Digital Health Platform for Integrated and ProACTive Patient Centred Care (ProACT): Protocol for an Action-Research Proof of Concept Trial.

John Dinsmore, Caoimhe Hannigan, Suzanne Smith, Emma Murphy, Janneke Kuiper, Emma O'Byrne, Mary Galvin, An Jacobs, Myriam Sillevis Smitt, Cora van Leeuwen, Patricia Sheridan, Lorraine Tompkins, Anne-Marie Brady, Mary McCarron, Julie Doyle

Submitted to: JMIR Research Protocols
on: July 05, 2020

Table of Contents

Digital Health Platform for Integrated and ProACTive Patient Centred Care (ProACT): Protocol for an Action-Research Proof of Concept Trial.

John Dinsmore[1] PhD; Caoimhe Hannigan[1, 2] PhD; Suzanne Smith[3] MSc; Emma Murphy[1, 4] PhD; Janneke Kuiper[5, 6] MSc; Emma O'Byrne[7, 8] MSc; Mary Galvin[1, 9] PhD; An Jacobs[5] PhD; Myriam Sillevis Smitt[5] MSc; Cora van Leeuwen[5] MSc; Patricia Sheridan[3] MSc; Lorraine Tompkins[1] MSc; Anne-Marie Brady[1] PhD; Mary McCarron[10] PhD; Julie Doyle[3] PhD

[1]Trinity Centre for Practice and Healthcare Innovation School of Nursing and Midwifery Trinity College Dublin Dublin IE
[2]Department of Psychology National University of Ireland Dublin IE
[3]NetwellCASALA Dundalk Institute of Technology Dundalk Institute of Technology Dundalk IE
[4]School of Computer Science TU Dublin Ireland IE
[5]Imec-VUB-SMIT Brussels BE
[6]Centre for Sociological Research KU Leuven Leuven BE
[7]Home Instead Senior Care Dublin IE
[8]School of Applied Psychology University College Cork Cork IE
[9]Department of Design Innovation Faculty of Social Sciences Maynooth University Maynooth IE
[10]Trinity Centre for Ageing and Intellectual Disability School of Nursing and Midwifery Trinity College Dublin Dublin IE

Corresponding Author:
John Dinsmore PhD
Trinity Centre for Practice and Healthcare Innovation
School of Nursing and Midwifery
Trinity College Dublin
GAS Building, 24 D'Olier Street, Dublin 2
Dublin
IE

Abstract

Background: Multimorbidity is defined as the presence of two or more chronic diseases and associated comorbidities. There is a need to improve best practice around the provision of well-coordinated, person-centred care for persons with multimorbidity (PwMs). Present health systems across the European Union (EU) focus on supporting a single disease framework of care; the primary challenge is to create a patient centric integrated care ecosystem to understand and manage multimorbidity. ProACT is a large-scale Horizon 2020 funded project, that involved the design, development and evaluation of a digital health platform to improve and advance home-based integrated care, and supported self-management, for older adults (aged 65+) living with multimorbidity.

Objective: This paper describes the trial implementation protocol of a proof of concept (PoC) digital health platform (ProACT) in two EU member states (Ireland and Belgium) to support older persons with multimorbidity self-managing at home, supported by their care network.

Methods: Research was conducted across two EU member states, Ireland and Belgium. A twelve month action research trial design, divided into three evaluation cycles, lasting three months each, with a reflective re-design phase of one month after cycles 1 and 2 was conducted. Participants were 120 (n=60 in Ireland and Belgium respectively) older persons with multimorbidity (PwMs) diagnosed with two or more of the following chronic conditions: diabetes; chronic obstructive pulmonary disease (COPD); chronic heart failure (CHF); cardiovascular diseases (CVDs). With permission from the PwM, members of their care network (CN) were invited to participate in the study. PwM participants were provided with ProACT technologies (tablet/devices/sensors) to support them in self-managing their conditions. CN members also received access to an application to remotely support their PwM. Qualitative and quantitative feedback and evaluation data from PwM and CN participants was collected across 4 time-points: baseline (T1); at the end of each 3-month action research cycle (T2; T3) and in a final post-trial interview (T4). Thematic analysis was used to analyse qualitative interview data. Quantitative data were analysed via platform usage statistics (to assess engagement) and standardised questionnaires (using descriptive and inferential statistics).

This study was approved by ethics committees in Ireland and Belgium.

Results: The trial implementation phase for this 44 month (2016-2019) funded study was April 2018 to June 2019. Trial outcomes are at various stages in the process towards publication from 2021.

Conclusions: ProACT aims to co-design and develop a digital intervention with PwMs and their CN, incorporating clinical guidelines with the state of the art in; human computer interaction, behavioural science, health psychology and data analytic methods to deliver a digital health platform to advance self-management of multimorbidity at home, as part of a proactive integrated model of supported person-centred care.

(JMIR Preprints 05/07/2020:22125)
DOI: https://doi.org/10.2196/preprints.22125

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**
Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
Only make the preprint title and abstract visible.
No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**
Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

Original Manuscript

Original Paper

John Dinsmore[1]; Caoimhe Hannigan[1]; Suzanne Smith[2]; Emma Murphy[1;] Janneke Kuiper[3;] Emma O'Byrne[4]; Galvin Mary[1]; An Jacobs[3]; Myriam Sillevis Smitt[3], CoraVan Leeuwen[3], Patricia Sheridan[2], Lorraine Tompkins[1], Anne-Marie Brady[1]; Mary McCarron[1]; Julie Doyle[2]

1. Trinity Centre for Practice and Healthcare Innovation, Trinity College Dublin, School of Nursing and Midwifery, D'Olier Street, Dublin 2, Ireland

2. NetwellCASALA, Dundalk Institute of Technology, Dublin Rd, Dundalk, Co. Louth, A91 K584, Ireland

3. Imec-VUB-SMIT, Boulevard de la Plaine 9, 1050 Etterbeek, Belgium

4. Home Instead Senior Care (Ireland), 305 Q House, Furze Road, Sandyford Business Park,, Dublin 18, Ireland

Digital Health Platform for Integrated and ProACTive Patient Centred Care (ProACT): Protocol for an Action-Research Proof of Concept Trial.

Abstract

Background: Multimorbidity is defined as the presence of two or more chronic diseases and associated comorbidities. There is a need to improve best practice around the provision of well-coordinated, person-centred care for persons with multimorbidity (PwMs). Present health systems across the European Union (EU) focus on supporting a single disease framework of care; the primary challenge is to create a patient centric integrated care ecosystem to understand and manage multimorbidity. ProACT is a large-scale Horizon 2020 funded project, that involved the design, development and evaluation of a digital health platform to improve and advance home-based integrated care, and supported self-management, for older adults (aged 65+) living with multimorbidity.

Objective: This paper describes the trial implementation protocol of a proof of concept (PoC) digital health platform (ProACT) in two EU member states (Ireland and Belgium) to support older persons with multimorbidity self-managing at home, supported by their care network.

Methods: Research was conducted across two EU member states, Ireland and Belgium. A twelve month action research trial design, divided into three evaluation cycles, lasting three months each, with a reflective re-design phase of one month after cycles 1 and 2 was conducted. Participants were 120 (n=60 in Ireland and Belgium respectively) older persons with multimorbidity (PwMs) diagnosed with two or more of the following chronic conditions: diabetes; chronic obstructive pulmonary disease (COPD); chronic heart failure (CHF); cardiovascular diseases (CVDs). With permission from the PwM, members of their care network (CN) were invited to participate in the study. PwM participants were provided with ProACT technologies (tablet/devices/sensors) to support them in self-managing their conditions. CN members also received access to an application to remotely support their PwM. Qualitative and quantitative feedback and evaluation data from PwM

and CN participants was collected across 4 time-points: baseline (T1); at the end of each 3-month action research cycle (T2; T3) and in a final post-trial interview (T4). Thematic analysis was used to analyse qualitative interview data. Quantitative data were analysed via platform usage statistics (to assess engagement) and standardised questionnaires (using descriptive and inferential statistics). This study was approved by ethics committees in Ireland and Belgium.

Results: The trial implementation phase for this 44 month (2016-2019) funded study was April 2018 to June 2019. Trial outcomes are at various stages in the process towards publication from 2021.

Conclusions: ProACT aims to co-design and develop a digital intervention with PwMs and their CN, incorporating clinical guidelines with the state of the art in; human computer interaction, behavioural science, health psychology and data analytic methods to deliver a digital health platform to advance self-management of multimorbidity at home, as part of a proactive integrated model of supported person-centred care.

Keywords: Multimorbidity; digital health; chronic disease; self-management; older adults; integrated care; behaviour change.

Introduction

Within the European Union (EU) an estimated 50 million people live with multimorbidity, defined as two or more chronic health conditions [1]. For individuals living with multimorbidity, self-management of multiple conditions can impose a significant burden [2], with activities that include managing multiple symptoms, medications, information on their conditions and clinical appointments. Added to this burden, healthcare services for individuals with multimorbidity are often repetitive (multiple appointments), inconvenient, inefficient (individuals may see different clinicians who give conflicting advice), burdensome and potentially unsafe due to poorly integrated and coordinated care [3, 4]. The outcome for individuals is reduced quality of life, as time and energy is spent managing multiple conditions, limiting their opportunity for social or personal activities [5].

