ROUTES FROM DIAGNOSIS

The most detailed map of cancer survivorship yet

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National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.

We are a network of organisations working across the UK, including the National Cancer Registration Service (NCRS), the NHS and health departments, cancer charities, research funders and other organisations with an interest in using information to improve outcomes for cancer patients.

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- Promoting efficient and effective data collection throughout the cancer journey.

- Providing a common national repository for cancer datasets.

- Producing expert analyses, to monitor patterns of cancer care.

- Exploiting information to drive improvements in cancer care and clinical outcomes.

- Enabling use of cancer information to support audit and research programmes.

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FOREWORD

The story of cancer is changing – by 2020, nearly half of us can expect to get cancer in our lifetime, but almost four in ten will not die from the disease. The number of people living with cancer in the UK will double from today's two million to four million in the next twenty years. But how well do we really understand what happens to patients after diagnosis?

In 2013, Macmillan Cancer Support revealed that at least one in four of those living with cancer – around 500,000 people in the UK – face poor health or disability after treatment. But we knew this wasn't the full picture. In order to support people affected by cancer better, we need a much more detailed understanding of what happens after diagnosis. Crude measures like one and five-year survival are no longer enough.

Patients understand well how disjointed their care can be. This report shows how often patients are facing cancer in the context of other illnesses, either during treatment or during the years that follow. All the clinicians who see cancer patients after their treatment need to be aware of the issues cancer survivors may face. We need to know not only how many patients are dealing with significant consequences of cancer and its treatment and other morbidities, but which particular patients are affected. We believe the key to unlocking improvements in cancer care is to understand the variations in survival outcomes, morbidity and cost between patient groups, joining up previously disparate sets of data to paint a detailed picture of cancer survivorship.

This is exactly what our Routes from Diagnosis (RfD) programme allows us to do for the first time. A major cross-sector research effort drawing on the charitable, private and public sectors, it is driven by a collective desire to improve standards of cancer care and clinical outcomes by using routinely-collected data. RfD combines powerful analytics from Monitor Deloitte and expert clinical insights from the National Cancer Intelligence Network's Site-Specific Reference Groups with Macmillan's vision of the outcomes we want to achieve for everyone affected by cancer.

Routes from Diagnosis shows that with the technology and data already available to the NHS it is possible to understand cancer journeys at an unprecedented level of detail. However, this work is not easy. Until recently, routinely collected health data has been treated as an 'exhaust' of the healthcare system – a byproduct of the payment and commissioning systems rather than being seen as a vital source of invaluable information about the quality and outcomes of NHS care. The realisation of the potential of this 'treasure chest' of data has nowhere been better understood than in the cancer world, but

this is not always well understood more widely and there is a need to continue to show why access to these data sources is of vital importance to all of us.

Only now are we starting to realise the benefits of 'big data' analysis, allowing us to unpick, for example, the large variations in the inpatient costs associated with cancer survivors, and how these costs relate to outcomes. Macmillan knows well that poor care is often more costly care, and that outcomes and costs can be improved together. Using insights from RfD, commissioners and other decision makers can target interventions, spot trigger points, and understand how costs accumulate and are segmented. This allows us to match our understanding of needs to solutions, seeing where to make better use of acute oncology services, or physical activity schemes.

This report describes the findings of analysis of linked Cancer Registry and inpatient Hospital Episode Statistics data for four cancers. Further detail on the methodology behind this work will be described in a forthcoming academic publication.

In the future, we will be adding datasets and expanding the analysis to a wider range of cancer types and treatments. We also believe the Routes from Diagnosis technique could be a valuable approach for the NHS to adopt itself. In the meantime, we hope the findings in this report will improve the healthcare system's understanding of these four cancers.

When used as an evidence base to support service and system redesign, big data has the power to change lives. Macmillan is excited to see what others make of the RfD programme and how the NHS can use these insights to improve the lives of people affected by cancer.

Jane Maher
Chief Medical Officer
Macmillan Cancer Support

Mick Peake
National Clinical Lead
National Cancer Intelligence Network

INTRODUCTION

This report summarises the results of the first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and morbidities associated with breast cancer, lung cancer, prostate cancer and brain and central nervous system tumours.

What is Routes from Diagnosis?

RfD is a programme of research performing retrospective analysis of almost 85,000 cancer patients' interactions with the NHS in England over seven years – the richest picture yet of cancer survivorship. Pairing 'big data' analysis with clinical insight, it reveals significant variation in outcomes, survival and cost within and between cancer types. It allows us to understand just how many people affected by cancer are living with serious long-term conditions.

A second report will follow, containing findings for colorectal, head and neck, bladder, cervical and ovarian cancers, as well as adding analysis of outpatient and A&E datasets.

As part of the National Cancer Survivorship Initiative (NCSI), Macmillan commissioned the RfD programme[1] to find a way to map the cancer journey from diagnosis to death or continued survival, describing the health outcomes that patients experience. By linking and analysing routinely collected data including Cancer Registry data and Hospital Episode Statistics, RfD provides greater insight than was previously possible into patients' pre- and post-diagnosis clinical journeys. This gives us a new way of understanding the cancer journey.

Context: the changing story of cancer

There are now two million people living with or beyond cancer in the UK. Higher incidence, an ageing population and improved survival rates all mean this figure is set to double to four million over the next 20 years.

By 2020, almost one in two people will get cancer in their lifetime ...

... but nearly four in 10 of those will not die from it.

More people are living with and beyond cancer than ever before, and they need support after treatment to meet their ongoing needs and to live with cancer as a long-term illness. This requires a shift in the way we think about survival and life after cancer. Crude measures like one and five-year survival rates alone are no longer enough.

How can this analysis be used?

RfD turns routinely collected data into insight to show which groups of patients in particular need more support. The project was set up with the objective of providing the cancer community with a scientific, evidence-based framework to apply to cancer care commissioning, service and system design, policy formulation, and to inform the direction of academic research. This insight can also be used to improve outcomes surveillance and management, and provide information for people living with or affected by cancer about life after diagnosis.

Clinical teams and commissioners who understand the variations in clinical journeys can then target improvements to ensure people living with and beyond cancer receive the right tailored care, at the right time, in the right place. The insight offered by RfD is already being used to improve cancer services in the UK. Leading the way is a pathway redesign project run by the South Yorkshire, Bassetlaw and North Derbyshire Clinical Commissioning Groups in partnership with Macmillan, which is featured in the Case Study chapter of this report.

OVERVIEW OF SURVIVORSHIP BY CANCER TYPE

Limited survival

- ■ **Group 1**
  Limited survival

- ■ **Group 2**
  More aggressive complications/ recurrence

Limited–moderate survival

- ■ **Group 3**
  Patients with other inpatient diagnoses

- ■ **Group 4**
  Limited intervention

- ■ **Group 5**
  Less aggressive complications/ recurrence

On-going survival

- ■ **Group 6**
  Living with or beyond cancer

- ■ **Group 7**
  Living with or beyond other inpatient diagnoses

- ■ **Group 8**
  Living beyond cancer

Breast
Although 69% of breast cancer patients experienced ongoing survival, illustrated by the three circles shaded in green, only one in five patients lived for at least seven years without metastases, recurrence or an additional primary cancer, or other inpatient morbidities.

Full findings for breast cancer are available on pages 17–24.

Total diagnosed in 2004 = 36,756
Analysis based on patients with inpatient records = 26,926

Lung
A large proportion of lung cancer patients experienced limited survival and poor outcomes, illustrated by the large red circle. Less than 1% lived for at least seven years without metastases, recurrence or an additional primary cancer, or other inpatient morbidities.

Full findings for lung cancer are available on pages 25–32.

Total diagnosed in 2004 = 31,233
Analysis based on patients with inpatient records = 21,634

Prostate
Outcomes for prostate cancer patients are mixed. A large proportion experienced limited survival with poor outcomes, illustrated by the circle in red, though many patients experienced continued survival with no other inpatient morbidities, as illustrated by the green circles.

Full findings for prostate cancer are available on pages 33–40.

Total diagnosed in 2004 = 31,200
Analysis based on patients with or without inpatient records = 27,213

Brain/CNS
Patients with brain/CNS tumours also experienced mixed survivorship outcomes, due to the different tumour types contained within this group. A large proportion of patients experienced limited survival (predominantly those with glioblastomas), however a substantial proportion of patients lived for at least seven years (predominantly those with meningiomas or nerve sheath tumours).

Full findings for brain/CNS tumours are available on pages 41–50.

Total diagnosed in 2004 = 11,362
Analysis based on patients with inpatient records = 8,762

The larger the bubble size, the greater the percentage of patients.

Note: details of survival time periods for each cancer cohort can be found in their respective chapters.
More information to assist with interpreting this diagram can be found in the next chapter ('How the work was done').

Breast

Lung

Prostate

Brain/CNS

HOW THE WORK WAS DONE

Routes from Diagnosis (RfD) was initiated and commissioned by Macmillan Cancer Support and conducted by Monitor Deloitte, with guidance from a clinical advisory group composed of the chairs of the National Cancer Intelligence Network's (NCIN) Site Specific Clinical Reference Groups (SSCRG) and a team from Macmillan.

The datasets

RfD links data from almost 85,000 patients in the National Cancer Data Repository (NCDR) with Inpatient Hospital Episode Statistics (HES) data, and uses this to map patients' long-term 'journeys' from diagnosis through to a set of clinically defined and meaningful outcomes. This is presented as a survivorship outcome framework. The cancers included in the analysis were chosen to include some of the most prevalent cancers in the UK – breast, lung and prostate cancers – in addition to rarer brain and central nervous system tumours about which less was known. The study examined the complete national database of patients with these tumours diagnosed in England in 2004, tracking their inpatient hospital activity over a seven-year period.

The 2004 cohort was identified as the optimal 'core' study population on which to base the survivorship outcome frameworks. This balanced a substantial period of follow-up (up to seven years) while ensuring any conclusions would be sufficiently relevant to modern practice, though it must be acknowledged that some important changes in practice have taken place during this time. For brain/CNS tumours, incidence was particularly low, so cohorts diagnosed in 2003 and 2004 were combined to ensure a sufficiently large study population.

Outpatient and A&E data were not available in time for the first phase of this project, though these data will be added into the analysis when they become available. It is expected that these sources will add further insight into less acute morbidities and complications than those identified through inpatient data (particularly for cancers frequently managed in an outpatient setting, such as prostate cancer), as well as more complete information on the costs of cancer to the NHS.

Data cleaning removed patients with invalid records or evidence of prior tumours from the study. For breast cancer, lung cancer and brain/CNS tumours, patients with no inpatient records were removed as they were not judged to be representative of the overall cancer populations, as most patients have their primary tumour removed by inpatient surgery. However, as many prostate cancer patients are managed with outpatient biopsy, hormone therapy, monitoring or radiation that does not involve an inpatient stay, the clinical advisory group determined that prostate cancer patients from NCDR with no inpatient records in HES should be included in the study to avoid skewing the survivorship frameworks.

Clinical review

The clinical advisory group was composed of pathologists, surgeons, oncologists and data experts involved in the NCIN SSCRGs. The group provided clinical and data analysis expertise at key stages of development to determine the most appropriate way to break down the survival groupings.
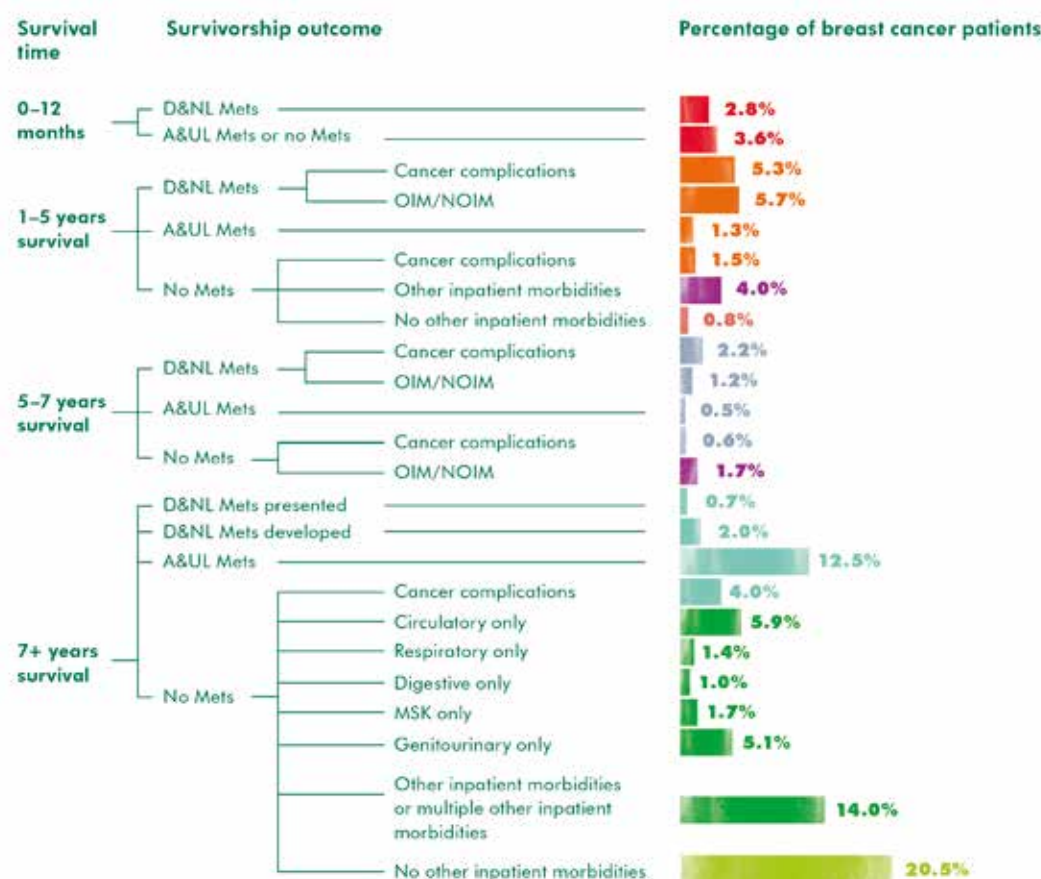
UNDERSTANDING THE SURVIVORSHIP OUTCOME FRAMEWORKS

Routes from Diagnosis uses survivorship outcome frameworks to separate patients into mutually exclusive, collectively exhaustive groups, first by survival length and then adding layers of detail appropriate to each cancer type. These have been produced in both detailed and simplified formats.

Detailed survivorship outcome frameworks
Figure 1 provides an example of the detailed survivorship outcome framework for breast cancer. In this example, 24 detailed outcome pathways have been identified.

Figure 1: example of a detailed survivorship outcome framework (breast cancer)

Survival time	Survivorship outcome		Percentage of breast cancer patients
0–12 months	D&NL Mets		2.8%
	A&UL Mets or no Mets		3.6%
1–5 years survival	D&NL Mets	Cancer complications	5.3%
		OIM/NOIM	5.7%
	A&UL Mets		1.3%
	No Mets	Cancer complications	1.5%
		Other inpatient morbidities	4.0%
		No other inpatient morbidities	0.8%
5–7 years survival	D&NL Mets	Cancer complications	2.2%
		OIM/NOIM	1.2%
	A&UL Mets		0.5%
	No Mets	Cancer complications	0.6%
		OIM/NOIM	1.7%
7+ years survival	D&NL Mets presented		0.7%
	D&NL Mets developed		2.0%
	A&UL Mets		12.5%
	No Mets	Cancer complications	4.0%
		Circulatory only	5.9%
		Respiratory only	1.4%
		Digestive only	1.0%
		MSK only	1.7%
		Genitourinary only	5.1%
		Other inpatient morbidities or multiple other inpatient morbidities	14.0%
		No other inpatient morbidities	20.5%

Variables
The variables that are used to construct each framework describe the clinical elements of survivorship that the clinical advisory group agreed were most important for each cancer.

For example, for cancers associated with poor outcomes more detail is provided for patients who experienced short survival, whereas for cancers associated with longer survivorship, the descriptive focus is on longer survival lengths.

This is well illustrated in the differences between lung cancer, where more detail is provided on short survival intervals, and breast cancer, where long-term morbidities are described in greater depth.

Once appropriate survival breakdowns had been identified for each cancer, the clinical advisory group highlighted the key factors that are both known to affect cancer patients after their cancer diagnosis and can be recorded as a diagnosis in inpatient records. This added a layer of detail to the frameworks beyond simple survival lengths.

All patients are allocated to one outcome pathway only, using a 'hierarchy' to prioritise the characteristics which had the greatest bearing on patients' lives after diagnosis. First, survival was prioritised as the most important outcome for cancer

Key
Mets: Metastases
D&NL Mets: Distant and non-lymph node metastases
A&UL Mets: Axillary and upper limb metastases (i.e. local metastases)
Cancer Complications: Recurrence or additional primary cancer
OIM: Other inpatient morbidities
NOIM: No other inpatient morbidities
MSK: Musculoskeletal

patients. This is then followed by cancer recurrence, spread or new cancers, and if these did not occur, then other inpatient morbidities. For example, if a patient experienced 'cancer complications' this will always take priority over 'other inpatient morbidities', which takes priority over 'no other inpatient morbidities'. This means that a patient could have experienced both 'cancer complications' and 'other inpatient morbidities' but would only be categorised and included in a 'cancer complications' pathway.

