Evaluation and Usage Analysis of IBD Tool: A Telemonitoring Platform for Inflammatory Bowel Disease

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Abstract: Telemedicine brings numerous benefits to healthcare as a support to traditional medicine. On this basis, IBD Tool was developed. It consists of a web-app through which some of the patients suffering from Inflammatory Bowel Disease (IBD) of the Mauriziano Hospital of Turin are followed. Thanks to IBD Tool, physicians can follow the evolution of the disease over time, having the ability to identify periods of remission and relapse and to reduce hospitalization's frequency of patients. Furthermore, IBD Tool is a powerful tool also for patients, who thanks to the web-app are always in close contact with the healthcare staff and do not feel neglected in the months that normally elapse between a visit and the other. In this first year of use of the platform, telemedicine has proved to be a valid support for the treatment of chronic intestinal diseases, providing clinicians a versatile telemonitoring tool. Considering the current health situation, it is increasingly evident that the health system cannot ignore telemedicine. In this study, we have investigated the results collected in this first period of use of the platform, monitoring the activity state of the web-app and patients' evaluations about the tool.

1 INTRODUCTION

The current coronavirus pandemic of 2019 has caused a significant strain on medical center resources. Thus, the COVID-19 pandemic has radically and rapidly changed the way physicians deliver patient care. In early 2020 there has been a rapid adoption of digital tools and technologies such as telemedicine and virtual assistance which refer to the provision of digital or remote healthcare services using information and communication technologies for the treatment of patients (Bokolo, 2020).

In this scenario IBD Tool web-app was developed and tested. The goal is to provide timely care while minimizing the need for patients to travel to the hospital. This study provides information on the possible implications and potential of using virtual assistance solutions.

IBD Tool consists of a web-app through which some patients of the Mauriziano Hospital of Turin suffering from Inflammatory Bowel Diseases (IBD) are monitored. The IBDs are pathologies that accompany patients throughout their life. Therefore, for these patients a periodic check-up is essential to avoid degenerations of pathology. However, the IBDs can remain silent even for long periods of time. Telemedicine in this field has the role of ensuring that the patient goes to hospital only if strictly necessary. This web-app administers specific questionnaires to patients, focusing on the disease but also on habits and quality of life. In this way IBD Tool monitors the overall health of patients and provides them with an

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integrated communication tool that puts them in contact with the physicians of the Mauriziano Hospital in Turin.

This project arises from a scientific experimentation which is evaluating over time the effects of telemedicine usage on patients.

IBD Tool collects questionnaires filled out by patients since March 2020 and has evolved over time following user requests. The platform includes several sections: the section for receiving, sending, and reading questionnaires for both physicians and patients, a section with clinical data, a dedicated chat and a dashboard to view the progress of patients considering several parameters (which we will see later in this paper).

IBD Tool was developed with the aim of making the application easy to use for both clinicians and patients.

Physicians recruited volunteer during the first follow-up visit after the start of the platform testing phase. The patients who joined the trial signed an informed agreement, and they were then registered by the physicians on the web-app. Among the patients who joined the trial, not all had the same type of access to the platform. The 50% were randomly referred to *telemedicine care* and the remaining 50% to *standard care*. It is a compromise between ethical aspects (to not deprive the patient of a potentially useful tool especially in the pandemic period) and the need to have a control sample. The difference between patients in telemedicine and those in standard care is the administration frequency of questionnaires, which are more frequent in the first group.

In a year and a half of use, physicians have always been able to give direct feedback to improve the web-app. In this study, we investigate patient feedback to assess whether the objectives of simplicity of use have been achieved and possibly accept proposals for changes to improve it. Main focus is the use of the web-app among patients-users, their involvement, and their activity rate with respect to the application.

2 METHODS

2.1 Questionnaires

The monitoring function of IBD Tool is based on questionnaires. IBD Tool automatically administers specific questionnaires to patients based on their category. Presence of a new questionnaire is notified by mail and by the platform through the notification section. When a user-patient is registered on the platform by the clinician, he is automatically and randomly assigned to a specific treatment category, STANDARD or TELEMEDICINE, which identifies two different levels of remote assistance.

