Developing excellence in cancer networks
A report from the Cancer Campaigning Group

February 2012
Background

The Cancer Campaigning Group (CCG) was delighted that the Government committed in May 2011 to embed and strengthen clinical networks, ensuring that cancer networks are funded until 2013 and supported by the NHS Commissioning Board in the longer term. We are optimistic that, as a result of this guarantee, clinical commissioning groups, local authorities, health and wellbeing boards and other bodies involved in the commissioning of cancer services, will receive the support they need in the short term to commission cancer services effectively.

In Autumn 2011 Dr Kathy McLean was appointed as Clinical Transitions Director with the task of developing proposals for the role of clinical networks in the modernised NHS. In February 2012 preliminary high level proposals were published, which included commitments to establish a number of strategic clinical networks that will be prescribed by the NHS Commissioning Board. This report intends to inform and feed into the development of these early proposals, setting out how existing cancer networks can evolve in the longer-term to form strategic clinical networks that support the continued improvement of both the outcomes and experience of people with cancer.

Although the CCG believes that cancer networks have a vital role to play in ensuring the outcomes and experiences of cancer patients continue to improve, data, including those collected by the National Cancer Intelligence Network (NCIN) and the Office for National Statistics (ONS), suggest that cancer networks vary in their effectiveness. This report, therefore, is not calling for the status quo to be maintained. Rather, we are calling for all cancer networks to be strengthened to the level of the very best and retained as strategic clinical networks, meeting the core principles set out in Dr McLean’s review. We propose key markers of quality that we believe should be the basis of a cancer network’s role in supporting the effective commissioning of cancer services across every region of England. We are also confident that our recommendations, in particular our suggested quality markers, could be used as a template for what is expected of other non-cancer strategic clinical networks.

Our recommendations are based on qualitative interviews into the views of cancer network staff (undertaken by the research consultancy Frontline between October and November 2011 – for the methodology see Annex 1), analysis of published data and information on cancer commissioning, and insights from the views and experiences of our member charities.
Key recommendations

*Improving Outcomes: A Strategy for Cancer* (IOSC) set out the Government’s ambition for improving the experiences and outcomes of cancer patients in England. Most notably, the strategy sets out the principal aim of saving an additional 5,000 lives a year by 2014/15, while narrowing the inequalities gap.

The Cancer Campaigning Group believes that effective, high quality cancer networks have a crucial role to play in supporting commissioners to deliver on the objectives set out in IOSC. As such, the Group sets out key recommendations here regarding the role cancer networks should play as strategic clinical networks in the reformed health service:

**Defining the responsibilities and performance standards of a quality cancer network**

- The NHS Commissioning Board should develop a model contract based on the themes and quality markers set out in this report:
  - Acting as an ‘honest broker’
  - Analysing and collating data
  - Supporting commissioning
  - Engaging stakeholders in the delivery of national strategies
  - Ensuring the provision of quality care and services
- The Board should set out measures against which performance in each of these areas can be measured
- Cancer networks should report annually on their performance in these areas

**The role for cancer networks in delivering improved cancer outcomes and experiences**

- Clinical commissioning groups should demonstrate through the authorisation process how they plan to harness the expertise of cancer networks to ensure year-on-year improvements against indicators set out in the Commissioning Outcomes Framework
- When developing national strategies, the Board should provide clear actions for specialist clinical networks to support implementation
- Cancer networks have a clear role in working with clinical commissioning groups and the Board to ensure that national strategies which affect cancer services are implemented at a local level
- The Board should support cancer networks, setting out clear guidelines on data that should be analysed and assessed
- As part of the requirement that strategic clinical networks publish their annual reports, cancer networks should be required to analyse and assess data collected through the Cancer Patient Experience Survey

**The role for cancer networks in ensuring integration and involvement**

- Local authorities, clinical commissioning groups and health and wellbeing boards should work with cancer networks to develop a cancer specific section of local joint strategic needs assessments
- National and local HealthWatch organisations should work with cancer networks to ensure that patients are involved in the development of cancer services in their area
- Once confirmed as strategic clinical networks, all cancer networks should set out how they intend to involve patients and carers in their work
Managing the transition

