

wait for review from different members of the multi-disciplinary team is better. All would recommend this service to family and friends.

**Conclusion:** The results demonstrate increased satisfaction with the locally provided service at New Cross Hospital. This decentralisation of services may help those with CF engage with the multi-disciplinary team to help keep them as well as possible for as long as possible. We think this unique outpatient satellite service could be replicated at other district general hospitals to improve overall patient experience and help reduce clinical burden from the specialist CF centres.

#### P043

##### Explore patient experience of care and of life with cystic fibrosis in order to determine measures that matter to patients and parents: the ExPaParM study

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**Objectives:** Identify and prioritise the patients' care pathways and life situations in France to assess the quality of care based on the patients' experience and their experiential knowledge

**Methods:** Collaborative study: Establishment of a research group including 2 transplanted patients, 2 non transplanted patients and 2 parents, CF clinicians and researchers. Patients and parents are trained to qualitative research to collaborate at all steps of the study with researchers and clinicians. The nominal group technique is used to identify and prioritise patients' health and life situations from diagnosis to life post transplantation.

Qualitative study: Definition of patients' profiles and associated CF centres to recruit patients representing the spectrum of health and life situations; development of interview guides using open-ended questions to cover domains of patient experience and experiential knowledge.

##### Results:

1. Paediatric and Adult CF care pathways in France in 2020 taking into account the diversity of patients' situations (co-morbidities, stages of child development, social and family life of adults);
2. Patients' profiles for their recruitment in the associated CF centres representing a cross-sectional view of the care pathway in 2020;
3. Interview guides including open-ended questions to explore patients' and parents' experience and their experiential knowledge applied to quality of care and life with CF

**Conclusion:** This first step aims to set up the conditions for this collaborative study and the methods and tools to investigate the different patients' situations. Interviews with patients will then be carried out to collect their 12-month retrospective experience. The verbatims will be analysed using the grounded theory method to identify the quality of care and quality of life criteria from the point of view of patients and parents.

#### P044

##### A prospective randomised controlled mixed-methods pilot study of home monitoring in adults with cystic fibrosis (HOME-CF)

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**Objectives:** Pulmonary exacerbations (PEX) are common in people with CF resulting in impaired quality of life and progressive lung function decline. Home monitoring (HM) has potential as an effective method of detecting

PEX which could enable more prompt treatment and result in improved outcomes. The primary aims of this study were to

1. determine whether HM is effective compared with routine care (RC) in reducing hospital inpatient bed days; and
2. assess whether this results in differences in health-related quality of life.

**Methods:** We conducted a single-centre, non-blinded, randomised controlled mixed-methods trial recruiting CF adults with at least 1 admission to hospital to receive intravenous antibiotics over the preceding 24 months. Participants were randomised 1:1 to HM (twice-weekly FEV<sub>1</sub> and CFRSD-CRISS transmitted instantaneously) or RC for the 12-month study period. Quantitative outcomes (including health economic analysis) were collected at baseline and 3-monthly study visits and semi-structured qualitative interviews were performed at baseline and 12-month time points.

**Results:** 88 participants were randomised (44 HM, 44 RC) with no significant differences in baseline characteristics. Participants in the HM group that required admission were in hospital for (mean (S.D.)) 23.2 (20.3) days compared with 29.5 (24.8) for the RC group ( $p=0.3$ ), with no significant difference in other quantitative outcomes. The total societal costs were approximately £1,650 more per patient for the RC group than the HM group ( $p=0.775$ ). Qualitative interviews revealed that HM was generally well-received, with participants feeling empowered, with improved self-management and improved awareness of their own health status.

**Conclusions:** This data supports the outcomes of the eICE study in demonstrating that HM is effective in detecting PEX with potential to reduce inpatient bed days. In addition, HOME-CF provides evidence for reduced costs and positive participant experience of receiving HM.

