Whitepaper on the needs and requirements of older people with multiple chronic conditions to self-manage their health

Authors

Julie Doyle, Evert-Jan Hoogerwerf, Janneke Kuiper, Lorenzo Desideri, Valentina Fiordelmondo, Caoimhe Hannigan, An Jacobs, Lorenza Maluccelli, Emma Murphy, Suzanne Smith

Editors

Emma Murphy, Caoimhe Hannigan, John Dinsmore

Published

July 2017

Contents

Executive Summary

The key challenge facing healthcare systems worldwide is their ability to provide continued, well coordinated, person centred management, care and support for the increasing number of people with multiple chronic diseases. The European Union Horizon 2020 ProACT (Integrated Technology Systems for ProACTive Patient Centred Care) project aims to address this issue by utilising existing and designing new digital technologies to improve and advance home based integrated care for individuals over the age of 65 living with multiple chronic health conditions.

This report presents findings from the needs analysis and scoping phase of the project conducted between January and September 2016. The aim of this phase of the project was to investigate the challenges that different actors in the care ecosystem face and how these are currently addressed in the two main ProACT trial sites: Ireland and Belgium. The findings detailed in this report will serve as crucial building blocks for the design of the ProACT system. We also present an overview of the findings from an additional trial site in Italy as part of a ProACT system 'EU transferability study'.

Introduction

© Philips Image

Introduction

Health systems across the EU are currently designed to support people with one chronic health condition, without due consideration for people who are managing multiple health conditions at the same time (Barnett, 2012; Rijken 2013). The 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 (Wallace et al., 2015). For people with multimorbidity, services are often inefficient, repetitive, burdensome and potentially unsafe due to poorly integrated and coordinated care (Starsfield et al, 2005). 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).

The ProACT Approach

ProACT (Integrated Technology Systems for ProACTive Patient Centred Care) is an EU funded Horizon 2020 project that aims to develop and evaluate a digital integrated care ecosystem to support older adults living with multimorbidity. ProACT will integrate a wide variety of new and existing technologies to improve and advance home-based integrated care. The development of a digital platform for integrated care such as ProACT has the potential not only to support existing practices in healthcare, but also to improve the management of complex and integrated care, introducing new ways for key actors (e.g. informal caregivers, general practitioners, pharmacists etc.) to work together and support the PwM.

ProACT Trial Sites

Trial sites in Ireland and Belgium will use Living Lab facilities to ensure the co-design of ProACT technologies with key stakeholders. Technology to support self-management will be deployed to 120 people with multiple chronic conditions and their formal and informal care networks. The main trial sites will also be supported by a European transferability study in Italy to assess the cultural, social, infrastructural and political determinants for adoption and scalability.

Requirements gathering

As a first step in the design of the ProACT system we have conducted a research study to explore the experiences of older adults with multiple chronic health conditions and the people who support them in managing their health. This report outlines the main findings from this requirements gathering study, which involved 124 participants across our two trial sites in Ireland and Belgium, and 41 participants at our transfer site in Italy.

Here, we list and define the key end user groups who took part in this study:

Persons with Multimorbidity (PwM): Older adults, over the age of 65 managing two or more of the following chronic conditions: Diabetes, Chronic Obstructive Pulmonary Disease (COPD), Coronary Heart Disease (CHD) / Chronic Heart Failure (CHF) and Mild Cognitive Impairment (MCI).

Informal carers: Adults over the age of 18 informally caring (unpaid) for a PwM managing two or more of the above chronic conditions. Informal carers have a personal relationship with the care recipient, and might include spouses, children, siblings, neighbours/friends etc.

Formal carers: Carers employed to provide care to a client managing two or more of the above chronic conditions.

Healthcare professionals: A number of healthcare professionals have been identified across hospital and community settings. These include **General Practitioners (GPs),** community health nurses, geriatricians, disease specialists, multi-disciplinary teams (including dieticians, physiotherapists and occupational therapists) and social workers.

Pharmacists: Pharmacists play an important role in the care of older adults with multimorbidity, particularly in relation to medication dispensing and management as well as medication reviews. Many pharmacies also provide services to measure clinical symptoms.

ProACT needs and requirements study (trial sites)

ProACT needs and requirements study (trial sites)

Aims

This qualitative study was designed to explore the experiences, barriers, motivations and contexts of people living with multiple chronic conditions and the roles and challenges of the ecosystem of care that supports them. The findings from this study will be translated into design requirements for the ProACT system.

Methods

Interviews and focus groups were carried out with people with multimorbidity, their carers (informal and formal) and the healthcare professionals that they interact with (such as the GP, geriatrician, public health nurse and pharmacist). Semi-structured interview schedules were created for each stakeholder group, and translated for use across both trial sites. The format of the data collection (interview versus focus group) was dependent on participant preferences and convenience. Questionnaires were also created for PwMs and informal carers for use across all three trial sites. The purpose of these questionnaires was to collect basic demographic information about the main participants.

All interviews and focus groups were audio recorded and transcribed verbatim for analysis. All transcripts were analysed using emergent thematic coding in NVivo qualitative data analysis software. For both sites the recruitment of participants with multimorbidity was based on the following ProACT inclusion criteria:

- Participants must have at least two of the following conditions: Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Failure (CHF)/ Coronary Heart Disease (CHD), Diabetes, Mild Cognitive Impairment (MCI)
- Participants must be over 65
- Participants must be able to give informed consent

ProACT needs and requirements study (trial sites)

Recruitment in Ireland

In Ireland, ethical approval was received from three ethical committees (the Health Service Executive, Dundalk Institute of Technology, and Trinity College Dublin) to recruit participants for the requirements gathering phase of the research. PwM participants were recruited through a variety of sources, including through healthcare professionals, through ProACT partner Home Instead Senior Care and through various social groups for older adults run by DkIT. Informal carers of the PwMs recruited were also invited to take part. Other informal carers were recruited through Home Instead Senior Care and through social groups at DkIT.

Healthcare professionals were recruited through existing links at DkIT's living lab, and additional healthcare professionals were recruited using a snowball sampling method. Formal carers were recruited through Home Instead, while pharmacists in the local area were approached directly by project researchers about taking part.

