Co-Design of a Data Summary Feature with Older Adults as part of a Digital Health Platform to Support Multimorbidity Self-Management

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Abstract. *Background:* The ProACT technology system helps older people living with morbidities (PwMs) to measure symptoms and activities related to their health and well-being, while also allowing them to share this information with their care networks. User centered research has been undertaken as part of the SEURO project to further design the ProACT App with older people, based on findings from a proof-of-concept trial. This paper describes the co-design process used to develop a 'Data Summary' (DS) feature. *Methods:* Participants are PwMs aged $\geq$ 65 years living with $\geq$2 conditions (diabetes, chronic respiratory disease, heart disease/failure). Activity-based workshops took place where PwMs and researchers worked collaboratively to design the DS feature. Interactive activities and guided discussions were inspired by participatory design techniques to promote proactive involvement of participants who may not be familiar with design research. *Findings:* A concise DS displaying a self-selected month of data could help PwMs to communicate key health information to their healthcare professionals, optimising time-constrained appointments. A colour-coded priority list within the DS would highlight important health issues that a PwM could utilise for goal-setting. In conclusion, the rigorous co-design process led to a clear design brief for the new DS feature, guided by 7 individuals who shared their lived experiences of navigating multimorbidity-related health challenges.

Keywords: Multimorbidity, Digital Health, Co-Design, Older Adults.

1 Introduction

An estimated 50 million people in the European Union live with multiple chronic conditions or multimorbidity [1-3], which is typically defined as the presence of two or more chronic conditions in the same individual [4]. For people with multimorbidity (PwMs), services are often inconvenient and burdensome [5-7]. Diminished quality of life is often a result of negotiating burdensome care pathways, as time and energy spent managing multiple conditions reduce their opportunity to engage in social or personal activities [8]. In response, there has been a necessary shift toward flexible and convenient home-based services [9-14], offering an evidence-based alternative to existing services while also reducing the distance of care [15]. One way this has been achieved is through the empowerment of PwMs to use digital health technology to play an active role in the self-management of their health and wellbeing.

In recent years, a small number of researchers have examined how to design digital health for multimorbidity self-management, and older adults in particular [16-19]. These studies showed that it is imperative to consider how such technologies can be designed to deal with the complexities of multimorbidity, as the management of various self-care tasks can be cumbersome. A previous requirements gathering study carried out for the ProACT technology system [20] highlighted that the PwM is often the co-ordinator of their own care, given the lack of integration among healthcare professionals. Thus, it is imperative that the design of a comprehensive digital health platform is centred around the PwM, creating opportunities for them to actively participate in the development process.

1.1 Overview of the design of the ProACT Platform

The ProACT platform- designed, developed and trialled during the ProACT Horizon 2020 (H2020) project[1] aims to ease treatment burden by facilitating a number of complex multimorbidity self-management tasks including symptom monitoring, managing medication, inter-stakeholder communication, information management and coordination. People with more than one chronic health condition sometimes find it difficult to keep track of the different symptoms, medications, and tasks that are needed to manage their health and well-being. PwMs and members of their care network were involved in the design and development process of the first version of the ProACT digital health platform as part of the ProACT H2020 project. This involved an extensive 'requirements gathering' process [20] that included semi-structured interviews and focus groups, co-design workshops, and usability testing. The output of this process was the ProACT platform, consisting of a suite of devices for measuring symptom and wellbeing parameters and the ProACT App for viewing and reflecting on data, answering daily questions, receiving education content, and setting goals [21]. The iterative, user-centred design process aimed to ensure that the user interface and the information it presents were understood by, met the needs of, and fit into the daily lives of older individuals with varying cognitive capacities, health literacy and digital literacy.

Findings from a 12-month proof-of-concept (PoC) trial revealed that the ProACT digital integrated care platform, designed with the complexities of multimorbidity self-management in mind, was engaging and useful [21, 22]. Qualitative findings also revealed that the ProACT platform facilitated perceived improvements in participants' health and wellbeing, self-management, and support [21, 23]. Such a platform may facilitate self-management at home, and also facilitate greater coordination between people with multimorbidity and their care networks in relation to their healthcare; ensuring that healthcare systems become more sustainable and accessible to people with multimorbidity when necessary [24].

