

Cystic Fibrosis our focus

South-East Scotland Paediatric Cystic Fibrosis service

The South-East Scotland Paediatric Cystic Fibrosis Service cares for 150 children and young people with cystic fibrosis (CF). The service is based in NHS Lothian at the Royal Hospital for Sick Children in Edinburgh, and shares care with centres in NHS Fife, NHS Forth Valley and NHS Borders. This service has experienced and dedicated staff providing quality care for people with cystic fibrosis (CF) across the network. It features unique elements in the form of the 'CF Office', an associate specialist supporting cystic fibrosis nurse specialist (CFNS), and its approach to exercise and cardiopulmonary assessment.

With the new hospital in Edinburgh, inpatient facilities will improve. The network needs a more consistent partnerships approach; currently, many models of network care exist and the annual review experience is variable.

Resources required:

- social work support across the network,
- more definition of the psychology role,
- more dietetic input,
- more pharmacy cover, and
- additional secretarial/admin support – currently 0.7 whole time equivalent (WTE) for 150 patients (recommended 1.0 WTE).

It may be appropriate for network partners to develop a clear understanding of the role of each partner (akin to a service level agreement). Funding arrangements are complex, but the children's commissioner wants to work constructively to ensure the sustainability of an excellent service. If St John's is to continue to provide CF care then investment is required to support their local resources.

Service users noted that the availability of the team, outpatient cross infection and outpatient facility cleanliness are areas of excellence, and car parking, inpatient facility cleanliness and food are areas for improvement.

The Peer Review team have identified the following as areas of good practice:

- Academic approach, illustrated by exercise physiology and contributions to international studies and national initiatives.
- Patient-focussed approach, illustrated by the joined up thinking of the CFNS and other team members, in particular, the Clinical Associate. A constructive relationship with the commissioner.

The following are identified as areas for improvement:

Urgent requirements

- access to nebuliser devices (clear long-term funding stream),
- clarification and protection of psychology time,
- a package for physio to provide exercise support,

- ensure protected pharmacy time, and
- dedicated space within the clinic for the team to administrate between patients.

A larger piece of work on developing a coordinated network approach is also required.