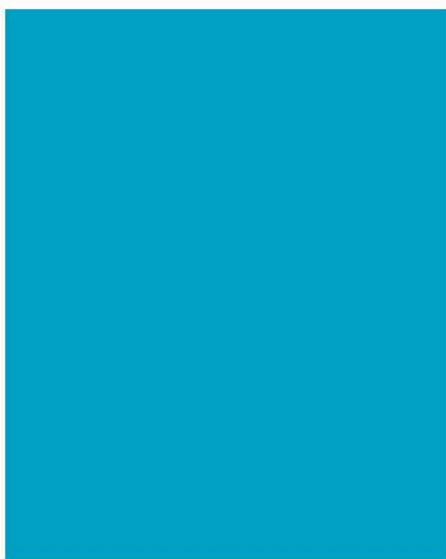


**Clinical  
Reference  
Groups for  
Specialised  
Services**

**A Guide for  
Stakeholders**



# Clinical Reference Groups: A Guide for Stakeholders

First published: March 2013

There is a separate guide, **Clinical Reference Groups: A Guide for Clinicians**, which is published by the NHS Commissioning Board Medical Directorate, and can be found at <http://www.commissioningboard.nhs.uk/files/2013/01/crg-guide.pdf>

The clinical and stakeholder guides have been published separately in order to accommodate recruitment processes. The two guides will be amalgamated into a single publication at a later date.

**Prepared by the Medical, Operations, and Patients and Information Directorates,  
NHS Commissioning Board**

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# Introduction

This guide is aimed at providing you with some background information about Clinical Reference Groups (CRGs), and an insight into the ways in which patients, patient groups, carers and organisations can contribute to their work.

CRGs bring together – on a voluntary basis – groups of clinicians, commissioners, Public Health experts, patients and carers, all of whom have a shared interest/expertise in a particular specialised service area. The members of each CRG work together to provide the NHS Commissioning Board (NHS CB) with clinical advice about each of the specialised services it will be responsible for commissioning from 1 April 2013. CRGs will work with all stakeholders including charities, patient groups, staff from service providers, and commercial organisations.

This is an exciting time to become involved with the CRGs. The way that health care services are delivered and managed is changing. The NHS CB – a new national organisation – will be responsible for ensuring that all NHS services meet defined standards and improve the health of service users.

The majority of health services will be commissioned at a local level by groups of GPs and other clinicians, working together to form Clinical Commissioning Groups, or CCGs. These services will be commissioned according to the health needs of the local population.

The NHS CB will commission some services directly. These are services which have been identified as too specialist or complex to be commissioned across a smaller footprint by CCGs. They include specialised services, and some unique services such as offender/prison health, and elements of military health.

CRGs will use their specific knowledge and expertise to advise the NHS CB on the best ways that specialised services should be provided. In their first year of work, the CRGs developed 128 service specifications and 44 clinical commissioning policies, which set out how specialised services should be delivered by providers, and to what standard. This is just one example of the kind of work which CRGs will continue during the coming year.

The contribution of patients, carers and patient group representatives was key to this process. My thanks go to the dozens of volunteers who were members of CRGs during their first year, giving up their time – on a voluntary basis – to provide a patient and carer voice at the table.

I would also like to make special mention of the Specialised Services Patient and Public Engagement Steering Group, whose members worked with us on the production of this guide, and helped us in the design of the patient and carer member recruitment process for 2013/14. We hope to see many former patient and carer members of CRGs return to work with us again during the coming year. We would also like to recruit more volunteers to take part in the work of the CRGs, both as individuals, and as representatives of patient groups. In addition to this, the NHS CB is committed to working with wider groups of stakeholders, ensuring that the patient and public voice is heard at every step of the decision-making process.

The purpose of this guide is to explain the work of the CRGs, particularly for those considering applying to be a patient or carer member or registering as a stakeholder

(interested party). I hope this guide answers any questions you may have. Thank you for your interest.

A handwritten signature in black ink, appearing to read 'James Palmer', with a stylized, cursive script.

James Palmer  
Clinical Director, Specialised Services  
Medical Directorate  
NHS Commissioning Board

# Background

1. From 1 April 2013, the NHS CB will be formally established, with an overarching role to ensure that the NHS delivers better outcomes for patients within its available resources, whilst upholding and promoting the NHS Constitution.
2. The NHS CB will support, develop and hold to account a new system of Clinical Commissioning Groups (CCGs), responsible for commissioning the majority of health services for local populations; it will provide leadership in the driving up of standards and quality of care, and as a single, national organisation, it will ensure that health services are commissioned in a consistent way, ensuring that patients receive the same level of service, and access to those services, regardless of where they live.
3. In addition to this, the NHS CB will directly commission specialised services; primary care services; offender healthcare, and some services for members of the armed forces. This direct commissioning function will be delivered consistently, and in a coordinated way, through a network of 27 locally based Area Teams, and 4 regional offices. 10 of these Area Teams will be responsible for the contracting of specialised services. Each of the direct commissioning functions of the NHS CB has its own 'Operating Model'. Links to each of these documents can be found in the Bibliography at the back of this guide.
4. Central to the NHS CB's work is an ambition to place patients and the public at the heart of everything. The organisation will practice open, evidence-based, inclusive and transparent decision-making, encouraging patient and public participation at every level.
5. This commitment to wide stakeholder and patient and public engagement will ensure that all of the NHS CB's commissioning processes are underpinned and informed by the meaningful involvement of those who are using services, and by those who care for and support them.

## What are Specialised Services?

6. Specialised services are provided in relatively few hospitals, to catchment populations of more than one million people.
7. The number of patients accessing these services is small and services tend to be located in specialist hospital trusts in major towns and cities. Concentrating services in this way ensures that specialist staff can be more easily recruited, and their training maintained. It is also more cost-effective and makes the best use of resources such as high tech equipment.
8. Historically, a list of all services defined as 'specialised' was captured in the Specialised Services National Definition Set (SSNDS). Services broadly fell into three categories:

- i. Highly specialised services – services which are currently nationally commissioned e.g. heart and lung transplantation. There are around 70 highly specialised services. Conditions in this category usually affect fewer than 500 people across England, or involve services where fewer than 500 highly specialised procedures are undertaken each year.
  - ii. Specialised services which form part of a wider patient pathway e.g. cardiac, mental health, spinal and kidney care services.
  - iii. Specialised services which are not generally part of a pathway e.g. paediatric intensive care, and burn care.
9. In general, these services can be expensive to provide and some may be described as high cost/low volume services. Specialised services account for approximately 10% of the total NHS budget and spend about £11.8 billion per annum. A list of 143 services defined as ‘prescribed specialised services’ can be found here:  
<http://www.dh.gov.uk/health/2012/09/cagreport/>
10. Until March 2013, specialised services in England were commissioned by 10 separate, regionally-based Specialised Commissioning Groups (SCGs) and a National Specialised Commissioning Team (NSCT), with the latter responsible for commissioning the highly specialised services. The regional teams evolved and operated in different ways which has resulted in differential access to services with different service standards and specifications across SCGs.
11. From 1 April 2013, when the NHS CB takes on responsibility for commissioning these services, these arrangements will end and 10 of the 27 Area Teams will be responsible for the contracting of specialised services, using a single national set of service specifications, standards, policies and quality measures. The 10 Area Teams are:
- Cumbria, Northumberland, Tyne and Wear
  - South Yorkshire and Bassetlaw
  - Cheshire, Warrington and Wirral
  - East Anglia
  - Leicestershire and Lincolnshire
  - Birmingham and Black Country
  - Bristol, North Somerset and South Gloucestershire
  - Wessex
  - Surrey and Sussex
  - London
12. A single, national commissioning structure and process, underpinned by a comprehensive programme of patient and public engagement, will eradicate those

variations described above, and will enable the NHS CB to implement its vision of equity and excellence in the provision of specialised care and treatment.

13. The NHS CB will work with a range of stakeholders at a national level, through the CRGs, to determine the outcomes expected for specialised services. This will be achieved through the development of clinical strategies set out within five National Programmes of Care which group together the specialised services and their relevant CRGs. The Programmes of Care are:

- Internal Medicine – digestion, renal, hepatobiliary and circulatory system
- Cancer and Blood – infection, cancer, immunity and haematology
- Trauma – traumatic injury, orthopaedics, head and neck, and rehabilitation
- Women and Children – women and children, congenital and inherited diseases
- Mental Health

14. The Programmes of Care span three portfolios covering acute, highly specialised and mental health services. They will be clinically led and supported by Programme of Care management teams at both a national and regional level. Regional teams will in turn provide support to the 10 area teams responsible for contracting for specialised services at a local level.

## The Clinical Reference Groups (CRGs)

15. Clinical engagement, in addition to engagement with patients and the public, is vital to successful commissioning. Clinical advice to specialised commissioning needs to be service specific and the role of the CRGs, within their Programmes of Care, is essential in ensuring that the NHS CB retains a clear service specific focus.