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[1] https://cordis.europa.eu/project/id/689996

Extensive feedback was collected during the ProACT H2020 project, resulting in updates and refinements being made to the platform, primarily in terms of aesthetics and navigation. While reviewing videos from usability testing sessions conducted with participants of the trial, it was observed that the majority of participants were reflecting on and making correlations across their various health and wellbeing data visualisations. For example, a participant might notice a high blood pressure reading on the blood pressure-specific section of the ProACT App, and subsequently navigate to other related data visualisations (e.g., heart rate, physical activity, blood oxygen) in an attempt to reflect on multiple data streams. To visualise the various related data, the user was required to switch to multiple new windows within the ProACT App, which added multiple additional steps, increasing the burden and complexity of their health data comparison. In response, a '*My Data Summary*' feature was considered as part of the platform redesign, which is the primary focus of this paper.

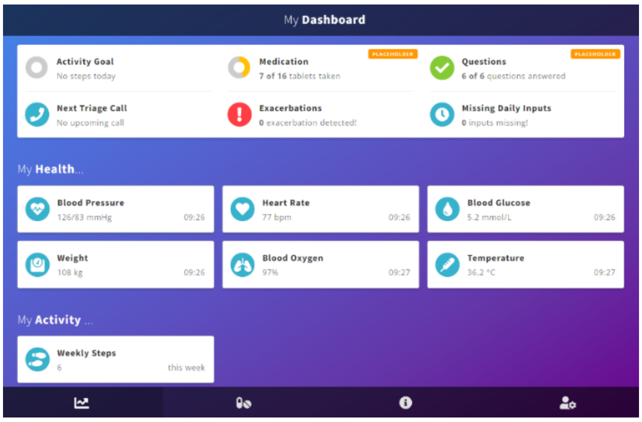

Fig. 1. Example of the ProACT App prototype.

1.2 Data Summary Feature

The '*My Data Summary*' was an additional ProACT App feature that came about through the initial design processes and a review of PoC feedback (Table 1). In essence, the concept of a data summary (DS) feature is to provide PwMs with a monthly overview of their individual health and wellbeing data. It could also support the comparison of trends across a PwMs' different health and well-being parameters and include a series of important and relevant insights to the individual about their health or disease trajectory. This type of digital health innovation aligns well with recent calls for research into data visualisation for chronic disease self-management [25]. This type of research is being highlighted due to the well-documented complexities and challenges of integrating various types and large volumes of data into health self-management technologies [25].

Table 1. Sources of information from ProACT H2020 Project underpinning the design and development of 'Data Summary' feature

Source	Extended Synopsis
Doyle et al, 2019 [20]	*Qualitative Needs Assessment* - DS as a tool for goal setting and health data communication with supporters. - Consider design to support a more informed approach to goal-setting which is guided by the system e.g., contextual summary of previous and current health data. - PwMs also expressed the need for support to ease the burden of managing multimorbidity. Design solutions to provide clear & concise communication of health data to supporters in seek of self-management support is critical.
Doyle et al, 2021 [21]	*Proof-of-Concept Trial* - Participants spent more time checking their vitals than entering data or looking at their Dashboard. The 'View Readings' section (where participants could see an overview of all their health and well-being data) was one of the most frequently visited sections. - Would suggest that in depth review of personal data is important to PwMs, but this appears to require a lot of over-and-back interaction with current app iteration to summarise current health status. - PoC findings in line with existing literature reporting greater PwM self-efficacy due to technology-supported self-management, which enabled improved communication with health care providers. Comprehensive DS could further improve PwMs' autonomy in communicating health data to health care professionals/carers/supporters.
Expert review of recorded usability testing [Unpublished]	*Review of ProACT H2020 Project Collective Outcomes* - Comprehensive view of multiple health data in one place for set time period (e.g., month). - Usability issues identified as part of the review process, that need to be addressed to provide optimal experience to future users. - Important reflection was the lack of flow when PwMs are reviewing their own data. Particularly important for multi-morbidity cohort who must review multiple health measures to ascertain health status. - Lack of integration/summarization of data may add to usability barriers.

As the DS concept was further explored, several design questions were raised such as: what is the best timeframe for a DS (e.g., a weekly or monthly summary)?; how would it be visualised (e.g., through infographics or charts)?; and how would it be shared with care network members if desired (e.g., automatically shared monthly through ProACT App, PwM-initiated sharing via ProACT App, or an additional mechanism to download summary)? As the DS was an entirely new concept for the ProACT App, an extensive co-design process was planned to explore the construction and implementation of this feature.

