Care Navigation in Older People with Multimorbidity
Feasibility and Acceptability of using ICT

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1 RESEARCH PROBLEM

Recent years have seen significant changes in the age profile of populations of Western European countries, where more people are living longer. In many ways, an aging population reflects progress (i.e., in health care and political stability), and is something to be proud of. However, it also raises concerns; while people are living for longer, they are not necessarily living well for longer.

Incidence of long-term health conditions (LTCs) increases linearly with age (Office for National Statistics [ONS], 2013). Further, the chances that one is diagnosed with more than one LTC (multimorbidity) also increases with age (DH, 2012). Health and social care systems were initially not designed to support people with multimorbidity. These patients are in need of integrated, on-going care. Patients, with multimorbidity, need a seamless connection between systems (i.e., health and social care) as well as between the different people involved (i.e., providers). Rather, health and social care systems present patients with a variety of options for highly specialised care, provided at different settings (Health Foundation [HF], 2014). In the health care system, each body system has its own scientific discipline, resulting in several specialisms and even sub specialisms. In the social care system, the list of services is constantly expanding.

Patients currently have little to no guidance in finding their way through this care system maze. They are expected to navigate through the different options (Albert, 2012), building, as it were, their 'personal care network' (PCN) in relation to the multiple LTCs they have. It is unclear how patients do this, what those self-composed PCNs look like, how they are structured or how the different people involved communicate with one another.

Accessing the 'right' type of care, at the 'right' time and in the 'right' place (care navigation) is necessary if we want to optimise patients' well-being. Besides causing poor patient satisfaction (Albert, 2012), difficulties in navigating the care system also lead to delays in access to services, inappropriate use of services and inadequate use of resources (Bhandari and Snowdon, 2012). Care navigators (people who support patients in finding their way through the system) are beneficial in the context of single diseases (Ferrante, Cohen & Crossen, 2010). Their widespread use in primary care for patients with multimorbidity is however not without obstacles (Albert, 2012; Ferrante et al., 2010). For instance, in the context of multimorbidity, care navigators tend to be involved for long periods of time. The number of staff needed to support this growing group of patients is almost impossible to cover.

A promising opportunity to address this challenge is that of Information and Communication Technology (ICT) (Czaja, 2015; Marchibroda, 2015). Research has shown that ICT can provide valuable opportunities for older people, especially by supporting age-related needs (Goodman-Deane, Keith and Whitney, 2009), while also reducing the cost of health care (Khosravi and Ghapanchi, 2016). However, there are no insights into the benefits of ICT on navigation through the care system.

This issue is addressed by my PhD research, which explores the feasibility, acceptability, and requirements establishment to support the design of ICT interventions to support older adults with multimorbidity to independently navigate the care system. To this end, a five-step research process has been implemented.

Firstly, we bring together the existing literature around care navigation in older people with multimorbidity (1). We then aim to visualise PCNs of older people with multimorbidity (2) and gain an understanding of how these PCNs function (3). In the fourth phase of the PhD we investigate how ICT can provide a sustainable alternative for care navigation support in older people with multimorbidity (the end-users) (4). This includes the identification of end-users' needs and requirements

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for such an ICT support tool. The fifth phase concludes this PhD by producing usable personas of older people with multimorbidity (5).

The hands-on design phase of the ICT tool for navigation is beyond the scope of this PhD. However, the output of this PhD will fill the gaps in knowledge with regard to PCNs and care navigation, provide suggestions on how to improve care navigation and deliver usable personas and requirements for design teams focussing on older people (with multimorbidity).

Even though these issues are occurring on a global scale, this PhD mainly focusses on the situation in England.

2 OUTLINE OF OBJECTIVES

The overall goal of this PhD is to outline requirements for the development of an ICT support tool for care navigation. In order to reach a feasible and acceptable support tool to help older people with multimorbidity navigate the care system, the following objectives were set:

1. Conduct a Scoping Review: Synthesise and chart the current literature regarding care network navigation in older people with multimorbidity.
2. Visualise PCN Data: Visualise the structure of 'PCNs' (i.e. the network that the patient with multimorbidity builds to get the care he/she needs) using quantitative data. The visualisation is to show the main actors ('who') involved in the care for the patient, their frequency of contact ('when') and the ways in which people interact in this network ('how').
3. Understand the PCNs: Gain in-depth understanding, through qualitative data, of how PCNs function. This includes information on obstacles patients encounter when navigating through their PCN, identification of the support they need to make the navigation as easy as possible, etc.
4. Integration of PCN information: Translation of the data into personas. The personas created in this study can then support prototyping of an ICT tool for care navigation support.