Risk of multimorbidity increases with advancing age, with prevalence rates estimated at 65% in people over 65, and 85% in people over 85, and rising [6]. The rapid ageing of the global population brings significant concerns over the sustainability of health services, due to associated increases in healthcare expenditure, as well as disparities in the number of practising health professionals. It is therefore important that efforts are made to explore sustainable digital approaches to support home based self-management of chronic diseases and multimorbidity. Self-management (or self-care) can be described as the ability of the individual to manage symptoms, treatment, emotions and lifestyle changes as part of living with a chronic condition [7]. Improving best practice around the provision of person-centred care for PwMs requires empowering the PwMs to self-manage, actively supported by their care network, which primarily involves informal carers (ICs), formal carers (FCs) and healthcare professionals (HCPs). The care network of each PwM plays an important role in diminishing the impact of disease management, which may subsequently improve health outcomes and quality of life [8].

Digital health technologies have the potential to improve and advance home-based self-management for older PwMs, yet the majority of digital solutions focus on single disease management (e.g. diabetes) [9, 10]. Therefore, digital solutions which address complex disease management and multimorbidity taking into account the role, views and needs of the PwM’s and their CN are also

required.

To date there has been limited research examining the potential of digital health support for multimorbidity management. This includes understanding the challenges faced by people managing multimorbidity, as well as design requirements for digital technologies to address these challenges [11-15]. While such research is necessary, to the best of our knowledge, research on digital systems to support multimorbidity has not progressed beyond examining requirements and suggesting design recommendations.

Within the EU the ICARE4EU programme provides the most robust examination of digital or eHealth utilisation to address multimorbidity management within the context of integrated care [16]. Managers of 101 integrated care programmes in Europe were surveyed to understand if they had utilised e-health (or digital) solutions and if so, what were the benefits and barriers for the solutions in relation to multimorbidity care. Of these programmes, 85 adopted e-health solutions and 42 of these were targeted specifically at older adults. The types of e-health technologies implemented within these programmes included; remote consultation and monitoring, self-management tools (including electronic reminders and online decision support), healthcare management technology such as patient databases and e-referral systems and electronic health records (EHRs). However, neither detailed descriptions of these technologies nor their evaluation was presented. Furthermore, the authors note limitations in that HCPs, patients and their carers were not consulted in terms of the availability of e-health within these programmes.

With such limited research in the area of digital health, integrated care and multimorbidity management, a need exists for large scale, longitudinal programmes or projects to better understand both the complexities of multimorbidity and how digital technologies can be designed, developed and implemented to support PwMs and their CN. The ProACT project, funded under the European Commission (EC) Horizon 2020 programme brings together a multidisciplinary consortium of 13 European partners for the purpose of developing and evaluating a digital integrated care system to empower home-based, patient-centric care and proactive self-management of conditions for Europe's 50 million PwMs.

This paper reports the protocol for the ProACT H2020 project main PoC trial conducted in Ireland (by the Trinity Centre for Practice and Healthcare Innovation, Trinity College Dublin, NetwellCASALA at Dundalk Institute of Technology and Home Instead Senior Care) and Belgium (by imec-VUB-SMIT) between the months of April 2018 and June 2019. Prior to the PoC trial the ProACT platform was designed and developed between 2016-2018 through an iterative user-centred process involving input from 166 key stakeholders (older people with multiple chronic conditions, carers and healthcare professionals) across Ireland, Belgium and Italy [17-21].

Study Aim and Objectives

The study evaluated at a PoC level a digital health platform (called 'ProACT') for older PwMs to self-manage their conditions with support from their CN. ProACT was implemented in two EU trial sites (Belgium and Ireland). The specific aims of the trial were: 1) To explore the potential benefits of the ProACT platform for PwMs and 2) get feedback from all relevant participants on their experiences using the ProACT platform, and on the potential for the platform to improve integration of care and support for multimorbidity disease management.

Specific objectives for all participants focus on evaluation of the: usability, accessibility and acceptability of the ProACT platform; user adoption and satisfaction with the technology and

services; experiences of participants using ProACT. Additional objectives for PwMs were to evaluate the potential impact of the ProACT platform on a range of health, well-being, psychological, and psychosocial outcomes and evaluate the efficacy of ProACT as a behaviour change intervention that aims to improve self-management skills for the PwM. Additional objectives for IC and FC participants were to evaluate the potential impact of the ProACT platform on their psychological and psychosocial outcomes.

ProACT - Intervention Description

ProACT is a citizen driven, self-management orientated, digital care platform capable of supporting disease management and well-being parameters (e.g. mobility and sleep) single user application. The overall (Figure 1) consists of:

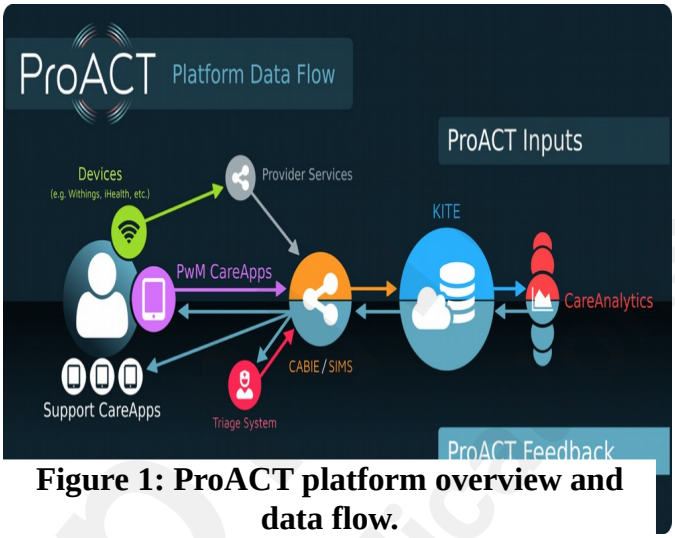


Figure 1: ProACT platform overview and data flow.

- A kit of home-based integrated measurement and sensing devices (e.g., blood pressure cuff, weight scales, smart watch, home based sensors).
- A suite of end-user applications and support tools (CareApps – Figure 2). Applications are available for the PwM, HCP, IC and FC.
- A source-agnostic data collection system (CABIE).
- A portal to support: (1) Management of trials and participants (2) Clinical triage support (SIMS).
- Cloud-based storage and analytics system (KITE).
- Advanced analytics to provide risk assessment, support PwM goal setting and support person-centric care (CareAnalytics).

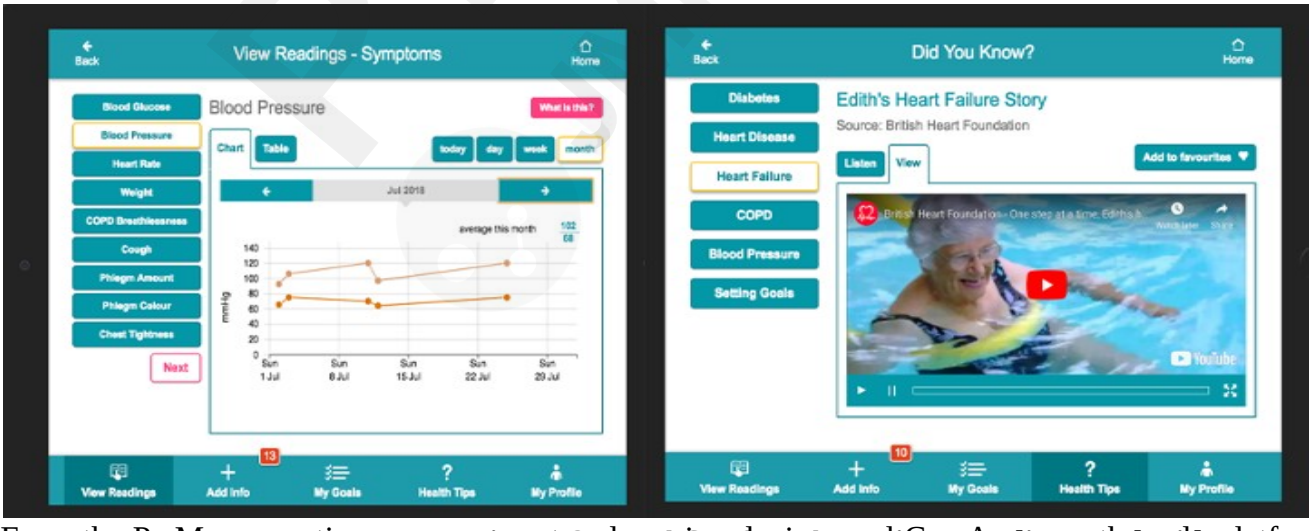


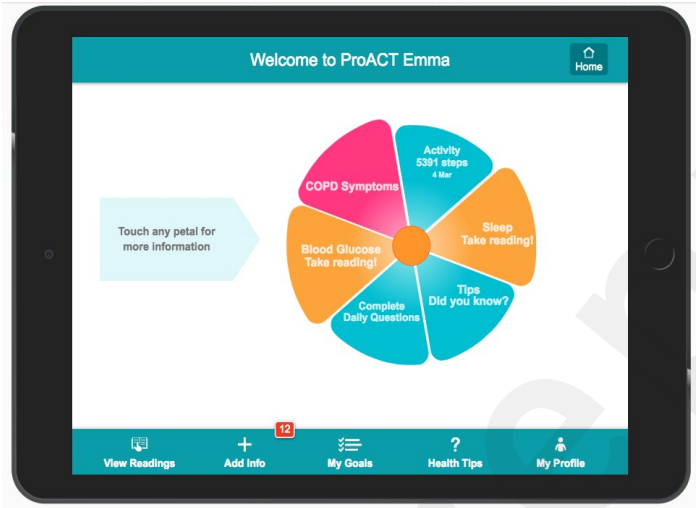
Figure 2: ProACT CareApp View Readings and Did You Know (educat interfaces

From the PwM perspective, measurement and sensing devices and CareApps are the only platforms technologies visible and interacted with on a regular basis. For CN users CareApps tailored to their requirements are their point of interaction with the platform. The full list of devices for use by the PwM are included in Table 1 below.

