

POLICY ASPIRATIONS AND PRACTICE IN
ENGLISH TELECARE: A CASE STUDY OF
STORY-LINES AND INVISIBLE WORK

By

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Abstract

Telecare – the use of technology to facilitate access to health and social care services – has risen in prominence over the last decade in the context of population ageing, a rise in long-term conditions and economic uncertainties. UK policy advocates adoption of telecare at scale, citing the promotion of independence and empowerment as benefits, but local implementation has been variable and the experiences of service users show a nuanced picture.

This thesis investigates telecare policy, and its interpretation and implementation. It draws on an argumentative discourse analysis and material-semiotic approach to understand the experiences of telecare at a case study site. Narrative interviews and observations were undertaken, involving service provider and technology industry stakeholders and service users. Findings reveal four ‘story-lines’ of telecare policy but discrepancies between this discourse and local experiences. People are shown to engage with telecare to different extents, with the prevailing technology ‘script’ influencing non- or mis-use of devices. New work roles created by telecare sometimes appear ‘invisible’ or devalued. Furthermore, there is a lack of meaningful involvement of service users in decision-making. This study adds a theoretically-informed voice to the academic field and makes recommendations for future telecare policy, practice and research.

For Cian and Darcey

Now we can play.

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'You talk as if a god had made the Machine,' cried the other. 'I believe that you pray to it when you are unhappy. Men made it, do not forget that. Great men, but men. The Machine is much, but it is not everything. I see something like you in this plate, but I do not see you. I hear something like you through this telephone, but I do not hear you. That is why I want you to come. Come and stop with me. Pay me a visit, so that we can meet face to face, and talk about the hopes that are in my mind.'

'Kuno' in *The Machine Stops* by E. M. Forster (2011, pp.3–4)

(First published in 1928)

Chapter 1 Introduction

Telecare has been described as ‘the use of information and communication technology to facilitate health and social care delivery to individuals in their own homes’ (Barlow *et al.*, 2006, p.396)¹. It is not a new concept but use of this technology in health and social care provision has seen a global rise in prominence over the last decade (Turner and McGee-Lennon, 2013; World Health Organization, 2010). As governments around the world tackle increased demand on health and social services, telecare is being viewed as a key tool for tackling the challenges presented by ageing populations, particularly in relation to shrinking budgets and uncertain economic futures (Bayer *et al.*, 2007). In response to these struggles, the technology industry has been eager to demonstrate the seemingly limitless capability of technological innovations to present solutions to the health and social care conundrums forcing commissioners to reconsider traditional service pathways².

The UK Government has recently reiterated its continued and unequivocal support for the adoption of telecare and telehealth with the publication of ‘A concordat between the Department of Health and the telehealth and telecare industry’ (Department of Health, 2012b). This declaration, however, has been accompanied by complex and indeterminate results from the Whole System Demonstrator (WSD)

¹ This definition is by no means universal and use of terminology in the field of telecare is discussed in detail in Chapter 2.

² Advances in medical technology have been profuse in recent years, taking innovations from the realm of science fiction to hospital wards and patients’ homes. For example, in the USA, the Food and Drug Administration (FDA) has recently approved pills containing ingestible sensors that collect biometric data (Guta *et al.*, 2012) and ‘robotic doctors’ that use an iPad interface and sensors to navigate hospital wards enabling specialists to provide advice to multiple patients remotely (Jaslow, 2013). Similarly, a European project (ACCOMPANY) has explored the potential for robots to become ‘carer-companions’ for older people, providing physical, cognitive and social assistance in everyday home tasks as part of an intelligent environment (Sorell and Draper, 2014).

programme – the largest randomised controlled trial of telecare and telehealth in the world, set up to provide a clear evidence base for investment in technology (Department of Health, 2011). The details of this highly-publicised project and the impact it has had on government policy is discussed further in Chapter 2. The concordat coincided with the publication of a report identifying that much can be learnt about the roll out of telehealth at scale from the US Veterans Health Administration (VHA), the world's largest user of telehealth services (Cruickshank, 2012). The Australian Federal Government similarly declared its support for telehealth at the same time by committing \$30 million to new trials in the 2012-13 budget.

To date, international research into telecare and telehealth has focused principally on providing proof of concept and evidence of cost effectiveness (Barlow *et al.*, 2006; Bensink *et al.*, 2006; Dang *et al.*, 2009; Paré *et al.*, 2007; Polisena *et al.*, 2010), but in general has been under-informed by theoretical concepts and the experiences of patients and service users. Evaluation of services has been further complicated by multifaceted definitions of telecare and telehealth and under-developed approaches to identifying appropriate recipients of the interventions. The critique of telecare and telehealth has focused on why these services have not become embedded in the health and care sectors, citing organisational culture issues and patient fears over potential loss of services, depersonalisation of care, and the implications for service user isolation as probable reasons (Barlow *et al.*, 2006; Pols, 2010; Pols and Willems, 2011; Sorell and Draper, 2012; Woolham *et al.*, 2006).

What is largely missing from this debate is an understanding of the everyday telecare experiences of patients and service users and their perspectives on the technological turn as recipients of services and shared decision makers about care (May *et al.*, 2011; Rogers *et al.*, 2011; Greenhalgh *et al.*, 2013; Obstfelder *et al.*, 2007). While there has been international commitments to 'putting patients first' and ensuring health and social care departments make 'no decision about me without me' (Department of Health, 2010a, p.3; Department of the Premier and Cabinet, 2010) there is a lack of evidence in the case of telecare and telehealth that those assessed for this type of support are involved in any meaningful way in the decision-making processes leading to the provision of telecare and telehealth equipment. Furthermore, while many studies report largely positive outcomes for those who engage with telecare and telehealth services, some have questioned these reports as unduly confident with little coherence about what constitutes a successful outcome (Bensink *et al.*, 2006; Barlow *et al.*, 2007; Polisena *et al.*, 2009; Bolton *et al.*, 2011; Cartwright *et al.*, 2013); and a lack of attention given to identifying the aspirations of patients, service users and carers begs the question of whose needs are being met through this provision.

The aim of this study is to look beyond the question of whether or not telecare equipment 'works' and investigate the intended public purposes of these services. It is concerned with whether these purposes are fulfilled in practice at a case study site where the local authority has jointly funded (with the NHS) a telecare service providing a wide range of high and low tech equipment to service users with a variety of needs. The study will take into account how various stakeholders involved in different aspects of the telecare service perceive the purposes and benefits of this

type of technology, and will reflect on service user experiences of telecare, including their desired outcomes and level of involvement in decision-making processes.

This research contributes to knowledge in a number of ways. Firstly, in a field that has been characterised by largely atheoretical studies, this thesis has sought to engage with two interdisciplinary and complementary frames that bring together an interrogation of the policy discourse with a reconceptualization of technology as a socio-cultural agent, revealing the complex and disjointed context in which telecare is being implemented through the negotiation of relationships between people, organisations, practices and technology. Secondly, the study provides a perspective on the discrepancy between the policy narrative and the local practice experience that challenges the political reliance on the rhetoric of austerity and deficit models of ageing and disability. It shows how this rationalisation of telecare implementation can lead to coercive practice and the undermining of service user aspirations. Furthermore, it demonstrates how the simplification in policy of contested terms such as 'independence' and 'empowerment' can result in wildly variable experiences for individuals, depending on their personal characteristics and circumstances. Thirdly, this research identifies a number of missed opportunities in local practice regarding the needs and desires of service users; and the value attached to certain professional roles. Recommendations are made both in terms of engaging in a more meaningful way with service users and in making best use of the new roles created by the telecare service. This study adds a voice to a small but growing body of work that challenges the field of telecare research, policy and practice to keep the

question of ‘what it means to care’³ a part of the conversation on the future of health and social care services.

1.1 *Thesis content and structure*

The thesis is concerned with answering the following research questions:

1. What are the public purposes of telecare provision and whose needs does it meet?
2. What are the aspirations for telecare and are these realised in practice?
3. Is telecare practice fit for purpose⁴ where the avowed purpose is to promote independence?
4. How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

These questions were proposed for the study following exploratory work at the case study site and they are discussed later in the thesis in relation to the literature reviewed (Chapter 3) and the methods chosen (Chapter 5). To answer these questions, the thesis is structured to present the background to telecare policy and a review of academic literature in the field before moving on to detail the design, methods and theoretical frame chosen for this empirical study. Findings are then

³ The potential for technology to ‘reconfigure’ care is addressed by a number of scholars in different ways. Eccles (2013) suggests that care relations are increasingly mediated by technologies and both Oudshoorn (2012) and Milligan *et al* (2011) assert that technologies contribute to a redistribution of responsibilities between people, place and technological devices. Whereas Pols and Moser (2009) take the example of the therapeutic benefits of robotic pets to suggest that certain technological developments in care have the potential to blur the line between what has traditionally been portrayed as ‘warm’ (human-centred) care and ‘cold’ (non-human centred) care technologies.

⁴ The term ‘fit for purpose’ refers to the extent to which telecare practice (as defined in Chapter 2.3.3) supports the key objective (in policy and at a local level) of promoting independence.

reported in two chapters, followed by a discussion of key issues, and the thesis concludes with recommendations and reflections.

It is perhaps helpful to begin with a brief description of each chapter. Chapter 2 aims to situate the study within the policy context that has laid the foundation for the surge in telecare promotion and provision in recent years. It provides the first indication of the importance of the research question ‘what are the public purposes of telecare provision and whose needs does it meet?’ This chapter also highlights issues relating to the inconsistent use of terminology, putting forward working definitions of telecare and telehealth as well as raising awareness of the contentious nature of terms such as ‘independence’ and ‘empowerment’ that are central to the research questions tackled by this study. This setting of the scene is followed by Chapter 3, which provides a thorough review of academic empirical research in the field that is concerned with telecare policy or practice and has attempted to gauge the views of service users, patients, carers or professionals. The purpose of the review is to ascertain recent research focus, identify how far the existing literature addresses the research questions posed in this study, and reveal gaps in knowledge that this thesis can presume to fill. The chapter begins with a detailed explanation of the search strategy and literature included before discussing the overlapping themes identified, which relate to evaluations of effectiveness, ethical issues, and a concern with self-management.

Chapters 4 and 5 present the study design, methodology and methods employed, and engage in a discussion of the two theoretical frames that have provided the ontological position of this study and practical approach to data analysis. The first of

these is an argumentative discourse analysis conceptualised by Maarten Hajer (1995) in his work on environmental politics. Hajer's approach has rarely been applied to telecare or telehealth research but his focus on discourse-coalitions and story-lines provides a useful lens for comparing the messages from telecare policy with the 'messy' reality of social care and health practice. When employed in this study it reveals a policy narrative that is presented as a coherent and straightforward argument on the public purposes and benefits of the technological turn; but at a local level this narrative can become vague, opaque and complicated by the different priorities of multiple stakeholders. The second framework used in this study is a material-semiotic approach rooted in Science and Technology Studies (STS) and Actor Network Theory (ANT), and most notably applied to telecare by Nelly Oudshoorn (2011) in her research into devices monitoring people's chronic conditions at home. The material-semiotic view affords a reconceptualisation of technologies as socio-cultural agents rather than as tools that solve problems. Focus is placed on the relationship between users and technological devices, whose identities are mutually constitutive and are situated within a network of actors (both human and non-human), practices, knowledge and discourses (Pols, 2012). This provides a helpful perspective on the data from this study in relation to how telecare is used (and not used) by service users, the ways in which telecare practice produces new and sometimes invisible work, and the role of service users in decision-making processes.

Having established this commitment to interpretivist and constructivist paradigms, the findings from the research are presented in two discrete chapters that attend to the multiple interpretations of policy discourse reported by participants that have

implications for service user outcomes (Chapter 6) and the observations of local practice and the telecare process experience of service users (Chapter 7). These chapters demonstrate the application in practice of the theoretical approaches described in detail in Chapter 4. Taken together they provide an account of telecare practice and service user experience that appears at odds with the discourse presented in policy and reveals telecare to be having an impact on care practices in unintended and sometimes unacknowledged ways. These findings lead to a discussion in Chapter 8 of who is really benefiting from the technological turn in health and social care, gleaned from further interrogation of the concepts of independence and empowerment based on the findings from the literature and empirical work that show how these terms are understood and applied in practice in varying ways, resulting in different outcomes for different people. The thesis concludes (Chapter 9) with a reiteration of the contribution to knowledge that this study has made and recommendations for future research, policy and practice.

This chapter has given a brief introduction to the context for this research and established the remit of the study, as well as the contribution it makes to knowledge. The next chapter provides a more thorough discussion of telecare policy and how political rhetoric on the wider challenges facing the welfare state – particularly in relation to the ageing population and global economic crisis – has influenced the promotion of telecare as a key component in the transformation of health and care services. The chapter begins with a detailed explanation of the terminology used in this thesis, including a discussion about the problematic use of multiple definitions of ‘telecare’ and other related terms.

Chapter 2 Situating the study

2.1 Introduction

The introductory chapter provided a brief background to the current telecare landscape, highlighting the international commitment to developing use of technologies in health and care settings. In this chapter, the policy context is explored in more detail in relation to the 'crises' in demographic ageing and financial resources that have been portrayed as potentially debilitating for the NHS and social care. These challenges have been presented politically as vindication for major transformation of the way health and care services are provided, and it is in this context that particular focus has been placed on technology as a problem solver for the welfare state. The discussion of policy in this chapter lays the foundation for the critique later in the thesis. For example, the policy discourse on the professed benefits of telecare is compared with the narratives of service users and professionals in Chapter 6. Furthermore, the messages disseminated by government policy shows an adherence to an instrumental view of telecare as a passive 'tool' that can be applied to a problem to predictable effect. This way of framing technology is contested throughout this thesis – through the literature review presented in the next chapter, as well as in the theoretical approach to this study detailed in Chapter 4 and the subsequent reporting and discussion of findings from the empirical research in later chapters. An alternative shaping of technology as a socio-cultural agent is adopted in this study allowing for a more nuanced approach to considering the impact of telecare at the micro and meso level.

In the first instance, however, this chapter establishes the key terms employed in this thesis and how they should be defined. The field of telecare (research, policy and practice) is characterised by confusion when it comes to definitions of terms and differentiations between interventions variously labelled as telecare, telehealth and telemedicine, among many other names. Often terminology is applied loosely, encompassing a range of equipment and terms are used interchangeably, even within the same document, meaning different things to different people (Barlow *et al.*, 2006). The following section explains the problematic nature of defining telecare, something that has affected this study in relation to the searching and reviewing of relevant literature, and is discussed further in Chapter 3. This is followed by the proposal of a working definition of telecare for this study and a clarification on the understanding of other key terminology in the thesis.

2.2 *Defining telecare*

The coining of the term ‘telecare’ in the UK has evolved from global developments in the use of two branches of technology – devices with a medical focus that can be categorised as telemedicine and those that are socially-oriented and concerned with the functional ability of users, broadly termed assistive technologies. Although much of the early work in telemedicine was carried out in Scandinavia (Wootton, 2000) common understanding of this form of technology has been heavily influenced by developments in the US, as the world’s largest market for telemedicine.⁵ Telemedicine was pioneered in the early 1970s and at this time, definitions focused on patient care as the core activity and medical care as the only function and

⁵ In December 2013, business analysts predicting health trends for 2014 forecast the US telehealth market growing to \$1.9 billion in 2018, an annual growth rate of 56 percent (Graham, 2013).

justification for telemedicine (Bashshur *et al.*, 2000). Bashshur, an American academic, offered a further definition of telemedicine in 1995 to clarify it as a system of care using telecommunications and communication technology 'as a substitute for face-to-face contact between provider and client' (Bashshur, 1995, p.19). Telemedicine has also been considered an umbrella term referring more broadly to the remote delivery of healthcare and the exchange of health information, however there is no consensus on this usage: when Sood *et al.* (2007) conducted a multi-national literature review of perspectives on telemedicine, they found 104 peer-reviewed definitions of the word. The World Health Organisation has defined telemedicine as:

The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities.

(World Health Organization, 2010, p.9)

In this rather inclusive definition the term 'exchange of valid information' is key, as is the emphasis on the education of health care providers. Barlow *et al.* (2006, p.397) differentiate telemedicine from other 'tele' technologies due to the application of 'ICT-based systems to facilitate the exchange of information *between healthcare professionals*⁶ rather than between doctor and patient (a similar emphasis is used in Bayer *et al.*, 2007; Rogers *et al.*, 2011). In fact, in the UK literature telemedicine

⁶ Italics added.

is generally considered the domain of medical professionals and easily distinguishable from telecare:

Telemedicine [is] the remote diagnosis, monitoring and management of patients' medical conditions, and *telecare* [is] monitoring that assists people with more general care needs to live in their own homes.⁷

(Draper and Sorell, 2013, p.365)

Here, the distinction between telemedicine and telecare is important as it is indicative of other differences in terminology used in medical and social care environments – for example, the language of 'patients' and 'medication' as opposed to 'service users' and 'practical support', which is also highlighted by Fisk (2003) . In a UK practitioner environment this differentiation between telemedicine and telecare also seems to be universal, except perhaps where telecare is used as the umbrella term – this will be discussed further below. However, the distinction between telemedicine and telehealth is not always clear in academic or practice and policy literature.

The World Health Organisation states that it views telemedicine and telehealth as synonymous terms (World Health Organization, 2010), and as early as 1978 discussions of telemedicine were being broadened out to include the concept of telehealth (Bennett *et al.*, 1978). Bashshur *et al.* asserted in 2000 (p.614) that:

In both telemedicine and telehealth, all applications share two common elements, namely the geographic separation between two or more actors engaged in health care and the use of telecommunication and related technology to enable, facilitate, and possibly enhance clinical care and the gathering, storage, and dissemination of health-related information.

⁷ Italics in the original

The authors include in this form of information exchange patient and provider education and health services administration as well as patient care (Bashshur *et al.*, 2000). There is still a lack of international consensus on the use of either telehealth or telemedicine as umbrella terms – the literature variously describes one as a sub domain of the other (Wootton, 2001; Nuffield Council on Bioethics, 2010; Rudel *et al.*, 2011). In the US, some have argued that conceptually, telemedicine and telehealth relate to each other as do the terms medicine and health (The American Telemedicine Association, 2012; Bashshur *et al.*, 2011). In their most recent taxonomy of telemedicine Bashshur *et al.* (2011, p.487) claimed the term telehealth reflects an awareness of behavioural and environmental factors affecting health, as well as the role of non-clinical health professionals, but equally:

A form of political correctness in modern discourse also evident in the adoption of a more inclusive nomenclature in medical care generally. This is manifest in relabelling hospitals as medical or health centres, physicians as providers, and patients as clients or consumers.

There is evidence in UK policy documents of using the terms telehealth and telemedicine interchangeably (Department of Health, 2005a; Department of Trade and Industry, 2003). The Audit Commission (2004, p.5) stated clearly in its guidance for implementing telecare that:

‘Telecare’, ‘telehealth’, ‘telemonitoring’ and ‘telemedicine’ are terms that are used interchangeably to describe the remote delivery of health and social care using information and communication technology.

However, the Whole System Demonstrator programme established governmental focus on telehealth, defined as ‘the remote exchange of data between a patient and health care professional to assist in the diagnosis and management of a health care

condition' and excluded references to telemedicine (Bower *et al.*, 2011, p.2). Similarly, documents such as the concordat between the government and the telehealth and telecare industry (Department of Health, 2012b) and NHS England's business plan for 2014/15 to 2016/17 (NHS England, 2014a) state the promotion of both telecare and telehealth as a key priority for health and care services but make no mention of telemedicine.

It is perhaps useful to consider the differentiating factors that have been proposed by some to clearly define research that has been carried out. For example, VandenBos and Williams (2000, p.490) make an important point in defining telehealth as covering 'real-time service provision that occurs when the patient and the provider are physically separated at the time the service is rendered'. Here, it is clear that telehealth is about the provision of a service rather than information exchange, further distinguishing it from some definitions of telemedicine (Audit Commission, 2004b). Polisen *et al.* (2009, p.340) also talk of telehealth bringing 'healthcare delivery to the home environment by connecting the patient with medical professionals'. Notably, while Bashshur (1995) sees telemedicine and telehealth as a substitute for face-to-face interaction between patients and physicians, Polisen *et al.* (2009, p.340) state that home telehealth is not intended to replace health professional care or visits, 'but rather to enhance the level of care'.

However, when telehealth is compared with telecare the former appears to lose its identity as a method of direct service provision (Goodwin, 2010) and is defined more narrowly as a way of monitoring people with chronic conditions through the remote

exchange of physiological data between patient and clinical staff to assist in diagnosis and monitoring:

Telehealth equipment is used as a tool in the management of long-term conditions in the community to proactively monitor patients and respond promptly to indicators of acute exacerbations.

(Stowe and Harding, 2010, p.195)

The UK Department of Health has published several iterations of the definitions for telecare and telehealth over the past decade (for example, Department of Health, 2005, 2012c, 2010a) but in documents relating to the Whole System Demonstrator both forms of technology are seen to have monitoring functions, although they are distinguished from each other by the focus of their monitoring. While telehealth is concerned with helping people to manage their health specifically through the monitoring of vital signs, telecare is more readily linked to the promotion of independence, with a focus on social care needs and attending to the 'risks' associated with independent living to help older and vulnerable people to remain 'safe' at home (Bower *et al.*, 2011; Department of Health, 2011; Davies and Newman, 2011). In many ways, this mirrors the structural divisions that exist in most parts of the UK between 'health care' (the responsibility of a more medically-led NHS) and 'social care' (the responsibility of local government). The way telecare has emerged as a term in the UK is distinct from other countries partly due to the 'Berlin Wall' that characterises the separation between UK welfare arrangements (Doughty *et al.*, 2007; Dickinson *et al.*, 2014).

Fisk (2003) has argued that while telecare can be discussed within the realm of clinical outcomes, particularly when equipment focused on falls prevention and medication management are considered, this does not tell the full story and attention must be paid to the development of social alarms and assistive technology more generally. The term 'assistive technology' is commonly considered to include a broad range of equipment:

Assistive technology is an umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed.

(King's College London and the University of Reading, 2004, p.2)

This definition can refer to both low-tech portable devices such as walking sticks and more complex fixed systems such as stair-lifts, and has equally been applied to devices characteristic of 'smart homes', such as environmental sensors (Doughty *et al.*, 2007; Demiris and Hensel, 2008). Social alarms are a type of assistive technology located within the home either as part of a hard-wired system or an individual device that, when activated, 'facilitate communication with a responder and the sending of information relevant to the user's wellbeing' (Fisk, 2003, p.4). They are also referred to as pendant or community alarms and form the first of what has been termed the 'three generations' of telecare (Doughty *et al.*, 1996). In this first generation of monitoring systems the onus is on the user to contact the responder when the need arises. Second generation equipment has been developed so that sensors may provide continuous monitoring and automatically trigger an alarm without the input of the person. Third generation systems could be viewed as a departure from the focus purely on responding to emergency situations

as they capitalise on advancements in telecommunications technology, such as broadband internet, to allow for virtual contact between the individual and their support network (for example, clinicians, social workers or friends and family) in a bid to tackle a broader range of issues, such as reducing loneliness and engaging the person in health behaviour change (Doughty *et al.*, 1996). In the UK, telecare equipment in common use spans all three generations of technology as described by Doughty *et al.* (1996). However, this account of the evolution of telecare does not satisfy all as some argue that telecare devices should always comprise automatic monitoring, taking the decision to trigger an alert out of the hands of the individual (Brownsell and Bradley, 2003). Furthermore, while Doughty *et al.* (1996) concentrate on the interaction between the person and the responder, a selection of devices such as programmable medication dispensers are intended to prompt the individual to take action rather than a third party.

In the government's various published definitions of telecare emphasis has been on the use of sensors and continuous monitoring. Reporting on early findings from the Whole System Demonstrator programme, the Department of Health (2011, p.4) described telecare as:

Personal and environmental sensors in the home that enable people to remain safe and independent in their own home for longer. 24 hour monitoring ensures that should an event occur the information is acted upon immediately and the most appropriate response put in train.

However, it is notable that in the announcement for long-term investment in this technology the government description of telecare was less concerned with how

equipment should function in order to be classed as telecare than with how it should contribute to the overarching policy purposes:

Telecare is as much about the philosophy of dignity and independence as it is about equipment and services. Equipment is provided to support the individual in their home and tailored to meet their needs.

(Department of Health, 2005a, p.8)

This statement brings to the fore the relationship between telecare and the independence of the user, placing focus on whether equipment achieves the aim of promoting independence and how the technological turn is transforming care – topics that are explored in depth throughout this thesis.

Given the prominence in current UK health and social care policy of plans for service integration and the increasing acknowledgment that those with complex conditions require a range of complementary responses (Health and Social Care Act 2012; Department of Health, 2012a), it may seem unhelpful to categorise technologies based on their ability to tackle a particular social care or clinical need. Emphasis on ‘whole-person treatment’ that moves away from viewing patients and service users as a series of symptoms leading to a fragmented and specialised response puts pressure on those advocating technology to demonstrate its breadth of application rather than designate devices as applying to one sphere or another (Department of Health, 2012c; Nuffield Council on Bioethics, 2010). As a consequence, there has been a move by some to embrace a more comprehensive account of health technology that does not ‘solely reflect clinically driven responses to the higher-level needs of some “patients”’ (Fisk, 2013, p.1). For example, the recently published European Code of Practice for Telehealth Services has sought to align its definitions

of telecare and telehealth with the preventative agenda that encourages people to adopt lifestyles that are conducive to better health (Fisk, 2013). The project team that developed the code of practice (TeleSCoPE) offered the following explanation for both telecare and telehealth:

The means by which technologies and related services at a distance are accessed by or provided for people and/or their carers at home or in the wider community, in order to facilitate their empowerment, assessment or the provision of care and/or support in relation to needs associated with their health (including clinical health) and wellbeing. Telehealth always involves and includes the service user or client. It includes remote patient management.

(Rudel *et al.*, 2011, p.32)

Crucially, the focus here is on the desired outcome from technology use rather than presenting a way of classifying eligible devices. Furthermore, instead of highlighting aspects that may primarily appeal to concerned relatives and professionals, such as continuous monitoring, reducing risk and increasing safety, this definition privileges the experience of the end user. The TeleSCoPE project also identifies emerging terms such as mHealth – referring to the use of mobile communication and network technology for health care – and eHealth, which is used as an umbrella term for the application of information and communication technologies across the whole range of functions that affect the health sector (Rudel *et al.*, 2011). They apply this definition to proffer eHealth as an overarching term within which telecare, telehealth and telemedicine sit (see Figure 1). Here, eHealth is treated as a twin domain alongside ‘assistive technologies’, which covers all aids and adaptations required to support disabled people and other potentially vulnerable groups. The diagram illustrates how far the definitions overlap, demonstrating that certain devices could

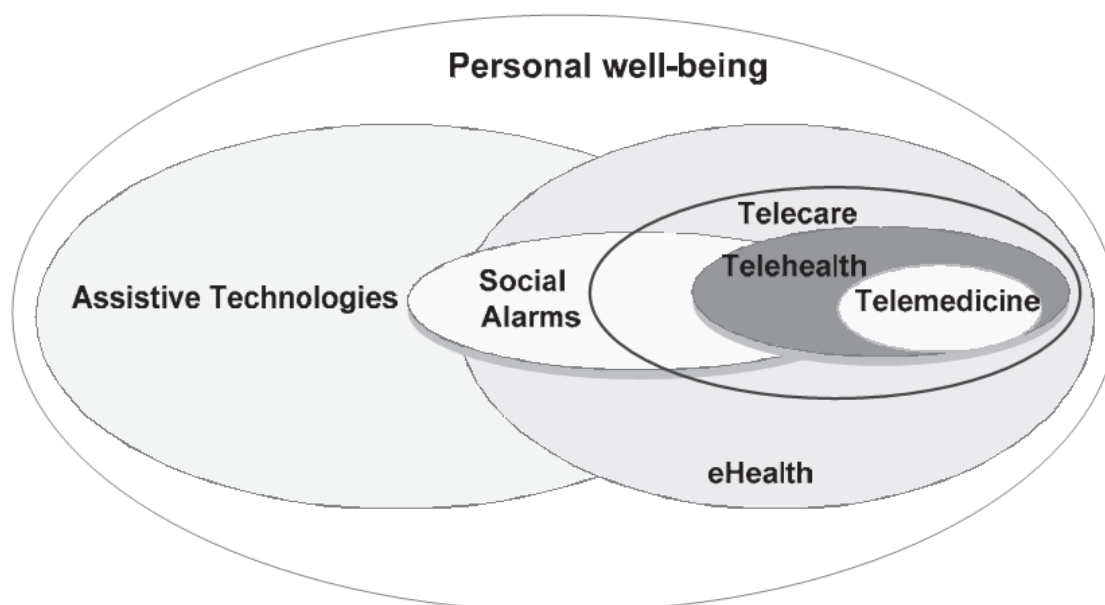


Figure 1 Scope of Telehealth by TeleSCoPE in Rudel et al. (2011, p.33)

be termed a social alarm or an assistive technology, as well as a form of telecare under the umbrella of eHealth. However, on the TeleSCoPE website (<http://www.telehealthcode.eu/glossary-of-terms.html>) eHealth is described in more detail as ‘the transfer of health resources and health care by electronic means’ covering three main areas:

- The delivery of health information, for health professionals and health consumers, through the internet and telecommunications.
- Using the power of IT and e-commerce to improve public health services, e.g. through the education and training of health workers.
- The use of e-commerce and e-business practices in health systems management.

None of these areas refers explicitly to service users or patients and in fact appears to frame eHealth in terms of providing support to health professionals with an

emphasis on business rather than being in any way relevant to health and care service recipients. Nevertheless, eHealth is an increasingly favoured term – for example, NHS Scotland has an eHealth strategy encompassing telecare and telehealth but also outlining aims in relation to technology-enhanced working practices (The Scottish Government and NHS Scotland, 2012). The Welsh government is also intending to publish an ‘eHealth and care’ strategy in the summer of 2015 (The Welsh Government, 2015). This adoption of ever-broadening terms is perhaps reflective of a desire globally to combat the confusion surrounding terminology that may be inhibiting the embedding of this form of technology into everyday practice. A leading telecare website run by international academics, industry representatives and health practitioners has conducted a ‘terminology campaign’ for a number of years, arguing that the continued confusion over language is off-putting for potential users and is stifling the development of new technologies (Hards, 2008).

It is likely that there will remain a lack of clarity around universal definitions of the key terms, such as ‘telemedicine’, ‘telehealth’, and ‘telecare’ and that they will continue to be used interchangeably, at least between individual researchers. This is reflective of the rapid development and application of a wealth of new technological interventions, as well as the independently developed use of terminology in different countries (Doughty *et al.*, 2007). For the purposes of this study, the definition proposed by the TeleSCoPE project has been adopted as a useful way of categorising technological devices that contribute to personal wellbeing. A list of the technology in use at the case study site can be found in Appendix 1. As such, the term ‘telecare’ is used predominantly in this thesis as the

TeleSCoPE definition sufficiently captures the equipment encountered in this study. However, because this research is rooted in local practice, where the terms 'telecare' and 'telehealth' refer to equipment supporting social care and that supporting medical care respectively, reference is made to telehealth where this distinction is emphasised. In the literature review (Chapter 3), studies are discussed using the terms stated in their associated papers. However, the problem of inconsistent terminology is further considered in the chapter in relation to the literature search.

2.3 A note on other terminology

2.3.1 Independence and empowerment

The issues of independence and empowerment are central to the research questions posed in this study and, as such, these terms appear frequently throughout this thesis. In order to ascertain the extent to which telecare promotes independence or is empowering for the user, an understanding of what is meant by these terms is crucial. They are undoubtedly contested terms and the language of independence, in particular, has been an integral part of campaigns by disability rights activists. Both words were included as search terms in the literature review and a discussion of how they are framed in the studies is included in Chapter 3 as part of the analysis of the literature. Further detailed discussion of interpretations of independence and empowerment are included in Chapter 8 taking into account the findings from the empirical work presented in Chapters 6 and 7.

What is clear from the literature analysed is that both independence and empowerment are presented with the use of vague language and a common

understanding of either term is difficult to establish. Independence is often discussed in reference to autonomy, although definitions are rarely proffered and they sometimes appear to be used interchangeably. In the literature review in Chapter 3, the impact of telecare on autonomy, as an aspect of independence, is discussed as a key theme of studies concerned with the ethics of technology in care. Thus, in order to engage with the conceptualisation of independence in the policy and research literature and in the data from the empirical work, this study has sought to disentangle the notion of autonomy, considering this separate concept in relation to telecare as part of the discussion on independence in Chapter 8. Analysis of the literature in Chapter 3 further revealed an understanding of empowerment that is intrinsically linked to the policy discourse around self-management. The association between these concepts is similarly returned to in the discussion chapter (Chapter 8) in order to consider the implications of telecare for empowerment as it is framed in policy and practice.

2.3.2 Participants: Older people and learning disabilities

In this study, most of the participants had a connection with the local authority partner on the basis of the service they accessed from the social care department. Those over the age of 60 were categorised as 'older people' and this term is used frequently in this thesis to refer to people in this age bracket who may or may not have additional needs in relation to physical or sensory disabilities. Other participants were classed as having one or more 'learning disability' in line with the language used by the community learning disability team (CLDT) that provided services in the local authority. The term 'learning disabilities' can be viewed as

contentious, with other terms sometimes preferred, such as 'learning difficulties' or 'intellectual disabilities'. The British Institute of Learning Disabilities states that the words 'difficulties' and 'disabilities' can be used interchangeably in the sphere of adult social care, although where children are concerned, 'learning difficulties' tends to include people who have a specific learning difficulty, such as dyslexia, but who do not have a significant general intellectual impairment (Holland, 2011). Internationally, the term 'intellectual disabilities' is most common and there are suggestions that the UK should adopt this terminology (Emerson and Heslop, 2010). Nevertheless, an influential definition of learning disabilities has been provided by the Department of Health in its 2001 white paper, and is commonly understood in the UK adult social care and health context. It states that learning disability includes the presence of:

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)...A reduced ability to cope independently (impaired social functioning)... [An impairment] which started before adulthood, with a lasting effect on development.

(Department of Health, 2001, p.14)

As the term 'learning disabilities' was in standard use at the case study site it was deemed the least ambiguous term to employ in this study.

2.3.3 Policy, practice and patients

A final, brief note should be issued to clarify the meanings of the frequently used terms 'policy', 'practice', 'patients' and 'service users'. The research questions require a comparison of policy and practice. Here, the term 'policy' refers to the conventional understanding of a statement of intended action made by the

government through its various publications, such as command papers. Under the term 'practice' this study incorporates all activity at a local level that contributes to the working of the telecare service. This includes strategy work at senior management level, commissioning practices (including input from the technology industry), frontline work across service boundaries and the actions of those in receipt of services.

In the same way that 'telecare' and 'telehealth' can differentiate between the spheres of social care and health, the terms 'service users' and 'patients' invariably identify the environment, context and type of service that individuals are accessing. In this thesis, reference is made to 'patients' for those in receipt of medical care and to 'service users' for those accessing social care. It is recognised here that the term 'service user' is contentious. For many service user organisations, the term 'service user' implies an identity as nothing more than a passive recipient of services – someone who has things 'done to' them (Levin, 2004). The Shaping Our Lives National User Network, which campaigns for service users, has embraced the label 'service user' as a positive term that acknowledges the unequal relationship between the individual and the state, and the separation it creates between 'service users' and other people; but also demonstrates a shared experience with a wide range of people (Shaping Our Lives, 2013). The term is undoubtedly embedded in social care practice and appears throughout this thesis. However, it is used in a way that is mindful of the Shaping Our Lives campaign and the words 'individual' and 'person' or 'people' are also frequently employed as alternative descriptions.

2.4 *The policy context*

2.4.1 The challenge of ageing

Over the past 15 years, telecare has emerged as a key component of UK social care and health policies, largely in response to the global challenges to welfare systems of ageing populations and economic uncertainty (Parker and Hawley, 2013; Department of Health, 2005a, 2006). The ageing demographic is a truly global phenomenon – for the first time in history, older people in the world aged 65 and over are set to outnumber children under 5 years old within the next 5 years (Suzman *et al.*, 2015). The World Health Organisation (WHO) has heralded the increase in longevity as a success for socioeconomic development and medical advances, but it also warns that the main health challenge facing older people is from chronic diseases and that current health systems worldwide are poorly designed to tackle this ‘complex burden’ (World Health Organization, 2012, p.6). A recent series of articles in *The Lancet* claimed that issues of mortality, morbidity, disability and wellbeing related to ageing have been neglected by the health sector and social and economic policy makers, leading to ill preparedness to deliver age-appropriate, integrated care (Prince *et al.*, 2015).

In the UK, the greatest increase has been seen in the ‘oldest old’ (those aged 85 years and above), who are predicted to reach 5% of the total population by 2034, while declining fertility and changes to family formation have seen a reduction in numbers of potential caregivers (AKTIVE Consortium, 2013; Office for National Statistics, 2012). More than 15 million people in the UK have a long term condition, and their care accounts for 70% of the health services budget (Health Committee,

2014). Multimorbidity is also increasing, leading many in the NHS and the government to argue that the cost is threatening to overwhelm the current system (Eaton *et al.*, 2015; NHS England, 2014b). Furthermore, a recent report on the state of adult social care has suggested that the rising need for social care services combined with reductions in local authority spend are putting unsustainable pressure on care and health systems, as well as on informal carers (National Audit Office, 2014).

Debate on the future of the welfare state has intensified in the last couple of years with the passing of the Health and Social Care Act (2012), Care Act (2014) and the publication of other key documents such as the NHS Five Year Forward View (NHS England, 2014b). However, concerns about the ageing demography, the rise in chronic conditions and financial pressures have been central to government policy on health and social care for many years. Since the late 1990s government policies have placed preventive provision at the heart of proposals to reduce cost to acute health and long-term care services (Porteus and Brownsell, 2000; Iliffe *et al.*, 2010; The Royal Commission on Long Term Care, 1999; Department of Health, 1998, 2005b). Plans have emphasised greater personalisation and self-directed support (Department of Health, 2005b, 2006, 2001) as well as a need for integrated services that can reduce fragmentation and poor coordination of services, taking a 'whole system' approach to tackling people's multiple, co-existent and interrelated health needs (Chrysanthaki *et al.*, 2013; Department of Health, 2006; Prince *et al.*, 2015). A further objective has been to connect with housing policies to focus on providing services in the community and to facilitate 'ageing in place' (Sixsmith and Sixsmith, 2008; Department of Health, 2001; Barlow *et al.*, 2005; Audit Commission, 1997).

Remaining at home for as long as possible has been shown to be a priority for older people and has been supported by successive governments as key to promoting independence and enabling people – particularly those with chronic conditions – to self-manage outside of health and care settings. The idea of ageing in place has been presented as beneficial for state resources as well as for improving the wellbeing, independence and social participation of older people (Sixsmith and Sixsmith, 2008). However, this straightforward argument has been challenged by researchers alongside concerns about the rhetoric of the ‘ageing tsunami’ (Mort *et al.*, 2013; Pols and Willems, 2011; Cook *et al.*, 2013; Sixsmith and Sixsmith, 2008). The discourse on ageing in place including concerns about the potential isolation of older people and inadequate support at home have been raised in studies included in the literature review for this study and are discussed further in Chapter 3.

This section has highlighted the global focus on population ageing and the next section will demonstrate the relationship this issue has with UK policy on telecare. What is important to note for this study is that the inextricable link between older people and telecare development has been formed to the detriment of a considered view on the position of – and implications for – other ‘groups’ of potential service users. Later chapters in this thesis will show how the empirical work in this study revealed a commitment to implementing telecare across client groups, and particularly in learning disability services. Government policy on telecare barely mentions the impact on people with learning disabilities – *Building Telecare in England* (2005) only signposts to an earlier white paper on learning disabilities that supports the development of telecare (Department of Health, 2001). There have been calls for the remit of telecare to be extended deliberately to include people with

learning disabilities and a more recent government publication highlighted the benefits of telecare for people with learning disabilities (Department of Health, 2009c; Perry *et al.*, 2009; Miles and Doughty, 2011). Currently, there are an estimated 905,000 adults with learning disabilities in England, compared with around 11 million people over the age of 65 across the UK (Thorpe *et al.*, 2014). From a national policy perspective, it is not difficult to understand the priority of focusing the telecare strategy where it could have the greatest impact in terms of numbers. However, the empirical work in this study will show in later chapters that local priorities can significantly impact on this priority, as concerns at the case study site about overspending on the learning disability budget led to a systematic approach to implementing telecare within the learning disability service as a cost-cutting measure.

2.4.2 Locating telecare in the policy

The policy response to the challenge of population ageing and financial uncertainty has been presented as a clear argument for an overarching transformation agenda for health and social care. This argument was established in the Department of Health's publication *Putting People First* (2007), in which prevention, early intervention, and especially personalisation and the maximisation of choice and control were the key phrases. *Putting People First* (2007) also highlighted the role of telecare in this agenda as an integral part of personalisation. The association between technology and the ability to meet the challenges facing social care and health had been drawn much earlier, however, in a royal commission into long term care that saw the potential for telecare to support older people at home (The Royal

Commission on Long Term Care, 1999). This report was followed by a series of papers from the Audit Commission further conceptualising ageing as a challenge to public services and identifying assistive technology as meeting the needs of the individual and the state:

The potential of technology to support independence is enormous. It offers one way to break the downward spiral that all too often leads to dependency, wasted lives and higher public expenditure.

(Audit Commission, 2004a, p.2)

Such statements heralded the government's commitment to facilitating widespread adoption of telecare services as part of the investment in preventative and community-based primary care at the expense of costly in-patient services (Department of Health, 2006). This began in earnest with the launch of the Preventative Technology Grant (Department of Health, 2005a), which allocated £80 million to local authorities between April 2006 and April 2008 for the purpose of setting up telecare innovations to support people to live independently in their own home and so reduce avoidable admissions to residential care. In Scotland, just over £8 million was allocated to the Joint Improvement Team, establishing the national Telecare Development Programme (TDP) to enable 32 Scottish partnerships to develop telecare services from 2006-08 (Beale *et al.*, 2009). A focus on self-directed support and patient self-management in the NHS similarly highlighted the use of assistive technology and remote monitoring as a way of giving more control to patients and linked it directly to personal budgets for people with complex long term conditions (Department of Health, 2008a; Wanless, 2002). Similarly, the Quality, Innovation, Productivity and Prevention (QIPP) programme had telecare and

telehealth playing an important role in prevention and promoting self-care and the management of chronic conditions. A further range of policy reports has aimed to demonstrate the need for telehealth and telecare to be viewed as routinely necessary services that give older people – particularly those with complex health conditions – confidence, reduce risk and increase their safety at home (Department of Health, 2009a, 2008b, 2009b, 2010a).

This robust governmental support for telecare and telehealth has been tempered, however, by accusations that the evidence base is still limited (Finch *et al.*, 2003; May *et al.*, 2011; Broens *et al.*, 2007; Pare *et al.*, 2007). For telecare, following the influx of investment from the Preventative Technology Grant, several early pilot studies demonstrated the benefits for users, carers and other stakeholders – particularly well cited in policy papers were pilots at Kent County Council (Alaszewski and Cappello, 2006) and West Lothian (Bowes *et al.*, 2006). A plethora of other studies followed reporting individual benefits such as reduced use of high cost care, improved quality of life, greater patient security and self-management, and reduced mortality (Williams, 2008; Barlow *et al.*, 2007; Martínez *et al.*, 2006; Bower *et al.*, 2011). However, the ability to translate these outcomes to demonstrate system benefits, such as the cost-effectiveness of sensor-based monitoring at scale, has not been evidenced (Goodwin, 2010; Bower *et al.*, 2011).

Dispute over what constitutes good evidence has been partly blamed for poor adoption of telecare and telehealth at the level of local service delivery (May *et al.*, 2011; Hendy *et al.*, 2012; Clark and Goodwin, 2010). In response to criticisms of inadequate evidence, the UK Government established the Whole System

Demonstrator (WSD) programme (Bower *et al.*, 2011). Believed to be the world's largest randomised controlled trial of telecare and telehealth, with more than 6,000 participants in three pilot sites, the WSD pilot constituted an investment of £31 million and aimed to provide a 'proof of concept' to enhance reliance on small-scale pilots, case studies and expert opinion. Using a 'gold standard' to evaluate the clinical effectiveness of telecare and telehealth within an integrated care setting, the headline results suggested telehealth could substantially reduce mortality and time spent in hospital (Department of Health, 2011). The findings demonstrated that, when given to people with diabetes, COPD and CHF, the telehealth was associated with reductions in mortality rates of 45% against the control group and a decrease of 20% in emergency hospital admissions (Steventon *et al.*, 2013).

However, the WSD programme yielded 20 reports over 3 years and in addition to the clinical effectiveness of telehealth, the research team also published findings on cost effectiveness; impact on service utilisation; quality of life and wellbeing; the attitude of various stakeholders, including the views of service users; and the role of organisations in successful adoption (Steventon *et al.*, 2013; Hendy *et al.*, 2012; Cartwright *et al.*, 2013; Henderson *et al.*, 2013; Sanders *et al.*, 2012; Rixon *et al.*, 2013; Henderson *et al.*, 2014; Steventon *et al.*, 2014; Hirani *et al.*, 2014). For telehealth, the WSD found that the probability of cost-effectiveness was relatively low and that the intervention did not improve quality of life or psychological outcomes for patients (Cartwright *et al.*, 2013; Steventon *et al.*, 2013; Newman *et al.*, 2014). Furthermore, in relation to patient self-management, analysis of the data revealed the telehealth to have no effect on 'generalised self-efficacy, self-care self-efficacy or self-care behaviour' (Newman *et al.*, 2014, p.144). With regard to telecare,

analysis found that systems implemented as part of the WSD were not a cost-effective alternative to usual care and did not lead to reductions in use of other health and social care services, although it was judged that such benefits may only materialise after longer time periods (Newman *et al.*, 2014).

Overall, the WSD concluded that major service change, such as that required by telecare and telehealth implementation, could only be achieved with strong leadership and vision, commissioning support and good communication between stakeholders across organisational and service level boundaries (Newman *et al.*, 2014). The evaluation team reflected that the programme had struggled with shifting organisational priorities and the translation of the telecare agenda on the ground as it was seen as misaligned with local policies, care practices and staff working practices (Newman *et al.*, 2014). The evaluation itself was a complex and protracted procedure beset by concerns that the government agenda for implementing telecare and telehealth at scale unduly influenced the reporting of results before the peer-review process had run its course (Greenhalgh, 2012). As the results emerged over time, the evidence appeared to be presented as more rather than less equivocal but the prolonged nature of the reporting led to accusations that the findings had become irrelevant as the development of technology in the meantime made it unrecognisable from the devices in the trial, both in terms of design and cost (Lowe, 2013b). Despite this and debate over whether the results supported the government's policy on telecare and telehealth (Car *et al.*, 2012), two further projects – 3millionlives and the DALLAS programme – were established through the Department of Health with the aim of increasing uptake of technology.

During the period of the WSD trial programme there were around 1.7 million users of telecare in the UK but implementation of telehealth for managing long term conditions had been minimal, with reportedly only 5,000 users of telehealth, most of whom had been recruited as part of the WSD (Clark and Goodwin, 2010). By contrast, in the US the Veterans Health Administration (VHA) has been running the most advanced telehealth programme in the world since 2003 (Clark and Goodwin, 2010; Cruickshank, 2012). As with the intentions of UK telehealth policy, the Care Coordination/Home Telehealth (CCHT) programme was set up to improve integrated care for veteran patients with chronic conditions and therefore avoid unnecessary admission to long-term care. At the time of its evaluation it was serving more than 30,000 patients and had demonstrated a 25% reduction in the number of bed days; a 19% reduction in the number of hospital admissions; and a mean satisfaction score rating of 86% (Darkins *et al.*, 2008). The cost of CCHT is \$1,600 per patient per year as opposed to \$13,121 per year for VHA's home-based primary care service and \$77,745 per year for private nursing home care (Darkins *et al.*, 2008).

Inspired by success in the US and the headline findings from the WSD, 3millionlives constituted an agreement between the Department of Health and the telecare industry that they would increase the use of technological interventions to 3 million people by 2017 (Department of Health, 2012b). However, just a year later, having been accused of being a top-down project that was industry-led (Goodwin, 2012), and having failed to reach the interim target of 100,000 new users, the campaign was taken over by NHS England. As part of the Technology Enhanced Care Service (TECS), a new vision was articulated that placed the focus on information

governance and supporting new commissioning and procurement practices to encourage use of a broader range of technology (Cashman, 2013; NHS England, 2014a). The DALLAS programme (Delivering Assisted Living Lifestyles At Scale) comprised a £37 million investment to show how new technologies and innovative services can help support independent living for older people and people living with long-term conditions. The money was awarded to four consortia across the UK, who were tasked with recruiting 170,000 services users by the end of 2015. Findings from the pilots are due to be reported in the next year – however, a survey of 2000 potential users carried out by DALLAS in 2014 found that more than 90% of people did not know what telehealth or telecare was, 38% could not see the benefits of this type of technology and 43% would not consider telehealth for self-care as they preferred face-to-face appointments with clinicians (DALLAS, 2014).

2.5 Summary

Reports from the government-led telecare and telehealth initiatives described in this chapter suggest there is still a lot of work to be done to convince potential service users and service delivery organisations of the benefits of the technological turn. Indeed, the survey of potential service users conducted by DALLAS illustrates that the debate about telecare terminology should not be dismissed as merely a discussion about semantics. The determination of the UK government to forge ahead with investment and policy commitment to this kind of technology illustrates a complex picture of priorities and objectives that are being considered alongside the findings from trials and pilot programmes. Attempts are made in this study to ‘unpick’ the complexity presented by policy and competing priorities. In Chapter 6,

in particular, elements of the policy narrative – or story-lines – discussed here are compared with findings from the case study site to understand the extent to which the policy agenda presents as a coherent message to local service delivery organisations and has translated into local practice and priorities.

What is clear from the policies discussed in this chapter is that transformation of welfare services in order to cope with the demands of population ageing and the burden of chronic conditions in economically-fragile times is at the forefront of government decision-making – and technology is seen as an intrinsic part of measures to relieve the pressure on the health and care system. Since the establishment of the Whole System Demonstrator programme the policy questions about the use of telecare and telehealth interventions have moved on from ‘if’ they should be implemented to ‘how’ they can become successfully embedded in provision. However, results from the WSD and other initiatives raise further questions about the circumstances in which telecare and telehealth can be used successfully, particularly in relation to who is benefiting from technology use, how service user views are being taken into account, and whether local practice reflects the policy intentions. These issues are central to the questions posed in this thesis and the next chapter discusses further how the research questions were formulated. That chapter also details a review of academic literature in the telecare field. The review of empirical studies notes the problems of inconsistent terminology outlined in this chapter and the themes identified in the literature highlight a number of issues raised in this discussion of policy – specifically, making sense of evaluations of technology, the impact of telecare on the independence and empowerment of

service users, and changes to social care and health practice. The chapter also highlights gaps in knowledge that this study aims to address.

Chapter 3 Reviewing the literature – establishing the debate

3.1 Introduction

This chapter provides an in-depth review of the literature relating to telecare and telehealth. While presenting a comprehensive understanding of relevant studies, its aim is to draw attention to the ways in which empirical investigations into telecare and telehealth have been carried out – their focus, theoretical perspectives, analyses and findings. By identifying the range of literature that has influenced current telecare and telehealth debates, the review seeks to highlight gaps in thinking that this study aims to fill. The chapter begins with a detailed explanation of the search strategy employed to uncover relevant literature before discussion ensues on the results of the search and findings from the literature. The review has been influenced by both narrative and realist approaches to synthesis (Pawson *et al.*, 2004; Popay *et al.*, 2006) and was carried out in accordance with the six stages detailed by Popay *et al.* (2006) in their guidance:

1. Identifying the review focus, searching for and mapping the available evidence
2. Specifying the review question
3. Identifying studies to include in the review
4. Data extraction
5. Evidence synthesis

6. Reporting the results of the review and dissemination

These stages of the systematic search process are detailed below and findings from the synthesis are then presented in a narrative form based around key themes.

