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cc. HOSC members
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members
Cystic Fibrosis Trust

Specialised Commissioning
Midlands and East
NHS England
St Chad's Court
213 Hagley Road
Edgbaston
Birmingham
B16 9RG

Email address Kieren.Caldwell@nhs.net

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West Midlands Cystic Fibrosis services

Dear Chair

I am writing to let you know about some long term developments we are starting to think about to meet a rising demand for adult Cystic Fibrosis services in the West Midlands, and also some short term changes we are having to make to address some immediate challenges. We are working closely with the Cystic Fibrosis Trust on both these matters and I would welcome your views on how best we can engage you and your members.

Background

Cystic Fibrosis (CF) services in the West Midlands are commissioned by NHS England's specialised commissioning team. There are currently two adult CF centres in the West Midlands; one based at Heartlands Hospital in Birmingham and one at the Royal Stoke University Hospital; and an adult outpatient service at New Cross Hospital in Wolverhampton. There are 487 patients currently in adult care and 392 patients in paediatric care across the West Midlands who will need to transfer to adult care in the future. These figures include those who have not yet needed inpatient care. They include patients from outside the West Midlands being treated in a West Midlands unit but do not include a very small number of West Midlands patients travelling to areas outside the West Midlands.

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 and are designated as CF centres. One of the challenges for CF 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.

Long term

Life expectancy for patients living with Cystic Fibrosis has been improving and we anticipate we will need a new adult CF centre within the next few years to meet rising demand for the service.

Several years ago, commissioners began working 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 will still need a new inpatient provider in the West Midlands.

We have issued an expression of interest to gauge the interest from providers and want to ensure key stakeholders, patients and local people have the opportunity to have their say in the selection and planning of this service over the coming months and years.

Short term

In order to cope with rising demand in the intervening time before a new specialised CF centre can open, we are increasing capacity at our other CF centres in the Midlands.

- Working with providers, we have ensured that although the RWT will not now develop inpatient services and become a CF centre, outpatient clinics at the New Cross site will continue, and will be provided by the University Hospitals of North Midlands (UHNM) as an outreach from the CF centre in Stoke.
- This means that **13** adult patients who have had their care provided solely at New Cross Hospital because they have not needed inpatient care, will continue to have their outpatient care at New Cross but provided by UHNM. Any future inpatient care would be delivered at the CF centre in Stoke.
- The **8** adult patients at New Cross who also have some of their care provided at Heartlands Hospital will become the full responsibility of the Heart of England NHS Foundation Trust (HEFT).
- We are also increasing the capacity of the East Midlands CF centres at Leicester and Nottingham by a small amount in order to give patients more choice of provider, recognising that these might be preferable options to patients living in the north-eastern part of the region.

However, due to the specialist facilities required for adult CF services, it is not possible to increase capacity at Heartlands Hospital without refurbishing the unit. Longer survival has increased the demand on the HEFT service to the point that they have informed us they do not have the capacity to admit new patients until an upgrade to their facilities, including a much needed modernisation of their negative pressure rooms, can take place. The eight patients from New Cross that already receive some of their care at Heartlands are considered as existing Heartlands patients.

We are working with the Trust to resolve this issue but anticipate they will be unable to admit new patients before summer 2017 once the refurbishment has been completed. This includes young people who are due to transition from paediatric into adult care.

Working closely with clinicians, the CF Trust, and discussing options with individual patients, we are able to offer young people due to transition during the next few months, and new patients, the choice of the alternative providers in the Midlands, with outpatients at New Cross Hospital for those opting to be cared for by UHNM:

- Between now and summer 2017 when a refurbished unit can open at HEFT, **27** young people under the care of the lead paediatric CF centre at Birmingham Children's Hospital (BCH) are due to transition into adult care. Of these,
 - There are **10** young people who live in or around Staffordshire and the Black Country and will transition to the adult CF centre at UHNM with the option of outpatient clinics at New Cross Hospital.
 - From the Coventry / Hinckley area, there are **6** young people expected to transition to care at the adult CF centre in Leicester and **1** young person to the adult CF centre at Nottingham.
 - In addition, **10** young people who are due to transition into adult care are expected to remain under the care of BCH until the HEFT refurbishment is completed, if they prefer to. This is based on clinical assessment and the age of the young person, the oldest of whom turned 18 in September 2016.

