Delivering effective care through mobile apps

Citation for published version:
Cucciniello, M, Chiarini Tremblay, M, Tarricone , R, Porumbescu, G & Desouza, K 2020, Delivering effective care through mobile apps: Findings from a multi-stakeholder design science approach. in S Hofmann, O Müller & M Rossi (eds), *Designing for Digital Transformation. Co-Creating Services with Citizens and Industry. DESRIST 2020. Lecture Notes in Computer Science.* Lecture Notes in Computer Science, Springer, pp. 3-14. https://doi.org/10.1007/978-3-030-64823-7_1

Digital Object Identifier (DOI):
10.1007/978-3-030-64823-7_1

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Peer reviewed version

Published In:
Designing for Digital Transformation. Co-Creating Services with Citizens and Industry. DESRIST 2020. Lecture Notes in Computer Science

Delivering Effective Care through Mobile Apps: Findings from a Multi-Stakeholder Design Science Approach

Abstract. In this paper, we use a design science approach to develop a mobile app for lung cancer patients that facilitates their interactions with their clinicians, manages and reports on their health status, and provides them access to medical information/education. This paper contributes to the information systems literature by demonstrating the value of design science research to co-create solutions that advance health care outcomes through technological innovations. The design process engaged a diverse cast of experts and methods, such as a survey of oncologists and cancer patients, a workshop, roundtables and interviews with leading patient and clinician association representatives and focus groups, including two panels each of clinicians and cancer patients. Our approach also develops actionable knowledge that is grounded in evidence from the field, including design guidelines that recapitulate what we learned from the design-testing-redesign cycles of our artefact.

Keywords: healthcare, m-health, cancer care, value co-creation

1 Introduction

Mrs. Rossi[1] found it difficult to describe how angry, depressed, and betrayed by her own body she felt when she was initially diagnosed with lung cancer almost 3 years ago. These feelings intensified once she began therapy.

> "*When necessary, I would prefer to easily communicate with my clinician because he's the only one who really understands how I feel and explains what I should do or expect. However, I know that he's very busy and takes care of many patients. I am embarrassed to call him whenever I feel like I need to speak to him*".

Mrs. Rossi was one of the many participants who we interviewed during this research. Many of the patients we spoke with reflected upon numerous instances in which they wished they could have had closer contact with their physician. Patients noted feeling alone during this long and difficult journey. Given the demands on a physician's time, patients reported that they felt uncomfortable sharing updates on their condition or requesting information because they did not want to be a nuisance. Patients also regularly failed to measure key indicators (e.g., weight and temperature) due to the lack of real-time and personalized reminders between hospital visits (which could be 21–30 days apart). Thus, their ability to manage their care on a regular basis was limited.

The sentiments expressed by the cancer patients we interviewed are not surprising. Research shows that care models that are successful at improving outcomes and reducing costs succeed in enhancing patient and family engagement in self-care and coordinating care and communication among patients and providers [1]. For example,

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[1] The quotes are translated from Italian.

Singh, Drouin [2] conducted a scoping review[2] and found that self-management is essential to caring for high-need, high-cost populations. Furthermore, Hong, Siegel [3] found that successful care management programs 1) consider care coordination to be one of their key roles, 2) focus on building trusting relationships with patients and their primary care providers, 3) match the team composition and interventions to patient needs, 4) offer specialized training for team members, and 5) use technology to bolster their efforts. In general, patient understanding, trust, and clinician-patient agreement affect intermediate outcomes (e.g., increased adherence and better self-care skills) that in turn affect the health and well-being of the patient [4].

Identifying interventions capable of improving self-care and coordination with health care providers for cancer patients is a topic of growing importance in that chronic diseases, such as cancer, are a major reason for increased healthcare spending [5]. Among chronic diseases, cancer is the second leading cause of mortality and was responsible for 8.8 million deaths in 2015. Globally, nearly one in six deaths is due to cancer [6]. We focus on lung cancer, which is the most common cancer worldwide, accounting for 1.8 million new cases and more than 1.6 million deaths per year – more than breast, colon and prostate cancers combined [7].

In this paper, we investigate the use of mobile phones, one of the most accessible forms of IT that has served as a platform for significant innovations that have impacted almost all aspects of society. According to the Pew Research Centre's 2017 report, more than three-quarters of American adults (77%) now own a smartphone, but the fastest growing demographic is people over 50, 74% of whom now own a device. In recent years, the emergence of mobile health apps in health care management has helped to overcome geographical and organizational barriers to improve health care delivery [8]. In 2018, approximately 50% of mobile phone users had at least one mobile health app on their mobile phones [9].

