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Digital healthcare in cystic fibrosis. Learning from the pandemic to innovate future care (Commentary)☆

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The delivery of effective, high quality healthcare requires a combination of strong underpinning science, clinical measurement, diagnostic skills and the ability to empathetically interact with people who are vulnerable because of illness [1]. Over centuries we have built up ways of delivering healthcare through consultation, diagnosis and investigation and a relationship between the physician and patient delivered in community and hospitals settings [2]. In the majority of chronic conditions and particularly in the care of people with cystic fibrosis (CF) we have successfully developed sophisticated interdisciplinary interactions with patients, parents and their families, to provide access to optimal advice and health care [3]. This multidisciplinary team approach has been key to the success of improving quality-of-life and other key outcomes for people with CF, but is financially costly to the healthcare system and to the individual and family with CF [4].

The COVID-19 pandemic has disrupted healthcare delivery across the world due to enormous pressures to deliver hospital and intensive care unit support for patients with symptomatic infection with SARS-CoV-2 [5]. The pressures of COVID-19 care and now the significant backlog of routine care and management of chronic conditions has resulted in the disruption of the usual business in healthcare due to limitations of availability of space and staff [5]. In addition there is an understandable reluctance of some individuals to attend hospital for routine appointments because of concern around cross infection, particularly in individuals with long-term conditions. These concerns are particularly around risk of infection control risks of attending hospital, which are not new issues for people with CF. People with chronic conditions have also been instructed to shield during the waves of the pandemic to reduce the likelihood of acquiring infection. Across healthcare systems these events and the responses to manage patients as effectively as possible has resulted in a significant shift to a telehealth model across many disease areas, particularly in long-term conditions [6]. Virtual consultation and remote measurement have replaced in-person visits to healthcare professionals. e-health in general has also been explored beyond healthcare delivery, and is increasingly finding applications in training and education [6,7].

Telemedicine/health and the more generic digital or e-health has been implemented for a number of decades as a way of improving access to healthcare, particularly in rural and remote geographies [6,8]. As for a number of areas in society, the COVID-19 pandemic has accelerated change in behaviour, with increased application of digital solutions including a shift to the use of e-health systems. This has been with general support from patients and practitioners as it has aligned with the restrictions during lockdown during the various waves of the pandemic [6]. This change provides an opportunity to learn some positive lessons and consider what the evidence base for future application of such technology might be as we emerge from the pandemic and re-establish new routines within the healthcare sector and wider society. It is likely that we will find value in some of the tried and tested approaches to care delivery but also, we should support change, particularly where technology provides an opportunity to improve quality, reduce the burden of care on patients and increase the capacity and efficiency of clinicians.

In a rapid systematic review of available evidence on the application of e-health, during the COVID-19 pandemic, some early evidence indicates that this approach is acceptable and has a number of attractions for healthcare systems practitioners and patients

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[9]. These studies, in general show promise in the use of e-health, particularly virtual consultation, in delivering suitable healthcare services to people with chronic conditions. This was consistent across countries, healthcare systems and diseases. Although primarily focused on virtual consultation the conclusions encourage further application of supervised of e-health, virtual consultation and remote monitoring. The review rightly emphasises the importance of further research in application of e-health solutions and the need to ensure the appropriate information technology infrastructure and training of multidisciplinary teams and of people with the conditions, to ensure optimal delivery [9].

The prospect of patients undertaking a home spirometry as part of e-healthcare in CF has been an opportunity to examine the role of remote monitoring of lung function. In the UK at home spirometry was endorsed by NICE and has widely been applied in CF and other respiratory diseases and there has been wide uptake [10]. In this edition of the Journal of Cystic Fibrosis, Ong and colleagues report the uptake of remote monitoring in the context e-healthcare delivery in a survey of CF Centres all in the United States of America [11]. The survey suggests that the use of home spirometry, measurement of weight using home scales and pulse oximetry were widely adopted during the past two years with significant increases in the use of spirometers and pulse oximeters between the first and second waves of the pandemic. Most patients reported the frequency of use of these measurement modalities to be between weekly and monthly. Frequent measurement of FEV_1 is unnecessary and has the risk of generating concerns around minor fluctuations. Measurement every 1 to 2 weeks and during changes in symptoms may be a reasonable approach. Airway microbiology and blood draws were somewhat more problematic with around 50% of programs undertaking remote sampling for an airways culture. The reasons for this may be partly patient related, but also due to the additional operational challenges of requiring delivery to a laboratory. Remote testing and blood sampling using small volumes from finger pricks or near patient testing will be an important part of e-health delivery and with good data from these various modalities can potentially provide a basis for successful virtual consultation. In CF, if patients can do reliable spirometry, measure weight and oxygen saturation and have access to providing airways mucus samples and blood tests by post, a virtual consultation could fulfil all of the current requirements for a physical visit to a CF centre.

There are, however, some concerns around the validity of FEV_1 measurements undertaken with handheld spirometers at home [12] Although reasonable correlations have been demonstrated in CF and other respiratory diseases such as idiopathic pulmonary fibrosis, the decline in this measurement tool is of key importance in CF care [12,13]. Spirometry, particularly FVC, in people with idiopathic pulmonary fibrosis showed a significant difference in rate of decline comparing home and hospital measurements [13]. It is clear that to use these technologies the quality of the measurement needs to be optimised and this can also be done virtually through supervised training and possibly for critical measurement. This general approach has been adopted in many countries during the pandemic and the quality and accuracy of the results are dependent on issues such as training, support, and communication. It is important that there is a rigourous collection of data and robust evaluation of the validity of measurements in order to evaluate whether the application of home investigations are of sufficient quality for clinician/patient consultation. In a useful review of experience at the Royal Brompton Hospital, Richardson and colleagues reported success of home spirometry in CF, PCD and asthma during the COVID-19 pandemic [14]. This narrative review provides very useful practical advice on how to roll out home spirometry, solve the technical issues associated with the IT technology and has additional helpful guidance for training and support. Regular remote measurement and monitoring by individual patients has many attractions in that empirically it may pick up deteriorations that could result in effective early interventions. However, with moderate monitoring in adults with CF in the eICE study [15], such benefits were not demonstrated and there are reasonable concerns about whether such monitoring may increase unnecessary interventions, and possibly increase anxiety in individual patients.

For these reasons, e-health, in general, and remote monitoring requires further pragmatic research, using innovative study designs, in addition to more conventional randomised controlled trials, as systems interventions such as these are difficult to blind and have a high likelihood of contamination across interventions [16]. We have much to learn in this regard from complexity science and how to assess patient pathways and indeed healthcare systems with complex interventions. The UK Health Hub study that is investigating adherence to nebulised therapies will provide some useful information on remote monitoring of adherence and a study in Germany also focused on adherence will provide additional useful data on patient generated spirometry [17,18]. These, and other studies currently underway in this area, will be important to help determine which patients will benefit and what the pros and cons are of remote spirometry and other measurements combined with virtual consultation. It is particularly important that we explore ways to ensure there is equality of access and that there are no cognitive or economic barriers.

In CF, we have opportunities, with sophisticated registries which are already being used to generate real world evidence, to make a significant contribution to improving care for people with CF and to pioneer and innovate in e-health by testing the value to patients, clinicians, and health care systems of these emerging technologies. The use of e-health, including remote monitoring, is a very attractive proposition for our healthcare commissioners, clinical teams, and patients and it is incumbent upon us to respond to this in a positive way and ensure that we have good evidence to support its use where it brings benefit.

Declaration of Competing Interest

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