An Exploration of Engagement and Collaboration between Healthcare Professionals and Older Adults with Multimorbidity using a Digital Health Platform

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Abstract. Multimorbidity, the occurrence of two or more chronic conditions in an individual, is a significant global health issue. It requires individuals to engage in complex self-management. It is understood that support from a care network, including healthcare professionals (HCPs), is crucial and can motivate adherence to self-management, act as an enabler to effective self-management and guide and reassure the person. However, people with multimorbidity (PwMs) often report challenges in their relationships with HCPs. Digital health technologies have potential to facilitate PwMs to share responsibility in their care by equipping them with the tools to better self-manage and to collaborate with their HCPs. This paper reports on findings from 60 PwM and 16 HCP participants who took part in the ProACT trial, whereby PwMs used the platform for a period of 12 months. Semi-structured interviews with participants resulted in four themes relating to engagement and collaboration in care, including HCP Scenarios of Engagement; The PwM Becoming a Collaborator in their Care; The Utility of Data; and Towards Integration of Care – Benefits and Challenges.

Keywords: Older adults, self-management, multimorbidity, healthcare professionals, digital health.

1 Introduction

Multimorbidity, the occurrence of two or more chronic conditions in an individual, is a significant global health issue [1]. A recent systematic review estimates that the global prevalence rate of multimorbidity is 37.2%, with the highest prevalence in South America (45.7%), followed by North America (43.1%), Europe (39.2%) and Asia (35%) [2]. It is estimated that 50 million people in the European Union (EU) live with multimorbidity [3]. Further, more than half the global population of people aged 60 and over have multiple chronic conditions [3] and ageing populations are expected to worsen this scenario. However, multimorbidity is not solely an ageing problem with prevalence rates rising in younger populations across both high-income countries and low- and middle- income countries [1]. It is unsurprising therefore that countries globally face strong concerns over the sustainability of health services due to the increase in healthcare expenditure, as well as disparities in the number of practicing health professionals [4]. In the EU, 70-80% of healthcare costs are spent on chronic diseases, which corresponds to €700 billion [3].

There are significant challenges for people living with and managing multimorbidity. Multimorbidity is associated with high mortality rates, increased healthcare utilization and increased healthcare expenditure. Healthcare services are often repetitive (multiple appointments), inconvenient, inefficient (patients may see different clinicians who give conflicting advice), burdensome and potentially unsafe due to poorly integrated and coordinated care [5, 6]. In addition, people with multiple conditions may take many medications, which can be difficult to remember with some combinations potentially dangerous. These issues compound and significantly impact on reducing quality of life.

Many of these challenges occur because healthcare systems and clinical practice guidelines focus on a single disease model of care [7, 8], which are not appropriate to adequately manage the complexity of multimorbid care. People with multimorbidity therefore must navigate complex ecosystems of care, often seeing multiple different specialists and doctors for their different conditions. The lack of integration and communication amongst different providers results in fragmentation and disruption of care [9]. People with multimorbidity also often face challenges in their relationships with their healthcare professionals, which can negatively impact self-management efforts [10 – 12]. There is a need, therefore, to improve best practice around the provision of continued, well-coordinated, person-centred integrated care ecosystems for individuals with multimorbidity. Digital health solutions hold great potential to fulfill this need.

With this in mind, the ProACT Horizon2020 project[1] aimed to co-design, develop and evaluate the ProACT digital health platform with older PwMs and those who care for them. The platform was evaluated in a 12-month proof-of-concept trial in both Ireland and Belgium with 120 PwMs aged 65 or over and members of their care networks, including healthcare professionals (HCPs), informal and formal carers. This paper presents findings from 60 PwMs and 16 HCPs who took part in the Irish trial.

1.1 The ProACT Digital Health Platform

The platform supports PwMs in self-management of their multiple chronic conditions [13]. It was designed following an extensive requirements gathering and co-design process involving PwMs, informal carers (ICs), formal (paid) carers (FCs) and HCPs [14]. It has been initially designed to support those with diabetes, Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Disease (CHD) and Chronic Heart Failure (CHF), however the platform is flexible and new conditions can be easily integrated. From the PwM's point of view, the platform consists of sensing devices for measuring symptom and wellbeing parameters and a Health and Wellbeing application (Figure 1).

