

Challenges towards a Connected Community Healthcare Ecosystem (CCHE) for managing long-term conditions

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Background Societal, demographic and economic changes have encouraged us to reconsider how we deliver health and social care to older people and their families in our communities. The emergence of 'Connected Health' (CH), through the use of information and communication technology (ICT) has gained increased attention. CH is considered to offer the potential for cost-effective, innovative care solutions which can help to support and empower older people and family carers. In doing so there exists potential to help older people and family carers manage the impact of living with long-term conditions (LTC) at home. **Method** We undertook a systematic mapping study to (i) identify the key challenges for older people suffering from long-term conditions and their carers and (ii) explore how CH could support older people suffering from long-term conditions and their carers. This article presents a review and mapping of the current status of CH with a particular focus on the use of ICT to empower older people and their families to manage LTC. **Results** The findings identify key challenges to LTC and the drivers for the emergence of CH presented as a Connected Community Healthcare Ecosystem (CCHE). This work also provides a roadmap for future research. Moving forward there is a need to engage all key stakeholders of older people, family carers, policy makers and health care practitioners to examine alternative health-care models alongside those who develop ICT solutions.

Keywords: Connected Health, empowerment, ICT, long-term conditions

Societal and demographic changes coupled with recent economic challenges have challenged us to reconsider how we deliver health and social care in our communities¹⁻⁵. Considering the key healthcare drivers which support longevity (for example, healthy living, medicine developments and healthcare technology), long-term conditions (LTC) will continue to place a significant and growing burden on healthcare service systems. A long-term condition is a medical condition that cannot be cured, but can be controlled by medication and other therapies.

Thus, as the population of older people increases, it is inevitable that such changes will continue to place pressure on our healthcare systems. As a result, there is a growing interest in examining the potential of information and communication technology (ICT) to support a transition from a hospital-focused healthcare system to a home-care-focused health system⁶.

OECD, EU AND WHO

The Organisation for Economic Co-operation and Development (OECD) defines the elderly dependency rate as "the ratio between the elderly population and the working age (15-64 years) population"⁷. The elderly population is defined as people aged 65 and over. There has been a significant increase (ranging from 7-25%) in the growth of the older population across OECD countries between 1970 and 2014 (*Figure 1*). This also has a number of implications for government and private spending especially on healthcare which warrant immediate attention in terms of providing proactive healthcare service solutions.

Sustaining this ageing population requires focus on prolonging and achieving equity in good health and well-being throughout the life course. Many services for the ageing population are typically packaged in long-term care, which is often delivered through a combination of social ser-

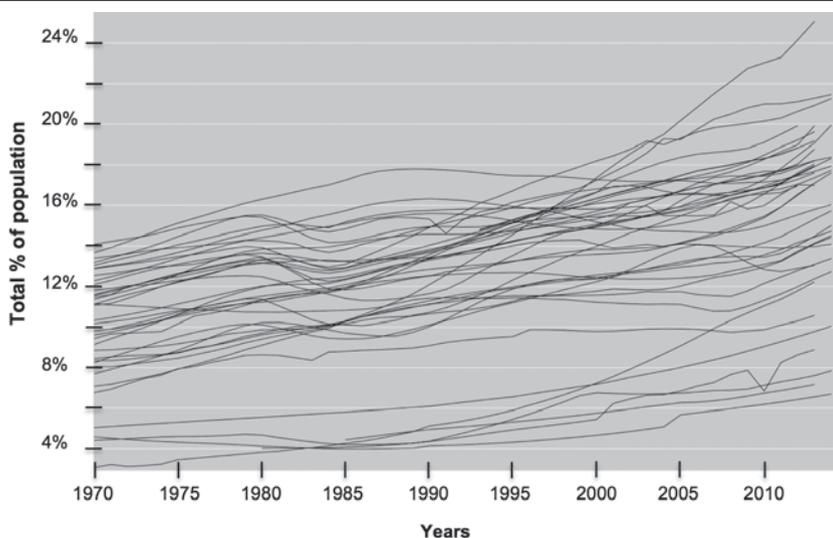


Figure 1. Population over 65 years old across the OECD (Organisation for Economic Co-operation and Development): Total % of population, 1970-2014⁶⁹; each line represents a different OECD country and indicates an increase in the elderly population

vices and healthcare services and must become a priority. However, Sharpe et al.⁸ identify the relationship between available support of services and the burden from the unmet needs of patients and caregivers.

The core issue may be simplified adopting a ‘supply-and-demand’ perspective. According to a recent European Commission report⁹ entitled ‘Ageing Report: Europe needs to Prepare for Growing Older’, the population of the EU is projected to reach 517 million in 2060, when almost one third of the citizens will be aged 65 or over. Life expectancy at birth is projected to increase from 76.7 years in 2010 to 84.6 in 2060 for males and from 82.5 to 89.1 for females. This will ultimately put additional pressures on the healthcare systems, increasing the incidence and prevalence of LTC across the EU and possibly worldwide. Thus, supporting people at home and keeping them out of acute care as a healthcare model is receiving growing attention as a necessary way forward for healthcare¹⁰⁻¹².

