

An Intelligence Framework for Cancer

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Acknowledgment

This cancer intelligence framework has been produced by the National Cancer Intelligence Network (NCIN), following a commitment made by the Department of Health to the Public Accounts Committee in May 2011. The NCIN is a UK-wide initiative working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Foreword from Professor Sir Mike Richards

High quality cancer intelligence is critical to improving cancer outcomes. We are fortunate in this country to have many of the elements required to collect, analyse and publish the information required by commissioners, providers and clinicians to make appropriate decisions about cancer services. These include country-wide cancer registration, the collection of administrative datasets and information on waiting times and radiotherapy. We also have dedicated staff working together under the umbrella of the National Cancer Intelligence Network.

However, a recent Public Accounts Committee report (May 2011) has highlighted the deficiencies in cancer intelligence that still exist in this country. We do not, for example, routinely collect information on stage at diagnosis of cancer: this is urgently needed to help tackle late diagnosis and thereby improve survival in line with the Government's commitment to save an additional 5000 lives each year by 2014/15 (*Improving Outcomes: a Strategy for Cancer*, January 2011).

In addition to providing intelligence to those working in the health service we need to do far more to make information about cancer services and outcomes available to patients and the public. This is at the heart of the 'information revolution' and the commitment to 'no decision about me without me'.

This Cancer Intelligence Framework sets out what we have committed to doing. It also sets out aspirations for the future. Our aim is to make our cancer intelligence services truly world class and to meet the needs of all stakeholders. Developments are needed in particular in order to improve intelligence on screening, access to diagnostic tests from primary care, chemotherapy, date of recurrence and cost-effectiveness, as well as a major drive to modernise cancer registries.

Much of this work is already in progress. I am confident that, with the continued goodwill of a large number of partner organisations, major steps forward can be made in the next one to two years.

A handwritten signature in black ink, appearing to read 'Mike Richards', written in a cursive style.

Prof. Sir Mike Richards

Executive summary

The Government has set out ambitious plans to improve cancer outcomes, saving an additional 5,000 lives by 2014/15 and improving the experience reported by patients of their treatment and care.

If this aspiration is to be delivered, cancer intelligence will need to play a critical role by:

- Empowering patients to make the choices which are right for them;
- Supporting clinicians to take actions to improve the quality of the care they provide;
- Enabling service providers to focus on the outcomes which matter;
- Assisting commissioners in ensuring that resources are focused on delivering high quality and efficient services;
- Informing regulators to ensure services are well run on behalf of patients and taxpayers;
- Supporting local government and health & well being boards in the development of Joint Strategic Needs Assessments and health and well being strategies; and
- Contributing to Public Health England's role of advising on the state of the public's health.

Cancer intelligence is the product of expert interpretation of one or more pieces of information to inform future action. Intelligence in cancer relies upon specialised analytical and interpretive skills from a variety of sources. The provision of cancer intelligence is not simply an academic exercise – it should be fundamental to improving outcomes. The contribution that high quality intelligence can make to improving cancer outcomes is set out in Chapter 2.

In order to achieve these aims, information needs to be:

- Credible – providing a firm basis for improving services;
- Comparable – enabling patients, clinicians, commissioners and others to assess differences in services;
- Confidential – protecting the personal information of cancer patients;
- Clear – enabling users to act upon it to improve services; and
- Compelling – providing evidence to influence decision making.

Chapter 3 sets out the wide range of organisations involved in the collection, analysis and publication of cancer intelligence at different points in the care pathway and information cycle.

Progress has been made in improving the quality of the available intelligence covering cancer services. However, as set out in Chapter 4, significant challenges remain. The

Public Accounts Committee has identified a number of areas where urgent improvement is required and this framework meets the commitment made to the Committee to set out, with timelines, the actions being undertaken to address this.

This framework sets out the actions that are being taken to ensure that high quality, timely intelligence is available to all those who need it to play their part in improving cancer outcomes. It is intended to ensure clarity and accountability about who will do what, and when, in improving cancer intelligence, improving the information which is available, removing duplication and maximising efficiency.

Chapter 5 sets out the action which is currently being undertaken by a range of organisations to design and deliver interoperable cancer data, collected as part of clinical practice, quality assured and consistently processed. This will include integrated information on screening and symptomatic pathways.

Cancer intelligence can help empower patients, clinicians, providers and commissioners, but it will only do so if it is accessible and used. Chapter 6 sets out how commissioners, providers and patient groups are being supported in putting information to work to improve cancer outcomes.

The role that cancer intelligence can play in improving outcomes does not begin and end with this framework. The framework sets out the priority actions that are being taken but, as our cancer intelligence capacity and our understanding of its potential to improve outcomes develop, so our aspirations for the future will grow. Chapter 7 sets out the future roles of those organisations involved in cancer intelligence, whilst chapter 8 sets out some potential aspirations for the future, although these will not distract attention from delivery of the core actions set out in this framework.

Our Cancer Intelligence Framework should be seen in the context of the Government's broader proposals for better use of information, more openness, transparency and comparability. The White Paper consultation *Liberating the NHS: An Information Revolution* closed earlier this year – a summary of responses to the consultation giving views on the way information is controlled, accessed, collected, analysed and used by the NHS and adult social care services, so that people are at the heart of these services, was published in August 2011 (see – www.dh.gov.uk/health/2011/08/information-responses).

Following further anticipated input from the NHS Future Forum, work to develop the subsequent Information Strategy for health and social care in England is ongoing, aiming to publish by April 2012. The immediate actions to improve cancer intelligence, set out below, are broadly in line with the Information Revolution proposals.

1. Introduction

- 1.1. *Improving Outcomes: a Strategy for Cancer* set out the Government's ambitions for improving cancer outcomes, including saving an additional 5,000 lives a year by 2014/15 and improving the experience reported by patients.
- 1.2. As the first outcomes strategy to be developed after the publication of *Equity and Excellence: Liberating the NHS*, it made clear that providers of cancer services should focus on improving the outcomes that matter to patients, setting out the range of actions to be taken by the Department of Health and public health, NHS and social care services in applying the Government's reforms. Critical to these are the collection, analysis, publication, presentation and use of data and intelligence.
- 1.3. Cancer intelligence is the product of expert interpretation of one or more pieces of information to inform future action. Cancer intelligence is used to inform the planning, development, monitoring and improvement of cancer services. Intelligence is developed from a range of different data sources, including population-wide and patient-level information, and relies on specialised analytical and interpretative skills. The primary purpose of intelligence is to ensure that every cancer patient and carer receives high quality care and/or support at every point where it is needed.
- 1.4. A recent report by the National Audit Office (NAO), *Delivering the Cancer Reform Strategy*, recognised that progress had been made in improving the quality of information but also identified significant gaps, as well as scope for efficiencies in the way that data are collected and the way they are used. As a result the Public Accounts Committee stated:

"There are shortcomings in the availability, consistency, timeliness and quality of key data such as on chemotherapy which accounts for a fifth of the overall cancer budget...The Department [of Health] should develop a cancer information strategy which includes common standards for the quality and timeliness of data on cost, activity and outcomes. It should clarify how it intends this information to be used to improve patient outcomes and to inform patient choice."

Public Accounts Committee, May 2011, Cm 8069

- 1.5. This framework sets out how these criticisms are being addressed, meeting the commitment made in the Treasury Minute of May 2011 on the implementation of the *Cancer Reform Strategy* to bring together all that is currently being done to improve cancer information, with timelines.

It aims to:

- Highlight the importance of cancer intelligence as a driver for better cancer outcomes, improved choice for patients, reductions in inequalities and improvements in productivity/efficiency;
- Provide a critical analysis of current strengths and weaknesses of cancer intelligence in England;
- Identify the roles of the wide range of partner organisations which contribute to the collection, collation, analysis and presentation of cancer intelligence and the users of cancer intelligence;
- Ensure that cancer intelligence processes avoid duplication of effort and burden on providers of information. Wherever possible, data used to drive quality improvement should be drawn from that needed for clinical care and essential administrative purposes;
- Set out the actions currently being undertaken to strengthen cancer intelligence, with clear delineations of responsibilities and timescales;
- Highlight future aspirations for cancer intelligence which could help to drive quality and productivity and reduce inequalities; and
- Apply the focus on outcomes and the principles underpinning the Information Revolution to cancer services, ensuring that cancer can be used as an exemplar for efforts to improve equity and excellence in health services.

1.6. For patients, access to cancer intelligence can help them make better informed decisions about their package of care. The purpose of this document is not to identify necessary improvements in patient information, which are being addressed through programmes such as cancer information prescriptions, but rather to set out how the cancer intelligence which underpins information for patients might be strengthened.

1.7. Wherever possible, intelligence should draw on data being collected for patient care, or other purposes, both by government and other organisations. Building on the successful partnership approach embodied by the National Cancer Intelligence Network (NCIN), this framework is intended to showcase, stimulate and support action from charities, patient support groups and professional bodies together with the providers of health services.

1.8. This framework covers the same period as *Improving Outcomes: A Strategy for Cancer* – i.e. to 2014/15 – with the aspiration of ensuring that England has a world class cancer intelligence system in the world by then. The actions contained in this framework are intended to support the measurement and delivery of the relevant domains of the Public Health, NHS and Social Care Outcomes Frameworks, as well as the administration of commissioner and provider incentive programmes, such as the Commissioning Outcomes Framework and Commissioning for Quality and Innovation (CQUIN).

Cancer in numbers

- 8 million people invited for cancer screening each year (breast, cervical and bowel)
- More than 8,000 general practices involved in diagnosing cancer and supporting patients
- Over 1 million patients referred urgently with possible cancer each year
- Around 265,000 new cancers registered each year (excluding non-melanoma skin cancer)
- Around 130,000 deaths from cancer – 29% of all deaths
- Over 1.55 million attendances for radiotherapy
- Over 1 million day case attendances for cancer
- Over 800,000 inpatient episodes for cancer
- Over 4.5 m bed days used by cancer patients
- Around £6.3bn spent on cancer each year
- Around 1.8 million people living with and beyond cancer
- Approximately 150 acute trusts providing cancer services
- Around 1,500 specialist (multidisciplinary) cancer teams
- 50 radiotherapy centres

2. The importance of cancer intelligence

- 2.1. In order to be effective in informing the planning and delivery of high quality, effective and efficient cancer services, cancer intelligence needs to be credible, comparable, confidential and clear. High quality cancer intelligence is necessary to:
- Enable clinicians to provide the best possible professional advice to patients;
 - Empower patients, enabling them to make informed decisions based on what matters to them;
 - Enable clinicians to take action to improve the services they provide;
 - Enable service providers to focus on cancer outcomes, or proxy indicators for them, rather than process targets;
 - Strengthen commissioning, ensuring that efficient, high quality services are rewarded and poor services are improved;
 - Ensure that support and resources are targeted on the areas of service and groups in society that need it most; and
 - Support democratic involvement in cancer services, enabling informed local and national scrutiny of performance, facilitating discussion about the priorities for improving cancer outcomes and enabling public accountability.
- 2.2. Cancer intelligence is relevant to several of the domains of the proposed Public Health Outcomes Framework, eg to provide information about cancer screening coverage, to inform steps to improve this. Table 1 sets out how improving cancer intelligence will support the measurement of improvements in relation to all five domains of the NHS Outcomes Framework.

