Improving awareness of the English cancer registry amongst patients, health professionals and the public

Review of Informed Choice for Cancer Registration

September 2016
Executive summary

1 in 2 people born since 1960 will be diagnosed with cancer in their lifetime, with that proportion expected to rise. In order to improve survival and care, and to deliver the commitments in the 2015 Cancer Strategy for England, high-quality cancer intelligence is crucial.

When a person is diagnosed with cancer in the UK, information about them is automatically included in the relevant national cancer registry. It is data from the cancer registries that tells us how many people are diagnosed with cancer, what treatments they have, how long they live, and whether overall this is getting better or worse.

The high-quality, population-level data held within the cancer registry has played a vital role in efforts to improve outcomes for people affected by cancer. It is important that this utility is maintained and that those who are in the cancer registry are aware of how their data is being used and the choices they have.

Dame Fiona Caldicott, the National Data Guardian (NDG), recently led a review into how health and social care data is managed in England, which was published in July 2016. The NDG recommended ten new security standards to be followed by all organisations using health and social care data, as well as a new consent and opt-out model, enabling people to make choices about how their personal confidential data would be used for purposes beyond direct care.

During the NDG’s review it was identified that the way that people are currently informed about cancer registration needs to be improved. In this context, Cancer Research UK and Macmillan Cancer Support offered to review how people with cancer in England can be better informed about how their data is used in cancer registration. This includes being given enough information to make an informed choice about their data being included, and how to opt-out. A decision on whether cancer registration would be part of the NDG’s proposed new consent model was to be taken following the outcome of this review.

The scope of our review was to specifically consider how people with cancer can best be informed about cancer registration, rather than the consent model itself, working under the assumption that a separate opt-out currently remains the most appropriate model for the cancer registry. This and other assumptions were tested through the review; evidence to support them is presented later in this report.

Following the publication of the NDG’s review, we recognise that there are opportunities in time to integrate the registry with the new consent model. While these should be explored in future, ensuring that people affected by cancer and health professionals are properly informed about the cancer registry must be an immediate priority. Regardless of the consent model, improving awareness of how cancer data is used is the right thing to do.

In order to form our recommendations we listened to the views of 1,400 people affected by cancer, 1,000 members of the public, 340 health professionals and 20 cancer charities. Over three months we ran two online surveys and nine engagement events, commissioned a piece of independent research and met with many stakeholders in order to ensure that we had as complete an understanding as possible of a wide range of views and perspectives. The review was governed by a panel made up of patient representatives, health professionals, senior staff from both Cancer Research UK and Macmillan Cancer Support, the Department of Health, the NDG’s Panel and Public Health England (PHE).

Throughout this review we were struck by the overwhelming support shown for the cancer registry by people affected by cancer and health professionals, as well as a desire to learn more about the registry and the use of data more broadly. We heard from people affected by cancer that the majority wanted their data to be used but they wanted to know for what reason, by whom, and that it was secure. We heard from health professionals that, with the right support, starting conversations about the use of data with patients would be both manageable and important.
Findings and recommendations
In an online survey of people with cancer and the general public we commissioned from Ipsos MORI, just six per cent of people with cancer said that they knew a great deal or a fair amount about the cancer registry; three quarters had never heard of the registry (74 per cent). However, the desire from people affected by cancer to be given information about the cancer registry is clear: 83 per cent in our commissioned research and 93 per cent in our in-house survey said it was important that patients were informed.

Ambition
Awareness of the cancer registry is significantly improved among people with cancer.

Our principal recommendation is therefore that soon after a cancer diagnosis, people with cancer should be told about the registry and its uses as well as their ability to remove their data from the registry if they wish. Each hospital trust should have a policy in place to state that this should take place, with the Caldicott Guardian having ultimate accountability. The Lead Cancer Clinician should then work with multidisciplinary team (MDT) leads to ensure that the policy is implemented by cancer teams. We have recommended a system with local ownership and the flexibility to make decisions on a case-by-case basis on when and how to inform people with cancer about the registry.

However, there are some factors that should be consistent across trusts. We heard from people affected by cancer that they would like this conversation to happen soon after the time of diagnosis, but that diagnosis itself was likely to be a bad time. This should take the form of a brief face-to-face conversation with a health professional involved in their care. That health professional should talk through key information about the registry, hand over a leaflet containing the relevant information and tell the person where they can find more information if they wish.

Recommendation 1
Hospital trusts should be accountable for ensuring that patients are made aware of the cancer registry and their ability to opt-out at the earliest appropriate time after diagnosis.

Recommendation 2
There should be multiple channels through which people affected by cancer can find out about the registry and all communication materials need to be tailored to the relevant audiences.

Ambition
Information provided about the cancer registry is accessible and tailored to relevant audiences.

It is important that this conversation is not the only mechanism by which people are informed about the cancer registry; there are some patients who it will not be possible to reach through a face-to-face conversation and some who may have a conversation but may be too distressed to process the information at that time. In order to maximise awareness of the registry, there should be multiple channels by which people with cancer are informed.

It is also important that communication materials are accessible and appropriate, and are tailored to the relevant audiences. This responsibility mainly rests with PHE, who should work with people affected by cancer, local care providers, national bodies and cancer charities to develop the information content and ensure it is placed where it is appropriate and will reach patients.
Executive summary

Ambition
Awareness of the cancer registry is significantly improved among health professionals.

Over three quarters (80 per cent) of the health professionals that we surveyed had some awareness of the cancer registry, with most interviewees having a basic understanding of the data collected. However, only one quarter (26 per cent) were aware patients could opt out of having their data collected. Four in five (83 per cent) said that they never have conversations about the registry with patients. There is therefore a clear need to improve awareness of the cancer registry amongst health professionals directly interacting with people affected by cancer.

We heard a clear willingness from health professionals to have conversations about the cancer registry with their patients, but a lack of confidence in doing so. This is partly because there has been no clarity about who should have these conversations, and partly because at present health professionals have not been given any training or information about the registry. Recommendation 1 addresses the first of these points; this recommendation addresses the latter point.

Recommendation 3
All healthcare staff that directly interact with people affected by cancer (including support staff and health professionals in primary care and palliative care) should be able to answer basic questions about the registry and signpost to further sources of information.

Ambition
Processes for providing people affected by cancer with information about the cancer registry should be measurable.

Given that 74 per cent of people with cancer have never heard of the cancer registry, there is considerable scope for improvement. In order to ensure that progress is made and that staff at all levels are encouraged to change practice, it is vital that there are mechanisms by which this can be assessed. Our proposed system of measurement involves three levels: at trust level where the policy is held, at MDT level where the policy is enacted and at patient level, where measuring awareness can show whether staff have put the policy into practice. It would be up to each hospital trust to determine whether any additional recording or tracking processes needed to be put in place to support this.

Recommendation 4
The implementation of local and national awareness-raising strategies should be measurable.

Ambition
The general public are more aware of how healthcare data, including cancer data, is used and shared by the NHS and others.

Of the members of the public surveyed, 74 per cent thought it was important that people knew about the cancer registry regardless of whether they themselves had a cancer diagnosis. Increasing the level of public awareness could also benefit people with cancer, making it less of a surprise when they are told about the registry. It could also mean that those who it may not be possible to inform through a face-to-face conversation soon after diagnosis may already have some knowledge of the registry.

The NDG’s report placed a strong and welcome focus on the need for effective communication about healthcare data with the public, as well as patients. In an increasingly digital health service it is vitally important that the way the NHS uses and shares data is trustworthy, transparent and well communicated. All organisations that use cancer registry data have a role to play in facilitating this – including PHE and cancer charities.

Recommendation 5
General awareness of how the NHS uses healthcare data, including cancer data, should be improved.

Each of these five recommendations is supported by specific sub-recommendations and, where appropriate, more detailed guidance.

Next steps
We look forward to continued engagement with PHE, NHS England and the Department of Health on the consideration and subsequent implementation of these recommendations.

We are aware that there is further work to be done in order to determine the specific interactions between the cancer registry and the new model proposed by the NDG. Although addressing this issue was not in the scope of our review, we look forward to continuing to work with the NDG’s panel, the Department of Health, PHE and NHS Digital to ensure that the resulting consent model serves its purpose.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Introduction</td>
<td>6</td>
</tr>
<tr>
<td>2 Ambitions</td>
<td>14</td>
</tr>
<tr>
<td>3 Findings and recommendations</td>
<td>16</td>
</tr>
<tr>
<td>4 The consent model for cancer registration</td>
<td>28</td>
</tr>
<tr>
<td>Appendices</td>
<td>34</td>
</tr>
</tbody>
</table>
1

Introduction
Dame Fiona Caldicott, the National Data Guardian (NDG), recently led a review into how health and social care data is managed in England, which was published in July 2016. This review recommended a new way for people to make a choice about what happens to data about their medical treatment and care.

During the NDG’s review, which covered all areas of health and social care data, it was highlighted that the way that people are currently informed about cancer registration needs to be improved. In this context, Cancer Research UK and Macmillan Cancer Support offered to review how people affected by cancer in England can better be informed about how data is used in cancer registration, including being given enough information to make an informed choice about their data being included and how to opt-out.

The premise of our review was that the current model for cancer registration is appropriate, as long as the level of awareness amongst people affected by cancer is improved. This was based on our understanding of the views and experiences of people affected by cancer and health professionals, gained through many years of close collaboration with and involvement of people affected by cancer in our work. Although the scope of our review was limited to how people with cancer can best be informed about cancer registration, rather than the consent model itself or how this should operate, we did gather evidence during this review to test the assumptions we held about the appropriateness of the current model. A summary of the evidence gathered and our conclusions can be found later in this report.

The evidence provided in this report underpins a proposed new approach to raising awareness of cancer registration that we hope will be taken forward by the Government and the NHS. We believe that this approach will work for people affected by cancer, health professionals and those that are responsible for implementation.

Cancer registration

When a person is diagnosed with cancer in the UK, information about them is automatically included in the relevant national cancer registry. There are also a small number of people listed on the registry who have certain conditions that can lead to cancer.

It is data from cancer registries that tells us how many people are diagnosed with cancer, what treatments they have, how long they live, and whether overall this is getting better or worse. This hugely valuable information is used to help plan cancer services, compare cancer outcomes across regions, nationally and internationally, and identify where further progress is needed in order to improve survival and care for all people with cancer.

A large part of the cancer registry’s value comes from covering everyone living in England, as opposed to only people seen at specific hospitals or diagnosed or treated in particular ways. This is described as population based registration. Population based cancer registration allows the incidence of cancer (how many cases occur) and its prevalence (how many people are alive following a diagnosis of cancer) to be accurately calculated.

Population based cancer registries are viewed as ‘an essential part of any rational cancer control programme’ by the World Health Organisation’s International Agency for Research on Cancer. Their essential role is to inform the allocation of resources to meet current and future needs and to evaluate the success of cancer control overall and of specific prevention, screening or treatment initiatives.

England is one of the largest countries in the world to have achieved high-quality population-based cancer registration. This allows the NHS to monitor how patients present with cancer, how they are treated, their outcomes, and how people living with and beyond cancer are supported. Information from the cancer registry informed the 2015 Cancer Strategy for England and will play a fundamental role in implementing this and assessing whether it has achieved its aims.

England, Scotland, Wales and Northern Ireland each have their own cancer registry. Our review relates specifically to the English cancer registry, because we are submitting these recommendations directly into the Government’s consultation on the NDG’s review of health and social care data in England. However, we hope our review and its findings will also be of interest to the other UK cancer registries.


Uses of cancer registration data

Some examples of how information from the cancer registry is used include:

- Answering fundamental questions about trends in cancer diagnosis, survival, treatment and care. This is vital for informing NHS planning and policy decisions. The Routes to Diagnosis and Routes from Diagnosis projects outlined below are good examples of how information held by the cancer registry can be used to transform service provision.

