for mindfulness meditation to address the issue of stress and overall wellbeing among older informal carers, with interventions involving general populations and older adults having had success addressing stress (Wahbeh, Goodrich and Oken, 2016); (Li, Yuan and Zhang, 2016); (Kor, Liu and Chien, 2019) and also emotional wellbeing, loneliness, emotional distress, depression and anxiety (Mallya and Fiocco, 2016); (Hofmann *et al.*, 2010); (Khoury *et al.*, 2013); (Vøllestad, Nielsen and Nielsen, 2012). A core tenet of mindfulness-based practice is training the individual to accept and attend to unpleasant experiences or feelings without immediately rushing to avoid or ignore them. Ultimately, this should allow the individual to better deal with situations which feel overwhelming and out of their control, reducing the urge to resort to avoidant behaviour. Mindfulness meditation can lead to a heightened sense of awareness which can in turn provide carers with the tools to better manage their emotional, cognitive and physical health while at the same time supporting any coping strategies they may already be in the process of implementing (Vinci *et al.*, 2019).

This PhD project aimed to address the challenges faced by informal carers by designing, developing and evaluating a digital health solution, the Mind Yourself application, to support older informal carers to self-manage their health (including stress, blood pressure) and wellbeing (activity and sleep). The application integrates health and wellbeing monitoring, self-report, feedback, education and a mindfulness intervention. A trial was conducted, whereby eight informal carers of people with dementia used the app in their homes over an eight week period. The trial was focused on evaluating the feasibility and efficacy of the application, primarily understanding participants' experiences of using the technology, including how they engaged, what worked for them and what did not. This type of evaluation is appropriate for novel, early stage digital health technologies and is necessary prior to larger trials to determine effectiveness (WHO, 2016); (Klasnja, Consolvo and Pratt, 2011). The findings showed that feedback from participants was positive. The app was perceived as usable and there were high levels of engagement with both the app, and the mindfulness content. Findings also indicate that participants experienced a number of benefits as a result of using the app, including lower levels of perceived stress. As such, the Mind Yourself application is considered feasible for this cohort to self-manage health and wellbeing, with the findings warranting further research and a larger scale trial.

The remainder of this chapter outlines the background and motivation for this work. The research aim and objectives are presented, followed by the contributions and a summary of the thesis structure.

1.1 Health and Wellbeing of Carers

It is becoming more common for care to be provided to older care recipients at home; such care is often informal and unpaid, and the carer is frequently a family member or friend who is also an older adult. Factors arising from caring such as physical and psychological strain, unpredictability, and lack of personal time have been shown to lead to chronic stress. Caring also impacts family and work relationships, with carers struggling to balance these elements with caring duties and responsibilities (Chen, Ngo and Young, 2013). Chronic stress can take a considerable toll on one's mental health, but other areas of health and wellbeing are also significantly negatively impacted, including poor sleep quality, high blood pressure and decreases in physical activity, as well as strain on family relationships (Brummett *et al.*, 2006); (Schulz and Sherwood, 2008); (Lane *et al.*, 2011); (Care Alliance Ireland, 2015). Poor sleep among older adults has also been shown to lead to negative health outcomes in general, including increased stress, with the result being a cyclical relationship between poor sleep quality and high stress levels as well as an increased likelihood of developing chronic disease, cognitive impairment and dementia (Landry, Best and Liu-Ambrose, 2015); (McCurry, Song and Martin, 2015). Older informal carers of persons with dementia (PwD) have been shown to suffer more from poor sleep quality than older non-carers, based on both objective measurements and self-reported data (Rowe *et al.*, 2008).

In older adults, physical activity has been shown to result in a number of positive health outcomes, including reduced symptoms of anxiety and depression, improved sleep, improved cognitive health, improved mortality in relation to chronic conditions such as heart disease and diabetes and prevention of falls and falls-related injuries (WHO, 2019). However, informal carers face significant barriers to engaging in exercise, particularly the requirement to be physically present and available to the care recipient in order to provide care appropriately (Stowell *et al.*, 2019). These reduced opportunities for physical activity mean the older carer's physical health is further at risk, which in turn could negatively affect the care recipient if capacity to provide care is impacted (Vinci *et al.*, 2019); (Orgeta and Miranda-Castillo, 2014); (Hill *et al.*, 2007); (Hirano, Suzuki, Kuzuya, Onishi, Ban, *et al.*, 2011). Solutions are required, therefore, which enable older informal carers to engage in physical activity and exercise in order to self-manage their physical health with the potential benefits including improvements in blood pressure, cholesterol levels, sleep quality, mental function, and decreased risk of falling, depression and hospitalization rate (HSE, 2019).

Providing care can be particularly challenging and this is even more so the case when the carer is older. Alongside the objective burdens involved with caring such as activities requiring physical effort, there are significant subjective burdens also, including emotional distress resulting from the caregiving process (Montgomery and Kosloski, 2009); (Vasileiou *et al.*, 2017). More focus needs to be paid to interventions and programs which could work to support and maintain cognitive and emotional health among older adults in general (Mallya and Fiocco 2015). With regard to carers of PwD specifically, feelings of social isolation and inadequate social support are prevalent, with the risk of anxiety and depressive disorders also increasing. Lack of support or adequate training can also have detrimental effects in terms of increased stress, resulting in reduced capacity to provide sufficient care, and an increase in the likelihood that the carer will fail to look after their own health appropriately (McKechnie et al., 2014). It has also been found that worse carer mental health predicted greater mortality in care recipients with dementia and other neurodegenerative diseases, further underscoring the importance of supporting carers in this regard (Lwi *et al.*, 2017).

1.2 Potential for Technology to Assist

There is considerable potential for technology to provide solutions to the challenges faced by older informal carers. Advancements in mobile and sensing technologies alongside a rise in the quantified-self movement have resulted in an increased interest in technologies to support disease and lifestyle management, in both the commercial and research spheres. There has been an exponential growth in mobile applications for self-monitoring and self-management. For example, growth in self-tracking smartphone-based devices and applications outside the United States was set to grow from 6.3 million in 2014 to 60.6 million by 2019[1]. Current research also shows that 53% of Americans over the age of 65 own a smartphone[2].

However, the possibilities for monitoring and managing areas of emotional wellbeing such as stress through mobile technologies, particularly for more specific and defined cohorts such as older informal carers, has not received as much attention in the literature or commercial space as other areas, for example chronic disease management, physical activity and diet (Brown *et al.*, 2019). With this in mind, opportunities have been highlighted for health technologies that can support older adults in monitoring and managing emotional wellbeing with a view to improving and maintaining health and wellbeing overall (Doyle *et al.*, 2014); (Forsman *et al.*, 2018); (Andrews *et al.*, 2019); (Seifert, Reinwand and Schlomann, 2019); (Vailati Riboni *et al.*, 2020). In the fields of HCI and digital health there has also been an increase in focus on solutions for in-home care (Tseng, Hsu and Chuang, 2013), health self-management (Mulvenna *et al.*, 2010); (de Barros, Rêgo and Antunes, 2014), assistive technologies and information support for carers (Daniel, Cason and Ferrell, 2009); however, the focus has largely been either patient-centric or related to the provision of effective care (Lindeman *et al.*, 2020), with much less attention being paid to supporting the carer in managing their own health and overall wellbeing (Bosch and Kanis, 2016).

There are other potential benefits to integrating digital technologies into daily life; engagement with such technologies could also serve to counteract the negative effects of social isolation while also building on existing social connections (Waycott and Vines, 2019). Moreover, for those participants who may have faced barriers to using computer technology, such as computer anxiety, or may have felt they would need significant training or education, engaging with systems that have been designed with the end user in mind could empower them with the

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[1] https://www.bccresearch.com/pressroom/hlc/mobile-devices-driving-unprecedented-growth-in-self-monitoring-technologies-markets

[2] https://www.pewresearch.org/internet/fact-sheet/mobile/

digital skills that will enable them to enjoy new ways to interact with others, and access a wider variety of information and community resources (Khosravi, Rezvani and Wiewiora, 2016). However, it is also the case that while interest in mobile health applications is increasing, sustained engagement remains low with issues around usability and design being among the contributing factors (Consolvo *et al.*, 2012). As such, it is necessary to consider all of these factors when approaching the design of novel technologies for supporting older adults in the area of health and wellbeing self-management.

1.2.1 Mindfulness-based interventions

Mindfulness meditation is defined as an active process in which careful attention is paid to the current moment, non-judgmentally, and without ruminating or attempting to avoid what occurs (Fresco *et al.*, 2011). The act of meditating is a practice used for the enhancement of mindfulness, which is a state to be achieved rather than a trait (Davis and Hayes, 2011). However, regular and sustained engagement in mindfulness practice is considered to result in what is described as trait or dispositional mindfulness, such to the extent that the sense of non-judgemental awareness that occurs during practice carries over to everyday life and how events are experienced (Garland, Gaylord and Fredrickson, 2011). Improved health measures in anxiety, stress, and sleep have been observed in interventions based on mindfulness meditation (Wahbeh, Goodrich and Oken, 2016). Mindfulness-based interventions (MBIs), including those based on Mindful-based Stress Reduction (MBSR) and Mindfulness-based Cognitive Therapy (MBCT), have been shown to be effective in improving psychological wellbeing and stress-related conditions in both general populations and older adults specifically, with improvements observed in emotional wellbeing, loneliness, emotional distress, depression and anxiety (Mallya and Fiocco et al. 2015); (Hofmann *et al.*, 2010); (Khoury *et al.*, 2013); (Vøllestad, Nielsen and Nielsen, 2012). Techniques typically found in MBIs include deep breathing, body scans, and activities aimed at developing skills relating to mindful awareness of everyday activities and experiences (Fresco et al., 2011). Modifications have been made to also allow for interventions to be aimed towards other areas of health and wellbeing, such as dealing with chronic pain, or focussing on unhealthy thought patterns and behaviours. As well as this, studies looking at how MBIs can be used to support family carers of PwD have resulted in improvements in self-rated psychological symptoms such as stress, depression and anxiety, suggesting modified MBIs for this cohort are both feasible and acceptable for carers of PwD (Li, Yuan and Zhang, 2016); (Kor, Liu and Chien, 2019).

Standardized MBSR programmes last eight weeks and involve weekly in-person group sessions as well as a day-long retreat. With these programmes also requiring the guidance of a trained facilitator or therapist, they can often be prohibitively expensive, time-consuming and requiring a considerable amount of travel on the participants' behalf (Morledge *et al.*, 2013). These barriers to access can be even more pronounced for carers of PwD as participation in such programmes requires the carer to spend time away from the care recipient for extended periods of time, often resulting in high attrition rates or non-participation entirely (Kor, Liu and Chien, 2019). MBIs which can be delivered to informal carers remotely and in their homes through the use of online technologies have the potential to address these barriers and offer a more convenient, cost-effective and accessible alternative to traditional, face-to-face formats (Jayewardene *et al.*, 2017); (Morledge et al. 2013). Providing a digital MBI as part of a user-centred digital health and wellbeing application allows older informal carers to self-manage their own wellbeing, and offers this cohort a solution that does not require attendance at a class in the manner of traditional, face-to-face MBI, thereby addressing the issue of informal carers having a scarcity of free time and frequently needing to be available to the care recipient at all times.

1.3 Research Aims and Objectives

The research presented in this thesis has been guided by the following research aim and set of objectives:

Research aim: Explore how older informal carers use a digital application that delivers a mindfulness intervention and supports self-management of health and wellbeing.

Objective 1: Gather requirements relating to the design of health self-management technologies for older adults, based on review of the literature and engagement with end-users.

Objective 2: Adopt a user-centred design process to design a useful and usable digital health application for older users.

Objective 3: Examine engagement with the application.

Objective 4: Explore attitudes towards the mindfulness intervention and use of the application in general.

Objective 5: Determine the potential effectiveness in reducing stress and improving quality of life and sleep hygiene.

Objective 1 was addressed in two ways. Firstly, a literature review was conducted to understand the challenges faced by older informal carers and how technology might help. Concurrently, focus groups and interviews were held with older adults to gain insights into what areas of health and wellbeing this cohort considered important, and how this could be supported through the use of digital technologies. Iterative, user-centred design cycles followed this based on feedback gathered, during which older users provided crucial input related to the design of the application. This resulted in the design and development of the Mind Yourself application, addressing Objective 2. Objectives 3-5 were achieved through conducting an eight-week trial of the Mind Yourself application with eight older informal carers to determine the feasibility of the application to support older informal carers to self-manage their wellbeing, in particular stress.

1.4 Contributions

The research makes the following main contributions to knowledge:

- The design of a user-centred application, Mind Yourself, that is usable and useful for older informal carers to self-manage their emotional wellbeing and related areas of health.
- An exploration and understanding of the experiences of older informal carers who used this application for two months, including patterns of usage, usability, acceptance and perceived usefulness.
- Evidence of the viability of a digital mindfulness intervention to support management of stress in older informal carers.

- Based on the lessons learned in evaluating the application and its deployment with older informal carers, a broad set of design recommendations for integrating digital mindfulness-based interventions into a digital health application is provided.

1.5 Structure of Thesis

The remainder of this thesis is structured as follows:

Chapter 2 presents a review of the literature on caring and its impact on health and wellbeing. Mindfulness-based interventions are introduced and their potential role in supporting carers is discussed.

In **Chapter 3** a review of the literature is presented in the areas of digital health and behaviour change technologies that support self-management of health and wellbeing, including emotional wellbeing, physical activity and sleep. Technology-mediated mindfulness-based interventions are discussed. The final part of the chapter focuses on considerations when designing for older adults and the importance of a user-centred design approach.

Chapter 4 provides an analysis of research methods in the fields of HCI and Digital Health. Qualitative and quantitative research methodologies are introduced and an overview of the methods used and justification for these is provided.

Chapter 5 discusses Iterative Design Cycle 1, which involved two focus groups, the first designs and the first round of usability testing. The initial focus groups explored issues around health and wellbeing important to older adults, as well as their preferences regarding various types of data visualizations. This formed the basis of the study and these findings fed in to the initial designs of the digital health application, while a further review of the literature was carried out. Usability testing sessions were held and further analyses allowed for the study to move into the next phase of the user-centred design cycle.

Chapter 6 presents Iterative Design Cycle 2, which included further requirements gathering with older adults and older informal carers, results from which fed into the further design of the application. Design decisions and changes were also made based on usability testing sessions.

Chapter 7 presents the final design of the application that was used in the main trial.

Chapter 8 presents an overview of the trial design, including the technologies deployed to users, inclusion criteria, procedures, data collection and analysis methods.

Chapter 9 presents the findings from the analyses of qualitative data gathered through interviews with participants during the trial. The profiles of the participants are first presented. A number of themes that arose from a thematic analysis of the data are outlined.

Chapter 10 presents the findings of the quantitative data analysis, including the results of questionnaires used to assess various health and wellbeing parameters pre, mid and post-trial, engagement with the system and a summary of the data derived from the objective sensor data.

Chapter 11 presents a discussion of the key findings from the trial and the overall project, and includes lessons learned and design recommendations for digital health technologies for older carers. The contributions to knowledge are outlined, and limitations and future work discussed.

Chapter Two: CARING, WELLBEING AND THE MINDFUL APPROACH

2.1 Introduction

This chapter presents the literature on caring and its impact on wellbeing. Aspects of caring which are explored include costs associated with providing informal care, the relationship between caring and stress, impacts on wellbeing and carer quality of life. Mindfulness-based interventions (MBIs) are discussed in the context of physical, cognitive and emotional wellbeing, sleep quality among older adults, factors relating to caring, as well as adherence to such interventions. Finally, physical activity and its importance for maintaining a healthy lifestyle is discussed with specific regard to older informal carers.

2.2 Provision and Cost of Informal Care

Informal care is care that is provided to a person with whom the informal carer has a personal relationship or close ties (Vasileiou *et al.*, 2017). This care is typically unpaid and involves provision from a few hours a week up to round-the-clock care with co-habitation (Carers UK, 2015). The role of informal carers in providing care, support and quality of life for older people has become valuable in today’s society. Changes in policy in terms of health care and residential care systems has resulted in more responsibility being placed upon older informal carers (Hill *et al.*, 2007). Data from the Irish Longitudinal Study on Ageing (TILDA) shows that the majority of carers (89%) providing care to community-dwelling older adults are unpaid (Kamiya *et al.*, 2012). Many of the 750,000 people with dementia (PwD) in the UK are cared for at home by a relative or friend. Carers of PwDs frequently report feelings of social isolation and inadequate social support. Risk of anxiety and depressive disorders is increased and older carers’ physical health and mortality can be affected by stress and anxiety which can in turn compromise ability to care (McKechnie, Barker and Stott, 2014); (Moreno *et al.*, 2016).

Carers are seen as a critical health care resource. Evidence on the health effects of caregiving gathered over the last 20 years has helped convince policymakers that this is a major public health issue (Schulz and Sherwood, 2008). From an economic point of view, studies have shown the value associated with informal care is massive with the estimated value of informal care in Ireland being €5.3 billion per year (O' Sullivan, 2019). A census carried out in Ireland in 2011 revealed that 4.1% of the total population was providing unpaid assistance to others in April 2011. The number of carers aged 60-74 years old increased by 33.6% from 2006 to 2011, with a further 39.5% in the group aged 75 and over (CSO, 2012). The economic value has been estimated to be in the region of €4 billion per year. This estimation shows a significant increase from the 2006 estimate of €2.5 billion (Care Alliance Ireland, 2015).

2.3 Caring Related Stress and Wellbeing

As the number of families affected by dementia grows, an aspect of dementia care in general that has come to be viewed as increasingly important is the mental health, wellbeing and quality of life of carers. Behavioural changes and impairment problems that arise due to dementia-related cognitive decline leads to an increasingly more challenging environment for a carer. Once coupled with a lack of support, these changes can then result in increased levels of stress, anxiety, depression and physical health problems. While traditional interventions for carer wellbeing are multi-dimensional in nature and focus on psychological, social-emotional, and educational issues, these programmes do not typically target chronic stress (Vinci *et al.*, 2019). Chronic stress occurs when stress becomes excessive and unmanageable. The stress response becomes activated repeatedly and persists for a long period, resulting in wear and tear on the body which causes a feeling of being in a permanent state of 'fight or flight' (Mental Health Foundation, 2020); (Seiler, Christian and Fagundes, 2020). Normally, when a perceived threat has left, levels of hormones such as cortisol will return to normal. However, long-term activation of this stress-response system and the resultant overexposure to these stress hormones can be disruptive and damaging to many of the body's processes. These can include digestive symptoms, headaches, sleeplessness, sadness, anger, or irritability (NHS Inform, 2020); (Mayo Foundation for Medical Education and Research, 2020); (National Institute of Mental Health, 2020).

There is a large amount of research linking informal caregiving to high levels of burden, anxiety, stress and poor overall wellbeing (Schulz and Sherwood, 2008); (Fonareva and Oken, 2014); (McKechnie, Barker and Stott, 2014); (De Carvalho *et al.*, 2013); (Moreno *et al.*, 2015); (Dharmawardene *et al.*, 2016). Caregiving has been shown to lead to chronic stress arising from a combination of a number of strenuous factors, including physical and psychological strain, unpredictability, duration, coupled with secondary stressors such as family and work relationships. Caregiving can be extremely stressful due not only to the caregiving itself but also to the need to balance work, family and other elements of one's personal life (Chen, Ngo and Young, 2013).

As well as objective burdens such as the physical activities associated with caring, there also exist considerable subjective burdens such as emotional distress which arise as a reaction to the caregiving process (Montgomery and Kosloski, 2009); (Vasileiou *et al.*, 2017); (Greenwood, Pound and Brearley, 2019). Chen, Ngo and Young (2013) point out that caring for older adults is often highly demanding, leading to frustration and sometimes depression in the carer. Findings from their study addressing carers' experiences revealed feelings of stress, frustration and difficulty across all interview respondents. Schulz and Sherwood (2008) discuss the physical and mental health effects of caring as reported in the literature over three decades. Research findings from this article indicate aspects of psychological wellbeing such as depression and stress are the most frequently reported consequences of caregiving, more so than physical effects. Indeed, the negative impacts on wellbeing are compounded when carers are older adults, with this population reporting poorer psychological and physical health than younger adult carers (Schulz and Sherwood, 2008). Feelings such as distress and depression can in turn lead to negative physical outcomes also. For carers of PwDs, these symptoms have been reported to a larger extent. As older adults have lower physiological reserves, they are more likely to be affected by stress (Fonareva and Oken, 2014).

The impact of stress on emotional wellbeing can also result in detrimental effects to overall health and wellbeing (Lane *et al.*, 2011). McCurry, Song and Martin (2015) suggest there is a clear link between sleep loss and caregiving stress, which can in turn lead to a vulnerability to chronic disease. For older adults, recent evidence indicates poor sleep quality furthers the possibility of developing cognitive impairment and dementia (Landry, Best and Liu-Ambrose, 2015). Sleep disturbances are very common in carers and have negative physical, medical and functional effects. Rowe *et al.*, (2008) compared data from a study on older dementia carers with a study with older non-carers and found sleep was worse for carers when measured objectively and using self-report data. Poor sleep among carers has also been shown to be associated with poorer psychological state (Willette-Murphy, Todero and Yeaworth, 2006); (Brummett *et al.*, 2006).

With reference to Ireland specifically, '*De-Stress: A study to assess the health & wellbeing of spousal carers of people with dementia in Ireland'* was published by The Alzheimer Society of Ireland in 2017 (Brennan *et al.,* 2017). A total of 200 participants took part, half of whom were between 65 and 74 years of age while a quarter were over the age of 75. 65% of the carers who participated were women. Results from the De-Stress study show that 79% of the participants provided the majority of the care for their spouse (81-100%) without extra support. As well as this, 42% reported receiving no assistance whatsoever from family or friends in the previous month, while 48% reported spending all of their waking time providing care to their spouse. Just one in four had availed of carer training. Among the negative elements to caring reported by the carers were certain distressing care-recipient symptoms, such as aggression, anxiety, irritability, and night-time behavioural disturbances. With regard to burden, 9% reported severe burden, 36% had moderate to severe levels, 40% reported mild to moderate burden, and 14% experienced little to no caregiving burden. Despite all of this, the majority of carers felt there exist positive aspects to caregiving, including an increased appreciation for life and feeling needed and useful.

Perceived stress and its associated factors among older carers have also been discussed by Luchesi *et al.*, (2016). A cross-sectional investigation was carried out wherein 341 participants in Brazil (76.8% = f, mean age = 69.6), completed household interviews and answered questionnaires. The care recipients were over 60 and were living with the carer. Results showed higher levels of perceived stress being associated with self-reported pain, difficulty sleeping, poor levels of self-rated health, poorer cognitive status and higher levels of carer burden. It should be noted that this study did not assess other potentially important aspects such as social support, personality, and assistance or support received. Nonetheless, Luchesi *et al.* point to similar results found following a study with Alzheimer's Disease and Parkinson's Disease spousal carers wherein higher levels of perceived stress were associated with poor physical and mental health. The authors also highlight another study carried out by Epstein-Lubow *et al.*, (2011) which used the same measurements to assess carers before and after a MBSR intervention lasting 8 weeks. Findings showed a reduction in perceived stress levels as well as burden after the intervention and in a one-month follow-up.

The quality of life (QoL) of family carers of PwDs has also been explored in the literature. Farina *et al.*, (2017) found that QoL of carers of PwDs is a complex construct with multiple factors involved. The theme most consistently associated with positive QoL was better carer health (physical and mental). The majority of carers felt a sense of satisfaction and reward as a result of caregiving, which in turn, improved QoL. A negative association between stress/burnout and carer QoL was found. Overall there was found to be a dissociation between objective and subjective burden, suggesting that perceived stress and carers' own appraisal of their situation are probable determinants of carer QoL. The authors do highlight, however, that the heterogeneity between groups (mostly spouses or children) suggests such results may not be generalisable to other carer/care recipient relationships.

2.4 Mindfulness as an Intervention

Mindfulness has been described as an active process during which attention to the present moment is accomplished to allow for a complete, meaningful experience of what is happening currently, 'without avoiding, judging or ruminating about certain features' (Fresco *et al.*, 2011). It has moved from a somewhat obscure Buddhist practice to a mainstream psychotherapy construct due to the success of MBIs (Davis and Hayes, 2011). MBIs are comprised of evidence-based programs which address stress-related ailments through training participants in 'the systematic practice of attending to moment-by-moment experiences, thoughts, and emotions from a non-judgmental perspective' (Black *et al.*, 2015 p.495). It is believed to work through arousal and neurocognitive processes that moderate the relationship between perception of stimuli and appraisal (Black *et al.*, 2015); (Dharmawardene et al. 2016). Mindfulness itself is seen as a state and not a trait, which can be promoted by practices such as meditation but is not synonymous with them; it is a state to be achieved rather than a trait equivalent to meditation, and the majority of empirical research shows the enhancement of mindfulness is achieved by mindfulness-meditation primarily (Davis and Hayes, 2011). MBIs have been shown to improve health measures, such as anxiety, sleep disturbances, and stress (Wahbeh, Goodrich and Oken, 2016).

2.4.1 Forms of mindfulness-based interventions

MBIs have been defined to commonly include both Mindful-based Stress Reduction (MBSR) as well as those integrating elements of mindfulness with behavioral therapies such as Mindfulness-based Cognitive Therapy (MBCT) (Liu, Chen and Sun, 2017). In MBSR, techniques were originally developed to address suffering related to chronic pain. These techniques include deep breathing, body scans and other mindful activities designed to combine ‘all aspects of experience into a meaningful whole’ (Fresco et al., 2011). While it was initially designed for chronic pain-related stress management, programmes now cover a range of disorders including anxiety, depression and immune disorders among others (Niazi and Niazi, 2011). Offered as an alternative to pharmacological treatments, traditional standardized courses include weekly sessions of 2.5 hours (with a guided practitioner), one full-day retreat, daily home practice, with courses lasting eight weeks. The aim is to enable participants to avoid the tendency to automatically engage in negative mental states. It emphasizes experience of the present moment and teaches participants to accept thoughts, feelings and behaviours that are out of their control (Fiocco *et al.*, 2019). Training is provided in formal mindfulness meditation techniques as well as simple yoga-based stretching exercises. Examples of meditation practices found in MBSR programmes include breathing- and body-focused exercises; exploring thoughts, sensations and emotions; as well as techniques for integrating mindfulness into daily life and activities. Participants are also trained to recognise behavior patterns and how these relate to thoughts. This is particularly relevant for noticing increases in stress levels, with practices aiming to demonstrate that circumstances are often beyond one’s control, but the response to such circumstances need not be (Institute for Mindfulness-Based Approaches, 2020); (Mallya and Fiocco, 2016).

MBCT differs slightly to MBSR in that it integrates cognitive-behavioral interventions simultaneously with mindfulness meditation practices. MBCT was developed in 2002 as a non-pharmacological treatment for depression (Segal, Williams and Teasdale, 2002). It was proposed that integrating cognitive behavioural therapy (CBT) elements, such as developing awareness, would allow for a decentered relationship to thoughts and feelings. Cultivating mindfulness in this manner allows for the interruption of the downward spiral towards depression among those who are vulnerable to low moods[3]. Results from a study determining the effect of MBCT on anxiety symptoms in older people living in residential care indicated that those in the MBCT group reported significantly greater improvements in anxiety symptoms than the control group (Helmes and Ward, 2017). This form of MBI is also discussed by Foulk *et al.*, (2014) wherein the results of an eight-week MBCT group for older adults with depression and/or anxiety also showed considerable improvements in reported anxiety, as well as ruminative thoughts, sleep problems and a reduction in depressive symptoms. These findings are supported by Liu *et al.* (2017) who investigated the efficacy of mindfulness training in improving stress-related outcomes in family carers of PwDs. MBCT could be especially appropriate for older adults as it potentially obviates the requirement for pharmacotherapy, which is a considerable concern for this population (Fiske, Wetherell and Gatz, 2009).

While both MBSR and MBCT are broadly similar and are often used inter-changeably, what separates them primarily is the increased focus on unhealthy thought patterns and behaviours in MBCT. Techniques used in CBT, such as learning to notice unhealthy thought patterns and keeping a journal to keep track of times certain behaviours are carried out, are typically carried over to MBCT in some form or another (Williams and Penman, 2011). Ultimately, both forms of MBI share the core characteristics of harnessing the ability to pay deliberate attention to present experience from one moment to the next. The aim with MBSR and MBCT is to both provide psychological insights about one's experiences and to learn and adopt skills to deal with these in a different and more effective manner.

2.4.2 MBIs and cognitive and emotional wellbeing in older adults

MBSR has been shown to be effective in various studies in improving psychological wellbeing and stress-related conditions (distress, worry, anxiety) in both clinical and healthy populations. Moreover, findings from studies examining the effectiveness of MBSR on older adults have shown improvements in emotional wellbeing, for example through reductions in loneliness, emotional distress, depression and anxiety (Mallya and Fiocco, 2016); (Hofmann *et al.*, 2010); (Khoury *et al.*, 2013); (Vøllestad, Nielsen and Nielsen, 2012). As well as this, improvements in physical symptoms such as blood pressure, pain and immune functioning have been reported

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[3] https://www.umassmemorialhealthcare.org/umass-memorial-medical-center/services-treatments/center-for-mindfulness/mindfulness-programs/mbct-and-mbsr-the-differences-0

(Bohlmeijer *et al.*, 2010); (Chiesa, Calati and Serretti, 2011); (Grossman *et al.*, 2004); (Bhasin *et al.*, 2018).

Mallya and Fiocco (2016) present the findings of a study investigating the effectiveness of MBSR on cognition and overall wellbeing in healthy older adults. The study recruited 97 participants, who were assigned to either MBSR or control groups. These individuals were at least 60 years of age and living independently in the community. Qualitative data from the study suggests that participants who engaged in MBSR felt improved physical and mental awareness, increased patience and acceptance, reduced physical pain and the ability to better deal with stressors.

Geiger *et al.*, (2016) present a review of the effects of MBIs on older adults' physical and emotional wellbeing. Many of the studies in the review found that mindfulness training has beneficial effects on a broad range of both physical and psychological problems, including pain, mood, anxiety, and stress-related disorders (Hoffmann *et al*., 2010); (Khoury *et al*., 2013); (Vøllestad, Nielsen and Nielsen, 2012); (Bohlmeijer *et al.*, 2010); (Chiesa, Calati and Serretti, 2011); (Grossman *et al.,* 2004). Positive effects on the wellbeing of participants were found in the majority of studies that measured psychological outcomes, including depression, anxiety, stress, general distress, loneliness, rumination, positive affect, satisfaction with life, and quality of life. Physical health outcomes included improvements in pain, sleep problems, physical function, disability, activity level, respiratory function, blood pressure and immune function. In terms of adherence and engagement, it was found that most participants regularly attended sessions, completed homework and continued to practice skills after the study had finished, with the attrition rate of 23% being largely due to unanticipated illness. The studies used standard MBSR, standard MBCT and also a variety of modified forms of MBSR and MBCT. These modifications were made to cater for the particular population and included simplifying yoga practice, eliminating the full-day retreat and shortening the amount of homework. Modifying protocols in this manner may sometimes be necessary to increase feasibility. However, it is difficult to draw conclusions about the success of these modifications as there was little consistency in how the protocols were modified. Geiger *et al.* also point out that the majority of the studies were exploratory, owing to the small body of literature to date in this area.

Significant findings regarding the potential benefits of MBSR for older adults were also reported by Young and Baime (2010). A retrospective analysis investigating the effect of MBSR training on mood states in older adults was conducted. Specifically, the program in question was the Penn Program for Mindfulness, an eight-week course with 27 hours of instruction and daily home practice of 45 minutes. 202 participants over 60 years of age, who had completed this program between 2003 and 2009, were identified. These participants had all completed the Prolife of Mood States Short Form pre- and post-MBSR training, which assesses overall emotional distress, with sub-scales measuring tension/anxiety, depression/dejection, anger/hostility, fatigue/inertia, confusion/bewilderment, and vigour/activity. Findings from this investigation showed significant improvements in overall psychological distress and across all sub-scales. Over half of those who had initially reported having significant depression and/or anxiety, did not do so following the MBSR training. A lack of a control group, the absence of a validated measurement of mindfulness and a reliance on self-report should be taken into account when interpreting Young and Baime’s findings, however.

Findings from a study investigating older adults’ perceptions about initiating and maintaining mindfulness and exercise practices suggest that training in these areas can support older adults who are undergoing mental, social, emotional and physical change by providing them with tools to cultivate important health and lifestyle qualities (Parra *et al.*, 2019). Participants in this study had recently taken part in MBSR and exercise-based interventions, and feedback provided though focus groups showed that awareness and self-reflection had been increased, along with a more self-accepting and less judgmental attitude. Among the primary benefits of the mindfulness intervention reported were a reduction in stress, improved sleep quality, and a positive perspective on life in general. Improvements discussed also included self-care habits, emotional state of mind, and better familial and social relationships. The authors stress that selection bias may need to be taken into account, however, given that participation in the focus groups was voluntary, and as such may have involved those individuals who were more engaged and enthusiastic about participating.

2.4.3 MBIs and sleep quality and physical wellbeing in older adults

By recent estimates, over half of people aged 55 and older suffer from some form of sleep disturbance, such as initiating and maintaining sleep (Crowley, 2011). These disturbances are associated with further difficulties, with older adults suffering deficits in daytime functioning, depressed symptoms, and a reduced quality of life. There is a tendency for sleep disturbances in older adults to go untreated, potentially leading to the onset of clinical insomnia, which in turn can result in physiological and psychological distress. When viewed from a cognitive perspective, sleep problems are the result of distress caused by automatic arousal and dysfunctional cognitions. Black *et al.* (2015) point to studies which show that mindfulness meditation has the potential to address these automatic responses and increase the relaxation response. This can be achieved by increasing attentional factors, which can influence the autonomic nervous system, minimize worry and rumination, and lessen mood disturbances.

Black *et al.* (2015) conducted an RCT investigating mindfulness meditation and improvements in sleep quality and daytime impairment among older adults with sleep disturbances. Mindfulness meditation was used as a mind-body medicine alternative to common treatment options for clinical insomnia, such as pharmacotherapy and psychobehavioural therapies. Pharmacotherapy, while often effective in the short term, has significant drawbacks, such as residual daytime effects and dependency. Psychobehavioural therapies, for example CBT and sleep hygiene education, are seen as effective non-pharmacological treatments for insomnia; but they are often intensive and require highly trained therapists throughout. MBIs, however, are seen as a practical alternative, which can address the drawbacks of pharmacotherapy and psychobehavioural treatments. For the study, 49 older adults were recruited and placed in two parallel groups, one engaging in an MBI, and the other receiving a structured sleep hygiene education program. Both programs lasted six weeks. The primary outcome measure was to determine between-group differences in moderate sleep disturbances, while secondary outcomes related to daytime impairment and included measures of insomnia, depression, anxiety, stress, and fatigue. Objective measures such as actigraphy were not included, however. The main findings from the study indicated the MBI resulted in improvements in sleep quality post-intervention and was superior to the structured education program. In addition, the MBI brought about improvements in sleep-related daytime impairment of depression and fatigue.

MBIs have also been shown to be effective in improving blood pressure (BP). In a study by Bhasin *et al.* (2018), improvements in BP were observed which are consistent with changes seen with antihypertensive medications. Moreover, these changes were consistent with related work showing the impact of MBIs on BP in a variety of populations. Based on psychological self-report measures, participants also reported significant improvements in anxiety symptoms.

Patients with high BP are typically treated pharmacologically. However, not all patients respond to this approach and it is common to have treatment-limiting adverse experiences. For these patients, alternative strategies can be invaluable.

Fiocco *et al.* (2019) employed a mixed-methods approach in an RCT investigating the effects of mindfulness training in healthy community-dwelling older adults. The authors proposed that training on mindfulness techniques could have beneficial effects for aging in later life. Ninety-six participants (f = 70) over the age of 65 and living independently took part. The control group consisted of a reading and relaxation program (RRP). For those in the MBI group, course content included formal practice such as sitting meditation, body scan, mindful movement, and mindful eating, as well as informal practice wherein the focus was on incorporating mindfulness into everyday activities. Participants were asked to engage with the formal practice content for 30 minutes per day. Guided, home practice was supported though audio recordings of formal meditations. Eight weekly group sessions lasting 2.5 hours led by experienced facilitators were included for both the experiment group and the control group.

Emotional and physical benefits were reported by participants in both groups though in different manners. MBI participants reported emotional benefits in the areas of relaxation, positivity, rumination, compassion, self-awareness, communication and acceptance. RRP participants meanwhile saw emotional benefits in relaxation, social interaction and support, and appreciation of discussions held around the stories read. Interestingly, physical challenges such as pain and difficulty keeping still for extended periods, and emotional challenges such as boredom, scepticism towards techniques, and difficulties concentrating were reported by the MBI group whereas this was not the case for the RRP group. It should be noted that a follow-up assessment was not carried out as part of this study, and as such these results may not have been sustained in the longer-term.

2.4.4 MBIs and caring

MBIs and their use among carers have been explored and discussed extensively in the literature, with the majority of studies suggesting high levels of feasibility and acceptability while also showing positive benefits in relation to perceived stress and overall psychological wellbeing as well as increases in dispositional mindfulness (Li, Yuan and Zhang, 2016); (Epstein-Lubow *et al.*, 2011); (Kögler *et al.*, 2014); (Jaffray *et al.*, 2016); (Kor, Liu and Chien, 2019). A systematic review aimed at evaluating the evidence for the effectiveness of MBSR/MBCT for carers of people with a wide range of conditions was carried out by Li *et al.* (2016). Fourteen studies involving 849 participants were selected for review. Outcome measures included subjective wellbeing, quality of life, physical functioning, stress, anxiety and coping. Adaptations to the standard MBSR protocol for one of the studies (Epstein-Lubow *et al.,* 2011) were made to meet the daily needs of the carers. Examples of these modifications included an increase in the classroom discussion, reduction in the classroom session length and expected home-based practice time, and cancellation of the silent retreat. Most of the 14 studies included in the review showed improvements in the self-rated psychological symptoms of the participants such as stress, depression, anxiety and mindfulness following the MBSR training. While Li *et al.* point out that not all of the studies included for review were high quality intervention studies, they do propose that MBSR could be considered a safe, simple, accessible means of promoting psychological wellbeing among carers.

Kogler *et al.* (2013) present a study investigating whether mindfulness could address mental distress and psychological wellbeing in carers of palliative patients. Results showed increased levels of dispositional mindfulness amongst carers corresponded to higher quality of life, life satisfaction, experience of meaning, and lower psychological distress. A review by Jaffray *et al.* (2016) also identified MBIs to be a feasible form of treatment amongst carers of palliative patients. Qualitative results indicate 'increased acceptance of the illness, self and others; increased sense of presence; feeling of peace and reduced stress and reactivity'. One potential issue, however, was levels of adherence as most studies reported a decreased rate of practice over time. While the majority of these studies used face-to-face group protocols, the authors point to emerging research in the area of delivering interventions via telehealth and online platforms which could be particularly suited to carers as they address problems such as scheduling difficulties, time constraints, and not wanting to leave the care recipient alone for extended periods of time.

Modified mindfulness-based therapy was evaluated by Kor, Liu and Chien (2019) in a study with family carers of PwDs to explore its effects on health and wellbeing. An RCT with 36 carers (F = 83.3%, mean age = 57.1) was carried out, which included an MBCT intervention group lasting 10 weeks, and a control group who received a standard family care and education dementia programme. Participants were recruited from a single community centre, which the authors point out may affect the generalisability of the findings. Both groups had similar sessions in terms of duration and frequency throughout the trial. The MBI was modified based on findings from a previous review by Kor *et al.*, (2018) investigating the effect of mindfulness in family carers of PwDs. In that review, it was found that the demands placed on participants in terms of the number of face-to-face sessions (a weekly 150-minute session over eight weeks, plus a 7.5-hour retreat) often results in high attrition rates. Thus, the protocol was modified for this study in terms of content, duration and number of sessions. As well as mindfulness activities typically found in MBSR/MBCT programmes such as mindful moment, body scan, and mindful eating, this program also included psychoeducation on caregiving and group sharing. Participants were also provided with an audio recording of guided mindfulness activities for use at home.

Findings from Kor, Liu and Chien's study indicate that this form of MBI is feasible and acceptable for carers of PwDs. The intervention group experienced decreases in perceived stress and depressive symptoms post-intervention. The same was found at the three-month follow-up as well as a decrease in burden and improved quality of life. The mean duration of weekly practice throughout the program was 180 minutes, which suggests that such a modified form of MBCT can lead to increased levels of mindfulness and support carers in developing the habit of practising mindfulness at home. Throughout the trial, participants were also supported and encouraged through telephone contact. Kor, Liu and Chien propose that monitoring progress in this manner helped to motivate the carers to both cultivate the habit of practicing mindfulness and apply a mindful attitude throughout their day. The authors believe these modifications resulted in the sustained effects at the 3-month follow-up, which were not observed in previous studies that omitted such modifications (Brown *et al.,* 2015); (Epstein-Lubow *et al.,* 2011); (Oken *et al*., 2010).

A small pilot study exploring mindfulness training for carers of frail older adults aimed to address negative health effects related to caring such as chronic stress and associated psychiatric symptoms (Epstein-Lubow *et al.,* 2011). Participants included nine female carers aged 48 to 73 (mean age = 56.2), and care recipients had either dementia (7) or were frail due to medical conditions (2). Qualitative results showed a positive response in relation to fostering compassion and forgiveness. Specifically, the mindfulness training resulted in the participants accepting their loved one's situation without judgement, and feeling more at ease being present with the care recipient. Participants also reported maintaining the use of mindfulness-based exercises for four weeks following the trial. While depressive symptoms improved during the intervention, they returned to baseline levels at week 12. However the study is limited in that the sample size was small and no control group was included.

Brown *et al.* (2016) explored the impact of MBIs on burden in carers of PwDs. Thirty-eight carers participated in an RCT and were randomized to either the MBSR group or a social support control group. The control group was structurally equivalent to the MBSR intervention group in terms of duration (eight weeks), and group attendance (1.5-2 hours per week); there was also a day-long retreat for the MBSR group only. With regard to the psychosocial outcomes post-intervention, participants in the MBSR group reported significant improvements in perceived stress, tension, and anger more so than the control group. The control group showed an advantage on carer burden, however. At three-month follow-up, there were improvements in psychosocial outcomes amongst participants in both groups, suggesting both approaches are suitable for supporting mental health and resilience among family carers of PwD.

2.4.5 Adherence to MBIs

As is evident from the studies outlined above, the issue of adherence to MBIs has been explored in the literature, with many studies recognising the need to adapt standard MBSR/MBCT programs to suit particular cohorts. Parsons *et al.* (2017) aimed to investigate the extent to which formal home practice was completed by participants in MBSR/MBCT programmes (eight weeks, 2-2.5-hour class time, one day retreat, and home-based practice of 45 minutes, six days per week), and whether completion was associated with treatment outcomes. Forty-three studies were included for review, with results showing that participants completed approximately 60% of the formal home-based practice. This equates to 30 minutes a day, six days a week – less than the 45 minutes as set out in the standardized format, but a substantial amount of time, nonetheless. With regard to positive intervention outcomes, a small to moderate association with formal practice was found. An interesting potential limitation was noted by the authors concerning tracking genuine engagement and the difficulty ascertaining whether or not a participant had actually listened to a meditation having pressed play.

The study by Fiocco *et al.* (2019) outlined in Section 2.4.1 found that healthy older adult participants only engaged in 75% of the home practice content that was provided, and as such likely missed out on some important content. Fiocco *et al*. suggest providing a facility whereby the individual can select the audio recording length at any time themselves. This is a feature offered in Headspace[4], with users free to choose from 10, 15, or 20-minute mediations. The content here is the same, rather it is the length of pause that is reduced. This type of personalization may be particularly for older adults, who may have physical limitations in terms of sitting still for extended periods of time, or for carers who have limitations in terms of time due to their caregiving duties.

2.4.6 Digital Mindfulness-based Interventions

Related research in this section has highlighted the potential of traditional MBIs in positively impacting the health and wellbeing of individuals, including improving mental health and emotional wellbeing (Section 2.5.2), improving sleep quality and physical wellbeing (Section 2.3.3) as well as being beneficial for carers (Section 2.3.4). With the advancement of digital technologies in the area of health and well-being, researchers are increasingly turning to technology as a solution to manage stress, anxiety, social isolation, and negative emotions. In parallel, traditional mindfulness practice is moving online to support people’s needs in the digital age (Zhu *et al.*, 2017). Online MBIs have been well-received by many with one cross-sectional survey revealing that 42% of individuals (500 adults) preferred this format (individual and online) to traditional group formats (Wahbeh, Goodrich and Oken, 2016). Research has also shown that half of Americans aged 65 and over are internet users, which provides support for the viability of delivering online interventions to people in this age group (Zickuhr and Madden, 2012). Similar to online psychoeducational or CBT programmes for carers noted in the previous section, advantages to online MBIs include accessibility, availability, self-directed pacing, cost, and the lack of necessity for a therapist.

A number of studies have demonstrated the feasibility of online MBIs delivering benefits and impact similar to those experienced in traditional MBI delivery, such as reduced stress, anxiety, depression and burden, and improved wellbeing (Tkatch *et al.*, 2017); (Spijkerman, Pots and Bohlmeijer, 2016); (Dowd *et al.*, 2015); (Morledge *et al.*, 2013); (Glück and Maercker, 2011); (Jayewardene *et al.*, 2017) although the majority have also cited issues with adherence.

Tkatch *et al.* (2017) outline a study involving 40 older carers who participated in an eight-week mindfulness intervention, that employed a combination of web-based content and phone

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[4] https://www.headspace.com/how-it-works

contact. The online platform contained session materials, downloadable brief meditation practices, access to short learning videos, and other support tools. Modules were also delivered in-person if participants were able to attend and favoured this approach. Results from this study indicate that the intervention reduced carer burden, perceived stress, anxiety, and loneliness and improved mental wellbeing. However, a lack of a control group as well as the participants having been recruited from a support group, and therefore likely eager to participate in such an intervention, need to be taken into account when generalising these findings to all carers.

Other research into online MBIs involving a general adult population experiencing pain found that participating in the online MBI resulted in improvements in life satisfaction, ability to manage emotions, and capacity to deal with stress, all of which were maintained at six-month follow up (Dowd *et al.,* 2015). Adherence and maintaining engagement with the MBI was found to be a challenge. However, Dowd *et al.* point to high completion rates (90%) reported in an online CBT study by Dear *et al.* (2013) which were achieved through the integration of weekly telephone contact, a requirement that participants must compete one session before progressing to another, and possibly effective interface design and content. In spite of the problems posed by low adherence in Dowd *et al*.'s study, however, the benefits offered such as flexibility and low delivery cost still suggest there is value and potential in delivering MBIs online.

The feasibility of shorter form web-based mindfulness training has also been tested within an RCT setting (Gluck and Maercher, 2011). Significant reductions in stress and improvements in negative effects were observed among the participants who participated for six days or more. The analysis indicated that those in the treatment group were nine times more likely to report changes in perceived stress than those in the control group. Benefits from training were also observed at three-month follow-up. However, the authors suggest conclusions are limited due to the difficulty in determining whether or not participants engaged with the content while on screen. This is difficult to avoid with non-interactive content that does not allow for user activity tracking or monitoring.

Findings from the studies outlined in this section demonstrate the scope and potential for digital MBIs in positively affecting stress and improving overall wellbeing for a range of populations. As well as this, they offer a low-cost and flexible alternative for difficult to reach groups, particularly those living in rural areas or providing full-time care. However, an issue that must be considered is engagement and how to overcome or effectively manage problems with adherence, given that this is an important factor with regard to sustained practice and ensuring that any long-term benefits of mindfulness meditation are realised.

2.5 Physical Activity in Older Adults and Carers

Regular physical activity can help maintain quality of life for older adults and is a crucial part of healthy living. The benefits are significant and include (among others) improvements to blood pressure, cholesterol levels, sleep quality, and mental function, as well as decreased risk of falling, depression and hospitalization (Langhammer, Bergland and Rydwik, 2018). These potential benefits could be seen as even more vital in the context of older carers given that they are often responsible for the wellbeing and quality of life of the care recipient (Vinci *et al.,* 2019); (Orgeta and Miranda-Castillo, 2014); (Hill *et al.*, 2007). Moreover, there are reduced opportunities for exercise amongst carers of PwDs, meaning their physical health can also be at risk (Hirano *et al.*, 2011). Research has indicated that physical activity interventions can have positive impacts for carers of PwDs, including reduced burden (Orgeta and Miranda-Castillo, 2013); (Hirano *et al.,* 2011a) and improved sleep (Hirano *et al.*, 2011b) and that this cohort are willing to engage in physical activity interventions (Farran *et al.*, 2008).

Hirano *et al.*, (2011a) explored the extent to which regular exercise affected subjective sense of burden as well as subjective physical symptoms in older carers of PwDs. Participants were 31 older carers (73.7 = mean SD age, 67.7% = F) who were living with the care recipient. The participants were randomly assigned to either an intervention group which involved a regular exercise program of moderate intensity (three times per week for 12 weeks), or a control group in which the subjects were not advised to exercise. Exercise progress was recorded through pedometers and a daily journal. Findings indicated that in the intervention group, regular physical exercise resulted in significant reductions in subjective sense of burden, improved quality of sleep and positively affected physical symptoms such as fatigue, while no such improvements were observed in the control group. The authors suggest that appropriate habitual interventions involving exercise have the potential to improve the quality of life in dementia carers.

A study by Hill *et al.* (2007) recruited 116 carers (average age = 64.4, f = 855) onto a six-month centre-based physical activity program, with activities including strength training, yoga, and Tai Chi, to examine the extent to which this program was effective in improving physical, psychological and general health outcomes for older carers, while also seeking to determine both barriers and enablers to sustained participation. Prior to the study starting, over half of the participants reported experiencing various stressors such as feeling unable to get everything done, needing to always be available for the care recipient, and being unable to rest while ill. Among the health benefits observed were improved balance, leg strength, gait endurance, and self-rated physical health, as well as reduced depression. The majority of carers also enjoyed participating in the program and reported a range of self-perceived benefits associated with it. There were no significant changes for either carer burden or carer quality of life. As well as this, carers reported that upon returning home, specific carer stressors remained the same as before. Hill *et al.* suggest that the findings from this study emphasise the need for further research exploring the degree to which carer burden, quality of life, and psychological and physical status are related in order to maximize the impact of support programs of all types. As well as this, the lack of a control group suggest future studies should also focus on comparison between groups to further support the findings reported.

Farran *et al.* (2008) found that carers of PwDs engaged in a physical activity intervention in terms of self-reporting on physical activity, wearing activity trackers for goal-setting and self-monitoring, and completing daily activity logs. Findings indicated that the intervention led to significant increases in physical activity in at least half of the participants. Some significant barriers to health promotion were discovered, however, including heavy responsibilities (both caregiving and non-caregiving) and carers' own concerns with respect to their mental and physical health (as well as a lack of support in this regard). As a result, it is recommended that individualized and tailored strategies for addressing these barriers would need to be implemented, taking into account the challenges posed by caregiving, to maximise the potential of physical activity interventions.

The link between older carer burden, health risks and opportunities for physical activity has been further explored by Hirano *et al.* (2011b). Factors associated with reduced physical activities in older carers of PwDs were investigated, with a specific focus on the link between particular types of physical activity and care burden. Subjective assessment of physical activity through self-report was the sole means of measurement. Fifty carers (65 years plus) were assessed with a view to identifying key factors. Results showed physical activities, in particular leisure activities, were inversely associated with care burden. High care burden can result in less temporal or psychological capacity with regard to making time for physical activity, as well as feelings of physical fatigue. While barriers exist for older carers to exercise regularly and maintain a healthy level of physical activity, results from Hirano *et al.*'s study indicate interventions which focus in particular on increasing leisure activities could prove effective in addressing care burden.

There is comparatively little research on recommended activity levels for older adults[5]. While step counting devices (accelerometers and pedometers) provide an opportunity to monitor daily ambulatory activity, current public health guidelines on recommended steps per day are aimed towards general populations and there remains a need for an appropriate translation of these for older adults. Tudor-Locke *et al.* (2011) aimed to address this. An early review of normative data from studies published between 1980 and 2000 found that healthy older adults should be expected to take 6,000-8,500 steps/ day. This figure was based on 10 studies involving adults over 50 years old who did not have any specific disabilities or chronic conditions. Updated normative data show that apparently healthy older adults average 2,000-9,000 steps/day. Tudor-Locke *et al.* conclude that the wide variance in habitual activity as shown from normative data indicates the natural diversity of physical capacity among older adults. They suggest that the evidence indicates that 30 minutes of daily moderate-to-vigorous physical activity alongside habitual daily activities in healthy older adults is equivalent to taking approximately 7,000-10,000 steps/day (Tudor-Locke *et al.*, 2011). These figures are important to consider when delivering physical activity recommendations to older adults. However, differences in instrument sensitivity need to be taken into account as these ultimately affect the number of steps that have been detected, which makes comparisons across studies using different step-counting devices difficult.

2.6 Summary

As is evident from the literature, the role of informal carers in today's society is vital with regard to provision of care, support and maintaining quality of life for the care recipient. The

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[5] Note: This was true during the time this research was conducted. In November 2020, the World Health Organisation produced a report on guidelines for physical activity for older adults.

majority of such carers are unpaid. Older carers typically receive minimal support from care agencies while at the same time providing a large degree of intensive care to the care recipient. Informal caregiving has been shown extensively to be connected with chronic stress, as well as high levels of burden, anxiety and poor wellbeing, with there being a direct link between caregiving stress, sleep loss and chronic disease. Mindfulness-based interventions have the potential to address these issues. As the literature demonstrates, MBIs have been shown to be effective in improving various health measures, including anxiety, stress and sleep disturbance across various populations and have been trialed successfully and extensively with informal carers. Another important area to consider in relation to wellbeing of older informal carers is physical activity, given the importance of maintaining physical activity in older age and the limited opportunities carers have to partake in physical activity. There exists an opportunity for digital technologies to address the areas of physical and psychological wellbeing among older informal carers through self-management, monitoring, education, and adapted MBIs. With this in mind, the following chapter presents a review of the literature in the areas of digital self-management technologies, technologies for informal carers and digital mindful-based interventions.

Chapter Three: DESIGNING FOR HEALTH AND WELLBEING SELF-MANAGEMENT

3.1 Introduction

Digital, or Connected Health encompasses health technologies that deliver health care remotely (Harte *et al.*, 2017). Research into digital health technologies in recent years has been driven by the rise in movements such as the Quantified Self and Wearable Computing, resulting in the design and development of sensors (including, for example, blood pressure monitors; weighing scales; sleep, diet and activity tracking devices) and applications that enable health and wellbeing self-monitoring and that encourage individuals to maintain healthy lifestyles by recording their everyday behaviours (Paredes *et al.*, 2014); (Harte *et al.*, 2017). As smartphones and tablet devices have become ubiquitous and more accessible in recent years, with rapid developments and advancements in design and functionality, new opportunities exist for personal health applications to monitor, model, and promote wellbeing (Lane *et al.*, 2011); (Fritz *et al.*, 2014). In addition, personal health technologies allow for the provision of feedback and interventions to encourage behavior change (Bardram *et al.*, 2013). These developments and advancements provide opportunities for assisting older adults in managing and maintaining their wellbeing. A challenge exists, however, in relation to sustained use and uptake of health monitoring technologies (Toscos, Connelly and Rogers, 2013), particularly by older adults. There also exist both challenges and opportunities regarding how digital technologies can be used to support informal carers in providing care and managing their own health and wellbeing. This chapter discusses how digital health technologies are used to support health and wellbeing self-management, encourage behavior change, deliver therapeutic and mindfulness-based interventions, provide education and support to informal carers, and encourage physical activity. A review of the literature is then provided in the areas of older adults' attitudes to technologies, as well as approaches taken when involving the older user in the design process.

3.2 Digital Technologies to Self-Manage Health and Wellbeing

Given the increasing prevalence of people with chronic and other serious conditions, and the resulting impact on healthcare services, the need to support people to actively engage in self-management of conditions and associated wellbeing parameters (such as mood, activity, sleep, diet) has become more urgent. A vast array of technologies and related research now exists in this space including medical devices for symptom monitoring; wearables such as activity trackers for lifestyle monitoring (Consolvo *et al.*, 2006); (Consolvo *et al.*, 2012); and smartphone, mobile device and web applications (Årsand *et al.*, 2012); (Chomutare *et al.*, 2011); (Spina *et al.*, 2013). Consolvo *et al.* (2012) discuss the common features of mobile health and wellbeing applications, including collecting symptom and behavioural data, providing self-monitoring feedback, and integrating specific behaviour change techniques, such as goal-setting. Such functions contribute to supporting health behaviour change, which in turn can lead to improved health, which are often goals of many of these applications.

Provision of self-monitoring feedback is a core function of the majority of mobile health applications (Consolvo *et al.*, 2012). This feedback comes in four main forms: counts, graphs, stylized representations, and narrative information, with counts and graphs being the most commonly used forms, as they allow users to explore trends and relationships in the data so as to effectively make decisions about behaviour. The delivery mode of the feedback is also important, with in-application being the most commonly used due to its flexibility and level of detail. However, Consolvo *et al.* stress that one potentially negative effect of this is the need for users to keep coming back to the application, representing a significant challenge for designers. One approach to at least partially mitigate this is the use of glanceable displays, which provide 'always-on' information that can provide key information at a glance, thus allowing the user to remain engaged with their health goals. Another approach to delivering feedback to the user is on-device (for example, showing step count on an activity tracker), with this option being the most efficient in terms of speed of access, though more limited in terms of the amount of information that can be displayed.

Hekler *et al.* (2013) discuss the implementation of behavior change theories by HCI researchers in persuasive technologies. Theory is typically used to inform design and to ascertain what functionality needs to be integrated. It is also used to develop design guidelines. Using Ubifit, an application designed by Consolvo *et al.* (2011) as an example, Heckler *at al.* identify techniques based on goal-setting theory, rewards for behavior, and a stylized display of information. Consolvo e*t al.* (2011) propose it is essential for persuasive technology to support an individual's changing needs. Based on insights following the design of Ubifit, they outline five design guidelines: engagement (technology must keep the user engaged in behavior and accommodate changes in activities); relevant behaviours (account for range of behaviours and not just those that are inferred automatically); irregular activity (taking breaks can often result in sustained long-term behavior); social implications (social implications for everyday experiences must be considered); and social networks (social support can be both a positive motivator and a temptation to slide into old habits).

There is considerable potential for mobile technologies and applications to support self-management of health and wellbeing. However, the manner in which these technologies are designed and implemented can affect how the application is experienced and used. In order to fully realise the potential of such technologies, attention must be paid to effective and robust design of systems as well as to how behaviour change techniques are implemented, how seamlessly they integrate into users' everyday lives as well as the manner in which user burden is limited as much as possible (Consolvo *et al.*, 2012); (Kim *et al.*, 2016). Despite interest in mobile health applications increasing, sustained engagement with and use of these applications remains low. Among the factors contributing to this are usability and design, and improvements in these areas are necessary if these technologies are to be effective in supporting users in reaching their health goals (Consolvo *et al.*, 2012). This is particularly important for older adults who may have less familiarity with such technology.

The remainder of this section focuses on digital self-management and behaviour change technologies that address areas of interest to this PhD study, including emotional wellbeing and mental health, sleep, physical activity and those designed specifically for older adults.

3.2.1 Emotional wellbeing and mental health

Related research has examined technology-based emotional wellbeing management with various populations (Paredes *et al.*, 2014); (Bardram *et al.*, 2013); (Doherty, Coyle and Sharry, 2012); (Doyle *et al.*, 2012). More recently, research has been conducted in the areas of online and/or digital tools for supporting mental health and emotional wellbeing, focussing on elements such as experiences of guided online therapies (Jardine *et al.*, 2020), use of digital mental health tools among younger adults (Pretorius *et al.*, 2020); (Lattie *et al.*, 2019), the role of the human supporter in digital mental health interventions (Chikersal *et al.*, 2020); (Pendse *et al.*, 2020), how people living with depression self-regulate their social media use (Eschler *et al.*, 2020) and how personal informatics could be designed for future-oriented stress management (Lee *et al.*, 2020).

Jardine *et al.* (2020) explored participants' experiences of the use of online interventions for depression and anxiety in a routine care setting, specifically looking at expectations of online treatment, challenges faced as well as when and how the intervention was used. It was found that expectations of self-development were high among those accessing this form of guided online therapy, with mid and post-treatment feedback concerning experiences being generally positive. Those events and impacts found to be helpful were similar to those found in more traditional forms of CBT and psychotherapy, namely insight/awareness, behaviour change, empowerment, and feeling understood. As well as this, Jardine et al. point to other areas emerging from this data of interest to designers:

1. Expectation management – there was a sense of hope for recovery and expectation that the treatment would be effective. While these are vital for the effectiveness of an intervention, they do not fall under the design of the intervention itself, suggesting pre-treatment methods of increasing hope and readiness for change may need to be implemented.
2. Usage patterns and mood state considerations – it was found that a significant number of people used the platform as a coping mechanism for low mood, anxiety and help-seeking in the moment, rather than a form of traditional and structured therapy delivery as was intended. It is important, therefore, for designers to take into account variance in usage patterns between people and provide insights into mood patterns along with suggestions for ways to improve mood.
3. Personalization and individual preferences – there was found to be a wide range of opinions concerning how sufficient/insufficient or positive/negative certain core features of online CBT were. These included flexibility, autonomy, personalisation, support, level of information provision and interactivity, and Jardine *et al.* suggest that the very personal nature of online CBT means supporting personalization in particular should be focussed on. This can be achieved through diversifying treatments (e.g. audio as an alternative to text), socio-cultural factors (education level, gender etc.), module

progression and length, all of which could address the inherent problems of a one-size-fits-all approach.

4. Longevity of use – it was found that many of the people using the platform felt they were gaining skills for life as opposed to simply receiving treatment for an illness, viewing the intervention as a long-term, lifestyle support system. Designers should therefore consider integrating elements that support long-term wellbeing such as positive psychology or blended methods that also provide m-health alongside traditional therapy.

Bardram *et al.* (2013) discuss a field trial of the MONARCA system, a mobile health technology designed to support self-management of bipolar disorder. MONARCA was designed in a user-centred participatory design process and integrates CBT-based treatment. Features of the system included self-reporting relating to mood, sleep and alcohol; activity monitoring; historical overview of self-assessment and sensor-based data; coaching and detection of early warning signs; and the facility to share data with a clinician. Results showed this system was considered both useful and very easy to use, with adherence to self-assessment higher when compared with paper-based forms. Bardram *et al.* suggest this study demonstrates that the fact a smartphone is always with a patient means adherence is likely to be higher than it would were paper-based solutions relied upon; it also indicates that a smartphone is a suitable platform for personal health systems. The authors argue that systems such as MONARCA can support health self-management of mental health and emotional wellbeing by allowing users to monitor behaviour, informing them of physical state, reminding them to perform tasks, and providing feedback on behaviour while offering recommendations. Doherty, Coyle and Sharry *et al.* (2012) support this and suggest this online, guided self-help model can be broadened out into other behaviour change research within HCI, such as cardiac rehabilitation, physiotherapy, exercise, and medication adherence.

A tool developed by Lee et al. (2020) for personalised stress-management interventions used a future-centric approach based on better preparedness for stressors through anticipation rather than a past-centric approach, which focusses on analysing stressful events that have already occurred. MindForecaster is a calendar application which allows users to activate and plan for stressful activities, as well as evaluate their actual stress levels in terms of what had been anticipated. Results from a 30-day deployment found that users who anticipated stressful events and planned accordingly using coping interventions reported reduced stress levels more than users who only expected these stressful events to occur (without planning). Design guidelines for future-centric approaches to stress management arising out of this study focus on three key areas: expectation (identify and predict how stress may arise from an upcoming scenario), preparation (create intervention plans to address the stress previously identified based on what has worked before as well as social data), evaluation (following the event, assess the perceived stress and the effectiveness of the intervention with a view to future stressful scenarios). It should be noted that sampling bias may have been an issue with this study, given that recruitment targeted individuals who were keen to regulate stress through participation.

The HCI and digital health literature for older adults has primarily focused on the 'three geriatric giants', of ageing, namely physical, cognitive and social health. As a result, the area of emotional wellbeing of older adults is often overlooked or neglected. Doyle *et al.* (2012) see a number of elements affecting an older adult's emotional wellbeing, including age-related declines in physical and cognitive health, the loss of a spouse, and the worry of growing older and being able to cope. As noted previously, many older adults also act as informal carers for their loved ones, and experience anxiety and stress as a result. There is an opportunity, therefore, for health technologies that can support older adults in monitoring and managing their emotional wellbeing, which could ultimately lead to an improvement in health and wellbeing overall.

3.2.2 Activity and exercise

A considerable amount of research in the HCI and digital health space has focused on monitoring and promoting physical activity. Consolvo *et al.* (2006) describe an evaluation of the Houston mobile phone application and outline a set of design requirements for similar physical activity applications. Houston provides users with awareness of daily step count with the goal of promoting self-reflection. This is achieved through a mobile journal, goal-setting and rewards for reaching a daily step count, as well as social influence by encouraging users to share their step count with friends. Some of the recommended design requirements include providing personal awareness of activity levels, supporting social influence, and considering practical constraints of users' lifestyles.

Ubifit, an application similar to Houston, used goal-setting and rewards to encourage physical activity, focusing on a weekly physical activity goal with the aim of promoting self-reflection and providing personal awareness of all physical activities (Consolvo *et al.*, 2008). A further application, GoalPost (Munson and Consolvo, 2012), differed from Houston and Ubifit in that no sensors for detecting physical activity were used. Instead, the mobile phone application was used to support goal-setting by encouraging users to set a primary and secondary goal each week, providing rewards such as trophies as goals were reached, using an activity journal to self-monitor and receive reminders, and sharing goal information and activities performed with friends on Facebook. Users reported benefits from being able to set and pursue both primary and secondary goals. It was found that the rewards used did not motivate as expected. This is in spite of these rewards taking the form of badges, which is common in many commercial applications. The self-monitoring aspect of the applications received a positive response from users, with reminder notifications being appreciated.

Performance is likely to be higher when commitment to a goal is made, but is also likely to be influenced by how important the goal is deemed to be, and the level of self-efficacy or belief the person has that the goal can be achieved. According to goal-setting theory (Locke and Latham, 2006), three type of goal sources exist: self-set, assigned, and participatively set. Consolvo *et al.*, (2012) point to a number of HCI projects which investigated goal sources, such as Fish'n'Steps (Lin *et al.*, 2006), the Mobile Lifestyle Coach (Gasser *et al.*, 2006) and Houston, which all used assigned goals; and a study by Bickmore, Caruso and Clough-Gorr, (2005) which had older adults participatively set goals with a system's animated wellness coach for the following day's step count. Other projects such as Ubifit and GoalPost, as well as commercially available applications and devices such as Fitbit, used self-set goals. Consolvo *et al.* (2012) acknowledge that goal achievement was low for Houston, Ubifit and GoalPost, but stress that each of these systems supported users in gaining an insight into how active they really were, and as such this acted as a motivating tool for them to integrate more physical activity into their daily lives.

In a study on the long-term deployment of activity trackers, Fritz *et al.* (2014) found that long-term users developed awareness of the value of their activities while also feeling they had made durable and long-lasting changes to their behaviour. They attribute this to the use of feedback on progress, goals and rewards motivating behaviour change. In order to maintain engagement, however, they recommend designing systems that support the evolution of rewards that change as the user progresses through the system. Research has also indicated that if technology does not support a person in making sense of their data in a manner that meets their emotional needs, it will likely be abandoned in the longer-term (Toscos, Connelly and Rogers, 2013).

Preusse *et al.* (2017) carried out heuristic evaluations of two activity trackers with a view to assessing usability and acceptance by older adults. Results from this study suggest that low adoption rates of activity trackers among older adults could be due to both a lack of awareness as to their potential benefits and concern surrounding costs, rather than a lack of willingness. A number of training strategies aimed at explaining some of the potential benefits to older adults were laid out. These include creating tutorial videos, incorporating start-up guides that explain navigation elements and offering trial-use periods if necessary. It should be noted that participants in this study were generally in good health, which the authors point out can be a predictor in senior technology acceptance models. As such, the likelihood of this sample containing a high number of early adopters needs to be considered.

3.2.3 Sleep

The HCI literature also includes some examples of monitoring and feedback technologies that aim to support better sleep hygiene. Choe *et al.* (2011) propose the use of persuasive technology systems to address sleep disturbances with a goal to reduce both fatigue and stress. Interviews with sleep experts as well as a survey with potential users were carried out to explore what people would consider practical and useful for improving sleep quality and to identify opportunities for technologies to support healthy sleep behaviours. Based on this a design framework was developed to inform and support designers of sleep management technologies. The framework consisted of six dimensions, with each dimension also having multiple elements: goals (diagnosis, treatment etc.), features (tracking, persuasion, education etc.), source (sleep medicine community, peer-reviewed literature etc.), technology platform (wearables, web application, mobile application etc.), stakeholders (people with or without sleep disorders, bed mates, clinicians), input mechanism (manual input, automatic via sensors). Choe *et al.* applied this framework to 10 sleep-related commercial and research products with the results showing considerable variance across the dimensions, highlighting the diversity in both the functionality and design of sleep technologies as well as the profile and needs of the user.

Bauer *et al.* (2012) discuss the design and deployment of ShutEye, a peripheral display on a phone which provides information about activities which positively and negatively affect sleep, such as caffeine/alcohol/nicotine use, napping, exercising, eating heavy meals, and relaxing, along with two user-specified activities. As well as this, the system consists of an interactive application which allows users to learn more about sleep recommendations, manage desired sleep schedules and specify their preferences. Results from a four-week field study with 12 participants focusing on increasing awareness about sleep recommendations showed the system was effective with all but one participant in raising awareness around good sleep hygiene practice, while also resulting in some short-term behavior change relating to adherence to recommendations. One potential limitation with this study was that engagement in terms of participants' actual use of the display, could not be measured given that it was peripheral and therefore designed to be used at a glance rather than through direct interaction. With regard to the design of technologies for promoting awareness of healthy sleep behaviours, the authors recommend splitting activities that may affect sleep into three categories or levels (encouraged, allowable, discouraged), while also providing practical suggestions concerning how to meet certain recommendations (e.g. notifications to remind the user it was close to bedtime). In addition, participants stressed the importance of trusting these recommendations and wished to know the source (e.g., link to a web page). Similar sentiments were expressed by participants in studies conducted by Doyle *et al.* (2014) and Doyle, Caprani and Bond (2015) in which users expressed an interest in more interactive feedback with sources provided, as well as information on how they could act on data to improve health and wellbeing as opposed to simply being shown the data with no further information or advice.

