

# **Needs and challenges of informal carers caring for elderly people: Opportunities for Technology Design.**

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**This report is submitted as part requirement for the MSc Degree in 'ICT Innovation', at University College London [2015]. It is substantially the result of my own work except where explicitly indicated in the text.**

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## **ABSTRACT**

With ageing, there are many long-term conditions (LTC) such as dementia, chronic pain and frailty. The elderly person with LTC needs support to carry out their daily activities. Usually family, friend or relative, often referred to as the informal carer, take care of the elderly person. Caring induces emotional turmoil and physical burden bringing adverse effect on the health of these informal carers. Furthermore, there is limited research on the well being of informal carers of elderly people. The aim of the study is to gain insights about the caring process of informal carers for the elderly person; the barriers they face; the strategies they use to overcome them; and the technologies they use. In addition, investigate on supporting them with the use of technology.

To explore the challenges of informal carer and understand the strategies they use to overcome barrier a three-phase qualitative study is performed involving 11 informal carers. i.e. Semi-structured interview (Phase 1); diary study (Phase 2); and follow-up interview(Phase 3).

Thematic analysis is used as the data analysis technique and eleven themes are emerged from it. The findings comprised of their usage of technology to carry out different activities, their thoughts on caring, the strategies they use, and their attitudes towards using technology.

Based on the findings and the literature, various design implications using technology are proposed to develop and support the informal care looking for elderly people.

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## **CHAPTER 1. INTRODUCTION**

Advancement in medical technology and economic stability in the past 50 years resulted in an increase in the life expectancy across the world. This has given rise to an aging population all over the world (World Health Organization, 2011).

With age comes a number of issues; predominantly long-term conditions (LTC)<sup>1</sup> such as dementia, diabetes, cancer, frailty (Clegg et al., 2013) as well as social isolation (Hutson et al., 2011). Elderly people need physical, mental, financial and emotional support. In the UK, there are at least 2 million elderly people who need additional support from family, friends and/or professional care providers, who monitor or look after them (Age UK, 2014); they are generally termed as caregivers or carers. Support includes various tasks such as providing timely medicine, health monitoring, coordinating for medical visits, emotional support, handling paperwork (for example on legal and financial matters) and housework (Carers UK, 2014).

Carers can be broadly classified into formal and informal carers. A formal carer (FC) is defined as an individual who provides paid care in different care settings such as care homes, hospitals, or in the elderly person's residence (Judd, 2014). On the other hand, informal carers (ICs) are individuals providing unpaid care, usually in a home setting; for example, a spouse or other family member, or a friend (Davies et al., 2013).

The available evidence (Schinkinger & Tellioğlu, 2014) seems to suggest that the need for extra support by elderly is largely being met by informal carers (ICs) - some of whom are themselves at risk of a potential health issue, or in full-time work, putting extra stress and burden on their regular health and professional

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<sup>1</sup> A long-term condition (LTC) is a health issue that is not curable at the moment. However, it can be controlled through medication and/or medical treatments. (Dept. of Health, 2011)

activities. This study advances our understanding only of the role played by informal carers to help them.

Technologies have evolved exponentially (Saunders & Brynjolfsson, 2010) creating a void for the older people who are not familiar with ever growing technological avalanche. As older demographics was still in the pre-technological evolving era, also described as “technological alienation” (Morris, 1994). Hence it is difficult for them to get acquainted and adopted with technology (Ofcom, 2009) (Sydney Jones & Fox, 2009) (Hanson, 2010). Research is done to increase the adoption rate of technology for older adults by improving the usability, enabling free access to broadband technologies etc. (Hanson, 2010). There is an increase in the use of tablet computers by older adults aged 65-74 to go online, up from 5% in 2012 to 17% in 2013 (Ofcom, 2014).

There have been initiatives taken to increase the use of technology in the UK healthcare system to meet the challenges of the increasing ageing population. Most of these initiatives are to increase the efficiency and effectiveness of doctors, nurses and other medical professionals (Liddell et al., 2008). Furthermore, there are also technological services used by elderly people with long-term conditions; for example, Telecare and Telehealth (Goodwin, 2010).

Likewise, there is evidence from academic research on technology usage for health professionals and elderly people. Boulos et al., (2007) explains how 3D virtual environment like second life can be used to find new ways of pedagogical training for medical educators. Extensive ethnographic studies are also being done by the HCI community on enabling the older adults to stay independent or “age in place” using technology (Rowan & Mynatt, 2005) ( Forlizzi et al., 2004).

There is also previous research on technological usage of informal carers (Schinkinger & Tellioğlu, 2014) (Davis et al., 2014) (Czaja & Rubert, 2002) (Chambers et al., 2002) (Chiu & Massimi, 2006) ( Chen et al., 2013); however, this research is insufficient. As some of the researchers are based on a single problem, some do not follow a user-centred design. While some of it is based on the

technological solutions ignoring the users needs and sometimes the design is done taking the perspective of the elderly people; some has not considered the emotional, learnability and feasibility aspects. Consequently, specific research on informal carers (ICs) for elderly people is missing. Nevertheless, the existing literature provides strong use cases and design implications that can be used further in this study.

This study explores informal carer's caring habits to identify caring needs and thus, the aim is to understand the key concerns and barriers encountered and method used to overcome them. This is done by studying the existing research and commercial tools available, the present use of technology by informal carers (ICs) for caring and how it can be used to facilitate caring in the future. Thus, in summary, this thesis aims to find new ways and design opportunities using technology for fulfilling the needs of carers in a more efficient way.

The thesis consists of 5 chapters, structured as follows: Chapter 2 provides an overview of the existing literature in the area of technologies used by informal carers (ICs) of elderly people. Chapter 3 presents the research questions and the approach taken in this study, including the methodologies used for data collection and data analysis. Chapter 4 reports the findings from the data analysis. Chapter 5 provides discussion, taking evidence from literature review and the findings. Finally, Chapter 6 concludes by summarizing this study and discusses possible future direction.

## **CHAPTER 2. LITERATURE REVIEW**

This chapter presents the literature review for this thesis. It begins by describing the various tasks of elderly people and IC during caring. Then provides an overview of the existing research on technology that impacts the IC directly or indirectly while caring. In addition looks at some of the commercial tools available.

### **2.1. Elderly person and their carer: Context**

With age an individual's ability to perform certain tasks might be limited due to long-term conditions (LTCs) such as diabetes, arthritis or health conditions. There are 10 million elderly in the UK (UK Parliament, 2010) and 58% of those have at least one LTC (The King's Fund, 2012). Further, cognitive impairment for people associated with LTC such as dementia creates a barrier in performing daily activities and independent living (Mason et al., 2012). Therefore, an elderly person with such conditions seeks help from their family members, social workers, professional carers or the government to live a quality life. Informal carers (ICs) are the most probable due to their personal and emotional relationship with the elderly person who needs care (Montgomery, 1999) (Schulz & Beach, 1999). According to Carers UK, (2014) 87% of IC provides emotional support or monitors an elderly person.

There is overwhelming evidence (Carers UK, 2014) (Schinkinger & Tellioğlu, 2014) (Schulz & Beach, 1999) supporting the notion that informal carers face many difficulties and uncertainties. Besides they are at higher risks of mortality to their non-caring counterparts. They are also referred to as the “hidden patients” due to the continuous physical and psychological risks (Schulz & Beach, 1999).

Informal carer (IC) apart from their daily routines also supports the elderly person they care. Support might range from visiting them once a week for a few hours to assisting them full-time (Carers UK, 2014). Approximately 1.7 million informal carer provides over 20 hours of care per week in the United Kingdom (Age UK, 2010). This unpaid care is estimated to £119 billion per year, i.e. worth more

than the NHS's total spending (Carers UK, 2014). The health risk to IC due to caring is an alarming issue. Due to the emotional connection of IC with the elderly person it might be difficult for them to express their feelings. Further, they think the issue is sensitive or consider it to be trivial. Most ICs are not willing to admit it as a caring job. Therefore, informal caregiving can be characterised by additional burdens, stress and occasional loneliness together with social exclusion. It is hard to deal with these issues of informal caring causing a high adverse impact, especially when the ICs are themselves old, suffer from LTC or have full-time jobs (Schinkinger & Tellioğlu, 2014).

It is necessary to understand the typical activities of the IC to investigate how to support them. This literature categorises the tasks performed by IC into two segments.

The first segment discusses the typical activities where elderly people need help. Clough et al., (2007) identifies most of the typical activities, which includes: *Around the house and garden* such as doing laundry, gardening, vacuuming and cleaning the home; *Staying in and going out* such as getting in/out of the bathroom after a shower, getting in/out of bed, socialising to avoid loneliness, security outside the home, crossing the road and using public facilities; *Managing personal affairs* such as paying bills, replying to letters, writing Christmas cards, caring for pets; *Staying informed* about social gathering, old age benefits; *Shopping* including trips to the shop, checking nutritional information; *Transport* including accessibility in public transport, planning travel, driving; *Socialising* such as religious worship, community meet-ups; *Leisure and recreation* such as walking and swimming. Carers UK, (2014) and Schulz et al., (1999), also identified tasks that elderly people need help with which includes medication, hospital appointments, GP/hospital visits and monitoring of health status for people with long term conditions.

The second segment includes the task the informal carer performs during caring that includes activities such as communication and coordination with different

parties involved in caring; learning about symptoms; monitoring the elderly person; sharing emotions; and physical work.

A report by the European Network of Economic Policy Research Institutes (ENEPRI) (Mori et al., 2012) predicts positive implications of technology in the lives of elderly people and their informal carers (IC). This includes improvements in safety, prediction of untimely events, reduced hospital care all of which significantly reduce the load on ICs. In the next section, we discuss technology involved in caring for elderly people.

## **2.2. Technology for elderly caring**

Technology has the capability to aid the elderly in overcoming barriers by addressing some of their cognitive or physical limitations (Mason et al., 2012). For example, interactive memory aid devices such as pagers, pillboxes, and electronic organisers can help the person with memory impairment such as dementia in reminding them of the latest activity they need to perform. This will make the elderly person less dependent on ICs thus promoting independent living as well as aiding the caring process (Mason et al., 2012). Blythe et al., (2005) describes how various technologies can be used to promote independent living among elderly people keeping their health into consideration.

In the HCI field, extensive research into modern technologies has been done keeping elderly users in mind (Blythe et al., 2005) (Nansen et al., 2014) (Durick et al., 2013) . However, these technologies have indirectly impacted the life of ICs. In this section, we discuss various technologies related to caring. We organise the technology according to the tasks that informal carers perform to help themselves during the caring process.

### **2.2.1 Technology for monitoring**

Monitoring technologies are seen to be pivotal to care for elderly people. The monitoring technologies provide reassurance to the IC about the well-being of an

elderly person. It reduces anxiety, prevents mishaps and generates alerts for early intervention avoiding unnecessary GP/hospital visits. Monitoring technologies opens up a wide range of possibilities also from the perspective of elderly people by diminishing isolation, providing a sense of control and a way to live independently (Age UK, 2010).

Monitoring technologies like Telecare and Telehealth are well established in the UK market and cater to elderly people suffering from LTC. Telecare consists of emergency alarms and sensors. The individual can press the alarm in case of an emergency alerting their IC or the emergency units. The sensors can continuously monitor the elderly to detect any health-related issues. Whereas, Telehealth uses telecommunication technologies to provide health-related services (Goodwin, 2010). Davies et al., (2013) demonstrated that these services provide the IC with several benefits such as reducing stress, improving their sleep cycle and allowing them to continue their normal activities. However, Carers UK, (2012) claims that informal carers have concerns with Telecare and Telehealth. This includes slow or lack of response to alerts, reliability of technology and the elderly person's unwillingness to use such technology.

