

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

ProACT

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Contents

Executive Summary	3
Introduction	4
ProACT Needs and Requirements Study (Trial sites)	7
Findings from the main trial sites	14
Additional Requirements for Digital Goal Setting (Ireland)	28
Requirements gathering study at the Italian Transfer Site	37
ProACT User Needs and Requirements Key Findings	46
Translation of User Requirements to Design	48
References	65

Executive Summary

The key challenge facing healthcare systems worldwide is management and support for the increasing number of people with multiple chronic diseases. There is a need to create continued, well-coordinated, person-centred care for people living with multiple health conditions. The EU H2020 ProACT project aims to address this issue by designing new technologies to improve and advance home-based integrated care.

This report presents findings from a study investigating the needs of older people with multiple chronic health conditions and the people who support them in managing their health. The aim of the study was to investigate the challenges that different actors in the care ecosystem face and how these are currently addressed in 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 of an additional requirements gathering study conducted at the ProACT transferability site in Italy.

A first version of this report was originally published in July 2017 and this updated version (June, 2019) presents additional analysis of our user requirements findings. We have conducted further focus groups and re-examined our existing data to determine stakeholder requirements for digital goal setting (a core feature of the ProACT system). These additional requirements for goal setting are presented in detail on page 27. In the final section of this updated report, we have presented the work that we undertook to translate the findings from the user needs study into design requirements for the ProACT system.



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 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 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 and political determinants for adoption and scalability of the system.

Requirements gathering

As a first step in the design of the ProACT system we 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 GPs, community health nurses, geriatricians, disease specialists, multi-disciplinary teams (including dietitians, 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 Requirement Study (Trial Sites)



ProACT Needs and Requirement 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 were 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 were 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 Requirement Study (Trial Sites)

Recruitment in Ireland

In Ireland, ethical approval was received from three ethical committees (the Health Service Executive, Dundalk Institute of Technology (DkIT), 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 Senior Care, while pharmacists in the local area were approached directly by 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 PwM 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.

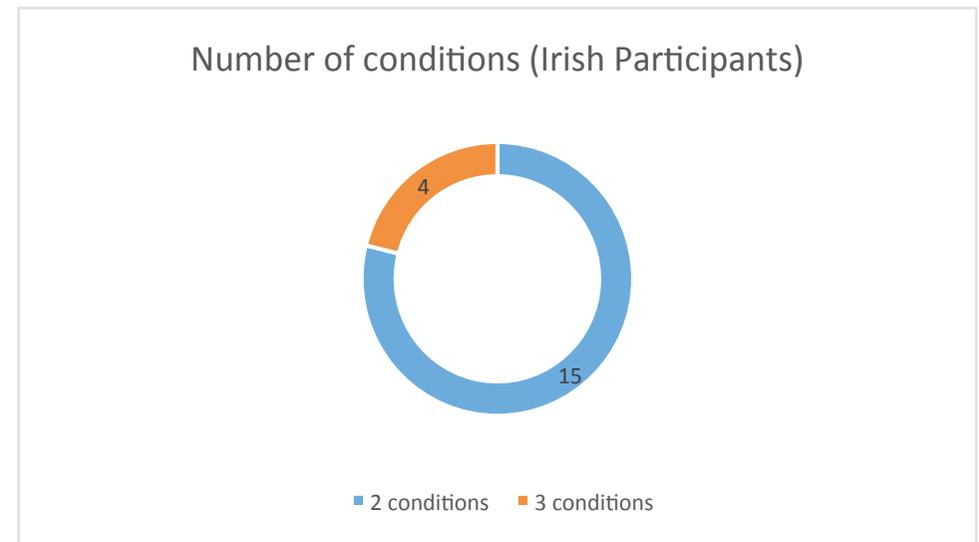


Figure 1: Number of health conditions (Irish PwM participants)

ProACT Needs and Requirement Study (Trial Sites)

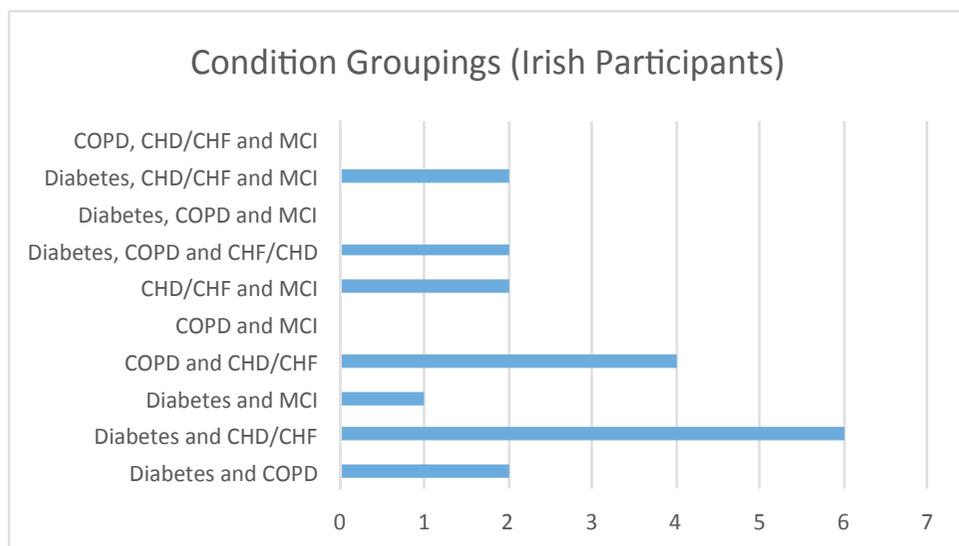


Figure 2 Groupings of health conditions for Irish PwM participants

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)	Acute, medical rehab and outpatient	1
Older People	Acute and outpatient	1
CNS COPD	Acute and outpatient	3
CNS CHF / CHD	Acute and outpatient	2
CNS Diabetes	Acute and outpatient	1
Physiotherapist	Acute, medical rehab 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 Requirement 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 took place 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 Brussel 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 two of the selected chronic health conditions).

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 PwMs 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 Requirement Study (Trial Sites)

