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Exploring eHealth Implementation: Understanding Factors Affecting Engagement and Enrolment in Consumer Digital Health

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Abstract

Introduction

At the dawn of the 21st century, ageing populations combined with rising numbers of people with chronic conditions are placing burdens on patients, carers, professionals, and health systems worldwide. Digital health interventions (DHIs) such as mobile, online, wearable and sensor technologies are being used to promote healthy lifestyles and encourage self-management of disease in an effort to address some of these global health challenges. However, these kinds of electronic tools can be difficult to implement. Engaging patients, the public and health professionals in digital health and getting them signed up to these technologies can be challenging in real-world settings.

Aim

The primary aim of this thesis is to examine the barriers and facilitators affecting engagement and enrolment in consumer digital health interventions. It examines these complex processes from the perspective of three key stakeholder groups: 1) patients and the public; 2) health professionals; and 3) those implementing the technologies. The secondary aim is to identify the strategies used to engage and enrol individuals in consumer DHIs.

Methods

An exploratory, multi-method qualitative study design was adopted. This included a qualitative systematic review and collection and analysis of primary and secondary qualitative data, gathered as part of a large (£37 million) digital health innovation programme called Delivering Assisted Living Lifestyles at Scale (dallas). The dallas programme deployed a wide range of digital health products and services in the United Kingdom ranging from telehealth and telecare systems through to mobile health applications, personal electronic medical records, and online health and wellbeing portals. These were deployed among patients with chronic illness and healthy people providing an ideal opportunity to study engagement and enrolment in DHIs. The systematic review explored the experiences of patients and the public when engaging with or signing up to DHIs.

Primary data collection during the dallas programme consisted of fourteen interviews and five focus groups with patients, carers, clinicians, and those implementing the various technologies. Secondary analysis was undertaken of forty-seven baseline, midpoint, and endpoint interviews with stakeholders implementing the DHIs during the dallas programme. All analyses followed the framework approach to identify key themes and subthemes. This was underpinned by Normalization Process Theory (NPT) to synthesise the findings and develop a conceptual model of digital health engagement and enrolment.

Findings

A wide range of factors affected engagement and enrolment in DHIs for the three stakeholder groups. Where patients or the public were concerned, four themes emerged from the systematic review. These were; 1) personal agency and motivation, 2) personal lifestyle and values, 3) engagement and enrolment approach, and 4) quality of the DHI. A preliminary Digital Health Engagement Model (DIEGO) was developed along with an initial catalogue of engagement and enrolment strategies. The results of the dallas programme expanded on the barriers and facilitators influencing patient and public engagement and enrolment in digital health. The main themes that arose were; 1) personal perceptions and agency, 2) personal lifestyle and values, 3) digital accessibility, 4) implementation strategy, and 5) quality of the DHI. For health professionals, three overarching themes came to light; health professional role, health service organisation and culture, and digital infrastructure. Those implementing digital health products and services were slightly different as two main themes, each of which has several subthemes, appeared to affect engagement and enrolment in DHIs. These were organisation of engagement and enrolment, and implementation strategy. Hence, the conceptual model highlighting key issues affecting patient and public engagement and enrolling in DHIs was refined and developed further based on the findings from the dallas programme. In addition, the initial catalogue of engagement and enrolment strategies was extended.

Conclusion

This thesis provides new insights into the digital health implementation process, in particular the early phases of engagement and enrolment. A preliminary conceptual framework of digital health engagement and enrolment, the DIEGO model, was developed which summarises key issues that need to be considered during the earliest stages of implementing digital health products and services. This new framework could help researchers, clinicians, businesses, and policy makers appreciate the dynamics of deploying digital interventions in healthcare. This work suggests that educating patients, the public, and health professionals about the benefits, risks, and limitations of health technology is needed, while supporting research that describes engagement and enrolment strategies for consumer digital health and examines their effectiveness. Implementation teams could benefit from building strategic partnerships with marketing specialists and third sector agencies, and having clear business plans and budgets to enhance the reach and impact of engagement and enrolment in digital health. A positive digital health culture also needs to be cultivated in the health service, with leaders that champion the appropriate use of technology. National policies and funding that supports health informatics education, digital literacy for citizens, and digital infrastructure may also be necessary to enable people to sign up for DHIs. These recommendations may help support implementation and improve uptake to digital health products and services in the future.

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Fear does not prevent death. It prevents life.

- *Naguib Mahfouz*

Author's Declaration

I declare, that except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

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Publications and Presentations

Publications arising from this research

- **O'Connor, S.,** Hanlon, P., O'Donnell, C. A., Garcia, S., Glanville, J., & Mair, F. S. (2016) Understanding factors affecting patient and public engagement and recruitment to digital health: a systematic review of qualitative studies. *BMC Medical Informatics and Decision Making,* 16, 120. https://doi.org/10.1186/s12911-016-0359-3
- **O'Connor. S,** Hanlon, P., Garcia, S., Glanville, J., O'Donnell, C. A., & Mair, F. S. (2016). Barriers and facilitators to engagement and recruitment to digital health interventions: protocol of a systematic review of qualitative studies. *BMJ Open*, 6, e010895. http://dx.doi.org/10.1136/bmjopen-2015-010895

Publications related to this research

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- **O'Connor, S.,** O'Donnell, C. A., & Mair F. S. (2016). *Demonstrating the value of co-design: a mobile application for persons with dementia and their carers*. In Royal College of Nurses (RCN) Annual Conference, 6-8th April 2016, Edinburgh, United Kingdom.
- **O'Connor, S.,** McGee-Lennon, M., Bouamrane, M., O'Donnell, C. A., Mair, F. S. (2015). Determining success in digital health engagement – the dallas case study. In Kings Fund Digital Health and Care Congress 2015, 16-17th June 2015, London, United Kingdom.
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Poster presentations

- **O'Connor, S.,** Garcia, S., Brewer, S., Glanville, J., & Mair, F. S. (2015). *Using texting mining in a qualitative systematic review of digital health engagement and recruitment – how to search and prioritise large text datasets.* In Royal College of Nurses (RCN) Annual Conference, 6-8th April 2015, Edinburgh, United Kingdom.
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Abbreviations

Abbreviation	Description
ACM	Association of Computing Machinery
ARCHIE	Anchored, Realistic, Continuously co-created, Human, Integrated, Evaluated
CFIR	Consolidated Framework for Implementation Research
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPD	Chronic Obstructive Pulmonary Disease
COREQ	Consolidated Criteria for Reporting Qualitative Research
dallas	Delivering Assisted Living Lifestyles at Scale
DHI	Digital Health Intervention
DIEGO	Digital Health Engagement Model
EHR	Electronic Health Record
GATE	General Architecture for Text Engineering
GDPR	General Data Protection Regulation
GP	General Practitioner
GPS	Global Positioning System
ICT	Information and Communication Technology
iF	i-Focus
IT	Information Technology
IVR	Interactive Voice Recognition
LiU	Living It Up
MeSH	Medical Subject Index Headings
Mi	More Independent
MIMR	Multiparadigm Indexing and Retrieval
MRC	Medical Research Council

NASSS	Non-adoption, abandonment, scale-up, spread and sustainability
NHS	National Health Service
NMAHP	Nurses, Midwives and Allied Health Professions
NPM	Normalization Process Model
NPT	Normalization Process Theory
PC	Personal Computer
PHR	Personal Health Record
PICo	Population, Phenomena of Interest, Context
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PROSPERO	International Prospective Register of Systematic Reviews
RCT	Randomised Controlled Trial
RE-AIM	Reach, Effectiveness, Adoption, Implementation and Maintenance
SMS	Short Message Service
WHO	World Health Organization
YHEC	York Health Economics Consortium
YZ	Year Zero

1 Introduction

1.1 Introduction and aims

This chapter introduces the concept of digital health, outlines the implementation process and summarises the potential steps involved in engagement and enrolment as part of this. It also explains the aims and objectives of this thesis and provides a brief overview of subsequent chapters.

1.2 Digital health

As Information Technology (IT) developed and advanced throughout the 20th century, it started to be incorporated into healthcare in various ways. Initially this began with computerised hospital administration systems to enable the organisation of clinical areas and service departments within a hospital to be more efficient (Haux, 2010). Later simple forms of clinical decision support systems were developed and implemented in hospitals and other healthcare facilities to support doctors, nurses, and other professionals to improve the decisions made and care delivered. As the years progressed, the trend to use technology in healthcare continued. Other types of computer applications such as order entry systems, Electronic Health Records (EHRs), and electronic prescribing were designed and deployed with the aim of reducing the amount of medical errors that occurred to improve the quality and safety of patient care (IOM, 2001; Leape and Berwick, 2005). This trend became known as electronic health (eHealth) and now digital health, which has been defined as:

> *“an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and*

> *communication technology"* (Eysenbach, 2001, p. 1; Oh, Rizo, Enkin and Jadad, 2005)

Although digital health traditionally centred on technology in acute hospitals or primary care settings, its focus has shifted in recent years to individual use of technology by patients and members of the public. This is due to technological and social developments over the last few decades. As personal computers and the World Wide Web evolved in the 1980's and 1990's, computer systems and online environments became more accessible and affordable for the general public (Ceruzzi, 2003). This was quickly followed by the rise of mobile technology which enables people to manage personal data electronically and gain access to a wealth of information and services via the Internet, almost anywhere and at any time. These types of technologies are now ubiquitous and becoming ever more sophisticated. Numerous applications and devices can be integrated into desktop computers or mobile platforms e.g. smartphones, tablet computers or laptops, enabling patients and the public to use them to manage their health and wellbeing if they so choose.

In tandem, huge social changes such as ageing populations and rising numbers of people with one or more chronic conditions began to change the nature of healthcare and how it is delivered (World Health Organization, 2015). Public health and disease prevention are being prioritised in many countries to reduce the utilisation and cost of healthcare and improve outcomes for citizens (Bauer, Briss, Goodman and Bowman, 2014). Individuals are being encouraged to manage their own illness and support themselves to live independently where possible. This has led to the design, development and deployment of a wide range of technologies that patients can use for self-care. Examples include telehealth and telecare systems, online self-management portals, mobile health applications (known as health apps) and assisted living devices. These have the potential to support the management of long-term conditions and enable independent living by those with a range of health and care needs. Technology can also enable people to communicate and share information easily with formal and informal care providers, although evidence of its efficacy in improving health and other outcomes varies (Flodgren, Rachas, Farmer, Inzitari and Shepperd, 2015). In addition, digital health products and services such as health apps and wearable devices are being used by the public or citizens, to monitor their diet and exercise. These may also be used to track numerous physiological, behavioural and environmental parameters to maintain a person's health and wellbeing, although evidence of their effectiveness is limited (Lewis, Eysenbach, Kukafka, Stavri and Jimison, 2010).

1.2.1 Consumer digital health

This new emphasis on the 'consumer' as a focus for digital health, instead of health professionals and health services, is often referred to as consumer health informatics and has been defined as:

> "*a branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems*" (Eysenbach, 2001, p. 1713).

Given the number and type of technologies available in healthcare, the World Health Organization (2018) have created a useful classification of digital health interventions. It has four major categories, one of which called 'Clients' is consumer focused and this has seven sub-categories within it (see Table 1). These sub-categories cover a variety of digital health products and services such as telehealth and telecare systems, mobile health applications, personal electronic health records, online and web-based health information and services, and wearable and assisted living devices.

Table 1: WHO Classification of digital health interventions

Clients	Healthcare Providers	Health Systems Managers	Data Services
Targeted Client Communication	Client Identification and Registration	Human Resource Management	Data Collection, Management and Use

Untargeted Client Communication	Client Health Records	Supply Chain Management	Data Coding
Client to Client Communication	Healthcare Provider Decision Support	Public Health Event Notification	Location Mapping
Personal Health Tracking	Telemedicine	Civil Registration and Vital Statistic	Data Extraction and Interoperability
Citizen Based Reporting	Healthcare Provider Communication	Health Financing	
On-demand Information Services for Clients	Referral Coordination	Equipment and Asset Management	
Client Financial Transactions	Health Worker Activity Planning and Scheduling	Facility Management	
	Healthcare Provider Training		
	Prescription and Medication Management		
	Laboratory and Diagnostics Imaging Management		

As consumer digital health is gaining prominence as a way to deliver a range of health services and for health promotion and public health, how technology is rolled out to patients and the public is important to understand as improving this process could lead to better outcomes.

1.3 Digital health implementation

Since the introduction of technology in healthcare, there have been degrees of success and failure when deploying it in clinical settings. Although some policy makers, health service managers and health professionals may be enthusiastic about the adoption of new technologies, many problems can occur as they are being rolled out (Miller, 1994; Sittig and Stead, 1994). For example, Ludwick and Doucette (2009) reviewed the literature on barriers that affected how EHRs were implemented in primary care. This showed numerous difficulties relating to how well the technical system fitted with clinical workflows and the culture of providing care. The type of project management approach used to procure and deploy the IT system and the level of training and support that was offered to those using the EHR was also problematic. In another study, Lorenzi, Kouroubali, Detmer and Bloomrosen (2009) focused on how EHRs were adopted in small ambulatory care settings and reported that the cost of the technology, resistance from health professionals towards changing their practice and the need for clinical champions were all challenges that had to be met to ensure successful implementation. These barriers indicate that embedding new technologies in healthcare can involve complex change processes at the individual and organisational level. This can lead to technology being abandoned or significantly changed, which may reduce its potential impact in improving service delivery or patient's outcomes (Keshavjee et al., 2006).

1.3.1 Digital health implementation among patients and the public

More recently, researchers have started to examine how technology is deployed among patients and people who are healthy. It is hoped that these consumer digital health interventions can improve health outcomes and enable people to have a good quality of life, throughout their lifespan. However, barriers to deploying these technologies with patients and the public exist. For example, a telehealth service rolled out in Denmark experienced problems as patients found the software interface difficult to use (Lilholt, Jensen and Hejlesen, 2015).

Jang-Jaccard, Nepal, Alem and Li (2014) noted numerous barriers experienced by patients with telehealth services being rolled out in Australia. These included not understanding the technology, having poor computer skills or lacking the equipment needed to use the digital service. Implementation issues highlighted in other telehealth services were limited physician endorsement of the technology and the high cost for patients (Weinstein et al., 2014).

In addition, some commercial technologies such as mobile health applications and assisted living and wearable devices aimed at patients and the public, are often standalone and may not be integrated into any healthcare system. Even these types of digital tools are not without their challenges during deployment. Whittaker (2012) interviewed key stakeholders working on mobile health in the United States and found that data privacy and security was a concern for some people when using mobile health applications. Poor wireless network coverage in some areas was also highlighted as making the roll out of health apps problematic. Recent reports about the mobile health market reveal that the volume of health apps is increasing but the numbers being downloaded are beginning to drop, hinting towards market saturation and other issues with implementation (Research 2 Guidance, 2018). Likewise, placing devices and sensors in people's homes to monitor environmental conditions and human behaviour does not always run smoothly. Sun, De Florio, Gui and Blondia (2009) reported that some individuals such as older adults do not have the skills to use these technologies or see them as an unwanted intrusion in their lives and do not interact with them. Thus, the implementation of technology among patients and the public is not straightforward and problems continue to occur when deploying these types of digital health tools in the real-world.

Therefore, implementation is a critical process that needs to be well understood, leading one group to define it as:

> "*the constellation of processes intended to get an intervention into use within an organization*" (Damschroder et al., 2009, p. 3)

This broad definition encompasses all the activities and events that people individually and collectively take part in, from the time it is recognised a new intervention is needed in everyday practice up to the point when it is used regularly as part of routine work. In healthcare this can be a long, complex process that involves numerous stakeholders such as clinicians, patients and their families, administrators, technicians, managers, and external vendors or other agencies. All these groups need to work together in various ways to enable a new digital health intervention to be adopted into practice. Research that helps to explain these processes is considered important so the complexity of implementation can be understood and barriers to introducing technology minimised where possible (Ross, Stevenson, Lau, and Murray, 2016). Factors that facilitate implementation can also be taken advantage of, if identified, to help ensure digital health products and services are taken up and used every day to improve outcomes.

1.4 Engagement and enrolment

As outlined previously, deploying new technology in healthcare is a complex process and one that needs to be better understood if digital tools are to be used to improve human health. The implementation process can follow a number of different paths, which will be discussed further in Chapter 2. It can involve several stages that range from planning and preparatory activities, to installation and use of a technology, right through to evaluating its impact and refining it where necessary. For example, Lorenzi et al. (2009) outline the stages involved in implementing an EHR system, which include:

- Making a decision to adopt a new technology,
- Selecting an appropriate platform,
- Pre-implementation stage that encompasses several activities such as communicating this upcoming change to staff and project planning,
- Implementing the EHR which could involve engaging patients, supporting staff through changes in practice, customising the hardware and software to enable it to be used, and
- Post-implementation which could comprise system and training updates and evaluating the new technology and how it was deployed.

Figure 1 summarises the steps described by Lorenzi et al. (2009) to illustrate how implementation may flow from one phase to the next.

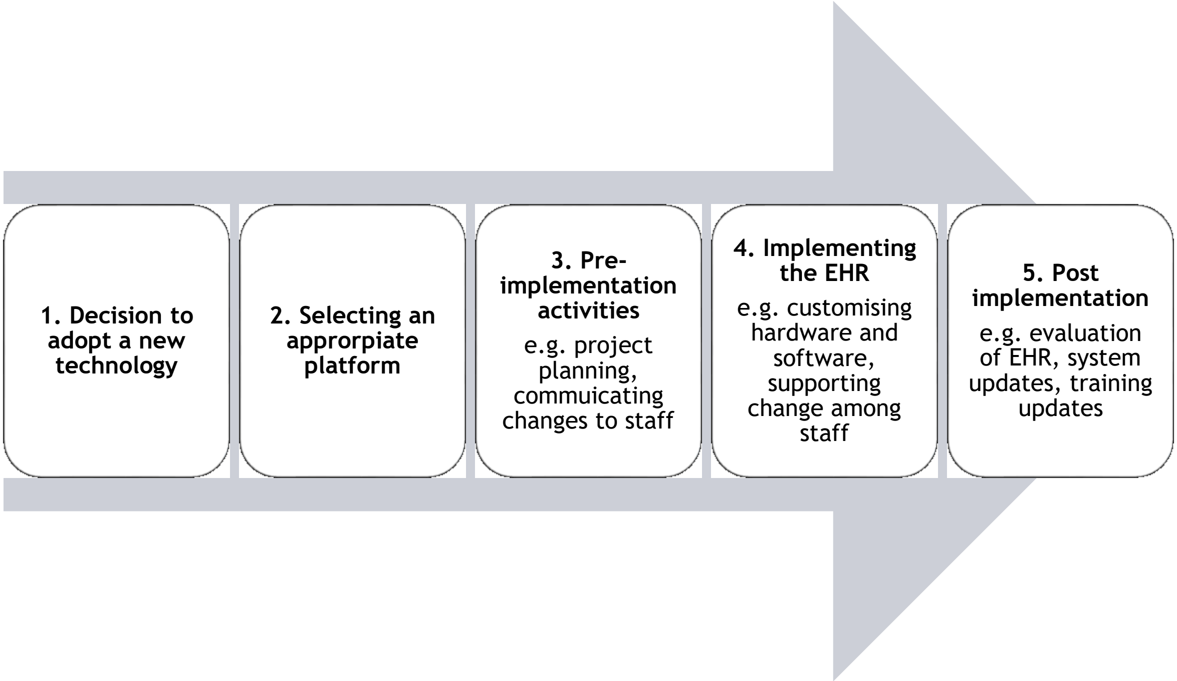


Figure 1: Process of implementing an EHR

However, when a digital tool is being rolled out with individual patients or the public for personal use at home this process can become even more complicated, as it happens outside of an organisational setting so it can be difficult to manage and control (Joseph, West, Shickle, Keen and Clamp, 2011). Less research exists about how technology is deployed in these types of settings. Many of the current models and frameworks on implementation such as the Diffusion of Innovation (Rogers, 1962) and Organizational Readiness for Change (Weiner, 2009), discussed further in Chapter 2, are not suited to this context as they have not been adapted to fit how patients or the public adopt and integrate digital health products and services into their daily lives.

In addition, most digital health research has focused on the middle stages of the implementation process to understand how health professionals, patients or the public use a digital application on a day-to-day basis and why they use it, or not, as it is being rolled out. While this is valuable to know, the earlier stages of the process are equally important to unpick as people cannot start to use a technology unless they first engage with and then in some cases register for it.

Therefore, it is important to explore and understand these processes if the aim is to promote uptake and use of health technology by patients and the public. Implementation thus begins with engagement, which refers:

> “*any process by which patients’ and the public become aware of or understand a DHI [digital health intervention]*” (O’Connor et al., 2016a, p. 5)

Examples include marketing and promotional campaigns or personal recommendations from family members or friends. At the end of this stage, the individual makes a decision whether to use a digital health product or service or not. Then they need to acquire the technology and may also need to sign up to it in some way before starting to use it. Therefore, the next step in implementation may be enrolment, which is defined as:

> “*any approach that involves people actively registering for or signing up to a DHI [digital health intervention]*” (O’Connor et al., 2016a, p. 5)

This could mean filling out a paper-based registration form, downloading a health app to a mobile device or creating an online account or profile.

The initial steps of engaging and enrolling in a DHI are necessary for patients or members of the public to begin using a technology. Unfortunately, barriers to uptake can occur during these early phases of the implementation journey. For example, Greenhalgh, Hinder, Stramer, Bratan and Russell (2010) reported patients had little interest in a personal EHR deployed in a health service in the United Kingdom and this lack of motivation meant people failed to sign up to use it. Miyamoto, Henderson, Young, Ward and Santillan (2013) detailed a litany of problems encountered when recruiting people to a rural telehealth service for diabetes self-management. Low literacy rates in some populations, healthcare clinics with limited resources and clinical staff with heavy workloads who did not have time to register patients to the new digital service, were some of the issues that arose. On the other hand, there are certain factors that can facilitate engagement and enrolment in digital health such as adequate funding to purchase a technology and staff who are trained to promote it with their patients (Darkins, Kendall, Edmonson, Young and Stressel, 2009).

1.5 Aims and objectives of this thesis

Some literature does exist on all phases of implementing digital health among patients and the public, but it typically focuses on a single population of people using one specific type of technology. For example, how a health app is deployed and used among patients with diabetes (Scheibe, Reichelt, Bellmann and Kirch, 2015) or how a home health monitoring system is rolled out and utilised by older adults living at home (Demiris, Oliver, Dickey, Skubic and Rantz, 2008). While there is value in examining how a digital health product or service is rolled out among a group of patients with a particular health problem, this limits our understanding of the overall picture of implementation in relation to digital health. It also fails to identify whether there are generic issues that exist and are likely to influence levels of success or failure with future digital health deployments. This thesis posits that general barriers and facilitators exist when anyone tries to engage or enrol in any type of digital health product or service. Due to the limited amount of research on the earlier phases of digital health implementation and the broad focus on all types of people and DHIs, the principal research questions addressed in this thesis are:

- What factors (barriers and facilitators) affect engagement and enrolment in consumer digital health interventions (DHIs)?
- What strategies have been used to engage and enrol individuals in consumer DHIs?

Hereafter, the term DHI will be used throughout this thesis to refer to all types of digital health products and services that are aimed at patients and the public. The two research questions have been addressed through qualitative approaches using a combination of: a systematic review of qualitative literature; secondary analysis of semi-structured interviews with a range of people implementing different digital health products and services during the Delivery Assisted Living Lifestyles at Scale (dallas) programme; and primary data collection and analysis of interviews and focus groups with patients, carers, members of the public and health professionals who engaged with and enrolled in a range of different DHIs. The empirical work focuses on the dallas programme, explained further in Chapter 3, which sought to deploy different digital health interventions to support the health and wellbeing needs of a range of people in the United Kingdom. The explicit objectives of this thesis were:

- To conduct a systematic review of the qualitative literature that explores the barriers and facilitators patients and the public experience when engaging with and enrolling in DHIs.
- To explore the experiences of key stakeholders i.e. patients and the public, health professionals, and those implementing digital health products and services in the dallas programme, to identify factors that influence engagement and enrolment in consumer DHIs.
- To integrate findings gained through the above two objectives to create a conceptual model of patient and public engagement and enrolment in digital health.
- To create a taxonomy of engagement and enrolment strategies that are employed to get patients and the public signed up to DHIs.

1.6 Overview of chapters

This chapter provides a brief introduction and overview of the thesis. In the second chapter a summary of background literature is provided to outline digital health implementation. The various steps involved in this process, in particular the initial phases of engagement and enrolment are described. The third chapter gives a detailed account of the methodology including the ontological and epistemological underpinnings of this study and the rationale for selecting the theory that aids conceptualisation of engagement and enrolment in DHIs. The qualitative approaches used to review and synthesise the literature and collect and analyse data from the dallas programme are also described. In the fourth chapter, the systematic review of the qualitative literature and its update is presented. A preliminary conceptual model of engagement and enrolment in consumer digital health is outlined and an initial catalogue of engagement and enrolment strategies is also provided.

The three empirical results chapters describing analysis of data collected in relation to the dallas programme are divided into: 1) an exploration of patient and public engagement and enrolment in digital health, 2) an examination of factors affecting health professionals when engaging and enrolling patients and the public or themselves in digital health products and services, and 3) the views of those implementing DHIs on the barriers and facilitators during the engagement and enrolment process. In the last chapter, the preliminary conceptual model is discussed and developed further and the catalogue of strategies used to engage and enrol people in DHIs is extended and refined. Overall findings are also discussed and recommendations made about how to improve the implementation of consumer digital health products and services in the future. The strengths and limitations of the thesis and directions for further research are also provided to conclude this work.

2 Background Literature

2.1 Introduction and aims

This chapter provides an overview of the underlying concepts and theories that are discussed throughout this thesis. First, it briefly outlines the history of digital health and the foundations of implementation research. Second, it describes the early phases of the implementation process i.e. engagement and enrolment and how these are involved in the deployment of digital health products and services. Third, the main theoretical models and frameworks in this field are summarised to conclude the chapter. The aim is not to provide an exhaustive review of the literature but to offer some context for the concepts that underpin this doctoral study.

2.1.1 Sources of evidence

A range of literature was used to inform this chapter. Papers that were identified during the systematic review in Chapter 4, which were broadly relevant to the thesis but did not meet the inclusion criteria for the review were used in this chapter. Four health related academic databases; PubMed, MEDLINE, CINAHL and Embase, were also searched for literature on implementation research and frameworks relevant to digital health from the year 2000 onwards. The work of key researchers in this area such as Glasgow in the USA, Grimshaw in Canada, and Eccles, Greenhalgh and May in the UK was also reviewed.

2.2 Background to digital health

As outlined in Chapter 1, social and technological changes over the last number of decades have influenced health policy and how health services are organised and delivered. Ageing populations emerged as a key issue in the 1980s and 1990s (Brody, 1985) and so a move from hospital to more community based settings was seen to be important to manage cost, improve accountability and enhance outcomes for patients. In the UK, this led to a major policy shift and the National Health Service and Community Care Act (1990) was introduced. This legislation saw the first major restructure of the National Health Service (NHS) since its inception in 1948, splitting up the role of health authorities and local authorities. Local authorities, a government agency responsible for public services and facilities in a specific geographical area, could now assess the needs of the local population and purchase services from healthcare providers. This introduced an internal market particularly in England, with the aim of increasing innovation and competition, as local authorities were given budgets to purchase services from providers such as hospitals and nursing homes (Walsh, Chaloner and Stephens, 2005). From this point on, self-governing NHS hospital trusts could be established to act as healthcare providers and large General Practitioner (GP) or family physician practices were encouraged to apply for their own budgets to offer more services in the community. A new GP contract negotiated in 1990 also provided incentives for more health promotion to help reduce the burden of chronic disease and enable people to lead healthier lifestyles (Scott and Maynard, 1991).

In line with these social and policy changes, technology became more embedded in NHS hospitals. Computer systems were used more for hospital administration to help manage the growing numbers of patients and introduce efficiencies in clinical care, to enable hospitals remain competitive in the new internal marketplace. In 1992, the first national IT strategy for the NHS was published which introduced key infrastructure, some of which is still in place today (NHS Management Executive, 1992). For example, the Picture Archiving and Communication System (Cho, Huang, Tillisch and Kangarloo, 1988), that generates digital medical images like x-rays, and electronic health records, that hold clinical and administrative patient data, began to be introduced in acute settings. However, a decade later the Wanless Report highlighted the poor use of IT in the health service in the UK and recommended that significant investments be made (Wanless, 2002). The '*Delivering 21st Century IT Support for the NHS*' strategy from the UK Department of Health followed, that led to the creation of the National Programme for IT, later called NHS Connecting for Health (Department of Health, 2002). This saw a multi-billion-pound investment in integrated Electronic Health Records (EHRs) across NHS England to connect acute and primary care systems. Hence, research began to focus on how these types of technologies were implemented and the impact they were having on health professionals and patients (McDonald et al., 1984; Huang et al., 1993; Hendy, Reeves, Fulop, Hutchings and Masseria, 2005).

2.2.1 Emergence of consumer digital health

During this period, 1980 – 2000, personal computing began to increase and the World Wide Web was created. Mobile telecommunications advanced and hand-held devices such as basic mobile phones and personal digital assistants started to become popular (Metropolis, Howlett, and Rota, 2014). This allowed more affordable, accessible technologies to be used by the general public. Personal computing, mobile technology and the Internet also gave patients and the public direct access to electronic health information and online health services. This prompted research into the development, deployment and use of more consumer facing digital health interventions (Impicciatore, Pandolfini, Casella and Bonati, 1997; Eysenbach and Jada, 2001).

Due to the changing population demographics and how health services were restructured, GPs were also keen to reduce costs as they had to manage large caseloads of predominantly older adults with complex needs. Therefore, many GPs began to turn to technology as one way to improve how they delivered health services, which was encouraged in part through the NHS Primary Care Act (1997). Some began pioneering telemedicine to remotely monitor patients' health at home and connect them to their primary care practice (Grundy, Jones and Lovitt, 1982; Wootton, 1999). For example, in England the Department of Health commissioned the Whole System Demonstrator pilots in May 2008 to test the efficacy of telehealth and telecare systems (Steventon et al., 2012) and examine their implementation (Sanders et al., 2012). This was driven in part by a white paper from the Department of Health called 'Our health, our care, our say' that proposed a new way to deliver community health and social care services for people with long-term health and social care needs, especially those living in deprived areas (Department of Health, 2006). It was thought that advanced assisted living technologies could facilitate the redesign of health and care services, leading to better outcomes. This formed part of the "Three Million Lives" campaign, to improve outcomes for three million people in the UK who had long-term conditions or social care needs and might benefit from technolgoies that could support self-care at home. Hence, the Department of Health signed a concordat with a number of telehealth and telecare industries, who partially funded this initiative (Department of Health, 2012). Some claimed this partnership had vested interests and that it purported these technologies produced better outcomes for patients and health service than scientific results published from the clinical trials (Greenhalgh, 2012; Oliver, 2013).

Regardless of a somewhat limited evidence base, consumer facing technology continued to develop in healthcare. As EHRs became more sophisticated and new legislation was introduced, such as the Data Protection Act (1998) and the Freedom of Information Act (2000), patients in the UK were allowed access their electronic medical data. Having smaller, more flexible, independent organisations meant some GPs were able to offer patients access to their health information via online patient portals and waiting-room kiosks in GP practices (Fisher, Fitton, Poirer and Stables, 2006). In tandem, another driver for the adoption of technology among family doctors emerged in 2004 when a new NHS contract was introduced that included a detailed pay for performance framework, the Quality and Outcomes Framework (NHS England, 2004). GPs began to get paid for achieving key indicators in relation to the management of a range of chronic diseases. This prompted some clinicians to invest more in EHRs, telehealth, and other systems to ensure they maximised income through accurate recording of patient data.

In other parts of the United Kingdom, a more top-down approach was adopted to give patients’ access to an NHS Summary Care Record called “HealthSpace” under the NHS Connecting for Health initiative (Greenhalgh, Wood, Bratan, Stramer and Hinder, 2008b). NHS Connecting for Health, established by the UK Department of Health in 2005, aimed to modernise the use of information technology across NHS England and provide digital tools to improve the delivery of a range of health services, with an emphasis on the ability to share data across acute and primary care systems (Cross, 2006). However, some felt it was an overly ambitious, politically driven initiative that failed to take into account the diversity within NHS trusts in England. Since the introduction of commissioning and the internal market several years earlier, customising the EHR in local hospitals was challenging (Robertston, Bates and Sheikh, 2011). Due to spiralling costs of an estimated £10-20 billion, complex contractual arrangements, and a perceived lack of value for clinicans and patients, the national EHR and personal health record systems were abandoned in 2013, although some technical infrastructure remained in place (House of Commons Committee of Public Accounts, 2013; Greenhalgh et al., 2010).

The trend towards consumer digital health interventions continued into the 21st century as mobile and computing technology became more advanced. The first iPhone, launched in 2007, led to the emergence of mobile based software applications, known as apps. This spawned numerous commercial and research interest in health apps, with thousands flooding the market over the following decade (Boulos, Brewer, Karimkhani, Buller and Dellavalle, 2014; Donker et al., 2013). Wearable technologies such as fitness trackers and smartwatches were the next trend to follow, with Fitbit releasing its first wearable in 2009 and Apple's smartwatch launching in 2015. Some of these devices connect to and share data with smartphones and health apps enabling patients and the public to track their diet, exercise and some physiological parameters (Sultan, 2015; Patel, Asch and Volpp, 2015).

As these technologies were emerging government policy began to place more emphasis on health promotion and preventing illness through individual lifestyle changes such as having a healthy diet and taking regular exercise. This was due to rising levels of chronic disease brought about by changes in working patterns and lifestyles in the latter half of the 20th century. For example, mechanisation and computerisation in many sectors of society has led to a more sedentary way of life. In addition, unhealthy diets with high levels of sugar and fat are contributing to obesity, cardiovascular disease and diabetes mellitus among other chronic illnesses. Harmful habits present in contemporary society such as smoking can lead to long-term conditions such as Chronic Obstructive Pulmonary Disease (COPD) or binge drinking and recreational drug use may cause chronic kidney disease. Thus, the white paper 'Choosing Health: Making healthier choices easier' published by the UK Department of Health in 2004, outlined how smoking, obesity and high alcohol intake could be tackled by delivering better health promotion interventions and ensuring patients made more informed choices (Raine, Walt and Basnett, 2004). This was followed by another white paper called ‘Healthy Lives, Healthy People’ in 2011 focusing on active lifestyles and reduced calorie intake to improve public health in England (Department of Health, 2011a). Similar developments were taking place in Scotland, as Scottish Government’s first eHealth strategy published in 2008 noted that along with clinical areas becoming “paper-light”, providing more online resources to citizens was also important to sustain and improve their health (Scottish Government, 2008). This was followed by an updated eHealth strategy in 2011 which emphasised providing technology products and services to improve health outcomes for all, with a special emphasis on establishing telehealth programmes in Scotland (Scottish Government, 2011).

Following these social, technological and policy changes, research began to examine how commercially available mobile apps and wearable devices, along with those developed via research, might help people to lead healthier lifestyles and manage chronic disease (Huckvale, Morrison, Ouyang, Ghaghda and Car, 2015; Zhang, Luo, Nie and Zhang, 2017). However, despite a decade or more of research on these consumer digital health tools, evidence surrounding the efficacy of health apps in changing people’s behaviour and improving health outcomes remains limited (McKay et al., 2018). In addition, some are critical that health apps are overly simplistic and do not account for multimorbidity, polypharmacy, and other complexities around people’s experiences of health and illness (Khan, Gill, Cott, Hans and Gray, 2018).

This early period of the 21st century also saw the development of an array of sensors and devices from both commercial providers and research institutions to address the needs of a growing population of older adults through telecare (Bower et al., 2011). Health problems such as musculoskeletal decline associated with older age has led to the creation and testing of sensors and other equipment to detect and prevent falls (Hawley-Hague, Boulton, Hall, Pfeiffer and Todd, 2014). Neurological conditions such as Alzheimer’s disease, which are more prevalent in older populations, can affect people’s cognition and memory. Hence, technologies such as GPS trackers and other tools to sense movement have been designed to help families and carers look after people with dementia and ensure they remain safe (Liu, Miguel Cruz, Ruptash, Barnard and Juzwishin, 2017). Older adults who live alone can also employ home monitoring systems to regulate the temperature of their environment, get medication and other reminders, and provide reassurance to their families and carers that they are safe and well (Liu, Stroulia, Nikolaidis, Miguel-Cruz and Rincon, 2016). There is a growing body of research on these assisted living technologies to evaluate whether they can support older adults to live independently and improve health outcomes (Sun et al., 2009; Wherton, Sugarhood, Procter, Hinder and Greenhalgh, 2015).

Despite the problems in the Whole System Demonstrator programme, telehealth and telecare continued to be championed by national governments. A new policy called ‘Equity and Excellence: Liberating the NHS’ was published in the UK in 2010, outlining the long-term vision for NHS England. This aimed to give patients more choice and control over decision making and care (Department of Health, 2010). The Health and Social Care Act (2012) followed, setting out how NHS England and new Clinical Commission Groups should monitor health and wellbeing and work to integrate health and social care services to ensure patients have a smooth transition between care organisations and better outcomes. A complementary policy called ‘Innovation Health and Wealth’ explained how innovation would be accelerated in the health service by working with industry, academia, patients, and professionals to address barriers to innovation, adopt new products and services, and ensure these were taken up across the whole system generating economic growth and better outcomes for all (Department of Health, 2011b). To facilitate this new focus numerous digital health initiatives were funded. For example, the Delivering Assisted Living Lifestyles at Scale (dallas) programme, described in more detail in Chapter 3, began in 2012 to enable social and service innovation. It involved a large scale roll out of a range of digital health products and services across the United Kingdom, aimed at numerous groups of patients and the public (Devlin et al., 2016). In tandem, a Technology Enabled Care programme was launched in Scotland to scale up the use of existing telehealth and telecare services, forming part of the National Telehealth and Telecare Delivery Plan for Scotland (Scottish Government, 2012).

2.3 Evaluating digital health

Evaluating interventions in healthcare is undertaken to ensure they are beneficial to patients, the public, and professionals. Given the increasing volume of technology available in healthcare, this area of research is of growing importance to help determine whether digital health products and services are beneficial or not. Research to evaluate digital health and other interventions spans a number of methodological approaches from purely qualitative methods to a plethora of quantitative and mixed study designs. A hierarchy of research evidence has emerged where Randomised Controlled Trials (RCTs) are seen as the “gold standard” in establishing the evidence base for effective interventions (see Figure 2). Systematic reviews and meta-analysis are considered robust ways of synthesising literature and guiding clinical decision making (Guyatt et al., 1995).

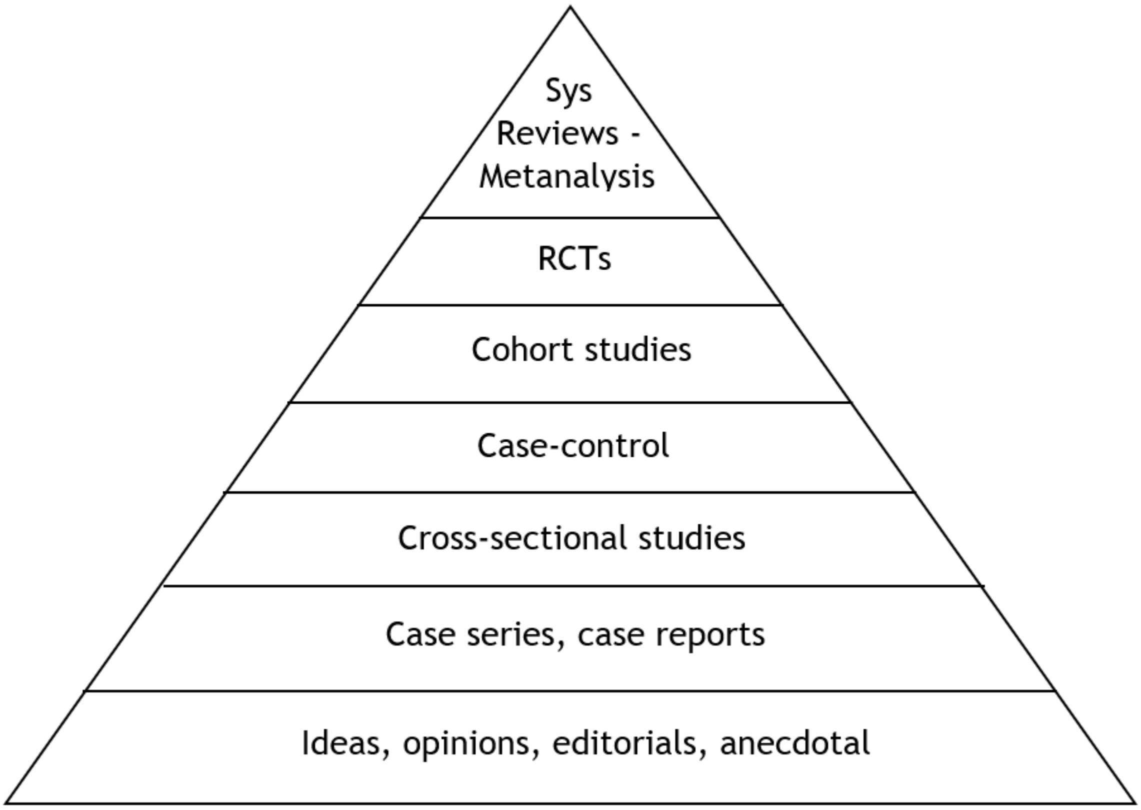


Figure 2: Hierarchy of research evidence (Philips, 2014)

However, this hierarchy has been critiqued as some feel it is overly reliant on RCTs to the detriment of other forms of knowledge. For example, the social, political and economic context within which people live are not always addressed in clinical trials and other forms of quantitative research (Ashcroft, 2004). In addition, the tacit knowledge gained by professionals through clinical experience is seen as inferior. Therefore, people have argued that the best available evidence can be limited in its scope and quality which could lead to inappropriate clinical guidelines and an overly dogmatic approach to delivering care. Others question whether the results of RCTs can be applied in the real world given that many types of patients are excluded and do not fit the controlled confines of clinical trials (Greenhalgh, Howick and Maskrey, 2014). Furthermore, when digital or other interventions are put into practice they often are not carried out as originally intended and tested during a clinical trial. Therefore, interventions with statistically significant results from RCTs could in reality have limited benefit. Finally, clinical trials have not helped elucidate how to implement new interventions in professional practice or in patients' real lives as they focus primarily on answering effectiveness questions. Therefore, other forms of research are necessary to understand and improve digital health.

2.3.1 Evaluating complex interventions

The process of developing, evaluating and deploying new interventions such as technology in healthcare is long and complex. The UK Medical Research Council (MRC) published a framework (see Figure 3) to help researchers recognise the key phases involved and methodologies that can be used (Craig et al., 2008). The first step in the framework focuses on how to develop a new intervention such as a digital health product or service. It recommends doing this iteratively and systematically by using a combination of evidence synthesis on the topic, along with employing an appropriate theory or conceptual framework to understand and construct the key components of the new intervention. Reviewing process and outcome models is also suggested to assist in defining how the new intervention should work with patients, carers, professionals or policy makers. The second phase is the 'Feasibility/Piloting' stage, where the initial intervention is tested with a small group of people to see if the intervention operates as intended. As Figure 3 suggests, the findings of both phases can inform each other and the intervention may go back to the 'Development' phase after the pilot study has finished if it needs to be refined and improved (Campbell et al., 2007).

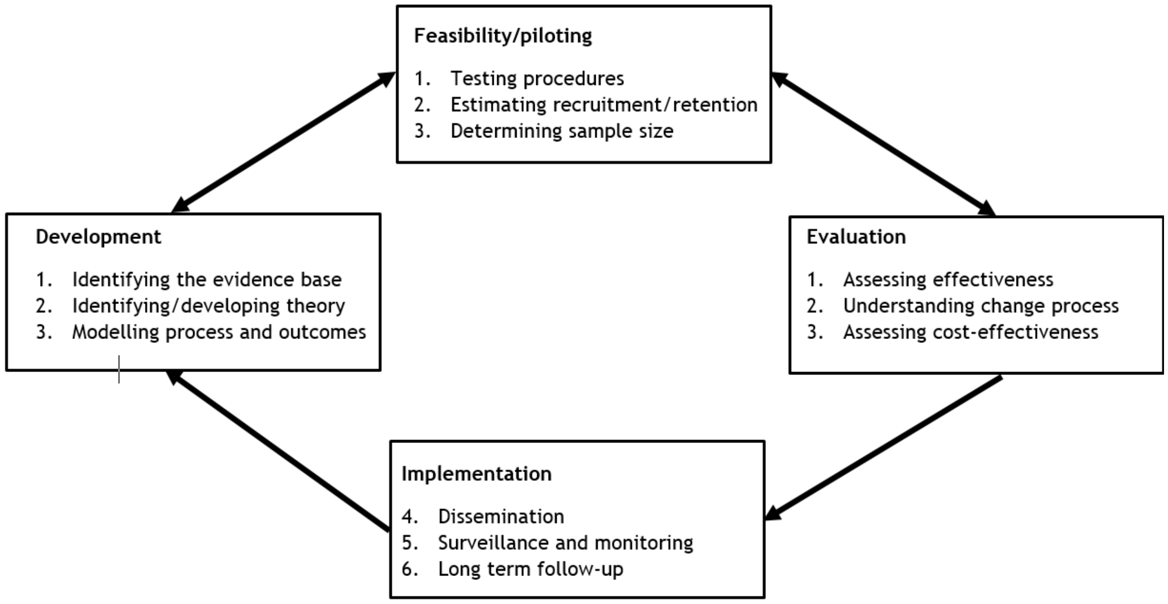


Figure 3: MRC Complex Intervention Framework adapted from Craig et al. (2008)

The third phase of health research, ‘Evaluation’, involves assessing the effectiveness of a new intervention. Numerous different study designs exist to undertake evaluations of health interventions but a RCT is often used due to its rigorous design. This sets up a controlled experiment comparing those who use a new treatment or intervention against a control group who receive standard care and/or an alternative intervention (Friedman, Furberg, DeMets, Reboussin and Granger, 2015). Due to the limitations of clinical trials research, guidelines now recommend incorporating a process evaluation alongside a RCT to examine how an intervention could be implemented in the future. A process evaluation involves collecting data that can help identify contextual factors, both barriers and facilitators, that affect the uptake, utilisation and embedding of the intervention during a clinical trial. This can assist in providing a blueprint for real-world implementation (Moore et al., 2015). Cost-effectiveness research is also increasingly seen as important in terms of assessing a new intervention to ensure there is evidence that it offers value for money.

The fourth and final phase of the MRC Complex Intervention Framework is ‘Implementation’. If an intervention has proven successful in the previous three stages, it then needs to be deployed in a real setting with patients, the public, health professionals or policy makers so it can improve health and service outcomes. Until recently, there has been less emphasis on how interventions are implemented in real life settings and many are often not taken up and used by people due to the difficulties in this process (Haines, Kuruvilla and Borchert, 2004; Glasgow, Klesges, Dzewaltowski, Bull and Estabrooks, 2004). A myriad of factors can make deploying new interventions in healthcare, such as technology, challenging. They can be utilised in different ways, by different people and applied in a variety of settings that did not occur in the clinical trial. Unanticipated barriers and facilitators may emerge once an intervention is used in day-to-day practice, in particular when it is deployed beyond the walls of a healthcare organisation. For example, Levy, Janke and Langa (2015) found barriers to older adults accessing online health information and services such as patient portals or electronic medical records, as some lacked the digital skills necessary to do this. This issue may not arise during a clinical trial as those with poor literacy skills may be specifically excluded. Likewise, Douthit, Kiv, Dwolatzky and Biswas (2015) identified poor Internet services in rural areas as a significant barrier to accessing healthcare. The lack of good quality broadband or WiFi services in some regions may not occur during a RCT, depending on the populations involved and where they are located. Similarly, the cost of technology can affect implementation among certain groups of patients and the public who may not be able to afford to pay for it (Ross et al., 2016). Participants are often given equipment for free as part of a trial so this may not be an issue.

As we move from feasibility studies and RCTs, to scaling up and rolling out interventions in healthcare systems worldwide a better understanding of implementation processes is necessary (Grimshaw, Eccles, Lavis, Hill and Squires, 2012). The evidence base for implementation is now growing as this gap in knowledge has been highlighted. A systematic review of the diffusion of innovations in service organisations by Greenhalgh, Robert, MacFarlane, Bate and Kyriakidou (2004, p. 610 and 620) reported:

> *"the evidence regarding the implementation of innovations was particularly complex and relatively sparse"*, emphasising that it is "*the most serious gap in the literature*"

Implementation research is seen as the critical last step to turning evidence of what works into practice (Woolf, 2008). Hence, a new research discipline known as "Implementation Science" has emerged over the last decade in response to the difficulties academics, health professionals, policy makers, and others experience translating research evidence into practice, as integrating new interventions into a complex health system is challenging (Eccles and Mittman, 2006). The renewed focus on the implementation process as a means of ensuring effective interventions are adopted in the real-world has led to a growing literature on this aspect of research, practice, and policy.

2.4 Implementation research

Implementing interventions in any healthcare setting is a long and complicated process. As outlined in Chapter 1, the implementation process can follow a number of different paths depending on the complexity of the intervention and people involved, as well as the context or setting within which it is being deployed. Edmondson, Bohmer and Pisano (2001) explained the process of how a new technology to enhance cardiac surgery was deployed in sixteen hospitals in the United States (see Figure 4). The model focused on leadership actions and team learning processes in acute clinical settings. These were required to adopt minimally invasive cardiac technology into surgical practice. In this case, implementation consisted of four stages:

- Enrolment – leaders i.e. chief surgeons motivated key team members to participate in training,
- Preparation - practice sessions were run with the new technology and the entire surgical team,
- Trials - the new technology was trialled with real patients in surgical settings, and,

- Reflection - outcomes and feedback from staff on how the new technology worked to improve the cardiac surgery were reviewed.

After several iterations of phases three and four, the new technology eventually became embedded in routine professional practice in cardiac surgery. Although this model was developed in a specific context, it alludes to some of the generic mechanisms that occur during the digital health implementation process.

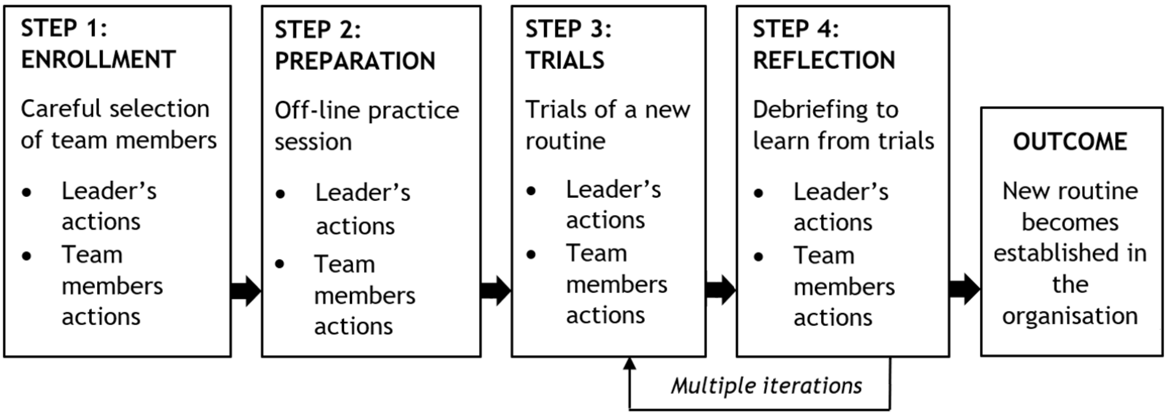


Figure 4: Process model for establishing new technological routines adapted from Edmondson et al. (2001)

This research along with other literature on digital health implementation has predominantly focused on examining how technologies are rolled out with groups of professionals in clinical settings. For example, Cresswell and Sheikh (2013) provide an extensive systematic review of issues that can affect the implementation and adoption of health information technology in organisational settings. This included a wide range of technologies such as EHRs, decision support tools and other types of health IT. Three themes encompassing; 1) technical characteristics such as the usability of digital platforms, 2) social aspects like computer literacy, and 3) organisational factors such as senior leadership support were reported as affecting the implementation of health IT. They conclude that these three dimensions interact with each other dynamically over time, affecting how health IT is deployed and used in healthcare organisations. How technology is rolled out in a primary care context has also been explored such as how EHRs are deployed among GPs. Ludwick and Doucette

(2009) reviewed the literature in this area and highlighted a number of factors such as the design of the EHR interface, project management, finance and staff anxiety which affected its implementation. These organisational contexts and populations of health professionals can operate in unique ways, which affect how technology is deployed.

2.4.1 Implementing digital health among patients and the public

Where patients or consumers are concerned, how digital health products and services are deployed in peoples' homes and communities outside of an organisational setting can be different. The contexts within which people live their everyday lives, at home and in their local communities, can mean the implementation process does not follow the same path and other barriers and facilitators can come into play. Granger et al. (2018) found that only 16% of patients who lived in high poverty, inner city areas and suffered from COPD had a computer, making the uptake of telehealth challenging. Furthermore, only 14% had Internet access which was another barrier for this group. Quanbeck et al. (2018) examined a mobile health system called Seva for people with substance abuse disorders. They found the reach of the mHealth initiative was limited due to an inability of the healthcare provider to pay for phones and data plans for patients. Furthermore, much of the health research to date has typically focused on the middle phases of implementation, around patients using an intervention such as a digital health product or service. For example, Powell, Stone and Hollander (2018) described patients experiences when using a telehealth programme run at a large urban, multihospital health system in the United States. Many felt it was easy to use, although a few patients had technical issues with the technology or did not like interacting via a videoconferencing system. Bardosh, Murray, Khaemba, Smillie and Lester (2017) looked at a text messaging medication reminder system called WelTel for HIV patients. When the mHealth system was operationalised, the software needed to be refined and customised so it was easier for patients and clinicians to use. However, less is known about the beginning of the implementation journey before people start using a technology, such as how they find out about and start to understand its value (engagement) and then take the steps needed to begin using it (enrolment).

Some exploratory work such as a literature review on public engagement with eHealth undertaken in 2009 has been published (Hardiker and Grant, 2011). It identified a multitude of factors such as the characteristics of users and eHealth services themselves, technological issues and social aspects as affecting how members of the public engaged with digital health interventions. But this review is now out of date and limited in its technological scope, as it focused mainly on people who searched for health information online and did not look at engagement with other types of digital health interventions. Although the growth in the use of DHIs and their potential benefits is promising, without a fuller understanding of the initial steps of engagement and enrolment, the implementation of consumer oriented DHIs could continue to be stymied by barriers that crop up in the early phases of deployment. These first steps are critical to understand as any complications during engagement and enrolment, may prevent patients and the public from moving onto using technology that has the potential to improve their health and wellbeing.

2.4.2 Engagement and enrolment

Some evidence examining the barriers and facilitators people experience when engaging and enrolling in DHIs exists, but it has primarily been generated through quantitative study designs. For example, recent research has highlighted many barriers that prevent patients and the public from taking up DHIs such as individuals being unable to use electronic platforms or disliking their impersonal nature (Gorst, Armitage, Brownsell and Hawley, 2014; Sanders et al., 2012). On the other hand, there are factors that help people to engage with DHIs such as being motivated to improve and manage personal health and wellbeing (Miyamoto et al., 2013). However, what is understood about deploying health technologies in everyday settings typically comes from evaluation studies such as pilot projects and RCTs (Lakerveld et al., 2008). Due to the nature of this type of quantitative research, it can provide limited information to help us understand the difficulties people face when consumer oriented DHIs are deployed in real-world settings.

Firstly, these types of research designs typically recruit participants who have specific health or social care needs and come from particular socioeconomic and cultural backgrounds. In addition, the settings within which the technology operates can be limited and extra support and resources may be provided as part of the research study which would not normally be available to people. For example, Standen et al. (2017) conducted a pilot RCT to test the effectiveness of a virtual reality system for home-based rehabilitation with stroke patients. Specific inclusion criteria such as patients who were no longer receiving other forms of intensive rehabilitation and who had some residual impairment in their arm were used and only these types of individuals were invited to take part. Likewise, there were several exclusion criteria such as experiencing severe arm or shoulder pain, severe visual impairments, those with other neurological conditions or psychiatric illness, stroke patients with a cardiac pacemaker or those living in a care home. Only 29 people consented to participate and 18 completed the study. Limited information on participant characteristics was provided, with gender and mean age being the only personal features reported and no socio-economic indicators were described. This meant the population of people using the technology was very small, had specific characteristics and their home environment and other important personal and social factors were not taken into consideration. Interestingly, several patients who were approached to enrol in the study refused to do so, as four were “not interested” (the specific reasons why were not reported), three did not want to use a computer and two patients wanted to focus on leg mobility instead of functional arm movement. This demonstrates that studies taking place in controlled research settings such as clinical trials do not always reflect real-world environments and results pertaining to implementation can be limited.

Secondly, the recruitment process that takes place within pilot studies and RCTs can be intensive and does not represent what happens naturally. For example, research staff, who may be doctors or nurses, actively recruit patients to participate in trials by reaching them or their carers in inpatient, outpatient or community settings (Bee et al., 2016). The personnel responsible for enrolment will also discuss and explain the digital health product or service in detail, an ethical requirement, so patients are aware it exists and begin to understand how it might be of value to them. Furthermore, research staff may also assist patients and the public to sign up to a DHI such as helping them set up an online account or profile or installing equipment or a computer system in their home (Hirani, Rixon, Cartwright, Beynon and Newman, 2017). The added assistance, time and recruitment expertise that often occurs in pilot studies and RCTs does not always translate to the real world. Many commercially available digital health products and services are advertised via traditional and online media to ensure patients and the public know they exist, as businesses do not always have direct access to clinical environments or staff who can relate their technologies to patients and carers (Lefebvre, Tada, Hilfiker and Baur, 2010). In addition, Joseph, West, Shickle, Keen and Clamp (2011) reported that some nurses and other health professionals did not encourage patients to consider signing up to telehealth services as they did not understand the technology themselves. Therefore, what we know about the barriers and facilitators that occur during enrolment to DHIs in non-research settings is limited.

Thirdly, feasibility studies and clinical trials have funding and resources to ensure the technologies they are testing are available to participants. However, once the research study is finished the DHI may not be sustainable if a healthcare provider does not cover the cost or other ways to fund the digital health product or service are not found (Devlin et al., 2016). In addition, the hardware and software that make up the DHI being tested are easily accessible for participants during a research study as they will be given the technology for free and often receive training on how to use it (Sun et al., 2018). Data privacy and security issues around technologies being examined in clinical research are also minimised, as the ethical process guarantees that participant data is handled sensitively and securely and is destroyed or anonymised after a reasonable period of time (Emmanuel et al., 2011). Due to the unique ways in which research is conducted, the barriers and facilitators that occur when patients and the public engage and enrol in DHIs in real-world settings remains largely hidden. As such the literature is fragmented and does not represent a clear picture of all the factors that affect engagement and enrolment in DHIs.

Therefore, as outlined in Chapter 1, this thesis focuses on the first two stages of implementation i.e. engagement and enrolment to unpick the key components of these steps and what factors influence patients or members of the public to take up a digital health product or service. For the purposes of this doctoral study engagement is defined as:

any process by which people become aware of and understand how a DHI is of value

For example, this might occur through advertising or personal recommendations from family members or friends. Enrolment is defined as:

any process by which individuals sign up for or gain access to a DHI

For example, completing a paper-based registration form or setting up an online account or profile.

2.5 Theoretical Background

A theoretical perspective is usually considered beneficial within a research study, whether one is building a new theory or applying an established theory to the subject under examination. A theory can be developed through inductive and deductive reasoning from experiential or empirical practice, helping us to understand and explain a complex phenomenon (Brazil, Ozer, Cloutier, Levine and Stryer, 2005). It involves the creation of abstract concepts which taken together can be used to explain something conceptually as a whole. Theory can be regarded as:

> *“a set of interrelated constructs (concepts), definitions and propositions that presents a systematic view of phenomena by specifying the relationships among variables, with the purpose of explaining or predicting the phenomena”* (Kerlinger, 1973, p. 9).

Researchers can apply theory in various ways such as utilising it when designing research questions and as a guide to data collection and analysis. It is predominately used to aid in the description, explanation and understanding of multifaceted phenomena. Davidoff, Dixon-Woods, Leviton and Michie (2015) advocate using theory in the evaluation of healthcare improvements, as it can shorten the time to develop new interventions, along with optimising their design and identifying the contextual factors needed for their success. Eccles et al. (2009) also stress the advantages of using theories in implementation research such as incrementally accumulating knowledge, producing generalisable frameworks that apply across different populations and settings and as explicit analytical tools.

2.5.1 Implementation theories and frameworks

Several models of implementation have been created or adopted from other academic disciplines to help researchers understand the complexities of deploying new interventions, such as technology, in healthcare. These help build the evidence base for what works in terms of implementation. One such framework is the Diffusion of Innovation (Rogers, 1962) as it explains how new ideas and technologies are adopted and spread within social systems. Roger posits that a new idea or tool is taken up early on by individuals who are innovators and like to try new things. Over time, early adopters try the technology and eventually it moves onto early and late majority users before finally being taken up by laggards, who are the last group to adopt the new concept or system (see Figure 5). Greenhalgh et al. (2008a) used the Diffusion of Innovation framework to explore how an electronic patient record was implemented in the health service in England. Others have used it to examine the behaviour of nurses towards a new computerised care planning system, to reveal how they adopted this new technological innovation in clinical practice (Lee, 2004). While Diffusion of Innovation is relevant to how a technology becomes adopted over time, it tends to focus more on specific groups of users of a new intervention and how they perceive the innovation. It therefore misses some of the external factors that can affect why people adopt technology both individually and collectively, in particular outwith a health service setting.

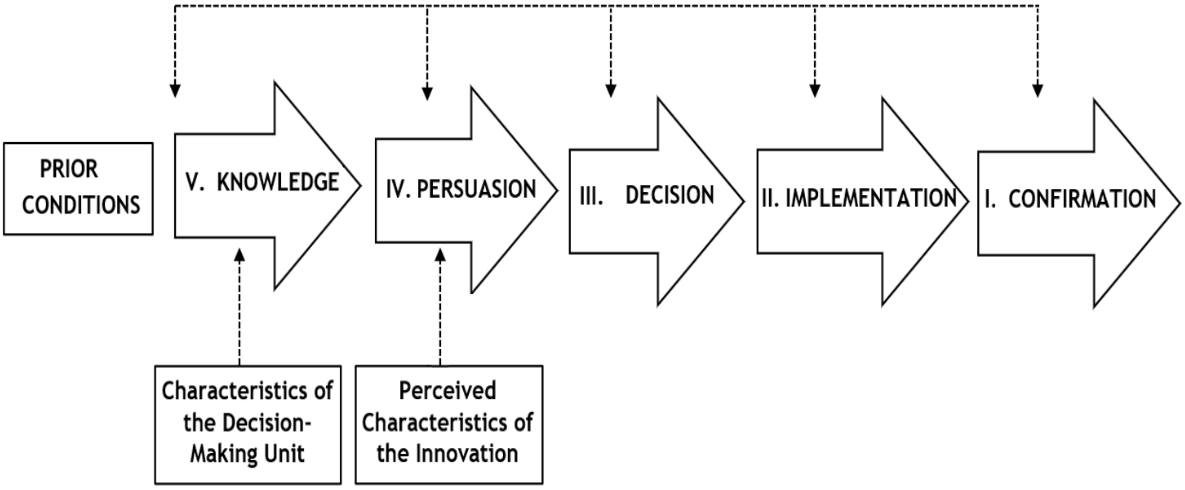


Figure 5: Diffusion of Innovation adapted from Rogers (1962)

The Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework is another model that has been used across all stages of the research process to help plan, deliver, evaluate and translate health research into practice (Glasgow, Vogt and Boles, 1999). Although there is debate within the academic literature on what constitutes a theory, RE-AIM is considered a programme level theory as it specifies components of an intervention and links them to outcomes (Knowles, Cotterill, Coupe and Spence, 2019). Each dimension of the framework addresses a distinct element of the impact of an intervention (see Figure 6). ‘Reach’ looks at the numbers that participated and those that declined and their sociodemographic makeup. ‘Effectiveness’ examines the positive and negative effects of the intervention on participant outcomes. ‘Adoption’ studies the number and type of settings that adopted the intervention or rejected it. ‘Implementation’ measures the extent to which the intervention was delivered as intended. Finally, ‘Maintenance’ looks at the sustainability of the intervention over time in terms of participants and settings.

RE-AIM has been used in the digital health domain to translate a clinical decision support system into practice (Bakken and Ruland, 2009), and to help deploy a mobile app to promote physical activity and reduce ankle sprains (Vriend, Coehoorn and Verhagen, 2014). However, it is more of an evaluation framework as it seeks to measure different aspects of a technology and how it is rolled out but it does not identify specific processes that occur at the various stages and whether they hinder or facilitate implementation.

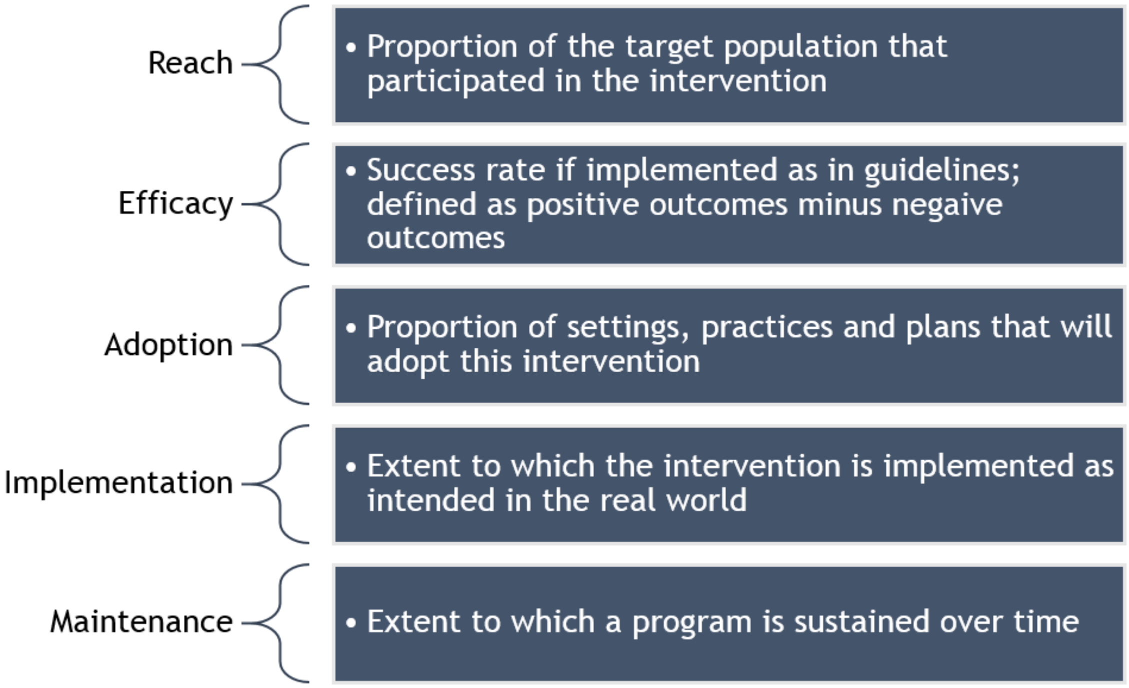


Figure 6: RE-AIM Evaluation Dimensions adapted from Glasgow et al. (1999)

Organizational Readiness for Change is one more approach that has been used to assess if an institution has all the necessary elements to enable a new intervention to be adopted (Weiner, 2009). This theory encompasses a number of interrelated components including a range of possible contextual factors, change valence (motivation), informational assessment, change commitment and efficacy, and change-related effort, all of which can lead to implementation effectiveness (see Figure 7). This theory has been used to examine the readiness of a hospital in Africa to implement an electronic patient record (Adjorlolo and Ellingsen, 2013) and how prepared staff working in an out-patient rehabilitation centre were to adopt technology in their practice (Touré, Poissant and Swaine, 2012) among others. However, Organizational Readiness for Change essentially looks at the pre-implementation phase and is only useful to explore individual and organisation preparedness for technology. Therefore, it is missing the major phases in the implementation process when people start to engage with technology and use it, so it cannot be applied to examine these in depth. It is also focused exclusively on organisational settings which misses how everyday people take up technology at home.

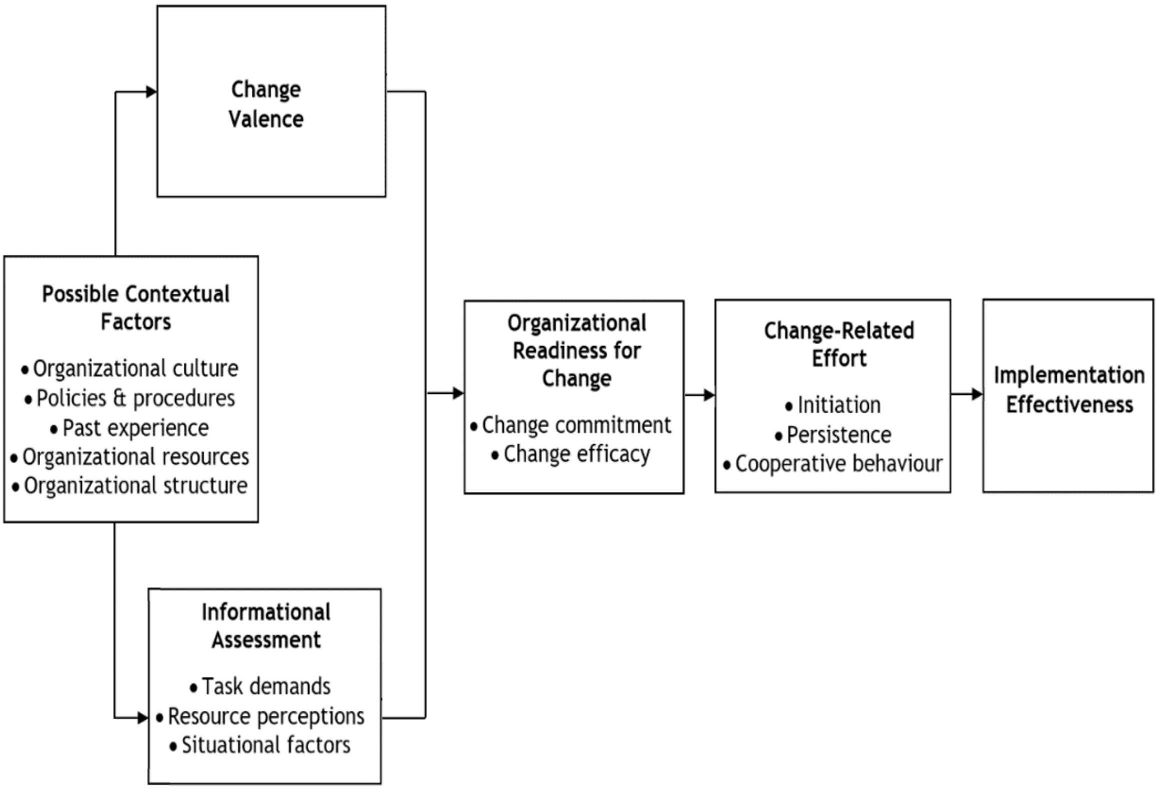


Figure 7: Organizational Readiness for Change (Weiner, 2009)

The Consolidated Framework for Implementation Research (CFIR) has five main domains, one of which is the “Implementation Process” (Damschroder et al., 2009). This outlines four stages in the implementation process; 1) Planning, 2) Engaging, 3) Executing, and 4) Reflecting and evaluating, that can be accomplished in a linear, cyclical or iterative fashion (see Figure 8). The planning phase focuses on establishing ways to effectively implement an intervention such as taking into account the needs and opinions of all stakeholders or delivering tailored education about the new intervention to these different groups. Performing dry runs of the new intervention before it goes live and building people’s capacity for change can also be elements of the planning stage. Engaging is the next phase which concentrates on involving key people in facilitating the deployment of the new intervention. These 'champions' are highly influential, either within or external to the organisation, and are utilised to lead different stakeholder groups through the process. The third phase, Executing, is about putting the implementation plan into practice and ensuring the intervention is used by the various staff members and teams in an organisation. Finally, Reflecting and evaluating involves gathering feedback about the implementation process from those who took part and identifying what worked, what did not and how to refine and improve the use of the new intervention.

Varsi, Ekstedt, Gammon and Ruland (2015) used CFIR to identify barriers and facilitators when implementing an Internet based patient-provider communication service in a university hospital in Norway. They acknowledged it as a comprehensive overview of all aspects that can affect implementation, which helped them prepare interview guides for participants. However, they also noted this as a weakness as the framework may be too broad to capture all constructs that emerged during implementation. In addition, CFIR includes the entire deployment journey and does not focus exclusively on engagement or enrolment.

