Designing Remote Patient Monitoring Technologies for Post-Operative Home Cancer Recovery: The Role of Reassurance

Constantinos Timinis[1][0000-0003-4738-119X], Jeremy Opie[2,3][0000-0002-1529-5847], Simon Watt[3], Pramit Khetrapal[3,4,5], John Kelly[1], Manolis Mavrikis[1], Yvonne Rogers[2][0000-0001-7612-0234], and Ivana Drobnjak[1][0000-0002-3989-1715]

[1] Centre for Medical Image Computing & Department of Computer Science, University College London, UK
[2] University College London Interaction Centre, University College London, London, UK
[3] Wellcome/EPSRC Centre for Interventional and Surgical Sciences, University College London, London, UK
[4] Division of Surgery, University College London, London, UK
[5] Department of Urology, Royal Free Hospital, London, UK
`constantinos.timinis.17@ucl.ac.uk`

Abstract. While cancer patients are recovering in hospital after major surgery, they are continually monitored by clinical teams. However, once discharged, they spend their remaining recovery isolated at home with minimal contact with the clinical team. The first 30 days upon returning home after surgery are identified to be a critical and challenging period for patients not only emotionally, practically, and mentally, but also poses a real danger of further complications, readmission, and potentially surgical related death. Remote Patient Monitoring (RPM) systems are extremely promising, allowing clinicians to care for and support patients remotely, however, although these technologies are mature, the level of adoption by the patients is still very low. To address this challenge, we focus on identifying and understanding the patients' concerns and requirements when adopting a novel RPM technology. We conducted a series of iterative Patient Public Involvement workshops following a user-centred approach. We explored various scenarios based on prototypes and facilitated reflective discussions with cancer patients to identify existing barriers preventing them from adopting RPM technologies. The workshops revealed a wide range of concerns expressed by participants, categorised in five themes. However, lack of reassurance was identified as the central theme during the 30-day post-operative post-discharge period. In conclusion, reassurance proves to be central in engaging patients and making RPM technologies fit for purpose, potentially leading to elevated levels of adoption and improvement on health outcomes and quality of life.

Keywords: remote patient monitoring · user-centred design · reassurance.

1 Introduction

Cancer, despite the huge amount of research already conducted, remains one of the leading illnesses people currently face, with over 19 million new cases and 10 million deaths globally in 2020 [51]. Living with cancer is a major challenge [12] and the cancer trajectory along with its different events and phases, needs at each phase, and ways to address these needs have been the subject of research for a long time [14,42]. One of the key events in this trajectory is surgery, as more than half of cancer patients are having at least one during their cancer journey [33]. After surgery, the recovery of patients happens in two phases: in the hospital where monitoring is continuous with both devices and clinical teams, and after hospital discharge where monitoring is minimal.

The post-operative post-discharge (POPD) period is particularly critical for cancer patients undergone major surgeries since as many as 27% of patients are re-admitted with serious complications [36]. Over 90% of these cases arise within the first 30 days post-operative, which is also when most surgical related deaths occur [56,24]. It is also the time when patients are left on their own after a period where others were responsible for looking after them [49]. At the same time, patients need to manage unprecedented conditions and incidents including surgery complications, following specific rehabilitation instructions, and monitoring their progress [27]. On top of this, patients still need to live with the disease, attend doctor appointments and treatments, and take their medication. As a result, more than any other period of the cancer journey, patients experience feelings of fear, anxiety, and uncertainty. It is this period of the 30-day POPD period that this research focuses on (see Figure 1), a period in which reassuring patients becomes crucial [50].

Remote Patient Monitoring (RPM) technologies have a strong potential to address the challenges outlined above [43,22] whilst reassuring patients effectively. RPM is a healthcare delivery model that uses technological advances to monitor patients outside of a traditional care setting [55]. RPM can collect a

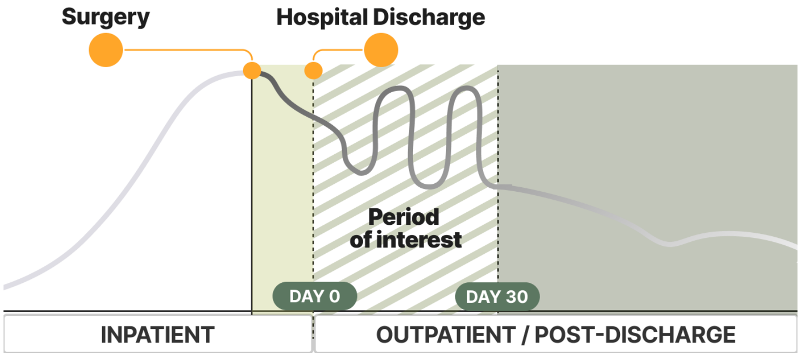


Fig. 1: The *Acute Care & Treatment* phase as identified by Hayes et al. [14], highlighting the period of interest of this study along with other major events.

variety of patient data, including vital signs, symptoms, and medical history through smart watches, wearable sensors, and mobile phones [39]. This data is shared with health care professionals (HCPs) and can be analysed to inform treatment decisions in a timely and informed fashion. Simultaneously, through portals, patient dashboards, and remote consultations, RPM enables patients to track their disease progress and acquire support and guidance [23,44]. These attributes are particularly important in the POPD period which carries some of the highest risks, thus early action can prevent life-threatening situations [31].

