

Cancer Commissioning:

Making the reforms
work for patients

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About this publication

In January 2011, the Department of Health published its new strategy for cancer care – Improving Outcomes: a Strategy for Cancer. Andrew Lansley, Secretary of State for Health, subsequently announced on May 20th that the Cancer Networks would receive funding for 2012/13 and that, “beyond 2012/13, the NHS Commissioning Board (NHSCB) will support strengthened Cancer Networks”.

The new reforms will move both national and regional specialised commissioning into the hands of the NHSCB, but what is yet to be determined is how the new changes will impact both the national and regional commissioning of specialised services in the treatment and diagnosis of rarer cancers. It is therefore unclear how the structure of specialised commissioning will be defined, and how this will affect outcomes for patients with rarer cancers, or the operation of the Cancer Drugs Fund.

This project has sought to undertake a review of the specialised commissioning of cancer care with particular reference to the rarer cancers. It examines the role of cancer networks within this process and identifies important strengths and weaknesses in view of new commissioning arrangements.

During the course of this work we benefited from interviews and discussions with many of those working in this field. We would like to thank all those who contributed to this piece of work, and in particular we would like to thank our steering group for their advice and support throughout the project.

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Julia Manning
Chief Executive
May 2012

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He has a wide ranging portfolio of expertise which spans the arenas of public policy, academia and third sector, including working as a parliamentary researcher for an MP and shadow minister. Matt has convened numerous series of public symposia which have helped initiate and bring together key stakeholders to discuss the ethical, social, medical and legal implications of new technologies. With a particular focus on how emerging technologies are challenging the very essence of humanity and our relationships with each other, our bodies, with medicine, privacy, security and policy, Matt has been involved with writing and speaking on these issues as well as participating in several EU funded projects along these lines.

Matt has an undergraduate degree in political history and sociology as well as a Master's degree in bioethics and medical law. He was recently elected as a Fellow of the Royal Society of Arts and Commerce (FRSA).

Executive Summary

The purpose of this project was to review the way that Cancer Networks deal with rarer cancers and how various stakeholders think the new specialised commissioning structure will impact the treatment of rarer cancers, especially with respect to patient access to services and drugs, and value for money.

Building on the substantial level of good quality work which has taken place in the field of cancer services over the last 5-6 years, the report aims to provide practical recommendations and suggestions on how further improvements and significant gains can be made.

The project was undertaken between February-April 2012 and involved conducting in-depth telephone interviews with various stakeholders from across the UK including clinicians, clinical commissioning groups, cancer networks, clinical managers and representatives from the third sector. A semi-structured schedule was used to establish a basic interview framework, whilst also allowing opportunities for respondents to explore specific issues in depth, drawing upon their areas of expertise and experience.

From reviewing and analysing the interviews, significant and reoccurring themes were identified along with key points for consideration. Given the scale of the changes being proposed and the variation in understanding of how the changes to the system will take effect, we felt it would be helpful to first establish a framework to summarise the various steps in the process of commissioning cancer care. This framework provided a basis of assessment for the emerging key themes. The key themes identified and aggregated from the interviews then informed a 2-dimensional review. First, looking at the present modus operandi, we identified the perceived strengths and weaknesses of the current system. Secondly, looking to the future, we mapped out the perceived benefits of new proposals and considered how the new specialised commissioning structure, with specific reference to rarer cancers, would impact patient pathways.

This report represents the culmination of this process. It is not intended to be either exhaustive or prescriptive but it is hoped that it will help stimulate further discussion and consideration amongst key stakeholders as the commissioning of cancer care moves forward. Based upon our framework of functions the following recommendations are proposed:

Recommendations for the NHS Commissioning Board

1. In order to increase responsibility and ownership outcome measures should be assigned to local CCGs. Necessary levers and infrastructure need to be put into place which the Commissioning Outcomes Framework may well help to provide and give direction to.
2. The accountability relationship between specialist commissioners, CCGs and networks needs to be clearly defined so everyone knows where the authority lies.
3. Process targets and outcome measures need to be introduced to track progress. NHS Outcomes Framework¹ should be enhanced in order to take account of all rare cancers. This should be a key priority.
4. That commissioning adopts an approach which considers the total pathway of care thus truly releasing 'value' into the system in terms of outcomes and resource benefits. The introduction of a collective governance structure in the NCB could help to promote collaborative decision making in this regard. An incentivisation scheme needs to be introduced for commissioners.
5. Of the three options we propose for commissioning, collaboration needs to be at the centre of whichever option is adopted in order to safeguard the patient's best interests.
6. That the reach of the cancer networks' and how far their boundaries extend is more clearly defined, perhaps with reference to the ICS model in London.
7. Consideration needs to be given to hospitals commissioning the whole pathway and subcontracting against a robust outcomes framework.
8. Transparent contractual arrangements with clear targets and outcomes should be introduced to add rigour to the system.

1. See Department of Health (2010), Equity and Excellence: Liberating the NHS - July 2010, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@cn/@ps/documents/digitalasset/dh_117794.pdf [accessed 9th May 2012]

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9. Greater powers should be given to networks in order to afford them increased clout and influence. In order to do this they should be given status as a stand alone authority with the agreement they do not receive funding unless key delivery of outcomes are met.
 10. Pathways are developed from the perspective of the patient and not the commissioning divisions (supported by the cancer networks).
 11. The peer review process should be strengthened and enhanced. External reviews need to be impartial and transparent set against pre-defined criteria, with less self assessment.
 12. The patient should be involved in deciding if the service has been satisfactory and if full payment should be received.
 13. That commissioners build into contractual arrangements the requirement to review disposition of service and develop appropriate business cases with reference to quality of care and patient experience. Public awareness should be more robust and decisions transparent regarding clinical outcomes in order to support this process.

Recommendations for Clinical Commissioning Groups (CCGs)

14. The use of cancer Care Coordinators should be explored. Consideration should be given to using the third sector. Contractual agreements with suitable governance and accountability frameworks would need to be put in place.
15. To counteract the power of large cancer centres, Payment by Results needs be modified so that Trusts or other providers only receive the full amount if they meet delivery and outcomes targets, as in the Work Programme. The information capability needs to be in place to manage this change.

Recommendations for Cancer Networks

16. That specialist services and end of life care teams work more closely together to ensure continuity of care from the hospital into the community. The introduction of designated Care Coordinators ‘on

the ground’ charged with specific responsibility to liaise with specialist services would address this need. Consideration should be given to professional training to assist potential coordinators to fulfil this role.

17. A full mapping of pathways and their costs needs to be adopted and supported by clear outcome measures and a well defined accountability and responsibility structure.
18. That cancer networks oversee and maintain a pathway level risk register that monitors actual pathway care against best practice pathways.

Recommendations for Clinical Support Services

19. An adequate mix of skill sets in CCGs and networks would need to be established to promote and guide effective commissioning. A balance between clinical and commissioning staff would be required in order to establish this mix. This would be defined by the NHS Commissioning Board.

Recommendations for CCGs and Specialised Commissioning

20. The pursuit of improved data collection and gathering needs to continue. Penalties should be factored in for contractual failure, such as fines and/or a reduction in referrals. Greater weight to data management could also be factored into the Care Quality Commission (CQC) assessment.

Recommendations for CCGs and NHS Trusts

21. An emphasis placed on ‘grass roots’ understanding of the commissioning and delivery of cancer care.
 22. That the patient becomes an active participant of the cancer team and is given full access to their record including all relevant non-medical information and data.
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Introduction

Cancer is a prevalent disease, with more than one in three people developing some form of cancer during their lifetime.² An estimated 12.7 million people were diagnosed with the disease worldwide in 2008, 309,500 of them in the UK.³ On average, over 250,000 people are diagnosed with cancer every year in England, and roughly 130,000 people die of the disease.⁴ Although cancer can develop at any age, it is predominantly an age-related disease, with three out of five new diagnoses being in people aged 65 and older. Given the increasing average age of the global population, it is unsurprising that the rate of cancer diagnosis has also risen over the last four decades.

The first NHS Cancer Plan in 2000 saw significant investment in cancer services which has since increased from £3.4bn in 2003 to £5.8bn in 2010.⁵ Part of the Cancer Plan was the creation of ‘cancer networks’, designed to drive change and improvement in cancer services for the population in a specific geographical area. They have played an important role in coordinating the planning, commissioning and delivery of cancer care.

Improving Outcomes

In 2011 the Department of Health made some important pledges to improve cancer outcomes. At the start of the year came its new strategy for cancer care, *Improving Outcomes: a Strategy for Cancer*, then in May, Andrew Lansley’s announcement that the cancer networks would receive funding for 2012/13, with strengthened support from the NHS Commissioning Board thereafter. This was welcome news for cancer patients, professionals, carers, and the many people involved in running the 28 English networks.

The NHS Future Forum published a report in mid-June that not only supported the establishment of the NHS Commissioning Board (NHSCB), but recommended that its role include overseeing clinical commissioning groups (CCGs) and supporting local commissioning in areas where CCGs are not ready to take on full responsibility. It also supported the role of clinical networks in providing advice to commissioners on single areas of care, and recommended that they be embedded at all levels of the commissioning process. At the end of June, the government published a response to the Future Forum

report stating that it has accepted the Forum’s core recommendations. The Health and Social Care Bill was amended before it passed into statute to establish the NHSCB’s role in overseeing clinical networks and also new ‘clinical senates’, which will provide advice on local commissioning plans in each area of the country.

What is yet to be determined is how the new changes will impact both the national and regional commissioning of specialised services in the areas of diagnosis and treatment of rarer cancers. A service is considered specialised if the planning population (catchment area) for that service is greater than one million people and/or is provided in fewer than 50 hospitals in England. Such services are set out in the Specialised Services National Definitions Set, which is determined in accordance with NICE guidelines. Currently, national specialised commissioning is delegated by the Strategic Health Authorities to NHS London, who host the National Specialised Commissioning Team. Commissioning funds flow from PCT allocations transferred annually into a budget held by NHS London. Regional commissioning of specialised services is delegated to ten regional Specialised Commissioning Groups (SCGs), which are overseen by the National Specialist Commissioning Group (NSCG). The cancer networks work closely with their constituent SCGs to support specialised commissioning.

The new reforms will move both national and regional specialised commissioning into the hands of the NHSCB, but apart from that, the Act does not address in detail how it intends to handle specialised commissioning. It is therefore unclear how the structure of specialised commissioning will be defined, and how this will affect outcomes for patients with rarer cancers, or the operation of the Cancer Drugs Fund. Those with rare and complex diseases historically fall through the net, but as “rarer cancers” comprise up to 50% of the incidents of cancer in the UK, it is important that this is not the case.

The purpose of this project was to review the way that Cancer Networks deal with rarer cancers and how various stakeholders think the new specialised commissioning structure will impact the treatment of rarer cancers, especially with respect to patient access to services and drugs, and value for money.

2. Cancer Research UK, August 2011.

3. Cancer Research UK, April 2011.

4. Department of Health, January 2011.

5. Parliamentary Office of Science & Technology, March 2012.

Introduction

Methodology

The project was undertaken between February-April 2012 and involved conducting in-depth telephone interviews with 18 key stakeholders from across the UK. Participants included clinicians, clinical commissioning groups, cancer networks, clinical managers and representatives from the third sector. A semi-structured schedule was used to establish a basic interview framework, whilst also allowing opportunities for respondents to explore specific issues in depth, drawing upon their areas of expertise and experience. Interviewees were assured that their comments would remain unattributed and were encouraged to offer their own personal opinions.