Table 1: Supporting the NHS Outcomes Framework

How cancer intelligence will support delivery of the NHS Outcomes Framework	Is information currently available?
Domain 1: Reduce premature mortality <ul style="list-style-type: none"> • 1 year and 5 year survival • Cancer mortality • Stage at diagnosis (proxy outcome measure) • Diagnoses via emergency routes (proxy outcome measure) 	Yes Yes Partial Not yet
Domain2: Improving Quality of Life <ul style="list-style-type: none"> • Patient reported outcome measures 	Pilot survey only
Domain 3: Enhancing recovery from episodes of illness <ul style="list-style-type: none"> • Proportion treated as day cases • Lengths of stay for cancer surgery • Proportion of patients readmitted • Return to work 	Yes Yes Yes No
Domain 4: Improving patients' experience of care <ul style="list-style-type: none"> • Cancer patient experience survey • Surveys of bereaved relatives regarding care given at end of life 	Yes From 2012
Domain 5: Improving safety <ul style="list-style-type: none"> • 30 day mortality following surgery • 30 day mortality following chemotherapy • 90 day mortality following radical radiotherapy 	Yes – colorectal Not yet From 2012

2.3. At every stage of the pathway, intelligence has the potential to improve the quality of services, contributing to better outcomes, including:

- Prevention – identifying risk factors for cancer in order to develop and evaluate targeted interventions to minimise these;
- Early diagnosis – maximising the impact of screening, assessing and addressing variations in awareness and ensuring high quality referral practices from primary care;
- Treatment – identifying variations in access to appropriate treatment and ensuring that the quality of interventions is high;
- Care and support – helping people have a positive experience of treatment and care, supporting people in adjusting to life after cancer, reducing the risk of recurrence, as well as managing ongoing and late effects of treatment; and
- End of life care – supporting people in being cared for in the setting of their choice.

- 2.4. For patients, cancer intelligence can help them make informed decisions about what form of treatment to have, as well as where to be treated. In order to support choice, intelligence needs to be timely, accurate, and relevant to their condition. Patients may wish to know:
- The level of experience a clinical team has in undertaking a particular procedure;
 - How long they will have to wait;
 - The outcomes achieved by a particular service, and how these compare with other services;
 - How the outcomes for a particular treatment compare with other appropriate treatments;
 - Whether and to what extent the team complies with key national guidance; and
 - The experience reported by other patients in their position of treatment and care.
- 2.5. For those involved in commissioning, planning or delivering cancer initiatives or services either locally or nationally, the provision of high quality intelligence on populations of patients can be used to assess:
- Trends in incidence, survival and mortality;
 - The need for services and initiatives;
 - The quality of individual services;
 - The outcomes achieved for different groups of patients (e.g. based on geography, demographic factors, different provider organisations) across each of the domains of the NHS and Public Health Outcomes Frameworks;
 - Inequalities in access to and outcomes of care;
 - The impact of local and national initiatives aimed at improving outcomes;
 - Progress towards the Government's goal of saving an additional 5000 lives by 2014/15; and
 - The productivity and efficiency of cancer service delivery to ensure best value for money for the taxpayer.
- 2.6. For the research community, cancer intelligence can highlight research needs which might include:
- Gaps in knowledge that need to be filled;
 - A need to understand the drivers of outcome at population or individual level; and
 - Development and evaluation of new interventions aimed at improving outcomes, relating to the prevention, diagnosis, treatment and support of cancer patients and carers.

- 2.7. Research makes use of intelligence data to generate new knowledge and understanding which itself becomes part of the body of intelligence. It creates a virtuous cycle of knowledge generation and potential for improvement.
- 2.8. The information required to provide the support to the Outcomes Frameworks will be derived from multiple sources, including clinical history and examination, pathology departments, radiology departments, records of surgery, radiotherapy and chemotherapy and records of consultations and 'follow up'. Effective cancer intelligence is necessary to bring disparate sources of information together to inform clinical decision-making.
- 2.9. Improving cancer intelligence is vital to supporting the Government to meet the commitments it set out in *Improving Outcomes: a Strategy for Cancer*. To support delivery of those commitments, we made the following commitments in relation to intelligence:

Intelligence commitments in *Improving Outcomes: A Strategy for Cancer (IOSC)*, January 2011

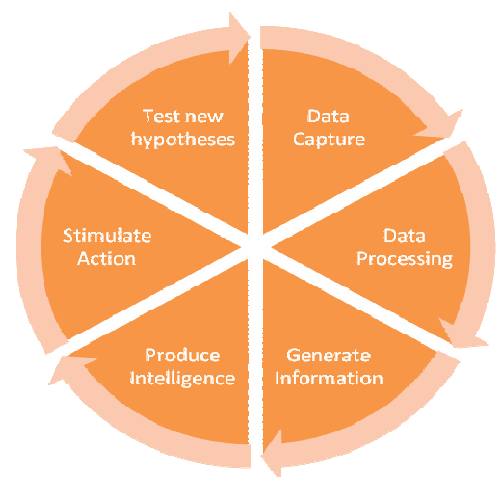
- 2.9 Moving forward, and taking on board the comments made by the NAO and the Public Accounts Committee, our priorities for 2011/12 will include:
- collating and publishing high quality information that commissioners and providers need about incidence, prevalence and survival, as a basis for planning services;
 - collating and publishing high quality information on different aspects of cancer services and the outcomes they deliver at both a provider and a commissioner level;
 - investigating different aspects of cancer care so that trends, patterns and good practice may be identified;
 - working with regulators to ensure that the information on cancer services which is collected is used to inform effective regulatory oversight and, where necessary, action;
 - improving the quality of the data which underpins expenditure information on cancer services;
 - providing transparent information so that policy makers and others may scrutinise the quality of cancer services by inequality/equality group; and
 - encouraging other organisations, such as cancer charities, to provide information to patients and carers and to help them make informed choices.
- 2.10 In addition, in 2011/12 we will pilot the collection, through cancer registries of data about metastatic disease.
- 2.12 In moving forward, we need to ensure that analyses are provided that are important for the public as well as for commissioners and providers, such as:
- the range of cancer services provided by each Trust;
 - whether each team has core members from all the relevant disciplines;
 - whether the team has a clinical nurse specialist;
 - how many patients by equality characteristic were diagnosed/treated in the previous year;
 - compliance with waiting time requirements;
 - compliance with peer review measures;
 - major resection rates; and
 - mortality rates within 30 days of treatment.

3. Working together to deliver high quality cancer intelligence

- 3.1. Generating high quality cancer intelligence is a complex process, involving a large number of statutory and non-statutory organisations at different stages of the process and at different points in the care pathway.
- 3.2. Information needs to be:
- Credible – providing a sustainable basis for improving the development of cancer services;
 - Comparable – enabling patients, clinicians, commissioners and others to assess variations in service provision, usage and outcomes;
 - Confidential – protecting the personal information of cancer patients;
 - Clear – enabling users to act upon it to improve services; and
 - Compelling – Providing evidence to influence decision making.
- 3.3. This chapter sets out the different stages in the cancer intelligence process, as well as the organisations which contribute.

The intelligence cycle

- 3.4. There are several stages in the information process, including:
- Capturing activity – the individual actions or interventions about which information is collected;
 - Recording and processing data – ensuring that the interventions are captured and stored in a secure and consistent manner;
 - Generating information – aggregating the data to provide comparable information on cancer services;
 - Producing intelligence – analysing, interpreting and communicating the information
 - Stimulating action – using the intelligence to improve services; and
 - Formulating and testing new hypotheses – using the data and information to generate new knowledge.
- 3.5. Delivering world class cancer intelligence will require actions at each stage of the information cycle.



Organisations involved in collecting data, delivering and utilising cancer intelligence

3.6. There is a wide range of organisations involved in cancer intelligence, either as users or providers, as set out in Table 2.

Table 2: Organisations involved in cancer data and intelligence

Organisation	Current/future roles on cancer intelligence
<p>The Department of Health (DH)</p>	<ul style="list-style-type: none"> • Sets policy context and overall strategies for improving the health of the population in respect of cancer • Funds cancer registries, the NCIN and cancer services • Funds national cancer audits • Leads International Cancer Benchmarking Partnership • Commissions National Cancer Patient Experience Survey • Commissions the National Cancer Waiting Times Monitoring Dataset (CWT) database from NHS Connecting for Health (CfH) • Publishes national and official statistics on waiting times for suspected and diagnosed cancer patients • Commissions the Office for National Statistics (ONS) for national cancer registration function and production of national statistics on cancer survival and incidence
<p>Public Health England (PHE)</p>	<ul style="list-style-type: none"> • Will take on responsibility for cancer prevention, cancer screening, for cancer registration and the NCIN and the End of Life Care Intelligence Network • Will provide data for the NHS Commissioning Board (NHS-CB) and will set out what the NHS-CB needs to provide it with (via s7A agreement or a memorandum of understanding) • Will drive delivery of improved outcomes in health and wellbeing and protect the population from threats to health. • Will ensure access to expert advice, intelligence and evidence • Promote evidence-based practice and support local public health delivery • Be a source of information, advice and support for local authorities and clinical commissioning groups as they develop local approaches to improve health and wellbeing • Generate information on the state of public health in England to support the development of local Joint Strategic Needs Assessments

Organisation	Current/future roles on cancer intelligence
	<ul style="list-style-type: none"> • Report on local government contribution in improving population health outcomes as part of the public health outcomes framework; • Enable local action to promote and protect health and tackle health inequalities through advice, support and the provision of world-class evidence and intelligence
NHS Commissioning Board (NHS-CB)	<ul style="list-style-type: none"> • Will be responsible for delivering the 'Mandate' as it applies to cancer including measurement of progress by the NHS through the NHS Outcomes Framework • Will be jointly responsible with Monitor for setting tariffs for cancer services which will both depend upon and deliver critical information on cancer services
Providers	<ul style="list-style-type: none"> • Record data on individual cancer patients • Provide data on individual cancer patients to registries, chemotherapy and radiotherapy data to other central groups • Provide data on individual cancer patients (for specific cancer-types) to national audits • Provide data on individual cancer patients to the NHS Commissioning Datasets • Complete the National Cancer Waiting Times Monitoring Dataset for individual suspected and diagnosed cancer patients • Provide aggregate data on returns to NHSIC
Cancer registries	<ul style="list-style-type: none"> • Operate under Section 251 of the NHS Act 2006 (see National Information Governance Board) • Collect and quality assure data on patients on the diagnosis and/or treatment of all cancer within defined geographical areas • Provide summarised information on individual cancer patients to a national registry, currently held at ONS • Provide detailed, validated, quality assured information on individual cancer patients to the NCIN National Cancer Data Repository • Facilitate the clinical genetics service to validate patient family records of cancer • Provide feedback to local service providers • Contribute anonymised data to international studies to benchmark disease levels and outcomes • Facilitate monitoring of cancer screening services • Undertake analysis and interpretation of cancer data to inform planning, commissioning and evaluation of cancer services at national and local level