Given the lack of research on designing a DS for multimorbidity self-management, a first step in this process was to engage a group of affiliated clinical triage nurses who had significant experience in using the ProACT platform to support the care of PwMs during the ProACT H2020 PoC trial, and who themselves regularly visualised multiple streams of data to fulfill their role [23].

The concept of the DS feature was presented to them during some informal group meetings and, in liaison with the study team, a number of important design considerations were developed from these discussions (Figure 2). These discussions formed the basis for the co-design process described in this study, which was used to further explore how these DS requirements might be visualised within the ProACT App, and to further explore DS design considerations from the perspective of the PwM. Lor et al [26] suggest that user-centered participatory approaches should be prioritised for the development of data visualization features, with a focus on which visualization elements work best for the desired population (PwMs) and in which contexts.

Goal - Easily compare trends across parameters and see relevant insights

Will be able to scroll to past summaries - design should be consistent

Highlight good data too - motivates engagmeent

View number and type of alerts over past month

summary should show person's thresholds so they can see how far off they are

Overview of goals set and goals achieved, goals missed

Show engagement levels E.g. you took X BP readings this month, or an average of X readings per week this month

View trends for each parameter over the period (e.g. high, low, average)

View number of alerts compared to previous month. Should this be for all individual health parameters E.g. 2 breathlessness alerts, 3 SpO2), by condition (e.g.4 COPD alerts), or just total alerts?

benefit of feature: should help people to engage with all conditions and not prioritise

Just visualise data for now - look into analysis and recommendations for later. Keep simple and digestible

Fig. 2. Design considerations for DS feature following discussions with triage nursing teams.

1.3 Paper Objective

This paper describes the rigorous co-design process that was conducted to develop a DS feature to support PwM self-management. It outlines the proactive activity-based workshop methods used and describes the resulting design considerations for DS incorporation within future iterations of the ProACT App, and greater ProACT platform.

2 Methods

As the ProACT redesign progressed throughout 2022, co-design workshops were held with a panel of older adults to guide the process. The five workshops were carried out on a monthly basis to allow for an ongoing process of analysis and iterative platform development (May to October 2022). The overarching goal of two of the five workshops was to explore the design of a new DS feature, that had been identified during the review process as being beneficial for inclusion within the optimised ProACT App. A working iteration of the ProACT App (which had been updated since the ProACT project trial) was used as a tangible workshop resource that could be critiqued by participants during workshop activities (Figure 1) - which included placeholders for entirely new developments, such as the DS feature.

2.1 Participants

The workshop participant panel consisted of 7 participants, who between them participated in 5 workshops over a 5-month period. Inclusion criteria for this study were that PwMs were aged 65 or older; were community dwelling; had sufficient cognitive capacity to provide written informed consent; and had at least two of the following conditions: diabetes, chronic respiratory disease (e.g., chronic obstructive pulmonary disease (COPD), asthma), chronic heart failure, chronic heart disease. Sources of recruitment included a *Living Lab* panel, as well as participants from the previous ProACT H2020 trial who had consented to take part in additional research. PwMs were also invited to ask their informal carers if they would like to take part in the study, one of whom attended workshops.

2.2 Data Collection

Activity-based workshops were facilitated in small groups, consistent with recommendations that approximately four to six participants per session is optimum for this type of interactive research [27-29]. Two DkIT researchers facilitated the workshops. Workshops were up to 3 hours in length to allow organic conversations to unfold, which is a well-regarded qualitative research technique [30]. Participants engaged in hands-on activities to stimulate discussion and inspire design ideas (Figure 3) [31]. Techniques used in the activities were derived from multiple interrelated disciplines that have been widely used in digital health platform development, such as participatory design research and user experience design [32, 33].

Fig. 3. Participants engaging in hands-on activities in co-design workshop.