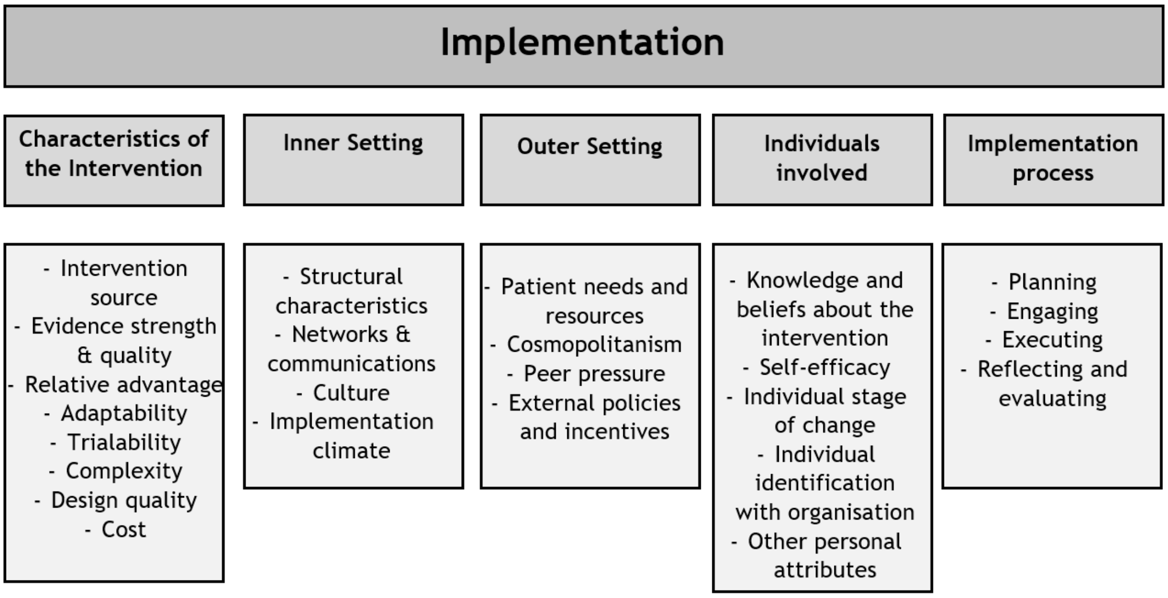
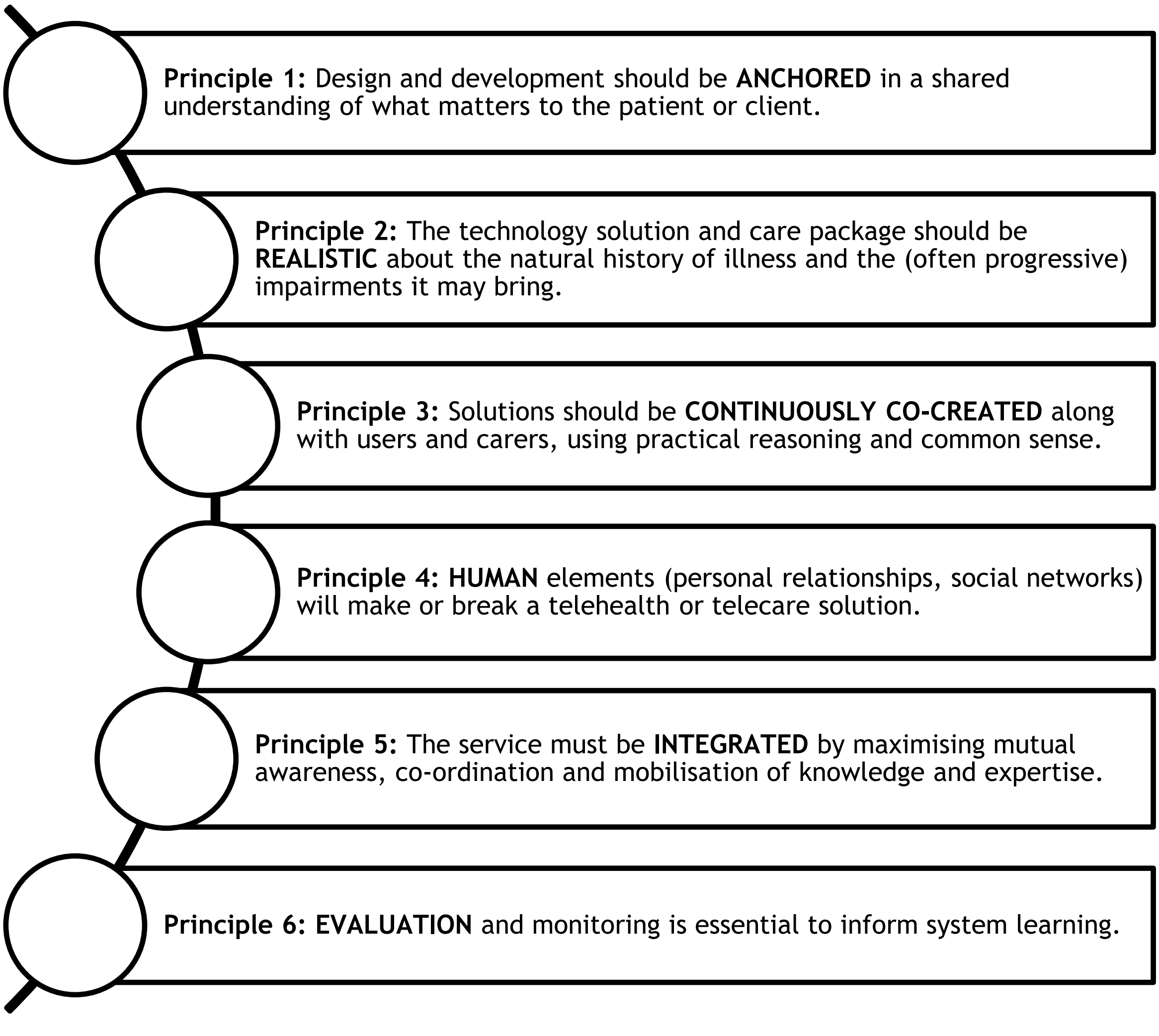


Figure 8: Consolidated Framework for Implementation Research adapted from Damschroder et al. (2009)

A newer framework aimed specifically at telehealth and telecare products, called ARCHIE (Anchored, Realistic, Continuously co-created, Human, Integrated, Evaluated) was developed by Greenhalgh et al. (2015). It consists of six quality principles for designing, installing and supporting telehealth and telecare in people's homes (see Figure 9). While it presents a useful framework to support these processes, it mainly offers dimensions of quality thought to be important for assistive technologies being deployed with patients in homely settings. In addition, it covers the entire implementation process from creating the technology right through to someone using it day to day and only focuses on one specific type of digital health tool. Hence, it is of limited value to explore the initial phases of patient and public engagement and enrolment in digital health more broadly.



Principle 1: Design and development should be **ANCHORED** in a shared understanding of what matters to the patient or client.

Principle 2: The technology solution and care package should be **REALISTIC** about the natural history of illness and the (often progressive) impairments it may bring.

Principle 3: Solutions should be **CONTINUOUSLY CO-CREATED** along with users and carers, using practical reasoning and common sense.

Principle 4: HUMAN elements (personal relationships, social networks) will make or break a telehealth or telecare solution.

Principle 5: The service must be **INTEGRATED** by maximising mutual awareness, co-ordination and mobilisation of knowledge and expertise.

Principle 6: EVALUATION and monitoring is essential to inform system learning.

Figure 9: ARCHIE framework adapted from Greenhalgh et al. (2015)

One of the newest theories to be published around implementation is the Non-adoption, Abandonment, Scale-up, Spread and Sustainability (NASSS) framework based on a review of existing theories and empirical case studies of technology implementation in healthcare (Greenhalgh et al., 2017). The NASSS framework helps to explain the different aspects that affect how patient-focused health and wellbeing technologies are taken up and sustained over time. The seven identified domains include the condition of the patient, a variety of organisational elements needed for change and wider structural aspects such as the policy and regulatory environment (see Figure 10). While this overarching framework will no doubt be beneficial in planning and rolling out health technologies at scale, it is too high-level and does not explore the intricacies of the beginning of the implementation process when people engage with and enrol in DHIs.

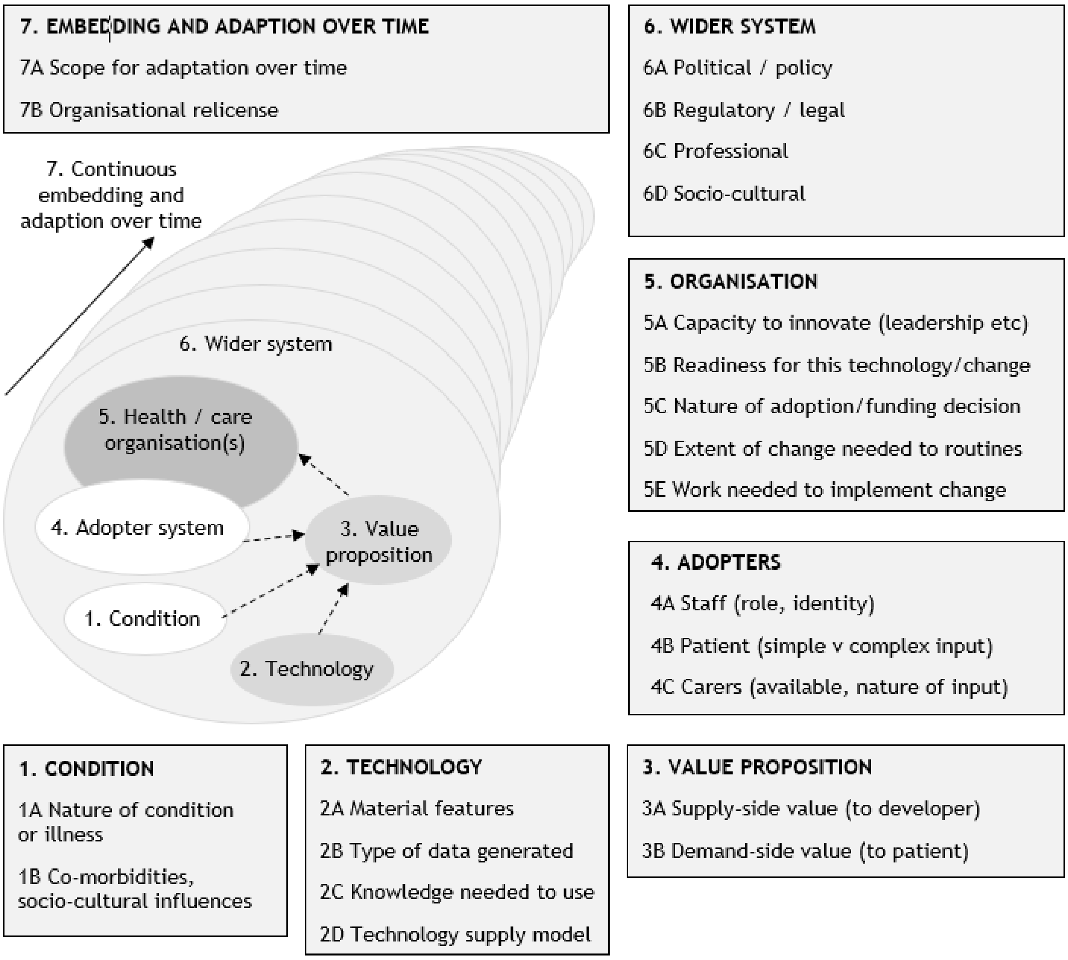


Figure 10: NASSS framework (Greenhalgh et al., 2017)

While these models help to unpick all phases of implementation and what is required to successfully introduce a new intervention in healthcare, they do not explore the beginnings of the process in detail. Furthermore, they have primarily adopted an organisational, health service focus and do not explore how interventions such as technology might be taken up by patients and healthy people in their own lives. As this is a very different context a sociological model, Normalization Process Theory (NPT), is presented in Chapter 3 to address this gap (May and Finch, 2009). It focuses on the individual and collective processes that people go through to adopt a new intervention into their everyday life and is used to underpin this thesis to explore engagement and enrolment in consumer digital health. A more detailed discussion of the process models and theories on integrating new technologies in healthcare is presented in Chapter 3.

2.6 Conclusion

This chapter provides an overview of digital health and its evaluation, in particular the need for more implementation research when deploying technology in healthcare. It also outlines why engagement and enrolment are important parts of the process to understand when rolling out digital health interventions among patients and the public. This is taken up and explored further in Chapter 4, when qualitative literature on this topic is reviewed and synthesised to lay the groundwork for the proceeding doctoral study. This chapter concludes by highlighting some theories and models that have been used to explain how digital health products and services are rolled out. The specific theoretical approach taken in this thesis is discussed in more detail in the following chapter.

3 Methodology

3.1 Introduction and aims

The overall aim of this chapter is to present the methodological approach used throughout the thesis to address the research questions. The strengths and limitations of the chosen methods will also be discussed.

3.2 Background

Traditionally scientific research was grounded in the quantitative paradigm as people experimented with the laws of science to understand the natural world. The written record of this scientific approach stretches back to Classical Greece, from approximately 600 BC onwards. Individuals such as Thales, Socrates, Plato and later Aristotle laid the foundations of empirical and philosophical inquiry into the natural world (Gribbin, 2003). It is likely that humans have always tried new ways of thinking and working. There is evidence that early civilisations tested novel agricultural practices, had some knowledge of astronomy and developed techniques to write and record language among others. This desire to understand the world continued throughout the centuries. As science and society became more sophisticated new disciplines and areas of inquiry emerged. The birth of modern science began in the 19th century when the fundamental principles of physics, chemistry, and biology were proven by researchers such as Albert Einstein, Robert Boyle, Charles Darwin, and Gregor Mendel among many others. These advances were primarily based on the positivist assumption that all knowledge is founded on naturally occurring phenomena, which can be observed and measured in objective ways (Kothari, 2004).

However, an alternative view which stands in contrast to positivist thinking gained popularity in the 20th century. Sociologists criticised the narrow view adopted by pure scientific methods as they felt quantitative approaches were not appropriate to understanding aspects of society such as ethics, politics, language, culture and other areas that sought to comprehend human thought and behaviour. From a post-positivist standpoint, a researcher is inexorably linked with the subject they study and their experiences and beliefs can affect the research process (Hennink, Hutter and Bailey, 2010). This means that the world is seen through a subjective lens and that aspects of society cannot be explored through quantitative means alone because no universal rules govern social behaviour and interaction. As societies are constructed in a variety of complex ways it means they cannot be observed and objectively measured in isolation. Therefore, qualitative methods are needed to explore and understand human experiences and perceptions of social phenomena (Patton, 1990). Both quantitative and qualitative paradigms have helped shape contemporary health research. Quantitative methods are employed to test the efficacy of drugs and other interventions to try and improve health outcomes for patients (Tunis, Stryer and Clancy, 2003). Qualitative approaches are used to understand the human experience of illness and recovery and the social determinants of health (Speziale, Streubert and Carpenter, 2011). As there is a range of research perspectives, the underpinning viewpoint of this thesis and its methodological approach will be outlined next.

3.3 Ontology and epistemology

Ontology is a branch of philosophy that studies the nature of reality and how the world and the things in it exist. These can be real objects and processes or abstract ones and can be temporal or occur independent of time. Epistemology follows on from ontology and seeks to understand what knowledge is, how it is created and if it is true or false. Various complementary and contradictory ontological and epistemological perspectives exist but they broadly fall into two categories. Firstly, realism posits that objects have certain properties and relations that exist independent of human understanding and experience of them (Poli and Seibt, 2010). This train of thought can be linked to an objective view of the world, which believes that we can understand the truth about reality through empirical observation or scientific experimentation (Kuhn, 2012).

The main opposing ontological and epistemological position is that of subjective idealism which says that entities cannot exist except in the minds of those who perceive them. This worldview has led to the development of qualitative forms of inquiry, where researchers believe that there is no objective truth and everything we know is socially constructed and influenced by our perceptions of ourselves and the world around us (Lincoln and Guba, 1985). Therefore, how people perceive the world (ontology) and come to know something about it (epistemology) can vary widely. Hence, researchers must examine their own perspective on a subject and the methodological strategies used to understand it, as it will influence their findings to some degree (Finlay, 2002). Here, the doctoral student is a nurse in her mid-thirties who grew up with technology and worked with patients in a variety of acute and community settings. She had first-hand experience of the difficulties they faced in relation to engaging and enrolling in different kinds of technology. This prior knowledge and personal perspective is likely to have had some influence on this work, which is reflected on and discussed further in this chapter.

For the purposes of this thesis, a post-positivist approach was taken as the human experience of engaging with digital health interventions (DHIs) and signing up to use them is grounded in the specific context within which patients, the public, health professionals and others live and work. Therefore, the two research questions posed in Chapter 1, and reiterated below, are best addressed through interpretative means.

- What factors (barriers and facilitators) affect engagement and enrolment in consumer digital health interventions (DHIs)?
- What strategies have been used to engage and enrol individuals in consumer DHIs?

The research questions were addressed using the following approaches:

1. A systematic review of the qualitative literature exploring the factors that affect patient and public engagement and enrolment in digital health. This provided a synthesis of the barriers and facilitators involved in these two complex processes and an initial catalogue of approaches to engagement and enrolment (Chapter 4).

2. Secondary analysis of interviews with a range of stakeholders implementing a variety of DHIs. This included health service managers and administrators, government sector staff, academics, employees of technology companies, third sector staff and volunteers. It helped shed light on the experiences of many individuals and what they perceived were the main elements that

helped and hindered engagement and enrolment in consumer digital health (Chapters 5, 6 and 7).

3. Primary data collection and analysis of interviews and focus groups with a range of patients, carers, service users and health professionals who signed up for DHIs and other individuals who helped develop, deploy or promote them were conducted. This supported and expanded on the findings of the systematic review and the initial qualitative dataset (Chapters 5, 6 and 7).

3.4 Theoretical perspective

A theoretical perspective is usually considered beneficial within a research study, whether one is building a new theory or applying an established theory to the subject under examination. It is developed through inductive and deductive reasoning from experiential or empirical practice, helping us to understand and explain a complex, intangible phenomenon (Brazil et al., 2005). It involves the creation of abstract concepts which taken together can be used to explain something conceptually as a whole. Theory can be regarded as:

> *"a set of interrelated constructs (concepts), definitions and propositions that presents a systematic view of phenomena by specifying the relationships among variables, with the purpose of explaining or predicting the phenomena"* (Kerlinger, 1973, p. 9)

Researchers can apply theory in various ways such as utilising it when designing research questions and as a guide to data collection and analysis. It is predominately used as it aids in the description, explanation and understanding of multifaceted phenomena (Francis, Stockton, Eccles, Johnston and Cuthbertson, 2009). Theories fall broadly into three domains; 1) grand theory, 2) mid-range theory, and 3) micro level theory, each of which has a different focus. A grand theory is broad in scope and looks at universal concepts that can be applied to all processes or problems within a domain. Mid-range theory, on the other hand, focuses more on local systems and provides a less abstract conceptual schema that can be empirically tested. Finally, micro-theory is the narrowest in scope and concentrates on the individual level and personal contextual factors (Reeves, Albert, Kuper and Hodges, 2008).

Mid-range theories are often used in health research to understand and explain complex phenomena. They can be divided into three main categories: 1) descriptive, 2) explanatory, and 3) predictive theories. Descriptive theories can be generated through qualitative and quantitative descriptive studies. They depict the various elements of a phenomenon and categorise these into sequential, hierarchical or overlapping dimensions. This approach enables researchers to describe abstract concepts. Explanatory theories go a step further as they are generated through correlational research and specify the relationships between the various components of a theory and to what extent they interact with each other. This enables researchers to explain cause and effect within a phenomenon. Finally, predictive theories are generated through experimental research and move beyond explanation to predicting the associations between components to estimate the likelihood of a phenomenon occurring in a particular way. This enables researchers to forecast what may happen in the future if a given set of variables exist (Peterson and Bredow, 2009).

Theory is an essential component of this thesis as it seeks to explore and understand the factors that affect engagement and enrolment in consumer digital health. This study aims to identify the barriers and facilitators that affect patients, the public, health professionals and implementers during engagement and enrolment to DHIs. Therefore, a descriptive theoretical approach is needed to understand the complexity of these initial steps within the wider implementation process, as they have not been explored and illustrated in-depth. This allows the key elements of the phenomenon to be identified and the abstract concepts represented in a more easily accessible form. Research on how technology has been implemented in the health service has been conducted for several years (Miller, Frawley, Wright, Roderer and Powsner, 1995; Berg, 1999). This literature now encompasses a wide range of theories and frameworks for understanding the various social, technical, cultural and other aspects involved as summarised in Chapter 2. A review of theories and models in the wider health implementation literature has identified an even greater number and diversity of theories, models and frameworks in use (Nilsen, 2015). A justification is given here for the chosen theoretical model that is used as the basis of this doctoral study.

3.4.1 Theoretical Underpinning

Few robust models or theories exist that help explain how DHIs are implemented with patients and the public, as general health and digital health implementation models have typically adopted an organisational, health service focus. Patients or members of the public who want to use technology at home to manage their health and wellbeing live and work in a very different context that is not related to an organisational or health service setting. Thus, the models discussed in Chapter 2 do not adequately explain how digital health products and services are deployed by everyday people in community settings. Researchers have called for more robust conceptual models that detail the exact processes of implementation. These will aid our understanding of how new interventions are adopted in practice as progress in incorporating new evidence has been slow, taking anywhere from five to twenty years (Proctoret al., 2009). Once such model is Normalization Process Theory (NPT), which has been used extensively in the healthcare domain to explore how different types of interventions, such as digital health technologies, are implemented (McEvoy et al., 2014). It is a mid-range, sociological theory that helps explain how people individually and collectively adopt a new intervention into their day-to-day practice (May and Finch, 2009). As NPT is not context specific but focuses on individual and group processes, it was appropriate to apply in a community setting. Therefore, NPT was used to underpin this thesis to provide a better understanding of how technology is implemented with patients and members of the public in their daily life.

3.4.1.1 Normalization Process Model

NPT was created and expanded upon over several years. It is grounded in extensive research and theoretical development across a range of healthcare settings, the majority of which examines the deployment of technology in a variety of clinical settings (McEvoy et al., 2014). Originally it began in a more focused form called Normalization Process Model (NPM). This initial model was developed to assist in identifying the factors that help and hinder how complex interventions are rolled out in practice. It was built and tested on data from a number of studies, in an attempt to theorise how translational barriers occurred during implementation. This work was undertaken to provide researchers with a conceptual model that could support the implementation of complex interventions (May, 2006). Through a process of iterative analysis and the development of analytic propositions, four concepts emerged that formed NPM (see Table 2).

1) Interactional Workability - centres on how a new intervention affects people and their work practices. It is composed of two dimensions; that of *congruence* and *disposal*.

2) Relational Integration - refers to how people communicate and are confident in knowledge needed to adopt the intervention. It consists of two dimensions; *accountability* and *confidence*.

3) Skill-set Workability - is about how tasks to implement the new intervention are allocated and how well these are performed. *Allocation* and *performance* are its two dimensions.

4) Contextual Integration - is about how individuals and organisations agree and enact the resources required to employ a new intervention. It involves two dimensions; *execution* and *realisation* (May and Finch, 2009).

Table 2: Constructs of Normalization Process Model (NPM)

Interactional Workability	Relational Integration	Skill-set Workability	Contextual Integration
Congruence - explores how people cooperate and work together to incorporate a new intervention using existing resources	**Accountability -** internal knowledge people have relevant to the new intervention, whether it is adequate and how best to share it with others	**Allocation -** policies for distributing the work of implementation, identifying and appraising skills to enable this work to happen and surveying what is done	**Execution -** how resources are allocated to people to implement the intervention, who bears the costs of these and how to evaluate their use
Disposal - examines the outcomes of these actions, whether they were shared expectations or if the goals of the intervention were negotiated and reached over time	**Confidence -** external knowledge related to the new intervention, whether it is valid and reliable and how best to assess and apply it	**Performance -** skills people use to organise and incorporate a new intervention into their day-to-day work practices and how these skills are managed and assessed	**Realisation -** how to define and manage risks associated with the new intervention and utilise resources for these purposes

NPM is an applied theory and one which underwent further development. Researchers realised the limitations of NPM when it began to be applied in a variety of healthcare settings, as it mainly focuses on the middle phases of implementation when people start taking actions and utilising resources needed to use a new intervention in their day to day work. As the implementation process consists of several phases, it became clear that NPM could not explain how health professionals or patients came to understand a new intervention and how they start to engage with it. In addition, NPM does not address the later stages of implementation when people reflect on and evaluate the advantages and disadvantages of a new intervention after it has been employed for some time and whether it needs refinement to enable it to be used long-term. Therefore, NPM began to be expanded and refined over a period of time to address these gaps and become a more robust analytical framework, called Normalization Process Theory (Gask et al., 2010).

3.4.1.2 Normalization Process Theory

Normalization Process Theory (NPT) provides a series of sociological propositions that help explain the processes people undertake during the entire implementation journey, from beginning to end. It consists of four main constructs which are: 1) Coherence, 2) Cognitive Participation, 3) Collective Action, and 4) Reflexive Monitoring (see Figure 11).

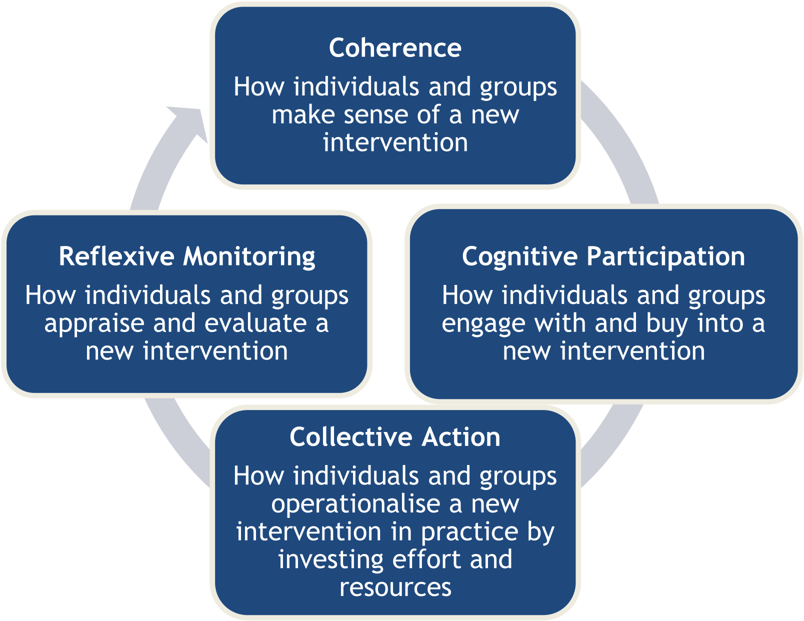


Figure 11: Four mechanisms of Normalization Process Theory (NPT)

Coherence encompasses the ways in which individuals and groups of people understand and make sense of a new intervention and new ways of working with it. It consists of four sub-constructs; Differentiation, Communal Specification, Individual Specification, and Internalization (see Table 3). The second mechanism is Cognitive Participation. This concept helps to explain how individuals and groups of people engage with and buy into a new intervention. In particular, it elaborates on the relational work that people do to build and sustain an intervention such as a digital health product or service. It consists of four sub-constructs which are Enrolment, Activation, Initiation, and Legitimation.

The third generative mechanisms of NPT is Collective Action, coming directly from NPM. This describes how individuals and groups operationalise a new intervention such as a DHI in practice, by investing effort and resources in it to ensure it is incorporated into day to day work. This element of the theory also has four sub-constructs; Skillset Workability, Contextual Integration, Interactional Workability, and Relational Integration. The fourth and final mechanism of NPT is Reflexive Monitoring. This describes how individuals and groups of people evaluate a new intervention and use this feedback to modify it if necessary. It consists of four sub-constructs, Reconfiguration, Communal Appraisal, Individual Appraisal, and Systematization.

Table 3: Constructs of Normalization Process Theory (NPT)

Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
Differentiation - how one defines, divides up and categorises work that needs to be done to	**Enrolment** - how people are recruited to undertake tasks associated with	**Skill-set Workability -** how different jobs and roles are allocated and undertaken and the skills	**Reconfiguration -** how people modify or change tasks related to a new

implement a new intervention	implementing a new intervention	necessary to use a new intervention on a routine basis	intervention based on their needs
Communal Specification - how a person or persons understands shared versions of tasks related to the deploying a new intervention	**Activation -** how different tasks are organised and shared between different people	**Contextual Integration -** how a new intervention is supported within its specific context, by allocating resources such as money and time to its deployment and regular use	**Communal Appraisal -** how people assess the shared contribution to the work surrounding a new intervention and whether this is worthwhile or not
Individual Specification - how someone makes sense of their own personal versions of implementation tasks	**Initiation -** how tasks related to implementation are organised and planned by individuals	**Interactional Workability -** how different tasks related to the new intervention are undertaken and completed by individuals and groups of people to achieve its associated outcomes in practice	**Individual Appraisal -** how an individual reflects on and evaluates their own contribution to deploying and utilising a new intervention in practice
Internalization - how individuals	**Legitimation -** how people	**Relational Integration -** how	**Systematization -** collating a reliable

or groups of people learn how to do the work of rolling out a new intervention within a specific context	individually and collectively make responsibilities for rolling out an intervention the right thing to do	people develop confidence in and communicate knowledge about how a new intervention works in practice	body of knowledge about how a new intervention was implemented and works on a day-to-day basis

NPT continues to be used to explore various aspects of deploying a whole range of interventions in healthcare, which typically focus on healthcare contexts and the entire implementation journey (Bridges et al., 2017; Cummings et al., 2017). Given the direct relevance of this theory to the aims and research questions of this study, it was decided to use NPT as the underpinning framework to explore engagement and enrolment in consumer digital health.

3.5 Methods

3.5.1 Study design

The questions posed in this thesis lend themselves to qualitative exploration and so a choice had to be made from a range of study designs about how best to answer them. As a specific culture or context was not the focus of this work due to the plurality of people, technologies and settings that needed to be captured, ethnographic methods were not deemed as the most appropriate choice (Savage, 2000). In addition, it was not possible for the researcher to easily access participants to observe them in real world contexts, making ethnography difficult to undertake. Likewise, phenomenology was not a good fit as it centres on describing and understanding a small number of human experiences of a particular event or activity (Benner, 1994). Due to the diversity of perspectives and situations required in this doctoral study, this would not have been a suitable approach. A third option was grounded theory but this was also disregarded, as it requires researchers to approach a topic from an unknown viewpoint and build their understanding of the area as they undertake fieldwork, resulting in the generation of a new theory about the subject through rigorous data collection and analysis (Glaser and Strauss, 2009). As a robust theoretical framework had been chosen for this thesis, and the researcher and her supervisors had knowledge of issues when implementing technology with patients and the public, grounded theory was not deemed a good fit as a study design. Narrative inquiry was also examined as it helps build a cohesive story by weaving together multiple forms of qualitative and quantitative data from one or two individuals to form a comprehensive understanding of their perspective on a phenomenon (Sandelowski, 1991). This method was also discounted as it would not be useful to identify the barriers and facilitators that many different types of people came across when engaging and enrolling in digital health products and services. Finally, it was decided that a qualitative multi-method approach was the best fit for purpose.

A qualitative multi-method design has been described as the coordination and triangulation of different qualitative approaches to address research questions (Collier and Elman, 2008). Hall and Rist (1999) argue that the accuracy and reliability of qualitative research can be enhanced by utilising a range of methods in a study. A multi-method design enables a degree of flexibility, allowing a range of data e.g. interviews, focus groups, participant observation, and documentation to be collected and analysed. A pluralistic approach can also involve looking at whole organisations, entities, individuals or events as they change over time depending on the requirements of the research. This strength along with the ability to capture multiple realities enables a rich, holistic account of a subject to emerge, which fitted well with the overall aim of this thesis as it would allow for the exploration of engagement and enrolment in DHIs from a variety of perspectives. Therefore, the approaches adopted in this thesis to address the research questions consisted of the following:

1) A systematic review of the qualitative literature (Chapter 4), which explored patient and the public engagement and enrolment in digital health interventions.

2) Secondary analysis of interviews with a range of people implementing a variety of DHIs was undertaken to better understand their experiences and thoughts about what helps and hinders engagement and enrolment in consumer digital health (Chapter 5, 6 and 7). After some discussion with the supervisory team it was decided it would be prudent to utilise this qualitative dataset, in addition to undertaking primary data collection. This would enable a deeper understanding of the early phases of digital health implementation and build on the findings of the systematic review (Long-Sutehall, Sque and Addington-Hall, 2011).

3) Primary data collection in the form of interviews and focus groups with patients, carers, service users, health professionals and those who helped roll out DHIs in real settings, were conducted to examine what affects engagement and enrolment to DHIs (Chapter 5, 6 and 7). These data were analysed to support and expand on the findings of the systematic review and the initial qualitative dataset.

The rationale for these methods and an explanation of how each stage in the multi-method design was carried out is provided below.

3.5.2 Qualitative reviews

The advent of the post-positivist paradigm within research emerged from the critique of the positivist approach (Clark, 1998). Many types of qualitative research have been designed to explore social phenomena and understand the complexities of the world from a more subjective and contextually driven viewpoint. The increasing volume of qualitative research in the health field has led to the creation of numerous ways to review and synthesise qualitative literature. These methods are essential to complement intervention effectiveness research, generated through quantitative means, and create robust evidence that clinicians and others can use to improve decision making and change practice (Popay, Rogers and Williams, 1998). Qualitative approaches can also be used to inform policy makers on areas that need investment and development. More recently they are being used to demonstrate to the public the value of research and make it more meaningful to lay audiences (Martin, 2008).

There are some who believe that qualitative reviews and syntheses are not appropriate to undertake, as they destroy the integrity of the individual studies and the rich context within which they take place, rendering the results meaningless. Sandelowski, Docherty and Emden (1997, p. 366) suggest that,

> *"Turning idiographic knowledge into data for synthesis seems to represent an unconscionable loss of the uniqueness of individual projects and a departure from the larger pedagogic and emancipatory aims of qualitative research. Indeed, it is precisely this knowledge that offsets the recurring failure of generalizations from quantitative studies to fit individual cases. To summarize qualitative findings is to destroy the integrity of the individual projects on which such summaries are based, to thin out the desired thickness of particulars"*

In addition, the challenges of bringing together the results of qualitative studies from varying ontological and epistemological perspectives and where a variety of different data collection and analysis techniques have been used can be substantial. While the merits of qualitative reviews and syntheses are debated, they are popular approaches used by researchers across many disciplines in healthcare to gain a better understanding of the current evidence around a particular topic or area (Barbour and Barbour, 2003).

A host of qualitative review methods exist such as scoping, integrative and systematic reviews, along with realist and narrative reviews (Grant and Booth, 2009). Each approach follows a similar process in terms of; 1) identifying a research question(s), 2) searching for literature using a variety of techniques, 3) screening the results to determine whether a study is relevant to the research objective(s), 4) undertaking some form of quality appraisal of articles that are deemed relevant, and 5) analysing and synthesising the results of these studies to answer the original research question(s). However, the individual activities can vary depending on the method used, in particular the synthesis approach.

When choosing the means of reviewing and synthesising qualitative research certain factors including the research question, epistemological perspective and the time, resources and expertise available to undertake the work need to be considered (Booth et al., 2016). While it is not feasible to provide a detailed account of each individual approach, a summary of some of the common ways to review qualitative studies are outlined in Table 4. A justification is then provided for the approach taken in this thesis.

Table 4: Common qualitative review methods

Type	Review Approach	Advantages	Disadvantages
Critical Interpretative Synthesis	Interpretative review method that uses a loosely defined research question, an exploratory, emergent search process and meta-ethnography in its approach to synthesis (Dixon-Woods et al., 2006).	• Enables all types of studies to be included but selection driven by emerging theoretical framework. • Takes into account how the body of literature constructs its central tenets.	• Sampling method (purposive and theoretical) may limit scope of a Critical Interpretative Synthesis review. • Quality appraisal is limited. • Lacks reproducibility.
Integrative Review	Five stage literature review method to provide a comprehensive understanding of a topic (Broome, 1993; Whittemore and Knafl, 2005).	• Enables a summary of empirical and theoretical literature including quantitative and qualitative designs. • Used for various purposes such as reviewing theories, evidence and methods.	• Criticised for lack of rigour, especially in the analysis and synthesis phases.

Meta-Narrative Review	A six-phase literature review method incorporating conceptual, theoretical, methodological and instrumental dimensions. Builds a “storyline” of a research discipline or topic over time (Greenhalgh et al., 2005).	• Incorporates key principles of pragmatism, pluralism, historicity, contestation and peer-review to build a rich picture of a research paradigm or topic. • Enables a review of diverse types of research within and across disciplines.	• Time consuming to conduct. • Not suitable for all types of research questions. • Synthesis requires experienced researchers and can be difficult.
Realist Review	Five-step review that explains how complex social interventions work in real settings by describing key aspects of causality (Pawson, Greenhalgh, Harvey and Walshe, 2005).	• Offers a rich description as it focuses on mechanisms of action and the contextual setting to explain cause and effect of an event/intervention. • Useful to understand differences in programme implementation.	• Limit to what the review can encompass due to the complexity involved.
Scoping review	Six-stage literature review framework to map relevant concepts and literature within a	• Provides an overview of the size and scope of a particular research topic and its associated literature.	• Can be challenging to find a balance between breadth and depth in a review (Pham et al., 2014).

	research field (Arksey and O'Malley, 2005).	- Can inform the conduct of subsequent reviews in the topic area.	
Systematic Review	An explicit statement of specific review objective(s) followed by clear, rigorous and reproducible review methods (Greenhalgh, 1997; Jones, 2004).	- Uses comprehensive search methods to identify as many relevant studies as possible. - Employs critical appraisal techniques to judge the quality of evidence and its contribution to the topic.	- Time-consuming activity.

This thesis has adopted a systematic review approach to identify and synthesise relevant qualitative literature on the barriers and facilitators that affect patient and public engagement and enrolment in digital health. Some thought was given when choosing this review method, as other types of reviews could have been used to address the research questions. However, it was felt that scoping reviews, meta-narrative reviews and critical interpretative synthesis were more apt for exploring and understanding broader social phenomena and research disciplines and would not fit with the focus of this study, which concentrates on the early phases of digital health implementation. Integrative reviews were also considered but as they are more appropriate for combining quantitative and qualitative data, it was felt this approach would also be unsuitable. Finally, realist reviews offer a unique way to look at implementation but they tend to centre on specific programmes or elements within programmes and examine what works, for whom, and in what context. However, as this study sought to examine the factors affecting engagement and enrolment across a range of digital health products and services, settings and patients or members of the public, the realist approach was incompatible as its scope was limited and it would be impractical to apply. Therefore, a systematic review of the qualitative literature aligned best with the aims of this doctoral study and is described in detail in Chapter 4.

3.5.3 Qualitative synthesis

Upon deciding that a systematic review of qualitative studies was the most appropriate review methodology for this thesis, further consideration was then given to the type of synthesis that would complement and enhance this. Common qualitative synthesis methods include meta-ethnography, grounded theory, critical interpretative synthesis and thematic synthesis (Barnett-Page and Thomas, 2009). While a detailed account of each one is not feasible to provide in this thesis, a summary of some of the popular ways to conduct qualitative synthesis are outlined in Table 5. A justification is then provided for the approach taken in this work.

Table 5: Common qualitative synthesis methods

Type	Synthesis Approach	Advantages	Disadvantages
Framework Synthesis	A highly structured five phase synthesis process (familiarisation, identification, indexing, charting and mapping) that can produce an explanatory analysis (Ritchie and Spencer, 1994; Miles and Huberman, 1994).	• A priori framework can be used to guide the synthesis. • Uses inductive and deductive analysis to organise and understand large amounts of data.	• Risk of forcing data to fit the framework rather than allow concepts to emerge organically.
Grounded Theory	Preliminary analysis guides future data collection and synthesis. Constant comparative analysis and three types of coding (open, axial and selective) used to build model/theory of social phenomenon (Corbin and Strauss, 1998; Rodriguez, 1998).	• Helpful in generating new theory. • Produces thick descriptions that acknowledge areas of contention. • Can incorporate studies of diverse.	• No clear rules to follow when identifying categories. • Can produce large amounts of data that are difficult to manage. • Fails to recognise the influence of the researcher in the process.

Meta-ethnography	Combination of three complementary synthesis approaches; reciprocal translation (identify key themes/concepts), refutational synthesis (explain differences in themes/concepts) and lines of argument analysis (conceptual interpretation/theorising) (Noblit and Hare, 1988; Atkins et al., 2008).	• Enables theory to be produced. • Rigorous, transparent approach. • Strong interpretative process suited to synthesising ethnographic and other types of qualitative research.	• Poor guidance on sampling technique. • Difficult to translate studies into one another if there are a large number of studies. • Reproducibility of the process is questionable as it depends on the review team.
Meta-study	Synthesis encompasses three types of analysis; meta-data-analysis (analysis of findings), meta-method-analysis (analysis of methods) and meta-theory (analysis of theory) (Paterson, Thorne, Canam and Jillings, 2001).	• Acknowledges qualitative research is a construction of social, historical and ideological contexts. • Iterative, reflexive process that can account for qualitative and quantitative studies.	• Time consuming to conduct. • Lack of clarity on the integration of the three types of analysis.
Narrative synthesis	Four stages of synthesis; developing a theoretical model of the intervention, a preliminary analysis, exploring	• Can be used to explore effectiveness of interventions or their implementation.	• Lacks transparency.

	relationships in the data and assessing robustness, which use a number of techniques e.g. content analysis, rubrics and tabulation, conceptual mapping (Popay et al., 2006; Snilstveit, Oliver and Vojtkova, 2012).	• Can combine quantitative and qualitative data. • Enables explanatory theory to be developed.	• Plurality of techniques means an experienced research team is necessary.
Thematic synthesis	Three-phased synthesis incorporating line-by-line coding, organising these ‘free codes’ into related constructs or descriptive themes and drawing these together into overarching analytical themes (Dixon-Woods, Agarwal, Jones, Young and Sutton, 2005; Thomas and Harden, 2008).	• Clear, rigorous process and identification of themes. • Useful to answer more specific types of review questions.	• Can be difficult to distinguish between ‘data-driven’ and ‘theory-driven’ themes. • Criticised for lacking theoretical depth.

Some of the qualitative synthesis methods which are focused purely on generating new theories, such as grounded theory and meta-ethnography, were immediately dispensed with as a highly relevant underpinning theoretical framework i.e. NPT had already been chosen to support the review and analysis process. A meta-study was also dismissed as this thesis would not be analysing the methods or theories of the included studies in-depth and how they contributed to the findings. Narrative synthesis was also deemed incompatible as its strength lies in combining quantitative and qualitative data, which is not the focus of this work. Finally, thematic synthesis was given some attention as its structured approach to analysis and delineating higher order themes could have been useful in identifying the barriers and facilitators to engaging and enrolling in DHIs. However, on final consideration it was felt that framework synthesis offered the most robust approach as it not only had a clear, rigorous coding process to identify categories and concepts in the data but it also allowed an a priori framework to be used to guide the coding matrix. Given that NPT had been identified as being directly relevant to understanding the subject of this thesis, framework synthesis was selected as the most pertinent method of analysis. The precise approach followed for the synthesis of qualitative findings is described in detail in Section 3.5.8 and in Chapter 4.

3.5.4 Delivering Assisted Living Lifestyles at Scale (dallas)

The overall study focused on a large £37 million digital innovation programme called Delivering Assisted Living Lifestyles at Scale (dallas), which ran in the United Kingdom from June 2012 to May 2015. The dallas programme consisted of four distinct ‘communities’ or groups of stakeholders who developed and implemented a wide range of digital health products and services with numerous patient and consumer groups (Devlin et al., 2016; Lennon et al., 2017). The four communities were called;

1) Living It Up

2) Year Zero

3) More Independent

4) i-Focus

Each dallas community was overseen by a programme manager, who had a team to support them in planning, developing and implementing a range of digital health products and services. The stakeholders in each dallas community included a variety of health professionals (e.g. family doctors, health visitors, community nurses and midwives), health service managers and administrators, employees of technology companies and government agencies, academics, third sector staff and volunteers. The technologies that were designed and deployed comprised of health apps, online digital health and wellbeing portals, telehealth and telecare, personal health records and many kinds of assisted living devices and sensors. The DHIs were made available to a range of patients, namely older adults with chronic illnesses, carers, users of services such as healthy pregnant women and members of the public as consumers. An overview of each dallas community and the DHIs they developed and rolled out can be found in Table 6.

Table 6: Overview of the four dallas communities

Living It Up (LiU)	Year Zero (YZ)	More Independent (Mi)	i-Focus (iF)
LiU Stakeholders: Consortium involving over 30 public and private healthcare, technology and third sector partners. Led by the NHS.	YZ Stakeholders: Consortium, led by a commercial company, which included numerous public and private healthcare and technology partners.	Mi Stakeholders: Consortium which included numerous public and private healthcare providers, technology, local authority and third sector partners. Led by the NHS.	iF Stakeholders: Consortium, led by a commercial company, that included numerous public and private partners.
LiU Target Audience: 55,000 people across five groups; 1) active and healthy between 50 and 70 years of age, 2) those with long-term conditions in the same age bracket, 3) those over 75 years with long-term	YZ Target Audience: 54,684 users across all the digital health products and services.	Mi Target Audience: 54,000 people.	iF Target Audience: 10,000 older adults.

conditions, 4) service providers and 5) the general population.			
LiU Location: Five regions of Scotland.	YZ Location: several areas of England and Scotland.	Mi Location: Liverpool city and surrounding region.	iF Location: One initiative was nationwide and the others were in England.
LiU Digital health interventions: 1) An online health and wellbeing portal offering four digital services. 2) A service collaboration with a private company to log, monitor and report physical activity via wearable devices, a health app and an online system.	YZ Digital health interventions: 1) A digital child health record. 2) A personal health record and care planning application. 3) A prescribed personalised video packages explaining health conditions and local services. 4) A social networking application for circle of informal carers. 5) A health app for diabetes self-management. 6) An online care planning application and a	Mi Digital health interventions: 1) A remote monitoring programme using telehealth and SMS service technologies for people with long-term conditions. 2) A personal health record was developed for use in NHS England but not piloted within the lifetime of the dallas programme. 3) An online shop where a range of assisted living technologies were available to view and a	iF Digital health interventions: 1) Development of technical, service and business interoperability profiles. 2) A not-for-profit member driven organisation to assist with interoperability of DHIs. 3) Sensor technologies to support older adults living alone. 4) A health app to monitor and manage chronic pain.

	remote video consultation with family doctors.	freephone number given to purchase a product. 4) A reminiscence app co-designed by people with dementia and their carers.	

A large team of researchers based at the University of Glasgow were involved in evaluating the dallas programme using mixed methods research. The main focus was:

1) Describing the programme as it evolved over the three-year period,

2) Exploring general implementation barriers and facilitators, and,

3) Examining the reach and benefits of the programme.

In terms of examining digital health implementation and the barriers and facilitators in the process generally, the research team were interested in exploring two aspects. The first was understanding the main stakeholder groups deploying the various technologies i.e. the public sector (health service), the private sector (technology and other industries), and the voluntary or third sector. The second aspect was to discover how various stakeholder groups such as patients, health service users, and the general public began using the technologies and if this persisted over time. This would help determine if the dallas programme was successful or not in terms of a large-scale, real-world deployment of technology in a complex health system. This type of digital health implementation rarely happens and so the dallas programme offered a unique opportunity to study how multiple types of DHIs were rolled out with different groups of people (Devlin et al., 2016; Lennon et al., 2017). The research team included post-doctoral researchers, two PhD students, research associates and professors with a wealth of experience across a range of disciplines including medicine and primary care, nursing, computer science, social science and health economics. This group had collected a large qualitative dataset (e.g. interviews and project documentation) on the dallas programme when this doctoral study began in April 2014. They continued to gather both quantitative and qualitative data until October 2015.

3.5.5 Ethical considerations

Ethics are the moral obligations and its applications inherent in health research to protect participants and researchers from harm. Ethics encompasses four main principles; 1) beneficence, 2) non-maleficence, 3) autonomy and 4) justice

(Beauchamp and Childress, 2001). Beneficence focuses on doing something for the benefit of others while non-maleficence is the avoidance of harm. Autonomy emphasises that the choices an individual makes must be informed and free from undue influence. Justice refers to giving people what they are entitled to and treating them equally, fairly and impartially. These four concepts are the cornerstone of modern health research ethics and are incorporated in numerous local, national and international guidelines governing the field. For example, the Council for International Organizations of Medical Sciences (2002) provides detailed ethical guidelines for research involving human subjects that are based on the Declaration of Helsinki and its subsequent revisions (World Medical Association, 2002). All higher education institutions and other types of organisations that undertake health research in the United Kingdom are bound by ethical codes, some of which have also been enshrined in law. Therefore, ethical approval was a key step to protect the wellbeing of the participants and researchers involved in this doctoral study and the university as the sponsoring institution. Ethical approval for this doctoral research was granted as part of an amendment to a large ethics application that was submitted by the research team at the University of Glasgow, who were working on the evaluation of the dallas programme. Ethical approval was granted by the University of Glasgow, College of Medicine, Veterinary and Life Sciences ethics committee (Ethical Approval ID: 200140091, see Appendix 1.1) in March 2015.

3.5.6 Sampling and recruitment

Sampling is an important consideration in qualitative research as it helps to identify specific elements of a phenomena of interest. This might be a population of people, certain events or activities, or organisations that need to be explored to understand the overall phenomena in-depth (Miles and Huberman, 1994). Given the complexity of the dallas programme, the populations of interest, who served as the units of analysis, included a number of groups. These were;

1) users of the DHIs (both patients and service users),

2) professionals in the health service (health professionals, health service managers and administrators),

3) individuals working in the third sector (both staff and volunteers), and

4) employees of private companies that were involved.

These four groups had already been identified by the research team at the University of Glasgow in terms of understanding implementation more generally during the dallas programme. They were also identified as being important for this specific study as they signified a range of different perspectives on engagement and enrolment in DHIs that were necessary to capture to address the study's research questions. Non-probability sampling strategies were employed by the larger research team and by the doctoral student to identify and recruit participants to represent each of the four groups (Tuckett, 2004). Two types of sampling used were: 1) convenience sampling, and 2) purposive sampling.

3.5.6.1 Convenience sampling

Convenience sampling has been defined as "*where members of the target population that meet certain practical criteria, such as easy accessibility, geographical proximity, availability at a given time, or the willingness to participate are included for the purpose of the study*" (Etikan, Musa, and Alkassim, 2016, p. 2). Some of the benefits of this approach to sampling include that it can offer a level of pragmatism when time, resources, access to information, and expertise are restricted. Hence, subjects to study can be selected based on their ease of accessibility, which can save the researcher time and money. However, it also has some significant limitations that can affect the credibility of a study's findings. Yin (2012) argues that convenience sampling is neither purposeful nor strategic and hence it can yield information poor cases that offer an incomplete picture of a phenomenon. A further critique, is that bias can occur if a narrow range of participants are opportunistically sampled by the researcher. These cases may not adequately represent the general population or phenomenon of interest, which could reduce the transferability and utility of a study's findings (Emerson, 2015).

3.5.6.2 Purposive sampling

Purposive sampling is an alternative method and has been defined as "*selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling. Studying information-rich cases yields insights and in-depth understanding rather than empirical generalizations*" (Patton, 2002, p. 230). Patton (2002) identified a number of ways to undertake purposive sampling which are outlined in Table 7.

Table 7: Techniques used in purposive sampling

Technique	Description	Limitations
Confirming and disconfirming cases	Uses cases that fit or do not fit already emerging patterns	Identifing confirming and disconfirming cases may be challenging
Criterion sampling	Predetermined criteria of importance used to select cases	Prior knowledge of phenomenon required to determine criteria
Critical case sampling	Uses critical cases that yield the most information	Broad generalisations can be difficult to make

Extreme or deviant case sampling	Uses cases that have unusual conditions or special or extreme outcomes	May be difficult to access participants
Homogenous sampling	Uses a small sample that is similar in nature	Specific subgroups are required to sample
Intensity sampling	Uses information rich cases but not unusual or extreme ones	Prior information or exploratory work required to identify intense cases to sample
Maximum variation sampling	Uses cases that are purposively as different from each other as possible	Requires a certain amount of variation in the sample
Opportunistic sampling	Uses cases that emerge during fieldwork to explore new areas	Unable to plan sample and its characteristics in advance
Purposive random sampling	Uses a random sample of a small number of selected cases	Generalisation can be limited if sample is not representative

Sampling politically important cases	Uses or avoids a politically sensitive case	
Snowball or chain sampling	Uses cases suggested by participants in the study	Unrepresentive sample with limited generalisability
Stratified purposeful sampling	Use cases that capture major variations	Sample size may be too small for generalisations to be made
Theory based or operational construct sampling	Uses cases based on their potential representation of important theoretical constructs	Requries appropriate theoretical knowledge and the ability to select relevant samples
Typical case sampling	Uses cases with typical characteristics	Selection of typical cases requires insider knowledge and generalisation is not possible

Overall purposive sampling can be advantageous as the numerous techniques can suit a wide range of qualitative research designs and its flexibility allows for multiple sampling methods to be used within a single study. This approach to sampling also enables information rich cases to be gathered from individuals who are knowledgable about or experienced in the phenomenon of interest. This can allow for an in-depth understanding of the topic of interest (Palinkas et al., 2015). However, like other methods it has some limitations such as the potential for bias as decisions about who to sample and why are based on the judgement of the researcher. If these are ill-conveived or poorly considered then it could lead to a level of subjectivity that invalidates the representativeness of the sample and a study's findings.

3.5.6.3 Sampling techniques used

The research team at the University of Glasgow used a mixture of critical case sampling and intensity sampling to help evaluate the overall dallas programme and reach people in three of the four stakeholder groups (professionals in the health service, individuals working in the third sector, and employees of private companies) for interview (Devlin et al., 2016). For instance, critical case sampling was utilised to reach the programme managers responsible for running each of the four dallas communities, i.e. Living It Up, Year Zero, More Independent and i-Focus, as they had unique and insighful overviews of implementation as it progressed. Intensity sampling was also employed to identify information rich cases about implementation of the DHIs through regular contact with the four dallas programme managers. The people they suggested represented typical cases from the respective stakeholder groups and were subsequently recruited and interviewed. Finally, convenience sampling was used periodically to interview additional people involved in developing and deploying DHIs during the dallas programme. A handful of people from government agencies and academic staff who were accessible and available to speak at key timepoints were also interviewed during the three-year timeframe (Lennon et al., 2017).

Based on the interview data being collected by the research team, it was decided to focus more on patients, health service users, and health professionals when gathering primary data as their voice was not well represented and was essential to capture to help answer the research questions. The primary data collection for this study consisted of of focus groups and interviews, explained in more detail in Section 3.5.7. Users of the DHIs (both patients and service users) and health professionals who worked directly with them were targeted for focus groups to gather data on the barriers and facilitators they experienced during engagement and enrolment to digital health produt. This population were identified using purposive random sampling as a random sample of patients, health service users and health professionals were reached based on a small number of selected cases. These cases were digital health products or services that had progressed reasonably well during the dallas programme, had been rolled out successfully to some degree, and enrolled a number of users. Two focus groups were about a personal electronic child health record, two centred on personalised video packages explaining local maternity services and one a mobile application for people with dementia. In addition, a number of carers, health service managers, employees of technology companies and one government sector staff member were opportunistically sampled.

Hence, the same sampling strategy was used for the focus groups. This doctoral study also included interviews with all four of the stakeholder groups. Critical case sampling was used by the doctoral student to reach and recruit the four dallas programme managers for interview. Gaining their specific views on engagement and enrolment to the various DHIs was thought to be important given their central role in managing all aspects of the dallas programme and the breadth of knowledge they had amassed over the three years of the digital health programme. They were also able to verify and expand on comments other particiapnts had made on various aspecfts of engagement and enrolment to DHIs, enabling richer data on barriers and facilitators to be gathered.

Convience sampling was also used when volunteer digital champions, delivering a digital skills training programme to raise awareness of DHIs through a third sector partner, became available for interview. It was felt their perspective could add another valuable dimension to understanding patient and public engagement and enrolment in DHIs specifically, as this stakeholder group were underrepresented in the overall sample. Finally, criterion sampling was used by the doctoral student to identify information rich cases, in particular patients and their carers who had been involved in co-designing one digital health product. This was a mobile application to facilitate communication between people with dementia and their carers. Some of the participants who had been involved in the focus group in March 2015 were interviewed in August and September 2016 to illict detailed information from this key stakeholder group as it was underrepresented. This approach also helped gather more data on a novel digital health engagement strategy, co-design, to further our understanding of engagement and enrolment in consumer DHIs.

3.5.6.4 Sample sizes

Miles and Huberman (1994) emphasise that there is no perfect sampling strategy and that data saturation lies at the heart of any qualitative method, as a comprehensive understanding of a phenomenon is only possible by continuing to sample until no new substantive information is obtained. Hence, sample size is an important consideration as it can determine the richness and quality of a study’s findings (Sandelowski, 1995). Morse (2000) suggests that a number of aspects should be considered when determining an appropriate sample size, which are:

- *The scope of the study.* The broader the research questions are then the longer data collection will take as many more participants will be needed to reach saturation. On the other hand, if the study is quite narrowly focused then it risks being superficial regardless of the sample size.
- *How clearly a topic has been defined.* It can be easier to gather relevant data from interviews, focus groups or participant observation if a topic is clearly defined and so a smaller sample size may be appropriate. Whereas, if a topic is more complex and nuanced then a larger number of participants with varying perspectives may be needed to understand it in depth.
- *The quality of data that is collected.* This can also determine sample size as some participants will be better able to express their opinions and

reflect on their experiences and so be more articulate than others (Bernard, 2002). If this richness is achieved than fewer participants may be needed than a study where those sampled were less forthcoming. Morse (2000) also highlights that there is an inverse association between the volume of usable data obtained from every participant and the number of those recruited to a study. Hence, the richer the data that is gathered per person than the fewer interviews, focus groups or observation are necessary. The reverse also holds true, as shallow data may reveal very little and if this is being collected from some individuals than a larger number and variety of participants may need to be sampled.

- *Collection of 'shadowed data'*. This is data where participants discuss their perceptions of how others have experienced the same phenomenon and reacted to it, which may be different or similar to their own. This "speaking-for-others" perspective can help enrich the understanding of a complex subject, particularly if it is gathered from expert informants rather than people who are relatively new to the subject of interest. This type of data could possibly reduce the required sample size, although it may need to be verified (Morse, 2001). While the perceptions of others about a particular stakeholder group may not reflect how the people within the group see themselves, this alternative view may enrich a study's findings.
- *Type of study design*. Some study designs such as a longitudinal exploration of a complex phenomonen may require a much larger sample size than a standard study.

Although these factors do not enable an accurate prediction of the exact number of participants that need to be sampled, they can guide a researcher in choosing a reasonable sample size for qualitative research. This can then be adjusted as recruitment, data collection and analysis unfolds. The sample size for this study was based on a number of factors. First, this doctoral study was broadly focused on three groups involved in the implementation of consumer DHIs, 1) patients and the public, 2) health professionals, and 3) implementers. Second, it revolved around relatively complex processes i.e. engagement and enrolment that make up the early phases of implementation. And third, it was unclear who the individual participants from each of the stakeholder groups would be in terms of their level of experience and expertise. Hence, a large sample size was deemed necessary. Although the topic was clearly defined in terms of identifying the barriers and facilitators for each of the three groups and the engagement and enrolment strategies employed, and a certain amount of shadowed data was expected, an estimated sample size of 10-15 participants per group (30-45 participants in total) was initially planned to enable analytical and theoretical data saturation to be reached.

3.5.6.5 Recruitment

Recruitment of most participants was mediated by the programme managers of the four dallas communities, who had to be contacted to enable the identification of suitable candidates. The research team and the doctoral student used a mixture of emails, telephone calls and written letters to recruit a cross-section of people from the various stakeholders in the dallas programme. These individuals were sent the relevant participant information sheet and consent form. In the case of the focus groups, the ethical documentation was brought along on the day for potential participants to review and sign before taking part in the focus group (see Appendices 1.2 and 1.3).

3.5.7 Data collection

Two types of qualitative data collection methods, interviews and focus groups with participants of the dallas programme, were used in this thesis. A large amount of documentary evidence, such as contract bids, evaluation reports, user stories, recruitment and membership reports, and observation logs were also collected on the dallas programme by the research team. However, it was not feasible to incorporate these into this study due to the large qualitative dataset that required analysis and the time limitations of the PhD student. Although this documentation did not undergo formal analysis it was read periodically and helped inform aspects of this thesis, in terms of describing how the dallas programme was designed and delivered, and understanding the context in which the secondary data was collected.

3.5.7.1 Interviews

A qualitative research interview aims to understand a person's experience of or perspectives on a particular subject which cannot be obtained through other methods. A persons's thoughts, feelings and intentions can be attained through interviews, as their stories may hold useful information that helps answer a research question and understand a phenomenon of interest (Polit and Beck, 2004). It is conducted between two people, a participant and a researcher, either face-to-face or over the telephone or other electronic means. This differs from other types of interviews such as clinical/diagnostic or motivational interviews, as the interviewer does not offer advice or feedback to illict change but poses questions and then listens and records dialogue and observations. A traditional type of research interview can be structured, where specific questions are asked to illict particular answers and done so consistently throughout each interview. It can also be semi-structured, where the researcher has a set number of questions to cover but can ask additional ones to probe for more detailed answers, or an interview can be completely unstructured which uses an open format and allows the participant to tell their story uninterrupted (Britten, 1995; Bryman, 2004). A relationship is developed between the two people involved in a research interview and the process unfolds based on their interaction, meaning the skills, experience and behaviour of the interviewer can affect a participant's responses and the quality of the data collected.

Patton (2015) provides guidance when conducting interviews to enhance the interaction, maintain objectivity and control bias, and improve the quality of data collected. These recommendations include taking time to establish a rapport with the participant, while maintaining neutrality, and building trust by using emphatetic language and responding in a non-judgemental way. The participants perspective needs to be respected throughout to avoid researcher bias influencing the questions posed and responses provided. He also suggests asking open-ended questions and being clear about the line of questioning so as not to confuse the participant and allow them space to reflect and respond naturally. Listening is another key skill that needs to be used during the interview process so that pertinent follow-up questions can be asked to gain more in-depth responses if using a semi-structured approach and the interviewee feels appreciated and attended to from beginning to end.

While interviews are a useful way to gather qualitative data, they do impose some limitations. For instance, interviews can be time consuming to plan and conduct and may be impractical if participants are not easily accessible or able to communicate orally (Polit and Beck, 2004). The quality of an interview can also vary depending on the expertise of the researcher undertaking it. For example, a participant could feel obliged to tell a researcher what they think they want to hear or they may be reserved in their responses if an interviewee believes telling their true story could adversely affect them. Therefore, an array of interpersonal and communication skills are required to ensure the process goes well and rich data pertinent to the research questions is collected.

3.5.7.2 Focus groups

Another common method of gathering qualtitative data is a focus group or group interview. Focus groups offer another type of qualitative inquiry as participants are able to discuss a subject with others and this social interaction can prompt more in-depth and meaningful dialogue around shared experiences of a phenomenon, even though participants' views may vary (Robinson, 1999). This approach differs from interviews with just a single individual, as focus groups can offer a diverse range of perspectives that can be gathered together in a short timeframe. In addition, some participants may be more comfortable speaking about their experiences in a group as it may feel less intrusive than a one-on-one interview and be more stimulating and supportive. Focus groups are usually conducted with small groups of 5-10 participants with similar backgrounds, allowing them to consider and respond to the views of others. Acting as a moderator, the researcher should guide the conversation between those in the group using a set of prepared questions and prompts. Krueger (1994) recommends that two researchers should conduct a focus group so that one can concentrate on asking questions and facilitating the discussion, while the other can take field notes and help participants who may need to leave early or require extra support.

Although focus groups can be advantageous in terms of the diversity and richness of the perspectives gathered, they do pose some drawbacks. For instance, the number of questions that can be posed is usually much less than an individual interview as the group discussion requires enough time to be fruitful and the available response time may limit the contribution from some members. Another problem is that group interviews need to be carefully planned and managed so that participants feel comfortbale sharing their thoughts with others and everyone is included and can contribute if they so wish. Otherwise those with minority views may feel less inclined to speak up and risk a negative response from other participants (Barbour, 2007). Finally, focus groups are also not suitable for certain kinds of highly sensitive research topics that require intimate and private discussion through individual interview or observation.

3.5.7.3 Secondary data

The secondary dataset used in this thesis, comprised of 47 semi-structured interviews gathered from four different stakeholder groups, representing a cross section of people implementing a range of DHIs (see Table 8). The fourth stakeholder group, containing academics and government sector staff, were interviewed over and above what was originally planned by the research team as they became available to speak to as the dallas programme unfolded. The interviews were conducted by two experienced post-doctoral researchers at the

University of Glasgow who were part of the research team evaluating the dallas programme. They had chosen a semi-structured interview approach as it allows a degree of flexibility, enabling the researcher to ask specific questions that are relevant to the topic while probing and inquiring with additional questions as the interview progresses (Miles and Huberman, 1994).

These interviews were undertaken in three phases. The first phase involved a set of 17 baseline interviews (with 18 participants) from October 2012 to January 2013. These aimed to understand implementation generally by gathering perspectives from the three main stakeholder groups rolling out DHIs at the start of the dallas programme in 2012. The second phase of interviews occurred mid-way through the programme, between October 2013 and October 2014, and included twenty midpoint interviews (with 26 participants) from across the three stakeholder groups. The third and final phase centred on endpoint interviews, from May to October 2015 as the dallas programme was finishing up, where ten interviews (with 11 participants) were undertaken. In total, 55 participants were interviewed over a three-year period to understanding how the DHIs were implemented across a variety of real-world settings and at scale.

Table 8: Secondary interview data used

No	Stakeholder Group	No of Participants Interviewed
1	Health Professionals Health Service Managers and Administrators	0 25
2	Third Sector Volunteers	8 0

3	Technology Sector	17
4	Academics Government Sector	3 2
	Total	**55**

3.5.7.3.1 Interview guide development

A standardised approach to interviewing using a prepared interview guide or protocol can ensure the same line of questioning is used from participant to participant and all the major points of interest are covered. This can enhance the consistentcy of data and trustworthiness of a study's results, while leaving the interviewer scope to probe and ask additional questions for more detailed answers if needed. The interview guide can incorporate a nubmer of different styles of questions, outlined above, grouped into logical themes as well as a brief introduction to set the scene and a conclusion to wrap up. This framework can provide structure to the interview so conversation flows more smoothly. Kallio, Pietilä, Johnson and Kangasniemi (2016) recommend a number of steps when developing an interview guide which include reviewing and appraising existing literature both empirical and theoretical on a topic, running workshops with research colleagues or experts in the field to identify relevant questions, and piloting the guide to ensure questions are not closed or leading. Josselson (2013) stresses that researchers should not be overly concerned with wording questions perfectly, as it might interfere with the dynamics of an interview and the unfolding relationship between the interviewer and interviewee.

The interview guide and questions used for the 55 interviews that formed the secondary dataset were developed using the eHealth Implementation Toolkit (e-

HIT) (see Appendix 2.1). This is a set of questions, informed by a systematic review of the eHealth implementation literature and theoretically grounded using Normalization Process Theory, that help explore different aspects of this complex process such as the overall context, the digital health intervention and those adopting it (MacFarlane et al., 2011). The interviews lasted approximately 60 minutes, were conducted either in person or over the telephone by one of the research team and field notes taken as necessary. All these interviews were audio-recorded and then transcribed verbatim by administrators at the University of Glasgow. The transcript and audio recording were also cross-checked for accuracy by the doctoral student before seconday analysis began.

3.5.7.4 Primary data

The doctoral candidate also gathered primary data using both focus groups and interviews.

3.5.7.4.1 Primary focus groups

Focus groups were used as a way to reach larger numbers of people, especially patients and service users, to generate discussion on engagement and enrolment in DHIs (Kitzinger, 1995). The focus groups were aimed at both the health professional and patient/service user stakeholder groups that were missing from the secondary dataset, to ensure their views on signing up to DHIs during the dallas programme were captured (see Table 9). The focus groups ended up also including a small number of carers (n=4), health service administrators or managers (n=3), and technology sector staff (n=2) involved in promoting DHIs with different groups who became available to speak to as part of a focus group. Five focus groups were held in total, including 44 different participants. The focus groups were run in conjunction with the research team at the University of Glasgow as they also needed to gather information on other aspects of digital health implementation from these stakeholder groups. The focus groups were held together due to ethical considerations, limitations with recruiting these types of participants, and the short four-month timeframe that was available for data collection before the dallas programme concluded. Hence, the doctoral student conducted each focus group with an experienced post-doctoral researcher involved in the evaluation of the dallas programme.

The first focus group took place in March 2015 with ten people who were a mix of patients newly diagnosed with dementia, their carers, a health professional and a project manager. This group had been involved in co-designing and rolling out a mobile application that facilitates reminiscence and communication between a person with dementia and their carers. The second and third focus groups took place in April 2015 and included health professionals, service users and staff from the technology sector. They centred on an electronic child health record application for parents with newborn infants. The fourth and fifth focus groups also took place in April 2015 with health service users, health professionals, health service managers and an administrator, either using or promoting the use of prescribed, personalised video packages explaining health conditions and local maternity services.

Table 9: Primary data from focus groups

No	Stakeholder Group	No of Participants in Focus Groups
1	Patients Carers Service Users	4 4 16
2	Health Professionals Health Service Managers and Administrators	14 3

3	Third Sector Volunteers	0 0
4	Technology Sector	2
5	Academics Government Sector	0 1
	Total	**44**

Four of the five focus groups were led by the doctoral student whose questions on engagement and enrolment in DHIs were put to participants first, as this facilitated the flow of conversation and helped set the scene for discussions on digital health implementation more broadly. Hence, the focus group guide developed and used by the doctoral student incorporated questions on engagement and enrolment in DHIs that were drawn up based on;

1) reading the general digital health implementation literature and undertaking a systematic review of engagement and enrolment in consumer digital health, described in Chapter 4,

2) concepts from the baseline and some of the midpoint interviews from the dallas programme that had already been conducted, and

3) the constructs of Normalization Process Theory.

Open ended questions and guided prompts were posed to illicit detailed responses from participants and ensure they could discuss anything they felt was pertinent to the topic. In some cases, more focused questions were asked. For example, when discussing strategies for engaging and enrolling in a DHI questions such as ‘Did a family member, friend, colleague or health professional recommend it to you?’ were posed to gauge if specific types of approaches identified from the literature review and secondary interview data were experienced (see Appendix 2.4). Each focus group lasted approximately 90 minutes to allow an in-depth discussion and field notes were taken when feasible. Although other phases and aspects of implementation were discussed during each of the five focus groups, engagement and enrolment reoccurred throughout the conversations outside of direct questioning as many participants experienced barriers and facilitators when signing up to DHIs. All focus groups were audio-recorded and then transcribed verbatim by administrators at the University of Glasgow. The transcript and audio recording were also cross-checked for accuracy by the doctoral student before analysis began.

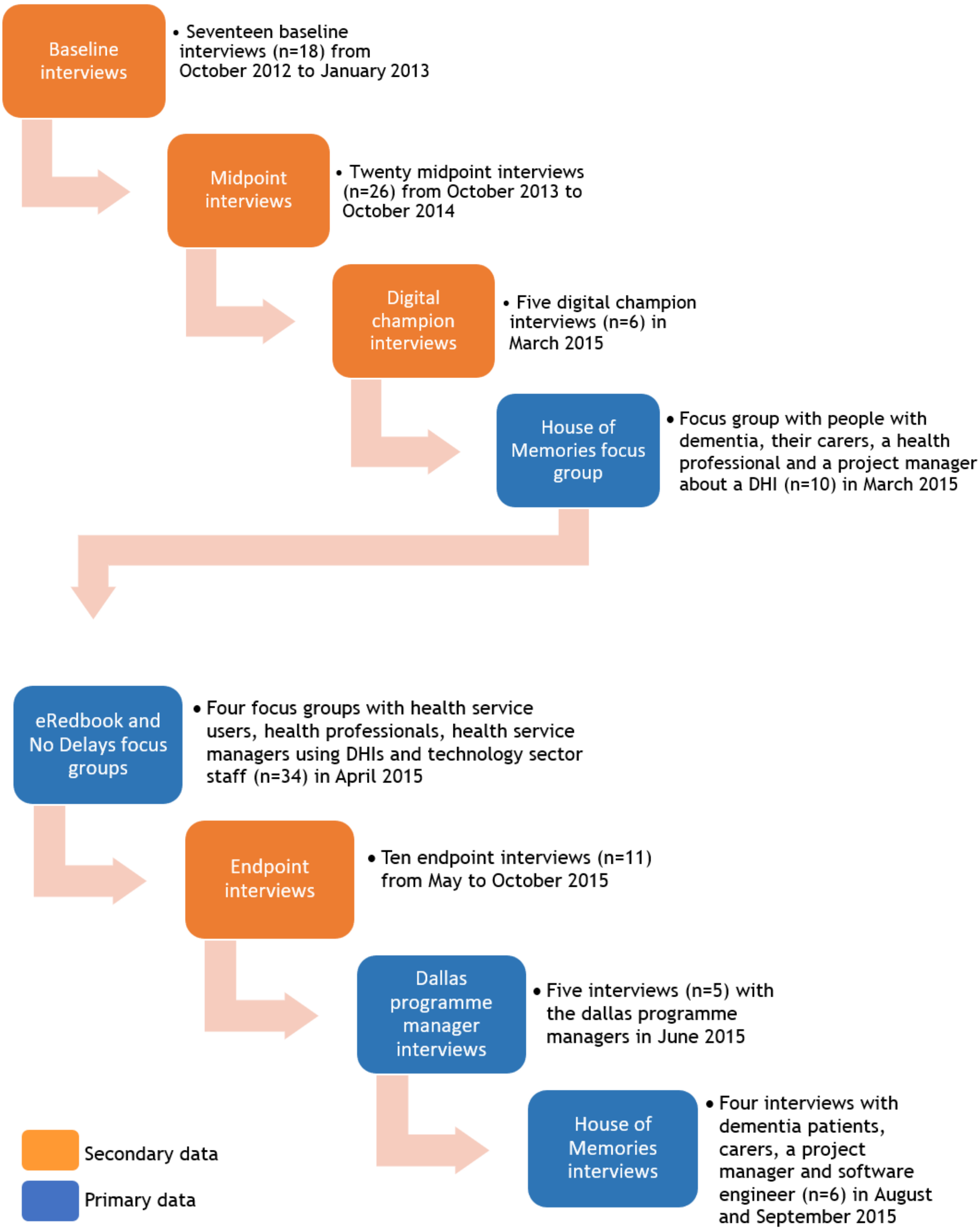
3.5.7.4.2 Primary interviews

Research interviews were the other method of primary data collection used in this thesis to gain a richer understanding of engagement and enrolment in digital health products and services. The doctoral student undertook 14 semi-structured interviews in total, involving 17 participants from the main stakeholder groups (see Table 10). The first five interviews took place in March 2015 with digital champions who had volunteered through a third sector agency to promote the use of telehealth and an online shop where assisted living technologies were available. Some of them also ran digital skills workshops in their local community as part of the dallas programme to encourage sign up to DHIs. The second round of interviews were with the dallas programme managers, in June 2015, who were a mixture of health service managers and technology sector staff. The third and final set of four interviews took place in August and September 2015 after the dallas programme had finished. These were follow-up interviews with patients with dementia and their carers, and the project manager who had taken part in the first focus group. A software engineer involved in co-designing this particular DHI, a mobile application that facilitated reminiscence and communication with people with dementia, was also interviewed. This helped gain an additional perspective on engagement and enrolment, particularly in reltion to co-creation as one type of engagement strategy used during the dallas programme.

Table 10: Primary data collected from interviews

No	Stakeholder Group	No of Participants Interviewed
1	Patients Carers Service Users	2 2 0
2	Health Professionals Health Service Managers and Administrators	0 3
3	Third Sector Volunteers	1 5
4	Technology Sector	3
5	Academics Government Sector	0 1
	Total	**17**

The questions and interview guides for these particular interviews were developed to explore engagement and enrolment in DHIs. These were identified from reading the general digital health implementation literature, undertaking a systematic review of engagement and enrolment in consumer digital health (described in Chapter 4), reading the baseline and midpoint interviews that had been collected on the dallas programme by the research team, and the constructs of Normalization Process Theory. Open ended questions and guided prompts were used to enable participants to discuss what they felt was relevant based on their experiences. More focused questions were also employed to probe further into specific aspects of engagement and enrolment in DHIs (see Appendices 2.2 and 2.3). The timeline of all data collection used in this thesis can be seen in Figure 12. The overall sample of participants from the dallas programme included in this thesis can be seen in Table 11. While a reasonable number of participants were recruited from most of the key groups, only a handful of patients (n=6) were spoken to directly. The limitations of the sample and its impact on the analysis and findings of this thesis are discussed further in Chapters 5, 6, 7 and 8.



- Seventeen baseline interviews (n=18) from October 2012 to January 2013
- Twenty midpoint interviews (n=26) from October 2013 to October 2014
- Five digital champion interviews (n=6) in March 2015
- Focus group with people with dementia, their carers, a health professional and a project manager about a DHI (n=10) in March 2015
- Four focus groups with health service users, health professionals, health service managers using DHIs and technology sector staff (n=34) in April 2015
- Ten endpoint interviews (n=11) from May to October 2015
- Five interviews (n=5) with the dallas programme managers in June 2015
- Four interviews with dementia patients, carers, a project manager and software engineer (n=6) in August and September 2015

Figure 12: Timeline of data collection used in this thesis

Table 11: Summary of primary and secondary data used in this thesis

No	Participant Group (Secondary data)	Participants Interviewed	Participant Group (Primary data)	Participants Interviewed (Primary data)	Participant Group (Primary data)	Participants in Focus Groups (Primary data)	Total
Group 1	Patients	0	Patients	2	Patients	4	**6**
	Carers	0	Carers	2	Carers	4	**6**
	Service Users	0	Service Users	0	Service Users	16	**16**
	Subtotal	**0**	**Subtotal**	**4**	**Subtotal**	**24**	**28**
Group 2	Health Professionals	0	Health Professionals	0	Health Professional	14	14
	Health Service Managers and Administrators	25	Health Service Managers and Administrators	3	Health Service Managers and Administrators	3	**31**
	Subtotal	**25**	**Subtotal**	**3**	**Subtotal**	**17**	**45**

Group 3	Third Sector Volunteers	8 0	Third Sector Volunteers	1 5	Third Sector Volunteers	0 0	**9** **5**
	Subtotal	**8**	**Subtotal**	**6**	**Subtotal**	**0**	**14**
Group 4	Technology Sector	17	Technology Sector	3	Technology Sector	2	**22**
	Subtotal	**17**	**Subtotal**	**3**	**Subtotal**	**2**	**22**
Group 5	Academics Government Sector	3 2	Academics Government Sector	0 1	Academics Government Sector	0 1	**3** **4**
	Subtotal	**5**	**Subtotal**	**1**	**Subtotal**	**1**	**14**
	Total	**55**	**Total**	**17**	**Total**	**44**	**116**

3.5.8 Data analysis

The analysis of data occurred in two main phases. The first focused on the analysis of secondary qualitative data and the second phase centred on analysing the primary qualitative dataset.