The Smart home has evolved as another monitoring and assistive technology to support carers and elderly. A smart home embeds technologies to provide advanced monitoring, accessing and control remotely to the dwellers using communication networks (Dept. of Trade and Industry, UK, 2003). However, it often needs per-user customization and activity-specific rules according to user needs and preferences. This makes user operation complex. To address this problem, Beattie et al., (2014) introduced a visual interface as part of the smart home. This visual interface allows easy creation of rules, which can then be shared and reused. This approach, however, requires domain expertise for operation. When tested with nurses, ICs and patients, it was observed that they might find it difficult to use due to different cognitive and technological abilities. Clinckx et al., (2013) asserts that the penetration of smart home is limited. This is due to its complexity in setting up,

environmental issues, cost etc. but it have a huge potential in the future as predicted by Pragnell et al., (2000).

### **2.2.2. Technology for communication and coordination**

Communication provides a way to stay informed about various aspects of the caring process (Mountain, 2014). In this literature, communication is categorised into emotional exchange, information exchange and coordination.

#### ***Emotional exchange***

Emotion is a crucial form of support. It prevents social isolation and loneliness (Wenger, 1997). Technologies used by elderly people in instances such as continuous status monitoring and emergency systems such as Telecare often neglect the psychosocial aspects of caring. They do not account for the emotional aspects and the social context of the elderly person, instead treat the person merely as a subject (Roberts & Mort, 2009). There is also a stigma associated with the conspicuous use of technology or health-related reasons. For example, use of emergency pendants reminds the user of their impairments such as frailty, immobility, etc. and their incapability of being independent. Also for some it makes them uncomfortable and socially isolate, as they do not want to show others their disability and weakness (De San Miguel & Lewin, 2008). Thus, it is imperative to combine emergency checks with the emotional aspects to make technology more useful while not stigmatising the elderly person (Davis et al., 2014).

To demonstrate the implementation of emotion with technology, Davis, et.al (2014) built an emotional communication system. It was based around a picture frame to facilitate communication between an elderly person and their IC. The picture frame was used as a means to emotionally connect the user with their extended family. It is embedded in a familiar object that is already present in their room and which does not require a change in habits. It demonstrated positive reactions, however, this kind of system has drawbacks. The picture frame cannot be moved and can be only viewed by the elderly person in the same place limiting the

context to a single place. Also, some elderly people are ruffled by technology. The paper tried to engage the IC and the elderly person but did not extensively explore the requirements of various technologies from the perspective and preferences of informal carers. As an example, the paper cites that using the system was time and energy consuming for the IC and needs future exploration.

### ***Information exchange***

Information exchange is crucial to informal carers for better decision-making, for interacting with the person being cared for and with formal carers (Whitlatch, 2008). In an institutional setting, elderly people's satisfaction and well being depend highly on communication with their formal carers (Park & Song, 2005). Czaja & Rubert, (2002) claimed that video communication could ease the information exchange process for IC while connecting them with their extended family and friends as well as with GPs and formal carers. However, Pew & Van Hemel, (2004) states video can be expensive, bandwidth hungry and sometimes complicated in setup.

### ***Coordination***

Coordination needs effective communication between various people involved in the caring process. Chiu & Massimi, (2006) investigates design decisions while building a technology that can help the ICs in coordinating. It considers context, time, role, availability, portability, ease of use and adaptability to suggest various tools to be included in a coordinating device. Such as a calendar for scheduling, whiteboard for casual communication, an online address book (Schinkinger & Tellioğlu, 2014) to search for local and emergency contacts. Chen et al., (2013) suggest calendars as a valuable tool for primary care, facilitating task scheduling, planning, and coordination between various people involved in care. However, the above technologies were limited in their use as functional tools and were not a complete solution to all the carer's requirements.

### **2.2.3 Technology for training and learning**

Yamashita et al., (2013) asserts that learning about caring and various diseases and symptoms is an important part of caring to better respond to requirements. There exist technologies such as video-based learning for informal carers, where they can learn about caring without leaving the home (Chambers et al., 2002).

Internet forum and blogs are important sources of information for carers who are in similar situations to learn and exchange information (Hardey, 1999). Carer in their desperation, search for new solutions to their problems on the Internet. But Internet also presents invalidated, unsuitable (Weisbord et al., 1997) or conflicting information (Hardey, 1999) that may delay or hamper the decision-making process (Yamashita et al., 2013), which is due to the unregulated nature of the Internet. In addition, the Internet search engine's content retrieval algorithms are not designed based on the most reliable materials about a particular disease or taking into user's consideration of knowledge. It is dependent on how relevant someone can type the search query (Shenker, 2014). Further, the information can be conflicting as the medical process, diagnosis of diseases are not standardised. Moreover, different geographic locations and medical systems have different approaches but due to the Internet anyone can gain information from various sources creating conflicts (Hardey, 1999). Eysenbach et al., (1998) states this problem more extensively and discusses some ideas on how to improve the quality of the information to help the Internet, users. The paper suggests that the information can be peer reviewed by a group of doctors in volunteering basis, it also proposes to introduce more robust and improved mathematical model to determine a better quality of information. However, with a vast open entity like Internet the solutions are still debatable and difficult to standardise.

Virtual reality is seen to be an emerging technology for training purposes. Chiu & Massimi, (2006) demonstrates a virtual reality based tool in pedagogical training for medical educators. There is research done to use virtual reality for intellectually disable people, which show positive responses even though the sample size is tiny to

generalise (Hall et al., 2011). On the other hand, Hervás, et al. (2011) discuss context awareness and semantic Web-based augmented reality technologies. It is developed for the elderly people to help them assist in learning new things whilst helping the informal carers to easily monitor their actions. Building high-tech solutions for elderly people have been in research for a long time. However, it is not yet tested and evaluated widely making it difficult to understand its accessibility (Hervás, Garcia-Lillo, & Bravo, 2011). Finally, similar researchers are still unexplored for training of IC.

#### **2.2.4. Other technologies**

##### *Social robots*

Jenkins & Draper, (2014) illustrated social robots to aid elderly people in their daily activities, for monitoring purposes and to provide companionship all of which will ease the burden of carers. However, it raises ethical issues (Sharkey & Sharkey, 2010) and conflict of interest between the carer, elderly person and a robot (Jenkins & Draper, 2014). Since robot might have access to health data, it might need to be handled properly by various people involved in the caring process. According to confidentiality laws, it might not be allowed to share this data with IC. This can create a level of hierarchy where the ICs might perceive themselves to be lower in the hierarchy than a robot raising conflict of interest.

##### *Medication*

Elderly people lose their nutrient consumption ability due to factors such as loss of taste, memory, poor dentition, LTC (Nieuwenhuizen et al., 2010), which increases the consumption of medication and supplements. Many medication risks might arise due to poor vision and cognitive impairment, similar medication packaging and prescription error (mostly due to doctor's handwriting) (Schachter, 2012). This risks includes medication errors, overdose, forgetting to take pills, side effects and mismanagement (O'Quin et al., 2015) (Cheung et al., 2014).

In a study conducted with the IC and elderly people various strategies were discussed to overcome the medication problem (O’Quin et al., 2015). It includes seeking help from community expert to know implications of medication; having a medical advocate to advise during medical appointments; and review of medication on a regular basis by health professionals.

Pillboxes are also widely used as a low-tech, high-value solution to medication problems. Pillboxes or pill organisers come in various different shapes (Halbich, 1981). It is a single airtight container with multiple compartments, each individual compartment with enough space to keep single or multiple pills. The pills are segregated on a timely basis, or depending upon the number of doses. Based on the prescribed drugs, the compartments are refilled on a daily, weekly or monthly basis (see Figure 1). The pillbox can prevent medication error by providing the correct doses at the right time ( Lipsky et al., 2007) .



**Figure 1: A Pillbox with different compartments separated by days in a week.**

### ***Stress-relief***

Evidence-based practice (EBP) is the treatment through conscious decisions from clinical expertise to the specific needs of the individual patient. It includes both external scientific research validation and internal experience gained by the clinician

[89-90]. reviewed evidence-based psychological treatment for informal carer that claims to reduce stress and found three important categories: psychoeducational–skill building programs, psychotherapy–counselling studies, and multicomponent interventions. Psychoeducational–skill building included teaching with coping skills for emotional problems, psychotherapy–counselling studies included individual or group therapy, and, multicomponent interventions involving a combination of various approaches. This research is important to understand how the emotional distress of informal carers is addressed and can technology play a role in either of the categories or all.

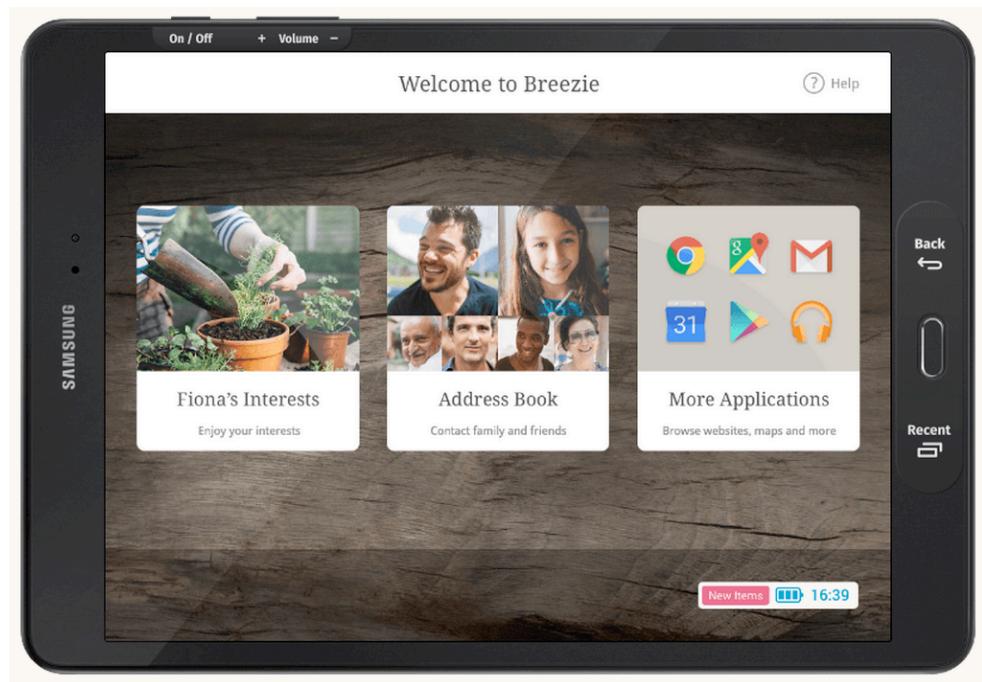
Marriott et al., (2000) discussed that care burden can be due to reduced family intervention (Marriott, Donaldson, Tarrier, & Burns, 2000). In this study, it combined three components i.e. carer education, stress management and coping skills training that effectively reduced the stress. A software application was build for informal carers based on the above combination that included coping strategies, information about physical and mental health, etc. The software started with a biography. Later questionnaire was used to get continuous feedback on their coping ability. Based on this they were directed to different coping sections. Also the informal carers could send the questionnaire to the professional carers for possible intervention purposes. It was found favourable by informal carers.

### **2.2.5 Commercial technologies**

Currently in the market there are several different commercial tools to aid elderly and ICs for the purpose of caring. We discuss some of the most prevalent use cases in the UK today that are not been involved as part of any academic research and are adopted by some user groups.