The first activity was centred around discussions of participants' experiences of communicating data with their healthcare professionals. Participants worked in pairs with a fictional PwM profile that had easily identifiable similarities to their own current health situation. Questions were posed to guide the activity using techniques such as memory elicitation (Think about the last time you went to visit a doctor/nurse for one of your own conditions. Do you remember any emotions or physical sensations that were part of this experience? What types of aids do you use in your own visits that help you to communicate with your healthcare professional?) and story completion (Think about the types of goals and self-management tasks this person has to complete on a day-to-day basis? Who are their guiding healthcare professionals? Think about what this person would like to achieve during one of their appointments? What would they need to bring with them? Are there any aids that you use in your own visits that might help you to better communicate with your healthcare professional?). The activity led to broader discussions that provided key information on time interval suggestions for a DS (e.g., weekly, fortnightly, monthly), identifying key information to be presented within the summary and how this might differ between various chronic conditions (i.e., disease-specific, HCP-specific, goal-specific, individual health measures), and how a DS may be used during healthcare professional appointments (e.g., to ameliorate time barriers, improve short/long term recall, improve health literacy on medications and goals/plan).

Activity 2 explored participants' understanding and interpretation of some existing data summary styles (Figure 4), followed by a deconstruction and reimagination of these graphical representations to co-create an appropriate DS feature for the ProACT App (Table 2).

Figure 4. Sample data summaries from various disciplines to inspire co-creation

Table 2. Sample questions to direct co-design of paper-based DS prototypes during activity.

	Timepoint
i	Use the cards on the table (or create your own) to create a bank of health information that would describe your health over the past month.
ii	For each of the data points, how would you know if your progress was good/bad/average?

iii Are there any colours or symbols that would alert you to a positive, negative, or no change in your data?

iv Do any of the data points relate to each other? How would you describe this relationship?

v Take a look at the different ways that the data can be laid out on the summary board e.g., charts, lines, boxes, calendars, icons and images. Using the creative tools on the table add colours, connecting lines, borders and any other details to your summary board.

vi Think about how you would explain your DS board to your GP in 5 minutes?

vii Now consider if there is any information missing from your summary that may have helped you to communicate it more effectively or to review the information more comprehensively at a glance.

The activity was developed with the understanding that participants' comprehension may be impacted by their own health literacy and personal health experiences. It posed questions to the PwM that related more specifically to their own lived experiences, rather than focusing on the complexity of a DS feature construction (e.g., 'Let's go back to thinking about your healthcare visits and the aids that you use to improve your communication', 'A weekly or monthly summary could potentially help you to communicate and could also help you to personally keep track of your own goals and health plan for the future', 'Take a look at these examples of summaries - at a first glance, do any of these summaries stand out to you? What do you like or dislike about it? What would you change about it? What types of information might you want to see here?').

Each of these examples are thorough in the data and details they present, but co-designing a contemporary DS feature based on reflections from PwMs' own lived experiences is an integral part of the research process. The following types of rhetoric were used to introduce this next stage of the task: "People in your position have been called 'experts of their experiences' [34] and your input can ensure ProACT caters to your priorities and the priorities of people like you. So, let's leverage your knowledge, experiences, and insights to design a DS tool. It can be as simplistic or as complicated as you like. There is no right or wrong way to summarise the information that is important to you.".

Activities 3 and 4 were conducted as part of the second DS workshop, acting as a type of member checking session and to ensure all design recommendations had been taken into consideration. The session started with a group reflection on drafted prototypes of the DS Feature based on the previous workshop (Data Summary I). PwMs were presented with a static DS prototype and researcher-interpreted action points related to their feedback from the first workshop were communicated. A detailed discussion was then encouraged- based on how PwM input was translated into prototype designs, which facilitated member checking of researcher interpretation and captured honest feedback from PwMs by creating an opportunity for them to ask more questions and push DS ideas further.

PwMs subsequently engaged in a role-playing activity. The main goal of prototyping is to make an idea just tangible enough to elicit a response from the PwMs. In role playing, participants imagine that they are interacting with others within a particular situation, while using the prototype data summary as a conversation starter. This method can help researchers to gauge participants' understanding of a new design feature as they describe the prototype aloud to another person. It also helped to identify gaps in the DS design feature, where the simple addition of ‘helper text’ or icons could optimise the use of the feature. For example, where a participant is attempting to explain an aspect of their DS aloud, researchers can use this activity to gauge the level of data interpretation required within the ProACT App to ensure that the summary is of use to the individual, or how to best label DS components for participants with varying levels of digital health literacy.

2.3 Data Analysis

As each workshop was completed, an annotated transcription of audio recorded data was collected for analysis. Between workshops, an expert panel of two researchers and two technology developers met to collaboratively review workshop data and draw on-going design and development conclusions in a timely manner [35].