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

All PwMs received a tablet device with the application, a blood pressure monitor, weight scales and a watch to monitor activity and sleep. Those with diabetes received a blood glucometer and those with COPD received a pulse oximeter. Some symptoms (for example breathlessness, sputum) as well as wellbeing parameters (mood, social activity) were measured through self-reporting in the application. The PwM application had the following features:

Health and wellbeing monitoring: A dashboard with a quick-glance overview of current status (Figure 1). Blue petals indicate that the data is within the person's personalised normal range (as set in collaboration with a nurse), a pink and slightly larger petal indicates that data is outside this normal range, while an orange petal highlights missing data (e.g. no data for a particular parameter received within the last five days). The logic behind the dashboard in terms of what is displayed ensures that if a condition is not being monitored, it is brought to the PwM's attention. This could be a prompt or alert to monitor symptoms relating to that condition and/or educational content being pushed to them. Simultaneously, highlighting the areas that need attention can reduce the complexity and the time burden of self-management [15]. The View Readings section of the app provided more detailed historical information on data trends over time for all parameters being monitored (Figure 1(a)).

Education: Research has highlighted that lack of information is a significant barrier to both effective self-management and to motivation to engage in self-management actions [14]. Within the Health Tips section of the application there are two categories of content: 'Did you know?' contains educational content relevant to self-management of specific conditions and wellbeing; 'How do I?' contains custom-made video training content on how to use the devices and the application. Educational information for each disease was sourced from reputable sources known to PwMs. Where possible, content was delivered in three modalities, (video, audio and text) to cater for differences in learning styles and accessibility.

Personal activity goals: PwMs could set their own physical activity goals (e.g., steps / distance / time spent walking) and review progress. Messages and prompts were used to help PwMs in setting achievable and incremental goals. If a goal was not achieved, the user could provide context by choosing a reason from a pre-defined list (for example, they were unwell this week). As an alternative to setting their own goal, an analytic within the platform would recommend a realistic goal, based on the PwM's most recent activity data but within physical activity guidelines for older adults and adults with chronic conditions [16] to avoid giving major leaps in recommendations. The user could choose whether to accept the platform goal or determine their own.

Add a Care Network: PwMs could choose whom, within their care network, can support and contribute to their digital self-management. Within the application, the PwM could add someone to their network and choose what data to share with them.

Applications were also designed and built for care network stakeholders, including HCPs, informal and formal carers to enable them to view PwM data. The dashboards of these applications were slightly different to the PwM dashboard, showing a four-square two by two grid highlighting four key pieces of data. All stakeholders had access to the 'How Do I?' education on how to use the application.

Figure 1 – (a) Application Dashboard showing current health and wellbeing status. Pink petals indicate a reading is outside a person's personalised range, orange indicates a reading hasn't been taken for a period of 5 days or more, while a blue petal indicates that all is ok (for symptoms) and acts as a quick link to another part of the platform; (b) Users can view historical readings by day, week or month in graph or table format

2 Methods

The study was a 12-month proof of concept (PoC) trial, which employed an action research design, to allow for continuous feedback from PwM participants and refinement of the platform throughout the trial. There were three action research cycles (ARCs) across the trial. Data collection from PwM participants was aligned with the end of each ARC, apart from ARC 1 where data was collected at the beginning of the ARC (T1 - which marked the start of the trial) and the end of the ARC (T2). T3 data collection took place at the end of ARC 2, while T4 data collection took place at the end of ARC 3. HCPs participated in an interview or focus group at T4. The study design incorporated a mixed methods approach across the ARCs. Ethical approval for the study was received from three research ethics committees, including two university committees and one health service committee. The full trial protocol has been published elsewhere [17].

2.1 Participant Recruitment

PwMs In total, 60 PwMs consented to take part. Inclusion criteria were that the participant was 65 or over and had two or more of the chronic conditions of interest (see Section 1.1). Participants were recruited through several channels, including social groups for older adults (n=11); diabetes and COPD support groups (n=5); social media, radio and local newspaper advertising (n=18); a formal care organisation (n=17); HCPs and pharmacists (n=8). One participant was also recruited following a referral from another trial participant. By the end of the trial, 8 participants had withdrawn, while 3 had passed away.