Organisation	Current/future roles on cancer intelligence
Office for National Statistics (ONS)	<ul style="list-style-type: none"> • Responsible for publishing National Statistics on cancer incidence, survival and mortality • Commission statistics on cancer survival from CR-UK Cancer Survival Group at London School of Hygiene and Tropical Medicine • Submits cancer cases to NHS Central Register for flagging • Links death registrations with the flagged NHSCR cohort management system to identify deaths to be notified to researchers • Provides monthly cancer (and non-cancer) deaths to cancer registries
National Cancer Intelligence Network (NCIN)	<ul style="list-style-type: none"> • Collates information from 8 English regional cancer registries • Links cancer registry data with other datasets (e.g. Hospital Episode Statistics) • Undertakes national analyses • Provides profiles of services (based on PCTs, Clinical Commissioning Groups (CCGs), general practices and providers) • Works to develop and test datasets and collection processes/systems • Responsible for radiotherapy and chemotherapy datasets • Develops intelligence tools
National End of Life Care Intelligence Network (NEoLCIN)	<ul style="list-style-type: none"> • Sister organisation to the NCIN • Undertakes national analyses on end of life, including cancer • Provides profiles of end of life • Develops intelligence tools
Primary Care Trusts (PCTs) and Clinical Commissioning Groups (CCGs)	<ul style="list-style-type: none"> • Commission cancer services for their registered populations, including the collection of information relevant to the care of their patients
National Cancer Action Team (NCAT)	<ul style="list-style-type: none"> • Responsible for National Cancer Peer Review Programme which produces information on the quality of services across the country • Commissions information tools and outputs from the NCIN • Coordinates and leads the work of the Cancer Networks to ensure the requirements of national cancer policy are implemented • Supports implementation of Improving Outcomes: a Strategy for Cancer • Promotes the use of cancer intelligence to improve services at commissioner, provider and stakeholder levels

Organisation	Current/future roles on cancer intelligence
<p>NHS Information Centre for Health and Social Care (NHS-IC)</p>	<ul style="list-style-type: none"> • Responsible for managing National Clinical Audits (in collaboration with professional bodies) • Will be responsible for collection and management of the Diagnostic Imaging Dataset • Produces official statistics for the cancer screening programme • Manages the Medical Research Information Service (MRIS), which runs flagging and tracing services for cohorts, including cancer • Commissions the production of patient-level Hospital Episodes Statistics (HES) records from NHS Commissioning Datasets, and manages dissemination and access to HES datasets • Produces online access to a range of standard aggregated HES analyses, including NHS Comparators • Runs the Review of Central Returns (ROCR) process, which supports the Department of Health (DH) and its Arms Length Bodies (ALBs) to implement the government's policy in 'Reducing the burden' of data collections from the NHS
<p>Information Standards Board for Health and Social Care (ISB)</p>	<ul style="list-style-type: none"> • Approves data and information standards for the NHS and adult social care in England
<p>National Information Governance Board (NIGB)</p>	<ul style="list-style-type: none"> • An independent statutory body established to promote, improve and monitor information governance in health and adult social care • Ensures lawful and ethical use of patient information for the benefit of the individual and the public • Provides advice on the appropriate use, sharing and protection of patient information • Advises on the use of powers under Section 251 of the NHS Act 2006 which permits the common law duty of confidentiality to be set aside
<p>DH Informatics Directorate (DH-ID)</p>	<ul style="list-style-type: none"> • Supports the NHS to deliver better, safer care to patients through improved IT systems and services • includes Connecting for Health
<p>NHS Connecting for Health (CfH)</p>	<ul style="list-style-type: none"> • Part of the DH Informatics Directorate • Maintains and develops the NHS national IT infrastructure. This infrastructure includes a number of national services and a range of national applications • Manages and supports the IT underpinning the cancer screening programme • Oversees NHS coding with the responsibility for OPCS4 procedure codes

Organisation	Current/future roles on cancer intelligence
Cancer charities	<ul style="list-style-type: none"> • Support work of the NCIN financially • Produce collaborative products and analyses with the NCIN • Use the outputs of ONS, cancer registries and the NCIN for research • Use outputs for enhancing patient choice and campaigning for better services
National Cancer Research Institute (NCRI)	<ul style="list-style-type: none"> • Umbrella organisation for the NCIN • Interface into the research community for use of NCIN data • Umbrella organisation for the NIHR Cancer Research Networks (NCRN)
Health and Wellbeing Boards	<ul style="list-style-type: none"> • Health and wellbeing boards will provide the vehicle for local government to work in partnership with commissioning groups to develop comprehensive Joint Strategic Needs Assessments and robust joint health and wellbeing strategies, which will in turn set the local framework for commissioning of health care, social care and public health services
Academic community	<ul style="list-style-type: none"> • Undertakes research using the NCIN data and develops novel analytical tools
Care Quality Commission (CQC)	<ul style="list-style-type: none"> • Regulates care provided by the NHS, local authorities, private providers and voluntary organisations • User of cancer intelligence to identify low/high quality care
National Institute for Health and Clinical Excellence (NICE)	<ul style="list-style-type: none"> • User of cancer intelligence to inform its appraisal process, and the development of guidance and of quality standards to support high quality patient care
NHS Improvement (NHSI)	<ul style="list-style-type: none"> • User of cancer intelligence to facilitate service improvement within the NHS
Healthcare Quality Improvement Partnership (HQIP)	<ul style="list-style-type: none"> • Commissioner of National Clinical Audits (funded by DH)

4. Strengths and weaknesses of current cancer intelligence

- 4.1. Encouraging progress has been made in improving the quality of cancer intelligence in recent years. These improvements have encompassed the processes of gathering and analysing data, the way in which this information is used to create intelligence and the way in which intelligence is translated into action to improve services across the patient pathway.
- 4.2. However, much remains to be done if patients, healthcare professionals, commissioners, regulators and the public are to have access to the necessary intelligence to improve outcomes, as was recognised by the National Audit Office.

Key strengths of cancer intelligence

- 4.3. There are a number of areas of strength in existing cancer intelligence arrangements, which need to be built upon. These include strengths in relation to information about the scale and impact of cancer; the nature of cancer interventions undertaken; and the infrastructure to support cancer intelligence.
- 4.4. In terms of information about the scale and impact of cancer, as well as the outcomes achieved:
 - England has comprehensive cancer registration covering the whole country and this has been in place for over 40 years, allowing trends in incidence, prevalence and survival to be monitored;
 - Information collected by the Office for National Statistics on death certification is routinely linked with that from cancer registries to provide information on survival and mortality; and
 - Information on age, gender and socioeconomic status (based on postcode) is available for almost 100% of cancer patients, with information on ethnicity being available for over 80%.
- 4.5. In terms of information about the nature of cancer interventions undertaken, as well as its quality:
 - Information on waiting times for suspected and diagnosed cancer patients is collected by all providers of NHS cancer services. This includes the date of urgent referral for suspected cancer from a GP or the NHS Cancer Screening Service, the date of decision to treat and date of treatment for all cancer patients at all stages of their pathway;
 - Coded information on all inpatient and day case admissions to NHS hospitals through Hospital Episode Statistics (HES), including information on surgical treatments;

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- Large scale surveys of cancer patients' experience of care, covering all NHS Providers in England and patients with all types of cancer;
- National cancer audits capture information on over 90% of incident cases for lung cancer, colorectal cancer and head and neck cancer;
- Data have been collected on all patients receiving radiotherapy from all 50 NHS radiotherapy centres in England since 2009/10; and
- The national cancer peer review programme provides objective assessments of the quality of care provided by over 1000 specialist cancer teams and services.

4.6. In terms of the infrastructure to support cancer intelligence, a variety of functions are supported under Section 251 of the NHS Act:

- Large datasets can be linked, predominantly through use of NHS Number; and
- Ongoing permissions granted to enable a dedicated and skilled workforce of data officers, analysts and cancer epidemiologists working in cancer registries and academic centres to undertake the analyses necessary to support improvements in cancer services.

4.7. In order to support this infrastructure, the National Cancer Intelligence Network (NCIN) was established in 2008 to bring together analysts, epidemiologists and clinicians interested in cancer outcomes, and to undertake major new analyses of linked datasets. The NCIN is an example of how the public, voluntary and private sectors can work together to develop the information which will put patients, the public and professionals in control.

4.8. Much of this information has recently been brought together in a series of profiles which provide relevant and tailored information at general practice, clinical commissioning group, Primary Care Trust (PCT) and provider levels. Examples are shown as appendices to this document.

4.9. Data on clinical trials and other research under way in the NHS is held by the Coordinating Centre for the NIHR Cancer Research Network, and is available on-line to professionals and public

Key weaknesses

4.10. There are, however, still significant weaknesses in existing cancer intelligence arrangements. These can be considered in two ways:

- Deficiencies in information at different points in the care pathway; and
- Deficiencies in processes and systems required for cancer intelligence, including making information available in a timely and accessible way.

4.11. There are a range of deficiencies in information at different points in the care pathway, including:

- A lack of information about the number and nature of diagnostic tests undertaken before a cancer diagnosis is established;
- Significant difficulties in the process and management of the systems and data which underpin the NHS Cancer Screening Programmes
- The absence of detailed information on cancer diagnoses based largely on radiological investigation;
- The absence of staging information at the point of diagnosis. Nationally, accurate information on staging is recorded on only 40% of cancer cases;
- Only patchy information on comorbidity, frailty or performance status at the time of diagnosis, especially for those cancers not covered by a national clinical audits;
- Inadequate information on the delivery of chemotherapy services, despite the fact that they constitute a significant proportion of the cost of NHS cancer services, around £1 billion each year;
- A lack of information on recurrences of cancer, meaning that the effectiveness of treatments for primary cancers cannot be adequately assessed and the care of patients with metastatic cancer cannot be evaluated;
- Inadequate information on outpatient care given to cancer patients following diagnosis, reflecting poor coding within the outpatient HES dataset;
- The absence of routine data on the quality of life of cancer survivors, including information on late effects of cancer treatments;
- A lack of information on care given in the community to cancer patients, except for those patients included in primary care research databases, such as the GP Research Database (GPRD), which covers 6% of the population;
- A lack of patient level data on hospice and specialist palliative care services delivered to patients dying from cancer; and
- Inconsistencies, inaccuracies and gaps in the way in which expenditure on cancer is recorded and made available.

4.12. Deficiencies in the processes and systems required for cancer screening include:

- The IT systems which support cervical screening are now around 30 years old and are no longer fit for purpose. One of the main problems is that information is held on over 80 separate systems covering different parts of the country. There is no national database. As cervical careening starts at age 25 and ends at age 65 many women will move across boundaries, making it very hard to track their screening histories. Linkage of cervical screening information with hospital information (e.g. on colposcopy and histology) is difficult to achieve, hampering quality assurance of the service.

The current IT system will not be able to support the introduction of primary HPV screening which will soon be piloted.

- The IT systems for breast screening are over 20 years old and are also run across 80 separate boxes. If a woman chooses to go for screening somewhere other than where she has been invited, information which is held on separate systems has to be transferred and replicated. This carries potential risk and delays and has resource implications.

4.13. Deficiencies in the processes and systems required for cancer intelligence include:

- The need for standardised datasets to be collected by all providers of cancer services;
- Problems with the IT infrastructure required for some aspects of cancer service delivery (especially to support cancer screening, e-prescribing and some multi-disciplinary teams) and cancer intelligence;
- Duplication in the way in which some data are collected, resulting in unnecessary burden on providers;
- Variations in the way in which cancer activity is coded, resulting in inaccurate information on costs and quality. Current coding of hospital procedures (OPCS4 codes), hugely important for monitoring cancer surgery, needs significant revision. There are many outdated and surplus codes and many more recently introduced procedures such as laparoscopic, video-assisted and robotic surgical techniques are not captured at all by these codes; and
- The outputs from cancer intelligence are not sufficiently accessible for commissioners, providers, patients and the public.

4.14. Good clinical decision-making on individual patients requires high quality information to be collected and available. The MDT meeting is a critical point in the planning and management of the care of individual patients. Whilst most MDT meetings now operate with the support of a comprehensive MDT management IT system, some do not.

4.15. In addition, there are deficiencies in cancer registration. The reliability of cancer survival data reported for England was questioned by two leading cancer epidemiologists in 2010, and questions were asked about the completeness of cancer registration, and the potential impact on statistics which rely on complete data.

