East of England
Specialised Commissioning Group

NHS

Pancreatic cancer:

Services to improve survival in the East of England

We need your views

Deadline for feedback Monday 1 June 2009

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SECTION 1

INTRODUCTION – WHAT THIS CONSULTATION IS ABOUT

Dr Rory Harvey

Consultant Medical Physician,
Bedford Hospital NHS Trust

Chair of the East of England
Pancreatic Cancer Project Steering Group

This consultation exercise is about listening to views on a proposal to improve the care and survival chances for people with pancreatic cancer in the East of England.

A national policy

We are proposing a change in the way specialised services are organised to treat pancreatic cancer, based on national and international evidence that we can improve outcomes for patients. The guidance on this is presented in a national policy document called *Improving outcomes in upper gastro-intestinal cancers,* referred to as the IOG (see Appendix A for a link to the IOG and further information).

The IOG requires that pancreatic cancer patients should have the care and expertise of a designated surgical centre that serves a population of 2-4 million people. The reason for this is that curative surgery is possible in only a minority of patients with pancreatic cancer, and the team responsible for care and treatment should cover a large population with more than 200 cases each year. This is considered to be the right number to ensure that the professionals in the team maintain their specialist clinical skills and continue to apply the latest medical techniques so that patients have the best possible chances of survival.

The IOG is being implemented throughout the NHS as part of a national cancer reform strategy.

Summary of our proposal

We have considered a number of options for implementing the IOG in the East of England. This involved a detailed review led by an independent clinical expert. The first review in 2005 established three interim designated surgical centres for pancreatic cancer.

The independent clinical expert then led a further review in 2007 and recommended that only one centre, the centre at Cambridge, was close to compliance with the IOG.

Our proposal is therefore:

To designate a single specialised team based in a specialised centre that serves a population in the region of around 3.2 million people, and that this team should be a development of the existing specialist team and centre at Cambridge University Hospitals NHS Foundation Trust.

We are now seeking your views on this proposal and its implications.

Later in this consultation document we explain more about the clinical reviews, the options considered, and how we have reached this proposal.

What the proposal would mean in practice

- The specialised team at Cambridge University Hospital would lead a network of local specialist teams based in the hospitals of Bedfordshire, Cambridgeshire, north east Essex, Norfolk, and Suffolk.
- The Cambridge team would have overall responsibility for all pancreatic cancer cases, however most patients would receive their care at their local hospital.
- GPs would continue to refer patients to their local hospital where the local specialist team would provide tests and treatment, supported by the leading expertise and guidance of the specialised team at the pancreatic cancer centre.
- Of 200-300 possible pancreatic cancer patients a year, around 60-120 could benefit from surgery to remove the tumour. These patients would need to have their surgery at the specialised centre in Cambridge, giving them access to the best possible clinical expertise and facilities. Pancreatic cancer requires a major complex operation with considerable risks.

Your views?

We are required to have an IOG compliant pancreatic surgical centre.

There are currently three providers in the East of England in hospitals in Cambridge, Ipswich and Norwich, none of which is fully IOG compliant.

The East of England Specialised Commissioning Group (EoE SCG) is now consulting formally on the recommendation of a clinical review led by an independent expert. This review recommended that Cambridge University Hospitals Foundation Trust be designated as the specialised pancreatic cancer centre. Further details on the review and its conclusions are included later in this document.

The EoE SCG is particularly interested to hear the views of patients, their carers and staff working in pancreatic cancer services. We need to know:

What is your overall view of the proposal for changes to pancreatic cancer services as described in this consultation document?

What benefits do you see and what concerns do you have regarding the proposed changes?

Are there any particular issues, for the people affected by these changes, that you feel should be taken into account?

What suggestions do you have to help the changes go smoothly?

We are asking for your views for two main reasons:

- The establishment of the network led by a specialised centre is an opportunity to improve the care and life-chances for all pancreatic cancer patients. It is important that all providers in the network work together to achieve maximum benefit for patients. We need a range of views to make the most of this opportunity.
- The proposal that surgery should only be done in the specialised cancer centre in Cambridge is a change from current arrangements where there are three specialist surgical teams operating in hospitals in Cambridge, Ipswich and Norwich. Around 40-80 patients per year would need to travel to Cambridge for their operation, where previously they would have gone to Ipswich or Norwich. We need to understand your views of the implications of this in order to support patients and staff.

This document gives you the background and then explains the proposal for consultation in more detail. You can let us know your views by:

- writing to us using the feedback form attached and available online, or by letter if you prefer. You can also feedback online from our website at **www.escg.nhs.uk**
- requesting a meeting
- attending one of the discussion workshops that we are organising across the region.

See Section 4 on How to have your say for further details.

The Project Steering Group, which I chair, and the East of England Specialised Commissioning Group will be listening carefully to what local people say and will take account of those views to ensure a smooth transition to a future service that is designed around the needs of patients and their families.

Rory Harvey

SECTION 2

BACKGROUND INFORMATION ON THE PROPOSED CHANGE

2.1 Pancreatic cancer - A rare but high risk cancer

There are 7,600 new cases of pancreatic cancer a year diagnosed in the UK. Pancreatic cancer mainly appears in older people. Younger people do get pancreatic cancer but 75% of patients are aged 65 and over.

Whilst the chances of having pancreatic cancer are fairly low – around 1 in 96 for men and 1 in 95 for women, it has the lowest survival chances of any cancer and is the sixth most common cause of all cancer deaths. The latest figures published in 2005 for England and Wales suggest that only around 13% patients survive beyond 12 months after diagnosis and only 2-3% of patients survive beyond five years.

Surgery to remove a pancreatic tumour is the best chance for a cure, but the pancreas tends to develop a type of tumour that shows no symptoms until it is well advanced and in most cases too late for surgery.

2.2 How pancreatic cancer affects people

The pancreas is a gland organ that is vital for digesting and processing food. It produces enzymes to digest food so that nutrients can be absorbed. It also produces insulin, a hormone that helps the body to burn sugar as fuel.

With an advanced pancreatic tumour, it can become impossible to eat or drink. Symptoms vary and can include nausea, vomiting, weight loss, severe pain and profound depression. Often, there are no symptoms in the early stages. Most people get symptoms when the cancer is at an advanced stage, which is mainly why the chances of survival are so poor.

In some cases, there may be jaundice, a yellowing of the eyes and skin. This is caused if the tumour obstructs the bile duct, another important part of the digestive system for digesting fats. When this happens, the liver cannot empty bile into the digestive system as normal and bile goes into the blood stream causing jaundice. This may require an operation to relieve the bile duct blockage.