Despite their numerous advantages, the spread of RPM technologies into healthcare and hospitals remains low, which is somewhat surprising given the range of advances commercially available [17,2]. This spread depends on each individual's decision to use technology, defined as *adoption*, and on the collective adoption process of groups of individuals using technology over time, defined as *diffusion* [30]. The low adoption rate by patients is attributed, but not limited, to data protection, privacy, safety, reliability, and accuracy [37]. Another factor affecting the adoption of such systems is the challenging design process [54,22], attempting to satisfy a diverse range of needs from varying end-users simultaneously [32]; the two primary groups being patients and the clinical teams. Both groups need to engage with the technology, while patients are also expected to comply with the given advice. In this study, we will refer to *engagement* as the time spent interacting with the employed technology, and *compliance* as following the instructions or advice given.

In this work, we focus on identifying and understanding the patients' concerns and requirements of adopting a novel RPM technology during the 30-day POPD period. A user-centred process built on a Patient Public Involvement (PPI) approach was used to understand how to increase patients' motivation and willingness to adopt RMP technology [47]. We accomplish this according to the five-stage process proposed by Bowen et al. [4] and conducting three iterative online PPI workshops with cancer patients. The goal of the workshops was to investigate and identify: (1) the post-discharge recovery journey of post-operative patients, (2) the needs and concerns of patients when returning home and the barriers that exist, and (3) what features would support patients in their recovery if they were to use an RPM system. We identify cancer patients' concerns in themes and highlight reassurance as the key theme, which if addressed by an RPM system, will potentially motivate patients to adopt such technologies.

2 Related Work

2.1 Cancer journey phases and needs

Cancer patients go through different cancer journeys attributed to their age, cancer type, stage of cancer, and treatment plan [7]. Despite this, there are commonalities between patients' cancer journeys described in five main phases: *Screening & Diagnosis*, *Initial Information-Seeking*, *Acute Care & Treatment*, *No Evidence of Disease*, and *Chronic Disease & Disease Management* [14]. While research has been conducted to identify and meet patient needs [18], these studies group all five stages of the cancer journey together rather than exploring their individual requirements [34]. Considering the challenges of each different phase can inform the focus which designers should have in designing health technologies, and patients to benefit the maximum [19]. Since we are expecting patients to adopt technologies, so must the technologies be designed according to each phase's needs.

Within HCI the *Acute Care & Treatment* phase has gained a considerable amount of attention due to the major events of surgery taking place; specifically the post-operative post-discharge (POPD) period. Only patients who undergo surgery experience the post-operative period, which is full of challenges including unexpected complications and feelings of anxiety and uncertainty as the result of the surgery [19]. The post-operative period becomes even more challenging when combined with the post-discharge period. Sanger et al [45] mentions that improper care of wound monitoring during this period can affect both clinical outcomes and quality of life of patients, while Saunders et al. [46] links poorer outcomes with untimely communication between patients and health care professionals (HCPs). However, existing research either concentrates on a specific type of cancer [1], on specific domains of needs like access to information [20,25,26] and psycho-social support [48], or is limited to the interactions patients made during their hospital visits [42]. Therefore, there is a need to re-evaluate cancer patient concerns specifically during the 30-day POPD period and suggest approaches which can practically be applied to treat these concerns.

2.2 Reassurance in Healthcare

One approach that has been examined to treat patients' concerns is to consider the role of reassurance. This is defined by Linton et al. [29] as "*a set of behaviours carried out by practitioners, which aims to reduce concerns in patients*". Reassurance is emerging as important to address in the contexts of non-specific conditions, like lower back pain [53], mainly in the occurrence of acute episodes [16] and during interactions between patients and HCPs [16,15]. The importance that reassurance has for cancer patients has already been demonstrated [52], but existing studies are limited to follow-up consultations [50] or tracking of symptoms [1].

Pincus et al. [41] addressed the need for reassurance during the particular phase of initial information-seeking and suggests reassurance as the main factor to improve patient outcomes by providing clear explanations and information during consultations. However, effectively reassuring patients in phases where uncertainty is present, like the acute treatment phase, is still unexplored. In addition, despite the measures used by Holt et al. [16], which solely rely on the patient's input, comprehensive and reliable measures of reassurance are still needed [41]. Such measures will enable the evaluation of reassurance's impact on patient outcomes, recalling information, compliance with advice, symptoms resolution, and well-being. In sum, reassurance is currently poorly understood when applied to clinical practice [9,16]. Our research seeks to address this in the context of when patients return home after surgery for cancer.

2.3 Supporting cancer patients when at home

Monitoring patients allows HCPs to detect whether the patient is recovering as expected and predict future complications and potential re-admissions [3]. Recent advances related to eHealth and mHealth (e.g., telehealth, electronic health records, web and mobile platforms) use health data provided by patients to facilitate self-monitoring in a range of conditions [38]. Remote Patient Monitoring (RPM) enable patients to control their disease progress and acquire support and guidance [31] by tracking symptoms, monitoring vital signs and receiving remote consultations through portals and dashboards [40]. These attributes are particularly important in the POPD period which entails some of the highest risks since RPMs can enable early intervention from clinicians to prevent deterioration and life-threatening situations [31]. Overall, RPMs are shown to have the capability of improving clinical outcomes, reduce healthcare costs, and empower patients to take control of their health [40].