3 STATE OF THE ART

Global increases in life expectancy contribute to the growing number of older people. The WHO (2014) reported, globally, an average increase of six years in life expectancy between 1990 and 2012. The prevalence of LTCs is linked to age, reaching almost 70% in the age group of 75 years and above (ONS, 2013). One quarter of people in England with a LTC and aged 60 years and older reported having two or more chronic conditions (multimorbidity) in 2009 (DH, 2012). With the second wave of baby boomers soon entering the older age groups, the amount of people diagnosed with multimorbidity is expected to continue its rapid increase over the next years (DH, 2012; Khosravi and Ghapanchi, 2016).The rise in multimorbidity is not confined to England. Across countries all over the world multimorbidity is becoming the norm rather than the exception (Fortin et al., 2007).

3.1 Challenges in the Care Landscape

Health and social care systems face significant challenges in adapting to these population trends (Khosravi and Ghapanchi, 2016). Four of the main, but strongly interlinked, challenges are outlined below.

Firstly, today's care delivery is characterised by specialisation (Smith et al., 2012; WHO, 2008). Specialisation of health and social care leads to people being trained and qualified to provide particular forms of care. As care becomes more specific medicine evolves specialisms and sub specialisms to cater for this. In the United States nine times more specialisms and subspecialties in medicine were reported in 2011 than in 1960 (Detsky et al., 2012). The US is not the only country with high numbers of specialties. The UK, for instance, is amongst the top three countries with both the most specialisms and sub specialisms registered (GMC, 2011). Increased specialisation is reported to enable higher quality of care (GMC, 2011). In the US, the drive towards specialism is praised because of the link it shows with improvements in patient outcomes (GMC, 2011). However, specialisation is often associated with fragmentation (Albert, 2012; Ravenscroft, 2010) which complicates working *within* health and social care as well as *between* these systems (Ravenscroft, 2010; Ferrante et al., 2010).

Secondly, the changes in population dynamics contribute to increasing care demands and changed types of care needs. The changing nature of diseases (i.e. from acute diseases to chronic conditions) demands different structures of care and integrated skills (Starfield, 2011). The current lack of integration and coordination of care frequently results in the need for patients to move within,

between and beyond different parts of the system (navigating the system). This is especially true for people with multimorbidity (HF, 2014). Some of their specialists are located in the hospital, others are based in the community, yet another group might fall under third sector care and relatives often provide informal care. Previous research found that patients with multimorbidity find navigating these different parts of the care system burdensome and, all too often, frustrating (Bhandari and Snowdon, 2012; Jackson et al., 2012; Ravenscroft, 2010). Yet, it remains unclear how these patients can be supported in this task of navigation.

Thirdly, today's care landscape has moved away from the 'disease oriented model' that was mainly concerned with curing and treating single events or acute diseases. The focus is now on patient-centred care (DH, 2012; Fortin et al., 2007; NHS Improvement, 2013; Smith et al., 2012; WHO, 2008). This model places patients at the core of the care plan and encourages them to take an active role in the management of their health. Considering the changed dynamics of our society, the patient at the centre of such a care plan is frequently an older adult, with LTCs, receiving care at multiple sites (Carla and Coleman, 2010). As such, patient-centred care organises care around the older adult with multimorbidity, but it often remains the patient's job to bridge the gaps by navigating within, between and beyond different parts of the care system. In order to do this (i.e., successfully navigate and be actively involved in their care), patients need to be empowered and well-informed. However, currently there is little to no information for patients with multimorbidity to help them navigate the care system.