Irish participant profiles

In Ireland, we engaged with 19 people (8 males and 11 females) with multimorbidity between the ages of 60 and 86 (Mean: 73.39 years). Six PwM’s took part in focus groups (three per focus group), and the remaining 13 participants took part in individual interviews which were conducted in their homes. Figures 1 and 2 illustrate the numbers and types of conditions of the Irish PwM participants.

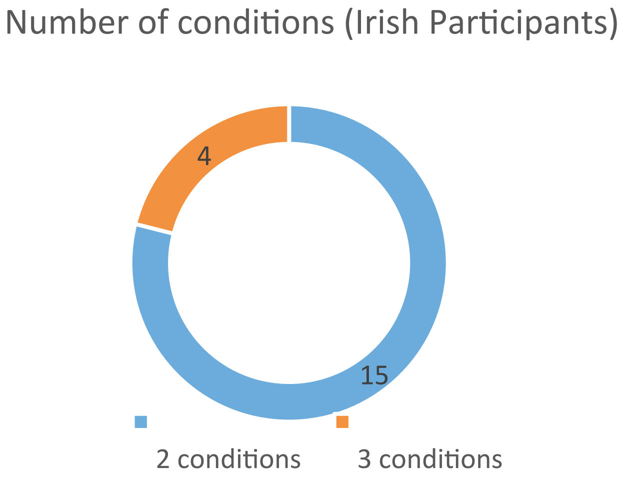

Figure 1 Number of ProACT health conditions (Irish PwM participants)

ProACT needs and requirements study (trial sites)

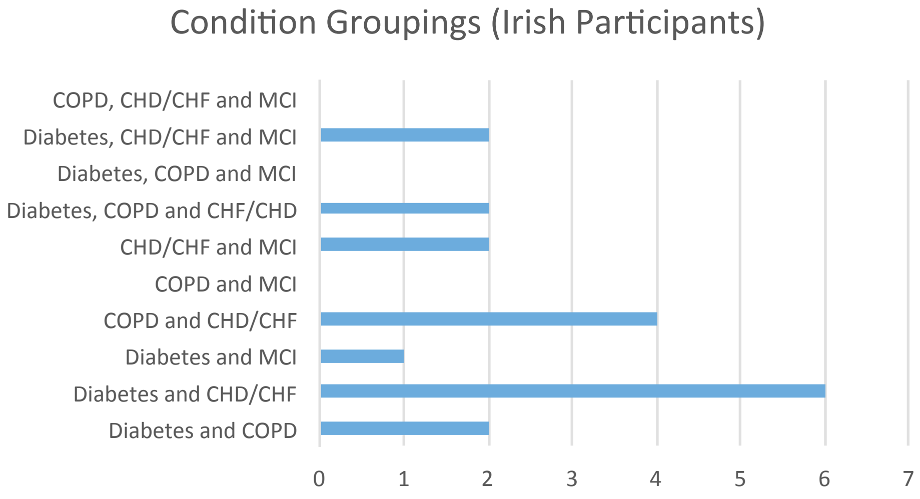

Figure 2 Types of ProACT health conditions for Irish PwM participants

7 informal carers (1 male and 6 female) aged between 49 and 74 (Mean: 59.57 years) participated in our requirements gathering study in Ireland. Four informal carers took part in focus groups (two per focus group), and the remaining three informal carers took part in individual interviews, which took place either in their home or in a location convenient to them. Some informal carers had a preference to be interviewed outside the home as they did not want the person that they cared for to be present for the interview.

Table 1: Overview of participants recruited in Ireland

Participant Group	Environment	N
Person with Multimorbidity	Home	19
Informal Carers	Home	7
Formal Carers	Home care organisation	11
Formal Care Quality Assistants	Home care organisation	5
GPs	Community	6
Public Health Nurse	Community	3
Geriatrician consultant	Acute, medical rehab and outpatient	1
Clinical Nurse Specialist (CNS) Older People	Acute, medical rehab and outpatient	1
CNS COPD	Acute and outpatient	1
CNS CHF / CHD	Acute and outpatient	3
CNS Diabetes	Acute and outpatient	2
Physiotherapist	Acute and outpatient	1
Occupational Therapist	Acute, medical rehab and outpatient	1
Dietician	Acute, medical rehab and outpatient	1
Speech and Language Therapist	Acute, medical rehab and outpatient	1
Pharmacist	Community	4
Total		**67**

ProACT needs and requirements study (trial sites)

In Ireland we also conducted a focus group with 11 formal carers recruited from Home Instead Senior Care. The majority of healthcare professionals took part in focus groups. Individual interviews were conducted with a geriatrician, a geriatric clinical nurse specialist, and two pharmacists. All focus groups/interviews with healthcare professionals twere conducted at their place of work. Details of the specific roles of the healthcare professionals interviewed in Ireland can be found in table 1.

Recruitment in Belgium

In Belgium, ethical approval was received from the medical ethical committee of the Universitair Ziekenhuis Brussel/Vrije Universiteit Brussels to recruit participants for the requirements gathering study. In Belgium, the PwM and informal caregiver participants were all recruited through Aging in Place in Aalst (AIPA, a care living lab with a panel of around 700 older end users). The PwM participants for ProACT were selected from the panel based on our inclusion criteria (having at least 2 of the selected single state diseases). Diversity on gender, combination of the illnesses, age and digital literacy was encouraged. When willing to participate, PwMs were also asked if they had an eligible informal caregiver that could be approached to participate. The participating informal carers were thus both people registered as such in the AIPA panel database, as well as informal carers of the participating PwM.

The healthcare professionals, formal carers and pharmacists were recruited using a snowball sampling approach, starting from the professional network of the project partners. The sampling was framed by required recruitment distribution among different categories of healthcare providers. Within this framework, the aim was to get a diverse and complete overview of the healthcare context the PwM are embedded in. Hospital based clinicians, community based clinicians, formal carers and other sub-categories were not targeted via one specific organisation. Participants were based in both rural and more urban areas in Flanders, and came from care organisations with differences in size and ideological backgrounds.

