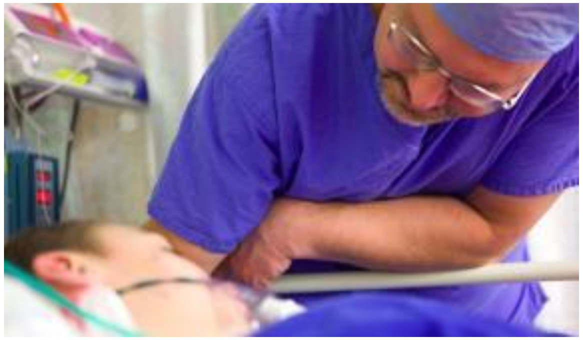
# The big conversation, March 2014

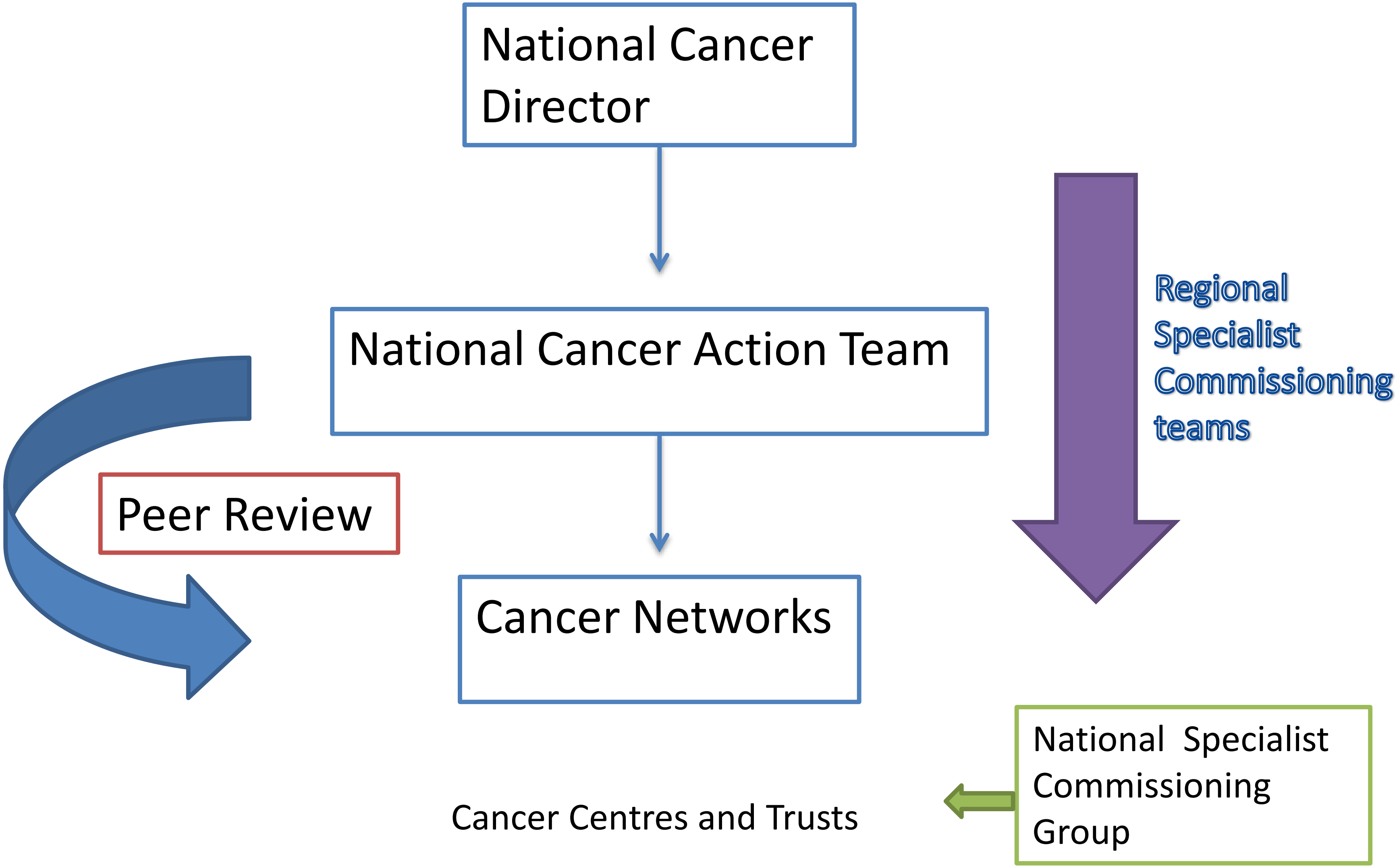
## NHS Sarcoma Services



Jeremy Whelan
CRG Chair
March 2014

THE NHS
CONSTITUTION
the NHS belongs to us all

# The Recent Past



National Cancer Director

National Cancer Action Team

Cancer Networks

Peer Review

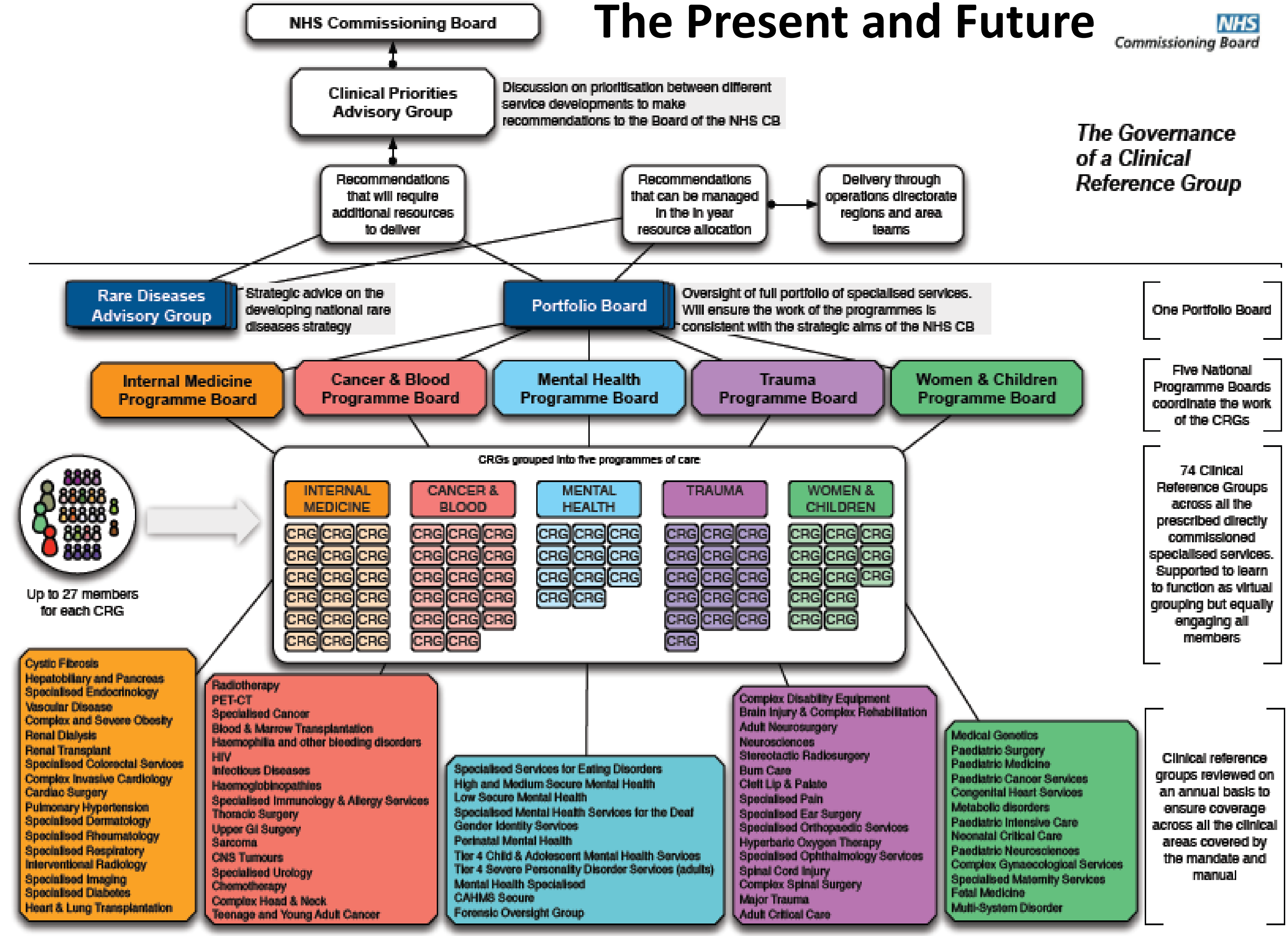
Regional Specialist Commissioning teams

Cancer Centres and Trusts

National Specialist Commissioning Group

# The Present and Future

NHS
Commissioning Board



*The Governance of a Clinical Reference Group*

**NHS Commissioning Board**

**Clinical Priorities Advisory Group**

Discussion on prioritisation between different service developments to make recommendations to the Board of the NHS CB

Recommendations that will require additional resources to deliver

Recommendations that can be managed in the in year resource allocation

Delivery through operations directorate regions and area teams

**Rare Diseases Advisory Group**

Strategic advice on the developing national rare diseases strategy

**Portfolio Board**

Oversight of full portfolio of specialised services. Will ensure the work of the programmes is consistent with the strategic aims of the NHS CB

**Internal Medicine Programme Board**

**Cancer & Blood Programme Board**

**Mental Health Programme Board**

**Trauma Programme Board**

**Women & Children Programme Board**

CRGs grouped into five programmes of care

| INTERNAL MEDICINE | CANCER & BLOOD | MENTAL HEALTH | TRAUMA | WOMEN & CHILDREN |
|---|---|---|---|---|
| CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG |
| CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG |
| CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG | CRG CRG CRG |
| CRG CRG CRG | CRG CRG CRG | CRG CRG | CRG CRG CRG | CRG CRG |
| CRG CRG CRG | CRG CRG CRG | | CRG CRG CRG | CRG CRG |
| CRG CRG CRG | CRG CRG | | CRG | |