The use of internet-based sleep interventions for older adults to address insomnia has been compared with psychoeducation programs offering sleep hygiene in a study by Johanson, Bohlen and Feliciano (2018) involving 46 participants aged 60 years and older. Adaptations were made to CBT for insomnia protocols which are typically resource intensive and difficult to access. Stimulus control therapy, a component of CBT for insomnia, was delivered online to half of the participants, with the other half receiving standard sleep hygiene psychoeducation only. Decreases in sleepiness, fatigue, anxiety and depression were observed in both groups, suggesting online delivery of aspects of CBT for insomnia such as stimulus control therapy may have similar efficacy to traditional approaches such as sleep hygiene education.

3.2.4 Older adults

HCI literature has also explored older adults' attitudes towards the use of technology for self-management. Research has examined wellness (Doyle *et al.*, 2014); (Hakobyan *et al.*, 2016); social wellbeing (Doyle *et al.*, 2010); functional abilities (Lee and Dey, 2011), physical activity (Gerling *et al.*, 2020); physical rehabilitation (Uzor and Baillie, 2013); medication management (Doyle *et al.*, 2017); (Siek *et al.*, 2011); and chronic disease self-management (Bhachu, Hine and Arnott, 2008); (Visser *et al.*, 2015). Research has also indicated that older adults are willing to change their behavior to adopt digital self-management (Hakobyan *et al.,* 2016). Despite this, a significant amount of research continues to question if older adults benefit from this technology or if they have a desire or ability to use it (Hakobyan *et al., 2016*); (Heart and Kalderon, 2013).

In a six-week study of a diet diary application with six older adults with age-related macular degeneration (vision loss), Hakobyan *et al.* (2016) found that using the application empowered participants to self-monitor their health, increased their awareness and resulted in increased confidence to take charge of their health. The authors also reported positive findings in relation to behavior changes by participants. However, caution is needed in interpreting results due to the small sample size, and relatively short evaluation period which didn't allow for evaluation of sustained health behavior change over a prolonged period of time.

Research has explored the experiences of older adults using blood glucometers to monitor Type 1 Diabetes (Visser *et al.,* 2015). The majority of participants reported that they began using a glucometer on advice from a caregiver. They continued using the devices to know how much insulin was required before meals and because using the device gave a sense of safety and confidence. Participants reported various reactions to their blood glucose data, including shock when results were not as expected despite having 'done the right thing' and primarily responding by injecting insulin.

Lee and Dey (2011) discuss how sensing technology can support awareness of functional abilities for older adults. Subtle changes in cognitive and physical abilities due to the onset of age can bring about declines in functional abilities in everyday life, such as taking medication and answering the phone. Lee and Dey (2011) suggest that enabling older adults to reflect on their abilities through home sensing technology can allow them to stay more self-aware and adapt where necessary. Prototypes of a sensing system were developed which aimed to monitor two activities critical to maintaining independence: medication/pill taking and phone use. Two older adults then used the system in their home for six months. Data collected was then fed back to the participants though visualizations which allowed them to reflect on their behavior. When inconsistencies with taking their medication were presented, both participants intended to change their behavior accordingly to manage these inconsistencies. The study also found that when engaging with this embedded data, the participants performed three different behaviours: trying to find mistakes, trying to explain the mistakes, and using the detailed data to verify their explanations. Lee and Dey suggest that presenting older adults with this embedded data can raise awareness and support self-reflection, which can then bring about behavior change. A later study by Lee and Dey (2014) found that while objective feedback of sensor data can support behaviour such as medication-taking and increase self-efficacy, once it is removed these improved performances do not persist due to the user having come to rely on this information in terms of their routines.

3.3 Digital Interventions for Informal Carers

The focus in HCI and digital health has centred largely on technologies which are patient-centric, with carers' need and wellbeing not being prioritized or considered to the same degree (Bosch and Kanis, 2016); (Yamashita *et al.*, 2017). However, as outlined in Chapter 2, there is recognition that there is a growing need for adequate and practical interventions and supports aimed at reducing burden and addressing negative health outcomes amongst informal carers. A wide range of technological solutions now exist, including online support tools or educational programmes (Parra-Vidales *et al.*, 2017); (Yamashita *et al.,* 2017), digital interventions to address burden, stress, anxiety and depression; (Moreno *et al.,* 2016); (Gallagher-Thompson *et al.*, 2010); (Kajiyama *et al.*, 2013), solutions aimed at social connection and peer support (Ploeg *et al.*, 2018); (Bosch and Kanis 2016) as well as those more focused on supporting the carer to self-manage their physical health (Stowell *et al.*, 2019). The different levels of experience and background knowledge among carers results in individuals requiring different levels of information and support, thereby making a 'one-for-all' solution for this target group difficult to achieve (Rettinger *et al.*, 2020).

3.3.1 Digital educational / support interventions

An increasingly popular approach in the delivery of interventions that aim to increase carer competence and knowledge is through Internet-based psychoeducation programmes (Parra-vidales *et al.,* 2017); (Yamashita *et al.,* 2017). These interventions aim to equip families with tools and strategies necessary to provide adequate care, allowing the care recipient to stay at home for as long as possible (Boots *et al.*, 2014). Among the benefits of interventions delivered online are the ability to gain access at home while remaining in the presence of the care recipient, as well as added privacy.

Parra-Vidales *et al.* (2017) carried out a systematic review of online psychoeducation interventions for carers of PwDs. Intervention characteristics varied, with different websites offering information around care delivery strategies, support from healthcare professionals, and the facility to exchange experiences with other carers online. The majority of studies reported considerable post-intervention improvements in self-efficacy, stress, depression and anxiety as well as increases in the knowledge of the disease and functional autonomy. Those that provided support from a therapist of some sort increased the carers' involvement with the intervention and the likelihood of implementing strategies learned. The authors conclude that online psychoeducation interventions, once guided or supported by a therapist, can be at least as effective as face-to-face approaches. The authors do not specify, however, if such guidance needs to be provided through in-person involvement, or if an automated approach could also be effective.

Boots *et al.* (2014) conducted a systematic review examining internet-based supportive interventions for carers of PwDs. Twelve studies were included for review and the interventions included websites with various content such as information and support, additional caregiving strategies, integrated telephone support, additional email support, and a facility to communicate with other carers online. Small but significant outcomes were observed across six of twelve studies in depression, sense of competence, confidence in decision-making and self-efficacy. Improvements in burden were only observed in two studies. In the studies that included qualitative outcomes, increased knowledge of the disease, increased coping skills, confidence, and reduced feeling of isolation were reported. This review was limited in that the intervention designs were inconsistent and varied. However, it does suggest that interventions delivered online can be effective in supporting informal carers' wellbeing. Carers across many of the studies highlighted the benefits of a guidance coach including increased commitment to the intervention as well as confidence to implement the strategies that had been learned. Those interventions that were multifaceted in nature, and offered a combined range of services and content (information, strategies, communication with other carers), were most effective and resulted in positive effects on confidence, self-efficacy, stress and depression. Focussing solely on information provision, however, was less likely to be effective as an intervention.

A study by Yamashita *et al.* (2017) exploring how health technologies could be used to support family carers of people with depression found that tracking and recording activities can improve communication with the care recipient and provide a better understanding of the illness. By recording their own caregiving activities as well as the care recipient's behaviours and moods and then reviewing and reflecting on these data, carers in this study were able to develop specific coping strategies as a result of becoming more attentive to changes and behavioural patterns. Using this tool to manually input the care recipient's moods and behaviours led to higher attentiveness and new perspectives, and acted as a trigger to engage in conversation with the care recipient.

3.3.2 Digital therapeutic interventions

Much research has indicated the potential benefits of online therapeutic interventions in positively affecting carer stress, burden and wellbeing. Scott *et al.* (2016) found that there is support for the efficacy of Technology-based CBT (TB-CBT) interventions with regard to reducing depression among carers of PwDs. In a systematic review of computer-mediated psychosocial interventions (therapy, professional, or peer support programs; educational or information programs) for carers of PwDs by McKechnie, Barker and Stott (2014), four of the 14 studies included found that interventions had a positive effect on stress and depression, with most studies reporting increases in positive aspects of caring and self-efficacy. The review also found there is a need with computer-mediated interventions for carers to be self-motivated; the more engaged the person is with the intervention, the greater the improvement on a composite outcome measure, including depression. Overall, there was found to be general acceptability among the participants in these studies of computer-mediated interventions.

Ploeg *et al.* (2018) carried out a qualitative study to understand how the use of a self-administered psychosocial web-based toolkit, My Tools 4 Care (MT4C), supported carers of older adults with dementia and related conditions. The website was designed to support those who are new to the role of caring, and it offered information regarding possible changes to expect, answers to frequently asked questions, links to resources, as well as video recordings of other carers sharing their experiences. Results suggest that this type of tool has the capacity to help carers. Interview data revealed using MT4C encouraged reflection and sharing of experiences, acted as a source of information and education, and provided affirmation (though some participants also reported it did not help at all). It allowed carers to identify supports while also caring for themselves. It was also effective in increasing carers' confidence in their ability to have a positive future. It should be noted that MT4C was only provided in the English language, and as such there was a lack of diversity in the sample both culturally and ethnically.

Studies such as these highlight the potential benefits of web-based interventions in equipping carers with the knowledge and tools needed to provide care, as well as in potentially reducing stress and burden. They are particularly beneficial in terms of cost, accessibility, convenience and overcoming existing barriers, and have potential to have a positive impact in terms of future demand for health care and its probable impact on staffing and support services. The design of custom technologies to support the wellbeing of carers has been explored less in the HCI literature, but there are some examples worth noting. Moreno *et al.* (2016) present iCarer - an adaptive platform which aims to reduce stress and improve quality of life among informal carers of older adults. iCarer monitors both psychological status and daily activities (via in-home sensors) and, through the use of a Virtual Carer, provides a set of personalised recommendations based on any problems detected. Stress is measured through a series of questionnaires on the platform. Once an increase in stress is detected, instant feedback is provided with possible solutions, such as educational videos, to reduce stress. Similarly, feedback with possible solutions is provided if problems related to the older adult care recipient's daily activities are detected through the in-home sensors.

A study by Bosch and Kanis (2016) exploring technology design for informal carers providing long-term in-home care identified a number of design opportunities. Interviews and questionnaire data showed that a key challenge for informal carers is preparing themselves for what may lie ahead due to both the unpredictable nature of the role and the level of uncertainty surrounding the needs of the care recipient from day to day. However, the sample size for the interview data (n=4) was somewhat small and findings should therefore be interpreted with caution. Nonetheless, the authors suggest that designers of technology to support carers should:

raise carers' awareness of existing solutions, increase how aware they are of their own wellbeing, create opportunities to become more mindful of precious and positive moments relating to caregiving, and highlight the value in meaningful social interactions with other carers.

3.4 Older Adults' Attitudes to Digital Technologies

As evidenced in earlier parts of this chapter, digital health technologies have the potential to support and motivate people to manage their health and wellbeing. However, the majority of such technologies and related research has focused on younger cohorts, despite the potential benefit for older populations. Social participation amongst older adults is also becoming negatively affected by the digital divide which exists in part as a result of a lack of representation within HCI research as well as commercially available technology design (Sarcar *et al.*, 2017). Nevertheless, the possibility for increased independent living and social contact is being strengthened by the use of mobile technologies amongst older adults, with smartphones and tablets increasingly being utilized for health solutions in place of purpose-built equipment (Nicol *et al.*, 2014).

In designing technology for older adults, it is necessary to understand the attitudes of older adults to technology, and what shapes these attitudes. Another crucial factor is understanding how to design for older adults – understanding how the ageing process can impact on technology usage, so that technologies can be designed to be intuitive to this cohort. Older adults can quickly become frustrated if they believe their existing skills do not match with a new technology, potentially resulting in a negative perspective on and rejection of new technologies in general due to a belief that such technologies are either overly complex or not worth learning (Kim *et al.*, 2016). Integrating technology in a way that is perceived as both relevant and useful into the lives of older adults is a significant challenge for designers (Kim *et al.,* 2016). A challenge also exists in reaching older adults who are less mobile and less engaged with technology as well as those living in disadvantaged areas (Nicol *et al.,* 2015). The remainder of this chapter focuses on these issues.

3.4.1 Older adults as a diverse population

Other work in the area of older adults' attitudes towards technology has focussed more on challenging common assumptions present in the literature from the fields of gerontology, gerontechnology, HCI and government policy. Lindsay *et al.* (2012) point out that there is a frequent perception among designers that older adults are resistant to technology and not the intended recipients of new digital technologies. Durick *et al.* (2013) outline six misconceptions relating to older adults and technology and argue that raising awareness of such misconceptions can serve to assist researchers and designers when designing technology for older adults. These misconceptions include:

1) Older people are the same – findings revealed that while participants' views surrounding the meaning of ageing were similar, the ways in which they embodied the ageing process was very different;
2) Older people are isolated and lonely – Durick *et al.* point to work by Lindley, Harper and Sellen (2008) and Russell, Campbell and Hughes (2008) which suggests that a delineation needs to be made between solitude and loneliness; the smaller social networks that many older adults keep are often due to both a conscious decision being made as to importance of maintaining the most meaningful relationships as well as their use of the internet to engage with wider social networks;
3) Older people are a burden on society – older adults contribute to society through activities such as community work and volunteering, as well as offering advice to family and assisting with childcare or financial support (Charness *et al.*, 2016); (Sarcar *et al.,* 2017);
4) Older people are chronically ill – it is important not to look at chronic illness as an inevitability; rather it should be viewed as something that can be and often is either prevented or delayed;
5) Older people are incapable of learning new, mainstream technologies – it is often the case that older adults' feel they do not need to learn a new technology more so than they do not know how or are incapable of doing so. Durick *et al.* point to Koren (2005) who stresses the importance of remembering the technological change that older adults have experienced and participated in throughout the 20th century. Older adults need technology to be useful, functional and meaningful; if they do not perceive it to be, they will not adopt it but including them in the design process could serve to address this;

6) Older people are unable to use new technology – it is important again not to look at this in term of ability. Instead, the focus should be on ‘how’ as well as ‘how often’ older adults use certain technologies. If technology is perceived as being without benefit or too difficult to learn it will be avoided. These embedded notions can limit design thinking, and Durick *et al.* suggest it is important to consider the six levels at which ageing occurs. Therefore, design for older adults should be approached such that users are defined by contextual needs rather than age.

Providing a rationale for such an approach, the authors point to work by Harvey and Thurnwald (2009), WHO (2002), Coleman (2003) and Fozard (2002) which suggest that there exists a gap between what the lived experiences of ageing actually encompass, and the approach to technology design for older users, with a default position existing involving design that is guided by assumptions around this demographic rather than findings from ethnographic engagement.

The World Health Organisation’s definition of health as consisting of positive self-ratings of physical, mental and social wellbeing led to a framework for optimising opportunities for wellbeing and active ageing, and this involves six areas of life: social, physical, economic, civil, cultural and spiritual. This concept of active ageing has implications for technology design and suggests that a more holistic approach needs to be taken that both considers the varied aspects of older adults’ lives and recognises the diversity of views concerning what may be needed in each of the six areas of life mentioned previously (WHO, 2002). Work by Coleman (2003) has found that designing specifically for ageing could in fact hinder more than help as too much focus is given to capability deficits. As well as this, emphasis within technology design is often on encouraging and maintaining physical activity, for example, which implies that the behaviour in question would not be happening without the technology intervention. Fozard (2003), Lindsay *et al.* (2012), Hakobyan *et al.* (2013) and Siek *et al.* (2011) support this and suggest that instead of focussing on age-related symptoms and homogeneity when designing new technologies, it would be more effective to turn attention to the diversity of abilities and interests among older adults as well as the difference between the manner in which younger and older people construct their decisions to accept or reject technologies.

3.4.2 Perceptions and attitudes towards health self-management technologies

More recently, older adults with multimorbidity's perceptions and use of technology has been explored by Murphy *et al*. (2017). A user requirements study was carried out for a planned digital integrated care system with 124 people with multimorbidity (PwM) and their care networks (both formal and informal) across three countries (Ireland, Belgium and Italy), with findings highlighting the needs and experiences of older adults with multimorbidity as well as their perceptions and use of technology for health. Results showed the majority of participants held a positive attitude towards technology, used some form of digital tool as part of their daily routines, and felt these tools could bring advantages. However, less than half believed they could keep up with new technologies and some avoided using digital tools at all where possible. It was also found that the participants in Ireland used their phones as a means of setting reminders and scheduling appointments, while participants in both Ireland and Belgium reported using technology as a tool for staying active or providing company. While some participants reported a sense of reluctance at the idea of integrating additional digital monitoring into their lives due to its potential to cause anxiety, others agreed that technology could be beneficial in terms of monitoring systems, verifying health status or showing trends over time. The need for technology to be accessible and usable was emphasised in order for it to be used to support and maximise health self-management. It should be noted that there were some differences concerning views and attitudes towards technology in the three countries involved in this study. For example, some Italian participants showed low levels of confidence concerning use of technology, often preferring to use phones to make and receive calls only whereas this was less the case in Ireland and Belgium. Concerns were also raised around accessibility and the level of sensory and physical impairments older adults can have. Though the Italian participants expressed a preference for direct contact with their doctors or carers, they did acknowledge that some technologies could be useful for health self-management. Murphy *et al.*'s study highlighted that while there is potential for digital monitoring to create additional anxiety about certain health conditions, the goal of remaining independent could motivate older adults to use such technologies, and ensuring design is accessible and usable through the involvement of stakeholders throughout the design process can address these issues.

Doyle, Caprani and Bond (2015) offer an insight into older adults' attitudes towards health self-management through smart-home data. Much research in the area of smart home data analysis has focussed on how data is used by healthcare professionals and family members and not older adults themselves. As such, little research exists on older adults' opinions on feedback derived from smart home data. Participants in this study, living independently in smart homes, ranged in age from 64 to 76 and had a variety of health issues including diabetes, back pain, heart disease and history of stroke. Findings indicated that older adults were interested in receiving feedback about their wellbeing which was derived from sensor data and self-reporting. Information on time spent inside and outside, walking time, sleep, activity and blood pressure was deemed as useful to better self-manage health and wellbeing. Results also indicated that this information needs to be simple, intuitive and supplemented with education and goals setting.

3.5 Involving the Older User in the Design Process

Digital health technologies can positively affect the lived experiences of older adults through monitoring and feedback, behaviour change interventions, education and communication and connectedness (Dahlke and Ory, 2015). While such technologies can support older adults in becoming more involved in their own health self-management and medical care, they can also act as a barrier if they are not easy to use or do not meet user needs appropriately (Demiris, Finkelstein and Speedie, 2001). Declines in both physical and cognitive abilities can also result in difficulties interacting with health technologies, which are frequently designed for unsupervised use (Or and Tao, 2012). A number of design considerations therefore need to be taken into account when designing personal health applications for older adults to ensure they are usable (de Barros, Rêgo and Antunes, 2014), (Harte *et al.,* 2017).

3.5.1 User-centred design

A common approach when designing with an older user in mind is to adopt a user-centered design (UCD) model. This iterative approach to design includes the user throughout the design process, such that the end-result matches the user's needs, habits and preferences as closely as possible (Vermeulen *et al.*, 2013). Employing a UCD approach can allow for the inclusion of individuals who have lived the experience of the end-user, such as patients of certain conditions or carers, and through this their insights and perspectives can be gathered to allow for meaningful design decisions (Maher *et al.*, 2016). Applying principles of UCD when developing health technologies can address the problem of alienating diverse populations, and evidence of usability and usefulness can be provided by considering users' needs and abilities during the design, testing, and evaluation stages (Maher *et al.,* 2016). As well as this, attention needs to be paid to the evaluation of health technologies for older adults, given that the unique characteristics of this population may not be appropriately or sufficiently addressed using general human factor design guidelines (Or and Tao 2012). Harte *et al.* (2017) see there being four activity phases to this approach: '(1) Identify the user and specify the context of use; (2) Specify the user requirements; (3) Produce design solutions; and (4) Evaluate design solutions against requirements' (Harte et al., 2017 p. 3). Typically, input is sought from end-users as early and as frequently as possible during these phases to allow for further redesigns and testing.

While involving users in the design process and following a user-centred design approach can address certain issues, other considerations can sometimes be overlooked, such as how to design to encourage motivation, engagement, and adherence, as well as assumptions pertaining to digital literacy in general (Wahbeh, Goodrich and Oken 2016). Indeed, it has been suggested that a 'user-sensitive inclusive design' approach may be more suitable for less homogenous groups such as older adults, and this could address those issues which may not be addressed within user-centred design (e.g. motivation, adherence, digital literacy). As such, adaptations may need to be made to traditional UCD methods used in HCI when working with older adults (Gregor, Newell and Zajicek, 2002); (Meiselwitz, Wentz and Lazar, 2009). HCI research involving older adults is unique in that attention must be paid to both the design, and also to the process; certain issues must be considered, such as preparing sessions, treating participants, and dealing with idiosyncrasies of the age group (Rubin and Chrisnell, 2008). Barriers to adoption of health technologies by older adults also need to be considered and these can be overcome by improving two design areas: including form factors that allow for physical needs such as decreased dexterity, and deterioration in hearing or eyesight; integrating behaviour change theories which are relevant to older adults' daily lives into the design of intervention design elements and content (Dahlke and Ory, 2015).

3.5.2 Participatory design with older adults

Participatory design is a common and inclusive approach to design, focussed on user experience, wherein not only is the end-user considered throughout the iterative design process, but they are involved in co-designing the solution, through providing requirements, input, feedback and testing. In this sense, the user is viewed less as a subject (reactive informer) and more as a partner (active co-creator) in the design process. Hakobyan *et al.* (2013) suggest participatory design is an element of user-centred design, similar to focus groups, interview-based studies and user evaluation studies. Dell'Era and Landoni (2014) see both user-centred and participatory design as existing on a matrix, with design-led and research-led being the domains within which each can be implemented. Research-led approaches which see the end user as collaborative partners during technology ideation could thus be described as both user-centred and participative, with methods and techniques including focus groups, scenarios and workshops being employed to engage users and elicit continuous feedback (Davidson and Jensen 2013); (Sutcliffe *et al.*, 2010).

Describing the absence of a complete methodology for working with older users when designing mobile technology, Nicol *et al.* (2015) suggest designers frequently need to improvise, with the result being both compromised co-design relationships and weak design insights. As such, modifications or adaptations to existing methods are likely needed when working with these users. Pointing to work by Antona *et al.* (2009) and Barrett and Kirk (2000), Nicol *et al.* (2015) write that many design techniques need to be modified in order to be useful for older adults, with only direct observation, activity diaries, scenarios and personas, prototyping, and art-based approaches being appropriate without modification. Special consideration needs to be given with brainstorming, surveys and questionnaires, interviews, group discussions, user trials and co-operative or participatory designs. As well as this, language and terminology needs to be compatible and use of technical language minimized in order to achieve a shared understanding, as was reported by Lindsay *et al.* (2012). Lindsay *et al*. also found that flexibility in approach is also key, with length of session affecting focus and concentration and lack of engagement resulting from a feeling that the design in question was likely to be of little value. With regard to the set-up of participatory design sessions involving older adults, the authors propose a number of factors which need to be addressed: locations need to be easily accessed, well lit, and free from distraction or ambient noise; timing of activities needs to be convenient and suitable for all participants, and schedules should be adhered to regardless of how well the session is progressing; and focus and structure in meetings must be maintained.

A study by Davidson and Jensen (2013) recommended keeping design sessions short, providing for a social element to the session, encouraging involvement and participation, and balancing the amount of input between the researcher and the participants. Davidson and Jensen state that the findings of their study give weight to the importance of involving older adults, with the insights that are revealed into needs, priorities, and attitudes not necessarily being evident to younger designers. Other examples of the effectiveness of participatory design with older adults have been demonstrated. For example, Vines *et al.* (2012) designed a digital payments system based on feedback from older adults, Lorenz *et al.* (2007) followed a user-centred design approach in the creation of a health monitoring tool for older adults, and Uzor, Baillie and Skelton (2012) used a co-design process to generate ideas for a fall rehabilitation tool.

3.6 Designing for Ageing

Changes in vision, attention, and motor control that occur as a result of the ageing process can negatively affect accessibility and usability of technology and devices (Leitão and Silva, 2011); (Nicol *et al.,* 2015). Age is not necessarily a predictor of ability with regard to technology, with skills and experiences varying considerably among older adults; this therefore represents a significant challenge for interface designers (Meiselwitz *et al.,* 2009). Areas in which older adults encounter particular usability problems are search performance and user interface complexity. As well as this, they employ problem-solving strategies which are less efficient, and have more difficulty correcting errors overall than younger users (Meiselwitz *et al.,* 2009). Usability evaluations with older adults have revealed general issues such as unfamiliar terminology, insufficient feedback for user actions, and a lack of online support; while system navigation, information search and interpretation, presentation, and readability have presented as interface usability problems (Or and Tao, 2012). It is therefore important to engage with older adults during the interface design process in order to address these problems and to review and refine elements such as font size, colour, placement, icons and symbols, as well as navigation and task flow processes (Dahlke and Ory, 2016).

Studies exploring interface usage among older adults have found that traditional computer interfaces can frequently be perceived as unnatural, too difficult to use and requiring considerable learning and adaptation, with other forms such as touch and gesture appearing more intuitive and easier to interact with. The deterioration in cognitive skills which comes with age, particularly concerning memory and learning, results in a reduced compatibility to learn and effectively use complex, traditional interfaces (Leung *et al.*, 2010); (Rodrigues, Carreira and Gonçalves, 2014); (Schiavo *et al.*, 2017). The advantage to touchscreens for older adults are numerous, with improved performance observed over the traditional keyboard and mouse (Chung *et al.*, 2010). Research has shown that touch interaction can yield a natural and intuitive means of interaction, can provide for easier overall interaction for older adults and that a low level of computer literacy is required, with those with low levels of literacy finding touch interaction both easy and motivating (Loureiro and Rodrigues, 2011).

3.6.1 Designing for mobile and touchscreen devices

Despite this, older adults have failed to be represented and adequately considered in designs of touch screen interfaces (Claypoole, Schroeder and Mishler, 2016). Based on a review of research in the area of mobile interface design for older adults, Claypoole, Schroeder and Mishler (2016) propose a set of design guidelines which aim to address common usability issues that negatively affect how older adults use touch screen technologies and which can result in non-acceptance:

1) Make information easy to find. Older adults can have difficulty locating targets in peripheral vision so icons, buttons and other interactive elements should be located as near to the middle of the screen as possible. Notifications specifying the location of items should be used when this is not possible;
2) Allow for alternative forms of input. Though there is much potential in touch screen technology and older adults, it is important to bear in mind there may be instances when other modes such as speech input or hard keyboards are more appropriate;
3) Design functions after conventional mental models. Older adults can have problems performing certain tasks on a touch screen if these actions are not perceived as natural or intuitive and do not match with their existing mental models;
4) Tolerate imprecise gestures. Older adults can have difficulty interacting with interfaces that involve precise physical actions such as scrolling, double-tapping or holding for a length of time;
5) Show users what actions are possible and what will result from those actions. Systems can be made easier to use by including clear terminology and transparent design of elements such as realistic and labelled icons;

6) Feedback and saliency are necessary. Communicating to users what they have done and where they are located within an interface can help compensate for age-related deteriorations in working memory;
7) Simple display designs are key. Overly complicated and detailed interfaces can be hard to decipher and navigate due to reduced attention skills;
8) Legible displays are better than fancy displays. Attention should be paid to ensuring components are legible in terms of size, style and colour with 12-point fonts being suggested for overall legibility;
9) Avoid computer-based interface designs. Older adults find traditional, computer-based interfaces more complex, intimidating and difficult to use than simplified tactile interfaces.

Other research has also examined how best to design for older adults using touchscreen devices. An important issue to consider with touchscreen user interfaces (UIs) is the size of onscreen buttons and the effect this can have on both speed and accuracy (Jin, Piocher and Kiff, 2007). With ageing affecting both navigation and learnability, other interface elements that can hamper usability for older adults are the function of buttons, use of scroll bars, and font choice (Balakrishnan and Yeow, 2007); (Gould and Schaefer, 2005); (Bernard, Liao and Mills, 2001).

Focussing specifically on mobile interface elements and older users Leitão and Silva (2012) carried out a study with 40 older adults over the age of 65 which aimed to ascertain optimal target sizes and spacing sizes between targets, with specific focus on two common smartphone gestures ('tap' and 'swipe') as well as accuracy rates and task completion times. It was found that while official guidelines for Apple iOS[6] and Google Material Design for Android[7] for general population users recommend tap target sizes of between 7 and 9mm, the most effect level of performance among older adults was observed with targets between 14 and 17.5 mm. Using larger target sizes will therefore address issues relating to movement control and dexterity, enabling older users to more easily interact with individual elements while also distinguishing between different targets. However, Leitão and Silva point out that doing so raises issues in other areas relating to usability and interaction and could call for compromises

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[6] https://developer.apple.com/design/human-interface-guidelines/ios/visual-design/adaptivity-and-layout/

[7] https://material.io/design/usability/accessibility.html#layout-and-typography

in the overall design to be made. Specifically, integrating larger target sizes can result in a loss of available screen real estate depending on the number of elements that need to be displayed at any given time. Two approaches to this discussed are pagination, with the content spread out over a number of separate pages of screens, and vertical lists, where the content is viewed as part of one continuous screen that is accessed through scrolling up or down. While both of these approaches result in the same amount of content being accessible to the user, they also add to the level of complexity required in terms of navigation, with pagination resulting in further taps, and vertical lists resulting in further swipes. Therefore, while increasing target size improves usability in one sense, it could also cause further problems in other areas, including system complexity, and increased physical interactions through redistributed content. A balance may need to be reached in instances where screen real estate is limited between target sizing, degree of functionalities offered and the amount of interaction required of the user. Claypoole, Schroeder and Mishler (2016) support this and suggest that while attributes such as simplicity, legibility, and transparency should be aimed for, consideration also needs to be made to the effect these can have on overall functionality.

3.6.2 Usability as a factor of user experience

Though a set definition is yet to be agreed upon (Lewis, 2014), usability is seen as a core factor of overall user experience, alongside usefulness, desirability, value, credibility, findability, and accessibility (Morville, 2004). Usability.gov (2020) describe usability as the user’s quality of interaction in terms of effectiveness, efficiency and the overall satisfaction, comprising factors such as intuitive design, ease of learning, efficiency of use, memorability, error frequency and severity, and subjective satisfaction. Preece, Sharp and Rogers (2015) place emphasis on products being easy to learn, effective to use and enjoyable, suggesting six usability goals for designers: effectiveness, efficiency, safety, utility, learnability, and memorability. Usability has also been described as a component of usefulness along with utility (Nielsen, 2012). When viewed in this sense, utility concerns functionality and whether a system can do what is required, while usability concerns how well a user can use that functionality. Regardless, usability can be considered a core component of user experience design, and it is seen as multidimensional in nature. With this in mind the following attributes need to be considered when designing for and evaluating usability: learnability, efficiency, memorability, errors, satisfaction, flexibility, and robustness (Dix *et al.*, 2016); (Schneiderman, 2016); (Nielsen 2012).

Learnability can be considered a particularly important attribute, owing to the user's first experience with a system often centring around having to learn it. As well as this, it is important to take into account that users frequently do not learn an entire interface prior to using it. Rather, they will use it once they have learned what they believe is sufficient to do useful work, highlighting the importance of measuring initial ease of learning (Nielsen, 1993). While both novice users and expert users need to be considered when designing for overall usability, the memorability attribute focusses more on casual users who have used a system before and a such are not novice users. This category of user interacts with a system intermittently and as such needs to be able to perform tasks based on previous learning (Nielsen, 1993). With regard to errors, the goal should be for the user to make as few as possible. Errors in this context can be described as actions that do not lead to a desired goal. While the goal is to minimise the number of potential errors, it is important also to consider that trade-offs are likely to be inherent in the design process. Focussing too much on avoiding any and all errors is likely to result in a user interface that in turn is less efficient and thus usability is affected in this manner. One method for addressing this is to provide multiple interaction styles, with the user starting with an interaction style that is easy to learn and then progressing on to another that is more complex but more efficient (Nielsen, 1993). Finally, subjective satisfaction concerns the degree to which a user finds a system pleasant to use. This attribute is particularly important for systems which are used in a non-work environment; it is typically measured by asking users using a questionnaire or interview as part of a debriefing session post-user test (Nielsen, 1993).

In terms of measuring overall usability, test users can be used to perform a pre-specified set of tasks or real users can be observed using the system naturally. The focus in both instances should be on measuring usability relative to specific users and specific tasks (Nielsen, 2012). Another way to measure usability is through considering quality of use, which concerns the degree to which a product can allow users to achieve specific goals with effectiveness, efficiency and satisfaction when carrying out specified tasks in specified environments (Bevan, 1995). Similarly, usability can be described (and thus evaluated) as the quality of an interaction when considering time taken to perform tasks, number of errors made, and the time required to become competent as a user (Benyon, 2005). Harrison, Flood and Duce (2013) point to the difference between Nielsen (1993)'s five attributes of usability and those put forward by the

International Standards Organization (ISO), which describes usability as specified users achieving specified goal in particular environments in terms of effectiveness, efficiency and satisfaction (International Standards Organisation, 1997). Nielsen sees efficiency, satisfaction, learnability, memorability, and errors as key attributes to be considered when measuring and evaluating usability. As Harrison *et al.* point out, however, learnability, memorability, and errors could be interpreted as being contained within the three ISO attributes. Indeed, Harrison et al. build on these two models with the PACMAD (People at the Centre of Mobile Application Development) model which aims to address any potential limitations present in the Nielsen and ISO models when evaluating usability within a mobile context (Figure 3.1). This is achieved through combining the attributes of both models while also introducing the attribute of cognitive load. As well as this, three usability factors are considered in this model: user, task and context. Cognitive load was included as an attribute as traditionally it was assumed that the user would be performing only a single task and would therefore be able to concentrate fully on that task. This is less so the case within a mobile context wherein a second task is often being completed simultaneously. This is perhaps less likely for older users using a tablet application than, for example, someone walking down a street using a smartphone, but it is still relevant and pertinent in that a tablet is not fixed in one place like a desktop computer.

Another approach to the development of usable interactive systems is suggested by Bruno and Al-Qaimari (2004), which takes into account the definitions, attributes and goals suggested by Nielsen, Schneiderman and others and focusses on four common factors: targeted users, the tasks, the type of technology, and context of use. Given that these factors are dynamic and tend to evolve over time, applying a fixed set of usability attributes may not be practical, suggesting usability attributes are application specific and depend on these four common factors (Bruno and Al-Qaimari, 2004). Finally, it is important to take into account that along with domain knowledge and level of proficiency, users also differ in other ways, such as spatial memory, reasoning abilities and preferred learning styles. As such, designers need to consider a wide range of possible user profiles and design interfaces such that they are usable by as many users as possible (Nielsen, 1993). However, it is also important to note that systems need not necessarily be designed to accommodate everyone. Rather, a user-centred design should consider the needs and capabilities of those who will ultimately use the system (Issa and Isaias, 2015).

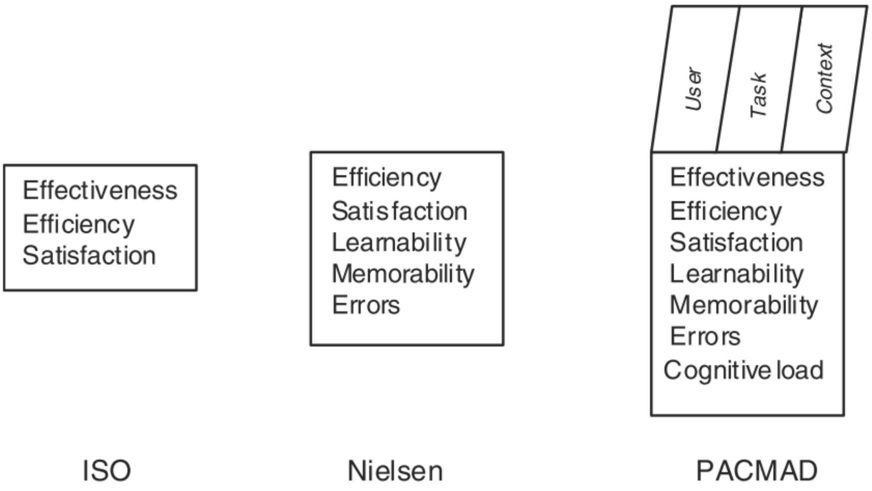

Figure 3.1 Comparison of Usability Models

3.6.3 Considering usability when designing for older adults

Given the importance of usability in general with regard to user experience and effective design, it follows that this is also a crucial aspect that needs to considered when designing for older adults. While technology use is increasing among this cohort, this is happening at a much slower pace than the general population and widening the digital divide, which brings with it design challenges, the potential for increasingly limited access to essential services and even a decline of participation in society for those who may eventually opt not to use technology entirely (Czaja, 2019). Among the reasons for such non-use are cost, physical limitations and challenges, belief that such technology is too difficult and exceeds one's abilities, and the fact that support or training involving external sources is often needed (Anderson and Perrin, 2017). Failing to consider older adults as end-users can also result in a disconnect between perceiving a system as valuable and being able to use such a system. Such an example of this was observed in a study examining older adults' ability to use patient portals of electronic records (Taha *et al.*, 2013). In this instance, the older users were receptive to the concept, could see the value in the system and in fact wanted to engage with it. However, due to usability issues including highly technical language, navigational difficulties, and how information was provided, they were ultimately limited in their ability to use the system in an effective and useful manner. While perceived value is in fact a predictor of technology adoption with older users, this is unlikely to occur if usability has not been considered during design and evaluation and adequately addressed. This example also emphasises the need to focus on learnability when designing for older adults and the importance of differentiating between inability to learn new systems altogether, and capacity to learn once sufficient time, training and support is provided

(Cjzaja, 2019). Another issue that needs to be taken into account when designing and implementing technology that will be used by older adults is the degree to which age-related factors such as cognitive and motor ability and sensory changes affect interaction. Adopting a user-centred approach which takes into account and involves typical end-users with a range of such age-related factors is thus likely to lead to a system that is usable for a diverse population.

3.6.4 Acceptability and acceptance among older adults

Related to the area of usability is system acceptability, which Nielsen (1993) considers a broader concern given that this relates to whether or not a system can satisfy a user's needs and requirements sufficiently both in social and practical terms. Among the categories within which practical acceptability can be analysed is usefulness, which itself can be further broken down into both utility and usefulness as discussed previously. A systematic review of the usage of acceptability and acceptance in the mobile heath literature found that these terms are often conflated and used interchangeably (Nadal, Sas and Doherty, 2020)). However, it is perhaps useful to think of acceptability as a user's perception before use, and acceptance as their perception after use, as is the approach taken by Distler, Lallemand and Bellet (2018) and Martin *et al.* (2015). Nonetheless, when considering design for older adults and overall user experience it is important to consider the areas of acceptability and acceptance, given the role they have to play in whether or not users ultimately choose to reject novel technologies.

Investigation into older adults' acceptance of mobile technology has found there is a need to further extend current theoretical models of technology acceptance for this particular age group (aged 60+). Following an interview study with 16 older adult users of activity trackers, Kim *et al.* (2016) suggest there is an additional phase to technology acceptance for older adults (intention to learn) as well as three factors related to this phase (self-efficacy, conversion readiness and peer support) present among older adults' behaviours, which are not accounted for in existing acceptance and adoption models such as the Unified Theory of Acceptance and Use of Technology (UTAUT) model (Venkatesh *et al.,* 2003). Elements which influence intention to use that were present in existing models, such as perceived usefulness, perceived ease of use, social influence and user context, were also evident with the older adults interviewed as part of Kim *et al.*'s study. It was also found that the gap between perceived and actual usefulness and ease of use among older adults can be bridged when the person is given hands-on experience, resulting in initial perceptions being reshaped.

These initial perceptions often act as a barrier, with older adults hesitant to learn a new technology due to a belief that it may be too difficult. As such, there exists a distinction with this age group between perceived usefulness and ease of use and perceived ease of learning. This lack of perceived capability was found to be the primary negative influencer. It was also determined that the most critical influencer of acceptance of new technologies was whether peers could provide information and offer support. Kim *et al.* suggest this gap between perceptions of and the actual usefulness and ease of learning of new technologies can be addressed both through providing ways to more easily explore new technologies and also through communicating benefits that are actually relevant to them. For this reason, new scenarios are needed when describing typical use cases. For example, showing somebody trail-running with a phone strapped to their arm is likely to be less relevant and engaging than showing somebody how to use the same device to video chat with their grandchildren. Coleman *et al.* (2010) support this and found that older disengaged participants were more likely to accept new technology if they felt it provided them with a direct, tangible benefit.

3.6.3 Additional considerations and approaches when designing for older adults

One of the key points to consider when designing for older adults is simplicity, and this has implications for both the amount of content or information to be presented at any one time, and the level of visual clutter that could negatively affect usability. With this in mind, interfaces should be designed taking into account changes in visual function so that information and content is consistent in its design, large, uncrowded and clearly in the line of sight (Farage *et al.*, 2012). In order to reduce error rates and improve overall performance, relevant information should be clearly highlighted, and demands on working memory should be reduced where possible (Meiselwitz *et al.,* 2009). This is particularly important with regard to vital health information being fed back to an older user, for example (Farage et al., 2012). One way to address the issue of working memory as well as navigation is to avoid a deep hierarchy in the information structure with the number of steps required to achieve a single outcome being kept to a minimum (Demiris, Finkelstein and Speedie, 2001); (Farage *et al.* 2012). In order to allow for cognitive changes, information should also be presented in a manner that it is intuitive and logical, moderately paced, and with a minimum amount of non-relevant content (Farage *et al.,* 2012).

Given the range of changes mentioned previously that can occur with ageing, it has been suggested that good design for older adults can be considered good design for everyone (Farage *et al.,* 2012); (Raviselvam *et al.*, 2016). Older adults may have different needs to the general population but they do not necessarily have more (Raviselvam *et al.,* 2016). These needs which are addressed when designing for an older user could represent the latent needs in the general population as a whole, and in this sense adopting a design approach with the diverse needs of the older user in mind could be considered a form of future-proofing at the same time (Raviselvam *et al.,* 2016).

3.7 Summary

This chapter has discussed the literature relevant to the areas of digital health technologies, behaviour change, technology-mediated interventions for informal carers, digital mindfulness-based interventions and designing with and for older adults. From reviewing the literature it is apparent that a number of considerations need to be taken into account when designing digital health technologies for older adults. While there are some studies on older adults opinions on digital health technologies, there are few on their experiences of engaging with such technologies. Furthermore, there is limited research within the HCI space on designing for older informal carers. In terms of the design process, while user-centred design and participatory design are seen as effective and valuable approaches, especially in terms of requirements gathering and involving the user, there is also a need to consider the diversity within older populations as well as the potential challenges younger designers may face when designing for ageing. This is particularly relevant when one consider the diverse range of characteristics that come with ageing in areas such as behaviour and conditions, physical and cognitive abilities, as well as existing skills or prior experiences. Addressing the needs of older adults when designing systems takes into account the latent needs of the general population and as such design for older adults can be considered design for everyone. The literature has also shown the importance of interface design when designing for older adults with simplicity and visual clarity essential for effective and intuitive interaction. The following chapter discusses research methodologies in the fields of HCI and digital health.

Chapter 4: RESEARCH METHODOLOGIES

4.1 Introduction

This chapter discusses common research methodologies in the fields of HCI and digital health The first part of the chapter provides an overview of qualitative, quantitative and mixed-methods approaches to research while a rationale is also provided concerning the selection and use of each of the methodologies within the PhD study. The methods employed throughout this study were mixed in approach, with the earlier stages comprising qualitative measures and the later stages mixing both qualitative and quantitative methods. A discussion is provided on the background to these methodologies, including the differences and similarities between various styles, approaches, techniques and methods within both qualitative and quantitative research, as well as their relevant underlying theories.

4.2 Qualitative vs Quantitative Research

What sets qualitative research apart from quantitative is its focus on language as opposed to numbers. With qualitative research the goal is not to measure; rather, the focus lies on how meaning is constructed and communicated. As such, it is accepted that the researcher cannot remain entirely neutral or objective as it is necessary to assume the role of the subject in order to interpret meaning. Qualitative research can often be viewed as ‘bottom up’ or emergent (though not exclusively as a framework can be used to build on existing themes), with the research question or hypothesis developing throughout the process. When approached in this manner, it differs from quantitative research which is seen as top-down; the researcher sets out to test an existing hypothesis through numerical assessment and measurement (Biggerstaff, 2012); (Coleman and O’Connor, 2007). Another way to look at this is to consider a continuum, as suggested by Biggerstaff. At one end sit data sources such as in-depth interviews, while at the other sit measurable data such as demographics. There then exist data which sits in the middle; instances of this could include content analysis (coding a transcript for numerical purposes), or questionnaire responses used for statistical analyses. Qualitative research can provide data which is in-depth and rich. In order to achieve this depth, sample sizes are typically smaller which in turn can raise questions around generalisability. Quantitative research is much broader with much larger sample sizes; owing to the lack of depth, however, less information on context and subjective experience is provided (Creswell, 2014)

Clarke and Braun (2014) stress that a fundamental and defining feature of qualitative research is that it does not assume or posit that only one correct and real version of knowledge can exist. By this, the authors suggest that by its nature, qualitative research is subjective and ultimately relies on perspective and perception. With this in mind, qualitative research is much more than a set of techniques; it is a paradigm or framework, within which exist beliefs, assumptions, values and practices that are common within a research community. To further illustrate how it differs from quantitative research, Clarke and Braun point to Silverman (2000) who sees qualitative research as involving analysis of words which are not reducible by numbers, collection methods that are more naturally occurring, and an interest in meaning rather than measures with regard to behaviour. Context must also play a role; naturally occurring conversation, for example, loses meaning if it is not clear who the participants are, nor the setting where and when the conversation is taking place. As well as this, a degree of critical reflection is necessary if the researcher is to recognise their own existing assumptions and values in order to prevent them from shaping the data interpretation (Clarke and Braun, 2013). Such nuance and discovery of meaning does not hold as much importance with quantitative measurements. These differences also further highlight why qualitative research is frequently inductive and theory generating, while quantitative research is deductive, and theory testing.

Both qualitative and quantitative research methods are common in HCI. The former is typically used for interviews and focus groups, observations during usability testing , open-ended survey responses, and audio and video material relating to usability. The latter is typically used to gauge and measure data such as speed, engagement, error rate, fixed survey responses, adoption and rankings (Lazar, 2010). This PhD study employed a mixed methods design, with a range of sources providing data for collection and analysis, which in turn provided opportunities for triangulation and data synthesis. The research involved focus groups, interviews, usability testing sessions, surveys and questionnaires, self-report data, sensor data, as well as metrics to assess engagement with the developed application (see Chapters 5-9). However, owing to the fact that the majority of data collected and analysed was qualitative in nature, further discussion is next provided on qualitative data analysis methods and methodologies, as well as employing a mixed-methods approach.

4.3 Grounded Theory

Grounded theory, as a form of inductive research, was first developed and proposed by Glaser and Strauss (1967). The aim of grounded theory is the discovery and construction of new theory from data through constant comparative analysis and to ground an emerging theory in both qualitative and quantitative data that had been systematically collected and analysed (Lazar, 2010); (Chun Tie, Birks and Francis, 2019). This differs significantly from other forms of experimental research which set out to test an existing theory or hypothesis. Rather, the bottom-up approach uses inferences and insights gathered from the data itself to generate new theories (Foley and Timonen, 2015). Further to this, it is necessary to approach the research without any preconceived ideas or assumptions so as to allow new discoveries to emerge naturally.

There are two defining characteristics of grounded theory. The first is constant comparative analysis, which involves the systematic and continual collection and analysis of data throughout the study. The analysis occurs concurrent to the collection so that one continuously feeds into the other (Cho and Lee, 2014); (Biaggi and Wa-Mbaleka, 2018). The data is then used to either further inform the research process, or support the generation of theory (Biggerstaff, 2012). This iterative process involves the second defining characteristic, which is theoretical sampling. Here concepts are identified which can then enable the researcher to recruit new participants and further explore these new concepts, such to the point that theoretical saturation is reached (Chun Tie, Birks and Francis, 2019). This occurs when all new issues, concepts, and categories have been fully explored and a sufficient level of validity has been achieved with regard to the emerging theory (Hennink, Kaiser and Marconi, 2017). With regard to what constitutes a theory, a grounded theory approach considers there to be four defining characteristics: fitness (what emerges from the data must also fit the data), workability (the theory should work to explain what is under inquiry), relevance (the theory needs to be relevant in terms of interpreting reality), and modifiability (new data should be able to modify the theory) (Biaggi and Wa-Mbaleka, 2018).

Grounded theory has been described as an ‘approach’. Biaggi and Wa-Mbaleka (2018) point to its foundations as a means of generating theory from data. As such, it is not only a method of data analysis, but also, and principally, a research design. This is in contrast to thematic analysis, for example, which could be seen more as a method or a set of techniques. In this sense, thematic analysis or indeed content analysis could be implemented within a larger grounded theory approach of framework (Cho and Lee, 2014). Further to this, another differentiating factor is grounded theory’s broader application to research in general. While methods such as thematic and content analysis are implemented only within the qualitative domain, grounded theory is applicable with either qualitative or quantitative data (Grounded Theory Institute, 2014).

4.4 Thematic Analysis

A frequently-used technique for analysing qualitative data analysis is thematic analysis. This differs from grounded theory and other approaches in that it is an analytic method rather than a methodology. It is used with qualitative data to identify patterns of meaning which can then be translated into themes. Here, themes refer to patterns of meaning within the data set which are pertinent to the research question (Braun and Clarke, 2006); (Clarke and Braun, 2014). Identifying these themes is achieved through active, interpretative decisions while generating codes. Thematic analysis is seen as thematically flexible in the sense that it can be used within an inductive or bottom-up approach such as grounded theory, or with a deductive or top-down framework wherein it is influenced and affected by existing theoretical concepts. The goal of grounded theory, as discussed previously, is to generate a plausible theory that is grounded in data. However, Braun and Clarke (2006) point out that what is frequently described as grounded theory is in fact ‘grounded theory-lite’. That is to say, it follows some procedures laid out in this methodology, but does not adhere strictly to the goal of theory generation. In many such instances, what in fact is being described is inductive thematic analysis wherein bottom-up coding and categorisation is used to develop themes rather than a fully-formed theory. Vaismoradi, Turunen and Bondas (2013) and Biggerstaff (2012) support this analysis, suggesting that thematic analysis is employed when a relatively low level of interpretation is required, while grounded theory is employed to establish a higher level of interpretive complexity.

Braun and Clarke (2006) and Clarke and Braun (2014) see thematic analysis as a six-stage process, with some of the stages being common to qualitative research in general:

1. Familiarisation with the data. This involves becoming immersed in the entire data thoroughly.
2. Generating initial codes. The entire dataset is coded systematically to reveal interesting features.
3. Searching for themes. Once initial codes have been selected, these are collated and sorted into groups to identify themes.
4. Reviewing themes. Themes are checked and refined further in relation to the entire data set. At this point a thematic map demonstrating relationships between themes can be drawn up.
5. Defining and naming themes. Clear and refined definitions are given to each theme through continued analysis
6. Producing the report. Selected extracts are used to provide compelling examples which can be used to refer back to the research question and literature.

Thematic analysis has been implemented in numerous HCI studies as a means of both providing insights with regard to the design of new technologies and evaluating current technologies. Results suggest the first three phases of Braun and Clarke's six-phase cycle are particularly effective when the aim is to improve usability or provide insights for the design of new technologies. The full six-phase cycle, meanwhile, is more appropriate when a full summary of the data is needed through a high-level thematic map (Brown and Stockman, 2013). It should be noted, however, that the degree of detail around thematic analysis with regard to background, coding techniques and phases varies between studies, and is dependent on the degree to which analysis is the focus of the publication. However, this technique is popular within HCI and offers value when considering collecting and analysing data as part of the design and/or evaluation process.

4.5 Content Analysis

Content analysis has been described as a method that allows for both qualitative and quantitative analysis of qualitative data. While it shares some elements with thematic analysis, it is different in the sense that the focus lies not specifically on the patterns, meaning and themes found when coding the data, but more so on the frequency, quantity and relationship between certain elements. For this reason it is viewed as an effective method for coding large amounts of data, and has been described as an unobtrusive, systematic and practical means for exploring trends of words used. Thematic analysis, however, is purely qualitative and as such places emphasis on detail and nuance (Vaismoradi, Turunen and Bondas, 2013). Indeed, Vaismoradi, Turunen and Bondas (2013) point out that implementing content analysis in a manner that focusses purely on the frequency of codes could potentially result in a removal of meaning from its context.

Due to there being some overlap between the two methods, and the similarity with regard to techniques, the two methods are often confused, with content analysis sometimes used as a blanket term owing to its use and appearance in the literature coming before thematic analysis. Biggerstaff (2012) for example, notes that they are often used interchangeably, but believes them to be much the same regardless. Lazar (2010) sees qualitative data analysis in HCI as involving either grounded theory, or content analysis, with no specific mention given to thematic analysis; Neuendorf (2019) meanwhile, suggests the difference between the two methods is more definitive; with thematic analysis the texts themselves are the data whereas with content analysis the texts are the phenomena and from there the coded units are the data. Viewed in this light, the focus with content analysis is concerned more with occurrences of codes in terms of frequency and quantity and for this reason the codes are most often numeric. Neuendorf (2019) also asserts that for these reasons thematic analysis is likely to be inductive in nature, with codes and then themes emerging in a flexible manner. Content analysis, however, is more likely to be deductive and as such will involve codes which have been developed *a priori*. Vaismoradi, Turunen and Bondas (2013) do not share this view and believe both methods of analysis can be either inductive or deductive in nature. Another element that Neuendorf (2019) believes sets content analysis apart from thematic analysis is the influence of the researcher on the process; with content analysis the researcher or coder can remain objective, provided a set of a priori codes exist. Inductive thematic analysis, meanwhile, relies on subjective interpretation to a degree.

4.6 Mixed Methods Research

According to Bazeley (2018), consensus exists that mixed methods involves a combination of qualitative and quantitative methods with the aim of gathering insights which would go unseen were the individual component to be used solely. Mixed methods research as an approach emerged due to the increasing complexity of research questions within the social and behavioural sciences. Complexities in many different fields of inquiry exist, leading to calls for methods capable of examining and probing a problem from a number of perspectives while also allowing for flexibility with regard to changing situations and scenarios (Bazeley, 2018); (Timans, Wouters and Heilbron, 2019). Mixed methods research is particularly useful and effective in health research as it is often necessary to source health evidence from both qualitative and quantitative perspectives (Biggerstaff, 2012). Caffery, Martin-Khan and Wade (2017) outline the potential advantage to implementing a mixed-methods approach by referring to the axiom that quantitative research seeks to answer the 'what' while qualitative research seeks to answer the 'why' behind something. Mixed-methods research, meanwhile aims to combine the two and looks to answer 'what has happened and why it happened'.

However, it remains to be seen and agreed upon the degree to which one component should be used over the other and in what context. Indeed, defining the difference between qualitative and quantitative methods can in itself be challenging as there exists some overlap at times, for example: numerical values assigned to the number of specific codes or themes in an interview transcript. Bazeley (2018) points out that an inductive and exploratory approach can include numeric data and statistical analyses while a deductive study that is more confirmatory in nature can include observational data such as interviews. For this reason, it could be said that an 'approach' is a more apt term to use when describing either the qualitative or quantitative element of research rather than a method. Creswell (2014) sees mixed methods more as a method than a philosophy or methodology, however, with the emphasis placed on data collection, analysis and interpretation. With this in mind, it can be viewed as an approach taken to research in 'the social, behavioural, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems' (Creswell, 2014, p.2).

Creswell does stress, however, that mixed methods should not be assumed to be a matter of simply collecting two different forms of data, nor simply the addition of qualitive elements to a quantitative design (and vice-versa). Rather, it involves integration and the strength lies in combining the two forms of data to arrive at a fuller understanding of a specific research problem. Bazeley (2018) and Caffery, Martin-Khan and Wade (2017) echo this point and consider there to be one core characteristic which sets mixed methods apart from other approaches: any research which 'involves multiple sources and types of data and/or multiple approaches to analysis of those data, in which *integration* of data and analyses occurs prior to drawing final conclusions about the topic of the investigation'. Here integration refers to the degree to which the sources, methods and approaches are interdependent. That is to say without one component, the research fails to meet the overall study purpose. Gallivan (1997) supports this view and stresses that triangulation across methods is necessary to ensure consistent outcomes. Biggerstaff (2012) points out that triangulation has value in both qualitative and mixed-method research as it allows the researcher to uncover insights which may have been missed due to over-reliance on one element of the data. Lazar (2010) echo these viewpoints and suggest that triangulation can provide evidence for the scientific truth of findings.

Bazeley (2018) points to Creswell and Plano-Clark (2011)'s commonly used method-oriented typology, which is made up of four designs. The first is a convergent parallel design. Here quantitative and qualitative data are collected and analysed separately. Results are then compared, followed by interpretation. The second design is an explanatory sequential design. In this case quantitative data collection and analyses occurs before the qualitative component so as to support the interpretation of the quantitative findings. The third design is an exploratory sequential design. Qualitative data collection and analysis adds to a larger quantitative study. The fourth of Creswell and Plano-Clark's designs is the embedded design wherein a qualitative component is carried out as part of a quantitative trial. Bazeley stresses, however, that such typologies are intended to be comprehensive and not exhaustive and points to Maxwell (2013), who prefers to focus on the *process* of design over the type of design, seeing design as 'interaction between research purposes, conceptual frameworks, research questions, methods (sampling, data collection, and analysis), and the need to ensure validity' (Maxwell, 2013 in Bazeley, p23, 2018).

Referring to thematic analysis within the context of mixed methods, Bazeley (2018) points out that frequently this form of analysis (along with some form of attempt at grounded theory) is perceived as simply a matter of identifying, coding, and describing prominent categories. This perspective and approach is common when thematic analysis is implemented as part of a qualitative element supplementing a more prominent quantitative component within a mixed-methods approach. Both Bazeley (2018) and Creswell (2014) stress that it is important to bear in mind, however, that while the qualitative component can at times be the smaller component, the form of analysis used is complex, detailed and rich, and must contain the same degree of academic rigour found in a study that is purely quantitative.

4.7 Rationale for Study Methodology

The goal of this PhD study was to establish if the design of a digital mindfulness application, integrating health and wellbeing monitoring, can support older informal carers in managing stress and to gain an understanding of the users' experiences with the technology. As such, the goal was not to evaluate whether behaviour change had been achieved, or whether the application was effective in helping manage or reduce stress. Rather, the focus lies on the users' experiences with the technology in terms of understanding why and how the system did or did not work. Klasnja, Consolvo and Pratt (2011) note the importance of this type of focus for early stage digital health applications. The methods employed throughout the present study were mixed in approach, with the earlier stages comprising qualitative measures and the later stages mixing both qualitative and quantitative methods. The goal was not to develop theory, and as such grounded theory as a methodology was not applied. However, as discussed previously in this chapter, some techniques commonly found in grounded theory can be applied within other approaches, such as inductive and ongoing analysis to allow for the emergence of themes and patterns in the data (Braun and Clarke, 2006). During thematic analysis of the qualitative data collected, Braun and Clarke's six-stage process was followed and this is outlined in the following chapters (see Chapters 5-8).

Owing to the nature of this PhD study, it was considered appropriate that the majority of the data be qualitative in nature. Having small sample sizes across the different phases of the study allowed for collection and analysis of a considerable amount of rich data through interviews, focus groups and usability studies. Analysis of this kind would not have been feasible or manageable with a larger sample set. However, there was also the opportunity to collect some valuable quantitative data during the main trial, such as questionnaires, sensor data, self-report answers, engagement with the mindfulness and education content, and system engagement data (Lazar, 2010). It was possible, therefore, to use this data to complement the qualitative data to provide a richer and broader picture of what was being explored. This approach corresponds with a convergent parallel design as discussed with Creswell and Plano-Clark (2011)'s method-oriented typology. The quantitative and qualitative data were collected and analysed separately, with results then being compared and integrated, followed by interpretation.

Figure 4.1 present an overview of the project phases, beginning with Design Cycle 1 (discussed in Chapter 5), Design Cycle 2 (discussed in Chapter 6), the development and implementation phase (discussed in Chapter 7), and finally the digital intervention trial (discussed in Chapter 8). As can be seen in the diagram, a literature review was carried out throughout each phase.

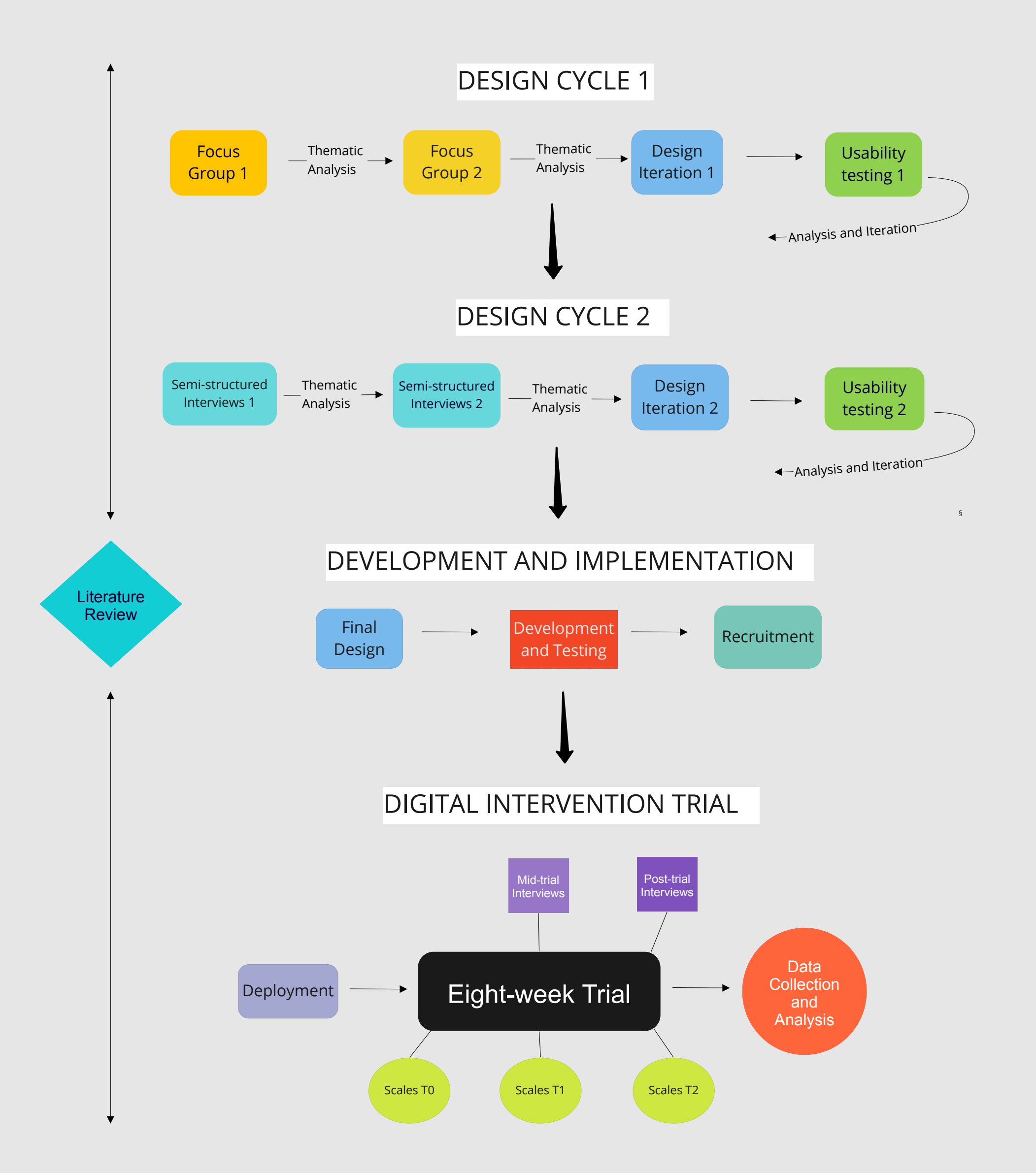

Figure 4.1 – Overview of Project Phases

4.8 Summary

This chapter discussed qualitative and quantitative research methodologies, focusing primarily on qualitative and mixed-methods approaches, given their relevance to this PhD study. A comparison was drawn and outlined between qualitative and quantitative research, which showed the possible strength and weaknesses to each approach, as well as the most appropriate scenarios in which each or both should be used. A brief history of grounded theory was outlined, alongside some examples of how this has been implemented in the digital health space. Next an analysis was provided on thematic analysis and how it can be used effectively within qualitative data analysis to provide insights that are rich and detailed and could go unseen in analyses that are strictly quantitative in nature. From here an overview was provided on the emergence of mixed-methods research and how, if implemented correctly, this can be a valuable means of analysis that can draw on the strengths of both qualitative and quantitative research, providing insights that are both broad and rich. Finally a rationale was presented for the approach taken in the present study, with a description provided of the approaches and techniques used throughout the study. The following chapter outlines the study design of the various phases of the research.

Chapter Five: ITERATIVE DESIGN CYCLE 1

5.1 Introduction

Chapters 5 and 6 of this thesis describe the iterative user-centred and participatory design process of the Mind Yourself application, which resulted in the final application, described in Chapter 7, for deployment in the trial. This chapter will discuss the first iterative design cycle, which took place over a two-year period. A total of 14 participants took part in this stage. Within this design cycle, two focus groups were conducted to gather user requirements, initial designs were developed, and these were evaluated through user testing and interviews. The participants in the first design cycle were not informal carers as the initial focus for the research project was on older adults in general. However, as the project advanced and further literature was reviewed, it became apparent that this cohort could potentially benefit greatly from a health self-management application that provided interventions to help manage stress and improve sleep. As such, the second iterative design cycle involved informal carers specifically to allow for more insights of relevance to this cohort (see Chapter 6). Interviews held with informal carers aimed to delve deeper into some of the findings from the initial focus groups, while also further informing the design of the application in terms of aesthetics, layout, language, icons and ensuring accessibility and easy navigation. Ethical approval for this phase of the study was granted by the ethics committee of the School of Health and Science in DkIT.

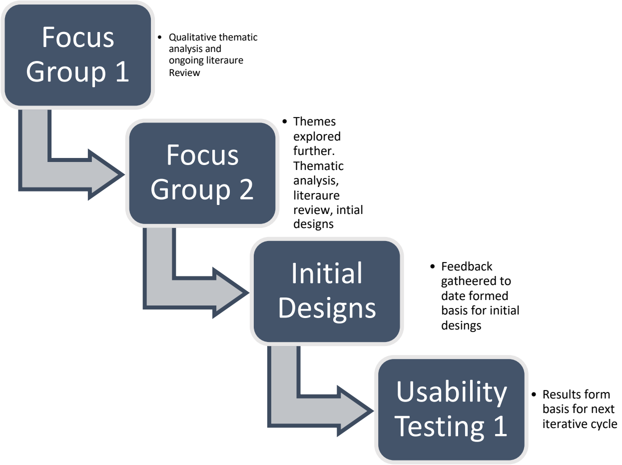

Figure 5.1: Phases of Design Iteration 1

5.2 Focus Groups 1 and 2

5.2.1 Methodology and participants

Two semi-structured focus groups, each lasting approximately 90 minutes, were carried out with older adults. Participants for the first group (3F, 2M, age range 68-86) were recruited from a local iPad class for older adults. A protocol was developed prior to each session which included areas of discussion and a running order for various topics (Appendix 1). As the goal was for themes to emerge, as opposed to seeking responses and opinions surrounding a prior set theme, it was important to follow the path the conversations took (where appropriate and within reason) (Lazar, 2010). In order to ensure each participant had the opportunity to offer an opinion, the interviewer interjected at times with new questions or with the same question directed to a different participant. The first focus group was divided into two sections. The first part explored attitudes to monitoring health and wellness, including for example what concerns older adults may have, how they are currently dealt with, how they feel about self-management of these areas of wellbeing both now and in the future. The second part focused on how participants interpreted data visualizations (presented in the form of paper-based mock-ups) in order to gauge opinion on the most effective means of presenting information through visualizations, for example using metaphors, bar charts, pie charts etc. to understand how older adults might interpret feedback on their wellbeing.

The second semi-structured focus group also lasted approximately 90 minutes and was carried out with four more older adults (2F, 2M, age range 65-86). Participants this time were recruited from a local panel of volunteers who had expressed prior interest in participating in projects with NetwellCASALA. This protocol (Appendix 1) was also split into two sections – the first section built on the themes and topics discussed in the first focus group, validating the themes that emerged and gaining further insights. The second section focused on participants' opinions on wearable sensors and continuous tracking, in particular their opinions on the look and feel of two devices (Withings Activite Pop[8] and Fitbit Charge HR[9]), that were at this stage being considered, following outcomes from the first focus group. The protocol also explored their willingness to engage with this type of technology and whether they would have any concerns

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[8] https://support.withings.com/hc/en-us/categories/200208646-Withings-Activité-Pop

[9] https://myhelp.fitbit.com/s/products?language=en_US&p=charge_hr

using such devices. Participants were also shown the companion applications from Withings and Fitbit as well as other common consumer health applications and were asked about how they interpreted the data representations presented in these applications. The goal was to ascertain whether there was consensus regarding the opinions expressed in the first focus group and to gain further insights into older adults' preferences regarding data visualizations.

5.2.2 Data collection and analysis

Data was collected using a dictaphone and field notes. The notes were an important component as they allowed for both on-the-spot observations and points of analysis, as well as issues not caught on the recording such as body language, smiles, nodding, and facial expressions. Prior to analysis, the recordings were transcribed using a word processor by the researcher. Participants were given ID numbers which were then continued throughout the entire study. The transcripts were imported into NVivo for Mac v10[10] (qualitative data analysis software) for analysis. Inductive thematic analysis was employed, using the six step approach outlined in Braun and Clarke (2006). This allowed for the coding of elements during analysis through the use of nodes and sub-nodes to create a hierarchy of topics (Biggerstaff, 2017). From here it was possible to develop and recognize themes which emerged from the data.