4.16. An extensive independent review was commissioned by the Department of Health, working with Cancer Research UK (CR-UK). A range of analyses and comparisons were undertaken, with original research undertaken by epidemiologists in the CR-UK Survival Group at the London School of Hygiene and Tropical Medicine (LSHTM) and in cancer registries, with the results of the work being subject to independent review by an international panel. The findings

and conclusions of the panel will be published soon, both as an analytical summary report and as a journal article, but in summary this work has shown that:

- Some cases of cancer are missed. These include cancers with both good and poor prognosis;
 - There is a lack of standardisation of the sources of information used by cancer registries to ascertain new cases (e.g. pathology systems, clinical management systems, waiting times databases, patient administration systems etc), although this is already being addressed;
 - In some registries there is overreliance on death certification and retrospective tracing of date of diagnosis; and
 - Only 40% of all cancer patients have information on stage of disease on the diagnosis record held by cancer registries. This hampers evaluation of efforts to drive earlier diagnosis and also limits case mix adjustment for comparisons of survival. The population of patients with stage recorded varies widely between cancer registries.
- 4.17. There are also variations in the timeliness of reporting between cancer registries. Although timeliness has improved considerably over the past decade and compares very favourably with that in other countries, further improvements would increase the value of cancer intelligence to commissioners and providers who are responsible for planning, delivering and monitoring cancer services.
- 4.18. The range of actions being taken to address these weaknesses are described in the next chapter.

5. Improving cancer intelligence

- 5.1. Improvements are required in the quality, comprehensiveness and timeliness of information collected across the cancer pathway, as well as the way in which it is collected, processed, stored, analysed and used in improving services and outcomes. This chapter summarises the improvements which are planned to cancer intelligence.

Improving data standards and consistency

- 5.2. In order to ensure robust information is captured for all patients with a diagnosis of, or high suspicion of cancer, it is imperative that all the data items required have been approved as an NHS Information Standard. This means that all providers of NHS services (NHS and Foundation Trusts and other NHS and independent sector providers) are mandated, as part of the NHS Standard Contract, to collect and submit these data and that collection and submission happens in a streamlined way which avoids duplication.
- 5.3. The NCIN and its partner organisations are working to develop a suite of interoperable cancer datasets which together will form a comprehensive dataset for all cancer cases, with data from different systems and datasets being linked together by the cancer registration service, allowing data to be captured once through existing NHS IT systems and used throughout NHS data return processes.
- 5.4. The Systemic Anti-Cancer Therapies (or chemotherapy) Dataset (SACT) will be collected from April 2012, alongside a new diagnostics imaging dataset. These will fill important gaps in cancer intelligence. In addition, data from an audit of recurrent and metastatic breast cancer will be available from April 2012, providing new intelligence on services for women with advanced breast cancer. More details of these developments are set out below.
- 5.5. A new Cancer Outcomes and Services Dataset (COSD) is being developed and taken through the standards-approval process, with the aim of being mandated for use across the NHS from January 2013. This will better reflect the current needs of the NHS in supporting epidemiology, international comparisons, service planning, patient outcomes, commissioning, audit and research, and will contain generic data required for all patients with cancer, along with data items that are specific for individual cancer sites.
- 5.6. In order to facilitate the submission of appropriate information, MDT management systems should be extended to run across all MDTs for all providers.

- 5.7. In order to ensure data recorded as part of the clinical decision making process are used to monitor outcomes, the MDT management systems should supply information directly to the national cancer registration service, in line with approved Information Standards Notices.

Improving cancer registration

- 5.8. A major modernisation programme is being undertaken across cancer registries with the aim of:
- Providing near real-time comprehensive data collection and quality assurance over the entire cancer care pathway on all patients treated in England;
 - Using these data, collected already as part of routine clinical practice, as the underpinning resource for monitoring patient care, quality, safety and performance management, audit, research and outcomes;
 - Ensuring near-real-time information feedback to clinical teams, enabling them to benefit from their efforts in submitting data;
 - Enforcing consistency of recording and interpretation;
 - Reducing costs by simplifying processes through the move to integrated national processing;
 - Supporting the measurement of outcomes, late effects and quality of life; and
 - Linking with stratified medicines initiatives, enabling the NHS to be a world leader in this area.
- 5.9. The process of cancer registration will be revolutionised by the introduction of a unified cancer registration service across England, which will include standardised ways of working by all registration teams, with a new process of centralised management and accountability for all registration staff.
- 5.10. The new system will be based on the Eastern Cancer Registration and Information Centre operational model, which was identified as an exemplar by the National Audit Office and Public Accounts Committee, but will also draw in good practice from other registries. Over the next two years all registries will migrate to the English National Cancer Online Registration Environment (ENCORE) and all electronic data feeds from local and national sources will be processed automatically through a single, central clearing house. Three registries will migrate to the new ENCORE system by the end of 2011, with the remaining five to follow during 2012. The process will be complete by the end of 2012/13. The registries will work as part of a distributed managed network of the national service. Data quality, workload and timeliness will be monitored continuously and automatically by the ENCORE system and the results published regularly.

- 5.11. Significant progress has already been made by cancer registries to improve their timeliness – the time taken to complete all cases for a particular calendar year. The previous target of 18 months (following the completion of a calendar year) has been improved upon, with 2009 registrations being completed within 15 months and 2010 registrations due to complete in 12 months. Once registries have migrated to ENCORE, near-real-time data collection will be possible, feeding back data to clinical teams on a monthly basis, reporting incidence data within six months. This will match or exceed the best cancer registration systems in the world.
- 5.12. Improving the recording, consistency and accuracy of staging will be a major focus for cancer registration, with the intention of ensuring that over 90% of cancers cases where staging is possible have it accurately recorded by the end of 2012 (this equates to just over 70% of all cancer registrations). In order to support this, a National Cancer Staging Panel has been established to ensure high quality and consistent recording, interpretation and usage of staging information. Information on staging will be available for use by commissioners and providers as a proxy for 1-year survival by Q2 2013.
- 5.13. The use of multiple data sources remains essential to ensure high ascertainment and accuracy. Registration will use routine patient-level local data sources including:
- Full text pathology;
 - Multi-Disciplinary Team (MDT) data;
 - Diagnostic imaging information;
 - The National Cancer Waiting Times Monitoring Dataset
 - Hospital Episodes Statistics;
 - Radiotherapy data
 - Chemotherapy data (from 2012)
 - Death certification data; and
 - Embarkation and re-entry data (when people move or return from abroad).
- 5.14. Standardised national data sources will become increasingly important as the role of the NHS Information Centre for Health and Social Care (NHS-IC) develops, and as the nature, types and scale of data sources that it holds grows. The new Diagnostic Imaging Dataset would be an example of this. The NHS-IC already manages several key data sources (such as HES), but its role should develop into being the key supplier of national data into the cancer registration process.
- 5.15. In relation to pathology, the new national cancer registration system (ENCORE) has been designed to process full text pathology reports. A variety of sophisticated processes in the ENCORE system help registration staff extract

core data items from pathology reports and many of the key data items can be extracted and quality assured efficiently. Work is also underway – driven by the Royal College of Pathologists – to move towards synoptic reporting, which should further improve efficiency if this includes coded data.

- 5.16. Diagnostic imaging is increasingly important for cancer registration as there are several cancers that are diagnosed and managed using radiology alone. A pilot project is exploring a system that would allow the cancer registration service to query all Radiology Information Systems (RIS) remotely and securely through the Image Exchange Portal (IEP). These patient-level data will then be used to populate ENCORE with relevant information and will allow the registry to find information on cases diagnosed and managed using radiology alone, use imaging information for tumour staging and potentially to maintain surveillance of radiologically-detected recurrences.
- 5.17. The migration of the cancer registries to a single processing system will begin to deliver efficiencies in 2012/13. Removal of previously duplicated work is estimated to reduce some registration activity by 10%, allowing an increased focus on data quality and intelligence.

Improving information on early diagnosis

- 5.18. Promoting earlier diagnosis of cancer will be vital if the service is to deliver the Government's required cancer outcomes improvements set out in Improving Outcomes: a Strategy for Cancer. There is an inevitable lag in the availability of survival data and therefore it will be necessary to use proxy indicators to assess progress on this, which could include:
 - The proportion of cancers diagnosed at Stages 1 and 2;
 - The proportion of cancers diagnosed through emergency routes; and
 - GP usage of diagnostic tests.
- 5.19. As set out above, a series of actions are underway to improve the recording of staging through cancer registration. In addition, the Operating Framework for the NHS in England for 2011/12, published by the Department of Health, emphasises the importance of providers supplying staging information to cancer registries.
- 5.20. Information on the proportion of patients who are first diagnosed following an emergency presentation will also be reported on a routine basis, as this has shown to be a powerful predictor of poor one-year survival. This information will be published at a commissioner-level through the NCIN. NCIN is developing a programme of work, partly funded by Cancer Research UK, to develop new analyses and research in these areas. This will form a substantive part of the NCIN work programme from January 2012.
- 5.21. A new diagnostics imaging dataset covering imaging test activity across the NHS is in development and has been submitted to the Information Standards

Board for Health and Social Care for approval, with a proposed mandate all NHS Providers to supply to the NHS Information Centre from April 2012. If approved, from a cancer perspective this dataset will provide national information on GPs' direct access to tests, as well as tests requested via other referral sources. Benchmarking data will be fed back to GPs and, where appropriate, used to encourage increased use of tests, leading to earlier diagnosis and improved outcomes. The data will also support better analyses of cancer pathways by linking to cancer registry data and the National Cancer Data Repository.

Improving information on cancer screening

- 5.22. Within the cancer screening services, more needs to be done to improve the supporting IT systems. Better integration of systems and datasets will be an important part of knitting together information and intelligence on screening and symptomatic services.
- 5.23. The NHS Cancer Screening Programme and the Systems and Service Delivery directorate of NHS Connecting for Health have worked together on the national Bowel Cancer Screening system (BCSS), launched in 2006, with a view to avoiding the perpetuation of these deficiencies in the new system. The principle design approach was to design a system around the Screening Subject/Patient and the events along the Screening Pathway. A single national Screening Subject Population Index (SSPI), derived from NHAIS Exeter system data is used to collect information to initiate the process and maintain up-to-date demographic information. The NHS number is used as the key identifier throughout the system. This aids in both the BCSS business processes which cross organisational boundaries, but also help to enable linkage to additional data set information as required (this is same as the approach taken in the Cancer Waiting Times system).
- 5.24. The records held within the system are viewed and updated by many different people, performing many roles in many organisations as and when required by the business. The system uses workflow principles to support the users of the system in carrying out their day-to-day activities and the movement of Screening Subjects/Patients between areas is dealt with automatically by the system through transfer of care. Screening Subjects and patients are kept informed throughout the pathway with result information also being communicated to GP Practices via electronic messaging.
- 5.25. Much effort has been taken by the NHS Cancer Screening Programme to ensure the capture of detailed information about the diagnosis and treatment of patients. This information together with that captured during the earlier parts of the screening pathway means that this system is one of the best resources in the world for information about Bowel Cancer. An Oracle Business Intelligence

Enterprise data warehouse is used to support multi-level reporting to fully utilise this valuable resource.

- 5.26. The lessons learnt from implementing the processes and system adopted by the Bowel Cancer Screening programme present opportunities in addressing the issues that remain in the other cancer screening programmes. The actions that are needed are:
- Creating a national Screening Subject Population Index (SSPI) database to support call/recall for both cervical and breast screening programmes into the future;
 - Developing cervical screening and breast screening systems which will support the effective management of the start to end screening pathway for individuals, collection of an integrated clinical and cancer dataset for national quality assurance purposes, and a single national screening database with a full dataset adequate for effective programme evaluation; and
 - Ensuring an integrated approach to information is taken, such that outcomes for screen-detected and symptomatic patients can be directly compared, and that screening services are able to monitor performance by equality group, including ethnicity.