3.5.8.1 Secondary qualitative data analysis

Secondary analysis involves using existing data from a previous study or studies to address a research question, which may have a different focus to the primary study or studies from which the data originated. It can be a convenient, cost-effective and fast way to undertake research and generate new knowledge on a subject (Ziebland and Hunt, 2014). It can also help to maximise the use of existing data, thereby reducing respondent burden for populations of people, particular vulnerable or over-researched groups, who take part in primary research. Secondary analysis can also provide a level of objectivity when interpreting data as the researcher was not immersed in the context of the primary data collection. Heaton (1998) proposes this can be done in a number of ways. The approach can involve formal data sharing where publicly available datasets are accessed and re-used for secondary research but the original researchers are not part of the team who undertake secondary analysis. Another avenue is to pursue informal data sharing where researchers may share qualitative datasets and become part of the secondary analysis, bringing insider knowledge that can aid in understanding the context of the primary study and resulting data. A third option would be to re-use self-collected data to examine new areas or ask additional questions that expand on the findings of the initial study.

A number of typologies exist for categorising techniques to analyse a secondary qualitative dataset. Heaton (2004) proposes five which are outlined in Table 12 and advantages and disadvantages of the various approaches.

Table 12: Secondary qualitative data analysis techniques

Type	Technique	Advantages	Disadvantages

Supplementary analysis	In-depth analysis of an emergent concept in the qualitative dataset not fully explored in the primary study.	A retrospective interpretation could yield useful insights quickly and easily.	May limit the understanding of the emergent concept if the qualitative data is not rich enough.
Supra analysis	Analysis of qualitative data to address a new research question in a separate study.	Analytic expansion can allow additional perspectives and settings that aid understanding a phenomenon.	Risk of introducing bias if the secondary data does not “fit” the focus of the new questions or study design.
Re-analysis	Additional analysis of qualitative data to confirm or validate results of a primary study.	Can strengthen the findings of a primary study quickly and easily.	Reinterpreting data could lead to misconceptions and alternative results.
Amplified analysis	Two or more qualitative datasets are combined and compared using secondary analysis.	Richer dataset from which to examine and understand a phenomenon.	Potential loss of contextual and conceptual insights by combining datasets.
Assorted analysis	Secondary analysis of qualitative data	Insights from analysing both	Risk of cross contaminating

	is undertaken alongside analysis of primary data.	datasets in parallel could enrich the results.	coding and the analysis process leading to inaccurate results.

There are a number of epistemological and ethical issues that arise when re-using qualitative data. Some argue that data collected for one purpose cannot and should not be re-used to help answer another question. The depth and breadth of data collected in specific settings or using certain qualitative methods, particularly those informed by theory, may not easily fit another study (Hinds, Vogel and Clarke-Steffen, 1997). Hence, verifying primary data collected by analysing a secondary dataset, not related to the primary study, could be challenging as it may not adequately support concepts or emergent themes through triangulation. Some question if this meets the rigour qualitative research requires. A further issue revolves around interpreting data when analysing it out of context, as the researcher may miss important nuances during interpersonal contact with or when observing participants and environments that are only possibly to gather when collecting data first hand. Swanson (1986) contends that this could intensify bias, in either a positive or negative way, which may result in misleading findings and unsubstantiated knowledge claims. On the other hand, if the study questions are about closely related phenomena and the extent of the data is detailed enough than secondary analysis is more likely to be successful. There are also numerous techniques to make inductive analytical processes more robust and transparent so that errors when interpreting data can be minimised as outlined in Section 3.5.10.

Some ethical aspects also need to be considered when undertaking secondary analysis such as whether informed consent was gained from participants for sharing their data with others and reusing it for another purpose. In essence, the original participants are unable to consider how their data will be used to address new research questions and whether their experiences and perspectives accurately reflect this new direction (Hinds et al., 1997). Therefore, the researchers undertaking secondary analysis must consider how they intend to use the secondary dataset to ensure it is fit for purpose and does not violate the conditions under which informed consent was gained. There are also issues around confidentiality as Thorne (1998) highlights that primary researchers become sensitive to the communities and cultures they study while immersed in data collection and may take great care to protect the anonymity of participants. This level of diligence could be missed by those undertaking secondary analysis as they do not have the same insights into the people or phenomenon that was studied and may not understand the risks of divulging sensitive information. Fidelity has also been emphasised by some as an ethical aspect necessary to consider in secondary qualitative analysis, as the onus for honest representation of secondary data and its meaning is a priority when presenting findings as dependable and credible. There is a risk that data could be misinterpretation and results falsified and so researchers undertaking secondary analysis should utilise sound judgement and techniques to enhance qualitative rigour to ensure they report what is there and not what they expect to find (Sandelowski, 1991).

There are also practical elements that need to be worked through when undertaking secondary analysis such as negotiating and gaining access to the secondary data as this can be time consuming and costly in some cases. Validating secondary data or assessing its quality is also recommended before using it for analytical purposes so its origins and limitations can be understood as this could influence the analysis process. Beck (2019) provides a list of measures by which to judge if a primary qualitative dataset is feasible for secondary analysis. These include the following:

1) Team who conducted the primary research – this could involve assessing the qualifications and experience of the Principal Investigator, each member of the team and whether they are available for consultation before, during and after secondary analysis.

2) Contextual information that is accessible – this might be audio or video recordings of participants, field notes, interview transcripts, the characteristics of the interviewee and those interviewed, and ethical approval among others.

3) Completeness of the primary dataset – this could be the quality of the recordings and transcription, the richness of the data gathered, notes about any missing data, and complete data for every participant.

Reviewing and considering these aspects can help a researcher to gauge if the qualitative data is adequate for secondary analysis and can address the research questions.

3.5.8.2 Secondary qualitative data analysis on the dallas programme

The secondary dataset, of 47 interviews, collected on the dallas programme examined general implementation issues related to DHIs and did not focus specifically on engagement and enrolment. However, the doctoral candidate spent time reading the baseline and midpoint interviews when her PhD studies began and noted that many issues related to engaging and enrolling people in DHIs were present in comments from various participants. She also had easy access to the research team to clarify any ambiguities in the data and the approach to data collection as well as reviewing supporting files and documentation on the dallas programme. Therefore, the breadth of data available on engagement and enrolment to DHIs was substantial, enabling trends in this phenomenon to be identified quickly and explored in some depth.

Although the secondary dataset that was available was from the evaluation of the dallas programme, the number and types of participants interviewed, and the questions posed did not always align directly to the research questions in this thesis. Another difficulty was the lack of direct contact with participants, as their body language and personal interaction with the interviewer could have given some additional insights into their unique experiences of digital health implementation (Cheng and Phillips, 2014). The doctoral student spent time listening to the audio recordings and reading the interview transcripts and other documentation from the dallas programme to appreciate the strengths and weaknesses of the dataset before undertaking analysis. She also attended regular team meetings and was able to ask questions and gain clarification on the dataset from the post-doctoral researchers who conducted the interviews and the context within which it was collected. This helped address some of the limitations when analysing the baseline, midpoint and endpoint interview data. On the other hand, having a large qualitative dataset to draw on meant richer descriptions and more detailed analysis of engagement and enrolment processes were possible. The range of participants and timeframe over which the interview data were collected meant the perspectives of three key stakeholder groups i.e. patients and the public, health professionals, and implementers were captured. This enabled a broader understanding of engagement and enrolment in digital health interventions which would otherwise have been difficult to obtain. Finally, secondary analysis also removes researcher bias to some degree as the qualitative data were collected by a third party. This allowed the doctoral candidate to be more objective when analysing the dataset, as she had not met the participants and was less likely to be influenced by their personality (Heaton, 2008).

Supplementary analysis was the most appropriate secondary analysis technique to employ as it allows emergent concepts, not fully explored in the primary dataset, to be examined in detail. This fit well with the focus of this thesis and the secondary dataset that was available to the doctoral student. As outlined in Table 5 there are many ways to analyse qualitative data and framework synthesis was chosen as the most appropriate method to understand the secondary dataset collected on the dallas programme. This is because both inductive and deductive methods of analyses are feasible and a priori theory, NPT in the case of this thesis, can inform the coding process. Furthermore, comparing the findings of the systematic review and the qualitative results from the dallas programme was necessary to build an in-depth understanding of engagement and enrolment in DHIs. Hence, utilising the same synthesis method was considered important when analysing these datasets.

The framework approach, which involves a five-stage analytical process (see Figure 13) was applied to code, categorise and classify data into overarching themes and sub-themes (Ritchie and Spencer, 1994). The qualitative dataset was anonymised and then transcripts were read and re-read to become immersed in the data. As no field notes were available for the secondary dataset, the audio recordings of the interviews were listened too to verify and check the accuracy of the transcript. It also enabled any nuances in the spoken word that might indicate the personal feelings or opinions of participants on the subject of engagement and enrolment in DHIs to be identified. This helped to confirm some of the barriers and facilitators noted in the typed transcripts which aided analysis. A preliminary analysis of some of the secondary data i.e. baseline and midpoint dallas interviews was undertaken using Microsoft Excel. Separate worksheets were created for each stakeholder group i.e. patients and the public, health professionals and implementers. Each of these were further sub-divided into sections for barriers, facilitators, and engagement and enrolment strategies according to the type of individual who reported it.

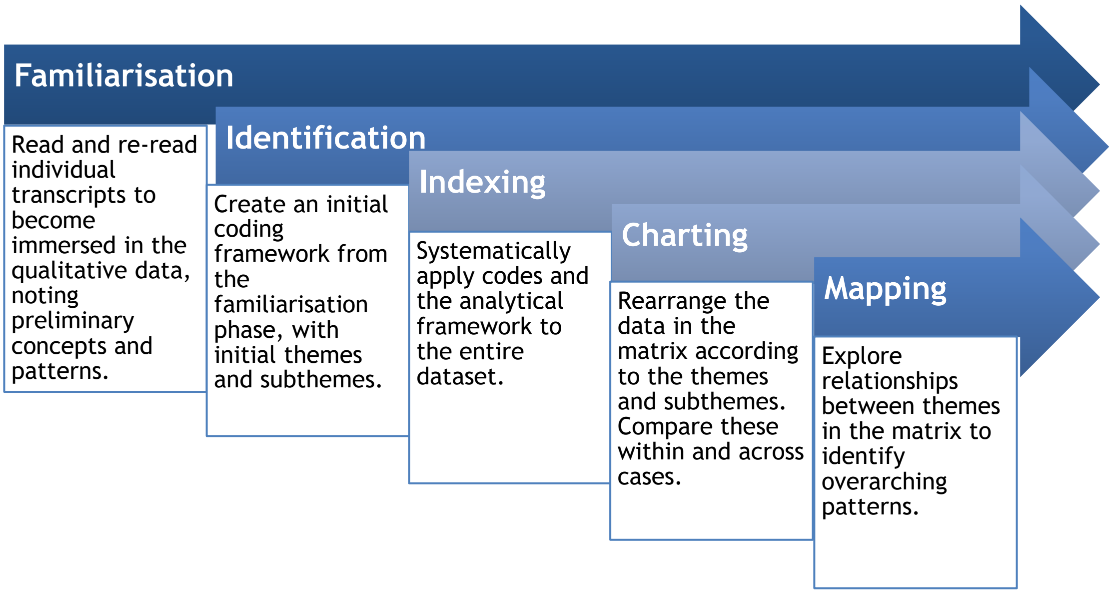


Figure 13: Steps in the framework approach

The first round of analysis concentrated on the baseline interviews. As each transcript was read concepts related to barriers and facilitators during engagement and enrolment in DHIs were noted. Some of these initial concepts were terms the participants referred to themselves such as the ‘privacy’ and ‘security’ of DHIs, later merged together under the ‘Privacy and trust’ subtheme. Other concepts such as ‘agency’ were imposed by the doctoral student whose analysis of participants views on how much ‘choice’ and ‘control’ people wanted when engaging with DHIs were classified under this term, which eventually led to the subtheme ‘Personal agency’. As coding proceeded concepts were merged, added, and refined as participant quotes confirmed or expanded upon existing concepts, enabling an initial coding matrix to be created. A basic catalogue of digital health engagement and enrolment strategies used within the dallas programme was also documented. This preliminary coding matrix was then refined and extended upon when conducting analysis of the midpoint and endpoint interviews, as new codes emerged which built on or added new themes and subthemes, while others were combined or reclassified (see Appendix 3). Where possible, the perspectives of stakeholder sub-groups were compared and contrasted within each subtheme to help corroborate the results or identify divergent views. Data saturation occurs when the same themes or concepts recur in the data in various ways so that no new insights are gained through new data form additional sources (Morse, 1994). Saturation was reached during secondary analysis for some subthemes such as ‘Cost and funding’ and ‘Digital knowledge and skills’ as these were raised and discussed by numerous participants in a variety of ways. However, the analysis was limited in places as certain stakeholder groups such as patients, carers, service users, and health professionals were not represented in the secondary dataset.

Conceptual coding was then undertaken to map the subthemes to the main constructs of NPT. This required deductive analysis so that the meaning of the subthemes were interpreted in relation to the mechanisms of the theory, which facilitated the identification of key processes around engagement and enrolment in DHIs. A series of coding clinics were held with one of the PhD supervisory team (FM) who checked a sample of interviews that had been analysed. While they agreed with the barriers and facilitators identified, approximately 30% of the conceptual coding linked to NPT needed to be refined. This was due to slight ambiguity in some of the qualitative quotes and their meaning, as the data was not always easy to link directly to some of the abstract theoretical constructs in NPT (Gale, Heath, Cameron, Rashid, and Redwood, 2013). For example, a quote from a dallas programme manager highlighted the challenge of communicating the benefits of certain DHIs to healthy people.

> *"It's a bit more difficult to frame the offer for those people who haven't got any needs, for those people who may be fit, may be healthy younger people and I think that's the lesson for, more generally for how we try to describe [DHI] and what it can do for the general population"* (Midpoint Interview, Dallas Community Programme Manager - health service, Participant 31, December 2013)

Initially, this was coded to the NPT mechanism 'Cognitive Participation – Enrolment (CP-e)', as implementers where attempting to recruit people to a digital health product or service. However, discussions during the coding clinic led to this participant quote being recoded as 'Coherence – Individual Specification (CO-is)'. It was felt the quote aligned more to people understanding a DHI which was more suited to the Coherence construct.

3.5.8.3 Primary qualitative data analysis

Primary qualitative data analysis is the analysis conducted on the raw data from participants collected directly by a researcher as part of a study. This data can come in a number of forms such as recorded interviews or focus groups. Primary analysis needs to be undertaken to attain rich descriptions and an in-depth understanding of a phenomenon of interest. This can help answer the original research questions or aims the study set out to achieve (Kim and Liu, 2017). Some of the benefits of analysing primary data is that the researcher can be confident the data is accurate and reliable, given they collected it first hand from participants. The data is also specific to the researchers needs and there is no room for third-party interference, unless a language translator was involved.

However, analysing primary data can be time consuming and challenging. It can take time to prepare data for analysis as the process may include transcribing interviews or focus groups, anonymising relevant parts of transcripts, cross checking the transcripts against audio recordings for accuracy, and writing up any field notes taken to supplement the analysis. In addition, the analysis process itself can take a lot of time, from several weeks to several months or longer, depending on the size of the dataset and the time the researcher has available to undertake the work. The transcripts need to be read multiple times and data coded, categorised and compared in an iterative fashion to derive appropirate themes and subthemes. This intense process, particularly for a novice researcher, can be difficult as the challenge lies in making sense of a massive amount of data. Patton (2015, p. 521) emphasises the process can include "*reducing the volume of raw information, sifting the trivial from the significant, identifying significant patters, and constructing a framework for communicating the essence of what the data reveal*". Simply put, there is no easy or clear way to identify concepts or interpret the real meaning of qualitative data. Hence, a researcher must follow general guidelines or principles of qualitative analysis and intersperse periods of being immsersed in coding information which can be subjective, with periods of being more distant and reflexive to gain a thorough understanding of the data.

3.5.8.4 Primary qualitative data analysis on the dallas programme

The second major round of analysis took place throughout 2016 and 2017 focusing on the primary dataset which consisted of fourteen interviews and five focus groups. NVivo QSR 10.0 software was used to facilitate coding. The interviews were transcribed by the doctoral student while the focus groups were transcribed by administrative staff at the University of Glasgow, as they also formed part of the overall evaluation of the dallas programme. All transcripts were checked against the audio recordings for accuracy before primary data analysis began. Framework synthesis was also used to interrogate the primary dataset to maintain the consistency of analysis and enable a comparison with the findings of the systematic review. This later stage of analysis used the coding matrix that had been developed from analysing the secondary dataset. It was applied to the interview data in the first instance to identify the factors affecting engagement and enrolment to DHIs for patients and the public, health professionals, and implementers. This analytical process was more confirmatory as much of the coding deepened insights into themes and subthemes already identified from the earlier stage of secondary analysis. When possible, stakeholder perspectives were cross checked within and between subthemes to verify the results. For example, a handful of interviews were with patients and carers (n=4) which enabled some of the perceptions of the others stakeholder groups about their experiences to be confirmed. Instances of this occurred in the 'Quality of DHI design' and the 'Digital knowledge and skills' subthemes among others when the same facilitators and barriers were reported. In a few cases, analysis of the primary data generated new insights into existing themes and subthemes. In the case as digital champions, some of these interviews enabled socioeconomic deprivation in parts of the UK to be identified as impacting people's ability to afford and purchase a DHI, enriching the 'Cost and funding' subtheme.

Once the interview data were analysed, framework synthesis was used again to examine the remaining five focus groups. The updated coding matrix was employed to code and categorise the qualitative data. Some of the focus groups reiterated factors, both barriers and facilitators, raised by previous participants enhancing the depth of existing themes and subthemes. As the focus groups consisted mainly of service users, patients, carers, and health professionals, nuances on existing subthemes in relation to 'Patients and the Public' and 'Health Professional' emerged. For instance, a point was raised a number of times by patients and service users that they perceived some technologies such as health apps to be affordable which enhanced the 'Cost and funding' subtheme. In addition, rich data from service users in the focus groups meant a new concept around having a busy personal life arose. This factor led to the creation of a new subtheme ‘Personal lifestyle’ for patients and public which refined the overarching theme into ‘Personal lifestyles and values’. Towards the end of analysing the primary dataset, saturation was being reached for many, although not all, of the subthemes confirming the results of the earlier analyses on engagement and enrolment in DHIs. The last phase involved mapping the final subthemes to the mechanisms of NPT to synthesise the findings and enable a conceptual model explaining key processes around engaging and enrolling in DHIs to be created. Three separate matrices outlining the barriers and facilitators to engagement and enrolment for each stakeholder group can be found in Appendix 3 and detailed in Chapters 5, 6 and 7. The initial catalogue of digital health engagement and enrolment strategies was also expanded upon in Chapters 7 and 8. More coding clinics were held with one of the supervisory team (FM) during primary data analysis to check the quality of the analytical process.

3.5.9 Conceptual modelling

An added layer in qualitative synthesis is the creation of a conceptual diagram, which can be used to highlight the scope of a phenomenon and map its main components. This enables a complex subject to be more easily understood through visual representation. Earp and Ennett (1991) note that there are many different meanings and uses for a conceptual model, which they describe as:

> “concepts denoted by boxes and processes delineated by arrows, provides a visual picture that represents a research question under investigation or the present focus of a specific intervention effort” (Earp and Ennett, 1991, p. 164)

Conceptual models can be informed by theory, represent multiple layers of context e.g. micro, meso, macro and reciprocal relationships. They are created and used in research for a variety of reasons such as organising abstract ideas into a coherent whole, defining concepts, generating hypotheses, explaining causal links and interpreting statistical models among others (Paradies and Stevens, 2005). Theory plays an important role in developing a conceptual model as it helps to identify the concepts to include and aids in understanding and predicting the relationships between these concepts. Several theories can inform the design of a conceptual diagram if there are a large number of variables and the model can also be modified and adapted as new findings emerge about the social phenomenon (Gray and Sockolow, 2016). A preliminary conceptual model, informed by NPT, was created from the findings of the systematic review to describe the factors that affect patient and public engagement and enrolment in digital health. How this was done is explained in Chapter 4.

In addition, the findings of the systematic review (see Chapter 4) were cross-checked with the qualitative results from the dallas programme of the factors affecting patients and the public who tried to engage with and sign up to DHIs (see Chapter 5). Some initial barriers and facilitators such as the cost and funding of technology did not occur frequently or at all in the studies included in the systematic review. Therefore, certain themes were not a distinct feature in the preliminary conceptual model created. However, new barriers and facilitators were discussed by participants in the dallas programme and a subsequent revision and update of the model includes these concepts (see Chapter 8). This helps explain the barriers and facilitators that affect patients and the public when engaging with and enrolling in DHIs, which enables a better understanding of the complexities of digital health implementation. This second phase of analysis helped improve the preliminary conceptual model to better explain what factors help and hinder patients and members of the public when engaging and enrolling in DHIs.

3.5.10 Rigour

A frequent criticism of qualitative research is that it lacks the rigorous methods used in quantitative research and therefore its results are not as reliable. This criticism can be overcome by paying attention to four important elements; 1) credibility, 2) dependability, 3) confirmability and 4) transferability to establish a study's trustworthiness (Lincoln and Guba, 1985). Credibility refers to how believable or 'true' the results of the research are thought to be. Dependability considers how stable or sound the qualitative data is over time and how consistent the interpretations of it are within a changing context, in essence, could the study be repeated by another person and the same conclusions arrived at with reasonable accuracy. Confirmability is the idea that the qualitative results should be corroborated through other sources. Finally, transferability considers whether the results of the study can be applied and are still valid in other contexts (Noble and Smith, 2015).

Each of these aspects of rigour are important to apply in qualitative research and how this was achieved in this thesis is outlined below.

- Credibility – To improve the credibility of the methodology and findings, informal peer debriefing took place periodically. The research process and interpretation of transcripts and field notes from interviews and focus groups were discussed with experienced research colleagues. These conversations were useful in considering personal perspectives and beliefs that could have influenced the chosen approach and results, to minimise researcher bias (Spall, 1998). For example, two focus groups were conducted on an electronic personal child health record being promoted to parents with new-born infants. The doctoral student, who is a nurse, was concerned about the privacy of data on this platform as it was held by a private company and not the NHS. In addition, she felt there were ethical issues surrounding health professionals who were being asked to promote a technology from a private company for which there was no evidence of effectiveness and which parents potentially would be expected to pay for in the future. These issues were discussed in debriefing sessions with a colleague, from a different professional background, to ensure the personal views of the researcher did not interfere with data collection and analysis. Respondent validation, where participants check transcripts are accurate and provide feedback on findings, is another technique used to enhance credibility in qualitative research (Mays and Pope, 2000). However, this was not undertaken due to the limited time and resources available during the PhD programme.

- Dependability – To enhance the dependability of the results presented in this thesis, clear descriptions are provided of all methods utilised including approaches to data collection and analysis and decisions taken at each stage. For example, a detailed protocol outlining how the systematic review would be carried out was drawn up, published (O'Connor et al., 2016c) and strictly adhered to when undertaking the review to ensure consistency in the reported methods and the results of the synthesis of qualitative literature. This would enable a fellow researcher to follow the same process and arrive at similar findings. The consistency of data was also enhanced by collecting it periodically over three years (2012 – 2015) and re-questioning participants, such as the dallas programme managers, about key issues concerning engagement and enrolment in digital health. Furthermore, the robustness of the analysis process was enhanced through a series of coding clinics held with a senior researcher, who checked samples of analytical coding (Lincoln and Guba, 1985).

- Confirmability – To augment the authenticity of this thesis and its findings several techniques were used. The researcher's own perspective on this topic is clearly stated and the rationale for the choice of literature review, underpinning theory and methodology is evidenced. Moreover, the strengths and limitations of the approach used are also outlined, so it is clear where there are gaps in data and its analysis and how this influenced the results. As it is important to clearly document and check that qualitative data is accurate, the audio-recordings were listened to and compared against transcripts to ensure they corresponded with one another. The triangulation of results on engagement and enrolment was feasible due to the variety of participants, technologies, timelines and settings present in the data. Therefore, the diversity of the data and the chain of evidence collected on engagement and enrolment for each stakeholder group helped support the findings, which were verified against those of the systematic review to ensure the results are valid (Barbour, 2001).

- Transferability – To increase the applicability of the findings of this thesis to other areas it was important to describe the context in as much detail as possible. Therefore, this chapter explains the theoretical and methodological approach in-depth and the choices made at each stage of the research process. In addition, many qualitative quotes for each theme and subtheme were noted and are provided in the results chapters of this thesis to support the findings (Chapters 5, 6 and 7). Furthermore, a clear overview of the dallas programme and its setting within the United Kingdom is also given, as this richness will enable readers to understand the context and limitations inherent in the results and make the best judgement on how transferable they are to other areas (Malterud, 2001).

3.5.11 Researcher reflexivity

Reflexivity in the qualitative research process is vital to ensure the researchers' own personal views and opinions on the subject are recognised and any potential influence on the results made clear. Research is inherently '*co-constituted*' as findings are mutually built between the researcher who designs and conducts the study and the participants who take part (Finlay, 2002, p. 531). Therefore, self-awareness and reflection are required from the researcher throughout the study, as ones' prior experiences and understanding of a subject can affect how research questions are framed, how participants are sampled and selected, and how data are gathered, analysed and reported.

The prior experience of the doctoral student encompassed both academic and industry expertise in IT, and clinical and academic knowledge and skills in adult nursing across acute and primary care settings. This is particularly relevant to this thesis as digital health was of personal interest to the PhD candidate. She had worked with many types of patients and saw first-hand the difficulties they faced when trying to engage with and sign up to technology to support their health and wellbeing. These experiences guided the doctoral researcher to the topic of this thesis (Jootun, McGhee and Marland, 2009). On reading the digital health implementation literature at the beginning of her doctoral studies, it was clear there was a lack of consensus on factors affecting engagement and enrolment in consumer digital health. No robust synthesis of evidence on this topic had been undertaken or working model/framework proposed to explain how it operated. This point along with the initial data collected on the dallas programme reinforced the motivation to undertake this specific work and the two broad research questions that underpin it.

It is important to note that the researcher was completely independent of all aspects of the dallas programme and had no material influence on the stakeholder groups involved, the technologies developed and deployed, the types of people that were reached and recruited to the DHIs, and the strategies used to do so. However, the doctoral candidate did directly interview each of the dallas programme managers about engagement and enrolment and several patients and carers who had participated in a focus group. This personal contact could have had both a positive and negative influence on the results. On the one hand, participants may have felt under pressure to agree to additional questioning and been more optimistic in their responses to maintain the relationship, especially those who were suffering from a chronic illness as they relied heavily on nursing care and support at home (Carolan, 2003). However, the upside of this could be that the PhD researcher had credibility and was trusted by participants as an independent person and qualified health professional. Hence, they may have felt more comfortable talking openly about the barriers and facilitators they faced knowing that confidentiality and anonymity would be maintained. As previously stated, samples of coding were cross-checked by an experienced member of the research team, informal discussions with a colleague also took place to ensure interpretations of the data were accurate, and findings were compared to those of the systematic review to ensure the results reflected participant accounts of barriers and facilitators (Dowling, 2006). This helped to minimise researcher bias in the results of this thesis.

3.6 Conclusion

In this chapter, a detailed breakdown of the methodological approach used in this thesis has been described. The ontological and epistemological perspective has been discussed and an explanation provided as to why an underpinning theoretical framework, Normalization Process Theory, was used. The exact methods of reviewing and synthesising the qualitative literature on patient and public engagement and enrolment in consumer digital health were outlined. The rationale for the study design was documented and each stage of the research process, from ethical approval, to sampling and recruitment, data collection and analysis was explained. Lastly, the researchers' own personal views and their influence on the chosen methodology were explored to ensure transparency and rigour. This helps set the scene for the systematic review, results of the dallas programme and discussion on engagement and enrolment in consumer digital health which follows in Chapters 4 through 8.

4 Systematic Review

4.1 Introduction and aims

This chapter describes the background, methods and results from a systematic review of the qualitative literature on factors affecting patient and public engagement and enrolment to digital health. A systematic review seeks to answer a research question by identifying, evaluating and synthesising the results of all relevant studies (Popay et al., 1998). The aim of this systematic review was to identify, critically analyse and synthesise what was already published in the qualitative literature about the barriers and facilitators patients and the public experience when trying to engage with and sign up to all types of digital health interventions. The review also aimed to create a catalogue of engagement and enrolment strategies.

4.1.1 Contributors

This review was conceptualised and planned by the doctoral student with the support of her supervisory team. As is best practice with systematic reviews, a second and sometimes a third person is required to assist with screening, quality appraisal, data extraction and analysis. These roles were undertaken by Dr Peter Hanlon and Professor Frances Mair. Furthermore, specialist expertise was required to undertake the text mining approach outlined in the methods section. This work was completed by Mrs Julie Glanville and Ms Sonia Garcia Gonzalez-Moral at the University of York, with support from Mr Steve Brewer from Text Mining Ltd. These individuals are referred to in the method sections by their initials. Table 13 below lists those who contributed to the review in alphabetical order.

Table 13: Systematic review contributors

Initials used	Full name
FM	Frances Mair
JG	Julie Glanville
PH	Peter Hanlon
SB	Steve Brewer
SGG	Sonia Garcia Gonzalez-Moral
SOC	Siobhan O'Connor

4.2 Overview of methods

4.2.1 Rationale

As described in Chapter 3, a systematic review approach was adopted as a methodology to allow a thorough understanding of the literature on digital health engagement and enrolment. This step was crucial to develop a preliminary conceptual framework of these complex processes and to inform the development of interview and focus groups guides to ensure primary data collection was robust.

4.2.2 Protocol development

The protocol was developed and refined over several months to determine appropriate search terms to use and criteria to apply to identify which studies to include or exclude. Several rounds of meetings were held with the supervisory team and the York Health Economics Consortium (YHEC) to discuss the search strategy and the text mining approach. Following international best practice, the final protocol was registered on PROSPERO, the international prospective register of systematic reviews (http://www.crd.york.ac.uk/PROSPERO) and can be found under review number CRD42015029856. A more detailed version of the protocol was published (O'Connor et al., 2016c) and can be found in Appendix 4.

4.2.3 Search strategy

An initial scoping search was carried out to help identity relevant papers and search terms. These were used to inform the development of the final search strategy. We focused on three groups of search terms relevant to the research questions:

1) Engagement and enrolment

2) Digital health interventions

3) Barriers and facilitators

A preliminary search of several online bibliographical databases, i.e. PubMed, Medline and CINAHL, was carried out via Ovid. Then a professional systematic review company, the YHEC (JG, SGG), and a text mining company, called Text Mining Ltd (SB), were consulted for their expertise due to the challenges of searching for literature on such a broad topic. A combination of Medical Subject Index Headings (MeSH) headings, free text search terms and text mining (Thomas, McNaught and Ananiadou, 2011) were used to ensure the online database searches identified appropriate studies. The following six bibliographic databases were searched; CIHAHL (EBSCHOHost), Embase, Medline, PubMed, Scopus and the ACM Digital Library. The searches were limited to English language publications between 1 January 2000 and the 19 August 2015 (see Appendix 5). The year 2000 was chosen as an appropriate start date for the search as most modern technology such as smartphones, tablet PCs, wearable and sensor devices, and many online services were only developed and deployed in healthcare after this date. Additional search techniques were used to ensure the review was comprehensive and to overcome the known limitations of electronic searching (Greenhalgh and Peacock, 2005). These were reference and citation tracking of relevant studies, personal knowledge, contacting experts in the field and the 'Similar articles' function in PubMed. An Endnote file of all results was created and duplicate citations were removed.

4.2.3.1 Text Mining

The breadth of this review topic, which encompassed all types of digital health interventions, patient populations, settings and qualitative study designs, the volume of published literature on digital health and the complexity of the research question that incorporated the concept of enrolment or 'recruitment', all posed major challenges to undertaking the search strategy. Through discussions with the team at YHEC it was decided that text mining was an appropriate way to overcome these issues. Text mining is an umbrella term that describes a range of software methods used to retrieve information from natural language or unstructured text (Thomas, McNaught and Ananiadou, 2011). It comprises three major activities;

1) Retrieving text relevant to the search query,

2) Extracting fragments of text based on the query, and

3) Mining the data to find both direct and indirect associations between information extracted from the text.

The text mining technique first employed was bibliometric mapping using a software programme called VOSviewer (http://www.vosviewer.com). This was chosen to assist in search strategy development as it generates visual representations of the content of a large set of records. This can help identify concepts and search terms that might be useful in refining a search strategy (van Eck and Waltman, 2010). The first search on PubMed, using the three concepts outlined in 4.2.3, returned a total of 147,734 records and these were loaded into VOSviewer. The algorithm searches each record (title and abstract) for the most commonly occurring terms and the co-occurrence of terms. Co-occurrence is

> *"the above chance frequency of occurrence of two terms from a text corpus alongside each other in a certain order" (*Tijssen and Van Raan, 1994, p. 98*)*

Based on this frequency analysis, VOSviewer then constructs visual maps of keywords found and allows for these maps to be examined in detail. Hence, heat maps were generated from the analysis of terms in the titles and abstracts of the 147,734 records (see Figure 14). The colour in the heat map refers to the density or frequency of the terms at that point, with red being the highest point. Using VOSViewer it is possible to click on specific search terms in the heat map and uncover the additional terms that occur most frequently in relation to that search term.

The results of the heat map were examined but they did not reveal any additional concepts that could be used to refine and improve the search strategy. However, through the heat map it was discovered that the term 'recruitment' had an alternative meaning that had not been considered, as it is also a term often used in genetic studies involving mouse models. As the concept of 'recruitment' was key to the review question and could not be removed or altered, the search strategy was refined by linking the term 'recruitment' with the 'people' terms using Boolean operators.

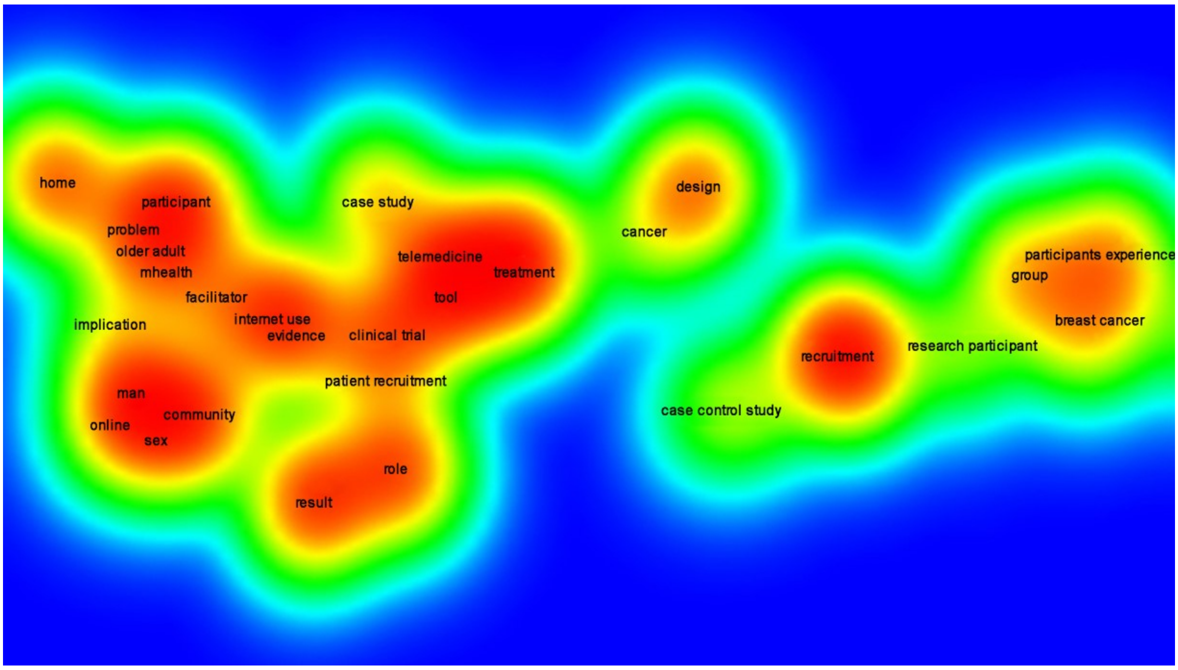


Figure 14: Heat map of terms

In addition, the results of the heat map were used to populate what are called gazetteers (list of inclusion terms), described later in this section. The modified search strategy was then run in Medline (Ovid) and translated to run in the other biomedical databases. The results of the database searches were downloaded into EndNote. Duplicates and articles published before the year 2000 were removed. Studies that were Randomized Controlled Trials (RCTs) were also removed as this was one of the exclusion criteria in the review. It was decided to omit RCTs as the focus of the review was on how technology was implemented with patients and the public in real-world not research settings. This left a total of 54,886 records (see Table 14).

Table 14: Systematic review search results by database

Database	Number of results retrieved
PubMed	15,767
Medline	21,327
Embase	36,198
CINAHL	11,902
Scopus	229
Total number of records	**85,423**
Total after duplicates and RCT studies removed	**57,367**
Total after manual removal of records pre-year 2000	**54,886**
Prioritized records (after GATE 8.0 analysis)	1,423
ACM Digital Library	22
Total	**1,445**

The 54,886 records were exported to RIS format and loaded into General Architecture for Text Engineering (GATE) 8.0 (https://gate.ac.uk). GATE is another text mining package that supports the analysis of human language in textual form. It provides the technical infrastructure that allows a range of software approaches to be applied to a large body of text (Cunningham, 2002; Witten, Don, Dewsnip and Tablan, 2004). In this case, it was used to prioritise relevant records from the set of records retrieved through database searching. An application in GATE called Multiparadigm Indexing and Retrieval (MIMIR) was utilised as it can apply a set of pre-defined rules to a corpus of documents to retrieve relevant records. Three gazetteers or lists of relevant search terms based on the previous results of the heat map were created (see Appendix 6). The gazetteers were used to develop rules, listed below, that helped identify and retrieve the most relevant records.

1. Records where terms from all three gazetteers (barriers/facilitators AND eHealth AND recruitment) appeared in the same sentence.

2. Records where terms from two gazetteers (barriers/facilitators AND eHealth) appeared in the same sentence and a word from the recruitment gazetteer appeared in the title of the record.

3. Records where terms from two gazetteers (barriers/facilitators AND recruitment) appeared in the same sentence and a word from the eHealth gazetteer appeared anywhere in the abstract of the record.

Of the total volume of records that were analysed in GATE 8.0 using the three rules in combination, 1,423 records met one or more of the rules. Ten random samples of 100 records each from the original 54,886 were manually screened to check for any potentially relevant records that may have been missed using text mining and none were found. Hence, the 1,423 results were exported to EndNote for screening. An additional database, the ACM Digital Library, was identified after the text mining process as a potential source of relevant studies. Therefore, a separate search was run on this database and 22 records were retrieved and added to the EndNote file (see Appendix 5.6). Although the text mining strategy applied does have some limitations, namely the use of a partial number of search terms in the gazetteers populated through frequency analysis, it was a useful way to identify relevant literature on this broad research topic from a large volume of published studies.

4.2.4 Study selection

The PICO (Population, Intervention, Comparison, Outcome) format is often used to structure a research question, as it can help improve the scientific rigour of a systematic review (Cullum, Ciliska, Haynes and Marks, 2013). In this case, a modified PICo framework (Population, phenomenon of Interest, Context) was used as the research question did not involve a comparator or outcome. Instead it focused on a phenomenon of interest (a digital health intervention) and a context (implementing a DHI in a real-world setting with patients or the public) which is better suit to using PICo. This helped structure the inclusion and exclusion criteria for screening studies based on the requirements of this review. Table 15 outlines the inclusion criteria and Table 16 outlines the exclusion criteria.

Table 15: Systematic review inclusion criteria

INCLUSION CRITERIA	
Population	Any individual (adult or child). This includes patients, the public and health professionals who would be aware of the experiences of these groups.
Phenomena of Interest - digital	Any health intervention delivered by a digital technology (hypothetical or in development, simulated or real-world)

health interventions	which takes information from patients or the public or provides some form of advice or feedback about their health. This includes, but is not limited to: • Web-based interventions on personal computers (PCs) or mobile platforms, • Mobile health applications or apps, • Patient portals or personal health records, • Interventions delivered by short message service (SMS) or interactive voice recognition (IVR).
Context - phase of implementation	Engagement and enrolment phase of a digital health intervention, which can span from gauging an individual's readiness for a digital health intervention, to the initial marketing or reach of the initiative, to actively signing individuals up to use the technology so they are registered on the digital application or system.
Context - setting	Any 'usual' setting (hypothetical or in development, simulated or real-world) such as primary, secondary or tertiary care, the home or workplace.
Study type	Publication date from 2000 present.

	Studies from any geographical location.
	English language.
	Original qualitative studies, studies involving secondary analysis of qualitative data or qualitative studies that are part of a mixed methods study (e.g. the study also has a quantitative component but the major component is qualitative and a qualitative methodology is described). The study must have direct contact with individuals or direct observation using any form of qualitative method.

Table 16: Systematic review exclusion criteria

EXCLUSION CRITERIA	
Phenomena of Interest - digital health intervention	Primary digital intervention is; telephone based with no additional technological function (e.g. telephone counselling or triaging service); Internet based with no additional interactive function (e.g. searching for health information online); or an implantable device that is remotely monitored.

Context - setting	Any non-usual setting e.g. prison, armed forces in active duty.
Context - stage of implementation	Pre-implementation work based solely around designing the interface and functionality of the digital health intervention.
	The post engagement/enrolment phase was not explored. For example: • why patients or the public use or do not use digital health interventions, • why they drop out (attrition) or fail to continue using them (retention), • their attitudes or beliefs towards digital health interventions, or their satisfaction with them outside of that pertaining directly to engagement and enrolment.
Study Type	Published pre-2000.
	Non-English language.
	Grey literature / not published in a peer reviewed journal.

	Dissertation / thesis.
	Published abstracts or conference proceedings.
	Studies using the following methodologies: descriptive case studies, lexical studies that analyse natural language data presented as qualitative results; qualitative studies using questionnaires or other methods that do not involve direct contact or observation of participants.
	Any type of literature review, systematic review and meta-analyses, or a qualitative study that did not involve direct contact or observation of participants.
	Randomized Controlled Trials due to the focus of the review on implementation in real-world not research settings and the large volume of literature on the difficulties recruiting to clinical trials that already exists (Treweek et al., 2010).
	Commentary articles, written to convey opinion or stimulate research / discussion, with no research component.

4.2.4.1 Software

DistillerSR software was used to screen studies as this online software allows multiple users to view and screen titles, abstracts and full papers simultaneously. It also enables inclusion and exclusion criteria to be set up to aid the screening process.

4.2.4.2 Article screening

The screening process was undertaken by the PhD student and one other independent researcher (PH). Firstly, both researchers screened the 1,445 titles independently based on the inclusion and exclusion criteria for the review. Any titles that were ambiguous were moved onto the second stage of screening and those deemed irrelevant were discarded. Next, both researchers screened the abstracts of the 997 remaining articles and any that did not meet the inclusion criteria were discarded. Where discrepancies arose, both reviewers discussed the abstract. It was included in the next stage if a clear decision to include or exclude could not be reached. Finally, the full-text of the remaining 290 articles were reviewed. 271 full papers that did not meet the inclusion criteria were excluded. Where disagreements arose on the relevancy of a full paper to the review, both reviewers discussed it and a third party (FM) was contacted to arbitrate the process if a definite decision could not be reached. At the end of the screening process, 19 full papers were included in the review. The PRISMA diagram in section 4.3 (see Figure 15) depicts this process.

4.2.4.3 Quality appraisal

Quality assessment was undertaken by two reviewers (SOC, PH) working independently. Each reviewer performed critical appraisal of the included studies using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury and Craig, 2007). Any disagreements that arose were discussed and adjudicated by a third party (FM) if necessary. The results of the quality assessment process for each study can be found in

Appendix 7. An overview of the results based on the three domains within the COREQ reporting criteria can be found in Appendix 9. No study was excluded from the review based on the results of the quality appraisal process as even methodologically weak studies can offer valuable insights into a topic (Popay et al., 1998; Dixon-Woods et al., 2007).

4.2.4.4 Data extraction

The next step in the systematic review process involved extracting relevant information from the result and discussion sections of the included studies. A data extraction template was designed on Microsoft Excel and piloted on a small sample of studies to refine and improve it. The final template used can be found in Appendix 11. Two reviewers (SOC, PH) independently performed data extraction with text pertaining to barriers or facilitators, and engagement or enrolment strategies, extracted from the results and discussion section of each study. This included both direct quotes from participants and the interpretations written by the authors of the study. Where disagreements arose over the relevancy of data to the review questions, both reviewers discussed the data and an independent third party (FM) made the final decision.

4.2.5 Data analysis and synthesis

To aid data synthesis, the framework approach (Ricthie and Spencer, 2002; Oliver et al., 2008) was adopted as it enables a priori theory to be used and it supports a robust analysis. Following the five analytical steps in the framework approach (see Figure 13), initial codes were developed independently by two researchers (SOC, PH) through reading and re-reading the extracted data from the included studies. The initial codes were then categorised and classified into higher order themes and subthemes during the identification phase to produce a draft coding framework. This framework was then reapplied to the dataset by both researchers to verify the concepts identified and refine them where necessary. Then comparisons of coding were made within and across themes and subthemes to ensure the barriers and facilitators to engagement and enrolment in digital health that were identified were as accurate as possible.

The final mapping phase used Normalization Process Theory (NPT) to help explain how people engage and enrol in digital health interventions in everyday life. As outlined in Chapter 3, NPT has four concepts to explain this; sense-making; relational work; operational work; and appraisal work, and has been used extensively to describe the process of implementing new interventions in healthcare (McEvoy et al., 2014). The detailed NPT coding framework used for analysis can be found in Chapter 3 (see Table 3) and in the published systematic review (O'Connor et al., 2016a). A summary is provided in Table 17 below. The subthemes that were identified from the prior rounds of qualitative coding were mapped to one of the four generative mechanisms of NPT; Coherence, Cognitive Participation, Collective Action or Reflexive Monitoring. This led to the creation of a new conceptual model of these processes discussed later in this chapter.

Table 17: NPT Framework

Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
Differentiation	Enrolment	Skillset Workability	Reconfiguration
Communal Specification	Activation	Contextual Integration	Communal Appraisal
Individual Specification	Initiation	Interactional Workability	Individual Appraisal

Internalization	Legitimation	Relational Integration	Systematization

Coding clinics were held with one of the supervisory team to ensure consistency of analysis was achieved and any disagreements in relation to coding could be resolved. NVivo QSR 10.0 was used to facilitate the analysis process and ensure a clear and transparent audit trail was maintained. This helped enhance the rigor and credibility of the review findings (Gale et al., 2013).

4.3 Results

The combination of electronic searches from the systematic review found 54,886 results, which were prioritised using text mining to 1,445 records. A further 15 records were identified through additional search strategies, meaning 1,460 were available to screen. This screening process is illustrated in the Preferred Reporting of Systematic Reviews and Meta-analysis (PRISMA) diagram (Moher et al., 2009) (see Figure 15). This resulted in 19 studies being included in the systematic review.

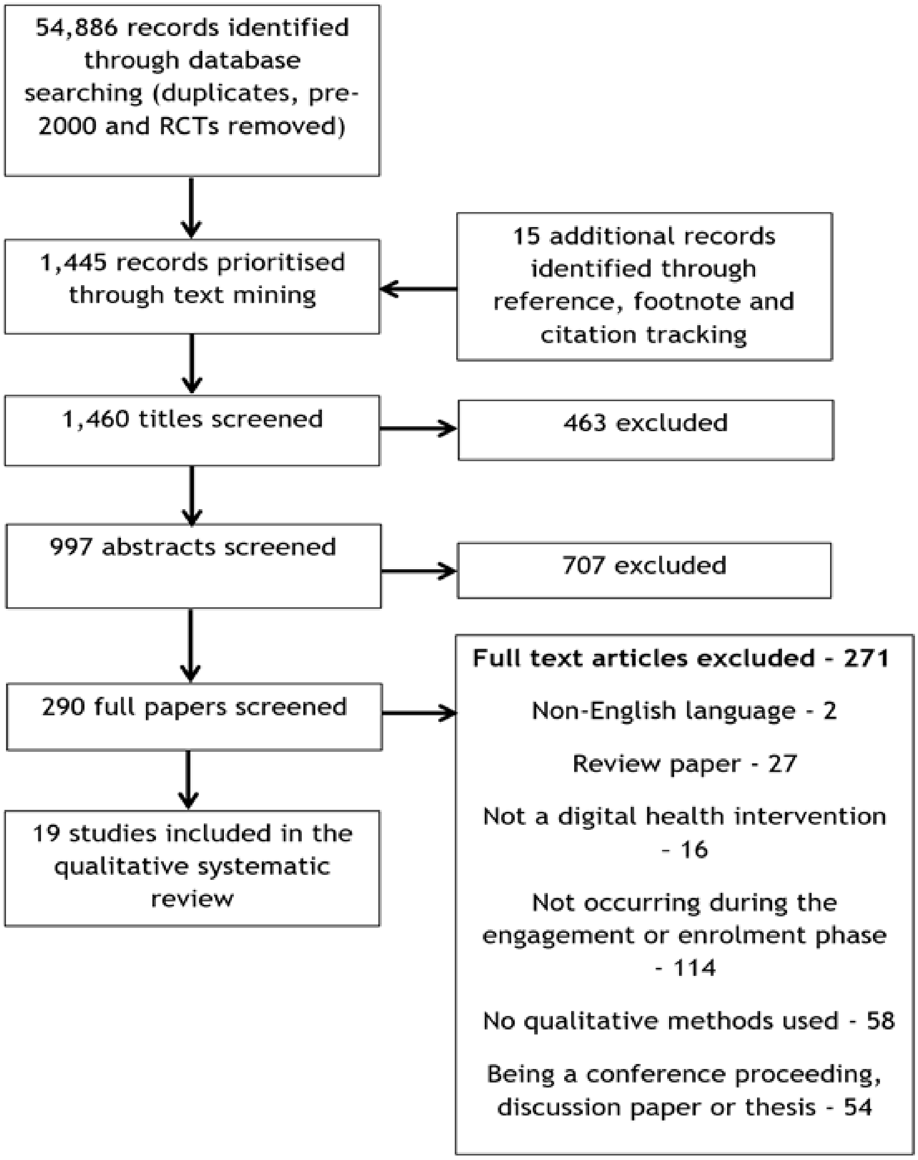


Figure 15: PRISMA flow diagram of search strategy in the systematic review

4.3.1 Characteristics of included studies

A summary of the characteristics of the included studies and participants from the systematic review can be found in Appendix 12 and are also available in the published review (O’Connor et al., 2016a). Overall the quality of reporting in the included studies in the systematic review was reasonable, ranging from 10 to 24 out of the 32 items on the COREQ checklist (see Appendices 7 and 9). All nineteen studies included details of the sample size, presented the main themes clearly and demonstrated consistency between data collected and the results.

Seventeen described how participants were sampled and provided the duration of data collection method. Only one study reported returning transcripts to respondents for validation and one repeated interviews that were done. The included studies were published over a ten-year period between 2005 and 2015 and conducted in five different countries. Eight took place in the United Kingdom, five in the United States, four in Canada and one each in Spain and Norway.

The participants in the nineteen studies in the systematic review were predominantly a mixture of patients, carers and members of the public who were healthy (see Appendix 14). However, six studies examined the views of health professionals such as nurses or family doctors (Trujillo Gómez et al., 2015; Hopp, Hogan, Woodbridge and Lowery, 2007; Lorimer, Martin and McDaid, 2014; Middlemass et al., 2012; Flynn, Gregory, Makki and Gabbay, 2009; Greenhalgh et al., 2010). Three studies focused on other types of participants such as employees from large public and private firms, staff employed at general practice clinics, and a range of people from local and national organisations who were associated with the implementation of the digital health intervention (Bardus, Blake, Lloyd and Suggs, 2014; Flynn et al., 2009; Greenhalgh et al., 2010). The participants were from various socioeconomic backgrounds, ages, genders and ethnicities. Overall, there was a general trend towards younger and middle-aged participants, rather than older adults, and those of “white” ethnicity. However, participant characteristics were not described in detail in many of the studies; with three not highlighting gender (Hopp et al., 2007; Middlemass et al., 2012; Greenhalgh et al., 2010), four not depicting age (Hopp et al., 2007; Lorimer et al., 2014; Middlemass et al., 2012; Greenhalgh et al., 2010), eleven not portraying ethnicity in any detail (Bardus et al., 2014; Beattie, Shaw, Kaur and Kessler, 2009; Das and Faxvaag, 2014; Flynn et al., 2009; Greenhalgh et al., 2010; Hopp et al., 2007; Lorimer et al., 2014; Middlemass et al., 2012; Trujillo Gómez et al., 2015; Winkelman, Leonard and Rossos, 2005) and nine not outlining socioeconomic status (Beattie et al., 2009; Flynn et al., 2009; Trujillo Gómez et al., 2015; Greenhalgh et al., 2010; Hopp et al., 2014;

Lorimer et al., 2014; Middlemass et al., 2012; Shoveller, Knight, Davis, Gilbert and Ogilvie, 2012; Winkelman et al., 2005).

A range of different digital health interventions were identified in the systematic review with several studies having similar DHIs (see Appendix 12). These included a telehealth system for people with diabetes (Hopp et al., 2007), an online booking and patient provider communication system (Das and Faxvaag, 2014; Flynn et al., 2009), personal health records or patient portals (Greenhalgh, Wood, Bratan, Stramer and Hinder, 2008b; Greenhalgh et al., 2010; Winkelman et al., 2005), web based sexual health and cognitive behavioural therapy services (Beattie et al., 2009; Hottes et al., 2012; Lorimer and McDaid 2013; Lorimer et al., 2014; Middlemass et al., 2012; Shoveller et al., 2012), online support groups (Im, Lee and Chee, 2010), a social networking application (Horvath et al., 2012) and email, SMS or mobile phone based smoking cessation, weight loss or health promotion programmes (Bardus et al., 2014; Trujillo Gómez et al., 2015; Speirs, Grutzmacher, Munger and Messina, 2015; Fukuoka Kamitani, Bonnet and Lindgren, 2011). One study was a mixed intervention that used a pedometer with a nutritional education and meal preparation training programme (Dasgupta et al., 2013).

4.3.2 Engagement and enrolment strategies in the included studies

A wide range of engagement and enrolment strategies were used in the included studies in the systematic review. Engagement was defined as:

> *"any process by which patients' and the public become aware of or understand a digital health intervention"* (O'Connor et al., 2016a, p. 5)

The types of engagement approaches used in the studies in the systematic review included multiple forms of advertising on radio, in print media such as newspapers, personal letters, posters on notice boards, and flyers and leaflets, via electronic means using email, social media, television screens and digital notice boards, and on websites and Internet forums. Traditional engagement techniques were also used such as promoting DHIs through health professionals, employers and personal recommendations from family and friends. In a few cases, people were approached directly by research and management staff at healthcare facilities. More novel methods were also employed such as running co-design events with patients and the public to get them involved in creating a DHI. However, six studies did not describe the engagement strategies used (Horvath et al., 2012; Im et al., 2011; Lorimer et al., 2014; Middlemass et al., 2012; Shoveller et al., 2012; Winkelman et al., 2005). A summary of engagement techniques employed in the studies in the systematic review can be found in Table 18.

Table 18: List of engagement approaches in the included studies in the systematic review

Engagement Approach	
Advertising (Indirect)	Electronic media - television screens and digital notice boards (Bardus et al., 2014; Flynn et al., 2009) Online media – email; social media; websites; Internet communities or forums (Flynn et al., 2009; Greenhalgh et al., 2010) Print media - newspaper advertising; personal letters; posters on notice boards; printed flyers and leaflets (Bardus et al., 2014; Flynn et al., 2009; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Hopp et al., 2007; Speirs et al., 2015) Radio (Greenhalgh et al., 2008b; Greenhalgh et al., 2010)

Personal Contact (Direct)	Health professional (Beattie et al., 2009; Hopp et al., 2007; Greenhalgh et al., 2008b; Greenhalgh et al., 2010) Research or management staff within a healthcare facility (Das and Faxvaag, 2014; Flynn et al., 2009) Employer (Bardus et al., 2014) Family, friends or peers (Dasgupta et al., 2013) Co-design activities (Fukuoka et al., 2011; Hottes et al., 2012; Lorimer and McDaid, 2013; Trujillo Gómez et al., 2015)

Enrolment strategies used in the included studies to sign patients and the public up to a DHI were equally wide ranging. Enrolment was defined as

> “any approach that involved people actively registering for or signing up to a DHI” (O’Connor et al., 2016a, p. 5)

These included getting personal assistance from a health professional, researcher or administrator, filling out a paper-based registration form, setting up an online account or profile, or sending a SMS text message. In one study, the consent of participants was implied if they did not respond to an initial written invitation to withdraw from the DHI and an online account was automatically created. However, twelve studies did not describe the strategies used to enrol patients and the public in DHIs (Dasgupta et al., 2013; Flynn et al., 2009; Fukuoka et al., 2011; Horvath et al., 2012; Hottes et al., 2012; Im et al., 2011; Lorimer and McDaid, 2013; Lorimer et al., 2014; Middlemass et al., 2012; Shoveller et al., 2012; Trujillo Gómez et al., 2015; Winkelman et al., 2005). A summary of the techniques used can be found in Table 19.

Table 19: List of enrolment plans in the included studies in the systematic review

Enrolment Plan	
Automatic	Consent is assumed and a digital profile or account is created (Greenhalgh et al., 2008b)
Online	Register via a website (Bardus et al., 2014; Greenhalgh et al., 2010; Speirs et al., 2015)
Paper based	Complete a paper-based registration form (Beattie et al., 2009; Das and Faxvaag, 2014; Greenhalgh et al., 2010)
Personal Assistance	Healthcare professional helps to create a digital profile or account (Hopp et al., 2007; Greenhalgh et al., 2010; Speirs et al., 2015)
Telephone or mobile phone	Telephone registration line or sending a SMS text message (Speirs et al., 2015)

4.3.3 Issues affecting digital health engagement and enrolment

The analysis of included studies in the systematic review revealed four major themes and a number of subthemes related to barriers and facilitators to engagement with and enrolment in DHIs. The main themes were;

1) Personal agency and motivation

2) Personal life and values

3) Engagement and enrolment approach

4) Quality of the DHI

Throughout the findings presented here participant quotes identified in the text of included studies are provided to corroborate the results of each theme and more are available in Appendix 16.

4.3.3.1 Personal agency and motivation

Personal agency and motivation was the first theme to emerge from the review findings. Patients and the public who were personally motivated to improve their health and wanted more choice and control over this process tended to engage and enrol in DHIs. Some people thought technology was a useful way to keep fit and encourage themselves to lose weight, thus preventing ill health (Bardus et al., 2014; Dasgupta et al., 2013; Hopp et al., 2007; Trujillo Gómez et al., 2015). Others registered for a DHI as it enabled them more flexibility in terms of when and where they could access health information and health services, which helped reduce individual's anxiety in some cases (Bardus et al., 2014; Hottes et al., 2012; Lorimer et al., 2014; Shoveller et al., 2012; Trujillo Gómez et al., 2015). The level of control that technology offered in terms of being able to monitor and understand diet and exercise habits on a regular basis as well as manage chronic conditions also appealed to people, which encouraged registration (Greenhalgh et al., 2010; Hopp et al., 2007; Winkelman et al., 2005).

> *"[I subscribed] to get the reminders, because if you're sat, if you are in a lunch break and you're sat at your desk just on the Internet and you're not moving and you're eating something that's not good and then you get a reminder and it's just: 'have a walk!', or something. Straight away*

> *there is a trigger in your mind and you think: 'yeah, that's right, I can do that!"* – Facilitators (Bardus et al., 2014)

In contrast, a barrier for some people was their lack of awareness of DHIs or a poor understanding of how technology could help them with their health. In some cases technology was seen as being disruptive in everyday life or only as having entertainment value, which meant certain people did not engage with it (Fukuoka et al., 2011; Greenhalgh et al., 2008b; Greenhalgh et al., 2010). This was compounded by poor motivation to understand and improve personal health through digital means, as some individuals thought this was not their responsibility but something that their healthcare provider should manage (Greenhalgh et al., 2010; Hopp et al., 2007). Others felt DHIs were discouraging and could be a constant reminder if people failed to meet healthy goals, which meant they did not sign up for the technology (Dasgupta et al., 2013; Fukuoka et al., 2011). Another challenge was that many people already used alternative ways to manage their health such as using paper-based systems to record physiological signs and lifestyles habits or gaining support directly from family, friends, peers or health professionals (Bardus et al., 2014; Hottes et al., 2012; Flynn et al., 2009; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Im et al., 2010). All these factors contributed to low rates of engagement and enrolment in DHIs.

> *"For me, it does not change anything because I am always in a car. I walk very little so I will feel even guilty for not having walked. I will look down at the low numbers and I'll feel anxious."* – Barrier (Dasgupta et al., 2013)

4.3.3.2 Personal life and values

Personal life and values was the second theme to affect patients and the public's ability to engage with and enrol in DHIs. Individuals who thought the technology was relevant, could be tailored to their specific needs or fitted easily around their personal life tended to sign up for it (Bardus et al., 2014; Fukuoka et al., 2011; Hottes et al., 2012; Lorimer et al., 2014; Shoveller et al., 2012; Trujillo Gómez et al., 2015; Winkelman et al., 2005). Other aspects that made it easier for people to register for DHIs was if they were digitally literate (Hopp et al., 2007; Lorimer et al., 2014; Winkelman et al., 2005) or already familiar with the technology (Hopp et al., 2007; Lorimer et al., 2014), as they had the necessary knowledge and skills to enable them to engage. In addition, some people liked the privacy that online health services provided, as being relatively anonymous meant they felt more secure and could avoid the embarrassment and stigmatisation they sometimes experienced in the real-world (Beattie et al., 2014; Greenhalgh et al., 2008b; Hottes et al., 2012; Im et al., 2010; Lorimer et al., 2014; Shoveller et al., 2012; Winkelman et al., 2005).

> *"This is definitely a service I would use, not only for the convenience factor but I mean, no matter how old we are, it's still an embarrassing issue for a lot of people."* – Facilitator (Hottes et al., 2012)

On the other hand, people who had busy personal lives, with demanding careers and caring responsibilities in their family or financial worries, tended not to engage and enrol in DHIs as they had less time, energy and interest to do this (Bardus et al., 2014; Dasgupta et al., 2013; Flynn et al., 2009; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Horvath et al., 2012; Im et al., 2010). Some individuals were also worried about the security of personal health information as it could be compromised in an online environment or on mobile devices. This might mean that sensitive information could be unintentionally or maliciously disclosed to family, friends, peers or employers or used by government agencies or private industry to infringe on citizens' rights (Das and Faxvaag, 2013; Fukuoka et al., 2011; Horvath et al., 2012; Hottes et al., 2012; Lorimer and McDaid, 2013; Lorimer et al., 2014; Middlemass et al., 2012; Shoveller et al., 2012). Poor access to computer equipment and the Internet was another reason people could not register for a DHI (Flynn et al., 2009; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Hopp et al., 2007; Horvath et al., 2012; Middlemass et al., 2012). In some cases, this was due to the prohibitive costs involved in purchasing the hardware, software and Internet services needed to get online as people were not able to access affordable technology (Fukuoka et al., 2011; Horvath et al., 2012; Middlemass et al., 2012; Speirs et al., 2014). Another significant barrier that affected people's ability to engage and enrol in DHIs was poor digital literacy skills, as those who had little or no experience using technology struggled to take part. In a minority of cases this problem was complicated by the fact that some people were not native English speakers, making it more difficult for them to engage with DHIs (Beattie et al., 2009; Flynn et al., 2009; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Fukuoka et al., 2011; Hopp et al., 2007; Hottes et al., 2012; Middlemass et al., 2012).

> *"I'm very wary of the internet, we leave digital footprints wherever we go and you never know what's going to come back and haunt you and I think the more that you are in a professional working environment the more you need to be careful about what you put online. You've got to keep it within certain parameters."* – Barrier (Das and Faxvaag, 2014)

4.3.3.3 Engagement and enrolment approach

The type of strategy used to make patients and the public aware of a DHI and get them signed up was the third major factor that affected engagement and enrolment. When individuals received personal recommendations from their family members, friends or peers, or got help from them directly, they were more likely to engage and register for a technology, whereas those who lacked support often failed to sign up (Bardus et al., 2014; Dasgupta et al., 2013; Horvath et al., 2012; Greenhalgh et al., 2010; Im et al., 2010). Engagement and enrolment strategies that actively promoted technology and were tailored to the individual, where possible, also seemed to be more successful in reaching the right audiences and persuading them to participate (Bardus et al., 2014; Lorimer and McDaid, 2013; Flynn et al., 2009). In one case, a health professional mediated the process and decided which patients were suitable to be enrolled on a telehealth programme (Hopp et al., 2007). Another study reported its participants who worked at a university only signed up for a DHI because they wanted to support their colleagues who were conducting research on the technology (Bardus et al., 2014).

> *"I make that decision by the patient's need. If their diabetes is poorly controlled, then you need to use more tools to get them under control... you don't really need it with all your patients with diabetes. You need it on the ones that need extra help."* – Facilitator (Hopp et al., 2007)

Unfortunately, the lack of promotion and marketing of DHIs meant that many people were unaware of their existence and did not know the technology could be used to support their health needs. Few of the engagement strategies used any aspect of public health education which could have meant people had a poor understanding of what a DHI could do. This seemed to lead to low levels of engagement as individuals had little interest or enthusiasm to sign up for a technology (Trujillo Gómez et al., 2015; Flynn et al., 2009; Greenhalgh et al., 2008b). Another difficulty lay in the recruitment approach, as some used complicated language and were not clear about why the technology was relevant for people and how to go about registering for it (Bardus et al., 2014; Speirs et al., 2015). Certain DHIs lacked the endorsement of trusted clinicians or healthcare organisations which was a barrier for some people, who felt the technology must have limited value if their doctor or nurse did not promote or use it and hence they would not enrol (Flynn et al., 2009; Winkelman et al., 2005). On the other hand, if health professionals or associations affiliated with healthcare did support the technology then this seemed to reassure people it was worth signing up to (Middlemass et al., 2012; Fukuoka et al., 2011).

> *"I would probably if I knew that the physician would access that prior to an appointment. If the physician didn't read it, if it was more of a personal thing [just for me to do], I don't know if I would kind of follow through with that."* – Barrier (Winkelman et al., 2005)

4.3.3.4 Quality of the DHI

The last factor to affect patients and the public's ability to engage and enrol in DHIs relates to the quality of information and interaction afforded by the technology. Some people wanted to engage with technology as they could quickly and easily gain access to social support they needed to manage their illness, which seemed to encourage them to enrol (Dasgupta et al., 2013; Fukuoka et al., 2011; Im et al., 2010; Winkelman et al., 2005). Others liked digital products or services as they provided an open and continuous communications channel through which individuals could contact their healthcare provider and this was the reason they signed up to a DHI (Beattie et al., 2009; Speirs et al., 2015). In one case, participants reported medical errors they had experienced due to the lack of technology in the health service as the reason they registered for a DHI. They felt electronic systems were a good way to reduce the number of mistakes made and to improve the quality of health information and care they receive (Greenhalgh et al., 2008b). Furthermore, technology which was automated and integrated with other applications and devices appeared to encourage enrolment as people felt it was quicker and easier to use (Shoveller et al., 2012).

> *"I was so down and my peers/family couldn't handle it and I needed someone who could tell me that it would be OK and that it was normal but also that I needed to stop feeling sorry for myself in a nice way…. I just went online and look for my support group [sic]."* – Facilitator (Im et al., 2010)

In contrast, others did not like the impersonal nature of technology and felt they would receive a poorer level of care through this type of electronic medium, as it could not make up for the nuances of human interaction. This was particularly important for patients who valued the therapeutic relationship they had with their clinician as they considered them a valuable social support mechanism, especially when sensitive health issues were involved and so they tended not to sign up for DHIs (Beattie et al., 2009; Dasgupta et al., 2013; Flynn et al., 2009;

Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Horvath et al., 2012; Hottes et al., 2012; Shoveller et al., 2012; Trujillo Gómez et al., 2015; Winkelman et al., 2005). The usability of a digital product or service was another aspect of quality that people thought about, as some refused to enrol in a technology if it was too slow or difficult to register and use (Bardus et al., 2014; Greenhalgh et al., 2008b; Greenhalgh et al., 2010; Shoveller et al., 2012). In a few cases, individuals thought that health information accessed online could be poor quality and unreliable depending on the source. Therefore, without the advice of a qualified health professional people would not engage with some digital products and services. The potential for identity fraud was also a concern where virtual sessions were held with clinicians the patient had never met in person and they were unsure whether to trust the advice given (Beattie et al., 2009; Hottes et al., 2012; Shoveller et al., 2012; Winkelman et al., 2005). Finally, one study reported its participants observed abusive or threatening behaviour online which acted as a barrier to engaging and enrolling in the DHI (Horvath et al., 2012).

> *"I don't think you would get the same feeling as if you were one-to-one in a room. You get more, you get to know the other person, so in a way you would. To me it would be like talking to a machine."* – Barrier (Beattie et al., 2009)

4.3.5 Developing a conceptual understanding of digital health engagement and enrolment

A preliminary conceptual model of digital health engagement and enrolment was created based on the findings of the systematic review. As described in section 4.2.5, the subthemes identified in the systematic review were mapped to one of the four generative mechanisms of NPT (see Table 20); 1) Coherence, 2) Cognitive Participation, 3) Collective Action, or 4) Reflexive Monitoring, using the coding frame (see Appendix 3). For example, a quote from one of the included studies outlined below was coded to the ‘Skills and equipment’ subtheme as the person seemed to think older adults had lower levels of computer skills, which could act as a barrier to engaging with digital health. Therefore, Collective Action was selected as the most relevant NPT mechanism as it reflects the operational work that people must do to engage and enrol in a digital health product or service.

> *"There might be an issue here too with the age. I mean young people really—they have these machines down, you know. They do it in their sleep, you know, text. But there might be a hurdle for people who are older and there might be some fear around—I mean I still can't text. I mean I'm lucky when I can text correctly."* (Fukuoka et al., 2011)

In another example, one participant quote, given below, was coded as 'Motivation' during analysis as the individual seemed to recognise this as the reason for enrolling in a 12-week emailing and text messaging service promoting physical activity. Upon further reflection it was felt 'Motivation' best aligned with the Coherence construct of NPT which describes the sense making work people do when faced with a new intervention.

> *"[I enrolled] basically because it was asking for information about people's activity levels and […] I was sort of curious as how they were doing, benchmarking, if you like, on people's fitness levels and what sort of criteria they were using to measure what we're doing and really to see where I was in terms of my own physical fitness and ability"* – Facilitator (Bardus et al., 2014)

Table 20: Factors affecting digital health engagement and enrolment identified from the systematic review mapped to NPT

Theme 1: Personal agency and motivation			**Mapping to NPT**
Subtheme 1.1: Motivation	Barrier - Lack of motivation to understand or improve health	Facilitator - Motivation to understand and improve health	Coherence
Subtheme 1.2: Awareness and understanding	Barrier - Unaware of or lacks understanding of how a DHI could be helpful	Facilitator - Ability to understand a DHI and personal health data	Coherence
Subtheme 1.3: Personal agency (choice and control)	Barrier - Alternative ways of documenting health information and managing illness	Facilitator - Ability to choose time and location of DHI, Ability to control electronic personal health data	Coherence

Theme 2: Personal life and values			Mapping to NPT
Subtheme 2.1: Personal lifestyle	Barrier - Busy lifestyles with competing priorities	Facilitator - DHI fits with personal lifestyle	Collective Action
Subtheme 2.2: Skills and equipment	Barrier - Poor digital literacy, Lack of access to equipment and the Internet, Cost of DHI	Facilitator - Good digital literacy, Has or can afford computer equipment or mobile devices and network connectivity	Collective Action
Subtheme 2.3: Security and privacy	Barrier - Concern over the security and privacy of DHI information or interaction	Facilitator - Values the privacy and anonymity of DHI information or interaction	Collective Action

Theme 3: Engagement and enrolment approach			Mapping to NPT
Subtheme 3.1: Recruitment strategy	Barrier - Difficulty understanding the recruitment message	Facilitator - Active promotion and engagement strategies, Health professional acts as a gatekeeper	Cognitive Participation
Subtheme 3.2: Direct support	Barrier - Lack of support from family members, friends or peers	Facilitator - Support from family members, friends or peers offline	Cognitive Participation
Subtheme 3.3: Personal advice	Barrier - Lack of advice and recommendations from trusted sources	Facilitator - Recommended by family members, friends or peers	Cognitive Participation
Subtheme 3.4:	Barrier - Lack of clinical	Facilitator - Clinical accreditation and support for a DHI	Cognitive Participation

Clinical endorsement	endorsement and support for a DHI		
Theme 4: Quality of digital health intervention			**Mapping to NPT**
Subtheme 4.1 Quality of digital health information	Barrier - Poor quality information, Lack of trust in DHI information	Facilitator - Previous negative experience of health services without DHI	Reflexive Monitoring
Subtheme 4.2: Quality of digital health interaction	Barrier - Impersonal DHI (poor quality interaction), Lack of trust in DHI interaction, Digital health interaction can be abusive	Facilitator - Open, honest digital interaction with healthcare provider, Social support from peers online	Reflexive Monitoring
Subtheme 4.3: Usability	Barrier - Usability of the DHI, Complex	Facilitator - DHI is easy to enrol in and	Reflexive Monitoring

	registration process via technology	use (automated and integrated)	

As conceptual coding proceeded more subthemes were mapped to the four main mechanisms of NPT, until all thirteen subthemes were associated with the most appropriate element of the theory. Once this was completed, each of the four mechanisms of NPT were reframed for the digital health implementation context. Hence, Coherence was named “Making sense of a digital health intervention”. Cognitive Participation was termed “Gaining support for enrolling in a digital health intervention”. Collective Action was named “Registering for a digital health intervention” and Reflexive Monitoring was called “Considering the quality of a digital health intervention”. From this an initial diagram was constructed to illustrate the four processes involved in engaging and enrolling in DHIs and the subthemes (barriers and facilitators) related to them.

Regular coding clinics were held with one of the supervisory team (FM) to discuss how subthemes was being mapped to Normalization Process Theory. During these discussions it was noted that two overarching concepts were emerging in relation to engaging and enrolling in a digital health intervention. The first was based around the ‘Decision making’ that an individual must undertake to make sense of a DHI in terms of their own personal circumstances and consider different aspects of its quality. This helps a person to decide whether or not they want to proceed to signing up for a DHI. From there, one must put this decision into action by gaining the support needed to enrol and then signing up for a digital health product or service. Therefore, ‘Operationalising’ is the second concept that guides engagement and enrolment. These two overarching concepts were added to the initial diagram to help explain the myriad of factors (both barriers and facilitators) that affect how patients and the public progress through the early phases of the digital health implementation journey. This new preliminary framework was called the Digital Health Engagement Model (DIEGO), as outlined in Figure 16.