Studies have indicated that socio-economic factors play an important role^{12,13} in supporting changing healthcare requirements. We describe this as a ‘healthcare accessibility’ issue. For example, according to Kringos et al.¹², good primary care is associated with better population health, lower rates of unnecessary hospitalisations and relatively lower socio-economic inequality. They also propose a link between education levels and self-rated health. Research indicates that this is creating what may be described as a health divide between people within the EU healthcare system¹⁴. Many of these issues have been further

pressed by the increased cost associated with providing healthcare services, particularly relevant to a growing older population. Indeed, healthcare systems across the world are attempting to address the challenges that result from an ageing population, the growth in chronic diseases, burgeoning technical possibilities and public expectation¹⁵. Healthcare in Europe is provided through a wide range of different systems run at the

national level. Regardless of how they are funded, healthcare proves to consume an increasing proportion of GDP across OECD countries – Europe being no exception. Therefore continued efforts will focus on deriving greater healthcare efficiencies and effectiveness to cope with dwindling resources¹⁶.

Ultimately, the provision of healthcare places considerable financial burdens on the public purse. From a government perspective, health expenditures are noticeably higher in countries where there are stronger primary care structures¹², pacing what Tarricone and Tsouros¹⁷ describe as the ‘growing need for homecare in Europe’ which warrants the need to focus on LTC. The potential use of ICT is gaining increased attention as a possible solution to this problem. However, it is critical that we gain a thorough understanding of LTC from various perspectives rather than focusing on a technology push approach. Considering the demographic challenges and the inevitable increasing demand on healthcare¹⁸, there is a need to radically reform^{19,20} how we deliver healthcare services to older people suffering from LTC.

LONG-TERM CARE

Providing long-term care service requires the organisation and delivery of a broad range of services and assistance over an extended period of time to people who are limited in their ability to function independently on a daily basis, due to mental and/or physical disability. The level of care provided to LTC sufferers requires a combination of (i) personal assistance (for example, meals, shopping, and housework) (ii) medical

services (for example, wound dressing, medication, health monitoring, rehabilitation or services of palliative care) and (iii) psychological support (for example, basic interaction and discussions, education or counselling).

Recognising that LTC requires a combination of health and social care highlights the complexity of care pathways associated with various conditions. In fact, the relationship between family carers, healthcare professionals and a healthcare service system is described by Magnusson et al.²¹ as often being “complex and sometimes conflicting”. Long-term care may be provided in a wider range of environments including home-care, nursing homes, and hospitals. LTC is typically provided through medical professionals, formal (skilled and paid professionals) and/or informal care services (voluntary friends and/or family). Much of the emphasis is placed on the provision of homecare to empower older people in the home. Empowerment may be defined as “strengthening the individual’s capacity to participate in decision-making regarding his or her care”²². Magnusson and Hanson²³ describe this as “ageing in place” and suggest that the majority of older people wish to remain in their own homes.

According to the World Health Organisation²², ‘ageing in place’ is concerned with: “Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing. Ageing in place is designed to prevent or delay more traumatic moves to a dependent facility, such as a nursing home”. Ageing in place becomes the focus of our review.

RELATIONAL PRACTICE

For the past number of years increasing importance has been placed upon the need to support relationships which exist between healthcare service users, family caregivers and healthcare professionals. A key focus of our contentions is the concept of ‘relational practice’²⁴ which is often discounted, considered ‘softer’, invisible and off-record, yet it is a vital link to support the relationship growth and support amongst LTC service users²⁵⁻²⁷. Relational practice has been defined as activities “necessary to develop and sustain interpersonal relationships” based on an understanding of individuals’ circumstances and their contexts^{27,28}. There are a number of key factors to support relational practice including²⁷:

- (i) Accessibility: staff needs to be available when they are needed;
- (ii) Boundary management: staff needs to make emotional connections with service users, but

- also need to avoid being overloaded;
- (iii) Connection: the ability to create engagement and empathy and demonstrate emotional authenticity;
- (iv) Collaboration: all parties need to share information and be involved in relational work; and
- (v) Continuity: the ability to relate past and present experiences.

Research indicates that informal homecare (i.e. relatives, friends and neighbours) plays a much more important role in the longevity of older people – often “filling the gap left by formal services”²⁰. A major pan-European study of informal caregiving for older people highlighted the need to improve the nature of relationships and the degree of cooperation between formal and family carers²⁹. The Pew Fetter Task Force³⁰ highlights the need to understand that the quality of relationship between provider, patient and carer is the most significant factor in being able to achieve successful outcomes and prevent further social and medical deterioration.

CONNECTED HEALTH

As technological solutions seek to enable new healthcare relationships and partnerships, there is a growing interest in examining information and communications technology (ICT) to support the development of Connected Health (CH). CH has been defined by Richardson³¹ as: “where patient-centred care results from process-driven health care delivery undertaken by healthcare professionals, patients and/or carers who are supported by the use of technology (software and/or hardware)”.