The differences between the two categories are:

- The administration frequency of questionnaires: patients in “TELEMEDICINE” category fill out questionnaires more intensively than patients in “STANDARD” category.
- The type of sent questionnaires: patients in “TELEMEDICINE” category fill out more types of questionnaires than patients in “STANDARD” category.

The IBD Tool’s questionnaires assess various life aspects. Monthly questionnaires are:

- HBI (Harvey Bradshaw Index): it consists of 5 questions, and it is used only for Crohn’s patients (Harvey, 1980). It evaluates the patient’s well-being, abdominal pain, the number of liquid or soft bowel movements, the presence of abdominal mass and the presence of complications. It is sometimes compiled by clinicians to compare the results with patient scores.
- SCCAI (Simple Clinical Colitis Activity Index): it is used only for ulcerative colitis patients, and it is composed by 13 questions that refer to the symptoms of the last week, to bowel movements, episodes of fecal incontinence, blood in the stool, joint pain, erythema and any infections (Bennebroek Evertsz’, 2013). It is sometimes compiled by clinicians to compare the results with patient scores.
- MIAH (Monitor IBD at Home): it is constructed in both a version for patients with Crohn’s disease (MIAH-CD) and for patients with ulcerative colitis (MIAH-UC), with respectively 6 and 5 questions (de Jong, 2018).
- IBD-DISK (Inflammatory Bowel Disease - Disability Index disk form): it was validated starting from a previous questionnaire (the IBD-DI: Inflammatory-Bowel-Disease Disability Index) with some modifications; it is based on 10 items, about abdominal pain, regulating defecation, education and work, sleep, energy, emotions, body image, sexual functions, and joint pain (Gosh et al., 2017).

3-Monthly Questionnaire are:

- PRISM (Pictorial Representation of Illness and Self Measure): it is not made up of questions, but of two circles, one represents the disease, the other represents the patient; the user must indicate, by moving the circles, how much he

suffers due to his illness. The final score is returned in terms of distance (Gosh et al., 2020). It is sometimes compiled by clinicians to compare the results with patient scores.

- PHQ9 (Patient Health Questionnaire 9 items): it is used for the diagnosis of depression consisting of two questions, the first of which evaluates the symptoms of depression (Kroenke, 2001).
- IPAQ-SF (International Physical Activity Questionnaire - Short Form): it is aimed at measuring the amount and type of physical activity performed in the last seven days (Craig CL, 2003).
- WPAI (Work Productivity and Activity Index): it is used to assess the impact of the disease, both Crohn's disease and ulcerative colitis, on work and daily activities (Reilly MC, 1993).
- IBDQ (Inflammatory Bowel Disease Questionnaire): it is for quality of life assessment. Its composition consists of 32 questions, which take into consideration different fields about social life, emotional health, and symptoms (Hlavaty, 2006) (Ciccocioppo, R., 2011).
- MMAS8 (Morisky Medication Scale 8 items): it is based on 8 questions that assess adherence to therapy. The questions relate to times when a patient forgets to take the tablet or stops taking it because it is believed to be ineffective or causes discomfort (Hu W, 2020).
- TSQM (Treatment Satisfaction Questionnaire for Medication): it is used to assess the level of satisfaction or dissatisfaction with the drug that the patient is taking. In particular, the effectiveness, the side effects, the use of the drug, its planning and the convenience or inconvenience of taking it are evaluated (Vermersch, P., 2017).

6-monthly Questionnaire are:

- EQ5D5L (European Quality version 5D - 5 Levels): it is about the measurement of the quality of life, work, personal care, physical and psychological health, usual activities, pain, and discomfort (Herdman, 2011).
- PSQI (Pittsburgh Sleep Quality Index): it is for the evaluation of sleep in the last month, with questions regarding the time a person fell asleep, the time taken to fall asleep, the wake-up time in the morning, the total hours of sleep, the general sleep quality, how many times a person wakes up during sleep, whether a person has been taking sleep medications, etc. (Curcio, 2012).

Patients in "standard of care" category only compile: HBI, IBD-DISK, MIAH-CD if they suffer of Crohn's disease, PATIENT-SCCAI, IBD-DISK and MIAH-UC if they suffer of ulcerative colitis, IBD-DISK if the pathology is undefined; the administration frequency is of three months.