- To ensure stability and the retention of staff, the Board should confirm that cancer networks will be retained as strategic clinical networks beyond 2013. Funding arrangements should be set out in the model contract between the Board and cancer networks
The need for cancer networks

The CCG believes that the plans set out in *Equity and Excellence: Liberating the NHS*¹, and developed through the Health and Social Care Bill², to create a multi-level system of commissioning for cancer services present both opportunities and challenges for cancer services. We support the intention of clinical commissioning to bring commissioning decisions much closer to the patient. However, given the complexity of commissioning cancer services – there are over 200 different types of cancer, most of which have highly complex care pathways – commissioners will be required to have an excellent grasp of entire pathways of cancer care. This will be essential in ensuring the integration of services, which will be commissioned and provided by a wider range of organisations, from the clinical commissioning groups themselves to local authorities.

The CCG’s research into the readiness of GPs for commissioning, published in May 2011, showed that four in five GPs (82%) believed GP commissioners would need specialist support to commission cancer services effectively³. There is therefore a need for organisations with a specific expertise in cancer services to support clinical commissioning groups in their work.

*Improving Outcomes: A Strategy for Cancer (IOSC)* notes that “a significant amount of cancer care is best commissioned for populations covering 1.5 to 2 million. This includes chemotherapy and radiotherapy services”⁴. This is a population size that few, if any, clinical commissioning groups are likely to cover. The need for organisations operating at a regional level is therefore clear: to ensure services are integrated, as well as commissioned at the most appropriate level; and to provide advice and expertise to those involved with the commissioning of cancer services locally, as well as integrating with the new Board which will have responsibility for commissioning services for a number of less common cancers.

When performing at their very best, cancer networks are excellently placed to fulfil these functions. Cancer networks work with stakeholders in their area on a wide range of tasks. For example, they have:

- Led the implementation of clinical guidance, such as NICE Improving Outcomes Guidance
- Translated national policy into local action in areas such as cancer pathway redesign and reducing cancer waiting times
- Identified population needs through baseline assessment
- Supported commissioners by ensuring that service specifications for providers of cancer services are part of commissioners’ contracting arrangements with providers
- Provided governance and assurance of services, primarily through peer review and national audit findings
Meeting the criteria to be a Strategic Clinical Network

To correspond with Dr McLean’s review the CCG has attempted to assess what key roles, responsibilities and functions a strong cancer network can perform and how these might evolve to meet the challenges and opportunities of the NHS reforms. We believe that cancer networks should be retained as strategic clinical networks (SCNs), and that they meet the seven criteria suggested by Dr McLean.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>How it is met by cancer networks</th>
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<tbody>
<tr>
<td>A clear link to a national outcome ambition</td>
<td>Improving Outcomes: A Strategy for Cancer sets out the central ambition to “save an additional 5,000 lives every year by 2014/15, aiming to narrow the inequalities gap at the same time”. Cancer networks will contribute to improving outcomes and experiences for patients in their area, including reducing mortality.</td>
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<td>The need for a change process and/or co-ordination across complex pathways</td>
<td>There are over 200 different types of cancer, most of which have highly complex care pathways. Increasingly services will be commissioned by a range of organisations, from local authorities and clinical commissioning groups to the Board. Cancer networks will be critical in terms of coordinating across different levels of commissioning and in encouraging integration across the NHS, social care and public health services.</td>
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<td>Significant potential for quality improvement through a network model, involving multiple professionals and organisations</td>
<td>Cancer diagnosis and treatment involves a broad spectrum of professionals. Cancer networks have demonstrated the ability to gain input from a range of professionals to improve the quality of care provided to patients.</td>
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<td>The need for a pan-England approach</td>
<td>As cancer is such a diverse disease in terms of tumour types and the patient pathway, there is a need for cancer networks to play a coordinating role and to provide a certain level of pan-England consistency.</td>
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<td>Clear rationale for why quality improvement cannot be driven by another means (e.g., by a clinical commissioning group)</td>
<td>A significant amount of cancer care is best commissioned for populations covering 1.5 to 2 million – larger than the population covered by the average clinical commissioning group.</td>
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<td>An assessment of how the absence of a SCN would result in a lack of continuous quality improvement</td>
<td>GPs have indicated that they would require specialist advice to effectively commission cancer services – the CCG’s research from May 2011 showed that four in five GPs believe GP commissioners would need specialist support to commission cancer services effectively.</td>
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<td>A major part of the pathway will be commissioned by the NHS Commissioning Board</td>
<td>The Board will commission screening services (funded by Public Health England), some radiotherapy services, and services designated by the NHS Specialised Services Definitions Set (e.g., chorionicarcinoma, eye cancer treatment and children’s cancer services).</td>
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Defining the responsibilities and performance standards of a quality cancer network

