

Perceptions and use of technology to support older adults with multimorbidity

Emma MURPHY^{a1}, Julie DOYLE^b, Caoimhe HANNIGAN^a, Suzanne SMITH^b,
Janneke KUIPER^c, An JACOBS^c, Evert-Jan HOOGERWERF^d, Lorenzo DESIDERI^d,
Valentina FIORDELMONDO^d, Lorenza MALUCCELLI^e, Anne-Marie BRADY^a,
John DINSMORE^a

^a*Trinity Centre for Practice and Healthcare Innovation, School of Nursing and Midwifery, Trinity College Dublin, Ireland*

^b*NetwellCASALA, Dundalk Institute of Technology, Ireland*

^c*imec-SMIT, Vrije Universiteit, Brussels, Belgium*

^d*AIAS Bologna Onlus, Italy*

^e*ASP - Agenzia Servizi alla Persona Città di Bologna, Italy*

Abstract. Digital technologies hold great potential to improve and advance home based integrated care for older people living with multiple chronic health conditions. In this paper, we present the results of a user requirement study for a planned digital integrated care system, based on the experiences and needs of key stakeholders. We present rich, multi-stakeholder, qualitative data on the perceptions and use of technology among older people with multiple chronic health conditions and their key support actors. We have outlined our future work for the design of the system, which will involve continuous stakeholder engagement through a user-centred co-design method.

Keywords. Multimorbidity, Older adults, Perceptions of technology, Co-design

1. Introduction

Health systems across the EU are currently designed to support a single-disease framework of care for chronic health conditions, and are not well equipped to support people who are managing multiple health conditions at the same time [1-2]. Existing guidelines and scientific literature do not provide sufficient information on self-management for people with multiple health conditions (also referred to as multimorbidity), where interactions and conflicts in treatment and care may arise [3]. For people with multimorbidity, services are often inefficient, repetitive, burdensome, and potentially unsafe due to poorly integrated and coordinated care [4]. This can result in reduced quality of life for people with multimorbidity and their carers. There is a need to improve best practice around the provision of continued, well-coordinated, person-centred care for people with multimorbidity (referred to from here as PwMs).

This study is part of ProACT, an EU funded Horizon 2020 (H2020) project that aims to create and evaluate a novel digital integrated care ecosystem for older adults

¹ Corresponding author, Emma Murphy, Trinity Centre for Practice and Healthcare Innovation, Trinity College Dublin, 2 Clare Street, Dublin 2, Ireland; Email: emma.murphy@tcd.ie.

living with multimorbidity. This digital system will integrate sensor technologies with a custom built application to improve and advance home-based integrated care for people with multiple conditions. Trial sites in Ireland and Belgium are using living lab facilities to ensure the co-design of this digital system with key stakeholders. Technology to support self-management will be deployed in these primary trial sites to 120 PwM's and their care networks (both formal and informal). The primary trial sites will also be supported by a transfer site in Italy consisting of 15 PwM's and their care network, where a European transferability will be conducted to assess cultural, social, infrastructural, and political determinants for adoption and scalability of the system.

1.1. Older adults' perceptions of health technologies

There is a well-established and growing field of research dedicated to developing tools and standards to ensure that digital technologies are accessible and inclusive to people with disabilities and older adults, particularly in the field of web development [5]. However, only a small number of empirical investigations have explored the barriers and drivers affecting uptake and deployment of digital health and wellbeing technologies [6-7]. The field is in its early stages for longitudinal evidence but research to date has produced mixed results in relation to older people's attitudes to technology to support health and wellbeing. Studies have illustrated that older adults generally have positive opinions and attitudes about trying and using new technologies [8]. However, we must also acknowledge that there can be significant barriers to the adoption of health technologies by older people. It is widely recognised that sensory, physical and cognitive impairments associated with the ageing process can hinder older users' perceptions and experiences when interacting with technology [9]. Furthermore, health status itself is a moderating factor for computer use and digital literacy [7]. As a result, older adults with illness or disability - the cohort who are often the intended beneficiaries of digital technologies - are likely to have the most difficulty using them.