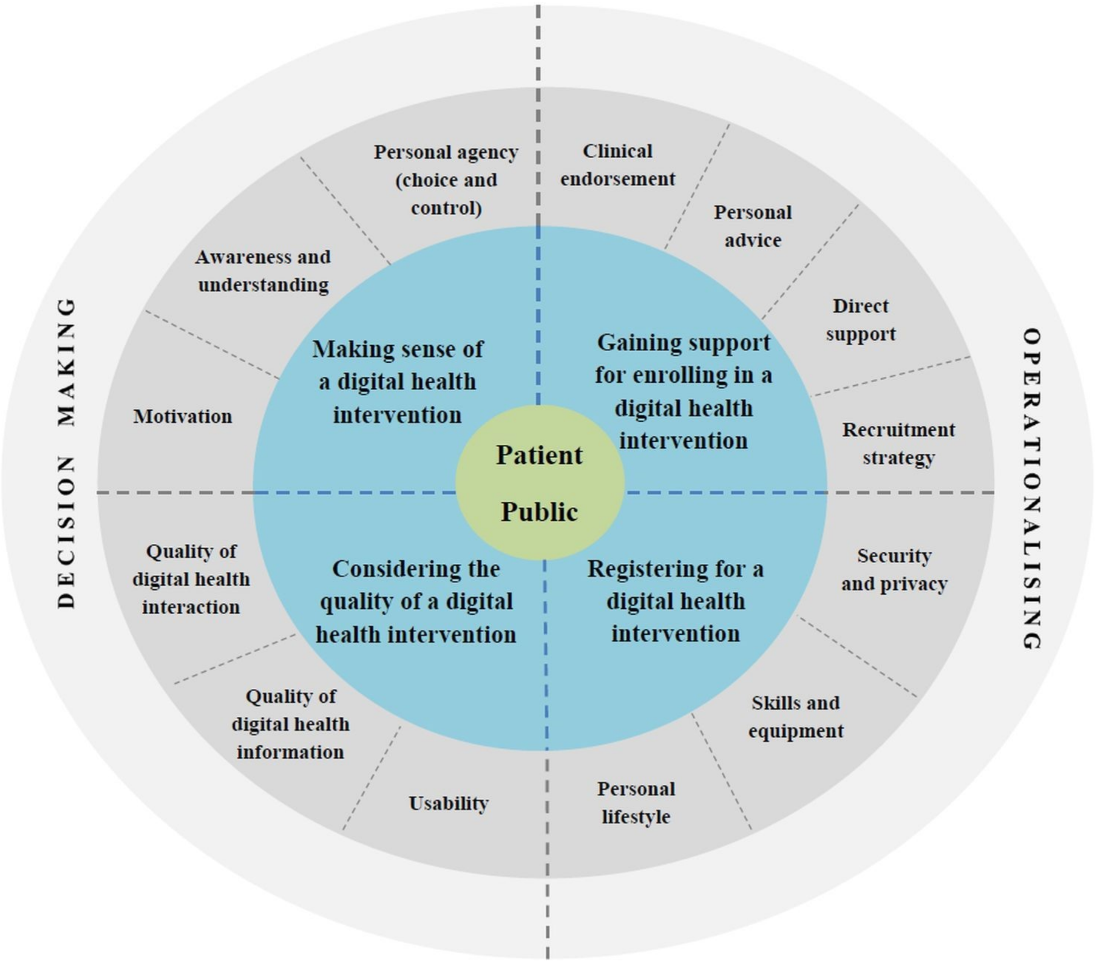


Figure 16: Digital Health Engagement Model (DIEGO)

4.4 Discussion

The systematic review provided a description of included studies and participants as well as a list of engagement and enrolment strategies used. It also offered a catalogue of barriers and facilitators patients and the public experience when engaging with and registering for a DHI. Importantly, from the systematic review findings a preliminary conceptual model of these complex processes and their key components were developed. Although none of the nineteen studies comprehensively covered the entire engagement and enrolment journey, each explored one or more aspects of people's positive and negative experiences.

4.4.1 How the systematic review findings fit with existing knowledge

The systematic review examined the factors that affect patients and the public when they try to engage and enrol in all types of DHIs. These findings mirror and expand on those of an earlier review that mainly explored people accessing health information online (Hardiker and Grant, 2011). None of the studies in the earlier review are present in this one, as they did not meet the inclusion criteria for a digital health intervention. However, a theme that was evident in the earlier review was that the characteristics of users, such as peoples' age, ethnicity, socioeconomic status and level of education, was an element that affected engagement with digital health. Unfortunately, this finding was not very evident in our review due to the diversity of participants involved and the lack of data reported on aspects of their characteristics such as age, ethnicity, educational attainment and employment. The studies in the systematic review also involved very few people over the age of sixty-five. The earlier review found older people were less likely to engage with the Internet and those who did found it more difficult to navigate than younger age groups. Other research has also highlighted older adults as a group that have more usability issues with technology (Czaja et al., 2013). Liu et al. (2016) note that this may become less of an issue over time as younger generations age, although declining health as people get older may continue to challenge their ability to engage with DHIs. Therefore, it will be important for research to continue to explore why this user group do or do not engage with and enrol in DHIs and how to address the issues they face.

Similarly, ethnicity and socioeconomic status were not well described in the studies in the systematic review, so it is not possible to draw any conclusions about how ethnicity, social class and culture affects engagement with DHIs.

However, the earlier review by Hardiker and Grant (2011) noted that ethnicity appeared to affect uptake of digital health services, with non-white populations less likely to engage with technology for their health. This theme reoccurs throughout the literature (Choi and DiNitto, 2013; Kontos, Blake, Chou and Prestin, 2014; Gordon and Hornbrook, 2016) but may be partially attributable to the language barrier (Nagler, Ramanadhan, Minsky and Viswanath, 2013; Zibrik et al., 2015) and the lack of engagement of different ethnic and migrant groups with health services and research more generally (LaVeist, Nickerson and Bowie, 2000; Garrett, Dickson, Young and Whelan, 2008; Jayaweera and Quigley, 2010). In terms of employment, the earlier review also highlighted that those who earned less money were less likely to have a computer at home and less likely to access health information online. While it was not possible to identify this as a factor affecting engagement with DHIs in the systematic review, people's ability to afford technology has been noted in the literature as playing a part in whether they sign up for a DHI or not (Neter and Brainin, 2012). Likewise, the earlier review reported educational attainment as an aspect affecting uptake of digital health products and services. Higher levels of education such as attending college or having graduated from high school were attributed to increased Internet access and use. People's literacy skills have been described in the wider literature as affecting their interest in and ability to take part in DHIs (Cashen, Dykes and Gerber, 2004; Kontos et al., 2014), which is consistent with the findings of this systematic review.

4.4.2 Strengths and limitations

A strength of the systematic review was it was based on a well-developed, published protocol (O'Connor et al., 2016c) to ensure the process was transparent and replicable. It also followed a robust methodology to identify and synthesise relevant literature. Although the text mining strategy applied does have some limitations, namely the use of a partial number of search terms in the gazetteers populated through frequency analysis, it was a useful way to identify pertinent literature on a broad research topic from a large volume of published studies. In addition, best practice guidelines such as PRISMA were used to improve the reporting of the review. The findings include a number of recommendations about how to address the barriers patients and the public face when engaging and enrolling in DHIs. A preliminary conceptual model was also developed and knowledge gaps identified to elicit further research that could aid our understanding of engagement and enrolment in DHIs. These could help health professionals, health service managers, researchers, policy makers, private companies and others overcome some of the challenges faced during the initial phases of implementation, so people can quickly and easily sign up to digital health products and services.

This review does have some limitations. Firstly, a number of constraints can be found in the search strategy given the broad focus of the review. Only English language publications were included which could have omitted useful studies in other dialects. However, there is some evidence that limiting search strategies in this way does not introduce significant bias (Moher, Pham, Lawson and Klassen, 2003). Secondly, the search was limited to a specific timeframe, after the year 2000, which may have excluded some potentially useful studies. It was felt this decision was justifiable given the rapid growth in digital health during this period and the distinct advancements in technology, which did not exist to the same degree prior to the year 2000. Thirdly, in the search we removed studies that focused on recruitment to clinical trials or RCTs, as we wanted to identify literature on engagement and enrolment to “real-world” DHIs and avoid duplicating other research such as the Cochrane review published on recruitment strategies to clinical trials (Treweek et al., 2010). In addition, many DHIs are developed and sold commercially and never undergo academic evaluation, which means the literature and hence this review is limited to only those that have been evaluated and peer-reviewed (Lennon et al., 2017). This does mean that some relevant studies from grey literature could have been missed.

In terms of the review results, some limitations exist here also. The analysis of the studies in the review was based on published data and not the original qualitative data. Only participant comments selected by the authors for publication were available for analysis, meaning some bias may be introduced as important contextual information could be missing. The populations in the included studies were relatively homogenous, with white, middle-aged people being the predominant participants and therefore data about different age, socioeconomic and ethnic groups are missing. Furthermore, the studies in the review were from high-income, Western cultures (i.e. United States, Europe and Australia) and low and middle-income countries are missing. Hence, some cultural and socioeconomic variations may be absent from the review findings (O'Connor et al., 2016a). The digital health products and services described in the review did cover a number of different technologies, but more such as virtual and augmented reality (O'Connor, 2019) are emerging which may limit the findings of the review somewhat. Finally, the engagement and enrolment strategies were not described in enough detail in the included studies to enable a robust taxonomy of approaches to be created.

4.5 Review update

The systematic review was published in 2016 (O'Connor et al., 2016a), with search dates ranging from January 2000 to August 2015. As digital health is a fast-moving field and the review encompassed a wide range of technologies and populations of people, an update was conducted to identify additional literature on patient and public engagement and enrolment in digital health. A new search was run, encompassing dates from September 2015 to December 2018, using the same databases and search terms outlined in 4.2.3. From this search a further 81,733 records were found and extracted to EndNote. As before duplicates and RCTs were removed leaving 59,276 records (see Table 21). This Endnote library was searched further, as described below.

Table 21: Review update search results by database

Database	Update search
PubMed	19,282
MEDLINE	16,851
Embase	32,333
CINAHL	13,007
Scopus	235
ACM	25
TOTAL	**81,733**
Total after duplicates and RCT studies removed	**59,276**

It was not feasible to utilise text mining to refine the search results further, as was performed in the original review, due to the costs involved. Therefore, a number of alternative strategies, listed below, were employed to identify and screen potentially relevant articles from the large number of search results.

- All papers that cited the original systematic review up to December 2018 were identified via PubMed (n=31) and Google Scholar (n=62). On screening the titles and abstracts of these studies, fourteen warranted full-text screening and one article was deemed relevant.

- All authors (n=101) from the included studies in the original review were searched for in the EndNote library of 59,276 records. The titles and then abstracts of these publications were screened (n=658). Eight articles underwent full-text screening, resulting in two relevant studies.
- EndNote records were organised alphabetically by author surname. Well-known researchers who publish on the subject of implementing technology in healthcare were identified e.g. Martin Eccles (n=0), Trish Greenhalgh (n=13), Jeremy Grimshaw (n=14), Ray Jones (n=10), Anne Rogers (n=19) and Michel Wensing (n=15). The titles and abstracts of their publications were screened, followed by full-text screening of four studies, resulting in two relevant articles.
- Endnote records were organised alphabetically by journal name and publications from the top health informatics (n=5) and implementation science journals (n=1) were identified. The titles and abstracts of these (n=750) were screened. Full-text screening of six studies was then undertaken, resulting in two relevant articles.

After the removal of duplicates, five papers were included in the update of the original systematic review (Blackstock, Shah, Haughton, Horvath and Cunningham, 2015; Greenhalgh et al., 2015; Guendelman, Broderick, Mlo, Gemmill, and Lindeman, 2017; Schueller, Neary, O'Loughlin and Adkins, 2018; Zamir, Hennessy, Taylor and Jones, 2018). The doctoral student undertook quality assessment using the COREQ checklist (see Appendices 8 and 10), extracted relevant data from the five studies and conducted analysis to update the review.

4.5.1 Results from the review update

Five studies were included in the review update. A summary of the characteristics of the included studies and participants can be found in Appendices 13 and 15. Overall the quality of reporting in the included studies in the review update was reasonable, ranging from 15 to 21 out of the 32 items on the COREQ checklist (see Appendices 8 and 10). All five studies described how participants were approached, where data was collected and the characteristics of the sample. Four included how many people coded the qualitative data and three outlined the researchers' credentials and the methodological orientation of the study.

4.5.1.1 Characteristics of included studies in the review update

The included studies in the review update were published over a three-year period between 2015 and 2018 and conducted in two countries. Two took place in the United Kingdom and three in the United States. The review update had a mixture of participants with three including patients (Blackstock et al., 2015; Greenhalgh et al., 2015; Zamir et al., 2018), one study with pregnant women and young mothers (Guendelman et al., 2017) and one with healthy participants (Schueller et al., 2018). Two studies included the views of other stakeholders such as technology providers (Greenhalgh et al., 2015) and staff working in a care home for older adults (Zamir et al., 2018). The participants were from a range of ages, genders, ethnicities and socioeconomic backgrounds but were predominantly female with ages ranging from 18 to 98 years. One study did not depict gender (Zamir et al., 2018), two did not describe ethnicity (Schueller et al., 2018; Zamir et al., 2018) and one did not outline participants' socioeconomic status (Blackstock et al., 2015).

The review update had a mixture of consumer DHIs including an online support group for women with HIV (Blackstock et al., 2015), assisted living technologies for people with multimorbidity (Greenhalgh et al., 2015), multiple kinds of digital health interventions such as apps, wearables, social networking, video chats and patient portals (Guendelman et al., 2017), health apps covering a range of functions (Schueller et al., 2018) and Skype for older residents in a community hospital and a number of care homes (Zamir et al., 2018).

4.5.1.2 Engagement and enrolment strategies in the review update

A number of engagement strategies were employed in the studies in the review update. Similar to the systematic review both indirect and direct methods were used. The review update confirmed that online media such as commercial websites to advertise health apps was a popular way to reach some people (Schueller et al., 2018). However, unlike the review other indirect approaches such as multiple types of electronic media, print media and radio were not reported. Direct methods such as personal contact with health, care or other professionals, recommendations from family and friends and co-design events were also reported in the review update as being used to engage patients and the public in DHIs (see Table 22). However, two studies did not describe the engagement approach used (Blackstock et al., 2015; Guendelman et al., 2017). These mirror and build on the results of the systematic review as an additional type of professional, a support worker based in a care home, was reported in one study as helping older residents to engage with a DHI (Zamir et al., 2018). However, unlike the review other direct methods such as research or management staff within a healthcare facility and employers were not reported. As a result of the review update, the definition of engagement was refined slightly to emphasise ‘people’ more generally as opposed to ‘patients’ or the ‘public’, as this language may exclude some important groups of service users such as pregnant women or older adults residing in a care home.

> “*any process by which people became aware of or understand a DHI*”

Table 22: List of engagement approaches in the included studies in the review update

Engagement Approach	
Advertising **(Indirect)**	Online media – websites (Schueller et al., 2018)
Personal Contact **(Direct)**	Health, care or other professional (Greenhalgh et al., 2015; Zamir et al., 2018) Family, friends or peers (Zamir et al., 2018) Co-design activities (Greenhalgh et al., 2015)

A number of enrolment strategies were also employed in the studies in the review update. Similar to the systematic review online and personal assistance approaches were both used to sign people up to DHIs but automatic, paper and telephone or mobile phone based methods were absent. The review update added a new online strategy that of downloading software via a website to enrol in a DHI (Schueller et al., 2018). The approaches to personal assistance were comparable with those in the systematic review and enhanced slightly (see Table 23). An additional type of professional, a support worker based in a care home, was reported as helping older residents set up a Skype on Wheels device to ensure they could commumicate with their family (Zamir et al., 2018). However, two studies did not describe the enrolment plan (Blackstock et al., 2015; Guendelman et al., 2017).

Table 23: List of enrolment plans in the included studies in the review update

Enrolment Plan	
Online	Download software via a website (Schueller et al., 2018)
Personal Assistance	Health, care or other professional help to set up the technology (Greenhalgh et al., 2015; Zamir et al., 2018)

However, studies in the review update emphasised the importance of patients and the public acquiring a digital health product or service as part of the process before they began using the technology. For example, where commercial health apps are concerned Schueller et al. (2018) noted that people needed to pay for and download the software from a website before use. In addition, Greenhalgh et al. (2015) discussed how health professionals and technology providers undertook telehealth assessments to gauge if patients needed this technology and helped install the equipment in their homes prior to use. Zamir et al. (2018) also mentioned staff in a care home testing the safety of a Skype on Wheels device before they made it available to older residents to use. Therefore, the definition of enrolment was refined slightly based on findings from the review update to incorporate the concept of patients and the public acquiring a DHI in some way, an aspect that is necessary before it can be used.

> “any approach that involves people actively registering for, being signed up to or acquiring a DHI”

4.5.1.3 Issues affecting digital health engagement and enrolment in the review update

The analysis of the included studies in the review update revealed a number of barriers and facilitators, which build on and support the themes and subthemes identified in the original systematic review. As before, all four major themes of 'Personal agency and motivation', 'Personal life and values', 'Engagement and enrolment approach' and 'Quality of the DHI' emerged from the findings of the review update to some degree. In addition, under the 'Personal life and values' theme, two new subthemes: 1) Cost and funding, and 2) Health and wellbeing emerged, which were not present in the results of the systematic review. Another subtheme under the 'Quality of the DHI' theme, was refined with 'Usability' being renamed to 'Quality of DHI design'. The themes and subthemes identified in the review update are explained further below. Participant quotes are provided to support the barriers and facilitators to patient and public engagement and enrolment in DHIs and more are available in Appendix 17.

4.5.1.3.1 Personal agency and motivation

The 'Personal agency and motivation' theme was present in the findings of the review update. Some people wished to engage and enrol in technology as it was convenient for them because they could choose when to access digital health information (Blackstock et al., 2015). However, others had difficulty understanding a DHI, how it worked and would be of value to their health (Greenhalgh et al., 2015; Zamir et al., 2018). These barriers and facilitators build on and support the findings from the systematic review.

> *"It will help because you have more time to get on the computer. You can get on the computer anytime and it won't be just that 1 week, that 1 day a week, or whenever the [in-person] group is."* (Blackstock et al., 2015)
>
> *"You get, "Oh, you pull this, you pull that," and you get muddled…We get five minutes, perhaps. They're used to the piece of equipment,*

> *whatever you like to call it. And it is very difficult because, especially in my age group, we look such utter fools in asking for more help to understand what is going on and how it can help."* (Greenhalgh et al., 2015)

4.5.1.3.2 Personal life and values

The theme of 'Personal life and values' also emerged from the findings of the review update, as it seemed to affect patients and the public's ability to engage with and enrol in DHIs. The convenience that technology offered people was one reason they tended to engage with a digital health product or service, as information or interactions they needed were easily accessible to them (Blackstock et al., 2015). On the other hand, those with other priorities such as caring responsibilities or whose life did not involve virtual interactions tended not to engage or enrol in DHIs (Blackstock et al., 2015; Greenhalgh et al., 2015). In addition, while some people were digitally literate others were less so, which caused difficulties if they wished to enrol in a digital health product or service (Blackstock et al., 2015; Guendelman et al., 2017; Zamir et al., 2018). Getting access to computer equipment and Internet services was also reported as being problematic in some cases (Blackstock et al., 2015). Furthermore, some patients and members of the public liked the anonymity of virtual interactions, a reason they participated in DHIs. However, others worried about personal privacy and the security of digital health information they shared via technology, which seemed to reduce uptake to DHIs (Blackstock et al., 2015). All these subthemes confirm and strengthen the results of the systematic review.

> *"Oh I don't know how to use these complicated things…. I'd look silly using it …I wouldn't bother…I think it's a great idea so interesting but oh not me"* (Zamir et al., 2018)

> "*There's a positive aspect of being able to form an online group full of women that communicate with each other about issues pertaining to their health. I still would just be a little leery of discussing specific*

> *things on the Internet right now until I can get a sense of being able to trust them…being secure in the knowledge that what we were talking about wasn't going to go any further*" (Blackstock et al., 2015)

Two new subthemes emerged from the review update under 'Personal life and values' which were not present in the systematic review. Firstly, 'Cost and funding' appeared to affect some individuals when thinking about whether to enrol in a DHI or not. Schueller et al. (2018) was the only study to report that people took the price of commercial health apps into consideration when deciding whether to download them. Some individuals were happy to pay a certain amount if they felt the technology would be of benefit, while others refused to bear any cost. Secondly, 'Health and wellbeing' featured in a number of studies as illnesses or disabilities hindered some patients' ability to engage with or enrol in a DHI (Greenhalgh et al., 2015; Zamir et al., 2018). However, one study noted that a health issue was the reason some patients with HIV/AIDS signed up to an online support group, as it was an easier alternative to meeting people face-to-face when they were feeling unwell (Blackstock et al., 2015). These barriers and facilitators extend the findings of the systematic review.

> *"they gave the option to pay $50.00 a year. And I did that, because I liked the idea of what they were trying to do, kind of create a social community of people"* (Schueller et al., 2015)

> *"So, if they don't have the free trial and they want money, I'm not even gonna look at it. I'm not gonna pay for something before I've gotten the chance to see if it's gonna work for me or not; free always wins."* (Schueller et al., 2015)

4.5.1.3.3 Engagement and enrolment approach

The 'Engagement and enrolment approach' theme also emerged from the results of the review update. The recruitment strategies employed to make patients and the public aware of a DHI and get them signed up for one appeared to affect engagement and enrolment. Online advertising including reviews of a technology from other users was one technique that seemed to work well (Schueller et al, 2018), as did support from health, care or other professionals who spent time explaining digital health products or services, undertaking needs assessments or setting up a technology in a person's home (Greenhalgh et al., 2015; Zamir et al., 2018). In one case, care professionals acted as gatekeepers and decided whether or not older residents in a care home should know about a DHI or not (Zamir et al., 2018). Families also played a part in the process as Zamir et al. (2018) reported they sometimes did not engage in video calls with patients due to limitations on their time or technical issues with technology such as poor Wi-Fi connections. This turned some people off enrolling in a DHI. When individuals received recommendations from someone they trusted, such as a friend or colleague or a digital health product or service was endorsed by a healthcare provider this seemed to encourage engagement and enrolment (Schueller et al., 2018). These barriers and facilitators confirm and enhance the findings from the systematic review.

> *"However, much training you do and however good people are at delivering telecare, unless they take into account the person's situation and how they live in their home, it's going to be rubbish. I mean, ranging from not noticing they've got a dog, a large dog, which can muck up the bed sensor something rotten, or, for instance, that they use a wok to cook with, which is not very good if you've got a high temperature alarm in the kitchen…But it's really about talking to the person, spending time with them, not just once."* (Greenhalgh et al., 2015)
>
> *"I don't want to involve [residents] because of their cognitive impairment they won't be able to understand what's going on…I'm not sure how they will react so it's best to not"* (Zamir et al., 2018)

4.5.1.3.4 Quality of the DHI

The last theme in the original systematic review 'Quality of the DHI', encompassing both the quality of the digital health information and interaction, also appeared in the review update. As before, the quality of the digital health information available on a DHI appeared to affect engagement and enrolment. Blackstock et al. (2018) reported women with HIV/AIDS were willing to participate in an online support group so they could access useful information from others with the same condition. Some people valued the quality of the digital health interaction afforded by technology, as they could communicate with family who were far away or they felt more comfortable interacting with others virtually (Blackstock et al., 2015; Zamir et al., 2018). In contrast, certain individuals preferred face-to-face contact with family, friends, peers and healthcare providers over a DHI, as they believed this was a better way to maintain their health (Blackstock et al., 2015; Guendelman et al., 2017).

> *"I do get bored… I don't have anyone to talk to…I have family that visit once in a while…I'm here now…I'm not well and I feel alone…I have family I would like to see…Yes I think it's a great idea this."* (Zamir et al., 2018)

> *"I signed up to use a portal, but I never used it. I forgot about it...I just prefer calling and visiting the center. When it comes to my health, I'd rather come and talk to someone in person and same for my child."* (Guendelman et al., 2017)

The 'Usability' subtheme for the original systematic review was refined due to new findings that emerged from the review update. This subtheme seemed to play a more prominent role in engagement and enrolment, compared to the studies in the systematic review, as patients and the public wanted different aspects from a digital health product or service before taking part in it. Numerous features and functions of technology were mentioned in two studies including visual aspects of design such as the colour and images used, along with functions such as tracking patterns in health data and sharing this with other people or devices (Schueller et al., 2018; Zamir et al., 2018). Hence, the subtheme was renamed 'Quality of DHI design'. These new barriers and facilitators extend the findings from the systematic review.

> "*In general, participants wanted apps that were useful, easy to use, and aesthetically pleasing. Across participants, there were commonly reported desired features within apps including tracking, analytics (e.g. reports and insights based on tracked data), data sharing, and notifications.*" (Schueller et al., 2018)

> "*Staff suggested that the residents should 'dress up' the SoW device as it did not appear user friendly. It looks scary and not that user friendly… maybe it should be a bit colourful with some soft material on it….put some colourful stickers and colourful wrapping around the poles*" (Zamir et al., 2018)

4.5.1.4 Strenghts and limitations of the review update

The review update benefits from following similar systematic processes to the original review, such as using the same search terms and research databases, screening titles, abstract and full papers, undertaking quality assessment using the COREQ guidelines, as well as extracting and analysis data in the same way to enhance the quality of the findings. Although the review update adds new knowledge on patient and public engagement and enrolment to DHIs and confirms and strengthens some of the results of the original systematic review, it does have some limitations. Firstly, studies in other languages (non-English), those that were RCTs and grey literature were excluded in line with how the original review was conducted. Secondly, the 59,276 search results from the review update were not refined using the text mining techniques employed in the original systematic review due to time and financial restrictions. Although a number of strategies were used to try and identify relevant studies and five were found, it may mean other studies pertinent to the review question published since 2015 were missed. Thirdly, a PRISMA flow diagram was not provided to clearly show the screening process in the review update although it was described in Section 4.5. Fourthly, a second independent researcher did not screen, critically appraise, extract and analyse data and compare the results of each stage of the review update with the doctoral student, as happened in the systematic review. Finally, as before the analysis was based on published not primary data meaning, the populations in the included studies were relatively homogenous and based in only two developed countries, meaning some important contextual information could be missing. All these limitations may have reduced the quality of the findings of the review update.

4.6 Conclusion

To summarise, the issues that need to be addressed to promote the uptake of digital health based on the best evidence available to date have been concisely synthesised and highlighted in this chapter. It is clear from the findings of the systematic review and update that digital health engagement and enrolment is a complex process, with many interconnecting factors (both barriers and facilitators) that affect patients' and the publics' ability to engage with and sign up to a technology. Although the review and update incorporated a wide range of DHIs others such as virtual and augmented reality are emerging. Therefore, a further update of this systematic review in due course would be prudent to incorporate new technological developments, create a detailed taxonomy of engagement and enrolment strategies, and expand on the barriers and facilitators in the implementation process. However, it is likely that many of the same factors will emerge as the generative mechanisms of digital health engagement and enrolment have been teased out through this conceptual work. While the Digital Health Engagement Model (DIEGO) is preliminary, it is expanded upon further in Chapter 8 from the results of the review update and the dallas programme. Its components could help health professionals, health service managers, researchers, policy makers, industry and others think about the initial challenges of engaging patients and the public and how to implement digital health in the real world.

5 Factors Affecting Patient and Public Engagement and Enrolment in Digital Health

5.1 Introduction and aims

This chapter details the methods, results and discussion regarding the factors that affect patient and public engagement and enrolment in digital health. The overall aim of this phase of work is to describe the barriers and facilitators for patients and the public when they tried to engage with and sign up to DHIs being implemented as part of the Delivering Assisted Living Lifestyles at Scale (dallas) programme.

5.2 Overview of methods

As described in Chapter 3, both interviews and focus groups were conducted with a range of stakeholders participating in the dallas programme to understand engagement and enrolment in digital health. An outline of the specific data collected and analysed for presentation in this chapter can be found in Table 24. This is a mixture of both primary and secondary datasets, with the majority of qualitative data coming from those who were not patients or members of the public (n=69/98). These individuals gave their perspectives on what barriers and facilitators they perceived patients and the public experienced when engaging and enrolling in digital health products and services. Three patients with dementia, six carers of people with dementia and twenty health services users, a mixture of healthy women who were pregnant or had just had a baby, also contributed their opinions on what helped and hindered them when engaging or enrolling in a DHI. The framework approach illustrated in Chapter 3 was followed to analyse the qualitative dataset and draw out key themes and subthemes (see Appendix 3).

Table 24: Data collected to understand patient and public engagement and enrolment in digital health

Participant Group	No of Participants Interviewed	No of Participants in Focus Groups	Total
Patients Carers Service Users	2 (PD) 2 (PD) 0	4 (PD) 4 (PD) 16 (PD)	**6** **6** **16**
Health Professionals Health Service Managers and Administrators	0 17 (SD) & 3 (PD)	14 (PD) 3 (PD)	**14** **23**
Third Sector Volunteers	7 (SD) 5 (PD)	0 0	**7** **5**
Technology Sector Academics Government Sector	11 (SD) & 3 (PD) 2 (SD) 2 (PD)	2 (PD) 0 1 (PD)	**16** **2** **3**
Total	**37 (SD) & 17 (PD)**	**44 (PD)**	**98**
Legend: PD = primary data, SD = secondary data			

5.3 Results

A number of factors appeared to affect how patients and the public engaged with and registered for different DHIs deployed throughout the dallas programme. These are grouped into five overarching themes; 1) Personal perceptions and agency, 2) Personal lifestyle and values, 3) Digital accessibility, 4) Implementation strategy and 5) Quality of the DHI. Each of these have several subthemes described below.

5.3.1 Personal perceptions and agency

People's perceptions of DHIs and personal agency seemed to influence engagement and enrolment in digital health products and services in a number of ways. Several sub-themes emerged under this theme including; 1) Awareness of DHIs, 2) Understanding DHIs, and 3) Personal agency (choice and control).

5.3.1.1 Awareness of DHIs

Some people felt there was a lack of awareness of different digital products and services that could be used to manage and improve health. This low level of cognisance may have negatively affected engagement and enrolment. However, in one large English city where telehealth, assisted living devices and other digital tools were being deployed, it was felt the activities of the dallas programme helped heighten public awareness of DHIs.

> *"The availability, the cost, the lack of profile at the moment is just maybe hindering it, so you say tele-care, tele-health to 99.9% of the population and they'll go what?"* (Midpoint Interview, Third Sector, Participant 27, December 2013)

> *"I've seen how hard it's been to raise the awareness of the technology in [x city] and I think we are probably light years ahead now as a result of many other cities and areas across the country, so there is still going to be massive knowledge gaps across other areas of the country."* (Endpoint Interview, Third Sector, Participant 46, June 2015)

Various promotional activities were run as part of the dallas programme in an attempt to improve the visibility of DHIs in the public domain and ensure they reached a wide audience. For instance, one dallas community ran a series of engagement events in local communities across several regions. Another used mass marketing techniques such as printed flyers and advertising in newspapers to raise the profile of their digital products and services among a broad range of people. These activities may have facilitated engagement and enrolment to some extent. To illustrate this a few women using a digital child heath record reported getting printed promotional material about the technology from their midwife or Health Visitor, which is how they found out about the digital application. However, it is difficult to gauge exactly how effective these approaches were and their impact on people's awareness of technology.

> *"We did a selection of different engagement tools I guess, one they were the training in each area, so we did one in community pop up where we popped up in various different community locations, hospitals, shopping centres, wherever was appropriate really in the community"* (Baseline Interview, Third Sector, Participant 6, November 2012)

> *"And there's the newsletter which will go out to all carers so in terms of the newsletter, that gives people information about what's going on in the local area for carers but it'll also give them information about all the tele-care and tele-health stuff as well."* (Midpoint Interview, Dallas Community Programme Manager - health service, Participant 31, December 2013)

5.3.1.2 Understanding DHIs

When people became conscious of a DHI, there was still the issue of understanding how it worked and whether it could be used to manage and improve personal health. The results of the dallas programme indicate that certain people such as older adults who had not grown up with technology, did not appreciate what it could do for their health and were confused about its potential risks and benefits. In addition, some people thought those from more disadvantaged backgrounds believed DHIs were not a realistic proposition but something that would only be feasible in the distant future. This lack of knowledge about DHIs may have prevented some from engaging and enrolling in them.

> *"I think there is barriers particularly for older people with technology ..... and I think people don't know what it is and then if you don't understand the value"* (Midpoint Interview, Third Sector, Participant 27, December 2013)

> *"[x staff] came along from the [x] museum and presented the app to us and what you ya think about it and we were all round the table and stuff. And to be honest with ya I thought what the hell is this gonna do to help people with dementia, you know"* (Standalone Interview, Carer, Participant 64, September 2015)

> *"For some people, it's a revelation and there are lots of technically or digitally disadvantaged people in the city and I think for them the idea of technology in the home is something very futuristic"* (Midpoint Interview, Third Sector, Participant 28, December 2013)

These barriers were noted early in the dallas programme and a range of engagement strategies employed to address people's limited understanding of DHIs. One novel initiative used was the establishment of a physical and virtual smarthouse. This was an interactive show home that was built and put on display at a national museum to maximise visibility among the public. A virtual version was also made available online for those who did not live close to the museum or would have limited opportunity to visit. The smarthouse showcased a range of different technologies in the simulated home environment to help the public understand how digital health products and services could be used on a day-to-day basis to manage their health needs. For example, a sensor in the smarthouse could measure the room temperature and adjust the heating automatically to a comfortable level. Another dallas initiative involved partnering with a carers charity to develop online training material that was used to increase the knowledge and understanding of informal carers about DHIs. Unfortunately, it is not clear to what extent these engagement approaches, along with others that were used, worked to improve people's comprehension of technology and their interest in signing up for it.

> *"we are developing a virtual smart house as well. So this is an online tool where you can actually sort of go round virtual rooms and see the same equipment in situ and click on it and watch a, you know, watch a video of someone using it, a case study of someone where they've found it useful or just additional information on where it's available."* (Baseline Interview, Dallas Community Programme Manager - health service, Participant 3, Oct 2012)

> *"we've been partnering [x carers charity] and developing an eLearning asset that informal carers can use to get support and signposting to resources."* (Midpoint Interview, Industry Sector, Participant 39, October 2014)

5.3.1.3 Personal agency (choice and control)

Some service users and health professionals felt people preferred the freedom to choose the type of health service interaction or information that suited their lifestyle and personal preferences. In certain cases, this meant picking a more traditional style of healthcare and going to see their doctor or nurse face-to-face rather than engaging with digital health products and services. Therefore, some individuals may not have signed up for a DHI being offered as part of the dallas programme for this reason.

> *"it's a very personal thing as to whether you prefer to do it electronically or whether you think, I have to go and see a professional"* (Focus Group, Health Service User, Participant 67, April 2015)

> *“Well if you force it down that way, and if you say this is the only way we’re going to do this anymore, how does that make people feel, that makes me feel anxious for my elderly ladies, of people who are going to have to immediately make that change. It feels like you’re forcing something onto people, and actually, in a health service, it needs to be about what people feel they can manage, what they can cope with.”* (Focus Group, Health Professional, Participant 74, April 2015)

In a few cases, the exact rationale for deciding not to enrol was not given but being fit and healthy was suggested as one reason people did not consider self-management or self-monitoring via technology to be necessary for their health needs.

> *“It’s a bit more difficult to frame the offer for those people who haven’t got any needs, for those people who may be fit, may be healthy younger people and I think that’s the lesson for, more generally for how we try to describe [DHI] and what it can do for the general population.”* (Midpoint Interview, Dallas Community Programme Manager - health service, Participant 31, December 2013)

On the other hand, some people preferred the convenience that DHIs offered as they could access health information or services online when and where it suited them. This appeared to be important for individuals who lived in more remote and rural areas where access to traditional health services was limited and often involved travelling long distances to see a clinician. The amount of choice and control that DHIs offered seemed to encourage some people to engage and enrol in them, particularly those who had difficulties accessing standard healthcare services.

> *“It's also quite useful and up here we’ve also got quite a lot of partners because a lot of the guys are in the oil industry and we’ve got a lot of military as well. So, if they are not able to come to antenatal classes they can access at any time you know when they come back they can have*

> *a look at it [x technology - video package of maternity services].”* (Focus Group, Health Service User, Participant 93, April 2015)

> *“But it will be really useful in the more rural areas when you live in [x region] for example where you know distance is a, can be very challenging at sometimes particularly with the weather so whereas if you have got you know maybe a mum in for example it would be probably more time efficient to send her the link.”* (Focus Group, Health Professional, Participant 99, April 2015)

5.3.2 Personal lifestyle and values

People’s personal lifestyle and values were also thought to influence their ability to engage and enrol in digital health products and services. Two sub-themes emerged under this concept; 1) Personal lifestyle, and 2) Privacy and trust.

5.3.2.1 Personal lifestyle

A barrier that seemed to affect people’s ability to engage with and enrol in DHIs in the dallas programme was a busy personal life. Some individuals felt those with demanding jobs and a lot of caring responsibilities had little time or interest in signing up for a digital health product or service. They tended to prioritise other activities or needs above their own health. A further observation was that those from lower socio-economic groups, who had to grapple with complex social problems such as unemployment, may also have had little time or interest in DHIs due to competing priorities.

> *“they come to see me in the clinic for instance and I can say everything that’s on the videos but the minute they have walked out the door it's gone out their head you know it's just part and parcel of being pregnant and of having a busy life.”* (Focus Group, Health Professional, Participant 95, April 2015)

> *"as I mentioned, sort of deprived areas and areas of health inequalities where people don't necessarily care about their own health, you know they've got more important matters like kids, trying to pay the mortgage or the rent, a whole range of issues that you know can cause a great deal of stress and things so health isn't necessarily their top priority"* (Endpoint Interview, Third sector, Participant 46, June 2015)

However, people who felt technology would fit easily with their personal lifestyle and help them to manage some aspect of their health in a faster or more effective way tended to enrol. For instance, some pregnant women used an online video library to help them prepare for labour and birth. They could access the application easily on their smartphone and some of the videos were tailor-made to their local maternity service. In another case, a mobile app that was co-designed by people with dementia and their carers was taken up because it could improve their ability to communicate.

> *"when I've showed them the [DHI], everyone is really positive, they like it, they like the fact that it can be personalised, they like the photographs, they like the information that can be stored on it"* (Focus Group, Health Service Professional, Participant 74, April 2015)

> "*because sometimes people can't get the words out properly and it's difficult for them but if they can point to something on the app and so it's helped their communication and it's just making so much, so much easier for them*" (Focus Group, Health Service User, Participant 103, March 2015)

5.3.2.2 Privacy and trust

A number of people felt patients and others were concerned about the privacy and security of data on DHIs. This may have reduced their participation in the digital health products and services offered during the dallas programme. Some worried that sensitive health information could be accidentally or deliberately disclosed to others, which could be a reason for patients and the public not enrolling in certain technologies.

> *"I think mostly around data protection, because don't forget the whole of [x technology] is built around a bigger thought around personal health records and clearly that's a very sensitive area and, you know, people need convincing that they are secure, that a patient is able to maintain and look after their own records without them sort of getting into the public domain."* (Baseline Interview, Industry Sector, Participant 12, November 2012)

People also reported being cautious about their health information as they felt it could easily be shared without their knowledge through a DHI. In addition, trust in some large technology companies was low because individuals believed they did not always inform the public about changes to their data security settings.

> *"I think [x platform] I'm always a bit wary because I know they have a habit of tweaking their privacy settings on a regular basis and you only ever find out later on … To me, [x platform] just sounds it's out there for everybody to see and you've just got to be careful what you put on, you know."* (Focus Group, Health Service User, Participant 80, April 2015)

Furthermore, there were reports that technology which monitored people at home could be seen as intrusive. This lack of trust may have prevented some people enrolling in digital health products and services being deployed as part of the dallas programme.

> *"it's not just you know, particularly with the telecare and telehealth you know the sort of devices that come with a system or a support or a call centre behind them are you know it's quite daunting for people and it feels a little bit big brother"* (Midpoint Interview, Third Sector, Participant 28, December 2013)

However, others using DHIs were not overly concerned about the privacy of health information. For example, some individuals using a personal health record were happy for their child's data to be shared among health professionals. They acknowledged that a wide range of people in the health service need access to clinical data in an efficient way which technology provides.

> *"It's their Date of Birth and NHS number and things like that, but I suppose I'm quite trusting that my data is safe, so until you know what actually is the worst thing that could happen if someone got hold of it maliciously, then I suppose you trust it until you hear a story like that."* (Focus Group, Health Service User, Participant 68, April 2015)

> "*I don't know if I'm just more trusting, but I personally wouldn't mind any medical professional having access to data about my child, because to me it's his medical information and I would rather whoever I am asking would have that data, be it my GP or a Health Visitor*" (Focus Group, Health Service User, Participant 71, April 2015)

5.3.3 Digital accessibility

The accessibility of technology required to engage and enrol in a DHI and the availability of a DHI itself appeared to influence people's ability to register for one. A number of concepts emerged under this theme including; 1) Cost and funding, 2) Access to equipment, 3) Digital infrastructure, 4) Digital knowledge and skills and 5) Language.

5.3.3.1 Cost and funding

A barrier that some people came up against when they wished to engage or enrol in some of the dallas technologies was the cost of DHIs. Paying for hardware such as smartphones and a network connection to get online was not always feasible. Some thought that DHIs were too expensive for those from lower socioeconomic groups who lived in deprived areas. While many of the DHIs were free as part of the dallas programme, the long-term plan was that people would partially or fully pay for some of the technologies they had registered for. Certain individuals refused to pay for DHIs as they felt the technology should be provided for free under the NHS.

> *"I wouldn't pay, I don't buy any Apps. I only get free ones, and I suppose you'd get a lot of argument with people saying, this is the NHS, we shouldn't pay for our healthcare."* (Focus Group, Health Service User, Participant 72, April 2015)

> *"you know, a lot of people, we imagine that lots of people out there with iPhones but, you know, some of the population can't afford them and don't dare to have them because they get nicked all the time"* (Baseline Interview, Health Professional, Participant 7, November 2012)

On the other hand, others could afford technology and thought in some cases a DHI was a cheaper alternative that current models of healthcare. In addition, they felt it provided numerous benefits so they were happy to pay for a digital health product or service, demonstrating that the ability to afford technology is a factor that can influence a person's choice to engage and enrol in a DHI.

> *"But I think also there is a small group of people, like, to be honest with you, because it's my first baby, I'm quite excited, if there was an app for 69p I'd probably buy it because I paid more the Baby Centre and God knows what else."* (Focus Group, Health Service User, Participant 85, April 2015)

Monetary incentives were offered by some of the implementation teams during the dallas programme to encourage patients and members of the public to register for a technology. Supporting people with certain financial aspects of purchasing a DHI could have enabled some individuals to sign up to it.

> *"they might offer six months' free remote support. So, if you wanted to try buying your mother-in-law a remote alarm and so on, they would therefore support it for free for a while, yes, that type of thing"* (Baseline Interview, Health Service Manager, Participant 3, October 2012)

5.3.3.2 Access to equipment

There was also an issue with patients and the public getting access to some technologies they needed to engage and enrol in DHIs if they did not have them. Gaining access to a computer or mobile device was essential to sign up to some digital health products and services offered during the dallas programme. Some felt individuals living in more deprived areas had limited access to technology in their locality as resources in community centres and libraries were being cut back. This may have made it challenging for them to engage with or enrol in a DHI.

> *"and you're always going to get people anyway who haven't got access to the Internet, you know, it's all right for the government to say that nearly every household's got a PC and they want every household to have a PC, but actually the reality is that a lot of them don't"* (Baseline Interview, Health Professional, Participant 7, November 2012)

> *"they can use maybe libraries but the libraries also are reducing back, or UK online centres which again sometimes it's their opening hours and things like that. That's the main barrier, the access the access to them."* (Digital Champion Interview, Government Sector, Participant 60, March 2015)

In response to the difficulties people were having getting access to technology, one dallas community chose to invest in digital accessibility programmes. They set up digital hubs in one city in the United Kingdom. This involved replacing old computer equipment in local libraries and community centres with modern technology or setting up brand new digital facilities in places where people already visited such as sports and health centres. Improving access to technology via these methods may have helped some people engage and enrol in DHIs.

> *"So what we're doing is putting digital access in places where people go, not putting digital services and expect people to come to them. So that could be medical centres, it could be community centres, it could be local organisations and agencies like housing associations that we're dealing with that we can open up their internet access and we can put equipment in place, so whether it's PCs or laptops and route systems, Wi-Fi and broadcasters to make the internet available. So we've already got, I think we've got 50 of those set up, about 50 hubs set up and we're looking, I think we've already got another ten that we're going to be funding because we've just got so many of them. I can see us funding even more than that via the NHS because the NHS have now looked at putting digital hubs in all of their new neighbourhood health centres."* (Midpoint Interview, Dallas Community Programme Manager (health service), Participant 26, December 2013)

5.3.3.3 Digital infrastructure

Another difficulty that some people experienced was getting access to high-speed broadband or Internet coverage due to a lack of telecommunications infrastructure. Poor network connectivity seemed to prevent them from engaging with and enrolling in DHIs.

> *"I don't even have 3G, I have no signal on my phone where we are, it's terrible."* (Focus Group, Health Service User, Participant 83, April 2015)

> *"I think there's probably a wee bit of, not scepticism, probably more concern as to that all sounds great, but do we have the infrastructure here to be able to allow us to do those things, if people are keen and they want to be able to access things, there's something in say [x town]*

> *or wherever, is having a problem, having an unreliable Internet connection. There's been a concern there, they want to see that being supported"* (Midpoint Interview, Health Professional, Participant 34, December 2013)

However, during the dallas programme investments were being made by national governments and local authorities to upgrade infrastructure and provide better Internet services in rural areas, which could facilitate engagement and enrolment in DHIs in the future.

> *"I think there are other challenges which we're taking care to do with the telecommunications infrastructure, you know, that's required for this bid. [Government agency] are investing £150 million in upgrading those challenging parts of the infrastructure to bring greater backup capacity to all the islands, and to bring high-speed broadband"* (Midpoint Interview, Government Sector, Participant 36, December 2013)

5.3.3.4 Digital knowledge and skills

The final barrier that affected people's ability to participate in DHIs was having poor technical knowledge or skills. This was noticeable among older generations who did not grow up with technology, as some did not have good digital literacy skills. They were not able to use a computer or navigate an online environment, which could have prevented some older adults from accessing DHIs.

> *"I think it was convincing ourselves that we could use technology, I'd used a computer and that before but some people's never used a computer."* (Standalone Interview, Carer, Participant 64, Sept 2015)

> *"But you've still got generations of people who that is not suitable for, because that's not how they've been brought up. So, at the moment we're in that transition of having people that actually don't have the skills and don't have the mind set of the way things work, and people*

> *who socially don't have that option at the moment."* (Focus Group, Health Professional, Participant 89, April 2015)

However, younger populations were perceived to be more digitally literate and thought of as having less difficulty engaging with and enrolling in DHIs, as they had the knowledge and skills to use technology. Furthermore, some older adults were reported as being more adept with computer systems and mobile devices than others and were able to use their technical skills to sign up to a digital health product or service. These insights demonstrate digital literacy can be an aspect that facilitates engagement and enrolment in DHIs.

> *"you are dealing with people who have just had a baby who generally speaking generationally will be young enough to be digitally adept and not be a big issue not fighting illness to try and get to learn how to use a digital system"* (Endpoint Interview, Industry Sector, Participant 49, June 2015)

> *"it's made me learn is that sometimes we underestimate our old people, and we sometimes think that they are not as technologically savvy as they sometimes are, and through some of the workshops that've been happening, I certainly know that people have been coming along with their own tablets, all different kinds of tablets, and looking for advice from X [person name] about how they can utilise them and get the best out of them"* (Midpoint Interview, Government Agency, Participant 37, December 2013)

Training opportunities were made available during the dallas programme to facilitate patients and the public to engage with and enrol in DHIs. Along with digital hubs that were established, digital and community champion programmes were also set up to teach people how to use computers and the Internet. These initiatives appeared to help individuals to learn the fundamental aspects of technology and how to navigate online environments, which they could then utilise to register for a digital health product or service.

> *“that’s where the digital champions and the community engagement side of it come in. So around each hub we train up digital champions in those organisations where they will be there. So it’s not good enough to just expect people that need to access these things to come and sit down and they just know what to do. These are not advanced IT practitioners. These are people who can just help you get online and do the minimum that you need to do.”* (Midpoint Interview, Dallas Community Programme Manager - health service, Participant 26, December 2013)

> *“As a digital champion I work with a number of groups, usually on basic ICT, very basic ICT…so doing that very basic this is a mouse, this is a keyboard, this is how you get online, this is how you get an email address so that’s really the stuff that we were doing.”* (Digital Champion Interview, Government Sector, Participant 60, March 2015)

5.3.3.5 Language

Some people had problems with the English language as they were not fluent speakers. All of the DHIs developed and deployed as part of the dallas programme were designed in English. This seemed to cause difficulty for patients and members of the public who did not have a strong grasp of the language. It meant they may have been excluded from engaging with digital health product and services and registering for them.

> *“one of the other big challenges is our non-English speaking families. We have big pockets of that across the city, one of the children’s centres in the [x] area I think 83% is non-English speaking so the [x DHI] is potentially a challenge for them because it’s all in English”* (Midpoint Interview, Health Service Manager, Participant 24, December 2013)

> *“we have quite a lot of cultures, different cultures in this city and so you can be saying like I taught a couple of people last year and whilst this guy was only born in [x town] he was actually of an Arab family, so English*

> *was his second language even though he was born in country. And so he didn't speak English very well but also he didn't understand the meaning of some words....So there's the language barrier"* (Digital Champions Interview, Third Sector, Participant 55, March 2015)

5.3.4 Implementation strategy

The type of engagement and enrolment strategies that were used in the dallas programme seemed to influence some people to sign up for the digital health products and services on offer. Two sub-themes emerged under this concept; 1) Engagement approach and 2) Enrolment plan.

5.3.4.1 Engagement approach

Four approaches to raising people's awareness and understanding of DHIs were used during the dallas programme. These were 1) Branding, 2) Advertising, 3) Personal and clinical contact, and 4) Personal involvement in a DHI.

5.3.4.1.1 Branding

All of the digital health products and services in the dallas programme were branded in some way through the use of recognisable names for the DHIs, logos and other associated visuals. These were used to help market the technologies to patients and the public. However, one DHI in particular was given a name that was already in use by a private company. Hence, this technology had to be rebranded which may have caused confusion amongst consumers and reduced their level of engagement with it.

> *"We've also had a curve-ball in relation to the [x DHI] name in that we were going to secure the brand but it's already been secured by a, I think it's a multinational gym tech company so we can't use the [x DHI] brand. So we're going to have to go through a process of rebranding, something quick and dirty so there has been distractions"* (Baseline Interview, Health Service Manager, Participant 4, October 2012)

5.3.4.1.2 Advertising

A range of advertising methods were used to enhance people’s awareness and understanding of DHIs. Traditional media outlets such as newspapers and radios, along with online media such as websites were used during the dallas programme to reach a wide audience. In one case, a digital health product was promoted in a specialised retail outlet that stocked equipment for people with mobility problems. In another, a technology show home called a ‘smarthouse’ was set up in a national museum to showcase how DHIs could be used in everyday life. These approaches may have facilitated engagement and enrolment if they helped patients and the public become more aware of a DHI.

> *“The smart shelf is an actual shelf that’s [x DHI] grounded and it looks beautiful. And it’s got this sort of, it’s like a shelf, it’s like a cabinet with two orange metal ribbons that come out and attached to the ribbons you’ve got different products with explanations and you can look and feel. What it gives us an ability to do is have a presence in retail establishments that are already out there”* (Midpoint Interview, Health Service Manager, Participant 29, December 2013)

In one case advertising became problematic as it interfered with plans to have a personal electronic child health record endorsed and promoted by a medical association. It was felt this could help reach a large number of patients and encourage enrolment. However, the medical regulator would not allow any professional association to support a commercial product or service with private advertising and so clinical endorsement had to be abandoned. This may have reduced engagement and enrolment in the digital health application.

> *“And, we had sponsors lined up, sponsors who the health service works with all the time … and the Royal College just and thereby sidekicks, they can’t afford to piss off the regulator …. They wouldn’t be able to use their own brand in it that it would have to be two clicks away to any kind of retail, all that kind of thing, they all went for all that, all that*

> *works. But, we can't do it, and it's immensely frustrating, because we could deal with 600,000 users through that"* (Midpoint Interview, Industry Sector, Participant 27, June 2014)

5.3.4.1.3 Personal and clinical contact

People's awareness and understanding of digital health products and services seemed to be mediated by personal contact with family, friends and peers during the dallas programme. Patients and members of the public who had close relationships with individuals that enjoyed using technology were reported to be more likely to engage with a DHI, as these people helped them become aware of it and understand its value. For example, patients with dementia who used a mobile app to improve their memory and ability to communicate recommended it to others with the same illness and their carers which could have increased uptake.

> *"It's been incredibly valuable to have people living with dementia involved and using it independently with older people who are caring for them and seeing them benefit from it has been absolutely brilliant and really that has helped to have it endorsed and give it life as people have took it on board."* (Standalone Interview, Government Agency, Participant 68, September 2015)

> *"the best part of it for me was my son is very techy and he loved it and really got into it and he can show me round it and then my husband has got into the techy stuff as well now"* (Focus Group, Patient, Participant 107, March 2015)

This also appeared to be the case with health professionals. If a patient's doctor or nurse recommended a particular DHI, it was felt this facilitated engagement as there was a degree of trust in the relationship and some patients valued the opinion of their clinician.

> *“we found is that trusted referrals, referrals in a softer way but trusted signposting and people saying [x DHI] will be good for you has been quite a successful mechanism for it so if the physio tells you this is a good thing you are much more likely to go than if you just see an advert in the paper has been our experience to date.”* (Standalone Interview, Health Service Manager, Participant 57, June 2015)

5.4.3.1.4 Personal involvement in a DHI

In a few cases, a co-design approach was used during the dallas programme. This meant having patients, the public or health professionals involved in creating the look and functionality of some DHIs. This strategy may have helped get people engaged and understand what a digital health product or service was about, which could have improved enrolment.

> *“I guess the way we're designing it is that it's very positive, and it's focusing on the opportunities that are there and what we're aiming to achieve., and people can see that designing around their lifestyles and around their needs, and people-centred services are… and that they can get involved with and be part of the design, so designing with them, rather than for them. I think there's a huge appetite for that, and people are very, very interested and very keen to get involved”* (Midpoint Interview, Academia Sector, Participant 20, October 2013

5.3.4.2 Enrolment plan

The ways in which people enrolled in DHIs during the dallas programme broadly fell into three categories; 1) Tailored support, 2) Incentives, and 3) Self-enrolment.

5.3.4.2.1 Tailored support

Tailored support provided to patients and the public seemed to encourage uptake of the digital health products or services in the dallas programme. This took numerous forms. For example, free digital hubs were set up in one city to give people in local communities' access to computer equipment and Internet services needed to engage with and sign up to DHIs. A lay champions programme, used to teach people digital literacy skills required to access some DHIs, was also expanded upon. These types of tailored support mechanisms may have helped some individuals sign up for a technology.

> *"if we want to get tele-health and tele-care rolling at scale we need to make sure that individuals and communities are digitally connected and they haven't only got to have the hardware, the software and the skills to be digitally included, they've got to have an interest in being digitally included. So we are creating a number of digital hubs across the city and wrapped around those digital – those digital hubs are either fixed in one place, they are – that's with desktop computers – they are mobile, so laptops out and about, identifying particular community resources; maybe supermarkets, church halls. And then we've got pop-up digital inclusion hubs which are tablet-based hubs where people pop up and surprise the local community"* (Midpoint Interview, Health Service Manager, Participant 31, December 2013)

In a few cases, clinicians actively recruited patients to certain technologies and helped get them set up on the electronic system. For example, Health Visitors were used to reach parents with newborn infants to promote a personal child health record and enrol them on it. This type of direct, one-to-one support from a trusted healthcare professional seemed to facilitate enrolment.

> *"I was first introduced to it by the Health Visitor, and she actually, it wasn't just in the pack, it was in kind of like a poly-packet, and she explained to me, this is the [x DHI], and if you want to register then this is how you do it."* (Focus group, Health Service User, Participant 88, April 2015)

5.3.4.2.2 Incentives

Incentives such as free technical support for a trial period were offered with some of the DHIs during the dallas programme to encourage patients and members of the public to register for a technology. Supporting people with certain financial and technical aspects of purchasing and using a DHI could have reassured some individuals and encouraged sign up.

> *"they might offer six months' free remote support. So, if you wanted to try buying your mother-in-law a remote alarm and so on, they would therefore support it for free for a while, yes, that type of thing"* (Baseline Interview, Health Service Manager, Participant 3, October 2012)

5.3.4.2.3 Self-enrolment

During the dallas programme, there were some cases where people were able to register for a DHI themselves by creating a user account or profile. For instance, an electronic child health record was one digital product that potential users could access online and sign up for. The self-enrolment process involved following instructions on the DHIs website to set up an account using an email address and some personal information.

> *"the main reason I logged on was the sticker on the front of [X child's named paper health record] that we were given when he was born"* (Focus Group, Health Service User, Participant 77, April 2015)

However, this enrolment strategy proved problematic in a few cases as registering for a DHI was not always an easy process to follow. For example, information about how to sign up for a video package explaining local maternity services was sent via a personalised email but this sometimes got lost in the milieu of other electronic messages people received. This may have made it difficult for some to sign up to digital health products or services.

> *"I think it needs to be an app, it's a long protracted way of getting the email because sometimes the NHS.net or the [X DHI] goes into the spam so you as a service user have to be a bit more persistent in order to find the information and lots of people are too busy"* (Focus Group, Health Service User, Participant 104, April 2015)

5.3.5 Quality of the DHI

How people perceived the quality of the digital health product or service being offered as part of the dallas programme appeared to affect their decision to engage and enrol in it. Three sub-themes emerged under this concept; 1) Quality of DHI design, 2) Quality of digital health information or interaction, and 3) Integration with healthcare.

5.3.5.1 Quality of DHI design

A barrier that hindered some people when registering for a DHI were difficulties they experienced setting up accounts and logging in online. For example, one of the technologies had complicated enrolment procedures that required registration data across multiple screens. The way this digital interface was designed took time for people to become familiar with, which could have caused some individuals to disengage from the sign up process.

> *"I also find it very confusing having to set up the [x DHI] account, just the process of going through the log in pages. Yes, I wanted to do it, and I was okay with it being a partner, but just the process of clicking on the links was quite confusing, so I eventually got to the point where I knew what I was doing, and once I'd logged in four or five times I was like okay, I get it now."* (Focus Group, Health Service User, Participation 85, April 2015)

> *"Yes we were given the iPads just to take out to show some mums and get mums, kind of, to use it. And we, sort of, went through some of the*

> *teething problems initially of trying to work out what mums need…the input just put on each screen in order to log on and set up the accounts and those things. And realising how long it took sometimes just to register in the first place."* (Focus Group, Health Professional, Participant 76, April 2015)

Another issue that cropped up was having to remember passwords, as some people struggled to recall them which made setting up accounts on certain DHIs troublesome.

> *"The problem I've found, when we have got the [x DHI] at Health Clinic, is that parents come in with their physical [x named health record] and when they try to remember the password, they can't remember the password, so you can't access it. That's one of the issues for them to remember."* (Focus Group, Health Professional, Participant 78, April 2015)

The quality of design of the digital health products and services also depended on the how the applications worked on different devices. Some mobile platforms were easier to access, view and use software on than others. For example, a health record application accessed via a smartphone was difficult to view and use as it had not been adapted for a smaller screen size. This may have turned people off registering for some of the technologies available in the dallas programme.

> *"if you had all the information but just with a single button click rather than having to go onto a website, especially when you're using the Mobile phone. You've got limited screen size. You want something that's, sort of, more streamlined for, you know, small working."* (Focus Group, Health Service User, Participant 82, April 2015)

On the other hand, a DHI that was easy to use tended to facilitate engagement and enrolment. A helpful design feature was a simplified login process or one that had been integrated with other electronic applications. This meant people could use a single username and password to access their data on several systems, which may have made it easier to register for a digital health product or service.

> *"I actually found it easier, because I've got a Hotmail account, so it's the same e-mail address and password, so I knew I couldn't forget it, whereas I think I think I would have been less likely to log on, because I think I would have, for whatever password I set up, if it wasn't already through an existing portal that I used, so actually I found that quite useful."* (Focus Group, Health Service User, Participant 82, April 2015)

Another helpful aspect of design was some of the technologies required minimal input and interaction from users. For example, it was reported people were happy to sign up for assisted living devices and have them installed in their homes if the system was fully automated. Very little time had to be spent learning how to use these DHIs and they also required minimal interaction. This simplicity may have appealed to some patients or members of the public which could have encouraged engagement and enrolment.

> *"I think they love the reassurance, the peace of mind, the simplicity, the fact that the user doesn't have to do anything at all, they don't even have to interact or press any buttons. For example, one of the sensors is a temperature sensor, so what they wanted initially was that that would give an in-house message, and then the person in the house has the option to then turn the heating up, or to do something about it, if it's getting very cold, before a message would be sent out to the neighbourhood. Unless they want to cancel any particular messages, because they're doing something about it, then they just go about their normal activity with their living, and don't have to worry about, you know, pressing buttons, or remembering to do anything. The whole system has been automated."* (Baseline Interview, Academic Sector, Participant 15, January 2013)

How a DHI was created could also have affected its design and peoples' interest in registering for it. Co-design was utilised by some of the dallas communities to create digital applications that suited the specific needs of patients or members of the public. For example, some patients' illness required specific design features and functionality to enable them to enrol in and use a digital tool. A mobile app was co-created by people with dementia and their carers using specific digital objects, large icons and a simple interface. By involving people in the software design and development process, the finished digital product was potentially more usable and tailored to patients' needs which seemed to facilitate both engagement and enrolment.

> *"As I said they'd come and then they'd say right try this and we'd say yeah that works but that doesn't work but rather than just say it doesn't work we'd say why it didn't work. You know because it's more important to, if you know if you've got a problem give someone the solution. The only people that can give them the solution is the people that can't use it in the first place. So, say what the problem is for because they didn't think because they are so good on technology. They just assume everyone would be able to go like that [made a swiping motion with his hand] so you've got to be able to take it back from a person that doesn't really understand to press a button but that you need someone to make you know when it moves to press a button. That was one of the biggest things that we got was how to make it dementia friendly rather than user friendly."* (Standalone Interview, Health Service User, Participant 63, September 2015)

5.3.5.2 Quality of digital health information or interaction

Reports from those implementing various technologies during the dallas programme were that some people saw little value in enrolling in a DHI if a health professional had little or no interaction with it. This seemed to be due to the fact that individuals perceived that the quality of the information or interaction would be limited without the involvement of a clinician.

> *"the problem you have about consumers you have with doing that is the motivation – why would I track all this data about myself if my clinician won't engage with it? So that's kind of the big takeaway the big finding if you like….."* (Standalone Interview, Industry Sector, Participant 54, June 2015)

> *"they are not getting feedback on it you know a clinician or somebody who is saying well done you know the last six months you've kept within all your readings ….. You know that's the kind of the thing people need to hear if they are going to have the motivation to keep these."* (Endpoint Interview, Industry Sector, Participant 49, June 2015)

Where digital health products and services had been designed with input from clinicians, people felt they could rely on the accuracy of the electronic information or virtual interaction as it would be good quality. For example, a repository of online videos were created by a team of health professionals to educate the public about services that were available locally. This helped pregnant mothers familiarise themselves with maternity services and prepare for labour. This indicates that high quality information that is endorsed by health professionals and provided by DHIs can give consumers confidence and facilitate engagement and enrolment.

> *"You know it's relevant, you know its coming from people who are actually you are going to see, they are looking after you in your care districts. Kind of makes you a bit more reassured."* (Focus Group, Health Service User, Participant 93, April 2015)

> *"It adds to the reassurance I think that the information you are getting is, it's not Google it's not any old nonsense it's people that you trust. It's*

> *relevant it's in your area as well."* (Focus Group, Health Professional, Participant 95, April 2015)

5.3.5.3 Integration with healthcare

A final consideration for patients or members of the public signing up for a digital health product or service was how well integrated it was with their healthcare provider. When DHIs were well-integrated people seemed more willing to sign up to the technology. This appeared to be because both individuals and clinicians could access relevant health information in a timely manner which seemed to improve the efficiency of the service provided.

> *"I thought it was quite good because obviously the midwife then didn't have to talk me through everything in the midwife appointment, sometimes I had to take half an hour out of my working day to go to my appointment so she couldn't always discuss everything she wanted to so she could say ah well I've got video clips on this I'll send you the link so I can then go and watch it once I've finished work at home, so that was quite good."* (Focus Group, Health Service User, Participant 93, April 2015)

The opportunity to personalise health information or interaction via technology also appealed to some people and may have encouraged enrolment. The ability to access, monitor and tailor personal health data on a regular basis was only possible through the use of technology that was integrated to some degree with clinical IT systems. This may go some way to explaining why people engaged and enrolled in DHIs.

> *"The thing I like the most is being able to put the weight chart on and seeing it electronically, because I think it's more accurate to see it electronically than perhaps doing it freehand in the manual [system]. I also like that I can record my baby's developmental firsts, and it brings up the weeks for me, so again I don't have to track back and think, oh*

> *what date was that and what week was it, it's there for me at the touch of a button"* (Focus Group, Health Service User, Participant 71, April 2015)

> *"everyone is really positive, they like it, they like the fact that it can be personalised, they like the photographs, they like the information that can be stored on it"* (Focus Group, Health Professional, Participant 77, April 2015)

5.3.6 Broadening the conceptualisation of patient and public engagement and enrolment in digital health

Based on the results of this chapter, the Digital Health Engagement Model was developed further using Normalization Pro digital tools cess Theory to enhance the understanding of engagement and enrolment in digital health. The conceptual model described in Chapter 4 was refined further by mapping the subthemes identified from the analysis of data from the dallas programme to one of the four generative mechanisms of NPT; 1) Coherence, 2) Cognitive Participation, 3) Collective Action, and 4) Reflexive Monitoring (see Table 25). For example, a participant quote given below was coded under the 'Quality of the digital health information or interaction' subtheme during analysis, as an individual considered the electronic information available on a DHI to be good quality as it originated from a healthcare provider. Upon further reflection it was felt this best aligned with the 'Reflexive monitoring' construct of NPT which describes how people assess or evaluate a new intervention.

> *"It adds to the reassurance I think that the information you are getting is, it's not Google it's not any old nonsense it's people that you trust. It's relevant it's in your area as well."* (Focus Group, Health Professional, Participant 95, April 2015)

Table 25: Factors affecting patient and public engagement and enrolment in DHIs from the analysis of data from the dallas programme

Theme 1: Personal Perceptions and Agency			**Mapping to NPT**
Subtheme 1.1: Awareness of a DHI	Barrier - Unaware that a DHI exists	Facilitator - Aware that a DHI exists	Coherence
Subtheme 1.2: Understanding of a DHI	Barrier - Lacks understanding of a DHI (risks and benefits)	Facilitator - Understands about a DHI (risks and benefits)	Coherence
Subtheme 1.3: Personal agency (choice and control)	Barrier - Preferred traditional ways of accessing health information or health service interaction; Felt a DHI was unnecessary for personal health needs	Facilitator - Ability to choose time and location of accessing health information or health service via a DHI	Coherence

Theme 2: Personal Lifestyle and Values			**Mapping to NPT**
Subtheme 2.1: Personal lifestyle	Barrier - Busy lifestyle with competing priorities e.g. career or caring responsibilities; Social issues prioritised over health e.g. unemployment	Facilitator - DHI fits with personal lifestyle	Cognitive Participation
Subtheme 2.2: Privacy and trust	Barrier - Concern over the security/privacy of information on a DHI; Low level of trust in a technology company; DHI seen as intrusive	Facilitator - No concern over the security/privacy of information on a DHI; Values the benefits of sharing health information via a DHI	Reflexive Monitoring
Theme 3: Digital Accessibility			**Mapping to NPT**
Subtheme 3.1: Cost and funding	Barrier - DHI not affordable; Internet services not affordable; Refusal to pay for a DHI due	Facilitator - Can afford a DHI	Cognitive Participation

	to free public health service		
Subtheme 3.2: Access to equipment	Barrier - Lack of access to a computer or mobile device	Facilitator - Has a computer or mobile device	Collective Action
Subtheme 3.3: Digital infrastructure	Barrier - Lack of access to the Internet	Facilitator - Has access to the Internet	Cognitive Participation
Subtheme 3.4: Digital knowledge and skills	Barrier - Poor digital literacy knowledge or skills	Facilitator - Digitally literate	Collective Action
Subtheme 3.5: Language	Barrier - Poor grasp of the English language		Coherence
Theme 4: Implementation Strategy			**Mapping to NPT**
Subtheme 4.1: Engagement approach	Barrier - unclear and confusing branding; inappropriate advertising channel or message	Facilitator - clear and unambiguous branding; appropriate audience, channel or advertising message; personal	Coherence

		contact with family or friends; Personal involvement in a DHI (co-design)	
Subtheme 4.2: Enrolment plan	Barrier - complicated sign up process for self-enrolment	Facilitator - Tailored support from professionals or voluntary groups; free technical support as an incentive; easy sign up process for self-enrolment	Collective Action
Theme 5: Quality of the Digital Health Intervention			**Mapping to NPT**
Subtheme 5.1: Quality of DHI design	Barrier - Complex enrolment or difficult login process; How a DHI operated on different devices	Facilitator - Simple enrolment or integrated login process; Automated DHI requiring minimal interaction	Reflexive Monitoring
Subtheme 5.2: Quality of information	Barrier - Poor quality health information via a DHI	Facilitator – Better quality health information via a DHI	Reflexive Monitoring

Subtheme 5.3: Quality of interaction	Barrier - Poor quality health interaction via a DHI	Facilitator - Better quality health interaction via a DHI	Collective Action
Subtheme 5.4: Integration with healthcare	Barrier - Little or no integration of a DHI with a healthcare provider	Facilitator - DHI integrated with a healthcare provider; Tailor health information or interaction via a DHI	Reflexive Monitoring

As conceptual coding proceeded more subthemes were mapped to the four main mechanisms of NPT, until all sixteen were associated with the most appropriate element of the theory. Regular coding clinics were held with one of the supervisory team to discuss how the mapping was being done. This resulted in several subthemes being refined and reframed within the Digital Health Engagement Model and new elements were added to further explain how patients and the public engage with and enrol in DHIs. These changes to the conceptual model based on the findings of the dallas programme are described and discussed further in Chapter 8.

5.4 Discussion

5.4.1 Overview of findings

The findings in this chapter indicate that there were various interconnecting factors that affected patient and public engagement and enrolment in digital health during the dallas programme, as summarised in Table 25 above. Those who were aware that DHIs existed and had some understanding of how they worked and might be of value tended to sign up to them. However, individuals with limited awareness and knowledge of DHIs appeared to be at a disadvantage making uptake more challenging. Personal agency also seemed to be a factor as there was evidence that those who liked the convenience technology offered were more inclined to sign up for a DHI. Others preferred to choose more traditional face-to-face interactions with their healthcare provider. Personal lifestyle and values also appeared to affect engagement and enrolment as people with busy careers and caring responsibilities seemed to have less time to spend on their own health and consequently a DHI. However, if a technology fitted seamlessly into day-to-day life this appeared to encourage sign up. Privacy and trust in DHIs also featured in the results of the dallas programme, as some individuals reported low levels of confidence in technology companies and others felt their data may not be confidential or secure on a DHI. However, a few were not concerned about the privacy and security of their health information on a digital health product or service, which may have contributed to their willingness to enrol in a technology.

The findings on engagement and enrolment in DHIs during the dallas programme led to the creation of a new theme called ‘Digital Accessibility’. This incorporates some concepts from the results of the systematic review in Chapter 4 that have been refined and expanded upon such as access to technology and its cost. Whether someone could afford a DHI was a consideration they made before enrolling in one, as some felt digital tools should be provided for free as part of the health service. Accessing computer, mobile or other equipment including high speed Internet services also affected people’s ability to engage with or sign up to a digital health product or service. The technical knowledge or skills a patient or member of the public had could also be a barrier or facilitator, as those with limited digital literacy seemed to find it more difficult to engage with or enrol in a DHI. As the technologies in the dallas programme were only available in English, non-native speakers sometimes struggled to engage with a DHI due to the language barrier. The quality of a DHI was the final theme to emerge from the results of the dallas programme which seemed to affect patient and public engagement and enrolment in digital health. This encompassed different aspects of the quality of health information or interaction via a technology, the quality of its design and how integrated it was with a healthcare provider.

5.4.2 Comparison with other literature

Many of the barriers and facilitators to patient and public engagement and enrolment in DHIs, identified in the systematic review in Chapter 4, have been confirmed in real-world settings by those participating in the dallas programme. Other aspects have been expanded upon and some new concepts emerged, adding important knowledge about the early phases of digital health implementation.

Similar to the findings of the systematic review, the dallas programme highlighted that awareness and understanding of DHIs facilitated engagement and enrolment. Older adults were one group recognised as having difficulties appreciating the value of digital health products and services during the dallas programme. This specific user group was not highlighted in the review, as the participants of the included studies were mainly younger and more middle-aged people. However, a survey in the United States showed rates of DHI use ranged from 32.2% in those aged 65 to 74, to 14.5% in those aged 75 – 84 and then it dropped to 4.9% for those over 85 (Choi, 2011). Likewise, Liu et al. (2016) noted older adults' readiness for home health monitoring technologies was low and Smith et al. (2015) found only 57.5% of older patients had registered for an online portal to access their medical records and message their hospital physician. This indicates older people may not engage with or enrol in DHIs as often as others. Some dallas participants also thought those from more disadvantaged backgrounds struggled to understand how technology could be used at home to manage one's health. This is a new finding not present in the systematic review which may be due to differences in socio-economic status, a characteristic that was underreported in the included studies in Chapter 4.

The wider literature has shown ethnicity may be a factor that affects uptake of DHIs. Gordon and Hornbrook (2016) highlighted that Black, Latino and Filipino seniors were less likely than Caucasian and Chinese seniors to register for and use a patient portal. Mitchell, Chebli, Ruggiero and Muramatsu (2018) also found that older Blacks and Hispanics were less likely to use technology for health related reasons than their White counterparts. In an effort to raise awareness of DHIs and encourage sign up among many groups, comparable engagement approaches such as mass marketing via television and websites were found in both the review and the dallas programme. These seem to be popular ways for public health interventions to be promoted (Yadav and Kobayashi, 2015; Sato et al., 2019). Some novel methods such as a physical and virtual 'smarthouse' were used in the dallas programme that have not been reported elsewhere, although how effective these were in improving engagement with digital health products and services remains unclear. In keeping with the findings of the systematic review and update, personal agency seemed to influence patient and public engagement and enrolment in DHIs during the dallas programme. Lee, Han and Jo (2017) also demonstrated consumers like the convenience of mHealth apps as they can choose when to look for and track health information. In addition, Kaambwa et al. (2017) confirmed some patients prefer telehealth as it gives them more control over when and how they can access their healthcare provider. Therefore, personal agency seems to be a mediating factor when engaging and enrolling in DHIs.