Despite the development of RPMs for self-monitoring of chronic diseases, the lack of adopting such technologies remains unknown. People stop using self-tracking technologies, referred to as *abandonment*, mainly due to a mismatch between users' hopes and expectations and device capabilities [8] or technology not fitting in their lives nor supporting their goals [10]. Lazar et al. [28] classifies abandonment into three main categories: (1) devices not fitting with participants' conceptions of themselves, (2) acquired data not useful, and (3) devices needing effort and maintenance. While recommendations to avoid abandonment [11] and influence adoption have already been made [11], currently there is no research that has identified the reasoning behind why the uptake and adoption of mHealth technology, specifically for cancer patients, is so low.

3 Methods

The aim of this study is to identify and understand the needs of cancer patients in using a Remote Patient Monitoring (RPM) system. Designing such novel technologies for users with different characteristics and perspectives is challenging and requires different concerns and expectations to be taken into account [54]. To achieve this, we relied on the first three of the five-stage approach developed by Bowen et al. [4] consisting of (i) understanding and sharing experiences, (ii) exploring blue-sky ideas, (iii) selecting and developing blue-sky concepts, (iv) converging to practical proposals, and (v) prototyping and evaluating. These stages were adopted through three iterative Patient Public Involvement (PPI) workshops, as illustrated in Figure 2. The methodology of the study relies on an iterative user-centred process where the findings of each workshop informed the design of each subsequent workshop [13].

The theoretical framework of the '*Understanding and sharing experiences*' stage was used to define the agenda and aim of workshop one (W1). The goal of W1 was to understand the patients' experiences and get their views on how remote monitoring could be facilitated throughout their cancer journey; thus, allowing us to identify and classify cancer patients' needs in terms of specific themes. These themes informed the design of the prototypes used in W2 and W3. In W2 participants verified the identified themes and discussed which theme they think as the most important when using RPMs. In W3 we explored user requirements focusing on the key theme identified by the previous two workshops. Throughout the workshops we adopted a sharing, suggesting, and exploring methodology [5] through discussing lived experiences, using case scenarios to promote discussion, and interacting with a prototype.

3.1 Participants

The participants recruited for the workshops were found through advertising via online events, university networks, and referrals from health care professionals (HCPs). Sampling criteria were developed collectively by the research team and the HCPs to ensure adequate sampling in terms of gender, age, cancer type and stage, and treatment type, with all participants having had surgery at some point in their cancer journey. Eight accepted our invitation and made it to the first workshop, with their characteristics detailed in Table 1. All eight participants were able to join the second workshop, whilst only six were able to attend the third. All participants were recovered or recovering cancer patients, thus, for some participation was more difficult than others and subject to unexpected incidents, e.g., feeling ill or exhausted from undergoing treatment.

Once the participants were recruited they each received a participant information sheet detailing the project and how their data would be obtained and stored. Prior to each workshop participants' consent was acquired before any data collection in both written and oral form, as part of our ethical clearance

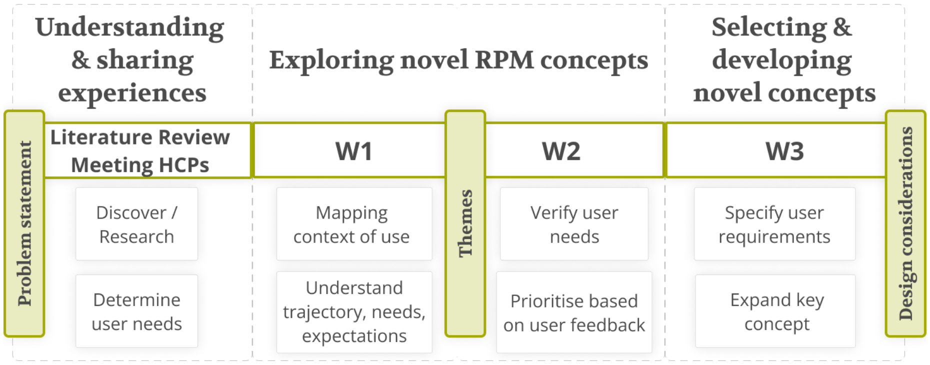


Fig. 2: The first three stages of Bowen et al. [4] approach used to inform our iterative, user-centred design process consisting of three PPI workshops.

Table 1: The information of the PPI workshops' participants.

Patient ID	Sex	Age Group	Cancer Type	Cancer Stage	Treatment(s) Type
P1	F	70-75	Breast	-	Surgery, Chemotherapy, Radiotherapy, Hormonal Therapy
P2	F	65-70	Colon	-	Surgery, Chemotherapy
P3	M	65-70	Bowel	III/IV	Surgery
P4	M	51-55	Lung	IV	Surgery, Chemotherapy
P5	M	55-60	Bowel	IV	Surgery, Chemotherapy, Radiotherapy, Drug treatment
P6	F	45-50	Breast	-	Surgery, Radiotherapy, Drug treatment
P7	F	61-65	Breast	-	Surgery, Radiotherapy, Drug treatment
P8	M	65-70	Bowel	III	Surgery, Radiotherapy, Drug treatment

#UCLIC/1819/008/RogersProgrammeEthic. Each workshop lasted for approximately 2.5 hours with participants being compensated for their time with a cash voucher. Participants were also free to withdraw at any time without providing a reason. To reduce the strain on participants, and to allow time for reflection and iteration from the research team on prototypes, the workshops were held every 5 months, with the first in September 2021, and the last in June 2022. Owing to the COVID-19 pandemic, the workshops were conducted remotely.