As non-statutory bodies, the core roles and responsibilities of cancer networks have never been systematically defined at a national level. When those working in cancer networks were questioned about the key functions performed by their network, the range of responses and subtly differing focus of individual networks served as a reflection of how the activities undertaken by cancer networks have evolved in response to local priorities and stakeholders.

While it is right that cancer networks are responsive to their local health economy and its needs, we believe more clarity is needed over the core tasks that are currently carried out by cancer networks and which of those will be essential for the cancer networks of the future. This would provide the opportunity for the Board to develop clear guidelines on the responsibilities of a cancer network to ensure that their member organisations know what to expect when procuring support services from these networks.

Based on our discussions with cancer networks and their staff, as well as with our members, the CCG has identified five key elements that we believe should form the basis of the role of a quality cancer network:

| Acting as an 'honest broker' | • Facilitates effective partnership working in their region  
| | • Co-ordinates delivery of services across organisations and administrative boundaries  
| | • Has strong working relationships with service providers based on trust  
| Analysing and collating data | • Provides robust baseline information to enable the effective allocation of resources  
| | • Collates and analyses data, working with organisations including the National Cancer Intelligence Network, to provide information and advice to local commissioners and service providers  
| Supporting commissioning | • Has strongly developed relationships with clinical commissioning groups and local authorities, and is able to support them to commission good cancer services  
| | • Actively engages with primary care to ensure that the awareness and early diagnosis agenda is incorporated into cancer services  
| Engaging stakeholders in the delivery of national strategies | • Supports implementation of government strategies  
| | • Is able to demonstrate additional lives saved (and contribution to the national ambition of ‘saving an additional 5,000 lives’)  
| Ensuring the provision of quality care and services | • Is able to ensure – and assure – that quality services are provided and maintained  
| | • Delivers and monitors equality of service  
| | • Supports the delivery of high quality care while improving productivity and value for money  

We appreciate that individual networks will want to work with commissioners and providers locally to determine how they can best support the delivery of cancer services that best meet the particular needs and challenges of a specific area. However, the five themes above represent what the CCG believes should be the core tasks of cancer networks in the new system. Success measures should be attributed to each of these to act as a marker for network quality.
Recommendation 1: The Board should develop a model contract based on the themes and quality markers set out in this report:

- Acting as an 'honest broker'
- Analysing and collating data
- Supporting commissioning
- Engaging stakeholders in the delivery of national strategies
- Ensuring the provision of quality care and services

Recommendation 2: The Board should set out measures against which performance in each of these areas can be measured

Recommendation 3: Cancer networks should report annually on their performance in these areas
The role for cancer networks in delivering improved cancer outcomes and experience

The ultimate role of cancer networks should be to support commissioners and providers to drive up improvements in outcomes and experiences for cancer patients in their area. As one participant in our research said, a gold standard cancer network is “one that delivers real reduction in mortality rates [and] improves outcomes”. This principle is identified in the recent review of clinical networks, where it is set out that strategic clinical networks should be focused on quality improvement and the achievement of outcome ambitions for patients.

The need for the delivery of improved cancer outcomes is also clearly set out in the IOSC:

“Despite improvements in survival and mortality in recent decades, cancer outcomes in England remain poor when compared with the best outcomes in Europe. Although improvements have been made in the quality of cancer services, a significant gap remains in both survival and mortality rates.”