Further insights were gained from the results of the dallas programme about how people's personal lives and values affected engagement and enrolment in DHIs. Similar to the review, those with busy personal lives or people struggling with complex social problems such as unemployment, seemed to have difficulty engaging and enrolling in DHIs as they were preoccupied with important personal issues. This is evident in the wider literature as Kontos et al. (2014) reported that differences in people's socioeconomic status affected uptake and use of digital health. The national survey data they used revealed those with lower levels of education did not go online to look for health information or interact with healthcare providers as often as those with higher levels of education. Public trust in DHIs identified in the review and update was also mirrored in the results of the dallas programme, as some patients or members of the public thought health information may be compromised on a digital health product or service and so did not engage with it. Russell et al. (2015) also found trust was a significant predictor of older Australians adopting telehealth and Deng, Hong, Ren, Zhang and Xiang (2018) showed trust was a factor for patients in China when adopting mobile health applications. Several new aspects around trust in DHIs emerged from the dallas programme. Some individuals reported lower levels of trust in technology companies as security and other settings could easily be changed without their knowledge, making personal data less private and secure. Another new barrier was a few people felt that home monitoring systems could be seen as invasive which might discourage engagement and enrolment. Lie, Lindsay and Brittain (2016) also found something similar among older adults who were considering home health monitoring technologies. Some did not want their personal space encroached upon, while others were happy for their family and care providers to monitor their daily activities. Unlike the systematic review, the dallas programme revealed some individuals were not worried about the privacy of their health information on a DHI and therefore not discouraged from signing up for one.

New knowledge was gained from the dallas programme around digital accessibility and how this impacted engagement and enrolment in DHIs. As highlighted in the review and results from the dallas programme, some people could pay for a DHI and were happy to register for one for the conveniences it offered. Roettl, Bidmon and Terlutter (2016) undertook a survey in Germany which showed some patients, particularly those with greater incomes and higher levels of education, were willing to pay for online health services. Lithgow, Edwards and Rabi (2017) also found diabetic patients were willing to pay for a mobile app if it could help them manage their condition, although the amount they were will to pay varied from $5 - $20. A fresh perspective was offered on who should pay for digital health products and services as some felt technology should be provided for free by the health service. Although this was not reported in the systematic review, a survey by Callan and O'Shea (2015) revealed people were willing to pay for telecare in Ireland but valued formal state and family care. Kaga, Suzuki and Ogasawara (2017) also noted citizens would pay for elderly telecare in Japan. Another new viewpoint from the dallas programme was that technology might provide a cheaper alternative to traditional healthcare services, which might encourage enrolment. A novel engagement strategy, free technical support for a DHI, was employed during the dallas programme to encourage sign up. This may have increased uptake as it may have made the technology more affordable.

Access to technology was another aspect in the review and update that was expanded upon from the results of the dallas programme. A new insight was some felt those living in deprived areas might struggle to access computer equipment and Internet services locally due to cutbacks in libraries and other community resources. This could affect their ability to engage and enrol in DHIs. Calhoun et al. (2017) found that older African Americans and those less educated were less likely to have Internet access at home, affecting participation in a web-based smoking cessation intervention. Similarly, Granger et al. (2018) reported poor computer and Internet access among COPD patients with lower levels of education, affecting uptake of telehealth. A recurring barrier, both from the review and results of the dallas programme, was poor broadband speeds and Internet coverage in some areas. Poor telecommunications infrastructure seemed to reduce people's ability to engage with and enrol in DHIs. High-speed Internet access can be an issue as Taylor et al. (2015) noted when poor mobile data services resulted in difficulties delivering a telehealth programme in Australia. Oderanti and Li (2018) suggest further investment is needed to improve the availability of broadband and its bandwidth, particularly in rural areas, to enable large-scale uptake of digital health in the UK. Digital hubs were established in one UK city during the dallas programme to help address these digital accessibility barriers, a new engagement strategy not reported in the systematic review or update.

Digital literacy, both knowledge and skills, was a factor that appeared to affect engagement and enrolment in DHIs both in the review, its update and the dallas programme. Those with poor technical skills seemed to find it more difficult to engage with a digital health product or service, with older adults in particular experiencing this problem during the dallas programme. On the other hand, populations of people who were digitally literate, such as younger generations, appeared to be able to sign up to DHIs. A study by Simblett et al. (2019) found digital literacy was an issue for some patients when trying to engage with mobile health applications. A systematic review by Latulippe, Hamel and Giroux (2017) also highlighted that the digital divide, where those with poor technical skills are excluded from accessing technology, is a serious barrier to accessing DHIs that seems to affect lower socioeconomic groups more. A digital champions programme that used lay volunteers to train people to use computers and online services was a new approach used during the dallas programme which may have enhanced uptake of DHIs. Although digital champions have been identified as important in supporting healthcare organisations when introducing technology (Kennedy and Yaldren, 2017), they may also be useful in helping patients and the public engage and enrol in DHIs. Finally, language was the last barrier under digital accessibility that was present in the systematic review and dallas programme. This issue has been highlighted by others as those not fluent in English can experience problems with digital health products and services (Zibrik et al., 2015; López, Tan-McGrory, Horner and Betancourt, 2016).

A more in-depth understanding about the quality of DHIs and how this affects engagement and enrolment was gained during the dallas programme. Similar to the review findings, complicated enrolment processes turned some people away from a digital health product or service. On the other hand, DHIs that were automated and integrated with other technologies seemed to encourage enrolment noted in both the results of the review and dallas programme. Simblett et al. (2019) also reported patients preferred mobile health monitoring technologies that were discrete and collected data passively, as complicated features were seen as a barrier to engagement and use. In addition, Macdonald, Perrin and Kingsley (2017) noted that poorly designed interfaces, requiring manual data entry, were barriers to diabetic patients using self-management technologies as highly automated systems were preferred to reduce the workload involved in self-care. Co-design was used as an engagement approach in both the systematic review and the dallas programme to improve the quality of some DHIs. Co-design is being used to create some digital health products and services to ensure they are tailored to people's specific needs (Eyles et al., 2016; Thabrew, Fleming, Hetrick and Merry, 2018), although how effective it was to get patients or the public engaged with DHIs is inconclusive. The opportunity to personalise health information or interaction via technology appealed to some people in the dallas programme, a new finding not present in the review. Triantafyllidis et al. (2015) tested a personalised mobile-based home monitoring system with patients with heart failure and reported the tailored interfaces facilitated engagement with and use of the technology. Furler et al. (2015) also highlighted that telehealth services in rural Australia would benefit from more personalised feedback as it could improve uptake and use. The final novel aspect was some dallas participants felt that digital health products and services designed with the help of clinicians were better quality, in terms of the electronic information or virtual interaction gained, which seemed to facilitate engagement and enrolment in DHIs.

5.4.3 Strengths and limitations

Due to the nature of the dallas programme a number of strengths and limitations are present in the results of this chapter. A strength of this study is the variety of technologies and settings that were captured across the United Kingdom. As the dallas programme involved a large-scale implementation of DHIs aimed at patients and the general public in England and Scotland, many types of digital health products and services were rolled out including telehealth and telecare systems, personal health records, mobile health apps, online self-management portals and a whole range of assisted living devices and sensors. These were used by people living at home in rural and urbans regions. For example, an online self-management portal was piloted in five different regions of Scotland which included four NHS health boards i.e. NHS Lothian, Highland, Forth Valley and the Western Isles, and Moray Community Health and Social Care Partnership. Its target populations were those who were active and healthy between 50 and 70 years of age, those in the same age bracket who had a long-term health condition, those over 75 years of age with one or more long-term health problems or were frail, service providers and the general public. By July 2015 registration data for this digital portal was available for 3,687 people. Although the exact location of these registered users was not feasible to obtain, it is likely that they came from a mixture of remote, semi-rural and urban regions given the areas of Scotland that the technology was piloted in. Therefore, the generic barriers and facilitators that affect patients and the public when they try and engage and enrol in DHIs identified and discussed in this chapter have emerged from all types of technologies and settings. This diversity adds strength to the applicability of the results to wider eHealth contexts internationally.

Although attempts were made to reach and recruit as many patients and members of the public as possible, there was a limit to those that were available through the four dallas communities. The four dallas programme leads were responsible for identifying appropriate groups of people to contact, as direct access to end users of the DHIs was not feasible. As the programme experienced delays in developing and deploying some of the digital health products and services, many end users were not available to access until its final year, which reduced the amount of data collection that was possible for this stakeholder group. In addition, the programme experienced challenges recruiting people to its DHIs for the reasons outlined in this chapter and so had much smaller numbers enrolled on its electronic platforms than had been anticipated. This left a smaller pool of participants to recruit. Furthermore, some of the engagement and enrolment processes used for the DHIs did not capture the contact details of end users and so they could not be followed up and invited to take part in this doctoral study. As a result, the forty-seven baseline, midpoint, and endpoint interviews, along with fourteen primary interviews, with various people implementing digital health products and services and data from five focus groups, which included health professionals, were used to gather perceptions of what patients and the public experienced during engagement and enrolment.

Another drawback of the results of this chapter is that, of the patients, carers and service users spoken to during primary data collection, 12 used a personal child health record and 12 used a mobile app to help manage certain aspects of dementia. The remaining 4 used a digital application preloaded with helpful videos about local pregnancy and midwifery services. Therefore, the majority of people were young and healthy which could have introduced bias into the findings. In addition, all of the people spoken too were using a health service at the time and the DHI was related to this interaction. Hence, real ‘consumers’ who register and use technology themselves independent of a health service were not reached in this study. Their experiences of engaging and enrolling in digital health products and services could be quite different, as their motivation for using DHIs would not be linked to an established health service but it is likely that the findings in this chapter will resonate across all groups.

5.5 Conclusion

In this chapter, a summary of the barriers and facilitators that patients and the public experienced when they tried to engage with and enrol in digital health products and services during the dallas programme were outlined. The findings build on the results of the systematic review in Chapter 4 and show that multiple factors affect people’s ability to engage with and sign up for DHIs. These need to be taken into consideration, and addressed where possible, when developing and rolling out technologies in healthcare and the strategies used to register people for them if uptake is to improve. This could improve our understanding of the beginnings of the eHealth implementation journey and work that needs to be done by multiple stakeholders e.g. health services, academia, the technology industry and governments to ensure DHIs can be taken up long term.

6 Factors Affecting Health Professional Engagement and Enrolment in Digital Health

6.1 Introduction and aims

This chapter presents the results and discussion regarding factors affecting health professionals (HPs) when engaging and enrolling patients, the public or themselves in digital health. The methods used have been described in detail in Chapter 3 but a brief summary is provided here, along with a description of the data analysed. The overall aim is to describe the barriers and facilitators that impact on HPs when they tried to get patients, the public or themselves engaged with and sign up to digital health interventions implemented as part of the Delivering Assisted Living Lifestyles at Scale (dallas) programme.

6.2 Overview of methods

As described in Chapter 3, both interviews and focus groups were conducted with a range of stakeholders participating in the dallas programme to understand engagement and enrolment in digital health. An outline of the specific data collected and analysed for presentation in this chapter can be found in Table 26. This is a mixture of both primary and secondary datasets, with the majority of data coming from those who were not HPs (n=55/69). These individuals gave their perspectives on what factors they felt affected HPs when engaging and enrolling patients, the public or themselves in digital health products and services. Fourteen health professionals, who were Health Visitors (n=11), Community Nurses or Midwives (n=2) and an Occupational Therapist (n=1), also contributed. They gave their opinions on what helped and hindered people when trying to engage with or enrol in a DHI during the dallas programme. The framework approach illustrated in Chapter 3 was followed to analyse the qualitative dataset which was underpinned by Normalization Process Theory (see Appendix 3). This helped draw out key themes and subthemes related to HP engagement and enrolment in digital health.

Table 26: Data collected on health professional engagement and enrolment in digital health

Participant Group	No of Participants Interviewed	No of Participants in Focus Groups	Total
Health Professionals	0	14 (PD)	**14**
Health Service Managers and Administrators	17 (SD) & 3 (PD)	3 (PD)	**23**
Third Sector	7 (SD)	0	**12**
Volunteers	5 (PD)	0	
Technology Sector	11 (SD) & 3 (PD)	2 (PD)	**16**
Academics	2 (SD)	0	**2**
Government Sector	2 (SD)	0	**2**
Total	**37 (SD) & 13 (PD)**	**19 (PD)**	**69**
Legend: PD = primary data, SD = secondary data			

6.3 Results

A number of factors appeared to affect HPs when engaging patients, the public or themselves in digital health products and services and signing up for them during the dallas programme. These are grouped into three overarching themes; 1) Health Professional Role and Responsibility, 2) Health Service Organisation and Culture, and 3) Digital Infrastructure, which have several subthemes described below.

6.3.1 Health professional role and responsibility

The role a HP held in the health service seemed to influence the way they could engage patients, the public or themselves with digital health products and services and register for one. Four sub-themes emerged under this heading which were; 1) HP workload, 2) HP status, 3) HP knowledge, and 4) HP skills.

6.3.1.1 HP workload

The first issue that arose around HPs workload was that some clinicians who were going to demonstrate DHIs to patients and use the technology themselves would have additional work to do. These HPs were predominantly those working in primary care such as Health Visitors and General Practitioners (GPs). In certain cases, this was because paper-based systems would have to be maintained while DHIs were piloted with patients and service users. For others, the digital platforms were not integrated into clinical systems within the National Health Service (NHS) and so HPs had to enter data twice. This was seen as a waste of time and energy for staff who were already very busy and dealing with a high workload. Some people felt this added burden acted as a barrier to getting health professionals to engage with DHIs and encourage patient sign-up. This might have affected the implementation of some of the technologies during the dallas programme.

> *"The same with both [x NHS area] and [y NHS area] was additional work on top of what they already do because we weren't at the stage where we were getting rid of a paper product and replacing it with a digital product and it was testing the digital product alongside the paper version. So we were effectively asking them maybe not to double their workload, certainly increase it."* (Standalone Interview, Industry Sector, Participant 60, June 2015)

> *"I think at the moment there's... this is just my impression from the conversations that I've had, but that there is... there is certainly a sense among GPs that they are beleaguered and that they're being put under enormous pressure and they don't have any time to change."* (Midpoint Interview, Industry Sector, Participant 39, October 2014)

Another challenge for HPs was the time and energy required to recruit patients to DHIs. Some GPs, health visitors and community nurses had to do this on top of their current workload. Those who were busy in clinical practice had little time or enthusiasm for showing patients digital health products and services as it disturbed their usual interaction. Some HPs did not see signing patients up to a DHI as a priority during clinical consultations which may have reduced engagement and enrolment during the dallas programme.

> *"we trialled getting the GPs to you know to identify patients getting the staff to phone the patients and refer them into our service but it didn't work because of the pressures on the you know within primary care"* (Endpoint Interview, Health Service Manager, Participant 51, June 2015)

> *"when people are coming to clinic, it's been quite distracting, because you're talking about a whole host of other things, and then the time available to do this doesn't seem as important when you think about some of the other things that you're talking about."* (Focus Group, Health Professional, Participant 83, April 2015)

6.3.1.2 HP status

Another barrier that emerged was some felt HPs were threatened by new technology and perceived it as a way to replace them in the health service. This could be one reason that HPs did not engage with or enrol in DHIs on offer during the dallas programme, as they wanted to protect their jobs and professional status.

> *"I think there is some negative… negativity among different staff groups thinking technology will be replacing people"* (Baseline Interview, Third Sector, Participant 9, November 2012)

> *"people think that if you service redesign there's going to be job losses in the end, and that is a key challenge"* (Midpoint Interview, Health Service Manager, Participant 41, January 2015)

Another suggestion as to why some HPs did not engage with and enrol in DHIs was they were not compensated for the time and effort required to promote digital health products and services. Most of the technologies offered during the dallas programme were from private companies. HPs were not affiliated or associated with these companies or offered any financial or other incentive to promote their technologies, which may have prevented engagement and enrolment.

> *"it's all well and good to say to a GP if you get your GP patients on maintaining their own care plan and personal health record and being more pro-active about their health, if they don't get paid some fee against getting somebody onto [X DHI] there is no incentive in it for them so you know the way that the system is structured at the moment is flawed and is the biggest barrier to integrating e-health."* (Endpoint Interview, Industry Sector, Participant 54, June 2015)

Alternatively, some digital health products and services were thought to empower HPs and enhance how they interacted with their patients. Some felt this could improve the professional status and role that HPs play in the health service and encourage them to engage more with technology.

> *"Well, I think that the use of telehealth... you're giving the nurses – most likely to be community matrons – you're adding to their skill set, so that will enable them to make better clinical decisions. And in the past they may have required a GP to assist them in that clinical decision-*

> *making, but by using technology they may not require that. So I think that will be an enhancement of their skills and professional development."* (Baseline Interview, Health Service Manager, Participant 15, November 2012)

6.3.1.3 HP knowledge

The knowledge HPs had in relation to digital health seemed to impact their ability to engage or enrol patients, the public or themselves in DHIs. Two subthemes emerged under this heading including; 1) Awareness of DHIs, and 2) Understanding DHIs.

6.3.1.3.1 Awareness of DHIs

A barrier that appeared to influence HPs ability to engage with and enrol in DHIs in the dallas programme, was a lack of awareness of different types of technologies being developed and deployed for people's health. As the digital health products and services were only being piloted in a few areas of the UK and not nationwide, only some HPs were exposed to them.

> *"I've seen health visitors at my centre and none of them knew about the electronic [DHI] and we never used it with a health visitor."* (Focus Group, Health Service User, Participant 89, April 2015,)

> *"I think not so much specifically training, I think more awareness raising, you need to know what [X DHI] all about. You need to know what the technologies are that we are proposing to use, how the products will be delivered in order to think about your own specialist area, cardiology or whatever it is and say oh I can see who that could help me, you know I could see how an app on the smart phone will help my patients."* (Midpoint Interview, Health Service Manager, Participant 21, November 2013)

A range of activities and events were run during the dallas programme to promote the digital health products and services on offer. Some of these may have facilitated HPs to engage and enrol in DHIs, as they could find out what technology was available and how it might benefit patients. For example, a smarthouse was designed which became a mobile show home that had a range of sensors and devices integrated into it. This walk-through, interactive installation was used to demonstrate how technology could be used in a person's home to keep them healthy. The smarthouse was moved to different areas of the UK so HPs as well as members of the public could visit and see what digital tools were available. This may have helped raise awareness of DHIs among health professionals which could have facilitated their uptake.

> *"You know we've had a mobile smarthouse that has been taken to events, we've done promotions not just with the public but with professionals as well because we found there was a gap in the knowledge of professionals you know you might say to a GP what can you tell me about the telecare or telehealth and they couldn't have told you anything"* (Endpoint Interview, Third Sector, Participant 50, June 2015)

6.3.1.3.2 Understanding DHIs

Another difficulty some HPs had when engaging and enrolling patients, the public or themselves in DHIs was that they lacked knowledge of digital health. How the technologies being implemented worked or how they might benefit patients, the public or the health service was not well understood by some HPs. This may have resulted in a lack of interest in signing up to a DHI as its value was under appreciated. A compounding factor was the challenge of keeping up to date with technological developments. Some HPs felt overwhelmed by the volume of digital tools such as mobile apps that were available. They worried they lacked expertise to judge the quality and usefulness of health apps to be able to recommend them safely to patients, which could have hindered engagement and enrolment.

> *"For me as well, it's more training. I mean, I wasn't brought up in a digitalised age, so I've learnt as I've gone along, and then there's always things that I've been, oh God, I didn't realise about that, you know, so you're talking about web browsers and everything, I've had to sort of think, what's the difference between a Web browser and an App"* (Focus Group, Health Professional, Participant 81, April 2015)

> *"But we also need to be quite discerning about the kinds of things we put people onto, we say oh there's this app and the other app, but we don't always know, you know. Are they okay, we need to be checking them out before we start saying to people, oh, have you seen this and done that, you know."* (Focus Group, Health Professional, Participant 80, April 2015)

Some of the groups implementing DHIs during the dallas programme undertook a range of educational activities to raise the profile of digital health products and services among HPs and other care providers. For example, training was provided on telehealth and telecare. This may have helped them appreciate how the technology worked and why they should sign up for it.

> *"We've undertaken training for a whole host of agency staff across the city in relation to telehealth and telecare so I think it's something like 33 care and health organisations and I think it's three or 400 individual members of staff. I don't know what the numbers are but significant numbers of staff have had general awareness of what telehealth and telecare's all about."* (Midpoint Interview, Health Service Manager, Participant 35, December 2013)

6.3.1.4 HP skills

The technical skills HPs had in relation to digital health seemed to impact their ability to engage and enrol patients, the public or themselves in DHIs. Some had low levels of digital literacy and were not able to use the software or hardware being deployed during the dallas programme. This may have made it challenging for HPs to demonstrate the digital health products and services to patients and register them on one, which may have negatively affected engagement and enrolment.

> *"we haven't had the chance to keep using those skills, so you get shown the skills, then you don't use it for ages, then you feel a bit nervous and probably a bit uncomfortable to do it in front of somebody"* (Focus Group, Health Professional, Participant 79, April 2015)

> *"Other staff, you know we've had the focus groups around the [DHI] and again we've got a mixture of staff and some staff are really sort of quite anxious and are not comfortable using IT so there is a whole range of issues around IT and literacy that we need to overcome."* (Midpoint Interview, Health Service Manager, Participant 26, December 2013)

On the other hand, some of the dallas groups offered training to HPs involved in recruitment to ensure they could use the digital health products or services they were asked to promote. In addition, HPs were starting to use other technologies in their clinical roles which meant they were developing some technical abilities. This up-skilling meant it may have been easier for certain health professionals to engage with and sign up to DHIs.

> *"[X DHI] staff has been brilliant and she's come out and we've done loads of training, on a one to one level, but I think the whole system about IT, I feel first and foremost I am a nurse and that's what I was trained to do, so before IT came in, we were doing everything on paper, and now things are changing for us, and we've never really been giving training"* (Focus Group, Health Professional, Participant 80, April 2015)

> *"I've seen, our staff are becoming more technologically savvy than I have seen... I mean, we've got more staff that are now using technology, you know, in terms of the digital pen, they're using pens and things like that as well, and we've got the community psychiatric nurses who are using*

> *the tablets, who will use the same kind of tablets, using tablets, there's phones, and you know, for all the documentation and...they're going to basically be using it for everything. So, I think that kind of skill level is improving"* (Midpoint Interview, Government Body, Participant 40, December 2013)

6.3.2 Health service organisation and culture

How health services functioned and the type of organisational culture that was present appeared to have an impact on HPs ability to engage and enrol patients, the public or themselves in DHIs during the dallas programme. A number of subthemes emerged under this heading including; 1) Access to technology, 2) Cost and funding, 3) Information governance, 4) Clinical and technical integration, 5) Restructuring public services, 6) Organisational culture, and 7) Organisational policies.

6.3.2.1 Access to technology

A barrier mentioned by some HPs which hindered their ability to register for a DHI was the lack of access to certain technologies in the health service. This was evident in the case of an electronic Personal Health Record (PHR) for children as many Health Visitors were still using paper-based systems to document care and manage health information. They did not have access to up-to-date mobile platforms to sign up to this digital health product and demonstrate it with parents. Simpler technologies such as basic mobile phones were available but needed modernisation to enable Health Visitors to successfully engage and enrol parents in the PHR.

> *"I do think the problem we've got is that we're not role-modelling IT across [x region of the UK] at all. So as health visitors, we don't go in with an iPad; we don't use iPads with parents to do our professional work. Therefore, we can't promote… the [x DHI] come too soon for us, because we're slightly too... In [x area of the UK], we're quite far behind*

> *in our IT. We don't have electronic records as such, so we're still writing in records. And I think that's probably half the problem. So the infrastructure is poor."* (Focus Group, Health Professional, Participant 95, April 2015)

> *"I just think that the health system service really has, we've dragged behind really, you know, where our clients are at, and we need to catch up. As Health Visitors we had a little phone that when you text, it was very slow, you know, and it was really difficult."* (Focus Group, Health Professional, Participant 83, April 2015)

However, health services in some areas did purchase computer and mobile equipment for their staff which seemed to make it easier for Health Visitors to start encouraging patient engagement and enrolment in DHIs.

> *"I think we have about 180 health visitor's right across [x region]. So that's what we are working to, they all have iPads now. So that will help them to engage with [x DHI] and with parents in their own homes, they are all 3G enabled so that they can use them wherever they are."* (Midpoint Interview, Health Service Manager, Participant 26, December 2013)

> *"for me to have an iPad was just brilliant!!! Because I learnt a lot and it dragged me into the next century"* (Focus Group, Health Professional, Participant 84, April 2015)

6.3.2.2 Cost and funding

The cost to the health service associated with purchasing DHIs or the technology needed to access them may have hindered engagement and enrolment. In certain cases, the budget that was in place during the dallas programme did not adequately cover the cost of purchasing enough equipment such as tablet computers for all HPs. This may have prevented clinicians from registering for a digital health product or service and promoting it with their patients.

> *"it felt a little bit like that, so we don't know how much it's going to cost, and I don't know how much it's going to cost. I'm just hoping that we've got enough money in that budget to be able to do what we need to do, but I would have liked more because I would have quite liked to have bought some of the health visitors some iPads so that they could have demonstrated a little bit easier to clients."* (Baseline Interview, Health Service Manager, Participant 7, November 2012)

Another issue was the on-going cost of DHIs after the dallas programme finished. Some people reported that NHS trusts did not have the capacity to cover the costs associated with continuing the implementation of the technology or maintaining it in the health service long-term. This meant that once the budget for the dallas programme was spent, health services could no longer afford some of the digital health products or services. Hence, HPs may not have been able to encourage their patients to register for a DHI after the dallas programme concluded in 2015.

> *"[X NHS trust] aren't continuing with the [X DHI] but they've taken the decision that they don't have the resources to, they were basically funded through the project to do this am so they don't have the resources."* (Standalone Interview, Industry Sector, Participant 60, June 2015)

On the other hand, one of the technologies was mooted as being able to help family doctors meet national quality targets for assessing, diagnosing and treating patients in the United Kingdom. This could increase the financial reimbursement this group of health professionals received from the government. Although this did not materialise during the course of the dallas programme, it is one aspect around funding that was suggested could improve the uptake of DHIs among clinicians.

> *"From a GP's point of view if it's something that, you know, if they could tick a box to say I've done this and it ties in, it helps me meet some of my targets and I get paid for it in some shape or form then that's the place where we're trying to get to with this. To be able to say by using this and prescribing this tool out to your patients it can, you know, meet your, kind of, day-to-day objectives, you know"* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

6.3.2.3 Information governance

The security and privacy of people's health information was an area of concern for some HPs, which may have affected their decision to engage and enrol patients, the public or themselves in DHIs. Some health professionals expressed a worry that health information held by private commercial companies, may not be secure, which could lead to patient data being compromised or used inappropriately.

> *"I mean one of the feelings, I think one of the things that worries me is that… is that I'm not entirely confident about [x private company] holding this clinical data. If it was NHS Health Vault…..And even if it was held by [x private company], if I kind of knew that the contract was with the NHS…"* (Focus group, Health Professional, Participant 95, April 2015)

> *"It's one of the challenges to moving the initiative forward. There's issues in terms of that we're working on within our programme in terms of the data transfer from tele-health to tele-care records, then from tele-care records into the private domain. The incoming challenge is, particularly from health practitioners, is around how secure is the information, especially if patients start to hold the information themselves."* (Baseline Interview, Health Service Manager, Participant 4, October 2012)

6.3.2.4 Clinical and technical integration

A barrier to HPs engaging and enrolling patients, the public or themselves in some of the digital health products and services in the dallas programme was their lack of technical integration with current systems and processes in the health service. In some cases, DHIs could not exchange patient data with computer systems in the NHS which delayed deployment of the platform. This may have reduced HPs interest and motivation in signing up for technology.

> *"Can I just add to the fact that what has stopped us using it, is really the infrastructure, in the NHS we have not got the technical infrastructure for mobile working in this way, nor have we got the integration"* (Focus group, Health Professional, Participant 80, April 2015)

> *"they have spent the best part of the last ten months trying to have a conversation with [X provider of clinical IT systems] to get a message going into and coming out of [clinical IT system] from [x DHI], you know that's mind numbing and frustrating and what that does on the ground is you've got a group of champion health visitors who think yeah I'm prepared to double my workload….but if you are then sort of saying to them a year, 18 months on we are no further to having this integrated into our work processes they start to lose interest you know they start to see this as just you know an on-going exercise, no end in sight and it's very hard to keep that motivation up"* (Endpoint Interview, Industry Sector, Participant 54, June 2015)

A further complication was the fact that certain types of DHIs such as home monitoring systems and wearable technologies were controlled primarily by patients. Some reported that HPs might be concerned they would be inundated with irrelevant data from patients they did not want to manage, if these DHIs were integrated with their clinical IT systems. The prospect of this may have turned some HPs away from informing patients about these technologies and promoting registration to them.

> *“I think they are deeply concerned about it in and on the hand and I think they certainly don’t want to see the stream of patient generated spam landing in their professional systems.”* (Endpoint Interview, Industry Sector, Participant 47, September 2015)

Another difficulty was that DHIs were not always integrated into clinical pathways. For example, a personalised online care planning tool which was developed for patients and their families did not link in with formal care providers. It was implied that this could have made some HPs less inclined to promote and endorse it which could have affected engagement and enrolment in the technology.

> *“you don’t really get uptake of something like [x DHI] without it being part of a managed clinical pathway, that’s a big take home lesson we have learnt with the [dallas x] project”* (Endpoint Interview, Industry Sector, Participant 54, June 2015)

A further worry around integration was that some thought that HPs viewed digital health products and services as temporary solutions that would not continue long-term. The transient nature of some DHIs may have discouraged HPs from engaging and enrolling in them as it was reported they had experienced many technologies come and go.

> *“Because you know again it's a short time funding opportunity even although it was significant funding over that kind of five year period and you know again traditionally when you work in the public sector you see lots of things come and go and you do get a bit nervous about engaging ……and then you find that it's not there in six months’ time and you’ve been sign posting to it so there is a bit of that about in terms of its life span which we need to address.”* (Standalone Interview, Health Service Manager, Participant 57, June 2015)

6.3.2.5 Organisational restructuring

Some parts of the health service in the UK were undergoing restructuring during the dallas programme, which may have hindered the ability of HPs to engage and enrol patients, the public or themselves in digital health products and services. In some regions, organisational change was occurring in terms of how health professionals worked and who they worked with. In certain instances, senior managers who were championing digital health were replaced which meant organisational commitment and resources were not always dedicated to implementing technology. This may have hindered HPs ability to access DHIs and sign patients up to them.

> *"the other element is that there is huge change going on in the public sector just now, both health and social care landscape and lots of restructuring, changes in staffing so (my throat is drying up). So actually, it's then difficult to keep people focussed on what they have got to do when they have got a wide range of things that they are looking at all the time and there is so many changes happening."* (Standalone Interview, Health Service Manager, Participant 57, June 2015)

> *"And just to finish [x area of the UK] had challenges because although they were the ones who were most engaged throughout and had very good kind of senior buy-in in the later stages of the project they have gone through pretty major upheaval as well with changes in senior management and loss of a kind of digital champion senior managers that were really behind [x DHI] which has put the future of the [x DHI] in [x area of the UK] into question a bit, which is a shame."* (Standalone Interview, Industry Sector, Participant 60, June 2015)

6.3.2.6 Organisational culture

The type of culture that was present in the health service could also have affected HPs ability to engage and enrol patients, the public or themselves in

DHIs. The biomedical approach to healthcare emphasises a more paternalistic view, whereas patient empowerment and self-management was the focus of many of the DHIs deployed during the dallas programme. As HPs were used to traditional models of care, they may have found digital health products and services disrupted conventional ways of thinking and working. Some health service managers involved in the dallas programme felt this culture may have prevented some HPs from engaging and enrolling in DHIs.

> *"I think our challenge is actually on the clinical side and the mind set change that has to happen, that people could actually potentially self-manage and give them that ownership over that. I think that's one of the biggest challenges. We're still as clinical staff protective over our patients, thinking… and risk-averse, I suppose, thinking that, actually, they don't have the ability to look after themselves; and we have that traditional 1940s methodology, that: don't worry, we'll fix you, or don't worry, come back to us – than actually trying to empower them with the relevant tools to help themselves. So, I think that's a massive barrier."* (Midpoint Interview, Health Service Manager, Participant 41, January 2015)

Another fundamental principle of modern healthcare is Evidence Based Practice (EBP). This requires rigorous research on new interventions to prove they are effective before being adopted into the health service. It was reported that some HPs may not have engaged with the technologies on offer during the dallas programme as there was limited or no evidence of benefit to patients or health professionals.

> *"also chicken and egg, because they don't have time to change they don't want to try it because you don't have the evidence but you can't get the evidence unless they try it so"* (Endpoint Interview, Health Service Manager, Participant 48, May 2015)

On a positive note, some areas of the health service had more innovative cultures and were open to change. Where there was an established digital health service in operation, it may have been easier for HPs to engage and enrol in a DHI as their organisation had a positive attitude towards technology and had invested in it.

> *"I mean in [x region of the UK] I've got neurology, dermatology, stroke, psychiatry, diabetes all done remotely consultations by VC so the patient is in [x region of the UK], the consultant is in [y region of the UK]. So, we've already got that ethos within the organisation that we'll try that and we'll do it."* (Midpoint Interview, Health Service Manager, Participant 21, November 2013)

6.3.2.7 Organisational policies

Whether or not a health service had robust strategies in place that supported digital health may have impacted on HPs ability to engage and enrol patients, the public or themselves in DHIs. Where policies were not in line with the aims of the dallas programme it meant equipment, training and other resources were not in place to support HPs to engage and enrol in the technologies being deployed.

> *"when they came into the process my understanding was that they had a digital rollout strategy within the organisation that we understood, and I think one of their concerns when they joined [x dallas community] was that we wouldn't have products ready quick enough for them. Again as the project developed it became blatantly obvious that they were way behind in their digital strategy to the point that we even had to acquire iPads for champion Health Visitors to roll out the [DHI] ….. so they were nowhere as far along in terms of digital enablement as they really needed to have been to deploy any digital product or service."*
> (Standalone Interview, Industry, Participant 60, June 2015)

Conversely, one participant mentioned that the technology they were rolling out and the ways in which this was being done aligned with the strategies of their healthcare organisation, which could have helped some HPs sign up for these DHIs.

> *"[x city], as I say, they're much further developed in terms of their own digital strategy as an organisation so their staff do mobile working, they have tablets and, you know, they're digitally enabled"* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

6.3.3 Digital infrastructure

The digital infrastructure that was in place externally, outside of the health service, also impacted HPs ability to engage and enrol patients, the public or themselves in digital health products and services. One theme emerged under this heading; 1) Broadband and network connectivity.

6.3.3.1 Broadband and network connectivity

A recurring barrier that came up which appeared to impact HPs ability to engage and enrol patients, the public or themselves in DHIs was poor broadband access and network connectivity in some regions of the UK. Remote and rural areas were reported as suffering from a lack of investment in telecommunications and had slow or non-existent Internet services. This may have made it difficult for health professionals working in community settings to enrol in some DHIs and support their patients to do the same.

> *"Personally, when you haven't got Wi-Fi, to use it over 3G, personally, I am Health Visitors, please add in, it's so slow, it's too slow to be practical."* (Focus group, Health Professional, Participant 82, April 2015)

> *"Yes, the other significant area is mobile, very challenging, mobile coverage is frail, in terms of it comes and goes, but where it does exist,*

> *and in many places, it just doesn't exist."* (Midpoint Interview, Health Service Manager, Participant 38, December 2013)

It was reported that local and national governments were aware of the lack of digital infrastructure and investing in this to ensure it is upgraded. In the future, this could help HPs working in community settings to engage and enrol in DHIs.

> *"I think there are other challenges which we're taking care to do with the telecommunications infrastructure, you know, that's required for this bid. [x government agency] are investing £150 million in upgrading those challenging parts of the infrastructure to bring greater backup capacity to all the islands, and to bring high-speed broadband"* (Midpoint Interview, Government Body, Participant 39, December 2013)

6.3.4 Conceptualising health professional engagement and enrolment in digital health

To enhance the understanding of engagement and enrolment in digital health in relation to health professionals, Normalization Process Theory was used to underpin the analysis. The subthemes presented in this chapter were mapped to one of the four generative mechanisms of NPT; 1) Coherence, 2) Cognitive Participation, 3) Collective Action, and 4) Reflexive Monitoring (see Table 27). For example, a participant quote given below was coded to the 'HP Knowledge' subtheme as the health professional felt they were unaware of technologies available for patients, which could have facilitated engagement in digital health. Therefore, 'Coherence' was selected as the most relevant NPT mechanism as it reflects the sense making work that people need to do to engage with and enrol in a digital health product or service.

> *"I think not so much specifically training, I think more awareness raising, you need to know what [X DHI] all about. You need to know what the technologies are that we are proposing to use, how the products will be delivered in order to think about your own specialist area, cardiology or*

> *whatever it is and say oh I can see who that could help me, you know I could see how an app on the smart phone will help my patients."* (Midpoint Interview, Health Service Manager, Participant 21, November 2013)

Table 27: Factors affecting HP engagement and enrolment in DHIs from the analysis of data from the dallas programme

Theme 1: Health Professional (HP) Role			**Mapping to NPT**
Subtheme 1.1: HP workload	Barrier - Extra work to manage a DHI along with paper-based systems; Additional workload promoting DHIs or recruiting patients to them		Collective Action
Subtheme 1.2: HP Status	Barrier - Status threatened by DHIs; Engagement or enrolment work for a DHI not recognised	Facilitator - DHI could empower and enhance professional status	Coherence
Subtheme 1.3: HP knowledge	Barrier - Low awareness of DHIs; Lacks understanding of DHIs; Knowledge cannot keep up with	Facilitator - Aware of DHIs; Educated about DHIs	Coherence

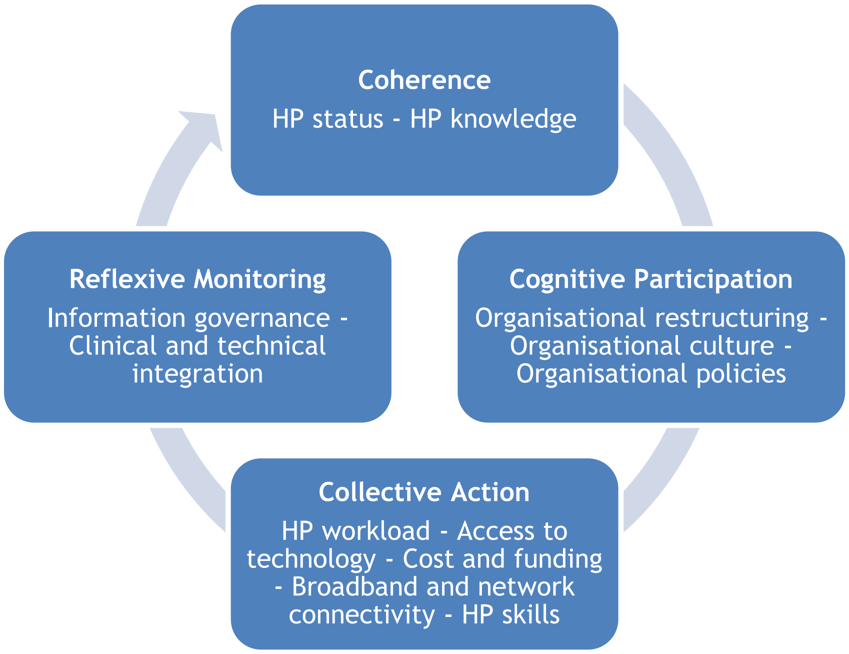
	pace of technological change		
Subtheme 1.4: HP skills	Barrier - Poor digital literacy skills	Facilitator - Trained how to use DHIs	Collective Action
Theme 2: Health Service Organisation and Culture			**Mapping to NPT**
Subtheme 2.1: Access to technology	Barrier - Lack of access to mobile technologies	Facilitator - Had access to the necessary technologies	Collective Action
Subtheme 2.2: Cost and funding	Barrier - Cost of purchasing DHIs; Cost of maintaining DHIs long-term	Facilitator - DHI may attract funding	Collective Action
Subtheme 2.3: Information governance	Barrier - Security or confidentiality of health information on a DHI		Reflexive Monitoring
Subtheme 2.4: Clinical and technical integration	Barrier - DHIs not well integrated with clinical IT systems; Irrelevant personal data entering clinical IT systems;		Reflexive Monitoring

	DHI not well integrated with clinical pathway or process; Perceived transient nature of DHIs		
Subtheme 2.5: Organisational restructuring	Barrier - Restructuring of health service or staff; Loss of DHI champion or leader		Cognitive Participation
Subtheme 2.6: Organisational culture	Barrier - Traditional models of care favoured over DHI; Lack of evidence of DHI effectiveness	Facilitator - Open, innovative work cultures; Established digital health service	Cognitive Participation
Subtheme 2.7: Organisational policies	Barrier - Lack of policies to support DHIs	Facilitator - DHI aligned with organisational policies	Cognitive Participation
Theme 3: Digital Infrastructure			**Mapping to NPT**
Subtheme 3.1: Broadband	Barrier - Poor broadband access; Slow network speed		Collective Action

and network connectivity			

As conceptual coding proceeded more subthemes were mapped to the four generative mechanisms of NPT, until all twelve were associated with the most appropriate element of the theory (see Figure 17). This helped to uncover the processes by which health professionals engage with and enrol patients, the public or themselves in DHIs. Firstly, HPs must make sense of a new digital health product or service by understanding how it will affect their clinical workload and professional role when interacting with patients. Secondly, HPs need to buy into engaging and enrolling patients, the public or themselves in a DHI by gaining management support, reorganising models of care and cultural norms, and putting adequate policies in place to support this. Thirdly, HPs must operationalise engagement and enrolment by paying for or gaining access to the necessary technology and digital infrastructure, and have the right skills to actively sign themselves or others up for a DHI. Finally, HPs need to assess the new DHI by considering its impact on information governance and how it can be integrated into the existing clinical and technical processes and systems in their organisation for engagement and enrolment to be successful. Underpinning the results of this chapter with a robust implementation theory has provided further insights into how health professionals help patients, the public or themselves to take up digital health products and services.

Figure 17: Conceptualising health professional engagement and enrolment in digital health



6.4 Discussion

6.4.1 Overview of findings

The results described in this chapter have indicated that numerous factors can affect HP engaging and enrolling patients, the public or themselves in DHIs. Firstly, the role health professionals' play may have influenced whether they or their patients engaged with and registered for digital health products and services during the dallas programme. Aspects which seemed to contribute to this included the workload HPs had to undertake when engaging with and registering for technology themselves, promoting it among their patients and helping them sign up to it. If this process became quite burdensome and time-consuming it may have discouraged HPs from participating in digital health products and services. In addition, DHIs were believed to both add to the professional development and status of some HPs while possibly diminishing that of others. There was a perception that technology was seen to be replacing health professionals in some areas which could have turned HPs away from engaging with it. Finally, how knowledgeable and skilled HPs were with technology appeared to influence their understanding of DHIs during the dallas programme and whether they had the skills to get patients, the public or themselves signed up to use them.

The findings of this chapter also revealed that the organisation and culture of the health service seemed to have a part to play in HPs engaging and enrolling patients, the public or themselves in DHIs. How accessible a technology was and if the health service could pay for it, in the short and long-term, was a factor that looked to influence HP involvement in digital health products and services. The privacy of health information on commercially owned DHIs appeared to concern some HPs, as did the integration of a new technology with systems in the health service and the way clinicians worked. These issues may have discouraged doctors, nurses and other professionals from signing patients, the public or themselves up to DHIs during the dallas programme. Other factors that emerged as affecting HPs participation in digital health were a lack of senior managers or leaders and organisational strategies to support this type of approach. More traditional forms of health services which focus on biomedical models of care could also have negatively impacted engagement and enrolment as this is the culture HPs are familiar with. In addition, the weak evidence base underpinning some DHIs may have meant HPs were unwilling to change their professional practice and adopt new technologies. Finally, it became apparent that insufficient digital infrastructure in terms of high-speed Internet services were lacking in areas of the UK. This hindered some clinicians from engaging with and registering patients, the public or themselves for digital health products and services.

6.4.2 Comparison with other literature

The results of the dallas programme indicate that health professionals encountered a number of barriers and facilitators when trying to engage and enrol patients, the public or themselves in DHIs. These findings mirror other literature but there are some novel results presented here also, reflecting the unique context. The added workload for HPs when engaging and enrolling patients, the public or themselves in digital products and services has been identified in previous studies. Laws et al. (2016) highlighted that when clinicians have to actively recruit patients to a DHI such as a mobile app it could be a time consuming, slow process. Similarly, Tuot et al. (2015) found the length of time it took HPs to interact with a new electronic referral system was problematic, as some reported it took up too much of their time. Some of this literature explores the whole implementation process. As this doctoral study focused solely on engagement and enrolment, it helps to clearly identify workload as a barrier that occurs for HPs during the early phases of implementation.

Professional status appeared to be another factor that could influence whether HPs engaged with and signed patients, the public or themselves up for DHIs. This was recently highlighted by Kayyali et al. (2017) who reported that nurses perceived telehealth as a threat to their professional role with patients. Additionally, their study revealed that doctors and pharmacists felt key information and decisions could be missed by using telehealth instead of meeting a HP face-to-face, which could compromise their role and the care provided. The technology in this case was already in use and so the findings of the dallas programme confirm that professional status is also a mediating factor in the earlier phases of implementation i.e. engagement and enrolment. The need to reimburse HPs for their professional input when implementing DHIs has also been noted elsewhere. Reginatto (2012) examined the view of older adults towards telehealth who felt financial incentives from governments, in particular reimbursements for GPs, were necessary to ensure the technology was adopted.

The level of knowledge and skills that HPs had in relation to technology also seemed to impact their ability to engage and enrol patients, the public or themselves in it. Some clinicians were unaware of or did not fully understand the technologies on offer during the dallas programme or lacked the skills to sign up to and promote them with patients. This has been noted elsewhere as negatively affecting the wider implementation journey, although it is a new finding in relation to engagement and enrolment specifically. A systematic review by Ross et al. (2016) identified training as a potential barrier to HPs deploying technology. More recently, Ariens et al. (2017) reported that healthcare professionals felt training prior to the introduction of e-consultations and web-based monitoring with dermatology patients could have helped its adoption. In addition, the pace of technological change worried HPs during the dallas programme as some felt they could not keep their digital health knowledge up to date, a new insight into the difficulties of engaging and enrolling in DHIs.

The cost of DHIs emerged as a factor during the dallas programme that could affect the ability of HPs to engage and sign patients, the public or themselves up to technology. A recent review of systematic reviews found cost was a barrier to implementation in 29 different studies across all domains of digital health (Ross et al., 2016). Although the early phases of engagement and enrolment were not elaborated upon in detail, high set-up costs such as the purchase and installation of equipment was mentioned as a major barrier to the initial take up of health IT. Participants in the dallas programme were also concerned whether long-term investment in health IT in the health service would materialise, a novel finding that has not been linked to HP engagement or enrolment in DHIs previously.

The security of personal health information on electronic systems and devices was also a concern for HPs during the dallas programme which appeared to be a factor in their decision to sign patients, the public or themselves up for a DHI or not. This issue resounds in the wider literature as Ariens et al. (2017) and Lluch (2011) reported that the security of digital health services and the confidentiality of electronic health information was a barrier for HPs adopting these technologies. Likewise, a recent white paper by Samsung (2018) identified fears over IT security and the potential loss of sensitive patient data and risks around information governance as a barrier to HPs taking up DHIs.

Another challenging area that prevented HPs from fully engaging and enrolling patients, the public or themselves in a DHI, was how well integrated the technology was with clinical pathways or technical systems already in place in the health service. Although not directed at engagement or enrolment specifically, a recent review of systematic reviews by Ross et al. (2016) also emphasised this point. They highlighted that DHIs need to be as compatible as possible with existing systems and work practices to ensure they are implemented successfully. In particular, the interoperability of hardware and software is a sticking point for HPs who want to enrol in a technology as sharing data between different systems can be challenging (Kruse et al., 2018), which corresponds to the findings in this chapter. Furthermore, a new insight provided by the dallas programme was HPs were concerned with being overwhelmed with excessive data from patient self-monitoring technologies, which they did not have the capacity to manage with current IT systems. This presented a barrier to taking up a DHI for some individuals.

The culture within health service organisations and the types of leaders and policies in place also appeared to influence HPs when engaging and enrolling patients, the public or themselves in DHIs during the dallas programme. This resonates with other work, as Newman, Bidargaddi and Schrader (2016) found similar issues when implementing telehealth in rural Australia as professionals felt the digital culture of their hospital needed to be strengthen to enable this technology to be utilised effectively. Organisational policies around workforce development and staffing levels were also inadequate to enable the uptake of the telehealth system. Gagnon, Ngangue, Payne-Gagnon and Desmartis (2015) also noted healthcare policies were a barrier to HPs adopting mobile health solutions. A new finding from the dallas programme was healthcare organisations that had positive cultures, which embraced change, seemed to enable HPs to sign patients, the public or themselves up to digital health products and services.

Finally, digital infrastructure that was in place throughout the dallas programme to support HPs use of DHIs varied, which affected their ability to engage and enrol patients, the public or themselves in some of them. The lack of high-speed Internet services has been identified as a barrier to implementing technology with HPs numerous times. For example, McPhee (2014) discussed the challenges of rolling out telehealth in rural areas and highlighted broadband was lacking in remote regions of Australia, hindering the participation of some GPs. Likewise, Koivunen and Saranto (2018) undertook a systematic review of nursing professionals experience of telehealth spanning almost 20 years of research and found a lack of Internet access and connection problems such as slow network speeds were barriers to uptake.

6.4.4 Strengths and limitations

This chapter benefits from the depth and breadth of participant data collected by the research team conducting the dallas evaluation at the University of Glasgow. Baseline (n=17), midpoint (n=20) and endpoint (n=10) interviews with a wide range of stakeholders over a three-year period were undertaken. Although none of these were health professionals; health service managers, staff from third sector organisations, volunteers, and commercial companies were interviewed. Secondary analysis of this qualitative dataset was carried out and most of these participants spoke about the barriers and facilitators they believed HPs experienced when engaging and enrolling patients, the public or themselves in digital health products and services as part of the dallas programme. There were also several patients, carers and service users (n=24) in the focus groups who had enrolled in a DHI. They too discussed the barriers and facilitators they felt HPs had come across when signing up to the various technologies. As a result, the indirect findings from these different stakeholder groups helped to reinforce and enhance the data gathered directly from HPs (n=14) in focus groups to overcome some of the limitations with the dallas dataset. Another strength of this chapter is the use of a robust theoretical framework, Normalization Process Theory, which helped to conceptualise the processes by which HPs engage with and sign up to digital health products and services. This furthers our understanding of digital health implementation for this stakeholder group which could help improve uptake to DHIs in the future.

Due to the nature of the dallas programme a number of limitations are present in the results of this chapter. Firstly, the number and type of health professionals that were accessible was limited and data on their gender, age, clinical background and other characteristics were not accessible making comparisons between different types of HPs in terms of what affected their engagement and enrolment in DHIs impossible. The four dallas programme leads were responsible for identifying appropriate groups of people to contact, as direct access to HPs involved in deploying digital health products and services was not feasible. As the dallas programme experienced delays in developing and deploying some of the DHIs, many health professionals were not involved in promoting them with their patients until the final few months of the project. This reduced the amount of data collection that was feasible for this stakeholder group. In addition, the programme experienced challenges recruiting HPs to its DHIs for the reasons outlined in this chapter and so had much smaller numbers enrolled on its platforms than anticipated. Furthermore, many of the DHIs were aimed at the consumer market and no HPs were involved in rolling them out which left the doctoral candidate with a smaller pool of clinicians to recruit.

Another challenge was the three-year timeframe of the dallas programme as it spanned from June 2012 to June 2015. This doctoral study began in April 2014 and ethical approval for primary data collection was granted in March 2015, when an amendment to a previous ethical application for a service evaluation of dallas programme was submitted. Therefore, the timeframe within which to identify and recruit suitable HPs was limited and the process was mediated by the four dallas programme leaders who were busy concluding the project and moving onto other work. This along with the other difficulties outlined above restricted the numbers of HPs that could be recruited to this study. In total, 14 HPs took part in the focus groups, 11 of whom were Health Visitors, 1 was a community midwife, 1 was a community nurse and there was 1 occupational therapist. No HPs were interviewed by the doctoral student or the larger research team at the University of Glasgow due to the recruitment challenges outlined above. Of the 14 HPs spoken to during the focus groups, 9 used a personal electronic child health record, 4 were involved in an educational video package aimed at pregnant women and 1 was involved in designing and promoting a mobile app for people with dementia. Therefore, lots of other types of HPs are missing from the analysis, especially family doctors who work with patients in the community. This could have introduced bias into the findings. In addition, all of the HPs spoken too were involved in the dallas programme in some way and engaging with or enrolling in a DHI. Hence, any HPs who had enrolled in technology independently or refused to do so and had not engaged with the programme were not reached. This may limit the applicability of these findings somewhat.

6.5 Conclusion

In this chapter, a summary of the barriers and facilitators affecting how HPs engaged with and enrolled patients, the public or themselves in digital health products and services during the dallas programme were outlined. With the help of NPT, the findings show that these take place throughout key processes affecting HPs ability to engage with and sign patients, the public or themselves up for DHIs. These aspects need to be taken into consideration, and addressed where possible, when developing and rolling out technologies in healthcare to improve clinicians' uptake of DHIs. Health professionals also mediate the deployment of technology with patients to some degree, so they are a critical group to consider when implementing a digital health product or service. This could improve our understanding of the beginnings of the digital health implementation journey and work that needs to be done by multiple stakeholders e.g. health services, academia, the technology industry and governments to ensure DHIs can be taken up long term.

7 Factors Affecting Implementers Role in Engagement and Enrolment to Digital Health

7.1 Introduction and aims

The overall aim of the chapter is to describe the barriers and facilitators that implementers experienced when engaging and enrolling patients, members of the public and health professionals in digital health interventions (DHIs) deployed as part of the Delivering Assisted Living Lifestyles at Scale (dallas) programme. These are presented and discussed in the following chapter.

7.2 Overview of methods

As explained in Chapter 3, both interviews and focus groups were conducted with a range of stakeholders participating in the dallas programme to understand engagement and enrolment in digital health. An outline of the specific data collected and analysed for presentation in this chapter can be found in Table 28. This is a mixture of both primary and secondary datasets, from a range of individuals involved in different aspects of the implementation process. These included people working in the third sector and volunteers, researchers from academia, employees of technology companies, government sector staff, health service managers or administrators, and health professionals themselves. As outlined in Chapter 3, some implementation teams were health service led while others were headed up by industry partners. The framework approach, underpinned by Normalization Process Theory, as illustrated in Chapter 3 was followed to analyse the qualitative dataset. This enabled key themes and subthemes related to the experiences of implementers who promoted DHIs and signed patients, members of the public and health professionals up to them to be drawn out (see Appendix 3).

Table 28: Data collected to understand implementers' experiences of engagement and enrolment in digital health

Participant Group	No of Participants Interviewed	No of Participants in Focus Groups	Total
Health Professionals Health Service Managers and Administrators	0 25 (SD) & 3 (PD)	14 (PD) 3 (PD)	**14** **31**
Third Sector Volunteers	8 (SD) 5 (PD)	0 0	**13**
Technology Sector Academics Government Sector	17 (SD) & 3 (PD) 3 (SD) 2 (SD) & 2 (PD)	2 (PD) 0 1 (PD)	**22** **3** **5**
Total	**55 (SD) & 13 (PD)**	**20 (PD)**	**88**
Legend: PD = primary data, SD = secondary data			

7.3 Results

A number of factors affecting how implementers were able to engage and enrol people in DHIs emerged from the results of the dallas programme. These are grouped into two overarching themes; 1) Organisation of Engagement and Enrolment, and 2) Implementation Strategy, which have several subthemes described below.

7.3.1 Organisation of engagement and enrolment

Those implementing digital health products and services encountered a number of aspects that affected how well engagement and enrolment activities were organised. This had knock on effects in terms of reaching and recruiting patients, the public and health professionals to the various DHIs. Five sub-themes emerged under this concept, which were: 1) Planning and Managing Workload, 2) Timing and Timeframe, 3) Knowledge and Skills of Implementers, 4) Partners, and 5) Budget and Cost.

7.3.1.1 Planning and managing workload

A key challenge for the dallas programme was that insufficient attention and resources had been allocated to the initial work of engagement and enrolment. Many felt the original recruitment target of 169,000 users across the different digital health products and services was unrealistic. Exactly how the implementation teams, both health service and industry led, would identify and enrol this many people to the DHIs on offer was not thought out in detail from the beginning but only discussed and agreed in more general terms.

> *"I think everybody got a little distracted by the aspirational figure of the... you know, the 169... Magic figure, and I think that distracted everybody to start with because that was the number that was being put out there as what scale meant, rather than, you know, reality, that 50,000 is scale."* (Midpoint Interview, Technology Industry, Participant 44, October 2014)

> *"we probably couldn't have expected they had the perfect contractual framework at the beginning of the day and no one knew to what extent the numbers on recruitment could really be delivered"* (Midpoint Interview, Health Service Manager, Participant 24, November 2013)

This lack of detail meant that the complexity of engaging and enrolling large numbers of people was not given adequate consideration in terms of the workload involved. This appeared to have had a negative impact on the implementers' ability to reach people and sign them up for the DHIs.

> *"I think it's more a case of they didn't realise the extent of the resources that they would need to do the work, to meet the objectives of the work, so for things, for example, like they thought of it more, like, having somebody on the ground, local layer as a manager doing the work but not thinking about, although it was flagged up to them, not thinking about the marketing cost, the PR cost, the necessary additional work that they might have to do to spread the message in terms of stakeholder engagement. "* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

Some of the implementation teams, in particular those that were industry led, did undertake some preliminary market research to understand the types of people that might be interested in their digital health products and services. This could have enabled them to plan how to market the technologies in the most appropriate way to the right groups of patients and members of the public, which may have enhanced engagement and enrolment. For example, some assisted living devices were promoted among adults who had older parents, as this consumer group wanted to know if their family members were safe and secure at home. Other technologies such as telehealth services were aimed at people with diagnosed chronic conditions, who could be reached and recruited through their family doctor.

> *"It's early days, we've only really just started so… but certainly at the moment we've got good intelligence on the recruitment process … so that all helps inform the customer journeys thinking. So for example, just to, it helps to explain better with one, with an example; we've found that most interest has come from, you know, employed children of end users.*

> *They’re, you know, they’re maybe working full-time, living with mum and dad, maybe wanting a bit of reassurance that, you know, mum’s okay.”* (Baseline Interview, Industry Sector, Participant 16, November 2012)

7.3.1.2 Timing and timeframe

The length of time that it took to reach different types of patients and the public and make them aware of the technologies on offer did not appear to be adequately factored into the original implementation plans. The time-consuming nature of face-to-face promotional activities was a barrier to getting large numbers of people registered on some DHIs. This appeared to be the case for certain assisted living devices that required installation at home as the process was sometimes mediated by family members. Therefore, the implementation teams had to lower their expectations and refine their recruitment activities and targets as the dallas programme proceeded.

> *“But then it takes a while for them to actually get back to see, you know, the parent, talk to them and then get signed up and then get installed so from initial interest it can be several weeks before the actual install takes place. I guess we’d not, maybe we hadn’t really thought about it. I thought it’d be quicker than that but in actual reality we have to help people along that journey and give them information that helps them move along that path.”* (Baseline Interview, Industry Partner, Participant 16, November 2012)

> *“I think that it is quite time intensive. That you do have to, initially, in terms of the recruitment numbers, I think that you… it can't all be face-to-face, because the numbers are so big, but actually, it loses its… it may lose its value a little bit if it's not, so that's a bit of a barrier, is how you can spread the word about [x DHI], in a, kind of, human way, rather than in a… just in an email. That might be a barrier if it's getting to that*

> *scale"* (Midpoint Interview, Academic Partner, Participant 20, October 2013)

The premature timing of promotional strategies that occurred before some DHIs were ready for market seemed to affect both the development process of the technology and people's engagement with it. This was particularly the case where co-design methods were used to create a new digital tool as this was a slow, time-consuming process. For example, an online self-management portal that was co-created with service users started recruiting people before the design and full functionality of the platform was established. This could have negatively affected enrolment long-term if the quality of the digital health product or service was not as good as it could be before being advertised.

> *"the service partners spend a lot of their time recruiting and so there is a lot of capacity being taken up by recruitment so there is less capacity then for service innovation"* (Midpoint Interview, Health Service Manager, Participant 19, October 2014)

> *"I think it would need five years, so I think you would implement, so you would community engage, co-design, develop, reiterate development with the users in mind…. You know, these things take time to develop. So I think you could certainly do the development within two years, three years, really robustly, and then I think you have to then ramp up and make the whole experience richer, so layer richness onto it, to show the change start to happen."* (Midpoint Interview, Health Service Manager, Participant 41, January 2015)

Furthermore, if the promotion of and registration for a technology occurred at the wrong stage in the patient journey, it appeared to make it more difficult for patients and members of the public to sign up to it. For example, an electronic personal child health record was shown to parents at home after their baby was born. However, the implementation teams realised that it would be easier to introduce the technology to expectant mothers early in their pregnancy. If pregnant mothers had a longer period to understand how the technology worked and would be of benefit to them before they became busy caring for a new-born infant, then this could improve engagement and enrolment in the DHI.

> *"but one thing that we've been thinking about a lot lately is the timing because we know that that is a massive... has a massive impact on whether people decide to choose to do it or not, and what... our thinking around it now is that it really needs to be set up at antenatal stage when people are nesting and they're... they've got time."* (Focus Group, Health Professional, Participant 93, April 2015)

7.3.1.3 Knowledge and skills of implementers

Implementers faced certain challenges when planning and managing engagement and enrolment throughout the dallas programme. For some, this stemmed from the inexperience of the implementation teams. For example, the health service led implementation teams understood the NHS well but underestimated the technical challenges involved in developing and rolling out technologies at scale. Many of those working in healthcare were new to promoting digital health products and services with patients and the public and lacked marketing skills, which took time to learn and apply.

> *"I think for the service managers barrier, the barrier there is capacity and also competence. I think they are getting very stretched in terms of their skills and knowledge. I think this programme places a lot of demands on them. It needs a very wide variety of skills, knowledge and that people I don't know, probably don't have really. We need to learn a lot on the job…...I guess there is the distance between the great intentions you know the positive vision that you'll hear from the partners and actually the capacity and capability to implement so we need to be aware of that, aspirations outrun ability"* (Midpoint Interview, Health Service Manager, Participant 19, October 2014)

On the other hand, the industry led implementation teams tended to lack an in-depth understanding of the health service, how it operated and why different groups of patients might be interested in DHIs. Therefore, staff from technology companies struggled with recruitment as they sometimes selected the wrong approach or audience for a DHI which inhibited enrolment. For example, a digital self-care planning tool was originally promoted to patients in hospital but these individuals were too unwell to engage with and sign up to the product.

> *"However, what we're realising is that for [X DHI] to succeed it needs to be a prescribed service and most of our partner organisations are dealing with acute patients who are too ill and too deep into the system to actually embrace taking on a digital project."* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

Therefore, some individuals in the implementation teams lacked the necessary knowledge and skills to reach wide audiences and communicate effectively with different types of patients, members of the public and health professionals which became a barrier to engagement and enrolment.

7.3.1.4 Partners

The type of partners in each dallas community seemed to affect how well the implementation teams were able to engage and enrol patients, the public and health professionals. These fell into three sub-categories; 1) Industry partners, 2) Public partners, and 3) Third sector partners.

7.3.1.4.1 Industry partners

A problem for some of the dallas community was that certain private partners who were responsible for getting people engaged and enrolled in the DHIs pulled out in the middle of the programme. For instance, a national energy company who would have been able to reach a wide audience of potential users withdrew due to financial pressures and uncertainty with their business model. This meant some of the implementation teams lost a way to engage with many consumers who were regular customers of this company. This hindered recruitment of patients and the public as the implementation teams were not able to quickly replace a large commercial partner.

> *"Yes, they were very interested and then obviously we saw a big utility partner as a key route to market for an informal care service. They just got to the point I think where last winter there was a lot of pressure on the business …. As happens sometimes in big corporations they just took a strategic decision that they needed to focus on their core business and not stretch themselves too widely."* (Midpoint Interview, Industry Sector, Participant 42, October 2014)

A further complication was that other commercial partners who were delivering technical and service elements of the DHIs did not always identify potential challenges to deployment they might encounter across different parts of the UK. For example, an electronic child health record was developed for use across the UK but due to differences with clinical IT systems in some regions it was not possible to deploy it nationally, which was not made clear from the outset. This limited the reach of the digital health intervention and meant it was not promoted to people and health professionals in some areas in the way that had originally been envisaged.

> *"we commissioned an [x DHI] for four partners one of whom was based in [region of the UK]. Now as project developers we would have assumed [industry partner] would have done a bit of due diligence around what was required in [region of the UK]. And likewise we would have expected that the [region of the UK] partner might have highlighted what was different in [region of the UK] in terms of our understanding it's not really a personal health record in the same way as it is in [X region of the UK], the [y DHI]. The information that's gathered and how the [y DHI] is used in [Z region of the UK] is quite significantly different to [X region of*

> *the UK].”* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

Another challenge for implementers was convincing some potential industry partners to invest time and energy in the dallas programme and promote the digital health products and services on offer. Larger retailers were targeted for this purpose. However, most did not envisage large profit margins from marketing these types of technologies to their customers and so would not stock them. The time spent with these commercial partners, which was not fruitful, may have prevented implementers from talking to a range of other partners who might have been better placed to deliver the promotional work.

> *“For the health equipment, you know if they are not necessarily prepared to take a punt on trialling or showing some of this because you know every sort of square meter is profit lost, if they have got stock in there that isn’t selling so that’s been a real challenge”* (Endpoint Interview, Third Sector, Participant 50, June 2015)

While some industry partnerships were not productive, others appeared to help reach patients and the public and seemed to facilitate the work of the implementation teams. Marketing companies who had a lot of expertise in advertising products and services to consumer groups were used to promote various DHIs.

> *“So, we are a marketing and advertising agency by background. We’ve been brought into the consortium to essentially take the products, official health products and apps and platforms that they are developing, which are doing all the wonderful, clever stuff, and it’s our job to make sure that they deliver at scale across a national audience. So that’s essentially using the skills of consumer marketing, which is advertising, PR, and content and digital and all the rest of it to reach a specific audience in a big way”* (Baseline Interview, Industry Sector, Participant 13, November 2012)

Other types of commercial partners seemed to facilitate engagement and enrolment as they had the capacity to integrate promotional activities for the DHIs into their current processes. For example, a premiership football club was used in one region of the UK to publicise some of the technologies on offer during the dallas programme.

> *"Working with trusted organisations, so working with organisations, facilities, assets that that they know, so it's part of the local landscape, so we haven't imposed something new, we've just built onto existing stuff, so football clubs are probably the biggest brands we have in the city and using them to penetrate the city"* (Standalone Interview, Health Service Manager, Participant 59, June 2015)

7.3.1.4.2 Public partners

Sometimes the implementers, both the industry and health service led teams, were reliant on public sector partners to deliver certain aspects of engagement and recruitment such as health professionals telling their patients about the DHIs and encouraging them to sign up. This caused problems as some clinicians working in the public health service did not see the value of the technology and resisted its implementation, which negatively affected engagement and enrolment as documented in detail in Chapter 6.

> *"the service managers need to recruit GPs to prescribe these postcards so the GP would have to be recruited to work differently and that's where the service manager say well that's difficult you know, so which to me they are saying well I have resistance from established service ... to get people to buy into new ways of working. So, I think that's where the barriers will come from."* (Midpoint Interview, Health Service Manager, Participant 19, October 2014)

Although partnering with public health services was sometimes problematic, they did offer a reliable and direct avenue to engage with both patients and health professionals and encourage them to enrol in DHIs, especially those that had established digital health services already in operation. In certain scenarios, the digital health product or service was integrated into existing clinical and administrative workflows to make registration easier. In another, a database of registered patients was used to reach large audiences and advertise a DHI in conjunction with usual health promotion programmes. Health professionals such as community nurses and health visitors were also used to directly recruit patients to some of the technologies or promote it among their client base.

> *"there is some work around video consultations for respiratory services and what we want to do is kind of retro-fit [x DHI] into those so the work has already started before [x DHI] …. might have been just delivering VC consultations with the respiratory consultant but what we do is as I described earlier we put [x DHI] in and when they are signing people up for that cohort of video consultation patients they get them to sign up to [x DHI] as well"* (Midpoint Interview, Health Service Manager, Participant 21, November 2013)

> *"Also, we're getting feedback from some GPs that we're consulting with to attach it to campaigns like flu campaigns, drug campaigns, you know, diabetes week, you know, to go down that route as well where we're actually linking it in"* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

Other collaborations that appeared to work quite well in terms of engaging and enrolling people, were relationships that implementers fostered with government agencies and public sector organisations outside of healthcare. These institutions, such as libraries, museums, housing associations and others had well-established educational, housing, social care or other services. This gave them regular contact with groups of clients and members of the public, proving a useful way to reach and register them for a DHI. In one case, an academic partner with expertise in design was included in recruitment activities to ensure their creative influence formed a positive engagement experience for potential users of the DHIs.

> *"On the front, we looked at things that people wanted to do and needed to do and that was our root to engagement so working with housing associations, people needed to pay their rent so how could we jump on the back of their messaging, and the engagement activity and the customer contact the housing associations had"* (Standalone Interview, Health Service Manager, Participant 59, June 2015)

> *"So, we are going to community use, [x public transport company] for instance, to communicate to [x public transport company] travellers what, how we are, how [x public transport company] think that the communication should be framed, what aspect of my offer is going to be really attractive to [x public transport company] travellers? So for those people who have got concession cards, the bus pass and the train cardholders then it's part of the core [x dallas community] offer. This is technology and advice and services that can keep you independent, can put you in control, can keep you travelling about and using your bus passes"* (Midpoint Interview, Health Service Manager, Participant 35, December 2013)

7.3.1.4.4 Third sector partners

Third sector organisations were another good source of expertise when engaging and enrolling certain patient groups and members of the public. These types of partners had direct access to people in the community and understood the social circumstances in which they lived and worked. This meant they often knew which types of DHIs were suitable for different individuals and could actively promote them directly to their clients.

> *"we've been having conversations with is [charity x] around their kind of installer, you know, their handyman type service, you know, we're*

> *looking at that kind of reach. And you can image the power that, you know, [charity x] could have in terms of a kind of consumer trust, you know, could be really powerful."* (Baseline Interview, Academic Sector, Participant 17, January 2013)

> *"we've been partnering [charity y] and developing an eLearning asset that informal carers can use to get support and signposting to resources" (*Midpoint Interview, Industry Sector, Participant 42, October 2014)

Another tactic used, which facilitated engagement and enrolment, was tapping into existing resources that third sector agencies had. For example, one had a well-established volunteer programme which was used to train lay members about technology so they could promote DHIs to the people they worked with in local communities.

> *"the champions, we train them up, we give them information around health and wellbeing but also around assisted technology, and it's about them being able to talk to family, friends, go to health events to start raising the profile around assisted technology and particular telecare products"* (Baseline Interview, Third Sector, Participant 10, November 2012)

7.3.1.5 Budget and cost

The budget with which all the implementation teams in the dallas programme had to work with over three years seemed to limit what they could achieve in terms of engaging and enrolling large numbers of patients, the public and health professionals. The problem of adequate resources can be linked to the unrealistic figures and strategies agreed at the outset as implementers appeared to have a poor understanding of what was possible with the allocated resources within the given timeframe. This meant time was wasted pursuing strategies that were financially or practically unachievable, which reduced the opportunities for real engagement and recruitment of users.

> *"It is an issue so I believe perhaps we are under resourced. We need more manpower and we need more funding basically."* (Baseline Interview, Industry Partner, Participant 11, November 2012)

> *"Well, only because we haven't got a clue how much this is all going to cost, I don't think. You know, they plucked a figure out of their heads to give us, you know …. I'm just hoping that we've got enough money in that budget to be able to do what we need to do, but I would have liked more because I would have quite liked to have bought some of the [X health professionals] some iPads so that they could have demonstrated a little bit easier to clients."* (Baseline Interview, Health Service Manager, Participant 7, November 2012)

In addition, some implementers questioned the sustainability of the engagement and enrolment approaches in financial terms. The long-term costs of getting patients, the public and health professionals engaged and signed up to various technologies was a barrier as it could not be sustained after the three-year programme finished.

> *"I think whenever you've got an external funded programme I think you will always have organisations that worry about when the funding is over, what happens then and that conversation about sustainability. I think that often is a barrier."* (Midpoint Interview, Health Service Manager, Participant 29, December 2013)

Although some the implementation teams felt they had limited amounts of money for engagement and enrolment, a few used it to leverage other resources and ensured these combined funds allowed for a certain amount of activities to take place. They also explored what they considered to be cost-effective strategies to reach large numbers of people such as partnering with local organisations who had large membership networks that could be tapped into using methods that were already in place.

> *"I mean, for example, the membership card we talked about could actually prove a much more cost-effective way of getting public health messages out there than the channels that are currently used"* (Baseline Interview, Health Service Manager, Participant 3, October 2012)

7.3.2 Implementation strategy

The type of strategies that were used to promote DHIs and get people signed up to them, seemed to affect the implementation teams' ability to reach patients, members of the public and health professionals and ensure they registered for a digital health product or service. Two sub-themes emerged under this concept; 1) Engagement Approaches, and 2) Enrolment Plans.

7.3.2.1 Engagement approaches

A variety of approaches to engaging people and making them more aware of DHIs and their value arose under this sub-theme. These were: 1) Branding, 2) Advertising, 3) Personal and Clinical Contact, and 4) Personal Involvement in a DHI.

7.3.2.1.1 Branding

A difficulty arose in terms of branding digital health products and services as one of the dallas implementation teams, which was health service led, did not market themselves appropriately at the beginning of the programme. A trade name was adopted that had already been taken by another company, which meant a period of rebranding had to occur. This delayed engagement and enrolment until an alternative could be found to market the DHI appropriately.

> *"We've also had a curve-ball in relation to the [x DHI] name in that we were going to secure the brand but it's already been secured by a, I think it's a multinational gym tech company so we can't use the [x DHI] brand. So we're going to have to go through a process of rebranding, something*

> *quick and dirty so there has been distractions"* (Baseline Interview, Health Service Manager, Participant 4, October 2012)

7.3.2.1.2 Advertising

Some implementation teams, such as those led by the health service, encountered problems when advertising the DHIs as certain technologies had a wide remit. For example, a health and wellbeing portal that also incorporated self-management tools was aimed at a wide range of people and age groups some of whom were healthy, while others had long-term chronic health conditions. This made advertising to distinct user groups challenging, as the digital health product or service had to be pitched differently depending on the audience. It took time and resources to figure out how to promote technology correctly to the right groups of people. This may have slowed down the process of engagement and been a barrier to raising awareness and understanding of the technologies available.

> *"So, I think that is one of our lessons learned that you know, if we are going wide because you are trying to appeal to the 52 year old that is still working and just wants to go hill walking but and you are trying to appeal to the 75 year old that has got COPD and can't use a computer, you know there is quite a big challenge around the marketing, advertising, and language tone."* (Standalone Interview, Health Service Manager, Participant 57, June 2015)

In addition, difficulties emerged when one dallas implementation team, led by an industry partner, developed a commercial personal child health record. The group had planned to gain clinical endorsement for the DHI from a UK medical association to enhance its reputation and help promote it nationwide. However, the medical profession's regulatory body did not allow its members to endorse commercial products with private advertising. The idea of clinical endorsement had to be abandoned, which may have set back implementers ability to reach and enrol users on the digital health application.