During the workshops, all of the discussions were video recorded, transcribed, anonymised, and analysed using NVivo, a tool used to interpret qualitative data. The data was analysed using thematic analysis and systematically categorised into themes and sub-themes [6]. Thematic analysis is a commonly used method for analysing and reporting themes within qualitative data by becoming familiar with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing a report [6].

3.2 Workshops

Workshop One (W1) Participants received a short introduction to the background of the research, followed by a general discussion to set the scene and establish expectations and understanding around the key concept. Group discussion explored the idea of "remote monitoring of well-being". Then, participants were divided into two smaller groups, with a mix in terms of background based on their profile. The breakout groups covered several aspects of remote monitoring including: benefits, opportunities, requirements, practicalities, concerns, and motivation. Specific questions served as a catalyst for initiating discussion. To conclude, participants were shown screenshots of an early prototype, designed by the HCPs' team prior to the workshops without any input from patients. While exploring the prototypes participants were asked two specific questions that were intended to prompt focused discussion and encourage them to broadly comment on their preferences looking for an initial understanding of whether there is consensus (or not). The questions examined: (a) whether patients would prefer being in control of the information they provide or letting clinicians ask the questions that are important to them, and (b) whether patients would prefer the welcome screen of the app to be task-oriented or information-oriented.

Workshop Two (W2) To initiate W2 we explored the concept of "Nice-to-have" vs. "Need-to-have", a widely used concept in user experience (UX) to describe and categorise end-users' requirements [35]. This concept provides insights regarding the importance of the identified requirements, while at the same time evoking end-users to think about the difference between critical and non-critical requirements. As the workshop was online, we used Menti, which is an audience engagement platform that supports live and instant polls, quizzes, and informative Q&As, thus allowing participants to interact with the data easily without requiring any registration on their end. Menti also enabled a real-time visual representation of the results according to each patient's vote, allowing participants to provide their input while not creating bias. To prioritise the sub-themes and determine which themes are most important to participants we ran a dot-voting activity. This was achieved using Miro, another online platform where participants could place votes on the sub-themes. Each participant was granted three votes, which they could place on any of the sub-themes they deemed most important, and participants had the ability to place more than one dot on the same sub-theme if they deemed it more important than other sub-themes. The second part of the workshop involved discussing and gathering feedback on the top two sub-themes according to the dot-voting activity. Since the two sub-themes were not known in advance of W2, the research team had to prepare a prototype app to showcase examples for each sub-theme. The two top sub-themes were presented by case scenarios alongside prototype app displays to initiate discussion and promote further understanding of how RPM could support each sub-theme.

Workshop Three (W3) The third workshop focused on the key theme as identified in W1 and W2 and its relationship to RPMs during the 30-day post-operative post-discharge period. To begin, a review of W1 and W2 was given, explaining how the conclusions drawn from these workshops inspired the next, resulting in setting the scene for W3. Following this, a group discussion covered four questions relating to the identified key theme. To complete W3, suggested features relating to the key theme which identified in W1 and W2 were presented to the participants, introduced by five case scenarios, see Table 2. These scenarios were based on the concerns of the participants gathered in prior workshops and

Table 2: The five case scenarios used to introduce the prototype for each of the suggested features during W3.

Case scenario	Description
1	You need to be able to interpret your progress: (1) Set and follow specific & achievable goals, (2) Understand how you are doing by comparing among patients with similar characteristics, (3) Receive informed feedback on each different day and adapt goals accordingly
2	You had your latest interaction with your healthcare team two weeks ago: (1) You don't remember part of the given instructions, (2) You need to recall what was mentioned, (3) You want to share with a family member who could not make it to the appointment
3	You get back home after your latest interaction, but not everything is clear: (1) You want to know more regarding a term, (2) You need to trust information you find, (3) You want to get this information through different mediums, (4) You need to translate this information
4	In the 30 days after surgery and hospital discharge you have several things to remember: (1) Medications uptake, (2) Attend appointments, (3) Keep track of your progress, (4) Keep up with monitoring tasks
5	You need to talk with your healthcare team about something that troubles you: (1) You can't find the point of contact you were given, (2) You need to know when someone is available, (3) You need to know your healthcare team is aware you are trying to contact them

based on lived experiences, allowing participants to explore new features whilst giving feedback for each scenario. Additionally, we investigated possible overlaps with other identified themes in relation to the key theme to ensure that we have prioritised the correct theme.

4 Results

This section presents the findings of our iterative design process based on the three Patient Public Involvement (PPI) workshops. The findings include the themes identified through the thematic analysis, how the key theme was selected, promotes further understanding of the key theme and suggests design considerations on how the key theme can drive the development of Remote Patient Monitoring (RPM) technology.

4.1 Themes and sub-themes

The thematic analysis of the data obtained in W1 identified five themes and 13 supporting sub-themes (see Table 3), which describe the needs of patients that should be satisfied in the implementation of RPM technology.

Table 3: The identified five themes along with its sub-themes.