Metastases
The first of these additional factors was the presence or development of metastases.

Patients with metastases need appropriate treatment and support, and so the ability to distinguish these patients from those without metastases adds a valuable level of detail to the frameworks, helping to tailor care.

The way metastases are incorporated in the framework differs by cancer type, based on advice from the clinical team. For example, the breast cancer framework differentiates between 'axillary and upper lymph node' and 'distant and non-lymph node' metastases, as axillary and upper lymph node metastases are often still considered curable. Such a clear-cut distinction was not deemed appropriate for the other cancer types.

Furthermore, for breast and prostate cancer, a distinction was made between patients who presented with and developed metastases. Patients diagnosed with metastases up to 90 days after diagnosis were described as having presented with metastatic cancer, whilst metastases diagnosed 90 days or more after diagnosis were described as having 'developed', as this was found to have a significant impact on outcomes.

High and low inpatient care
Levels of inpatient care utilisation were used as a proxy to give some indication of quality of life for patients in some of the lung, prostate and brain/CNS limited survival outcome groups.
If a patient spent more than 25% of their survival in hospital, they were described as having had 'high inpatient care', and if they spent less than 25% of their survival in hospital they were allocated to the 'low inpatient care' group. This method was felt to be the best way to combine 'frequency of visit' with 'time in hospital' as an indication of post-diagnosis quality of life.

Cancer complications
In addition to the presence or development of metastases, the RfD methodology was designed to capture the development of additional primary cancers and the recurrence of an index cancer following a period of remission. These are described using the term 'cancer complications'.

As brain/CNS tumours seldom metastasise (and because when they do, they usually metastasise only within the brain/CNS), metastases were included in the 'cancer complications' groups for these tumours.

Other inpatient morbidities
Uniquely, RfD also captures a more detailed description of a patient's survivorship through the identification of 'inpatient morbidities'. The clinical advisory group identified what they believed were clinically important inpatient morbidities during the survivorship phase for each index tumour. These were defined as:

- Common morbidities likely to be more prevalent for the tumour type population than a general population;

- Common morbidities likely to affect treatment decisions;

- Common complications of the cancer or cancer treatment.

Individual ICD-10 codes[2] were used to identify these occurrences, i.e. any occurrence of a specific relevant circulatory ICD-10 code would count as an occurrence of 'disease of the circulatory system'. Once codes had been identified and finalised for each cancer, inpatient HES data was used to identify the occurrence of these relevant morbidities. These were grouped into high-level categories to avoid too much complexity in the final presentation of outputs.

No other inpatient morbidities
Patients with no recorded cancer complications or other inpatient morbidities were described as having 'no other inpatient morbidities'.

It is important to say that these patients do not necessarily live without any health issues – rather that RfD currently only describes inpatient activity. For example, a 2011 study of general practice data found that many breast, colorectal and prostate cancer survivors living five years or more after diagnosis presented to their GPs with chronic illnesses[3], but unless such illnesses resulted in an inpatient admission they are not described in RfD, as they do not appear in inpatient HES. To some extent this may restrict what RfD can say about morbidity; however, as the recording of an inpatient morbidity can be taken as a reasonable proxy for acuity, the methodology should capture the most severe morbidities of each type.

Simplified survivorship outcome frameworks

Whilst the detailed survivorship outcome frameworks provided a deeper understanding of survivorship, there was also a need to create simplified outcome frameworks for those involved in service redesign, for whom a large number of pathways is impractical.

The simplified survivorship outcome frameworks apply a consistent set of four principles across all cancers to describe the length and complexity of survival:

A. Survival is the overwhelming priority in cancer
B. Early in survivorship, the cancer itself is the priority
C. Later in survivorship, morbidities are more impactful
D. Wherever possible, it is important to describe factors that may have a bearing on quality of life

Within this framework, it is possible to identify 8 simplified groups (see Figure 2) which cover the full spectrum of survivorship over the 7-year period of the RfD study.
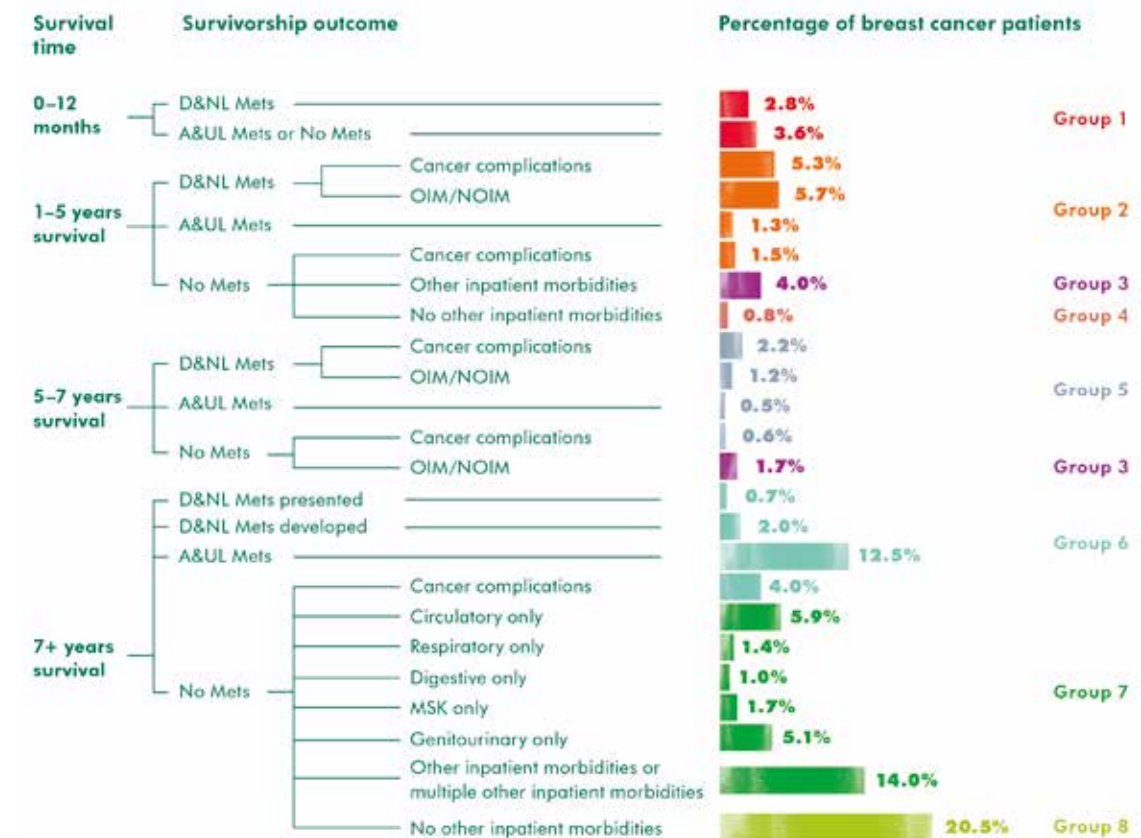
Please note that in the simplified survivorship outcomes frameworks, 'cancer complications' includes metastases, in addition to recurrence or additional primary tumours.

Figure 3 provides an example of how the pathways in the detailed frameworks were grouped together to form the simplified frameworks. This varies slightly between the four cancer types.

Figure 2: identifying the simplified survivorship outcome groups

	A	B	C	D
Survival	**Cancer complications**	**Other inpatient morbidities**		**No other inpatient morbidities**
Limited			**Group 1** • 0–12 months • Limited survival	
Limited	**Group 2** • 1–5 years • More aggressive complications/recurrence	**Group 3** • 1–7 years • Patients with survival limited by other morbidities		**Group 4** • 1–7 years • Limited intervention
Moderate	**Group 5** • 5–7 years • Less aggresive complications/recurrence			
On-going	**Group 6** • 7+ years • Cancer as a chronic disease	**Group 7** • 7+ years • Living with or beyond cancer with other morbidities		**Group 8** • 7+ years • Living beyond cancer

Figure 3: example of simplified survivorship outcome groups mapped against a detailed survivorship outcome framework (for breast cancer)

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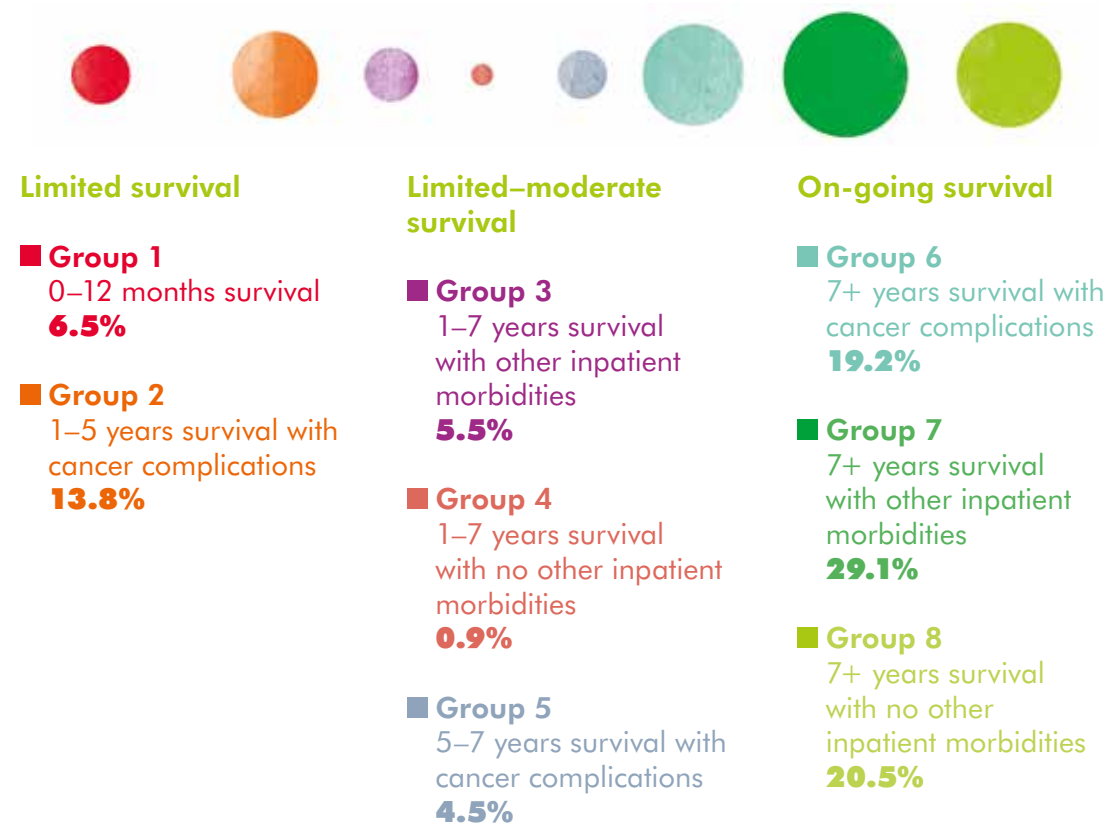**OIM:** Other inpatient morbidities
NOIM: No other inpatient morbidities
MSK: Musculoskeletal

Figure 4, below, illustrates the relative distribution of patients across the simplified groups:

Figure 4: example of a simplified survivorship outcome framework (for breast cancer)

Limited survival

■ **Group 1**
0–12 months survival
6.5%

■ **Group 2**
1–5 years survival with cancer complications
13.8%

Limited–moderate survival

■ **Group 3**
1–7 years survival with other inpatient morbidities
5.5%

■ **Group 4**
1–7 years survival with no other inpatient morbidities
0.9%

■ **Group 5**
5–7 years survival with cancer complications
4.5%

On-going survival

■ **Group 6**
7+ years survival with cancer complications
19.2%

■ **Group 7**
7+ years survival with other inpatient morbidities
29.1%

■ **Group 8**
7+ years survival with no other inpatient morbidities
20.5%

A cancer with poor survivorship outcomes will have larger circles coloured in shades of red, while a cancer with better outcomes will have larger circles in shades of green. This visual language helps to inform more broadly an on-going conversation about cancer, and provides a structured way for the cancer community to think about survivorship in the context of planning and service improvement.

Costing data
RfD includes economic analysis[4] describing the cost of all activity within inpatient HES. This includes all episodes of admitted patient care including elective care, non-elective care, day cases and regular attendances coded in inpatient HES. Activity delivered in any other setting, such as outpatient clinics, primary care (e.g., oral chemotherapy, follow-up) or A&E, is not included in the analysis.

This means a large proportion of the coded surgical activity and approximately just over half of chemotherapy delivered in secondary care is included, but the data misses much radiotherapy, oral and injected chemotherapy as well as the initial consultation and diagnosis and many monitoring appointments, which are delivered in an outpatient setting. In addition, chemotherapy and radiotherapy costs have historically been negotiated at a local level and are not in the national dataset. For the purposes of this study national average costs are included for some activity (that which happens in an inpatient setting). The costs do not include: critical care days, neonatal care, specialist palliative care and rehabilitation.

Unfortunately some elements of cancer treatment are not well recorded in HES. New national datasets, such as the Radiotherapy Data Set (RTDS) and the Systemic Anti-Cancer Therapy (SACT) data set, will ultimately enable a fuller understanding of the treatments being provided and their costs.

Comparison population
To enhance our understanding of how best to manage survivorship care, we needed to know which non-cancer morbidities were more prevalent among cancer patients than in patients who did not have cancer.

Building on the work of McBride et al,[5] an age and sex matched comparison population of 50,000 was created to compare with each of the four cancer population (i.e. four different representative 50,000 patient groups). This comparison group was drawn from patients with a HES record in 2004.

It should be noted that the 40% of the UK population who use the secondary care system in a given year are likely to be in poorer health than the 60% who do not.

More detailed methodology
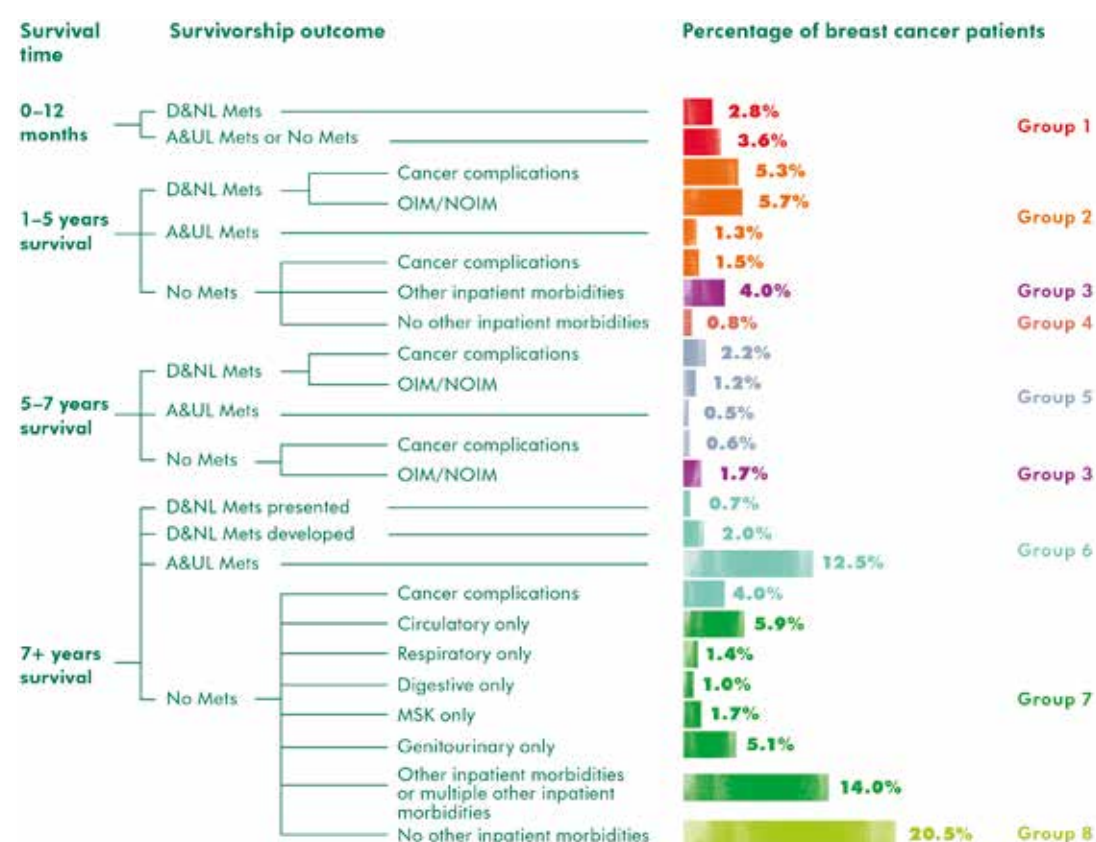Full details of the RfD methodology will be outlined in an academic paper currently being prepared for publication.

FINDINGS FOR BREAST CANCER

Survivorship

The full population of 36,756 patients diagnosed with breast cancer in England in 2004 were considered for inclusion in the RfD datasets. Patients with invalid records (2,583), no inpatient records (6,176), or evidence of any prior tumours (1,071) were removed from the cohort. This resulted in 26,926 patients being included in the detailed survivorship outcome framework for breast cancer (see figure 5).