Table 1: Hardware/devices included in PwM ProACT toolkit*.

Category	Device/Hardware
Vital signs monitoring	iHealth Blood Glucose monitor
	Withings Blood Pressure monitor
	Withings Weight scales
	iHealth Pulse Oximeter
Wellbeing monitoring	Withings Watch (physical activity and sleep)
General	Tablet device (e.g. iPad)
	Broadband connection (supplied where needed)
	Peripheral supplies (batteries, extension leads etc.)

*Note: this toolkit is customisable according to preferences and conditions of the PwM



Within the overall intervention the primary point of information exchange with the end user (PwM or CN support actor) is their CareApp. Table 2 below outlines the structure and use of each respective CareApp. Figure 3 provides an overview of the PwM home screen co-designed with the users. The petal based interface presents a brief summary of health and well-being data tailored to each PwM's conditions and self-management preferences. Using a colour coded 'traffic light' system PwMs are alerted if their data is below or above their personal thresholds (pink), when they haven't taken a reading for five days or more (orange) or when all is deemed normal for the PwM (blue).

Table 2: CareAPP Components and Associated Features

User	Component	Feature Summary
PwM	Home Screen	Provides quick glance overview of current health and wellbeing status, educational tip of the day and goal progress

		tailored to individual disease profiles and self-management preferences (e.g. Blood pressure, step count, blood glucose, daily questions etc.). Home button and quick links to; view readings, add info; my goals; health tips and my profile (described below).
	View Readings	Users can choose to view their data across 5 key areas – Symptoms, sleep, activity, daily question responses and personal reflections on these responses.
	Add Info	Allows for manual entry of data from personal or non-digital devices and presents daily questions around general wellbeing, anxiety, satisfaction with sleep and social interactions, as well as symptom monitoring questions for those parameters not measurable by a digital device (for example, breathlessness, sputum colour for COPD; oedema for Heart Failure).
	My Goals	Supports the PwM to set personalised, flexible and collaborative (with their CN) goals around their health and well-being (e.g. exercise).
	Tips	Tips and educational content relating to conditions and self-management (covers information related to: individual Conditions; managing multiple conditions; medication management; activity, social and goal Planning etc.) as well as training on how to use devices (including the iPad) and the CareApp(s).
	My Profile	Supports the PwM in having control over various aspects of their CareApp, including who they would like to share their data with and how often they would like reminders/alerts to take readings etc.
Informal Carer	The app view has a similar structure and navigation to the PwM app. The home screen is based on a grid rather than a flower shape petal and presents a mixture of education content (this includes the same content as in the PwM app along with education material on providing care to a PwM, addressing topics such as self-care and time management) and PwM health readings. The app also allows the user to send brief notifications that they have viewed the data and/or encourage the PwM in their self-management practices.	
Formal Carer	The app has the same structure and navigation as the informal carer app with similar features. This app is limited so that formal carers can only view wellbeing data (such as sleep and activity) and not the PwM's health (e.g., symptom data such as blood pressure, blood glucose etc.) readings, as this was not allowed due to regulations within the formal care organisations at trial locations.	
HCPs	The HCP CareApp has similar functionality to the Formal Carer CareApp in that HCPs can view a list of their patients and with permission, view their readings, and their profile. Within this app HCPs have access to the patient health (e.g., symptom data) readings.	

Methods

Study Design

The study was a longitudinal (12 month) PoC trial using an action research design and mixed methods approach. Action research is a period of investigation that 'describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement' [22]. The strength of this approach is the capability to generate solutions to practical problems, while garnering methods to understand the context of care, needs and experiences of the PwM group, drawing upon a range of research methods (e.g. participant observation, in-depth interviews), to involve and build relationships with PwMs and associated CN support actors. Within the PoC trial this allowed for modifications to the technology based on quantitative and qualitative data collected from: platform usage statistics (e.g. how often participants engage with the platform); platform data (i.e., data coming from sensors and the technologies); observational and usability testing methods to understand participant interaction with CareApps; PwM and CN responses to interviews, questionnaires and standardised assessments (e.g. to evaluate quality of life, device proficiency, usability etc).

Participant inclusion and exclusion criteria

PwMs and their CN (which consists of ICs, FCs and HCPs) were eligible for this study. For inclusion, PwM participants were; aged over 65 years and had at least 2 of the following conditions: Diabetes, COPD, CHF or CVDs (Chronic Heart Disease/Coronary Artery Disease including Hypertension, Atherosclerosis, Angina, Arrhythmia); were capable of giving written informed consent; had access to broadband services (this refers to regional infrastructure) or lived in an area with sufficient coverage for mobile broadband/internet. Implemented service costs were covered as part of the trial.

CN participants were invited only on the permission of the PwM and were required to be; aged over 18 years; providing care or support to a PwM participant; had access to a computer, tablet or smartphone with an internet connection; capable of giving written informed consent.

Sample

A purposive sample of n=120 PwMs (n=60 PwMs per trial site in Ireland and Belgium) was recruited to take part in the PoC trial. While sample size is often cited as a key factor in determining the potential success of a study, this is more relevant for randomized controlled trial type studies that seek to answer specific questions regarding the efficacy of interventions (Does it work?) and is less relevant for studies relating to care and service improvement (How does it work?) [23]. Thus, to determine PoC sample size we took a pragmatic approach and reviewed two important factors; (i) that it is large enough to provide a reliable analysis of the ecosystem and (ii) small enough to be financially feasible. Analysis of literature suggests overall sample size in a PoC, telemedicine/ICT trial is low. A review of 1030 studies on telemedicine based technological interventions for chronic disease management, looking at CHF (436), Stroke (422) and COPD (172) programmes between 2005 and 2013 (including 35 systematic reviews and one review of the reviews), suggests methodologically robust, samples size for each condition were; 17 (COPD), 21 (Stroke) and 19

(CHF) [24]. The selected studies were conducted primarily in the United States and Europe.

Ethical approval and consent

Ethical approval from participating health service organisations where recruitment took place and academic partners was granted. Informed consent was obtained on an individual basis in accordance with legal and ethical guidelines at each trial site region, following careful explanation of the study and provision of patient information and informed consent forms for the PwMs and participating members of their CN. All participants had the right to withdraw from the study at any time, without question. Following review of recruitment procedures by ethical committees in Ireland and Belgium, it was agreed researchers should only contact a person's HCP if they had provided this consent.

Recruitment procedures

In both Ireland and Belgium participants were selected by several different methods, depending on which recruitment source they were accessed through, as outlined below:

- Health professional and formal care services *(*e.g. in Ireland: the Health Service Executive (HSE) and Home Instead Senior Care (HISC) and in Belgium: the hospitals UZGent and OLV Aalst, and the homecare organisations Solidariteit voor het Gezin and Rivierenland): Participants were selected from the service clinic records or via professional familiarity by healthcare professionals employed directly in the services; healthcare professionals within the services selected any potential participants who met the study inclusion criteria. Research team members did not view health service records to identify participants.
- ProACT 'requirements gathering' panel: This research panel consisted of individuals linked to the first phase of the ProACT project, which focused on the design and development of the platform. Phase 1 received ethical approval and participants consented to be re-contacted regards participation in the PoC trial.
- General Practices: Participants were selected by general practitioners (GPs) following the same procedures as outlined for health professional services. Study information was also left in participating GP waiting rooms. Self-selecting participants who viewed this information could then contact the research team directly. Researchers assessed potential participants to determine whether they met the inclusion criteria (e.g. whether they have been diagnosed with the ProACT conditions). If they were unsure, they were asked to check with their GP.
- Relevant older persons and chronic disease networks (e.g. Diabetes and COPD support groups etc.): Participants were a self-selecting sample. These organisations disseminated study information to their members, who could then contact the research team directly to participate. The same assessment procedures as outlined for General Practices applied.
- Additional recruitment sources in Ireland included: social media, radio and local newspaper advertising; referrals directly from pharmacists; participants who also referred another PwM. Researchers contacted individuals who expressed interest in participating to ensure they met the inclusion criteria.
- Additional recruitment sources in Belgium included: several recruitment agencies (IVOX, Tendens, imec Living Lab, Zorglab Aalst) via their respective panels; a pharmacy organisation; a newspaper advertisement; participants who also referred another PwM.
- In relation to the additional recruitment channels in Ireland and Belgium, researchers assessed potential participants to determine whether they met the inclusion criteria (e.g. whether they have been diagnosed with the ProACT conditions). If they were unsure, they

were asked to check with their GP.

Technology deployment and trial set up

Invited PwM participants had at least 7 days to review the participant information leaflet and have queries answered prior to technology deployment, which occurred over two visits to the PwM's home. All researchers ensured that ProACT technology was deployed correctly and in a consistent manner across trial sites, following a strict deployment plan.