ProACT needs and requirements study (trial sites)

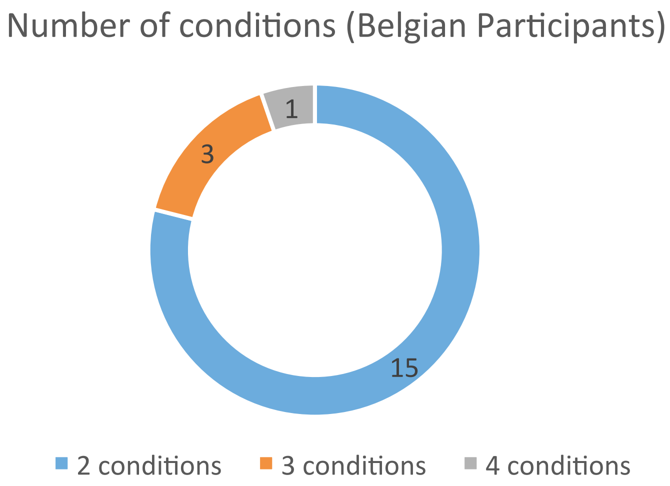

Figure 3: Number of ProACT health conditions for Belgian PwM participants

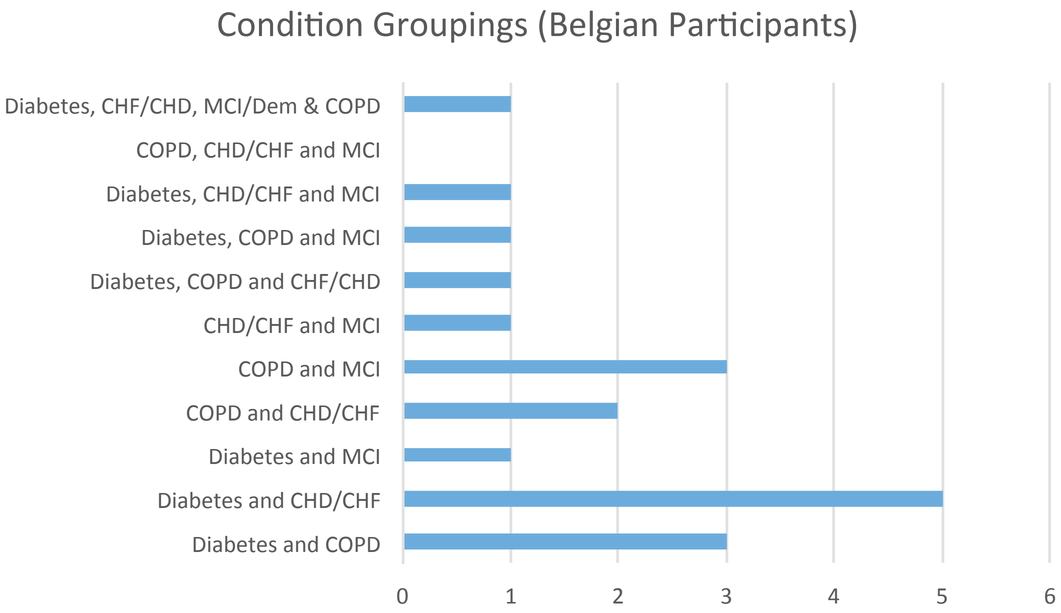

Figure 4: Types of ProACT health conditions for Belgian PwM participants

Belgian Participants

In Belgium, 19 people with multimorbidity (8 male and 11 female), aged between 65 and 90 years (mean 76.11 years), took part in the study. Eleven participants took part in the three focus groups. The remaining eight PwM took part in individual interviews which were conducted in their homes. Figures 3 and 4 illustrate the average number and types of conditions of the Belgian PwM participants.

10 informal carers (1 male, 9 females) took part in the study in Belgium between the ages of 36 and 80 years of age (Mean: 60.4 years). Nine informal carers took part in two focus groups and the remaining informal carer took part in individual interview, which also took place at the AIPA location in Aalst.

ProACT needs and requirements study (trial sites)

10 formal carers took part in the study from Belgium. Two formal carers took part in a mixed focus-group with other primary care providers and six took part in a focus group made up exclusively of formal carers. The other two formal carers took part in a focus group together with the management level formal carer from their organisation. All focus groups took place at their place of work.

The majority of healthcare professionals took part in focus groups in Belgium. Individual interviews were conducted with a geriatrician, two endocrinologists, a cardiologist, a pharmacist, a pharmacist, a physiotherapist and a coordinator of an initiative for cooperation in primary care. All focus groups/interviews with healthcare professionals took place at their place of work. Details of the specific roles of the healthcare professionals interviewed in Belgium can be found in table 2.

Table 2: Overview of participants recruited in Belgium

Participant Group	Environment	N
Person with Multimorbidity	Home	19
Informal Carers	Home	10
Formal Carers	Home care organisation	10
Formal Care Quality Assistants	Home care organisation	2
GPs	Community	5
Geriatrician	Acute, medical rehab and outpatient	1
Cardiologist	Acute, medical rehab and outpatient	1
Physiotherapist	Acute and outpatient	2
Endocrinologist	Acute, medical rehab and outpatient	2
Pharmacist	Community	4
Coordinator cooperation initiative primary care	Community	1
Total		**57**

Findings from the main trial sites

© Philips Image

Findings from the main trial sites

In total 124 participants took part in the main trial sites across Ireland and Belgium, resulting in a very large, rich qualitative data set. In the following sections we have outlined key themes that emerged from the analysis of focus groups and interviews with PwMs and the support actors involved in their care.

Empowering people to self-manage at Home

Irish healthcare professionals felt that people should take ownership of their conditions and that a PwM's insight into their symptoms and conditions is a form of empowerment. One of the main challenges faced by PwMs in self-managing appears to be to lack of awareness of strategies for condition management beyond medication and vital sign monitoring. Healthcare professionals confirmed that they can find it difficult to attribute exacerbations to a single disease, as symptoms can be similar across conditions. As a result of this lack of awareness, along with the complexity of the interactions between multiple conditions, PwMs reported difficulties identifying exacerbations and expressed uncertainty about knowing at what point a symptom becomes an exacerbation that requires attention.

"So if you are judging for yourself it's like with the heart, getting the pains or something like that. With the Angina is it just an ache? Or is it what? How long does it stay? or when do I go and do something about it?" (PwM interviewed in Ireland).