New codes were developed during analysis of the second focus group relating to topics that had not been discussed previously while existing codes were also used for tagging certain sections of relevant dialogue. While themes had already emerged from the previous focus group – namely surrounding sleep quality and stress among older adults – these themes were further developed and expanded upon. As well as this, new codes led to the emergence of other themes within this area of health and wellbeing among older adults. However, given the focus going into the second group was on these two areas (stress and sleep) while also covering any other areas the participants wished to discuss, the overall approach here could be described more as deductive than inductive thematic analysis (Braun and Clarke, 2006). To a degree, participants were guided during this conversation and were these questions not posed, it is possible the topics would not have been raised. For this reason, the focus overall was less on emerging themes, and more on the development and further dissection of existing themes.

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[10] https://www.qsrinternational.com/nvivo/nvivo-products/nvivo-12-mac

5.2.3 Findings

Findings are presented from both focus groups. Participants P1-P5 took part in FG1, while P6-P9 took part in FG2.

Attitudes to health and wellbeing

The initial response to questions on general feelings towards health was one of optimism. Participants demonstrated a positive mental attitude towards health in general, discussing how they '*go with the flow*' and '*live for today*'. This was motivated by a desire to remain independent, and not to have to move to a nursing home. There was a consensus among the majority in this regard: '*And I think that when you do go into a home, you are medicated maybe too much*' (P1); *'Ah you're sedated. You're sedated for sleep and all that'* (P2). Retaining a sense of independence, maintaining social interactions and staying active were all reported as important aspects of ageing, but also deemed important in maintaining positive emotional wellbeing: *'I'd get a bit depressed and feel miserable and think "oh I've got to get out"'* (P6). One participant saw keeping fit as dual purpose in that it results in both staying active and getting 'out and about' and remaining part of the community. While both P9 and P8 felt physical exercise and keeping active are key when growing older, they had differing views on the idea of goal-setting and targets, with P8 setting clear weekly targets to be achieved, and P9 not seeing much inherent value in doing this.

Health in general (either one's own or that of somebody close) was also discussed as a cause of stress *'I suppose health would be the biggest stress factor for most people'* (P5). The idea of being helpless leads to constant worry and this preoccupation results in an inability to relax. Thinking about ageing and mortality is also a cause of stress and anxiety. Emotional wellbeing and stress were also touched upon in relation to getting a good night's sleep with the idea of something being on your mind affecting sleep. P1 said: *'You see it depends what's on your mind when you go to bed'*, while P4 said: *'That's the time you only get a few hours or unless there's somebody on your mind and your head's going, your brain's going and...*'. This echoes findings from a study carried out by Choe *et al.* (2011) whereby racing thoughts caused by stress, worries or fears that stem from work, school, or personal life cause sleep disruption. Thoughts centring around one's health, not being able to help family members in times of need and the notion of growing old resulted in some of the participants having disturbed sleep which would in turn have detrimental effects the following day.

The discussions showed that there are differing views on what constitutes sleep quality. There was a feeling that a bad night's sleep will have a negative effect the following day, with napping and sleeping during the day likely to happen as a result of a poor night's sleep: *'You'd be just ten steps behind'* (P4)*; 'I just always felt every time that I had a nap in the day.... when I went to bed at night, I wouldn't sleep'* (P5). Participants had different routines and also views on what will lead to a good or poor night's sleep, for example eating, drinking water (and its effect on toilet use), reading and TV. Medical conditions were also highlighted as something that can affect one's ability to perform physical tasks and activities and can also affect routine and pattern, which could in turn impact sleep. There was a consensus that six hours plus is a good night's sleep for older people, and the importance of having a routine when it comes to sleep was significant to all of the participants. P4 said: *'Routine is a big thing. Going to bed at one o'clock one night, and going at 10, it's not working because if you get to bed at 10 o'clock, you're waking at one'.* The importance of routine was also discussed by the older informal carers later on in the study (see Chapters 6 and 9), suggesting this is an important area for older adults in general. Given that this could consequently affect sleep quality - and therefore overall wellbeing - sleep tracking and educational information concerning sleep hygiene was integrated into the design of the digital health application used in the trial.

Participants also discussed the importance of sleep quality versus sleep quantity. P9 saw quality of sleep as more important than quantity: '*I sleep better, not longer'* (P9). Sleep quality was seen as subjective by participants, with the idea being you will know you have had a good sleep by how you feel the following day. P9 said '*if you get a good sleep, you're going to feel it'.* P7 pointed out that physical activity is important for maintaining good sleep hygiene, mentioning that having vertigo and not being as physically active as she had been in the past had caused her sleep quality to suffer: '*And this is it, how important it is to keep active. I do exercises but it's not the same. You know, you do slow yoga type exercises'* (P7).

Participants also recognised the importance of keeping active and busy with regard to the potential negative impact of being inactive on overall wellbeing: *'keeping active is the secret'* (P5). This point was expanded upon by P1 who referenced an example of a relative who moved to institutionalized care, partly due to staying at home too much and becoming inactive in general. She said '*Well, I've seen it where people get comfortable being in, and as they say, if you don't use it, you lose it. And a sister-in-law of mine went like that, you know, and now she's, she's in a home now'.*

Feedback on visualisations

During the second part of the first focus group, various visualisations of sensor-based data were shown to participants to gather their opinions on how intuitive each was and to understand how they might react to receiving such data (see Figures 5.2 to 5.8). These included bar and line charts, various custom-made visualisations developed previously at NetwellCASALA and visualisations from various self-tracking applications such as Fitbit and Withings as well as research applications such as UbiFit (Consolvo et al., 2008).

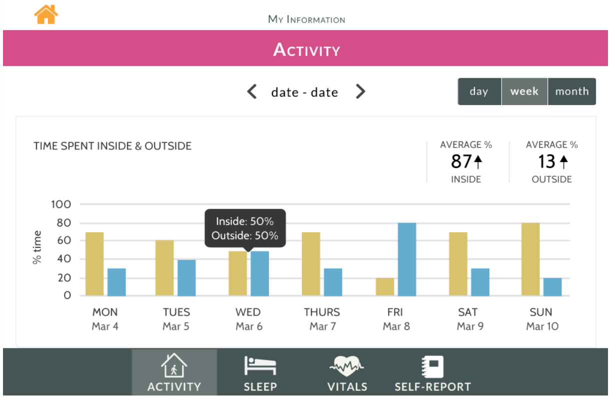

Figure 5.2: *Example data viz.– bar chart*

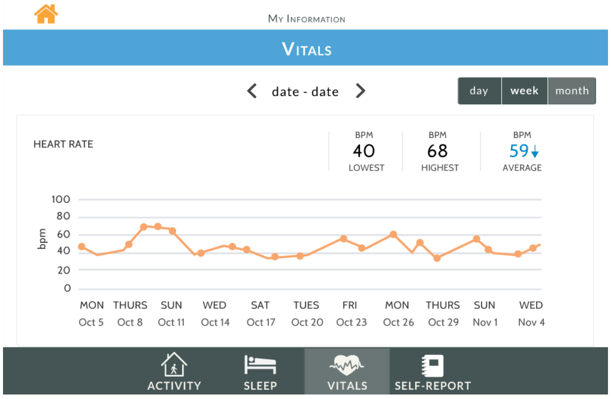

Figure 5.3: Example data viz. –line graph

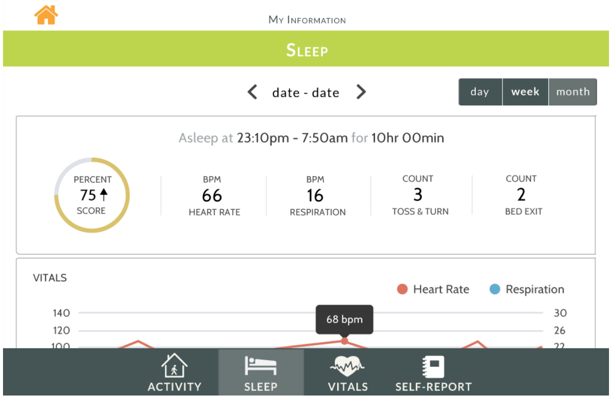

Figure 5.4: Example data viz.– sleep data overview

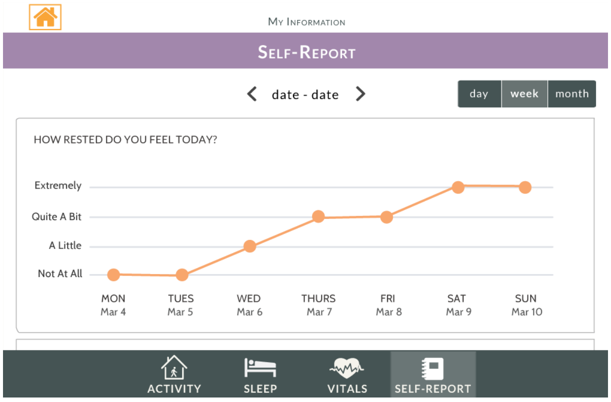

Figure 5.5: Example data viz. –self-report line graph

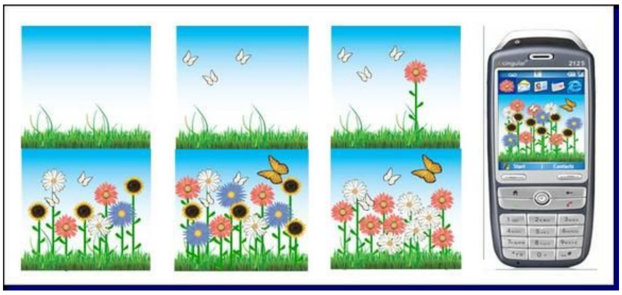

Figure 5.6: Example data viz.- metaphors ('Ubifit', Consolvo et al, 2008).

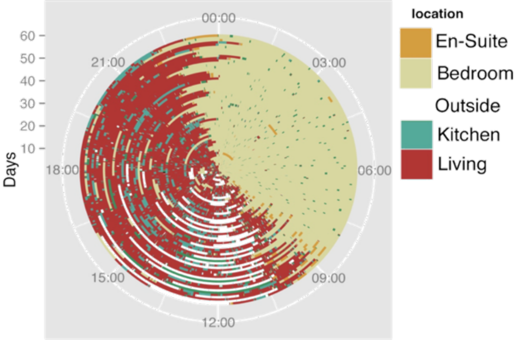

Figure 5.7: Example data viz.: clock plot

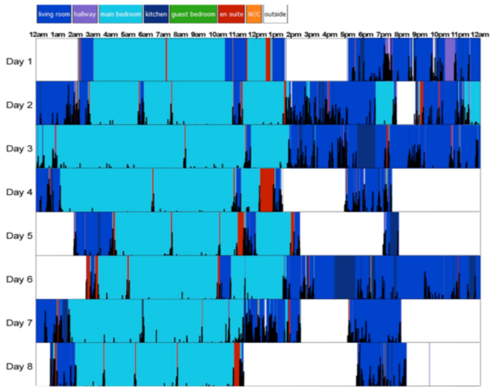

Figure 5.8: Example data viz.: activity in the home - bar chart

One of the primary issues with some of these interfaces and data visualisations was their complexity, resulting in information overload and participants finding it difficult to interpret them. While the bar chart and line graphs did not present many problems, the clock plot visualisation (Figure 5.7), which shows movement within and outside the home over a 60-day period, was not easy to understand and there was a sense of frustration at this. P2 suggested it would be better to focus on feedback/advice rather than just showing complex data representations. P2 also suggested some visualisations could be too difficult for older people in general to understand but he felt this would work when the current generation gets older. There was a consensus that bar charts are the easiest form to understand. Participants expressed an interest in the idea of an objective sleep score, as was depicted on one of the visualisations. However, there was initial confusion as to what 'good' is in terms of percentages: *'And would that be good, 75%? I suppose it would'* (P5).

When shown sleep graphs based on wearable sensor data, two participants felt they could use this data to gain an insight into sleep trends and subsequently learn to alter habits and sleep better. P2 expressed an interest in knowing the reason behind a poor night's sleep. P5 also felt it would be '*interesting to know what to do'* (with the data). P2 felt that the information in the graphs alone is not enough, suggesting it should be accompanied by suggestions or health tips.

Participants were also asked about the inclusion of educational information in digital health applications, and there was a positive reaction to the idea of educational messages and advice to assist in health and wellbeing self-management. Participants felt that more education and feedback could potentially result in less dependence on medication and support from health professionals. There was also a feeling that it would be good to not have to rely on doctor visits so much, partly because not enough time is afforded to patients when they visit a doctor: *'They haven't time. The doctors only have 10 to 15 minutes'* (P5)*; 'That's what I'm saying. 30 years ago they listen to you and advise you. You've to die now before you make an appointment. You've to make an appointment 24 hours before to see a doctor now* (P2).

Feedback on devices and companion applications

During the second part of the second focus group, participants were shown two wrist-worn activity trackers; Withings Activite Pop, and Fitbit Charge HR. Examples of data visualizations from both accompanying mobile applications were used as prompts to gain insights on the usefulness of feedback. Given that these were the only two devices being considered and tested at this time, no other dashboards from other applications were used for requirements gathering purposes at this stage in the research process. The visualizations shown included charts and graphs displaying sleep and steps data, with focus also being drawn to the use of various icons and symbols used in these applications, and opinions sought on these (Figures 5.9 and 5.10). However, the participants appeared more interested in the devices themselves and their potential benefits and offered less during the discussion concerning their views and preferences regarding the companion applications.

Figure 5.9: Data Visualizations –Fitbit Android (Dashboard)

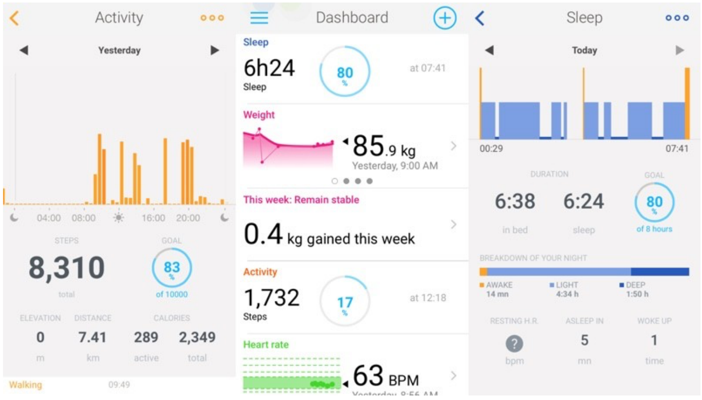

Figure 5.10: Data Visualizations –Withings iOS (Dashboard)

The initial reaction to the Withings watch was positive, with participants finding it aesthetically pleasing and easy to read. In terms of comfort, P9 found it to be comfortable and non-intrusive: *'It's just a watch'*. The Fitbit device also received a positive response in terms of look and feel. The on-screen display was somewhat confusing at first, but participants understood once shown. It is possible that screen size on this device could be an issue for older adults, however. P8 saw the Fitbit Charge HR data as useful due to an existing heart condition: *'I'd have a very elevated heart rate. So he told me to watch my heart rate, you know?'*. P8, however, had a negative reaction towards these devices due to fact that he does not like watches in general, saying '*I don't wear a watch, so I don't like it'*. As well as this, he has had negative experiences before with wearable medical devices, which he found bothersome and intrusive: *'I don't know why but it was constant, maybe I didn't know how to set it or whatever, but it was constantly beeping'* (P8). P7 was positive and somewhat curious about the devices overall but like P8 did not wear a watch in general. She indicated she would not have a problem sleeping while wearing the device, but she would generally not wear a watch while performing household activities for fear of it being damaged or not being resistant to water. She found it positive that the Withings watch was waterproof.

With regards to viewing sleep data, there was consensus that you know when you have had a good sleep, indicating that this cohort may not consider objective measures relevant. 'Gut feeling' was seen as more important than objective data. P8 said '*if I wake up in the morning, I know whether I feel good or I feel bad. I don't need to see 58 was my resting pulse. It's a subjective thing and I don't need that to tell me'*. This is very relevant for self-report and how it compares to objective sensor data. P9 could perhaps benefit from actionable insights based on data if they contrast with subjective measures. For example, suggestions could be given regarding sleep hygiene and good practice and the impact this can have on overall wellbeing if the objective sensor data is indicating poor sleep quality. In terms of interpreting and using data from these types of devices, contextual feedback supplemented with education and advice that can be acted upon was seen as important. P7 said, '*yes but what can you do about it?*' while P6 said, '*but what advantage would that be? Like, I mean, em, to have it, what advantage would it be?*'. This echoes sentiments expressed in Focus Group 1. P9 later came back to this point when discussing objective sensor data and its value, saying *'it's handy to know it but it doesn't make a difference to me. What good is it? You get information, it goes in the brain and stays there'*. It was also highlighted that feedback should not cause alarm or lead to unnecessary worry. P6 said *'you see I'd worry, "oh no there's something wrong there, I shouldn't have, I should get more"'*.

When discussing the heart rate readings from the Fitbit Charge HR, it emerged that three of the participants were already familiar with blood pressure readings. While P2 was able to understand some of the icons used in the Fitbit application ('*one is run*' and '*that's your heartbeat*' (P2)), there was some confusion over the relationship between BP and HR, highlighting the need for training and education. Blood pressure was brought up as an important parameter of health by the participants and was sometimes used as an indicator of overall health: *'Well, I take my heart rate and blood pressure now once a week'* (P6); *'I take mine every day'* (P9). P7 did not see as much value in it as she had done in the past, however. Two of the participants used journaling/logging as a means to track changes and see trends in their blood pressure readings. Data was seen as more useful if it involves informing a doctor or when feeling ill as opposed to everyday feedback for self-reflection.

5.2.4 Summary and discussion of key findings

Insights gathered from the focus groups were vital in gaining an understanding of parameters of health which are important to older adults, feelings towards wearable devices and monitoring, as well as preferences for data visualizations. Findings revealed stress and sleep being areas of particular concern and interest and the second focus group built on the themes identified from the first group. Maintaining a sense of independence was again emphasised as a key factor in overall wellbeing. Related to this was the need to remain active both physically and socially. There were differing views on the usefulness of setting goals in terms of physical health, but consensus in the importance of remaining aware of blood pressure levels. Sleep was seen as important in maintaining overall health and wellbeing, with physical activity as well as a fixed routine considered relevant to this. With regard to health data and feedback provided though an application, contextual feedback supplemented with education was considered important, with participants emphasising the need for meaning and relevance behind objective data visualizations such as bar charts. In order for this data to make sense, training and education may need to be provided, and it was seen as important that this data not cause alarm or undue worry. Feedback concerning the wearable devices was positive, with the importance of the device being non-intrusive and robust being stressed.

A range of sensors were then sought to monitor stress, sleep and general health and a number were purchased for testing. An important requirement was that sensors from a third-party company provided an open API, as the aim was to create a custom application using the data from these devices. Based on feedback from the participants, the Withings Activite Pop was selected to monitor activity and sleep over the Fitbit Charge HR. Among the advantages to the Withings device are its unobtrusiveness, its long (eight-month) battery life meaning it would not require charging during the main trial, and that it can also be worn in the shower or while swimming. The Withings cuff was selected to measure blood pressure as similar to the watch it also uses the Healthmate application, which was already integrated with NetwellCASALA's CABIE+-SIMS platform for collection of sensor data (discussed in Chapter 8).

It was thought initially that either the blood pressure cuff or the Fitbit Charge HR could also be used to monitor stress. However, upon reviewing the literature further around this topic, it became apparent that it is much more difficult to sense psychological stress than physiological stress. This is particularly the case for a heart rate monitor. While it is certainly useful for tracking vigorous exercise levels, this data is not useful with regard to emotional stress or anxiety. Similarly, blood pressure data cannot be relied upon as an indication of high stress levels. However, raised blood pressure can certainly be a result of stress or anxiety (National Institute on Ageing, 2018); (HSE Health A-Z, 2011); (Mindell and Herrick, 2007) and it was therefore considered an important parameter of health to monitor in this application.

Qualitative feedback from the requirements gathering stage indicated that stress management and sleep hygiene are areas which affect older adults' wellbeing, and persuasive technology could allow for behaviour change interventions to address these issues. However, based on the literature review, it was felt that promoting physical activity was also an important area to consider, given that maintaining activity levels and engaging in physical exercise has been shown to be important for promoting overall health and wellbeing among older adults. As well as this, an important factor in promoting and maintaining healthy sleep is exercise which further highlights the necessity of monitoring and reflecting on this aspect of wellbeing. Similarly, exercise is commonly recommended as a technique for managing stress and maintaining positive mental health in general. Taking all of this into account, it was determined that the application should support monitoring of parameters related to stress, sleep and physical activity, through a combination of sensors and self-report, and should include intuitive data visualisations and daily educational tips.

5.3 Designing the App – Iteration One

Once the data from the focus groups had been analysed, the first round of designs were developed that integrated these findings. These designs were then brought to end-users for usability testing. This phase of the study lasted six months and was concurrent to an ongoing literature review. The literature review had by this point come to encompass newer fields of study, with the focus moving to stress among older adults and informal carers in particular, and mindfulness-based stress reduction as an intervention. These areas of study would go on to become key elements of the final application design.

The designs started with rough hand-drawn sketches of graph types, icons, element placements and other interface ideas. This was followed by rudimentary wireframes made on an iPad using Adobe Comp[11]. From here it was necessary to move to a full-featured design tool to allow for richer and more detailed mock-up designs. Having experimented with Adobe Illustrator it was decided to use Sketch for Mac[12], owing to the lightweight, cost-effective and user-friendly nature of this particular application. This interface design tool offers a significant range of features and functionality and integrates smoothly with Invision, a prototyping tool that allows for clickable and interactive porotypes using design mock-ups to be deployed on an iPad for

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[11] https://www.adobe.com/products/comp.html

[12] https://www.sketch.com

user-testing. Refinements were made to a number of iterations in terms of layout, colour, features, and task flows prior to the first user-testing session.

5.3.1 Determining features and functionality

Taking into account findings from the literature, as well as findings from both focus groups, such as the importance of certain health and wellbeing parameters, and preferences regarding data visualizations, an initial wireframe was designed which aimed to present sensor-based feedback to the user through the use of bar charts to show data trends, and percentage goal completion (Figure 5.11). The main features at this stage were:

- **Visualising data** from three main parameters - sleep and steps (measured through the Withings watch) and heart (blood pressure, measured through the Withings cuff) – and showing progress made towards goals (the View Data tab)
- **Self-reporting** health and wellbeing, for example stress (the Report tab) and
- **Providing feedback** through comments or annotations (the Feedback tab).

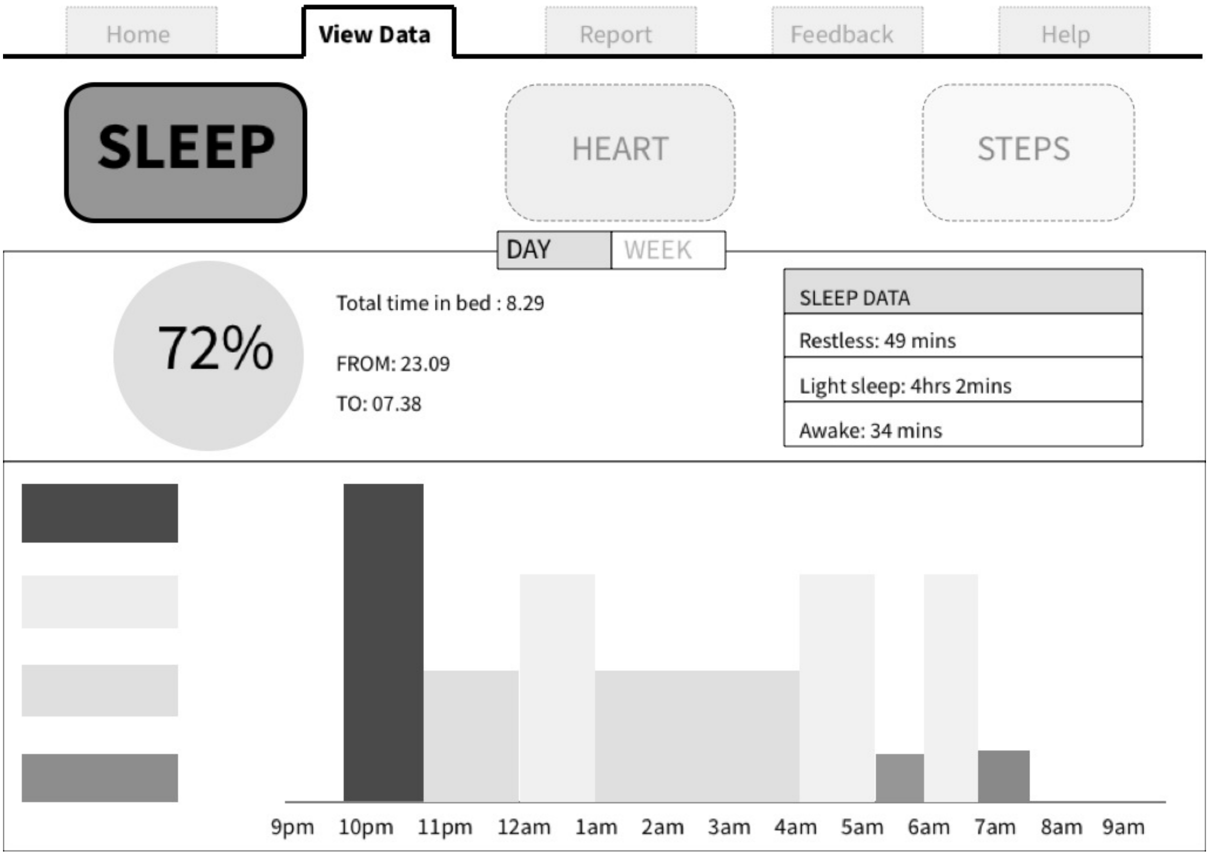

Figure 5.11: Initial wireframe

On reflection, it was felt some of the terminology used might confuse users, for example ‘report’ and ‘feedback’. A user could potentially view this as viewing a report or receiving feedback. As a result, ‘self-report’ was considered (Figure 5.13), as was the use of a pencil icon without any text (Figure 5.14); the term ‘feedback’ was also removed from the design. The design made use of tabs so that the user was not relying on a ‘back’ button for navigation. Feedback from prior experience delivering iPad classes to older adults (not discussed as part of this thesis) indicated that a back button can cause confusion in terms of orientation within an interface. Implementing tabs was therefore considered preferable as it would provide the user with a sense of location within the interface at all times where possible.

During the early stages of the design, this initial concept was iterated upon and refined regularly, particularly as the literature review progressed and discussions took place with other HCI researchers within the research centre. During this stage, for example, it was decided to integrate a mindfulness intervention to address stress management. A high fidelity mock-up was designed, using Sketch for Mac and the Invision Web App[13], which included four parameters of health: stress; sleep; steps/activity; and blood pressure. As with the first mockup, this design had three main elements:

- **Sensor data input** – collected via the Withings wrist-worn sensor for sleep and steps and via the Withings blood pressure cuff for blood pressure.
- **Subjective data input** – self-report and annotation allows for the collection of subjective measures of wellbeing (for example, daily stress).
- **Feedback / output** – educational tips and advice messages based on health and wellbeing parameters being measured and goals achieved. This section also includes the mindfulness based intervention (MBI).

As the application displays data from multiple sources, the challenge was to design an interface which aggregates these data sources and presents them in a manner which is easily understood by an older user. Moreover, it was important not to overload the application with unnecessary features. This is particularly important with this user profile as there could be a risk of ‘feature saturation’, which might result in unnecessary user burden, or lack of interest. Close consideration was paid throughout the design process to understanding the attitudes of older

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[13] https://www.invisionapp.com

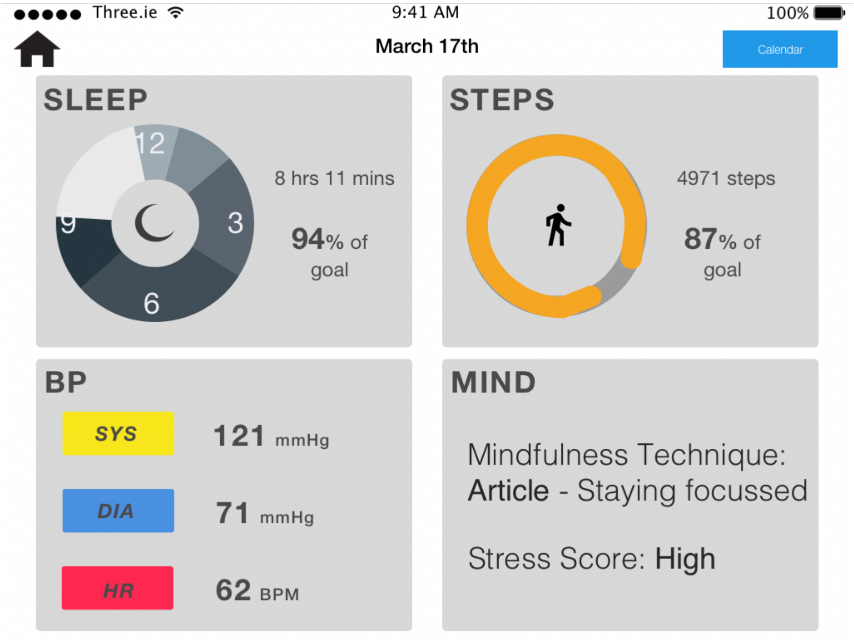
adults towards technology as well as guidelines on designing for older adults, as outlined in Chapter 3, Sections 3.5-3.7.

5.3.2 Interface design - mock-ups version 1.0

This section outlines and describes the initial iterative design cycle. Examples of various versions are presented and some of the design decisions taken are explained. This section also presents the design of the interface used for the first round of usability testing.

The Dashboard

The dashboard (Figure 5.12) allows for a quick overview of all recent sensor data and self-reported stress scores. The user can click on any of these tiles to view more detailed information including trends over time and a piece of educational feedback (e.g. Figure 5.13). The mindfulness intervention can also be accessed through the dashboard.



March 17th

SLEEP
8 hrs 11 mins
94% of goal

STEPS
4971 steps
87% of goal

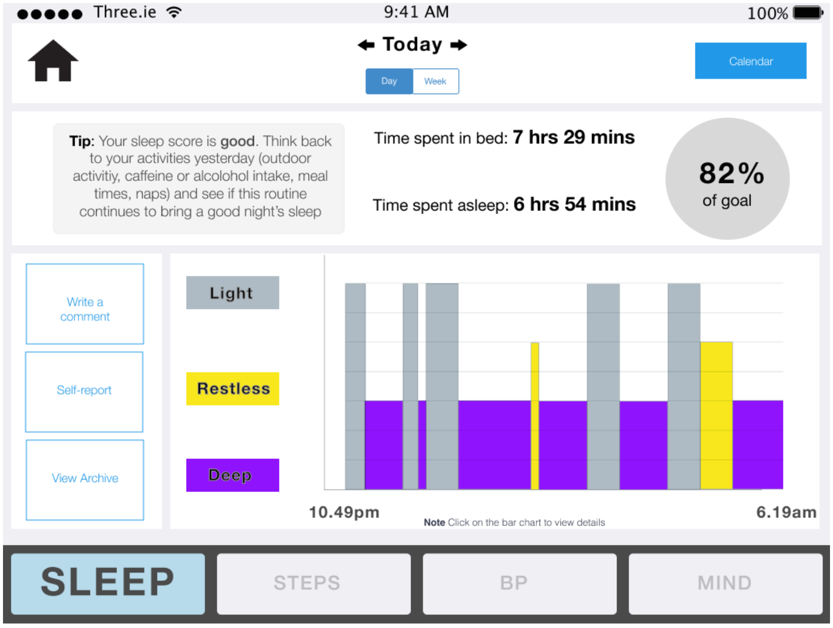
BP
SYS 121 mmHg
DIA 71 mmHg
HR 62 BPM

MIND
Mindfulness Technique: Article - Staying focussed
Stress Score: High

Figure 5.12: Dashboard (as used in Usability Testing)

The Sleep Section

Figure 5.13 shows an initial mock-up of the sleep interface which built on the initial wireframe design in Figure 5.11. Changes and updates included an overlay tab menu at the bottom for navigation, a calendar function, a tip of the day displayed on the interface, and a sub-menu to the left of the graph. The Day view provided feedback on the previous night's sleep using a bar chart, with a breakdown of sleep states throughout the night. A personalised educational tip was also provided based on the percentage of goal reached. Users could also annotate to provide further contextual information, which could be used for review and for self-reflection. Users could view previous days using the arrow at the top centre of the screen. The house icon at the top left of the screen would bring the user back to the dashboard. The overlay menu at the bottom of the screen was used for navigation throughout the four main sections and also provided a sense of location within the application.



Tip: Your sleep score is **good**. Think back to your activities yesterday (outdoor activitiy, caffeine or alcolohol intake, meal times, naps) and see if this routine continues to bring a good night's sleep

Time spent in bed: **7 hrs 29 mins**

Time spent asleep: **6 hrs 54 mins**

Note Click on the bar chart to view details

Figure 5.13: Sleep Day View v1 (pre-usability testing)

Further iterations to the sleep interface design (Figure 5.14) included moving the tips to the bottom of the screen while also using an icon to represent annotation. Self-report was moved to another section of the application (Mind). The summary breakdown was also moved to the right of the graph. These changes allowed for more space for the graph and legend.

Time spent in bed: **7 hrs 29 mins**

Time spent asleep: **6 hrs 54 mins**

Note Click on the bar chart to view details

Tip: Your sleep score is **good**. Think back to your activities yesterday (outdoor activity, caffeine or alcoholol intake, meal times, naps) and see if this routine continues to bring a good night's sleep

Figure 5.14: Sleep Day View v2 (pre-usability testing)

The final changes to the design prior to the usability testing (Figure 5.15) included moving the tips and annotation section to the top of the graph as it was felt they could be missed easily being placed at the bottom of the screen. The graph structure was also changed so that each of the bars were the same height in order to give a sense of uniformity. This also differentiated this graph further from the steps graph (described later).

Tip: Your sleep score is **good**. Think back to your activities yesterday (outdoor activity, caffeine or alcoholol intake, meal times, naps) and see if this routine continues to bring a good night's sleep

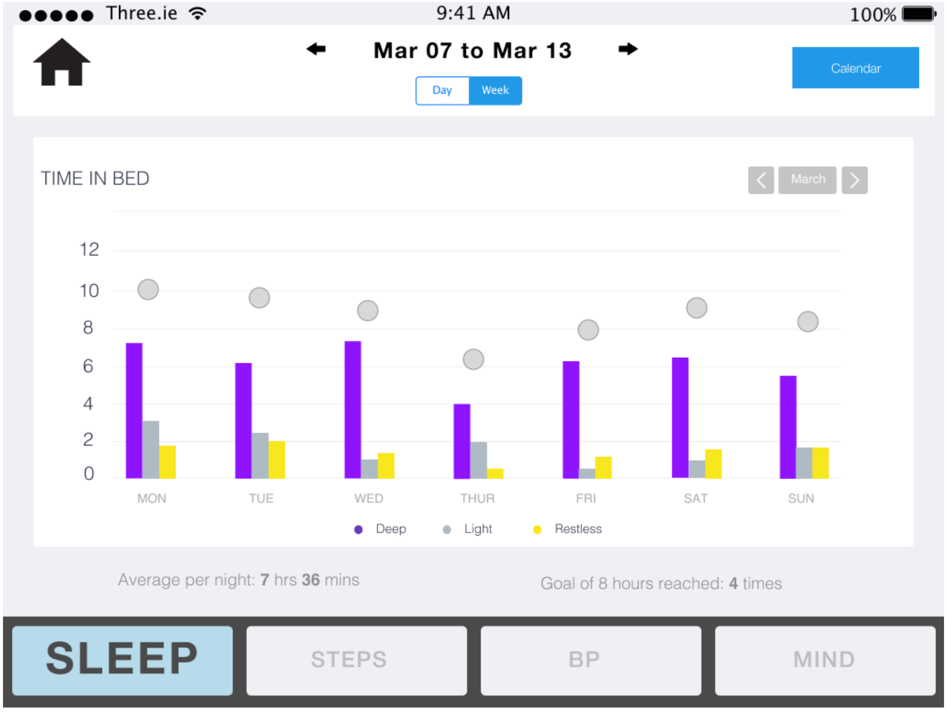
Time spent in bed: **7 hrs 29 mins**

Time spent asleep: **6 hrs 54 mins**

Note Tap on the bar chart to view details

Figure 5.15: Sleep Day View v3 (as used in Usability Test 1).

Using the toggle buttons at the top centre of the screen (Figure 5.15), users could view their data by day or as weekly overviews using the arrows either side of the toggle. This functionality was provided for each of the four sections of the app and allowed for an overview of different levels reached throughout the week. Such an overview allows the user to 'compare different values, to become aware about their health status, and to even find patterns to test and adjust their self-management' (Nunes *et al.,* 2015, pp. 33:34). Users could navigate from week to week for further reflection using the left and right arrows above the toggle. Figure 5.16 shows the sleep (week view) interface as used in the usability test. The idea with this design was to present both a quick-glance overview of sleep data as well as a more detailed breakdown of total sleep. The dots were to act as if in a line graph so that patterns across the week could be easily viewed. Below this, the bars showed the breakdown between deep, light and restless sleep. As described in the next section, this design was confusing to users during the usability testing sessions and received poor feedback.



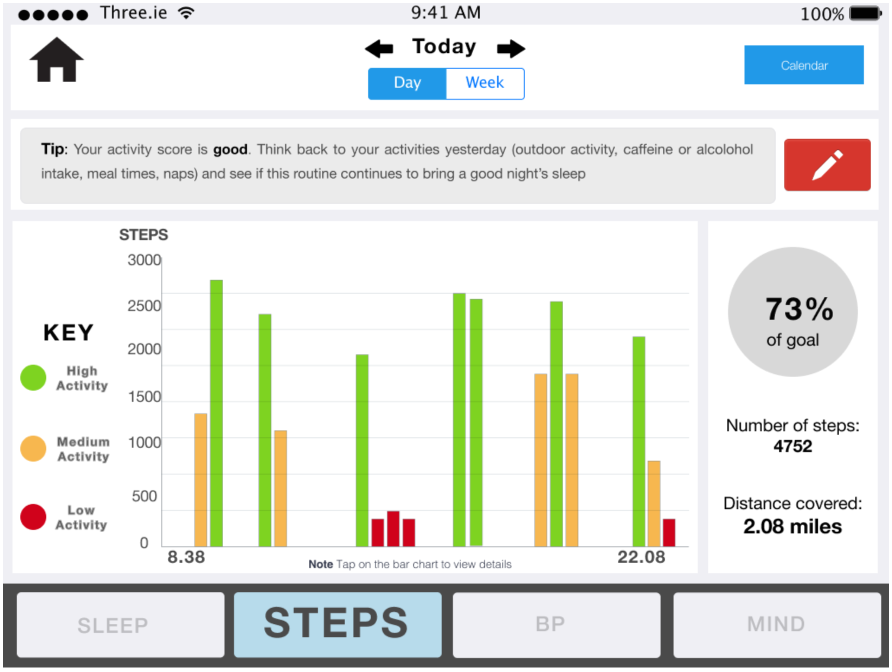
Average per night: 7 hrs 36 mins

Goal of 8 hours reached: 4 times

Figure 5.16: Sleep Week View v4 (as used in Usability Test 1)

The Steps Section

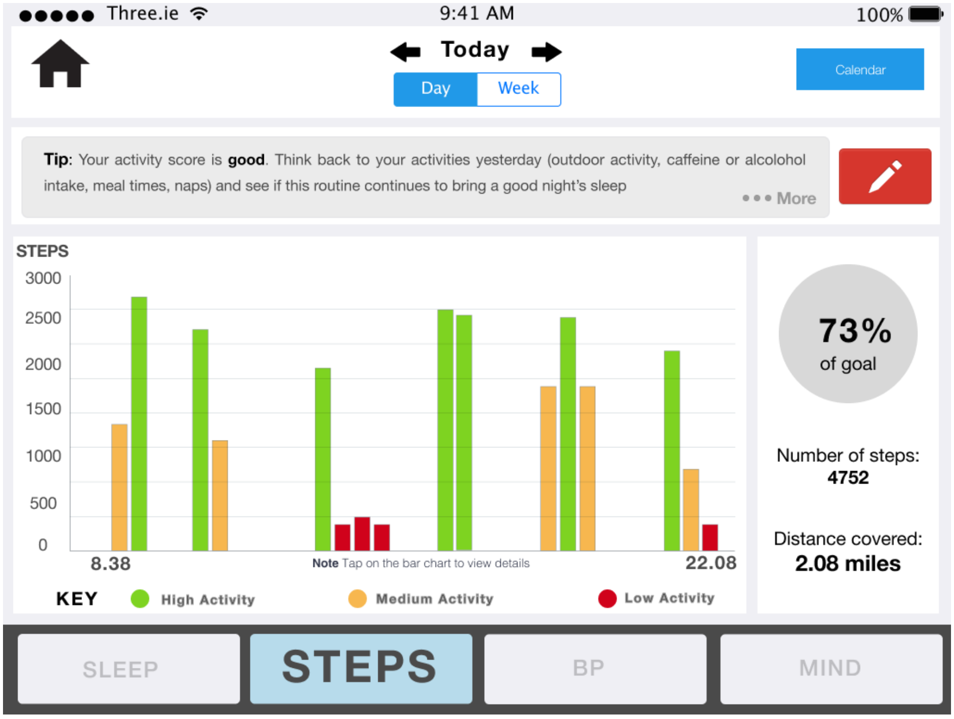
The interface for the Steps Day View mirrored the Sleep Day View in structure and layout, creating a sense of uniformity within the application. Again, the tips and annotation were placed above the graph, with the summary and breakdown placed to the right.



Tip: Your activity score is **good**. Think back to your activities yesterday (outdoor activity, caffeine or alcolohol intake, meal times, naps) and see if this routine continues to bring a good night's sleep

Figure 5.17: Steps Day View v1 (pre-usability testing)

Further changes were made to the Steps Day View interface prior to the usability testing sessions (Figure 5.18). The legend was moved to the bottom of the graph to allow for more space to present the steps data. This made sense as the graph represents a timeline moving from left to right; screen real estate was more valuable in the horizontal space than the vertical.



Tip: Your activity score is **good**. Think back to your activities yesterday (outdoor activity, caffeine or alcoholol intake, meal times, naps) and see if this routine continues to bring a good night's sleep ••• More

Note Tap on the bar chart to view details

Number of steps: **4752**

Distance covered: **2.08 miles**

Figure 5.18: Steps Day View v2 (as used in Usability Test 1)

The Steps Week View interface was similar to the Sleep Week View (post-testing) in that simple bars were used for each day, with the colour representing the level of activity achieved (Figure 5.19).

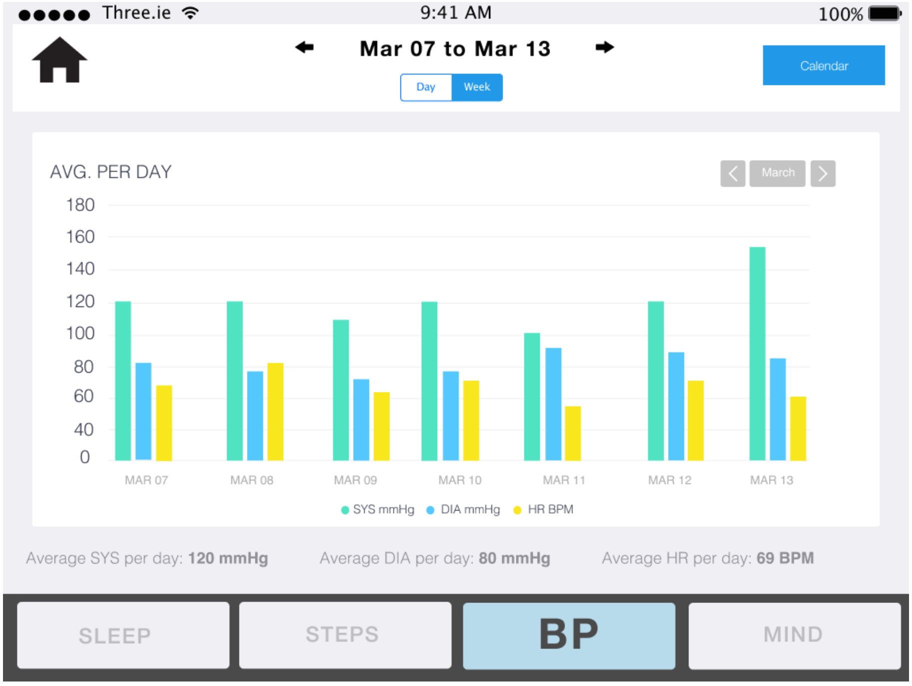
Average per day: **6000 steps**

Goal of 8000 steps reached: **2** times

Figure 5.19: Steps Week View (as used in Usability Test 1)

The Blood Pressure (BP) Section

Users could get an overview of their blood pressure and heart rate readings each day and this could also be viewed in Week view (Figure 5.20.). Colours were used to signify each type of data, i.e. systolic, diastolic and heart rate.



Average SYS per day: **120 mmHg**

Average DIA per day: **80 mmHg**

Average HR per day: **69 BPM**

Figure 5.20: Blood Pressure Week View v1 (pre-usability testing)

Changes were made to the blood pressure graph ahead of the usability testing (Figure 5.21). The blood pressure readings were paired together so as to feel like one reading. The heart rate reading was separated, and the chart made wider so as to further differentiate from the blood pressure reading. In addition, the colours were changed to appear more striking, with the red now used for heart rate.

Average SYS per day: **120 mmHg**

Average DIA per day: **80 mmHg**

Average HR per day: **69 BPM**

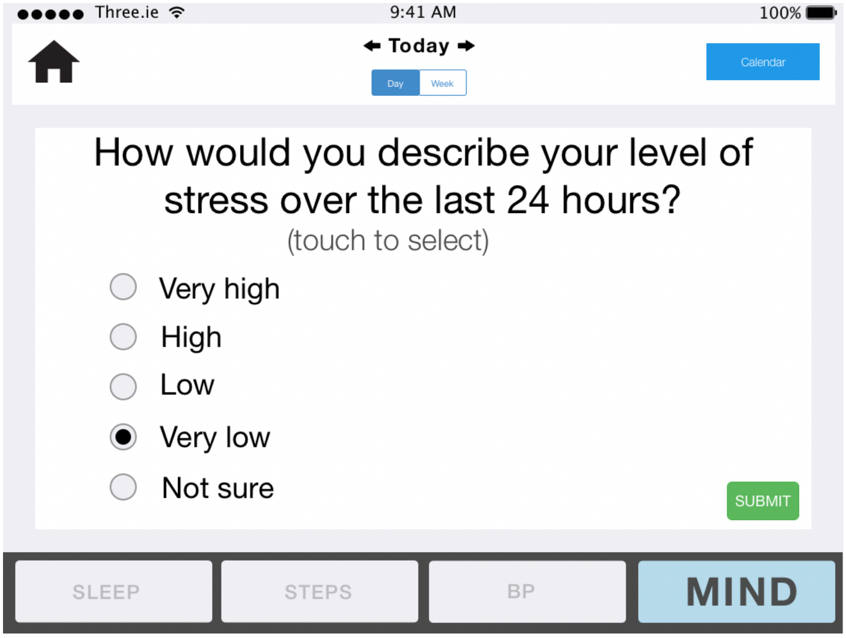
Figure 5.21: Blood Pressure Week View v2 (as used in Usability Test 1)

The Mind Section

Mindfulness meditation content (Figure 5.22) would be provided through the Mind section of the application. Content would be text or multi-media-based. Users could annotate as per other sections. How frequently to deliver this content and in what format was at the time still under consideration. For example, whether this should be delivered as a structured course, or with various tips each day that build from a beginner's level. Within the Mind section, users could also self-report each day using multiple-choice questions (Figure 5.23). Wahbeh et al. (2016) see multiple-choice as the most effective means of self-reporting on a touch screen for older adults due to the length of time required when typing an answer into a text box.

Today's technique: watch the video and follow the steps

Figure 5.22: Mind Day View (as used in Usability Test 1)



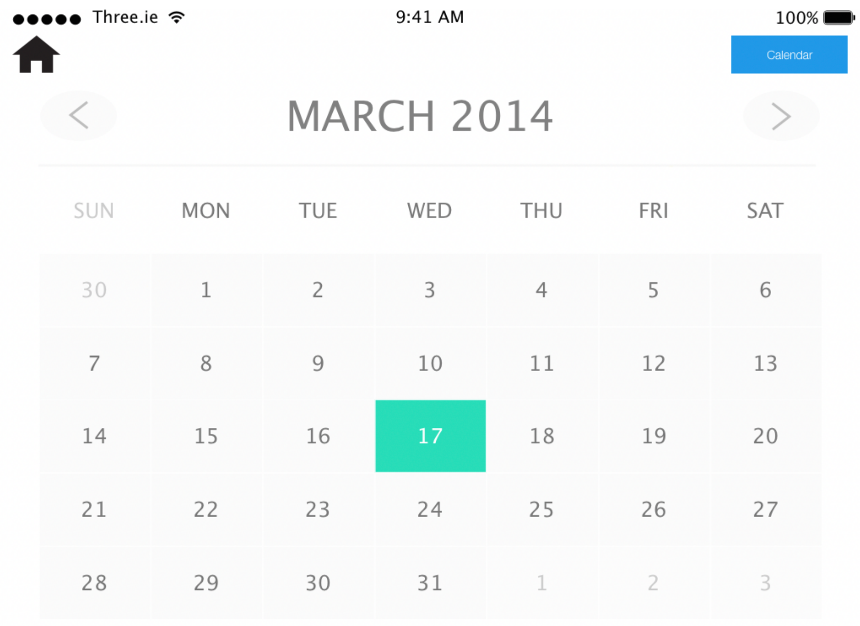
How would you describe your level of stress over the last 24 hours?
(touch to select)

○ Very high
○ High
○ Low
● Very low
○ Not sure

Figure 5.23: Mind Self-report v1 (as used in Usability Test 1)

Other Features

The calendar function (Figure 5.24) was added as a means of providing quicker and more direct navigation to a particular day. Users may want to compare certain days for further insight and self-reflection and relying on arrows to navigate in this manner would be too cumbersome.



SUN	MON	TUE	WED	THU	FRI	SAT
30	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3

Figure 5.24: Calendar v1 (as used in Usability Test 1)

An additional feature being considered was the ability to annotate in order to add contextual information alongside the sensor data (Figure 5.25), which would then have been added to that day's data. Feedback from the usability testing sessions indicated this is a facility older adults would want to use. However, this feature proved troublesome in development and was later removed.

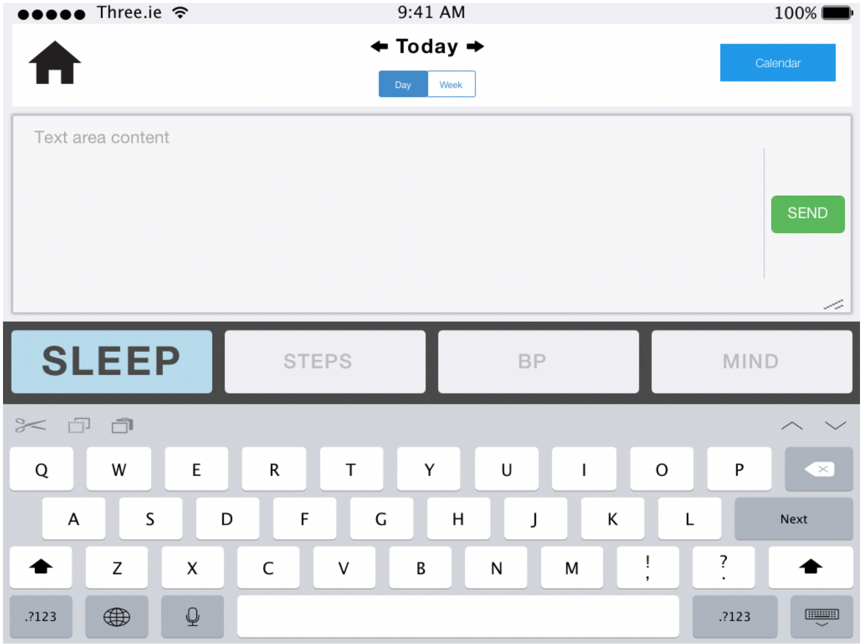


Figure 5.25: Write a Comment v1 (as used in Usability Test 1)

5.4 Usability Testing of Iteration One Design

The next phase of this first design cycle was usability testing. This was the first time the designs were evaluated with what was considered at this stage to be the end-user, namely older adults over the age of 65. As noted above, the focus later narrowed to older informal carers in particular. Individual usability testing sessions were held with five more older adults (3F, age 67- 75) with each session lasting approximately 60 minutes. The participants here were recruited through convenience sampling as this method is considered appropriate for pilot testing, and allowed for ready availability (Palinkas *et al.,* 2015). Such an approach is logical at an earlier stage of a study design before the focus narrows further and the population becomes more specified and defined (Burke Johnson and Christensen, 2012). One participant wore a wrist-worn activity tracker to monitor steps. Digital literacy varied, with three participants familiar with iPads.

Once a high-fidelity mock-up of the application had been designed, the designs were put onto an iPad using the InVision web application, which allows for the design of clickable prototypes with points of interaction. Five separate user testing sessions were held with each individual user in order to gauge usability and effectiveness in the following areas: interaction, size and spacing, ease of use, functionality, engagement and motivation, look and feel, navigation. A user task flow and protocol was created prior to the session (Appendix 2). Participants in the usability testing session were then asked to carry out the tasks unaided. A Think-aloud Protocol[15] was used, wherein participants were encouraged to verbalize their thoughts as they performed a particular task, for example whether or not they liked certain elements, considered the features useful or found parts too confusing. This approach can provide valuable insights into feelings, perspectives and opinions which could otherwise go unnoticed.

The International Organization for Standardization (ISO) describe usability as the 'extent to which a product can be used by specific users to achieve a goal with effectiveness, efficiency and satisfaction in a specified context of use' (ISO 9241-210, 2010). This was borne in mind when writing the task flow narrative. As well as this, the idea of specific context of use was taken into account, with the usability testing sessions taking place in the participants' homes. Three factors need to be taken into account when evaluating usability according to the ISO: user (person who interacts with the product), goal (intended outcome), context of use (users, tasks, equipment, and the physical and social environment). These were addressed as much as possible through recruiting older typical users, setting out clear tasks, and placing the design onto an iPad to be used in the person's home. The attributes put forward by the ISO and Nielsen, as well as the additions and modifications made by Harrison et al. (as discussed in Section 3.6.2) were taken into consideration during analysis of the interview and Think Aloud protocol transcripts, with a view to evaluating usability as robustly as possible.

5.4.1 Data collection and analysis

Each session was recorded using an audio recorder and interactions were also video-recorded to allow for analysis of interactions with the iPad. Both recordings were then used to analyse any usability issues. Recordings were transcribed using a word processor by the researcher. Participants were given ID numbers following on from those assigned in Focus Group 2.

The transcripts from the recordings were imported into NVivo for analysis. The usability testing sessions introduced new categories of codes with the themes varying significantly from

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[15] https://www.nngroup.com/articles/thinking-aloud-the-1-usability-tool/

those raised in the focus groups. This was to be expected since the focus here was on issues pertaining to the design of the system and the interface in particular. However, the creation of new codes did allow for overlap in terms of content, with participants during the testing sessions commenting on aspects such as graphs displaying sleep quality or activity progress and comparing what they were seeing to how they would view their own health and wellbeing. Due to the use of the Think Aloud Protocol used during the sessions, themes emerged naturally when analyzing the transcripts. The participants were asked to perform a task, but how they verbalized this and what observations they made were not prompted in any way, with follow-on questions asked depending on what was raised. Questions were not asked regarding existing themes which had stemmed from the previous focus groups. For these reasons, the approach could be described as inductive thematic analysis (Braun and Clarke 2006).

5.4.2 Results

Navigation

Overall, participants had few issues with navigating through the application. Tapping on tiles to navigate from the dashboard did not cause any problems (Figure 5.12) and the use of a primary overlay menu at the bottom of the screen helped in both providing a sense of location within the application and in providing a means of quickly switching between the four main parts of the interface (Figures 5.13-5.17). There was some difficulty with the use of a toggle for switching between Day and Week view with one participant not understanding they could be used to switch, and some participants having a problem with the size of the buttons themselves. The toggle may need to be placed further from the navigation arrows as this caused some confusion with P13 saying, '*you see your attention is drawn to the arrow… not to the day, you know'*. Each of the participants was able to use both the arrows and the calendar to navigate to different days (Figure 5.18). Indeed, this means of navigation proved popular and felt intuitive for each of the participants*: 'left presumably would be yesterday'* (P10); *'The left arrow? Bring you back to yesterday presumably'* (P11). With regard to navigating to a specific date, the calendar function also made sense.

Interface elements

There were elements of the design, such as text size and font, which did not pose difficulties for any of the participants, with all reporting being able to read from a normal distance. One person did recommend making one line of text bolder, however. Input elements, such as buttons and selecting multiple-choice options during self-reporting, were clear to participants and felt intuitive. However, terminology in some places caused confusion, for example using 'Send' to post comments or annotate instead of 'Finished' or 'Done' (Figure 5.18): '*Yeah, I don't know, I mean, if I hit send am I actually sending it anywhere?'* (P11); *'What would the next thing be? Em, I don't know what the next, what I would be supposed to do next'* (P12); *'Done is good…that I would understand'* (P14). Timelines indicating hours slept and steps achieved were clear and obvious and the sidebar summary containing more detailed breakdown such as percentage of goals next to the graphs seemed logical and straightforward.

Understanding and interpreting graphs

There were mixed responses with regard to the graphs and data representations. Certain elements were understood, such as using percentages to depict the level of goal reached: *'We can see what the achievement is over the night, that we had a goal to achieve a certain amount of sleep and we have achieved 82% of it, which I would imagine is probably a good percentage'* (P10). The use of a timeline in the sleep graph was clear and easy to grasp for some, with P14 saying '*so light, it says light, so obviously, that's light sleep and that's deep sleep and there's a hell of a lot of deep sleep there… yes I do understand it',* and P12 describing the data as '*here there was a little restless, whatever happened, where I woke or something'.* However, there was some confusion for P10 as to how this was presented: *'I don't see it as obvious'.* This was also the case with P12 for the daily steps graph. It was not clear that certain parts represented low or high activity. This confusion was compounded by the lack of a clear legend: *'It's the least clear page… surely somewhere you would have your colours with the indication of high, medium and low'* (P12).

None of the participants were able to follow the data representation for Weekly Sleep, indicating a combination of bar charts and line charts causes too much confusion (Figure 5.16). Initially, P11 felt she understood the number of hours for each day but the combination of bars and dots was ultimately too confusing (P11: '*It's a different form of graph, and in a way it's an easier graph to understand',* I: '*So your total on Monday was 10 hours, 7 of which were purple, so deep',* P11: *'Where did you get 10 hours?.. Why is it showing, only showing…oh* *you add them together').* P14 also had significant issues with this form of data representation, saying '*no, it's not obvious*'. It was clear that the Week View sleep graph needed to be completely redesigned. The responses to the Week View steps graph (Figure 5.19), however, were markedly different. The participants were able to ascertain activity levels for different days and whether goals had been reached: '*So this person hasn't done the recommended amount'* (P12); *'there you have steps in hundreds, in thousands'* (P11).

Use of colour and icons

Exploration of the colours used within the interface revealed some interesting and important insights. While three of the participants did not have any issue with the colours used, each person felt a legend or guide explaining the significance of each colour was essential for understanding: '*But because your little guide, you see, is useful to have'* (P12)*; 'you need a colour code on each day'* (P14); '*it doesn't tell me what these mean, the colours'* (P11); *'I've forgotten what the colour significance is here. Green and the amber'* (P10). As well as this, P10's initial response to seeing red was to infer that something bad had happened: '*And red is bad'*. It could be important therefore to stress that it does not mean 'danger'. More significant than that, perhaps, was the issue of colour-blindness, with P13 failing to see any difference between green and orange: *'I can see the darker one but I really can't see much difference in those two',* I: *'Ah, you see it in tones',* P13: *'that's right'.* It appeared that his issue was more to do with tone rather than the colour itself, suggesting it may still be possible to integrate a 'traffic-light' colour code system using red, orange, and green, as was used in the Steps section of the application. However, this is something that needed to be considered in future iterations as degrees of colour-blindness may vary significantly between people.

When asked about icons and symbols, there was again a mixed response. Those with some familiarity of computers and digital devices recognised the use of a house icon to signify returning to the homepage, but this concept was lost on two of the participants: '*Activity in the home?'* (P14). Once it was explained to them, they understood the idea. The use of a curved arrow was suggested to signify returning to the homepage but this could also possibly be confusing as it could be interpreted as 'refresh'. The same was the case with the annotation icon. While each participant recognised that it was a pencil (I: '*What's the red button next to the tip?',* P11: *'That's if you want to write')*, it did not follow for some that this would be the point of interaction for adding or posting a comment. Again, it may be necessary to include text to provide extra context.

Feedback on features and content

As was put forward in Focus Group 2, there was a positive response to the idea of contextualized feedback dependent on score received: *'It's giving you the reasons why you've got a certain achievement'* (P10). Responses from participants also suggest users would be interested in comparing different days in order to self-reflect and learn from past behaviour: '*I'd be inclined to do it, to see the good days'* (P13); *'what contributed to a good day'* (P14). Feedback with regard to goals achieved and progress reached was also touched on. P14 was interested in the idea of goal-setting both for steps and sleep, but felt it would be important to not set goals too high as this could have a de-motivating effect on users. She said '*I think for older people you want to change the goal because eight hours is too much for an older person'.* This was also the case for activity goals; she felt goals should be attainable and should increase gradually over time so as not to demotivate the user.

Participants saw the value in being able to act on the feedback they received and saw this as a useful addition. Most felt, however, that there should also be usability tips throughout the application in case a user forgot what to do or what something meant. This was particularly true for the abbreviations and acronyms used in the blood pressure part of the application: '*I can't remember what HR stands for'* (P10). P10 viewed spikes in blood pressure as more important than averages. A redesign may be needed for this or it may be necessary to include highlighted spikes if possible. More frequent readings would be necessary in order to present data in this manner. He said '*Well, I don't know how significant the average would be. I think it is more significant where you have hit the high spot… I think you might be interested in the frequency of the spikes'.*

The idea of being able to add extra information to provide further context was received positively by most of the participants. The feature of annotating and adding self-reported feedback seemed appealing and useful to some, with P11 seeing value in being able to amend or add a note to data: *'Sort of "I don't' agree with something…Or I think I should have done something"* (P11). Annotating to add contextual information was also seen as useful to P12, who said '*you could add something to it… that explains why I slept…. So this is where you would type what caused you to sleep… Good sleep or bad sleep now and what the reason was'.*

While providing the function for annotating and leaving comments did receive favourable responses, it later became apparent in development that this feature would have been too difficult to implement and thus it had to be dropped from the application.

While P13 felt the applications was *'nearly self- explanatory',* most participants felt a user would need training before using the application and devices: '*I think to do this I think you need a little bit of instruction'* (P10); *'You see what's important is to people who are using it... that elderly people particularly, are not afraid'* (P13).

P12 made the point that there needs to be a sense of progress as the application is used over time: '*I think if you're going on forever for weeks, people will give up and they won't do it. They need a sense of survey for a specific time… the week that you indicate is whatever week of the study'.* This is particularly relevant when it comes to both engagement and adherence and was later addressed through stating on the screen the day and week number throughout the eight-week trial (see Chapter 7). Both P13 and P14 felt that it would be important that potential participants are made aware of the benefits of engaging with such a system. P14 said '*you've to tell them why you're doing it… you can make them believe if you give them a good enough explanation'.*

The usability testing sessions were crucial in revealing certain user experience and interface issues, which had previously been overlooked or had not been considered, such as the 'house' icon being mistaken for activity in the home, and the possibility of colour intensity causing issues for people with colour-blindness. Lessons learned from analyses of these user interactions and qualitative feedback then allowed for further iterations in the design cycle. Owing to the negative responses from all participants during testing to the Sleep Week View interface, a redesign (Figure 5.26) was carried out immediately following the testing, and prior to the next design cycle. As can been seen, the graph was simplified significantly, with simple bars representing each night's sleep. The height of the bar shows the total number of hours while the colour-coded sections within the bar showed the breakdown of deep, light, and restless. Improvements in functionality were implemented through changing the style of toggle button under the calendar, introducing a 'back' button, and labelling certain buttons, such as the self-report feature. Further changes were also made to improve the aesthetic quality of the interface, such as the new fonts and colours in the tab menu at the bottom of the screen, These design changes and updates among others are discussed in more detail in Chapter 6, Section 6.3.

Average per night: **7** hrs **36** mins

Goal of 8 hours reached: **4** times

Figure 5.26: Sleep Week View (as updated following Usability Test 1)

5.5 Summary

This chapter discussed Iterative Design Cycle 1, which involved two focus groups, the first designs and the first round of usability testing. The focus groups aimed to explore issues around health and wellbeing which are important to older adults, their preferences regarding various types of data visualizations, as well as their views on some wearable devices and companion applications. The main themes to emerge from these were stress (due to worry about one's own health or a loved one's) and sleep, (and the degree to which the two are interlinked), while feeling and preferences regarding both wearables and data visualization types were revealed. Findings from both of these focus groups then fed into to the initial designs of the digital health application for this trial. These initial designs were then put onto an iPad and individual usability testing sessions were held with five older adults. Analysis from these sessions as well as the findings from the two focus groups and the ongoing literature allowed for the study to move into the next phase of the user-centred design cycle, Iterative Design Cycle 2.

Chapter Six: ITERATIVE DESIGN CYCLE 2

6.1 Introduction

Design Cycle 2 built on the results from the first iterative design cycle, described in the previous chapter. Interviews were held with older adults in order to gain an insight into their views and experiences regarding mindfulness as a technique for stress management. Following this informal carers participated in semi-structured interviews so as to get a fuller picture of issues and topics pertinent to this particular cohort. Concurrent and subsequent to this, further iterative designs were made, integrating feedback from the qualitative data to date alongside learnings from the ongoing literature review. During this evaluation, mindfulness content was also sourced for the application. The mindfulness user interface then went through a number of iterations before being tested with another group of informal carers. Findings from these data led to further insights into issues and challenges faced by this cohort and informed the final design of the system prior to the main trial. This chapter outlines each phase of Iterative Design Cycle 2, including methods used and findings.

6.2 Semi-structured Interviews 1

6.2.1 Methodology and participants

The first stage of Design Cycle 2 involved a round of semi-structured interviews held with the same five older adults who had taken part in the usability testing sessions discussed in Chapter 5 (3F, age range 68-76). These participants had expressed an interest in participating further in the study and as such they were recruited for these interviews. The focus here was on stress management, mindfulness and meditation in general, with participants invited to discuss any experiences they may have had or indeed any preconceptions, thoughts or feelings they had surrounding this topic. Participants were asked questions related to their prior experiences, if any, with meditation, their understanding of the concept, and also how interested they would be in trying it. In addition, they were asked to describe general stress levels, stressors and sources of stress or worry, and what techniques they employed to manage stress. The protocol for the interviews can be found in Appendix 3.

Each interview lasted approximately 45 minutes. The interviews took place in the participants' homes. Participants were shown a video at the outset of the interview, which was a short and accessible introduction to the area of meditation and mindfulness. From there, they were encouraged to discuss their thoughts and opinions and were also encouraged to ask questions themselves. The video was used as a 'starting-off' point and it also served the purpose of providing some basic information regarding the science and physiology behind mindfulness.

6.2.2 Data collection and analysis

Participants had already been assigned ID numbers. Data was collected using a Dictaphone. Prior to analysis, the recordings were transcribed using a word processor by the researcher. The transcripts from the recordings were then imported into NVivo for analysis. With regard to analysis, the process was quite open in terms of coding. This was the first time the area of mindfulness had been discussed with participants, and as such topics and themes emerged naturally and inductively from the data (Braun and Clarke, 2006).

6.2.3 Findings

As in the earlier focus groups, participants spoke about the triggers of stress and the impact stress has on life and general wellbeing. Among the examples of things that can cause stress were worrying about one's own health, retaining a sense of independence, and having to rely on a healthcare system: *one can start worrying about what the hell is going to happen you in terms of a deteriorating health system, home care* (P10). P11 also suggested worry about getting older and not knowing what will happen is a cause of stress or anxiety, saying, '*I think quite often fear of the future… fear of the unknown I suppose'*. These sentiments were expressed in previous focus groups also. P12 also suggested modern life and constant stimuli can contribute to stress levels and sleep problems

The participants in general felt that stress reduction was an important part of health and wellbeing management. P12 already used stress-reduction techniques, such as muscle relaxation, to help her get to sleep. She also felt that some form of meditation practice or stress-reduction programme is needed to address these issues. She said, '*It's really needed in this day and age because people are, the silence is gone, there's no silence anywhere and people can't take silence'.* P12 was the first participant at this stage of the study to describe using meditation-based techniques as a means of stress reduction. Participants reported employing different techniques to handle feelings of stress, with one participant using distraction and acceptance: *I don't think it's of benefit to dwell on things like that. If you can do something about it, that's fine. If you can't do anything about it, it's pointless* (P11).

Each of the participants responded positively to the idea of mindfulness, with some more familiar with the concept than others. With regard to barriers to engagement, the point was raised about how practical incorporating mindfulness meditation into an older person's routine would be, particularly someone who is caring for another person. P11 said, '*it would be very difficult to do it with somebody there… you'd have to do it on your own'.* Having seen the introductory video about meditation shown at the start of the interview, P10 was interested in finding out about the science behind the practice and also suggested ten minutes a day is practical and realistic. This amount of time was reasonable to P10 and he suggested this type of practice would appeal to older users. He said, *'I think that would be a very interesting part of a programme like that… When something can be done inside a practical time frame, like 10 minutes, because that's the kind of thing that people can sit down and do'.*

Instructions and background were seen as important by two participants, with one in particular suggesting education would be very important for motivation*: 'A reason why you're doing it'* (P14). P11 also touched on this, saying training and clear guidelines as to how to practice mindfulness meditation would be very important. She suggested that a person who is struggling to clear their mind while meditating would find it very difficult to continue, saying '*not being able to clear your mind, not being able to concentrate, bringing it back to your breathing all the time…that would be difficult to get on top of'.*

6.3 Interviews With Informal Carers

6.3.1 Methodology and participants

The next phase of Design Cycle 2 consisted of another round of semi-structured interviews. The participants in this phase were informal carers; six participants (5=f, age 53-74) were each interviewed for approximately 60 minutes. The participants were caring for relatives with various co-morbidities, including dementia, ranging in age from 75-92. In this case, participants were recruited as part of a larger research project within NetwellCASALA that was focused on designing technology for people with multimorbidity and those who care for them.

