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with CF (pwCF). Our aim was to facilitate collaboration across adult and paediatric teams to identify areas for improvement.

Method: We led a process of stakeholder engagement including meeting with other CF and non-CF transition services. Multidisciplinary Team (MDT) QI meetings were held within the adult service to identify what was considered a successful transfer of care. We observed the first in-person transition clinic since the pandemic, and distributed electronic surveys of the clinic experience to pwCF, carers, and staff. Lastly, we held a virtual cross-service QI meeting to present findings, aiming to reach consensus on areas for change.

Results: 5/5 pwCF and 5/5 carers completed the clinic surveys. Both identified their main priorities: to meet the adult team and receive a clinical review. Comments identified anxiety discussing future life plans too young or repetitively. 3/5 pwCF and 3/5 carers preferred the carer to be present throughout the visit.

7/9 staff completed the survey. There was general agreement of clinic objectives that 6/7 felt were met. Comments were around clinic location, pre-meeting, and coordinating MDT review content. Holding a face-to-face clinic was perceived as important.

Overall, the MDTs agreed on 5 areas for improvement: documentation; patient information; clinic meetings; individual profession handovers; and identifying pwCF requiring bespoke transition.

Conclusion: Protected time for QI provided a forum to bring paediatric and adult CF teams together to identify shared priorities for improvement of local transition care. A QI lead role has allowed us to drive service development during the COVID-19 pandemic and introduction of CFTR modulators.

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Transition to adult care in children with cystic fibrosis – experience over a decade from a large tertiary centre in the northwest United Kingdom

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Objectives: Cystic fibrosis (CF) care is delivered by a multidisciplinary team (MDT), and adolescence represents a challenging time, both in terms of growing patient independence and changing physiology. This is further complicated by the transition of most paediatric patients to adult services, which involves a completely new MDT team. As the transition is a lengthy and tortuous process, a coordinated effort is required for smooth processing and better patient outcomes. This study aimed at exploring the average age at transition, and the average duration of the transition process over a decade.

Methods: Royal Manchester Children's Hospital (RMCH) is involved in the tertiary CF care of 201 children in the northwest UK. RMCH has an established practice of transitioning all eligible children to adult services by their 18th birthday. This is achieved through a highly coordinated approach undertaken by all members of the CF MDT team and the creation of a common transition document. For the purpose of this study, this process was reviewed for all children transitioned to adult services between 2006 and 2018.

Results: Over the 13-year period, a total of 119 children with CF were transitioned to adult services, averaging 10/year (range 3–15/year). One record was excluded due to the missing date of MDT documentation. Overall, the average age at transition was 18.3 years (range 16.1–22.8 years). The average time for transition was 141 days (range 16–1,142 days).

Conclusion: Overall, RMCH performed well in a coordinated transitioning of most of its patients by the stipulated age, but it fell short with the time taken with the actual process. The process itself needs to be reviewed for a transition undertaken in a timely manner.

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Transitioning to adult services for children with cystic fibrosis (CF): what matters to all stakeholders?

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Objectives: Transition to adult services can reflect a crucial point in the clinical journey of our paediatric patients. Changes occur not only in the healthcare providers, but also the attitudes towards ownership and independent decision-making. The National Institute of Clinical Excellence (NICE, 2022) recognises these challenges and advocates a patient-centric approach. The approach advocates involving the young person and their carers in co-producing the fundamentals of the transitioning process. Therefore, we wanted to evaluate and co-design our process of transitioning children with CF to adult services, in our tertiary hospital in Cambridge.

Scope and understand the views of stakeholder groups (patients, families and healthcare providers) on the current transitioning process

Co-design informed ideas for change alongside stakeholder groups

Select the area of focus that reflects mutual priorities

Co-design the change process

Evaluate the effectiveness

Collaborate with adult services to identify gaps in year 1 of transition

Methods: Parents and families were invited to focus groups held on Zoom. Surveys were also provided in the clinic for patients and families to fill and sent to clinicians via SurveyMonkey. Data was then collected and themes were drawn from the initial findings to inform the next steps.