For Belgian and Irish healthcare professionals, motivation is crucial for older people with multiple chronic conditions to successfully self-manage at home. At both sites, maintaining independence and remaining at home emerged as key motivators for older adults with multimorbidity to self-manage their conditions.

"To be able to stay alive long enough that you can look after yourself without having really to depend on some[one else]" (PwM interviewed in Ireland)

Findings from the main trial sites

“I did tai chi for years, I gave stick fighting lessons, and now I have difficulty opening an umbrella.” (PwM interviewed in Belgium).

Not wanting to be a burden on others also emerged as a strong motivator for staying healthy and independent, as is having to care for others (e.g. a spouse) or wanting to be there as a support for others (e.g. grandchildren and family).

"I don’t want to worry my family, that’s my top priority" (PwM interviewed in Ireland).

There were multiple themes that emerged as potential barriers to health behaviour change and ability to self-manage at home. The limitations imposed by the conditions and co-morbidities are perceived as major barriers to effective self-management of their health for many PwMs. For example, PwMs are aware of the importance of exercise, however it is not always possible to increase activity due to health conditions, co-morbidities or mobility issues.

The frustration of not being able to be active due to health conditions was often apparent in participants' responses. Almost all of the PwMs at both trial sites experienced a certain degree of reduced mobility, which was often identified as a reason for not engaging in physical activity and as a cause of frustration:

"I cannot ride my bike or take a walk anymore. To where can I go now? From here to my car and no further. Of course a doctor will say out of principle that you have to walk more to keep you moving, but if it's not possible anymore, it's not possible". (PwM interviewed in Belgium).

Findings from the main trial sites

Personality emerged as a key factor in determining motivation to self manage and change health behaviours. Some informal carers described resistance of the PwM to behaviour change and self-management - there was a feeling among the informal carers that if the PwM decided they did not want to do something, they could not be convinced otherwise:

"You would try and encourage her to eat healthily and try to discourage her from eating sweet things but she would be 'oh, I am fine, the age of me' and… 'I have to live'?" (Informal Carer interviewed in Ireland).

A healthcare professional at the Belgian trial site noted that she does not recognise many differentiating factors in people who will engage in behavioural change and self-management, but acknowledged the impact of personality.

Public Health Nurses in Ireland agreed with this, noting:

"It's different. It's personality as well, a lot of it is individualised, you know, what way people, how they see things. And a lot of people who are maybe quite unwell with COPD can when they feel unwell and fair enough they are very sick and they don't want to go out, whereas maybe the neighbour might have the same thing and maybe the same symptoms but they are most positive to get up and get out and do something with their day that kind of thing. So I think it's very individual what people, what way they perceive themselves and how they are" (Healthcare professional interviewed in Ireland).

"I think your personality type is more important than what background you have." (Healthcare professional interviewed in Belgium).

Findings from the main trial sites

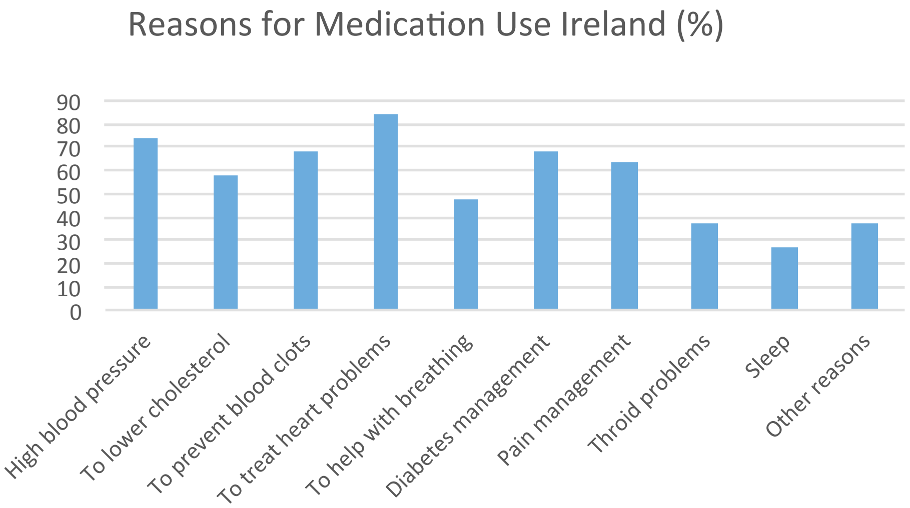

Figure 5: Reasons for Medication Use (Ireland)

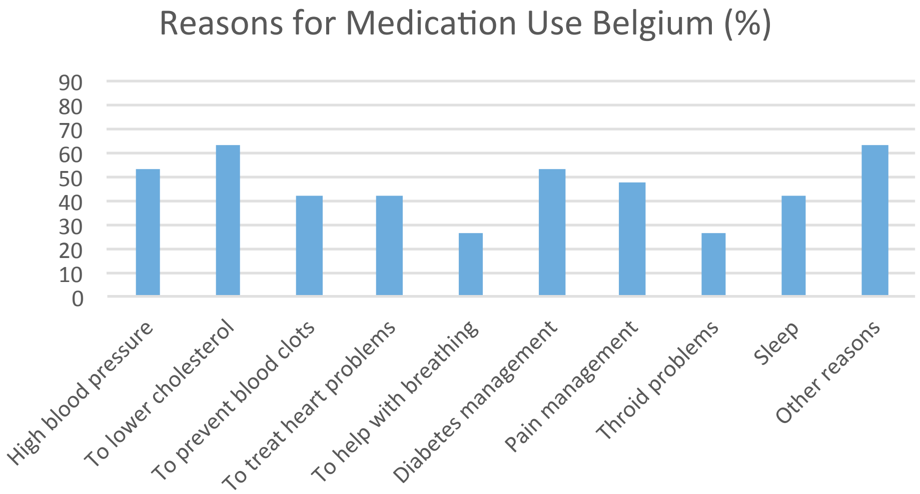

Figure 6: Reasons for Medication Use (Belgium)

Medication management

Medication management was identified as a key factor in managing multiple conditions. On average, PwMs across Ireland and Belgium take 10-11 medications per day. Figures 5 and 6 illustrate the specific reasons for medication use in Ireland and Belgium. For healthcare professionals, the effective management of medications was seen as essential to effective self-care and avoidance of exacerbation of conditions or hospitalisation:

"If there was one thing I believe that would help people that end up going back into hospital, or end up being at home safer, is a much better pathway in minding their medications" (Healthcare professional interviewed in Ireland).