Fourthly, care navigation support, if at all available, currently takes the form of a 'person' assisting the patient in their navigation task. Depending on the literature, the term to refer to these people differs slightly. Commonly used terms include care navigators, patient navigators, community navigators and case managers. All of these roughly carry out the same tasks. These roles have been successfully implemented in cancer care settings and recently demonstrable benefits are also shown in patients with single LTCs such as COPD (Jackson et al., 2012). The on-going use of care navigators more widely in primary care or in complex chronic care settings (e.g. multimorbidity) has been limited. However, the problem when encountering multimorbidity is that it is not just a sum of LTCs (Blozik, van den Bussche, Gurtner, Schafer and Scherer, 2013; Perruccio, Katz and

Losina, 2012; Sinnot, Mc Hugh, Browne and Bradley, 2013). For example, common LTCs have care pathways, but when someone is diagnosed with multiple LTCs, these pathways may interfere. The few primary care navigator programmes that were conducted in this context, further reported obstacles relating to both implementation and sustainability of the program (Ferrante et al., 2010).

3.2 Aging in a Digital Society

An increasingly popular field that is looked at for support in tackling today's health and social care challenges is this of ICT. Just as our population dynamics changed over the last decennia, so did the environment in which we age. Whereas the early use of computers was restricted to 'expert' users (Campbell-Kelly, Aspray, Ensmenger and Yost, 2013) today programming skills and expertise are not necessary in the generic use of a computer (Wright and McCarthy, 2010). As such, we are facing an aging population in an increasingly digital era.

3.3 Designing for Older People

The possibilities ICT holds for health and social care have not gone unnoticed. The improvements it can bring to the quality of, especially, later life have also been acknowledged (Goodman-Deane, Keith and Whitney, 2009). It can for instance support the creation of social networks, transform services to help people live independently at home for longer or empower and increase participation (Age Concern and Help the Aged, 2009).

It is often said that 'the full potential of ICT for health and social care in older people has not yet been examined', but this can only be realised in the first place if the systems and products are adopted and used appropriately by this group (Czaja, 2015). Since ICT is no longer restricted to 'expert use' (Wright and McCarth, 2010), one cannot always assume a certain set of skills or knowledge will be present in the user. This might be particularly true for people in the older age groups.

The evidence regarding the use of ICT in care, and especially in later life, is ambiguous (Wandke, Sengpiel and Sönksen, 2012). Some studies show an increasing amount of older people using ICT (Wagner, Hassanein and Head, 2010) and being aware of its benefits (Age Concern and Help the Aged, 2009) others are more reserved. Inconsistency in results might be due to how 'age' or 'older people' is conceptualised or which dependent

variable is studied (Wagner, Hassanein and Head, 2010). However, regardless of the exact numbers, the use of ICT in daily life, and in care settings specifically, is likely to rise (Czaja, 2015). Moreover, the current group of middle aged people are the older old of tomorrow, which makes research into digital inclusion and designing for older people a priority today.

The UK government, as others, acknowledged the importance of the digitalisation. In 2012 the *'Government Digital Strategy'* was published, outlining how it will make government services 'digital by default' (GOV, 2012). Digital by default refers to 'digital services that are so straightforward and convenient that all those who can use them will choose to do so while those who can't are not excluded' (National Audit Office [NAO], 2013). However, this is easier said than done. A digital divide, albeit it relating to education or income, can create differences in access to technology. The same can be said about usability of technology systems among older age groups of the population (Czaja, 2015). The benefits and impact of ICT largely depends on how well it is designed (Goodman-Deane, Keith and Whitney, 2009). In the case of older people, well-designed systems require a multidisciplinary team (Khosravi and Ghapanchi, 2016) since computer use by older adults is a multidisciplinary topic by nature (Wagner, Hassanein and Head, 2010).

3.4 Digital Tool for Care Navigation

With a focus on patient-centred care, the care landscape displays a partnership model. Managing one's health has become a shared responsibility in which patients are expected to play a more central role in the care plan (Czaja, 2015). This requires patients to be well-informed and empowered. Both of these elements can be established and strengthened through ICT, but only if the technology used is suitable and accessible for the patient. That is exactly what the field of Human Computer Interaction (HCI) is concerned with. Although older and younger users might share certain characteristics (e.g., they use the internet for roughly the same purposes), it is important to identify the differences and especially how these impact older people's use of ICT (Wagner, Hassanein and Head, 2010). HCI for older people has indeed become its own field and numerous projects are providing information on older people and the use of ICT. However, the information with regard to older people with multimorbidity is scant, considering the amount of

people this applies to.