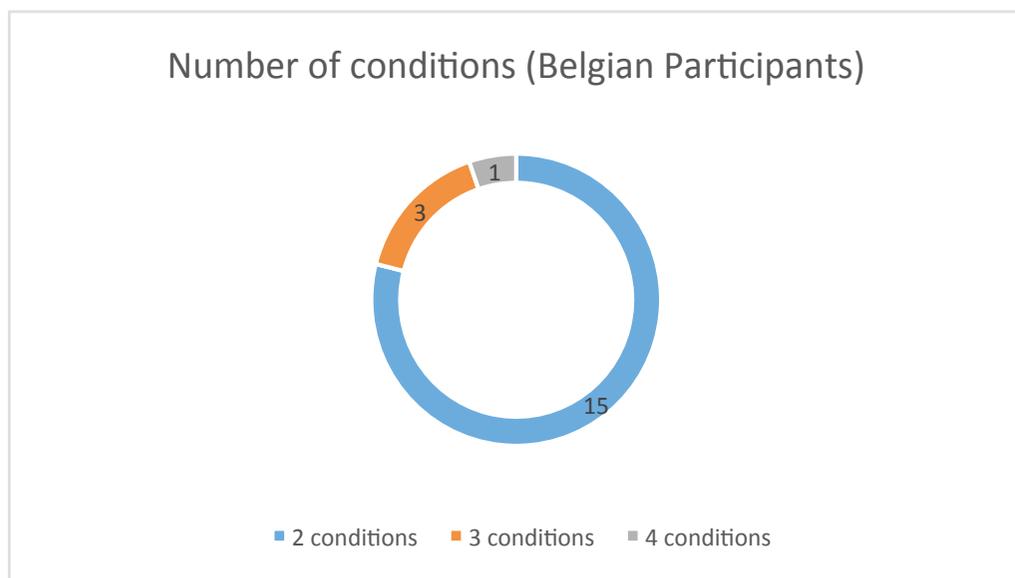


Figure 3: Number of health conditions for Belgian PwM participants

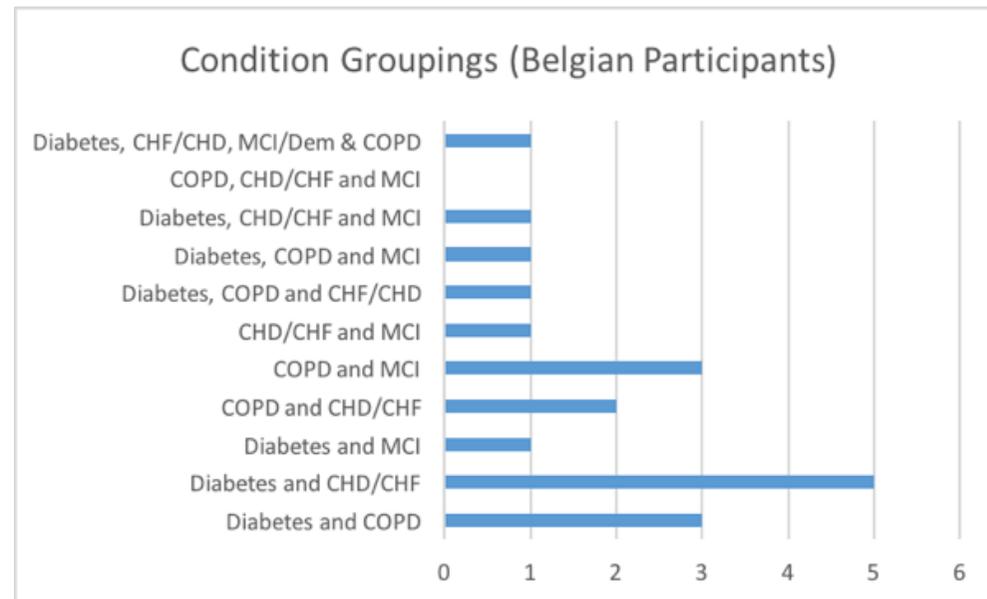


Figure 4: Type of health conditions for Belgian PwM participants

Belgian Participants

In Belgium, 19 people (8 males, 11 females) with multimorbidity took part in the study between the ages of 65 and 90 (Mean: 76.11).

Eleven PwMs took part in the three focus groups. The remaining eight PwMs 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 interviews, which also took place at the AIPA location in Aalst.

ProACT Needs and Requirement 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, four pharmacists, two physiotherapists 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 for cooperation in primary care	Community	1
Total		57

Findings from the main trial sites



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 living at home emerged as key motivators for older adults with multimorbidity to self-manage their conditions at home.

'To be able to stay alive long enough that you can look after yourself without having really to depend on [others].' (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 site experienced a certain degree of reduced mobility, which was often named as a reason for not engaging in enough physical activity and a cause of frustration:

'I can not 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 recognize many differentiating factors in people who will engage in behavioural change and self-management, but acknowledged the impact of personality:

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

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).

Findings from the main trial sites

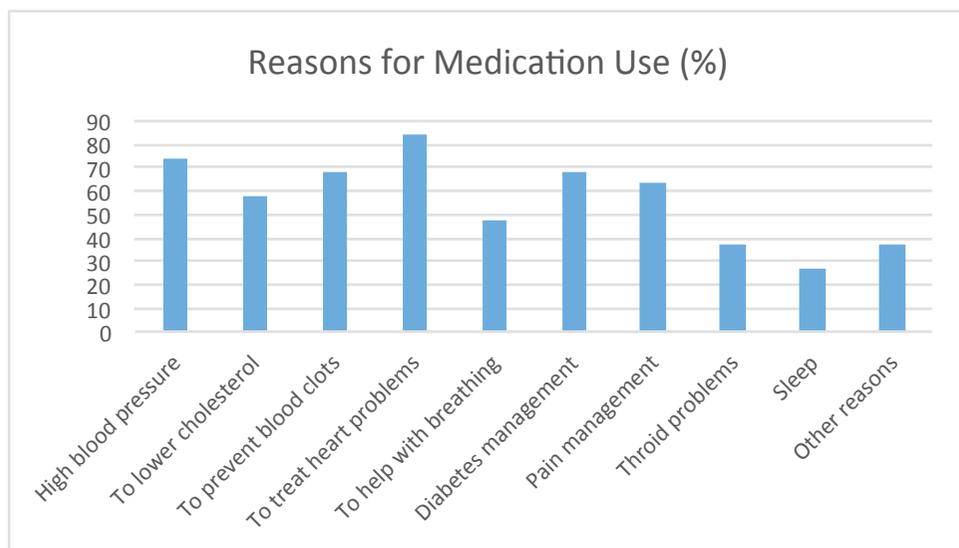


Figure 5: Reasons for Medication Use (Belgium)

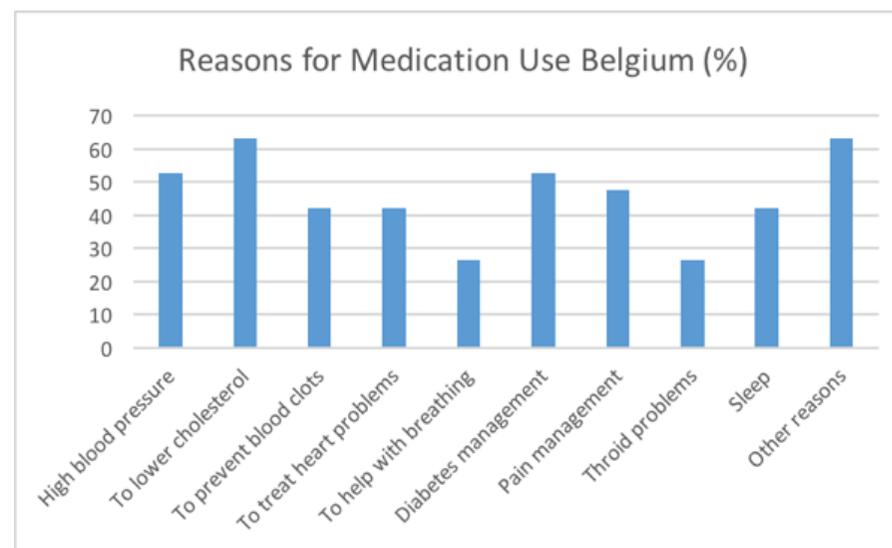


Figure 6: Reasons for Medication Use (Ireland)

Medication Management

Medication management was identified as a key factor in managing multiple conditions. PwMs across Ireland and Belgium reported taking between 4 and 20 different medications each 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).