The aim was to explore these participants' experiences as informal carers, including the challenges they face as a result of providing care and to gain insight into how these challenges affect quality of life, health and wellbeing in general, and their capacity to provide care. The interviews also explored participants' strategies for dealing with stress and any education and training (or lack thereof) they had received. The semi-structured interview protocol can be found in Appendix 3. Interviews were held wherever was most convenient for the participant, with some taking place in the participant's home, and some at the research centre. Mindfulness and meditation in general was not discussed with these participants as this data was being collected as part of another project, where mindfulness was not the focus. However, on analysis of this data it was determined this cohort could likely benefit from such an intervention. Later interviews and usability testing were carried out with older informal carers, where mindfulness was specifically explored, and these are discussed in Section 6.4.

6.3.2 Data collection and analysis

Participants were given ID numbers following on from those assigned previously. As with previous interviews, data was collected using a dictaphone and field notes. Audio recordings were transcribed for analysis and imported into NVivo. As the profile of the participant was more defined and the questions and areas for discussion were in a sense more specific, the analysis gave rise to both new codes entirely, and also sub-nodes of previous codes. This allowed for more content, detail and nuance overall in terms of the level of analysis. Participants were asked to discuss their experiences as carers, leading to broad and open-ended responses frequently. Specific questions were also asked concerning aspects of caring, such as care burden, family support, education, health system, stress and its impact on their ability to provide care, and the effect on their health and wellbeing in general. As such, this phase of the study could be considered both inductive and deductive thematic analysis (Braun and Clarke 2006).

6.3.3 Findings

The interviews revealed a number of themes shared across participants. Broadly speaking, these themes can be grouped into the two categories of 'Carer Burden and Challenges', and 'The Impact of Caring on Emotional Wellbeing'. An overview of the main insights and themes to emerge from these interviews are included in Table 6.1.

Table 6.1 Themes and sub-themes from interviews with informal carers

Theme	Sub-theme
Carer Burden and Challenges	- Challenges and Stressors - Burden and lack of support
The Impact of Caring on Emotional Wellbeing	- Negative effect of condition on the informal carer - Constant worrying and chronic stress - Resentment and guilt

Carer Burden and Challenges

Challenges and Stressors

The responsibility of caring for someone with complex care needs or dementia, along with related daily stressors were discussed throughout the interviews. P16 spoke about how her mother will sometimes realise she is forgetful, which leads her to become angry and defensive, often leading to confrontation, with P16 feeling inadequate. Other challenges include the care recipient forgetting to take medication or forgetting to eat. The difficulty in managing these scenarios and the lack of a clear solution with regard to how to explain to her mother what was happening, represented a significant challenge for P16, yet this was also something she felt a considerable amount of responsibility for managing. At the same time, P16 expressed how she wanted her mother to have some degree of independence and quality of life, but she felt worried and anxious that something bad may happen if she does not check in regularly: *'you can't wrap her up in cotton wool… it is a risk and you just think oh God'*. Other daily challenges and stressors discussed by participants included mobility issues: '*the lack of mobility is really the hardest… she can't move unless you are there'* (P18); keeping track of medication, needing to accompany the care recipient on any trips, and the challenge of having to balance all of these responsibilities at once: '*that's a huge challenge as well trying to keep that balance in place'* (P16).

Participants also spoke of the challenges in dealing with the effects of the condition(s) on both the care recipients and themselves. P15 explained that she would find it very difficult to live with her mother and indicated their relationship is strained*: 'I just could not live with her, wouldn't want to.. because she would control you*'. She also explained that as the carer, she is tasked with taking care of everything herself and faces considerable burden as a result. P16 supported this sentiment but stressed that it was the work that was burdensome, not her mother. Various challenges in dealing with the way dementia can affect a person were discussed by P17, who explained that tasks such as communication with the care recipient as well as with medical professionals presented significant problems. She explained that her mother prefers not to speak with the GP and expects P17 to do so instead. This is particularly difficult when P17 does not know what the medical problem at hand is: '*She won't tell him what's wrong. I am supposed to tell him*'. Her mother can also become reluctant to communicate in general and forcing the issue can often result in arguments. Similar issues with communication were expressed by P18, who said, '*when you push Mam, she just shuts the door'*. All of this can subsequently lead to both feelings of resentment and worry on the part of the carer.

The issue of lack of communication and integration between various healthcare professionals within the health system was also noted as a challenge by many participants: '*there is no joined up thinking'* (P15); '*they didn't look for histories when she goes to the consultant*' (P17); '*the systems don't talk to each other…I find it very challenging'* (P19). This results in further challenges for the carer, as they are left with what can appear to be contrasting or confusing recommendations.

Burden and lack of support

Another common theme that was revealed during the interviews was the sense of feeling overwhelmed by the burden of caring and the lack of support available. P19 explained that '*there would have been times I would have loved just to lay down on the bed and had a rest*', while P16 discussed how she needs to take things one day a time to avoid feeling too overwhelmed: '*sometimes it's just "let's get through this day"*'. The challenges posed by having to manage time and balance responsibilities resulted in feeling under pressure and difficulty coping for some of the participants. P16 explained that the progress of the disease lead to a very demanding schedule, and there is a particular need for support from family and friends as a result. She said, '*you also have to walk away from it, and you have to know that somebody else is there and you have to have your own space at home*'. The impression from the interviews was that without such relief, the participants would find their daily lives overwhelming and unmanageable: '*it's just too hard to do it on your own particularly with dementia… you just need to have somebody to bounce it off*' (P16). P18 explained that she often felt trapped as a result of being the sole carer, saying '*you just can feel…trapped sometimes so you kind of get a bit… you get stressed just being there. You kind of want to scream'*. As well as feeling trapped, some participants expressed feelings of isolation and being cut off from the community.

P16 explained that as the illness progresses, more help and support is required: '*she really needs monitoring all the time*' (P16). However, this very often falls on the carer as there is only so much support available from the health service. There were also contrasting experiences described regarding the sufficiency of the support offered. While some felt they could access adequate support relatively easily, others expressed frustration at the lack of support: '*They wouldn't give me any home help, I have to do it all myself*' (P19); '*nobody was coming to me… from the community'* (P16); '*I have no support, my family obviously, that's it'* (P20).

Where support was potentially available, there were also sometimes barriers, for example some participants reported support being offered but then ultimately rejected, typically because the care recipient would become upset when somebody they are not familiar with comes into their home: '*I don't think I'd be able to get a carer in the door, because I think he'd just go mad'* (P20); '*she doesn't like them interfering with her privacy*' (P15). As well as this, often it was the case that travel became a barrier to access, with the participants finding it very challenging to get the care recipient from one place to another.

Lack of support further contributed to burden and stress. Some participants, such as P18 didn't have other people to rely on in terms of support. P18 said: '*I don't have kids…and I am more in a position to do it - it's just at times, it gets to you, you know'*. Lack of support not only increased the caring burden, but also impacted on emotional wellbeing. P20 said *'it's hard, being at home and not having someone to lean on'.* This was echoed by P19, saying '*There is no-one caring for the carer… You feel vulnerable'.*

The Impact of Caring on Emotional Wellbeing

Negative effect of condition on the informal carer

The interviews revealed that the effects of the disease on the care recipient can in turn negatively affect the carer, as well as the relationship between the two. Deterioration in the care recipient's condition typically results in increased worry and prolonged stress for the carer. Some participants also reported a lack of sleep, for example due to a fear that the care recipient might get up during the night and fall and injure themselves: '*It was just draining and like you'd be pretending you're asleep, but you are watching with one eye at the same time*' (P20).

For some participants it was difficult to come to terms with what was happening, both to the care recipient and to their own lives: '*It's the change in the person itself…it's just shattering to look at him'* (P20); *'she's a different person*' (P16). Emotional wellbeing was also negatively affected with regard to how the relationship between the care recipient and the carer and family members had changed. P16 discussed how for her it was distressing that her children were seeing how their grandmother was changing as the disease progressed. She said, '*you don't want them to start resenting her…I want them to remember…the person they love not the person that is kind of struggling with their illness now'*.

The impact of caring on wider relationships was also discussed, with P16 saying '*it's very demanding and it takes a toll on all of your relationships',* and later '*so that's a huge challenge as well trying to keep that balance in place'.* These comments suggest she finds it a struggle to balance family relationships and other external commitments with the time and efforts required to care for somebody. P18 also discussed this and explained how living with and caring for her mother eventually took its toll on her relationship with her husband, saying '*so we did stay for a couple of months, but we just found it was impeding our relationship as well'.*

It was evident from participant comments that the responsibilities associated with caring result in loneliness: ‘*Saturdays and Sundays you kind of feel everybody is doing things…weekends I find harder… I want to be out and about and it isn't working…I miss the socialising’* (P18); ‘*I have 4 sisters… we’d always socialise together, and we’d go to one another’s houses; there’s nobody coming to mine now’* (P20). P20 described how the care recipient’s limited mobility means she is unable to leave the house, likening it to ‘*a prison sentence’*. P19 said ‘*You put yourself last… You put them first’*. Such comments suggest informal carers see caring as having a significant impact on their emotional wellbeing and quality of life.

Constant worrying and chronic stress

A recurring theme throughout the interviews was constant worry. One result of this was either neglecting oneself in terms of health management or simply not having time to oneself to unwind: ‘*your time isn't really your own…if you are not physically there you are still worrying*’ (P16). Another result of being solely responsible and having a constant sense of worry about another person is a feeling of resentment, with P17 commenting that ‘*she is always at the back of your mind…we should be retired now and having no worries’*. P18 compared these feelings of constant worry and stress with the type of stress one undergoes at work when meeting a deadline, for example, and suggested that it is quite different. She said, ‘*it's not a stress you would feel when you are in work… had to have a deadline…it's not that kind of a stress’*. Her comments suggest she is suffering from chronic stress, which is not as pronounced as when someone is highly stressed for a short period and for a particular reason and purpose; rather, it endures and offers little respite. This was also the case for P20 who commented that ‘*it does take over your life…you are watching all the time’*, and also for P19, who said, ‘*you are always on duty’*. P20 explained that she becomes fearful and second guesses her ability to provide care. She said, ‘*Fear, I have to say fear… I’m watching him all the time when he’s walking that he doesn’t fall, I hate when he goes out to the backyard and it’s constant*’. All of these comments demonstrate the degree to which caring for persons with dementia can lead to a sense of chronic stress and constant worrying, which has the potential to lead to negative health outcomes for the carer if not addressed.

Resentment and guilt

A smaller theme to emerge was a sense of resentment coupled with feelings of guilt. Resentment appeared to be borne out of both a sense of frustration as well as lack of gratitude: '*it's just the bit of resentment I suppose as well. I know I did offer to look after her and that but she expected it too … sometimes, you feel…that she doesn't recognise that I am married and because we don't have children she feels well if you don't have kids, what have you got to worry about'* (P18). P18 also spoke of feeling guilty as a result: '*you are kind of feeling guilty because you…don't want to be in the house'*. She also explained how one can have mixed emotions, saying '*you are feeling bad because you want her to live but you just kind of don't want to have the whole responsibility'*. P20 was also quite direct in how she expressed her feelings on this matter. She commented that, '*it is quite boring I'll be honest with you – for me. He's* (care recipient) *not here now I can say that. It is*'.

6.4 Designing the App – Iteration Two

The interviews held with the older informal carers confirmed that chronic stress is indeed an area of concern for this particular cohort, giving weight to the need for an intervention to address this. As such, the next iteration of the design focused on integrating a mindfulness-based intervention into the design. The remainder of this chapter describes the design and content for the mind user interface (the area of the Mind Yourself application through which the mindfulness intervention is delivered) as well as the second phase of usability testing with informal carers.

This phase of the study lasted approximately six months. At regular intervals, design decisions were discussed with HCI and software development researchers within NetwellCASALA to gather feedback on usability and feasibility in relation to software development. The overall design went through a number of iterations, with a considerable amount of time afforded to the mindfulness interface. This was due to the unique challenge in presenting what is essentially content to be consumed via audio and with eyes closed, in a logical and comprehensive manner that communicates to the user a sense of progression and structure. Refinements were also made to the iterations of each part of the interface in terms of layout, colour, features, and task flows, based on feedback from the first usability testing sessions.

6.4.1 Mindfulness content and initial mind UI designs

A goal of the application was to deliver guided mindfulness meditation daily. The content for the digital intervention was sourced from the book ‘Mindfulness – a practical guide to finding peace in a frantic world’ by Mark Williams and Danny Penman (2014). This book presents a modified version of mindfulness-based cognitive therapy and provides a guided 8-week course of mindfulness practice. It does not require group sessions or day retreats as commonly found in most full MBSR courses. Rather, a series of simple practices which can be incorporated into daily life are provided. The goal is to educate the user such that they will arrive at a point wherein mindfulness awareness practice can be deployed and utilized at will in times of high stress or anxiety (Visser *et al.,* 2015).

Topics and practices covered are common to typical MBSR and MBCT courses and include meditations including Habit Releaser, Mindful Awareness of a Routine Daily Activity, Mindfulness of the Body and Breath, Body Scan, Mindful Movement meditation, Three-minute Breathing Space meditation, Sounds and Thoughts meditation, Exploring Difficulty meditation and Befriending meditation. Each day the application presents the user with that day’s practices, both in audio and text format. As they move through the eight-week course, they are encouraged to incorporate these new skills and practices into their everyday lives[8].

The mindfulness content within the application can be accessed through the Mind tile of the dashboard, or the Mind tab in the bottom menu. In Figure 6.1, four mindfulness meditation activites are presented in a grid and the user is on day 4 of week 1 in the programme. A brief description of the week’s theme and content is provided. As the mindfulness content changes from week to week, the grid interface needed to adapt to integrate fewer or more meditations (Figure 6.2). The difficulties and potential confusion this can cause for users is discussed further in Section 6.3.4.

A task flow of the Mind interface at this stage of the iterative cycle would proceed as follows: Starting from the Mind tile on the dashboard, the user is brought to the overview screen, which presents information about that week’s content. From there the user can select a number of options. Self-report brings up a modal window with multiple choice inputs, while selecting one of the meditation buttons then displays the text and audio guide, again on a modal window.

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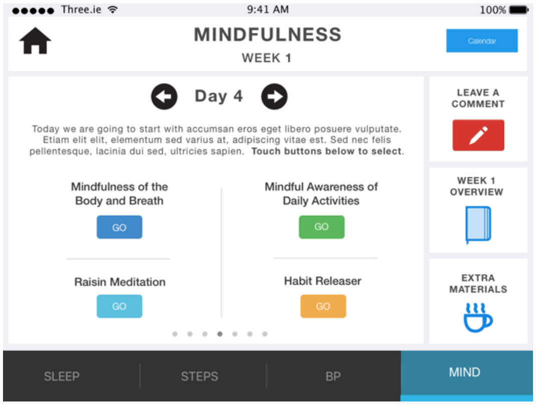
[8] (https://mindfulness.ie/about/mindfulness-courses-mbsr-and-mbct-explained/)

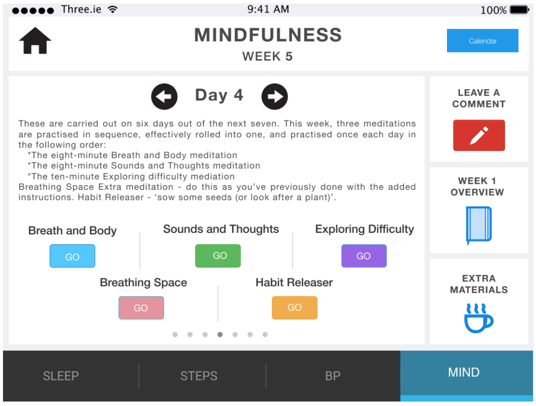
Selecting ‘extra materials’ brings the user to a new page. From here they can select either ‘readings’ or ‘videos’. ‘Readings’ leads to a new page with a selection of articles relating to mindfulness. Selecting one of these will bring up a modal window of text. Selecting ‘videos’ brings the user to a new page also with a selection of YouTube videos on the same topic.

Changes were also made to the overlay menu at the bottom of the interface throughout the application. A black background with a thinner font was used throughout and cyan was used to indicate current selection. This was done to futher simplify the design and to provide a cleaner aesthetic overall (see Chapter 5 Section 5.3.2 for initial mock-ups).



Today we are going to start with accumsan eros eget libero posuere vulputate. Etiam elit elit, elementum sed varius at, adipiscing vitae est. Sed nec felis pellentesque, lacinia dui sed, ultricies sapien. **Touch buttons below to select.**

Figure 6.1: Mind Week 1 Day 4 (early design)



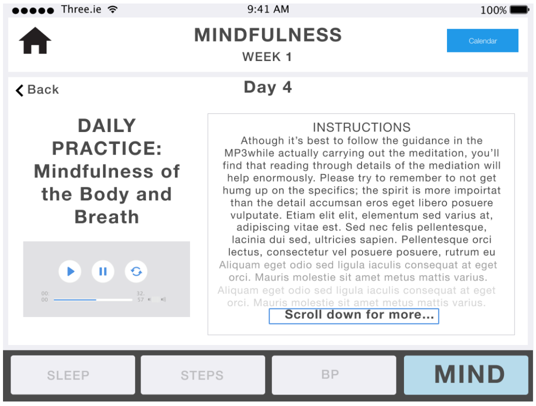
These are carried out on six days out of the next seven. This week, three meditations are practised in sequence, effectively rolled into one, and practised once each day in the following order:
*The eight-minute Breath and Body meditation
*The eight-minute Sounds and Thoughts meditation
*The ten-minute Exploring difficulty mediation
Breathing Space Extra meditation - do this as you’ve previously done with the added instructions. Habit Releaser - ‘sow some seeds (or look after a plant)’.

Figure 6.2: Mind Week 5 Day 4 (early design)

Figure 6.3 presents one of the earlier design ideas for the meditation guide which displays an audio player and accompanying text. The challenge in terms of design was to present the audio and text-based content together in a way that was clear, accessible, and logically structured. As the text guides for some of the meditations are quite long, one possibility considered was to fade out the lower end of the visible text and place ‘scroll down for more’ as an overlay button. Integrating this type of functionality was considered necessary as it was speculated that without something to signify further content, a user could possibly consider what was on screen as the extent of the content.

Figure 6.4 presents a further iteration of the meditation guide interface. In this example, the audio player and title were placed at the top of the section with the text making use of the space below. This felt more natural and logically segmented and allowed the text to be presented in a horizontal fashion, rather the vertically. However, this was not ideal for vertical scrolling, particularly for older users who may have issues with this type of interaction on a touch screen, and as such called for further redesigns. Issues around short scrolling had been observed in iPad classes held with older adults prior to this study.

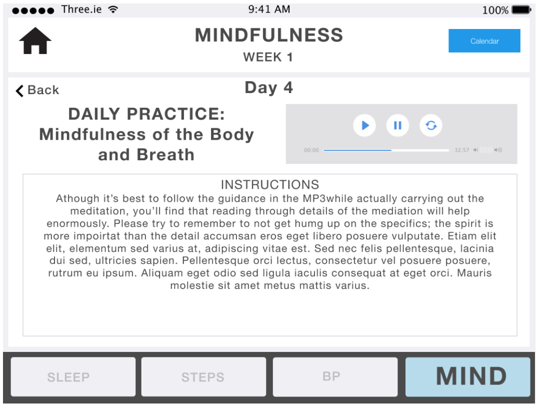
The next iteration (Figure 6.5) formed the basis for the updated and final design, as discussed later in Chapter 7. In order to maximize space while also maintaining simplicity, a modal window was used to display the meditation practice content. This made use of the space of the screen without needing to navigate away from the page at hand, underlining and maintaining the sense of location within the interface (Jacobs, 2019). Modality in this context can be described as a 'design technique that presents content in a temporary mode that's separate from the user's previous current context and requires an explicit action to exit' (Apple, 2020). Content in a modal window has been described as 'critical information that requires a specific user task, decision, or acknowledgement' (Google, 2019). In the example provided in Figure 6.5 ,the explicit action to exit is the use of the 'done' button. It was decided to label the button as 'done' as opposed to 'cancel' or 'finish', as this language was preferred by participants in the first usability testing session. When a modal window is present, functionality as it existed on the main screen is disabled while still visible in the background. This is achieved through the use of shading wherein the user is aware they are still on the same page, but their focus and attention is drawn to the bright content on the modal window and the idea of content below or behind the modal being blocked or disabled is clearly communicated (Jacobs, 2019). An alternative to scrolling was also integrated into the design through the use of a 'continue reading' button. This moves the content down one page while still displaying within the modal window. Figure 6.6 presents the end of the meditation text within the modal window. The user can in this instance use 'back to top' to return to the start point of the text.



INSTRUCTIONS

Athough it's best to follow the guidance in the MP3while actually carrying out the meditation, you'll find that reading through details of the mediation will help enormously. Please try to remember to not get humg up on the specifics; the spirit is more impoirtat than the detail accumsan eros eget libero posuere vulputate. Etiam elit elit, elementum sed varius at, adipiscing vitae est. Sed nec felis pellentesque, lacinia dui sed, ultricies sapien. Pellentesque orci lectus, consectetur vel posuere posuere, rutrum eu Aliquam eget odio sed ligula iaculis consequat at eget orci. Mauris molestie sit amet metus mattis varius. Aliquam eget odio sed ligula iaculis consequat at eget orci. Mauris molestie sit amet metus mattis varius.

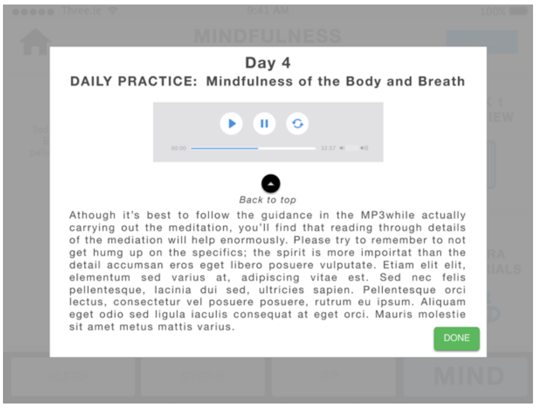
Figure 6.3: Meditation Guide (early design)



INSTRUCTIONS

Athough it's best to follow the guidance in the MP3while actually carrying out the meditation, you'll find that reading through details of the mediation will help enormously. Please try to remember to not get humg up on the specifics; the spirit is more impoirtat than the detail accumsan eros eget libero posuere vulputate. Etiam elit elit, elementum sed varius at, adipiscing vitae est. Sed nec felis pellentesque, lacinia dui sed, ultricies sapien. Pellentesque orci lectus, consectetur vel posuere posuere, rutrum eu ipsum. Aliquam eget odio sed ligula iaculis consequat at eget orci. Mauris molestie sit amet metus mattis varius.

Figure 6.4: Further design idea for Meditation Guide

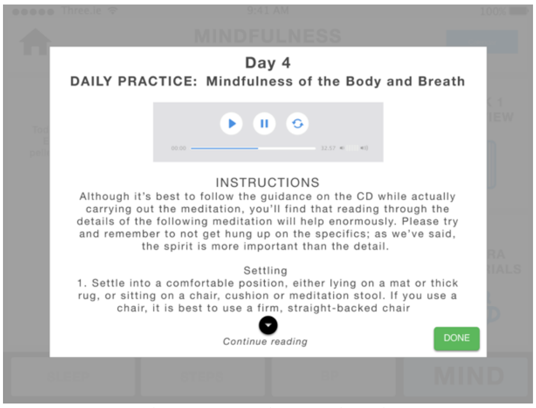


Day 4

DAILY PRACTICE: Mindfulness of the Body and Breath

Athough it's best to follow the guidance in the MP3while actually carrying out the meditation, you'll find that reading through details of the mediation will help enormously. Please try to remember to not get humg up on the specifics; the spirit is more impoirtat than the detail accumsan eros eget libero posuere vulputate. Etiam elit elit, elementum sed varius at, adipiscing vitae est. Sed nec felis pellentesque, lacinia dui sed, ultricies sapien. Pellentesque orci lectus, consectetur vel posuere posuere, rutrum eu ipsum. Aliquam eget odio sed ligula iaculis consequat at eget orci. Mauris molestie sit amet metus mattis varius.

Figure 6.5: Meditation Guide – audio player 1



Day 4

DAILY PRACTICE: Mindfulness of the Body and Breath

INSTRUCTIONS

Although it's best to follow the guidance on the CD while actually carrying out the meditation, you'll find that reading through the details of the following meditation will help enormously. Please try and remember to not get hung up on the specifics; as we've said, the spirit is more important than the detail.

Settling

1. Settle into a comfortable position, either lying on a mat or thick rug, or sitting on a chair, cushion or meditation stool. If you use a chair, it is best to use a firm, straight-backed chair

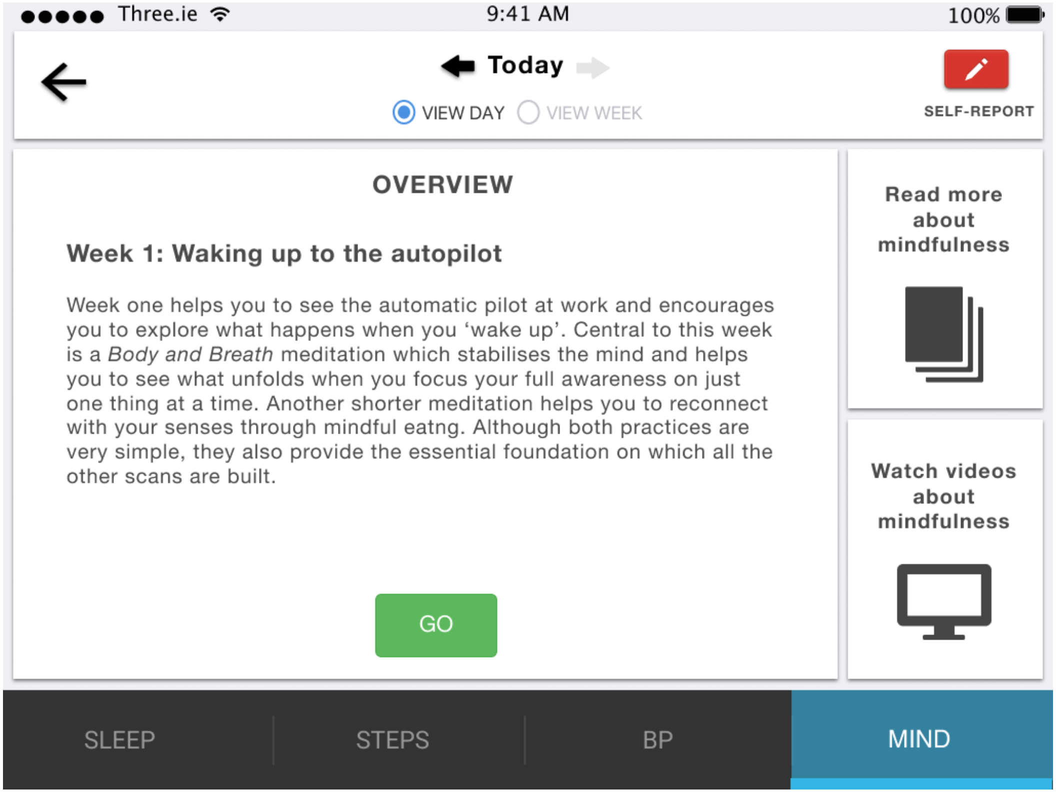
Figure 6.6: Meditation Guide – audio player 2

6.4.2 Mind interface redesign

Following on from discussions between the design team (researcher, developer and supervisor), it was decided that the Mind section of the application as described in the previous section needed to be modified. This decision was borne out of a realization that the user flow for this section was not sufficiently intuitive. For example, landing on the Mind screen, the user would have been presented with a grid which contained each of the guided meditations. However, it was not clear where to begin or what to do, nor was it obvious what each of the tiles on the grid represented (Figures. 6.1 and 6.2). As such, an interface redesign for this section was implemented, involving a complete overhaul in terms of interaction, flow, presentation, and overall aesthetic.

Overview screen

Once the user selects the Mind tab at the bottom of any screen, they are brought to the Overview screen of the Mind interface (Figure 6.7). Here there is a synopsis and description of that week's theme and area of focus. Selecting 'Go' will then bring the user to the Planner screen (Figure 6.8). When designing this screen, it was important to minimise clutter, avoid feature saturation so as to provide a clean interface with a clear call to action.



OVERVIEW

Week 1: Waking up to the autopilot

Week one helps you to see the automatic pilot at work and encourages you to explore what happens when you 'wake up'. Central to this week is a *Body and Breath* meditation which stabilises the mind and helps you to see what unfolds when you focus your full awareness on just one thing at a time. Another shorter meditation helps you to reconnect with your senses through mindful eatng. Although both practices are very simple, they also provide the essential foundation on which all the other scans are built.

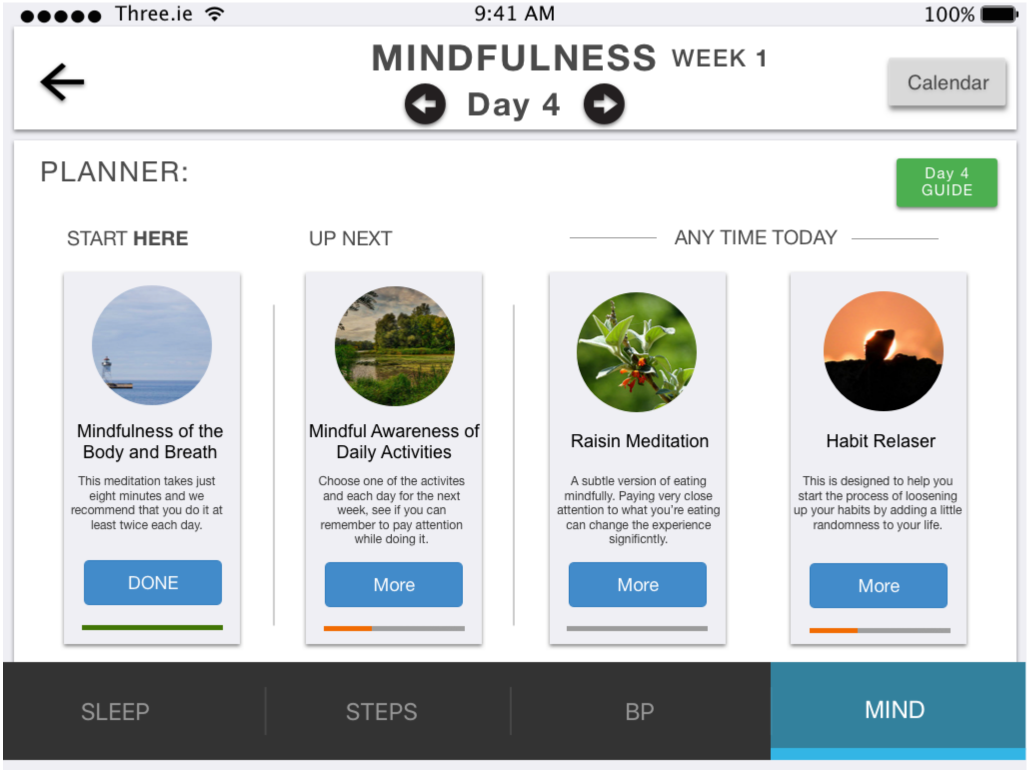
Figure 6.7: Mind Week 1 Overview/Introduction to Week (redesign as used in Usability Test 2)

Planner and guide

A challenge also existed in how to present multiple meditations on a tablet interface. The MBCT course as outlined in 'Mindfulness: a practical guide to finding peace in a frantic world' (Williams and Penman, 2011), the content of which formed the basis for the meditation content in the application, includes prescribed meditations which change from week to week. Included in this are both formal, guided meditations, and other shorter techniques which were designed to be practiced at any time. As such, there was a significant amount of content to be integrated into the interface. Providing instructions to guide a user through this was difficult, as the screen could soon become cluttered and text-heavy. Two options initially considered were vertical scrolling and a carousel (left and right arrows) as both would have allowed for sequential content. However, a potential issue with this is the possibility of lost or missed content. Scrolling or tapping arrows is not necessarily intuitive to a user unfamiliar with touchscreen interfaces. While this is necessary for rich content such as text, the aim here was to avoid such functionality, and present the relevant content on one screen. The idea then emerged to present each technique/practice as vertical. The user is guided to move from left to right in a sequence.

On the right side of the screen, the shorter meditation techniques are labelled ‘any time’ so as to differentiate from the more formal, guided meditations. This design allowed for a clear starting point and it also allowed for a brief description as well as a picture to be included in each tile. Given that the space available for the Mind content was rectangular and landscape, spacing the content from left to right made the most use of the screen real estate available. Later in the development phase, however, it became clear that portrait mode would need to be provided also. This was due to a requirement for web applications running in Safari that was not known to the development team during the initial design phase.

Figure 6.8 presents the Planner screen of the Mind interface. The top section was redesigned (Figure 6.7.) prior to Usability Testing 2. In Figure 6.8, the user is guided as to where to start, in this case with the ‘Mindfulness of the Body and Breath’ meditation. On the right side of the screen, ‘Raisin Meditation’ and ‘Habit Releaser’ are separated into a section tagged as ‘Any Time Today’ (informal meditations). The meditation tile cards are made up of three elements in this iteration. An image is provided in a circle so as to communicate a sense of calm and to provide colour. Below this there is the title as well as a short description. This was considered important as some of the meditation titles in themselves are not necessarily obvious or easy to understand. Below this there is a button which has three states: ‘go’, ‘more’, and ‘done’, with the colour codes grey, orange, and green respectively to communicate to the user the degree to which a particular meditation had been practiced already. The user is also provided with a guide button on the Planner screen, which brings the user to a modal screen providing instructions as to how many meditations should be practiced each day, and in which order if necessary (Figure 6.9).



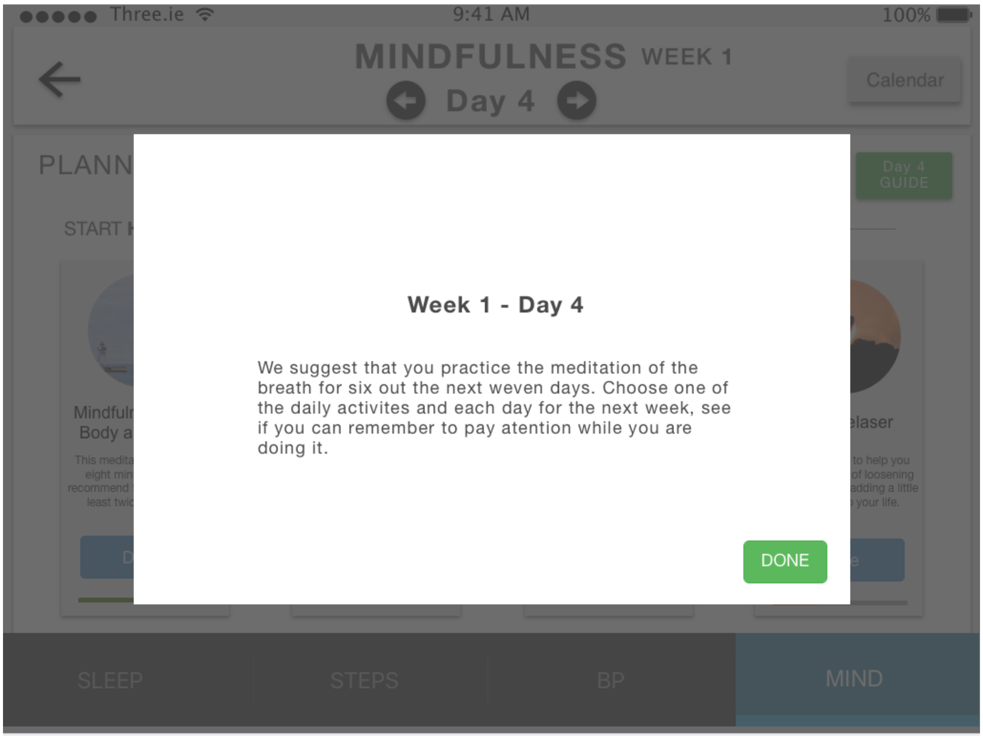
This meditation takes just eight minutes and we recommend that you do it at least twice each day.

Choose one of the activites and each day for the next week, see if you can remember to pay attention while doing it.

A subtle version of eating mindfully. Paying very close attention to what you're eating can change the experience significtly.

This is designed to help you start the process of loosening up your habits by adding a little randomness to your life.

Figure 6.8: Mind Week 1 Planner v1 (pre-usability testing)



Week 1 - Day 4

We suggest that you practice the meditation of the breath for six out the next weven days. Choose one of the daily activites and each day for the next week, see if you can remember to pay atention while you are doing it.

Figure 6.9: Mind Week 1 Guide

Extra materials

The extra materials and videos from the original designs were included again in the redesigns. Two elements were included within the Extra Materials section: ‘read more about mindfulness’ and ‘watch videos about mindfulness.’ (see Figures 7.48 and 7.49 in Chapter 7). Content was later sourced from various websites and YouTube respectively.

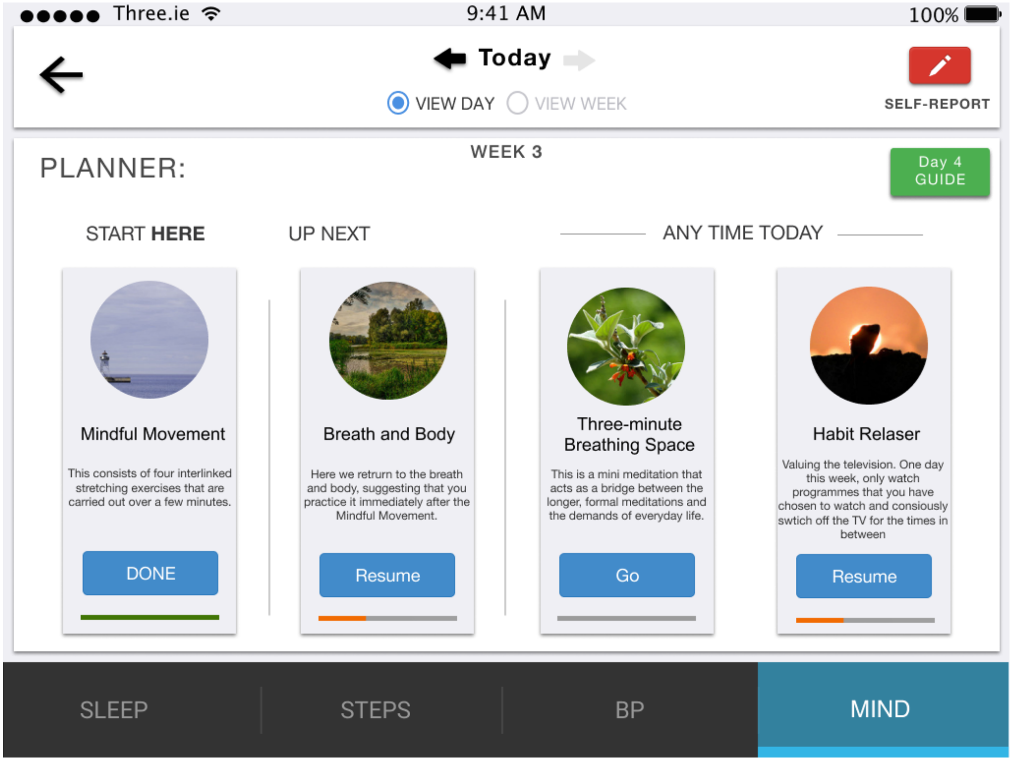
6.4.5 Further changes to the overall user interface

Navigation

The House/Home icon in the top left corner was also replaced with a back arrow as well as a ‘logo’/app name on the dashboard. This allowed the user to navigate back to a previous screen instead of landing back on the Dashboard screen. It also removed the potential for confusion as one Usability Testing 1 participant commented that they thought this represented activity in the home rather than ‘homepage’. Aside from this, it was also necessary to integrate back button functionality as there were sections of the interface in which modals were not practical, therefore requiring the user to navigate through screens.

Calendar, self-report and other minor changes

Further changes were made in relation to the calendar and self-report features. As self-report was an important element of the application and the intervention, it was felt it should have prominence and presence throughout the interface. As a result, the calendar was moved to the centre of the screen and the self-report button was placed in the top right corner as an overlay, meaning it was present on every screen (see Figures 5.15 and 6.10). This meant the user no longer had to navigate to a particular screen to self-report. The calendar was integrated with the date so as to reduce clutter and to allow for a date picker either side (left and right). The title ‘mindfulness’ was also removed as it was unnecessary given the menu at the bottom of the screen, creating additional space. The week number was also moved to the top-centre of the main panel. These changes also allowed for more space on the Mind Overview screen on the right-hand side. Both the top section (back arrow, date picker/calendar, day/week toggle, self-report), and the bottom section (menu tabs) remain the same throughout the interface, save for the dashboard. Modal windows were also used to present tips/educational information within the sensor-based sections of the application (Figure 6.11).



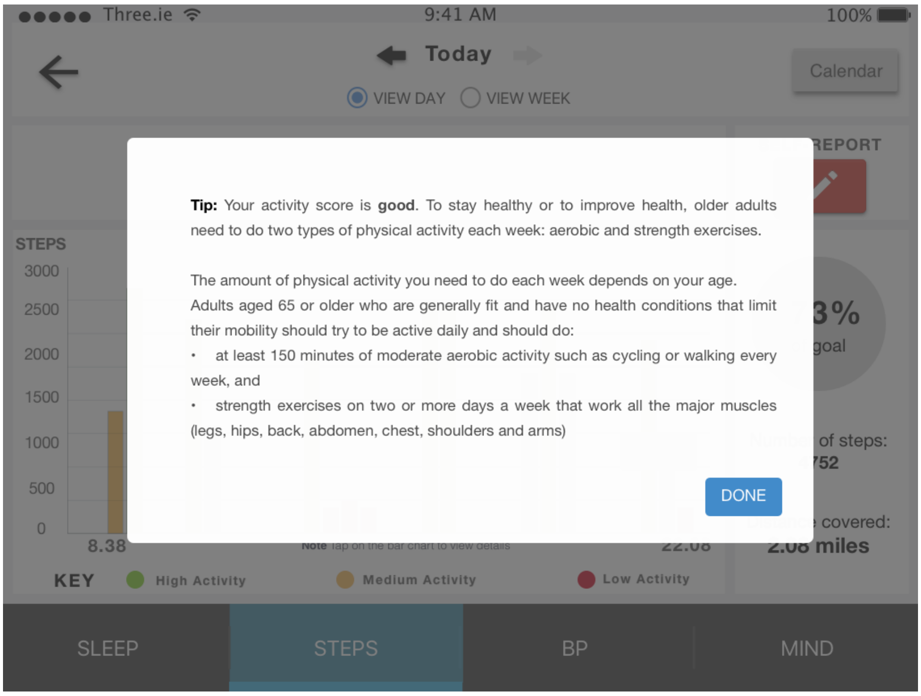
This consists of four interlinked stretching exercises that are carried out over a few minutes.

Here we retrurn to the breath and body, suggesting that you practice it immediately after the Mindful Movement.

This is a mini meditation that acts as a bridge between the longer, formal meditations and the demands of everyday life.

Valuing the television. One day this week, only watch programmes that you have chosen to watch and consiously swtich off the TV for the times in between

Figure 6.10: Mind Week 3 Planner v2 (as used in Usability Test 2)



Tip: Your activity score is **good**. To stay healthy or to improve health, older adults need to do two types of physical activity each week: aerobic and strength exercises.

The amount of physical activity you need to do each week depends on your age. Adults aged 65 or older who are generally fit and have no health conditions that limit their mobility should try to be active daily and should do:

- at least 150 minutes of moderate aerobic activity such as cycling or walking every week, and
- strength exercises on two or more days a week that work all the major muscles (legs, hips, back, abdomen, chest, shoulders and arms)

Figure 6.11: Activity tip

6.5 Usability Testing 2

6.5.1 Methodology and participants

The next phase of Design Cycle 2 was Usability Testing 2. This differed substantially to the first testing sessions in that the designs were more refined and more defined in terms of content and functionality, but also in that the participants were older informal carers. The designs used were very similar to the final designs used in the main trial in terms of layout, user flows, and overall aesthetic. Individual usability testing sessions were held with three older informal carers (2F, age 61-64) with each session lasting approximately 60 minutes. Participants were recruited through a local service which offers support and provides information to carers of persons with dementia. These participants then went on to participate in the main trial. Each of the participants owned and used smartphones, and one also owned a tablet, but none had any experience using health or activity-tracking applications or devices.

Once again, a Think Aloud Protocol was used. Following this, participants were asked questions in a semi-structured format. Questions related to their initial thoughts and opinions on the application, whether or not they would be interested in using such a system, aspects they found difficult or confusing, if any, as well as any other issues they wanted to raise (see Appendix 2 for interview protocol). As was the case with the first round of semi-structured interviews, participants were shown a short, accessible video on mindfulness meditation and what it entails prior to using the mindfulness interface.

6.5.2 Data collection and analysis

Data was collected using a dictaphone and field notes, as well as a video camera. A tripod was placed over the participant's shoulder facing down onto the iPad so as to capture the movement of the hand across the screen (Figures 6.12 and 6.13). This position was less obtrusive and it also removed the camera from the view of the participant so as not to act as a distraction. Prior to analysis, the audio recordings were transcribed using a word processor by the researcher. Participants were given ID numbers following on from those assigned in the second round of semi-structured interviews. Testing was again carried out with a clickable prototype using Invision for iPad as this was prior to final development.

Figure 6.12: Usability Testing 2 (set-up)

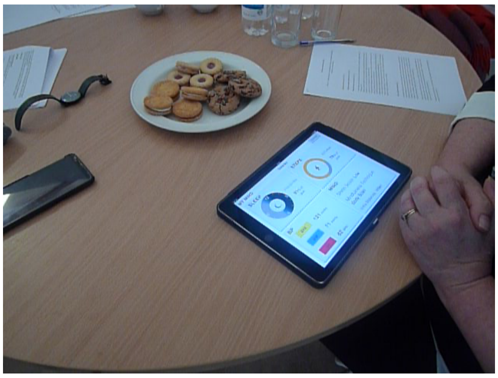


Figure 6.13: Usability Testing 2

The transcripts from the recordings were imported into NVivo for analysis. The analysis was particularly revealing and brought about a number of new codes and sub-nodes regarding usability, interaction, and interface issues. There was some overlap with previous codes and resultant themes from the previous usability testing session, but this round of sessions gave rise to issues which had not been revealed to date. The reason for this is primarily due to the addition of new content and functionality, namely the mindfulness intervention and the education and tips component. Coupling this with the fact that a Think Aloud Protocol had been implemented led to a form of thematic analysis that was inductive in nature (Braun and Clarke, 2006).

6.5.3 Findings

Interaction, navigation and user interface

Upon seeing the dashboard for the first time, the participants understood broadly what they were looking at and could communicate that this was an overview of various data derived from both the watch and the blood pressure cuff. The content was reported to be clear and the text legible; the data was easy to understand at a glance. Blood pressure data as presented on the dashboard was not immediately clear. P23 was not familiar with systolic and diastolic readings and did not understand HR for heart rate, demonstrating the need for legends for abbreviations and training. With regard to the Mind tile on the dashboard, it was clear to the participants that this section related to stress reduction techniques.

With regard to navigation elements within the app, the use of the back button was clear for the participants and became the first choice when prompted to return to a previous screen. The calendar function was also understood as a means to navigate to different days: I: *'We want to look back at Week 5 because we did an interesting meditation that day and we want to see how well we slept',* P23: *'em, ...go to the calendar?',* P22: *'go into Calendar is it?'*

There were no major issues related to colour choices throughout the application. Participants were asked about colour in terms of clarity and differentiation on each screen and responses were consistent. The traffic-light code used for low/medium/high activity was effective and made sense to each of the participants: '*well your green is your high activity, you're out walking'* (P22); I: '*what does the red mean to you?',* P21: '*well that's very low'.* P21 also immediately understood the colour code used for sleep stages, saying '*well the grey is the light sleeper, and the purple, I'd be the purple (laughing)'.* Throughout the application there were no issues with text in terms of colour, font, size, or legibility.

Within the mindfulness user interface, a number of issues arose. The first screen presented once a user clicks on the 'Mind' navigation tab is the Overview (Figure 6.7), which was designed to provide an overview and description of the meditation techniques to be used during that particular week. It became apparent, however, that its function was not immediately clear: I: '*So what's that telling you?',* P21: '*well, you just have to get yourself up and get going like, you know what I mean?'.* In this example the participant was looking at the overview screen for Week 1 and appeared to view the content as instructions or tips, rather than an overview of that week's meditation content.

The Planner screen (Figure 6.8) also presented problems for some participants in terms of where to begin. Despite techniques being labelled 'start here' or 'up next', participants appeared confused and there was some hesitation. When asked what the first thing to do on the Planner screen was, P23 said *'you breathe and concentrate on your breathing'.* It could make sense instead to label elements in this section as techniques and provide more differentiation in terms of category (formal v informal). P22, however, understood the instructions and the sequencing. When prompted, he began with 'start here' and then moved over to the informal techniques, understanding he could do these at a time that suited him: *'yeah, and then you can do these two any time... at the traffic lights say'.*

Another issue on the Planner screen was the difficulty one participant had in locating the Guide button. This button was designed to provide more information relating to which techniques need to be completed each day and how many times etc. As such, being an essential component, it would need to be visible, prominent and easy to locate. There was also some confusion with this screen concerning the 'read more' and 'watch videos' tiles on the right of the screen. These sections were included to provide users with the opportunity to learn more about mindfulness should they so wish. However, during the testing session P23 felt this may have been an advertisement as this is where advertisements and sponsored content often appear on a website.

Each of the participants was able to find the self-report section and understood both the concept and the functionality it offers: '*how you felt, how you think things went for you, so you'd just, say it was very high you'd push that and then submit'* (P22). P22 did not see this as burdensome and compared it to sitting at home relaxing, saying*: 'well I would sit there, and I'd be doing puzzles and things on the computer at night... and it would be much the same thing as that'.* The format of questions provided in terms of how they were phrased and presented (e.g., multiple-choice) during the testing sessions did not present any issues.

The interface designs for the objective sensor-based elements of the system (sleep, steps, blood pressure) were generally well-received. Both the steps and sleep user interfaces did not present any significant problems to the participants. For example, participants were able to ascertain how many hours' sleep has been recorded and the extent to which the goal had been reached. As well as this, the participants could see trends over the course of the week: '*seems to be sort of gradual like during the week or whatever'* (P22)*, 'a scale of how well you slept.... and this one here on the 8th, em, you didn't get much sleep, 4 hours, 4 and a half'* (P23).

This was not the case, however, with the blood pressure user interface. The data presented here was not immediately clear due to the fact that the participants were not familiar with the meanings behind the blood pressure readings in general, for example what would be considered 'good' in terms of systolic over diastolic: *'I haven't a clue what my blood pressure, or anyone's blood pressure, what should be normal*' (P22).

Interaction and navigation elements were clear for P22 and P23 but there was some confusion concerning task flow for P21 as discussed previously. Two main areas of confusion in terms of interface and layout, however, were progress bars and placement of the date. For P23 it was not immediately clear what day she was looking at. The progress bars used to indicate how much audio had been listened to of a particular mediation also needed to be made more prominent as they were not immediately obvious and were thus overlooked.

Content and potential benefit of the application

When asked about their overall feelings towards the system with regard to content, functionality and potential benefits, the response was in the main positive. While the overall concept of the app was confusing at first for P21 due to a lack of familiarity with health applications and indeed mindfulness, once she had the chance to interact with the app she reported seeing value in the functionality provided by it, particularly in the sleep tracking and mindfulness techniques. P22 echoed this. P23 was interested in all aspects of the system. She was familiar with wearable devices and said she would feel motivated by data feedback and tracking information in general. Feedback and relevant tips were viewed as useful by each of the participants. P23 suggested they could act as further support and a source of encouragement*: 'yes, yeah, that's motivation again*'.

The mindfulness content yielded a positive response from each of the participants. P21 was interested in the idea of mindful awareness practice, as they were experiencing chronic stress: I: '*is it something that you could see yourself trying to do?* P21: *'I could, I could yeah...because there's time my head would be all over the shop*'. P23 was already familiar with mindfulness, having bought books in the past on the topic. P22 was less familiar but understood the concept of mindful awareness practice in terms of reaching a state where guided meditation is no longer necessary: *'you can just do it on your own*'. As well as this, he was open to the flexible nature of the practice and could see value in having techniques to hand when trying to get to sleep: *'yeah. I'd find that great now*'.

Changes implemented

Following on from the usability testing sessions, a number of design changes and adaptations were implemented as result of feedback and analysis. Ongoing discussions within the development team were also held to determine whether issues that were observed were a result of wider design issues or likely the result of a lack of training, explanation or clarity during the testing sessions. These iterative updates and design changes are discussed in the following chapter. A summary is provided below:

- A question mark icon was added for the guide.
- A colour code was implemented for Mind tiles ('any time' vs 'start here' etc.) in order to differentiate.
- A lightbulb icon was included to highlight tips.
- The sidebar was removed.
- Tips were included for blood pressure.
- A new colour code was implemented for blood pressure.
- Changes to Dashboard:
    - Steps, sleep and blood pressure tiles
        - Interactive data was implemented on tiles to provide quick access to data without needing to leave dashboard (user could hold tile to reveal information)
    - Mind

        - The most recent stress self-report score was included.
        - The name of main mindfulness practice for that day was included.
        - An icon was included.
- Mind Interface:
    - Colour coding was implemented for tile cards (light green for ‘formal’, and light orange for ‘when you have time’)
    - A change was made to only include two categories - changed from ‘Start here’, ‘Up Next’, ‘Any time’ – to ‘formal’ and ‘when you have time’

6.6 Summary

This chapter discussed Design Cycle 2, which started with interviews with five older adults. These interviews aimed to explored the participants views and experiences regarding stress and ageing, mindfulness and any specific stress-management techniques they employ in times of need. There was a positive response to the idea of mindfulness-based stress reduction. Further interviews were held with six older informal carers to explore their experiences as informal carers, gaining insight into how challenges can affect quality of life, health and wellbeing in general, and their capacity to provide care. Findings from both rounds of semi-structured interviews then fed into to the next cycle of designs. Finally, usability testing sessions were held with three older informal carers. Analysis from these sessions as well as the findings from the two rounds of semi-structured interviews allowed for the final design of the digital health application used in the main trial.

Chapter Seven: DESIGN AND IMPLEMENTATION OF DIGITAL INTERVENTION

7.1 Introduction

The requirements gathering and usability testing over the course of the two design cycles resulted in a feature list and content to meet user needs and allowed for design decisions to be made to ensure that the resulting application was efficient, effective, and satisfactory as per ISO guidelines[9]. This chapter presents the final design as used in the main trial and provides a description of each design with a rationale for any changes implemented. An overview is also provided on the eight-week mindfulness programme, including details on content such as individual mindfulness techniques, topics and themes.

It should be noted that changes and redesigns were also made separate to the results from the usability testing data analysis. These were the result of:

- development issues/practicalities
- ongoing discussions with researchers/designer/developer/supervisor
- further feedback - mid-trial (see Chapter 9).

This final phase of the design process lasted approximately six months and involved continuous discussion and collaboration between the researcher/designer and the developer. All of the content, designs, and user flows by this point had been finalized and agreed upon and a period of continuous testing and trialling was necessary in order to ensure the system functioned as robustly and efficiently as it needed to. For this reason the researcher acted as a daily user of the system, which involved wearing the wrist-worn sensor, taking regular blood pressure readings, self-reporting daily, and engaging with the mindfulness content. This resulted in real data each day which in turn served a number of purposes: it was possible to see how the

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[9] https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en

interface behaved and performed as the trial progressed and also how it appeared to the user, it allowed for insights into how the data could be viewed and analysed from the back-end, and it revealed any hardware and device issues which otherwise would have gone unseen.

The system architecture can be seen in Figure 7.1. The overall system consists of several components:

- The user facing Mind Yourself app (along with sensors monitoring health and wellbeing), which is the focus of this PhD thesis,
- The accompanying server application,
- The pre-existing CABIE+-SIMS platform developed by NetwellCASALA, which both acted as the data aggregator and allowed for the Mind Yourself app to be personalised to individual participants. Details on how CABIE+-SIMS was used for the trial is presented in Chapter 8.

The software developer was provided with detailed design files including error and empty states (what the user sees if there is no data or if there has been an error), along with user-flow maps, a colour palette and the requisite typographic details.

The following was carried out by the software developer: the overall application architecture was outlined in order to define the composition of components, communication between components and the management of application state. Each component was then individually created in code. Elements were defined using HTML, styled using CSS and made functional using JavaScript. The components that comprise the application shell were developed first (i.e. the header, bottom navigation, login, registration, layout). Following this the components that comprise each section (i.e., sleep, BP, steps, mind) were developed while incorporating real world data from CABIE+. A custom Node.js server application along with an accompanying database was created in order to store user accounts, handle authentication and log application usage. User accounts were integrated with the associated CABIE+ accounts on creation. Finally, a custom Linux based cloud server was created in order to securely host both the frontend and the server application.

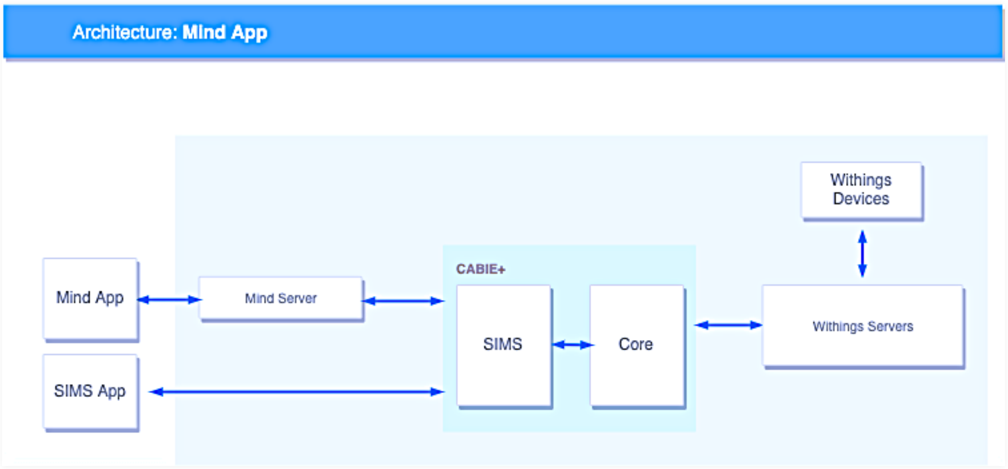


Figure 7.1: System architecture

Engagement data pertaining to application features that were designed to function independently of the SIMS application were tracked using custom logging and stored in the Mind Server. The model for these logs was as follows:

```
_id: (Unique ID)
login: (User login name)
modalTitle: (Title of modal window)
action: ['open', 'close']
createdAt : ISODate
```

Engagement with the Withings devices (Withings Steel, BP Cuff), and self-report data was logged and stored within the SIMS system. For readings from the Withings devices the data model was follows:

```
subject    : (User Id)
type       : (Reading type e.g. Steps, Blood Pressure)
time       : Date;
value      : (Reading Value);
provider   : (E.g. Withings);
UpdatedAt  : Date
```

The model for the self-report data was as follows:

```
subject   : (User Id)
date      : Date,
questions: {
  content: (E.g. how well do you feel you slept last night?),
  answers: {
    content : (E.g. Not very well),
    selected: true
  }
}
```

7.2 Dashboard

The updated design of the dashboard (Figure 7.2) remained the same in overall visual design but also brought a number of changes. The upper left of the screen houses the application name alongside a brain icon to emphasise the focus on mental wellbeing and mindfulness. The date element in the top centre uses drop shadow to communicate to the user a point of interaction. As well as this, a small calendar icon was placed next to it. Below this button, the selection options for day and week view remained as per the previous design. Placing these elements in the centre of the screen allowed for the self-report button to be moved to the top-right of the screen. As can be seen in this screen, the button is blue and there is a small, red '6' in the top left corner. This is intended to show the user that questions have not been answered yet. The design goal was to remain unobtrusive, while also acting as a subtle reminder to the user to answer the questions when convenient. Once these have been answered the button changes to grey with a blue '0' in the top left.

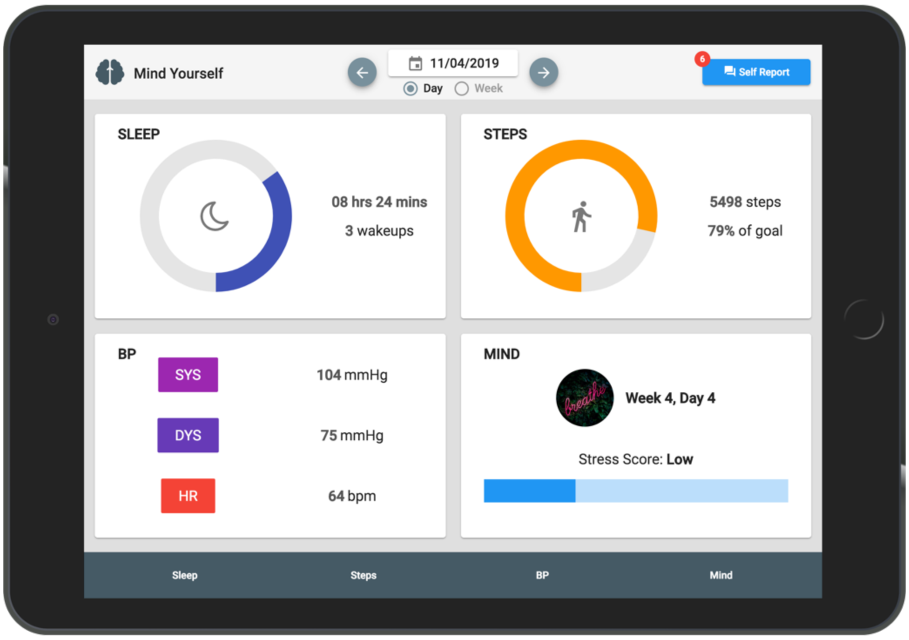
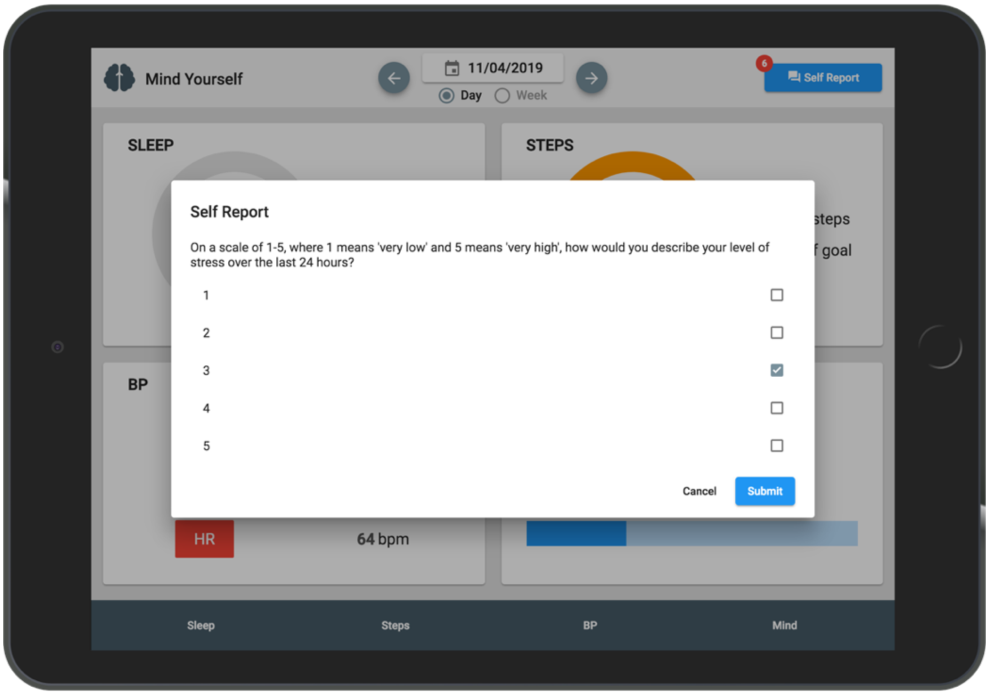


Figure 7.2: Dashboard

In order to provide a sense of consistency and uniformity throughout the interface, it was decided that the overlay menu (grey section at footer) would also be used at the bottom of the dashboard in the same way as throughout the entire application. This was used for navigation instead of the tiles themselves, given the issues discovered during the usability testing sessions. Having this feature here then allowed for further functionality to be integrated into each of the tiles. For example, if the user placed their finger on the sleep tile, further contextualised information would appear relating to that data, such as when he/she went to bed and woke up. Providing this extra layer of functionality enables the user to get a view and understanding of their data ‘at a glance’ from one screen without needing to navigate further into the interface. The Mind tile informs the user of the day and week of the mindfulness program alongside the image used for that week’s primary meditation practice. The most recent stress self-report score is also shown. Overall, the aim when designing the dashboard was to reduce clutter and to present a clean, consistent and simple interface.

7.3 Self-Report

Each day users were provided with six self-report questions. Figure 7.3 shows a Likert scale question relating to stress levels over the last 24 hours. Questions were asked each day around stress/mindfulness, sleep, and physical activity, with two questions for each topic. Of these two questions, one was ‘local’, meaning it related to the last 24 hours, and the other was ‘global’ and referred to the previous month. The ‘local’ question was the same each day in order to allow for insights into trends over the 8-week programme. The ‘global’ questions were randomized and as such changed each day; these questions were taken from the scales used pre-, mid-, and post-trial. The decision to randomize these questions was made in order to provide variety and address the possibility of automatic answering through repetition. Questions did not require text input and involved either multiple choice, range selection or scale rating. A modal window was used to present the self-report questions. Users could answer the question and select ‘submit, or they could answer at a later stage by either selecting ‘cancel’ or by tapping outside of the window in the shaded area.



Self Report

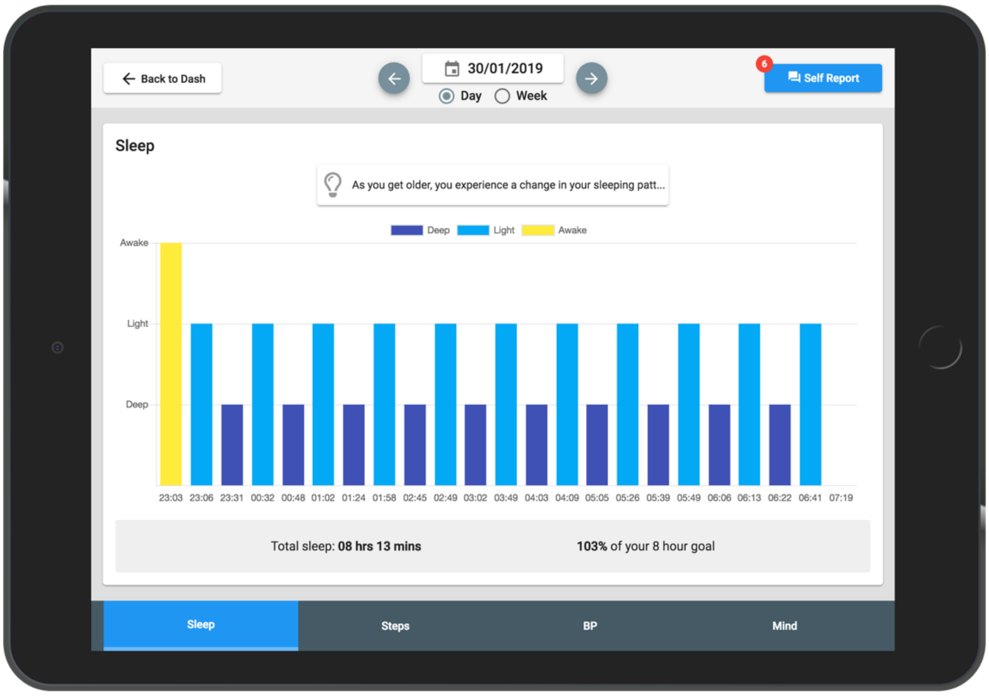
On a scale of 1-5, where 1 means 'very low' and 5 means 'very high', how would you describe your level of stress over the last 24 hours?

1 ☐
2 ☐
3 ☑
4 ☐
5 ☐

Figure 7.3: Self-report – Stress (last 24 hours)

7.4 Objective sensor-based data (Sleep, Steps, Blood Pressure)

The design for the sleep, activity, and blood pressure elements of the interface was the same in terms of structure and layout. This included three sections: daily tip/information, objective data feedback through a graph, and data breakdown. Figure 7.4 provides an example of the sleep interface where the user can view the previous night's sleep data. Touching on a bar in the graph willl bring up a small pop-up window with further inforntion, for example duration. Touching on the Tip above the graph opens up a modal window to view the full text of the tip. A lightbulb icon was used to signify the daily tip as this issue arose in Usability Testing 2. These tips changed each day and were sourced from wellbeing advice sections on Health Service Executive (HSE) and National Health Service (NHS) websites. Figure 7.5 provides an example of sleep data on week view.



As you get older, you experience a change in your sleeping patt...

Total sleep: **08 hrs 13 mins**

103% of your 8 hour goal

Figure 7.4: Sleep graph (day view – self-report notification and different tip)

As you get older, you experience a change in your sleeping patt...

Average per night: **07 hrs 19 mins**

Goal of 8 hours reached: **1** times

Figure 7.5: Sleep graph – week view

The goal when designing the interface for the objective data elements of the application was to provide a design that was clean, consistent, legible, and useful. With this in mind, consideration was given to colour, font, white space/background, and uniformity throughout each part.