- Identifying environmental causes of cancer, especially those where the risk to any individual is relatively low and effects can only be seen at a population level. For example, cancer registry data allows investigation of proposed causes such as mobile phone masts and power lines. Cancer registry data has also allowed us to determine the future burden of mesothelioma, which is linked to asbestos exposure. Incidence of mesothelioma is expected to peak in 2022 for men and 2027 for women; knowing this allows for appropriate planning of health services.

- Genetic counselling. The registry allows clinical geneticists to confirm cancer diagnoses in their patients’ relatives. Often, especially when medical records have been destroyed, the cancer registry is the only available source of such information. Knowing someone’s family history has a significant impact on how they are cared for.

- Tracing and contacting patients at risk from late effects of aggressive treatments that may only become apparent years after treatment has ended. For example, women treated with radiotherapy to the chest wall for Hodgkin’s lymphoma at a young age are at much higher risk of breast cancer a few decades later, so can be offered breast screening at an earlier age.

- Planning for NHS services, such as deciding how many radiotherapy machines are needed in England, and where they should be placed.

6 Bunch, K.J. et al Residential distance at birth from overhead high-voltage powerlines: childhood cancer risk in Britain 1962-2008 British Journal of Cancer (2014) DOI: 10.1038/bjc201415


Case study

Routes to diagnosis

The award-winning Routes to Diagnosis analyses, created in partnership between the National Cancer Intelligence Network and Cancer Research UK, was first published in 2010 and led to a huge shift in our understanding of where most cancer patients are diagnosed.

The most significant finding was that in 2006–2010 almost one in four cancer patients were diagnosed as emergencies.

To identify the routes through which patients in England were diagnosed, analysts link cancer registry data with other health datasets. Routes include GP referrals, screening programmes and emergencies. Within emergencies, the two largest routes are emergency referrals from GPs and A&E admissions. Follow up studies have shown that these patients generally have lower survival and are diagnosed at a later stage.

This work drove activity to reduce the proportion of cancers diagnosed as an emergency and highlighted opportunities for improvement in primary and secondary care. This focus is clearly shown in the Cancer Strategy for England published last year. Further work is underway to understand how and why some patients are diagnosed as an emergency.

The data has also contributed to a major focus on optimising the ways in which patients are diagnosed with cancer so that they have the best possible chance of surviving the disease. An example of that work is the NHS-led ACE programme in England, supported by Cancer Research UK and Macmillan Cancer Support, which aims to streamline and optimise patient pathways.

The ACE Programme aims to promote early diagnosis of cancer (at stages 1 and 2), decrease the number of cancers diagnosed through emergencies and improve overall patient experience.
How cancer patients are diagnosed
Percentage of cancer patients diagnosed in England, 2006-2010

By GP referral
- 5% By screening
- 27% By urgent GP referral for cancer suspected symptoms
- 27% By routine GP referral
- 23% In an emergency
- 10% Hospital outpatient
- 3% Hospital inpatient

In an emergency
- 7% By GP referral after a GP makes and emergency referral to hospital
- 1% As an impatient whilst in hospital due to an emergency
- 14% Via A&E during a hospital appointment after an emergency hospital visit e.g. to A&E
- 1% As an outpatient during an accident and emergency visit

People diagnosed in an emergency often have worse outcomes

*Incomplete data

Source: National Cancer Intelligence Network Routes to diagnosis (2010)
In an emergency data breakdown from 2006-2008
## Variations in breast cancer patients' routes from diagnosis

### Survival time

#### 0-12 months

- **Survivorship outcome**
  - D&NL Mets
  - A&UL or No Mets
  - D&NL Mets
  - Cancer complications
  - OIM/NOIM
  - A&UL Mets
  - Cancer complications
  - No Mets
  - Other inpatient morbidities
  - No other inpatient morbidities

#### 1-5 years

- **Survivorship outcome**
  - D&NL Mets
  - Cancer complications
  - OIM/NOIM
  - A&UL Mets
  - Cancer complications
  - No Mets
  - Other inpatient morbidities
  - No other inpatient morbidities
  - D&NL Mets
  - Cancer complications
  - OIM/NOIM

#### 5-7 years

- **Survivorship outcome**
  - D&NL Mets
  - Cancer complications
  - OIM/NOIM
  - A&UL Mets
  - Cancer complications
  - No Mets
  - Other inpatient morbidities
  - No other inpatient morbidities
  - D&NL Mets presented
  - D&NL Mets developed
  - A&UL Mets
  - Cancer complications

#### 7 years

- **Survivorship outcome**
  - Cancer complications
  - Circulatory only
  - Respiratory only
  - Digestive only
  - MSK only
  - Genitourinary only
  - Other inpatient morbidities or multiple other inpatient morbidities
  - No other inpatient morbidities

### Key

- **No Mets**: No metastases
- **D&NL Mets**: Distant and non lymph node metastases (i.e. local metastases)
- **A&UL Mets**: Axillary and upper limb metastases
- **Cancer Complications**: Recurrence or additional primary cancer
- **OIM**: Other inpatient morbidities
- **NOIM**: No other inpatient morbidities
- **MSK**: Musculoskeletal
## Review of Informed Choice for Cancer Registration

### Introduction

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<td>Limited survival</td>
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<td>2</td>
<td>More aggressive complications/recurrence</td>
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<td>3</td>
<td>Limited – moderate survival</td>
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<td>4</td>
<td>Patients with other inpatient diagnosis</td>
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<td>5</td>
<td>Limited intervention</td>
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<td>Less aggressive complications recurrence</td>
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<td>7</td>
<td>Ongoing survival</td>
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<td>8</td>
<td>Living with or beyond cancer</td>
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#### Percentage of breast cancer patients

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<td>1</td>
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#### Case study

**Routes from diagnosis**

Macmillan Cancer Support’s ‘HSJ Highly Commended’ Routes from Diagnosis is a programme of research performing retrospective analysis of almost 85,000 cancer patients’ interactions with the NHS in England between 2004 and 2011.

As Macmillan learns much more about the 2.5 million people currently living with cancer, Routes from Diagnosis provides a valuable evidence-based view of the effect of disease on the people living with cancer and on the health system.

This project involves linking and analysing data from the cancer registry and Hospital Episode Statistics. This allows analysts to map the cancer journey from diagnosis to death or continued survival, describing the health outcomes that patients experience. This can include survival times, the rate and frequency of cancer recurrence, and non-cancer related morbidities.

The approach also lets us see how the frequency and rate of cancer diagnoses is affecting the health care system, for example the length of time patients spend in hospital, when they access a health care service and how much this costs.

Understanding later health implications of cancer can ensure successful planning, development and implementation of cancer services. Cancer services need to be tailored to meet the different health and support needs of people living with cancer, be effective and make economic sense.

The results from Routes from Diagnosis have provided an evidence base for key decision makers in the NHS aiming to tailor and improve cancer care, as well as for initiatives that have transformed follow-up and survivorship care.

#### Key

- **Limited survival**
  - Group 1: Limited survival
  - Group 2: More aggressive complications/recurrence

- **Limited – moderate survival**
  - Group 3: Patients with other inpatient diagnosis
  - Group 4: Limited intervention
  - Group 5: Less aggressive complications recurrence

- **Ongoing survival**
  - Group 6: Living with or beyond cancer
  - Group 7: Living with or beyond other inpatient diagnosis
  - Group 8: Living beyond cancer
**Data collection by the cancer registry**

In England, the cancer registry is managed by the National Cancer Registration and Analysis Service (NCRAS), part of PHE. The cancer registry collects information about the patient (their name, address, age, sex and date of birth), their diagnosis, how they were diagnosed, their treatment, and whether they are still alive. This can be linked to other health information, for example about admissions to hospital or their responses to patient experience surveys.

The register is populated through data collected directly from hospital and laboratory systems, and is held centrally by NCRAS. There is some variation between hospitals and systems in when exactly the data are sent to the registry. For the main NCRAS dataset, the Cancer Outcomes and Services Dataset (COSD), data must be submitted to the registry 25 working days after the month in which a diagnosis occurs. Further information about treatment or other events in subsequent months would continue to be sent to the registry on the same schedule.

As data about a patient will be received from different hospital systems and at different times, NCRAS needs to be able to uniquely identify each patient so that they can combine data from different sources and ensure that each cancer is only included once.

**Data security and access**

With strict ethical and security safeguards in place, cancer registry officials and data analysts within NCRAS are permitted to access and use cancer registry data, to support the provision of health and social care or the promotion of health. When data are released outside NCRAS there is a strict approval process that is overseen by PHE’s Office for Data Release.

Most releases of data from the cancer registry involve aggregated and anonymous data from which individual identifiers have been removed. An example of this is official statistics about the number of people diagnosed with cancer and how many people survive for a year or more after diagnosis.

Data that identifies an individual may only be released if that person gives their consent, the data is being provided to those involved in their direct care or an independent advisory group grants special legal permission. Data will only be released if the recipient will use it for providing health or social care or for the promotion of health, and they can prove they can keep the data secure.
A register of releases of identifiable or potentially identifiable information is published quarterly by PHE\(^9\). Recipients include healthcare providers (such as NHS trusts), government agencies and academic institutions – or partnerships of these.

Examples from PHE’s data release register of where identifiable or potentially identifiable data have been used include:

- When evaluating the effectiveness of new treatments by following up with patients directly – the data must be identifiable so the patients can be contacted
- When evaluating diagnostic and treatment pathways, for example comparing long-term outcomes of patients who had a certain diagnostic test and other similar patients who did not
- When studying rare cancer types, where the numbers of patients are so small that it may be possible to identify individuals.

**Informed choice for cancer registration: the current situation**

Cancer registration currently works on an opt-out basis: information about people with cancer is automatically collected, but they can request that their data are removed. A leaflet to inform people affected by cancer about the inclusion of their data in the cancer registry is sent by PHE to English NHS trusts treating people with cancer. The content of the leaflet was updated in 2014 with input from people affected by cancer and support from Cancer Research UK\(^12\). As well as information about the registry itself, the leaflet contains information about how patients can request that their data are removed from the registry.

Before starting this review we had heard anecdotal evidence of low awareness of the cancer registry amongst people affected by cancer and health professionals.

However, we know that having conversations about data with patients is not easy. For health professionals and their patients, time is precious and discussions about data are not the top priority. It is understandably very difficult to conceive a ‘good’ time for such conversations.

This is further complicated by the lack of a clear chain of responsibility for informing patients about cancer registration. Although PHE is responsible for producing communication leaflets, once these reach hospital trusts there is no further guidance on how this information should be disseminated, when this should happen or which health professionals are responsible. Our review recommends specific actions to address these issues.

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\(^10\) Ibid.


\(^12\) A copy of the leaflet is available from http://publications.cancerresearchuk.org/downloads/Product/CS_Cancer%20Registration_Leaflet.pdf
2

Ambitions
Our ambitions throughout this review were as follows:

• **Awareness of the cancer registry is significantly improved among people with cancer.**
  Only 26 per cent of people with cancer have ever heard of the cancer registry. While finding out about the registry is not the top priority following a cancer diagnosis, 83 per cent believed it was still important to be informed. Furthermore, improving awareness of the registry is also helpful for ensuring that the registry meets fair processing requirements.

A reformed system must deliver on the following ambitions:

• **Information provided about the cancer registry is accessible and tailored to relevant audiences.**
  Although some information about the cancer registry has been developed, it is not tailored to different audiences and has not reached many people affected by cancer. In addition, it is only available in written format and in English, and for an adult audience with high levels of literacy. This means that the leaflet in its current form is inaccessible to many people affected by cancer.

