Developing renal dialysis services for people in the east of England

Full consultation document

Your chance to have your say

Deadline for feedback March 8, 2010

Published December 14, 2009
East of England Specialised Commissioning Group
1. INTRODUCTION

1.1 What is the East of England Specialised Commissioning Group (SCG)?

The East of England SCG purchases (commissions) services on behalf of all 14 Primary Care Trusts (PCTs) in Essex, Bedfordshire, Hertfordshire, Norfolk, Suffolk and Cambridgeshire.

It was established to commission high cost/low volume services that are either very expensive in terms of treatment costs or are for rare conditions with very low numbers of cases.

These ‘specialised services’ include: rarer cancers, burn care, medical genetics, some mental health services, specialised services for children, renal services, morbid obesity and cardiac surgery, amongst others.

1.2 Developing services for the future

The East of England SCG is asking for your views about services for adults with chronic renal failure in the region.

The document describes:

- What renal failure and dialysis is
- What services are currently available
- Why services need to develop
- Our proposals for services in the future, and
- How you can have your say on the proposals

Any changes will affect patients, their families and carers and NHS staff working in this area of healthcare in the east of England.

Your ideas will help us decide how best to develop these services for the people involved across the region.

The way we have developed our proposals, and the way we will reach a decision on them, is being overseen by the Joint Health Overview and Scrutiny Committee (JHOSC), which is made up of representatives from local authorities in the east of England.
2. BACKGROUND

2.1 What is kidney disease?

Under normal circumstances, the kidneys work continuously to keep you alive and well. They act as filters and remove waste products from the blood and excess water from the body. In addition, the kidneys help influence haemoglobin production, blood pressure and bone formation.

Four conditions are needed for the kidney to be able to work properly:

1. A supply of blood that needs to be cleaned
2. A cleaning or filtration system to clean the blood
3. A way for the cleaned blood to return to the rest of the body
4. Excess water and waste needs to be able to leave the kidney and then the body

If any of the above do not work as they should, then the kidney is unable to produce urine and therefore waste cannot be removed from the body properly. If these problems persist, then it is possible that kidney disease will be the result.

Renal failure is the general term used when the kidneys fail to function properly. For some patients renal failure can develop over the course of months, even years, but for others it can occur very quickly.

Chronic Kidney Disease (CKD) is defined as the presence of kidney damage, or a decreased level of kidney function, for a period of three months or more. CKD can be divided into five stages, depending on severity. The final stage of this is known as ‘End-Stage Renal Failure’ (ERF), which requires ongoing dialysis. People with renal failure will need some form of treatment for the rest of their life. For most people, the treatment they receive can be tailored to suit their lifestyle.

2.2 What causes chronic kidney disease?

Some kidney diseases are inherited and others develop as we grow older. Often kidney disease is associated with other medical conditions including diabetes, hypertension and heart disease. In addition, members of certain ethnic groups are also at higher risk because of the greater incidence of diabetes and high blood pressure. These include people of Aboriginal, Asian, south Asian, Pacific Island, African/Caribbean and Hispanic origin.

The exact cause of many types of kidney disease is not yet well understood. However, over the last 40 years there have been significant advances in the ability to treat CKD, enabling people to survive much longer.
2.3 How renal failure affects people

ERF is an irreversible, long term condition for which regular dialysis treatment or transplantation is required. Since the introduction of modern treatment methods many people have enjoyed a near normal life span. Nevertheless, the rigours of treatment are considerable. For example, four hours a day, three days a week are normally devoted to the renal dialysis process in hospital.

Treatment presents social, financial and practical problems for the whole family. As well as the time spent on renal dialysis, there is considerable travelling time to and from the dialysis unit, and often additional time spent waiting to be treated or for transport home. Additional time will also be needed for other clinical appointments.

Many people with renal failure consider a kidney transplant the best treatment. However, not everyone can benefit from a transplant, and there is also an increasing proportion of patients starting dialysis who are not clinically eligible or may not be healthy enough to have a transplant.

2.4 What is renal dialysis (Renal Replacement Therapy)?

Renal Replacement Therapy (RRT) is a term used to encompass life-supporting treatments for renal failure.

Clinicians and nurses have been working over the past few months to develop a future strategy for commissioning renal services in the region that cover three treatments.