Managing medications was seen by the majority of PwMs as the main aspect of self-managing conditions:

'The biggest thing is to make sure I take my tablets when I should take my tablets.... that's the key - if I keep that regular I don't have a problem.' (PwM interviewed in Ireland).

Findings from the main trial sites

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 multidisciplinary care plans coming out of multidisciplinary meetings set up by an external party (such as a homecare

coordinator linked to an insurance company) committed to this. 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 Stakeholders in Support 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 in 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, but 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.

Findings from the main trial sites

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 digital 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 with 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 may find it 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 the carer 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.

Findings from the main trial sites

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 (8 of 19 participants reported not using any devices to

monitor their health). 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 useable 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 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, tests 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 novel 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 and whether external devices could 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 or service to support this. In Belgium concerns were raised about PwM privacy with the use of technology. Less concern was expressed in Belgium about security but participants expressed hope that someday the government might impose a single unified system.

Social and socioeconomic issues

Financial issues and healthcare cost were identified by many PwMs in Ireland as a burden, but not in Belgium. This may be due to differences in the healthcare system and methods of funding services, whereby PwMs in Belgium may be less aware of how much they are paying for healthcare. 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.

Findings from the main trial sites

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 key factors 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.



ProACT User Needs and Requirements Key Findings



ProACT User Needs and Requirements Key Findings

Key Findings

The requirements gathering process 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 was the first step in an iterative design process which required ongoing reflection and analysis. We have continued to engage with key stakeholders through the entire interactive design process. This initial requirements phase 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.

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 are the key

Findings from ProACT requirements gathering study:

- Effective medication management was identified as 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 adoption and compliance.
- 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.
- It is important that goals for health and wellbeing for PwMs should be realistic, personalised and flexible in terms of target achievement.

Additional Requirements for Digital Goal Setting (Ireland)



Additional Requirements for Digital Goal Setting (Ireland)

Goal Setting for Health

Goal-setting, combined with progress feedback, is a technique often used in digital behaviour change interventions. However, there is little knowledge of digital goal setting practices of older people, particularly those with multiple complex health conditions. In this section, we describe a study that focuses on current goal setting practices for older people with multiple chronic health conditions.

Study Design and Methods

In order to explore goal setting in detail we conducted a co-design workshop with a subset of PwMs, informal carers and formal carers from the Irish participant cohort described above to delve deeper into some of the findings from our requirements gathering. We recruited an additional PwM, two additional informal carers and three additional formal carers to take part in these workshops, in addition to a subset of the 124 participants who took part in the initial requirements gathering phase. A total of four co-design workshops were held with PwMs, however only the fourth focused on goal setting. Other workshops were organised to inform the design of the frontend applications in terms of aesthetics, layout, language, icons, accessibility and navigation. Topics explored in the fourth co-design

workshop on goals (n=7) included current goal setting behaviours, the process of setting health and lifestyle related goals, goal timelines, support with setting or meeting goals, and motivation and barriers to meeting goals. In addition, two co-design workshops were held with support actor stakeholders and as part of these sessions we explored their perceptions of goal setting as part of caring for PwMs (ICs (n=4) and two with FCs (n=6)).

Main Findings on Goal Setting

The majority of PwM participants spoke of setting general goals in relation to their health and wellbeing. These included goals around keeping physically active (walking, swimming, dancing), remaining socially active (attending groups and events), getting adequate sleep, keeping medical appointments, losing or gaining weight, adhering to a specific diet (e.g. reducing salt intake) and monitoring symptoms (e.g. blood glucose levels).

Additional Requirements for Digital Goal Setting (Ireland)

Current Goal Setting Practices

According to care network stakeholders, setting specific and personalised goals with PwMs is not common, despite wide acknowledgement of the benefits of such practice for people with multiple chronic conditions. Health care professionals reported that goals are broadly contained within general care instructions to PwMs, usually delivered orally, through information leaflets, or handwritten notes. Such goals could range from frequency of symptom measurement to dietary guidance.

GPs identified a reluctance to engage in greater specificity around health and wellbeing goal-setting with older people with multiple, chronic conditions, due to a perception that this would constitute information overload and that PwMs would find such an approach excessively disruptive and stressful, especially at a time when they may already be ill:

“It’s probably the worst time, you know they come in and they are sick, and you are talking to them about ‘you should give up cigarettes’, and they are probably feeling, you know, low anyway.” (GP interviewed in Ireland).

PwMs spoke of various strategies they used in both setting and meeting goals. Creating lists of tasks and then ticking these off gave a sense of achievement:

“The big challenge is setting targets and making a list of things that need to be done. Because I find if I don’t.. ‘Oh there’s nothing to do today, I’ll watch the telly’.. If I’ve made a list then I’ve got a list of achievements and that makes a big difference.” (PwM interviewed in Ireland)

Additional Requirements for Digital Goal Setting (Ireland)

Some PwMs preferred to think of goals as ‘natural progressions’ that you can build on over time as you are able to:

“When you are setting goals for yourself they are progressions. You just say to yourself ‘I am going to go from here to the door today... And then I’ll try go from the front door to the gate the day after.” (PwM interviewed in Ireland)

Linked to this, setting realistic goals is important to ensure they are met:

“Don’t set them too high or you’ll never reach it.. If I did 20 minutes a day [of walking] I’d be clapping myself on the back because of my arthritis.. But if I set my goal for that and then increased it as I went along...” (PwM interviewed in Ireland)

Some PwMs also recognise that there are some things that they do just not want to do or give up:

“My practice nurse tries to do a bit of that [goal-setting] on the HeartWatch programme. She encourages me to take some exercise. But I am not a great one for exercise.” (PwM interviewed in Ireland)

Collaborative Goal Setting

Some PwMs noted that their family members might be involved in prompting them to meet goals, though this wasn’t always perceived as a positive support but rather as pressure. Informal Carers (ICs) spoke of how it was important to be subtle when prompting PwMs to meet goals:

“It’s just learning as much as you can about [the health behaviour] so that you can subtly try and influence it, rather than be too overtly dictatorial.” (Informal Carer interviewed in Ireland)

Additional Requirements for Digital Goal Setting (Ireland)

Formal Carers (FCs) noted that they don't help their PwM clients set goals, although they do help the PwM to try to meet goals that may have been set by others, for example, helping PwMs with CHF to weigh themselves daily. It was also noted by FCs that PwMs might not ask for help because they don't want to bother anybody. But if an offer of help is made, they would appreciate this. FCs also employed subtlety:

“You can't force the client.. Try to encourage them, let them see the reasons why they should or shouldn't do this. But some let you know that you are not their boss. ‘I'm the boss of my house’.” (Formal Carer interviewed in Ireland).

HCPs spoke about the importance of having the PwM involved in setting any plan or goal:

“I think you do strive to make the patient see that you're not really the teacher, coming down on them. You want them to have good quality of life, so you want them to see it's for

their benefit and you want them on board... with whatever advice or goals or plans that you're working on.” (Hospital HCP interviewed in Ireland).

This idea of having the PwM involved is particularly important given the context of multimorbidity:

“Because of the lack of integration and communication between systems, it's the one common person is the patient. So, they should hold the information which they allow you access into” (GP interviewed in Ireland).

