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equipment with virtual appointments. Areas suggested for improvement included the ability to do lung function at home.

Conclusion: Parents were supportive of the use of virtual clinics during COVID-19 but there were mixed views with continuing virtual clinics post-COVID-19.

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A survey of family experience of cystic fibrosis care during the COVID-19 pandemic

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Objective: The feedback will be used to improve the delivery of future cystic fibrosis (CF) care.

Method: A SurveyMonkey of 10 questions with an option to free text was sent to our 21 paediatric CF families.

Results: 12 responses were received. 83% (10) responses felt that the team was accessible during the pandemic. 50% (6) responses felt their child's care has been impacted by COVID-19. 83% (10) responded that they do not feel that their child's health has differed during the pandemic. 33% (4) of responses had concerns about attending appointments. 25% (3) of responses rated virtual or phone appointments as 'excellent' and 42% (5) rated them as 'good'. For future clinic appointments, 42% (5) would prefer face-to-face appointments, and 42% (5) preferred a mixture of virtual, phone and face-to-face appointments. Only 1 family felt entering the hospital grounds increased exposure to COVID-19.

Free text responses:

"Delay in annual review tests"

"The team were available and there when needed"

"Thanks to shielding my son hasn't had as many bugs, coughs or colds"

"She wasn't as physically active"

"Want to limit exposure to infection"

Conclusion: The survey provided insight into the family's experience of their care during the pandemic. Most families adapted to changes in service provision and recommendations for shielding. They felt the CF team were accessible and supportive. 1 family stated 'the care was outstanding even with COVID'. Most respondents felt their child's health was stable, probably due to less exposure to viruses and bacterial infections as some responses suggested. As expected, some families have anxieties about attending appointments due to increased infection risk. As a result of COVID-19, the CF team have mainly been completing virtual/phone appointments and only completing face-to-face appointments when deemed essential. This change in practice will hopefully be embraced as a part of future CF care; however we need to consider our families' preferences.

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Cystic fibrosis social workers' experience of working during COVID-19

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Objectives: The COVID-19 pandemic ushered in a whole new range of changes and challenges for cystic fibrosis (CF) teams which were introduced at a rapid rate. A proposal was put forward for UK CF Social Workers (SW) to meet virtually to discuss emerging issues for people with CF, professional and personal impacts of COVID-19. We aimed to explore SW experiences of new ways of working during COVID-19.

Methods: All 45 UK CF, SW were invited to complete an online anonymised 24 item questionnaire with a mix of Likert scale matrix and open-ended questions. There was a focus on transition to homeworking, what worked well and what didn't, and an exploration of what practices developed during the pandemic SW would like to see employed permanently.

Results: Response rate = 38% (17/45) Paediatric (3) Adult (13) Lifespan (1). Pre-COVID-19, 76% of SW had never worked from home (WFH); now 47% were entirely home-based with a further 29% WFH a few days per week.

57% felt the transition to homeworking went smoothly and 75% felt management were supportive. 76% ceased all face-to-face contact with patients with increased use of video technology to facilitate remote consultations. 65% expressed concerns about returning to pre-COVID working patterns and most wanted flexible working arrangements to continue. 82% attended at least one virtual meeting, 76% found these meetings very useful and 100% felt they should continue.

Conclusions: Attendance at the SW virtual meetings has grown, indicating SW value the sharing of insights and experience. In light of the escalation of remote working and working in isolation, CF SW are rethinking peer support and online learning events. Initially informal in content, these meetings have evolved into a structured format with plans to broaden the context to make them more purposeful. Plans for future working and discussing emerging needs for patients with CF will need to be explored further.

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Concerns for people with cystic fibrosis when travelling pre-COVID-19

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Objectives: To ensure the provision of appropriate travel healthcare guidance, this service improvement study examined travel-related difficulties and concerns which adult people with cystic fibrosis (PWCF) experience and if there are potential situations detrimental to patient health.

