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# An Online Community for Patient with Psoriasis with Built-in Self-Reported Questionnaires

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#### Abstract

This study presents an online psoriasis community developed with dermatologists in a PHR. We describe the interaction of users with this platform and the relationship between the use of self-report questionnaires, their results and users' subsequent contact with the healthcare system. Out of 2175 users that interacted with the platform, 477 visited the forums. 60% of those who completed questionnaires presented at least one abnormal result that prompted a recommendation for an outpatient visit. Although our data suggest a trend, we failed to find a statistically significant association between questionnaire severity and visits scheduling. To our knowledge, this is the first study that analyses the relationship between patient self-reported disease severity and the subsequent contact with the healthcare system.

## Keywords:

Personal Health Records, patient online communities, psoriasis.

#### Introduction

There is a growing need for patients to understand the context in which their health care takes place [1,2]. Patient portals are applications that can effectively promote communication of "health related" information [3], thus reducing patient anxiety due to information gaps [4]. In addition, they offer the possibility of registering symptoms, communicating with healthcare providers, receiving information about diseases and scheduling outpatient visits, among other functionalities [5].

"Psoriasis is a chronic inflammatory skin disease associated with a reduced life-quality" [6]. The information received by patients with psoriasis is often insufficient to support informed and shared decisions regarding treatment options. This affects treatment adherence and patient outcomes [6]. Online communities for patients with psoriasis provide education about the disease as well as psychosocial support. These benefits could be greater if specialized physicians participate in these communities [7].

For dermatologic conditions like psoriasis, available self-report tools such as the Dermatology Life Quality Index (DLQI) enable a more comprehensive approach of the disease that takes the patient's perspective into account. Patient-reported outcomes on psoriasis are also used to guide treatment and follow-up [8].

Personal Health Records (PHRs) have the potential to be a tool for patient self-management of chronic diseases [9]. Since 2007, the Hospital Italiano de Buenos Aires (HIBA) features a PHR aimed at giving patients access to their own health information and promoting communication with healthcare providers [10]. Considering the potential of a PHR to cover patient information needs, we developed an online community for patients with psoriasis. The platform was designed in collaboration with the Dermatology Department at HIBA to educate patients and families on their condition, promote the sharing of experiences between community members and improve patient follow-up [11]. This community was implemented as a functionality of our PHR in October 2019. It includes a section on information for patients; a forum for active participation (users can participate anonymously); a dynamic timeline displaying psoriasis related events such as scheduled visits to dermatologists; and a section offering selfreport questionnaires on disease severity.

Previous studies suggest that PHR's are a key route to engage patients in care. Despite their rising popularity and potential, there is no strong evidence for the positive effect of patient portals on health care processes and outcomes [5]. This low impact on health care outcomes could be due to low adherence to recommendations issued by the PHR.

The aim of this study was to describe an online community for patients with psoriasis and report user interaction with the platform. In addition, we analyzed the use of self-report questionnaires and subsequent contact with the healthcare system. We measured scheduled dermatology or rheumatology visits and their association with recommendations provided by self-report questionnaire results.

#### Methods

HIBA is an academic non-profit tertiary level organization that covers all health specialties at different levels of the health care system. Since 1998, HIBA has had its own health information system (in-house) [12]. An integrated PHR has been available since 2007. Its main functionalities include: appointment scheduling, test results visualization, patient-practitioner secure messaging, health information sharing, management of prescribed medication, and different modalities of teleconsultation. At present, it has more than 400,000 registered users [10]. For this study we included users of the psoriasis community who accessed the platform between September 30 and December 30, 2019.

The online psoriasis community features 4 validated self-report questionnaires: the Patient Report of Extent of Psoriasis Involvement (PREPI), the Psoriasis Symptom Inventory (PSI), the Dermatology Quality of Life Index (DLQI) and the Psoriatic arthritis screening and evaluation questionnaire (PASE). We used pre-specified thresholds to identify altered questionnaire scores, according to published literature [13-16].

Online versions of the questionnaires were designed to be included in the online community. Each questionnaire can be filled once a week, except the PASE, which is only available once a year. Dermatologists created rules to suggest in-person follow-up based on questionnaire results. Upon completing a questionnaire, the screen shows a follow-up recommendation, such as: "We suggest that you visit your dermatologist within the next month if you have not already done so".

Self-reported test results are available in the patient's EHR, and their physician can retrieve them during a consultation.

To analyze whether users considered the recommendations of the virtual community, we analyzed how many users scheduled an outpatient visit during the 3-month period following the implementation of the virtual community.