HCPs HCP participants were nominated by PwM participants. Following nomination, the research team contacted the nominated HCP to go through the details in the participant information leaflet and consent form. If the nominated HCP expressed a wish to be involved in the trial, a consent form and information leaflet were sent to them either via email or post.

2.2 Procedures

PwMs who consented to participate were visited at their homes on two occasions at the start of the trial, to deploy the technology (see section 1.1), provide training and conduct the first phase of T1 data collection. In addition to the training content within the application, participants were provided with a paper-based training manual. Throughout the trial, a clinical triage nursing team monitored the symptom data. Within one to two days of deployment, triage nurses called each participant to introduce themselves and further explain their role. Throughout the trial, the nursing team monitored for any alerts in the data, refined alert thresholds in collaboration with individual participants and scheduled a monthly check-in call. HCP participants who consented to take part were provided with login details to the application, typically via email or phone. Data was available to all participants in close to real-time (i.e. within one to two minutes) from time of entry by the PwM.

2.3 Data Collection and Analysis

For PwM participants there were four time points in the trial. Members of the research team conducted data collection, including questionnaires and semi-structured interviews at each time point, which coincided with the end of each ARC. All data collection took place at the participants' homes. HCP participants completed a demographic questionnaire on entry into the study and took part in a semi-structured interview or focus group at the end of the study period at their place of work.

All interviews and focus groups were audio recorded and transcribed verbatim. Transcripts were loaded in NVivo for qualitative analysis.

Engagement data was logged automatically through the platform. For PwM participants this included the date and time of symptom or wellbeing data being input (either through a digital device or through self-report) as well as how often participants engaged with different sections of the application. For HCP participants, the number of days a participant logged into their app was recorded.

Qualitative interview data underwent inductive Thematic Analysis (TA) to construct relevant themes [18]. 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. NVivo for Mac (Version 11) by QSR International was used to conduct the coding part of the analysis.

3 Findings

This section presents participant demographics, participants' objective engagement with the platform and findings from the thematic analysis. Four themes were constructed from the qualitative data and are presented below. Quotation attributions throughout the findings section are structured as (participant id, gender, age, condition profile, timepoint).

3.1 Participants

Sixty PwMs consented to take part in the trial. PwM participants ranged in age from 65 to 92 years (mean age 74.23 ± 6.4). Sixty percent (n=36) were male. Ninety seven percent (n=57) had two of the included chronic conditions, while three percent had three conditions.

Twenty PwM participants invited thirty-one HCPs to join their care network, of whom sixteen agreed to take part. The HCP average age was 48 years with females dominating by 70%. The average number of years of experience in their role was 16 years. There was a mix of professional backgrounds, including three General Practitioners (GPs), two diabetes clinical nurse specialists (CNS), one respiratory CNS, two respiratory consultants, two physiotherapists, three heart failure CNS's, one cardiologist consultant and two pharmacists. The environment of work was mainly acute hospital and GP practice. One HCP was working in the community in pharmacy and a physiotherapist was doing home visits to some patients. The duration of work experience with people with multimorbidity varied from substantial experience (89%) to some experience (11%).

3.2 Objective Engagement with the Platform

Detailed analysis of PwM engagement with the ProACT platform has been described elsewhere [13, 19]. In summary, the majority of PwM participants remained engaged with the trial, with three participants passing away and 8 withdrawing. PwMs took on average of 2 readings from the various sensing devices each day and there was an average of 40 participants taking daily readings throughout the trial.

Logged data from engagement with the HCP CareApp indicated that there were logins from HCPs on 24 days during the trial (out of a total of approximately 250 possible days due to HCPs being onboarded later than PwM participants). The next subsection indicates scenarios of engagement for HCPs.

