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LIVING WITH AND BEYOND CANCER: TAKING ACTION TO IMPROVE OUTCOMES



National Cancer Survivorship Initiative (NCSI):

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Policy	Clinical HR / Workforce Management Planning / Performance	Commissioner Development Provider Development Improvement and Efficiency	Estates IM & T Finance Social Care / Partnership Working
Document Purpose	For Information		
Gateway Reference	18455		
Title	Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)		
Author	DH, MacmillanCancer Support & NHS Improvement		
Publication Date	March 2013'		
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Directors of Children's SSs		
Circulation List			
Description	Living with and beyond cancer: Taking action to improve outcomes is intended to inform the direction of survivorship work in England to 2015, whilst describing the progress and learning since the publication of the NCSI Vision (DH 2010).		
Cross Ref	N/A		
Superseded Docs	The National Cancer Survivorship Initiative Vision (DH 2010)		
Action Required	N/A		
Timing	N/A		
Contact Details	Jo Partington National Cancer Survivorship Initiative Cancer Services and End of Life Care Team, Department of Health Floor 6, Zone B, Skipton House 80 London Road London SE1 6LH 020 7972 5106		
For Recipient's Use			

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Foreword

When the National Cancer Survivorship Initiative (NCSI) was launched in 2007, most of the focus in terms of improving cancer services was on the diagnosis and treatment of cancer. In contrast, one of the main aims of the NCSI was to develop services to support and enable cancer survivors to live as healthy and as good a quality of life for as long as possible.

At that stage we had limited evidence about the needs of cancer survivors and about what should be done to provide the best possible support for them, although we were aware of the likely impact on services of predicted increases in cancer survivors, and had some understanding of the implications in terms of funding pressures for the NHS and social services.

In 2010, we published our vision for cancer survivorship, which set out the major shifts that were necessary to improve the wellbeing of cancer survivors. But that vision was, of necessity, quite thin in terms of detailed advice for commissioners and providers about the types of services that need to be available for cancer survivors. We have now started to develop an

evidence base about what support cancer patients need, and how that support can be provided in the most cost effective way. This document aims to provide that evidence, as a basis for action, for commissioners and providers – to whom this document is addressed.

Over the past few years, intelligence has been gathered on cancer patients' experience of treatment and care, their quality of life, the services they use and the types of support they need; furthermore, possible models for providing that support have been piloted. This document pulls this information together. We are now in a position where we can share good practice and recommend several of these models, whilst making recommendations for future improvements.

Failing to meet the needs of survivors of all ongoing conditions, including cancer, will prevent us from delivering the improved outcomes that are central to the Government's focus for the NHS and social care. By commissioning and providing the right support, based on need and not on diagnosis, we can improve survival rates,

quality of life and patient experience for all
– in a cost-effective way.

If the evidence gathered from survivors of cancer, and the services that they use, leads us to do one thing to improve survivorship in the future, it should be to ensure that all patients are offered a package of advice, information and support.

The NCSI is an example of how, through working together, the NHS, voluntary sector and academia can innovate to start to understand and improve outcomes, realise efficiencies and empower patients. Yet these innovations will only matter if spread to every survivor of a long-term condition, including cancer.

We hope that this document will mark a step change in how improved outcomes and personalised care can be commissioned, and delivered, in the future.

Professor Sir Mike Richards

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Executive summary

The challenge of cancer survivorship

1. Around 1.8 million people in England are currently living with a diagnosis of cancer. This number is increasing by over 3% a year and the total figure will rise to over 3 million by 2030¹.

2. Evidence shows that many of these cancer survivors have unmet needs², particularly at the end of treatment, whilst others are struggling with consequences of treatment^{3,4} that could be either avoided or managed^{5,6,7}.

3. Changing the way we support cancer survivors is therefore both an outcomes priority to address unmet needs, and a financial priority to meet the increasing demand and subsequent unfunded cost pressure: simply doing more of the same will not deliver the outcomes improvements cancer survivors expect, nor will it be affordable for the NHS. This is reflected in the recent Mandate to the NHS Commissioning Board, in which the Government has made it clear that it expects progress in supporting people with

long-term physical conditions, including cancer survivors, and in particular for them to remain in, or find work⁸.

4. This document is intended to support commissioners, providers and others to take the actions necessary to drive improved cancer survivorship outcomes. It sets out what we have learned about survivorship, including interventions to meet needs that have been tested and are ready to be spread across England.

5. There are a number of key interventions that could make an immediate difference, including the introduction of an integrated package of:

- > Structured Holistic Needs Assessment and care planning;
- > Treatment Summaries;
- > Patient education and support events (Health and Wellbeing Clinics); and
- > Advice about, and access to, schemes that support people to undertake

physical activity and healthy weight management.

6. Underpinning the recommendations in the document is the need to promote a cultural shift in professionals towards shared decision making and supporting patient self-management.

7. This report draws together the key learning from these developments to build on the 2010 NCSI Vision. It sets out a framework for survivorship in five different steps and details the actions needed at each:

1. Information and support from the point of diagnosis;
2. Promoting recovery;
3. Sustaining recovery;
4. Managing the consequences of treatment; and
5. Supporting people with active and advanced disease.

This framework will be used to describe the key messages, learning and interventions throughout the report.

Information and support from the point of diagnosis

8. Key messages:

- > Offer support from the point of diagnosis.
- > Patient experience is improving, but there are gaps in services that need addressing.
- > Clinical Nurse Specialists can play a key role in improving patient experience.
- > The decisions taken about treatment options may impact upon quality of life long after treatment has finished: offer patients support in making the decisions that best reflect their individual priorities.
- > Early cancer rehabilitation is important: it can prevent avoidable ill health and is more effective when provided early to avoid conditions becoming more complex and costly to treat later on.
- > Offer patients support in considering work and education options from a very early stage; offer patients with complex work support needs onward referral to specialist vocational rehabilitation services.

- > Using Patient Reported Outcome Measures (PROMs) to collect patient symptoms, concerns and quality of life routinely from diagnosis onwards, will help focus on what really matters to patients.

To translate these messages into action, areas that require further exploration are:

- > Consider the best mechanisms to audit provision of information on working with cancer.
- > Learn from examples of cancer rehabilitation; adopting pre-treatment 'pre-habilitation' at scale would prevent avoidable ill health and avoid conditions becoming more complex and costly to treat later.
- > Ensure that work support is a more explicit component within the assessment and care planning process.
- > Investigate the feasibility of packaging up rehabilitation budgets into rehabilitation prescriptions, which should include specialist vocational rehabilitation. This process should include potential pilot schemes.
- > Undertake further work to investigate change through the use of financial incentives such as local Commissioning for Quality and Innovation (CQUIN) frameworks.

Promoting recovery

9. Key messages:

- > Patients' wellbeing will be greater and their demand for services lower if they get the support that is relevant to their particular needs, and which promotes healthy lifestyles and independence.
- > The 'recovery package' – a combination of assessment and care planning, Treatment Summary, and a patient education and support event (Health and Wellbeing Clinic) – is potentially the most important building block for achieving good outcomes. Providers and commissioners who wish to achieve good patient outcomes will want to implement these measures.
- > These interventions can deliver immediate benefits to patients, as well as supporting improvements in care further down the survivorship pathway.
- > Re-allocate any cost efficiencies, achieved through follow-up, to other areas of the survivorship pathway, such as assessment and care planning, or community support.

The way that these messages can be translated into action is by:

- > Offering all patients a Treatment Summary.
- > Offering all patients a Holistic Needs Assessment. The assessment may require input from a range of doctors, nurses and allied health professionals (e.g. dieticians, physiotherapists, occupational therapists, and speech and language therapists) depending on the nature of a patient's problems. These assessments can be delivered in a number of ways, one being dedicated clinics.
- > Offering all patients advice on vocational rehabilitation.
- > Offering all patients advice on physical activity, weight management and how to access appropriate programmes.
- > Offering all patients a written care plan.
- > Copying the care plan, or advice that a patient has declined a care plan, to the GP to document receipt and offer the patient a cancer care review within six weeks.

In order to support the promotion of recovery, more work is needed to:

- > Explore how the delivery of the package of survivorship interventions provided in secondary care could be incentivised through either financial or national audit measures.
- > Build on work being piloted in trauma, diabetes and other disease areas to develop a 'recovery tariff' for those elements of the pathway beyond initial treatment.
- > Work with commissioners to explore how best to include recovery support in commissioning intentions.

Sustaining recovery

10. Key messages:

- > Offer tailored follow-up to meet the needs of individual patients – stratifying patients for follow-up according to their risk can ensure that needs are better met and that resources are used more efficiently.
- > Offer specific support to adults who had cancer as a child or young person, who may develop particular issues, years or decades later.

- > Helping patients to self-manage their condition is an important part in improving follow-up – it is popular with those patients who are suitable and can reduce health service utilisation.
- > Physical activity can be as effective as many drugs in reducing recurrence – offer all patients support to be as active as possible.

The way that these messages can be translated into action is by:

- > Discussing new approaches to follow-up with commissioners, commissioning support units and providers. Nurse-led follow-up and/or remote monitoring are likely to bring benefits to patients and to reduce overall costs to the NHS, but appropriate tariffs and/or gain-share arrangements will be needed to incentivise these changes. The NCSI will develop a CQUIN exemplar to encourage stratification of patients for follow-up according to need.
- > Clinical Commissioning Groups (CCGs) will want to consider how best to ensure that exercise programmes are available for all appropriate cancer patients. These are likely to be highly cost effective as they will reduce recurrence and improve quality of life.

- > It will be useful to measure changes in the proportions of cancer survivors who are undertaking at least moderate levels of physical activity through PROMs.

Managing the consequences of treatment

11. Key messages:

- > Consequences of treatment affect many patients and will be an increasing challenge as the number of cancer survivors grows.
- > The nature of cancer treatment means that the subsequent consequences vary significantly between patients in frequency, timing, severity and impact on quality of life – the level and nature of support that patients require will therefore vary.
- > Failure to manage the consequences of treatment can have a significant impact on patients and on the NHS, so it makes sense to design and commission pathways and services that minimise consequences and address need.
- > Begin the assessment and monitoring of patients for consequences of treatment during the active treatment phase, and continue for as long as necessary.

- > Empower patients and primary/ community care professionals to manage the consequences of treatment; providing the Treatment Summary is an important enabler for this.

The way that these messages might be translated into action is by spreading the adoption of practice that:

- > Minimises the risk of long-term consequences by commissioning innovative treatments where these have been shown to be safe and effective (e.g. laparoscopic surgery, intensity-modulated radiotherapy (IMRT) /image-guided radiotherapy (IGRT).
- > Provides information on the potential short- and longer-term side effects of treatments to patients.
- > Includes information on potential consequences of treatment, the symptoms and signs to be aware of and recommended surveillance tests in care plans.
- > Assesses all patients for the emergence of consequences of treatment through the routine use of PROMs, which are tailored to patients' specific risks based on diagnosis and the treatments provided. Methods for doing this in clinical practice need to be developed and evaluated, and consideration

given to developing a model Commissioning for Quality and Innovation (CQUIN) goal to incentivise the use of PROMs in this way.

- > Recognises that certain survivorship services may be appropriately commissioned by the National Commissioning Board such as services for patients suffering from the 'intermediate' prevalence consequences of treatment, or highly specialist services for 'rare' consequences of treatment such as the new breast radiotherapy injury rehabilitation service (BRIRS), or services for adult survivors of childhood cancers.
- > Supports GPs through education and training on the 'common' consequences of treatment, such as cardiovascular disease and osteoporosis, and by offering easy access to specialist advice and care.

Supporting people with active and advanced disease

12. Key messages:

- > Key principles for survivorship – assessment and care planning, access to key workers and proactive management of health issues – are every bit as important for active and advanced disease as for other parts of survivorship.

- > A priority is to address weaknesses in the intelligence available about people living with active and advanced disease, as well as the treatments and support they receive.
- > Further work is required to understand the most effective ways for multidisciplinary teams (MDTs) to support the management of people with active and advanced disease.
- > Palliative care is an essential component of management, not something that commences when active treatment ceases.
- > Offer a smooth transition between cancer support, palliative care and end of life services to patients.
- > Recording of recurrence/metastasis of cancer, piloted by breast cancer teams, to be extended; exploring the use of data from different IT systems (e.g. pathology, imaging, radiotherapy, chemotherapy) to assist this process.
- > Strengthening data collection on treatments for active and advanced disease.
- > Publishing data on the availability of CNSs for people with active and advanced disease.
- > Exploring the potential for personalised outcome goals, to be developed by patients in partnership with clinicians, to focus care on what matters most to patients.

The way that these messages might be translated into action is by:

- > Commissioners and providers agreeing on how patients who are concerned about a recurrence should re-access specialist care.
- > Considering all patients who are re-referred as urgent.
- > Offering all patients a full assessment at first recurrence, and a further care plan.
- > Producing guidance on multidisciplinary input to support people with active and advanced disease.
- > Developing triggers for alerting palliative and end-of-life care services, and for considering entry of a patient into the end-of-life care register. These might include the receipt of palliative radiotherapy or second-line chemotherapy.
- > Understanding at population level the concerns leading to re-referral.

Improving survivorship intelligence

13. Key messages:

- > Intelligence on the needs of cancer survivors, and the extent to which they are being met, is critical to improving outcomes and understanding the costs of meeting those unmet needs.
- > A range of initiatives are underway to ensure that patients, clinicians, commissioners and providers are able to access timely and accurate information.
- > Healthcare professionals to understand better and more accurately predict likely outcomes for cancer patients, and thus to advise them appropriately.
- > People affected by cancer to have an increased understanding of what the cancer journey may look like, to have the knowledge to make informed treatment and life decisions, to know who can help them and to have confidence in what they need to do to help themselves, with appropriate clinical and social support.

Once these messages are translated into action, they will enable:

- > The identification and improvement of the information needed to enrich our understanding of the cancer population.
- > Comparison of the survivorship outcomes delivered by different providers of cancer services.
- > A better understanding of the clinical pathways patients follow, providing timely and accurate information to cancer patients, planners and decision makers.
- > Service developers to have a better understanding of the local cancer population, and enable improved

evidence-based discussions to allow cancer pathways to be redesigned and patients' care to be tailored to their health requirements.

This document is intended to assist the NHS Commissioning Board in identifying its priorities on a national level; to assist Clinical Commissioning Groups and Commissioning Support Units, at a local level, to meet the needs of their citizens and, ultimately, to benefit all patients who are living with cancer and other on-going health conditions.

England cancer survivorship in numbers

1.8 million increasing to **3 million**: the projected increase in cancer survivors by 2030⁹

47.3% of survivors express a fear of their cancer recurring¹⁰

40% of prostate cancer survivors report urinary leakage¹¹

19% of colorectal cancer patients report difficulty controlling their bowels¹²

24% of people were offered a written assessment and care plan (averaged across Trusts)¹³

2.4 million follow up appointments for clinical and medical oncology in 2011/12¹⁴

1. Introduction: The challenges of cancer survivorship



1.1 There are now almost 1.8 million people living in England who have had a diagnosis of cancer. This will increase to 3 million by 2030¹⁵ as more people are diagnosed with cancer, treatment becomes more effective and people live longer after a cancer diagnosis.

1.2 Evidence shows that many of these cancer survivors have unmet needs¹⁶, particularly at the end of primary treatment, whilst others are struggling with consequences of treatment that could be either avoided or managed.

1.3 The current system is failing to meet existing needs, and faces challenges in expanding sufficiently to support the increasing number of cancer survivors.

1.4 Failing to meet the needs of cancer survivors has significant cost implications for the NHS and wider economy, resulting in increased use of health resources, reduced economic activity and an increased dependency on benefits. This means that the NHS is facing a significant cost pressure at a time of financial austerity.

1.5 Changing the way we support cancer survivors is therefore both an outcomes priority and a financial priority: simply doing more of the same will not deliver the outcome improvements we want for

cancer survivors, nor will it be a good use of tight NHS resources.

1.6 This document seeks to offer helpful advice to support commissioners, commissioning support units, providers, and others with a commitment to supporting cancer survivors, in taking the actions necessary to improve outcomes. It sets out what we have learnt about survivorship needs, and describes interventions to meet those needs, with evidence about outcome improvements and cost effectiveness.

1.7 It recognises that carers may also need support, particularly those who care for a child with cancer, or a person with cancer who also has learning disabilities or mental health problems.

1.8 Key interventions that could make an immediate difference should be prioritised, including the England-wide introduction of:

- > Structured Holistic Needs Assessments and care planning;
- > Treatment Summaries given to patients and all those involved in their care;
- > Patient education and support events; and

- > Information and access to schemes that support people to undertake physical activity and healthy weight management.

1.9 The interventions required to support cancer survivors have much in common with those required to support people with long-term conditions generally. It is important for support for cancer survivors to be developed hand in hand with the broader programme of work on long-term conditions, allowing each to learn from the other.

2. Work to date



2.1 The NCSI was established in 2007 as an initiative led by the Department of Health and Macmillan Cancer Support, with very significant support from NHS Improvement. Many other organisations from the health, voluntary and other sectors have also contributed their time and expertise in developing our knowledge about cancer survivorship. In 2007, our understanding of the needs of cancer survivors and the effectiveness of services in place for them was limited. We did not even have an accurate estimate of the number of people alive following a cancer diagnosis. Considerable progress has been made in:

- > Establishing and improving the evidence base in survivorship;
- > Creating a community of interest and committed advocates for survivorship;
- > Developing and testing new approaches to delivering follow-up care;
- > Understanding the implications for the workforce; and
- > Providing advice and support to commissioners and providers.

2.2 This chapter summarises our work to date.

Establishing and improving the evidence base in survivorship

2.3 We now know more about the needs of survivors than ever before:

- > At a population level – how many cancer survivors there are and which diagnosis they have received.
- > At a patient level – the quality of life issues in the short, medium and longer term.
- > At a health service level – the services that patients use and the health problems for which they require treatment.

2.4 Population level: Work undertaken using cancer registry data gives a clear picture of the number of people living with or beyond cancer in England (Box 1).

Box 1: Number of people living with or beyond cancer in England, 2010¹⁷

Total	1.74 million	
Males	710,000	41%
Females	1,030,000	59%
Age 0–44 (0–17) ¹⁸	140,000 (17,000)	8% (1%)
45–64	500,000	29%
65+	1,100,000	63%
Breast	480,000	28%
Colorectal	200,000	12%
Prostate	210,000	12%
Lung	50,000	3%
Other	790,000	46%

2.5 Each cancer is different and the distribution of patients according to phase of care will vary. Work by Macmillan Cancer Support¹⁹ classifies the stage at which patients are in terms of needs-based segments – be it diagnosis and treatment, recovery and adjustment, monitoring, progressive illness or end-of-life care. This varies according to cancer type, as set out in Figure 1 which examines the distribution of the number of patients with breast, colorectal and lung cancer.

2.6 Data are currently not routinely collected to enable calculation of the numbers of people living with cancer into needs-based segments, which would allow the targeting of interventions and redistribution of resources. Using clinically

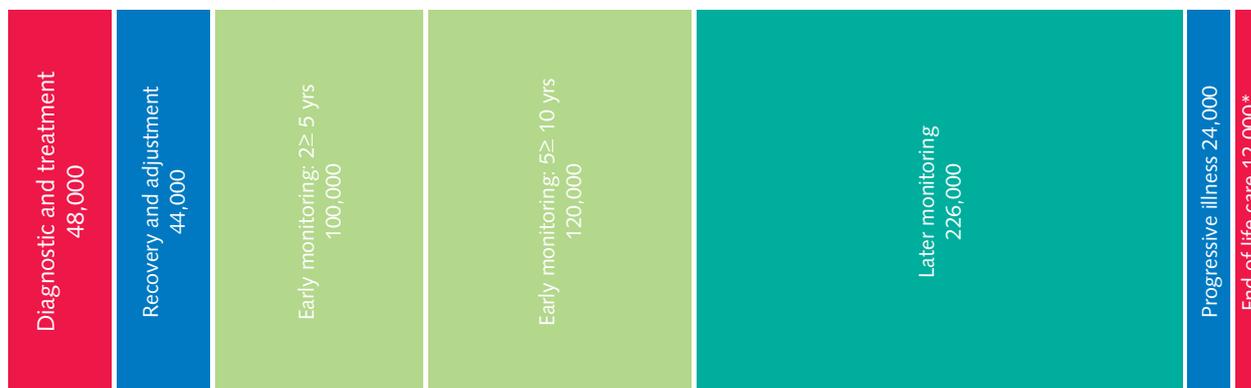
led assumptions about patient need and outcomes, and readily available data on cancer incidence, survival, prevalence and mortality, indicative estimates have been made to quantify possible need across a cancer care pathway. This analysis helps in planning the levels of services needed in any given area, whilst recognising that patients may start at any phase, and that the different phases may not occur in order (for example, a patient may have progressive disease on diagnosis and go straight to end-of-life care).