Interaction steps were also minimized in that navigation away from the page was not required while viewing or interacting with the data. As such, modal windows were used for the daily tip, and small pop-ups were used when further contextual information was required from a graph.

Figure 7.6 provides an example of the Steps interface. For the final design, the traffic-light colour code remained. A legend was provided above the graph (the importance of which was stressed in Usability Testing 1). Colour intensity was also taken into account so as to address any potential issues with colour blindness as strong colours can be effective once separated within a visualization[10].

Examples of activities that require moderate effort for most pe...

Average steps per day: **8637**

Goal of 7000 steps reached: **4** times

Figure 7.6: Steps graph

The interface design used for the blood pressure data (Figure 7.7) followed the same format as the Sleep and Steps sections. At the bottom of the main section, a breakdown of the data is provided including average readings for systolic, diastolic and heart rate data. A new colour code was also used in the final designs in order to further differentiate this element of the interface from the sleep and steps sections.

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[10] https://www.tableau.com/about/blog/2016/4/examining-data-viz-rules-dont-use-red-green-together-53463

For a healthy level of blood pressure it's important to:

Average Systolic: **111** mmHg

Average Diastolic: **74** mmHg

Average Heart: **72** bpm

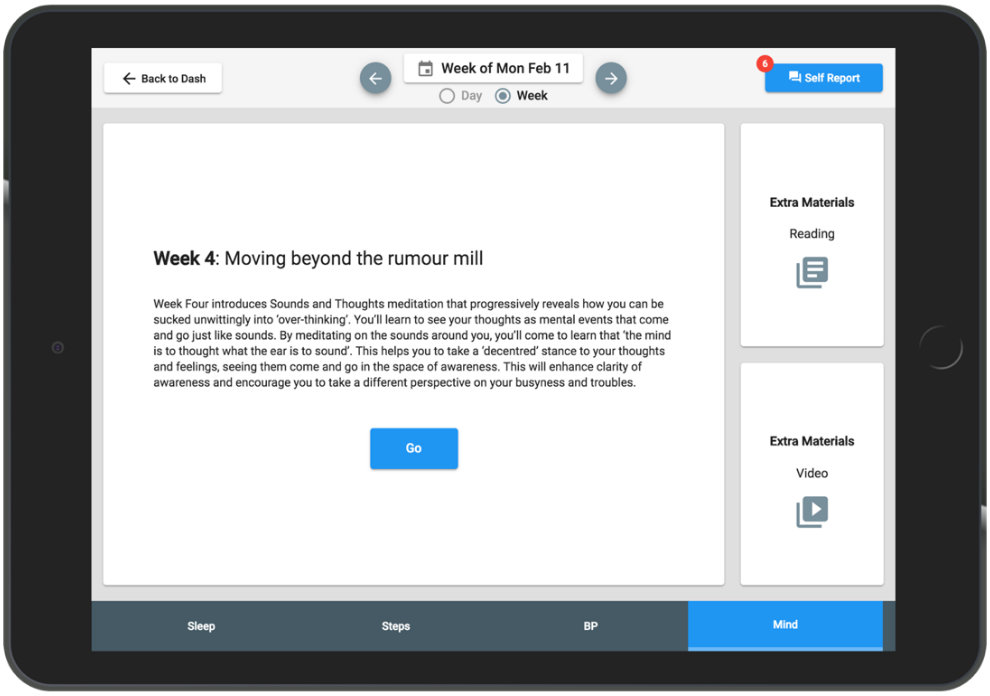
Figure 7.7: Blood pressure graph - week view

7.5 Mind Interface

This section outlines the iterative interface redesigns implemented to present the mindfulness content as well as a brief description of the themes each week. A more thorough overview and description of the mindfulness programme in terms of content, structure, topics and themes addressed each week is then provided.

7.5.1 Overview

Each week the user is presented with an overview prior to viewing the Planner screen (Figure 7.8). This provides an overview of that week's content and the title. Below the text there is a call to action titled 'Go' to bring the user to the Planner screen. To the right of the Overview section, the user can access the extra material provided, both web articles and YouTube videos (Figures 7.14 and 7.15).



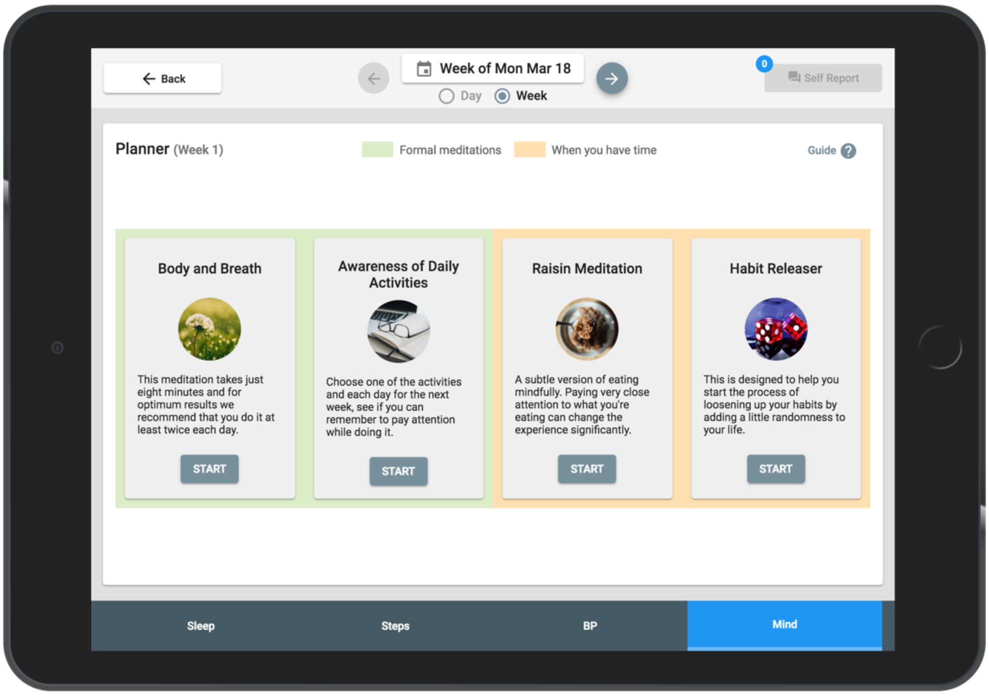
Week 4: Moving beyond the rumour mill

Week Four introduces Sounds and Thoughts meditation that progressively reveals how you can be sucked unwittingly into 'over-thinking'. You'll learn to see your thoughts as mental events that come and go just like sounds. By meditating on the sounds around you, you'll come to learn that 'the mind is to thought what the ear is to sound'. This helps you to take a 'decentred' stance to your thoughts and feelings, seeing them come and go in the space of awareness. This will enhance clarity of awareness and encourage you to take a different perspective on your busyness and troubles.

Figure 7.8: Mind interface –Overview Week 4

7.5.2 Planner

Figure 7.9 shows the Planner screen for Week 1. The main theme in terms of content for Week 1 was a focus on both the body and the breath. The aim was to introduce the notion of operating on 'autopilot', and to encourage mindful awareness through focussing on one thing at a time. This was supplemented by a short meditation which explored awareness of the senses through mindful eating. In this example, the instruction centred around eating a raisin. The 'habit releaser' for Week 1 asked the user to try sitting in a different chair at home or at work to one they would normally or habitually sit in. These practices are designed to provide the user with the foundations necessary for mindfulness mediation going forward.



This meditation takes just eight minutes and for optimum results we recommend that you do it at least twice each day.

Choose one of the activities and each day for the next week, see if you can remember to pay attention while doing it.

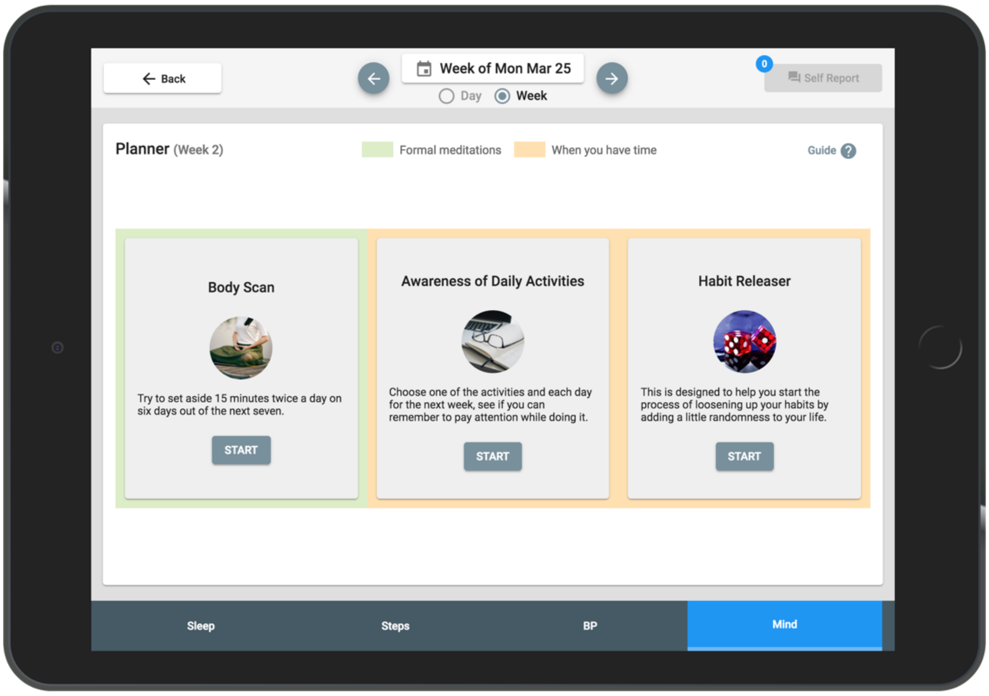
A subtle version of eating mindfully. Paying very close attention to what you're eating can change the experience significantly.

This is designed to help you start the process of loosening up your habits by adding a little randomness to your life.

Figure 7.9: Mind Interface – Planner Week 1

As mentioned in Chapter 6, the Mind interface progressed on to a tile card design, which was then used in Usability Testing 2. As a result of testing, a number of changes were made to the visual design while the overall interface structure and layout remained the same. The tile card idea was used for the final design as it was positively received during the session in terms of usability, intuitiveness and practicality. In the top left there is the screen name ‘Planner’ which also states the week number of the programme. Next to this in the centre is the legend. Owing to development considerations in terms of laying out and presenting the tile cards, as well as testing by the research team prior to deployment, it was decided that categories would be used. These were called ‘formal mediations’, and ‘when you have time’. A colour code was also used to differentiate these as this was brought up in usability testing.

Each of the tile cards were uniform in design. An image was used for each practice that was intended to evoke a sense of calm and reflection as well as provide a link to the theme or topic. Below the image there was some text describing the practice so as to provide a glanceable overview. At the bottom of the tile was the call to action titled ‘Start’. The progress bar mentioned in earlier designs (see Chapter 6) was removed as its function was largely redundant. This was due to the fact that this programme is designed to be flexible with practices being repeated and returned to when convenient. For this reason, a progress bar indicating whether or not something had been tried yet, or the degree to which something has been tried, was not necessary.



Try to set aside 15 minutes twice a day on six days out of the next seven.

Choose one of the activities and each day for the next week, see if you can remember to pay attention while doing it.

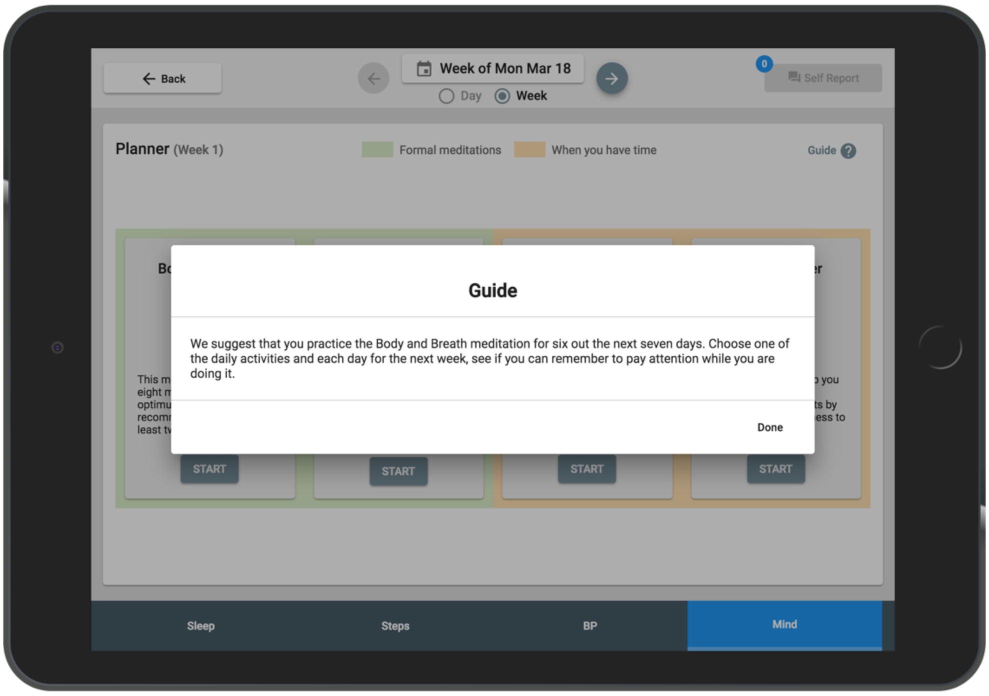
This is designed to help you start the process of loosening up your habits by adding a little randomness to your life.

Figure 7.10: Mind interface – Planner Week 2

As can be seen from Figure 7.10, the number of meditation practices varied from week to week. In Week 2 for example, there are three tile cards present in the Planner screen. As such, the tile cards are wider so as to take advantage of the screen real estate. Again, the colour code is used to determine which practices are formal or informal.

7.5.3 Guide

The top right of the main section on the Planner screen in Figure 7.10 contains the ‘guide’ button, which is marked with a question mark icon. Touching this opens a modal window (Figure 7.11) that provides the user with information relating to how often certain meditations should be practiced and over how many days. The user can exit the modal window either by selecting ‘done’ or by touching anywhere in the shaded portion outside the window.



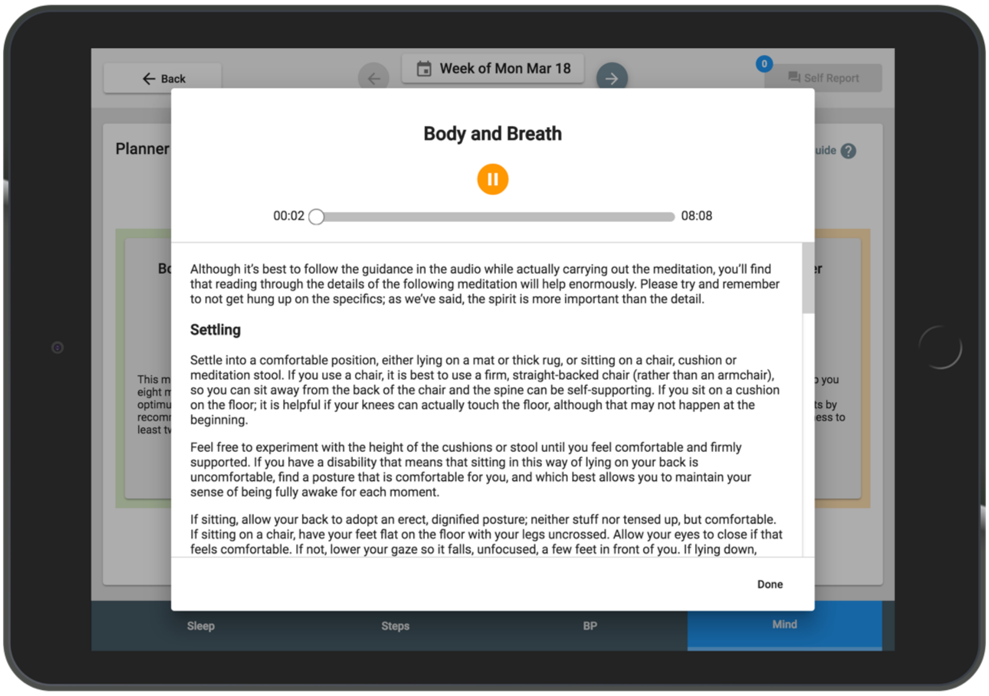
We suggest that you practice the Body and Breath meditation for six out the next seven days. Choose one of the daily activities and each day for the next week, see if you can remember to pay attention while you are doing it.

Figure 7.11: Mind interface – Guide Week 1

7.5.4 Meditation player

The guided meditations are also displayed within a modal window. Figure 7.12 shows the ‘Body and Breath’ meditation. The audio player sits at the top of the window. The audio auto-plays once the window is open and the user is presented with an orange ‘pause’ icon should they wish to pause listening. Below the audio player is the guided text. As can be seen in the image, there is a scroll bar to the right which indicates to the user the length of text. The user can, however, touch anywhere on the text portion of the screen to scroll up and down so as to prevent accidentally touching outside the window while attempting to interact with the scroll bar itself. Again, the user can exit the window by selecting ‘done’ or by touching anywhere outside the modal window.

Mindfulness practices which did not utilize audio were also presented within a modal window. Figure 7.13 shows the ‘Awareness of Daily Activities’ practice. In this instance, the user is asked to read the content and incorporate what is discussed into their daily life.



Body and Breath

Although it's best to follow the guidance in the audio while actually carrying out the meditation, you'll find that reading through the details of the following meditation will help enormously. Please try and remember to not get hung up on the specifics; as we've said, the spirit is more important than the detail.

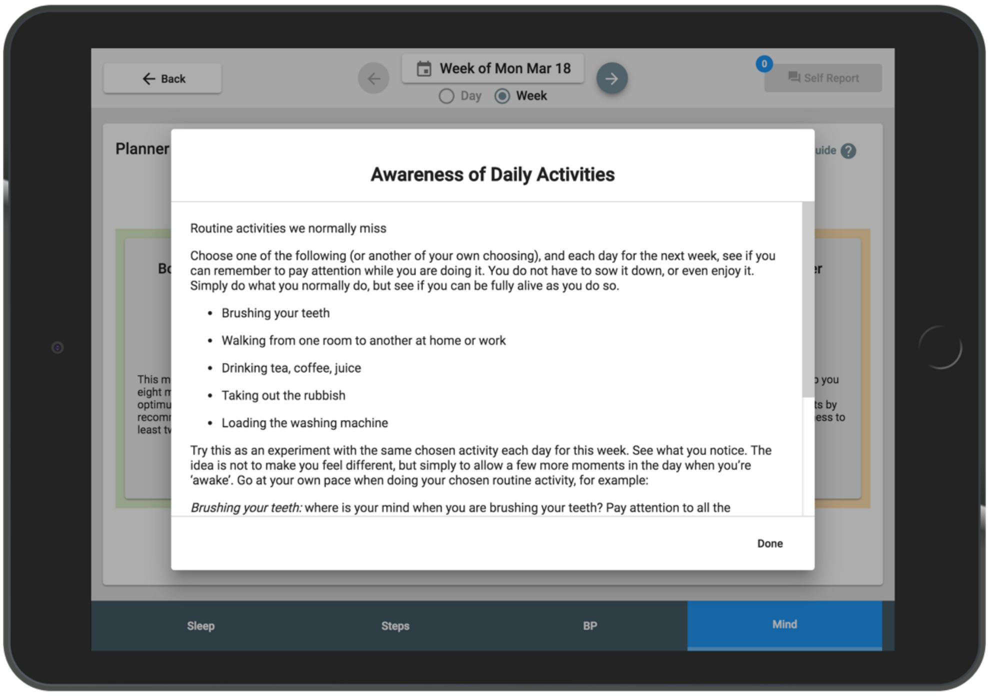
Settling

Settle into a comfortable position, either lying on a mat or thick rug, or sitting on a chair, cushion or meditation stool. If you use a chair, it is best to use a firm, straight-backed chair (rather than an armchair), so you can sit away from the back of the chair and the spine can be self-supporting. If you sit on a cushion on the floor; it is helpful if your knees can actually touch the floor, although that may not happen at the beginning.

Feel free to experiment with the height of the cushions or stool until you feel comfortable and firmly supported. If you have a disability that means that sitting in this way of lying on your back is uncomfortable, find a posture that is comfortable for you, and which best allows you to maintain your sense of being fully awake for each moment.

If sitting, allow your back to adopt an erect, dignified posture; neither stuff nor tensed up, but comfortable. If sitting on a chair, have your feet flat on the floor with your legs uncrossed. Allow your eyes to close if that feels comfortable. If not, lower your gaze so it falls, unfocused, a few feet in front of you. If lying down,

Figure 7.12: Mind interface – Body and Breath Meditation



Awareness of Daily Activities

Routine activities we normally miss

Choose one of the following (or another of your own choosing), and each day for the next week, see if you can remember to pay attention while you are doing it. You do not have to sow it down, or even enjoy it. Simply do what you normally do, but see if you can be fully alive as you do so.

- Brushing your teeth
- Walking from one room to another at home or work
- Drinking tea, coffee, juice
- Taking out the rubbish
- Loading the washing machine

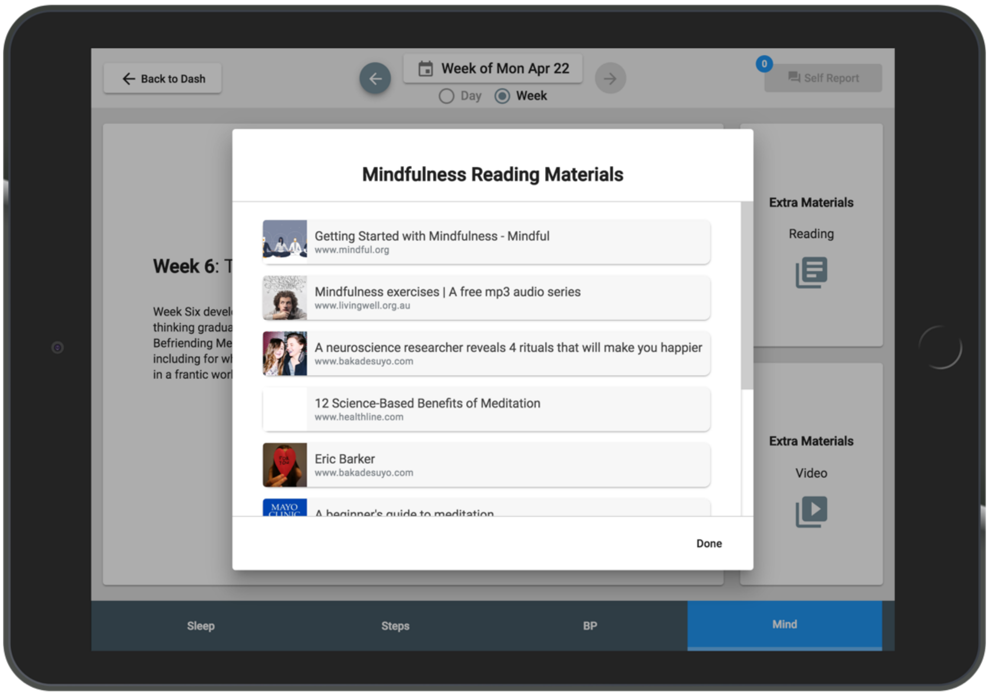
Try this as an experiment with the same chosen activity each day for this week. See what you notice. The idea is not to make you feel different, but simply to allow a few more moments in the day when you're 'awake'. Go at your own pace when doing your chosen routine activity, for example:

Brushing your teeth: where is your mind when you are brushing your teeth? Pay attention to all the

Figure 7.13: Mind interface – Awareness of Daily Activities

7.5.5 Mindfulness extra materials

Extra materials were provided within the Mind interface in the form of web articles (Figure 7.14), and YouTube videos (Figure 7.15). These materials were sourced from non-academic and accessible websites and full links to the original sources were provided. Selecting one of the web articles would bring the user to that webpage within the Mind Yourself application, thereby preventing a scenario where the user would have to leave the application entirely. This was also the case for the YouTube videos, which were embedded within the application. The list of videos was presented as a playlist as it would appear within the YouTube application. Instructions were provided above the current video as to how to proceed to the next video.



Mindfulness Reading Materials

Getting Started with Mindfulness - Mindful
www.mindful.org

Mindfulness exercises | A free mp3 audio series
www.livingwell.org.au

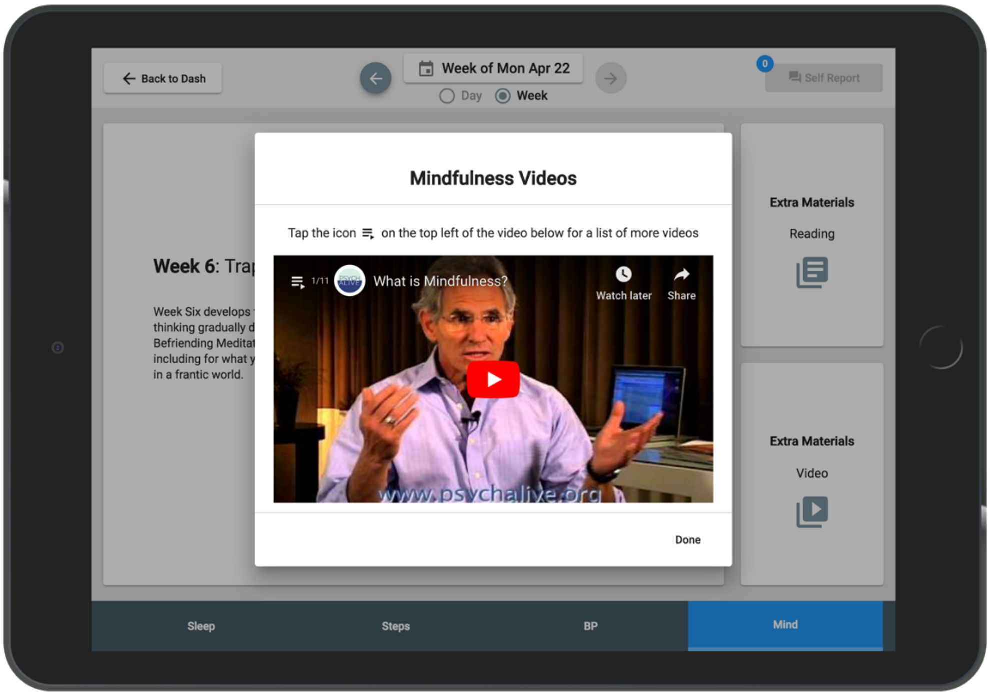
A neuroscience researcher reveals 4 rituals that will make you happier
www.bakadesuyo.com

12 Science-Based Benefits of Meditation
www.healthline.com

Eric Barker
www.bakadesuyo.com

A beginner's guide to meditation

Figure 7.14: Mind interface – Extra Materials (Reading)



Tap the icon on the top left of the video below for a list of more videos

Week Six develops
thinking gradually d
Befriending Meditat
including for what y
in a frantic world.

Figure 7.15: Mind interface –Extra Materials (Videos)

7.6 Summary

This chapter discussed the design and development of the final iteration of the MindYourself application used in the main trial. Analysis of the second usability sessions informed the final designs and represented the last step in the iterative user-centred design cycle. This phase lasted six months and involved the transition from interface design to software development. During this time the researcher acted as the end user and interacted daily with the devices to be used in the trial (Withings Steel and Withings blood pressure cuff) while also self-reporting and engaging with the mindfulness content. The real data generated during this development phase allowed for insights into how the interface behaved in terms of regular use and served as proof of concept with regard to its readiness for a field trial.

Chapter 8: DIGITAL INTERVENTION TRIAL

8.1 Introduction

This chapter will discuss the main trial of the Mind Yourself app, described in Chapter 7. The third and final stage of the overall study involved the deployment of the Mind Yourself app to eight community-dwelling older informal carers to evaluate usage of and experiences with the application. This trial lasted eight weeks as per standardized MBSR programmes. Ethical approval for the trial was received by the ethics committee in the School of Health and Science, DkIT. During the trial, participants self-monitored using a combination of sensing and self-report and received information and education feedback alongside a mindfulness intervention. Data collection was varied in order to provide for rich and mixed data for analysis. Quantitative measures included scales and questionnaires administered pre-, mid- and post-trial. Engagement metrics with the system were collected to allow for insights into levels of adherence. Participants also self-reported daily directly through the application. With regard to qualitative data, phone call interviews were carried out during the trial and longer in-person semi-structured exit interviews were conducted at the end of the trial. The primary focus was on understanding how and why participants used the application. This happened through an exploration of usage, usefulness, acceptance, motivation and user experience. Secondary outcomes involved examining any reductions in stress and improvements in sleep. Results are presented in detail in Chapters 9 and 10, with a discussion provided in Chapter 11.

The remainder of this chapter is structured as follows. A description of the aims, objectives, and expected outcomes is provided, followed by an overview of the study technologies, and details of the trial design and methodology. Ethical considerations for the study can be found in Appendix 4.

8.2 Aims and Objectives

The overall aim of the study was to explore how older informal carers used a digital application that delivers a mindfulness intervention and supports self-management of health and wellbeing, over an 8-week period. The trial addressed objectives 3-5 of the PhD:

- Objective 3: Examine engagement with the application.
- Objective 4: Explore attitudes towards the mindfulness intervention and use of the application in general.
- Objective 5: Determine the potential effectiveness in reducing stress and improving quality of life and sleep hygiene.

8.3. Study Technologies

The following technologies were used in the trial. Chapter 5 discussed the process and considerations for choosing the sensors and devices.

'Mind Yourself' Application: This was the core application designed for the purposes of this PhD project. The application was described in Chapter 7.

Apple iPad Air 2[11]**.** While the app was developed to be responsive and works across various platforms and operating systems, participants were provided with a tablet for this study to take advantage of more screen space.

Withings Watch: To measure sleep and activity, Withings Steel[12] was selected. Automatic background synchronization via Bluetooth should occur when the user has walked more than 1,000 steps since the last sync, or six hours has passed since the last sync. Manual sync occurs when the Withings app is opened. The watch captures walking, sleep and swim activity. The watch does not have a screen and displays information through a sub-dial. This analogue sub-dial allows for continuous insights into daily activity progress in terms of step-count activity.

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[11] https://support.apple.com/kb/sp708?locale=en_IE

[12] https://www.withings.com/ie/en/steel

The watch automatically detects sleep onset and provides insights relating to light and deep sleep, wake-ups and sleep duration. Advantages to this device include an 8-month battery life, it is waterproof and no interaction with the device itself is needed.

Withings Blood Pressure Cuff: The Withings BPM+ blood pressure cuff was chosen to monitor participant blood pressure and heart rate throughout the trial. Prior testing had been conducted to ensure that older users could use the device with some training. The cuff provides measurements of systolic and diastolic blood pressure as well as heart rate which are medically accurate.

Withings Healthmate App: Withings Healthmate is the third party application which is required to sync the relevant Withings devices. In order to retrieve data from the devices to send to the end-user application, the participants were required to open the Healthmate app at least once a day. It was also necessary to use the Healthmate application to take blood pressure readings. NetwellCASALA's CABIE+-SIMS system (described below) then pulls this data from Withings for display in the Mind Yourself app.

CABIE+ The Context Aware Brokering and Inferencing Engine (CABIE+) is a system developed by NetwellCASALA. As such, it was not developed as part of this PhD project, but used for the purposes of this study. In this study, CABIE+ was used to centrally collect data from all connected devices used by participants. CABIE+ normalises this data for storage and to provide a configurable processing pipeline which allows incoming data to be inspected and reacted to in close-to-real-time.

SIMS (Subject Information Management System): SIMS has been developed by NetwellCASALA as an administrative tool to facilitate management of studies, such as that described in this chapter, and to provide research and technical teams with a user-friendly, centralised service for monitoring and inspecting various elements and data collected during such studies. For example, the SIMS system was used to add trial participants and their details to the system and to link their Withings accounts so that data from the devices came into CABIE+. Creation and scheduling of the self-report questions that were delivered in the app happened in SIMS. SIMS was also used to examine engagement with the app and to inspect the data for individual participants (e.g. to look at a participant's activity data over a certain period of time). Figure. 8.1 shows the dashboard of SIMS which shows engagement with the application (graph on the left) and engagement with self-report (chart on the right) for each participant over the previous week (participant names have been hidden). In addition to these features, SIMS also provides a user-facing API which has been used in the creation of Mind Yourself. The CABIE+-SIMS system has been developed to be GDPR compliant.

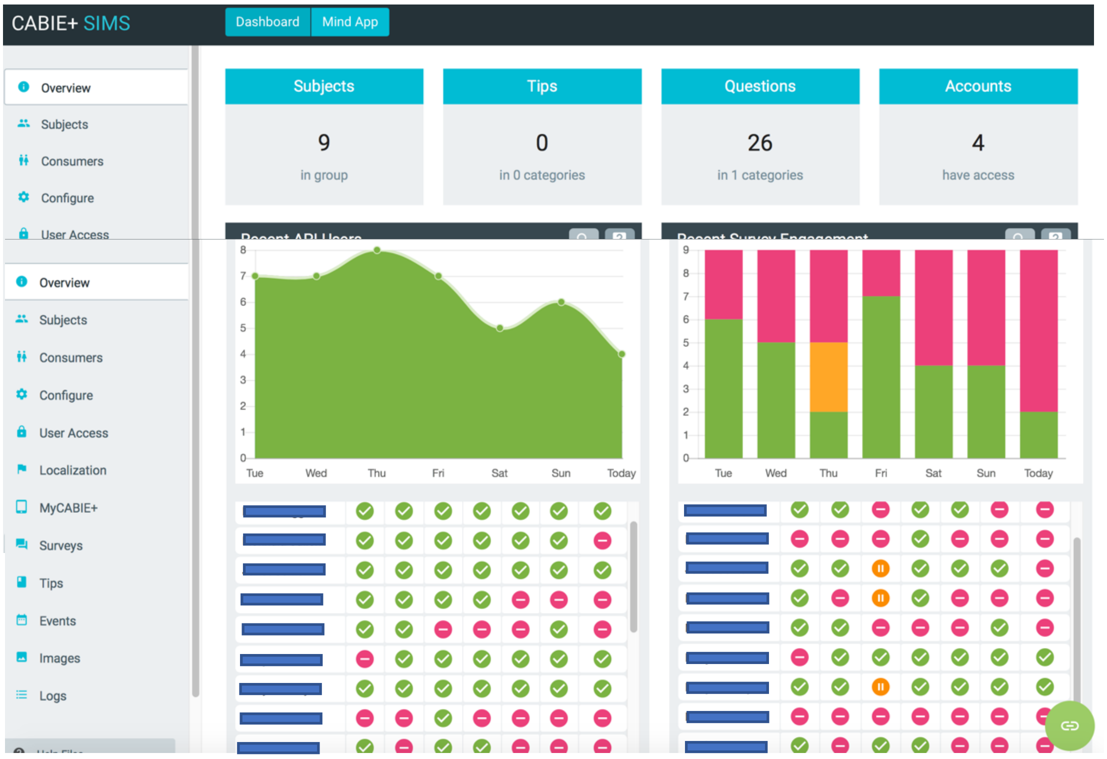

Figure 8.1: SIMs Screenshot (25/03/19) with trial participant names hidden

8.4 Methodology and Trial Design

The study was a proof-of-concept to understand how and why older informal carers used the application. Participants used the application for a period of 8 weeks, in line with standard MBSR guidelines. The study employed a mixed-methods approach to data collection and analysis. Questionnaires, outlined in Section 8.4.3, were administered at week 1, at the end of the fourth week, and on completion of the trial at the end of week 8. The data collected was supplemented with subjective data derived from self-reports of stress and sleep quality status, collected from users on a daily basis through the application. De-briefing interviews also took place with the participants at the end of the trial. Furthermore, engagement data and health and wellbeing data from the sensors used by participants was also captured. This resulted in a rich data set for analysis.

8.4.1 Recruitment

The trial commenced in January 2019 and lasted eight weeks, with commencement dates staggered due to participant availability. Participants were recruited through a local service which offers support and provides information to carers of persons with dementia. Staff within the service identified possible participants and made initial contact. Once initial interest had been expressed, telephone contact was made to provide more information and answer any queries. A participant information leaflet and consent form were then sent out by post with the researcher's contact details provided. Further telephone contact was made to provide more information where necessary and confirm expressions of interest. At this stage five people declined due to various reasons (availability issues, doubts about potential benefits, health problems). Those who then consented to take part were contacted again and a provisional start date was agreed upon. As mentioned in Chapter 6, first identification for three of the participants had happened prior to the main trial with these individuals also taking part in the second usability testing sessions. Participants were given ID numbers following on from those assigned in Design Iteration 2.

Inclusion Criteria

- Individuals over the age of 50.
- Capable of giving informed consent.
- Currently caring for another older adult in an informal way (unpaid).

Exclusion Criteria

- Not capable of giving informed consent.
- Suffering from depression or severe anxiety (this was informally assessed by the dementia service staff who knew the carers).

A sample of eight persons meeting the inclusion criteria completed the home study. This number is suitable for HCI research as the focus is on understanding how and why people used the application as opposed to clinical effectiveness. The study looks at the effectiveness of the intervention but only in terms of feasibility for future work. In addition, financial constraints resulted in a limited number of devices being available for this study. As such, it was not practical to run the study with more than eight participants.

8.4.2 Procedures

Sims Set-up

Each participant who consented to take part was added as a subject to SIMS. Within each profile, basic information relating to age and gender, as well as the start and end date for the trial were added. The Withings account that had been set up for each participant was also linked. API use then allowed for insights into the degree to which the user was engaging with the Withings devices, as well as what each device was measuring. The self-report content was also integrated into SIMS using the 'Surveys' feature. This allowed for a range of content and question types (multiple choice, Likert scale, yes/no plus follow-up etc.) to be added, which could then be stored and tracked both in terms of engagement as well as specific answers provided each day.

Deployment to Participants' Homes

On the commencement date, the researcher visited the homes of each participant with the technology kit to demonstrate and set up the system. This involved setting up the iPad on the participant's local network, as well as connecting and testing the Withings devices. The participant was shown how both devices work, and two sample blood pressure readings were taken. Training was then provided on the Mind Yourself application.

8.4.3 Data collection and analysis

A large amount of data was collected throughout the trial. A summary is provided in Table 8.1 with further detail outlined below.

Table 8.1. Data captured and frequency of capture

	Data Captured	***Frequency***
Smart Watch (Activity)	Steps Distance Timeline of steps activity	Daily
Smart Watch (Sleep)	Percentage sleep quality Hours in bed Hours asleep Timeline of sleep activity	Daily
Blood Pressure Cuff	Blood Pressure Heart Rate	Requested to use daily but at user's discretion
Self-Report Questions	Mood Sleep Activity	Requested to use daily but at user's discretion
Wellness Tips/Educational Advice	Engagement with Activity, Mood, Sleep, Vitals educational tips	Requested to use daily but at user's discretion
Mindfulness Intervention	Engagement with meditation content	Requested to use daily but at user's discretion
Clinically Validated Self-Report Questionnaires	Quality of life (CASP19 questionnaire) Sleep (PSQI questionnaire) Dispositional Mindfulness (MAAS questionnaire) Activity (RAPA questionnaire)	Three time points: Week 1, week 5 and week 8 following commencement of trial

	Stress (Cohen PSS scale) Burden (Zarit Short-form Scale)	
Usability	System Usability Scale (SUS)	End of trial
Qualitative Interview data	Experiences, satisfaction, challenges, benefits, outcomes, technology	Two time points: mid-trial and post-trial

Participant Interviews

Interviews were held at two time points in the trial – mid way through and at the end. Phone calls were made to each of the participants during the mid-point of the trial. These calls lasted between 10 and 30 minutes and occurred between weeks 3-5, depending on participant availability. The calls allowed for the opportunity to check in on progress and address any potential concerns. The calls were recorded with the participant's permission and then transcribed for analysis. Discussions centred around their initial feelings towards the system, and covered engagement, usability, hardware, interface, data feedback and mindfulness content. The phone calls followed a semi-structured format, with follow-up questions asked when appropriate or relevant, and participants free to raise any issues themselves. The protocol for these interviews in in Appendix 5.

Exit interviews were held separately with each of the participants at the end of the trial, in their homes, lasting approximately 90 minutes. This was an opportunity to gain a detailed insight into how participants had used the system, and whether it had had any impact on their overall wellbeing. Participants were asked to discuss their experiences as well as any issues they may have had. The format was semi-structured with areas for discussion decided upon prior to the interviews. The protocol can be found in Appendix 5.

Interviews at both time points were recorded using a dictaphone. Prior to analysis, the recordings were transcribed by an external transcription agency. The transcripts from the recordings were then imported into NVivo for analysis by the researcher. As the profile of the participant was more defined and the questions and areas for discussion were in a sense more specific, the analysis gave rise to new codes entirely, allowing for more content, detail and nuance overall in terms of the level of analysis. While a significant part of these interviews concerned usability issues and as a result touched on areas explored in previous interviews, analysis revealed new codes and categories and therefore allowed new theme to emerge. For these reasons, this phase of the study could be considered both inductive and deductive in its level of thematic analysis (Braun and Clarke, 2006).

Scales and Questionnaires (T0, T1, T2)

A battery of scales and questionnaires were administered at T0 (first day of trial and deployment of technology), T1 (start of week 5) and T2 (last day of trial). Owing to the burdensome and time-consuming nature of such a number of questionnaires (in particular with this cohort), the participants were provided with a stamped addressed envelope and asked to post the completed copies at a time that suited them. While this was welcomed broadly by the participants and allowed them to complete them at their own convenience, it did result in both incomplete questionnaires being included, as well as some being omitted entirely. The following questionnaires were used for the trial:

- The Rapid Assessment of Physical Activity (RAPA) Among Older Adults. The RAPA scale is used to assess levels of physical activity among adults older than 50 years. It has been described as easy to use and is a valid means of measuring physical activity among older adults (Topolski *et al.*, 2006).
- Pittsburgh Sleep Quality Index (PSQI). The PSQI was designed as a self-rated questionnaire which assesses both sleep quality and disturbances over the course of a month (Buysse *et al.*, 1989). It has been used as an effective means of measuring quality and patterns of sleep in older adults and measures sleep across seven domains (Smyth, 2012).
- Mindful Attention Awareness Scale (MAAS). The MAAS scale was introduced in 2003 as an instrument to assess individual differences in the frequency of mindful states over time (Brown and Ryan, 2003).This scale has been described as a valid measure of trait mindfulness with a long empirical track record (Black *et al.*, 2015).

- The Zarit Caregiver Burden Interview Short Form (ZBI-12). The ZBI is used to assess and evaluate caregiver burden and was initially designed as a 29-item instrument. The shortened version has 12 items and is seen as a more practical and accessible tool, particularly for use with older adults (Gratão *et al.*, 2019).
- CASP-19 Scale. CASP-19 is used to measure and assess quality of life (QoL), and uses four sub-scales covering control, autonomy, self-realization, and pleasure. It focusses not only on measuring poor or declining health and its impact on QoL, but also positive aspects of ageing. It has been used widely and is described as a 'quick, effective, multidimensional instrument with generally good psychometric properties' [13].
- Cohen Perceived Stress Scale (PSS). PSS was introduced in 1988 and has become the most widely used tool for assessing an individual's perceived level of stress. Specifically, it uses situations in daily life and looks at the degree to which they are considered stressful. It explores how unpredictable, uncontrollable, and overloaded respondents find their lives (Cohen, Kamarck and Mermelstein, 1983).
- System Usability Scale (SUS). SUS is a 10-item questionnaire and is a quick and reliable too for measuring usability on both hardware and software products. It is widely used and it is considered suitable for small sample sizes (U.S. Department of Health and Human Services, 2013).

During the first visit the participants were shown the battery of scales and questionnaires which were used in the trial, and guidance was provided on completing them. Initially, the intention was to sit with the participants while they filled out the questionnaires for T0. However, it became apparent during the set-up process with the first participant (P22), that this could potentially be both impractical and obtrusive. This was due to the time already required to deploy and demonstrate the equipment and system, as well as provide training and answer any questions. Integrating a full round of questionnaires into this session evidently was asking too much of P22, given that his wife (and care recipient) was present and required assistance or attention at times throughout. A stamped addressed envelope was then left with the participants and they were asked to send them in the next day or at their earliest convenience. This was then repeated for T1 and T2.

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[13] https://casp19.com/background/

Once these scales and questionnaires had been collected, they were manually entered into Microsoft Excel to conduct a simple comparison of responses across time points. Given the relatively small data set in terms of the number of participants, this was considered a sufficient tool for analysis. The analysis was used to identify participants' highest and lowest values at each time point. Groupings or clusters with similar scores were also described. Trends across the three time periods were identified and described and outliers were also discussed. The most marked changes among participants were highlighted, as were those who recorded little variation.

System Engagement Data

Engagement data was captured indicating number of days logged in to the Mind Yourself application, days self-reported, as well as levels of interaction with the mindfulness content and the educational tips across the 8 week trial period. It was possible to ascertain how frequently a modal window had been opened, as well as for how long. These were stored as logs and were then accessible as simple text files. From here it was necessary to manually enter the data into Microsoft Excel in order to generate graphs for analysis.

Sensor Data

Sensor data was pulled directly from the Mind Yourself application. While this data was also available within SIMS, it was presented in a less accessible fashion in SIMS than the end-user application. As such, each user's profile was accessed from web server hosted by NetwellCASALA for the purposes of this study. From here it was possible to log in to a particular profile and view steps, sleep, and blood pressure data and graphs in the same way the users had throughout the trial. This was practical and adequate given the small sample involved. The data was then copied into tables. The Steps data showed average number of steps taken per day in a week and the number of times the goal of 7000 steps per day was achieved, as well as the number of times the goal was exceeded or not reached. The Sleep data showed average number of hours sleep per night in a week, the number of times the goal of eight hours was achieved, and the number of wake-up/disturbance times. Overall increases or decreases in average steps or hours sleep were also identified.

Self-report Data

Participants self-reported daily through the application on recent sleep, activity, and stress levels. This data was then accessed through SIMS and exported as graphs. The aim was to identify any changes from week 1 to week 8. Again, the most marked increases or decreases were highlighted, as were those who remained consistent throughout. The highest and lowest recorded scores across all participants throughout the trial were also identified.

8.5 Summary

This chapter has presented an overview of the design of the main trial, including the objectives, technology used, trial procedures and the data collected. Chapter 9 outlines findings from the qualitative interviews conducted with the participants, while Chapter 10 presents the results of the quantitative data (questionnaires, self-report data, engagement data).

Chapter 9: QUALITATIVE RESULTS

9.1 Introduction

This chapter details the qualitative findings from the trial. An overview of the participants is provided in Section 9.2. Section 9.3 provides an overview of the themes resulting from the thematic analysis. Sections 9.4 – 9.10 outline each of the themes and sub-themes from the analysis.

9.2 Participant Profiles

- P21 (63, F) - P21 is caring for her mother, who has dementia and lives with her. P21 is the primary carer and is not in employment. She has little family support. P21 does not live in an urban area, near to amenities or health services. She does not drive and relies on public transport. She described the caring process as having an impact on her sleep quality and physical activity prior to the trial. She had no experience of meditation practice. P21 has an iPad which is mainly for her daughter, but she has some experience with it. She does not use a smartphone. She had not used any sort of activity-tracking devices prior to the trial.
- P22 (64, M) - P22 is caring for his wife, who has dementia. P22 works full-time and receives some support from family members. P22 drives and has a car and he lives in an urban area. He reported high levels of stress due to the need to balance work and caring for his wife during the initial conversations prior to the trial. He had no experience of meditation practice. P22 does not own an iPad but he uses an Android smartphone and as such is familiar with touchscreen interfaces. He had not used any sort of activity-tracking devices prior to the trial.
- P23 (61, F) - P23 is caring for her husband, who developed quick onset dementia at a young age. She has been struggling to cope and found herself having to deal with responsibilities which had normally been looked after by her husband. She has two adult children, one of whom lives abroad. The other is at university and is only available occasionally at weekends. She drives and lives in an urban area. She had no experience of meditation practice. P23 is familiar with both iOS and touchscreen interfaces as well

as desktop. She had not used any sort of activity-tracking devices prior to the trial but was familiar with some brands.

- P24 (67, M) - P24 is caring for is wife, who has dementia. He is retired and is his wife's primary carer. He did not report high levels of stress during the initial conversations but felt he needed to make improvements with regard to physical activity and sleep quality. He drives but does not live in an urban area. He had no experience of meditation practice. P24 does not own an iPad but uses an Android smartphone. He had not used any sort of activity-tracking devices prior to the trial.
- P25 (77, F) - P25 is caring for her husband, who has dementia. She is his primary carer but receives home help on weekdays. Due to her own health issues she is unable to engage in much physical activity. She drives and lives in an urban area. She had some experience of meditation practice having bought books on the topic. P25 does not own an iPad but uses an Android smartphone. She had not used any sort of activity-tracking devices prior to the trial.
- P26 (53, F) - P26 is caring for her mother, who has dementia. Her husband works abroad and her children are at university. As a result, she is the primary carer and reported high levels of stress during the initial conversations about participation in the trial. She drives and lives in an urban area. She had some experience of meditation practice. P26 owns an iPad and an iPhone and is familiar with both iOS and desktop interfaces. She owns and uses a Garmin smartwatch which she uses to track her activity and sleep.
- P27 (69, F) - P27 is caring for her husband, who has dementia. She is the primary carer and does not receive much family support as her children live abroad or far from the family home. She did not describe herself as stressed prior to the trial but did report issues relating to physical activity and sleep quality. P27 drives but lives in a rural area. She had no experience of meditation practice. P27 does not own an iPad but uses an Android smartphone. She had not used any sort of activity-tracking devices prior to the trial.
- P28 (75, F) - P28 is caring for her sister, who has dementia. They both live in a shard community living complex for older adults but live separately. P28 spends most of her time with her sister, however, and describes herself as always needing to be available. She reported high levels of stress and dissatisfaction with her activity levels during the initial conversations prior to the trial. P28 drives and lives in an urban area. She had some experience of meditation practice having done yoga in the past. She owns an iPad

and is familiar with iOS. She had not used any sort of activity-tracking devices prior to the trial but was familiar with some brands.

9.3 Overview of Themes

The following sections present the themes from the trial interviews. Themes that arose during the mid-trial interviews were also present during the final interviews. As such, the findings are presented by theme rather than by time-point. Where a finding or a quotation relates to the mid-trial interviews, this is highlighted. An overview of the themes and sub-themes is provided in Table 9.1. A summary of the thematic analysis and coding process can be found in Appendix 6.

Table 9.1 – An overview of themes and sub-themes from the main trial

Theme	Sub-theme
Carer Related Stress and it’s Management	- The nature of dementia and its impact on the carer - Changes in circumstance and external factors or influences - Lack of supports and its impact - Techniques for managing stress
Caring, Sleep and Physical Activity	- Impact of caring on sleep - Mindfulness and its effect on sleep - Finding value in reflecting on sleep data - Caring and physical activity
Benefits and Positive Outcomes	- Increased awareness, reflection and behaviour change - Perceived improvements in health, wellbeing and mindful awareness - Intentions to continue self-managing after the trial
Experiences with the Mindfulness-based Intervention	- Perceptions of and engagement with the mindfulness content - Putting the various techniques into practice - Challenges with mindfulness techniques and content - Considerations related to modality of content delivery

Experiences with the Application and Devices	- Experiences with sensors - Self-report, data feedback, tips - Goal-setting and motivation - Experiences with the Mind UI
Interaction, Design and Areas for Improvement	- Routines and patterns of engagement - Using the Healthmate app versus using the Mind Yourself app - Suggested changes and new features
Perceptions of the trial as a whole	

9.4 Care-related Stress and its Management

The interviews revealed a number of key factors connected to stress and its effect on health and wellbeing. Participants discussed the degree to which stress affects their everyday lives as a carer, and how they felt participating in the trial affected this. The link between stress and caring was brought up frequently and the interviews shed light on the degree to which the two can be interlinked as well as various forms of triggers and stressors for this population.

9.4.1 The nature of dementia and its impact on the carer

For many of the participants, the symptoms of dementia and how it affected the quality of life of the care recipient were key factors contributing to stress. Anxiety, agitation, forgetfulness and the unpredictable nature of the disease were discussed and were clearly associated with levels of stress.

P25's husband suffers from considerable anxiety. She explained that he needed to reduce his anxiety medication due to an interaction with another medication for a different condition. This resulted in much distress both for P25 and her husband: '*But since they've started to reduce it, the levels of stress for him, I feel for him as well because he gets himself into an awful state*'. P25 stated she would like her husband to also start meditating, as she felt it would help him relax and it could address his anxiety issues. She also considered herself to be constantly stressed.

P24 discussed how when his wife becomes upset and agitated, this acts as a trigger and directly affects his stress levels. He spoke of how dementia can be unpredictable and erratic, which in turn can make looking after one's own life very difficult and uncertain: '*But see, this is a whole new environment for people... this dementia. One day, things are normal, then all of a sudden, you're thrown into this'*. Deterioration of the care recipient's condition and health also contributes to stress. P23's husband has Parkinson's and Alzheimer's and his condition had continued to deteriorate. She explained '*He has got worse… He's very hard to understand. His speech…'*. P23 felt that she would feel relaxed having meditated but that her stress levels could then rise depending on the caring situation. P22 spoke of how his wife becomes convinced he is away with another woman and then refuses to speak to him. Another example of his wife's behaviour includes hiding things as she is convinced someone is trying to steal from her. Support from the dementia training service helped him realise to expect and accept this type of behaviour. Nonetheless, situations such as these do contribute to P22's stress levels and require consistent patience and understanding.

The manner in which the participants believed stress can affect physical health and wellbeing was also discussed. P22 explained that increased stress will result in sensations of tightness in his chest: '*I get the tightness here in the chest with it. I can feel it actually tightening up here…. But then once I calm down, it goes back down to normal'*. During the mid-trial interviews, P24 mentioned that he had become aware that his blood pressure was high, which prompted him to visit his GP: '*normally, I wouldn't have bothered checking my blood pressure now for another couple of months probably… it probably helped me get it on time, in case something worse down the line'*. P24 was advised to continue taking readings and to contact his GP again if there were further high readings. P24 suggested that his raised blood pressure levels were related to stress and re-iterated this during the final interview. P28 also viewed blood pressure as being directly connected to high stress.

9.4.2 Changes in circumstance and external factors or influences

During the trial, some participants experienced changes in circumstance which impacted on their perceived stress. Both P21's and P26's mothers were taken into care. Initially, this was extremely stressful for P21, as her mother was hospitalised, and she had to travel each day to be with her. However, once her mother moved into long term care P21 reported feeling less stressed. P26 explained that since her mother had gone into care, her stress went from chronic to periodic: '*So like some days, I would be really stressed and other days then, I would be ok again. Whereas the other way* (before her mother was in care)*, it was constant stress*'. P26 said she felt that her reduced stress levels were a result of both the change in circumstance and her engagement with the mindfulness content.

During the trial, P27's husband began going to a day care centre for people with dementia regularly. She discussed how she needs this time as she feels she is constantly busy and 'on the go': *'Because I'm trying to tie everything around him all the time'.* However, she also discussed how the experience of leaving her husband to day care was a cause of distress for her, resulting in feelings of sadness. She compared how she felt in this situation with how she felt when she first left her children at school, saying '*it was the first time and I felt it was like leaving a child to school… I was more stressed about it and upset than he was'.*

9.4.3 Lack of supports and its impact

Lack of support in care provision or lack of financial support was a considerable burden for three participants, resulting in stress. As the only daughter in her family, P21 spoke of how she shoulders the majority of the responsibility in relation to caring, with her siblings visiting their mother '*an odd time.. maybe 10 or 15 minutes once or twice a week'*. She receives help from her granddaughter or neighbour when she needs to be somewhere else. Monetary support from P21's family is also an issue as family members are on the state pension. It was clear that the financial implications of caring as well as various family conflicts as a result of financial issues is a significant cause of stress.

Such conflicts with family were not reported by other participants. However, issues relating to supports and the lack thereof were discussed by some. P23's husband goes to an Alzheimer's day centre on weekdays between 10am and 3.30pm. Aside from this she is the sole carer. Both her sons live abroad and she does not receive any support*: 'He's with me all day'* (P23). P25 also reported challenges relating to support. She needs someone to be with her husband at all times. However, the state-provided support is for 30 minutes a day during weekdays and is essentially for assistance getting dressed and showering. This lack of support in turn has affected her opportunities for physical activity and has limited her social interactions. She said '*I used to do aqua aerobics twice a week, but I haven't had anybody to sit with him'*. This has also resulted in further limits to social interaction for P25. Recently, however, she has started receiving support through another organisation. From 9.30 to 14.30 on a Wednesday somebody comes to stay with her husband. This allows her to get out of the house for other things such as dental or hair appointments, which makes a significant difference to her wellbeing and quality of life. It has also become part of her husband's routine and it does not affect him negatively.

9.4.4 Techniques for managing stress

During the interviews the participants shared some of the self-management techniques they employ to help cope with stress and carer burden. For some participants, these techniques were a direct result of participating in the trial.

During the mid-trial interview, P24 commented on increased awareness in relation to stress and a realisation that he was 'always on': '*I definitely wasn't aware of the stress. I thought I wasn't stressed. It turns out now I am stressed',* and later '*I was literally sitting down for 10 minutes and then "what have I to do now" and then up I'd get, and there'd be something, or there'd be a demand on me'*. P24 discussed how he is addressing this issue, explaining that he is trying to take on less and manage his time better. During the final interview P24 spoke of how he now consciously tries to switch off and relax. Switching off to what is troubling you or what is running through your mind involves a sense of mindful awareness – the ability to move away from the noise and be present in the current moment.

P22 described his stress levels as low at the time of the final interview. However, he emphasised that anxiety/stress is his main area of concern in relation to his health. He uses stress-management strategies based on advice from the dementia training service for carers that he attends. This involves taking himself away from the situation once a week. He uses this time for himself and does something he enjoys, which in his case is fishing*: 'Just the anxiety thing… I'd feel that affects me a lot more than anything else… I'm going away fishing tomorrow. I'm looking forward to that'*. For P21, focussing on health self-management during the trial helped to distract and shift attention away from care burden and triggers of stress. She felt she now had a raised level of awareness and a sense of noticing when stress begins to take hold due to thinking about her own health: '*I'd say it has now, yes, yes. I just, I know when I'm stressed and when I'm not, like you know what I mean'*.

P28 noticed a change in her caring process since commencing the trial. She cares for her sister who is 81, has dementia, a number of physical difficulties and has always had problems with depression. She felt she has been allowing her sister to be more independent by giving her more initiative in terms of communication, for example by letting her sister come to her if she needs anything instead of constantly checking on her first: '*There probably has been some change in that I probably have benefited from the last two months in that I'm leaving more of the communication to her and letting her come to me more'*. She explained that her stress levels were relatively low currently as her sister was doing well.

Each of the examples provided during the interviews serve to illustrate the varied and unpredictable nature of caring for persons with dementia and highlight how stressors and factors contributing to burden often differ from case to case due to individual circumstances as well as the profiles and personalities of the people involved.

9.5 Caring, Sleep and Physical Activity

Themes that arose within the topic of sleep related to the relationship between sleep and caring, how mindfulness practiced through the application impacted sleep, as well as experiences tracking and reflecting on sleep data. Participants also spoke about how their opportunities to engage in physical activity were limited due to the responsibilities of caring.

9.5.1 Impact of caring on sleep

The participants shared their views and experiences regarding caring and its effect on sleep quality, while some spoke of changes observed as a result of participating in the trial. At the mid-point interview P24 spoke of how he felt his increased awareness of stress also resulted in improved sleep in terms of fewer interruptions and longer periods of unbroken sleep: '*I can see, I'm sleeping better… now I seem to be going further without having to get up… I think there's a link there and also that I'm aware of the stress'*. During the final interview P24 reported that his sleep quality worsened during the last weeks of the trial, due to his wife's condition deteriorating, resulting in her sleep (and as a result his) being interrupted. However, he reiterated how prior to this he had been feeling more energised throughout the day, as he had started to tackle his stress: '*I don't find myself tired. I've a lot more energy than I had, you know. I didn't realise I was a bit stressed in the beginning, but now I find that I've a lot more energy'*. While P24 did not engage with the meditation content regularly throughout the trial, his attempts at meditating initially led him to realise that he is 'always on', and needs to find more time for himself to relax.

Other participants also reported improvements in sleep. During the mid-trial interviews, P27 reported an effect on her sleep hygiene as a result of data feedback and the daily tips in the application, saying she had cut out caffeine: '*it took me off the caffeine then*'. P22 explained felt he had fewer interruptions and that it wasn't taking him as long to get back to sleep, saying '*Yes, I'd notice it, normally I'd wake maybe once, maybe twice during the night, but I'd go back straight now to sleep you know'*. Some participants' sleep was also clearly linked with their caring responsibilities. P25's sleep quality mid-week is very poor due to her husband's disrupted sleep patterns and because he needs help with using the bathroom to ensure he doesn't fall. As a result, she can find herself tired during the day and feeling she needs a nap. She also finds it difficult to go to bed at the same time each night, as recommended for healthy sleep hygiene. P26 experienced a considerable change in sleep patterns when her mother was taken into care. She went from severely under-sleeping to what could then be described as over-sleeping. She said '*Some days, I mean like this, the app is indicating that I was getting, you know, 10, 12, 14 hours' sleep. So I was like, 'I think I'm getting too much sleep. I need to get myself back'*.

9.5.2 Mindfulness and its effect on sleep

The degree to which mindfulness practiced through the app had an effect on sleep quality was also discussed during the interviews. P26 felt her sleep quality improved as a result of the mindfulness content. She felt overall that she had more clarity of thought than before, saying '*I think the mindfulness did have an effect in allowing me to sleep better and just clear my head'*. This was also the case for P23, who believed that meditating had made her feel more relaxed which in turn positively affected her sleep quality. P28 also noticed an improvement in her sleep as a result of engaging with the mindfulness content and without the need for any sleep medication. She still woke during the night but did not feel this was a problem as she finds it easier to get back to sleep now if she meditates. She said '*And that's the part that if you put on something and help yourself to relax back into the sleep, that's the bit that benefits me'.* While she has in the past meditated unassisted, she now uses an audio guide and finds this to be more effective.

P25 also employed mindfulness techniques to help her sleep. She explained that prior to the trial sleep latency, or the onset of sleep, was not an issue. She would employ techniques common with good sleep hygiene such as having a routine and reading for 30 minutes. However, if she woke up she would have problems getting back to sleep. Since starting the trial and using the application, however, she uses some of the mindfulness techniques found in the application such as focussed breathing and the body scan to help her get back to sleep: '*I do the body scan… that one is the one that I find helps me most'.* She found this to be effective in addressing feelings of anxiety and stress and eventually getting to sleep, saying *'Your mind is brought away from what was upsetting you, you know'.* Further detail on how participants engaged with and used the mindfulness intervention is discussed in Section 9.7.

9.5.3 Finding value in reflecting on sleep data

Many participants reported engaging with their sleep data and finding it useful. P23 found value in viewing her sleep data and became accustomed to analysing various stages of sleep and reflecting on sleep quality. For P27 reflecting on and analysing sleep data brought a sense of raised awareness about the importance of sleep quality in general. She feels she does not sleep enough and also came to realise that she is not getting enough deep sleep. She had never viewed sleep data in this manner before and expressed how she was shocked to see how poorly she had been sleeping. She said '*Sleep quality is not good. I don't really have much deep sleep. It's usually light sleep and looking at that, I didn't realise I woke up so many times during the night… That was a bit of a shock'* (P27). She followed a routine in terms of when she would go to bed but this was often very late. She would still wake up early, however, resulting in her sleep quality (and sleep hygiene) being quite poor. Reflecting on her sleep data for this first time in this manner prompted P27 to discuss this with her doctor, who then recommended sleeping tablets. There was a noticeable improvement as a result, with her feeling better overall during the day. Getting feedback on her sleep and viewing the data through the application also motivated P28 to keep an eye on this aspect of her health and wellbeing: '*that gave me great encouragement to, not to neglect it, you know'*.

Some participants reported comparing their sleep data to their routine or known sleep interruptions, to determine its accuracy. P22 believed the sleep tracking element to be very accurate, based on comparisons to his routine. He reported an interesting use of his sleep data, whereby he would show it to his wife to demonstrate sleep disturbances: '*You'll find when I'd wake up, that'd be her with one of her wee panic attacks... I'd say to her, 'Right, you were awake at twenty to six this morning' and it's there'*. Similarly, P25 was able to match sleep interruptions she saw on the graph with her experience of how the night's sleep had been. She pointed out that the times matched when her husband had woken up to go to the bathroom. For P26, reflecting on her sleep data led her to question its accuracy, as she felt that at times the data from the Withings watch did not match how she herself felt she had slept. While she would remember having a broken sleep, she felt the device and application would either overestimate the time asleep or fail to register the interruptions and times she had woken up: '*Sometimes it doesn't come across that way on the app that it was broken, but I felt it was… I found it was more broken and it would indicate that I'd a lot more sleep'*. P24 also felt that the data from the watch was at times not accurate. His memory of when he got to sleep and how he slept occasionally did not correlate with what was presented in the graph. Overall, however, he felt the watch was accurate enough in tracking sleep and his answers to the self-report question (in terms of how well he slept - length and interruption etc.) generally matched how the data was presented in the sleep graph.

9.5.4 Caring and physical activity

Physical activity levels during the trial varied among the participants. Both P27 and P28 consider themselves to be quite active, going for regular walks. However, for most participants, their role as carers afforded them little opportunity for physical activity. At the start of her interview, P25 wanted to stress that she was sorry she could not do more physical activity. She explained that aside from an exercise class once a week, and the occasional walk with friends at the weekend, she does not get the chance to do much physical exercise due to lack of time and not being able to leave the house. This is something she would ideally like to change: '*it's* *not as regular as I would like it to be… I want to do more… I'm motivated to do it. I wish I could get out to do it'*

P21 explained how she could not be physically active while caring for her mother, saying '*I couldn't get out walking… You don't. I just hadn't time'*. Her mother being taken into hospital resulted in a commute involving four buses each day and as such any opportunities for physical activity were reduced even further. Similar sentiments were expressed by P26, whose mother was also taken into care during the trial. She differed from P21, however, in that prior to her mother being taken into care she had been very active and exercised regularly, and she had been using it as a coping mechanism. While this was effective in addressing psychological issues, it was somewhat counter-productive in that it also left her tired overall. However, the change in circumstance affected P26's routine and her motivation to keep exercising. She noticed a considerable drop in her activity levels since her mother was taken into care. She found herself having so much more free time that she did not know initially what to do with it. It then became easier to put exercising off, whereas beforehand she would make sure she was using any opportunity for exercise she could get. She said '*I just feel like well, sure I can do it later, but I'm not doing anything now, you know* '.

9.6 Benefits and Positive Outcomes

The following section presents the findings from the participant interviews regarding benefits and outcomes of participating in the trial and using the technology, in terms of raised awareness, behaviour change, impact on perceived wellbeing, and a heightened sense of mindfulness awareness.

9.6.1 Increased awareness, reflection and behaviour change

Throughout both the mid-trial and final interviews, participants spoke about increased focus on and awareness of their health and wellbeing as a result of using the application. The feedback and content in the application prompted reflection and for many, resulted in changes in behaviour. As mentioned above, P24 spoke about using the app made him more aware of how stressed he is and how he is 'always on'. This increased awareness resulted in P24 feeling that he now had the ability to self-manage his stress to a degree. During the mid-trial interview he said: '*I'm kind of getting to manage it a bit better… it's early days but it's handy to have the, to have it down on paper (*referring to the application) *as a back-up because you can see what's going on'*.

P21 reported that a low stress score would cause her to reflect on it, linking it to that particular day's activities: '*I'd know why… You know. Like look at this* day'. P21 also explained how she used the graphs to self-reflect. She said that potentially negative feedback, such as seeing a low step-count, did not have a negative impact on her emotionally, but noted that it caused her to reflect and could possibly act as a motivator. However, she felt lack of time was the main barrier to increasing her behaviour in relation to physical activity.

P22 also discussed how he had a heightened sense of awareness with regard to being on 'autopilot' since commencing the trial. When addressing stress specifically, he said '*It was interesting… Normally just before, I'll go through this. It's an everyday thing. I wouldn't give it any thought. Now you're aware of how it affects you'*. His main goal in relation to the trial, was to reduce his anxiety and stress; he felt the tracking element of the system helped with this but would still like to have engaged more with the mindfulness content: '*Well, the anxiety and all…Just to relieve that…I can now, but I still get that bit anxious and that… But with that there, it's not too bad…It gives you something to fall back on'* (P22). P22 also reported being more motivated to maintain progress or increase his steps if he noticed that his count was low, saying '*a thing that I wouldn't normally do… I'd take a walk out to the forest, a few steps even'*.

Raised awareness and reflecting on behaviour were also outcomes for P25, who found benefit in each of the four health and wellbeing sections of the application. She spoke about how she had learned to turn to the Three-minute Breathing Space as a coping mechanism when she was feeling annoyed by something, saying '*if I was very annoyed or upset, I'd go and just do the three minute and that, you know… Whereas normally, I wouldn't take the time to do a three-minute break'*. Reflection, realisation self-care and taking time for oneself are possible outcomes to participating in a trial such as this according to P25.

Having access to health and wellbeing data through the application prompted some participants to take action, for example by changing some aspect or their behaviour or by deciding to visit their GP. Before the trial, P27 had been taking blood pressure medication and regular blood pressure readings for some time. During the trial, she discussed her high readings with her GP, who told her not to be too concerned as she was taking medication. P24 was also worried by an initial high blood pressure reading. This motivated him to have it checked with his GP. He brought his iPad to the visit, with his data from the trial. P24's awareness with regard to salt content in food was also raised since commencing the trial. He said '*I've made a diet change… An exercise change and a kind of a relaxation change. Yes, so I've made everything that's in there, you know. I made changes, you know'*. P24 is now very conscious of the potential damage too much salt can do and makes a point of checking food labels. P24 also reported reduced stress and improved wellbeing since commencing the trial as well as increased clarity of thought. He attributed this to three things: having more energy due to increased activity levels, tracking his blood pressure and more focus on diet. He also reported taking time to relax to help manage his stress levels. Going forward P24 plans continue with his increased activity and to monitor his blood pressure and will purchase his own cuff to do so at home.