"The biggest thing is to make sure I take my tablets when I should take my tablets. I take 8 tablets in the morning when I get up. I take around this time, I take 3 tablets and then I take 6/7 tablets going to bed and that's, that's the key - if I keep that regular I don't have a problem" (PwM interviewed in Ireland).

Informal carers identified the management of medications as a key challenge for the management of multimorbidity in the home.

"And then you know because of her heart condition she needs to have her medications and she needs to have them regularly at the right time and in the right dosage. We have to manage that…" (Informal carer interviewed in Ireland).

Perhaps one of the most interesting themes to emerge from the study is that the PwM is the person who ‘owns’ and manages their most current medication list, and healthcare professionals often rely on them knowing their list of medications. This was evident in both Ireland and Belgium, although there appeared to be less reliance on the PwM for this information in Belgium, given the coordinating role of the GP. However, healthcare professionals in Belgium noted that they appreciated people bringing their medication lists to appointments.

Supporting the PwM in owning their medication management and having accurate knowledge of their medication is seen by all stakeholders as critical. Given the central role played by the PwM in this regard, it is important that they are knowledgeable about their medications, including names of medications and dosages.

"I think if there was only one thing out of this research that everyone had a digital list of their prescribed medication" (Formal Care manager interviewed in Ireland).

Importance of information and care plans

Lack of information about how to navigate the healthcare system and secure the right supports and care were highlighted by all participants. Formal carers in Ireland described witnessing families struggling to secure care and support, because there is no clear information about who to contact and how to go about putting supports in place:

"Because you really do not know, it's trial by error, and then you don't know whether you are getting the right care for the person...that's what I am saying about, about the system the way it is now. It's so disjointed, and people are running blind - families, carers, you name it, everyone." (Formal carer interviewed in Ireland).

Findings from the main trial sites

In a healthcare setting, most of the information received by PwMs and their informal carers is provided verbally during consultations or in information leaflets, which can be difficult to take in and remember at a later date. Time pressures among healthcare professionals were considered a barrier to provision of sufficiently detailed information for the PwM. In Ireland, specialist clinics appear to be a particularly useful source of information related to managing conditions, but often there is a lack of follow-up after initial educational programmes. In Belgium, the GP was the main source of information, and specialist clinics were not relied on for education or information to the same extent as in Ireland.

The absence of one unified care plan for the management of multiple chronic conditions was discussed across stakeholder groups in both Ireland and Belgium. In Ireland, several healthcare professionals (particularly GPs) acknowledged that providing a formal plan for the PwMs overall care would be useful, but cited time and resource pressures as barriers to them creating such a plan for their patients. In Belgium, healthcare professionals had some experience of working with care plans coming out of multidisciplinary meetings set up by an external party called SEL (Samenwerkingsinitiatief Eerstelijnsgezondheidszorg). SEL is an organisation subsidised by the Belgian government, that focuses on improving the quality of care for individuals by stimulating and coordinating cooperation between primary caregivers and healthcare professionals. However, these plans remain quite broad and these meetings are only set up in cases where there were particular problems or complexities in a patient's care provision; participants who discussed this process were also critical about the lack of follow up after the care plan was devised.

The role of support actors as sources of care for the person with multimorbidity

Most PwMs in the study were self-managing and were the primary person with responsibility for managing their own conditions. Despite this, family members were identified, at both Irish and Belgian sites, as the primary source of informal care support. In Ireland it was mainly adult children of the PwM who provided support with transport to appointments and help with household tasks. In Belgium partners were the main support with children and grand-children providing additional support such as transportation to appointments.

Findings from the main trial sites

The essential role played by informal carers was evident throughout focus groups and interviews with all stakeholders. The importance of seemingly trivial actions, such as sitting to eat a meal with the PwM or going for a walk with them, was not lost on carers or healthcare professionals, though PwMs did not always recognise these as forms of support when provided by informal carers/family members. Informal carers at both trial sites had generally received little or no training related to caring for someone with multiple chronic conditions. The time pressures faced by informal carers may prevent them from attending courses and information evenings to increase their knowledge and training.

Only a small number of the Irish PwMs received any form of formal care support. This was limited and mostly funded by the state. While clearly necessary where provided, formal care provision was identified as presenting additional challenges for PwMs and family members in some instances. These challenges included resistance by the PwM to having a formal carer in their home, especially to provide personal care (the primary reason such care support is funded in Ireland). Belgian PwMs were more likely to have formal care support than PwMs in Ireland. This was likely due to a different system of resourcing formal care support in Belgium. A minimum level of basic training is required for formal care workers in Ireland; this is either provided by the formal care organisation or external training that is required as a condition of employment. In Belgium specific training requirements may be in place but these were not discussed by formal carers. Formal care workers identified a number of areas where more training would be useful such as access to information about how to use medical devices e.g. oxygen machines. Formal carers also noted that practical, hands-on experience was also a key method of acquiring knowledge and skills.

Pharmacists were identified as a reliable and trusted source of support and information about both medications and general health concerns related to conditions. Pharmacists also saw this support as an important part of their role. In Belgium, while this was the case, the emphasis was mainly on support with medications rather than other health monitoring or general health information. Pharmacists at both sites saw potential for them to play a greater role in medication reviews but did not anticipate this responsibility being placed on them in the near future.

Poor communication as a barrier to integration and care coordination

Participants from all stakeholder groups identified poor communication of information as a barrier to effective management and coordination of care. In both Ireland and Belgium most healthcare professionals saw the GP as having a coordinating role in the care of the PwM, as well as being a source of information and first point of contact. Contact with the GP was therefore seen as an important part of the healthcare professional's role. In Ireland this mainly took place via letters, in Belgium it was either letters, digitally or via phone.