Breezie (see Figure 2) is a customizable interface built for people with less technology experience. It is build on top of Google Android operating system running on a Samsung tablet (“Breezie,” 2015). It is a way for non-technical natives to get online and to connect with friends and family. It uses icons that are easily recognizable and familiar to the user. Users can personalise it by themselves or can

nominate someone to set it up for them. An IC can also set it up according to the elderly person's preferences. Such as the most frequent contact list, apps, etc. by remotely accessing the interface through their device ("Breezie - the internet made easy," 2015).



**Figure 2: Breezie interface supported by a Samsung tablet equipped with an Android OS**

Mindings (see Figure 3) is an online social network that runs on computer, tablet or smartphone ("Mindings," 2015). An elderly person can communicate privately with their friends, family and relatives. Also, the family members can share pictures, messages and send reminders from around the world. The app does not need any technological expertise. It simply shows content on a touch platform and the elderly can respond using cultural stereotypes such as thumbs up for 'I am ok' without needing to learn something new. National Health Service (NHS) in certain parts of UK ran the app as a pilot. There have been overwhelmingly positive responses with customers mentioning that they have felt more connected to their family and friends (Riaz, 2014).



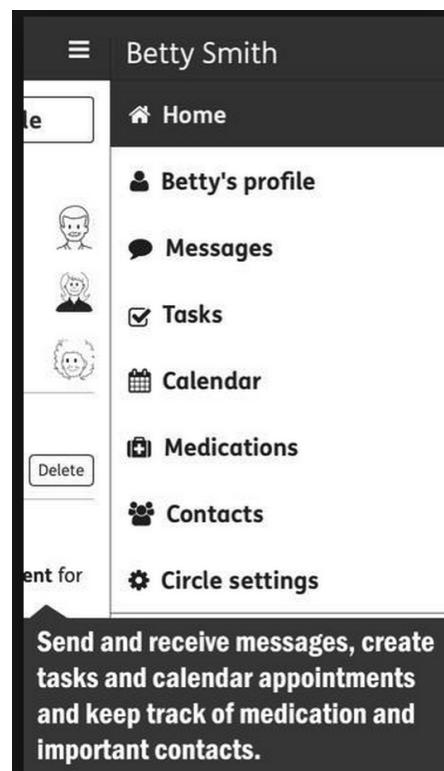
**Figure 3: Mindings hardware and user interface**

Elderly people may not have the ability to prepare food. Casserole Club is a platform that allows people to share home cooked food among their neighbours (“Casserole Club,” 2015). So that the elderly can have a hot meal and also have the added social benefit of connecting with others around them (Skinner, 2013). It is a community initiative started in Staffordshire, UK. There has been positive feedback from elderly people who are happy to have someone to chat combating loneliness and social isolation (Jones, 2015).

My Support Broker (MSB) connects anyone with caring experiences to people in need of care such as someone suffering from a LTC like dementia, mental health, etc. (“My Support Broker.com: Your ticket to choice and control,” 2015) . It is a way to connect ICs to use their experience to help other families in a similar situation and meanwhile also getting paid. Although they become formal carers for other families, they have the empathy as they have done similar tasks for their own. MSB trains the carers through their registered college regulated by Department of Education (UK) so that they can deal with specific requirements of caring for the elderly people (“MSB: Training and jobs,” 2015). MSB also help the carers create a personalised plan for the elderly people (Lenton, 2015) .

Jointly (see Figure 4) is an app that helps carers organise and collaborate during the caregiving process with other carers. Care circle can be created through this app

by inviting other carers. It's an application with various features. Such as contact page to know the other carers and for emergency; messaging for easy communication between the carers; TODO list to know what everyone is doing; calendar to schedule things among the carers and also get notifications. It also has a profile page where the carers can get all the information needed on a single page such as what kind of medication does she takes now or in the past ("Jointly: Care together from anywhere," 2015).



**Figure 4:** A screenshot of the Jointly app menu screen, showing different functions that the app can do.

Patients Know Best (PKB) is a care management tool. It provides a way to manage an individual's health record, such as health plan, medication, medical conditions, etc., that they can share with their trusted circle. Trusted circle includes family, friends, GPs and other healthcare professionals involved in the caring process. It is also being integrated with the NHS system.

### **2.3. Technological design implications**

Chen et al., (2013) & Consolvo et al., (2004) suggests that two important requirements for IC in any ambient integrated solution are ease of access and privacy to protect all the sensitive data. Likewise, Pew & Van Hemel, (2004) describes potential barriers in technology acceptance in the context of health-care that needs to be considered. It includes an individual's dignity, right to freedom of choice and control over technology, customization of the technology to the specific user needs, privacy, trust, safety and usability.

Technologies usually focus on addressing a single problem. Integrated solutions with the ease of use and novel interaction techniques can overcome informal carers barriers (Schinkinger & Tellioğlu, 2014). It is important for technology to be efficient and easy to use while simultaneously being adaptable to individual preferences (Czaja & Rubert, 2002) (Chambers et al., 2002). Chiu & Massimi, (2006) suggests that providing multi-modal interactions such as speech and handwriting recognition, large displays and touch screens support adaptation to different user needs (Chiu & Massimi, 2006).

Finally in the above literature it was noted that there is also a major gap in testing the products with the users. Innovative solutions are built by keeping technology in the centre rather than how the user can use it, lacking the user-centric approach. The user-centred approach of design is needed to understand the users and make them comfortable using it (Keogh et al., 2010).

### **2.4. Summary**

Technology has provided some relief to ICs by facilitating guidance, training and monitoring. However, there remain many issues with current technology such as the lack of emotion, some not being suitable for specific diseases and some technologies stigmatising the elderly. There is a need of research on what will work in various conditions for the informal carer without making a change to the existing behaviour.

It is of concern that the IC have a varied demographic and the needs of each might be different. For example, old carers might themselves have issues with technology, which need to be considered. On the other hand, younger carers are usually technologically savvy and more willing to adopt new technologies. By gaining insights about how this will impact the way caregiving technology will be interesting for future technological design.

Thus, there is a need for understanding informal carer's behaviour, habits and attitudes towards the adoption of new technology.

## **CHAPTER 3.     METHODOLOGY**

This chapter addresses the research questions of the study. Further it discusses the various techniques and approaches used to collect and analyse data.

The aim of this thesis is to gather a better understanding of the needs and challenges met by informal carers (ICs) caring for an elderly person, and how technology usage can support them. The literature review of existing research, commercial tools and design implications put forward the need to explore the attitudes, behaviours, and difficulties of informal carers (ICs) when dealing with caring of elderly people. The research questions that have driven these investigations are addressed below:

- What are the key concerns of an informal carer (IC)? What are the barriers they encounter and how do they overcome them?
- How do carers use technology? Under what conditions and circumstances do they use technology? What kind of problems do they face with technology?
- What design opportunities exists for technology to better respond and manage the needs of informal carers (ICs)?

Further, to investigate these research questions, an exploratory qualitative study was proposed (Ravasion et al., 2004).

### **3.1.   Study approach**

This study implements a qualitative study. Qualitative methods are subjective, and some data may not be relevant. To make the study robust, reliable and oriented towards an in-depth qualitative study, the data collection was divided into three phases i.e. semi-structured interview (Phase 1), diary study (Phase 2) and follow-up interview (Phase 3). Initially, a semi-structured interview was conducted; a diary

study followed this, and finally a follow-up interview. A summary of the choice of methodologies used are as follows:

### **3.1.1. Semi-structured interview**

A semi-structured interview was chosen as a tool to gain insights into the thoughts of ICs during the caregiving process. A semi-structured interview is the most common format for data collection in health care that is used both in research and clinical studies (Britten, 2006) as they provide a profound comprehension of the individual. The semi-structured interview comprised of sets of few open questions relevant to the research topic. Those questions helped this study to gain insight, get new ideas, and discover information that might not have been previously thought of the research (Gill et al., 2008).

### **3.1.2. Diary study**

This study needed to understand the context of caring of IC that can support the interview. Diary study is usually used for a longer study to gain information about the context, frequency, problems, opinions, and the things that might impact one's performance or thought process. The participants describe their experiences independently without being observed (Rubin & Chisnell, 2008). They are inexpensive; there is no special requirement of equipment (Preece et al., 2015). Hence, a diary study was chosen for the study in phase 2. The disadvantage of diary study is to motivate the participant to write it every day for a certain period.

### **3.1.3. Follow-up interview**

The follow-up interview is used to address issues that came up during the data analysis or have been missed during the previous phases.

### **3.1.4. Pilot study**

A pilot study was run before the study to test the interview questions from the perspective of the research as well as the informal carer. Also, this minimises the

risk of failure of the project as this would clearly validate the meaning and usefulness of the questions, and test their appropriateness (van Teijlingen & Hundley, 2002).

### 3.1.5. Probes

Probes were used in the last part of the semi-structured interviews. Gaver et al., (1999) introduced probes in the field of HCI. They were used to instigate new ideas that the participants may not have thought about during the interview. This kind of probing is common to use in semi-structured interviews (Ravasion et al., 2004). In this study, it is used as a strategy to discuss existing and experimental technological designs and obtain more insights from the participants on their needs and barriers.

#### *Probes used in this study*

Seven technology-related probes were used (see Table 1) - Skype, Jointly app, Microsoft band, Telecare emergency pendant, smart home, pillbox and social networking sites. These probes were shown as pictures to the participants and the functionalities were described verbally. The probes were based on various tasks performed by the informal carer which were mentioned in the literature review i.e. communication, coordination, monitoring, emergency, reminder, daily activities, social networks.

**Table 1: Probes used in the study**

Tasks	Probes
Communication	Skype
Coordination	Jointly app

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Monitoring	Smart home
Activity Tracker	Microsoft band
Reminder	Pillbox
Emergency	Telecare emergency pendant
Social network	Facebook, Twitter etc.

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For communication, Skype (see Figure 5) was used as an example. Skype is a voice and video communication application that is available to download in various devices such as laptops, tablets and mobile phones; it needs Internet accessibility. Users can also use it for instant messaging, file transfer, video and audio messages, and for conferencing.



**Figure 5: An elderly person is engaged in Video conferencing using Skype with his daughter.**



**Figure 6:** A Microsoft band showing its home screen.

Microsoft band (see Figure 6) was used as an example of an activity tracker for the carers. Microsoft Band is a smart activity tracker, which also has features of a smartwatch. It can track various physiological data, including heart rate, sleep, Galvanic Skin Response, and movement, along with other features such as sending text messages, email, reminders, other alerts and notifications, and a microphone (“Microsoft Band,” 2015).



**Figure 7:** A Telecare emergency pendant.

For coordination, Jointly was used as an example. Pillbox was used for reminder and for emergency probe, Telecare pendant (see Figure 7) was used as an example.

For daily activities, smart home (see Figure 8) was used. These were previously discussed in chapter 2.