In order to create a system that will effectively support people with multiple chronic conditions to self-manage their health, we must involve end users throughout the entire design process, and maximise our understanding of potential barriers to system uptake and usage. As a first step in this inclusive design approach we conducted an empirical study to explore the needs and experiences of older adults with multimorbidity, and of the people who support them in managing their health. This paper outlines the main findings concerning current perceptions and use of technology for health from this user requirements study. This study involved 124 participants across two trial sites in Ireland and Belgium, and 41 participants at the transfer site in Italy.

The aim of the requirements gathering study in Ireland and Belgium was to elicit requirements for the design of the digital care system, and the interviews and focus groups explored key aspects of multimorbidity management and integrated care. While a large number of themes emerged from this rich, multi-stakeholder dataset, the results presented in this paper focus on data related to participants' perceptions and use of technology. In comparison to the main trial sites, the requirements study at the Italian transfer site had a wider focus, examining the broader needs of older persons with chronic health conditions and their formal and informal carers in a specific institutional health and social care system. This choice was made to reflect the challenges faced by systems developed in one region/country upon entry into the competitive market of e-health and e-care solutions, particularly given that large health care providers look for

technology driven innovative solutions to be integrated in their existing service delivery systems. The thematic analysis of the data collected revealed specific needs, areas of improvement and possible requirements related to innovation and impact.

2. Perceptions and Use of Technology in Ireland and Belgium

2.1. Methods

PwM participants in Ireland and Belgium were recruited through a variety of sources, including healthcare professionals (HCPs), formal care organisations, living labs and various social groups for older adults. Inclusion criteria for PwMs were people over 60 years of age who were managing two or more conditions (Diabetes, Chronic Obstructive Pulmonary Disorder (COPD), Coronary Heart Disease (CHD) or Congestive Heart Failure (CHF) and Mild Cognitive Impairment (MCI)). In Ireland, 19 PwMs participated (mean age 73.39, range 60-86; 11F). In Belgium 19 PwMs participated (mean age 76.11, range 65-89; 11F). In each country, 15 participants had two of the included conditions. Four participants in Ireland and three in Belgium had three conditions, while one in Belgium had four conditions. The most common combination of conditions was Diabetes and CHF/CHD (IE n=6; BE n=5), followed by COPD and CHF/CHD (IE n=4). The majority of PwMs (IE n=16; BE n=13) reported having additional conditions (to inclusion criteria). If PwM participants had an informal carer, these were also invited to take part. Other informal carers were recruited through a formal care organisation. Inclusion criteria included anyone over the age of 18 caring for a PwM with two or more of the above conditions. In Ireland, 7 informal carers participated (6F, 1M; mean age 59.57, age range 49-74). In Belgium, 10 informal carers took part (9F, 1M; mean age 60.4, age range 36-80).

Using a snowball sampling method, HCPs were recruited through existing links in both countries. Across both regions, 11 GPs took part. Specialists included consultants and clinical nurse specialists of each condition, including gerontology (n=12). Other HCPs, included public health nurses, physiotherapists, occupational therapists, a dietician, a speech and language therapist and a care coordinator (n=10). Formal care workers (n=21) and managers (n=7) were recruited through formal care organisations while pharmacists (n=8) were approached directly by researchers.

A mixture of semi-structured individual interviews and focus groups were conducted in Ireland and Belgium. All interviews/focus groups were audio recorded and transcribed verbatim for analysis. A thematic analysis of these transcripts was then conducted using NVivo. Stakeholders are identified with the following legend, where IE represents Ireland and BE Belgium: 01 – Person with Multimorbidity (PwM); 02 – Informal Carer (IC); 03– Community HCPs; 04 – Hospital HCPs; 05 – Formal Carers or Managers (FC).

2.2. Results

2.2.1. PwM and informal carers' use of and perspectives on technology

Approximately half (47.4% of total sample; IE 42.1%; BE 52.6%) of the PwMs interviewed reported owning and using a laptop or PC; an additional 5.3% of the sample owned a computer but did not use it, and the remaining participants did not own

or use a laptop/PC. The majority of PwM participants (73.7%) owned and used a mobile phone. Among this group, 13 participants (34.2% of total sample; 46.4% of mobile phone users) reported using smartphones. Ten PwM participants (26.3% of total sample) owned and used a tablet device. From the total sample across Ireland and Belgium, 57.9% of PwMs had an Internet connection in their home, and 26.3% had a mobile Internet connection.