Themes	**Sub-themes**
Reassurance	- Progress Indicators - Comparison (with other patients) - Informed feedback / advice - Guidance based on data
Access to information	- Effortless / Reliable / Targeted - Translatable
Personalisation	- Cancer type & stage / Treatment type & status - Control / Track of ongoing events - Reminders
Communication	- Out-of-office hours contact - Talk with the right person
Data use	- In charge of **who** is accessing & **how** is used - Efficient use / Coordination among various doctors - Responsiveness / Real-time monitoring

4.2 Prioritising sub-themes

Participants undertook a theme prioritising task during W2 aiming to resonate which of the sub-themes identified during W1 were the most important. The only theme with two of its sub-themes voted was '*Reassurance*', indicative of its importance. In addition, participants were repeatedly raising the theme of '*Reassurance*' while discussing the other themes, even though it was not mentioned directly. The indicative overlapping between reassurance as noted during the analysis of W2, led the research team to revise the data obtained from W1. This was corroborated by a statement from P8 during W1 "*So if your app doesn't cover the reassurance piece, it can be functionally very rich, maybe over rich, but I think that's an issue*". At the time reassurance was identified as an individual theme amongst others, but upon reflection and in conjunction with the results from W2, we decided that reassurance held a critical role in the adoption of RPM technology. Therefore, we identified reassurance as a concept arising during the discussions of both, W1 and W2, and collectively interwoven throughout the other four themes (Personalisation, Access to information, Communication, Data use). Thus, a new arrangement of the themes was proposed, illustrated in Figure 3, with reassurance highlighted as the key theme. To investigate further how the participants' needs might be met in regards to reassurance, a potential prototype of an mHealth app was designed and demonstrated to participants, gauging their feedback on how well it could address their needs, see Figure 4.

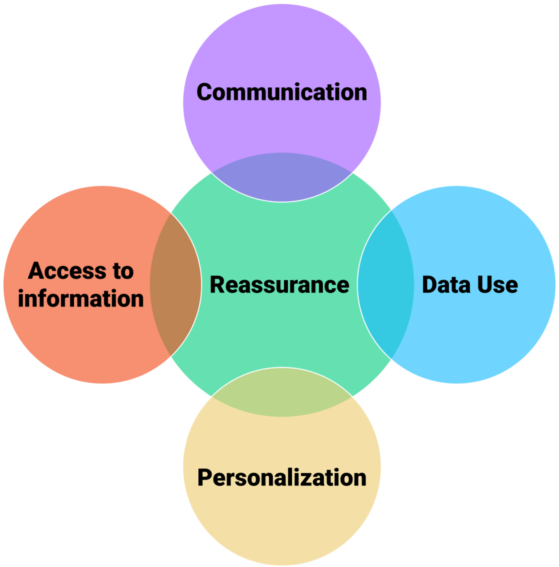


Fig. 3: The connection which the workshops revealed between the '*Reassurance*' theme and the other four themes.

4.3 Reassurance: The key theme

The discussion during the first part of W3 was framed by four questions aimed to offer insights into understanding the key theme. The results for each of the four questions are given in the following sub-sections.

What does reassurance mean for patients? Reassurance, as defined by the participants, is connected with: (1) confidence, when things do not turn out as expected ("*The first line of reassurance is to give people back confidence if they are feeling certain symptoms*" - P4, W3), (2) understanding the unknown and building knowledge ("*So what you need to provide is a form of being informed and being reassured that this is normal or not for where you are in your journey at the moment*" - P8, W3), (3) effective communication and timely support ("*I don't want to ring 999 if it's not a 999 situation, but how, as a patient, am I supposed to know that?*" - P8, W3) and (4) using the deployed technology efficiently ("*Having this sensor feeding information back provided we know that is going to be monitored, I think that would have given me a really good sort of reassurance in a lot of ways*" - P2, W3).

What does reassurance mean for patients during the post-operative post-discharge period? Building on the previous views, participants were asked to think about reassurance in the specific context of the POPD period. In this specific context, participants related reassurance with the uncertainty of having someone looking after them, which occurs when they leave the hospital (“*[..]You know someone is there to look after you. That’s the reassurance you need when you leave that environment*” - P8, W3).

Is reassurance more important at any (other) period of your cancer journey? When discussing reassurance it became apparent that the most critical time patients require reassurance is after being discharged from the hospital. This was emphasised by P1 who stated *“I think the scary time came when I was discharged.”* and P8 adding that *“The time when I was the most concerned and needed reassurance it was when I was left on my own, so certainly on hospital discharge.”*. The previous statements were followed by P2 adding *“With infections and stuff picked up during surgery, post-surgery is when you need reassurance.”*

How can it be practically applied? Can you visualise it? Participants were asked to recall cases when they successfully received reassurance as well as cases when they did not receive the reassurance they were seeking. P2 stated “*I would like rather than an app, to contact another person - this is more important to me*”, underlining the importance of communication in receiving reassurance. Additionally, P4 visualised reassurance in the form of a feature which can monitor vital signs in real-time and provide guidance to the patient “*Particularly to give you all the indicators you need to know. If your temperature goes up or you’re feeling unwell, ’hey, you know, this is normal’. If this is included in the app, the patient might feel reassured at the time and would be very beneficial*”. Following a comment from a member of the research team, participants discussed whether reassurance could be provided by people other rather than HCPs, such as previous patients. P2 stated “*I was a community champion on the Bell Cancer Forum for six years and I was able to give a lot of reassurance to a lot of people because I had been there*”, with P5 having a similar opinion “*Forums mean a lot to me and have been really helpful*”.