A ‘live’ content analysis of qualitative workshop datasets was conducted, where workshop data were utilised to make solution-focused decisions in a short time period. The ongoing iterative process of analysis and design is typically facilitated to ensure that PwMs’ needs are being met through member-checking in follow-up workshops.

A summative content analysis was used for coding and categorisation of the data from the workshops. This consists of a combined manifest and latent approach. Manifest content analysis focuses on the words themselves and offers surface-level descriptions of workshop discussions/notes- which allowed researchers to quickly highlight key areas of interest for App development and refinement. For example, the number of times the word “personalisation” (or related synonyms) appears within the text would dictate whether this was a core category that required a design action for the DS feature. Following on from this, the context in which the words presented themselves in discussion (latent analysis) were used as a guide for researchers and technology developers to further consider appropriate development solutions during collaborative meetings. A deductive or ‘top down’ approach was used for analysis, centred around design expectations determined following the ProACT trial such as: what the timeframe would be within the feature; how it would be visualised; and how it would be shared with care network members if desired. However, it is important to note that the analysis process is not limited by predetermined categories, as the nature of co-design data collection methods (i.e., activity-based workshops) allow for open discussions which are inductive, unexpected, and guided by the participants themselves.

2.4 Ethics

Ethical approval for this co-design process was received from the School of Health and Science at DkIT.

3 Findings & Discussion

Six PwMs and one informal carer formed the workshop participant group (71% Male, Age Range 73-79 years). This study resulted in a preliminary design of the '*My Data Summary*' feature. Design recommendations from the first dedicated workshop (Data Summary I) were included in the preliminary analysis and visual protypes were produced based on PwM feedback to facilitate the follow up workshop (Data summary II). Valuable input was provided by participants as to how the DS should look, what information it should present, and how this information might be used by an individual. The following sections present findings from the workshops and discuss some of the contextual uses offered by PwM participants for a DS feature.

3.1 Visualisation of a Data Summary

Participants were not drawn to overly complex infographics or line charts. However, they noted, where there is a necessity for multiple pieces of information or extra detail- providing 'something' concrete to help them to understand their monthly summary at a glance would be preferred. These indicators could be simple icons or short text so that the PwM knows what they are looking at immediately. For example, one participant mentioned that the words 'poor' and 'room for improvement' on a sample design "struck me immediately". Despite the negative connotations, the participant valued the interpretation. This is consistent with literature which suggests that improving PwMs' interpretive capacity of their health data may lead to improved motivation [36].

Participants also mentioned the potential benefit of including an overall monthly health score incorporating all of their health data relating to their multimorbidity. Similar to the body mass index (BMI) scale, which takes a person's height and weight into account and creates an overall score- participants questioned whether this is something that could be considered for a multimorbidity-focused DS feature. This type of numeric health data summarization is well-researched in the management chronic conditions and risk factors amongst older people [37-39], whereby the modelling of various health data information is to produce a single 'score'. Research suggests that these scores could be utilised to improve communication and shared decision-making between PwMs and their healthcare professionals [37].

Participants did not feel that a graph-style summary was the best approach- adding that if a graph was chosen as the medium for the DS, then it should be goal-oriented and "specific to the person". This aligns with a recent systematic review of health data visualisation [26] which suggests that, with a multitude of creative digital tools and software available in the digital health space, the design and dissemination of data visualization features should extend beyond the typical bar graphs and line graphs etc.

One participant explained that personalisation using individual goals and personal thresholds are vital for a DS to work (e.g., 10,000 steps is a global recommendation, but 5,000 steps is my own personal goal). The participant added that "there's no point in telling me that I am obese. I am obese and if you give me an [impersonalised] chart I'm always going to be obese… but if you give me something that recorded my current weight and gave me a target of 10% to lose then I could be very positive moving from

[from one data summary to another] by 5-10%. Instead of hitting me with the ‘Boom’… the negative”. In a simpler form, using an icon or colour to indicate where the PwM is at in terms of their own monthly health data or personal goal was perceived as helpful- especially if there is some indication of what “you’re aiming for” (e.g., inclusion of personal goal or optimal reading).