Patients in "telemedicine" compile all the questionnaires with their regular administration frequency.

2.2 Platform Structure

The web-app was built by using different technologies. IBD Tool comprises two parts: the frontend and the backend. The frontend is the user interface of the platform, and it is the visible part of it, which can be reached from every browser.

The used framework is Angular, an open-source framework for the creation of single page client applications, based on Typescript, an object-oriented programming language, CSS (Cascading Style Sheet), and HTML (HyperText Markup Language). Furthermore, Angular is a tool for developing multi-platform applications. Through some toolkits, it is possible to develop responsive applications.

To implement the backend, Java programming language is chosen. This language is an object-oriented programming language, and it can be used on Spring Boot, one of the frameworks for creating web applications based on microservices. The IBD Tool backend is organized following the multitier architecture, which matches perfectly with the instruments made available by Spring. Specifically, IBD Tool is a 4-tier architecture, and these layers are:

- Presentation Layer
- Service Layer
- Data Domain Layer
- Data Access Layer

Communication between frontend and backend is done by the HTTP (HyperText Transfer Protocol). For all the features, IBD Tool can be defined as a REST (Representational State Transfer) architecture, completely compatible with the HTTP (Figure 1).

Security issues were considered by guaranteeing the access to the platform by username and password and checking the role of the user who logs into the application. Furthermore, Spring Security and use of a JWT (Json-Web Token) permit an additional security level.

All data is saved in some collections of a MongoDB cluster, specifically created for IBD Tool.

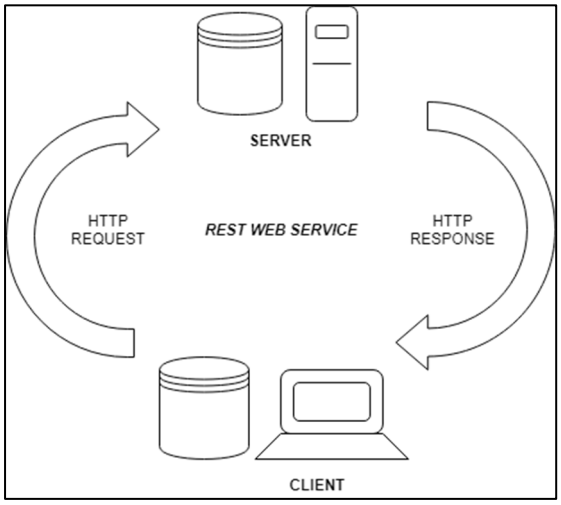

Figure 1: Web-Platform Architecture. the Figure Shows How the Web-Client and the Web-Server Interact through the HTTP.

2.2.1 Supporting Instruments for Development

Some other tools are used to support the development and the release of the web-app. GitHub is used to host all the code of the backend and the frontend, facilitating updates, and merging code's procedures. Heroku is used as a server service, where the backend is hosted and directly linked to the GitHub code. Firebase Hosting is used to host the frontend of the web-app, while Firebase Cloud Messaging is used to manage the real-time communication. IBD Tool also relies on a Gmail account to send emails to users.

2.3 Validation's Instruments for the Platform

To assess the web-platform's efficiency, a new satisfaction questionnaire was created by consulting widespread questionnaires for the evaluation of telemedicine services, as TUQ (Telehealth Usability Questionnaire) (Parmanto, 2016) and TSQ (Telemedicine Satisfaction Questionnaire) (Yip, 2003).

This new questionnaire is composed of 10 questions about the quality of care provided, the ease of use and learnability, the satisfaction and future use, and the interaction quality. Last question is an empty box where users can give their suggestions. This questionnaire is administered only to patients. Each answer can be in a range of 1-10, where 1 means "not-at-all" and 10 "very much". The structure of the questionnaire is in Table 1.

Table 1: Satisfaction Questionnaire for IBD Tool.