3.2 *Review focus and questions*

Popay *et al.* (2006) judge that in order to set the right questions for a review, mapping of the relevant available evidence must be carried out before the specific questions can be established. In developing their meta-narrative approach to systematic reviews, (Greenhalgh *et al.*, 2005, p.420) specify an ‘initial search led by intuition, informal networking and ‘browsing’, with a goal of mapping the diversity of perspectives and approaches.’ This constitutes a process of ‘conceptual sharpening’ (Pawson *et al.*, 2004, p.13) whereby close attention is paid to defining the topic or intervention under consideration and stipulating the outcome of interest. For this study, the policy context within which telecare and telehealth initiatives have been developed provided the starting point for this scoping exercise, along with the identification of ‘seminal conceptual papers’ (Greenhalgh *et al.*, 2005) in order to establish how the telecare problem has been defined in previous research. The findings from this mapping exercise constitute the previous chapter and show how a policy discourse focused on the challenges to health and social care arrangements presented by demographic changes in an age of austerity has led to the vigorous promotion of technology by international governments. Having ascertained the policy discourse and key texts in the telecare field to date, the task of specifying the review questions was aided by an additional process afforded by the study design –

that of exploratory work at the pre-determined case study site⁸ to ensure that issues observed in practice informed the literature review and the ongoing direction of the research. This exercise provided clarification of the purpose of the review, revealing a 'reality testing' (Pawson *et al.*, 2004, p. vi) aspect that is concerned with the translation of the policy intent into practice. As a result, the following questions were proposed:

1. What are the public purposes of telecare provision and whose needs does it meet?
2. What are the aspirations for telecare and are these realised in practice?
3. Is telecare practice fit for purpose where the avowed purpose is to promote independence?
4. How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

The review, therefore, started from the premise that government policy papers frame telecare as a response to the demographic and economic pressures facing global health and social care systems. The policy narrative of the supposedly indubitable benefits of the technological turn nevertheless raises questions about the introduction of telecare and telehealth services at the local level relating to evidence of effectiveness, to issues about implementation and concerning the experiences of end users and other stakeholders. Attention must therefore be turned to providing a

⁸ The funding of the research stipulated the establishment of a case study partner prior to the recruitment of the researcher. This arrangement is reflected on in more detail in Chapter 5 Case study design and methods.

comprehensive account of empirical investigations concerning these aspects of telecare and telehealth development.

3.3 Review methodology

3.3.1 Literature searching

In order to ensure this review represents a rigorous and replicable account of the literature, a systematic approach to the search was undertaken. Telecare and telehealth attract research interest from a range of disciplinary backgrounds, including social sciences, health, management and economics, so a broad approach was needed to do justice to such a breadth of material. An important first step was to devise appropriate search terms that would capture research from different standpoints but also identify those studies most relevant to the focus of the research questions. This endeavour was not without challenge: Chapter 2 has already highlighted the issue of variable terms being employed to refer to telecare and telehealth services, meaning potentially relevant literature could be hidden behind differing terminology. This scenario was realised in the initial results when the first search using Boolean operators to look for ‘telecare’ or ‘telehealth’ or ‘telemedicine’ returned papers heavily weighted towards a clinical/hospital-based view of health technology and under-represented research in the social care field.

Following these results, consideration turned to the definition of telecare and telehealth proposed by the TeleSCoPE project (charged with developing a comprehensive code of practice for telehealth services in Europe) and was adopted by this study as a useful working definition. Chapter 2 of this thesis provided a detailed account of how key terminology in the field has evolved and the TeleSCoPE

definition was discussed as reflective of recent developments in thinking. For ease of reference, the definition, which is the same for telecare and telehealth is re-stated here:

The means by which technologies and related services at a distance are accessed by or provided for people and/or their carers at home or in the wider community, in order to facilitate their empowerment, assessment or the provision of care and/or support in relation to needs associated with their health (including clinical health) and wellbeing. Telehealth always involves and includes the service user or client. It includes remote patient management.

(Rudel *et al.*, 2011, p.32)

As part of the TeleSCoPE project an exploration of interrelated terms was presented by (Rudel *et al.*, 2011) and this provided a useful benchmark for ensuring all possible terms for telecare and telehealth meeting the TeleSCoPE definition were searched.⁹ This included the addition of the terms ‘assistive technology’ and ‘social alarms’, which spoke specifically to the social care perspective, although it also opened the search up to the inclusion of equipment that would not be considered telecare or telehealth under the TeleSCoPE definition, such as mobility aids and home adaptations. Likewise, the inclusion of the term ‘eHealth’ is problematic: as discussed in Chapter 2, Rudel *et al.* (2011, p.36) cite a definition by the European Commission that appears to be focused on the use of technology by professionals rather than by individuals accessing services. Nevertheless, eHealth is a widely used term in the telecare and telehealth field and the TeleSCoPE project shows the importance of including the term in the literature search. The additional MeSH term (‘social care’ AND ‘technology’) was also added to the search. All search terms were

⁹ A diagram depicting the key interrelated terms identified by Rudel *et al.* (2011) has been reproduced in Chapter 2 as part of the discussion on defining telecare.

entered using the advanced 'keyword' field in the databases. The full list of search terms and the search strategy can be found in Table 1.

Table 1 Search terms and strategy

		Ovid Medline	HMIC via Ovid	Embase via Ovid	PsycINFO via Ovid	Social Policy and Practice via Ovid	ASSIA via ProQuest	Web of Science (ISI)	CINAHL Plus via EBSCO
1	'Telecare' or 'Telemedicine' or 'Telehealth' or 'eHealth' or 'Assistive technology' or 'Social alarms' or ('Social care' AND 'technology')*	16,607	2,288	19,658	4,545	2,088	5,069	19,944	16,949
2	'Policy' or 'Practice'	870,114	78,174	1,236,706	306,772	120,254	133,319	1,298,243	407,008
3	'Satisfaction' or 'Views' or 'Perspective'	322,113	28,020	380,327	268,310	37,886	74,283	1,217,288	118,140
4	'Empowerment'	6,804	1,891	9,454	11,634	4,838	3,755	15,065	10,688
5	'Independence'	30,555	1,932	38,551	23,424	5,185	4,366	67,592	8,552
6	'Aspirations' or 'Aspire'	5,546	552	6,228	10,878	2,032	1,755	75,221	1,317
7	1+2+3+4	6	2	11	2	2	7	16	6
8	1+2+3+5	12	2	10	3	9	6	14	12
9	1+2+3+6	0	1	0	1	0	5	5	1

Table 1 Search terms and strategy

*MeSH or other database descriptor

The online databases searched¹⁰ were chosen for the range of sources that could be accessed bringing together perspectives from physical and mental health, social care, health management and other social sciences, such as economics. Table 1 shows a substantial amount of literature in the health and social care technology field, as well as a large number of papers related to the general themes of policy, practice and gathering different views or perspectives. The keyword 'independence' was equally present in a considerable number of articles. However, there was much

¹⁰ Databases searched were: Ovid Medline; HMIC; Embase; PsychINFO; Social Policy and Practice; ASSIA; Web of Science; and CINAHL Plus.

less evidence of interest in the consideration of empowerment and relatively few papers talking about aspirations – in fact, an initial review of these results showed that a majority of the studies using the term ‘aspiration’ were referring to the specific medical event of a patient inhaling a foreign substance into the lungs. The combination of the key search terms limited the results significantly but 133 citations were exported from the databases to a reference manager programme for further interrogation. This body of papers was supplemented by a process of snowballing – hand searching reference lists and further online searches of highly-cited authors and keywords using Google Scholar.

3.3.2 Identifying studies to include in the review – inclusion/exclusion criteria

Once duplicate papers had been removed from the study, titles and abstracts were read and a series of inclusion/exclusion criteria were applied to identify articles that were most relevant to answering the research questions. Due to the inconsistent use of terminology relating to telecare and telehealth resulting in a wide variety of papers (including many referring to equipment outside the scope of this study) there were a number of focused criteria for inclusion in the review applied to the literature.

Inclusion criteria were as follows:

- Empirical investigations.
- Studies concerned with the provision of services to adults.
- The technological intervention is the main focus of the study.
- The equipment under investigation falls under the definition proposed by Rudel *et al.* (2011) through the TeleSCoPE project. Specifically, the

technology enables the provision of health or care services at a distance to individuals at home.

- The equipment is used by patients, service users or carers rather than providing clinician to clinician support, such as diagnostic equipment or electronic health records.
- The technological intervention must have been introduced as an additional service to support someone in the community or as a replacement for other forms of health or care provision.
- Equipment has been issued to someone being supported by a social care-related agency (either statutory or third sector) and/or in response to the needs of a person with a long term condition (LTC).

Exclusion criteria were as follows:

- Systematic and other literature reviews, as well as purely conceptual or theoretical papers.
- Studies concerned with the provision of services to children.
- The technological intervention is mentioned as a recommendation or consideration resulting from empirical work with a different focus.
- The technology is for use in a hospital or other acute setting – this excludes, for example, telestroke initiatives that use video conferencing equipment to link inpatients to specialist clinicians.
- The equipment forms a fundamental part of an individual's health or care package for which an alternative service is inapplicable, such as a wheelchair.

- Studies investigating the use of a telephone or online service with a sole purpose of providing information or advice, for example a customer service telephone line or internet search engine.
- Papers that were not available in English.
- Papers that were not accessible through electronic means, physical holdings at the University of Birmingham or inter-library loans.

One of the inclusion criteria refers to long term conditions (LTCs), which may also be known as chronic conditions. An LTC is defined by the Department of Health as:

A condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies.

(Department of Health, 2012c, p.3)

This definition is not disease specific and LTCs may include, but are in no way limited to, hypertension, asthma, diabetes, coronary heart disease, chronic kidney disease, stroke and transient ischaemic attack, chronic obstructive pulmonary disease, heart failure, severe mental health conditions and epilepsy (Department of Health, 2012). Studies were included if they described the condition to be addressed by technology as chronic or long term.

Given the limiting factor of the search terms used, a 'cut-off' point in terms of date of publication was not considered to be a necessary inclusion in the review criteria. A decision tree diagram (Figure 2) illustrates the process for judging the literature against the inclusion/exclusion criteria.

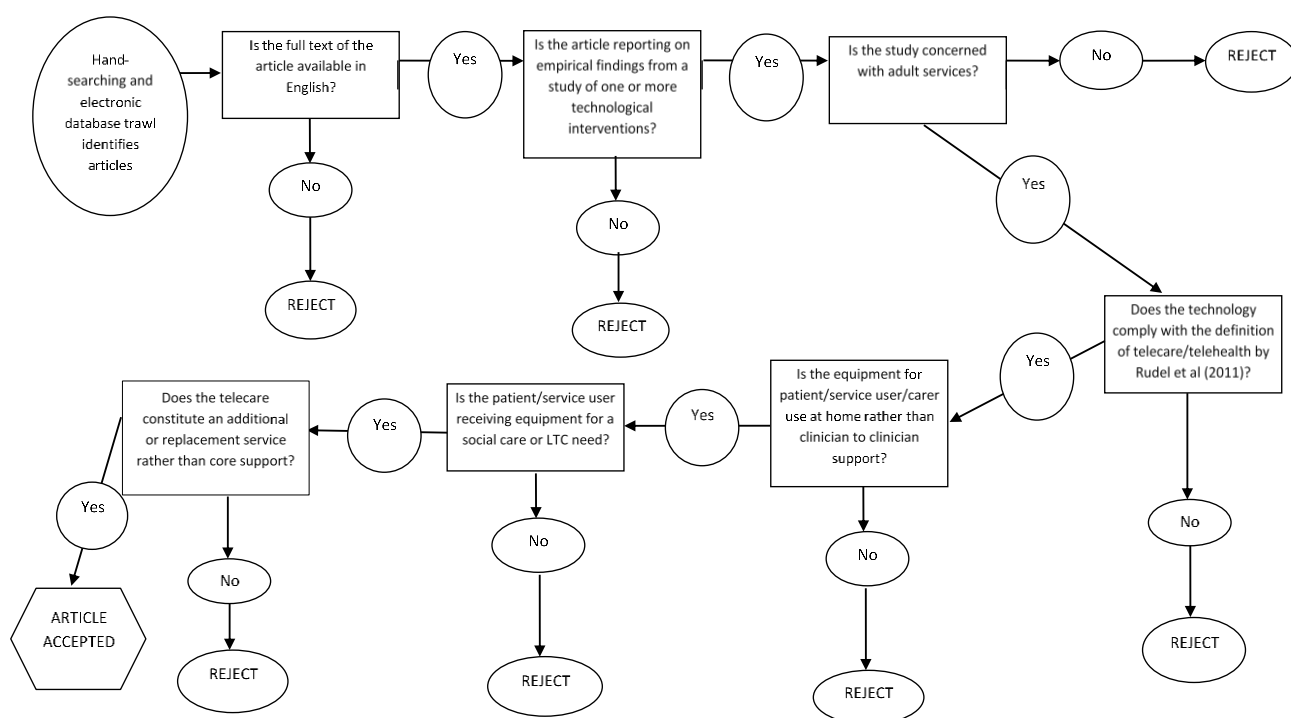


Figure 2 Literature review decision tree

3.4 Review stages

3.4.1 Reviewing the literature – data extraction

In accordance with Popay *et al.*'s (2006) guidance on narrative synthesis, the data extracted from the included studies were informed by the review questions. A spreadsheet was created to capture information about the research questions addressed, participants, methods employed and findings. Of relevance to this review was also the terminology used, the specific equipment under investigation and any reference to theoretical framing. The data extraction sheet can be found in Appendix 2.

3.4.2 Reviewing the literature – evidence synthesis

Following data extraction, a narrative synthesis of evidence was produced, whereby words and text were used to summarise and explain the findings from the literature, providing a more flexible approach to the review than other methods may have enabled (Mays *et al.*, 2005). This allowed for the consideration of mixed methods papers and for the heterogeneity between studies in terms of approach and questions answered (Popay *et al.*, 2006). The narrative synthesis became a process in developing the story of previous empirical research, highlighting overlapping research interests as well as identifying gaps.

3.5 *Review findings*

3.5.1 The nature of the literature

In total, 63 papers met the inclusion criteria and formed part of the narrative synthesis. These are provided in a list alongside the data extraction sheet in Appendix 2

3.5.1.1 *Academic discipline*

Studies came from a range of disciplines that may be considered related but reveal a variety of perspectives (see Appendix 2). A large proportion of studies can be categorised as on the health spectrum, for example, from primary and public health, from the view of specific clinical groups such as nurses or GPs, or with an interest in a particular clinical condition, such as COPD. There was a cohort of studies that had a focus on social care provision and a number of different research strands related to this, such as gerontology, learning disabilities, physical or sensory

disabilities and dementia. Many of these also gave perspectives on policy and political imperatives, such as the role of austerity. While health and social care provided the broad agenda for the studies in this review, authors also aligned themselves with other disciplines giving a particular angle to their research, such as psychology, biomedical ethics, science and technology studies or computing and engineering.

3.5.1.2 Year of publication

Telecare and telehealth are considered emerging areas of academic interest, even though 'first generation telecare' (usually amounting to a form of social or community alarm service) has been in use for decades. It is not surprising, therefore, that the earliest publication date of papers included in this review is 2000. Similarly, more than half of the total number of papers included (35) were published in the last 3.5 years. This not only points to an increased interest over recent years in the topic in general but also indicates a growing concern for approaches to empirical investigation that privilege qualitative data with a focus on the experiences of key stakeholders.

3.5.1.3 Geographic spread

The majority of papers reported on UK research (37 studies) with most gathering data on England but there were also some with a specific focus on experience in Wales and Scotland respectively. This perhaps reflects the UK Government's commitment to invest in activity promoting the UK as a global leader in telehealth and telecare implementation (Healthcare UK *et al.*, 2013). There were also a number of studies from the USA (10) and fewer examples from different European countries,

including the Republic of Ireland, Spain, The Netherlands and Israel. There were 5 papers from Nordic research, one each from Taiwan and Canada, and 4 studies including empirical research across two or more European countries (see Appendix 2).

3.5.2 Terminology and equipment investigated

The issues raised as a result of inconsistent terminology have been discussed in the previous chapter and were highlighted in the development of the search strategy for this literature review. They equally created problems in assessing the literature found as it often was not clear from titles and abstracts what kind of equipment was under investigation and therefore whether studies met the inclusion criteria. Even when papers were read in detail, not all specified devices in use but referred to umbrella terms. (Sheffield *et al.*, 2013, p.909) refer to ‘assistive devices’ and ‘home modifications’ as part of an ‘Ageing in Place’ intervention but they do not give details of what is included in these categories. Similarly, a survey of ‘community equipment’ use by (Sainty *et al.*, 2009) has been included in this review as devices were categorised as meeting mobility, domestic, personal care or sensory needs and could therefore have met the definition of telecare and telehealth adhered to by this study, but there was no comprehensive description of the devices in question provided by the authors. A few studies recognised the problem of defining technology as part of their research. Clark and McGee-Lennon (2011) developed their own phrase: ‘home care technology’ as an umbrella term for telecare and telehealth devices. This was deemed necessary as many of the older people and relatives in their study did not understand the term telecare; and those who did

considered it to be synonymous with pendant alarms, which was confusing for their research into advanced technologies such as mobile phone applications. Similarly, King *et al.* (2007) had difficulties with the term telemedicine as, for the practitioners they interviewed, this was most commonly associated with videoconferencing, while the authors were using it in the broadest sense to encompass any method of delivering healthcare at a distance, including the use of email. Both of the studies mentioned were indicative of the inconsistent terminology used throughout the literature under investigation here. In these cases, at least, definitions were proposed that were helpful for understanding the specific research carried out but they did not contribute much to a universal interpretation of terminology. Nevertheless, across all papers there was a general trend towards the use of broad terms that could encompass a range of technological devices that were typically under investigation. This also served to cross health and social care boundaries, particularly where telecare was understood to meet social care needs while telehealth and telemedicine were specified as supporting medical and health-related issues (Clark and McGee-Lennon, 2011; Cook *et al.*, 2013; Odeh *et al.*, 2013). For example, (Cook *et al.*, 2013, p.586) employ the term 'assistive technology' to 'include functional assistance aids and equipment, home-based telecare, telemedicine and telehealth devices and systems'. Finch *et al.* (2007, pp.86–87) prefer the term 'telehealthcare' to refer to 'doing healthcare at a distance, and employing technical artefacts, usually ICTs, to mobilise representations of and information about patients'. The authors claim this term includes devices labelled telecare but the language of health and patients were used rather than that of social care and service users. However, Finch *et al.* (2007) acknowledge that perceived distinctions between

the common terms (for example, telehealth, telecare and telemedicine) are problematic as they can be contested and there is significant overlap.

3.5.3 Methodological approaches

There were a number of different research designs and data collection methods employed by the studies in this review (see Appendix 2). These included randomised controlled trials, case study research and ethnographies; and the use of mixed methods, including surveys, interviews, observations, focus groups, documentary analysis and ethnographic field notes. Most of the studies discussed to some degree the analytical techniques used, such as thematic analysis of interview data or quantitative analysis of patient satisfaction questionnaires. Fewer papers were explicit about relying on a theoretical framework but those that were can be loosely grouped into studies that employed a form of evaluation methodology, including cost-benefit analyses (Cahill *et al.*, 2007; Duff and Dolphin, 2007; Ryan *et al.*, 2003); those interested in organisational dynamics, such as through diffusion of innovations theory and normalization process theory (Chrysanthaki *et al.*, 2013; May *et al.*, 2003a, 2011; Peeters *et al.*, 2012); and studies focused on phenomenological accounts (López and Domènech, 2008; May *et al.*, 2003b; Mort *et al.*, 2013; Pols and Willems, 2011).

In a paper providing an overview of theories employed in the field of telemedicine research, Gammon *et al.* (2008) found that theoretical concepts played only a modest role in this area of research and that they were most prominent in the social sciences, leaving technological and medical studies generally under-theorised.

Their analysis of the theories employed by telemedicine¹¹ identified theoretical concepts in only five per cent of journal articles in the field (Gammon *et al.*, 2008). They asserted that amongst the theories that *were* identified none illuminated any distinguishing features of telemedicine as a research field or stimulated theoretical advancements. The literature carried out for this study appears to concur with that conclusion – a couple of papers in this review acknowledged this point, highlighting systematic reviews that have deemed many evaluations to be methodologically inadequate, particularly in relation to reports of high patient satisfaction (Barlow *et al.*, 2005; Finch *et al.*, 2007). The lack of theoretical grounding in telecare studies is something that this research aims to address, and Chapters 4 and 5 provide a detailed account of the theoretical underpinning to the work presented in this thesis. In two papers, May and colleagues (May, 2006; May *et al.*, 2003b) had methodological criticisms of the value placed on particular types of knowledge, namely the drive for evidence-based policy and practice, that can be problematic for research into health technology. The authors claim that the reliance on biomedical research procedures places focus on normative expectations of generalizable results and does not take into account the instability of social and technical processes that affect implementation. Furthermore, May's (2006) research found that while those conducting clinical trials of technology such as telemedicine linked their work methodologically to policy values, those making decisions about NHS investment 'saw clinical trials as an ineffective way to identify and promote the benefits of telemedicine, precisely because the contextual and processual insights about *workability*...were in practice lost from sight' (May, 2006, p.521).

¹¹ 'Telemedicine' was used as an umbrella term, also including references to 'ICT for health', 'medical informatics', 'health information systems', 'telehealth' and 'ehealth'.

3.6 *Thematic analysis of the literature*

The purpose of this literature review was to identify empirical papers that had considered telecare and telehealth policy and practice through the lens of different stakeholder experiences and perspectives; and with a focus on some of the key themes of the policy narrative, such as the impact of technology on the independence and empowerment of service users and patients. Given the parameters of the search, it is not surprising that many of the studies meeting the inclusion criteria for this review addressed similar questions and reported on many of the same issues. Papers cannot be grouped into discrete categories, although a number of different but overlapping themes were identified. A selection of studies constituted evaluations of effectiveness of one or more technological intervention, albeit with an emphasis on service user, patient or professional views on the success or otherwise of the service. A similar number reported more generally on the telecare and telehealth experiences of service users or patients, often in relation to self-reporting on quality of life measures and people's views on the technological turn in social care and health. Some of these studies also spoke of the experiences of workers but only 6 (King *et al.*, 2007; MacNeill *et al.*, 2014; Richards, 2004; Segar *et al.*, 2013; Tudiver *et al.*, 2007; Wilhelmsen *et al.*, 2014) focused exclusively on the perspectives of health and social care professionals.

A cohort of studies analysed the role of organisational change in the embedding of telecare and telehealth and how far the introduction of these services constituted a systemic shift in the way health and care services were provided. In these studies the views of professionals were sought on the impact of technology on working

practices, health and wellbeing outcomes, and challenges faced. Barriers to implementation were discussed, both at the meso and micro level, including the consideration of cultural issues and incidents of prospective service users rejecting or abandoning the technological intervention.

A common focus was the consideration of ethical dilemmas such as debates on autonomy and safety 'versus' privacy (Landau and Werner, 2012; Magnusson and Hanson, 2003; Melander-Wikman *et al.*, 2008; Percival and Hanson, 2006). In some studies this discussion was couched in a more fundamental challenge of policies promoting 'ageing in place' at the expense of institutional settings (Mort *et al.*, 2013; Sixsmith and Sixsmith, 2008). Aspects of autonomy were examined in relation to risk, coercion and self-management, and were bound up in questions about the meaning of independence and empowerment, particularly regarding the ability of service users and patients to 'opt out' of using the equipment (Pols and Willems, 2011; Mort *et al.*, 2008; López and Domènech, 2008; Fairbrother *et al.*, 2013; Finch *et al.*, 2007; Rogers *et al.*, 2011). In addition, a group of papers considered self-management in terms of the proliferation of different types of telecare 'work' – for example, from the perspective of increased responsibility for service users and patients but also in relation to the changing roles of professionals, including in providing the ongoing support required by telecare and telehealth users (Lyndon and Tyas, 2010; MacNeill *et al.*, 2014; Tudiver *et al.*, 2007; Segar *et al.*, 2013; Richards, 2004).

3.6.1 Evaluations of effectiveness

A large cohort of studies comprised some kind of evaluation of effectiveness for one or more device in a particular setting involving participants with a specific condition. Some of these studies conducted a variation on a cost-benefit analysis or considered questions of value for money and the potential to achieve monetary savings. All included a report on the perspectives of service users, patients, carers, professionals or other stakeholders gathered through interviews, surveys or self-assessment questionnaires on outcome measures such as the EQ-5D instrument for reporting health related quality of life. In focusing on the evidence of key informants, some studies were only concerned with gauging general views on attitudes to the cost of technological interventions versus the perceived benefits; while others were concerned with specific issues such as quality of life measures, barriers to uptake of a particular intervention or organisational challenges.

3.6.1.1 *Cost-benefit and cost-effectiveness analyses*

In a study of telecare's value for money, Dafydd *et al* (2009, p.43) assert that 'there seems little doubt that telecare services are associated with significant cost savings to all parts of the health, social care and housing economies'. This statement appears to be supported by a number of other studies making the economic case for telecare (Berkley *et al.*, 2010; Bondmass, 2007; Porteus and Brownsell, 2000). Beale *et al.*'s (2010) evaluation of the Scottish Telecare Development Programme (TDP) reported investment in technology had resulted in significant savings to health and social care, as well as reduced avoidable emergency admissions and care home use. Duff and Dolphin (2007) also concluded that the relatively cheap

equipment being used by participants with dementia in their study had an extremely positive impact on users and their carers. However, claims of cost-effectiveness appear more contestable in the light of the results of the Whole System Demonstrator programme (discussed in detail in Chapter 2) that concluded the quality adjusted life year (QALY) gain for patients using telehealth in addition to usual care was similar to those with usual care only and that the technology was not a cost effective addition to standard care (Henderson *et al.*, 2013). Furthermore, Dafydd *et al.* (2009) observe that councils are increasingly considering introducing charging policies for their telecare services due to budgetary pressures. In this light, they reported varied opinions of older people on their appetite for paying for the service, which was described as commissioning equipment based around sensors and alerts. While most participants felt the service was value for money and all participants said they were happy (in theory) to pay towards the equipment cost, a large majority said they would not be prepared to pay extra for a response service in the case of family and friends being unable to attend. Similarly, Lu *et al.* (2014) asked patients with chronic conditions in Taiwan whether or not they would be prepared to pay for their telehealth service and very few said they would be willing to pay even a minimal price.

The usefulness of economic arguments in the implementation of telecare and telehealth has been questioned by two studies that draw on evidence from participant-observation of strategic decision-making. Williams and Bryan (2007) observed meetings of NHS decision-making committees and noted their discussions about proposed new technologies. They found that economic considerations were less important to officers than expected and some officers had ethical complaints

about the perceived underlying values of health economics, viewing them as at odds with the priorities of clinicians who had the best interest of patients at heart (Williams and Bryan, 2007). Similarly May (2006) undertook a longitudinal study of the use of evidence in health technology decisions, observing over the course of 7 years a series of public and private meetings involving senior NHS and social care managers, including two sessions of the UK House of Commons Health Committee. May (2006) reported an increasing disregard for quantitative evidence about clinical and cost effectiveness drawn from trials:

[Quantitative evidence] had little to say about the contingencies of everyday inter-professional work, and – because of the rigorous inclusion and exclusion criteria that are applied in the delivery of trials – it was also seen to have little to say about the complexities of service users' problems, whether these were 'co-morbidities' as seen by NHS managers, or 'complex social problems' as seen by social care managers.

(May, 2006, p.524).

Instead, qualitative data showing 'practice-based evidence' rather than 'evidence-based practice' was more compelling for senior managers' spending decisions as it was seen as more closely connected to their experiences (May, 2006). Evidence about cost effectiveness was seen as fundamentally important, but this was framed in terms of an accounting model that emphasised savings, and related to local spending decisions and outputs, rather than economic modelling that focused on system level costs (May, 2006). This evidence was supported by Beale *et al.* (2010) whose analysis of providers' self-reporting of monetary savings revealed they mostly amounted to efficiency savings predicated on decreased use of secondary care and more intensive social care services, which were unlikely to be 'cash-releasing' if, for example, care home places were purchased on a block contract. The cost-benefit

model that May (2006) observed was also seen to take into account the interests of external stakeholders, such as the manufacturing and service supply sector and the professional skills of information technologists, who argued that their perspectives were always absent from medically dominated accounts. In a similar vein, Duff and Dolphin (2007) incorporate different kinds of costs into their cost-benefit analysis of telecare implementation with people with dementia, including the number of hours the carer spent helping the person with dementia with the product once it was installed; the cost of time spent caring; and lost productivity by working carers. The use of evidence can be questioned at a more fundamental level, however, as Barlow *et al.* (2005) found that a telecare programme involving the use of devices for vital signs and environmental monitoring in conjunction with rehabilitation services was sanctioned by a local authority without any apparent evidence of the benefits of this approach. The researchers claim that there were no other schemes in existence with the same mix of objectives, and concluded that the drive for innovation had overridden the requirement for evidence of efficacy (Barlow *et al.*, 2005).

3.6.1.2 Quality of life and patient satisfaction

Many studies referred loosely to the objective of ‘improving quality of life’ through technological interventions. When asked about the impact of telecare on their quality of life, 60.5% of participants in an evaluation of a national programme in Scotland felt that their quality of life had improved to varying degrees since using the technology, although the devices in use are never explained (Beale *et al.*, 2010). Over half felt that their health had not changed but 93.3% felt safer, although there is no further interrogation of this very high percentage or discussion of meanings of ‘safety’ (Beale *et al.*, 2010, p.67). In a European project testing a system of

environmental sensors and alerts in the homes of older people, Damant *et al.* (2013) found some positive effects on users' perceptions of quality of life. For example, users with a higher number of disabilities at baseline reported increased confidence in their safety at home than those with fewer disabilities. However, overall findings showed that healthier, more independent users perceived more benefits from the services than users who reported more health problems and were considered less independent (Damant *et al.*, 2013). A Norwegian study of younger adults using telemedicine to support home dialysis reported users interpreting improvements in their quality of life as being able to spend less time in hospital (and less time travelling there), which resulted in them feeling they spent less time as 'patients' and in a 'sick role' (Rygh *et al.*, 2012).

Research that makes use of validated measures such as SF-12 and EQ-5D finds no statistically significant improvements in quality of life scores following technological interventions (Cartwright *et al.*, 2013; Lewis *et al.*, 2010). However, device-specific findings must be flagged up here. In the studies by Cartwright *et al.* (2013) and Lewis *et al.* (2010) both were concerned with telehealth monitoring of people with long term conditions, including Chronic Obstructive Pulmonary Disease (COPD). It could be argued that while such equipment could improve people's understanding of their condition and ability to manage it, this does not change the everyday experience of living with a chronic condition that will never be cured. In the Beale *et al.* (2010) study, however, while the range of equipment in use is unspecified, it is clear that vital signs monitoring was not the only intervention and a spectrum of devices to meet a variety of needs was employed, meaning the telecare could have impacted on different aspects of people's lives leading to an overall

perception of an increase in quality of life. This is supported by research in the USA which saw telehealth monitoring introduced alongside a video conferencing programme for veterans with long-term conditions and in need of mental health interventions (Sorocco *et al.*, 2013). The researchers found a number of benefits of a combined approach, including improved social functioning evidenced by self-reporting of improved relationships with others, which could be viewed as a quality of life measure. It may be assumed that the video consultations were more effective in tackling social dysfunction than the vital signs monitoring, although this is not clarified in the discussion. It is easy to see, therefore, how generalised conclusions can be made about the impact of technology on quality of life when in fact the specific devices and contexts involved provide the crucial information.

Quality of life was also reported in terms of the impact of technology on carers. A number of studies presented evidence that the 'burden' on family carers was reduced by various technological interventions, calling for this impact to be included in future cost-benefit analyses (Duff and Dolphin, 2007; Mortenson *et al.*, 2013; Sorocco *et al.*, 2013). Some showed that carers were more receptive and potentially felt more reassured by telecare interventions than the people they cared for (Dafydd *et al.*, 2009; Porteus and Brownsell, 2000). Cahill *et al.* (2007) found that carers sometimes used and valued different products to the person with dementia that they cared for, which shows the importance of clarity about the intended recipient of technology and the outcomes being prioritised.

A number of papers reported on patient satisfaction, most using quantitative analysis of participant questionnaires (Bondmass, 2007; Odeh *et al.*, 2013; Riain *et al.*, 2014;

Rohland, 2001; Ryan *et al.*, 2003; Sainty *et al.*, 2009; Wakefield *et al.*, 2008), although some discussed participants expressing satisfaction in interviews and through tick-box surveys (Beale *et al.*, 2010; Dafydd *et al.*, 2009; Porteus and Brownsell, 2000; Rygh *et al.*, 2012). Without exception, all reported that satisfaction levels, regardless of equipment specification, were high. Often, studies that did not record patient satisfaction referenced other studies citing high patient satisfaction levels, although some made the point that satisfaction levels reveal nothing about the quality of care and service being provided (Melander-Wikman *et al.*, 2008). Gramstad *et al.* (2014) challenge received wisdom on measuring the satisfaction of users by taking a hermeneutical phenomenological approach to capturing older people's experiences of the technology service delivery process. They emphasise the importance of gathering the views of service users throughout the process of service delivery as there may be complicating reasons why older individuals do not acknowledge unsatisfactory experiences:

The investigation of client experiences during the service delivery process uncovered diverse experiences related to expectations, disappointments, fear, and abandonment but also hope, mastery, and resourceful and dynamic self-management of care.

(Gramstad *et al.*, 2014, p.311)

From the studies that reported on patient satisfaction, it is difficult to draw comparisons between them or make firm conclusions as the methodologies differed and the tools and questions used were not always explained. Although not meeting the inclusion criteria for this review, Mair and Whitten (2000) identify a series of limitations in the literature on patients' satisfaction with telemedicine, particularly in relation to reliability and validity, as most studies purported to measure 'satisfaction'

with a service but failed to define what satisfaction meant. This is a question that could be levelled at studies in this review.

3.6.1.3 Organisations and barriers to implementation

An organisational level perspective on technology implementation is a feature of recent research and was a consideration for a number of studies in this review. Some recognised that technology changed the routines of professionals, introducing new ways of working both in relation to the use of their time and in their interactions with service users. Berkley *et al.* (2010) found that community nurses were able to take on a bigger case load when their patients with chronic heart failure made use of telehealth; and they felt more involved with the running of GP practices and more informed about long-term conditions as a result. The impact of technology on professional work is discussed later in this chapter but some studies also noted that the change initiated by services such as telecare needed to be acknowledged on a system-wide scale in order for implementation to be successful (Lyndon and Tyas, 2010). In the recommendations from a Scottish telecare evaluation, the authors advised ‘a significant amount of time is usually required to develop a positive local culture toward telecare and to win people’s hearts and minds’, and further argued that ‘a local champion, preferably working at senior officer level, is important’, as is staff training (Beale *et al.*, 2010, pp.68–69). Other studies of organisations warned against viewing the implementation of a technology-based service as a trigger for whole-system redesign, whereby services would provide more integrated provision (Chrysanthaki *et al.*, 2013). A key problem was identified in the lack of a shared understanding of what a whole-system approach would require, and technology implementation did nothing to clarify this. Nevertheless, the benefits of local

'ownership' of telecare services and the role of champions or sponsors were identified in terms of achieving normalisation of technology and greater collaborative practice across the care system (Chrysanthaki *et al.*, 2013; May *et al.*, 2003a).

Organisational culture and structures were also identified as potential barriers to technology implementation (Barlow *et al.*, 2005; Chrysanthaki *et al.*, 2013). In recent years there has been general interest within the field in what has been termed the 'chasm' between early adoption and wider uptake of telecare and telehealth services (Clark and Goodwin, 2010). Some authors in this review put forward their own ideas about what might be perceived as barriers to implementation. Barlow *et al.* (2005) point to a lack of awareness and knowledge among health and social care professionals, which must have abated as a concern in the ten years since the publication of their paper. However, more recent studies have supported their assertions that telecare services often have complex objectives, which, when compounded by a lack of service integration, could lead to unrealistic expectations (Barlow *et al.*, 2005; Chrysanthaki *et al.*, 2013; May *et al.*, 2011). In addition, May *et al.* (2011) raised a number of points that previously had not been addressed, centring on the uncertainty surrounding telecare's fit with existing provision. From interaction with key informants they revealed concerns that organisational links between policy and practice lacked coherence, leading to uncertainties about responsibilities for service development and sustainable business models. Professionals also highlighted a perceived lack of continuity between telecare policy and other self-care work already implemented by frontline staff, as well as the absence of financial incentives for primary care providers (May *et al.*, 2011). This study also revealed a lack of confidence, in some instances, in the adequacy of

telecare – a finding that was replicated in other studies (Edwards *et al.*, 2014; Lu *et al.*, 2014).

3.6.2 Ethical issues

Around a third of the studies included in this review investigated ethical arguments in favour of, or challenging, the implementation of telecare and telehealth. Most of these tackled questions of autonomy (including aspects of independence and empowerment) and privacy, and these themes will be discussed in detail below. However, some asked bigger questions by challenging the premise on which telecare and telehealth interventions are being introduced. Mort and colleagues criticise a ‘crisis’ account of ageing (Mort *et al.*, 2013, p.803) that has declared there are too many old people living for too long, with costly care needs and too few carers to look after them. This narrative has provided the basis for the UK government’s promotion of ‘ageing in place’, which was discussed in Chapter 2 as a key component of the fundamental changes to health and social care policy in recent years (Sixsmith and Sixsmith, 2008). The notion of ‘ageing in place’ appears to be simply the branding of the understanding that supporting older people to remain living at home positively impacts on their wellbeing, independence and social participation; and it has been widely promoted as the goal of policies for older people and housing (Sixsmith and Sixsmith, 2008). A far from immaterial dimension to this story is that this aim is judged to be a more cost effective solution to the ageing ‘crisis’ than encouraging vulnerable older people to move to institutionalised care. It would seem difficult to argue with the ‘ageing in place’ discourse, but Sixsmith and

Sixsmith (2008) have asserted that what may be marketed as benign common sense fails to address the potential downsides in everyday life for some older people:

Home in old age can be a place of intense emotional experiences, frustrations and negative experiences, such as loneliness. There may also be significant weaknesses in terms of informal support, physical environment of the home and neighbourhood and social network, which undermine the person's ability to live independently.

(Sixsmith and Sixsmith, 2008, p.233)

Furthermore, they suggest that the focus on home-based care as the preferred course of action can lead to insufficient or inappropriate provision and the potential marginalisation of nursing and other forms of residential care, which could reduce people's options further down the line (Sixsmith and Sixsmith, 2008). Mort *et al.* (2013) take their critique of 'ageing in place' further by arguing that it has created the environment for an indiscriminate technology push that, combined with the narrative of austerity, could result in the coercion of older people, particularly those with the highest level of need who have become the focus of the increasingly limited resources of statutory providers. While making it clear that telecare is not inevitably coercive, Mort *et al.* (2013) suggest that the state risks creating conditions where it compensates for overstretched domiciliary care services by narrowing older people's choices, forcing individuals to comply with intensive monitoring via their 'telehome'. Instead of enhancing independence and giving peace of mind, technology implemented in this way could create isolation and dependence.

3.6.2.1 *Independence and autonomy*

As noted in Chapter 2 of this thesis, the term 'independence' is subject to multiple interpretations from a range of perspectives, and this issue was apparent in the

literature included in this review. 'Independence' was employed liberally by the studies in this review, although there was a distinct lack of discussion about what this term meant. The majority of papers were concerned with older people (with or without a long-term condition or other physical or mental disability/illness) and presented an opaque, subjective and potentially loaded understanding of independence. In contrast, the only two papers with a focus on adults with learning disabilities put forward starkly functionalist explanations of independence, employing the term singularly to describe 'enabl[ing] people to do things for themselves' or specifically 'to perform activities of daily living on their own' (Wilkie, 2010, p.51). One of these studies concentrated entirely on measuring the completion of household tasks as directed by formal carers versus being prompted via telecare (Taber-Doughty *et al.*, 2010). Based on the number of tasks, such as 'baking cookies' and 'changing batteries', effectively completed, the authors concluded that 'results indicated consumers achieved slightly more independence when prompted by the telecare support provider' (Taber-Doughty *et al.*, 2010, p.843). Neither of the two studies reported on any attempts to gather feedback or any qualitative data from the service users.

What became clear in the ethically-centred literature was that authors employed the word independence almost interchangeably with autonomy. One way that Mort *et al.* (2013) recommend combating the conditions of coercion they cite is to acknowledge the autonomy of the people accessing care, even if this means providing space for them to decide not to use telecare or to misuse it. The theme of autonomy is strong within the literature concerned with ethical perspectives but there is no single description of the autonomy afforded by telecare use. López and

Domènech (2008, p.181) critique the framing of telecare as a disembodied care that presents autonomy as ‘a result of managing the users’ problems as a virtual management of information rather than a hands-on care activity that demands physical intervention at home’. They instead argue a similar line to Mort *et al.* (2013) – that telecare is not a disembodied care as it cannot be introduced as a substitute for hands-on care and in fact its use requires the enactment of different ‘bodies’ and the emergence of competing definitions and practices of being autonomous.

In their study, López and Domènech (2008) compare interview data gathered from two older women involved with a Catalan telecare service to show the different ways they express autonomy with telecare (in this case, a pendant alarm) use and non-use. One of the women is presented as enacting the ‘risky body’ while the other is the ‘vigorous body’. In the first case, the woman describes a common scenario of how despite not feeling well she refuses to bother anyone by pressing her pendant. López and Domènech (2008) assert that while the pendant alarm is presented as a simple system whereby a single action of pressing a button is required to instigate help, in actual fact this action is not a logical consequence of need on the part of the user and knowing the appropriate situations in which to press the button is the result of a complicated process incorporating practices, technology and discourses. This process involves the use of household medical technology, such as thermometers, blood pressure monitors or medication; drawing on practices such as reminders from family members to wear the pendant and not engage in risky activity – check-ups with the doctor that serve as guidelines for interpreting what is happening to them, and visits from the telecare service to provide advice on equipment use (López and Domènech, 2008). The result is that telecare users are encouraged to view their

bodies as problematic, unstable ('whenever you feel something just press' - López and Domènech, 2008, p.187), risky and in need of constant surveillance.

In the second, similarly familiar, scenario López and Domènech (2008) report on a woman who refuses to wear her pendant on occasions due to the way she feels it portrays her as ill. The dilemma identified is that telecare discourse implies autonomy through wearing the pendant and choosing when to call for help, and yet this woman resists wearing the pendant. The researchers argue that this resistance demonstrates an alternative embodiment of autonomy. While the first woman grapples with interpreting her 'risky body' and the daily action she should take, the second refuses to live all the time with the continuous surveillance required of a body-at-risk, preferring to trust her body's capabilities to overcome obstacles (López and Domènech, 2008). Here she is enacting the 'vigorous body', one that cannot allow the body to be constantly problematic but must remain durable, strong and consistent, sitting in the background of daily activity and not as the object of this activity. While users are told to wear their pendants and take few risks with their health, embodying this form of autonomy requires the rejection of this advice to preserve their desired lifestyle (López and Domènech, 2008). These examples also highlight the impact of framing telecare primarily as a risk-management tool – a definition which is repeated in other studies (Barlow *et al.*, 2005; Chrysanthaki *et al.*, 2013). In rejecting the risk-management of their bodies (for different reasons) the two women in the López and Domènech (2008) study are forced also to reject the technology that is tasked with meeting this objective.

The theme of autonomy as risk taking is presented in other study findings, particularly where technology has been associated with negative stereotypes of illness. Percival and Hanson (2006) discuss interpretations of 'risk-taking behaviour' whereby service providers focus on the management of physical risk while older people are more concerned about the risk to their personal and social identities and the stigma of being perceived as frail or vulnerable. Taking risks is part of the construction of self-esteem – a hallmark of older people's sense of independence and autonomy (Percival and Hanson, 2006). This view was supported by the participants in a study from Melander-Wikman *et al.* (2008) where, in a similar turn of events to the López and Domènech (2008) study, advice on falls prevention relating to avoidance of activity and restricting mobility had been rejected by some older people as a threat to identity and autonomy. The stigma of illness and disability had also been extended to a fear that the wearing of devices (in this case consisting of a GPS receiver with built-in falls detector) outside the home exposed the user as vulnerable and increased their fear of being the victim of crime, such as robbery or assault (Melander-Wikman *et al.*, 2008). Conversely, researchers involved in the evaluation of a Scottish telecare programme declared an entirely different association between risk and independence, concluding that service providers' intention to 'minimize client risk' and 'promote client independence' amounted to similar objectives as 'minimizing client risk will help to promote client independence' (Beale *et al.*, 2010, p.64). A related argument was put forward in the study by Sheffield *et al.* (2013) whereby an increase in safety was equated to an increase in independence. However, in this study of 'adaptive equipment' and 'home modifications' results showed an increase in home safety and a reduction in the fear

of falling, but it did not produce statistically significant results in a measure of the increase in functional independence or in actual falls.

Perceptions of vulnerability are not necessarily associated with stigma but can also be rejected on grounds of 'felt need' (Sanders *et al.*, 2012). McCreadie *et al.* (2006) observe that among their focus groups of older people and their carers, some participants did not associate with identities of illness or disability and did not feel a need for the help accessed through assistive technology or did not associate their difficulties in life with their illness or disability. Evans *et al.*'s (2011) review of a system of alerts and sensors monitoring the movements of a woman with dementia reported that the participant was not keen on the system calling staff when she left the flat as she felt competent to do this without alerting anyone else. Exploring barriers to participation and adoption of telehealth and telecare as part of the Whole System Demonstrator trial, Sanders and colleagues (2012) found that respondents who had been identified as eligible for the programme but had refused the intervention often saw themselves as 'too healthy' or 'too independent' for the technology to be of value to them. Nevertheless, a small number of respondents deemed the people they cared for 'too sick' or 'too dependent' to make use of the equipment, raising questions about the extent to which people felt that telecare and telehealth could make a positive impact on their lives (or those of the people they care for).

The views of carers on autonomy was taken up by Landau and Werner (2012) in their study of GPS tracking of people with dementia. They found that this controversial intervention should not be seen as inherently unethical but that the

views of individual service users were crucial to the judgement of the conditions of use. Similarly, McCabe and Innes (2013) reported that potential users of the GPS device seemed less concerned about the ethical implications of 'tagging' than those writing in academic journals. However, Landau and Werner (2012) discussed the conflicted feelings of carers as supported by other empirical research in the field, giving examples of carers favouring GPS tracking to reduce the risk of harm to their loved one while worrying about the implications for autonomy and privacy. One cited study found that despite the devices reducing anxiety in carers this did not result in the person with dementia being afforded any more freedom by their family: 'the ethical consideration is thus not the maximization of autonomy but rather reducing the time that someone is lost' (Landau and Werner, 2012, p.359). Participants in the McCabe and Innes (2013) study also discussed the difficult balance between managing the anxiety of carers and promoting the independence of people with dementia, admitting that the GPS device did not lead to more freedom for service users as carers often used it as a back-up and focused on reducing risk.

The propensity for caution in relation to allowing autonomy is also reflected in accounts of the views of health professionals. Those charged with monitoring people with COPD who took part in a study on home telemonitoring by Fairbrother *et al.* (2013) took a markedly different stand on the use of technology to the enthusiastic one taken by patient participants. They judged patient empowerment to be beneficial as long as patients took a responsible approach to their health and lifestyle choices 'within medically acceptable parameters' (Fairbrother *et al.*, 2013, p.408). It was the role of the healthcare professional to define how the empowered patient should exert their autonomy and independence. Moreover, MacNeill *et al.* (2014) found that GPs

were suspicious of telehealth interventions as potentially undermining their professional autonomy by forcing them to monitor patients and direct resources in a certain way. However, this study of telehealth monitoring of people with long-term conditions, which was embedded in the Whole System Demonstrator trial, also found that GPs were worried about the burden telehealth monitoring placed on patients – particularly those who were generally healthy and active and were considered by doctors to be prematurely drawn into clinical surveillance (MacNeill *et al.*, 2014). This point was also highlighted by professional participants in the study by Percival and Hanson (2006), linking it back to Mort *et al.*'s (2013) argument that without appropriately targeting the intervention it could be considered coercive. The paternalistic flavour to the perspectives of healthcare professionals was reflected in Magnusson and Hanson's (2003) cross-European study of the implementation of videophone and other multimedia, internet-based technology to support older people and family carers. While service users spoke of their increased information about the different types of services accessed through the technology, professionals registered concerns about raising the expectations of service users, both in terms of the range of technological supports available to them and choice about other services.

In summary, discussions in the literature about independence were often bound up in questions about the impact of technology on autonomy. These questions incorporated a range of perspectives on the capacity of technology to cause users to take or prevent risks; to feel independent or coerced; empowered or stigmatised. What is clear, and indeed noted by some authors (Landau and Werner, 2012), is that there is no current consensus on this point and in fact the long-term implications

of the technological turn on autonomy and empowerment are not well understood (Finch *et al.*, 2007).

3.6.2.2 *Privacy and safety*

The question of privacy, particularly in relation to the trade off with safety, is frequently addressed by the literature. In an exploration of barriers to uptake of home care technology, Clark and McGee-Lennon (2011) highlight concerns of older people about privacy related to surveillance and accusations of 'Big Brother'-style tracking. This particular study enlisted focus groups to consider the design of advanced technology applications to be used on everyday devices such as mobile phones and television to improve self-care and health management at home. Given the technology was still in the design phase, the researchers judged the worries expressed to be misconceptions about the capability of the technology being considered – for example, people believed the device would be able to monitor all kinds of activity beyond the realm of health, which the authors claimed to be an inaccurate assumption (Clark and McGee-Lennon, 2011). Nevertheless, these fears did not dampen older people's acceptance of the proposed technology – a finding which contrasted with social care staff's predictions about service users' supposed 'technophobia'. Concerns about 'Big Brother' were repeated in other studies, however (Magnusson and Hanson, 2003; Percival and Hanson, 2006; Wakefield *et al.*, 2008). In one, the implementation of videophone technology into the homes of older people in a number of different European countries made people feel self-conscious about their appearance and worry that others could see into their homes – leading to the suggestion that screens could be erected to physically block the

videophone when not in use ‘to avoid “big brother syndrome” or “unjustified paternalism”’ (Magnusson and Hanson, 2003, p.436).

Discussion about the fears of ‘Big Brother’ were not limited to worries about being watched, but also related it to the idea of creeping surveillance in the name of safety and security (Percival and Hanson, 2006). In some studies, the sacrifice of some privacy to increase safety and convenience was seen as justified. Thus, research by Landau and Werner (2012) into the ethics of GPS tracking of people with dementia found that all carers who participated viewed the principle of non-maleficence¹² – particularly in relation to the protecting of people with dementia from harm – as more important than any issues about privacy (see also Magnusson and Hanson, 2003). Moreover, a project conducted in Sweden with cognitively unimpaired participants reported that individuals felt their privacy was being protected by technology that enabled them to remain in their own homes rather than having to move into institutionalised care (Essén, 2008). In these studies it was deemed that the key to solving such ethical dilemmas was to ensure the full consent of the person being monitored, although Magnusson and Hanson (2003) point out that clearly this is not always possible with very ill people and even when it is, the sense of dependency some older people feel on family and professional carers makes it difficult for them to refuse suggestions about modifying their ‘care’, making it more likely that the principle of beneficence or non-maleficence will be prioritised.

¹² The bioethical principle of non-maleficence requires that, above all, the clinician must not ‘do harm’ to the patient (Beauchamp and Childress, 2009)

Older people raised concerns about different aspects of gathering data – some felt that health and well-being information was private and should not be shared or communicated digitally (Clark and McGee-Lennon, 2011). This led onto questions about how much data should be collected, who owns the data captured and who has access to it (Clark and McGee-Lennon, 2011; Coughlin *et al.*, 2007). Older people in a study in the USA by Coughlin and colleagues (2007) felt that the more medical data collected the more likely it would be used in an unethical way by healthcare providers, and particularly in relation to health insurance. This issue links back to the debate about autonomy and the question of ‘who finds out about your deteriorated state’ (Percival and Hanson, 2006, p.898). The participants in the Coughlin *et al.* (2007) study feared the development of technology to perform certain functions simply because it was possible rather than because it was necessary or desirable. They questioned whether ethical or value-based decisions were being taken in the design of technology, yet at the heart of these fears lies the problem of trust – this is clearly not a question of the capabilities of the technology alone, but a judgement of who decides what should be done set against the knowledge of what can be done.

3.6.3 Self-management and telecare work

If the concepts of autonomy and independence were intertwined in the literature, so too were ideas about empowerment and self-management. For some research participants, self-management through the use of technology was believed to be the key to empowerment (Finch *et al.*, 2007), and this was the only way to perceive autonomy:

Patients...enjoy the autonomy and self-care confidence that remote monitoring gives.

(Berkley *et al.*, 2010, p.3)

A number of studies concerned with this issue reported service users' enthusiastic accounts of gaining a better understanding of their conditions through home monitoring (Berkley *et al.*, 2010; Fairbrother *et al.*, 2013; Finch *et al.*, 2007; Paget *et al.*, 2010; Riain *et al.*, 2014; Rogers *et al.*, 2011; Tudiver *et al.*, 2007) and this was, to some extent, supported by responses from health and social care professionals. However, the linear narrative of knowledge leading to empowerment did not always tell the whole story. Clinicians, while encouraged by attempts to engage patients in the management of their illnesses, felt that self-management was, or in some case *should be*, limited. In the Fairbrother *et al.* (2013) exploration of telemonitoring with COPD patients, doctors observed patients actively deferring responsibility for the medical management of their condition to healthcare professionals during periods of ill health. Some put this down to a lack of acceptance on the part of patients that their illnesses were chronic and required continuous intervention for the rest of their lives. This view is supported by another study showing how patient and professional satisfaction with telehealth monitoring was high, as were adherence levels to the intervention, and visits to medical centres had decreased, and yet no discernible improvements in clinical outcomes had been detected (Riain *et al.*, 2014). Research by Rogers *et al.* (2011) concurred with Fairbrother *et al.* (2013) in their finding that self-management equated to better understanding of conditions but did not necessarily alter behaviour:

Although there were exceptions patients did not usually make independent decisions based on the readings or express the need to understand the meanings of the readings in relation to their own illness. In this respect there is little sense of the use of telecare creating empowered or activated patients.