2.3 Improving outcomes for pancreatic cancer patients

Surgical and medical techniques are improving all the time and the outcomes for patients with pancreatic cancer are much better than they used to be. It is possible to give people more time to live and have a better quality of life.

International evidence shows that the best chances are achieved when patients have the services of a highly trained specialised team working in a centre that assesses more than 200 a year or more cases of pancreatic cancer, from a population of 2-4 million. The number of cases is important and has a direct influence on the clinical expertise.

Some individual surgeons and smaller teams do achieve good outcomes, but this would not be a good enough reason for continuing with a small team. When the European Working Time Directive comes into full force in 2011, teams will need more specialists to ensure sufficient surgical and medical cover 24 hours a day.

The challenges:

- Because the pancreas is deep within the body it requires specialised techniques for investigation, diagnosis and treatment.
- Diagnosing pancreatic cancer and assessing the tumour for surgery needs complex scanning techniques that may involve surgical procedures.
- Surgery is currently the first option for effective treatment, but only for about 15-20% of patients. Most tumours are inoperable.
- If surgery is possible, it will be major surgery with a significant risk of complications that needs the expertise of a specialist team backed up by intensive and high dependency care.
- Because of the difficulties of surgery, the assessment of patients for operation is complex and requires the expertise of a specialised multidisciplinary team and access to specific technologies. This is to ensure that only patients who will benefit from surgery will undergo this risky procedure.

The opportunities:

Compared with other countries such as Japan and USA, the UK has until recently tended to do fewer surgical operations on pancreatic cancers, possibly because it is difficult to establish whether a tumour is operable. The development of specialist pancreatic centres should improve UK expertise. Studies show that surgeons working in centres that see more patients do more operations and get better results than those in smaller units seeing fewer patients.

- Specialists in larger teams working in a centre that sees more than 200 cases a year have been shown to increase surgery rates – they become better skilled and able to offer surgery to more patients. Once services are streamlined and a pancreatic cancer centre is fully up and running, the number of surgical operations could reach 20-40 per million.
- A centralised surgical team offers patients the best possible surgical skills and better outcomes.
- If surgery is not possible, then there are treatments using chemotherapy and possibly radiotherapy to shrink or stall the cancer and control its effects. A central specialised team can work together with the patient and the local hospital team to determine which approach will get the best outcomes.
- Larger teams in pancreatic centres are in a better position to adopt the latest medical and surgical techniques. They are more involved in research and quicker at giving patients the benefits of new treatments.
- A pancreatic cancer centre can improve clinical expertise throughout the region, with more opportunities for training and development for the whole network of hospital teams as well as for the central specialised team.
- A pancreatic cancer centre that is IOG compliant and maintains an excellent reputation will continue to attract the best specialists.

2.4 Why change?

The NHS must make sure that pancreatic cancer patients come under the care of a specialised pancreatic cancer centre serving a population of 2-4 million.

This is required by the national *Improving Outcomes Guidance (IOG)* for pancreatic cancer where the number of cases per year is very low - about 100 per 1 million population. International evidence shows that the best chances of survival depend on the skills of a highly specialised team that sees more than 200 pancreatic cancer patients a year from a population of 2-4 million.

There are many advantages to having a specialised centre and we cover these later in this document, but the main benefit is that the more patients a team cares for, the better the clinical capability and the better the outcomes for patients. The proposed change will increase the chances for pancreatic cancer patients of having as long as possible with their families and a better quality of life.

Most of the East of England population does not currently have access to a pancreatic cancer centre that is IOG compliant.

Currently, there are three specialist teams that provide pancreatic cancer services in Cambridge, Ipswich and Norwich. These teams each serve a population of around 1-1.2 million, which means they are not compliant with the national *Improving Outcomes Guidance (IOG)*. The proposed development covered by this consultation is an IOG compliant pancreatic cancer centre serving 3.2 million people living in the northern parts of the East of England.

People living in south Essex have access to the specialised centre at Barts and The London in north east London, which is IOG compliant. People living in Hertfordshire and parts of Bedfordshire have access to centres in North West London that are moving towards IOG compliance.

2.5 What services should be available to pancreatic cancer patients – the national guidance

A pancreatic cancer centre team should work as a single multidisciplinary team that is responsible for all patients in the region. It works closely with local multidisciplinary teams at the local hospitals who are responsible for investigation and diagnosis and for non-surgical treatment, which is the majority of the care for pancreatic cancer patients.

All of the professionals involved work in a network, led by the centre, where everyone is working to the same agreed protocols and standards to provide the best care for their patients.

- All hospital providers should be part of a cancer network with linked units and a specialised pancreatic cancer centre.
- Specialised teams at the centre should be responsible for patients with pancreatic cancer from populations of 2-4 million, expecting to see more than 200 new patients a year.
- There should be documented local referral policies for diagnostic services jointly agreed between GPs, primary care trusts and NHS trusts.

- There should be documented policies for referral between hospitals, and for local hospitals to seek advice from the centre.
- Support and specialist care needs the involvement of hospital, community, local authority and voluntary services.
- There should be common data sets for monitoring performance and audit of outcomes.