We are asking for your views on the provision and expansion of these three types of renal dialysis services in the region:

- Haemodialysis (cleaning the blood through a machine)
- Peritoneal dialysis (a process by which fluid is introduced into the abdomen to clean the blood - can be conducted in a unit or through home therapy)
- Home therapies (patients receive treatment at home when clinically suitable)

The terms ‘renal dialysis’ or ‘renal dialysis services’ in this document therefore refer to all three types of treatment.
2.5 Home therapies – a closer look

NICE (National Institute for Health and Clinical Excellence) produced guidance on home therapy in 2002, which was subsequently supported by both the renal National Service Framework (NSF) in 2004 and the Department of Health Operating Framework 2008/09.

NICE estimated that between ten and 15 per cent of patients would prefer home therapy, if offered a choice. This percentage has been met (and exceeded) in certain places (including Manchester). However, in the rest of England less than two per cent of renal dialysis patients are currently self-caring at home.

The East of England SCG has been carrying out work to explore the rejuvenation of home therapies, adding to that already carried out for this consultation. There has been some success and new mobile dialysis technology has been piloted.

The aspiration is to have ten per cent of renal dialysis patients in the east of England self-caring by 2015.

Patient groups are strongly supportive of choice in renal services – including choice of home therapies if clinically suitable.

Clinicians and nurses have established that the provision of renal services needs to be expanded in order to meet future need, but also to improve the experience of existing patients.
2.6 What renal dialysis services are available now?

Renal dialysis services in the east of England are provided by eight ‘principal’ units and nine ‘satellite’ units. Patients are also treated outside of the region.

The table below shows the current provision of renal dialysis services (haemodialysis and peritoneal) available in healthcare settings but not home therapy provision.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Number of existing dialysis stations</th>
<th>Number of existing patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Principal Units</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addenbrooke’s Hospital, Cambridge</td>
<td>35</td>
<td>129</td>
</tr>
<tr>
<td>Basildon &amp; Thurrock Hospital</td>
<td>26</td>
<td>149</td>
</tr>
<tr>
<td>Broomfield Hospital, Chelmsford</td>
<td>24</td>
<td>115</td>
</tr>
<tr>
<td>Colchester Hospital</td>
<td>20</td>
<td>120</td>
</tr>
<tr>
<td>Ipswich Hospital</td>
<td>19</td>
<td>94</td>
</tr>
<tr>
<td>Lister Hospital (East &amp; North Hertfordshire Hospitals)</td>
<td>20</td>
<td>122</td>
</tr>
<tr>
<td>Norfolk and Norwich Hospitals</td>
<td>28</td>
<td>165</td>
</tr>
<tr>
<td>Southend Hospital</td>
<td>28</td>
<td>168</td>
</tr>
<tr>
<td><strong>Satellite Units (and their principal units)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aldeburgh (Ipswich Hospital)</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Cromer (Norfolk &amp; Norwich Hospital)</td>
<td>8</td>
<td>47</td>
</tr>
<tr>
<td>Huntingdon (Addenbrooke’s Hospital)</td>
<td>14</td>
<td>45</td>
</tr>
<tr>
<td>James Paget Hospital (Norfolk &amp; Norwich Hospital)</td>
<td>18</td>
<td>95</td>
</tr>
<tr>
<td>Kings Lynn (Addenbrooke’s Hospital)</td>
<td>14</td>
<td>83</td>
</tr>
<tr>
<td>Luton &amp; Dunstable (East &amp; North Hertfordshire Hospitals)</td>
<td>23</td>
<td>145</td>
</tr>
<tr>
<td>Peterborough (Leicester)</td>
<td>16</td>
<td>90</td>
</tr>
<tr>
<td>St Albans (East &amp; North Hertfordshire Hospitals)</td>
<td>16</td>
<td>104</td>
</tr>
<tr>
<td>West Suffolk (Addenbrooke’s Hospital)</td>
<td>13</td>
<td>56</td>
</tr>
<tr>
<td>Watford (with north west London satellite)</td>
<td>22</td>
<td>150</td>
</tr>
<tr>
<td><strong>Principal units providing treatment outside east of England area</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barts &amp; The London Hospital</td>
<td>56**</td>
<td></td>
</tr>
<tr>
<td>Royal Free Hospital and satellites</td>
<td>66*</td>
<td></td>
</tr>
<tr>
<td>Oxford (with Milton Keynes satellite)</td>
<td>17***</td>
<td></td>
</tr>
</tbody>
</table>

* Predominantly east and north Hertfordshire residents, Essex and a small number from Bedfordshire
** Predominately Essex residents
*** Bedfordshire residents

‘Principal’ units are those at hospitals. These are supported by one or more ‘satellite’ units that are closer to patients’ homes.
2.7 What needs to change and why?