P28 reported paying more attention to her activity levels since wearing the watch: '*I probably was more attentive to it and was probably more keen to walk every day instead of just some of the days and I did really walk most of the days'*. She enjoys walking but felt that she also needed to focus on upper body strength. Wearing the watch and using the app prompted P28 to reflect more on her physical health and also to think about herself a bit more: '*Yes, so I'm looking at it. You see, it does help you to, I suppose, focus a bit on yourself*'. Since commencing the trial P28 felt motivated to get out of the town and take a walk in the countryside. She has changed her behaviour and now tries to experience different environments for her physical exercise. Her awareness has been raised with regard to the importance of not only the act of walking, but also the location and how this affects emotional wellbeing. She emphasised that she now recognises the importance of quality as well as quantity with regard to physical activity.

9.6.2 Perceived improvements in health, wellbeing and mindful awareness

The participants reported experiencing improvements in different aspects of their health and wellbeing, as a result of different elements of the application. Improvements included reduced stress, increased levels of physical activity, increased confidence and improvements in social interactions.

P23 reported being much less stressed, losing her temper less and in a better state overall as a result of participating in the trial: '*the meditation, the mindfulness and the exercise… just calmed me down'*. She said '*I was motivated to, you know, do the steps… And the meditation, you know, it wasn't a chore*'. She noted that during the trial she used her treadmill if she was finding it hard to get outside. Prior to the trial she had not been motivated to use it. She described an increased sense of mindful awareness and appreciation of everyday things, such as noticing small things like new flowers or the smells while chopping vegetables. P23 felt more present and attentive to what is happening around her: '*you could see all that as you walked round the park and taking it in, whereas before, I probably wouldn't have thought about doing that*'. P23 felt her confidence had also improved since taking part in the trial, to the extent that she wanted to engage in social activities that she had not done in some time. She said '*And I also had my sister and her husband over for dinner on Sunday, which I haven't done since my son left home because it's just me doing everything… I just felt more confident or something, you know… I'm glad I didn't forget to tell you that one'*. This is a particularly positive outcome. It is also significant that she expressed how she had wanted to discuss this and she felt glad she had not forgotten to mention it. Later in the interview P23 provided some very positive and frank feedback. It appears she had been in a bad way prior to the trial and that it had a particularly positive effect on her wellbeing in general: '*Delighted to have done it… It kind of got me out of a rut'*.

Since participating in the trial, P27 reported feeling much more relaxed and appreciating small things in life. She believed she was paying attention more to the present moment, which suggests a heightened sense of mindful awareness. This allowed her to appreciate things she may have overlooked or neglected previously. She provided examples in relation to eating, tasting, and cooking: '*But it made me appreciate and I spend more time now if I get something handed to me… Or even when I'm cooking, I'm more involved in it… I'm paying attention and I'm really tasting the food*'. She believed this to be a direct result of engaging with the content in the application. The area in her life where P27 felt she benefited most in terms of the trial was this heighted sense of mindful awareness: '*The benefits I got was to be aware of everything around me'*.

P28 reported that engaging with the application raised her awareness about the importance of her wellbeing in general and helped her focus on herself, which resulted in improvements: '*What I've liked most is the fact that it encouraged me to focus on myself enough, which enables* *me to do everything I do better'.* Awareness raising appears to have been the driving force behind P28's change in behaviour, and she explained that this resulted in more motivation to exercise, as well as an improvement in sleep: '*it encouraged me to be more keen to do enough exercise every day and it also helped the sleep*'. She felt participation in the trial reminded her to look after herself more, in the same way she had done in the past. This sense of realisation concerning aspects of her life that she had been neglecting appears to have come about as a result of managing her wellbeing through both mindfulness meditation and reflecting on sensor-based feedback.

For the other participants improvements as a result of participating in the trial were more pronounced in other areas of their overall wellbeing. As discussed earlier, P22, P24 and P25 all reported a heightened sense of awareness around stress levels, with each employing different techniques for addressing this. Both P22 and P24 had been making an effort to exercise more since commencing the trial and had felt better as a result. Similar to P23, P24 had also started to pay more attention to blood pressure levels and had sought advice from a GP. Improvements in sleep quality in terms of interruptions were reported by P22, P24 ,P25 and P26, with both P25 and P26 implementing mindfulness techniques to support them in this regard. Both P21 and P26 underwent significant changes in their personal circumstances and daily lives yet still benefits were reported, with P21 explaining that her awareness had been raised as a result of self-monitoring, with the data feedback and self-report scores causing her to self-reflect more.

9.6.3 Intentions to continue self-managing after the trial

Participants also discussed their intentions with regard to continuing to self-manage their health and wellbeing beyond the trial. Participants spoke about wanting to continue to meditate and manage stress, as well as track and monitor activity and sleep. P23 intends to continue practicing mindfulness in the future. Since participating in the trial she became aware of industry leaders in this space, such as Headspace. She also reported that she intends to focus more on physical activity. P26 reported feeling sufficiently familiar with two of the meditations within the application, to the extent that she will be able to practise them without having access to the application. Going forward she believes she will continue to meditate but on an occasional basis and when she feels she needs to. She said, '*I haven't looked into apps yet, so.*

But those two anyway would be easy to recall yourself…, because they came up quite frequently'. Mindfulness meditation was new to P26 and it is something she hadn't thought she would like to do or have any interest in. However, her opinion changed after taking part in the trial. She feels an added advantage is the fact that it can be practised alone, without the need to attend a class: '*That you can do it in your own time and your own space*'.

P27 said that she will continue to carry out some of the meditation exercises, such as the 3-minute breathing space. However, she did not feel that she would need an app on her phone for this. Commercially available meditation apps and fitness trackers were discussed with P22, as he wanted to continue with health and wellbeing self-management activities. P24 did not share the same views as the others and did not think he would continue meditating. He felt it had served its purpose in raising his awareness about the importance of finding time to relax but he would not be particularly interested in continuing to practice it.

Some participants also expressed an interest in continuing to track their activity and sleep. Both P21 and P28 felt they would benefit from using an activity tracker going forward. P21 was positive towards the Withings watch and felt she would benefit from it more in the future as she would have more time to focus on using it and getting the most out of it. A turbulent few weeks impacted how she used the device in terms of activity tracking. P23 also expressed a desire to continue with activity tracking and would like to purchase her own wearable sensor: '*Well, Mother's Day is on Sunday, so I hopefully might get one*'.

9.7 Experiences with the Mindfulness-based Intervention

Participants discussed their experiences interacting with the mindfulness content in the application. Topics related to levels of interaction and preferences regarding specific meditations. While the previous section touched on some of the benefits participants experienced through engaging with the MBI, this section presents further detail on how participants found this element effective or helpful in terms of stress and health self-management.

9.7.1 Perceptions of and engagement with mindfulness content

Broadly speaking there was a positive response to the mindfulness content across participants. As will be discussed in Chapter 10, engagement levels with the mindfulness content, as measured through interaction logs, varied. However, these interaction logs could not capture how often participants used the techniques learned within their daily lives. At the end of the trial most participants reported being comfortable with how frequently they were meditating. P22 was positive towards the mindfulness content but was not able to engage with all of it. He explained that he was keen to learn more about meditation and would like to know if he could get something similar for his phone: '*Is there an app you can get for that? Because I'd like, you know, if you had more time just to sit'*. P26 was positive towards the mindfulness content overall. In the early stages of the trial, while she was still caring for her mother, she reported experiencing high stress levels and considerable burden. She found the mindfulness content helped to address these issues at that time. However, once her mother was taken into care, she started to feel more relaxed in general and as a result felt less of a need for stress reduction techniques. The downside to this approach is that the original problem can reappear if left untreated.

P27 showed high levels of engagement with the mindfulness content, engaging more than any other participant, but she was not particularly positive towards the idea of meditating and did not believe it was for her. However, as discussed above, P27 had reported heightened awareness and when prompted further she admitted that she had in fact benefitted from the mindfulness content: '*It was ok. Just is not my thing…. It made me aware of what I was eating… The taste. And it also made me aware, I suppose, yes, it was good in that sense, it made me aware even out walking*'. This suggests that P27 does not particularly like meditating, but does see the positives in being more mindful in general. P21 was the only participant who did not engage with the mindfulness content at all and did not express any interest in it.

It became apparent from the interviews that some participants were experienced and thus more skilled in a sense when it came to engaging with the mindfulness content. P28 was already familiar with the concept behind paying attention to the present moment while carrying out everyday activities, saying '*I would have come across that now in many different ways, in many different things that I would have done*'. She explained that she was familiar with the Body Scan technique and used to do it unaided at night to help her get to sleep. P25 was also familiar with mindfulness meditation prior to the trial. She had completed a course a few years previously and also owned some CDs with audio guides. As a result, she was familiar with some of the key concepts and techniques. She also felt comfortable meditating without any audio guide: '*When you're washing the dishes, just paying total attention to what you're doing'*. However, she would use materials such as the app or her own CDs if it was convenient.

The other four participants who engaged with the mindfulness component of the trial (P22, P23, P26, and P27) were not familiar with any of the key concepts underpinning mindfulness going into the trial. As such, there was likely a steeper learning curve for these four. It is understandable, therefore, that the most popular mediations (as discussed in the following section) were the earlier ones focussed around breathing, which are more accessible and easier to practice. More research would be needed into the effect experience with mediation and the concepts behind it has on adherence and the success of a mindfulness-based intervention.

The extra materials such as the YouTube videos and the web articles on the topic of mindfulness were not used by any of the participants. P23 was aware of the extra materials but did not spend any time with them as she also did not have much free time. However, she was also not aware that there was a list of YouTube videos included in the extra materials. Lack of awareness of features and/or content is something that would require further research, for example regular training on the application, or using prompts within the application to highlight specific features and remind participants where to find them.

9.7.2 Putting the various techniques into practice

Some meditations and techniques were generally more popular than others, while some were easier to recall than others when needed. Most participants enjoyed the meditations that focussed on breathing (Breath and Body, Three-minute Breathing Space), as they act as a relatively simple means for the user to stop the mind from wandering and focus on one thing: the constant inhalation and exhalation of the breath. P22 reported using the breathing meditations in times of need such as trying to get to sleep, saying '*Take it back to the centre. I found that very, very relaxing and go back, instead of letting your mind wander, go back'*. Here, P22 was describing what is recommended in the mindfulness content and suggested with these particular practices - a 'go-to' practice for when you need to bring stress levels down, or when your mind is racing. This issue of something being on your mind at night and the resulting negative impact on sleep arose throughout the entire study (see Chapters 5-6). P22 found that practising breathing-focussed meditation can alleviate stress and he noticed himself becoming calmer, allowing him to sleep: '*You'd feel yourself calming down'*. P25 enjoyed and found benefit in the short Three-minute Breathing Space meditation and explained how she also had success getting her husband to practice it too: '*And actually a couple of the short ones, I succeeded in getting* (husband) *to sit with me and actually engage in them in his head, you know'*. P27 was similarly very positive towards this practice and appeared to find it very useful and effective. She reported turning to this as a stress coping-mechanism in times of need and finds it very relaxing. Indeed, P27 referred to this practice as '(her) *little space'*.

The Body Scan was also popular with many participants. This guided practice involves scanning or moving down through the body slowly, paying close attention to each part. The user is asked to hold their focus on each region in a sense of non-judgemental awareness, which is achieved though analysing what is happening in a specific part of the body. This appeared to be P25's 'go-to' meditation and the one she felt most comfortable with: '*that's the one I'm finding quite good myself…. It's the best one really*'. P23 said: '*I loved the one where you lay on the bed. And you start at the feet. And work through the body'*. P26 found the this meditation useful and used it to relax and get to sleep. Similar to this, P28 explained that she was already familiar with the Body Scan and used to do it unaided at night to help her get to sleep: '*The effect of relaxing each part of the body…I would have started to do different things 20 years ago, whatever it would be, and I used to do it in my head. As you asked me, there at night, I used that to help me to get to sleep by starting at my toes and working my way up'*. It is unsurprising that the breathing and body scan meditation techniques proved popular, as they are typically the starting-off point for many meditation courses and are relatively short to practice and easy to integrate into daily life.

The Sounds and Thoughts meditation focusses on developing skills that assist with noticing when negative thoughts are forming and how to deal with them appropriately. The user is encouraged to focus intensely on the current moment, specifically to any sounds around them. These could be anything, from the sound of the breath to a passing car. This meditation aims to raise awareness and allow the user to accept and observe a thought as it arises, without dwelling on it or attaching unnecessary meaning or emotion to it. Sounds and Thoughts appeared to have been very effective for P27, leading her to listen attentively to the sounds around her. She provided examples of traffic on her road outside the house and being aware of what the sounds were, as well as paying attention to the birds singing in the morning: '*It left me more aware of noise. More aware of the lorries going up and down the road here. Well, the birds start here at half five, six in the morning. And you know, you really start now to listen to them'.* P26, on the other hand, pointed out that the Sounds and Thoughts meditation is only enjoyable and therefore effective if there are interesting sounds to hear. There was construction work taking place next to P26's house and this was particularly disruptive and intrusive with regard to this particular meditation. She said '*Yes, some days then, that would kick in and you're going, 'I really don't want to focus in on them, you know'.* P28 was positive towards the Sounds and Thoughts meditation and her comments suggest she understood and grasped the concept behind this particular meditation: '*But I do think that that thing of bringing all the senses into it is very good*'.

While the Body Scan technique involved paying close attention to each part of the body while in a sitting position, the Mindful Movement meditation aims to do the same with the moving body. The practice consists of four stretching exercises that aim to release tension associated whit stress. Four participants, P23, P25, P27, and P28 tried out this meditation and reported finding it useful. However, participants may have missed the point of the exercise. P28 commented that it raised her awareness as to her physical flexibility, saying '*That's probably one of the ones that reminded me that I'm not as good as I used to be'.* P27 enjoyed the Mindful Movement meditation but did not consider it to be much more than stretching.

Observing without reacting or responding forms the basis for the Exploring Difficulty meditation. The sense of acceptance involved in Exporting Difficulty is two-staged: the first involves noticing the initial attempt to banish difficult or unsettling emotions. The second stage involves facing up to and simply observing the thoughts in a non-judgmental manner for what they are. This meditation garnered a negative response from all but one of the participants. P27 considers herself a positive person in general and did not seem interested in exploring negative thoughts. However, she felt this could be beneficial to her husband, who she cares for, as she considered him to be very negative at that time. P26 did not want to engage with this technique at all: '*Yes, didn't like that one… No, I don't want to go there… I just want to calm down and relax… I don't want to start bringing up the stuff that I'm trying to forget in the first place'.* This could be a particularly important meditation for this cohort given the stressors and burdens they are likely experiencing. It is possible that the potential benefits of such an exercise were not adequately communicated. P28 was the only participant who felt positive towards this meditation. She believed it is important to include exercises such as this, which focus the mind not only on what is positive, but also on accepting difficult thoughts and emotions: '*But you do have to deal with the stuff as well, you know'*.

The Befriending Meditation aims to make the user aware that it can very often be more difficult to find a sense of compassion for oneself than it is for others. This was received slightly more favourably than the Exploring Difficulty meditation. P25 tried the Befriending Meditation with her husband as she believes he is naturally a very pessimistic person. P28 was familiar with the concept behind this practice. She expanded on her attitude towards practices such as this, explaining that she has engaged with this type of exercise in the past and believed it could have a positive effect on how we interact with people in general: '*Because it does have a... It has an effect on your whole attitude to everybody you meet when you go out there*'. P26 thought it was too sentimental and unnecessary.

The Raisin Meditation acts as the beginning of the mindfulness meditation programme. The user is asked to set aside five to ten minutes. The process involves mindful awareness of the raisin through paying attention in the following ways: holding, seeing, touching, smelling, placing, chewing, swallowing, after-effects. This meditation was not particularly popular**,** with only one participant reporting anything positive**.** P27 noticed a change in her sense of present-moment awareness very soon into the course. The Raisin meditation is part of Week 1's mindfulness content and it was this exercise that revealed to P27 the extent to which she does things on autopilot without paying attention to the present moment. Since doing the Raisin Meditation, P27 started to appreciate food more and paid closer attention to the food she was tasting. She said, '*Nearly from the beginning. The raisin, that really...made me appreciate taste and all, yes... But I suddenly started to taste them and even if we go out now, I really do taste the food'.* P25 was already familiar with the Raisin mediation but she was not interested in it. For the rest of the participants, they either decided against trying it or forgot to.

Another element of the programme involves techniques designed to harness awareness of everyday activities which Williams and Penman describe as 'habit releasers'. The aim is to address and eliminate ingrained habits with the goal of increasing awareness and present moment mindfulness in general. There were some interesting findings in relation to the Habit Releaser technique. This was purely text-based**,** and as a result it was not universally popular.

However, for those who did engage with this practice, it was relatively effective. P25 engaged with the Habit Releaser content but reported that this was something she tries to incorporate into her daily life anyway: '*What did I do this week? Changing… Oh yes, I know, yes. Putting your toothbrush in your other hand… And putting your cup in the other hand… Yes. I would do that from time to time, you know'.* She appeared engaged during this part of the interview and was interested in discussing the potential merits of practices such as the Habit Releaser. She agreed with the idea of there being two 'modes', and felt that she was now finding herself in the less mindful 'doing' mode frequently (Williams and Penman, 2011). She said '*As human beings, I think, aren't we inclined to be in that mode all the time?...The being, so just you have to change your way of being, yes'.* It appears P27 engaged with all of the content, including the Habit Releasers, which she found helpful. An interesting insight was provided by P27, who tried out one Habit Releaser that involves sitting in a different chair for the week. She found this helpful with regard to caring as it meant she had to sit where her husband could see her; she would normally sit perpendicular to him. However, she had been advised by a public health nurse previously to sit where he could see her all the time, and in a sense the Habit Releaser forced her to do that: '*It helped me to make sure I'm not sitting alongside* him'. P28 was interested in the concept behind the Habit Releasers but found them hard to do in practice, saying '*I wish I'd done better on that'.*

As is evident, the interviews revealed that participants developed personal preferences and habits with regard to the mindfulness content during the trial, with many trying out the various techniques to understand which were most effective for them. P26 felt she tried out the majority of the meditations at least once. She then stuck with what she felt was proving most effective and useful and forged her own course: '*And then as things progressed, it was like right, we'll stick with those two*'. The four meditations P26 found the most effective and useful were Body and Breath, Mindful Movement, Sounds and Thoughts, and Body Scan. She did not feel she would need the other meditations and would be comfortable only focussing on these four. P27 reported that she would generally meditate once a day, and would follow what was suggested on the Planner screen. She would occasionally meditate a second time also. P24 was much less positive about the mindfulness element of the system than the other sections. He put this down to individual preference: '*I found it a bit… Like some people are into that, yoga and mind things… Some people aren't, you know… It didn't appeal to me now'.* Although he was not very interested in the mindfulness content, he did listen to a few of the meditations.

9.7.3 Challenges with mindfulness techniques and content

There were also some challenges experienced by the participants in relation to the mindfulness techniques and content which potentially impacted on engagement and overall experience. Participants reported issues such as the time required to complete meditations and a lack of guidance.

One of the main challenges for the participants was the time needed to fully engage with the mindfulness intervention element of the application. P26 had a fixed routine when she was caring for her mother. As a result she had to fit her time engaging with the system and the mindfulness content into this routine. She said, '*You fit everything in on the time that you can fit them in, so it was very scheduled'*. Indeed, P26 pointed out the amount of time required or suggested can in fact be counterproductive in that it can cause a certain amount of anxiety if the user feels they are not meeting what is required: '*you're thinking about I need to finish this'*. This was supported by P27, although in relation to interaction with the overall system rather than just the mindfulness content, who suggested that feeling it necessary to use the system in terms of monitoring, self-reporting and meditating could in itself be a stressor, and could perhaps be a factor in her varying BP readings. She said '*And then as it kept going up and down, I thought maybe it was just stressful doing this course or something'.*

Some participants also found the time it takes to practice some of the meditation techniques as a barrier with some feeling their time would be better spent doing other things. The main issue with regard to meditating for P24 was the difficulty in staying still and essentially doing nothing: *'you find 10 minutes is a long time... It's longer than you think*'. During the mid-trial interview he had described a feeling of restlessness and guilt while sitting and doing nothing. He felt he should be doing something all the time. However, this was what made him aware of his 'always on' state of mind. P27 felt some of the meditations were too long, particularly those around 15 minutes*: 'Towards the end, there was one. One of them was 15 minutes nearly… far too long'.*

There were other practical challenges reported by participants. P27 described a meditation wherein she was to lie on a bed or on the floor (Body Scan). Having done this, she then found it difficult to get up and ultimately felt quite dizzy after it. This is something that needs to be kept in mind for older users. It would need to be made explicit that such a position is not essential and sitting down as an alternative is also possible. P22 noted that location, surroundings and who was present in the room at the time were also significant obstacles to him engaging with the mindfulness content. The use and necessity of audio with the mediations caused significant problems for him. The audio from the meditations resulted in his wife believing he was talking to somebody, raising suspicion and perhaps causing distress. He said, '*it's getting the time to do it… you wouldn't be on your own to really do it'.* He expressed that he regretted not having been able to engage with it more, saying '*I'd have loved to be able to do it*'. P25 spoke of similar issues in terms of the difficulty in finding quiet time and space and how this was frequently an obstacle to meditating. Her husband would become distressed if he did not know where she was: '*Finding a space for myself and sitting quietly is very difficult… It's 'P25, P25, where are you?'.*

Somewhat related to the issue of the time required to engage fully with a meditation course, is the area of discipline. P25 pointed out on a number of occasions that discipline plays a crucial role in getting value from meditating and felt guidance and assistance of some sort is necessary to enable regular and effective meditating. However, she also felt that regular interruptions impacted on her ability to be disciplined in terms of engaging fully with the course content. She said, '*You know, you can maybe we'll say start doing something and then you see something else and you go off and you do something else and then you come back and five hours later, that job is sitting there and you didn't get it finished… Whereas if you're more disciplined, it would train you to be more disciplined'.* This was something she brought up on a number of occasions and identified it as something she would focus on were she to participate in such a trial or course again.

9.7.4 Considerations related to modality of content delivery

The eight-week mindfulness programme is based on two elements. As mentioned previously, there are what can be considered formal and informal meditation practices. The more formal elements are guided and as such are more prescribed in nature. These involve both audio and text guides and participants are asked to practise for up to 30 minutes per day. Participants discussed their preferences with regard to the delivery modality of the mindfulness content, some of which was delivered through text and some through audio. P22, P23, P26 and P27 reported finding the audio guide more useful. They initially tried both but then decided to just use the audio guides. Although P26 skimmed the text in case there was anything particularly important, she found that it was not practical to read something and then have to recall it while meditating. She said, '*I found it easier to listen to something. Like I read it the first time and I just thought, 'Hmm'. There's too much going on. You're trying to think about it and then do it or do it while you're reading it'*. P27 noted that while she relied on the audio guide primarily she also found the text guide useful and felt it was an important element to have. P23 noted that she preferred to have an audio guide while meditating but felt having practiced for the eight weeks she could possibly do it unassisted. Ultimately, she did not engage with much of the content that was solely text-based. This included the Habit Releasers, which form an important part of the overall course. It is possible, therefore, that such content would also need to be provided in audio format. P28 read the text guide for the meditations as well as the introduction texts for each week. She explained that she thinks the narrator's voice is important, saying '*But this one was good…and you do have to look for that because some of them are really hopeless'*. For P28, the speed of the narration was also important as it is vital that the listener can keep up with what the narrator is saying and explaining.

9.8 Experiences with the Application and Devices

Participants were asked to discuss their views on and experiences with the Withings devices and the application, specifically concerning data feedback, self-reporting educational tips, the Mind user interface and goal-setting.

9.8.1 Experiences with sensors

Importance of Comfort and Discrete Design

There were mixed reactions and experiences to the sensors and hardware used in the trial. However, positive feelings towards the Withings watch were expressed by most of the participants. The majority of the participants found the watch to be both comfortable and aesthetically pleasing: '*It's very comfortable actually...I never took it off* (P21), *It's a comfortable watch to wear…very comfortable'* (P22). Some participants (including P23, P24, P25) found the sub-dial useful for tracking progress towards their goal. The majority of participants had no issues with reading, understanding and using the watch, and they enjoyed wearing it overall: '*Yes. I quite liked it now. The face was good and big and, you know, the old eyesight's not great, so..*' (P23). P25 enjoyed wearing the watch and it did not pose any problems for her. A particular benefit for her was that she could wear it into the shower without worrying: *'And I could leave it on in the shower, which was great'* (P25).

Challenges with devices

Although the responses were broadly positive regarding the Withings watch, there were also some negative issues reported. P22 felt there were issues with the time needed to sync the watch and the application. This resulted in a slight delay when he wanted to check his sleep data on the application, for example, with the watch taking some time to send the most recent data to the Healthmate application over Bluetooth. P24 noticed that the watch had lost time after a while, which could not be remedied through syncing. However, he explained that this generally only involved the watch running approximately five minutes slow. Both of these issues could potentially negatively affect user experience and overall usability. P26 was also wearing a Garmin watch to track her sleep, which did not match the data from the Withings device. She felt the Withings watch was underestimating the amount of steps she was doing with it showing a lower step count than the Garmin device. She said '*The steps are slightly different per day. The one that you gave me, I reckon was about 2,000 steps lower'.* The most negative experience was reported by P27 who was very keen to stop wearing it once the trial had finished. The issues for P27 related to wearing the watch all of the time ('*I don't like wearing something 24/7').* She explained that she would not have a problem wearing an activity tracker during the day to track her steps, provided she did not have to wear it at night.

The experiences the participants had with the Withings blood pressure (BP) cuff were less positive than the watch. Though some found using the BP cuff useful and relatively easy to use, the majority reported usability issues. For example, both P21 and P22's batteries ran out mid-trial and needed to be replaced. P22 said '*It wouldn't connect… I tried new batteries in it'.* The casing for the battery with the cuff is quite difficult to remove and the battery itself is small. In spite of this, they were both successful in replacing it. However, this is far from ideal, particularly for older users who may not be familiar with this type of device and battery, or who may have eyesight or dexterity issues. Both participants felt blood pressure was an important aspect of the system and wanted to continue to take readings each day.

The blood pressure element of the system failed completely for P23: '*It didn't work for me'*. During set-up it had been difficult to get a successful reading and involved numerous attempts. It should be noted, however, that the researcher also tried taking his own reading and was successful on the first attempt. P23 was not able to take a reading following this first day. However, the initial high reading during set-up did motivate her to contact her doctor and as a result she is now on blood pressure medication and has purchased her own cuff. P25 also found the BP cuff difficult to use. She said '*Some days, I'd have to do it three or four times before I could take my blood pressure… It'd keep cutting out'*. Similar failed attempts were reported by P22 and P27. There were also times when P27's blood pressure reading was much higher than she felt it should be. This prompted her to use her own monitor, which then confirmed the reading on the Withings cuff. A possible reason for issues with the BP cuff could relate to an issue identified by Withings during the trial, whereby they stated the device was not accurate for people with a very small or quite large arm circumference. Some participants, including P24, P26 and P28 did not experience any difficulties using the BP cuff.

9.8.2 Self-report, data feedback, tips,

Experiences with self-reporting

In discussing the self-report feature most participants had positive comments, indicating that it was not burdensome or intrusive to complete them and that they were quick to answer. P27 said she tried to answer at the same time each morning, typically after she had taken a blood pressure reading. P24 felt a sense of purpose from answering the self-report questions. He compared it to having to do something as if part of a job role, saying '*It kind of gave you a purpose, the whole thing, because you felt you were answering to somebody, you know… It was like going to work again or something like that'*. He felt he was answering specifically to someone, and that somebody was reading it. It is possible that he felt a sense of responsibility and duty to complete these because he was part of a research trial. P22 enjoyed the process of answering the self-report questions and used them as a means of relaxing: '*The time it takes, like you know, it's not. Actually, it's actually relaxing'*. However, he explained that initially he had forgotten about this feature of the application. Following on from the mid-trial phone call interview, he was reminded and from then on used it. P28 stated that she found the questions somewhat repetitive. P25 knew the self-report section was there but felt she did not have enough time to answer the questions. She would either forget or she would get interrupted somehow: '*I'd do it and then, you see, I'd have to get up and do something else'*.

Both P26 and P28 highlighted a challenge with answering questions that asked about how you have felt in the previous month. P26 explained that she felt self-reporting about long-term past events may not be accurate as current mood will affect the manner in which one reflects: '*Some days, you just could be not in a happy space, so everything's negative anyway… then the next day, it's like oh, everything's wonderful. And then you're going, 'The last month, I'm not sure"*. If this were the case with a majority of users with an application such as this, it could have implications as to how to integrate this type o functionality, and whether the focus should shift to changes observed and experiences felt on a day-to-day basis rather than longer-term, such as over a month-long period.

Self-reporting supports self-reflection

A common theme across participants regarding self-reporting was that answering the questions caused people to reflect, which increased awareness of various aspects of wellbeing. P21, P22, P23, and P24 all found value in self-reporting. P23 explained how she felt her answers provided on the scales and questionnaires would be quite different having self-reported regularly and completed the trial to those given prior to commencement. P24 explained that he reviewed his stress scores and reflected on what had contributed to that particular score, for example, how his wife's condition or behaviour on a particular day could have affected how he self-reported on his level of stress at that time: '*I went back over the whole thing, yes, to see what way it was going… It could have been herself had a problem or something like that, you know. Because she has her good days and her bad days'* (P24). P27 did not find the process of self-reporting particularly beneficial in terms of awareness-raising or reflecting. However, she stated that would like to get feedback in some form to her answers. She felt that after spending such a long time answering the questions, some form of feedback should be given: '*I'd like feedback on them… I spent eight weeks doing it, so'*.

Mixed experiences interpreting and analysing graphs and data feedback

Participants were invited to share their views and opinions regarding their experiences with the data feedback within the application. Assessments varied with some finding more value and use than others. P21 found most value in the blood pressure information, saying *‘I used to love the blood pressure thing, you know. You'd always know where you kind of stood with it’*. P28 was still not clear on the meaning of the blood pressure readings by the end of the trial. She said, ‘*I'm not that clear on what the difference between the purple and the, you know, those two are’*. This information can be found in the tips section but P28 had not seen these. P26 did not have any issues with her blood pressure readings over the course of the trial, while P27 reflected on and analysed differences between days in her data, particularly regarding blood pressure.

P25 reviewed and reflected on her sleep data each day, saying ‘*And it's amazing. Unknown to yourself, there are different levels, you know, of sleep and that’*. This involved viewing her graph in the Sleep section and viewing her sleep patterns both in Day and Week view. She explained that she was not concerned with any of the readings she took and did not feel like she had to contact anyone about them: ‘*I didn't have to run to the doc anyway’*. P28 also viewed her sleep data each day and found it easy to understand. This data interested her quite a lot and had a positive effect on her overall. She said, ‘*That kind of fascinated me, I have to say… It was very informative, very good’*. She found it informative and useful, but did not know exactly why. When shown an example of her sleep data which showed six wake-ups, P28 confirmed this was normal for her. In terms of the dashboard, both P27 and P28 found this useful, utilizing it in order to get an overview of steps and sleep data before viewing each element in more detail using the overlay menu at the bottom of the screen. P27 was also familiar with the stress score on the Mind tile in the dashboard, and was able to connect this to her most recent self-reporting score.

Colour codes were used in certain sections of the interface, for example to convey activity levels and different meditation types. Some participants understood this and found the concepts clear and logical, while others failed to realise that the use of colour conveyed meaning. The colour code was clear and made sense to P22, who said ‘*Yes. Ah, well, green, you're actually not too bad, isn't it? Then you're not so good, so probably lying in bed all day’*. P23 and P24 felt the traffic light colour code to convey step count achievement was effective and the use of orange and red can act as a motivating agent: ‘*No, I think it’d make them wake up and do something’* (P24).

Educational tips were useful but need to be more informative

With regard to the educational content provided in the application, the participants reported varying experiences. There was some positive feedback, but a number of limitations and potential design issues were also revealed. P22 found the daily education tips useful, particularly in the areas of blood pressure and sleep. P24 looked at the tips each day but felt they were perhaps common knowledge and not necessarily new information: '*you kind of knew most of them*'. The blood pressure tips were helpful, but he felt it would have been more useful if all of the tips could be accessed in one section of the application. There was not a facility, however, to view these tips as a list. P26 could vaguely recall the tips content but did not find them important or particularly useful and as such did not engage with this element. She said, '*I think the odd time, I read them and yes, I wouldn't really have focused on them, shall we say'*. P27 did not seem particularly enthusiastic about the tips. She read them occasionally but also felt it was information she already knew. However, she explained that she found some of them useful, particularly around sleep and regular bedtimes. P28 engaged with some of the tips content but felt it was less relevant when she had been sleeping well. She agreed that she would be more likely to read them if her readings were poor (for example, if her blood pressure was high). She said, '*Just because it was going well, you see, I didn't dip into it all that much'.*

A couple of participants did not notice or remember the Tips content and as such didn't interact with them: '*Oh, I never went into* those' (P25). The same was true for P21 who said '*I forgot about them'.* The Tips feature was not the only part of the application that users spoke of not being aware of. For example, as discussed elsewhere, some participants noted not being aware of the Self-report and Guide parts of the application. This suggests that some sections were not made obvious and clear enough and/or additional training may have been beneficial.

9.8.3 Goal-setting and motivation

In relation to physical activity, the areas of motivation and goal-setting were discussed. Participants discussed factors that motivated them to act or change their physical activity behaviours.

The Withings watch acted as a motivating tool for some of the participants. The fact that it uses a sub-dial on the watch face to indicate the number of steps that have been achieved helped to remind some participants about their daily step goal and encouraged others to move around more in order to increase their step-count. P28 stated that she will miss wearing the Withings watch, explaining that she will no longer be able to know how many steps she has done: '*I've got used to that now… I won't know how many steps I've taken any more.'* The watch initially motivated P24 to achieve more steps each day, but this became less important over time as his daily activities resulted in more steps anyway. This was probably due to the timing of the trial, starting in winter and finishing at the beginning of spring. At the start of the trial, P24 made a point of going for very long walks to reach his desired step count. However, later on he needed to get outside for activities such as grass-cutting, which helped him meet his step count goal: '*Then it settled down because I was doing… Some of the normal things I was doing took up an awful lot of steps. Like cutting the grass there, for instance*'.

The sub-dial also acted as a motivating tool for P25 and would encourage her to do more if she felt she needed to. She said '*the little one that tells me how much I have walked… I'd look at it and say, "Well, I've done better today than I did yesterday" or "Oh my God, I'm bad today"'.* Viewing her data and reflecting on this with regard to progress towards her goal motivated P23 to keep active and do more than before. She was aware of her goal and exceeded it at times. While the sub-dial on the watch acted as a motivator for some participants to reach a step goal, for others, the colours used to display the activity data in the application played an important role in motivation. The use of the traffic light colour code acted as a motivating factor for P23 to get more exercise: '*you're saying to yourself, 'Well, you know, I need to get my skates on'.* P25 also explained that the traffic light colour code motif acts as positive tool to motivate a person to achieve more steps.

Personalised goals would be preferable

There was also the potential for goals to appear unattainable or too difficult to achieve which may have been counterproductive. Having a goal of 7000 steps per day did not motivate P21 and instead had the opposite effect of making her feel guilty that she was not doing enough. She said, '*I'd feel, you know, like I'd say I didn't do enough today now'.* Despite this, she enjoyed wearing the watch and tracking steps through the sub-dial. P25's activity levels were very low in general prior to the trial and thus she felt the target of 7000 was not attainable for her: '*I never got near it'*. However, it would appear that being aware of her step count and having a theoretical target helped motivate her to get more steps where possible. This highlights the importance of allowing users to set personalised goals that they feel are achievable, or perhaps the system setting a personalised goal based on the person's typical activity levels.

9.8.4 Experiences with the Mind UI

As discussed in previous chapters, the mindfulness element of the application presented an entirely different interface design to the sections displaying sensor-data feedback, owing to the fact that the content and functional requirements were considerably different to the other sections. Section 9.7 discussed experiences of engaging with the mindfulness intervention and practicing meditation in detail. This section focuses more on experiences in relation to the design of this section of the application.

The majority of participants were positive towards the interface design of the Mind section. The use of tiles was logical, participants felt the Planner was well laid out and most participants understood the difference in hierarchy or importance with regard to the formal vs informal meditation content.

Participants' experiences using the Guide button on the Planner screen were revealing and have implications for the design and implementation of this feature. P22, P23, P24, P25 and P28 did not see or notice the Guide button at all until it was pointed out to them during the interview and as a result did not learn about the recommended approach to each week's meditations. This would have prevented them from learning about when meditations should be practised, in what order, and how frequently. In terms of redesign, this would need to be made clear during initial training and perhaps redesigned to be more prominent. Despite not following the recommended course in terms of frequency and order of meditations, P23 practised the meditations at her own leisure, fitting them into her schedule: '*No, I would do them at different times… I wouldn't do that one and then that one'*. Although she missed out on a particularly important aspect, she did say she benefitted from this part of the application. However, it is likely that she could have gained considerably more had she known about the guide.

P25 agreed that the Guide button was not as prominent as it would need to be and she felt the placement of the button needs to be changed and brought into the centre, more in the line of sight: '*Make it more obvious, definitely*'. She also suggested using a different word to 'Guide'. It appears P26 did in fact use the Guide initially, but then she either forgot about it or did not feel it was relevant or important. She said, '*maybe I looked it up the first day of the week or something'*. P27 was familiar with the Guide and had used it, saying '*that told you sometimes some of them, you had to do twice'*.

Most participants (P25, P26, P27 and P28) understood the use of colour in the Planner: light green signified the formal meditations, and light orange signified the informal meditations. A legend signifying this was provided above the tiles. Neither P22 or P24 noticed the colour code use for the formal and informal meditations; they did not see the legend either. This would need to be taken into account with regard to redesigns and training protocols.

9.9 Interaction, Design and Areas for Improvement

Participants were asked to share their views and experiences regarding the design of the application and discussed their patterns of engagement. Most users had no major usability issues, finding the application easy to use and navigate. However, some issues were identified, which could signify areas for improvement in a future iteration. Some of these have been discussed in previous sub-sections (for example, making interface elements such as Tips and the Guide button on the interface more prominent). Additional considerations are discussed in this section. Some participants also proposed additional features they felt would be beneficial.

9.9.1 Routines and patterns of engagement

Most of the participants reported regular engagement with the application. Objective data on engagement will be presented in Chapter 10, Section 10.4. This section focuses on how participants reported developing a routine with regard to using the application.

Some participants noted the importance of developing a routine with using the app, both for themselves as well as for the care participant. However, others noted the difficulty in sometimes sticking to a routine, due to the nature of caring. A typical use case scenario for P22 involved using the application in the evening. His typical user flow would involve opening the Withings app and then taking a blood pressure reading which would also allow for syncing with the watch. From here, he would open the Mind Yourself app to check his steps and sleep data, complete his self-report and if he felt he had time and space, some meditation also: '*it'd be in the evenings, say about maybe half eight…my blood pressure would be the first thing I'd do…And what else? The steps, the mind, if I had time, I'd go into that… I'd do my self-assessment then*'.

P27 tried to stick with a routine in terms of when she used the application. This was centred around whenever she wanted to take a BP reading which was in the morning and then again in the evening. However, this was disrupted for a while as she had visitors for a time during the trial. She only engaged with the mindfulness content in the evenings. P21 also followed a routine each day with the same user flow, which involved viewing the previous night's sleep and then answering questions. She would then navigate straight to the previous day's activity data. Conversely, P28 did not have a fixed routine with regard to when engaged with the application, despite intending to do so. She said '*And I did think about that and I thought I must set up a system, but I never did'.*

P24 developed a routine after a while. He would take a blood pressure reading in the morning but then would self-report in the evening. This made sense to him as the questions referred to the last 24 hours. He said, '*And then I'd use it last thing at night for the questionnaire thing…over the last 24 hours, you know'.* P24 noted how daily routine is important for both carer and care recipient. His wife likes the sense of stability a routine can bring. Indeed, deviating from this can upset her so this sense of habit and routine is very important. This in turn gives P24 time for himself which he feels is particularly valuable: '*Because she seems to work in a routine, but if she goes out of her routine, it gets upsetting, you know, for her, do you know, so I keep her in a routine… I can work around that*'. P24 initially took two BP readings a day but then changed to just the one in the morning.

P25 tried to integrate her usage of the application into her daily routine. This would depend on her husband and whether or not he went back to sleep in the mornings. Time and convenience appeared to be the two main issues for her. She said '*some days, he might come down and I'd forget about it and it might be later in the afternoon by the time I get to it. I wasn't as regular as I should have been… Well, I was trying to do that thing in the morning and that'.* She would look at the dashboard each day and use it as an overview of all of her data. After viewing her data on the dashboard, P25 would typically take a blood pressure reading and would then go into the Mind section, select a meditation, start listening and would also read the text guide. She was open to trying out any of the meditations presented each week.

9.9.2 Using the Healthmate app versus using the Mind Yourself app

Withings devices require the user to open and use the Withings Healthmate application to synchronise their watch data and to take a blood pressure reading. The researcher's preference for engagement with the Healthmate app, outlined to participants at the start of the trial, was that they use the Healthmate app to collect their data, but view it in the Mind Yourself App, which has additional features designed specifically for their needs. However, in reality, when participants went into the Healthmate app, they could view their data there.

P23 appeared to be using both apps, but using the Healthmate app more so for a quick glance overview of her steps and sleep data. However, from her comments it appears she may also have viewed her steps and sleep data within the Mind Yourself app. She was using the tips and self-reporting regularly so would have to have spent time on these screens. A similar scenario was observed with P26, who used the Mind Yourself app primarily for the mindfulness content. She used the Healthmate app to view all of her sensor data. P26 found the sleep graph design in the Healthmate app easier to understand and analyse than the Mind Yourself app. This was due to a development issue whereby longer periods of certain sleep stages were not represented properly in the graph. Instead, each period was the same size, and the user needed to look at the timeline to assess how long a period was. She said, '*because I felt with this one* (Mind Yourself app) *that the bars just didn't work for me… I like them to indicate the amount of sleep you got, rather than… You know, this is just they're all the same'*.

The reliance on third party devices and applications is potentially a disadvantage in a trial like this, reducing the need to open the trial app. The most obvious added value of the Mind Yourself App is the integrated mindfulness course. However, the rest of the app was also designed specifically for older adults and based on requirements from the iterative design process. Particular attention was paid to designing data feedback, additional educational information, facility to self-report as well as considerations around elements such as colour and text legibility. The user can therefore potentially miss out on these features if they believe they are getting what they need from the Healthmate application. This reliance on third party devices and applications may have impacted on some participants' engagement with the Mind Yourself app, or parts of it. Ideally, the user could take a reading without having to open up a third party app. However, this is a restriction imposed by the third party provider and therefore there was no way to avoid this for this trial.

9.9.3 Suggested changes and new features

During the interviews a number of the participants provided their own suggestions as to how the application could be adapted or improved.

P22 felt being able to access the app on a smartphone rather than just an iPad would be beneficial for him in terms of accessibility and convenience, particularly in relation to the mindfulness content. He provided an interesting example wherein he drives his son to the supermarket and waits in the car while his son does the shopping. He noted that this would be a perfect opportunity for him to meditate as he would be on his own without any distractions. P22 appeared keen and eager to try this out, saying '*And I'd let him and the wife go in and do their shopping and I'll just sit back there… Instead of reading the paper, I can put on the app there'*.

The option to annotate data to provide context was mentioned as being a potentially useful feature by three participants. P24 noted that generally he would like to have the facility to comment as well as self-report. This would enable him to provide context alongside data feedback and provide insights and explanation as to why something had happened in the way it had. He said, '*If you had a little commentary section for everything… Say I only slept six hours or seven hours or I woke three or four times and there could be a reason for that, as I said. Somebody woke me up… And then the stress, you could just say what it was. Anything. The car broke down or something'*. For P24 this comment function would need to involve open-ended answers and not multiple choice, as the input would be too varied and broad. He felt this would be useful in each of the sections.

P26 also felt annotating would be useful, but for a slightly different reason. She felt there were times when the data collected by the Withings watch did not match how she felt she had slept. In these instances she felt it may be useful to have the opportunity to annotate or leave a comment to provide more context or to correct and adjust what was recorded. She said, '*But maybe it would be helpful just to have kind of what you actually think about that night's sleep,* *rather than… Like if you feel that you didn't have a good night's sleep, at what point is the app different to what you're thinking? It might indicate that you had like six hours sleep and a few hours broken, but maybe you actually felt that you didn't sleep at all'.* P27 said she would like to be able to add context to her activity data, and add additional activities not recognised by the watch. She had been doing a lot of work around the house, and this did not register as steps. However, she felt this work was legitimate and vigorous and as such it should register as physical activity: '*But I was actually doing physical work*'. As noted in earlier chapters, the ability to annotate data was considered as a feature of the application, but was deemed too complex in terms of the available timeline for development. However, future iterations of the app could integrate such functionality.

9.10 Perceptions of the Trial as a Whole

Participants were asked to discuss their general experiences of taking part in the trial, for example, what they enjoyed or didn't enjoy, or any suggestions they had to improve the overall experience. Participants were primarily positive in relation to their participation and the benefits they had experienced as a result. However, some participants spoke of how they felt they didn't have sufficient time to engage as they would have liked, primarily due to their caring responsibilities.

Participants mentioned a number of reasons why they were happy they had participated in the trial, including an increased focus on managing one's health, the benefits in terms of managing stress and wellbeing, which in turn could have a positive impact on caring: '*I think anybody who's a carer should be encouraged to do that in the early stages'* (P24). P24 said he felt carers can neglect their own health sometimes, and participating in a course of health and wellbeing self-management such as this could be very helpful. He found it easier than he had been expecting and felt it did not take up too much time or interfere with daily life. He said '*basically I'd recommend it to anybody*'.

Two participants discussed how they would appreciate the opportunity to do the trial again. P21 was positive about her experience but felt that if she were to take part again, she would have a better understanding of the technology and would engage with the feedback more. The timing of the trial was an issue for P21 as by Week 3 her mother had to be taken into a hospital and then by the end of trial she was placed in a home, with a return home not likely at any point. This resulted in three very different situations and resultant daily routines: living at home with care recipient, commuting to hospital every day with very little sleep, and living at home with care recipient now in a nursing home. She said '*But it was a bad time there for me, you know… It couldn't happen at a worse time now'.* Similarly, P26 enjoyed taking part in the trial but felt it was something she would have needed more when she was involved in full-time caring. She explained that she was previously caring on a 24-hour basis and under considerable stress and as such, mindfulness meditation could have been very helpful. Owing to the change in her circumstances during the trial, however, she became less engaged with the system as the trial went on, particularly nearing the end: '*The last few weeks, it just was like more difficult to do because I felt it probably wasn't as relevant as it had been'.* P25 was also positive in her summation of the trial, but she felt she would like to have another go at it and take a more determined, focussed or disciplined approach: '*It showed me a lot of things. I would actually like to do it again and be more thorough… And more disciplined… And more exact about what I'm doing'*. She believed one would need at least eight weeks to benefit from the course content.

While the majority of participants had no issues with the questionnaires, some were returned incomplete or with errors and one participant had difficulty with some of the questions. P23 pointed out that self-administering the questionnaire was challenging and quite burdensome. P23 said that she needed assistance with them to understand what was being asked, as some of the questions were difficult and confusing. She explained that she had to meet her sister for a coffee to help her with it. As mentioned above, the decision was taken to allow people to answer the questionnaires in their own time to reduce the burden on them during the visit, which also involved training on the system. In hindsight, having two sessions with the user at the start of the trial, one focused on data collection and one focused on training, may have been a better option to reduce potential issues and the potential for missing data.

9.11 Summary

This chapter presented the results of analysis of the semi-structured interviews carried out at T1 and T2. Themes which emerged from the data through inductive thematic analysis were discussed. Topics presented included care-related stress, impact of caring on sleep and physical activity, benefits and outcomes as a result of participation in the trial, experiences with the application and the devices used, as well as the participants' feedback on the trial. The following chapter presents the findings from the analysis of the quantitative data. The implications of all of the findings from the trial are then discussed in Chapter 11.

Chapter 10: QUANTITATIVE RESULTS

10.1 Introduction

This chapter details the quantitative findings from the trial and their analysis. Findings are presented in relation to (1) the questionnaires administered to participants at the various time points in the project, (2) engagement metrics concerning four aspects of the system (app log-ins, self-report, mindfulness content and wellbeing education tips and (3) the objective sensor data. For the purposes of conciseness, the following approach was taken when calculating probability values (*p*-values) and discussing statistical significance: if $p > .10$ - "not significant", if $p \leq .10$ - "marginally significant", if $p \leq .05$ - "significant", if $p \leq .01$ - "highly significant". Therefore, the smaller the *p*-value, the stronger the evidence that the null hypothesis (i.e. no relationship exists between the variables being studied and the results are random) should be rejected (McLeod, 2019). It should be noted that the findings in relation to the questionnaire data should be cautiously interpreted as they pertain to the secondary outcome measures and were derived from a small sample size.

10.2 Psychosocial Variables

This section outlines findings in relation to the psychosocial measures used in the trial, including stress, mindful awareness, quality of life and carer burden. The degree to which these findings are interlinked and supported by the qualitative findings are discussed in Chapter 11.

10.2.1. Cohen Perceived Stress Scale (PSS)

The Cohen PSS (Cohen, Kamarck and Mermelstein, 1983) assesses how unpredictable, uncontrollable, and overloaded respondents find their lives. Respondents are asked to consider the previous month and questions use a frequency scale (0-4) ranging from 'never' to 'very often'. There are 10 questions, which examine the frequency and severity of stressful situations in the respondent's life. Four of these questions are positively framed and thus are scored in a reverse manner to the others. A score of 0-4 is given for each answer leading to a global score range of 0-40, with higher scores indicating higher perceived stress. Scores ranging from 0-13 are considered low stress; scores ranging from 14-26 are considered moderate stress and scores ranging from 27-40 are considered high perceived stress.

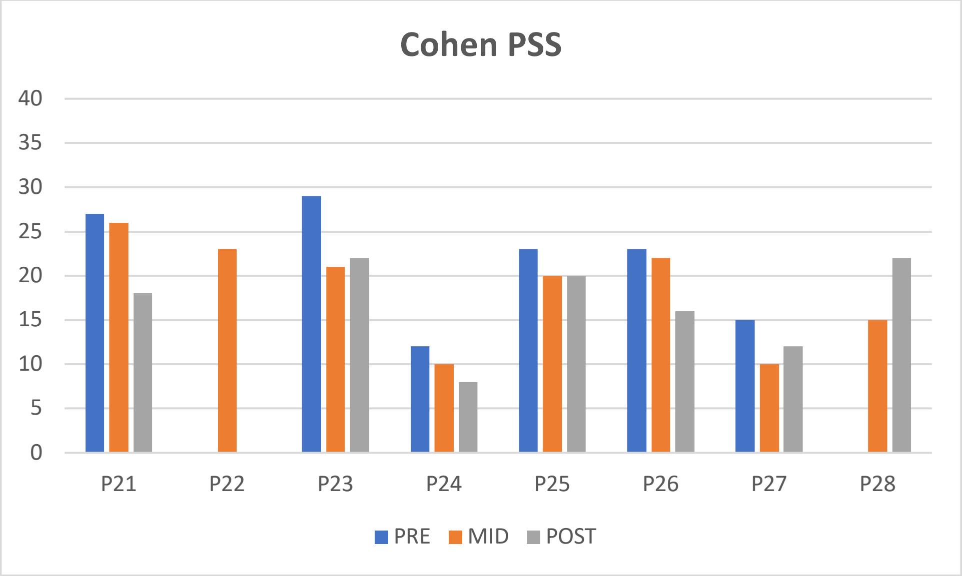


Figure 10.1 Cohen Perceived Stress Scales

Participant scores across the trial can be found in Figure 10.1. At baseline one participant was reporting low stress (P24), three were reporting moderate stress (P25, P26, P27), and two were reporting high stress (P21, P23). These were the only two instances of high perceived stress (27-40) being reported during the trial (P21 scored 27 while P23 scored 29). Scores falling in the range of moderate stress (14-26) were recorded fourteen times across all participants. Scores falling in the range of low stress (0-13) were recorded five times across all participants.

There was a reduction in perceived stress for six participants from T0 to T2 (P21, P23, P24, P25, P26, P27). The most marked reductions in stress were for P23, who dropped from 29 (high perceived stress) at T0 to a score of 21 at T2 (moderate stress) and P21 who moved from 27 (high perceived stress) at T0 to 17 (moderate stress) at T2. P27's score dropped from 15 (moderate stress) at T0 to 12 (low stress) at T2. The change was less marked for P25 and P26, with both participants showing a decrease within the category of moderate stress. P24 scored consistently in the range of low stress from T0 to T2. An increase in stress was observed for one participant (P28) from T1 to T2, with no questionnaire submitted at T0. It should be noted that during the exit interview, P28 commented that during the trial she had undergone eye surgery, and this may have contributed to her increase in perceived stress. Questionnaires were not submitted by P22 at T0 and T2, and a score of 23 was recorded at T1.

There was a mean score of 17 and a median score of 18.35 across all participants surveyed for the eight weeks, with a standard deviation of 5.68. At T0 analysis showed a mean of 23 (median = 20.4, SD = 6.12), T1 showed a mean of 18.37 (median = 20.5, SD = 5.63), and T3 showed a mean of 16.86 (median = 18, SD = 4.88). Given that sample sizes differed across time points due to missing or incomplete questionnaires, two-sample unequal variance t-tests (Welch's t-test) were run comparing the results pre-mid- and post-trial. *P*=.388 was calculated when comparing T0 and T1 indicating a lack of significance between the two means. When comparing both T1 and T2, however, *P*=.003 was calculated, which indicates a highly significant difference between the these two means (18.37 at T1 and 16.86 at T2). Similarly, a *P*=.01 was calculated when comparing T0 and T2, which again indicates a significant difference. An ANOVA single factor test run on all of the scores throughout the trial generated a *p*-value of 0.608 which suggest that there was not a statistically significant difference in scores among all participants across the three time points.

10.2.2 Mindful Attention Awareness Scale (MAAS)

The MAAS (Brown and Ryan, 2003) uses a 15-item scale to measure trait or dispositional mindfulness. It aims to assess the degree to which the respondent is aware of what is occurring in the present and to what extent the mind is in a receptive state with regard to paying attention to what is taking place. The instrument uses a frequency scale (1-6) ranging from 'almost always' to 'almost never'. Respondents are asked to consider their everyday experiences when answering the questions. To score the scale, a mean of the 15 items is computed, resulting in a total score ranging from one to six. Higher scores reflect higher levels of dispositional mindfulness.

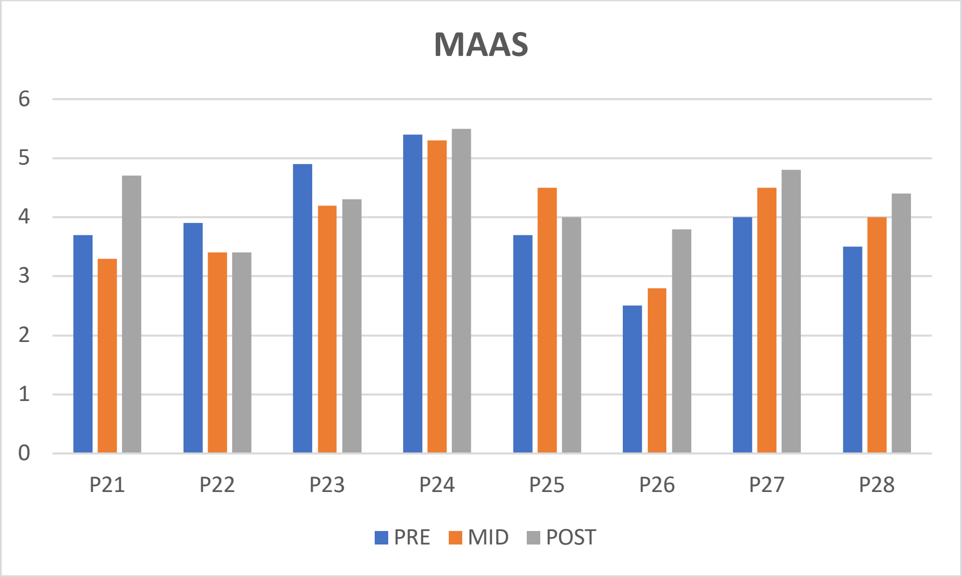


Figure 10.2 Mindful Attention Awareness Scale

At baseline the lowest score was 2.5 (P26), five participants scored between 3.5 and 4 (P21, P22, P25, P27, P28), and the remaining two participants (P23, P24) scored 4.9 and 5.4 respectively. An overall increase in dispositional mindfulness from T0 to T2 was observed in six participants. The most marked change was observed in P26, who scored 2.5 at T0 and 3.9 at T2. This score of 2.5 at T0 was the lowest observed among all participants at any time point. P24 showed the most consistent level of dispositional mindfulness and scored high throughout, with scores of 5.4, 5.3, and 5.5. The score of 5.5 at T2 was also the highest observed among all participants at any time point. Small decreases in dispositional mindfulness were observed in two participants. P22's score decreased from 3.9 at T0 to 3.2 at T1, and remained the same at T2. P23 recorded a score of 4.9 at T0 and finished the trial with a score of 4.3.

There was a mean score of 4.1 and a median score of 4 across all participants surveyed for the eight weeks, with a standard deviation of .78. At T0 analysis showed a mean of 3.95 (median = 3.8, SD = .83), T1 showed a mean of 4 (median = 4.1, SD = .76), and T3 showed a mean of 4.37 (median = 4.35, SD = .61). Questionnaires were administered to and submitted by all participants throughout the trial which allowed for paired t-tests to be run comparing the three different time points. Significant differences were not observed between any of the three time points, with *P*=.805 when comparing T0 and T1, .127 between T1 and T2, and .142 between T0 and T2. An ANOVA single factor test run on all of the scores throughout the trial generated *P*=.528 which suggests that there was not a statistically significant difference in scores among all participants across the three time points.

10.2.3 Casp19 Quality of Life

The CASP-19 scale (Hyde *et al.*, 2003) measures quality of life (QoL) in older age across a number of different dimensions including Control, Autonomy, Self-realisation and Pleasure. Scores are measured on a 0–57 scale, with 0 representing a complete absence of quality of life, and 57 representing total satisfaction. Therefore, a higher score indicates higher quality of life and corresponds to greater wellbeing (Howel, 2012). A study by TILDA (The Irish Longitudinal Study on Ageing) found that the Irish older population as a whole experience a high quality of life. The mean in their study was 42.7 (Barrett *et al.*, 2011).

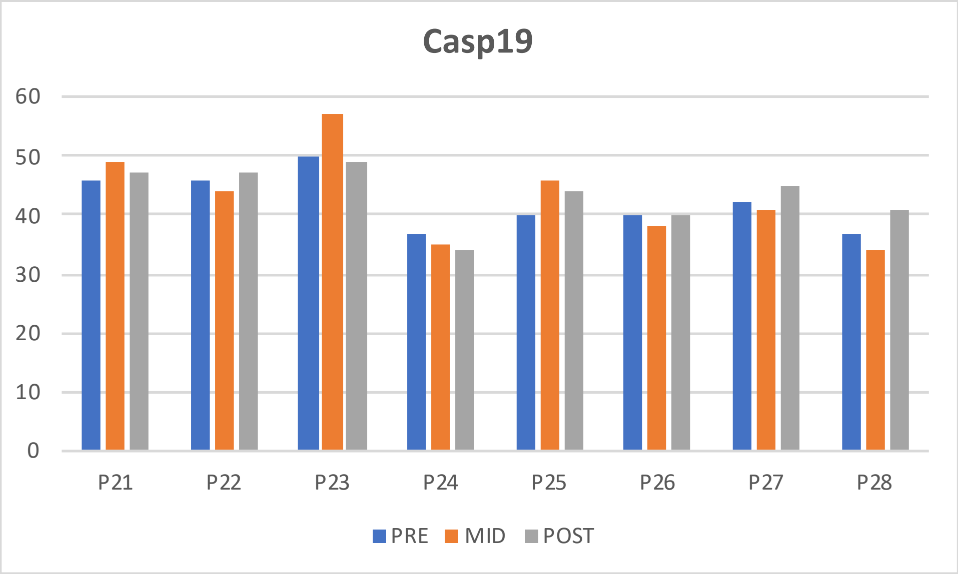


Figure 10.3 Casp-19

There was a mean score of 42.88 and a median score of 43 across all participants surveyed for the eight weeks, with a standard deviation of 5.56. At T0 analysis showed a mean of 42.25 (median = 41, SD = 4.38), T1 showed a mean of 43 (median = 42.5, SD = 7.21), and T3 showed a mean of 43.38 (median = 44.5, SD = 4.55). Questionnaires were administered to and submitted by all participants throughout the trial which again allowed for paired t-tests to be run comparing the three different time points. Similar to the MAAS, significant differences were not observed between any of the three time points, with *P*=.612 when comparing T0 and T1, .825 between T1 and T2, and .239 between T0 and T2. An ANOVA single factor test run on all of the scores throughout the trial generated a *p*-value of .93 which suggests that there was not a statistically significant difference in scores among all participants across the three time points.

At baseline four participants scored below 40 (70% of total score), with the remaining four scoring between 40 and 50 (70-88% of total score). There was a slight increase in reported QoL from T0 to T2 for five participants (P21, P22, P25, P27, and P28). A slight decrease in QoL from T0 to T2 was observed in two participants (P23, P24). P26's QoL score was the same at T0 as T2 (40), with a slight decrease at T1 (38). The biggest increase in QoL was observed in P25 and P28, whose scores rose by four points.

The lowest score at T2 was recorded by P2, who scored 34. His score decreased throughout the trial, going from 37 at T0 to 35 at T1. The lowest score observed throughout the whole trial was 34, which was recorded by P24 at T2, and P28 at T1. Two participants recorded their highest score at T1 (P23 with 57, and P25 with 46). There was very little variation observed in P22, P21, P26, P27 with scores remaining within a 2 or 3 point range throughout the trial. One score that stands out as unexpected and perhaps unlikely is P23's score at, T0 score (50). As discussed in Chapter 9, P23 was under a considerable amount of stress prior to the trial and had described how she had found it very difficult to cope. P23 also mentioned that she had difficulty with understanding some of the questionnaires and asked her sister to help her fill them in. As such, she may not have been honest in her answers.

10.2.4 The Zarit Caregiver Burden Interview Short Form (ZBI-12)

The Zarit Burden Interview (ZBI) is the most commonly used tool for assessing burden experienced by carers of persons with dementia (Hébert, Bravo and Préville, 2000), as well as being the most extensively evaluated in the literature (Whalen and Buchholz, 2009); (Stagg and Larner, 2015). The scale originated as a 29-item questionnaire (Zarit, Reever and Bach-Peterson, 1980). The revised standard version uses 22 questions (Gratão *et al.*, 2019) and respondents are asked to consider the impact caring has on their lives. For this PhD study, the short form ZBI-12 was used (Bédard *et al.*, 2001). This version uses 12 questions and was developed to be more accessible and less burdensome to administer. The scale uses a frequency scale ranging from 'never' to 'nearly always'. Respondents are asked to consider how often they identify with and experience what is described. The scale is scored by summing the scores of the 12 items, with a score of greater than 20 indicating ‘high’ burden, a score of between 10 and 20 indicating ‘mild to moderate’ burden and a score of 0-10 indicating ‘no to mild’ burden.

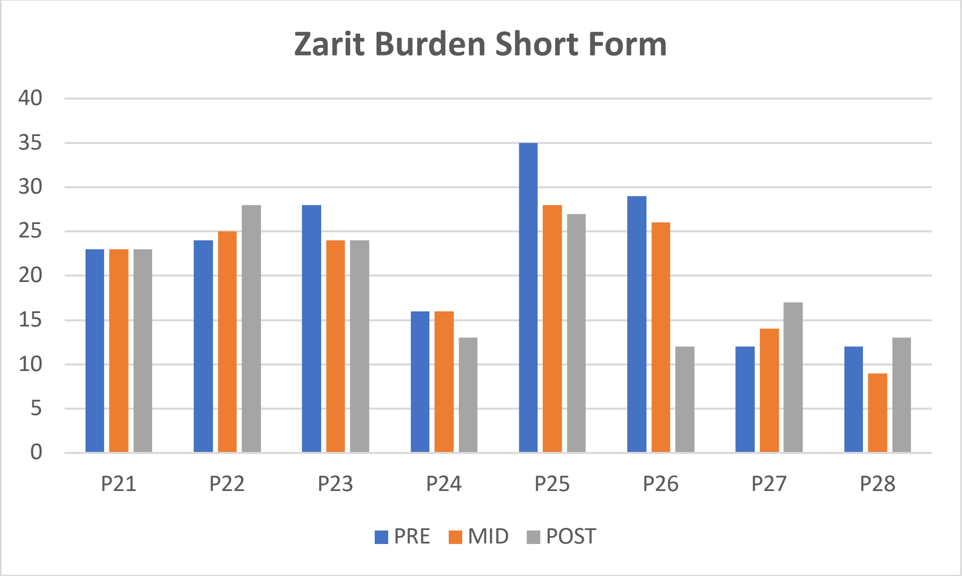


Figure 10.4 Zarit Burden Short Form

There was a mean score of 20.88 and a median score of 23 across all participants surveyed for the eight weeks, with a standard deviation of 6.93. At T0 analysis showed a mean of 22.38 (median = 23.5, SD = 7.86), T1 showed a mean of 20.63 (median = 23.5, SD = 6.23), and T3 showed a mean of 19.63 (median = 20, SD = 6.2). Questionnaires were administered to and submitted by all participants throughout the trial allowing for paired t-tests to be run comparing the three different time points. Once again significant differences were not observed between any of the three time points, with *P*=.144 when comparing T0 and T1, .638 between T1 and T2, and .314 between T0 and T2. An ANOVA single factor test run on all of the scores throughout the trial generated a *p*-value of .751 which suggests that there was not a statistically significant difference in scores among all participants across the three time points. Throughout the trial mean burden remained at or around 20 (moderate to high), which highlights the issue of burden among this cohort.

High burden as scored by the ZB-12 (>20) was reported by five participants prior to the trial commencing (P21, P22, P23, P25, P26). Of these participants, only P26 scored in the lower category of ‘mild to moderate burden’ (10-20) at T2. The remaining four participants remained in the category of ‘high burden’ (>20) at T2, with two reporting a slight decrease overall from T0 (P23, P25).

There was an overall decrease in reported burden from T0 to T2 for four participants (P23, P24, P25, P26). The most significant decrease was observed in P26 whose score at T0 of 29 decreased down to 12 at T2. An improvement was also evident in P25 with her initial higher score of 39 at T0 falling to 27 at T2. Burden increased for three participants over the course of the trial (P22, P27, P28) while no change was observed throughout for P21 with her score remaining at 23. At T2, four participants (P24, P26, P27, P28) scored in the category of ‘mild to moderate burden’ (10-20). A score in the lowest category of ‘no to mild burden’ was only reported on one occasion throughout the whole trial across all participants. P28 scored 9 at T1; this then increased to 13 at T2.

10.3 Physiological Variables

This section outlines findings in relation to the physiological measures used in the trial, including physical activity levels and sleep quality.

10.3.1 The Rapid Assessment of Physical Activity (RAPA) Among Older Adults.

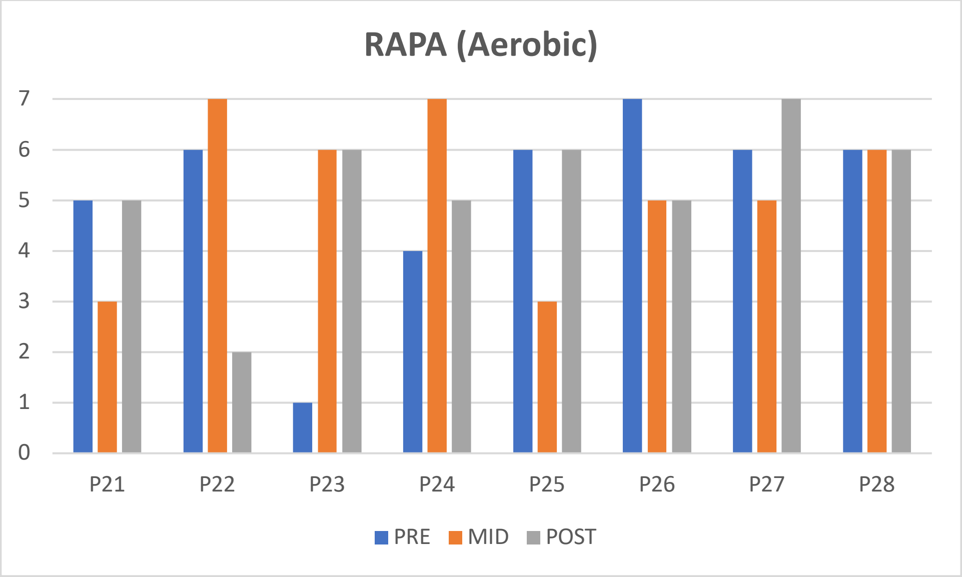


Figure 10.5 The Rapid Assessment of Physical Activity

The RAPA scale (Topolski *et al.* 2006) provides a quick assessment of physical activity in aerobic ability and condition in older adults. With regard to aerobic activity, a score of less than six is seen as suboptimal. Seven questions are provided for the aerobic assessment with each requiring an affirmative or negative response. If the respondent does not provide an affirmative response to the final two questions, they are scored as under-active. Within the category of under-active there are further sub-categories (light and regular). The lowest category scores the respondent as sedentary.

There was a mean score of 5.2 and a median score of 6 across all participants surveyed for the eight weeks, with a standard deviation of 1.55. At T0 analysis showed a mean of 5.13 (median = 6, SD = 1.76), T1 showed a mean of 5.25 (median = 5.5, SD = 1.48), and T3 showed a mean of 5.25 (median = 5.5, SD = 1.39). Questionnaires were administered to and submitted by all participants throughout the trial which allowed for paired t-tests to be run comparing the three different time points. Significant differences were not observed between any of the three time points, with *P*=.901 when comparing T0 and T1, 1 between T1 and T2, and .896 between T0 and T2. An ANOVA single factor test run on all of the scores throughout the trial generated a *p*-value of .985 which shows there was not a statistically significant difference in scores among all participants across the three time points.