4.4 Features to support reassurance

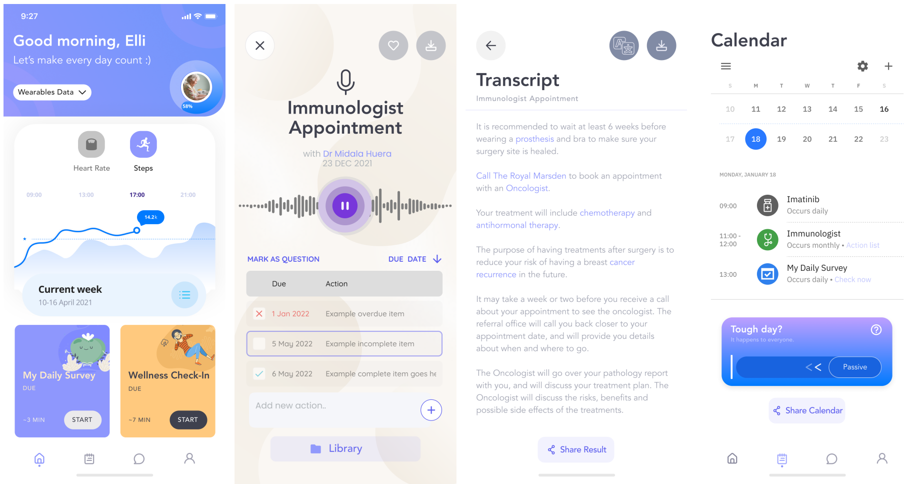
To investigate further the views of participants on specific features relating to reassurance, the last part of W3 incorporated discussion based on case scenarios (Table 2). Each of the following subsections describes a specific solution given to satisfy the reassurance needs, expressed either directly or indirectly, according to the presented case scenarios.

Direct reassurance Direct reassurance relates to all features that are satisfying reassurance directly and not as part of other themes. Participants expressed the need to know and interpret their progress. This was complemented by the need to know how good patients were doing compared to other patients with the same conditions (“*I like being part of this data collection, you can compare yourself with others like you, people like me*” - P1, W1). To address this we introduced the feature of '*Hub*' (Figure 4a). The '*Hub*' feature demonstrates the progress of passively (e.g. vital signs, steps) or actively (e.g. surveys) collected data, and if desired patients can enable an average indication and population progress, thus allowing patients to compare themselves with patients with the same characteristics. Additionally, honest feedback ("*You don't always want positive comments. Honest comments are the most helpful*" - P8, W2), was collectively described by participants as a way to help them interpret what they were seeing in the progress charts and collectively agreed that should be expressed with encouragement and positivity ("*Even if we have failings, highlight the shortcoming, but balance it with encouragement and positivity*" - P5, W2), whilst avoiding repetitive messages ("*Receiving the same message day after day, it's a bit like Amazon recommendations: you may have bought it a night ago, but they're still recommending it to you*" - P8, W2).

Reassurance as the result of access to information Participants expressed the need to recall important information communicated during their interactions with HCPs. When discussing this scenario participants were raising reassurance as the reference point to discussions they had with HCPs, with P3 stating that "*[..] doctors being recorded when they give a diagnosis or an opinion, this is reassurance that has to be given*". To address this need, we suggested '*Recording*' a feature which supports voice recording and that could easily be activated by either the HCP or the patient, see Figure 4b. The feature was designed to support a function entitled '*Library*', serving as an archive of recordings, allowing filtering by date and HCP for easier and more convenient access to data.

Another concept discussed by participants was the extent of which clinical terminology is used during their interactions with HCPs and the subsequent lack of interpreting such terminology by accessing reliable sources ("*[..] there are links if I want to dive further, [..] my question is what would make that reliable?*" - P8, W2). Thus, this is a common place where potential misinterpretation between what the clinicians are instructing and what patients interpret, happens. P4 stated that "*I wonder why you are collecting certain information. People don't always understand [..], but if you explain to them, then they improve their health literacy and it can be both educational and motivating*", expressing the importance of understanding the information they receive from HCPs and linked it directly with health literacy. To address these needs we introduced a function to auto-transcribe recording (Figure 4c), highlight clinical terms and link with resources approved by HCPs, providing patients with the reassurance that they can interpret information effectively and with reliability.

Participants also reached a consensus that more options for interpreting relevant information ("*A cartoon or something more expressive would be more appreciated than textual form.* - P1, W3") are indicative of increased levels of reassurance; especially relevant to those with English as an additional language ("*It would be helpful to have some images particularly for people whose English is not their first language* - P1, W3"). To satisfy this we proposed a feature that makes the relevant information available in multiple forms including text,



Due	Action
☒ 1 Jan 2022	Example overdue item
☐ 5 May 2022	Example incomplete item
☑ 6 May 2022	Example complete item goes he

It is recommended to wait at least 6 weeks before wearing a prosthesis and bra to make sure your surgery site is healed.

Call The Royal Marsden to book an appointment with an Oncologist.

Your treatment will include chemotherapy and antihormonal therapy.