In January 2004, the first part of the renal NSF was published with the aim of recognising the need for significant expansion of services for patients with chronic renal failure. The NSF suggested that between 2004 and 2014 the number of patients needing RRT would double.

Although transplantation rates are planned to increase, it is expected that the most significant service pressure will relate to renal dialysis services, with growth of five per cent per annum until 2030, and possibly beyond.

Therefore it is predicted that the number of patients will rise from 1,769 in 2008 to 2,143 in 2015 and to 2,868 in 2020.

An assessment that was developed by clinicians, nurses and commissioners from across the region predicted a rise in the demand for dialysis services up to 2014. This forecast was based on population growth, current inequality in access to services and was also designed to meet national policy guidelines.
2.8 What has national policy said about renal care?

The key national policy documents in relation to future dialysis requirements are:

- Department of Health Operating Framework 2008/09

The renal NSF

The renal NSF published in January 2004 encompasses issues relating to dialysis and transplantation. The NSF requires the NHS to:

- Use national data to support planning and to identify local priorities, including the needs of black and minority ethnic groups
- Continue to expand renal dialysis capacity
- Join the UK registry of the Renal Association and take part in a national comparison
- Implement the NICE guidelines on home therapies
- Implement the NICE appraisal of immunosuppressive therapy

NICE guidance

NICE has recommended that all patients who are suitable for home therapies should be offered the choice of receiving therapies in this way, provided they are clinically suitable.

‘Saving Lives, Valuing Donors’ – Organ Donation Taskforce report

This report sets out key aims for organ and tissue transplantation over the next ten years and identifies good practice.

‘Organs for Transplant’ – Organ Donation Taskforce Report

This report made a series of recommendations relating mainly to reorganisation, which have been accepted by the Department of Health.

Department of Health Operating Framework 2008/09

This framework includes guidance relating to RRT growth and reinforces NICE guidance in relation to the provision of home dialysis:

‘Demand for Renal Replacement Therapy (dialysis and transplantation) is projected to rise by around five per cent per year until at least 2030. SCGs [Specialised Commissioning Groups] will wish to consider options for expanding the provision of satellite dialysis centres and offering more people the option of home dialysis, as well as expanding traditional acute dialysis units’.
3. VISION

3.1 Our vision for renal dialysis services

Taking into account national policy and feedback from patient groups, the vision of the East of England SCG is to provide:

A service which where possible actively encourages enhanced and independent dialysis. It provides sufficient renal dialysis capacity to appropriate quality standards for those patients who choose renal dialysis or for whom home dialysis or peritoneal dialysis is not an option. Service provision across the region will be equal, based on patient need. The standards and markers of good practice stated in the renal NSF will form the basis of all future service development plans.
3.2 Supporting this vision

The planning assumptions to support this vision and guide our proposals are based on:

- *Six per cent growth in haemodialysis need*
- *Ten per cent of patients receiving home therapies by 2015*
- *Peritoneal dialysis at national average of 10.7 per cent by 2015*

The planning assumptions are set out below:

<table>
<thead>
<tr>
<th>Vision</th>
<th>Planning assumption</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouragement and support of the self care approach (where possible)</td>
<td>Choice of type of treatment for patients (where clinically appropriate) with support to make an informed choice. Home therapy to be offered to all patients where clinically appropriate.</td>
</tr>
<tr>
<td>Sufficient renal dialysis capacity</td>
<td>Expansion of renal dialysis capacity, including satellite unit provision to improve access with effective transport services.</td>
</tr>
<tr>
<td></td>
<td>Expansion of renal dialysis capacity to take account of increase in home therapy and transplantation rate.</td>
</tr>
<tr>
<td></td>
<td>Patients on hospital/satellite dialysis to receive dialysis three times per week.</td>
</tr>
<tr>
<td></td>
<td>Renal dialysis facilities to be offered within 30 minutes travel time for the majority of patients.</td>
</tr>
<tr>
<td>Standard of dialysis facilities</td>
<td>New and current facilities to be developed and improved in line with specified requirements of size and cost efficiency.</td>
</tr>
<tr>
<td>Equality of services</td>
<td>Taking into account population age, deprivation and ethnicity to ensure fair access based on need.</td>
</tr>
<tr>
<td>Renal NSF standards and markers of good practice to form basis of future planning</td>
<td>Ensuring the relevant standards and markers have been reflected.</td>
</tr>
<tr>
<td></td>
<td>Standards beyond the scope of this plan will be taken forward by nurses, clinicians and individual PCTs.</td>
</tr>
</tbody>
</table>
### 3.3 Financial implications

Each of the 14 PCTs have already agreed to set aside £22 million to improve renal services in the region, so that if the proposals are approved the money is available to support the changes.

### 3.4 Service specification

Clinicians and nurses have been working over the summer to develop a clinical service specification so that any new renal dialysis unit providers will meet quality standards, if the proposals are approved.

As part of the service specification we also need input from you telling us what you want to see as part of service development across the east of England.

The feedback from this consultation will form part of the service specification which will be used to secure new, and improve existing, services.
4. PROPOSALS AND CONSULTATION

4.1 Our proposal

To expand renal dialysis services across the east of England region with a focus on areas of greatest need, including hospitals, satellite units and home therapies.

The aims of our proposals are to:

- Improve equality of access to services, based on population need
- Improve the experience of patients by expanding patient choice where clinically appropriate
- Improve the balance of geographic access to services, including shorter travel times for patients, so that the majority are no longer than 30 minutes away from a unit
- Ensure that renal dialysis units are the right size and therefore provide cost-effective services

No services are to be taken away, and existing patients will not be forced to move to another place for treatment.
4.2 What do renal dialysis patients value?

Informal consultation with patient groups and members of the public showed the key issues to be:

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment standards and patient choice</td>
<td>Patients value choices about their treatment and care.</td>
</tr>
<tr>
<td>Location of services</td>
<td>Patients value services that are closer to home, that are also co-located with other services they use.</td>
</tr>
<tr>
<td>Specification and design of units</td>
<td>Patients have helped to develop national specifications covering main renal units, satellite units and transplant units.</td>
</tr>
<tr>
<td>Patient transport</td>
<td>Transport is particularly important to renal patients, due to the frequency of hospital/satellite unit attendances. In relation to transport, parking cost and provision is also a key factor.</td>
</tr>
<tr>
<td>Holistic care</td>
<td>Patients have identified a range of services required to support them in the management of their condition. In particular these include psycho-social support, cultural needs and considerations, advice and information, excellence in staff communication, dietetics support, support to go on holiday, finance/benefits counselling and employment support.</td>
</tr>
<tr>
<td>Dignity and privacy</td>
<td>The need to be treated with dignity when undergoing treatment and having privacy when necessary.</td>
</tr>
<tr>
<td>Communication with health professionals</td>
<td>Patients and their carers value clear communication with staff caring for them and need to feel that they can ask questions.</td>
</tr>
</tbody>
</table>
Patient representation

We appreciate the enormous value of working with patients and public representatives in the early stages of service development and planning, so we have incorporated a representative onto our Renal Project Board.

Fiona Loud
Chair of The Kidney Alliance, a local Kidney Patient Association and East of England Renal Project Board member

“The East of England SCG recognises that dialysis services need to grow in line with increasing demand and that patients value choice and high quality in their care. Having had dialysis treatment in our area for five years, I know how important it is that the services are there to meet our needs.

This is your chance to influence the way in which services are developed. Your involvement is important to ensure you get the service you need.”

Specialist medical representation

Having kidney specialists on the Renal Project Board allows us to tailor our plans, so that we can improve the quality of care for patients and receive a greater insight into how services work on a local level.

Dr Alex Heaton
Nephrologist, Norfolk & Norwich University Hospitals NHS Foundation Trust and East of England Renal Project Board Member

“The East of England SCG will be listening carefully to what people say and will take account of those views to ensure future service provision meets the needs of patients and their families.