In the first visit, members of the research team obtained participant written consent. Each participant received devices depending on their condition profile. Participants also had the option to use any existing device (that they currently use at home) to measure an included parameter (e.g. blood glucose monitor) by manually entering readings from the device into the PwM CareApp. ProACT sensor devices were connected by Wi-Fi or Bluetooth and broadband internet connection was provided for the duration of the trial for any participants who did not have existing broadband in their home. Participants were trained on how to use their ProACT devices during the initial visit. This included a brief introduction on how to use the ProACT CareApp and associated 3rd party applications (for example, using the Withings HealthMate[1] application to take a blood pressure reading), as it was important that the PwM was not overloaded with information on all ProACT technology features during the first visit. Participants were also provided with a paper-based manual, containing detailed instructions for using each device, along with common troubleshooting instructions.

Approximately one week after the first visit, researchers conducted a second deployment visit. Detailed training on the CareApp took place with additional online training materials and videos made available through the ProACT CareApp. A study helpdesk, staffed by respective research team members in Ireland and Belgium was available (from 9.30am – 4.30pm, Monday to Friday), to assist participants with queries and technical difficulties. In both Ireland and Belgium a dedicated clinical triage service for monitoring of vital signs was also available (9am - 5pm, Monday to Friday). Triage personnel (clinical nursing staff) had access to data from all PwMs taking part in the trial via SIMS. A protocol for dealing with potential adverse events was developed with triage personnel. This included defining thresholds for abnormal vital sign values for each parameter being monitored. For example, thresholds for high and low blood glucose values were set in the SIMS system for those participants with diabetes. At the outset of the trial, global threshold values were set for all participants. However, over the course of the trial, such thresholds were often adjusted for individuals based on their normal values. If a participant vital sign reading is outside the normal threshold, an alert is triggered on the SIMS triage interface and as noted above, the participant will see a pink petal on their CareApp dashboard (Figure 3). In such instances, the triage nurse calls the participant to discuss the reading and determine whether an escalation is required. In both trial regions clinical triage was not provided for non-vital signs data (e.g. sleep, activity). Participants were reminded that this is a research study, and that the triage service would not be considered as a replacement for normal care. In the event a PwM felt ill, they were recommended to seek medical advice or care as they normally would. PwMs were also reminded of this at regular intervals through a pop-up message on the PwM CareApp, as requested by the ethics committees. Following completion of the 2nd deployment visit participants began their trial period.

Invited members of the PwM's CN were provided with access to their relevant CareApp, that they

[1] https://www.withings.com/uk/en/health-mate

could use on their own devices (smartphone, tablet or computer). These customised CareApps allowed those in the CN to view relevant data from the PwM participant and educational materials related to condition management, well-being and technology use. The PwM participant chose what data to share with each CN participant. The data viewed by HCP participants via their CareApp was not used to make clinical decisions. This was clearly outlined in the participant consent forms and information leaflets for all trial participants.

Trial Implementation, outcome measures and data collection

The PwM CareApp and toolkit were deployed to the PwM participants in their homes for up to 12 months (participants used the application for a minimum of 9 months to cover the 3 action research cycles), across a 15-month period. Recruitment was staggered across action research cycle 1 as outlined in Figure 4. Introducing participants at various stages in the 1st action research cycle did not impact on the final analysis, as elements of the system were re-designed/developed at two separate points, as part of the action research methodology. Invited CN participants also received access to their respective CareApp following nomination from the PwM. Outcomes from the trial were assessed using a mix of ProACT platform data (engagement with app and data from sensors), CareApp questionnaires (self-report data on health and well-being), standardised assessments (see Table 3), usability testing and semi-structured interviews. Further detail of the process for PwMs and CN members was as follows:

PwM

PwM participants were asked to use their CareApp to record information and measure key parameters related to their health and wellbeing on a regular basis (at their convenience), using sensors/devices and by answering self-report questions presented via the CareApp. They could also use their CareApp to view their recorded data and to view educational materials and training videos related to condition management, well-being and technology use. Adherence to physiological monitoring and usage of the ProACT CareApp was monitored via system usage statistics and data collected by the ProACT platform.

PwM questionnaire/assessment and qualitative semi-structured interview data were collected across 4 time-points: baseline (T1 during 2nd deployment visit); at the end of each 3-month action research cycle (T2 – month 3; T3 -month 7) and in a final post-trial interview (T4-month 12). Figure 4 presents the study timeline for the PwM.

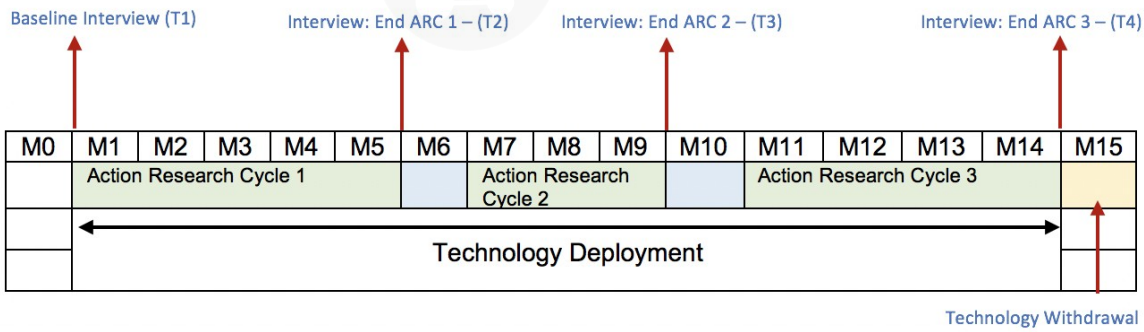


Figure 4: Study timeline across action research cycles for PwMs.

A paper questionnaire containing scales and measures that were suitable for self-completion was posted to each participant in advance of each interview. This allowed the participant to complete these measures at a time(s) that was convenient to them in order to reduce participant burden. Interviews were conducted in the participant's home. Researchers reviewed the questionnaires briefly during interviews and assisted the participant in completing any questions where necessary. Table 3 presents the key assessment domains and measures issued to PwMs across the trial. Semi-structured qualitative interviews were also conducted. Themes that were addressed in the interviews included: understanding expectations of how ProACT might change health and well-being; PwM use of ProACT; understanding how ProACT has changed self-management routines/strategies; the impact of ProACT on the role of the CN; frequency of healthcare utilisation and cost of care; accessibility and usability of ProACT; user satisfaction and effectiveness of ProACT; technology adoption and perceived future use of ProACT.

Following action research cycle 3, the trial concluded with a one-month period of phased withdrawal of technology. The timeline for the withdrawal of technology was clearly explained to participants throughout the study, in order to manage participant expectations.

In order to assess whether the ProACT CareApps were usable and accessible, we conducted user evaluations with a small subset of users over repeated time points (in line with the action research cycles) during the trial. Participants were asked to conduct a number of tasks and give their opinions and feedback on the application using a “think aloud” protocol [25]. This involves encouraging participants to verbalise what they are thinking as they use the application to expose potential usability and accessibility issues. Users were video recorded during these evaluations. The resulting videos were transcribed, annotated and analysed by researchers to explore participant interactions with the technology and identify any barriers or difficulties that they encountered. The results of these evaluations were used to update the CareApp interfaces during the trial, to enhance usability and accessibility of the application.

Table 3: PwM key assessment domains and measures.

Note: Measures administered at each assessment time point were a subset of those listed in this table; an indication of the time-point for each assessment is indicated in the table below. Measures marked with an asterisk (*) were included as part of a paper-based questionnaire sent to participants in advance of the relevant interview.

Domain	Scale/ Measure	Description of measure	Assessment Time-Point
Demographics	Self-report questionnaire	**7 self-report items** collecting information on: gender; date of birth; marital status; educational level; living alone/with others; employment status; primary occupation.	T1
Medication List	Self-report list	Interviewer recorded a list of the names, dosage and frequency of each participant’s medication(s). This data was used to initially populate the triage system for nurses, who then managed the on-going collection and updating of medication information.	T1
Comorbidity	Multimorbidity	**22 item list** of common conditions /	T1; T4

Index/Disease Burden	Assessment by Self-Report [26]	comorbidities: yes/no to indicate presence of conditions; then 5-point Likert scale to assess the extent to which each condition limits daily activities	
Technology Use and Proficiency	Mobile Device Proficiency Questionnaire [27]	**16 item scale** to assess older adults' proficiency with mobile technological devices. Participant rated ability to carry out different operations (e.g. internet, calendar etc.) on a 5-point Likert scale.	T1; T4
Cognitive Function	Montreal Cognitive Assessment [28]	**30-item scale** measuring cognitive function in several domains; total score gives measure of global cognition; cognitive screening test.	T1; T4
Health related quality of life/ Health outcome measure	EQ-5D 5L [29]	**5 item self-report Likert scale:** rate level of problems in five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. **1 item visual analogue scale**: own judgement of health status between 1-100 (from 'best health you can imagine' to 'worst health you can imagine').	T1; T2; T3; T4
Quality of Life	CASP-19 [30]	**19-item scale** measuring quality of life across 4 dimensions: Control, Autonomy, Pleasure and Self-realisation). Developed for an older adult population.	T1; T2; T3; T4
Illness Perceptions	MULTIPleS (Multimorbidity Illness Perceptions Questionnaire) [31]	**22 item scale** measuring illness perceptions related to multimorbidity in 5 dimensions: emotional representations; treatment burden; prioritising conditions; causal links and activities limitation.	T1; T2; T3; T4
Self-Efficacy	General Self-Efficacy Scale [32]	**10 item** self-report Likert scale: assesses perceived self-efficacy and ability to cope with daily hassles and stressful life events.	T1; T2; T3; T4
Locus of Control	Multidimensional Health Locus of Control Scale [33]	**18 item scale** assessing beliefs about control individuals have over their own health in 3 main dimensions; internal control; chance and power.	T1; T2; T3; T4
Social Connectedness	Lubben Social Network Scale [34]	**18-item** version to measure social connection in 3 domains: family, friends and neighbours.	T1; T4 (18-item) T2; T3 (6-item)

