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Impact of COVID-19 on mental health of children with cystic fibrosis and their parents

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Objectives: The aim of this study was to examine the impact of COVID-19 pandemic on 1) the psychological health of children with cystic fibrosis (PWCF) and their parents and 2) education of CWCF.

Methods: A cross-sectional online survey was conducted via SmartSurvey UK for a period of six-to-eight weeks in September/October 2020. The survey was hosted and advertised by CF Ireland via social media platforms (Twitter, Facebook, Instagram, and WhatsApp). The survey was advertised widely by CFI via social media (Twitter, Instagram, Facebook), the CFI website and via CFI PWCF WhatsApp groups.

Results: There were 16 self-reported cases (age 18–59 years, FEV1% 26–133, 10 male), 5% of the clinic. Of these, 11 (69%) had social contact with an individual with the virus or related symptoms, 2 (13%) were tested prior to vacation, 2 (13%) underwent routine testing as part of community testing program and 1 (6%) was positive at hospital admission for an unrelated problem. As regards symptoms, 2 (13%) reported loss of smell and/or taste and 1 (6%) had pyrexia. None needed hospital admission or additional/change in supplementary oxygen and there were no deaths.

Conclusion: As with the general population, COVID-19 infection in pwCF is associated with a range of symptoms. Although the numbers of pwCF who have been diagnosed with COVID-19 are currently relatively low, it is imperative for this high-risk group to limit social contact and ‘shield’ during the current pandemic.
Results: remote monitoring between March - July 2020. outpatient care, emergency consultations, annual reviews (AR), and use of pwCF. We undertook a UK-wide survey to study how CF centres adapted shielding to protect vulnerable individuals included minimising face-to-face (FTF) contact and visits to hospital for people with cystic fibrosis (pwCF). We undertook a UK-wide survey to study how CF centres adapted their practice during this time. Method: We contacted CF nurses to explore service changes to routine outpatient care, emergency consultations, annual reviews (AR), and use of remote monitoring between March - July 2020. Results: Nineteen centres (13 adult) caring for 34% of the UK CF population replied (response rate 35%). Eleven (58%) ceased routine FTF appointments until virtual clinics were implemented, in 1 centre solely by telephone. Six centres suspended AR, the remainder integrating them into virtual or outpatient care. Nine continued existing research activity. Most centres replied (response rate 35%). Eleven (58%) ceased routine FTF appointments and impact during the COVID-19 pandemic. Objectives: In December 2019 our new Service Manager successfully led BACFS’ transition from paper records to an Electronic Patient Record (EPR) called EMIS. The clinical team had intermittent EPR engagement with Trust IT and Governance for 3 years prior with limited progress. This summarises the team’s experience including impact during COVID-19. Methods: A questionnaire was sent to the BACFS multidisciplinary team (n = 13) asking for success scores (0–10) for 11 key areas and comments on challenges, lessons learnt and future development. Results: BACFS has successfully adopted EMIS and is now the principal recording system for CF clinical data, without which BACFS could not have worked remotely during COVID-19. The main challenges identified by users were IT authorisation/ Governance delays, lack of suitable IT, staff knowledge and use during inpatient episodes. Key lessons learned were it needs a designated project manager, a team ready for change, appropriate technology and a deadline. Recurrent users development suggestions included improvements to templates and inpatient processes. Conclusion: It has been a varied team experience yet hugely positive from a service perspective; EMIS has been pivotal for BACFS to function safely and effectively during COVID-19. None of the challenges were insurmountable with correct stakeholder engagement, investment in IT kit, peer support and, most importantly, an implementation lead. Challenges were easier to overcome in a service with low patient numbers and a small team, all of whom supported change. We are keen to further optimise our EPR use and share our experience with other services.

| Question | Percentage success |
|----------|--------------------|
| Initial access to EMIS/ set up | 76% |
| Initial training from IT | 65% |
| Ongoing support from IT | 63% |
| Peer support with embedding within BACFS | 68% |
| EPR format/template suitability | 90% |
| Enabling of BACFS remote working during COVID | 68% |
| Ease of general navigation | 89% |
| Ease of use/access for face to face outpatient Consultations | 86% |
| Ease of use/access for face to face outpatient Consultations | 88% |
| Ease of use/access for home visits | 90% |
| Ease of use/access for inpatients | 45% |
| Ease of use | 70% |