(Rogers *et al.*, 2011, p.1081)

In fact, patients felt that the data produced by telehealth devices were mainly for the benefit of doctors and tended to 'arm' themselves with results to confirm whether or not they were feeling well and to support appeals to professionals about adjusting treatment or seeking help (Fairbrother *et al.*, 2013; Rogers *et al.*, 2011). Consequently, there was a sense that patients were carrying out work on behalf of health professionals but without the power or responsibility to take action off the back of the readings (Rogers *et al.*, 2011). For their part, practitioners felt they should be responsible for drawing up parameters for patient self-management, sharing concerns that their professional expertise could be deemed obsolete (Fairbrother *et al.*, 2013; Finch *et al.*, 2007). This was especially true of GPs, who felt that telehealth could cause fragmentation in patient care and undermine their role as generalists (Segar *et al.*, 2013). Other (non-clinician) telehealth experts saw benefits to patients in using telehealth to access services on their own terms, no longer receiving care as and when the specialist could provide it, and therefore redressing the perceived imbalance in power relations between doctors and patients (Finch *et al.*, 2007).

This issue of the redistribution of work through telecare raised different concerns in different studies. The MacNeill *et al.* (2014) research highlighted practitioners' worries that patients were being drawn into medical work. Magnusson and Hanson (2003) even reported care workers' attempts to sabotage telecare implementation

for fear that their jobs were at risk by actively failing to recruit families to use the equipment. However, this unease about different ways of working was offset by equally concerned practitioners who foresaw technological interventions causing an increase in their workload rather than making them redundant (Lyndon and Tyas, 2010; MacNeill *et al.*, 2014; Richards, 2004; Tudiver *et al.*, 2007). A frequent example was the creation of new boundaries in nursing work, where most of the responsibility for long-term condition care has been delegated over recent years (Segar *et al.*, 2013). From a practical point of view, nurses reported becoming part of a new clinical triage system whereby their roles were re-branded as telehealth or telemonitoring nurses and they responded directly to alerts as well as making decisions about action to take following abnormal readings (Segar *et al.*, 2013).

In a UK study of telehealth, which was being conducted as part of the wider Whole System Demonstrator programme, the researchers deemed concerns about increased workload unfounded but also reported that a team of 'telehealth nurses and patient support assistants' had been recruited to supplement the existing community matrons and specialist nurses (Lyndon and Tyas, 2010, p.13). A pilot study of telehealth monitoring of veterans in rural Oklahoma found that not only did healthcare professionals experience an increased workload but they also found themselves carrying out unexpected tasks – for example, a psychologist became responsible for providing technical support, troubleshooting problems with the equipment (Sorocco *et al.*, 2013). Segar *et al.* (2013) noted a certain amount of reflection from nurses about what their new roles meant for their identities as hands-on carers – some lamented the erosion of face-to-face time and the chance to engage directly with patients, while others saw their role narrowing so that they were

only involved with patients with long-term conditions. However, in another study, district and community nurses reported feeling more involved in the running of general practices after telehealth, for which they had primary responsibility, was introduced (Berkley *et al.*, 2010).

A further point about telecare work, and one that is consistently neglected in empirical research, relates to the ongoing support service users require to continue using technology in the long term. A couple of studies mentioned the value that should be placed on getting the assessment of need right and that service providers should not be complacent about follow-up processes (Evans *et al.*, 2011; Sainty *et al.*, 2009). Cook and colleagues (2013) assert that very little is known about the characteristics of telecare service users, although there is an increasing amount of information available about those using a social alarm. In their study of older people using a range of devices that were linked to a contact centre, (Cook *et al.*, 2013) found that service users who were registered disabled and living alone were the most frequent users of the telecare contact service. This finding was supported by another study included in the literature review that reported people living alone were more likely to adopt telecare in the first instance (Peeters *et al.*, 2012). Both studies noted the importance of analysing this information, as much to understand who is *not* using devices issued to them as to respond appropriately to those asking for help. Once again, the issue of non-use was highlighted as an indicator of older people's struggle with identifying as frail and vulnerable. As part of the Whole System Demonstrator programme, the rejection of telehealth after initial use was explored and a number of factors were identified as leading to non-use, including objections to the disruption to normal routine, perceptions of no discernible benefit,

the low educational attainment of the user, and overly complex systems affecting user confidence (Rixon *et al.*, 2013). The confidence of the user was certainly a factor in other studies: Odeh *et al.* (2013) reported that telehealth increased the confidence of their participants while Edwards *et al.* (2014) presented analysis identifying confidence as a key indicator of likely interest in using technology, particularly among older people.

Gramstad *et al.* (2014) make an illuminating and generally overlooked discovery that the situation in which the technology is delivered or installed is a crucial point in the process for affirming or reversing a person's positive expectations, helping them to feel competent or potentially abandoned, and ultimately impacting on the likelihood of sustained engagement with the equipment. Cook *et al.* (2013) also considered the relevance of the nature of the contacts with the telecare responders as many episodes were not emergencies but requests for access to other services, such as home repairs and pharmacy, or ongoing support and advice; suggesting that appropriate responses to these requests could be just as pivotal to 'ageing in place' as managing emergency situations. Peeters *et al.* (2012) also recommended fixed daily contact between telecare staff (usually a nurse) and service users to ensure they continue to feel supported. Further research into the everyday use of telecare and the ongoing support required by service users would surely aid better understanding of who is benefiting from the devices and how they should be targeted.

A final and crucial aspect of telecare work addressed is the role of the technology itself. Few studies considered the relationship between service users and the

technological devices. Finch *et al.* (2007) remarked how the tendency of participants to view telehealth simply as a tool for service delivery meant they considered the technology should always sit in the background – be invisible or not too obvious to the patient. The researchers contend that this perspective frames technology in efficiency terms – its primary use is as a conduit, a way to exchange information and to enable speedy access to services. What is problematic about emphasising the benefits of technology in this way is that such priorities are assumed rather than based on empirical evidence of what patients choose for themselves and there is no mention of the trade-offs that patients make, such as a reduction in direct contact with clinicians (Finch *et al.*, 2007). These assumptions also serve to exclude patients from decision-making processes in relation to the development and implementation strategies of telecare and telehealth. Finch *et al.* (2007, p.92) found:

No consistent understanding of how different priorities that patients have for their care, and for their role as patients, might be valued – this echoes a very important shortcoming within the research and policy literature concerning the place of citizens in the development and use of telehealthcare as a mode of healthcare provision.

There was evidence elsewhere that acknowledging the relationship between service users and technology is a vital step towards ensuring ongoing use of devices (Cahill *et al.*, 2007; Evans *et al.*, 2011; Wakefield *et al.*, 2008). A couple of studies reported that malfunctions or other problems with individual pieces of equipment undermined people's trust in the system and sense of security (Cahill *et al.*, 2007; Cook *et al.*, 2013). In a study testing digital annotation of physical objects with voice tagging for visually impaired people, Konttila *et al.* (2012) found that, while many participants responded well to the innovation, there were some who struggled to integrate the device into their everyday practices and were unable to think of scenarios in which

they would find the technology useful. Evans *et al.* (2011) reviewed a system of environmental sensors, alerts and pre-recorded prompts that had been installed in the very sheltered housing flat of a single tenant with moderate dementia. They concluded that the technology had the potential to support independent living, but that 'it cannot just be switched on' (Evans *et al.*, 2011, p.253). They emphasised careful assessment of need, the matching of technology to this need and training for staff and carers to enable them to support individuals with their ongoing technology use. Understanding the needs of particular users was further picked up by Percival (2012) in his study of people with sight loss and Zulman *et al.* (2014) in their paper on the challenges presented by those with multiple chronic conditions. While Percival (2012) highlights the need for practical technological solutions to routine problems, Zulman *et al.* (2014) assert that technological solutions for their participants should not be condition-specific but should support them in managing a high volume of self-management tasks and streamlining communication. Both noted the importance of staff awareness, confidence and training.

Pols and Willems (2011) found that policy promises of efficiency and access were irrelevant to patients and carers – claiming the effectiveness of certain devices was meaningless as their workings could only be understood in the context of particular practices. They emphasised the importance of understanding the adjustments service users had to make to integrate devices in their homes and incorporate them into their daily lives (Pols and Willems, 2011; Rogers *et al.*, 2011). Furthermore, they did not observe evidence of 'self' managing so much as new ways of connecting to others and 'managing together' (p.494). Devices were 'tamed' or rejected according to the circumstances involving different actors, practices and environments in which

they were incorporated. This perspective was supported by Gramstad *et al.* (2014) who reported that service users' positive expectations and optimism about a device could be dampened by unexpected outcomes, having implications for their enthusiasm for ongoing use. Ryan *et al.* (2003) conducted the only study in this review with a central focus on how best to identify potential service users by developing an algorithm to match the needs and capacities of patients with different types of technology.¹³ Participants in the programme had a 94% satisfaction rate with their primary device at 12 months post-enrolment, demonstrating the value in assessing both the needs of potential service users and their compatibility with different types of technology (Ryan *et al.*, 2003, p.86). In a related finding, Bondmass (2007) conducted secondary analysis of results from a randomized trial of telehealth monitoring of people with Chronic Heart Failure (CHF). She extracted data from African American participants only – recognised as generally under-represented in clinical research studies, and having worse outcomes than ethnically white patients following a CHF diagnosis – and noted that not only were health outcomes of those within this ethnic group improved with the use of technology but that they reported higher satisfaction rates than other ethnic groups. Bondmass (2007) concluded that this was a significant finding given the correlation between satisfaction and compliance with medical regimen – a known challenge with CHF management, and particularly so among African American patients. This study further shows the importance of a nuanced approach to technology implementation.

¹³ (Dafydd *et al.*, 2009) mentioned use of an algorithm to ascertain service users' telecare 'prescription' based on self-assessed need but this approach was not subject to further analysis or discussion in the paper.

3.7 *Summary*

This literature review has been concerned with empirical research into telecare and telehealth, as described by a number of different terms discussed earlier in this chapter. Although the inclusion/exclusion criteria were designed to focus the review, the studies included revealed a range of research questions that were difficult to group into distinct categories – this was partly due to the field attracting interest from a variety of disciplines. Studies were discussed based around their adherence to three broad themes: evaluations of effectiveness, ethical issues, and the impact on self-management and telecare work. In the previous chapter, the Whole System Demonstrator (WSD) programme was discussed as a response to poor quality and small-scale evaluations. The WSD faced its own criticisms when the reporting of results was subjected to lengthy delays and findings that were reported did little to ascertain a coherent argument in favour of telecare and telehealth. The evaluation studies reviewed in this chapter similarly reflected a lack of clear evidence for the benefits of technology, either in terms of cost-effectiveness or in relation to improved quality of life for service users. Equally, questions should be raised about the use of ‘satisfaction’ data as what constitutes satisfaction is rarely explained in studies and this may not be the best measurement of how service users feel throughout their engagement with the service delivery process or indeed over long-term use.

Studies considering organisations and barriers to implementation highlighted infrastructure and organisational culture, as well as a lack of information and awareness among key staff, as potential obstacles for widespread implementation of technology. There was also concern about the translation of the policy agenda

into local practice, where national priorities may appear to be misaligned with local ones. The policy agenda was further questioned by studies challenging the population ageing narrative through ethical arguments against the deficit model of ageing. Other ethical debates pertained to the relationship of technology with autonomy and coercion, and the impact on privacy and safety. Finally, research on telecare for self-management and telecare 'work' was discussed, demonstrating equivocal results for the ability of technology to improve users' ability to self-manage. The issues of telecare 'work' were largely considered from the point of view of the professionals, with studies reporting that technology implementation often changed the nature of the work carried out by health and care professionals. Where the activity of service users was discussed it was concluded that insufficient attention has been paid to the relationship between people and the technology they use and little is known about the work carried out by service users to embed technology into their practices.

3.7.1 Contributions to the research questions

Returning to the research questions, there are a number of issues discussed in the literature that contribute to answering the research questions. Combined with the policy background outlined in Chapter 2, the literature gives a good indication of the public purposes of telecare and aspirations for the service. It suggests that there is a policy desire to achieve multiple goals through technology – drawing on several narratives about the future of care and health services relating to tackling demographic challenges, maintaining people outside of acute services and reducing budgets. The intentions for telecare services are to promote independence and self-

management whilst also cutting costs to public services and reducing the work burden on professionals and informal carers.

In relation to the key concepts at the heart of the research questions, the literature points to the multi-interpretability of terms such as ‘independence’ and ‘empowerment’. Many studies that explicitly discuss telecare with respect to the relationship with independence couch the debate in ethical terms, questioning the impact on autonomy. Equally, discussions of empowerment are associated with the ability of an individual to self-manage their condition at home. In navigating these interpretations the literature becomes aligned with the policy narrative detailed in Chapter 2 and subsequently raises questions about how far this understanding of independence and empowerment reflects the aspirations of service users.

3.7.2 Gaps in knowledge and implications for this study

What the literature does not tackle is the question of who is benefiting from the technological turn, and this has implications for understanding whether aspirations are realised in practice, whether telecare can be considered empowering and if telecare practice is fit for purpose. Discussion in the literature about telecare work is pertinent to the research questions as studies demonstrated that the nature of work carried out by professionals changed with technology implementation. However, investigations did not consider whether changes to practice supported or undermined the policy purposes of promoting independence and empowerment. Some studies in this review called for a better understanding of the characteristics of telecare users, where a lack of longitudinal data has made it difficult to ascertain the long-term use of equipment that is not being regularly monitored. Here it is clear

that differentiation needs to be made between types of devices and yet, as a whole, equipment studied was implemented on a condition-specific basis and little attention has been paid to comparing different devices in different circumstances. With the exception of a notable handful of studies, there appeared to be little acknowledgement of technological innovations as complex interventions that require various responses and impact people differently, resulting in multiple challenges as well as potential benefits. The implementation of devices as ‘fixers’ or ‘problem solvers’ when faced with a particular situation was prominent and in general, the views of patients or service users were bound up in reports of ‘satisfaction’ with equipment that did not get to the heart of the individual experience.

In particular, this review (along with the policy discussion in Chapter 2) has revealed that perspectives on independence – particularly in relation to autonomy – and empowerment, as linked to self-management, tend to cluster around research involving older people and there has been very little work in a similar vein on, for example, people with learning disabilities. It is clear that ‘independence’ is an aspiration of telecare but what this term means for different people has not been sufficiently explored in relation to telecare. Equally, few papers addressed the subject of equipment being issued under different conditions – such as the impact of technology as *additional* support for some alongside its implementation as a *replacement* for usual care for others.

Despite including in the literature search the keywords ‘policy’ and ‘practice’ the relationship between the two was not the subject of lengthy discussion in the studies in this review. A handful of papers focusing on the debates around demographic

challenges, integrating health and social care and the economic crisis considered the implications of these policy preoccupations for care involving technology. However, fewer still considered the roles of different stakeholders both within and beyond the boundaries of health and social care in setting the agenda at a local level. Moreover, there was no consideration in the literature of service user involvement in the formal decision-making processes around telecare.

Thus, whilst contributing to answers to the research questions, the academic literature has also highlighted some gaps in knowledge that this study aims to address. These can be framed in broad terms as a need to provide a more nuanced account of the telecare experience that considers a variety of perspectives and the relationship between policy and practice.

As noted earlier in this chapter, the field has been criticised for engaging only modestly with theory in research and this study aims to address this issue by offering a theoretically-informed inquiry, contributing to a small but growing body of literature represented in this review that is informed by phenomenology, the sociology of health and illness, and science and technology studies (STS). In the following two chapters, the methodology and methods adopted to fulfil this aim are detailed; and, firstly, the specific theoretical framework underpinning this research – informed by two complementary approaches – is presented. This establishes an ontological position that influences the perspective on data analysis and the discussion of findings in relation to the research questions. The case is made for an argumentative discourse analysis and reconceptualization of technology in order to understand the policy and practice of UK telecare.

Chapter 4 Conceptualising telecare policy and practice

4.1 Introduction

One of the stated aims of this research is to contribute to the field of telecare and telehealth research by advocating – and developing – a more theoretical approach to studies of these technological interventions. Prior to focusing on the research design, methodology and associated methods for data collection in Chapter 5, here I establish the ontological position that underpins the research and detail the theoretical framework that has been adopted. The chapter introduces the argumentative analytical frame proposed by Maarten Hajer (1995), and Nelly Oudshoorn's (2011) material-semiotic approach to telecare analysis, both of which have provided a theoretical basis for analysis of the data from this study. It demonstrates how an interest in narrative inquiry has led to the application of these complementary interdisciplinary analytical techniques in a bid to address the complexity of the issues raised by the research questions.

4.2 An argumentative approach to discourse

Hajer's (1995) exploration of contemporary environmental policy led him to develop an 'argumentative' analytical framework for the study of political processes. In the context of the post-positivist interpretative tradition, Hajer proposes a social constructivist discourse analysis to investigate why particular understandings of environmental problems gain dominance while other understandings are discredited. This highly adaptable approach can be applied across disciplines to analyse how complex policy problems are represented, their differences are played

out, and 'social coalitions on specific meanings somehow emerge' (Hajer, 1995: 44). Discourse is not simply viewed as synonymous with discussion – different, competing discourses may be apparent in a particular discussion (Hajer, 2009) – rather it is defined in ontological terms as 'a specific ensemble of ideas, concepts, and categorizations that are produced, reproduced, and transformed in a particular set of practices and through which meaning is given to physical and social realities' (Hajer, 1995: 44). In his later re-working of this definition, Hajer (2009: 60) includes the term 'notions' to distinguish less rational or cognitive categories that ascribe meaning to phenomena, such as 'things reiterated through stories, metaphors, or catchphrases'. A discourse refers to the concepts that structure contributions to a discussion, therefore a discourse *analysis* illuminates a particular discursive structure in a discussion (Hajer, 2006).

Hajer (1995) grounds his analytical framework in Foucauldian concepts of power and the 'discursive order' that focus on the interaction between agency and structure, whereby discourse is perceived as a set of regulated practices that make it function as a structure to behaviour within which the discoursing subject operates and forms his or her own ideas. In this light, discourse can be both enabling and constraining but it is not to be seen as a medium through which individuals can manipulate the world – power is constituted through the constant reproduction of a dominant discursive position, which has been legitimised by the rules inherent in discursive practices (Hajer, 1995). Foucauldian approaches have been criticised for failing to explain how discourse influences people to act in a prescribed way; and to account for why certain discourses are adhered to while others are not (Alvesson and Kärreman, 2000; 2011). Similarly, the influence of Foucault's historical

arguments on his discourse theory and his structuralist approach seem to emphasise the constraining, rather than enabling, aspect of discourse, and eliminate the role of individual strategic action (Hajer, 1995; Kärreman, 2014). Here, Hajer (1995) identifies a conceptual gap in Foucauldian theory, which he seeks to address by introducing the a priori thinking subject and the role of argumentation in discourse formation. Further drawing on social interactionist theories, Hajer (1995) highlights the importance of recognising the argumentative nature of human interaction, particularly in relation to political controversies. Actors put forward contradictory suggestions of how to make sense of reality and seek to persuade others of their discursive positions, thereby becoming active, dynamic subjects in the production and transformation of discourse (Hajer, 1995). Discourse analysis can then be seen as an exploration of 'how a particular framing of the discussion makes certain elements appear as fixed or appropriate while other elements appear problematic' (Hajer, 1995: 54).

The argumentative approach illuminates the struggle for discursive hegemony, in which actors try to secure support for their definition of reality (Hajer, 1995). The capacity of a discourse to achieve domination will depend on its credibility and acceptability, as well as on trust in the author or practice that gave rise to this definition of reality. Its success may be judged by the appearance of discourse structuration, i.e. if the credibility of actors depends on usage of the ideas and concepts of a given discourse; and of discourse institutionalisation, i.e. the translation of discourse into institutional arrangements, such as changes in investment or departmental restructures (Hajer, 1995). To demonstrate how discursive orders are maintained or transformed, Hajer (1995) presents two middle-

range concepts: story-lines and discourse-coalitions, to enable the analysis of complex policy problems such as the phenomenon of acid rain. This particular environmental issue demonstrates the convergence of interdisciplinary knowledge where comprehension of the complexity of the issue requires an understanding not only of the ecological factors but also of economic considerations, abatement techniques, social repercussions, and ethical concerns, meaning any single unified, natural scientific discourse would prove an unsatisfactory explanation (Hajer, 1995). The variety of actors from different domains required to come together to tackle the issue defines acid rain as an inter-discursive issue and in need of an analytical approach that taps into its multi-interpretability.

This is resonant of telecare and telehealth policy, which also features an incoherent discourse resulting from multi-disciplinary viewpoints. Hajer (1995) identifies inter-discursive problems as those where few actors understand the issue in its entirety but knowledge becomes politically relevant once it is transcribed to a higher discourse, leading to the need to constantly reproduce arguments in different ways, for example utilising scientific findings in non-scientific discourse. It is at this point where generative metaphors are utilised to provide common ground between discourses (Schön, 1993). Metaphors give actors an opportunity to create their own understanding of the problem – they process and potentially reinterpret knowledge outside of their own expertise, filling gaps in their understanding to achieve ‘discursive closure’ by reducing complex research into pithy soundbites (Hajer, 1995). Metaphors allow the understanding of one thing in terms of another – such as the ‘war on drugs’ invoking ‘war’ to show serious commitment on the part of the political leadership (Hajer, 2009). The acid rain problem can be deemed to function

as a metaphor and be emblematic of how a general understanding of environmental issues is constructed: 'As an emblem [acid rain] had a central role in facilitating much more than a "mere" change in policy: it brought about a larger conceptual shift' (Hajer, 2006: 68-69). A similar shift in concept is apparent in the volume of policy papers that refer to the transformation of the UK social care system. In this light, the technological turn in care, which is proliferated across policy papers and government reports, can be viewed as emblematic of a fundamental change in expectations about social care. Furthermore, an example of discursive closure can be seen in the publication of results from the Whole System Demonstrator programme (WSD). While the complexity of analysing data gathered from multiple sources through mixed methods has been publicly recognised by the research teams involved in the trial, the UK Government has insisted that the debate around telecare and telehealth can 'move on' from the quest for further robust evidence now that positive yet truncated headline findings have been revealed, reducing the world's largest randomised control trial of this technology to a series of percentages relating to mortality and hospital admission rates.

4.2.1 Story-lines

The simplification of the argument for telecare and telehealth has undoubtedly led to a loss of meaning and the potential for multi-interpretability but argumentative discourse theory holds that just such conditions are required for regulation, and it is the story-lines of the discourse, when understood as metaphors themselves, that determine how regulation occurs. Hajer (1995) describes story-lines as narratives of social reality that combine elements from different domains to provide actors with

symbolic references that suggest a common understanding. This is in keeping with Foucault's idea of the 'tactical polyvalence of discourses' enabling apparently contradictory discourses to cohere at the level of a grander strategy (Bingham, 2010). Story-lines work metaphorically referring to wide and complex debates through simplified narratives, emblematic topics, buzzwords and other reductive discursive devices. By referring to these symbols the story-line as a whole is invoked, overcoming fragmentation in the argument and reducing complexity to achieve discursive closure. As particular story-lines become accepted by actors they are utilised more and gain a sense of permanence, becoming tropes that rationalise specific approaches and make a problem appear coherent (Hajer, 1995). Storylines provide narratives that can disguise contradictions and voids of understanding, allowing actors from different domains to envisage how they fit into the jigsaw and stimulating discussion and action where it otherwise may not take place (Bingham, 2010). This can also have the effect of legitimising policy-makers by disguising incomplete arguments and institutional biases (Hajer and Versteeg, 2005). Nevertheless, Hajer (2009: 62) cautions against viewing the use of story-lines and metaphors as a cynical approach to politics – rather actors with different frames of reference can be brought together to produce meaningful political interventions: 'the multi-interpretability of metaphors and story-lines is a vital aspect of their political efficacy'.

In addition to 'discursive closure' other mechanisms are apparent in operational story-lines. 'Black-boxing' refers to an actor's ability to place beyond question and reconsideration certain 'modes of thought, habits, forces and objects' making them appear fixed, natural or essential (Callon and Latour, 1981). In a similar vein, Hajer

(1995) detects the ‘mobilisation of bias’ to refer to what is strategically included or omitted in discourse. In another area of public policy Feldman *et al.* (2004) employ two concepts drawn from semiotics and rhetoric – opposition and enthymeme – to the same effect. Here Feldman *et al.* (2004) draw attention to the elements of a story that derive meaning from what they are implicitly contrasted with, what they are not (opposition), and the use of argument or syllogism where the premise is missing but is nevertheless inferred (enthymeme). The persuasive quality of the enthymeme is that the audience of the argument supplies some of the information – the taken-for-granted assumption that connects the given information rendering the overall argument complete (Elston, 2014; Feldman, 2004). Actors will adhere to particular story-lines as a result of ‘discursive affinities’, a mechanism for explaining arguments that may vary in origin but still have a similar way of conceptualising the world and appear to present a certain amount of coherence (Hajer, 1995). An example from pollution politics is the discursive affinity between the moral argument about respect for nature, the scientific argument about the complexity of ecosystems and the economic thesis that pollution prevention is the most efficient mode of production (Hajer, 2006). Although these arguments are different they have a similar cognitive and discursive structure that suggests they belong together (Hajer, 1995). This mechanism can be extended with attention to linguistic practices as highlighted by Fairclough’s (2003) analysis of discursive differentiation. Fairclough (2003: 88) argues that ‘the “work” of classification is constantly going on in texts, with entities being either differentiated from one another, put in opposition to one another, or being set up as equivalent to one another’. Differentiation or the collapsing of differences between discourses is therefore not only implied through the formation

of story-lines but is also apparent in texts through the identification of the contrastive ('but', 'however') and additive ('and', 'which') relations within and between discursive units (Elston, 2014; Fairclough, 2003).

The power of the story-line, therefore, lies in the idea that essentially 'it sounds right' (Hajer, 2006: 69). To this end, actors may resort to three discursive tactics to support their argument: credibility (whether or not the argument is plausible and the author has authority), acceptability (whether the position presented is either attractive or necessary), and trust (whether there is enough confidence in the author or practice to suppress doubts and inherent uncertainties) (Hajer, 1995). This is not dissimilar to the Aristotelian theory of argumentative interaction, which holds that influence is determined by *logos* (the persuasiveness of the case), *ethos* (the credibility of the speaker), and *pathos* (appeals to the emotions of the audience). However, people often use story-lines as 'short hand' for complex narratives with the assumption that the hearer will understand what is being inferred and receive the intended message, yet discourse analysis habitually reveals the assumption of mutual understanding to be wrong and actors frequently talking at cross-purposes (Hajer, 2006). Nevertheless, this lack of understanding can still produce meaningful political coalitions, as outlined in Hajer's second middle-range concept of discourse-coalitions.

4.2.2 Discourse-coalitions

It is the argumentative struggle for discursive hegemony that leads to the formation of coalitions among actors who, in actuality, may perceive their position according to widely different discourses (Hajer, 1995). A discourse-coalition refers to 'a group

of actors that, in the context of an identifiable set of practices, share the usage of a particular set of story-lines over a particular period of time' (Hajer, 2006: 70). This ensemble of actors, story-lines and practices operate beyond the institutional contexts within which actors are situated – those involved need never have met and their adoption of common story-lines may not be based on the same fixed beliefs or interests but the practices in which those story-lines are produced and reproduced provide the context within which discourses gain traction. Thus, discourse-coalitions are not connected to a particular person and therefore allow for actors making utterly contradictory statements within them (Hajer, 2006). Analysing discourse by means of coalition formation has three main advantages (Bingham, 2010; Hajer, 2006):

- It provides the context for, and bridges understandings between, the strategic action of subjects and resultant practices while connecting specific policy problems to broader political debates.
- It takes the explanation beyond mere reference to interests, analysing how interests are played out in the context of specific discourses and organisational practices, enabling an examination of, for example, compromise and co-option.
- It illuminates how different actors and organisational practices mobilise around specific biases, either strategically or unintentionally and without necessarily sharing deep values.

Through discourse-coalitions, the 'problem' narrative can be constructed whereby particular aspects of reality are portrayed as harmful (even if it is not self-evidently so) and yet amenable to diagnosis and treatment through 'solutions' that compliment

the dominant discourse (Hajer and Wagenaar, 2003; Atkinson *et al.*, 2011) To illustrate this argumentative framework in telecare terms, one must look to the broader social care narrative influencing the telecare debate. As stated above, developments in telecare and telehealth can be seen as a response to the wider challenges facing social care, largely as a result of an ageing population and the economic crisis. Telecare is promoted as a way of supporting people to stay as independent as possible, preferably in their own homes, and as an enabler of self-management, reducing people's dependency on state-funded care. In this way, the turn towards technology can be seen as emblematic of the transformation of social care and a 'solution' to this policy 'problem'.

It is worth noting at this point that in a recent paper on telecare and telehealth discourses, Greenhalgh *et al.* (2012) partly employed Hajer's framework to identify four macro-level discourses that contribute to the organising vision of telecare and telehealth. These were termed modernist (technology-focused, futuristic, utopian), humanist (person-centred, small-scale, grounded in present reality), political economy (critical, cautious of vested interests) and change management (recognising complicatedness but not conflict) (Greenhalgh *et al.*, 2012). These discourses were overlapping although conflicting and they engaged only minimally with one another's arguments. Greenhalgh *et al.* (2012) focused on analysis of key documents and have undoubtedly provided a valuable initiation into the use of discourse analysis in this field, something that has not been applied to telecare research previously. Nevertheless, this study asserts that a focus on the narratives of key stakeholders of telecare will reveal the telecare debate itself to be best understood as a discourse-coalition encompassing a number of story-lines that may

have multiple interpretations but nevertheless achieve discursive affinity. Identification of these story-lines will show how telecare discourse is being interpreted by different actors through (and within) different practices, enabling the research to look beyond the purely technical test of whether or not telecare is effective to answer the research questions:

- What are the public purposes of telecare provision and whose needs does it meet?
- What are the aspirations for telecare and are these realised in practice?

4.3 Reconceptualising technology

A focus on discourse is also the starting point for Nelly Oudshoorn's (2011) research on the changes in healthcare implicated in telecare technologies. In her book, *Telecare Technologies and the Transformation of Healthcare* (2011), Oudshoorn argues that the development and promotion of telecare has sprung from the intersection of a number of discourses that have generated a 'political economy of care' (2011: 13) which has allowed for the proliferation of a specific (unhelpful) view of healthcare and technology. She identifies these as:

- The discourse on an increase in chronic diseases due to an ageing population.
- The discourse on the modernisation and rationalisation of healthcare work.
- The discourse on the neo-liberalisation of healthcare.

The first discourse asserts the notion that the financial burden on health and social care is increasing, and becoming potentially unmanageable, because of demographic changes. The second subscribes to the view that telecare and other forms of technology will rationalise health and care work and make it more efficient. The third discourse serves to redefine healthcare as a market driven by individual demands and the ability of citizens to pay for services – recasting patients as consumers and medicines as commodities (Oudshoorn, 2011). It also perpetuates the view that healthcare is a personal responsibility of citizens and that individuals should be expected to take increased responsibility for their own health. In this light, telecare becomes an instrument to support the liberalisation of health and social care and is represented as serving narrow economic interests, taking no account of other changes (Oudshoorn, 2011).

As a counter-argument to these discourses, Oudshoorn (2011) takes a material-semiotic approach to framing technologies as socio-cultural agents:

Not as tools that solve problems but as actants that transform them by redefining the nature of the problem and the identities of the people and objects considered relevant to solving the problem.

(Oudshoorn, 2011, p. 18).

The transformative quality of the technology is not inherent – as with Hajer's (1995) view on discourse, actants (both human and non-human actors) do not have intrinsic, pre-ordained qualities that are defined once and for all, rather they acquire their characteristics through the socio-cultural dynamics of the networks in which they are supposed to act (Oudshoorn, 2011). Technologies work when they are embedded in heterogeneous networks in which people, organisations, knowledge,

skills, and technological devices interact to produce a specific practice of work or, in the case of telecare, a practice of care (Oudshoorn, 2011). The material-semiotic view is often associated with actor-network theory (ANT) and the work of Michel Callon, Bruno Latour and John Law (see for example, Callon and Latour, 1981; Latour, 2005; Law, 2009). ANT is a notoriously difficult concept to summarise¹⁴ but the key influence of ANT on Oudshoorn's approach is an adherence to semiotic relational materialism – both people and objects have agency and interact continuously according to the actions, competencies and responsibilities that have been delegated and redistributed among them (Law and Mol, 1995; Oudshoorn, 2011). This signals a move away from an instrumental view of technology to one that acknowledges the presence of socio-technical networks that are ongoing processes made up of uncertain, fragile, controversial, and ever-shifting ties, which are nevertheless constantly performed to create interdependencies between people and technological devices to the extent that they define each other mutually rather than create causal relationships (Latour, 2005; Law, 2009; Law and Mol, 1995; Oudshoorn, 2011).

A material-semiotic perspective is helpful for the second part of this research which focuses on the roles, practices and processes involved in the telecare service. The research questions directed towards this aspect of the study are:

- Is telecare practice fit for purpose, where the avowed purpose is to promote independence?

¹⁴ John Law (2009: 142) issued his own health warning about explanations of ANT: 'Beware...of any text about actor network theory that pretends to the objectivity of an overall view.'

- How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making.

There are three aspects to Nelly Oudshoorn's work that provide particularly valuable perspectives from which to analyse the findings in relation to these research questions – one is the attention to user-technology relations; another is the importance of place in health and care provision; and the third is a focus on the distribution of work and resultant creation of new roles.

4.3.1 User-technology relations

The semiotic approach to theorising the relationship between users of technology and the devices themselves has led to the concept of 'script' being developed to explain how technological objects enable or constrain human relations as well as the relationships between people and things (Akrich, 1992; Oudshoorn and Pinch, 2008). Madeleine Akrich (1992) suggests that technical objects define a framework of action together with the actors and the space in which they act. It is in the design phase that technologists anticipate the interests, skills, motives and behaviours of future users, thus materialising these representations into the design of the device (Oudshoorn and Pinch, 2008). This results in the technology containing a 'script' that pertains to the actions, competencies and responsibilities that have been attributed to the users and objects alike (Akrich, 1992). It is important to note here that the script does not amount to a technological determinist view, rather the reciprocal relationship between people and objects is emphasised, capturing the active role of users in shaping their relationship with technology (Oudshoorn and Pinch, 2008). Users demonstrate tactics for rejecting or renegotiating the prescriptions of the script

– for example, a seatbelt is designed to restrain the user but an individual has the capacity to refuse to wear it or subvert the intention behind it by jamming a piece of metal into the lock to fool the car into thinking the belt has been attached (Oudshoorn and Pinch, 2008). Pols and Willems (2011) further focus on the reciprocal nature of the relationship by considering how telecare is ‘tamed’ – tinkered with to fit the practices of users – and ‘unleashed’ to affect care practices in unforeseen ways. This makes the behaviour of users and technology hard to predict as ‘although technologies may be good at some things rather than others, their workings can only be understood in the context of their use in particular practices’ (Pols and Willems, 2011). These practices form part of the process of technological ‘domestication’ but Pols and Willems (2011) argue that it is too early in the life of many of these telecare technologies to consider them domesticated.¹⁵

4.3.2 Multiple sites of care

As scripts of technology are important for understanding the pre-structuring of human action, so too are places as the contexts for use that have been inscribed in the technologies (Akrich, 1992). Places are also important as they may shape how technological devices are used, or not, and (de)stabilise the specific identities of technology (Oudshoorn, 2011). For their part, technologies can redefine the meaning and practices of the spaces in which they are used. The changing landscape of health and care has seen a shift from institution to what has been termed ‘extitution’, putting greater significance on the home as a site of care and

¹⁵ Pols and Willems (2011: 485) define a domesticated technology as ‘a technology that is widely used, and that has a recognisable repertoire of (culture-bound) uses, such as computers and mobile phones have.’

raising questions about how these care arrangements may reconfigure people's relationship with their home (Milligan, 2009). The concept of 'ageing in place' has sought to demonstrate how home-based care can place more power in the hands of the person receiving services, and this has certainly been promoted as an attractive selling feature of telecare and telehealth (Milligan, 2009; Oudshoorn, 2011). However, as Christine Milligan's (Milligan, 2009, 2001) work has argued, the blurring of boundaries between the home and institution can change how people experience and view their homes as the interior is rearranged to make way for care aids and adaptations, and the previously private sphere becomes a site of work for formal and informal carers, as well as for the individual in their 'role' as care-recipient.

Milligan and others (Milligan, 2009; Mort *et al.*, 2008; Oudshoorn, 2011) argue that the shifting landscape of care should be analysed within a 'relational framework' in which the practices of care-givers and care-recipients are viewed in relation to the sites of care – places and practices are inextricably linked. When adding in the dimension of technology, Oudshoorn (2011) further posits that the use of telecare and telehealth, particularly in relation to managing chronic conditions, signifies not just a shift in the location of healthcare work but also a partial delegation of medical work from experts to patients: 'telecare technologies make patients active in "gazing into their own bodies"' (Oudshoorn, 2011: 7). Telecare creates a distinction here between the 'work' of care professionals and the 'work' of patients – the latter cannot simply be framed in terms of performing tasks as the use of technological devices in a medical sense transforms the relationship between the individual and their body, placing expectations on them to become more active and responsible as participants in the management of their condition (Oudshoorn, 2011). Telecare technologies

have a disciplining effect on individuals – integrating them into a network of care that guides and restricts their actions and binding them to inspect their bodies through activities that are sold as liberating but are in fact controlled by care professionals and the technological devices themselves (Oudshoorn, 2011). Moreover, while the inspection of bodies may take place at home, the results of this act can be distributed across a large network of actors and locations, for example, a telehealth vital signs monitor may transfer data to specialist departments and laboratories in hospitals; at the same time this data may also be held in a purpose-built telehealth centre to be seen by newly-created telehealth professionals before a decision is taken to pass the data on. Therefore, it would seem misleading to depict the home as an isolated, independent site of healthcare when it is practically and materially integrated by technology with acts of care at hospitals, GP surgeries, laboratories and telehealth centres (Oudshoorn, 2011). The changing landscape is not about moving care from one site to another, it is an acknowledgement of the dispersal of activity across many sites and actors.

4.3.3 Multiple actors and invisible work

Oudshoorn (2011) asks ‘who cares’ when telecare forms part of healthcare provision? It is a pertinent question when telecare implies multiple sites, multiple actors and multiple technological objects. According to the neo-liberal discourse, acts of care are no longer seen as the domain of doctors and nurses alone – rather patients are expected to play an active role in their own care, making use of telecare devices to perform tasks previously delegated to healthcare professionals, such as taking blood pressure (Oudshoorn, 2011). In social care arrangements home care

or warden 'checking' visits may be replaced by recorded voice prompts from medication dispensers or pendant alarms linked to a community alarm service. Furthermore, the representation of telecare reducing human labour as work is partly delegated to technological devices can be viewed as problematic as it makes invisible the work involved in operating this technology (Oudshoorn, 2008). Work does not disappear, rather it is redistributed among a variety of different actors. Studies (Cartwright, 2000; Mort *et al.*, 2003) have shown how the introduction of telecare devices in clinic settings has led to a redistribution of interactional work away from doctors to nurses and patients. New categories of professionals are created to support and manage telecare provision, be it in the form of specially trained nurses or healthcare workers who monitor and manage data from telehealth devices or call centre staff to respond to a pendant alarm, or even technicians charged with ensuring equipment is fully functioning. Some of these new roles are not only outside the traditional health and social care infrastructure but also point to a potential de-professionalisation of telecare work by failing to stipulate a requirement for any formal health or social care training.

The proliferation of telecare work is distributed far and wide as actors become involved in health and social care from positions largely outside of this realm, for example other frontline services, such as the fire service, which are expected to identify and refer individuals for telecare whilst carrying out their core work. This creates novel interdependencies between old and new actors in health and social care, which is particularly apparent where private sector players such as manufacturers and suppliers are intervening in spaces that used to belong exclusively to the public sector (Oudshoorn, 2011). The discussion about the

interplay between the public and private sectors in healthcare is not unique to technological interventions – a fleeting look at current debate about new NHS proposals would confirm that – and private industries, such as pharmaceuticals, have always played a prominent role in healthcare, but the telecare industry is now carving out a new role in the health and social care landscape, that of running fully managed and networked systems where employees of the device manufacturer may become first responders to a distressed person raising the alarm. This disrupts the order of care because it intervenes in long-established care pathways – newly-created roles in telecare and telehealth are not entering an uncontested space, they are likely to experience resistance to their work and their acceptance as new actors in healthcare (Oudshoorn, 2011).

A final word on work distribution should be said in the context of implications for gender roles. Oudshoorn (2011) refers to feminist studies that show how the well-evidenced gendered hierarchy in healthcare could lead to women shouldering the major responsibility of the redistributed workload that the introduction of technology enacts. Furthermore, as the primary providers of informal care work, telecare could leave women with a new responsibility for their own health whilst maintaining the need for them to continue taking care of loved ones. This perspective sheds an intriguing light on the findings from this study as telecare practice at the case study site had led to the creation of two distinct new roles in telecare work – the telecare assessor and the telecare technician – which appeared to reinforce gendered work practices in the way that they were recruited for and portrayed within the telecare team. Viewing these roles through a gender lens could also provide insight into the

'visibility' of the work carried out and the implications of particular working practices on the success of the telecare service.

4.4 Summary

This chapter has laid out the ontological position that has brought together two different but related theoretical frames that underpin the approach to data analysis in this study. A narrative inquiry has led to a focus on discourse-coalitions and story-lines in a bid to understand how public policy on telecare and telehealth has been interpreted by different stakeholders, and how far the aspirations of those directly involved in the service are realised in practice. Analysis then takes a material-semiotic turn as focus moves away from discourse to telecare practice and an investigation into the complex interactions and creation of multiple interdependencies between people and technological objects, which results in new and redistributed work in the name of telecare. The semiotic frame enables examination of whether telecare practice is fit for purpose and how far service users are involved in decisions about their care. Taken together, these perspectives demonstrate how the technological turn in health and social care is proving transformational, but not necessarily in a way that is intended.

The thesis now moves from the theoretical to the practical, detailing the empirical research that operationalises the frameworks presented in this chapter. In the next section, the design, methods and methodology employed to address the research questions are explained, and the approach to selecting the case is discussed.

Chapter 5 Case study design and methods

5.1 Introduction

Having established the theoretical position that underpins my approach to this research and the analytical framework that has directed my consideration of the data, in this chapter I will discuss my chosen methodology, the design of my research and the methods selected to facilitate data collection. This includes reflections on the role of my PhD funding – how this has influenced not only the outline and agenda of my project but also decisions about my approach to the study throughout. This chapter is deliberately written in the first person to acknowledge my role as a researcher in making decisions about the approach to this study.

5.2 Choosing case study research

There are some compelling features of case study research. A key strength of this method is in the ability to use a variety of data collection methods to provide a rounded and holistic study. Case studies provide a flexible research design that, when performed with intellectual rigour, offer the strengths of experimental research within natural settings (Hakim, 2000). Indeed, as Yin (2014) explains, it is imperative for a case study to be examined at the holistic level and not viewed merely by its constituent parts, as the whole will be more revealing than the sum of its individual elements. The real value of case study research is the opportunity, through in-depth study, to explain how and why certain outcomes occur – the relationships and processes involved – rather than just discovering that they do occur (Denscombe, 2010). There is a commitment in case study research to avoid artificial settings

where situations are generated for the purposes of the researcher (Denscombe, 2010; Yin, 2014). The case study method has the ability to encompass important contextual conditions that are highly pertinent to the understanding of the real-life phenomenon under scrutiny (Yin, 2014).

Yet, there is a history of defensiveness in the appraisal of case study research:

Despite its apparent applicability in studying many relevant real-world situations and addressing important research questions, case study research nevertheless has not achieved widespread recognition as a method of choice. Some people actually think of it as a method of last resort.

(Yin, 2012, p.5)

Yin's observation is particularly evident in the physical sciences and medical research, where the concepts of objectivity and research hierarchy deem systematic reviews and randomised controlled trials to be the 'gold standard', with qualitative approaches further down the chain (Glasby and Beresford, 2006). This attitude has long been infiltrating the social sciences, notably in areas of health and social policy where the politics of 'evidence-based practice' has dominated approaches to research, placing the pursuit of evidence of 'what works' and value for money at the heart of perceived good research practice (Glasby and Beresford, 2006). As Glasby and Beresford (2006, p. 269) point out, 'who could possibly argue that what we do in public services should not be based on what we know to work?' And indeed, the responsibility to enable public funds to be channelled as efficiently as possible weighs inexorably on the mind of the public policy researcher. Nevertheless, this narrow focus on what constitutes 'evidence' can serve to distort the evaluation of 'good' practice by privileging the (scientifically-informed) academic insight over the

views and experiences of those who work in and use health and social services (Glasby and Beresford, 2006).

The case of telecare presents as indicative of how the drive for evidence-based practice at a time of great financial pressure on public services has turned the focus of research in this area firmly towards providing proof of concept and evidence of cost effectiveness, whilst relegating the perspectives of professionals, service users and families to be recorded simply as supporting or anecdotal evidence. The controversial and inconclusive results from the Whole System Demonstrator (WSD) programme, discussed in Chapter 2, further point to the potential pitfalls of experimental methods that control for context, ignoring the impact of political agendas on research (Greenhalgh, 2012). The complex study has been beset by accusations of a conflict of interest by the Department of Health, which funded the project and appeared to pre-empt the analysis of data by declaring its commitment to telecare and telehealth (Department of Health, 2012b) prior to the publication of results (Greenhalgh, 2012; Kidholm *et al.*, 2014).

Greenhalgh and Russell (2010) call for a move away from viewing technological interventions such as eHealth as the domain of scientific testing to a critical-interpretivist approach that allows for a social practice view of evaluation whereby the researcher actively engages with the social context and continuously reflects on the values, relationships and meaning-making that impact on practice:

eHealth “interventions” may lie in the technical and scientific world, but eHealth dreams, visions, policies, and programs have personal, social, political, and ideological components, and therefore typically prove fuzzy, slippery, and unstable when we seek to define and control them.

(Greenhalgh and Russell, 2010, p.1)

Greenhalgh and Russell (2010) offer an alternative set of principles for eHealth evaluation that encourage reflexivity in terms of the role of the researcher as well as the individual, meso-level and macro-level contexts that will have a bearing on the outcome of the technological intervention (Greenhalgh and Russell, 2010). The positivist preoccupation with 'what works' has also led to a preponderance of atheoretical studies published in the telecare and telehealth field. This was discussed in Chapter 3 in relation to a study by Gammon *et al.* (2008), who argue that research in healthcare technologies demonstrates a woeful lack of engagement in theoretical concepts, making it difficult to establish itself as a distinct research field. It would seem therefore that, rather than being the poor relation of RCTs, a well-designed case study can rise to the challenge posed by academics in the field of healthcare technologies to engage in context-aware research that tests or builds theory in a bid to understand how and why certain outcomes result from technological interventions in health and social care. The details of the research design for this study are now explained below.

5.3 Research design

This research has been designed as a case study involving a single case site. The design is underpinned by a theoretical approach informed by two complementary frameworks that are discussed in detail in the next chapter – Hajer's argumentative discourse analysis and Oudshoorn's adaptation of material-semiotics. The study employs a number of qualitative methods for collecting and analysing data from

multiple sources. Neuman (2014) describes three types of social research – exploratory, descriptive and explanatory – and Yin (2014) equally uses these three terms to define case studies. Neuman’s (2014) descriptions are broadly applicable as explanations of the different intentions behind approaches to case study research (see Table 2). This case study has combined elements of all three of these approaches, which reflects the nature of working in an emerging research field where exploratory work is required prior to embarking on the core research.

Table 2 The purposes of exploratory, descriptive and explanatory case study research

<i>Exploratory</i>	<i>Descriptive</i>	<i>Explanatory</i>
Become familiar with the basic facts, setting and concerns involved.	Provide a detailed, accurate picture.	Test a theory’s predictions or principle.
Develop a well-grounded mental picture of what is happening.	Locate new data that contradict past data.	Elaborate and enrich a theory’s explanation.
Generate ideas, hypotheses and conjectures.	Create a set of categories or classify types.	Extend a theory to new issues or topics.
Determine the feasibility of doing additional research.	Clarify a sequence, set of stages or steps.	Support or refute an explanation or prediction.
Formulate questions and refine issues for more systematic enquiry.	Document a causal process or mechanism.	Link issues or topics to a general principle.
Develop techniques and a sense of direction for future research.	Report on the background or context of a situation.	Determine which of several explanations is best.

Source: Adapted from Neuman (2014)

Yin's (2014) book is probably the most cited on case methodology (Steenhuis and Bruijn de, 2006). It has provided a helpful guide to this research, particularly in the design phase, although not all of Yin's suggestions for conducting case study research are a good fit for this project. In particular, Yin shows a preference for quasi-experimental conditions where replication logic and analytic generalization are key aims of the research (Steenhuis and Bruijn de, 2006). It has been suggested that case study researchers either ignore issues of validity or attempt to adjust their practice to better meet this criteria of evaluation (Bryman, 2008). Yin (2014) is a proponent of case study researchers addressing issues of validity in a bid to generate theory rather than to present case studies as simply representations of a population. Making distinctions between cases can compel researchers to be clearer about the contribution they are making to the development of theory (Greener, 2011). Nevertheless, Flyvbjerg (2006) takes a more robust position on the usefulness of generalisability – arguing that this is only one method for creating knowledge and overrated as the main source of scientific progress:

That knowledge cannot be formally generalized does not mean that it cannot enter into the collective process of knowledge accumulation in a given field or in a society. A purely descriptive, phenomenological case study without any attempt to generalize can certainly be of value in this process and has often helped cut a path toward scientific innovation.

(Flyvbjerg, 2006, p.229)

Yin's (2014) preoccupation with external validity is (deliberately) in direct contrast to the inductive, theory-developing approaches proposed in, for example, grounded theory, where no attempt is made to ascertain either universality or proof of suggested causes accounting for specific behaviour (Glaser and Strauss, 1967;

Steenhuis and Bruijn de, 2006). In this research, I do not claim to take a grounded theory approach – for example, theoretical literature was sought and considered carefully prior to embarking on fieldwork – but I consider my study to be aligned to inductive ideas about case study research that are oriented in the interpretivist paradigm. Nevertheless, there are advantages to Yin's (2014) structured approach to designing a case study. By working through the thought process he proposes, identifying the data to be collected becomes clearer and there is a greater chance of anticipating the future analytical techniques required. This approach to the design phase also ensures a theoretical underpinning to the study, something that this study is keen to address in the field of telecare research. As such, I have sympathy with Steenhuis and de Bruijn's (2006) attempt to find a middle ground between Yin and grounded theory, and their proposal of an alternative approach they term the 'progressive case study' speaks to much of what this research design is aiming to achieve – namely an approach where:

The outcome is some theory that should not be considered validated but rather it contains concepts and possible relationships which creates new insight (grounded in empirical data) and that can be tested in subsequent research.

(Steenhuis and Bruijn de, 2006, p.7)

For Steenhuis and de Bruijn (2006) the credibility of the study is the most important criteria and they suggest this is achieved in interpretivist research through triangulation techniques. This point is addressed in this research through the selection of a number of different data collection methods and sources. These methods and sources are detailed later in this chapter after a full explanation of the case study design.