Depression and Anxiety	Hospital Anxiety and Depression Scale (HADS) [35]	**14 item** scale to measure depression and anxiety – developed as screening tool for clinical levels of depression and anxiety.	T1; T4
Sleep Quality	Pittsburgh Sleep Quality Scale [36]	**9 item scale** to assess subjective sleep quality: can provide an overall score as well as domain specific scores.	T1; T4
Fatigue	Functional Assessment of Chronic Illness Therapy Fatigue Scale (FACIT-Fatigue) [37]	**13 item scale** measuring feelings of fatigue/weakness/energy etc. and impact on daily activities.	T1; T4
Physical Activity	Rapid Assessment of Physical Activity (RAPA) [38]	**10 item** scale to measure engagement in physical activities.	T1; T4
Usability	System Usability Scale (SUS) [39]	**10 item scale** (Likert scale item) to provide subjective assessment of the usability of a technology system.	T2; T3; T4
User Burden (Technology)	User Burden Scale [40]	**18 item[2] self-report scale** used to evaluate user burden when engaging with technology. Likert scale.	T2; T3; T4

Care Network

Consenting CN participants came onto the trial during the PwM's ARC 2 based on referrals from PwMs during ARC1. All users in the care network were provided with relevant data for the PwM participant and relevant training/educational content via their customised ProACT CareApp. This data could be viewed at a time and frequency that was convenient for them. The purpose was to evaluate experiences of people within the CN using the ProACT platform, and to understand whether they would find this type of system and data useful to them in their role, supporting the PwM with their self-management, care and treatment plans. Members of the research team collected feedback and evaluation data from people in the CN as follows:

ICs: A member of the research team conducted interviews with ICs, either by phone or at a location convenient to the participant at T1 (i.e. when the CN participant consented to take part) and T4 (at the end of the trial). While a PwM could have more than one IC in their CN who had access to the CareApp, only one, the primary IC, was asked to complete the assessments/interviews. During this interview, the researcher administered scales and questionnaires to collect information on health, psychosocial, psychological and demographic characteristics (see Table 4). A semi-structured qualitative interview was also conducted covering areas including; expectations to the use of

[2] The original questionnaire is 20 item, but two questions in relation to financial burden were not used, due to lack of relevance

ProACT, usability of the CareApp; whether ProACT has benefitted them in their role or not; and how they felt it benefited the PwM. ICs were also asked to complete a short questionnaire to provide feedback on the technology at the end of the trial (T4).

FCs and HCPs: Participants were asked to complete a short questionnaire at T1 (i.e. when the CN participant consented to take part) and T4 (at the end of the trial). These questionnaires collected information on usability and acceptability of the technology, along with experiences of using the ProACT platform (see Table 4). FC and HCP participants also took part in qualitative interviews or focus groups at baseline (T1) and post-trial (T4). Themes addressed; whether ProACT helped in their role; how they felt it benefitted the PwM; what would they change about the system; usability of the CareApps.

Table 4: CN participant key assessment domains and measures.

Domain	Measure	Timepoint	Who
Demographics	Self-report items* **ICs:** Age; Gender; Education; Relationship to PwM, Employment status; Primary occupation; hours and type of care; Self-rated health. **FCs and HCPs**: Age; Gender; duration of care provided to PwM; type of care provided to PwM.	T1 only	IC, FC, HCP
Technology Use and Proficiency	The Mobile Device Proficiency Questionnaire* [27]	T1; T4	IC, FC
Usability	System Usability Scale (SUS) [39]	T4 (with a subset only)	IC, FC
User Burden (technology)	User Burden Scale* [40]	T4 (with a subset only)	IC, FC
Self-efficacy	General Self-Efficacy Scale* [32]	T1; T4	IC, FC
Stress	Perceived Stress Scale [41]. **14-item** scale of the degree to which situations in an individual's life are appraised as stressful.	T1; T4	IC, FC
Caregiver Stress /	Caregiver Self-Assessment	T1; T4	IC

Psychological impact of caregiving	Questionnaire [42] **18 item** scale to measure the psychological impact (including stress) of caregivers.		
Caregiver Burden	Zarit Burden Interview [43] **22 item** scale to measure the level of burden experienced by caregivers of patients.	T1; T4	IC

Data Analysis

As a PoC trial, a key outcome is to understand whether a larger trial, that makes a definitive assessment of benefit, is warranted. Pilot and PoC studies are more about learning than confirming or formally assessing evidence of impact or benefit associated with an intervention. It is therefore recommended that analyses should be focused on providing descriptive evidence and indications of the range of possible responses rather than on formal hypothesis testing [44]. Analyses were therefore mainly descriptive and aimed at understanding user experiences in relation to the use of the ProACT platform. Qualitative methods encouraged participants to speak about both their experiences of living with and managing multimorbidity, and their experience of using the ProACT technologies. While the quantitative data analysis ensured comparability and consistency of questions across participants and time points.

Qualitative data were analysed using Thematic Analysis (TA) in order to identify and understand emerging themes. An inductive approach was adopted, identifying themes at a latent level. An inductive thematic analysis is data-driven as opposed to analyst-driven TA [45]. This approach helps generate novel insights from interview data that may have differed greatly from pre-existing research in the area pertaining to the research questions. This is essential to the action research design of the trial in order to analyse differences in responses across time points. Further to this, identifying themes at a latent or interpretative level goes beyond the semantic meaning of the presented data, encouraging interpretative analysis by the researchers. Across the PoC trial locations a protocol (including in person and online training) was put in place to ensure that the TA followed a strict analytical process, with researchers ensuring transparency and consensus across each step. Individual researchers coded transcripts according to an established analysis protocol. Pairs of researchers worked to collapse and categorise codes into themes. Discussions and re-coding workshops took place to ensure agreement on theme and sub-theme names were reached amongst the wider trial site teams. In Ireland, NVivo for Mac (Version 11) by QSR International[3] was used to conduct the coding part of the analysis, while in Belgium MAXQDA Analytics Pro by VERBI GmbH[4] was used. Using different software did not impact on the analysis, as the same methodological approach was used at both sites.

Quantitative questionnaire data was analysed in both trial sites using SPSS V25 statistical software by IBM SPSS Statistics[5]. The primary analysis was to seek to evaluate changes in scores between

[3] https://www.qsrinternational.com/nvivo/home
[4] https://www.maxqda.com/products/maxqda-analytics-pro
[5] https://www.ibm.com/products/spss-statistics

assessment points. Descriptive statistics were used to summarise participant demographic data and general outcomes from questionnaire data. A sensitivity analysis was completed to treat missing data. Missing data was imputed based on the suggested methods for each questionnaire. In case a standardised method was not reported in the literature, mean substitution, using similar imputations for all questionnaires, was used for all time points, if less than 20% of the data was missing. Initial analyses were conducted to assess the distribution of all variables and check relevant assumptions including normality. Given the small sample size at each trial site the majority of variables violated normality. Therefore, to maintain the intrinsic value of the quantitative data in this circumstance, no transformations were performed and for further inferential analysis, non-parametric (Friedman and Wilcoxon signed-Ranks) tests were implemented.

The SIMS component of the ProACT platform supported analysis of additional data (including sensor data from the devices and engagement with the devices and ProACT CareApps). Metrics of interest for analysis include symptom (e.g. blood pressure, blood glucose, SpO2, weight) trends/patterns over time; the ratio of alerts to symptom readings over time; trends/patterns in activity and sleep data over time and engagement with various parts/features of ProACT and the CareApp; responses to self-report questions on health and well-being.

Results

This was a 44 month funded study (2016-2019). The implementation phase was completed in June 2019. In total 120 PwMs (n=60 in Ireland and Belgium) and 73 CN participants (n=43 Ireland and n=30 Belgium) were recruited. Trial outcomes are at various stages in the process towards publication from 2021. We believe that the ProACT platform can potentially improve how older adults with multimorbidity self-manage their health and well-being from home supported by their CN.

Discussion

Across the EU, there is a growing drive to appropriately meet the complex care needs of older people with multimorbidity. eHealth or digital health options are now recognised as a potential support [22]. However, EU healthcare systems are not yet equipped to address the comprehensive care needs of people with multimorbidity [46]. Use of innovative person-centred digital health technologies are increasingly viewed as a means to address the challenge of multimorbid care (e.g. tools to support patients' self-management and multidisciplinary collaboration between professionals [47] may play a key role in advancing the integration of health and social care needs). Despite this, research into the design and development of digital health systems, focused on multimorbidity management, particularly for older adults, is in its infancy.

It is important to re-emphasise the focus of this research is on multimorbidity (multiple co-occurring chronic conditions, but with a focus on multiple conditions) as opposed to comorbidity (multiple co-occurring chronic conditions, but with a focus on a singular condition) [48] and that this research seeks to advance a multi-country understanding of the challenges to defining, designing, implementing and evaluating a digital intervention, focused primarily on multimorbidity management across diverse populations. To our knowledge, ProACT is also the first digital intervention to systematically incorporate (and evaluate) behavioural change and human computer interaction (HCI) methods in order to advance PwM self-management practices in relation to

multimorbidity.