2.7 In addition to adults diagnosed with cancer, there is also a growing population of adults whose cancer was diagnosed and treated when they were a child or young person. By 2021, there is projected to be nearly 11,000 more adult survivors of childhood cancer (a 34.9% increase on 2011) (see Figure 2). For the first time, the wider health service must monitor and support a population of older people who may have long-standing consequences from their cancer treatment as a child or young person.

2.8 Patient level: Some evidence previously existed about the quality of life for cancer survivors, although studies tended to be relatively small scale and to focus on single forms of cancer. In 2010, the Department of Health commissioned pilots of PROMs surveys of individuals 1, 2, 3 and 5 years after cancer diagnosis.

Figure 1: Distribution of patients according to needs-based segments²⁰

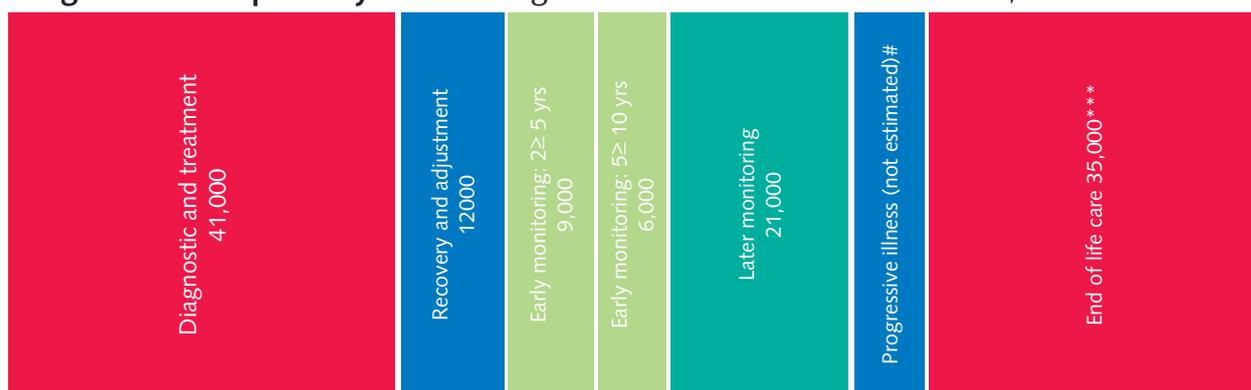
Breast cancer care pathway – estimating the number of women in the UK, 2008



Colorectal cancer care pathway – estimating the number of women in the UK, 2008



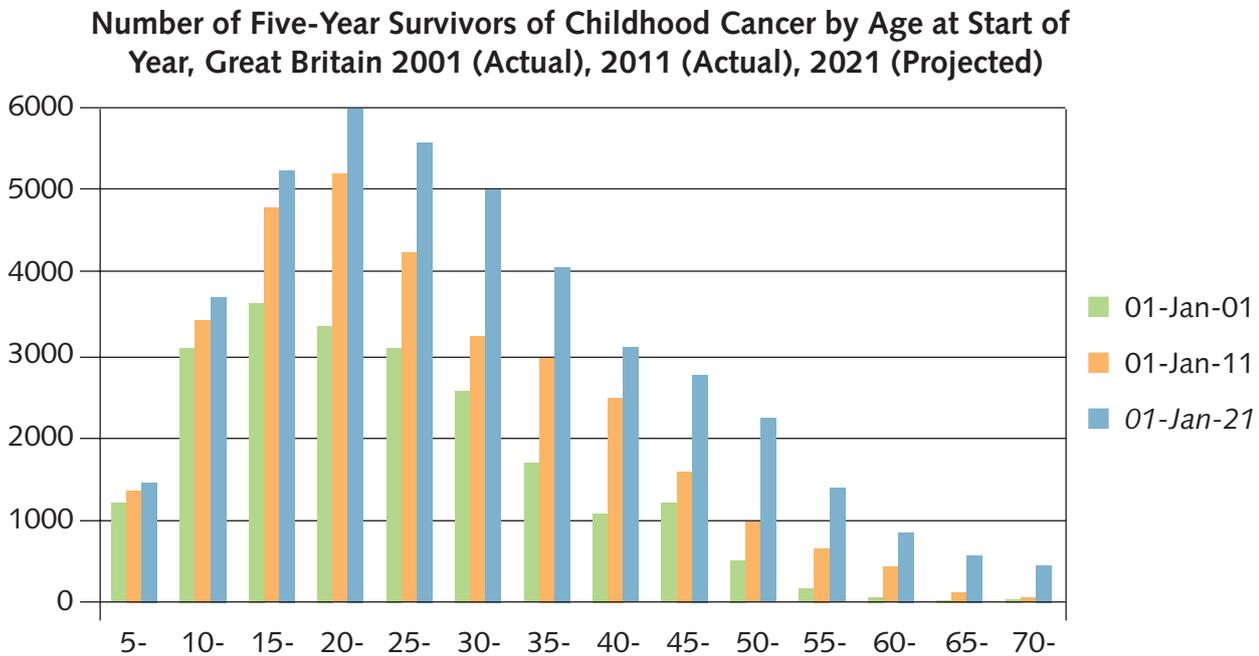
Lung cancer care pathway – estimating the number of women in the UK, 2008



For each cancer type, the size of the boxes reflects the approximate proportion of people in each phase (however, there is double counting for people who are diagnosed and die in the same year – these numbers are estimated as *2,000 breast, **11,000 colorectal and *** 28,000 lung cancer).

Estimates for progressive illness for lung cancer have not been made as we have been unable to make estimates of progressive disease beyond metastatic disease at this time – for lung cancer those with metastatic disease will be reflected in end of life care.

Figure 2: Projected increase in survivors of childhood cancer²¹



The pilots provide an unprecedented level of information on the quality of life and health needs of survivors with breast, bowel, prostate cancer and non-Hodgkin’s lymphoma. Patient comments from this survey have been used to illustrate points throughout this document. Key findings are in Box 2.

2.9 The survey findings²² are available to help inform improvements to survivorship support.

2.10 Health service level: Unpublished work in North Trent²³ has contributed to our understanding of the pattern of healthcare usage amongst cancer patients with certain types of cancer. It is discussed in Chapter 4.

Research about needs and effective models to meet needs

2.11 A core focus of NCSI has been to engage members of the research community to review and develop evidence about the needs of cancer survivors, and effective service models to address these, including:

- > Undertaking evidence reviews of survivorship research;
- > Assessing evidence on support for patient self-management, lifestyle changes and physical activity

Box 2: Key findings from PROMs survey²⁴

- > Quality of life for breast, colorectal, prostate cancer and non-Hodgkin's lymphoma is related to disease status, current age and the presence of one or more long-term conditions.
 - > Overall, just under half (47.3%) of respondents expressed a fear of recurrence, and this fear appears to persist over a period of at least five years, although with significant reductions over time.
 - > As measured by the EQ5D quality of life score, 24.4% of breast cancer patients reported a high quality of life, compared to 31.2% for colorectal cancer, 31.7% for non-Hodgkin's lymphoma and 40% for prostate cancer.
 - > As measured by the EQ5D quality of life score, 8.9% of breast cancer patients reported a low quality of life, compared to 10.8% for colorectal cancer, 13.1% for non-Hodgkin's lymphoma and 9.4% for prostate cancer.
 - > Problems relating to urinary and bowel control are common, with nearly 40% of prostate cancer survivors reporting urinary leakage and 13% reporting difficulty controlling their bowels. Similarly, amongst colorectal cancer patients nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. The presence of these symptoms was significantly associated with poorer quality of life.
 - > Increased physical activity was significantly associated with better quality of life, although it is unclear whether this is cause or effect.
 - > Erectile dysfunction is common in prostate cancer patients but, surprisingly, did not appear to impact significantly on quality of life.
 - > Physical problems and the resultant impact on quality of life appear to persist, suggesting that individuals are not receiving effective help for these conditions.
 - > A significant decrease in employment, around one third in each tumour group, was observed between pre-diagnosis and one year from diagnosis.
-
- > Conducting research into the attitudes of clinicians to survivorship issues, such as work after cancer;
 - > Researching the extent and nature of consequences of treatment, and how well professionals are equipped to manage them; and

> Establishing a robust methodology to link routinely collected data sets in order to map the clinical journey cancer patients take after diagnosis.

2.12 The British Journal of Cancer supplement²⁵ brought together new and emerging cancer survivorship research and will inform the development of the future research agenda.

2.13 A major issue was the lack of UK data and evidence relating to health outcomes for individuals following primary treatment for cancer. It is recognised that there is a need to stimulate a new field of enquiry to address gaps in data and evidence. Since 2007, work has commenced to fill these gaps, and is described in Chapter 10.

Creating a community of interest and committed advocates for survivorship

2.14 A key task was to develop a community of interested people willing to undertake research, test new approaches and champion the needs of cancer survivors at national and local levels.

2.15 A range of National Clinical Advisors were appointed by NHS Improvement to advise on the programme of piloting, a collaborative was established to examine

the consequences of treatment, and Expert Advisory Groups on physical activity and health behaviour changes were set up, as well as other groups.

2.16 An engagement strategy has raised awareness of survivorship issues, including supplements in the Health Service Journal, the Nursing Times and the British Journal of Cancer, to bring together evidence for different audiences. A range of conferences and 'learn and share' events have been organised, enabling health professionals, charities, managers, researchers and patients to engage with the issues around survivorship. Local communities of interest have been created through cancer networks and the development of pilot projects.

2.17 Progress has been made in creating national and local communities of interest. For example, over 180 professionals and patients from across the NHS and voluntary sector participated in workshops to inform this document, and it is estimated that over 900 have been involved in developing knowledge about changing cancer pathways to better meet the needs of cancer survivors.

Developing and testing new approaches to delivering survivorship support

2.18 A range of new models of care and redesigned pathways have been tested by Macmillan Cancer Support and NHS Improvement, working with cancer charities and NHS Trusts, including:

- > Assessing patients' holistic needs and care planning, developing Treatment Summaries and testing their impact, producing cancer care review templates and testing electronic solutions for self-assessment.
- > Stratifying patients according to their ability to self-manage with support, which includes remote monitoring, developing follow-up pathways for six tumours and testing new models of care in forty pilot sites.
- > Introducing Health and Wellbeing Clinics to enable patients to identify the most beneficial support.
- > Cancer rehabilitation programmes and ways in which exercise can be embedded in care pathways.
- > Self-management and alternatives to hospital-based follow-up, including developing courses for patients and promoting improved communication skills for clinicians, regarding patient self-management.
- > Specialist services for managing consequences of cancer treatment, including the new national service for radiation-induced brachial plexopathy, and developing guidelines for the treatment of people with gastrointestinal problems arising from cancer treatment.
- > The provision of high quality information, including personalised information and the support to understand it.
- > Supporting patients in getting back to work or education; and developing a model of work-related information, work support and vocational rehabilitation, tested across seven sites.
- > Services for people with active and advanced disease, including testing the concept of 'virtual' multidisciplinary teams, exploring data linkages and conducting a qualitative evaluation of lung cancer care in two different sites.
- > New pathways for children and young people with cancer, including testing four models of aftercare and three defined aftercare pathways across ten centres.

2.19 These projects have substantially developed our thinking about what works in improving survivorship support, and we are very grateful for the participation of so many organisations and professionals.

Macmillan Cancer Support's values based standard

2.20 Macmillan Cancer Support developed a values based standard, due for publication in 2013, which aims to support healthcare professionals in adopting a personalised approach to cancer care, tackling inequalities and ensuring that the needs of different groups are met throughout the cancer pathway.

2.21 The standard, developed by patients and professionals working together, identified eight 'moments that matter' to people receiving cancer services, as set out in Box 3. It is now being tested in London, Birmingham, and Merseyside and Cheshire, with input from the Parliamentary and Health Service Ombudsman, Department of Health, Care Quality Commission, Royal College of Nursing, Equality and Human Rights Council and the Nursing and Midwifery Council.

Box 3: Macmillan Cancer Support's values based standard

- > Naming: *"I am the expert on me"*
- > Private communication: *"My business is my business"*
- > Communicating with more sensitivity: *"I'm more than my condition"*
- > Clinical treatment and decision making: *"I'd like to understand what will happen to me"*
- > Acknowledge me if I'm in urgent need of support: *"I'd like not to be ignored"*
- > Control over personal space and environment: *"I'd like to feel comfortable"*
- > Managing on my own: *"I don't want to feel alone in this"*
- > Getting it right: *"My concerns can be acted upon"*

Understanding the implications for the cancer workforce

2.22 Health and social care professionals are likely to need support to implement the recommendations made in this document in delivering services differently, including:

- > Supporting survivors with diet and physical activity/lifestyle choices.
- > Shared decision making and assessment and care planning skills.
- > Consequences of treatment (e.g. prostate cancer and urinary leakage).
- > Providing basic psychological care (not therapy).
- > Signposting to organisations who provide these services.
- > General health and social care professionals are likely to be required to develop enhanced cancer expertise and skills as they increasingly support people living with and beyond cancer.

2.23 There is more to be done in this area, which may offer an opportunity for the emergent Academic Health Science Networks to develop the workforce and equip health professionals with new survivorship knowledge and skills, working in partnership with Local Education and Training Boards.

2.24 The children and young people workstream have worked with the Royal College of Nursing (RCN) to produce nursing competencies: "An integrated career and competence framework for nurses working in the field of long term

follow up and late effects care of children and young people after cancers", 2011.²⁶

2.25 Macmillan and the BMJ are developing an online tool to support primary care providers to care for cancer survivors in the community.

2.26 National Cancer Action Team have developed a workforce model for allied health professionals involved in survivorship support, to help providers plan the workforce necessary to meet patients' needs²⁷.

Raising awareness amongst patients and carers of the role that they can play in meeting their survivorship needs

2.27 'No decision about me without me' should be the guiding principle for survivorship support. Carers may also need support, particularly those who care for a child with cancer, or a person with cancer who also has learning disabilities or mental health problems. Many cancer charities and other organisations have been working to empower patients and carers to take a more active role in their own survivorship care. Examples include Breast Cancer Care's *Moving Forward* course, Maggie's *Where Now?* event and Penny Brohn's *Living Well* course. Written

material includes recent work funded by Macmillan Cancer Support to identify 'top tips' for patients, summarised in Box 4.

Box 4: Macmillan Cancer Support's '10 top tips for patients'²⁸

1. Discuss your needs with a healthcare professional at the end of treatment
2. See a copy of your end-of-treatment assessment and care plan
3. Find out who is your ongoing 'main contact'
4. Be aware of any post-treatment symptoms
5. Get support with day-to-day concerns
6. Talk about how you feel
7. Take steps towards healthier living
8. Find out more about what to look out for if you are worried about treatment side effects or the cancer coming back
9. Monitor your own health and go to your follow up appointments
10. Make suggestions based on your experiences of treatment and care

A framework for survivorship thinking

2.28 *The National Cancer Survivorship Initiative Vision* document (Department of Health 2010) identified five key shifts to improve survivorship outcomes:

1. A cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and wellbeing after cancer treatment.
2. A shift from a one-size-fits-all approach towards assessment, information provision and personalised care planning based on identification of individual risks, needs and preferences.
3. A shift towards support for self-management. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences and with the appropriate clinical assessment, support and treatment.
4. A shift from a single model of clinical follow-up to tailored support that enables early recognition of and preparation for the consequences of treatment, as well as early

recognition of signs and symptoms of further disease.

through routine use of PROMs in aftercare services.

5. A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors

2.29 To achieve these shifts, the NCSI has looked at survivorship within a five-step framework, identifying actions in each step to improve survivorship outcomes:



This framework will be used to describe the key messages, learning and interventions throughout the report.

Further reading

Evidence review of survivorship research: <http://www.ncsi.org.uk/wp-content/uploads/NCSI-Evidence-Review-Richardson-et-al.pdf>

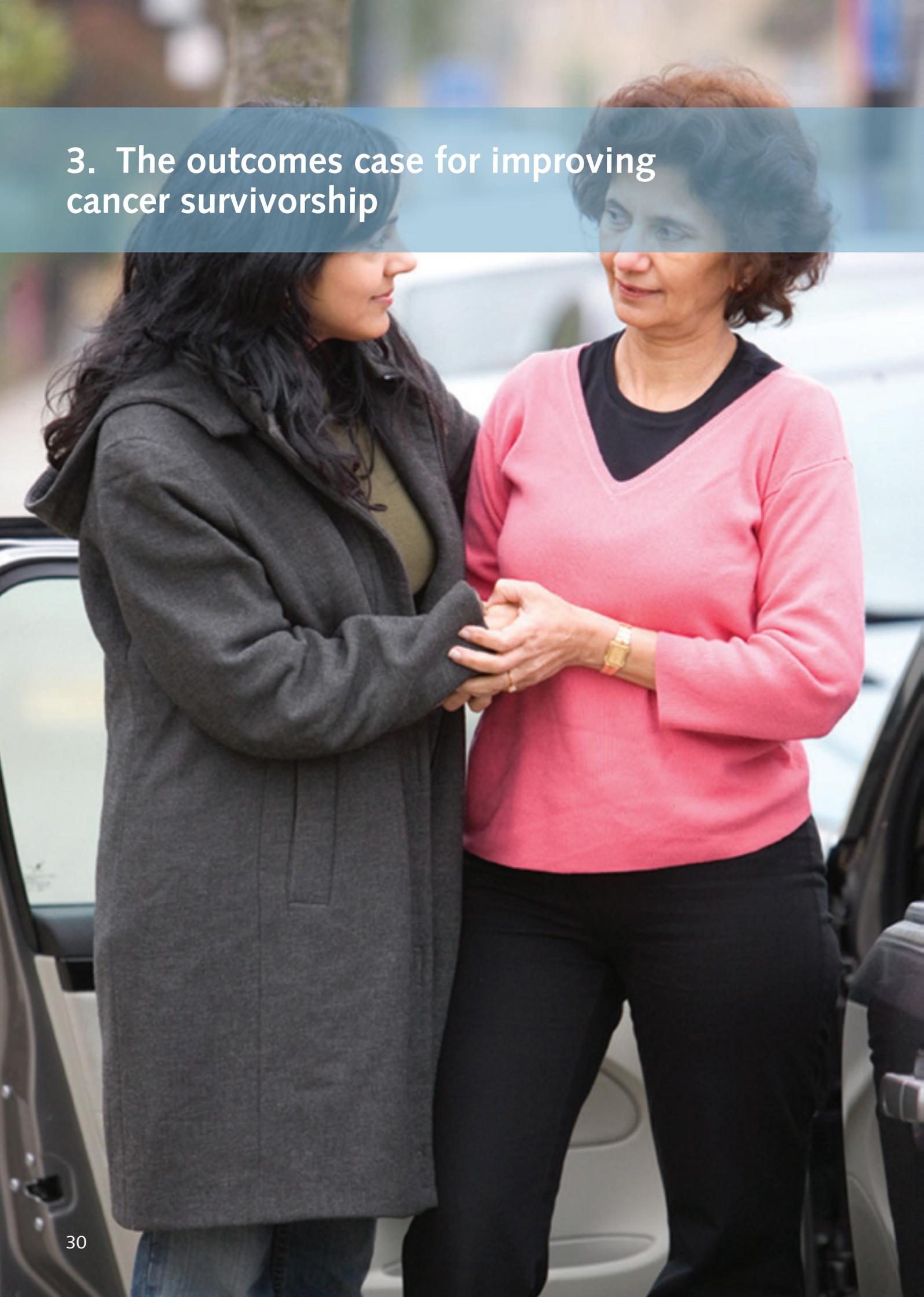
Evidence on self-management support and lifestyle: <http://www.ncsi.org.uk/what-we-are-doing/supported-self-management/evidence-synthesis/>

Evidence on physical activity:
<http://www.ncsi.org.uk/what-we-are-doing/physical-activity/>

Guidance on services for living with cancer and the survivorship elements of the care pathway: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127785

Care pathways and a workforce model for allied healthcare professionals involved in survivorship support:
<http://www.ncat.nhs.uk/our-work/living-with-beyond-cancer/cancer-rehabilitation>

3. The outcomes case for improving cancer survivorship



Delivering on the NHS Outcomes Framework

3.1 The Government has set out ambitious plans to improve cancer outcomes in England. This chapter sets out the outcomes case for improving survivorship care.