Figure 5: detailed survivorship outcomes framework for breast cancer

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

Given the large proportion of patients experiencing continued survival, the framework provides a higher level of detail for these groups.

To provide more detail on metastatic breast cancer, the framework distinguishes between whether metastases were distant and non-lymph node (D&NL) metastases or axillary and upper limb (A&UL) metastases, and for some survival lengths, whether patients presented with metastases or subsequently developed them.

A large proportion of patients who presented with or developed axillary and upper limb metastases lived to over seven years, which demonstrates the effectiveness of treatment and monitoring for localised cancer.

3.6% of breast cancer patients died within a year of diagnosis despite having only locally advanced disease or no metastases. However, 70.0% of breast cancer patients in this outcome pathway were aged over 75 years, compared to 20.8% of the breast cancer cohort as a whole.

The survivorship outcome pathways with the highest prevalence were:

- 7+ year survival with no metastases, complications or inpatient morbidities (20.5%);

- 7+ year survival with no metastases, with other or multiple inpatient morbidities (14.0%); and

- 7+ year survival with axillary or upper limb metastases (12.5%).

'In a busy NHS setting it is easy to view the success or failure of management as survival or disease-free survival. The reality is that each surviving patient may be living with significant physical and psychological issues, and a lot of the non-cancer morbidity would get missed in a busy clinic.
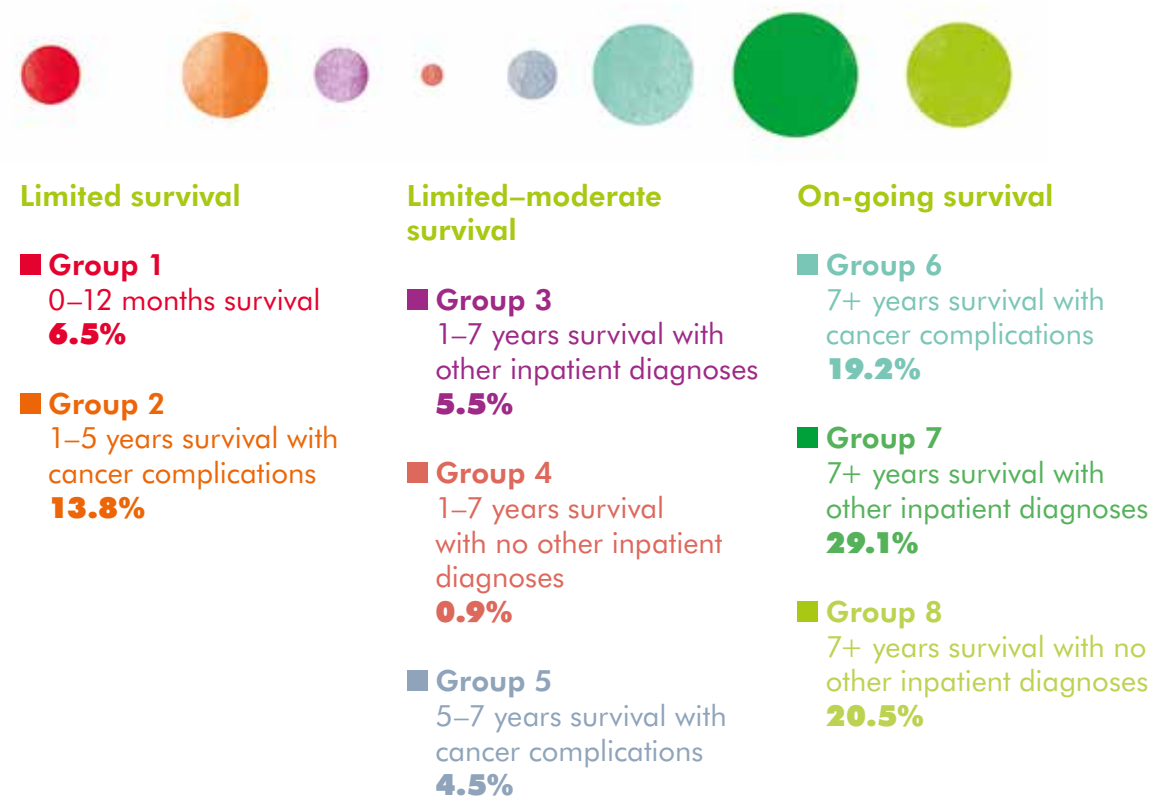
Routes from Diagnosis shows us the situation in a clearly understandable way, and could lead to a more accurate description of the potential future for patients embarking on their treatment journey. Where the majority of patients survive, as for breast cancer, this is particularly pertinent.'

Dr Murray Brunt, Consultant Clinical Oncologist

Simplified survivorship outcome frameworks
Simplified frameworks (see figure 6) were developed to help easily communicate the distribution of patients into each group, and to offer a consistent way of talking about and comparing each cancer.

Figure 6: graphical view of simplified survivorship outcomes framework for breast cancer

Limited survival

■ **Group 1**
0–12 months survival
6.5%

■ **Group 2**
1–5 years survival with cancer complications
13.8%

Limited–moderate survival

■ **Group 3**
1–7 years survival with other inpatient diagnoses
5.5%

■ **Group 4**
1–7 years survival with no other inpatient diagnoses
0.9%

■ **Group 5**
5–7 years survival with cancer complications
4.5%

On-going survival

■ **Group 6**
7+ years survival with cancer complications
19.2%

■ **Group 7**
7+ years survival with other inpatient diagnoses
29.1%

■ **Group 8**
7+ years survival with no other inpatient diagnoses
20.5%

Note: 'Cancer complications' includes metastases, additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; colour coding indicates severity of disease, from most severe (red) to least severe (green)

While it is already known that the majority of breast cancer patients survive, we now know that more than two thirds of patients surviving seven years or more experienced either cancer complications or other inpatient morbidities. This tells us that the health journey for breast cancer patients can be long-term and complex.

RfD also provides further evidence of the presentation of later-stage disease in older patients and the link to poorer survival rates.[6] It was possible to identify 19.9% of the cohort as having experienced metastatic disease. Of those patients

identified, 14.7% of patients aged 25–64 had already developed metastases at the time of their breast cancer diagnosis. This proportion was higher for each of the older age brackets; 65–69 (19.9%), 70–74 (22.3%) and 75+ (25.9%). Taking a single age bracket, 54.7% of patients aged 65–69 who presented with metastases at diagnosis lived to one year, whilst one-year survival for patients of this age who developed metastases after diagnosis was 95.5%. Five-year survival was 19.7% and 32.1% respectively.

Post-diagnosis inpatient costs
Healthcare commissioners need to unpick variations in costs, linked to outcomes, if they are to deliver high value care. As well as describing outcomes, RfD allows us to see how inpatient costs vary by survivorship outcome group, helping to build a fuller picture of the costs of cancer and its treatment. Uniquely, this includes the cost of inpatient treatment in the survivorship phase up to seven years after diagnosis, including for relevant non-cancer conditions.

Figure 7 displays the average post-diagnosis inpatient cost for breast cancer patients in each outcome group, and the volume of patients within each group.

The average post-diagnosis inpatient cost was £10.2K per patient, however there is significant variation in cost depending on outcome. The relationship between inpatient post-diagnosis cost and survival is not linear – the highest inpatient costs are associated with patients
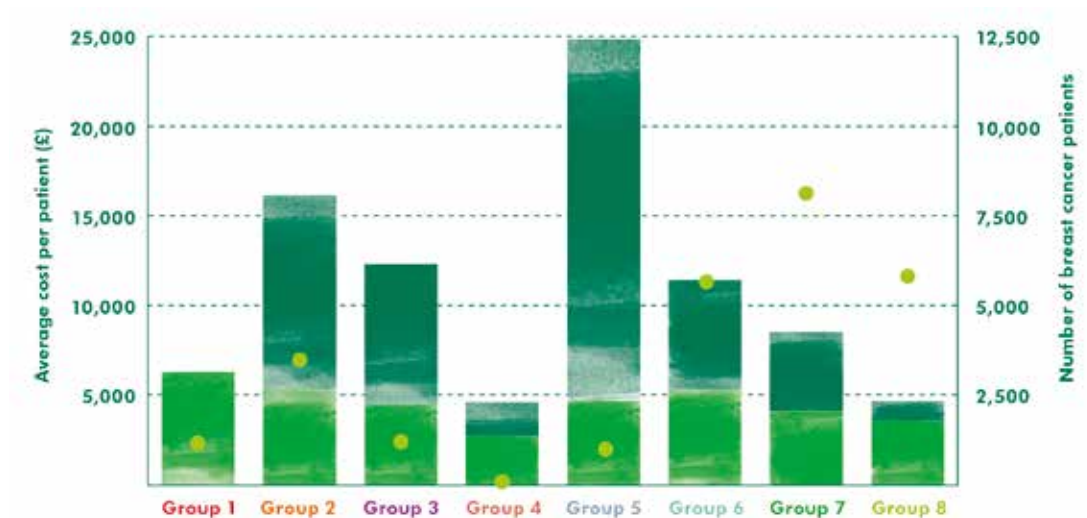
who experienced medium term survival (groups 2, 3 and 5).

As the chart shows, although there is some amount of variation in treatment costs, the largest variations are in the cost of the inpatient care that follows during the recovery and survivorship phases.[8]

Differences in cost can be explained, in part, by the greater costs for patients with slowly progressive but partially responsive disease who undergo repeated episodes of treatment; and the higher initial costs of treating those with more aggressive disease, ultimately limited by their compromised survival.

High inpatient treatment costs are associated with the relatively small (4.5%) group of patients in outcome group five whose inpatient costs continue to accumulate at a rapid rate particularly in the last years of survival. These patients have continuing care needs due to metastases and complications and live

Figure 7: average post-diagnosis inpatient costs[7] of breast cancer patients split by phase, by simplified survivorship outcome, with number of patients

■ **Cost after first year post-diagnosis**
■ **Cost in first year post-diagnosis**
● **Number of patients**

Table 8: % of breast cancer population and comparison population living with each morbidity at one and five years post-cancer diagnosis / post-earliest 2004 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	Genitourinary	New Primary
Patients living with morbidity at one year	Cancer population	2.5%	2.3%	7.5%	4.9%	19%	7.8%	1.3%
	Comparison population	1.4%	3.2%	4.7%	3.9%	11.3%	5.7%	1%
	Cancer morbidity burden (ratio)	1.8	0.7	1.6	1.3	1.7	1.4	1.3
Patients living with morbidity at five years	Cancer population	4.7%	7.7%	12.8%	11.5%	29.3%	20.7%	3.8%
	Comparison population	4.1%	9.4%	11.5%	12.1%	26.6%	14.5%	2.9%
	Cancer morbidity burden (ratio)	1.1	0.8	1.1	0.9	1.1	1.4	1.3

■ Significantly lower proportion in cancer patients with p ≤0.001
■ Significantly higher proportion in cancer patients with p ≤0.001

long enough for high costs to be accrued over a long period.

Other morbidities
Two thirds of breast cancer patients (67%) experience other inpatient morbidities.[9]

RfD makes it possible to identify the extent of morbidities and the rate at which morbidities accrue across cancer survivorship outcome groups and between cancer types.

Table 8 draws a comparison between the proportion of the breast cancer population alive at one and five years after diagnosis who experienced other inpatient morbidities, and the proportion of an inpatient, non-cancer comparison group who experienced the same morbidities.

Across a range of morbidities, a significantly higher proportion of cancer patients were living with health issues other than their primary cancer at one and five years after diagnosis, compared to the comparison group.

Circulatory morbidities are the most prevalent among breast cancer patients, rising from 19% of the living breast cancer population at one year to 29.3% at five years. Respiratory and genitourinary morbidities are also significantly more prevalent in the cancer population than in the comparison group, whereas prevalence of digestive morbidities is significantly lower at one year.
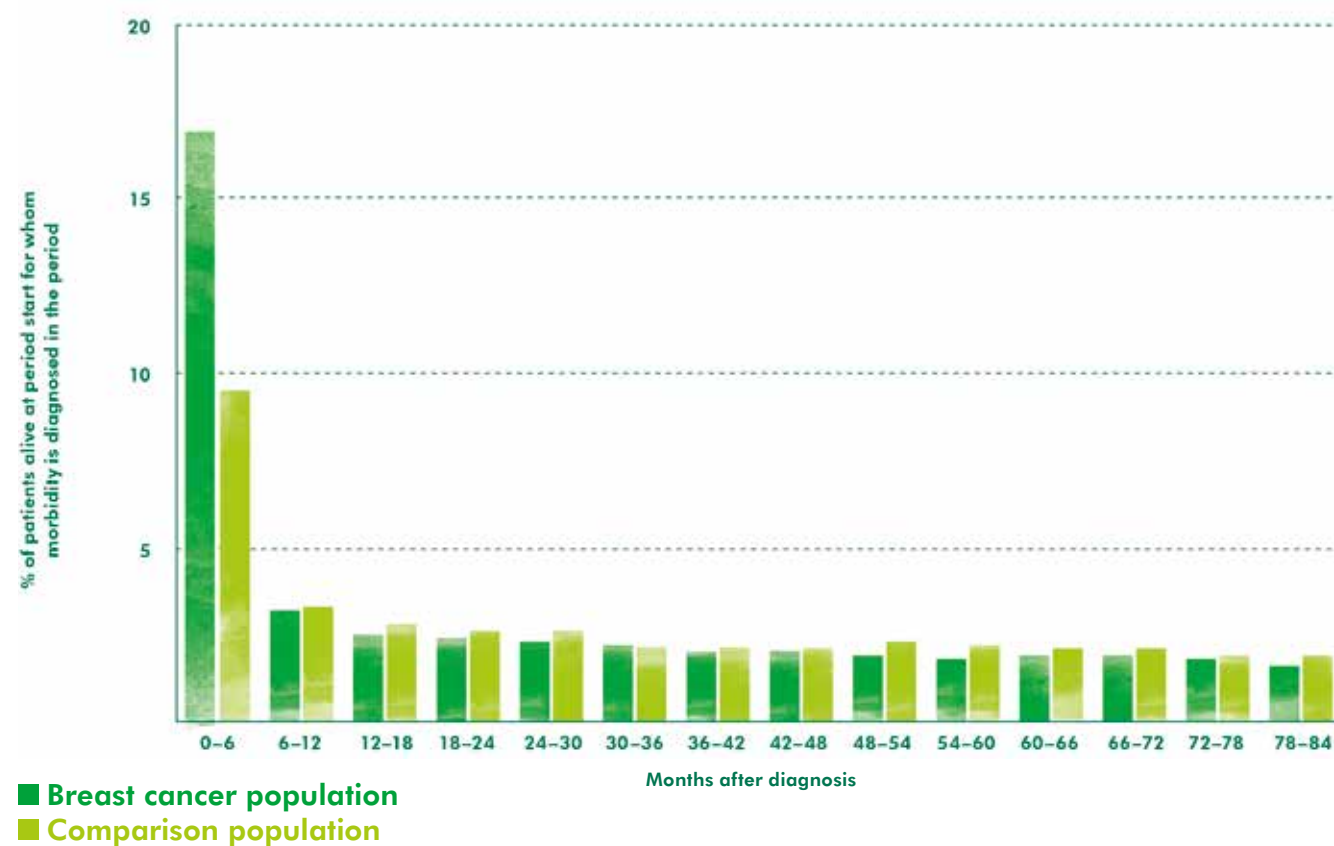
While the percentage of the living breast cancer population with non-cancer inpatient morbidities increases over the study period, much of this morbidity is diagnosed shortly after the initial cancer diagnosis – morbidity incidence

is highest in the first six months, when patients are under surveillance and further tests identify undiagnosed pre-existing conditions and new morbidities. After this point, the incidence of new morbidities drops to a level similar to that experienced by the comparison group. For example figure 9 shows the incidence of new circulatory morbidities at six monthly time periods after cancer diagnosis. The good news story for breast cancer patients is that over time, the risk of acquiring a new inpatient morbidity becomes very similar to that of the general population.

Breast cancer and its treatments can result in long-term side effects, some of which may seriously affect quality of life. Lymphoedema, body image issues, cognitive changes, hormonal symptoms (such as hot flushes), pain, fatigue, fertility issues, peripheral neuropathy, sexual difficulties and psychosocial problems may occur. Some treatments increase the risk of longer term cardiac disease or osteoporosis. Specialist services are needed to manage severe symptoms, but some problems can be minimised or avoided through, for example, earlier identification of lymphoedema, or monitoring heart and bone health.
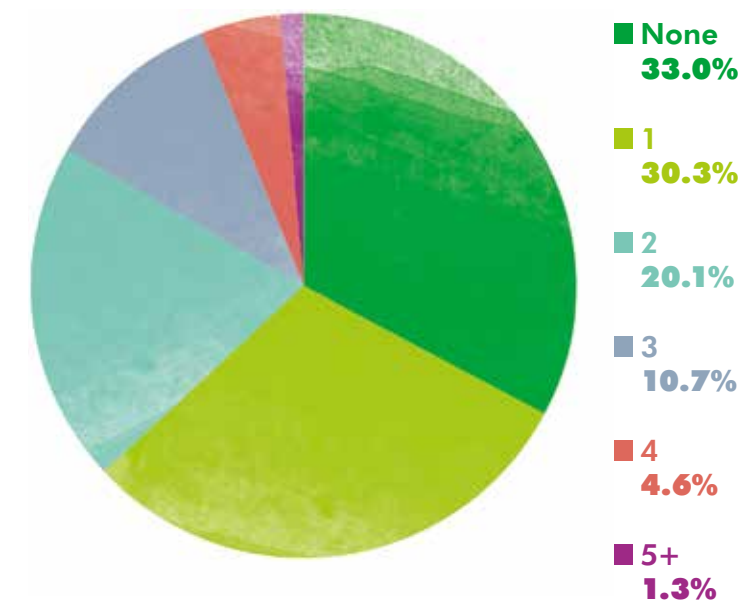
The RfD analysis of the breast cancer cohort can help us to understand better patterns of hospital admissions and associated costs resulting from conditions which may be associated with the consequences of cancer and its treatment.