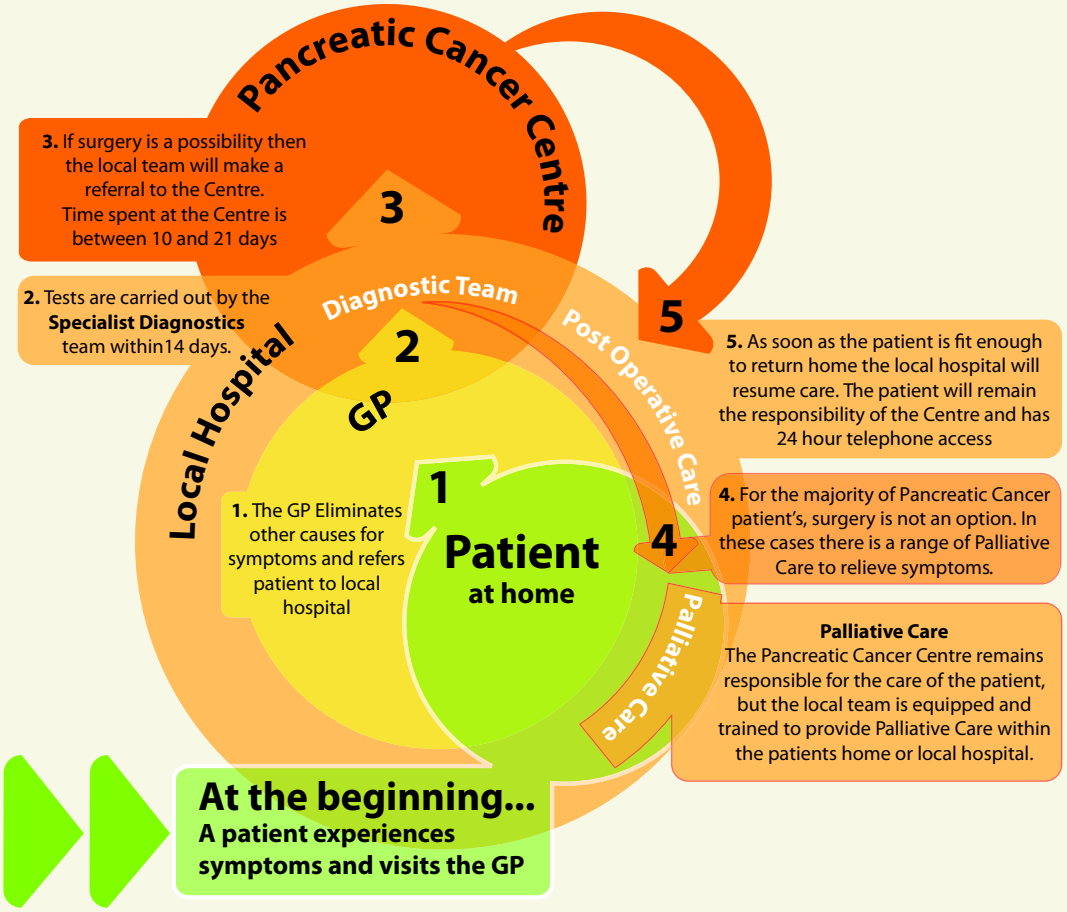
2.6 How services should work from a patient's perspective

Comment from Paul Morris, independent patient representative

Almost three years ago, I was diagnosed with pancreatic cancer. As is often the way with this disease, my tumour was found to be inoperable at first. Fortunately, I had access to excellent care. Chemotherapy, followed by radiotherapy succeeded in shrinking the tumour so that it became possible to remove it by surgery. In my case, I had to travel to three different hospitals for this treatment and I agree with many fellow cancer patients that this was difficult and stressful for me and my family. However, the overwhelming principle for me was to get the best possible care and the best possible outcome.

The section below outlines the way that services should work for patients and, along with many other pancreatic patients across the country, I am keen to see national progress on implementing the *Improving Outcomes Guidance* to achieve the best for patients and to provide the best environment for future treatment options.

Paul Morris is a member of the Project Steering Group to implement the IOG in the East of England. He lives outside the region and provides an independent patient perspective.



At the beginning

A patient experiences symptoms and visits the GP. Depending on how the disease is at this stage, the GP may need to spend some time eliminating other causes. Symptoms can be vague and the same as many common ailments.

The GP then refers the patient to a specialist diagnostic team at the local hospital for further tests. If the GP suspects cancer, then the patient will have rapid access to a special diagnostic service within 14 days.

Diagnosing the disease

At the local hospital, the patient goes though a series of tests that may include x-rays, ultrasound scans, possibly an endoscopy where a tiny camera is inserted through a tube through the mouth and into the stomach.

The local hospital team explains each step and discusses the findings with the patient and their family. Expert counselling and emotional support is on hand to help people with decisions about their own care.

Test results are discussed with the central team. If surgery is a possibility and this is what the patient wants, then the local team will refer the patient to the centre.

Preparing for surgery

This may involve further tests and specialist investigative procedures to determine the best approach for the operation. Ideally, this would take place at the local hospital, but could involve a visit to the centre if a more specialised investigation was needed. The patient agrees a date with the centre for his or her operation and plans a stay in the centre to have it done.

The operation

The patient goes into the centre for around 10 days or possibly up to three weeks in some cases. Specialists at the centre will make sure that the patient and their family are fully involved in decisions and supported throughout the whole stay.

Immediately after the operation, patients may need specialist post-operative care in intensive care or high dependency care before recovering in a hospital ward.

As soon as the patient is fit enough, he or she can return home, but will remain the responsibility of the specialised central team and will continue to receive the care of the local hospital team, the GP and community health services. The patient has 24 hour telephone access to the centre and a continuing regular relationship with local health professionals that includes emotional as well as clinical support.

In most cases, especially for older people, the patient will need a range of care that could include health, social care and voluntary support services.

Managing the disease and palliative care

For the majority of pancreatic cancer patients, surgery will not be a suitable option. However, there are treatments to relieve symptoms and improve quality of life. This is what is referred to as "palliative care".

Whilst the care of the patient is still the responsibility of the regional pancreatic cancer centre, the local team of specialists will be equipped and trained to provide the treatment and the patient may not need to travel to the centre, unless they need a specialist surgical procedure to relieve their symptoms.

All local hospitals will have specialist palliative care teams that can provide access to chemotherapy and radiotherapy, pain control and emotional and psychological support. These teams are trained in working in partnership with people to adapt treatments to people's choices and needs. As end-of-life approaches, many people prefer to stay in their own home supported by palliative care teams providing special equipment and nursing care.

2.7 How we arrived at the proposal for the East of England - independent expert clinical review

This section provides a summary of the clinical review led by a leading independent expert in pancreatic cancer. If you are interested in more details on the findings of the review, please see the two reports, one dated February 2005 and the second dated January 2008. Both are available from the website section on the pancreatic cancer consultation at www.escg.nhs.uk

Following the publication of the national *Improving Outcomes Guidance* (IOG) in January 2001, the NHS in England has been working to develop regional pancreatic centres. The change is complicated. It has needed time and resources to review existing services, to identify where regional centres could be and to plan a smooth transition to the new arrangements.

A "no change" option for services in the East of England is not a viable option because, unless they are serving a population of 2-4 million, the current services are not compliant with the *Improving Outcomes Guidance (IOG)*. Even though the individual clinicians in the current teams are providing, high quality care, the arrangement does not offer the best possible chances for patients with pancreatic cancer.

In the East of England, a detailed review was carried out during 2005 and again in 2007. Both reviews were undertaken by a panel that was chaired by a leading independent expert in pancreatic cancer and included a local patient representative.

