MEDINFO 2023 — The Future Is Accessible
J. Bichel-Findlay et al. (Eds.)

doi:10.3233/SHTI231012

Oncology Patient Portal: Understanding User's Needs and Expectations

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Abstract. The objective of this work was to explore the needs and expectations of the users of the Alexander Fleming Institute (IAF) regarding patient-oriented information systems, with the purpose of planning and prioritizing the implementation of improvements in the patient portal. The textual comments of patients who were treated at the institution between November 2021 and April 2022 and answered the satisfaction survey sent by IAF were analyzed using the content analysis technique. The results showed 6 main emerging issues: (1) the need for patients to have their clinical and administrative information in a single platform; (2) to have their clinical documentation available at the appropriate time; (3) to have clearer and more friendly information on preparation before diagnostic studies and (4) chemotherapy first time talks; (5) more accessible information on complementary treatments in the oncological context; (6) in-app appointment queue functionalities. The findings reported in this work served as an input to design an improvement plan for the patient portal and the institution's digital ecosystem.

Keywords. Patient portal, oncology, qualitative study, patient survey

1. Introduction

The emergence and integration of new information and communication technologies (ICTs) into people's daily lives is changing the way patients receive health care [1]. ICTs have significant potential at giving patients access to their own clinical information [2]. Particularly, patient portals can favor the communication of health information [3-5] and contribute to reducing stress in patients due to lack of information [6]. Patients usually value positively having instruments that facilitate their health management [7].

The arrival of this technology accounts for a paradigm shift in the doctor-patient relationship [8]. Taking advantage of the improvement of access to information and communication provided by the internet. This change empowers patients, who gain greater control over the actions and decisions that affect their health [9].

Regarding oncology patients in particular, there is evidence on how the use of health ICTs can help people undergoing oncological treatments [10-12]. However, to ensure its optimal use, it is important to take into account the need for more adapted designs, the soundness of the information provided, as well as security and privacy issues [13].

The Alexander Fleming Institute (*Instituto Alexander Fleming* | IAF) has more than 25 years of history, dedicated to the diagnosis, treatment and monitoring of patients with

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oncological diseases. It is a private reference center located in Buenos Aires City. It has 95 inpatient beds and carries out more than 10,000 external consultations (EC) annually. Furthermore, IAF has a Day Hospital with 21 Chemotherapy treatment chairs, providing assistance to approximately 70 patients per day.

As a central piece of its Health Information System (HIS), the Institute began implementing an Electronic Medical Record (EHR) in 2018. In 2021, a patient portal called "Mi Portal" was implemented. At the time of this work, it was in its first public version, limited to appointment scheduling.

The objective of this work was to explore the needs and expectations of the institution's users regarding patient-oriented information systems, with the purpose of planning and prioritizing the implementation of improvements in "Mi Portal" and in IAF's digital ecosystem.

2. Methods

A qualitative exploratory-descriptive study was carried out. The qualitative method was chosen because it allows us to understand, from the perspective of the users, the needs they have regarding the information system.

Since the beginning of the COVID-19 pandemic, in order to implement improvements in the quality of care, satisfaction surveys have been conducted for patients being treated at IAF. Surveys are sent via email to each patient's registered email address the day after any visit at the institution. Either after a medical appointment, lab or image studies, chemotherapy treatment, etc. There were a number of different surveys, depending on the care received by the patient. At the end, every questionnaire had a free text field to express comments or opinions regarding the care received and the service provided by IAF. In this work, we explored all the free text comments entered by the surveyed patients in the period from November 1, 2021 to April 30, 2022.

The analysis was carried out by a team of specialists in health informatics in two stages. During the first stage, those comments that referred to needs and expectations regarding patient-oriented information systems were selected. This concept was defined as demands or suggestions about potential improvements in the HIS, which can generate greater satisfaction and ease of use by users.

Once these comments had been identified, now at the second stage, they were analyzed using the thematic analysis technique [14], using a collaborative spreadsheet. First the emerging categories were identified and then the textual material was classified, assigning tags according to the group each comment belonged.

The study was carried out in accordance with national and international regulations. All data was treated with the utmost confidentiality, with restricted access on local servers, available only to authorized personnel.

3. Results

A total of 3,326 surveys were answered by patients during the study period. Since the comment field was mandatory, all respondents completed it. Of the total comments analyzed, 431 were selected during the first stage, for the thematic analysis of the second stage.

The selected comments belonged to 422 people, (a person could have answered the survey more than once, after different appointments). These patients mostly identified themselves as women (65%) and the most common age group (45%) was from 61 to 75 years old (Table 1).