The IOSC aims to increase cancer survival rates in England to the European average, saving 5,000 lives every year. There will be many different mechanisms through which cancer networks can help to achieve this goal – from The NHS Outcomes Framework 2012/13 at a national level, to the Commissioning Outcomes Framework and quality standards at a more local level.

Four specific cancer indicators have been identified in The NHS Outcomes Framework 2012/13. The quality of treatment and care received by cancer patients also sits across the Framework – with measures including patient experience, support in returning to work and patient safety. These measures, which will be used to hold the NHS to account at a national level, should be replicated in the COF, which in turn will be used to hold individual clinical commissioning groups to account. Cancer networks should take a key role in this process of ensuring accountability, by bringing together the outcome and performance data for their area, from sources including the NCIN, identifying any areas of concern and working closely with clinical commissioning groups to address them.

Recommendation 4: Clinical commissioning groups should demonstrate through the authorisation process how they plan to harness the expertise of cancer networks to ensure year-on-year improvements against indicators set out in the Commissioning Outcomes Framework

The IOSC is one of a number of national strategies designed to create improvement in cancer services, and therefore outcomes, at a local level. Our research and discussions with cancer networks identified a clear role for helping to ensure implementation of national strategies at a local level. There is also a role for cancer networks in ensuring the implementation and monitoring of new NICE quality standards of relevance to cancer services.

With a library of over 150 quality standards to be developed in the next four years, clinical commissioning groups will be under pressure to prioritise a broad range of topics and service areas. As NICE produces quality standards which affect cancer services, cancer networks should work with their local clinical commissioning groups to assess barriers to delivery against quality markers, and consider how these can be overcome to ensure that everyone accessing cancer services receives high quality care in line with national expert guidance.
Recommendation 5: When developing national strategies, the Board should provide clear actions for specialist clinical networks to support implementation

Recommendation 6: Cancer networks have a clear role in working with clinical commissioning groups and the Board to ensure that national strategies which affect cancer services are implemented at a local level

For cancer networks to effectively identify areas where change or improvement is needed, and take action to address these challenges, they will need to be able to accurately measure and track variations in outcomes within their local area. This will also be central to ensuring that patients know the quality of services available to them. As one respondent told us:

“a gold standard cancer network would be able to...provide information on what care is available.”

There is, however, evidence that there remain gaps in the data and information used and produced by cancer networks. For example, the National Audit Office reported that many networks do not have confidence in the data available to them\textsuperscript{10}. When asked about confidence in the information available to detect variations in cancer outcomes in their network area, 60% said they were very or fairly confident, with 40% saying that they were either not very confident or not at all confident. On expenditure there was less confidence still, with 65% of networks not feeling that they have the information needed to detect variations\textsuperscript{11}. This is particularly concerning at a time when networks will have to operate within tight budgets and deliver efficiencies.

The Board should support cancer networks by setting out clear guidelines on the outcomes, service and expenditure data they should analyse. This should include information on patient experience, as collected through the Cancer Patient Experience Survey\textsuperscript{12}, and form part of the requirement that strategic clinical networks publish their work programmes and annual reports. As well as providing a clear assessment of cancer services and outcomes, and allowing for any concerns to be identified, this should give cancer networks a means of demonstrating the value that they add – a challenge identified through our interviews.

Recommendation 7: The Board should support cancer networks, setting out clear guidelines on data that should be analysed and assessed

Recommendation 8: As part of the requirement that strategic clinical networks publish their annual reports, cancer networks should be required to analyse and assess data collected through the Cancer Patient Experience Survey
The role for cancer network in ensuring integration and involvement

A clear message which emerged from our interviews with cancer networks is that effective local relationships will be crucial for delivering quality services and improving outcomes for people with cancer. This is also apparent in the National Audit Office’s census of cancer networks, where 100% of cancer networks surveyed said that a lack of collaborative working was one of the main barriers to more effective commissioning of cancer services in their network area\(^\text{13}\).

This will be more salient than ever given the change created by the NHS reform process, with a wider range of organisations now involved in the commissioning and delivery of cancer services. Cancer networks are well placed to ensure that the full range of stakeholders are involved in the process of commissioning cancer services, and that there is integration between those services delivered across public health, the NHS and social care.