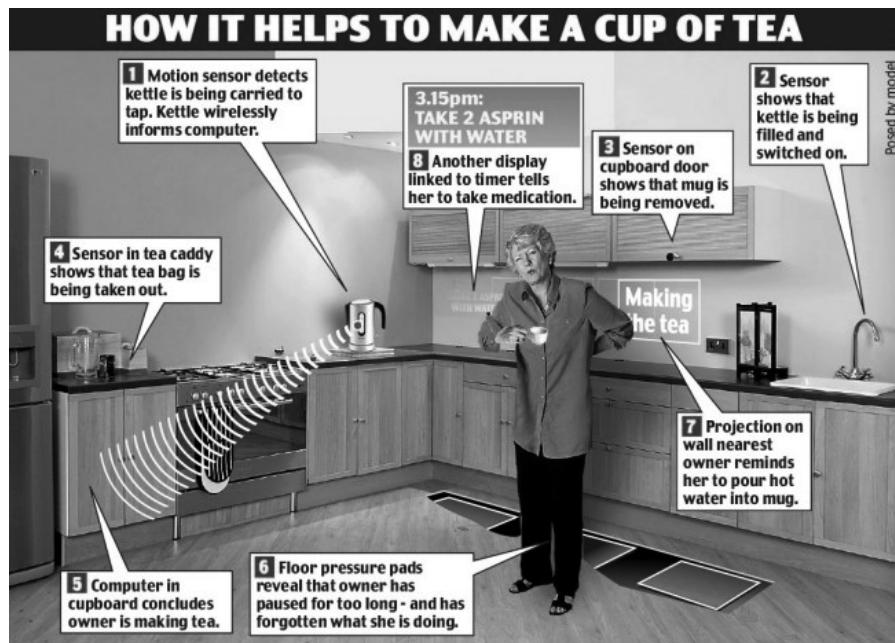


Figure 8: A smart home demonstrating an old woman making coffee.

For social networking sites (see Figure 9), Facebook and Twitter were provided as the examples. Social networking was used as a probe to see if people use it as a tool to connect with like-minded people and talk about their conditions.



Figure 9: Social network sites

### 3.2. Participants

The study set requirements while recruiting participants. The participants had to be aged 18 or above, caring for an elderly person and a British national. Also, they should have been involved actively in the caring for at least 6 months.

**Table 2: Demographics of the participants**

ID	Gender	Age	Relation	Hours /Week	Issue	Primary Carer
P1	M	46-65	Mother	4	Frailty	Elder sister
P2	F	18-30	Grand-mother	7	Dementia	Mother
P3	M	18-30	Grand-mother	8-10	Type 2 diabetes	Parents
P4	F	46-65	Father	10	Dementia	Mother
P5	F	46-65	Parents	4-5	Frailty	Sister
P6	F	46-65	Husband	10	Semantic Dementia	-
P7	M	46-65	Mother	5	Self confidence	Brother

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P8	F	46-65	Mother	5	Dementia	Father
P9	F	20-30	Great aunt	10	Cancer	Mother
P10	F	46-65	Parents	10	Dementia	-
P11	F	46-65	Mother	10	Dementia	Father

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Data included 11 participants that comprised of three males and eight females (See Table 2). All the participants hold an important role and are involved in the caring process at least once a week, directly or indirectly. It was also interesting that the demographics of the carers were diverse - they were from various financial backgrounds, and the age range was from 18 years up to 60 years old. The participants cared for wide range of diseases that consisted of older adults with dementia, cancer, frailty, mobility issue and diabetes. Further, the participant included both living together as well as remotely. Even the relationships between the carers with the elderly people were different such as spouse, grandmother, parents and great aunt.

The recruitment of participants was done through personal contacts, emails, advertisements and social networks. Due to the sensitivity of the topic, it was difficult to get all the participants at the same time, and not everyone was willing to participate in all the phases. The study was done on a rolling basis over a period of one month. The number of participants was decided based on the resources available<sup>2</sup>.

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<sup>2</sup> The thesis was part of a joint project between various stakeholders that included Microsoft, Kent County Council and University College London. The other stakeholders who were the care agencies,

### **3.3. Procedure of data collection**

Two pilot studies were conducted before the data collection. One was done with a researcher (non-carer) on formal carers; and the other with an informal carer who was caring for her mother, but was not able to participate in the study, as she was a citizen of New Zealand.

To protect the rights of participant ethics permission was obtained from the UCLIC Research Department's Ethics Chair. An information sheet was provided to the participants before the study that describes about the study, the data collection method, and the data handling policies (see Appendix 2). Also, an informed form was given to participants to sign, consenting their agreement to participate (see Appendix 3).

For the study, it is important to consider carers from a wide range of caring needs such as preparing meals, physical support, shopping, emotional support etc. Due to the heterogeneous nature of the carer (Health and Social Care Information Centre, 2013), we tweaked the interview questions according to the participants. A questionnaire was given after the consent form was completed to gather the demographics of the carer, which would help in the semi-structured interview questions. The information sheet and the questionnaire helped to establish rapport with the participants prior to the interview and familiarise themselves with the study (Gill et al., 2008).

For anonymity of the participants, participant ID was given to the informal carer who participated in the study. The semi-structured interview was done face-to-face, either via phone or Skype. It was a 30-40-minute interview. The participants were asked not to mention any names or personal contact information before recording, and then the audio recorder was turned on. For face-to-face and Skype interviews,

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involved in the project that promised to provide participants and help with the study backed out from the project in the final days due to uncertain circumstances. This delayed the project resulting in a change in the strategy to recruit participants and a very tight timeline for the study.

the QuickTime recorder in an Apple Mac laptop was used; for phone interviews, call recorder software in an iPhone was used. The initial 10-15 minutes was used to explain the information sheet and make sure they understood about the study. The face-to-face interviews were conducted in meeting rooms of UCL, which were booked for at least an hour so that there were no distractions. All the interviews were done at a suitable time for the participants.

The questions that are not sensitive and easy to answer are asked in the beginning, to make the participant comfortable. The interview questions focused on their caring habits and their experiences with technology during the caring process such as the typical caring tasks, the problems they faced during the typical tasks and their main concerns. For example, they were asked '*whether they have any emergency plan or strategy*'; '*what kind of health information they gather or are interested in*'; '*how they find various information*', '*whether they use technology during their caring process*'; '*whether they have a social circle of friends and relatives*'; '*how they coordinate and communicate with them*' and so on (see Appendix 1). All the participants (P1-P11) participated in phase 1 of the study.

After the interview, a week-long diary study was run with the participants who chose to participate in the second phase. Five informal carers participated in this study i.e. P1, P2, P3, P6 and P7. It helped to gain more in-depth information. As described in Preece et al., (2015) online diary template is created. It includes three questions consisting of 2 open-ended questions with graphics to trigger thinking (see Appendix 4). The questions included '*How many hours of caring were you involved today?*' '*Please describe your caring process today including if they have used any technology during the process?*' and finally asking them to write down anything they may have missed during the interview. To inspire the participants during the data collection and make the process look simple Typeform software was used as the data collection tool. It was recommended by the IDEO LABS (Perkel, 2014) as a tool providing more pleasant experience and human-centred online surveys. The participants were prompted to fill in the diary every day.

After the analysis of the initial transcripts of the interview (phase 1) and diary (phase 2), the follow-up interview (phase 3) was carried out with four IC (i.e. P1, P5, P6 and P8.) who agreed to participate in the final phase. The follow-up interview was done through phone. Three questions were asked to the participant since the participant agreed to spend only 5 minutes. The first question was to confirm their most important problem with the data analysis, the second question was about the technological solution they wish or was using at the moment to solve this problem and finally considering the literature the futuristic concept of social robots as aid was used to know their agreement.

### **3.4. Data Analysis**

The data analysis used thematic analysis (Braun & Clarke, 2006) as the coding method. Based on the themes found during the data analysis and literature review, follow-up interview questions were formed.

#### **3.4.1. Thematic analysis**

An exploratory data analysis process was used in this thesis to induce emerging theories from the data to get insights on the research question about how technology could be used to help carers. Therefore, the coding technique used was thematic analysis. It does not consider any specific theory or preconceptions beforehand. It identifies detailed themes from the data (Braun & Clarke, 2006).

#### **3.4.2. Procedure of data analysis**

The data was analysed following the six phases (see Figure 10) of thematic analysis (Braun & Clarke, 2006) for a reliable and systematic approach to data analysis. NVIVO<sup>3</sup> [1] and paper/pen/highlighter were used as the data analysis tool.

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<sup>3</sup> NVIVO is software developed by QSR International that supports qualitative research and is designed to handle non-numeric data such as interview, focus groups, etc.

In the first stage, the audio recordings were transcribed verbatim and were crosschecked multiple times for any errors. The transcripts were read thoroughly for multiple times until the researcher was familiarised and gained a basic understanding of the data prior to coding (Braun & Clarke, 2006).

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 10: The six phases of thematic analysis

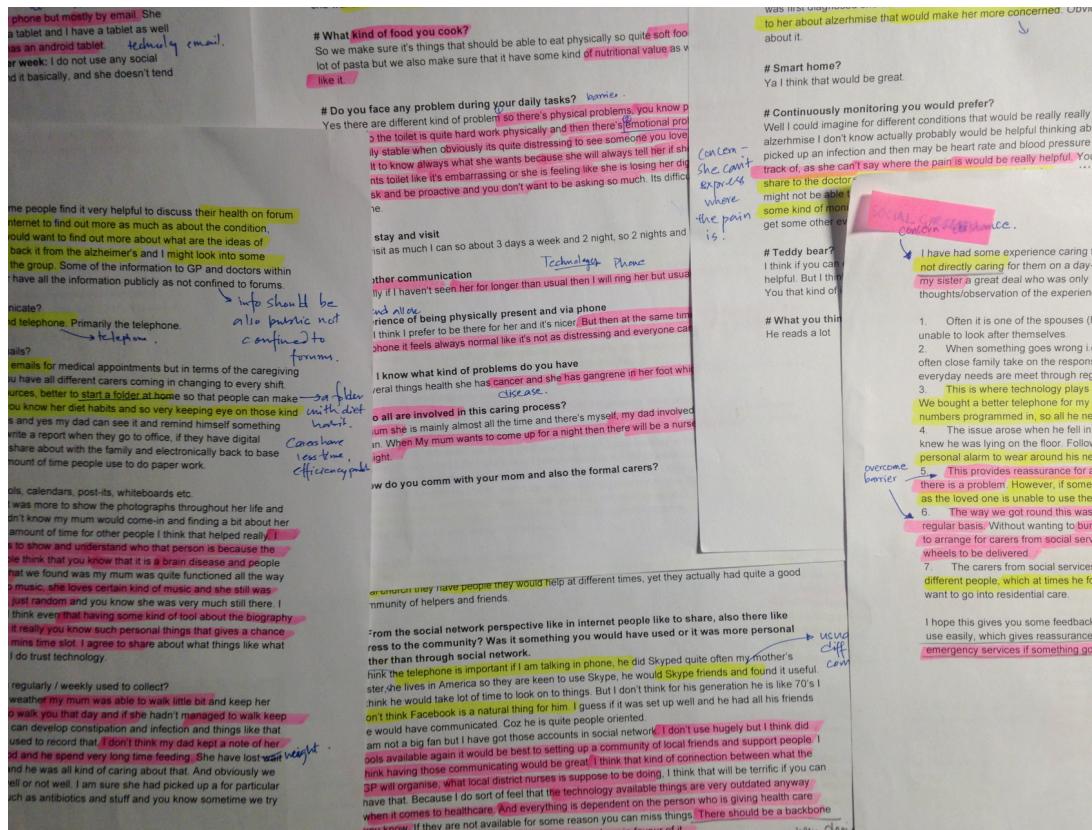
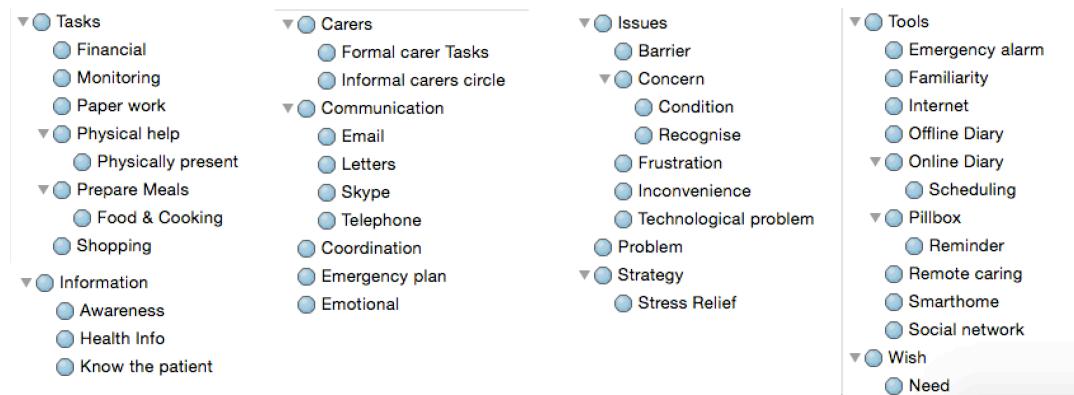
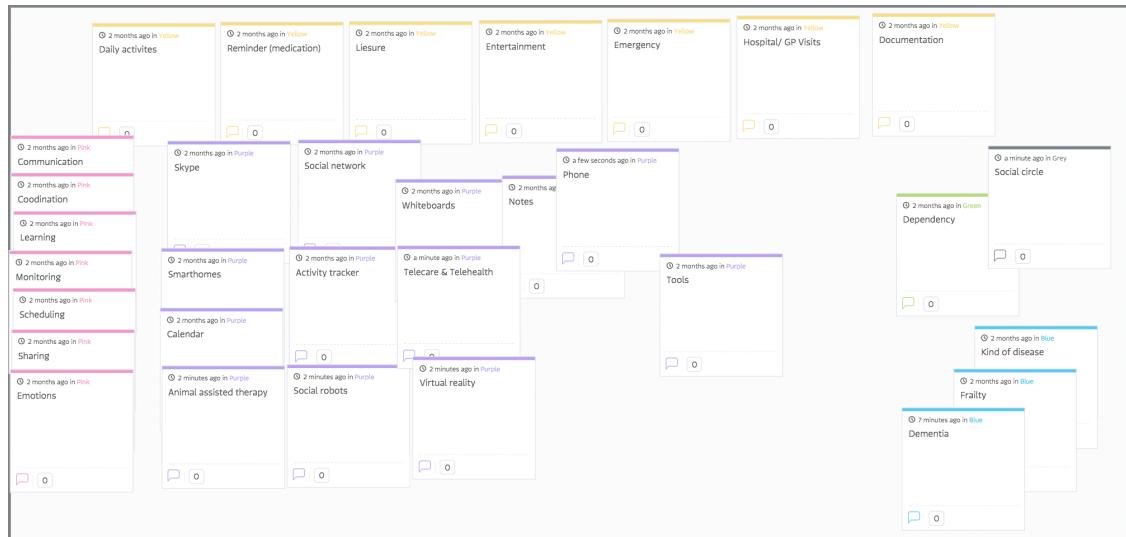