At baseline five participants scored as ‘active’ (6-7), two scored as ‘under-active regular’ (4-5), and one scored as ‘sedentary’ (1). There was an increase from T0 to T2 for two participants (P23 and P27). P23 showed a marked change, initially scoring very low (sedentary) prior to the trial, followed by 6 (active) at both T1, and T2. P27 meanwhile had an initial score of 6 and post-trial scored 7. Across all phases of the trial, a sub-optimal score (below 6) was recorded 11 times. Four of these scores were recorded at T2. The highest score of 7, meanwhile, was reached four times, with only one of these coming at T2.

Of the eight participants, only P21 scored below 6 at each time stamp. There was a an overall decrease from T0 to T2 for two participants (P22 and P26), with P22 showing a noticeable decline from active at T0 (6) and T1 (7) to under-active at T2 (2). P24 also demonstrated an increase from T0 (4) to T1 (7) followed then by a decrease at T2 (5). On the other hand, initial decreases followed by an increase at T2 can be observed in the scores achieved by three participants (P21, P25, P27). Both P25 and P27 finished the trial with scores at or above 6 (active). Only one participant scored consistently from T0 to T2, with P28 scoring at 6 (active) throughout.

10.3.2 Pittsburgh Sleep Quality Index (PSQI).

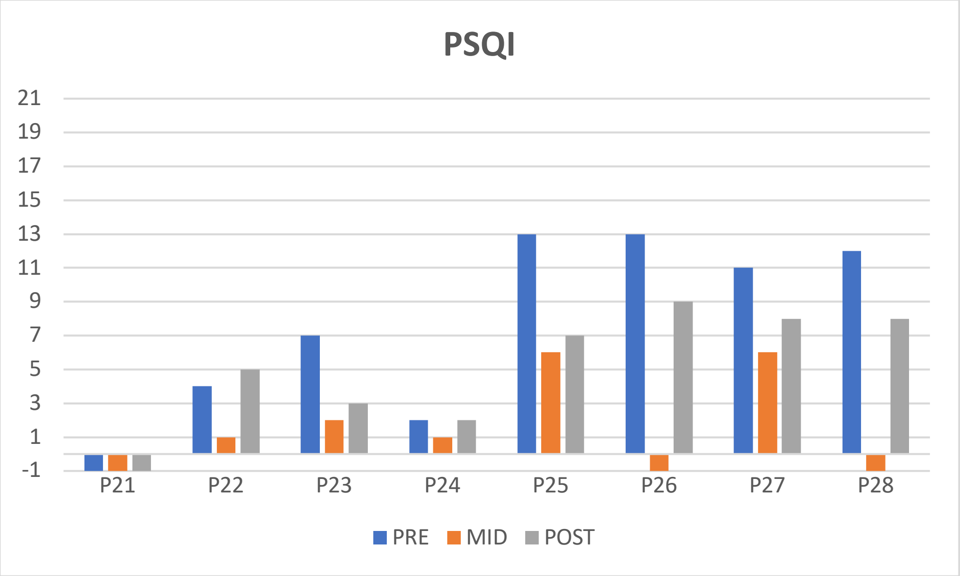


Figure 10.6 Perceived Sleep Quality Index

The PSQI (Buysse *et al.* 1989) assesses sleep quality in the last month and covers the following areas: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, daytime dysfunction. Each question is scored on a range of 0-3, with 0 indicating ‘no difficulty’ and 3 indicating ‘severe difficulty’. A global score is reached (0-21) with higher scores indicating poorer sleep quality. The PSQI contains 24 questions. The first nineteen of these are self-rated with the remaining five being answered by a bed partner. These five questions were omitted owing to the profile of the partners in question and their capacity to answer such questions.

There was a mean score of 6.31 and median score of 6 across all participants surveyed for the eight weeks, with a standard deviation of 3.89. At T0 analysis showed a mean of 8.86 (median = 11, SD = 4.19), T1 showed a mean of 3.2 (median = 2, SD = 2.32), and T3 showed a mean of 6 (median = 7, SD = 2.5). Similar to the Cohen PSS, sample sizes differed across time points due to missing or incomplete questionnaires, two-sample unequal variance t-tests (Welch’s t-test) were run comparing the results pre-mid- and post-trial. *P*=.868 was calculated when comparing T0 and T1 indicating a lack of significance between the two means. *P*=.156 was calculated when comparing T1 and T2, which again indicates a lack of significance. When comparing T0 and T2, however, a *P*=.025 was calculated, which indicates a significant difference between the these two means (8.86 at T0 and 6 at T2). An ANOVA single factor test run on all of the scores throughout the trial generated a *p*-value .041 which suggest that there was a statistically significant difference in scores among all participants across the three time points, with an overall decline in scores among participants from T0 to T2.

An incomplete questionnaire was submitted each time by P21. Both P26 and P28 submitted incomplete questionnaires at T1. In each of these cases, the omission was due to the open-ended element of the questionnaire, which at times required inputting a response as opposed to selecting a multiple-choice answer. These incomplete submissions are indicated on the graph with a -1 score. Baseline scores between 11 and 13 were recorded by four participants (P25, P26, P27, P28). The lowest score at this point was 2, recorded by P24. P22 and P23 scored 4 and 7 at baseline respectively.

An improvement in sleep quality from T0 to T2 was recorded for five participants (P23, P25, P26, P267, and P28). The most marked improvement was observed in P25, whose initial score of 13 at T0 dropped to 7 at T2. A decline in sleep quality was only recorded in one participant (P22), whose initial score of 4 dropped to 1, and then increased to 5 at T2. It should be noted that these scores are low, and still indicate an overall level of good sleep quality. The lowest scores, and therefore the best with regard to overall sleep quality, were recorded by P24, who answered below 3 throughout. The highest score recorded at T0 was 13 (P25 and P26) while the lowest was 2 (P24). The highest score recorded at T2, meanwhile, was 9 (P26), with the lowest again coming from P24 (2).

10.4 Usability

The System Usability Scale (SUS) (Brooke, 1996) is considered a reliable tool for assessing the overall usability and ease of use of a product. It uses a 10-item questionnaire with respondents answering questions based on a 5-option Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’. A score of 68 and over is seen as above average. Given that these scores are not precise percentages, however, it might instead be more appropriate to assign scores to a percentile ranking. In that case, a score of 68 (average) is placed at the 50th percentile. Distribution of scores in this manner is equivalent to grading on a curve. The graph shown in Figure 10.7 (Sauro, 2011) illustrates how scores can be assigned to a percentile ranking with an accompanying grade. The SUS score of 68, for example, would achieve a grade C and the descriptive adjective of ‘okay’ (see Figure 10.8 by UIUX Trend, 2017[15]). Sauro (2011) also suggests that the SUS can be used for more than just an overall indication of ease-of-use. Specifically, it can be used a global measure of system satisfaction.

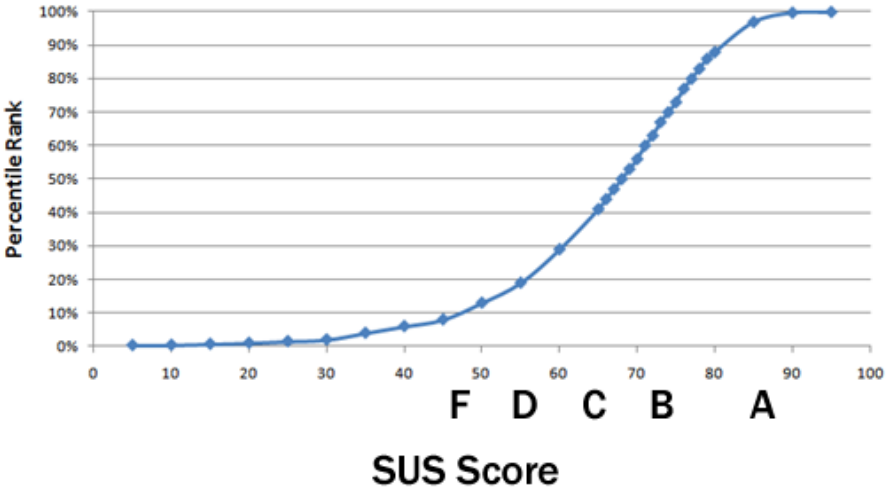
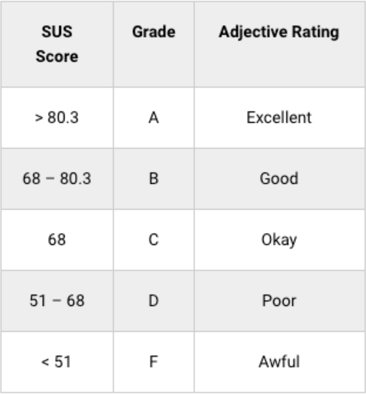


Figure 10.7: Percentile ranks associate with SUS scores and letter grades (Sauro 2011)



SUS Score	Grade	Adjective Rating
> 80.3	A	Excellent
68 – 80.3	B	Good
68	C	Okay
51 – 68	D	Poor
< 51	F	Awful

Figure 10.8: General guideline on the interpretation of SUS score (UIUX Trend 2017)

As can be seen Figure 10.9, five of the eight participants scored above 68 (P23, P24, P26, P27, P28). These participants all rated the system as ‘excellent’ or grade A with SUS scores above

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[15] https://uiuxtrend.com/measuring-system-usability-scale-sus/

80.3. The highest score was attributed to P24 (97.5). The lowest score, meanwhile, was by P25 (47.5), which rates the system as 'awful' or grade F. The rating of 'poor' or grade D was provided by P21 with an SUS score of 62.5. One participant (P22) did not submit a questionnaire. There was a mean score of 80.71 and median score of 90 across all participants surveyed at post-trial, with a standard deviation of 17.25.

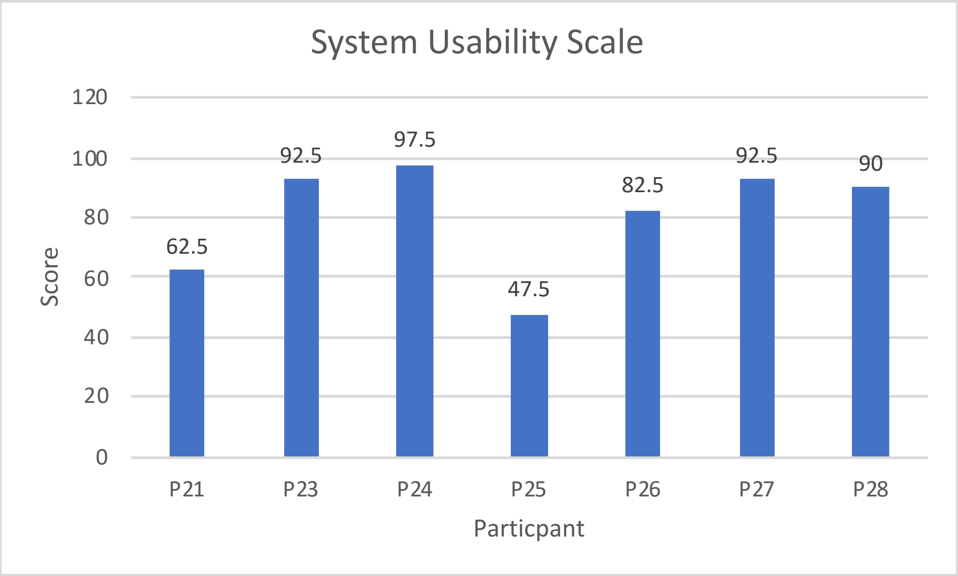

Figure 10.9 System Usability Scale

10.5 System Engagement Data

System engagement data was captured indicating degrees of interaction with various elements of the application: app log-ins, self-reporting, mindfulness content, and educational tips. These data are presented below while a discussion on the role engagement and adherence play in digital mindfulness-based interventions is provided in Chapter 11.

10.5.1 Daily app log-ins

Figure 10.10 shows the number of days each participant logged in or opened the app throughout the eight weeks of the trial. The mean number of days participants logged in throughout the trial was 51.75 and the median was 53, with a standard deviation of 4. P26 used the app the most, recording only one day without a log-in (98% of total), followed by P27 who logged in on 56 of the 58 trial days (97%). The app was used on 53 (91% of total) of the 58 trial days by three participants (P21, P23, P28). P24 opened the app on 50 days (86%) and P25 on 48 days

(83%) throughout the trial. The lowest number of days logged in was recorded by P22, with 44 days (76%).

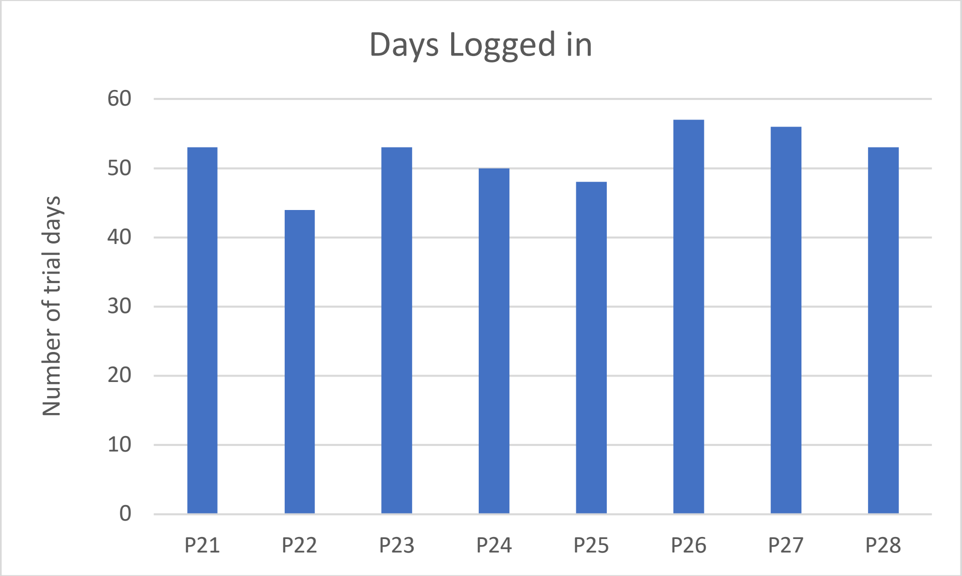

Figure 10.10: App log-ins

10.5.2 Engagement with mindfulness content

Figure 10.11 shows the number of times mindfulness content was accessed in a given week for each participant. Specifically, this refers to the number of times a modal window in the Mind section of the application was opened. These modal windows displayed a particular meditation's text as well as the audio controls to play the accompanying guided mediation. As discussed previously in Chapter 6, the prescribed or recommended content varied from week to week. Following what was laid out in the guide for week 3, for example, would result in the user engaging with the content approximately 25 times (Mindful Movement followed by Breath and Body six out of seven days, Breathing Space twice a day, Habit Releaser at least once). What was contained in the Guide was a recommendation, however, and participants were free to engage with the content at their discretion. However, in order to fully experience what is involved in an MBSR intervention, it is likely that such levels of engagement would be considered necessary.

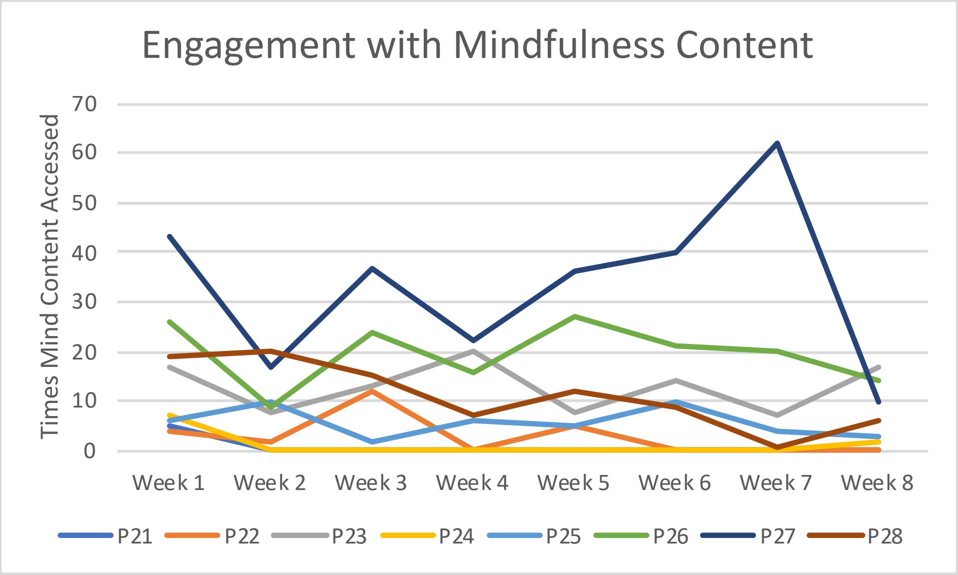

Figure 10.11: Engagement with mindfulness content.

The vertical axis represents the number of times the mindfulness meditation content was accessed in a given week with the horizontal axis indicating weeks 1 to 8 of the trial.

Across all participants over the eight weeks the mean number of engagements per week with the mindfulness content was 14.89 and the median was 12, with a standard deviation of 12.35. As can be seen in Figure 10.11, levels of engagement varied considerably across the eight participants. Among most of the participants there was a decrease in engagement in Week 2 but this was followed by an increase in week 3 for four of the participants (P27, P26, P22, P23). The highest level of engagement with the mindfulness content was observed in P27, followed by P26. P21, P22 and P24 showed very low levels of engagement throughout the whole trial. P21 accessed the content five times in week 1 and did not engage at all with this element of the application for the rest of the trial. P22's level of interaction, while also low, was more mixed, with engagement observed in weeks 1, 2, 3, and 5. P24 accessed this content in weeks 1 and 8 only.

10.5.3 Engagement with education content

Figure 10.12 shows the number of times the health and wellbeing education and advice content was accessed in a given week. Specifically, this refers to the number of times a 'tips' modal window in the Steps, Sleep, and Blood Pressure sections of the application was opened. These tips were randomized such that if the user were to exit the tip on the screen in question, returning later to that same screen would result in a different tip being displayed. This design was implemented so as to avoid repetition. It was also considered necessary as users are likely to view sensor data more than once in a given day. Taking this into account, viewing data relating to each metric (sleep, steps, blood pressure), and reading a tip from each section at least once a day would result in three engagements per day (or approximately 20 a week).

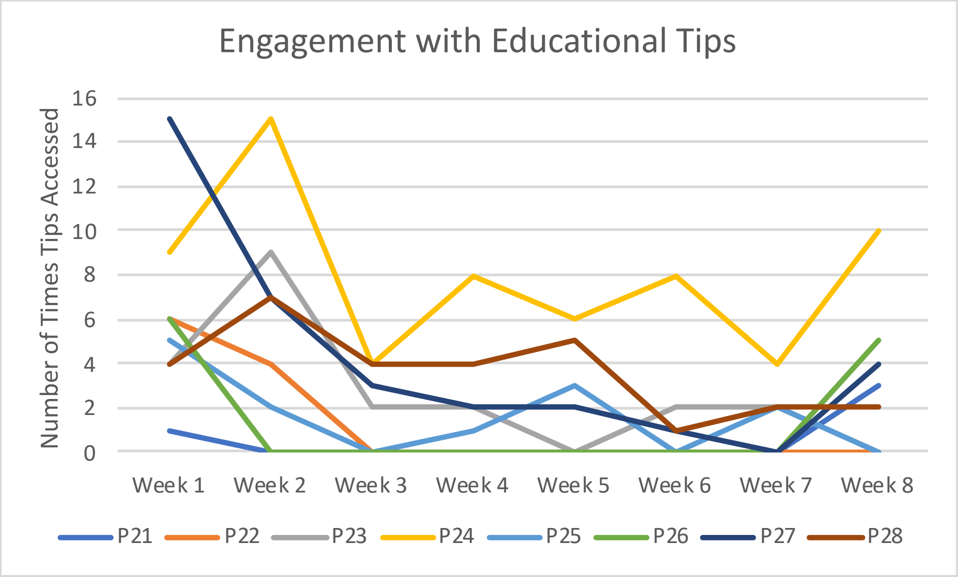

Figure 10.12 Engagement with education content.

The vertical axis represent the number of times the educational tips content was accessed in a given week with the horizontal axis indicating weeks 1 to 8 of the trial. Tips provided each day offered educational advice and information regarding sleep, physical activity and blood pressure.

Across all participants over the eight weeks the mean number of engagements per week with the educational tips was 4.65 and the median was 4, with a standard deviation of 3.37. As can be seen in the graph, there was a decrease in engagement levels across all participants as the trial progressed. However, there were also considerable variations in engagement levels among the participants. The highest level of interaction throughout the trial was observed in P24. Both P24 and 27 recorded the highest number in a given week, accessing the content 15 times in week 1 (P27), and week 2 (P24). P27's level of engagement dropped significantly after week 1 to an average of two interactions per week. The decrease observed in P24, meanwhile, was much less significant, resulting in an overall average of 8 interactions per week.

The lowest level of engagement with the wellbeing education content was observed in P21, who did not use this content at all throughout the trial, save for one recorded instance in week 1 (which was likely during the set-up and demonstration process during deployment). It should be noted that during the exit interview, P21 commented that subsequent to the demonstration during the set-up process, she simply forgot entirely about this element of the application. Similar patterns of engagement were observed in both P22 and P26. Having engaged with the content somewhat at the start of the trial (6 interactions in week 1 for both participants), there was no interaction recorded for the rest of the trial, with the exception of P26 accessing the content 6 times in week 8. The remaining three participants (P23, P25, P28) demonstrated relatively similar levels of engagement throughout the trial. Both P23 and P28 showed an increase in engagement in week 2 which was then followed by a steady decrease, with both participants finishing the trial on 2 interactions for weeks 7 and 8. The trend was slightly different for P25, whose pattern of interaction fluctuated throughout, with her average per week coming to 1.6 interactions.

10.6 Objective Sensor Data (Withings Steel)

Objective sensor data was collected via the Withings Steel wrist-worn watch and is presented below in Figures 10.13 – 10.16. For the purposes of conciseness a summary evaluation is used whereby averages per week are shown alongside the number of times a goal was achieved in a given week.

10.6.1 Steps

The mean daily step count across participants was 5771 and the median was 6031, with a standard deviation of 1954. There was an overall increase in the average number of steps per week from weeks 1-4 to weeks 5-8 for four participants (P22, P23, P26, and P28). The highest average steps per day recorded was for P26 in week 5, who registered 9576 steps. The lowest average steps per day recorded was for P25 in week 2, who registered 2436 steps.

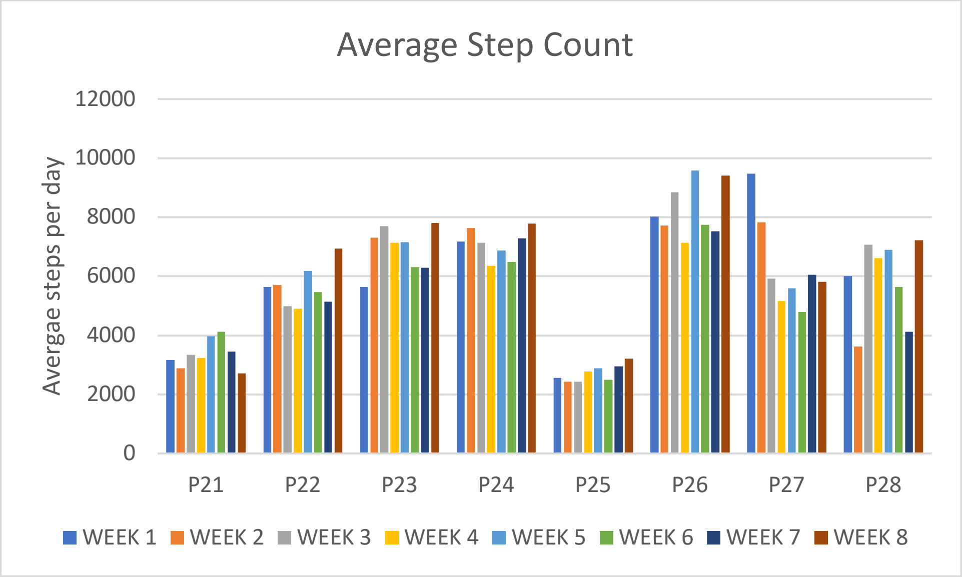

Figure 10.13: Withings Steel data – average daily step count per week

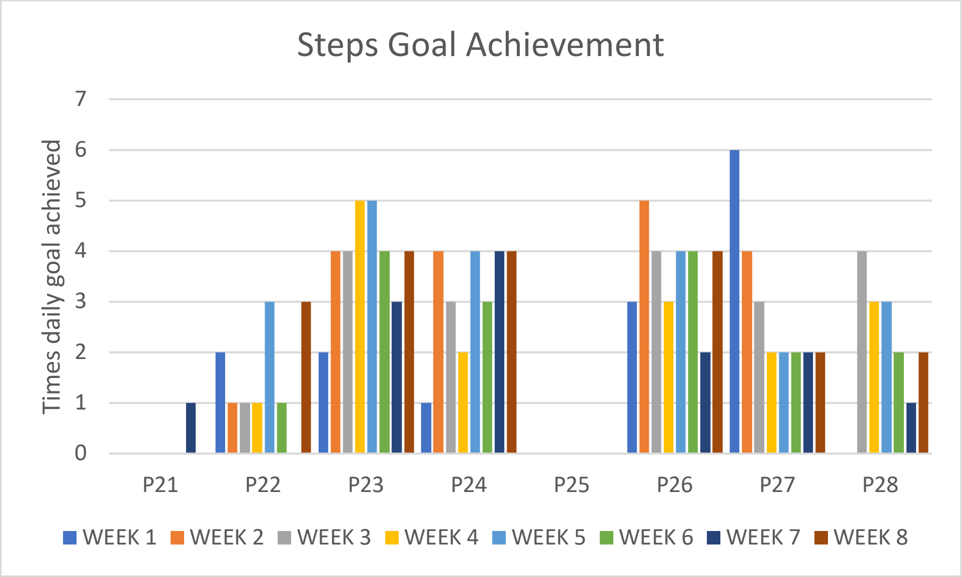

Figure 10.14: Withings Steel data - number of times daily goal of 7000 steps achieved per week

The mean number of goal achievements per week across all participants was 2.13 and the median was 2, with a standard deviation of 1.7. The goal of 7000 steps per day was reached on 135 occasions across all participants throughout the eight weeks. The average number of steps per week exceeded the goal of 7000 steps per day on 20 different occasions across all participants. This goal of 7000 steps per day was based on work carried out by Tudor-Locke *et al.* (2011), as discussed in Chapter 2.

P25 did not achieve the target of 7000 steps per day at any time throughout the trial. P23 achieved the target the most times, with 31 recorded instances throughout the trial. The biggest variation in average steps between weeks was observed in P27 with the highest average steps per day of 9481 steps in week 1 and the lowest average of 4801 steps in week 7. The smallest variation in average steps between weeks was observed in P25 with the lowest average steps per day of 2436 steps in week 2 and the highest average of 3200 steps in week 8.

10.6.2 Sleep

Both the mean and median hours sleep across all participants were 7.5 hours, with a standard deviation of .97. The average sleep duration per night was relatively consistent week to week for P23, P24, and P27 (average per week stayed within a one hour range). The biggest variation in average sleep duration between weeks was observed in P26 with the lowest average of 7.33 hours in week 2 and the highest average of 9.46 hours in week 6. The lowest average sleep per day recorded was for P22 in week 6, who registered 5.25 hours. The highest average sleep per day recorded was for P26 in week 6, who registered 9.46 hours. There were improvements overall in average sleep duration per week observed in P28. The poorest results in terms of average sleep duration were recorded by P22.

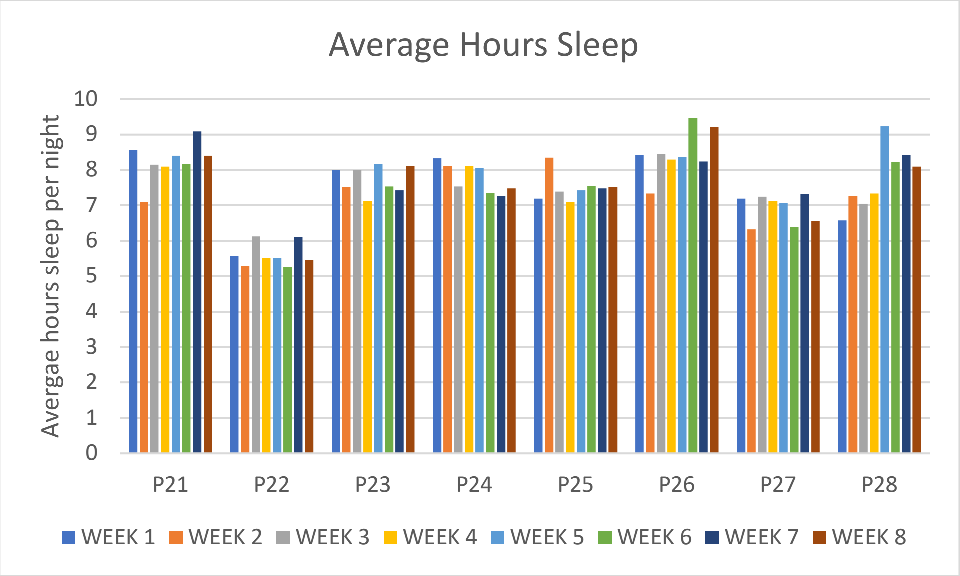

Figure 10.15: Withings Steel data – average nightly sleep per week

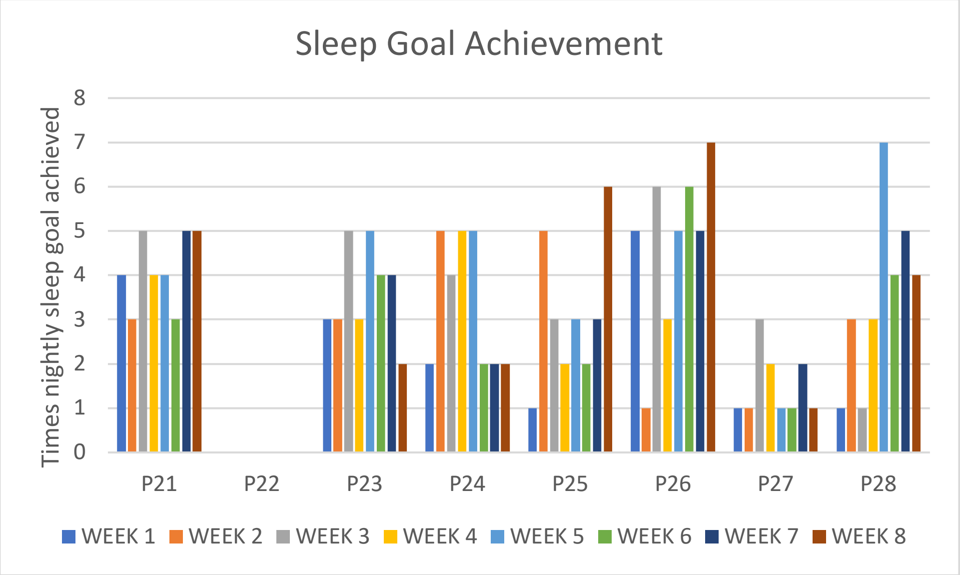

Figure 10.16: Withings Steel data - number of times nightly goals of eight hours sleep achieved per week

Both the mean and median number of times the sleep goal was achieved per week across all participants were 3, with a standard deviation of 1.92. The goal of 8 hours sleep per night was reached on 192 occasions across all participants throughout the eight weeks. The goal of eight hours per night was reached the most times throughout trial by P26 (38), followed by P21 (33). This goal was reached the fewest times throughout the eight weeks by P22 (1). There was an increase in the number of times the goal of 8 hours per week was reached from weeks 1-4 to week 5-8 for five participants (P21 ,P23, P25, P26, and P28).

10.7 Objective Sensor Data (Withings Blood Pressure Cuff)

Objective sensor data was collected via the Withings blood pressure cuff and is presented below in Table 10.1. For the purposes of conciseness a summary evaluation is used whereby averages readings are shown in a given week.

Table 10.1: Withings Blood Pressure Cuff Data

Key: values indicate average systolic over diastolic reading per week. ‘

ID	WEEK 1	WEEK 2	WEEK 3	WEEK 4	WEEK 5	WEEK 6	WEEK 7	WEEK 8
P21	153/99	138/78	138/80	138/82	133/74	144/79	140/72	124/73
P22	153/79	170/80	157/79	173/84	169/81	158/81		
P23	194/111	220/81						
P24	175/91	159/81	145/77	138/75	122/68	137/76	126/71	132/72
P25	164/73	140/73	139/69	131/66	135/69	139/69	136/67	133/68
P26	115/73	117/72	116/75	113/73	122/79	122/75	119/76	112/71
P27	165/96	156/95	155/96	149/91	156/91	155/92	153/92	149/89
P28	138/86	128/80	130/79	118/73	127/79	116/74	131/84	116/68

Blood Pressure Data

At baseline six participants recorded high blood pressure readings above 140/90mmHg (P21, P22, P23, P24, P25, P27). P28’s reading at this point was just below this at 138/86mmHg. The lowest baseline reading was recorded by P26 (115/73mmHg). Six participants took readings each week during the trial. There was an overall decrease in readings from weeks one to eight for four participants (P21, P24, P25, P27). The biggest decrease between average readings taken in the first week of the trial and the last was observed in P24 (175/91 in week one, 132/72 in week eight). This represents a shift from high blood pressure to pre-high (Blood Pressure UK, 2008). Readings remained relatively consistent throughout the trial for two participants (P26, P27), with the largest variations recorded being 165/96 in week one and 149/89 in week eight for P27, and 122/79 in week five and 112/71 in week eight for P26. This lower reading by P26 was also the lowest average reading recorded in a week across all participants throughout the trial.

A reading of 140/90mmHg or higher (or 150/90mmHg or higher if over the age of 80) is seen as high blood pressure (NHS 2019, Irish Heart Foundation 2020). Average readings in a week above this were recorded on 22 occasions. P25’s average readings in week one were high (164/73) but then dropped below 140/90 for the remainder of the trial. Both P26 and P28’s readings were below 140/90 throughout the trial. High blood pressure readings were recorded consistently throughout the eight weeks by P22, P23, and P27.

Readings were not taken for weeks seven and eight by P22, and for weeks three to eight by P23. High readings were observed in weeks one and two for P23. Her average reading in week two (220/81) was the highest recorded across all participants throughout the trial. It should be noted that at this point P23 contacted her GP. She was then put on BP medication and purchased her own BP cuff. She then proceeded to take readings with this new cuff as she found it difficult to take consistent readings with the Withings cuff.

10.8 Self-report Data

Participants were provided with the facility to self-report daily and answered questions relating to satisfaction regarding recent activity and sleep, as well as their level of stress. Two questions for each section were asked. The randomized questions were set up such that the same question would not be offered more than once in a week if at all. The other question was the same each day, and the results of these answers are presented in the graphs below. The number of days participants self-reported are presented below.

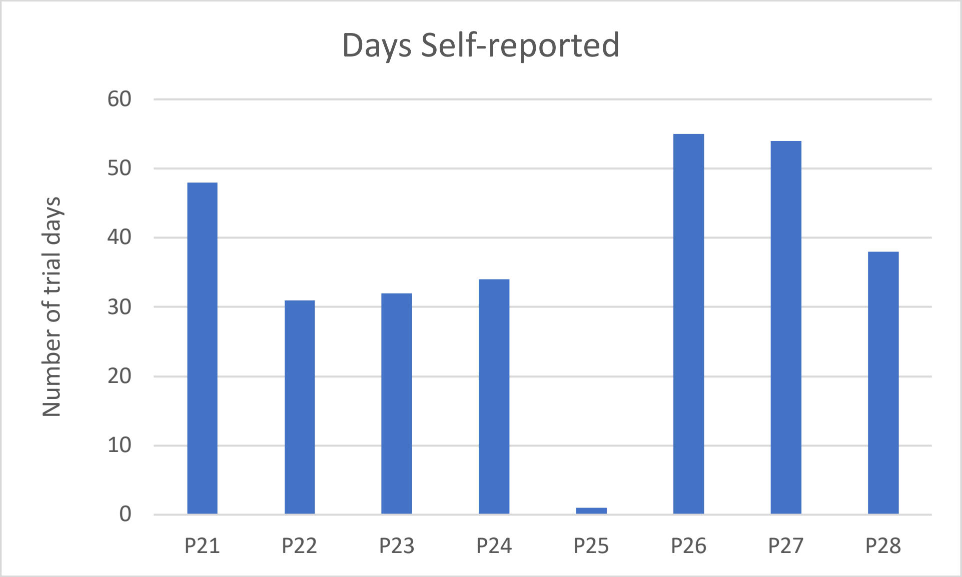

Figure 10.18: Self-report engagement

The mean number of days self-reported throughout the trial was 36.62 and the median was 36, with a standard deviation of 16.2. Participants self-reported less frequently as the trial progressed. Four participants self-reported on fewer than 66% of the trial days (P22, P23, P24, P28). Engagement with this element of the system was higher for P21, P26 and P27, who self-reported on more than 82% of the days in the trial. The participant who self-reported most frequently was P26 (55 days/95%). The lowest number of days self-reported was recorded by P25, who only self-reported once throughout the trial. This was likely recorded during the set-up and demonstration process.

Each day, two questions relating to stress, two relating to activity and two relating to sleep were delivered to participants. One question in each category was randomized and came from validated questionnaires, with participants typically required to reflect on that parameter over the previous month. The questions were set up such that the same question would not be offered more than once in a week if at all. The other question was the same each day, and the results of these answers are presented in Figures 10.18 – 10.20 below. For these questions, participants were asked to reflect on how they felt over the past day. For the purposes of conciseness and clarity, averages per week for each participant are provided in the graphs below rather than scores for each of the 56 days of the trial. It should be noted that there existed days in which some participants did not self-report. The scores provided in the graphs are adjusted to reflect this.

10.8.1 Stress

The data shown in Figure 10.14 below represent weekly averages of the self-reported scores on stress provided by each participant. The mean reported score was 2.64 and the median was 2.8, with a standard deviation of .62. There was an overall decrease in self-reported stress from week 1 to week 8 for five participants (P21, P22, P24, P26, P28). The biggest decrease was observed in P21, who scored 3.5 in week 1 and 1.3 in week 8; this was also the lowest average score across all participants throughout the trial. The highest average score reported in a week was by P28 who scored 3.9 in week 1; her score for week 8 was 3. P24's score remained quite steady throughout the trial, with scores ranging between 2.8 and 3.2. P27's scores were relatively low and steady for the first five weeks of the trial (1.6 – 2), but they then increased to 2.6 for each of weeks 5 to 8.

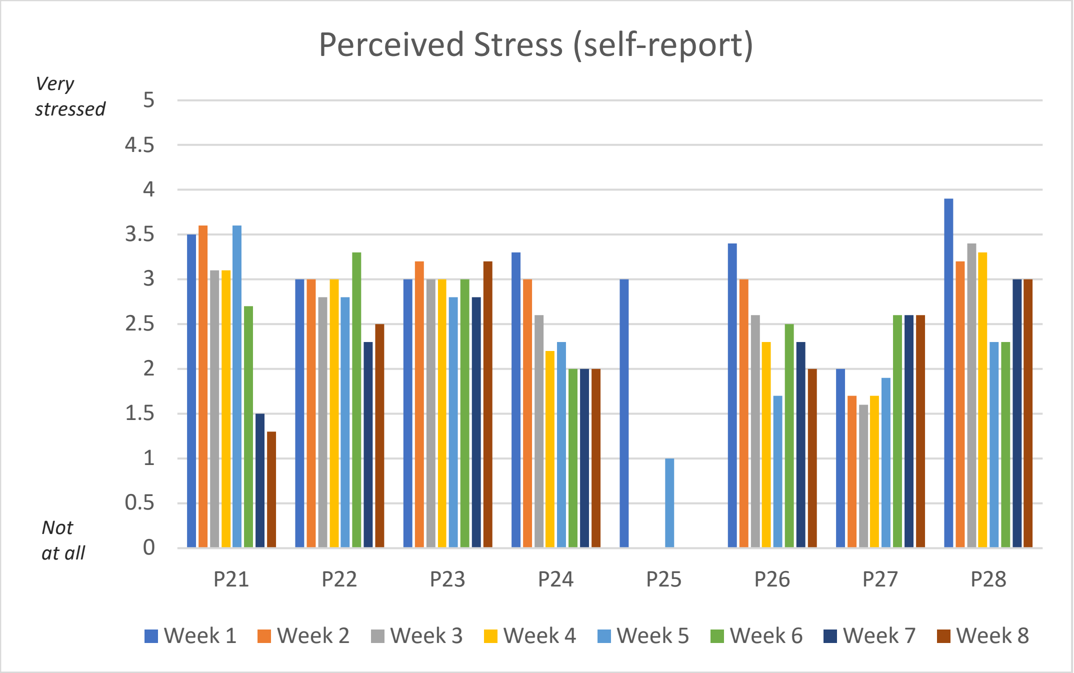

Figure 10.19 Perceived stress (self-report)

10.8.2 Activity

Data representing weekly averages can be seen in Figure 10.15. The mean reported score was 3 and the median was 3.3, with a standard deviation of 1.03. There was an overall increase in satisfaction levels from week 1 to week 8 observed in three participants' scores (P22, P24, P28). The highest average satisfaction score in a week was recorded by P24 in week 8 (5 = 'very satisfied'). The biggest increase from week 1 to week 8 was also observed in P24's scores (4.1 to 5). The biggest decrease, meanwhile, was observed in P26, whose week 1 score of 4 fell to 2.5 in week 8. P21 recorded consistently low scores throughout the trial, ranging between 1 and 1.3. This score of 1 by P21 was also the lowest recorded throughout the whole trial. The biggest increase from one week to the next was observed in P24, with a score of 3 in week 7 increasing to 5 in week 8.

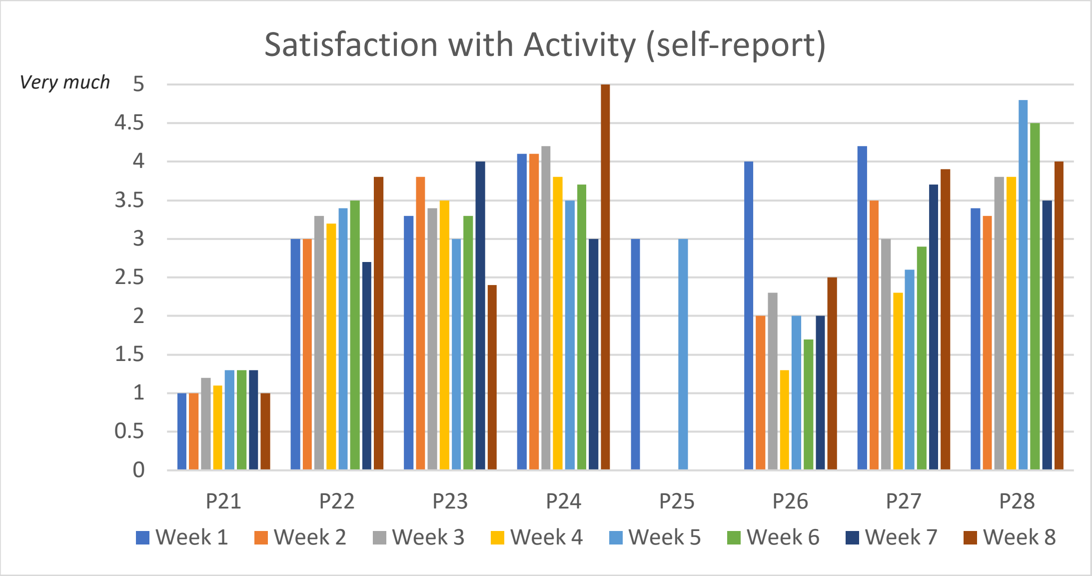

Figure 10.20 Satisfaction with activity (self-report)

10.8.3 Sleep

The data shown in Figure 10.16 represent weekly averages of the self-reported sleep scores. The mean reported score was 3.78 and the median was 3.75, with a standard deviation of .62. There was an increase in satisfaction levels from week 1 to week 8 observed in five participants' scores (P21, P22, P24, P27, P28). P25 did not submit any self-report sleep data throughout the whole trial. P23's scores remained relatively consistent throughout the trial, ranging between 3 and 3.8. The biggest increase in average satisfaction levels from week 1 to week 8 was observed in P28 (3.2 to 5). P28's score of 5 in week 8 was also the highest recorded across all participants throughout the trial. The biggest decrease, meanwhile, was observed in P23, whose week 1 score of 3.5 fell to 3 in week 8. The lowest score recorded throughout the trial across all participants was by P21, who scored 2.3 in week 2. The biggest increase from one week to the next was observed in P21, with a score of 3 in week 3 increasing to 4.4 in week 4. P21 also recorded the biggest week-on-week decrease, with her week 1 score of 3.8 falling to 2.3 in week 2.

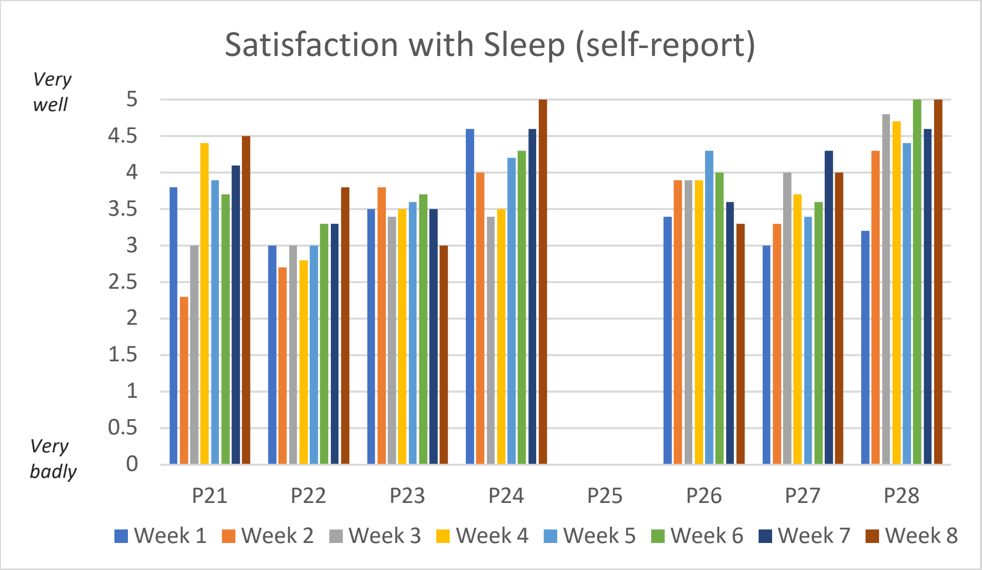

Figure 10.21 Satisfaction with sleep (self-report)

10.10 Summary

This chapter presented and detailed the quantitative findings from the trial. Results from the questionnaires administered to participants at the three time points in the trial were presented as well as engagement metrics concerning the number of times the app was opened, participants self-reported and that mindfulness content and wellbeing education tips were accessed. Tables containing a summary of the data derived from the objective sensor data (Withings watch and blood pressure cuff) were then presented. Finally, graphs were presented and analysed showing the participants' responses to the daily self-report questions around sleep, activity, and perceived stress. While the sample size was small and there were some instances of missing or incomplete data for some participants, the quantitative allowed for analysis of the secondary measures and provided insights particularly at the individual level. As well as this, running tests for statistical significance did in fact reveal instance of significance, namely with the Cohen PSS and the PSQI. Thus, the null hypothesis can be rejected in these instances, suggesting that the trial helped to lower stress as measured by the Cohen PSS and the daily self-report, and it also helped to improved sleep quality as measured by the PSQI. The findings presented in this chapter will be further interpreted and discussed alongside the qualitative findings in the following chapter.

Chapter 11: DISCUSSION

11.1 Introduction

This chapter presents a discussion of the findings presented in chapters 9 and 10 and draws comparisons to previous research to highlight the implication of the findings within the context of HCI, digital health and ageing research. Relevant findings and analyses from the study as a whole are also presented where appropriate. As discussed in Chapter 4, given the small sample size, the majority of data gathered were qualitative in nature, and this data thus provides the basis for the discussion points. The findings revealed a number of both perceived and observed improvements and positive outcomes for informal carers using the Mind Yourself application. These include raised awareness regarding overall wellbeing, increased reflection on lifestyle habits, behaviour changes, perceived improvements to health and wellbeing, including reduced stress, and a heightened sense of mindful awareness. With regard to the mindfulness content, for example, the interview findings revealed that certain positive wellbeing effects were brought about in part as a result of engagement with particular meditations, including reduced stress, increased confidence, a willingness to engage in more social activities and interactions, heightened sense of present moment awareness and an improvement in sleep quality. These outcomes were largely supported by the quantitative data (which will be discussed further below) thus allowing for a number of possible conclusions as to the advantages and feasibility of mobile health and wellbeing applications and digital mindfulness-based interventions for older informal carers.

11.2 Aims and Objectives

The overall aim of the study was to explore how older informal carers used a digital application that delivers a mindfulness intervention and supports self-management of health and wellbeing. The objectives were addressed as follows and are discussed in further detail throughout this chapter:

Objective 1: Gather requirements relating to the design of health self-management technologies for older adults, based on review of the literature and engagement with end-users.

An initial review of the literature in the areas of digital health and older adults' health and wellbeing was carried followed by focus groups with older adults. As the investigation progressed the literature review continued and became more refined, examining stress, mindfulness, and user-centred design for older informal carers. The rationale for focussing on these areas was borne out of the initial discussions and interviews held, wherein stress and its effect on other areas of wellbeing such as sleep quality and physical activity was found to be an area of concern for older adults.

Objective 2: adopt a user-centred design process to design a useful and usable digital health application for older users.

An iterative, user-centred design process was employed arising from the initial requirements gathering carried out in Objective 1. Having gathered requirements and sought feedback relating to preferences regarding different forms of data visualisations, early mock-ups were designed as part of the first design cycle. These were brought to typical end-users to gather feedback and then refined, a process which was repeated until a point was reached that the system and interface design was both useful and usable to older informal carers managing stress.

Objective 3: Examine engagement with the application

Engagement was tracked regarding the number of log-ins, the number of times the meditation content and education tips were accessed, and the frequency of self-reporting. Coupled with the interview data, it was possible to ascertain overall engagement patterns of participants. Results were positive and suggest that interest was maintained throughout the trial, and the overall engagement levels observed lend support to the use of such a system with this cohort. Connected health systems such as this have been found to encourage healthy behaviours and support health self-management among the general population (Harte *et al.* 2017), and results from this trial suggest this is also the case for older informal carers.

Objective 4: Explore attitudes towards the mindfulness intervention and satisfaction with the application in general.

Attitudes and satisfaction were explored through the interviews with the participants at two time points during the trial. For some of the participants, this was their first experience engaging with any form of mindfulness meditation. With the exception of two participants, the attitude towards the mindfulness element of the application was very positive, to the extent that some participants expressed an interest in continuing with this practice in some form following the trial. Positive effects on stress and overall wellbeing were both observed and reported, and this was certainly due in part to participants having engaged with the mindfulness content and integrated the techniques they learned into their everyday lives. Feedback towards the application in general was positive. While two participants reported low usability scores on the SUS, all of the participants described the system as both easy to use and useful during interviews. While two participants did not find the mindfulness content appealing, they both described finding value in other areas of the system such as blood pressure monitoring and activity tracking.

Objective 5: Determine the potential effectiveness in reducing stress and improving quality of life and sleep hygiene.

While the overall aim of the project was to explore how carers used the system, as part of understanding how best to design such an application, exploring the *potential* effectiveness was also considered important, for example to justify future work on the system and future trials. Results from the trial suggest a system such as this can potentially be effective in reducing stress, and improving sleep hygiene. Findings were less clear regarding quality of life, at least as measured as a construct, with little variance observed throughout the trial. During interviews, participants were not asked directly about whether their quality of life had improved. However, participants reported improvements in various areas of health and wellbeing as a result of using the technology and application. A more thorough assessment of stress and sleep was carried out (scales, self-reporting, interview feedback), than was with quality of life. However, a longer trial with larger participant numbers and a control group would be necessary to determine ‘effectiveness’ in relation to any construct.

11.3 Overall Engagement and User Experiences

Findings from the trial indicate that participants engaged regularly with the Mind Yourself application, with the majority of participants having some form of interaction on over 90% of trial days. There are a number of possible reasons for participants sustaining engagement over the course of the trial, which are discussed below.

11.3.1 User experience design

Firstly, the iterative nature of the design process, exploring and understanding challenges and requirements, likely helped to ensure that needs were met, with respect to how a digital health application could support this cohort to better manage their health and wellbeing. Thematic analysis of the initial focus group data allowed for themes to emerge, without any preconception or desired focus. Thus, the identification of both sleep and stress as areas of both concern and importance to older adults triggered the investigation of these two areas with regard to how digital technologies could be used to support older adults in self-managing these two aspects of wellbeing. Integrating findings from these requirements gathering sessions into iterative design cycles allowed for experimentation and exploration in terms of concepts and system design, with prototypes being presented to older adults for usability testing and feedback. Adopting this type of user-centred approach to design involved including the user throughout the design process so that needs, habits and preferences could be matched as closely as possible (Vermeulen *et al.* 2013). These early focus groups and usability testing sessions allowed for the selection of devices for use in the main trial, as well as providing insights into data visualization preferences and feedback on other aspects of visual design such as colour, icon and interface elements.

Maher *et al*. (2016) point out that user-centred design in digital health is important as it allows for those who have the lived experience of the end-user to provide insights which can then inform design decisions. This was certainly the case with the design process of the Mind Yourself application. Having initially involved older adults in the first focus groups and usability testing session, the focus shifted such that the end user became more defined and the approach continued to be both user-centred and participatory (Davidson and Jensen, 2013), (Sutcliffe *et al.*, 2010). Conducting interviews and further usability testing sessions with informal carers informed the design process in a number of ways. More insight was provided around the caring process, and the degree to which carers experience chronic stress, indicating a need for an intervention to specifically target stress. Opinions were sought around the inclusion of mindfulness meditation as a stress reduction tool with positive feedback giving weight to the validity of its inclusion. Feedback from the participants also confirmed an interest in taking blood pressure readings, but at the same time a lack of knowledge around the meaning behind these readings, prompting the inclusion of educational tips. Furthermore, usability sessions allowed for refinements to the interface design and user flows within the application. Examples included removing the side bar as well as the in the header to reduce clutter, integrating a colour code within the meditation tiles to clearly signify purpose, and changing the terms used to describe the types of mediation tiles. This approach followed what Harte *et al.* (2017) see as the four activity phases of user-centred design: (1) Identify the user and specify the context of use; (2) Specify the user requirements; (3) Produce design solutions; and (4) Evaluate design solutions against requirements.

11.3.2 Sustaining engagement

The iterative, user-centred design of the application also potentially played a role in sustaining engagement. Throughout the project, participants were engaged in usability testing, supporting regular, iterative updates to the application to ensure as high a level of usability as possible prior to deployment of the application in the trial. The majority of trial participants gave ratings above 80 on the SUS usability scale, which corresponds to an A grade or ‘excellent’ adjective rating. While P25 provided a poor score on the SUS scale, she didn’t raise any specific usability issues during the interview, nor did she appear to have any major issues during the walkthrough of the application. Usability barriers are recognised within the literature as negatively impacting on older adults’ adoption of and engagement with technology (Lee and Coughlin, 2015); (Kim *et al.,* 2016). As such, the usability findings, along with the engagement data, indicate that the extensive focus on user-centred design and usability over the course of the PhD project cannot be underestimated.

As was presented in Chapter 9, and is discussed further in Section 11.4, participants experienced a number of benefits as a result of taking part in the trial and using the Mind Yourself application. The literature on technology acceptance and adoption highlights the importance of perceived benefit in influencing these constructs (Davis, 1989); (Venkatesh *et al.*, 2003) as well as activation of effective self-management behaviours (Morton *et al.*, 2017). The benefits perceived may have also therefore been a factor influencing sustained engagement.

While overall engagement could be considered high, the data presented in Chapter 10 shows varying levels of engagement with the different elements of the application, with no two participants behaving in the same manner, and each either expressing a particular interest in one or more specific components or neglecting to use others for various reasons. P21, for example, engaged regularly with the Mind Yourself application (91% of trial days), taking regular blood pressure readings and self-reporting on 83% of the trial days. Yet, she reported no interest in engaging with the mindfulness element. In comparison, P26 commented during the exit interview that she used the Mind Yourself application primarily for the mindfulness content and self-reporting (which she used on 94% of trial days) while she preferred to use the Withings Healthmate dashboard for viewing data from the sensors.

Overall, findings in relation to engagement and user experiences are promising. It is important to reiterate that participants were older adults, between the ages of 53 and 77, the majority of whom had not used any sort of health monitoring technologies or applications prior to taking part in the trial. The literature in relation to older adults, or older informal carers, engaging with digital systems for health and wellbeing self-management is limited. The majority of studies that examine digital self-management for chronic diseases exclude older adults, for example (Stellefson *et al.*, 2013). Research has also suggested that older adults are not ready to adopt digital health technologies, and has questioned whether they have a desire or ability to use it and whether they will benefit from such technology (Hakobyan *et al.*, 2016); (Heart and Kalderon, 2013). As well as this, it has been found that older adults could ultimately reject new technologies if there is a perception that it is overly complex and their existing skills do not match what is required to engage with the technology (Kim *et al.* 2016). However, it has also been suggested that older adults are willing to change their behaviour to adopt digital self-management (Hakoybyan *et al.,* 2016). Nevertheless, there are relatively few studies on older adults' self-management practices and engagement with digital technology (D'Haeseleer *et al.*, 2019); (Stellefson *et al.,* 2013). Therefore, little is understood about what might encourage and support older adults, and particularly older carers, to engage with digital health technologies on a long-term or ongoing basis.

This PhD contributes to this knowledge by outlining how a user-centred and iterative approach was taken to design a digital health and wellbeing application for older informal carers managing stress. The eight participants in this trial were older informal carers who used the application daily in their homes for eight weeks and as such, a considerable amount of both qualitative and quantitative data was collected. These data showed that the system designed was easy to use, supported these users in self-managing their health and wellbeing, and resulted in high levels of engagement regardless of which areas of the application individual users considered most beneficial or relevant. Consolvo *et al.* (2014) see both usability and design as key factors in sustaining engagement with mobile health applications so that these technologies can be effective in supporting users in meeting health goals.

However, it is difficult to define what represents 'good' or 'high' engagement. Yardley *et al.* (2016) argue that it may be more valuable to establish and promote 'effective' engagement, defined as "*sufficient engagement with the intervention to achieve intended outcomes*". It is particularly important to examine engagement with / adherence to the mindfulness intervention within the application specifically, as adherence is seen as a key indicator of efficacy and success with regard to mindfulness-based interventions (Ribeiro, Atchley and Oken, 2018); (Scott-Hamilton and Schutte, 2016). Mindfulness allows one to change the behavioural response to current events through acceptance of current thoughts without judgement, but this is a skill that needs to be acquired and honed through long-term practice (Dutton, 2008); (Spijkerman, Pots and Bohlmeijer, 2016). Adherence rates varied significantly across the participants, with two participants recording little-to-no engagement with the mindfulness content, and others fully engaging with the content as per the recommended guidance or finding their own preferred level of engagement, which allowed them, for example, to integrate particular techniques into their daily lives when needed for stress management. Despite this, participants reported experiencing benefits, which potentially suggests that the engagement was 'effective'. Glück and Maercker (2011) suggest that even six days of meditation can bring about reductions in stress and improvements in negative effects but contend that continued practice is indeed required for long-term benefit. Nonetheless, the interviews as well as the quantitative data suggest that at least some amount of mindfulness meditation can bring about positive change for some people. With this is mind, the following section discusses the viability of the Mind Yourself application in supporting older informal carers to self-manage and explores the degree to which adherence may have affected outcomes.

11.4 Viability of the MindYourself Application to Support Older Informal Carers Self-managing Health and Wellbeing

The literature reviewed in Chapter 2 showed that there exist considerable challenges and health-related issues facing carers which arise as a result of the caring process. Due to the behavioural issues that arise from cognitive decline among dementia patients, as well as the challenges relating to supports, informal carers are at risk of chronic stress, poor sleep quality and physical health problems (Vinci *et al.* 2019); (Parra-Vidales *et al.* 2017); (De Carvalho *et al.*, 2013). There is also an increased likelihood in neglecting one's own health and wellbeing. The semi-structured interviews held with informal carers as discussed in Chapter 6 as well as the interviews both during and subsequent to the trial further underscored the degree to which these issues affect this cohort. Among the challenges described were a lack of support, a sense of constant worrying, feeling invisible and undervalued, as well as mixed emotions of resentment and guilt. It is also the case that the majority of HCI and digital solutions to date have been patient-centric in their focus, with comparatively little research focused on how to support those providing informal care to self-manage health and wellbeing (Bosch and Kanis, 2016), (Yamashita *et al.* 2017).

It is clear, therefore, that there is a pressing need to support older informal carers through whatever means possible, including the use of digital health self-management solutions. The importance of this concerns not only the health and wellbeing of the older informal carer themselves, but also their continued ability to provide adequate care to their loved ones such that both parties can remain at home for as long as is possible. The present study has demonstrated that a digital health application designed with older informal carers in mind can support this cohort in self-managing aspects of their health such as stress and sleep.

11.4.1 Supporting informal carers managing stress

Throughout the various phases of the study, it was evident that older informal carers experience both chronic and acute stress, coupled with feelings of being overwhelmed by their caring responsibilities. This sense of feeling overwhelmed has been reported in numerous studies involving informal carers, as pointed out by De Carvalho *et al*. (2013). As such, one of the key objectives of the Mind Yourself app was to support carers in managing, and ideally reducing, stress. Both the T1 and T2 interviews during the main trial allowed for insights into the everyday experiences of the participants, including various stressors related to the caring process and how using the app may have addressed these.

The Cohen PSS found a reduction in perceived stress for six participants following the trial, with only one instance of an increase found. The degree to which this can be attributed to use of the application and/or the mindfulness intervention explicitly or exclusively is uncertain. Some participants engaged with this element of the system more than others (as discussed later), while some participants experienced changes in circumstances, outside of the application, which likely contributed (for example, the care recipient being taken into care). The reductions in perceived stress as measured by this scale were largely supported by the daily self-report data, though with some divergences. For example, decreases in stress as measured by the Cohen PSS were observed across the trial with both P23 and P27. However, the daily self-report stress scores remained relatively static for P23 and showed a slight increase for P27 (albeit with both participants still reporting scores of low-to-moderate stress). Conversely, an increase in perceived stress according to the Cohen PSS from T1 to T2 was observed with P28, whereas her daily self-report scores showed an overall decrease across the eight weeks.

In addition, findings from the Zarit scale assessing burden, and the Casp19 scale assessing quality of life, did not mirror those found with the stress scale and stress self-report data. Specifically, while the overall trends with regard to stress showed reduction for all participants except one (P28), little variance was observed in quality of life as assessed by Casp19. Similarly, decreases in burden across the eight weeks were observed in four participants, with the other four either remaining the same or increasing slightly. As well as this, four scored in the ‘high’ burden category at T2. It is clear from looking at the stress, quality of life, and burden data together that changes in one did not necessarily correspond with changes in another. It is useful, therefore, to turn to the qualitative data to attempt to draw insights as to whether the Mind Yourself app may have played a role in stress management and reduction.

Based on the interview data, as well as the scores from the T0 Cohen PSS it would appear that the majority of participants, including P21, P22, P23, P25 and P26 were experiencing what would be considered chronic stress at the outset of the trial. A reduction in stress on the Cohen

PSS scale was observed for each of these participants (apart from P22 who didn't complete the questionnaires) and the qualitative data gives insights into why. During P23's exit interview, it became apparent that she was aware that the type of stress she was experiencing had changed from chronic to acute. She spoke about how she felt she was now able to address this type of acute or periodic stress by using meditation relaxation techniques, even despite her husband's condition deteriorating in terms of speech and mobility. This shift in perception with regard to how one views stressful situations is in line with what Dutton (2008) sees as an increased sense of control over goals and behaviours resulting from self-acceptance and self-awareness through mindfulness.

P25 similarly described a sense of constant stress when discussing her daily life prior to the trial. Her perceived stress decreased but remained at moderate levels. P25 discussed how implementing techniques learned through the mindfulness content were effective in addressing her feelings of anxiety and stress. She also discussed using some of the mindfulness techniques to help her get back to sleep if her sleep was disturbed during the night or if feelings of anxiety and stress were affecting her ability to get to sleep. As well as this, she had come to view the shorter, more accessible meditation, 'Three-minute Breathing Space' as a coping mechanism, utilising it whenever she felt annoyed or upset. This had allowed her to analyse her own feelings and reveal to her the presence of stress. However, she highlighted a number of times that she felt she would need to be more diligent and disciplined with such a mindfulness programme in order to fully benefit with regard to eliminating chronic stress.

Both P21 and P26 had a significant change in their caring-related circumstances during the trial, which likely played a significant role in reducing their stress. Indeed, P26 explained during the exit interview that prior to her mother being taken into care, it was 'constant stress'. She did point out, however, that she was still experiencing some stress, but that it was transient and would depend on the current situation. P26 was enthusiastic about and positive toward the mindfulness practice, but it is unclear what role, if any, this played in her transition from chronic to acute or periodic stress. She did point out, however, that engaging with the mindfulness content had resulted in more clarity of thought as well as improved sleep.

The type of caring-related stress as described by the other three participants in the trial could be considered more acute than chronic. This difference was also reflected in their Cohen PSS scores as well as the daily stress self-reports. P24 explained that caring for someone with dementia can be unpredictable, with some days relatively normal and others particularly stressful. He felt his high blood pressure was specifically connected to whatever caring-related stressors he was experiencing at a particular moment. His engagement with the mindfulness content (specifically the Body and Breath meditation) early on in the trial led to his realising that he was constantly on the move and needed to find more time to relax, having found it difficult to effectively sit still without rushing to turn his attention to something that he felt needed to be done.

P27 did not consider herself as someone with high stress levels, though she did describe herself as being constantly 'on the go'. The negative effects of this, according to P27, were felt in her sleep quality more so than feeling stressed. As discussed previously, P28's PSS score increased from T1 to T2 but this was likely in part due to having had an eye operation during the trial. She did comment during the interview, however, that she felt her stress levels were low due to how she had changed her approach to engaging with her sister since commencing the trial.

11.4.2 Raised awareness and taking action

One of the most noticeable positive outcomes observed and discussed was how using the application resulted in raised awareness of various aspects of health and wellbeing, which in turn positively impacted behaviours and perceived wellbeing. There were various ways in which awareness was raised through use of the system, including through monitoring and tracking various parameters, gaining understanding on the meaning of readings (for example what represents a high blood pressure reading), self-reporting and viewing and reflecting on visual feedback in the form of graphs highlighting trends and areas for improvement. Furthermore, the act of meditating highlighted to some participants the degree to which they found it difficult to sit still, relax and focus on the present moment.

Raising awareness in these ways also had the knock-on effect of motivating some participants to take action, for example to implement techniques to better manage stress, and prompted others to seek out professional advice for further investigation. Feedback from three of the participants suggested interventions in the form of blood pressure medication and sleeping tablets prescribed by a GP would not have happened had they not been made aware of areas of concern though using the application. It was also the case for some participants that the combination of all of the elements in the application served to raise awareness of the importance of health self-management, resulting in self-reflection and a sense of realisation that was previously lacking or absent.

Reflecting on activity data was successful in motivating participants to increase their behaviour. This was achieved through both the Withings watch and the sub-dial on the watch face acting as a visual reminder as to goal progress, as well as the feedback provided through the graphs in the application. Both P21 and P22 discussed how seeing their activity progress on the sub-dial motivated them to increase their step count in an attempt to further their progress towards the daily goal. Another element that resulted in an increased sense of self-reflection and raised awareness was self-reporting. For some, it was simply the act of having to pause and think, and to reflect on one's health and wellbeing over the previous 24 hours that raised awareness overall. One interesting example of this was P24 who used the stress score on the dashboard to reflect on how his wife's (care recipient) condition had contributed to this score on the previous day.

Participants also discussed a sense of raised awareness due to reflecting on sleep data and the effects this had on overall sleep quality. For some participants, such as P23, P27 and P28, this was the first time they had analysed their own sleep stages, and it allowed them to reflect on the importance of sleep in general and highlighted the importance of not neglecting this aspect of their health and wellbeing. Indeed, this even led to P27 consulting with her doctor, having discovered her sleep quality was poor overall, and then being prescribed sleeping medication. This then resulted in a noticeable improvement in sleep, and a better overall feeling during the day. P22 described how he had started using the sleep data to remind his wife of sleep disturbances that had occurred during the night. It was also the case for some participants (P25 and P28) that increased awareness of stress had the knock-on effect of improved sleep quality, resulting in fewer interruptions and longer periods of unbroken sleep.

The findings from the trial indicate that the Mind Yourself application supported older informal carers in integrating self-management into their daily lives, facilitating reflection and behaviour change. While there is limited research on digital health applications for older carers, other research has reported similar findings and benefits for other cohorts. Lee and Dey (2011) reported two case studies examining how older adults engaged with data from a sensing system tracking medication intake and phone use. They found that reflecting on sensor-based data resulted in greater awareness and allowed for an accurate perception of abilities. Similarly, Marcu, Bardram and Gabrielli (2011) found that persuasive technology which enables users (people with bipolar disease) to monitor and visualize behaviours and physical states, while also providing effective feedback and advice, ultimately allows for self-reflection and behaviour change.

11.4.3 Relationship between mindfulness adherence and outcomes

Adherence to regular meditation practice has been shown to be associated with higher levels of dispositional mindfulness, reductions in depression (Sephton *et al.*, 2007), stress reduction and improved psychological wellbeing (Carmody and Baer, 2008). It is important, therefore, to analyse and discuss engagement levels with the mindfulness content across the participants with a view to ascertaining what effect, if any, regular engagement had on outcomes. However, work by Riberio, Atchley and Oken (2018) suggests that it is the quality of practice rather than the duration or frequency that may have more influence on these outcomes.