3.2 High quality cancer survivorship can improve outcomes in all domains of the NHS Outcomes Framework²⁹, as set out in Box 5 below. It can also contribute to improved outcomes within the Public Health Outcomes Framework – for example, reducing people’s risk factors for developing other conditions – and the Social Care Outcomes Framework – for example, through promoting independence.

Box 5: How high quality cancer survivorship can improve NHS outcomes

**Domain 1:
Preventing
people from
dying
prematurely**

Reducing cancer mortality and improving cancer survival are not simply about early diagnosis and high quality treatment. Good survivorship care can help to reduce mortality by:

- > Supporting people in reducing their risk of recurrence. For example, there is growing evidence that regular physical activity can help reduce some cancers’ recurrence.
- > Helping people prevent or manage co-morbidities that may arise from treatment such as elevated risk of cardiovascular disease, diabetes, osteoporosis and depression, which can cause premature loss of life but, if recognised, can be managed.
- > Identifying recurrence earlier. For example, prompt identification of recurrence or spread of cancer can mean that patients can be referred for treatment and palliative care at a time when they have the best chance of longer-term survival.

<p>Domain 2: Enhancing quality of life for people with long term conditions</p>	<p>Domain 2 is of critical importance to the survivorship agenda. Many cancer survivors will live with long-term conditions, either as independent co-morbidities, or caused by their cancer or treatment. Improving survivorship support can make significant improvements to people's quality of life.</p> <ul style="list-style-type: none"> > It will enable better management of currently undetected or poorly managed anxiety, depression, fear of recurrence, and physical consequences of treatment. > It will offer the opportunity to address psychosocial effects such as relationship difficulties and loss of self-confidence, or sub-optimal physical recovery. > It will offer support to minimise loss of/inability to retain/difficulty in reintegrating or accessing education, employment or training.
<p>Domain 3: Helping people to recover from episodes of ill health or following injury</p>	<p>Cancer survivors are more likely to be admitted to hospital, and for longer periods, than people who do not have a cancer diagnosis.</p> <p>Ensuring access to cancer rehabilitation from the point of diagnosis can support patients in their recovery, including:</p> <ul style="list-style-type: none"> > Physiotherapy, getting patients mobile and able to perform more daily tasks following cancer and its treatment. > Specialist nutritional advice, making sure that cancer patients are supported to be properly nourished, either because they can no longer eat certain types of food (e.g. for patients with head and neck cancers) or because particular foods are no longer tolerated. > Speech and language therapy, to assess and treat swallowing, speech, language and communication problems. > Psychological support, to support the whole patient, including emotional needs as well as physical needs. > Occupational therapy, to support patients in undertaking meaningful and purposeful activities that promote independence.

Domain 3: <i>(continued)</i>	<ul style="list-style-type: none"> > Vocational rehabilitation services for patients with complex needs and who require specialist support to return to work or education. > Emotional and practical support from social workers.
Domain 4: Ensuring that people have a positive experience of care	<p>Areas that relate to survivorship in the National Cancer Patient Experience Survey (NCPES)³⁰ include those in which patients report the least positive experience:</p> <ul style="list-style-type: none"> > Only 24% were offered a written assessment and care plan (averaged across Trusts). > Only 52% of people who needed information about how to get financial help or benefits said that staff gave it. > Only 81% said they received easy to understand written information about the side effects of treatment. <p>The survey reveals significant variation between providers, and significant differences between age groups, with the youngest age group (16–25) usually the least positive (on 30 out of 43 questions). This needs further exploration.</p>
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	<p>Providing support to cancer patients can reduce the risk of avoidable harm. Survivorship interventions can support this through:</p> <ul style="list-style-type: none"> > Documenting treatment decisions so that side effects and the longer-term consequences of treatment can be managed well. > Ensuring timely access back into services when necessary. > Stratifying patients according to the level of support needed so that those cancer patients who require more intensive monitoring, follow-up and treatment do not get lost in the system.

3.3 The service innovations in this document will help deliver improvements in all domains of the NHS Outcomes Framework:

- > Increasing survival rates, by reducing recurrence rates and helping patients with advanced disease live longer;
- > Enhancing quality of life and health, enabling cancer survivors to play more active roles in society;
- > Assisting recovery from cancer-related ill-health;
- > Improving patients' experience of treatment and care across the pathway; and
- > Reducing avoidable harm by enabling patients to be active participants in their own care, thereby identifying issues as they occur and seeking appropriate help.

4. The financial case for improving cancer survivorship



4.1 Increasing incidence means that more people will receive a cancer diagnosis. Improved survival means that they will live with and beyond cancer for longer, but often with ongoing support needs.

4.2 The result is that the NHS is facing a significant cost pressure. Changing the way we support cancer survivors is therefore a financial as well as an outcomes priority: simply doing more of the same will not deliver the outcomes improvements we want, nor will it be affordable for the NHS.

4.3 There are opportunities to deliver services in a different way where feasible and agreed by patients and relatives, unlocking resources to provide different forms of survivorship support and improving outcomes for patients. This chapter sets out the financial case for change.

The financial impact of cancer survivorship

4.4 Cancer has a significant financial impact on:

- > The NHS and social care, in providing treatment and services for people living with and beyond cancer;

- > Patients and carers, including lost income and the cost of trips to hospital³¹; and
- > The wider economy through lost productivity.

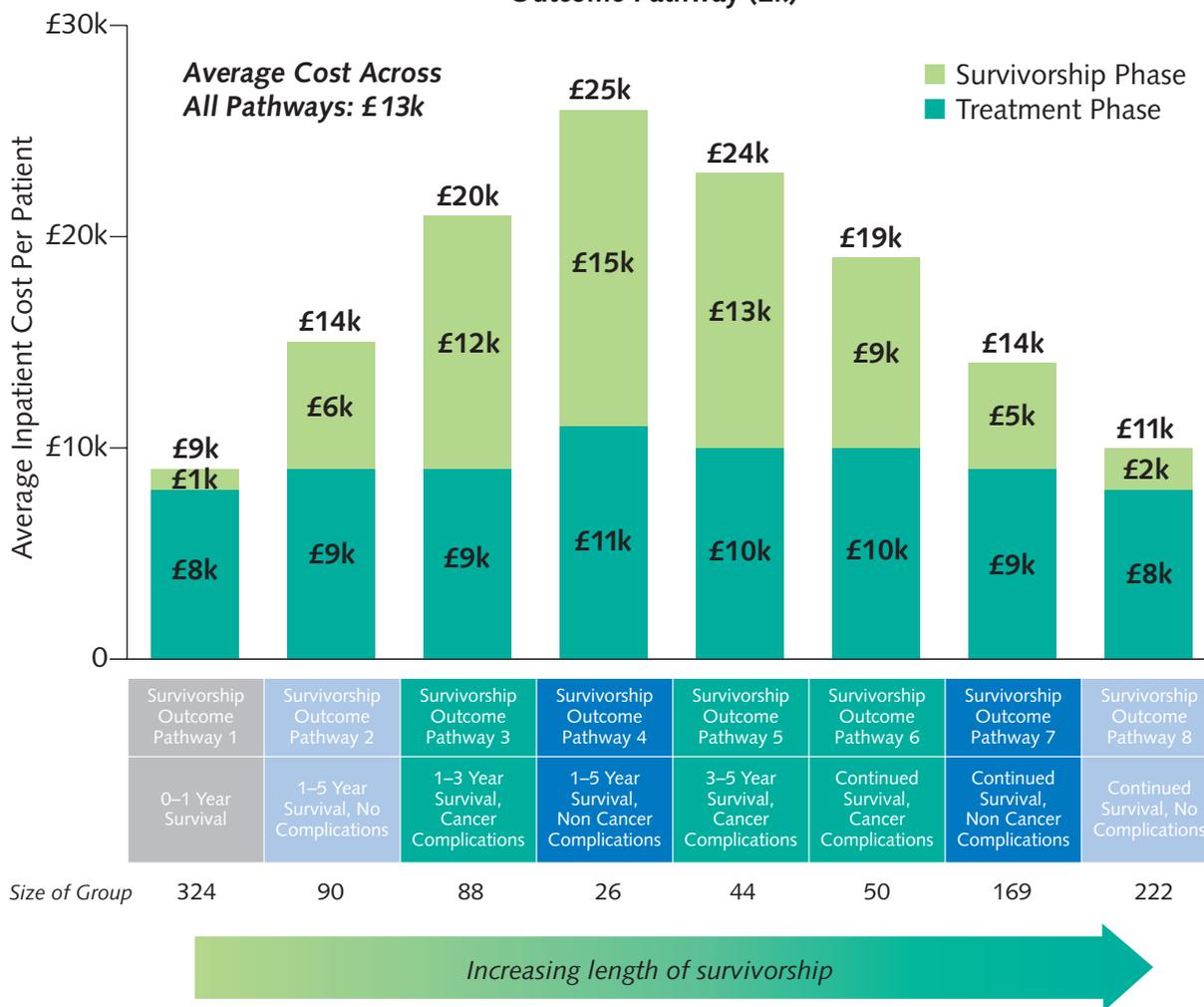
4.5 In total, it was estimated that cancer cost the English economy over £18 billion in 2008, with nearly £5.5 billion of this sum related to lost productivity from cancer survivors³². In addition, a significant proportion of the overall cost of cancer services to the NHS results from support for cancer survivors.

4.6 A study in Manchester³³, using theoretical modelling of patient data informed by expert clinical opinion, indicated that savings in the region of £170,000 could be released annually to the wider economy through saved benefit payments and increases in tax contributions, if half of the sample of lung and breast cancer patients who currently return to work and then leave were more effectively supported through vocational rehabilitation.

4.7 Box 6 details the findings of a study that describes the activity of colorectal cancer patients diagnosed within North Trent between 2006 and 2008³⁴. Analysis showed that patients grouped into eight different survivorship pathways, and the costs for each grouping were estimated.

Box 6: Costs associated with different survivorship pathways

Spend per Patient in Treatment and Survivorship Phases by Survivorship Outcome Pathway (£k)



Note: To obtain spend per patient, HRG 4.0 codes were costed using the 2010/11 National Tariff; costs are inpatient only, excluding locally agreed costs (such as chemotherapy), and priced at the spell, rather than episode, level (in line with how hospitals receive funding from their PCT)

The survivorship costs vary according to the nature of the person's needs, and for some cases can potentially be greater than the treatment phase³⁵. This insight offers the opportunity to explore how each group of patients is managed, and whether there are ways to manage treatment that avoid potential complications for each group, and thus the subsequent costs, which may fall within the cancer treatment period or afterwards (non-cancer).

Improving outcomes and reducing expenditure

4.8 To unlock resources, it is necessary to identify the points at which it is possible to intervene. This requires analysis of patient needs and pathway phases, as the requirements of patients will be different. An example of this approach is shown in Box 7.

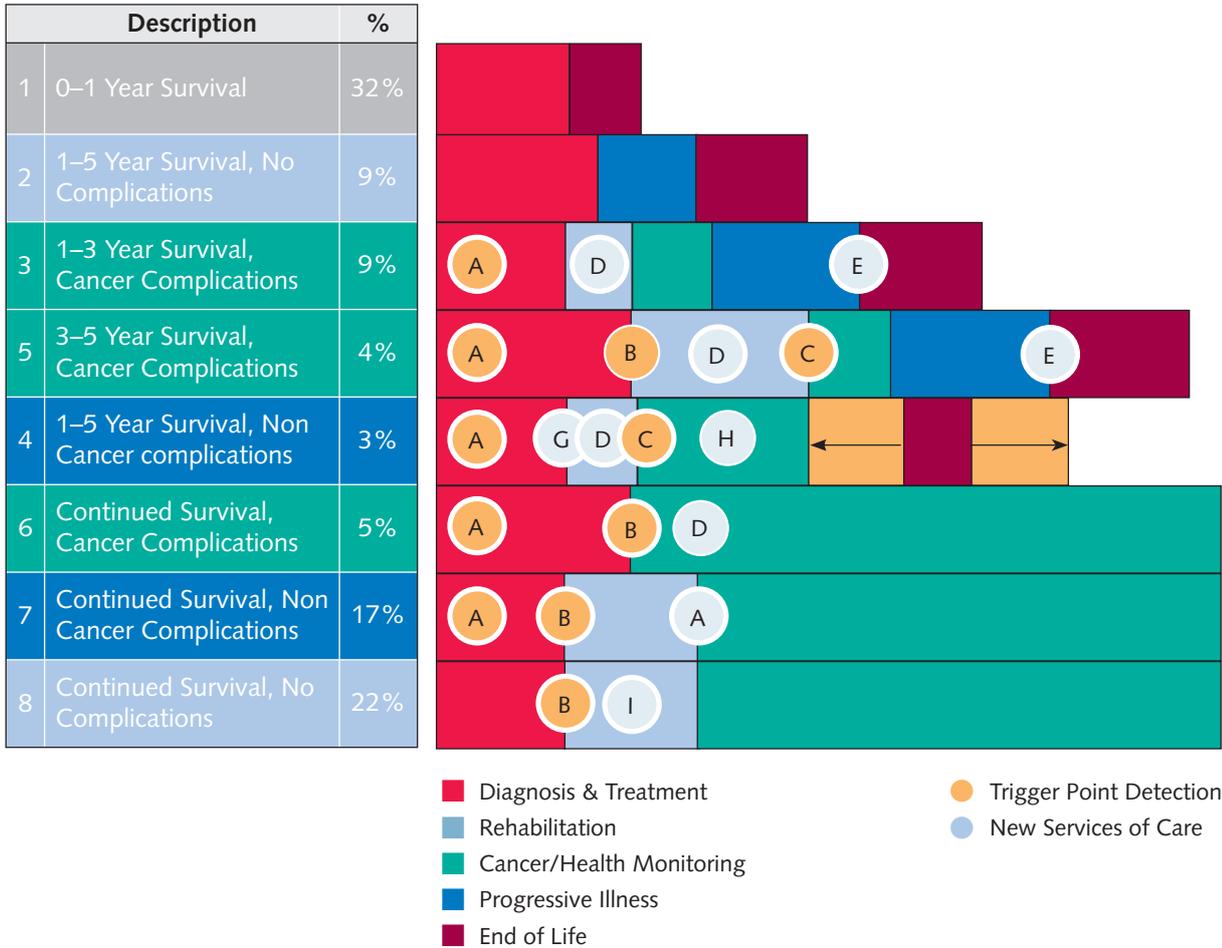
4.9 Such modelling gives a framework to explore other ways of meeting needs; for example, investigating whether:

- > Patients who survive for 1–5 years with non-cancer complications (Group 4) could be alternatively supported through increased GP management of co-morbidities;

- > Patients who continue to survive with cancer complications (Group 6) may be better supported through access to an MDT at the point of diagnosis, with subsequent on-going MDT support;
- > Patients who continue to survive with no complications (Group 8) may require fewer resources, provided that they receive appropriate cancer rehabilitation, are educated about the symptoms of recurrence, and know how to rapidly re-enter the system.

4.10 From a data perspective, the redesign of services to incorporate stratified care pathways requires the identification of groups of patients who can be differentiated according to their need for resources. However, there are challenges to achieving this: real-time information on cancer survivors is under developed, and the costing systems used by commissioners hinder accurate identification of certain activity. This highlights the need to improve survivorship intelligence.

Box 7: Assessing the interventions that can improve outcomes – the example of colorectal cancer in North Trent



Note: x-axis indicates weeks relative to colorectal cancer diagnosis; letters indicate interventions

Key:

- A = MDT special consideration at diagnosis (and consequently may require on-going MDT involvement)
- B = Symptom education and supportive information
- C = Remote carcinoembryonic antigens (CEA) test monitoring/ CEAs at 125 to 150 weeks
- D = One-to-one care and support
- E = Enhanced active palliative care Advanced Care Planning – early review with intermediate care
- F = GP-led monitoring for chronic co-morbidities
- G = Tailored treatment summaries to GPs
- H = Provision of single point of contact with care services to support patients with multiple morbidities and ensure joined-up care
- I = Rapid care re-entry contact points

Unlocking resources: the example of follow-up

4.11 A review of case notes of cancer survivors estimated that follow-up costs £1,554 per patient over a 5 year period³⁶. Excluding inpatient costs, this is equivalent to 4–5% of the total cancer budget.

4.12 However, as set out in Chapter 6, a one size fits all approach may not be the most appropriate. Some patients will require consultant-led follow-up, however a growing proportion can be prepared and supported to self-manage, with remote monitoring and timely re-access to the system initiated either by patient or professional, and encouraged to take as much responsibility for their health and well being as possible.

4.13 To unlock resources we need to:

- > Support patients in self-managing their condition where appropriate. It is projected that this could save two outpatient appointments per year per patient.
- > Adopt shared care arrangements for those at moderate risk of recurrence or who are suffering some consequences of disease.

- > Provide consultant-led care for those patients receiving on-going treatment, or with complex care needs.

4.14 In low- and medium-risk patients the use of outpatient appointments for follow-up can be reduced and the resources reallocated to more appropriate care, including:

- > Holistic assessment of needs and care planning
- > Regular remote monitoring; and
- > Empowering patients to manage the consequences of cancer and its treatment.

4.15 Breast and bowel cancer have been used as example pathways to estimate the demand for new models of survivorship follow-up support up to five years after initial diagnosis, and following completion of primary treatment. This study design permits us to estimate the reduction in the number of outpatient appointments that might be possible.

4.16 The number of bowel and breast cancer survivors is estimated to increase substantially:

	Bowel ³⁷		Breast	
	2015	2020	2015	2020
Newly diagnosed	35,000	38,000	44,000	48,000
Survive 1 year	27,000	29,000	43,000	47,000
1–5-year survivors	98,000	107,000	164,000	179,000

4.17 Using evidence from the stratified cancer care pathway pilot sites³⁸, which was validated by a range of experts for this analysis, we can estimate the number of patients who would require each kind of follow-up support. Given the uncertainty inherent in this estimation, an upper- and lower-bound figure has been used rather than a central estimate.

	Bowel		Breast	
	2015	2020	2015	2020
Supported – self-management (lower bound: bowel = 15%; breast = 50%)	14,000	16,000	82,000	89,000
Supported – self-management (upper bound: bowel = 50%; breast = 70%)	49,000	53,000	115,000	125,000
Shared care (lower bound: bowel = 35%; breast = 35%)	34,000	37,000	57,000	62,000
Shared care (upper bound: bowel = 35%; breast = 15%)	34,000	37,000	24,000	26,000
Complex care (lower bound: bowel = 50%; breast = 15%)	49,000	53,000	24,000	26,000
Complex care (upper bound: bowel = 15%; breast = 15%)	14,000	16,000	24,000	26,000

4.18 On the basis of the assumption that a patient on a supported self-management pathway would need two fewer outpatient appointments per year, and that those on shared care would need one fewer per year, we can estimate the reduction in the number of outpatient appointments required to deliver the new models of care.

	Bowel		Breast		Breast + Bowel	
	2015	2020	2015	2020	2015	2020
Outpatient appointments (lower bound)	62,000	69,000	221,000	240,000	283,000	309,000
Outpatient appointments (upper bound)	132,000	143,000	254,000	276,000	386,000	419,000
Central estimate	97,000	106,000	237,500	258,000	334,500	364,000

4.19 To put this into context, in 2010/11 there were 70 million outpatient appointments, of which 2.178 million were follow-up appointments for clinical and medical oncology. Other specialties will be responsible for some cancer patient follow-ups, but we are unable, at this stage, to quantify this.

4.20 At the levels of clinical activity estimated for breast and bowel cancer in 2020, 364,000 outpatient appointments at present day tariff costs (£98 per clinical oncology follow-up appointment)³⁹ represents £35.7 million of resource. Some of this would need to be reinvested within survivorship services.

Wider resource savings projections

4.21 Using the experience of bowel cancer in North Trent and similar cost analyses undertaken in London, it is possible to project wider survivorship savings across some cancers.

4.22 Studies show that a major driver of costs is progression of disease. So it is important that the NHS does everything it can to diagnose cancer early and to treat it promptly and effectively. However, there are also steps that can be taken in the survivorship pathway. A study in Manchester⁴⁰ suggests that once inpatient, outpatient and emergency costs are considered, it should be possible to unlock savings of £1,000 per patient through a stratified approach to follow-up, pathway

efficiency and better management of co-morbidities.