From reviewing and analysing the interviews, significant and reoccurring themes were identified along with key points for consideration. Given the scale of the changes being proposed and the variation in understanding of how the changes to the system will take effect, we felt it would be helpful to first establish a framework to summarise the various steps in the process of commissioning cancer care (Whilst responsibilities and process may change and be revised, the key functions of a system will remain fairly consistent). This framework provided a basis of assessment for the emerging key themes. The key themes identified and aggregated from the interviews then informed a 2-dimensional review. First, looking at the present modus operandi, we identified the perceived strengths and weaknesses of the current system. Secondly, looking to the future, we mapped out the perceived benefits of new proposals and considered how the new specialised commissioning structure, with specific reference to rarer cancers, would impact patient pathways. We also aimed to identify important options for consideration as plans move forward.

The project has had the support of an external steering group of unpaid experts. 2020health discussed the process and the findings from the research with these experts in a number of meetings.

This report represents the culmination of this process. It is not intended to be either exhaustive or prescriptive but it is hoped that it will help stimulate further discussion and consideration amongst key stakeholders as the commissioning of cancer care moves forward.

Part 1:- establishes the context of commissioning cancer care, both currently and into the future.

Part 2:- sets out the main emerging themes from the interviews and our framework of functions.

Part 3:- the concluding section, summarises the key challenges and points for consideration.

1 Commissioning Cancer Care

Context

Cancer is a common disease. In addition to rate increases caused by an aging population, the last decade has seen large increases in preventable cancers such as oral and liver cancers. Cigarette smoking is the single biggest cause of preventable death in the UK, with more than a quarter of all deaths from cancer (including almost 90% of lung cancer deaths) linked to smoking. Melanoma incidence rates have also increased in both men and women, highlighting a disturbing trend in the prevalence of cancers that could be avoided by lifestyle changes, such as stopping smoking, reducing alcohol intake, maintaining a healthy weight, and avoiding excessive exposure to UV radiation from the sun or tanning beds. With the aging population worldwide and a spreading Westernised culture of excess, the prevalence of cancer is set to increase exponentially in the coming years.

The UK has poor cancer survival rates compared to many other Western nations. In January 2011, an international benchmarking study investigated outcomes for four cancers (colorectal, lung, breast, and ovarian) in six countries (Australia, Canada, Sweden, Norway, Denmark, and the UK).⁶ The findings showed the UK to have one of the worst cancer survival rates in the Organisation for Economic Co-operation and Development (OECD). It was determined that if England were to achieve survival rates at the European average, 5,000 lives would be saved each year, and this would increase to 10,000 at the European best.

In a recent European research project, rare cancers were found to have, on average, worse relative survival than common cancers. For patients with rare cancers diagnosed in 1995–1999, 1, 3 and 5-year relative survival was 68%, 52% and 47%, respectively; the corresponding figures for patients with common cancers were 80%, 69% and 65%.⁷ Survival is usually better for women than men in those aged 75 years or older, with northern Europe boasting higher rates of survival than in other parts of Europe.⁸ Further research is required in order to ascertain why this is the case, particularly as many effective treatments are currently available for rare cancers.

This “survival gap” has been attributed to both later diagnosis and differences in treatment. Research by the UK National Cancer Intelligence Network, which analysed data from the National Cancer Data Repository, has shown that 23% of newly diagnosed cancer patients come through as emergency presentations. This indicates that the cancer was quite advanced at the time of diagnosis, and that one year survival rates are lower for those presented via emergency than those presented via any other route.⁹ Over a quarter of cancer patients are first diagnosed with stage 3 and 4 cancer¹⁰ meaning that the cancer has spread to other sites in the body with the development of metastatic disease. Delays in diagnosis and treatment can be broken down into either patient delay or treatment delay. Patient delay is the time from first experience of a potential cancer symptom to telling a healthcare professional about it, and treatment delay is the time from first diagnosis by a healthcare professional to first treatment.

Factors contributing to patient delay:

- Low public awareness of the signs and symptoms, so that people do not seek help sooner
- Lack of national screening programmes
- Emotional/cultural barriers preventing patients from seeking doctor intervention

Factors contributing to treatment delay:

- Lack of recognition of signs and symptoms by primary care doctors
- Delay in GP referral caused by a culture that disincentivises referrals to secondary care
- Prolonged time spent in secondary care before diagnosis, which can occur when patients are referred to an inappropriate speciality

In light of critical gaps in NHS cancer services and the rising demand for cancer care, the Department of Health issued its white paper *Improving Outcomes: A Strategy for Cancer* (January 2011). This national strategy, backed with more than £750m over four years, includes steps to reduce the incidence of preventable cancers and increase early diagnosis.

6. Coleman, M.P. et al. 2011.

7. Gatta et al., 2011. The project Surveillance of Rare Cancers in Europe (RARECARE) analysed population-based cancer registry (CR) data on European patients diagnosed from 1988 to 2002, with vital status information available up to 31st December 2003 (latest date for which most CRs had verified data). Cancer incidence and survival rates for 1995–2002 and prevalence at 1st January 2003 were estimated.

8. Gatta et al., 2006.

9. National Cancer Intelligence Network, November 2010.

10. Rarer Cancers Foundation, 2011

1 Commissioning Cancer Care

Actions to reduce the incidence of preventable cancers include (this is ongoing):

- The Public Health Responsibility Deal (March 2011), setting out actions that industry, the voluntary sector, NGOs and local government can take to help people make healthier choices
- The white paper Healthy Lives, Healthy People (July 2011), setting out the Government's commitments to tackle obesity
- NICE guidance on skin cancer prevention, focusing on raising awareness and preventing the first occurrence of skin cancer
- A tobacco control plan publication to reduce smoking prevalence

Actions to increase early diagnosis:

- Provision of a £450m investment to increase early diagnosis which will fund two million extra tests including:
 - o chest x-ray
 - o non-obstetric ultrasound
 - o flexible sigmoid/colonoscopy
 - o MRI brain scan
- Introduction of new screening programmes funded by Public Health England and commissioned by the NHS Commissioning Board
- Implementation of HPV testing as triage for women with mild or borderline cervical screening test results
- A risk assessment tool for GPs, developed and soon to be piloted

Other actions to improve cancer outcomes:

- Pilot of a national cancer survivorship survey in 2011
- Pilot data collection on the number of women with secondary breast cancer
- Provision of £4.7m in funding over five years for a policy research unit on cancer awareness, screening and early diagnosis

Cancer commissioning

Background

Currently, there are four main categories of cancer: breast, colorectal, lung, and prostate, and they account for over half (54%) of the cancer incidents in the UK. All cancers that fall outside these four categories are considered rarer cancers. There are more than 200 types of cancer, each with different causes, symptoms, and treatments.

Commissioning for cancer is an inherently complex process due to the large number of different types of cancer which have different patient pathways from diagnosis to treatment, requiring commissioners to have a wide range of knowledge in order to commission effectively. In addition, most cancers, whether common or rare, require multiple different interventions at various steps in the pathway, some of which are commissioned at a local level, and some of which are considered specialised and need to be commissioned at a regional or national level due to the small number of patients that require the service.

Primary Care Trusts (PCTs)

At the local level, under the Local Government and Public Involvement in Health Act 2007, local authorities and PCTs have a duty to undertake a Joint Strategic Needs Assessment (JSNA) of the health and well being needs of the local community. On this basis, the priorities arising from the JSNA proceed to inform and guide the development of joint health and well being strategies. These in turn are implemented by commissioners who commission the appropriate services. The PCT involvement will be replaced by CCGs in 2013.

Specialised Services

A service is considered specialised when it has a planning population of more than a million people, or is provided by less than fifty hospitals in England. Services are defined as specialised according to the Specialised Services National Definitions Set (SSNDS), which is determined in accordance with NICE guidelines. Due to the nature of specialised services, the SSNDS will change on a fairly consistent basis, with new services being provided by the NHS and other services becoming more commonplace, so that they are no longer classified as specialised. The SSNDS therefore needs to be considered and reviewed as an ongoing process.

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Prior to the transition, services listed on the SSNDS were commissioned by ten regional Specialised Commissioning Groups (SCGs), which were overseen by the National Specialist Commissioning Group (NSCG). The SCGs commissioned specialised services for their regional populations, which ranged in size from 2.8 million people to 7.5 million people.¹¹ The NSCG facilitated working across the 10 SCGs at a regional and pan-regional level, overseeing and coordinating commissioning undertaken by SCGs where the specialised service had a catchment bigger than that of a single SCG. As an approximate guide, 60 highly specialised services are commissioned on a national basis, representing services that affect fewer than 500 people across England or involving fewer than 500 highly specialised procedures each year.

Appropriate population and activity thresholds for different cancer services were defined by NICE in a series of evidence-based cancer Improving Outcomes Guidance (IOG) documents. The rarest cancer treatments were commissioned nationally by the National Specialised Commissioning Team with a body called the Advisory Group for National Specialised Services (The AGNSS) which advised ministers on which services, products and technologies should be commissioned nationally and which centres should provide them.

The future of cancer commissioning

Under the new clinician-led commissioning system, the ten regional SCGs will no longer exist in their current form, and specialised services that fall outside the catchment area of the Clinical Commissioning Groups (CCGs) will be handled by the NHS Commissioning Board and subject to arrangements similar to those described above.

Clinical Commissioning Groups (CCGs)

PCTs will cease to exist in April 2013. By this time GPs will be members of either an authorised CCG or a 'shadow' CCG – one that is legally established but operating in a shadow form with the NHS Commissioning Board commissioning on its behalf.¹² A robust form of authorisation will determine this, overseen by the NHS Commissioning Board, with input from Health and Wellbeing Boards and local clinicians.

Changes to the commissioning process will broaden the range of professional involvement. CCGs will have the duty to promote integrated health and social care around the needs of users¹³ while operating with a degree of flexibility in terms of the commissioning process. If they so wish, CCGs can work in partnership with other local groups, local authorities and the NHS Commissioning Board. However, they cannot delegate their statutory responsibility for commissioning to private companies or contractors. CCGs will also have a new duty to promote research and innovation in line with the current duty of the NHS Commissioning Board.

NHS Commissioning Board

Under provisions in the Health and Social Care Act a new independent NHS Commissioning Board is to be created. This Board is charged with the responsibility and function to a) arrange for the provision of services for the purposes of the health service in England in accordance with this Health and Social Act, and (b) exercise the functions conferred on it by the Act in relation to clinical commissioning groups so as to secure that services are provided for those purposes.¹⁴

The NHS Commissioning Board will be established by October 2012 so that it can commence authorisation of CCGs. Full responsibilities will be assumed from April 2013. Ultimately, the NHS Commissioning Board will replace the remaining four Strategic Health Authorities (SHAs), which will remain as statutory bodies until April 2013. In the meantime some form of reorganisation and merging will occur in order to create a number of cluster groups for management purposes. In effect, the areas of cancer commissioning currently covered by national or regional specialised commissioning will come under the remit of the NHS Commissioning Board.

Clinical Senates

Clinical Senates, comprising doctors, nurses and other professionals, are to be established to provide a forum for cross speciality collaboration and innovation. They will offer support and advice to the CCGs on how to make patient care fit together in a cohesive whole.