> *“The consumer product was going to have to be paid for, if you like, or supported in some way by advertising and sponsorship that was a huge bone of contention with them.”* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

In one case, a promotional tool was selected for a DHI which could have been less effective in reaching its intended audience. A technology show home, called a ‘smarthouse’, was set up in a national museum to showcase how digital health products and services could be used at home. However, using this specific location may have meant that some patients, members of the public and health professionals never visited thereby reducing the chances of engagement and enrolment with key groups.

> *“the smarthouse is based in the [x national museum] but it’s a tourist destination; the museum is a tourist destination. So how many people in the city who could benefit from the technology are going to be visiting the museum? Even though it is having a huge impact on the people that we are speaking to. But I think it definitely needs to be pitched more to the residents of the city not the tourists.”* (Midpoint Interview, Third Sector, Participant 32, December 2013)

While some aspects of advertising were challenging, others such as using newspapers, radio and websites enhanced engagement to the DHIs. This seemed to make people more aware of a piece of technology. Furthermore, telecare products were sold in a local retail outlet in one city which may have helped improve awareness of the technology in this region.

> *“we still need to do general marketing, advertising, recent exposure because we have done quite a lot of like radio, national ads, flyers, our website, presentations the usual kind of marketing activity”* (Standalone Interview, Health Service Manager, Participant 57, June 2015)

7.3.2.1.4 Personal and clinical contact

The implementation teams also ran numerous engagement activities that put them in direct personal contact with potential users of DHIs, whether they were patients, the public or health professionals. For example, one of the dallas implementation teams spent time with healthcare professionals to educate them about the benefits the technologies could offer. Others ran pop-up events in the community to talk directly to local people about digital health products and services available in their area. These types of direct, one-to-one methods seemed to work well and could have facilitated engagement and enrolment.

> *"She's been using pop-ups a lot, I think. Pop-ups were a tool that we developed, obviously, to get into like, in to chat, to start conversations in, but the project managers have been using them for recruitment"* (Baseline Interview, Academic Partner, Participant 18, October 2013)

> *"I did some research groups with NHS frontline staff, one [x DHI], and it's true to say on the one hand a lot of resistance to change initially, but on the other hand when you explain the efficiencies in the system, the long-term benefits, the better cover, the better care they can offer mums in particular and children, they become advocates."* (Baseline Interview, Industry Sector, Participant 13, November 2012)

7.3.2.1.5 Personal involvement in a DHI

As noted in Chapter 5 a few of the implementation teams, both industry and health service led, used a specific design methodology which involved patients, the public or health professionals in creating a DHI. This type of co-creation approach may have helped people understand what a digital health product or service was about, which could have improved uptake.

> *"Living it Up have spent a lot of time co-designing of designing the service; it's also spent a lot of time understanding the user experience*

> *from the ground up. So a lot of UEX work has gone into delivering the front-end interfaces, and, again, taking that back to workshops with users, to make sure the usability and accessibility is as good as it can be at this point in time”* (Midpoint Interview, Health Service Sector, Participant 38, January 2015)

7.3.2.2 Enrolment Plans

Implementers used several methods to get patients, members of the public and health professionals signed up to the DHIs. These fell broadly into three categories: 1) Tailored Support, 2) Incentives, and 3) Self-Enrolment.

7.3.2.2.1 Tailored support

Tailored support was used by some of the implementation teams which seemed to encourage enrolment in certain DHIs during the dallas programme. For example, one team further developed an existing lay champions programme that was active in a UK city, so that the volunteers could teach people basic computer skills required to sign up to some DHIs.

> *“we’ve recruited, how many is it at the moment, we’ve recruited over 300 digital champions so they are volunteers who are prepared to sit with people and help people in their community get online and we’ve had 3,500 people through our digital hubs. And again, not just to get people online but also a way to push out messages around healthcare and self-care and technology”* (Standalone Interview, Health Service Manager, Participant 59, June 2015)

In a few cases, clinicians actively recruited patients to a digital health product or service and helped them get set up on the system. For example, community nurses who visited patients at home were used to discuss a DHI and get them registered for it.

> *“make an appointment for one of our recruiting nurses, when the recruitment teams go out so they can see that patient in their home and provide a more detailed information so it's very much an introductory course, say this is what our service is, do you like the sound of it, if so, this is the next step for getting involved”* (Endpoint Interview, Health Service Manager, Participant 52, June 2015)

7.3.2.2.2 Incentives

The implementation teams during the dallas programme used incentives, such as free installation or technical support, with some of the DHIs to encourage enrolment.

> *“So we want to offer people discounts on purchasing bits of kit and/or support, and/or bundles of support and kit”* (Baseline Interview, Health Service Manager, Participant 3, October 2012)

In addition, one of the technologies was mooted as being able to help family doctors meet national quality targets for assessing, diagnosing and treating patients with a chronic illness in the UK. It was suggested that using the DHI could increase the financial reimbursement that these health professionals received from the government. Although this did not materialise during the course of the dallas programme, it is one aspect that could potentially improve the uptake of DHIs among clinicians.

> *“From a GP’s point of view if it’s something that, you know, if they could tick a box to say I’ve done this and it ties in, it helps me meet some of my targets and I get paid for it in some shape or form then that’s the place where we’re trying to get to with this. To be able to say by using this and prescribing this tool out to your patients it can, you know, meet your, kind of, day-to-day objectives, you know”* (Midpoint Interview, Industry Sector, Participant 25, October 2013)

7.3.2.2.3 Self-enrolment

For a few digital health products and services deployed during the dallas programme, people could register on the technology themselves. For example, an online health and wellbeing platform allowed anyone to set up an account or profile without having to go through another individual or organisation. This was also the case for some digital products as pregnant women could sign up for the online child health record without having to go through a health professional.

> *“the main reason I logged on was the sticker on the front of [X child’s name] Red Book that we were given when he was born”* (Focus Group, Health Service User, Participant 77, April 2015)

However, self-enrolment was problematic in some cases if it was not an easy process to navigate. For instance, registration for an electronic child health record involved creating an email account with an associated technology company, which seemed to make it difficult for some to sign up to the digital health product.

> *“I also find it very confusing [baby crying] having to set up the [X technology company] account, just the process of going through the log in pages. Yes, I wanted to do it, and I was okay with it being a partner, but just the process of clicking on the links was quite confusing, so I eventually got to the point where I knew what I was doing, and once I’d logged in four or five times I was like okay, I get it now.”* (Focus Group, Health Service User, Participant 69, April 2015)

7.3.3 Conceptualising implementers role in engagement and enrolment in digital health

As a way to develop a deeper understanding of implementers’ role in engagement and enrolment in digital health, Normalization Process Theory was used during the analysis process. The subthemes identified from the analysis of data from the dallas programme were mapped to one of the four generative mechanisms of NPT; 1) Coherence, 2) Cognitive Participation, 3) Collective Action, and 4) Reflexive Monitoring (see Table 29). For example, a participant quote, given below, was coded under the ‘Enrolment plans’ subtheme during analysis as the individual believed directly talking to people in the community at face-to-face events facilitated take up of DHIs. This aligned well with the ‘Collective Action’ construct of NPT as it describes the work that people do both individually and collectively to put a new intervention into everyday practice.

> *“She's been using pop-ups a lot, I think. Pop-ups were a tool that we developed, obviously, to get into like, in to chat, to start conversations in, but the project managers have been using them for recruitment”* (Baseline Interview, Academic Partner, Participant 18, October 2013)

Table 29: Factors affecting implementers role in engagement and enrolment found from the analysis of dallas interviews and focus groups

Theme 1: Organisation of Engagement and Enrolment			Mapping to NPT
Subtheme 1.1: Planning and managing workload	Barriers - Lack of planning on engagement or enrolment; Lack of understanding of workload involved in engagement or enrolment	Facilitator - Market research on target audience or recruitment channel	Coherence and Reflexive Monitoring
Subtheme 1.2: Timing and timeframe	Barriers - Time-consuming nature of engagement of enrolment;		Coherence and Reflexive Monitoring

	Inappropriate timing of engagement or enrolment strategy; Timeframe too short to engage or enrol users		
Subtheme 1.3: Knowledge and skills of implementers	Barriers - Inexperienced implementers; Poor technical or market knowledge		Collective Action
Subtheme 1.4: Partners	Barriers - Partner pull-out; Poor communication about risks or challenges; Business model unsustainable; Staff within partnerships resistant to DHIs	Facilitators - Partners with specific expertise in engagement or enrolment; Partners with a wide customer base with established engagement channels	Cognitive Participation
Subtheme 1.5: Budget and cost	Barriers - Engagement and enrolment costly and underfunded;	Facilitators - Budget used to leverage resources; Cost-effective	Collective Action

	Unsustainable funding source	engagement or enrolment strategies used	
Theme 2: Implementation Strategy			**Mapping to NPT**
Subtheme 2.1: Engagement Approaches	Barriers - Incorrect branding; Complex advertising for multiple audiences; Clinical endorsement unfeasible with private advertising; Inappropriate marketing channel used	Facilitators - Advertising via traditional or online media; Retail advertising; Personal or clinical contact; Personal involvement in a DHI (co-design)	Collective Action
Subtheme 2.2: Enrolment Plans	Barrier - Complicated registration process	Facilitators - Tailored support to engage and enrol users; Incentives to engage or enrol; Self-Enrolment	Collective Action

As conceptual coding proceeded more subthemes were mapped to the four generative mechanisms of NPT, until all seven were associated with the most appropriate elements of the theory (see Figure 18). In two instances, subthemes were mapped to more than one NPT mechanisms. For example, ‘Planning and managing workload’ was mapped to both Coherence and Reflexive Monitoring as it includes aspects of implementers making sense of recruitment (or not) at the beginning of the dallas programme and evaluating and changing recruitment activities throughout.

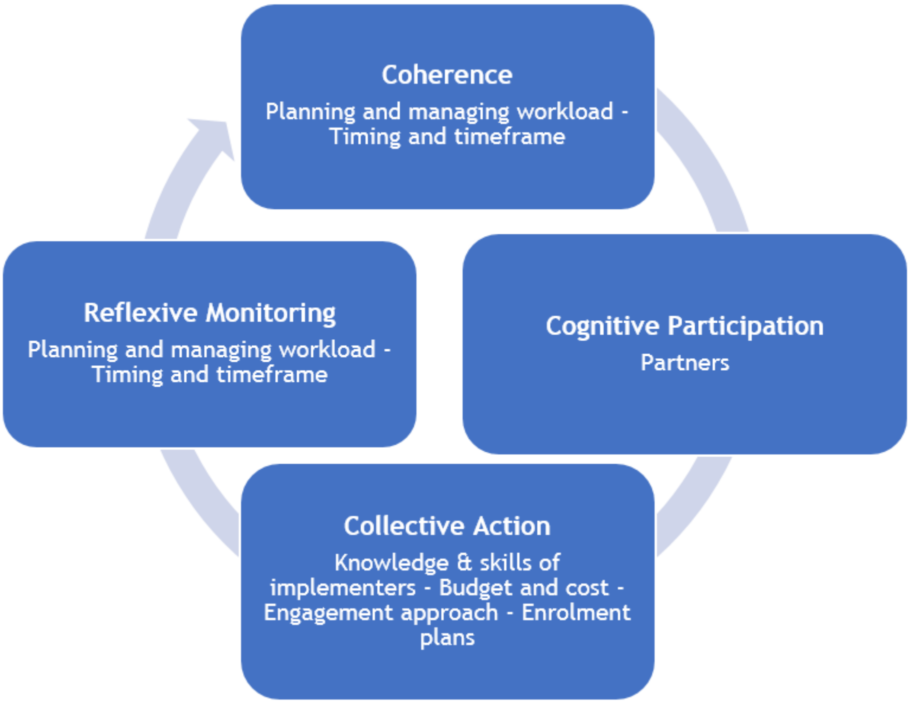
> *"we probably couldn't have expected they had the perfect contractual framework at the beginning of the day and no one knew to what extent the numbers on recruitment could really be delivered"* (Midpoint Interview, Health Service Manager, Participant 24, November 2013)

> *"it's not necessarily been done in a way that it's been ideal, if it's fitted in with what the national delivery will be, so the likes of the versions, Version 1, Version 2, we had an original project plan that we would review kind of the Recruitment Plan and so on, we would have different feedback sessions, after the first delivery date, and then the first delivery didn't happen, so then that obviously threw everything out of sync. So there's been a continual revisiting all of that*" (Midpoint Interview, Health Service Manager, Participant 14, December 2013)

In the case of 'Timing and timeframe', this is also mapped to both Coherence and Reflexive Monitoring as it includes the poor understanding some implementers had about the time needed for certain digital health engagement and enrolment activities, and how they felt these could be adapted and improved upon.

Mapping subthemes to NPT helped to conceptualise the processes that implementers' go through during engagement and enrolment in DHIs, providing a clearer picture of their role in the early stages of digital health implementation (see Figure 18). Firstly, implementers must make sense of the complexities involved in rolling out a new digital health product or service to patients, members of the public and clinicians and how they can become engaged with and enrolled on it. This includes understanding the workload involved and how much time it will take to complete various activities. Secondly, implementers need to get suitable partners to buy into these processes so they can build on and sustain engagement and enrolment in DHIs. Thirdly, implementers must operationalise this work by using a variety of engagement approaches and enrolment plans, along with having the necessary finances and skills to ensure these happen. Finally, implementers need to evaluate their progress with engaging and enrolling people in technology and make any changes necessary to ensure it is successful. Underpinning the results of this chapter with a robust implementation theory has provided further insights into the role implementers play in influencing uptake of digital health products and services.

Figure 18: Conceptualising implementers' role in engagement and enrolment in digital health



Coherence
Planning and managing workload - Timing and timeframe

Cognitive Participation
Partners

Collective Action
Knowledge & skills of implementers - Budget and cost - Engagement approach - Enrolment plans

Reflexive Monitoring
Planning and managing workload - Timing and timeframe

7.4 Discussion

7.4.1 Overview of findings

The results of this chapter have shown that the engagement and enrolment approaches used and how they were organised and delivered is likely to influence uptake of digital health products and services. Those implementing

DHIs, whether they were professionals working in the health service, third sector staff and volunteers, employees of technologies companies or government personnel, came across numerous barriers and facilitators when getting people engaged with or signed up to technologies during the dallas programme. Planning and managing the workload involved in deploying DHIs appeared to affect their roll out as did the expertise of the implementation teams. Building key partnerships with a variety of industry, public and third sector agencies also seemed to enhance engagement and enrolment to some degree. These partners tended to have specific implementation knowledge or access to a wide range of consumers, which was seen as beneficial. The dallas programme also highlighted that the cost of publicising DHIs could be significant and insufficient resources allocated to this aspect of deployment appeared to be a barrier to signing people up to technology. The type of engagement and enrolment approach used by the implementation teams also seemed to impact how easy or difficult it was for people to become aware of and sign up to a DHI. Tables 30 and 31 outline the main methods used. These build on the results of the systematic review and its update in Chapter 4 and the strategies listed in Tables 18, 19, 22 and 23, but they are not exhaustive lists of all possible approaches.

Table 30: Types of digital health engagement approaches used in the dallas programme

Engagement Strategy	
Branding (Indirect)	Brand name
Advertising (Indirect)	Electronic media –telephone advice line Online media – email, social media, websites

	Print media - newspapers, posters on notice boards, printed flyers and leaflets, membership cards Exhibits - display spaces in retail, museums and other outlets
Personal Contact (Direct)	Consultation with a health care professional Family, friends or peers Lay or digital champions Third sector or local authority staff Exhibit or retail/sales personnel Co-design activities

Table 31: Types of digital health enrolment plans used in the dallas programme

Enrolment Plan	
Tailored Support (Direct)	Digital hubs offer free training and use of equipment Help from another person to set up a digital account or

	profile Financial incentive
Self-enrolment **(Direct)**	Complete a paper-based registration form Register online via an app or website Sign up via email or telephone

7.4.2 Comparison with other literature

These results indicate that implementers of the dallas programme encountered a number of barriers and facilitators when running engagement and enrolment activities to DHIs. These findings mirror other literature that explores barriers and facilitators that implementers have come up against when trying to help people become aware of, understand, sign up to or acquire digital health products and services. Planning and managing the deployment of DHIs and the amount of time this takes or is allocated to this task were highlighted as important factors during the dallas programme. Thompson et al. (2006) reported that those implementing a web-based obesity prevention programme with young African American girls spent time planning engagement and enrolment. This included detailing who they should target, how to recruit them, what cultural sensitives to take on board and how much time would be required to run these activities. Although this level of planning was not evident during the dallas programme, it supports the findings of this chapter that how these strategies are organised and delivered is critical to engagement and enrolment in DHIs and will vary depending on the type and number of users needed and the kinds of technologies on offer. Harrison, Cupman, Truman and Hague (2016) also identified a number of techniques such as using market research to help identify suitable people to attract to different products and services. On a positive note as demonstrated by one of the dallas implementation teams, this can feed into and support the planning of engagement and enrolment activities.

It was clear that recruiting patients to digital health products and services can be time consuming and affect uptake. Similarly, Jones, O'Connor, Brelsford, Parsons and Skirton (2012) noted this issue when signing patients up to an email support service in primary care, as did Lane, Armin and Gordon (2015) when reviewing recruitment methods for mobile health applications. However, a new insight was the time that had to be spent negotiating with family members during the dallas programme to get older adults signed up to some of the DHIs, as this was not factored in during the planning phase. Another novel finding was the premature timing of some promotional strategies that took place before the design and functionality of a DHI was finalised, negatively impacting engagement with consumer groups.

The types of partnerships used to enhance engagement and enrolment in DHIs during the dallas programme are mirrored in other literature. Industry partners were employed by Do, Barnhill, Heermann-Do, Salzman and Gimbel (2011) who described teaming up with large commercial providers such as Microsoft to roll out personal electronic health records. Others such as Weinstein et al. (2014) set up an umbrella organisation that captured the knowledge and resources of fifty-five public and private healthcare providers when rolling out a large telehealth programme. A new insight into these types of partnership evident from the dallas programme was the financial uncertainly among some industry partners who pulled out of engaging and enrolling in DHIs, while others did not disclose technical challenges to deployment in a timely manner which potentially affected uptake. Associating with public and third sector services when implementing digital health products and services, as was done during the dallas programme, is well documented in the literature. In particular, health service organisations with clinician expertise and access to patients have been widely used. Subramanian, Hopp, Lowery, Woodbridge and Smith (2004) used nurses delivering home care services to register patients for a telemedicine programme, while Martin-Khan et al. (2015) included clinical and administrative staff from numerous departments of a tertiary hospital to set up and enrol patients in a centralised telehealth service. In May et al. (2011) health professionals noted that third sector agencies were prescribing telehealth in the UK and recommending it to people. Staff from the third sector were also involved in delivering telehealth and telecare services, and helped source patients and provide advice on patient information needs (Hendy et al., 2012). However, the dallas implementation teams worked with a range of other public services such as museums and housing associations which are rarely used to engage or enrol patients or the public in DHIs.

This chapter showed that the cost of engaging and enrolling people in DHIs can be significant depending on the type of approaches used and the intended reach of the technology. This issue has also been highlighted in other studies. Jones et al. (2012) described the costs involved in recruiting people to an email support service in primary care, which was an average of £77 per patient signed up, as a number of different strategies were used. Similarly, Miyamoto et al. (2013) paid participating rural clinics $2,500 to offset the time their staff spent recruiting diabetic patients to a telehealth programme, while Nagler et al. (2013) estimated the total cost of strategies to enrol over 300 people in a digital health literacy intervention was $101,538. The results of the dallas programme added the sustainability of funding for engagement and enrolment in DHIs as a new barrier, over and above the initial costs of running these activities, as some felt budgets that were only for a short period of time would negatively affect sign up long-term.

In terms of the engagement approaches and enrolment plans used by implementers during the dallas programme, a number of traditional and new methods were employed. The usual means of reaching and enrolling patients, and the public in DHIs such as television and online advertising, self-enrolment and direct contact with health professionals are well documented in the literature (Brewster, Mountain, Wessels, Kelly and Hawley, 2014; Matthew-Maich et al., 2016; Sato et al., 2019). Likewise, co-design has been used a number of times to engage patients in digital health products and services (Thabrew et al., 2018; Kildea et al., 2019). However, some novel approaches were used by implementers during the dallas programme including promoting DHIs via a smarthouse and upskilling patients and the public through a digital champions programme, potentially encouraging sign up to the technologies on offer. In addition, new incentives not previously reported in the literature including offering free installation of equipment and technical assistance to support registration to DHIs were used.

7.4.4 Strengths and limitations

Due to the nature of the dallas programme a number of strengths and limitations are present in the results of this chapter. One strength is the diverse number and type of people who implemented the different DHIs as they ranged from front-line health professionals, to health service managers, staff from the third sector and some government agencies, and employees of technology companies. In total, 88 people were spoken to who were involved in some aspect of the implementation process. The majority of these discussed the advantages and disadvantages of engaging and enrolling people in the digital health products and services. This helped provide a rich understanding of the different experiences of the implementation teams and the barriers and facilitators they faced. Another aspect that helps increase the utility of the findings in this chapter, is the wide variety of technologies that were deployed by implementers during the dallas programme. These ranged from telehealth and telecare services, to online health and wellbeing portals, mobile health applications, electronic personal health records and assisted living devices. The breadth of DHIs helps to confirm that the barriers and facilitators identified apply to those rolling out any type of digital health product or service. Furthermore, a robust theoretical underpinning was used throughout data analysis, which furthers our understanding of implementers’ role in engagement and enrolment in digital health by providing clarity on the key processes involved.

However, as each individual was involved in different stages, at different time points and at varying operational levels of the dallas programme, some factors affecting engagement and recruitment to DHIs may have been missed. This is particularly the case for the specific strategies used to reach people and get them signed up to a digital health product or service, as a huge variety of engagement and enrolment approaches were used. Due to the size and length of the dallas programme and the speed at which techniques were tried and tested, it was not possible to document them all or adequately capture how they were planned and delivered and all of the barriers and facilitators that arose. This limited the level of detail that could be reported in relation to the different engagement and enrolment methods used. For example, how often they occurred during the dallas programme and for how long they took place is missing.

In addition, as the focus was the dallas programme, the findings of this chapter relate to this specific context. It is possible that the experiences of people rolling out other kinds of consumer facing DHIs, in other types of healthcare systems, such as those in low and middle income countries may differ. This means some pertinent barriers and facilitators could have been missed as other DHIs, user groups and implementation settings may have revealed additional insights into factors that affect engagement and enrolment in digital health products and services. Furthermore, a large amount of secondary data was analysed. These interviews were not solely focused on engagement and enrolment but discussed the entire implementation of the dallas programme from beginning to end. Hence, some issues implementers experienced in the early phases could have been missed. However, given the breadth of individuals who participated in the interviews and focus groups, and the range of technologies they were deploying across a variety of contexts, the results presented in this chapter are indicative of the main factors that affect those implementing DHIs.

7.5 Conclusion

In this chapter, a summary of the barriers and facilitators that implementers experienced when engaging and enrolling people to DHIs were outlined. The findings show that many factors affected their ability to sign patients, the public and health professionals up to digital health products and services. These indicate that engagement and enrolment activities, which form part of any implementation strategy, need to be planned in detail, budgeted for appropriately and have a skilled team along with the right partners delivering them to ensure success. The results suggest that greater attention and resources need to be invested in initial engagement activities to promote enrolment in digital health products and services.

8 Discussion

8.1 Introduction and aims

This discussion begins by integrating the findings of the systematic review (Chapter 4) and the empirical results from the dallas programme on engagement and enrolment in DHIs (Chapters 5, 6 and 7). A refined set of strategies used to engage and enrol people in digital health interventions is presented. The DIEGO model on engagement and enrolment to digital health products and services described in Chapter 4 is then extended and discussed. Next, the overall strengths and limitations of this doctoral study and the researchers' personal reflections on this thesis are presented. Following that, how the research findings fit with current knowledge and where gaps still exist are outlined. The chapter concludes by making recommendations on how to improve the uptake of digital health and suggesting future directions for research.

8.2 Catalogue of engagement and enrolment strategies

The results of the systematic review and update in Chapter 4 uncovered a number of different strategies used to engage and enrol patients and the public in digital health products and services. These were expanded upon in Chapter 5, 6 and 7 when the results of the dallas programme showed health professionals and others implementing the technologies using a variety of methods to make people aware of and understand DHIs and help them register for one. These are discussed next and the initial catalogue of engagement and enrolment strategies outlined in Chapters 4 (see Tables 18, 19, 22 and 23) and 7 (see Tables 30 and 31) have been refined and integrated into a single set of approaches (see Table 32 and 33).

8.2.1 Engagement approach

The engagement approaches comprise both indirect and direct activities (see Table 32). Branding and advertising were identified as the indirect ways in which patients and the public find out about DHIs and understand the value they can bring. Brand name was the only aspect of branding a product or service mentioned during the dallas programme. Other literature has identified aspects such as brand logo and tag line or trademark as being an important part of a marketing strategy to capture people's attention (Evans and Hastings, 2008), which could help promote technology. Future research could explore which aspects of branding are necessary to create awareness and understanding of DHIs among the public to encourage uptake. Uncovering these characteristics could help develop a more detailed taxonomy of engagement approaches for DHIs as branding may need to be personalised in various ways. This could improve the appeal of DHIs to certain social and cultural groups, an aspect not explored enough during the dallas programme due to the broad focus of the thesis and limitations in the sampling frame.

Numerous forms of advertising including electronic, online, and print media as well as radio were reported as being used in the studies in the systematic review and throughout the dallas programme. This finding echoes other research that has employed multiple ways to raise awareness of DHIs through various forms of advertising (Boudreaux et al., 2014; Bradford et al., 2015; Brusse, Gardner, McAullay and Dowden, 2014; Reginatto, 2012). In the dallas programme, exhibit spaces such as designated areas of specialist retail outlets and museums were used to promote engagement and this involved collaborations with public and private organisations (Devlin et al., 2016). This approach could be considered when promoting DHIs in the future given the numbers of people who frequent such spaces, although they may only be visited by particular types of people such as tourists or those from higher socio-economic groups. This may mean others such as the unemployed or those living in impoverished communities are not reached, two groups who did not seem to participate in the dallas programme. This bias has been noted in some digital health literature as studies tend to include only white participants from higher socio-economic groups, meaning others who may have different perspectives are excluded (Marrie et al., 2019; Reiner, Sturm, Bouw and Wouters, 2019; Strekalova, 2018). Another difficulty highlighted in the dallas programme, was general retailers and commercial companies in some sectors did not seem interested in promoting certain DHIs as it was not part of their traditional business model. Hence, further research exploring what advertising channels could be used and how best to tailor the marketing of DHIs for different ages, genders, socio-economic groups, and cultures would also be useful to promote engagement and enrolment.

The direct engagement approaches encompass two main methods i.e. personal and clinical contact, and personal involvement in a DHI. Personal and clinical contact was deemed useful in the dallas programme and refers to the range of people that can be utilised to help someone become aware of and understand DHIs. These can be family members, friends, co-workers, employers, or health and social care professionals. This finding resonates with existing literature which says that if a technology is suggested by a health professional then patients seem more inclined to sign up for it (Glasgow, 2007; Sanders et al., 2012). However, it can be difficult to track and measure how and when this happens, especially when it is an informal process that can occur in an ad-hoc fashion. In addition, as noted during the dallas programme, some health professionals were reluctant to suggest DHIs to their patients as some felt there was a limited evidence base to support their use and there were risks and limitations with commercially provided products and services. This barrier also resonates with other literature that details why health professionals do not always recommend digital health products and services to patients and their families (Chen et al., 2017; Scott Kruse et al., 2018). Specific groups such as third sector staff, sales personnel in specialised retail outlets, and lay champions were used in the dallas programme to target people in the community and ensure they were aware of and understood what the various technologies could do (Lennon et al., 2017). How well this worked is not clear but this strategy might be employed more in the future to increase awareness and uptake of DHIs. Further research on why and how people recommend digital health products and services to patients, the public, and health professionals could help shed further light on this area. Measuring the effectiveness of these approaches in more depth would also help us understand which ones are better at improving engagement in DHIs.

Personal involvement in a DHI refers to individuals themselves participating in the design and development of a technology, which could improve their understanding of it. As identified in the systematic review in Chapter 4, this process could lead to better quality digital health products and services that are easier to use which could facilitate enrolment, a finding noted elsewhere (Eyles et al., 2016). Various forms of co-design were used in the dallas programme and reported in the systematic review to involve patients, carers, and members of the public in creating DHIs. For example, during the dallas programme a group of people with dementia and their carers participated in a series of co-design workshops with a software company to create a mobile application that aids communication (O'Connor et al., 2016b). As described in Chapter 4, Fukuoka et al. (2011) employed a single focus group to explore the opinions of diabetic patients on how text messages and other mobile software applications could be used to help manage their disease. The different approaches to co-design may have helped individuals appreciate how technology functioned and what benefits it could bring. However, the effectiveness of these engagement strategies was not examined within the dallas programme, nor was it the focus of the systematic review or this thesis. Some literature in this area exists which shows co-creating technological solutions with patients and carers may improve the design and use of DHIs (Wherton et al., 2015; Marzano et al., 2015). Limitations of this approach have also been reported such as its time-consuming nature, higher cost, and finding ways to compromise on the content and functionality of a digital health product or service (Ospina-Pinillos et al., 2019; Lipson-Smith et al., 2019), as it may not be possible to tailored technology to the specific needs of every individual. Kildea et al. (2019) also recommends the process needs an experienced team to guide the development of digital health solutions so that the personal preferences of the researchers or participants do not unduly sway the final product. Hence, further research on whether co-design methods are suitable for specific groups of people and technologies and examining their effectiveness at improving uptake could be valuable. This could help implementers decide whether it is important to include co-production or not as part of their development and deployment strategy for a digital health product or service.

Table 32: List of digital health engagement approaches

Engagement approach
Branding (Indirect) - Brand name that is clear and unambiguous to enable people to clearly identify a product or service
Advertising (Indirect) - Electronic media such as televisions, digital notice boards and telephone advice lines - Exhibits such as retail or museum display spaces - Online media including email, social media, websites, and Internet communities or forums - Print media such as newspapers, personal letters, posters on notice boards, printed flyers and leaflets, and membership cards - Radio
Personal and clinical contact (Direct) - Consultation with a health or social care professional - Employer or co-worker/colleague - Exhibit or retail/sales personnel - Family or friends - Lay or digital champion

- Research, administrative or management staff within a healthcare facility - Third sector or local authority staff
Personal involvement in a DHI (Direct) - Co-design activities such as individuals (patients, carers, members of the public) participating in workshops, focus groups or other collaborative methods that aid in the design or development of a DHI

8.2.2 Enrolment plan

The enrolment plans used consist of two main approaches; indirect and direct (see Table 33). Automatic enrolment was the only identified indirect way that patients and the public signed up to digital health products and services. This emerged solely from the systematic review as this method was not reported in the qualitative data from the dallas programme. Only one study in the systematic review created a digital account for people as a way to get them registered on a personal electronic health record, although this did not seem to improve uptake (Greenhalgh et al., 2010). This approach has been tried elsewhere such as automatically giving people access to patient portals so they can obtain health information (Ronda, Dijkhorst-Oei and Rutten, 2014). As the uptake to these DHIs were low, it may not be a useful method to employ on its own. Whether this practice is ethical or legal after the introduction of General Data Protection Regulation (GDPR) across the European Union (De Hert and Papakonstantinou, 2016) may require further investigation, as consent may be necessary before automatically including people, their personal contact information, and health data in digital health products and services.

The direct enrolment activities are grouped into three main areas: 1) self-enrolment, 2) incentives, and 3) tailored support. A range of enrolment mechanisms were identified during the dallas programme and from the findings of the systematic review. If patients, the public, and health professionals are going to use digital health products and services then a range of options may need to be made available to encourage them to sign up (O'Connor et al., 2016a). Self-enrolment was used to help people register for a digital health product or service in both studies identified in the systematic review and the dallas programme. Several methods of self-enrolment were reported such as electronic means like email, telephone, SMS messaging, and mobile or Internet-based applications. These featured more than traditional practices such as filling out a paper-based registration form for a DHI. These types of electronic enrolment strategies have been reported elsewhere as being successful (Heffner, Wyszynski, Comstock, Mercer and Bricker, 2013; Martinez et al., 2014) and are likely to continue given the prevalence of technology and its mass reach in today's society. However, for individuals living in rural or urban areas with poor Internet access or people who cannot afford smartphones, computers or other technologies that connect to the Internet, it may mean they are excluded from signing up to DHIs through electronic means. This may heighten existing inequalities these groups experience if they have limited or no access to digital health products and services, which could lead to poorer health outcomes (Latulippe et al., 2017; Hong and Zhou, 2018).

No incentives were identified during the systematic review, but free technical support for a trial period was offered during the dallas programme to encourage people to sign up for a DHI. Financial incentives have been utilised to attract people to digital health interventions previously (Mitchell and Faulkner, 2014), which is one approach that could be considered to aid implementation. Whether incentives of different kinds benefit enrolment, if these should be provided via the public or private sector, and if they are cost-effective long-term needs further examination. It will also be important to explore and consider the ethical and legal aspects of offering monetary rewards to health professionals to encourage sign up to DHIs, particulary when those digital health products and services come from private commercial companies, may have risks and limitations associated with them, and there is an absence of robust evidence underpinning their use.

The first type of tailored support utilised was personal assistance from a range of people including health professionals, family members or third sector staff to help people set up a digital account or profile on a DHI. This method was reported in both the systematic review and the dallas programme. These findings resonate with some of the digital health literature as others have used nurses to sign patients up to telehealth services (Hunkeler et al., 2000; Jódar-Sánchez et al., 2013). Where a DHI is part of and integrated into an established health service than utilising health professionals such as doctors and nurses may be an apporiate way to encourage patients to sign up. However, for technologies that lie purely in the commercial sector such as many health apps and wearable devices, then it could be argued that asking or expecting health professionals to spend time during a clinical consultation supporting enrolment in these types of DHIs is not an appropriate use of their time and expertise. Alternatively, partnerships with the third sector seemed to work well during the dallas programme and could be worthwhile pursuing in the future to facilitate better uptake of digital health products and services.

The second type of tailored support utilised was free access to computer equipment, Internet services, and digital skills training. Often those from more disadvantaged areas availed of this so they could get the support they needed to enrol in a digital health product or service. This was only employed during the dallas programme and did not emerge from the systematic review. However, access to the right digital tools, skills, and infrastructure has been noted elsewhere as a way to encourage people to sign up to DHIs and so is worthy of consideration (Fleming et al., 2009; Darkins, Kendall, Edmonson, Young and Stressel, 2015). How effective any of these enrolment strategies were was not assessed as part of the dallas programme, nor was it the focus of the systematic review or this thesis. Therefore, the available information about the effectiveness of any of these approaches described here is limited. Further research on which enrolment methods work best for different groups of people and technologies would be useful to aid our understanding of this aspect of implementation. Experimental studies, such as randomised controlled trials, could be one way to test the efficacy of these strategies in improving uptake to DHIs. Furthermore, detailed descriptions of uptake rates across different populations and contexts using different approaches would also be beneficial. Enhanced knowledge of the relative effectiveness of different enrolment approaches could inform future implementation plans and potentially improve the numbers of patients, members of the public, and health professionals signing up to digital health products and services.

Table 33: List of digital health enrolment plans

Enrolment plan
Automatic enrolment (Indirect) - Consent is assumed and a digital profile or account is created
Self-enrolment (Direct) - Email sign up - Online enrolment via an app or website - Paper based registration form - Telephone or SMS text message registration
Incentives (Direct) - Financial incentive
Tailored Support (Direct) - Personal assistance (in person or over the telephone) from a healthcare

professional, family member, friend or third sector staff to set up the technology and create a digital profile or account

- Help from a volunteer to access equipment and/or the Internet to complete the registration process

Although this initial taxonomy of engagement and enrolment strategies is simplistic, it is a starting point in helping to categorise the ways in which digital health products and services are offered to people and how they take them up. There is scope to expand on these further and achieve a more in-depth understanding of how they are delivered. Further research describing different aspects of engagement and enrolment interventions in detail such as their frequency, intensity, mode of delivery, and fidelity would be useful (Powell, et al., 2017). Hoffmann et al. (2014) created a Template for Intervention Description and Replication (TIDieR) which may be useful to use going forward to describe the characteristics of digital health engagement and enrolment strategies. This could help create more robust taxonomies that aid digital health implementation in the future. These could be incorporated into the Expert Recommendations for Implementing Change, a compilation of general implementation strategies for innovations in healthcare (Powell et al., 2012; Powell et al., 2015).

8.3 Conceptual model of digital health engagement and enrolment

In Chapter 4, the results of the systematic review of qualitative studies revealed a number of barriers and facilitators that patients and the public experienced when engaging and enrolling in digital health interventions. Through deductive analysis these factors were mapped to Normalization Process Theory to create a preliminary conceptual framework known as the Digital Health Engagement Model (DIEGO) (see Figure 16). This focuses on four processes; 1) making sense of a digital health intervention, 2) considering the quality of a DHI, 3) gaining support for enrolling in a DHI, and 4) registering for one. Surrounding these interactive mechanisms are two overarching actions; 1) decision making, and 2) operationalising, that people take to engage and enrol in a digital health product or service. The inductive and deductive analysis of the qualitative data from the dallas programme reported in Chapter 5, 6 and 7 was used to strengthen this conceptual model and refine it further as outlined below.

8.3.1 Changes to the Digital Health Engagement Model

The structure of the DIEGO model has been changed from a circular diagram to an affinity loop to make the two main processes more distinct and highlight their interdependence. Many of the concepts identified in the systematic review remain unchanged; there are, however, important modifications and additions from the findings of the review update and the dallas programme which are as follows. An “Engagement approach” concept has been included on the left-hand side of the model to clearly differentiate the four types of strategies summarised in Table 32. In addition, it is visually represented as being adjacent to but linked to the main DIEGO model. This makes it clearer that these strategies can influence decision-making when patients or the public start to engage with a DHI (see Figure 19).

A new sub-theme “Language” has been added to the upper left section of the model as this arose during the dallas programme as impacting some people’s understanding of a digital health product or service if they were not fluent English speakers. The remaining three concepts ‘Motivation’, ‘Awareness and understanding’ and ‘Personal agency (choice and control)’ remain the same as in the original DIEGO model, as the findings of the review update and the dallas programme helped to strengthen the results from the systematic review to show that these factors affect patients and the public’s ability to make sense of a DHI (see Figure 19).

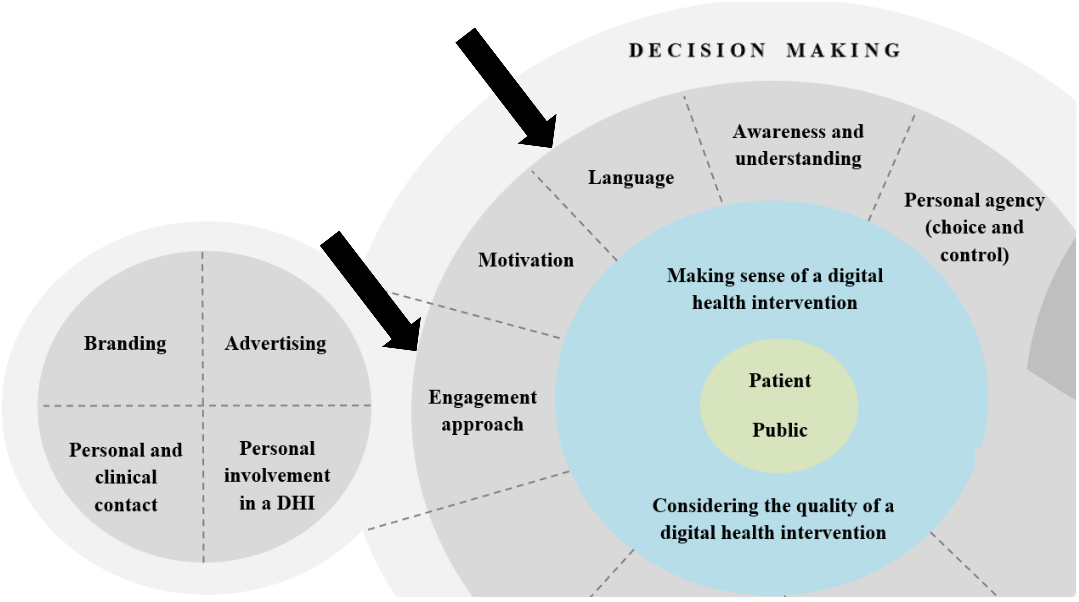


Figure 19: Upper left section of the updated DIEGO model

In the lower left section of the DIEGO model an additional concept “Integration with healthcare” has been included. This emerged from the findings of the dallas programme as some participants would not sign up to a technology unless it was connected to their healthcare provider, who would receive and review their digital health information and provide personalised feedback (see Figure 20). This perspective was only briefly mentioned in two studies in the systematic review, so it was not identified as a distinct sub-theme. Hence, it has been added to the update of the model to ensure this new factor, which people consider as part of the quality of a DHI, is captured and made clear. Another small change is that “Security and privacy” has been renamed to “Privacy and trust” and moved to this lower left section of the DIEGO model. It aligns more closely with the idea of considering the quality of a digital health product or service as revealed from the results of the dallas programme in Chapter 5, rather than influencing people to register for a DHI as shown in the preliminary model in Chapter 4.

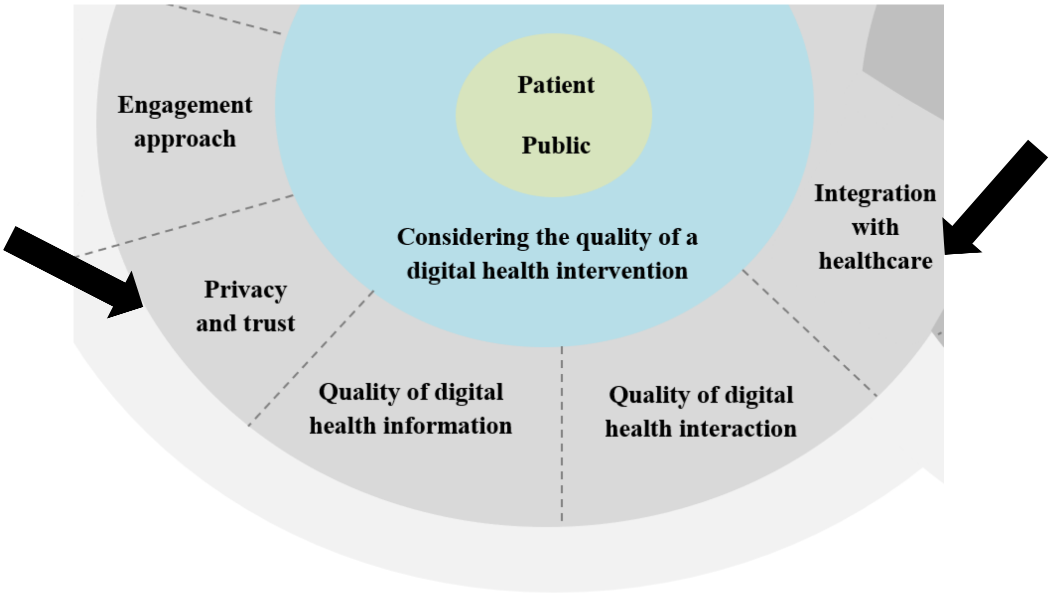


Figure 20: Lower left section of the updated DIEGO model

The upper right section of the DIEGO model has been completely revised due to new sub-themes that emerged from the systematic review update in Chapter 4 and the qualitative findings of the dallas programme in Chapters 5, 6 and 7. Firstly “Cost and funding” for a DHI is now represented in the updated model (see Figure 21). This idea came to the fore in the review update and the dallas programme as some people had to pay for technologies or were asked to consider this possibility. Although the affordability of technology did not emerge as a significant issue in the original systematic review, the importance of the topic warrants specific inclusion in the model as it is a factor for some people when trying to operationalise enrolment in a digital health intervention.

“Digital infrastructure (network)” has also been added to this section of the model as the findings from the dallas programme highlighted that a high-speed telecommunications network i.e. broadband Internet access was an important element that needed to be in place to support the enrolment process. This is closely aligned to the affordability of technology, given that Internet access can be expensive and is an on-going cost people must pay for to access digital information and services online. Hence, it appears beside “Cost and funding” in the updated DIEGO model.

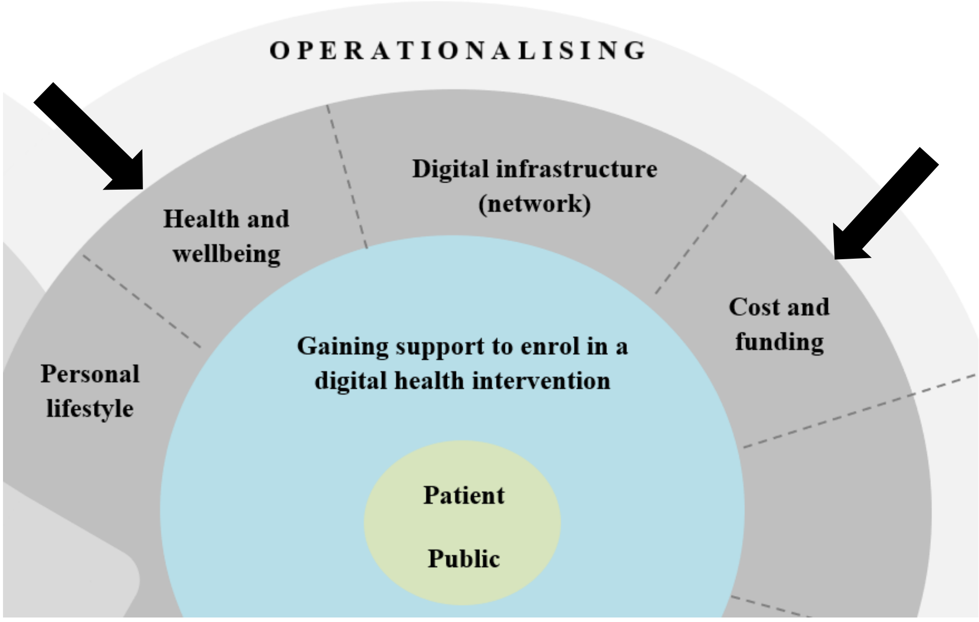


Figure 21: Upper right section of the updated DIEGO model

“Health and wellbeing” is another new sub-theme that arose from the systematic review update in Chapter 4, as some people who were unwell struggled to engage with or sign up for DHIs. Although this did not emerge as a clear theme in the dallas programme, there were a handful of qualitative comments that hinted it might be an issue. Therefore, it has been added to the updated model as a factor that can support or hinder people to enrol in a DHI. “Personal lifestyle” has been moved to the upper right section of the DIEGO model as the findings of the dallas programme in Chapter 5 demonstrated this concept aligned more with gaining support to enrol in a DHI rather than registering for it. In addition, two old concepts of “Direct support” and “Personal advice” present in this upper right section of the preliminary model have been merged into a single concept called “Tailored support” discussed in the next paragraph. Furthermore, “Recruitment strategy” has been renamed to “Enrolment plan”. These have been moved to the lower right section of the updated model as the results of the dallas programme showed they align more to registering for a DHI.

Finally, in the lower right section of the DIEGO model a number of changes can be seen. The original “Recruitment strategy” concept has been broken down into four distinct elements based on the different types of enrolment plans in Table 33. It has also been renamed to “Enrolment plan” to more accurately reflect the unique approaches it represents, enabling it to be linked to the taxonomy of strategies outlined in Table 33 and any future developments of this. In addition, this concept is visually represented as being adjacent to but linked to the main DIEGO model. This makes it clearer that the “Enrolment plan” could be the last step in the process that patients and the public take when signing up to use a digital health product or service but it is not always necessary (see Figure 22).

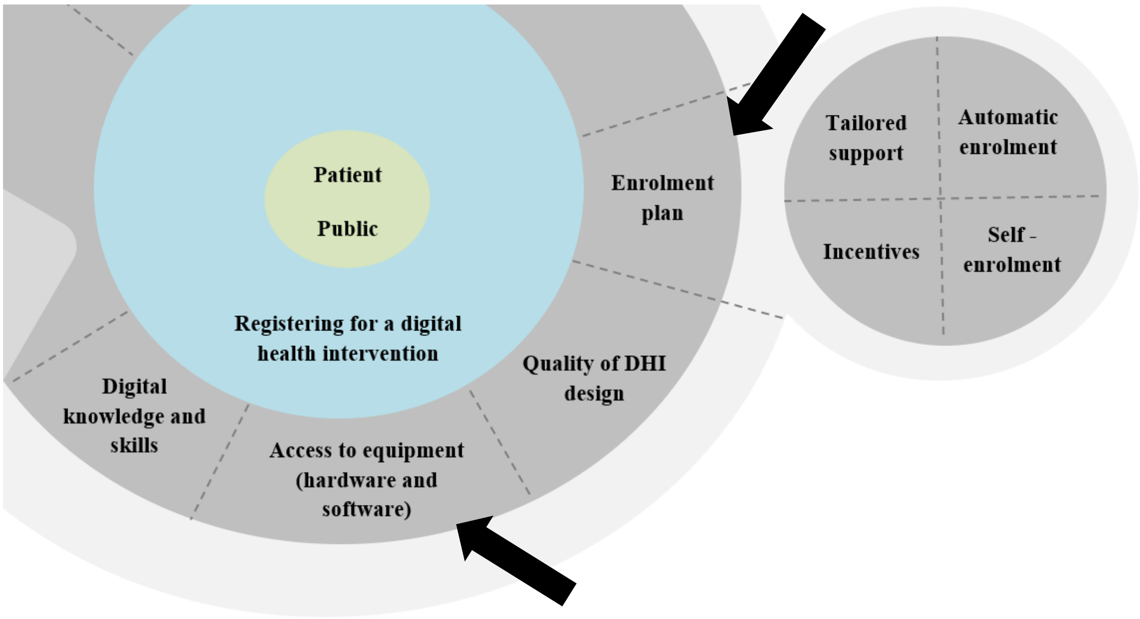


Figure 22: Lower right section of the updated DIEGO model

The original concept of “Skills and equipment” has been split into two separate elements, “Digital knowledge and skills” and “Access to equipment (hardware and software)”, reflecting the wealth of data from the dallas programme surrounding these two factors. The results showed that access to technology, both hardware and software, and good technical abilities were important factors when people were trying to register for a DHI which need to be clearly represented as distinct elements in the model. Therefore, they now appear as separate components of the updated DIEGO model as they can influence people’s ability to register for a DHI.

Finally, the old concept “Usability” has been renamed to “Quality of DHI design” as described in Chapters 4 and 5, as it better represents the role that the design of a digital health product or service can play in getting patients or the public signed up to it. Although it was in the lower left section of the preliminary model as an aspect of considering the quality of a DHI, it now occurs under registering for one as the review update and the findings of the dallas programme showed it can influence this process more.

8.3.2 The updated Digital Health Engagement Model

The fully updated DIEGO model with all the changes outlined above can be seen in Figure 23. This refined conceptual model depicts the aspects that affect patient and public engagement and enrolment in consumer digital health. However, it is worth noting that these complex processes are not static but ever changing depending on the circumstances of the individual and their context, and the DHI at any point in time. One aspect that did not explicitly emerge from the systematic review findings, its update or those from the dallas programme was around policies and guidelines that could potentially affect how patients or the public engage with or enrol in a DHI. However, they may underpin some of the existing concepts such as “Privacy and trust” or “Digital infrastructure” as national policies and international guidelines that govern data protection, the digital economy, and digital health among others could influence some of the concepts in the DIEGO model. This is a limitation of the current model as it was absent from the systematic review and the dallas programme, and so “Policies and guidelines” may warrant inclusion in future versions as a distinct component. Another element missing from the systematic review, its update and the dallas programme was detailed information on the ethnicity and cultural background of participants which could influence how people perceive and understand digital health products and services. Therefore, “Culture” may become another future component of the DIEGO model which future research should address.

The relationships between digital health engagement and enrolment concepts in this model are currently represented by dashed lines indicating loose associations between the different components, as the degree to which they influence one another is as yet unknown. The strength and influence of the connections between all the different variables could change depending on the context of the individual person and the type of DHI they are considering. Therefore, the DIEGO model will need to be tested with various groups to determine exactly how the components interact for people from different age groups, genders, ethnicities, and socio-economic backgrounds, and the technologies they wish to enrol in and use. This type of research would aid our understanding of these complex processes and how to improve the early phases of implementing consumer digital health.

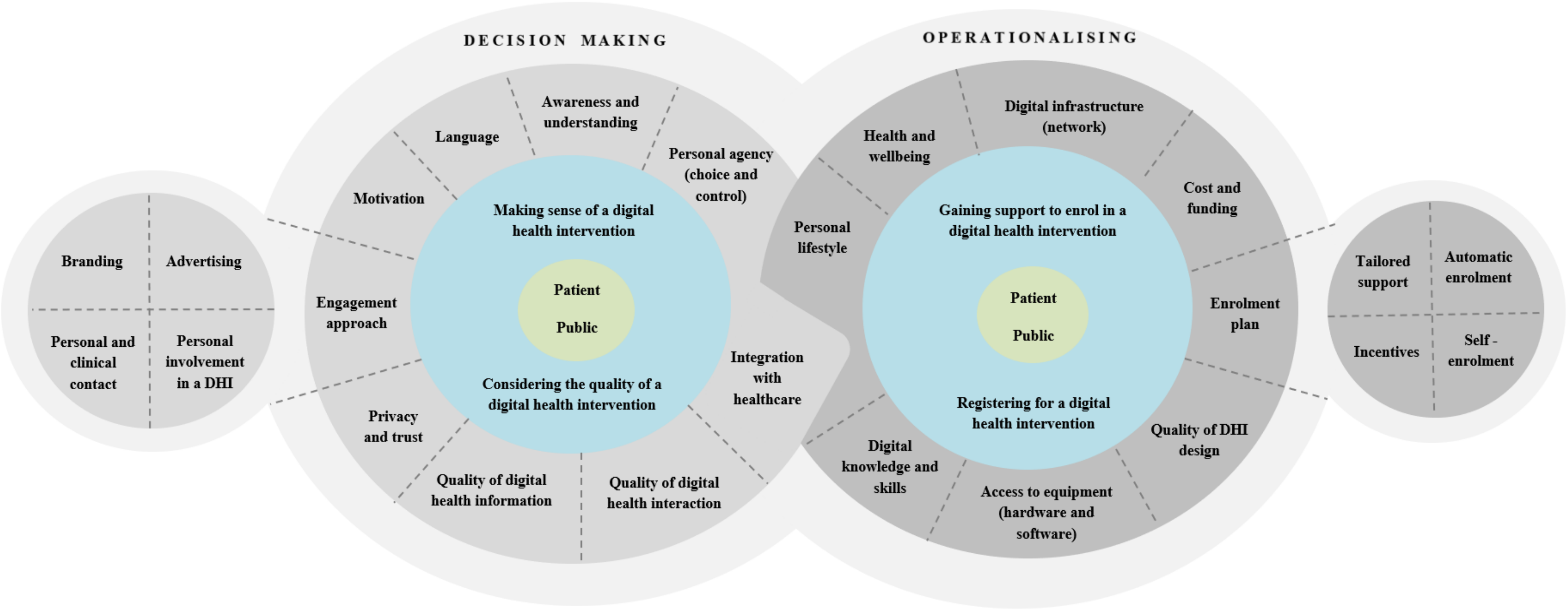


Figure 23: Updated Digital Health Engagement Model (DIEGO 2)

8.4 Strengths and limitations

The strengths and limitations of different aspects of this thesis have already been discussed in Chapters 4, 5, 6 and 7. Therefore, the stronger and weaker aspects of this doctoral research in relation to understanding engagement and enrolment in consumer digital health are discussed here.

8.4.1 Strengths

The breadth of data collected during the dallas programme, which spanned a three-year timeframe (2012 - 2015), has helped uncover some of the factors affecting engagement and enrolment in consumder digital health. Baseline, midpoint and endpoint interviews (n=47) allowed an examination of how people engaged with and signed up to various health technologies on offer in the UK during this period of time. In addition, two sources of primary qualitative data, interviews (n=14) and focus groups (n=5), were used with a wide range of people including patients and carers, service users, health professionals, third sector staff and volunteers, and employees of technology companies some of whom were deploying various DHIs (Chapters 5, 6 and 7). These multiple stakeholders and their views on deploying a wide range of digital health interventions from patient portals, to telecare through to mobile apps and personal electronic medical records were key to unpicking the early phases of implementation from a range of perspectives (Chapters 4, 5, 6 and 7). This facilitated a richer understanding of the subject as varying opinions and experiences were gathered. Digital health implementation is often only looked at and reported in silos, and in relation to a single type of patient or DHI. This can make it challenging to understand the bigger picture and the general factors affecting deployment of a digital health intervention which this thesis begins to address.

The chain of evidence was systematically documented, analysed, and linked to a theoretical framework, Normalization Process Theory. As recommended in the published systematic review of the theory, this thesis has highlighted why NPT was chosen over other implementation theories (Chapters 2 and 3). NPT helped to strengthen the understanding of patient and public engagement and enrolment in digital health presented in Chapter 4. The application of this theory aiding the conceptualisation of key processes involved in implementating consumer digital health, leading to the creation of the Digital Health Engagement Model (DIEGO). This model was then refined and extended further through the application of NPT during the analysis of data from the dallas programme. This helped highlight where the barriers and facilitators occur for patients and the public when engaging and enrolling in digital health (Chapter 8). Another strength of this thesis is that it builds upon past research that has been conducted using NPT. The development and application of this theory has focused on understanding and explaining the social processes by which people embed new technologies and other interventions in healthcare contexts (McEvoy et al., 2014). The four constructs of NPT form the basis of the DIEGO model and helped identify where the barriers and facilitators occured in the engagement and enrolment process. It also enabled a greater understanding of the factors affecting patients and the public (Chapter 5), health professionals (Chapter 6) and implementers (Chapter 7) during engagement and enrolment to DHIs during the dallas programme, by making the processes by which these happened more explicit.

8.4.2 Limitations

Due to the broad research questions posed in this thesis, the systematic review of engagement and enrolment in digital health focused solely on the experience of patients, the public, and DHIs that were deployed and evaluated in real-world settings. However, undertaking a process evaluation to undercover barriers and facilitators during implementation is becoming a key part of clinical trials when assessing the effectiveness of an intervention (Moore et al., 2015). RCTs were specifically excluded in the systematic review due to the fact that their implementation issues are more specific to the artificial context of clinical trials than the real-world. This means knowledge gained through process evaluations of trials centred on DHIs could have yielded some relevant information but these are not included in this thesis, which may limit the findings to some degree. The studies in the systematic review also took place in developed, wealthy nations. How DHIs are implemented in low and middle-income countries may be different. It is likely that additional barriers and facilitators during engagement and enrolment to consumer digital health might be faced by the three stakeholder groups, patients and the public, health professionals and implementers, in these contexts.

Several limitations are present in the thesis due to the nature of the dallas programme, some of which have been discussed in Chapters 5, 6 and 7. One restriction is that two postdoctoral researchers carried out the baseline, midpoint and endpoint dallas interviews and this dataset focused on the entire implementation process and not just the initial phases which are directly relevant to this thesis. Although pertinent data were found in nearly every one of these interviews, questions specific to engagement and enrolment in consumer digital health were not included which limited the exploration of these concepts to some degree. A major limitation present in this thesis stems from the sampling frame which is largely missing the perspective of patients and the public. Only six patients and sixteen service users were spoken to directly by the doctoral student and no members of the public who tried to engage with or sign up to DHIs during the dallas programme were reached. Although 96 other types of individuals (from carers, to health professionals, health service managers and administrators, third sector staff and volunteers, employees of technology companies, along with researchers and government staff) who would have had some appreciation of the barriers and faciltitators experienced by patients and the public were spoken to, some important contextual information could have been missed. This is particularly the case for members of the public whose engagement with and enrolment in DHIs would not be directly linked to an established health service, potentially making the process a little different.

In addition, the sample consisted primarily of white, healthy, middle-aged participants from middle to upper class backgrounds, although a few older adults over the age of 65 were reached in one of the focus groups and the primary interviews. Hence, no participants were children or young people, those with disabilities conditions, or the very elderly, and few besides four people diagnosed with dementia had any physical, mental or social health problems.

Many of the technologies on offer during the dallas programme were also not aimed at some of these groups such as children and young people, those with disabilities, or those with mental health illnesses. This may help explain the limited amount of data from the dallas programme on ‘Health and wellbeing’ that could affect engagement and enrolment in consumer digital health in numerous ways. Participants from other ethnicities and those from lower socio-economic groups, bar a handful of people in one focus group from working class backgrounds, were also not reached as part of the dallas programme or its overall evaluation. This could be one of the reasons that ‘Culture’ is missing from the updated DIEGO model as it was not present in the findings of Chapter 5 and could influence uptake of consumer digital health. There were some indications that people in lower socio-economic groups faced additional hurdles in relation to engagement and enrolment in DHIs, as noted in Chapter 5, but data presented in the thesis on these issues is partial at best. A further limitation is a geographic one, as Northern Ireland and Wales were not involved in the dallas programme, meaning the perspectives of people in these more economically deprived regions of the UK are missing from the results of this thesis. The UK is also a developed nation located in Western Europe and its social, economic, political, and cultural context may not fully reflect how people in other parts of the world, particulary those in low and middle income countries, experience engagement and enroment in consumer digital health.

Finally, the timeframe of the dallas programme and the doctoral study also placed further restrictions on the results of this thesis. The doctoral study began in April 2014 when the dallas programme was more than half way complete, meaning there was limited ways to influence how data could be collected. By the time ethical approval was obtained in March 2015, only four months were available for data collection before the programme finished completely. This severely restricted the number and type of participants that could be reached and spoken to via interviews and focus groups. The doctoral candidate wanted to concentrate on speaking to as many patients, carers, and service users as possible during this time and so missed interviewing health professionals directly, although 14 were included in focus groups. In addition, only two patients and two carers were interviewed by the doctoral student, although a few more participated in focus groups, and only 16 service users were reached via focus groups. All these limitations may restrict and reduce the applicability of the findings of this thesis on engagement and enrolment in consumer digital health to some degree.

8.5 Personal reflections

The professional and personal interests of the doctoral student, who had prior qualifications and experiences of working in the IT sector and using technology for personal health, undoubtedly influenced this thesis. In addition, being a registered nurse and caring for patients who for the most part did not engage with technology, contributed to some extent to the research questions posed and the methodological approach taken in this study. Although the research questions were broad, encompassing all types of consumer related DHIs and populations of people (patients, the public, health professionals and implementers), the PhD candidate was keen to pursue this line of inquiry. This was due to her own multidisciplinary background, personal and clinical experiences as well as the shortcomings of the digital health literature which was too focused on single cases or contexts and therefore prevented an overarching view of engagement and enrolment in DHIs. Doctoral candidates are often advised to focus their research interests and pursue narrowly defined research topics. On personal reflection, there is merit in thinking more broadly about issues that affect all patients and health professionals and encouraging PhD students to consider wider topics within their field, a view represented in this thesis. However, this should be balanced with the practicalities of undertaking research within a relatively short timeframe and with limited experience, as the doctoral journey is a training ground for future professional practice and the study design needs to be planned and executed as competently as possible.

In saying this, the research gap identified posed a number of challenges such as searching and selecting literature on such a wide-ranging subject for the systematic review. By consulting with the supervisory team, a new research collaboration with the University of York and a private company resulted in the application of a novel software technique i.e. text mining to overcome this barrier as described in Chapter 4. It became clear that tackling the complexities of real-world implementation requires interdisciplinary research and the expertise and input of many professionals. As this doctoral study progressed the need for interdisciplinary research continued to be important. Research colleagues from other disciplines such as computing science collected some of the dallas dataset used in this thesis, assisted in the peer debriefing process and enabled a broader understanding of the dallas programme and digital health implementation. On further reflection, other disciplines such as sociology and social policy would have been important to consider as they are grounded in a strong qualitiative approach and tend to work with more marginalised and underrepresented groups.

The systematic review indicated that literature on qualitative studies looking at barriers and facilitators to patient and public engagement and enrolment in digital health was limited. One omission was the lack of theoretically informed studies, as only 3 of the 19 included articles and 1 in the review update had used some type of conceptual framework to guide the research process. Given the doctoral students' limited experience and understanding of theory at that stage, this did not appear to be a significant flaw. In addition, the student held some reservations about the benefits that theory could bring to qualitative research. On further reading and as Normalization Process Theory (NPT) began to be used to analyse the included studies in the review, the value of applying an a priori framework to the dataset became apparent. Firstly, the theory guided the development of a preliminary conceptual model of these processes, as the doctoral student was able to map the emerging themes to the four generative mechanisms of NPT. This enabled a clearer picture of engagement and enrolment in DHIs to emerge as documented in Chapter 4. Secondly, NPT aided the conceptualisation of the processes that people go through individually and collectively when trying to implement a new intervention in healthcare. This enabled a robust analysis of the secondary dallas dataset leading to the identification of five main themes in Chapter 5, encompassing a range of barriers and facilitators to engagement and enrolment in digital health. It then became critical to analyse the dataset using this theory, leading to a revision and update of the DIEGO model in Chapter 8. In hindsight, without the application of a well-developed implementation theory the new insights gained throughout this work in Chapters 4, 5, 6, 7 and 8 would not have been as in-depth. Developing a theory from scratch would have been unnecessary given the body of work around theories of implementation that already exists. Going forward the doctoral candidate intends to develop the DIGEO model further and ensure any future digital health research she undertakes is theoretically grounded where appropriate.

Finally, researcher reflexivity required thoughtful consideration throughout the doctoral journey to reduce the potential for personal bias to impact the research findings. As such numerous techniques such as coding clinics, peer debriefing and triangulation of data from many participants were used to ensure the analysis reflected the data collected and not any personal perspectives. In addition, the doctoral students' role as a nurse was not disclosed to participants before interviews or focus groups were run but only after data had been collected. This should have reduced any material influence on people's responses due to their perceptions of health professionals. Nonetheless, participants were aware the student was a researcher based at the University of Glasgow with an interest in their opinions on digital health engagement and enrolment which could have affected some replies (Kuper, Lingard and Levinson, 2008). In retrospect, it would have been beneficial to keep a reflexive journal where regular entries on personal perspectives and values could have been recorded. This would have enhanced the transparency of the research process further. In future, this will become an integral part of this researchers' toolkit to ensure any preconceived ideas or potential biases are noted and reported.

8.6 Comparison with other literature

As described in Chapter 2, there is a large body of literature on how technology is implemented in healthcare. This has predominantly focused on hospital and primary care based computer systems used by health professionals. Only in the last decade or so has evidence begun to be published on how digital health products and services are deployed with patients, carers, and the public in general. This research has tended to concentrate on one specific piece of technology such as a telehealth system or mobile health application. It has examined how this was rolled out with single populations of patients who have a distinct clinical problem (Miyamoto et al., 2013; Whittemore et al., 2013) or groups of people who were generally healthy such as pregnant women or adolescents (Thompson et al., 2006; Bot, Milder and Bemelmans, 2009). The literature has also focused predominantly on the middle stages of implementation when people start using a DHI. In contrast, this thesis takes a broader view and sought to identify generic factors, both barriers and facilitators, affecting the early phases of implementation across the major stakeholder groups and all health-related consumer technologies.

Other researchers have examined factors that affect engagement and enrolment to DHIs which correspond with the findings of this thesis (Hardiker and Grant, 2011). Several studies exist which elucidate the experiences of specific groups of patients and carers when signing up for a particular DHI. For example, Sanders et al. (2012) found that several people declined to take part in a telehealth trial due to concerns over a lack of technical abilities to use the equipment and personal values that preferred a sense of control and independence around health and wellbeing. Huygens et al. (2016) reported that patients with a range of chronic illnesses were hesitant about engaging with digital health as some did not like being reminded of their illness and felt it should be a person’s choice whether to use technology or not. One the other hand, certain respondents believed clinicians reviewing their data and providing feedback would be useful. These echo the barriers and facilitators identified in Chapters 4 and 5. Fewer studies have looked at healthy populations of people as technologies such as mobile applications and wearable devices to maintain health and wellness are a relatively recent addition to the digital health landscape. However, where these groups were included in digital health implementation research the results mirror those of this thesis. For example, parents considering an electronic childhood obesity screening and intervention tool felt they did not have adequate time to take part due to busy personal lives (Byrne et al., 2016). In Muessig et al. (2015) some men who were asked to use a web resource for sexual health, that was accessible via mobile phones, expressed concerns about privacy and confidentiality online but liked the convenience it offered.

Health professionals such as family physicians and practice nurses have also been the subject of research exploring engagement with various types of digital health products and services. These studies reflect some of the barriers and facilitators discussed in Chapter 6 such as the lack of resources and technical skills, concerns over the confidentiality of electronic patient information and health professionals lack of familiarity with digital health (Odeh, Kayyali, Gebara and Philip, 2014; Reginatto, 2012). However, general implementers such as those from the technology industry, staff from the third sector, and health service managers have been largely overlooked in the current literature as the focus has predominantly been on patients and health professionals. Some recent studies of these stakeholder groups do exist and their findings resonate with the results presented in Chapter 7. In particular, using co-design to create more personalised technology (Reay et al., 2017) and partnering with other organisations to facilitate the implementation process (Peek, Wouters, Luijkx, and Vrijhoef, 2016) have been reported.

Greenhalgh et al. (2017) recently published a new Non-adoption, Abandonment, Scale-up, Spread and Sustainability (NASSS) framework based on a review of existing theories and empirical case studies of technology implementation in healthcare. The NASSS framework helps to explain the different aspects that affect how patient-focused health and wellbeing technologies are taken up and sustained over time. The seven identified domains include the condition of the patient, a variety of organisational elements needed for change and wider structural aspects such as the policy and regulatory environment (see Figure 10). While this overarching framework will no doubt be beneficial in planning and rolling out health technologies at scale, it is too high-level and does not explore the intricacies of the early stages of the implementation process when people initially engage and enrol in DHIs. As the NASSS framework has some concepts such as features of the technology and the value proposition in common with the updated DIEGO model, future researchers may combine these two frameworks in a useful way to aid our understanding of digital health implementation even further.

8.7 Recommendations

The focus of this thesis lies in disentangling the early phases of digital health implementation and it offers a clearer picture of what happens during the initial engagement and enrolment processes. This doctoral study also helps to differentiate the initial from the later stages of implementation, as the middle to later phases involve using a digital health intervention on a daily basis and embedding or normalising use so it becomes sustained over time. The early, middle and later stages of implementation can often become muddled making it difficult to identify at which point certain barriers and facilitators occur. By focusing solely on the initial steps when implementing digital health product and services, this thesis helps to clarify what barriers and facilitators occur during engagement and enrolment to DHIs for three key stakeholder groups.

Although a range of DHIs were deploying during the dallas programme, few of them are still operational in 2019. The myriad barriers to engagement and enrolment identified in this thesis across the three stakeholder groups, may have contributed to short-term engagement and use of the digital health products and services. Some common themes emerged across patients and the public, health professionals and implementers on how these barriers could be addressed, leading to a number of recommendations for education, research, professional practice, and policy, particularly within the context of the United Kingdom. These are outlined below and could be used to help improve the initial stages of implementing consumer digital health.

8.7.1 Education

Health educators should create general training programmes to assist in spreading the word about DHIs among different groups of clinicians. Online portals are being developed to host training webinars and educational material for HPs on digital health topics (O'Connor, Hubner, Shaw, Blake and Ball, 2017). Some undergraduate and postgraduate programmes in higher education do contain aspects of health informatics (De Gagne, Bisanar, Makowski and Neumann, 2012) and these developments should be expanded. Despite a long period with no national initiative to train clinicians and other professional staff on digital health, this is finally beginning to happen in the UK. NHS England established a new virtual NHS Digital Academy that is helping to train leaders in the health service about technology (NHS England, 2019). It is focusing on Chief Clinical Information Officers and Chief Information Officers initially, as part of the new NHS Five Year Forward View (NHS England, 2014), as they are some of the key people responsible for introducing and maintaining technology in the NHS. The Wachter '*Making It Work*' report that emphasised the need for better digitisation in the NHS also helped spurred this new educational initiative, as one of its recommendations included health informatics training for the workforce (Department of Health and Social Care, 2016).

Scotland's new Digital Health and Care Strategy also includes a commitment to producing a health and social care workforce competent in digital health (Scottish Government, 2018). NHS Scotland's national training organisation, NHS Education for Scotland, is producing a series of online 'Technology Enabled Care' courses that any clinical and non-clinical staff can take to improve their understanding in this area (NHS Education for Scotland, 2019). It also emphasises that staff should participate in a number of other initiatives including the NHS Digital Academy, the Nurses, Midwives and Allied Health Professions (NMAHP) eHealth Leadership Programme and the Digital Champions Development Programme. This may go some way to addressing the lack of knowledge and skills some health professionals have about technology, which could aid the implementation of consumer digital health in the future.

Training programmes may also help address the lack of awareness and understanding of DHIs among patients and the public, and ensure they have the digital knowledge and skills they need to enrol in and begin using them. In particular, the public needs to be better informed about the benefits, limitations, and risks associated with managing and sharing personal health information via technology. Digital champion initiatives such as those used with local community organisations in the dallas programme could be extended and scaled up. This may give people, especially those in more deprived regions of the UK, the computer skills and equipment they need to get online and sign up for DHIs. Health inequalities that stem from risk factors such as smoking, poor diet, high blood pressure, obesity, alcohol and lack of exercise are highlighted in the NHS Long Term Plan which also includes a committement to a '*new digital option to widen patient choice and target inequality*' (NHS England, 2019, p. 37). The new strategy also highlights more use of telehealth and telecare systems to prevent or reduce hospital admissions and digitally enabled primary care services such as GP appointments, consultations, and prescriptions. However, the digital divide and how those excluded from participating in digital health due to poor computer skills, the inability to pay for technology, or limited Internet connectivity is not explicitly addressed in this long-term plan. Equally, Scotland's Digital Health and Care Strategy mentions inequalities in relation to understanding these drivers, without acknowledging that some stem from digital exclusion or how these will be addressed. However, it does refer to the overall digital strategy for Scotland as it covers "*increasing digital participation*" (Scottish Government, 2018, p. 4) and mentions health and social care organisations should sign up to a Digital Participant Charter to ensure everyone has basic digital skills (Scottish Council for Voluntary Organisations, 2019).

On a positive note, other policies such as the UK Digital Strategy (Department of Digital, Culture, Media and Sport, 2017) and Scotland's Digital Strategy (Scottish Government, 2017) make a clear commitment to enabling all people to access and use the Internet by funding more community digital skills projects. However, the UK Digital Strategy omits a key barrier, the ability to afford Internet access, which requires buying a device and paying for data. The use of local libraries with free computer equipment and Wi-Fi that this policy highlights, may not be adequate on its own to educate people or give them free access to online information and services as many libraries in England are being closed (BBC, 2016) and others are not open every day or around the clock. Hence, upskilling the public with better digital skills and finding ways to provided subsidised or free computer equipment and Internet access for those who need it should be prioritised, if these ambitious policies and their long-term health and health service goals are to be achieved for all.

8.7.2 Research

More research that examines engagement and enrolment strategies in consumer digital health and their effectiveness in detail and investigates how to apply and extend the DIEGO model could be helpful as it may support implementation. A new policy paper from the UK Department of Health and Social Care outlines the vision for digitalisation in the NHS (Department of Health and Social Care, 2018). That and Scotland's Digital Health and Care Strategy (Scottish Government, 2018) both emphasise delivering more personalised services that will "*empower citizens*" to use technology to stay healthy and well at home. In particular, the Scottish strategy highlights co-production as one way to achieve this, while the UK policy paper mentions co-creation with industry and innovators. As co-design was one approach identified in this thesis that could support engagement and enrolment in consumer digital health it should be researched in more depth. However, Erikainen, Pickersgill, Cunningham-Burley and Chan (2019) note this empowerment and participatory agenda as a potentially dangerous discourse in digital health, as it could lead to an over medicalised life which focuses on individual responsibility for health through technology over state action addressing the social determinants of health and the provision of health services. In addition, it may allow unnecessary commodification and control of personal health data and health services by commercial interests, cementing consumerism and privatisation within healthcare systems and the health inequalities that this often brings. Hence, the policy rhetoric around co-producing technology with patients, carers, and the public needs to be unpicked and robust evidence generated on whether it has merit or not, as the results of this thesis provided only limited insights into this approach.