Up to 27 members for each CRG

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

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

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

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

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

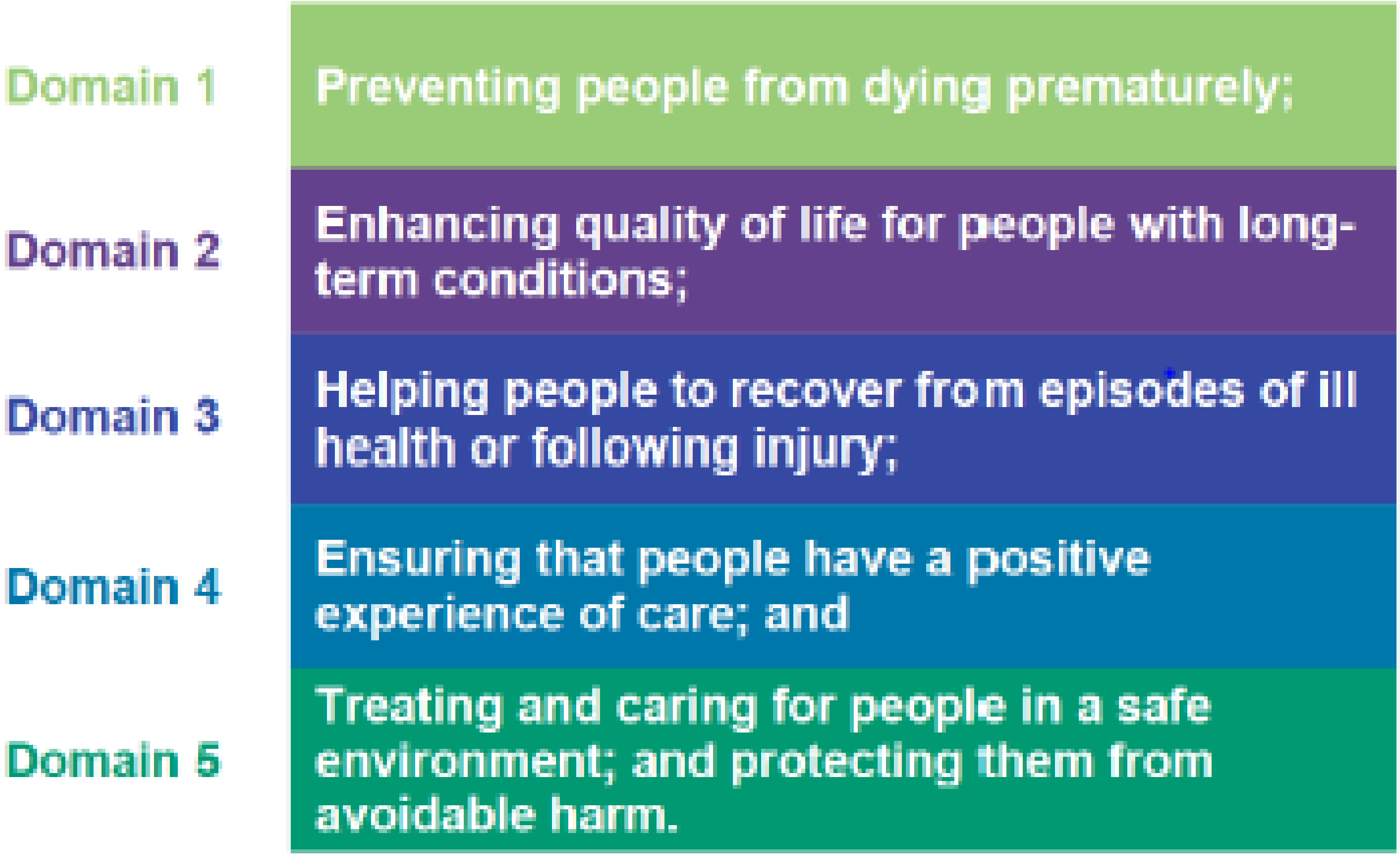
One Portfolio Board

Five National Programme Boards coordinate the work of the CRGs

74 Clinical Reference Groups across all the prescribed directly commissioned specialised services. Supported to learn to function as virtual grouping but equally engaging all members

Clinical reference groups reviewed on an annual basis to ensure coverage across all the clinical areas covered by the mandate and manual

# The Context for Commissioning
# NHS Outcomes Framework



| | |
|---|---|
| Domain 1 | Preventing people from dying prematurely; |
| Domain 2 | Enhancing quality of life for people with long-term conditions; |
| Domain 3 | Helping people to recover from episodes of ill health or following injury; |
| Domain 4 | Ensuring that people have a positive experience of care; and |
| Domain 5 | Treating and caring for people in a safe environment; and protecting them from avoidable harm. |

# The Context for Commissioning NHS Constitution

- Promoting equality and reducing inequalities
- Be excellent
- Live within our means

# What is Commissioning?

- **Process for planning, agreeing and monitoring services**
  - 211 Clinical Commissioning Groups
  - Public Health England
  - NHS England (27 Teams – operating as one)
    - Specialised services (10 Area from the 27)
    - Primary care
    - Offender health
    - Military health
    - Commissioning support units

# Clinical input into Commissioning

- 12 Clinical Senates

  Helping CCGs, Health and Wellbeing Boards and NHS England make the best decisions about healthcare in their populations
- Strategic clinical networks
  - Cancer
  - Cardiovascular
  - Maternity and children, mental health, dementia and neurological conditions
- Operational Delivery Networks
- Clinical Reference Groups

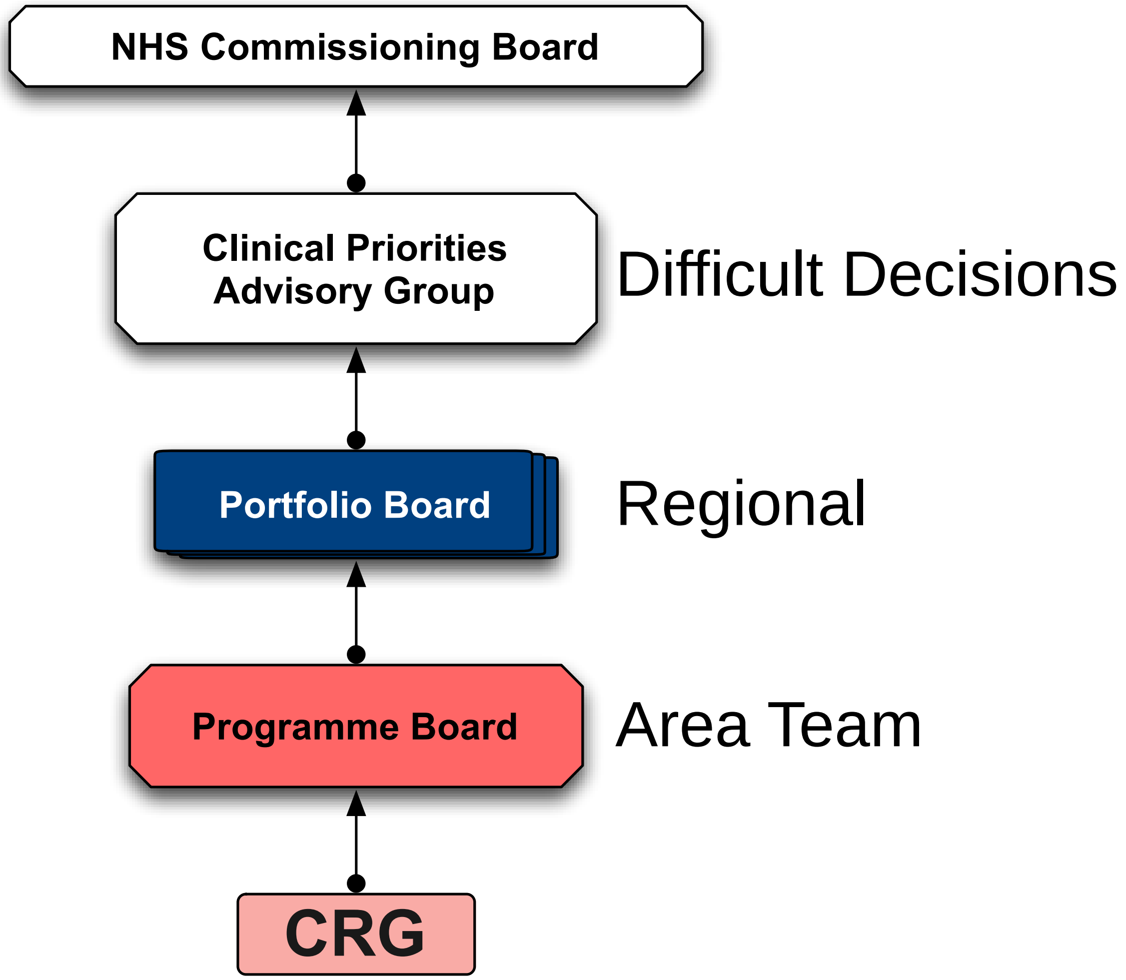
# What about specialised services?