Patient Choice

Engagement with the CF community has to take place on an individual patient basis as patients are unable to meet each other for clinical reasons described earlier. The care of each of these adults and young people has been individually reviewed with their clinician and in each case patients are being offered a choice of any Midlands centre, with the temporary exception of HEFT, and are able to discuss options beyond the Midlands if they wish. We have involved the CF Trust in the development of the long and short term options for patients.

The numbers contained in this paper relate to the choices patients either have or are expected to make following initial discussions.

Patients will also be able to discuss moving their care in future if they wish to move to the new CF centre when it opens, or if HEFT have sufficient capacity following the refurbishment.

Future Engagement

The following pages provide further detail about these plans, including clinical and patient engagement, patient choice, timescale and an overview of the current service. The purpose of this letter is to ensure that you are aware of the challenges we are facing, engaged in helping to identify and develop a long term solution, and understand the measures we have taken to ensure patients receive safe care in the interim.

We would be grateful if you could provide us with an indication of how best to engage with you as we develop these plans. Please could you respond in writing to confirm your support

or otherwise to the approach we are taking and indicate how best to involve you.

Please do not hesitate to contact me if you have any questions, or if you would like me, or a colleague to attend one of your meetings.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Kieren Caldwell', with a small number '2' written below the end of the signature.

Kieren Caldwell
Head of Service and Supplier Management
Specialised Commissioning (West Midlands)
NHS England

Table of providers:

| Adult care | | | |
|--|---|-------------------------------------|-------------------|
| Provider name | Inpatients 1 st Sept | Outpatients 1 st Sept | Total patients |
| Heart of England NHS Foundation Trust | Yes | Yes | 376 |
| Royal Wolverhampton Hospitals NHS Trust | No | Yes | 21 |
| University Hospitals of North Midlands | Yes | Yes | 90 |
| University Hospitals Leicester | Yes | Yes | 81 |
| Nottingham University Hospitals | Yes | Yes | tbc |
| Paediatric care | | | |
| Provider name | Inpatients 1 st Sept | Outpatients 1 st Sept | Total patients |
| Lead provider: Birmingham Children's Hospital | | | 298 |
| | <i>These patients also receive care at:</i> | | |
| Birmingham Children's Hospital | Yes | Yes | 112 |
| Heart of England NHS Foundation Trust | Yes | Yes | 42 |
| Sandwell and West Birmingham Hospitals | Yes | Yes | 13 |
| University Hospitals Coventry and Warwickshire | Yes | Yes | 43 |
| Royal Wolverhampton Hospitals | Yes | Yes | 45 |
| Wye Valley Trust (Hereford) | Yes | Yes | 11 |
| Worcester Acute Hospitals Trust | Yes | Yes | 32 |
| Lead provider: University Hospitals of North Midlands | | | 94 |
| | <i>These patients also receive care at:</i> | | |
| University Hospitals of North Midlands | Yes | Yes | 65 |
| Shrewsbury and Telford Hospitals | Yes | Yes | 29 |

Clinical and patient engagement

We have been working with clinicians from the existing providers of Cystic Fibrosis services across the Midlands to establish how much scope there is to expand our current services. The local Clinical Reference Group for Cystic Fibrosis met on 12th September 2016 and went through the challenges we were facing and resolved some of the issues. This group is continuing with this work and we are supporting clinicians to come together to go through patient lists and planning the next steps.