Figure 11: The initial nodes generated in NVIVO

During coding, the interview transcripts were read line-by-line (see Figure 11) and broken down into small chunks of text. These chunks were provided with nodes or labels. Nodes are words that describe the key concepts behind the piece of text. There were 55 nodes generated in the initial analysis (see Figure 12).



**Figure 12: The initial nodes generated in NVIVO**



**Figure 13: Thematic map of the data analysis**

The individual chunk of text was read multiple times to adjust into most relevant nodes. The generated nodes were categorised into common themes and forming a thematic map (see Figure 13). The themes were analysed continuously and refined by removing, combining or finding new categories. This was done several times until comprehensive and well-defined themes were formed. The analysis findings are discussed in the next chapter.

## **CHAPTER 4. FINDINGS**

This chapter discusses the key findings of the data analysis. The data represented a wide range of demographics (see Table 2), giving us a broad perspective on the experiences of various kinds of informal carers (ICs) involved in caring for the elderly. It revealed their needs, challenges, strategies used to overcome barriers, attitude towards caregiving and technology.

This chapter is broadly divided into two sections: findings from semi-structured interviews (phase 1) and diary studies (Phase 2); and findings from follow-up interview (phase 3). The findings are categorized according to themes identified during data analysis from all the three phases. The themes are supported by quotes from the transcripts and may overlap as some of the themes are interlinked. To illustrate the quotes from the three-phased data collection and aid the reader in differentiating the quotes, specific identifiers are used<sup>4</sup>.

### **4.1. Findings from interviews and diary studies**

The results from the data analysis of semi-structured interviews and the diary studies presented us with nine themes: Problems with formal carers; social circle of caring; importance of information; IC uses different communication tools for different purpose; coordination tools used by IC are mostly low-tech; caring is emotional; Reassurance of the loved ones health; strategies to overcome barriers; and technological adaption problem.

#### **4.1.1. Problems with Formal care**

Participants interviewed in the study were engaged in full-time jobs or studies and found it difficult to fully support for the elderly caring. Seven participants have

been seeking help from formal carers to aid their caring activities. The most common activities included physical support, health check-ups and monitoring. Unfortunately, there are various barriers to the employment of formal carers. The main issues related to formal carers are discussed below.

### ***High Cost***

Informal carers raised concerns over the expensive service charges of formal carers. Moreover, the cost of formal care increases with increasing working hours. Many who want to opt for full-time formal care for support find it difficult due to budgetary constraints. P10 was remotely caring for her father and found it difficult to manage her job and caring. She wished for a full-time carer but was not able to afford it (*see QUOTE 1*).

*“... Honestly! Low-income labour - so I [participant 10] could afford for someone to be with him [participant’s father] 24/7 or winning the lottery so I could move him into a 24x7 care....” (P10i)*

### **QUOTE 1**

### ***Inflexibility and persistence in caring***

Due to lack of mutual agreement on sharing responsibilities, coordination with the FC is another significant concern for the IC. The FCs have strictly assigned tasks with an intensive time agenda, thus are very persistent to their schedule. Due to this the informal carer who depends on the formal carer needs to rush back to be with the elderly person. Even though they might be occupied for some uncertain circumstances, as in the case of P10 (*see QUOTE 2*).

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<sup>4</sup> *P#i* was used to denote the quotes of semi-structured interview, *P##d* for diary studies and *P##f* for debriefing interview. *P#* represents participant’s number. For example, if a quote is identified by *P3f*, it means the quote is a part of the debrief interview of participant 3.

*“... Being told on phone that the staff could not be expected to take a new prescription 50 yards to the chemist as it was not their responsibility...”*  
*(P10i)*

#### **QUOTE 2**

#### ***Inefficient and intrusiveness***

Two participants raised concerns over the frequent change of carers from the carer agency. Different FCs need time to get acquainted with the client (elderly person). Often this is inefficient for the IC in terms of familiarizing the various needs repeatedly. The participant and the elderly also found the frequent change of FC uncomfortable and invasive.

*“...The carers from social services usually visited him 3-4 times a day, and often the carers were different people, which at times he [participant’s father] found intrusive...”* (P11i)

#### **QUOTE 3**

#### ***Lack of bonding***

Some IC has unpleasant experiences with care homes. They revealed that some care homes are highly understaffed and ill managed. Besides this, the FCs is seen to lack emotional attachment with the elderly person possibly due to their tight time schedule.

*“...My parents thought she [grandmother of participant] would be better cared for in a care home [...] we soon saw that the "care" was not really what we expected.”* (P2i)

#### **QUOTE 4**

#### 4.1.2. Social circle of caring

Informal caring involves many individuals with various levels of caring roles. Figure 14 shows a representation of carers in the form of concentric circles.

An informal carer closest to the older adult is the primary IC. They are the most involved person in caring. Whereas, the secondary IC are the next, and this category can vary from being the closest of kin to the distant relatives and friends. For example P8 is the secondary IC and her father is the primary IC. Most of the participants interviewed were secondary ICs.

*“... My father is the primary carer for my mother, he cares for her 24X7 hours a week with a little bit of support from the external services” (P8i)*

**QUOTE 5**



**Figure 14: Social circle of caring**

Primary IC are the ones most affected by the burden of care. The primary IC are the one who have all the information about the elderly person's preferences, diet habits, medication, likes, and dislikes. They manage all the caring needs. They do not realise the negative effect they experience due to caring. Likewise, the concern of secondary IC is about the health of the primary carer more than the elderly person requiring care.

*“... I think for me the kind of the stress is for my father [...] I am concerned about his health and I think for my father’s point of view he was always very very concerned about my mum end up going into the care home.” (P8i)*

#### **QUOTE 6**

#### **4.1.3. Importance of information**

The participants were keen to know various kind of information during the caring process and sometimes they do not know or miss some information. The following section describes the kind of information participant look for and the barriers they face.

##### ***Information related to health***

The primary information the participants would look for or want to have access to during the caring process is related to health and well being of the elderly person. The aim of the IC is to look for information on symptoms, diagnosis techniques and the future consequences of elderly person's condition. As in the case of P6, she used Google search to find about Semantic dementia and to know how the LTC can develop over time (*see QUOTE 7*).

*“... I did actually do some research actually at the time I googled it and I looked to see what semantic dementia is [...] how quickly it’s going to develop.” (P6i)*

#### **QUOTE 7**

### ***Information on similar conditions***

Participants are interested in looking for others having similar conditions. Yamashita et. al., (2013) also provides evidence on IC being pacified when reading blogs of people with similar conditions (Yamashita et al., 2013). This would help the IC to learn more about the caregiving experience. This was also accompanied by searching for information about similar symptoms and the condition that could be associated with it. However, they refused to participate actively in blogs and forums to discuss their status. They passively browsed through the information and wished to remain anonymous as they think it to be a private issue.

For instance, P4 thinks publicly sharing her thoughts would make her noticed over the Internet. She wanted to keep her inner thoughts private and fears that sharing them on the Internet might make it go viral. As with time, those feelings will diminish but being publicly out on the internet will remain forever (*see QUOTE 8*).

*“... if you would really want to be sharing those desperate feelings online [...] you cannot delete them and they are out there publicly. [...] Moreover it's for the moment and after that you realise that it was just a part of the caring process.” (P4i)*

**QUOTE 8**

### ***Information on medication***

Medication error is being cited as the most common problem amongst elderly people and informal carers (Hardey, 1999) (Shenker, 2014). Participant needed access to information about the prescribed drugs to protect the elderly from any such errors. Since at the moment, except for the dose they were not aware of all other information. They would like to know the impact of having the drug, the side effects, and the mishap of over-dosing or wrong medication.

*“... My mother sometime will get up in the night and take drugs. My biggest fear is that there is a whole range of drugs and they probably have all sorts*

*of different facts and I [participant] have no idea what those are all about.”*  
*(P1i)*

#### QUOTE 9

#### ***Lack of Information during absence of Primary IC***

It is overwhelming for primary IC to communicate all the information along with the caring activities. There needs to be a way for the primary IC to share this information easily. As this could be crucial in circumstances such as an emergency. For example, P8 had an emergency situation with her mother. Her father was the primary IC and he was hospitalised so the participant had to manage the caring for her mother. However, she as the secondary IC found it difficult to explain the paramedics about the elderly person’s preferences or other specific health related information (*see QUOTE 10*).

