

Summary of QI Share & Learn: Transition – Tuesday 20th June 23

Case Studies

Developing transition to adult care through quality improvement

Tracy Barnett and Lou Warnock, Oxford Adult CF service

- Transition clinics were paused during Covid and the service saw an opportunity to review processes and practice when these restarted
- Initially, observed transition clinics and carried out survey with staff, patients and carers
- Then used Plan-Do-Study-Act (PDSA) cycles to implement and test changes to transition processes and practice, including:
 - New electronic patient record (EPR) transition summary and documentation
 - Pre-transition clinic meetings (virtual)
 - Closer working between staff in paed and adult service
 - Adult staff attendance at paed AR for those due to transition soon
 - First adult appointment always offered as face to face
 - Updated patient information (leaflet & website; this work is ongoing, [view current Oxford website as example](#))
- Additional work with CF Trust to gather feedback on transition issues using focus groups, which will inform further improvements in line with CF community feedback
- Learning from quality improvement work at Oxford:
 - Involving paed colleagues early and working to common goals is key to success
 - Shared notes and handover documentation aid smooth transition
 - Setting out and managing expectations is critical, e.g. using clear patient information

The power of involvement – focus groups insights on transition

Claire Walter, Cystic Fibrosis Trust Involvement team

- Cystic Fibrosis Trust Involvement team ran a focus group in 2022 with CF community members to explore views of and issues with transition from paed to adult CF care
- Key recommendations from focus group to improve transition:
 - Avoid making assumptions and find out from patients what the challenges are
 - Familiarisation to adult team and physical setting are helpful prior to transition
 - Setting expectations and making information easily accessible are important
 - Transition should be planned with the young person and it is important to consider the approach to family members (they are transitioning too)
 - Peer support from young people with CF / parents who recently completed transition could be useful for some (incl. parents) and might reduce burden on CF teams

Bridging the gap: a youth worker's role in supporting transition

Sophie Sinnott, Southampton Paediatric CF service

- Core purpose of Youth Worker role is to work holistically alongside the young person to facilitate their personal, social and educational development, and reach their full potential
- Transition is not just a simple transfer, it is a process and journey over time – it is vital to allow each young person to progress at their own pace (e.g. use Ready Steady Go)
- Southampton Youth Worker role will work jointly with adult service and be present in the adult service, facilitating the patient and parent voice to be heard (e.g. via a Young Persons Transition Steering Group)
- Youth worker will offer transition packs, conversation guides and support, and plans to implement a post-transition questionnaire
- Further information and links to resources used by Southampton:
 - [PEEER Youth Workers](#)
 - [Ready Steady Go Programme](#)

- Learning:
 - Close joint working with adult service and presence of Youth Worker in the adult setting are recommended, which will also provide continuity for young people
 - Resources available via the Ready Steady Go programme and PEEER network can support assessment of readiness and ensure person-centredness

Experience with a Youth Worker role working across adult and paediatric units

Emma Guy and Faith Ochelle, Leeds CF service

- Leeds service secured funding from Cystic Fibrosis Trust in 2018 via the Clinical Excellence & Innovation Awards for a Youth Worker role to work across paed and adult CF units
- The programme was a success and the role has been maintained
- There are now 11 designated Youth Workers at Leeds, incl. in the emergency department (not just focused on CF); the service regularly engages with young people, incl. via a Youth Forum and Duke of Edinburgh programme
- Other innovations used in Leeds to support transition in CF care: transition register and dedicated clinics, written pathway and timeline, continuity post transition, Ready Steady Go to assess readiness and 'Hello to Adult Services'
- Further information and links to resources from Leeds:
 - [Youth work: transitioning to adult services | In clinic - YouTube](#)
 - [Join the Youth Forum on Vimeo](#)
- Learning:
 - Collaboration between adult and paediatric MDT facilitates a smooth transition
 - Involvement of patients' named GP is useful
 - Need to educate and support parents, as well as the young person with CF
 - Patients are ready at a different pace – need to ask the right questions
 - Important to work with other teams, e.g. learning disabilities and autism team, where this is relevant (recommend having a hospital passport)

Notes from the Q&A and open discussion

- Cornwall service have an adolescent clinic every other month; the adult team join the paediatric clinic and see patients aged 12/13 years, who then have a few years getting to know the team. Physio's and Dietitian work across paed and adults so it's only the Nurse and Consultants who change going into the adult service.
- Is there a consensus of whether 'transition clinic' or 'adolescent clinic' is preferred?
 - Leeds service uses 'transition clinic', but others use 'adolescent clinic'
 - Queried whether some young people might not define themselves as an 'adolescent'
- If there are limited numbers [of CF patients] could a Youth Worker work across other lifelong conditions?
 - General agreement that it depends on the service, but that there are Youth Worker posts that are part-time or that work across different specialties
- Are there learning points for paed-adult transition that could help improve adult-adult transition, given this may be happening more often in future, e.g. university students?
 - Communication is key; ARs for university students often done by 'home' CF team with an understanding that the CF team closest to term time address may provide acute care

Further resources on Transition for young people with CF and parents can be found on the Cystic Fibrosis Trust website: [Cystic fibrosis and transition](#)

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