Quality of care provided
I think that IBD Tool improved the quality of service offered by Mauriziano Hospital of Turin
I think the service I obtained was better thanks to IBD Tool
Thanks to IBD Tool, I felt more followed between a visit and another
Satisfaction and future use
I will continue to use IBD Tool in the future
I am satisfied of the quality of service offered by IBD Tool
Ease of use and learnability
I need assistance to use IBD Tool
IBD Tool is easy and intuitive to use
Usefulness
I think IBD Tool lets me go to the hospital only when strictly necessary
Interaction quality
IBD Tool made the communication with Mauriziano Hospital's clinicians faster
Suggestion box
Blank (To fill)

2.4 Analysis Method

All information about patients registered on the platform are saved in different collections of a MongoDB cluster, specifically created for IBD Tool. In order to communicate with MongoDB, the repository support offered by Spring is used, making this communication much easier than traditional implementations.

2.4.1 User Activity Analysis

In the 'user' collection of MongoDB cluster, there is a record for each enrolled patient containing clinical variables such as, pathology, presence or absence of previous surgery, sex, type of active therapy, age etc.

A “lastLogin” field indicates the timestamp of the user's last login.

This configuration allows division of patients into different subgroups with the aim of analysing whether the use of the platform was influenced by certain characteristics, such as patient age or the duration of the disease. Patients are divided in the following subgroups:

- Category: Telemedicine or Standard of care
- Pathology: Crohn disease, Ulcerative colitis or other
- Sex: Men or Women
- Age – Age at diagnosis: Four different ranges (0-20, 20-40, 40-60, 60 or more years)
- Pathology duration: Four different ranges (0-10, 10-20, 20-30, 30 or more years)
- Active therapy: 5ASA-OS, TOPICA, GCS-OS, IMM., BIO
- Presence of previous surgery

For each of the subgroups, activity and inactivity rate of patients are calculated, considering:

$$activity\ rate = \frac{active\ users\ in\ a\ group}{total\ users\ of\ a\ group} \quad (1)$$

$$inactivity\ rate = \frac{inactive\ users\ in\ a\ group}{total\ users\ of\ a\ group} \quad (2)$$

Being inactive has a different meaning if users are in “telemedicine” or “standard of care” category. When a user of category “telemedicine” is inactive he/she has not accessed the platform for 4 months or more. When a user of the category “standard of care” is inactive he/she has not accessed the platform for 7 months or more. Furthermore, users who are classified as “unlogged in” are those who did not log in the platform after at least 2 weeks from the registration phase.

2.4.2 Questionnaires Filling Frequency Analysis

All the compiled questionnaires are saved into a ‘questionnaire’ collection of MongoDB cluster. Each record contains the answers given by the patient, final score, and type of questionnaire.

Mean number of compiled questionnaires per patient is calculated with the aim of analysing user activity, considering:

$$mean\ per\ user = \frac{total\ compiled\ questionnaires}{total\ receiving\ users} \quad (3)$$

This number is calculated for each type of questionnaire. Furthermore, questionnaires are addressed to different patients, based on category and/or pathology.

Regarding the satisfaction questionnaire, it was created following the template of the clinical questionnaires. To warn all the users of the platform, a new section was added to the user "personal page" and an email was sent to each patient with the link to the questionnaire.

3 RESULTS AND DISCUSSION

3.1 Results

From the analysis of how many users are active or inactive, referring to the access and the utilization of the platform, it was found that among a total number of patients of 677, 86,9% logged in the platform at least once, while the 13,1 % did not. Among users who logged in at least once, the 73,6% are active, so they constantly access the platform, compile questionnaires and/or write some chat messages to the clinician, while the 13,3% are inactive (Figure 2).

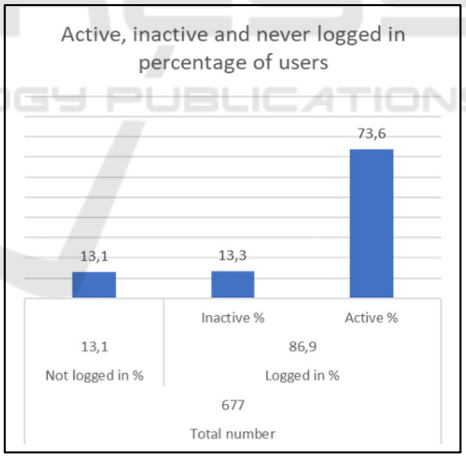

Figure 2: Distribution of the 677 registered users in logged and unlogged in. Logged in users are divided into active and inactive. Only active users are those who regularly use the web-platform.