Table 1. Stage 2 participants characteristics N=422

Age	Number or participants
16 to 30 years	8 (1,9%)
31 to 45 years	51 (12%)
46 to 60 years	126 (29,9%)
61 to 75 years	191 (45,3%)
> 76 years	46 (10,9%)
Gender	**Number or participants**
Female	275 (65,2%)
Male	146 (34,5%)
Others	1 (0,3%)

Based on the thematic analysis, we identified 6 emerging themes (Table 2): platform unification (having all their information in a single portal); clinical information availability; information on study preparation; information on complementary treatments; chemotherapy first time talk; in-app appointment queue screen.

Table 2. Emerging themes identified from patient's comments N=431

Themes	
Platform unification	263
Clinical information availability	58
Information on study preparation	51
Information on complementary treatments	37
Chemotherapy first time talk	11
In-app appointment queue screen	3
Others / Non-relevant	8

4. Discussion

Our results showed that the main emerging issues were the need for patients to have all their clinical and administrative information on a single platform. Furthermore, patients indicated that they need to have their clinical documentation available, in a timely and legible manner. They also reported the need for clearer and more friendly information on preparations before carrying out diagnostic studies and before starting treatment in the day hospital, as well as more accessible information on complementary treatments in the oncological context. Likewise, with regard to face-to-face outpatient care, they suggest that better queueing channels be offered.

Regarding the comparison with other experiences, it should be noted that there is a variety of bibliographic evidence that inquires about patient needs prior to HIS design. Focusing the design process on the needs and expectations of potential end users is key to developing patient-oriented computer tools that are usable, useful and functional [15]. Within the bibliographic corpus, we highlight two works that focus on oncological patients, to dialogue with our results.

First of all, a German work published in 2015 [16], where the authors set out to explore the needs of users with respect to the desired information and functions of patients, to design a personal patient portal. They conducted focus groups with patients and their caregivers, as well as with health professionals. The results highlighted that it was essential for patients to have a tool that represented the chronology of their disease and care processes. Also, the need for patients to have general and specific oncological information about each type of tumor emerged. Finally, the importance of designing health information in an accessible way for the patient was underlined.

For its part, a more recent study, published in 2020 [17], aimed to investigate the information needs of Taiwanese women with breast cancer to design a mobile application that accompanies women in their oncological treatment. They conducted focus groups and individual interviews to gather information on the needs and expectations of potential end users regarding the application. In the results, the authors identified as main topics information on oncological treatments, recommended physical activity and diet, emotional support, self-registration of health data, social resources, peer-to-peer experience exchange and expert consultation.

The results reported in both publications have points in common with the findings of our work. First of all, information on oncological treatments, as well as on complementary therapies to treatment (nutritional, psychological monitoring, physical activity) occupy a prominent place among the expectations and needs of oncological patients. Secondly, the importance for the patient of accessibility and availability of their clinical information. Regarding the differences, in the last commented work, the exchange of experiences between peers and social resources arise as needs, topics absent in our findings, probably due to the differences between the specific contexts.

The strength of this work focuses on the possibility of developing an improvement plan in the services offered to patients, taking into consideration the perspective of the users themselves. Knowing the needs of patients allows prioritizing the stages of development and implementation, in a context of limited resources. In this way, an attempt is made to deliver first functionalities that the patient perceives as most needed and of greater impact.

Following these results, we prioritized for the second version of the patient portal app to merge “Mi Portal” with the imaging results portal and laboratory results. So users can have their results and appointments available on a single platform. At the same time, it was planned to review the information on study preparation and make it available in an accessible format for patients. Regarding the need to have clinical documentation, progress is being made with EHR implementation projects on the field of hospitalization and digital order. Concerning the need for information on complementary treatments, it was planned to make this information available not only on “Mi Portal”, but also on other patient-oriented channels (social networks, screens in waiting rooms and the IAF website). On the other hand, we produced prerecorded and interactive videos focusing on the “chemotherapy first time talk”, which will be available on the patient portal, with the aim of facilitating access by the patient and his family to information about the treatments. Finally, we are evaluating an integration between the queue screen system with “Mi Portal”, so that patients can be notified of their appointment on their cell phone.

As future lines of work, after implementing the action plan, a range of lines of research opens up to continue exploration. It would be pertinent to collect and analyze usage data of the portal in general and of each functionality in particular and to carry out usability and satisfaction evaluations.

5. Conclusions

The findings reported in this work served as an input to design an improvement plan for the patient portal and the institution's digital ecosystem.