Membership of the 2007 review panel:

- **Mr Richard Charnley** (independent Chair)
  Consultant Hepato-Pancreato-Biliary (HPB) surgeon and Lead Clinician for Hepato-Pancreato-Biliary Cancers at the Freeman Hospital in Newcastle upon Tyne. President of the Pancreatic Society of Great Britain and Ireland and Chairman of the Pancreatic Section of the British Society of Gastroenterology.
- **Deborah Knight**
  Head of Clinical Strategy, East of England Strategic Health Authority
- **John Lancaster**
  Patient representative and leader of a local cancer support group in Chelmsford.

The options considered in 2005

In 2005, the review work considered options for the whole of the population of the East of England – around 5.6 million.

The following trusts in the East of England were providing specialist pancreatic cancer surgery:

- Addenbrooke's Hospital (Cambridge University Hospitals NHS Foundation Trust)
- Ipswich Hospital (The Ipswich Hospital NHS Trust)
- Luton and Dunstable Hospital (Luton and Dunstable Hospital NHS Foundation Trust)
- Norfolk and Norwich Hospital (Norfolk and Norwich University Hospitals NHS Foundation Trust)

Each trust was asked to produce a proposal to be a specialist pancreatic cancer centre, which included completing a self assessment against the pancreatic cancer IOG measures. Ipswich and the Norfolk and Norwich submitted a joint proposal.

The review panel visited each Trust to gather more information, meet key clinicians and see the facilities available.

Outcome of the 2005 review

Options for a designated centre	Recommendations
Cambridge University Hospitals NHS Foundation Trust	Interim designated pancreatic cancer centre until a further review in 2007. The 2005 review found that the service at Addenbrooke's had reached a high level of development with significant capacity to provide specialist pancreatic services. The recommendation was that Addenbrooke's should be designated as an interim centre and should work towards full compliance with IOG by addressing a number of issues identified by the review panel.
Joint proposal from The Ipswich Hospital NHS Trust Norfolk and Norwich University Hospitals NHS Foundation Trust	Interim designated pancreatic cancer centre until a further review in 2007. The review identified strengths at both hospitals, but concluded that the Norfolk and Norwich Hospital did not have the required surgical specialisation to be considered as a location for an interim pancreatic cancer centre. Services had reached a higher level of development at Ipswich and there was significant capacity to provide specialist pancreatic services. It was recommended that Ipswich should be the designated interim centre, subject to a further assessment in 2007, by which time, the Norfolk & Norwich would cease to provide specialist pancreatic services.
Luton and Dunstable Hospital NHS Foundation Trust	Interim designated cancer centre until a further review in 2007. In the meantime, the Luton and Dunstable should take part in the London Pancreatic Cancer Review

During 2006, Luton and Dunstable was considered as part of the London Pancreatic Cancer Review and it was decided that the Trust would refer into the pancreatic cancer centre based at the Royal Free Hospital in London.

The options considered in 2007

The 2007 review considered a smaller population living in the northern parts of the East of England region – a population of around 3.2 million (not the original population of 5.6 million).

This was because in 2005, the then South Essex Cancer Network confirmed that its population would continue to access specialist services from Barts and The London NHS Trust. Similarly, the decision for the Luton and Dunstable Hospital to refer patients to the Royal Free Hospital, following The London Pancreatic Cancer Review, meant that south Bedfordshire and Hertfordshire residents would look to London for specialised pancreatic services.

The complexities of providing a joint centre between Ipswich and Norwich were more challenging than originally envisaged. By 2007, it had not proved possible to establish the single multidisciplinary team nor to centralise surgery at Ipswich. Consequently the review panel assessed each hospital individually.

In 2007, the three possible providers were:

- Cambridge University Hospitals NHS Foundation Trust
- Norfolk and Norwich University Hospitals NHS Foundation Trust
- The Ipswich Hospital NHS Trust

The second review that took place between August and November 2007 was lead by the same independent expert and had two of the same panel members from 2005.

Each trust was asked to complete a self assessment against the IOG measures, to provide evidence of improvement since the 2005 report and to provide further activity and outcomes data.

The review panel visited each Trust, met with key clinicians and asked further questions.

The panel examined:

- Population and referrals
- Organisation of the surgical team
- Number of patients seen per year
- Number of operations and outcomes achieved
- Arrangements for 24 hour cover
- The working of the multidisciplinary team
- Intensive and high dependency care
- Radiology capacity and capability
- Endoscopic ultrasound capacity and capability
- Palliative care
- Communications with other hospitals
- Plans for expansion
- Non-surgical oncology
- Research

The geographical location of the centre was not a major factor in the panel's considerations when weighed against the clinical issues. The centre must serve a very large geographical area with a population of 2-4 million. No matter where the centre is located, some people will have to travel a long way from home for their operation.

Outcome of the 2007 review

The review panel found that Cambridge University Hospitals NHS Foundation Trust had progressed the furthest towards IOG compliance, and therefore should be designated to provide the centre. For example, the team at Cambridge is fully sub-specialised in pancreatic cancer and the most experienced in pre-operative diagnosis.

Cambridge	Ipswich	Norwich
Separate team of 4 Hepato-Pancreato-Biliary (HPB) surgeons i.e. the highest specialists in pancreatic cancer	Separate team of 3 Hepato-Pancreato-Biliary (HPB) surgeons i.e. the highest specialists in pancreatic cancer	1 HPB surgeon with 2 Upper GI surgeons i.e. not a separate sub-specialised team
781 patients seen during the year i.e. significant experience	515 patients seen during the year i.e. significant experience	86 patients seen during the year

Cambridge	Ipswich	Norwich
Excellent radiology including experience of 190 endoscopic ultrasound procedures	Good radiology. 41 endoscopic ultrasound procedures and increasing	Highly trained radiological team, no endoscopic ultrasound facilities
Excellent research, good data collection, extensive investment in a strong research team	Research links established with other European centres	Potential for expansion in research
Good palliative care and excellent oncology	Good palliative care and good oncology	Good palliative care and good oncology

Given the different volumes of activity, it is not easy to compare mortality rates. However, the review did confirm that the mortality rate for Cambridge was good and within the range that you would expect for a high volume centre.

2.8. Recommendations from the independent expert clinical review

The panel unanimously agreed that there should be a single pancreatic centre within the East of England to serve the population of 3.2 million. The current situation with surgery on three sites is not sustainable in the long term.

The panel unanimously recommended that the surgical centre be sited at Cambridge University Hospitals NHS Foundation Trust.