Multimorbidity, as discussed earlier, poses its own unique set of challenges. To reach digital inclusion of these patients, their needs, experiences, and changes in physical and cognitive abilities need to be known. When designing systems to support older people with multimorbidity in care navigation, chances are that many designers are almost everything that the end-user is not. They are likely to be fit, healthy and relatively young professionals, engaging with elaborate types of technology on a daily basis. The end-user of their yet-to-be-designed system on the other hand, is probably less familiar with novel technological applications. The end-user is likely to have age-related changes in physical and cognitive abilities. Gaining this understanding is the first step in the process of designing a feasible and acceptable care navigation tool for them.

4 METHODOLOGY

To deliver requirements for the design of a feasible and acceptable navigation tool for older people with multimorbidity, the following information needs to be known: what problems do these patients encounter; how do they currently navigating the care system; what do their PCNs look like and what do they need the navigation tool to do for them? As this information is currently missing and there are no digital tools to aid care navigation for older people in England, this PhD was set up. Four phases (see section 4.2) compose this PhD to thoroughly answer the following question: "Navigating the care system: What is feasible and acceptable with regard to the use of ICT to support older people with multimorbidity?"

4.1 Theoretical Framework

Three theories underpin the PhD: the person-centred care model (1), patient empowerment (2) and experience centred design (3). Although these theories stand in their own right, within this PhD they are strongly interlinked. Based on these three theories, we developed the 'Patient Centred Design' framework (figure 1).

Person-centred Care is care delivered and organised *in partnership with* the patient (and his/her relatives) and *around* the patient. It focuses on the patient as a 'whole', his/her needs and his/her strengths. Four main principles underpin this care model, namely treating people with dignity, respect and compassion (1), deliver coordinated (2) and
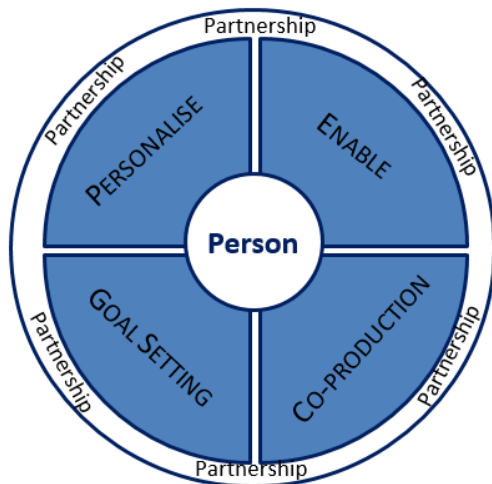
Figure 1: Framework of Patient Centred Design.

offer personalised (3) care, support or treatment and enable patients (HF, 2014). If we are to deliver care organised around the patient, person-centred care, rather than around the disease, patients become an active player in their care plan. They are seen as experts in their personal life and encouraged to take an active role in setting out the care plan. In order for them to do this, they need to be provided and supported with tools to help them in this role, they need to be empowered. **Patient empowerment** is a process as much as it is an outcome. Patients are empowered when they are supported in their development of knowledge, skills and confidence to effectively manage (including decision making) their own health (HF, 2014). The World Health Organisation (WHO) defined patient empowerment as: *'A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation'* (WHO, 2009).

Patient empowerment directly links to person-centred care as it is one of the four key principles for this care model (HF, 2014).

New technology can support patient empowerment and person-centred care. However, 'a tool' will not provide the 'whole answer' (WHO, 2012), especially if that 'tool' is designed with limited input from the intended user. We need to *'shape systems and technology, in the direction of collaboration and co-production between patients and the health system'* and we need to *'use technological and other means to increase knowledge generation and exchange from patient to patient'*.

Just like 'person-centred care' puts the people at the centre (HF, 2014) of their care, **'experience-centred design'** places the users at the core (Wright and McCarthy, 2010). It is exactly this idea of giving end-users a voice throughout the designing process that is the core of experience centred design (Wilcox, Hur and Miller, 2010). In this particular case, those people aged 55 years or older and living with multimorbidity are at the centre. As such, it is almost person-centred care in the design setting using empowerment both as a process and an outcome.