In terms of commissioning, clinical senates will have a formal role in the authorisation of CCGs. Senates will also advise the NHS Commissioning Board on matters

11. NHS Specialised Services, 2012.

12. Department of Health, June 2011.

13. Department of Health, June 2011.

14. Health and Social Care Act 2012

pertaining to changes in services and the clinical robustness of commissioning plans. Senates may provide a way for CCGs to meet their statutory duty to secure advice from a wide range of health professionals. Nevertheless, senates will not possess a right of veto on plans or proposals.

Crucially, both clinical senates and clinical networks will be hosted by the NHS Commissioning Board.

Health and Wellbeing Boards

To establish a mechanism for bringing together local NHS, public health and social care commissioners, the Government has set out details concerning proposed Health and Wellbeing boards (HWB).¹⁵ HWBs will exist in every upper-tier local authority and help to create a forum through which cross cutting commissioning approaches to cancer services can be discussed and devised.

HWBs, consisting of elected representatives, local HealthWatch and local commissioners for health and social care among others, should operate as equivalent executive bodies do in local government, with the aim of providing greater engagement between local government and NHS commissioners. In turn the expectation is that local needs and priorities will be better represented in the services that are commissioned.

HWBs will take a formal role in CCG authorisation. The NHS Commissioning Board will have to take into account the views and perspectives of the HWBs in the annual assessment of commissioning groups undertaken by the Board.

HWBs are to be fully involved throughout the planning and development of commissioning plans devised by the CCGs. Whilst possessing no veto, HWBs will have the ability to refer plans back to the CCG or NHS Commissioning Board for further consideration.

Similarly, local authorities and commissioners will each have an equal and explicit obligation to prepare the Joint Strategic Needs Assessment (JSNA).

HealthWatch England

HealthWatch England will operate as a subcommittee of the Care Quality Commission (CQC) and provide a

means by which to monitor and address, where necessary, cancer inequality issues. In many respects it will seek to champion the views and interests of the patient.

Public Health England

Established as an executive agency of the Department of Health, Public Health England will take over from the abolished Health Protection Agency and National Treatment Agency for Substance Abuse. It will help to ensure that expert and scientific advice remains independent, and will also seek to integrate policy and action to foster a joined-up approach to health protection.

NICE and Improving Outcomes Guidance Documents (IOGs)

The IOGs, devised by NICE, will remain a key aspect of all commissioned services. The transfer of specialised commissioning to the NHS Commissioning Board is viewed by many to be a step in the right direction, as a significant amount of cancer care is best commissioned for populations covering 1.5 – 2 million, which is larger than the population size of the average pathfinder CCG of approximately 202,000. In fact, a recent survey of GPs conducted by the Cancer Campaigning Group found that most GPs believed that cancer surgery, chemotherapy, and radiotherapy should be commissioned at a regional or national level, with only post-treatment support being coordinated at a local or CCG level.¹⁶

However, the shift to GP-led commissioning and an “any qualified provider” model could create significant challenges for cancer commissioning as well. Due to their smaller size, CCGs may not have the knowledge and expertise required. 71% of the GPs who responded to the Cancer Campaigning Group survey said that they strongly agree/agree that they will require specialist advice to effectively commission cancer services. In addition, transfer of specialised commissioning to the NHS Commissioning Board would physically and culturally distance specialised commissioning from local commissioning, which could result in pathway fragmentation. Funding flows from multiple sources (national vs. local) could add to the difficulties, resulting in disjointed care and poorer patient outcomes. Finally, the introduction of the “any qualified provider” model necessitates the implementation of strict accreditation guidelines and performance oversight to ensure provider excellence.

15. Department of Health (2011), Commissioning Cancer Services

16. Cancer Campaigning Group, May 2011

1 Commissioning Cancer Care

The role of cancer networks in commissioning

Cancer networks started to be formed after the Calman-Hine Report (1995) but following the Cancer Plan in 2000 were expanded to cover England in order to provide support for cancer commissioning at all levels. The Calman-Hine Report outlined the need for multi-disciplinary care, with the first Improving Outcomes Guidance (IOG) issued in 1996 for breast cancer published by NHS Executive. Traditionally, the core network team have been hosted by PCTs, with the wider network being made up of organisations covering primary, secondary and tertiary care. The core network team coordinates the cancer pathways across the multiple organisations, supporting all organisations in the diagnosing, commissioning and provision of cancer services.

Cancer networks have helped to develop relationships between commissioners and local providers, coordinating the development and delivery of care pathways that span multiple groups. They have successfully engaged patients, improving patient involvement, and have been instrumental in developing and delivering patient information prescriptions to ensure that patients, particularly those with rarer cancers, are well informed about their conditions. Whilst the cancer networks do not have set of functions and relationships defined in law, they have nevertheless played a key role in facilitating access to cancer treatments and improving collective decision-making about the uptake of new drugs and technologies. Since their inception, cancer networks have helped the NHS achieve important improvements, implementing national strategy and policy locally, such as reducing waiting times and increasing responsiveness to patient needs.

The future role of networks in cancer commissioning

Whilst the Department of Health is committed to the continued and strengthened funding of cancer networks beyond 2013,¹⁷ there is much uncertainty surrounding the operation of the networks within the planned GP-led commissioning system.

The Rarer Cancers Foundation published a report in September 2011 on the future role of cancer networks, recommending that networks function as a bridge between CCGs and providers by supplying support and specialist expertise to both.¹⁸ Key recommendations from the report include:

- Supporting commissioners in achieving improvements in outcomes for all sections of the population
- Promoting integration of services across public health, NHS and social care, and between different providers of services
- Advising on the needs of the local population as they relate to cancer
- Assessing and managing the performance of providers on the basis of quality in line with knowing what good looks like as opposed to in relation to direct performance monitoring.
- Enabling informed choice for patients

There is a question however of whether networks are robust enough in their current form to function in this enhanced role, and to provide the support that CCGs need to commission effectively when the PCT and SHA structures are removed.

17. Department of Health, May 2011

18. Rarer Cancers Foundation, September 2011.

1 Commissioning Cancer Care

Access to cancer drugs

Background

The £600m Cancer Drugs Fund (CDF) was instituted from April 2011 as a successor to the Interim Cancer Drugs Fund, which supplied £50m from October 2010 – April 2011 as a means for improving patient access to cancer drugs. The CDF was intended as a stopgap measure before the anticipated reform of the Pharmaceutical Price Regulation Scheme (PPRS), the NHS's current branded drug pricing scheme. Since its inception the CDF has helped over 7,500 patients access drugs that are not normally available on the NHS. Barriers to access have been due to:¹⁹

- Drug/indication combinations not recommended by NICE on the basis of cost effectiveness, or where the recommendations materially restrict access to the treatment to a smaller group of patients than the specifications set out in the marketing authorisation (an 'optimised' recommendation)
- Drug/indication combinations on which NICE has not, or not yet, issued appraisal guidance (this may include drugs that are not licensed for the clinical indication of interest, where the clinician considers such a treatment to be the most appropriate based on clinical need)

Research has found that bevacizumab is the most popular drug paid for through the fund, with 570 applications made for the drug for patients with bowel, kidney, or breast cancer between October 2010 and June 2011. The next most popular drug was cetuximab, for which 250 applications were made for patients with bowel or head and neck cancer.²⁰ Interestingly, there was also found to be significant variation in the use of the fund regionally, with some PCTs making over a hundred applications, and others making just eight.

The future of cancer drugs

The CDF is funded until April 2014, after which the controversial value-based pricing (VBP) scheme is set to come into play. It is expected that VBP will cover all new drugs that enter the market after 2014, whilst all of the drugs on the market prior to 2014 will be covered by a yet to be determined successor to the current PPRS scheme. The main aims of VBP are:

- Better access for patients to drugs
- More innovative drugs
- Better value for the NHS

However, there has been a lack of clarity around how value will be defined, which can significantly affect the price of a drug, particularly cancer drugs. This could in turn prevent patients from accessing some drugs which do not meet the new pricing scheme's definition of value for money. It is vital during and after the transition to VBP that cancer patients continue to have access to innovative drugs. In December 2011, Macmillan Cancer Support published a document on the CDF which included the recommendation that all the treatments currently made available through the CDF be automatically made available on the NHS when the new VBP system comes into place.²¹

19. Department of Health, March 2011.

20. Kmietowicz, 2011

21. Macmillan Cancer Support, December 2011.

2 Emerging themes

Overview of interview process

This project's methodology was founded upon a literature review and a series of interviews with a cross section of professionals involved in the commissioning, managing and delivery of cancer care, as well as representatives from the patient and third sector communities. The semi-structured interview schedule covered 11 open questions and covered a variety of issues relating to the cancer care pathway. Particular focus was applied to the future of cancer commissioning and the role cancer networks may play in this.

Establishing interviewees' understanding and perceptions of the current commissioning processes was the first priority. Interviewees were also asked to reflect on what they perceived to be the strengths and weaknesses of the process, and more specifically, the degree to which cancer networks have been and are able to influence providers and commissioners. Opinions were sought on the relationship between networks, commissioners and providers, and how this impacts efficiency and accountability.

The focus then switched to commissioning processes. Interviewees were asked about the impact of networks on the delivery and quality of services, on outcomes, and on expenditure. We then asked them how they thought commissioning would take place in the future, with reference to specific cancers. Various risks were discussed, including technological risk, clinical risk, financial risks and risks of low volume activity, any one of which may develop as a result of the new commissioning arrangements.

With the above in mind, interviewees were asked to describe how in their opinion commissioners and networks could be configured in the future to ensure best outcomes for patients. This question explored configuration at local, regional and national level. Views were sought on whether networks should be given responsibility for commissioning, with or without financial control.

Next, we gathered understanding and opinion on how stable and effective relationships may be developed between CCGs and those commissioning rarer cancers. Two areas were reviewed:

- did the interviewee understand who does what in the new environment?
- did they, more specifically, understand the role of networks, CCGs and GPs?