5.3.1 Study questions

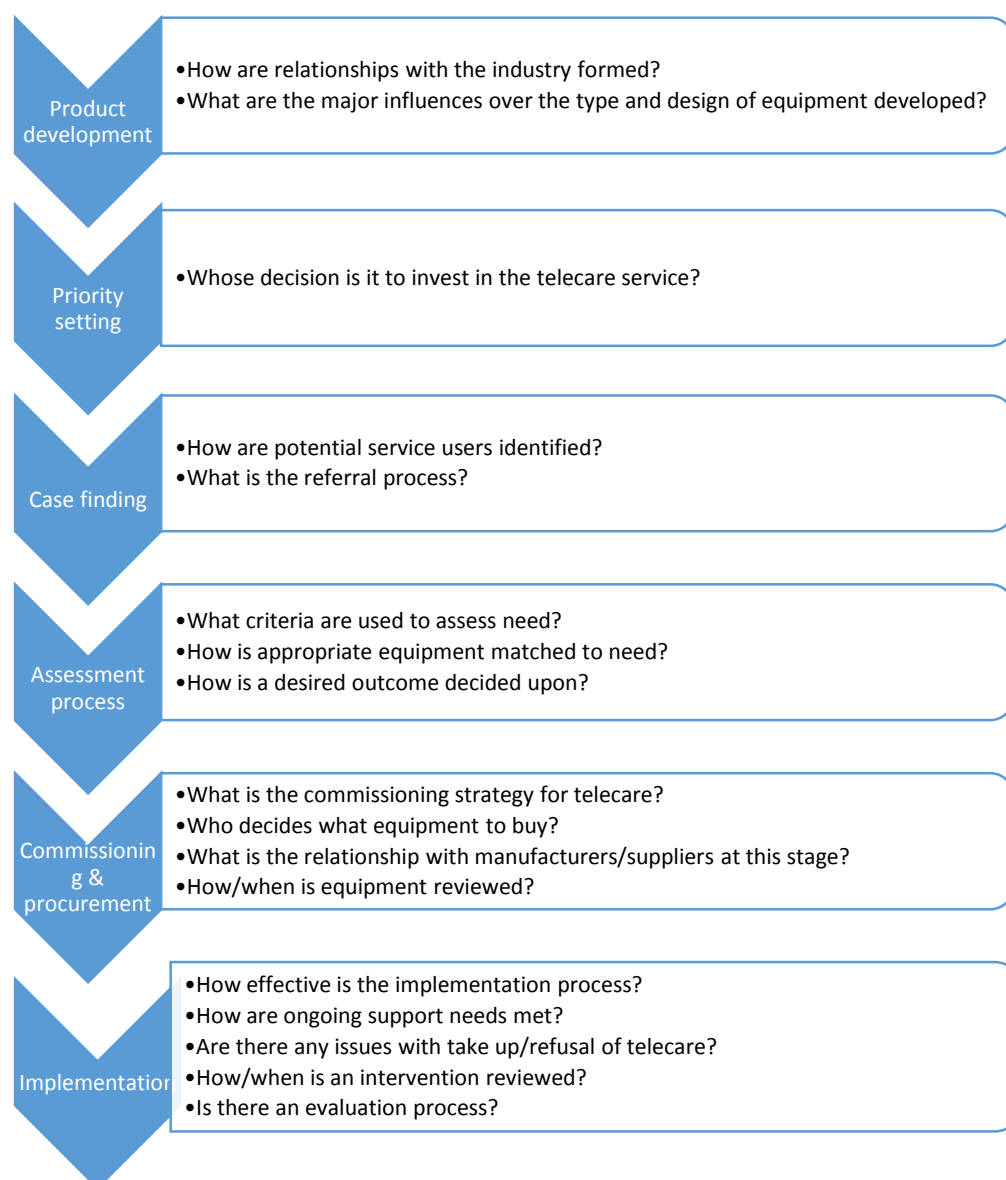
The form of research questions, in terms of 'who', 'what', 'where', 'how' and 'why', provides an important clue regarding the most relevant research method to be used, with case study research most appropriate for tackling 'how' and 'why' questions (Yin, 2014). Much of the exploratory work for this case study involved becoming familiar with the case, developing a mental picture of what was happening, and generating ideas and hypotheses (Neuman, 2014). The formation of research questions took a considerable amount of time as I sought to understand the ways in which the case site reflected (or otherwise) the key issues identified in the literature and attempted to pinpoint areas of interest that raised new questions about this evolving field.

The Whole System Demonstrator (WSD) programme provided a useful starting point for considering the gaps in knowledge left by this large-scale project and it became a central discussion point with the case site, which was eagerly (if sceptically) anticipating the publication of results. While the focus on evidence was welcomed, there was doubt that the results would be relevant at a local level in terms of presenting data that would prompt investment in the service and guidance for developing practice that would be more responsive to local need. The WSD was specifically concerned with the need to say, categorically, that telecare and telehealth 'work' – but this binary consideration failed to communicate the essential caveat that numerous interventions could be labelled 'telecare' or 'telehealth' and the contexts within which each of these is implemented dictate outcomes, making it difficult to give sweeping assurances. The focus of the WSD reflected a wider

preoccupation in policy circles with advances in technological capabilities and debates about the commitment from service users to engage with the equipment. However, this seemingly overshadowed the question of whether telecare and telehealth services are achieving what was intended for them, if indeed the intentions were clear, and to what extent the aspirations of service users – particularly with regard to the promotion of independence – are being properly considered and met.

Furthermore, pertinent questions can be raised about the empowerment of service users through shared decision-making, for example in relation to how telecare assessments are made, how options for meeting an individual's requirements are considered, and discussions about the acceptability of equipment (Fisk, 1998, 1997; Orton, 2010). As was noted in Chapter 3, current research is relatively deficient on the involvement of service users and their carers in the decision-making processes surrounding the provision of telecare and telehealth, and the exploratory work of this study identified a number of points in the process of considering technology where questions about empowerment could be raised. The diagram at Figure 3 illustrates the essential stages where decisions could result in the provision of a telecare service, and yet the involvement at each of these stages of those directly affected by the service user is debatable. This issue is explored in greater detail through the empirical findings presented in Chapter 7 and the discussion in Chapter 8.

Figure 3 Decision-making process for telecare



In response to the issues highlighted the following key research questions were proposed to be addressed by this study:

- What are the public purposes of telecare provision and whose needs does it meet?
- What are the aspirations for telecare and are these realised in practice?

- Is telecare practice fit for purpose, where the avowed purpose is to promote independence?
- How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

5.3.2 Theoretical propositions:

As noted earlier, for Yin (2014) it is vital that the case study method is still grounded in developing or testing theory, and that this is incorporated into the design phase of the study so that it guides data collection and analysis. The role of theory development at this stage is one point of difference between case study research and related qualitative methods such as ethnography or grounded theory (Lincoln and Guba, 1985; Yin, 2014). The use of the term ‘theory’ at this design phase can be misleading, however, as it does not refer to the formal proposition of a grand social science theory, or what Flyvbjerg (2006) terms the ‘hard’ sense comprising explanation and prediction, but rather should be considered as the presentation of a blueprint for the study – the ‘soft’ sense (Flyvbjerg, 2006) that is a hypothetical story about why certain things occur, which can be gleaned, for example, from the research literature or through observed behaviour in organisations (Yin, 2014). Central to this research is the consideration of difference between the aspirations of the stakeholders involved with telecare and actual practice. The research questions are concerned with how telecare is promoted and perceived by those with experience of it but they also reflect wider interest in expectations about health and care provision, and engagement in the debate about what future ‘care’ should look like as well as the role of different stakeholders in shaping that future. With this in

mind, a number of propositions are being tested through this research and will be considered further in the discussion chapter (Chapter 8) of this thesis. It is asserted that:

- Telecare is failing to be incorporated into routine health and social care practice because current policy on telecare and telehealth employs a simplified discourse that fails to acknowledge the complexity of technological interventions that can result in different outcomes for different people.
- Current practice in telecare does not reflect the grand claims made by successive governments and industry, and in fact the purposes being pursued are quite other than those stated publicly.
- Service users have little say in decisions around telecare provision, for example in strategic commissioning or in individual choices about care.

5.3.3 Units of analysis

Defining the units of analysis for a case study (identifying ‘the case’) may appear straightforward but has been noted as a particularly troublesome stage of the research design and a common cause for confusion (Bryman, 2008; Yin, 2014). Yin (2014) points to a number of examples where the unit of analysis has been defined one way even though the phenomenon under study follows a different definition – for example, when a research question asks how a geographic area such as a neighbourhood is responding to a specified social change, although in fact it is the behaviour of a particular small group that is of interest. He describes a further example of a study portrayed as the story of the development of a new technology, and yet the ‘case’ appears to be the engineering team at the root of the invention.

This issue, then, must be a consideration for this study and it is important to relate it to the framing of the research questions (Yin, 2014)

As the research questions suggest, the interest of this study lies in the experiences of those who are affected by telecare and telehealth provision, whether they use the service, support someone who uses it, work in it or supply the equipment for it. It became clear in the exploratory phase of the project that the research should not and could not amount to an evaluation of technology. Current literature in the field is saturated with evaluations of particular devices implemented in specific localised contexts for use by bounded cohorts of people sharing identified health characteristics. In these cases, the focus (and unit of analysis) is the technological equipment under test. In this research, however, exploratory work revealed myriad devices were in use at the case site (see Appendix 1), with many overlapping in core features, and decisions about what was distributed depended on individual circumstances. Equally, there was no single, homogenous group of people identified as representing a particular 'need' – with the possible exception of adults with learning disabilities living in supported accommodation – or automatically requiring a specific device. Therefore, raising questions relating to 'what works', including any suggestion that the technology itself was being analysed would be, as discussed earlier in this chapter, misleading and inappropriate. By the same token, it is clear that although the case *site* was selected for a number of reasons, which are explained later in this chapter, the geographic location is not as important to the study as the constituent elements – or embedded units – that make up the case (De Vaus, 2001). Here it is helpful to distinguish between the case as a whole and the various components within it. De Vaus (2001) uses the example of a school to

illustrate – at the holistic level the researcher may focus on the size, location and type of school under study but the embedded units may include the teaching staff, governing body, students and local community, amongst others. A full picture of the complexity of the school is only possible with the inclusion of information from a wide range of these constituent elements (De Vaus, 2001).

This research can be established as an embedded case study design, where a particular local authority was chosen as it had introduced telecare as an addition to (and sometimes in replacement of) its traditional social care offer. There is a need, therefore, for this research to investigate thoroughly the ‘embedded’ elements of the case, such as the decision-making processes; the role of key stakeholders – in organisational and individual terms – and the perspectives of service users and carers (De Vaus, 2001). It is still crucial, though, to be certain about what are the units of analysis. Returning once again to the research questions, the lines of enquiry naturally split between a focus on policy and individual experiences on the one hand, and health and social care practice and processes on the other. This is indicative of an embedded case study design, where units of analysis are multiple and potentially overlapping. With regard to questions 1 and 2 (outlined earlier in the chapter), public policy on telecare and telehealth and individual narratives are the units of analysis, but findings will also be presented on loosely defined groups to differentiate between the perspectives of service users, employees of the local authority (including care workers commissioned by the local authority but employed by external agencies), and those who work in the telecare industry, highlighting the complexity of the case. In relation to questions 3 and 4, individual accounts again present as ‘the case’ but different areas of telecare practice, including assessment,

reviewing processes and technical support, as well as the different stages of decision-making across these processes are also analysed.

5.4 Studentship and case selection

There is a wealth of advice for the case study researcher on the appropriate selection of a case study. Flyvbjerg (2001) identifies two ways: through random selection or information-oriented selection. A random selection is preferred for generalisability as a case would be chosen for its representativeness of the population, while an information-oriented case is carefully chosen for its significance – as an extreme or critical case, for example (Flyvbjerg, 2006). The decision to select the case in question for this research was multi-factored. On the one hand, it can be described as a ‘representative’ or ‘exemplifying’ case (Yin, 2009; Bryman, 2008) as although the case study site has some distinguishing features in terms of approach to service design, it is fairly typical of how many statutory and non-statutory agencies are interpreting and implementing telecare and telehealth policy on the ground. Bryman (2008) considers a case to be ‘exemplifying’ if it provides a suitable context for certain questions to be answered and allows the researcher to examine key social processes. Flyvbjerg (2001) terms this a ‘critical case’, as it has strategic importance in relation to the research problem and enables logical deductions of the type: ‘if this is valid for this case, then it applies to all cases’ (Flyvbjerg, 2001).

On the other hand, it would be disingenuous to suggest that the relative ‘typicality’ of this case was the sole reason for its selection. This research was funded through an Economic and Social Research Council (ESRC) Collaborative Award in Science and Engineering, or CASE studentship. CASE studentships are intended to

encourage and develop collaboration and partnerships between organisations (public, private and voluntary sector) and university departments by providing doctoral students with the opportunity to gain experience of work outside an academic environment (ESRC, 2014a). The ESRC stipulates that the non-academic partner must be fully involved with discussions regarding the description of the research project; the arrangements for joint supervision; the arrangements for seeking ethical approval and for agreements on intellectual property arising from the research; and the means of identifying an appropriate student (ESRC, 2014b). The decision to collaborate and the research proposal are both established prior to the identification of the doctoral student.

This process clearly had implications for my role in developing the research – it left some key decisions, such as the topic and case selection, beyond my control (although I applied for the researcher role with full knowledge of the decisions that had already been made). However, the CASE dimension to this research could simply be viewed as additional criteria in the selection of the case, and the formal partnership that had been agreed before my recruitment provided an added benefit of securing committed participants for my study with a vested interest in the research running smoothly. Conversely, the involvement of participants with a keen interest in the outcome of the research, both in terms of the process followed and the findings, highlighted potential issues for me in relation to how much influence the partners may try to exert over the questions I wanted to address and what I might have access to during the exploratory and data collection phases. I was also concerned about how they may respond to me feeding back any less favourable

findings. In the event, national policy changes to NHS arrangements¹⁶ (Health and Social Care Act 2012) leading to major organisational change within the key local partner had a liberating, if de-emphasising effect on my research. For example, the non-academic supervisor, whose job was moving from the ill-fated Primary Care Trust to the local authority, authorised my complete discretion to establish my own research questions to allow me to address issues that had become apparent to me during the exploratory phase of my study. The apparent 'trade-off', however, was a lack of consistent support at a (practice-based) supervisory level during this turbulent and protracted reorganisation. Nevertheless, a commitment to collaboration from the CASE partners undoubtedly benefited my research, in terms of facilitating access to data wherever possible, and had a positive impact on how I was received by research participants within the organisations. A profile of the case study site is described below.

5.4.1 Case study profile

In order to achieve ESRC funding for this project, a case study site had been identified at the bidding stage, with the local authority and NHS trust committing to the study as 'partners' prior to commencement. Confidentiality was agreed with the site so a brief profile¹⁷ only is provided here.

¹⁶ In 2010 the health white paper, which became the Health and Social Care Act 2012, announced the abolition of Primary Care Trusts by 2013, with public health aspects becoming the responsibility of local councils.

¹⁷ Source: 2011 Census; Public Health England and local authority held data.

5.4.1.1 Population

The borough for which the partner organisations have responsibility is part of an urban conurbation and has a population of around 300,000, which is steadily increasing. It is an ethnically diverse borough that has seen a significant decrease in the White British population in the ten years up to the last Census and a corresponding increase in all Minority Ethnic groups.

The borough has a relatively younger population compared with the whole of England and Wales, with people aged over 65 making up around 15% of the population and those 85 years and over comprising around 2% of the population.

5.4.1.2 Health and deprivation

The borough has high levels of deprivation, with more than 5% of the local working age population (16-64) claiming Job Seekers Allowance (JSA), compared with 2.7% across Britain. Figures on long term unemployment are some of the worst in the country.

In absolute terms, health in the borough has been improving over time, though at a slower rate than the country as a whole. Life expectancy is below national figures and almost all indicators for adult health measured by Public Health England show the borough to be doing significantly worse than England – levels of recorded diabetes are particularly high and the percentage of physically active adults is notably low. A greater proportion of people do unpaid care work in the borough compared with the national average. The Joint Strategic Needs Assessment

highlights tackling long term conditions through integrated care as a key priority for 2013-15.

5.4.1.3 *Telecare arrangements*

Telecare was commissioned jointly through the local authority (a council with adult social services responsibility (CASSR)) and the NHS trust, although the telecare team that held the budget was based within the structure of the council. A team structure chart and discussion of roles is provided in Chapter 7 of the thesis. The council's senior management team was proud of the fact that the telecare team had not engaged in any strategic contracting with equipment suppliers. There was a belief that more *ad hoc* commissioning practices could result in greater flexibility to be responsive to the requirements of local service users and achieve better value for money from 'equipment only' contracts, and through different negotiation tactics, such as forming a consortium with other geographically co-located councils and dealing with local SMEs. However, this also meant the telecare team had built up a stockroom full of over 200 different types of equipment. Although many devices had similar functions, the decision to buy stock from multiple suppliers was often taken on account of interoperability issues between certain manufacturers and differences in design that met different needs.

The list of equipment held by the telecare team at the time of the fieldwork (supplied on 16.04.13) is presented in Appendix 1. Not included in this list is the Virtual Visiting equipment – a package that included teleconsultation software, a camera and large button remote control. This kit which was purchased on a quasi-pilot project basis, with 40 devices bought initially and issued to service users as part of a strategy to

reduce paid carer hours, particularly in the learning disability service. The impact of Virtual Visiting is considered further in the findings and discussion chapters of the thesis.

5.5 Methods of data collection

5.5.1 Exploratory work and adoption of a narrative approach

To develop the methods used in this research, I carried out exploratory work at my case study site in the early stages of my project – both as a means for familiarising myself with the case, its processes and organisational culture, and in order to build rapport with key stakeholders in the research and telecare service. This work enabled me to focus my study and develop distinct research questions that reflected issues observed in practice and articulated by key stakeholders. It also provided the opportunity for me to carefully consider the range of methods I intended to employ for the later, explanatory phase of the case study (Yin, 2012). In devising the research questions it became clear that an interest in people’s experiences of telecare would be well served by a narrative approach to data collection. The decision to take this approach influenced the choice of methods insofar as they had to be both practical for use at this site and fruitful in data terms. The chosen methods are outlined here (in Table 3) and discussed in more detail below, as is the narrative approach.

Table 3 Methods for data collection

Method	Purpose
<p>23 Narrative interviews:</p> <ul style="list-style-type: none"> • 9 Key staff in organisations (Board; commissioning; service delivery) • 3 Industry representatives • 11 Service users 	<p>To understand how the telecare service is experienced by service users and other stakeholders; and identify what issues are deemed important and privileged in their accounts.</p>
<p>Non-participant observation of organisational meetings (3 meetings).</p>	<p>To get additional perspective on how decisions about telecare are made and how the service is discussed in a strategic sense. Forums will also provide access to service users who could become participants in the study.</p>
<p>Observations of needs assessments carried out by professionals in visits to potential service users' homes (6 visits).</p>	<p>To view the assessment process to understand how need is identified and communicated to service users.</p>
<p>Observation of review visits conducted 12 months after equipment is installed (5 visits).</p>	<p>To understand how the telecare process is experienced by service users from start to finish and how far collaborative decision-making occurs.</p>

Analysis of the key database held by the commissioning authority, which contains details of equipment issued; needs being addressed; and demographic information about service users.	To provide contextual data on the service being delivered through categorisation and regression analysis.
Analysis of key UK Government policy documents advocating the implementation of telecare as part of the reform of health and social care in the England.	To investigate the espoused public purposes of telecare through the analysis of the Government's narrative of telecare.

Narrative inquiry has a robust, if disputed, tradition across a broad range of disciplines (Riley and Hawe, 2004). It does not fit neatly within the boundaries of any single field, but its applicability belies lack of consensus over approach (Riessman, 2008). Key tenets of narrative, however, are the emphasis on human sense-making, that is, the way people use stories to make sense of their experiences (Green and Thorogood, 2009). Narratives may serve additional purposes, such as persuasion, justification of behaviour or rationalisation; but of fundamental importance is the way meaning is constructed through the consequential linking of events or ideas (Riessman, 2008). Narratives may change over time and in place, but how they are structured and what is deemed important to the narrator at that point is of paramount importance.

In this research, a social constructionist view of narratives is taken, as described by (Sparkes and Smith, 2008): that narratives are ongoing social practices that people perform in relation to others as opposed to something that is part of the inner realm of individuals. Gergen and Gergen (2006) describe narratives as ‘discursive actions’ that derive their significance from the way in which they are employed within relationships. The meaning-generating process of telling stories is inherently social, enabling the narrator to display certain characteristics, soliciting attention, sympathy or intimacy. This study is also concerned with personal narratives that are experience-centred (Squire, 2008). This is distinct from stories that are focused on events, as it seeks to view the story in its totality as significant – rather than consisting of a number of highlights – and as a representation, co-constructed through the interactions between the storyteller and the listener (Squire, 2008). It is the emphasis on experience-centred personal narratives that has sparked an increasing interest in narrative in health research, both in terms of the stories people tell about their health and illness, and as a form of analysis to make sense of this data (Green and Thorogood, 2009). Bingley *et al.* (2008) note, for instance, that giving time and space to patients’ stories of end of life experience has a long tradition in palliative care; but that in recent years more healthcare professionals are writing narratives about their own experiences of caring for those facing death. There are also examples of the importance of narratives to healing, demonstrating that storytelling in clinical encounters (between patient and physician) can lead to more patient-centred care (Clark and Mishler, 1992).

A focus on narratives in health and medicine has been described as a counterpoint to what many experience as the growing bureaucratisation of healthcare in many

countries (Green and Thorogood, 2009). There have been questions raised, however, about the quality of narrative research in health and how researchers and ethics committees can qualify 'good narrative research' in this field (Greenhalgh and Wengraf, 2008). This has led to the publication of guidance detailing quality criteria for considering narrative research in health – although this in turn has caused debate amongst those who take a phenomenological view (Greenhalgh and Wengraf, 2008). There is a clear methodological case for taking a narrative approach to this research on telecare, which is made by the explicit objective to capture the voice of the service user, as well as the stories of other stakeholders involved in delivering this service. The key point here is that the participant's role in narrative research is to be a story-teller rather than a respondent to questions (Hollway and Jefferson, 2000). In more structured interviews it is the researcher who sets the agenda and exerts control over proceedings by selecting the themes and topics to be discussed and the order in which the questions are asked (Bauer, 1996). With a narrative approach, it is the participant's story and the ongoing development of this viewpoint that is the topic of interest, rather than any 'facts' that might lie within it (Miller, 2000). It gives prominence to human agency and subjectivity in a way that will enable this study to privilege participants' experiences and accounts of telecare to better understand the motivations and viewpoints at play. Nevertheless, there are few examples of telecare or telehealth narratives, but where they have been collected researchers have concluded that they can be powerful motivators for healthcare practitioners needing to reconsider the focus of their attention (Carter *et al.*, 2011). It is argued that technologists and health professionals can become preoccupied by the sophisticated technologies on offer and the need to manage the new

infrastructures required, while the 'human element' depicted as frontline workers and patients are overlooked (Carter *et al.*, 2011).

The depth of study afforded by a narrative approach will also provide a unique contribution to the field of telecare and telehealth research. In an area dominated by normative claims with research driven to question whether or not a particular technological intervention 'works' or is cost effective, the narrative turn allows for a different set of research questions to be posed and for multi-dimensional responses to be revealed.

Consideration of the narrative construction also presents one of the issues that causes debate around this approach – that of ensuring reliability and validity of the data. If there is an acceptance that experience-centred personal narratives are representations co-constructed between the storyteller and the listener, and that the temporal nature of these stories is important, then there is also a belief that these stories cannot be repeated exactly or 'mean' the same thing twice (Ricoeur, 1980; Squire, 2008). The guidelines produced by Greenhalgh and Wengraf (2008) can be considered a partial response to this issue for health researchers looking to find ways of triangulating and interrogating narratives against data from other sources. However, for many this is somewhat missing the point of narrative research and risks undermining the approach by imposing positivist objectives. For Denzin (2001), a reiteration of the aim of narrative research is required, and the essential question of validity must be discarded as an inadequate pursuit where the understanding of subjective experience is key. Riessman (2008) engages with this debate a little further by encouraging narrative researchers to ensure rigorous development of

their methods and theoretical assumptions. She does, however, assert that the validity of narratives lies in their ability to inform future research and contribute to social change through the empowerment of participants. In this study validity is considered through the triangulation of different research methods producing data from multiple sources, but this should not be viewed as an attempt to validate the individual narratives gathered as the aim of the research is firmly aligned with Denzin's (2001) assertion that the subjective experience of participants should be placed at the heart of the investigation.

Squire (2008) notes that, unlike other forms of qualitative research, narrative offers little in the way of rules about suitable material and modes of investigation, resulting in varied approaches to data analysis. While the origins of narrative inquiry sprung from anthropological research concerned with socio-linguistics and the structuring of events (Czarniawska-Joerges, 2004), the approach in this study has been influenced by experience-centred work, exploring stories that range in length and topic, and always viewing the overall *experience* as the true narrative (Squire, 2008). Thematic analysis can be applied to narrative data in a way that allows the content of the data to be the focus, while the researcher theorises from the case 'intact' rather than from component themes across cases (Riessman, 2008). A process of early thematic analysis was carried out on the data through a manual, systematic reading of the interview transcripts. A long list of 'free' codes were identified revealing how individuals talked about their experiences of telecare. These codes were then reviewed, with some eliminated due to repetition while others were combined (Gibbs, 2007). Following this stage of immersion in the data and recording of descriptive themes, an initial attempt at interpretation was made by grouping the

codes into broad categories – for example, those that related to discussion of the telecare equipment; codes that spoke to the overarching theme of economic pressures; and those referenced in discussions about independence and empowerment. A ‘mind map’ of these themes and their groupings can be found in Appendix 3. This process revealed a range of overlapping and interlinking issues reported by participants, giving a sense of the overall narrative of telecare. This then led to a more analytical stage whereby consideration was given to relating themes to theoretical ideas outlined in the previous chapter (Bryman, 2008).

A narrative analysis of these codes can provide a ‘window’ into the subjective aspect of the narrator’s experience but it risks missing the communicative power of narratives that arise from shared socio-cultural resources and practices (Sutherland *et al.*, 2013). If stories are given shape in the course of social interaction then it is essential that analyses address the activities and social practices that are produced by them and give rise to them (Gubrium and Holstein, 2009). A focus on this aspect of the narratives gathered led the research to a more discursive form of inquiry and later to a reconceptualization of the relationship between technology and the transformations of health and social care, as outlined in the previous theoretical chapter.

5.5.2 Narrative interviews

The narrative interview approach to data collection envisages a setting that encourages and stimulates the interviewee to tell a story about something important in their life (Bauer, 1996). Conceptually, narrative interviewing presents a critique of the question-response-schema of most other forms of interview, in which the

interviewer imposes a three-fold structure privileging their own agenda by: choosing the theme and topics; ordering the questions; and wording the questions in his or her language (Bauer, 1996). This does not mean that there is no structure or framework to a narrative interview – Bauer (1996) outlines four phases of conducting a narrative interview:

1. Initialisation – the context of the investigation and initial central topic for narration are established, as in other forms of interview. Consent is sought to tape record the interview.
2. Main narration – the narration must not be interrupted until there is a 'coda' or signal the story has ended. The interviewer abstains from comment, as far as possible, other than non-verbal signals of attentive listening and paralinguistic feedback to encourage continuation of the narration. The interviewer may take notes for questions later.
3. Questioning phase – once the narration has come to a 'natural' conclusion, the interviewer may ask questions to fill any gaps in the story, although this must be done in a way that avoids 'a climate of cross examination' (Bauer, 1996: 7).
4. Small talk – this phase aims to capture the informal discussion that may occur once the tape recorder is switched off. Making notes of the additional information provided here can be crucial for a contextual interpretation of the informants' accounts.

The narrative approach to interviewing in this research was also informed by Hollway and Jefferson's (2000) study of the fear of crime. Their research advocates a

biographical-interpretative method, developed in life-story research, which requires the researcher to elicit stories 'intact' without destroying them through the following of their own concerns. To this end, questions must be as open-ended as possible, with an invitation to narrativise rather than give a one-word answer; 'why' questions should be avoided; and any follow-up during the questioning phase should use the informant's ordering and phrasing (Hollway and Jefferson, 2000).

Hollway and Jefferson's (2000) use of this technique was influenced by the psychoanalytically-derived method of free association, which sees narrative questioning as an opportunity for informants to structure answers according to unconscious, rather than conscious, logic. Therefore they tend to follow pathways defined by emotional motivations rather than rational intentions (Hollway and Jefferson, 2000).

To embrace a narrative line of enquiry, only three questions were devised as an interview schedule and these were developed from themes related to the overarching research questions, derived from the literature and exploratory work at the local authority (the themes and schedule can be viewed in Appendix 3). The narrative interviews involved participants linked to telecare and telehealth in a variety of ways. Thus, the formulation of the questions was adjusted for each audience (the alternative questions in brackets were sometimes found to elicit narratives more successfully than the initial questions):

1. Can you describe for me how someone gets telecare / how you got telecare?
(What is the process that someone goes through to get telecare?)

2. Can you describe for me how equipment is chosen? (What's your experience of the decision-making processes around the choice of equipment?)
3. Can you tell me about what you want from a telecare / telehealth service? (What is important to you about the telecare / telehealth service?)

For the questioning phase, the intention was to explore issues in more detail that had been touched on during the narration or for points of clarification, or to raise themes that were important for the research that had not previously been mentioned during the narration. In many cases these questions also served to elicit new narratives (Miller, 2000). Two questions were prepared in advance of the interviews to be asked in the questioning phase if the topics were not previously raised:

1. Can you tell me about what it means to stay at home (How important is it that people/you are able to stay at home? Are there any disadvantages?)
2. Has anything changed with the use of telecare? (Do you think there is anything different about care provision with telecare?)

As a general rule, and as far as was possible and appropriate, minimal interaction and interruption during the narrative interview was exercised to prevent inadvertent changes to the narrative. However, my approach to narrative interviewing acknowledges the existence of interviewer effects and subscribes to the view that attempts to reduce the researcher's involvement at the interview to simply 'being present' does not ensure the researcher's objectivity or provide countenance to the informant's response to the researcher (Miller, 2000). Furthermore, it presents some

ethical considerations in relation to the potential negative effect of unresponsiveness on the participant, particularly if the narrative is very personal. It will be shown later in this chapter that in certain circumstances (in this case, with the participants with learning disabilities) minimising the researcher's impact on the interview can have the opposite effect to what is intended by causing anxiety and effectively 'shutting down' narration. Miller (2000) explains that the nature of this type of research means that particular care should be taken to ensure there is a clear understanding of what is being asked of participants. This should include explanation of the approach, confidentiality, and opportunities to withdraw from the study.

5.5.2.1 Interview sample, participant information and consent

Purposive sampling was chosen to ensure that the necessary cross-section of people required for the investigation was included in the sample and so that interview participants were selected on the basis of their known attributes, i.e. their relevance to the issue being investigated and their privileged knowledge or experience about the topic (Denscombe, 2010). Purposive sampling is also a way of getting the best information by selecting people who are likely to provide valuable insights and quality information on the research topic (Denscombe, 2010). It also ensures good correspondence between the research questions and the sample (Bryman, 2008). The exploratory phase of the case study allowed me to identify, with the help of my partner organisations, key individuals working with telecare to invite to participate. This phase also helped to give the partner organisations insight into how I wanted my research to develop and thus enabled them to compile an initial list of potential service user participants from which I could identify individuals to approach. In each case, the service user was first contacted by the telecare or

social work team within the local authority to ask for their consent to receive information about the research prior to my approach. In two cases, contact was facilitated by a voluntary sector user-led organisation that supports people with physical and sensory disabilities, rather than through the local authority. I felt it was important to attempt to recruit participants this way to reduce bias, as it was possible that those approached by the local authority may feel a sense of duty or even pressure to participate due to their relationship with social care. I also considered that people recruited away from the local authority may give a different perspective on the telecare service to those recruited through social care, who may associate me and the research with the organisation and ultimately the service they receive. In the event, the voluntary sector organisation struggled to get interest in the topic from the people they supported and only two agreed to be interviewed, so I had no choice but to rely on the local authority as gate keepers.

The majority of telecare and service users at the case site were older people (over the age of 60) who were considered vulnerable due to their frailty or were showing early signs of dementia. However, the telecare service was extended to adults of all ages with learning disabilities; physical and/or sensory disabilities; and mental health issues. Thus the age of potential participants did not preclude them from involvement in the study. It was agreed with the local authority and as part of the ethical review process that I would only approach potential participants who were considered by the social care department or the service user's carer to have capacity to consent and would not be distressed by their involvement in the study.

Apart from capacity to consent, the only inclusion/exclusion criterion for participants who were not involved in the research from a professional perspective was:

- Someone with experience as a recipient of local telehealth services

I devised a plain language, large print invitation/information sheet to approach potential participants about taking part in the study (Appendix 4). These were informed by best practice examples of communicating with older people about research studies, and in particular with people who have dementia (Ellins *et al.*, 2012; Harris and Dyson, 2001). The use of simple language and supporting pictures is intended to make the invitation to participate informative, unthreatening and engaging. To promote simplicity of communication, a single sheet was designed to function as both an invitation to participate and information about the study. This sheet was used for all participants.

The final list of participants was as follows:

- 9 key staff in the local authority, including
 - 1 assistant director;
 - 2 senior managers;
 - 1 assistant team manager (telecare team);
 - 1 senior telecare assessor (qualified social worker);
 - 1 telecare assessors (no social care qualifications);
 - 1 senior technician;
 - 2 frontline social workers (1 for older people; 1 for learning disabilities)

- 3 telecare industry representatives

- 11 telecare service users, including
 - 2 people with physical disabilities;
 - 6 people with learning disabilities;
 - 3 older people

5.5.3 Non-participant observation

For this research, observation offers a useful additional method of data collection. The research questions demand an investigation into the potential differences between the stated intentions for telecare and actual practice. Interviews provide much of this data but as Denscombe (2010: 196) notes: 'Observation...does not rely on what people say they do, or what they say they think...it draws on the direct evidence of the eye to witness events at first hand'. It is important for this study that the dynamics of the relationships between the different stakeholders are viewed as well as talked about.

Observation is usually described in the social sciences under two broad headings: systematic (structured) observation and participant (unstructured) observation (Denscombe, 2010). Participant observation is generally associated with ethnography and the prolonged immersion of the observer in a social setting, while the systematic approach looks to the use of a schedule with clear rules and parameters for observation that often elicit quantitative data (Bryman, 2008). Which of these methods is chosen depends on the research questions and the paradigm underlying the study – positivistic research will generally use structured observation

while interpretivist research is inclined to favour the unstructured approach (Mulhall, 2003). For this study, I engaged in non-participant observation of three strategic telecare meetings involving multiple stakeholders. I also observed members of the telecare team carrying out assessments of potential service users and reviewing current service users. Tope *et al.* (2005, p. 5) identify non-participant observation as 'field observation that does not involve active participation by the researcher'. In this position, it is clear to all who are present what the role of the researcher is and there is less concern about introducing bias into the data than in ethnographic research, but it must be acknowledged that researchers cannot entirely extricate themselves from the observed environment (Schwartz & Schwartz, 1955). It is important to recognise that non-participant observer involvement with the observed 'may range from sympathetic identification to projective distortion' (Schwartz & Schwartz, 1955: 343).

The act of non-participant observation presented something of a dilemma about how to record data. While my position as a non-participant 'objective' researcher observing (and tape recording) formal meetings was not comparable to the ethnographic observer's experience, I wanted to remain true to the narrative methodology that had guided my interviews by not pre-empting themes and potential topics of interest by using a structured schedule for observation. Therefore, field notes were taken throughout the meetings to be thematically analysed in conjunction with the transcribed recordings. In addition to notes about topics discussed in the meetings, other behaviours were recorded, such as the levels of participation of different attendees and non-verbal responses of individuals.

Non-participant observation was carried out at three strategic meetings relating to the telecare service. These three meetings were chosen as core issues relating to the success and development of the telecare service were on the agenda and those in attendance included internal and external stakeholders, such as representatives from the social work teams, Board level senior managers, NHS commissioners and housing association staff who manage the community alarm service. Two of the meetings were classed as 'steering group' events that were considering the future strategy of the service as well as reporting on day to day issues. The third meeting was between the telecare service manager, a telehealth industry partner and several hospital consultants, and constituted an attempt by the telecare service manager to promote the benefits to health professionals afforded by the introduction of telehealth consultations and patient monitoring using the Council's 'Virtual Visiting' system. The intention of observation was to collect data on how telecare was spoken about amongst stakeholders tasked with directing strategy and how the debates about the benefits and potential concerns were perceived at a local level, particularly among frontline workers.

5.5.3.1 Observation of assessment and review processes

In order better to understand the service user experience of telecare, I felt it was necessary to observe the entire pathway of telecare service provision – from identification of a potential service user through to installation of equipment and evaluation. This would provide a unique insight into the multiple processes and decisions made in the provision of telecare, from the service user's perspective.

Working with commissioners and frontline care staff in the local authority, I was able to identify a number of individuals at different stages of the telecare process, some at the assessment stage, others being reviewed 12 months on from receiving their equipment. All were due a routine visit by different members of the telecare team as part of the service provision and it was agreed, with the consent of the people being visited, that I would accompany these visits. Some people represented what the professionals regarded as 'typical' cases involving telecare at the case study site – i.e. cases reflecting the most usual reasons given for requiring telecare, resulting in the implementation of the most commonly issued equipment. Other cases were deemed more complex, presenting problems for the commissioners and care staff both in terms of the needs of the service user and the resulting questions about the most appropriate solution. These cases had often been escalated to the most senior member of the telecare assessment team, who was the only qualified social worker in the team.

By experiencing the breadth of cases presented to the telecare team I was able to consider the array of different circumstances that could lead to a person being referred to the telecare service as well as the range of needs being addressed through the implementation of a technological intervention. This allowed me to assess telecare practice from the perspective of how the expectations of the service match up to observed practice and where the challenges to telecare practice might come from in the least straightforward cases.

5.5.4 Documentary analysis

Creswell (2007) refers to four basic types of qualitative information: observations; interviews; documents; and audiovisual materials. There was a clear need to analyse government policy papers and other grey literature in response to the first two research questions:

- What are the public purposes of telecare provision and whose needs does it meet?
- What are the aspirations for telecare and are these realised in practice?

This was done by searching for policy documents through the House of Commons Parliamentary Papers (HCPP) database, the government's own portal for accessing policy documents (www.gov.uk) and Google Scholar. Documents were then read, using keyword searches to map concepts that were central to the research questions. This mapping exercise formed the basis for the identification of story-lines, which are discussed further in the next chapter. In addition, there was an intention to analyse the telecare database maintained by the telecare team at the local authority. First sight of the titles of the files held suggested an exhaustive amount of data was being held on the telecare devices in use as well as demographic data about the client groups making use of the service. However, further investigation revealed that data were not only incomplete (for example, some fields were no longer routinely filled in) but also inconsistent use of coding meant that data that had been recorded could not be cross-referenced between files holding different types of information. This resulted in a complete inability to carry out meaningful analysis on the data or draw any clear conclusions about how

equipment was being used and who was benefiting from it. Several attempts were made to discuss the database with the telecare team and to better understand the process for recording data but it was evident from their response that minimal information was inputted on a regular basis and the database was rarely interrogated, usually upon specific request from senior managers wanting to report on the success of the telecare service in broad terms.

5.6 Ethical considerations and approval process

Ethical approval for this research was granted by the University of Birmingham's Humanities and Social Sciences Ethical Review Committee on 12th February 2013 (ref. ERN_11-0598). As the planned research was likely to involve NHS patients, albeit in their capacity as receivers of social care, advice on ethical approval was sought from the NHS National Research Ethics Service (NRES). However, the study was deemed a service evaluation by NRES and no further approval was required. R & D approval was granted by the local authority.

Although this study was dealt with in a straightforward way by the ethical review committee, there were particular aspects of the research that required ethical consideration on account of the vulnerability of participants (Iphofen, 2011). This was highlighted in two particular examples: one related to the attempted recruitment of an older man who was profoundly deaf; and the other concerning the involvement as participants of adults with learning disabilities.

During the recruitment of participants process, I had worked with the telecare team to identify people from the social care database who would meet the criteria for

involvement. Having compiled a list of suitable service users, it was agreed that the telecare team would then telephone people to ask permission for me to approach them about being interviewed as part of the study. In one case, Mr F – an older man who was profoundly deaf and living on his own – was identified as a potential participant as he made use of a range of telecare devices. However, contacting him to ask permission required a letter to be sent to his home rather than a telephone call being made as his hearing loss meant he did not use standard telephone and the only contact detail provided on the database was his home address. Nevertheless, Mr F responded to the letter by sending a note via his social worker and agreed that I could discuss his involvement in the study with his daughter, who would provide sign language interpretation. I proceeded to have a number of telephone calls with Mr F's daughter in which she relayed his enthusiasm for being interviewed. I provided Mr F with an information sheet and consent form and we arranged a date for the interview. Unfortunately, the interview was contingent on Mr F's daughter's presence as the interpreter¹⁸ and it became clear after a number of cancellations on her part that she could not prioritise attending and facilitating the interview with her father. Eventually, I decided to abandon attempts to rearrange as I had run out of time to complete my fieldwork. While this did not unduly affect the study in terms of data gathered, I could not help but feel frustrated that gatekeeper issues had prevented a willing participant from involvement in the research and the opportunity to recount his experience of telecare.

¹⁸ I did not have the funds to pay for an independent interpreter and Mr F was keen that his daughter was in attendance.

Advice on conducting research with deaf people often focuses on the ethical issues related to gaining informed consent, ensuring anonymity of the participant and reporting data gathered through sign language in a way that maintains the integrity of the signed data (Stone and West, 2012; Young and Hunt, 2011). As in other areas of disability research, concerns have been raised about the marginalisation of the deaf voice through exclusion from the process of social research (Young and Hunt, 2011; Jones, 2004; Pollard, 2002). It is a regret that I did not have the capacity, either financially, in terms of time or as a solitary, inexperienced researcher, to find a way to involve Mr F in my research. This could be cited as a limitation of the PhD project and a learning experience from which to adapt my future research practice.

A second issue for ethical consideration in this study was the involvement as participants of people with learning disabilities. When I began this study into telecare I had not anticipated recruiting participants with learning disabilities. Whilst I was aware that the case study site provided telecare services to a variety of different people based on their individually assessed needs, initial conversations had indicated that older people at risk of falling or requiring support to manage their medication were the primary recipients of this service. However, in the early stages of my research a specific project had been undertaken by the community learning disability team (CLDT) in conjunction with the telecare team to reassess the care packages of service users with learning disabilities. This initiative is discussed in more detail in Chapters 6 and 7. Implementation of telecare played a key role in the reconfiguration of the care packages under review so it was decided that I would need to include the learning disability service in my research and therefore seek to recruit service users as interviewees.

Having sought guidance on providing accessible information and consent sheets, and conducting interviews with people with learning disabilities (Ellins *et al.*, 2012; Nind, 2009), I arranged my first interview with Peter, a service user living in supported housing. I had no further information about Peter prior to my interview with him, but I felt reasonably confident that the narrative approach I had taken to interview all previous participants could work well. On the day, however, the interview did not go as I had hoped or planned and I reflected on this a couple of days later in the observational notes I kept throughout the fieldwork stage of my research:

I asked Peter if it was OK for me to have a chat with him about telecare and if he wanted the carer with him. At this point, the carer interrupted and said it would be best if she wasn't there as she felt Peter would engage with me better without her. Peter looked uncertain about this and when the manager arrived a few minutes later he asked her to stay. She too was unsure about staying as she reiterated that Peter was quite capable of coping with the interview alone but eventually agreed to stay for a short while until she felt Peter was comfortable. Both women felt that their presence might inhibit him.

I asked Peter if he had seen the information I sent through and we talked through the consent sheet, which he was happy to sign. I showed him my digital recorder, how it worked, and put it to one side on a coffee table. He was amused by the idea of having our conversation recorded and giggled a lot but also kept putting his hands to his face as if showing he was embarrassed or shy. I decided to sit on the floor in front of the sofa where Peter and the manager were sitting, and told them that I would take some notes while we were talking. I introduced the interview for the benefit of the recorder and then began with my questions.

It was clear almost immediately that this approach was not going to work with Peter. Every time I asked him a question he looked over to the manager for reassurance and gave me one-word answers or simply said 'I don't know'. It was also often difficult to understand what he was saying and I felt anxious having to ask him to repeat himself. He was smiling and seemed happy throughout but was fidgeting and looked uncomfortable and nervous. I tried for about 10 minutes to ask my questions in different ways in an attempt just to get him talking, and I put my notebook to one side. The manager also tried to assist me by reiterating my questions and occasionally prompting Peter or

answering on his behalf, but eventually I gave up and switched off the recorder.

(Observational notes, 8/8/13)

Challenges associated with interviewing people with learning disabilities have been well documented and often relate to inarticulateness (linked to low self-esteem, isolation and anxiety as well as language skill levels); unresponsiveness in open questioning; difficulty generalising from experience and thinking in abstract terms; and, conceptual difficulty around time, making it difficult for them to tell their story (Booth and Booth, 1996; Nind, 2009). The experience of interviewing Peter and further reading influenced my approach to the five further interviews I conducted at the supported living scheme. Largely, this resulted in spending more time with participants with learning disabilities prior to interview to reduce their anxiety about the interview, and to 'informalise' the interview process by not taking notes and enabling participants to carry on with their daily routines, such as making tea and hanging out the washing during the interview. These techniques were required to a greater or lesser degree depending on the individual as people with learning disabilities are not a homogenous group and therefore different interview styles were appropriate for different individuals (Goodley, 1998).

5.7 Summary

This chapter has detailed the design, methods and methodology that are the building blocks for this research. The rationale for choosing case study research and the path to narrative inquiry have been explained, as well as the range of data collection methods most suited to tackling the research questions. Having developed the 'blueprint' for conducting this research, the next two chapters present the findings

from the empirical research, demonstrating the practical application of the theoretical approaches discussed in Chapter 4. Chapter 6 focuses on the policy narrative – the identification of a discourse-coalition and the story-lines it contains. This serves to interrogate the policy pretensions, consider the range of priorities that are taken into account at a local level and compare the aspirational rhetoric with the experiences of service users. This is followed by a second findings chapter that shifts the spotlight onto local practice and the role of technology as a socio-cultural agent. In this section, the material-semiotic view provides the framework for considering the network within which people, organisations, practices and technological devices interact to produce a particular practice of care.

Chapter 6 Story-lines and the telecare discourse-coalition

6.1 Introduction

It becomes imperative to examine the specific idea of reality or of the status quo as something that is upheld by key actors through discourse. Likewise it becomes essential to look at the specific way in which oppositional forces seek to challenge these constructs.

(Hajer, 1995, p.55)

This observation by Hajer notes the importance of analysing policy papers alongside empirical data. This chapter enlists Hajer's argumentative discourse analysis in the presentation of findings from UK government policy documents and 23 interviews that reveal four of the dominant story-lines that constitute the telecare discourse-coalition. These story-lines are present in the policy papers as discussed in Chapter 2 of this thesis, and they serve to reduce the discursive complexity of the telecare debate in a bid to achieve discursive closure. It could be suggested that their success in doing this is apparent in many of the studies reviewed in Chapter 3 as, for example, the independence story-line is regularly invoked without discussion about the meaning of independence in the context of telecare. Attempts at discursive closure do not, however, explain why actors from various backgrounds adhere to them – it is the empirical research that reveals these specific strategic reasons, both at an individual level and through the creation of discursive affinities (Hajer, 1995). The four story-lines are detailed below and can be summarised as:

- The outcomes storyline – centred around arguments that telecare will improve people's quality of life;

- The independence story-line – focused on narratives that view the promotion of independence as a core benefit of telecare, although definitions of independence are vague;
- The transformation story-line – highlights the disconnect between government policy on the transformation of social care and local practice;
- The reassurance story-line – represents arguments that promote telecare as a safety net, reassuring family carers and alleviating risk to service users.

6.2 *The Outcomes Story-line*

Government papers on telecare and telehealth are filled with claims that the use of technology will result in better outcomes for individuals, giving them greater control over how they manage their needs and improving their quality of life.

Telecare offers the promise of enabling thousands of older people to live independently, in control and with dignity for longer.

(Department of Health, 2005a, p.6)

Telecare has huge potential to support a diverse range of individuals to live at home. It can also give carers more personal freedom, meet potential shortfalls in the workforce and complement the work of clinicians and social care and housing providers to achieve outcomes that improve the health and well-being of people using services.

(Department of Health, 2005a, p.4)

[With telehealth] people are more in control of their conditions and not the other way around. They can plan, make decisions, choose the support that suits their needs and retain their independence, avoiding unnecessary admissions to hospital.

(Department of Health, 2012b, p.1)

Assistive technology...helps people to live independently and have greater control over their health and wellbeing, improving the quality of life for both users and their carers.

(HM Government, 2012, p.28)

This emphasis on better outcomes was reflected in a number of interviews with professionals, although they often highlighted the contradictory, and sometimes confused, way in which people talk about the aims of the service and what telecare can achieve. An example is the interview with Andrea, a senior social worker in the community learning disability team (CLDT), in which she identifies that telecare can reduce dependency and create efficiencies (transcribed below in bold italics) but she seems undecided on the impact this has on the service user – initially stating plainly that ‘it’s not always beneficial to the service user’ before going on to assert that ‘the service user is key in all of this’:

R: It’s made great efficiencies to [the council], mainly in the residential homes, you know, the efficiencies are...you know, it’s mainly...it is beneficial to [the council]. It’s not always beneficial to the service user, unless they get irritated by the one to one. Because changing two waking nights to one sleep and one waking doesn’t really affect a service user, but it affects the cost. If it’s not needed, why are we paying for it? And that is the issue. Telecare works in both ways. ***One, it can support to reduce the dependence which has been created with service users. Secondly, it enables efficiencies to be made within the local authority.***

....Because the service user is key in all of this, you know. And the first thing to target is, you know, we need to look about their needs, their wants. The efficiencies come later. Our priority is always the service user. If we can make efficiencies within that, then brilliant. But like I’ve said to you, sometimes no amount of telecare can make efficiencies or can minimise the level of risk. It very much depends on the individual.

(Andrea, CLDT, pp.8-9)

There are two main points to reflect on in this section of Andrea's interview, and this is aided by reference to Hajer's (1995) thoughts on discursive affinities and Fairclough's (2003) identification of discursive differentiation. First is the juxtaposition of the words 'needs' and 'wants' in the last paragraph. At this point Andrea does not differentiate between what the service user is deemed to 'need' and what they might 'want', they are synonymous and a key priority for the service. Most professionals offered views on what service users want and how telecare can support them in these desires:

I can't understand why, if you have lived in a place all your life, why, simply because you're getting just a tad older than you used to be, why you would want to move out, unless you are forced to move out. And I think these days there are sufficient ways in which a house can be adapted, to enable most people to stay where they would be most comfortable for as long as they would want to be there.

(Graham, Senior Manager, p.16)

There is less funding to have people physically present with other people the majority of the time. And a lot of people don't want that either; they don't want someone who's there checking up on them all the time.

(Meena, Senior Telecare Assessor, p.5)

So if we can keep people at home within their own communities, within their own support networks, it improves their quality of life and level of functioning, and the feedback that we get is that, that's what people want and desire.

(Julie, Senior Manager, p.3)

Certainly a lot of the elderly generation, they don't want to be a fuss. So we've had them where they've had pendants and they've lay there 'til five hours for a carer to come in, and that's with the pendant, that's with people telling them you should [press] it, but [they] don't want to be a bother to anybody.

(Robert, Senior Telecare Technician, p.8)

So everybody, all the surveys say that people want to live in their own home, they want to live independently, er, they want as good a quality of life as they can manage. And the typical risks that threaten that are, in many cases, things that a proper telecare service can help you with.

(Nick, Telecare Industry, p.12-13)

However, when referring to what is 'wanted' from a telecare service, professionals don't always speak in terms of better outcomes for service users – they also paint a picture of competing considerations that impact on the provision of telecare. The extracts below highlight (underlined) some of those desires:

...instead of trying to think that we've got to get everybody on board with [telecare], we want the customer journey to be through prevention first, so that we make sure that we can do everything we can from a prevention perspective before it hits a formal care management route in the future.

(Julie, Senior Manager, p. 9)

So the way in which it's being developed - I wouldn't say we're actually there yet - it's looking at where that team that we are training is coming from, what they're wanting to achieve, what their outcomes are.

(Graham, Senior Manager, p.2)

There was a lot of barriers, mainly from providers. Providers didn't want changes in services because that meant staff redundancies, changes in rotas.

(Andrea, CLDT, p.2)

I suppose our advantage is, again, with the virtual meeting where we can actually make proper service re-engineering, redesign, in terms of service provision, by using technologies. [Pause 0:53:37-0:53:45]. So I suppose the vision is that obviously we want to be the best, but we are the best in the [REDACTED], if not England.

(Iain, Telecare Service Manager, p.15)

[Industry] is underhand and they're only out for themselves, they're not actually out to help people, they're a business. They just want to get boxes

off their shelves and into people's shelves... I think it should be health, social care and public health that are saying, this is what we want.

(Iain, Telecare Service Manager, p.13)

[We're] constantly trying to update [equipment] and constantly trying to improve it. And we use both existing, if you like, professional customers, so local authorities, housing associations, NHS organisations, and go to them to ask what kinds of things they want. And we also go to clients and patients. So we do focus groups and user groups to understand what the actual end users would like, I think. And so, you know, based on what sort of input from those, um, different settings, we'd then try and develop the right product.

(Nick, Telecare Industry, p.7)

These examples show that there can be any number of different priorities that decision-makers must consider and better outcomes for service users make up just one part of the picture. Furthermore, when it comes to service users, the focus on 'wants' changes in the discussion of how potential service users are assessed for services. Here there is a shift towards the professional language of 'assessed needs' and this appears to instigate a change in attitude away from what service users 'want' to what they 'need'. The two terms are no longer synonymous and this leads to very different judgements about what social care and health services should be aspiring to. Financial considerations come into play, seemingly trumping any previous concern for the aspirations of service users:

A review was normally sit down, cup of tea, how are you getting on, is everything alright, have you got enough money in your budget and stuff. Now it will be actually let's reassess you, let's see what you actually need now, you don't need this or you might need this extra or...so it's more....we have to look at it on a financial basis, where social workers have never really looked at finances before. It's more about needs and just said, well, you know, people were never critically reviewed, so we didn't know whether they were having more money than they needed.

(Iain, Telecare Service Manager, p.6)

If you're saying, well, you've got dementia so you can have this, is that actually gonna meet the need, has it been assessed to meet the need, and do you actually need to give them all of that equipment.