• **Awareness of the cancer registry is significantly improved among health professionals.**
  Our survey of health professionals found that over 80 per cent do not discuss cancer registration with any of their patients and are unclear who is currently responsible for doing so. The vast majority of both health professionals and people affected by cancer felt that this information should be given by the professionals managing that patient's care. It is therefore important that clear lines of responsibility are established and that those interacting with people affected by cancer have the knowledge and support they need to speak confidently to their patients about the registry.

• **Processes for providing people affected by cancer with information about the cancer registry is measurable.**
  Given the importance placed on cancer registration by patients, and the current low level of awareness, it is important that we are able to measure how successfully these recommendations have been implemented.

• **The general public are more aware of how cancer data, and other healthcare data, is used and shared by the NHS and others.**
  Just 19 per cent of the general public had heard of the cancer registry. Given that 1 in 2 people will in future be diagnosed with cancer in their lifetime, increasing general awareness would mean fewer surprises when it comes to being told about the cancer registry. Both patients and public supported this: 73 and 74 per cent respectively think it is important that people know about the registry regardless of whether they have been affected by cancer. Beyond the cancer registry, we also saw a clear need for improved public dialogue about how healthcare data is used in the NHS and beyond, so that the cancer registry is seen as part of a wider programme of evidence-based improvements to treatment and care.

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13 Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
14 See Appendix (survey of health professionals)
15 See Appendix (Ipsos MORI, in-house survey of people affected by cancer and survey of health professionals)
16 Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
3 Findings and recommendations
Methodology
We gathered evidence from people affected by cancer, health professionals and cancer charities using a mixture of surveys, interviews and workshops. Full details of our approach are included as an appendix with a brief overview below.

Engagement with people affected by cancer
In the initial stages of planning this review, we consulted Cancer Research UK’s patient sounding boards (a total of 16 patients). Two patient representatives were recruited to the review panel; these representatives were consulted throughout the project and helped deliver the engagement events.

We held four engagement events: two in London, one in Manchester and one in Leeds. We made an effort to recruit attendees who had not previously attended Cancer Research UK or Macmillan Cancer Support events. Two of these events were used as ‘discovery’ events to inform initial thinking; the final two were used to refine emerging recommendations. We also held a solution development workshop specifically for members of Use MY Data and Independent Cancer Patient Voices, groups with a particular interest in the use of cancer patients’ data. For those who were unable to attend the engagement workshops we ran an in-house survey, which received 303 responses.

In order to provide more robust evidence, we commissioned Ipsos MORI to conduct a survey of 1,000 people with cancer and 1,000 members of the general public. Of the members of the public, 64 per cent reported having a close friend or relative who had been diagnosed with cancer.

Engagement with health professionals
Our Review Panel contained four health professionals with representation from primary care, oncology, surgery and a clinical nurse specialist. To assess knowledge of the cancer registry and opportunities for information provision we conducted interviews with 27 health professionals and ran an in-house survey which received 273 responses. We then held two solution development workshops in London and County Durham, attended by roughly 40 health professionals.

Engagement with cancer charities
Twenty cancer charities were directly involved in this review, co-ordinated by the Cancer Campaigning Group, and many more were informed about its progress and given the opportunity to input. We held two solution development workshops, one with charities representing common cancers and one with charities representing rarer cancers and seldom heard from groups.

Rationale for our proposed approach to improving awareness of the cancer registry among people affected by cancer
Before starting this review we had heard that awareness of the cancer registry was very low amongst people affected by cancer. This was confirmed in our commissioned survey18, which found that, among people affected by cancer, only 16 per cent knew ‘a little’ or more about it; this was even lower among the general public at 10 per cent. Our in-house survey found that health professionals had greater awareness but were also not well informed: 80 per cent had heard at most ‘a little’ about the registry.

When given information about the registry and its uses, the majority of people with cancer and the general public believe the use of cancer data to improve services and treatments outweighs the risk to privacy and security, with people with cancer more supportive than the general public (85 per cent and 72 per cent support respectively)19. Past literature on this topic has found similar themes: a national survey in 2006 found that, although awareness was low, most people were supportive of the registry20.

Both people with cancer and the public strongly support having a face-to-face conversation as the main way of finding out about the registry. In order to ensure that not everything rests on this conversation, we have recommended a number of ‘secondary’ mechanisms by which people can find out about the registry. This includes integrating information about the registry into existing leaflets, letters or websites, as well as improving awareness among the general public.

However, we know that no matter how thoroughly these recommendations are implemented, it may never be possible to reach every person diagnosed with cancer.

For growing numbers of people with cancer, diagnosis occurs at an early stage and treatment follows well-defined clinical pathways. For these people, such as the approximately 32,000 patients diagnosed with breast cancer at an early stage each year in England21, it should be relatively easy to ensure that a conversation about the registry happens for every patient.

18 Ipsos MORI were commissioned to carry out an online survey of people with cancer and the general public. Quotas were set and weights applied to the data. Fieldwork was carried out between 13th June and 4th July 2016. More detail of the methodology and findings can be found in their report: Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
19 Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
20 Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
22 70.9% early stage, 44 831 diagnoses (2013)
Unfortunately, a significant proportion of people are diagnosed in circumstances where it is not easy to ensure that they are informed. The rationale for our recommended approach in these circumstances are set out below.

**Those diagnosed in difficult circumstances**
Many people with cancer are still diagnosed at a late stage and rapidly enter palliative care. In this instance it is still important that those people are informed, but it would be more difficult to ensure that every person has been. Table 1 shows the proportion of people for the ten most common cancers who survive their disease one month after their diagnosis.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female breast (C50)</td>
<td>99%</td>
<td>44,481</td>
</tr>
<tr>
<td>Prostate (C61)</td>
<td>98%</td>
<td>40,147</td>
</tr>
<tr>
<td>Lung (C33-C34)</td>
<td>79%</td>
<td>36,264</td>
</tr>
<tr>
<td>Bowel (C18-C20)</td>
<td>92%</td>
<td>33,654</td>
</tr>
<tr>
<td>Malignant Melanoma (C43)</td>
<td>100%</td>
<td>12,283</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma (C82-C86)</td>
<td>92%</td>
<td>11,335</td>
</tr>
<tr>
<td>Bladder (C67)</td>
<td>94%</td>
<td>8,722</td>
</tr>
<tr>
<td>Kidney (C64)</td>
<td>90%</td>
<td>8,429</td>
</tr>
<tr>
<td>Pancreas (C25)</td>
<td>71%</td>
<td>7,816</td>
</tr>
<tr>
<td>Brain Tumours (C71, D330-D332, D430-D432)</td>
<td>86%</td>
<td>5,001</td>
</tr>
</tbody>
</table>

Hardly a priority at end of life, but if possible, should be informed. Important to include the data to see what failings, if any, led to the late diagnosis a patient

The person should still be told what the registry is and asked if their details can be added. If for some reason they are unable to do this themselves due to illness, then a family member could be asked on their behalf a patient

It’s useful, but again don’t be bothering someone who’s dying asking them how they can help everyone else… If I was gonna die and you keep asking me whether I’d like to join the cancer register or not over and over in an attempt to make “EVERY EFFORT” to ensure I had the opportunity to say no to it, I’d probably get up and punch you a patient

While the majority of people thought it was important to inform those diagnosed towards the end of life about the registry, around a third (32 per cent) thought it was not important. When we asked people what they thought should happen to someone’s data if it is not possible to inform them about the registry, 57 per cent thought it should still be included, 18 per cent thought it should not, 11 per cent thought the decision should be made by relatives and 12 per cent were unsure. When explored in more detail during our workshops, the vast majority of people affected by cancer were highly supportive of their data still being included in the registry. On balance, we therefore recommend that data should still be included in these circumstances.
Improving outcomes for those patients who are diagnosed late relies on learning from other people in that situation. It is the fact that the cancer registry is population-based and therefore contains a near-complete record of all patients, regardless of how they were diagnosed, that makes it so valuable.

For other people with a cancer diagnosis it may not be possible to ensure they are informed about the registry either because they are too unwell, do not have capacity or are simply too distressed to take in such information.

As demonstrated by the Routes to Diagnosis work described earlier, 20 per cent of cancer patients were diagnosed via an emergency route in 2013. These patients can be extremely unwell and, in some cases, the bulk of their care is given by emergency medicine professionals rather than oncologists. Those patients who survive and enter into an oncology team’s care can be informed by that team. For those who unfortunately do not survive their initial treatment we do not believe it is appropriate to force a conversation about data. As discussed above, it is these patients who we most need to understand if we are to improve survival in the future.

Table 2 shows the proportion of people diagnosed through an emergency route and the percentage who survive their disease for at least one month²⁴

<table>
<thead>
<tr>
<th>Cancer site (ICD-10 code)</th>
<th>Patients diagnosed in an emergency (2006-2013)</th>
<th>1 month relative survival (2006-2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female Breast (C50)</td>
<td>4%</td>
<td>77%</td>
</tr>
<tr>
<td>Prostate (C61)</td>
<td>9%</td>
<td>81%</td>
</tr>
<tr>
<td>Lung (C33-C34)</td>
<td>37%</td>
<td>61%</td>
</tr>
<tr>
<td>Bowel (C18-C20)</td>
<td>25%</td>
<td>78%</td>
</tr>
<tr>
<td>Malignant Melanoma (C43)</td>
<td>2%</td>
<td>86%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma (C82-C86)</td>
<td>26%</td>
<td>77%</td>
</tr>
<tr>
<td>Bladder (C67)</td>
<td>18%</td>
<td>77%</td>
</tr>
<tr>
<td>Kidney (C64)</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>Pancreas (C25)</td>
<td>47%</td>
<td>59%</td>
</tr>
<tr>
<td>Brain Tumours (C71, D330-D332, D430-D432)</td>
<td>61%</td>
<td>83%</td>
</tr>
</tbody>
</table>

For these people it should be up to health professionals, not Cancer Research UK or Macmillan Cancer Support, to make a judgement call about whether it is appropriate to have such a conversation.

Children and young adults

More than 1,700 children aged 14 or under are diagnosed with cancer each year in the UK²⁵. We have suggested in our guidance that health professionals should inform the young person or their parent or guardian, depending on the age and capacity of the young person. Research conducted by the Teenage Cancer Trust suggests that this group are similarly supportive of being informed through a face-to-face conversation²⁶. We therefore propose that the same approach is taken, alongside producing tailored information.

Well firstly I assumed this already existed anyway and I don’t see anything wrong with it as long as the information is kept safe and secure and is not exposed. If this method is beneficial and useful in gathering information and coming up with accurate data then it is a good thing but I believe people have a right to know what information about them is stored a patient

Some people may be anxious at the time of an appointment and may not give their true answer so giving a patient time to think is good a patient

It will benefit everyone involved if all the information was available in order to create statistics to help research. It is also important to make sure that patients are able to withdraw their consent at any time and have their data taken out a patient

²⁶ My Data and the NHS – Teenage Cancer Trust 2016
Recommendations
In this report we recommend how people with cancer in England can be better informed about how their data are used in cancer registration, enabling them to make an informed choice about their data being included in the cancer registry and how to opt-out. Our recommendations were drawn from the results of our surveys of people affected by cancer and health professionals, and engagement events. We then tested and refined our draft recommendations at engagement workshops with these audiences, as well as through discussions with professionals working closely with cancer registry data.

**Ambition**

Awareness of the cancer registry is significantly improved among people with cancer.

Just six per cent of people with cancer said that they knew a great deal or a fair amount about the cancer registry; three quarters had never heard of the registry (74 per cent). However, the desire from people affected by cancer to be given information about the cancer registry is clear: 83 per cent in our commissioned research and 93 per cent in our in-house survey said it was important that patients are informed.