The reformed NHS structures mean that cancer networks can play an even greater role in fostering integration, working with a wider range of stakeholders. Emphasis will need to be placed on the important role of health and wellbeing boards in bringing relevant groups together to discuss local cancer services and how commissioners can best work together to ensure that services for people with cancer, and their carers, are fully integrated.

**Recommendation 9:** Local authorities, clinical commissioning groups and health and wellbeing boards should work with cancer networks to develop a cancer specific section of local joint strategic needs assessments

As well as engaging local stakeholders involved in the commissioning of cancer services, cancer networks can take a central role in ensuring that patients and the public are involved in the delivery and design of cancer services in their area. This will be crucial for improving both outcomes and experience for patients. As one cancer network told us, quality means delivering on the “principle that patients are at the centre of care and expect a seamless pathway, with equitable levels of quality and access.” Another told us that what is needed is a “greater focus on listening to patients to improve services... to deliver a seamless pathway for patients and improve the overall quality of care”.

The CCG welcomed government plans to support patient and public accountability in the NHS through a duty on commissioning groups to consult service users on their plans. However, it will be important that commissioners are supported to ensure that they are using effective methods to reach and engage with all patients and their families. Many cancer networks have excellent models for involving people affected by cancer in the process of reviewing and designing services, and these models should be replicated by networks across the country and harnessed by clinical commissioning groups.

Cancer networks can also play an important role in supporting Local HealthWatch branches to ensure that local patients and residents are consulted on the design and delivery of cancer services in their area. As the local HealthWatch bodies and indeed Healthwatch England are established, cancer networks should work closely with them to consider mechanisms by which they can support public and patient involvement. It will be important that this engagement includes not only those affected by the more common cancers, but also those with less-common cancers which have smaller patient populations.
Recommendation 10: National and local HealthWatch organisations should work with cancer networks to ensure that patients are involved in the development of cancer services in their area.

Recommendation 11: Once confirmed as strategic clinical networks, all cancer networks should set out how they intend to involve patients and carers in their work.
Managing the transition

The opportunity to improve outcomes for cancer patients is clear, and cancer networks, established as strategic clinical networks, can and should play a significant role in helping to achieve the Government’s ambition of saving 5,000 lives every year. However, there is a danger that the progress that has been made in improving cancer outcomes and mortality in recent years could be threatened by the uncertainty in the structures of the new NHS.

The need for stability was mentioned by many networks in our interviews, with the prevailing view that stable funding is the most important resource requirement that will enable cancer networks to deliver their key functions successfully. Referring to the challenges faced by cancer networks, one respondent said:

“Volatility and instability in the healthcare system [is a challenge]. Cancer networks have no statutory standing, and therefore rely entirely on credibility they build and the relationships they have been able to develop – when the system changes they have to rebuild these.”

Networks also identified the need to attract and retain the right people with the relevant analytical, influencing and communication skills as a key challenge:

“Getting the right staff in the current climate, particularly with regards to the uncertainty around the future of key organisations within the health economy.”

There is therefore a sense that, while the future of cancer networks is still unclear, it will be difficult for networks to attract the staff necessary to support improved outcomes.

We welcome the recent update on progress being made in the review of clinical networks, and the commitment that national funding will be provided for infrastructure and support at least initially. The Cancer Campaigning Group is now calling for the Board to confirm that cancer networks will be retained as strategic clinical networks beyond 2013.

**Recommendation 12:** To ensure stability and the retention of staff, the Board should confirm that cancer networks will be retained as strategic clinical networks beyond 2013. Funding arrangements should be set out in the model contract between the Board and cancer networks.
Annex 1: Methodology

The primary research for this work was conducted by Frontline Consultants and included 31 in-depth interviews with people involved in ten of the 28 cancer networks in England. The sample of networks was selected to ensure broad coverage of functions, success rates, population sizes and characteristics. A breakdown of the roles of those we spoke with is provided in table 1 below.