(Iain, Telecare Service Manager, p.9)

Because I believe in giving services to needs, not wants. And I think having telecare as part of my working practice enables me to ensure that the frontline funding is going to needs, rather than wants.

(Andrea, CLDT, p.5)

The inclusion of financial considerations here demonstrates the second notable point about the earlier extract from Andrea's interview – that the outcomes story-line represents a discursive affinity between the arguments of 'telecare improves outcomes for service users' and 'telecare saves the council money'. Andrea proposes this affinity explicitly:

Telecare works in both ways. One, it reduces, it can support to reduce the dependence which has been created with service users. Secondly, it enables efficiencies to be made within the local authority.

(Andrea, CLDT, p.8)

The details of these two arguments are never explained in the interviews and in accordance with Hajer's (1995) framework the complexity of the debate is often reduced to key words or phrases that appear abstract or subject to multi-interpretability – such as 'maximising choice, control and independence' or 'making efficiencies' – which appear to represent the broader arguments in a coherent way so as to provide discursive closure. One example is in variations on the phrase 'staying at home', which is often used as a representation of the overarching social care strategy employing a raft of measures and activities to keep people out of formal or institutionalised care and health services as much as possible. The phrase

'staying at home' also has an enthymematic quality, implying that people remaining in their own homes is always the desirable result in terms of outcomes for both the individual concerned and the local authority:

So our universal offer is this, don't worry, you don't need to pay for [telecare] because we know we're saving money on you by you staying at home and staying away from us, in the nicest possible way.

(Iain, Telecare Service Manager, p.17)

Respondents who refer to the 'telecare improves outcomes for service users' and 'telecare saves the council money' arguments clearly feel 'they belong together' (Hajer, 1995), and sometimes present them as two sides of the same coin:

I guess, again, it's not just one driver, I think it's a bit of a mixture of a number of drivers. One, that we ultimately have a duty to support people and their carers, and we want to do that in a way that does maximise individual's choice, control, independence. So that's, I guess, some of the core values that we, as an organisation, would want to promote and action. And I suppose, which supports that is the budget strategy, which is about saying how do we keep people well, keep them socially engaged, keep them active, and enable people to maximise their well-being in a way that also ultimately reduces the impact on the demand for FACs eligible services...

(Julie, Senior Manager, p.2-3)

So it's about making sure the solution fits the person and their needs, as part of an overall integrated package. But I suppose there's a financial element which is, it's a lot higher cost to keep people in residential care and in nursing care... It's all about how we deliver services more effectively and efficiently. And if we can access somebody in the home remotely as well, then we're saving money elsewhere.

(Iain, Telecare Service Manager, p.18)

So the way in which the service succeeds is by helping people stay independent for longer...helping them manage their independence, they're able to live safely at home for longer. Therefore, they don't need things like residential care, they need less domiciliary care, they need less carer care

from family and friends. And so the knock on impact of having an improved effect on the client is that you're not paying for that additional care.

(Nick, Telecare Industry, p.3)

The financial argument for telecare is seen to follow on logically from the argument for better outcomes for service users, and viewing the above extracts through Fairclough's (2003) lens (highlighted with underlining) the collapsing of differentiation between these arguments is apparent. This sense of coherence is posed despite the continued presence nationally of uncertainty about claims that telecare can save money (Steventon *et al.*, 2013) and scepticism from frontline staff about such evidence:

I'm not sure necessarily about the figures but I do think it is being drummed into people that Telecare can be used to make savings, cost savings.

(Meena, Senior Telecare Assessor, p.7)

As a budget holder, I don't see that assisted technology necessarily reduces what a homecare package cost would be...

(Rachel, Social Worker, p.12)

Returning to social worker Andrea's earlier statement further demonstrates the confusion evident above about whether or not telecare creates efficiencies and the extent to which outcomes for service users are prioritised over other considerations. Yet, the outcomes story-line remains intact and dominant within the telecare discourse-coalition. Despite the competing elements and discrepancies among the arguments that contribute to it, this story-line is consistently adhered to and proffered as the fundamental tenet on which telecare strategies are developed.

6.3 *The Independence Story-line*

If the outcomes story-line represents an amalgamation of different, and sometimes competing, arguments brought together to imply a coherent message about the positive outcomes resulting from telecare, the independence story-line indicates the need to question the aspirational nature of these intended outcomes – specifically in relation to service users. Wherever Government papers refer to improving outcomes for service users through the use of technology, achieving ‘independence’ is invariably stated as a typical benefit of engaging with telecare. However, nowhere is there offered a definition of independence in relation to what telecare can achieve – how much independence can be expected and is sufficient to deem telecare beneficial? It is clear from interviews carried out as part of this study that independence is a subjective matter, and while certain key phrases, such as ‘remain at home’, ‘feel in control’, ‘feeling safe’, were employed by respondents to convey a coherent message about independence, the details of these arguments were left unexplained and subject to interpretation. Most respondents spoke about independence at some point in the interview, but the context within which it was referred was often subtly different. When talking about the government’s programme for promoting telehealth nationwide, the manager of the telecare service was keen to note its shortcomings:

Now, as far as I'm concerned, 3millionlives¹⁹ is about using technology or should be, er, using technology to provide services in a better way, enhance people's experience of those services, allow them to self-manage conditions,

¹⁹ 3millionlives was the campaign to increase access to telehealth launched by the Department of Health following headline findings from the Whole System Demonstrator. It is discussed further in Chapter 2.

to remain safe at home, independent, less reliant on services. That's not the way 3Million Lives has panned out.

(Iain, Telecare Service Manager, p.11)

It is significant that Iain frames independence in reference to self-management, staying at home (and being safe there), and becoming less reliant on services. In these terms independence is definable as the opposite of dependence, and specifically dependency on health and social care services, and the technology can be used to reinforce this definition by enabling people to become independent of state support. This view invokes a familiar rhetoric of professional conceptions of independence that is regularly challenged by disability rights activists and scholars by contrasting it with disabled people's conceptions (Goble, 2013; Barnes, 2012). This debate points out that while there is a policy discourse promoting the social model of disability many professionals still work to a personal-deficit-based conception of disability that relies on a medically-defined assessment of people's functional independence (White *et al.*, 2010; Brisenden, 1998). This pits the 'defective' mind, senses or body of the disabled person against the normative standard, with the performance of interventions (and of the individual themselves) judged by a professional 'expert' as successful depending on the person's proximity to 'normality' (Goble, 2013):

[With telecare] you need less actual formal care staff, but that you can still maintain an appropriate response that's less obtrusive, more promoting people's independence, um, and more enabling them to live and function as the rest of us would want to.

(Julie, Senior Manager, p.2)

Such a model serves not only to infantilise adults with perceived impairments but in the exclusion of these people from adulthood it also reaffirms notions of dependency through controlling discourses of professional and informal care (Priestley, 2000). Moreover, if viewed through the lens of Hajer's (1995) argumentative discourse framework, a discursive affinity is apparent between the arguments of 'promoting independence' and 'reducing dependency on the state' which allows for a process whereby needs are defined by what social systems can afford rather than by the actual barriers that people are facing and effectively places a ceiling, either in terms of cost or eligibility criteria, on the level at which independence is desirable (Zarb, 2003). In contrast, the disabled person's conception of independence is based on the social model of disability that views disability as a form of social oppression whereby people are forced into dependency on systems that segregate them from mainstream opportunities (Goble, 2013). Independence must therefore be gained through (legal) rights, access and control rather than through functional capacity (Goble, 2013).

Nowhere in the interviews is this discursive affinity more apparent than in the discussion of people with learning disabilities. Unlike in older people's services, the community learning disability team (CLDT) had introduced telecare into care packages as a direct substitution for care staff hours. Many of the service users had care packages including up to 24 hours of one to one time with support workers and the service was trying to reduce its budget deficit. There was also a widely-held view that a 'culture of dependency' had developed in CLDT, with risk-averse social workers and influential care providers conspiring to ensure service users were monitored at all times, the result being that individuals were increasingly 'de-skilled':

My angle is more about promoting people's independence and discouraging people from becoming dependent upon carers coming in. Because that's probably one of the biggest things I come across, particularly in the sphere of learning disabilities, where, over a period of time, a number of clients with learning disabilities have been given these big packages of care, sometimes where there is the potential for them to be independent and then in turn, the person has become dependent on having that level of support. And now in times where cuts are to be made, there's that recognising of maybe that person can do particular tasks independently, and now we're having to sort of intervene and look at where we can use Telecare to assist them in performing those tasks safely and independently.

(Meena, Senior Telecare Assessor, pp.7-8)

I felt that the culture within [the council] specifically, um, had not enabled service users to reach their full potential, had, in a way, disabled them from, and lost a lot of their skills. And I feel that...because what providers were mainly doing is they'd give us an argument, such as, he's too anxious to be left on his own. So my role was to look at what telecare equipment can meet that anxiousness.

(Andrea, CLDT, p.2)

The learning disability narrative firmly correlates independence with a reduction in contact time and an increase in time being spent doing things alone. It is perhaps noteworthy that people are being considered more able in this period of austerity. Furthermore, this emphasis on dependency rather than interdependency contrasts with the way professionals speak about services for older people, where social isolation is often highlighted as a concern and encouraging older people to interact and engage with others is seen as an aim of social care.

Other interviews continued to reinforce a medical model of independence, not only linking it to functional ability but specifically associating it with the ability to manage medication:

I feel that Telecare can be used...when used appropriately, it can be used to promote that independence and enable that person to feel in control again of

their own life, they manage their own medication. Yes, someone may have to fill a dispenser for them but ultimately, day to day, they are able to manage their own medication without someone having to come in and check, or without them having to be at home for certain periods of time.

(Meena, Senior Telecare Assessor, p.5)

I: What sort of...what does independence mean in [residential care] settings then?

R: Well, it's about people still being able to manage their own medication. Why can't they manage their own medication, if they're able to, within a residential and nursing home?

(Rachel, Social Worker, p.15)

The reason why the equipment is out there is to make people's lives easier, to hopefully stop them from struggling, um, you know, and to make 'em hopefully a bit more independent. Because I think sometimes there's a lot of people out there who are getting a lot of things done for 'em and they feel a bit useless. I've had a couple of ones who've sort of said, you know, I used to do this, I used to do that, I'd love to do it again. Sometimes we can put equipment in that will help 'em do that again, like especially when it comes to like medication and things.

(Vicky, Telecare Assessor, p.5)

I think the things that, I suppose, we've already mentioned is that people stay at home or they have a sense of feeling safe and secure at home, um, they feel more independent, perhaps their daughter and son don't ring them up nagging them all the time [laugh] to take their tablets. Um, I think they're the successes...

(Deborah, Telecare Assistant Manager, p.10)

There was only one professional, a telecare industry representative, who spoke in more aspirational terms by emphasising how the technology could support people to live how they wanted rather than focusing on the impact on services:

Well, the most important thing is it helps people to live the life they want to live. So everybody, all the surveys say that people want to live in their own home, they want to live independently, er, they want as good a quality of life as they can manage. And the typical risks that threaten that are, in many

cases, things that a proper telecare service can help you with. And so, you know, just being able to, um, extend people's quality of good life is what's important, and that's what we do.

(Nick, Telecare industry, p.12-13)

Of the 11 service users interviewed for this study, 3 were involved with telecare services as older people, 2 were using equipment to support them with their physical disabilities, and 6 were people with learning disabilities using telecare within a supported living environment. Four of the respondents without a learning disability spoke about independence in line with the professional perspective by framing it in terms of what they could and could not physically do:

[Telecare] makes life a lot easier and a bit more independent, so you haven't got to ask someone to come and open the jar for you.

(Margaret, p.5)

I like my independence. And my daughter said, can I take your wheelchair? I said, no, thank you, I'll take my frame [laugh].

(Zainub, p.21)

I'm independent, that's my trouble... And that's the wife's trouble as well... What we can't do, we don't ask anything. We manage it one way or another.

(Gordon, p.7)

If people can get out and about, and keep their independence, that's a quality of life and less pressure on the social services and the hospitals, and all that, you know.

(Arthur, p.16)

This assessment of independence could have resulted from the fact that these people had become ill and in need of support from social care and health services as older adults meaning their experiences of independence and dependence at this

point in their lives stood in contrast to a fit and healthy early adulthood. This contrast was most manifest in their physical deterioration and therefore at the forefront of their minds when considering their independence. It could also be explained with reference to Hajer's (1995) account of story-lines as creating new insights into the social order. Actors can only interpret discourse based on the narratives available to them and if these respondents had only been exposed to the independence story-line through contact with health and social care professionals, the alternative rights-based conception may be unfamiliar to them but could offer them the 'argumentative ammunition' to empower their position (Hajer, 1995, p.64).

Only one of the 6 people with learning disabilities used the word 'independent', in response to being asked what he liked about the supported living scheme that he had recently moved in to ('Being, like, independent and everything like that.' Peter, p.6). Several people did, however talk about being on their own or doing things on their own, for example:

I do my own meds, I do, but the staff have to watch me, help me take my medication... I pop out my own tablets.

(Edith, p.5)

But occasionally, when the weather's cool, not too hot and not too cold, I don't mind going out, but as...but as...but while I'm out, I feel unsafe while I'm out by myself.

(Harry, p.7)

I can just watch what I want on telly. And I haven't got to, like...when I'm on my own, I haven't got to worry because I haven't got, like, anybody telling me what to do.

(Suzie, p.12)

R1: I'm alright on my own anyway.

R2: Yeah, we're alright on our own...

(Edith & Helen, p.12)

The fifth interviewee without a learning disability, Lloyd, did not refer to the term 'independence' at all, although he did talk about telecare equipment in terms of how it 'makes life a bit easier' (Lloyd, p.5). However, Lloyd, who is wheelchair-bound, did hint at the suggestion that his ability to be independent was more a question of the attitude of others rather than his disability:

I mean, I can get around the property, there's room enough for me to get around the property, but the access issue was the main issue. If you can't get into the property, it's of no value what inside is like. And that's what a lot of people seems [sic] to fail to understand. I mean, many a times, I've had friends who have invited me out, and the first question I've had to ask is, is there any access to the place. If they say no, I've got to say, sorry, I can't go. It's that simple. And I want to go, but I can't.

(Lloyd, p.13)

Lloyd's point also relates to another issue – the importance of the home for people's understanding of independence. For many, notions of independence are inextricably tied to being able to live at home, although the people interviewed emphasised different aspects of the home as being crucial to their own sense of independence, for example, remaining with a spouse or pet, attachment to the neighbourhood or community, or simply the house itself. There was variation in their experiences of having moved house over the years, and in housing tenure, but all respondents, with the exception of Lloyd, considered their current location to 'feel like home'. Lloyd, however, had always lived in council-owned accommodation, and the references he made to his home appeared more practical than emotional and linked to what would

make his life easier – could he manoeuvre his wheelchair into all rooms? Could he access the garden? Did he have control over who entered the property? When asked ‘does this feel like home?’ Lloyd (p.12) replied:

No. Not at the moment, no. It didn't feel like I was moving home, it doesn't feel like home, definitely not.

He went on to explain:

So I've always liked [REDACTED], so it's not the issue of where I'm living, it's the issue of the mess they made of the assessment of the property, and the turnaround... [CUT]... And they said...the garden is totally inaccessible, massive garden, all slabs and everything. I can't get into it, I can't use it. So I said, what's the point of having something that you can't use? No access. One single most important thing to anyone who's wheelchair bound, single most important thing. Without that, it could be a palace inside, you can't get in, it's no use; simple. And that's all they keep going on about, oh, it's the biggest in the borough...

(Lloyd, pp.12-13)

In Lloyd's case, independence was defined by how he could live his life within whatever property he was allocated, rather than an emotional attachment to 'home'. He appeared resigned to the medicalisation of his personal space but it was here that he identified how telecare equipment could have a positive and impactful bearing on his quality of life, for example with a door entry system that allowed him to control who entered the house; and remote-controlled lighting, which improved his sleep when night-time carers forgot to switch the lights off as they left. Nevertheless, Lloyd's experience demonstrates the complexity of notions of independence that belies the one-dimensional presentation of this story-line in government policy.

6.4 *The Transformation Story-line*

Telecare and telehealth services have been introduced into the health and care economies as part of an overarching agenda for change, where the need for transformation of health and social care provision has been continuously asserted as a response to demographic pressures for nearly a decade by successive UK governments (Department of Health, 2012a, 2010a, 2009b, 2008b, 2007, 2006). The transformation agenda was established as a new direction for health and care services with the publication of *Putting People First* (2007), a concordat between government departments, local authorities, the NHS and other agencies. This document became the foundation for future government command papers reinforcing the need for radical change in health and care provision and focusing firmly on personalisation as the key theme – services needed an overhaul if they were to legitimately claim to place the individual in need at the heart of decision-making:

The time has now come to build on best practice and replace paternalistic, reactive care of variable quality with a mainstream system focussed on prevention, early intervention, enablement, and high quality personally tailored services. In the future, we want people to have maximum choice, control and power over the support services they receive.

(Department of Health, 2007, p.2)

Personalisation will be the foundation of the new National Care Service and it extends beyond being offered a tailored package of care. It means shifting control to the individual and enabling them to identify how needs will be met.

(Department of Health, 2010a, p.91)

To enable such 'system-wide transformation' (Department of Health, 2007, p.3) a raft of measures were put forward in *Putting People First* (2007) to promote new

ways of working, including the embedding of direct payments and individual budgets; the introduction of a common assessment process; person-centred planning and self-directed support becoming mainstream; and telecare ‘to be viewed as integral not marginal’ (Department of Health, 2007, p.3). In addition, *Putting People First* (2007) emphasised the shared vision being presented and subsequent government papers continued to underline the theme of collaborative working between statutory agencies – particularly the integration of health and social care – but also across sector boundaries:

The transformation envisaged by this White Paper and the forthcoming Care and Support Bill²⁰ will come about only if it is a genuinely collaborative endeavour. We need to dissolve the traditional boundaries that lie between the third sector, private organisations, local authorities and individuals.

(Department of Health, 2012a, p.3)

The transformation agenda, therefore, has created a backdrop to the development of telecare and telehealth services where terms such as ‘personalisation’, ‘collaboration’ and ‘new ways of working’ are routinely adopted in the presentation of technology implementation as a coherent discourse. Government papers on telecare and telehealth not only reference the use of technology in relation to the transformation agenda but denote it in technologically determinist²¹ terms as a manifestation of already-transformed services – simply having access to telecare implies changes to the way care is provided:

Using technology to enable delivery of high-quality support will be a vital element of the future care and support system.

²⁰ Now the Care Act 2014

²¹ Technologically determinist views on technology are challenged in depth in the next chapter.

(Department of Health, 2009b, p.51)

New technologies will change the options available to people, and we need to encourage innovative ways of providing care and support.

(Department of Health, 2009b, p.73)

Telecare is indicative of the new approach to social care and health provision, moreover it is a material example of it occurring before our eyes. While this transformation story-line is invoked strongly in the policy documents, findings from this study show how it is appealed to in much weaker terms in the local context. Where identified in participant narratives it is less representative of the pursuit of marked change in service provision and more an example of gradual evolution in working practices. References to the personalisation agenda are a case in point. Of the twelve professionals interviewed in the local authority and technology industry, only two made explicit references to personalisation – one was the most senior manager at the council participating in the study and the other was a representative from the telecare industry:

So it's trying to be as proactive as we can and introduce things to people that they're gonna use, because if they're not gonna use it, we don't want to...one, we don't want to waste the equipment, but two, I think we don't want to bother people with stuff that they're never gonna get any benefit from. So it...you know, I have to stress, it is more personalised these days.

(Julie, Senior Manager, p. 8)

What we strive very hard to do is make sure that you always get a personalised solution because everybody's circumstances are slightly different.

(Nick, Telecare Industry, pp.4-5)

Julie did not just speak of personalisation in abstract terms – she also mobilised the rhetoric of choice and control, resorting to the reductive discursive device to show her allegiance to the personalisation agenda whilst failing to explain what this means in practice:

We ultimately have a duty to support people and their carers, and we want to do that in a way that does maximise individual's choice, control, independence...

(Julie, Senior Manager, pp.2-3)

But it is about what people's needs are, what people's aspirations are, and how we can support them at that lowest level all the time, with a recognition that there still has to be that whole breadth of choice and opportunity...

(Julie, Senior Manage, p.5)

Similar acts of discursive closure (Hajer, 1995) can be noted in the narratives of other professionals:

I feel that Telecare, when used appropriately, it can be used to promote that independence and enable that person to feel in control again of their own life...

(Meena, Senior Telecare Assessor, p.5)

However, in general, the language of personalisation was notable for its absence from the interviews with professionals. The multifaceted way in which professionals spoke about the needs and wants of service users was detailed in the 'outcomes story-line' above and it was clear here, too, that in some cases the objective of discussions about telecare with service users and their carers was less to put the person at the centre and more to persuade them of the council's position:

R: It took a long time to break down the barriers. With one provider, it took me five meetings of heated almost arguments before they would even let me through the front door...

CUT

I: Mm. [pause] But the families were always pleased?

R: Always pleased. They would always listen to us...

(Andrea, CLDT, p.7)

At times, it was admitted that conversations about telecare could bypass the intended recipient entirely:

I do feel that the assessment function is important...to get the views of the person, the end user because a lot of the time, discussions are made between the referrer and the family, and the person is at risk of being lost if you don't then assess.

(Meena, Senior Telecare Assessor, p.3)

Conversely, however, it was a frontline worker arguably further removed from the influence of social work values and the transformation agenda – the senior telecare technician²² in the telecare team – who articulated the clearest intention to put the individual first:

It's just trying to tell [the technicians] when you go out with them: just talk to the people, listen to what they've got to say and explain things to them, whatever they're asking for, especially around the equipment we're fitting... But from our point of view, it's just listening to them and try and allay any fears that they may have with what they're doing.

(Robert, Senior Telecare Technician, p.10)

²² The value of the role of technicians in the telecare team was consistently underplayed by other professionals and this issue is discussed in depth in the next chapter.

Descriptions of the exchanges between professionals, service users and other stakeholders bring another element of the transformation agenda to the fore – the emphasis on collaborative working. The ‘genuinely collaborative endeavour’ insisted upon by the Department of Health (2012b: 3) is not only indicative of the new approach to health and social care provision but highlights the variety of perspectives involved in favoured initiatives such as telecare and telehealth. Yet the focus on collaboration in the policy discourse was less easily identified in narratives at the local level. Participants spoke readily of their dealings with other stakeholders but their stories were weighted with a sense of friction and images of jostling for superior position rather than presented as a process of working together to achieve a common goal. Consideration of collaborative working reveals the complex relationships involved in telecare provision and the multi-dimensional issues that could create barriers to necessary partnership working. For example, social worker Andrea spoke, somewhat predictably perhaps, of the problems working with care providers who saw telecare as a potential threat to their employment. However, she also described the difficulties she faced trying to persuade her own social work colleagues to introduce telecare as an alternative to traditional domiciliary care provision:

[My role] was to complete independent assessments...When you have another social worker going up to them, saying, no, I don't agree, you've put too much services in here, in a way, they thought that their professional judgement was being questioned.

(Andrea, CLDT, p. 5)

Whilst the government policy documents emphasised the need for statutory organisations to work effectively with the telecare industry, it was made apparent by

participants in this study that this relationship is complicated by competing pressures, and even the transformation agenda itself:

So from the outside, it is not an easy task to penetrate local authorities, find the right people and then have ongoing relationships, because of the changeovers and reassignments or redevelopments for services which have gone on now since 2008.

(Mike, Telecare Industry, p.5)

And I hear this on a regular basis: 'no, it's not a priority' or 'nobody's asked for this'. And when I hear the 'nobody's asked for this', I realise, yeah, because you've not made them aware that it exists... And this is where I get frustrated with local authorities and government-based organisations as well.

(Mike, Telecare Industry, p.5)

The NHS, in my own personal view, are further behind [social care]. They're still, I guess, more dictatorial, they're more formal, they're more specification-driven; which, you know, in my view, rather stifles creativity, it stifles innovation, it stops you, trying to push the envelope in terms of what's possible.

(Nick, Telecare Industry, p.5)

We were challenging industry to make their systems compatible with one another, [the conversation] has been running for years, and it's just not gonna happen. It's not in industry's best interests.

(Iain, Telecare Service Manager, p.11)

The local authority's telecare manager went as far as to suggest a rejection of collaborative working as prescribed by policy papers:

We're so far ahead of the pack, as it were, and we're not actually going down the desired DH/government/industry route. So we'll effectively show them how it should be done.

(Iain, Telecare Service Manager, p.21)

Organisational restructure and the redesign of services was noted by a telecare industry representative as a barrier to effective long-term collaboration but clearly such changes to social care and NHS arrangements has been deemed a key part of the transformation policy and was equally a dominant factor in the transformation story-line as told by participants in the study. Changes in working practices that related to how telecare was provided were recognised by a number of different professionals and it was central to the narratives of two local authority workers – a lead social worker in the community learning disability team (CLDT) and the telecare manager. For social worker Andrea, her perspective on telecare was shaped by her view that the council fostered an approach to learning disability services that was inappropriate and required ‘culture change’ to remedy:

I feel the culture within [this council] is difficult...we have a lot of providers telling us what support is needed for the client. [The council] are, however, trying to break down that barrier. [They] recognise that this is what some providers have been doing, our working practices have allowed it to happen. Which, in itself, is the reason why breaking down the barriers was so difficult.

(Andrea, CLDT, p.7)

As discussed in the independence story-line above, the perceived ‘culture of dependency’ was peculiar to conversations about learning disability services and linked directly to commissioning practices and the, perhaps, overly-collaborative relationship between the council and care providers working with this client group. In this context, Andrea’s narrative described using telecare as a tool for engineering the necessary change to this culture, stating that telecare implementation had brought ‘significant advantages beside the budget, besides the quality of life for the service user...in terms of social work practice, our values, the way we see things...there has been a significant change (Andrea, CLDT, p.9). As with

discussions about independence in relation to people with learning disabilities, it was unclear from Andrea's story how telecare itself had prompted culture change beyond ensuring a replacement of traditional domiciliary care provision with technological equipment. In fact, Andrea pointed to her own temporary post as an independent reviewer of 30 service users' assessments as the key factor instigating a change in social work practice:

I went to review a service user who had been reviewed previously by a social worker a month before. I identified significant reductions in that package for £800 a week. So because I've got the skills and the knowledge now - that social worker what did the review, didn't have that skills and knowledge - because I've got the skills and knowledge, it has changed my working practice to be able to go out, know what I'm doing, know what I'm talking about, and reduce a service user's package; creating more independence and saving the local authority £800 a week.

(Andrea, CLDT, p.5)

The introduction of telecare had undoubtedly provided the mechanism for creating this role – the remit was to review packages of care and consider if telecare could be used to reduce contact hours with care staff – but in terms of practice change, telecare could be considered a red herring here as the core issue related to the assessment process and the charge that social workers were over-prescribing care hours. Andrea's job to tackle this problem could have occurred whether or not telecare was involved – in this case telecare was used as leverage to raise the issue whilst also providing tangible reassurance that people were not being left with no semblance of support.

While Andrea's focus on culture change appeared to use technology as an excuse to root out deeper issues, telecare manager Iain saw technology as fundamental to practice change:

The important elements are...making [telecare] the norm. So digital first, technology's the default position. In one, two years' time, it shouldn't be that we're doing something different, we're doing what we normally do.

(Iain, Telecare Service Manager, p.15)

Iain's vision was for telecare to be completely embedded in social work practice although it is possible this reflected a concern to justify the investment in the team he managed as much as adherence to the government's transformation agenda:

[The council] don't have a choice but to make these savings. And a lot of that is badged on...keeping people in their homes for longer, supporting them in the best way. So we should see a reduction in our costs against that budget, but we need to make sure that we evaluate them properly and make sure that we've got the causal link and say, by using the technology we've saved this, and it's not any other intervention... But I think what we'll find is [telecare] will make efficiencies within other services left, right and centre. But we also need to make sure that we identify where we've done that as well. So if they are making grand efficiencies and budget savings, we've got a claim to say well, actually, put some more into the [telecare] platform so it's supporting the platform's functions and costs.

(Iain, Telecare Service Manager, pp.5-6)

This excerpt reveals how the pressures of service management are not easily separated from the implementation of policy ideology – telecare must be seen to be instigating change in a tangible and quantifiable way but this is not necessarily related to a greater personalisation of services. And yet, this bid to make telecare indispensable does not tell the whole of Iain's story – while pursuing a 'technology first' scenario, he simultaneously asserted that technology was not an agent of change in itself, services would need to adapt prior to the introduction of telecare for authentic transformation:

Everybody talks about transformation with telecare, especially telehealth. You won't transform services by forcing technology, you've got to integrate

the services and use technology. Technology's just part of the journey, part of the tool, it's not the answer.

(Iain, Telecare Service Manager, p.6)

The view that service transformation is needed to create the right environment for a successful telecare service does not sit entirely comfortably with Iain's own descriptions of pushing technology into all aspects of adult social care. It is also at odds with Andrea's experience and the council's overarching approach to learning disability services. What is apparent is that the transformation story-line, much like the independence and outcomes story-lines, represents a more nuanced set of considerations than the policy documents admit. Furthermore, while government makes strong links between its transformation agenda and the dawning of the technological turn in social care and health, at a local level this story-line was largely invoked in weak, abstract terms and occasionally used as a proxy for raising other issues.

6.5 The Reassurance Story-line

Like the outcomes and independence story-lines, the reassurance story-line represents one of the dominant messages in the telecare discourse-coalition and is presented as a coherent message even though there is no concrete explanation of what is meant by phrases such as 'telecare provides reassurance', 'telecare reduces anxiety', and 'telecare minimises risk'; and the argument is interpreted in multiple ways by different actors. In a similar way to the transformation story-line, some of the policy rhetoric is also absent from arguments made by local practitioners and service users meaning that while some participants claimed it to be fundamental to their approach to telecare, the impression is left that this is an additional, secondary

consideration. Government policy refers to the reassurance story-line in abstract terms, with particular emphasis on the aspect of safety:

Our values are not weakened but strengthened by using these technologies to complement traditional forms of care to provide residents and their families with increased reassurance, safety, and, above all, peace of mind.

(Department of Health, 2005a, p.5)

Telecare can be particularly helpful in keeping people safe in their own homes, and giving them confidence.

(Department of Health, 2009b, p.51)

A greater emphasis on preventative services, and the use of assistive technology, can give greater peace of mind for those providing care.

(Department of Health, 2010a, p.92)

This story-line was invoked in different ways by different professionals interviewed. A few spoke of telecare providing reassurance for family carers, in particular senior manager, Julie, who stipulated that the needs of carers were a high priority for the council, not least because the struggle carers often faced in coping with the demands of their role was the biggest potential risk to long-term home care arrangements:

What we want to do is to develop more of that 24-hour wraparound support and response, so that...the prevention platform is be able to transfer [an alarm call] to a monitoring system, um, and have a team of care and support and potentially health workers who can respond in an appropriate way, and it not keep falling back to the carer.

(Julie, Senior Manager, p.5)

Telecare assessors, Meena and Vicky also saw reassurance as a key part of their work:

A lot of the equipment that we provide is to sort of reassure the family.

(Vicky, Telecare Assessor, p.6)

What's important for me is...that ability to provide what are relatively simple solutions which can enable a person to feel safe within their own home, and reassure their relatives that they have a means of alerting someone if they were to get into difficulties... So I think those are the biggest things for me around reassurance and independence, and ultimately safety.

(Meena, Senior Telecare Assessor, p.4)

Here, Meena also hints at a discursive affinity between the arguments that 'telecare provides reassurance' and 'telecare enables people to feel safe at home'; the suggestion being that families will feel reassured if their loved ones feel safe at home. Yet, it is questionable to proffer these arguments as wholly compatible, particularly where – as is the case with Meena's statement – the subject of independence is also thrown into the mix. Meena is not the only professional to create an affinity between safety, reassurance and independence:

Telecare [gives] a sense of feeling safe and secure at home, um, they feel more independent, perhaps their daughter and son don't ring them up nagging them all the time...

(Deborah, Telecare Assistant Manager, p.10)

This discursive affinity contrasts with the narrative of one service user who felt that the imperative to increase the safety of her home environment, although reassuring for her family, was a potential threat to her independence:

I mean, sometimes, I'm doing something and my husband will say, let me do it because, you know, you're gonna hurt yourself. And I say, don't take it off me, let me do it; it might take me ten minutes longer to do it and I'm hanging onto the unit like sort of thing. Um, and he'll say, I'm not taking your independence off you, I'm just trying to make it safe. But that's...you're losing

that little bit of independence each day, and that worries me more than anything.

(Margaret, pp.8-9)

However, where professional narratives were concerned, references to reassurance were minimal in comparison to statements about telecare's role in managing risk:

I think that telecare has played a significant role in [enabling] the service users, the providers and the families to manage risk.

(Andrea, CLDT, p.3)

[Telecare] alleviates risk, or is able to respond to elements of risk during the times that care calls aren't taking place.

(Rachel, Social Worker, p.11)

Variations on the above statements were common in interviews with local authority staff, for whom managing risks to service users was of utmost importance. For example, the form designed by the telecare team to help frontline workers make referrals for telecare focused on the technology's role in responding to risk – it asked for only three pieces of information, known as the '3Rs': risk (to the service user that telecare was to mitigate), requirement (the technological response envisaged by the frontline worker) and response (identifying who would respond to an alert). One telecare industry representative suggested that the preoccupation with risk affected other forms of decision-making, particularly in relation to trialling new technology:

Local authority, as with all government organisations, looking at it from the outside coming from private sector, is, um, they're not risk takers, they're risk averse. So anything new which hasn't been proven, they can always find an excuse not to use because there may be some risk against it.

(Mike, Telecare Industry, p.5)

Ironically, the Department of Health claimed in its launch of the preventative technology grant in 2005 that telecare would enable councils to become less risk-averse, although it failed to give details on how this might be achieved:

Increased reassurance for service users and carers resulting from the use of telecare will release services from constraints created by risk-averse policies and practices

(Department of Health, 2005a, p.7)

Very few of the service user participants spoke of risk or the need for reassurance, and where they did, it was not in the context favoured by the policy documents. There was no mention at all of how telecare impacted on family carers, even though a number of people had a high level of support from their families. Only one man, Arthur, directly linked the telecare equipment he used to feeling reassured, and those references related to his own feelings of vulnerability as an older, albeit physically able man who had always lived alone. Arthur's narrative was coloured by his own sense of being wholly responsible for his wellbeing and the increasing worry he had about becoming less able to cope:

So I've been on my own 40 years, and on my own, having to do everything myself... Now, I've worked all my life, unsocial hours, and my body is [like] a car, I'm wearing out. At times, I feel worn out. And so when you're on your own, you think...I mean, as I was saying to Thelma yesterday, she said 'I don't see anybody'. I said, no, I said, but Thelma, you're a bit different, you've got kids and grandkids. And they're fairly good. But when you're on your own...you're more conscious of it.

(Arthur, p.12)

More than any other service user interviewed, Arthur saw the community alarm installed in his house as a lifeline that provided him with continual reassurance. He

wore the pendant around his neck at all times, including on his regular trips away from home as an avid football supporter. Arthur was fully aware that the alarm would not work outside of the home but it nevertheless provided him with comfort and a feeling that he was taking responsibility for his wellbeing:

Wherever I go, I don't take it off me. If I go into [town] or I go down to London regular, it's always round my neck. It's no good but at least I've always got it round my neck. And when you're on your own, things feel always far worse than they really are. I can always press it. And that's reassuring... But if I collapsed, what else do they use [for identification]? I've got this round my neck. This tells people, because they can check up with that. Although it's no good effectively where you are, you've got your [pendant] and so you've got the reassurance.

(Arthur, pp.9-10)

Arthur's perspective was undoubtedly influenced by his previous work experience in the police force and a sense of duty that he should help others to help him should the need arise. Nevertheless, the pendant alarm appeared to provide no more than symbolic reassurance as despite describing a number of incidents where he had become suddenly ill Arthur had never resorted to pressing the alarm:

I: But even on that day when you were up at one o'clock in the morning, struggling to breathe, you didn't press it?

R: No, because I'd had it before and I've raced out of the house before... But I got my breath. But it gives you that reassurance.

(Arthur, pp.10-11)

Another service user gave an entirely different account of the impact telecare had on his anxiety levels. Harry was a middle-aged man with a learning disability and a form of epilepsy living in supported accommodation. He had a number of low-tech devices, such as automatic lights and an alarm to remind him to take his medication.

However, he also had a wrist-worn falls detector that was linked up to community alarms and the council's 'Virtual Visiting'²³ system had been installed, all of which appeared to be causing him some confusion and anxiety:

I: So do you use [the Virtual Visiting system]?

R: I haven't used it for a while because I know the times, with the machine that's on there, every so often, when I haven't even touched anything, seems to ring off as if somebody's trying to get in touch.

I: What seems to ring?

R: That, er, machine at the back, that white one.

[Interviewer tries to identify machine Harry is referring to]

I: Oh right. So somebody...you think somebody's trying to call you on that, that's the community alarms box?

R: I mean, it seems as if it keeps going off every so often.

I: How does it go off, is it an alarm?

R: I don't know if it's an alarm or what when it goes off. Because I know when I press that, er...the whatsaname in the middle of that watch type thing...

I: Oh, yeah, the falls watch. Yeah.

R: That, er...that sets it off at times when I've used that, and got through to the people I've got to talk to.

I: Yeah. So do you mean that when it goes off, it goes off when you don't want it to?

R: It makes me wonder what's caused it to go off.

²³ Virtual Visiting is a software-based initiative that allows video communication through a person's own TV using a set-top box. It was introduced by the council to enable calls between health and social care professionals and the individuals they care for as an alternative to some outpatient appointments or home care visits.

- I: Yeah. And does that worry you?
- R: Making me wonder if they're trying to get in touch for any reason.
- I: And do they try and call you through that [community alarm box] or through this [Virtual Visiting box]?
- R: I'm not sure.
- I: You're not sure. Has anybody ever tried to call you? Does any...has anybody called you using the Virtual Visiting?
- R: I don't know, I can't remember.

(Harry, pp.2-3)

This lengthy exchange at the beginning of Harry's interview followed his description of his health and care needs and the concern he had that since his care hours had been cut back and replaced with the Virtual Visiting system, he would be more likely to be on his own during an epileptic episode:

- I: Do you have a lot of fits?
- R: No, not just recently, it's just when I felt I've had them when there's no staff here to witness it, because it don't get put in the book if they don't witness it.

(Harry, p.1)

Harry's narrative was punctuated with references to his overall level of anxiety – he was worried about leaving his house, particularly going out alone, and equally anxious about his ability to cope alone with household tasks such as cooking a meal. The Virtual Visiting system had been implemented at this particular supported living scheme in a strategic way – all residents had it installed despite the varying nature of their needs and understanding of this type of technology. Harry was the only

participant of the six living at the scheme who was openly negative about Virtual Visiting during interview and he was adamant that he had not been consulted about the system before it was installed. Virtual Visiting clearly did not provide him with the reassurance the council intended it should, although Harry's narrative was more generally characterised by negative feelings towards the council and this may well have influenced his receptiveness to the new technology:

And it really makes me sick how they do things. Because since I was growing up, since my parents wanted help from the council, the council have always let me down in not getting the help that's needed.

(Harry, pp.6-7)

Harry was not the only service user whose feelings towards the council and health professionals appeared to influence accounts of telecare. Gordon, an older, physically able man with multiple medical conditions had been issued with a carer alarm in order to call for help from his wife if necessary, but he claimed not to know anything about telecare or what the council's telecare team did, dismissing technological interventions as part of a wider narrative on feeling abandoned by the healthcare system:

What annoys me most of all, they put stuff on that I'm not really interested in, and they talk a lot of rubbish, a lot of them. I'm not interested in that either. Now, if it's something sensible, yes.

(Gordon, p.37)

Lloyd, a physically disabled man, also spent much of his interview talking about his conflicts with the social care department but his attitude to telecare was markedly different from the other two men in that he saw the equipment he had acquired as a personal triumph over the council – his own knowledge of technology and

persistence with the local authority, he felt, had enabled him to secure more hi-tech telecare support than he might otherwise have received:

Looking at the Internet and things like that, I see some of the gadgets that I think would be, um...would be quite useful. So I usually ask them if they've got anything like that, and so on... So I feed them information inasmuch as then they can give me what they've brought. But at the same time, I'm also trying to get them to think that bit further, rather than having all these bits and pieces of gadgets and different remote control for this and that, just having a wireless system will do the job just fine, and all I need is one remote, you see... So it's just ideas I come up with, um, and that will get them to start thinking as to how further they can go, you see.

(Lloyd, pp.8-9)

The narratives of service users illuminate the different perspectives on the extent to which telecare can be seen as providing reassurance; and the link between this factor and ideas of safety and risk. As with the previous story-lines, government policy attempts to present a coherent and incontestable argument when a more nuanced understanding of this issue is required.

6.6 *Summary*

Hajer (1995) argues that story-lines are essential political devices that allow the overcoming of fragmentation and the achievement of discursive closure. They have a functional role of facilitating the reduction of the discursive complexity of a problem; and as individual story-lines are accepted they give a certain permanence to the debate, simultaneously allowing different actors to expand their own understanding of a phenomenon and of how their 'work' fits into the jigsaw. The four story-lines detailed in this chapter draw attention to the complex and, at times, incoherent arguments that constitute the telecare discourse-coalition and appear to achieve discursive closure on the public purposes and benefits of the technological turn in

social care and health. Viewing telecare as a discourse-coalition looking to assert power and domination in a wider debate on the future of social care and health policy brings new meaning to a field that has too often focused on the technical test of 'what works', allowing for a more sophisticated and theoretically-informed assessment of how the aspirations of service users are being realised through telecare and who is really benefiting from technological interventions.

Chapter 7 Telecare script, invisible work and decision-making

7.1 Introduction

The literature review in Chapter 3 highlighted how previous studies had dealt with the issue of practice in terms of organisational culture and the challenges to widespread telecare and telehealth implementation. Oudshoorn (2011) argues that such research takes an instrumental view of technology, and while the policy discourse discussed in the previous chapter emphasises the hand-in-glove relationship between technology and service transformation, the framing of technology as a tool is inadequate for addressing how technology challenges the norms of care and what it means to care and be cared for. This chapter draws on the material-semiotic approach presented by Oudshoorn (2011), and discussed in detail in Chapter 4, to question the adequacy of current telecare practice for achieving its espoused goal of promoting independence. This is discussed through the presentation of findings that demonstrate the importance of the relationship between individuals and technology; the creation of new roles in the provision of care through technology; and the proliferation of new work brought about by telecare implementation. In addition, the theme of service user involvement in decision-making is discussed in relation to strategic practice, and the concept of 'boundary work' (Oudshoorn, 2011) is introduced as a way of preventing the meaningful engagement of service users in strategic as well as everyday decisions about telecare use.

Taken together, these concepts provide a valuable lens for answering the research questions:

- Is telecare practice fit for purpose, where the avowed purpose is to promote independence?
- How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making

The chapter draws on the narrative interviews (n=23) and observational work carried out as part of the fieldwork. Interviews were conducted with a range of stakeholders, including older service users, with and without disabilities, younger adults with learning disabilities, technology industry representatives and social care professionals involved with telecare and telehealth provision. Non-participant observation was carried out at assessment and annual review visits with service users and at strategic meetings about the development of telecare and telehealth provision at the case study site. A range of technological devices then was in use by service user participants, including medication prompts and dispensers, sensor-triggered lighting and teleconsultation software. The appropriate matching of equipment to potential service users forms part of the analysis presented here.

7.2 User-technology relations

Throughout the interviews and observations, it was evident that telecare was implemented by frontline staff and incorporated into the lives of service users and their carers in a variety of ways. The telecare team was often presented with complicated cases in which a single device was unlikely to provide all of the answers, or even meet the most prominent need of the service user. This resulted in the assessment and review processes revealing some situations where products were well-matched to individuals but many more where the context required an

element of adaptation of the telecare 'script' (Akrich, 1992; Oudshoorn and Pinch, 2008). Examples are presented here of cases where such adaptation occurred – to enable service users to incorporate equipment successfully into their lives but also, it will be argued, to allow the telecare team to issue equipment in atypical circumstances as part of their role as problem solvers. Furthermore, it will be shown how service users subvert the telecare script through sabotage or refusal to engage with it in the prescribed way.

7.2.1 The telecare script

Oudshoorn and Pinch (2008) describe how the script for telecare is written during the design phase, where manufacturers anticipate the interests, skills, motives and behaviours of future users. In the interview with a representative of one of the nationally dominant telecare manufacturers, an easy relationship with potential service users was suggested, whereby meaningful input from the intended recipients of the products was an integral part of the design and development process:

[We're] constantly trying to update it and constantly trying to improve it... So we do focus groups and user groups to understand what the actual end users would like. And so, based on input from those different settings, we'd then try and develop the right product.

(Nick, Telecare Industry, p.7)

The approach of this particular supplier was to be proactive in putting forward new technology to commissioners, using the work they had done with potential users during product development as evidence that their devices were broadly applicable and should be implemented on a large scale. They were largely successful in this

endeavour as evidenced by the majority of service users observed and interviewed having been given their pendant alarm almost as standard. By conceptualising this practice as part of the development of the telecare script it can be argued that the implementation of telecare amounts to a standardisation rather than personalisation of care, whereby anyone judged as 'vulnerable' should be issued with, for example, a pendant alarm and therefore adhere to a particular norm of 'good care' (Pols, 2012). This chapter will show, however, that there were variations in how well this equipment was used, which raises questions about the assessment process and a technology script that leads to the tendency to distribute certain equipment by default, as a safety net.

Another telecare industry representative from a local SME felt the strategy of manufacturers driving procurement led to a situation where some needs were not being met:

We've found unmet need within the fact that you can't get a GPS device that you can actually wear on your wrist that's got a battery life longer than 12 hours...we saw an opening there. But that's a small company like ourselves. The bigger companies, as I say, it comes back to, they're never gonna shift 100,000 of these, therefore they're not necessarily gonna put the effort and time into doing that, because it's not their core business.

(Mike, Telecare Industry, p.13)

This perspective challenges the assertion by the large manufacturer that they are in touch with what is needed. Observations of telecare assessments further highlighted situations where the equipment currently on the market was unsuitable for some people. Box 1 summarises observation notes taken at an assessment visit. Liz's story was complex, hence it had been taken up by Meena, the senior telecare

assessor (STA), and it raises important questions about the script for the medication dispenser, which had been developed on the assumption that the archetypal user would not be accessing their medication outside the home and would have minimal interaction with the device itself. There is no place in this script for a socially active person who may require a robust and portable device. If the representations from the industry participants above are to be believed, it would equally seem unlikely that a manufacturer would be interested in taking up Liz's cause. This appears contradictory when considering that in another part of his interview, large manufacturer representative Nick complained about the marketing of telecare to the old and frail:

The way a lot of it gets advertised, in my view, is wrong. You know, it's advertised with pictures of old ladies lying on the floor, looking desperate. You know, it's completely the wrong image because what it does is help you to live the independent life you want to live. But unfortunately, at the minute, it obviously gets promoted, in the opposite direction. And so, you know, it's not an aspirational product.

(Nick, Telecare Industry, p.11)

Box 1

Liz has been living in supported housing since her discharge from hospital. Her admission resulted from a suicide attempt by prescription medication overdose. She wants to move into a shared flat with her boyfriend but has problems remembering to take her medication and a history of overdosing. She was issued with a medication dispenser, which has compartments for 8 doses of tablets and a timer prompt but it doesn't limit access to tablets and staff feel it is too risky to allow her to move out if there are questions about her ability to manage her medication at

home. She now picks her prescription up from the pharmacy every Friday and takes it to her family, whom she visits every weekend, and who help her manage her tablets while she is there.

The senior telecare assessor (STA) says that the alternative dispenser is not suitable as although it limits access to medication and can hold more tablets, it assumes that the patient will always be in the same place when taking medication and cannot cope with travel – if it is destabilised the mechanism could fail, either preventing medication from being released or allowing the patient access to their entire prescription in one go.

Meena (STA) feels there will be nothing more they can do to help. She says some people find it hard to accept that there isn't a technological solution for every problem.

Another key point in this case is the implication for Liz of the inadequacy of the technology to meet her needs. The management of medication is pivotal to Liz's ability to live independently and fully participate in the lifestyle she wants. Without an appropriate medication dispenser – something that for others provides the simplest of solutions – she is unable to achieve these outcomes and faces the ongoing disruption and dependency of having her medication given to her by a responsible third party.

While Liz provides an example of the lack of personalised solutions based on a prescriptive characterisation of the telecare user, other cases observed demonstrate attempts to implement telecare in situations that were not part of the original script.

Box 2 summarises field notes from the first telecare assessment observed in this study. Despite conversations with the telecare team prior to this visit pointing to a focus on preventive care, this first assessment was with a man who had been referred at the very end of his life.

Box 2

John has physical and sensory disabilities and multiple co-morbidities. He lives with his wife, who is also in a wheelchair, and adult son. He was referred by his support planner for a sensor lamp so that he doesn't disturb his wife when he needs to get up in the night. He was given a carer alert after a previous assessment.

John's wife is confused by the referral as John has recently been transferred to palliative care and has carers and family with him at all times. An assessment cannot be carried out with John as he is having help with personal care during the visit. John's wife and the telecare assessor discuss what equipment might continue to help John. She is unsure what has happened to the carer alert, and John has problems grasping and touching so cannot manage the equipment anyway. Community alarms have recently installed telephone points in preparation for their equipment.

It is decided that the smoke alarms should be linked up to community alarms (once that is installed). The telecare assessor orders a large button carer alert for John but no other equipment is deemed of help at this stage.

After a number of observations it became clear, however, that John was not an isolated case – others were being assessed for telecare when they already lived in extra care housing²⁴ and one visit was made to a hospital reablement unit that was using chair- and bed-leaving sensors throughout the ward. Furthermore, in his interview, telecare service manager Iain laid out plans to start a project to implement a range of telecare and telehealth devices in residential and nursing homes. It is not being suggested here that people in these environments would not benefit from the technology on offer – older people living in care homes are three times more likely to fall than older people living in the community (Department of Health, 2010b) – but a strategy of targeting this end of the spectrum seemed at odds with a policy rooted in the preventive agenda and the promotion of independence outside a care home setting.

7.2.2 Telecare as problem solver

John's case also highlights the issue raised by Oudshoorn (2011) of telecare being framed in 'problem solving' terms. Her point is made in the context of a discourse that reinforces the instrumental view of technology: telecare devices are tools that are expected to solve financial and other resource problems in health and social care whilst also improving quality of life and care. Such a restricted view not only assumes that technologies will always realise the aims of innovators but also 'ascribes a kind of magic' (Oudshoorn, 2011, p.68) to technologies, which inevitably

²⁴ One example was a very old and immobile woman living with her husband in a purpose-built complex of extra care flats with an on-site care team making regular checks during the day. Alarms and sensors were embedded in the flats and linked up to a hub within the complex. The woman being assessed was never left alone and did not leave the flat. The husband managed her medication and although he felt he was managing well, the outcome of the assessment was that the couple should be issued with a medication prompt to remind him to give her the pills at the right time, in case he starts to forget.

leads to disappointment when promises are not as readily fulfilled. It is this ‘telecare as problem solver’ discourse that provides the foundation for a material-semiotic rebuttal of the instrumental account. Moreover, the findings from this study point to a shaping of technology’s problem solver role in a very overt sense at the frontline. In her interview, Meena (senior telecare assessor) describes her role in problem solving terms and admits to feeling dissatisfied when there isn’t a technological solution available:

There are times when we don't provide anything. And sometimes that can be quite difficult because we're used to going out and meeting people's needs and providing a solution... I mean, in most cases, we do try and think of alternative solutions... So yeah, we do try and be as creative as possible, a little bit Blue Peter on occasions [laugh].

(Meena, Senior Telecare Assessor, pp.2-3)

What is problematic about this approach to the role is that assessors could try to shoe horn telecare into any situation with which they are presented. In John’s case, his wife appeared baffled at his referral and admitted to having no idea where his previously allocated equipment had gone. Nevertheless, the assessor persisted with offers of equipment and despite being at a stage in his life when he was rarely left alone and had great difficulty with dexterity, the assessor issued him with an additional large button carer alert. John’s case does, however, demonstrate the importance of a face to face assessment over the desktop exercise that was common with other referrals – without this, John may have been issued with the inappropriate equipment (a sensor lamp) that he was referred for.

The telecare referral for John seemed an almost inadequate response to the situation facing him and his family and raises the possibility that viewing telecare as

a problem solver restricts the capacity of the telecare assessors to consider other, more appropriate interventions. Nevertheless, in John's case, telecare was not offered as the only option – he was being supported by a number of different services more suited to his immediate needs. This was not the case for all assessments observed. Nowhere was this more poignantly illustrated than in the case of Colin, a working age older man who had no contact with adult social care prior to his telecare referral following a fire incident. Box 3 summarises observations made at Colin's assessment and stresses how a telecare response can feel insufficient, bordering on irresponsible, if the only point of contact between an individual and council support is focused purely on technology and fails to identify the wider issues affecting wellbeing.