16. During transition to the new commissioning arrangements, a total of 60 CRGs were established which brought together a range of service speciality experts – patients, clinicians, public health experts and commissioners, all of whom were acting on a voluntary basis. The CRGs were, in their first year, responsible for the production of the first ever national NHS service specifications and policies for a number of different clinical areas. The CRGs were reviewed at the end of their first year of work and have been re-shaped for 2013/14 to ensure integration with the new area teams of the NHS CB and the clinical commissioning groups.

In 2013/14, there will be a total of 74 separate CRGs, each focusing on a specific specialised service area and organised into the five Programmes of Care. (An additional two CRGs – offender health and military health – are also being developed, but do not cover specialised services and therefore do not sit within the Programmes of Care).

17. The CRGs for 2013/14 are listed below. Appendix A includes a short description of each CRG service area.



### 1. Internal Medicine Programme of Care

Cystic Fibrosis	Cardiac Surgery
Hepatobiliary and Pancreas	Pulmonary Hypertension
Specialised Endocrinology	Specialised Dermatology
Vascular Disease	Specialised Rheumatology
Morbid Obesity Surgery	Specialised Respiratory
Renal Dialysis	Interventional Radiology
Renal Transplant	Specialised Imaging
Specialised Colorectal Services	Specialised Diabetes
Complex Invasive Cardiology	Heart and Lung Transplantation

### 2. Cancer and Blood Programme of Care

Radiotherapy	Specialised Immunology and Allergy
PET-CT	Thoracic Surgery
Specialised Cancer	Upper GI Surgery
Blood and Marrow Transplantation	Sarcoma
Haemophilia and Bleeding Disorders	CNS Tumours
HIV	Specialised Urology
Infectious Diseases	Chemotherapy
Haemoglobinopathies	Complex Head and Neck
Teenage and Young Adult Cancer	

### 3. Mental Health Programme of Care

Specialised Services for Eating Disorders	Tier 4 Child and Adolescent Mental Health Services
High and Medium Secure Mental Health	CAMHs Secure
Low Secure Mental Health	Tier 4 Severe Personality Disorder Services (adults)
Specialised Mental Health Services for the Deaf	Mental Health Specialised
Gender Identity Services	Perinatal Mental Health

#### 4. Trauma Programme of Care

Complex Disability Equipment	Specialised Ear Surgery
Brain Injury and Complex Rehabilitation	Specialised Orthopaedic Services
Adult Neurosurgery	Hyperbaric Oxygen Therapy
Neurosciences	Specialised Ophthalmology Services
Stereotactic Radiosurgery	Spinal cord injury
Burn Care	Complex Spinal Surgery
Cleft Lip and Palate	Major Trauma
Specialised Pain	Adult Critical Care

#### 5. Women and Children Programme of Care

Medical Genetics	Neonatal Critical Care
Paediatric Surgery	Paediatric Neurosciences
Paediatric Medicine	Complex Gynaecological Services
Paediatric Cancer Services	Specialised Maternity Services
Congenital Heart Services	Fetal Medicine
Metabolic Disorders	Multi-System Disorders
Paediatric Intensive Care	

### The role of CRGs

18. CRGs are the main source of clinical advice to the NHS CB. They are responsible for:

- the development of nationally consistent service specifications. CRGs have already delivered a set of 128 service specifications during the transition year, which have been subject to public consultation. Service specifications describe what the NHS CB expects to commission for the population of England in terms of standards and patient outcomes, and forms part of the contract between a commissioner and service provider. CRGs will now focus on 2014/15 specifications and will be developing robust quality standards for each of the services, as well as thinking long-term about what these services might look like in three to five years' time.
- the rolling development of commissioning policies. A commissioning policy is an important document that describes the healthcare treatment that the NHS proposes to routinely commission for a defined patient group with a particular illness within a defined financial year. CRGs have already developed a number

of nationally consistent commissioning policies, which have been the subject of public consultation, and will continue to review similar policies as a matter of priority.

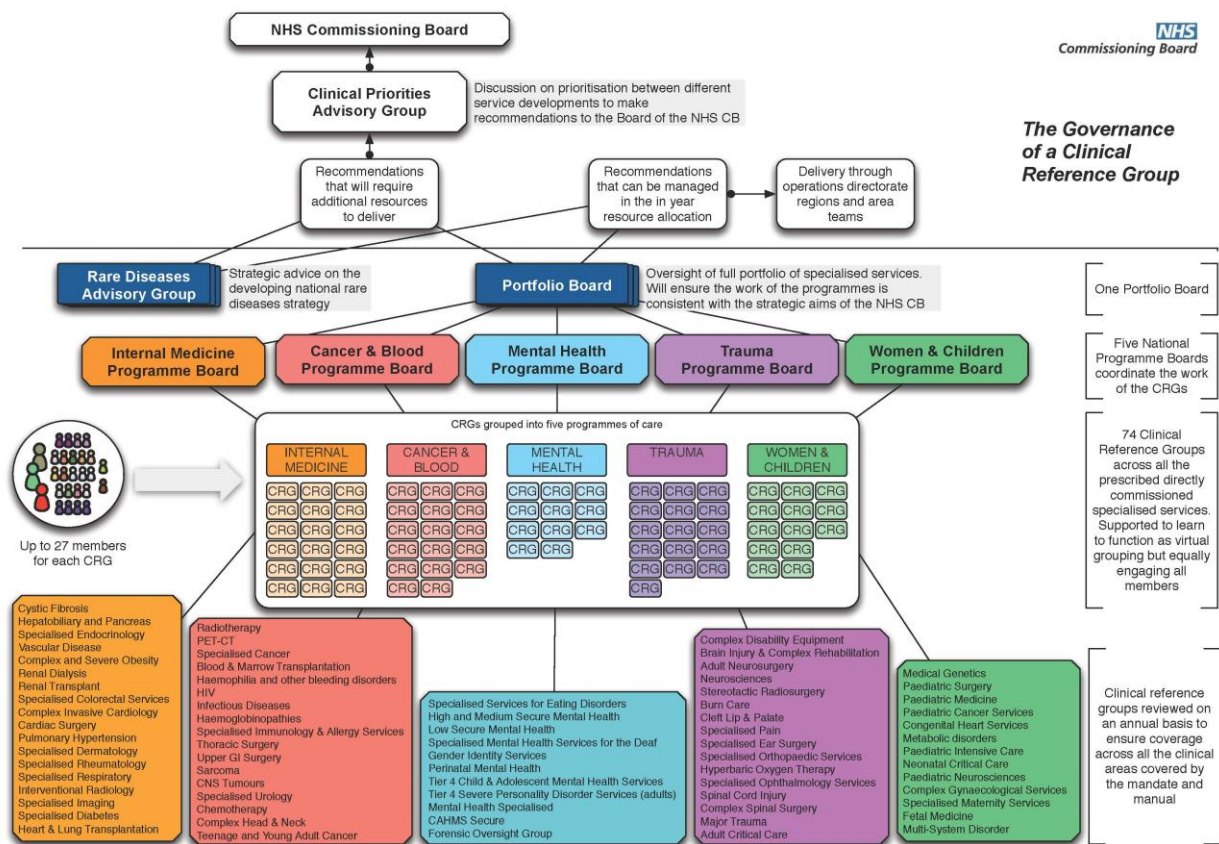
- development of CQUINs. The Commissioning for Quality and Innovation framework was established as part of the 2009/10 NHS Operating Framework as an incentive scheme which forms part of the contract between a commissioner and a provider. The purpose of a CQUIN scheme is to drive quality improvements focusing on clinical effectiveness, safety, patient experience and innovation. CRGs that are involved in CQUIN development will be provided with guidance and support to assist them in the process.
- development of productivity and efficiency schemes to affect clinical service redesign, often referred to as 'QIPP' plans (Quality, Innovation, Productivity and Prevention). CRGs will continue to develop such schemes within their particular service area in 2013/14, building on existing schemes, generating new ideas, and participating in 'confirm and challenge' clinical panels, via the Programme and Portfolio Boards, to shape the schemes into robust costed plans.
- helping to identify potential innovations within each service area.
- agreeing consistent measures of quality for each service area, and looking at provider performance against those measures.
- identifying organisations or stakeholders with an interest in the work of the CRG and developing a plan for communicating with them. This process is supported by an online stakeholder registration programme which will be accessed via the NHS CB website.

## Governance of CRGs

19. CRGs are not decision-making bodies. Their role is to provide clinical advice about a particular specialised service and to make recommendations to the Programme of Care Boards within the NHS CB. However, these groups will have considerable influence on how specialised services are delivered in future.
20. CRGs are organised into five groups known as Programmes of Care. Programme of Care Boards are responsible for reviewing the performance of CRGs against their agreed work plan, and checking and challenging their process and recommendations. For example, this might include checking the extent to which interested parties have been involved in designing recommendations for service change.
21. All CRG members will be asked to operate in accordance with guidance on standards of conduct, including conflicts of interest, which are set out in the Terms of Reference for CRGs.
22. At the time of writing, the Board of the NHS CB is developing the governance of a Clinical Priorities Advisory Group (CPAG) for all areas of direct commissioning,

including specialised health services. It is anticipated that recommendations developed by CRGs will be routed through to the CPAG via the five Programme of Care Boards and the Portfolio Board, which has oversight of the full portfolio of specialised services.