Within this area, interviewees were also asked how they thought commissioning changes might influence individual provider trusts, with reference to cancer centers and units. They were asked to consider any potential risks. Finally interviewees were asked to define the obstacles and the facilitators to achieving good outcomes as a result of the changes in commissioning and the changes to networks. Four key areas were discussed, relating to:

- (1) **finances**
- (2) **the levels of bureaucracy**
- (3) **whether clinical resistance would change**
- (4) **the impact of political resistance**

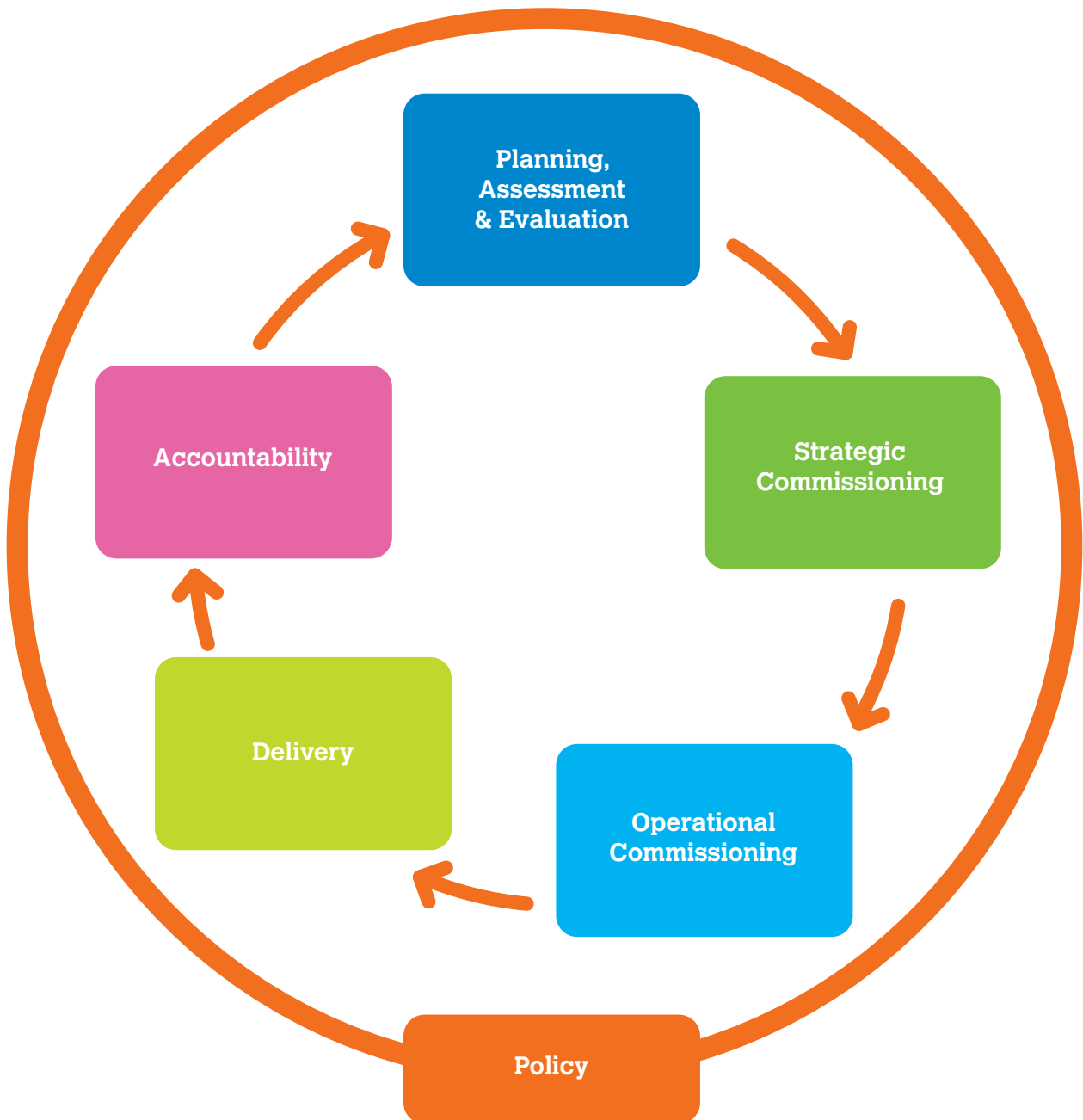
Framework for analysis

To analyse and present the findings from the interviews we established a framework of functions, which summarises the cancer care pathway as follows:

- **Planning, Assessment and Evaluation** – The planning, assessing and evaluation of the needs of the defined population in terms of volume and capacity as well as predicting need. Future proofing also constitutes part of this process in reviewing past outcomes and incidents to predict future requirements. Compliance with pathway models of care would also fall within this function.
- **Strategic Commissioning** – The commissioning of strategic services and the allocation of resources with the aim of best meeting the assessed needs of users.
- **Operational Commissioning** – The commissioning of the operational infrastructure to help operate and support services and resources at the strategic commissioning level.
- **Delivery** – The delivery of healthcare services at the point of need.
- **Accountability** – Acknowledging and assuming responsibility for decisions, actions and services within the scope of delivering specific services for the defined population; also covers the responsibility to explain and be answerable for the resulting consequences arising from those decisions.
- **Risks** – In respect of the future, the perceived risks associated with the proposals and processes under discussion.

2 Emerging themes

Overarching all of these functions is the function of policy which helps to plan, shape and give direction to each part within the framework. It is the context within which we research, observe and write and therefore does not form part of the list of subsections as stated above.



2 Emerging themes

Key Results from the Interview Process

Assessment, Planning and Evaluation

Strengths

All respondents agreed that the cancer networks had been instrumental in overseeing a vast improvement in the assessment of need, and in the strategic and local planning of services within defined populations. There was also general consensus that networks had facilitated a joined up approach to the planning process. It is believed that their constituency means they are better placed to define service requirements. While the initial drive had been to improve the management of cancers not defined as rare, good progress was being made to assess and plan for patients with rarer cancers. Because there are so many cancer types, involving a large and diverse spread of services, prioritisation has been a necessity. Overall, it was agreed that the prioritisation process was largely successful.

There was general acknowledgement that some improvements had been made in the understanding of service demands, and in the planning processes of delivery of care. Likewise there was a degree of agreement that processes had improved for the evaluation of high cost drugs and treatment. While it was accepted that there were still some problems, overall the system was judged to have significantly improved over the last 10 years.

The role of NICE was commented on. While there was agreement that NICE had further work to do the overall process was perceived to be relatively robust. IOGs were felt to have been an effective method of improving the quality of treatment and outcomes, although for many this was a subjective view. It was felt there was now a better understanding of the costs of treatments and evaluation of treatment efficiency. However, there is a greater need to develop transparency and educate both the public and clinicians on how decisions are made, and why certain treatments are not approved by NICE.

Weaknesses

Looking at the present

A number of areas for improvement were identified. Many of these areas were described as being addressed or well known about and judged to be widespread across the system.

The most common problems identified related to poor data quality and the availability of high quality information; incomplete data entry on the cancer registry being an example of an unresolved issue. While some respondents felt gentle persuasion and encouragement was a solution, there were others who felt a tougher stance (even a system of fines) was required in order to improve information gathering. It was felt that not all Trusts gave proper consideration or attached the right amount of importance to this area. Cost savings and financial cut backs had taken place at administrative/support levels and this was potentially impeding the input and completeness of the information. Stress was placed on the outcomes of data incompleteness which leads to gaps in knowledge of the current situation and can compromise planning.

While networks had played a significant role in improving data entry and the utilisation of information, they had largely done so by encouraging financial support from commissioners and providing encouragement at the provider level through clinical teams and CEOs. Networks have little formal powers to enforce compliance in this area. However, as the relationship between networks and providers has become more distinct, there was felt to be a greater ability to exert influence on CEOs.

The outcome of poor data entry, incomplete data sets and paucity of information ultimately means that commissioning, delivery of care, evaluation of the care given and the outcomes are not as robust as they could be. This in turn leads to poorer assessment of need and thus the cycle goes on without gaining the complete picture. The end result can only be inferior commissioning and provision of services to the defined population.

Looking to the future

Such is the clear dependency on cancer networks, there is a real fear that NHS reforms will fundamentally change the role of the networks and threaten, even reverse, progress. This is largely in part due to the 'honest broker' role the cancer networks have proven themselves to fulfil; a role which in many respects NHS management have appeared to be unable to bridge.

But the opportunity now exists to capitalise on the expert knowledge that networks have accumulated, especially their in-depth understanding of local population needs and local issues facing providers. They could have a greater impact on defining needs by working alongside Clinical Commissioning Groups, local authorities and providers of care and where appropriate influencing the JSNA.

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While some interviewees had reservations about the networks' ability to influence strategy with the creation of the National Commissioning Board and the four Local Boards, others argued that the networks would provide the in-depth knowledge and the organisational memory that these much larger strategic groups lack. It was felt their multidisciplinary approach and clinical expertise were vital in securing improvements to assessment and planning; they could even become the vehicle for delivery.

Conversely, others expressed concerns about the continuity of the networks and how they would be configured in the near future. There were worries that this interim phase could lead to a break down in the development of the holistic approach currently being adopted. For example, concerns were expressed over the assessment of the needs of complex cases. Many patients have multiple morbidities and co-morbidities, and disease specific solutions are not the answer. Furthermore within each cancer group, however prevalent, there will be complexities within pathways and treatments. It was felt to be essential not to lose this understanding in any future reconfiguration.

Despite the widespread consensus on the identification of current deficiencies, opinion was divided as to how they could be addressed and the risks mitigated. The key question seemed to focus on whether or not the networks should be given full responsibility for commissioning cancer services, and with it the managing and planning of care at a strategic level. Concerns were expressed about the networks' ability to stay neutral and remain objective, or whether indeed they would have the necessary skills set for the task.

In terms of improving and tracking progress, process targets and outcome measures need to be introduced. One way in which this could be addressed is by enhancing the NHS Outcomes Framework.²² Under Domain 1: Preventing people from dying prematurely, instigating clearer targets and measures to help improve rates of early diagnosis and increased public awareness, particularly in terms of the rarer cancers, is recommended. Likewise, under Domains 2, 3, 4 and 5 which address enhancing quality of life for people with long term conditions, helping people to recover from episodes of illness, ensuring a positive experience of care and creating a safe environment, greater clarity in terms of outcomes for survivorship should be included. This would build upon

progress to date and help future commissioning of rehabilitation and end of life care to be conducted in a more cohesive way with cancer centres and cancer units exchanging information and working in a more collaborative fashion.

All interviewees were asked if they believed that the current method of defining cancers into the big four large groups, and defining the rest as rare, was a satisfactory way forward in terms of planning, commissioning and delivery. Many felt that it had its problems but were unsure what could replace it. The point was made many times that fragmentation of commissioning with the 'big four' was problematic, and that even these patients sometimes had highly complex pathways. Breast cancer can be classified in a number of ways according to cell type and can therefore be broken down into rarer cancers. On the other hand all paediatric cancers are rare and require a high degree of specialisation. In reviewing head and neck, it is clear that they are not rare in terms of how radiotherapy departments work, but are rare in terms of incidence within the population. The general consensus is that the system is not perfect, but for planning and management purposes it is an adequate proxy.

In conclusion there are a number of concerns issues relating to how well assessment of need and high level planning is carried out and managed. There is no indication that any of these issues will be addressed by the changes planned within the reconfiguration of the NHS. However some interviewees saw opportunities for networks to provide either more support, or take on additional roles to address these outstanding shortfalls. The success of networks in achieving real change was identified as an important factor for the future and that any change should ensure the same level of support and expertise.

22. See Department of Health (2010), Equity and Excellence: Liberating the NHS - July 2010, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf [accessed 9th May 2012]

2 Emerging themes

Recommendation	Action taken by
In order to increase responsibility and ownership outcome measures should be assigned to local CCGs. Necessary levers and infrastructure need to be put into place which the Commissioning Outcomes Framework may well help to provide and give direction to.	NHS Commissioning Board
The accountability relationship between specialist commissioners, CCGs and networks needs to be clearly defined so everyone knows where the authority lies.	NHS Commissioning Board
Process targets and outcome measures need to be introduced to track progress. NHS Outcomes Framework ²³ should be enhanced in order to take account of all rare cancers. This should be a key priority.	NHS Commissioning Board
The pursuit of improved data collection and gathering needs to continue. Penalties should be factored in for contractual failure, such as fines and/or a reduction in referrals. Greater weight to data management could also be factored into the Care Quality Commission (CQC) assessment.	CCGs and Specialised Commissioning

Strategic Commissioning

Strengths

Looking at the Present

In terms of strategic commissioning, a strong consensus emerged from the interviews that the cancer networks' understanding of the commissioning process allowed them to work effectively with commissioners and providers at all levels. This has helped to promote a healthy sense of working together and an 'honest broker' role, facilitating and organising effective coordination between the different parties of commissioners and clinical groups. Moreover, the control of finances at a strategic level was noted to have greatly improved as a result of the involvement of cancer networks, not least in terms of providing informed strategic direction on how money is spent.