- are patient-centred and outcome based. The patient must be placed at the centre of planning and delivery. Commissioners, working with providers, must deliver improved outcomes for them across each of the five domains of the 2013/14 NHS Outcomes Framework;
- are fair, consistent throughout the country, ensuring that patients have equal access to services regardless of their location, and;
- Improve productivity and efficiency.

# What about specialised services?

- NHS England
- Five Programmes of Care
- 75 Clinical Reference Groups covering 143 specialised services
- 10 Area Teams linked to 4 Regions

# Specialist Commissioning- A single operating model



NHS Commissioning Board

Clinical Priorities Advisory Group

Difficult Decisions

Portfolio Board

Regional

Programme Board

Area Team

CRG

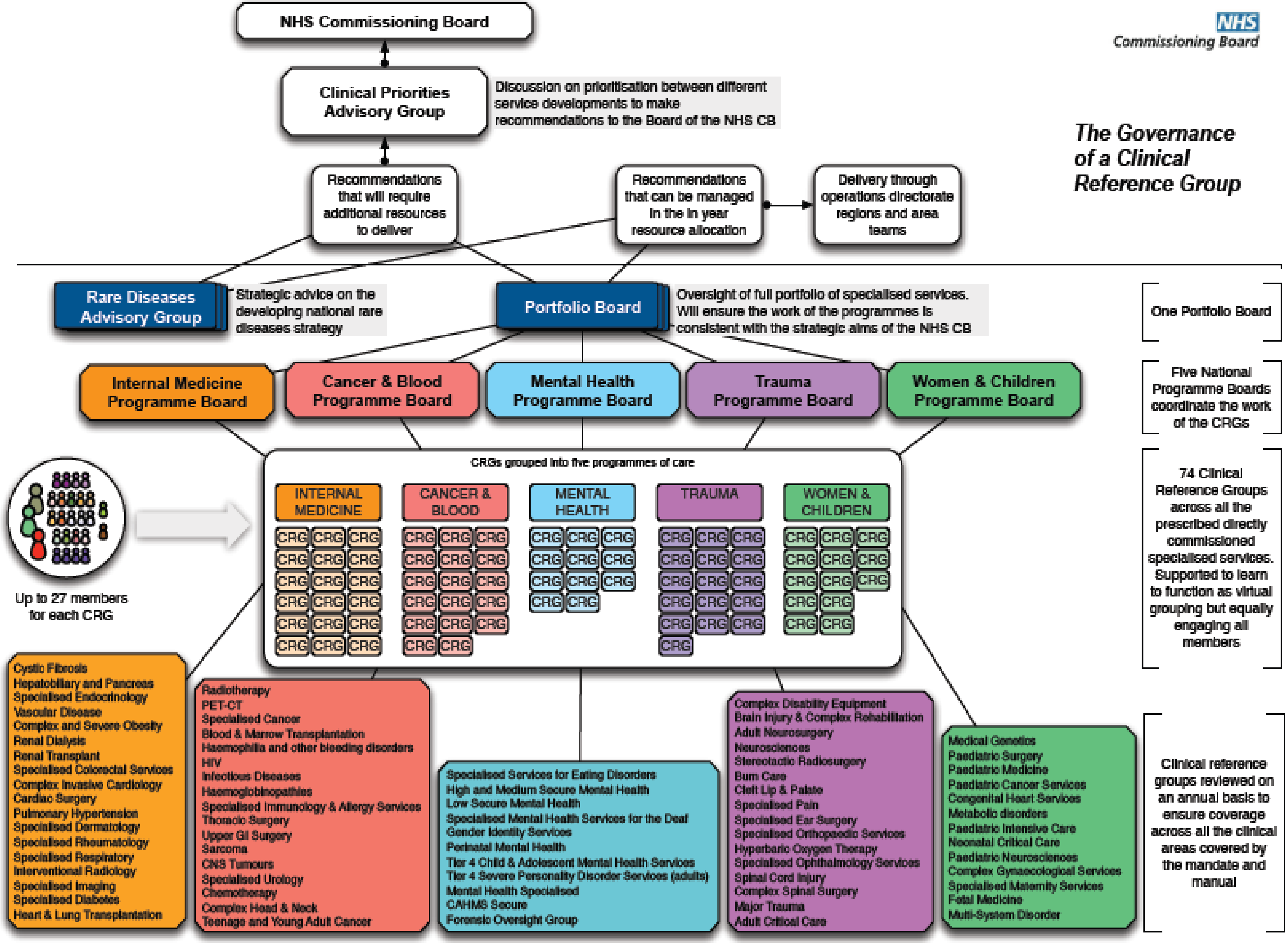
# Clinical Reference Groups

- Clinical membership of CRGs supported on a voluntary basis
- Patient and public involvement
- Stakeholders
- Responsible for producing ‘contract products’
  - Service specifications/Clinical access policy/Quality measures and dashboards
- Regional and Area Teams responsible for contracting with specialist service providers and implementing CRG products