I was not told and although I have no problem with it many people would and I feel it is a violation of trust/privacy if this information is not explained.

I think the benefits drawn from holding information at national level for all cancer and prospective cancer patients outweigh any concerns individuals may have. But I still think cancer patients need to know how their personal information is being used.

I did not know that I had been on the Cancer Register for 18 years, but I am delighted that such a register exists.

In both our surveys of people affected by cancer, the most popular time to be told about the registry was at diagnosis; after a diagnosis came a close second. This was tested further at the engagement workshops; it was felt that although there is never a ‘good’ time, close to the time of diagnosis would be the best option for most patients. This is also helpful for ensuring compliance with fair processing requirements.

A conversation soon after diagnosis is likely to be before any information has entered the registry, which should happen within 25 working days of the month in which a cancer diagnosis is given.

Although it is not a fair processing requirement from the Information Commissioner’s Office to inform patients before data is submitted to the cancer registry, it should be possible for this to happen in most cases.

After you’ve been told you got cancer, everything else is a blur. You need time to adjust and take in the information.

People with cancer surveyed by Ipsos MORI were most likely to want to hear about the registry in a leaflet or letter, either directly from a health professional or from the registry itself. Our in-house survey found that 71 per cent preferred a face-to-face interaction. When we tested this with people affected by cancer at our engagement workshops, we heard that a direct letter from the registry might come as too much of a shock and a face-to-face interaction was preferred. It was also felt that there would be some risk that a letter could arrive at an inappropriate time or even after someone had died.

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27 Including staff from PHE and NHS England, Caldicott Guardians and cancer managers.
28 Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
29 Ibid. 42%; 36% chose options after diagnosis (during treatment: 19%; between treatments: 4%; after treatment: 13%)
30 “In compliance with the fair processing requirement within the Data Protection Act, provider organisations are expected to inform patients of this purpose for reporting their information and of the potential use of the information for service development, analysis and statistical research”
31 Ibid.
To reflect these views, we have recommended a short face-to-face conversation, in which a leaflet is given to the patient. This approach was also supported by health professionals.

I think a leaflet that’s written well is the way of doing it. It’s not something you have to talk through, you can give it to people and say ‘if you’ve got any questions, come back’ or ‘this is the person you need to contact for more advice a GP

Of the people with cancer who expressed a desire to be informed by a health professional, their preference was for the conversation to be with a consultant (62 per cent; Ipsos MORI). Health professionals interviewed suggested that either the treating or diagnosing clinician, or the Clinical Nurse Specialist, could be well placed to have a conversation.

The clinicians involved with the patient’s care know them best at that time and are best placed to discuss this a Clinical Nurse Specialist

We have also recommended that each hospital trust develops a policy, so that we can ensure that informing patients about the registry is recognised as important while allowing a flexible approach, adaptable to different patient populations and trust processes.

We do not intend to be overly prescriptive about the content of this policy, just that it should state that people with cancer should be made aware of the cancer registry and their ability to opt-out in a face-to-face interaction, and that this should happen at the earliest appropriate time following diagnosis. Guidance on this is set out below:

The relevance of the cancer registry to data protection and information governance requires that someone with such experience should be held ultimately accountable for such a policy. We felt that a trust’s Caldicott Guardian would be best placed for this.

However, clinical involvement and clear chains of responsibility are crucial to ensuring that this policy is enacted. In order to allow flexibility between clinical teams caring for patients with different types of cancer, multidisciplinary team (MDT) leads should determine which health professionals should be responsible for having conversations with the patients under their care. Compliance with this policy should therefore be assessed at MDT level. MDTs are assessed by NHS England’s Quality Surveillance Team, who could include an assessment in their annual peer review of cancer services.

Recommendation 1

Hospital trusts should be accountable for ensuring that patients are made aware of the cancer registry and their ability to opt-out during a face-to-face interaction with a member of staff at the earliest appropriate time after diagnosis.

1.1 Each hospital trust should have a policy in place outlining how people with cancer will be made aware of the cancer registry and their ability to opt-out at the earliest appropriate time after diagnosis. This should include clear lines of accountability and responsibility within the trust, as well as how trust staff should be trained and supported to inform patients.

1.2 The Caldicott Guardian in each trust is ultimately accountable for ensuring this policy exists and is implemented across the trust. The Lead Cancer Clinician, or equivalent, should then work with the Caldicott Guardian and MDT Leads to ensure implementation. NHS England’s Quality Surveillance Team should ensure that the policy is being implemented as part of their peer review of cancer services.

1.3 The trust policy should state which member(s) of trust staff is responsible for deciding, on a case-by-case basis, who is best placed to make the patient aware of the cancer registry and at what stage in their journey after diagnosis. This decision making process should be flexible enough to account for variation in patients’ routes to and from diagnosis, including whether they will undergo active treatment or enter palliative care.
Guidance

The named staff members should be responsible for ensuring that:

• As far as is practically possible, patients are told at the earliest appropriate time after diagnosis.

• The relevant staff member is aware of their responsibility to tell people affected by cancer about the registry at this time.

• The relevant staff member has the information and materials needed to undertake the task.

In this face-to-face conversation, the person with cancer should be told:

• About the existence of the cancer registry, how it is kept safe and how it is used to benefit people with cancer.

• That their information is automatically included on it and their opportunity to make a choice about their inclusion.

• Where they can go for further information and who else they can talk to within the trust if they want a more detailed conversation or have further questions.

They should also be given an appropriate leaflet that summarises this information; receiving a letter or leaflet was the most popular option selected by people with cancer in our commissioned survey.

This could be achieved by informing the patient at diagnosis. However, we have heard from patients and health professionals that this may not be an appropriate time. Our guidance is therefore to only inform patients at diagnosis if other information is also being given, for example, as part of an information pack.

NHS England could also explore ways to prompt health professionals to inform patients about the cancer registry through the pilot sites trialling the 28-day standard being developed as part of the Cancer Strategy for England Implementation Plan.

Alternatively, many patients could be told at appointments between receiving a diagnosis and starting anti-cancer treatment. This will not be appropriate for all patients, however, because of their prognosis or how they are diagnosed.

For patients whose circumstances may make such a conversation more difficult, we suggest the following:

• Those patients who are diagnosed and quickly enter palliative care could be informed about cancer registration during their advanced care planning.

• Patients diagnosed through emergency presentation could be informed about cancer registration only once they have left emergency care are and are looked after within an MDT. However, a proportion of patients may not live long enough to leave emergency care and so may not be formally told about their inclusion on the cancer registry.

• When cancer is not diagnosed until after death, or if a patient has not been made aware of the cancer registry before death, the patient’s next of kin could be told if deemed appropriate.

• For teenagers and young adults, parents or guardians should also be informed and be given tailored information about cancer registration.

• For those who lack the capacity or legal ability to make a decision this information should be given to their next of kin or power of attorney as appropriate.

33 Directly from a health professional: 3.08/5 support; from the registry: 3.06. Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016

34 In-house survey: 73% of health professionals said that the CNS could be well placed to tell people with cancer about the registry, and 62% and 54% said the treating or diagnosing clinician, respectively (see Appendix).

35 Proportion of people with cancer and general public who rated the following information as ‘very important’, respectively, as follows: who can access information (27%; 70%), what safeguards are in place (26%; 73%), what it’s used for (71%; 71%), what information is kept (59%; 69%), what the benefits are (69%; 58%) and potential risks and drawbacks (52%; 55%). Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
**Ambition**

Information provided about the cancer registry is accessible and tailored to relevant audiences:

As previously discussed, it will not be possible to reach all patients through a face-to-face conversation, and some patients may have a conversation but may be too distracted to properly process the information. Being made aware of the cancer registry will be just one of many important pieces of information they receive.

Information about the cancer registry needs to be repeated because we don’t all take information in at the same time or in the same way and we will forget things we’re told a patient.

It is therefore important that the proposed face-to-face conversation is not the only mechanism by which people with cancer are informed. Although it should be the most significant, other secondary mechanisms should also be in place.

**Communication materials:**

PHE has an existing leaflet, which was produced in 2014 with input from people affected by cancer. When we showed this leaflet at our engagement events it was felt by some that it would benefit from a refresh. The leaflet is currently only available in a written format and in English. It was felt that the complex language used would make it inaccessible for many people, in particular those with learning difficulties or children and young adults. There is significant scope, therefore, to improve the information available on cancer registration and to perhaps also tailor it to different audiences, such as parents or guardians. For those with visual impairment, or who would prefer to take in information in different ways, providing a podcast or short video online could also be beneficial. Many at our workshops had not ever heard of PHE, and felt that more people would read and trust the leaflet if it was given NHS branding.

PHE should refresh the cancer registration leaflet and supporting information, such as their web content, but should work closely with cancer charities and people affected by cancer to ensure that this is done appropriately.

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**Recommendation 2**

There should be multiple channels through which people affected by cancer can find out about the registry and all communication materials need to be tailored to the relevant audiences.

**Local actions:**

**2.1**

Local care providers should make information about the cancer registry available in places where people affected by cancer will see it. This should include displaying leaflets and posters in hospital information centres, waiting rooms, GP practices and hospices, for example.

**2.2**

Local care providers should include a short statement about the cancer registry and where to go for more information when they refresh relevant patient information leaflets and web pages, or in appointment letters, if appropriate. This should include integrating information into leaflets developed locally.

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**It’s really helpful being able to point people towards solid websites, as even the elderly have children that can help them.** That means they can do it in their own time and come back with any questions a palliative care specialist
**National actions:**

2.3 Information about cancer registration should be included in websites used by people affected by cancer, including those of the NHS, PHE and cancer charities.

2.4 NHS England, PHE and cancer charities should integrate information about cancer registration into existing leaflets, for example about urgent GP referrals for suspected cancer, along with where to go for more information.

2.5 PHE should also consider establishing an information line, staffed by experts, for patients and healthcare staff wishing to find out more about the cancer registry.

2.6 PHE, working with people affected by cancer and cancer charities, should refresh its existing materials on the cancer registry. This could include ensuring that:

- The patient information leaflet and poster are co-branded with the NHS, visually appealing and concise. The leaflet should also be available in a number of languages and formats in order to be accessible.

- Online content gives the information patients need, including what action they need to take if they would not like to be on the registry. This should be easily found through search engines.

- A short statement about the cancer registry, including where to go for more information and how to opt-out, is made available to local care providers for inclusion in relevant patient information materials (Recommendation 2.2).

- PHE work with charities that represent children and young adults with cancer to develop tailored materials for them and their relatives/guardians.

**Ambition**

Awareness of the cancer registry is significantly improved among health professionals:

In our survey of the health professionals, 80 per cent had some awareness of the cancer registry, with most interviewees having a basic understanding of the data collected. However, only 26 per cent were aware patients could opt-out of having their data collected. A large proportion (83 per cent) said that they never have conversations about the registry with patients.

It comes up only rarely. When it does, my patients seem very keen that some good should come out of their records

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A palliative care consultant

There is therefore a clear need to improve awareness of the cancer registry amongst health professionals that directly interact with people affected by cancer; both clinical and support staff.

From our interviews with health professionals we heard a clear willingness from them to have conversations about the cancer registry with their patients, but that they lacked the confidence to do so. They felt they needed additional training and support before this would be possible.

I’ve never been told anything about it at any point, even during medical training

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A GP

We explored how health professionals could best be supported with these conversations in more detail during the engagement workshops. It was felt that training would be more effective if integrated into existing mandatory training about information governance, and included in hospital trust inductions for oncology staff. This could be supported by a short, engaging video.

As with the patient information, PHE should work closely with people affected by cancer and cancer charities to produce these materials.