With specific regard to cancer drugs, interviewees highlighted the ability of cancer networks to make strategic decisions about the purchasing and allocation of

drugs and services to a far greater extent than was previously experienced. The reasoning behind this was put down to an accompanying increase of information on volumes, the quality of which has helped to make a notable difference to the decision making process. Nevertheless, there was still a perceived need for ongoing improvement and development in this area.

Looking to the Future

Emerging from the interviews was the feeling that there needed to be a substantial link between specialist commissioning, managed through the National Commissioning Board, and local commissioning.

Adopting the approach of commissioning the 'big four' cancers at a local level with the others commissioned centrally was generally perceived to be a strength of the process going forward, largely because of the sense of responsibility and ownership it affords local clinical commissioning group (the point was made that there is very little point in assigning a target to someone who does

23. See Department of Health (2010), Equity and Excellence: Liberating the NHS - July 2010, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@cn/@ps/documents/digitalasset/dh_117794.pdf [accessed 9th May 2012]

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not have the necessary levers available to ensure the target is met). It was felt that the rarer cancers do need wider strategic approach. This in turn assists GP engagement and participation in the planning of cancer services.

Weaknesses

Looking at the Present

Turning to the current perceived weaknesses, it was largely felt that specialist commissioning has been engaged in the contract process without a full understanding of the clinical pathways involved. In contrast to the perceived strength of cancer networks (which have a recognised clinical component), specialist commissioning has largely been concerned with fulfilling sufficient numerical requirements in terms of who is involved, while not necessarily maximising the professional or clinical skill set potential. In like manner, this lack of understanding of clinical pathways was further exacerbated by the fact that specialist commissioning took place far removed from the point of delivery. Insufficient knowledge and understanding of what is required ‘on the ground’ has tended to result in commissioning which does not really meet the needs of the population in question, focusing more on targets as opposed to outcomes.

By becoming commissioners it was felt cancer networks would lose the ability to influence both providers and CCGs, and that GPs would take limited responsibility for addressing some of the issues in cancer care that are relevant in primary care. Other concerns included the loss of the clinical makeup of the networks should they become commissioners. However there were others who saw real opportunities for networks to succeed in this role.

With specific regard to the rarer cancers, interviewees argued that pathways are very complex and lack the necessary data to establish the pricing and costs involved in each part of the pathway. For example, attempts to tidy up the tariff process, what is paid for and what is not and how to properly reward a malignant brain tumour (MBT), has varied across the country. Consequently various interviewees expressed the fear that different agreements at different levels will all start to emerge as steps are taken towards NHS Commissioning, particularly for rarer cancers.

Another perceived current weakness was the fact that there is lack of evidence to demonstrate improvements that have taken place in terms of survivorship. There could be a 5-10 year wait before the necessary evidence

can be generated in order to demonstrate improvements. It was suggested that if pure outcomes were the ultimate goal, sufficient process targets were required in order to keep things on track.

Looking to the future

When turning to the future there were varied concerns and differing levels of understanding as to how both commissioning would work and the role the networks would play in the commissioning and delivery of services. The overall concern was that much of the good work done by networks in providing support to the development of models of care and service reconfiguration would be lost.

Within the new arrangements for commissioning there was a need expressed by some for a collective governance structure would bind cancer networks into supporting clinical commissioning groups. This would mean that while the money and the commissioning responsibility would sit with the CCGs, the cancer network could be responsible for developing a proper commissioning strategy within a defined timeframe, as well as helping to shape annual business plans and key milestones in consultation and agreement with CCGs.

It was also felt that the area of focus for the National Commissioning Board was too broad and did not allow for adequate understanding and appreciation of local needs. This in part led to further concerns expressed over the splintering of care. It is understood that whilst breast cancer care is commissioned locally, the radiotherapy which forms the rest of the ‘package’ is commissioned as a specialist service. This broken pathway for commissioning also triggered concerns in terms of supportive care, rehabilitation and survivorship. In a classic example of the right hand not knowing what the left hand is doing, interviewees expressed concerns over just how many of the component parts would actually work in isolation to one another with a lack of unity of the overall pathway. In the case of breast cancer treatment, for example, several interviewees said that commissioning was not being properly undertaken. Commissioning was being carried out as a hospital and not as a service or pathway. Thus, in the case of someone entering the hospital for breast cancer treatment, there is no way to easily establish the patient’s experience, how much is being paid for the service, what the outcome is or where the best intervention for that particular patient is. This situation arises because commissioning is undertaken horizontally as opposed to vertically along a pathway. Thus any opportunities to make efficiencies to the system are being missed. This also points to the complexity and

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difficulty surrounding the effective commissioning of pathways, because it comes down to moving money around a system and incentivising that system.

We therefore propose that there are three main ways the commissioning process could be managed. They are as follows:

1. **Hospitals commission**
2. **Networks commission**
3. **Collaborative commissioning**

Many interviewees expressed a genuine desire for a more integrated system, acknowledging that this was reliant on the collaborative involvement of all stakeholders. Thinking and talking across commissioning boundaries (for instance NHSCB versus CCGs) needs to be actively encouraged so that efficient and effective solutions can be found. Collaborative commissioning between CCGs and all other stakeholders seems to be well worth pursuing. Crucial to the success of this is ensuring that the commissioning process is truly collaborative and not a pragmatic approach which sees all stakeholders coming together around the same table but still guarding their own budgets. Given that under the current plans CCGs will hold the budget for some parts of the pathway and the NHSCB other parts, there is the real risk that should commissioning occur without true collaboration it will lead to the process becoming a complete mess. A collaborative culture is therefore essential and CCGs are well placed to hold the accountability for commissioning the pathway, with networks supporting them as their agents. CCGs should commission integrated care from integrated providers but care should be taken to avoid slipping into monopolistic behaviours. The networks are well placed to help in this regard by providing expert support but if this approach were to be adopted CCGs need to find the sufficient finance in order to fund networks in this role. Otherwise there is the risk that CCGs will not receive the support they require.

Related to this is the fact that whatever model is adopted, leadership is absolutely crucial in order to navigate through this time of change and transition. A reoccurring theme from many of the interviews was real concern over the lack of staff with the necessary skills and expertise being in the right positions to oversee and implement the changes being proposed. It is not a case of the right people and skills never being present in the first place but rather given the speed of change and transition, staff have either been moved from key roles or have moved on from the health service entirely. Thus moving forward there is

a risk that either more gaps in leadership will emerge or become even more pronounced at a time when vision, strategy and skills are needed the most.

Establishing strong and effective connections between end of life care teams, palliative care teams and specialist services was felt to be crucial if effective care packages were going to be implemented. Equally it is vital that healthy links are made between these stakeholders and representatives at the local level to ensure that the care package is built around the patient. It is our belief that commissioning as a whole pathway is the only way to release 'value' and deliver the outcomes and resource benefits that integrated care affords.

Turning to the matter of the number of cancer networks, there was widespread agreement that having too few networks may well have less impact. Interviewees were supportive of the role cancer networks have played in terms of promoting and supporting strong collaborative work at the local level. Steps towards reducing numbers of networks, heading towards a more centralized structure, was considered the wrong approach to adopt, with the belief that services on the ground would be adversely affected. It is doubtful that other stakeholders will find it easy to fill each and every void resulting from this process. It would be naïve to think that disbanding or reducing the number of networks will mean that other bodies in the process will simply pick up on the work that the removal of the network would leave to be addressed. One of the critical issues here concerns defining the reach of the cancer networks' and how far their boundaries extend. One option could be to establish cancer networks for fifty or so local arms of the NHSCB or those CCGs representing a certain size of population. However, on the basis of tumour type a predefined size may either be too small or too big for the network to work effectively. Consequently, there may be greater value in working collaboratively across boundaries and sharing expertise, knowledge and skills. We understand that the networks met in May 2012 to review referral flows and explore alliances which would keep the referral flows intact but reduce the number of networks. The number of networks were reduced to around twenty using this approach which has been forwarded to the NHSCB for information. Furthermore, the integrated cancer system in London could also be a model to look at and learn from.

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Integrated cancer systems and the example of London Uncertainty

A reoccurring issue from the interviews was the example of the reconfiguration and operation of services in the London area. It was clear that what is happening in London is unique and distinctly different to other parts of the country, generating a certain degree of nervousness as to how things will progress into the future. At the heart of these changes has been the formation of integrated cancer systems (ICSs). Comprising a network of hospitals, two ICSs will operate across 5 key areas of London: the north east, north central, north west, south west and the south east. The ICS works as a partnership that aims to provide services across the whole cancer pathway. These groups would work together as a set of providers who would seek innovative solutions to exploit best practice along the total cancer pathway, reducing local variations in quality of care, and consolidating specialist care for rarer cancers. Heavy oversight and commissioner involvement would be kept to a minimum so as to release these groups to do what they think is best.

Cost effectiveness appears to one of the major influences behind this model. In terms of cancer services, such as chemotherapy care at home, rather than the hospitals, in a sense, passing out something to a community service, the community service forms part of the ICS. The incentive is to think beyond the doors of the hospital in terms of income and expenditure. The approach is designed to exploit a cost-effective means of operating services at scale, with the ICS implementing efficiencies as necessary.

Interviewees felt that such an approach will probably not be easy to implement and requires further trialling and testing to determine its effectiveness, particularly in terms of delivery. But the experiences to date of certain key London hospitals demonstrate that a single Trust cannot effectively cover the full pathway alone. Thus in order to maximise resources in a given locality, an ICS model appears expedient.

In all of this there was a general sense of uncertainty as to how the new commissioning system will work in practice. There is a certain element of risk in any form of transition; localism and centralisation both have risks attached to them. So there is a mix of optimism on the one hand and concern on the other as to how things will progress in reality.

2 Emerging themes

Recommendation	Action taken by
That commissioning adopts an approach which considers the total pathway of care thus truly releasing 'value' into the system in terms of outcomes and resource benefits. The introduction of a collective governance structure in the NCB could help to promote collaborative decision making in this regard. An incentivisation scheme needs to be introduced for commissioners.	NHS Commissioning Board
Of the three options we propose for commissioning, collaboration needs to be at the centre of whichever option is adopted in order to safeguard the patient's best interests.	NHS Commissioning Board
That the reach of the cancer networks' and how far their boundaries extend is more clearly defined, perhaps with reference to the ICS model in London.	NHS Commissioning Board
That specialist services and end of life care teams work more closely together to ensure continuity of care from the hospital into the community. The introduction of designated Care Coordinators 'on the ground' charged with specific responsibility to liaise with specialist services would address this need. Consideration should be given to professional training to assist potential coordinators to fulfil this role.	Cancer Networks
Consideration needs to be given to hospitals commissioning the whole pathway and subcontracting against a robust outcomes framework.	NHS Commissioning Board

Operational Commissioning

Strengths

Looking at the Present

There was overwhelming consensus that cancer networks have made a positive contribution to the operational commissioning of cancer care. They have been effective at bringing together various stakeholders and facilitating collaborative working. Having a strong clinical component was also cited as a strength, enabling them to shape and inform the decision making process. Whilst it was recognised that the cancer networks have had their set back from time to time, they have been one of the more consistent stakeholders in terms of driving forward policy, stimulating the delivery of services, development research and audit. The engagement of networks directly with providers has also helped to establish changes and embed

them in the system. Multidisciplinary working concerned with peer review was often regarded as a crucial (considered in more detail later) component of the networks' role. When clinicians work in isolation from one another, it is very often to remain content, unaware of how things can be done differently. By bringing clinicians together to exchange experiences and best practice, it was felt that both patient care and patient experience can be improved.