Improving information on cancer treatment

- 5.27. The quality of treatment available to cancer patients is also a vital determinant of outcomes. Information about the treatments available and the outcomes delivered is necessary for patients to make informed choices, for commissioners to effectively performance manage services and for healthcare professionals to be free to introduce improvements.
- 5.28. Strengthening the information available on cancer treatment should also help healthcare professionals take steps to improve the services they provide to patients. The new cancer registration system will enable the rapid feedback of information to individual clinical teams so that they can act upon information to improve services and data recording – for example rolling one-year survival, work load analyses, quality assurance and clinical audit data will be available.
- 5.29. Information on cancer surgery has been available through Hospital Episode Statistics (HES), although this has only recently been exploited by linkage to cancer registration data by the NCIN. However, information on radiotherapy and chemotherapy has been lacking. In order to address this:
- The Radiotherapy Dataset (RTDS) has required that, since April 2009, all NHS providers providing radiotherapy services submit records on the use of external beam radiotherapy. Summary records for all radiotherapy courses delivered now flow on a monthly basis to cancer registries for registration purposes. In addition summary data will also be made available to the NCDR in 2012; and

- The Systemic Anti-Cancer Therapies Dataset (SACT) will from April 2012 require all providers which deliver chemotherapy services for adult solid tumours, haematology and paediatric cancers to submit data on all patients treated. Implementation will be staged over two years to enable all providers to develop and embed robust e-prescribing (or equivalent) systems to manage and report chemotherapy. Data will be captured centrally by the new NCIN Chemotherapy Intelligence Unit (hosted at the Oxford Cancer Intelligence Unit) and shared prospectively with the regional registries via the single central ENCORE system and retrospectively with the NCDR.

Improving data on outpatient activity

- 5.30. The NHS Information Centre for Health and Social Care (NHS-IC) is responsible for assuring the quality of national data collections and publicly available data.
- 5.31. The NHS-IC currently produces guidance and tools on improving the quality of all Commissioning Data Set (CDS) data submitted to the Secondary Uses Service (SUS) - from which HES is sourced. This includes a number of dashboards and KPIs for data submitters to access and review key sections of their data for issues. At present there are over 900 users accessing these resources, with more subscribing each month.
- 5.32. The NHS-IC is also working in partnership with the Academy of Royal Colleges to improve outpatient HES data and coding. This includes expansion of the outpatient HES to include coding of diagnoses and co-morbidity, which will greatly improve not only the primary clinical utility of these data, but also for its secondary uses including cancer intelligence.
- 5.33. To improve HES data quality, the NHS-IC is developing a national framework for data quality assurance which will set out the roles and responsibilities of local and national organisations (including standards, and incentives for improvement in data quality).
- 5.34. In the first half of 2012 the NHS-IC will make assessments of data quality more visible and publish them as a national summary report on data quality. The NHS-IC will, over time, work to a model which identifies, monitors, reports and supports improvement in data quality.
- 5.35. There are ongoing discussions by the NHS-IC with key stakeholders in Public Health England (PHE) around specific data quality issues for public health intelligence. It is anticipated that this will include cancer intelligence.

Improving national cancer audit

- 5.36. National clinical audits are currently in place for lung cancer, head & neck, upper GI and bowel cancer. The NHS-IC collates data from these national clinical audits through standardised processes, and provides and maintains a repository

of these audit data, making these available for bespoke analyses, interpretation and dissemination by specialist clinical communities and their intermediaries.

- 5.37. A national audit for breast cancer has been in place for some years combining the NHS Breast Screening Programme (NHSBSP) audit and the data from the Breast Cancer Clinical Outcome Measures (BCCOM) audit, managed through the NCIN.
- 5.38. National audits have proved effective in informing clinical practice and driving improvements in the quality of treatment. However, in order to minimise duplication of effort, enhance the quality of data available to them and to free up resources to implement new audits, existing audits should become interoperable with the cancer registration process. The NHS Medical Director has asked the National Clinical Director for Cancer and End of Life to undertake a review of national cancer audits to ensure best value for money. This will be completed in 2012.
- 5.39. In future much of the information required for the audits of services for individual cancer types should be collected routinely with additional data collection being kept to a minimum and limited to information which is not available nationally (except for identifiers for linkage purposes). Retrospective audit datasets should be merged with the National Cancer Data Repository to enhance the completeness of data (e.g. on staging) and facilitate new analyses of outcome measures, for example survival and 30-day mortality. By comparing the NCDR and the audit datasets it should be possible to identify items that are already collected to the required standard through routine mechanisms therefore enabling the streamlining of audit datasets, as well as pre-populating online audit forms so that clinical teams need only add additional data items.
- 5.40. The close link between timely clinical audit and cancer registration is key to improving data quality. The ENCORE system is already being used by the Breast Cancer Clinical Outcome Measures (BCCOM) audit for symptomatic breast cancer, providing secure access for individual clinicians to allow them to check the specific patient details, re-allocate individual cases to others or query and update specific data items. Prospective national audit datasets should directly feed both the current audit mechanism and the national ENCORE system.
- 5.41. For cancers which are not yet covered by comprehensive audits, the starting point will be to evaluate what can already be learned from existing linked data items. Consideration can then be given to selecting additional items which are likely to be most informative.
- 5.42. Given their key national roles, the NHS-IC, Public Health England (PHE) and the National Cancer Intelligence Network (NCIN) will need to work in partnership to improve the quality of the existing audits, to broaden the scope of topics

covered, for development of alternative methodologies for obtaining data to reduce the burden on data collection at source, ensuring that the appropriate information governance requirements are met.

Cancer waiting times

- 5.43. Statistics on waiting times for diagnosed and suspected cancer patients have been published by the Department of Health since 2001/02, with data being collected via a secure on-line database since 2002. This dataset covers all patients urgently referred with a suspicion of cancer by their GP or from a cancer screening service. The National Cancer Waiting Times monitoring Dataset also covers the one month (31 day) and two month (62 day) maximum waiting times for cancer treatments. These requirements and the dataset were extended to cover all patients, for all treatments from 01 January 2009, including for patients presenting and receiving treatment for both metastatic and recurrent disease. These data are already made available to cancer registries and will be made available to the NCIN National Cancer Data Repository (NCDR) in 2012.

Improving information on recurrence

- 5.44. Information on patients with recurrence and metastatic disease is currently incomplete. In order to address this, a pilot project is being undertaken by the NCIN, the Association of Breast Surgery (ABS) and Breast Cancer Care (BCC) to develop the processes within local services to capture these data, initially for breast cancer, but with a view to extend to other cancer sites over time. Data will be available from April 2012.

Improving information on care, support and survivorship

- 5.45. Intelligence can also play an important role in informing efforts to improve the ongoing care and support provided to cancer patients. The National Cancer Patient Experience Survey Programme (NCPESP) has provided invaluable detailed information on the experience of treatment and care, enabling comparisons of the experience reported by patients between:
- Different multi-disciplinary teams;
 - Different types of cancer; and
 - Different demographic groups, including by age, gender, ethnicity, social class and sexuality.
- 5.46. The NCPESP is to be repeated and the results will be made publically available. The NCIN will also explore the possibilities created by linking the information from the Survey to other datasets, such as clinical audit and HES.
- 5.47. Cancer survivors often have ongoing support needs which endure long after treatment has ended. The NHS has a responsibility to ensure that these needs are met and, to this end, the National Cancer Survivorship Initiative (NCSI) is leading efforts to improve the support available to cancer patients on issues

such as follow-up, supported self-care, the management of ongoing side effects or the late effects of treatment and in helping people return to work. In this respect, the outcomes reported by patients are as important as clinical indicators.

- 5.48. In order to improve understanding of the quality of life outcomes for cancer survivors, the NCSI is developing a national survey of cancer survivors which has been piloted in 2011. The information provided by this survey, the national cancer patient experience survey and the wider routine use of Patient-reported outcome measures (PROMs) with cancer survivors, will enable commissioners and providers to better understand how services can improve outcomes for cancer survivors.
- 5.49. Information on late effects of treatment, often referred to as natural-histories, will become an increasingly important and useful tool in the improvement of services which are effective and efficient from a commissioner and patient perspective. The NCIN is developing a programme of work, partly funded by Macmillan Cancer Support, to develop new analyses and research in these areas. This will form a substantive part of the NCIN work programme from January 2012.

Improving information on end of life care

- 5.50. The Coalition Government has committed to implement the End of Life Care Strategy which was published in 2008. It has also committed to developing a per-patient tariff for palliative care. This will require improved data collection relating to end of life care. The National End of Life Care Intelligence Network (NEoLC-IN) has been leading efforts to improve the quality of intelligence on end of life care services for all conditions, including cancer, and to improve the information on the circumstances in which people die and the care that is offered to them in the last months of their life. This is particularly important in:
- Supporting commissioners and providers to understand how their local services compare with each other and with the national picture;
 - Taking forward the work, following the Palliative Care Funding Review, on developing a tariff to support the delivery of dedicated palliative care; as well as
 - Improving end of life care outcomes, in particular by enabling more people to have more choice of where they wish to be cared for at the end of life, and to die, in line with the Government's commitment on choice.

Improving information on inequalities

- 5.51. Assessing the nature and extent of cancer inequalities is critical to being able to tackle them. Work undertaken by the NCIN in partnership with the National Cancer Equality Initiative (NCEI) has revealed profound inequalities in cancer outcomes in England. Tackling these inequalities will play an important role in efforts to achieve cancer outcomes which are comparable with the best in Europe.

An Intelligence Framework for Cancer

- 5.52. The NCIN has also played a key role in developing accurate information, disaggregated by demographic group, much of which is now publically available through the Equalities Portal (www.ncin.org.uk/equalities), which provides information to commissioners on key equality metrics.
- 5.53. The NCIN will continue to publish information on cancer equalities in an openly accessible format. Existing equality data will be added to, in line with the commitments made in “Reducing cancer inequality: evidence, progress and making it happen”. The NCIN will operate a presumption that data will be made available disaggregated by demographic group where this is technically possible, including for the new datasets on the use of imaging, radiotherapy and chemotherapy.

Improving information on cost

- 5.54. The implementation of consistent and interoperable datasets, described earlier, will allow new insights to be gain into the activity of cancer across the NHS. The NCIN has already run a workshop in November 2011 bringing together leading national and international experts on health economics and will be developing a programme of partnership working to develop and publish information and intelligence on the health economics of cancer.
- 5.55. The Department of Health (DH) has made significant changes to the Programme Budgeting collection for 2010/11:
- Information is compiled from commissioners' own information systems based on price paid (rather than cost of services to providers);
 - Information is broken down by care setting - leading to greater transparency of data and allowing a more rigorous validation process of expenditure figures; and
 - More detailed guidance and mappings information and a more comprehensive training programme
- 5.56. The guidance has been strengthened to ensure greater consistency of estimates, including for outpatient expenditure on cancer. Overall variation in expenditure between PCTs has increased slightly in 2010/11 but this is expected to fall in future years as the new collection beds in (although obviously the move to collecting information from CCGs will have an impact).
- 5.57. Some PCTs have been unable to separate out expenditure on prevention and health promotion, including cancer screening and HPV vaccinations. The greater transparency of data provided by the care setting breakdown enables issues such as this to be identified and the expenditure information to be explored in more detail, leading to further improvements in data quality.
- 5.58. Moving to estimating Cancer expenditure in A&E based on A&E diagnosis codes rather than overall non-elective inpatient splits will enable more accurate

estimates of expenditure in this area. The DH will continue to work with experts from across the NHS to improve data quality.