4.23 The Nuffield Trust's report, *Understanding Patterns of Health and Social Care at the End of Life* (2012), identifies the use and associated costs of NHS and social care services by more than 73,000 individuals in the last months of their lives. Significantly, it shows how important the interaction between health and social care can be for many people at the end of life. Nuffield are currently working on a project looking at the use and cost of social care and hospital-based care by cancer patients following their diagnosis, due for publication in 2013⁴¹. This will help commissioners better understand the complex relationships between health and social care resource utilisation.

4.24 Improved survivorship services will require investment. For example, assessment and care planning requires clinical nurse specialist time, and it is estimated that this may cost between £15–20 million per year in England in staff time costs for 200,000 patients. This cost is approximately equivalent to one additional outpatient appointment on completion of first definitive treatment⁴².

Taking action

4.25 Adopting new models of care requires a reallocation of resources across the pathway, including between providers. At present, secondary care providers maintain ownership of cancer patients during the follow-up period, typically for five years. The tariff does not currently break down follow-up activity into its component elements of care, and consequently there is a lack of clarity about how diagnostic tests and on-going support for patients is funded. Most outpatient activity is funded through block contracts, not by speciality, and further work is needed to understand how to effect these changes.

4.26 Work is required to further understand whether funding models for chronic conditions can inform cancer commissioning, and whether personal health budgets may be suitable for cancer survivors.

4.27 It will be important for commissioners and providers to agree local tariffs or gain share arrangements to incentivise the changes required.

4.28 There is more work to be done to understand the cancer population, and Macmillan will focus on this in 2013 and onwards with their Cancer Population Evidence Programme.

Summary of evidence

National Routes from Diagnosis (Wells, J. Woolmore, A., Welchman, T., Edwards, K.L., Harris, K., Nai, H., Flynn, F., Ritchie-Campbell, J, Forman, D.) described patient outcomes from diagnosis onwards, based on their use of services, co-morbidities and length of survival. This 'survivorship outcomes framework' was reported for national cohorts diagnosed in 2001 with three cancers: colorectal, multiple myeloma and Hodgkin's disease. The work was presented at the National Cancer Intelligence Network (NCIN) Cancer Outcomes Conference 2011 and a paper is in preparation.

Routes from Diagnosis North Trent (Woolmore, A., Adrian, R., Edson, C., Maher, J., McClelland, S., Flynn, J., Thomas J.) took *National Routes from Diagnosis* to a local level, testing the stability of the original structure and simplifying the framework to assist in service redesign. The project was performed in collaboration with Macmillan Cancer Support and presented at the NCIN Cancer Outcomes Conference 2012.

Evaluation of the Midhurst Specialist Palliative Care Service. (Noble, King, N., Woolmore, A., Hughes, P., Winslow, M., Melvin, J., Brooks, J., Bravington, A., Ingleton, C., Bath, P.) Macmillan Cancer Support commissioned an evaluation of the Midhurst Service, designed to assess whether the service is meeting its operating principles, its replicability as a model of care, and to gather evidence to inform future commissioning and funding intentions. The evaluation consisted of an economic and qualitative component. This work informed the Palliative Care Funding Review and a paper is in preparation.

Further reading

Mistry, M., Parkin, D., Ahmad, A. & Sasieni, P. Cancer incidence in the United Kingdom: projections to the year 2030. *Br. J. Cancer* **105**, 1795–1803 (2011).

Halsall, D. personal communication – Cancer survivorship: taking action to improve outcomes – draft economic case. (September 2012)

Living for Survival: Median Cancer Survival Times (Macmillan Cancer Support, November 2011).

Maher, J. & McConnell, H. New pathways of care for cancer survivors: adding the numbers. *Br. J. Cancer* **105** (Suppl. 1), S5–10 (2011).

5. Taking action: Information and support from the point of diagnosis



Key messages:

- > Offer support from the point of diagnosis.
- > Patient experience is improving, but there are gaps in services that need addressing.
- > CNSs can play a key role in improving patient experience.
- > The decisions taken about treatment options may impact upon quality of life long after treatment has finished: offer patients support in making the decisions that best reflect their individual priorities.
- > Early cancer rehabilitation is important: it can prevent avoidable ill health and is more effective when provided early to avoid conditions becoming more complex and costly to treat later on.
- > Offer patients support in considering work and education options from a very early stage; and offer patients with complex work support needs onwards referral to specialist vocational rehabilitation services.
- > Using Patient Reported Outcome Measures (PROMs) to routinely collect information about patient symptoms, concerns and quality of life, from diagnosis onwards, will help focus on what really matters to patients.

5.1 As part of the engagement process in developing this document, we have heard from a range of clinical, charity and patient stakeholders that empowering and preparing people for their life after cancer treatment should begin from the point of diagnosis. This is the first step in the survivorship pathway.

5.2 “Ensuring that people have a positive experience of care” is Domain 4 of the NHS Outcomes Framework. The National Cancer Patient Experience Survey (NCPES) shows that large proportions of

respondents report positive experiences of care and that, importantly, patients’ experiences are improving.

5.3 However, there are areas of weakness across the pathway, as well as variations between Trusts, tumour groups and different groups in society (e.g. older and younger patients). There is further work to be done to understand more about the reasons for this. There are also specific gaps in services, many of which relate to survivorship (e.g. on issues such as access to advice on finances, help when

patients have left hospital and on the quality of written information).

5.4 To improve this step in survivorship all patients should be offered:

- > Information about their cancer, and their support and treatment options, including the short- and longer-term consequences of treatment.
- > Support in making decisions that are appropriate for them.
- > Optimal treatment to maximise their chances of cure and minimise the risk of long-term consequences.
- > Support through treatment itself, including support for lifestyle interventions that may have a positive impact on the outcomes of treatment and survivorship.
- > Advice and support on longer-term planning, including considering options on work, finances and education, as appropriate.

5.5 The support needs of carers should also be addressed.

5.6 This chapter sets out how the survivorship agenda can play a role in delivering this support.

Information about cancer support and treatment options

*"I would have liked more information on my diagnosis, my status and the X-rays/ test results ... I think having a copy of my own hospital notes would have been helpful."*⁴³

(Female with non-Hodgkin's lymphoma, 5 years after diagnosis)

5.7 Informed patients tend to have a better experience, feeling able to participate fully in shared decisions about their treatment and care. A range of actions have been taken to support the process of informing patients, including:

- > Improving the consistency of written information on different aspects of the cancer pathway;
- > Tailoring information so that it can best meet the individual needs of cancer patients;
- > Supporting healthcare professionals in accessing, prescribing and dispensing information to patients in a timely and accessible manner; and
- > Developing the communication skills of healthcare professionals so that they feel confident in entering into often

challenging discussions with patients, such that patients may make informed decisions.

5.8 The National Cancer Patient Experience Survey (NPCES) found that the majority of patients had positive experiences of the written or verbal information received, as set out in Box 8. However, there was significant variation between the best and worse providers, and there are clear gaps in some areas of information, such as financial help for people affected by cancer.

5.9 Patients and carers may require information about issues other than their cancer or treatment options. For example, the financial impact of cancer can be felt very early in the cancer journey and it is important that patients are given information on the benefits and other forms of financial support that may be available. Despite this, access to financial benefits was the worst aspect of cancer patients' experience.

5.10 The evidence of financial need amongst cancer patients is clear. In 2011, for example, benefits advisers accessed

Box 8: Patients' experience of written and verbal information (2012 survey)

Issue	Overall percentage	Highest performer	Lowest performer
Given written information about tests that was easy to understand	86%	98%	67%
Given written information about type of cancer they had that was easy to understand	69%	86%	45%
Given written information about side effects of treatment that was easy to understand	75%	87%	61%
Given information about support/self-help groups by hospital staff	82%	91%	60%
Given information about financial help and benefits by hospital staff	52%	77%	32%
Given written information about the operation that was easy to understand	73%	88%	43%
Family or someone close to them definitely received all the information they needed to help care for them at home	60%	87%	45%

over £200 million for cancer patients⁴⁴. To help patients understand what support they may be eligible for, an online tool has been developed, which was accessed 38,000 times in the last year⁴⁵.

5.11 There is a huge range of information and support provided by cancer charities to patients and carers. This includes provision of information, telephone support and information lines, buddy schemes, online forums, patient and carer events, and support for parents and siblings of children who have cancer.

Support in making decisions that are appropriate for them

5.12 Cancer treatment and care involves complex decisions in which the benefits and drawbacks of different options can be finely balanced, and that can have both short- and longer-term implications. For example, one treatment may offer the chance of a better clinical response, another a more favourable side-effect profile. It is important that clinicians support patients in making these choices using a process of shared decision making – ‘no decision about me without me’.

5.13 Patient decision aids (PDAs) help patients make difficult decisions about their treatment when there is no clinical

evidence to suggest that one treatment is better than another. PDAs help create a personal summary by recording questions asked and answers given. This can be useful to discuss treatment preferences with clinicians. Research shows that PDAs are effective in helping patients make informed choices about their healthcare, and increase patients' awareness of expected risks, benefits and likely outcomes.

“Nobody warned me that having 16 centimetres of intestine removed would have such a severe effect on my bowel movements, and little dietary advice has been forthcoming.”

(Male with colorectal cancer, 1 year after diagnosis)

Box 9: Example of PDA for cancer

Breast cancer

A patient decision aid has been developed for older women considering adjuvant radiotherapy after a lumpectomy for breast cancer. It details each treatment option's benefits, risks and side effects, tailored to the patient's clinical profile, with steps to guide the patients to their decision. It has tested well, with patients experiencing a significant reduction in decisional conflict⁴⁶.

5.14 Information from PROMs and clinical audits also help patients understand the clinical outcomes and quality of life experienced by other patients who have received the treatment they are considering, and so help manage their expectations.

Optimal treatment to maximise chances of cure and minimise risk of long-term consequences

5.15 Although access to treatment is outside the NCSI's scope, it is important that clinicians and patients consider the long-term consequences of treatment, as well as immediate efficacy, when making decisions. For example:

- > Nerve-sparing prostate cancer surgery can reduce the impact of longer-term problems such as erectile dysfunction and incontinence.
- > Newer targeted forms of radiotherapy – for instance, IMRT – may reduce long-term side effects, such as mouth dryness and soreness.

"I feel I am one of the lucky ones but feel that one should be made much more aware of the magnitude of the side effects of this particular radiotherapy treatment, i.e. how you will feel, the mood swings and how best to deal with them and also the time to expect a good recovery. (It seems too optimistic to me!)"

(Male with prostate cancer,
2 years after diagnosis)

Support during treatment itself

"I have had tremendous support and treatment and cannot speak highly enough of all the staff with whom I have come into contact. The support has been invaluable and has made all the difference, both physical and mental, to my recovery."

(Female with colorectal cancer,
2 years after diagnosis)

5.16 The support offered during treatment can be important in helping patients withstand the effects of treatment, and in preparing them for longer-term survivorship. Evidence shows that access to a clinical nurse specialist (CNS) has a very positive impact on patients' experience of care. On every question in the NCPES, patients who had contact with a CNS were more positive than those who did not. However, there is evidence that some older patients in some tumour groups, and some patients who started treatment over 5 years ago, have unequal access to the support of a CNS. Given this, commissioners and service providers will want to assess their CNS provision.

5.17 Patients and their carers will benefit from a range of support, such as specialist nutritional advice, physiotherapy, lymphoedema care, speech and language therapy, occupational therapy, social work and psychological support. These are often known as cancer rehabilitation, and are intended to help improve patients' quality of life, and to maximise the efficacy and tolerability of treatments they receive. Although cancer rehabilitation encompasses many different interventions, its objective can be summarised as helping patients to help themselves lead as full a life as possible. There is a perception that cancer rehabilitation only starts after cancer treatment – however, there are significant advantages for some patients

to starting in advance of treatment, sometimes called 'prehabilitation'. Box 10 provides an example.

5.18 A range of resources have been developed to support commissioners and providers in enabling patients to access high-quality cancer rehabilitation tailored to their level of need, as set out in Box 11.

Advice and support on longer-term planning, including considering options on work and finances

"I have returned to work full time because I want my life to return to 'normal'."

(Female with breast cancer,
1 year after diagnosis)

5.19 There are around 600,000 people of working age living with cancer in England⁴⁷. Around 100,000 people of working age each year in England are diagnosed with cancer. This means that, on average, there will be around 550 patients per provider per year for whom returning to work will be a consideration.

5.20 Cancer and its treatment can impact upon patients' ability to work. It can also lead to major changes in a person's attitude to work/life balance. However, many people who have had cancer want

Box 10: 'Prehabilitation' in preparation for lung cancer surgery

Curative lung cancer surgery removes a substantial portion of normal functioning lung to ensure clearance of the tumour and the incision also disrupts the chest wall. Both lead to a loss of lung function and reserve, which puts the patient at risk of complications in and out of hospital.

Heartlands Hospital developed a programme to help patients prepare for surgery so that they might recover as quickly as possible, including:

- > Smoking cessation advice (for patients who need it)
- > Nutritional support (for patients who need it)
- > Education on lifestyle change, prognosis, what to expect, pain management and dealing with breathlessness
- > Pulmonary rehabilitation

The programme was evaluated with 37 patients from May 2010 to April 2011. Data were compared with a non-intervention group of 155 patients over the same period.

The results show reductions in complications, intensive care admissions, length of hospital stay and readmissions. Patients responded well to the programme and the new service costs of £188 per patient were offset by reductions in other costs, resulting in an overall saving of over £1,250 per patient.

A female patient on the programme, aged 73, said:

“At the beginning the physiotherapist explained to me the implications of the diagnosis. This knowledge helped me to understand my forthcoming surgery and lessened the fear and anxiety. I also understood that by taking part in the physiotherapy classes my fitness before surgery would aid a quicker recovery and it did as I was only four days in hospital after surgery. I have experienced excellent rehabilitation due to the process.”

Box 11: Cancer rehabilitation care pathways

Rehabilitation care pathways have been developed by NCAT for the following forms of cancer:

- > Breast cancer
- > Brain and CNS
- > Colorectal cancer
- > Gynaecological cancer
- > Head and neck cancer
- > Lung cancer
- > Upper GI and oesophago gastric cancer
- > Urological cancer

Pathways have also been developed for the following conditions associated with cancer and its treatment:

- > Anorexia, cachexia and weight loss
- > Breathlessness
- > Continence
- > Dysphagia
- > Fatigue
- > Lymphoedema
- > Metastatic spinal cord compression
- > Mobility and loss of function
- > Pain

These pathways are available here: <http://www.ncat.nhs.uk/our-work/living-with-beyond-cancer/cancer-rehabilitation#tab-ncrab>

Other useful pieces of guidance and evidence include:

- > Cancer and palliative care rehabilitation, a review of the evidence – update:
http://ncat.nhs.uk/sites/default/files/work-docs/NCAT_Rehab_EvidenceReview__2012FINAL24_1_12.pdf
- > Cancer rehabilitation workforce model, briefing paper:
<http://ncat.nhs.uk/sites/default/files/work-docs/NCAT%20Rehab%20Workforce%20model%20Briefing%20Paper.pdf>

Supporting and improving commissioning of cancer rehabilitation services.

to go back to work when they feel ready and able. Despite this, they can struggle to do so. Cancer survivors are 37% more likely to be unemployed than people who have not had cancer⁴⁸. This can have an important impact on outcomes: work contributes to financial independence and material comfort. It provides a sense of purpose in life and has a strong influence on identity and self-esteem. It creates structure and order in daily routines and is an important source of social interaction and community engagement. All of these factors contribute to a person's quality of life. Cancer can also have a significant impact on the finances of carers, who may need to take time off work, reduce hours or leave employment entirely.

"My quality of life changed when I was diagnosed. Clearly, I am very happy to be in remission but I am very worried about the future and the chance of cancer returning. I don't think I will ever be able to do a job that will pay enough to clear our debts and this scares me."

(Male with non-Hodgkin's lymphoma,
2 years after diagnosis)

5.21 The costs to the Exchequer of cancer patients not being able to work when they want to are significant. NCSI work shows that, through targeted support, many cancer patients can return to work, although this can require some NHS

investment to deliver savings elsewhere in the system, as set out in Box 12 below.

Box 12: Supporting cancer patients in returning to work – The Christie Hospital and Shaw Trust⁴⁹

The Christie Hospital and Shaw Trust worked together to create a pilot programme to adopt a case-management approach to vocational rehabilitation. This service model provided one-off advice and guidance to patients, with signposting to other services, as well as expert and on-going support with specific return to work problems, legal and benefits issues, and liaison with employers.

In total, 260 patients received the intervention, with the average cost per patient just under £385. For patients who received an intervention between referral and discharge, 43% went from 'not working' to 'working' (11.4%) or 'sick leave' to 'full work or modified work' (31.6%). An evaluation found that the intervention paid for itself if a patient worked an additional 12 weeks.

5.22 For patients who would like to return to work after cancer, it can be important to begin planning for this early in their treatment, not least because their treatment options may have different impacts on their ability to work. Healthcare

professionals can play an important role in facilitating this, as set out in Box 13.

Box 13: The 5 Rs – the role of healthcare professionals in supporting patients in returning to work⁵⁰

Health professionals need to be able to:

Raise work issues with patients early in the treatment pathway in a sensitive and acceptable manner

Recognise the risk factors for patients who wish to return to work but are struggling to do so

Respond effectively to the straightforward work problems that patients identify

Refer patients who have more complex difficulties to the appropriate specialist services

Revisit work issues at intervals during treatment

5.23 In order to support patients effectively, it is not necessary for health professionals to become experts in vocational rehabilitation and employment law. Instead they need to understand that work is an important component of health and wellbeing, and to do all they can to enable patients to think positively about work.

5.24 There is a distinction between ‘work support for people with cancer’ and ‘specialist vocational rehabilitation’.

Everyone with a cancer diagnosis who is employed, or has the potential to be employed, should receive support to remain in or return to work. A subset of people have more complex needs that are best met by specialist services, where the interventions are provided by skilled vocational rehabilitation professionals.

5.25 A range of tools have been developed to support health and social care professionals in signposting patients to obtain further support. For cancer patients, work support and vocational rehabilitation is required at three levels:

- > Level 1 – open access to information and support. All patients who are in work, or have the potential to work, should be asked about their employment and receive information on working with/after cancer and signposting to further support through, for example, personalised information and the support to understand it.
- > Level 2 – active support for self-management. People with specific concerns or worries should be provided with resources and services to support self-management, including access to self-management courses.

- > Level 3 – vocational rehabilitation. People with complex needs should be referred to a vocational rehabilitation service for specialist support.

5.26 In order to support patients, providers should be:

- > Making available adequate training and ensuring processes are in place to enable delivery of the 5 Rs by health professionals (Box 13)
- > Discussing with the patient their wishes in relation to work, the impact cancer will have on their work and where patients can go for help (this discussion is likely to be led by the clinical nurse specialist as part of the Holistic Needs Assessment); and
- > Signposting to appropriate specialist vocational rehabilitation services to meet the needs of patients who have Level 3 support requirements.

5.27 The final evaluation of the NCSI vocational rehabilitation project is now available to support commissioners and providers in planning and delivering effective back-to-work services⁵¹. It includes:

- > A new model of work support interventions for people with cancer;

- > A strategic framework that presents a blueprint for the planning and delivery of cancer work support services;
- > An outline of specialist vocational rehabilitation interventions for people with cancer;
- > A competency framework to underpin the delivery of specialist cancer vocational rehabilitation; and
- > Evidence from the pilots run.

5.28 Macmillan has a comprehensive range of free tools and resources and e-learning courses about work and cancer; see <http://www.macmillan.org.uk/work>

Making action happen

5.29 To provide support from the point of diagnosis, areas that require further exploration are:

- > Consider best mechanisms to audit provision of information on working with cancer.
- > Learn from examples of cancer rehabilitation; adopting pre-treatment 'pre-habilitation' at scale would prevent avoidable ill health and avoid conditions becoming more complex and costly to treat later.

- > Identifying the likely needs of patients before treatment commences.
- > Ensuring that work support is a more explicit component within the assessment and care planning process.
- > Investigating the feasibility of and piloting schemes to package up rehabilitation budgets into rehabilitation prescriptions, including specialist vocational rehabilitation.
- > Investigating change through the use of financial incentives such as local CQUIN frameworks.

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6. Taking action: Promoting Recovery



Key messages:

- > Patients' wellbeing will be greater and their demand for services lower if they get the support that is relevant to their particular needs, and which promotes healthy lifestyles and independence.
- > The 'recovery package': a combination of assessment and care planning, Treatment Summary, and a patient education and support event (Health and Wellbeing Clinic) is potentially the most important building block for achieving good outcomes. Providers and commissioners who wish to achieve good patient outcomes will want to implement these measures.
- > These interventions can deliver immediate benefits to patients as well as supporting improvements in care further down the survivorship pathway.
- > Re-allocate any cost efficiencies, achieved through follow-up, to other areas of the survivorship pathway, such as assessment and care planning, or community support.