The purpose of having treatments after surgery is to reduce your risk of having a breast cancer recurrence in the future.

It may take a week or two before you receive a call about your appointment to see the oncologist. The referral office will call you back closer to your appointment date, and will provide you details about when and where to go.

The Oncologist will go over your pathology report with you, and will discuss your treatment plan. The Oncologist will discuss the risks, benefits and possible side effects of the treatments.

(a) (b) (c) (d)

Fig. 4: (a) '*Hub*' - Collated progress from wearable & survey data. (b) '*Recording*' - Voice recording, note-taking, and "action" flags. (c) '*Transcription*' - Auto-transcribe, highlighting clinical terms with reliable links. (d) '*Calendar*' - Appointments, medication reminders, daily tasks, and '*Passive mode*'.

visual, audio, audio-visual and discussion (forums). We also suggested that the transcriptions are auto-translated into the patient's native language.

Reassurance as the result of personalisation During the 30-day POPD period patients are required to continue taking their medication, attending appointments, and keeping track of their progress. P4 stated "*[..] create a positive influence for a cancer patient to have some control back in their life. And if an app can provide that, I think that's great*", with P6 adding "*I know it's difficult because everybody is different and not everybody will experience the same things at the same time*", emphasising the different perceptions regarding how patients would like to track their progress. P8 suggested reminders stating "*It's about that time, is it? Time to take your tablets. That's a useful reminder [..]*". Participants emphasised the meaning of personalising reminders and notifications according to the ongoing events or tasks, or according to a particular day. '*Calendar*' is a feature developed to assist patients to organise their upcoming events (Figure 4d) classified in categories. Actions required by the patient are also linked, e.g., scheduling a blood test. The '*Calendar*' feature allows personalising reminders and notifications (e.g., time of the day, muted, etc.), setting personal goals, and scheduling notifications with associated tasks.

Participants expressed their willingness to be prompted according to their daily tasks and monitoring instructions. However, due to patients' continual changes in conditions, ongoing treatments, and needs for medication, sometimes completing such tasks is not feasible. On such days patients do not want to complete tasks, do not want to receive notifications, and do not even want to get out of bed as clearly indicated by P2 "*When I had my surgery and I came home I was fine. I could cope with filling in a survey more or less every day, but when I was going through chemo, the last thing I would want to do was fill in the survey because I was ill. Some days I didn't want to get out of bed. I didn't want to do other things*". Considering this we proposed a function called '*Passive mode*' (Figure 4d), which allows patients to manually toggle this function and silent tasks and notifications resulting from the app. From the HCP's perspective, we know that this creates a gap in data, however, it offers insights about the underlying reasons why this gap occurred, e.g., the patient did not feel capable at that time. These underlying reasons can become more insightful for HCPs if combined with the information included in the '*Calendar*', e.g., a scheduled treatment, creating patterns which HCPs can identify. HCPs could then follow up on these cases by reaching out to patients to identify specific needs, thus, providing qualitative data to explain gaps identified in quantitative data.

Reassurance as the result of communication Participants expressed the need to know that someone is available when they need them most. These concerns arise in cases when their point of contact is on vacation, during out-of-office hours, or when phone lines are busy and staffing resources are limited. P2 stated "*Things happen, but I don't know whether anybody is aware of it. Chatting online is fine when you know people, but sometimes if there's a voice at the end of the line, they can give you far more reassurance than someone chatting to you online can*". P3 agreed saying "*Coaching and support are crucial. Links to people like Macmillan or Cancer Research, whoever deals specifically with the type of cancer that people have been suffering from*".

To rectify this we proposed a chatbot informed by: (1) collected patient data from wearable devices and manual input, (e.g., surveys, questionnaires), (2) data captured by other functions of the app, (e.g., automatic transcription of recordings) and (3) geographical data, (e.g., local weather). The chatbot is intended to provide reassurance for patients when human contact is not feasible. Some participants agreed that chatbots could be helpful and address the issue of the unavailability of HCPs, such as P3 who stated that "*Research indicates that the automated diagnosis programs and routines are just as good as an actual human. Maybe the chatbots could be very useful. You know they could actually be very accurate indeed and address the problem of availability of humans*". Others thought they could not adequately substitute a HCP such as P8 who stated that "*My experience with chatbots has not been great, it's like an interactive version of FAQ. The answer you get doesn't relate to the question you asked, so it's not going to be a personalised thing anyway*". In sum, participants were not against the idea, but all were highlighting their shortcomings.

Reassurance as the result of data use Patients want to be reassured regarding who is able to access their data, for example, P2 stating "*It's one thing I* *hadn't thought about: who has access to this data?*". P6 then mentioned the issue of the efficient use of data stating "*[..] that data being collected is brilliant. But if it's going to sit for ages before somebody accesses it and does something with it then you could have a really sharp period of decline and deterioration before it's acted upon*". Another common issue is the coordination between the various doctors a patient is attending. This was raised by P5 - "*A disconnection between my clinician for IBS and the urologist it was the reason of becoming stage four*". Thus, when patients become either sceptical regarding providing their data or unsure whether the employed technology can be of any help, their assurance in using the app is lost.

To address these concerns we proposed the '*Share*' function, designed to allow patients to be in control of their files and documents and who has access to them (Figures 4c and 4d). To provide patients with the reassurance that HCPs have reviewed their data, we introduced the '*Delivery receipt*' function, so patients can view who has accessed what information and when.