Improving the efficiency of cancer intelligence

- 5.59. We will not be able to achieve our aspirations for cancer intelligence in the future if existing functions are not undertaken more efficiently. Yet improving the quality of cancer intelligence can also improve its efficiency by:
- Designing and seeking approval for a single national dataset covering the process of care, diagnostics and outcomes, bringing together disparate data sources;
 - Ensuring that where data are already collected, they are not requested again from another source by strengthening the technical and governance framework;
 - Focusing on using the data that are already recorded for good clinical practice; and
 - Ensuring that the data that are recorded are those that are needed to improve outcomes.
- 5.60. The NCIN, which brings together the strengths of various partners within the cancer intelligence community, has a critical role to play in maximising the impact of resources, ensuring that duplication is eliminated and leveraging the resources, commitment and expertise of non-statutory partners.
- 5.61. It is important to recognise that, given the range of analyses and intelligence that will be needed; the types of skills required will be at a premium. It is therefore essential that existing skills are used most effectively, whether these currently exist in the central NCIN team, the cancer registries, other parts of Public Health England, the National Cancer Action Team (NCAT), NHS Improvement, cancer partners (such as Cancer Research UK and Macmillan Cancer Support), and specialist intelligence and research groups (such as the CR-UK Cancer Survival Group at the LSHTM) and the Office for National Statistics.
- 5.62. In order to facilitate this, the efficiencies to be delivered by the implementation of the single cancer registration system will allow more work to be done by the distributed intelligence teams based in the cancer registries, often with close ties to a local university. The analytical expertise which is distributed across the cancer registries will be used in a much more coordinated way, so that national analyses are undertaken not just by the core team, but by the whole of the distributed intelligence network and their academic collaborators. In addition, the NCIN central analytical team is being expanded to cater for the growing analytical requirements.
- 5.63. As part of Public Health England (PHE), the distributed cancer intelligence community will be part of a wider public health intelligence function, and will be working closely with colleagues with a range of specialist interests but related

methodological challenges. There is also the opportunity to link the various datasets that will be available in PHE to look at such areas such as smoking cessation and lung cancer, alcohol use and alcohol related cancers, obesity data and cancer incidence, chemical and environmental hazard data and cancer clusters.

- 5.64. Public Health England (PHE), within which the registries and the NCIN will reside, will have a role in training and developing both its own information and intelligence (I&I) professionals and supporting training and development for I&I professionals throughout the wider public health system. This is due to the high concentration of skilled professionals likely to work for PHE in the future system, and the relatively scarce nature of this type of expertise more generally. A number of the constituent organisations already provide training to their own and other staff, which PHE will need to build upon.

Making cancer data more transparent and available

- 5.65. In line with government policy, there is a significant amount of cancer data and information which should be made more accessible in a readily processible format. In addition the practicalities of actually making data public need to be considered, including considerations relating to those data and underlie official and National Statistics; frequency of data release etc. The NCIN, ONS and the NHS-IC will need to work collaboratively to support making cancer intelligence data publicly available.

6. Applying intelligence to improve services and outcomes

- 6.1. The purpose of the Information Revolution is not for the state to prescribe what information can be used and how, but rather to make available information so that groups with an interest in improving services can use it in innovative ways, and so it is for cancer. The purpose of this framework is to set out what is being done to ensure that high quality information is available so that others may interpret and act upon it.
- 6.2. Moving forward, the NCIN will focus on stimulating demand for and the use of information, as well as ensuring it is supplied in a timely, accurate and accessible manner, by:
- Collating and publishing high quality information on different aspects of cancer services and the outcomes they deliver at both a provider and a commissioner level, enabling easy and relevant comparisons to be made about the quality of cancer services;
 - Supplying information to commissioners and providers of care so that they may use it to improve the quality of services;
 - Investigating different aspects of cancer care so that trends, patterns and good practice may be identified;
 - Working with regulators to ensure that the information on cancer services which is collected is used to inform effective regulatory oversight and, where necessary, action;
 - Providing transparent information so that patients, the public and policymakers may scrutinise the quality of cancer services;
 - Supplying data for research that will improve outcomes for cancer patients in the future;
 - Encouraging other organisations, such as cancer charities, to provide information to patients and carers, using this to support the development of competition based on the principle of quality, helping patients make informed choices; and
 - Encouraging scrutiny of methodologies and results through peer reviewed publications.
- 6.3. This chapter sets out how information could be made available in a way which encourages different stakeholders to make better use of it, as well as setting out some inspiring examples of how non-statutory organisations are already using the information which is being generated.

Supporting commissioners

- 6.4. In order to support the measurement of progress in improving outcomes at a local level, the NCIN have started to produce commissioner-level data, setting out performance on key outcomes indicators.
- 6.5. Information which will be useful to cancer commissioners has been gathered together through the Cancer Commissioning Toolkit (CCT) (www.cancertoolkit.co.uk). This is intended to signpost commissioners to a variety of different information sources, including epidemiology, screening uptake, cancer waits, inpatient activity, treatments, equalities, patient experience and horizon scanning for new technologies. There has been feedback from commissioners that steps could be taken to improve the usability of the CCT and measures are now being undertaken to achieve this, with additional or changed metrics being included in the CCT.
- 6.6. The NCIN is also developing 'cancer profiles' for Primary Care Trusts (PCTs) (and in future potentially for Local Authorities) drawing together information from multiple sources, which enable commissioners to assess the 'burden' of cancer on their population, as well as to compare the performance of cancer services they commission on a range of metrics. The purpose of these profiles will be to ensure that commissioners have access to appropriate and timely information to inform their decisions. The profiles are intended to:
 - Understand the effect of age and socio-economic deprivation inequalities at a practice level;
 - Compare the practice to the PCT and national average;
 - Understand patterns of urgent referrals geographically and by socio-economic deprivation;
 - Assess variation in the use of investigations for potential cancer, such as colonoscopies, sigmoidoscopies, and Upper GI endoscopies across the PCT and between the PCT and England; and
 - Examine variation in the route to diagnosis across the PCT and between the PCT and England.
- 6.7. An example cancer profile is included in Annex 1. This will be updated to reflect Clinical Commissioning Groups as they develop.
- 6.8. The programme budgeting and health investment tools supplied by the Department of Health to support commissioners tie in closely with both the CCT and cancer profiles.

Supporting GP Practice

- 6.9. GP Practice Profiles have been developed by the NCIN and National Cancer Action Team (NCAT), bringing together a range of process and outcomes

information relevant to cancer in primary care, for benchmarking and reviewing variations at a General Practice level. Data sources include:

- Regional Cancer Registries in England;
- Hospital Episode Statistics;
- The National Cancer Waiting Times Monitoring Dataset;
- The Quality and Outcomes Framework; and
- The NHS Cancer Screening Programme.

6.10. The profiles are intended to help GPs consider what improvements could be made to clinical practice and service delivery, particularly with the intention of encouraging earlier diagnosis. The profiles are not intended as performance management and there are no 'right or wrong' answers. The profiles are currently only available within the NHS, and can be accessed via the Cancer Commissioning Toolkit (CCT). The profiles will be updated by the end of December 2011 and will by March 2012 include the ability to select groups of practices in line with the proposed Clinical Commissioning Groups (CCGs). An example of a GP profile is included in Annex 1. The intention is to make the profiles available to the public, subject to patient confidentiality being safeguarded.

Supporting Providers

6.11. In addition to the new Clinical Commissioning Groups (CCGs) understanding the local 'burden of cancer' and the needs of their population, it is imperative that they have access to robust, timely and accurate data relating to local services to support the commissioning process. In order to support this, the NCIN is developing service profiles, working in partnership with NCAT and cancer networks. The first wave covers the secondary care elements of bowel and breast cancer and will include provider-level information on:

- The number of patients treated each year;
- Survival outcomes (e.g. one and five year survival, subject to a suitable methodology being identified);
- Patient experience scores;
- Patient safety outcomes (e.g. 30 day mortality following surgery);
- Compliance with peer review measures; and
- Achievement of waiting time requirements.

6.12. An example of the service profiles is included in Annex 2.

6.13. In parallel, the NCIN is working with NCAT and the Radiotherapy Clinical Information Group to develop a similar set of profiles for radiotherapy services, including the information shown in Table 3 below:

Table 3.

	Total number of RT metrics
1	<i>Attendances per Million Population</i>
2	<i>Fractions profile by cancer site</i>
3	<i>Number of Linacs per million population by provider</i>
4	<i>31 day standard performance profile by provider</i>
5	<i>% Fractions delivered by inverse planned IMRT</i>
6	<i>% Fractions delivered with IGRT</i>
7	<i>% prescription delivered to plan (prescribed vs actual fractions)</i>
8	<i>Overall Pathway Length</i>
9	<i>Average fractions per Linac per centre</i>
10	<i>Exposure profile per Linac per service</i>
11	<i>Number ECAD adjustments by cancer type</i>
12	<i>Age profile of Linacs</i>
13	<i>Cost profile</i>
14	<i>% Peer review measures met</i>
15	<i>% patients reporting positively from the cancer patient experience survey</i>
16	<i>A metric to be agreed, but to cover reporting of incidents and IVD (Safety)</i>
17	<i>Access to radiotherapy</i>

6.14. The profiles are initially available to the NHS through the Cancer Commissioning Toolkit, although the intention is to release them to the public once they have been tested.

Supporting Public Health

6.15. In the future, one of the key functions of Public Health England (PHE) will be to deliver an effective information and intelligence service to support effective action, locally and nationally, to promote and protect health and wellbeing, prevent illness, tackle inequalities and improve public health outcomes. Information and intelligence about cancer is an important part of this, including:

- Risk factors for cancer:
- Levels of awareness about cancer symptoms:
- Incidence rates;
- Cancer screening coverage;
- Referral rates;
- Stage at diagnosis;
- Access to treatment;
- Treatment Outcomes; and
- Survival and Mortality rates.

- 6.16. The analytical expertise currently in cancer registries and the NCIN will be used within PHE to provide coordinated support to local government and health & well being boards in the development of Joint Strategic Needs Assessments and health and well being strategies. It will also provide cancer information and analysis as part of Public Health England's intended role as the primary route for accessing information about the state of the public's health.

Putting data to work

- 6.17. There are already some good examples of different organisations using cancer intelligence to help support patients, as well as improving services or outcomes. These include:
- Beating Bowel Cancer has published the Bowel Cancer Map to raise awareness of bowel cancer signs and symptoms by profiling local information on incidence and outcomes. The map led to an additional 9,000 unique visitors viewing information on signs and symptoms in one day;
 - The Roy Castle Lung Cancer Foundation has published an analysis of the variations which exist in the lung cancer health needs of local communities, as well as in the quality of local lung cancer services, drawing on the NCIN and National Lung Cancer Audit data. The analysis has been used by policymakers, commissioners and patients to understand the differences in services which exist, as well as to identify and plan required improvements;
 - The Rarer Cancers Foundation has published local profiles on the Cancer Drugs Fund, aimed at supporting patients and clinicians in navigating the process. The profiles have been downloaded over 12,000 times and will – in future – draw on information from the chemotherapy dataset;
 - NHS providers in London have responded to the NCPESP, in which many were rated poorly on a number of factors, by developing improvement action plans focusing on enhancing access to clinical nurse specialists, improving the experience of ward nursing and expanding access to support on finances and welfare advice;
 - Macmillan Cancer Support is using data provided by the NCIN to develop a website, providing information to patients on key indicators of clinical quality in an accessible and relevant format;
 - Cancer Research UK is using information provided by the NCIN as part of its stratified medicines initiative, which aims to discover new targeted treatments for different cancers;
 - Pancreatic Cancer UK published its Study for Survival using new data produced by the NCIN; and
 - The Skin and Urology Hubs have been developed, enabling commissioners to access a wide range of information from one location.
- 6.18. Many of these examples are only possible because of the interaction between providers of cancer information who receive public funding and non-statutory organisations who wish to use the information to support and engage patients.