Many of the PwMs interviewed in both Ireland and Belgium reported positive attitudes towards technology: 50% said that using digital tools was part of their daily routine, and 63.2% said they felt digital tools bring advantages. Four participants at each trial site (21.1% of total sample) said that they easily keep up with new technologies. However, some participants had a more negative view, with 21.1% of the total sample (IE 15.8%; BE 26.3%) reporting that they avoided using digital tools when possible. Eight Irish participants (IE 42%) reported not using any devices to monitor their health and two Belgian participants (BE 11%) reported that they did not use any monitoring devices specifically for their health.

PwMs in Ireland reported using their phone as a reminder to help with self-managing (e.g. to take medications) and to help with scheduling appointments and reminders; however, this was not mentioned by participants at the Belgian trial site. Use of technology for 'company' and for keeping the mind active (e.g. playing games on an iPad) was reported in both countries. At both trial sites, some PwMs were reluctant to consider additional digital monitoring as they believed it would generate anxiety for them. Nonetheless, others could see benefits of monitoring symptoms as a means of verifying their health status, alerting them to impending condition exacerbations and providing an accurate and comparative record of health data over time. In Belgium, PwMs had greater difficulty seeing how this would work or how additional digital monitoring might help them.

Participants emphasised the importance of ensuring that technology is accessible and usable by the PwM in order to support and maximise their use of health technologies: *"A lot of these digital things are just in general too difficult for seniors. Someone has to think about making it easy. It is technically more difficult to make something simple than to make it difficult"* (BE-02-0005). *"As you get older, again you know, your sight is failing and you need to have something that is instantly recognisable as what it is you want, you know. And if you have to go and get your glasses to see it, you know it's not good enough, as far as I'm concerned because people won't go and get the glasses and then they will have forgotten about what they were about to do"* (IE-01-0005).

This participant also felt that to maximise accessibility, technology needs to be adaptable to the specific and changing needs of the user as part of the design of the system: *"Declining ability of faculties over time needs to be built into the systems. While you might start off with a system that would be very dependent on the individual himself or herself in their 60s but by the time you get them into - you know my age - you are probably beginning to think in terms of, you know, more of it being done by a carer - because of the declining faculties."* (IE-01-0005)

Informal carers reported using devices to monitor vital signs alongside the PwM that they care for. They also reported using laptops/computers or tablets to look up health information online.

2.2.2. HCP Perspectives on technology

Pharmacists interviewed at the Irish trial site reported using various types of technology. Many pharmacies have an online presence and support online shopping and ordering of prescriptions or booking appointments. At the Belgian trial site, the pharmacists used fewer types of technology. They work with a computer system that registers their clients and their prescriptions. Issues related to data protection prevented integration and sharing of information between pharmacies at both trial sites.

In Ireland, there is currently very little, if any, technology usage by HCPs for communicating about patients or supporting integration. Referrals, patient notes etc. are all typically communicated on paper, via post: *“You file a letter to be put into the medical notes. There's no online system.”* (IE-04-0003). However, there were some reports of GP practices using digital systems to manage patient records. In Belgium, the communication between HCPs about patients is also mainly conducted on paper or by phone. Within the same hospital or same hospital-group patient notes could be made in an electronic dossier. Some specialists reported using e-mail to have contact with their patients or get measurements from the patient, but most only had face-to-face or phone contact. Most GP's in Belgium use an electronic database for their patient records. *‘There's an insufficient flow of data. If a patient is treated within the same hospital or hospital group, it's ok, but if you have you retrieve it from different centres it's a problem’* (BE-04-0001).

Healthcare professionals noted that new technologies aiming to support digital integrated care or self-management should be easily integrated with or accessible by digital systems that are currently in use (e.g. in GP practices): *“And also integration. Like if you want something on to the system, I think it has to be scanned and then saved into the patient record, I've not seen ways of just being able to copy across electronically if you have an electronic copy elsewhere”* (IE-03-0005). *“I mean if [the PwM] have invested months in kind of getting together readings and things like that they should be able to have a backup process as well as the system. Because otherwise it is just a waste of time”* (IE-03-0007).