However, FCs noted the importance of the GP's opinion to the PwM. In relation to the PwM setting their own goals, one FC said:

“Even those [self-set] goals though, depend on what the GP told them.” (Formal Carer interviewed in Ireland).

Additional Requirements for Digital Goal Setting (Ireland)

Goal Support and Feedback

The idea of sharing goals and goal progress with others, to allow them to provide feedback, emerged often in participant responses. One PwM likened this to having a personal trainer. There was a strong sense from PwMs that they would like to share goals with a friend, or someone who also has similar goals:

“Well I think it would have to be someone who is doing it as well as you. Yeah, someone who understands what you’re doing” (PwM interviewed in Ireland)

One PwM commented to her friend in the focus group:

“I’d want to share with you and you’d want to share with me, if you were doing good or if you were doing bad, you’d share that too.” (PwM interviewed in Ireland)

Friends were generally seen as a big motivator:

“Getting me moving? My friend. When I’m in a bad place he will come and we will go out somewhere. I think it’s just having a network of friends.” (PwM interviewed in Ireland)

In the co-design workshop on goals, PwM participants were shown visuals of different types of feedback, including badges, rewards, messages of praise and messages regarding progress that are typical in many digital applications that include a goal-setting component. PwMs particularly liked the idea of getting messages of support, a thumbs-up or acknowledgment of achievements with one PwM likening this to a ‘pat on the back’:

“I think when you get to our age, people don’t say that [well done] anymore, you never get that. Older people like to hear it as well.” (PwM interviewed in Ireland)

Additional Requirements for Digital Goal Setting (Ireland)

Multiple Conditions and Goal Setting

Our findings indicated that the biggest barrier to both setting and meeting goals resulted from the enormity and complexity of the task of managing multimorbidity. Managing multiple conditions necessitates having multiple goals. A key issue with this, which was also noted above by a GP participant, is the impact of information overload. A geriatrician highlighted the various clinical disciplines a PwM would meet with during a review with her team. In addition, to disease specific goals, there are also goals relating to the general process of ageing, such as mobility and cognitive function:

“So I as the consultant would go through their medical diagnosis and go through each co-morbidity. And then I would hand over to each member of the team so the occupational therapist would go through goals for cognition, and function, the physiotherapist would talk about, this was your balance score before, this is your balance score now, this is what we recommend. The dietician will go through recommendations like, you are

actually low on protein, you need this or whatever. There is a huge amount of information. In fact, that's very hard for people to process". (Geriatrician interviewed in Ireland)

The geriatrician noted that this information is currently provided orally, but that there are plans to develop a paper-based pack for PwMs. Goal prioritisation was seen as an important way of dealing with multiple goals and information overload for PwMs:

“It might be that you don't want to bombard them. You might focus on one thing... you might prioritise it. Because sometimes it's a lot for patients to take in.” (Geriatrician interviewed in Ireland)

From our interviews with HCPs, it was evident that prioritising goals for PwMs only happens if they visit a geriatrician, who has dedicated time for a full review. GPs reported not having enough time and consultants, other than the geriatrician, only focused on their own specialty. However, access to geriatricians is challenging, and none of the PwMs in our study had ever visited one.

Additional Requirements for Digital Goal Setting (Ireland)

A key finding was that the lack of integrated care amongst different services added to the challenges of self-managing multimorbidity. HCPs noted that it is possible for a person to be advised to set conflicting goals, which is potentially very dangerous. For example, a PwM with a heart condition who is taking warfarin medication, might be advised to eat more vegetables, but may not be told that they should avoid green vegetables, (as these can make Warfarin less effective in preventing blood clots), if the HCP providing the advice is not aware of their heart condition, or their current medication list. One CHF nurse specialist noted how they would be aware of this:

“We’d be conscious, if someone’s got heart failure, you’d ask ‘Did they say you’re ok to exercise?’ because we’d be encouraging exercise. So, we’d know to adapt our advice from a safety point of view.” (CHF nurse interviewed in Ireland).

General consensus, however, indicates that this is the exception rather than the norm.

PwMs also noted the challenges associated with both managing conditions and general ageing, that can affect goal achievement:

“Maybe I set my targets too high. Maybe I’m not acknowledging my age... my abilities anymore, or lack of them. Being realistic.” (PwM interviewed in Ireland)

Issues such as poor mobility, arthritis and the time required to perform other self-management activities such as monitoring symptoms, taking medications and attending appointments were all noted by PwMs as potential barriers to meeting goals:

“I have certain things I did change – I don't play football anymore, I don't swim as much as I used to but I still swim an odd time, that sort of thing. And I used to do a lot of walking but I don't walk as much as I used to because of the arthritis and because of the COPD and the heart” (PwM interviewed in Ireland)

Additional Requirements for Digital Goal Setting (Ireland)

ICs also highlighted the impact of multiple conditions, indicating that sometimes management of particular conditions can be forgotten due to the general impact of ageing and health problems:

“...because you've got many things you are dealing with you've got to look at what's the one that is going to get us through this day, there is a huge element to that, much more than... the bigger picture kind of has to get lost a little bit.”. (Informal Carer interviewed in Ireland)

Key Findings on Goal Setting

We need to recognise that goal-focused approaches to care that tend to work for those with general health issues, may not be appropriate for those with multiple conditions (Rijken et al., 2013). The unique challenges facing those managing multiple conditions demands specific, novel requirements to ensure digital behaviour change interventions can address PwM needs. Our findings indicated that multiple goals are necessary for older adults managing multiple conditions. Information overload can occur when multiple goals are set orally by healthcare professionals and can be further

complicated by the added complexity of trying to manage and keep track of goal progress. On the other hand, our findings also highlight that older PwMs often need to focus on management of a single disease. Sometimes this is necessary, for example as a result of an exacerbation relating to one particular condition. However, it also means that sometimes other conditions are temporarily overlooked or neglected. Understanding how best to balance these two crucial issues is an important research question for digital health. We therefore suggest it is important that goal systems to support multimorbidity should also focus on a single disease if necessary. If a PwM is experiencing an acute difficulty with one condition, the system should recognise this and bring attention to it. However, this should not be to the detriment of managing another condition, if that condition also begins to become acute, or requires regular self-management. As a PwM's condition improves, the system should nudge the PwM towards goal-setting in other areas that may have been neglected.

Requirements gathering study at the Italian Transfer Site



Requirements gathering study at the Italian Transfer Site

At the transferability site in 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.

Background

Over the last decade integration in the care system has become a central issue for the Italian National Government, prompted by policies at European 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 resulted in a need to redefine the priorities and to reorganise aspects of the system.

In Italy, health and social services still represent two different and only partially integrated sectors. The Italian National Health Service (NHS) ensures the provision of public health care services while public social services come under the responsibility of the local authorities.

There are two Italian partners involved in the ProACT project, AIAS Bologna onlus and ASP Città di Bologna. Both partners are based in the municipality of Bologna, the capital of the Emilia-Romagna Region in which the ProACT system will be tested in a small pilot within the framework of a larger study into factors that determine success in the transfer of integrated care solutions and systems from one context to another.