8.7.3 Professional practice

Clear plans should be developed and budgets assigned by implementation teams in the public or private sector to deliver, monitor and evaluate their activities in advance of deploying DHIs. Partnering with marketing specialists and with other relevant agencies such as the third sector organisations could also enhance the reach and impact of engagement and enrolment strategies to improve the uptake of DHIs. A positive digital culture must be cultivated within the health service which should include managers and leaders at all levels of an organisation that champion DHIs, as this could facilitate the uptake of technology by health professionals. This approach can be seen in the new NHS Long Term Plan with a commitment to work across the wider NHS, voluntary sector, developers, and individuals to create a range of health apps for particular conditions such as diabetes that could be added to the NHS Apps library (NHS England, 2019). This new stratetgy also highlights a further investment in informatics leadership by expanding the NHS Digital Academy programme. The new Digital Health and Care Strategy from Scottish Government also emphasises the importance of key delivery partners from health, social care, local authorities, government directorates, and Integration Authorities, the new mechanism that leverages multidisciplinary teams from a range of local organisations to deliver integration of health and social care services (Scottish Government, 2018). ‘Technology Enabled Care’ leads and clinical champions have also been identified as key individuals to help deliver this new digital strategy after an inquiry into ‘Technology and Innovation in Health and Social

Care' by Scottish Parliament in 2017 recommended some of these approaches (Scottish Parliament, 2017). These types of investments might facilitate the roll out of consumer digital health products and services in the future.

And then there is Brexit to consider and how this evolving political process, of withdrawing from the European Union, might unfold and affect professional practice. Some have predicted it will negatively impact the UK. Fahy et al. (2017) describe three potential scenarios for the NHS that include a number of significant risks as well as some opportunities. These may influence consumer digital health in a number of ways. For example, the recruitment and retention of the health workforce may become more challenging, meaning health professionals may have less time and enthusiasm to promote DHIs if their workload increases. The regulatory framework surrounding clinical trials might become more complex which could reduce the volume and quality of technology related research and the evidence needed to put it into practice. Funding for health and digital health may be reduced if the UK economy declines due to strict trade agreements and tariffs on imports among other factors. This could result in many digital health initiatives being scaled back, delayed or not undertaken. Negotiations between the UK government and the European Commission are still ongoing and an upcoming general election in the UK in December 2019 may be a deciding factor on whether Brexit happens at all (Bennett, 2019).

8.7.4 Policy

Digital infrastructure such as broadband networks need investment and upgrading to improve online accessibility for all as this could enhance uptake of DHIs. National policies around the digital economy in the UK do include a commitment to installing advanced data networks. The UK Digital Strategy includes an assurance that free Wi-Fi will be rolled in public places and a 'Universal Service Obligation' will be set up to give everyone the right to request an affordable high speed broadband connection. It also outlines that it will upgrade the current telecommunications infrastructure to full fibre and introduce 5G networks to increase Internet bandwidth (Department of Digital, Culture, Media and Sport, 2017). In Scotland the government's digital strategy is continuing to invest in both superfast broadband for homes and businesses as well as a community broadband scheme to extend Internet access into more rural and remote areas (Scottish Government, 2017). A Mobile Action Plan was also published in 2016 to address mobile hot-spots where not Internet connectivity is available. This is giving telecommunications companies access to public assets to improve 4G and 5G networks (Scottish Government, 2016). Funding needs to follow these policies to ensure these changes are delivered to improve digital infrastructure and Internet accessibility across all regions of the UK. This might make it easier to roll out consumer digital health products and services in the future.

8.8 Conclusion

This doctoral study has adopted a qualitative approach to explore the early phases of the digital health implementation journey by examining the experiences of three key stakeholders involved in the process; 1) patients and the public, 2) health professionals, and 3) implementers. This has led to numerous barriers and facilitators to engagement and enrolment for each group being identified and some potential solutions and ways forward have been highlighted. A catalogue of engagement and enrolment strategies has also been compiled and a conceptual model focusing on how patients and the public engage and enrol in DHIs was created. Based on this, further work should focus on developing robust and comprehensive taxonomies of digital health engagement and enrolment approaches. It should also include testing and refining the DIEGO model with different populations of people, to aid in understanding the relative importance of the different components of the model and their impact on digital health engagement and enrolment. This could help simplify implementation processes and improve uptake to digital health products and services, which could positively impact the wellbeing of citizens and how health systems operate in the future.

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Exploring eHealth Implementation: Understanding Factors Affecting Engagement and Enrolment in Consumer Digital Health

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Submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy (PhD)

General Practice and Primary Care

Institute of Health and Wellbeing

University of Glasgow

September 2019

VOLUME 2 – APPENDICES

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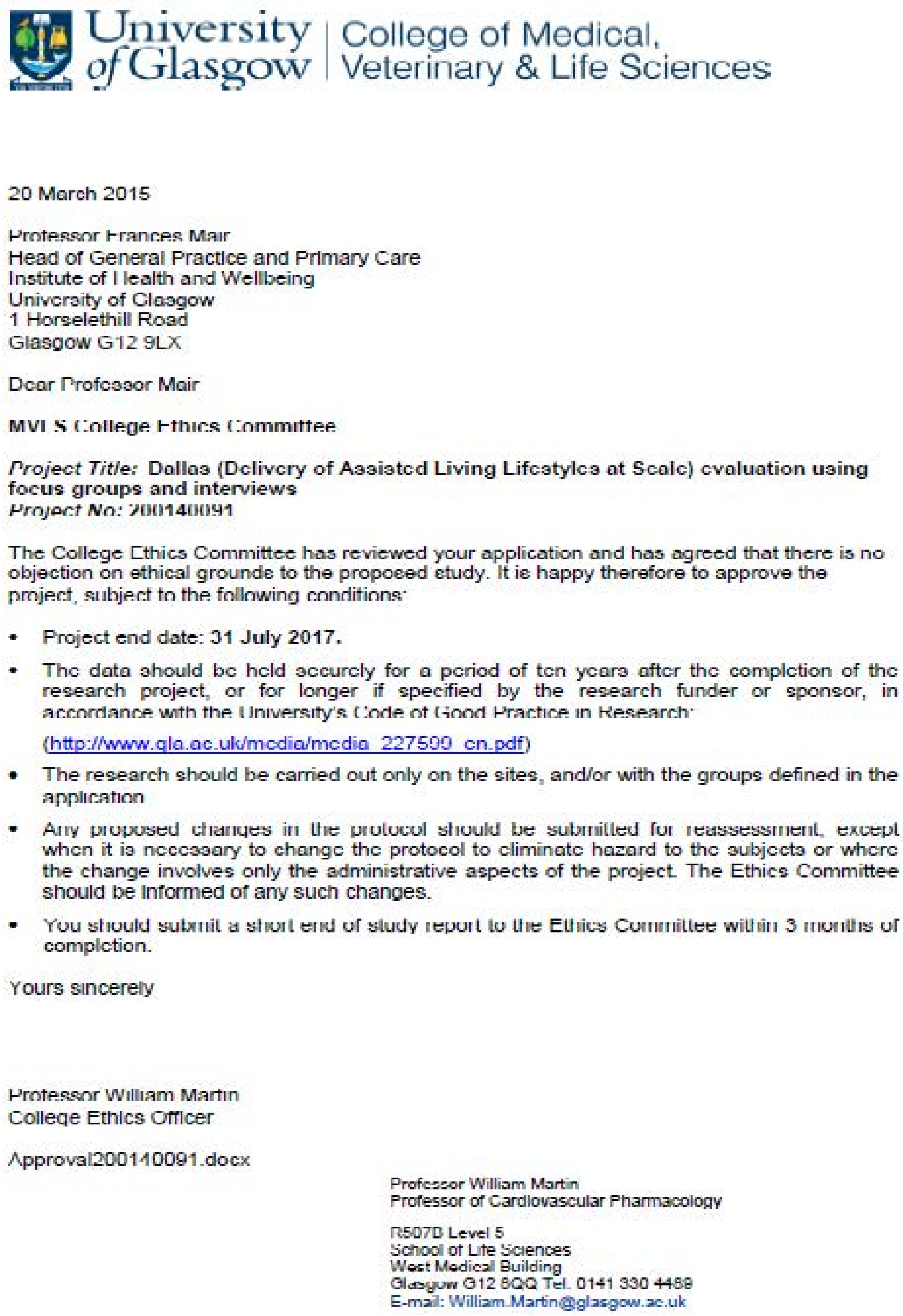
Appendix 1 Ethical documentation

1.1 Ethical approval letter



University of Glasgow | College of Medical, Veterinary & Life Sciences

20 March 2015

Professor Frances Mair
Head of General Practice and Primary Care
Institute of Health and Wellbeing
University of Glasgow
1 Horselethill Road
Glasgow G12 9LX

Dear Professor Mair

MVLS College Ethics Committee

Project Title: **Dallas (Delivery of Assisted Living Lifestyles at Scale) evaluation using focus groups and interviews**
Project No: **200140091**

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: **31 July 2017.**
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:

  (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Professor William Martin
College Ethics Officer

Approval200140091.docx

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1.2 Participant information sheet

University of Glasgow | Institute of Health & Wellbeing

INFORMATION SHEET

University of Glasgow evaluation of the U.K. Delivering Assisted Living Lifestyles at Scale (dallas) programme

1. What is the purpose of the study?

The University of Glasgow is conducting an evaluation of the U.K. Delivering Assisted Living Lifestyles at Scale (dallas) programme. Dallas aims to promote the use of independent and assisted living services and digital technologies in order to improve people's health, well-being and lifestyles across the United Kingdom (http://connect.innovateuk.org/web/dallas).

2. Why have I been chosen?

You have been asked to consider taking part in this study because you were involved in the design and development of one or more of the digital products/service or you are promoting the use of one or more of the digital products or services, which have been developed or adapted as part of the dallas programme.

3. Do I have to take part?

It is up to you to decide whether or not to take part in this evaluation study. It is completely voluntary in nature.

4. What do I have to do?

If you do decide to take part you will be contacted by a researcher from the University of Glasgow, who will organise a short telephone **interview** with you at a time and location that is convenient for you. You will be asked questions only relating to your experiences of the dallas programme. You will be asked to sign a consent form before the interview begins to show you are willing to participate in the study. You are free to withdraw at any time and without giving a reason.

5. What are the possible disadvantages and risks of taking part?

There will be no risks relating to your health. There is a small risk related to data privacy and confidentiality but the evaluation is working within strict rules governing how to handle personal data so this has been minimised.

6. What are the possible benefits of taking part?

Although you will receive no direct benefit from taking part, it is anticipated that this study will bring benefits in sharing and reporting examples of best-practice in digital technology development and implementation for people's health & well-being.

7. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it.

8. What will happen to the results of the research study?

Results will be disseminated through reports, scientific publications, conferences presentations, seminars and briefing papers. You will not be personally identified in any report/publication. We will send you copies of published results, if you would like us to do so.

9. Who is organising and funding the research study?

Innovate UK (formerly known as the UK Technology Strategy Board) is funding this research.

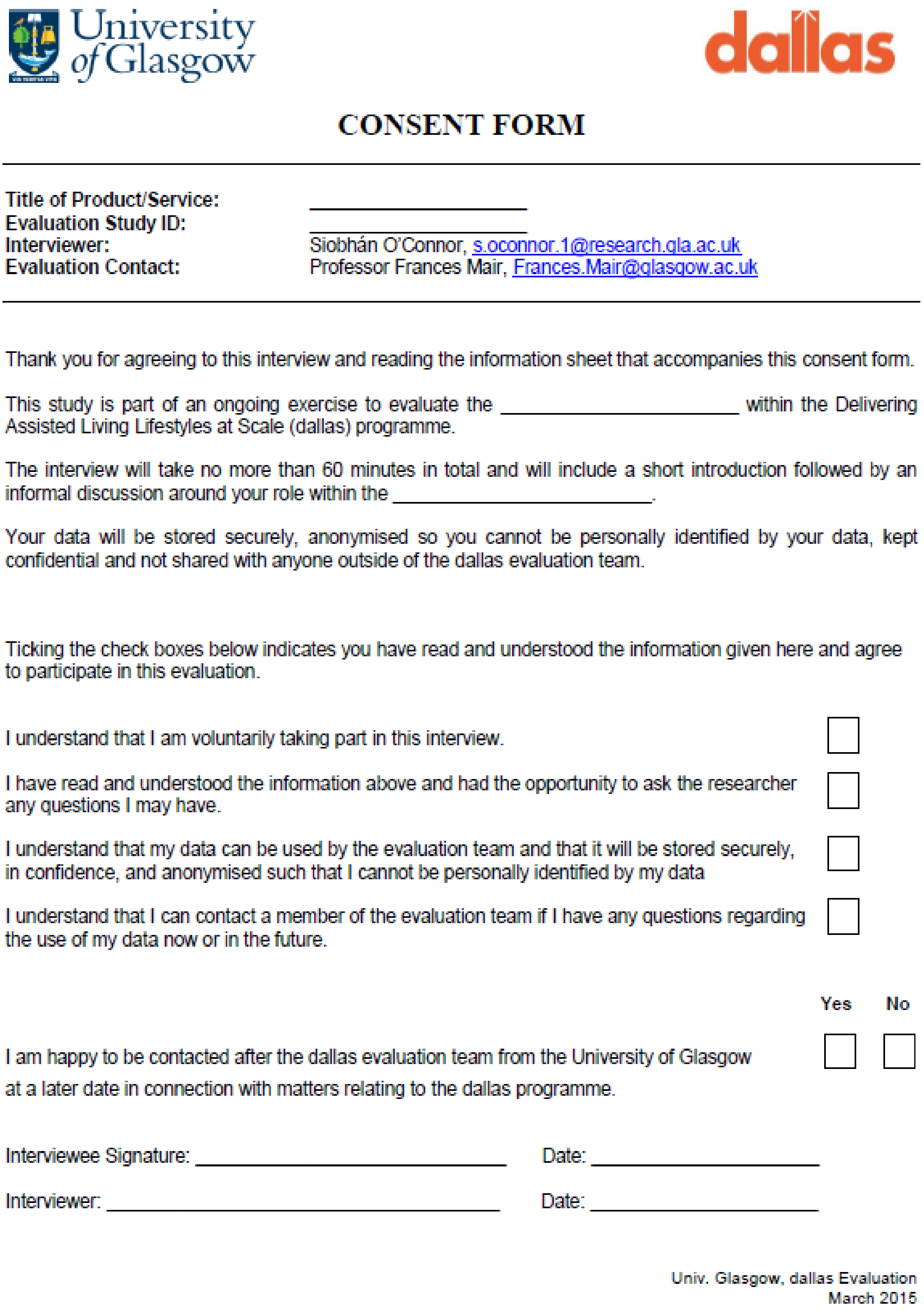
10. Who has reviewed the research study?

This study has been reviewed and accepted by the University of Glasgow, College of Medical, Veterinary and Life Sciences Ethics Committee.

Contact for Further Information

Professor Frances Mair
General Practice and Primary Care
1 Horslethill Road
University of Glasgow
Glasgow G12 9LX
Tel: 0141 330 9317
Email: Frances.Mair@glasgow.ac.uk

1.3. Informed consent form



University of Glasgow

dallas

CONSENT FORM

Title of Product/Service: ____________________

Evaluation Study ID: ____________________

Interviewer: Siobhán O'Connor, s.oconnor.1@research.gla.ac.uk

Evaluation Contact: Professor Frances Mair, Frances.Mair@glasgow.ac.uk

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Thank you for agreeing to this interview and reading the information sheet that accompanies this consent form.

This study is part of an ongoing exercise to evaluate the ______________________ within the Delivering Assisted Living Lifestyles at Scale (dallas) programme.

The interview will take no more than 60 minutes in total and will include a short introduction followed by an informal discussion around your role within the ________________________.

Your data will be stored securely, anonymised so you cannot be personally identified by your data, kept confidential and not shared with anyone outside of the dallas evaluation team.

Ticking the check boxes below indicates you have read and understood the information given here and agree to participate in this evaluation.

I understand that I am voluntarily taking part in this interview. ☐

I have read and understood the information above and had the opportunity to ask the researcher any questions I may have. ☐

I understand that my data can be used by the evaluation team and that it will be stored securely, in confidence, and anonymised such that I cannot be personally identified by my data ☐

I understand that I can contact a member of the evaluation team if I have any questions regarding the use of my data now or in the future. ☐

	Yes	No
I am happy to be contacted after the dallas evaluation team from the University of Glasgow at a later date in connection with matters relating to the dallas programme.	☐	☐

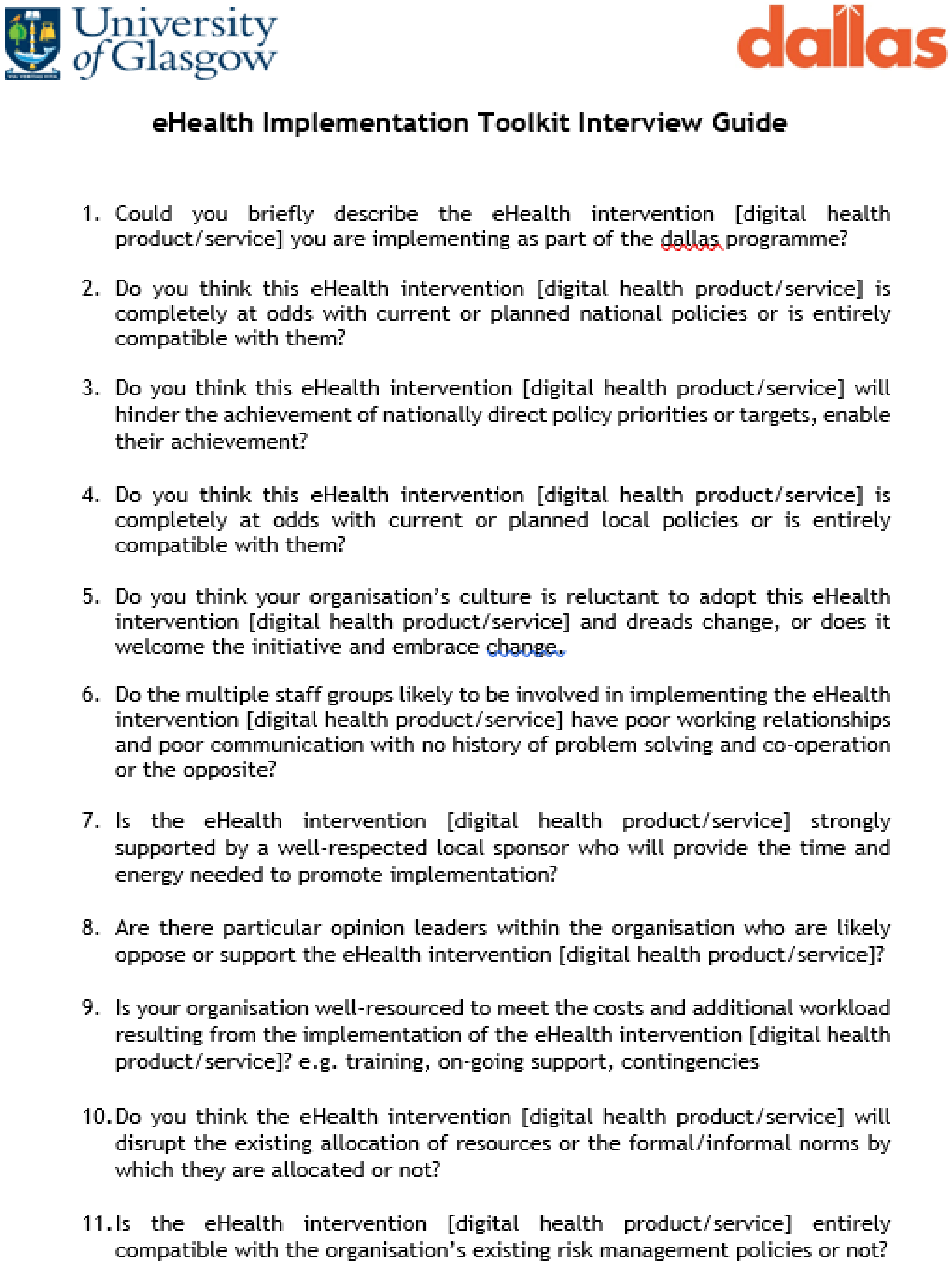
Interviewee Signature: ______________________________ Date: ____________________

Interviewer: ____________________________________ Date: ____________________

Univ. Glasgow, dallas Evaluation
March 2015

Appendix 2 Interview and focus group guides

2.1 e-Health implementation toolkit interview guide



University of Glasgow

dallas

eHealth Implementation Toolkit Interview Guide

1. Could you briefly describe the eHealth intervention [digital health product/service] you are implementing as part of the dallas programme?
2. Do you think this eHealth intervention [digital health product/service] is completely at odds with current or planned national policies or is entirely compatible with them?
3. Do you think this eHealth intervention [digital health product/service] will hinder the achievement of nationally direct policy priorities or targets, enable their achievement?
4. Do you think this eHealth intervention [digital health product/service] is completely at odds with current or planned local policies or is entirely compatible with them?
5. Do you think your organisation's culture is reluctant to adopt this eHealth intervention [digital health product/service] and dreads change, or does it welcome the initiative and embrace change.
6. Do the multiple staff groups likely to be involved in implementing the eHealth intervention [digital health product/service] have poor working relationships and poor communication with no history of problem solving and co-operation or the opposite?
7. Is the eHealth intervention [digital health product/service] strongly supported by a well-respected local sponsor who will provide the time and energy needed to promote implementation?
8. Are there particular opinion leaders within the organisation who are likely oppose or support the eHealth intervention [digital health product/service]?
9. Is your organisation well-resourced to meet the costs and additional workload resulting from the implementation of the eHealth intervention [digital health product/service]? e.g. training, on-going support, contingencies
10. Do you think the eHealth intervention [digital health product/service] will disrupt the existing allocation of resources or the formal/informal norms by which they are allocated or not?
11. Is the eHealth intervention [digital health product/service] entirely compatible with the organisation's existing risk management policies or not?

12. Will the eHealth intervention [digital health product/service] disrupt health professional - patient interactions e.g. will make them slower, or introduce tasks inappropriate to the encounter or will it have the opposite effect and facilitate these interactions in some way?

13. Do you think the eHealth intervention [digital health product/service] is entirely credible in terms of security, confidentiality and reliability or not?

14. Is the eHealth intervention [digital health product/service] easy to use and fit for purpose or not?

15. Has the eHealth intervention [digital health product/service] been well evaluated and demonstrated to improve healthcare in a cost-effective manner?

16. Will there be a period of increased workload during implementation or not?

17. Will the eHealth intervention [digital health product/service] increase the efficiency of current work patterns or not?

18. Is the eHealth intervention [digital health product/service] compatible with current divisions of labour or not?

19. Do you think staff who use the eHealth intervention [digital health product/service] will need substantial training prior to use or not?

20. Will the eHealth intervention [digital health product/service] disrupt existing power relationships between different staff groups or is it compatible with them?

21. Will the eHealth intervention [digital health product/service] undermine or enhance confidence in each other's expertise and performance between different professional groups?

22. Is the responsibility for how the eHealth intervention [digital health product/service] is used and the accountability for its outcome aligned to one or more staff groups?

2.2 Digital champion interview guide

Interview Guide - Digital Champions

1. Please could you introduce yourself and your role within the digital champions programme?

2. Why did you volunteer as a digital champion/ how did you get involved with the programme?

3. What activities do you undertake in your role as a digital champion?

4. Who do you engage with, in your role as a digital champion?

5. How to you reach these people? Describe the steps you take to engage people and encourage them to sign up to use a digital product or service. For example, do you demonstrate the application to them or do you help them to register for the digital product or service.

6. Do you engage all individuals such as patients, carers and others and encourage them to sign up to a digital product or service or only a select few? If you select them, what criteria do you use to choose individuals you feel are suitable for the digital product or service?

7. Do you engage with people once or more than once?

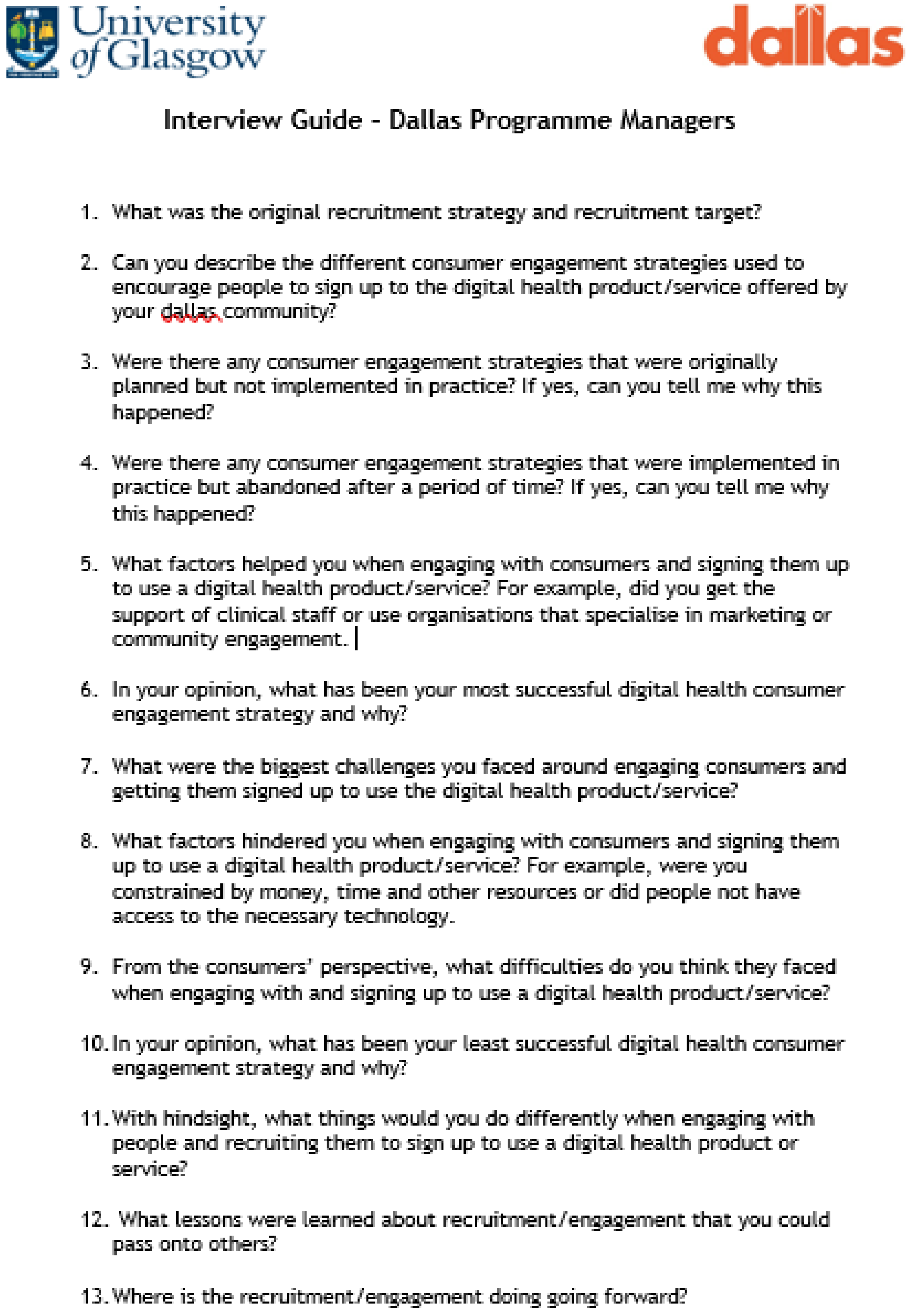
8. What factors help you to recruit people such as patients, carers or others and sign them up to use the digital product or service?

9. What factors hinder you when recruiting people such as patients, carers or others and signing them up to use the digital product or service?

10. With hindsight, what things would you do differently when recruiting individuals such as patients, carers or others and signing them up to use a digital product or service?

11. Is there anything else you would like to talk about?

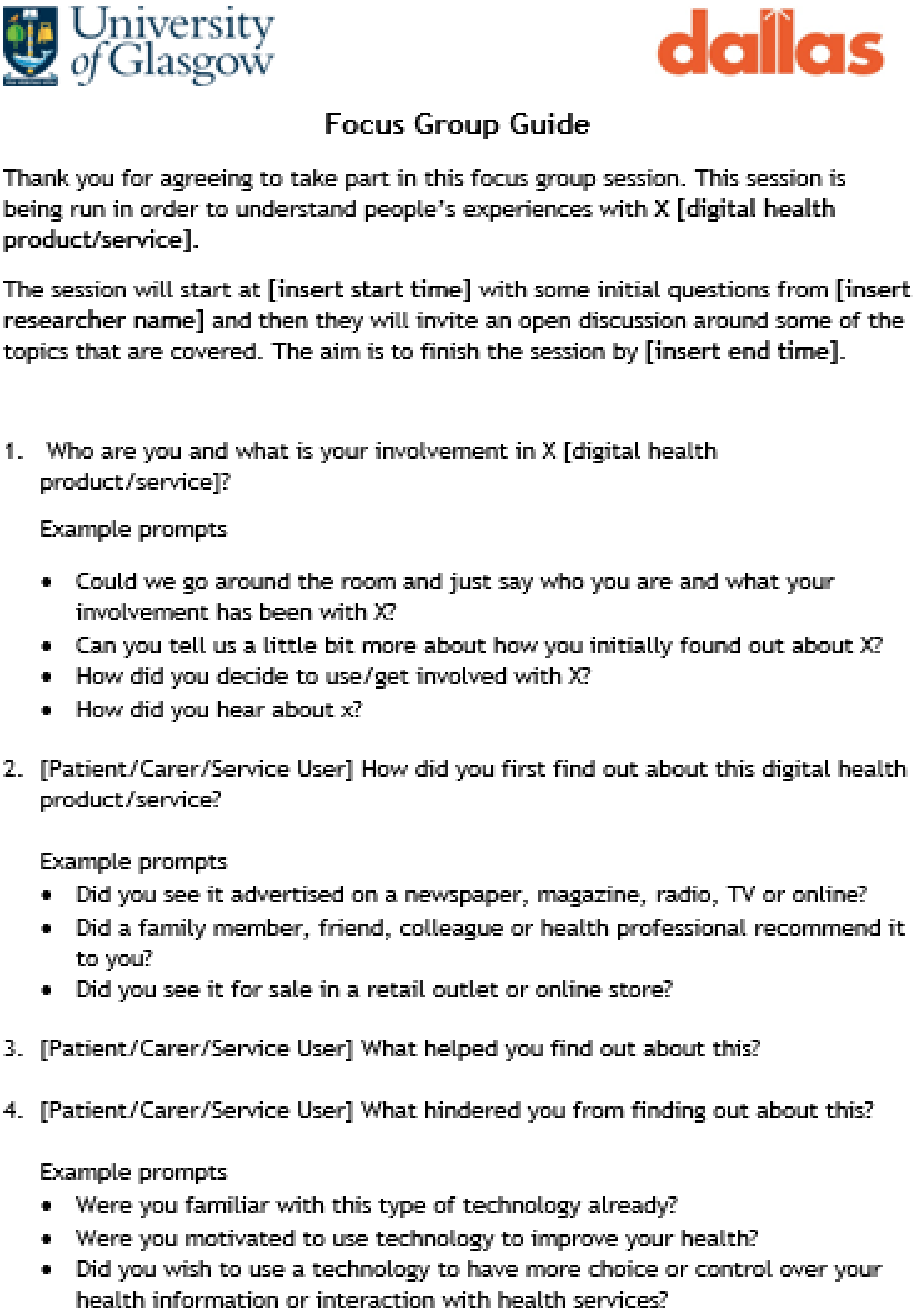
2.3 Dallas programme manager interview guide



Interview Guide - Dallas Programme Managers

1. What was the original recruitment strategy and recruitment target?
2. Can you describe the different consumer engagement strategies used to encourage people to sign up to the digital health product/service offered by your dallas community?
3. Were there any consumer engagement strategies that were originally planned but not implemented in practice? If yes, can you tell me why this happened?
4. Were there any consumer engagement strategies that were implemented in practice but abandoned after a period of time? If yes, can you tell me why this happened?
5. What factors helped you when engaging with consumers and signing them up to use a digital health product/service? For example, did you get the support of clinical staff or use organisations that specialise in marketing or community engagement.
6. In your opinion, what has been your most successful digital health consumer engagement strategy and why?
7. What were the biggest challenges you faced around engaging consumers and getting them signed up to use the digital health product/service?
8. What factors hindered you when engaging with consumers and signing them up to use a digital health product/service? For example, were you constrained by money, time and other resources or did people not have access to the necessary technology.
9. From the consumers' perspective, what difficulties do you think they faced when engaging with and signing up to use a digital health product/service?
10. In your opinion, what has been your least successful digital health consumer engagement strategy and why?
11. With hindsight, what things would you do differently when engaging with people and recruiting them to sign up to use a digital health product or service?
12. What lessons were learned about recruitment/engagement that you could pass onto others?
13. Where is the recruitment/engagement doing going forward?

2.4 Focus group guide



Focus Group Guide

Thank you for agreeing to take part in this focus group session. This session is being run in order to understand people's experiences with X [digital health product/service].

The session will start at [insert start time] with some initial questions from [insert researcher name] and then they will invite an open discussion around some of the topics that are covered. The aim is to finish the session by [insert end time].

1. Who are you and what is your involvement in X [digital health product/service]?

   Example prompts

   - Could we go around the room and just say who you are and what your involvement has been with X?
   - Can you tell us a little bit more about how you initially found out about X?
   - How did you decide to use/get involved with X?
   - How did you hear about x?

2. [Patient/Carer/Service User] How did you first find out about this digital health product/service?

   Example prompts
   - Did you see it advertised on a newspaper, magazine, radio, TV or online?
   - Did a family member, friend, colleague or health professional recommend it to you?
   - Did you see it for sale in a retail outlet or online store?

3. [Patient/Carer/Service User] What helped you find out about this?

4. [Patient/Carer/Service User] What hindered you from finding out about this?

   Example prompts
   - Were you familiar with this type of technology already?
   - Were you motivated to use technology to improve your health?
   - Did you wish to use a technology to have more choice or control over your health information or interaction with health services?

5. [Patient/Carer/Service User] Describe how you signed up to use the digital health product/service.

   Example prompts
   - Did you fill in a paper based or an online registration form?
   - Did you download the software on a mobile device?
   - Did you log into the application online and set up an account or profile?

6. [Patient/Carer/Service User] Was there anything that helped you when signing up to or enrolling on this digital health product/service?

7. [Patient/Carer/Service User] Was there anything that hindered you when signing up to or enrolling on this digital health product/service?

   Example prompts
   - Did you have the digital skills necessary to sign up to the X?
   - Were you able to afford to pay for the X?
   - Did you have access to the equipment e.g. mobile device, laptop, desktop computer needed to sign up to the X?
   - Did you have good quality Internet access in your area?
   - Did you consider how private and secure your data on the X might be?

8. [Health Professional] Describe the steps you take to engage people (e.g. consumers, patients, family members and/or carers) with this product/service and get them to sign up to use it.

   Example prompts
   - Do you demonstrate the X to them?
   - Do you help them to register for the X?

9. [Health Professional] Can you describe what made it easy or difficult for you to recruit individuals (e.g. consumers, patients, family members and/or carers) and sign them up to use a digital health and wellness product or service?

   Example prompts
   - Did you/they have the digital skills necessary to sign up to the X?
   - Were you/they able to afford to pay for the X?
   - Did you/they have access to the equipment e.g. mobile device, laptop, desktop computer needed to sign up to the X?
   - Did you/they have good quality Internet access to enable registration?
   - Did you/they consider how private and secure personal data on the X might be?

10. [Health Professional] With hindsight, what things would you do differently when recruiting individuals (e.g. consumers, patients, family members and/or carers) and signing them up to use a digital health product or service?

11. Is there anything else you would like to talk about?

Thank you for taking part in this focus group session.

Appendix 3 Coding frameworks

The coding framework used in the analysis process in Chapter 5 Factors Affecting Patient and Public in Engagement and Enrolment in Digital Health, is outlined in the table below.

Theme	Subtheme	NPT Code	Category	Example of codes
Personal Perceptions and Agency	Awareness of a DHI	Coherence		The availability, the cost, the lack of profile at the moment is just maybe hindering it, so you say tele-care, tele-health to 99.9% of the population and they'll go what?
	Understanding of a DHI	Coherence		I think there is barriers particularly for older people with technology....and I think people don't know what it is and then if you don't understand the value
	Personal agency (choice and control)	Coherence		it's a very personal thing as to whether you prefer to do it electronically or whether you think, I have to go and see a professional
Personal Lifestyle and Values	Personal lifestyle	Cognitive Participation		they come to see me in the clinic for instance and I can say everything that's on the videos but the minute they have walked out the door it's gone out their head you know it's just part and parcel of being pregnant and of having a busy life

	Privacy and trust	Reflexive Monitoring		it’s not just you know, particularly with the telecare and telehealth you know the sort of devices that come with a system or a support or a call centre behind them are you know it’s quite daunting for people and it feels a little bit big brother
Digital Accessibility	Cost and funding	Cognitive Participation		I wouldn’t pay, I don’t buy any Apps. I only get free ones, and I suppose you’d get a lot of argument with people saying, this is the NHS, we shouldn’t pay for our healthcare
	Access to equipment	Collective Action		and you’re always going to get people anyway who haven’t got access to the Internet, you know, it’s all right for the government to say that nearly every household’s got a PC and they want every household to have a PC, but actually the reality is that a lot of them don’t
	Digital infrastructure	Cognitive Participation		I don’t even have 3G, I have no signal on my phone where we are, it’s terrible
	Digital knowledge and skills	Collective Action		I think it was convincing ourselves that we could use technology, I’d used a computer and that before but some people’s never used a computer

	Language	Coherence		one of the other big challenges is our non-English speaking families. We have big pockets of that across the city, one of the children's centres in the [x] area I think 83% is non-English speaking so the [x DHI] is potentially a challenge for them because it's all in English
Implementation Strategy	Engagement approach	Coherence	Branding	We've also had a curve-ball in relation to the [x DHI] name in that we were going to secure the brand but it's already been secured by a, I think it's a multinational gym tech company so we can't use the [x DHI] brand. So we're going to have to go through a process of rebranding, something quick and dirty so there has been distractions
			Advertising	The smart shelf is an actual shelf that's [x DHI] grounded and it looks beautiful. And it's got this sort of, it's like a shelf, it's like a cabinet with two orange metal ribbons that come out and attached to the ribbons you've got different products with explanations and you can look and feel. What it gives us an ability to do is have a presence in retail establishments that are already out there
			Personal and clinical contact	the best part of it for me was my son is very techy and he loved it and really got into it and he can show me round it and then my husband has got into the techy stuff as well now

			Personal involvement in a DHI	I guess the way we're designing it is that it's very positive, and it's focusing on the opportunities that are there and what we're aiming to achieve., and people can see that designing around their lifestyles and around their needs, and people-centred services are… and that they can get involved with and be part of the design, so designing with them, rather than for them. I think there's a huge appetite for that, and people are very, very interested and very keen to get involved
	Enrolment plan	Collective Action	Tailored Support	I was first introduced to it by the Health Visitor, and she actually, it wasn’t just in the pack, it was in kind of like a poly-packet, and she explained to me, this is the [x DHI], and if you want to register then this is how you do it
			Incentives	they might offer six months’ free remote support. So, if you wanted to try buying your mother-in-law a remote alarm and so on, they would therefore support it for free for a while, yes, that type of thing
			Self-enrolment	the main reason I logged on was the sticker on the front of [X child’s named paper health record] that we were given when he was born

Quality of the Digital Health Intervention	Quality of DHI design	Reflexive Monitoring		Yes we were given the iPads just to take out to show some mums and get mums, kind of, to use it. And we, sort of, went through some of the teething problems initially of trying to work out what mums need…the input just put on each screen in order to log on and set up the accounts and those things. And realising how long it took sometimes just to register in the first place
	Quality of information	Reflexive Monitoring		You know it's relevant, you know it’s coming from people who are actually you are going to see, they are looking after you in your care districts. Kind of makes you a bit more reassured
	Quality of interaction	Collective Action		the problem you have about consumers you have with doing that is the motivation – why would I track all this data about myself if my clinician won’t engage with it? So that’s kind of the big takeaway the big finding if you like…..
	Integration with healthcare	Reflexive Monitoring		I thought it was quite good because obviously the midwife then didn’t have to talk me through everything in the midwife appointment, sometimes I had to take half an hour out of my working day to go to my appointment so she couldn’t always discuss everything she wanted to so she could say ah well I’ve got video clips on this I’ll send you the link so I can then go

				and watch it once I've finished work at home, so that was quite good

The coding framework used in the analysis process in Chapter 6, Factors Affecting Health Professionals Role in Engagement and Enrolment in Digital Health, is outlined in the table below.

Theme	Subtheme	NPT Code	Category	Example of codes
Health Professional (HP) Role	HP workload	Collective Action		we trialled getting the GPs to you know to identify patients getting the staff to phone the patients and refer them into our service but it didn't work because of the pressures on the you know within primary care
	HP Status	Coherence		people think that if you service redesign there's going to be job losses in the end, and that is a key challenge
	HP knowledge	Coherence	Awareness of DHIs	I've seen health visitors at my centre and none of them knew about the electronic [DHI] and we never used it with a health visitor

			Understanding of DHIS	But we also need to be quite discerning about the kinds of things we put people onto, we say oh there's this app and the other app, but we don't always know, you know. Are they okay, we need to be checking them out before we start saying to people, oh, have you seen this and done that, you know
	HP skills	Collective Action		we haven't had the chance to keep using those skills, so you get shown the skills, then you don't use it for ages, then you feel a bit nervous and probably a bit uncomfortable to do it in front of somebody
Health Service Organisation and Culture	Access to technology	Collective Action		I just think that the health system service really has, we've dragged behind really, you know, where our clients are at, and we need to catch up. As Health Visitors we had a little phone that when you text, it was very slow, you know, and it was really difficult
	Cost and funding	Collective Action		[X NHS trust] aren't continuing with the [X DHI] but they've taken the decision that they don't have the resources to, they were basically funded through the project to do this am so they don't have the resources
	Information governance	Reflexive Monitoring		I mean one of the feelings, I think one of the things that worries me is that… is that I'm not entirely confident about [x private company] holding this clinical data. If it was NHS Health Vault…..And even if it

				was held by [x private company], if I kind of knew that the contract was with the NHS…
	Clinical and technical integration	Reflexive Monitoring		Can I just add to the fact that what has stopped us using it, is really the infrastructure, in the NHS we have not got the technical infrastructure for mobile working in this way, nor have we got the integration
	Organisational restructuring	Cognitive Participation		the other element is that there is huge change going on in the public sector just now, both health and social care landscape and lots of restructuring, changes in staffing so (my throat is drying up). So actually, it's then difficult to keep people focussed on what they have got to do when they have got a wide range of things that they are looking at all the time and there is so many changes happening
	Organisational culture	Cognitive Participation		also chicken and egg, because they don’t have time to change they don’t want to try it because you don’t have the evidence but you can’t get the evidence unless they try it so
	Organisational policies	Cognitive Participation		[x city], as I say, they’re much further developed in terms of their own digital strategy as an organisation so their staff do mobile working, they have tablets and, you know, they’re digitally enabled

Digital Infrastructure	Internet services	Collective Action		Personally, when you haven't got Wi-Fi, to use it over 3G, personally, I am Health Visitors, please add in, it's so slow, it's too slow to be practical

The coding framework used in the analysis process in Chapter 7, Factors Affecting Implementers Role in Engagement and Enrolment in Digital Health, is outlined in the table below.

Theme	**Subtheme**	**NPT Code**	**Category**	**Example of codes**
Organisation of Engagement and Enrolment	Planning and managing workload	Coherence and Reflexive Monitoring		we probably couldn't have expected they had the perfect contractual framework at the beginning of the day and no one knew to what extent the numbers on recruitment could really be delivered
	Timing and timeframe	Coherence and Reflexive Monitoring		the service partners spend a lot of their time recruiting and so there is a lot of capacity being taken up by recruitment so there is less capacity then for service innovation

	Knowledge and skills of implementers	Collective Action		However, what we're realising is that for [X DHI] to succeed it needs to be a prescribed service and most of our partner organisations are dealing with acute patients who are too ill and too deep into the system to actually embrace taking on a digital project
	Partners	Cognitive Participation	Industry partner	Working with trusted organisations, so working with organisations, facilities, assets that that they know, so it's part of the local landscape, so we haven't imposed something new, we've just built onto existing stuff, so football clubs are probably the biggest brands we have in the city and using them to penetrate the city
			Public partners	Also, we're getting feedback from some GPs that we're consulting with to attach it to campaigns like flu campaigns, drug campaigns, you know, diabetes week, you know, to go down that route as well where we're actually linking it in
			Third sector partners	we've been partnering [charity y] and developing an eLearning asset that informal carers can use to get support and signposting to resources
	Budget and cost	Collective Action		I think whenever you've got an external funded programme, I think you will always have organisations that worry about when the funding is over, what happens then and that conversation about sustainability. I think that often is a barrier

Implementation Strategy	Engagement Approaches	Collective Action	Branding	We've also had a curve-ball in relation to the [x DHI] name in that we were going to secure the brand but it's already been secured by a, I think it's a multinational gym tech company so we can't use the [x DHI] brand. So we're going to have to go through a process of rebranding, something quick and dirty so there has been distractions
			Advertising	The consumer product was going to have to be paid for, if you like, or supported in some way by advertising and sponsorship that was a huge bone of contention with them
			Personal and clinical contact	She's been using pop-ups a lot, I think. Pop-ups were a tool that we developed, obviously, to get into like, in to chat, to start conversations in, but the project managers have been using them for recruitment
			Personal involvement in a DHI	Living it Up have spent a lot of time co-designing of designing the service; it's also spent a lot of time understanding the user experience from the ground up. So a lot of UEX work has gone into delivering the front-end interfaces, and, again, taking that back to workshops with users, to make sure the usability and accessibility is as good as it can be at this point in time
	Enrolment Plans	Collective Action	Tailored Support	make an appointment for one of our recruiting nurses, when the recruitment teams go out so they can see that patient in their home and provide a more detailed information so it's very much an introductory

				course, say this is what our service is, do you like the sound of it, if so, this is the next step for getting involved
			Incentives	So we want to offer people discounts on purchasing bits of kit and/or support, and/or bundles of support and kit
			Self-enrolment	the main reason I logged on was the sticker on the front of [X child's name] Red Book that we were given when he was born

Appendix 4 Systematic review protocol

Open Access **Protocol**

BMJ Open

Barriers and facilitators to patient and public engagement and recruitment to digital health interventions: protocol of a systematic review of qualitative studies

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ABSTRACT

Introduction: Patients and the public are beginning to use digital health tools to assist in managing chronic illness, support independent living and self-care, and remain connected to health and care providers. However, engaging with and enrolling in digital health interventions, such as telehealth systems, mobile health applications, patient portals and personal health records, in order to use them varies considerably. Many factors affect people's ability to engage with and sign up to digital health platforms.

Objectives: The primary aim is to identify the barriers and facilitators patients and the public experience to engagement and recruitment to digital health interventions. The secondary aim is to identify engagement and enrolment strategies, leading if possible to a taxonomy of such approaches, and a conceptual framework of digital health engagement and recruitment processes.

Methods: A systematic review of qualitative studies will be conducted by searching six databases: MEDLINE, CINAHL, PubMed, EMBASE, Scopus and the ACM Digital Library for papers published between 2000 and 2015. Titles and abstracts along with full-text papers will be screened by two independent reviewers against predetermined inclusion and exclusion criteria. A data extraction form will be used to provide details of the included studies. Quality assessment will be conducted using the Consolidated Criteria for Reporting Qualitative Research checklist. Any disagreements will be resolved through discussion with an independent third reviewer. Analysis will be guided by framework synthesis and informed by normalization process theory and burden of treatment theory, to aid conceptualisation of digital health engagement and recruitment processes.

Discussion: This systematic review of qualitative studies will explore factors affecting engagement and enrolment in digital health interventions. It will advance our understanding of readiness for digital health by examining the complex factors that affect patients' and the public's ability to take part.

Trial registration number: CRD42015029846.

Strengths and limitations of this study

- This will be the first synthesis of qualitative studies to explore patients' and the public's experiences of engagement and recruitment to a broad range of digital health interventions.
- We will systematically identify and critically appraise the available evidence on this important topic, identify research findings and highlight any knowledge gaps.
- It is envisaged that the results of this review will contribute to a catalogue of barriers and facilitators that affect people's ability to engage with and sign up to digital health interventions; a taxonomy of engagement and enrolment strategies used if possible; and a preliminary conceptual model of digital health engagement and recruitment processes.
- This work will advance our understanding of the readiness of patients and the public for digital health.
- Findings may be limited by (1) the inclusion of English language publications as this could exclude potentially useful studies, which may result in cultural and publication bias, (2) the synthesis of qualitative studies which may result in the loss of some explanatory context that could limit the generalisability of findings or (3) the data analysis and synthesis which will be based on a sample of data extracted by the review team and not the original data.

INTRODUCTION

Changing lifestyle patterns over the last century have seen growing numbers of people with one or more chronic illnesses, including heart disease, diabetes and cancer. Such conditions are the leading cause of death, disease and disability worldwide.[1–3] This combined with ageing populations, who have complex health and social care needs, is creating a huge resource burden on health systems[4 5] with increases in healthcare usage and unplanned admissions.[6] To become more sustainable, health services are beginning to move from treating illness in acute hospital settings to promoting more preventative care and the self-management of long-term conditions in the community where possible.[7 8]

Person-centred digital health interventions are being developed and trialled to further this agenda, by promoting active and healthy ageing, supporting individuals to manage long-term conditions at home and assisting them to remain connected with health and care providers. Examples include telehealth and telecare systems,[9] electronic personal health records (PHRs)[10] and mobile health applications or 'apps'[11] among others. It is hoped that these types of digital products and services could lead to better health outcomes and to a reduction in the usage and cost of primary, secondary and tertiary health services.[12]

Many of these digital health interventions have only been evaluated in small pilot studies or randomised controlled trials (RCTs). While the results of these can sometimes demonstrate positive outcomes,[13] many people choose not to enrol as they can experience numerous barriers, some of which relate to the complex recruitment procedures in trials.[14–16] While non-participation is a significant issue,[17 18] there are also many factors that can facilitate patients and the public to engage with and sign up to digital health platforms.[19 20] Although there is a large literature on difficulties recruiting to trials,[21] many challenges only emerge when technologies are scaled up and implemented in 'real-world' complex health systems.[22 23] This is an important distinction, as RCTs have predefined protocols and strict inclusion criteria that can often mask wider implementation issues.[24 25] Problems that can arise when technologies are scaled up begin in the initial phases of implementing a digital health intervention in practice, when engaging with different stakeholders, when encouraging people to register for digital products and services on offer (or which might be offered in the future) and then facilitating them to sign up for it. The journey by which such technologies are implemented can span a long timeline of individual and organisational change processes, not all of which occur sequentially.[26] As a result, this review is focusing on the initial phases of rolling out digital health products and services, in particular the engagement and recruitment of users. By engagement, we mean the processes by which patients and the public become aware of and understand digital health interventions, for example, through promotional efforts and marketing campaigns. Recruitment, on the other hand, encompasses the processes that people are involved in when enrolling or signing up to digital health products or services, such as actively filling out paper-based registration forms or creating online profiles or accounts. There has as yet been no attempt to synthesise what this literature tells us about the key challenges or the outstanding research gaps surrounding patient and public engagement and recruitment to digital health.

There have been repeated calls for more research that synthesises the findings from qualitative evidence to support policy and the translation of research into clinical practice.[27] For example, a synthesis of qualitative research can aid in the understanding of complex interventions as well as human experiences and behaviour, all of which can be used to inform health policy and practice.[28 29] The volume of qualitative systematic reviews has been growing slowly over the last number of years[30] due in part to the work of the Cochrane Qualitative and Implementation Methods Groups (CQIMG) and others who are championing the role qualitative synthesis can play in building the base for effective evidence that can be adopted and implemented in everyday practice.[31 32] At present, there are limited, if any published, systematic reviews of qualitative studies looking at different aspects of person-centred digital health interventions. In particular, there is no systematic review on the topic of digital health engagement and recruitment, although it has been highlighted as a research gap that needs attention.[14 25] An understanding of the barriers patients and the public experience when trying to engage and enrol in digital health products and services, would help ensure the full value of these interventions can be realised. Similarly, robust evidence on the factors that facilitate this process could improve recruitment to future digital health initiatives.

In addition, theoretical frameworks have been used previously to aid many types of qualitative synthesis[24 33 34] as established models can help to explain the phenomenon under consideration and make the findings of the synthesis more accessible to application in practice.[35 36] Therefore, this review will incorporate two empirically grounded sociological theories, normalization process theory (NPT) and burden of treatment theory (BOTT), as they are relevant to understanding how individuals embed new interventions in everyday routine and the burden that this process entails.[37 38] NPT in particular has been widely used in eHealth implementation research to examine different stages of the process through its four main constructs: 'coherence', 'cognitive participation', 'collective action' and 'reflexive monitoring' (see figure 1).[39 40] BOTT was built on the conceptual foundations of NPT to expand our knowledge of the difficulties patients experience when coping with new treatment modalities and enacting self-care strategies,[41] so they are both directly applicable to this qualitative synthesis. This systematic review of qualitative studies aims to identify and synthesise currently available knowledge about barriers and facilitators to engagement and recruitment across a range of digital health interventions

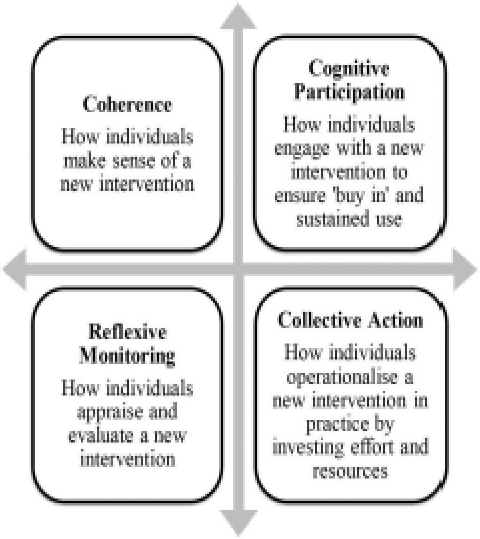


Figure 1 Four constructs of normalisation process theory (NPT).

and highlights knowledge gaps and areas for further research. If possible, we will also aim to develop a taxonomy of digital health engagement and recruitment strategies used and a preliminary conceptual model of digital health engagement processes. Arguably, a better understanding and detailing of these difficulties and the processes involved will help researchers and those in industry design better systems and enrolment strategies and inform health service managers and policymakers of changes that need to be made to improve digital health engagement and recruitment.

Objectives

Primary

To examine the factors (barriers and facilitators) that affect patients' and the public's ability to engage with and enrol in digital health interventions.

Secondary

To determine what engagement and recruitment strategies have been used to sign people up to digital health products and services.

METHODS

This protocol was written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) checklist.[42] Reporting of the full systematic review will follow the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement.[43] An interdisciplinary team of researchers will be involved in the systematic review with expertise ranging from general practice and primary care, to nursing, health informatics and information science. Members of this team have conducted and published numerous high-quality systematic reviews and the collective skill set will enable a robust review to be carried out.[33 34] An initial 'scoping search' will be undertaken to help identify key papers and search terms that are relevant to the research topic. This process will be carried out by conducting a preliminary search of online bibliographical databases via Ovid; the use of the 'related articles' function in PubMed, reference and footnote tracking of relevant papers found, citation tracking of relevant papers found, the use of personal knowledge, and consultation with experts in the field. The results will help to inform the initial design of the search strategy for the review which will be piloted and refined as appropriate. Figure 2 outlines the detailed workflow of the proposed review.

Search strategy

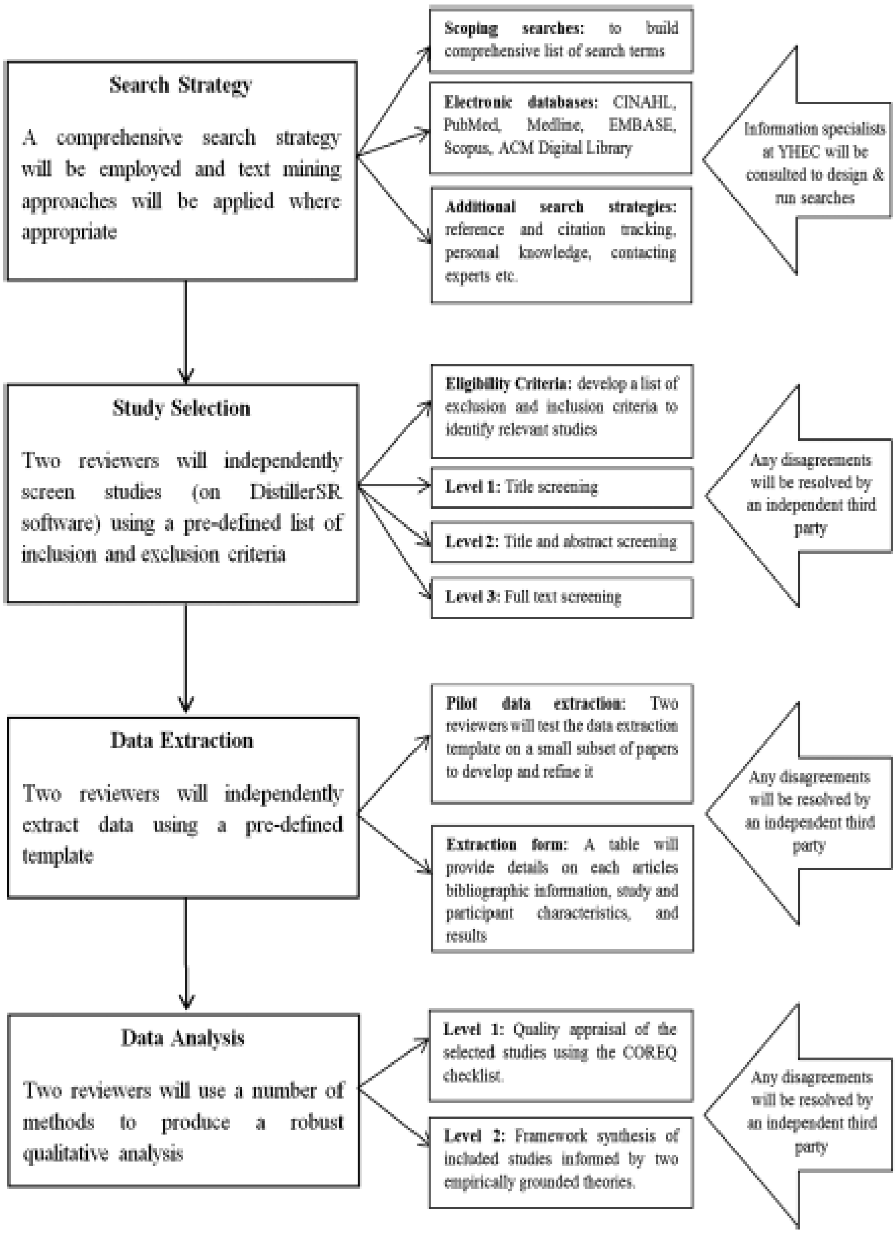
A team of information specialists at the York Health Economics Consortium (YHEC), who specialise in conducting systematic reviews, will be consulted to assist with the design of the search strategy. There is likely to be three groups of search terms, referring to digital health interventions, engagement and recruitment, and factors that affect these processes, that is, barriers and facilitators (table 1). Guidance will be sought from the Cochrane Handbook for Reviews of Interventions on the most robust way to systematically search the literature,[44] and other novel strategies such as text mining[45 46] will be explored and applied where appropriate. The following six electronic databases, CINAHL (EBSCHOHost), PubMed, Medline, EMBASE, Scopus and the ACM Digital Library, will be systematically searched to identify published peer-reviewed scientific literature that are relevant to the research objectives. YHEC will run searches, remove duplicate citations and provide an EndNote database file of citations for screening.

The challenges of searching the qualitative literature have been well documented[47–49] and studies have shown that traditional database searching can reveal as little as 30% of research papers that are relevant to the topic under review.[50] Therefore, other search methods will be used to supplement the results of the systematic review and identify relevant studies. These will include reference or footnote tracking; using the 'related articles' function in PubMed; citation tracking; personal knowledge and personal contacts and contacting experts in the field.

Eligibility criteria

The review will adhere to the following criteria. These were developed using a modified population, intervention, control and outcome (PICO) framework (see table 2).

Papers will be included if they meet the PICO criteria. Below is a detailed description of the inclusion and exclusion criteria.



Search Strategy

A comprehensive search strategy will be employed and text mining approaches will be applied where appropriate

Scoping searches: to build comprehensive list of search terms

Electronic databases: CINAHL, PubMed, Medline, EMBASE, Scopus, ACM Digital Library

Additional search strategies: reference and citation tracking, personal knowledge, contacting experts etc.

Information specialists at YHEC will be consulted to design & run searches

Study Selection

Two reviewers will independently screen studies (on DistillerSR software) using a pre-defined list of inclusion and exclusion criteria

Eligibility Criteria: develop a list of exclusion and inclusion criteria to identify relevant studies

Level 1: Title screening

Level 2: Title and abstract screening

Level 3: Full text screening

Any disagreements will be resolved by an independent third party

Data Extraction

Two reviewers will independently extract data using a pre-defined template

Pilot data extraction: Two reviewers will test the data extraction template on a small subset of papers to develop and refine it

Extraction form: A table will provide details on each articles bibliographic information, study and participant characteristics, and results

Any disagreements will be resolved by an independent third party

Data Analysis

Two reviewers will use a number of methods to produce a robust qualitative analysis

Level 1: Quality appraisal of the selected studies using the COREQ checklist.

Level 2: Framework synthesis of included studies informed by two empirically grounded theories.

Any disagreements will be resolved by an independent third party

Figure 2 Proposed workflow of the qualitative systematic review. COREQ, Consolidated Criteria for Reporting Qualitative Research; YHEC, York Health Economics Consortium.

1. *Types of studies:* Original qualitative studies, studies involving secondary analysis of qualitative data or qualitative studies as part of a mixed methods study (eg, a major component must be qualitative and describe a qualitative methodology). Certain types of studies will be excluded from the review including those using the following methodologies:
   A. literature or systematic reviews and meta-analyses;
   B. descriptive case studies; lexical studies that analyse natural language data presented as qualitative results;
   C. qualitative studies using questionnaires or other methods that do not involve direct contact or observation of participants;
   D. commentary articles written to convey opinion or stimulate research/discussion with no research component;
   E. studies describing an individual's experience(s) in an RCT. This review is focusing on barriers and facilitators to engagement and enrolment to digital health interventions rather than the wider

Table 1 Search strategy

Search	Search terms that will be modified for use across multiple databases
#1	Search Electronic Health Records [MeSH Terms]
#2	Search Cellular Phone [MeSH Terms]
#3	Search Social Networking [MeSH Terms]
#4	Search Telemedicine [MeSH Terms]
#5	#1 OR #2 OR #3 OR #4
#6	Search recruit*
#7	Search enrol*
#8	Search participat*
#9	Search engage*
#10	#6 OR #7 OR #8 OR #9
#11	Search barrier*
#12	Search challenge*
#13	Search impediment*
#14	Search facilit*
#15	#11 OR #12 OR #13 OR #14
#16	#5 AND #10 AND #15

Table 2 PICO criteria for including studies

Population	Any individual (adult or child). This includes patients, the public and health professionals who would be aware of the experiences of these stakeholder groups.
Intervention	Any health intervention delivered by a digital technology (hypothetical or in development, simulated or real world) which takes information from people or provides some form of advice or feedback about their health. This includes, but is not limited to: ▸ web-based interventions on PCs or mobile platforms, ▸ mobile health applications or apps, ▸ patient portals or personal health records, ▸ interventions delivered by SMS or IVR.
Control	None.
Outcome	Qualitative data on the factors (barriers and facilitators) to engagement and recruitment. Qualitative data on engagement and enrolment strategies.
Study type	Original qualitative studies, studies involving secondary analysis of qualitative data or qualitative studies that are part of a mixed-methods study. The study must have direct contact with individuals or direct observation using any form of qualitative method.
Setting	Any 'usual' setting (hypothetical or in development, simulated or real world) such as primary, secondary or tertiary care, the home or workplace.
Timing or phase of implementation	Engagement or recruitment phase only.

IVR, interactive voice recognition; PC, personal computer; PICO, population, intervention, control and outcome; SMS, short message service.

literature on recruitment to clinical trials that has been addressed in previous reviews.[21]

2. *Types of eHealth interventions:* Any health intervention delivered by a digital technology (hypothetical or in development, simulated or real world), which takes information from patients or the public, or provides some form of advice or feedback about their health. This includes, but is not limited to, web-based interventions on personal computers (PCs) or mobile platforms, mobile health applications or apps, patient portals, PHRs and interventions delivered by short message service (SMS) or interactive voice recognition (IVR). Certain technologies will be excluded from the review including those whose primary intervention is telephone based with no additional technological function (eg, telephone counselling or triaging service), internet based with no additional interactive function (eg, searching for health information online), or an implantable device that is remotely monitored.
3. *Types of participant:* Any individual (adult or child). This includes patients, the public and health professionals who would be aware of the experiences of these stakeholder groups.
4. *Types of settings:* Any 'usual' setting (hypothetical or in development, simulated or real world), such as primary, secondary or tertiary care, home or workplace.
5. *Phase of implementation:* Qualitative research which explores the initial phases of implementation, that is, engagement and recruitment phase, before individuals start using a digital health intervention. This can span from gauging an individual's readiness for a digital health intervention, to the initial marketing or reach of the initiative, to actively signing people up to use the technology so they are registered on the digital application or system. Therefore, we will not explore: pre-engagement work based solely around designing the interface and functionality of a digital health intervention; patients' or the public's use of these types of technologies; why they drop out or fail to continue using them (non-usage or attrition)[52] or sustain their use of them (retention);[53] their attitudes or beliefs towards a digital health intervention or their satisfaction with it, except as pertaining directly to engagement or recruitment.
6. *Date of publication:* Between 1 January 2000 and 19 August 2015.
7. *Language:* English.

Screening

Each title and abstract will be screened by two independent reviewers using DistillerSR software (DistillerSR. Systematic Review and Literature Review Software from Evidence Partners. 2016. https://distillercer.com/products/distillersr-systematic-review-software/). All journal articles that meet the inclusion criteria set out above will be obtained in full-text format for further screening and assessment. Two independent reviewers will conduct the second level full paper screening by applying the inclusion and exclusion criteria. A third party will be involved to resolve any conflicts that occur in determining the relevance of the titles, abstracts and full-text papers, so that a consensus over inclusion and exclusion of each article can be reached. A flow diagram will be used to report the selection process and reasons for exclusion as suggested by the PRISMA guidelines.[54]

Data extraction

Data extraction will be carried out using a comprehensive, standardised extraction template that will be designed based on the specific characteristics of this review, including aims of the study, design and methodological approach taken and key findings such as barriers and facilitators and a description of engagement and recruitment strategies. It will be piloted on a subset of relevant papers and refined where appropriate. The extraction process will be conducted by two individual reviewers based on the relevant articles previously identified through the screening process. A third party will be involved where disagreements arise over the relevancy of the data to the review topic which will assist in reaching consensus and creating a robust dataset. This will result in a table that provides the following details:

- Bibliographic information such as the journal name, year, volume and page numbers;
- Study characteristics such as the type of technology and qualitative approach taken;
- Participant characteristics (sociodemographic) and information about the number and type of individuals who signed up or declined to take part;
- Main findings such as the barriers and facilitators to engagement or recruitment;
- Details of engagement or enrolment strategies used.

Quality assessment of included studies

The CQIMGs and others recommend critically appraising qualitative research as it helps assess whether the study adequately addresses the different dimensions of research quality such as credibility, transferability, dependability and confirmability.[55] [56] Although some are sceptical of this approach,[57] a range of tools and checklists have been devised for this purpose. One such checklist is the Consolidated Criteria for Reporting Qualitative Research (COREQ), which offers a list of questions for assessing qualitative studies.[58] [59] While the review team acknowledges that the assessment of qualitative research involves well-honed interpretative skills rather than relying solely on simplistic scoring criteria,[60] the COREQ checklist will be applied to this review as it can enable a rapid evaluation of different types of qualitative studies and their major strengths or weaknesses. Two reviewers will independently assess the quality of the relevant studies and discussion will be used to resolve any conflicts. An independent third reviewer will be contacted if necessary to settle unresolved disagreements. No study will be excluded based on quality assessment as methodologically weak studies may still offer valuable insights.[61]

Data analysis/synthesis

This review will synthesise qualitative literature on patients' or the public's experiences of digital health engagement and recruitment. Our analyses will be informed by framework synthesis as it allows a priori model to be used to facilitate analysis.[62] As outlined, NPT[37] [39] [40] will be used during coding and synthesis, due to its highly conceptual relevance to the review topic. This process will be guided by the framework approach, which follows a five-stage process: (1) familiarisation, (2) identifying a thematic framework, (3) indexing, (4) charting and (5) mapping and interpretation.[63] This series of analytical steps will facilitate in-depth interpretation of data until a rich and coherent understanding emerges. Overarching concepts will be mapped onto constructs from NPT and findings viewed through the lens of BOTT, although we will be open to the identification and coding of emergent themes that sit outside these theoretical frameworks, in order to inform development of a preliminary model of digital health engagement and recruitment.[64] The engagement and enrolment strategies identified during the analyses will also be classified, if possible, to create a taxonomy of approaches. These might include traditional forms of mass media and recruitment via health professionals, to more contemporary methods using social media and online advertising to reach and enrol large numbers of people. NVivo software will be used to aid analysis.[65]

DISCUSSION

Engaging and recruiting patients and the public to digital health interventions is a complex process that needs to be fully explored if we are to capitalise on the value these technologies can offer. To date, existing research on this topic has not been synthesised. The systematic review of qualitative studies aims to address this gap in the scientific literature by providing insights into what helps and hinders patients and the public to engage and enrol in digital health products and services. This will inform our understanding of the readiness of these important stakeholder groups for digital health. We will use the findings of our analysis and synthesis work to create a catalogue that describes the barriers and facilitators that affect people's ability to sign up to digital health interventions, and if possible, devise a taxonomy of digital health engagement and enrolment strategies. We will produce a preliminary conceptual model of digital health engagement and recruitment processes. We anticipate that this work will be highly relevant to a wide range of stakeholders including researchers and industry who are developing and evaluating person-centred digital health interventions; health professionals who may want to recommend new electronic systems and applications to people; patients and the public who want to engage with and sign up to use novel technologies; local and national health services who wish to implement new digital services and enrol a variety of users on them; and policymakers who wish to address barriers to digital health engagement and recruitment. The results of this systematic review will be widely disseminated through publication in peer-reviewed, open-access academic journals, research meetings, conference presentations and social media. Public engagement is also important and will be achieved through knowledge translation events and activities such as seminars, workshops and the use of social media.

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Contributors SOC, FSM and CAOD conceptualised the study and designed the review. JG and SG designed the search strategy with input from SOC and FSM. SOC wrote the first draft of the protocol with input from FSM and CAOD. SOC, FSM, CAOD, PH, JG and SG contributed to the writing of the final manuscript. All authors read and approved the final version of the manuscript. FSM is the guarantor of this research.