In Belgium, the PwMs and hospital specialists often stated that the communication between healthcare professionals within the same hospital or hospital group runs smoothly, because they work together in the same electronic medical dossier. However, healthcare professionals did often mention difficulties in communication with other healthcare professionals not working at the same hospital or care organisation. Healthcare professionals noted they had often had to call external colleagues (for instance other specialists or GPs) for extra information, when this was not directly in the dossier and the patient was not able to provide it. This was also reported in Ireland. At the Belgian trial site, most healthcare professionals expressed a strong desire to have a system in which they would be able to communicate with all different carers, or at least have the different systems that are currently in place become connected. In Ireland, healthcare professionals in both the clinics and the community reported frustration with the pace and/or method of communication and in some cases the lack of information provided or available to them when trying to work with the PwM. A member of the hospital-based Multidisciplinary team (MDT) in Ireland noted:

"No, it's like you're playing detective sometimes... And then sometimes it doesn't equate to what you think. It's definitely a case of detective work and linking into the community, the family, and any of the MDTs that the patient is linked in with. God it's hard." (Healthcare professional interviewed in Ireland).

Findings from the main trial sites

The absence of ICT-based methods of communication between providers is evident, though not always identified by healthcare professionals as a key concern. A greater source of frustration was the more fundamental issue of the speed and content of information provided or missing. For example, at one of the specialist clinics it was reported:

> "There could be a change in tablets every fortnight, so we contact the pharmacy, but then the GP needs to be brought into the equation too, so if the GP isn't aware of the change he's going to write down the [...] usual prescription on the medical card sheet" (Healthcare professional interviewed in Ireland).

Problems and delays in status updates, letters and referrals between healthcare professionals also regularly came up in interviews with PwMs and informal carers at both sites and public health nurses at the Irish site. However, most Belgian and Irish PwMs were satisfied with the communication between healthcare professionals and their GP when it came to the exchange of lab results and status updates. The lack of a communication channel between formal carers is a notable problem, particularly as there can be many different carers visiting the same client and it is easy for information to become lost between carers. Most reported using a paper based care plan record to leave notes for the other carers and communicating via phone or text with known colleagues. Formal carers noted that sometimes they did not have time to, or were unable to read handwritten notes, or they were difficult to find:

> "Sometimes you mightn't be able to understand the person's writing, you know" (Formal carer interviewed in Ireland)

> "Or the notes might be in the front of the book, it mightn't be in the place where it should be in the book" (Formal carer interviewed in Ireland)

Formal care workers described supplementing this procedure with measures such as leaving notes stuck on cupboards or in other prominent locations, or leaving letters for other formal carers within the client's home. Formal carers also often mentioned the lack of information received during and after hospitalisation of their clients as there is no standardised method of communication between the hospitals and formal carers.

Communication between PwMs and healthcare professionals is another challenge impacting self-management. Many PwMs reported both a need and an expectation that information would be provided to them by their healthcare professionals and saw this communication of information as an important tool in enabling them to keep track of and self-manage their conditions. At the Irish site the informal carers reported positive appraisals of communication with and by the healthcare professionals, whereas in Belgium, reports were less positive, mainly regarding contact with hospital healthcare professionals. Formal carers mostly reported involving the informal carers or friends and family of the PwM when possible. They recognised possibilities in improving this type of communication so that both the carer and the PwM’s social network are better informed and can work together to support the PwM.

Perceptions and use of technology for health

A very mixed response emerged from the interviews with PwMs on the uses and perceptions of health devices. Some participants were enthusiastic about the benefits of the devices and some had no interest. Eight of the 19 Irish participants reported not using any devices to monitor their health and two of the 19 Belgian participants reported that they did not use any monitoring devices. 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).

At both trial sites, many PwMs were reluctant to consider additional digital monitoring as they believed it would only 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.

Findings from the main trial sites

"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". (PwM interviewed in Ireland).

Ensuring the technology is easily usable by the PwM will be important for compliance with use of ProACT, as noted by one participant,

"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" (PwM interviewed in Ireland).

PwMs, pharmacists and carers in Ireland, as well as pharmacists in Belgium, saw potential benefits in having all of their data, such as prescriptions, in one place. They felt this could reduce duplication, missed information and the need for them to have to remember all of their medications, test results etc. to relay to other healthcare professionals. Having all this information in one place was seen by PwMs as helpful to keep all relevant stakeholders accurately informed. In Ireland, different mechanisms were suggested such as barcodes on medications which could be scanned into the PwM’s digital tablet but in Belgium the concept did not seem sufficiently relevant or understandable for participants to consider methods of operation.

Findings from the main trial sites

Healthcare professionals in Ireland reported limited technology use in communicating either with each other or with PwMs or carers. Much of the communication within the health system in Ireland was reported as being oral or paper-based. Technological communication was reported as limited to intra-departmental communication, within specific departments, facilities or disciplines, not inter-disciplinary to any significant degree. This was also the case in Belgium, although there appears to be somewhat greater integration of data within hospitals or hospital groups.

Where IT systems were in use, for example by GPs or pharmacists, there were significant concerns expressed about security of data should external devices have access to deliver or receive data to/from their system. The concerns 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. Less concern was expressed in Belgium about security. There were expressed hopes that someday the government might impose a single unified system in Belgium. This would have been seen as highly aspirational at both sites.

Social and socioeconomic issues

Financial impact was identified by many PwMs in Ireland as a burden, but not in Belgium. This may be due to differences in the healthcare systems and methods of funding services, whereby PwMs in Belgium may be less aware of how much they are paying for healthcare. The lack of detailed information on financial impact, may also be due to the difference between how care is provided and funded in the Belgian trial site region, where private insurance, social/political/religious organisations and government subsidisation all contribute to the cost of care provision. All of these organisations have different systems of contributions, and as a result people may not have a good overview of what they actually pay for their care. This is in contrast with Ireland where fully funded healthcare is rationed by age and socio-economic status under the medical card scheme, resulting in different financial experiences across the participant group.

Findings from the main trial sites

It is apparent from the data that living with multiple conditions hugely impacts on many aspects of a PwM's life, particularly lifestyle, relationships and psychological well-being, with many adaptations needing to be made to a person's way of living. Stress, frustration, anxiety and depression were prevalent among many of the PwMs we spoke to, both in Ireland and Belgium. This often appeared to be a result of fear of symptom exacerbation or future deterioration of health in addition to lack of support and companionship. All support actors recognised the impact on psychological well-being for PwMs.