# Principles of CRG functioning

- Single source of clinical advice
- Equitable access to service planning
- Devolved clinical leadership
- Small single national team crosses directorates
- Linkage across all parts of NHS

## *The Governance of a Clinical Reference Group*



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MENTAL HEALTH

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Clinical reference groups reviewed on an annual basis to ensure coverage across all the clinical areas covered by the mandate and manual

# Sarcoma Clinical Reference Group

## STAKEHOLDER MAP

### SUPPLIER

Supplier/commercial organisation within or outside the NHS that plays a part in the supply chain of the functions relating to the service area. This may include a company developing drugs or devices for the service area

### OTHER ORGANISATION

Other organisation – this might include regulators, professional bodies, media and political organisations

### HEALTH SECTOR PARTICIANT

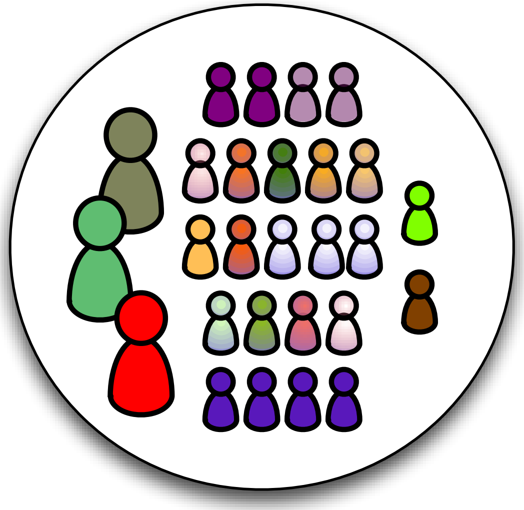
Health and social care service provider or commissioner interested in a particular CRG service area

### 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.

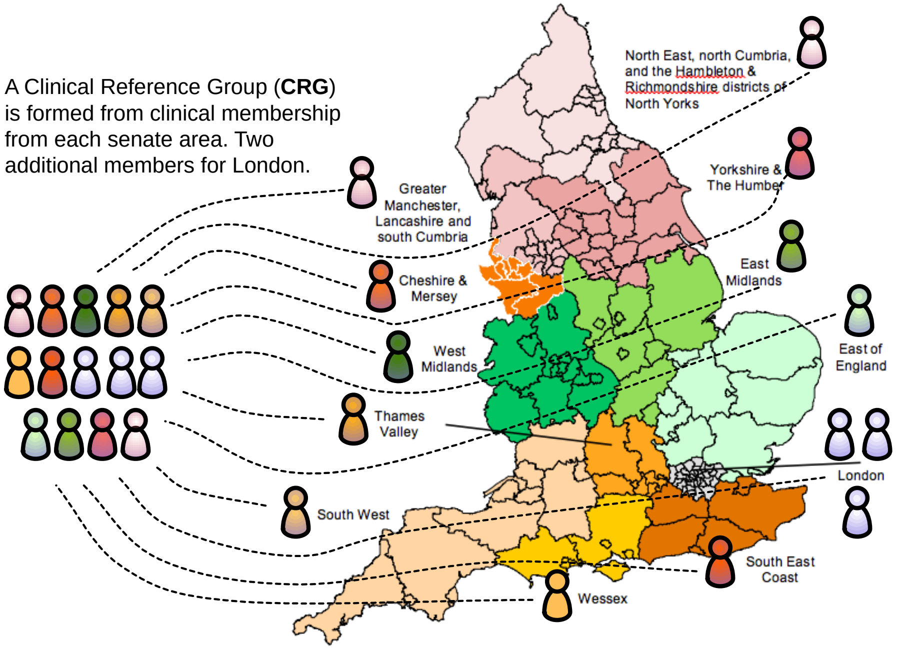
### PATIENT OR CARER ORGANISATION

Patient or carer organisation that directly or indirectly represents the interests of people who use the services covered by the CRG. They may provide direct support for the PPE Members on the CRG.



