

## **West Midlands Cystic Fibrosis Services**

### **Wolverhampton Health Oversight and Scrutiny Committee**

**Thursday 24<sup>th</sup> November 2016**

#### **Introduction**

Cystic fibrosis is an inherited condition in which the lungs and digestive system can become clogged with thick, sticky mucus. It can cause problems with breathing and digestion from a young age. Over many years, the lungs become increasingly damaged and may eventually stop working properly. Most cases of cystic fibrosis in the UK are now identified through screening tests carried out soon after birth. It's estimated that 1 in every 2,500 babies born in the UK has cystic fibrosis

Cystic Fibrosis services in the West Midlands are commissioned by NHS England's specialised commissioning team. There are 487 patients currently in adult care and 392 patients in paediatric care across the West Midlands, including those that do not yet need inpatient care.

Due to the specialised nature of the service, relatively small number of patients, standards that need to be met and very specific environmental requirements for patients, there are only a small number of hospital trusts across the Midlands who provide both inpatient and outpatient care. One of the challenges for Cystic Fibrosis services is that two patients can never be in the same room or area as the risk of cross infection is too great. This means that for outpatient and inpatient care, specially designed facilities are required.

Several years ago, commissioners identified a growing demand for services and the need for another Cystic Fibrosis (CF) inpatient unit in the West Midlands. This led to work being undertaken with the Royal Wolverhampton Hospitals NHS Trust (RWT) which opened a new, specially designed outpatient unit in April 2016. However, the Trust has concluded it is unable to develop the facilities required for an inpatient service and so we are still in need of a new inpatient provider in the West Midlands.

#### **Implications for Wolverhampton Patients**

On 1<sup>st</sup> September 2016 there were 21 adult patients accessing CF services at RWT. If no inpatient stays were required they were seen for all their care at Wolverhampton. If they had more complex care needs they received elements of their care including inpatient stays at the longest established CF centre at Heart of England Foundation Trust (HEFT). Owing to capacity issues it has not been possible to transfer all patients to the centre at HEFT but patients receiving care across the two units have been offered the option of transferring all their care, both inpatient and outpatient to HEFT. Patients accessing all their care at Wolverhampton have been offered the possibility of having inpatient care at Royal Stoke Hospital whilst continuing to access outpatient care at Wolverhampton. This option is also available to patients identified as potentially transferring to HEFT. Moving to an alternative CF centre with capacity, the closest being in Nottingham and Leicester is an option for all patients but may have implications for the range of community input available to patients. Current indications suggest that 17 patients are choosing to move to the adult centre at Stoke with outpatient services close to home whilst 4 have moved to sole care at HEFT. All patients have had face to face discussions with the clinical team at Wolverhampton backed up by written

communications and the option to meet with the Stoke clinical team and to visit the facilities in Stoke.

Ten of the 45 young people aged 0-17 in the paediatric service at Wolverhampton will be moving into adult services over the next couple of years. The initial suggestions for these patients will be inpatient care at Stoke and outpatient services at Wolverhampton. The option of transferring to alternative CF centres with space remains an option for all patients.

### **Recommendations**

- That the board reviews that the actions undertaken by commissioners in partnership with providers and the CF Trust to secure services for the Wolverhampton including future updates as required
- That the board considers the preferred model of future CF delivery for the West Midlands including the development of a new adult centre.