Figure 10 shows the percentage of breast cancer patients who experienced none, one or multiple morbidities throughout their cancer survivorship journey.

When compared to the other RfD cancer cohorts, a smaller proportion of breast cancer patients experienced multiple inpatient morbidities (at just less than 40%) than prostate and lung cancer patients.

Figure 10: percentage of breast cancer population by number of inpatient morbidities taken over the seven year survivorship period
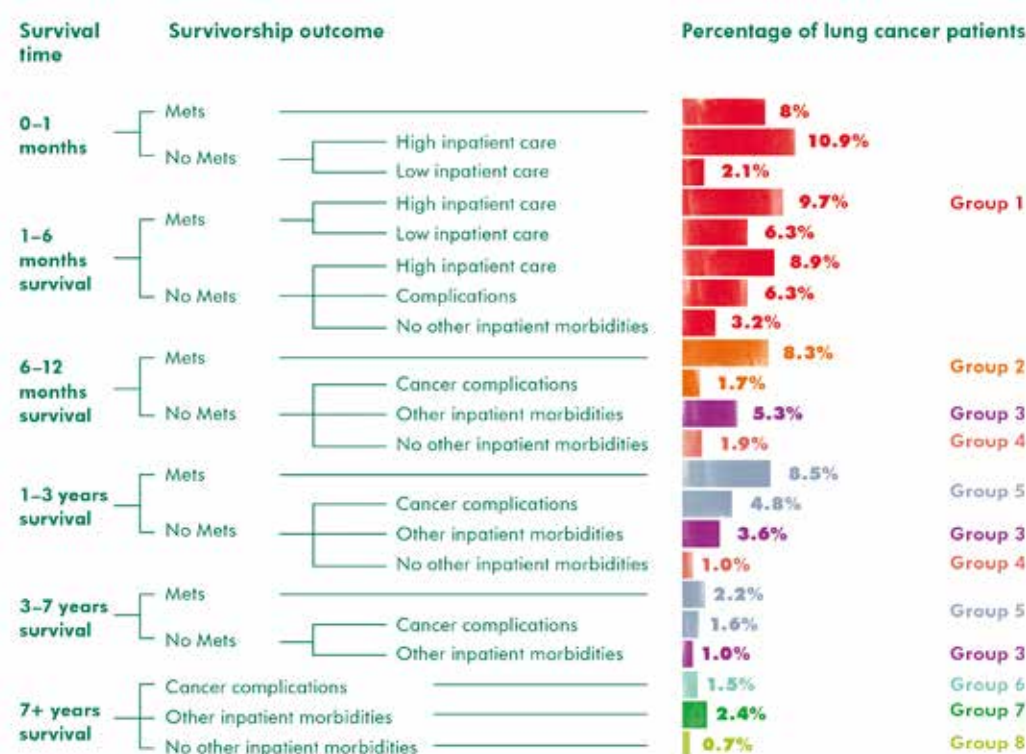

■ **None** **33.0%**

■ **1** **30.3%**

■ **2** **20.1%**

■ **3** **10.7%**

■ **4** **4.6%**

■ **5+** **1.3%**

Figure 9: circulatory morbidity acquisition for breast cancer

Months after diagnosis

■ **Breast cancer population**
■ **Comparison population**

FINDINGS FOR LUNG CANCER

Survivorship

The full population of 31,233 patients diagnosed with lung cancer in England in 2004 were considered for inclusion in the RfD data sets. Patients with invalid records (727), no inpatient records (5,142), or evidence of any prior tumours (3,730), were removed from the cohort. This resulted in 21,634 patients being included in the detailed outcome survivorship framework for lung cancer (see figure 11).

Figure 11: detailed survivorship outcome framework for lung cancer

Key

Mets: Metastases
Cancer Complications: Recurrence or additional primary cancer
High inpatient care: Patient spent more than 25% of survival length in hospital
Low inpatient care: Patient spent less than 25% of survival length in hospital

- To best describe the clinical journeys of the large number of patients who died within a year of diagnosis, further survival breakdowns within the first year were introduced (at 0–1 month, 1–6 months and 6–12 months).

- The lung cancer framework firstly segments patients by whether they had metastases at any point or not. Further segmentation of patients by level of inpatient care was performed to consider the aggressive nature of the tumours; helping to describe the experience and resource usage of these patients.

Almost three quarters of lung cancer patients (73%) die within a year of diagnosis. While this is comparable with previously published statistics, RfD provides additional knowledge about the survivorship outcome pathways. The survivorship outcome pathways with the highest prevalence were:

- 0–1 month survival with no metastases and high inpatient care (10.9%);

- 1–6 month survival with metastases and high inpatient care (9.7%); and

- 1–6 month survival with no metastases and high inpatient care (8.9%).
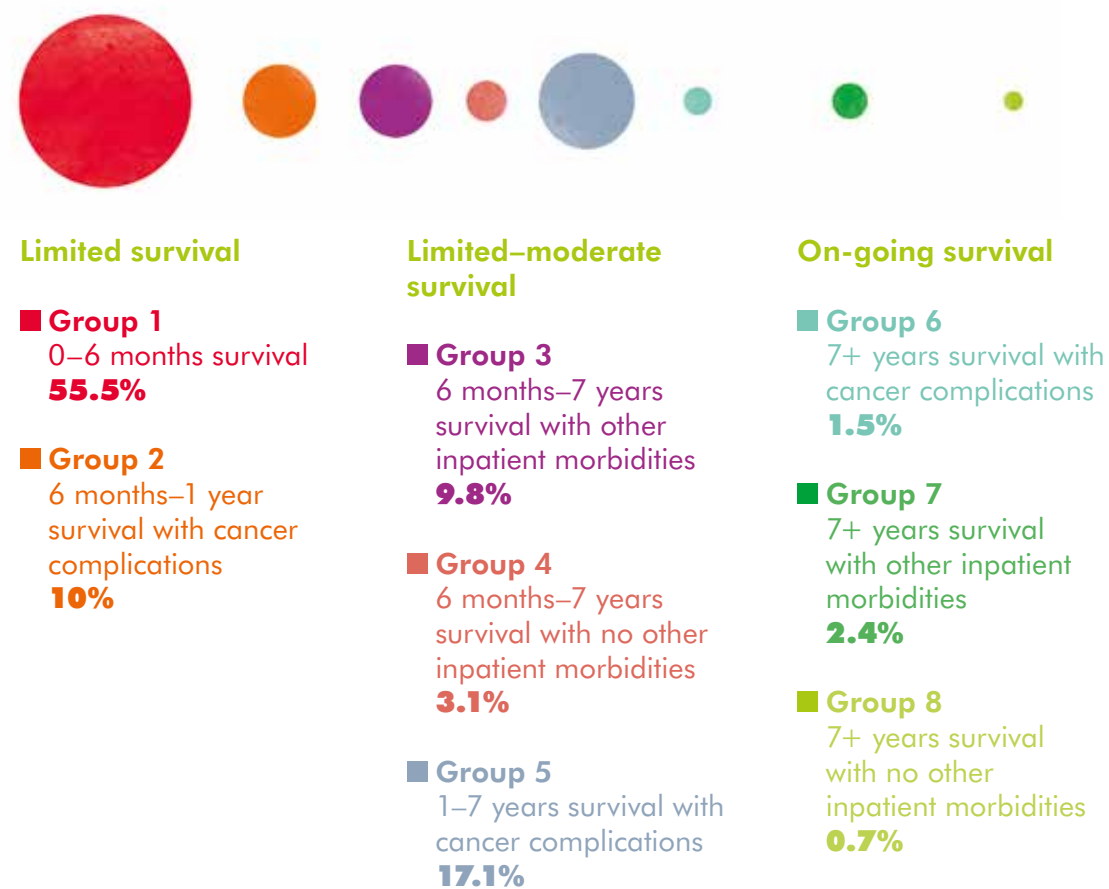
'The process of being involved in RfD has been very interesting. It shows that we need to look again at treatment for people with longer survival, and provide a package of care. Lung cancer survival rates are beginning to improve so this will become much more pertinent in the coming years.'

Michael Lind, Professor of Clinical Oncology

Simplified survivorship outcomes framework

Simplified frameworks (see figure 12) were developed to help easily communicate the distribution of patients into each group, and to offer a consistent way of talking about and comparing each cancer.

Figure 12: graphical view of simplified survivorship outcome framework for lung cancer

Limited survival

■ **Group 1**
0–6 months survival
55.5%

■ **Group 2**
6 months–1 year survival with cancer complications
10%

Limited–moderate survival

■ **Group 3**
6 months–7 years survival with other inpatient morbidities
9.8%

■ **Group 4**
6 months–7 years survival with no other inpatient morbidities
3.1%

■ **Group 5**
1–7 years survival with cancer complications
17.1%

On-going survival

■ **Group 6**
7+ years survival with cancer complications
1.5%

■ **Group 7**
7+ years survival with other inpatient morbidities
2.4%

■ **Group 8**
7+ years survival with no other inpatient morbidities
0.7%

Note: 'Cancer complications' includes metastases, additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; colour coding indicates severity of disease, from most severe (red) to least severe (green)

Even among patients with long-term survival, there is a high burden of disease due to cancer complications or morbidities.

Although Macmillan estimates that by 2020 fewer than half of those who get breast and prostate cancer will ultimately die as a result of their cancer, around three quarters of those who get lung cancer will die from it.[10]

Macmillan believes that there are three key things that could help close the gap between survival rates for different cancers and give everyone the best possible chance of recovery. Firstly, supporting the call for plain packaging of cigarettes to discourage people from taking up smoking; secondly catching the illness earlier through better awareness; and making sure access to surgery is more uniform across the country to reduce inequalities in cancer survival.

Post-diagnosis inpatient costs

Healthcare commissioners need to unpick variations in costs, linked to outcomes, if they are to deliver high value care. As well as describing outcomes, RfD allows us to see how inpatient costs vary by survivorship outcome group, helping to build a complete picture of the costs of cancer and treatment. Uniquely, this includes the cost of inpatient treatment in the survivorship phase up to seven years after diagnosis, including for relevant non-cancer conditions.
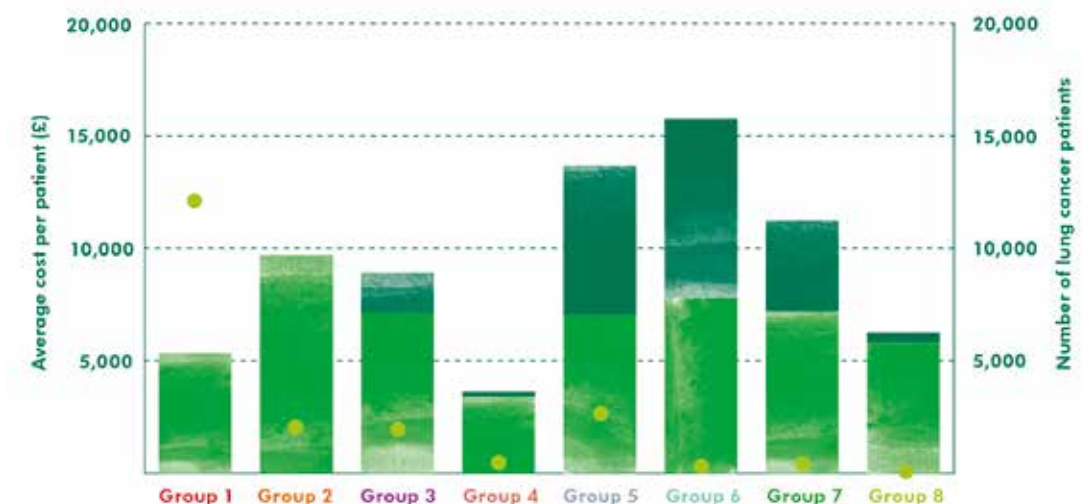
The graph below (figure 13) displays the average post-diagnosis inpatient cost for lung cancer patients in each outcome group, and the volume of patients within each group.

Lung cancer patients had lower post-diagnosis inpatient costs on average when compared to the other cancer cohorts (at around £7.9K per patient). Conversely the average inpatient costs for lung cancer patients during the first year post-diagnosis are among the highest (along with brain/CNS tumour patients) when compared to the other RfD cancer frameworks. This means that the majority of inpatient costs for lung cancer patients are attributed to the first year post-diagnosis. This is not a surprise due to the large number of lung cancer patients who are acutely unwell upon diagnosis, for example, where they present with late-stage cancer.

The average inpatient costs post-diagnosis for groups 1 and 8 are almost the same at around £5K/£6K; demonstrating once again that the relationship between inpatient cost post-diagnosis and survival is not linear. This shows that the small percentage of lung cancer patients who survive past seven years post-diagnosis with no other inpatient morbidities are no more or less expensive to treat in the secondary care setting than patients with limited survival.

Figure 13: average post-diagnosis inpatient costs[7] of lung cancer patients split by phase, by simplified survivorship outcome, with number of patients

■ **Cost after first year post-diagnosis**
■ **Cost in first year post-diagnosis**
● **Number of patients**

Note: 'Cancer complications' includes metastases, additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; Colour coding indicates severity of disease, from most severe (red) to least severe (green)

Table 14: % of lung cancer population and comparison population living with each morbidity at one and five years post-cancer diagnosis / post-earliest 2004 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	New Primary
Patients living with morbidity at one year	Cancer population	15%	11.8%	32.6%	7.9%	31.9%	5.9%
	Comparison population	7.4%	8.4%	5.6%	3.1%	16.9%	2.6%
	Cancer morbidity burden (ratio)	2.0	1.4	5.8	2.5	1.9	2.3
Patients living with morbidity at five years	Cancer population	24.8%	29.9%	40.4%	13.9%	43.8%	33%
	Comparison population	20.4%	22.8%	13.4%	9.7%	38.6%	8.3%
	Cancer morbidity burden (ratio)	1.2	1.3	3.0	1.4	1.1	4.0

■ Significantly lower proportion in cancer patients with p ≤0.001
■ Significantly higher proportion in cancer patients with p ≤0.001

Other morbidities
Over three quarters of lung cancer patients (77%) experienced other inpatient morbidities.[9]

RfD makes it possible to identify the extent of morbidities and the rate at which morbidities occur across cancer survivorship outcome groups and between cancer types.
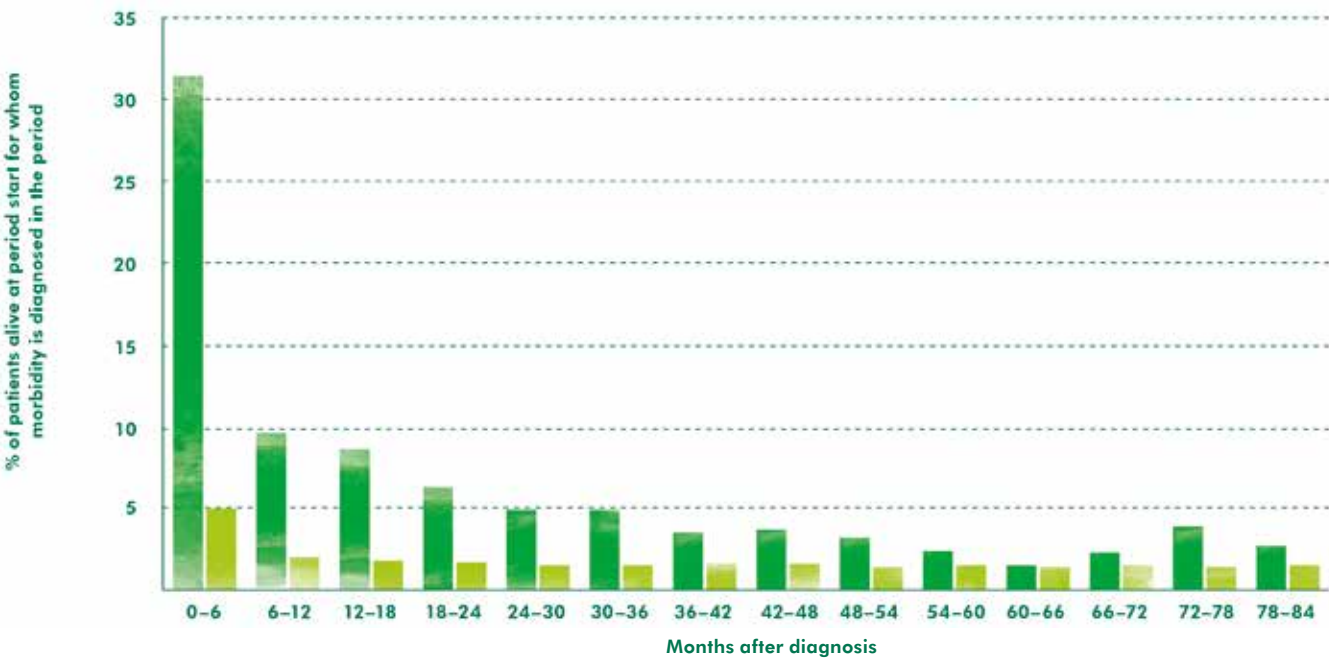
Table 14 shows the proportion of the lung cancer population alive at one and five year intervals after diagnosis who experienced other inpatient morbidities, compared with an inpatient, non-cancer comparison group.