Box 3

Colin has multiple co-morbidities and some mobility problems, and was referred for telecare by the fire service after they attended a fire at his council flat in a high-rise block. He had left eggs boiling on the hob before falling asleep but due to the medication he had taken, he was not woken when the subsequent fire set off his smoke alarms. The fire brigade eventually had to break in to evacuate him.

Colin's financial situation is very bleak. His flat looks to have been stripped bare of all floor and wall coverings and there are no soft furnishings. He no longer works as he is 'permanently on sick' and he struggles with anxiety but has been given notice that his benefits will soon change. He says he spends no more than £2 a day on food and does not have a TV as he cannot afford the licence. The only electronic

equipment he has is a glucose monitor and a radio. He cannot afford a shower but struggles physically with the bath – his illnesses cause dizzy spells, particularly when he overheats, and he is worried he will collapse in the bath.

Colin does not have a landline as he cannot afford it but has a pay as you go mobile phone. However, he rarely carries it with him as he cannot really hear it or feel the vibration alert. He says if he needed help urgently he has no contingency plan in place and accepts that he may die because of this. He says he was shocked that anybody called the fire brigade during his fire as he couldn't think of anyone who would care enough to do so. He says he does not go out much as he cannot afford the bus and struggles to walk long distances.

Colin should be taking his medication at strict times and sometime he forgets, having taken double doses in the past. The assessor suggests he takes a medication reminder but says he will need the vibrating alert as he is unlikely to hear the alarm. She also wants to connect Colin's smoke alarm to community alarms but this requires a landline and a management fee. Colin is unable to afford this so the assessor agrees to explore options for having this funded by the council.

Once again the assessment process comes to the fore as a vital opportunity to connect with potential service users and uncover the underlying issues that need to be addressed. However, these findings raise the question whether telecare assessors are enabled to undertake assessments in this way when their role is framed in such limited terms. The visit to Colin revealed multiple issues but the assessment process seemed to prevent a conversation about how to improve his

self-esteem and social capital. The creation of new roles and work as a result of telecare implementation is discussed in further detail later in this chapter.

7.2.3 Non-use and misuse

Employing the concept of the telecare script allows for analysis of examples where the script has been subverted. In some cases this amounted to little more than adapting the technology to an individual's lifestyle, although even here questions should be raised about the appropriateness of the telecare provision in the first place. In other cases, however, service users' actions led to their not using the equipment. In one extreme case, a service user had tampered with equipment in an act of wilful sabotage (see Box 4). Such occurrences were apparently not unusual – the telecare team reported a number of cases where equipment had been returned damaged. However, there seemed to be no clear understanding of why this was happening – were they acts of protest against telecare provision? Could they be framed as different ways of asserting autonomy? Or did these acts reflect a level of incompetence or confusion on the part of the culpable service users about the workings of these devices? Few explanations were offered by those involved in telecare provision. In the case described in Box 4, the senior telecare assessor (STA) appeared to understand the woman's actions as a cry for attention and a desire to assert control over a regime of care that had recently been changed.

Box 4

When we return from an assessment visit, another assessor asks advice from the STA about a woman with learning disabilities who is persistently tampering with her

medication dispenser so that the prompt no longer works. The assessor explains that this is an ongoing saga resulting in the technician going out to fix the item every couple of weeks. At the last visit, the technician removed the buttons but the client is now taking out the batteries so the timer keeps resetting. She is a very able and active citizen in her community but rings the telecare team for support on a frequent basis. The STA says that the dispenser will have to be removed and an alternative solution to manage the woman's medication is needed.

Observations of review visits – in which a telecare technician checked equipment after 12 months in use – found more commonly a lack of knowledge about how to adjust equipment so that it worked more effectively for individual service users. Mrs C was 90 years old and living alone. She had a community alarm system and sensor-controlled lighting upstairs so that lights would be triggered when she got up in the night to go to the toilet. However, the technician had been asked to remove the sensors as Mrs C had memory loss and was increasingly distressed by the lights coming on because she kept forgetting why they were there and had begun to damage the sockets in efforts to turn them off. In a separate visit, Mrs W was also using the sensor controlled lights and had tampered with the mechanism in an attempt to adjust the timer but this caused it to stop working. As she hadn't reported the fault she had been managing without the lights for some time. In both these cases a lack of understanding of the workings of the devices led to their not being used. Wyatt *et al* (2002) have described this as involuntary non-use due to the technology's poor integration into the individual's circumstances. In the case of Mrs W this led to her realisation that she could cope without the equipment with few ill effects.

Examples of adaptation or misuse of the equipment were frequently observed in this study and sometimes reported by interviewees. In a review visit with Mr and Mrs F, the telecare technician reported that the community alarm system linking up to a number of different triggers was frequently switched off at the mains. During an interview with service user, Zainub, she showed me how she had used a cushion to cover up the sensor that controlled her bedside lamp, as she was fed up with the light coming on every time she walked past it. In her case, although she appreciated the automatic light at night, the sensor seemed inappropriately placed as Zainub's bed had been moved downstairs into the living room which, during the day, was a hub of activity for her large family who frequently visited and often inadvertently triggered the lamp. Thus, Zainub had to adapt the equipment to integrate it with the different aspects of her life – one of which led her to be appreciative of the technology, another to be exasperated by it. In addition, Zainub had a pendant alarm that she did not like wearing but kept by her bed. In her interview she recalled an incident where she had decided to hide her alarm under her bed to keep it out of reach of her visiting grandchildren. Once they had left, she attempted to retrieve it but, being unsteady on her feet, had fallen and injured herself. At this point, instead of reaching for her alarm, she crawled across the living room to the telephone and called her son, who subsequently phoned for an ambulance. This incident highlights not only the poor fit of the technology into Zainub's lifestyle but also suggests a demonstration of autonomy akin to that described by López and Domènech (2008) whereby Zainub embodied the 'vigorous body' – not only choosing not to wear the pendant as prescribed but also rejecting its usefulness at a time of emergency.

Zainub was not the only participant who chose not to wear their pendant alarm. All six of the participants with learning disabilities had pendant alarms and talked about wearing it on different occasions but none wore it at all times as expected. Many kept it by their bedside as they anticipated needing it during the night more than in daytime. Suzie had her pendant replaced with a wrist-worn device as she had complied with wearing it in bed but kept accidentally triggering the alarm by leaning on it. However, she did not like wearing the wrist device and seemed unconvinced by the need for it:

I: Is it not very comfortable or do you not like the look of it or...?

Suzie: I just don't like wearing it.

I: You don't like wearing it?

Suzie: No.

I: OK. Do you get worried about falling over?

Suzie: Um, I don't get worried about falling over, no.

Similarly, during a telecare assessment, Mr J spoke of his embarrassment at having the police break into his house in the middle of the night, after he inadvertently pressed his pendant alarm whilst wearing it in bed. He had been in deep sleep and had not responded to the community alarm service, causing them to take drastic measures. This incident meant Mr J no longer wanted to wear his pendant at night. Furthermore, while he wore the alarm around his neck during the day, he found it obtrusive and preferred to hide it under his several layers of clothes, meaning it was not easily accessible, particularly with his arthritic hands.

These small acts of telecare script subversion can be viewed as demonstrations of autonomy but also had the potential to result in serious consequences, such as Zainub's fall. They also ran the risk of rendering the telecare worthless where, as in the case of the pendant alarm, the script *required* rather than just expected proactive engagement with the device i.e. by pressing a button:

The problem with a lot of the devices is, again, it's like pendant alarms... If the person's not prepared to work with them, in other words, it's sitting on the bedside table or it's in the drawer beside the TV, then they're next to useless.

(Mike, Telecare Industry, p.11)

Examples of misuse were not confined to the actions of service users, however. In the complex case of Mr M (Box 5) a number of different professionals had colluded to issue him with a device that did not relate directly to his assessed needs but met wider objectives to ensure his ongoing care.

Box 5

Mr M is in supported living due to mild learning disabilities and challenging behaviour. He has other mental health illnesses and co-morbidities. Mr M is assessed as needing one-to-one care 24 hours a day and had previously been given a pendant alarm, which was subsequently removed due to persistent misuse. He has been referred for a door sensor by staff at the supported living scheme as he is deemed a high risk for leaving his flat late at night undetected.

Due to a violent incident involving Mr M just before the appointment, the assessment cannot be carried out with him and is instead conducted with the social work team manager. The manager says that Mr M is very 'able' but he is in supported living

due to his persistent calling of the emergency services and staff are continuously required to distract him and prevent this.

The manager admits that there has only been one serious incident relating to Mr M leaving his flat undetected but he ended up in hospital after feigning a collapse and asking a passer-by to call an ambulance. She claims this situation occurred because Mr M's own mobile phone is diverted so that he cannot get through to the emergency services without going via social work staff, therefore he knows someone else must call on his behalf. He was able to leave the house undetected as his behaviour is particularly problematic at night and he is currently refusing to allow night staff into the property.

In addition to the door sensor, the manager asks for him to be reissued with a pendant alarm to divert his attention away from calling 999. She says she would rather have persistent calls to community alarms. She also thinks he needs to feel that his requests are being seriously considered if his behaviour is to improve. Meena (STA) agrees with the assessment.

The provision of a pendant alarm both as a means to tackle unacceptable behaviour and as an attempt to convince a physically and emotionally formidable service user of their autonomy (whether or not this is a reality) is unlikely to have been foreseen by technology developers who have built a community alarm industry on the image of providing reassurance to frail, older people and their concerned families. Mr M illustrates a wholesale reinterpretation of the script for a pendant alarm, although the appeal to telecare in this instance says more about the lack of options available in

the standard care system to cope with challenging behaviour than it does about the vision for telecare. Nevertheless, the findings reported in this section demonstrate the value of a material-semiotic perspective in focusing on the reciprocal relationship between service users and their technology, and the importance of understanding how the same devices must be understood differently in the ways they are ‘tamed’ through the practices of users and ‘unleashed’ to affect care practices in unforeseen ways (Pols and Willems, 2011).

7.3 Multiple actors, new and invisible work

7.3.1 Service user work

Oudshoorn (2011) reconceptualises the implementation of health technology, such as vital signs monitoring equipment, as a process in disciplining patients to scrutinise their own bodies. Moreover, the popular policy discourse that frames technology as a mechanism for reducing human work fails to acknowledge the involvement and actions of patients that are fundamental to the success of the initiative, rendering this work invisible. Oudshoorn (2011) claims this invisible work does not just include instrumental tasks but requires patients to perform as diagnostic agents, making sense of their bodies and the technology, and effectively becoming assistants to health professionals.

In this case study, the work carried out by service users might be considered slightly differently. Unlike vital signs monitoring, social care related devices did not require specific tasks to be carried out at specific times in order to relay particular medical information back to clinicians. Only in the case of medication prompts was timing a crucial element. Much of the equipment in use, such as falls detectors, pendant

alarms, and the teleconsultation 'Virtual Visiting' software, has a monitoring function that is only triggered following an incident where a third party response is required. This would suggest that the equipment intrudes less into the daily activities and routines of service users and requires less commitment from them than in the case of the telehealth monitoring used in Oudshoorn's study.²⁵ That is not to say that the telecare involved in this study did not require the service users to carry out work. Service users were not required regularly to 'inspect' their bodies in a manner akin to health professionals as described by Oudshoorn (2011). However, they were expected to remain 'on alert' as constantly 'at risk' bodies. While the simple act of a telehealth user submitting data from their device could potentially predict an exacerbation in their illness leading to a timely intervention, telecare users, such as those with a pendant alarm, were required to make their own judgements on the status of their bodies and proactively request attention. In this way it might be argued that the onus on telecare users was greater than on those being monitored externally by medical professionals.

As was shown in the earlier section on user-technology relations, telecare equipment can be perceived as having developed according to a script that contains an expectation about the role, characterisation and participation of the user. All participants in this study to a greater or lesser extent worked with the telecare they were given. Some fully embraced the script – like Arthur, who wore his pendant at all times, even on trips to see his beloved football team play away games. He knew

²⁵ This kind of equipment had previously been in use at the case study site under a pilot scheme but had been funded by the now-defunct Primary Care Trust and equipment had been withdrawn after a lukewarm evaluation of the benefits.

the alarm would not work outside of his home but he wanted to show how well engaged he was with the idea of telecare and felt reassured that if something did happen to him, his wearing the alarm would identify him and help anyone who was with him to respond in an emergency:

I can't swear, they are essential, they're a lifeline for people... I mean, I'm a football supporter and I go to the matches. And I have difficulty now climbing steps, I feel the cold. And if I collapsed, they'd think 'who is this?' I've got this [pendant] round my neck. So wherever I go, I've got that reassurance, which is a very, very big thing. Reassurance is a wonderful thing.

(Arthur, pp.8-9)

In this way, Arthur was a dutiful service user, following the script to the letter, even attaching more value to the equipment than was prescribed. On other occasions, however, Arthur's adherence to the script was challenged by other overriding feelings, perhaps related to worries about being a burden or the consequences of being seen as vulnerable. He admitted during the interview that even when he felt quite unwell, he had never pressed the button for help:

I've had difficulty with my breath, I've had to get out of my house. You panic. Up and down the road. And I can remember one time about 18 months ago, I went up the road half past one in the morning. I was in the gulley trying to get my bloody breath. I thought, oh my bloody God. And in the end I was alright... I've never had to [press the alarm] in distress.

(Arthur, p.10)

Arthur's attitude towards his pendant alarm raises the question: at what point does the work required of service users lead to non- or mis-use of the equipment? López and Domènech (2008) talk of the complicated process of sense-making that a service user must go through to evaluate the situation they are in and the potential

consequences before they decide to press the button on their pendant alarm. Other evidence from this study shows that a level of technical work is expected from service users, even where relatively low-tech devices are concerned – for example, remembering not to turn off community alarm boxes or sensors at the mains, or regularly checking batteries (both scenarios that were observed during telecare review visits). With regard to the Virtual Visiting system, users needed to learn the process for switching it on and making/ending calls, which was not particularly intuitive and in some cases – such as the example of James (discussed later in this chapter) – being unable to meet certain fundamental expectations (for example, being able to read) led to the equipment being completely inaccessible. This in turn meant that the crucial work of raising the alarm in an emergency was beyond the capability of the user.

7.3.2 Role creation

The implementation of telecare at the case study site amounted to a redistribution rather than reduction in work, and this can be seen in the expectation of service users to engage with the equipment in a way that placed more responsibility on them to act as partners with professionals in the management of their social care needs. This reconfiguring of the service user role is accompanied by a number of additional professional roles that further highlight the proliferation of new and sometimes invisible work through the establishment of a telecare service.

Figure 4 shows the structure chart of the telecare team that participated in this research. At the time of the study not all positions were filled and a process of restructuring was looming. However, the chart was accurate during the fieldwork

stage, indicating that the budget was in place to fund each of the roles included. It shows the range of jobs that had been created by the introduction of a telecare service and many of them, such as the technicians, assessors, publicity officer and training officer, were unique to this service. It is noteworthy that the team contained a publicity officer as this demonstrates an acceptance of the need to actively promote telecare both within and beyond the local authority. Similarly, the training officer's remit was to familiarise council staff and other stakeholders with the available equipment and train them in making referrals to the telecare team. Both roles highlight the ongoing struggle the team had to embed telecare in the everyday practice of other professionals.

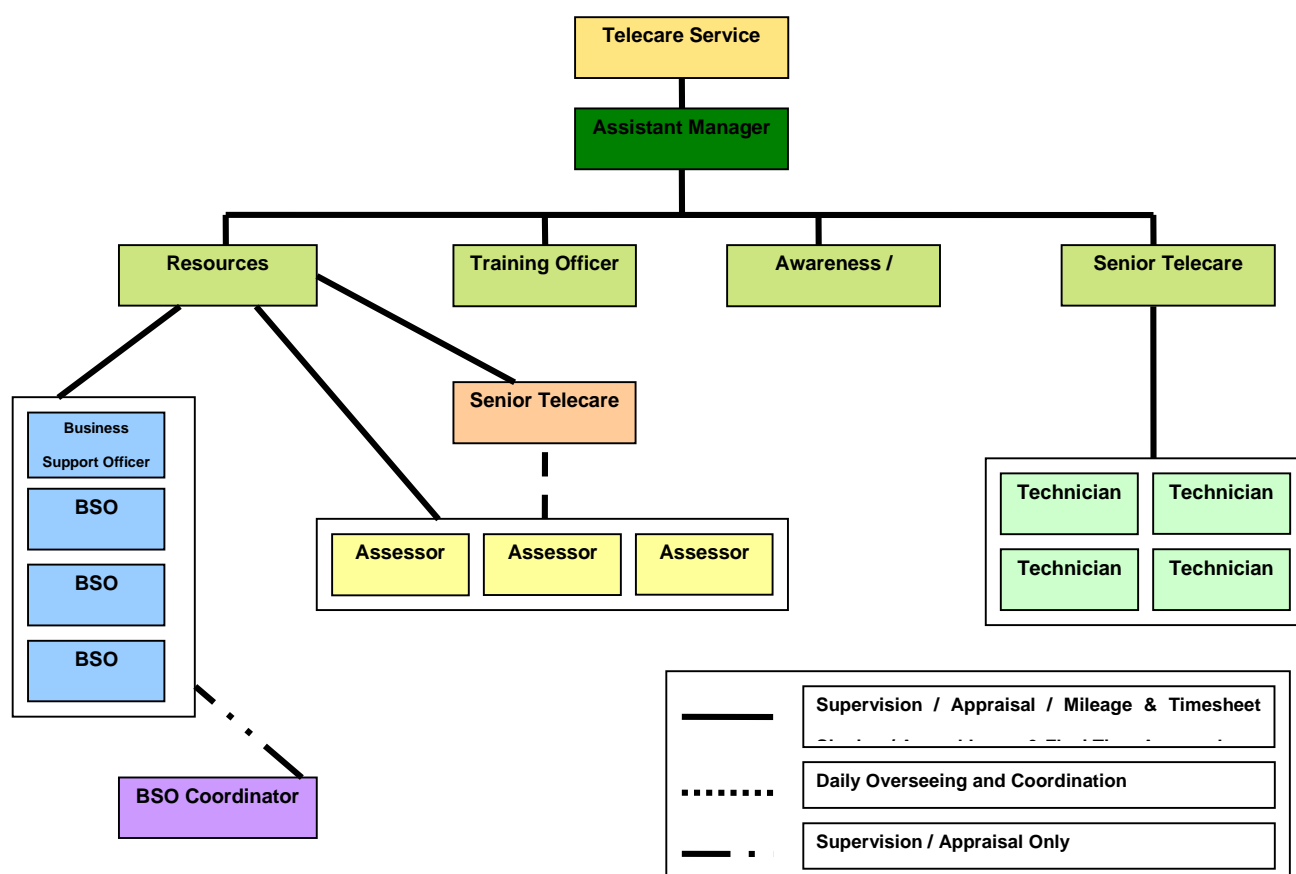


Figure 4 Telecare team structure chart

Of central importance to the team was the telecare assessor role. At this particular local authority this role had been created to demonstrate a clear commitment to rolling out equipment at scale by employing officers to focus entirely on issuing technology. It was also intended as an evolutionary approach to embedding telecare into practice by creating discrete roles rather than immediately adding the burden to social work teams as part of their general assessment process. This reflected an acknowledgement that it may take time for social workers to get to grips with the new service, as well as a tacit acceptance that social work teams were largely sceptical about the benefits of telecare.

At the time of this study talk of restructuring in the telecare team was threatening a reduction in telecare assessors from four to three, maintaining a senior assessor as line manager of the other assessors and the escalation point for more complex cases. The senior assessor was a qualified social worker who had transferred from another frontline team, but none of the other assessors had any social care qualifications, having been moved into these roles after initially spending some time as administrators within the team. The reduction in assessor numbers reflected the objective of the telecare team service manager to transfer the responsibility for carrying out assessments on prospective service users to the social work and other frontline teams. There had been a systematic approach to training these teams to assess for telecare with the intention of establishing the telecare team assessor role as predominantly desk-based – reviewing and approving paperwork on assessments that had been carried out by the frontline teams and making desktop judgements on referrals for telecare rather than visiting the proposed recipient in person. However, through the course of the study it was clear that a backlog of

referrals for telecare meant there was an ongoing need for the telecare team assessors to visit potential service users to carry out assessments, and this was occurring two or three times a day. Four weeks after equipment installation, the telecare assessor would ring the individual to see how they were getting on and talk through any teething problems. However, this phone call rarely resulted in the assessor visiting the service user again – most issues were put down to the functioning of the equipment and this was the domain of the technician. Overall, once individuals had been assessed, the telecare assessors' involvement with the service users appeared to cease. Notes of their input were added to the centrally-held care records system and the equipment was supposedly absorbed into the overall package of care supported by the social work teams and other associated care agencies. From the observations carried out, it appeared there was no formal handover of responsibility to other teams or family carers, and no discussion about ongoing support for using the technology beyond functional issues, which were to be picked up by the technicians within the team. No direct contact details for the telecare team were given to service users – if any problems were to arise, people were advised to call the local authority customer service centre where a triage system would forward a written account of the issue to the team for response. The majority of problems reported related to the equipment (something not working due to a fault or user error) or requests to return equipment that wasn't being used, and this was automatically passed to the technicians to follow up. The only time the assessors would get involved with an existing service user was if a further assessment was deemed necessary after a change in circumstances or a mismatching of equipment to identified need.

Earlier in this chapter, the framing of telecare as ‘problem solving’ was discussed, including how telecare assessors spoke of their own role in these terms. Despite attempts by the telecare service manager to diminish the active role of his team in making assessments for telecare, it was clear that the assessors had established themselves as problem solvers, particularly in relation to the more challenging cases dealt with by the senior assessor, and had carved out a role that was relied upon by other frontline professionals. On the one hand, the reliance on the assessors as problem solvers may be entirely appropriate, in the way that all frontline professionals are expected to draw on their expertise to find solutions to immediate problems. However, as Meena (senior telecare assessor) pointed out in Box 1 at the beginning of this chapter, her value as a qualified social worker could be overlooked by other professionals who expected the telecare team to be able to find a technical, equipment-based fix for every problem that was presented. Many of the professionals attending assessments that I observed were well aware of much of the technology available to them – some had even requested items by brand name on their referral forms – but they automatically deferred to the judgement of the telecare team assessors, wanting them to meet the service user rather than just issuing equipment. Again, in contrast to the claims of senior managers, members of the telecare team seemed to be complicit in fostering this role as expert advisors:

I think the most important thing for me is that it is a service. I think it's very easy to make it into a stores department. So, you know, we do have regular contact with [service users]: they can call us and ask questions about their equipment, they can report faults and know that we'll go out and fix it for them...To me, that is the most important thing, that it's a service.

(Deborah, Telecare Assistant Manager, p.7)

Deborah was keen to align telecare provision with other services provided at the frontline of social care and this framing corresponded to the assertions, particularly by senior staff, that telecare was about *care* not equipment. This point has also been made in policy papers (Department of Health, 2005a). However, the account of the telecare team activity above seems to suggest most roles were focused on the assessment and issuing of equipment processes, with minimal acts of care involved. The observational evidence presented on telecare assessors would seem at odds with Deborah's assertion that the team had 'regular contact' with service users, except that the examples of contact that she recalls almost entirely relate to the work of the telecare technicians. It is true that service users could report issues to the telecare team but, as described above, the triage system in place meant that the response was often deemed to be the realm of the team's technicians. In interviews, members of the telecare team rarely referred to the role of technicians, except in relation to their links with suppliers – in this case they were presented as the gadget experts, introducing the rest of the team to the latest devices:

We have a senior technician [who] liaises with our suppliers, so he does a lot of the feeding back, you know, reporting on what's new, where suppliers are, or going in the future.

(Meena, Senior Telecare Assessor, p.10)

In this way, the technicians were characterised by other team members as being entirely focused on the technical aspects of telecare work, and this role was placed in contrast to that of the assessors:

Obviously, they've got a different take on the functionality of the equipment and, you know, the assessor tends to be looking more at its usability for the

client, whereas the installer's looking more at what he can make it do and what it can record, etc.

(Deborah, Telecare Assistant Manager, p.5)

Yet, the activity that Deborah previously constituted as 'regular contact' with service users – that prevented the telecare service from becoming an equipment store – was almost exclusively carried out by technicians. Furthermore, while much of this activity looked like technical work – for example, dealing with faults – the reality of this work was that technicians spent many hours out in the community, in people's homes having face-to-face contact with service users. Once the telecare assessors had decided to issue equipment, it was the technicians who were charged with installing the equipment and ensuring the service users knew how to use it, meaning they were the last professionals to influence whether or not the service users would successfully engage with the equipment once left alone. In the assessment of Mr J, a frail 90 year old with vascular dementia, telecare assessor Vicky offered him a medication dispenser and insisted that when the technician came to install it, he would not leave until he was convinced that Mr J was confidently and successfully using it (observation notes, 8/5/13).

In a similar vein to the service user work described above, there is a danger in viewing the work of technicians as simply instrumental because this misses the nuances of the work they were actually carrying out. When faults were reported, more often than not the problem lay with how service users were using the equipment. This immediately calls into question the success of the technicians in ensuring service users understood what to do with the equipment in the first place. Nevertheless, when they returned to the homes of service users to repair equipment,

retrieve it or carry out annual reviews, this was the ideal opportunity to strike up a dialogue and gain an understanding of service users' experiences. There were several occasions observed where this opportunity was missed – on a number of annual review visits the only interaction was between the technician and the formal carer present, while the service user was largely ignored. In a more worrying incident, the technician entered the house of one service user through an unlocked back door after the older man with learning disabilities did not respond to knocking on the front door. On entering the house, the technician told the man he was there to test the community alarm but the man did not respond and the technician did not try to engage him in further conversation or show any form of identification (observation notes, 13/6/13).

However, it also seems unfair instantly to malign the efforts of technicians as they were generally poorly equipped to carry out this kind of telecare work. Not only was it invisible to the rest of the telecare team, but overall the positions they occupied were not considered social care roles and therefore the technicians had little training in working with vulnerable people. This raises the question of whether technicians *should* have been better prepared to support the people whose homes they were visiting. For the rest of the telecare team, the technician role was no more requiring of social care training than the average tradesperson. However, in comparison to another scheme commissioned by the council – the handyperson scheme – there appear to be potential benefits being overlooked. A national evaluation of the handyperson programme found there was added value to having 'council-authorised' people attending to small jobs around the homes of vulnerable people as they would identify potential risks and hazards in the house as well as previously

unrecognised and unmet need, often directing people to other sources of help (Croucher *et al.*, 2012). The evaluation also found that having 'handypeople' who had 'bought in' to the idea of helping vulnerable people rather than viewing the role as just a series of tasks added to its success as a preventive service (Croucher *et al.*, 2012)

This lack of social care training was not confined to the technician roles. As previously mentioned, only one of the telecare assessors had a social work background, with the others acquiring their roles after time spent as team administrators (titled business support officers in the structure chart illustrated in Figure 4). This trend is indicative of what might be an assumption that *anyone* could do telecare work and care qualifications were not required. In some instances this could be deemed a welcome development as frontline workers outside of social care were beginning to get involved in the business of telecare. Colin's situation (described earlier in Box 3) was a prime example of this working well as he was previously unknown to social care services but had been rescued from a house fire and then referred for telecare by the fire service. In the case of the technicians, the senior technician Robert took pride in the fact that he hired young people on apprenticeships. He talked about his keenness to use the available positions to help young people with few opportunities turn their interest in technology into a long-term job prospect.

[One] lad worked with us on a bit of a job scheme with the fire service and he left... But he was young. And I like to try and give people...young people don't get much of a break at the moment, so I thought, well, it's a technical thing, a lot of it is...you know, it's all based around handheld devices, phones, that sort of stuff, so they'll be more clued up than generally the older generation anyway.

(Robert, Senior Telecare Technician, p.7)

Robert's conceptualisation of the telecare technician role also raises another under-analysed point: the gendered nature of telecare work. Oudshoorn (2011) considers gender in telecare work in terms of how responsibility for care is continuously placed on women. She observed how telehealth monitoring became absorbed into the caring practices of women in the home, but also notes that gendered work extended into the professional realm. In call centres providing the first response to emergencies, Oudshoorn found that women were often recruited to roles that required contact with patients:

Management preferred women, considering them better equipped because of their social competencies, their ability to remain calm and to cope with stress in crisis situations, and because a female voice would be more effective to reassure callers.

(Oudshoorn, 2011, p.94)

Similarly, in this case study the gendering of work was notable in the recruitment to different roles within the telecare team. While senior technician Robert was focused on targeting gadget-savvy young men in need of a second chance, the route to the supposedly more caring role of the telecare assessor could be tracked back to the predominantly female administrator role. Not only did these personnel practices conform alarmingly to gender stereotyping of caring and technical jobs but they evidently misunderstood the actual work being carried out by the individuals in these roles.

7.4 *Decision-making processes*

7.4.1 Engagement with service users

So far, this chapter has presented findings that show how telecare implementation is challenging the norms of care by creating new tasks and roles, and redefining the identity of the service user. While the resultant practice raises important questions about the impact of implementation on outcomes for service users, it nonetheless would appear to provide the ideal opportunity for service users and their carers to have meaningful involvement in decisions about their care and input into broader commissioning decisions related to the procurement of technology. With increased responsibility for self-management surely comes the right to influence how and with what tools this should be done. Yet, evidence of any aspirations for co-production in telecare services was singularly lacking in this study. It was difficult to get a sense from the service users interviewed about their involvement in decisions about the equipment they should use.

I: Who decided that you might benefit from [telecare]? Can you remember?

Zainub: I think somebody from council, social workers.

(Zainub, p.6)

I: Who decided that you should have all the different bits and pieces that you've got?

Suzie: Er...

Carer: Social services, social worker.

I: Right, yeah.

- Carer: Because what they did, um, they reduced a lot of the hours. So in place, they put these.
- I: Yeah. So did people talk to you about what you might want to have?
- Suzie: Er, yeah, they did, didn't they, Becky?
- Carer: Yeah.
- Suzie: Yeah.
- I: Did they come and ask you what you wanted?
- Suzie: We had a few meetings, didn't we, Becky? And about the hours.
- I: And so...they talked to you about the hours first did they, and then...
- Suzie: Yeah. Told me about the telecare.

(Suzie, p.1)

The overarching decision to provide telecare to some individuals pre-empted discussions with service users and their carers about what devices would be suitable for their personalised needs. This was particularly apparent where a strategic decision had been taken to implement telecare on a larger scale, such as in the case of learning disability services. In the six interviews carried out at one supported living site where the teleconsultation Virtual Visiting equipment had been introduced to replace formal care hours, only one service user could recall using the system on a separate occasion to when it was installed and tested with the help of the technician. When asked about how they got on with the telecare, it was evident from some responses that the individual requirements of service users had not been taken into account. James was a young man with learning disabilities sharing a bungalow with

another young man, Peter, whose learning disabilities were less profound. While Peter generally understood how to use the system and had previously used it to contact the community alarms service just for a chat, James was completely unable to engage with the system unaided due to the way the equipment functioned. His carer explained that changes to the design by adding more call options to the standard community alarm call meant it was no longer accessible to him:

Before, all you'd got to do was switch the television on and wait for it to come on... all we did was press green for go... It doesn't work anymore like that. They put all these pictures on [so he has to scroll] and he wouldn't know what to do. I mean, he just wouldn't. Peter can grasp it but James has no idea because he can't read... It's just totally been spoilt now. I'm just a bit upset for James. I've spent weeks showing him how to do it, and he got it... And now it's all gone, because he doesn't have to do that anymore. It's a shame isn't it?

(Carer, James, pp.9-10)

In a further example of the lack of attention to personalisation, Harry (another person living at the same scheme as Peter and James) reported being frustrated that despite being promised that he would be able to use the Virtual Visiting system to call his mother – the only person he really wanted to contact – six months on, this had not been set up and nobody had spoken to his mother with the intention of giving her the relevant access:

It don't seem to be done at my mum's yet because nobody seems to have been in touch with her. But seeing I can't talk to my mum, as they said they were supposed to be doing, means my mum hasn't had anybody to come... Because I'm the only one who rings my mum the majority of the time.

(Harry, p.8)

Away from the frontline, there were other opportunities for service users to be consulted about telecare decisions that weren't realised: at the strategic commissioning level, for example, there were no discussions about the involvement of service users in decision-making. There was, however, a clear objective to involve other stakeholders in strategic decisions about telecare. UK telecare policy has placed great weight on the integration of health and care services for effective technological implementation, and a lack of integrated services was identified in the literature review chapter of this thesis as a potential barrier to widespread uptake of telecare. Therefore, it is not surprising that senior managers involved in strategic decision-making about telecare at the case study site were concerned about the relationship with other agencies and professions with a responsibility for telecare, not just as frontline providers but also as long-term investors in the service.

The previous chapter described how the UK transformation agenda has put the spotlight on service integration, although the data showed the reality of collaborative working in relation to telecare was a story of complex relationships and competing pressures. Observation of the first two meetings of the local authority's strategic telecare project group (that took place on 19/3/13 and 7/5/13) further revealed adherence to the policy imperative for joint working in this area, with discussions emphasising the need to facilitate integration between adult social care departments and health agencies such as the clinical commissioning groups (CCGs) and the local NHS trust:

Manager 1: There is a will at this time for this integration. The Health & Wellbeing Board set 4 key priority areas, one of which is long term conditions and integrated care, and the focus for a lot of that is around the integration... there is an appetite to do this, if

you can show them something that will work across the organisations.

Manager 2: I think that's key for me – the success of the [telecare] platform is having those services working from the same building, working together, having that interaction and that integration.

(Meeting 2, 7/5/13)

A lot of time was spent discussing how to secure financial commitment from NHS stakeholders by convincing them that telecare and telehealth would meet their needs as much as those of social care in order to secure financial commitment:

Manager 3: It does feel very social care and council centric around some of the developments in the [telecare] service.

Manager 2: No...With the telecare, I think it was 60:40 health [savings] even though they were only putting in 40% of the funding.

(Meeting 2, 7/5/13)

Manager 2: The lights have switched on for [the divisional manager of intermediate care] that she can utilise technology and virtual visiting a lot more to meet the demands on their services as well as meeting the financial efficiencies and doing the service re-engineering...If we can show that we hitting those, particularly QIPP targets, then we're ticking their boxes and doing their work for them.

(Meeting 1, 19/3/13)

In all of these discussions about collaborative working and service integration, however, service users were completely absent, both as stakeholders and potential collaborators in the telecare service, and as providers of a perspective on the shaping of future services. In fact, they were only spoken about in the context of gathering evidence through evaluations:

Manager 4: We know that it's worked for certain groups. We've targeted certain groups and we've had some positive outcomes...Going forward, it's how we get the volume out there that's going to make the monitoring of it more cost effective and the outcomes for the individuals maximised.

Manager 2: That's it, but like you say, measuring that, getting the information back from those that are using it and using that information to promote it to others as well...

Manager 1: If you can show [GPs] a way of stopping those frequent flyers from coming into their surgeries every week, they will bite your hand off.

(Meeting 2, 7/5/13)

The focus on numbers and evidence of proof of concept left no room for discussion of the potential to involve service users in decisions about the service prior to telecare implementation. Furthermore, the perspectives of service users failed to feature in any conversations about the project team's role in managing a redesign of preventive services to place technology at the heart of provision. In the third meeting observed, which entailed members of the telecare team presenting the case for Virtual Visiting to clinicians at the local hospital, telecare service manager Iain insisted that the technology would only work as part of a whole service redesign:

I've been asked by services, 'can we use virtual visiting?' and I've said to them, 'well, what are you going to do differently?' 'Oh we're just going to use virtual visiting.' And we've refused to do it because it's just an additional cost then. If we're not redesigning the service provision...then we wouldn't deliver this sort of technology. Unless there's real change.

(Iain, Telecare Manager, Meeting 3, 9/5/13)

However, the argument for redesign was not only couched in purely financial terms but was focused entirely on professional practice and took no account of the changing role of patients. There was no suggestion in any of the meetings observed,

for example, that there could be a place for service users or patients in the commissioning and procurement processes, although this is hardly surprising given the discussion highlighted above demonstrating the apparent intention to implement equipment at scale and assess need through evaluation after the fact. It would seem that the rhetoric of transformation can be extended only as far as the boundaries of the existing structures – technology may instigate a redefinition of the role of service users and patients but it is within a system that adheres to the status quo of strategic decision-making processes.

7.4.2 Boundary work

Oudshoorn (2011) presents examples of resistance to technology from clinicians through an account of boundary work²⁶, demonstrating how healthcare professionals maintain their authority by engaging in processes that demarcate and protect their qualifications. She identifies the marketing of telecare devices direct to patients as consumers as a potential threat to the professional autonomy of clinicians who feel it is their role to be gatekeepers to healthcare. The reported reluctance of patients to buy the equipment direct from the supplier is understood by Oudshoorn as a success for the boundary work of clinicians. Other studies have considered the effect of technology implementation on how traditional healthcare tasks are carried out, demonstrating ways in which the technological turn can reconfigure professional roles and boundaries (Petракaki *et al.*, 2012; Nancarrow and Borthwick, 2005; Segar *et al.*, 2013). Here, it is suggested here that the concept

²⁶ Oudshoorn's account is inspired by the work of Abbott (1988), who has conceptualised the 'cultural work' of professions, such as medicine, to establish a sphere of competence leading to inter-professional contests.

of boundary work should be extended beyond the realm of protecting scientific knowledge to the preservation of strategic decision-making processes in social care and health. The non-clinical roles of commissioning and procurement represent a further act of gatekeeping to health and social care services carried out by key professionals whose repeated practices serve to maintain particular decision-making processes, validating their expertise and authority while systemically preventing meaningful engagement from those without an official remit. This boundary (or cultural) work is explained by Abbott (1988) as the development of a system of knowledge governed by abstraction which establishes and maintains professional boundaries, feeding inter-professional competition and enabling the appropriation of various problems under certain jurisdictions.

This understanding of boundary work is apparent in the accounts of members of the telecare team about what the telecare service is and should be. As discussed earlier in this chapter, there were some who resisted attempts to reduce their active input at the frontline, claiming they should prevent the service from becoming merely a stockroom. One assistant manager, Deborah, emphasised the value her team could bring to the service users' experience and this could be viewed as an attempt to emphasise their particular expertise and mark out this new professional boundary. Similarly, descriptions of the different roles within the team, such as the assessors and technicians demonstrated an element of inter-professional competition. Again, Deborah differentiated between these particular roles by describing her perception of how assessors and technicians would analyse the usefulness of new technology.

Other inter-professional contests were apparent away from the frontline in the tension between the need to engage in collaborative working across departments and organisations whilst also pursuing competing priorities, as described in the previous chapter in the 'outcomes story-line'. Despite the strain evident in attempts at collaboration and service integration, the emphasis on joint working in telecare provision has at least forced strategic decision makers to balance professional competition with the need to identify and work with other stakeholders with similar boundaries in order to achieve overarching objectives. However, boundary work also constituted the positioning of professionals in relation to service users and here it was clear that the potential for collaborative working with service users was not even contemplated at the strategic level. Collaboration between professionals with an input into telecare commissioning decisions may have widened the pool from which knowledge has been drawn but it has also redirected focus away from the perspectives of service users, reinforcing the boundaries between professionals and lay people. During the first meeting of the telecare project group there was a brief discussion about whether the right people were in attendance:

Manager 4: We do need a public health voice on this because if we're talking prevention, it's a key element... As a group then, have we got the right people in the room now to move this agenda forward? Are there any key players that we're actually missing?

Manager 5: Do we need anyone from the social work side?

Manager 2: We're involved with [them] in other ways – we meet re support planning and care management services. We only met last week

Manager 5: All right that's fine then...

(Meeting 1, 19/3/13)

The suggestion of asking someone from a social work team to attend could be seen as an attempt to incorporate the perspective from the frontline, even perhaps as a proxy for service user views. Nevertheless, the swift response that the social work lead was involved in other ways could be perceived as an act of boundary work – the particular views likely to be expressed by social workers are perhaps more suited to another forum, they fall within a different jurisdiction and there is no place for them at this particular decision-making table.

Evidence from interviews and observations demonstrate that service users were not involved in a meaningful way in decisions about either their personalised telecare requirements or strategic commissioning of telecare. Furthermore, while at an individual level there was a recognition that professionals should consult with potential service users about their needs, at a strategic level the professional boundary work at play ensured that the role of service users in commissioning decisions was not even contemplated beyond their framing as evidence for future investment.

7.5 Summary

This chapter has analysed the practice of telecare through the re-conceptualisation of technology as an agent in challenging the norms of care, rather than as a tool that can be applied to solve the ‘problems’ presented by individuals and by the care system as a whole. Through the lens of the ‘script’ that embeds assumptions in technological equipment and consideration of the framing of telecare as a problem solver it has been shown that assessment processes can become constrained and less able to provide a personalised response to need, leading to non- and mis-use

of the equipment issued. Despite the telecare industry claims of involving service users in technology development, examples from this study showed a lack of fit between devices and users, with assessors unable to offer better alternatives. In addition, while senior staff spoke of telecare being about care rather than technology, frontline staff relied on the telecare team to provide technical 'fixes' for their problems and occasions were observed where alternative provision was potentially overlooked in favour of technology.

Observing the practices of the telecare team showed how new roles, such as that of the technician, had been created but in some ways had become 'invisible' with key tasks and opportunities to support service users being unacknowledged. Similarly, the work of service users as pivotal in making the equipment a success was generally overlooked. A lack of knowledge about how and whether service users were engaging in ongoing use of the equipment stemmed from the delegating of the reviewing process to technicians, who were ill-equipped to discuss with service users their ongoing support needs. Moreover, observations of frontline and strategic decision-making revealed a distinct absence of service user involvement in these processes, which was particularly apparent when focus was being directed at integrating services and meeting the needs of other stakeholders. It has been argued that this can be partly explained through extending the concept of 'boundary work' to include the roles of professionals making strategic decisions about telecare. A preoccupation with collaborative working across team and organisational boundaries – as required by the most recent health and social care policy pronouncements – has led to an emphasis on establishing professional boundaries as part of the efforts to coordinate competing priorities. It has been suggested here

that this has the potential to take focus away from engaging with service users at this level. This has contributed to a lack of awareness on the part of service users of what the telecare team does, what equipment is available to them and how the equipment that is issued to them is benefiting their lives.

The presentation of these findings has a bearing on the research question of whether telecare practice is fit for purpose in the pursuit of the aspirations of telecare policy. It has suggested that opportunities to fulfil the potential benefits of telecare are being missed through current practice. Similarly the question of whether telecare is an empowering service has been addressed through the consideration of service users' involvement in decision-making, which has been shown to be marginal at the case study site. In the next chapter, these findings and those from the telecare story-lines presented in Chapter 6 will be brought together with key issues from the policy and academic literature reviewed to discuss the impact of telecare practice on the promotion of independence and empowerment of service users; and ascertain who is benefiting from the technological turn in health and social care.

Chapter 8 Discussion

8.1 Introduction

This study had the aim of ascertaining the public purposes of telecare and comparing the policy aspirations to observed practice, in a bid to understand how far these are realised and whose needs are being met through technology implementation. The research questions were:

- What are the public purposes of telecare provision and whose needs does it meet?
- What are the aspirations for telecare and are these realised in practice?
- Is telecare practice fit for purpose, where the avowed purpose is to promote independence?
- How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

The study drew on two conceptual frameworks that have rarely been applied to telecare research previously. In the first instance, use of Hajer's (1995) argumentative discourse analysis provided a lens through which to assess the policy rhetoric against the reality of local practice and service user experiences. This revealed four story-lines that have reduced the telecare debate to key statements that are presented as a coherent and, to some extent, indisputable message about the benefits of technology. However, the local picture was shown to be less coherent, with multiple perspectives on what telecare is, and should be, achieving;

and for whom. The second findings chapter moved the focus from the impact of policy discourse on local practice and the service user experience to that of telecare as a socio-cultural agent. For this, the work of Oudshoorn (2011) and the material-semiotic view provided a basis from which to assess the relationship between technology and users, and the role of telecare in creating new and invisible work. The concept of boundary work was also considered in relation to the involvement of service users in the decision-making processes of telecare.

The questions of aspirations and purpose have proved to be multifaceted, with a number of goals for telecare apparent in both policy and practice. There is a clear focus in the policy documents on promoting independence and empowerment to improve outcomes for service users. Running concurrently to these aims are the imperatives that telecare implementation will reduce the pressure on budgets and human resources by minimising physical interaction between professionals and users and by preventing unnecessary escalation to emergency and long-term care facilities. What has become apparent through the focus on discourse in this research is, firstly, the multi-interpretability of terms such as 'independence' and 'empowerment'; and secondly, the tension between aims related to the aspirations of service users and those embedded in the interests of public service providers. Chapter 6 explored the story-lines of the telecare discourse-coalition, uncovering a discursive affinity between the arguments of 'telecare improves outcomes for service users' and 'telecare saves the council money' that is presented in a logical and compelling way in the policy documents but nonetheless was observed to have repercussions (mainly for the interests of service users) at the local level.

Furthermore, the wider policy context within which telecare has been developed has been shown to be problematic for the realisation of service users' aspirations. A preoccupation in policy and the telecare literature with viewing telecare as a solution to the ageing 'crisis' and the challenges presented by the economic downturn introduces the possibility that technology will become coercive rather than liberating; and it raises important questions about the implications for service users categorised as other than 'older people'. In particular, this study has pointed to a number of problems related to telecare provision for people with learning disabilities, which can, in part, be attributed to the poor fit of a policy focused on older people being applied to an entirely different cohort of people.

This chapter, then, is concerned with bringing together findings from the literature, policy and theoretically-informed empirical research to discuss the extent to which telecare practice at the case study site achieves the aims of promoting the independence and empowerment of service users. It will do this with reference to the tension created by setting these aspirations against the interests of other stakeholders in the service, and to the impact that a lack of common understanding about these concepts has on telecare practice's fitness for purpose.

8.2 Conceptualising independence

A focus on independence has proved significant as a key theme in the literature, policy documents and in the findings from this study, but at least in its association with telecare it is so often expressed in abstract terms. As the literature review discussed, the term 'independence' is habitually applied in telecare research in a

somewhat opaque manner and the studies reviewed regularly conflated the issue with discussions about autonomy, without defining either term. It is not the purpose of this study to offer definitive definitions of independence or autonomy – these are contested terms in the fields of health and social care research as well as in a philosophical sense, and the topics of wide-ranging debates that are beyond the realm of this thesis. Rather it has been the intention to assess the value of telecare, as applied at a local level, against the parameters set by those in charge of implementing and evaluating telecare at a national level and within local contexts. Nevertheless, there are fundamental tenets of these terms that establish a normative position and are important to emphasise here as they enable a differentiation between autonomy and independence that has implications for how each is understood in relation to different groups of people.

A basic understanding of personal autonomy refers to the ability to self-govern – to make choices and plans, and be able to act in accordance with those freely-chosen plans (Beauchamp and Childress, 2009). This ability is reliant on conducive ‘inner’ and ‘outer’ aspects: the internal capacity of the individual to rule oneself and the freedom from external manipulation (Christman, 2015; Coeckelbergh, 2004). It is worth dwelling for a moment on these conditions for autonomy. In biomedical ethics there is a certain consensus that while there is an aspirational *ideal* of autonomy, the principle acts on a continuum so that for an action to qualify as autonomous it needs only to meet a minimum threshold, for example following a degree of understanding of information and freedom from constraint ‘not a full understanding or a complete absence of influence’ (Beauchamp and Childress, 2009, p.101). Thus,

it is accepted that a theory of autonomy should be kept consistent with the way 'ordinary persons' govern their lives and not be presented as an ideal beyond the reach of 'normal choosers' (Beauchamp and Childress, 2009, p.101). This means that someone with diminished autonomy – such as a person with learning disabilities – may occupy a location on the continuum that is far from the ideal state but nonetheless enables them to make meaningful autonomous decisions, such as stating preferences regarding domestic and social life or refusing to abide by medication or care regimes (Varelius, 2006).

While autonomy is concerned with the capacity to make choices, this does not account for the requisite ability to act upon these decisions independent of the support from others:

Independence is being able to act on one's choices without depending on the consent or co-operation or resources of others.

(Sorell and Draper, 2014, p.189)

This seems a rather fundamental and necessary point of clarification for assessing the impact of telecare as there are potentially different consequences for autonomy as for independence. Yet, this simple distinction is not made explicitly by the policy papers or academic literature considered in this study. Analysis of the telecare policy discourse revealed an independence story-line that comprised different accounts of independence whereby key phrases such as 'remain at home' 'self-management' and 'feel in control' were liberally employed but largely unexplained. These phrases were invoked as rationalisation for local telecare practice and they were by no means benign as they signalled a particular understanding of what it means to be

independent based on functional ability. Implicit within them were assumptions about the empowerment of service users and the choice and control they could exercise both in response to being offered telecare and as a result of engaging with the technology. In this chapter it will be argued that the literature and empirical findings from the current study demonstrate that this understanding of independence, with its underlying assumptions, is founded on – and aimed at meeting – the needs of stakeholders other than the individual recipients of the telecare service. This issue forms part of a broader question of whose needs are being met by telecare provision, which will be discussed following a brief assessment of the implications of telecare for autonomy.

8.3 Implications of telecare for autonomy

The literature review noted a lack of consensus among academics about the implications of technology on autonomy. Where telecare is used to control someone's environment – for example, preventing a frail older person from going into residential care or giving a person control over how they are supported by presenting telecare options as an alternative to carer visits – the introduction of a telecare service has the potential to extensively improve autonomy (Perry *et al.*, 2010). The commonly-used community alarm can be interpreted as such by providing a safety net that not only affords a level of reassurance that can delay the imperative to move into more formalised caring arrangements but also negates the need for potentially intrusive and coercive monitoring, allowing the user to choose when to call for assistance. In this light, the Virtual Visiting system introduced at the case study site could be perceived as generating an enhanced level of autonomy by

offering the user further options – not just deciding when to call but *who* to call and in what circumstances. For example, the system could be used in a social as well as emergency response capacity. However, this example makes two glaringly contestable assumptions about the presence of the conditions for autonomy: firstly, that the reassurance offered by the alarm is in the interests of the individual; and secondly, that the individual has a genuine choice about when to request support.

Dealing with this latter point first, the question emphasises the importance of differentiating between the range of telecare devices that aim to connect the user with appropriate support in response to an alarm being triggered. While the community alarm comprises a pendant with a button that needs to be pressed in order to call for assistance, other devices, such as wearable falls detectors require no active engagement from the user to set in motion a third party response to an incident. (Percival *et al.*, 2009) point to studies noting that older people do not always want falls within the home to be known about, let alone responded to, for fear of negative consequences that could see them being pressured to move into institutionalised care. Sorell and Draper (2014, p.187) further press that those who are ‘medically needy but perfectly competent’ should indeed maintain control over the decision to call for an intervention. In the literature review of this study, examples were given of the dilemma faced by pendant alarm users regarding when to press the button (López and Domènech, 2008). Similarly, the findings from this research drew attention to the decisions made by some participants not to call for help in situations that might have been considered by an observer to require an emergency response. These acts appear to be consistent with the argument that telecare can

be autonomy-promoting as the choice to resist making an emergency call was left in the domain of the service user. However, these choices may not be seen as free from external interference if the individuals concerned felt that calling for help could have consequences for their future care choices. Furthermore, in the case of Virtual Visiting, the findings from the current study presented a number of situations in the learning disability setting where the choice to call for help using this system was removed due to the lack of attention to the needs and capacities of individuals.

These scenarios introduce a picture of service users engaging in autonomous acts that are in defiance of a care regimen stipulated by the telecare device (and the policies behind it). The community alarm may be perceived as providing a safety net but this is predicated on the understanding that the individual complies with their role as service user or patient, insofar as they take action to reduce risk to their health and wellbeing. This action could be to take prescribed medication or reduce the likelihood of falling by minimising movement; or it could be a risk-averse approach to assessing an emergency situation that would ensure the pendant alarm button is pressed more readily. This increasingly undermines the autonomy-promoting arguments for telecare and brings the discussion back to the question of reassurance. If part of the role of telecare is to provide reassurance, it begs the question: who is being reassured? In Chapter 6 of this thesis, the 'reassurance storyline' was identified as comprising accounts of reassurance in policy and practice that equated the concept with feelings of safety and managing risk. Conversely, few service users spoke about feeling reassured by telecare and one study participant, Harry, reported feeling more anxious since having the Virtual Visiting system as its

implementation had been combined with a reduction in his face-to-face care hours, which was causing him to worry about his ability to cope alone. Taken on this evidence, it would seem that the idea of telecare being reassuring and offering a sense of safety appealed more to professionals (and potentially to family and friends) than to the individual concerned.

8.4 Whose needs are being met?

The issue of reassurance signals the need for a broader discussion about whose needs are being met with telecare provision. This study has highlighted the problem of a policy discourse that is not singularly interpreted by those involved with telecare, leading to the incorporation of different priorities in local implementation. The question therefore has to be asked, are these priorities always in the interests of the service user or do they suggest a privileging of the interests of others, such as government policy, local authority priorities or private industry? This is the question to which this discussion now turns, by focusing firstly on the implications of telecare implementation for models of independence and empowerment that are prominent in policy and then by reflecting on the part local practice has played in diverting focus away from individuals in the bid to address other aims.