23. CRGs will not be the only way in which the patient and public voice is heard in specialised commissioning in the NHS CB. Wider governance structures for specialised commissioning will include opportunities for patient and carer involvement at various levels, the detail of which is currently being developed. Insight programmes will also be established to enable the NHS CB to better understand patient experience and outcomes in specialised services, making the most of digital technology. Again, further details will follow on the NHS CB website.



## Membership of CRGs

24. It is anticipated that the CRGs will each have up to 27 members – this means that there could be as many as 1,900 people involved in their work at any one time. The ambition for each of the CRGs is that all members maintain an active interest. However, given the geographical spread of the membership, it is realistic to expect

that a lot of the work of the CRGs will be carried out 'virtually' and that an individual's level of involvement in the CRG may fluctuate throughout the year.

25. The members are:

- Chair – a clinical leader in the field of the identified clinical service, responsible for enabling the meaningful involvement of all members of the CRG. CRGs will be co-chaired by National Clinical Directors. At the time of writing, 21 National Clinical Directors have been appointed to part-time roles, working for the NHS CB. The National Clinical Directors will provide expert advice to the NHS CB Medical Directorate, whilst retaining their current roles. For more information about the National Clinical Directors, please go to <http://www.commissioningboard.nhs.uk/2013/03/13/ncd/>
- For 2013, CRG membership will reflect the new model of direct commissioning, and will include representatives of Senates. The new Senates, which are based around major patient flows into specialist, or tertiary centres, will be clinically led and will provide strategic, independent advice and support to commissioners and providers of healthcare. A document describing the role of Senates can be found in the Bibliography at the back of this guide. In terms of CRG membership, there will be a single clinical representative on each CRG from each of the 12 Senate areas. There will be three representatives from London, due to the different structure of commissioning and the concentration of a number of specialised and highly specialised services in London. Again, these members will be clinical leaders with an expert understanding of a specific clinical field.
- Up to four patient and carer members, acting as individuals, or coming from a patient organisation. For more detail, please see below.
- Up to four professional organisations membership places for those organisations that play a key role in the coordination and assurance of training and professional leadership of clinical staff in the service e.g. Royal Colleges and Associations.
- The Accountable Commissioner (part of the new Programme of Care structure) plus additional commissioning representatives where appropriate.
- In addition to the core membership, Area Team Public Health and/or Pharmacy Leads will be allocated to CRGs on an annual basis, depending on the needs of the work programme.
- Non-members of CRGs may be invited, in an advisory capacity, to specific meetings at the discretion of the Chair of the CRG.

## Getting involved with the work of CRGs

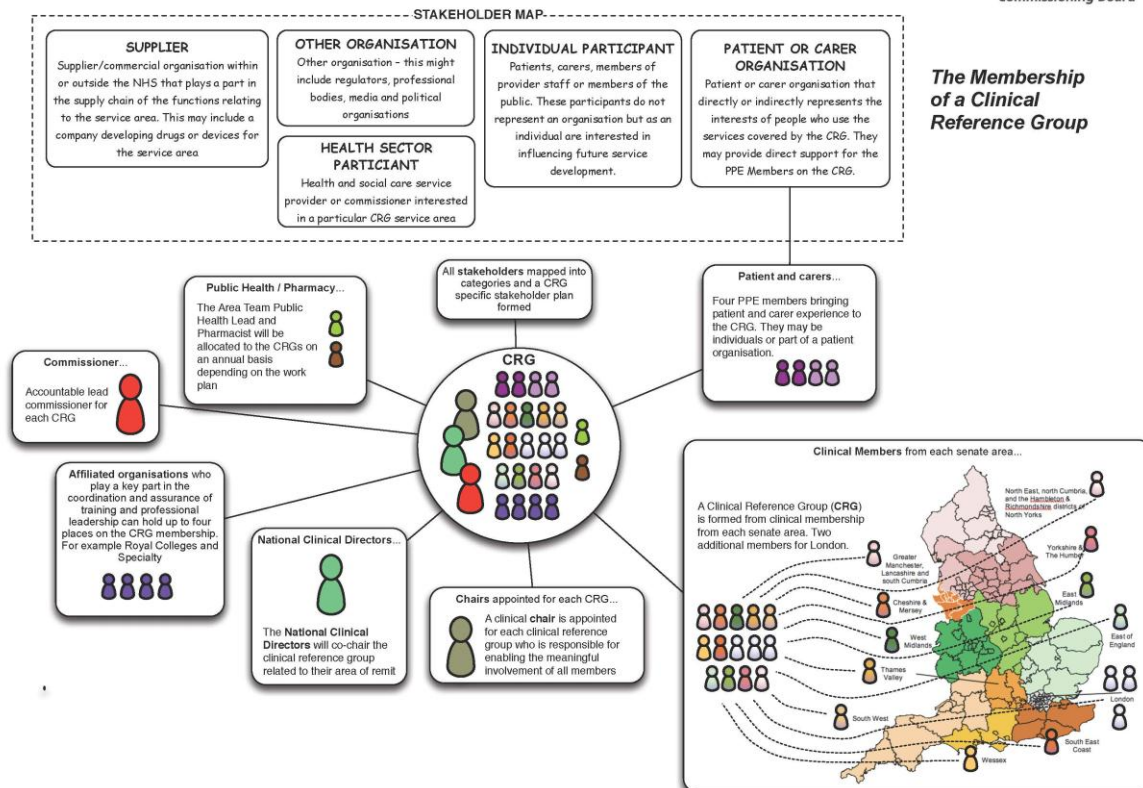
26. The NHS CB welcomes the involvement of interested parties in the work of the CRGs and has developed a process of stakeholder identification and registration to support this. The process for self-registration of stakeholders will be launched in the near future on the NHS CB website. All stakeholders are asked to self-register with the CRGs that are of interest, and if appropriate with Programmes of Care. This will enable stakeholders to interact with specific services as well as with broader work streams within specialised services. Stakeholders can register with more than one CRG or Programme of Care.
27. Stakeholder engagement plans will be developed for each CRG and more widely across specialised commissioning, with the aim of promoting openness and transparency in the decision-making process, and ensuring that seldom-heard groups (both patients and staff) are included. CRGs will develop their engagement in partnership with stakeholders, tailored to meet the needs of their annual work plans and working with area teams to ensure that local engagement processes are coordinated and effective.
28. At registration, stakeholders are asked to identify themselves into one of the following categories:
  - Patient or carer organisation that directly or indirectly represent the interests of people who use the services covered by the CRG
  - Individual participant: patients, carers, members of provider staff or members of the public. These participants do not represent an organisation but as an individual are interested in influencing future service development.
  - Health and social care service provider or commissioner interested in a particular CRG service area
  - Supplier/commercial organisation within or outside the NHS that plays a part in the supply chain of the functions relating to this service area. This may include a company developing drugs or devices for the service area.
  - Other organisation – this might include regulators, professional bodies, media and political organisations

Registered stakeholders will be kept informed about the work of the CRG and will have the opportunity to get involved in a range of ways:

- Responding to queries, surveys, and consultations about future service developments
- Seeking feedback from their own networks on proposals and consultations by organising activities (for example focus groups, meetings, digital engagement)
- Developing information materials
- Passing on information to their networks



- Supporting patient and carer members of the groups



**The Membership of a Clinical Reference Group**

## The patient and carer voice on CRGs

29. A core function of the NHS CB is to champion the effective involvement of patients and carers in making decisions about, and managing, their own care. The NHS CB also has a role in promoting collective engagement by patients, carers and the public in decisions affecting health services in their area. The needs and views of patients, carers and the public are at the heart of the new commissioning structure for the NHS and their experience and feedback will be used to improve the quality of NHS services provided.
30. The ambition for the patient and carer members is that they provide the CRG with insight, information, and views about the service from the viewpoint of patients and carers. This is in order to ensure that the experience and views of patients inform and influence the planning and delivery of the specialised service so that those services are better able to deliver the kind of experience and outcomes that patients actually want.
31. Full details regarding the roles and responsibilities of patient and carer members of CRGs are available in the accompanying 'Information Pack for Patient and Carer

Members' which can be found on the NHS CB website at

<http://www.commissioningboard.nhs.uk/ourwork/d-com/spec-serv/crg/>

32. The Information Pack also contains details about the kind of personal qualities, skills and experience the NHS CB is looking for in potential patient and carer members, and outlines the recruitment process for joining a CRG.
33. Patient and carer members of CRGs are just one aspect of a wider approach to ensuring that citizens are meaningfully involved in the work of the NHS CB. This includes specialised commissioning at a national level. It is anticipated that there will be patient and public voice representation on the Programmes of Care and Portfolio Boards, as well as on the CPAG. Plans are also being developed to ensure engagement at a more local level, through the work of the Area Teams.
34. This wider patient and public voice is beyond the scope of this Guide, but approaches and opportunities for engagement at all levels will be developed with partners and will be publicised both on the NHS CB website and via partner networks.