Promoting research

- 6.19. The National Cancer Intelligence Network (NCIN) and the National Cancer Research Institute (NCRI) are working closely together to foster investigator-led research using cancer intelligence data. This collaboration will continue to facilitate access to such data for research in the academic community, as well as the cancer registries, within the framework of an appropriate data governance policy. Wherever possible, the results of this research will be published in peer-reviewed journals in the usual way. At the same time, the output from research will itself become part of the body of available cancer intelligence with the potential to lead to service improvement.
- 6.20. Cancer intelligence plays an increasingly important role in supporting research, through the provision of data to support both interventional studies (e.g. via flagging and tracing services) and observational research. Recent improvements in linkages between datasets (for example to HES and primary care data via the General Practice Research Database) are enabling novel research on diagnosis, treatment and outcomes.
- 6.21. Powerful alliances are developing between academic researchers and NHS analysts, with expertise being brought to bear from a variety of disciplines including epidemiology, clinical medicine, behavioural science and mathematical modelling at population level

7. Cancer intelligence: a forward look

- 7.1. It is important that roles and responsibilities relating to cancer intelligence in the new health service are clearly defined. This chapter summarises requirements described in earlier chapters and seeks to clarify responsibilities.
- 7.2. It is important to be clear that this chapter only highlights current intentions. As the NHS Commissioning Board and Public Health England become fully established the roles shown below will need to be examined and are likely to change. The table should therefore be seen as entirely provisional.

Table 4.

	Organisation	Responsibility/Roles	Notes
1.	Department of Health (DH)	<ul style="list-style-type: none"> • Will sponsor cancer informatics work in Public Health England (PHE) • Will fund specific dataset development (such as the new diagnostics data set) • Will be responsible for determining the nature of the Outcomes Frameworks and the indicators 	
2.	DH Systems and Service Delivery Directorate (NHS Connecting For Health)	<p>Responsible for the development, support and hosting of the following national systems:</p> <ul style="list-style-type: none"> • Breast Cancer Call/Recall Screening • Bowel Cancer Screening • Cervical Cancer Call/Recall Screening • Bowel Cancer Audit • Lung Cancer Audit • Cancer Waiting Times • Primary Care GP Practice Registration <p>Responsible for the development of the OPCS coding structure, including the creation of new OPCS-4.7 codes to cover those procedures not yet picked up by the OPCS-4.6</p> <p>Also responsible for the Organisation Data Service</p>	It has not yet been decided where this function will reside within the new organisation model. This information is unlikely to be available until early 2012

	Organisation	Responsibility/Roles	Notes
3.	Information Standards Board for Health and Social Care	<p>Will assess submissions related to:</p> <ul style="list-style-type: none"> • Chemotherapy dataset • COSD • Diagnostic Imaging Dataset 	<p>During 2011/12</p> <p>During 2012/13</p> <p>During 2011/12</p>
4.	Public Health England	<ul style="list-style-type: none"> • Will take on responsibility for cancer registries, the NCIN and EOLC intelligence network 	"shadow form" from 2012/13
5.	NHS Commissioning Board	<ul style="list-style-type: none"> • In order to deliver against the NHS Outcomes Framework and Mandate, and to support CCGs in delivering against the Commissioning Outcomes Framework, will need to ensure that there is the intelligence to support and monitor delivery • Will need to consider future funding for surveys such as the cancer patient experience survey and the survivorship PROMs survey 	
6.	National Cancer Research Institute (NCRI)	<ul style="list-style-type: none"> • Umbrella organisation for the NCIN • Conduit for financial support for the NCIN from NCRI funders • Interface into the research community for use of NCIN data 	
7.	Cancer registries	<ul style="list-style-type: none"> • Will all adopt ENCORE • Will have standardised inputs (e.g. PAS, Path, CWT etc.) • Will submit information on new registrations to ONS/NCDR within 6 months of year end for 2012 data (June 2013) • Will ensure that 90% of patients with 'stageable' cancers have stage recorded (NB currently approximately 80% of cancers are deemed to be stageable) • Will undertake sub-national cancer analysis and intelligence, national analysis and intelligence as part of an integrated national work programme, and specialist national analysis and intelligence for specific cancer types 	<p>End 2012</p> <p>End 2012</p> <p>End 2012</p> <p>Ongoing and as part of Public Health England</p>

	Organisation	Responsibility/Roles	Notes
8.	National Cancer Intelligence Network (NCIN)	<ul style="list-style-type: none"> • Publish information on the proportion of patients presenting with stage 1 + 2 disease (nationally and by commissioner) • Publish information on the proportion of cancer patients presenting as emergencies (nationally and by commissioner) • Publish 30-day mortality following surgery for cancer types • Provide information for annual progress reports on major initiatives (e.g. NAEDI, NCSI, Inequalities) • Publish annual reports by cancer type/group • Publish updated GP practice profiles • Publish commissioner-level profiles • Publish service profiles <ul style="list-style-type: none"> - Breast and colorectal cancer - Radiotherapy and chemotherapy - Other cancers <p>Coordinate the national integrated analysis and intelligence programme</p>	<p>April 2013 onwards</p> <p>From April 2013</p> <p>From 2012</p> <p>From 2012</p> <p>2012</p> <p>Annually From 2012/12</p> <p>2012 From 2012 From 2012/13</p> <p>From 2012</p>
9.	Office for National Statistics (ONS)	<ul style="list-style-type: none"> • Publish National Statistics on cancer incidence, survival and mortality • Commission statistics on cancer survival from CR-UK Cancer Survival Group at London School of Hygiene and Tropical Medicine • Link death registrations with flagged NHSCR cohort management system to identify deaths to be notified to researchers <p>Provide monthly cancer (and non-cancer) deaths to cancer registries via ENCORE</p>	
10.	NHS Information Centre for Health and Social Care (NHS-IC)	<p>Following the Health and Social Care Board (HSCB) and Arms Length Body Review (ALBR), the NHS-IC has a statutory role:</p> <ul style="list-style-type: none"> • as the single body authorised to conduct national data collection • provide the national repository for data relating to health, social care and public health • provide data quality assurance of national 	By 2013

	Organisation	Responsibility/Roles	Notes
		<p>data</p> <ul style="list-style-type: none"> • data standards • develop indicators • provide a secure data linkage service • disseminate / make public (de-identified) national data 	
		<p>Current and future roles in cancer intelligence for the NHS-IC:</p> <ul style="list-style-type: none"> • Will continue to manage HES • Commission the production of patient-level Hospital Episodes Statistics (HES) records from NHS Commissioning Datasets, and manages dissemination and access to HES datasets • Will continue to manage national clinical audits and will work with the NCIN and the cancer registries towards an interoperable process • Will be responsible for collection and management of the Diagnostic Imaging Dataset • Will provide information from DID and HES to the NCIN • Produce official statistics for the cancer screening programme • Manage the Medical research Information Service (MRIS), which runs flagging and tracing services for cohorts, including cancer • Run the Review of Central Returns (ROCR) process, which supports the Department of Health (DH) and it's Arms Length Bodies (ALBs) to implement the government's policy in 'Reducing the burden' of data collections from the NHS 	<p>Ongoing Ongoing</p> <p>Ongoing</p> <p>From 2012</p> <p>From 2012</p> <p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p>
11.	Commissioners – Primary Care Trust (PCT) clusters/Clinical Commissioning Groups (CCGs)	<ul style="list-style-type: none"> • Provision of cancer data to cancer registries should be a contractual responsibility for providers 	From 2012 onwards

	Organisation	Responsibility/Roles	Notes
12.	Providers	<ul style="list-style-type: none"> • Submit COSD dataset information to registries • Submit radiotherapy and chemotherapy to central specialist analytical units • Submit data to national clinical audits • Submit data on recurrence and metastatic breast cancer • Submit data on recurrence of other cancers 	<p>end 2012</p> <p>From April 2009 & 2012 respectively</p> <p>from April 2012 (subject to ISN) 2013 (subject to ISN)</p>
13.	National Cancer Action Team (NCAT)	<ul style="list-style-type: none"> • Publish annual reports on cancer peer review • Supply information from cancer peer review to the NCIN for service profiles • Currently fund international comparisons of cancer survival (ICBP) 	<p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p>
14.	National End of Life Care Intelligence Network (NEOLCIN)	<ul style="list-style-type: none"> • Provides the NCIN with information on place of death and on admissions and bed days in last year of life for cancer patients 	
15.	Cancer Research UK	<ul style="list-style-type: none"> • Funder of the NCIN • Co-leading the NAEDI initiative • Produce UK-based cancer-stats, using NCIN and registry data • Produce contextualised statistical information for patients • Focus on earlier diagnosis and stratified medicine 	
16	Macmillan Cancer Support	<ul style="list-style-type: none"> • Funder of the NCIN • Relies on NCIN and registry data and stats to produce targeted information on services, outcomes and experience. • Used to produce contextualised information for patients and allows development of novel approaches to information provision • Provides critical data to analyse and understand longitudinal aspects of cancer survival in terms of late effects, co-morbidities and survival. This is critical for targeted and effected service development and design. 	

An Intelligence Framework for Cancer

	Organisation	Responsibility/Roles	Notes
		<ul style="list-style-type: none">• NCIN data allows hypothesis led research into cancer survivorship in a cost effective and timely way	

8. Aspirations for the future

- 8.1. This framework sets out the immediate actions to improve cancer intelligence which have been agreed with stakeholders and are currently funded. It represents an ambitious programme to move forward the Information Revolution in cancer, harnessing the skills, ideas and resources of the wide range of stakeholders involved in cancer intelligence
- 8.2. Once the contents described in Chapters 1 to 7 are implemented, this framework will help to:
 - Give clinicians the data they need to inform action to improve outcomes;
 - Support the development of high quality commissioning; and
 - Shift power towards patients, placing information in the public domain which will help them make informed decisions.
- 8.3. However, our ambitions for cancer intelligence do not end with the actions set out in the preceding chapters. Cancer intelligence is a rapidly developing field and, through the implementation of this framework, we will learn more about what is possible and indeed desirable to support patients and cancer services in delivering the best possible outcomes. Longer term work will be set within the broader strategic plans to follow in the forthcoming Information Strategy for health and social care in England, planned for publication by April 2012.
- 8.4. A critical part of cancer intelligence will be ‘information research and development,’ linking new datasets and using the information collected as a result of this framework to generate fresh insights. This in turn is likely to identify new areas where intelligence could support better outcomes, as well as opportunities to deliver further quality and efficiency gains in intelligence processes.
- 8.5. There is a limited capacity within the cancer and wider healthcare intelligence field and a key task for the next few years will be to develop this, as well as ensuring that the resources which are available are used as efficiently and effectively as possible. A key focus of this framework is to ensure that core intelligence requirements (such as the chemotherapy dataset) are delivered in a timely manner. As and when these are delivered, and more capacity becomes available, steps to further strengthen cancer intelligence will be considered.
- 8.6. The framework itself is designed to be robust and lasting, whilst the activities which are taken forward within it will grow and develop over time to meet the evolving needs of the healthcare system. If and when further improvements can be made, they will be introduced carefully, and only once they are fully funded.