6.1 Cancer can be an extremely debilitating disease, and the impact of treatment can add to this. Promoting recovery is the second step on the survivorship pathway.

6.2 Patients frequently report that the period after completing primary treatment can be particularly difficult. They may lack confidence and feel isolated or abandoned. The recent PROMs survey highlighted high levels of anxiety and fear of recurrence and dying one year after diagnosis. This period is particularly important as a time for empowering patients towards supported self-management.

"Cancer has taken my self-esteem. My confidence disappeared, as did my sex life. Such a huge sadness for me (I still cry about it in private when I'm low), my husband just couldn't cope and wouldn't talk about any of it. He stayed but became distant – I hardly get even a kiss now or a hug. I long to be cuddled."

(Female with breast cancer,
3 years after diagnosis)

6.3 The process of physical and psychological recovery can be lengthy and require tailored support. This chapter sets out the steps to improve the support available to cancer patients in promoting their recovery, including:

- > Ensuring that holistic assessment and care planning are a routine part of every patient's pathway;
- > Ensuring that all patients are offered a Treatment Summary;
- > Promoting Health and Wellbeing Clinics and other patient and education events as a way of raising awareness of the support available and enabling patients to engage with these services; and
- > Providing tailored support to children and younger people, with their specific recovery needs.

"When treatment ends you feel very vulnerable that the cancer will return, but I had no-one professional to turn to for support ... It took a year to recover from my treatment and I still feel 'haunted' by some of my experiences. I felt very alone, and most of my care and support fell on the shoulders of my daughter."

(Female with non-Hodgkin's lymphoma, 3 years after diagnosis)

"I do have a fear of dying and cancer returning (I seen what it did to my mother!) and I would have liked someone to sit down with me for 10 minutes and explain what's happening and can happen. This has never been done. Maybe the fears of this illness can be reduced by some straight talking."

(Male with non-Hodgkin's lymphoma, 1 year after diagnosis)

Assessment and care planning

6.4 A key to good survivorship is creating a shared understanding between patient and healthcare professionals about what to expect during recovery, and identifying any needs to be addressed. Three interventions support this:

- > Conducting Holistic Needs Assessments in partnership with the patient, using appropriate assessment tools, and preparing a subsequent care plan, focusing time and resources on areas where need is greatest.
- > Producing a Treatment Summary documenting the care provided, informing the GP and patient about prognosis and planned future care, and highlighting signs and symptoms of recurrence and consequences of treatment.

- > Developing a patient education and support event such as the Health and Wellbeing Clinic.

6.5 Holistic Needs Assessments should take place at or near diagnosis, and at the end of treatment. Further assessments may be required if circumstances change. Holistic Needs Assessments and care planning were included as a Cancer Peer Review measure in April 2011. It is estimated that conducting a Holistic Needs Assessment (including relevant paperwork) takes about one hour of nursing time. The cost of this proactive care planning will be offset by reduced unplanned contact, as it ensures that patients have appropriate information and a clear management plan. An electronic self-assessment tool to expedite the process is currently being tested. Such a tool will also populate the care plan with patient information, following appropriate discussion.

6.6 The Treatment Summary should include the READ codes that inform the GP IT systems that the patient had cancer, their treatment and whether they are at risk of developing other conditions, such as cardiac disease, osteoporosis and diabetes. The purpose is to inform primary care of actions to be taken, and who to contact with questions. The patient should also receive a copy to improve understanding and share with others if they choose. It is available in an electronic format on the

main cancer information systems – Somerset Cancer Registry and Inflex CIMs Ltd.

6.7 These interventions should be supported by a primary care cancer care review. The Quality and Outcomes Framework gives points for all patients diagnosed with cancer who receive a review by their GP within six months of confirmation of diagnosis of cancer. However, it does not stipulate what form the review should take, or how comprehensive it should be. To support GPs in conducting high quality cancer care reviews, the NCSI has worked with the main GP IT system providers, INPS and EMIS, to develop and test cancer care review templates.

6.8 The Macmillan Cancer Care Review templates enable GPs to code key areas of care consistently, and also act as an aide memoir for GPs to trigger discussions. Evaluation has been positive, with 79% of GPs finding the template fairly useful or very useful, and appreciating the prompts for reviewing medication and noting carers' details. Work is now underway to encourage the widespread use of the templates.

6.9 These interventions, when used in combination, can play an important role in establishing a baseline from which a patient's recovery can be planned and

Box 14: Implementing the Holistic Needs Assessment

Hull and East Yorkshire Hospitals NHS Trust, supported by the North East Yorkshire and Humber Clinical Alliance, redesigned the gynaecological cancer patient pathway to incorporate the Holistic Needs Assessment and to address the long-term consequences of cancer and treatment. The initiative has created a more efficient and cost-effective service, and enables patients to be referred to the most appropriate professionals to meet their needs. The work was highly commended in the Cancer Care category in the Nursing Times and Health Service Journal Care Integration Awards 2012.

supported. There is evidence from some test sites that this approach may help reduce emergency admissions and other forms of health service utilisation, as well as evidence that proactive care is a more efficient way of planning support⁵². Longitudinal data on the full benefits and costs are still being collected.

6.10 It is important to recognise that the interventions require a time investment, at least initially. At present, clinicians will often conduct an assessment without discussing it with a patient, so moving to this more structured process will require an adjustment. Staff may need training in assessment and care planning.

Patient education and support programmes

"I have recently (June 2011) been discharged from the hospital follow-up system ... I feel a bit lost. It might be helpful if there was a group to join, to share experiences and worries with fellow sufferers – you feel silly telling non-affected people about the horrors you imagine in the wee small hours!"

(Female with breast cancer,
3 years after diagnosis)

6.11 Once patients have completed their initial treatment, they may not be aware of available forms of support that may help them. This support can come from a range of sources, including the NHS, other statutory bodies, charities and support groups.

6.12 Patient education and support events at the end of treatment should be seen as an integral part of the recovery package. They aim to enable patients to have the confidence to take control and participate in their recovery, give them necessary information, and promote positive lifestyle change. Events typically include information about:

- > Healthy lifestyle choices, including being physically active and healthy weight management;
- > Signs and symptoms of recurrence or potential consequences of treatment, and what to do in the event of experiencing them;
- > Specific issues for their type of cancer;
- > Benefits and other financial support;
- > How to get back to work; and
- > Local services, facilities and other opportunities available.

6.13 Macmillan has piloted the Health and Wellbeing Clinic, a half-day event using a range of presentations and 'market stall' approaches to deliver the above aims. The evaluation found that:

- > Clinics are more effective if they are tailored to the needs and concerns of patients with particular forms of cancer.
- > The optimum number of participants is probably around 20–25.
- > Sessions should be interactive and informal.
- > Volunteers can play an important role alongside professionals, and are most effective if facilitated jointly by professionals and trained cancer survivors.
- > The major expense in delivering the clinics is staff time, which varies according to the model adopted. Estimated costs per session range from £1,000 to £3,000 in staffing/venue/materials/refreshment⁵³.

6.14 As a result of the clinics, patients' self-reported use of health services reduced⁵⁴, resulting in NHS savings. Patients also reported feeling less isolated, more empowered and having greater confidence to manage their own condition.

6.15 By the end of 2011, 26 clinics were in operation across England. If an average trust treats approximately 1,600 cancer patients each year, and roughly half of them opt to attend a Health and Wellbeing Clinic, this suggests that 5,000 clinics need

to be held each year. This does not include demand from relatives or carers, or reflect that some patients may wish to attend more than once. Take up will depend on whether Trusts recognise/adopt this as a mandatory part of treatment.

6.16 A range of other patient events using different methods of delivery are now available across England.

"I have not got the energy for day to day lifestyle, most things in life take a lot longer to complete and you have to work harder, i.e. to keep up with challenges at work or even to socialise. Pre-cancer people seem to live life in the fast lane whilst you feel as if you are on the outside looking in."

(Female with breast cancer,
5 years after diagnosis)

Box 15: Maggie's *Where Now?* pilot study

Maggie's *Where Now?* is a seven-week course to help people make the transition between active treatments and building the life they want beyond cancer. It provides support and information to:

- > Make lifestyle changes in exercise, nutrition and stress
- > Adjust to living with uncertainty and fears of cancer recurrence
- > Make effective post-treatment partnerships with medical teams
- > Take a fresh look at priorities at work, in home life and in relationships

Each 3-hour session includes a themed group discussion facilitated by a psychologist, a 40-minute exercise session with an exercise trainer and a shared meal around the kitchen table. A fundamental aspect of *Where Now?* is the support participants receive from other group members going through similar experiences.

Where Now? was introduced to Maggie's core programme in 2011. An on-going evaluation checks its effectiveness in providing the right form of support to help people make post-treatment changes and maintain these changes over time. Initial data from the pilot study of 32 participants show very promising results.

Box 16: Penny Brohn Cancer Care's *Living Well with the Impact of Cancer* courses

Penny Brohn Cancer Care has run over 100 *Living Well with the Impact of Cancer* courses across England since 2009. The course is modular, and can be delivered in a variety of formats, residential and non-residential, two-day, three-day and weekly. Led by trained facilitators, the course provides people with a tool kit of techniques that can help support physical, psychological and emotional health, and encourage self-management. Information is provided on healthy eating, exercise, and understanding the impact of cancer on emotions and relationships.

Different methods of relaxation and mindfulness are taught as self-help techniques to help people manage the stress of their cancer journey. People are encouraged to share experiences, and think about future steps they could take to 'live well'.

Early findings from a Westminster University evaluation show on average that reductions in the level of people's concerns still continue six-months later, and on average people report a significant improvement in their wellbeing, which remains six-months later.

Primary care support

6.17 It is now anticipated that, within a GP population of 10,000 patients, there may be up to 275 people who are at least 5 years from a cancer diagnosis⁵⁵. With increased survival from cancer and an ageing population, it is important that primary care proactively plans to support the growing number of people who are living with and beyond cancer. The GP is well placed to support these patients, both in identifying unmet needs and supporting them in the context of other illnesses.

6.18 To help with this, Macmillan and the BMJ Group are developing an online educational module to help GPs and other healthcare professionals assess and improve their knowledge and skills in specific areas of caring for people with cancer. Areas covered include the benefits of a proactive review in primary care, understanding the benefits of physical activity during and after treatment of most cancers, knowing the range of available information that can support people, and knowing more about the late effects of cancer treatment. This new module aims to reach up to 1,000 healthcare professionals in the first six months of use.

Children and young people

6.19 For children and young people, it will be particularly important to take into account educational needs as they begin their recovery from cancer. A range of pathways have been developed to support this, set out in Chapter 7.

6.20 The needs of family members should be taken into account, including the impact on any siblings, and the need for support for the parents.

Making action happen

6.21 In future we believe that:

- > All patients should be offered a Treatment Summary.
 - > All patients should be offered a Holistic Needs Assessment. The assessment may require input from a range of doctors, nurses and allied health professionals (e.g. dieticians, physiotherapists, occupational therapists, and speech and language therapists) depending on the nature of a patient's problems. These assessments can be delivered in a number of ways, one being dedicated clinics.
 - > Patients should have access to advice on vocational rehabilitation.
- > All patients should be offered advice on physical activity and weight management, and how to access appropriate programmes.
 - > All patients should be offered a written care plan.
 - > The care plan, or advice that a patient has declined a care plan, should be copied to the GP, who should document receipt and offer the patient a review within six weeks.
- 6.22** In order to support the promotion of recovery, more work is needed to:
- > Explore how the delivery of the package of survivorship interventions provided in secondary care could be incentivised through either financial or national audit measures.
 - > Build on work being piloted in trauma, diabetes and other disease areas to develop a 'recovery tariff' for those elements of the pathway beyond initial treatment.
 - > Work with commissioners to explore how best to include recovery support into commissioning intentions.

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7. Taking action: Sustaining recovery



Key messages:

- > Offer tailored follow-up to meet the needs of individual patients – stratifying patients for follow-up according to their risk can ensure that needs are better met and that resources are used more efficiently.
- > Offer specific support to adults who had cancer as a child or young person, who may develop particular issues years or decades later.
- > Helping patients to self-manage their condition plays an important part in improving follow-up – it is popular with those patients who are suitable and can reduce health service utilisation.
- > Physical activity can be as effective as many drugs in reducing recurrence – offer all patients support to be as active as possible.

7.1 Providing the right support to patients as they seek to sustain their recovery can improve quality of life and generate savings, which can be reinvested in other aspects of the survivorship pathway.

7.2 Key elements help sustain recovery for patients in remission at the end of treatment(s):

- > Provision of adjuvant therapies where effective, and maintenance therapies for some other cancers.
- > Information and education for patients is crucial to sustaining recovery and knowing when to ask for help.

- > Maintaining a healthy lifestyle, and in particular undertaking at least moderate levels of physical activity.
- > Providing appropriate remote monitoring and support to re-access specialist help when concerns arise.

7.3 In addition, many of the principles set out in step 2 remain important.

7.4 This chapter sets out:

- > The improved outcomes and cost efficiencies of new approaches to follow-up care;
- > How patients can be supported in self-managing their condition;

- > How remote monitoring is a major enabler in this phase of survivorship;
- > The significant role that physical activity, diet and weight management can play in helping patients stay well; and
- > The support required to help children and young people who have had a cancer diagnosis sustain their recovery.

New approaches to follow-up

"At the first follow up appointment with the surgeon (one year after surgery) I was disappointed to see a registrar who hadn't opened my file before meeting me – had no knowledge of my diagnosis or treatment etc. I found this insulting."

(Female with breast cancer,
1 year after diagnosis)

7.5 Routine follow-up of cancer patients takes up a good deal of service capacity, time and resources, and although individual professionals try to meet the on-going needs of patients, care is often organised around the convenience of services, conducted in overstretched outpatient clinics, with people often experiencing long waits. There is no capacity to expand to meet the increasing numbers of cancer survivors.

7.6 There is little evidence for the current model of follow-up; clinicians support the model as providing a way to monitor complications following treatment, detect recurrence and identify late effects of treatment⁵⁶, but there is no reason why these issues would coincide with an appointment scheduled months in advance.

7.7 For some patients follow-up can be expensive, inconvenient and cause anxiety, whilst others are very satisfied. Research suggests that different models of follow-up are acceptable to patients, if informed of the risks and benefits, given a choice and with a clear way to access further support⁵⁷.

"I attend the hospital approximately every six months for a scan (it is now yearly). Having a scan scares me more than when I was diagnosed with cancer."

(Female with colorectal cancer,
2 years after diagnosis)

"I have nothing but praise and gratitude for the nurse-led cancer follow-up team. Their positive attitude and cheerful kindness has helped me to remain positive too."

(Male with colorectal cancer,
2 years after diagnosis)

7.8 The NCSI tested a range of new approaches, focusing on tailoring the level and form of follow-up to the needs of individual patients, using stratified care pathways. Three levels of follow-up were identified:

- > Level 1 – Self-care with support and open access;
- > Level 2 – Shared care between patient and clinician; and
- > Level 3 – Complex case management through MDT.

7.9 The pilots showed that changing models of care requires a fundamental shift in the way follow-up is approached, as set out in Box 18.

A qualitative and in-depth study to explore patient experiences was undertaken; the results are shown in Box 19.

Box 17: Locations of testing of stratified pathways⁵⁸

<p>Breast</p> <ul style="list-style-type: none"> > North Bristol > Hillingdon > Brighton > Hull > Ipswich > Southampton 	<p>Colorectal</p> <ul style="list-style-type: none"> > North Bristol > Guy's and St Thomas' > Salford > Southampton 	<p>Prostate</p> <ul style="list-style-type: none"> > Hillingdon > Luton > North Bristol > Ipswich
<p>Lung</p> <ul style="list-style-type: none"> > Brighton > Hull 	<p>Testicular</p> <ul style="list-style-type: none"> > Southampton 	

Box 18: A new approach to follow-up	
Then...	Now...
Standard medical follow-up pathway	✓ Tailored pathway to meet patient needs
Holistic Needs Assessment — at diagnosis	✓ Holistic Needs Assessment — at diagnosis and post-treatment
Unmet needs post-treatment	✓ Needs identified and actioned
Verbal care plans	✓ Written care plans
Traditional clinic letters	✓ Treatment Summaries
Ad-hoc education	✓ Group learning, education and peer support
Little/no lifestyle advice post-treatment	✓ Improved access to physical activity, diet and weight management, and other support services
Clinic visits to receive test results	✓ Implementation of remote monitoring systems mean that many patients will not need to visit the clinic to receive their results.
Poor access to support and cancer rehabilitation programmes for those living with the consequences of treatment	✓ Improved access to support and cancer rehabilitation for those living with the consequences of treatment

7.10 NHS Improvement developed stratified cancer care pathways, an example of which is shown in figure 3 below, and which can be seen at <http://www.improvement.nhs.uk/cancer/Home/AdultSurvivorship/tabid/253/Default.aspx>

Box 19: Qualitative evaluation of test sites⁵⁹**Findings of the evaluation of NHS Improvement test site pathways for patients with breast, colorectal and prostate cancer**

Changes positively received by patients	Results that highlighted the importance of ability to re-access specialist services
59% of patients rated their care as very good or excellent.	47% of patients had needed to contact a health professional due to a concern related to their cancer.
Of those patients who were given a care plan, 84% found it to be useful.	78% of patients felt that they had enough information to help them manage their health.
83% of patients said that they felt confident in managing their own condition.	77% of patients felt that they had enough information to help them with the effects of their treatment.
42% had taken action to do more physical activity.	Only 55% felt that they had sufficient information and advice on the signs and symptoms of recurrence.

7.11 NHS Improvement prototypes in breast, colorectal and prostate cancer in adults were targeted to achieve 50% reductions in routine follow-up. Results show that stratifying patients for follow-up according to risk can realise significant financial savings, which can be re-invested in enhanced community support and services at other points in the pathway.

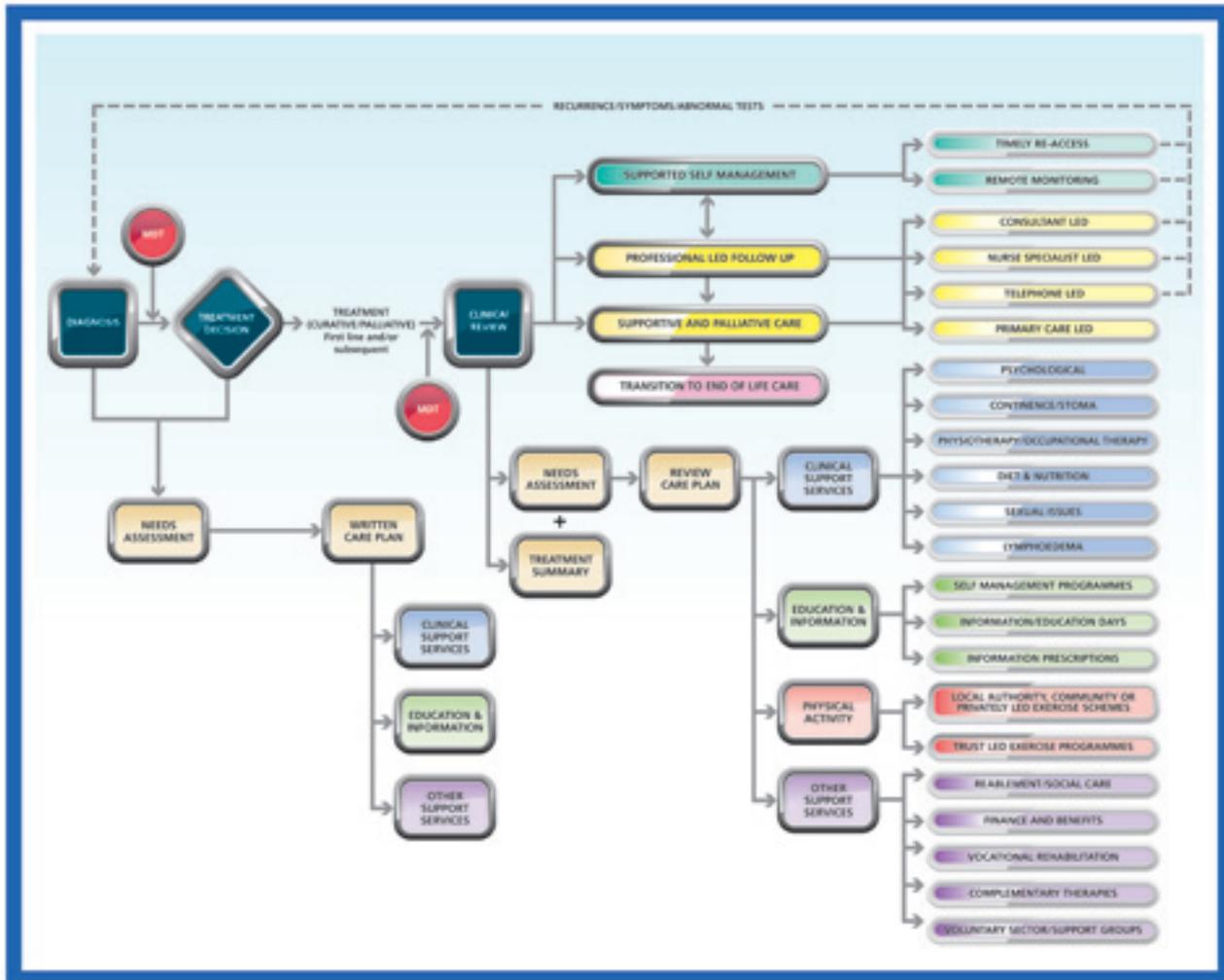
- > Reduced outpatient activity, with 3,400 prospective outpatient slots over 6 months saved across 7 prostate and colorectal tumour project sites as a result of using remote monitoring systems. It should be noted that there

was a wide variation in follow-up practices in different project sites and for different tumour types.