# Glossary

Accountable commissioner		Part of the new Programme of Care structure, these regional programme managers and service specialists will have national accountability for 2/3 CRGs.
Area Team		The 27 Area Teams are 'local offices' of the NHS Commissioning Board. Core functions include primary care, Public Health, and local relationship management. 10 of the Area Teams are also responsible for specialised commissioning contracting across England.
Clinical Advisory Group	CAG	A national group, providing formal clinical advice to ministers, the CAG tested the scope of each specialised service against the four factors in the Health and Social Care Bill to determine whether a service was truly 'specialised' or not.
Clinical Commissioning Group	CCG	Established as statutory organisations from 1 April 2013, these are groups of GP practices which will be responsible for buying the majority of hospital and community-based health services for patients within their local communities, taking over the role previously performed by Primary Care Trusts.
Clinical Reference Group	CRG	There are 74 CRGs, covering the full range of specialised services, providing clinical advice in support of the NHS CB's direct commissioning function.
Clinical Priorities Advisory Group	CPAG	At the time of publication, the Board of the NHS CB had agreed in principle to the establishment of an advisory group to advise the NHS CB on the clinical and cost effectiveness, and the relative priority, of certain treatments.
Commissioning for Quality and Innovation	CQUIN	The CQUIN framework was established as part of the 2009/10 NHS Operating Framework as an incentive scheme which forms part of a contract between a commissioner and a provider. CQUIN schemes link the successful delivery of specific outcomes and actions with the release of an additional payment to the provider, with the overall aim of driving quality improvement.
Commissioning policy		Describes the healthcare treatment that the NHS proposes routinely to commission for a defined patient group.
Clinical Reference Group	CRG	The key delivery mechanism for the development and assurance of specialised services contract products. The CRGs cover the full range of specialised services and are

		comprised of clinicians, commissioners, patients and Public Health experts. The CRGs provide clinical advice to the NHS Commissioning Board.
Highly Specialised Services	HSS	There are around 70 highly specialised services which are commissioned nationally. These are services which usually affect fewer than 500 people across England or involve services where fewer than 500 procedures are undertaken each year e.g. heart transplantation and secure forensic mental health services for young people.
National Programme of Care	NPOC	CRGs are organised into five National Programmes of Care – mental health, women and children, cancer and blood, trauma, and internal medicine. The NPOCs will work at both a national and regional level and will be responsible for the development of clear and consistent clinical strategies and standards of care.
NHS Commissioning Board	NHS CB	Established in October 2012 as an executive non-departmental public body. The NHS CB is responsible for improving health outcomes for people in England; supporting, developing and holding CCGs to account; overseeing emergency resilience of the NHS system, and directly commissioning primary care, specialised services, military and offender health.
Portfolio Boards		There are three clinically-led Portfolios covering acute, highly specialised, and mental health services, maintaining oversight of the five Programmes of Care
Senate		Hosted by the NHS Commissioning Board, Clinical Senates are advisory groups of experts from health and social care, each covering one of 12 broad geographical areas of England. They will provide advice and leadership at a strategic level to Clinical Commissioning Groups, Health and Wellbeing Boards and the NHS Commissioning Board.
Service specification		CRGs have developed a set of 130 nationally-consistent service specifications for each of the specialised services. These, together with the 70 national service specifications for highly specialised services, determine the nature of the service to be commissioned from a provider.
Specialised services		Services provided in relatively few hospitals, to catchment populations of more than 1 million people. These services are often referred to as ‘high cost/low volume’ services.
Specialised Services National Definition Set	SSNDS	Describe in detail those services which are deemed to be ‘specialised’ i.e. with a planning population of more than 1 million people. The definitions provide a helpful basis for

		service reviews and strategic planning and help with the identification of activity that is regarded as specialised. The third edition of the SSNDS was published in 2009/10.
Strategic Portfolios		There are three Strategic Portfolios – acute, highly specialised, and mental health. Portfolio Directors and their teams will maintain oversight of the National Programmes of Care.
Quality, Innovation, Productivity and Prevention	QIPP	A large-scale transformation programme for the NHS, aimed at improving quality of care and ensuring that the NHS delivers high quality services whilst making up to £20bn of efficiency savings by 2014, which will be reinvested in frontline care.
Quality Standard		A key component of the national service specification template. Where Quality Standards are prioritised and summarised as part of a Quality Dashboard, they provide a helpful and credible level for improvement at service delivery levels.

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## **Appendix 1: An Introduction to the CRGs**

The purpose of this Appendix is to provide you with some information regarding the nature of the services covered by each of the individual Clinical Reference Groups (CRGs). This information is by no means exhaustive, and more detailed information about individual CRGs and their umbrella Programmes of Care will be available on the NHS Commissioning Board (NHS CB) website soon.

What all of the CRGs have in common is a clear focus on improving outcomes for patients, driving quality and innovation in specialised services, and ensuring greater equity in the care that patients receive. Their core work includes the delivery of commissioning 'products'. These products are the set of tools, such as service specifications and commissioning policies, used by the NHS CB's Area Teams to secure services from commissioned providers on an annual basis. You can find more information about commissioning products in the main body of this Guide.

### **Clinical Reference Groups**

#### *Internal Medicine Programme of Care*

##### **Cystic Fibrosis**

Cystic fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. CF affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. About 9,000 people in the UK are living with cystic fibrosis.

##### **Hepatobiliary and Pancreas**

Hepato-pancreato-biliary (HPB) services treat patients who have disorders of the liver, bile ducts and pancreas. A large volume of HPB services are delivered in local hospitals but, because of the complexity and high cost of care, delivery in conjunction with or at specialist tertiary centres may be necessary. Such conditions include hepatitis C (about 2,000 cases each year), serious complications of cirrhosis (about 3,000 cases each year) and complex liver, biliary and pancreatic surgery (about 5,000 cases each year).

##### **Specialised Endocrinology**

Endocrine glands secrete hormones directly into the blood stream. The main endocrine glands are the pituitary gland, thyroid gland, pancreas, ovaries, testes and adrenal glands. Many endocrine conditions may be treated in local hospitals, but patients with complex or co-morbid conditions may require referral to specialist centres for consultant opinion or further management.

##### **Vascular Disease**

Vascular services manage the treatment and care of patients with vascular disease relating to disorders of the arteries, veins and lymphatic system. The diseases can be managed by medical therapy, minimally-invasive catheter procedures and surgical reconstruction.

Patients with vascular disorders are cared for by specialist vascular teams, which include vascular surgeons, vascular interventional radiologists, vascular anaesthetists, vascular scientists, nurses, radiographers, physiotherapists and rehabilitation specialists.

### **Complex and Specialised Obesity Surgery**

Currently, secondary prevention treatments for obesity include behaviour modification interventions such as diet, exercise and life style; referral to specialist weight loss clinics; drug therapy; low and very low calorie diets; and behaviour modification therapies. Surgery to aid weight reduction may be considered when all other non-invasive measures have been tried but have failed, and the patient has been adequately counselled and prepared for surgery. The services encompassed by this CRG relate only to surgery for weight management.

### **Renal Dialysis**

Each year, in England, about 5,500 people start treatment for kidney failure and there are currently about 43,000 people receiving such treatment. Around 4 in 10 patients are treated by circulating their blood through a machine which cleans it of toxins (haemodialysis). This can be done either in hospital or at home. Approximately 1 in 10 patients are treated using the thin membrane that lines the abdominal cavity (the peritoneum) as a filter. This is called peritoneal dialysis.

### **Renal Transplant**

Each year in England approximately 5,500 people start treatment for kidney failure and there are currently about 43,000 people receiving such treatment. Approximately half of these patients are treated by having a kidney transplant.

### **Specialised Colorectal Services**

Specialist colorectal services require a critical mass of expertise in surgery, medicine, radiology, pathology and nursing. This is possible only in units large enough to allow specialisation in all of these disciplines, and it is only in units receiving referrals from a wide geographical area that sufficient experience is gained in dealing with the more difficult and complex cases.

### **Complex Invasive Cardiology**

The services encompassed by this CRG include:

- the diagnosis and treatment of fast heart rhythms using cardiac electrophysiology studies;
- the use of devices to treat abnormally fast, life-threatening heart rhythms;
- services to treat people with inherited cardiac diseases;
- the use of a tube (catheter) to treat specific heart problems which might otherwise have required open surgery (invasive cardiology);
- the opening of narrow coronary arteries with a balloon catheter as the first treatment following specific types of heart attack (primary percutaneous coronary intervention);
- magnetic resonance imaging of the heart.

### **Cardiac Surgery**

Cardiac surgery is a surgical sub-specialty within the specialism of cardiothoracic surgery and includes provision of surgical interventions for coronary artery disease requiring surgical revascularisation, and valve disease requiring surgical valve repair or replacement.

The services encompassed by this CRG relate specifically to open surgical procedures on the heart.

### **Pulmonary Hypertension**

Pulmonary hypertension is high pressure inside the pulmonary arteries, which are the vessels carrying blood from the right-hand side of the heart to the lungs. The condition results in damage to the right-hand side of the heart, making the heart less efficient at pumping blood around the body and getting oxygen to the muscles. If it is not treated, pulmonary hypertension can cause heart failure, which is when the heart struggles to pump enough blood around the body. This can be fatal. It is estimated that pulmonary hypertension affects 15 to 50 people per million of the population each year. Functional classifications are used to indicate the severity of symptoms. These range from functional class I (the mildest symptoms) to functional class IV (the most severe).

