A Patient Passport Application for Adults with Cystic Fibrosis

Authors : Tamara Vagg, Cathy Shortt, Claire Hickey, Joseph A. Eustace, Barry J. Plant, Sabin Tabirca

Abstract : Introduction: Paper-based patient passports have been used advantageously for older patients, patients with diabetes, and patients with learning difficulties. However, these passports can experience issues with data security, patients forgetting to bring the passport, patients being over encumbered, and uncertainty with who is responsible for entering and managing data in this passport. These issues could be resolved by transferring the paper-based system to a convenient platform such as a smartphone application (app). Background: Life expectancy for some Cystic Fibrosis (CF) patients are rising and as such new complications and procedures are predicted. Subsequently, there is a need for education and management interventions that can benefit CF adults. This research proposes a CF patient passport to record basic medical information through a smartphone app which will allow CF adults access to their basic medical information. Aim: To provide CF patients with their basic medical information via mobile multimedia so that they can receive care when traveling abroad or between CF centres. Moreover, by recording their basic medical information, CF patients may become more aware of their own condition and more active in their health care. Methods: This app is designed by a CF multidisciplinary team to be a lightweight reflection of a hospital patient file. The passport app is created using PhoneGap so that it can be deployed for both Android and iOS devices. Data entered into the app is encrypted and stored locally only. The app is password protected and includes the ability to set reminders and a graph to visualise weight and lung function over time. The app is introduced to seven participants as part of a stress test. The participants are asked to test the performance and usability of the app and report any issues identified. Results: Feedback and suggestions received via this testing include the ability to reorder the list of clinical appointments via date, an open format of recording dates (in the event specifics are unknown), and a drop down menu for data which is difficult to enter (such as bugs found in mucus). The app is found to be usable and accessible and is now being prepared for a pilot study with adult CF patients. Conclusions: It is anticipated that such an app will be beneficial to CF adult patients when travelling abroad and between CF centres.

Keywords : Cystic Fibrosis, digital patient passport, mHealth, self management

Conference Title : ICMDSH 2018 : International Conference on Medical Data and Smart Health
Conference Location : Zurich, Switzerland
Conference Dates : January 15-16, 2018