User characteristics and online community access are reported using descriptive statistics. Continuous variables are expressed as means and standard deviation, or median and range, depending on distribution shape. For categorical variables, absolute and relative frequencies (percentages) are reported. To compare scheduled outpatient visits (with dermatology and/or rheumatology) among users with and without altered questionnaire scores, we dichotomized users based on their self-reported scores (high vs. normal), considered the proportion of patients scheduling outpatient visits in each group and conducted a test of 2 proportions with a significance level of 0.05. We used R software version 3.6.0 for data analysis.

Written consent was obtained from all users accessing the PHR's privacy policy. This study was conducted in accordance with the Helsinki Declaration of 1975 and its late amendments. The study protocol was approved by the institutional Ethics Committee, with IRB approval number 5221.Written consent was obtained from all users accessing the PHR's privacy policy.

## Results

We included 2175 users who accessed the online community between September 30th. and December 30th., 2019. Mean age of users was 45 years (range 30-63), 60% were women.

During the 3-month study period, the online community was accessed by an average of 25.8 users per day (range 4 - 74 daily users). From the 2175 users, 217 accessed the online questionnaires and 447 visited the community forums. The most visited forums were those related to treatment topics (47.6% of all forum visits).

97 users completed 240 self-report questionnaires. PSI, DLQI and PASE were completed in a similar proportion (between 30 and 32.5%) while PREPI had the lowest rate of use (6.67%). Out of 97 users that completed online questionnaires, 60 users had at least one altered questionnaire score. Figure 1 shows the distribution of the scores for each questionnaire.



Figure 1–Distribution of the scores for self-report questionnaires

From the 97 users that completed the self-reported questionnaires, 12 users scheduled visits to dermatologists or rheumatologists. Table 1 shows the proportion of users that scheduled visits grouped by questionnaire results (normal or altered). 15% of patients with altered questionnaire scores scheduled outpatient visits (vs. 8% with normal questionnaire results). This difference was not statistically significant in our sample (p = 0.37).

Table 1-	- Scheduled	outpatient	visits
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		Scheduled outpatient visits (n)	Proportion of users who scheduled visits (95% CI)
Questionnaire	Users		
results	(n)		
Normal	37	3	0.08 (0.03 -
			0.21)
Altered*	60	9	
			0.15 (0.08 -
			0.26)

\*at least one questionnaire above normal

### Discussion

In this study, we described the interaction of users with the online community of patients with psoriasis during 3 months following its implementation. Besides, we explored the relationship between the use of self-report questionnaires, its scores and recommendations, and the subsequent contact with the healthcare system through scheduled dermatology or rheumatology visits.

Out of 2175 users that interacted with the platform, 477 visited the forums, their main interests being those topics related to treatment options. Regarding online questionnaires, 60% of respondents presented at least one abnormal questionnaire result that prompted a recommendation for an outpatient visit.

Key strengths of our study include the use of structured user data and questionnaire results, our selection of validated questionnaires and interdisciplinary design/development of the patient community.

Limitations include the relatively short study period. Another limitation is that the symptom severity reported by patients was not verified by specialists. This limitation is shared by many online patient communities with built-in self-report tools. We sought to diminish this problem by selecting widely used questionnaires that had been validated in previous studies.

Our data suggest relatively low adherence to recommendations issued by the PHR, which might explain other authors' findings regarding the PHR's lack of measurable impact on clinical outcomes. We failed to find a statistically significant association between questionnaire severity and scheduling of outpatient visits. This could reflect insufficient power due to a relatively small sample size, or a lack of true association. However, our results are similar to other studies that report a lack of impact on health care outcomes.

Other studies have examined the role of online communities as sources of education and psychosocial support, highlighting that these values could be enhanced if they were used by the dermatology community to deliver integrated care to patients affected by this disease [17]. The value of obtaining online selfreported experiences on patients with psoriatic arthritis was also reported [18]. On the other hand, Fraccaro P. et al. reported that PHRs are considered valuable conduits for patient's selfmanagement. However, they often fail to prove a measurable impact on health care processes and outcomes [5].

From our knowledge, this is the first study that analyses the relationship between patient self-reported disease severity into an online community and the subsequent contact with the healthcare system. Further investigation with a greater sample size and study period is needed to explain the reasons behind the lack of compliance to recommendations given at a virtual community into a PHR and if this aspect could explain the little impact of these interventions on healthcare outcomes.

## Conclusions

We presented an online community for patients with psoriasis developed by specialists in clinical informatics and dermatologists in our PHR. In our sample, we did not find a significant association between reported disease severity (measured by self-report questionnaires) and subsequent visits to specialists.

Online communities for patients with psoriasis provide education about the disease as well as psychosocial support. This paper suggests that the use of questionnaires for selfreported outcomes is not significantly related to the use of healthcare services according to its recommendations. Further studies are needed to explain the reasons for this phenomenon.

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