The services encompassed by this CRG relate to the treatment of patients with the most severe disease who need to be treated at one of a small number of highly specialist pulmonary hypertension centres.

### **Specialised Dermatology**

It is estimated that around 10% of patients requiring dermatology services (about 10,000 each year) need care from Highly Specialist Dermatology Centres.

Both adult and paediatric dermatology services are provided in local hospitals and deal with a wide range of conditions. Specialist adult dermatology services include the diagnosis, investigation and treatment of rare diseases and the management of severe diseases not suitable for, or not responding to, conventional treatment available in local dermatology departments. All dermatologists are trained in both adult and paediatric dermatology.

Paediatric dermatology services are usually provided by dermatologists in local hospitals often with support from paediatricians. Specialist paediatric dermatology services incorporate any skin condition affecting a child, which a general dermatologist or paediatrician has been unable to diagnose or manage because it is atypical, severe, or complicated by other paediatric, medical or social factors. The services encompassed by this CRG relate to the treatment of patients with rare diseases or patients with specific common diseases who have complex needs.

### **Specialised Rheumatology**

Rheumatology is a multi-disciplinary branch of medicine that deals with the investigation, diagnosis and management of patients with arthritis and other musculoskeletal conditions. This incorporates over 200 disorders affecting joints, bones, muscles and soft tissues, including inflammatory arthritis and other systemic autoimmune disorders, vasculitis, soft tissue conditions, spinal pain and metabolic bone disease.

The services encompassed by this CRG relate to the treatment of patients with rare diseases or patients with specific common diseases who have complex needs.

### **Specialised Respiratory**

Respiratory services deal with patients with breathing difficulties. Respiratory disease services are usually provided by respiratory physicians in local hospitals. However, some diseases are very rare whilst other more common ones lead to more complex problems.

The services encompassed by this CRG include:



- the management of patients with complex respiratory disease who need assisted ventilation at home;
- services for people with severe and difficult to control asthma;
- services for people with interstitial lung disease.

### **Interventional Radiology**

Interventional radiology (IR) refers to a range of techniques which rely on the use of radiological image guidance (e.g. x-ray fluoroscopy, ultrasound, computed tomography (CT) or magnetic resonance imaging (MRI) to precisely target therapy. Most IR treatments are minimally invasive alternatives to open and keyhole surgery, and are used to treat a wide range of conditions such as vascular disease and a number of tumours.

### **Specialised Imaging**

This is a new CRG for 2013/14 which has been established to enable a focus on the broader range of issues associated with the specialised elements of diagnostic imaging and imaging assisted / guided treatments. The work will require close liaison with other CRGs which rely on specialised imaging techniques for the accurate diagnosis and treatment of a range of conditions requiring specialised care.

### **Specialised Diabetes**

Specialised diabetes refers to the services accessed by a small group of people with diabetes (both adults and children) but whose condition is resistant to insulin treatment. This may be because of either a genetic condition or because the person has developed antibodies to insulin.

### **Heart & Lung Transplantation**

Heart and lung transplant services affect between 100 and 200 adults and children each year. The service may be available for people whose heart or lungs are failing. Conditions in which heart, lung or heart and lung transplants may be appropriate include defects of the heart or lungs that exist at birth (congenital), pulmonary hypertension and cystic fibrosis. The service also includes providing some people with a mechanical device which supports the function of their heart until a donor can be found. These are called ventricular assisted devices and 'bridge' the period until a transplant can be carried out.

## ***Cancer and Blood Programme of Care***

### **Radiotherapy**

Radiotherapy is the controlled use of high energy x-rays to treat many different types of cancer. Around 40% of people with cancer have radiotherapy, although evidence suggests this should be about 50%. In a few cases, radiotherapy can also be used to treat benign (non-cancerous) tumours. Radiotherapy may be used to cure an illness – for example, by destroying a tumour (abnormal tissue); to control symptoms – for example, to relieve pain; to shrink a tumour to make it easier to remove, prior to surgery, and after surgery, to destroy small amounts of tumour that may be left.

### **PET-CT**

A PET-CT scan combines a CT scan (anatomical) and a PET (metabolic) scan into one scan. A CT (computerised [axial] tomography) scan takes a series of x-rays and uses a computer to put them together. The CT machine takes pictures of the body from different angles and gives a series of cross sections or 'slices' through the part of the body being

scanned. PET (positron emission tomography) uses a very small amount of an injected radioactive material (for example, glucose) to show where cells are active in the body.

A PET-CT scan can provide important information about cancer and other diseases. Approximately 50,000 PET-CT scans are carried out in England each year.

### **Specialised Cancer**

More than 300,000 people are diagnosed with cancer each year and more than 1 in 3 people will develop cancer during their lifetime. There are over 200 types of cancer, of which about 50% are classified as 'rare'. This CRG consists of the Chairs of all the other CRGs which have a responsibility for cancer flow. It will provide a strategic overview of specialist cancer care and link with the wider cancer world.

### **Blood & Marrow Transplantation**

Haematopoietic stem cell transplantation (HSCT), also known as blood and marrow transplantation (BMT), is used to treat a wide spectrum of haematological and, increasingly, non-haematological, disorders. The most common clinical indications for HSCT are leukaemias, lymphomas and myeloma.

### **Haemophilia and other bleeding disorders**

Bleeding disorders are medical conditions in which the blood fails to clot properly. These conditions are rare in the general population, affecting about 24,000 people in the UK. Most are genetically inherited. They include Haemophilia A and B (classified as mild, moderate or severe), Von Willebrand disease and platelet disorders. Bleeding disorders are treated by replacing the missing clotting factor.

### **HIV**

Human immunodeficiency virus (HIV) is a virus that causes acquired immunodeficiency syndrome (AIDS), a condition in which progressive failure of the immune system allows life-threatening opportunistic infections and cancers to thrive. About 91,500 people were living with HIV in the UK at the end of 2010, of whom a quarter were unaware of their infection.

### **Infectious Diseases**

Infectious diseases are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; the diseases can be spread, directly or indirectly, from one person to another. Zoonotic diseases are infectious diseases of animals that can cause disease when transmitted to humans. Infectious diseases can cause a range of symptoms, which in some cases can be life threatening.

### **Haemoglobinopathies**

There are around 1,000 patients with thalassaemia and 15,000 with Sickle Cell Disease (SCD) living in England at present, a large number of whom are under 19 years of age. The disorders occur predominantly but not exclusively in ethnic minority communities. SCD is the most common inherited condition in England; about 350 babies are born in England each year with SCD compared with 20-30 babies with thalassaemia. 60% of patients with SCD live in Greater London with the majority of the others within other inner city areas.

## Teenage and Young Adult (TYA) Cancer Services

This CRG covers the age range of 19 – 24 years for teenagers and young adults with cancer. Cancer is more common in adolescents (aged 15 – 19 years) than in children, with a reported incidence of 150-200 per million. In young adults aged 20 – 24 years, the incidence is higher again at 226 per million. It is estimated that every day in the UK six young people aged between 13 - 24 years old will have to face a cancer diagnosis. Young people can get some of the most rare and aggressive forms of cancer. Their rapidly growing bodies work against them, enabling cancer to grow at a faster rate. The emotional upheaval of adolescence can make a cancer diagnosis even harder to cope with.

Based upon the best available evidence, the National Institute for Clinical Excellence (NICE) published Improving Outcomes Guidance (2005) which made recommendations for the optimum organisation and improvement of cancer services for children and young people. Key recommendations for TYA cancer are:

- age appropriate facility provision for patients aged 13-24 years inclusive;
- all patients aged 16-18 years inclusive should be referred to a Principal Treatment Centre for treatment;
- all patients aged 19-24 years inclusive should be offered choice of referral to a Principal Treatment Centre (Young People) for treatment;
- all patients aged 16-24 years inclusive should be discussed at both a site-specific multi-disciplinary team (MDT) meeting and TYA MDT meeting.

The TYA MDT offers holistic expertise in not only treating the cancer, but also in ensuring the young person's psychosocial and emotional needs are addressed.

## Specialised Immunology and Allergy Services

Allergy specialists deal with allergic reactions, particularly anaphylactic reactions to drugs, venoms and foods, as well as angioedema (swelling under the skin), hypereosinophilic disorders (conditions in which there is a marked increase in a type of white blood cell called an eosinophil), mastocytosis (where the presence of a type of white blood cell called a mast cell is increased) and urticaria (swelling in the upper layer of the skin).

Allergic disease is very common affecting up to 30% of adults and 40% of children at some point in their lives. This service provides care for the complex and/or rare subgroup of those allergic conditions. There are an estimated 20,000 new referrals of patients in England annually with adult allergic disease of sufficient complexity to require specialist opinion or management.

## Thoracic Surgery

Adult thoracic surgery involves the surgical assessment and operative treatment of all thoracic diseases. Although dominated by the management of lung cancer, about 50% of patients managed by thoracic surgeons are affected by other conditions. Data on thoracic surgical activity in the UK and Ireland collected on behalf of the Society for Cardiothoracic Surgery (SCTS) showed that for the year 2009/10 a total of 27,584 patients required thoracic surgery of which 17,406 were major operations.