*“... For example my mother had an accident while my father [Primary IC] was admitted to the hospital. [...] as the secondary carer role [participant] it would have been very helpful for me to have a set of separate hand notes that had overall summary [...] since my father was not there to help her.“*  
*(P8i)*

#### QUOTE 10

#### ***Information on government support and finances***

Almost all the informal carers at some point have looked for information on Government support, financial schemes and emergency services. The information is not easily discoverable. For instance, if there is funding available for ICs supporting specific conditions such as dementia; what kind of financial assistance is they eligible to apply for; and how to receive it?

*“... That I tried to work out whether they are qualified for financial help or not to try to get my dad into a nursing home.”* (P4i)

## QUOTE 11

### ***Lack of awareness***

The probes inspired much discussion surrounding technology during the semi-structured interview. Participants lack awareness about various technologies available for facilitating caring. A participant (P2) has explicitly stated that "*I (participant) didn't know, obviously these things will make life easier*" (P2i).

### ***Information overload***

Participants reported the problem in acquiring information. They said the information is overloaded, which makes it difficult to consume. Some of the information is not readily available, takes much time for the informal carer to find, or sometimes they miss some crucial information.

*"... We are a lot of information from the formal carer. If you are an informal carers there are lots of useful information as I said information about drugs etc., what I need to look for is a decent way of accessing this information." (P1i)*

## QUOTE 12

### **4.1.4. IC uses different communication tools for different purpose**

Communication plays a vital role for the IC. It includes both physical face-to-face interaction and technology-mediated communication when they are not physically at the same place. Communication involves IC communicating with the elderly person, other IC, FC and the council. The conventional communication tools used by informal carers include phone, email, letters, Skype, Whatsapp and text messages.

IC prefers direct face-to-face interaction to other communication channels with the elderly. It is because during physical interaction many non-verbal body

communication (such as face gestures) happens which is not possible with technology-mediated communication.

*“... So much of communication is obviously seeing somebody reacts when you speak to them.” (P7i)*

**QUOTE 13**

Informal carers use the phone as their primary communication tool to connect with anyone in the caring process including the person they care. However, it is found that phone communication can be deceptive as people can pretend to be fine.

*“... But then at the same time when you are talking in the phone it feels always normal like it's not as distressing and everyone can just pretend it's ok.” (P9i)*

**QUOTE 14**

Also, phone communication with the elderly person may be challenging or in some cases not possible due to cognitive, visual or hearing impairments.

*“... It's probably easier when it is face to face and also both my parents are little bit hard of hearing.” (P5i)*

**QUOTE 15**

Whatsapp and text messages are used for short messages between informal carers. Whereas video communication tools such as Skype and Facetime are used for long distance communication and in most of the case informal carers or the elderly person, have used it for their relatives outside the country.

*“... she uses Skype when she speaks to my brother in Canada. She is Swiss so she also Skype with the rest of my family in Switzerland.” (P7i)*

**QUOTE 16**

The main means of communication with the officials for finances and the local authority, consultancies and GP, are letters.

*“... Communication with GPs, consultancies would include groups of written letters I compose on my laptop. I wrote a letter then print it out and send it to the dementia consultant just to explain things.” (P4i)*

QUOTE 17

#### **4.1.5. Coordination tools used by IC are low-tech**

There was much coordination going on during the caring process. The coordination was an important part of caring. Most of the coordination was between different people involved in the caring process i.e. Primary IC, secondary IC, GPs and formal carers.

From the findings, it was found that primary IC were usually using low-tech strategies to carry out their caring activities. Such as the mother of P4i who was a primary IC to her father used an offline diary to take notes (*see QUOTE 18*).

*“... Because my mum would be very stressed, she forgets stuff quite quickly so everything that we will be told verbally by social workers or consultants or GP, I would write down in a note book.” (P4i)*

QUOTE 18

To schedule important events, such as a doctor’s appointment the participants used calendars; this included both offline paper calendars as well as online-shared calendars.

*“...we put together a shared calendar based on Hotmail just so that everybody knew when who was on” (P1i)*

QUOTE 19

Participants like the idea of an integrated coordination platform as a care management tool such as Jointly app. However, some of them were not comfortable with an app as they think it might be complex.

*“... It will be nice to have it all at the same page [Jointly app], so no one has to talk out loud. The problem with my family is my mum does not really use any app.” (P9i)*

**QUOTE 20**

#### **4.1.6. Caring is emotional**

Participants reported that caring was an emotionally heavy process. Due to their emotional attachment they also go through a state of stress and denial. P2 describes how she is heartbroken about the situation of her grandmother's worsening condition every day (*see QUOTE 21*).

*“... Seeing a loved one slowly deteriorating and losing more and more memories is heart-breaking. When my sister and I visit she sometimes doesn't know who we are.” (P2i)*

**QUOTE 21**

Whereas, P6 explains that she is still in denial to accept the whole truth about her husband, as she is not ready (*see QUOTE 22*).

*“... I am still in denial. I mean I know I can't really deny it anymore but still do feel slightly in denial you know.” (P6i)*

**QUOTE 22**

Participant 8 showed concern for her father who cared for her mother full-time as he was worried about the fact of her mother going to care home (*see QUOTE 23*).

*“I think for me the kind of the stress had was for my father. [...] I think for my father’s point of view he was always very concerned about my mum end up going into the care home.” (P8i)*

QUOTE 23

#### **4.1.7. Reassurance of the loved ones health**

The single most important thing the participants want was the reassurance that their loved ones whom they care for are alright and safe. Therefore, they would monitor the elderly while supporting them emotionally and physically.

*“... the issue seem to be finding a device that elderly people can use easily, which gives reassurance for both carers and loved ones and informs the carers or emergency services if something goes wrong.” (P11i)*

QUOTE 24

There is overwhelming evidence corroborating the notion of the importance of monitoring from the data collected. The participant thinks that monitoring the elderly is important as to keep a check on taking timely medication and food; prevent from wandering and fall etc.

Activity tracker as a probes illustrated positive response from participants. P8 supported the idea of monitoring and provided an interesting case of how it could be helpful for them (*see QUOTE 25*).

*“... I mean mom picked up an infection and then maybe heart rate and blood pressure would be useful. [...] As she can’t say where the pain is would be really helpful. You get concrete evidence to share to the [...] sometime she might not be able to express and maybe I cannot interpreted it the best.” (P8i)*

QUOTE 25

#### **4.1.8. Strategies to overcome barriers**

Finally, there were strategies discussed by the informal carers, whom they use today to overcome some barriers, or which they have also thought might have made their work easier and more efficient. Some of this might overlap with the previous findings.

P8 used a whiteboard with artefacts such as old pictures, everyday diet plan of the elderly person, etc. to familiarize new formal carers. Similar to this strategy, some participant suggested to maintain health records with personalised diet plans or biographies of the people, which could be used in various situations such as an emergency (*see QUOTE 26*).

*“... My dad did have a whiteboard to show the photographs throughout her life and some personal things for people to find a bit about her as a person [...] I think having some kind of tool about the biography of the person about who they are would be an useful tool” (P8i)*

**QUOTE 26**

Coordination between the informal carer and an elderly person was difficult remotely. P6 used paper printouts with pictures of the shopping list for her husband to recognise product easily (*see QUOTE 27*).

*“... He also has difficulty [...] he doesn’t sometimes know what it is [...] He has paper printouts, just a picture which we print.” (P6i)*

**QUOTE 27**

Many participants used different strategies to relax and calm them during the caring process such as reading books, listening to music and talking with their closed relatives. P4 used to listen to three of her songs in loop to make her feel better (*see QUOTE 28*).

*“Yes, um you saying, social networks... Music became very important to me, popular pop music so I listened to iTunes and perhaps YouTube. There were three songs quite upbeat and so I would play them over and over and over on my headphones on my iPhone you know. “(P4i)*

#### **QUOTE 28**

Some informal carer used tools to convert the traditional notes to digital format using a group of technologies such as phone, scanner, printer etc. P1 made use of his mobile to scan, view and share the daily note left by the formal carer.

*“... I checked the notes left by the home care worker [...] I took copies [...] by using the "scanner" function on my mobile so that I could refer to the information and share it with family.” (P1d)*

#### **QUOTE 29**

The worry about the failure of emergency technological devices after a hospital admission made P11 to seek help from neighbour, formal carer and meals on delivery (see *QUOTE 30*).

*“... The way we got round this was to have a neighbour (a retired policeman) to check on him on a regular basis. [...] we arranged carers from social services to go in every day [...] and arranged meals on wheels to be delivered.” (P11i)*

#### **QUOTE 30**

#### **4.1.9. Technological adaption problems**

There are various technology-related tools used by the participants. This section discusses the informal carers' major concerns with technology.

Participants raised concern about the role of technology devices such as phones and alarms. They pointed out that in an emergency, the failure or the unreachability of technology would pose a major risk to health.

*“... We bought a better telephone for my father [...], so all he needed to do was press one button to either of us. The issue arose when he fell in his home and could not get up to make a call, so none of us knew he was lying on the floor. ” (P11i)*

#### **QUOTE 31**

The stages of a disease from mild to severe have a high impact on the level of dependency on informal carers and need of care. Informal carer usually seeks professional care in the advanced stage of LTC. Since, they believe human care is more responsive, emotional, safe, trustworthy and have decision-making and social skill capability. Consequently, in the advanced stage of LTC informal carer do not want to accommodate technology. P4 explains that how her father had problems with technology and made him more irritated (*see QUOTE 32*).

*“... but problem with technology is in the advanced stage of Alzheimer [...] where your loved one is basically having hallucinations they can’t really understand the world around them. And I think devices like mobile phones, Skype, laptop or tablet for advanced Alzheimer’s are problematic because they would perhaps have more hallucinations. ” (P4i)*

#### **QUOTE 32**

Technology also has ethical concerns and for some participants they thought the person they care for would not like to be monitored, as they would find it intrusive.

*“... I think they might not like the idea of monitoring by technology as they might find it too intrusive [...] since they grew up at a time when this was not like that. ” (P5i)*

#### **QUOTE 33**

Technology also has the problem of privacy, and a more secured system might be difficult to use for a simple task. For example, P6 was not able to lend her iPad to

her husband because it had password. Since, her husband suffers from Semantic Dementia, thus most likely he will forget the password.

*“... I was going to lend him my iPad, but it is password protected and he won’t remember the password” (P6i)*

#### QUOTE 34

Participant also claims that health care technology is still not matured. As some of the monitoring technology such as sleep monitoring sensors are not precise.

*“... but I am afraid the sensor of her smartphone is not sharp enough to detect her movement.” (P7i)*

#### QUOTE 35

Trust is an important matter. P9 thinks it is too early to trust technology for vital roles but is good as a care organising and management tool (*see QUOTE 36*).

*“... If it was monitoring her I can feel that I can leave her alone but then you don’t always trust. Suppose if it is not working properly or it goes bad” (P9i)*

#### QUOTE 36

## 4.2. Findings from follow-up interview

Two major themes arose from the follow-up interview: Technology can be used for aid to informal carers; and social robots as an aid to informal care.

### 4.2.1. Technology can be used for aid to informal carers

Participants used technology in many different ways during the caring process. For participant 1 email have become a ubiquitous and is the most important piece of technology to provide continuous update on his mother’s health to the rest of his family (*see QUOTE 37*).