One use of CH is to connect technologies to support independent living. This has the potential to support LTC. For example, Rossi Mori et al.³² explain that: “...the phenomenon of technology-assisted long-term care is still in its infancy, and must be properly understood and addressed both to maximise its effects on society, and to improve the lives of citizens and their informal carers”.

CH solutions have the potential to enable the development of a homecare healthcare system within which formal (provided by health and social care providers) and informal (provided by family carers) care can be supported. However, Wherton and Monk³³ suggest that within a healthcare context, “technologists rarely have time to obtain at first hand an understanding of the precise needs of the people they are designing for”. This can impact on many factors including healthcare quality, acceptability to older people and both informal and professional carers and the health economics of delivering healthcare solutions.

There exists some evidence that leveraging the use of ICT can provide us with effective solutions to enhance the quality and expected outcomes of healthcare services^{11,34,35} but there is little evidence-based research on its impact in a homecare context. According to Black et al.⁶, there is an apparent paradox between the increasing application of technology within healthcare environments and insufficient understanding of the acceptability of technology for older people, family carers and health care professionals. However, quality of care is linked to the delivery of care within a strong and supported relationship based context²⁴.

Enhancing relational practice is a core focus of using ICT to improve the quality of care offered to those suffering from LTC. However we know relatively little about the relationships between the use of ICT to connect care for those managing LTC. The research we present in this paper acknowledges the need to develop insights into the dimensions of CH and how ICT improves the quality of life for people living with LTC. One such example is the Joseph Rowntree Foundation³⁶ programme for those with high support needs. This programme highlights that understanding, measuring, improving and monitoring the overall quality of life (not just the quality of care) is one of the main challenge in healthcare³⁷.

In addition, across Europe where there are approximately 100 million family carers, self-management is an important policy driver³⁸. The contributions of family carers are estimated to exceed financial expenditure on nursing services³⁹. Considering the ageing European population and the corresponding incidence and prevalence of LTCs in those over 65 years of age there is a need to better understand to what extent ICT can empower older people and their family carers to self-manage LTC.

The purpose of this paper is to establish what factors might influence the extent to which ICT can empower older people and their family carers to manage LTC within the community. To do so, we set out to address the following research questions:

- (i) What are the key challenges for older people suffering from long-term conditions and their carers?
- (ii) How can CH support older people suffering from long-term conditions and their carers?

We have undertaken a mapping study which has resulted in our identifying a how CH can work for LTC. From this we have defined a Connected Community Healthcare Ecosystem (CCHE).

METHOD

Our systematic mapping study examined previous work⁴⁰ in order to identify relevant research using Web of Science, EMBASE, CINAHL, Psychinfo, Google/Google Scholar and grey literature. Mapping offers a key strategy commonly employed to conduct literature reviews⁴¹ and using this approach enabled the authors to map ideas, arguments and concepts from a body of literature to support how we presented the literature in this paper. The review inclusion criteria were as follows:

- (i) Published between 2003-2013;
- (ii) Published in English from Europe, North America and Australasia;
- (iii) Focus on empowering citizens to maintain informal healthcare through ICT solutions;
- (iv) Explicit search criteria; and
- (v) Outcome contributes towards the identification of existing gaps in the field of CH.

The key words were: ('Information and Communication Technology' OR 'Connected Health') AND ('healthcare' OR 'e-health' OR 'home care' OR 'patient empowerment' OR 'patient self-management' OR 'long-term care') AND ('Europe' OR 'North America' OR 'Australasia').

We retrieved a total of 2270 references of which 95 met the inclusion criteria and were selected for review⁴². A summary of the key results is reported qualitatively in the form of a narrative summary of the key contributions identified and discussed in the next section. The findings were extracted and synthesized using inductive coding techniques through which we identified the main categories and their relationships to support the development of the CCHE. These were refined through ongoing discussions amongst the team. The organisation of the synthesis was guided by our review question.

RESULTS

Connected Community Healthcare Ecosystem

From our mapping study, we identified a Connected Community Healthcare Ecosystem (CCHE) (*Figure 2*) where social, technological, demographic and economic drivers impact on the provision of formal and informal healthcare in the community. We also identified the impact of caring responsibility for older people and the opportunity for technological interventions to support LTC sufferers. This enables connectedness between people, ultimately providing the older person with self-management and empowerment capabilities and the carer with flexibility and empowerment capabilities.

The remainder of this paper discusses the significance of each sub-section for the CCHE.