At one and five years post-cancer diagnosis, a significantly higher proportion of lung cancer patients were living with morbidities compared to the comparison population, for all types of morbidities identified.

The percentage of patients experiencing other morbidities is higher across all morbidities than for other cancer cohorts, particularly at one year post-diagnosis.

We now know that the risk of acquiring a new primary cancer is higher for lung cancer patients than for patients with breast cancer, prostate cancer or brain/CNS tumours. A third of the patients (33%) who survived to five years developed a new primary cancer at some stage after diagnosis, and were four times more likely to acquire a new primary cancer than the comparison group. Over the same time period, no more than 10% of patients from the three other RfD cancer cohorts developed a new primary cancer (with the exception of glioblastoma brain tumour patients at just under 20%). It is believed that this could be partly due to some lung cancer patients continuing to smoke, resulting in other primary tumours caused by tobacco (e.g. bladder and pancreas), and other lifestyle factors.

Figure 15: respiratory morbidity acquisition for lung cancer

■ Lung cancer population
■ Comparison population

Circulatory and respiratory are the most prevalent inpatient morbidities among lung cancer patients, both increasing from just over 30% of patients to over 40% from one year post-diagnosis to five years post-diagnosis.
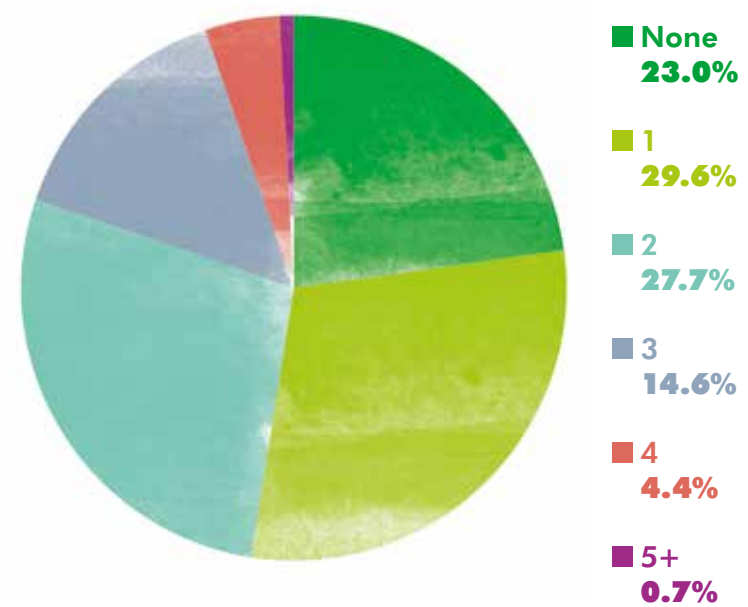
The morbidity incidence rate is highest in the six months post-cancer diagnosis, particularly for circulatory and respiratory morbidities, as further tests identify pre-existing conditions and new morbidities arise. Following this, the incidence of new morbidities reduces to a steady rate (see Figure 15 for the incidence of new respiratory morbidities at six monthly time periods after cancer diagnosis).

The accumulation of respiratory morbidities shows that lung cancer survivors can require very complex care plans. Figure 16 shows the percentage of lung cancer patients who experienced none, one or multiple morbidities throughout their cancer survivorship journey.

A higher proportion of lung cancer patients (at just less than a half) experienced multiple inpatient morbidities post-diagnosis than all other RfD cancer cohorts. This demonstrates the complexity of the survivorship journey for many lung cancer patients, suggesting that effective management of lung cancer survivorship may require more active management of other conditions.

Figure 16: percentage of lung cancer population by number of inpatient morbidities taken over the seven year survivorship period
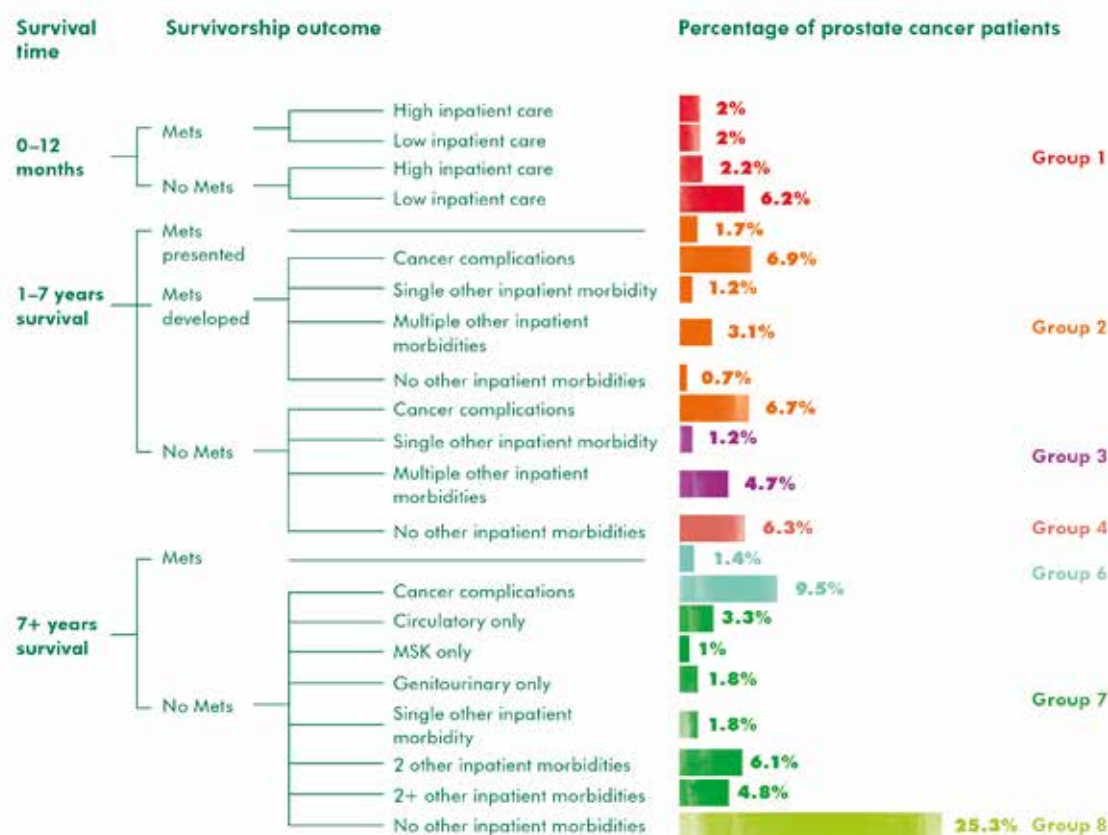

■ None
23.0%

■ 1
29.6%

■ 2
27.7%

■ 3
14.6%

■ 4
4.4%

■ 5+
0.7%

FINDINGS FOR PROSTATE CANCER

Survivorship

The full population of 31,200 patients diagnosed with prostate cancer in England in 2004 were considered for inclusion in the RfD data sets. Patients with invalid records (2,392) or evidence of any prior tumours (1,595) were removed from the cohort. This resulted in 27,213 patients being included in the detailed Survivorship Outcome Framework for prostate cancer (see figure 17).

A large proportion of prostate cancer treatment takes place in an outpatient/primary care setting. Therefore the 7,391 prostate cancer patients with no inpatient records were retained within the prostate cancer data sets as these could feasibly include a significant proportion of patients who have only outpatient treatment.[11]

- Similarly to the breast cancer framework, the majority of prostate cancer patients experienced continued survival with around 55% of patients surviving for seven or more years. Hence a large amount of detail is shown for 7+ years of survivorship.

- As with lung cancer, the prostate cancer framework segments patients by whether they had metastases at any point or not, with a further split of metastases presented or developed for the medium term survival. Further segmentation of patients by level of inpatient care helps to describe the experience and resource usage of these patients.

- As a statistically meaningful number of patients had more than one other inpatient morbidity, further segmentation for single and multiple inpatient morbidities was taken.

- The survivorship outcome pathways with the highest prevalence were:
  - 7+ year survival with no metastases and no other inpatient morbidities (25.3%);
  - 7+ year survival with no metastases and cancer complications (9.5%); and
  - One to seven year survival with metastases developed and cancer complications (6.9%).

Figure 17: detailed survivorship outcome framework for prostate cancer

Note: Group 5 is not applicable to the prostate cancer framework

Key
Mets: Metastases
Cancer Complications: Recurrence or additional primary cancer
High inpatient care: Patient spent more than 25% of survival length in hospital
Low inpatient care: Patient spent less than 25% of survival length in hospital
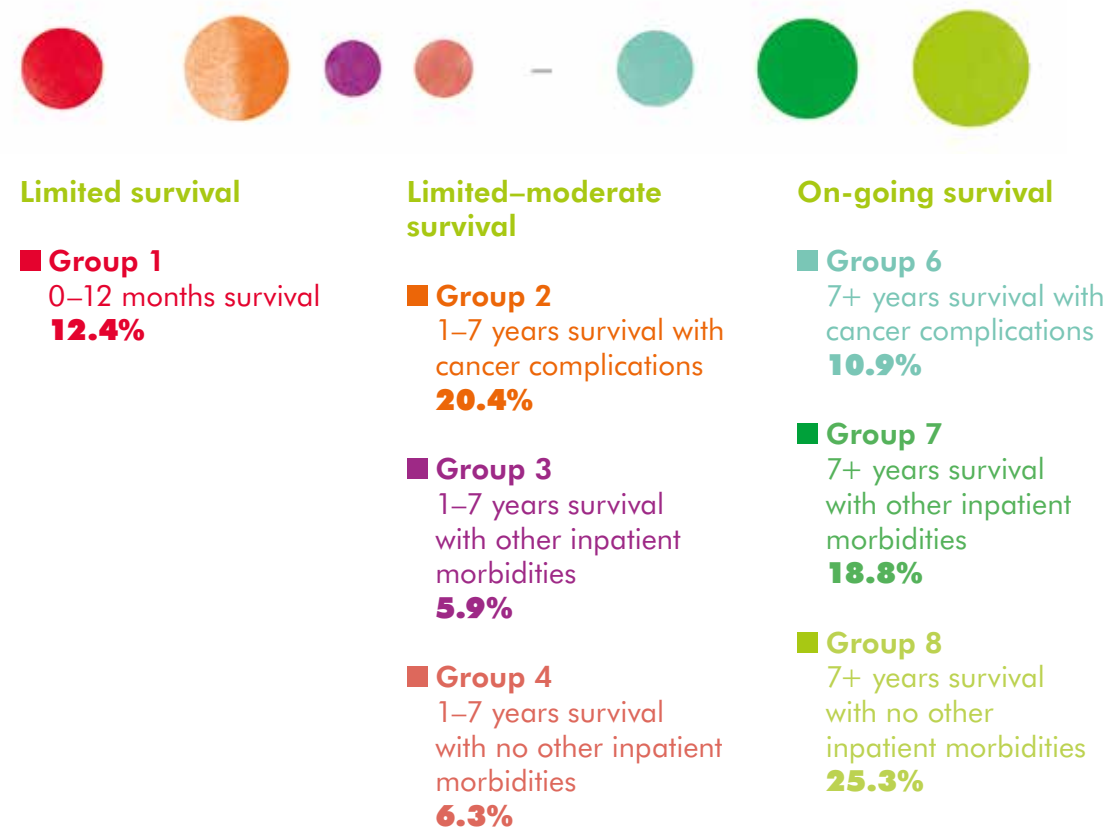**MSK:** Musculoskeletal

Simplified survivorship outcomes framework
Simplified frameworks (see figure 18) were developed to help easily communicate the distribution of patients into each group, and to offer a consistent way of talking about and comparing each cancer.

Figure 18: graphical view of simplified survivorship outcomes framework for prostate cancer

Limited survival

■ **Group 1**
  0–12 months survival
  12.4%

Limited–moderate survival

■ **Group 2**
  1–7 years survival with cancer complications
  20.4%

■ **Group 3**
  1–7 years survival with other inpatient morbidities
  5.9%

■ **Group 4**
  1–7 years survival with no other inpatient morbidities
  6.3%

On-going survival

■ **Group 6**
  7+ years survival with cancer complications
  10.9%

■ **Group 7**
  7+ years survival with other inpatient morbidities
  18.8%

■ **Group 8**
  7+ years survival with no other inpatient morbidities
  25.3%

Note: 'Cancer complications' includes metastases, additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; colour coding indicates severity of disease, from most severe (red) to least severe (green). Group 5 is not applicable to the prostate cancer simplified survivorship outcomes framework.

There are two sides to the prostate cancer survivorship story. While over half (55%) of patients survive for more than seven years, a considerable percentage of prostate cancer patients (20.4%) survived between one and seven years with cancer complications.

Post-diagnosis inpatient costs
Healthcare commissioners need to unpick variations in costs, linked to outcomes, if they are to deliver high value care. As well as describing outcomes, RfD allows us to see how inpatient costs vary by survivorship outcome group, helping to build a complete picture of the costs of cancer and its treatment. Uniquely, this includes the cost of inpatient treatment in the survivorship phase up to seven years after diagnosis, including for relevant non-cancer conditions.

Figure 19 displays the average post-diagnosis inpatient cost for prostate cancer patients in each outcome group, and the volume of patients within each group.
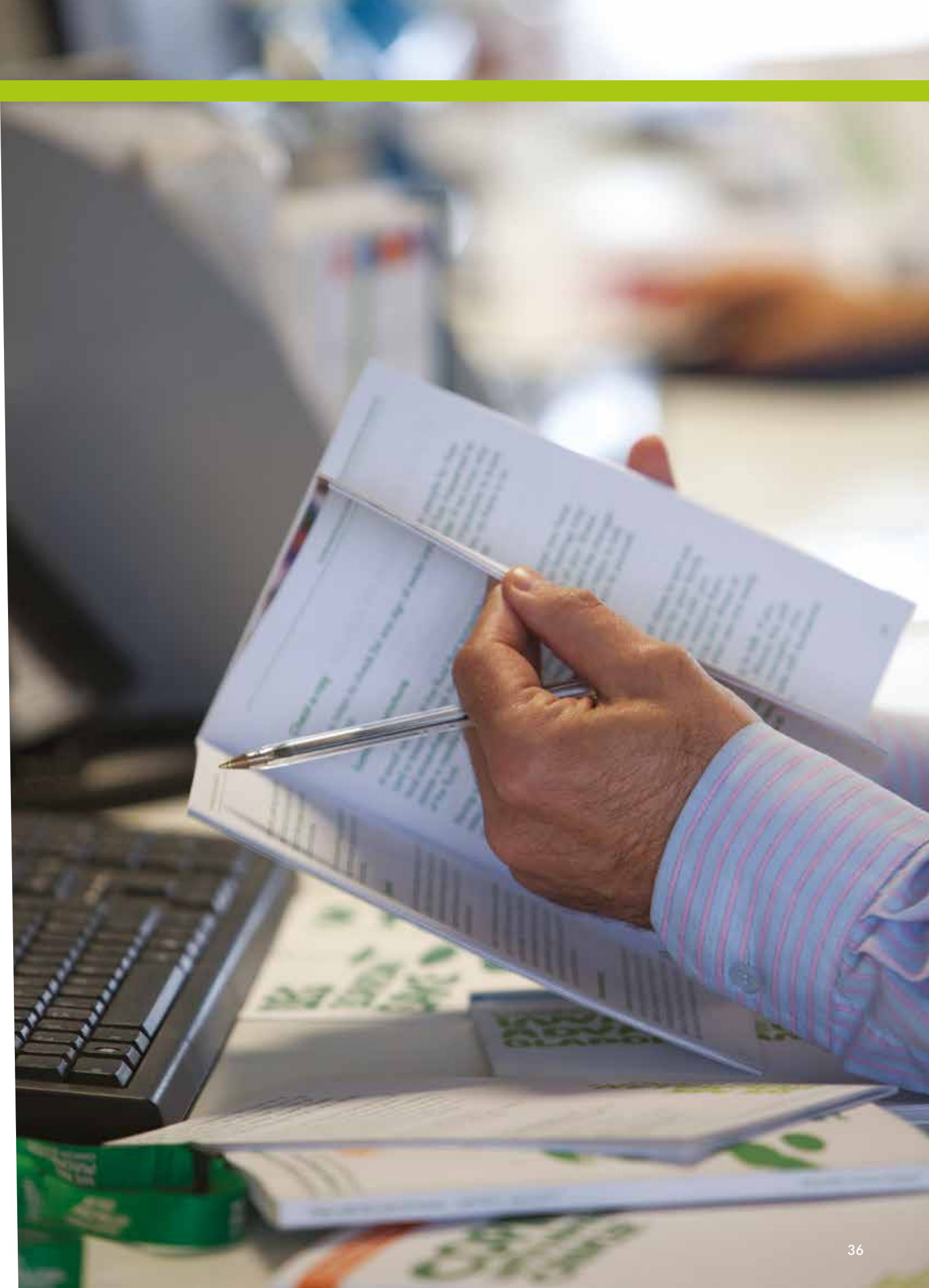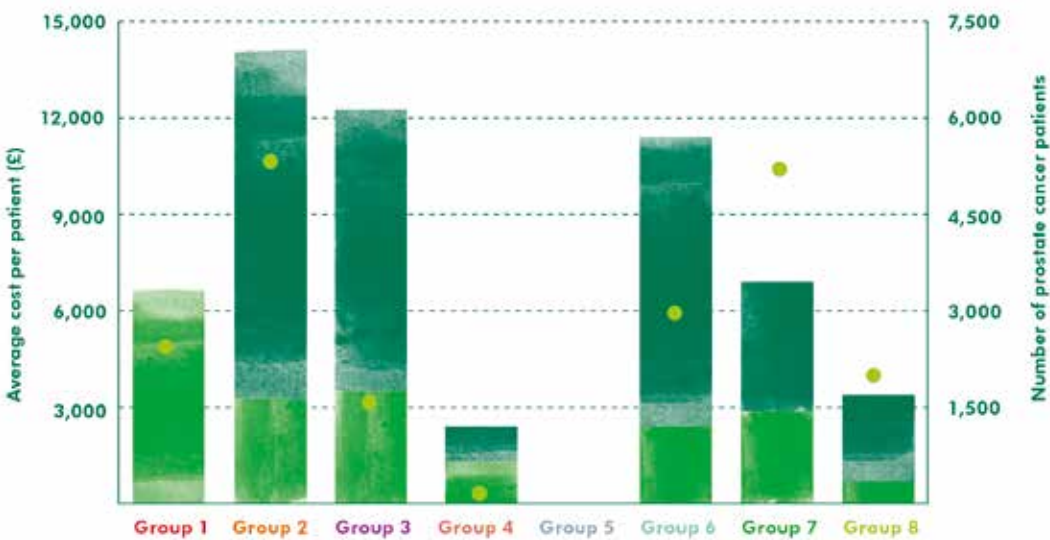
Figure 19: average post-diagnosis inpatient costs[7] for prostate cancer patients split by phase, by simplified survivorship outcome, with number of patients

