

## **Birmingham Health Overview and Scrutiny Committee**

### **West Midlands (South and Central) Paediatric Cystic Fibrosis Network – proposed changes to shared care arrangements with City Hospital, Birmingham**

**Report submitted by: NHS England West Midlands Specialised Commissioning  
Team and Birmingham Women's and Children's NHS Foundation Trust**

**Date: March 2019**

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#### **1. Purpose**

The purpose of this report is to inform the Committee of a recommendation from Birmingham Women's and Children's NHS Foundation Trust (BWC) to make a change to the West Midlands (South and Central) Paediatric Cystic Fibrosis Network following feedback from families.

#### **2. Background to Paediatric Cystic Fibrosis Services in the West Midlands**

Cystic Fibrosis (CF) is a genetic condition affecting 10,400 adults and children in the UK. People are born with CF, it cannot be caught. About 1 in every 2,500 babies born in the UK has CF. In 2018/19 it is expected around 29 babies will be born with CF in the West Midlands, around 7 or 8 of whom will be from Birmingham and Solihull.

The gene affected by CF controls the movement of salt and water in and out of cells. People with CF experience a build-up of thick, sticky mucus in the lungs, digestive system and other organs, causing a wide range of challenging symptoms affecting the entire body.

People with CF are vulnerable to different bacteria. While these are usually harmless to people who don't have CF, they can settle in the lungs and be harmful for those who do. These bugs can be easily transmitted from one person with CF to another. The risk of spreading infections to each other means that two people with CF can never meet face to face.

Paediatric Cystic Fibrosis services in the West Midlands are commissioned by NHS England's specialised commissioning team from:

- Birmingham Women's and Children's NHS Foundation Trust
- University Hospitals of North Midlands NHS Trust

Birmingham Women's and Children's NHS Foundation Trust provides a service for the South and Central West Midlands. They operate a 'shared care' model which means they partner with other NHS trusts to run paediatric outpatient clinics across the area so that patients receive some of their treatment at Birmingham Children's Hospital (BCH) but some can also attend outpatient clinics at a more local hospital. The hospitals where shared care takes place are:

- Birmingham Heartlands
- Coventry
- City Hospital
- Wolverhampton
- Hereford
- Worcester

### **3. Case for Change**

The change proposed by BWC affects only the shared service run at City Hospital in Birmingham.

There are currently 11 patients (9 families) registered for the City Hospital clinic, all of whom receive at least some of their treatment at Birmingham Children's Hospital.

The standard is that children with CF have an appointment every two months. Children attending the City Hospital clinic alternate every two months between appointments at City Hospital and Birmingham Children's Hospital, although some have chosen not to attend the City Hospital Clinics.

BWC recently undertook a survey to find out what was working well and what was not working well for families using the existing shared care arrangements. The survey asked open questions about their experience. Six of the nine families (8 of the 11 patients) used the survey to express a preference to receive all of their care at BCH. The reasons given were:

- Accessibility
- Confidence in the service
- Can see the whole MDT
- Has moved house so Birmingham Children's Hospital is more convenient
- Has not attended City Hospital since 2013 and happy to continue at BCH

Over the past 5-10 years the number of patients choosing to attend the City Hospital clinic has been reducing. Four of the remaining nine families have now requested to have their all their care provided at BCH, with a further two families indicating through the survey that given the choice, they would also prefer to attend BCH for all their care. This would mean the City Hospital clinic would serve three families.

In addition to patient choice, there are a number of other challenges for the City Hospital clinic:

- The full CF Multi-Disciplinary Team (MDT) at City Hospital is not always available when families attend for clinics.
- When admission is required, this usually takes place at Birmingham Children's Hospital owing to the small numbers of patients and specialist skills required to manage their care.
- There is one consultant who provides the clinic at City Hospital, as a small part of a wider clinical role at City Hospital.

As a consequence, the service is recommending that BWC does not renew its sub-contract for the City Hospital clinic, and that the patients receive all their care at Birmingham Children's Hospital.

As each family affected is being consulted directly, it has not been assessed as proportionate or necessary to undertake a wider piece of public engagement.

In addition to the survey, clinical teams have sought verbal feedback from the families and are now in the process of feeding back the output of their engagement and the change that is being proposed as a result of their feedback.

#### **4. Next Steps**

The recommendation not to renew the sub-contract with the City Hospital clinic will be formally put to the Network Oversight Board on 29<sup>th</sup> March.

Once agreed, this will mean that patients will be invited to attend all six of their annual outpatient appointments at Birmingham Children's Hospital from April 2019, rather than splitting their appointments between Birmingham Children's and City Hospitals.

There are currently no patients with booked appointments for the City Hospital clinic beyond March 2019, and the decision on the future of the clinic will be taken before further appointments are made. This process will not delay the treatment of any patient and does not affect the appointments that are planned for the patients at Birmingham Children's Hospital.

Of the three families who did not indicate a preference to receive all their care at BCH, one family (one patient) indicated they would be happy to either continue with the existing shared care arrangement or move all their care to BCH.

The remaining two families (two patients) were happy with the shared care arrangements. One of these did not hold a strong view, whilst the other felt strongly they would want the shared care arrangement to continue, primarily in order to continue to see the same consultant.

The City Hospital consultant currently undertakes sessions at Birmingham Children's Hospital to ensure he is undertaking sufficient CF work to maintain his expertise. BWC has agreed to continue to offer him these sessions which would enable the family to continue to see him. Following a further conversation between the family and a BWC CF consultant regarding the results of the survey, the family is much clearer about the reasons for the planned change and does not have a problem with the proposed change.

Communication with the families is planned to ensure they understand the change that is being proposed, and particular support provided to the two families who had initially expressed a preference for the shared care arrangements to remain in place.

### **Recommendations**

The Health Overview and Scrutiny Committee is asked to **NOTE** the recommendation from BWC to change the shared care arrangements with City Hospital, and to **NOTE** the approach that has been taken to engage with the families concerned.