Results: Key themes identified from patients and their families were medication, motivation, building a rapport with the new team, and the parents being the main point of contact. The clinical professionals were similarly concerned regarding the rapport and self-management by the patient. They also identified the transition clinic itself as needing development. As such, key themes of overlap included the independence of the patient and building rapport.

Conclusion: Collaborating with all stakeholders enabled an informed approach to bring about systems change. For the next step, strategies are being co-designed to improve the overlapping priorities.

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Change in the anxiety levels of children with cystic fibrosis and their mothers at the beginning of the COVID-19 pandemic and after 1 year

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Objectives: The COVID-19 pandemic may increase the anxiety levels of children with cystic fibrosis (CF) and their primary caregivers, but anxiety levels may change over time. We aimed to evaluate the change in anxiety of children with CF and their families at the beginning of the COVID-19 pandemic and after one year.

Methods: This was a questionnaire-based study conducted via teleconference. A total of 41 children with CF and their mothers were included. The State-Trait Anxiety Inventory for Children (STAI-C) was used for children aged 9–12 years and State-Trait Anxiety Inventory (STAI) was used for all mothers and children aged 13–18 years. The anxiety levels of children and mothers were evaluated and compared at the beginning of the COVID-19 pandemic and after one year.

Results: There were 23 children under aged 9 years, 12 children aged 9–12 years and 6 children aged 13–18 years; 51.2% of children were female. The median anxiety level of children with CF aged 9–12 years was 28.5 (20.0–42.0) and 31.0 (22.0–36.0) at the beginning of pandemic and after one year, respectively ($p=0.454$). The median anxiety level of children with CF aged 13–18 years was 29.0 (27.0–33.0) and 47.0 (41.0–51.0) at the beginning of pandemic and after one year, respectively ($p=0.027$). The median anxiety level of all mothers was 48.0 (24.0–73.0) and 43.0

(35.0–56.0) at the beginning of pandemic and after one year, respectively ($p=0.013$). When mothers were evaluated according to the age group of children, anxiety levels of mothers of children with 9–12 years decreased significantly after one year compared to the beginning ($p=0.017$), and there was no significant change in other age groups ($p=0.465$, $p=0.173$).

Conclusions: Reducing certain pandemic restrictions and returning to school over time may have increased the anxiety levels of children aged 13–18 years. In addition, reducing restrictions and adapting to living with the pandemic over time may have reduced the anxiety levels of mothers.

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Who's talking about cystic fibrosis continued: the effects of the COVID-19 pandemic on the cystic fibrosis online landscape

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Background: Due to COVID-19, we saw an increased usage of digital platforms for healthcare delivery. However, its effect on internet postings for CF during 2021 is unknown.

Methods: CF key phrases were identified by a CF MDT and entered in Google Alerts and tracked for 6 months in 2021. Alerts were also created for

Asthma, COPD and Lung Fibrosis. Data recorded for each alert includes the date, title, URL, category, country of origin; if a discussion, like/share took place. This was then compared against previous data collected (2015, 2019).

Results: The number of CF alerts recorded decreased (2021:1846–2015:2742) while the number of blocked alerts increased (2021:325–2015:89). Almost half of the CF alerts originated from the USA. In 2021, News was the most common category (33.96%) followed by Financial/Marketing (25.73%) and Medical (21.07%). The most common category for 2015 was News (58.35%) and Financial/Marketing in 2019 (35.2%). The majority of CF terms experienced an increase in quantity, specifically alerts relating to CF pathogens or changing condition expectations, such as *Pseudomonas* (2021:718, 2015:149), CFLD(2021:428, 2019:865, 2015:37), and CF Pregnancy (2021:91, 2015:5). For the comparative lung conditions, in 2015 Asthma was the most common alert (985) followed by CF, COPD, and Lung Fibrosis. In 2019 CF (605) was the most common. In 2021, the quantity of alerts decreased for all conditions, with CF (316) and Asthma (336) being of similar magnitude.

Conclusion: The landscape for CF internet postings continues to evolve. CF is discussed frequently online, with the focus of these discussions changing to news items in 2021. The increased frequency of specific CF terms may reflect changing expectations (e.g Pregnancy). The number of blocked alerts continues to increase, potentially reflecting different global GDPR practices. Online non-EU healthcare resources need to factor this into their practice to avoid potential correct information loss for EU patients.