- ■ Cost after first year post-diagnosis
- ■ Cost in first year post-diagnosis
- ● Number of patients

Note: average post-diagnosis inpatient costs exclude patients with no inpatient records. Group 5 is not applicable to the prostate cancer simplified survivorship outcomes framework.

The average cost of post-diagnosis inpatient care for those prostate cancer patients who had an inpatient record was £9.9K per patient. This was slightly lower than the average for breast cancer (£10.2K).

The relationship between cost and outcomes is not linear – the highest inpatient costs are associated with moderate survival rather than with the longest periods of survival. Groups who experienced cancer complications or other inpatient morbidities also accrued some of the highest inpatient costs. These patients saw an above-average number of specialists during their cancer journey, which may partly explain the higher costs.

As was the case for breast cancer patients, for some outcome groups higher costs were accrued during the survivorship phase than during the first year after diagnosis. This suggests the costs of ongoing care and support can be higher than the cost of the cancer treatment itself.

Other morbidities
Just under two thirds of prostate cancer patients (60%) experienced other inpatient morbidities.[9]

RfD makes it possible to identify the extent of morbidities and the rate at which morbidities occur across cancer survivorship outcome groups and between cancer types.

Table 20 shows the proportion of the prostate cancer population alive at one and five year intervals after diagnosis who experienced other inpatient morbidities, compared with an inpatient, non-cancer comparison group. As with breast cancer patients, circulatory morbidities are prevalent among prostate cancer patients, increasing from 22.5% to 45.1% from one year post-diagnosis to five years post-diagnosis. Other inpatient morbidities that are significantly more prevalent in the cancer population than in the comparison population at five years are musculoskeletal (which could be as a result of hormone treatment weakening the bones) and genitourinary morbidities.

Prostate cancer patients have a significantly higher risk of acquiring digestive inpatient morbidities when compared to the comparison group at one year. This may be due to the consequences of radiotherapy treatment.

Although the percentage of the living prostate cancer population who experience other morbidities increases over the years post-diagnosis, the incidence of new morbidities is highest in the first six months post-diagnosis, when patients are under surveillance and further tests identify pre-existing conditions and new morbidities. After this point the incidence of new morbidities returns to a steady rate (see figure 21 for the incidence of new genitourinary morbidities at 6 monthly time periods post cancer diagnosis).

Table 20: % of prostate cancer population and comparison population living with each morbidity at one and five years post-cancer diagnosis / post-earliest 2004 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	Genitourinary	Bone	New Primary
Patients living with morbidity at one year	Cancer population	5%	3.4%	6.7%	6.5%	22.5%	13.8%	1.4%	2.4%
	Comparison population	4.8%	3.3%	6.8%	5.8%	18.5%	6.2%	1.0%	2.5%
	Cancer morbidity burden (ratio)	1.0	1.0	1.0	1.1	1.2	2.2	1.4	1.0
Patients living with morbidity at 5 years	Cancer population	10.0%	16.7%	15.6%	17.9%	45.1%	26.9%	4.0%	9.1%
	Comparison population	12.1%	10.6%	15.5%	16.3%	41.5%	17.1%	3.7%	7.2%
	Cancer morbidity burden (ratio)	0.8	1.6	1.0	1.1	1.1	1.6	1.1	1.3

- ■ Significantly lower proportion in cancer patients with p ≤0.001
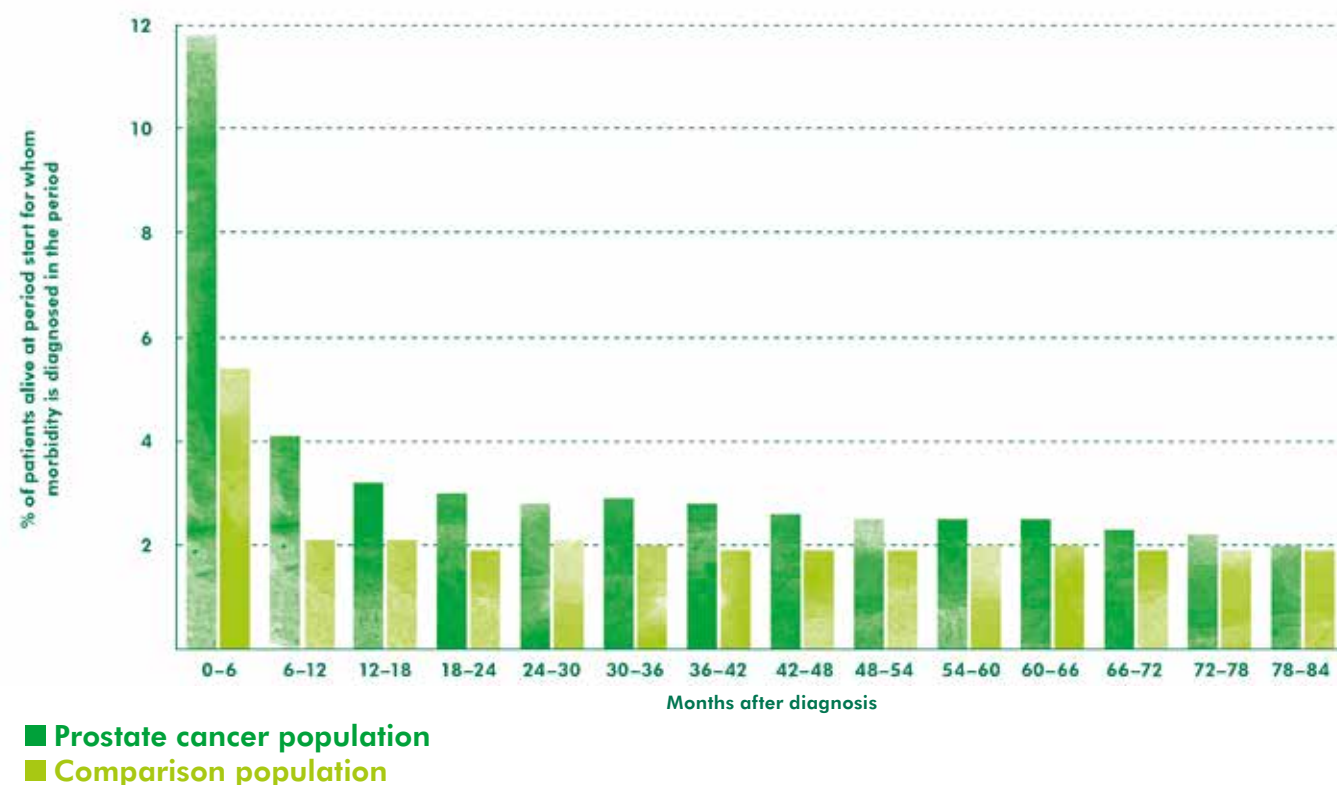- ■ Significantly higher proportion in cancer patients with p ≤0.001

'We've known for a long time that large numbers of prostate cancer patients have prolonged survival, but the size of the groups at this level of detail isn't well described elsewhere.

It is not clear why prostate cancer patients have an increased risk of developing a new primary tumour elsewhere. This may be an important avenue for further study.'
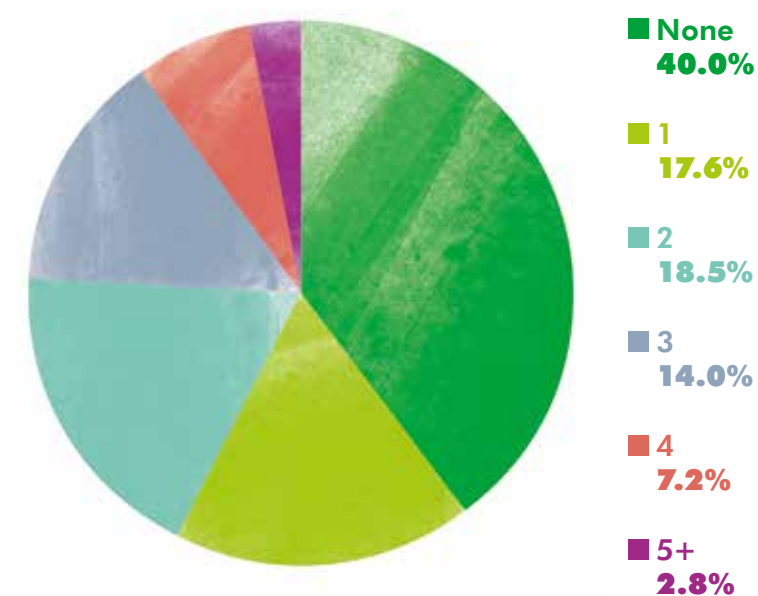
**Mr Roger Kockelbergh,
Consultant Urological Surgeon**

A higher proportion of prostate cancer patients (40%) experienced no other inpatient morbidities than all other RfD cancer cohorts. Conversely, the percentage of patients who had four or more morbidities was also higher than any other RfD cancer cohort. This supports the notion that prostate cancer can be complex for many patients, and effective management of cancer survivorship may require more holistic management of multiple other conditions.

Figure 22: percentage of prostate cancer population by number of inpatient morbidities

- **None 40.0%**
- **1 17.6%**
- **2 18.5%**
- **3 14.0%**
- **4 7.2%**
- **5+ 2.8%**

Figure 21: genitourinary morbidity acquisition for prostate cancer

% of patients alive at period start for whom morbidity is diagnosed in the period

Months after diagnosis

- **Prostate cancer population**
- **Comparison population**

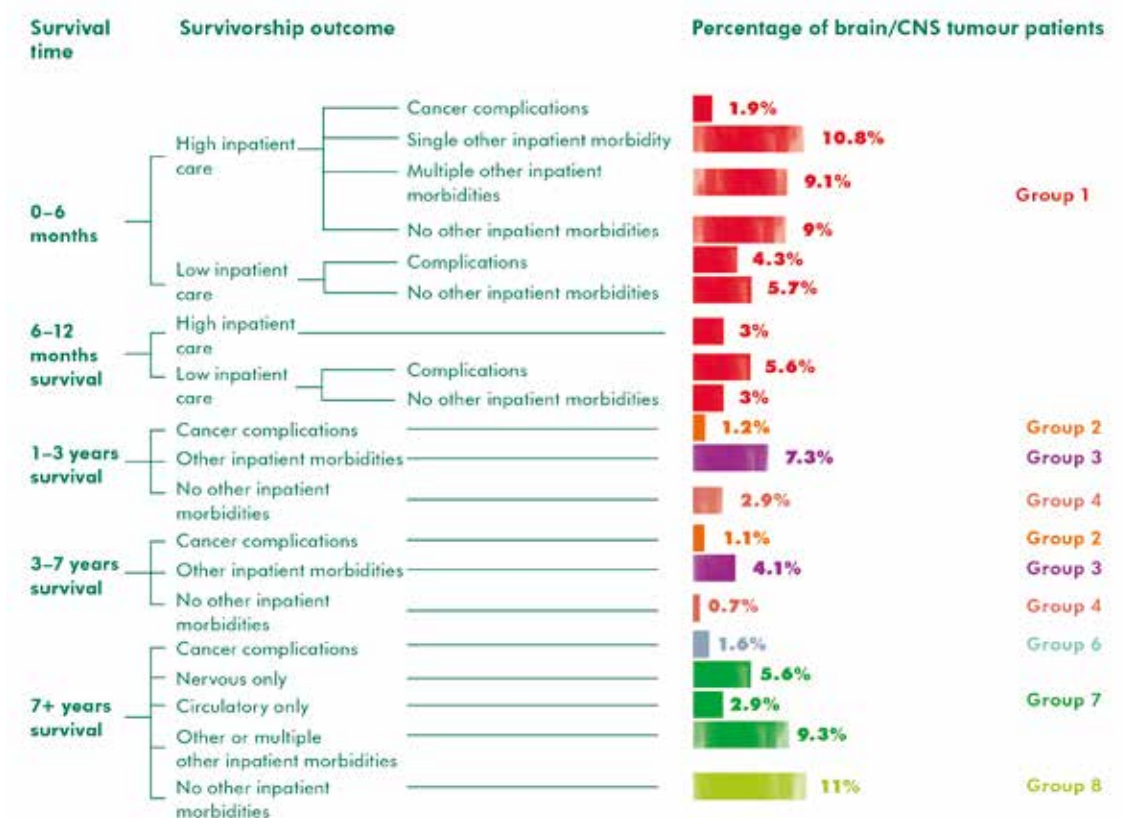# 4 FINDINGS FOR BRAIN AND CENTRAL NERVOUS SYSTEM TUMOURS

Survivorship

The full population of 11,362 patients diagnosed with a brain/CNS tumour in England in 2003 and 2004 were considered for inclusion in the RfD data sets. Patients with invalid records (439), no inpatient records (1,624), or evidence of prior tumours (537), were removed from the cohort. This resulted in 8,762 patients being included in the detailed outcome survivorship framework for brain/CNS tumours (see figure 23).

For the three most common tumour types, 2,694 patients (30.7%) had a glioblastoma, 1,812 (20.7%) had a meningioma and 957 (10.9%) had a nerve sheath tumour.

Figure 23: detailed survivorship outcome framework for brain/CNS tumours

Note: Group 5 is not applicable to the brain/CNS tumour framework

Key

Cancer Complications: Recurrence or additional primary cancer
High inpatient care: Patient spent more than 25% of survival length in hospital
Low inpatient care: Patient spent less than 25% of survival length in hospital

- The brain/CNS tumour group is a disparate collection of tumour types with markedly different outcomes and treatment profiles. Patient outcomes are displayed for the three most common tumour types that make up 62.3% of the cohort, chosen as data was available for a sufficiently large cohort to allow a valid comparison. For the remaining brain/CNS tumours that do not fall into these tumour types, the number of cases is insufficient and the data is not complete enough for meaningful analysis at this time.

- The survival breakdowns applied for brain/CNS tumours were chosen to match up with the widely used WHO classification of tumours of the CNS [12] and its malignancy grading scheme, with an additional breakdown at 0–6 months in order to take account of the large number of patients who did not survive beyond 1 year.

- Segmenting patients specifically by the development of metastases was not believed to add value to the brain/CNS framework due to the rare occurrences of metastases. In clinical practice brain/CNS tumours metastasise rarely and, when they do, do so rarely outside the brain/CNS.

- However, further segmentation of patients by level of inpatient care was determined to be important due to the aggressive nature of the tumours where a significant proportion of patients have shorter survival; helping to describe the experience and resource usage of these patients.

- Furthermore, differences were highlighted between patients with different numbers of additional morbidities. Patients with single and multiple inpatient morbidities were therefore segmented.

Simplified survivorship outcomes framework

Simplified frameworks (see figure 24) were developed to help easily communicate the distribution of patients into each group, and to offer a consistent way of talking about and comparing each cancer.

The survival outcomes for these patients vary greatly. Over half (55%) of the cancer patients with glioblastoma tumours did not survive past six months post-diagnosis, showing similar short-term survival outcomes to lung cancer patients.