This is an opportunity to expand renal dialysis services in a way which makes them more accessible to the people who need them now and in the future.”
4.3 Locations for expansion of renal services

During the summer of 2009, clinicians were consulted about current services, capacity and future growth.

The factors that they identified as key to the improvement of renal dialysis services in the region are:

- **To release pressure on existing units when provision in areas close by may not be adequate**
- **Journey times to units (based on 30 minutes for the majority of patients), taking into account the rural locations of some existing and future patients**
- **Accessibility of new units (close to main roads or on existing hospital sites)**
- **Areas where there are more patients will need better service provision**
- **Proposed sites need to have the capacity to expand as patient numbers increase**
- **Build quality of new and existing units needs to meet national NHS standards**

Taking into account these factors, the proposed sites were identified by each PCT and are shown on the map below:

**Current and proposed sites**
### Proposed sites (table)

<table>
<thead>
<tr>
<th>Primary Care Trust</th>
<th>Location</th>
<th>Number of new dialysis stations</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Essex/ East &amp; North Hertfordshire</td>
<td>M11 corridor (eg Harlow, Bishop’s Stortford) (or within a 30 minute radius)</td>
<td>Minimum 22 stations (with room for further expansion)</td>
</tr>
<tr>
<td>Bedfordshire</td>
<td>Bedford (or within a 30 minute radius)</td>
<td>Minimum 20 stations (with further room for expansion)</td>
</tr>
<tr>
<td></td>
<td>Biggleswade (or within a 30 minute radius)</td>
<td>Minimum 8 stations (with further room for expansion)</td>
</tr>
<tr>
<td>North East Essex</td>
<td>Colchester (or within a 30 minute radius)</td>
<td>Minimum 8 stations (with room for further expansion)</td>
</tr>
<tr>
<td>Great Yarmouth &amp; Waveney</td>
<td>Beccles or Bungay (or within a 30 minute radius)</td>
<td>Minimum 5 stations (with further room for expansion)</td>
</tr>
<tr>
<td>Norfolk</td>
<td>Aylsham (or within a 30 minute radius)</td>
<td>Minimum 6 stations (with room for further expansion)</td>
</tr>
<tr>
<td>Suffolk</td>
<td>A14 corridor (eg Stowmarket) (or within a 30 minute radius)</td>
<td>Minimum 5 stations (with room for further expansion)</td>
</tr>
</tbody>
</table>

### Other areas in the east of England

The East of England SCG is responsible for commissioning renal dialysis services throughout the east of England region.

We are constantly reviewing all of our renal dialysis services and during this consultation are inviting the views of patients, the public and staff right across the region – including the PCT areas not specified above.
4.4 Key Questions for Consultation

We would like to hear the views of patients, their families, carers and the staff working in this area of healthcare.

We are asking:

1. Do you agree that renal dialysis services within the region need to be expanded?
2. Do you agree with the proposed locations for expansion of renal dialysis services?
3. Do you agree with the numbers of stations in each location?
4. What benefits or concerns do you see regarding the proposed developments for patients, families, carers and staff?
5. Are there any aspects of renal dialysis service provision you feel should be taken into account to ensure a positive experience for renal dialysis patients?
6. If you are a patient and are clinically eligible, would you consider home therapies?

Please see the feedback form inserted into this document to give us your views.

Evaluation of responses to the consultation

There will be an independent evaluation of all the responses to the consultation, including all written responses and outcomes of discussions from the consultation meetings.

This evaluation will then be fed into the final decision-making process, where your views will be taken into account by the Renal Strategy Board.

4.5 Decision-making process

Key dates for consultation

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 14, 2009</td>
<td>Start of public consultation, including consultation with local Health Overview and Scrutiny Committees, patient groups and NHS staff. Consultation documentation and public information available to view.</td>
</tr>
<tr>
<td>December 14, 2009 – March 8, 2010</td>
<td>Consultation meetings and collation of feedback.</td>
</tr>
<tr>
<td>March 8, 2010</td>
<td>Deadline for consultation feedback.</td>
</tr>
<tr>
<td>March 9, 2010</td>
<td>Analysis of consultation outcome.</td>
</tr>
<tr>
<td>April 2010</td>
<td>Final outcome document published.</td>
</tr>
</tbody>
</table>
5. **HOW TO HAVE YOUR SAY**