GPs were hesitant to recommend the use of devices for self-monitoring symptoms at home. They were wary of creating additional anxiety and burden for the PwM, and were also concerned about the accuracy of some devices (e.g. pulse oximetry and spirometry sensors). For example, GPs reported being wary of deploying blood pressure cuffs and other health monitoring devices in the home for self-management purposes as they could generate increased anxiety if appropriate expectations were not set for user: *“The other thing I guess is to watch out for increased anxiety around measuring things. You know some patients can be quite fixated on their blood pressure with their home blood pressure monitors, and they will come screaming through the door if it is above a certain level”* (IE-03-0005).

Where IT systems were already in use, for example by GPs or pharmacists, there were concerns expressed about security of data should external devices have access to deliver or receive data to/from their system. The concerns were particularly evident in Ireland, and were related to data protection but also to the integrity of the data and systems, which were reported as extremely costly to install and maintain, without any subsidy from the health system to support this. In Belgium concerns were raised about PwM privacy with the use of technology but less concern was expressed about security.

3. Perceptions and Use of Technology at the Italian Transfer site

At the transferability site in Italy, a requirements gathering exercise was conducted in parallel with that of the main trial sites. This study aimed to engage with a wider range of stakeholders relevant to the local context and to issues related to transferability of the system. The Italian requirements study involved older adults with frailty and individuals with severe motor impairments living with a high level of independence, key actors in the local public health and social care sector and informal carers. Care ecosystems, both at personal and institutional level were identified and analysed, using focus groups and interviews for information gathering. It was acknowledged in Italy that technology is an important ally for persons with motor impairments, whose conditions could increase the risk of the development of chronic pathologies. Their drive for independence may be an important motivator for these users to engage with a digital integrated care system, as long as remote communication and ambient assisted living features could be integrated into the care platform. Italian stakeholders are identified with the following legend, where IT represents Italy: 01 – Person with Multimorbidity (PwM); 02 – Informal Carer (IC); 03– Formal Carers; 04 – Community care clinicians; 07 – Health and social care managers

Demographic questionnaires and a focus group revealed low levels of confidence among older participants in relation to use of technology and “high-tech” devices. Older adults reported using mobile telephones to make and receive calls from their relatives and friends. *“With my mobile phone I just receive and make calls, I do not even use text messages.”* (IT-01-0007) However, they expressed the desire to have more control over ICT and medical devices. Although older participants reported that they would prefer a direct relationship with their doctors and carers, they also acknowledged the usefulness of some technologies in the area of health management.

Italian participants also raised concerns around accessibility of technology and the fact that older people have other sensory and physical impairments in addition to their chronic health conditions: *“Having a severe visual impairment, let’s say not at 100% but at 70%, I often have to turn to the help of others.”* (IT-01-0001) Conversely, participants also recognized the value of technology to enable people with disabilities. For example, one participant described how new technology could help them to communicate with the emergency services: *“Me and him have speech difficulties and then whether we need to call the emergency medical service it is difficult; we would like to be connected with an emergency call centre. [it is useful] for a person with disability that lives alone, when you feel bad to push a button and the app automatically call the emergency service.”* (IT-01-0009); *“An app with a pre-registered message that directly calls the emergency service would be very useful”* (IT-01-0008)

The requirements gathering in Italy also highlighted the fact that new technologies face challenges to be accepted at all levels, both by health care professionals and by end users: *“GP tends to be reluctant to consider [on-line/digital communications], despite they have been informed and trained in this project of the [area name] Region.”* (IT-03-0010). *“I prefer human relationship[s].”* (IT-01-0004). This resistance may be due to, a cultural background that often produces a plain opposition between technologies and human relationships, and also the current state of the welfare system in which significant social resources for citizens have been reduced.

4. Discussion

A rich, multi-stakeholder, qualitative dataset has been generated and analysed in order to inform and define the design requirements of the ProACT system. In relation to the perception and use of technology among older PwMs and their key support actors, the following key findings have emerged:

- Both PwMs and GPs highlighted the potential for digital monitoring to create additional anxiety about health conditions.
- Ensuring the technology is accessible and useable by all stakeholders will be crucial to ensure the adoption and continued use of a digital integrated care system.
- Desire for independence may motivate PwMs to use health technologies that support self-management.
- Certain stakeholder groups (such as the pharmacists in Ireland) were receptive to the idea of novel technology; greater levels of receptiveness were observed among those stakeholders who already have technology embedded into their current work practices. GPs were more cautionary in their perception of the role of new technology to support PwMs, primarily due to privacy and security concerns.
- There is great potential for technology to enhance communication among healthcare professionals and carers working with PwMs.
- New technology should integrate with existing digital health systems.
- The engagement and support of all key stakeholders will be critical for the success of a digital integrated care system.
- PwMs interviewed in Ireland and Belgium were aged between 60 and 86 years. This is a large age range potentially spanning two generations. This cohort should not be considered a homogenous group; participants may have diverse experiences and perceptions of technology. We will take this into consideration in future analyses of this data. The larger sample size for our main proof of concept trial will allow for subgroup analyses.