3.3 Themes

HCP Scenarios of Engagement

HCPs reported a range of reasons for consenting to participate in the trial, including an interest in seeing how the technology could help people self-manage, how it could enhance care, and general curiosity about the research. Most HCPs reported that they only logged into the application at the start, to test their login details (which was evidenced in the logged engagement data from the platform). Their engagement with ProACT typically only occurred when a PwM participant brought their data with them to a clinical visit, which many PwM participants did proactively. In addition, this engagement was with the PwM's application, rather than the HCP's. In relation to reasons for non-usage of their personal CareApp, each HCP reported lack of time and resources as the reasons for not engaging, while some also mentioned the application being something 'new': *"it's just time again and resources, you know, and it's something new. I'm sorry but that's the reality"* (HCP016, F, HF CNS).

HCPs confirmed that they did, and in the future would, look at the application if one of their patients brought it to a visit. Some HCPs felt it would be ideal to be able to review their patient's data in between visits, but all felt that this would not be feasible with their current workloads: *"You're dealing with what you're dealing with on the day"* (HCP014, F, Respiratory physiotherapist); *"It's too much like pre-emptive work and there isn't capacity for that"* (HCP027, F, GP). The only scenario where data potentially would be reviewed pre-emptively, would be in advance of a scheduled clinic visit (e.g., a 6-monthly check-up appointment at one of the specialist clinics), whereby the data might be able to show that the person was stable and therefore didn't need to attend the appointment, and where a check-up phone call in relation to the data would be sufficient. However, during the trial this wasn't the case. A heart failure CNS reported that a participant called to report a slow heart rate, and rather than her checking the application to review the heart rate and other data, she brought the patient in for an ECG: *"a patient did ring us because his heart rate was a bit slow… and I suppose if I had time or if I had, if it was more familiar to me, I might have gone in (to the application) to see what they were talking about, slow, but we brought, we did bring him in and we did an ECG and we checked him out and it wasn't actually that slow at all. We were quite happy because we like heart rate slow, you know what I mean?"* (HCP016, F, heart failure CNS).

HCPs also spoke of conditions for future use, with all HCPs noting they would adopt the platform into practice under various conditions. The main condition cited was that it must benefit patients in terms of helping them self-manage, followed by it must be easy to use. Three HCPs noted that they would not need to see effectiveness data from a trial to adopt the application into their practice, as they are already requesting that their patients monitor this type of data as it's useful for them to have: *"I don't think we'd need to see a trial to show that it actually improves outcomes because I think we want to know this information anyway from our patients"* (HCP020, F, Cardiac Consultant). Another condition regularly cited was that using the application would have to be *"productive work"*, i.e., reduce or offset workload in some way, such as reducing the need for clinic visits, as outlined above. At the same time, some HCPs understood that patients are beginning to engage more with these types of technologies and that healthcare systems may need to adapt: "*even with our younger people… a lot of them are heading now towards wearing continuous glucose monitors and that information can be sent to their phone and things like that. So, we just have to – we have to keep up to date with it"* (HCP004, F, diabetes CNS).

The PwM Becoming an Active Collaborator in their Care

Many PwM participants also reported that they brought their tablet device with their CareApp and data with them to doctor visits. For PwMs, their HCPs were not necessarily in their formal trial care network (i.e. were not participants of the ProACT trial). Furthermore, even those PwMs who did not formally invite a HCP to be part of their care network reported bringing their data to clinical visits. Several PwMs reported that the triage nurses would help them to prepare for clinical visits, encouraging them to bring their tablet with their data and helping them to form questions to ask their HCPs. PwMs reported mixed views and opinions of their HCPs of the trial and their data. Some HCPs looked favourably upon their participation in the trial: *"I used to bring that iPad with me* [to the heart efficiency clinic]. *They thought it was absolutely brilliant, the heart efficiency girls thought they were great because they could run back on it and look at my blood pressure and my weight going back for weeks and months, you know"* (P031, M, 70, CHF+CHD, T3). Other PwMs reported more negative feedback from HCPs: "*I did* [show my GP my readings], *yeah. And comments, words like 'daft' were used"* (P009, M, 71, COPD+CHD+diabetes, T3).