With the mixed methods, action research PoC study of the ProACT platform, we are further addressing the need for increased longitudinal and applied research in the area of digital health, integrated care and multimorbidity management. The two primary aims of ProACT are:

- To explore the potential benefits of technological supports (i.e., the ProACT platform) that aim to improve integrated care and support self-management for older PwMs.
- To get feedback from all relevant participant groups on their experiences using the ProACT platform, and on the potential for the ProACT platform to improve integration of care and support disease management for older PwMs.

Outcomes from trials (to be published) are positive in terms of user engagement with ProACT and a shift in behaviour to adopting this digital intervention. These outcomes will help advance both the state-of-the-art on how to design and conduct research with older PwMs and their CN, as well as deliver a new digital health solution to address the challenge of multimorbidity management and care.

Conclusions

While substantial research has been conducted in the implementation and use of digital health technologies to address single disease management, a clear gap exists in understanding the requirements for managing multimorbidity, from the perspective of older PwMs and their CN and how supported self-management happens in practice. The findings from the ProACT PoC trials will seek to contribute significantly to research in this field. With 120 older PwM and 73 CN participants, the trials have provided a novel multi-stakeholder, multi-country perspective to multimorbidity self-management and integrated care. With a primary focus on qualitative outcomes, the PoC trials have provided detailed insight into the PwMs self-management journey facilitated by a digital health platform, longitudinally over 12 months. Outcomes will evaluate the impact of ProACT at a PoC level to determine whether a larger trial, that makes a definitive assessment of benefit, is warranted.

Acknowledgements

The ProACT project received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement no. 689996. We would like to sincerely thank all of the participants of this research. The authors wish to further thank all consortium partners (see: http://www.proact2020.eu) for the input across project.

Conflicts of Interest

None declared

Abbreviations

AIPS: Aging in Place Aalst (Belgium)
CABIE:
CN: Care Network
CHF: Chronic heart failure
COPD: Chronic obstructive pulmonary disease

CVD: Cardiovascular disease (also termed chronic heart disease/coronary artery disease).
EC: European Commission
EU: European Union
FC: Formal carer
H2020: Horizon 2020
HCP: Healthcare professional
HISC: Home Instead Senior Care
HSE: Health Service Executive (Ireland)
IC: Informal carer
PoC: Proof of Concept
PwM: Person with Multimorbidity
SIMS: Subject Information Management System
T1-4: Time points 1-4 respectively

References

1. Rijken M, Struckmann V, Dyakova M, Melchiorre MG, Rissanen S, van Ginneken E. 2013. ICARE4EU: Improving care of people with multiple chronic conditions in Europe. In Eurohealth 2013;19(3):29-31URL: http://www.icare4eu.org/pdf/icare4eu-improving.pdf [accessed 2020-06-15]

2. Haggerty J. Ordering the chaos for patients with multimorbidity. British Medical Journal (BMJ) 2012;345:e5915. [doi: 10.1136/bmj.e5915] [PMID: 22960377]

3. Starsfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. The Milbank Quarterly 2005;83:457–502. [doi:10.1111/j.1468-0009.2005.00409.x] [PMID: 16202000].
4. Schoen C, Osborn, R. 2019. Commonwealth Fund international health policy survey URL:https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_chartbook_2010_pdf_2010_ihp_survey_chartpack_full_12022010.pdf [accessed 2020-06-27]
5. Banjeree S. Multimorbidity - Older adults need health care that can count past one. The Lancet 2014;385(9968):587-589.[doi:10.1016/S0140-6736(14)61596-8] [PMID: 25468155]
6. Marengoni S, Angelman R, Melis F, Mangialasche A. Karp A, Garmen A, Meinow B, Fratiglioni L. Aging with multimorbidity: a systematic review of the literature. Ageing Research Reviews 2011;10(4): 430-9. [doi:10.1016/j.arr.2011.03.003] [PMID: 21402176]
7. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient education and counselling 2002; 48(2): 177-187. [doi:10.1016/s0738-3991(02)00032-0] [PMID: 12401421]
8. Le Reste JY, Nabbe P, Manceau B, C. Lygidakis, C. Doerr C, Linger H, Czachowski S, Munoz M, Argyiadou S, Claveria A, Le Floch B, Barais M, Bower P, Van Marwikj H, Van Royen P, Lietard C. The European general practice research network presents a comprehensive definition of multimorbidity in family medicine and long term care, following a systematic review of relevant literature. Journal of the American Directors Association 2013;14(5):319-325. [doi:10.1016/j.jamda.2013.01.001] [PMID: 23411065]
9. Stellefson M, Chaney B, Barry A, Chavarria E, Tennent B, Walsh-Childers K, Sriram PS, Zagora J. Web 2.0 Chronic Disease Self-Management for Older Adults: A systematic review. J Med Internet Res 2013;15(2). [doi: 10.2196/jmir.2439]. [PMID: 23410671]

10. Klasnja P, Kendall L, Pratt W, Blondon K. Long-term engagement with health-management technology: A dynamic process in diabetes. AMIA Annual Symposium Proceedings 2015; 756-765. [PMID: 26958211]
11. Ancker JS, O Witteman H, Hafeez B, Provencher T, Van de Graaf M, Wei E. "You get reminded you're a sick person": Personal data tracking and patients with multiple chronic conditions. J Med Internet Res 2015;17(8)e202. [doi: 10.2196/jmir.4209] [PMID: 26290186]
12. Cantor GS. Designing technological interventions for patients with discordant chronic comorbidities and Type-2 diabetes. In CHI Conference on Human Factors in Computing Systems (CHI) Extended Abstracts 2018;1-6. [doi: 10.1145/3170427.3180304]
13. Ongwere T, Cantor G, Ramirez Martin S, Shih PC, Clawson J, Connolly K. Design hotspots for care of discordant chronic comorbidities: patients perspectives. In Proceedings of the 10th Nordic Conference on Human-Computer Interaction (Nordi-CHI) 2018; 571-583. [doi: https://doi.org/10.1145/3240167.3240221]
14. Lim CY , Berry ABL, Hartzler AL, Hirsch T, Carrell DS, Bermet ZA, Ralston JD. Facilitating self-reflection about values and self-care among individuals with chronic conditions. In CHI Conference on Human Factors in Computing Systems (CHI) 2019; 1-12. [doi:10.1145/3290605.3300885]
15. Berry ABL, Lim CY, Hirsch T, Hartzler AL, Kiel LM, Bermet ZA, Ralston JD. Supporting communication about values between people with multiple chronic conditions and their providers. In CHI Conference on Human Factors in Computing Systems (CHI) 2019;1-14. [doi:10.1145/3290605.3300700]
16. Melchiorre MG, Papa R, Rijken M, van Ginneken E, Hujala A, Barbabella F. eHealth in integrated care programs for people with multimorbidity in Europe: Insights from the ICARE4EU project. Health policy 2018; 122: 53-63. [doi: 10.1016/j.healthpol.2017.08.006] [PMID: 28899575]
17. Doyle J, Murphy E, Smith S, Hannigan C, Kuiper J, Jacobs A, Dinsmore J. Addressing medication management challenges for older people with multimorbidities: a multi-stakeholder approach. Pervasive Health: ACM SIGCHI 2017;78-87: [doi: 10.1145/3154862.3154883]
18. Murphy E, Doyle J, Hannigan C, Smith S, Kuiper J, Jacobs A, Hoogerwerf EJ, Desideri L, Fiordelmondo V, Maluccelli L, Brady AM, Dinsmore J. Perceptions and use of technology to support older adults with multiple chronic conditions. Age and Ageing 2017; 242:160-167 [doi: 10.3233/978-1-61499-798-6-160] [PMID: 28873794]
19. Doyle J, Murphy E, Hannigan C, Smith S, Bettencourt Silva J, Dinsmore J. Designing digital goal support systems for multimorbidity self-management - insights from older adults and their care network. PervasiveHealth '18: Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare 2018;166-177. [doi: 10.1145/3240925.3240982]
20. Malavasi M, Fiordelmondo V, Hoogerwerf EJ, Maluccelli L, Desideri L, Doyle J, Dinsmore J. Towards the development of an integrated care platform for frail older adults: setting the technological priorities from a stakeholder perspective. In: Casiddu N., Porfirione C., Monteriù A., Cavallo F. (eds) Ambient Assisted Living. ForItAAL. Springer, Cham 2017;540:198-197. [doi:10.1007/978-3-030-04672-9_12]
21. Doyle J, Murphy E, Kuiper J, Smith S, Hannigan C, Jacobs A, Dinsmore J. Managing multimorbidity: identifying design requirements for a digital self-management tool to support

older adults with multiple chronic conditions. Proceedings of the CHI Conference on Human Factors in Computing Systems 2019;1-14. [doi 10.1145/3290605.3300629]