Too much information is hard to read and can be complicated to interpret at first [“You want it to be simple”], but clear signposting could alleviate this. For example, participants liked the use of a traffic light system and a simple icon (e.g., dot, star, checkmark) to pinpoint where they fall on the colour chart, line or grid (Figure 5). These findings are consistent with research that describes the data interpretation support required by PwMs who are self-managing their conditions [40]. A content analysis identified interrelated skills that make-up and define a person’s health literacy level, including the filtering, interpretation and evaluation of health information, and subsequent engagement in informed health-related decision making [40]. People living with chronic conditions, who have lower health literacy, could achieve better levels of informed self-care if supportive technology functionalities, such as the ProACT DS feature, were made available to them for self-evaluation [40, 42].

Participants also mentioned that the colour red could signify danger to those who are managing life-threatening conditions. For one participant, red is “a bit triggering, a very worrying colour… y’know, red is danger”, asking his co-participant who was admiring the traffic light system “but what about if it was red?!”. To which she reacted negatively and agreed with him. Further group discussions led to the potential for a two-colour traffic light system (Figure 5) that could incorporate amber (room for improvement) and green (good) on a scale.

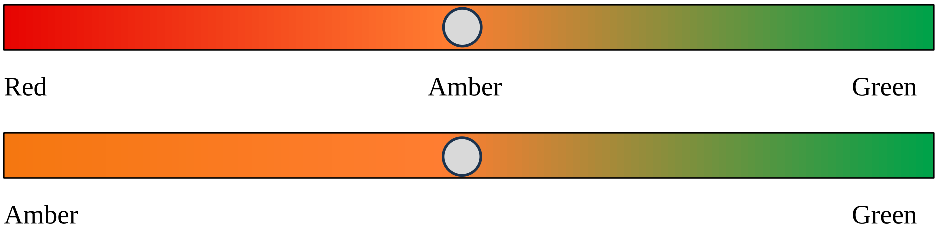

Figure 5. Variations of potential ‘traffic light system’ use in DS feature

There was an overall feeling from participants and researchers alike, that a certain “balance” is required, whereby a true summary of monthly data is provided to a PwM but with a level of appropriateness that does not alarm the reader. If a PwM’s monthly DS is showing health data that is less than optimal for them as an individual, participants agree that this needs to be communicated via the ProACT App. On the other hand, there is an undercurrent of “anxiety” or “danger” that must be acknowledged in the presentation of less-than-optimal readings within a summary. A DS feature can be both informative and “stress-inducing” for the PwM and their care network. Participants emphasized that information presented within a monthly summary should act as “encouragement”. Even if data is not ideal, the data should be “descriptive” rather than disheartening for PwM: “You need ‘encouragement”; “[PwMs] want to improve themselves”. Similarly, when presenting a month of multiple health data points, participants highlighted the importance of keeping successes in mind, to keep them focused and motivated. If multiple data points have been below thresholds or expectations over a month, this could affect PwM’s subsequent performance and stress levels: “The only trouble with all this, is if you are going downhill, it highlights it for you too, doesn’t it?”; “It does, but you don’t want to know”; “ You want to think you’re going to be feeling better next month”; “Yes, Yes!” Participants shared the potential negative impact that looking at a summary of multiple bad health data may have, “I’m talking about if everything is going downhill and no matter what I do y’know… I’ve now got my weight right, and my exercise is good, but the blood pressure is still going sky high. Certainly, I want to know in the current situation anything that’s wrong”.

Furthermore, having explored a range of structures (e.g., pie charts, imagery, infographics, line graphs), a list format that provides a monthly overview of a PwM’s health and wellbeing information at a glance was preferred. Participants felt that the DS design should include a type of hierarchal structure that draws the eye to important self-management behaviours that need attention or improvement. This is consistent with existing research reporting that older PwMs will prioritise their health problems which are of immediate concern, uncontrolled, or at risk of restricting their usual activities [43].

Through variations in colour (e.g., amber, green), icons (e.g., tick, exclamation mark) and basic data interpretation (e.g., comparisons with previous month over national averages), participants felt that the data summary feature could trigger important questions (e.g., ‘What am I already achieving and what do I need to improve on next?’) to further improve self-reflection and personal goal setting (discussed further in section 3.2). For example, should a PwM’s blood pressure be maintained well over the course of a month (within normal threshold ranges, measure taken regularly), their DS would place this information further down the list i.e., little to no attention needed. However, if this individual’s blood glucose levels were regularly outside of recommended thresholds, or readings were taken sporadically throughout the month, this health measure would be placed further up the DS list to highlight it as needing more attention.