Connected Health

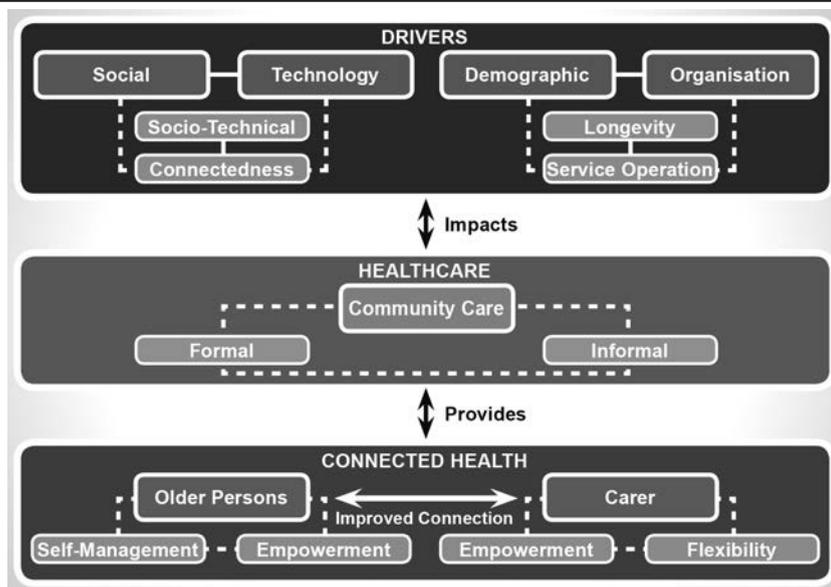


Figure 2. The CCHE model: Connected Community Health Ecosystem

Drivers

Our findings indicate that over the past decade sociological drivers are increasingly focusing on the need to identify and understand preferences of older people, many of whom would desire to stay in their homes, remaining close to family members^{21,22}. Family caregivers provide 80% of care at home and their total contribution in monetary terms exceeds that of the entire nursing budget⁴³. This raises questions about how care and support at home is organised and how ICT can contribute¹⁷. There exist opportunities for technologists to collaborate with healthcare professions to seek alternative solutions to redesign the ‘homecare health service’ model.

Technology is becoming an increasingly important driver in healthcare provision. E-health developments have been experimented with “in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research”⁴⁴. Technologies can improve healthcare quality, provide cost-effective solutions and reduce the burden on carers’ personal lives^{21,45}. In recent years, the growth of applications (or ‘apps’) can support and monitor older people’s activity and conditions⁴⁶. The Internet plays an enabling role²⁰. Within our review, we identified a growing interest amongst healthcare professionals in applying ICT to provide on-demand healthcare support while in some cases there is a growing resistance of technological advances amongst healthcare providers⁶.

From a holistic perspective, the socio-technical environment is a key driver within healthcare

as oftentimes, both social and technological drivers work together. Socio-technical systems can provide an understanding of the complexity of a working environment where people and technology interact⁴⁷. For example, Heeks⁴⁸ explains that “the importance of socio-technical approaches is well recognised already within at least a fraction of the medical informatics community”. In healthcare, they play a critical role

whereby ICT affords citizens the opportunity to effectively manage healthcare activities³².

Longevity and the change in demographics⁷ coupled with increasing healthcare costs, has added to the challenge of providing care for older people through alternative methods. There have been improved medical developments and healthcare technology innovation (for example, assistive technology, robotics, home automation, and home care-based healthcare monitoring and telemedicine) but there is a lack of empirical evidence to support claims of CH innovation⁶. There have been attempts to re-examine new methods of healthcare delivery through policy development²⁰.

Drivers for new innovative methods to deliver healthcare using ICT work largely in response to external factors such as economics. For example, as part of the Health Service Executive ‘Strategic Framework for Reform of the Health Service 2012-2015’, the Irish Government announced an ICT capital allocation of approximately €40 million⁴⁹ and approximately €70 billion is allocated within the EU for strategies on ICT for ‘active and healthy ageing’⁵⁰. Therefore, at a much wider level, the EU has promoted the need for more technological developments to improve healthcare and quality of life⁵¹.

The key drivers identified in the CCHE influence the carer’s responsibility in improving the lives of people. We identified the concept of ‘caregiver burden’ as being the emotional, physical and financial demands and responsibilities of an individual’s illness that are placed on family members,

friends or other individuals involved with the individual outside the health care system²². The relationship between family carers, healthcare professionals and a healthcare service system is described by Magnusson et al.²¹ as often being “complex and sometimes conflicting”. While this is true for the healthcare profession, such blurring is also apparent within the overall healthcare system. For example, Kringos et al.¹² report that there is a blur between primary and secondary healthcare and that primary care can contribute to a “high-performing healthcare system”.

To some extent, this has also widened the definition of ‘healthcare’ and ‘carer support’. For example, Sharpe et al.⁸ examine the relationship between available support of services and the burden from the unmet needs of patients and caregivers. Thus, homecare should provide an environment which satisfies¹⁷:

“...people’s health and social needs while in their home by providing appropriate and high-quality home-based health care and social services, by formal and informal caregivers, with the use of technology when appropriate, within a balanced and affordable continuum of care”.

Within the CCHE, the notion of appropriate use of technology is critical to home healthcare initiatives. This is particularly important to support informal carers since “informal care has provided the bulk of home care and still remains the largest source of home care”¹⁷.

While there have been many innovative approaches towards the use of ICT to support older people in healthcare management, the focus of technological introduction is often on how it can bring about economic advantages in healthcare rather than the health or social aspects such as social inclusion or reducing carer anxiety³². Arno et al.⁵² provides a comparison of the economic value associated with individual caregivers and the various stresses and responsibilities of caregiving in the USA, estimating that the economic cost to replace informal care would be \$196 billion. In Europe, van den Berg et al.⁵³ explain that informal care is often neglected in economic evaluations of health care programs. In fact, they call for the need to develop improved methods to identify and value the full costs and (health) effects of informal care for the informal caregiver.

