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A mHealth Patient Passport for Adult Cystic Fibrosis Patients

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Abstract. Life expectancy for some Cystic Fibrosis (CF) patients is rising and new complications and procedures are predicted. Subsequently there is need for education and management interventions that can benefit CF adults. This paper proposes a CF patient passport to record basic medical information through a smartphone application (app), giving the patient access to their own data. It is anticipated that such an app will be beneficial to patients when travelling abroad and between CF centres. This app is designed by a CF multidisciplinary team to be a lightweight reflection of a current patient file. The passport app is created using PhoneGap so that is can be deployed for both Android and iOS devices. The app is introduced to seven participants as part of a stress test. The app is found to be usable and accessible. The app is now being prepared for a pilot study with adult CF patients.

Keywords: Cystic Fibrosis, mHealth, patient passport

1 Introduction

Cystic Fibrosis (CF) is the most common life limiting genetic disease affecting Caucasians. Ireland has the highest occurrence of this disease in the world. Patient education is considered to be an integral part of care and can often improve quality of life [1]. Adult Cystic Fibrosis patients are often considered to be a well-educated cohort, however previous studies have identified knowledge gaps with this population [2,3]. Life expectancy of this population is predicted to rise, with some patients expected to live to retirement age and as such further disease complications and or medical procedures may arise [4,5]. With these medical obstacles, CF patients will be given new information and educated respectively. From a study conducted by Kessels it was found that between 40% and 80% of the medical information provided to

patients by practitioners is forgotten immediately [6]. With this comes the need for education strategies and interventions which can be of benefit to the care of these patients and overcome education barriers. It is also imperative that such interventions will not impede on their daily lifestyles.

Self management often falls under the umbrella of patient education. An intervention such as a patient passport, may aid in the delivery of such care and education materials [7]. A patient passport is a paper based intervention which allows the user to collect pertinent medical data to aid in the management and care of their condition. This often used for those with long term illnesses or learning difficulties. One such passport was developed by Newell et al. [8] for asthma management. The passport is paper based and can be folded so that it can fit into a wallet. The agenda of this passport is to store the information needed for an asthmatic to receive care on arrival to an emergency unit. By storing the information in a passport it lessens the onus on the patient to repeat this information to various medical professionals and allows the care professionals more time with the patient rather than sourcing the information [8]. Similarly, a medication aid passport was developed by Barber et al. [9] which allowed patients to record details of their medicines. This study found that the passport had a positive effect on those patients and that it can aid in the dialogue of medications between patients and healthcare team members [9].

Life expectancy for CF adults is rising, and considering the benefits of a patient passport, it can be stipulated that such a tool would be beneficial to adult CF patients. This paper proposes a patient passport targeted at adults with cystic fibrosis. However, unlike the aforementioned passports, the proposed passport will be developed as a mobile application (app). To the authors knowledge this is the first passport app created for CF. The agenda for this app is to provide CF adult with their basic medical information and also to allow them to record their medications. By doing so, adult CF patients may become more educated to their condition which may improve therapy compliance. Additionally, three scenarios have been identified in which the proposed app may be of significance to a CF adult. Firstly, it can allow a patient to receive immediate care when traveling abroad. Secondly, to receive care if travelling between adult CF centres. Lastly, to bridge the gap between health care team members. These scenarios and the design of the passport app will be discussed further in the following section.

2 Design

This section will discuss the aforementioned three use scenarios for the proposed app. It will then move on to discuss other design consideration such as the intended data to be recorded, potential pitfalls, solutions implemented, and additional features.

2.1 Usage Scenarios

Providing a tool for adult CF patients to record their basic medical information may prove beneficial, however it is pertinent to highlight scenarios that may require the use of the passport so that such a tool can be incorporated into the current care

system. The scenarios in which this passport is considered to be of use are outlined in the following subsections.

Travel between centres: There are currently 5 adult CF centres in Ireland. As such patients may transfer between hospitals to receive care, depending on medical/personal reasons. CF patient files are hard copies only and it is not always possible to gain access to this file. As such scenarios where patients will move from one hospital to another, or are transferred, involves a patient arriving to a unit with limited information. This is resolved by frequent phone calls or requests for information. However with this proposed app, a patient can arrive with their basic care information such as genotype, medications, recent history of lung function results, allergies and other medical conditions.

Travel outside of the country: Similarly if a patient is to travel abroad and is then in need of care, the patient will have access to their most basic information necessary to receive care. The app also records contact details of their health care team members for further information.

Bridging Gaps for the health care team: It is pertinent that all antibiotics that are prescribed to a patient are recorded. Generally, it can be two months between standard clinical visits. In this time it is possible for a patient to begin a new antibiotic as prescribed by a General Practitioner (GP). During the next clinical visit, CF nurses will ask patients if they have been on any new medications, which can be either forgotten or only partial information is remembered. With the use of this app, a patient can record any interaction with any member of their health care team from phone calls to clinic visits in order to provide a broader view of their care.