## Upper GI Surgery

This CRG covers surgery of the Upper-Gastro Intestinal Tract – the oesophagus (gullet) and stomach. Cancers here are rarely diagnosed early as symptoms of early tumours are very vague and not specific for cancer. It is not uncommon for symptoms to have been present for some time before medical attention is sought or further investigations or referral are initiated.

In 2009 more than 6,700 cases of oesophageal cancer and nearly 6,200 new cases of stomach cancer were diagnosed in England, and around twice the number of men are affected as women.

Surgery offers the chance of long-term survival for some patients with early stage cancer however around 75% of patients have inoperable cancer at the time of diagnosis and will require palliative and non-surgical treatment such as chemotherapy, radiotherapy or endoscopic intervention to relieve symptoms.

Teams looking after these patients should generally be seeing at least 185 patients each year and therefore covering a population of around 1 million.

## Sarcoma

Sarcoma tumours (bone and soft tissue) are relatively rare and can occur almost anywhere in the body. Although there are a number of important areas of care that are common to all these tumours, the management of patients with bone and soft tissue tumours involve different care pathways.

Delays in diagnosis for soft tissue sarcoma are common. The diagnosis is often not suspected before biopsy or excision. Many soft tissue sarcomas are discovered incidentally following excision of a lump, with no prior suspicion that it could be a sarcoma. The treatment of soft tissue sarcoma is largely surgical excision of the tumour with an adequate margin of normal tissue around it. Radiotherapy and chemotherapy are also used to treat soft tissue sarcoma.

The team looking after patients with sarcomas should include sarcoma experts in chemotherapy, radiotherapy, surgery cancer imaging, histopathology, laboratory investigation and specialist palliative care.

The specialist team should be seeing at least 100 new patients with a soft tissue sarcoma every year. Teams which additionally care for patients with bone tumours should see 50 of these cases each year.

## CNS Tumours

Central Nervous System (CNS) tumours include all tumours inside the cranium (the part of the skull which contains the brain) or in the central spinal canal (spinal cord). Primary tumours of the CNS are relatively rare however secondary tumours (metastatic) from other cancer sites can also occur.

## Specialised Urology

Urological cancers include a range of tumours with different presentations including: prostate, bladder, kidney, penis and testicles.

Prostate cancer is a form of cancer that develops in the prostate (a gland in the male reproductive system) which can spread to other parts of the body. In 2009, there

were nearly 35,000 newly diagnosed cases of prostate cancer in England. One year relative survival estimates in England are very high at 95%.

**Bladder cancer** is any of several types of tumour of the urinary bladder. The most common type of bladder cancer begins in cells lining the inside of the bladder and is called transitional cell carcinoma. Incidence of bladder cancer is higher in males than in females, with over 6,400 cases in 2009 in males compared to under 2,400 in females. One year relative survival estimates for bladder cancer also differ between males and females at 78% and 64% respectively.

**Kidney cancer** is a form of cancer that develops in the kidneys. Kidney cancer is often asymptomatic until an advanced stage. In 2009, there were over 4,000 cases of kidney cancer in males and over 2,500 in females. Cancer of the renal pelvis is less common with around 500 cases per year. Relative survival estimates for kidney (excluding renal pelvis) are similar for both sexes at 70 per cent for males and 68 per cent for females.

Cancer of the penis is rare in England and is most often diagnosed in men aged 50 and over, although it does occur in younger men too. There are around 400 cases of penile cancer diagnosed in England each year.

There were almost 1,850 cases of testicular cancer in England in 2009.

The specialist urological cancer team should cover a population of more than one million and carry out a combined total of at least 50 radical prostatectomies (surgical removal of the prostate) and/or total cystectomies (surgical removal of the bladder) per year.

### Chemotherapy

Chemotherapy is the use of certain drugs to treat solid tumours cancers and haematological (blood) cancers through the systemic delivery of agents that have anti-tumor effects. Chemotherapy may be given through a number of routes including intravenous (in a vein), subcutaneous (under the skin), intrathecal (around the spinal cord), oral (swallowed) and topical (applied directly to a body surface).

Chemotherapy may be used in any type of cancer, often in combination with other treatments such as surgery or radiotherapy.

### Complex Head & Neck

**Head and neck cancer** refers to a group of very different cancers including: oral (mouth, lip and oral cavity), larynx (voice box), pharynx (throat) and thyroid cancer amongst others. In 2009, there were approximately 9,400 newly diagnosed head and neck cancers in England.

#### **Mouth, lip and oral cavity (oral cancer)**

Oral cancer has the highest incidence of the head and neck cancers. The most common symptom of oral cavity cancer is a persistent sore or lump on the lip or in the mouth, but there may also be pain and/or a lump in the neck. Other symptoms are a white or red patch on the gums, tongue or lining of the mouth, and unusual bleeding, pain or numbness in the mouth.

## **Cancer of the larynx**

Symptoms may include chronic hoarseness, pain or problems with swallowing (dysphagia), or can also be a lump in the neck, sore throat, earache, or a persistent cough.

## **Cancer of the pharynx**

Cancer of the pharynx occurs in three principal locations: the oropharynx, (includes the under surface of the soft palate), the base of the tongue and the tonsils, the hypopharynx (bottom part of the throat), nasopharynx (behind the nose).

**Thyroid cancer** is a thyroid neoplasm that is malignant. It is most likely to develop in women of reproductive age. It is treated initially by surgery (usually total thyroidectomy) followed by radioactive iodine ablation. In a small number of cases external beam radiotherapy may be used. It usually presents as a solitary nodule in a patient with normal thyroid hormone levels, other less common symptoms include swollen glands in the neck (cervical lymphadenopathy), hoarseness, difficulty in breathing or swallowing, changes in voice, and discomfort in the neck.

## **Other cancers of the head and neck**

There are a wide range of other cancer sites and rarer pathologies of the head and neck. There are around 600 cases of cancer of the salivary glands each year, which mainly occur in the parotid gland. Not all salivary gland tumours are diagnosed by head and neck multidisciplinary teams and some patients undergo surgical excision by general surgeons. However all diagnosed salivary cancers should be discussed and managed in a head and neck multidisciplinary team. Neck lump pathways referring patients to head and neck multidisciplinary team members are improving the situation following implementation of improving outcomes guidance in 2004. Cancers of the nasal cavity, middle ear and accessory sinuses make up the majority of the other head and neck cancers, along with bony tumours of the jaw, peripheral nerves, connective and soft tissues. For sarcomas of the head or neck - please refer to the specialist sarcoma service specification.

Skull base cancers form a subset of rarer head and neck cancers, and should be managed by a dedicated skull base team. Skull base cancers either arise from the accessory sinuses (anterior skull base) or originate in soft tissue adjacent to the temporal bone (bone which contains the ear) –lateral skull base and originate in soft tissue.

Advanced skin cancers adjacent to the ear and nose are frequently managed by members of the head and neck multidisciplinary team.

## ***Mental Health Programme of Care***

### **Specialised Services for Eating Disorders**

Eating disorders refer to a group of conditions defined by abnormal eating habits that may involve insufficient food intake, excessive exercise or purging behaviour that result in very low weight to the detriment of an individual's physical and mental health.

Patients with eating disorders may require care in a Specialist Adult Eating Disorder Centre if they experience rapid and/or sustained weight loss with evidence of system or



organ failure, which is potentially life threatening; have had outpatient psychological treatment that has not been sufficient to effect a change or improvement, and/or are very low weight (usually chronically unwell), are not able to manage in daily life and require help with weight stabilisation or modest weight restoration.

About 900 individuals each year need access to this service.

### **High and Medium Secure Mental Health**

Secure mental health services are specialist services for people who are a risk to others (where risk cannot be managed in a less restrictive environment); or are subject to custody and who cannot be transferred to open conditions due to the nature of their offence or Ministry of Justice directions.

Services are provided in 'secure' units, which means that people who are referred there are not free to come and go. People are detained in secure units under mental health legislation.

The time spent in secure units depends on an individual's recovery and progress towards rehabilitation.

### **Low Secure Mental Health**

Low secure services are for people aged 18 years and over detained under the Mental Health Act who cannot be treated in other mental health settings because of the level of risk they present to others or because they are subject to custody. Patients will not require the level of physical security provided by high or medium secure services.

### **Specialised Mental Health Services for the Deaf**

Specialist mental health services for deaf adults are services for those patients who cannot be effectively managed and treated in an acute mental health service ward. Specialist mental health and deaf services have environments specifically adapted to the needs of the patient group and are staffed by mental health professionals who are expert in assessing and addressing the needs of people who are deaf and experience mental ill health.

About seven per 10,000 people in the general population have severe or profound Deafness where onset was before language was established. About 50% of these individuals experience mental health difficulties at some time in their lives, ranging between mild depression and psychosis.

The National Deaf Child and Adolescent Mental Health Service is commissioned to provide specialist mental health services to deaf young people and hearing children of deaf adults, in both the community and in-patient settings.