Overall, cancer networks have effectively and skilfully influenced both providers and commissioners. They have played a pivotal role in the assessment of local populations needs, providing outcome definitions upon which monitoring can be established to evaluate performance and delivery. Their work with providers has aided national initiatives, as in the case of waiting time standards and in transforming patient pathways. Interviewees agreed that

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the cancer networks have helped place the patient at the heart of the commissioning process.

Looking to the Future

Given the track record of cancer networks to date it was felt that there was a clear need for networks to continue into the future, not least in continuing to promote and develop collaborative working and responsibility for outcome indicators.

It was felt that networks represented a significant way forward as a commissioning body across geography, working on behalf of CCGs rather than just supporting them, in the commissioning process. Some interviewees articulated a scenario based on a collective governance framework (noted above) which would see networks bound to supporting the local CCG over a set population (say 1.5 to 2 to 3 million). Whilst the funding and responsibility would lie with the CCG, the cancer network would be working at developing a proper strategy for cancer commissioning.

Along similar lines, many of the interviewees discussed the range of powers the networks possess. The majority felt that any change in this regard needed to be done carefully so as to not disturb the basis of relationship the networks have so successfully established. An increase of power was considered to be a step in the right direction, although some interviewees did not want to see the networks becoming an authority. They argued that the move to an authority would cause the networks to lose their supportive value and change their relationship with other parties, who would view them as a form of management. But others disagreed. Whilst getting the delicate balance was acknowledged to be difficult, the benefits would be found in that the supportive element, which has engendered engagement and collaboration, could remain whilst ensuring the networks possess the necessary power to neither be ignored nor neglected. Suggestions in relation to this centred on developing a reciprocal relationship between commissioners and networks.

Developing the relationship between networks and commissioners still further, it was suggested that a small number of network specialised commissioners should work across Trusts and clinical teams to facilitate the planning and development of specialised commissioning. Interviewees pointed to the need for networks to up skill themselves should they take on commissioning responsibilities. There was the general feeling that there needed to be two distinct skill sets: one that understands

contracting levers and mechanisms and another conversant with facilitation and knowledge exchange. There is a need for both and these will often be found in different types of people.

The networks were considered important to the management of changes to the roles of cancer units and centres. For example, decisions concerning whether there will be one cancer centre with five units or an integrated centre but with some services provided in location A and location B could be made and informed far more effectively based upon the local understanding and knowledge which the cancer networks possess. This could also help to allay the common fear that providers could rapidly expand into new services without due control or thought or that the smaller hospitals could lose out as bigger hospitals take on all the work.

Weaknesses

Looking at the Present

With all cancers, including the rarer cancers, late presentation of cancer was given as a key problem that the cancer networks could try and address more successfully. Improving outcomes was recognised as being hard work, although rapid access to diagnostics, access to clear pathways and systematised care has improved alongside the introduction of a 2-week wait and the expansion of diagnostics to tackle the 8-week waiting time over all. Thus, in general it was felt that the hospital system has been much improved that the hospital system has been much improved. So key challenges remain in patient presentation and GP recognition of signs and symptoms, and speed of referral.

Some interviewees thought that where networks serve to drive service improvement there needs to be a three-pronged approach, targeting increased public awareness on cancer, increased GP knowledge, and more efficient secondary care. These three areas needed to be tackled together in order to address early diagnosis and survivorship. Optimistically, some interviewees felt that the move to GP commissioning could help facilitate this closer working together. In addition to this, extending the current Map of Medicine pathways to include early detection and survivorship may also assist progress in this area. Economic models could then be developed from this, as has occurred with breast and lung cancer.

Most of the interviewees stated that there is a distinct lack of understanding as to the cost of pathways. This was

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partly attributed to a piecemeal commissioning process, but also to the fact that cancer patients are rarely identified within a broader clinical speciality. For example, it was cited that cancer patients are not normally specifically identified within say the clinical field of bowel disease or gynaecology. It was felt that not enough work is being done to draw out such information. By tracking patients through a system framed through contracts means that they remain anonymous, part of a number count within a clinical team's activities. We understand that steps are beginning to be taken in this regard which is encouraging. Three networks have costed patient pathways, NE London for breast; Avon, Somerset and Wiltshire for colorectal and Central South Coast for lung. This is being rolled out across the country.

Linking in with this were concerns over data entry (as noted earlier), which was cited as a particular weakness of current operational system. Whilst a national data set is starting to mature, local commissioners still lack sufficient information and data to make well informed judgements. For example, a small local commissioner is not well placed to comprehend the bigger picture and will only be able to draw upon what local providers are informing them. There is the need for clinicians to decide upon what the benchmarks are in order for the appropriate data to be measured and collected, ensuring against variance in data type and quality. The measurement itself needs to be a robust tool in order to help in this process.

Despite the strength of networks in various ways, it was noted that their ability to influence decision making has varied at the local level. This was felt to directly relate to the issue of influence versus power, and was seen as a potential barrier to progress.

It was felt that there was little formal power within the networks to influence poor performers or those clinicians not adhering to guidelines. The networks and the clinicians within them do seem to have enormous influence but this was felt to be informal rather than formal and whilst largely successful there was a feeling that the networks were not fully empowered to take action when necessary. It is our understanding that technically the power lies with the commissioners who are part of the network so poor performance is relayed to them who can use contract leverage. Nevertheless, from the interviews it is perceived that commissioners seem to have limited power to take action and where there is only one provider of care there is little scope for change. Set against this was the belief that there was real strength in the role of the networks transforming into advisors on commissioning

rather than provider development. The networks were perceived to have a real role in developing contractual frameworks and developing outcome measures.

Addressing the specific issue of outcomes and the difficulty surrounding tracking and measurement, a theme emerging from the interviews was the tendency to revert to commissioning on process rather than outcomes. It was generally felt that it was a mistake for commissioners to contract commission detailed pathways. In actual fact providers are better placed to fulfil this role so long as the necessary mechanisms are in place to hold them to account for delivery.

Connecting with earlier issues discussed under strategic commissioning, interviewees on the ground did not always understand the commissioning process and as such did not feel ownership of it, something which clearly exacerbates a sense of fragmentation and disenfranchisement.

Looking to the Future

Looking at potential future weaknesses, one danger expressed by interviewees was that if networks merge for various reasons, not least costs, the resulting area of network responsibility could be too large to sufficiently represent and inform local issues and needs. There is concern that the networks' makeup will become more managerial in function, as opposed to facilitative, supportive and collaborative. GP 'buy in' could remedy this – that is if CCGs are well supported by GPs who pay special interest to commissioning. Conversely, where there is weaker GP buy in (and in the absence of strong network input), the commissioning process may be severely compromised. We are aware of some cases where networks have merged forming larger networks, such as the North of England, East Midlands and Anglia, where the referral flows are intact and the management is successful. It remains to be seen as to the long term impact and effectiveness of this move as well as its effectiveness across the country but initial signs seem to be encouraging.

Historically, some networks have functioned exceptionally well whilst others have failed to add much value to their constituent PCTs. If networks are to function in a key supportive capacity to CCGs and providers, it is vital that there are measures put in place to prevent post-code lotteries from occurring. One way in which the issue of failing networks could be addressed is by engendering a greater sense of accountability and introducing measures of success against which the activities of the networks could be held to account.

2 Emerging themes

Most interviewees agreed that designating different parts of the commissioning process to different bodies was an obstruction to an integrated, cohesive pathway.

Some interviewees pointed to the fact that not all networks were seen as being able to fully commission due to the fact there were considered to be too close to providers.

The link between provider and GP was also seen as crucial and in need of review. Owing to poor communication between the two, very often too many gaps can emerge for patients to fall through when ensuring all care needs are met from a commissioning perspective. In relation to this, the lack of information and data exchange and collation makes planning and evaluation difficult and was of particular concern when considering the future.

Recommendation	Action taken by
An emphasis placed on 'grass roots' understanding of the commissioning and delivery of cancer care.	CCGs and NHS Trusts
Transparent contractual arrangements with clear targets and outcomes should be introduced to add rigour to the system.	NHS Commissioning Board
Greater powers should be given to networks in order to afford them increased clout and influence. In order to do this they should be given status as a stand alone authority with the agreement they do not receive funding unless key delivery of outcomes are met.	NHS Commissioning Board
An adequate mix of skill sets in CCGs and networks would need to be established to promote and guide effective commissioning. A balance between clinical and commissioning staff would be required in order to establish this mix. This would be defined by the NHS Commissioning Board.	Clinical Support Services
Pathways are developed from the perspective of the patient and not the commissioning divisions.	NHS Commissioning Board supported by the cancer networks.

2 Emerging themes

Delivery

Strengths

Looking at the Present

There was strong agreement that cancer networks had advanced the understanding of clinical and pathways, and facilitated improved linkages at clinical level between cancer centres, units and local GPs. These two areas were considered to have had most impact on the quality of care and the delivery of services.

Although survival rates could not be evidenced the belief was held that the advances in pathway management and the provision of holistic care had improved patient outcomes and experience. The strides that had been made were now enabling commissioners, GPs and providers to think about survivorship, rehabilitation and end of life care in a more perceptive and holistic way than before. The consensus seemed to be that the basics in cancer care were significantly improved enough to focus on the issues that were important to patients and carers, once survival was achieved or the outcome of the condition defined. However there was agreement that there was still much to do to bring all providers and commissioners up to the same standard.

Though progressing slowly, the current programme for reviewing and developing pathways is considered well underway, even for many of the rare cancers.

Peer review, a strong and reoccurring theme throughout all the interviews, was considered to have had a profound effect on services. This successful implementation of peer review was seen to be as a direct consequence of the actions and energy of the networks. There was little doubt that the overall process had been a significant factor in cancer centres and units improving practice and providing the necessary focus on the quality of care.

However there was a view expressed by many that peer review had not yet realised its full potential with regard to strategic impact or influencing behaviours and standards of care.

There were some concerns over the peer review process being largely self assessed and the problems that brings with it, and that too much of peer review focused on process rather than outcome. Most respondents felt this was an area where significant improvements could be made. A role of networks could be to oversee and maintain a pathway level risk register that monitors where

actual provision of pathway care falls significantly short of the clinically effective and best practice pathway.

Throughout the interview process those concerned felt there was no doubt that the networks had been a support in developing the role of other multidisciplinary teams (MDTs) and bringing them together across both centres and units. Teams have reviewed patients through using modern technologies and this has enabled speedier diagnosis and treatment planning. At the same time centres and units have been able to monitor activities and review progress. Information, both input and output, appears to remain problematic. The networks were acknowledged to have made significant improvements in these areas through the funding of MDT coordinators, however there was a concern that that these posts were being reduced due to costs. Trusts may not appreciate the full value of these posts and their significance in importing cancer care and outcomes.