4.2 PhD Outline

This study uses a mixed methods approach to investigate the feasibility and acceptability of ICT to support care navigation. Underpinned by the pragmatist paradigm (Polit & Beck, 2010; Tashakkori & Teddlie, 2003), mixed method research typically integrates both qualitative and quantitative methods (Creswell, 2009). A combination of both techniques was applied to enrich data analysis and provide integrated results.

In the *first phase* of the PhD, a scoping review synthesises the evidence of current research in the field. The *second and third phase* of the PhD respectively involves quantitative and qualitative data collection. Individuals who aged 55 or over, living in England and diagnosed with at least two LTCs are invited to participate in the questionnaire (second phase). The type of LTCs is not specified and both physical and mental conditions are considered. Questionnaire data are analysed using Gephi for the visualisation of the PCNs and SPSS for descriptive statistics for the PCNs.

Participants for the interview (third phase) are selected through the questionnaire. Those who indicated an interest for the interview and are living in Lincolnshire (England) were eligible. The interviews are audio recorded and transcribed verbatim. After transcription, data are analysed using NVIVO for framework analysis. *The fourth*, and final, *phase* integrates the quantitative and qualitative data.

The study received ethical approval from both the University of Lincoln as well as the NHS ethics committee.

4.3 PhD: Research Plan

A specific instrument for data collection and/or integration was developed for each phase of the PhD. The four instruments are discussed below.

4.3.1 Phase One: Data Chart for Literature

Scoping reviews aim to cover the available literature in breadth rather than in-dept. They are used when the topic under study is broad and not precisely confined. In this PhD a scoping review was used to examine the extent, range and nature of research activities and summarise research findings and identify gaps (Arksey and O'Malley, 2005). Because of their focus on coverage in breath, different study designs were included, without too much focus on the quality of the different studies (Arksey & O'Malley, 2005). However, to ensure the quality of the literature synthesis, a systematic approach for literature selection and data extraction was used. The charting framework (appendix 1) for data extraction was designed to capture data from both grey and published literature.

4.3.2 Phase Two: Questionnaire

A specific questionnaire for self-completion was developed for the study as no existing questionnaires were found suitable. The study aimed to visualise PCNs of patients with multimorbidity. Social Network Analysis (SNA) theoretically underpins this phase of the study. SNA investigates the social structure of networks, usually social networks. In this study SNA, egocentric SNA in particular, is used to analyse the 'care networks' of older people with multimorbidity. Starting from the individual patient, we look at his/her relationship with the actors (carers) that are present in their network. SNA uses two kinds of tools from mathematics to represent the information: graphs and matrices (Hanneman and Riddle, 2005). A complex series of algorithms and relation algebras results in matrices and graphs. Graphs are, in this case, the visual representation of a social network. Matrices are the numerical output of network information. Gephi was found to be the most suitable visualisation software to produce graphs of individual PCNs. Numerical output is accomplished through the use of SPSS.

Because we use SNA, questions had to be phrased in such a way that they prompted participants to elicit information based on their memory. We sought information that would help us answer the questions of *who* the patient has contact with in relation to his/her care; *why* these carers are relevant to them; *what* the frequency and type of contact (e.g., face-to-face) generally looks like. All three, health, social and informal care were inquired, prompting patients with different types of providers. The answer options relating to health and social care

providers were based on the list used by Personal Social Services Research Unit (PSSRU) in their 2010 report on *'Unit Costs of Health and Social Care'* (PSSRU, 2010). The options relating to 'informal care' were based on studies around social support. To put the data into context, descriptive statistics and numerical outputs were used. Firstly, sociodemographic questions were based on the final recommendations published in the white paper *'Help shape tomorrow'* for the Consensus 2011 (ONS, 2009). Secondly, participants were presented with a list of potential LTCs and had to indicate those that apply to them. The LTC list was based on the '*Long term health conditions 2011'*- report from the DH (2011). No sample size and power calculations were done as this is uncommon in SNA and no detailed community data relating to multimorbidity were available.