5.1 **Responses in writing**

There are many ways in which you can feedback your views on the proposals to us:

1. **Fill in the form at the back of this document and return it to us by post using the envelope provided (no stamp is required)**
2. **Write us a letter and return it to us using the envelope provided (no stamp is required)**
3. **Log on to www.eoescg.nhs.uk and complete our form online**
4. **Scan and email your completed feedback form to renaldialysis@eoescg.nhs.uk**
5. **Fax the form to us on 01279 666982**

If there is not a FREEPOST envelope enclosed in this document, simply send your feedback form or letter to:

FREEPOST RSEL-JKTR-LLCE  
East of England Specialised Commissioning Group  
Endeavour House  
Coopers End Lane  
Stansted  
Essex  
CM24 1SJ

**The deadline for all feedback is March 8, 2010**

5.2 **Come along to one of our consultation meetings**

We are looking to speak with patients, families, carers, experts, staff and anyone with an interest in working with us on plans to develop renal dialysis services.

We are running a series of consultation meetings at the venues listed on the back page of this document. You will have the opportunity to listen to a presentation given by one of our commissioners, find out more about the proposed developments to renal services, talk informally with professionals and patients, participate in discussions and give us your views.
Appendix A – Further information

Organisations

Kidney Care Matters Online
The e-communications tool from NHS Kidney Care that aims to keep you informed and aware of what is happening across England to ensure successful consistent implementation of the renal National Services Framework

The Kidney Alliance
Organisation bringing together patients’ voices and professionals committed to renal medicine to promote prevention and early identification of kidney disease, and high quality treatment for all patients at risk from, or identified with, kidney failure on an equal and uniform basis throughout the UK.
http://www.kidneyalliance.org/

UK National Kidney Federation (NKF)
UK national charity run by kidney patients to promote both the best renal medical practice and treatment, and the health of persons suffering from CKD or ERF. The NKF also supports the related needs of relatives and friends who care for kidney patients.
http://www.kidney.org.uk/

The East of England Specialised Commissioning Group (SCG)
Information about the East of England SCG and further documentation behind the renal project
www.eoescg.nhs.uk

The Department of Health
www.dh.gov.uk

NHS Direct
www.nhsdirect.nhs.uk

Documentation

The Renal National Service Framework (NSF)

Department of Health Operating Framework for 2008/09

Guidance on home therapies from the National Institute for Health and Clinical Excellence (NICE)
http://www.nice.org.uk/TA048

‘Organs for Transplant’ - Organ Donation Taskforce report

‘Saving Lives, Valuing Donors’ – Organ Donation Taskforce report
Appendix B – Key stakeholders

Service user networks and voluntary sector
We are aware of the existence of the following service user groups, but would be delighted to hear from your group if you would like to have a say on renal dialysis services in the east of England

Patient and public involvement groups linked to PCTs and other Trusts in the East of England
Addenbrooke’s Kidney Patient Association
United Norwich Kidney Patient Association
Southend Hospital Association for Renal Patients
Lister Kidney Foundation
Family carers associations
Councils for voluntary services
Local Involvement Networks (LINks)
Racial Equality Councils
Age Concern
Diabetes UK
National Kidney Federation
British Kidney Patient Association
Kidney Alliance
Kidney Research UK
British Renal Society
UK Renal Registry

Government and public representatives
Health Overview and Scrutiny Committees
County councils and unitary authorities
District councils
Local MPs
All Party Parliamentary Kidney Group

Health and social care sector
The Renal Association
The Renal Pharmacy Group
NHS Kidney Care
NHS hospitals
Primary Care Trusts
Local authority adult services
GP practices and practice-based commissioning groups
Local medical committees
Local pharmaceutical committees
Staff-side and union representatives
Department of Health

East of England Specialised Commissioning Group
Appendix C – The team for this project

**Renal Advisory Group Chair:**
Andrew Morgan, Chief Executive, NHS Bedfordshire

**Senior Responsible Owner:**
Trevor Myers, Interim Chief Operating Officer, East of England Specialised Commissioning Group

