Background

Cystic Fibrosis

- Result of genetic mutations in the CFTR encoding gene. Now routinely diagnosed at birth. Multisystem condition
- Chronic condition characterised by long periods of stability interrupted by lung infection and inflammation (Acute Pulmonary Exacerbations: APEs)
- Enormous person-to-person variability in nature of CF complications and the way these progress
- Cycles of infection/inflammation cause progressive lung damage and associated loss of lung function
- Lungs become chronically infected with pathogens such as Pseudomonas aeruginosa, Mycobacterium abscessus
- In 50% of CF was entirely paediatric condition with 80% mortality by age 3 years. Incremental improvements in life expectancy: so by 2020, >95% of people with CF were adults
- Clinical management can be managed exclusively by CF Centres

Unsustainable model of care

- Burden of care identified as key issue for people with CF (James Lind Alliance consultation)
- Standards of care come at significant costs to the individual, healthcare professionals and payers
- Existing adult CF centres under increasing strain following rise in life expectancy
- From 2012-2022, new genotype-dependent disease-modifying drugs are now available to >90% of CF people
- Significant differences in response to these drugs between individuals
- Drugs improve well-being, reduce the rate of lung function loss BUT APEs are still an issue albeit at lower frequency

SmartCareCF – Project Breathe

SmartCareCF: First exploratory study (Funded by CF Trust, EPSRC, Microsoft Research Institute). Multicentre non-interventional study (148 people) established feasibility of home-based monitoring using blue-toothed devices. Data only returned to patient.

Key success: Machine learning analytics used data to develop Predictive Algorithm for APEs.

Project Breathe: Second study (Funded by CF Foundation (USA), EPSRC & HDR UK Multicentre study)

i. Create a tool for adults with CF to inform and assist self-management
ii. With consent, home-based data provided to CF centre to assist clinical decision-making
iii. Validate and refine predictive algorithm as research project

Next steps: Supported by LifeArc

Improve care and widen access

ACE-CF: Formal clinical trial to test Predictive Algorithm in Real-time to provide self-management tool to adults with CF. Co-funded by LifeArc and NHRI (All in Healthcare competition). UKRA registration.

Further research funded by LifeArc:

- Plug and Play: Testing novel sensors. Can passive sensors enrich existing data acquisition devices?
- Bronchiectasis: Can learnings in CF be applied to other chronic respiratory conditions? Study at Royal Papworth Hospital led by Dr Charles Haworth

Summary

All to improve healthcare

Meeting unmet medical/societal/financial needs

Chronic health conditions place an increasingly heavy burden on patients, healthcare professionals and payers. Existing standards of care are inflexible and do not adapt well to the enormous variation in patient need. We have successfully explored alternative care models for Cystic Fibrosis (CF) by using blue-toothed devices for home-monitoring for CF. Supervised machine learning using these anonymised datasets has created a predictive algorithm (research tool) able to identify a worsening in condition, up to 10 days before the clinical team. We are now planning to provide this directly to patients the algorithm outputs to inform a safe but more flexible and more timely approach to keeping people healthy.