Methods: A voluntary, anonymous questionnaire was distributed to patients (n=68; 17–71y) attending routine clinic and a virtual focus group with PWCFs and healthcare team discussed issues and experiences to enable the co-production of appropriate healthcare-related guidance. The availability of published online guidance, from other UK CF centres and CF charities, were examined.

Results: On vacation, 38% (25/66) took a break from nebulised therapies and 9% (9/67) were not aware of travel adapter requirements. Cleaning of nebuliser responses (n=59) varied, involving tap water with/without soap (57.6%), heat/chemical disinfection (30.5%), cloth/wipes (5.1%), rinsing in cooled boiled water (3.4%), dishwasher (1.7%) and nothing (1.7%). PWCF concerns included travel insurance costs, medication (having enough; maintaining cold chain during travelling and accommodation), airport security (searching of bags, swabbing of nebulisers, scrutiny of medicine list and issues if incomplete, concern with presence of a PEG) and flights (acquiring infections, travelling with other potential passengers with CF, concern that medicines will get lost or damaged hence necessity to carry as cabin baggage with restrictions; passengers complaints about coughing). Information available from online resources was varied in content and depth. Patients indicated the value of comprehensive advice from their healthcare team.

Conclusions: Healthcare teams should prepare travel guidance and stress the importance of continued nebulised therapies during vacations and proper nebuliser cleaning and disinfection methods to minimise the risk of contaminating nebulisers with environmental/water organisms.

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Children and young people with cystic fibrosis enhanced multi-disciplinary pathways to address their educational needs during the evolving COVID-19 pandemic

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Background: Our paediatric cystic fibrosis (CF) team's pathway to address the educational needs of children with CF was based on a systems approach that benefited from coordinated, holistic, personalised foci adapting multidisciplinary and inter-agency working (BASW'20). Issues arising in the UK from shielding during the COVID-19 pandemic highlighted the unequal effect of lockdown on children's learning (Lancet'21). In addition,

arrangements for supporting pupils at school and ensuring good education provision for children with long-term medical needs (DoE'13,'15,'20) necessitated piloting and reviewing our Enhanced Education Pathway through the pandemic.

Methods: Six children with CF who were considered clinically, educationally, emotionally and socially most vulnerable were reviewed via patient notes, psychosocial meetings, multidisciplinary and multi-agency meetings along with the child, parent and schools. A qualitative thematic synthesis of this pilot cohort examined the potential impact of disruptive access to education to educational outcomes. This informed the development of the CF enhanced education pathways.

Results-thematic synthesis: Recurring emergent themes identified as potentially impacting educational outcomes included: facilitating decision-making; access to quality teaching and technology, parental literacy and capacity to monitor and support learning; robustness of trusting relationship; and advocacy for enhanced education provision.

Conclusion: This pilot helped to support equal and fair access to education for our children with CF by prioritising access to blended learning, teaching, access to technology and addressing parenting challenges. The collaborative working with children, their families, CF clinical and psychosocial teams, along with Hospital Education team and schools, have highlighted the added value of multidisciplinary and inter-agency working to further develop enhanced education pathways.

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A review of paediatric cystic fibrosis care during the COVID-19 pandemic

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Objective: To explore the impact of COVID-19 on paediatric cystic fibrosis (CF) patient care.

Method: A retrospective review of data on 20 CF patients between 1 March - 30 November 2020 compared to data from 1 March - 30 November 2019. This included: courses of oral antibiotics; days requiring intravenous antibiotics (IVAB); routine IVAB; home IVAB; face-to-face/phone appointments; acute hospital presentations; and microbiology samples.

Results: In 2020 the number of courses of oral antibiotics for exacerbations or bacteria growth decreased from 29 to 14; total IVAB days decreased from 177 days to 107. 2 courses of routine IVAB were cancelled and 1 course was postponed, home IVAB decreased from 125 days to 85 due to reduced aseptic IV services. Face-to-face appointments decreased from 76 appointments to 15. In 2019 no phone appointments were completed; in 2020 there were 51. 10 patients presented to Paediatric Observation and Assessment Unit in 2019; this halved to 5 in 2020. Microbiology samples nearly halved from 276 to 141 samples.