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 also major Assistive Technology resource centres in the city. Further AUSL di Bologna, the local public health trust was involved. 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 to integrate 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

Aims

Against this background the aims of the requirements gathering study in Bologna were 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 issues that impact on the transferability of integrated care solutions from one context to another.

Participants

In Italy the stakeholders have been recruited through:

- ASP Città di Bologna (the public social care agency of the Municipality of Bologna)
- AUSL di Bologna (the local health Trust)
- AIAS Bologna onlus

All three organisations are primary stakeholders in the transferability study and potential users of the ProACT platform following its availability on the market. At a preliminary stage they expressed their interest in a care platform that can be introduced in 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 disabled adults living independently was expressed. They further highlighted the need to consider the informal caregiver a primary resource for care plan coordination and thus a key player in any integrated care ecosystem.

Requirements gathering study at the Italian Transfer Site

As a consequence the following stakeholders groups were identified:

- Older Adults with Frailty. Older persons (over 65) with chronic diseases but not necessarily those included in ProACT and neither with multimorbidity, but with decreasing levels of independence, high likeliness to develop the typical ProACT pathologies and thus 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 that support the

transition process from hospital to community care in case of risk factors related to health condition, social condition, 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.

Table 3: Overview of participants recruited in Italy

Participant Group	Environment	N.
Elderly	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

Requirements gathering study at the Italian Transfer Site

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 and translated into Italian. All focus groups were audio recorded, transcribed and analysed in order to find recurrent themes and ideas.

Key findings

The thematic analysis revealed specific needs, areas of improvement and possible requirements in the main areas where ProACT is expected to bring innovation and impact. In addition to the requirements study in the main trial sites, an additional study was undertaken in Bologna in Italy, the place where the transferability study of ProACT had its own experimental pilot starting from Month 29. The requirements study has involved key actors in the local public health and social care sector, including possible 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.

A major difference between the main trial sites and the transfer site is that the main trial sites have focused on the (self-)management of multimorbidity conditions from a predominantly clinical, psychological and technological perspective, which is as a matter of fact the core aim of ProACT, while the transfer site has widened the focus, examining the broader needs of older persons with chronic 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 digital health solutions where large health care providers look for technology driven innovative solutions to be integrated in their existing service delivery systems.

Requirements gathering study at the Italian Transfer Site

The context in Bologna can be summarised as such: 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. One of the principal problems is that too many people with light chronic conditions or disabilities are often unknown or too poorly supported by the integrated health and social services, that are focused on the most critical situations. These people often emerge from this “dark zone” for the services too late, and only after a severe critical event (fall, stroke, accident etc.) that could probably be avoided or delayed with a better supportive, preventive and oriented to self-management strategy.

Among these big institutional players there is awareness 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 aims include the reduction of hospital (re)admission, the delivery of health care at community level by way of the “Casa della Salute” concept, keeping people as long as possible

independent in their life environment and valuing the role of the informal care network.

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 adults with frailty will have chronic conditions or will very likely develop them in the near future. The policy aim is to identify older adults with frailty early 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 education on maintaining a healthy lifestyle are important pillars of this approach.

Requirements gathering study at the Italian Transfer Site

The outcomes of the requirements study in Bologna are reflected in the table which is presented in the previous chapter and which can be summarised as such: ProACT constitutes 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 24h/day assistance to the population of no longer independent older people. 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 in the backend should be able to dialogue with existing databases and client management systems which are well developed in Emilia Romagna.

The authors of the study are aware that it will not be possible to fully realise this in the context of ProACT, but 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. 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 has been evidenced. 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 seem to be quite sceptical about the possibility of success in the self-management of conditions. Stakeholders at all trial sites 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

Medication management and adherence was a key issue for all trial regions. The absence of a unique care plan in the case of multimorbidity, which emerged from the Irish and Belgium sites, was not addressed in these terms in Italy, although the impression is that the formal health care system in Bologna is better prepared to integrate different aspects of 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 case of 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 them and other health professionals is sometimes difficult.

Nevertheless, in Bologna the GP's seem to be better informed about the conditions of their patients, at least theoretically, having access to electronic health records at regional level and other digital information systems. 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 disabilities whose lifestyle (less mobility) brings important risk for the development of chronic pathologies. Their drive for independence makes ProACT an interesting opportunity for living as independent as possible, as long as remote communication and ambient assisted living features could be integrated on the care platform.

Requirements gathering study at the Italian Transfer Site

The following lessons have been learned for the transferability study:

- The importance of the assessment of the care ecosystem context where ProACT is to be localised. This includes an analysis of roles and responsibilities, as well as communication patterns and needs.
- The importance of starting from the assessment of specific problems in designing holistic solutions.
- The importance of the involvement of all stakeholders in the definition of requirements and the co-design of solutions, which does not mean that each experience has to start from scratch.
- The impact of linguistic and cultural factors on the reciprocal understanding in cross-national collaborations.



Translation of User Requirements to Technology Design



Translation of User Requirements to Technology 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 was the first step in an iterative design process which involved continuous reflection and analysis of the findings presented in this report.

This user 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.

Designing the ProACT system

We employed traditional user-centred HCI techniques to help to translate the qualitative data, gathered from 124 stakeholders (in Ireland and Belgium) and 41 in Italy, into meaningful requirements for the design of ProACT technology by:

- Creating personas of PwMs and other key stakeholders to help to translate the qualitative data into meaningful requirements for design.
- Creating scenarios around these personas based on real data from our study to explore how technology can support all key stakeholders.
- Using versions of these scenarios as part of our co-design sessions with end users, to try to focus users to help us to design core concepts and features for the system.

Translation of User Requirements to Technology Design



ProACT Persona: Meet Sarah

Sarah is 85

She lives alone after her husband passed away

She has Diabetes and Heart Failure

Sarah's GP recommended that she try a new technology called ProACT to help her monitor her symptoms

Before ProACT

Everyday for the last 5 years she has measured her weight, blood pressure, blood sugar.

She writes readings in notebooks and brings them with her to her GP and specialist clinics that she attends for her conditions.

Sarah is finding it hard to remember to take symptom measurements and to write down the different readings into separate notebooks every day.

With ProACT

ProACT helps Sarah to keep track of other important parameters such as sleep, activity, mood and breathlessness.

Her new devices now send her readings automatically to a tablet where she can view her symptoms over the last day, week or month.

The system also provides Sarah with tips that might be useful for her to manage her conditions and stay as healthy as possible.

She can now share her symptom readings with her GP and her daughter who cares for her. They can log in remotely and access her health data.

Translation of User Requirements to Technology Design

In addition to the user-centred HCI techniques listed above, ProACT used a systematic behavioural science methodology the Behavioural Change Wheel (Michie, 2014) to design both the ProACT technology and the Proof of Concept trial. At the heart of the Behavioural Change Wheel (BCW) is the COM-B system, which we applied as part of the design process to assess individuals' capability, motivation and opportunity to use the ProACT system. This methodology has provided us with a useful tool to translate and further refine our user requirements study data and enabled us to understand the importance of features within the system that we may not have otherwise focused on during our design process. For example, using the BCW method to identify specific behaviour change targets we explored the fact that a participant could use ProACT as a digital monitoring tool to reflect regularly on their health readings. This led to the design of a symptom-reflection feature that prompts users to reflect on their recent symptom readings in relation to their baseline readings.