#### P045

##### User experience of virtual consultations

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**Introduction:** The use of technology in healthcare is no new concept. Most CF adults CF are now staying in education, working and starting families. The disruption of routine clinic visits have time and financial cost to individuals. At this adult CF service, we are introducing virtual consultations (VC) supported by video conferencing and Bluetooth spirometry.

**Objective:** To review patient satisfaction with VC and evaluate the financial and time saving costs for patients.

**Methods:** After each consultation a survey was sent to the patient via email to evaluate their experience. This included ten closed-ended or multiple-choice questions and seven open-ended questions. This was analysed for positive and negative feedback, time and cost implications to the patient.

**Results:** N=42 survey responses over 18 months from 115 new patient virtual consultations.

Number of virtual consultations replacing 'usual care' (n = )  
Routine clinic follow-up n = 23 (54%), Annual review follow-up n = 5 (11%), Day case review n = 8 (19%), CFD review n = 3 (7%), Other n = 3 (7%)

##### Survey responses:

- Use of technology and conversation flow: excellent or good - 80%
- VC rating: very satisfied - 71%
- Ability to express thoughts and feelings: excellent or good - 85%
- 52% rated the VC as 5/5
- 100% highly likely or likely to opt for VC again
- Travel cost saving: median €35 (IQR 16.4–40.2)
- Travel time saved: median 180 minutes (IQR 120–240)
- Time saved off work: whole day - 38%, half day - 21%
- Arranging care for dependents: 21%

**Conclusion:** This new service is well received with all respondents stating they would use it again. There were savings for patients' financially, and reduced travel time and time off work, in some instances quite significantly. Further investigation of the health economics of this new service is currently under review. Questions remain around the perception of the teams completing such consultations and the long-term engagement of the clinical team and CF patients.

#### P046

##### Social deprivation as a marker for lung function decline in adult cystic fibrosis patients

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**Objectives:** Poorer socioeconomic status has been demonstrated to be associated with worse health outcomes in CF patients (1). We aimed to investigate the association of social deprivation in Bristol, UK, with lung function in our CF patients.

**Methods:** We reviewed data from the Bristol Adult CF Centre (n = 244). Patients were excluded if they had previous lung transplants, insufficient FEV<sub>1</sub> measurements or unavailable deprivation scores; this gave 175 eligible patients. We measured social deprivation using the Index of Multiple Deprivation decile score for each patient's postcode (1 = 10% population most deprived, 10 = 10% population least deprived). We measured lung function using rate of change of min FEV<sub>1</sub> level over the last 3 years, performing subgroup analysis for gender, BMI and confounding factors (CF-related diabetes, gene-modifying medications (GMM), NTM and BCC infection).

**Results:** Correlation coefficients and R<sup>2</sup> values were determined per group. Only very weak positive linear relationships exist in regression models for: all patients, male, CFRD, GMM and NTM subgroups. A weak negative correlation exists for the female subgroup.

All patients n = 175 (0.067, R<sup>2</sup> 0.003), male n = 100 (0.237, R<sup>2</sup> 0.03), female n = 75 (−0.119, R<sup>2</sup> 0.009), CFDiabetes n = 64 (0.137, R<sup>2</sup> 0.011), NTM n = 35 (0.27, R<sup>2</sup> 0.04). Only 12 patients had BCC colonisation. A moderate positive correlation was shown between BMI and change in FEV<sub>1</sub> (0.366, R<sup>2</sup> 0.079), with no significant relationship between BMI and IMD score (0.005, R<sup>2</sup> 0.00001).

**Conclusion:** No significant relationship was found between lung function and social deprivation in BACFC patients, although a weak link was noted in female patients. Future studies of a larger cohort are warranted to support further evidence of a relationship between these factors. Other confounding factors (e.g. health literacy) may not have been accounted for.

#### Reference

- [1] David Taylor-Robinson *et al.* (2013). *Lancet Respiratory Medicine*, Vol. 1:121–128.