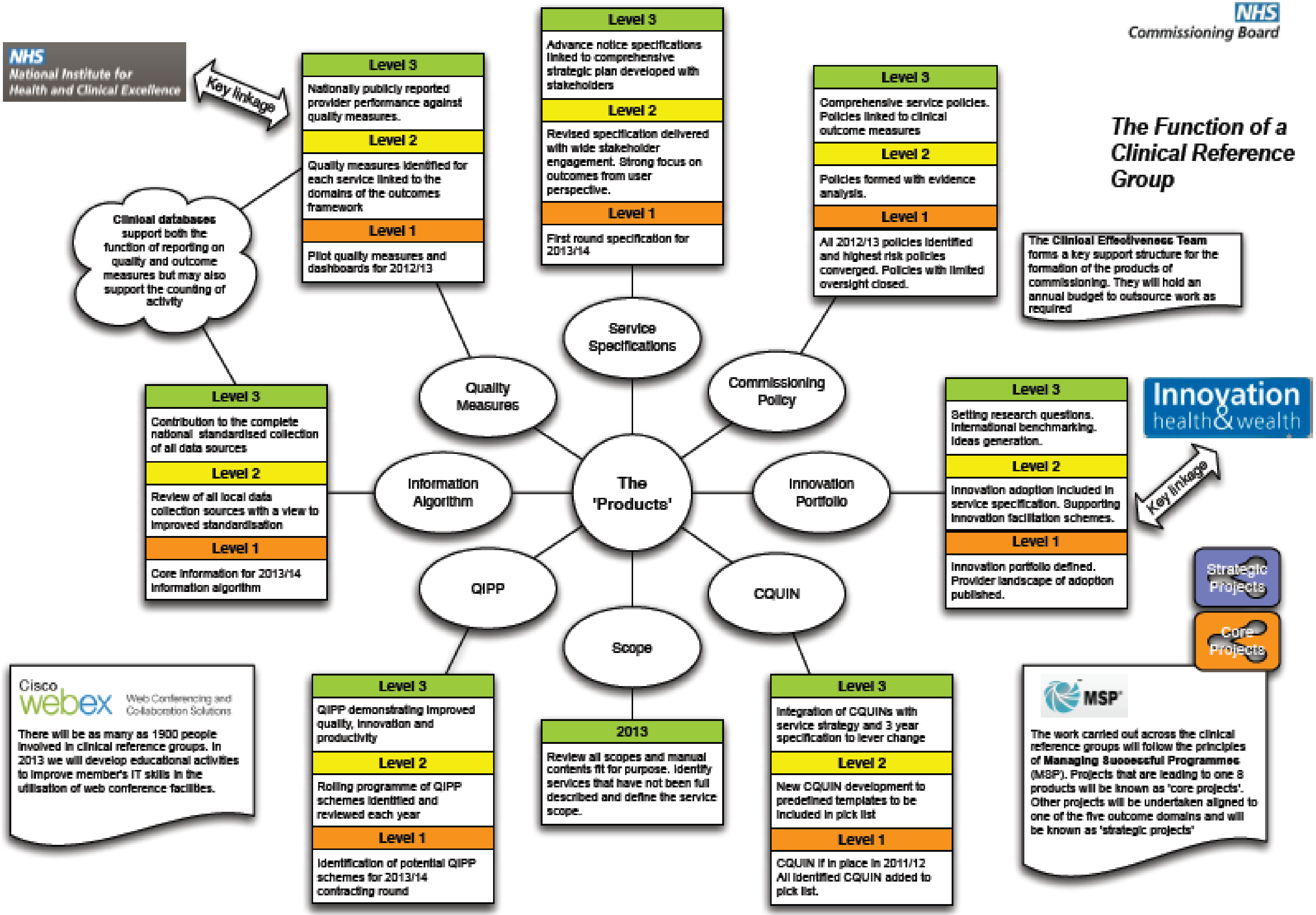
**Clinical Members** from each senate area...

A Clinical Reference Group (**CRG**) is formed from clinical membership from each senate area. Two additional members for London.



NHS
Commissioning Board

# The Function of a Clinical Reference Group



**NHS**
**National Institute for Health and Clinical Excellence**

Key linkage

**Clinical databases** support both the function of reporting on quality and outcome measures but may also support the counting of activity

The 'Products'

## Quality Measures

**Level 3**
Nationally publicly reported provider performance against quality measures.

**Level 2**
Quality measures identified for each service linked to the domains of the outcomes framework

**Level 1**
Pilot quality measures and dashboards for 2012/13

## Service Specifications

**Level 3**
Advance notice specifications linked to comprehensive strategic plan developed with stakeholders

**Level 2**
Revised specification delivered with wide stakeholder engagement. Strong focus on outcomes from user perspective.

**Level 1**
First round specification for 2013/14

## Commissioning Policy

**Level 3**
Comprehensive service policies. Policies linked to clinical outcome measures

**Level 2**
Policies formed with evidence analysis.

**Level 1**
All 2012/13 policies identified and highest risk policies converged. Policies with limited oversight closed.

**The Clinical Effectiveness Team** forms a key support structure for the formation of the products of commissioning. They will hold an annual budget to outsource work as required

## Information Algorithm

**Level 3**
Contribution to the complete national standardised collection of all data sources

**Level 2**
Review of all local data collection sources with a view to improved standardisation

**Level 1**
Core information for 2013/14 information algorithm

## Innovation Portfolio

**Level 3**
Setting research questions. International benchmarking. Ideas generation.

**Level 2**
Innovation adoption included in service specification. Supporting innovation facilitation schemes.

**Level 1**
Innovation portfolio defined. Provider landscape of adoption published.

Innovation health&wealth

Key linkage

Strategic Projects

Core Projects

## QIPP

**Level 3**
QIPP demonstrating improved quality, innovation and productivity

**Level 2**
Rolling programme of QIPP schemes identified and reviewed each year

**Level 1**
Identification of potential QIPP schemes for 2013/14 contracting round

## Scope

**2013**
Review all scopes and manual contents fit for purpose. Identify services that have not been full described and define the service scope.

## CQUIN

**Level 3**
Integration of CQUINs with service strategy and 3 year specification to lever change

**Level 2**
New CQUIN development to predefined templates to be included in pick list

**Level 1**
CQUIN if in place in 2011/12 All identified CQUIN added to pick list.

Cisco webex Web Conferencing and Collaboration Solutions

There will be as many as 1900 people involved in clinical reference groups. In 2013 we will develop educational activities to improve member's IT skills in the utilisation of web conference facilities.

MSP

The work carried out across the clinical reference groups will follow the principles of **Managing Successful Programmes** (MSP). Projects that are leading to one 8 products will be known as 'core projects'. Other projects will be undertaken aligned to one of the five outcome domains and will be known as 'strategic projects'

# What do we want to achieve?

1. Best possible care for all
2. All patients with newly diagnosed sarcoma will be referred to specialised sarcoma services
3. Improving sarcoma patient experience
4. Developing quality outcomes for sarcoma
5. Getting diagnosis right
6. Reducing unplanned operations
7. Clear pathways with other MDTs
8. Appropriate procedure prices
9. Radiotherapy standards
10. Chemotherapy standards

# What are the levers?

- Develop service specification
- Other products
    - 5 year strategy
    - NICE Quality Standard
- Work across other CRG’s
- Work with LATs
- Disseminate through SAG’s

# Developing Service Specifications

- Significant lag times and short deadlines
- Use plain English as far as possible
- Use cancer intelligence to support change/resolve ambiguity as far as possible.
- Where further work is required flag this to our work programme
- Integrate the primary malignant bone tumour specification with soft tissue sarcoma to produce one document
- All patients with newly diagnosed sarcoma will be referred to specialised sarcoma services.