Caregiver burden was very apparent among informal carers interviewed, particularly in terms of psychological impact. It was also a cause of concern for PwMs, who reported not wanting to be a burden on their carers. Formal carer burden was also identified in both Ireland and Belgium relating to the lack of sufficient time carers have with their clients, resulting in a feeling of not being able to adequately address client needs. Personal psychological burden was also identified in Ireland amongst those formal carers who had built close relationship with clients.

Loss or lack of social contacts and isolation were identified by healthcare professionals in both sites as a key factor in the deterioration of PwMs health and wellbeing, and in the diminishing of their ability to self-manage. In Belgium healthcare professionals saw the social context as an important factor impacting PwM motivation. Likewise, in Ireland the role of the family was highlighted as essential for successful self-management of multimorbidity for older people.

Requirements gathering study at the Italian transfer site

Requirements gathering study at the Italian transfer site

At the transferability site in Bologna (Italy), an additional requirements gathering exercise was conducted in parallel with the main trial sites, that aimed to engage with a wider range of stakeholders relevant to the local context and to issues related to transferability of the future ProACT system. The requirements study has involved key actors in the local public health and social care sector, including end users and informal carers. Care ecosystems, both at personal and institutional level have been identified and analysed, using focus groups and interviews for information gathering.

In comparison to the main trial sites, the transfer site has widened the 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 ProACT will have to face in entering the competitive market of e-health and e-care solutions where 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 in the main areas where ProACT is expected to bring innovation and impact.

Background

Like in many other countries, Italian health and social services represent two different and only partially integrated sectors. The Italian National Health Service (NHS) ensures the provision of public healthcare services while public social services come under the responsibility of the local authorities. Over the last decades integrated care has increasingly become a priority for the governments at national, regional and local level. The evidence of the increasing number of chronically ill citizens and the weakening of the social and parental network, together with the lack of economic resources, has resulted in a need to redefine the priorities and to reorganise aspects of the welfare system.

Requirements gathering study at the Italian transfer site

The situation in the Bologna metropolitan area reflects these challenges: the public health authorities and the municipalities see themselves faced with the challenge to provide high quality services to a rapidly expanding and ageing population with chronic conditions, while financial resources are under pressure and concentrated on the most severe cases. One of the principal effects is that many older people with frailty and chronic conditions are often unknown to the public health services or supported only incidentally. They often emerge from this “dark zone” very late, and only after critical events that could probably be avoided or delayed with a more focussed, supportive and preventive self-management strategy.

Older adults with frailty are older persons that score high on different indicators, both in the demographic domain (age), the health domain (presence of one or more chronic diseases, etc.) and the social domain (living conditions, absence of informal carers, poor social network, low income, etc.). Most older people with frailty have chronic health conditions or will very likely develop them in the near future. The policy aim of the public health institutions in Bologna is to identify older people with frailty earlier and to start supporting them with situation appropriate interventions in their living environment thus reducing and delaying the development of more intensive and expensive care needs. Prevention and healthy lifestyle education are important pillars of this approach.

The public institutions responsible for delivering care in Bologna are aware that the quality of care should be maintained or could even be improved by putting the person at the centre, breaking through institutional silos and integrating health and social care efforts in a unique personalised care plan. Other policy aims include the reduction of hospital (re)admission rates, the delivery of health care at community level, keeping people as long as possible independent in their living environment and valuing the role of the informal care network.

Requirements gathering study at the Italian transfer site

Aims

Coherent with this background information, the aims of the requirements gathering study in Bologna were defined as follows:

- To identify sets of requirements starting from the needs expressed in a specific existing local care ecosystem and involving the most relevant actors and stakeholders in that system;
- To identify needs and areas of improvement at institutional, organisational and operational level;
- To identify other groups potentially interested in a care platform like ProACT and retrieve their needs;
- To identify key factors that impact on the transferability of integrated care solutions from one context to another.

Participants

In Bologna the stakeholders have been recruited through:

- ASP Città di Bologna
- AIAS Bologna onlus
- AUSL di Bologna

ASP is the public social care institution, with the municipality of Bologna as its main shareholder, while AIAS Bologna is a social care service provider staffing the major Assistive Technology resource centres in the city. Both are partners in ProACT. AUSL di Bologna, the local public health trust was also involved in the study. It is responsible for planning and delivering public health care in Bologna’s metropolitan area. Both ASP and AUSL are engaged in a process aiming at integrating their services in a unique integrated care ecosystem, especially in the domain of care for older people, though each organisation is keeping its specific role.

Requirements gathering study at the Italian transfer site

All three organisations are primary stakeholders in the transferability study and potential users of the ProACT platform following its availability on the market. In an early stage in the project representatives of all three organisations expressed their interest in a care platform that can be introduced at an early stage of the development of chronic diseases, accompany the person while his or her condition is worsening and more chronic diseases occur, and that allows self-management, remote monitoring, integrated care plan management and maintained social connectedness. Also the wish to use part of the system to meet the needs of adults with a disability living independently was expressed. They further highlighted the need to consider the informal caregiver a primary resource for care plan coordination and as a key player in any integrated care ecosystem.

As a consequence the following stakeholder groups were identified:

- Older adults with frailty: Older persons (over 65), not necessarily with multimorbidity, but with decreasing levels of independence due to age and chronic diseases, with a high likeliness to further develop the typical ProACT pathologies and as a consequence with evolving health and social care needs. Identifying this group is relevant as both the health and social care authorities have developed preventive measures to slow down the development of high dependency and thus intensive human care needs.
- Adults with disabilities: Individuals with severe motor impairments living with a high level of independence.
- Informal caregivers: Family members (sons and daughters) of older people living with chronic pathologies.
- Care workers: Professional social care workers supporting older people on a daily basis.
- Social workers: Professionals involved in the design and monitoring of individual social care plans.
- Transition nurses: Highly qualified nurses, case managers, that support the transition process from hospital to community care in the presence of risk factors related to health conditions, social conditions, age, etc.
- Health professionals: Nurses and doctors in community care services.
- Managers in health and social care: Heads of services that have responsibilities in the design, planning, delivery and evaluation of public health and social care services.