Weaknesses

When considering the weaknesses of the current system of delivering care the impact on patients was expressed by most of those interviewed. The wealth of information gained has been reviewed using the patient pathway itself and the experience the patient might go through.

For patients suffering from rarer cancers, and those with complex treatment needs within the more common cancer groupings, it was agreed that pathways could be difficult to deliver and manage across multi-agency boundaries. The co-ordination and integration of care could often be sub-optimal. This made it not only confusing and frustrating for those receiving care or indeed their carers but also those managing the patients' care.

The pathway of a cancer patient from diagnosis to completion of treatment or into palliative care is complex and multi-factorial, involving a large number of professionals within different care settings and multiple agencies, even for the treatment of the most common cancers. For many patients there will be additional comorbidities, some complications and social or family problems that need to be resolved. Managing this in a holistic way is often not achievable

From the time the patient sees his or her GP they may experience difficulties with the management of their care. Diagnosis of rarer cancers remains an issue, as GPs are not often exposed to many of these forms to recognise

2 Emerging themes

them straight away. There was universal agreement that improvements in recognition of these cancers, the development and implementation of guidelines for early diagnosis and referral are crucial. However there were concerns that the future commissioning arrangements would not address this issue.

As discussed above, for patients with a rare form of cancer the actual treatment pathway can be very complex. It may be necessary to be treated in a cancer centre many miles from their home. Patients may find themselves in a strange environment with no relatives or friends around to support them during a difficult and vulnerable time. Furthermore the cost of the fares or petrol for the patients may not always be easy to cover. For parents of children suffering from cancer there is the additional factor of caring for other children and managing work commitments, as well as the strain this can bring on relationships. The impact of children's ill health on education is well documented. All of these issues are a worry without thinking about the actual care they receive.

Often there is no central information point for patients, who can find themselves passed along a number of agencies and may not always be successful in navigating the system. The nurse specialist in cancer centres or units is often the key worker with most knowledge of how to navigate the system. Difficulties arise when the number of patients does not allow for such in-depth support or where nurse specialists have been reduced to meet savings targets.

The solutions debated included the importance of well documented pathways that could in simpler forms be discussed with patients. The importance of all staff understanding the pathways was also stressed. There was acknowledgment that pathways cannot detail every action movement between cancer unit and cancer centre and back again, but patients need confidence regarding continuity of care and management.

The need to feel that information is being passed between clinicians and that everyone involved has an understanding of the treatment plan is important. This in reality does not always happen and information or results may not always appear on time. Missing scans and blood results which result in repeats or delays cause anxiety and shake confidence. Changes in treatment without good explanations also cause anxiety, particularly if the patient is unsure where the decision was made.

Patients with other pre-existing conditions or multiple morbidities could also find themselves being managed by a variety of teams, all of whom need to know the patients' full history and management plan. This was quoted as the area where there was least joined up clinical management. Decisions made by GPs and other hospital specialists could be taken without proper reference to the patient's cancer. This was believed to be caused by the breakdown in communication between teams and in particular with the GP who may not always be fully up to date. The importance of real time information was stressed, especially the need for swift access to the patient records.

Of note was the comment made regarding lost results and scans and the delay in receiving reports. This is a common cause of complaint and concern of cancer sufferers. Their confidence can be wiped out very quickly and take some time to rebuild. To the nurse or doctor this may be a daily occurrence; to the patient it is only happening to them. The waste in time and money of repeated scans, lost notes or poor information given to patients has never been fully assessed, however best practice points to the fact that doing things right first time not only increases quality but drives down cost. Delays in getting results of scans to patients were also commented on as this involves a 14-day wait. Whilst this may be due to operational issues there is a feeling that the NHS operates on a 14 day rule.

Once the patient had been treated for the acute phase of the disease there seemed to be another hiatus where management of rehabilitation could often fall between the GP, cancer units and cancer centres. Often quoted examples were head and neck cancer and sarcoma; the first requiring speech and language therapy and the latter extensive physiotherapy or home adaptations. Both are commissioned locally, though the GP may not be aware of the patient's need, the funding may not exist or local waiting times maybe lengthy. The cancer centre, whilst knowing of the imperative, cannot influence local providers or GPs and does not hold the purse strings. Likewise survivorship and palliative care were not felt to be as embedded in the whole pathway as they might be. The overall feeling was that patients could easily become bewildered, frustrated and sometimes receive inadequate treatment and support. For many there was inadequate information for patients regarding specific aspects of their care. While there were mixed views on how this could be overcome, suggestions included that centres be commissioned for the whole pathway and be responsible for subcontracting. This is not without its difficulties and would involve a transfer of responsibility and finances to service.

2 Emerging themes

In cases where the patient had been cured and is on a follow up regime, it was felt this too lacked sufficient support. Patients are confused about how often they should be followed up and scanned. The evidence base may point to one thing, but practice within individual hospitals another. Breast cancer was the most often quoted example where there is no evidence to suggest that frequent follow up is essential in managing recurrence, but this is still a practice that occurs. When follow up regimes change, patients then become anxious, so more needs to be done to enable the development of patient understanding.

The final issue raised here was the matter of letters to patients. There is evidence to suggest that not all patients receive copies of letters to their GPs and in some cases these are denied. In this day of transparency it seems incongruous that patients are being denied information about themselves.

Another area identified for improvement concerned the entry of patients into clinical trials. There remains insufficient information given to patients about the importance and availability of clinical trials. Conversely others expressed the view that informed or semi informed patients were sometimes distressed when they were not entered into trials for good clinical reasons. It was felt that a greater emphasis on trials should be made with clearer information for patients.

Alongside this there are concerns over the information patients are given generally about both their condition, and the drug therapies and treatments open to them. With the advent of the internet, and media focus on post code lotteries and the NICE approval process, patients were increasingly demanding treatments they had read about. These are of course not always suitable for every patient depending on the type of cancer being treated. It was felt that more needed to be done to make this information more transparent and less technical. Involving the patient in the decision process must be embedded.

Transparency was discussed with reference to benchmarking and the use of outcome measures. Overall it was felt that benchmarking had improved but it was still not being used sufficiently well to improve the quality of care. The systems to tackle variation in performance against clinical guidelines and best practice need to be made more robust, and improved systems introduced to reduce variation. Patient friendly outcome measures are thought not to be in place, so it is difficult for patients to

assess the performance of their clinical team. This view was frequently expressed with regard to commissioning and seems to be an issue that must be addressed urgently. Those at the centre of delivery commented on some of the issues they faced in their working lives with regard to disposition of services. It was acknowledged that cancer centres and units had to work well together and that it is important for the patient to be treated locally where possible. However for some the politics behind where services were placed was not always seen to be in the best interests of patients. This was particularly true for the very rare cancers. Services duplicated or divided for non-clinical reasons placed additional hazards into the system. There was a belief that for some larger trusts, securing the bottom line or preserving high profile services was the imperative. Views depended on the roles of those responding, but for some clinicians the travelling element was an ineffective use of their time. There was acknowledgment that a great deal of improvement had been made in locating services in the right place, and while problems remain, this was largely a success story, with improved clinical care overall. The networks were believed to have had most responsibility for effecting these changes and their neutrality had been beneficial in negotiations between trusts.

Despite the above there were some concerns that networks and commissioners had not entirely been able to prevent services being delivered where they should not be. Greater powers are needed to enforce changes and re-configuration; achieving the optimum balance of service provision for patients and staff must be a priority.

Looking to the future

Interviewees wanted to see improved collaborative working between cancer units and cancer centres. The strengthening of regional networks was thought to be instrumental in achieving this.

There was divided opinion on whether networks should be commissioning bodies in order to achieve improvements in delivery. Once again the emphasis was on measuring outcomes and patients' experience, rather than process. Regardless of how services are technically commissioned it was suggested that payment on delivery might enable a focus on improving the patient's journey. There was strong agreement that the new commissioning arrangements should place an emphasis on improving diagnosis times and access to diagnostics.

2 Emerging themes

In terms of improving the patient's journey, one way in which this could be addressed is by creating Care Coordinators who would be charged with responsibility to ensure that all aspects of the patient's care from beginning to end is organised and 'joined up'. Utilising agencies and organisations from the third sector to provide this role could be an effective way of drawing upon skills, abilities and insights which already exist in the system and would be extremely useful in care coordination. One way in which this could be practically applied is that care coordinators be based in the cancer centre and carry a certain case load. Assistance and support could be provided by a liaison officer in the relevant cancer unit. These individuals would then be able to support the patient through gaining access not only to medical and nursing care but also to those other areas where support is so often required, for example in transport, benefits and counselling.

Concerns about the future could be described best as a fear that we would fail to put in place the mechanisms and structures to address the weaknesses of the current system. Public education with regard to screening, early identification and reporting of signs and symptoms was not felt to be sufficiently addressed. There was insufficient acknowledgment of the importance of survivorship and not enough emphasis on integrated care.

There were very real concerns that the work begun on reviewing total pathways may not continue if networks covered larger areas or merged with other clinical networks. A change in role to supporting commissioners might halt the work on provider development and restrict collaboration. It was considered important that the networks continue their work in developing communication and dialogue between primary and secondary care. The new commissioning process could not be allowed to set back this good work. Likewise, some felt there to be a real danger that individual cancer centres would decide where services are delivered, potentially reducing services within some units and adversely affecting trusts. Reduction in income streams and a destabilisation of other services could occur. Conversely, others thought centres could be asked to provide the whole pathway and decide where to subcontract. Clearly this would have to be done in the best interests of the patient, with due regard to clinical safety and outcomes. Centres in this case would need to be held accountable through outcomes and pathway management.

A similar fear concerned the possibility that individual trusts would develop services on their own supported by local GPs. There was general anxiety that measures would not in place to halt poor services.

In summary it can be seen that good progress has been made in the delivery of care to cancer patients but there are still a number of outstanding issues to be tackled. It would appear that the planned changes in themselves are unlikely to resolve these issues; indeed there is a real fear that they will destabilise the current progress.

2 Emerging themes

Recommendation	Action taken by
The peer review process should be strengthened and enhanced. External reviews need to be impartial and transparent set against a pre-defined criteria, with less self assessment.	NHS Commissioning Board
That cancer networks oversee and maintain a pathway level risk register that monitors actual pathway care against best practice pathways.	Cancer networks
The use of cancer Care Coordinators should be explored. Consideration should be given to using the third sector. Contractual agreements with suitable governance and accountability frameworks would need to be put in place.	CCGs
That the patient becomes an active participant of the cancer team and is given full access to their record including all relevant non-medical information and data.	CCGs and NHS Trusts
The patient should be involved in deciding if the service has been satisfactory and if full payment should be received.	NHS Commissioning Board
That commissioners build into contractual arrangements the requirement to review disposition of service and develop appropriate business cases with reference to quality of care and patient experience. Public awareness should be more robust and decisions transparent regarding clinical outcomes in order to support this process.	NHS Commissioning Board
A full mapping of pathways and their costs needs to be adopted and supported by clear outcome measures and a well defined accountability and responsibility structure.	Cancer networks

2 Emerging themes

Accountability

Accountability was a reoccurring theme throughout the interviews and cut across every discussion from planning to commissioning and into delivery. It could be said to be the glue that needs to hold it all together; the success of holding people and organisations to account is vital in improving how we plan and manage for these patients. Much has been discussed already with regard to accountability, but there are some points worth remarking. As previously noted, there was a firm belief that peer review had increased clinician and trust accountability in respect of adherence to guidelines and outcomes of treatment. However it is still a process with no outcomes measures with which to hold providers and commissioners to account, and encourage changes in clinical practice or behaviours. While many believed the reforms are an opportunity to focus on outcome measures, rather than process measures, it is certainly not the case that the reforms in themselves will achieve this without the English Commissioning Board making it mandatory.