Studies stress the importance of stakeholder input in mHealth application development for them to reach their potential. Unfortunately, many mHealth apps are designed without considering the needs of either patients or clinicians [10]. The literature lacks empirically validated guidelines or process models on how to design apps *with* stakeholders rather than *for* stakeholders [11]. We utilize a design science approach to develop a mobile app for lung cancer patients that facilitates their interaction with their clinicians, manages and reports on their health status, and provides them access to medical information/education. Our approach co-creates the IT artefact in collaboration with cancer patients and clinicians, who are the two important stakeholders. Our four aims are as follows: 1) identify what functionality is to be included in the mHealth app so the app is valuable for healthcare processes (improving patient-clinician relationships and the effectiveness of care delivery); 2) design an mHealth app that is valuable for patients and clinicians and includes them at the center of the design process; 3) test, redesign, and evaluate the validity of the mHealth app; and 4) identify generic design guidelines that can be utilized for the creation of mHealth apps for the management of chronic diseases. After completing the research process de-

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[2] For details on the scoping review, please see http://hlwiki.slais.ubc.ca/index.php/Scoping_reviews

fined above, we conducted a reflective examination of our findings and identified emergent themes that we further developed into design guidelines. These design guidelines summarize what we learned from the design-testing-redesign evaluation cycles of our artefact and represent actionable knowledge that is grounded in evidence from the field.

2 Background

mHealth can be particularly important to cancer patients receiving treatments because they experience one or more side effects that can have a profound effect on their quality of life [12] and can also lead to dose delays, dose reductions, reductions in dose density and, in some cases, dose discontinuation. This reduces the effectiveness of chemotherapy and leads to worsening health for the patients [13]. Furthermore, these patients substantially increase the utilization of healthcare resources through increased hospitalization, emergency room visits, and the adoption of palliative treatments and ultimately increase the care-giving burden, which results in increased costs for healthcare systems, patients and care givers.

Mobile monitoring devices could allow patients who experience severe symptoms to measure and record their health conditions and send the data electronically to physicians or specialists without delay, which also empowers patients to increase their self-confidence and self-management [14]. Currently, mHealth solutions are used for limited purposes in cancer care, with a prevailing focus on treatment activities [15]. This underutilization may be due to several factors, including environmental, regulatory, technological, and organizational elements [14] or the distinctive characteristics of the target populations (patients and clinicians). For example, consumers are concerned about the use of their data when using mobile devices for health-related activities, which dilutes the potential to collect real-world data for research and development. Some medical doctors fear that mHealth may jeopardize the patient-physician relationship and increase their workload [16]. Providers are reluctant to adopt mHealth technologies unless these services are adequately reimbursed [17]. Huckvale and Car also noted that apps are normally designed without considering the needs of their users, including both patients and clinicians [10]. In fact, despite the important role physicians play in the success of mHealth initiatives, little empirical research has examined how physicians use mHealth to manage patient health outcomes [18].

3 Design-Test-Re-Design: The Case of LuCApp

We designed, tested, redesigned and evaluated LuCApp, an mHealth app for lung cancer. Our research process is described in Figure 1.

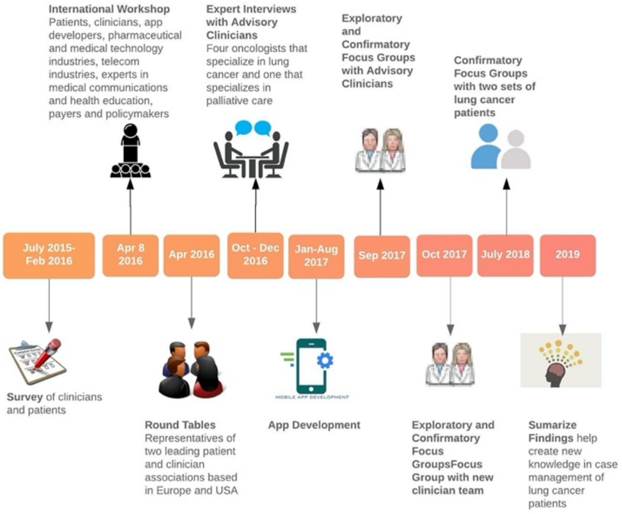

Fig. 1. Research Process

We distributed two surveys targeting two populations of mHealth application stakeholders – randomly selected cancer clinicians and patients who use Internet-enabled mobile devices, such as smartphones. The two survey instruments were developed after consulting the literature and previous experiments on mHealth[3]. The results from the survey were shared with several stakeholder groups to solicit input and feedback. An international workshop was organized in Milan on April 8, 2016, to facilitate interactions with more than 100 stakeholders, including patients, clinicians, app developers, the pharmaceutical and medical technology industries, telecom industries, experts in medical communications and health education, payers and policymakers.