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Appendix 5 Systematic review search strategies

5.1 Search strategy used on PubMed

Interface/URL: http://www.ncbi.nlm.nih.gov/pubmed

Search Strategy:

#01	Search Online Systems[mh:noexp]	7190
#02	Search Medical Informatics[mh:noexp]	8373
#03	Search Medical Informatics Applications[mh:noexp]	2059
#04	Search Educational Technology[mh:noexp]	1130
#05	Search Electronics, Medical[mh:noexp]	6164
#06	Search Audiovisual Aids[mh:noexp]	6192
#07	Search Telecommunications[mh:noexp]	4341
#08	Search Multimedia[mh:noexp]	1505
#09	Search Hypermedia[mh:noexp]	388
#10	Search Cell Phones[mh:noexp]	4763
#11	Search Social Networking[mh:noexp]	928
#12	Search Telemedicine[mh:noexp]	11652
#13	Search Telenursing[mh:noexp]	126
#14	Search Telephone[mh:noexp]	9247
#15	Search Ambulatory Care Information Systems[mh:noexp]	1157
#16	Search Mobile Applications[mh:noexp]	255

#17 Search Wireless Technology[mh:noexp] 1161

#18 Search Electronic Mail[mh:noexp] 1890

#19 Search Electronic Health Records[mh:noexp] 6972

#20 Search (("personal health record" [tiab] OR "personal electronic health record" [tiab] OR PHR [tiab]) 1047

#21 Search (phone*[tiab] OR mobile*[tiab] OR smartphone*[tiab] OR handset*[tiab] OR hand-set*[tiab] OR handheld*[tiab] OR hand-held*[tiab]) 87377

#22 Search ((electronic*[tiab] OR digital*[tiab] OR device*[tiab]) AND tablet*[tiab])1344

#23 Search ("tablet PC"[tiab] OR "tablet computer"[tiab]) 223

#24 Search device-based[tiab] 1398

#25 Search ((digital*[tiab] OR electronic*[tiab] OR communicat*[tiab]) AND device*[tiab]) 22166

#26 Search ((device*[tiab] AND technolog*[tiab])) 19965

#27 Search ((PDA[tiab] OR PDAs[tiab] OR "personal digital"[tiab])) 6978

#28 Search (mp3-player*[tiab] OR mp4-player*[tiab]) 89

#29 Search (online[tiab] OR on-line[tiab] OR internet[tiab] OR www[tiab] OR web[tiab] OR website*[tiab] OR webpage*[tiab] OR broadband[tiab] OR broad-band[tiab]) 174772

#30 Search (wireless[tiab] OR wire-less[tiab] OR wifi[tiab] OR wi-fi[tiab] OR "global positioning system*"[tiab] OR bluetooth*[tiab]) 7972

#31 Search (text messag*[tiab] OR texting[tiab] OR texter*[tiab] OR texted[tiab] OR SMS[tiab] OR short messag*[tiab] OR multimedia messag*[tiab] OR multi-media messag*[tiab] OR mms[tiab] OR instant messag*[tiab]) 8062

#32 Search (social media*[tiab] OR facebook[tiab] OR twitter[tiab] OR tweet[tiab] OR tweets[tiab]) 2766

#33 Search (webcast*[tiab] OR webinar*[tiab] OR podcast*[tiab] OR wiki[tiab] OR wikis[tiab] OR youtube[tiab] OR you tube[tiab] OR vimeo[tiab])1452

#34 Search (app[tiab] OR apps[tiab]) 14179

#35 Search ((electronic*[tiab] OR digital*[tiab] OR device*[tiab]) AND application*[tiab]) 53728

#36 Search (iphone*[tiab] OR i-phone*[tiab] OR ipad*[tiab] OR i-pad*[tiab] OR ipod*[tiab] OR i-pod*[tiab] OR palm os[tiab] OR "palm pre classic*"[tiab]) 1160

#37 Search (android*[tiab] OR ios[tiab] OR s40[tiab] OR symbian*[tiab] OR windows[tiab]) 14731

#38 Search (video*[tiab] OR dvd[tiab] OR dvds[tiab]) 66751

#39 Search (email*[tiab] OR e-mail*[tiab] OR electronic mail*[tiab]) 9154

#40 Search (chat room*[tiab] OR chatroom*[tiab]) 268

#41 Search (blog*[tiab] OR blogging[tiab] OR blogger*[tiab] OR weblog*[tiab]) 888

#42 Search skype[tiab] 112

#43 Search (bulletin board*[tiab] OR bulletinboard*[tiab] OR messageboard*[tiab] OR message board*[tiab])421

#44 Search (software*[tiab] OR soft-ware*[tiab]) 93613

#45 Search (interactiv*[tiab] OR inter-activ*[tiab]) 35876

#46 Search (ehealth*[tiab] OR e-health*[tiab] OR mhealth*[tiab] OR m-health*[tiab] OR m-learning[tiab]) 2596

#47 Search (electronic learn*[tiab] OR e-learn*[tiab]) 1367

#48 Search (telephone*[tiab] OR telehealth[tiab] OR telemedicine[tiab] OR telenursing[tiab] OR telemonitor*[tiab]) 50718

#49 Search ((digital*[tiab] OR electronic*[tiab] OR communicat*[tiab] OR information*[tiab]) AND technolog*[tiab]) 55799

#50 Search ((digital*[tiab] OR electronic*[tiab]) AND (intervention*[tiab] OR therap*[tiab] OR treatment*[tiab] OR medicine[tiab] OR medical*[tiab] OR health*[tiab])) 78019

#51 Search (ICT[tiab] OR ICTs[tiab]) 3070

#52 Search medical informatics[tiab] 1782

#53 Search (remot*[tiab] AND (care[tiab] OR caring[tiab] OR cared[tiab] OR manag*[tiab] OR consult*[tiab] OR monitor*[tiab] OR measur*[tiab])) 18099

#54 Search (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 R #48 OR #49 OR #50 OR #51 OR #52 OR #53) 145894

#55 Search (recruitment strateg*[tiab] OR recruitment method*[tiab]) 1657

#56 Search (recruit*[tiab] AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 127518

#57 Search ((participation[tiab] OR participating[tiab]) AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 91719

#58 Search ((sign up[tiab] OR take up[tiab] OR enlist[tiab]) AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 1947

#59 Search ((engagement[tiab] OR engage[tiab] OR engaging[tiab) AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 37503

#60 Search ((involvement[tiab] OR involve[tiab] OR involving[tiab]) AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 320397

#61 Search ((enrolment[tiab] OR enrollment[tiab] OR enrol[tiab] OR enroll[tiab] OR enrolling[tiab] OR enrolled[tiab) AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 173815

#62 Search (invit*[tiab] AND (patient[tiab] OR patients[tiab] OR volunteer*[tiab] OR participant*[tiab] OR people[tiab] OR person*[tiab] OR woman[tiab] OR women[tiab] OR man[tiab] OR men[tiab] OR child[tiab] OR children[tiab] OR elder[tiab] OR elderly[tiab] OR students[tiab] OR adolescen*[tiab] OR rural[tiab])) 19828

#63 Search Consumer Behavior[mh:noexp] 17705

#64 Search Consumer Participation[mh:noexp] 14268

#65 Search Patient Participation[mh:noexp] 18279

#66 Search Social Participation[mh:noexp] 669

#67 Search Community-Based Participatory Research[mh:noexp]2105

#68 Search ((difficult*[tiab] OR problem*[tiab] OR deterrent*[tiab] OR obstacle*[tiab] OR hindrance*[tiab] OR barrier*[tiab] OR challenge*[tiab] OR impediment*[tiab] OR experience*[tiab]) AND (access[tiab] OR participation[tiab] OR engagement[tiab] OR enrollment[tiab] OR enrolment[tiab] OR recruitment[tiab] OR uptake[tiab])) 128946

#69 Search Communication Barriers[mh:noexp] 4855

#70 Search (#55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69) 850208

#71 Search (#54 AND #70) 18218

#72 Search (animals[mh] not humans[mh:noexp]) 3975150

#73 Search ((editorial[pt] OR news[pt] OR case reports[pt]) NOT randomized controlled trial[pt]) 2241721

#74 Search case report[ti] 168264

#75 Search (#72 OR #73 OR #74) 6205772

#76 Search (#71 NOT #75) 17694

5.2 Search strategy used on Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Interface/URL: Ovid Sp

Search Strategy:

1 Online Systems/	7208
2 Medical Informatics/	8459
3 Medical Informatics Applications/	2067
4 Educational Technology/	1129
5 Electronics, Medical/	6172
6 Audiovisual Aids/	6200
7 Telecommunications/	4348
8 Multimedia/	1510
9 Hypermedia/	389
10 Cell Phones/	4790
11 Social Networking/	932
12 Telemedicine/	11676
13 Telenursing/	125
14 Telephone/	9312
15 Ambulatory Care Information Systems/	1157
16 Mobile Applications/	256

17 Wireless Technology/ 1166

18 Electronic Mail/ 1900

19 Electronic Health Records/ 7141

20 ('personal health record' or 'personal electronic health record' or 'PHR').ti,ab,kf. 1036

21 (phone$1 or mobile$1 or smartphone$ or handset$ or hand-set$ or handheld$ or hand-held$).ti,ab,kf. 77611

22 ((electronic$ or digital$ or device$) adj2 tablet$).ti,ab,kf. 159

23 (tablet PC or tablet computer).ti,ab,kf. 213

24 device-based.ti,ab,kf. 1506

25 ((digital$ or electronic$ or communicat$) adj2 device$).ti,ab,kf. 5274

26 (device$ adj2 technolog$).ti,ab,kf. 1192

27 (PDA or PDAs or personal digital).ti,ab,kf. 6922

28 mp?-player$.ti,ab,kf. 91

29 (online or on-line or internet or www or web or website$ or webpage$ or broadband or broad-band).ti,ab,kf. 151153

30 (wireless or wire-less or wifi or wi-fi or global positioning system$ or bluetooth$).ti,ab,kf. 7860

31 (text messag$ or texting or texter$1 or texted or SMS or short messag$ or multimedia messag$ or multi-media messag$ or mms or instant messag$).ti,ab,kf. 8094

32 (social media$ or facebook or twitter or tweet or tweets).ti,ab,kf. 2655

33 (webcast$ or webinar$ or podcast$ or wiki or wikis or youtube or you tube or vimeo).ti,ab,kf. 1492

34 (app or apps).ti,ab,kf. 13967

35 ((electronic$ or digital$ or device$) adj2 application$).ti,ab,kf. 3124

36 (iphone$ or i-phone$ or ipad$ or i-pad$ or ipod$ or i-pod$ or palm os or palm pre classic$).ti,ab,kf. 1165

37 (android$ or ios or s40 or symbian$ or windows).ti,ab,kf. 14456

38 (video$ or dvd or dvds).ti,ab,kf. 79080

39 (email$ or e-mail$ or electronic mail$).ti,ab,kf. 8891

40 (chat room$1 or chatroom$1).ti,ab,kf. 264

41 (blog$1 or blogging or blogger$ or weblog$1).ti,ab,kf. 821

42 skype.ti,ab,kf. 103

43 (bulletin board$1 or bulletinboard$1 or messageboard$1 or message board$1).ti,ab,kf. 402

44 (software$ or soft-ware$).ti,ab,kf. 91606

45 (interactiv$ or inter-activ$).ti,ab,kf. 35024

46 (ehealth$ or e-health$ or mhealth$ or m-health$ or m-learning).ti,ab,kf. 2679

47 (electronic learn$ or e-learn$).ti,ab,kf. 1353

48 (telephone$1 or telehealth or telemedicine or telenursing or telemonitor$).ti,ab,kf. 50091

49 ((digital$ or electronic$ or communicat$ or information$) adj2 technolog$).ti,ab,kf. 12970

50 ((digital$ or electronic$) adj (intervention$ or therap$ or treatment$ or medicine or medical$ or health$)).ti,ab,kf. 13408

51 (ICT or ICTs).ti,ab,kf. 3011

52 medical informatics.ti,ab,kf. 1933

53 (remot$ adj3 (care or caring or cared or manag$ or consult$ or monitor$ or measur$)).ti,ab,kf. 3174

54 or/1-53 565058

55 (recruitment strateg$3 or recruitment method$).ti,ab,kf. 1625

56 (recruit$ adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 46438

57 ((participation or participating) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 21324

58 ((sign up or take up or enlist) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 280

59 ((engagement or engage or engaging) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 8905

60 ((involvement or involve or involving) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or

child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 53891

61 ((enrolment or enrollment or enrol or enroll or enrolling or enrolled) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 83507

62 (invit$ adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kf. 4661

63 Consumer Behavior/ 17718

64 Consumer Participation/ 14294

65 Patient Participation/ 18353

66 Social Participation/ 676

67 Community-Based Participatory Research/ 2165

68 ((difficult$ or problem$1 or deterrent$1 or obstacle$1 or hindrance$1 or barrier$1 or challenge$1 or impediment$1 or experience$1) adj3 (access or participation or engagement or enrollment or enrolment or recruitment or uptake)).ti,ab,kf. 12568

69 Communication Barriers/ 4875

70 or/55-69 275039

71 54 and 70 21650

72 exp animals/ not humans/ 3984249

73 ((editorial or news or case reports) not randomized controlled trial).pt. 2241320

74 case report.ti.	164932
75 or/72-74	6211072
76 71 not 75	21327
77 limit 76 to yr="2000 -Current"	19481

5.3 Search strategy used on Embase 1974 to 2015 August 19

Interface/URL: Ovid SP

Search Strategy:

1 online system/	18059
2 medical informatics/	14690
3 educational technology/	2380
4 electronics/	22908
5 audiovisual aid/	227
6 telecommunication/	19524
7 multimedia/	2458
8 hypermedia/	343
9 mobile phone/	8888
10 social network/	6495
11 telemedicine/	11801
12 telenursing/	148
13 telephone/	26915
14 hospital information system/	17988
15 mobile application/	675
16 wireless communication/	2070
17 e-mail/	10249

18 electronic medical record/ 27028

19 ('personal health record' or 'PHR').ti,ab,kw. 1244

20 (phone$1 or mobile$1 or smartphone$ or handset$ or hand-set$ or handheld$ or hand-held$).ti,ab,kw. 107249

21 ((electronic$ or digital$ or device$) adj2 tablet$).ti,ab,kw. 266

22 (tablet PC or tablet computer).ti,ab,kw. 373

23 device-based.ti,ab,kw. 1664

24 ((digital$ or electronic$ or communicat$) adj2 device$).ti,ab,kw. 5533

25 (device$ adj2 technolog$).ti,ab,kw. 1510

26 (PDA or PDAs or personal digital).ti,ab,kw. 10301

27 mp?-player$.ti,ab,kw. 149

28 (online or on-line or internet or www or web or website$ or webpage$ or broadband or broad-band).ti,ab,kw. 192340

29 (wireless or wire-less or wifi or wi-fi or global positioning system$ or bluetooth$).ti,ab,kw. 9023

30 (text messag$ or texting or texter$1 or texted or SMS or short messag$ or multimedia messag$ or multi-media messag$ or mms or instant messag$).ti,ab,kw. 10428

31 (social media$ or facebook or twitter or tweet or tweets).ti,ab,kw. 3709

32 (webcast$ or webinar$ or podcast$ or wiki or wikis or youtube or you tube or vimeo).ti,ab,kw. 2241

33 (app or apps).ti,ab,kw. 17517

34 ((electronic$ or digital$ or device$) adj2 application$).ti,ab,kw. 2729

35 (iphone$ or i-phone$ or ipad$ or i-pad$ or ipod$ or i-pod$ or palm os or palm pre classic$).ti,ab,kw. 2106

36 (android$ or ios or s40 or symbian$ or windows).ti,ab,kw. 32140

37 (video$ or dvd or dvds).ti,ab,kw. 106981

38 (email$ or e-mail$ or electronic mail$).ti,ab,kw. 17305

39 (chat room$1 or chatroom$1).ti,ab,kw. 355

40 (blog$1 or blogging or blogger$ or weblog$1).ti,ab,kw. 1226

41 skype.ti,ab,kw. 214

42 (bulletin board$1 or bulletinboard$1 or messageboard$1 or message board$1).ti,ab,kw. 540

43 (software$ or soft-ware$).ti,ab,kw. 142102

44 (interactiv$ or inter-activ$).ti,ab,kw. 43352

45 (ehealth$ or e-health$ or mhealth$ or m-health$).ti,ab,kw. 3198

46 (electronic learn$ or e-learn$).ti,ab,kw. 2166

47 (telephone$1 or telehealth or telemedicine or telenursing or telemonitor$).ti,ab,kw. 65052

48 ((digital$ or electronic$ or communicat$ or information$) adj2 technolog$).ti,ab,kw. 16007

49 ((digital$ or electronic$) adj (intervention$ or therap$ or treatment$ or medicine or medical$ or health$)).ti,ab,kw. 21539

50 (ICT or ICTs).ti,ab,kw. 4141

51 medical informatics.ti,ab,kw. 3088

52 (remot$ adj3 (care or caring or cared or manag$ or consult$ or monitor$ or measur$)).ti,ab,kw. 4521

53 or/1-52 813366

54 (recruitment strateg$3 or recruitment method$).ti,ab,kw. 2227

55 (recruit$ adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 71144

56 ((participation or participating) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 28982

57 ((sign up or take up or enlist) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 410

58 ((engagement or engage or engaging) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 11471

59 ((involvement or involve or involving) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 72283

60 ((enrolment or enrollment or enrol or enroll or enrolling or enrolled) adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 138179

61 (invit$ adj4 (patient or patients or volunteer$1 or participant$1 or people or person$1 or woman or women or man or men or child or children or elder or elderly or students or adolescen$ or rural)).ti,ab,kw. 7310

62 consumer attitude/ 1481

63 consumer/ 37901

64 patient participation/ 17823

65 social participation/ 2103

66 participatory research/ 2373

67 ((difficult$ or problem$1 or deterrent$1 or obstacle$1 or hindrance$1 or barrier$1 or challenge$1 or impediment$1 or experience$1) adj3 (access or participation or engagement or enrollment or enrolment or recruitment or uptake)).ti,ab,kw. 16654

68 or/54-67 387908

69 53 and 68 36429

70 (animal/ or animal experiment/ or animal model/ or animal tissue/ or nonhuman/) not exp human/ 5066706

71 ((editorial or news or case reports) not randomized controlled trial).pt. 466306

72 case report.ti. 210307

73 or/70-72 5729463

74 69 not 73 36198

75 limit 74 to yr="2000 -Current" 34591

5.4 Search strategy used on CINAHL Plus

Interface/URL: EBSCO Host via University of York

Search Strategy:

S71 S67 NOT S70

Limiters - Publication Year: 2000-2015 11,327

S70 S68 NOT S69	52,445
S69 (MH "Human")	1,296,899
S68 (MH "Animals")	58,171
S67 S66 AND S52	11,911
S66 S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65	87,174
S65 (MH "Communication Barriers")	3,818
S64 TI ((difficult* OR problem* OR deterrent* OR obstacle* OR hindrance* OR barrier* OR challenge* OR impediment* OR experience*) N3 (access OR participation OR engagement OR enrollment OR enrolment OR recruitment OR uptake)) OR AB ((difficult* OR problem* OR deterrent* OR obstacle* OR hindrance* OR barrier* OR challenge* OR impediment* OR experience*) N3 (access OR participation OR engagement OR enrollment OR enrolment OR recruitment OR uptake))	6,410
S63 (MH "Social Participation")	1,047
S62 (MH "Consumer Participation")	12,724
S61 (MH "Consumer Attitudes")	4,091

S60 TI ((invit* N4 (patient OR patients OR volunteer* 1 OR participant* 1 OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB ((invit* N4 (patient OR patients OR volunteer* 1 OR participant* 1 OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 1,410

S59 TI (((enrolment OR enrollment OR enrol OR enroll OR enrolling OR enrolled) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB (((enrolment OR enrollment OR enrol OR enroll OR enrolling OR enrolled) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 18,967

S58 TI (((involvement OR involve OR involving) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB (((involvement OR involve OR involving) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 13,806

S57 TI (((engagement OR engage OR engaging) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB (((engagement OR engage OR engaging) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 5,919

S56 TI (((sign up OR take up OR enlist) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB (((sign up OR take up OR enlist) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 201

S55 TI (((participation OR participating) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) OR AB (((participation OR participating) N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural))) 10,180

S54 TI (recruit* N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural)) OR AB (recruit* N4 (patient OR patients OR volunteer* OR participant* OR people OR person* OR woman OR women OR man OR men OR child OR children OR elder OR elderly OR students OR adolescen* OR rural)) 15,219

S53 TI (recruitment strateg* OR recruitment method*) OR AB (recruitment strateg* OR recruitment method*) 1,564

S52 (S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51) 219,831

S51 TI (remot* N3 (care OR caring OR cared OR manag* OR consult* OR monitor* OR measur*) OR AB (remot* N3 (care OR caring OR cared OR manag* OR consult* OR monitor* OR measur*) 975

S50 TI medical informatics OR AB medical informatics 1,102

S49 TI (ICT OR ICTs) OR AB (ICT OR ICTs) 677

S48 TI (digital* OR electronic*) N (intervention* OR therap* OR treatment* OR medicine OR medical* OR health*digital* OR electronic* OR communicat* OR information*) N2 technolog*) OR AB (digital* OR electronic*) N (intervention* OR therap* OR treatment* OR medicine OR medical* OR health*) 26

S47 TI (digital* OR electronic* OR communicat* OR information*) N2 technolog*) OR AB (digital* OR electronic* OR communicat* OR information*) N2 technolog*) 6,935

S46 TI (telephone* OR telehealth OR telemedicine OR telenursing OR telemonitor*) OR AB (telephone* OR telehealth OR telemedicine OR telenursing OR telemonitor*) 19,664

S45 TI (electronic learn* OR e-learn*) OR AB (electronic learn* OR e-learn*) 1,254

S44 TI (ehealth* OR e-health* OR mhealth* OR m-health* OR m-learning) OR AB (ehealth* OR e-health* OR mhealth* OR m-health* OR m-learning) 1,555

S43 TI (interactiv* OR inter-activ*) OR AB (interactiv* OR inter-activ*) 12,658

S42 TI (software* OR soft-ware*) OR AB (software* OR soft-ware*) 17,807

S41 TI (bulletin board* OR bulletinboard* OR messageboard* OR message board*) OR AB (bulletin board* OR bulletinboard* OR messageboard* OR message board*) 1,568

S40 TI skype OR AB skype 67

S39 TI (blog* OR blogging OR blogger* OR weblog*) OR AB (blog* OR blogging OR blogger* OR weblog*) 1,335

S38 TI (chat room* OR chatroom*) OR AB (chat room* OR chatroom*) 192

S37 TI (email* OR e-mail* OR electronic mail*) OR AB (email* OR e-mail* OR electronic mail*) 4,578

S36 TI (video* OR dvd OR dvds) OR AB (video* OR dvd OR dvds) 17,907

S35 TI (android* OR ios OR s40 OR symbian* OR windows) OR AB (android* OR ios OR s40 OR symbian* OR windows) 1,697

S34 TI (iphone* OR i-phone* OR ipad* OR i-pad* OR ipod* OR i-pod* OR palm os OR palm pre classic*) OR AB (iphone* OR i-phone* OR ipad* OR i-pad* OR ipod* OR i-pod* OR palm os OR palm pre classic*) 673

S33 TI (electronic* OR digital* OR device*) N2 application*) OR AB (electronic* OR digital* OR device*) N2 application*) 401

S32 TI (app OR apps) OR AB (app OR apps) 1,570

S31 TI (webcast* OR webinar* OR podcast* OR wiki OR wikis OR youtube OR you tube OR vimeo) OR AB (webcast* OR webinar* OR podcast* OR wiki OR wikis OR youtube OR you tube OR vimeo) 1,201

S30 TI (social media* OR facebook OR twitter OR tweet OR tweets) OR AB (social media* OR facebook OR twitter OR tweet OR tweets) 4,579

S29 TI (text messag* OR texting OR texter* 1 OR texted OR SMS OR short messag* OR multimedia messag* OR multi-media messag* OR mms OR instant messag*) OR AB (text messag* OR texting OR texter* 1 OR texted OR SMS OR short messag* OR multimedia messag* OR multi-media messag* OR mms OR instant messag*) 1,480

S28 TI (wireless OR wire-less OR wifi OR wi-fi OR global positioning system* OR bluetooth*) OR AB (wireless OR wire-less OR wifi OR wi-fi OR global positioning system* OR bluetooth*) 1,857

S27 TI (online OR on-line OR internet OR www OR web OR website* OR webpage* OR broadband OR broad-band) OR AB (online OR on-line OR internet OR www OR web OR website* OR webpage* OR broadband OR broad-band) 86,877

S26 TI mp?player* OR AB mp?player* 7,484

S25 TI (PDA OR PDAs OR personal digital) OR AB (PDA OR PDAs OR personal digital) 1,227

S24 TI device* N2 technolog* OR AB device* N2 technolog* 516

S23 TI ((digital* OR electronic* OR communicat*) N2 device*) OR AB ((digital* OR electronic* OR communicat*) N2 device*) 1,029

S22 TI device-based OR AB device-based 162

S21 TI (tablet PC OR tablet computer) OR AB (tablet PC OR tablet computer) 93

S20 TI ((electronic* OR digital* OR device*) N2 tablet*) OR AB ((electronic* OR digital* OR device*) N2 tablet*) 51

S19 TI (phone* OR mobile* OR smartphone* OR handset* OR hand-set* OR handheld* OR hand-held*) OR AB (phone* OR mobile* OR smartphone* OR handset* OR hand-set* OR handheld* OR hand-held*) 14,850

S18 TI ('personal health record' OR 'personal electronic health record' OR 'PHR') OR AB ('personal health record' OR 'personal electronic health record' OR 'PHR') 336

S17 (MH "Computerized Patient Record") 13,851

S16 (MH "Electronic Mail") 4,495

S15 (MH "Wireless Local Area Networks") 89

S14 (MH "World Wide Web Applications") 4,252

S13 (MH "Ambulatory Care Information Systems")	268
S12 (MH "Telephone")	12,928
S11 (MH "Telenursing")	1,617
S10 (MH "Telehealth")	3,580
S9 (MH "Telemedicine")	5,558
S8 (MH "Social Networking")	714
S7 (MH "Wireless Communications")	9,243
S6 (MH "Hypermedia")	136
S5 (MH "Multimedia")	1,502
S4 (MH "Telecommunications")	1,692
S3 (MH "Educational Technology")	1,181
S2 (MH "Medical Informatics")	2,662
S1 (MH "Online Systems")	1,513

5.5 Search strategy used on Scopus

Interface/URL: http://www.scopus.com/

Search Strategy:

Searching in Article title, abstract and keywords in the Health Sciences and Social Sciences Databases limiting to year 2000 onwards.

(TITLE-ABS-KEY (telemedicine OR ehealth OR electronic health OR digital health) AND SUBJAREA (mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND PUBYEAR > 1999) AND (TITLE-ABS-KEY (patient OR participant OR consumer OR volunteer) AND SUBJAREA (mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND PUBYEAR > 1999) AND (TITLE-ABS-KEY ((barrier OR impediment OR obstacle OR difficulty OR deterrent OR problem) W/3 (access OR participation OR engagement OR enrolment OR enrollment OR recruitment OR uptake)) AND SUBJAREA (mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND PUBYEAR > 1999)

5.6 Search strategy used on ACM Digital Library

Interface/URL: http://dl.acm.org/

Search strategy:

Searching in advanced search with date limits from year 2000 onwards. Results were assessed for relevancy and imported into Endnote separately.

Search strategy has been adapted to the content of this database. No technological terms have been searched. Only aspects of recruitment, barriers and facilitators have been used.

The search interface doesn’t allow complex searches.

Importing is done one by one for each individual reference.

First search string:

In Abstract: barrier and facilitator and ehealth

Results: 1

Relevant: yes

Downloaded into Endnote

In title: barrier and facilitator and ehealth

Results: 0

In any fields: barrier and facilitator and ehealth

Results: 36

Relevant: 14

Downloaded into Endnote

Second search string:

In any field (abstract, title or review): recruitment and participants and “digital health”

Results: 7

Relevant: 1

Downloaded into Endnote

Third search string:

In any field: “electronic health” and “digital health” and ehealth

Results: 18

Relevant: 4

Downloaded into Endnote

Fourth search string:

In any field: "consumer participation" and ehealth

Retrieved: 6

Relevant: 1

downloaded into Endnote

Fifth search string:

In any field: engagement and ehealth

Retrieved: 175

Relevant: 1

Total of relevant records downloaded: 22

Appendix 6 Gazetter lists

e-Health	Barriers	Recruitment
Apps, digital evaluation, digital media, digital observation, e-Health¸ eHealth, electronic health, internet, mHealth, mobile application, mobile applications, mobile technologies, mobile technology, online, on-line, remote control, remote evaluation, remote monitoring, remote observation, remote sensing, remote sensory, remote trial, remote trials, smartphone, SMS, telehealth, telemedicine, telemetry, text message, text messages, text messaging, videoconference, videoconferencing, web based¸ web-based	Barrier, barriers, challenges, difficult, difficulties, difficulty, encouraged, encourages, engagement, enhanced, enhances, facilitate, facilitated, facilitators, impede, impedes, impediment, impediments, inequality, issues, non-use, obstruct, obstructed, obstructer, obstruction, obstructor, obstructs, perceptions, politics, prevent, prevented, preventing, prevention, prevents, problem, problematic, problems, regulations	Employed, employing, employment, enlist, enlisted, enlistee, enlisting, enrol, enrolled, enrolling, enrolment, enrolment, implementation, non-participation, participant, participants, participate, participated, participates, participation, recruited, recruiting, recruitment, recruits, service user, signed up, signed-up, volunteer, volunteered, volunteers, withdrawal

Appendix 7 COREQ checklist from the systematic review

The Consolidated Criteria for Reporting Qualitative Research (COREQ) is a 32-item checklist that can help report important aspects of research quality. This critical appraisal tool was used to assess the quality of the nineteen studies included in the original systematic review and the five studies that form the review update in Chapter 4.

No	Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17
1	Bardus et al, 2011	1	1	1	1	1	0	1	0	1	1	1	1	0	1	1	1	1
2	Beattie et al, 2009	1	1	0	1	0	0	1	0	0	1	1	1	1	1	0	1	1
4	Das & Faxvaag, 2014	0	1	0	1	1	0	1	0	0	1	1	1	0	1	0	1	1
5	Dasgupta et al, 2013	1	1	1	1	1	0	1	0	1	0	1	1	1	0	1	1	1
6	Flynn et al, 2009	0	0	0	1	0	0	1	0	1	1	1	1	1	1	0	1	1

7	Fukuoka et al, 2011	0	1	0	0	1	0	0	1	0	0	1	1	1	0	0	1	1
8	Greenhalgh et al, 2008b	0	0	1	1	0	0	1	0	1	1	1	1	0	1	0	1	1
9	Greenhalgh et al, 2010	0	0	1	1	0	0	1	0	0	1	0	1	0	1	0	0	1
12	Hopp et al, 2007	1	0	0	1	0	0	1	0	0	1	1	1	1	0	0	0	1
13	Horvath et al, 2012	1	0	0	1	0	1	1	1	0	1	1	1	0	1	0	1	1
14	Hottes et al, 2012	0	1	0	1	0	0	1	1	0	0	1	1	0	1	1	1	1
15	Im et al, 2010	0	1	1	0	1	1	1	1	0	1	1	1	1	1	0	1	1
16	Lorimer & McDaid, 2013	0	1	0	1	1	0	1	0	0	1	1	1	1	1	0	1	0

17	Lorimer et al, 2014	1	0	0	1	0	0	1	1	1	1	1	1	0	1	0	1	1
18	Middlemass et al, 2012	0	1	1	1	1	0	1	0	0	1	1	1	0	0	0	0	1
19	Shoveller et al, 2012	0	1	0	1	1	0	1	0	1	1	1	1	0	1	0	1	1
20	Spiers et al, 2015	0	0	0	1	0	0	1	0	0	0	1	1	1	1	0	1	0
22	Trujillo Gómez et al, 2015	0	0	0	1	0	0	1	0	1	1	1	1	1	1	1	1	1
23	Winkelman et al, 2005	0	1	0	1	1	0	1	0	1	1	0	1	0	0	0	1	1

No	Author	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Q29	Q30	Q31	Q32	Total
1	Bardus et al, 2011	0	1	0	1	1	0	1	1	1	1	0	1	1	1	0	**24**
2	Beattie et al, 2009	1	1	0	1	0	0	1	0	1	1	0	1	1	1	1	**21**
4	Das & Faxvaag, 2014	0	1	0	1	1	0	1	0	1	1	0	1	1	1	0	**19**
5	Dasgupta et al, 2013	0	1	1	0	0	0	1	0	1	0	0	1	1	1	1	**21**
6	Flynn et al, 2009	0	1	1	1	0	0	0	0	1	1	0	1	1	1	1	**19**
7	Fukuoka et al, 2011	0	1	0	0	0	0	1	1	1	1	0	1	1	1	0	**16**
8	Greenhalgh et al, 2008b	0	0	1	1	1	0	1	0	1	0	0	1	1	1	0	**20**

9	Greenhalgh et al, 2010	0	1	1	1	0	1	0	0	1	0	1	1	1	0	1	**17**
12	Hopp et al, 2007	0	1	0	1	0	0	1	0	1	0	1	0	1	0	0	**17**
13	Horvath et al, 2012	0	1	0	1	0	0	0	0	1	0	1	0	1	0	0	**17**
14	Hottes et al, 2012	0	1	1	1	0	0	1	0	1	0	1	1	1	0	0	**18**
15	Im et al, 2010	0	1	1	1	0	0	0	0	1	0	1	1	1	0	0	**20**
16	Lorimer & McDaid, 2013	0	1	0	1	0	0	1	0	1	0	1	0	1	0	0	**18**
17	Lorimer et al, 2014	0	1	0	1	1	0	1	0	1	1	0	1	1	1	0	**20**
18	Middlemass et al, 2012	0	0	0	0	1	0	1	0	1	1	0	1	1	1	1	**17**

19	Shoveller et al, 2012	0	1	0	1	1	0	1	0	1	1	0	1	1	1	0	**20**
20	Spiers et al, 2015	0	0	0	0	0	0	0	0	1	0	0	0	1	1	0	**10**
22	Trujillo Gómez et al, 2015	0	1	1	1	1	0	0	0	1	1	0	1	1	1	0	**20**
23	Winkelman et al, 2005	0	0	1	1	1	0	0	0	1	1	0	1	1	1	0	**17**

Appendix 8 COREQ checklist from the systematic review update

The Consolidated Criteria for Reporting Qualitative Research (COREQ) is a 32-item checklist that can help report important aspects of research quality. This critical appraisal tool was used to assess the quality of the five studies included in the systematic review update in Chapter 4.

No	Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17
1	Blackstock et al, 2015	0	1	1	1	0	0	0	0	0	0	1	1	0	1	0	1	0
2	Greenhalgh et al, 2015	1	0	0	1	0	0	0	1	1	0	1	1	0	1	0	1	1
3	Guendelman et al, 2017	1	1	0	1	1	0	0	0	1	0	1	1	0	1	0	1	1
4	Schueller et al, 2018	0	1	0	1	1	0	0	0	0	1	1	1	0	1	0	1	1

5	Zamir et al, 2018	1	0	0	1	0	0	0	0	1	1	1	1	1	1	1	1	1

No	Author	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Q29	Q30	Q31	Q32	Total
1	Blackstock et al, 2015	0	1	0	1	0	0	1	0	1	1	0	1	1	1	0	**15**
2	Greenhalgh et al, 2015	0	1	1	0	0	0	1	0	1	0	0	1	1	1	1	**17**
3	Guendelman et al, 2017	0	1	1	1	0	0	1	0	1	0	0	1	1	1	0	**18**
4	Schueller et al, 2018	0	1	0	0	0	0	1	0	1	0	0	1	1	1	1	**16**
5	Zamir et al, 2018	0	1	1	0	1	0	0	0	1	1	1	1	1	1	1	**21**

Appendix 9 COREQ reporting criteria from the systematic review

The overall results of the critical appraisal of the 19 studies in the systematic review using the COREQ checklist are outlined below.

COREQ Domain 1: Research Team and Reflexivity

This domain covers both the personal characteristics of the research team, in terms of their research experience and qualifications, and it also includes the relationship between the researchers and participants.

COREQ Domain 1 results from the systematic review				
No	**Research team and reflexivity**	**Yes**	**No**	**Unclear**
1	Interviewer or facilitator identified	6	13	0
2	Researcher(s) credentials	11	8	0
3	Researcher(s) occupation	6	13	0
4	Researcher(s) gender	17	0	2
5	Researcher(s) experience and training	9	10	0
6	Relationship established before study started	2	17	0
7	Participant knowledge of interviewer	18	0	1
8	Interviewer characteristics	5	5	9

COREQ Domain 2: Study Design

This domain covers the design of the study in terms of what methodology and theoretical framework was used, how participants were selected and recruited and how and where the data was collected.

COREQ Domain 2 results from the systematic review				
No	**Study Design**	**Yes**	**No**	**Unclear**
9	Methodological orientation and theory	8	9	2
10	Sampling of participants	15	2	2
11	Method of participant approach	17	1	1
12	Sample size	19	0	0
13	Number or reasons for non-participation	9	8	2
14	Setting of data collection	14	4	1
15	Presence of non-participants	4	15	0
16	Description of the sample	16	3	0
17	Interview guide provided	17	2	0

18	Repeat interviews conducted	1	18	0
19	Audio or visual recording	15	3	1
20	Field notes taken	8	11	0
21	Duration of interviews or focus groups	15	4	0
22	Data saturation	8	11	0
23	Transcripts returned to participants	1	18	0

COREQ Domain 3: Data analysis and findings

This domain cover data analysis and how the results were reported in the study.

COREQ Domain 3 results from the systematic review				
No	**Data analysis and findings**	**Yes**	**No**	**Unclear**
24	Number of data coders	12	6	1
25	Description of coding tree	2	16	1
26	Derivation of themes	19	0	0

27	Software used	13	6	0
28	Participants’ feedback or checking	1	18	0
29	Participant quotations provided	18	1	0
30	Data and findings consistent	19	0	0
31	Clarity of major themes	19	0	0
32	Clarity of minor themes	7	5	7

Appendix 10 COREQ reporting criteria from the systematic review update

The overall results of the critical appraisal of the 5 studies in the systematic review update using the COREQ checklist are outlined below.

COREQ Domain 1: Research Team and Reflexivity

This domain covers both the personal characteristics of the research team, in terms of their research experience and qualifications, and it also includes the relationship between the researchers and participants.

COREQ Domain 1 results from the review update				
No	**Research team and reflexivity**	**Yes**	**No**	**Unclear**
1	Interviewer or facilitator identified	3	2	0
2	Researcher(s) credentials	3	2	0
3	Researcher(s) occupation	1	4	0
4	Researcher(s) gender	5	0	0
5	Researcher(s) experience and training	2	3	0
6	Relationship established before study started	0	5	0

7	Participant knowledge of interviewer	0	5	0
8	Interviewer characteristics	1	4	0

COREQ Domain 2: Study Design

This domain covers the design of the study in terms of what methodology and theoretical framework was used, how participants were selected and recruited and how and where the data was collected.

COREQ Domain 2 results from the review update				
No	**Study Design**	**Yes**	**No**	**Unclear**
9	Methodological orientation and theory	3	2	0
10	Sampling of participants	2	3	0
11	Method of participant approach	5	0	0
12	Sample size	5	0	0
13	Number or reasons for non-participation	1	4	0
14	Setting of data collection	5	5	0

15	Presence of non-participants	1	4	0
16	Description of the sample	5	0	0
17	Interview guide provided	4	1	0
18	Repeat interviews conducted	0	5	0
19	Audio or visual recording	5	0	0
20	Field notes taken	3	2	0
21	Duration of interviews or focus groups	2	3	0
22	Data saturation	1	4	0
23	Transcripts returned to participants	0	5	0

COREQ Domain 3: Data analysis and findings

This domain cover data analysis and how the results were reported in the study.

COREQ Domain 3 results from the review update				
No	**Data analysis and findings**	**Yes**	**No**	**Unclear**

24	Number of data coders	4	1	0
25	Description of coding tree	0	5	0
26	Derivation of themes	5	0	0
27	Software used	2	3	0
28	Participants’ feedback or checking	1	4	0
29	Participant quotations provided	5	0	0
30	Data and findings consistent	5	0	0
31	Clarity of major themes	5	0	0
32	Clarity of minor themes	3	2	0

Appendix 11 Data extraction template

ARTICLE DETAILS	
Study Title	
Authors	
Journal, Vol, Issue, Page(s)	
Year	
DOI/Article ID	
Digital Health Intervention (DHI)	
Telehealth system/application	
Mobile application or SMS service	
Online or web-based service	
Other	
Unclear	
Engagement/Recruitment strategy	
Health or social care professional	

Traditional mass marketing e.g. TV, radio, newspaper advertisement	
Internet and Social Media	
Other	
Unclear	
Engagement/Recruitment process	
What did the engagement or recruitment process consist of?	
Setting of DHI	
Home	
Workplace	
Community e.g. family practice, nursing or care home, rehabilitation centre	
Hospital inpatient	
Outpatient clinic	
Other	
Unclear	

Study Details	**Provided**	**Not Provided**	**Unclear**
What is the research question or research aim(s)?			
What sampling procedure is used to select participants?			
What form of data collected is used?			
What form of data analysis is used?			
What is the overall conclusion or recommendations of the study?			
What (if any) study limitations are declared?			
How is the study funded? Are any conflicts of interest declared?			
Participant Details			
Inclusion criteria			
Exclusion criteria			
Number of Participants			
Types of Participants			

Min age of participants		
Max age of participants		
Number of males		
Number of females		
Chronic or other health condition		
Socioeconomic status		
Ethnicity		
Quote	**Barrier / Facilitator**	**NPT Code**

Appendix 12 Details of included studies from the systematic review

The study details of the nineteen articles from the systematic review are outlined below.

Author, Yr, Country	Research Aim	Methodology	Participants	Digital Health Intervention	Engagement or Recruitment Strategy	Results
Bardus et al, 2014, United Kingdom	To investigate reasons for participating or not participating in an e-health workplace physical activity (PA) intervention.	Interviews and focus groups. Thematic analysis (informed by categorisation of determinants of participation in PA programmes).	Employees of universities, service companies, petrochemical companies & borough councils (n=62).	12-week e-mail and text messaging (SMS) communication intervention promoting leisure time and workplace physical activity.	Workplace promotion through posters, brochures and emails. Online recruitment via a website which required consent, eligibility & baseline assessment.	Enrolment processes should be quick and simplified as much as possible to reduce burden on participants. Participation in workplace physical activity initiatives will be influenced by participants' needs, program resources and external factors.
Beattie et al, 2009, United Kingdom	To explore expectations and experiences of online CBT among primary	Pre and post interviews. Thematic analysis.	Primary care patients with a GP diagnosis of depression (n=24	Online cognitive behavioural therapy (CBT).	Recruited via their family doctor, followed by a letter and telephone call from research staff, or patients identified through electronic	Online CBT was perceived to be more convenient and provided a level of anonymity some patients wanted. However, an impersonal virtual relationship that could promote

	care patients with depression.		pre-therapy, n=20 after therapy).		medical records and mailed an invitation letter.	dishonesty and concerns over computer literacy were barriers to engagement.
Das et al, 2014, Norway	To explore how individuals undergoing bariatric surgery used an online discussion forum and to better understand what influenced their participation.	Participant observation (virtual) and interviews. Content and thematic analysis.	Adult patients involved in the bariatric weight loss program at a hospital (n=7).	Online discussion forum (patient-provider communication) which was a feature of a secure eHealth portal.	Recruited at a bariatric surgery clinic by a researcher.	Factors that positively influenced participation included the individuals' motivation to get information and advice, and their need for social support and networking among peers. However, concerns over self-disclosure (poor literacy skills, fear of revealing personal health issues) limited engagement.
Dasgupta et al, 2013, Canada	To identify elements that would enhance participation in a type 2 diabetes	Focus groups. Content analysis.	Women within five years of a diagnosis of gestational diabetes (n=29).	Mixed intervention combining meal preparation training ("cooking lessons"),	Women previously followed at gestational diabetes clinics received up to three focus group invitation letters, signed by their physician (who	Factors that would enhance participation included strong social support from partners, peers and health professionals to encourage behaviour change. The Internet and social media were seen as additional modes of support. Barriers

	prevention program.			nutritional education and pedometer based self-monitoring.	were members of the research team).	were child-related responsibilities and busy working lives and careers.
Flynn et al, 2009, United Kingdom	To assess expectations and experiences of an eHealth service in primary care for booking appointments.	Interviews, questionnaires, a Web-based survey and log (usage) files. Content analysis and constant comparative method.	90 primary care patients (36 users and 54 non-users) and 28 staff across the three participating GP surgeries were interviewed; 135 completed surveys.	Online appointment booking system in GP surgeries called Access, which also had e-prescribing functions and allowed patients to send messages to the practice.	Each GP practice had a mix of strategies. Some advertised via printed flyers and digital screens in GP waiting rooms. Some advertised on their website and others used personal contact with patients through a dedicated project manager for direct recruitment.	More active promotion of the eHealth service would have resulted in more use including endorsement by GPs. Different patient groups were identified with characteristics that may be used as predictors of eHealth services e.g. computer literate, Internet access, preference for electronic communication.
Fukuoka et al, 2011,	To explore the applicability of the components	Focus groups. Descriptive statistics and	Adults with a BMI >25 having a self-reported diabetic	Mobile phone based healthy lifestyle program	Co-design.	Aspects that would motivate individuals to engage with the mHealth intervention included real-time social support (both

United States	of a mobile phone-based healthy lifestyle program and the motivators and barriers to engagement.	thematic analysis.	condition and sedentary lifestyle (n=35).	for overweight or sedentary adults (hypothetical technology).		peers and health professionals), personalised messages for self-monitoring. Barriers included fear of failing to meet goals, cost of technology, digital illiteracy, and loss of interest over time.
Greenhalgh et al, 2008b, United Kingdom	To document the views of patients and the public towards the Summary Care Record and HealthSpace.	Semi-structured interviews and focus groups. Analysis informed by a socio-technical approach and the principles of critical discourse analysis.	Mix of patients with various health conditions accessing a range of services and some and lay people (n=170).	Summary Care Record (SCR) a patient accessible electronic health record. HealthSpace an online personal health organiser.	Some were aware of SCR and HealthSpace through their healthcare professional (primarily a family doctor) or via mass media or direct mailing but the recruitment strategy is not described in detail.	Most people were not aware of the eHealth interventions or saw no benefit in them. Factors influencing their decision to sign up included level of health literacy, trust in health professionals, experiences of healthcare and government surveillance, the type of illness.
Greenhalgh et al, 2010,	To evaluate patients and	Mixed methods including	Patients and carers (n=56) as	HealthSpace an internet	Locally advertised in participating general	A low uptake of HealthSpace was due in part to the limited interest of patients,

United Kingdom	carers experiences of efforts to introduce an internet accessible personal electronic health record (HealthSpace).	participant observation, interviews, documentary evidence and national statistics.	well as staff in national and local health and affiliated organisations (n=160).	accessible personal health record with a secure message exchange function called Communicator.	practice (GP) surgeries, via consultations with family doctors and also promoted through GP websites. Local and national mass media campaigns were also used as was direct mailing. In certain cases practice staff assisted with the registration process.	who felt it was the responsibility of health professionals to manage their data, along with a cumbersome registration process. Others lacked computers or Internet at home or the skills to use them. Some patients were using other means to manage their illness and had other priorities that took precedence over using HealthSpace.
Hopp et al, 2014, United States	To describe barriers and facilitators to implementing monitoring and messaging device (MMD) programs.	Interviews with clinicians using MMD-based telehealth programs.	Telehealth providers (community nurses, n=10) using a MMD program with diabetic patients.	Telehealth service with diabetic patients in a Veterans Association (VA) health system.	Patients were referred for nursing services (case management or home care) and telehealth providers then decide which of these patients were suitable for the MMD program.	Several factors hindered patients' participation in MMDs such as the severity of their clinical condition, poor digital skills, no telephone line at home and poor motivation to manage diabetes care. Nurses acted as the gatekeeper to enrolment and selected suitable patients for the MMD program.

Horvath et al, 2012, United States	To explore the reasons why people with HIV would participate in social networking health websites.	Mixed methods study consisting of a survey and an online focus group.	People living with HIV (PLWH, n=22).	Online social networking health websites.	The recruitment strategy for the online social networking websites was not explored. The researchers wanted to examine reasons for participating to develop a HIV specific social networking website.	Some participants believed social networking sites to be exclusionary and irrelevant if a person had other social outlets. They had concerns over privacy and anonymity of personal data and having negative experiences online. Some participants did not have access to a computer and were worried about costs of accessing the site.
Hottes et al, 2012, Canada	To identify perceived benefits, concerns, and expectations of an Internet-based STI and HIV testing system.	Qualitative study using six focus groups.	Participants were men who have sex with men (MSM) and men already accessing in-clinic STI testing services (n=39).	An Internet-Based HIV and STI testing application.	Co-design.	Some participants felt the anonymity, accessibility and sense of personal control of an Internet service for sexual health would facilitate engagement. Others had concerns over security of health information, identify theft and a possible reduction in the quality of care received online. Digital literacy and

						access to the Internet were other aspects that could hinder engagement.
Im et al, 2011, United States	To explore what facilitated or inhibited Asian Americans living with cancer to participate in Internet Cancer Support Groups.	Qualitative online forum. Theoretically guided by a feminist perspective on Internet interactions.	Asian American cancer patients (n=18).	Internet Cancer Support Group (ICSG).	Recruitment was only discussed in relation to the research study and not how participants signed up to use the ICSG.	Some patients considered not participating in the ICSG as they had enough family support or were burdened with caring responsibilities and were the breadwinners in their families. Others wanted to sign up to get social support and advice from fellow peers experiencing cancer & they liked the anonymity ICSGs provided.
Lorimer et al, 2013, United Kingdom	Explore young men's views on barriers and facilitators of implementing an Internet-based	Qualitative study with 15 focus groups.	Young heterosexual men, aged 16-24 years (n=60).	Internet based chlamydia screening programme.	Co-design.	Some participants had concerns over privacy and confidentiality of the digital health intervention while others thought they would engage if the web service was personalised to their needs in terms of content, design and functionality.

	screening program.					
Lorimer et al, 2014, United Kingdom	To examine the opinions of general practitioners and practice nurses towards Internet-based STI screening.	Qualitative study using semi-structured telephone interviews.	General practitioners (n=10) and practice nurses (n=8).	Internet based chlamydia screening programme.	Not reported. Recruitment was only discussed in relation to the research study.	Some health professionals felt young men would sign up to use the online service as they had access to smartphones and had the skills to use them. They also felt the service was easily accessible, convenient and confidential which would appeal to younger people who may be embarrassed about sexual health.
Middlemass et al, 2012, United Kingdom	Explore patient and health professional views on social networking for computerised cognitive behavioural therapy (CBT).	Qualitative study using focus groups and interviews. Underpinned by the Theory of Planned Behaviour.	17 interviews and 3 focus groups with patients (n=28), 8 interviews and 3 focus groups with health professionals (n=23).	Computerised cognitive behavioural therapy (CBT) for insomnia integrated with online communities or social networks.	Not reported. Recruitment was only discussed in relation to the research study.	Some barriers identified by participants included limited access to computers due to financial constraints, poor digital literacy, security and confidentiality concerns of personal information online. Others felt accreditation by a trusted organisation and clinician endorsement would help and wanted to sign up for social support and reduce isolation.

Shoveller et al, 2012, Canada	To examine youth's perspectives on: online STI/HIV testing services and online counselling and education services.	Grounded theory approach using qualitative semi-structured interviews.	Men and women aged between 15 and 24 who were sexually active and had either tested or considered STI/HIV testing (n=52).	Online STI/HIV testing services and online counselling and education services.	Not reported. Recruitment was only discussed in relation to the research study.	Many participants liked the convenience, accessibility, immediacy and privacy of online testing which could help reduce anxiety. However, others noted that the online service might be poorer quality than an in-person interaction, they were concerned about data privacy and the lack of integration or full automation of an online health service.
Spiers et al, 2015, United States	To explore the barriers to enrolment to an SMS-based nutrition and physical activity promotion program for parents.	Mixed methods with a post-test, post implementation and drop-out survey and a post-implementation focus group.	Parents of children attending primary schools (n=250).	SMS messages for nutrition and physical activity promotion program.	Parents received promotional material explaining how to self-enrol by sending an SMS. Manual enrolment was also done by FSNE educators at school events. During year two parents could self-enrol online.	Some parents experienced barriers to enrolment as the registration process was too complex and they were concerned about the costs, duration and content of the SMS based initiative.

Trujillo Gómez et al, 2015, Spain	To gather opinions from health professionals and smokers about an email-based application to help smoking cessation.	Semi-structured interviews & discussion groups. Phenomenological perspective.	Smokers (n=11) attending a primary care centre and health professionals (n=12; GPs & nurses).	Emailed based application to support smoking cessation.	Co-design.	Many participants were unaware of technology for smoking cessation. Some felt the lack of personal contact with a health professional and the possibility of cheating using the technology would prevent engagement. Others believed it could motivate them, help save time and facilitate access to expert advice.
Winkleman et al, 2005, Canada	To explore how patients living with chronic IBD value Internet-based patient access to electronic patient records.	Qualitative, exploratory, descriptive study using a grounded theory approach. Interviews and focus groups were conducted.	Patients with IBD of at least one-year duration (n=12).	Online Electronic Medical Record.	Not reported. Recruitment was only discussed in relation to the research study.	Some patients wanted the DHI to be endorsed and used by clinicians as an adjunct to their therapeutic relationship before engaging and others had concerns about data security and privacy of personal health information. Others wanted the EMR to be tailored to their needs and saw it as facilitating personal access and control of their health data.

Appendix 13 Details of included studies from the systematic review update

The study details of the five articles from the review update are outlined below.

Author, Yr, Country	Research Aim	Methodology	Participants	Digital Health Intervention	Engagement or Recruitment Strategy	Results
Blackstock et al, 2015, USA	To understand the perspective of women with HIV on implementing an Internet support group.	Semi-structured interviews. Inductive coding – constant comparative approach.	27 women with HIV.	An online support group for women with HIV.	Not reported. Recruitment was only discussed in relation to the research study.	Six themes including a need for groups and increased sense of connectedness, convenience and accessibility, trust as a precondition for participating, online groups as a potential facilitator or barrier to expression, limited digital access and literacy, and privacy concerns.
Greenhalgh et al, 2015, United Kingdom	To explore the quality in the design, implementation and use of	Phase 1: interviews with stakeholders, Phase 2: ethnographic	Technology suppliers (n=7), service provider organisations (n=14), 40	Assisted living technologies for patients with multimorbidity.	Co-design used with patients.	Results include the need to customise and adapt assisted living technologies, the importance of information sharing and coordination, and the need for

	telehealth and telecare and how might it be achieved.	observation, Phase 3: co-design technologies. Informed by Merleau-Ponty's work on perception and Heidegger's concept of technology.	ethnographic case studies, co-design workshops (10 with 61 participants).		Support from health, care or other professional.	ongoing social interaction and support among others.
Guendelman et al, 2017, USA	To understand the extent of adoption and use of digital health tools.	Mixed-methods study with focus groups and a survey.	Pregnant women or young mothers (n=92) from disadvantaged backgrounds.	Health technologies such as using the Internet to search for information or making medical appointments, patient portals, email, video chats, apps, and wearables.	Not reported. Recruitment was only discussed in relation to the research study.	Some prefer face-to-face interactions with healthcare providers so had no interest in DHIs. Limited digital skills.

Schueller et at, 2018, USA	To understand how people search for apps and what influences their decision to use an app.	Survey and focus groups.	Seven focus groups with 30 participants.	Health apps.	User reviews on app websites and online forums. Download the health app from a website.	The results included apps coming from trusted sources, personal use guides adoption and the features of the app can be influential.
Zamir et al, 2018, UK	Identify barriers, facilitators and benefits of video-calls in a community hospital and care home environments.	Action research - ethnographic observations in 7 care homes, unstructured interviews, memo writing, feedback forms and reflective diaries.	32 care staff across one community hospital and six care homes (4 withdrew before end of study). 8 older residents and their families.	Skype on Wheels (SoW) - iPad to make video calls to family and friends from care home residents.	Care staff introduced the technology to older residents. Families provided support.	Some older adults felt the technology was confusing or could not use it, while others tried and liked it. Family time and commitment was required to encourage engagement. Some staff mediated access to the SoW while others integrated it into daily activities. Some residents thought the DHI could help address loneliness and isolation they felt.

Appendix 14 Details of participant characteristics from the systematic review

The participant characteristics of the nineteen studies from the systematic review are outlined below.

Author, Yr, Country	Digital Health Intervention	No of Participants	Types of Participants	Gender % (n)	Age range (years)	Ethnicity	Socioeconomic status
Bardus et al, 2014, United Kingdom	Email and text messaging (SMS) communication intervention promoting leisure time and workplace physical activity.	62	Employees of universities, service companies, petrochemical companies and borough councils.	74% female (n=46); 26% male (n=16)	20-63	Ethnicity not described.	Most had higher education degrees (n=36) and worked full-time (n=44).
Beattie et al, 2009, United Kingdom	Online cognitive behavioural therapy (CBT).	44	Primary care patients with a diagnosis of depression.	71% female (n=17); 29% male (n=7)	20-69	Ethnicity not described.	No educational or employment status described.

Das et al, 2014, Norway	Online discussion forum (patient-provider communication) in an eHealth portal.	7	Adult patients involved in the bariatric weight loss program at a hospital.	86% female (n=6); 14% male (n=1)	25-55	Ethnicity not described.	1 educated to primary school level; 4 to high school level; 2 university/college level. No other socioeconomic status described.
Dasgupta et al, 2013, Canada	Mixed intervention combining meal preparation training ("cooking lessons"), nutritional education and pedometer based self-monitoring (hypothetical).	29	Women within five years of a diagnosis of gestational diabetes	100% female (n=29)	Not described.	Ethnicity not fully described.	14 were employed; 15 university educated. No other socioeconomic status described.
Flynn et al, 2009, United Kingdom	Online appointment booking system in GP surgeries, which also had e-prescribing functions and allowed patients to send messages to the practice.	118	Primary care patients some of whom have a chronic illness (n=36 users and n=54 non-users); 28 staff across the three participating GP surgeries were	49% female (n=58); 51% male (n=60)	18-80	Ethnicity not described.	No educational or employment status described.

			interviewed; 135 completed surveys.				
Fukuoka et al, 2011, United States	Mobile phone based healthy lifestyle program for overweight or sedentary adults (hypothetical).	35	Adults with a BMI >25 having a self-reported diabetic condition and sedentary lifestyle.	57% female (n=20); 43% male (n=15)	Not described.	19 White; 11 African American; 3 Asian; 2 others.	41 (40%) college educated; 9 in part or full-time employment; 17 earn <$20,000 per year.
Greenhalgh et al, 2008b, United Kingdom	Summary Care Record (SCR) a patient accessible electronic health record. HealthSpace an online personal health organiser.	170	Mix of patients with various health conditions e.g. HIV, mental health, drug addiction etc. accessing a range of services and some were lay people	58% female (n=99); 42% male (n=71)	16-84	141 White; 13 South Asian; 11 African; 5 mixed race.	Occupations: managerial - 23; white collar - 12; manual - 16; unemployed - 12; housewife - 33; student - 10.
Greenhalgh et al, 2010,	HealthSpace an internet accessible personal health record with a secure message	216	Patients and carers (n=56) as well as staff in national and local	Gender not described.	Not described.	Ethnicity not described.	No educational or employment status described.

United Kingdom	exchange function called Communicator.		health and affiliated organisations (n=160).				
Hopp et al, 2007, United States	Telehealth service with diabetic patients in a Veterans Association (VA) health system.	10	Telehealth providers (community nurses) using a MMD program with diabetic patients.	Gender not described.	Not described.	Ethnicity not described.	No educational or employment status described.
Horvath et al, 2012, United States	Online social networking health websites (hypothetical).	22	People living with HIV	9% female (n=2); 91% male (n=20)	Not described.	18 white, other ethnicities not described.	12 people earned less than <$30,000. No other educational or employment status described.
Hottes et al, 2012, Canada	An Internet-Based HIV and STI testing application (hypothetical).	39	Participants were men who have sex with men (MSM) and men already accessing in-clinic STI testing services.	10% female (n=4); 82% male (n=32); 8% two-spirit (n=3)	20 ≥50	Ethnicity not described.	Level of education: 1 primary school; 10 high school; 23 university; 5 postgraduates. No educational or employment status described.

Im et al, 2011, United States	Internet Cancer Support Group (ICSG).	18	Asian American cancer patients.	83% female (n=15); 17% male (n=3)	22-62	8 Chinese, 1 Japanese, 2 Filipino, 2 Indian, 1 Persian, 4 other.	Educational level: 2 college, 16 postgraduate or more. 12 employed, 6 not employed. Family income sufficient 11, insufficient 5, more than sufficient 2.
Lorimer et al, 2013, United Kingdom	Internet based chlamydia screening programme (hypothetical).	60	Young heterosexual men, aged 16-24 years across 15 focus groups (FGs).	100% male (n=60).	16-24	13 FGs were white British; 2 FGs were black and minority ethnic.	9 FGs from deprived area and 6 from non-deprived area based on Scottish Index of Multiple Deprivation. No other educational or employment status described.
Lorimer et al, 2014, United Kingdom	Internet based chlamydia screening programme (hypothetical).	18	General practitioners (n=10) and practice nurses (n=8).	72% female (n=13); 28% male (n=5)	Not described.	Ethnicity not described.	No educational or employment status described.

Middlemass et al, 2012, United Kingdom	Computerised cognitive behavioural therapy (CBT) for insomnia integrated with online communities or social networks (hypothetical).	51	17 interviews and 3 focus groups with patients (n=28), 8 interviews and 3 focus groups with health professionals (n=23).	Not described.	Not described.	Ethnicity not described.	No educational or employment status described.
Shoveller et al, 2012, Canada	Online STI/HIV testing services and online counselling and education services (hypothetical).	52	Men and women aged between 15 and 24 who were sexually active and had either tested or considered STI/HIV testing.	27% female (n=14); 73% male (n=38)	15-24	6 Aboriginal; 8 East Asian; 26 Euro-Canadian; 2 South East Asian; 10 Other	No educational or employment status described.
Spiers et al, 2015, United States	SMS messages for nutrition and physical activity promotion programme.	250	Parents of children attending primary schools.	88% female (n=220); 12% male (n=25)	Not described.	139 African American; 58 White; 18 Hispanic; 14	Income: 84 earn <$20,000; 51 earn $20-40,000; 38 earn $40-60,000; 42 earn >$60,000. No other

						Asian; 13 Other	educational or employment status described.
Trujillo Gómez et al, 2015, Spain	Emailed based application to support smoking cessation (hypothetical).	23	Smokers (n=11) attending a primary care centre and health professionals (n=12; GPs and nurses).	78% female (n=18); 22% male (n=5)	26-64	Ethnicity not described.	No educational or employment status described.
Winkleman et al, 2005, Canada	Online Electronic Medical Record (hypothetical).	12	Patients with Irritable Bowel Disorder (Chron's and Ulcerative Colitis) of at least one-year duration.	58% female (n=7); 42% male (n=5)	21-60	Ethnicity not described.	No educational or employment status described.

Appendix 15 Details of participant characteristics from the systematic review update

The participant characteristics of the five articles from the review update are outlined below.

Author, Yr, Country	Digital Health Intervention	No of Participants	Types of Participants	Gender % (n)	Age range (years)	Ethnicity	Socioeconomic status
Blackstock et al, 2015, USA, (Update)	An online support group for women with HIV.	27	Women diagnosed with HIV.	100% female (n=27).	Average age was 48.	Hispanic (55%, n=15), non-Hispanic Black (45%, n=12).	Not reported.
Greenhalgh et al, 2015, UK	Assisted living technologies for patients with multimorbidity.	122	Phase 1: Technology suppliers (n=7), service provider organisations (n=14), Phase 2: ethnographic case studies (n=40) of patients with multimorbidity, Phase 3:	Phase 2 only reported: male =13, female =27	Phase 2 only reported: median age 81 (range 60	Phase 2 only reported: White =24, Other European =1, South Asian = 4, Chinese = 3, Caribbean	Phase 2 only reported: Housing status – Own house or flat = 19, Privately rented = 1, Housing association = 7, Local authority = 10, Sheltered housing = 3.

			co-design workshops (n=16).		- 98 years).	= 5, African = 2	
Guendelman et al, 2017, USA	Health technologies such as using the Internet to search for information or making medical appointments, patient portals, email, video chats, apps, and wearables.	**92**	Pregnant women or young mothers (n=92) from disadvantaged backgrounds.	100% women (n=92)	18 - 24 years = 23, 25 - 34 years = 44, 35+ years = 25	White = 8, Black = 40, Hispanic = 22, Asian = 15, Mixed race or other = 7	Employed = 32, Unemployed = 14, Not in labour force = 34, Student = 12. < High school = 17, High school diploma = 19, Some college education = 40, Bachelor's degree or higher = 16
Schueller et al, 2018, USA	Health apps.	30	Seven focus groups with 30 participants.	23 females and 7 males.	Age ranged from 21 - 72 years.	Not reported.	Education: < High school = 1, High school graduate = 0, Some college = 7, Associate's degree = 2, Bachelor's degree = 11, Masters = 6, PhD = 3

Zamir et al, 2018, UK	Skype on Wheels (SoW) - iPad to make video calls to family and friends.	40	32 care staff across one community hospital and six care homes (4 sites withdrew before the end of the study). 8 older people and their families.	Staff or residents gender not reported.	Residents aged over 65 years. Staff age not reported.	Not reported.	Education level of staff some college / degree. Hourly wage of staff ranged from £7.50 - £10+.

Appendix 16 Participant quotes from the systematic review

Participant quotes for each major theme and subtheme identified in the original systematic review in Chapter 4.

Theme 1: Personal Agency and Motivation
Subtheme 1.1: Motivation
Quote 1: "*[I subscribed] to get the reminders, because if you're sat, if you are in a lunch break and you're sat at your desk just on the Internet and you're not moving and you're eating something that's not good and then you get a reminder and it's just: 'have a walk!', or something. Straight away there is a trigger in your mind and you think: 'yeah, that's right, I can do that!"* – Facilitator (Bardus et al, 2014) **Quote 2:** *“For me, it does not change anything because I am always in a car. I walk very little so I will feel even guilty for not having walked. I will look down at the low numbers and I’ll feel anxious.”* – Barrier (Dasgupta et al, 2013)
Subtheme 1.2: Awareness and understanding
Quote 1: “*Anything you can learn is helpful. When you have something, you want to know everything about it, the good and the bad. What can happen to you if you don’t eat properly or medicines don’t take? I want to know the worst and the best.*” – Facilitator (Winkleman et al, 2005)

Quote 2: *“Many were unsure of the purpose of HealthSpace, describing it as “pointless,” “irrelevant,” and not fit for purpose (“I would just rather write it down in the diary or just hide it underneath my bed or something”)”* – Barrier (Greenhalgh et al, 2008b)
Subtheme 1.3: Personal agency (choice and control)
Quote 1: *“One thing that appeals to me is that you could do it immediately, as opposed to having to book an appointment with a clinician and maybe you won’t be able to do that for a few days. Especially if I was very concerned about something and wanted answers immediately.”* – Facilitator (Shoveller et al, 2012) **Quote 2:** *“I just decided it wasn't worth my while because I cycle fifteen miles a day, so you know, I probably couldn't do much more exercise anyway. I've got my own exercise routine.”* - Barrier (Bardus et al, 2014)
Theme 2: Personal Life and Values
Sub-theme 2.1: Personal lifestyle
Quote 1: *"This is definitely a service I would use, not only for the convenience factor but I mean, no matter how old we are, it’s still an embarrassing issue for a lot of people.”* – Facilitator (Hottes et al, 2012)

Quote 2: “*I didn’t sign up or I didn't do the programme for any other reason than simply due to constraints on my time and difficulties on my time, otherwise I think I would have gladly welcomed the participation. I work full time, and I've issues with my personal life, so I didn't really have a huge amount of time to do any sort of things*” **-** Barrier (Bardus et al, 2014)
Sub-theme 2.2: Skills and equipment
Quote 1: *"I presume that like technology is maybe the right way forward with this. Because that’s, you never see a young person that does not have a mobile phone."* – Facilitator (Lorimer et al, 2014) **Quote 2:** "*I’m not tech savvy, so, I’m from the “old school” and I hate the cell phones my children give me."* – Barrier (Fukuoka et al, 2011)
Sub-theme 2.3: Security and privacy
Quote 1: “*While not a single participant thought that these measures would guarantee the security of their data, most thought that the small risk of identity fraud, disclosure, or blackmail was worth taking. They contrasted personal health information (seen as a low security risk) with their bank details (much higher risk), and some people with serious illness joked that nobody would want to steal their identity*” – Facilitator (Greenhalgh et al, 2008b)

Quote 2: *"I'm very wary of the internet, we leave digital footprints wherever we go and you never know what's going to come back and haunt you and I think the more that you are in a professional working environment the more you need to be careful about what you put online. You've got to keep it within certain parameters."* – Barrier (Middlemass et al, 2012)
Theme 3: Engagement and Recruitment Approach
Subtheme 3.1: Recruitment strategy
Quote 1: "*I make that decision by the patient's need. If their diabetes is poorly controlled, then you need to use more tools to get them under control... you don't really need it with all your patients with diabetes. You need it on the ones that need extra help."* – Facilitator (Hopp et al, 2007) **Quote 2:** *"some parents did not enroll because they were apprehensive about signing up for an SMS program. These parents, who saw recruitment materials but did not speak with program staff, reported worrying about how much the program would cost them, how long they would have to remain enrolled, and the exact content of the messages."* – Barrier (Spiers et al, 2015)
Subtheme 3.2: Direct support
Quote 1: *"Two carers said that the patient did not have the skills to register or use the technology themselves, and another participant (visually impaired)*

needed a partner’s help because the grid card was not available in large print” – Facilitator (Greenhalgh et al, 2010) **Quote 2:** *"I was encouraged to sign up by my old boss at that time, he didn't really tell us about that thing. He encouraged just to sign up so I did and then, once I had, I didn't really hear anything else about it and I didn't know what it was all to be honest, really what it was about or anything."* – Barrier (Bardus et al, 2014)
Subtheme 3.3: Personal advice
Quote 1: *“It was a friend that recommended it last time we see: she had seen the posters and recommended it to me, because she knew I might have been interested.”* – Facilitator (Bardus et al, 2014) **Quote 2:** *“I just thought that our husbands or mates- not that they don’t want us to be healthy and learn about this - but they also are feeling time constraints. Maybe if they had an information session at the beginning to underline how important this is… what it’s going to entail, that they might have to give up a little bit of their time for us to do that.”* – Barrier (Dasgupta et al, 2013)
Subtheme 3.4: Clinical endorsement

Quote 1: *"If it was accredited by a university or medical college or something like that it would be a good start."* – Facilitator (Middlemass et al, 2012) **Quote 2:** *"I would probably if I knew that the physician would access that prior to an appointment. If the physician didn't read it, if it was more of a personal thing [just for me to do], I don't know if I would kind of follow through with that*." – Barrier (Winkleman et al, 2005)
Theme 4: Quality of the Digital Health Intervention
Sub-theme 4.1: Quality of digital health information
Quote 1: *"I will feel more comfortable to join the Chinese cancer support group, due to the language the same, and especially the culture the same. The jokes we make will be understandable, a lot of time we care about what is happening back to our origin country."* – Facilitator (Im et al, 2010) **Quote 2:** *"I assume that my doctor will inform me regardless [not] just because I have access to this that I am going to be on it."* – Barrier (Winkleman et al, 2005)
Sub-theme 4.2: Quality of digital health interaction

Quote 1: *“I was so down and my peers/family couldn’t handle it and I needed someone who could tell me that it would be OK and that it was normal but also that I needed to stop feeling sorry for myself in a nice way…. I just went online and look for my support group [sic].”* – Facilitator (Im et al, 2010) **Quote 2:** *"I don't think you would get the same feeling as if you were one-to-one in a room. You get more, you get to know the other person, so in a way you would. To me it would be like talking to a machine."* – Barrier (Beattie et al, 2009)
Sub-theme 4.3: Usability
Quote 1: “*It would be nice if you didn’t need to print anything out. If you could just e-mail it to the lab, and … then just kind of show up.*” – Facilitator (Shoveller et al, 2012) **Quote 2:** “*I think the conception with e-mail is that you’re gonna have to wait a couple days for an answer. And, when you’re looking for an answer that can seem like a year.*” – Barrier (Shoveller et al, 2012)

Appendix 17 Participant quotes from the systematic review update

Participant quotes for each major theme and subtheme identified in the review update in Chapter 4.

Theme 1: Personal Agency and Motivation
Subtheme 1.2: Awareness and understanding
Quote 1: "The appearance of the SoW device caused anxiety and confusion among some residents in the care home environment. Staff reported that one resident of C1 became scared, anxious and confused as to why the device was in her room when a video-call was set up. (Author interpretation)" – Barrier (Zamir et al, 2015)
Subtheme 1.3: Personal agency (choice and control)
Quote 1: "Online groups were perceived by women as being convenient and increasing accessibility to information and social support. Some women felt they could use the online group to get information when their health care providers were not available. Others stated that an online group would enable women to participate without having to leave home and at times most convenient to them. (Author interpretation)" – Facilitator (Blackstock et al, 2015)

Theme 2: Personal Life and Values
Sub-theme 2.1: Personal lifestyle
Quote 1: ″The asynchronous nature of online groups (i.e., posting whenever it is convenient as opposed to at a set time during which all group members could converse) was highlighted as a positive feature as it could make participation more convenient (Author interpretation)” – Facilitator (Blackstock et al, 2015) **Quote 2:** “*I think for younger women who are already doing it, that's for them. But for older women - I'm not saying I’m old – but, I'm at an age where I'm comfortable with what I have and I think it's better in a [in-person] group setting. When it's younger people, [an online group] is for them*” – Barrier (Blackstock et al, 2015)
Sub-theme 2.2: Skills and equipment
Quote 1: ″ For instance, although most women reported Internet access and having used the Internet and social media (Author interpretation)″ – Facilitator (Blackstock et al, 2015) **Quote 2:** “*I don't know how to play with the Internet. I just don't know. Maybe if I had the ability to do so I would, but I just don't know*” – Barrier (Blackstock et al, 2015)

Quote 3: “*I’m interested in connecting more with my doctor and my kids’ doctor, but who is there to help me do it? If we don’t have time to sign up and they don’t have time to help us, then I won’t do it*” – Barrier (Guendelman et al, 2017) **Quote 4:** “*There are people that have a computer, but there’s also some people that don’t have computer. They gotta’ go to libraries or somewhere [to find a computer]*” – Barrier (Blackstock et al, 2015)
Sub-theme 2.3: Security and privacy
Quote 1: “*They would be able to just say things that they don't dare say to other people or people in front of them. They would be able to open up more. Some people don't want to say things in front of other people*” – Facilitator (Blackstock et al, 2015) **Quote 2:** “*I would feel a little insecure [using an online group] because you might have some great old computer whiz that can look at your computer address and find out who that actually belongs to.*” - Barrier (Blackstock et al, 2015)
Sub-theme 2.4: Cost and funding
Quote 1: “It is worth noting with regards to cost that participants did have thoughts about the value of apps with ongoing costs such as subscriptions.

Although participants reported that they would pay *some* ongoing cost for an app they perceived as useful, many participants voiced some sort of limit to how much they would be willing to spend (Author interpretation)" - Facilitator (Schueller et al, 2018) **Quote 2:** "*I wouldn't spend $100.00 on any app for a year.* [P13, FG3] *...well, no, I'm not likely to buy a $60.00 a year app. Screw that. Never mind.* [P7, FG2]" - Barrier (Schueller et al, 2018)
Sub-theme 2.5: Health and wellbeing
Quote 1: "Participants believed that an online group would provide an advantage for women with more advanced disease and were not able to leave home due to their disabilities (Author interpretation)" - Facilitator (Blackstock et al, 2018) **Quote 2:** "Many of the patients who were well enough had an inquisitive approach to the device, but patients' varying degrees of ill health affected their ability to talk (Author interpretation)" - Barrier (Zamir et al, 2018)
Theme 3: Engagement and Recruitment Approach
Subtheme 3.1: Recruitment strategy

Quote 1: "*Recently I did an OT assessment for a lady who was not eligible for social care. And so I went into – almost like in an advisor capacity, assessed her and everything, but it turned out what she really wanted, what was really of value to her, was completely out of the box, you know. And I kind of made loads of phone calls, I went online, to contact various people and look at websites, as we were doing this… And instead of kind of doing the standard, which I would have normally done, because it was outside of the statutory circuit I could do this. And I sort of felt, you know, this is really quite good, this is much more like a role that I believe would help people. … So it's not all about the technology itself, it's also about the approach*" – Facilitator (Greenhalgh et al, 2015) **Quote 2:** "Walter says that someone talked about him having a pendant alarm but it didn't arrive. He had fallen 3 or 4 times in his bedroom and he didn't know what had caused the falls. He would very much like to have a pendant alarm. (Author interpretation)*"* – Barrier (Greenhalgh et al, 2015)
Subtheme 3.2: Direct support
Quote 1: "*It's not a matter of the residents… we just can't get family members. With [resident] we tried to set it up but it didn't happen …she didn't bother to be part of it again because felt a bit let down …it's no one's fault though-* Barrier (Zamir et al, 2018)

Subtheme 3.3: Personal advice
Quote 1: “One important source of information about which app to use was to lean on the recommendations of “trusted sources. However, participants offered very different definitions of what a trusted source might be. Many participants identified “trusted sources” as people that they have an ongoing relationship with, be it a friend, colleague, or health care provider. (Author interpretation)” – Facilitator (Schueller et al, 2018)
Subtheme 3.4: Clinical endorsement
Quote 1: “However, participants also acknowledged the importance of professional or advocacy organizations in leading people toward effective products because of the perception that such groups would present less biased views or based recommendations on consensus and reviews of a variety of different apps. (Author interpretation)” – Facilitator (Schueller et al, 2018)
Theme 4: Quality of the Digital Health Intervention
Sub-theme 4.1: Quality of digital health information

Quote 1: “women believed that it would help facilitate exchange of important health-related information and provide support for socially isolated HIV-infected women (Author interpretation)*”* – Facilitator (Blackstock et al, 2015)
Sub-theme 4.2: Quality of digital health interaction
Quote 1: “*They would be able to just say things that they don’t dare say to other people or people in front of them. They would be able to open up more. Some people don’t want to say things in front of other people*” – Facilitator (Blackstock et al, 2015) **Quote 2:** **“***I’m slightly interested in My Chart but I’m not trippin’ about it because my daughter’s nurse comes to the house...and I trust the nurse because I can see what she is doing***”** – Barrier (Guendelman et al, 2017)
Sub-theme 4.3: Quality of design
Quote 1: “participants preferred visually appealing apps, although the sentiment of P13, FG3 that “*It has to be cute*” was not universal among our participants, many commented on different aspects of aesthetics including color schemes, images, and the use of visual metaphors (Author Interpretation)”- Facilitator (Schueller et al, 2018)

Quote 2: "*And for me, it's just too overwhelming and too discombobulating. I just want to tap in and get the information that I need without clicking and searching for dear life.*" – Barrier (Schueller et al, 2018)