The panel's view was based on determining which of the existing service providers was closest to complying with the *Improving Outcomes Guidance (IOG)*. This would ideally ensure the fastest transition to establishing a regional centre with full compliance. In view of the highly specialised clinical demands of this kind of service and the most important criterion to improve patients' chances of survival, it was considered best to build on the team and the services that were judged to be the strongest in clinical terms.

The reasons cited by the panel are as follows:

Clinical expertise

> The team at Cambridge is fully sub-specialised in Hepato-Pancreato-Biliary and is the most experienced in terms of preoperative diagnosis (including axial imaging and endoscopic ultrasound), surgery (where resection rates, mortality rates and outcomes are excellent), medical oncology (with an unparalleled commitment to new treatments and clinical trials) and pathology (full sub-specialisation in HPB).

Note: HPB stands for hepato-pancreato-biliary. HPB surgeons are the highest specialised consultants in diagnosing and treating pancreatic cancer.

Patient access and accommodation

Cambridge has a central location within the region with good road links. There is a Park and Ride service to the hospital and new car parking facilities and an access road from the M11. Hostel beds are being developed and planning permission being obtained for hotel accommodation.

Commitment of the management team

The Cambridge team has implemented all the recommendations of the 2005 review. The management team has costed the expansion necessary and the Chief Executive has made an explicit commitment to invest in the service.

Research

The leader of the research team is a full member of the multi-disciplinary team and an internationally recognised clinician scientist. All patients have the opportunity to be involved in groundbreaking research studies as well as having access to a wide range of clinical trials.

Development of a network

The panel recommended that the designated pancreatic cancer centre should be seen as an opportunity to develop the whole care network to achieve excellent local services in diagnosis, non-surgical treatment and palliative care.

Implementation involving the whole network should include:

- Development of models of care
- Improvements in communications across the network, for example, between clinicians, patients and GPs including electronic referrals, information and image transfer, video conferencing, same day decision-making and access to central databases.
- Expansion at the centre, for example, an increase in the number of surgeons and endoscopists, expansion in pathology, radiology, beds, theatres and critical care.
- Continuous regional audit, with regular analysis of the data to review activity, performance and outcomes.

It is quite likely that some patients who live at the edges of the network will choose to go to another network. In practice, the network in the East of England could serve a population of less than 3.2 million (but unlikely to be less than 2 million).

For further details on the recommendations of the independent expert clinical review, please see the review reports available at **www.eoe.nhs.uk**

SECTION 3

PROPOSAL FOR CONSULTATION

The proposal is to designate a single specialised team based in a specialised centre that serves a population in the region of around 3.2 million people, and that this team should be a development of the existing specialist team and centre at Cambridge University Hospitals NHS Foundation Trust.

3.1. The proposed change

Current specialist pancreatic cancer services	Proposed regional pancreatic cancer centre and network of services
Team of three surgeons within a multidisciplinary team at Norfolk and Norwich University Hospitals taking referrals from Norfolk, Great Yarmouth and Waveney. Team of three surgeons within a multidisciplinary team at Ipswich Hospital taking referrals from Suffolk and North East Essex. Team of four surgeons within a multidisciplinary team at Cambridge University Hospitals taking referrals from Peterborough, Cambridgeshire, north Bedfordshire, parts of Suffolk and north Essex. Chemotherapy and other non-surgical treatments available at local hospitals.	Local hospital teams to develop diagnostic services and rapid access clinics. Local hospitals to continue providing chemotherapy and other non-surgical treatments. Single specialist multidisciplinary team at the regional pancreatic centre at Cambridge University Hospitals to take lead responsibility for all cases. Local multidisciplinary teams to continue treating local patients through agreed shared protocols and close working links with the regional centre. One central surgical team at Cambridge with four to six hepato-pancreato-biliary (HPB) surgeons taking referrals from Peterborough, north Bedfordshire, Cambridgeshire, Suffolk, Great Yarmouth and Waveney, Norfolk and North East Essex.

3.2. Scope of the proposed change

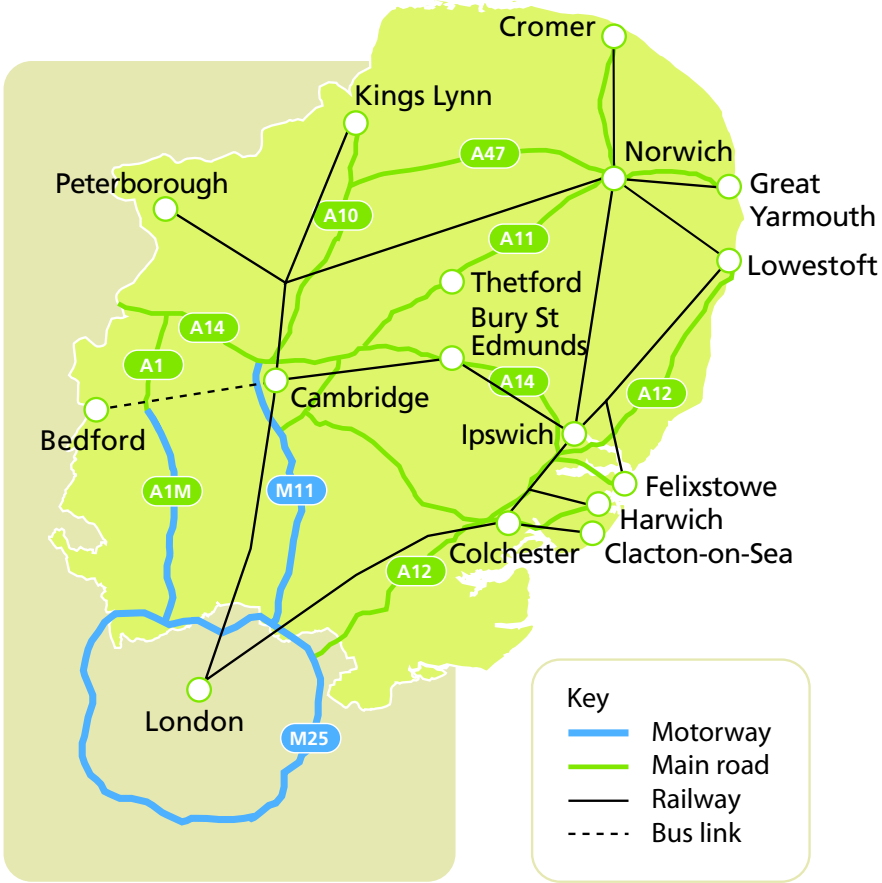
- **The proposed service change is relevant to around 300 pancreatic cancer patients a year** from a population of around 3.2 million living in Cambridgeshire, Norfolk, Suffolk and northern parts of Bedfordshire and Essex.
- **The majority (at least 80%) of pancreatic cancer patients that benefit from the change would not see a change in where they go for care, wherever the centre is located..**
- Once services are streamlined and a pancreatic cancer centre is fully up and running, the number of surgical operations could reach 20-40 per million. **There could be around 40-80 surgical patients a year that would be affected by the change.** Around 40-80 patients a year would need to travel to Cambridge to have their surgery, where before they may have gone to Ipswich or Norwich.