The feedback from the workshop was used to develop a set of questions that we posed to an expert roundtable. The roundtable consisted of four participants who represented two leading patients' and clinicians' associations based in Europe and the USA. The aim was to gather more specific insights and suggestions about the design and development of a lung cancer app. The discussion was moderated by a member of the research team. The roundtable was recorded and later transcribed for analysis. The moderator utilized probing questions to solicit suggestions from the participants concerning three main themes: 1) information content, 2) interface design, and 3) usability. The roundtable results were in turn used to create an interview script that was utilized to conduct five in-depth interviews with oncologists from different Italian hospitals. The participants included four oncologists that specialized in lung cancer

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[3] The study survey is available upon request. Citation blinded for review.

and one clinician that specialized in cancer palliative care[4]. Each interview lasted approximately 60 minutes, was recorded and was analyzed by two independent coders using content analysis to identify the main themes. The clinicians helped us identify a specific type of cancer patient who could benefit from an mHealth app – patients diagnosed with small or non-small cell lung cancer that were eligible for chemotherapy, immunotherapy or biological therapy.

We defined the requirements our mHealth application for supporting patients affected by lung cancer under treatment with chemotherapy, immunotherapy or biological therapy, LuCApp. It was designed with four main purposes:

1) Improve the patient's quality of life (QoL) by helping to achieve better management of side effects caused by cancer therapies.
2) Achieve earlier detection of any worsening of the disease by bridging the gap between clinicians and outpatients.
3) Reassure patients by providing them with a means for supporting their continuity of care (which is particularly important for fragile persons).
4) Improve the efficiency of the healthcare system by the real-time acquisition of critical data that can be useful for the clinician during patient visits. The app helps to collect and synthesize data for use by clinicians during a visit, which saves unnecessary collection time during appointments.

4 LuCApp Development

The app was developed by an IT firm in collaboration with the team of researchers involved in this study. The preliminary version of the app was built for both the iOS and Android platforms. The lung cancer application was designed and developed to be used in Italy; thus, all of its features and functions are in Italian. Figure 2 shows the main screen of the app. LuCApp also includes automatic alerts, reminders and tips that complement the patient's therapy. The app was developed to comply with EU privacy regulations and the General Data Protection Regulation (GDPR). In addition, the development followed all of the guidelines from the Apple Store Review Guidelines and Android Market Guidelines. There are two versions of the app, one for clinicians and one for patients. After the feasibility assessment, the first prototype was released to the research team for trial and feedback. The overall development effort, which lasted eight months, was performed utilizing DevOps methods [19] to provide the following for all nine releases in parallel: integration with the validated platform, full execution of the full test suite, quality control (according to European regulatory standards), and release reliability. By leveraging DevOps approaches, the team of researchers obtained rapid feedback throughout the development, test, and implementation processes, allowing them to evaluate all proposed improvements iteratively. In turn, the research team contributed feedback, thereby accelerating the review process in both the Apple and Android stores.

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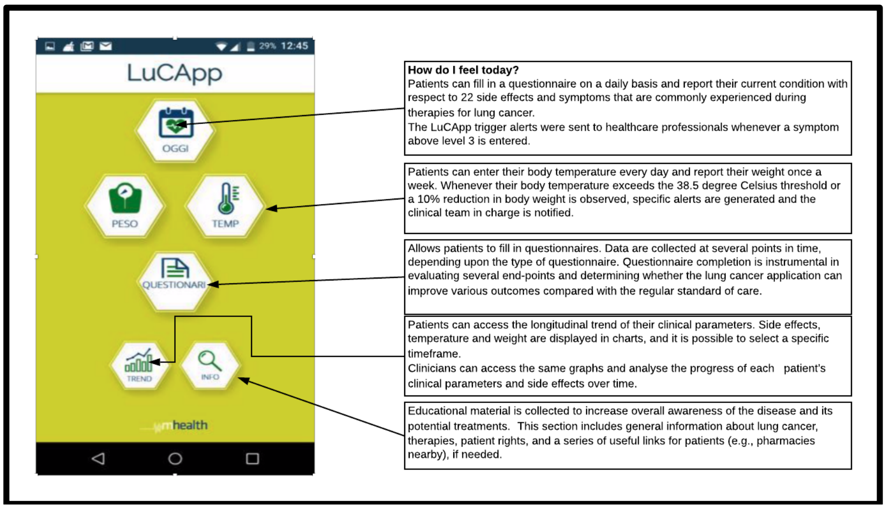
[4] Palliative care is any treatment that focusses on reducing symptoms, improving quality of life, and supporting patients and their families.



