

Cystic Fibrosis what, exactly?

Royal Brompton Hospital London, Adult Centre

This centre enjoys an international reputation as a specialist centre for cystic fibrosis and as a world leader in research and development, the panel recognised good practice in its high quality research programme.

The centre caters for the largest number of cystic fibrosis patients in the UK and benefits from an experienced and dedicated multidisciplinary team. The consultants are all very high calibre and very supportive of one another. The CNS team is extremely hard working, caring and dedicated with a high quality, nurse-led annual assessment programme. There is an excellent specialist physiotherapy service and a proactive dietetic team with a good food service.

User feedback identified good communication (treating patients as individuals), knowledge (multidisciplinary approach) and inpatient facilities. Areas for improvement included waiting times for admission, out of hours access (contact via email is good but not by phone) and car parking facilities.

The panel identified waiting times for admission and an under resourced team as their greatest concern. This included lack of staffing in pharmacy, psychology, physiotherapy and Clinical Nurse Specialist (CNS) input, however business cases have already been put in place for additional staff. In addition, a regional strategy and detailed plans are in development to address short and long term capacity and projected demand. The panel recommends appointing a dedicated social worker, although the local commissioner advised that it is not possible due to working practices and arrangements within London.