- > Reduced unplanned admissions for lung cancer patients, with a 6–8% reduction.
- > Reduced costs for patients, with fewer visits to hospital and less travel, parking and loss of work.

7.12 NHS improvement will publish a further document encapsulating the learning from all the adult cancer testing work, titled 'Adult Survivorship: From Innovation to Implementation', as a how

Figure 3: generic cancer care pathway



to guide to support implementation in practice. It is planned to be available end of March 2013 on the NHS Improvement website: <http://www.improvement.nhs.uk/cancer/Home/AdultSurvivorship/tabid/253/Default.aspx>

Supported self-management

7.13 An essential part of stratified care pathways is supporting patients to self-manage their condition where appropriate. Analysis from pilots suggests that a significant proportion of patients are suitable for self-management⁶⁰:

- > 70–77% of breast cancer patients can self-manage from two to three months after the end of treatment, or one year after diagnosis.
 - > 40–45% of colorectal patients can self-manage from four to six months after the end of treatment or stoma reversal.
 - > 28–44% of prostate cancer patients can self-manage, usually from two years after treatment.
 - > Some lung cancer patients will be able to self-manage for some periods, but, in general, are not suitable for this pathway.
 - > 90% of testicular cancer patients can self-manage from two months after the end of treatment.
- 7.14** As this approach is developed further by clinical teams, their experience will probably lead to more patients being seen to be suitable for supported self-managed follow-up.
- 7.15** Supporting effective self-management requires:
- > Comprehensive assessment of needs (see Chapter 5);
 - > Appropriate and effective remote monitoring systems (see Box 20);
 - > Personalised education and information (see Box 21);
 - > Good care coordination and a clear point of contact for patients, preferably someone who is already known to them;

Box 20: Remote monitoring

Self-managed follow-up at Southampton University Hospital

Two approaches have been developed and implemented to carry out safe remote monitoring for patients following treatment for breast, colorectal and testicular cancers. An in-house IT solution has been developed for remote monitoring of breast and colorectal cancer patients.

In addition, a pilot of a commercial web-based survivorship programme is being trialled with testicular cancer patients.

The pilots show that IT development needs to be accompanied by changes in team culture and practice. Further evaluation is required to establish the time and resource implications of this change.

Box 21: Personalised information and education

Enabling and empowering patients to self-manage.

If patients are to take on more responsibility for safely self-managing their follow-up, they need to be confident and have their skills for being able to assess their own progress and problems increased, particularly for understanding the signs and symptoms that may indicate a relapse. Self-management programmes provide patients with a set of skills to improve self-confidence. Examples include:

- > *Helping Overcome Problems Effectively (HOPE)* – six week (two and a half hour sessions) supported self-management programme for cancer survivors
- > *Healthy Essentials for Life after Testicular Cancer*, and *Healthy Essentials of Life after Colorectal Cancer*

Both courses are delivered by a clinical nurse specialist (CNS) and a cancer survivor, and cover issues such as identifying signs of recurrence, stress management, lifestyle and the emotional effects of cancer.

More information:

<http://www.ncsi.org.uk/what-we-are-doing/supported-self-management/>

- > Rapid re-access to help without recourse to a GP; and
 - > Payment mechanisms that reflect the true cost of delivering follow-up on all aspects of the system.
- savings in the cost of managing a patient over a year using this approach (£73 per breast cancer patient, £150 per colorectal cancer patient and £70 per testicular cancer patient) based on new local tariffs.

7.16 There are costs involved in implementing supported self-management, including ensuring that remote monitoring systems are in place, that tailored patient information is available, and providing self-management courses. On-going service redesign work at Southampton University Hospital Trust suggests modest

7.17 Brighton and Sussex University Hospitals NHS Trust tested better models of support for people with lung cancer, including a weekly joint clinic, proactive management of symptoms through attending physiotherapist and dietician appointments, benefits advice (at their Health and Wellbeing Clinic) and, early assessment and care planning. This

Box 22: Changing follow-up for patients with prostate cancer

At St George's Hospital in London, a 'PSA (**prostate-specific** antigen) tracker' was introduced for selected patients following their treatment for prostate cancer. The tracker enables the specialist to schedule, monitor and send the PSA result to the patient, replacing the need for a face-to-face follow-up appointment. This new service has been welcomed by both patients and staff. During the initial 6-month pilot, over 70 patients were enrolled in this new pathway, and the Trust expects the initiative will both enhance clinical governance and release over 600 face-to-face outpatient appointments per year. Plans are underway to set up similar systems for patients with bladder and renal cancers.

achieved an 8% reduction in unplanned admissions, compared to the previous year, for lung patients and a 25% reduction in their use of bed days⁶¹.

Physical activity

"I found my hospital treatment was only looking after the medical needs but no information about lifestyle and prevention advice for future."

(Female with breast cancer,
1 year after diagnosis)

7.18 There is strong evidence to show that physical activity can play an important role for cancer survivors, as set out in Box 23.

7.19 Promoting access to physical activity is also cost effective. The National Institute for Health and Clinical Excellence (NICE) endorses the delivery of interventions for physical activity in primary care as being highly clinically and cost-effective. It has been established that brief interventions for physical activity cost between £20 and

Box 23: Five reasons to help cancer survivors be more active**1. Physical activity can improve the experience of, and recovery from, cancer treatment**

- > Fitter patients are less likely to have anaesthetic or surgical complications following surgery⁶².
- > Staying active during cancer treatment can help improve physical function, including muscle strength and cardiovascular fitness⁶³, plus reduce levels of anxiety and increase self-esteem⁶⁴.
- > After treatment, physical activity can help recover physical function, manage fatigue, improve quality of life and mental health, and control body weight⁶⁵.

2. Physical activity can reduce recurrence of cancer and cancer mortality

- > A growing body of evidence suggests that maintaining or initiating physical activity after cancer diagnosis can influence disease recurrence and mortality for some cancers, including breast cancer^{66,67,68,69}, colorectal cancer^{70,71} and prostate cancer^{72,73}.

3. Physical activity can reduce the risk of developing other conditions

- > Lack of physical activity is a risk factor for several major chronic diseases, including coronary heart disease, stroke, diabetes mellitus, osteoporosis, obesity, some cancers and dementia. Risk reductions of 20–50% are possible for people who are active at the recommended levels relative to those who are inactive⁷⁴.
- > Physical activity can also help to manage existing chronic conditions such as cardiovascular diseases, musculoskeletal health conditions, and mental illness⁷⁵.
- > A Macmillan study showed that just under half (49%) of cancer survivors have at least one other chronic condition⁷⁶.

4. Physical activity can help maintain independence and wellbeing towards the end of life

- > There is accumulating evidence of the benefits of exercise for patients with advanced cancer. Systematic reviews of six studies in palliative care settings⁷⁷ and eight studies of patients with metastatic cancer⁷⁸ concluded that exercise was feasible for these patients and offered important benefits in physical functioning, symptoms and quality of life.

5. Physical activity can help to reduce service usage

- > Few studies have looked specifically at the economic impact of increasing physical activity among people with cancer. One randomised controlled trial showed that women having adjuvant treatment for early breast cancer who took part in a physical activity scheme had fewer unscheduled NHS interventions, fewer GP visits and reported significant improvements in physical functioning, quality of life and positive mood⁷⁹.

£440 per quality-adjusted life year (QALY) when compared with no intervention.

7.20 In cancer-specific physical activity interventions, a randomised controlled trial has demonstrated a significant reduction in NHS appointments for those in the exercise group in contrast to those receiving usual care⁸⁰.

7.21 However, provision of advice on physical activity is still not routinely incorporated into clinical practice and appropriate exercise programmes are not always easily available. Nearly one in five respondents to the 2011 PROMs survey would have liked more information on physical activity.

7.22 Research shows that cancer survivors want support in becoming more active, want this to be tailored to their needs and want being active to be their choice. To encourage greater participation in physical activity, the NCSI has:

- > Brought together and reviewed the evidence on physical activity and cancer, as well as assessing which physical activity interventions are effective;
- > Developed a 'Move More' resource pack⁸¹;
- > Tested the physical activity pathway in cancer settings; and
- > Developed a qualification for exercise instructors wishing to work with cancer patients.

7.23 There is evidence that patients may be more receptive to making healthy lifestyle behaviour changes at certain points in the cancer pathway, the so-called 'teachable moment'. This can create an opportunity to encourage people who may have been previously inactive to increase activity levels. Appropriately trained healthcare professionals should assess patient motivation to consider the importance of physical activity for them as part of care planning. This is consistent with the Future Forum's recommendation that NHS services should seek to 'make every contact count', maximising the opportunities to encourage healthy living.

"My lifestyle has changed a great deal since dealing with breast cancer ... I am now feeling fitter than I was before cancer was diagnosed."

(Female with breast cancer, 2 years after diagnosis)

7.24 Although there is growing recognition amongst professionals that physical activity is important, there is concern that they do not know how best to support patients in taking more exercise. For many patients, additional physical activity opportunities do not need

commissioning, it is a case of motivating patients and signposting them to existing services, such as exercise on referral or walking groups. A range of opportunities exist, including:

- > Holistic assessment and care planning (before, during and after treatment);
- > Health and Wellbeing Clinics and other self-management events (after treatment);
- > The cancer care review (in primary care); and
- > Cancer rehabilitation services (during and after treatment).

7.25 Health behaviour change is a key aspect of improving and sustaining healthy lifestyle behaviours in cancer patients. Training and support for the cancer workforce is necessary to realise fully the benefits from promoting healthy lifestyles. Initially, the focus will be on enabling the cancer workforce to deliver low-intensity health behaviour change techniques as part of usual practice, based on foundation competencies in the Health Behaviour Change Competency Framework⁸². Theories of behaviour change can guide such development, and training should take into account the wider social context, beliefs and motivations that currently inhibit many healthcare professionals from

regularly addressing issues of lifestyle^{83,84}. Work has been undertaken to specify key evidence-based health behaviour change techniques to be used as the basis of training programmes for healthcare professionals^{85,86}. This will equip them with the skills and behaviours to:

- > Raise/prompt issues of lifestyle (physical activity, healthy eating) with patients;
- > Prompt self-monitoring of behaviours;
- > Prompt specific goal setting related to behaviours; and
- > Refer to appropriate specialist (lifestyle change support) services if required.

Future developments will focus on training and support for other key groups responsible for providing medium- and high-intensity health behaviour change interventions.

7.26 Commissioners may wish to emulate interventions tailored to cancer survivors and delivered at a local level, including Aquaterra Leisure, which launched a free 12-week programme for cancer survivors in Islington to promote physical and psychological wellbeing. In Bournemouth, health professionals raise the importance of being active at the end of treatment, and refer patients to the local leisure trust, where trained exercise professionals deliver

a brief intervention and provide access to a wide variety of physical activity opportunities.

7.27 In April 2012, Macmillan Cancer Support and the Ramblers formed a partnership to support *Walking for Health* – an England-wide scheme that has been in operation for a decade. It provides short, easy, friendly, free walks for the public. *Walking for Health* has 70,000 participants and 600 local schemes, usually coordinated by local authorities and led by 10,000 trained volunteer ‘walk leaders’. Through *Walking for Health*, Macmillan aims to inspire and support more people living with cancer to become and stay more active, to promote the benefits of physical activity to people affected by cancer and the wider community, and to encourage more health professionals to signpost people to the scheme.

Diet and weight management

7.28 The World Cancer Research Fund⁸⁷ estimates that around a third of the UK’s most common cancers could be prevented if people have a healthy diet, maintain a healthy weight, drink less alcohol, and take regular physical activity.

7.29 Evidence is growing that healthy eating and weight management can counteract some adverse effects of cancer

treatment^{88,89} and reduce the risk of cancer recurrence. For example, substantial weight gain after diagnosis and treatment for breast cancer is associated with an increased risk of recurrence and death among survivors by around 30%⁹⁰. Excess body weight (obesity) may also lead to poorer outcomes for colorectal and prostate cancer survivors⁹¹.

7.30 Health professionals can play an important role in encouraging physical activity, supporting patients in adopting a healthier diet and maintaining a healthy weight, stopping smoking and reducing alcohol consumption. However, telling people that they need to change is not enough. A package of education, guidance and support is also required, integrated into wider cancer support.

7.31 Studies of cancer services that are already integrating weight and diet advice into wider packages of support and feedback suggest that the involvement of cancer professionals does increase motivation. For example, a study in North Bedfordshire showed that, although 52% of cancer patients accepted referral for exercise, a further 23% decided to attend classes after additional prompting from a nurse⁹².

Self-management techniques for stress

7.32 Evidence shows that a variety of self-management techniques for stress can be helpful in sustaining recovery.

- > **Relaxation:** A randomized controlled trial⁹³ found that cognitive behavioural therapy seems to be a safe and effective treatment for women who have hot flushes and night sweats after breast cancer treatment, with additional benefits to mood, sleep and quality of life. Guided imagery and progressive muscle relaxation techniques were found to reduce anxiety in a sample of patients with breast or prostate cancer⁹⁴.
- > **Mindfulness:** A meta-analysis⁹⁵ that focused on one type of mindfulness – mindfulness-based stress reduction (MBSR) – found a moderate positive effect on psychological outcomes, including quality of life, stress, anxiety and depression in breast cancer patients. A systematic review⁹⁶ also found evidence for MBSR improving stress and anxiety.
- > **Imagery:** A review⁹⁷ of studies that used imagery alone found that imagery reduced anxiety and depression, increased quality of life, and significantly improved people's experiences during chemotherapy and radiotherapy.

7.33 These techniques are often available either through NHS pathways or through services run by cancer charities, and patients who would benefit should be signposted to them as part of assessment and care planning.

Children and young people

7.34 There have been dramatic improvements in the quality of treatment for children and young people with cancer in recent decades, meaning many more survivors. As this population gets older, many will still have support needs.

7.35 For children and young people diagnosed with cancer, the period of sustaining their recovery can last for many decades, during which time their needs and preferences will change. The nature of the support provided to people diagnosed with cancer when a child or young person can have significant implications for the quality of survivorship, as well as for NHS costs.

- > Unmet needs can affect a person's ability to lead a full and active life, with implications for work and education.
- > A 20% reduction in outpatient appointments amongst the 40,000 childhood cancer survivors could save 8,000 appointments per year.

7.36 Although outcomes for childhood cancers in England are generally good, the quality of survivorship support is variable. In particular, problems can occur at the transition of services (either between children's, teenage and adult services, or at different points on the pathway).
CLIC Sargent and Teenage Cancer Trust

contributed their knowledge and expertise about the issues that children, young people and their families face. The Treatment Summary and care plan are critical to getting transitions right.

Box 24: Ten working principles for survivorship support for children and young people

1. All cancer survivors, wherever they live, can and should expect to have informed choices in relation to the services on offer to them through an established aftercare MDT.
2. All aftercare services are based on consistent, defined patient pathways.
3. All aftercare is based on safe, risk-stratified levels of care endorsed by clinicians.
4. All cancer survivors should have access to the appropriate models of aftercare that are 'right for them' and in line with NICE guidance.
5. All cancer survivors can expect to be given a Treatment Summary and care plan at the end of their treatment and at all stages of transition.
6. All cancer survivors should have access to a care coordinator function to streamline their care.
7. All cancer survivors should have pre-planned and pro-active transition arrangements at all stages of their aftercare.
8. All cancer survivors who are clinically safe to self-manage, will be provided with comprehensive information and be involved in a remote monitoring and/or alert system that prompts screening investigations.
9. All cancer survivors' patient experience feedback should be routinely monitored and directly influence commissioning decision making.
10. There will be a minimum 20% reduction in volume, nationally, in hospital based outpatient appointments (if these measures are implemented for those patients already routinely receiving outpatient follow-up aftercare).

7.37 To improve the quality and efficiency of survivorship support, the NCSI has developed:

- > Ten working principles to underpin survivorship care for children and young people (see Box 24);
- > Four defined models of aftercare – clinician-led follow-up, professionally led shared care, nurse-led follow-up and supported self-management;
- > A competency framework for nursing roles in supporting children and young people after cancer (see Box 25);
- > Interactive pathways for paediatric patients, teenage and young adult patients, and teenage and young adult patients with complex needs;
- > Four prototype centres to test new ideas;
- > An economic evaluation approach in collaboration with the Centre for Health Economics at the University of York; and
- > An engagement pack to facilitate the spread of ideas, alongside an evidence review and the publication of key findings.

Box 25: A competency framework for nursing roles in supporting children and young people after cancer

Nurses can play a critical role in supporting children and young people after cancer. In order to support this, a competency framework has been developed covering nurses' roles in:

- > Assessing, planning, implementing, reviewing and documenting individualised care plans;
- > Supporting self-care and monitoring;
- > Creating services that can work/link with primary care services;
- > Ensuring a smooth transition to adult services;
- > Participating in educational programmes; and
- > Facilitating the development of evidence-based practice.

The framework can be read at:

http://www.rcn.org.uk/__data/assets/pdf_file/0005/408254/004172.pdf

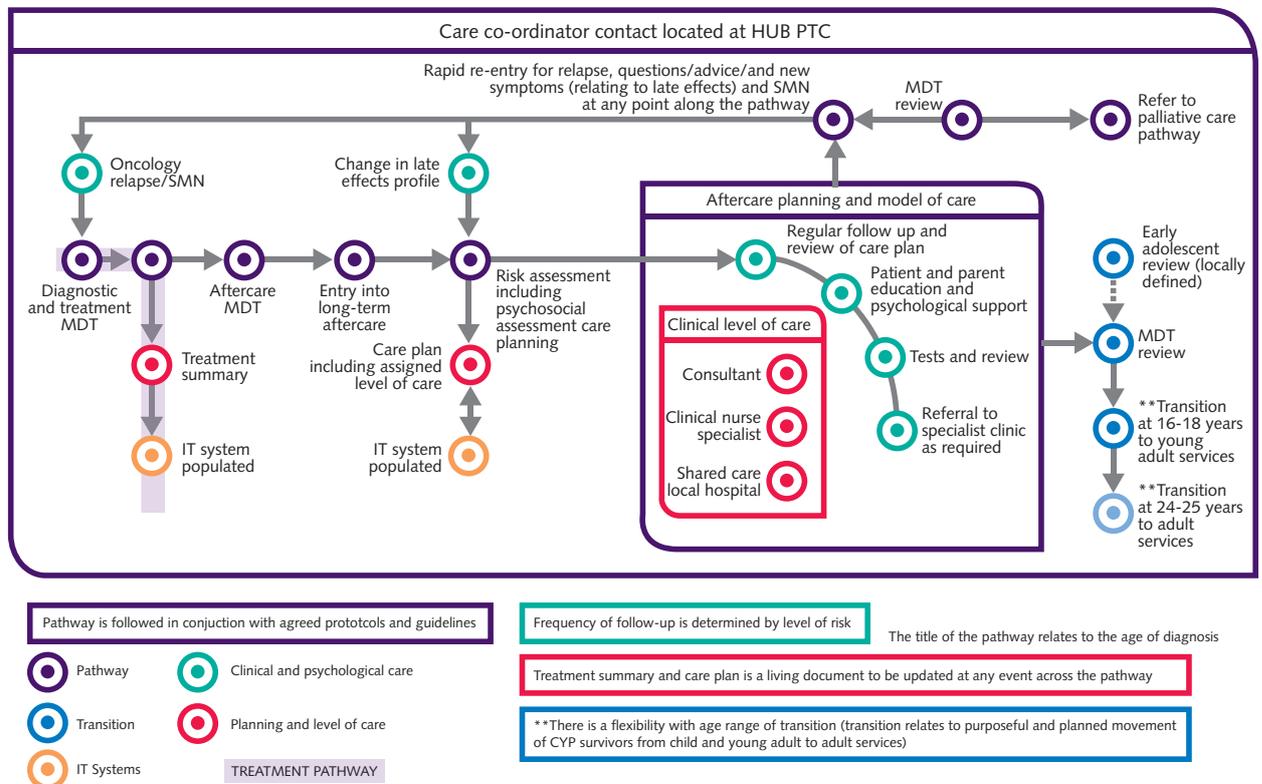
7.38 A range of care pathways has been developed to demonstrate best practice to NHS trusts in redesigning their services^{98,99}. An example of the paediatric pathway is shown in figure 4.

