

Cystic Fibrosis our focus

The Royal Belfast Hospital for Sick Children

The Belfast Children's Hospital covers the whole of Northern Ireland, caring for around 196 children with cystic fibrosis, with no network care. There is a high prevalence of the R117H genotype within the clinic, compared to the UK population as a whole.

Users identified the accessibility and communication of the service and the dedication of the multidisciplinary team as areas of excellence. Areas for improvement cited included the car parking facilities, inpatient food, and the need to provide increased community services.

The review panel highlighted the good relationships and communication across the extended multidisciplinary team (MDT), including close links to microbiology and the newborn screening service, as a good practice example. Other examples include the annual data report produced and presented to the whole team, which allows constant service improvement; and the availability of the whole MDT in the outpatient setting, despite inadequate facilities.

Key recommendations from the panel focused on the need to fully utilise the outpatient facilities to allow all patients to be seen in their own outpatient room, and the need to address shortfalls in staffing levels, particularly in consultant time available to the service. The car parking facilities were seen as a barrier to allowing families to access clinics in a timely manner.