22. Waterman H, Tillen D, Dickon R, de Koning K. Action research: A systematic review and guidance for assessment. In Health Technology Assessment 2001;5:23. [doi: 10.3310/hta5230] [PMID: 11785749]
23. Lee, MS. How to conduct research for service improvement. A Guidebook for Health and Social Care Professionals. In: Byrne M editor. How to Match Research Designs to Organisational Issues in Health and Social Care. Tullamore: Health Service Excutive; 2014. p18-33.
24. Wood H. Telehealthcare for chronic care - what are we waiting for? HIMSS Europe Insights 2015; 3(2): 26-30.
25. Boren T, Ramey J. Thinking aloud: reconciling theory and practice. IEEE Transactions on Professional Communication 2000;43(3):261-278. [doi:10.1109/47.867942]
26. Bayliss EA, Ellis JL, Steiner JF. Seniors' self-reported multimorbidity captured biopsychosocial factors not incorporated into two other data-based morbidity measures. Journal of Clinical Epidemiology 2009;62(5):550-557. [doi: 10.1016%2Fj.jclinepi.2008.05.002] [PMID: 18757178]
27. Roque NA, Boot WR. A new tool for assessing mobile device proficiency in older adults: the mobile device proficiency questionnaire. Journal of Applied Gerontology. 2018; 37(2):131-156. [doi:10.1177%2F0733464816642582] [PMID: 27255686]
28. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. The montreal cognitive assessment, MoCA: a brief screening tool for mild cognitive impairment. Journal of the American Geriatrics Society 2005;53(4): 695-699. [doi:10.1111/j.1532-5415.2005.53221.x] [PMID: 15817019]
29. EuroQol Research Foundation. 2020. EQ-5D-5L user guide URL: https://euroqol.org/wp-content/uploads/2019/09/EQ-5D-5L-English-User-Guide_version-3.0-Sept-2019-secured.pdf [accessed 2020-06-25]
30. Hyde M, Wiggins RD, Higgs P, Blane DB. A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). In Aging Ment Health 2013;7(3):186-194. [doi:10.1080/1360786031000101157] [PMID: 25847497]
31. Gibbons CJ, Kenning C, Coventry PC, Bee P, Bundy C, Fisher L, Bower P. Development of a multimorbidity illness perceptions scale (MULTIPleS). Plos One 2013;8(12):e81852. [doi:10.1371/journal.pone.0081852] [PMID: 24376504]
32. Schwarzer R, Jerusalem M. Generalized Self-Efficacy Scale. In: Weinman J, Wright S, Johnston M, editors. Measures in Health Psychology: A user's portfolio. Causal and control beliefs. Windsor: UK NFER-NELSON; 1995. p35-37.
33. Walston K, Strudler Wallston B, DeVellis RF. Development of multidimensional health locus of control (MHLC) scale. Health Education Monographs 1978; 6(2):160-170. [doi:10.1177%2F109019817800600107][PMID: 689890]
34. Lubben J. Assessing social networks among elderly populations. Family and Community Health 1998; 11(3): 42-52. [doi:10.1097/00003727-198811000-00008]
35. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. In Acta Psychiatrica Scandinavica 1983; 67(6):361-370. [doi:10.1111/j.1600-0447.1983.tb09716.x] [PMID: 6880820]
36. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh sleep quality index: A new instrument for psychiatric practice and research. In Psychiatry Research 1989;28(2):193-213. [doi:10.1016/0165-1781(89)90047-4] [PMID:2748771]
37. Webster K, Cella D, Yost K. The functional assessment of chronic illness therapy (FACIT) measurement system: properties, applications and interpretation. Health and Quality of Life

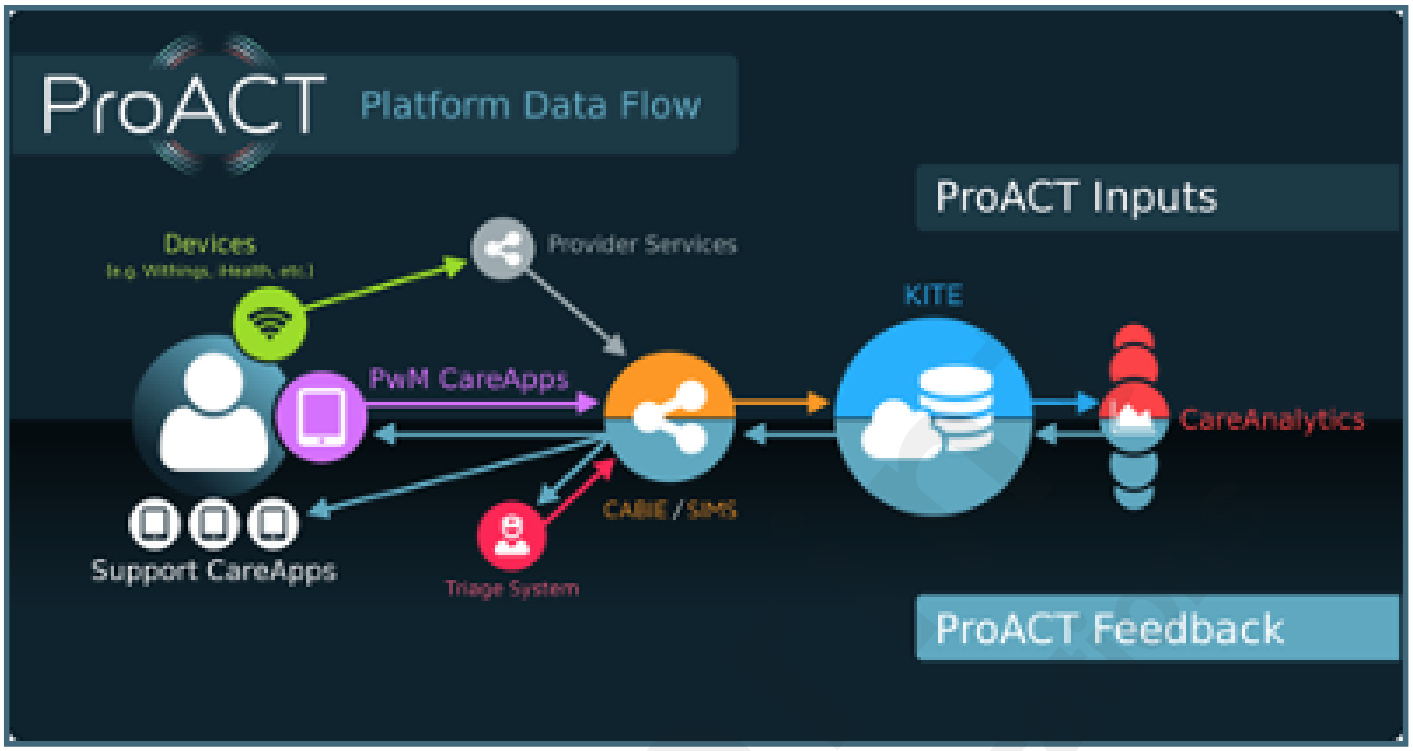
Outcomes 2003; 1:79. [doi:10.1186%2F1477-7525-1-79] [PMID: 14678568]

38. Topolski TD, LoGerfo J, Patrick DL, Williams B, Patrick MB. The rapid assessment of physical activity (RAPA) among older adults. Prev Chronic Dis 2006; 3(4): A118. [PMID: 16978493]
39. Usability.gov. 2020. System Usability Scale (SUS) URL: https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html [accessed 2020-06-25]
40. Suh H, Shahriaree N, Hekler EB, Kientz JA. Developing and validating the user burden scale: A tool for assessing user burden in computing systems. Proceedings of the CHI Conference on Human Factors in Computing Systems 2019; 3988-3999. [doi:10.1145/2858036.2858448]
41. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. Journal of Health and Social Behavior 1983; 24(4):385-396. [doi:10.2307/2136404] [PMID: 6668417]
42. HealthinAging.2020. Caregiver self-assessment questionnaire: How are you? URL: https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire [accessed 2020-06-25]
43. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlated feelings of burden. Gerontologist 1980; 20: 649-655. [doi:10.1093/geront/20.6.649] [PMID: 7203086]
44. Lee EC, Whitehead AL, Jacques RM, Julious SA. The statistical interpretation of pilot trials: should significance thresholds be reconsidered? BMC Medical Research Methodology 2014; (14) 41. [doi:10.1186/1471-2288-14-41] [PMID: 24650044]
45. Braun V, Clarke V. Using thematic analysis in psychology. In Qualitative Research in Psychology 2006; 3(2): 77-101. [doi:10.1191/1478088706qp063oa]
46. Vogeli C, Shields AE, Lee TA, Gibson TB, Marder WD, Weiss KB, Blumenthal D. Multiple chronic conditions: prevalence, health consequences, and implications for quality, care management, and costs. Journal General Internal Medicine 2007; 22(Suppl.3): 391–395. [doi:10.1007/s11606-007-0322-1] [PMID: 18026807]
47. Goodwin N, Dixon A, Anderson G, Wodchis W. 2014. Providing integrated care for older people with complex needs: lessons from seven international case studies URL: http://cdn.basw.co.uk/upload/basw_102418-7.pdf [accessed 2020-06-25]
48. Nicholson K, Makovski TT, Griffith LE, Parminder R, Stranges S, van der Akker M. Multimorbidity and comorbidity revisited: refining concepts for international health research. Journal of Clinical Epidemiology 2019; 105: 142-146. [doi: 10.1016/j.jclinepi.2018.09.008] [PMID: 30253215]