3.3. Support for surgical patients and their families

Travel and access to the surgical centre

For some patients who may be able to benefit from surgery, there may be a daunting prospect of having to travel a long way from home. Such journeys can be stressful for both patients and their families.

The map below shows the main transport links in the area:



During the consultation process, we aim to listen to views on the issues for patients and their families and to discuss ways of providing support in addition to the following points:

- Surgery is for those patients who are assessed as sufficiently fit. Patients who are very sick or frail are not likely to be suitable for surgery.
- Patients with clinical needs will be offered transport to and from the specialised cancer centre when they go to have their operation and for any appointments prior to that which may be necessary for assessment.
- Some families may be able to receive financial assistance with travelling to be with their loved-one at the centre, part of the NHS Low Income Scheme. More information on help with health costs is available from the link below and also from each hospital.

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Illorinjured/DG_10018978

- The site of the centre in Cambridge has undergone some recent improvements in terms of accessibility. There is a hospital bus station, a park and ride scheme near by, and parking is available on site, including a recently opened multi-storey car park. The hospital is continuing to improve access with the prospect of a new access road from the M11.
- Accommodation is available at the Cambridge University Hospitals site, so that family carers can stay overnight if they wish.

Care and support

All patients will have individual care plans and will be involved in decisions about their own care.

All of the local teams and the proposed central specialised team have specialist nurses that act as a named contact for the patient and his or her family. These nurses are trained in support and counselling for patients and carers. They can provide information on care and treatment options, they can offer advice and help the family to make contact with other professionals and services including those in other organisations and the voluntary sector.

All teams including the proposed central specialised team have palliative care experts, clinicians that specialise in symptom and pain control. If needed patients and carers can have the benefit of support from other professionals such as a psychologist or a spiritual adviser.

For those patients undergoing surgery, the specialised centre will provide a telephone number so that patients and carers can contact the centre for help and advice at any time before and after the operation.

Patient choice

At the initial stage of investigation, patients have a choice about which hospital they would like their GP to refer them to. That decision would determine which cancer network the patient would be going to for treatment. Having made that decision the patient would be under the care of the specialised team at the centre for the network. In other words, if a patient chooses to go to a hospital in the area covered by the East of England pancreatic cancer network, then they would be under the care of the Cambridge centre (even though most would receive most of their care from the local hospital of their choice.)

Having chosen a hospital for local care, it is advisable to stay within the network for all treatment including surgery. The benefit of receiving care from the network under the leadership of the specialised centre is to ensure the best possible care planning, clinical decisions and treatment. All providers in the network work as a team.

As part of care planning, patients are involved in decisions about their own care, including choices about drugs and recommended clinical procedures.

3.4. Plans into practice and financial implications

This is a proposal about development and investment in services.

There will be a need for an increase in capacity at the centre as the first priority and, over a longer period, further developments in local diagnostic capability.

A Project Steering Group has been set up to oversee the consultation process and the work on implementation plans. This will include work with the service provider trusts in the cancer network and with commissioning partners in the primary care trusts to draw up detailed implementation plans, subject to the outcome of consultation. As part of this work, the Specialised Commissioning Group will develop a supporting investment plan.

As part of the 2007 clinical review, the prospective providers were asked to confirm their potential capacity to provide the pancreatic cancer centre. All three of the providers confirmed their commitment to support the necessary development. Prior to the start of consultation, Cambridge University Hospitals NHS Foundation Trust reconfirmed that it will develop the required additional capacity, if the decision is taken to proceed with the proposal.

Following the outcome of the public consultation in June, implementation plans will be developed by September 2009 with a view to establishing the designated centre and networking arrangements by October 2010.

3.5. Key questions for consultation

Please see the feedback form that goes with this document

Around 300 pancreatic cancer patients a year, living in Norfolk, Suffolk, Cambridgeshire, Bedfordshire and Essex, will benefit from the expertise of a larger specialised team working with the network of local hospital teams, in line with *Improving Outcomes Guidance*. Most of these patients (at least 80%) will receive their care from their local district general hospital.

Around 60-120 pancreatic cancer patients a year could require surgical assessment and treatment at the designated specialised pancreatic cancer centre.

The East of England Specialised Commissioning Group (EoE SCG) is now consulting formally on the recommendation of a clinical review led by an independent expert. This review recommended that Cambridge University Hospitals NHS Foundation Trust be designated as the specialised pancreatic cancer centre.

The EoE SCG is particularly interested to hear the views of patients, their carers and staff working in pancreatic cancer services. We need to know:

What is your overall view of the proposal for changes to pancreatic cancer services as described in this consultation document?

What benefits do you see and what concerns do you have regarding the proposed changes?

Are there any particular issues, for the people affected by these changes, that you feel should be taken into account?

What suggestions do you have to help the changes go smoothly?

We are asking for your views for two main reasons:

- The establishment of the network led by a specialised centre is an opportunity to improve the care and life-chances for all pancreatic cancer patients. It is important that all providers in the network work together to achieve maximum benefit for patients. We need a range of views from local people and professional staff to make the most of this opportunity.
- The proposal that surgery should only be done in the specialised cancer centre in Cambridge is a change from current arrangements where there are three specialist surgical teams operating in hospitals in Cambridge, Ipswich and Norwich. Around 40-80 patients would need to travel to Cambridge for their operation, where previously they would have gone to Ipswich or Norwich. We need to understand your views of the implications of this in order to support patients and staff.

3.6. Decision-making process

The East of England Specialised Commissioning Group (EoE SCG) is a collaborative commissioning department of all 14 primary care trusts in the East of England. The EoE SCG commissions specialised services on behalf of the PCTs and is undertaking this consultation as part of that duty.