While lines of delegated responsibility are clear in terms of commissioning and the role the networks play, there was concern of how PCTs and commissioners are held to account. The introduction, uptake and funding of new drugs, despite NICE guidelines, was an area defined as needing attention. It is still possible for PCTs to decide not to fund drugs, and at present there are no sanctions. Post code lotteries can develop, and in fact there are some currently in existence.

Whilst the networks help to glue together those who are accountable, networks cannot hold others to account. Currently, the networks are accountable to their membership organisations through the network boards. Given what appears to be a disjointed working relationship, it is unclear how the performance of networks can be measured and value for money ascertained. If networks are to be successful in the future

and add greater value than that already in place, there needs to be a change in the accountability matrix.

Nowhere within the future plans is the patient enabled to hold commissioners or providers to account for services they receive. Networks do indeed have patient representatives, but these were reported as having varying degrees of success, with one network reportedly excluding the patients when drawing up the framework for engaging patients.

In order to hold those responsible to account at whatever level and where ever they operate (through planning commissioning to delivering and evaluating care) it is essential that meaningful engagement takes place. There needs to be clear accountabilities across the whole pathway from the board down to the ward or department. Each should be held accountable against simple measurable outcomes that give clarity to all, including the patient.

The biggest fear was that no-one would be held properly accountable in the future, that networks and commissioning organisations would be too big, measures become too cumbersome and that process would be continued to be used as the proxy measurement for good care. The fragmentation in commissioning pathways would enable too many gaps to develop where no-one was taking due responsibility.

While it was believed that at present Trusts can be held to account for their care and the services they provide, the mergers into larger organisations may impact here as well. This could reduce the choice for commissioner and patient and possibly result in powerful organisations immune to outside influence.

Recommendation	Action taken by
<p>To counteract the power of large cancer centres, Payment by Results needs to be modified so that Trusts or other providers only receive the full amount if they meet delivery and outcomes targets, as in the Work Programme. The information capability needs to be in place to manage this change.</p>	<p>CCGs</p>

2 Emerging themes

Risks

Transition

The main theme arising in the area of risk was the transition to the new process of commissioning itself. There appeared to a lack of full understanding of how the new process will work in theory and in practice. Some interviewees openly admitted they were not really aware of what any of the changes involved. Others expressed some level of understanding but did not really know how it would work in practice, adopting a position of waiting to see how developments unfolded and seeking to learn as they went along.

Lack of understanding

In general, there seemed an even split between cautious optimism and doubt over the potential efficacy of the proposed changes. Perhaps most crucially (as mentioned earlier), the changes proposed do not appear to address the weaknesses in the current system, particularly pertaining to delivery.

Lack of ability to drive forward change

The networks' lack of power to direct and really drive forward change is seen as a risk. As discussed within our framework of functions, the networks are well placed to serve in this role. Their present advisory and supportive role, whilst vital, has resulted in varying degrees of effectiveness.

Looking to the future, the area of information and data sharing underpins much of what is being discussed in terms of commissioning. If attempts are made to establish more integrated pathways of care, then outcomes and benchmarking become all the more important. However, if the corresponding steps are not taken to improve data sharing and dissemination then there is the risk that the information required will simply not be there.

Efficiency saving and budget restrictions

As with many areas in the current financial climate, with the drive for efficiency there is also the risk that no real tangible benefits will be felt. The danger is that decisions will largely be made on the basis of what saves money, as opposed to what will contribute to more of an effective and efficient service. Examples were offered in terms of treatments, where the cost of providing the treatment may be high, whilst the cost per patient may be quite low. For example, radio therapy was cited as an extremely cost effective treatment per patient. In total 5% of cancer spend goes on radio therapy, which is considerably small in comparison to the number of cures which can be attributed to it. Nevertheless, capital outlay is significant due to the price of equipment and the concrete bunkers for them to be sited in. Whilst a machine may cost approximately £1.5m, it may be used all day over 10 years; therefore the actual price per patient is very low. A lack of investment may result in the use of older equipment, which will ultimately become technically obsolete, thus challenging the ability to keep rolling forward with newer treatments and techniques.

Conversely, on the subject of generating more income, there was also concern expressed over the risk of the larger cancer hospitals and cancer centres taking on increased volumes of work and pushing out the smaller hospitals. There was also fear that some cancer units may do things in isolation and of their own accord. Whilst this risk was expressed it was also questioned as to how this would happen in reality. Nevertheless in order to negate risk, tighter and more transparent commissioning may well provide a solution.

3 Conclusion

Since the inception of cancer networks there has been an enormous change in the way cancer care is delivered. The networks have been instrumental in pathway improvement and costing, improving peer review, re-organisation of services to ensure safety and good practice and most recently making improvements to the patient experience. Importantly the networks have been able to function as an honest broker between commissioners, multiple providers and GPs. There can be no doubt as to their success.

Even the most basic level of enquiry in this area quickly provides ample evidence of the level of complexity involved in the commissioning of cancer care and services. Over the last 5-6 years we have found that good progress has been made in terms of improving services for the 'Big four' cancers and for rarer cancers as well. Within this context, cancer networks have played a crucial and valuable role which was readily identified and praised by all interviewees.

A number of issues arise for those working in the field. The current commissioning and organisational arrangements do not tackle concerns regarding integration and collaboration which are so important in the delivery of care. These concerns are not adequately addressed by the reforms and they may be made worse at least in the short term.

There is a real fear that with the changes being made to both the commissioning process and the structure and function of the networks that progress may be reversed or hindered.

From our interviews and research we have identified the following key issues:

Planning, Assessment and Evaluation

- Data collection is still incomplete. This has a direct bearing on the commissioning process, the effectiveness of peer review, service reconfiguration and ultimately patient outcomes.

Strategic Commissioning

- Commissioning of cancer services is still based on targets and not outcomes. This focus on targets distracts from the importance of commissioning pathways of care, where patient outcomes and experience are of paramount importance.

- There is real concern about the future and the fragmentation of the commissioning process and the impact this may have on patients.

Operational Commissioning

- Clinicians' understanding of the commissioning process is insufficient. This fosters a sense of disenfranchisement and ignorance of the bigger picture, which has a direct bearing on efficiencies and collaboration.

Delivery

- Pathways are still not fully designed around the patient and integrated services remain elusive. There is greater scope to involve patients in the design and evaluation of services. Patients should be allowed to become more active participants in the management of their care.

It is not clear that the new NHS reforms will address these issues. In many respects there is the real danger that the reforms could help to fragment still further the commissioning process.

Leadership will be crucial in navigating the way forward. Concerns are being voiced that leadership is lacking now and that this will be exacerbated as roles change and people move on. This needs to be addressed as a matter of urgency.

Nevertheless, the reforms could provide the context to tackle these issues and find solutions. In this regard, we believe that robust forms of accountability are essential in order to establish the basis for change. Accountability, from planning to commissioning and into delivery, was repeatedly urged throughout the interviews. Strengthen the mechanisms of accountability and we will improve how we plan and manage cancer care.

Whatever structures and processes are in place in the future, we must not lose the good work the networks have done. If they are to be replaced we need to ensure they are by organisations and people who can deliver changes across multidisciplinary and multi-organisational boundaries. Finally, cancer commissioners must be able to provide clear and transparent evidence that proves patient interests are at the heart of any changes.

Appendix

Steering Group Members

Jonathan Shapiro	2020health (Chair)
Professor Sir Mike Richards	National Cancer Action Team
Professor Hilary Thomas	KPMG Health Advisory
Dr Elspeth Macdonald	East Midlands Cancer Network
Mary Barnes	Avon, Somerset and Wiltshire Cancer Services
Georgina Grant	Portcullis Public Affairs
Bob Park	North East London Cancer Network
Mark Reale	Takeda UK, Ltd.
Ross Selby	Takeda UK, Ltd.
Gail Beer	2020health
Matt James	2020health

Telephone interviewees

Mr. Robert Ashford	Consultant Orthopaedic & Musculoskeletal Tumour Surgeon, University Hospitals of Leicester NHS Trust & East Midlands Sarcoma Service; Chair of the East Midlands Cancer Network (EMCN) Sarcoma Advisory Group (SAG)
Alex Berry	Divisional Commissioning Director, London Specialised Commissioning Group
Dr. Anthony Brzezicki	CCG Chair, Primary Care Lead for South West London Cancer Network, LHP and Member, Cancer Implementation Board; Chair, Public Health Primary Care Early Diagnosis Work Stream, Chair Implementation Group
Mia Card	Clinical Nurse Specialist in colorectal cancer, Bristol Royal Infirmary
Jon Currington	Acting Head of Strategy and Planning, Midlands and East Specialised Commissioning Group – East Midlands

Appendix

Telephone interviewees

Dr. Christine Elwell	Consultant Clinical Oncologist, Trust Cancer Lead, Northampton General Hospital; East Midlands Cancer Network's group on acute oncology services and radiotherapy
Mr. Nader Francis	Consultant Colorectal Surgeon, Yeovil District Hospital NHS Foundation Trust; Chair, Colorectal Network Site Specific Groups (NSSG) for the Avon, Somerset and Wiltshire Cancer Services Network
Russell Hart	Radiotherapy Services Manager, Nottingham University Hospital
Dr. Tom McCulloch	Consultant Histopathologist, Nottingham University Hospital
Teresa Moss	Director of National Specialised Commissioning Team; Director of National Cancer Action Team
Prof. Adrian Newland	Professor of Haematology, Barts and The London School of Medicine and Dentistry and Medical Director, North East London Cancer Network; Chair, London Cancer New Drugs Group
Dr. David Paynton	GP; National Clinical Lead for Royal College of General Practitioners Centre for Commissioning; Former Commissioning Director for a PCT
Ursula People	Lead for Rare Cancers, London and South East Coast Specialised Commissioning Groups
Malcolm Qualie	Head of Health Policy and Pharmaceutical Advisor, Midlands and East Specialised Commissioning Group
Ben Roe	Superintendent Radiographer, Musgrove Park Hospital, Somerset
Mr. Mike Stevens	Consultant Paediatric Oncologist at University Hospital Bristol NHS Foundation Trust
Prof. David Walker	Paediatric Oncologist, Nottingham University Hospital NHS Trust; Professor of Paediatric Oncology, University of Nottingham
Rose Woodward	Patient Advocate at The Rarer Cancers Foundation & Kidney Cancer Support Network

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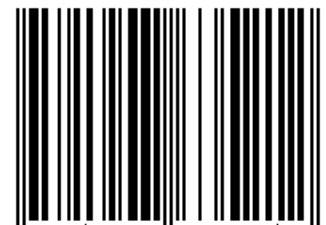
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