All glioblastomas are highly malignant tumours, biologically aggressive, and are relatively resistant to both radiotherapy and chemotherapy. Because they infiltrate the normal brain so widely, they are almost impossible to completely remove surgically. They are consequently given the highest malignancy grade in the WHO classification of CNS tumours, WHO grade IV. The vast majority of meningiomas are WHO malignancy grade I, which means they do not invade the brain and can often be completely surgically removed.

Patients with meningioma and nerve sheath tumours therefore have notably better outcomes, with the majority of patients surviving past seven years (63.8% and 87.2% respectively). A higher percentage of meningioma patients did not survive past 12 months than patients with nerve sheath tumours, which may, in part, reflect the older age profile of the meningioma patient group. Nerve sheath tumours are also mostly benign and appropriate treatment can lead to long term containment or cure.

Figure 24: graphical view of simplified survivorship outcome framework for the three most common brain/CNS tumour types

Limited survival

- **Group 1**
  0–12 months survival

Limited–moderate survival

- **Group 2**
  1–7 years survival with cancer complications

- **Group 3**
  1–7 years survival with other inpatient morbidities

- **Group 4**
  1–7 years survival with no other inpatient morbidities

On-going survival

- **Group 6**
  7+ years survival with cancer complications

- **Group 7**
  7+ years survival with other inpatient morbidities

- **Group 8**
  7+ years survival with no other inpatient morbidities

Note: 'Cancer complications' includes metastases, additional primary cancers and recurrence. 'Other inpatient morbidities' includes relevant complications as defined by the clinical advisory group; Colour coding indicates severity of disease, from most severe (red) to least severe (green). Group 5 is not applicable to the brain/CNS tumours simplified survivorship outcomes framework.

Viewing the survivorship outcomes of brain/CNS tumour patients in this way highlights the large percentage of patients with meningioma and nerve sheath tumours falling into Group 7, where there are major long-term health service demands.
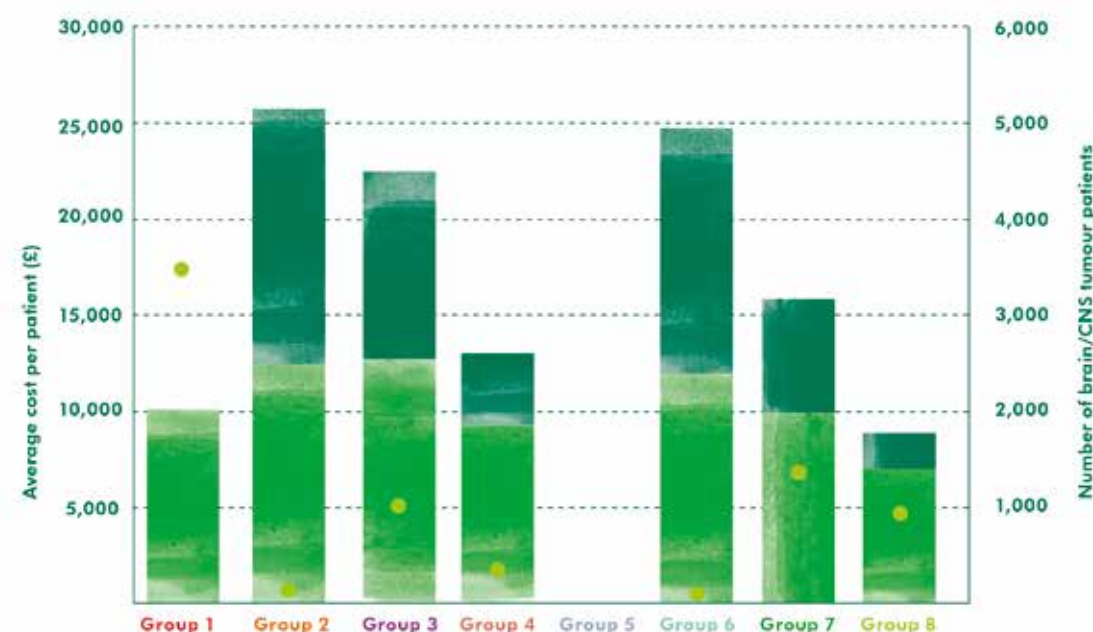
The degree of variation in outcomes supports the need for stratification processes that help to identify which care pathway is most suitable for each patient based on the level of care needed for the disease, the treatment and the patient's ability to self-manage, and therefore what level of professional involvement is required. In this manner RfD can help healthcare providers identify and plan for the likely ongoing needs of each patient group.

Post-diagnosis inpatient costs
Healthcare commissioners need to unpick variations in costs, linked to outcomes, if they are to deliver high value care. As well as describing outcomes, RfD allows us to see how inpatient costs vary by survivorship outcome group, helping to build a complete picture of the costs of cancer and treatment. Uniquely, this includes the cost of inpatient treatment in the survivorship phase up to seven years after diagnosis, including for relevant non-cancer conditions.

The graph below (figure 25) displays the average post-diagnosis inpatient cost for all brain/CNS tumour patients in each outcome group, and the volume of patients within each group. Costing trends were similar across the most common brain/CNS tumour types.

Figure 25: average post-diagnosis inpatient costs[7] of brain/CNS tumour patients split by phase, by simplified survivorship outcome, with number of patients

■ Cost after first year post-diagnosis
■ Cost in first year post-diagnosis
● Number of patients

Group 5 is not applicable to the brain/CNS tumour simplified survivorship outcomes framework.

The average inpatient cost post-diagnosis for brain/CNS tumour patients was £13,200, higher than for the other RfD cancer cohorts.

As with other cancer cohorts, some of the highest inpatient costs are associated with moderate survival, rather than the longest periods of survival.

For patients experiencing moderate and continued survival, the costs associated with cancer complications are higher than those associated with inpatient morbidities, which are higher than those associated with no other inpatient morbidities.

Overall, patients surviving one to seven years with cancer complications have the highest inpatient treatment costs post-diagnosis on average at £26,147, followed by patients surviving more than seven years with cancer complications at £24,800.

Brain/CNS tumour inpatient costs continued to accumulate after the initial high treatment phase costs, with the exception of the patients who experienced no other inpatient morbidities. As with the

findings from the lung cancer framework, this implies that there remains a high burden of acute illness in moderate to long-term survival due to cancer complications or other morbidities.

Other morbidities
Approximately two thirds of all brain/CNS tumour patients (66%) experienced other inpatient morbidities.[9]

RfD makes it possible to identify the extent of morbidities and the rate at which morbidities occur across cancer survivorship outcome groups and between cancer types.

Due to the very different survivorship outcomes associated with the heterogeneous mixture of tumour types within the brain/CNS tumour group, the following tables (tables 26, 27 and 28) show the proportion of the population for the three most common tumour types alive at one and five year intervals after diagnosis who experienced other inpatient morbidities, compared with an inpatient, non-cancer comparison group.

'Stark survival figures, high morbidities, and high healthcare costs for patients with glioblastoma demonstrate clearly the terrible nature of this disease for patients and their carers. The data presented argue forcibly for clear coordinated care pathways for patients, and for a massive increase in research funding to improve quality of survival.'

Mr Andrew Brodbelt, Consultant Neurosurgeon

Table 26: % of glioblastoma tumour population and comparison population living with each morbidity at one and five years post-cancer diagnosis/post-earliest 2003/4 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	Genitourinary	Nervous	New Primary
Patients living with morbidity at one year	Tumour population	5.4%	Numbers withheld	5.6%	1.9%	20.5%	Numbers withheld	23.8%	1.4%
	Comparison population	3.5%	2.7%	3.6%	0.5%	11.5%	1.1%	1.2%	2.1%
	Cancer morbidity burden (ratio)	1.6	Numbers withheld	1.6	3.7	1.8	Numbers withheld	19.8	0.7
Patients living with morbidity at five years	Tumour population	Numbers withheld						26.9%	19.2%
	Comparison population	8.9%	7.7%	8.9%	1.8%	26.5%	3.0%	3.4%	5.9%
	Cancer morbidity burden (ratio)	Numbers withheld						8.0	3.2

■ Significantly lower proportion in cancer patients with p ≤0.001
■ Significantly higher proportion in cancer patients with p ≤0.001

Note: the number of patients surviving to five years is very low so conclusions are limited. Some figures are withheld due to small numbers.

Many brain/CNS tumour patients suffer from morbidities relating to the nervous system, with glioblastoma tumour patients being no exception. Perhaps more interestingly, glioblastoma patients still alive at five years experienced significantly higher rates of new primary cancer compared to the comparison population and other brain/CNS tumour morphologies, making glioblastoma tumour patients 3.2 times more likely to acquire a new primary cancer than the comparison population (noting that only 52 patients survived to five years). It may be the case that the radiotherapy dose is important as an inducer of sarcomas or meningiomas.

Table 27: % of meningioma tumour population and comparison population living with each morbidity at one and five years post-cancer diagnosis / post-earliest 2003/4 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	Genitourinary	Nervous	New Primary
Patients living with morbidity at one year	Tumour population	8.3%	1.6%	5.4%	1.5%	22.7%	Numbers withheld	16.9%	1.1%
	Comparison population	3.5%	2.7%	3.6%	0.5%	11.5%	1.1%	1.2%	2.1%
	Cancer morbidity burden (ratio)	2.4	0.6	1.5	2.9	2.0	Numbers withheld	14.1	0.5
Patients living with morbidity at five years	Tumour population	10.7%	5.1%	9.2%	2.5%	29.8%	2.2%	25.4%	3.8%
	Comparison population	8.9%	7.7%	8.9%	1.8%	26.5%	3.0%	3.4%	5.9%
	Cancer morbidity burden (ratio)	1.2	0.7	1.0	1.4	1.1	0.7	7.5	0.6

■ Significantly lower proportion in cancer patients with p ≤0.001
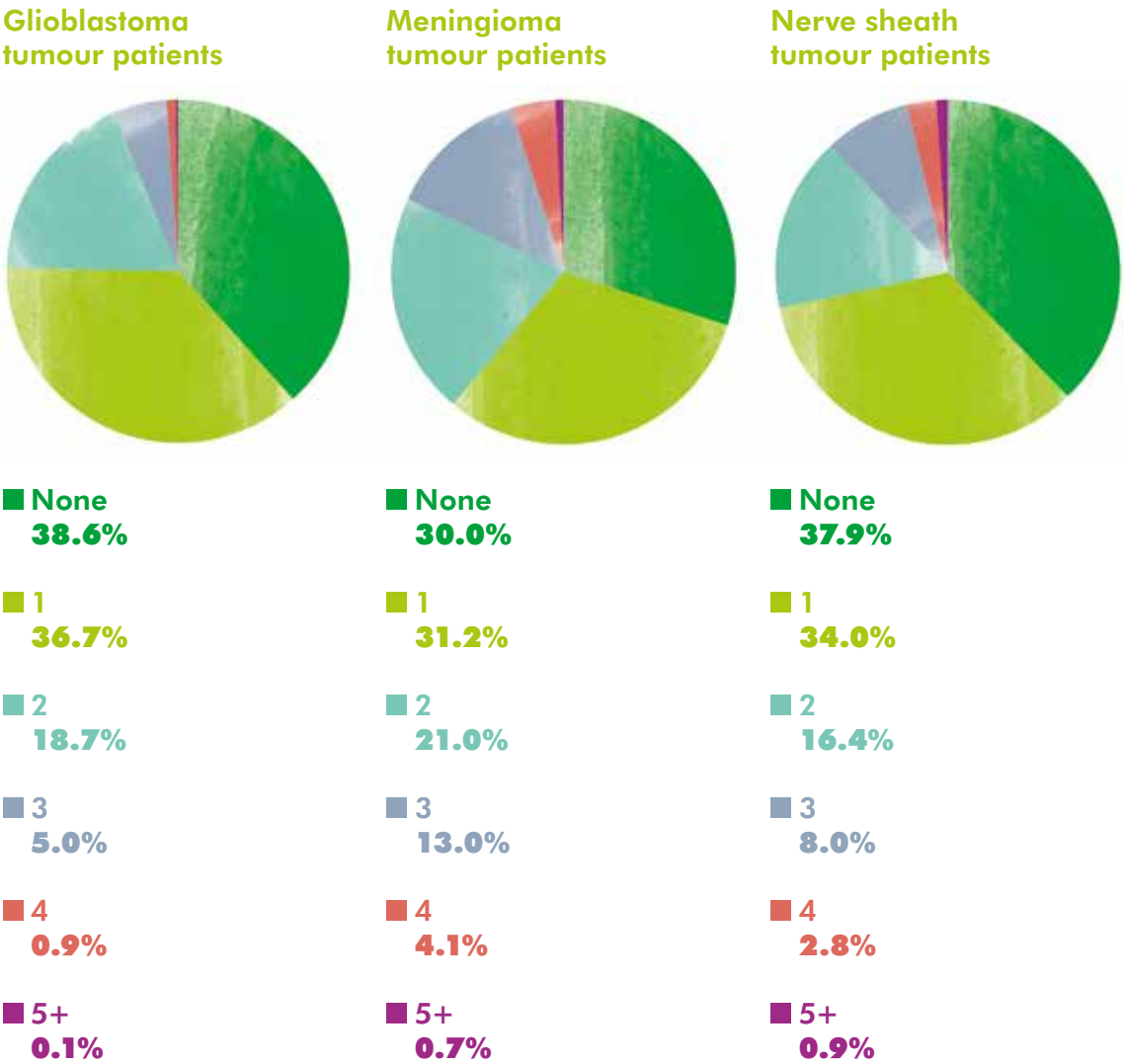■ Significantly higher proportion in cancer patients with p ≤0.001

Note: Some figures are withheld due to small numbers.

Patients with meningioma tumours suffered from a wider range of inpatient morbidities at significantly higher levels than the comparison population.

Meningioma patients still alive one year post-diagnosis suffered significantly more from circulatory, endocrine, respiratory and musculoskeletal morbidities than the comparison population.

Over time, morbidity incidence drops to a level comparable with the comparison group. This may be due to fewer brain/CNS tumour patients with endocrine, musculoskeletal and circulatory morbidities surviving to 5 years.

Table 28: % of nerve sheath tumour population and comparison population living with each morbidity at one and five years post-cancer diagnosis / post-earliest 2003/4 event

		Endocrine	Digestive	Respiratory	Musculoskeletal	Circulatory	Genitourinary	Nervous	New Primary
Patients living with morbidity at one year	Tumour population	2.9%	2.0%	3.7%	0.8%	13.4%	0.7%	20.5%	2.3%
	Comparison population	3.5%	2.7%	3.6%	0.5%	11.5%	1.1%	1.2%	2.1%
	Cancer morbidity burden (ratio)	0.8	0.7	1.0	1.5	1.2	0.6	17.1	1.1
Patients living with morbidity at 5 years	Tumour population	4.7%	5.6%	7.9%	1.6%	20.2%	2.2%	26.5%	4.7%
	Comparison population	8.9%	7.7%	8.9%	1.8%	26.5%	3.0%	3.4%	5.9%
	Cancer morbidity burden (ratio)	0.5	0.7	0.9	0.9	0.8	0.7	7.8	0.8

■ Significantly lower proportion in cancer patients with p ≤0.001
■ Significantly higher proportion in cancer patients with p ≤0.001

Nerve sheath tumour patients suffered from fewer of the majority of the studied morbidities, particularly endocrine and circulatory morbidities. Patients still suffered significantly higher levels of nervous system morbidities when compared to the comparison population, but generally no more than the brain/CNS population as a whole.

Figure 29 shows the percentage of patients with each of the top three tumour types who experienced none, one or multiple morbidities during their cancer survivorship journey.

'The average cost post-diagnosis for each pathway was an interesting insight explained in a way that has not been reported before. These data provide a valuable insight into the longer-term ongoing healthcare needs of patients with less aggressive cranial tumour types such as meningiomas and nerve sheath tumours.'

Dr David Greenberg, Senior Analyst, National Cancer Registration Service

Figure 29: percentage of brain/CNS tumour population (for the top three tumour types) by number of inpatient morbidities taken over 7 years

Glioblastoma tumour patients

Meningioma tumour patients

Nerve sheath tumour patients

Glioblastoma	Meningioma	Nerve sheath
■ None 38.6%	■ None 30.0%	■ None 37.9%
■ 1 36.7%	■ 1 31.2%	■ 1 34.0%
■ 2 18.7%	■ 2 21.0%	■ 2 16.4%
■ 3 5.0%	■ 3 13.0%	■ 3 8.0%
■ 4 0.9%	■ 4 4.1%	■ 4 2.8%
■ 5+ 0.1%	■ 5+ 0.7%	■ 5+ 0.9%

A higher proportion of meningioma tumour patients experienced two or more inpatient morbidities post-diagnosis when compared to the other brain/CNS tumour types; with almost two in every five patients (39%) experiencing multiple morbidities. When compared to the other three cancer cohorts, the glioblastoma and nerve sheath tumour groups had the smallest percentage of patients with multiple morbidities (at 25% and 28% respectively).

It must be noted that treatment has changed since this cohort of glioblastoma patients was treated. Noteably temozolamide chemotherapy, Multi-Disciplinary Teams, NICE's Improving Outcomes guidance and surgery and specialist oncology nursing have all improved care since 2004.