- 8.7. Looking across the care pathway, potential aspirations for the future include the following, some of which are described in more detail below:
- Enabling pathology and radiology reports to be generated containing coded data using online proformas;
 - Introducing better recording of co-morbidity alongside data on cancer treatment;
 - Linking information on treatment outcomes to the stratified medicines initiative;
 - Analysing the National Cancer Patient Experience Survey according to type of treatment given, by linking it with datasets such as HES, radiotherapy and chemotherapy; and
 - Enhanced access to data for researchers.

Linkages to Primary Care

- 8.8. The largest source of untapped data and intelligence lies in primary care, which has to date been difficult to link with information on diagnosis, treatment and outcomes in secondary care. A link is in place between data from registration and the General Practice Research Database (GPRD), although this only covers a proportion of the population. The planned implementation of the new GP Extraction Service (GPES) by the NHS Information Centre for Health and Social Care (NHS-IC) will, for the first time, allow secure, robust and comprehensive data linkage into primary care. Such linkages will be able to generate new insights, particularly into the pre-diagnosis and survivorship fields, as well as many other areas of research and analysis. There are ongoing discussions between the NHS-IC and the PHE Data Requirements project to specify the requirements for the GPES service.

Molecular Diagnostics

- 8.9. Current reporting within histopathology services is based largely on free-text transcription of pathological findings. When these free-text reports are submitted to cancer registries, extensive effort is required to codify the unstructured text into data which can be analysed robustly. This is not the case in all pathology laboratories though. Some laboratories have implemented synoptic, or structured, reporting protocols, collecting coded data online supported by IT systems capable of managing structured data. The implementation of synoptic reporting for histopathology across the country has to be seen as an ambition for the future.
- 8.10. The rapid development of personalised, or stratified medicine will open up the opportunity for complex molecular diagnostic tests to be linked to clinical data. Cancer Research UK's Stratified Medicine Initiative is using cancer intelligence systems to centrally host data collected in participating centres and link this to other datasets. The NCIN and NCRI are consulting on options for supporting this form of collaboration.

Interventional Radiology

- 8.11. Interventional radiology is currently poorly recorded in Health Episode Statistics (HES), making the robust monitoring of access to diagnostic radiology difficult to measure. There is the potential to extend the Diagnostic Imaging Dataset (DID) to include detailed information on all diagnostic tests. As with histopathology reporting, radiological reporting is based largely on free-text, and as with histopathology, we should have similar ambitions for the implementation of collecting coded data online within synoptic reporting for radiology across the country.

Survivorship

- 8.12. New methods of survivorship care, such as remote monitoring, require investment in new IT. It is important that the data and information collected as part of this care is used to augment the overall information on the total pathway of patient care, such that it provides new inputs to national cancer intelligence.

End of Life Care

- 8.13. The implementation of electronic palliative care coordination systems is intended to improve the service provided to people approaching the end of life, their families and carers. Such systems will record and make available people's preferences and wishes to the multidisciplinary team delivering care. This information, available 24 hours a day, will facilitate coordination of care between the members of the team and support appropriate treatment decisions to allow more people to experience a 'good death', in the place that they wish and with the appropriate intervention.
- 8.14. A national information standard, covering a set of core data, will support consistent recording of information which will improve accuracy and avoid misinterpretation, misunderstanding and duplication of questioning across the multidisciplinary team.

Provision of data to drive research

- 8.15. The richness and availability of clinical data is expanding rapidly providing new opportunities for research. The governance arrangements for access to such sensitive personal data must be stringent, and steps should also be taken to ensure that barriers to access for *bona fide* research to do become prohibitive. The development of a safe haven would allow approved researchers to access low level data running on a range of high powered analytical servers, to undertake innovative research. Such a programme could be based on the UK Data Archive model, which provides such a facility for social and economic data. The NCIN and NCRI are developing proposals to take this forward.
- 8.16. Existing links between data from registration, HES and the GPRD have already been the source of a significant number of new peer reviewed research

publications. There are further opportunities to link routinely collected cancer data to research datasets (for example those collected in clinical trials and cohort studies, or those associated with sample collections). Pilot work to test this is beginning with UK Biobank.

- 8.17. Looking beyond cancer, there will be opportunities to build on the existing linkage with the GPRD and support a wider range of cross disease work through the recently announced Clinical Practice Research Datalink (to be formed by combining the Health Research Support Service established by the Research Capability Programme with GPRD).

Opportunities for data sourcing, linkage and processing

- 8.18. A core role of the NHS Information Centre for Health and Social Care (NHS-IC) will be in the provision of a national data linkage service across large national datasets. Overlaps between this developing core role and that played by the ENCORE system and the cancer registries, and indeed the wider data management roles within Public Health England (PHE) will need to be considered as a whole, to identify potential efficiency gains within and beyond cancer. PHE, the NCIN and the NHS-IC will need ensure cancer data sourcing, processing, information management and intelligence generation is located and managed in the best place. Active dialogue should continue as the three organisations continue to develop to ensure clarity of roles and responsibilities.
- 8.19. The NHS-IC will also collate and maintain a National Data Repository of health, social care and public health data. Development of collaborative linkages between the NHS-IC repository and the specialist NCIN cancer repository will be important, to improve and facilitate wider access to data and intelligence, and to improve data flows.

Annex 2: Provider Profile for Cancer

Version 0.4, Sept 2011. Please direct comments and feedback to profiles@ncin.org.uk

Jo Bloggs NHS Trust

Section #	Indicator	No. of patients/cases or value	Proportion or rate		Trust rates or proportion compared to England mean		Source	Period
			Lower 95% confidence	Upper 95% confidence	England	Range		
1	Size	Number of new patients treated per year	90		0%		100%	Cancerwals 2010
2	Demographics (based on new patients treated per year)	Patients aged 70+	50%	49%	52%	60%	0%	100%
3		Patients with recorded ethnicity	89%	86%	92%	94%	0%	100%
4		Patients recorded as non white-British	15%	15%	16%	16%	0%	100%
5		Patients who are income deprived	17%	16%	18%	18%	0%	100%
6		Male patients	2%	2%	2%	7%	0%	100%
7	Patients with a registered cancer stage	70%	68%	72%	77%	0%	100%	
8	Patients with a Stage A or B disease at diagnosis	40%	39%	41%	46%	0%	100%	
9	Patients with a Charlson co-morbidity index >0	34%	34%	35%	38%	0%	100%	
10	The specialist team has full membership	Yes					0%	100%
11	Proportion of peer review indicators met	82%					0%	100%
12	Peer review: are there immediate risks?	No					0%	100%
13	Peer review: are there serious concerns	No					0%	100%
14	Patients reporting good availability of a CNS	92%	89%	95%	99%	0%	100%	
15	Surgeons not managing 20+ cases per year	4%	40%	39%	45%	0%	100%	
16	Number of two week wait referrals for cancer	42					0%	100%
17	Number and proportion of admissions that are emergencies	120	48%	47%	49%	52%	0%	100%
18	Patients referred via the screening service	17	17%	16%	18%	19%	0%	100%
19	TWW referrals with suspected cancer seen within 2 weeks	37	88%	85%	91%	93%	0%	100%
20	TWW referrals treated within 62 days	41	98%	95%	101%	103%	0%	100%
21	TWW referrals diagnosed with cancer	7	7%	7%	7%	14%	0%	100%
22	Patients treated within 31 days of agreeing treatment plan	91	91%	88%	94%	93%	0%	100%
23	Surgical cases treated laparoscopically	12	12%	12%	12%	21%	0%	100%
24	Patients resected for liver metastases	8	8%	8%	8%	16%	0%	100%
25	Patients undergoing a major surgical resection	29	32%	31%	33%	38%	0%	100%
26	Mean length of stay for elective admissions	4.5	4.4	4.4	4.6	4.6	0	10
27	Mean length of stay for emergency admissions	5.7	5.5	5.9	5.7	0	10	10
28	Surgical patients readmitted as an emergency within 28 days	4	4%	4%	4%	10%	0%	100%
29	New to follow-up outpatients appointments	76%	74%	78%	82%	0%	100%	
30	Patients treated surviving at one year	90	90%	87%	93%	91%	0%	100%
31	Surgical patients who die within 30 days	1	1%	1%	1%	1%	0%	100%
32	Patients reporting being treated with respect and dignity	92	92%					100%
33	Cancer patient experience survey questions scored as "green"	3	87%					100%
34	Cancer patient experience survey questions scored as "red"	6	4%					100%

Annex 3: List of Routine Outputs

The following list of routine outputs include what is already published and publications that will become routine. The table highlights who is responsible, when the report is scheduled to be (or was last) published and the period covered:

	Topic Area	Frequency	Last produced	Period covered	Organisation
1.	Public health and cancer				
	• HPV vaccine coverage	Annually	Jan 2011	2009/10	DH
	• Smoking statistics	Annually	Aug 2011	2009/10	NHS-IC
	• Obesity	Annually	Feb 2011	2009/10	NHS-IC
	• Physical activity	Annually	Feb 2011	2009/10	NHS-IC
	• Alcohol consumption	Annually	May 2011	2009/10	NHS-IC
2.	Cancer Screening				
	• Breast screening	Annually	Feb 2011	2009/10	NHS-IC
	• Cervical screening	Annually	Nov 2011	2010/11	NHS-IC
	• Bowel screening	Annually	tbc	tbc	tbc
3.	Headline Cancer Statistics				
	• Incidence by age and tumour type	Annually	June 2011	2006-2008	ONS
	• Mortality by age and tumour type	Annually	June 2011	2006-2008	ONS
	• Survival by age and tumour type	Annually	Nov 2011	2004-2008	ONS/LSHTM
	• PCT one year survival index	Annually	Dec 2011	Up to 2008	ONS/LSHTM
	• Proportion of patients presenting with stage 1 and 2 disease (nationally and by commissioner)	tbc	From April 2013	tbc	NCIN
	• Proportion of patients presenting as emergencies	tbc	From April 2013	tbc	NCIN
	• Cancer waiting times	Quarterly and annually	Sept 2011	2011/12	DH

	Topic Area	Frequency	Last produced	Period covered	Organisation
4.	Reports relating to NHS Outcomes Framework				
	• Radiotherapy activity (RTDS)	Annually	Planned 2012	2010/11	NCIN
	• Major surgical/radiotherapy activity	Ad hoc	Planned 2012	2009/10	NCIN
	• Chemotherapy dataset	tbc	From 2013	tbc	NCIN
	• Cancer Drugs Fund utilisation/outcomes	tbc	From 2012	tbc	NCIN
	• Cancer Patient Reported Outcome Measures (PROMs)	tbc	From 2012	tbc	DH
	• Cancer patient experience survey	tbc	July 2011	2010	DH
	• Bereaved relatives survey	tbc	From 2012	2010/11	DH
	• Activity/productivity (admissions, lengths of stay, bed days)	Quarterly	From 2012	2010	NCIN/CCT
	• Peer review overview report	Annually	2010	2009/10	NCAT/NCPR
	• National clinical audit reports <ul style="list-style-type: none"> - Bowel - Head and Neck - Lung - Mastectomy & Breast Reconstruction - Oesophago-Gastric 	Annually	Nov 2011 June 2011 Nov 2011 (Mar 2011) 2010	2009/10	NHS-IC