PwMs also spoke of how they discussed their readings with HCPs during clinical visits. Many reported a change in the conversations they were having with their HCPs, some querying about healthy ranges to aim for, and what they could do to achieve them: *"My doctor.. I asked him what should I be thinking about. I have no idea what a healthy sleep pattern is, if I sleep fifteen hours a day instead of eight or nine hours a day you know. Is that not good for me? I hadn't discussed the blood pressure with him at all* [before the trial]. *I just said you know… what sort of a range and he just threw it at me"* (P015, M, 82, diabetes+CHD, T3). For some, HCPs confirming that their readings were 'good' appeared to provide reassurance: *"But when I went for the annual check to the diabetic clinic, I took that* [app] *with me and the doctor that looked through, he said there was nothing to worry about. He said it was perfect. So, from that respect I think it's worth everything, you know"* (P023, M, 73, diabetes+CHD, T4).

For some PwMs, the nature of the visit and conversation changed due to them having more knowledge regarding their conditions and readings: *"Well, you know, maybe a bit more of where he's coming from when he speaks to you on where you are with different readings and that, whereas before this* [trial], *you wouldn't be aware of them and you didn't take it on board at all"* (P026, M, 75, COPD+CHD, T4). Others noted how using the platform made them more aware of additional supports they needed in relation to their health and prompted them to request these: *"Yes it has helped me question, because the supplies of* [oxygen] *I was put on. I went on this oxygen I think November '17… And the settings from the supplier on this had me on a flow rate of five. But I knew, well I mean I'm on a flow rate of two litres at the minute. And I got very sick with* *pneumonia in August. And I was in intensive care. And I asked them* [consultants] *to please… Figure out what flow rate. So* [this trial] *helped me sort of tune into that. To be very much aware of it and to try and investigate the flow rates more"* (P043, F, 77, COPD+CHD, T3).

PwM participants also reported taking more responsibility for their care as a result of using the platform, due to increased confidence in how to self-manage and increased knowledge of their health and wellbeing as a result of monitoring. Some participants felt that their perception of the role of the GP had changed since using the platform as they now felt ownership of their health, and more confident in telling the GP what was wrong with them: *"In a sort of a way yes in the sense that it's becoming more your own personal responsibility to track the numbers. That you're not just leaving it entirely to the GP to do it"* (P033, M, 65, diabetes+CHD, T4). PwMs also spoke about becoming less reliant on the GP: *"because when I got an attack* [during the trial]*, the COPD or whatever flared, I could recognise whether I needed an antibiotic or not and I didn't see the point in going to a doctor when I couldn't breathe right, but there was no sign of infection. Whereas before* [the trial] *as soon as my breathing sort of laboured I'd be at the doctor…"* (P045, F, 74, COPD and diabetes).

HCPs also spoke of discussing readings with PwMs and of being impressed at how they were using the technology to self-manage and how motivated they were: *"He actually did more of that* [showing graphs with data] *with me. He was actually, you know, showing me through the app. He was so motivated."* (HCP005, F, diabetes CNS); *"I've been surprised that the number of older people that are* [using the platform]*"* (HCP004, F, diabetes CNS). HCPs felt the data could help focus participants on a particular period in time in relation to the data, for example the time leading up to an out-of-range reading, which would then in turn prompt further discussion.

The Utility of Data

HCPs commented on the various data types within ProACT, whether they found them useful and how they would use the data. Each HCP specialty (e.g. COPD consultant, GP) had their own opinion on what symptom data they would find most useful for dealing with their patients. As one might expect, specialists were primarily interested in symptom data directly relevant to their specialty. Therefore, while one of the aims of the CareApp for HCPs was to provide a more holistic overview of the participant to the HCP on their dashboard (e.g. showing someone's COPD data, as well as their diabetes data), consultants and clinical nurse specialists wanted only the data of relevance to them on the dashboard of the app, stating they could dig deeper for other information if they wished: *"If we're looking at it* [the dashboard] *from a respiratory point of view, it's going to be different to what the diabetes people want to see. It's going to be different from what the heart failure people want to see"* (HCP012, M, respiratory consultant); *"It's a very busy - we are very a busy clinic and we are kind of trying to focus on the cardiac symptoms, whereas our heart failure nurses are excellent and they take a more holistic approach…"* (HCP020, F, cardiac consultant).