The BCW process has also enabled us to consider parts of the intervention that happen outside of the deployment of the digital tool. For example, the COM-B model highlighted the importance of education and training for all stakeholders as we cannot assume that users will have experience of using the devices or software that we are providing.

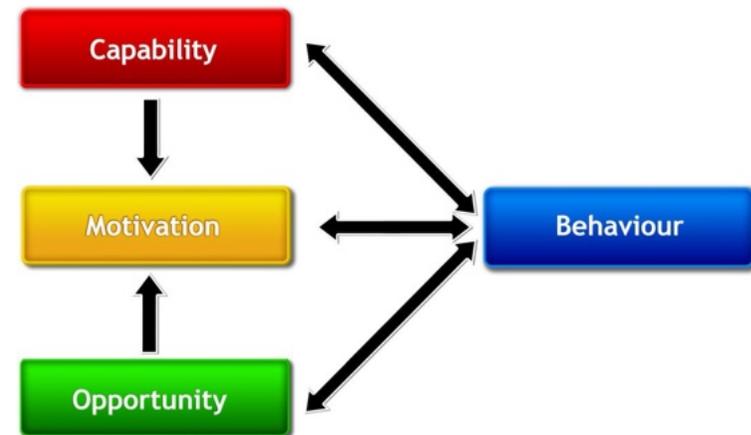


Figure 8: COM-B System (Michie et al, 2014)

Translation of User Requirements to Technology Design

In the following sections we have outlined how the key findings from our user requirement study have been translated into the design of ProACT technology that was deployed to:

- 60 PwM participants and 43 care network participants in Ireland
- 60 PwM participants and 30 care network participants in Belgium
- 23 PwM participants in Italy and 8 care network participants in Italy

In this updated version of this user requirement report, we have outlined learnings that specifically add to our previously identified user needs and requirements study. In order to understand how we have mapped the user requirements to the design of the system we have provided an overview of the ProACT platform below.

ProACT

In order to understand how we have mapped the user requirements to the design of the system we have provided an overview of the ProACT platform below.

The ProACT platform is made up of the following components:

- **Measurement and Sensing Devices:** Novel and “off-shelf” devices which are used to collect clinical, non-clinical and ambient parameters from PwMs in their home (e.g. blood glucose, blood pressure, weight, pulse oximetry, activity).



Figure 9: Pulse Oximeter

Translation of User Requirements to Technology Design

- **ProACT CareApp (Application):** Application delivered on an interactive device such as a tablet or smartphone, that supports monitoring of PwM status and provides feedback and education to support health and wellness self-management. The PwM is the main user of the ProACT CareApp. Customised CareApp interfaces will also be available to key people in the PwM's care network, to view and discuss data related to the PwM's health and wellbeing.
- **CABIE/SIMS:** A data collection and aggregation platform developed at DkIT. CABIE collects data from sensors, devices and CareApps and can push data, such as tailored education and advice to the frontend CareApps. The CABIE/SIMS system allows for integration of new future devices as well as tailoring of prompts, education content and questions in the frontend CareApps.
- **InterACT:** A cloud-based platform for secure storage, data mining, and analysis of anonymised PwM data. InterACT runs CareAnalytics on PwM data.
- **CareAnalytics:** Algorithms which can detect and react to data collected in ProACT. CareAnalytics are used to track and monitor clinical and non-clinical parameters (for example, changes in sleep patterns or activity levels; abnormal blood glucose readings).

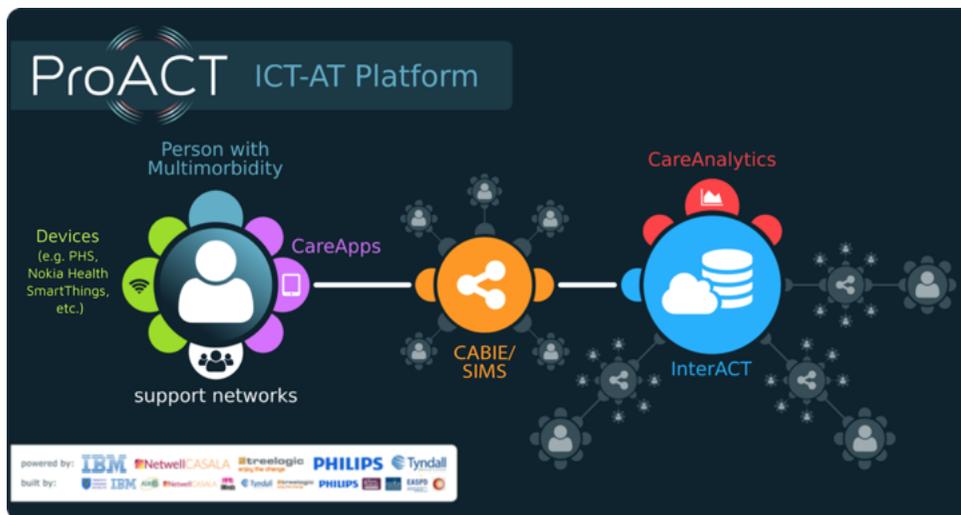


Figure 10: ProACT Platform

Translation of User Requirements to Technology Design

Table 4: Key findings from our initial requirement gathering study and how they have been addressed in the design and development of ProACT.

Key Findings from User Requirements	ProACT Design Element
Effective medication management was identified a key factor to managing multiple conditions in a home environment	The ProACT Medication Management Application provides users with a searchable database of widely available medications, supports maintenance of a digital medication list and facilitates management of an individual's medication-taking schedules.
Personality emerged as a key factor in determining motivation to self-manage and change health behaviours	Behaviour change theory and the use of data analytics provided us with a mechanism to refine and personalise the technology to individual participants.
Lack of care plans for multimorbidity were highlighted by all participants	By enabling PwMs to monitor and understand important clinical and wellbeing parameters across conditions over time, ProACT will help users and their care network develop effective strategies to manage multiple health conditions.
Poor communication was identified as a barrier to effective management and coordination of care	Poor communication is a critical issue for people managing multiple health conditions, redesigning communication channels for HCPs is difficult without changes to the wider health systems in Ireland, Belgium and Italy. However, by enabling HCPs and carers to view PwM's health and wellbeing information ProACT can make it easier for PwM's to discuss their recent health status with their care network.

Translation of User Requirements to Technology Design

Table 4: Key findings from our initial requirement gathering study and how they have been addressed in the design and development of ProACT.

Key Findings from User Requirements	ProACT Design Element
Ensuring the technology is easily useable by the PwM will be important for compliance with use of ProACT	We have involved end users throughout the entire iterative design and development process, in order to ensure that ProACT technology is accessible and usable by the PwM and their care network.
Healthcare professionals in Ireland reported limited use of existing technology	We designed customised interfaces for ProACT support actors, that they can access on their own devices (smartphone, tablet or computer). As we designed the app using accessibility guidelines and inclusive design principles, users can access and use the application quickly without the need for technical proficiency.
Caregiver burden was very apparent among informal carers interviewed	The structure of the education and training section in the informal carer app is the same as that of the PwM CareApp, but the content is slightly different – in addition to educational content on the conditions the PwM they care for is managing, ICs have access to education material on providing care to a PwM addressing topics such as self-care and time management.

