

***Providing High Quality Cancer Services in the East of England***

**Plans for a specialised surgical centre for secondary liver cancer at  
Cambridge University Hospitals NHS Foundation Trust:  
Your feedback and our response**



**Public Engagement Outcome Summary**

**Specialised Commissioning Midlands and East (East of England)  
NHS England**

**Strategic Clinical Network Cancer (East of England) NHS England**

**May 2015**

## Contents

|                                   |   |
|-----------------------------------|---|
| Introduction.....                 | 3 |
| Background .....                  | 3 |
| Responding to issues .....        | 4 |
| What we asked .....               | 5 |
| What you said .....               | 5 |
| Our Response.....                 | 6 |
| Public Sector Equality Duty ..... | 8 |
| Thank You .....                   | 8 |
| Keep in touch.....                | 8 |

### Introduction

Some people with bowel cancer may experience a spread of their cancer to the liver, called secondary liver cancer. Surgery provides potentially curative treatment for these patients, and evidence shows the best results can be achieved when this takes place in specialised centres with expert surgical teams and support services.

By making some changes to the way services are provided for residents of Norfolk, Suffolk and parts of Cambridgeshire, we have been able to create a specialised surgical centre for the treatment of secondary liver cancer. This will lead to improved patient outcomes and will increase the number of people we are able to treat.

While it was important to make these changes, we recognise that for some patients this will mean a longer journey or more complicated travel arrangements to reach the centre. Because of this, we wanted to ask patients, their families, carers and support workers about how to best provide this specialised service and how we could identify and overcome any problems they might have accessing the service.

### Background

A small number of patients with bowel cancer go on to develop a secondary cancer in the liver. One treatment option is for surgical removal, called liver resection. In Norfolk, Suffolk and Cambridgeshire three surgical centres were originally undertaking liver resection surgery: Cambridge University Hospitals NHS Foundation Trust (CUHFT), The Norfolk and Norwich University Hospital Trust (NNUH) and The Ipswich Hospital. Ipswich ceased performing this surgery in 2012 with patients transferring to the other centres.

Small numbers of patients were receiving this surgery every year - around 40 at CUHFT and 20 at NNUH. However, experts advised that a population the size of Norfolk, Suffolk and Cambridgeshire would expect to treat more patients than this, and that numbers should increase over time. While both hospitals had a good service, it was recognised that a specialised service at a single centre would lead to more operations, improve outcomes and increase survival rates for our population. Such a centre would also be compliant with Improving Outcomes Guidance (issued by NICE) regarding best practice for secondary liver cancer resection.

A decision was taken to locate the specialist centre at CUHFT. The new service will begin from September 2015 and clinicians will see all patients who have the potential to benefit from liver resection surgery. Importantly, patients will have only their surgery and first follow-up appointment at the centre. Thereafter, follow-up and management will be shared between the local hospital and community health providers/GP.

The decision to locate the service at CUHFT followed an extensive review and scrutiny process carried out over a number of years. Throughout this process there was strong patient representation and good engagement with patient groups and organisations, including Healthwatch. A consistent message was that quality, safety, improved outcomes and increased survival rates were the most important considerations.

As part of this review Healthwatch in Suffolk, Norfolk and Cambridgeshire carried out a public survey in November 2013. The survey was of patients who had received liver resection surgery at both hospitals, and members of the public. The aim was to gather views on the proposed plans. Findings were fed into the initial engagement which concluded that:

- There was little difference between patient experience in CUHFT and NNUH.
- The public did not express a preference for either CUHFT or NNUH to be the single regional centre for liver resection surgery.
- There was general acceptance and broad support for service centralisation.
- Development of specialist centres was recognised as a requirement of modern healthcare.

When asked to rate the characteristics that were most important when choosing a hospital, 'specialist centre for your illness' was the most important, while 'good access by public transport' was least important.

There was also good engagement with clinicians from referring hospitals and independent expert clinicians. They broadly agreed on the reasons for centralisation.

### Responding to issues

The engagement process around these proposals highlighted a number of areas of concern, particularly for those patients, families and carers living some distance from the specialist centre. To address these, the team in charge of implementing the proposals decided to speak to patients and carers about their concerns. They also wanted patients, carers and families to be able to contribute to the design of the new service.