HCPs also discussed the wellbeing data available in the app. Activity data was deemed to be useful for all HCPs across all conditions. This was often related to knowing that the person was being active but was also deemed useful because of the links between activity and symptom data: *"We know that the more active someone is, the better it is for the heart health, for the blood sugar levels – you know for the blood pressure so it's of – definite benefit"* (HCP005, F, diabetes CNS). HCPs noted how the wellbeing data, for example low activity or mood, or poor sleep also highlights issues, which could prompt earlier intervention or the need to come in for a visit. During a typical visit HCPs can take vitals and get some insight into symptoms, albeit point-in-time. However, they noted that they don't typically ask about sleep, physical activity or mood, even though they think these parameters are important for the person's care. However, having access to them during a visit was deemed useful.

The mood data available in the app (self-reported by PwMs participants) generated a lot of discussion. In relation to mood, HCP004, a diabetes clinical nurse specialist said: *"It would* [be helpful] *– it is, but it wouldn't be something we'd, I suppose, it wouldn't be something we would be looking at on a regular basis".* HCPs noted that if a patient reports they are experiencing low mood or anxiety they would be advised to go to their GP. However, it was generally agreed that having access to mood data would be beneficial for understanding certain readings (e.g. unstable blood sugars, low physical activity) or explaining lack of engagement in self-management. The specialist HCPs noted the importance of addressing mood and anxiety issues to facilitate self-management. HCPs felt that having access to mood data would be particularly useful for some people who may find it difficult to discuss issues they have around depression and anxiety. They felt the self-reported data on mood could help ease into a conversation on it. *"sometimes people come into a hospital setting or a primary care setting and they feel it's very clinical and they mightn't even discuss that aspect of their care so, you know, and it might be their first time to meet this, you, yourself as well so, it's bringing, you know, it might actually open up that conversation quicker."* (HCP005, F, diabetes CNS). However, mood was not deemed useful by any of the GP participants and not something they would typically ask about: *"Not unless they have a history of depression and anxiety and we are treating it and we want to see a response to treatment but if it is a new thing, no, I don't think so"* (HCP027, F, GP).

HCPs also spoke of how the data could help inform treatment, decision making and medication adjustments. As would be expected, HCPs all felt that having historical data from patients is more beneficial than point in time data on a particular day, in terms of providing a better picture of how the person has been in between visits. It was felt that having the trend of data could ultimately supporting more informed decisions around care: *"You have data over time, historical data, and that is very useful rather than just on the spot and things like blood pressure readings"* (HCP027, F, GP). Some HCPs recalled how they had made adjustments to a participant's medication having viewed data in the PwM's app that then led to further investigation. HCPs within the heart failure clinic felt that the data would be extremely useful for supporting them in titrating (adjusting to find the right dosage) their patients' medications, as the symptom data would show if the patient tolerated a medication change: *"We would definitely titrate them using this data... We could titrate up their medication much quicker and so that would all be of a huge benefit"* (HCP016, F, heart failure CNS). This in turn could negate the need for a clinic visit to assess this.

Towards Integration of Care – Benefits and Challenges

The care network feature in the CareApp (that allows a PwM to add people to their care network and choose which information to share with each individual) was discussed with PwMs and HCPs. PwM participants discussed their reasons for not involving a care network. For some participants, they did not think that their HCPs were interested in being involved in the trial or that they would have sufficient time to oversee their health readings: *"I mentioned it to* [clinic HCPs], *they didn't seem one bit interested. It didn't generate a conversation or anything"* (P005, M, 72, CHF+CHD, T2); *"And then again,* [doctors are] *pushed for time as well. They've enough paperwork and ticking boxes as it is, you know, so I'm with him 25 years. He's on board as well, but he expects me to do* [the trial] *independent of him"* (P034, M, 67, COPD+CHF, T2). Some participants expressed surprise that HCPs didn't want to be part of their care network when asked. However, most PwMs put this down to time pressures for HCPs: "*Actually told him that he could get me on the thing if he programmed into it and he'd be able to see it for himself, but I don't think he ever done it. I wouldn't run him down in any way. He's a brilliant doctor... but I know he's a very busy person, so he probably doesn't want to be going into my details when he knows I'm going into him"* (P047, M, 69, COPD+CHD, T4).