Analysis of registered users reveals that there are 677 global users (constantly increasing), who can be differently distributed depending on variables of interest (category, age, sex, pathology, pathology duration, etc.). The balance between telemedicine and standard of care users is about equal, as well as among users suffering from Crohn's disease (CD) and

ulcerative colitis (UC), while there is a small percentage of patients (1,6%) whose disease is still unclassified (IBD-U). In the web-platform male and female are balanced. Most of the recruited users belong to the age groups 20-40 and 40-60, followed by the age group 60+ and only lastly by the age group 0-20. This is because pediatric users have never been foreseen until now. In these data, pathologies are mostly diagnosed in the age range of 20-40 (52,9%), followed by 0-20 (23,5%), 40-60 (20,5%), and 60+ (2,2%). Then, pathology duration in this population of users is mostly about 0-20 years (40,8%), followed by 20-40 (30,4%), 40-60 (19,6%) and 60+ (8,3%). Furthermore, in the field of ongoing therapies, the most frequent therapy is the 5-ASA-OS because 52,9% of users are undergoing this therapy and some of them in combination with another. The second most frequent therapy is biologic, which involves 38,7% of users. All this information is reported in Table 2.

Table 2: Distribution of registered users by category, disease, sex, age, age at diagnosis, pathology duration, ongoing therapy, and previous surgery. For both age at diagnosis and pathology duration, there is information on 671 instead of 677 people because for 6 patients there are not information about these fields.

Users	**Total**	
Global	677	
Category	**Total**	
Telemedicine	338	49,9%
Standard	339	50,1%
Disease	**Total**	
CD	354	52,3%
UC	312	46,1%
IBD-U	11	1,6%
Sex	**Total**	
Men	333	49,2%
Women	336	49,6%
Missing	8	1,2%
Age	**Total**	
0-20 years	13	1,9%
20-40 years	265	39,1%
40-60 years	284	41,9%
60+ years	115	17,0%
Age at diagnosis	**Total**	
0-20 years	159	23,5%
20-40 years	358	52,9%
40-60 years	139	20,5%
60+ years	15	2,2%
Pathology duration	**Total**	
0-20 years	276	40,8%
10-20 years	206	30,4%
20-30 years	133	19,6%
30+ years	56	8,3%
Ongoing therapy	**Total**	
5-ASA-OS	358	52,9%
TOPIC	71	10,5%
GCS-OS	79	11,7%
IMM.	37	5,5%
BIO.	262	38,7%
Previous surgery	**Total**	
Yes	266	39,3%
No	411	60,7%

Distribution of logged in users (both active and inactive) is analysed by considering different sub-groups (category, sex, pathology, age, pathology duration, ongoing therapy, age at diagnosis, and previous surgeries) (Figure 3).

The difference in the involvement in the application is analysed in terms of activity rate and inactivity rate between each sub-group (telemedicine/standard of care, men/women, etc) (Figure 4).

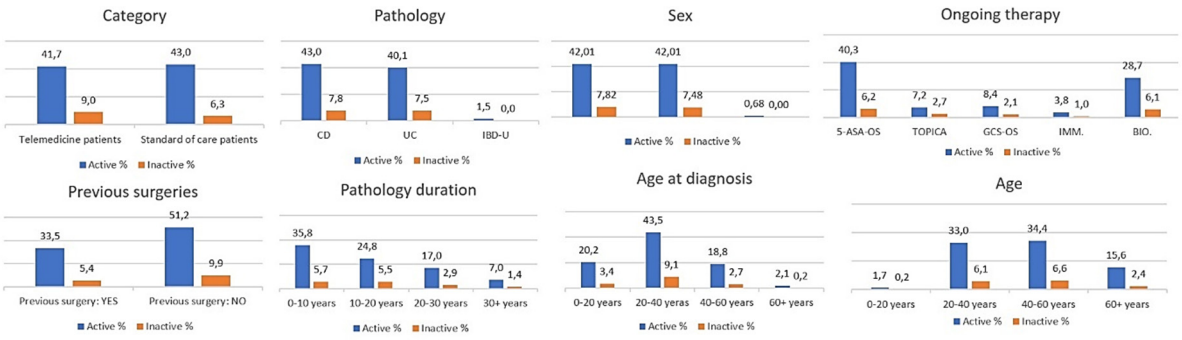

Figure 3: Active and inactive patient percentage divided by sub-groups. Each single graph is referred to a different patient distribution: category, pathology, sex, ongoing therapy, previous surgery, pathology duration, age at diagnosis, and age. Each percentage.