An initial draft of the questionnaire was brought to the Healthier Ageing Patient and Public Involvement group. Based on their feedback, the questionnaire was adjusted before pilot testing. The pilot test was conducted amongst two members of another Patient and Public Involvement group, two academics who were independent and unfamiliar with the research and three members of the public. Their feedback led to final changes to the questionnaire before it was rolled out in England. The final questionnaire (appendix 2) is available online and paper copies can be requested.

Three main ways are being used to disseminate the questionnaire. Firstly, the questionnaire link is spread through social media. Secondly, religious and non-religious organisations are actively approached by email to help with the dissemination. Thirdly, awareness of the study and the questionnaire is being raised among 101 family (general) practices in Lincolnshire. The latter is done to further assure that patients eligible for interviews are reached. The questionnaire is available for approximately a total of 10 months.

4.3.3 Phase Three: Interviews Topic Guide

The questionnaire is put in place to answer the questions on 'who' constitutes the PCNs and to some extent 'why'. Additional in-depth information on perceived obstacles, current behaviour in navigation and data on the way in which PCNs function is needed to reach the goal of this study.

Semi-structured interviews will address these aspects and enrich the data from the questionnaire. An initial interview protocol was designed based on findings from the scoping review and the study

purpose. After reviewing a set of 50 completed questionnaires, additions were made to ensure that interviews complement the questionnaire data. The final topic guide (appendix 3) will be open to modifications if and when previous interviews indicate to do so.

Before each interview, participants' questionnaire data will be reviewed. This helps the interviewer gain a first 'picture' of the patient's PCN and makes the interview more personal to the participant.

4.3.4 Phase Four: Data-driven Personas

Apart from using multiple techniques for data collection and analysis, mixed method research requires an integration of the results. By integrating the statistical and thematic techniques, the understanding of the issue is strengthened (Plano Clark, 2010).

Initially the *'integrative framework for inference quality'* as presented by Teddlie and Tashakkori (2009, p. 301) is used to assure thorough integration. After initial analysis of the data and evolution of the study, the creation of personas emerged as a valuable way to present the integrated data. This will make the research output concrete and usable. Especially since, currently, no data-driven personas in HCI reflect older user with multimorbidity.

'Personas' were introduced in the HCI and design environment by Cooper (1999). A persona represents a group of users, written in the form of a detailed narrative about a specific, fictitious individual (Miaskiewicz, Sumner and Kozar, 2008). It is almost a model of a user that focuses on the individual's goals. That means that personas are not descriptions of real, single nor

Figure 2: The Five Phases of the Persona Lifecycle (Adlin and Pruit, 2010).

average users, but they are also not just fantasies (Blomkvist, 2002). Although their popularity increased, specific guidance on how to create solid personas is scant. Our main steps in the creation of the final personas rely strongly on the model (figure 2) presented by Adlin and Pruitt (2010).

In particular the stage of conception and gestation will be relevant to our process of persona development. At this stage, data will be turned into information and information, in its turn, into personas (Adlin and Pruitt, 2010). To help us build strong and valid personas, six steps are provided by Adlin and Pruitt (2010) in this second phase. Initially an ad hoc persona will be created quickly, capturing the current thinking about the users and what they need. This is often largely based on assumptions, but provides a first structure for data processing (Adlin and Pruitt, 2010). Secondly, the data will be processed by looking for reoccurring themes in the data, segments, etc. This results in different categories and subcategories of personas. Based on this process, the third step involves the creation of skeletons. These are bullet point lists, highlighting important data points in the (sub)categories. In the fourth step the skeletons will be prioritised according to relevance and importance to the study. Afterwards, the most relevant skeletons are to be selected and created into solid personas, which are subject to validation. Validation will be done by checking the personas with the initial data. To be valid, final personas need to reflect the data (Adlin and Pruitt, 2010).

5 EXPECTED OUTCOME

By addressing a gap in the literature around care navigation in older people with multimorbidity, this PhD is expected to add to both the field of health and social care and the field of HCI in the following ways:

Firstly, the scoping review summarised the 'type' of support older people with multimorbidity need to efficiently navigate through the care system. Only one previous study provided information on the use of care navigation support for older people with multimorbidity. Delivering this support through a care navigator was found more difficult in this setting than in single or specific disease settings. No information was found on how the required 'types' of support could be delivered electronically. It is expected that this PhD will be able to address this and add to the field by delivering information on how this patient group navigates the system, what

the obstacles are and how they would like to be supported.