By identifying important relationships and trends within their DS (e.g., higher self-reported anxiety throughout the month could relate to lower levels of physical activity, which may affect blood pressure or weight trends), a PwM can begin to better understand their own health and wellbeing profile which could lead to optimised goal setting and better self-management of their symptoms.

Feedback

What is the aim of the data summary and how can it help people to take action? Printing summary for appointments could be helpful.

Feedback

'Just the same', 'Not as good', 'On the way to normal'? What kind of language can we use to put the month into context?

Feedback

Simple and easy to read summary. No need for infographics and diagrams. Clear, list-style data summary that can be easily comprehended by PwM and could be communicated if needed.

Feedback

Would be beneficial to able to select month (30 days) from a specific date? e.g., 03 June to 03 July, 28 Nov to 28 Dec

Feedback

Should most problematic measures of the month be highlighted first in the data summary? Would this help with future goal setting?

Feedback

Using ranges may help with interpretation of measures without contradicting medical advice. Can be applied to daily alert system or used within data summary.

Figure 6. Static DS prototype presented back to participants for discussion during follow-up DS workshop. Subject of discussion during activities 3 and 4 (see section 2.2 for detail).

3.2 Contextualising the use of a Data Summary

PwMs presented a multitude of uses for a DS feature within the ProACT App, three of which are presented below. Contexts for utilising a DS were both personal and as a communicative tool during interactions with healthcare professionals. A DS would provide a true representation of the individual PwM's health data and honest reflection of their disease or health trajectory. It could also act as a helpful preparatory tool for healthcare appointments, focusing topics for discussion in a time-sensitive scenario and providing a visible resource to prompt conversation. Furthermore, a primary objective of the ProACT platform, designed with the complexities of multimorbidity in mind, is optimised PwM self-management at home. A DS was highlighted by participants as a fundamental feature that could contribute to improved self-management behaviours and informed goal setting practices.

Participants valued the idea of a monthly DS for personal use, with selectable dates to coincide with healthcare appointments. They suggested that a DS representing a "running month", would be more helpful than a representation of a "month start to end". One participant provided context to this thinking, stating that: "If I have an appointment with the diabetes doctor tomorrow, I don't want to be writing up the last 13 days of data". Participants also provided important evidence to support the use of a monthly DS, as opposed to a short-term weekly or two-weekly summaries. They felt that the existing ProACT App provided useful daily representations of their individual data that would alert them to major health changes, however, it is the appearing patterns and trajectories that they felt were the primary focus of the DS: "The data summary would give a more precise reading of how the blood pressure has been. If you do it over [time] there's a pattern appearing". Another method used by healthcare professionals to capture health data patterns is ambulatory blood pressure monitoring, where the PwM would wear an automatic cuff for a 24- or 48-hour period. However, research indicates that participants are more accepting of and prefer home-based monitoring in comparison to ambulatory blood pressure monitoring [44]. Therefore, the use of a DS feature that permits PwMs to display longitudinal patterns of various health data using home-based technology devices could be a superior approach.

As mentioned previously (Section 3.1) participants were discussing the use of the colour red as stress-inducing. This also prompted a discussion about the contextual use of the feature, as one participant remarked that the use of red within daily summaries would hypothetically mean that you may be in "danger" one day, but this can be alleviated the next day. It was important to participants to note that the monthly DS would give them a better overview of "where you are" with regards to your self-management: "I ended up in hospital because I didn't manage [my data] for a month. The readings were a bit high, and I thought 'Ah I'll leave that for a month, and I'll come back to it' and I ended up in hospital". More simply put, participants valued the comprehensive and broad nature of the DS, describing it as "This is me in a month!".

Through the participants' labelling of the DS feature as "me in a month", it also emerged that there was a level of transparency that could be provided by presenting this summary to a healthcare professional. As opposed to depending on a single reading or an inaccurate recollection of progress, a month in review via the DS could improve the transparency of PwMs' actual progress and increase their accountability. When the researcher asked participants to consider a hypothetical situation where they had taken 2-3 blood pressure readings during the week that were 'high', participants unanimously agreed that they would not communicate this to the healthcare professional during a subsequent appointment and simply rely on the reading taken by the healthcare professional. However, participants jovially acknowledged that this was not the best use of their home-based self-management efforts; referring to the barriers associated with 'white coat syndrome' and its effect on health measure accuracy during healthcare appointments. One participant suggested that one high reading taken by a healthcare professional at an appointment could be elevated and "not represent the everyday" readings- potentially skewing treatment decisions and there could be "some alarm bells" set off unnecessarily. They compared this to the benefits of using the DS feature, which would represent a months' worth of integrated health readings, giving a truer representation of the individual and their health trajectory.