To ensure these materials reach the health professionals that need to use them, we have proposed that ‘local champions’ of the cancer registry can be identified who can take responsibility for this. These champions could have a range of job roles, including information support professionals. We heard from our engagement work that a major barrier to giving such information is a lack of clarity on who is responsible; these champions could therefore help embed the recommendations into trusts.
Recommendation 3
All healthcare staff that directly interact with people affected by cancer (including support staff and health professionals in primary care and palliative care) should be able to answer basic questions about the cancer registry and signpost to further sources of information.

3.1 PHE should make basic information and training on the cancer registry available to all support staff and health professionals that work with people affected by cancer. This should reinforce the importance of informing patients about the cancer registry and should be co-developed with people affected by cancer and cancer charities.

3.2 Named individual(s) within each trust should become designated ‘local champions’ of the cancer registry. PHE should help identify and support these local champions so that they can oversee and support the provision of information to health professionals and patients in each trust. These individuals should receive additional training so that people affected by cancer and interested staff can be directed to them.

Ambition
Processes for providing people affected by cancer with information about the cancer registry should be measurable

Given that 74 per cent of people with cancer have never heard of the cancer registry, there is undeniably considerable scope for improvement. In order to ensure that progress continues and that staff at all levels are encouraged to change practice, it is vital that there are mechanisms by which implementation can be assessed.

Our proposed system of measurement involves three levels: at trust level where the policy is held, at MDT level where the policy is enacted and at a patient level, where measuring awareness can show whether staff have put the policy into practice.

We did consider whether it would be possible to record that a conversation with a patient had taken place. However, we are aware that it is practically difficult to put such systems in place and ensure that it is functional across all hospital trusts and palliative care settings. Furthermore, we heard from health professionals that this could reduce the conversation to a tick-box exercise, restricted to the health professional responsible for using whichever IT system it is part of, rather than something that is carefully considered and delegated to the most appropriate professional. We therefore would expect each hospital trust to consider introducing some sort of formal recording or tracking mechanisms if they felt it would help support rather than hinder the effective implementation of our recommendations.

We believe the most effective way to monitor implementation would be to monitor implementation at either side of the conversation – ensuring that the hospital trust and MDT responsible has processes in place, and that people with cancer are receiving the information. We have heard from health professionals that when the outcome of interventions are measured as part of the Cancer Patient Experience Survey, they are taken seriously and are acted upon. An alternative option could be carrying out a yearly sampling survey of patients, although this may be less likely to galvanise action within trusts.

To support this formal measurement, we also recommend that PHE’s Data Liaison Team continues to support providers and monitors their processes for improving awareness. This would include working with local Caldicott Guardians and the individuals who are locally accountable for having a policy in place, liaising with NHS Quality Surveillance Team to check on the level of implementation and building effective relationships with ‘local champions’. An assessment of the effectiveness of our recommendations in improving awareness of the registry among people with cancer a year on from the publication of this report could also be considered.
**Recommendation 4**
The implementation of local and national awareness-raising strategies should be measurable.

4.1
PHE’s Data Liaison Team should work with local care providers to monitor their progress in informing patients about cancer registration.

This could include:

- Keeping a record of which hospital trusts have a policy in place for ensuring that people affected by cancer are made aware of the registry, and which of those are being satisfactorily implemented.

- Conducting walk-throughs and spot-checks to determine whether patient information materials are being displayed.

- Monitoring the number of leaflets it is providing and to which local care providers.

4.2
NHS England should consider including a question asking patients whether they remember being told about the cancer registry in the Cancer Patient Experience Survey when it is next reviewed.

**Recommendation 5**
General awareness of how the NHS uses healthcare data, including cancer data, should be improved.

5.1
All organisations using cancer registry data should credit the registry in public communications and sign-post to further information.

This should include occasions when:

- NHS England and others deliver products that are underpinned by cancer registry data e.g. the cancer dashboard and national cancer statistics.

- Cancer charities use cancer registry statistics or analysis in published research, media stories or cancer intelligence tools.

5.2
Every organisation using healthcare data (including PHE, NHS England, NHS Digital and cancer charities) should take responsibility for highlighting the ways in which healthcare data, including cancer data, are used for direct care, planning services and research and the benefits that brings to patients and the wider public.

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**Ambition**
The general public are more aware of how cancer data, and other healthcare data, is used and shared by the NHS and others

The NDG’s report placed a strong and welcome focus on the need for effective communication with the public, as well as patients. In an increasingly digital health service it is vitally important that the way that the NHS uses and shares data is trustworthy, transparent and well communicated.

Transparency is essential so that patients can have confidence in how their data is used

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37 For the general public, 74% thought it was “very important” or “quite important” for people generally to know about the cancer registry. Ipsos MORI Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
4
The consent model for cancer registration
England currently benefits from a comprehensive, population based cancer registry. By linking together a variety of NHS datasets this provides high quality information about cancer services and outcomes.

The aim of our review was to find a way to better inform people with cancer about the registry so that they can make an informed choice about their inclusion. We felt that a strengthened opt-out for cancer registration would provide the best level of patient choice, provided that the way people with cancer are told about the registry was significantly improved. This was based on our understanding of the views and experiences of people affected by cancer and of health professionals.

Our scope was to define an improved approach for informing people with cancer about cancer registration. We therefore did not directly consider which consent model should be used or the process by which opt-outs should be registered or applied. We did, however, agree to gather evidence to test the assumptions we hold about the appropriateness of the current opt-out model in comparison to the alternative options:

- Opt-in, where people with cancer are required to explicitly give consent before their information can be added to the registry or used for subsequent analysis;
- Cancer registration being part of the general opt-out that has been proposed by the NDG for all uses of healthcare data beyond direct care.

In testing these assumptions we have considered both the evidence we gathered about the views of people with cancer, including how these might change following a cancer diagnosis, and the implications for maintaining a population based cancer register.

**An opt-in model is not appropriate for cancer registration**

1. **The majority of patients support the current opt-out model**

The existence of the cancer registry is not a controversial issue for people with cancer: 98 per cent of respondents to our in-house survey said the registry was either quite important or very important. There was also strong support among people with cancer for the uses of cancer registry data, for example to plan services (90 per cent support), research into new treatments for cancer (93 per cent support) and enable patients to be re-contacted about new treatment or care (94 per cent support).
The consent model for cancer registration

**Figure 1. Support for the current opt-out model in our commissioned and in-house surveys.**
Respondents were told that ‘Currently, when a person receives a cancer diagnosis in England, the information collected about them is included in the registry automatically. People are able to contact the registry if they would like their data removed’. Respondents were then asked to what extent they support this method of data collection. In our in-house survey: 303 people affected by cancer. Ipsos MORI commissioned research: 1,033 England adults who have or had cancer (people with cancer) and 1,000 England adults (general public).
This needs to be an opt out not an opt in system to ensure that the information held is as full as possible for the benefit of researchers and treatment planning for the future for the general population.

Of the nine per cent of people with cancer that opposed the current model in our commissioned survey, free text comments suggested that over half (up to 54 per cent) supported a move to an opt-in system. However, we would not assume that this would lead to a five per cent opt-out rate from the cancer registry (based on 56 percent of nine per cent). Indeed, the key motivation people gave for supporting a move to a system that required consent before data flowed was the desire to ensure that they were being told about what was happening to their data, not because they did not want to be part of the cancer registry. This leads us to believe that the opt-out rate for cancer registration would remain very low, although we expect it might increase somewhat as awareness is raised.

If the person involved doesn’t know about the registry, how can they opt to have the information removed? So an opt in option is preferable.

It relies on competent staff to remember to tell the client about the registry, if they fail to do so then the info is there without anyone knowing that they can have it removed.

Because if they are really ill they might not be able to say that they don’t want to be included.

It should be that they are asked FIRST, not their data added first. In other aspects of life the first option is to opt in, not out so why for something so important as health and privacy are we having to opt out?

Our recommendations aim to significantly improve the opportunity that people with cancer are given to be made aware of the cancer registry and the choices they have about their involvement. This should mitigate these concerns around the current opt-out system while being sensitive to the other views we heard from people with cancer: that although being told about the registry is very important, dedicating too much time to these discussions would be unnecessary and inappropriate.

None of the little time available for a patient to have face to face contact with a doctor/nurse should be wasted with talking about registry data – there is not enough time as it is. Also, no money should be wasted on postage. Posters and leaflets in the relevant areas are enough to inform the people that are interested – many people will not be interested in this at the time of diagnosis and treatment when they already have to deal with a lot of information.

In our in-house survey, over half (51 per cent) of those that disagreed with the current model did so because they did not feel it went far enough: they felt that there should be no option to opt-out, and that inclusion in the cancer registry should be mandatory. This view was also strongly supported in our engagement events with people living with cancer, subject to concerns about confidentiality and commercial use that are shared with other uses of health data.
I do not yet know enough about it, although I learned a lot from this survey. I'm erring towards the Registry being compulsory but it all depends on confidentiality and private companies being prevented from profiting from it for me.

I would go further and include it by law, like contagious diseases. EVERYBODY knows someone who has had cancer; 1 in 2 of us will get it. We are all in it together; cancer registration should be a legal requirement.

We have to give people a choice if there is one but I don’t think a choice is necessary – people just need to know [their information] is being used.

2. An opt-in model for cancer registration would exclude some groups
The challenges of ensuring that all patients are made aware of the cancer registry and their ability to opt-out (as discussed in section 3) would also make it impossible to implement an opt-in system without significant long-term damage to the registry and disproportionately affecting certain groups.

As described above, those people diagnosed close to the end of life are likely to be the most difficult to reach. These are the cases that we most need to understand and excluding them from the cancer registry would seriously hinder work to improve England’s cancer outcomes. Two of the key measures in the English cancer strategy are the proportion of cancer patients diagnosed through emergency presentation and one year survival. Both would be compromised if these patients were missed.

Rarer cancers would also be particularly affected. It is already difficult to analyse some rarer cancers due to the small numbers involved. With a less complete registry it would become extremely difficult to determine the accurate incidence figures for rarer cancers. It would also be harder to distinguish between real changes and chance variation, and therefore to assess the relationships between incidence and risk factors or demographics.

Given the practicalities involved in reaching cancer patients, the mix of views expressed about the level of choice required, and the overwhelming support shown for the cancer registry as a whole, we believe that an opt-out remains the best approach.

Alignment with the NDG’s consent and opt-out model
At the time of our evidence gathering we had not seen the detail of the NDG’s model. Our discussions with patients and healthcare professionals focused on significantly strengthening the current opt-out for cancer registration by recommending how patients can be better informed about the cancer registry and their ability to opt-out.

We have heard from people affected by cancer that an opt-out approach is supported, although they want to know more about how their data is collected and used. Awareness of the cancer registry is low and should be dramatically improved amongst people with cancer and the healthcare professionals caring for them. Implementation of our recommendations can achieve this.

Based on the evidence gathered through this review, we maintain our view that at the present time a significantly strengthened opt-out is achievable and would meet the needs of cancer registration.

The NDG’s review recommends that people should be able to opt-out from personal confidential data being used beyond their own direct care. We recognise the desire for simplicity that underpins the NDG’s proposed new model and that patients must understand the different choices that they have and how these interact. We think this can be achieved whilst keeping cancer registration separate from the model proposed by the NDG through clear and careful communication and implementation.
However, we recognise that further simplification could in theory be achieved through integration of the registry with the new model proposed by the NDG. Before supporting any change to the registry we would have to be assured that it would retain its quality and population-level coverage, and maintain or increase its ability to improve outcomes for people affected by cancer. We would also need to be confident that the level of choice offered to people with cancer as a result of this change continued to align with their views and expectations.

We would welcome further discussions with the Department of Health, PHE, the NDG and others about how this might be achieved. We would particularly need to be assured on a number of points:

1. **People with cancer must have an appropriate level of choice about how their data are used.**
   
   Our surveys and engagement workshops showed that people with cancer share many of the same concerns around sharing healthcare data as the general public, such as data security, privacy and data misuse or access by commercial organisations (particularly insurance and marketing companies).