How do I feel today?
Patients can fill in a questionnaire on a daily basis and report their current condition with respect to 22 side effects and symptoms that are commonly experienced during therapies for lung cancer.
The LuCApp trigger alerts were sent to healthcare professionals whenever a symptom above level 3 is entered.

Patients can enter their body temperature every day and report their weight once a week. Whenever their body temperature exceeds the 38.5 degree Celsius threshold or a 10% reduction in body weight is observed, specific alerts are generated and the clinical team in charge is notified.

Allows patients to fill in questionnaires. Data are collected at several points in time, depending upon the type of questionnaire. Questionnaire completion is instrumental in evaluating several end-points and determining whether the lung cancer application can improve various outcomes compared with the regular standard of care.

Patients can access the longitudinal trend of their clinical parameters. Side effects, temperature and weight are displayed in charts, and it is possible to select a specific timeframe.
Clinicians can access the same graphs and analyse the progress of each patient's clinical parameters and side effects over time.

Educational material is collected to increase overall awareness of the disease and its potential treatments. This section includes general information about lung cancer, therapies, patient rights, and a series of useful links for patients (e.g., pharmacies nearby), if needed.

Fig. 2. – Screenshot of LuCApp.

5 LuCApp Test and Redesign Using the Exploratory Focus Group

After careful consideration of several possible techniques that would allow us to test, redesign and evaluate our LuCApp, we decided to use focus groups that consist of oncologists and patients [20]. The focus groups allowed us to probe them on key ideas – specifically, on the functionality and usefulness of the app. Furthermore, the interaction between the respondents allows for key insights that normally do not surface with other techniques. Tremblay, Hevner [20] described two types of focus groups: exploratory focus groups (EFGs) for the design and improvement of an artefact and confirmatory focus groups (CFGs) for evaluating the application in the field. We used the EFGs to provide feedback for the improvement of the design of the lung cancer application. In the second phase, no additional changes were made to the lung cancer application, and the CFGs were used to evaluate the app for usability and usefulness.

For the EFGs (as well as for the CFGs), the planning process included creating a carefully planned script. The main topics of both EFGs included understanding i) how using a mobile health app as part of the routine practice of managing cancer patients could affect how clinicians monitor and evaluate patient health outcomes and their decision-making process and ii) how the app could affect patient quality of life and the quality of services offered by healthcare institutions. Before each focus group, the moderators introduced the project, explained the objectives and provided general information about the focus group. Furthermore, possible improvements to the app were agreed upon, which was aimed at refining the app before the final release.

Specifically, sample screenshots were used to gather users' feedback on the overall usability (e.g., layout, font size, and color) and attractiveness of the functions (e.g., content and design). The focus group script was divided into several parts reflecting the main operational implications from a clinician's perspective (the script is in Italian and is available upon request). The focus groups (both the EFGs and the CFGs) were recorded and professionally transcribed. The transcripts were analyzed using computer-assisted qualitative data analysis software (CAQDAS). After the initial coding had highlighted relevant discussion themes, all of the text segments were iteratively analyzed. Themes were added or merged until they effectively represented all of the text segments and captured the essence of the discussion. The coding frame was refined with discussions about areas of disagreement and consensus, and any differences in interpretation were reconciled by the authors (the inter-rater reliabilities were 78% for EFG1, 76% for EFG2).