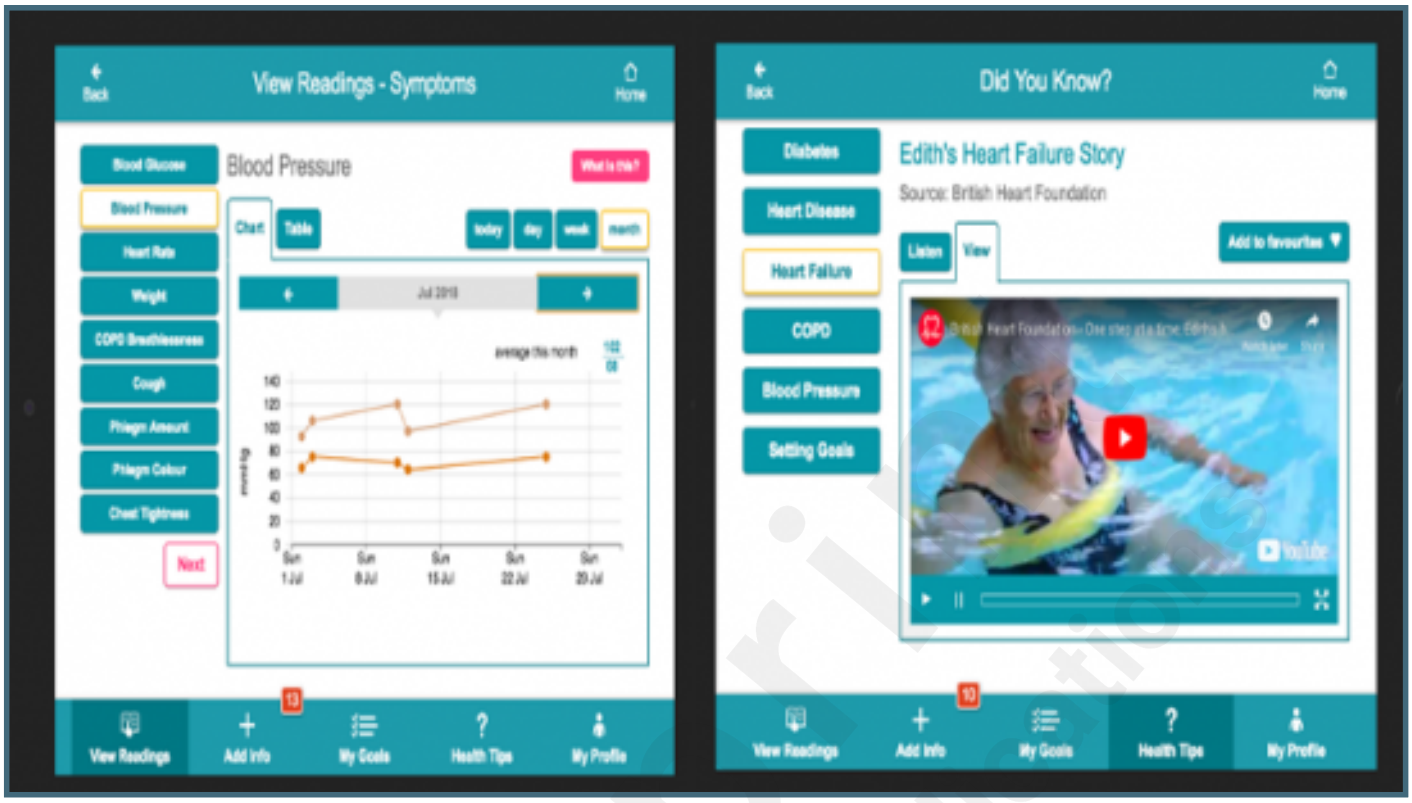
Supplementary Files

Figures

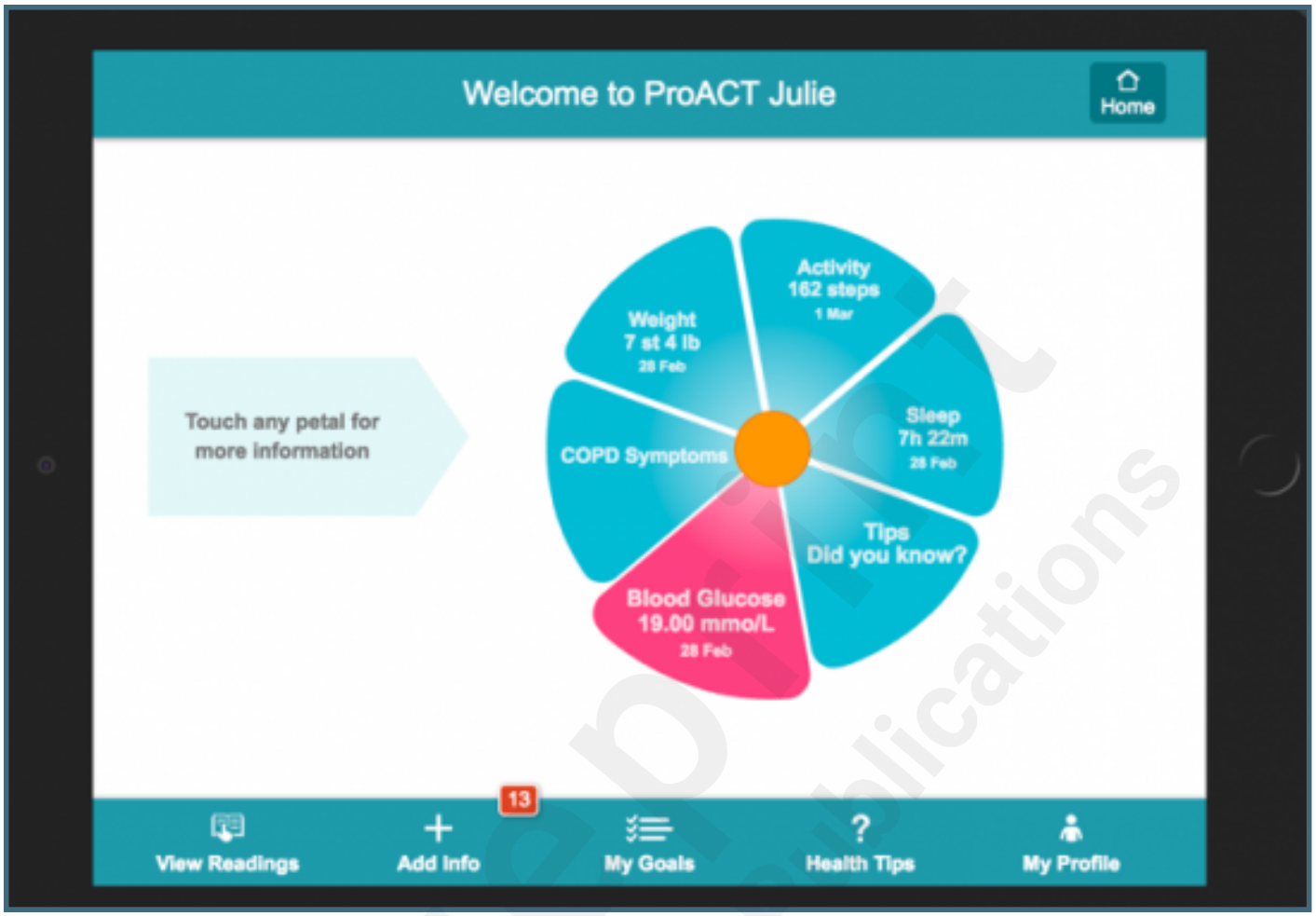
ProACT system overview and data flow.



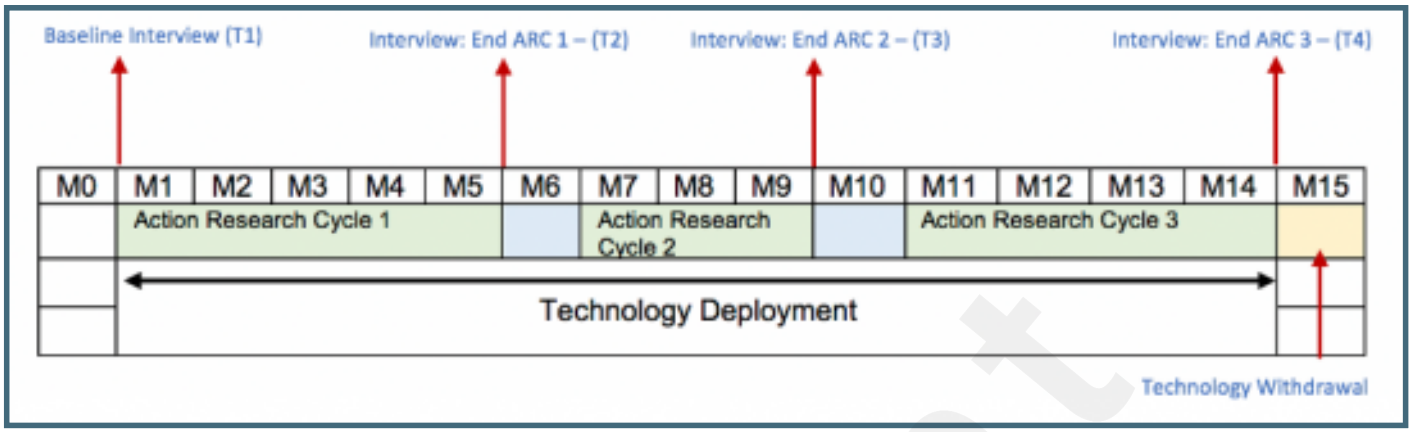
ProACT CareApp View Readings and Did You Know (education) interfaces.



PwM Homescreen User Interface.



Study timeline across action research cycles for PwMs.



Multimedia Appendixes

ProACT Evaluation Summary Report European Commission.
URL: http://asset.jmir.pub/assets/222c24218b72d7d81a796b181b79c87d.pdf

ProACT funding approval and invitation letter - European Commission H2020.
URL: http://asset.jmir.pub/assets/3c104834c432329d97167d41bcbbf5b7.pdf

TOC/Feature image for homepages

ProACT user.

ProACT logo.