*“... For some technologies you won't even think of them as technologies but they are the most useful. For example, my mother is now in hospital and we on a daily basis we simply have an **email distribution list** for all the family and close friends [...] and we do a one-day summary of how mum is. [...] it means that everybody knows what's going on.” (P1f)*

#### QUOTE 37

Shopping was a main problem for elderly people as well as for the informal carer who need to continuously coordinate with them or in some case need to go by themselves along with the elderly. Many technological solutions were proposed such as on-demand delivery for basic household products and eateries. P6 thinks coordinating with her husband during shopping was a major problem who was suffering from semantic dementia. She proposed a simple communicating device that she can control remotely and update. Instead of typing the device can have images of groceries and products that her husband can view and compare before deciding to buy “*A visual alternative to speaking really.*”

#### 4.2.2. Social robots as an aid to informal care

The initial analysis revealed that people were not comfortable with using technology during the caring process. However, in the follow-up interview participants were positive about owning social robot if they can perform the tasks and reassure the well being of their loved one.

Participant had strong opinions about access to health information in general. The power of choosing rights to access the health data of the elderly person should be left to them. As some participant thinks the medical professional should not decide on who it can be shared with. A social robot can also have access to the data if the person responsible for the data allows to do so.

Participant 1 sees robots as the future of caring and identified that how they are already using robotic technology such as cleaning the room that is cheaper than owning a daily cleaner (*see QUOTE 38*).

*“... Robots could be very valuable in the future. [...] in less than a 100 pounds you can buy a vacuum cleaner that can automatically go around room, [...] it can help with caring and also reduces expenses.” (P1f)*

**QUOTE 38**

Participant 5 needed reassurance of the well being of her mother and if the robot could prevent her from falling, she was happy to accept it (*see QUOTE 39*).

*“... So if there is a way that could give her reassurance that keeps her steady and prevents her from falling then yeah she may like it. Yes I think so.” (P5f)*

**QUOTE 39**

## **CHAPTER 5. DISCUSSION**

The findings have discovered insightful facts about informal carers. This chapter reviews the key findings and provides various approaches through which technology could facilitate the caring process, with the support of existing literature. Finally, discussing the limitations of the study and future directions to improve the study further.

### ***Ratings and reviews***

The findings clearly revealed that formal carer was a necessity for IC to reduce their burden during the advanced stages of long-term conditions. However, there were frustrations over formal care due to problems such as ill-management and persistence. These problems need immediate action, as they will negatively affect the conditions of both the IC and the elderly person. In addition, Internet was a common source of information for many participants. Hardey, (1999) also described it as the primary tool for information. On the other hand, Barton (2006) reports that ratings and reviews have been successful in raising awareness. In addition, people use these systems to view feedbacks by other people before deciding to buy a product and/or service. This kind of rating and review system implemented within the Internet can aid IC to discover the right care services. Moreover, this system will make the care service more transparent and open; thus, creating competition among carer services, compelling them to improve the quality and standard of service to increase their reputation.

### ***Context***

Preece et. al, (2015) discussed how the nature of context is essential for designing technology (Preece et al., 2015). The literature and findings revealed that the technology was mostly developed independently of the context. For example, the failure of an alert button in an emergency situation when the elderly person could not react to press the button in sudden outbreak inside the home setting.

### ***One size does not fit all***

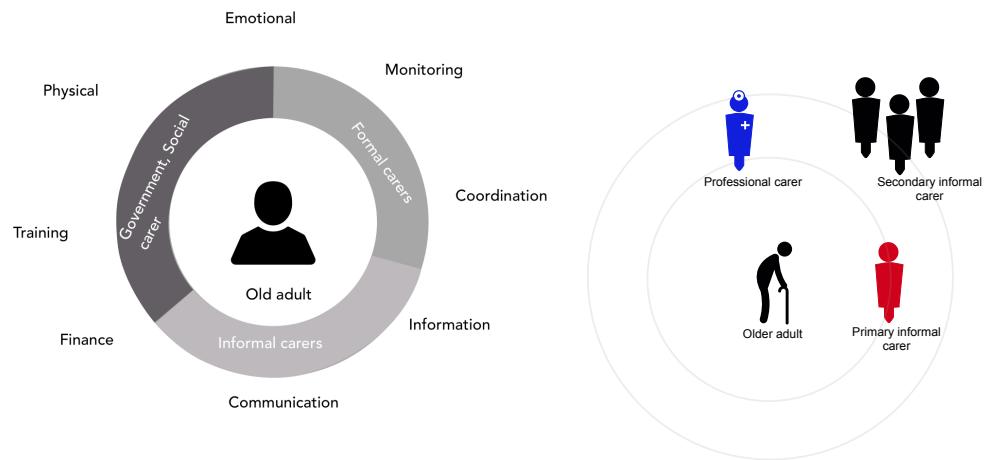
Participants have a broad range of demographics where the caring duty varies from an individual family with someone caring for their spouse, whereas some for their grandparents. Further, there are differences in the way care is carried out by different genders (Ribeiro, Paúl, & Nogueira, 2007). Varley, A. (2008) also highlights that women take the caring role in most cases. This kind of diversity brings a challenge to build a one size fits all solutions to the informal carers problems.

The findings also reports the different social circle of caring. Consequently, different groups of informal carers had different barriers, problems, needs, frustrations and strategies. Understanding each distinct circle of informal carers needs to be taken into consideration while designing technology. For example, in the findings it shows primary informal carers are usually confined to low-tech strategies to carry out their caring activities.

Therefore, a user-centred design approach keeping the informal carers in the centre is important when developing technology for them.

### ***Complex structure of caring and technology***

Findings infer that there are two kinds of ICs involved in the caring process: primary and secondary ICs. Primary ICs are those who are most involved in the care, and secondary ICs are the one who support the primary ICs. These form concentric circles of carers (see Figure 15). The findings clearly illustrate how each circle can impact the health and stress levels of the next circle of informal carers. ICs are less concern about their own health than the one in the next circle.



**Figure 15: a) Different parties involved in caring along with various kind of support and b) the level of concentric circle showing the involvement of different groups of carers for an old adult.**

The literature stated about evidence-based treatment (Gallagher-Thompson & Coon, 2007) and family intervention (Marriott et al., 2000) for reducing stress in IC. On the other hand, findings shows that the activity trackers were well received by ICs. So, probably activity trackers can keep a check on the IC and provide continuous feedback on their stress level. Further, to make it more effective to IC the activity tracker can provide stress recovery techniques based on evidence based treatment.

### ***Importance of information and need for an integrated solution in caring for elderly***

The findings show that there was an information crisis in terms of lack of information or information overload. It shows how the informal carers struggle to find the right information at the right time.

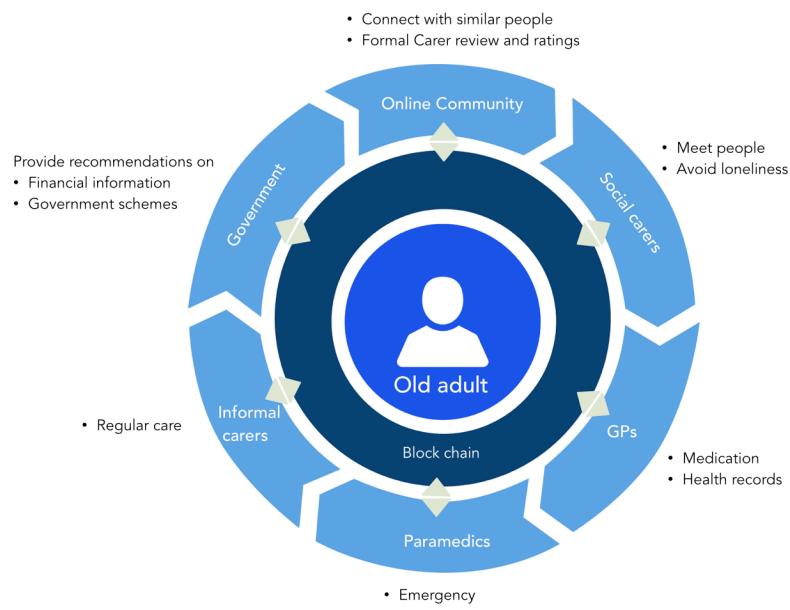
The information lacks proper structure and clarity. For example, traditional ways of writing notes on paper by a formal carer is still prevalent. The transformation of these records into a digital format by informal carers can be time-consuming; this

can be seen in the diary study, in which it took them almost two hours to perform this task. The follow-up interview also confirmed that the work was exhausting. Moreover, the literature review also reported that hand-written notes in health care might be prone to errors (Eysenbach et al., 1998).

Therefore, the information needs to be more structured and reachable to the IC. Care management tools such as Jointly app had positive reactions from the participants.

Kings Fund, 2014 have clearly mentioned for a need of a significant shift in the care of elderly people by transforming care into an individual's need (Chen et al., 2013 & Consolvo et al., 2004). Integrated care can be a potential design approach with the elderly person being in the centre (see Figure 16). This kind of care management platform can be important to achieve high-quality care.

The platform can be segmented into various parties involved in the caring process. Figure 16 shows the proposed design as an example. It displays the elderly individual in the centre. The platform can have all the information about the elderly, including diet, medication, previous history of health, and medical reports of health check-ups. While, various parties, including the elderly person, can be responsible for updating the platform with information.



**Figure 16: Integrated solution powered by Block chain**

On the other hand, trust, privacy and safety are found to be of high priority in the literature and the findings from the data analysis. Therefore, a secure system is a requisite in such as platform.

Block chain can be used to secure the system. Block chain technology is used for the transaction of crypto currency such as Bitcoin. It is a disruptive technology that allows complete strangers who do not necessarily trust each other to keep a shared journal. For every entry in that journal, it provides time stamping and authentication. It is considered a revolutionary disintermediation device that removes the traditional “third party” in many scenarios, such as for storing medical records (Swan, 2015).

A participant suggested a well-thought strategy on access rights. Control access rights should be left to the elderly person. However, this can be transferred to a nominee in case the elderly person is unresponsive, with proper permission much like the power of attorney.

***Use case:***

The paramedics can access the service in the event of an emergency with authentication. This will provide them with the daily habits and medical conditions of the elderly person. Also, based on the situation, paramedics can rapidly respond. On the other hand, Government authorities can send tailored recommendation about financial support and possible schemes based on the reports that the GP has updated. This will save time for the IC to look for information. While the IC and elderly person can anonymously discuss with the online communities at the same time due to an authentication process, the users will be still real, avoiding spam. The prescription can be easily sent via the secure system to the drug store, and the store can have a mobile delivery system to their home. There can be endless possibilities of this kind of a platform.

However, (Hanson, 2010) states that integrated, individually tailored approach might be difficult to implement. The main barriers include provided the fragmentation of health care, lack of coordination and communication, lack of sharing vital information due to psychological worries of medication, and more. However, with technology such as Blockchain, such barriers can be tackled.

### **5.1. Study limitations and future work**

Several factors can influence the study from data collection to analysis and therefore there is space of improvement. Firstly, most of the informal carers were looking after an elderly person with Alzheimer's that can make the data biased towards a single LTC. Secondly, due to last minute cancellation by a care group who was suppose to provide with participants made it challenging to recruit in a short notice. Moreover, as the issue was very sensitive and personal it was difficult to recruit participant, which resulted in a small sample size. Thirdly, participants were not involved in all the phases of the study, and this can influence the findings towards a particular technology or case. Finally, the questions were sometimes not relevant to the individual participant, due to wide demographics. However, the

initial demographics were known in order to frame questions to the individual's situation, and a pilot study was carried out.

Future work could address both informal carers and elderly people of the same family, to have a better contrast and overview of the situation, bringing more clarity. Due to ethical considerations, the elderly group was not able to be involved in this study. The researcher should also recruit a larger sample size from various backgrounds that could also provide individual design recommendations.