Caring responsibility

Community healthcare encompasses a broad range of daily supportive tasks for older people who lack the physical or mental capacity to successfully and safely complete their daily routines. Shura et al.⁵⁴ examine the “process of culture change within an LTC community”, suggesting

that the concept of ‘human engagement’ is a significant factor in the use of ICT in health. We describe this as Connected Community Healthcare to empower older people and manage the treatment of various illnesses. However, the concept of homecare is not very clear across literature which often contributes towards the “uncertainty in its application and in the training of those working in home care”⁵⁵. They also explain how the concept of homecare includes a number of overarching tasks, for example, care related to individual needs, actions and assessments as prevention, and post-hospital discharge.

There is also recognition⁵⁶ that home healthcare is typically delivered by a combination of:

- (i) Formal healthcare provided by professionals, and
- (ii) Informal healthcare provided by non-professionals such as family, friends and/or neighbours.

From a Connected Community Healthcare perspective, the notion of the appropriate use of technology is critical to home healthcare initiatives. This is particularly important to support informal carers since “informal care has provided the bulk of home care and still remains the largest source of home care”¹⁷.

The literature suggests that the notion of connectedness could have significant opportunity in the quest to merge various contributions from healthcare professionals. For instance, there is a clear tension between the nursing stakeholders, for example, between health professionals within a hospital and community context⁵⁷. This ultimately adds to the blurred boundaries in terms of homecare and the often unaccounted for healthcare services provided by the ‘informal carer’.

Carers

There is some evidence that ICT can provide a vital link to access information and support a sense of an online healthcare community between the older person(s) and carer(s). This link or relationship can also empower carers to overcome psychological and geographical challenges to providing healthcare (for example, The Princess Royal Trust for Carers⁵⁸). Carretero et al.’s research²⁰ has identified that, through ICT implementation, independent living, learning about healthcare, personal support, social integration and care coordination can be achieved. In addition, ICT-based services can provide many benefits for the health and life of informal carers and for the welfare system at large.

Self-management

Self-management has numerous definitions in various fields. Within the healthcare field,

self-management generally implies that there is some form of an intervention or skills which older persons acquire to support their ability to effectively take care of themselves to some reasonable standard of care. Older people's self-management implies that they hold responsibility to manage their own health conditions and suggest that they are in control of their own health improvement or deterioration. Self-management may be defined as³⁸ "...a process that requires knowledge, the ability to monitor signs and symptoms, and the capacity to deal with the emotional, physical, social and occupational impact of a long-term condition".

We expand on this when we discuss our case study (i.e. CCHE in Practice). To enable self-management, ICT can bridge the relationship between the older person and the carer or healthcare professional. For example, there are several methods which can support the self-management process for older people where ICT adopts various roles in healthcare support³²:

- (i) Passive role (for instance, environmental sensors);
- (ii) Limited participation (for instance, repetitive tasks);
- (iii) Interactive collaboration (for instance, interacting with carers and take joint decisions); and
- (iv) Autonomy (for instance, training towards self-manage under some form of supervision).

Technology has the potential to empower older people, for example, in a homecare setting, supporting relationships between patient and carer and monitoring the overall health of patients. However, to empower older people, one must be mindful of the balance between the triangular relationship between the:

- (i) Patient and carer;
- (ii) Patient and technology;
- (iii) Carer and technology.

This relationship can potentially provide a useful contribution towards raising older people's Preparedness (PR), Enrichment (E) from, and the Predictability (P) of their personal caring situation as identified by the PREP model^{21,59}. ICT can also play a supportive role to provide carers with greater flexibility which appears to be an area we have identified as being overlooked from a technological viewpoint.

Connectedness

The concept of connectedness is critical when we discuss the 'healthcare system' and how it comprises of "people, institutions and resources, arranged together..."⁷². Connected Community Healthcare encompasses a wider view of the healthcare system including homecare. Thome et

al.⁵⁵ have identified the connectedness required in the provision of homecare when they define homecare as: "...care provided by professionals to a person in his or her own home with the ultimate goal being not only to contribute to his or her life quality and functional health status, but also to replace hospital care with care in the home for societal reasons and covering a wide range of activities from preventative visits to end-of-life care".

Many older people affected by LTC spend most of their time at home, sometimes with periodic admission to hospital care as necessary for symptom control or respite care. It is at home that the challenges which LTC bring need to be met and supported. Older people require an extended support system for care within a specific context by which the proper facilities are sufficient to enable them to maintain a reasonable quality of life. Thus, the notion of homecare being an integrated system builds on the concept of 'connectedness' to deliver a healthcare service. ICT can provide a vital link to access information to support a sense of a healthcare community between the patient(s) and carer(s). This link can also empower them to overcome psychological and geographical challenges to providing healthcare (for example, The Princess Royal Trust for Carers⁵⁸).