8.4.1 Models of independence

The consideration of the presence and promotion of independence among service users has become a central interest of this research. The term is ubiquitous in telecare policy documents and academic literature, and the findings from this study have highlighted the different ways in which it has been interpreted and featured in

local practice. What has become clear is that the facets of independence are not universally understood and although its promotion is seen as a wholly positive thing for service users, policy and practice appear to invoke an interpretation of independence that is potentially harmful to the aspirations of service users. This can be termed a 'functionalist model' of independence and it is related to the long-standing debate on the conceptualisation of disability in medical or social terms (Barnes, 2012). There are two aspects of this dominant model of independence that warrant discussion here as they have implications for how telecare implementation should be judged. Firstly, a focus on clinically-defined conditions places parameters on when and how telecare should be implemented, and secondly it privileges a deficit model of disability that the findings from this study suggest has consequences for how different 'groups' of people are expected to live.

8.4.1.1 Functionalist independence and the implications for personalisation

By referring to the prevalent model of independence as 'functionalist' it is meant that ideas about independence expressed in telecare policy and practice foster a conceptualisation of disability and impairment that locates the 'problem' within the individual concerned rather than in environmental factors that create social oppression and discrimination (White *et al.*, 2010). This perception relies on individualistic medical definitions and bio-physical assumptions of 'normality' (Barnes, 2012; White *et al.*, 2010). Disability activists have criticised this model for focusing on medical issues and solutions, prioritising the clinical view and reducing the individual to a constituent of a medically-defined group:

These words that lump us all together – ‘the disabled’, ‘spina bifida’, ‘tetraplegic’, ‘muscular dystrophy’ – are nothing more than terminological rubbish bins into which all the important things about us as people get thrown away.

(Brisenden, 1998, p.21)

Interviews with professionals as part of this research appeared to reinforce rather than challenge the medical model by focusing on the functional ability of service users and how technological devices could mitigate tangible ‘problems’ such as taking the right dose of pills at the right time or alerting a carer in an emergency. However, this is not just a trait of policy and practice – telecare and telehealth research is characterised by studies focused on experimental research with particular devices used by specific groups of people, categorised by their condition. This leaves the field open to criticism that the environments in which technological interventions are implemented are given too little attention.

Such debate is further linked to the issue of personalisation – another aim of telecare according to policy documents but highlighted in this study for not featuring strongly in local practice. A report by the Nuffield Council on Bioethics (2010: 126) identifies telemedicine²⁷, when used for *more than* a substitute for face-to-face care, as ‘a tool that facilitates the delivery of increasingly individualised prevention and treatment measures and it may also be conducive to “whole-person treatment”.’ The report does warn, however, that this potential is very much dependent on how the technology is applied. Here the term ‘whole-person treatment’ is taken to mean

²⁷ Defined in the broadest sense as ‘an overarching term to include all forms of medicine and healthcare carried out at a distance’ (Nuffield Council on Bioethics, 2010, p.125)

action that takes into account a person's wishes, lifestyle and overall wellbeing as part of a key understanding of what personalisation means. It was noted in chapter 6 of this thesis that the language of personalisation was largely absent from interview narratives, despite it being prominent in the policy discourse. At the frontline, the case of study participant Colin detailed in Chapter 7 highlighted the pitfalls of a telecare assessment process that left little space for consideration of alternative ways of meeting the needs of a desperate man. In the end, the telecare equipment issued could only tackle his clinical need (by prompting him to take his medication) and other available devices did not appropriately match Colin's lifestyle (he could not afford the management fee for the community alarm). Moreover, the parameters of the assessment for technology closed off the potential for a more helpful discussion about other services or activities that might support Colin to reduce his isolation and increase his self-esteem.

Where there was the potential for a more holistic approach to telecare was in the implementation of Virtual Visiting equipment, which was being introduced in a systematic way with people in the learning disabilities service. It has been stated throughout this thesis (and will be reiterated later in this chapter) that there was much to criticise about the way telecare had been provided to this client group, particularly in relation to the lack of personalisation. That withstanding, there was at least some intention to make use of the range of features provided by Virtual Visiting software that could allow the user to engage with activities beyond the task of requesting an emergency response following a clinical need. It was suggested that individuals could reconnect with friends and family or create new support networks

through the teleconsultation software, for example. However, the lack of attention to the *individual* needs of service users in receipt of this equipment meant that for most, these opportunities were non-existent. Once again, the question of who is benefiting from telecare interventions comes to the fore, and the absence of personalisation in the provision of telecare in the learning disability service points to a stronger emphasis on the needs of the organisation rather than those of the individual, evidenced by interview narratives and observations of practice that placed greatest weight on reducing the care budget in this area.

8.4.1.2 Reducing dependency on the state

As discussed in Chapter 6, a deficit model of independence was often invoked by professionals who equated independence with reducing dependency on the state, thereby assessing 'needs' from the standpoint of what the system could afford (Zarb, 2003). The focus on what is affordable in times of austerity was mentioned by a couple of studies reviewed in Chapter 3 (Mort *et al.*, 2013; Sixsmith and Sixsmith, 2008). In these studies, concerns were raised about policies for older people's care that frame ageing as a crisis for society and suggest that interventions such as telecare risk becoming coercive when introduced as the only reasonable option for keeping people at home (and out of expensive residential services). Mort *et al.* (2013) argue that this has specific implications for older people – particularly those assessed as having high levels of need – who may become obliged to live in their 'telehome' with increasingly intrusive surveillance that could exacerbate isolation and dependence.

The findings from my research appear to concur with part of this argument, insofar as telecare was not offered to potential service users in a process of engaging the individual in making a genuine choice about their care. The service users observed were never given the choice between telecare and alternative provision – telecare was part of the commissioning strategy and a specific aim was to offer ‘digital first: technology’s the default position’ (Iain, Telecare Manager, p.14). However, in practice this was not a straightforward case of the local authority gradually replacing traditional services with technological interventions, even if this appeared to be the vision of the telecare manager. There was an observed distinction between different client groups in relation to how telecare was implemented. With older people and those with physical or sensory disabilities, telecare devices constituted an addition to their care packages meaning no *de facto* choice was required – most of the service user participants in this position saw the equipment as a welcome bonus to their standard care. The only departure from this approach was in attempts to reduce the volume of 15 minute medication compliance visits, which were replaced where possible by medication dispensers fitted with alarm prompts.

The vision for the learning disabilities service was markedly different in that telecare was rolled out as part of a systematic programme designed to significantly reduce contact hours between service users and contracted carers. In theory, conversations about alternative provision could have been presented to these service users in an empowering way with genuine choices to be made. However, service user participants in this study appeared perplexed by their telecare packages and the inability of all but one individual to demonstrate how to use the Virtual Visiting

software (the foundation on which contact hours were reduced) suggests an informed decision to agree to this kit was unlikely to have been taken by these service users. This is not to presume that the professionals working with this group of people were purposefully minimising opportunities for them to make choices. Perry *et al.* (2009) point to the high levels of acquiescence amongst people with learning disabilities reported in research and propose that, when asked about changes to service provision, they may try to give socially agreeable answers, particularly if the person suggesting the change is enthusiastic and perceived as being of higher status than the respondent. Nevertheless, from these observations, it seems reasonable to conclude on the basis of the research by Mort *et al.* (2013) that – at least at this case study site – people with learning disabilities are the most vulnerable to coercive practice and the consequences of it. Furthermore, the conceptualising of independence as a process in reducing dependency on the state appeared at the case study site to be applied exclusively to learning disability services.

8.4.1.3 The value of interdependence

An important element to any understanding of independence is the perspective on caring practices and what it means to care. Disability campaigners favour a model of independence that views the exercise of choice and control rather than physical ability as pivotal (Glendinning, 2008). As Barnes (1991, p.129) asserts:

Here, the term 'independent' does not refer to someone who can do everything for themselves, a feat that no human being can achieve, whether they have an impairment or not, but indicates someone who is able to take control of their own life and to choose how that life should be led. It is a thought process not contingent upon physical abilities.

There is a clear acknowledgement here that in not being able to do everything for oneself, being independent must allow for the provision of support from another human being. This view is complemented by the work of Wehmeyer and Garner (2003), which has shown that intellectual ability is not a primary predictor of self-determination – rather, it is the result of how people are supported to retain meaningful control over their lives. Moreover, it was found that the environments in which people with learning disabilities live and work contribute to their self-determination status, with those in more restrictive settings having lower self-determination, even when controlling for other factors such as intelligence (Wehmeyer and Garner, 2003). This finding adds to the argument that consideration for the environment in which service users live (and in which caring practices take place) provides valuable information about the likely impact of interventions. For example, at the case study site it was noted that all participants with learning disabilities lived in flats at the same supported living setting even though the individuals concerned constituted a broad spectrum of needs and abilities. Moreover, the Virtual Visiting package had been universally applied to residents, which could suggest that the equipment had been provided on the basis of where they lived – incorporating an assumption about what that setting said about their abilities – rather than due to a personal assessment of their individual needs and aspirations. It further reasserts the position taken by this thesis that the relationships between technological devices and their users should be understood in the context of the practices and conditions within which they function. Technologies are not benign objects, untouched by social conditions – they reflect the contexts within which they are implemented (MacKenzie and Wajcman, 1999; Mort *et al.*, 2013).

Notions of supporting people to take control are particularly resonant in literature on learning disabilities that recognises the interdependent nature of human agency (Caldwell, 2014). The ideology of interdependence was established by feminist and disability scholars and is framed by an ethic of care view of dependency that is nuanced and anti-reductionist. It exposes the binaries of independence versus dependence - care giver versus care receiver - as false dichotomies and the source of unhelpful categorisations of individuals (Ward, 2011). Ward (2011) further emphasises the problem of defining people in this way with reference to the growing numbers of people with disabilities who are also carers – something which can only increase over the coming years.

In the field of learning disability research, the relationship between paid carers and the individuals they support is acknowledged as being distinct in that the staff member may be the person's only source of social interaction and they often class them as friends (Perry *et al.*, 2009). This type of relationship was repeatedly observed during the fieldwork for this study: a prime example being Suzie and her carer who showed a particular affection for one another and told stories of shopping trips and birthday celebrations conducted outside of the carer's paid hours. Taking these observations and notions of interdependence into account, it is hard not to view telecare practice in learning disability settings as having particular implications for these service users, in terms of a loss of service, potential coercion and in the propensity to increase isolation. (Sorell and Draper, 2014, 2012) pose the question of whether telecare will inevitably lead to isolation due to the perceived relationship between promoting independence and keeping carers (informal or otherwise) 'out of

the homes of users' (2012, p.42). They assert that if carers are viewed as an important part of people's social networks then isolation is unavoidable. In the case of older people and those with physical and sensory disabilities it is possible to imagine that a formal carer may feature only minimally in a person's social life. Indeed, in situations where technology replaces some of the caring tasks carried out by friends or family members it may be the case that this strengthens the relationship between these loved ones (Huang and Goldhaber, 2012). However, if it is acknowledged that some people with learning disabilities rely on carers for their social interaction then the introduction of technology as a direct replacement for time with carers must lead to greater isolation.

8.4.2 Empowerment as self-management

Considering the empowerment of service users through telecare use is a key research question for this study. Empowerment is an elusive term, however, and attempts to define it are often based on disciplinary contexts (O'Cathain *et al.*, 2005). In a general sense, empowerment may be understood as a process of enabling power transfer from one individual or group to another (Rodwell, 1996). In a health context, however, the term has been imbued with more meaning and is much more closely linked with ideas about increasing autonomy, expanding freedom of choice, gaining knowledge and taking control (Feste and Anderson, 1995; Israel *et al.*, 1994; Rappaport, 1987). The issue of control is a common theme in the literature on empowerment in a health and social care context, with a focus on redressing the power imbalance between professionals and service users (O'Cathain *et al.*, 2005). Part and parcel of this gain in control, however, is the acceptance of responsibility

and accountability for choices made (Rodwell, 1996). It has also been noted that empowerment is not something that professionals can 'do' to people – it is a social practice involving reflexive activity (Starkey, 2003). However, health and social care professionals have been accused of appropriating the language of empowerment so that it has become part of professional practice, creating new types of professional expertise leading to an extension of their intervening powers rather than a diminution (Baistow, 1994).

The aspect of empowerment that focuses on control, responsibility and the role of professionals has implications for how telecare should be judged. In the first instance, it seems problematic to link empowerment as a social practice with telecare, when the service is predicated on (at least an element of) substituting the relationship between professional and individual with technology. The process of implementation alone appears to illustrate the view that service users can be empowered simply by taking control of task-oriented aspects of their care and there is little regard for the implication of the potential reduction in contact between individuals and their health or social care representatives. This issue is perhaps indicative of the telecare policy and practice approach to empowerment that seems particularly focused on self-management and responsibility. The literature and empirical research findings have demonstrated an attitude to self-management that includes assumptions about the increasing knowledge of service users and about autonomy based on a conception of functional independence.

In his description of three degrees of self-management for people living with a chronic health condition, Schermer (2009, p.689) asserts that empowerment must

entail the education of patients by healthcare providers to enable them ‘to make informed decisions, to set health-related goals and to make health-related behavioural changes of their own choosing.’ The success of this process results in degrees of self-management that range from compliance with medically-prescribed routines to the achievement of concordant relationships between professionals and patients. A number of studies presented in the literature review chapter expressed the worries of professionals related to the self-management aspect of telecare and ranged from raising the expectations of service users over the amount of choice and control they had over the services they received to increasing the burden on, for example, GPs to monitor patients in a certain way (Fairbrother *et al.*, 2013; MacNeill *et al.*, 2014; Magnusson and Hanson, 2003). The issue of empowerment can be viewed in two ways here: firstly, under the assumption that self-management through technology leads to a better-informed service user group; and secondly, that the increased knowledge and subsequent demands of service users has the potential to loosen the ‘knowledge-power knot’ on which professional power is based (Clarke and Newman, 2005). While some of the telecare studies discussed in the literature review reported service users’ improved understanding of their medical conditions, others challenged assumptions of increased knowledge leading to empowerment with results showing a lack of behaviour change in telecare users (Riain *et al.*, 2014; Rogers *et al.*, 2011).

It is helpful here to consider the impact of the different types of technological devices in use. As shown in the literature review (Chapter 3), the argument for telecare that centres on self-management is almost always applied to devices that support people

to manage long-term conditions at home through the monitoring of vital signs. In this instance it is more understandable to equate the use of technology with increased health knowledge as service users must engage directly with the equipment – at the very least becoming expert at successfully garnering a reading. Even though studies in the literature review poured doubt on the idea that increased knowledge should lead to behaviour change, there is some logic in the assumption that people using vital signs monitoring equipment are at least likely to get acquainted with what the device is reporting back to clinicians, and could potentially relate that information to how they are feeling at a given time. However, the case study site at the centre of this research did not commission this kind of equipment and the commissioned devices did not require service users to engage with them in the same way. Some equipment, such as the sensors for lights and bed or chair leaving mats, required no direct engagement from service users at all once they were installed. The primary function of this kit was to promote independence by preventing or reducing risk to the user. There was certainly no expectation that the telecare was dependent on service users' knowledge about their clinical condition or social care need, or indeed had any kind of educative function.

It is worth looking more closely at medication management as an example of this. Being able to manage medication independently was seen as a threshold for social care intervention and could mean the difference between living in a community or in an institutional setting. The case of Liz, described in Chapter 7, illustrates the impact a decision about someone's ability to manage their medication can have. Nevertheless, using telecare as an intervention to support medication management

demonstrated that being trusted with medication did not depend on increased awareness of the relevant condition. The pill dispenser is pre-filled with up to a month's worth of medication by a third party – the only requirement of the patient is to respond to the pre-set alarm prompt by taking the dispensed dose. The device certainly allows for patient autonomy by leaving the decision of whether or not to take that dose up to the individual. However, in terms of empowerment and self-management, it could be argued that such equipment removes from individuals the burden of understanding their conditions, enabling them to be less engaged with their personal health management than would have been the case with previous arrangements. Of course, the pill dispenser is often distributed in cases where individuals are already finding their medication regime difficult to manage, but comparing this kind of telecare intervention with a traditional service in which a nurse or carer dispenses the pills, it is possible to imagine that the latter may at least present an opportunity for an informative conversation about an individual's condition and medication management to ensue. From this perspective, medication management becomes a further example of how telecare has been implemented as a process in compliance with medical regimen rather than empowerment – respecting the interests of the care 'system' rather than those of the individual. It could be argued, of course, that medication compliance is also in the best interests of the individual, but if it becomes a process of disciplining this leaves little room for the wishes and views of the person to be taken into account. Further evidence of this is apparent in technology development aimed at tracking medication adherence. The United States Food and Drug Administration (FDA) has recently approved the first ingestible sensors that are imbedded in pills and collect biometric information

about the patient to be relayed to healthcare providers (Guta *et al.*, 2012). It is not unreasonable to suggest the potential uses of this information could enforce a kind of self-management that is neither empowering nor in keeping with autonomy.

If empowerment in relation to telecare is conceptualised in terms of increasing self-management, it is also based on increasing individual responsibility for present and future health and wellbeing. Telecare policy represents just one example of a government trend towards imposing this as a personal duty (Nuffield Council on Bioethics, 2010; Struijs and Have, 2013). Most demonstrably, the Wanless Report recommended that individuals become 'fully engaged' in protecting and promoting their own health (Harrison and McDonald, 2008; Wanless, 2002). Asking individuals to take more responsibility for their health is not inherently unfair. Such a duty requires that persons act in the interests of their future good health (prospective responsibility) as well as being held accountable for their actions (retrospective responsibility). This may well be acceptable for the average citizen and it could be viewed as serving both the personal and collective interest. However, responsabilisation is connected to the perceived strengthening of the patient and service user position and presumes a level of autonomy and empowerment that may be contestable in certain circumstances:

Personal responsibility presupposes at least some degree of freedom of choice, which presumes that persons are free to choose (without coercion), that they are able to choose (being competent and well-informed), and that they have options.

(Struijs and Have, 2013, p.240)

Moreover, a focus on personal responsibility seems to sit uneasily with notions of interdependence. In the light of the discussion so far pointing to concerns about potential coercion in telecare practice and the ability of service users to make informed and genuine choices, serious questions should be raised about the suitability of policies for older people and those with disabilities that place responsibility at the heart of the matter.

8.4.3 Technology-focused practice

Detailed discussion of the fundamental tenets of telecare policy discourse has shown how terms such as independence and empowerment are presented so as to seem innocuous, but in reality are understood in multi-dimensional ways and are deeply symbolic of cultural and philosophical norms. This discussion has been framed by the question of whose needs are being met by current telecare practice and the recurring answer has been that the aspirations and requirements of service users are often placed secondary to those of other stakeholders. Returning to the findings reported in earlier chapters of this thesis, the concept of empowerment appears to fall short of enabling service users to be involved in decision-making processes, either at an individual or service level. In Chapter 6 the 'outcomes storyline' was revealed as comprising a number of priorities that stakeholders negotiated, and better outcomes for service users was only one of those priorities. This meant that some professionals, such as Andrea in the learning disability service, made a distinction between attending to people's 'needs' as opposed to their 'wants'. This distinction was accounted for both in financial terms (a judgement on the best use of resources) and in terms of balancing the desires of service users with those of

other key stakeholders, such as commissioners and the technology industry. These findings were supported by the observational data from telecare practice presented in Chapter 7 demonstrating that strategic decision-making about the telecare service failed to involve service users in a meaningful way. A focus on integrating services and the need to collaborate with other professionals across the public and private sector was at the forefront of discussions, but there was little evidence of pressure from active and empowered service users demanding to have their views heard. Nor did it appear there was space for any such encounter to take place.

Further complicating the decision-making process is the influence of the private sector in the form of the telecare manufacturing industry. The point is made elsewhere in this thesis that while the role of private sector organisations in public sector services is by no means unique to telecare, the nature of that role disrupts the order of care in the way it sets a precedent for companies to shift from a purely manufacturing role into the realm of caregiving by offering fully managed services in addition to the product (Oudshoorn, 2011). Furthermore, evidence from this study points to influential technology producers having a key role in setting the agenda around national policy as well as the choice of products available on the market. A focus on 'script' has been a helpful way of illuminating issues in how technology is designed. In particular, the case of Liz, a socially active woman with mental health problems, highlighted the problem of gaps in provision that did not look like being readily addressed by manufacturers who had at least one eye on bottom line profits. This behaviour is not dissimilar to that which is disparaged in the pharmaceutical industry – the conscious neglect of drug development that is seen as unmarketable

and/or unprofitable (Trouiller *et al.*, 2002; Yamey, 2002). It is also resonant of moves towards activity-based funding in the acute health sector, which puts the focus on throughput and efficiency rather than meeting the needs of a particular population and has been criticised for allowing providers to ‘cherry pick’ patients and procedures that provide the greatest financial reward (Walshe and Smith, 2011). It is not surprising therefore that some scholars have challenged the consumerist-promoting assumption that people want public services to behave more like commercial organisations and indeed question whether we can really get what we want from the commercial sector (Clarke and Newman, 2005; Newman and Vidler, 2006). It has been acknowledged by some that a market-focused approach may produce standardised rather than highly customised products and services (Nuffield Council on Bioethics, 2010). The danger here, as noted in the earlier discussion, is the likelihood that such provision could result in the coercion of vulnerable people as overstretched services narrow people’s choices by forcing them to accept mass-produced technology as a poor substitution for face-to-face care (Mort *et al.*, 2013).

These perspectives demonstrate how the voices of individual service users can be easily overwhelmed by the general noise and jostling for position that has become characteristic of telecare implementation. Furthermore, this practice appears indicative of a focus on technology *at the expense of* the individual. While professionals interviewed in this study consistently spoke of starting with the needs of the individual and building the response around them, observed practice suggested that commissioners and frontline workers were restricted by the products available to them, resulting in flawed assessments and inappropriate ongoing

support. In particular, the job of the technician has been highlighted in this study as having a pivotal role in giving individuals confidence in their use of technology, but the potential of this role has not yet been realised. Technicians at the case study site were the last members of the telecare team to spend time with service users before they were left to fend for themselves with their equipment; and they were also the only professionals to regularly visit service users after implementation, in a bid to provide ongoing support. One of the studies reviewed in the literature chapter found that the moment of technology installation is a crucial point in the process for helping users to feel competent or potentially abandoned, ultimately impacting on the likelihood of sustained engagement with the equipment (Gramstad *et al.*, 2014). However, the support observed at the case study site merely constituted a check-up of the devices dispensed and technicians appeared ill-equipped to deal with issues raised by service users that were not technical in nature, even though they were implicitly relied upon to mediate between the individual and the telecare team.

The application of the technician's role not only highlighted a focus on technology but also revealed a lack of ongoing support for service users. Once telecare had been administered, contact between the team and individuals was sporadic and reactive, raising questions about the potential for signs of the changing needs of service users being missed. It could also lead to greater isolation by further reducing opportunities for service users to engage with care professionals at a time and on subjects that are important to them; and by increasing doubt that professionals actually care about their experiences. Furthermore, it brings attention to a current gap in telecare research that was noted in the literature review of this study: a lack

of understanding of the characteristics of telecare users. While some scholars have attempted to address this (Cook *et al.*, 2013; Peeters *et al.*, 2012) interest has concentrated on those who withdraw from telecare provision and the everyday use of telecare equipment is not well documented. At the case study site, most telecare equipment was not monitored externally or on a continuous basis and the onus was placed on service users to actively check their equipment was in good working order. The notable exception was the medication dispenser that had to be regularly refilled and was only issued to people who had a support network in place to help them manage this. One of the industry representatives interviewed for this research claimed confidently that, in his experience, commissioners have a good grasp of what is and is not being used successfully. However, the findings from this study suggest commissioners make assumptions about technology use based on a 'no news is good news' principle. This was particularly apparent in the learning disabilities service, where a reduction in calls from service users to the community alarms team through Virtual Visiting was heralded as a success but fieldwork from this study revealed that few people knew how to operate the system.

8.5 Reflections on the study and limitations

Having presented the findings from this research and engaged in a discussion of the salient issues, it is important to pause and reflect on the potential limitations of the approach to this study. The choice of a case study design was discussed in depth in Chapter 5, and it is clear that the limitations of that methodology apply here – particularly in relation to the single-case design that can be criticised for being less compelling than a multiple-case study (De Vaus, 2001). It is not clear whether all the

findings from this study are likely to be replicated elsewhere, although the issues identified with UK, and indeed global, policy would raise the same questions in relation to any other case site in the UK. However, the use of novel theoretical frameworks inevitably privileges a particular perspective on social phenomena to the detriment of others.

As with all PhD projects, this study has been limited by what can be achieved by a single, relatively inexperienced, and resource-poor researcher. This issue was particularly pertinent to this project when it coincided with major change in primary care arrangements that not only affected the case study site as a participant in the research, but also affected the course of the research in terms of changes to personnel through restructuring that delayed the fieldwork phase. Problems of access are a known feature of case study research (Denscombe, 2010). Yet the commitment that the funding arrangement afforded ensured there was no lack of willingness on the part of the case site to support the research but events occurred that were beyond the control of the researcher and partner organisation.

In addition to the delays caused by organisational changes, access to service users as participants became problematic as the recruitment of older people proved more difficult than expected. This was due to a lack of interest in becoming involved in the study – which may reflect a lack of importance that potential participants attached to talking about telecare – but was also the result of inaccurate information on eligible people. Although the telecare team helped to identify potential participants through access to the social care database, on a number of occasions the records of telecare

equipment were incorrect or out of date resulting in some wasted attempts to engage with service users who were ineligible to participate in the study.

Similarly, there were limits to the skills and resources of the researcher required to involve certain people as participants. For example, agreement had been made with the local authority that the study would only include people deemed to have capacity to consent, which had an impact on the ability of this study to reflect the experiences of those habitually more marginalised in research (and, indeed, in other aspects of society). It also proved beyond the reach of this study to involve people who had capacity but needed additional support to get involved. One such example of a potential participant with hearing loss was discussed in relation to ethical considerations in Chapter 5 as, despite several attempts to engage him as an eager participant in the research, a lack of support afforded to him meant I could not pursue his involvement in the study.

8.6 Summary

Analysis of policy and empirical data has exposed the need for detailed interrogation of a number of key terms that form the backbone of telecare policy and are central to the research questions posed in this study. Concepts of independence, and empowerment are pervasive in telecare policy, practice and research but they are rarely defined in this context and the findings from this study illustrate the lack of a coherent message about their relationship with technology development and implementation. This discussion chapter has sought to engage with the complexity surrounding these concepts as core aspirations for telecare in order to identify the

practice reality and assess the impact on service users. The question of whose needs are being met by telecare provision has been revealed as pivotal in subsequently answering the other research questions as the dominant conceptualisations of telecare aspirations point to the prioritising of organisational, political and industry interests above those of the individual. Such findings demonstrate how the realisation of policy aspirations in practice are seriously curtailed, raising questions about telecare practice's fitness for purpose. It also leads to the conclusion that telecare is not inherently empowering – the provision of certain devices has the potential to empower service users but this is dependent on the practices and conditions of use, as well as the existence of processes that enable the meaningful involvement of service user in decision-making.

In response to the issues raised in this discussion, the thesis will now conclude by returning to the research questions for the final time and making recommendations for policy, practice and research that seek to redress the central problem of failure to understand and prioritise the needs of the individual.

Chapter 9 Conclusions and recommendations

9.1 Introduction

This study was concerned with addressing gaps left by current telecare research trends and contributing to an emerging body of work that is challenging the policy premise on which technological interventions are being introduced into health and social care services. At the outset, the thesis asserted that international research into telecare and telehealth has been principally concerned with providing proof of concept and evidence of cost effectiveness (Bayer *et al.*, 2007; Bensink *et al.*, 2006; Dang *et al.*, 2009; Paré *et al.*, 2007; Polisen *et al.*, 2010). The literature review revealed that despite a search for studies under the keywords ‘independence’, ‘empowerment’ and ‘aspirations’ questions of technology efficiency and effectiveness remained central to analysis in many cases and they were largely under-informed by the lived experiences of service users. The field has been accused of being typified by poor quality evaluations, and systematic reviews deem many study designs to be methodologically inadequate (Barlow *et al.*, 2005; Finch *et al.*, 2007). Evaluations of services have been further complicated by multifaceted definitions of telecare and telehealth and under-developed approaches to identifying appropriate recipients of the interventions. In addition, while many studies report largely positive outcomes for those who engage with telecare and telehealth services, there is little discussion of the aspirations of service users or questioning of whose needs are really being met through this provision.

With all this in mind, this study posed the following research questions:

- What are the public purposes of telecare provision and whose needs does it meet?
- What are the aspirations for telecare and are these realised in practice?
- Is telecare practice fit for purpose, where the avowed purpose is to promote independence?
- How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

The aim was to look beyond the question of whether or not the equipment ‘works’ and investigate the intended public purposes of these services, considering whether they were fulfilled in practice at the case study site. This was achieved through the application of two theoretical frames underpinned by a narrative approach that allowed for an interrogation of the policy pretensions and a reconceptualization of technology through the privileging of the accounts of different stakeholders, such as the commissioners, social workers and other frontline staff, senior managers and telecare industry partners; as well as of telecare service users.

9.2 Returning to the questions

Having presented findings and discussed key issues, a final summary in response to the research questions is now provided.

9.2.1 What are the public purposes of telecare provision and whose needs does it meet?

When it came to the public purposes of telecare, the research showed that telecare was the subject of policy claims about tackling challenges presented by the demographic 'crisis' and economic uncertainty. Telecare was framed as a key component of the transformation agenda for health and social care, whereby greater collaborative working between agencies and more personalised services would be partly enabled through the technological turn. These macro and meso level concerns were assumed to work to the benefit of the micro level in terms of improving outcomes for service users. However, the analysis of discourse presented in this thesis and particular interrogation of the key terms 'independence' and 'empowerment' demonstrated a lack of direct translation of policy messages into local practice, where different and competing priorities were being managed, and those of service users constituted only part of the story. Moreover, multiple interpretations of the key concepts associated with telecare revealed potentially incompatible views on whether the needs of service users were being met.

9.2.2 What are the aspirations for telecare and are these realised in practice?

Aspirational statements were made in policy about promoting independence and increasing the empowerment of the individual but the study findings highlighted a lack of coherence about how to interpret these contested terms and challenged the extent to which the desires of service users were prioritised over the interests of others. Thus, on the basis that observed practice seemed rather unengaged with the aspirations of individual service users beyond enabling them to stay at home for

as long as possible, it was hard to conclude that telecare was realising its aspirations. Rather, it appeared to be achieving modest outcomes for individuals, implemented in response to a social care or clinically-defined need.

9.2.3 Is telecare practice fit for purpose, where the avowed purpose is to promote independence?

In terms of fitness for purpose, telecare practice at the case study site can be judged in different ways. As clarified in Chapter 1, the term 'fit for purpose' refers to the extent to which observed local practice can be deemed to be meeting the key aspiration of promoting independence. Following the findings already discussed it would appear that local practice is trying to fulfil a range of policy imperatives but is driven by the priorities of local stakeholders – from care providers, partner organisations and equipment suppliers; to frontline staff, commissioners and senior managers; to service users, carers and the wider community. This influenced the approach taken to 'promoting independence' and meant that very often maintaining someone's independence was interpreted as reducing their dependence on the state. This appeared to have a particular impact on participants with learning disabilities who were being issued with telecare equipment in a bid to decrease their care package.

A focus on telecare as a socio-cultural agent that influences both the relationship with the individual and the work of professionals and service users, revealed a number of flaws in telecare practice where service user outcomes are concerned. The 'script' ascribed to technology at the design phase was sometimes a poor fit to

service users and could inhibit their practices to the extent that it led to non- or mis-use of the equipment. This had the potential to be compounded by an assessment process that is too intent on a technical 'fix' and does not take into account alternative support better suited to the individual. In addition, a lack of acknowledgement of the new and sometimes 'invisible' work of professionals created by telecare created missed opportunities to provide ongoing support to service users and realise the full potential of telecare to benefit the individual.

9.2.4 How far is telecare an empowering service and to what extent is this linked to the involvement of service users in decision-making?

The concept of empowerment had been considered in the policy papers and academic literature in relation to self-management, and this was discussed further in Chapter 8 in the light of findings from this study. Here it was shown how empowerment in relation to telecare has been conceptualised in terms of the service user taking control through increased knowledge and behaviour change, and also taking on greater responsibility for their health and wellbeing. Findings from this study raised questions about the assumptions implicit in this framing, particularly in relation to the ability of some of the participants to 'take control' and become 'responsible' service users through their use of technology. The example of the medication dispenser was given as illustrative of the mismatch between ideas of empowerment and the reality of managing a medication regime.

A key part of the empirical research was to understand the decision-making processes in relation to telecare provision and the involvement of service users. This

was considered with regard to the empowerment of service users – a conceptualisation that was not apparent in either the policy or academic literature. The findings showed that telecare was rarely presented to service users as an opportunity to make decisions about their care – most of the older service users were grateful to be issued with equipment as an addition to the care they received, and study participants with learning disabilities largely failed to recall their involvement in the decisions to replace some of their care hours with telecare. At a strategic level, observations revealed senior managers' preoccupation with the policy imperative to work collaboratively to deliver telecare services. However, this had the potential to draw attention away from engagement with service users on commissioning decisions and discussions on the future development of the service. Service users had little contact with the telecare team following the assessment process, which left them feeling removed from discussions about their ongoing support needs. Overall, while telecare may have the potential to empower people, either through self-management or more meaningful engagement in decision-making about their care, evidence from this case study suggests this is not the reality for many – particularly where people with learning disabilities are concerned.

9.3 Contribution to knowledge

This study has aimed to make a theoretical contribution to the field of telecare research. This area of health and social care research has been characterised by a lack of engagement with theoretical concepts, as highlighted in the review of literature conducted for the thesis. By contrast, this study has sought to address this issue by drawing on two theoretical frames that are interdisciplinary in nature and

complement each other but nonetheless have not previously been applied to research in this field in this way. In using these theories, the thesis seeks to contribute to an emerging debate on what it means to care, which is intent on moving beyond questions of technology effectiveness to a judgement of telecare policy and practice that is grounded in the experiences of service users and acknowledges the role that stakeholders with competing priorities have in making the service work.

Through alignment with the specified methodological approach, the study has questioned the coherence of telecare policy, highlighting how competing priorities have the potential to undermine the needs and aspirations of the individual. It has also identified the presence of new and 'invisible' work that remains largely unacknowledged, under-valued and is not applied to full potential. Finally, this research has demonstrated how aspirational concepts that form the foundation of telecare policy have varied interpretations according to different stakeholders and are applied differently to different groups of people, resulting in variable outcomes for individuals.

The results of this study point to a number of recommendations for how policies on telecare should be framed, how the practice of telecare should be developed in the best interests of service users; and suggestions for future research in this area. These are described below.

9.4 Recommendations

Table 4 Details the recommendations made by this study in relation to research, policy and practice. This is followed by a final statement on the future of telecare and next steps for research.

Table 4 Recommendations table

Implication	Recommendation
Policy	Policy needs to be more nuanced in its promotion of telecare, making better use of research evidence to distinguish between devices and promote a more targeted approach to implementation.
Policy	In promoting independence through telecare use policy must move away from the rhetoric of austerity and a deficit model of ageing, which can lead to potentially coercive means of technology implementation.
Policy	Policy should engage with a user-led understanding of independence and empowerment in order to meet their aspirations.
Practice	More thorough consideration should be given to the real work that is being carried out by people involved with telecare. This should be accounted for in evaluations and actions should be taken – such as with more appropriate training – to ensure the most value is added through these roles.
Practice	The assessment process is flawed in the way it judges the needs of users and fails to join up with other services. User-centred assessments should be adopted to better identify need and link individuals with appropriate provision. This should reflect developments in other areas of health and social care where the co-production of services is encouraged.
Practice	Service users need better ongoing support that includes regular contact with the telecare team, a more thorough 'handing over'

	process when the technology is issued, and a more timely and frequent review process.
Practice	Service users should be provided with a formalised way of providing feedback to the telecare service and influencing commissioning or procurement decisions, either in terms of ongoing communication with the telecare team or by feeding into the strategic processes.
Research	The field must continue to build on a theoretically-informed approach to telecare research that addresses more pertinent questions about telecare than 'what works'.
Research	Current research is preoccupied with older people and the demographic 'crisis' but more work is needed to provide evidence for the appropriate implementation of telecare in learning disability settings.
Research	The characteristics of telecare users are not commonly understood and policy and practice would benefit from a research agenda that aimed to better inform these areas. To this aim, less focus should be placed on experimental designs in favour of methods that investigate the everyday use of telecare and support requirements of service users over time.

This thesis began with a discussion about the definitions of telecare, outlining the difficulties facing research, policy and practice in relation to conveying a shared message under a shared understanding of terminology. Research into technologies continues to be generated at pace, as is demonstrated by the fact that the majority of academic literature reviewed in this thesis was published within the last four years, and the debate around language is likely to continue. However, devices are increasingly being produced for wider audiences through the use of everyday

technology, such as smart phones, and some have suggested that this signals a shift away (at least in funding terms) from creating smart environments with a focus on the home to the development of wearable technology that can be wherever the user is (Hunn, 2013). It is therefore possible that specialist terms such as telecare and telehealth will become obsolete as the drive from government and the technology industry ensures technology will simply become a part of how people access services.

There is seemingly no doubt that the technological turn in health and social care has been established as the future of service provision: the NHS Mandate for 2013-2015 cites the objective to increase technology use within the service as a priority – stating that in a digital age the NHS should be at the forefront of new technologies that can help people manage their health and care (Department of Health, 2013). Similarly, the UK government's recent report on 'the internet of things' (where everyday objects are connected to a network to share data) reiterated the potential for networked technology to deliver enormous health benefits (Government Office for Science, 2014). Investment in telecare and telehealth has also been highlighted as good use of the new Better Care Fund, a plan to pool resources for integrated care (Bennett and Humphries, 2014).

Nevertheless, as technology becomes embedded as the method for providing services, new problems are set to arise that will need to be addressed by policy, practice and research. In addition to the issues raised in this study, there have been

increasing reports of technological and system failures putting service users at risk²⁸ (Lowe, 2013a). In the US there have been moves by some states to limit the growth of teleconsultations as a replacement for face-to-face appointments for treating patients due to concerns that they could damage the establishment of long-term patient-clinician relationships (Modern Healthcare, 2015) Furthermore, the government's chief scientific adviser has warned that 'the internet of things' risks several major threats in healthcare: data security and ownership, hardware security and interoperability, and change management (Government Office for Science, 2014). These threats relate to the amount of data generated through connected healthcare devices and questions about what should happen to it; the reliability of networked devices in terms of their resistance to hacking and their ability to connect with other applications; and the ability of healthcare professionals to give informed and up to date advice about the opportunities and risks of new devices and systems. These issues demonstrate the new challenges for telecare research and practice but equally represent a prospect for technology as a core part of future health and care provision.

²⁸ For example, a networked smoke alarm failing to alert the fire service, resulting in the death of a disabled woman (Lowe, 2013a).

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Appendices

APPENDIX 1: CASE STUDY TELECARE EQUIPMENT LIST

CASE STUDY TELECARE EQUIPMENT LIST

Supplier Name	Equipment Name
B.E.S. Ltd	Lockable gas valve for individual appliance
Byretech Ltd	Magiplug for bath
Byretech Ltd	Magiplug for hand wash basin
Byretech Ltd	Magiplug for kitchen sink
Chubb Community Care	Accept Pendant (for Horizon Plus)
Chubb Community Care	Actuator
Chubb Community Care	Additional pendant
Chubb Community Care	Bed occupancy alarm for Intellilink
Chubb Community Care	Bed occupancy sensor
Chubb Community Care	Bedlight sensor
Chubb Community Care	Bogus caller/ panic button for Intellilink
Chubb Community Care	Care Sensor for Intellilink
Chubb Community Care	Careousel pill dispenser
Chubb Community Care	Careousel pill dispenser TX
Chubb Community Care	Carer Buzzer (Intellilink)
Chubb Community Care	Carer Radio Board
Chubb Community Care	CO sensor for Intellilink.
Chubb Community Care	Dexterity adaptor for Verso button
Chubb Community Care	Enuresis sensor.
Chubb Community Care	Epileptic fit sensor for Intellilink
Chubb Community Care	Fall detector
Chubb Community Care	Fall detector (wrist worn)
Chubb Community Care	Fall detector belt large
Chubb Community Care	Fall detector belt small
Chubb Community Care	Flood detector
Chubb Community Care	Flood detector (for Horizon Plus)
Chubb Community Care	Flood detector for Intellilink.
Chubb Community Care	Gas shut off valve 15mm
Chubb Community Care	Gas shut off valve 20mm
Chubb Community Care	Gas/CO detector
Chubb Community Care	Heat Detector (H Plus compatible)
Chubb Community Care	Heat detector for Intellilink.
Chubb Community Care	High temperature sensor
Chubb Community Care	Horizon II with pendant
Chubb Community Care	Horizon II with speech board and pendant
Chubb Community Care	Horizon Plus with speech board and pendant
Chubb Community Care	Intellilink Executive Hub and Pendant
Chubb Community Care	Low temperature sensor
Chubb Community Care	Low Temperature sensor for Intellilink
Chubb Community Care	Magnetic contact set

Chubb Community Care	Magnetic contacts for Intellilink
Chubb Community Care	Magnetic Contacts with Keyswitch
Chubb Community Care	Natural gas detector
Chubb Community Care	Pendant adaptor
Chubb Community Care	PIR for Intellilink
Chubb Community Care	PIR Intruder Alert
Chubb Community Care	PIR movement detector
Chubb Community Care	Pressure mat
Chubb Community Care	Smoke detector
Chubb Community Care	Smoke Detector (H Plus Compatible)
Chubb Community Care	Smoke detector for Intellilink
Chubb Community Care	Temperature extremes sensor
Chubb Community Care	Transmitter / Controller (15 min delay)
Chubb Community Care	Transmitter / Controller (no delay)
Chubb Community Care	Universal transmitter
Chubb Community Care	Universal Transmitter Box (H Plus Compatible)
Chubb Community Care	Universal Transmitter for Intellilink
Chubb Community Care	Verso fall detector.
Chubb Community Care	Verso portable button
Chubb Community Care	Wrist worn fall detector
Conform UK	3 Event Talking / Recording Alarm
Dudley Hunt	Alarm pill reminder
Dudley Hunt	Tabtime 5 Medication Alarm
Dudley Hunt	Tabtime Medication Alarm
Duomo (UK) Ltd	Gas / CO shutoff self test system
Easylink UK	Adjustable Frequency Motion Detector
Easylink UK	Alphanumeric pager
Easylink UK	Alphanumeric Pager (enhanced features)
Easylink UK	Apnoea Alarm
Easylink UK	Audio visual alert for telephone and doorbell
Easylink UK	Bed leaving alarm
Easylink UK	Bed pressure mat
Easylink UK	Bed seizure alarm
Easylink UK	Bed seizure sensor
Easylink UK	Bed Sensor Mat
Easylink UK	Chair pressure mat
Easylink UK	Chair sensor mat.
Easylink UK	Chime / Strobe receiver (Byron)
Easylink UK	CTM-1 monitor
Easylink UK	Door strip monitor.
Easylink UK	Doorbell Transmitter (Byron)
Easylink UK	Enuresis sensor mat
Easylink UK	Epileptic bed seizure sensor (300m range)
Easylink UK	Heat Extremes Detector (Monitor and Sensors)
Easylink UK	Hypoglycaemia alarm
Easylink UK	Key fob call button for alphanumeric pager
Easylink UK	Key fob pendant transmitter

Easylink UK	Key fob switch
Easylink UK	Key fob transmitter
Easylink UK	Key fob transmitter
Easylink UK	Key Fob Transmitter for Remote Control Socket
Easylink UK	Magnetic contact set for vibrate tone pager
Easylink UK	Magnetic Contact Transmitter
Easylink UK	Magnetic contacts
Easylink UK	Magnetic switch
Easylink UK	MemRabel reminder device
Easylink UK	Monitor / Transmitter
Easylink UK	Motion Activated Voice Prompt (Mk 2)
Easylink UK	Motion Activated Voice Reminder
Easylink UK	Motion detector that operates RC socket
Easylink UK	Motion sensor
Easylink UK	Multi channel pager.
Easylink UK	Pager vibrating, 99 channel.
Easylink UK	Pendant button (part of RCG-04 kit)
Easylink UK	PIR motion sensor (part of RCG-04 kit)
Easylink UK	PIR movement sensor
Easylink UK	Portable Induction Loop Kit
Easylink UK	Portable Receiver
Easylink UK	Pressure mat
Easylink UK	Pressure mat and transmitter
Easylink UK	Pressure mat with long distance transmitter
Easylink UK	Radio controlled socket
Easylink UK	Remote control bulb holder (bayonet fitting)
Easylink UK	Remote Control Socket
Easylink UK	Resident Wristband for DoorWatcher
Easylink UK	Sensor Controller
Easylink UK	Sound activated (adjustable) alarm
Easylink UK	Telephone Transmitter
Easylink UK	Tone pager (part of RCG-04 kit)
Easylink UK	Transmitter
Easylink UK	Transmitter
Easylink UK	Transmitter
Easylink UK	Transmitter Connector Cable
Easylink UK	Transmitter for Alphanumeric Pager
Easylink UK	Unisocket wireless wall switch
Easylink UK	Vibrate Tone Pager
Easylink UK	Vibrate-Tone Pager
Easylink UK	Vibrating Pager (Byron)
Easylink UK	Vibrating Pager 4 channel (Needs Charger!)
Easylink UK	Vibrator pad for 4 channel pager.
Easylink UK	Wander Management System bundle
Easylink UK	Wireless staff reset button for DoorWatcher
Easylink UK	Wireless Video Receiver and Camera bundle
GBS Batteries	Battery Charger (Uniross)

Just Checking Ltd	Just Checking Data Transfer Equipment
Maplin Electronics Ltd	In/Out Thermo Alarm
Maplin Electronics Ltd	Personal Tracker
PivoTell Ltd	MEM-X
PivoTell Ltd	Minitell Pill Dispenser
PivoTell Ltd	Pill Dispenser Mk 3 with extra features
PivoTell Ltd	Pill Dispenser Mk 3 with light
PivoTell Ltd	Pill dispenser with spare cartridge
PivoTell Ltd	Tipper for pill dispenser
Possum	Bed Exit Sensor
Possum	Carpet / Floor alarm
Possum	Door and window alarm
Possum	Enuresis sensor
Possum	Epilepsy sensor
Possum	Fall detector
Possum	Flood detector
Possum	Info pager
Possum	INKA
Possum	PIR motion detector
Possum	Smoke detector
RNIB	Talking watch (large black and silver)
RNIB	Talking watch (small pink)
Sprue Safety Products Ltd	Base unit.
Sprue Safety Products Ltd	Fire detector: optical.
SRS Technology Ltd	Lite Environmental Control System
SRS Technology Ltd	Unisocket
SRS Technology Ltd	Unisocket controller
Tabtime Ltd	Tabtime Super 8
Talking Products Ltd	Elastic tie
Talking Products Ltd	Magnetic Adaptor for talking label
Talking Products Ltd	Metal Adaptor
Talking Products Ltd	Multi Message Voice Recorder
Talking Products Ltd	Neck strap
Talking Products Ltd	Self adhesive adaptor
Talking Products Ltd	Talking Label
Talking Products Ltd	Talking tin lid
TechReady	Voice Cue
Tunstall Group Ltd	(Non-Stock) Lifeline 400 or Connect
Tunstall Group Ltd	Amie+ pendant
Tunstall Group Ltd	any
Tunstall Group Ltd	Bed sensor mat
Tunstall Group Ltd	Bogus Caller button
Tunstall Group Ltd	CareAssist unit
Tunstall Group Ltd	Chair occupancy sensor mat.
Tunstall Group Ltd	Control unit for chair occupancy alarm
Tunstall Group Ltd	DDA Baby Cry Alarm
Tunstall Group Ltd	DDA doorbell

Tunstall Group Ltd	DDA Pillow Vibrating Alert
Tunstall Group Ltd	DDA Standard Pager
Tunstall Group Ltd	DDA Wrist pager
Tunstall Group Ltd	Door contact
Tunstall Group Ltd	Door exit timer, control and transmitter unit
Tunstall Group Ltd	Easy press adaptor for Amie pendant.
Tunstall Group Ltd	Easy press adaptor for Gem button
Tunstall Group Ltd	Enuresis sensor mat
Tunstall Group Ltd	Enuresis timer and control unit
Tunstall Group Ltd	Epilepsy Sensor
Tunstall Group Ltd	Fall Detector (Lifeline 400)
Tunstall Group Ltd	Fast PIR
Tunstall Group Ltd	Flashing Beacon
Tunstall Group Ltd	Flood detector
Tunstall Group Ltd	Gas detector
Tunstall Group Ltd	Gem pendant button
Tunstall Group Ltd	Green Gem cancel at source button
Tunstall Group Ltd	High Temperature detector
Tunstall Group Ltd	Lifeline 400 hub
Tunstall Group Ltd	Lifeline Connect+
Tunstall Group Ltd	Magnetic contact set for property exit sensor
Tunstall Group Ltd	Minuet watch.
Tunstall Group Ltd	Movement sensor for property exit sensor.
Tunstall Group Ltd	MyAmie
Tunstall Group Ltd	PIR motion sensor
Tunstall Group Ltd	RTX Telehealth package
Tunstall Group Ltd	Smoke detector (Lifeline 400 compatible)
Tunstall Group Ltd	Switch unit
Tunstall Group Ltd	Telephone transmitter.
Tunstall Group Ltd	Temperature extreme sensor 12/42 degrees
Tunstall Group Ltd	Temperature extreme sensor 16/42 degrees
Tunstall Group Ltd	Temperature extremes detector 2/42 deg C
Tunstall Group Ltd	Timer unit for bed leaving alarm
Tunstall Group Ltd	Universal Sensor (Transmitter)
Tynetec Ltd	Altec Response Pager
Tynetec Ltd	Ambient Temperature Monitor
Tynetec Ltd	Bed leaving sensor mat
Tynetec Ltd	Big button switch
Tynetec Ltd	Bogus Caller Button
Tynetec Ltd	Chair sensor mat
Tynetec Ltd	Dexterity adaptor for pendant
Tynetec Ltd	Door contact.
Tynetec Ltd	Enuresis sensor.
Tynetec Ltd	Epilepsy sensor kit
Tynetec Ltd	Epileptic seizure alarm (Alert-iT)
Tynetec Ltd	Fall detector (Altec)
Tynetec Ltd	Flood detector

Tynetec Ltd	Gas and Carbon Monoxide detector
Tynetec Ltd	Heat detector
Tynetec Ltd	High / Low Temperature Sensor
Tynetec Ltd	Personal pendant.
Tynetec Ltd	PIR for inactivity
Tynetec Ltd	PIR motion detector.
Tynetec Ltd	RNID Base unit and underpillow pad
Tynetec Ltd	RNID Smoke detector
Tynetec Ltd	Sayphone 21
Tynetec Ltd	Sayphone v2
Tynetec Ltd	Sensor controller
Tynetec Ltd	Sensor controller
Tynetec Ltd	Smoke detector.
Tynetec Ltd	Timed door exit alarm
Tynetec Ltd	Wander alarm
Westlake Communications Ltd	Cellroute GPRS Unit

**APPENDIX 2: LITERATURE REVIEW STUDIES AND DATA EXTRACTION
SHEET**

LITERATURE REVIEW REFERENCES AND IDs

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ID	Country	Terminology	Equipment	Methods/ Methodology	Discipline	Participants	Question/Aim	Findings
1	UK	Telecare	Monitoring of body measurements and home environment	Case study evaluation of factors affecting implementation success.	Implementation science.	Observation of single case study	To what extent do the barriers to telecare result from 'soft' issues, such as organisational behaviours, cultures and attitudes?	Two major problems were observed: a lack of a champion, either at user or policy level and a lack of understanding of care processes at systemic level. This led to confusion over funding and responsibilities, as well as a lack of appropriate infrastructure put in place for the new service. Moving from institutional to housing-based care model exposed differences in care cultures. The scheme was sanctioned despite lack of evidence of the benefits. There is a need to reconfigure existing organisational boundaries to allow telecare services to be integrated. Telecare heralds a change in concepts relating to housing provision and person-centred care.