2.2 Recorded Medical Data

Members of the CF multidisciplinary team discussed which data is of importance to a patient in the scenarios as outlined previously. It is agreed upon that this mobile application should follow the same structure as that of a patient file wherein there is data that is recorded only once, such as profile information. There is data that is recorded rarely and can be edited and amended, such as medical conditions and procedures. Lastly, there is data that will be recorded at each clinic appointment such as weight, height, FEV1 and FVC. To note, although the app follows the same structure as a patient file, it does not record all information that is stored in a patient file, only the basic information required for treatment.

The app is then divided into three sections to reflect the structure above. These sections are named “My CF Information”, “My Medical History”, and “My Clinic Appointments”, this can be seen in Figure 1 B. The data stored in these sections are discussed below:

My CF Information: Data in this section is recorded once and can be amended by the user if required. Information that can be recorded includes: date of birth, date of diagnosis, sweat test, genotype, blood group, allergies, medications, medical team contact numbers, and physiotherapy techniques. This can be seen in Figure 1 C.

My Medical History: The data in this section will be filled out once initially and amended over time. This section is broken down into two sub sections. The first is "My Medical Procedures" which records data such as the insertion and removal of a Portacath. The second section, "My Medical Conditions" records other diseases which can affect CF patients such as Diabetes.
My Clinic Appointments: This section is intended to record data for each meeting with a member of the health care team, which can occur every two to four months. The types of data that can be recorded here include Date, BMI, Weight, Health, blood Pressure, FVC Liters, FVC %, FEV1 Liters, FEV1 %, Bugs in Mucus, Treatment, and Comments. This section can also be used for annual assessments, phone calls to the health care team and General Practitioner visits. This can be seen in Figure 1 D.

2.3 Potential Pitfalls

Paper based patient passports have, in the past, been developed for diabetes patients, asmatics and also for the older adult, with each related study reporting a positive response from the patient. In a study conducted by Dijkstra et al. [10] it was found from interviewing patients that while these various patient passports have shown beneficial results, there continues to be issues which may result in a poor adaptation of the passport or negative effects. Such issues include: 1) Security, if the passport was to become lost or stolen there is potential for identity theft, 2) forgetting to bring the passport to appointments with various members of the health care team, 3) size and space, some patient passports can be the size of a small booklet and due to this can be unwieldy for patients to carry on the person, and 4) patients felt they had no time to enter information into their passport and did not want to waste valuable consultation time [10]. Dijkstra et al. [10] also found while interviewing members of the diabetes healthcare team that there are issues that affect using a patient passport as a patient intervention. One such issue is that of a clearly defined agenda for this intervention. As without clearly stating this agenda it is unclear as to how the passport should implemented into the patient's care and at which point of care it should be introduced [10]. Other discrepancies found in this study include: 1) If the passport is of any use to the health care team, 2) clearly stating who is responsible for filling out the passport, and 3) a sufficient introduction to the passport by the health care team so that the patient knows how to use the passport. [10].

2.4 Solutions and App Implementation

The issues as outlined above were focused on diabetes passports only, however these problems are transferable. As such the above has been considered in the design of the adult cystic fibrosis passport this paper proposes. From issues outlined by patients, a digital platform has been incorporated as a solution. The CF passport is intended for use as an app for a smartphone device. By doing this, the passport app can be password protected and all data encrypted to avoid security issues in the event the phone is lost or stolen. An image of the login screen can be seen in Figure 1 A. Physical size and space will no longer be an issue as no additional space will be used

to carry the app. Subsequently space in memory is now formed as a new consideration, however the data recorded through this app will be for basic information only, resulting in a minimal amount of memory being used on the smartphone device. Lastly, the issue of forgetting the passport is also reduced due to the popularity of smartphones. There has been a growth in smartphone users from 39% of the Irish population owning a smartphone in 2012 to 70% in 2015 [11]. It is also predicted that there are 2.32 billion smartphone users worldwide as of 2017 [12].

The remaining issues as highlighted by members of the diabetes team were discussed with the Cystic Fibrosis nurses, and the corresponding solutions were agreed upon by consensus. The app is intended to be introduced when CF pediatric patients transfer to the adult ward, however it can also be implemented for existing adult CF patients. For those patients who are interested in the app, they will be given a short workshop by the CF nurses who will explain the potential benefit of the app, what can be recorded and why this can of benefit, where to record the data, and how this app can be implemented into their care. During this workshop the nurses will also assist the patient in inserting data that needs only be recorded once. The nurses will also advise that it is the responsibility of the patient to enter and record data and all data recorded is voluntary and will not be viewed by any other persons. A standard adult CF clinic appointment in Ireland can take up to 1 hour and 15 minutes. In this time the patient will meet with the CF nurse, the physiotherapist, the dietician and a CF registrar or consultant. The patient will be encouraged to fill in data with the CF nurses and time will be designated for this. However if they would prefer not to fill it in with the nurses, there is approximately 15 minutes of non-contact time in between meeting the multidisciplinary team where the patient can record this information.