Conclusion: Oral antibiotic courses, IVAB therapy and acute hospital admissions were reduced in 2020. This could be due to a number of reasons such as shielding, closure of the paediatric unit to house adult patients, reduced aseptic IV services, family reluctance to access care at a different hospital or being hesitant to present to hospital due to increased infection risk. Microbiology samples are less practical to collect due to reduced face-to-face contacts. Some families may be apprehensive to drop samples at the hospital due to potential exposure to COVID-19. In 2020, most appointments were via phone; this is a change from 2019. Due to the increased risk of cross-infection for CF patients, limiting hospital attendance is a major step in the right direction to improve care. Although changes can be beneficial, it is important to recognise the limitations of reduced face-to-face patient contact and consider family preferences of care delivery.

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Patient experience of accessing a virtual cystic fibrosis service during the 2020 SARS-CoV-2 pandemic in Blackpool, North West of England

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In 2015 Regional Specialist Commissioners awarded Blackpool Teaching Hospitals the commission of a new regional cystic fibrosis centre in the North West of England. The Blackpool Adult Cystic Fibrosis Service (BACFS)

opened in February 2017 and was the first entirely new UK adult CF centre in three decades.

Objective: To explore patient experiences of accessing a virtual adult cystic fibrosis service during the SARS-CoV-2 pandemic, to inform future practice and service development.

Method: Between December 2020 and January 2021, 44 patients, accessing a blended approach to care through both virtual and face-to-face appointments, where necessary, were offered a CF-related adaptation of our hospital's Friends and Family Test. The questionnaire provided the mechanism to explore patient satisfaction and experience of BACFS during the pandemic (March 2020–December 2020) giving opportunity to critically appraise the service and their virtual experience.

Results: Response rate was 18%. 100% of patients rated the service as either good or excellent, demonstrating care and compassion, being listened to, developing autonomy over their healthcare with shared action plans and improving confidence in the management of their condition. 50% of patients reported their virtual experience was 'very good' and 50% 'good', with 100% of patients reporting the frequency of their appointments was 'just right'. Further qualitative themes of the virtual experience are presented, including convenience of appointments and feeling connected with the team during the pandemic.

Conclusion: The data presented demonstrates that patients value the service provided by BACFS. Patients have been supportive of the virtual service provision with a suggestion that the offering may continue as we consider service delivery post SARS-CoV-2. The adapted patient experience questionnaire continues to drive service development and inform our approaches in alternative ways to engage our patients.

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The impact of COVID-19 on the relationships between parents of young people diagnosed with cystic fibrosis and the cystic fibrosis multidisciplinary team

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Objectives: The COVID-19 pandemic has seen cystic fibrosis (CF) working practice move to more remote clinical models. This study assesses the impact of this shift in working patterns on the relationships between families of young people with CF and CF multidisciplinary teams (MDT). In addition, the study also assessed parents' perceptions of working remotely.

Methods: Six semi-structured interviews with parents of young people under the care of a regional UK CF specialist centre were analysed using inductive content analysis.

Results: Three domains emerged: Interpersonal Relationships, Remote Clinics and CF in the Context of COVID-19. The enduring and close relationships between the MDT and families were discussed, including changes brought about by COVID-19 and changes in working practice. Discussion also focused on the acceptability of remote clinics moving forwards.

Conclusions: The importance of the quality of the relationship between families and CF MDTs is vital to enhance ongoing care with parents highlighting key attributes in a successful working relationship. Remote working was acceptable in the context of COVID-19 and, with some considerations, could be useful moving forward.

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Treatment outcome preferences among people with cystic fibrosis: a discrete choice experiment

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Objectives: Simplifying treatment burden is a recognised priority for people with cystic fibrosis (CF). This study aims to quantify preferences and