   However, we have found that both people with cancer and the general public are more willing to share cancer data than other healthcare data, particularly when they are sufficiently informed about the cancer registry. Our commissioned survey showed that the proportion of people with cancer that ‘strongly support’ the use of cancer data for secondary purposes was between 7 and 12 percentage points higher than the general public. The general public were more supportive of secondary uses of cancer data than of other types of healthcare data. When asked about healthcare data in general, people with cancer were between 12 and 18 percentage points more likely to ‘strongly support’ its use than the general public.

2. **The quality of cancer data must not be negatively affected during or following any transition to the new model.**
   
   We have provided examples of the vital role that a population based cancer registry, and the ability to effectively use this data, plays in improving outcomes from cancer for people in England.

   In comparison to other data sets, the cancer registry undergoes a very robust process for quality assurance. Incoming data is reviewed by one of over 100 cancer registration officers working across the country, who combine information from up to 19 different data sources to produce the cancer registration record. Where activity that would be expected during standard care is missing, the registration officers are able to follow up with hospitals.

   Integration of the cancer registry into the new model of consent and opt-outs should maintain the quality of the dataset and maintain the close links between data collection staff, data providers, and the expert analysts that currently exist.

3. **The usefulness of the cancer registry for direct care must be maintained.**
   
   The cancer registry supports direct care, for example by allowing the re-contact of patients who may be at risk of previously unforeseen late effects of treatment, or providing information for genetic counselling. We would need to have assurances that these uses would not be affected by any change to the way in which cancer registration operates.

   Implementation of the new model proposed by the NDG’s review will take time. Until this is agreed and in place we believe that cancer registration should continue to function under a significantly strengthened opt-out as set out in our recommendations.

   We hope that the approach taken for cancer registration could act as an exemplar for how information about healthcare data could be communicated to patients more generally and so will support implementation of the new NDG model. We look forward to continuing to work with the NDG’s panel, the Department of Health, PHE and NHS Digital to ensure that ambition is realised.

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Cancer is such a big issue that to mix it in with other data may not give it the priority it needs a patient

This suggests that there will be people who wish to be part of the cancer register but not have their data shared in other ways, or whose preferences change following a cancer diagnosis. Any integration of the cancer registry with the new model would need to reflect this. Ensuring that the views of patients who are diagnosed late and only survive a short time are appropriately represented could be challenging but is particularly important.

I would have opted-out before my cancer diagnosis. How would I feel about it now? Maybe differently a patient

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40 Royal Statistical Society by Ipsos MORI. Public attitudes to the use and sharing of their data. July 2011

41 The Wellcome Trust by Ipsos MORI. The one-way mirror: Public attitudes to commercial access to health data. March 2016

42 Such as service planning, research into the causes of cancer and new treatments and re-contacting patients for care purposes. Ipsos MORI. Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. September 2016
Appendix 1
Governance and acknowledgements

Governance
The review was co-chaired by Sara Hiom, Director of Early Diagnosis and Cancer Intelligence at Cancer Research UK, and Fran Woodard, Executive Director of Policy and Impact at Macmillan Cancer Support.

The project was governed by an independent review panel, made up of staff from both charities, national organisations, health professionals and patient representatives. The members of the panel were as follows:

• Fran Woodard, Macmillan Cancer Support (co-chair)
• Sara Hiom, Cancer Research UK (co-chair)
• Cameron Robson/Emmy Clarkson, Department of Health
• Eileen Phillips/John Carvel, National Data Guardian review panel
• Professor Arnie Purushotham, clinical adviser (secondary care)
• Dr Rosie Loftus, clinical adviser (primary care)
• Dr Jane Maher, clinical adviser (secondary care)
• Karen Phillips, clinical adviser (clinical nurse specialist)
• Bonnie Green, patient representative
• John Marsh, patient representative
• Jem Rashbass, Public Health England (observer)
• Emma Greenwood, Cancer Research UK (observer)

We would also like to thank the Cancer Campaigning Group’s Data Task and Finish Group for their support. In particular we would like to thank Anthony Nolan, Bloodwise, Bowel Cancer UK, Brain Tumour Research, Breast Cancer Care, Cancer Recovery, Clic Sargent, Dimbleby Cancer Care, Independent Cancer Patient Voice, Jo’s Cervical Trust, Lymphomas Association, Maggie’s Centres, Marie Curie, NCRI Head and Neck Cancer Clinical Studies Group, NCRN Supportive and Palliative Care Clinical Studies Group, Ovarian Cancer Action, Pancreatic Cancer, Prostate Cancer UK, Teenage Cancer Trust, The Brain Tumour Charity and The Urology Foundation.

Appendix 2
Methodology

2a. Engagement with people affected by cancer
In the initial stages of planning this review, we consulted Cancer Research UK’s patient sounding boards (a total of 16 patients). Two patient representatives were then recruited to join the review panel; these representatives were consulted throughout the project and helped deliver the engagement events. We held four patient engagement workshops; two in London, one in Manchester and one in Leeds. Significant efforts were made to recruit attendees who had not previously attended Cancer Research UK or Macmillan Cancer Support events, and those from seldom heard from groups.

Two of these workshops were used as ‘discovery’ events to inform initial thinking; the final two were used to refine emerging recommendations. In total, we engaged with and listened to the views of 79 people affected by cancer across these events. Of the workshop attendees who completed our More About You feedback sheets:

15 were currently being treated for cancer, 38 had been treated for cancer in the past, 22 were caring or had cared for a friend or family member with cancer.

13 per cent had been diagnosed or had cared for somebody who had been diagnosed in the last year. For 29 per cent, diagnosis had taken place 2-3 years ago, for 17 per cent it was 4-5 years ago, for 20 per cent it had been 6-10 years ago and for 26 per cent diagnosis had been over 10 years ago.

27 per cent of attendees were male, 69 per cent were female and 3 per cent preferred not to say.

72 per cent were White or White British, 3 per cent were Black or Black British, 20 per cent were Asian, Asian British or from another Asian background and 5 per cent were from another ethnic background.

For those who were unable to attend the engagement workshops, we ran an in-house online survey, which received 303 responses. Of those respondents:

43 Seldom heard from and underrepresented groups such as people affected by cancer from BME communities, LGBT people affected by cancer, males affected by cancer and younger people affected by cancer
32 per cent were currently being treated for cancer, 44 per cent had been treated for cancer in the past and 17 per cent were or had previously cared for somebody affected by cancer.

22 per cent had been diagnosed or had cared for somebody who had been diagnosed in the last year. For 39 per cent, diagnosis had taken place 2-3 years ago, for 15 per cent it was 4-5 years ago, for 16 per cent it had been 6-10 years ago and for 13 per cent diagnosis had been over 10 years ago.

41 per cent of respondents were male, 58 per cent were female and 2 per cent of respondents preferred not to disclose their gender identity.

For all but one respondent, their gender identity was the same gender that had been assigned at birth, with 7 people preferring not to disclose this information.

Additionally, 91 per cent of respondents were heterosexual, 4 per cent were gay, 1 per cent were lesbian, 2 per cent were bisexual and an additional 1 per cent were other.

In terms of ethnic origin, 92 per cent of respondents were White, White British or from another White background, 3 percent were Chinese, 2 per cent were Asian, Asian British or from another Asian background, 1 percent from Mixed backgrounds and 2 per cent from other backgrounds.

A solution development workshop was also held with 22 members of Use MY Data and Independent Cancer Patient Voices.

In order to provide independent evidence, we commissioned Ipsos MORI to conduct a survey of 1000 people with cancer and 1000 members of the general public. Of the members of the public, 64 per cent reported having a close friend or relative who had been diagnosed with cancer. More information about this commissioned work can be found in the attached report from Ipsos MORI.

2b. Engagement with health professionals

The views of health professionals have been vital to help shape our recommendations and ensure that they are appropriate and achievable. We thought it vital to draw on the experience and expertise of those who directly care for people affected by cancer, and who were likely to be responsible for implementing our recommendations. To gain their input we:

- Co-opted four health professionals on to our Review Panel with representation from primary care, oncology, surgery and a clinical nurse specialist.
- Conducted telephone interviews with 27 health professionals from across the patient journey; 6 GPs, 6 cancer nurse specialists, 3 radiologists, 3 nurses, 2 practice nurses, 2 oncologists, 2 surgeons, 2 paediatric oncologists and a consultant in palliative medicine.
- We also ran an in-house online survey which gained 273 responses from health professionals. Among the respondents, there were 19 GPs, 17 cancer nurse specialists, 18 oncologists, 37 radiographers, 21 surgeons, 58 palliative care staff, 25 Information and Support Service professionals, 26 pharmacists, 5 gastroenterologists, a radiologist, a practice nurse and 37 other health professionals.
- Two solution development workshops were held in London and County Durham, attended by 37 health professionals. Of these health professionals, there were 12 nurses, 10 managers, 8 other clinical staff, 6 other non-clinical staff and one GP.

2c. Engagement with charities

20 cancer charities were directly involved in this review; many more were informed about its progress and given the opportunity to input. We held two solution development workshops organised by the Cancer Campaigning Group’s Data Access Task and Finish Group: one with charities representing common cancers and one with charities representing rarer cancers and seldom heard from groups. These workshops were attended by representatives from across 20 cancer charities and some associated patient representatives.

Teenage Cancer Trust also conducted their own research into younger patients’ attitudes towards cancer registration and healthcare data more widely in the form of two surveys, which gained 34 and 25 responses. The findings of this work can be obtained from Teenage Cancer Trust.

Appendix 3
Summaries of evidence

3a. Summary of findings from engagement with patients

In-house survey

Figure A: In response to the question ‘do you think that the NHS keeps a central record of people affected by cancer’, 15% said ‘yes, definitely’, 23% said ‘yes, probably’, 23% said ‘no, probably not’, 4% said ‘no, definitely not’ and 35% were unsure.
Expectations and concerns
Awareness of a central NHS record of cancer patients was mixed among people affected by cancer (see figure A) but there was strong support for all the uses of cancer data suggested, particularly service planning (86% of responses) and research (71%) but also direct care (67%). Only 1% said ‘none of the above’.

Over two thirds of people affected by cancer have no concerns about the NHS keeping the type of information recorded in the cancer registry; 19% had some concerns and 3% had many concerns of which data security, privacy and misuse as well as who can access the data were the most commonly cited.

Awareness of the cancer registry
Awareness of the cancer registry was overwhelmingly low – 73% had not heard of the cancer registry. Nearly 10% felt they have heard ‘a lot’ about it but only 7% of respondents had seen a copy of the current information leaflet. Instead most respondents said they had heard about the registry through patient groups and charities (35%).

Only 26% of those that answered knew that it was possible to opt-out of the cancer registry. This means that approximately half of people who said they had heard of the cancer registry were either unaware of or unsure about the fact they could opt-out.

Completeness of the registry versus patient choice
The people affected by cancer that we surveyed overwhelmingly saw the value of the cancer registry: 98% thought it was ‘very’ or ‘quite’ important. They also agreed that patients should be told about the registry and the fact their data is on it: 93% said ‘yes, definitely’ or ‘yes, I think so’.

“I was not told and although I have no problem with it many people would and I feel it is a violation of trust/privacy if this information is not explained”

“I feel I guess betrayed that 19 months into my partner’s cancer battle we didn’t know about this. I think honesty is the best policy and have no problem with the info being recorded but we should have been told and that the details can be removed at the patients request as not to be made aware at some point seems deceitful”

“No one ever told me my data was there. Not sure what to think”

“I think it is reassuring to know that data is being collected and can be used to monitor and improve outcomes”
When is the best time to tell cancer patients about the registry?