CCHE in Practice

To present how the CCHE can be used in practice, we apply it to a diabetes case study. We discuss how knowledge of this ecosystem has the potential to consider a holistic care solution rather than providing a disjointed solution which is more common for LTC care.

Case study 'Diabetes'

George is a 72 year old man who has suffered from Type 1 diabetes since he was a child. His diabetes has been well controlled until 6 months ago, following the death of his wife. George's wife had helped him to manage his diabetes, ensuring he ate well and monitoring his condition. George has recently missed his regular check-ups which is unusual. The community nurses are visiting to monitor his blood sugars and provide advice and support. However, they can only visit once or twice a month and George needs to cope the rest of the time.

George appears to be suffering from diabetes burnout, exacerbated by his recent bereavement, where he has lost interest in caring for his long-term condition. He is experiencing hypoglycaemic attacks as he is not preparing proper meals or is missing meals altogether. George appears to be depressed and has stopped going for his regular walks which helped him to keep fit and control his blood sugar levels.

Within existing healthcare systems, there are interventions which can be implemented to support and improve George's situation. As stated within Richardson's definition of CH³¹, these interventions should include people, processes and technology and could include:

(i) New easy recipes: these would be developed by a diabetic nutritionist, supported by a software application to guide George in cooking his meals.

(ii) Support group and access to information: working with the public health nurse, George would be put in touch with some relevant support groups. Apart from physically attending meetings, George could contact people via the internet. If he needed particular advice, he could skype other diabetics globally. In addition, to supplement available documents, he would be shown how to access different web pages where useful information is available.

(iii) New approach to Exercise: For this, the internet can be a very useful tool, as many exercise videos and on-line discussion sites are available. What is important is that all exercises which George undertakes are discussed in detail with a physiotherapist who can ensure that he is doing the correct exercises correctly.

(iv) Tool to monitor George's ability to self-manage his diabetes: In the first instance, he would be given access to an on-line food diary. With a blood glucose monitor his daily readings could be matched with the food diary. If George's glucose levels go out of control, he could be given on-line food advice, or, if the situation continues to disimprove or becomes more serious, he could be referred to the health services.

However, while each of the solutions presented here can work, the questions we ask when we see the implementation of sporadic technological interventions are:

(i) Can the solution not be more holistic?

(ii) Have the patients and their carers, in this case, George, his formal carers, and his informal carers (such as family and friends), been involved in the development of these solutions?

Given the systematic mapping study we have presented above, and the CCHE we have identified, we can now discuss the answers to these questions.

Interventions based on the CCHE

The drivers of the CCHE are technology, social, demographic and organisation. There is much technology that exists, for example, tools such as the internet, home measuring devices such as blood pressure monitors and blood glucose monitors, and on-line healthcare monitoring systems are becoming more and more prevalent in community care. However, many of these

are presented to the patient without considering the effects from a socio-technical perspective. In George's case, for example, his eyesight is failing (a common problem for diabetics), and, when presented with the on-line diary and food information, he finds it difficult to read the information given. The technologist who developed the system expected the patient to read using the 'zoom button', but this distorts the location of the information on the screen. Not only is the technology important, but the social context in which the technology is used is important.

We also identified demographic drivers within the ecosystem. In providing George with exercises, the physiotherapist needs to consider whether these should be done in a group, or whether George has a carer who can help him with these exercises. As George gets older does he need change of exercise, or, indeed, can technology be introduced, ensuring that George and / or his carers have an input into the choice of technology?

From an organisation perspective, each of the four solutions we presented in the previous section are doable in themselves, but the excitement of CH development is not within the small once-off solutions, but the solution that is considered for the full healthcare pathway. Let us consider how these solutions might be linked together to provide a more holistic intervention for George. In the first instance, George himself would be involved in the development of any solution. It is also important to involve his formal carers, in this case, physiotherapist, nutritionist, home carer, general practitioner and practice nurse, and informal carers – his family and friends. In discussion with him, we would establish that he has eyesight problems, and that he does not have access to shops outside of his rural village. He has a few friends of similar age that he likes to meet with once a week in the local community hall. Looking at the difficulties from George's perspective and taking an overall view of the social, technological, demographic and organisational drivers, we can modify our solution.

Most important is to provide George with some solution to self-manage his diabetes. We have identified such a tool, which can be modified for people with poor eyesight. The monitoring output would be connected to George's local general practitioner and practice nurse and also to the development of recipes. We can also ensure that George's taste for food, the difficulty of cooking, given that he is now living alone, and the availability of ingredients in his local area are all considered in the solution. We can work with his group of friends to include some dis-

cussion and workshops on ‘cooking for yourself’, sometimes focusing on diabetes. Through these workshops we can show George and his friends what is available on the internet. And, of course, we cannot forget his exercise regime. This would be linked to his food intake and the timing of his meals. In addition, there is the opportunity to set up group exercises which involve his friends.

The outcome using this solution impacts both formal and informal community care. In our case study, from a formal perspective, the physiotherapist, nutritionist, general practitioner and practice nurse have to work together to come up with the medical solutions. Any home carers and informal carers, such as family and friends have to be involved to ensure that George makes his appointments, and equally important, is supported in meeting his friends, doing his exercises and getting to the shop to buy the correct food.