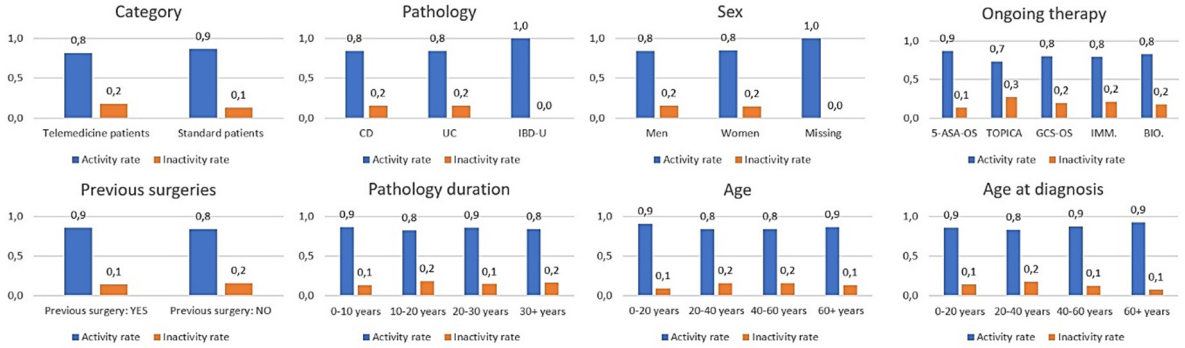

Figure 4: Activity and inactivity rate in each sub-group. Each single graph is referred to a different patient distribution: category, pathology, sex, ongoing therapy, previous surgery, pathology duration, age at diagnosis, and age. The figure shows high activity.

For each sub-group the number of users is different, except for category and sex, in which there is a major balance (Table 2). Considering the category, 50% of users belong to the "telemedicine" program (338 users) and 50% belong to the "standard of care" program (339 users). Active telemedicine users are 41,7%, while inactive are 9,0%; active standard of care users are 43,0%, while inactive are 6,3% (Figure 3). The inactivity rate of telemedicine users is 0,2 against the 0,1 of standard of care users (Figure 4). Considering pathology and sex, the balance between active and inactive users is quite the same. Although the percentage of active Crohn's disease users is 43,0% against the 40,1% of ulcerative colitis, the total number of Crohn's users (354) is higher than those who suffer from ulcerative colitis (312) (Figure 3). Considering sex, the activity rate of men is 0,8, for women is 0,8 (Figure 4). Considering age groups, it can be observed that they all have a similar degree of participation in the platform and the activity rate is in the range 0,8-0,9 for each group (Figure 4). Same can be said if the population is divided by pathology duration (activity range: 0,8-0,9) and age at diagnosis (activity range: 0,8-0.9) (Figure 4).

Furthermore, those who have had surgery (activity rate of 0,9) have a degree of involvement in the application quite higher to those who have not had any (activity rate of 0,8) (Figure 4). Considering the ongoing therapy, each group has an activity rate in the range of 0,7-0,9 (Figure 4).

The activity of users was also taken into consideration in terms of compiled questionnaires (Table 3). Clinician's questionnaires have a mean per user higher because all the patients are followed by 3 physician users.

Table 3: Compiled questionnaires and corresponding mean per users. Red part of the table indicates monthly questionnaires; light yellow part of the table scheduled 3-monthly questionnaires (except for PRISM which has been compiled also during the face-to-face visit with physicians); light blue part of the table indicates 6-monthly questionnaires; grey part represents satisfaction questionnaire; white represents questionnaires compiled by physicians.