These conversations were achieved in a number of ways:

- Information sheets were circulated through professional and public involvement networks to Clinical Commissioning Groups, GP surgeries and the East of England Local Government Authority, to be cascaded to local councils and Health and Wellbeing Boards.
- Community email and Twitter accounts were set up to send out information and to receive feedback.
- Meetings and conversations were held with Healthwatch and local health/patient groups.
- Professionals from CUHFT and NHS England who are involved in setting up and commissioning the new service attended meetings of patient groups, support networks and professional groups.
- A series of drop-in Discovery Events for members of the public was held between January and March 2015 in six locations across Norfolk and Suffolk. Venues were selected so as to be accessible from areas affected by the proposed new location.
- Professionals from CUHFT and NHS England were also available to attend meetings and events by invitation.

The Discovery Events were co-ordinated by the Patient and Public Participation Lead of the East of England Strategic Clinical Network, and were held in a variety of locations including libraries, cancer charity shops and a town hall. Events took place in Great Yarmouth, Eye, Norwich, King's Lynn, Cromer and Lowestoft. They were staffed by clinicians, NHS England Specialised Commissioners, CUHFT clinicians and managers, Public Health England and the Patient and Public Participation Lead. Attendees included representatives from local cancer charities, patient involvement and support group representatives, a Community Cancer Nurse Specialist and cancer patients and carers.

The Big C cancer charity in Norfolk assisted with publicising these events and hosted two within their charity shops. The charity was able to speak to patients and carers ahead of the events and get some honest thoughts about how changes might affect them.

### What we asked

Discovery Events were open to all and unstructured, enabling any comments or questions to be aired and raised. The operational team also had some questions which were:

- What are your main concerns with having a single specialised surgical centre?
- How can we make the service more accessible to patients and their families?
- What can we do to support a positive experience for patients and families?
- What information would be beneficial to you and how would you like this presented?

### What you said

A number of themes came out of the Discovery Events. They can be broadly divided into issues covering:

- Information
- Travel and accommodation
- Patient and carer support
- Aftercare and choice

#### *Information*

People felt strongly that comprehensive information should be provided by the specialised surgical centre. This included clear information about treatment, care and the support patients would receive. Information was felt to be the most important issue and it was felt that this should be available at the local hospital at the point of referral.

#### *Travel and accommodation*

Many concerns were related to the costs and difficulties associated with travel and accommodation for patients, relatives and other visitors. This was of particular concern for people on low incomes or with frailties, or where relatives might want to make frequent visits or to stay overnight nearby, for example when someone is admitted.

Travel information, including directions, details of public transport, car-parking and maps of the campus, are currently available on the CUHFT website. However, not everyone has online access and the information was considered difficult to find and in some cases contained inconsistent information.

Travel grants are available from a number of organisations, including local cancer charities, for people on low incomes. However it was felt that these may not be widely known about and that qualifying criteria and information on how to apply was not always readily available.

People attending the Discovery Events generally accepted that patients would be willing to travel to get the best treatment and care. They were generally in favour of a specialised unit, with one person saying: *'Inconvenience to relatives is a secondary issue if my life depends on it'*. (Former cancer patient).

### **Support for patients**

People said they valued the support for cancer patients provided by Cancer Information Services at the two hospitals, the Big C Cancer Charity in Norfolk, Maggie's Wallace Centre in Cambridge and Macmillan Cancer Support. These charities played an important role in keeping people informed and acting as a first contact point for information.

### **Follow-up and aftercare**

There was concern about follow-up and aftercare and where this would be provided, and also about the number of visits to the specialist centre. This was not just in relation to travel, but also with regards to aftercare and who retains overall responsibility for care.

Patients wanted reassurance that they would be given appropriate contact details in case of concerns following discharge, or if they did not receive follow-up information as expected.

Consideration should also be given to those patients who might need to stay in hospital longer in order to cope with lengthy journeys home.

### **Communication of patient information**

Concern was expressed about the handover of care from the specialised centre back to the patient's usual hospital and GP. Examples were given of where this hadn't happened, and reassurance sought that important personal information about care, medication and special requirements would be shared appropriately.