The highest level of engagement with the mindfulness content was observed with P27. She also adhered closely to the recommended approach to the content by using the guide feature in the manner for which it was designed. A number of positive outcomes were observed with P27, including improvements in perceived stress, dispositional mindfulness, and quality of life. She engaged with all of the content as recommended, both in terms of time required and sequence as well as repetition of practices. As a result, she reported high levels of dispositional mindfulness, meaning she was more aware of what was happening in the current moment than previously, and had come to appreciate everyday things such as birds singing and the taste of food. P27 was also not particularly interested in meditation prior to the trial, but had come to accept by the end of the eight weeks that it had in fact contributed to her heightened sense of mindful awareness. The quantitative data supports this, indicating that her stress levels decreased and dispositional mindfulness increased.

It is interesting to focus on P22 and P25 when discussing adherence and engagement with the mindfulness content in general as levels were low for both participants despite expressing genuine interest and enthusiasm for this aspect of the system. P22 reported high stress both through the interviews and also as measured on the Cohen PSS. He commented during the interview that he was very interested in the idea of mindfulness meditation but felt he was not able to commit in terms of the time required and also in terms of certain practical issues, such as his wife being in the same room while the audio is playing. However, during the interviews P22 did describe a heightened sense of awareness of his own stress levels as a result of meditating during the early stages of the trial, and a realisation that he was often operating on ‘autopilot’. He discussed using breathing-focussed meditations to calm himself in times of stress and he felt this had also led to improved sleep quality in terms of fewer interruptions while also finding it easier to get to sleep.

Similar sentiments concerning adherence were expressed by P25. While her level of engagement was higher than P22, it was still low enough (due to time constraints as a result of caring) to reduce the likelihood of deriving long-lasting benefits in terms of acquiring skills for stress reduction. On average she engaged with the mindfulness content seven times per week across the trial. While it has been suggested that even six days of meditation can lead to reductions in stress (Glück and Maercker, 2011), it has also been reported that long-term benefits are more likely to be achieved through regular and sustained practice (Grossman, 2011). While P25 did not report any significant changes in dispositional mindfulness, she did experience improvements in sleep quality and a slight decrease in perceived stress. During the interviews she discussed how she had been using mindfulness techniques to help her sleep and found these effective in addressing feelings of anxiety and stress while trying to get to sleep.

The examples of P22 and P25 both highlight that the responsibilities of caring can impact how and when someone can use a digital application such as this. However, the manner in which one approaches such a course is also important. In contrast, P27 was determined to adhere to the content as recommended, and as a result derived genuine benefit. This was in spite of not being particularly enthusiastic towards this type of practice. P22 and P25, meanwhile, were in fact enthusiastic but could not adhere due to both time constraints and discipline issues. It is possible therefore that they too would have derived further benefit had they adhered further. Time and discipline are genuine concerns when considering how to deliver digital mindfulness interventions into an application such as this for informal carers.

This is not to say that one needs to fully adhere to a full programme of MBSR/MBST-based content over eight weeks in order to positively affect stress levels or improve wellbeing in general, however. Indeed, results from the trial show that even some level of engagement with mindfulness content can contribute to noticeable improvements in various areas. Both P23 and P28 serve as good examples. Despite engaging less than would be required in terms of full adherence to a mindfulness meditation programme, both participants described significant improvements in stress, physical health and overall wellbeing arising from both the mindfulness component as well as the self-monitoring elements of the system. For P23 in particular, she had come to value her experiences more and also wanted to start to socialise more. Indeed even P22, whose engagement levels were among the lowest, reported benefits in terms of stress management from having engaged with some of the mindfulness content. Glück and Maercker (2011) found that participants who engaged with over 50% of internet-based mindfulness training also reported reductions in stress, while Ribeiro, Atchley and Oken (2018) found that changes in self-report measures including perceived stress among participants in a 14-week mindfulness meditation programme did not correlate with mindfulness practice time, suggesting quality of practice may have had more influence than frequency.

Positive outcomes in terms of reduced stress, lower level of perceived burden, and improved activity levels were also observed with P24, who did not engage with the mindfulness content after the first couple of weeks and who commented that 'yoga and mind things' do not appeal to him. His example suggests that opinions and views towards these types of practice may shape the manner in which one is willing to engage. As well as this, his experience during the trial demonstrates that engaging with the activity-tracking and self-report features can result in raised awareness and positive health outcomes such as reduced stress, lower burden and increased activity levels. Similarly, P21 did not engage with any of the mindfulness content. Reductions in perceived stress were also observed in her case and while no change was observed in perceived sleep quality, her activity levels increased across the trial and she described a raised sense of awareness around stress in general. The examples of P21 and P24 and indeed the other participants who also found benefit in the health-monitoring aspects of the application suggest that activity and sleep-tracking, blood pressure monitoring alongside integrated self-reporting and education are important elements in a digital health application and demonstrate that offering a suite of features is more likely to cater for a wider range of users, and as such those who do not have a predisposition towards meditating are not excluded. The need for such a broad and holistic approach to wellbeing management was also proposed by Lane *at al.* (2011).

Taking these use cases into account, it is important also to consider how individual preferences affected the manner in which the participants engaged with the content. It became apparent from the interviews that some meditations, particularly those focused on breathing, were more popular than others. These practices are likely the most accessible and at the same time easier to recall unaided than some of the others. The participants forged their own paths, and engaged primarily with those practices they felt most comfortable with and from which they were able to get the most benefit.

11.4.4 Intentions to continue self-managing

The perceived and observed improvements and the benefits the participants derived from participating in the trial were further underscored through their willingness to continue self-managing following the trial's completion. Their eagerness to find out about commercially available products and applications that could provide similar functionality to the Mind Yourself system is indicative of the level of interest that was created and sustained through participation in the trial. These sentiments were expressed by participants who had never meditated previously, and who prior to the trial did not have any interest in this area whatsoever. All of this points to digital mindfulness-based interventions being a viable and practical solution for this particular group with regard to stress and overall wellbeing self-management.

11.5 Lessons Learned and Design Recommendations

Previous sections of this chapter highlight that this type of application and intervention can have beneficial effects on the health and wellbeing of older informal carers, and further, that this cohort are interested in using such an application and willing to engage with it. With this in mind, this section presents lessons learned and recommendations in relation to designing and deploying an application such as Mind Yourself, to maximise the possibility of designing a useful, usable and engaging application for this cohort.

Consider the training needs of users, including in-person and in-app

Designers need to take into account the difficulties end users may face navigating a new interface when designing digital health application for older adults. While an interface may have been designed to be as simple, intuitive and usable as possible for all users, the possibility still remains that some users may encounter difficulties for a range of different reasons. These could include visual impairments, unfamiliarity with icons and symbols, confusion over different forms of navigation, a reluctance to explore the interface and features, or other unforeseen problems. For the trial outlined in this thesis, training and instruction were provided by the researcher during deployment, wherein the participants were shown the hardware and how to use it, while also being given a run-through of the application and its features. However, this was likely a lot to take in, particularly as the participants were unfamiliar with such technology. Furthermore, this visit also involved providing the participants with instructions concerning how to complete the questionnaires so it is possible that this experience was somewhat overwhelming for participants. The exit interviews also revealed that some participants had overlooked certain elements of the interface (for example, the Guide button, self-reporting, education tips), which is another issue that may have been mediated by training content. As well as this, for some participants there were problems using the blood pressure cuff, either as a result of the cuff being difficult to apply to the arm, or issues relating to training. Again, this problem may have been addressed through more thorough training.

As such, it is necessary to ensure that robust and thorough pre-trial or pre-deployment training is given, and that opportunities for further or repeat training are also provided. Demiris, Finkelstein and Speedie (2001) suggest older users receive training over a period of several days when being introduced to a new system, and this training could also be tailored to cater for individuals with functional limitations where necessary. However, this may not be practical for carers. A user guide should be provided, in the form of text, images, flow charts or a video demonstration. A paper-based version of a user guide is also likely to be important for this cohort, particularly those who are unfamiliar with tablets, smartphones, health monitoring devices and apps or those in the early stages of using the app. A paper-based manual would allow the person to read the user guide while at the same time interacting with the app to try features. Another feature that could be integrated onto a training section is the use of a prompt or hint, which could be used when engagement data indicates a certain feature (such as the

Guide button) has not been interacted with. Such functionality could also be used whenever new features are added.

Guidance on time, discipline, background information and context to different topics should be provided to sustain engagement

Among the key barriers to sustained engagement with the mindfulness content over the course of the eight weeks were discipline, perception that too much time was required, and a lack of understanding of the importance of adherence with mindfulness meditation in general. Some of these issues could perhaps be addressed through persuasive techniques such as prompts. However, guidance and education are also important. This would involve providing content and background as to the theoretical underpinnings of certain practices as well as advice on time management and how to fit meditating into a busy schedule. While there was extra material provided in the application which included links to web articles and YouTube videos on mindfulness, none of the participants engaged with this content. Concise and focussed content that is written specifically for this audience and integrated appropriately into the interface could go some way to addressing the challenges observed during the trial. Moreover, it could be advantageous to include a video guide the first time a user enters the mindfulness section of the application, outlining the potential benefits and how to get the most out of the content. This could then be saved or added to a list of favourites for future reference, while also being redelivered to users who are not engaging to encourage further interaction with the content.

Design applications to be customisable

Insights from the participants' preferences and habits using the application highlighted the need for customisation and personalisation throughout the design. One example of this was the desire of users to be able to set their own activity goal. The user's goal had been set in line with recommendations for older adults exercising, but some user's felt this was too high. Users should be supported in setting their own goal. For example, the application should explain both the meaning of the metrics used for activity goals and the guidelines on recommendations that are relevant to the cohort (for example, recommendations for older adults, or people with chronic conditions). Kientz *et al.* (2010) and Munson and Consolvo (2012) consider both the ability to set and pursue goals, as well as education as to how these goals are met through certain behaviours, as key elements to consider when designing persuasive technologies. Morrison (2015) noted that goals are more likely to motivate behavioural change if they are: (a) achievable; (b) sufficiently challenging; (c) specific; (d) specify proximal changes to behaviour that are tied to a distal aim; (e) learning orientated; (f) fit with already valued goals or self-conceptions. As such, digital health interventions should support users in setting goals that meet these criteria.

The interviews highlighted certain use cases where reading long sections of text was not practical, with audio being a preferred means of interaction with meditation content. At the same time, one participant described needing to be alone to be able to listen to audio content, so text-based interaction may have been more appropriate for him in certain scenarios. Providing such content in multiple modalities would allow the user to engage with the type of content that suits them. Participants also spoke of having preferences in relation to which meditations they preferred. As such, users could be provided with the facility to customize a 'favourites' list to allow for further personalization, such that certain meditation content can be easily and quickly accessed. Providing users with ability to customize both the interface and the content to their own liking addresses the issue of individual styles and preferences as was evidenced in this trial.

Educational tips should be linked to objective results and made personally relevant

Engagement with the educational tips feature was low overall. Evidence from the trial showed that the tips were easily overlooked and did not play as important a role in the overall experience as was expected. While this may have been due in part to insufficient training, it could also have been the case that the tips were not viewed as relevant enough. Work carried out by Doyle, Caprani and Bond (2015) showed that older adults are keen to have supporting and useful information relevant to whatever aspects of their health and wellbeing they are monitoring. Ideally, this educational information would be linked directly to whatever results are being shown. For example, if a user was registering poor sleep quality over the course of a few days and not reaching the recommended goal, the educational tips they receive would reflect that and aim to address it. This could also work for users who are doing well and reaching certain goals. For example, if a user was engaging in the recommended amount of physical activity, the educational tips could focus on sustaining these levels by explaining what the long-term effects and benefits would be. Both of these examples are what could be considered actionable insights: relevant information that can be used to positively affect behaviour. Such information would need to be prominent and in the line if sight, yet unobtrusive and seamless at the same time (Consolvo, McDonald and Landay, 2009).

Key interface design elements need to be situated in the line of sight with a clear call to action.

While a range of information often needs to be presented on a screen at any one time, it is important to take into account the placement of elements considered important in terms of information to be relayed and elements of the system that require increased engagement. A number of important items were overlooked at times by some participants (Guide button, self-reporting, educational tips) due to either their placement on the screen or the lack of a clear call to action. As stated earlier, this may also have been due in part to insufficient training being provided. However, while visual clutter should be avoided, it is also necessary to take into account line of sight, colour and size when designing for usability (Farage *et al.*, 2012). Reminders may need to be used for elements that have been overlooked, such as self-reporting. However, it is important to bear in mind that such features can appear obtrusive if poorly implemented.

Opportunities for communication with a guidance coach or other users should be considered

Previous studies of internet-based interventions have shown that carers of persons with dementia welcome the inclusion of a guidance coach, with some of the benefits including increased commitment to the intervention and increased feelings of confidence with regard to implementing new strategies (Boots *et al.,* 2014). It is possible that could have supported some of the participants who were positive toward the mindfulness content but found it difficult to adhere in terms of time and discipline (P22 and P25, for example). Spijkerman, Pots and Bohlmeijer (2016) highlight an online CBT study by Dear *et al.* (2013), which achieved high completion rates of 90% as a result of integrating weekly telephone contact. Much of the literature in Chapter 2 highlights the importance of social connection for informal carers. Parra-

Vidales *et al.* (2017) suggest that programs that offer contact with other carers address social isolation and can be successful in reducing stress, but point out that guidelines for such group intervention designs need to be established. There are opportunities to design and integrate functionality such as forums with other users, video chats, or voice calls (either with other users or a guidance coach) into an application such as Mind Yourself and this could serve to address both social isolation and also increased adherence to the intervention as well as reinforcing potential benefits to sustained participation (Glück and Maercker, 2011).

Design and testing of digital mindfulness-based interventions needs to also focus on the act of meditating while using the application

An iterative user-centred design cycle was implemented throughout this study. This was effective in making sure the application met user needs and requirements, highlighting any potential usability issues as well as identifying areas that caused confusion or needed to be adapted prior to the trial. As such, there were no issues with aspects such as interpreting data feedback and graphs, navigation and interaction amongst other things. However, while the second round of user-testing did involve eliciting feedback around the mindfulness component in terms of interface design and overall concept, it did not involve practical or real-world engagement with the mindfulness meditations. That is to say the participants who took part in earlier phases of usability testing were not asked to sit and meditate, nor were they given guidance as to how to do this. It was only during the trial that certain practical issues impacting the design became apparent, such as following a recommended guide, personal preferences, the lack of an option to customize and the use of text over audio in certain places.

A recommendation would therefore be to adopt an approach that involves an introduction to both the concept of meditating as well as the practicalities and techniques of meditating. As such, participants in a usability testing session to test a digital mindfulness intervention would ideally be asked to meditate in order to fully ascertain how appropriate the design of this aspects of the application is. In the case the user would be asked to work their way through the guide and individual meditations, allowing time to actually sit and meditate for each one.

Persuasive techniques and short-form meditations should be used to help maintain engagement with mindfulness content

Adherence to the mindfulness intervention was a challenge for a number of participants for various reasons, despite them wishing to engage more. As such, designers need to consider how to promote engagement. One possibility is to integrate persuasive techniques into the design of this part of the application. Solutions could include using rewards once a topic has been covered or completed (Fritz *et al.* 2014), gamification of some sort to provide a challenge, allowing users to set daily or weekly meditation goals (Munson and Consolvo, 2012) or the use of levels that need to be unlocked in order to reach the next stage of the course (Spijkerman, Pots and Bohlmeijer, 2016). Baumel and Muensch (2016) suggest supplementing a breathing exercise with visual aids such as a bar that shrinks and expands with each breath as well as the ability to adjust the breathing cycle is likely to result in a higher level of engagement than one which is purely text or audio-based. This approach could also be applied to a meditation program, with visual aids applied to each specific technique or topic.

Another solution is to provide more flexibility with regard to the length of meditations. It was apparent from the interviews that the shorter and therefore more accessible meditation practices were particularly popular. In order to entice users further with a view to maintaining engagement, an option could be to provide both short and long forms of each meditation. While this would likely effect the overall efficacy of the particular meditation in question, it could still be effective to some degree, and would be more welcome than a practice being overlooked or rejected completely. Both accessibility and convenience need to be taken into account when considering different use case scenarios (Meiselwitz, Wentz and Lazar 2009), and this certainly applies to carers given the range of contexts and individual demands or restrictions each carer is likely to face. Commercially available meditation applications such as Headspace provide a similar feature, with users able to decide if they want to engage in a 10-minute or 15-minute version of the same practice. Demiris, Finkelstein and Speedie (2001) and Baumel and Meunsch (2016) point out that users will perceive a system as a useful tool once tasks can be completed in a reasonable time. As such, the aim should be for the level of investment necessary for engaging in an activity to be minimized, such that the chances for the activity to be completed are higher. Adopting a similar approach with a digital mindful-based intervention for older users could lead to higher adherence rates overall, and could ultimately result in the user eventually choosing to engage with the longer form versions as the course progresses.

11.6 Strengths and Limitations

This study explored how best to design a digital health application to support older informal carers in self-managing health and wellbeing. While the study as a whole involved 28 participants, only eight participants took part in the trial itself, which may be considered a limitation to the generalisability of the findings. Related to this, the absence of a control group for comparison could be considered a further limitation. However, given that this trial was acting as a proof of concept, with the aim being to ascertain the reasons and approaches relating to engagement, usability and usage, such a small sample size could be considered appropriate. The small sample size also allowed for the collection of rich qualitative data to gain a deep understanding of older informal carers' experiences with such a system. Other research has noted that such an evaluation is appropriate for novel technologies prior to an evaluation to measure whether such a system can bring about a measurable change in behaviour or improved health outcomes (Klasnja, Consolvo and Pratt, 2011). Given that the trial demonstrated the viability of such an application for this cohort, and interest in engagement, future evaluations would ideally include a control group to evaluate effectiveness. A further strength of the study is that a mixed-methods approach was adopted, with data collected across a wide range of data sources, allowing for quantification of engagement levels and an indication of trends in relation to health and wellbeing data from questionnaire data across three timepoints, as well as sensor data. This resulted in a robust dataset that allowed for detailed analysis and a high level of validity in terms of drawing conclusions and suggesting design recommendations.

An additional strength of the study is that an iterative user-centred design process was employed, with end-users included throughout. This allowed for a design that was refined and updated as the study progressed, but that was also guided in terms of requirements and functionality by the users themselves. The result was a system that was perceived as useful and usable by the participants. The trial then allowed for analysis of real-world scenarios and contexts, and this in turn resulted in findings that reflect the lived experiences of older informal carers of persons with dementia.

11.7 Conclusion and Future Work

This study employed an iterative, user-centred design and evaluation process to explore the potential of digital health technology to support older informal carers in self-managing their health and wellbeing experienced as a result of the caring process. The early phases of the study, described in Chapters 5 and 6 explored the attitudes of older adults towards managing health and wellbeing, the challenges faced and led to a focus on self-management of stress, and associated areas of wellbeing. A parallel literature review and additional qualitative research identified older informal carers as a target cohort who could potentially benefit from such an application. Focus group sessions and usability testing were used to explore, test and refine design concepts, based on the user requirements identified through the qualitative research and literature review. This process ultimately led to the design of the Mind Yourself application, as described in Chapter 7, integrating monitoring of health and wellbeing and a mindfulness intervention to support older informal carers to self-manage.

The Mind Yourself application was deployed with eight older informal carers who used the system daily over a period of eight weeks. Results obtained from analysis of the qualitative and quantitative data collected suggest that such an application and intervention can be effective in supporting this cohort to self-manage their stress and aspects of their overall wellbeing, including sleep quality and physical activity. This study provides support for a digital-mindfulness based intervention integrated into a digital health application, and the trial demonstrated that such a system is acceptable, feasible, usable and useful for older informal carers to self-manage their health and wellbeing. At the time of deployment, this was the first study to explore the use of digital mindfulness-based interventions as part of a mobile health and wellbeing application specifically designed with and for older informal carers managing stress. Specific contributions of this PhD include:

- The design of a user-centred application, Mind Yourself, that is usable and useful for older informal carers to self-manage their emotional wellbeing and related areas of health. The iterative process followed during this study resulted in an application that was easy to use and fit for purpose, with each of the participants who used it finding value in different elements.
- An exploration and understanding of the experiences of older informal carers who used this application for two months, including patterns of usage, usability, acceptance and

perceived usefulness. A broad data set gathered over the course of the study allowed for insights into which aspects of the application worked for this cohort and why, as well as highlighting areas that need to be refined or adapted.

- Evidence of the viability of a digital mindfulness intervention to support management of stress in older informal carers. Findings were promising relating to the perceived benefits with regard to managing stress and maintaining positive psychological wellbeing in general.
- Based on the lessons learned in evaluating the application and its deployment with older informal carers, a broad set of design recommendations for integrating digital mindfulness-based interventions into a digital health application is provided. Application of these recommendations and insights to the design of applications in this field should improve efficacy, engagement, satisfaction and overall usability.

The trial, and the study as a whole, has demonstrated that there is certainly scope for further research in the area of digital mindfulness-based interventions and connected health for older informal carers. The informal carers who participated in the trial reported back to the dementia service, through which they were recruited, how much they had benefited from the trial. This resulted in a joint submission with the dementia service to the HSE for funding to run an additional trial. This funding was granted and the trial was due to begin at the end of 2020. However, this has been postponed due to restrictions arising from the COVID-19 pandemic, and will likely take place later in 2021 instead. In anticipation of this trial, the Mind Yourself application has been updated and refined based on feedback received during the PhD trial. This new trial will evaluate the effectiveness of the application within a pragmatic randomised control trial (p-RCT) to see if it has a positive impact on a number of parameters, such as stress, sleep, quality of life and carer burden. p-RCTs are often used to evaluate the effectiveness of digital health technologies, where a strict RCT is not possible. The trial will take place over six months, with 60 informal carers, 30 of whom will receive the technology, and 30 who will not (they will receive usual care).

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Appendices

Appendix 1: Focus Group Protocols

1. Focus Group 1 Protocol

Main tasks (overview):

1. Parameters of health that are most important to people
2. Introduction to sensor technology
3. Test reactions to self-report questions;
    1. SF-36, HADS-A, De-Jong, TILDA
    2. Sleep Quality
    3. Physical activity
4. Concept of feedback from self-reporting and sensor technology

Focus Group Part 1

Topic 1. Feelings on health and wellness - overview of system/concept

- Thinking about your health and wellbeing, what do you think are the most important factors of wellness as someone grows older? Why?

Introduce sensor technology here, set the context of ambient assisted living and talk a little bit about the potential use of it.

For each of the below categories, ask:

- Would you find this data useful?
    - What would you do with it / how would you use it?
- If sensor data showed your patterns were changing, how would you feel about this? What do you think you would do in this situation?

General Health and Wellness questions:

- What areas of health and wellness are you most interested in?
- Sleep - subjective: how do you know when you have had a good or bad night's sleep?
    - What do you feel affects sleep? Are there any certain behaviours/activities (certain foods/drinks etc?); Is there anything you currently do to alter/improve your sleep patterns?
- Activity - household, hobby, social
    - At what parts of the day do you feel you are at your most active?
    - Is it important to have regular patterns?
    - Would you want to know how many steps you take on a given day? Why/why not? If you knew this information, do you think you would act on it? Are there days when you walk more than others?

    - Within the home, does the location of the rooms result in more or less activity?
    - How much time would spend inside vs outside the home?
    - Do you need to use stairs much throughout the day? How much if so?
    - What do you feel causes fear of falling? Do you think people have the same fear if they've never had a fall? How could fear of falling affect activity levels? Does it lead to activity restriction?
        - *Ask if anyone has had a fall.* What measures have been taken to prevent it from happening again (trip hazards, ice, leaves etc)?
- Blood Pressure
    - How important do you feel it is to keep an eye on blood pressure? How do you do this?
- Weight
    - How important an issue is weight in comparison to the others above? What steps would you take to maintain/lose weight?
- Stress
    - Does stress play a part in overall wellbeing? In what ways?
    - What causes stress and anxiety in an older population?
    - Are mood and wellbeing connected? How? Is there a connection between mood, fear of falling and activity levels?

Topic 2. Self-reporting

How do people feel about being asked about wellbeing?

- Read out questions to focus group participants and ask them to think about how they might answer the question. Find out what concerns come to people's minds when they read the question.

Questions to ask regarding Questionnaires:

- Do you understand them? To what extent? How would you change/re-word any difficult questions?
- How would you feel about answering these questions at home?
- How do you think older people in general would feel answering these questions at home?
- Do you feel these questions are relevant/important? Why?
- Would you feel motivated to answer these questions regularly?
- Would you want feedback? In what form?
- How would you feel about keeping a journal to record health and wellness activity?

Topic 3. Feedback - include in both focus groups

- Thinking about these types of questions, what type of information or feedback would you like on this. I.e. if you knew all this data was being collected from you, what would you want to get out of it?
- What information would you be most interested in?
- How would you act on negative information?

2. *Focus Group 2 Protocol*

Main tasks (overview):

1. Parameters of health that are most important to people
2. Opinions on wearable sensors
   1. health tracking/self-management
   2. wearable sensors - look, feel etc
   3. insights from sensors
3. Concerns about such an application?
4. Engagement with such an application on a daily basis

PART ONE - Health and Wellbeing

Topic: Feelings on health and wellness - overview of system/concept

- Thinking about your health and wellbeing, what do you think are the most important factors of wellness as someone grows older? Why?

Introduce sensor technology here, set the context of ambient assisted living and talk a little bit about the potential use of it.

Sleep

- How do you know when you have had a good or bad night's sleep?
- What do you feel affects sleep?
  - Are there any certain behaviours/activities (certain foods/drinks etc?);
- Is there anything you currently do to alter/improve your sleep patterns?

Activity - household, hobby, social

- At what parts of the day do you feel you are at your most active?
- Is it important to have regular patterns?

Falls/Gait/Steps

- Do you need to use stairs much throughout the day? How much if so?
- What do you feel causes fear of falling? Do you think people have the same fear if they've never had a fall? How could fear of falling affect activity levels? Does it lead to activity restriction?

Ask if anyone has had a fall. What measures have been taken to prevent it from happening again (trip hazards, ice, leaves etc)?

Blood Pressure & Heart Rate

- How important do you feel it is to keep an eye on blood pressure/heart rate? How do you do this?

Weight

- How important an issue is weight in comparison to the others above? What steps would you take to maintain/lose weight?

Stress

- Does stress play a part in overall wellbeing? In what ways?
- What causes stress and anxiety in an older population?
- Are mood and wellbeing connected? How? Is there a connection between mood, fear of falling and activity levels.

PART TWO - Wearable Sensors

Health Tracking - What examples can they think of? Do they track any parameters of their health? What difficulties have they faced trying to do this?

Health Self-management - What examples in daily life? What would/does motivate you to do this? What are some potential barriers to managing your own health?

Wearable Sensors - Get feedback on look, feel, size, comfort, battery life, charging, taking off/on. Ask them to try them on for a while. How would they feel wearing them while sleeping? How would they feel wearing them in social situations (intrusiveness etc)?

What they can tell you - how important/relevant/interesting are the following and why (show web apps/ipad apps for Withings and Fitbit):

- Sleep (how long, how long to fall asleep, time awake/light/deep, time in bed, percentage of ‘goal’ e.g. 8 hours/sleep score, day and week view- also possibly info on REM, and ‘coaching tips’ based on patterns - Jawbone)
- Activity (number of steps, number of miles walked, what a healthy average/goal is, when you were most active/inactive, number of floors climbed, day and week view)
- Heart rate (resting heart rate - so overall indication of steps, beats per minute throughout day, heart rate ‘zones’)
- Calories burned (based on combination of data from activity and heart rate)
- Periods of high stress (with potential ‘coaching’ tips as to how to address it - Jawbone)
- Day and week view to see *trends*
- Health and wellness tips and educational; messages to help improve sleep and reduce stress (this is more about the app…)

Feedback

Bring in Education and Alerts here.

- Thinking about these types of sensors, what type of information or feedback would you like on this. I.e. if you knew all this data was being collected from you, what would you want to get out of it?
- What information would you be most interested in?
- How would you act on negative information?

General

- Comfort/look/intrusiveness vs value of data and what sensors can you? Would one outweigh the other?
- Viewing data on device vs app - do they have a preference?
- Acceptance of intervention techniques - would they be willing to engage in these techniques/methods if it lead to improved sleep/reduced stress (techniques such as mindfulness meditation and exercise tips).
- How frequently would they be willing to perform these tasks? To what extent would location and time of day be important?

Topic: Potential concerns/issues regarding the collected data

Prompt: What might people want done with the collected information? E.g.

- View it for their own info
- Send it to a nurse / other healthcare professional for checks
- Send it to a family member.

Topic : Engagement and Technology Use

- What might encourage you, or others, to engage with these sorts of devices/applications? *Prompts*
    - The device/technology itself
    - How the application 'looks'
    - Whether it's easy to use
    - The types of questions
    - Does it provide something 'fun'
    - What would make them continue using it? What would entice them?

- Do you use iPads? Smartphones? PCs?
    - *what have they used/bought/been given and stopped using? Why?*
- What are some barriers to adoption?
- What apps do you use most? Why?
- What apps are 'easy' to use? Why?
- What apps are difficult? Why? Text size? Interface? Layout?
- Do they you health apps? Do they know of any?
- Do your friends use health apps?

Appendix 2: Usability Testing Protocols

1. *Usability Testing 1 Protocol – MindApp - March 2016*

Main tasks (overview):

PART 1 (Usability) - Video recorded task flow, Think Aloud. Semi-structured interview

User Tasks:
- Start at Dashboard and from here start navigation.
- Select Sleep and answer self-report question, View Sleep data (Day and Week), write a comment and view previous day's data also.
- View Steps data (Day and Week).
- View BP data (Day and Week)
- View Mindfulness Tips (Day and Week).
- Access calendar to view overview of data on another day

Parameters to assess usability:
1. Interaction
2. Size
3. Spacing
4. Ease of Use
5. Functionality
6. Engagement/Motivation
7. Look and feel
8. Navigation

PART 2 (Mindfulness and Wellbeing)
1. Background
2. Common misconceptions?
3. Initial views/opinions
4. Possible benefits
5. Methods and techniques
6. Perceived willingness/Barriers to adoption

Part One: Set up InVision prototype of app on iPads – Will be necessary to first explain concept behind app, do demo and then request/set tasks to establish task flow efficacy.
Video record interface of iPad and participants' interactions (and audio with participants)

Part Two: Background to Mindfulness - use short educational video as introduction. Outline possible health benefits, explain secular nature, quick example of techniques including how long per day etc., touch on neuroscience?

Equipment needed:
- Camera

- Empty memory card
- Audio recorder as backup
- Laptop with InVision prototype web app as back-up
- iPad

PART ONE: Usability

INTRODUCTION

Start off by giving some background to the link between high stress levels and poor sleep hygiene and explain how this can negatively affect wellbeing overall.
Explain concept of using wearable wristwatch sensor to track steps and sleep and how this data can then be viewed later on a mobile app.
Outline how this app is intended for older adults who wish to improve sleep hygiene through stress reduction and increased physical activity using visual data, feedback and educational tips.
Make clear that this is an early prototype and the primary aim at this time is to establish areas which need to be improved, removed, adapted or maintained in terms of usability and navigation

DEMO FIRST

User Tasks

Home Page (Dashboard)
Can you describe what you are looking at? Is the text legible?

From here, select **Sleep**

- Ask user what they could do next from here? Prompt - Answer the self-report question and hit submit to continue. Is the text used for questions and options legible? Is it clear where to select option?
- View data and say aloud what you see - is it clear what is presented?
- Are the icons at top of page (Home, Calendar, Arrows Day/Week) clear? Are these icons a good size?
- Is the text in the Tip section legible? What does the red button next to the Tip mean?
- How would you leave a comment?
- Looking at the graph, can you describe what you are looking at? How would you go back to the previous screen?
- From the **Sleep** screen, view your **weekly** data.
    - How would you do this? Was this hard to figure out?
    - What does each colour in the graph represent?
    - What do the dots represent?
    - How would you go back and view today’s sleep data?
- Next view yesterday's Sleep data and then go back to today

From the Sleep day screen, select and view **Steps** information

- View data and say aloud what you see - is it clear what is presented?

- What do the colours in the graph represent?
- Is the text in the Tip section legible? What does the red button next to the Tip mean?
- How do you know what part of the app you are in? Is this obvious or difficult to see?
- From here, select **Steps Week** view
    - What do the bars in the chart represent?
    - What do the numbers on the vertical axis refer to?
    - Is the text below the bars legible/right size/colour?
    - How would you compare Steps Week data with Sleep Week data?
- Go back to Day view

Next go to **Blood Pressure Day** view

- Is the data presented easy to understand?
- How do you find the colours?
- What does HR refer to?
- From here select **Week** view
    - Is it clear what the bars for each day refer to?
- Go back to Day view

Next go to **Mind Day** view

- What can you see? Are there instructions as to what to do?
- Is the video big enough?
- From here select Week view
    - Is it clear what you are presented with here?
    - What would your next step on this screen be? Prompt user to go to a day

Get an **overview** of all your data for **March 17th**

Usability Feedback

- Did you find it hard to navigate the app? Did you feel 'lost' at any time?
- Did you find any parts of the app intuitive?
- Were the icons and symbols large enough?
- Were the colours ok?
- Which areas do you think might be difficult to use for an older adult?
- Which aspects of the app did you find most interesting?
- Which aspects of the app did you find least interesting?
- Can you think of anything else that could be added to this app?

Task Flow Narrative

Task Flow Narrative
Dashboard to display glanceable summary

User opens app and is presented with **home screen** showing four options as *tiles*: sleep, steps, blood pressure, self-report. Note: these four options will then remain as permanent (header or footer) overlays throughout app

If user selects **sleep**, she is brought to sleep screen displaying last night's sleep data:

- time spent in bed
- time spent asleep
- sleep score percentage
- breakdown/summary showing deep, light, and awake numerically
- interactive sleep graph - bar chart(user can tap on section of bar chart to display time spent in that particular sleep state - interaction brings up number below press and does not cause page to change)
- Educational tips based on previous night's sleep score - quality of sleep (score) will determine tip type

User can view sleep data as day view (as above) and can scroll through days left to right, or can select week view which will bring user to page showing summary of sleep data for previous week - also scrollable left to right.
User can select 'self-report' to answer questions about sleep
User can also *leave a comment* to provide further contextual information by entering comments into text field after tapping 'comment' button
User can select 'archive' to view older educational tips
(previous comments left - to appear at bottom of that day's graph)

If user selects **steps**, she is brought to steps screen displaying today's steps data:

- number of steps
- distance covered (miles or km?)
- sleep score percentage - goal to be set beforehand - with user?
- interactive steps graph - bar chart to display steps in 30 minute intervals (user can tap on section of bar chart to see time and number of steps - interaction brings up info below the press and does not cause user to leave page) - might be better to break up steps into morning, afternoon, evening as a less cluttered view of steps i.e. bar for morning, bar for afternoon etc - user could then tap on morning bar and see 1243 steps - or even have number of steps as a label so not necessary to touch bar
- Education tips based on *previous day's* step score - number of steps will determine tip type/category

User can view steps data as day view (as above) and can scroll through previous days left to right , or can select week view which will bring user to page showing summary of data for previous week - also scrollable left to right for more information.
User can select 'self-report' to answer questions about activity
User can also *leave a comment* to provide further contextual information by entering comments into text field after tapping 'comment' button
User can select 'archive' to view older educational tips
(previous comments left - to appear at bottom of that day's graph)

If user selects **blood pressure**, she is brought to blood pressure screen displaying:

- user lands on day view - if she hasn't taken reading, message will appear saying no data. If she has, three values for that day will be shown - three colours
- user can select week view of blood pressure data (average)
    - colour coded bar chart showing SYS, DIA, HR
    - User can view BP data as week view showing BP numbers data in bar chart form for previous week - scrollable left to right.
- Education tips provided if user has used cuff that day - score will determine tip type/category (will need to be personalized to each user based on their first four weeks' bp data)

User can select 'self-report' to answer questions about blood pressure
User can also *leave a comment* to provide further contextual information by entering comments into text field after tapping 'comment' button
User can select 'archive' to view older educational tips
(previous comments left - to appear at bottom of that day's graph)

If user selects **mind (*name to be confirmed),** she is brought to a screen displaying two options:

- answer questions now
    - User selects 'answer questions' and is presented with different questions and question types each day
    - User can also *leave a comment* to provide further contextual information by entering comments into text field after tapping 'comment' button
- mindfulness techniques
    - User selects 'mindfulness' techniques and is presented with a different technique (in varying formats e.g. text or video) each day
    - User can also *leave a comment* to provide further contextual information by entering comments into text field after tapping 'comment' button
    - User can view archive of previous mindfulness techniques and previous comments left

  Note:: these options to remain as permanent overlays at top of interface while user is in this section of app

2. Usability Testing 2 Protocol – MindApp - October 2018

Main tasks (overview):

PART 1 (Usability) - Video recorded task flow, Think Aloud. Semi-structured interview

User Tasks:

- Start at Dashboard and from here start navigation.
- Select Sleep and answer self-report question, View Sleep data (Day and Week), and view previous day's data also.
- View Steps data (see tip/feedback).
- View BP data (Day and Week)
- View Mindfulness Content (Day)
- Access calendar to view overview of data on another day (March 17)

Parameters to assess usability:

1. Interaction
2. Size
3. Spacing
4. Ease of Use
5. Functionality
6. Engagement/Motivation
7. Look and feel
8. Navigation

Nielsen Usability Testing: **Efficiency, Satisfaction, Learnability, Memorability, Errors**

PART 2 (Mindfulness and Wellbeing)

1. Background
2. Common misconceptions?
3. Initial views/opinions
4. Possible benefits
5. Methods and techniques
6. Perceived willingness/Barriers to adoption

Part One: Set up InVision prototype of app on iPads – Will be necessary to first explain concept behind app, do demo and then request/set tasks to establish task flow efficacy.
Video record interface of iPad and participants' interactions (and audio with participants)

Part Two: Background to Mindfulness - use short educational video as introduction if feasible. Outline possible health benefits, explain secular nature, quick example of techniques including how long per day etc.

Equipment needed:

- Camera
- Empty memory card
- Audio recorder as backup
- Laptop with InVision prototype web app as back-up
- iPad

PART ONE: Usability

INTRODUCTION

Start off by giving some background to the link between high stress levels and poor sleep hygiene and explain how this can negatively affect wellbeing overall.
Explain concept of using wearable wristwatch sensor to track steps and sleep and how this data can then be viewed later on a mobile app.
Outline how this app is intended for older informal carers who wish to improve sleep hygiene through mindfulness-based stress reduction and increased physical activity using visual data, feedback and educational tips.
Make clear that this is a prototype and the primary aim at this time is to establish areas which need to be improved, removed, adapted or maintained in terms of usability and navigation

DEMO FIRST

User Tasks

Home Page (Dashboard)

Can you describe what you are looking at? Is the text legible? What do the tiles represent/show? What should happen next?

From here, select **Sleep**

- Ask user what they could do next from here? Prompt - Answer the self-report question and hit submit to continue. Is the text used for questions and options legible? Is it clear where to select option?
- View data and say aloud what you see - is it clear what is presented?
- Are the icons at top of page (Back Arrow, Calendar, Arrows for Day/Week) clear? Are these icons a good size?
- Is the text in the Tip section legible?
- What does the red button in the top corner mean?
- Looking at the graph, can you describe what you are looking at? How would you go back to the previous screen?
- From the **Sleep** screen, view your **weekly** data.
  - How would you do this? Was this hard to figure out?
  - What does each colour in the graph represent?
  - What do the dots represent?
  - How would you go back and view today’s sleep data?
- Next view yesterday's Sleep data and then go back to today

From the Sleep day screen, select and view **Steps** information

- View data and say aloud what you see - is it clear what is presented?
- What do the colours in the graph represent? Are the colours clear and easy to decipher?
- Is the text in the Tip section legible?
- What does the red button at the top right of the screen mean?
- How do you know what part of the app you are in? Is this obvious or difficult to see?
    - What do the bars in the chart represent?
    - What do the numbers on the vertical axis refer to?
    - Is the text below the bars legible/right size/colour?
    - How would you compare Steps data with Sleep data?

Next go to **Blood Pressure Day** view

- Is the data presented easy to understand?
- How do you find the colours?
- What does HR refer to?
- From here select **Week** view
    - Is it clear what the bars for each day refer to?
- Go back to Day view

Next go to **Mind Day** view

- What can you see? Are there instructions as to what to do?
- What day and week of the mindfulness course are we in?
- Where can you find a guide for this week's content?
- How do you access the mindfulness content?
    - Is it clear what you are presented with here?
    - What would your next step on this screen be? (Prompt user to select a meditation)
- Is the text legible? How do you exit this section?
- How do you control the mindfulness audio guide?
- Is it clear from this screen what mindfulness practice is involved in Week X?
- What do the two tiles on the right of the screen do?
- How can you self-report from the Mind screen?
- Can you select Week View in the Mind section of the app?

Final Tasks

- Get an overview of all your data for Week 5 (*specific date to be inputted to prototype*)
- Go to dashboard for today. Select a meditation from Week X Mind section. Play audio, then exit Mind section. Return to dashboard, and then select sleep data for today. View daily tip.

Usability Feedback

- Did you find it hard to navigate the app? Did you feel 'lost' at any time?
- Did you find any parts of the app intuitive?
- Were the icons and symbols large enough?
- Were the colours ok?
- Was it clear which parts were 'clickable/tappable'?
- Which areas do you think might be difficult to use for an older adult?
- Which aspects of the app did you find most interesting?

- Which aspects of the app did you find least interesting?
- Would you feel motivated/engaged to use this app regularly? Why/why not?
- Can you think of anything else that could be added to this app?

PART TWO - Mindfulness and Wellbeing

Mindfulness - Introduction: First elicit any prior knowledge of mindfulness and discuss. Play introduction video to start off interview.(https://www.youtube.com/watch?v=HmEo6RI4Wvs)

- What are your initial feelings towards this type of practice?
- How would you feel doing this every day?
- What possible health benefits were mentioned in the video?
- If practicing these types of techniques meant there was a possibility you would feel less stressed and could therefore sleep better, would you be more inclined to try it out?
- What possible barriers could you see there being?
- Would you feel motivated to use this app?

Appendix 3: Interview Protocols (Requirements Stage)

1. *Semi-structured Interviews 1 protocol*

Mindfulness and Wellbeing

Mindfulness – Introduction: First elicit any prior knowledge of mindfulness and discuss. Play introduction video to start off interview.

- What are your initial feelings towards this type of practice?
- How would you feel doing this every day?
- What possible health benefits were mentioned in the video?
- If practicing these types of techniques meant there was a possibility you would feel less stressed and could therefore sleep better, would you be more inclined to try it out?
- What possible barriers could you see there being?
- Would you feel motivated to use this app?

Feelings on health and wellness

- Thinking about your health and wellbeing, what do you think are the most important factors of wellness as someone grows older? Why?

Sleep:

- How do you know when you have had a good or bad night's sleep?
    - What do you feel affects sleep? Are there any certain behaviours/activities (certain foods/drinks etc?);
    - Is there anything you currently do to alter/improve your sleep patterns?

Activity

- At what parts of the day do you feel you are at your most active?
- Is it important to have regular patterns?

Blood Pressure & Heart Rate

- How important do you feel it is to keep an eye on blood pressure/heart rate? How do you do this?

Stress

- Does stress play a part in overall wellbeing? In what ways?
- What causes stress and anxiety in an older population?
- Are mood and wellbeing connected? How? Is there a connection between mood, fear of falling and activity levels.
- How do/would you deal with stress?

2. *Semi-structured Interviews 2 (Informal Carers) protocol*

Topic 1.Challenges and Impacts on carer:

- Can you describe a typical day in your role as a carer?
  - *Prompts: how much time spent with person; main tasks*
- Can you tell me about your experience of caring for someone with multiple conditions and/or dementia?
  - *Prompts: Length of time; responsibility; how it fits into life*
- What are the main challenges you face in your role as carer?
  - *Prompts: caring at home; medications; dealing with health services*
- How does your caring affect your own life (for example your health or lifestyle)?
  - *Prompts: For example do you experience any social isolation, stress, anxiety, sleep disruption.*

Topic 2. Transitions through the health system

- Do you and the person you care for receive any formal care support
  - *Prompts: home help, public health nurse, personal assistant, day centre, voluntary organizations or other community supports?*
- Are there healthcare professionals that you regularly interact with as part of caregiving?
  - *Prompt: GP, public health nurse, pharmacist, other?*
- Do you get conflicting information from different healthcare professionals?
- How would you describe the communication between you and the healthcare professionals that you have interacted with? Do you think it could be improved?
- What or who are your key sources of support?
- Have your expectations regarding support been met?
  - Who has helped you most in coping with caregiving?
  - Who could have supported you more?

Topic 3. Care plan and Training

- If the person you care for was admitted to hospital how was the transition from hospital to home?
  - *Prompts: Difficulties, challenges, impact on person and family?*
- Was the person that you care for given a treatment plan? If so, what did this look like?
  - *Prompts: Paper-based? Interventions to self-manage?*
- Have you received any training, education or advice on caregiving? How did you find out about the training? Who provided the training and what did it entail?
- Did you receive any training for caring?
- If yes did this training happen in the hospital or at home?
- Were you offered any personal support as a carer? Either formal or informal?
  - *Prompts: help from other family members / informal carers; referrals to community support groups*

Topic 4. Behavioural Change and Self Management

- Does your care involve motivation for a change of behaviour*?*
    - *Prompt for example exercising, no smoking, low salt, fluid restriction*
- What strategies do you use to encourage behaviour change for the person that you care for?
    - *Use of education, involving other family?*
- If caring in the person's home, what are the challenges in managing the health conditions at home?
    - *Prompts: physical, financial, day-to-day management*
- How do you reach the decision that professional medical assistance is required i.e. hospital/ GP?
- How do you acquire knowledge, sources of information/education on health conditions?
    - *Prompt: leaflets from GP or other doctors/nurses; Internet?*

Topic 5. Technology

- Do you need to use any medical or technical devices as part of your caregiving? (devices to treat or to monitor?)
- Do you look up information online to learn more about the health conditions of the person you care for?
- What device do you use to go online? Laptop, desktop, tablet, phone, other?
- Any particular app or website that you use?

Final Questions

- Is there anything that I have not asked you about that you would like to add?

Appendix 4: Ethical Considerations for Main Trial

Ethical Approval

Ethical approval to conduct the study was provided by Dundalk Institute of Technology School of Health and Science Ethics Committee. Topics that were covered in the ethics application included:

(1) Informed consent

- All participants were given written and verbal information about the project so that they could make an informed decision about participation in the project.
- They were provided with opportunities to ask questions, prior to the project beginning and while the project was in process.
- Participants were made aware in the information leaflet and verbally that they had the right to withdraw at any point, or to refuse to allow data to be used and that there would be no adverse consequences for them in terms of their right to access services.

(2) Confidentiality

- The participants were informed that their identity is confidential, and their personal information is stored securely.
- Publications – Participants were informed that reports may be published outlining the study, but that their identity will remain anonymous.

(3) No harm

To minimize any anxiety from being assessed and monitored:

- Participants were given full written and verbal information about the study in order to give informed consent about participation.
- They had ample opportunities to ask queries, including having the phone numbers of the researchers so that they may call about any queries or uncertainties they had.
- The researcher was fully trained and alert to potential concerns or worries that participants may have and will be able to give full explanations / reassurance as needed. The PhD student worked with the primary supervisor who has extensive experience in conducting technology home deployments with older people.
- Participants were able to withdraw from the project at any time and without giving reasons.
- If they had any concern about the data from the sensors, they could follow the procedures as outlined in the opening paragraph of this section.

The participant information leaflet provided detail and information on interpreting the sensor data and what to do if the participant was worried about something. For example, if a high blood pressure reading was recorded and the participant was worried, the recommended protocol was to take the reading again, and if still worried, to go to a pharmacist and have a reading taken. It was unlikely that the activity data (step count) and sleep data would cause anxiety, although they would increase the participant's awareness of these aspects of their wellbeing. Should any concerns have arisen about this, the participants were encouraged to contact the researcher. They could also raise this with their GP and were provided with information and contact details of local support services that might be of benefit to them. The self-report questions were piloted prior to the study to ensure that they would not cause undue stress or anxiety while answering them.

Data Privacy

All data was made anonymous with only an identifier code to denote identity. Only the researcher and primary supervisory had access to these codes, as well as to the datasets for the purposes of analyses. It is standard procedure in NetwellCASALA for all computers to be password protected. Questionnaire data and any field notes/observations was converted into digital format, for storage on password protected computers. Once this occurred, all paper records were shredded. Audio recorders were used during interviews with consent from participants. These were then transcribed, linked to an id number, and any identifiable information was stripped away from data. Contact details about participants were also stored separately from data.

Sensor data came directly into the CABIE-SIMS platform, and was accessible to the researcher and primary supervisor through secure logins to the SIMS platform. The CABIE-SIMS platform is GDPR compliant and has been through a detailed Data Protection Impact Assessment.

Data protection legislation was and will continue to be upheld in line with the General Data Protection Regulation (GDPR), 2018. In order to comply with the GDPR all records not required will be destroyed 5 years after completion of data analysis. This is in line with Article 5 of the GDPR, which states "personal data should only be kept in a form which permits identification of data subjects for as long as is necessary for the purposes for which the personal data are processed”. Following completion of the PhD study, all data will be transferred to the primary supervisor who will be responsible for its deletion.

Appendix 5: Interview Protocols (Trial)

1. *T1 Interview protocol (phone call interviews)*

Stress and Overall Wellbeing

- How would you describe your level of stress at the moment?
- Have you noticed a change in recent weeks? If so, how?
- Has there been any change in circumstance?
- Has there been any change to caring process?
- Has there been any change in:
    - Level of activity
        - What?/When/where?
    - Sleep quality
        - Interruptions?/Length?/Daytime naps?/

Experience with Sensor Tech

- Comfort living with sensors
    - Intrusive?
- Wearing and using (watch, BP cuff, iPad)
- When do you use iPad? Same time each day? Routine?

Self-Report Questions

- You have been answering questions on the iPad everyday or so. How do you find answering these questions? (Easy/difficult)
- Is there anything you like or don't like about answering them?
- The questions related to your general wellness, how rested you are, how you slept etc. Do you think answering these raised your awareness of your health and wellness in any way?

Sensor-based charts

- Have you looked at the sleep, steps, and blood pressure charts?
- Did you notice any patterns in the charts?
- Is this data useful for you? If so how?
- How could you act upon this data?
- What additional information might make it more useful?

Mindfulness

- How are you finding the mindfulness content overall?
- How often do you practice?
- Have you noticed a change in wellbeing? How?
- Do you think your level of stress has changed?
- Which techniques are you enjoying? Which do you not enjoy? Why?

- What challenges/obstacles/difficulties are there?
- What would you change about this element to the application?
- Is the audio guide helpful?
- Are the text instructions useful?
- Have you used the extra materials?
- Will you continue to practice going forward?

Tips and Feedback

- Are you reading the daily tip for each section?
- Are they useful?
- Is there anything else you would like to see in this section?

Trial-Related

- What are you enjoying most about taking part in the research project?
- What have you liked the least about taking part so far?
    - *Prompts - of taking part in a trial; using the tech; learning the tech, is it manageable?*
- Describe a typical day for you using the system.
  Prompts - using it at certain times of day / days of week, or under certain circumstances; where
    - *do you use it.*

Health-Related / Efficacy

- Do you think the system helps with managing stress?
    - *Prompt: How?*
- Do you think using the system has had any impact on how aware you are of your health and wellbeing?
    - In what way? If not- why?
    - *Prompt – elaborate on what parts of system they are referring to – e.g. just taking readings.*
- Do you know what a good or healthy range should be for your readings? I.e. do you know what is a healthy blood pressure reading to you? If yes ,did you know this before using the system?
    - Is knowing the readings important to you? That is, knowing what your blood pressure (for example) readings are?
    - Has it had any impact on the management of your health.
    - In what way?
        - *If not* Why do you think that is? What do you think needs to be different for it to help you?
- Has your attitude to managing your health changed since starting the trial?
    - Could you elaborate on how?
    - Why do you think this is?
- Has this trial/self-managing had any impact on other aspects of your life? *Prompts e.g. different / new interactions with family / grandkids, e.g. around tech usage.*

Tech-Related / Training

- How have you found using the equipment?
  Prompt–app, as well as hardware .Prompt on each device /app and
- What has been the biggest challenge?
- What has surprised you most about using it?
- Have you had any help with using the app/iPad?
  - *Prompt from family/friends?*
  - Do you feel this help has been useful? In what way?

Usability

- How easy/difficult are you finding the app to use overall?
- Do you get lost at any time?
- Did you stop using it for any reason?
- What aspects do you like most?
- What aspects do you not like?
- What changes would you make?
- Future use of the app
  - Is there anything you would change about the system? *Prompt Anything else you think it should do? Or anything it should do differently?*

Last Comments

- What would you see as the potential benefits of having this type of system?
- What would you see as the drawbacks?
- Is this something you might use on an ongoing basis in the future?

Wrap-up

- So just to wrap up, could you tell me 3 good things about the app so far? Could you tell me 3 bad things about app?

2. T2 Interview protocol (main trial exit interviews)

Do a walkthrough and ask questions throughout. Start at dashboard and cover all screens.

Stress and Overall Wellbeing

- How would you describe your level of stress at the moment?
- Have you noticed a change in recent weeks? If so, how?
- Has there been any change in circumstance?
- Has there been any change to caring process?
- Has there been any change in:

    - Level of activity
        - What?/When/where?
    - Sleep quality
        - Interruptions?/Length?/Daytime naps?/

Experience with Sensor Tech

- Comfort living with sensors
    - Intrusive?
- Wearing and using (watch, BP cuff, iPad)
- When did you use iPad? Same time each day? Routine?
- Privacy of data
    - How would you feel about sharing data such as this? With whom? What circumstance?

Self-Report Questions

- You answered questions on the iPad everyday or so. How did you find answering these questions? (Easy/difficult)
- Was there anything you liked or didn't like about answering them?
- The questions related to your general wellness, how rested you are, how you slept etc. Do you think answering these raised your awareness of your health and wellness in any way?

Self-Report Charts

- Here are some of the charts coming from the daily questions.
- Have you looked at these charts over the past few weeks?
- Did you notice any patterns in the charts?
- Would this data be useful for you? If so how?
- How would you act upon this data?
- What additional information might make it more useful?

Activity Charts

Here are some of the charts coming from the smart watch.

- Have you looked at these charts?
- Did you notice any patterns in the charts?
- Would this data be useful for you? If so how?
- How would you act upon this data?
- What additional information might make it more useful?

Sleep Charts

Here are some of the charts coming from the bed sensor.

- Have you looked at these charts over the past few weeks?
- Did you notice any patterns in the charts?
- Would this data be useful for you? If so how?

- How would you act upon this data?
- What additional information might make it more useful?

Vitals Charts

Here are some of the charts coming from the BP cuff.

- Have you looked at these charts over the past few weeks?
- Did you notice any patterns in the charts?
- Would this data be useful for you? If so how?
- How would you act upon this data?
- What additional information might make it more useful?

Mindfulness

- How did you find the mindfulness content overall?
- How often did you practice?
- Did you notice a change in wellbeing? How?
- Do you think your level of stress has reduced?
- Which techniques did you enjoy? Which did you not enjoy? Why?
- What challenges/obstacles/difficulties were there?
- What would you change about this element to the application?
- Was the audio guide helpful?
- Was the text instruction useful?
- Did you use the extra materials?
- Will you continue to practice going forward?

Tips and Feedback

- Did you read the daily tip for each section?
- Were they useful?
- Is there anything else you would like to see in this section?

Trial-Related

- What have you liked most about taking part in the research project?
- What have you liked the least about taking part?
    - *Prompts - of taking part in a trial; using the tech; learning the tech, is it manageable?*

- Describe a typical day for you using the system.
  Prompts - using it at certain times of day / days of week, or under certain circumstances; where do you use it.

Health-Related / Efficacy

- Do you think the system helps with managing stress? - *Prompt: How?*

- Do you think using the system has had any impact on how aware you are of your health and wellbeing?
    - In what way? If not- why? - *Prompt – elaborate on what parts of system they are referring to – e.g. just taking readings.*
- Do you know what a good or healthy range should be for your readings? I.e. do you know what is a healthy blood pressure reading to you? If yes ,did you know this before using the system?
    - Is knowing the readings important to you? That is, knowing what your blood pressure readings are?
    - Has it had any impact on the management of your health.
    - In what way?
        - *If not* Why do you think that is? What do you think needs to be different for it to help you?
        - Since our last interview, do you think your health has changed in any way?
        - Could you elaborate on how?

- Has your attitude to managing your health changed since starting the trial?
    - Could you elaborate on how?
    - Why do you think this is?
- Has this trial/self-managing had any impact on other aspects of your life?

Tech-Related / Training

- Since our last interview, has the way you have been using the app changed? For example do you think you are using it more, less, differently? If yes, in what way? If not, why?
- How have you found using the equipment? - *Prompt–app, as well as hardware Prompt on each device /app and*
- What has been the biggest challenge?
- What has surprised you most about using it?
- Have you had any help with using the app/iPad? - *Prompt from family/friends?*
- Do you feel this help has been useful? In what way?
- Have you noticed any changes in the app? For example, how something looks, or works?

Usability

- How easy/difficult did you find the app to use overall?
- Did you get lost at any time?
- Did you stop using it for any reason?
- What aspects did you like most?
- What aspects did you not like?
- Is there anything you would change about the system?
- Is there anything you would change about the trial in general?

Last Comments
- What would you see as the potential benefits of having this type of system?
- What would you see as the drawbacks?
- Trust?

- Share data?
- Who do you think this information would be useful for? Self/Family/GP/Hospital
- Is this something you might use on an ongoing basis in the future?
- Under what circumstance do you think it could be used?

Wrap-up

- So just to wrap up, could you tell me 3 good things about the app? Could you tell me 3 bad things about app?

Appendix 6: Exit Interviews - Thematic Analysis Summary

This appendix outlines a number of examples to demonstrate the coding process applied to the transcripts from the interviews of the main study, the results of which were presented in Chapter 9. Within each example, a number of quotes from transcripts are provided outlining how quotes (in red) were coded initially (in blue) and then clustered, followed by categorization into sub-themes and themes.

Example 1

Quote:
P25: He can get very agitated.(Care Recipient(CR) in state of distress) That's the one thing and this, taking him off, this was helping, this medication was helping… It calmed him quite a bit. (Medication can help CR) But since they've started to reduce it, the levels of stress for him, I feel for him as well. (CR's distress affects the carer) because he gets himself into an awful state. (CR in state of distress)
R: Yes, and he can't get out of it then.
P25: No, he still sometimes thinks he's working… And he wants to go to Cork or he wants to go to… He has a court case in Ballydehob.
R: He thinks he's late for work.
P25: Or God knows where, you know… And no matter if you say, 'Alan, no, you're retired'. Like he's retired 22 years… But he's still back in that work situation. That work situation must have been very stressful for him really, (CR in state of distress) when I think of it.

Quote:
P24: But see, this is a whole new environment for people. (Carers unprepared for caring responsibilities) I mean you know, this dementia. I mean one day, things are normal, then all of a sudden, you're thrown into this, you know. (Carers unprepared for caring responsibilities) (Unpredictable nature of caring)

Quote:
R: So everything aside, so everything in terms of your lifestyle and everything has remained the same?
P23: Well, Jack has got worse… (CR deteriorating) He's very hard to understand. His speech and he's got more…(CR difficult to understand)
R: Tremors?
P23: Yes.
R: Yes. Because he's Parkinson's as well?
P23: Yes.

Quote:
R: When you're feeling stressed, do you feel it physically?
P22: Oh, I can feel it now, my chest now… I get the tightness here in the chest (Care-related stress can affect physical health) with it and there is damage to my lungs with the spaces and that. I can feel it actually tightening up here (Care-related stress can affect physical health) … You know, physically, you know. But then once I calm down, it goes back down to normal. (Care-related stress can affect physical health)
R: Goes away?

P22: Yes

Table 1 - Example of Clusters of relevant meaning

Cluster of relevant meaning	Category/Code:
P25: He can get very agitated I feel for him as well because he gets himself into an awful state. This medication was helping… It calmed him quite a bit Since they've started to reduce it, the levels of stress for him. I feel for him as well. He's still back in that work situation. That work situation must have been very stressful for him really	CR in state of distress CR's distress affects the carer Medication can help CR
P24: This is a whole new environment for people.. this dementia One day, things are normal, then all of a sudden, you're thrown into this, you know.	Carers unprepared for caring responsibilities Unpredictable nature of caring
P23: Jack has got worse… He's very hard to understand. His speech and he's got more…	CR Deteriorating CR difficult to understand
P22: I can feel it now, my chest now I can feel it actually tightening up here Once I calm down, it goes back down to normal.	Care-related stress can affect physical health

Table 2 - Example of Themes emerging from categorised clusters of data

Category/Code	Sub-theme	Theme
CR in state of distress CR's distress affects the carer Carers unprepared for caring Responsibilities Unpredictable nature of caring Care-related stress can affect physical health	The nature of dementia and its impact on the carer	Care Related Stress and its Management

Medication can help CR Changing medication can add to CR distress	Changes in circumstance and external factors or influences	Care Related Stress and its Management

Example 2

Quote:
P26: I think the mindfulness did have an effect in allowing me to sleep better (Mindfulness improves sleep) and just clear my head (Mindfulness helped clear head when trying to sleep)… You know, more than, yes, just more clear in my head (Mindfulness helped clear head when trying to sleep)… You know, it did have that.
R: And it would affect your sleep as well, right. That's interesting.
P26: Yes. I just kind of felt that I was a bit more relaxed (Felt relaxed after mindfulness) and just, there were times like it was finished, you know. There was a few times now it was finished and like I was supposed to turn off the thing and then, you know, 20 minutes later, I wake up and go, 'Jeez, where's that?'… I'd just fall asleep (Mindfulness improves sleep) , like you know what I mean, so obviously it did have the effect of relaxing me anyway (Felt relaxed after mindfulness).

Quote:
P28: Now, I do wake a lot in the night (Experiences broken sleep) and all of that… But I'm ok with that once I can get back to sleep, you know.
R: So that's the key? It's the getting back to sleep?
P28: It is getting back to sleep… And that's the part that if you put on something and help yourself to relax back into the sleep, that's the bit that benefits me (Mindfulness improves sleep), (Felt relaxed after mindfulness)..
R: The meditation element?
P28: Yes. Yes.
R: So would you put on some audio or would you just do it in your head?
P28: I used to do it in my head, but now I put on some audio (Uses mindfulness to help sleep).
R: Yes. It's more effective?
P28: Yes. Yes. Yes.

Quote:
R: And do you find it hard to get to sleep?
P25: No.
R: So if you wake up, you can…?
P25: Well no, if I wake up, when I wake up, it does take me a while to get back (Experiences broken sleep) because I can start solving problems and I can start, you know, in my head (Racing mind impacts sleep) … My head can go a bit… Then I have to take myself under control… And try and calm it down or change it (Uses mindfulness to help sleep) (Uses mindfulness to stop mind racing).
R: So what technique do you use for that?

P25: Oh God, I breathe… I do mindfulness (Uses mindfulness to help sleep).You know, things like that. I do the body scan (Uses mindfulness to help sleep)., you know… You know that and that one is the one that I find helps me most (Mindfulness improves sleep).
P25: You see, it goes, I think it's because, right, I get anxious and worried about something… (Anxiety impacts sleep) And then if I start doing body scan, you're concentrating on it (Uses mindfulness to help sleep and it takes, you know, it takes 20 minutes to a half an hour.
R: Yes, it's hard to do.
P25: To do it… And if you keep bringing yourself back, eventually next thing I'm gone asleep (Mindfulness improves sleep).
R: Yes, plus eventually you can't think about anything else because you're -
P25: Yes, you have to keep, you know, on. Your mind is brought away from what was upsetting me (Mindfulness helps manage anxiety), you know.

Table 3 - Example of Clusters of relevant meaning

Cluster of relevant meaning	Category/Code:
P26: I think the mindfulness did have an effect in allowing me to sleep better and just clear my head…I was a bit more relaxed it did have the effect of relaxing me anyway. I'd just fall asleep	Mindfulness improves sleep Mindfulness helped clear head when trying to sleep Felt relaxed after mindfulness
P28: I do wake a lot in the night if you put on something and help yourself to relax back into the sleep, that's the bit that benefits me. I used to do it in my head, but now I put on some audio.	Experiences broken sleep Uses mindfulness to help sleep Mindfulness improves sleep Felt relaxed after mindfulness
P25: when I wake up, it does take me a while to get back because I can start solving problems and I can start, you know, in my head Then I have to take myself under control… I breathe… I do mindfulness that one is the one that I find helps me most. I get anxious and worried about something… if I start doing body scan, you're concentrating on it and it takes, you know, it takes 20 minutes to a half an hour. keep bringing yourself back, eventually next thing I'm gone asleep. Your mind is brought away from what was upsetting me,	Experiences broken sleep Racing mind impacts sleep Anxiety impacts sleep Uses mindfulness to stop mind racing Uses mindfulness to help sleep Mindfulness improves sleep Mindfulness helps manage anxiety

Table 4 - Example of themes emerging from categorised clusters of data

Category/Code	Sub-theme	Theme
Uses mindfulness to help sleep Uses mindfulness to stop mind racing	Mindfulness and its effect on sleep	Caring, Sleep and Physical Activity

Mindfulness improves sleep Mindfulness helped clear head when trying to sleep Felt relaxed after mindfulness Mindfulness helps manage anxiety		
Experiences broken sleep Racing mind impacts sleep Anxiety impacts sleep	Impact of Caring on Sleep	Caring Sleep and Physical Activity

Example 3

Quote:
R: And you see the stress score?
P21: Yes.
R: Is that useful to look at?
P21: It was, it was. Now, there was some days it was… Nothing came up there.
R: You obviously missed that day. And if you saw that your stress score was very low, would you think about why that day for something like that?
P21: I'd know why. You know. Like look at this day.(Using data feedback to reflect)

Quote
R: That's good to know. And just in general, what did you like about taking part in this trial?
P22: It was interesting, you know, and it gives you a different outlook (New perspectives) in the way it affects different people, you know. You're more aware of the way it'd affect me (Raised awareness) Normally just before, I'll go through this. (Implementing behaviour change) It's an everyday thing. I wouldn't give it any thought. Now you're aware of how it affects you. (Raised awareness)
R: Stress, you mean
P22: Yes, stress-wise and actually how to get out of it (Has learned stress management techniques), you know.
R: All right. That's good to know. So going forward, what do you want to have gained from all of this?
P22: Well, the anxiety and all, you know. Just to relieve that, you know. I can now (Has learned stress management techniques), but I still get that bit anxious and that, you know… (Anxiety hasn't gone away – but can manage it now) But with that there (Mind App), *it's not too bad, you know. It gives you something to fall back on, you know… Like it'd help. now (Has learned stress management techniques)*

Quote:
P25: It's interesting. I found it very interesting… Like just seeing my blood pressure, how it was one day and how it was the next day, or at different times in the day… (Using data feedback to reflect) And also my sleep pattern and if I was very annoyed or upset, I'd go and just do the three minute (Implementing stress management techniques) and that, you know… Whereas normally, I wouldn't take the time (Implementing behaviour change) to do a three-minute break, you know… That kind of thing… Normally I wouldn't. I would have an idea of how well I slept possibly… But doing something like that, you are finding out exactly how you're behaving and how your life is going, (Raised awareness) you know.

Table 5 - Example of Clusters of relevant meaning

Cluster of relevant meaning	Category/Code:
P21: I'd know why. You know. Like look at this day	Using data feedback to reflect
P22: Different outlook You're more aware of the way it'd affect me… Normally just before, I'll go through this everyday thing. Now you're aware of how it affects you stress-wise and actually how to get out of it The anxiety and all, you know. Just to relieve that, you know. I can now It gives you something to fall back on. Like it'd help now	New perspectives Raised awareness Implementing behaviour change Raised awareness Has learned stress management techniques Anxiety hasn't gone away but can manage it now
P25: Just seeing my blood pressure, how it was one day and how it was the next day, or at different times in the day… Also my sleep pattern and if I was very annoyed or upset, I'd go and just do the three minute Whereas normally, I wouldn't take the time you are finding out exactly how you're behaving and how your life is going	Using data feedback to reflect Implementing stress management techniques Implementing behaviour change Raised awareness

Table 6 - Example of Themes emerging from categorised clusters of data

Category/Code	Sub-theme	Theme
Using data feedback to reflect New perspectives Raised awareness Implementing behaviour change	Increased awareness, reflection and behaviour change	Benefits and Positive Outcomes

Has learned stress management techniques Anxiety hasn't gone away but can manage it	Perceived improvements in health, wellbeing and mindful awareness	Benefits and positive outcomes
Implementing stress management techniques	Putting the various techniques into practice	Experiences of the Mindfulness-based Intervention

Example 4

Quote:
P22: Is there an app you can get for that? (Intention to continue practising)
R: There's a lot of mindfulness apps, yes… I can tell you about them, absolutely.
P22: Because I'd like, you know, if you had more time just to sit. (Intention to continue practising)

Quote:
R: So how did you find the mindfulness content overall, if we think about that for a second?
P27: It was ok. Just is not my thing. (negative perception of mindfulness) R: Yes, but you were saying earlier that you found - P27: It made me aware of what I was eating (Raised awareness) (Paying attention)… The taste. And it also made me aware, I suppose, yes, it was good in that sense, it made me aware even out walking…(Raised awareness) (Perceived benefits from meditating) I'd just be walking. But I was starting to look around me and appreciate what was around me…(Raised awareness) (Behaviour change) (Paying attention) Yes. So yes, if you think about it, it did.

Table 7 - Example of Clusters of relevant meaning

Cluster of relevant meaning	Category/Code:
P22: Is there an app you can get for that? Because I'd like, you know, if you had more time just to sit.	Intention to continue practising
P27: Just is not my thing. It made me aware of what I was eating it also made me aware I suppose, yes, it was good in that sense, it made me aware even out walking. I was starting to look around me and appreciate what was around me	Negative perception of mindfulness Raised awareness Paying attention Perceived benefits from meditating Behaviour change

Table 8 - Example of Themes emerging from categorised clusters of data

Category/Code	Sub-theme	Theme
Intention to continue practising Negative perception of mindfulness Paying attention Perceived benefits from meditating	Perceptions of and engagement with the mindfulness content	Experiences with the Mindfulness-based Intervention
Raised awareness Behaviour change	Increased awareness, reflection and behaviour change	Benefits and positive outcomes