Translation of User Requirements to Technology Design

Table 4: Key findings from our initial requirement gathering study and how they have been addressed in the design and development of ProACT.

Key Findings from User Requirements	ProACT Design Element
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.	Throughout our requirements gathering and co-design phases, social connection has emerged as a key support for PwMs. To design for this, it was decided that the Care Network feature within the main ProACT CareApp for PwMs would address social connectedness with educational content delivered through the Tips section to inform the participants of localised events and support groups.
It is important that goals for health and wellbeing for PwMs should be realistic, personalised and flexible in terms of target achievement.	The goals in feature in the front-end of the ProACT CareApp allows users to manually set and revise their own goals but they also have the option to accept the ProACT goal recommendation that is personalised based on their previous data.
The importance of linguistic and cultural factors on deploying technology in different localities; national and international.	ProACT CareApps have been designed so that they can automatically detect location and translate the language accordingly. Trial site staff in Belgium and Italy have contributed to the translations of language from the original English version in the front-end CareApps ensuring that translations are accurate and that any cultural references to health and medical language are appropriate and understandable.

Translation of User Requirements to Technology Design

Updates to User Needs and Requirements

Below we list seven key needs and requirements linked to the design and implementation of the ProACT solution building on the previous version of this report.

1. Symptom Monitoring and Reflection – *The Need to Consolidate Multiple Health and Well-being Management Parameters on a Single Application*

Findings from across the ProACT project highlight that those managing multimorbidity, specifically two or more of the following conditions: Diabetes, COPD, CHD and CHF, need to monitor a number of health and well-being parameters on regular basis. Where available, 3rd party sensors and devices were sourced to monitor these parameters (blood pressure, blood glucose, pulse oximetry, weight, sleep, activity) identified at the user needs and requirements phase (January-September 2016), while questionnaires delivered through the CareApp monitored additional parameters that could not be collected via devices (e.g. footcare, fatigue, perceived sleep quality).

ProACT meets the need of the participant by supporting the monitoring of a range of health and well-being information as outlined above in the PwM CareApp, through the Home page, View Readings and Add Info sections of the CareApp (Figure 11).



Figure 11: PwM CareApp Dashboard

Translation of User Requirements to Technology Design

Figure 11 shows the Home screen of the CareApp. The flower acts as a quick-glance overview of the PwM's current status (for example, current step count, last blood pressure reading). Petals can be blue or pink - pink represents a 'nudge' to the user to further explore the petal, for example if a reading is outside a defined 'normal' threshold, or no reading has been taken for a period of time, the user is brought to a reflection screen.

Our findings revealed that sometimes, management of one chronic condition can be forgotten, particularly if another is currently more acute. The flower design ensures that if a condition is not being monitored, it is brought to the PwM's attention. This could be a prompt or alert to monitor symptoms relating to that condition as well as a piece of relevant educational content being pushed. The flower acts as a subtle, unobtrusive prompt – it is up to the PwM to act on it. Furthermore, highlighting only the areas that need attention can reduce the complexity and the time burden of self-management, issues highlighted in our findings as well as by others (e.g. Banerjee, 2014; Starsfield et al., 2005).

2. Education and Training – *Ensure the provision of trusted, reliable information tailored to a PwMs specific conditions and management needs (including device and app training).*

Our findings highlighted that lack of information is a serious barrier to self-management. The selection of content for the education section of the CareApp, and its planned delivery have therefore been important tasks. Within the Health Tips section, there are two categories. 'Did you Know?' contains educational content relevant to self-management; 'How Do I?' contains custom-made training content on how to use devices and the CareApp. We have sourced educational information for each disease, relevant lifestyle advice and content specifically relating to the management of multiple conditions, from reputable sources that will be known to PwMs. Where possible, educational content has been sourced in two or three modalities, including video, audio and text to cater for differences in learning styles and accessibility.

Translation of User Requirements to Technology Design

3. Personal Goals - Setting goals and progressing toward goal achievement are key features to support self-management of multimorbidity.

PwM users can set goals in the ProACT CareApp for activity and have the potential to expand goal setting within measurable, predefined categories such as sleep, weight and frequency of symptom monitoring. An overview of progress as well as easy access to change goal sources and time frames are accessible through a goal overview or dashboard screen. Through messages and prompts, PwMs are supported in setting progressive goals. For example, they will be encouraged to start with small achievable goals and progressively review their targets. This is achieved through a goal recommender analytic, whereby realistic goals are suggested, based on the PwM's most recent data. As the user progresses and surpasses their targets, more challenging ones will be suggested.

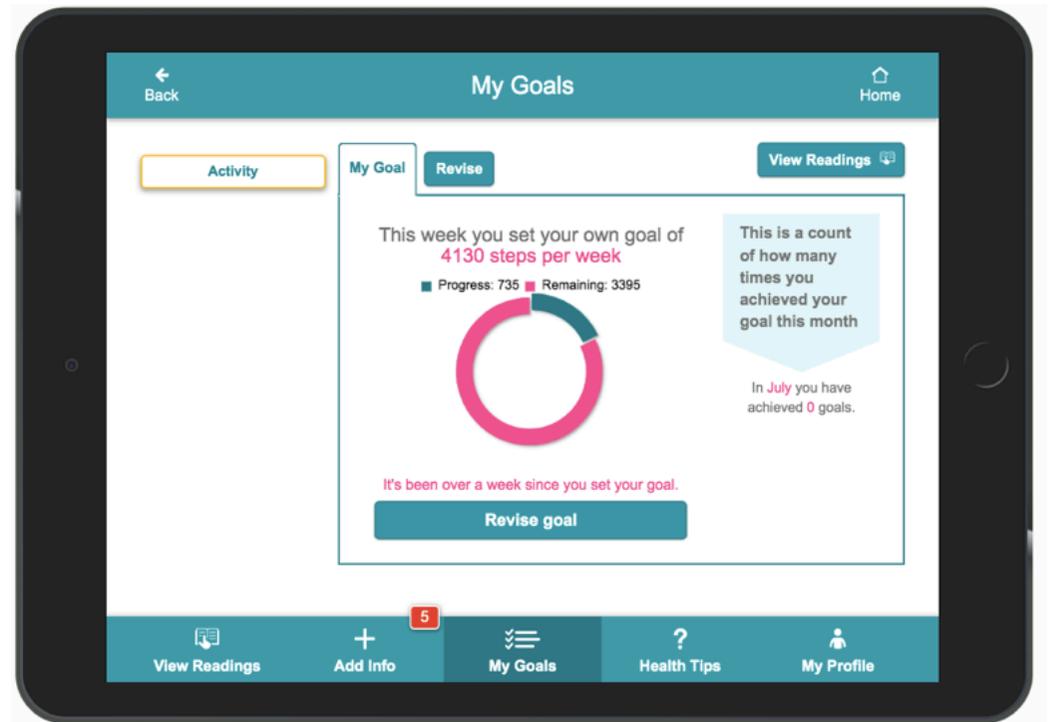


Figure 12: Goals Screen in PwM CareApp

Translation of User Requirements to Technology Design

4. Medication Management – *PwMs should have access to information and tools to maintain a digital medication list and schedule*

Our user requirement study highlighted that people managing multiple chronic conditions face burdensome and complex treatment plans. The prescription of several drugs is typical, which adds to the treatment burden, potentially resulting in dangerous drug interactions. The ProACT Medication Management Application was developed to support PwMs to manage medications and was deployed to a subset of 20 PwMs in Ireland and Belgium. The main design requirements for the application were that it should provide users with a searchable database of widely available medications, support maintenance of a digital medication list and facilitate management of an individual's medication-taking schedules.