### **Choice of Specialised Centres**

People asked if there were alternative centres and whether patients could travel out of the area to receive their treatment if they chose to do so.

## **Our Response**

A Service Implementation Group has been established to take forward the design and delivery of the new specialised centre. The group has members from the local NHS in Norfolk and Cambridgeshire, clinicians, patient representatives and commissioners. This group has considered all the feedback received from the Discovery Events. It has made a commitment to addressing these concerns and to ensuring processes are put in place to facilitate good access to the specialist service. The group and CUHFT have devised the following actions to address concerns raised during the public engagement process:

- CUHFT has confirmed that only three visits to the specialist centre would be required for each patient. These will be for assessment, treatment and follow-up.
- Wherever possible, care that can be delivered locally will continue to be delivered locally, reducing the need to travel.
- A detailed travel and accommodation information pack will be produced. This will be available at the patient's local referring hospital before the first appointment. This pack will be produced by CUHFT with assistance from patient groups.
- Comprehensive, up-to-date information on overnight accommodation for relatives will be included in this information pack. This will include information about CUHFT's onsite accommodation for patients and relatives.
- The pack will be made available to GPs and all those who provide support for patients.
- Easy-read material for people with learning disabilities and those for whom English is a second language will be made available as required.
- A 'Frequently Asked Questions' document will be developed by CUHFT to include information post discharge.
- The discharge pack will include details of the patient's key worker (nurse specialist) together with information on how to contact them.
- CUHFT will provide a standard form for the transfer of patient information between teams, prepared in consultation with GP and community services, to ensure consistent and comprehensive information is provided on each patient returning to the care of their usual hospital, community nurse and GP.
- Specific consideration will be given as to how the needs of individual patients will be met, and financial costs minimised.
- Appointments times will be made with regard to off-peak travel arrangements wherever possible.
- Patients may choose to be treated at another specialist surgical centre, out of area, if they wish. Examples include centres in Leicester or London that may be more convenient for those who have relatives and friends or are working nearby. Such discussions should take place with the patient's usual hospital and/or GP.

### ***Ensuring quality Information***

A comprehensive information pack will be made available for all patients to be given out before travel to the first appointment at CUHFT. It will include a simple map of the hospital site which will include the car parks and position of the required services.

#### **Box 1: Agreed recommendations for the content of an information pack**

- 1 Signposting to benefits advice, including assistance available from Macmillan, the Citizens' Advice Bureau and Big C.
- 2 Information on the availability of grants with contact details of the grant-giving bodies.

- 3 Accommodation, including information on hospital patient accommodation and local B&Bs. Information to be consistent and available in print.
- 4 Transport information, including how to claim for travel costs.
- 5 Parking information.
- 6 Emotional support (Big C, Maggie's-Wallace Centre, Macmillan).
- 7 Emergency and out-of-hours contact information. Also the names and contact details of key people at the centre and locally.
- 8 Space for the name of the key worker/clinical nurse specialist, plus information about how to contact them and how and when handover back to the CNS or community cancer nurse will take place.
- 9 It will include a simple map of the hospital site which will include the car parks and position of the required services.

### Public Sector Equality Duty

As with all service change we have a duty to consider how the change will affect those who will use the service. This includes those who are the most disadvantaged. In this case this would be those patients experiencing poverty, the homeless and others who are unable to cover the cost of transport to CUHFT either using their own transport or public transport. We are committed to undertaking an equity audit to ensure that no individuals or groups are or continue to be disadvantaged by this change and the design of the new service.

### Thank You

We would like to thank everyone who took the time to attend the Discovery Events or feedback their comments to us. In particular, we would like to thank the Big C cancer charity in Norfolk for supporting our public engagement and for hosting two Discovery Events. This document has been sent to all those involved with this project and engagement events. Please circulate this document if you wish to. Further copies are available from the e-mail address below.

#### Keep in touch...

We are keen to hear from you, your families and your carers as part of on-going efforts to deliver services which are safe, effective and suitable to your needs.

If you have any comments or wish to find out more about the service please contact: [england.eoecitizens@nhs.net](mailto:england.eoecitizens@nhs.net)