We are also working with the Cystic Fibrosis Trust (CF Trust) to develop these plans and ensure the most appropriate patient communication and engagement. Two representatives from the CF Trust sit on our project board, one of whom is a CF patient. There are particular challenges associated with engaging this group of patients and so clinicians have taken the lead in discussing the situation with individual patients and identifying with them the services they might prefer to access. We are using their feedback to help in our planning with providers. After these conversations, letters are being sent to patients to inform and reassure them and their families about their ongoing care situation and to confirm the options available to them. The CF Trust has been involved in developing these letters.

As a result of this work, we believe we are now in a position to put forward interim solutions that will meet the demand until a permanent new service is established.

The CF Trust and wider CF community will be central to the planning and commissioning of a new centre and to working with Heart of England NHS Foundation Trust to enable them to take on new patients early next year.

Proposed solutions

Ultimately the solution will be the resolution of the capacity constraints at Heartlands hospital and the development of a new CF centre within the West Midlands. However, there are four main groups of patients who need a more immediate solution. Our proposed solution is described in the table below. This table does not include alternative options that patients will have the opportunity of selecting.

| Group of patients | | Proposed change of service, prior to long-term solution | | | | | Alternatives available under patient choice |
|-------------------|---|---|--|---|-------------------------------|--------------------------------|--|
| | | Number of patients affected | Adult inpatient care 1 st Sept 2016 | Adult outpatient care 1 st Sept 2016 | Proposed adult inpatient care | Proposed adult outpatient care | |
| Group 1 | Adult patients who have not yet needed any inpatient care and have received all their outpatient care at the Royal Wolverhampton Hospitals NHS Trust. | 13 | None | New Cross | Stoke (if needed) | New Cross | <ul style="list-style-type: none"> • Move all care to Stoke • Move all care to Leicester • Move all care to Nottingham • Consider moving their care to a centre outside the Midlands |
| Group 2 | Adult patients who currently have their care shared between the Royal Wolverhampton Hospitals NHS Trust where they receive outpatient care, and Heart of England NHS Foundation Trust where they go should they need inpatient care. | 8 | Heartlands | New Cross | Heartlands | Heartlands | <ul style="list-style-type: none"> • Move inpatient care to Stoke and continue outpatient care in Wolverhampton • Move all care to Stoke • Move all care to Leicester • Move all care to Nottingham • Consider moving their care to a centre outside the Midlands |

| Group of patients | Proposed change of service, prior to long-term solution | |
|-------------------|---|--|
|-------------------|---|--|

| | | Number of patients affected | Adult inpatient care 1 st Sept 2016 | Adult outpatient care 1 st Sept 2016 | Proposed adult inpatient care | Proposed adult outpatient care | Alternatives available under patient choice |
|----------|---|-----------------------------|--|---|-------------------------------|--------------------------------|---|
| Group 3 | Young people due to transition into adult services where the Royal Wolverhampton Hospitals NHS Trust was expected to be the new service provider, had the inpatient service been able to be delivered (this mainly consists of patients living around Staffordshire and the Black Country) | 10 | (not currently using adult service) | (not currently using adult service) | Stoke | New Cross | <ul style="list-style-type: none"> • Transition their care to Stoke with outpatient care in Wolverhampton • Transition all their care to Stoke • Transition their care to Leicester • Transition their care to Nottingham • Consider transitioning their care to a centre outside the Midlands |
| Group 4: | Young people due to transition into adult services where the Heart of England NHS Foundation Trust was expected to be the new service provider (mainly patients from the Coventry / Hinckley side of Birmingham) | 6 | (not currently using adult service) | (not currently using adult service) | Leicester | Leicester | <ul style="list-style-type: none"> • Transition their care to Stoke with outpatient care in Wolverhampton • Transition all their care to Stoke • Transition their care to Leicester • Transition their care to Nottingham • Consider transitioning their care to a centre outside the Midlands • Remain under the care of Birmingham Children's Hospital until Heartlands can accommodate them* |
| | | 1 | | | Nottingham | Nottingham | |
| | | 10 | | | Remain BCH patients* | Remain BCH patients* | |

*If appropriate based on clinical assessment and their age, some patients have the opportunity to have their care retained at Birmingham Children's Hospital until Heartlands Hospital can increase its capacity (not before April 2017). The oldest of these patients turned 18 in September 2016.