7.39 Work has been undertaken to estimate the risk of specific adverse health outcomes for different groups of survivors, thereby informing risk stratified care pathways. This shows that childhood cancer survivors:

- > Are at increased risk of adverse health outcomes, when compared to the general population;
- > Can be risk stratified according to their risk and supported by care plans and re-education of survivors at age-appropriate transition points; and
- > Should only be subject to regular contact if surveillance examinations or investigations are likely to lead to early

Figure 4: paediatric aftercare pathway

Paediatric aftercare pathway



detection of recurrence, second malignancies or non-cancer late effects.

7.40 Moving forward, the NCSI will publish a model for risk stratification for children and young people, building on the lessons from adult stratified care pathways and enabling services to target support to areas of unmet need. A national financial model is being developed to enable commissioners and providers to assess the impact of a shift from a traditional model of aftercare to one of the four alternative models of care referenced above. A series of metrics will also be developed to inform national standards for children and young people.

7.41 In 2013, pilot work will be spread to all 19 centres for children and young people's cancer. Following on from the 2012 Department of Health *Report of the Children and Young People's Health Outcomes Forum*¹⁰⁰, in the future, testing should also take place to define and develop a transition model from young people to adult survivorship aftercare services.

Making action happen

7.42 In order to support sustained recovery:

- > New approaches to follow-up should be discussed between commissioners and providers. Nurse-led follow-up and/or remote monitoring are likely to bring benefits to patients and to reduce overall costs to the NHS, but appropriate tariffs and/or gain-share arrangements will be needed to incentivise these changes. The NCSI will develop a Commissioning for Quality and Innovation (CQUIN) exemplar to encourage stratification of patients for follow-up according to need.
- > CCGs will want to consider how best to ensure that exercise programmes are available for all appropriate cancer patients. These are likely to be highly cost effective as they will reduce recurrence and improve quality of life.
- > It will be useful to measure changes in the proportions of cancer survivors who are undertaking at least moderate levels of physical activity through PROMs.

Key evidence

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Further reading

Self-management: de Silva, D. Evidence: Helping people help themselves. *The Health Foundation* (May 2011).

Cancer follow-up: Davies, N. H. & Batehup, L. *Towards a Personalised Approach to Aftercare Services*. Literature review for the NCSI, self-management workstream. (November 2009; updated February 2012).

8. Taking action: Managing the consequences of treatment



Key messages:

- > **Consequences of treatment affect many patients. This will be an increasing challenge as the number of cancer survivors living with the consequences of treatment grow.**
- > **The nature of consequences of treatment means that they vary significantly between patients in frequency, timing, severity and impact on quality of life – the level and nature of support that patients require will therefore vary.**
- > **Failure to manage the consequences of treatment can have a significant impact on patients and on the NHS, so it makes sense to design and commission pathways and services that minimise consequences and address need.**
- > **Begin the assessment and monitoring of patients for consequences of treatment during the active treatment phase, and continue for as long as necessary.**
- > **Empower patients and primary/community care professionals to manage the consequences of treatment; providing the Treatment Summary is an important enabler for this.**

8.1 Cancer treatment is often invasive and intensive, and can have both short- and longer-term consequences, some of which may arise several years after treatment. Managing the consequences of treatment is step four on the survivorship pathway.

8.2 A failure to manage the consequences of treatment effectively can compromise survival, quality of life for the patient and their carers, recovery, patient experience and patient safety. This chapter sets out:

- > The nature and extent of consequences of treatment;
- > Some principles for prevention and clinical management of consequences of treatment;
- > The importance of empowering patients and professionals to manage the consequences of treatment better; and
- > A suggested care pathway and examples of service models.

The nature and extent of consequences of treatment

"I'm thankful the surgery allowed me to live. I try to remember that when debilitating pain makes me want to die."

(Male with prostate cancer,
5 years after diagnosis)

8.3 The significant number of people needing support with long-term consequences of treatment will increase due to:

- > Increasing numbers of cancer diagnoses;
- > Greater proportion of patients receiving treatment;
- > New treatment regimes;
- > Improving survival; and
- > Demand from patients whose consequences of treatment have previously been under-recognised.

8.4 The likelihood of a patient experiencing consequences of treatment varies according to many factors, such as tumour type, treatment regime, age and lifestyle. Many well-known consequences are experienced more frequently than is widely believed. For example, the PROMs survey found that:

- > Nearly 40% of prostate cancer survivors reported urinary leakage and 13% had difficulty controlling their bowels.
- > Nearly a quarter of colorectal cancer patients reported urinary leakage and 19% reported difficulty controlling their bowels.

8.5 There are also broader consequences of treatment, which appear to be greater than has previously been recognised or recorded by clinicians, suggesting a 'hidden' level of need that requires urgent attention. For example, Macmillan Cancer Support's Routes from Diagnosis project, undertaken as part of the NCSI, analysed large NHS datasets of over 13,000 patients and found that the extent of issues which required attention in secondary care is greater than previously thought. Initial findings suggest that approximately 24% of colorectal cancer patients experience intestinal morbidities, and 14% of Hodgkin's lymphoma patients get an additional primary cancer (unpublished data, paper in preparation). This analysis only assessed inpatient episodes, so it is likely to be an underestimate of overall morbidity.

8.6 There is currently a variation in the provision and quality of psychological approaches and services offered to patients with cancer. For example, women with breast cancer may need support due to traditional symbols of feminine sexuality

being challenged by treatments: loss of a breast(s), changes to breasts, loss of hair and, for some younger women, fertility issues. “As a consequence of the diagnosis of breast cancer at least a quarter of patients report anxiety and depression and a third report sexual problems.”¹⁰¹

8.7 There is also evidence that healthcare professionals do not feel confident in managing the consequences of treatment. For example, a survey found that many nurses and allied health professionals reported difficulty with long-term medications management, care planning and complex symptom management (e.g. bowel, urinary and sexual problems) relating to cancer treatment (manuscript in preparation)¹⁰².

8.8 It can be helpful for service improvement purposes to classify long-term consequences into three groups, as follows:

8.9 For children and young people, the consequences of treatment may only become apparent as adults and therefore ensuring good patient education and an appropriate handover and transition to adult services is critical to identifying and managing any problems. The Children and Young People aftercare pathway, developed by NHS Improvement, is now a Quality, Innovation, Productivity Prevention, (QIPP) approved case study. Test sites have developed a safe, stratified care pathway framework to identify those patients at low, medium and high risk as a consequence of late effects following surgery, chemotherapy and radiotherapy treatment. Rapid re-entry into the pathway at any point reduces the need for emergency admission, late relapse and prevention, and/or exacerbation of late effects with the consequent costs^{103,104}.

Classification	Estimated level of need in England	Example
Rare	Several hundred, requiring specialist services	Severe symptoms caused by damage to the brachial plexus from an obsolete form of radiotherapy for breast cancer
Intermediate	Tens of thousands, requiring proactive management by health services	Faecal incontinence, urinary incontinence and sexual difficulties caused by radiotherapy and/or surgery for pelvic cancers
Common	Risks affecting hundreds of thousands	Risks of cardiovascular disease, fatigue and osteoporosis caused by chemotherapy and/or hormone treatments for breast and prostate cancer

Principles for preventing or managing consequences of treatment

8.10 Key principles should be adopted in patient pathways for all cancer types, in order to minimise and optimally manage any consequences of treatment.

- > **Prevent** or minimise consequences of treatment where possible, through healthier lifestyle choices, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
- > **Inform** patients of potential consequences of treatments.
- > **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential consequences so they can be easily recognised in primary care.
- > **Assess** potential consequences through regular Holistic Needs Assessments, the use of 'power' questions and PROM tools at regular time points.
- > **Support** patients through local care pathways for consequences of treatment, which includes support for self-management and referral to appropriate specialist services.

- > **Monitor** groups of patients for increased risk of late consequences, including through the long-term follow-up of patients in clinical trials and better recording through national datasets of which patients have received which treatments. Where a risk is identified, a comprehensive approach should be adopted to responding and informing patients, and consistent approaches to monitoring and surveillance should be adopted.

Preventing consequences and informing patients

"I have lymphoedema in my left arm ... This condition is for the rest of my life. Patients should be told of the fact that they may develop lymphoedema after their operation. It was a shock to find out about it later."

(Female with breast cancer, 5 years after diagnosis)

8.11 The likelihood of long-term consequences will depend on the treatments given and should, of course, be discussed with the patient. Every attempt should be made to minimise consequences at the outset by using:

- > Minimally invasive surgery where this has been shown to be as safe and effective as standard surgery;

- > Modern radiotherapy techniques such as IMRT, IGRT, stereotactic ablative radiotherapy (SABR) and proton beam therapy (PBT) as and when appropriate in line with emerging evidence; and
- > Systemic therapies with the least toxicity.

8.12 Personalised information and the support to understand it can play a significant role in providing cancer patients with relevant and timely information about the consequences of treatment (such as Macmillan's information on the late effects of some cancers, and information produced by cancer-specific charities such as Prostate Cancer UK and Breast Cancer Care), as well as advice on lifestyle changes that could mitigate them.

8.13 The NICE Clinical Guideline on Colorectal Cancer (2011)¹⁰⁵ stresses the importance of discussing late effects (i.e. delayed or chronic consequences of treatment) with the patient prior to treatment. This is because of the potential impact on quality of life, and it recommends that specific information on managing the effects of treatment on bowel function should be provided after treatment. The Guideline also calls for research into "strategies to integrate oncological surveillance with optimising quality of life, reducing late effects, and detecting second cancers in survivors of

colorectal cancer". These principles of good, timely patient information and using on-going patient assessment to detect consequences apply equally to all cancers.

Identifying risk

"I was diagnosed with osteoporosis two years ago, possibly caused by hormone treatment."

(Female with breast cancer, 5 years after diagnosis)

8.14 Some consequences of treatment usually become apparent within 1–2 years of completion of treatment. Examples include urinary incontinence, rectal bleeding, lack of control of bowel function following some treatments for pelvic tumours, and arm swelling after surgery and/or radiotherapy for breast cancer. At present, these problems are often not reported to, or recorded by, clinicians and are inadequately treated, if at all.

8.15 Other consequences of treatment only become apparent several years, or even decades, after diagnosis. These can include damage to the heart from radiotherapy, and the emergence of second cancers. The major increase in incidence of breast cancer amongst young patients treated with radiotherapy for Hodgkin's lymphoma is an example of the latter.

8.16 Ultimately, the consequences of cancer treatment will only be effectively managed if patients and professionals are empowered to identify all risks and symptoms and to act upon them. However, many barriers exist that prevent patients and professionals from getting the information and education they need to ensure optimal outcomes for patients. For example, too many patients are not given adequate information about the possibility of treatment consequences, professionals do not take into account the reluctance of patients to describe embarrassing symptoms, and there is insufficient evidence-based guidance on effective clinical management of treatment consequences due to a lack of research in this field.

Assessing potential consequences of cancer treatment

"I feel not enough interest is shown in the 'side effects' of chemotherapy treatment by the oncologist. I am still affected by severe peripheral neuropathy in my hands and feet ... No real advice has been given even though my final chemotherapy treatment was not given as my symptoms were so severe."

(Female with colorectal cancer,
1 year after diagnosis)

8.17 PROMs and 'power' questions (such as "are you woken at night to defaecate?") are useful tools for systematic identification of problems. Patients should be encouraged to participate in PROMs surveys during primary treatment, ensuring that they are familiar with the process and providing a baseline from which to assess changes in their quality of life. These should be repeated at several points after treatment, and have the potential to be used to trigger follow-up by the cancer team or relevant specialist. All primary and secondary care professionals involved with the patient should be aware of potentially embarrassing symptoms, and should ask the patient regularly about on-going problems, including bowel, bladder and sexual issues.

Researchers in Leeds have been testing the feasibility of an electronic system (ePOCS) for collecting PROMs via the internet, at regular post-diagnostic time points, linking these data with patients' clinical data in cancer registries, and for electronically managing the associated patient monitoring and communications¹⁰⁶.

8.18 To support more effective assessment, the NCSI's Consequences of Cancer Treatment collaborative (CCaT) (<http://www.cancerconsequences.org>) has:

- > Developed the Ten Top Tips for cancer survivors¹⁰⁷;

- > Established several nurse-led or physiotherapist-led services, enabling wider evaluation of post-treatment service models;
- > Expanded knowledge of consequences of treatment through research involving thousands of patients and healthcare professionals; and
- > Influenced hundreds of healthcare professionals through educational programmes.

Supporting patients with long-term consequences of treatment

"I think more information should have been made available to me on my fertility changes/options – there was one small paragraph – out of date – in the cancer booklet."

(Female with breast cancer, 2 years after diagnosis)

8.19 Important interventions that will help improve outcomes for cancer survivors are already described in chapters 4, 5 and 6. For many patients, these interventions may be sufficient because they experience only minimal or short-term consequences. However, for those with consequences that are affecting long-term quality of life, specialist services are needed. In

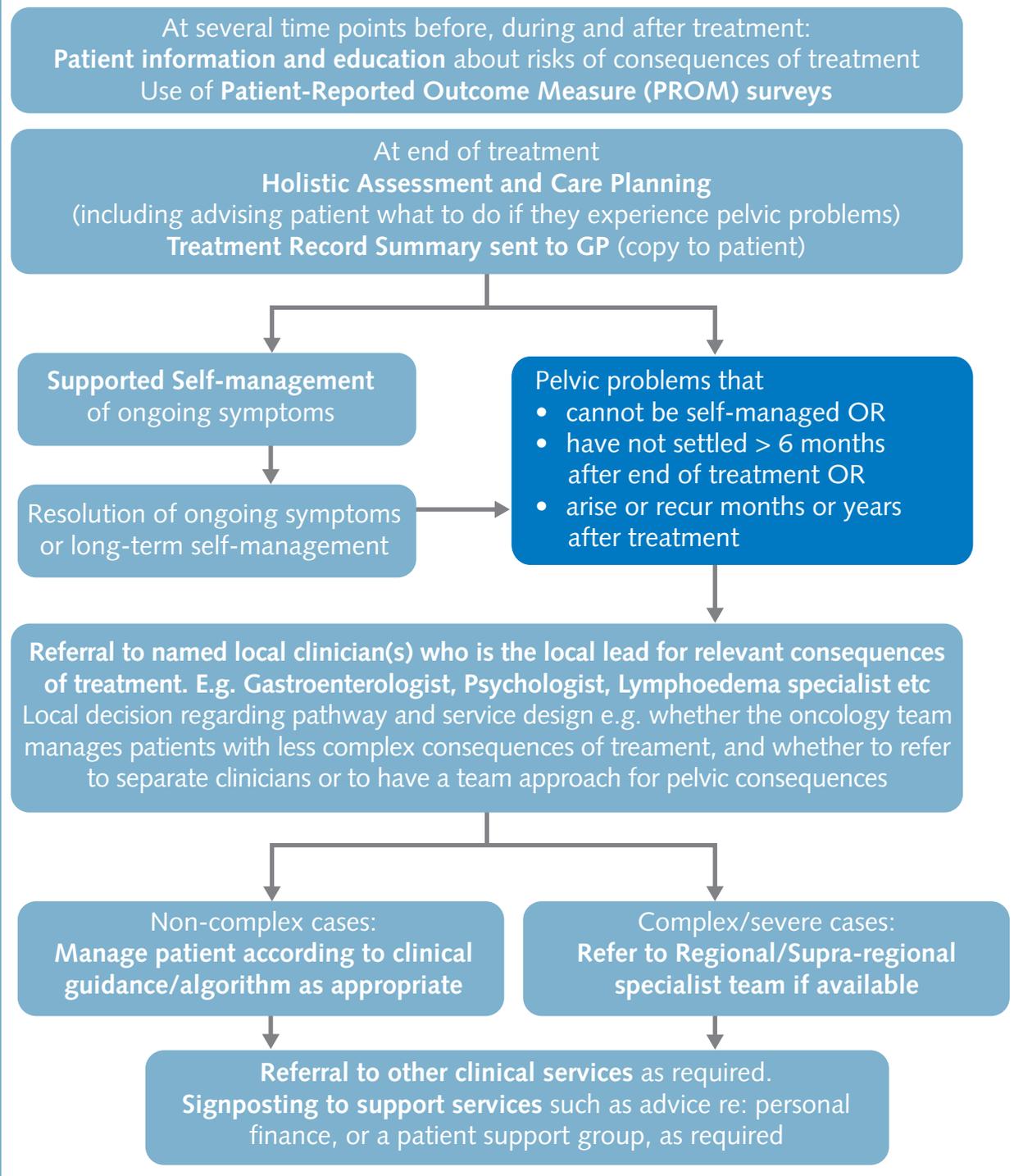
developing these services the following must be considered:

- > How many patients need these services?
- > How many services do we need?
- > How are such services accessed?
- > How can a multi-professional service be provided and who will lead this?
- > What specialist assessment, diagnosis and treatment facilities are needed?
- > What experts do we need to involve (e.g. gastroenterologists, cardiologists, endocrinologists, neurologists etc.)?
- > How can the NHS provide this cost effectively?

8.20 The NCSI has tested service improvements for 'rare' and 'intermediate' types of consequences.

- > **Rare:** A specialist service model for rare, complex conditions resulting from obsolete treatments was tested. It demonstrated that patients can self-assess and self-refer, and that assessment and care planning can be carried out in regional centres. The Breast Radiotherapy Injury Rehabilitation Service (now nationally commissioned; see

Box 26: Generic outline pathway for consequences of pelvic cancer treatment



<http://www.specialisedservices.nhs.uk/service/breast-radiotherapy-injury-rehabilitation-service>) consists of a specialist hub providing triage, multidisciplinary assessment and intensive therapy, which refers on to local champions and acts as an information centre for patients and health professionals.

- > **Intermediate:** Several service models for people suffering from chronic bowel problems after pelvic radiotherapy are being evaluated, which show that patient outcomes can be significantly improved by redesigning the post-treatment pathway for pelvic cancers, as set out in Box 26.

8.21 The evaluation of services for consequences of pelvic cancer treatments has also highlighted the need for a small number of supra-regional specialist centres, which would deliver/co-ordinate care for patients with severe, complex pelvic problems, and which would be a focus for education and research. An example of such a service is shown in Box 27.

Box 27: Example of a supra-regional specialist service for gastrointestinal consequences of pelvic cancer treatment

The Royal Marsden Hospital Gastrointestinal and Nutrition Service currently consists of a consultant gastroenterologist, a nurse consultant and a specialist dietician, and receives approximately 250 new referrals per year from across the UK.

The team is actively engaged in research on the influencing factors, diagnostic tests and treatments for pelvic radiation disease. Results from its large randomised controlled trial (ORBIT) show that intervention using their bowel algorithm can ameliorate radiotherapy-induced gastrointestinal symptoms. The team is also participating in a national double-blind placebo-controlled trial evaluating the benefit of hyperbaric oxygen therapy for modifying pelvic radiation disease, which will report in 2013.

8.22 Feedback suggests that patients with chronic bowel effects will already be using NHS resources (such as A&E visits, GP consultations, mental health resources, medications, continence pads or endoscopies), but that patients' needs are often not met, meaning that they are less likely to be able to be economically active

as a result of their bowel problems and, therefore, are more likely to claim state benefits.

8.23 There are also on-going pilots of service improvements for consequences of treatment, including for long-term risks such as osteoporosis. The results will be reported through the NCSI website (<http://www.ncsi.org.uk>).