## **CHAPTER 6. CONCLUSION**

This study aims at understanding the key concerns of informal carers, the strategies they use to overcome barriers and understanding the intervention of technology usage. The literature review identified that the existing technologies are not effective or efficient for the informal carer. There are problems adopting technologies, and there is a gap in understanding the needs and insights.

The study was significant as it revealed the essential needs of informal carers that can be used to design future technologies. There were eleven themes from the study.

Problem to coordinate and communicate with formal carers was an interesting finding as it was quite specific to the IC of elderly people. Further, the strategies used to overcome barriers provided new ideas on designing technologies.

Finally, the study proposed several design suggestions considering the various factors such as trust, context, ease of use, access to information, security and safety of both informal carer and the elderly people.

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## APPENDIX

### Appendix 1: Questionnaire and Semi-structured interview questions

#### Questionnaire:

Participant ID:

Age:

No. of hours:

Gender:

No. of caring:

People you care for:

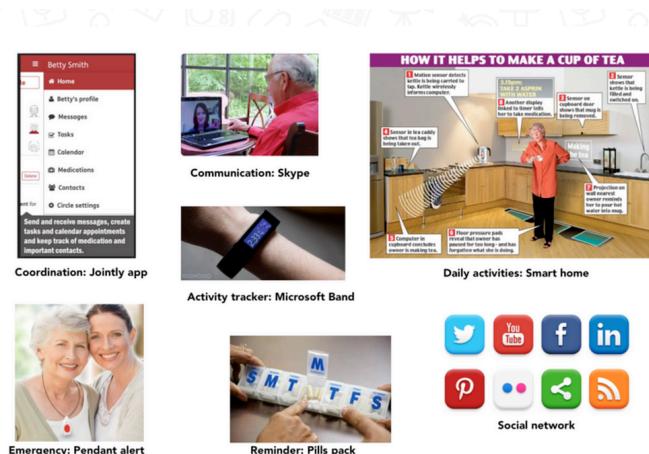
Do you stay with the person you care for:

What of the following do you use?:

#### Open interview Questions:

1. As you mentioned \_ hours/week, could you please describe a typical case during those hours,
  - a. What kind of tasks do you usually do?
  - b. Do you face any problems you would like to share?
  - c. Is there any concerns you have that makes you worry about the most?
2. As you stay away how do you usually keep in touch? Could you describe the experience you have during being physically present and other \_\_\_\_\_?
3. Who all are involved in the caring process? How do you coordinate/communicate with them?
4. Do you gather regular (often) health information about your mom?
  - a. What kind of information do you keep check on?
  - b. How do you do it?
  - c. What do you do with the information? *Do you also save it somewhere to show it to your local GP or nurse? Do you keep notes to show physician?*

#### Probes was shown one-by-one:



## **Appendix 2: Information Sheet for Participants in Research Studies**

Title of Project: Understanding the impact of technology interventions on carers.

This study has been approved by the UCL Research Ethics Committee as Project ID Number:

UCLIC/1415/011/MScBerthouze/Das/Anand

Name, Address and Contact Details of Investigators:

### **Research Supervisor**

Name: Dr. Nadia Berthouze

Work Address:

Contact Details:

### **Researchers (Master students)**

Name: Arindra Kumar Das

Contact Details:

We would like to invite you to participate in this research project. It is up to you to decide whether or not to take part. If you choose not to participate it will not disadvantaged you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and sign a consent form. Please discuss with others if you wish or ask us if there is anything that is not clear or if you would like to know more information.

Details of the study:

This study aims to gain a better understanding of how technology can be used by carers during their caring sessions. We aim to use these findings to develop better technology that can respond and manage the needs of the carer in a more efficient and effective way.

With your permission, we will be looking forward to gain a better understanding of your habits, needs, and the barriers you encounter during your work as well as the strategies you use to overcome them. The research to be conducted consists of three phases:

- Phase One (Questionnaire, Semi-structured interview)

- Phase Two (Diary studies)
- Phase Three (Focus group/Follow-up interview)

All the phases mentioned above would be organized at your convenience. It will be up to you to decide to take part in either of the phases. During this study, you will not be asked to provide any access to the people you care for.

#### Phase one

**Questionnaire:** You will be asked to fill out a questionnaire, which consist of seven closed questions. The theme of the questionnaire is to collect demographics such as age, gender, weekly hours of caring, technological product you are familiar with, for how long you have been using the technological products, e-Services (for more information, Please check the questionnaire attached to this form). It should take less than 5 minutes to fill in the questionnaire.

**Semi-structured Interview:** During the semi-structured interview, we would be interested in knowing your past and current experience of caring, your frequency of clients, what kind of health information you are interested in collecting regularly, how much time you spent on writing care notes, the needs and difficulties of writing a care note and how are care notes collected, analysed and shared with people who are involved with the care community such as GPs, nurses, care managers etc. With your permission, we would like to audio record this interview and this whole session will be no longer than 30 minutes.

#### Phase two

**Diary studies:** You will be asked to keep a diary for one to four weeks period to record your daily difficulties of using the paper care notes.

#### Phase three

**Focus group/Follow-up interview:** In the final phase, you will be invited to a focus group where you will be provided a chance to communicate with other participants in this study to exchange views together and to encourage discussion about technology use in collecting health information while raising points that were found out during the interview and diary studies. With your permission, we would like to take pictures, audio, and video recording during the session without capturing your face. The whole session would be no longer than 90 minutes.

All data will be collected and stored in accordance with the Data Protection Act 1998 and will be kept anonymous.

With your permission, we may also want to use the extracts of the video or audio recordings for teaching, conferences, presentations, publications, and/or thesis work.

## **Appendix 3: Informed Consent Form for Participants in Research Studies**

Title of Project: Understanding the impact of technology interventions on carers.

This study has been approved by the UCL Research Ethics Committee as Project ID Number:

UCLIC/1415/011/MScBerthouze/Das/Anand

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you. If you have any questions arising from the information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given copy of this form to keep and refer to at any time.

### **Participant's Statement**

I .....

agree that I have

- read the information sheet and/or the project has been explained to me orally;**
- had the opportunity to ask questions and discuss the study;**
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.**
- I understand that my participation will be taped/video recorded and that my face will not be visible and that my name will not be disclose to anyone. I am aware of and consent to the analysis of the recordings.**

**Type of session, please choose as applicable:**

Phase One (Questionnaire, Semi-Structured Interview)	YES / NO
Phase Two (Diary Studies)	YES / NO
Phase Three (Focus Group)	YES / NO

**For the following, please choose as applicable:**

I agree to be interviewed and observed while interacting with the tablet	YES / NO
I agree to participate in the focus groups	YES / NO
I agree to participate in the diary studies	YES / NO
I agree to be audio/ video recorded	YES / NO

I understand that I am free to withdraw from the study at any time without penalty if I so wish. I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed:

Date:

Investigator's Statement

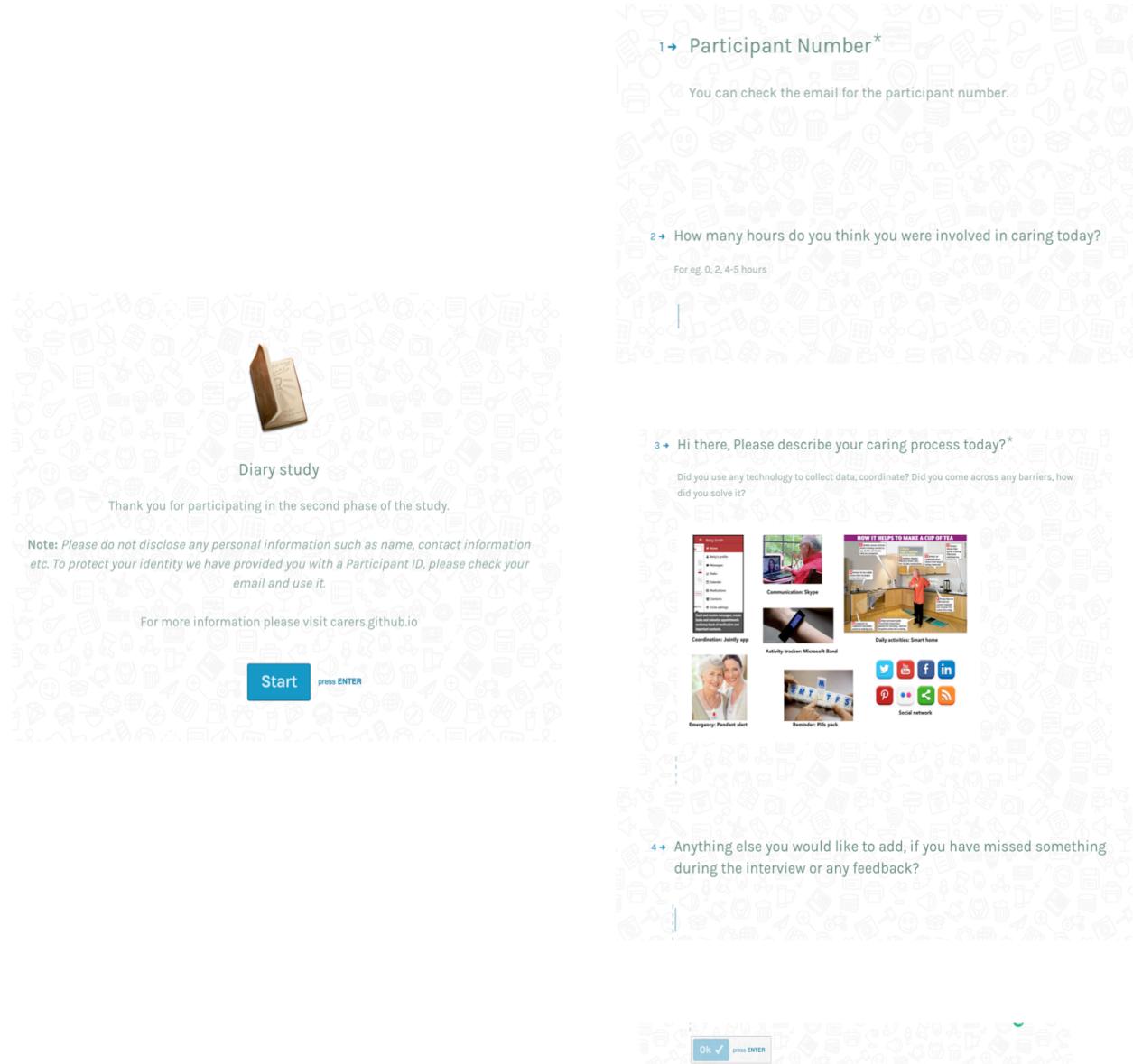
I .....

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed:

Date:

## Appendix 4: Diary study in Typeform [Online format]



The image shows a Typeform survey titled "Diary study". The background features a repeating pattern of small icons related to daily life and technology.

**1 → Participant Number\***  
You can check the email for the participant number.

**2 → How many hours do you think you were involved in caring today?**  
For eg. 0, 2, 4-5 hours

**3 → Hi there, Please describe your caring process today?\***  
Did you use any technology to collect data, coordinate? Did you come across any barriers, how did you solve it?

Below the questions are several examples of technology used in caring:

- Coordination: Junity app
- Communication: Skype
- How it helps to make a cup of tea
- Daily activities: Smart home
- Emergency: Pendant alert
- Activity tracker: Microsoft Band
- Reminder: Pill pack
- Social network: Icons for Twitter, Facebook, LinkedIn, Pinterest, Google+, and RSS feed.

**4 → Anything else you would like to add, if you have missed something during the interview or any feedback?**

At the bottom right is a button labeled "Ok ✓ press ENTER".