Requirements gathering study at the Italian transfer site

Table 3: Overview of participants recruited in Italy

Participant Group	Environment	N.
Older Adults	Protected Apartments	7
PwD	Home	4
Informal Carers	Home	5
Formal caregivers – care workers	Day care centres	6
Formal caregivers – social workers	Community	8
Transition nurses	Community	4
Nurse	Primary care coordination point	3
Doctors	Primary care coordination point	2
Managers in care organisers	Health and social care providers	2
Total		**41**

Method

The study design has followed as closely as possible the methodologies developed with colleagues in Ireland and Belgium for the main requirements gathering study at the primary trial sites. For each stakeholder group, focus group protocols have been co-designed, translated into Italian and used in focus groups. All focus groups have been audio recorded, transcribed and analysed using NVivo software in order to find recurrent themes. In an additional focus group participants discussed their experiences and expectations regarding the use of technology in care.

Comparison of findings with the main trial sites

Comparing the findings of the main trial sites and the study in Italy the following similarities and differences have been identified:

In all sites the impact of living with chronic conditions on the person's overall wellbeing was highlighted. After an initial destabilising moment people need time to cope with their changing conditions and are typically concerned about the future. The burden of care is particularly perceived by the informal carers who, especially in Italy, for economic and cultural reasons, are vested with responsibility for managing the resources needed for the care recipient and fully feel the psychological stress that comes with it. Most health care professionals in all three countries seemed to be quite sceptical about the possibility of successful self-management of conditions. In all sites stakeholders seem to be aware of the difficulties involved, although in Italy these seem to be more associated with a lack of experience in the use of technology from the side of the older PwM.

Requirements gathering study at the Italian transfer site

Management of medications and adherence to the therapy was for all countries a key issue. The absence of a unique care plan in the case of multimorbidity which emerged from the Irish and Belgian site did not emerge as strongly in Italy. To a certain extent the formal health care system in Bologna seems to be better prepared to integrate different aspects in a unique care plan, including social aspects. Even more than in the other countries, in Italy the informal carer was identified as the most important resource in the care ecosystem in the case of a loss of independence.

Like in Ireland and Belgium also in Italy the GP is a key person in the care ecosystem although the exchange of information between the GP and other health professionals is sometimes difficult. Nevertheless, in Bologna the health care professionals seem to be better informed about the conditions of their patients, at least on paper, having access to electronic health records at regional level and the existence of other digital information systems that exchange information between places of care. Workloads for GP's are reported to be high in all countries.

Regarding the communication between the different actors the same concerns were expressed among the three sites: lack or non-perfect communication among the HCPs involved, and, in Italy, between HCPs and social workers and social care providers. Different aspects of the use of technology were discussed in Ireland, Belgium and Italy. Doubts were raised about the reliability of self-reported data, the accuracy of the devices measuring vital parameters, privacy issues and the costs of the introduction of technology.

It was acknowledged in Italy that technology is an important ally for persons with motor impairments whose conditions (less physical exercise) could increase the risk of the development of chronic pathologies. Their drive for independence makes ProACT an interesting opportunity for living as independently as possible, as long as remote communication and ambient assisted living features could be integrated into the care platform.

Requirements gathering study at the Italian transfer site

Lessons learned from the transferability study

The following lessons have been learned from the transferability study in Italy:

- The importance of the assessment of the care ecosystem context before the transferred digital solutions can be deployed. This includes an analysis of roles and responsibilities, as well as communication patterns and needs.
- The importance of the involvement of all stakeholders in the definition of requirements and the co-design of solutions, which does not mean that solutions cannot be built on existing experiences and components.
- The impact of linguistic and cultural factors on the reciprocal understanding in cross-national collaborations aiming at transferring resources and delocalising systems.
- The importance of starting from the assessment of specific problems in designing holistic solutions.

Conclusions

The outcomes of the requirements study in Bologna can be summarised as such: ProACT is for Bologna a promising solution, as it responds to one of the basic needs of care institutions, which is facilitating self-management and remote monitoring, allowing people to cope with chronic conditions and to maintain a good quality of life. In order to be fully attractive the platform should respond to the diverse needs of the actors in the existing care ecosystem, including the informal carers and the family assistants who very often provide 24hour assistance to the population of older people without independence. This requires the system to be flexible, personalisable, expandable, interoperable, accessible and to include apps for communication, intervention reporting, data and other information exchange and training/education. Where possible ProACT should be able to communicate with existing databases and client management systems which are well developed in Bologna. The authors recommend the use of an open architecture based on the possible integration of different existing or not yet existing modules on an “as needs”-basis.

Conclusions

Conclusions

Implications for design

The requirements gathering process has elicited a number of user requirements based on stakeholder needs. A significant amount of data has been collected and analysed to help to define the design requirements of the ProACT system. This is the first step in an iterative design process which will require reflection and further analysis of the findings presented in this report. We will also continue to engage with key stakeholders through the interactive design process. This initial requirements phase has helped in identifying:

- Important clinical and wellbeing parameters to self-manage at home for each ProACT condition as well as overlaps between these conditions, important for designing a system to deal with multimorbidity
- The main areas that ProACT should address to support PwMs self-managing at home
- The roles of each support actor in the system, and the type of functionalities they need to support them in their role

Key Findings

While the aim of this study was to elicit requirements for the design of the ProACT digital care system the results presented in this report are significant for all of the stakeholder groups. Here is a summary of the key findings from the ProACT requirement gathering study:

- Effective medication management was identified a key factor to managing multiple conditions in a home environment
- Personality emerged as a key factor in determining motivation to self manage and change health behaviours
- Lack of care plans for multimorbidity were highlighted by all participants
- Poor communication was identified as a barrier to effective management and coordination of care
- Ensuring the technology is easily useable by the PwM will be important for compliance with use of ProACT
- Healthcare professionals in Ireland reported limited use of existing technology
- Caregiver burden was very apparent among informal carers interviewed
- Loss or lack of social contacts and isolation were identified as a key factor in the deterioration of PwMs health and wellbeing, and in the diminishing of their ability to self-manage

References

References

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 2012;380(9836):37–43

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 Incorporating Euro Observer. 19 (3): 2013

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

Starsfield, B., Shi, L., and Macinko, J. (2005). Contribution of primary care to health systems and health. Milbank Q. 83: 457–502.

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.