8.24 The NCSI, working with the British Childhood Cancer Survivor Study (University of Birmingham), identified absolute increased risks of adverse fatal and non-fatal health outcomes in survivors of childhood cancer compared to the general population. The data show a clear and strong difference between survivors assigned to stratified care, as recommended by NHS Improvement's work on children and young people, in terms of their long-term risk of serious adverse health outcomes up to 45 years from diagnosis.

8.25 The findings emphasise the need for individuals living beyond cancer, as well as their primary care providers, to be fully informed of potential late effects of the original cancer and its treatment. These findings further support the provision of providing care plans and re-education of survivors at age-appropriate transition points. (publication in progress). Stratified cancer aftercare, as per the

recommendations by NCSI/NHS Improvement, is indicated to deal effectively with potential consequences of treatment.

Making action happen

8.26 To support effective management of consequences of treatment, further work is needed to spread the adoption of practice that:

- > Minimises the risk of long-term consequences by commissioning innovative treatments where these have been shown to be safe and effective (e.g. laparoscopic surgery, IMRT/IGRT).
- > Provides information on the potential short- and longer-term side effects of treatments to patients.
- > Includes information on potential consequences of treatment, the symptoms and signs to be aware of and recommended surveillance tests in care plans.
- > Assesses all patients for the emergence of consequences of treatment through the routine use of PROMs, which are tailored to patients' specific risks based on their diagnosis and treatments provided. Methods for doing this in clinical practice need to be developed and evaluated, and consideration given

- to developing a model CQUIN goal to incentivise the use of PROMs in this way.
- > Recognises that certain survivorship services may be appropriately commissioned by the National Commissioning Board, such as services for patients suffering from the 'intermediate' prevalence consequences of treatment, or highly specialist services for 'rare' consequences of treatment. Examples of such services include the new breast radiotherapy injury rehabilitation service (BRIRS), or services for adult survivors of childhood cancers.
 - > Supports GPs through education and training on the 'common' consequences of treatment, such as cardiovascular disease or osteoporosis, and by offering easy access to specialist advice and care.

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9. Taking action: Supporting people with active and advanced disease



Key messages:

- > **Key principles for survivorship – assessment and care planning, access to key workers and proactive management of health issues – are every bit as important for active and advanced disease as for other parts of survivorship.**
- > **A priority is to address weaknesses in the intelligence available about people living with active and advanced disease, as well as the treatments and support they receive.**
- > **Further work is required to understand the most effective ways for MDTs to support the management of people with active and advanced disease.**
- > **Palliative care is an essential component of management, not something that commences when active treatment ceases.**
- > **Offer a smooth transition between cancer support, palliative care and end-of-life services to patients.**

9.1 Key principles of high-quality survivorship support are every bit as relevant to people with active and advanced disease. This is step five on the survivorship pathway.

9.2 Significant challenges have been identified at this step. Patients can find it difficult to re-enter specialist care and may not have access to CNSs, even though their need may be as great or greater. Equally, the coordination of different elements of care can be inadequate, resulting in unnecessary hospital admissions, poor links to social care and end-of-life care support, and huge pressures on carers. Underpinning this is the poor recording of recurrence and

metastasis, as well as patchy information on treatments and their outcomes.

9.3 Detailed management of patients with active and advanced disease is beyond the scope of this report. Our aim is to focus on the services needed to ensure patients are appropriately supported throughout the time that they have active and advanced disease, and to ensure that appropriate links are made to end-of-life care services. This chapter summarises:

- > Progress to date on improving the support available to people with active and advanced disease;
- > The critical importance of team working and communication; and

- > The role palliative care can play alongside active treatment in improving outcomes.

Progress to date

9.4 The NCSI's work on active and advanced disease is at an earlier stage than other aspects. Although accurate and comprehensive intelligence is of critical importance in planning improved services, to date it has not been possible to:

- > Identify how many people are alive with active and advanced disease, or the date of their recurrence or metastasis;
- > Analyse, at a population level, the treatments people with active and advanced disease receive or the health services they use;
- > Assess services or support for people with active and advanced disease; or
- > Identify the numbers of carers.

9.5 Work is underway to address these weaknesses, including:

- > Piloting data collection on people with metastatic breast cancer, with a view to expanding this form of data collection to all cancers.

- > Investigating the potential to use routine sources of NHS data collection to identify recurrences accurately.

- > Collecting data on radiotherapy and chemotherapy to provide comprehensive information on key treatments used for people with advanced forms of cancer.
- > Analysing detailed data on what happens to people with active and advanced disease in Brighton and Hull, and publishing a final report in summer 2013.
- > Capturing data on quality of life and experiences of people with advanced cancer through PROMs and patient experience surveys.
- > Assessing the resource utilisation of people with cancer in the last year of their life, compared to those with other long-term conditions.

9.6 Efforts to improve the services for people with active and advanced disease will be informed by the work to date of Breast Cancer Care's Secondary Breast Cancer Taskforce and Breast Cancer Care's current Spotlight on Secondary Breast Cancer campaign, as set out in Box 28.

Importance of team working

"I was given no help by social services when I was discharged from hospital despite my living alone and needing a home help temporarily."

(Female with colorectal cancer, 5 years after diagnosis)

9.7 Multidisciplinary team (MDT) working is of critical importance in supporting people with active and advanced disease and their carers, and in particular in:

- > Ensuring multi-expert input into decisions on treatment and care.

Box 28: Breast Cancer Care Secondary Breast Cancer Taskforce

Breast Cancer Care's Secondary Breast Cancer Taskforce was a two-year initiative, established in recognition that people with metastatic breast cancer were not receiving the best possible standard of care. A national coalition of healthcare professionals, charities, policy makers and people with metastatic breast cancer, the Taskforce identified gaps in the treatment, support and care of people living with metastatic breast cancer. The Taskforce identified a number of priorities for improving the care of people with metastatic breast cancer, which have helped inform the work of the NCSI and are being taken forward by Breast Cancer Care in their Spotlight on Secondary Breast Cancer campaign:

- > Data collection
- > Coordination of care, including through ensuring access to clinical nurse specialists or key workers
- > Information and support, including tackling the sense of isolation that many women with metastatic breast cancer feel
- > Integrating oncology and palliative care, ensuring that they are seen as complementary elements of care
- > Strengthening the support provided in primary care, recognising that many support needs occur in this setting
- > Access to information regarding employment rights and benefit entitlements
- > Improved access to information on clinical trials

- > Enabling effective assessment and care planning.
- > Providing a dedicated point of contact or key worker.
- > Supporting high quality communication between professionals and with patients.
- > Promoting an appropriate interface with end-of-life care services.

9.8 There is variation between MDTs in the way people with advanced cancer are discussed. To support improvement in this, the NCSI will be leading work on what appropriate advanced cancer MDTs should look like. This project takes into account the pressures on MDTs, as well as the different skills mix that advanced cancer MDTs may require, including non-medical specialities such as social workers. There may be a strong case for operating virtual MDTs for metastatic cancer patients.

9.9 As a result of the pilot data collection on metastatic breast cancer, we know that only half of patients with metastatic breast cancer were referred for CNS support.

9.10 In rarer cancers, the disease trajectory, impacts of treatment and the requirements for communication between professionals differ from those in more prevalent cancers.

9.11 People with progressive disease are living longer and often receiving intermittent treatment over an extended time period. Supported self-management is therefore an important option for many patients, helping them cope with all aspects of their condition.

Palliative care

9.12 Palliative care can play an important role at all stages of the cancer pathway, particularly for people with active and advanced disease. It should be seen as an essential component of treatment, not something that commences when active treatment ceases. An American study¹⁰⁸ shows that the early use of palliative care in lung cancer can extend survival, as well as improving quality of life. Similarly, there is evidence¹⁰⁹ that high-quality nutritional support can improve quality of life.

9.13 The disease trajectory from active treatment to death (whether treatment has cure or life extension as the intent) differs between cancers. When the final stage is short, any delays in delivering proper supportive care are doubly distressing. This emphasises the importance of establishing the palliative care link early in the pathway. For some cancers this might be earlier than for others, because the trajectory of decline is less predictable and may be sharper.

Making action happen

9.14 To support people with active and advanced disease further work is required in:

- > Commissioners and providers agreeing how patients who are concerned about a recurrence should re-access specialist care.
- > Considering all patients who are re-referred as urgent.
- > Offering all patients a full assessment at first recurrence, and a further care plan.
- > Recording of recurrence/metastasis of cancer, piloted by breast cancer teams, to be extended; exploring using data from different IT systems (e.g. pathology, imaging, radiotherapy, chemotherapy) to assist this process.
- > Strengthening data collection on treatments for active and advanced disease.
- > Publishing data on availability of CNSs for people with active and advanced disease.
- > Exploring the potential for personalised outcomes goals, to be developed by patients in partnership with clinicians, to focus care on what matters most to patients.
- > Producing guidance on multidisciplinary input to support people with active and advanced disease.
- > Developing triggers for alerting palliative and end-of-life care services, and for considering entry into the end-of-life care register. These might include the receipt of palliative radiotherapy or second-line chemotherapy.
- > Understanding at population level the concerns leading to re-referral.

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10. Taking action: Improving survivorship intelligence



Key messages:

- > **Intelligence on the needs of cancer survivors and the extent to which they are being met is critical to improving outcomes and understanding the costs of meeting those unmet needs.**
- > **A range of initiatives is underway to ensure that patients, clinicians, commissioners and providers are able to access timely and accurate information.**

10.1 Improving the intelligence on services to support cancer survivors has been a major priority for the NCSI. As a result of this, we now have some evidence regarding:

- > How many cancer survivors there are in England;
- > Where they are likely to be distributed on the cancer care pathway;
- > The experience they report of treatment and care, although this mainly relates to those close to the point of diagnosis;
- > The quality of life issues reported by breast, prostate, colorectal and non-Hodgkin's lymphoma cancer patients, through large scale PROMs surveys;
- > The co-morbidities experienced by people with a cancer diagnosis that require NHS attention;

- > The costs associated with survivorship support, from both an NHS and a wider societal perspective; and
- > The particular needs of children and young people.

10.2 However, there is more that we need to know if we are to improve the quality of support available to, and the outcomes experienced by, cancer survivors. For example, we need to understand more about:

- > The numbers and characteristics of people living with cancer, particularly people living with active and advanced disease;
- > The experiences and outcomes of people living with cancer, including the quality of life for people with cancers not yet studied through PROMs;
- > How the quality of life reported by cancer survivors can change over time;

- > The treatments patients have received, so that those at risk of late effects may be identified, informed and managed appropriately;
- > The long-term health issues experienced by people diagnosed with cancer as a child or a young person;
- > How to use resources effectively to maximise good-quality outcomes and reduce poor outcomes, thus potentially saving avoidable costs; and
- > The barriers that prevent patients receiving optimal care for consequences of treatment (such as reluctance to talk about embarrassing symptoms).

10.3 This chapter sets out the steps that will be taken to improve the quality and timeliness of cancer intelligence, ensuring that the appropriate information is available to inform commissioning, raise awareness and understanding of the importance of survivorship services and to scrutinise progress. It should be read in conjunction with wider efforts to improve cancer intelligence, set out in *An Intelligence Framework for Cancer*¹¹⁰, published in December 2011, which identified improving intelligence support to efforts on care, support and survivorship as a key intelligence priority.

Role of the National Cancer Intelligence Network

10.4 The NCIN is a UK-wide initiative working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. The NCIN has played a critical role in improving the quality of survivorship intelligence to date and will continue to do so when it moves into the new Public Health England in April 2013.

10.5 In an example of how different sectors can work together to improve the quality of health services intelligence, Macmillan Cancer Support agreed to provide dedicated resources to the NCIN to take forward work on survivorship intelligence in partnership. Some immediate priorities for the NCIN are set out in Box 29.

Evaluating the quality of survivorship support

10.6 To facilitate improvements in the quality of survivorship support the following factors are important:

- > Evaluation of the structure of services and whether they are consistent with good practice service models.

Box 29: Immediate survivorship intelligence priorities**Understanding the cancer population**

More detailed analysis of the cancer survivor population, using existing and new routine datasets. This will build upon what we already know about how many people are living with cancer, their needs and their pathways of care. Research will include developing a greater understanding of consequences of treatment, active and advanced disease, and NHS activity.

Extending *Routes from Diagnosis*

This work will build on the pilot project funded by the Department of Health and Macmillan *Routes from Diagnosis*. The pilot focused on three different types of cancer and will now be expanded to other cancer types.

Routine survivorship statistics

Analysis will be undertaken to determine which survival statistics are most useful to collect or be developed to collect on a routine basis.

Patient outcomes and experience

Analysis will be undertaken on the link between clinical and patient-reported outcomes, and patient experience.

Costings

We want to understand the cost of providing existing services and to be able to model the cost of optimal pathways. This will involve developing an understanding of healthcare resource groups, hospital activity costs and the coding of these.

Social care

By linking health and social care datasets, we hope to improve our understanding of the impact of cancer on social care.

> Evaluation of process measures, which are proxies for outcomes.

10.7 Examples of evaluating process measures that are linked to outcomes include the proportion of patients:

- > With access to CNS at diagnosis and recurrence;
- > Receiving information at different phases of the survivorship pathway;
- > Receiving Treatment Summaries/care plans;
- > Accessing cancer rehabilitation or reablement programmes;
- > Accessing services to help them manage the consequences of treatment; and
- > Admitted as an emergency admission in the first year after diagnosis and then subsequently.

10.8 These measures complement the measurement of outcomes achieved for cancer survivors, including:

- > The occurrence of life-threatening conditions in people with a diagnosis of cancer (Domain 1);
- > Quality of life (Domain 2);
- > Length of stay in hospital, as well as ability to regain functional independence (Domain 3);
- > Experience of treatment and care (Domain 4); and

- > Mortality within 30 days of treatment (Domain 5).

10.9 Ensuring that this information is available to support commissioners, providers and patients will require further improvements to the availability and quality of survivorship intelligence.

Gaining intelligence from health service datasets

10.10 A major step forward is the ability of the NCIN to link different NHS and cancer registry datasets, enabling detailed analyses of what actually happens to cancer patients. An example of the benefits of this approach is the *Routes from Diagnosis* work carried out by Macmillan Cancer Support with the University of Leeds and Monitor Group on what happens to cancer patients from the point of diagnosis.

10.11 By linking cancer registry and Hospital Episode Statistics inpatient data, it has been possible to create a detailed picture of health service utilisation by people with colorectal cancer, multiple myeloma and Hodgkin's disease. Initial findings identified that 24% of people with colorectal cancer had intestinal problems, many of which led to inpatient episodes, whereas patients with myeloma had renal problems and other co-morbidities (unpublished data, paper in preparation).

The next step for the project is to incorporate more datasets (e.g. primary care), and link the analysis with PROMs survey information.

10.12 Work is underway in Sheffield to test the applicability of these analyses to NHS service improvement. Macmillan Cancer Support is working with North Trent Cancer Network to develop self-management models of care for colorectal cancer patients with the intention of reducing emergency admissions by improving community support.

Patient Reported Outcome Measures

10.13 This document draws heavily on the PROMs data to understand:

- > Quality of life issues experienced by cancer survivors.
- > Impact of different treatments on quality of life and how this changes over time.
- > Differences between tumour types, enabling us to plan services effectively.

10.14 Further PROMs surveys of cancer survivors will be undertaken, including in 2012/13:

- > A longitudinal study following up patients from the initial pilot to track their responses 12 months on. The fieldwork for this has ended, with a response rate of 85%. An initial analysis will be published later this year.
- > Four pelvic cancer PROMs questionnaires have been developed for cancer of the ovary, cervix, uterus (womb) and bladder. To date, data collection for cohorts at 1, 2, 3 and 5 years from diagnosis of bladder cancer has been implemented, with fieldwork set to run until March 2013.
- > A national survey of colorectal cancer survivors between 1–3 years post-diagnosis, based on an existing questionnaire used in the 2011 pilot and 2012 follow-up surveys. This will generate a larger dataset, with the potential to feedback at treatment centre or network level. Fieldwork began in January and will run until March 2013.

Applications for survivorship intelligence

10.15 Survivorship intelligence is vital to identifying patients with unmet needs, planning, implementing and monitoring service improvements, monitoring public health outcomes and identifying any new long-term health problems arising from cancer treatment drugs and regimes.

Box 30: Different uses for survivorship intelligence, as identified in *Routes from Diagnosis*¹¹¹

Who	What	How
Patients and Carers	Improving patient experience Providing visibility	Helpful, forward looking information for short and long term life planning Visibility of risks and late effects associated with cancer treatment and possible future medical needs Facilitation of self management and enablement of an active role in cancer survivorship
Clinicians	Improving Outcomes	Better understanding of potential outcomes and effects of treatments Detection of triggering events that impact on outcomes, especially survival Identification of patients at high or low risk of co morbidities or potential unmet needs early on
Commissioners and Health Care Managers	Improving service development Increasing efficiency of health care spend	Information planning of care pathways, service development and improving coordination of primary and secondary care Determining financial impact of change initiatives and informing commissioning decisions Understanding the cost across the survivorship pathway
Public Health Planning and Policy makers	Improving survival Outcomes	Identification of new long-term health outcomes arising from cancer treatment Targeting of specific patient groups to improve health outcomes Tailoring of specific public health programs for 'later' as opposed to 'late' presenters

Making action happen

10.16 The actions outlined in this chapter will enable:

- > The identification and improvement of the information needed to enrich our understanding of the cancer population.
- > Comparison of the survivorship outcomes delivered by different providers of cancer services.
- > Better understanding of the clinical pathways patients follow, providing timely and accurate information to cancer patients, planners and decision makers.
- > Service developers to have better visibility of the local cancer population, and improved evidence-based discussions to allow cancer pathways to be redesigned and patients' care to be tailored to their health requirements.

- > Healthcare professionals to understand better and more accurately predict likely outcomes for cancer patients, and to share risk and choice information with patients and signpost to other healthcare services where needed.
- > People affected by cancer to have an increased understanding of what the cancer journey may look like, to have the knowledge to make informed treatment and life decisions, to know who can help them, and to have confidence in what they need to do to help themselves, with appropriate clinical and social support.

Key evidence

Maddams, J. *et al.* Cancer prevalence in the United Kingdom: estimates for 2008. *Br. J. Cancer* **101**, 541–547 (2009).

Maddams, J., Utley, M. & Møller, H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br. J. Cancer* **107**, 1195–1202 (2012).

Richards, M., Corner, J. & Maher, J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors *Br. J. Cancer* **105** (Suppl. 1), S1–94 (2011).

Further reading

An Intelligence Framework for Cancer (Department of Health, 2011).
Available at <http://www.dh.gov.uk/publications>

11. Conclusion



11.1 The NCSI has investigated the extent of survivorship needs in England, and tested new approaches to meeting those needs. Its work will ensure that the 1.8 million people who are living with cancer in England will receive the right support when they need it to live as healthy and as active lives as possible, as well as helping the NHS prepare to meet the future requirements of the increasing numbers of people alive with a cancer diagnosis.

11.2 Much work has been undertaken to develop cost-effective models that improve outcomes for cancer survivors. Other promising proposals will be tested for quality and cost implications, further developing the evidence base to support improvements in survivorship support.

11.3 Work is underway to explore levers and incentives to encourage the spread of good practice, evaluate progress and to reward innovation in survivorship care.

11.4 Local commissioners and providers need to explore the common outcomes desired across different conditions, and whether these outcomes can best be delivered through services that work across different diseases, including cancer, to use resources most efficiently.

11.5 Key interventions that could make an immediate difference should be prioritised,

including the England-wide introduction of:

- > Structured Holistic Needs Assessment and care planning;
- > Treatment Summaries;
- > Patient education and support events (Health and Wellbeing Clinics); and
- > Advice about, and access to, schemes that support people to undertake physical activity and healthy weight management.

11.6 If this document is successful by 2015 in promoting improved survivorship support, key indicators will be:

- > New services to promote faster and more comprehensive recovery.
- > Fewer patients requiring routine face-to-face follow-up.
- > More patients supported in caring for themselves, with better assessment of their needs, appropriate support to address those needs, and high-quality remote monitoring and surveillance systems in place.
- > Better ambulatory care assessment and management of patients when they develop problems.

- > New services for patients dealing with the consequences of treatment.
- > Better assessment and management in the community, which will reduce the number of avoidable emergency admissions.
- > More patients making healthy lifestyle choices that promote recovery, reduce cancer recurrence and reduce consequences of treatment.
- > Depending on the future of cancer PROMS, they could potentially provide a very robust set of metrics to understand progress.

11.7 Most importantly, outcomes for people living with and beyond cancer will have been improved.

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