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The life rafts sailed; Now let's take stock and set the course ahead (Commentary)☆

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The topics discussed in the article by Van Citters and colleagues [1] feel both totally familiar and shockingly foreign in equal part: on the one hand, the practicalities required for the rapid adaptation to telemedicine during the COVID-19 pandemic, likely similar to those encountered in many regions of the world. On the other hand, the impacts and considerations of a financial reimbursement system experienced directly by clinical team members and which, in some centres, adversely impacted service delivery. From the position of a nationally funded healthcare system, the latter is something we in the UK have mercifully avoided.

The team undertook a rigorous piece of qualitative research using the consolidated framework for implementation research (CFIR) seeking to identify facilitators and barriers to telemedicine for CF as experienced by US centres during the pandemic. Two groups of centres underwent detailed interviews and focus groups, based on how successful- or otherwise- their implementation of telehealth was considered to have been. 'Success' was based on a number of factors both practical and subjective: from a practical perspective, processes being in place for airway cultures, blood sampling, mental health screening and home spirometry- although, surprisingly, the bar for the latter was set at a very modest 25%. Subjective factors included perception by the CF team that quality of telehealth was similar or better than in-person care and they were thus likely to recommend its use for care delivery and their institutions having an interest in expanding in-home options to augment or improve telehealth. From this analysis, most of the findings are unsurprising, but provide crucial evidence for future planning: programmes which considered telehealth was as good as or better than standard care described more facilitators in terms of team opinions and flexibility, leadership engagement and provision of institutional resources.

A strength of the work is the inclusion of centres from various regions of the US, of differing sizes and providing care for both adults and children. One interesting observation mentioned only in brief was a tendency for paediatric centres to view telehealth less favourably than their adult counterparts, raising more concerns and barriers. The size of the study perhaps precluded any further detailed analysis of this, but it is an issue of concern for those of us in other regions also. My personal opinion has long been that a one-size-fits-all approach is suboptimal in paediatric CF, and this may be even more of an issue when considering telemedicine. Paediatric teams care for patients from infancy through to young adulthood, the requirements for care changing dramatically during this time. The infant and preschool child is totally dependent on parental/ carer support for their treatment and reporting of clinical status. School-age years see a hybrid of patient and parent involvement and the teens may herald the onset of new issues as the young person wishes to assert their independence; they may reject any involvement of parents and, at a precarious time for health,

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struggle with adherence to management. Overlaid on this developmental evolution are differences in individual families. The socioeconomic impact on CF health is well recognised and reported in many regions [2,3] - children from low income/ resource families fare less well than their counterparts. Much of the work of paediatric multidisciplinary teams (MDTs) is to act as a 'safety net' for non-clinical, social issues in a way likely unfamiliar to many adult teams. Picking up on these may not be straightforward and may rely heavily on non-verbal communication, which may be significantly more difficult over a video call.

The second half of the analysis focussed on financial facilitators and barriers; these were identified similarly by centres across the board but were more likely to have been negatively experienced by centres with less favourable views of telehealth. They included inability to bill for home monitoring, for team members' involvement in consultations and- in certain examples- for patients who lived across a state border. Some centres had lost patients to follow up, with subsequent reduction in income. In the UK we were hugely fortunate to be supported by the NHS in the rapid procurement and provision of home spirometers for a high proportion of CF children and adults. The financial implications of remote monitoring, whilst undoubtedly needing future focus, did not impact clinical care teams significantly at the height of the pandemic, funding currently being provided to centres through a national, severity-related tariff system. Many centres were rapidly enabled with video-consultation software and some have provided families with weighing scales/ stadiometers, although funding for these has not been centralised. The period during which almost no children were seen in person was relatively short at our centre, which has moved to a hybrid model based on assessment of individual needs [4], likely to continue to be embraced post-pandemic. A national assessment of future CF care will shortly be undertaken considering these widespread changes, the growing population of adults living with CF and the beneficial impacts of CFTR modulators realised over recent years.

So, how does the future look? Telemedicine and home monitoring were already being considered to ease the burden of care for people with CF pre-pandemic, which served to accelerate its roll out and widespread acceptability. Studies such as that by Van Citters and colleagues, as part of the larger CF Foundation programme of work, are of great value in assisting with the next stages and levelling up to achieve the highest quality possible in care. The stark differences in funding models across the globe will mean some findings are of greater relevance than others outside the US. It is essential that, in addition to seeking opinions of care teams, we also learn from patients and families what has worked for them, and what not; the companion articles in this focused edition [5,6] are therefore particularly welcomed. In addition to opinions, we also need to measure meaningful clinical outcomes, preservation of improvements in health the last few decades have brought, and to ensure that these are not being compromised. The value of national and international registries cannot be understated in this regard. And alongside clinical care, we need to consider research, adapting protocols where possible to enable remote involvement, and providing resource for in-person attendance where risks or investigations mandate it.

The CF community was forced to rush into telehealth to reduce risks to patients and teams. Many centres successfully built and equipped the life rafts, which are sailing pretty well. It's right that we now take a breath, look around carefully to see where we are, learn lessons wherever possible and plot the optimal course forward.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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