The EoE SCG has directed a Project Steering Group to steer the consultation, consider the views of local people and, in the light of those views, make recommendations on how the proposal should be taken forward into implementation.

The EoE SCG will then decide the designation of a pancreatic surgical centre and progress towards implementation by October 2010.

Key dates

26 Sep 08	East of England Specialised Commissioning Group approved plans for consultation
17 Nov 08	First meeting of the Project Steering Group
26-28 Nov 08	Office of Government Commerce Gateway Review
9 Mar 09	Start of public consultation, including consultation with local Health Overview and Scrutiny Committees Distribution of consultation documents and public information
Mar-May 09	Consultation discussions with service users, professionals and local people
1 June 09	Deadline for consultation feedback
June 09	Analysis of the outcome of public consultation
26 June 09	Recommendations from the Project Steering Group to the East of England Specialised Commissioning Group for a final decision.

Evaluation of responses to consultation

An independent team from the University of East Anglia will collect and analyse the responses to the consultation, including all written responses and the outcome of discussions from meetings and local workshop sessions.

SECTION 4

HOW TO HAVE YOUR SAY

Responses in writing

You can feedback to us in writing, using the feedback form attached, or by letter if you prefer. You can also feedback online from our website at **www.escg.nhs.uk**

Please complete and return the feedback form by email to **pancreatic@eoescg.nhs.uk**

Or by fax to **01371 877249**

Or by post to: **Pancreatic cancer consultation, EoE SCG, The Old Mill, Haslers Lane, Great Dunmow, Essex, CM6 1XS**

Deadline for written feedback – 1 June 2009

Requests for meetings

If your group would like a meeting, or you need any further information, please contact:

Ros Stevenson
Email: pancreatic@eoescg.nhs.uk
Tel: 01371 877263

Come along to a "discovery event"

We have given careful consideration to making sure that there is a range of ways in which people can have their say. Learning from previous consultation exercises, for example, we have tried to arrange events in locations where people with experience of cancer already meet, or in locations that are very much a part of local communities.

We are looking for patients, family carers, experts, staff and anyone with an interest in working with us on plans to improve services for pancreatic cancer. There are two ways to get involved:

- Just turn up at one of the morning drop-in events listed below. You will have a chance to talk informally with professionals and to give us your views
- We are running discussion workshops in the afternoons at the venues listed below. Please contact us if you would like to be involved:

Ros Stevenson, Email: pancreatic@eoescg.nhs.uk , Tel: 01371 877263

Dates and locations of Discovery Events:

Drop-in sessions are open from 10am to 12pm.
Discussion sessions run from 2pm to 4pm

Date	Area	Venue	Address
16 April 2009	Bedford	St John's Hospice	Moggerhanger, Bedford, Bedfordshire MK44 3RJ
21 April 2009	Great Yarmouth	Cobholm & Lichfield Resource Centre	Pasteur Road, Great Yarmouth, Norfolk NR31 0DW
22 April 2009	Norwich	Hellesdon	20 Hellesdon Park Road (Unit 20), Norwich, Norfolk NR6 5DR
28 April 2009	Cromer	Cromer Parish Hall	65 Church Street, Cromer NR27 9HH
29 April 2009	Bury St Edmunds	St Nicholas' Hospice	Hardwick Lane, Bury St Edmunds, Suffolk IP33 2QY
8 May 2009	Cambridge	Davison House	351 Mill Road, Cambridge CB1 3DF
11 May 2009	Colchester	St Helena Hospice Education Centre	Barncroft Close, Highwoods, Colchester CO4 9JU
20 May 2009	King's Lynn	The Norfolk Hospice, Tapping House	38a Common Road West, Snettisham, King's Lynn, Norfolk PE31 7PF
22 May 2009	Ipswich	St Elizabeth Hospice Education Centre	565 Foxhall Road, Ipswich, Suffolk IP3 8LX
28 May 2009	Peterborough	Longthorpe Memorial Hall	295 Thorpe Road, Peterborough, Cambridgeshire PE3 6LU

APPENDIX A

FURTHER INFORMATION

Improving Outcomes Guidance (IOG)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010025

Cancer Research UK
www.cancerresearchuk.org

Pancreatic Cancer UK
www.pancreaticcancer.org.uk

East of England Specialised Commissioning Group
www.escg.nhs.uk

NHS Direct
www.nhsdirect.nhs.uk

Department of Health
www.dh.gov.uk

APPENDIX B

LIST OF KEY STAKEHOLDERS

Service user networks and voluntary sector

The following user groups are known to us. We would be delighted to hear from any other group that is interested in having a say on services for pancreatic cancer.

All patient and public involvement locality groups linked to the cancer networks serving the East of England (via primary care trust contacts)

Chelmsford Cancer Services User Group

Men's support group

Trinity Centre (Colchester) Ltd

Big C Cancer Information and Support Centre

Wiggly

Ipswich Cancer Aid Network (ICAN)

Stowmarket and District Cancer Support Group

West Suffolk, Thetford & Sudbury Cancer Support Group

Arthur Rank Day Therapy

The Mary Wallace Cancer Support Centre

Ramsey and Warboys Acorn Support Group

St Neots Acorn Cancer Support Group

Hospices

Family carers associations

Councils for voluntary services

Local Involvement Networks (LINks)

Patient and public involvement groups

Racial Equality Councils

Pancreatic Cancer UK

Cancer Backup UK

Macmillan Cancer Support

Local Government and public representatives

Health Overview and Scrutiny Committees

County councils and unitary authorities

District councils

Local MPs

Health and social care sector

NHS hospitals and cancer networks

Primary care trusts

Local authority Adult Services

GP practices and practice-based commissioning groups

Local Medical Committees

Local Pharmaceutical Committees

Staffside and union representatives

Pancreatic Society of Great Britain and Ireland

Primary Care Society for Gastroenterology

NHS Cancer Programme for England

Department of Health

APPENDIX C

NHS IN THE EAST OF ENGLAND

The NHS in the East of England comprises 40 local NHS organisations led by a single strategic health authority that covers Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk. For more information visit **www.eoe.nhs.uk**

Primary care trusts (PCTs)

Primary care trusts (PCTs) are responsible for the health and healthcare of a local population. These organisations receive from the Government the health funds available for their local population.

They plan and buy healthcare to meet the needs of their residents by agreeing contracts with healthcare providers, such as local hospitals and mental health services. They work closely with GP practices and other primary and community services providers such as dentists, pharmacists, opticians, community nurses and therapists. They also work in partnership with social care services provided by local authorities and voluntary organisations.