5 Discussion

Our research has shown how it is possible to identify the requirements for a Remote Patient Monitoring (RPM) tool, that has the potential to improve adoption and compliance, through a series of Patient Public Involvement (PPI) workshops. This paper has focused on the concerns of cancer patients who have undergone major surgery while in the 30-day period rehabilitating at home. Our main finding identified by participants was the need for reassurance during this period. This work extends on existing studies of designing technologies for cancer patients and contributes to the body of knowledge in this area by exploring how reassurance is perceived by patients and how can be improved during self-monitoring of their health and general well-being.

The workshops revealed a high level of willingness and satisfaction from patients in using mHealth technology for self-monitoring. However, we found this contradictory given the low level of adoption of these technologies. The qualitative methodological approach we undertook, allowed us to reveal what the current technology lacks despite being over-rich in terms of features. First, we approached the *Acute Care & Treatment* phase, identified by Hayes et al. [14], independently from the rest of the cancer journey, as patients' needs change based on which phase they are in [19]. Second, coupling an mHealth app with a wearable sensor proved to be intriguing for patients and allowed us to explore additional dimensions of needs already identified in the literature [20,25,26]. This perspective enabled us to observe the prevalent role of uncertainty as the result of rehabilitating in the remote setting after major surgery, together with magnified concerns, fears and worries. Thus, more than any other period of the cancer journey, treating such feelings should become the priority of any health technology. Our research identifies the emerging need for reassurance specifically in the 30-day post-operative post-discharge (POPD) period and suggests tangible solutions which are capable of providing direct or indirect reassurance to patients through RPM technology.

Reassurance in healthcare is still poorly supported [9,16]. In this research we were able to identify key instances of reassurance that patients seek during the 30-day POPD period; specifically, when unforeseen symptoms occur, patients are unable to track their own progress, and when they are unable to recall or interpret information exchanged with HCPs. Pincus et al. [41] highlight that reassurance can be improved by providing clear explanations and information, but when patients are recovering at home, access to this information is not as easy to obtain. We relied on three core concepts to address these concerns that provide the necessary reassurance to patients. First, we provide patients with guidance on what they should expect based on their current stage of recovery through personalised and data-informed feedback. Second, we allow patients to view and interact with this data whilst tracking their progress against average patient data. Third, we allow patients to capture and review previous discussions with HCPs, while interpreting and recalling this information through reliable sources.

These design ideas can impact reassurance, potentially inspire engagement, and improve adoption and compliance. In addition, previous work has suggested that customisation, mobility, balance of information, and privacy are key to improving adoption [21]. However, we argue that in the phase of *Acute Care & Treatment*, patients are more likely to adopt and comply with technology if they know their data is being reviewed and be reassured they can reach the correct person when in need. Such tasks put a great deal of pressure on clinicians, mainly because of the workload and the number of patients in the clinician's care. As the workshops revealed, patients understand these struggles while also not wanting to be a burden or seeking assistance when it is not a real emergency. However, such judgements are built on each individual's level of health literacy and understanding of the technology's capabilities. Although our proposed app cannot fully replace the presence of clinical teams, it can mitigate the fears, concerns, worries, and uncertainty patients may harbour. Providing this certain level of reassurance could significantly reduce the burden on hospitals and prevent potential re-admissions. To achieve this, we propose applying machine learning on real-time data to determine whether a clinical intervention is needed coupled with chatbots to facilitate continuous reassurance based on available data (e.g., appointments, treatments, given advice).

A strength of our research is the iterative approach of three PPI workshops in which the outcome of each workshop informed the agenda and the aims of the subsequent workshop. Participants could reflect on the findings of the previous workshops by enriching their views and recalling specific personal experiences. At the same time, the research team could confirm the theoretical framework used to initiate the workshops, verify the findings of each previous workshop, and highlight key findings. However, the group setting of the workshops proved to be challenging, primarily due to the varying levels of PPI experience across the group, limiting any technical input from more experienced participants. In addition, the virtual activities did not engage the participants as much as the in-person workshops would have and required additional time. Despite the challenges, this setting allowed us to recruit participants that we otherwise would not have been able to as travelling to venues was no longer a burden. To understand how our proposed app can be effectively applied to clinical practice, we will need to deploy the app within the remote setting and gather feedback from both patients and healthcare providers. It is also important to evaluate the long-term effectiveness, scalability, and potential limitations of the app through usability testing studies and large-scale clinical trials. Additionally, determining whether reassurance has a measurable impact on adoption and compliance, including establishing comprehensive and reliable measures of reassurance, specifically in the context of RPM, are also potential areas of future investigation.

6 Conclusion

The majority of cancer patients go through the post-operative post-discharge period which involves additional challenges compared to the rest of the cancer journey. In this study, participants confirmed the special and additional needs which occur as a result of surgery and confirmed the period where they are left on their own post-surgery as one of the most critical. Participants identified reassurance as central to their recovery and that it should be incorporated within Remote Patient Monitoring (RPM) technologies. Through our design recommendations, we anticipate this can improve adoption and compliance of RPM technology during this specific period. Finally, these recommendations are capable of enhancing the care provided to cancer patients, improving health outcomes and expanding into the acute care for other chronic diseases, specifically those that involve a major surgery.

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