Patient Choice

In looking at where we can expand capacity and how we can minimise the impact on patients, we have given considerable thought to patient choice.

- We have secured an agreement between University Hospitals of North Midlands and the Royal Wolverhampton Hospitals that those patients whose care transfers to UHNM will be offered outpatient appointments at New Cross Hospital in Wolverhampton. These patients will only need to travel to Stoke if they need inpatient admission to a specialist CF centre. Some patients may choose to attend outpatient clinics at Stoke, particularly if they live equidistant or the travelling is easier. We will support this.
- Whilst we have made planning assumptions based on the centre that is geographically nearest to each patient's address, we will be offering every patient the opportunity to make an alternative choice.
- The choice will be between University Hospitals of North Midlands, University Hospitals Leicester and Nottingham University Hospitals; although we will support any patients who wish to travel to the adult CF centres in Oxford or Bristol if it is clinically appropriate for them and suits their personal circumstances.
- Some young people from Birmingham who would ordinarily transfer to adult services at Heart of England NHS Foundation Trust may have the option of remaining a paediatric patient for a few months longer than planned if it is clinically appropriate.
- As part of our patient engagement, some informal discussions between clinicians and patients have taken place and we already understand that one patient is likely to choose Nottingham over Stoke, and a small number of Heartlands patients may choose to have their care provided by University Hospitals of North Midlands in Stoke.
- We have held discussions with each of the Midland trusts to establish how far we can increase their capacity and believe that we should be able to accommodate patient choice. We will need to review this if one centre is unexpectedly overwhelmed with demand.

Timescale:

Formal clinical discussions between patients and their consultants are taking place, through joint clinics wherever possible. In order to resolve the pressure in the system, new pathways will be implemented within the next few weeks.

Group 1 patients: (Adults receiving outpatient care at the Royal Wolverhampton Hospitals NHS Trust and no inpatient care who we anticipate would have their care transferred to University Hospitals of North Midlands)

- We anticipate that we will be able to increase capacity at University Hospitals of North Midlands within the next few weeks. Ahead of transferring the care of these patients, we will be holding joint clinics between UHNM and the Royal Wolverhampton Hospitals and patients will be able to visit the CF centre in Stoke if they wish. Most patients will notice no difference as their outpatient care will continue in the new outpatient centre at New Cross Hospital, unless they choose to go to Stoke for their outpatient appointments.

Group 2 patients: (adults receiving outpatient care in Wolverhampton and inpatient care at Heartlands Hospital who we anticipate would have their care provided fully by Heart of England NHS Foundation Trust)

- Again, due to the urgent need for additional capacity, we would like to have everything in place within the next few weeks. Some informal discussions between patients and clinicians have taken place and we understand one person has expressed that they would prefer to go to Nottingham and a small number to Stoke.

Group 3 patients: (young people due to transition to adult services no longer possible at Wolverhampton, who are now expected to have their inpatient care at Stoke)

- Formal clinical discussions with these patients and their parents will take place during the next few weeks, although the date they move to the adult service will vary depending on their age and clinical status.

Group 4 patients: (young people due to transition into adult services at Heartlands hospital, but will now be offered care provided by services in Leicester or Nottingham, or wait until the Heartlands service can be expanded)

- Formal clinical discussions with these patients and their parents will take place during the next few weeks, although the date they move to the adult service will vary depending on their age and clinical status. Clinicians are in the process of identifying which patients may be appropriate to remain under the care of Birmingham Children's Hospital until the Heartlands service is able to admit new patients. It is expected that following a refurbishment which includes upgrading the negative pressure rooms, the earliest this will be is April 2017.