The total number of all deaf children in England is reported to be 20,160 (age 0-18 years), of whom 42% are severely or profoundly deaf. It is estimated that just over 50% of these children will have mental health problems, with approximately 3.4% requiring highly specialised services at any one time – circa 290 children. It is expected that the service will receive approximately 364 referrals per year, allowing for regional variations.

## **Gender Identity Services**

Gender dysphoria is a condition in which there is a psychological experience of oneself as a man or woman, which is incongruent with the individual's external sexual characteristics of the body. The individual's physical sex is not aligned to their gender identity.

Sometimes, the distress/discomfort is sufficiently intense that people undergo *transition* from one point on a notional gender continuum to another – most commonly from Male-to-Female (MtF) or Female-to-Male (FtM). This typically involves changes to social role and presentation, and may necessitate treatment with cross-sex hormones and/or having gender related surgery.

The national Gender Identity Development Service is a tier 4 specialist mental health service, and is commissioned to provide specialist mental health assessment and intervention to children and adolescents (and their families) up to the age of 18 years who present with Gender Identity Disorder. It is expected that the service will receive approximately 155-165 referrals per year and hold a caseload of approximately 300

## **Perinatal Mental Health**

Specialist perinatal mental health services provide a safe and secure environment for the care of seriously mentally ill women and their infants. These psychiatric units are separate from other acute mental health admission facilities. They provide care for women with serious mental illness including postpartum psychosis, schizophrenia, bipolar illness and other serious affective disorders and those with complex needs. They provide expert psychiatric care for the mother whilst at the same time ensuring the care of the infant and avoiding unnecessary separation of mother and baby.

Based on the known epidemiology of postpartum psychosis (2 per 1,000 live births) and the rate of admission for other serious and complex disorders (a further 2 per 1,000 live births), about 2,750 women need access to Specialist Mother and Baby Units each year.

## **Tier 4 Child & Adolescent Mental Health Services**

Tier 4 Child and Adolescent mental health services (CAMHS) are highly specialist services with a primary purpose of the assessment and treatment of severe and complex mental health disorders in children. These services are part of a highly specialist pathway and provide for a level of complexity that cannot be provided for by comprehensive secondary, Tier 3 community services. It is generally the complexity and severity rather than the nature of the disorder that determines the need for specialist care. About 2,500 children access the service each year.

This CRG will also work closely with the Adult Deaf MH CRG in relation to CAMHS Deaf Services and also the CAMHS Secure CRG.

## **Tier 4 Severe Personality Disorder Services (adults)**

Personality disorders are "... deeply ingrained and enduring behaviour patterns, manifesting as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels and, particularly, relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance."



About 450 individuals each year need access to this service.

### **Mental Health Specialised**

This CRG covers:

Severe obsessive compulsive disorder and body dysmorphic disorder service (adults and adolescents).

The national Obsessive-Compulsive Disorder & Body Dysmorphic Disorder service (OCD/BDD) is commissioned to provide highly specialised assessment and treatment for patients experiencing severe obsessive-compulsive disorder or body dysmorphic disorder.

The aim of the service is to improve the mental health state of both adolescents and adults suffering with the most profound OCD/BDD, who have failed all previous treatments (including home-based treatments). It has been estimated that approximately 1% of the European population suffers from clinically relevant OCD (Wittchen and Jacobi, 2005). However of this total it is calculated that approximately 11,520 potential patients would require treatment at Level 6. However it is known that currently only a small percentage of sufferers present for treatment, therefore the demand for these services has historically been much lower.

### **Veterans' Post Traumatic Stress Disorder (PTSD) Programme**

This programme is commissioned to provide a six-week intensive rehabilitation programme in a residential setting. The national service aims to treat those veterans who have served in the British Armed Forces suffering from complicated presentations of severe traumatic stress disorder as a result from multiple exposure to traumatic events whilst in combat or as a result of their military service and who have a co-morbidity in physical illness or injury, addictive disorder or problems in childhood that have an adverse effect on coping skill development.

It is expected the national PTSD service will treat 224 new veterans per annum.

### **CAHMS Secure**

These services are highly specialised and previously known as the National Secure Forensic Mental Health for Young People service (SFMHYPs). These services provide medium secure adolescent inpatient services for young people up to the age of 18yrs (and in some cases up to 19yrs depending on clinical and/or educational needs).

This service provides treatment for young people with severe mental disorders and high forensic risk, including services for young people with learning disabilities.

The aim of the service is to improve the mental health of young people by delivering tailored treatment packages in a safe and secure environment.

## *Trauma Programme of Care*

### **Complex Disability Equipment**

#### **Prosthetics (limb and artificial eyes)**

Prosthetics is a specialist service for all major upper and lower limb amputees and people with congenital limb deficiencies, who have a potential to use prostheses to help them mobilise or improve upper limb function.

The number of amputee and limb deficient people in England is about 45,000. Each year about 4,000 major lower limb amputations, 200 upper limb amputations and 150 congenital upper and lower limb amputations are referred to about 30 specialist centres. The service provides lifelong care to people with a congenital limb deficiency or who have had major limb amputations. Pre-amputation, re-amputation and antenatal consultations are also provided as required.

#### **Specialist wheelchairs (including complex postural seating and powered wheelchair controls)**

There are estimated to be about 500,000 wheelchair users in England but with only about 5% (about 25,000) requiring specialist services. These are patients who have the most profound disabilities and/or an unstable medical condition, who can only function adequately in a wheelchair with unique personalised modifications, often incorporating bespoke manufactured items. All aspects of provision (assessment, objective setting, specification, prescription, design, manufacture, commissioning, on-going support and maintenance) require greater knowledge and expertise than is available in most local wheelchair services. The specialist service addresses postural needs (facilitating comfort and function) as well as mobility.

People (adults and children) requiring specialist wheelchair services have a complex and /or fluctuating medical condition and multiple disabilities, which may include physical, cognitive, sensory and learning aspects. The most common diagnoses that need specialist wheelchair services are: cerebral palsy, muscular dystrophy, multiple sclerosis, brain Injury, motor neurone disease, high level spinal cord Injuries (with/without ventilation support).

#### **Specialist augmentative and alternative communication aids**

The Office of the Communication Champion estimates that approximately 6,000 children and adults require assessment and provision by specialist communication services each year.

Communication is fundamental to independence, achievement and quality of life. A communication system enables people who have lost, or never had speech or language to interact with their world, often allowing them to engage and be successful in education, vocation and work.

### **Brain Injury & Complex Rehabilitation**

Specialist rehabilitation services for patients with highly complex needs includes specialist rehabilitation for patients whose rehabilitation needs fall into Category A following brain injury or with other disabling conditions. These may be provided in designated Level 1 or

2a facilities, these are rehabilitation units that have the expertise and facilities to meet the demands of a highly complex caseload. This applies to provision in adults and children.

Rehabilitation is a process of assessment, treatment and management by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition.

### **Adult Neurosurgery**

Clinical neurosciences include both medical and surgical neurology as well as diagnostic support and neurological rehabilitation services. The services are interdependent and the care pathway for many patients with neurological problems may span several neurosciences sub-specialties.

### **Neurosciences**

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### **Burn Care**

Burn injuries range from the most minor, dealt with in the community, to the most severe and devastating, and affect all ages and social groups. In general terms, the definition of severity is based on the size and anatomical site of the injury, the depth of skin injury, the age of the patient and the presence of co-existing conditions.

Specialist burn care service activity is low volume and high cost, is driven by emergency admissions (although there is a very small number of elective cases) and requires multi-professional input and care delivered over a long period of time, involving acute, rehabilitation and community services. Demand for burn care varies significantly across the country, especially for the more severe injuries.

Specialist burn care services include all burn care delivered by Burn Centres, Burn Units and Burn Facilities delivered as part of a provider network. This covers the whole pathway including:

- specialist assessment
- admission to a Centre, Unit or Facility and
- rehabilitation and surgical reconstruction

### **Cleft Lip & Palate**

A cleft is a gap or split in either the upper lip or the roof of the mouth (palate) or sometimes both. It occurs when separate areas of the face do not join together properly when a baby is developing during pregnancy.

About 75% of clefts of the lip can be detected during pregnancy at the routine 20-week scan with the majority of the remainder detected at birth. Clefts of the palate are rarely detected on ultrasound scans. Between 1 in 600 and 1 in 700 babies is born with a cleft lip and/or palate.

The treatment of cleft lip and/or palate requires the multi-disciplinary involvement of many specialties throughout growth and development to the age of at least 20 years, as well as treatment of adults of any age.

### **Specialised Pain**

Chronic pain is recognised as a long term condition in its own right or as a component of other long term conditions. About eight million people in the UK suffer with chronic pain. The routine assessment and management of pain is a required competency of all healthcare professionals as well as being an important component of health care planning. Most patients with chronic pain can be well managed in the community or local hospitals by appropriately trained members of interdisciplinary Pain Management Services; however, some patients with more complex chronic pain problems require management in Highly Specialist Pain Management centres.

### **Specialised Ear Surgery**

Bone anchored hearing devices (BAHDs) are hearing aids which require surgical implantation to address either a specific type of hearing loss or to address hearing loss that cannot be corrected with conventional hearing aids. Around 60 hospitals implant approximately 900 devices each year.