The empirical investigation presented above is the first step in an iterative design process, which will require reflection and further analysis of the findings. We will also continue to engage with key stakeholders through an interactive and collaborative co-design process.

4.1. Next steps: Co-design with end users

Based on the extensive user requirements gathering study we have created personas of PwMs and other key stakeholders to help to translate the qualitative data into meaningful requirements for design. We have created scenarios around these personas based on real data from our study to explore how technology can support all key stakeholders. We have also used versions of these scenarios as part of our co-creation sessions with end users, to try to focus users to help us to design core concepts for the system. The use of such scenarios in design sessions has been proposed in the

literature for the purpose of triggering creative design ideas and user reactions while maintaining the discussion on a certain context and user character [10]. Gaps occur at appropriate points in the scenario, to introduce user interface elements or devices where user feedback is required from end users.

In our design work with the key end users we have taken a genuinely inclusive approach to co-design. We recognise that older adults can do much more than participate in interviews to elicit their technology requirements, they can have an active role in the design process [11]. Similarly, we have identified the importance of involving other key support actors in the design process, as the system we aim to develop will only be effective as an integrated care solution that involves all of the key actors including carers, pharmacists, GPs, consultants/specialists. We have invited participants from all stakeholder groups to participate in co-creation workshops where we will explore the conceptual issues of technology creation from interface design, preferences, aesthetics and capabilities to ethical issues and the wider implications for integrated health and care structures.

5. Acknowledgements

This research is funded European Union's Horizon 2020 research and innovation programme under grant agreement No. 689996. This document reflects the views only of the authors, and the European Union cannot be held responsible for any use which may be made of the information contained therein. We would like to thank all research participants for their time, commitment and valuable input.

6. References

- [1] Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie, B. (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 380(9836):37-43
- [2] Rijken, M., Struckmann, V., Dyakova, M., Gabriella, M., Rissanen, S., van Ginneken, E. (2013). ICARE4EU: Improving Care for People With Multiple Chronic Conditions in Europe. *Eurohealth* 19 (3): 2013
- [3] Wallace, E., Salisbury, C, Guthrie, B., Lewis, C., Fahey, T. and Smith, S.M. (2015) Managing patients with multimorbidity in primary care. In *BMJ*, 350
- [4] Starsfield, B., Shi, L., and Macinko, J. (2005). *Contribution of primary care to health systems and health*. *Milbank Q.* 83: 457-502.
- [5] Petrie, H., Savva, A., Power, C. (2015) Towards a unified definition of web accessibility. In *Proceedings of the 12th Web for All Conference (W4A '15)*. ACM, New York, NY, USA
- [6] Clark, J.S. and McGee-Lennon, M.R. (2011) A stakeholder-centred exploration of the current barriers to the uptake of home care technology *UK Journal of Assistive Technologies* 5 (1), 12-25.
- [7] Heart, T and Kalderon, E. (2013) Older adults: Are they ready to adopt health-related ICT?. *International Journal of Medical Informatics*, 82(11), pp.1-23
- [8] Mitzner, T. L., Boron, J. B., Fausset, C. B., et al. (2010). Older adults talk technology: Technology usage and attitudes. *Computers in Human Behavior*, 26(6), pp. 1710-1721.
- [9] Fisk, A.D., Rogers, W.A., Charness, N., Czaja, S.J., Sharit, J. (2009) *Designing for older adults: Principles and creative human factors approaches*. CRC Press.
- [10] Pirhonen, A., Murphy, E., (2008) Designing for the Unexpected: The role of creative group work for emerging interaction design paradigms *Journal of Visual Communication Special Issue on Haptic Interactions*, 7(3) 331-344
- [11] Rogers, Y. and Marsden, G. (2013) Does he take sugar?: moving beyond the rhetoric of compassion. *Interactions* 20(4) pp. 48-57.