Quality Improvement Share & Learn

Cystic Fibrosis Trust

Summary of QI Share & Learn: Remote Monitoring - Wednesday 19th October

Case Studies

Experiences from a remote monitoring pilot project in Northern Ireland

Damian O'Neill and Audrey Chada, Belfast

- Belfast adult CF service secured funding from the Public Health Agency for a six-month pilot to assess the benefits of remote monitoring for people with CF and clinical teams
- 50 patients were recruited (representative cross-sectional sample) and supplied with: tablet, BP cuff, O2 monitor, thermometer, scales and spirometer to use at home
- Patients provided readings prior to clinic appointments and could self-monitor at home
- Positive reinforcement and reassurance for patients, as well as improved health literacy
- Trends in the data supported early detection of issues, incl. deterioration and infection
- Helpline staff could use data to inform treatment decisions
- Learning:
  - Variable engagement with pilot means this approach doesn't work for all patients
  - Improved training and equipment familiarisation for patients should be provided
  - Patients would prefer a mobile app to a dedicated tablet device
  - Technology Enabled Care (TEC) service champions could support delivery

Using Nuvoair & CF Health Hub, and the challenges of sustainability

Tracey Daniels, York & Hull

- COVID pandemic drove rapid and widespread implementation of remote monitoring technologies and virtual clinics in CF care
- The York & Hull service for adults with CF uses a range of technologies, incl. CF HealthHub, Nuvoair, BEAM and Freestyle Libre to support in person and especially virtual consultations
- CF HealthHub is a learning health system which includes sharing practice, behaviour change and adherence monitoring using chipped nebulisers and a platform where people with CF can see this data and choose to share it with their clinicians and anonymously with researchers; this programme is generating data that helps clinicians to understand the impact of individuals discontinuing preventative treatments when taking modulators; researchers are exploring this data to understand the impacts of continuing or stopping preventative treatment on outcomes with modulators
- Learning:
  - Found that it is challenging to sustain virtual care and remote monitoring innovations in the absence of dedicated funding and standards/guidance around their use
  - Two main aspects are required to sustain innovations in remote monitoring: (i) ongoing engagement of people with the technologies and (ii) appropriate funding streams

Evaluation of a cystic fibrosis telemedicine outpatient service

Mary Ann Boyfield, Norfolk & Norwich

- Norfolk & Norwich adult service implemented a telemedicine CF outpatient service with virtual clinic appointments and MDT consultations during the pandemic
- Conducted a service evaluation gathering quantitative and qualitative feedback
- High endorsement of virtual clinics and their sustainability; over 80% of respondents wanted virtual clinics to continue in future
- Qualitative comments showed strong support from patients for a hybrid model using virtual clinics (with choice between video or phone, in combination with face-to-face appointments)

- Learning:
  - A personalised approach is important: offer a choice of appointment formats in the appointment letter (video, phone or in-clinic)
  - Support patients to see any MDT member individually where there is a need for this
  - Carry out annual reviews and new patient assessments as face-to-face appointments

Notes from the Q&A and open discussion

Questions from attendees for speakers and opportunity for attendees to share their own experiences and learning around remote monitoring

- From projects presented, it is clear there is a need for technologies to be simple, so they are easy to use for patients, e.g. Bluetooth connected devices to negate need for manual data entry, but what is the experience of and impact on clinical teams whose patients use remote monitoring tools? How have these impacted ways of working?
  - Functioning technology is required on both sides for remote monitoring and virtual clinics and having the right equipment is key; at the start of the pandemic this was a problem but since then teams have adapted and have better facilities now to support video calls etc., so virtual clinics are a smoother experience for everyone; it may be beneficial in future (e.g. via the CF Trust staffing tool) to explore if CF teams have the right equipment to support remote monitoring and virtual clinics
- How do we combat digital illiteracy & poverty? Will this be something that will inadvertently become a further burden on CF MDTs?
  - Some concerns that telemedicine has not made care more accessible to those who have always been hard to reach, in fact, it may exacerbate health inequalities, especially in current climate
  - Others saw increased engagement with virtual clinics among people who had not attended face-to-face clinic appointments in the past (DNAs)
  - Emphasis needs to be on personalised care, virtual clinics may be able to help with in-person inequity
  - Face-to-face visits can disadvantage low-income families due to travel and parking costs, though the group noted that there is support for families on benefits who may be able to claim back petrol and parking costs from the cashier's office
- Can I ask if there are data for children and if the results were similar? We tend to want height, weight and lung function for all old enough to do home spirometry.
  - There's a great recent paper focusing on virtual spirometry in paeds: Pediatric Pulmonology - 2022 - Davis - Real-world feasibility of short-term unsupervised home spirometry in CF
  - Glasgow paeds service still delivering large proportion of appointments virtually, though most clinicians would prefer to go back to face-to-face; continuing to deliver a lot of home visits for paediatrics; some concerns around missing child protection issues when using virtual sessions
- Are we entering an era whereby we could start connecting patients in any part of the UK with specialists anywhere else? Perhaps a 'big vision' idea?!
  - In theory this could be made possible with virtual clinics and other technologies available
  - Limitation is that referred patients might live far away from the specialist service they were referred to, so would likely only be seen virtually – how can we build rapport?

If you have any questions or comments, please contact QI@cysticfibrosis.org.uk