Cancer and Blood

# Sarcoma

**7 day**

## Strengths

- Expertise in centres and established multidisciplinary working based on NICE IOG, supported by peer review
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- Clinical Reference Group working well
- Close alliance between patients and the public and professional community, including the British Sarcoma Group
- National clinical research programme

## Weaknesses

- Diagnostic and treatment pathways inconsistent and confusing, with IOG ambiguities used to block access to specialist care
- Balance between local and centralised delivery of care uncertain due to lack of clarity of benefits
- Poor patient experience reported in national cancer patient experience survey
- Late diagnosis common and low awareness of sarcoma amongst professionals and public
- Future planning of services and resources fragmented at present

## Opportunities

- NCIN defining variations in care especially for sup populations and supporting outcomes measurement
- CRG will allow definition and delivery of a national service with positive impact on outcomes
- Patients and public to partner strategic development and delivery of change
- New technologies, treatments and research (e.g. proton therapy, new drugs)
- Greater sub-specialisation and centralisation supported by clearly defined pathways for sub-groups

## Threats

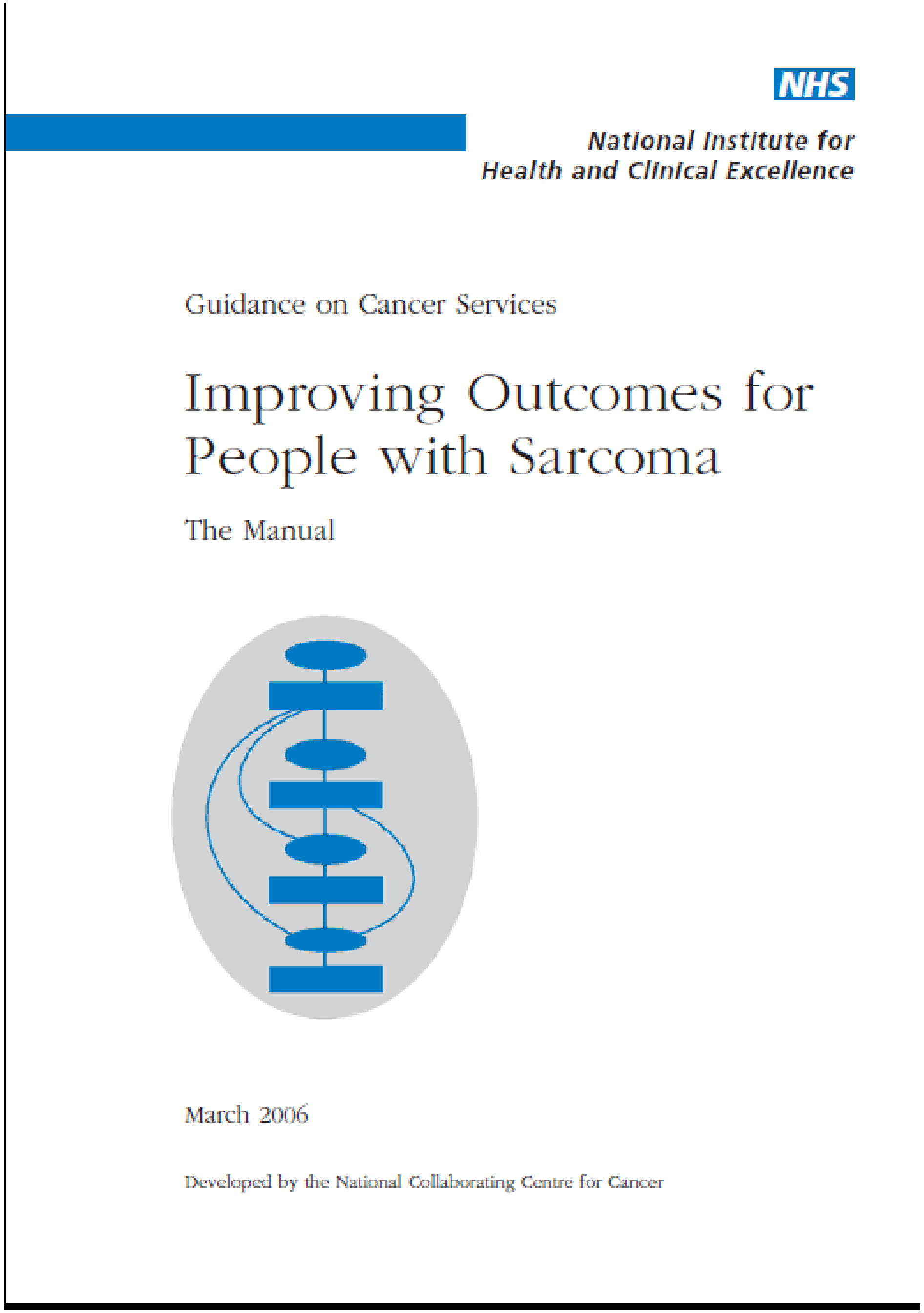
- CRG failing to have impact through non-delivery or lack of recognition
- Local professional and public resistance to change
- Imbalance between competition and collaboration between specialist centres and between local service delivery
- Increased incidence and prevalence of sarcoma
- Insufficient professional skilled manpower to sustain future highly specialised care delivery

# In summary

- Clinically led single commissioning system
- CRG specs at the heart of contracts with providers
- Potential to have a positive impact on patients
- Early days – we will get better at it
- Strategy developing
- Your input essential