#### P047

##### Lung function over the life course of people with cystic fibrosis

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**Objectives:** In people with cystic fibrosis (CF), Forced Expiratory Volume (FEV<sub>1pp</sub>) generally increases up to approximately 20 years of age, and then progressively decreases. Existing statistical models of this trajectory, however, have several limitations, including assumptions that that decline in FEV<sub>1</sub> is linear over time, and lack of censoring techniques, potentially leading to selection bias. We aim to establish and validate a multivariable longitudinal model of FEV<sub>1</sub> over the life span of people with CF, addressing current statistical methodological limitations.

**Methods:** This project uses data from the Australian Cystic Fibrosis Data Registry (ACFDR). The analysis included random effect mixed linear regression. A two-way random intercept model (by Centre and patient) along with a random slope for time from diagnosis for each patient was included. Potential predictors were sequentially evaluated in the model using the likelihood ratio test. Appropriate sub-group analyses were performed in the presence of interaction effects.

**Results:** Participants included 2,670 patients (age <21 years) and 1991 patients (age 21 and greater). For those aged less than 21 years, factors found to be significantly and independently associated with FEV<sub>1pp</sub> included years from diagnosis, BMI, age at diagnosis, mortality, pancreatic insufficiency and lung transplantation. The predictors were similar for patients aged 21 years and greater, except for pancreatic insufficiency, which became insignificant. There was significant variation in FEV<sub>1pp</sub> within sites and within patients. The FEV<sub>1pp</sub> trajectories were different between patients who underwent lung transplantation and those who did not, and between patients who died and those who did not.

**Conclusions:** This study reports initial findings to develop a longitudinal model of lung function in people with CF, which will help identify potential risk factors and also provide a baseline model of FEV<sub>1</sub> with which to evaluate interventions.

#### P048

##### *Pseudomonas aeruginosa* lung infection in paediatric cystic fibrosis patients: risk factors and impact on lung function

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**Objectives:** Lung disease is the primary cause of morbi-mortality in Cystic Fibrosis (CF) patients. Airways infections, particularly by *Pseudomonas aeruginosa*, are among the most pejorative factors associated with lung function decline. Infectious pulmonary exacerbations occur in about 40% of the patients and lead to chronic colonisation in 50%. Moreover, age of initial infection by *P. aeruginosa* varies considerably inter-individually. This study aims to investigate risk factors associated with earlier onset infection and chronic colonisation and to evaluate their impact on lung function decline.

**Methods:** We analysed paediatric patients with pancreatic insufficiency, born after 2000, and recruited into the French CF Modifier Gene Study since 2004. We evaluated demographic and clinical risk factors such as sex, *CFTR* genotype, history of meconium ileus and nutritional status; and hospital environmental risk factors such as CF centre sizes, *P. aeruginosa* prevalence per centre, and annual rate of visits per patient. We studied the impact of infection on the respiratory function by modelling jointly the decline of FEV<sub>1pp</sub> and age at *P. aeruginosa* first acquisition and chronic colonisation.

**Results:** Among the 1,395 paediatric patients analysed, 975 (69.9%) had an initial *P. aeruginosa* infection at a median age of 4.7 yrs [4.1–5.3]; 299 of those (27.2%) progressed to chronic colonisation. The principal risk factor for a younger age at onset infection was the high number (>3) of annual visits (HR = 3.68, p < 0.0001). The annual rate of FEV<sub>1pp</sub> decline before onset *P. aeruginosa* infection was −0.47% per yr, which accelerated by 0.94% after infection, leading to an annual rate of FEV<sub>1pp</sub> decline of −1.42% FEV<sub>1pp</sub> per yr.

**Conclusion:** Identification of these risk factors is a challenge that should offer a way to distinguish the patients at risk of developing earlier and/or chronic *P. aeruginosa* infection and to help to better understand its physiopathological mechanisms.