**Senior Renal Commissioner:**
Catherine Turner, East of England Specialised Commissioning Group

**Communications**
Tina Starling, Senior Communications Manager, East of England Specialised Commissioning Group

Lucy Dominy, Communications Assistant, East of England Specialised Commissioning Group
Appendix D

Glossary of terms

CKD (Chronic Kidney Disease)

ERF (End-Stage Renal Failure)

RRT (Renal Replacement Therapy)

NSF (renal National Service Framework)

NICE (National Institute for Clinical Excellence)

PCT (Primary Care Trust)

SCG (Specialised Commissioning Group)

Immunosuppressive therapy
Therapy used to decrease the body’s immune responses, such as drugs given to prevent transplant rejection

Home therapy
Renal dialysis in the home

Joint Health Overview and Scrutiny Committee
Contains representatives from all local authorities in the East of England

Renal Strategy Board
Established to assess the status of renal dialysis services in the East of England and create the strategy for improving it

Renal Project Board
Manages the overall planning and consists of clinicians, patient representatives, members of East of England Specialised Commissioning Group and a representative from a PCT that will make the final decision on the future of renal services following the feedback received from the public consultation

Renal Advisory Group
The Renal Advisory Group advises the Renal Project Board on the implementation of the renal dialysis services strategy
Feedback

The East of England Specialised Commissioning Group is keen to receive your feedback on the proposals for renal services for people in the east of England.

We invite you to complete the following questions – you may answer as few or as many as you wish.

Confidentiality

If you provide us with your details they will only be used as part of the public consultation and not be disclosed except as may be required by law. We would be grateful if you could provide personal information, as it will enable us to check we have received responses from a representative group of people and identify trends.

All consultation responses will be fully taken into account when decisions are made, irrespective of whether or not you provided personal details.

Questions

1. Do you agree that renal dialysis services within the region need to be expanded?
   Yes  No

   Why is this?

2. Do you agree with the proposed locations for expansion of renal dialysis services? (see pages 13 and 14)
   Yes  No

   Why is this?

Please continue on a separate sheet if necessary.
3. Do you agree with the numbers of stations in each location?  
   □ Yes  □ No  
   Why is this?

4. What benefits or disadvantages do you see regarding the proposed developments for renal services for patients, families, carers and staff?

5. Are there any aspects of renal dialysis service provision you feel should be taken into account to ensure a positive experience for renal dialysis patients?

6. If you are a patient and are clinically eligible, would you consider home therapies?  
   □ Yes  □ No  
   Why is this?

Please continue on a separate sheet if necessary.
1. Are you (please tick):
   - □ a) Providing your own response
   - □ b) Submitting your response on behalf of an organisation or patient group
      (Go to question 8)

2. How old are you? (please tick)
   - □ Under 25      □ 25-34      □ 35-44      □ 45-54
   - □ 55-64        □ 65 or over □ Prefer not to say

3. Are you (please tick):
   - □ Male        □ Female    □ Prefer not to say

4. Which ethnic group do you consider you belong to? (please tick)
   - □ White: British
   - □ Asian/Asian British: Indian
   - □ Asian/Asian British: other
   - □ Mixed: white and Asian
   - □ Black/black British: African
   - □ Other
   - □ White: Irish
   - □ Asian/Asian British: Pakistani
   - □ Mixed: white and black Caribbean
   - □ Mixed: other mixed background
   - □ Black/black British: Other
   - □ Prefer not to say
   - □ White: other
   - □ Asian/Asian British: Bangladeshi
   - □ Mixed: white and Black African
   - □ Black/black British: Caribbean
   - □ Chinese

5. Do you consider that you have a disability? (please tick)
   - □ Yes       □ No        □ Prefer not to say

6. Please can you give your full Postcode below. This will help us to monitor whether we are receiving responses from across the region.