George has been empowered through his active involvement of the CH implementation. Inclusion of his formal and informal carers ensures that all stakeholder requirements are understood and accounted for. This results in George taking ownership of his diabetes self-management. Carers can understand how changes in advice and requirements affect other parts of the implementation. Thus, the connection between carer and George is improved.

Case study discussion

Through the literature we have identified that the CCHE cannot be just about technology providing solutions, but must include social, demographic and organisation drivers. Mapping this case study to the ecosystem, we have illustrated the establishment of suitable interventions for George, an LTC sufferer.

DISCUSSION

ICT has the potential to empower older people in managing their LTC but there is a lack of evidence on its impact to LTC across literature²⁰. Within a homecare setting ICT can support relationships between older people, family carers and/or health professionals, and monitor the overall health of older people. However, to empower older people, one must be mindful of the drivers described within connected-community healthcare and the need for balance between older people and carer, older people and technology, carer and technology and older people, carer and health professional. We identified the key drivers (social, technological, demographic and organisational) in the CCHE model.

Much of CH development has been enabled through Internet technologies which support im-

proved connectivity amongst healthcare stakeholders and provide up-to-date information on health records. Thus, the internet proves to be a very useful tool to empower older people’s engagement. A study carried out by Sum et al.⁶⁰ examined the participatory relationship between social capital and well-being. They explain that the relationship is rather complex and explain that the use of the internet can be both positive and negative depending on the users’ self-awareness with regards to the nature of the internet. According to Kreps and Neuhauser⁶¹, e-health tools ought to be “interactive, interoperable, easy to use, engaging, adaptable, and accessible for diverse audiences”. In most cases, however, several questions appear to go unanswered throughout e-health literature. For example, Kreps and Neuhauser⁶¹ identify issues which fail to provide evidence-based analysis on whether specific technologies are suitable for their audience, whether e-health tools fit comfortably within the policies, practices, and technical infrastructure that are built into existing health- and social systems, whether tools are affordable, or whether the information generated from e-health tools is clear enough to inform decisions.

In our findings, we discuss how CH technologies can improve healthcare communication and social connectivity. We describe these benefits through the diabetes case study and highlighting how CH interventions can alter LTC care pathways. However, the unpredictable elements of human behaviour, attitudes to risk and healthcare, have all resulted in considerable tensions between healthcare stakeholders in recent years³². Traditionally, the ‘one size fits all’ healthcare paradigm across our hospitals, clinics and healthcare services is relatively limited by costs and availability of resources. We describe the importance of focusing on community care (formal and informal) to provide a CH service to older people and carers. Smart devices were quickly viewed over the past decade as being a possible solution to enable “personalised healthcare services delivered to individuals at any place and any time”⁶². The concept of personalisation is a key factor since it empowers the older person to self-manage healthcare and avail of personalised or tailored healthcare services. To date there are, however, too many unknowns to provide a complete summary of the potential of smart technologies and ICT in a CH ecosystem.

Applying technological innovations to support ‘unknown’ healthcare outcomes or consequences becomes too risky for healthcare stakeholders. We summarise this concern as the lack of established evidence on the impact or potential impact of ICT on LTC. This was also highlighted

by Blaschke et al.⁶³ when they expressed their concerns about the lack of empirical evidence: “This leads to the suspicion that the current status of our research knowledge.....[it may] simply provide an excuse for governments not to pay for potentially useful interventions that have no ‘established’ evidence base. Thus, it may fall to the commercial marketplace to develop – with some targeted field testing and evaluation – profitable products and services that can be sold to an ever growing market of ageing adults and their families”.

We proposed the need to take a step back to identify the drivers within a CCHE before we can identify specific healthcare innovations. We then described the promise of CH innovation using a diabetes case study to highlight where innovative interventions can empower older people suffering from LTC. In addition, we propose the need for CH evaluation models^{34,64} to support our understanding on the benefits of healthcare innovations to support self-management, empowerment and flexibility of healthcare delivery.

Recommendations

This section offers a summary on the key recommendations based on our research and offer a discussion on how we could achieve these within three categories: policy, stakeholder innovation and patient-centric solution design. We describe how these will promote the establishment of a CCHE.

Policy

We propose that policymakers need to develop new models based on the CCHE. According to the European Commission⁹, “local and regional actors will be at the forefront of capitalising on the opportunities for active ageing and for promoting solidarity between generations” and we outlined previously that the concept of ‘relationship’ plays a central role in a CH ecosystem. Building on what Kamel Boulos and Wheeler⁶⁵ suggested; “health care providers should aim to become social enablers, providing situations ...so patients can gather, learn from, and support each other, improving health outcomes” – a CCHE must adopt a similar outlook to apply ICT to empower older people in a home care context.