CASE STUDY: USING ROUTES FROM DIAGNOSIS FOR SERVICE REDESIGN

Routes from Diagnosis has been designed from the outset not only as a research programme but as the basis for evidence-led health service improvement. The use of Routes from Diagnosis informed service redesign as part of a Macmillan cancer survivorship programme, as a way to commission against outcomes rather than activity.

The problem
South Yorkshire, Bassetlaw and North Derbyshire Clinical Commissioning Groups (CCGs) have some of the highest levels of cancer incidence and mortality in the country. With national cancer prevalence predicted to double over the next 20 years, Macmillan and the CCGs recognised a need to design and test new stratified care pathways to make the most of limited resources and deliver better outcomes for colorectal cancer patients, and launched a survivorship programme.

Stratified care pathways involve clinicians and patients deciding together what level of care and support best matches the patient's needs. In addition to delivering a more tailored package of care, some evidence suggests stratified care pathways for people living with and beyond cancer can result in cost improvements – with net savings in England estimated to be £86m, if eligible patients with breast, colorectal or prostate cancer were moved to a supported self-management pathway.

The project described in this case study aimed to implement a comprehensive aftercare service for colorectal cancer patients using stratified care pathways, in order to provide more individualised, holistic care and transform local health and social care systems. These new pathways are designed to enable patients to move to self-managed care where appropriate, whilst providing quick access back into hospital services when needed. By matching patient needs to the correct level of support, the programme aims to contribute to a reduction in emergency attendances and admissions.

The solution – baselining and describing the local population
As part of the pathway redesign, the programme chose to use the RfD approach to map out the local colorectal population's outcomes and interactions with the health service, through linking cancer registry data on patients diagnosed in 2006, 2007 and 2008 with inpatient HES data from the same population from early 2003 to late 2010.[13] [14]

Fifteen discrete 'survivorship outcome pathways' were identified based on survival length and the presence/types of complications or health issues colorectal cancer patients faced. These were condensed down to eight groups, to consider the similarities between the outcome pathways in terms of patients' needs for support from the healthcare system. (figure 30) and balance the need to develop a feasible number of pathways for implementation.

Figure 30: simplified survivorship outcome pathways

Survival time	Survivorship outcome	
0–6 months	No patient management issues	**Group 1** 0–1 year survival (defocused for service development)
	Patient management issues	
6–12 months survival	No patient management issues	**Group 2** 1–5 years survival No other inpatient morbidities
	Patient management issues	
1–3 years survival	No other inpatient morbidities	**Group 3** 1–3 years survival Cancer complications
	Cancer complications	**Group 4** 1–5 years survival Non cancer survival
	Other inpatient morbidities	
3–5 years survival	No other inpatient morbidities	**Group 5** 3–5 years survival Cancer complications
	Cancer complications	
	Other inpatient morbidities	**Group 6** Continued survival Cancer complications
5+ years survival	Cancer complications	
	Other inpatient morbidities	**Group 7** Continued survival Other inpatient morbidities
	Other inpatient morbidities	
	Other inpatient morbidities	**Group 8** Continued survival No other inpatient morbidities
	No other inpatient morbidities	

Figure 31: final survivorship outcome pathways for testing and evaluation

Cohort	RfD group	Identified needs	Models to test
A	8=continued survival, no complications (22%) 2=1–5 years survival, no complications (9%)	• Symptom educations and supportive information	• Self management system and rapid access back • Moving on interview process at end of treatment (EOT) and discharge/FU • Shared care plan
B	7=continued survival, non cancer complications (17%) 4=1–5 years survival, non cancer complications (3%)	• Symptom education and supportive information • MDT special consideration at diagnosis review	• Self management and rapid access back • Moving on interview process at end of treatment (EOT) and discharge/FU • Shared care plane • Identification to primary care nurse for management of other co-morbidity • Care navigation • 121 complex care support • Complex case management
C	1=0–1 year survival (32%) 6=continued survival, cancer complications (5%) 5=3–5 years survival, cancer complications (5%) 3=1–3 years survival, cancer complications (9%)	• Resource usage e.g. advanced palliative care planning • Symptom education and supportive information • MDT special consideration at diagnosis review	• Interventions to trigger and shift services to managed care or prevention. • Advanced 121 support via case manager • Early adoption of end of life (EOL) care packages and enhanced palliative care planning

The outputs – designing new care pathways

By mapping out local patients' survivorship outcomes, Routes from Diagnosis provided clinicians and commissioners with rich insights into the different types of journeys cancer patients experience after diagnosis, their interaction with the health service and the distribution of patients across different outcomes. By examining the NHS 'footprints' of patients within each outcome group, the CCGs and clinicians were able to identify 'trigger' points in each journey where there was likely to be either additional or reduced need for follow up, and where other interventions could be added or reduced in order to tailor care to patients' needs. Interventions were identified for each of the outcome groups at various points along their pathways including:

• Shared care plan

• MDT special consideration at diagnosis and review

• Symptom education & supportive information

• One-to-one care and support from primary care nurses

'What Routes from Diagnosis adds is an understanding of non-cancer health issues that Clinical Nurse Specialists may not have had before. The knowledge of the different outcome groups can help CNSs empower patients to self-manage, providing they can always get quick access back into the system when they need it.'

Jane Rudge, Senior Macmillan Development Manager

• Tailored treatment summaries to GPs

• Rapid care re-entry pathway

• Enhanced active palliative care

The CCGs have started implementing the recommendations for three consolidated cohorts of patients (figure 31), which are currently being evaluated.

Lessons learned so far

RfD's descriptive power enables an enhanced understanding of a local cancer population's outcomes, provides useful analysis of costs and makes possible an evidence-based assessment of the relative value of interventions. The use of local data helped add credibility to the programme, facilitated clinical buy-in at a local level and importantly supported commissioning against outcomes rather than activity.

While condensing outcome groups may be necessary to facilitate practical pathway design, a balance needs to be found to avoid risking the loss of valuable detail.

The addition of outpatient and A&E data would add significant value to future projects' ability to understand patients' health care usage patterns – particularly those who are candidates for self-management – and the true costs of each outcome.

The most intensive part of implementing RfD in local service redesign is gaining an understanding of the outcome groups, becoming familiar with the characteristics of each group and developing ideas for trigger point detection and new services.

The pathways and services described here are currently being tested, and a full evaluation of the project is forthcoming.

RECOMMENDATIONS

Whilst cancer survival continues to improve in the UK, as the initial results from Routes from Diagnosis show, simply surviving does not necessarily mean living well. There is still a huge amount to do to improve survival outcomes.

Some of the key things Macmillan believes would deliver the greatest improvements for people with cancer in terms of survival are as follows:

- Earlier diagnosis

- Access to the best available treatment, regardless of age alone or where you live in the UK

- A 'Recovery Package' of care and support for everyone diagnosed with cancer

- Increased physical activity

Earlier diagnosis
GPs have a vital role to play in ensuring that cancer is diagnosed at an early stage to give people the best possible chance of survival. However, cancer is still a relatively unusual condition for an individual GP to encounter in their day-to-day practice. To help GPs decide which patients to refer for further tests, Macmillan has developed computer software that integrates with a GP's existing IT systems and alerts them when a patient's symptoms may indicate cancer. The Electronic Cancer Decision Support (eCDS) tool is being used by GPs across England and currently focuses on five cancer types, including lung cancer. The tool will be fully rolled out across England in 2014 and we urge all GPs to use it to aid early diagnosis.

Access to the best available treatment
Variation exists in access to treatments that offer the best clinical outcome, such as surgery for lung cancer. The likelihood of receiving surgery for lung cancer varies significantly between different areas of England and Wales, even after taking factors such as age, gender and overall health into account.[15] There is also evidence that some older people with cancer may not be receiving treatment because of their chronological age. A recent study found that women aged 85 or over in England are 80% less likely to receive surgery for breast cancer than women aged 70-74, after adjusting for the fact that older women are more likely to have poorer health. This is despite 26% of breast cancer occurring in women aged 85 or over.[16]

Everyone with cancer should receive the best available treatment, regardless of their age or where they live. The barriers that prevent people getting treatment – which may include age discrimination as well as inadequate assessment methods, postcode lotteries and other factors – must be tackled now.

Recovery Package
We know that too many people with cancer have unmet needs and concerns after the end of treatment. To better support people after treatment, health and social care leaders must ensure that everyone diagnosed with cancer receives a 'Recovery Package' of care and support. This should include:

- Holistic Needs Assessments and care plans at key points during treatment and recovery

- A Treatment Summary, completed at the end of treatment and sent to the patient and their GP

- A Cancer Care Review, completed six months after treatment by the patient's GP or practice nurse,

to discuss the patient's needs and the possible long-term consequences of cancer and its treatment

- A patient education and support event such as a Health and Wellbeing Clinic, to help the patient work towards supported self-management and a healthy lifestyle, including physical activity

The Recovery Package can help reduce the burden of other serious health conditions affecting people with cancer, as well as helping to prevent recurrence or diagnose it earlier.

Physical activity
Being physically active has clear benefits for people with cancer. A comprehensive evidence review carried out for Macmillan's Move More campaign showed that physical activity after treatment for cancer can reduce the risk of recurrence for some cancers.[17] Physical activity can also benefit people with cancer during treatment by helping them maintain their physical fitness and improving self-esteem and mood.

'GPs only have around ten minutes with each patient, so it's vital that they ask the right questions and can quickly calculate someone's cancer risk. Macmillan hopes that our clinical decision support tool will support GPs to identify the symptoms of cancer and help to improve cancer survival rates.'

Dr Rosie Loftus, GP and Joint Chief Medical Officer, Macmillan Cancer Support

WHAT NEXT FOR RfD AND 'BIG DATA' IN HEALTHCARE?

What Routes from Diagnosis could allow us to do

The case study described on page 51 gives an early example of how a Routes from Diagnosis approach to analysing routinely collected data can help the NHS identify and understand the long-term health needs of people at different stages of cancer survivorship, and the distribution of outcomes for a particular type of cancer at the population level.

Further work in local pilot sites will aim to improve care on a larger scale, using information from Routes from Diagnosis

'We should stop thinking of data as the 'exhaust' of providing health services, but rather as a central asset in trying to figure out how to improve every aspect of health care.'

Craig Mundie, former Head of Research, Microsoft[18]

to design new pathways of care that better meet patients' needs and make better use of resources. In particular, RfD will continue to be used to:

- Identify patient cohorts whose needs are not currently being met in the most appropriate or cost-effective way, and understand some quality-of-life issues;

- Spot trigger points, i.e. events that lead to distinct outcomes. In other words, by tracking the points in patients' survivorship at which they are admitted as inpatients, we can potentially gain an understanding of the timing and nature of events leading to (e.g.) a shorter length of survivorship;

- Understand what information patients may need after diagnosis and appropriately explain the risks they may face in the future;

- Understand how inpatient costs accumulate and are segmented over the course of particular survival pathways for each cancer, and begin to model the potential economic impact of implementing interventions.

Building on the research

This report is the first publication of findings from Routes from Diagnosis. At the time of writing, an academic paper on the methodology is being prepared for publication.

Future work will refresh the data, and add data on outpatient and emergency care, providing insights into out-of-hospital care and uncovering a fuller burden of health issues facing people affected by cancer. If possible, the addition of primary care data would add a more detailed understanding of illnesses treated in the community, and how patients interact with their GP over the course of their survivorship.

Whilst this report describes the costs of inpatient care, the addition of data from other sources would paint a fuller picture of the costs of cancer, and enable a joined-up understanding of how patients move through the healthcare system.

Spreading the approach

As cancer survival improves, crude measures such as one and five-year survival will not provide sufficient insights for the NHS to tailor care to patients' needs.

Macmillan believes applying Routes from Diagnosis to local data would provide healthcare commissioners and decision makers with unprecedented insights into their local cancer populations, and will be working with key stakeholders in this area to help develop this.

The value of big data in healthcare

The collection and publication of routine cancer data is by no means new; the Office of National Statistics (ONS) has collected a minimum cancer dataset since 1971, and cancer registries have been publishing good-quality local data since 1990. What has emerged in the last decade or so is an impetus to link disparate data sets together. This is a crucial step in turning routine data into the intelligence and insight that commissioners need.

Through work like Routes from Diagnosis, Macmillan Cancer Support is part of a wider movement of organisations using what has come to be known as 'big data' to improve healthcare.

The UK has one of the longest running universal healthcare services in the world, and a payment model that rewards service providers for collecting data about patients. Although every data system has its flaws, none of the analysis described in this report requires new systems or technology. In the cancer field, we have particularly good sources of data thanks to Cancer Registries.

You might therefore expect the UK to be at the vanguard when it comes to turning the vast quantities of data that are routinely collected into useful knowledge. Unfortunately as a health community we are only just learning how to do this effectively, and change often takes time in the NHS.

Macmillan Cancer Support feels strongly about improving outcomes for today's cancer patients as well as for those diagnosed in the future, which is why we and our partners have recognised the need to lead the way in terms of the analysis of cancer data.

A change of attitude towards NHS data

Until recently, health data that is generated has been treated as something of an 'exhaust' – a byproduct of the system, but not put to use. Having lots of data about a population but not using it to plan services is akin to a doctor having medical notes for an individual patient but not reading them before prescribing.

A working assumption in the NHS is that poor care is often inefficient, and therefore that efficiencies which save money will also improve care. Only by having all of the evidence and putting it together will we understand how to do this properly.

The ambition for Routes from Diagnosis is therefore for it not only to be a research programme, but for it to change the way the NHS thinks about cancer. Similarly, data-driven healthcare research must be seen not as an end in itself, but as one of the most fruitful means of understanding how to improve healthcare and design services to meet patients' real and varied needs.

Information governance

Getting access to the right data at the right time is often the first stumbling block for organisations trying to work with large sets of pseudonymous health data. Bodies such as the Health and Social Care Information Centre rightly need to protect patient privacy, and Routes from Diagnosis shows that this is possible while still realising the benefits of analysing patient level data. Routes from Diagnosis can work at a local level without patient-identifiable data, but someone does need to pseudonymise and link the raw data to prepare it for analysis. And at the highly granular level, where even without personal data there is a small risk of identifying individuals, the results need to be carefully managed. The clearest path forward seems

to be to work with CSUs and CCGs with Accredited Safe Haven status, but some commissioners are concerned they are already straining at the limits of even those regulations.

It is a complex issue for the NHS; but we must get a grip on it if we are to unleash the full potential of big data. CCGs and CSUs need to have access to the right information and be able to link it, and they need to know what the law does and does not allow them to do with it. Clearer guidance and more consistent interpretation of information governance is needed, and research such as this needs to be considered as part of any review of data policy.

Macmillan also believes that most people are comfortable with sharing patient level data for research purposes. In July 2013, the Wellcome Trust found that people support the use of aggregated and linked health data "for the greater good" and are comfortable with reciprocity (supplying data in exchange for better public services).[19]

In addition to academic analysis of patient data, charities like Macmillan Cancer Support have much to contribute. Our expert analysts work with a diverse range of experienced research partners – to help unpick poorly understood topics such as cancer survivorship. We understand the needs of people affected by cancer and can provide a different perspective that is unlikely to emerge from academic research alone.

Leading the change

The availability and linkage of data continues to improve. Plans are in place to integrate both outpatient and A&E HES data with the NCDR to give a more comprehensive picture of the patient's interaction with primary and secondary care. The National Cancer Intelligence Network (NCIN), which administers the NCDR, is looking at integrating the new national radiotherapy and chemotherapy datasets into the repository.

But better data alone is not enough – it needs to be turned first into information and then into insight. Organisations outside of the healthcare system cannot lead the charge alone. The NHS and the wider research community must also step up to the plate.

The good news is that attitudes seem to be shifting. In advance of a visit to the 2013 Health Datapalooza in Washington DC, health secretary Jeremy Hunt announced a drive from the government to make the UK a world leader in the way it uses health data and technology. In July 2013, NHS England medical director Bruce Keogh listed a greater use of data to drive quality improvement as one of eight ambitions for the health service in his report on high mortality rates at 14 hospital trusts. And in August 2013, the Berwick review into patient safety highlighted the need for increased data transparency and accuracy. We must make the most of this impetus in cancer care as in all other areas.

The mountains of patient data we are producing in cancer care are only growing larger. The number of people living with cancer in the UK is increasing by around 3% each year and will hit four million by 2030. That's a big challenge – but it's also four million reasons for us to get this right.

ACKNOWLEDGEMENTS

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[7] Note: Post-diagnosis costs include inpatient costs only and there may be other costs elsewhere (e.g. outpatient and primary care costs) that are not being picked up by this analysis. Also, some episodes may be included that are not as a direct result of the patient having cancer. Post-diagnosis cost indicates cost from 90 days pre-diagnosis onwards (to seven years post-diagnosis).

[8] Note: activity delivered in any other setting including outpatient clinics, primary care (e.g., follow up, oral chemotherapy) or A&E is not included in the figures as data are not available.

[9] Note: patients classified as having 'cancer complications' can also experience other inpatient morbidities and are included in this figure. Morbidities are those able to be identified in the HES inpatient data set.

[10] Macmillan Cancer Support. Cancer Mortality trends: 1992–2020 (May 2013) http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executivesummary-FINAL.pdf (accessed February 2013)

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NOTES

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. Whether it's concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we're here. Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

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