Perspective: Care in the age of COVID-19

The pandemic has accelerated the drive towards telemedicine for people with cystic fibrosis — but the system needs critical appraisal, says Jane Davies

Care for people with cystic fibrosis involves frequent hospital visits. Infants are seen every few weeks, older children and adults are recommended to have routine check-ups every few months. The implementation of these standards and the centralization of services delivered by highly trained, multidisciplinary teams have contributed to huge improvements in health and survival.

This pattern of care delivery does, however, have some downsides. Travelling to a specialist centre can be exhausting and result in missed school and work. Furthermore, people with cystic fibrosis are at risk of cross infection. The need to avoid mixing of patients poses logistical challenges and reduces the number of people who can be treated in a given time.

For these reasons, alternative solutions have been considered over the past few years, including telemedicine and video consultations, the provision of home monitoring equipment (such as spirometers to measure lung function), the use of smart devices to motivate and measure adherence to treatment, and research into point-of-care diagnostics for infection. In general, these approaches have only just started to progress beyond the research or pilot-study stage.

But these approaches were suddenly brought to the forefront in early 2020, when the COVID-19 pandemic overwhelmed many countries' health-care systems and intensive-care facilities. People with cystic fibrosis were among those identified as being particularly vulnerable to COVID-19 and were advised to take extra precautions. In the United Kingdom, this involved remaining at home, a process termed shielding. Many hospitals shifted their workforces to the rapidly escalating numbers of COVID-19 admissions and, for a time, closed routine clinical work, including outpatient services, to limit infection risks.

This prompted a rapid change in how care was delivered, at a pace rarely seen in the UK National Health Service. Appointments were conducted by telephone or video calls, rather than face to face. Equipment for the routine surveillance of respiratory infection and lung function was dispatched to patients' homes.

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Although most non-COVID research was halted, some drug trials were allowed to continue, with 'virtual' visits to facilitate access to therapies that were not yet available on prescription. Clinical teams, patients, families and pharmaceutical companies adapted quickly to the pressing situation.

It is tempting to use this evidence of adaptability as an argument for rapid, permanent change in how we care for people with cystic fibrosis. However, important questions remain and, in my opinion, need to be addressed.

What might be missed by such a switch, and how would that affect physical health? For example, the accuracy of lung-function measurements obtained at home has been understudied. In-clinic measurements of lung function are guided by a technician, who is trained to identify a result with unacceptable quality and encourage the patient to try again. How does unsupervised home testing affect the quality of the measurements? A number of devices are available; do they give equivalent and reproducible results?

What about mental health and well-being? Cystic fibrosis is associated with increased rates of depression and anxiety. The quality-of-life benefits gained from reducing hospital visits might seem obvious, but outside the context of a pandemic, will people miss the personal-contact aspects of their care? This might particularly be the case for support from specialist nurses and psychologists.

Is the technology widely available and affordable? It is probably naive to think that this approach will save money, and the infrastructure, information technology and data governance will all require assessment to determine what extra capabilities will be needed to safely implement any changes. The composition of teams might also need to alter, and the ways of working certainly will. Also, there is already a pronounced gap in health outcomes between patients with the greatest and least economic resources. Creating a dependence on access to a smartphone or high-speed Internet could widen this gap.

How should the system be tailored to monitor infants and children with cystic fibrosis? This is already challenging. The more-sensitive tests being used for younger age groups (such as specialized lung function tests, inhaled stimulants to provoke sputum expectoration and lung imaging) require the child to be physically present.

Can data collected remotely for clinical trials meet the rigorous standards required by regulators? Once the pressures of the current situation have lessened, it is imperative that this question is fully addressed by, for example, the studies within a trial approach launched by the UK National Institute for Health Research.

The flexibility of the cystic fibrosis community in adopting short-term measures during the pandemic has been impressive. However, moving too rapidly towards this as a permanent model for care and trial delivery, based on unfounded assumptions, could undo some of the progress achieved over recent years. These questions and more should be raised and answered in partnership with the patient community and caregivers.