# Big things

- Getting diagnosis right
- Defining specialist care – what is an MDT
- Local vs distant care
- Other site specific MDTs
- Very rare sarcomas/special groups
- Measuring improvement
- Finding the money
- The speed of change



NHS

National Institute for
Health and Clinical Excellence

Guidance on Cancer Services

# Improving Outcomes for People with Sarcoma

The Manual

March 2006

Developed by the National Collaborating Centre for Cancer

# Diagnosing sarcoma better

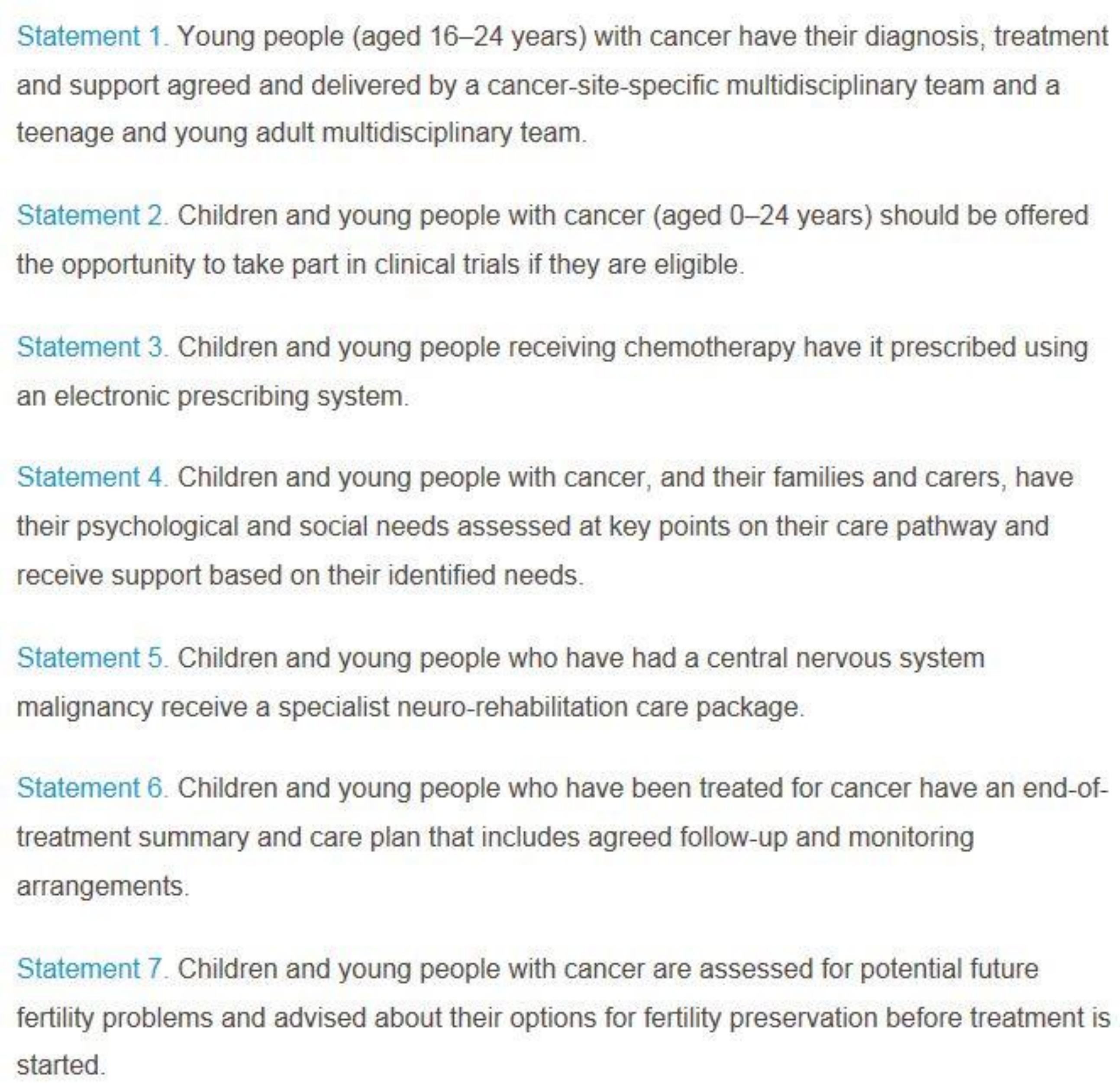
- Why is it a problem?
  - Rarity/diversity/NHS
- Consequences?
  - Distress/morbidity/survival
- What has been done?
  - 2WW/guidelines/diagnostic clinics
  - Education/awareness
- Is it working?
- What’s next?

# What is specialist care?

- Something agreed by cancer networks?
- An MDT?
- Something that has been peer-reviewed?
- 100 STS p.a +/- 50 BS
- A centre which can treat sarcomas arising at all sites?
- A team?
- Guidelines and pathways?

# Are sarcoma MDTs the right size?

| MDT | Number of new cases managed per year | Bone sarcoma |
|---|---|---|
| Combined 1 | 28 | B 13 |
| Combined 2 | 97 | B 64 |
| Combined 3 | 94 | NA |
| Combined 4 | 237 | NA |
| Combined 5 | 185 | B 133 |
| STS 1 | 29 | |
| STS 2 | 109 | |
| STS 3 | 46 | |
| STS 4 | 36 | |
| STS 5 | 38 | |
| STS 6 | 21 | |
| STS 7 | 75 | |
| STS 8 | 166 | |
| | 1161 | |



Statement 1. Young people (aged 16–24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

Statement 2. Children and young people with cancer (aged 0–24 years) should be offered the opportunity to take part in clinical trials if they are eligible.

Statement 3. Children and young people receiving chemotherapy have it prescribed using an electronic prescribing system.

Statement 4. Children and young people with cancer, and their families and carers, have their psychological and social needs assessed at key points on their care pathway and receive support based on their identified needs.

Statement 5. Children and young people who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

Statement 6. Children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Statement 7. Children and young people with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.