There was no clear consensus from our survey responses of when during the patient journey was the best time to inform people with cancer about the registry. Although at diagnosis was most popular (42%), when respondents were asked to compare being told about the cancer registry with other information usually shared around diagnosis (such as treatment options and where to go for emotional support), the cancer registry was considered the least important on average (see figure C). However, nearly 1 in 3 responded to say that they thought everyone should know about the cancer registry (i.e. the general public). Feedback from respondents also highlighted the need for ‘time to think’ between being told about the cancer registry and making a decision about their involvement.

![Figure C: Respondents were asked to rate each piece of information as either high, medium or low priority in response to the following question: ‘from first realising something is wrong to getting a cancer diagnosis and receiving treatment, people with cancer can be given a lot of information, Please indicate how important you this receiving the following information is’.]

“Probably slightly later than diagnosis as patients need to concentrate on other things”

“Information about the cancer registry needs to be repeated because we don’t all take information in at the same time or in the same way and we will forget things we’re told”

“Maybe it’s best if we don’t know. Or, does all society need to be generally aware of it thus avoiding the patient having to be formally told”

How should cancer patients be told about the registry?

There was a strong preference from respondents to be told face-to-face by a health professional (71%). A leaflet given by a health professional was also well supported (48%) and over a third (35%) liked the idea of receiving a letter in the post from the cancer registry.

The people affected by cancer that we surveyed struggled to determine what would be most important to know about the cancer registry, ranking all information related to the registry as being very important. The highest ranking were: what the data is used for, what data is collected, what the benefits are, who can access it and what safeguards are in place.

“Being told you have cancer dominates your mind and you don’t really take in everything else you are being told so all areas should give the information”

“First by their doctor/nurse and after a letter sent by post or email by the cancer registry itself to confirm and inform them that can be removed if is their wish”
Cancer data versus other healthcare data
Over half of respondents said they thought cancer data was different from other healthcare data (58%), but 20% thought it was the same and 22% were unsure. The group of people who saw no difference between the two included those who were very supportive of data sharing and those with privacy/security concerns.

Engagement events
Our engagement events asked people with cancer a series of questions about cancer registration. The views expressed at all five events are summarised below.

1. How important do you think it is that people are informed about cancer registration? Why?
The majority of people who attended our engagement events, although not all, were positive about the ways that cancer data could be used to improve treatment and care. Despite this, there was agreement that it was important for people to know what was happening to information about them.

For many this was because they felt that some people may not want to share their information, even though they themselves were happy to, so they needed to be told so they could make a choice. For others, they thought that knowing about the cancer registry was reassuring and helped them feel that someone was ‘keeping an eye’ on cancer and always trying to improve outcomes for people.

“It is important to tell people as it is important to ask them if they are happy to share their data”

“It just happens everywhere though doesn’t it? It has to be like that because if we didn’t have any of this information how would we get anywhere?”

2. What information would you want to know about cancer registration?
The information people wanted about the cancer registry was influenced by two main themes: making sure that the concerns they had, or that they thought others may have, about sharing healthcare data were addressed; and a desire to try and persuade people to stay part of cancer registration by being clear about the benefits.

People with cancer wanted to know why information about them was being collected. They wanted to know what it was being used for and how that would benefit people with cancer now and in the future. Many people felt strongly that contributing their information to the cancer registry would help others in the future, especially their own families. They also felt that it was very powerful to hear how the information about people who have had cancer before them has allowed the improvements in the care and treatment that they are now benefiting from. Attendees suggested using case studies to help illustrate these benefits with examples.

“It helps future generations, but also you are benefitting from the people recorded before.”

“I’d want to know what they have learnt from the data”

“I’m sure people would feel happy if they just knew [about the registry]”

The concerns people had, or anticipated others would have, mainly focused on whether commercial companies could access the data and whether it could be kept safe and not sold or ‘used against’ them. They were keen for the information to be reassuring about data security and the safeguards in place to prevent misuse – particularly by commercial companies. Being clear about what information is collected and when that happens was also felt to be important, particularly because it includes people’s names and addresses.

“I know people who are worried about what data is being used for – is it being used to help us or is it being used against us by insurers and things”

“[Data sharing] happens all the time and everywhere and we just hope that everything is safe”

Overall attendees felt quite passionately that the information given to people with cancer about the registry should be very positive and encourage people to stay part of the cancer registry. However, they agreed that it needed to include the details of how people could opt-out if they wished.

“It is important that people are told that it is kept safe so we can persuade more people to stay in”
3. When would have been the right time for you to be told about the cancer registry?
When compared with other information people wanted about their illness, such as their treatment options and potential side effects or what support is available, attendees consistently ranked being told about the cancer registry as their lowest priority. However, that was not to say that they didn’t see it as important: even though there were competing priorities they were keen that it didn’t ‘fall off the bottom of the list’ and that people were told. It was felt that the cancer registry wasn’t something that needed to be ‘made a meal of’, as most people would be fine with it and those who did have questions or concerns could look into it more themselves.

“There will be some people who really won’t care”

“You’ve got plenty of other things to get scared about when you have a cancer diagnosis”

“You might end up alarming people more than the choice really warrants.”

When asked to consider at what point in the patient journey might be most appropriate to have a conversation about cancer registration, people noted that at diagnosis was a very difficult and emotional time. They felt that this would not be a good time to talk about the registry because they might not be able to take the information in or may make a ‘rash decision’ about their involvement. They did though think that people should be told as soon after this as possible in order to have the best opportunity to have a meaningful choice about whether information about them is shared.

“All I care about at diagnosis is treatments and how long I have to survive.”

“If it’s to be taken seriously, it needs to be done at some other point [other than at diagnosis]”

“You come away from your early appointments not knowing half of what you’ve been told”

“I’d want to know straight away”

From some but not all of the events another theme was the importance of raising awareness of the cancer registry among the general public. They thought that this support a ‘no surprises’ approach and that it could take the pressure of needing to tell people about the registry at diagnosis as they will already know something about it. They also thought it would help the family or carers or someone with cancer to understand the registry.

“I would like to have been told, maybe in a TV advert. Because it’s not just patients but also people who are related to them”

4. Does your view about the right time to be told change if someone is diagnosed late, in an emergency or has a poor prognosis?
We specifically wanted to consider with this review how to ensure all people with cancer are made aware of the registry. As far as possible, we wanted this to include those diagnosed in challenging circumstances. In general, attendees at our engagement events felt it was important to tell people about the registry regardless of their circumstances but very much saw sensitivity to the patient of paramount importance. Knowing how difficult some of their own cancer experiences had been, they could imagine that being told about the cancer registry would be even less of a priority, and perhaps even inappropriate, for people diagnosed late or who have a poor prognosis.

To try and unpick this further and determine when might be the best time to inform people about the registry in different circumstances, we asked attendees to consider two patient journeys. The first was of ‘Joan’ who was diagnosed with rectal cancer following a visit to her GP and who soon undergoes radiotherapy and surgery which effectively treats her cancer. The second was the story of James whose pancreatic cancer is diagnosed late and is inoperable, meaning that he swiftly moves into palliative care. Attendees were asked to flag when they thought the best (green sticker) and the worst (pink sticker) time to tell the individual would have been.

“When you have your appointments something can be discussed”

“You might end up alarming people more than the choice really warrants”

“We might get scared about it”

“You can’t make anyone’s decisions for them”

“We don’t want cancer to take people by surprise”

“You come away from your early appointments not knowing half of what you’ve been told”

“Animals can’t think about it”

From some but not all of the events another theme was the importance of raising awareness of the cancer registry among the general public. They thought that this support a ‘no surprises’ approach and that it could take the pressure of needing to tell people about the registry at diagnosis as they will already know something about it. They also thought it would help the family or carers or someone with cancer to understand the registry.
James

James is 75 years old. He is retired and lives with his wife.

1st March: James is unwell over Easter, suffering from sickness and diarrhoea. He decides to call the surgery when it reopens on Tuesday if it hasn’t cleared up.

30th March: James speaks to the GP surgery. His symptoms are likely to be minor but he is told to stay at home and call again if they don’t clear up.

April and early-May: James’s symptoms improve after a few days but he still doesn’t feel himself. During April he loses weight and in early May notices that he is looking yellow.

2nd June: James is told he is not well enough for chemotherapy or radiotherapy and is referred to the palliative care team.

23rd May: James has a referral for a consultant gastroenterologist. He is diagnosed with advanced pancreatic cancer that has spread to his pelvis.

16th May: James has an appointment with his GP who refers him to hospital. He suspects gallstones but is concerned and wants to get James checked out.

24th May: James has an ultrasound at the hospital and blood tests. The ultrasound shows a mass on his pancreas and he is admitted to hospital.

Joan

Joan is a 54-year-old English teacher.

On Sunday 24th January Joan noticed some blood in her poo. This had happened a few times so she called the surgery on Monday morning and booked an appointment with her GP.

23rd January: Joan describes a lump to her GP. He refers her to hospital for urgent tests. During the consultation he explains that cancer is one possibility.

26th January: Joan has her first appointment with a consultant gastroenterologist. They arrange for a colonoscopy later that week.

27th January: Joan has a colonoscopy at her local hospital. The consultant finds a tumour in the large bowel. Joan is referred for further diagnosis and scans.

30th January: Joan has CT and MRI scans and discusses her treatment plan at a follow-up appointment.

2nd February: Joan has CT and MRI scans and discusses her treatment plan at a follow-up appointment.

7th March: Joan has a follow-up scan and is informed that the tumour is early stage and that Joan won’t need chemotherapy.

1st March: Biopsies confirm that the tumour was early stage and that Joan won’t need chemotherapy.

10th March: Joan undergoes surgery to remove the tumour.

1-4th March: Joan receives four fractions of radiotherapy to her abdomen before her surgery.
People’s views were mixed. Overall there was consensus that while someone is undergoing tests for suspected cancer, or the time that they are given a diagnosis was inappropriate. For Joan, people either identified the time soon after diagnosis, when she is discussing her treatment plan, or after he cancer has been successfully treated as the best time to be told about the registry. For James, some people identified the period where he was undergoing diagnostic tests for suspected cancer as a good time, while others felt that it was a conversation best had as part of palliative care. For the second workshop, attendees also expressed a need to raise general awareness of the registry, so that the patient doesn’t need to be specifically informed during their journey.

5. How do you think people with cancer should be told about the registry?
The main preferences shared by people with cancer were to be told about the registry face-to-face by someone involved in their care. They thought this would help people to trust the information and take it in. They also liked the idea of being able to ask questions. In addition, they wanted something in writing that they could take away, so that they could think about it in their own time if they wished to and could always refer back to. Some favoured a letter from the cancer registry but others felt strongly that this posed the risk of upsetting people or that it would be unnecessarily costly and could be ignored.

Face-to-face
Attendees agreed that whoever told them face-to-face would not need to be their treating or diagnosing clinician, but should be someone they know. They didn’t want the conversation to be long; just the key points and in a way designed to make people feel that it was standard practice, helps ensure people with cancer get the best treatment and care and was nothing to worry about.

“It never crossed my mind that my data wasn’t recorded centrally so it shouldn’t be a big deal”

“I’d want it to be something like, you know, ‘here’s a leaflet about the cancer registry. We usually put all patients on the registry as part of normal practice, but you can opt-out. Have a read of this leaflet and if you have any questions about it, there is a website or you can talk to me next time’ “

They wanted to make sure that the relevant member of their care team knew that it was their responsibility to tell someone about the registry so that the conversation definitely happened but only happened once. There was concern that people could get told repeatedly, and that this really wasn’t necessary and could worry people more.