5.1 Feedback from Clinician Exploratory Focus Groups (EFG1 and EFG2)

The clinicians in both EFGs agreed that LuCApp could improve their ability to evaluate the patient's condition. Most of the focus group participants made similar comments and discussed several instances in which this app would be useful in their daily activities. The clinicians particularly appreciated the possibility of being informed in real time by patients about their symptoms and about the severity of their symptoms; this timeliness would allow them to quickly contact the patients and make suggestions for next steps. Furthermore, clinicians found the "trend" component of the app of major importance. One doctor focused on how the use of the app could change current standards, highlighting that instead of using email and WhatsApp, this approach could be a more systematic, innovative and effective solution. However, one clinician in the second focus group noted that the effectiveness of the solution could depend upon the stage of the disease and the type of cancer; patients often have serious symptoms, and as they become worse, it would be difficult for them to use LuCApp by themselves.

The findings from the clinicians can be summarized in two categories: *functionality* and *usefulness*. In terms of functionality, it was clear that the navigation and structure of the app must be evident for both patients and clinicians. Regarding the usefulness of the app, physicians want the ability to evaluate patient progress and monitor patient symptoms; they felt that they could improve the patient's quality of life if the app provided mechanisms to reassure the patient. It is also important to them that the app integrate all necessary clinical information. Finally, the physicians want the app to give them the ability to continuously evaluate patient progress and monitor patient symptoms.

5.2 Feedback from Patient Exploratory Focus Groups (EFG3)

The patients stated that LuCApp reminded them of a powerful diary that they could fill in every day and share in real time with clinicians. The clinicians could then access the patient's information and be in contact with the patient when necessary. The patients also emphasized the relevance of symptom monitoring. This functionality would provide a mechanism to collect data that could be used to improve therapeutic treatment plans, not only for themselves but also for other patients now and in the future. The patients noted that LuCApp would make them feel safer. By using LuCApp, they would be able to communicate their symptoms in real time in cases when the symptoms were mild, moderate, severe or extreme. This ability is particularly important when patients have mild and moderate symptoms that could be serious but are not usually communicated to the clinician. The participants stated that this reporting could also help advance science; clinicians could learn what mild and moderate symptoms could lead to adverse outcomes.

An important emergent theme is how LuCApp could influence the patient's relationship with caregivers. Stressing the importance of keeping their caregivers in the loop, some participants suggested that it could be useful to create a login and password to LuCApp for them to access important information about the patient’s care. This ability would be helpful in reassuring the caregivers, particularly when the it is a spouse or son/daughter. The participants indicated that LuCApp would improve their relationship with the clinicians because the clinicians would be able to access all of the data and information in real time. The participants were aware that the app would not substitute for real contact with the clinicians during regular checks but felt that LuCApp would keep the clinician better informed and updated about what is happening with the patient.

We considered this initial feedback about the app from the patient EFG and particularly what this might mean for our design guidelines. Regarding the *functionality* and *usefulness* of the app, we learned from the patients that: 1) the navigation and structure must be clear; 2) the app must use fonts and colors that are appealing to patients; 3) patient quality of life can be improved if the app provides mechanisms to reassure the patient; and 4) the app must facilitate communication between clinician and patients.

5.3 Redesign of LuCApp

The comments on user needs and preferences and app functionality and usefulness from all three exploratory focus groups were classified using the following themes: content and information (e.g., features, functions and relevant symptoms), navigation and structure, and design and presentation (e.g., use of color, graphics, and amount of text). The considerations for selecting which modifications to apply included the number of participants who mentioned the app, the context of use, overlap/integration with existing information and technical feasibility.

6 LuCApp Evaluation Using Confirmatory Focus Groups

The same panel of clinicians was included in the two clinician EFGs. However, a new panel of patients was involved in CFG3. Like the EFGs, the CFGs were recorded and professionally transcribed (the inter-rater reliabilities were 79% for CFG2 and 77% for CFG3). We applied the same demo approach described for the EFGs; illustrating the revised version of the mobile app based on the comments and suggestions received in the EFGs. The participants were presented with a new list of symptom definitions. The list that was previously presented during the EFGs was revised and simplified using less medical jargon, a suggestion made by the clinicians during the EFGs to make the list less difficult for patients to understand. The clinicians (who had also participated in the EFGs) said the new labels were very clear. Moreover, the patients agreed even though they did not consider this issue to be a major one to be fixed because they considered themselves familiar with medical wording, and the issue was part of a single case; they did not request a specific modification to simplify the wording. The clinicians in EFG2 had suggested the elimination of graphs and trends because they were worried that they would unnecessarily scare the patient (e.g., if they saw that they vomited three times in one week). When we raised the issue to a different panel of clinicians (CFG1), they initially did not understand why the change was necessary, but after explaining the reasons, they eventually agreed that showing patients this type of information was of little use and could have a negative effect on their quality of life.