References

[1] Elder NC, Barney K. "But what does it mean for me?" primary care patients' communication preferences for test results notification. Jt Comm J Qual Patient Saf. 2012 Apr;38(4):168-76, doi: 10.1016/s1553-7250(12)38022-7.

[2] Choudhry A, Hong J, Chong K, Jiang B, Hartman R, Chu E, Nelson K, Wei ML, Nguyen T. Patients' preferences for biopsy result notification in an era of electronic messaging methods. JAMA Dermatol. 2015 May;151(5):513-21, doi: 10.1001/jamadermatol.2014.5634.

[3] Tavares J, Oliveira T. New integrated model approach to understand the factors that drive electronic health record portal adoption: cross-sectional national survey. J Med Internet Res. 2018 Nov;20(11):e11032, doi: 10.2196/11032.

[4] Baldwin DM, Quintela J, Duclos C, Staton EW, Pace WD. Patient preferences for notification of normal laboratory test results: a report from the ASIPS collaborative. BMC Fam Pract. 2005 Mar;6(1):11, doi: 10.1186/1471-2296-6-11.

[5] Johnson AJ, Easterling D, Nelson R, Chen MY, Frankel RM. Access to radiologic reports via a patient portal: clinical simulations to investigate patient preferences. J Am Coll Radiol. 2012 Apr;9(4):256-63, doi: 10.1016/j.jacr.2011.12.023.

[6] Ganiele, María de las Nieves; Peper, Francisco E.; Rodríguez Tablado, Manuel; Ruiz Yanzi, María Victoria. La complejidad en el pensamiento médico y la toma de decisiones (Spanish Edition). 2018, Edición de Kindle.

[7] Plazzotta D, Sommer J. Informática en Salud Orientada a la Comunidad (Spanish Edition). 2018, Edición de Kindle.

[8] Zhu J, Ebert L, Liu X, Chan SW. A mobile application of breast cancer e-support program versus routine care in the treatment of Chinese women with breast cancer undergoing chemotherapy: study protocol for a randomized controlled trial. BMC Cancer. 2017 Apr;17(1):291, doi: 10.1186/s12885-017-3276-7.

[9] Fishbein JN, Nisotel LE, MacDonald JJ, Amoyal Pensak N, Jacobs JM, Flanagan C, Jethwani K, Greer JA. Mobile application to promote adherence to oral chemotherapy and symptom management: a protocol for design and development. JMIR Res Protoc. 2017 Apr;6(4):e62, doi: 10.2196/resprot.6198.

[10] Mooney KH, Beck SL, Wong B, Dunson W, Wujcik D, Whisenant M, Donaldson G. Automated home monitoring and management of patient-reported symptoms during chemotherapy: results of the symptom care at home RCT. Cancer Med. 2017 Mar;6(3):537-46, doi: 10.1002/cam4.1002.

[11] Vo V, Auroy L, Sarradon-Eck A. Patients' perceptions of mHealth apps: meta-ethnographic review of qualitative studies. JMIR Mhealth Uhealth. 2019 Jul;7(7):e13817, doi: 10.2196/13817.

[12] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 Jan;3(2):77-101, doi: 10.1191/1478088706qp063oa.

[13] Silhavy P, Silhavy R, Prokopova Z. Patients' perspective of the design of provider-patients electronic communication services. Int J Environ Res Public Health. 2014 Jun;11(6):6231-45, doi: 10.3390/ijerph110606231.

[14] Minoletti S, Rapisarda R, Giraldo L, Grande M, Sommer J, Plazzotta F, Luna D. User-centered design of a pediatric vaccination module for patients. Stud Health Technol Inform. 2019 Aug;264:1096-100, doi: 10.3233/SHTI190395.

[15] Zhou L, DeAlmeida D, Parmanto B. Applying a user-centered approach to building a mobile personal health record app: development and usability study. JMIR Mhealth Uhealth. 2019 Jul;7(7):e13194, doi: 10.2196/13194.

[16] Baudendistel I, Winkler E, Kamradt M, Längst G, Eckrich F, Heinze O, Bergh B, Szecsenyi J, Ose D. Personal electronic health records: understanding user requirements and needs in chronic cancer care. J Med Internet Res. 2015 May;17(5):e121, doi: 10.2196/jmir.3884.

[17] Hou IC, Lan MF, Shen SH, Tsai PY, Chang KJ, Tai HC, Tsai AJ, Chang P, Wang TF, Sheu SJ, Dykes PC. The development of a mobile health app for breast cancer self-management support in Taiwan: design thinking approach. JMIR Mhealth Uhealth. 2020 Apr;8(4):e15780, doi: 10.2196/15780.