HCPs felt that a care network is very important for PwMs, and that data being available to those in their care network would be a selling point for them, and also provide reassurance. HCPs also said they would find it useful to know who is in their patient's care network, and they might not have this information otherwise: *"I suppose, at the moment we are trying to move heart failure care into the community with links to the hospital network so you could have multiple people looking after heart failure with all the same goals.. whoever is looking after the patient, the patient themselves, the heart failure nurse in the hospital, the consultant who's I suppose overseeing the heart failure clinic in the hospital, the GP and the heart failure nurse in the community. So, yes, I think that is very good, yes"* (HCP020, F, cardiac consultant). They highlighted, however, that integration of care could only be achieved if all relevant clinics and HCPs are linked into the care network. In addition, they noted that being able to communicate with other care network members would be necessary. In contrast, one GP felt that having too many people in the care network could cause problems: "*I think it shouldn't be a multiplicity of people, it should be just one or two specific care people or otherwise, yes, you would just have a talking shop and I think it would be – it wouldn't be very helpful if there are too many cooks in the kitchen"* (HCP028, M, GP).

While the benefits of a care network to support integrated care were acknowledged, several concerns were also raised. The primary concern raised was that there needed to be clarity, primarily for the PwM, on how regularly, if at all, their data was being checked or reviewed by HCPs. For example, in showing the care network feature within the app to one HCP, she noted how the PwM could see that she was in her network. However, she hadn't ever proactively logged in to review the participant's data: *"I suppose, now we're on that but to be honest I've never accessed it"* (HCP016, F, heart failure CNS). Thus, setting expectations was considered important. Another concern raised by some HCPs was that someone, whether it be a HCP, triage nurse or PwM, needs to be the ‘go-to’ person - the person who has responsibility for ensuring data is acted upon and that care network members are aware of it: “*So, unless it is integrated and then, you see, somebody has to be in control of it and make decisions, so it depends who is going to do that or who is going to kind of say if it was a hospital consultant – are they going to get in touch with us or how are they going to share that?... Because that is a level of responsibility that, you know, needs to be decided on so that somebody takes ownership of that and uses it and it depends how is that is worked”* (HCP027, F, GP).

Finally, GPs highlighted that informal carers would need training on understanding the data and thresholds, to ensure that having this data doesn’t result in increased calls to the GP due to informal carers panicking over data. “*they are phoning us up and saying so and so’s blood pressure is this, that and the other and you thinking yes but that could be just a temporary thing and unless, so, it depends what the network is used for and it depends who has responsibility for what”* (HCP027, F, GP).

4 Discussion

Digital health technologies have the potential to support individuals to become active collaborators in their health and wellbeing management, altering the power imbalance in traditional healthcare by empowering the person to share responsibility for their care with their HCPs [20]. While there is a substantial amount of research exploring collaborations and relationships between patients and their HCPs, including some involving people with multimorbidity [10, 11, 21] there is limited research on studies involving older adults with multimorbidity and their HCPs using such technology in practice. The ProACT trial involved 60 older PwMs in Ireland using the digital health platform ProACT to self-manage their health and wellbeing over a period of 12 months, with optional support from a care network. As indicated in our findings, older adults engaged with the platform regularly with low attrition rates observed. While HCPs did not engage with their own digital application, they did engage in discussion of the data with PwM participants who brought their data with them to appointments, with this sometimes impacting treatment, for example medications being altered.