Conversely, EFG3 (patients) was enthusiastic about the trends section, finding it one of the most useful functions. When we presented this functionality to CFG3 (patients), we asked them to decide whether to keep the trends functionality or to remove it. We explained that the clinicians were worried that this information could scare or stress them. The patients did not agree with the clinicians and were in complete concordance with the patient EFG. They felt that the trend section was one of the most important and relevant features. The research team decided to keep this functionality in the latest version of LuCApp. Based on results from this phase, we conclude that the app was well received by the users.

7 Design Guidelines

We derived three categories of design guidelines based on a reflexive examination of the themes that emerged from the survey, workshop, roundtable, expert interviews and focus groups: *design process, functionality* and *usefulness.*

Our process design guidelines indicate the fundamental role of stakeholders in the development of the app. Our two functionality design guidelines are related to the usability and attractiveness of an mHealth application. Three usefulness design guidelines indicate the functionality necessary in the mHealth application to achieve our goal – better coordination in the management of chronic disease.

Design Process

DG1: Stakeholder involvement. Stakeholders must be involved not only in the requirement gathering stage but also throughout the entire iterative design process. Direct and active interaction and cooperation between users and developers of the app enhances the quality, functionality, usability, design and utility. Different stakeholders might perceive information elements differently; thus, including different viewpoints improves the design.

Functionality of mHealth App

DG2: Navigation and structure must be clear for both patients and clinicians. The typical lung cancer patient is elderly and needs an app that is easy to navigate through the different sections and screens (i.e., scroll systems should be used). Conversely, clinicians do not want to spend too much time searching for information. Ease capturing of information (e.g., dropdown boxes) is important to minimize effort of use.

DG3: Presentation must use fonts and colors that are appealing to patients. The typical lung cancer patient is elderly; thus, the font size and spacing of text should ensure good readability, the text for labels and buttons should be clear and concise, and the colors should provide good readability and good contrast.

Usefulness of mHealth apps

DG4: Ability to evaluate patient progress and monitor patient symptoms. Symptom descriptions should be simple and clear. Symptoms list should be accurate, complete and disease-specific. Functionality should include the ability to monitor and assess side effects caused by cancer therapies.

DG5: Improve patient quality of life by providing mechanisms to reassure the patient. Provide the possibility of sharing patient's symptoms and side effects with clinicians in order to receive rapid feedback about what to do and facilitate earlier detection of worsening disease.

DG6: Integration of all clinical information. Provide the ability to port data directly into other systems and platforms they use.

DG 7: Ease of communication between clinician and patients, including the ability for the clinician to view patient history

8 Contributions

In this study, we introduce a mixed-methods design process based on a combination of quantitative, qualitative, exploratory and evaluation activities, such as a survey, workshops, interviews, and focus groups. This approach allowed us to obtain nuanced understandings of both the clinicians' and patients' needs and of the challenges and intricacies of chronic disease management of a particularly complex chronic disease, lung cancer. Lung cancer patients tend to be elderly and have a high symptom burden, and the disease has both difficult and painful physiological and major psychological effects.

As a team, we reflected that without following the design-test-redesign design science approach highlighted in the paper, *we likely would have developed a completely different app.* The direct and active interaction and cooperation between the users and developers of the app enhanced its quality, functionality, usability, design and utility, as was emphasized during the interviews and the focus groups we conducted with the clinicians. The overall process of our research highlighted how a design science approach can be used to build useful mHealth applications using approaches that bolster user acceptance. We proposed a series of design guidelines that highlight the overall implications and contributions of this work. Our guidelines (or technological rules) were built as a reflective cycle [21]. We chose the case management of a chronic disease, specifically, cancer. Our design guidelines were a result of the research team reflecting on our journey and can be categorized as design knowledge that can be tested and refined in subsequent cases in other chronic disease management contexts and/or be directly used by practitioners [21].

We acknowledge that in a perfect world, we would have had the opportunity to test the app live and collect feedback from a large number of users. However, we must reconcile this ideal with the realities of the world in which we live. The developed app was tested in a smaller group due to resource constraints. In addition, we believe that although the collected feedback might not be representative of every opinion of a potential user, is rich and informative. Another limitation of our study is that it was solely conducted in one country, Italy, which might hinder the generalizability of our results. Cultural beliefs and values might influence the opinions of both health professionals and patients. Therefore, further research is needed to investigate the validity of our work across different jurisdictions.

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