Secondly, this PhD brought together existing ideas in health and social care (i.e., patient-centred care and patient empowerment) and connected these with the field of HCI (i.e., experience-centred design). These models have not been linked with each other before and led to the development of a new framework: Patient-Centred Design. As HCI with a focus on health and social care is expanding, this new framework could provide a starting base.

Thirdly, the PhD applies popular techniques in a new setting. For instance, the use of SNA to display PCNs has not been used previously. However, by using SNA to visualise the PCNs of these patients, the field of health and social care is presented with concrete PCN maps (i.e., graphs). These visualisations allow us to highlight the care providers of particular importance or relevance, the main formats for communication, etc.

Fourthly, the PhD is expected to contribute in driving multidisciplinary work. We are having an equal influence in our team of computer scientists and researchers in health and social care. As such we assure to bear in mind age-related physical and mental changes whilst looking for ICT solutions that support or ease these changes rather than aggravate them.

Fifthly, the final phase of this PhD will integrate the data collected throughout the process. The integrated data will then be reported as usable documents (i.e., data-driven personas of older people with multimorbidity). Today no data-driven personas of this particular patient group exist in the HCI community. However, the design process has been shown to benefit from data-driven personas. This PhD delivers concrete and usable documents for design teams who might not be able to conduct thorough data collection from this unique set of end-users (e.g., older people with multimorbidity are often difficult to reach), who might not be familiar with this group of end-users, etc. As such, our data-driven personas can provide design teams an 'introduction' to this unique user group, complement internal customer service data, etc.

6 STAGE OF THE RESEARCH

This study started in 2013 and is currently in the third year of research. The scoping review (first phase) indicated that care navigation among older people with multimorbidity is difficult, frustrating and burdensome. The second phase (questionnaires) is close to completion, with data currently showing involvement of several care providers at different sites. Although studies in the scoping review revealed the types of information these patients need, they did not address how this information should be delivered. This gap will be addressed in the interviews (third phase) in the PhD. Semi-structured interviews will allow us to establish how ICT can support this. Over the coming months the data from the second and third phase will be integrated into personas. This integration process will be crucial to provide usable data-driven personas. A framework has been set up to guide this integration process.

7 DOCTORAL CONSORTIUM

Because of the stage of my PhD (i.e., just at the edge of getting into the HCI phases) I see this doctoral consortium as an exquisite opportunity to discuss current findings and next steps with peers. Since my PhD is situated at the cross point of health science and social computing, I often have to 'choose' for either health related conferences or conferences in the field of HCI. The overall theme and scope of this conference however, allow me to really bring together, integrate and strengthen both strings of my PhD. The conference will further give me the opportunity to broaden my network and form connections with experts in the field.

The doctoral consortium in particular, will give me the chance to connect with PhD students across a variety of disciplines and yet in the same main stream of research, in a way that is often difficult in day to day academic life. It provides me with a platform where I can both discuss my research and at the same time learn from my peers and their research journey. It has been my experience that bringing together PhD students with a shared interest leads to wonderful opportunities (e.g., sharing ideas on specific parts of research, collaboration). Previous doctoral meetings have left me stimulated, refreshed and with invaluable new connections.

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APPENDIX

Data Extraction Tool for Literature

Title	Full title of the article
Type of literature	Type of literature e.g. research, conference abstract, project description
Year	Publication year
Authors	Last name and letter of first name from authors
Study location	Continent/country where study took place
Aim of the study	Aims or goals of the study as given in the paper
Design/Methodology	Used method of study (e.g. qualitative research) and design if appropriate
Sample Characteristics	Relevant sample characteristics of the study
Important results and findings	Summary of findings of the study
Relevance	Notes on relevance of the study in function of the scoping review topic

Final Questionnaire

Free to obtain from the corresponding author (jvos@lincoln.ac.uk), not included as appendix due to its size.

Topic Guide for Interviews

Free to obtain the latest version of the topic guide from the corresponding author (jvos@lincoln.ac.uk), not included as appendix due to its size.