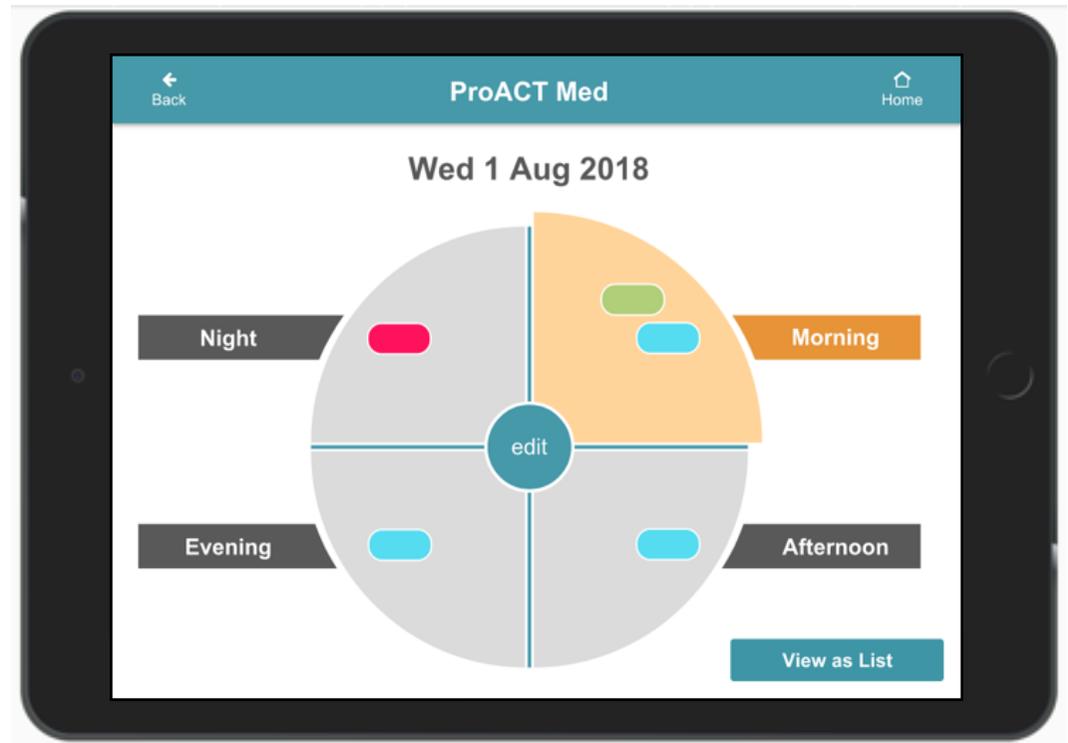


Figure 13: ProACT Medication Application

Translation of User Requirements to Technology Design

5. The Care Network – PwMs should be empowered to be contributors in the design of their care network

A significant theme to arise within both requirements gathering and co-design phases related to empowering the PwM to self-manage their health and wellbeing. The PwM is the owner of their data and, as our findings highlighted, is the one person with the most complete knowledge about their current health and wellbeing status, due to lack of integration between healthcare as well as social care services. A key factor in empowerment is to support ownership and choice. Therefore, the PwM should be able to choose whom, within their care network, to share their data and their goals with, including who can provide them with feedback and support them in both setting and meeting goals. We designed customised interfaces for ProACT support actors, that they can access on their own devices (smartphone, tablet or computer). These customised interfaces allowed those in the care network to view relevant data from the PwM and educational materials with the permission of the PwM participant.



Figure 14: Care Network CareApp

Translation of User Requirements to Technology Design

6. Triage Monitoring Application – *Provision of clinical triage support is important to home based management of multimorbidity*

A dedicated clinical triage service was available to participants in Ireland and Belgium to monitor vital signs and discuss any readings that generated alerts by phone. We have designed and developed a triage application for use by the triage nurse(s) in both Ireland and Belgium to manage vital sign parameters of trial PwM participants. The triage nurse can click into any participant and view their information, including their conditions, people in their care network and values of their latest readings. An alert is generated based on defined thresholds for different parameters in the system and triage staff follow a set protocol to advise PwMs on what (if any) action they should take i.e. take the measurement again, advise to speak to their GP or escalate to call emergency services.

7. Accessibility and Usability – *Key to supporting the use and evaluation of ProACT*

Usability and accessibility of the technology are crucial to the design and evaluation of ProACT as a digital behaviour change intervention. If the system is not fully usable by participants, we cannot evaluate how effective the system was to support self-management. We have involved end users as co-designers throughout the entire iterative design and development process. We also conducted feedback and observation sessions to explore the accessibility and usability at early stages in the design process and over repeated time points during the trials. The results of these evaluations were used to update the interface to enhance usability and accessibility of the application iteratively across the project.

Translation of User Requirements to Technology Design

Reflections on the transferability study

In order to test the transferability of ProACT to another cultural context, a transferability trial was conducted in Bologna, Italy. Requirements gathered from both older adults with multi morbidity, informal and formal carers are presented in this first version of this report. Since then, twenty three Individuals belonging to four different care contexts were selected to participate in one month trials to test the usability and the functionality of the ProACT system. Overall the requirements were found not to be very much different from those expressed in the main trial countries, which highlights that the needs are similar across Europe. Participants with good digital skills and in relatively good condition appreciated the system more than those with higher support needs, which highlights the need for training and ongoing support in using the technology.

Care professionals appreciated the system as a primary prevention tool, but though that quite a bit of customisation was needed to make it fully aligned with the existing public health and social care systems. The requirement to make ProACT as interoperable as possible was appreciated during the last trial in Bologna during where ProACT was embedded in a wider integrated care solution. In the same trial it emerged how a better control of self-management is important to a wider groups of users including those with disabilities. Participants with disabilities were enthusiastic to use technologies with functions currently not covered by “traditional” assistive technologies. In the same trial, participants showed a strong interest in technologies for environmental monitoring and control, highlighting how an increase in personal safety can be considered, by many users and carers, as an important element of integrated care pathways.

Translation of User Requirements to Technology Design

Conclusion

This report presents the initial requirements gathering study to identify the needs of older people with multiple chronic health conditions and the people who support them in managing their health. The aim of the study was to investigate the challenges that different actors in the care ecosystem face and how these are currently addressed two main ProACT trial sites: Ireland and Belgium and at the transferability site in Italy. The user requirement findings have been updated to reflect an additional exploration on goal setting for health and wellbeing. We have also presented how we have translated the findings from the initial user needs study into design requirements that informed the design of the ProACT system.



References

References

Banjeree, S. (2014). Multimorbidity - Older adults need health care that can count past one. *The Lancet*, 385(9968), 587-589.

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

Michie S, Atkins L, West R. (2014). *The Behavioural Change Wheel: A Guide to Designing Interventions*. Silverback Publishing. Great Britain.

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

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

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



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