2.5 Additional Features

Other features are also incorporated into the app to aid patients with self management. One feature which was added to visualise the recorded data to the patient are interactive graphs. There are two plot graphs currently. The first displays Weight and the second displays FVC % and FEV1 %. An example of this graph can be seen in Figure 1 E. Here the user has the ability to tap on the graph for more details on the data points, and hide/reveal values in the x and y axis. The app also provides access to the default device calendar. By doing this the user can save reminders for clinical and other related medical appointments.

3 Methodologies

The app is developed using Cordova Phonegap [13] which utilises web technologies such as HTML, JavaScript and CSS. The web technologies are then compiled so that the app can be deployed to both Android and iOS. The app also utilises the Framework 7 [14] framework for app navigation, style, and layouts for the appearance of a native app. The language used in the app is simple so that it can be understood by non medically trained persons. All data recorded through this app is encrypted using the Advanced Encryption Standard (AES) algorithm and stored in a

local SQLite database. Initially, the data is loaded from the database only after the user has successfully logged in. New data is entered into the local database once the user presses the submit button, and is reloaded each time the user enters new data. Once the user leaves or exits the app, this database is then closed. If the app deleted from the device, the databases will also be deleted. All graphs are developed using the Highcharts.js framework [15]. During the development process, the app was continuously reviewed and validated by members of the CF multidisciplinary team. The current app can be seen in Figure 1.



Fig. 1. Images showing: A) Login Screen. B) Main Menu. C) My CF Info Screen. D) My Clinic Appointments Screen. E) Graph with FEV1 % and FVC % data.

3.1 Stress Testing

The purpose of this test is to evaluate the performance of this app and its design. Seven participants were enlisted who all had Android devices. To note, the participants did not have CF. The decision to recruit non-CF participants was so that performance and design issues could be remedied before clinical testing. The participants included three females and four males. The youngest participant was 19 years old and the oldest was 51, this age range is similar to that of the CF adults that the app is intended for. The participants varied in technical background. Some participants were actively working in the technology industry and were familiar with stress testing devices, while others would be considered novices.

The participants were given the app for three months and asked to add, edit and delete information to the "My CF Information" and "My Medical History" sections once a month. Similarly, they were asked to do the same for "My Clinic Appointments" once a week. At the end of every month the participants were asked to report on any performance or usability issues they encountered using the app via email. The participants from technical backgrounds were familiar with stress testing and as such were asked to focus on performance issues. The other users who would be considered novice were asked to focus on usability issues and features of the app that were easy or found difficult.

Overall the app was received positively by the participants. No user reported difficulty using the app or of any serious issues in the apps performance. From the study, some minor cosmetic issues were identified with varying phone screen sizes and resolutions. For example, the button outline would remain stationary on larger

screen when the keyboard was visible, as opposed to moving with the button element. All users reported confusion with the format for a date entry. Another common issue reported by the users is that the "Go" Button on they keyboard did not navigate the user through a form as expected. These issues have now been addressed in a newer version of the app in preparation for pilot testing with CF adult patients. The app will be offered to CF adults who will also attend a workshop on how to use the app and its purpose with the Cystic Fibrosis Nurses. The CF adults will then be asked to use the app over a three month period before answering a short survey. This clinical study is pending ethical approval. It is anticipated that the app will then be made available for all CF adult patients through the app store or other platforms.

4 Conclusion and Future Works

Patient passports have proven to help patients with self management as it facilitates the ability to closely monitor their own condition, allowing for shared disease management. However as this is a paper based solution, possible issues arise such as the patient forgetting the passport, identity theft if lost, and the patient being over encumbered. These issues could be resolved by translating this intervention to a digital system such as an app. To the authors knowledge, a smartphone patient passport app has not been created for CF adults. This research proposes such a passport application which can allow CF adults to record their medications and basic CF information so that they can receive care. It is anticipated that providing a platform for CF adults to record and observe their CF information and actions may benefit medication compliance. The app is now being prepared to be pilot tested with a small cohort of adult CF patients. This pilot study will aim to evaluate the app and determine if a patient passport app will serve as a solution to the issues discussed with the paper based system. Following the results of this study the app will be subjected to a certification process before deploying to an app store or similar dissemination platform.

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