Table 1: Interview participants’ roles

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<tr>
<th>Role</th>
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<tr>
<td>Network Director</td>
<td>10</td>
</tr>
<tr>
<td>Commissioning Responsibility</td>
<td>6</td>
</tr>
<tr>
<td>GP/Public Health Lead</td>
<td>6</td>
</tr>
<tr>
<td>Oncologist</td>
<td>3</td>
</tr>
<tr>
<td>Nurse Director</td>
<td>3</td>
</tr>
<tr>
<td>Lead Cancer Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Medical Director</td>
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The approach to the qualitative interviews was underpinned by the use of an ‘issue tree’:

- Understanding the current state of play – how are cancer networks currently performing?
- In your view what functions are currently performed well and not so well by cancer networks? And why? What works well and not well in their own cancer network?
- Key functions: What should be the key functions of a cancer network in the new NHS? What support and resources are required to deliver against these?
- Training: What should a cancer network’s function be in delivering training to health professionals and social care staff?
- Support: What role should cancer networks have in supporting Clinical Commissioning Groups? (short term and medium term)
- What role should cancer networks play in supporting service providers?
- Patient care: What role should cancer networks play in ensuring care and services are of a high quality, in terms of both patient outcomes and experiences?
- How should a cancer network be involved in ensuring that a patient’s care is joined-up across primary, secondary and tertiary services?
- How can patients and carers be most effectively involved in the design and delivery of cancer services?
- Data: What role should cancer networks have in collecting and collating data? What data should they be collecting?
- Commissioning: What role should cancer networks play in facilitating contract negotiation and delivery between commissioners and providers?
- Overcoming challenges and barriers – what needs to be addressed to achieve a “gold standard”?
- What are some of the potential challenges/barriers to achieving a “gold standard” cancer network?
- How could these be overcome?
- Intelligence for better case making – ongoing monitoring to affect policy change
- How should the effectiveness of a cancer network in performing its key functions be measured and by whom?
- What should cancer networks’ top three priorities be in their first year of operation in the new NHS?
About the Cancer Campaigning Group

The Cancer Campaigning Group (CCG) is a coalition of nearly 50 cancer-related charities representing service providers, research, advocacy and campaigning groups for cancer patients and their families. Founded in 2002, the CCG is campaigning for world class prevention, treatment, support and care for every cancer patient in England to bring all services up to the standards of the best in Europe. At this crucial time in the development of health and cancer services, the CCG enables cancer charities to speak and campaign with a single unified voice – pooling expertise, amplifying the impact of individual organisations, and ensuring that our messages are heard and acted upon by the Government and the NHS. Please see our website at: www.cancercampaigninggroup.org.uk.

The Cancer Campaigning Group Steering Group and Secretariat

The CCG’s campaigning strategy and activities are developed by a steering group of representatives from six member charities – Cancer Research UK, CLIC Sargent, Macmillan Cancer Support, The Prostate Cancer Charity, the Rarer Cancers Foundation and the Roy Castle Lung Cancer Foundation. MHP Health Mandate provides the secretariat to the Group, including communications advice, support and implementation.

Supporters

The CCG’s work is supported by twelve pharmaceutical companies – Amgen, AstraZeneca, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, GlaxoSmithKline, Lilly, Roche, Pfizer, PharmaMar, sanofi-aventis, Roche – and one medical technology company, GE Healthcare. Supporting organisations do not direct or control CCG strategy, activities or literature in any way. The CCG ensures that all its relationships with supporter organisations comply with the Association of the British Pharmaceutical Industry (ABPI) code of conduct, governing the relationship between patient groups and pharmaceutical companies.
References

1 Department of Health, *Equity and Excellence: Liberating the NHS*, July 2010
2 Department of Health, *Health and Social Care Bill 2010-12*
3 Cancer Campaigning Group, *Ensuring effective commissioning of cancer services – A survey of GPs*, May 2011
5 NHS Commissioning Board, *Proposal for Clinical Networks in the Modernised NHS*, February 2012
7 NHS Commissioning Board, *Proposal for Clinical Networks in the Modernised NHS*, February 2012
10 National Audit Office, *Census of cancer networks*, November 2010
11 National Audit Office, *Census of cancer networks*, November 2010
13 National Audit Office, *Census of cancer networks*, November 2010
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