“It has got to be the same for everyone as you don’t want to have to see it over and over again”

“The more times I get told the more suspicious I get”

They also talked about the benefits of having a health professional tell them about the registry because it would mean that they would have to find out more about it and therefore would think more about how they could use it to improve the care they provide; creating a virtuous circle.

“Doctors are not very good at saying ‘I don’t know’, they’d want to find out”

“Face-to-face is best because that is the best way to tell patients but also it makes it more important that doctors know about [the cancer registry] too”

“At the moment doctors don’t recognise how important collecting data is”

Written information
As well as a face-to-face interaction, people with cancer said they would have liked to have been handed something by their health professional to take away, like a leaflet. They thought this was important as just being given a leaflet with no discussion would make them much less likely to read it.

“Just a leaflet isn’t enough without the physical process of giving the leaflet and answering any questions”

“If you get it at home, then you have time to sit down and read it; rather than a hospital setting when you have lots of other things to think about”

Attendees agreed that the current leaflet needed to be improved. They wanted to see something that was concise, easy to read and that had a bold design that looked appealing. They also wanted it to be personal; reflecting that the registry is made up of information about real people and that by being part of it you can make a difference.
“I don’t think I would pick it [the current leaflet] up because it doesn’t feel relevant to me.”

“I might have received one but I’ve got no memory of it. I probably wouldn’t if I’d seen [the current leaflet].”

People with cancer at our events were very clear that they wanted the leaflet to make the case for the cancer registry and to talk about the benefits for them and their family as well as people in the future. There was also a strong preference for the leaflet to be NHS branded in order to help people understand what the registry is about and make them have confidence in it.

Some people also talked about the benefits of renaming the cancer registry as the ‘NHS cancer record’ or similar. They felt that ‘registry’ sounded like something you had to ‘register for’ or that was very clinical, and didn’t help people to immediately understand its purpose.

Other information channels
As well as a leaflet and a face-to-face conversation, attendees felt that there were other ways to raise awareness of the cancer registry before someone is diagnosed with cancer and throughout their journey. This included putting posters and leaflets in waiting rooms at hospitals and GP practices and adding bits of information about the registry to other paperwork that patient’s receive. They also wanted there to be ways of finding out more information, both online but also from experts that could be contacted over the phone, such as a helpline, or face-to-face e.g. hospital information centres.

“I’ve spent enough time in waiting rooms to read all of the leaflets”

Many patients were also passionate about doing wider public awareness raising with national TV and poster campaigns but felt that this would probably cost more money than needed to be spent. They did feel, though, that a stronger ‘brand’ for the cancer registry would make it more visible and something people could relate to and start to recognise. If it was used in lots of places – like newspaper articles that used statistics from the cancer registry, people could see how the data was being used and the benefits even before they were given a cancer diagnosis.

“Everyone needs to know how important data is”

6. Do you think patients should be given a choice about whether their data is included in the registry?
There was a mix of views on this question at both engagement events. Overall it was felt that it was important that people were given a choice about their involvement on the registry as attendees could imagine that some people may not want their data to be shared. However, many people were torn and there was also a strong feeling that people shouldn’t be given a choice because the data was just too important. Some felt that by allowing people to opt-out it undermined the value of their own decision to share their data as it affected the quality of the research they had chosen to support. At the request of attendees, a straw poll was taken of the number of people who thought cancer registration should be mandatory. On each occasion the majority thought that it should be.

“I feel like saying no – but I can’t say that really. I know it’s a bit naughty but it’s for the greater good!”

“People need a choice, it’s their information”

“The message needs to be strong enough to persuade people not to opt out”

“We have to give people a choice if there is one but I don’t think that is necessary – people just need to know [their information] is being used”

3b. Summary of findings from engagement with health professionals
Health professionals (HPs) have a limited understanding cancer registration and rarely discuss it with patients.

55% of health professionals interviewed had some awareness of cancer registration with 62% being able to suggest examples of the types of data collected and 66% able to suggest how the data is used.

Only a small number of health professionals interviewed could confidently describe what data is collected and were able to give examples of where registry data had been used. Many health care professionals felt they should, and wanted to, know more.

“Never been told anything about it at any point, even during medical training.”
The percentage of health professionals who had at least heard about cancer registration was higher (80%) in our survey. But most health professionals never discuss cancer registration with their patients (83% in our survey). Only 26% of HPs surveyed were aware patients could opt-out of having their data collected.

“It comes up only rarely. When it does my patients seem very keen that some good should come out of their records.”

Conflicting priorities and a lack of supporting information, knowledge, resources, time and opportunity were all cited as major barriers to discussing cancer registration along with differences in patient’s views.

“It can be difficult to have those kinds of conversations if people are struggling to come to terms with their diagnosis as well, and it’s finding an appropriate time to have those conversations”

“Safety and patient trust – some, particularly older patients, are scared of computers and what’s being stored”

“As a clinician, I do not want to distract patients with information like this when they are at a vulnerable point in their cancer journey and need to understand diagnosis, prognosis and treatment choices and toxicities.”

In our in house survey, health professionals cited a patient’s diagnosis (99%), their treatment options (98%), signposting to different support organisations (51-78%) and research opportunities (49%) as more important topics to discuss than cancer registration (11%), given the limited time they have with them.

However they recognised that patients should be informed about how their data are used, and there were key aspects of cancer registration health professionals thought patients should be aware of.

“The bigger picture and reasons why it may be necessary to register people: research, development etc.”

“If patients understand the registry, how it works and what it is used for, it takes the fear of it away.”

“There are ethical reasons why we should all know how sensitive and confidential information about us is used.”

Clinical Nurse Specialists and the clinicians responsible for diagnosis and treatment were most commonly cited as roles that could be responsible for providing information on this topic.

Our interviews found uncertainty about who is currently responsible for informing patients about cancer registration and supporting an informed choice about whether their data included in the registry. Most HPs were unsure whether the responsibility sits with the right person, if anyone at all. However when asked who ‘should’ be responsible, health professionals thought the Cancer Nurse Specialist (73%) and treating or diagnosing clinician (62% / 51%) were roles that should be responsible for providing information on this topic. Clinical Nurse Specialists provided very similar answers.

“The clinicians involved with the patient’s care know them best at that time and are best placed to discuss this”

“When patients receive the cancer diagnosis they are complete shock, it requires someone with time to assess (the best time)”

“I believe these professionals are best placed to tell them as the patient knows and trusts them.”

Healthcare professionals said they wanted resources such as leaflets, online content, a patient helpline and training to help them discuss this topic with patients.

- When asked to rate types of information and resources that would support health professionals to discuss cancer registration with their patients, professionals rated ‘a leaflet to give to patients’ as their most preferred choice (88%), followed by online information (72%), telephone support line (61%), and better training on what cancer registration is and how to discuss it with patients (54%). Other supported methods were posters (37%), having expert members of staff (27%), and letter templates (20%).

These results were directly used to inform our recommendations and guidance. Draft recommendations were tested with health professionals at two engagement events and were refined following their feedback.
3c. Summary of findings from engagement with charities

We held two engagement events: one with charities representing common cancers and one for those representing rarer cancers and seldom heard from patient groups. These were held in order to ensure that we had gained insight from a range of patient populations and could feed that insight into the development of our draft recommendations. The views expressed at both events are summarised below.

Finding the right time to speak with cancer patients about cancer registration

- It was acknowledged that it would be difficult to find a time to inform people with cancer about the registry that would be suitable for everyone.
- Diagnosis was almost universally considered an inappropriate time, as patients may be too overwhelmed to be able to take additional information on board. Certain patient populations often experience feelings of frustration and distrust towards primary care staff following a late diagnosis or misdiagnosis.
- Secondary care is likely to be the most appropriate stage, as there are higher levels of patient trust and good patient-health professional relationships. Specific suggestions included during treatment plan discussions and after surgery or chemotherapy.
- Attendees proposed two models: one for people with cancer going into treatment who could be informed during treatment plan discussions, and one for those moving into palliative care after a cancer diagnosis who could be informed during advance care planning.

How to have the conversation

- A face-to-face conversation with a leaflet was felt to be the ideal method for informing and a good way to allay fears about data safety and misuse.
- Integrating information about cancer registration into existing patient information was considered a potential, although it was acknowledged that that was a danger of ‘bombarding’ people with information, when only a small proportion are likely to want it.

Who should have the conversation with cancer patients?

- It was seen as difficult to identity a health professional common to all patient pathways, who should have responsibility for giving information about cancer registration.
- Cancer Nurse Specialists are perhaps best placed to have the conversation, but decisions about informing patients should be left to the discretion of MDT teams.
- Caldicott Guardians or another ‘named person’ within each hospital could be tasked with knowing more about cancer registry in order to have more in depth conversations about cancer registration if required.
- Somebody at hospital trust level should be in charge of developing a policy of accountability.

Conversations during more difficult circumstances

- In more difficult circumstances, such as a poor prognosis, cancer registration may be considered even less of a priority for people with cancer, particularly around the time of diagnosis.
- Poor prognosis may also lead to the patient caring more about the value of their data and the importance of it being used for good.
- Carers may have a more prominent role in harder to reach circumstances and the ‘Voices’ survey for bereaved people was seen as a possible way to talk about data post-death.

How to measure that the conversation has taken place

- Strong support for a question about cancer registration being included in the annual Cancer Patient Experience Survey, although this is currently unavailable to under-16s.
- Sending letters or monitoring ‘managed racks’ of leaflets was seen as a simple way of measuring patient information about the cancer registry.
- Cancer Campaigning Group dashboard and trust policies on accountability were also popular ideas.
- There was discussion about the best forms of measurement. It was agreed that measuring process would be a useful first step. General awareness of cancer registration and supporting information.
- Strong agreement that awareness of cancer registration and health data before diagnosis was important.
• Multiple channels of communication are necessary to help achieve this, with signposting for those who want to find out more information

• Simple, consistent and positive messaging about cancer registration including in leaflet form, as a standardised text on cancer charity and other healthcare websites and on an easy-to-find website with more detailed information and examples

• Leaflet should be bold, engaging and more accessible than the current leaflet

• Written material should talk about cancer registration in a positive manner, explaining the benefits of data collection and use

• Patient led messaging and more recognisable branding were well-liked suggestions

• Written information about cancer registration should be visible to patients in appropriate settings such as cancer wards, chemotherapy rooms, waiting rooms, screening centres and information and support centres

• Further ideas for raising awareness included a Cancer Registry Awareness Week, and a recognisable cancer registration ‘brand’ or symbol that information taken from the cancer registry could display

**Supporting health professionals**

• It was felt that all professionals have a basic level of understanding about cancer registration, equivalent to the information included on the leaflet and the ability to signpost people with cancer to more information when required. PHE ought to take a proactive role in ensuring this and cancer registration information could be integrated into existing health professional training

• Charities could raise awareness among charity staff, engage with health professionals, use volunteer networks, brief charity hospital staff, host a Cancer Campaigning Group learning session and create information pages on websites for both audiences
We would like to thank the following charities for their involvement:

About Cancer Research UK
Cancer Research UK is the world’s largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2014/15, we spent £434 million on research institutes, hospitals and universities across the UK – including a £41 million contribution we made to the Francis Crick Institute. We receive no funding from the Government for our research. Cancer Research UK wants to accelerate progress so that three in four people survive their cancer for 10 years or more by 2034.

Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and the Isle of Man (1103).

Cancer is the toughest fight most of us will ever face. And the feelings of loneliness and isolation that so many people experience make it even harder. Now, more than ever, we need people like you to join our team and get involved. No one should face cancer alone. And with your support no one will. Call 0300 1000 200 or visit macmillan.org.uk/getinvolved

Macmillan Cancer Support, registered charity in England and Wales (261027), Scotland (SC039907) and the Isle of Man (604).