Questionnaire	Number	Mean per user
HBI	1764	5
PATIENT-SSCAI	1586	5,1
IBD-DISK	3068	9,5
MIAH-CD	1626	4,6
MIAH-UC	1420	4,6
PATIENT-SSCAI	1586	5,1
MMAS8	507	1,5
PHQ9	552	1,6
IBDQ	395	1,2
IPAQ-SF	529	1,6
PRISM	1165	3,4
TSQM	475	1,4
WPAI	484	1,4
PSQI	226	0,7
EQ5D5L	238	0,7
SATISFACTION	285	0,4
CLINICAL-HBI	561	187
CLINICAL-SCCAI	510	170
CLINICAL-PRISM	1071	357
Total	**16439**	

The last analysis section is about the user valuation of the web-platform through the satisfaction questionnaire. In the following analysis, only questionnaires completed within 5 days of publication and notification of the satisfaction questionnaire were considered. 285 over 677 users compiled the questionnaire, and they were mostly active users (only 2 over 285 inactive users compiled the questionnaire). IBD Tool obtained a global mean

score of 7,4 over 10 in "quality of care provided", 8,1 over 10 in "satisfaction and future use", 8,5 over 10 on "ease of use and learnability", 6,4 over 10 in "usefulness", and 6,9 over 10 in "interaction quality" (Table 4).

Table 4: Average score resulting from the analysis of the 285 satisfaction questionnaires.

Quality of care provided	Mean score
I think that IBD Tool improved the quality of service offered by Mauriziano Hospital of Turin	7,5
I think the service I obtained was better thanks to IBD Tool	7,1
Thanks to IBD Tool, I felt more followed between a visit and another	7,6
Satisfaction and future use	
I will continue to use IBD Tool in the future	8,4
I am satisfied of the quality of service offered by IBD Tool	7,8
Ease of use and learnability	
I need assistance to use IBD Tool	1,7
IBD Tool is easy and intuitive to use	8,7
Usefulness	
I think IBD Tool lets me go to the hospital only when strictly necessary	6,4
Interaction quality	
IBD Tool made the communication with Mauriziano Hospital's clinicians faster	6,9
Suggestion box	
Blank (To fill)	

3.2 Discussion

Rate of users who constantly access and use the platform is high, the 73,6%. Users who are classified as "unlogged in" are those who have been registered by the physician, but have never accessed the web-app. These users declared interest on the telemonitoring program, but never joined the service.

Active users compile with diligence all the received questionnaires; the different values of compiled questionnaires per patient are since not all the questionnaires are administered to the patients with the same frequency. Questionnaires like HBI, Patient-SCCAI, MIAH-UC, MIAH-CD and IBD-DISK are administered monthly to telemedicine users and, consequently, the number of compiled questionnaires of this type is higher. The number of questionnaires like PRISM, HBI, Patient-SCCAI or clinical ones is higher because they are compiled even at the time of the visit.

Evaluation results on satisfaction questionnaire show that most of analysis fields obtained good marks. Critical issues came from limitations of hospital face-to-face visits. Most of users think that IBD Tool is easy to use, intuitive and that there is no need of help for using it and answering to questionnaires. Most of them will continue to use IBD Tool in the future. Generally, satisfaction is good among active users.

4 CONCLUSIONS

Potential of this web-app is manifold, both in the short term and in the long term. In the short term, it has a direct effect on patients, allowing them to feel followed and accompanied by physicians even at a distance. This allows the consequent monitoring and prevention of the disease degeneration.

In the long term, the development of a machine learning algorithm is planned. The goal is to process the collected data, to assess the risk of degeneration considering combinations of variables present in the questionnaires.

Patient point of view should be highlighted. Therefore, they were provided with a *satisfaction questionnaire.* This questionnaire allows the evaluation of the application on the patient side. One of the goals was to facilitate all-ages patients to easily utilize the application.

In this questionnaire the possibility to add any suggestions was given. From the analysis of all the suggestions, it emerged that a considerable number of patients would like a *notes* section at the end of the questionnaires to be able to argue their answers when multiple choices are not enough.

Another emerging need concerns having a *patient section* where it is possible to have information about the disease using graphs that summarize the course of the pathology to have a greater awareness of their state of health.

Results of the analysis on the activity and on the use of IBD Tool have shown a great involvement. Patients constantly compile questionnaires, contact the clinicians through the platform for any kind of technical or medical problem. Also, clinicians constantly use the web-platform and take into consideration the questionnaire scores to make their clinical evaluations.

The results of this study encourage us to improve the platform and service by trying to consider patient suggestions.

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