Participants also valued the DS feature as a comprehensive tool that could be used to prepare for healthcare appointments. The month in review could assist PwMs to navigate the complex skill of communicating key health concerns to healthcare professionals or people in their care network- which could optimise PwMs' use of time constrained healthcare appointments and also improve their self-advocacy skills. When talking about current self-management behaviours, a participant shared that he "would have brought my [blood glucose] readings for the last few months with me. She [diabetes specialist] does look at them". However, he also added that this written documentation can be cumbersome, can be missing data, and is also not easily accessible to the healthcare professional during appointments as there are no summaries drawn on the plethora of individual readings. Another participant agreed with this sentiment of preparing information before appointments, sharing that "the last time I went in I had just one or two issues, but in case I forgot them, I wrote them down… for recall". However, this participant also shared her existing concerns of attending appointments without something "concrete" to present to the healthcare professional, referring to the potential benefits of having an easily accessible monthly DS that can be shared with others. She also emphasized the pressure felt to have her personal health data ready at a minute's notice for unexpected appointments- stressing that she cannot always prepare her data in advance for a visit: "I'd only go [to the healthcare professional] literally when I have to… I have been both regularly and irregularly [attending healthcare professionals] depending on how my [health] was. If I was going through a bad time, a very important point for me is, I have to be seen [immediately]".

Furthermore, participants highlighted the time and resource barriers that limit the type of care they receive during healthcare appointments. In particular, lack of communication between healthcare professionals of different specialties: "If you went in to have your nose looked after, they look after your nose, but that's all."; "They don't communicate. Even going back years ago you had a general consultant come in and they dealt with everything. Where now, they're only dealing with a specific area of your [health]". Participants felt that the integration of wide-ranging health information within a DS feature, and the representation of them as a holistic PwM, could help to overcome some of these barriers. Their experience is that healthcare professionals who ask about other symptoms or are interested in reviewing general health data presented to them by the PwM (not specific to one condition only) are of significant help to the individual; directing them to other consultant types or educating them on what to look out for which improves home-based self-management: "He might say to me, you've a few things going on. They're aware of it"; "My [healthcare professional] will pick up on it [health data that is slightly off] and send me… somewhere different".

Participants emphasized that an accessible DS feature that helps PwMs to visualise "priority" health data could guide their self-management behaviours and subsequently assist them with personal goal setting. Existing literature echoes this sentiment- recognising the competing demands of each condition for a PwM and how they are tasked with prioritising their most significant health concerns so as to inform self-management decisions [45]. Participants noted the potential of using a personalised DS feature to help them to better focus their self-management practices in the coming weeks, as it would assist them with making informed correlations across their various health and wellbeing data. They felt that a truly comprehensive DS should certainly highlight the areas that need work for the PwM.

Participants shared the importance of goal setting and using all resources available to them to remain active in their self-management behaviours despite the endless distractions that life brings. They discussed "life getting in the way" and how this can lead to certain health behaviours being abandoned: "It's not just that someone is bad at taking their [health] readings, it's that you can get [life] interruptions… trying to manage this and this and this, so rather than doing it all 'badly' you just abandon one and do one well, quite well". When thinking about monthly planning, participants argued for a DS feature that could be used to guide their focus towards the health measure(s) that are not being well managed, based on a summary of data from the previous month. These findings are consistent with the concept that decision-making amongst PwMs is grounded in the personal and social context of an individual's life [45], and that PwMs will take variable levels of control of their morbidities in order to live as normally as possible [45, 46].

4 Conclusion

This paper reports on the design of the '*My Data Summary*', as part of a larger digital integrated care platform providing self-management support for those living with multiple chronic conditions. This rigorous co-design process led to a clear and concise design brief for such a feature, led by 7 individuals who shared their lived experiences of navigating these particular health challenges. This paper presents the creative methods used to actively engage PwMs and informal carers in the process. It also discusses contextual considerations around proposed design choices and collaborative decision-making throughout the process.

5 Acknowledgements

This work was carried out as part of the SEURO project which received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement no. 945449. We would like to extend our gratitude to the 7 participants who dedicated an extensive amount of their valuable time to the redesign and further development of the ProACT App.

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