The 14 PCTs in the East of England are:

- NHS Great Yarmouth and Waveney
- NHS Luton
- NHS Bedfordshire
- NHS Cambridgeshire
- NHS Mid Essex
- NHS Norfolk
- NHS Peterborough
- NHS South East Essex
- NHS Suffolk
- NHS North East Essex
- NHS South West Essex
- NHS West Essex
- West Hertfordshire PCT
- East and North Hertfordshire PCT

NHS Trusts and Foundation Trusts

NHS providers of healthcare are known as Trusts. A Foundation Trust is independent of central Government and has more freedom to mange its own finances. It is accountable to local communities through a membership of local volunteers and elected Governors.

Trusts in the East of England are:

For hospital services:

- Basildon & Thurrock University Hospitals NHS Foundation Trust
- Bedford Hospital NHS Trust
- Cambridge University Hospitals NHS Foundation Trust
- Colchester Hospital University NHS Foundation Trust
- East & North Hertfordshire NHS Trust
- Hinchingbrooke Health Care NHS Trust
- Ipswich Hospital NHS Trust
- James Paget University Hospitals NHS Foundation Trust
- Luton and Dunstable Hospital NHS Foundation Trust
- Mid Essex Hospital Services NHS Trust
- Norfolk & Norwich University Hospital NHS Foundation Trust
- Papworth Hospital NHS Foundation Trust
- Peterborough & Stamford Hospitals NHS Foundation Trust
- Princess Alexandra Hospital NHS Trust
- Queen Elizabeth Hospital King's Lynn NHS Trust
- Southend University Hospital NHS Foundation Trust
- West Hertfordshire Hospitals NHS Trust
- West Suffolk Hospitals NHS Trust

For mental health services:

- Bedfordshire and Luton Mental Health and Social Care Partnership NHS Trust
- Cambridge & Peterborough Mental Health Partnership NHS Trust
- Hertfordshire Partnership NHS Foundation Trust
- Norfolk & Waveney Mental Health Partnership NHS Trust
- North Essex Partnership NHS Foundation Trust
- South Essex Partnership NHS Foundation Trust
- Suffolk Mental Health Partnership NHS Trust

For ambulance services:

- East of England Ambulance Service NHS Trust, head office in Bury St. Edmunds

Cancer networks

Cancer networks are a partnership between PCTs and hospital trusts overseeing the development of cancer services.

Cancer networks serving East of England residents are:

- Anglia Cancer Network
- Essex Cancer Network
- Mount Vernon Cancer Network
- North London Cancer Network

East of England Specialised Commissioning Group

The East of England Specialised Commissioning Group (EoE SCG) is a collaborative commissioning department of all 14 PCTs in Essex, Bedfordshire, Hertfordshire, Norfolk, Suffolk and Cambridgeshire.

The EoE SCG was set up in April 2007 to commission high cost/ low volume services - services that are either very expensive in terms of treatment costs or they are services for rare conditions with very low numbers of cases. Typically, such services require a planning population greater than 1 million.

Specialised services include, amongst others, services such as rarer cancers, burn care, medical genetics, some mental health services, specialised services for children, renal services and cardiac surgery.

APPENDIX D

THE TEAM FOR THIS PROJECT

Project Steering Group:

Lead clinician and Project Steering Group Chair:

Dr Rory Harvey, Chair of Pancreatic Site Specific Group for Anglia Cancer Network and Consultant at Bedford Hospital

Senior Responsible Owner:

Trevor Myers, Director, East of England Specialised Commissioning Team

Project Manager:

Pam Evans, Commissioner for rare cancers, East of England Specialised Commissioning Team

Members:

Audrey Bradford, Director of Anglia Cancer Network

Deborah Knight, Head of Clinical Strategy, NHS East of England

Paul Morris, independent patient representative

Wendy Smith, Communications Adviser to East of England Specialised Commissioning Group

Ros Stevenson, Communications Manager, East of England Specialised Commissioning Team

For further information contact:

Ros Stevenson, Communications Manager
Email: pancreatic@eoescg.nhs.uk
Tel: 01371 877263
Fax: 01371 877249

DISTRIBUTION

Please see the feedback form that goes with this document. You can also send us your views online at **www.escg.nhs.uk**

We have sent information about this consultation to the following groups and organisations in the East of England (and some national bodies). Please distribute to others in your organisation and to anyone that you think would be interested in giving their views on pancreatic cancer services.

Cancer support groups
Hospices
Family carers associations
Councils for voluntary services
Local Involvement Networks (LINks)
Patient and public involvement groups
Racial Equality Councils
Pancreatic Cancer UK
Cancer Backup UK
Macmillan Cancer Support

Health Overview and Scrutiny Committees
County councils and unitary authorities
District councils
Local MPs

NHS hospitals and cancer networks
Primary care trusts
GP practices and practice-based commissioning groups
Local Medical Committees
Local Pharmaceutical Committees
Staffside and union representatives
Pancreatic Society of Great Britain and Ireland
Primary Care Society for Gastroenterology
NHS Cancer Programme for England
Department of Health

Do you have experience of pancreatic cancer?

Are you interested in helping to improve cancer services?

We are looking for patients, family carers, experts, staff and anyone with an interest in giving their views on plans to improve services for pancreatic cancer.

We are holding discussion groups during April and May 2009

Please contact us – further details on page 23

This consultation document is produced on behalf of the following organisations:

Primary Care Trusts:
NHS Great Yarmouth and Waveney
NHS Bedfordshire
NHS Cambridgeshire
NHS Mid Essex
NHS Norfolk
NHS North East Essex
NHS Peterborough
NHS Suffolk
NHS West Essex

The document is available from **www.escg.nhs.uk**

If you would like information in another language or format, please ask us.

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

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Se desiderate ricevere informazioni in un'altra lingua o in un altro formato, siete pregati di chiedere.

如欲索取以另一语文印制或另一格式制作的资料，请与我们联系。

Jeżeli chcieliby Państwo uzyskać informacje w innym języku lub w innym formacie, prosimy dać nam znać.

Se deseja obter informação noutro idioma ou formato, diga-nos.

Если вы хотели бы получить информацию на другом языке или в другом формате, просим обращаться в администрацию.

Türkçe bilgi almak istiyorsanız, bize başvurabilirsiniz.

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Ros Stevenson
East of England Specialised Commissioning Team
Tel: 01371 877263
Email: pancreatic@eoescg.nhs.uk