Middle ear implants are surgically implanted hearing aids, which are placed within the middle ear, and are suggested as a therapy for certain patients with moderate to severe conductive hearing loss, sensorineural hearing loss or with a mixture of the two types of hearing loss who are unable to benefit from conventional prosthetic devices (e.g. conventional hearing aids, bone anchored hearing aids etc.).

### **Specialised Orthopaedic Services**

The majority of orthopaedic services are delivered in secondary care providers. Adult specialist orthopaedic services are defined by any one or more of the following criteria: the rarity of the condition; the complexity of the condition and the multi-disciplinary team required to treat it, and/or the expertise required to treat the condition.

### **Hyperbaric Oxygen Therapy**

Hyperbaric oxygen treatment (HBOT) involves delivery of oxygen inside a treatment chamber at a partial pressure greater than 100 kPa. HBOT is widely accepted as standard clinical care for the emergency treatment of decompression illness and air and gas embolism.

### **Specialised Ophthalmology Services**

Specialist ophthalmology services for children and young people encompass the investigation and management of visual, ocular and ocular adnexal disorders.

A large proportion of the paediatric ophthalmic workload comprises the investigation and treatment of amblyopia ('lazy eye') and strabismus (squint) and much of the day to day management of these conditions is delegated to orthoptists in local hospitals. The remainder of the workload consists of a wide variety of ocular, ocular adnexal and visual conditions, many specific to children and most not specialist. There are 20,000 bilaterally visually impaired children in England. The most common cause of visual impairment in children is visual pathway damage.

## **Spinal Cord Injury**

A spinal cord injury (SCI) is an injury to the spinal cord resulting from trauma, disease or infection. Complete injuries result in tetraplegia or paraplegia below the level of the injury and incomplete injuries result in neurological impairment affecting mobility, bladder and bowels. Patients with high-level injuries may require long term ventilation.

The incidence of SCI in the UK is estimated at between 12 and 16 per million with the majority of cases caused by trauma.

## **Complex Spinal Surgery**

Complex spinal surgery services include a number of specified procedures when performed in Specialist Spinal Surgery Centres or as outreach when delivered as part of a provider network. This service encompasses aspects of care provided by spinal surgeons from both orthopaedic and neurosurgery disciplines.

## **Major Trauma**

Major trauma means multiple, serious injuries that could result in death or serious disability. These might include serious head injuries, severe gunshot wounds or road traffic accidents. These sorts of severe and complex injuries are quite rare: major trauma represents only 0.1% of total Accident & Emergency (A&E) activity, with the average Major Trauma Centre seeing on average one case per day. In 2010, the National Audit Office estimated that there are about 20,000 cases of major trauma each year in England.

As major trauma is so uncommon, it is not possible for all hospitals to have the equipment, onsite specialties and specialist doctors needed to treat it effectively. For this reason, patients with multiple, serious injuries should be taken directly to or transferred into a Major Trauma Centre. This is a hospital designed for the definitive care of seriously injured patients.

## **Adult Critical Care**

Adult Critical Care is provided in Intensive care units (ICUs). These are specialist hospital wards providing intensive care (treatment and monitoring) for people in a critically ill or unstable condition. ICUs are also sometimes known as critical care units or intensive therapy departments.

A person in an ICU needs constant medical attention and support to keep their body functioning. They may be unable to breathe on their own and have multiple organ failure. Medical equipment will take the place of these functions while the person recovers/

## ***Women and Children Programme of Care***

### **Medical Genetics**

This CRG covers medical genetics which can be divided into two main service areas both covering children and adults: clinical genetics and laboratory genetics (consisting of molecular and cytogenetic tests and, in some regional centres, specialist biochemistry tests or other specialist tests).

Diseases with a genetic component are estimated to affect at least 5-6% of the population.

Clinical genetics departments provide diagnostic and genetic counselling services and, in some multi-system disorders, co-ordination of management and follow up for individuals and families with, or at risk of, conditions which have, or may have, a genetic basis. Laboratory genetics services provide either or both molecular and cytogenetic testing and, in some centres, specialist biochemistry tests.

### **Paediatric Surgery**

This CRG covers specialist surgical care for patients under the age of 18, which is required when: the surgery is complex; the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

### **Paediatric Medicine**

This CRG covers the more specialised elements of children's care across a range of medical specialities, including diabetes, rheumatology, immunology, and endocrinology. These more specialised paediatric services will not be provided by all hospitals in England.

### **Paediatric Cancer Services**

This CRG covers children's cancer services. Each year, about 1,200 children aged 0 to 14 years are newly diagnosed with cancer. Paediatric cancer is rare with about one in 600 children being diagnosed with a cancer by the age of 15.

In addition, 500 teenagers aged 15 to 18 years and 1,300 young adults aged 19 to 24 are also diagnosed with cancer - this is covered by the separate Teenage and Young Adults Cancer CRG but the two CRGs work closely together on key transition issues and all of the cancer related CRGs work together to ensure joint objectives are discussed and delivered.

### **Congenital Heart Services**

Congenital heart disease is sometimes diagnosed in the womb, but often it is not identified until after birth or may even remain undetected until adulthood. Thanks to medical advancements over the last few decades most people born with congenital heart disease now survive into adulthood, so there is a growing population of both children and adults in this country living with the condition. Major heart operations are most commonly carried out during childhood, but individuals with inherited heart conditions need networked and co-ordinated which also covers the non surgical elements of their care, including contributing to the management of routine care for other childhood illnesses or conditions.

### **Metabolic Disorders**

This CRG covers specialist inherited metabolic disorders (IMDs) - a diverse range of over 600 conditions, some of which are extremely rare.

Although varying widely in their presentation and management according to which body systems are affected, IMDs are caused by a disruption in normal biochemical processes. Conditions are life-long and most are due to single enzyme deficiencies that lead to severe disturbance of metabolic processes in the body, resulting in either a deficiency of products essential for health or an accumulation of unwanted or toxic products. This can cause



disease or damage in many organ systems, leading to severe learning or physical disability and death at an early age. Some disorders do not manifest symptoms for many years, and mature patients are referred frequently for investigation in other specialties, for example, nephrology, or cardiology. This can lead to misdiagnosis, delayed diagnosis or multiple investigations.

### **Paediatric Intensive Care**

This CRG covers intensive care services and associated specialised transport for children. Specialist paediatric intensive care services provide a care pathway for the very sick child from recognition and stabilisation, through retrieval (if necessary), to delivery of care in an appropriate paediatric critical care facility be that in a paediatric intensive care unit (PICU) or in a Paediatric High Dependency Unit (PHDU). PIC is also an important part of some other Specialist Paediatric Services (for example, paediatric cardiac, general surgery and neurosurgery) and has a number of significant interdependencies (for example, paediatric anaesthesia, ENT, nephrology). In England, 1.4 children per 100,000 of the population are admitted to a PICU each year.

### **Neonatal Critical Care**

This CRG covers hospital based intensive care, and associated specialised transport, for newborns with complex needs. Much of the care of newborn babies, either healthy or with lesser problems, is carried out at the district hospital where they are born. Complex and intensive care, particularly of the very preterm, is carried out in tertiary centres, falling within the responsibility of this CRG.

### **Paediatric Neurosciences**

This CRG covers specialised services for children with neurological disease (e.g. specialised epilepsy surgery). These children require a sustained and integrated network of care involving a variety of organisations, professionals and equipment, often over a prolonged period of time. Services operate within managed networks to provide care that revolves around the individual child's needs.

### **Complex Gynaecological Services**

This CRG covers the more specialised elements of gynaecological care, which would typically fall outside of the experience of local GP and hospital care. An example would be surgical treatment of urinary incontinence (approximately 15,000 operations each year) which is typically performed by gynaecologists and urologists in local hospitals who have a special interest in female urinary incontinence. In 10-20% of cases, the primary surgery fails and there is also a risk of recurrence of stress incontinence over time. These women require specialist expertise as the secondary surgery can be technically challenging and alternative techniques may be needed.

### **Specialised Maternity Services**

Most maternity care is provided in local hospitals, with the majority of potential complications of pregnancy or birth handled in local settings. This CRG focusses on the most specialised elements of maternity care, and in particular how individuals with conditions which might materially affect their choices and care during pregnancy and birth can best be supported.

### **Fetal Medicine**

Whilst common fetal conditions (for example, minor malformations, late fetal growth restriction) are managed in local hospitals, more complex and rare conditions (for example, major/multiple malformations, complications of monochorionic twins and severe fetal growth restriction and those secondary to maternal disorders, for example, alloimmunisation (where fetal blood cells are destroyed by maternal antibodies transferred across the placenta)) are managed in conjunction with one of around 16 specialist fetal centres in England. This CRG covers all fetal medicine services covered within these specialist centres.

### **Multi-System Disorders**

This is a new CRG for 2013/14 and has been established to provide a focus for a range of typically rare conditions in children that affect multiple organs or systems of the body, and might otherwise not be sufficiently captured within the responsibilities of the other CRGs already established within the Women and Children's Programme.



This Guide has been developed by the NHS Commissioning Board, in partnership with the Specialised Services Patient and Public Engagement Steering Group.

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First published March 2013

Published in electronic format only.