Healthcare has traditionally been paternalistic, with HCPs responsible for directing and managing all aspects of a person’s care [22]. However, with ageing populations expected to result in higher prevalence rates of chronic conditions, alongside the availability of digital self-management technologies, there is a shift towards more person-centred care, with individuals having shared responsibility for their health and wellbeing management [12]. Leveraging patient expertise and experience has been noted as important to empowering shared responsibility [22] and has the potential to increase adherence to self-management. It also has potential to create an “equalising effect” in the relationship between HCPs and their patients [20]. The findings from the ProACT trial, presented above and elsewhere [13, 19] indicate that PwM participants actively engaged in day-to-day self-management, becoming more aware of their health and wellbeing and more adept at self-management. As a result, PwMs reported feeling more responsible for their care and proactively brought their tablet devices with their data to clinical visits to engage their HCPs in discussions centred on the data and reported being more confident to initiate discussions with their HCPs and having more knowledge to ask informed questions. This demonstrates both initiative and a sense of ownership of one's self-management. At the same time, HCPs reported being impressed with their patients' motivation to self-manage and technology proficiency. Thus, PwM engagement in digital self-management facilitated a more equal partnership with their HCPs. In designing such technologies for older people, HCI researchers should ensure appropriate education and training content is available to end users, to facilitate their learning and their path to becoming experts in their own health and wellbeing management.

While empowering individuals to self-manage their health and wellbeing through digital technology is one key factor in moving towards shared responsibility, it is also necessary for HCPs to engage with the data generated from such technologies. Only half of the HCPs invited by PwMs in this study decided to participate, and those HCPs that did participate were emphatic in not wanting to be responsible for reviewing and reacting to their patients' data outside of clinical visits, indicating that this was the patient's responsibility. This confirms prior research which highlights that HCPs are not willing to monitor patient data [23]. Furthermore, despite PwM participants having multiple conditions, the majority of HCPs reported only being interested in data pertaining to their own specialty within the ProACT platform. This highlights the need for digital solutions to support PwMs to be the coordinators of their own holistic care. Designers should therefore ensure digital health technologies support PwMs in effective and efficient communication of the most pertinent health and wellbeing data with their different HCPs during short clinical visits, understanding that different specialties may wish to have certain data prioritised. For example, designers could support customisation of dashboards for different HCPs whereby prior to or during a visit a PwM could generate a data report highlighting data most relevant to a particular condition with the ability to then dig into additional data further if desired. Alternatively, a 'Me in a Month' summary could highlight the most important trends and anomalies in the data [24]. This type of summary could also highlight relevant wellbeing data, such as mood, which on the surface HCPs might not consider useful, but which could provide context for particular readings or behaviours. Other research has noted that while anomalies were easily identified in co-interpretation of self-tracked activity data by people with Parkinson's and their HCPs, identifying trends was difficult (e.g., recognising lower activity levels at weekends) [20]. A data summary automatically generated by a digital health platform could support easier interpretation or explanation of such trends.

Some research has cautioned against individual interpretation of self-tracked data by a patient (e.g., at home) as they may incorrectly interpret data [25]. Indeed, this may be particularly challenging in the context of the complexity of multimorbidity management, for example where conflicting advice can lead to PwMs prioritizing one condition over others without seeking advice from their HCPs [10]. However, the ProACT platform addressed this through the use of the dashboard (Figure 1) which prioritised those symptoms and other areas of self-management that were most important for the PwM to address at a particular point in time. Furthermore, the clinical triage service provided supplementary human support and was instrumental in helping PwMs to learn to self-manage [12]. During clinical visits, HCPs also contributed to the PwM's learning (for example confirming that the data readings look normal as was mentioned by HCP016 in relation to a PwM's heart rate). There were no reports of incorrect interpretation of data at any point during the study from either PwM or HCP participants. Therefore, it is likely that empowering the PwM with appropriate knowledge, through a combination of digital and human support, on how to self-manage is likely to help avoid incorrect interpretation of data. Despite this, it is important to consider that as an older person with multiple chronic conditions continues to age and potentially gets additional condition diagnoses, more frequent support may be required to help them to continue to self-manage effectively. Informal carers will have an important role to play. As such, digital health platforms should support adaptations to the care network over time and should ensure that informal carers also receive appropriate education and knowledge to support them in their caring role.

5 Conclusion

The contribution of this work involves providing insight into how a digital health platform can mediate collaborative care and multimorbidity management between older adults and their HCPs. Embracing such digital solutions not only has the potential to increase quality of life for those with multimorbidity but may also future proof healthcare systems to more effectively de-centralize health and social care to the community.

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