7. Are you employed by the NHS? (please tick)
   - □ Yes       □ No        □ Prefer not to say

8. Please complete the following section if you are responding on behalf of an organisation or patient group.
   Name of the organisation or patient group you are submitting this response on behalf of:

   Please tell us who the organisation patient group represents (patients, staff etc) and, where applicable, how you assembled the views of the members.
There are many ways in which you can feedback your views on the proposals to us:

1. Fill in and return this form to us by post using the envelope provided (no stamp is required)
2. Write us a letter and return it to us using the envelope provided (no stamp is required)
3. Log on to www.eoescg.nhs.uk and complete our online form
4. Scan and email your completed feedback form to renaldialysis@eoescg.nhs.uk
5. Fax the form to us on 01279 666982

If there is not a FREEPOST envelope enclosed with this document, simply send your feedback form or letter to:

FREEPOST RSEL-JKTR-LLCE
East of England Specialised Commissioning Group
Endeavour House
Coopers End Lane
Stansted
Essex
CM24 1SJ

The deadline for all feedback is March 8, 2010

If you would like to see a copy of the outcome summary from the consultation after the decision has been made in March 2010, please complete your details below to tell us how you would like to receive it (please tick)

☐ Post
Name........................................................................................................................................
Address ....................................................................................................................................
................................................................................................................................................
................................................................................................................................................

☐ Email
Name........................................................................................................................................
Email address............................................................................................................................

Thank you for taking the time to give us your views on our proposals for changes to renal services in the region.
**Dates and locations of consultation meetings in 2010:**

<table>
<thead>
<tr>
<th>Date</th>
<th>Area</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thursday, January 7</td>
<td>Great Yarmouth</td>
<td>Celebration Suite – James Paget Hospital, Burrage Centre, Lowestoft Road, Gorleston, Great Yarmouth, NR31 6LA.</td>
</tr>
<tr>
<td>10am – 12pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thursday, January 7</td>
<td>Norwich</td>
<td>Benjamin Gooch Lecture Theatre, Norwich and Norfolk Hospital, Colney Lane, Norwich, NR4 7UY.</td>
</tr>
<tr>
<td>2pm – 4pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuesday, January 12</td>
<td>Stowmarket</td>
<td>Civic Offices, Council Chambers, Milton House, Milton Road South, Stowmarket, Suffolk, IP14 1EZ.</td>
</tr>
<tr>
<td>2pm – 4pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thursday, January 14</td>
<td>Peterborough</td>
<td>Thorpe Lodge Hotel, 83-85 Thorpe Road, Peterborough, PE3 6JQ.</td>
</tr>
<tr>
<td>11am – 1pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friday, January 15</td>
<td>Cambridge</td>
<td>Addenbrooke’s Hospital Clinical School, Seminar room five, Hills Road, Cambridge, CB2 2SP.</td>
</tr>
<tr>
<td>2pm – 4pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monday, January 18</td>
<td>Rayleigh</td>
<td>Mill Hall, Bellingham Lane, Rayleigh, SS6 7ED.</td>
</tr>
<tr>
<td>10am – 12pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thursday, January 21</td>
<td>Luton</td>
<td>The Board Room, Old Ward Block, Luton and Dunstable Hospital, Lewsey Road, Luton, LU4 0DZ.</td>
</tr>
<tr>
<td>10am – 12pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thursday, January 21</td>
<td>Bedford</td>
<td>Medical Institute, Postgraduate Centre, Bedford Hospital, Kempston Road, Bedford, MK42 9DJ.</td>
</tr>
<tr>
<td>2.10pm – 4pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friday, January 22</td>
<td>Stevenage</td>
<td>Lister Hospital, Corey’s Mill Lane, Stevenage, SG1 4AB.</td>
</tr>
<tr>
<td>10am – 12pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friday, January 22</td>
<td>Harlow</td>
<td>Latton Bush Centre, Southern Way, Harlow, CM18 7BL.</td>
</tr>
<tr>
<td>2pm – 4pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monday, February 1</td>
<td>Colchester</td>
<td>Lecture theatre, Postgraduate Centre, Colchester Hospital, Turner Road, Colchester, CO4 5JL.</td>
</tr>
<tr>
<td>2pm – 4pm</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Request a consultation meeting**

If you are involved in a patient or community group and would like a separate consultation meeting, please contact:

**East of England Specialised Commissioning Group Communications team**

Email: renaldialysis@eoescg.nhs.uk
Tel: 01279 666388
This consultation document is produced on behalf of the 14 Primary Care Trusts (PCTs) in the east of England:

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

The document is also available from www.eoescg.nhs.uk

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

Renal Consultation

East of England Specialised Commissioning Group
Tel: 01279 666388
Email: renaldialysis@eoescg.nhs.uk