2	Scotland	Telecare	Unspecified equipment	<p>Initial evaluation of progress (as a whole programme) towards 8 predetermined measures based on self-reported performance of delivery partnerships. Analysis of use of data provided by the partnerships via quarterly returns, postal questionnaires that were distributed to service users and informal carers, and 5 case studies.</p>	Health economics / social care	telecare delivery partnerships (n=32); service users (n=461); carers (n=301)	<p>To measure progress against 8 objectives: 1. Reduce the number of avoidable emergency admissions and readmissionsto hospital. 2. Increase the speed of discharge from hospital once clinical need is met. 3. Reduce the use of care homes. 4. Improve the quality of life of users of telecare services. 5. Reduce the pressure on informal carers. 6. Extend the range of people assisted by telecare services in Scotland. 7. Achieve efficiencies (cash releasing or time releasing) from investment in telecare. 8. Support effective procurement to ensure that telecare services grow asquickly as possible.</p>	<p>Partnerships estimated that over 1200 hospital admissions were avoided as a result of the telecare, and that telecare had facilitated faster discharge from hospital. They estimated that 518 admissions to care homes (long or short stay) had been avoided. This resulted in estimated accumulative savings of over £11 million. Service user questionnaires: over 60% felt their quality of life had got better with telecare. 74% of carers felt the telecare had reduced pressures on them by reducing their stress. Evidence from case studies pointed to the need for appropriate infrastructure to be established before implementing telecare and a local 'champion' was key to success.</p>
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3	England	Telehealth	Vital signs monitoring for people with chronic heart failure.	Evaluation of pilot telehealth implementation run alongside Whole System Demonstrator. Descriptive analysis of patient and professional perspectives.	Primary care	Patients with CHF (n=18); community based health professionals (unspecified)	How can telehealth help the management of CHF in patients?	Professionals found that telehealth supported their treatment of CHF and patients' self-management. District /community nurses reported feeling more involved with the running of practices and individual patient care. Patients enjoyed becoming actively engaged in their own care and clinicians found improved adherence to medical regimen. There were significant reductions in hospital admissions (46%), A&E visits (67%) and GP visits (16%).
4	USA	Nurse Telemanagement (NTM)	Home vital signs monitoring with follow-up phone calls from nurses.	Comparison of chronic heart failure support methods - nurse home visits (NHV) vs nurse telemanagement (NTM)- with African American patients.	Primary care	African American patients with CHF (n=186)	Are there differences in physical, psychological, and socioeconomic outcomes for African Americans with chronic HF whose home care management is delivered by either the NTM or NHV method?	Results indicate significantly higher self-efficacy, home care satisfaction, and quality of life, with significantly lower symptom distress, HF rehospitalization, and intervention charges for African Americans whose HF home management was delivered by the NTM method.

5	Ireland	Assistive technology	5 products: Night and day calendar; lost item locator; automatic lamp; gas safety device; picture button telephone	Mixed methods approach. Semi-structured questionnaire for socio-demographic information and to collect baseline and follow-up data. Cost-benefit methodology developed. Interview data was thematically analysed.	Social care / dementia	20 people with dementia; 20 caregivers	Four research questions: i) Are new assistive technologies used and considered useful by people with dementia and their caregivers? ii) What kind of technical difficulties are experienced? iii) How can these technologies be further refined to address the unique needs of people with dementia? iv) How much are caregivers prepared to pay should technologies become commercially available?	The gas safety device was least used and considered the least useful - all participants withdrew from using it. The calendar and picture button telephone was the most useful and led to continuing use. The lamp and lost item locator were not well used. Use and usefulness of the products determined by their technical capacity - those with highest level of technical difficulty were least used and perceived as least useful. Items that are unfamiliar to people with dementia are problematic and misunderstood. The role of the caregiver can be crucial in technology use. The retail price of the products was more than caregivers were willing to pay.
6	England	Telehealth	Monitoring equipment for LTC (as defined in WSD programme)	Nested study of patient reported outcomes in RCT. Quantitative analysis of survey data of QoL measures and psychological outcomes, e.g. SF-12, EQ-5D; depression and anxiety scales. Includes intention to treat analyses and per protocol analyses.	Medical/health science.	Patients with COPD, diabetes or heart failure completed questionnaires at baseline (n=1573). Complete case cohort (n=759) and available case cohort (n=1201) incl.	To test the hypothesis that introduction of a broad class of home based telehealth improves quality of life, anxiety, and depressive symptoms over a 12 month period for patients with chronic obstructive pulmonary disease, diabetes, or heart failure, compared with usual care only.	Findings demonstrated no main effect of telehealth on generic health related QoL, anxiety, or depressive symptoms over 12 months. These null findings were consistent across a series of sensitivity analyses for the five validated outcome measures. The null findings for the primary intention to treat analyses show that telehealth is not effective, while the null findings for the secondary per protocol analyses show that telehealth is not efficacious. These findings concur with other studies that have found no effect of telehealth on

								QoL. However, many studies show unduly positive results.
7	UK	Remote care technologies; telecare; telehealth	Telecare and telehealth as described in WSD programme	Interviews, observations and strategic document analysis. Theories of innovation adoption and sensemaking. Organisational analysis.	Organisational management and implementation science.	Health and social care staff and government policy makers (n=184)	To explore the practicality of the 'whole system' approach in healthcare.	Findings suggest that 'whole system' approaches lack operational clarity, with no shared definition of what this idea means in practice, and ambiguity around how this vision might be achieved. Analysis of participant's perceptions shows that a whole system approach has not been realized. Whole system is a concept open to variation, negotiation and multiple interpretations. The case study revealed endemic barriers to changing organisational needs, anticipated gains and losses. A policy framework is required that provides clear definitions and supportive processes.

8	Scotland	Devised term 'home care technology' and 'home care system'. Also use Assisted Living Technologies and Telecare	Various devices, sensors and alarms that can be networked into a home care system or be used separately.	Focus groups followed by Framework Analysis.	Social policy and social work.	Unspecified: 11 focus groups of 2-7 participants each	To identify better-informed user requirements that could be directly fed into the development of home care technologies within the project. To identify and potentially resolve issues surrounding the use and uptake of telehealthcare in Scotland.	5 main themes identified across focus groups: 1. Acceptance issues; 2. Ethical, legal, privacy issues; 3. Availability of resources; 4. Personalisation and evolution of provision; 5. Awareness, education and training. These themes demonstrate a number of barriers to the uptake of technology. Evidence to support use of assistive technology for provision of health and social care still sparse - partly because these issues need to be addressed.
9	England	Telecare as a subset of Assistive Technologies	Range of devices categorised as 1st, 2nd or 3rd generation telecare, including social alarm (1st gen), heat and flood detectors (2nd gen with automatic alert) and movement detectors (3rd gen).	Analysis of contact data generated by interaction between one telecare call centre in North East England and service users over 5 years.	Social care	507 people categorised as older disabled users.	To better understand the characteristics influencing service use.	Little is known of the characteristics of telecare service users, except an assumption that they are similar to those using social alarms. In this study, 50.6% of contact episodes were due to activation of devices and sensors; 17.7% due to service users contacting the call centre for support or a referral to other services; and 31.3% to managing the system, e.g. testing equipment, battery or power failure.

10	USA	Smart home technology; telemedicine	Variety of unspecified equipment e.g. 'telemedicine systems', smart scales, health kiosk systems, personal advice systems to guide diet, home monitoring	Workshop and focus group. Thematic analysis of qualitative data	Science & technology	30 older people	What technologies do older people perceive as useful? What are the barriers to adoption?	General view on the interest of OP in further development of technology. Concerns fall into 4 categories: technology design; ethical considerations; user perceptions, e.g. stigma; role of markets in access.
11	Wales	Telecare	Alarm service triggering on-call emergency response team	Value for money survey of service users carried out by telephone. Details of data and analysis unspecified.	Social care	Unspecified (a sample of 400 users)	Do service users perceive telecare to be of value to them and their families?	Service users felt reassured by the telecare and rated it as valuable in helping them to remain independent. However, they felt their families were more reassured than they were. All service users were happy to pay the existing charge and over half were prepared to pay a bit more. They were not prepared to pay extra for the response service.
12	Sweden, Spain and Slovakia	Information and Communication technology (ICT); telecare	MonAMI technology - a variety of packages of telecare services, including monitoring, alerts and home control devices.	Trial of intervention. Mixed methods approach including structured interviews for quantitative QoL data (reported in this paper).	Health / social care	62 service users	What impact does technology have on service users' quality of life?	Some positive, significant effects on QoL. However, overall findings show that healthier, more independent users perceived more benefits from the services compared to users who report more health problems and are less independent.

13	Europe - England, Ireland, Finland, Norway, Lithuania	Assistive technology	Range of equipment, incl. gas cooker monitor, automatic lamp and picture telephone.	Cost benefit analysis following trial of assistive technology intervention. Analysis included survey of users	Health economics / social care	Service users with dementia (n=80)	Are the technologies a worthwhile investment? Do the benefits out way the cost in terms of net social gain?	Findings were very positive. Based on the feedback from service users and the relatively low cost of investment the project deemed the technologies a worthwhile investment. A very high majority of people with dementia and their carers reported that they used the devices, found them useful, were satisfied and would recommend. Carers were more likely to recommend than the people with dementia.
14	UK	Telehealth	Not specified.	Cross-sectional postal survey. Questionnaire to 54 patients (≥18 yrs) randomly selected through records of 34 GPs.	Primary care	54 patients	Are people with chronic diseases interested in using telehealth?	There was moderate interest in using phone-based and email/internet-based telehealth for self-management.
15	UK	Smart technology	System of pre- recorded prompts and messages, data monitoring/alerts and direct environmental controls.	Single case design. Testing of system with goals for using the technology set with the participant. Data reviewed 3 times over 12 month period. Use of Individually Prioritised Problem Assessment (IPPA) to measure effectiveness of assistive technology provision. Also used DEMQOL QoL questionnaire for people with dementia. Interviews with	Occupational Therapy	1 person with dementia; unspecified staff and family members.	Were the goals of using the technology met (according to participant, staff and family)?	The technology was seen as reliable and effective at different points by different people. Results of the DEMQOL reflected improved QoL rating in the final 6 months. The authors concluded that the system had potential as a tool to support independent living for people with dementia. Occupational therapy assessment skills were viewed as an important component influencing the outcome of the use of technology. Careful assessment of need and matching of technology to need are crucial.

				participant, family and staff.				
16	Scotland	Telemonitoring	Vital signs monitoring for people with COPD.	Semi-structured interviews with COPD patients and healthcare professionals participating in a telemonitoring RCT. Framework approach to data analysis	Primary care	Patients (n=38) and professionals (n=32)	To explore patient and professional views on self-management in the context of telemonitoring in chronic obstructive pulmonary disease (COPD).	Patients reported telemonitoring supporting self-management and empowerment through improving their understanding of their condition and providing justification for their decisions to contact health professionals. Clinicians spoke about telemonitoring promoting medical advice compliance and giving patients confidence. However, they worried about creating new dependencies on the equipment and the promotion of the 'sick role'.

17	UK	Telehealthcare as umbrella term for telecare, telehealth, telemedicine and eHealth	Specific equipment is not detailed - explanation of the term says it covers a range of devices to meet different health and care needs.	In-depth semi-structured interviews with key informants known to be involved with telehealthcare. Thematic analysis of data with cross-validated of data interpretations between the research team.	Sociology of Health	11 health professionals; 7 patient advocates; 6 telemedicine experts; 4 policy makers; 4 administrators; 3 researchers; 3 technologists (n=38)	To understand how policy and practice in relation to telehealthcare suggests new conceptualisations of 'the patient'.	The results showed a range of views about the role of the patient, although accounts of patients becoming 'educated self-managers', taking on a more active role in their healthcare, were predominant. Telehealthcare was seen to impact positively on patients' access to services and maintaining choice; however, there was little understanding of the potential trade-offs that patients might have to make with technologically mediated health care. The results also highlight ideas around how patients relate to technologies; the extent to which technologies might fragment care in new ways, and the involvement of patients in decision making about policies and services.
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18	Norway	Assistive technology	Various home adaptations.	Interviews with older people to gather their experiences of assistive technology delivery process. Drawing on hermeneutical, phenomenological view.	Social care	Older people (n=9)	To understand the experiences of older people during the technology delivery process.	Four themes were found to describe the process as experienced by older people: "hope and optimistic expectations", "managing after delivery or needing additional help", "having available help versus being abandoned", and "taking charge or putting up". These themes spoke to the different ways older people experience the process at different stages, showing that there is not a single linear process of implementation. The study suggests OTs must have a personalised approach to service delivery. The experiences of older people often related to expectations that weren't articulated to the OT.
19	Scotland	Telemedicine	Equipment transmitting results between patient and clinician. Also videoconferencing	Qualitative interviews with GPs and nurses	Primary care / Clinical health	19 GPs and 10 nurses	Examining attitudes of primary care staff to telemedicine. Including communication between staff; the effects on clinical consultation; the therapeutic relationship between the patient and professionals; the impact on professional isolation; and the potential to improve education and training.	Very few participants had experience of videoconferencing, although they were generally positive about the use of technology. There was widespread scepticism about the potential clinical applications for telemedicine. There were concerns about the loss of face-to-face meetings and adequate training for staff.

20	Finland	Mobile technology / digital annotation	Mobile technology-supported audio annotation system that can be used for attaching free-formatted audio annotations to physical objects.	Evaluation of use and usefulness of product developed through human-centred design. Qualitative field trials conducted with visually-impaired or blind users to evaluate emerging use cases.	Technology / social care	Visually impaired and blind users (n=10)	Is this technology of use and usable to people with visual impairments or who are blind?	The findings show that visually impaired users learned to use the application easily and found it easy and robust to use. Most users responded positively towards the idea of tagging items with their own voice messages. The most common targets for tagging were food items; however, some users had difficulties in integrating the solution with their everyday practices.
21	Israel	GPS tracking/ telemonitoring	GPS tracking for people with dementia	Thematic analysis of questionnaires and focus groups	Social work	Focus groups of professionals (n=32), family caregivers (n=36), older people without dementia (n=23); questionnaire of family caregivers (n=69), professionals (n=96) and older people (n=42); 2nd questionnaire with range of stakeholders (n=296)	What are the attitudes of caregivers toward the use of electronic tracking for outdoor mobility of elderly people with dementia in the community? Do family and professional caregivers have different attitudes? What do cognitively unimpaired older people think about using electronic tracking devices for people with dementia? Who should decide whether to use GPS tracking of people with dementia?	The decision of when, where and how to use GPS for tracking people with dementia should be made jointly with the person, the family and professional caregivers. The decision should be made when dementia is diagnosed and include examination of what constitutes acceptable risk for all stakeholders. It is important conversations about this technology are had 'up front' so the person and the family knows what's available and can have an honest conversation about it.

22	Wales	Telemonitoring	Home vital signs monitoring for people with COPD	6 month RCT. Patients completed the St George's Respiratory Questionnaire, Hospital Anxiety and Depression and the EuroQoL EQ-5D quality of life scores before and after pulmonary rehabilitation, and then periodically during the trial.	Primary care	Patients with COPD (n=40)	Does home telemonitoring improve the quality of life for people with COPD?	There were significant and clinically important improvements in the scores immediately following pulmonary rehabilitation, but thereafter there were no differences in quality of life scores between the groups at any time, or consistently within either group over time. Telemonitoring was safe but, despite being well used, it was not associated with changes in quality of life in patients who had stable COPD.
23	Spain	Telecare (also telemedicine and e-Health)	Community alarm service	Ethnography - participant observations and interviews. Phenomenology and Actor-Network Theory incl. material-semiotic approach	Sociology / Philosophy / Psychology	Professionals, incl. technicians, operators, volunteers; service users and relatives. Unspecified number.	To discuss how autonomy is embodied through the use of a telecare device. What kind of bodies are autonomous bodies? How are they constructed? By means of what practices and materials have they been built up?	There is not a single genuine or false autonomy - it is expressed in different ways depending on the technology, self-monitoring practices, people involved and spaces in which they live. This is apparent in use/non-use of technology and the embodiment of the 'vigorous body' and the 'body at risk'. Feelings of being safe are deeply linked to autonomy. This is a positive notion where to be safe has to do with the confidence with which one faces the dangers of everyday life.

24	Taiwan	Home telehealth	Not specified.	Qualitative content analysis of interviews (n=8) and focus group (n=12) data.	Public health / Nursing	20 patients	How do older people with chronic conditions use and perceive telehealth?	Four key themes were identified: perceived support and security (convenient and accessible), enhanced disease self-management, concern with using the devices and patient worries about the cost. Overall, patients were positive about the development.
25	UK	Telehealth	Vital signs monitoring for long term conditions	Part of Whole Systems Demonstrator cluster-randomised controlled trial.	Primary care	2,272 patients with long term conditions	This paper is reporting on early findings from one theme of the programme: Theme 4: Patient and professional experience. What is the experience of service users, carers and health and social care professionals during the introduction of telehealth and telecare?	Report from early findings at one site. New team of telehealth nurses were implemented to monitor patients. Concerns about workloads have not been founded - matrons report being able to free up capacity to visit other patients. Clinicians value biometric readings. Patients report being able to manage their conditions better; feeling empowered and that it promotes independence and peace of mind.

26	UK	Telehealth	Vital signs monitoring for long term conditions	Part of Whole Systems Demonstrator cluster-randomised controlled trial. This part of the study used semi-structured interviews with 32 frontline health professionals. Data analysed using modified grounded theory approach.	Primary care	13 community matrons; 10 telehealth nurses; 9 GPs.	To investigate telehealth care for people with long-term conditions from the perspective of the front-line health professional.	There were mixed views from front-line professionals, reflecting their levels of engagement. It was broadly welcomed by nursing staff as long as it supplemented rather than substituted their role in traditional patient care. GPs' views varied: some gave a cautious welcome but most saw telehealth as increasing their work burden and potentially undermining their professional autonomy. A shared understanding of patient self-management through telehealth is required; and a discussion about professional roles and responsibilities will contribute to this.
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27	England, N. Ireland, ROI, Sweden, Portugal	Technology / telematics	Multimedia caring programmes; videophone; internet access	Ethical analysis of data from questionnaires; focus groups; interviews	Social care/health sciences	39 families	<p>What are the key ethical issues arising from the use of ICT to support the autonomy, independence and everyday QoL of older people and their family carers?</p>	<p>As part of the research process and the project itself, a number of ethical issues came to light. On autonomy, there were fears that the technology would replace healthcare staff; the issue of the informed consent process and right to withdraw was raised as it was suggested that families might find it difficult to say no to the technology. On independence, the technology increased independence in some respects but also created dependencies on the technology in terms of families relying on the information and support provided through the technology making it ethically unsound to withdraw the equipment at the end of the project. On privacy, concerns were raised about the videophone, e.g. worries about 'big brother syndrome' and the location of the videophone in central areas, which made it difficult to hide from. On justice, the issue of accessibility and affordability was raised as none of the participants had access to a computer prior to the project. On empowerment, there were concerns from professionals about the raising of expectations in relation to the services that people could have access to.</p>
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28	UK	Health technology	Unspecified range of equipment that enables interaction between health professionals and patients	Ethnographic study using participant observations of a series of meetings and House of Commons sessions in which health technology assessment was discussed.	Primary care / social care	Senior clinical researchers; social care and health service managers	To investigate how evidence on health technology is considered in health technology assessments.	Trials and systematic reviews have become the normal level of evidence expected for telehealth. In telecare, clinical type evidence is almost entirely absent. However, suppliers are having success as evidence is defined locally and qualitatively. The study found in health technology assessments local managers are looking for more flexible models rather than highly medicalised evidence. The focus is on practice-based evidence rather than evidence-based practice as this responds to the contingencies of everyday practice.
29	UK	Telemedicine (and use of telehealthcare occasionally)	Various ICT tools for communication between patient and doctor or specialist, e.g. video conference or store and forward methods.	Retrospective and cumulative analysis of longitudinal qualitative data from observations and interviews. Use of constant comparison, textual analysis and Framework Analysis. Informed by Normalization Process Theory.	Organisational management and implementation science.	Approx. 582 'data collection episodes' including interviews with key informants, e.g. clinicians, technicians, managers, patients.	Why do telemedicine systems fail to normalise across different applications?	A rationalised linear diffusion model of telemedicine/ telehealth is inadequate in explaining uptake. Implementation depends on a positive link with a national or local policy level sponsor. Adoption depends on structural integration of organisations. Translation into clinical practice depends on the enrolment of cooperative groups. Stabilisation depends on the integration of knowledge and practice and the ability to develop new protocols and processes.

30	UK	Telehealthcare / health technology / telemedicine	Different types of store and forward devices to be used with different cohorts of patients.	Ethnographic data from 2 studies involving RCTs of technology implementation (10 types of devices involved). Interviews and observations of the implementation and evaluation processes from the clinical setting perspective. Documentary analysis. Use of constant comparison for analysis. 120 interview transcripts analysed	Primary care	Clinicians, technical experts, evaluators and other key informants (numbers not specified).	To understand the production of evaluative knowledge in health technology assessments - specifically in relation to telehealthcare.	The study established the levels of activity within which new technologies are evaluated, in terms of the kinds of knowledge and practice that circulate within them. The authors found 4 levels: (1) Ideation: where general notions of the definition and production of both a new technology and reliable knowledge about it are formed and circulated; (2) Mobilisation: in which models of evaluative knowledge and clinical practice are translated into a specific field of technological development; (3) Clinical specification: which disciplines the contingent processes through which reliable knowledge is produced, and clinical practices enacted, and; (4) Specific application: in which the procedures that form both knowledge production and clinical practice are made concrete at a micro-level. These levels interact, showing the social practices involved in evaluation. The study emphasises a key group of actors who are not champions or users of the technology but who are charged with the production of knowledge about effectiveness.
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31	England and Scotland	Telecare	Self-monitoring and 'remote monitoring' of people with LTC	Interviews, task groups and workshops. Framework Analysis informed by Normalization Process Theory	Health and social care; organisational management.	Range of stakeholders, incl. professionals, carers, patients and manufacturers (n=221)	What are the factors inhibiting the implementation and integration of telecare systems for chronic disease management in the community?	Telecare may be a cost-effective and safe form of care for people with chronic conditions. Its implementation is inhibited by a lack of understanding about how telecare systems can work, few financial incentives and uncertainty about the best way to develop, coordinate and sustain services.
32	UK	Assistive technology	GPS systems for people with dementia	Thematic analysis of data from 2 focus groups.	Social care	12 people with dementia; 3 carers; 5 older people	Can GPS devices support safe walking for people with dementia? Are these devices acceptable to potential users?	GPS devices for people with dementia were considered useful by older people, people with dementia and family caregivers to support independence and increase self-confidence. Potential users were less concerned with the ethical issues relating to 'tagging' than those writing in academic journals and the media although they are interested in how the device might be used to promote independence rather than just as a safety precaution offering caregivers peace of mind. They also recommended that GPS devices be discreet rather than exacerbate any potential stigma.

33	England	Assistive technology	<p>Fixed AT' (grab rails, light switches, etc.)</p> <p>'Portable AT' (adjustable beds, hearing aids, rollators, etc.)</p> <p>'Electronic AT' (community alarm, smart home tech, etc.)</p>	<p>Mapping of technology and information sources; interviews; focus groups; care home questionnaire.</p> <p>Descriptive findings and some thematic analysis.</p>	Gerontology	<p>Focus groups with OP service users and carers (n=28); interviews with professionals and information providers (n=40); questionnaire to care home managers (n=59)</p>	<p>How do older people and their carers gain the information about what AT could help them? What difficulties do they encounter in accessing information? How do those people who advise older people, or provide professional care to them, gain the necessary information about AT? What difficulties do they encounter in accessing information? How might access to knowledge about AT be improved in ways that are both convenient and accessible?</p>	<p>The mapping exercise showed there is an extensive range of products and information sources both provided through statutory organisations and the technology industry, as well as through the third sector. It can be difficult for people to know where to go for help. These issues are shared between older people and professionals. In care homes, responsibility for AT is ambiguous. There is plenty of scope to improve access to information across the board. Inconsistent use of terminology is problematic and adds to the confusion.</p>
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34	Sweden	safety alarm; telemedicine; telecare; telehealth	Mobile safety alarm with GPS sensor and drop sensor	Narrative interviews analysed with latent content analysis to reveal underlying meaning	Health sciences and technology	Older people with functional limitations (n=5) and healthy older people (n=4)	To describe the experiences of elderly persons through testing a mobile safety alarm and their reasoning about safety, privacy and mobility.	The result showed four main categories: feeling safe, being positioned and supervised, being mobile, and reflecting on new technology. From these categories, the overarching category 'Safety and mobility are more important than privacy' emerged. Participants felt the mobile safety alarm offered an increased opportunity for mobility in terms of being more active and as an aid for self-determination. Being located by means of the positioning device was seen as positive as long as they could decide how to use the alarm. Participants were happy to sacrifice privacy to the benefit of mobility and safety. The participants were actively contributing to the technology development process.
35	Canada	Assistive technology	Equipment to improve functional ability of the user - not specified.	Delayed intervention RCT. Outcome measures for service users and caregivers related to self-reported satisfaction and self-rated level of accomplishment for activities.	Social care / rehabilitation	Older people with physical disabilities and their carers - dyads (n=44)	Does the use of assistive technology improving the caring relationship by supporting activities and reducing burden on the caregiver?	Results showed the intervention had significant and sustained impact on users' and carers' satisfaction and feelings of accomplishment. Perceived task difficulty was significantly diminished and carer burden was reduced. The scope of cost-benefit analyses in future should include the 'cost' of caregiver burden.

36	England and Spain	Telecare; home monitoring; care technologies	Various monitoring and sensor-based equipment that involved a response service.	Ethnographic field notes; interviews; focus groups. Thematic content analysis. Socio-material practices. Ethical analysis.	Sociology of health and illness; science and technology studies; empirical ethics	Interviews with 39 older people (12 English; 27 Spanish); 56 episodes of extended observation (33 English; 23 Spanish); 12 older citizens' panels (8 English; 4 Spanish).	What kind of independence is experienced in the 'telehome'? Is telecare coercive? How can telecare systems be less coercive?	Telecare leaves little scope for creative engagement and adaptation of systems. A normative view of independence is often achieved that is connected to ideas of 'dignity'. Shrinking budgets means only highest level of need is addressed, which can lead to coercive technology as people are intensively monitored at home. Agency is preferable to independence as an aim and this is achieved through shared work. Recognising and respecting non-use and misuse as a legitimate response should form part of the aims for telecare.
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37	UK	Telehealth	Vital signs monitoring at home, in line with the whole systems demonstrator programme	Cross-sectional survey of patients through self-completion questionnaire or phone interview	Primary care	25 patients	Elicit patient perceptions of existing telehealth service	<p>Overall, patients were very satisfied with telehealth services. Patients agreed that telehealth had improved their health, it was a convenient form of health care delivery for them and they were more involved in the decisions about their care or treatment. They strongly agreed that using telehealth enabled the GP/Nurse to better monitor their conditions and helped them discuss what is most important about their own health. They had no concerns about confidentiality or the absence of direct contact with GP/Nurse during a telehealth consultation. Patients agreed that telehealth had saved them time but they disagreed that it saved them money. They didn't find equipment difficult to use or unreliable. Patients' confidence in managing their health increased from somewhat confident to confident.</p>
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38	Wales	Telehealth	Monitoring equipment for patients with heart failure or COPD.	Evaluation of pilot telehealth scheme. Patients were monitored for 12-week period. Clinical outcomes pre and post questionnaires; patient experience questionnaires; data on telehealth contacts; anecdotal evidence from professionals.	Primary care	Heart failure and COPD patients (n=22)	To evaluate clinical outcomes of the pilot intervention and report on patient experience. Does the telehealth promote proactive condition management?	This paper constitutes a report of early findings. Indications are that unplanned hospital admissions have been reduced. Patient feedback was largely positive. Support from the telehealth team made them feel secure and less anxious, and more confident in understanding and managing their symptoms at home. Professionals found patients became less passive in monitoring their disease. However, most patients had become dependent on the equipment by the end of the pilot and phased withdrawal of the equipment was required.
39	The N'lands	Home telecare	Care package' (for chronic illness e.g. advice, monitoring) 'Welfare package' (for healthy OP e.g. security alarms, education, social contact)	Postal questionnaire to service users. Analysis using diffusion of innovations theory	Health services research	Older or chronically ill people (n=254)	What are the characteristics of telecare users and the contacts they have through technology? What can be learnt about telecare adoption through diffusion of innovation theory? What is the relationship between characteristics and perceived attributes?	Roger's diffusion of innovations theory identifies 'perceived attributes' of innovations: relative advantage; compatibility; complexity; and observability. Results of the questionnaire show that all clients' perceived attributes had a significant influence on adoption. 'Complexity' had the most positive score, showing that people did not find the telecare difficult to use.

40	UK	Assistive technology	Range of daily living devices for people with sensory disabilities, e.g. boil alert, 'talking' devices, one-touch jar openers.	Observations of equipment demonstrations. Pre- and post-demonstration interviews with service users and focus groups.	Social policy / social care practice	Interviews and focus groups with 40 Older people with sight loss (60 observed); 30 Staff (35 observed)	Evaluation of demonstration project aimed at identifying information and support needs, as well as preferences and priorities, of older people with sight loss.	Participants had limited knowledge of devices but were keen to find technological solutions to daily problems. They valued practical design, ease of use and the promotion of safety and independence. Staff would benefit from training to increase confidence and knowledge of technology.
41	UK	Telecare as generic term for assistive tech; smart tech; smart support	Various, incl. bed sensors; falls detectors; flood detectors; vital signs monitoring	Focus groups with OP; carers; professionals. Thematic and content analysis	Engineering; Gerontology; Clinical health	Older people (n=92); carers (n=55); professionals (n=39) across 3 sites	What are the practical and policy implications of telecare? What are the possible uses of telecare? Do potential stakeholders see this as a valuable/potentially valuable service?	Results were presented in 3 categories: Individual choice and self-determination; privacy and surveillance; implications for resources and care services. Telecare was seen as giving people more options about how they manage their care. It was linked to self-determination and how people run their own lives. Concerns were raised about it increasing dependencies on the technology and reducing risk-taking opportunities. There were also concerns about 'big brother' and people being pressured to use it. Carers and professionals were positive about increasing information gathered through technology to reduce risk. They wanted assurances about strict confidentiality rules. All groups felt telecare should be part of a community care package to maintain human contact. There was concern that staff would be withdrawn with more pressure

								<p>put on carers as the 'back up'. People felt this wasn't a cheap option and worried about who was going to pay for it.</p>
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42	The Netherlands	Telecare	Webcam in rehabilitation of COPD patients	Ethnography - 6 months participant observation and interviews. Phenomenology and Actor-Network Theory incl. material-semiotic approach	Sociology / Medical ethics	Interviews with patients (n=9), volunteers (n=2), carers (n=2), technicians (n=2), manager (n=1), other informant (n=1)	How do users and practices shape the workings of the telekit? (taming) How does the telekit help create new care practices and users? (unleashing)	Innovation is a process of 'taming' and 'unleashing' whereby technology is incorporated into people's lives and practices but also released to create troubles or possibilities that weren't there before. Technology contains 'scripts' giving direction to the user. This may interfere with the way in which care practices are scripted. As a result, technologies may perform differently in different practices. The study found that local, practical goals were set to tame the telekit, rather than adherence to grand policy aims. The telekit also produced new goals and problems relating to guaranteeing effective treatment and connecting users with the outside world.
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43	UK	Telecare / telemedicine	Lifestyle monitoring equipment to capture activity and trigger alerts and biomedical monitoring (vital signs).	Devices were developed and then trialled with older people. Quantitative data from surveys and qualitative data from the service user focus group.	Gerontology / Social care	22 older people (lifestyle monitoring); 50 older people (biomedical monitoring)	Lifestyle monitoring: to test satisfaction levels after use. Biomedical monitoring: to investigate the attitudes of older people to new technology and to biomedical monitoring in particular.	Lifestyle monitoring - 86% of service users felt the technology was 'a good thing' while the remainder were unsure. Nobody thought it was 'a bad thing'. Users had high expectations of the service and a high degree of confidence in it, particularly in being able to raise the alarm. It was not deemed intrusive. Biomedical monitoring - the focus group found that older people were generally positive about technology as long as it worked the way they wanted and the cost was reasonable. They felt the specific technology developed could have great benefits. Some of their concerns were about carers/nurses losing jobs. They were worried about the potential cost and loss of the personal touch.
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44	Ireland	Telemedicine	Vital signs monitoring for people with chronic conditions.	Patients and primary care staff were interviewed. Patients also completed a satisfaction survey. Clinical data and information on health care utilisation were extracted from the medical records. Interviews were analysed using a thematic content analysis framework.	Primary care	Unspecified numbers of patients and primary care staff.	To examine the suitability, effectiveness and acceptability of telemonitoring to Irish patients and general practice staff and assesses the feasibility of implementing this approach across Irish general practice.	Patients were positive about ease of use of the technology. They felt it gave them a greater understanding of their condition and a greater sense of control. Practice staff identified shared understanding and patient empowerment as important. Patients made fewer visits to the Medical Centre during telemonitoring: total number of visits fell by 22%; number of visits to the GP fell by 19%; the number of visits to the practice nurse fell by 26%. Clinical parameters analysis revealed a mixed picture. The trends were for no worsening of clinical parameters. Health professionals need more convincing - a culture change is required.
45	Scotland	eHealth	ICT for communication between professionals or with patients either for routine matters, such as administrative emails, or for consultations, such as through videoconferencing.	Postal questionnaire to GPs and nurses in remote Scottish practices. Questions related to attitudes to eHealth and required a yes/no response or use of 5-point rating scale. Findings were presented as percentages with Chi-square significance test.	Primary care	Questionnaires sent to GPs (n=154) (87% response) and nurses (n=67) (88% response)	To elicit current use of, and attitudes towards eHealth of professionals in primary care in remote areas of Scotland.	Actual experiences of eHealth were positive and hypothetical scenarios presented to respondents were seen as beneficial. However, reported levels of access to eHealth equipment and use of eHealth was low, especially among nurses. There were concerns that videoconsulting could be detrimental to patient privacy and confidentiality, and that videoconferencing could reduce the enjoyment of educational meetings. Compared with GPs, nurses were less likely to report being experienced computer or

								eHealth users. eHealth was considered potentially useful for obtaining lab results, transmission of ECGs or videoconferencing for education.
46	England	Telehealth	Biometric monitoring of long term condition (LTC)	Part of Whole System Demonstrator RCT. Questionnaires at baseline and short-term follow-up. Quantitative analysis (logistic regression) of reasons for attrition.	Medical/health sciences	People who withdrew from the trial (n=215) (25% of participants)	Why do patients reject telehealth after having experience of using it?	Active rejection of telehealth was the most frequent reason for withdrawal. Taking into account a range of factors (trial-related, health, socio-demographic, cognitive, emotional and behavioural), patients with diabetes, as opposed to heart failure or chronic obstructive pulmonary disease, and patients' beliefs about the acceptability of the intervention predicted whether or not they withdrew from the trial.

47	UK	Telecare	A range of equipment for supporting people with chronic conditions, including teleconsultations and vital signs monitoring.	Qualitative interviews, observations and a focus group with service users and their carers. Thematic analysis of transcripts and notes.	Primary care	Service users (n=22) and carers (n=9)	To illuminate how people experience, understand and negotiate the transfer of technologies into their homes. To examine the extent to which telecare systems are incorporated into the life world of patients and carers and the factors that promote or inhibit integration.	The findings showed that telecare is an acceptable alternative to usual care, with added benefits such as reduced need to travel and the reassurance afforded by continuous monitoring. However, patient work was 'low' and rather than creating independent self-managers, the technology created new dependencies on the devices and telecare teams.
48	USA	Telemedicine; telepsychiatry	Audio-visual equipment for consultations	Comparative, crossover study of telepsychiatry versus face to face care at two rural sites. Use of self-reported patients satisfaction survey and clinical outcome assessment.	Mental health	26 patients (12 received both types of service)	Comparing functional status and service satisfaction of patients.	Although there are obstacles to successful programme implementation, telepsychiatry offers an acceptable and adequate alternative to face to face services in rural areas.

49	USA	telemedicine; telehealth	Range of vital signs monitoring devices with different functions, including Health Buddy that incorporates a messaging and information service.	Evaluation methodology including measurement of clinical outcomes, patient satisfaction and compliance.	Medical - chronic conditions and mental health	791 chronic medical disease patients; 120 mental health patients	Evaluation methodology was developed to determine patient satisfaction and functional status using technology.	Patient satisfaction was very high. Technology was deemed a useful bridge between patient and health care provider as part of the care coordination process. Patients' perception of health as surveyed with the functional status instrument showed improved perception in many factors including pain, physical, and social functioning.
50	Norway	Telemedicine	Home-dialysis	Qualitative inductive research strategy for understanding patient experiences with home dialysis. In-depth interviews	Medical / medical sociology	11 patients aged 23-82 yrs.	What is the impact of home-dialysis on daily life? What are the lived experiences of home-dialysis patients?	Patients experienced a normalization of daily life, less dominated by disease when performing home dialysis. They found the treatment easy to learn, had achieved considerable self-management skills, but still needed a very strong link to the hospital for communication and follow-up. There is a need for pre-dialysis advice, including patient experiences, and patients need ongoing support with the intervention. The authors feel these results have implications for chronic diseases in general.

51	UK	Community equipment	Range of equipment to meet mobility, domestic, personal care or sensory needs - mostly unspecified.	Postal survey	Social policy	251 adults prescribed community equipment	To explore the extent to which community equipment had an impact on the health and wellbeing outcomes of choice and control, quality of life and personal dignity.	There were high levels of satisfaction among respondents. 78% said they were using all of the equipment issued to them. Improvement in safety was found to be the most significant benefit to respondents. Understanding the potential benefits of community equipment is complex and influenced by multiple factors. Use of equipment varies by type, therefore results cannot be generalised. Service providers should not be complacent about assessment or follow-up processes in supporting service users.
52	England	Telecare and Telehealth	LTC monitoring and various aids for social care needs	Part of Whole System Demonstrator RCT. Interviews and observations of people declining to participate or withdrawing from study.	Medical/health sciences	Potential RCT participants (n=22)	What are the barriers to participation and adoption of telehealth and telecare interventions?	Three categories of barriers were identified: requirements for technical competence and operation of equipment; threats to identity, independence and self-care; expectations and experiences of disruption to services. Concerns were raised about special skills needed to use the equipment and that the intervention could undermine people's positive views of ageing and being able to cope. People were also worried about losing highly valued services as a result of agreeing to the technology.

53	UK	Telehealth	Use of ICT to provide support to patients with long term conditions.	Interviews and observations with professionals. Thematic analysis of data.	Primary care	Telehealth nurse care managers; practice nurses; GPs (39 interviews with 62 participants)	How does the implementation of telehealth interventions to support people with long term conditions affect the roles and responsibilities of professionals?	New roles and identities were found in the Telehealth nurse care managers' interviews, and they differentiated themselves from other nurses. Practice nurses and general practitioners were often sceptical about the contribution of telehealth to long-term condition work. Practice nurses demonstrated a sense of protectiveness about maintaining boundaries and GPs were keen to retain their positions as gatekeepers to resources.
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54	USA	Assistive technology	A package of OT support including unspecified home modifications and assistive devices.	Exploratory RCT to compare the intervention with usual care. Participants were evaluated at 3 months and assessed for changes in functional status, home safety, falls, health-related quality of life (HRQoL; EQ5D), depression, social support, and fear of falling; a 4 subgroup analysis also examined outcomes by waiting list status. An informal economic evaluation compared the intervention to usual care.	Gerontology	Older people: intervention (n=31) and control (n=29)	To assess whether the intervention (a) increased functional independence, (b) increased home safety, (c) improved self-reported quality of life, and (d) reduced subjective fear of falling.	Findings indicated improvements in home safety, health-related quality of life, and fear of falling. Findings did not show improvement in functional status or reduction in actual falls. The study showed this could result in a significant reduction in personal care hours leading to savings.
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55	UK	Telecare	Various 1st and 2nd generation devices with alarms and sensors	Interviews. Grounded theory approach with constant comparative analysis	Social policy	Older people (n=40)	What are the benefits, problems and challenges that exist in relation to Ageing in Place in the UK?	With increasing numbers of people living into very old age, the notion of 'ageing in place' has become a significant part of the health and social care transformation discourse. Older people value staying at home and there are many benefits of this to them. However, there can be significant downsides, particularly due to loneliness and a lack of support in the community.
56	USA	Telehealth / telemental health	Vital signs monitoring for people with complex chronic physical and/or mental health conditions. Video-consultation equipment to deliver psychotherapy sessions at a distance.	Evaluation of the intervention programme. Case study design with an intervention. Measurements taken at baseline, 3 and 6 months.	Primary care / mental health	Veterans (aged 70yrs+) (n=6).	Can telehealth be integrated with usual provision to support care of veterans in rural locations?	Over a 6-month period, case studies indicated improvements in strength, social functioning, decreased caregiver burden, and compliance with treatment plan. Findings suggest telehealth is a good addition to usual care, particularly in rural locations.

57	USA	Telecare	Sensors and video monitoring of homes. For adults with learning disabilities living in supported settings. Alerts can be sent and remote staff can use the video to monitor activity at set times.	Evaluation of effectiveness. Comparison of usual care with telecare for people with learning disabilities. Measures related to how and how many tasks were completed	Learning disabilities / social care	Adults with learning disabilities (n=4)	Will prompting provided by onsite standard care staff result in greater percentages of independent performance on a series of novel household tasks when compared with remote telecare staff? And, is there a difference in the duration for consumers to complete tasks when prompted by either onsite staff or remote telecare staff?	While both types of supports resulted in participants completing tasks, results indicated they achieved slightly more functional independence when prompted by the telecare support provider.
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58	USA	Telemedicine	<p>Home telemedicine units with 4 main functions: videoconferencing to interact with nurse case managers and a dietitian; remote monitoring of glucose and blood pressure with electronic uploading; dialup access to a web portal providing access to the patients' own clinical data and secure web messaging with nurse case managers; and patient access to an American Diabetes Association educational website created for the project.</p>	<p>Part of RCT. Longitudinal phone survey conducted with primary care providers who had diabetes patients taking part in the treatment arm of the RCT. Survey conducted at 12 and 24 months after randomisation. Thirty-six item survey quantitatively analysed; 6 open-ended questions were qualitatively analysed.</p>	Primary care	Primary care providers (n=116)	To determine the acceptability and perceived impact on primary care providers of telemedicine to deliver health care to diabetes patients.	Quantitative analysis showed positive results for acceptability to providers and impact on patients, particularly in terms of improved management of diabetes. Qualitative analysis showed providers were positive about patient control and motivation as well as the involvement of nurses and dietitians. They were more negative about excessive paperwork and conflicting advice and management information from the telemedicine team.
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59	USA	Telehealth	Videophone for nurse consultations with people with heart failure.	<p>RCT comparing telephone with videophone for nurse consultations.</p> <p>Evaluation of nurse and patient communication profiles, including longitudinal changes in communication, nurse perceptions and patient satisfaction. Interaction analysis used.</p>	Primary care	Patients (n=28)	Should videophones be used instead of telephones for consultations between nurses and patients with heart failure?	<p>Nurses were more likely to use open-ended questions, back-channel responses, friendly jokes, and checks for understanding on the telephone compared to videophone. Compliments given and partnership were more common on the videophone. Patients were more likely to give lifestyle information and approval comments on the telephone, and used more closed-ended questions on the videophone. Nurses perceptions of the interactions were not different between the telephone and videophone, nor did their perceptions change significantly over the course of the intervention. There were no significant differences in patient satisfaction between the telephone and videophone. The findings do not support the use of videophone over telephone. The important point is that technology is appropriately matched to patient needs.</p>
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60	Norway	Internet-based cognitive behavioural therapy (ICBT)	Pilot of a Norwegian translation of a programme, MoodGYM, to facilitate face to face online consultations with GPs and clients being treated for depression between CBT session	Semi-structured interviews with GPs. Thematic analysis of the data	Primary care / mental health	GPs (n=11)	To explore aspects perceived by GPs to affect the implementation of guided ICBT in daily practice.	GPs were attracted to ICBT as they wanted to improve treatment for patients and felt it might increase their own sense of work satisfaction. They also valued internet-based self-help as progress in depression treatment and they trusted the content of the MoodGYM programme as theoretically sound. GPs felt that it encourage patients to be active agents in their treatment. However, they felt the constraints of hectic practice, inadequate knowledge, and competing tasks made it difficult for them to commit to embedding this new way of working in their routine practice. One experienced GP said it was too much to expect her to change her approach to depression treatment at this point in her career.
61	UK	Assistive technology; telecare	Various, including epilepsy sensor; GPS tracking. All have response service.	Narrative descriptions of organisational experience of implementing telecare service	Social care	4 cases discussed	How should telecare be provided to people with learning disabilities? What are the ethical considerations?	The needs of people with learning disabilities should be understood as more than reducing risk. Technology can support LD service users to take more risks and do more for themselves. Ethical principles should be adhered to, e.g. beneficence, non-maleficence, autonomy and justice. Telecare can lead to significant cost savings.

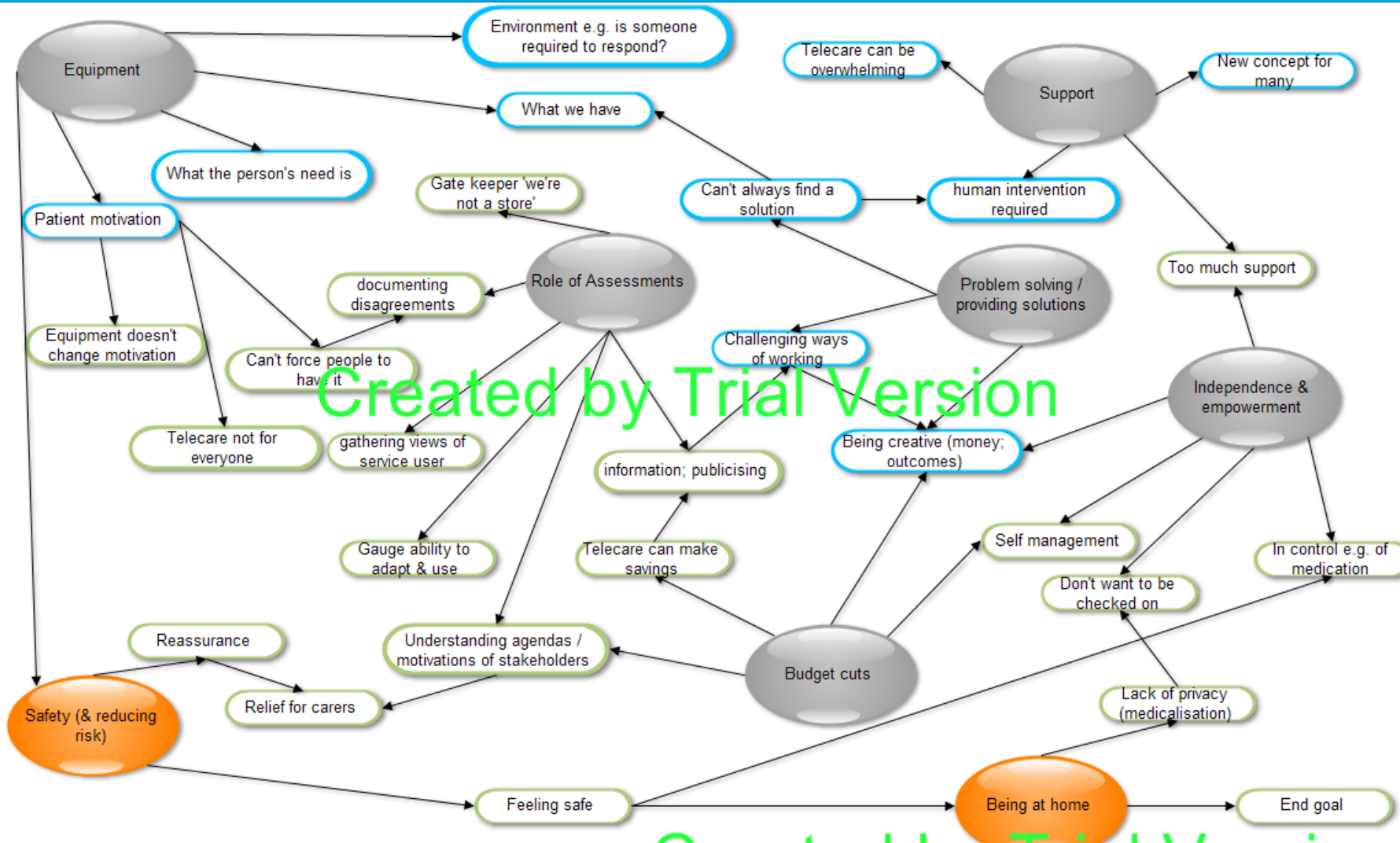
62	England	Health technology; telemedicine	Not specified	Documentary analysis of information pro-formas used in decision making committees (118 from secondary care organisations; 184 from primary care organisations); observations of meetings and interviews with key informants. Thematic analysis	Health economics	11 Committee meetings of 4 separate committees; key informant interviews (n=31)	How do formulary committees use economic evaluations in technology coverage decisions?	It is an exception for cost effectiveness analysis to inform technology coverage decisions. Most committees request clinical evaluations but few request cost effectiveness information and they have limited capacity to access or interpret economic evaluations. Concerns were raised by committees regarding bias in studies, constraints on decision making and ethical objections to the values of health economics.
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63	USA	eHealth technology	Unspecified - assumed vital signs monitoring equipment.	Qualitative needs assessment of patients with multiple chronic conditions. Conducted 10 focus groups with 3-8 participants each. Standard content analysis of focus group transcripts.	Medical	53 participants with ≥3 chronic conditions and experience of health technology use	How can eHealth technology support people to self-manage with multiple chronic conditions.	Patients described using technology most frequently to search for health information (96 %), communicate with health care providers (92 %), track medical information (83 %), track medications (77 %), and support decision making about treatment (55 %). Three overarching themes were identified as challenges that could be met through eHealth use: Patient needing to serve as expert and advocate due to unique health needs; patient needing to manage a high volume of information, visits, and self-management tasks; and patient co-ordinating, synthesising, and reconciling information from different providers and about different conditions. Patients with multiple chronic conditions have holistic, rather than condition-specific, needs from eHealth technology, and desire tools that reconcile information about different conditions and enhance communication across providers and systems.
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APPENDIX 3: INTERVIEW SCHEDULE AND THEMES

Created by Trial Version Interview themes

Description context



Created by Trial Version

Interview schedule

It is important with narrative approaches to interviewing that questions are open-ended, avoid 'why?' and elicit stories. Therefore, my research interests can be captured by a small number of questions, with an element of free association (i.e. allowing the narrator to interpret the question) and a focus on the individual's personal experience. Follow-up questions should pick up on themes identified in the narration and should be open-ended but use the respondent's own words and phrases to respect their meaning-frames. The suggested follow-up questions below are examples and may be adjusted or used if a narrative is not forthcoming.

4. Can you describe for me how someone gets telecare? (What is the process that someone goes through to get telecare?)
5. How is it decided what equipment is chosen? (What's your experience of the decision-making processes around the choice of equipment?)
6. Can you tell me about what you want from a telecare / telehealth service? (How would you like it to look? What is important to you about the telecare / telehealth service?)

Follow-up questions:

3. How important is it that people stay at home? (What are the benefits? Are there any disadvantages?)
4. Has anything changed with the use of telecare? (Do you think there is anything different about care provision with telecare?)

APPENDIX 4: INFORMATION SHEET

WOULD YOU LIKE TO HELP WITH SOME RESEARCH?

PARTICIPANT INFORMATION SHEET



What is the project about?

My name is Jennifer Lynch and I am a researcher from the University of Birmingham. I am interested in how telecare services are run in [REDACTED]. I want to find out what life is like for people who use telecare. I also want to know what it is like for the person's family or friends.

Before you decide whether or not to help me with my research, please take some time to read through the information below and discuss it with others if you wish. Ask me if there is anything that is unclear or if you would like more information.



Why are you asking me?

I will be speaking to different people in [REDACTED] who know what it is like to use telecare or who work with telecare. I will tell health and social care managers what I find out. I hope that in future this will help those working in telecare services to better understand what people who use the service want from it.



What would I have to do?

I will visit you at a place of your choice. I will ask you about how you started using telecare, what you like and do not like about it, and whether it has made your life better. If you want, you can ask somebody such as a friend or relative to be with you when you talk to me.



When will this happen?

I would like to come and talk to you on Monday 5th August at 9am.



What will happen to the information I give?

I will take what you tell me and put it together with what other people tell me to help me make sense of what happens when people are offered telecare equipment. I will use this information to say what is working well. I will also say how services can improve what they do. When I pass on what I have found out, I will not say who has taken part in the study or who has said what. I will store the record of what you have said safely. I will not share it with anyone else.

I will ask you whether I can record my conversation with you. I may want to include something you say during interview in my report, but I will not mention your name or anything that could identify you. You do not have to agree to either of these requests if you do not want to.



What if I say I will take part but then find I

Firstly, it is up to you to decide if you want to take part, you do not have to. If you decide you want to take part, you can still change your mind at any time up to 3 months after you took part. If you find you are no longer able to take part or you decide you would rather not for any reason, all you have to do is tell me. My contact details are at the end of this leaflet. If you decide to withdraw I will not bother you again.



Would I be able to take part?

- Have you used **telecare** services in the last 6 months or do you support someone who uses those services?
- Are you willing to **talk** to a researcher about your experiences?

If you have answered 'yes' to these questions, then it is likely you will be able to help me.

How do I find out more about the project?

Jennifer Lynch

If you would like more information about the project or have any questions, please contact me, Jennifer Lynch, on [REDACTED] or at [REDACTED]



What do I do now?

If you think you would like to take part, please fill out the form that comes with this leaflet. Or you can tell the person who gave you this leaflet. I will then get in touch with you to talk about the project in more detail.