Stakeholder innovation

We envisage that stakeholder innovation will require the close cooperation of a number of key stakeholders. The Quadruple Helix Innovation Model⁶⁶ encapsulates the need to shift from a linear approach to a collaborative, systemic, open and user-driven innovation models, and therefore can be used to support a CCHE. Consequently, we have modified this model to

reflect CH (Figure 3), where its success relies on the four key collaborative relationships between:

- (i) Government public sector;
- (ii) Business private sector;
- (iii) The general public;
- (iv) Academia higher education.

Holman and Lorig⁶⁷ also explain that “the crux of appropriate care for chronic disease is the partnership between patients and health professionals”. A connected and collaborative healthcare paradigm would allow us to concentrate expertise on patient requirements, for instance, an older people care system while empowering them to self-manage their own health. This is where technologists must play a vital role in providing the interface to enable healthcare relations, older people empowerment and self-management through software development and medical device or wellness product design.

Patient-centric solution

We envisage that healthcare co-production will require that technologists gain a better ethnographic understanding of the dynamics between older people and healthcare professional interactions to build and co-create improved healthcare outcomes. To achieve this, technology should become more immersed in healthcare. However, this cannot be accomplished in isolation (Figure 3) and other key stakeholders must become increasingly connected. This was highlighted by Reid et al.⁶⁸ when they explained success is often dependent on a “partnership between vendors, internal and external IT staff, and healthcare staff and involves unique relationships among stakeholders...with varying needs, interests, and objectives”. CH solutions align with the key drivers and impact of the CCHE.

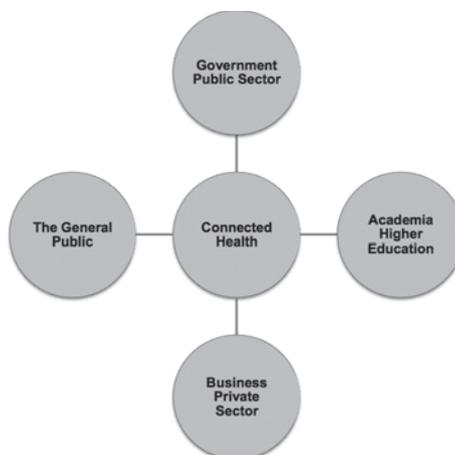


Figure 3. Connected Health Innovation Model (adapted from Carayannis and Campbell⁶⁶)

Limitations

While there has been considerable interest in exploiting technology to enhance the quality and safety of healthcare, there is a significant gap between “the postulated and empirically demonstrated benefits” of health technologies⁶. Reid et al. explained that this is largely due to the lack of robust research on risks, trust and cost-effectiveness that demonstrate the real benefits of e-health. As part of our future research, we set out to address this gap. Through a multi-stakeholder analysis^{34,64}, we can begin to both qualitatively and quantitatively assess the impact of CH innovation on healthcare from various perspectives, including the clinical, technological, business, policy and cultural ones.

CONCLUSION

Over the past decade, we continued to experience greater pressures for more economical (efficient and effective) practices across all sectors in society. One of the main sectors which have been dramatically impacted is healthcare. In parallel with these developments, we have learned that the shift in population demographics with regards to the longevity of older people will inevitably place pressure on healthcare services. Fortunately, there has been a continued growth within the field of ICT which offers considerable promise for service solutions across many sectors in our economy such as education and manufacturing. And ICT equally offers significant opportunities to contribute towards healthcare and the emerging field of ‘CH’.

We presented the CCHE model. Adopting a relational approach towards CH, this review offered a contribution by highlighting the need to become proactive to the growing demand placed on healthcare services from LTC. We need to build a future which embraces CH innovations and policy developments. This review has unveiled many expected and unexpected findings regarding the complex nature of healthcare and the potential barriers towards the realisation of a CH ecosystem. We have discussed the growing demands and constraints which will have impact on the future delivery of home healthcare for older people suffering from LTC.

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Many medical treatments traditionally provided by hospitals are now being administered within communities, allowing hospitals to provide more complex, specialised and emergency care. However, this also shifts a considerable level of responsibility and accountability at a local level to nurses and carers. Thus, CH can play a significant role serving as an interface between primary and secondary in-home care, focusing on prevention, self-management and providing support to the transition of older people across the health and social care services smoothly.

Notwithstanding the technological advances of ICT, progress has been slow, fragmented, and often lacks any evidence-based research to justify the potential contribution of ICT in home healthcare. Thus, we need a ‘conceptual leap’ towards a much more holistic concept of CH that does not focus primarily on older people and adopts a much wider relational view of a healthcare system. CH has the potential to alleviate some of the inevitable demand on healthcare resources.

We have identified the main challenges to CH and provided a roadmap for future research. We discuss the need to engage policy makers and practitioners to examine alternative healthcare models. However, this will require additional research through a number of interdisciplinary lenses including a social, technological, demographical, and economic one. These research areas cannot be examined in isolation and will require policy developments to reinforce the importance of interdisciplinary research and approaches towards CH innovation.

In conclusion, to achieve a CCHE, we must ensure that we focus on each of the drivers as identified in our mapping study. These will in turn impact formal and informal community care, providing empowerment and self-management for the older person. Additionally, the application of CH technologies can provide additional support for carers and the wider healthcare community and begin to pave the way for a much more inclusive CCHE.

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