



THROWING
LIGHT
ON THE CONSEQUENCES
OF CANCER
AND ITS
TREATMENT

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Note

This document is designed for an audience of health professionals, managers and commissioners, and will be of interest to the public. If you are concerned about the effect of cancer and its treatments on yourself or someone you know, please consult a health professional.

Disclaimer

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of May 2013, but since this is not a systematic review of the evidence, the estimates of prevalence should be used with caution and a document of this nature inevitably goes out of date. Macmillan has sought external validation of this document from clinical experts and we aim to regularly update the content. There may be data that have been released that do not appear in this document and Macmillan is under no obligation to include any particular data source.

Foreword

There are more than two million people living with cancer in the UK today, but not all of them are living well. Cancer and its treatment often leave a gruelling physical and mental legacy for many years afterwards. It begs the question – do we really understand the true cost of being cured?



In recent years Macmillan Cancer Support has been revealing the changing nature of cancer with startling milestone figures. In 2011, we showed that more than four in 10 of us would get cancer. In 2012, our research found that the number of people living with cancer would double to four million over the next 20 years. And in 2013, we highlighted that by 2020, while almost one in two people will get cancer, almost four in 10 of those will not die from it.

While it is clearly good news that more people are surviving cancer, progress can be a double-edged sword. *'Throwing Light on the Consequences of Cancer and its Treatment'* (and the accompanying lay summary report *'Cured – But at What Cost?'*) reveals another vital aspect of the changing cancer story. At least one in four of those living with cancer – around 500,000 people in the UK – face poor health or disability after cancer treatment.

Many cancer patients will complete their primary treatment and return, more or less, to the same level of health and wellbeing that they enjoyed before their diagnosis. But a significant proportion will experience a wide range of distressing long-term problems, such as bowel or urinary incontinence, crippling fatigue or sexual difficulties. Some will face an increased risk of

heart or bone problems, a second cancer, or other health conditions that may not emerge for many decades. And the consequences of cancer and its treatment can affect much more than just a person's physical or mental health. Some patients become isolated from friends or family, or are unable to continue working, causing financial difficulties as well as further isolation. For these patients, a cure comes with a heavy and often unexpected cost.

Of course, it is not just those given an 'all clear' who are affected. Many of the two million people living with cancer today are still undergoing primary treatment, or are living with incurable disease. We are not focusing on the acute side effects of treatment in this report, or on end-of-life needs, but we do not forget the additional burden they represent. Nor is this an issue restricted to older patients in poor health: a high proportion of those who were treated for cancer as children or young adults can face the long-term consequences of treatment, such as heart problems or second cancers, for the rest of their adult life.

By throwing light on the scale of the problem, it shows the Government and the NHS that we must take action, particularly if we are to cope with the increased demand on services. Many healthcare professionals underestimate the long-term consequences of

cancer and its treatment, and some can feel uncomfortable talking about something for which they may feel partly responsible. We must overcome this. Revealing these problems also shows people experiencing these issues that they are not alone. The current low profile of the long-term consequences of cancer and its treatment means that some people who are affected are reluctant to report them, particularly if they feel grateful to be free of cancer.

With more and more people living after cancer treatment, this issue is only going to get bigger. We need action from health professionals, commissioners and policy makers to ensure that up-to-date treatment and evidence-based services are available to prevent unnecessary disability. All patients should already receive information about potential long-term consequences before and after treatment, but they should also be supported with a Recovery Package once it is complete, which includes a Holistic Needs Assessment, Care Plan, Treatment Summary, Cancer Care

Review and an opportunity to attend a Health and Wellbeing Clinic. Local and national commissioners must ensure that good care is available for all and that specialist services are provided for those in particular need.

Most importantly, patients should feel able to ask for help if they are experiencing any physical or emotional issues after treatment.

It is good that we are curing more people of cancer. But we have to recognise that 'not dying' is not the same as 'being well'. No one should face the often severe long-term effects of cancer alone. And if we can gather better evidence and build more responsive services, no one will.

Lynda Thomas
Chief Executive
Macmillan Cancer Support

It is good that we are curing more people of cancer. But we have to recognise that 'not dying' is not the same as 'being well'. No one should face the often severe long-term effects of cancer alone.

Executive summary

This report is intended for people who are seeking to learn more about the consequences of cancer and its treatment, in order to inform their work in commissioning and providing services that meet the needs of people living with and beyond cancer.

It is aimed at:

- health and social care commissioners,
- health policy makers,
- clinical networks for cancer,
- healthcare professionals,
- health service managers, and
- cancer research professionals.

Many people with cancer experience short-term physical side effects during cancer treatment and usually these will resolve naturally within a few months. However, some will experience long-term or late-onset ‘consequences of treatment’ – the wide range of physical and psychosocial changes that reduce quality of life after cancer and its treatment, however long ago that treatment might have been given.

It is an accepted risk that both short- and long-term consequences of treatment may occur as a result of the inevitable damage to normal tissues in the body when undertaking treatments that are designed to be highly destructive to cancer cells. It is also well known that there can be serious, long-lasting psychosocial effects. However, it is less well known that problems can persist, or appear as new problems, years or many decades after treatment. People need a level of information about the risks of treatment and how to cope with problems should they arise. More research is needed on

the best strategies for personalising how these issues are communicated and discussed, within an overall approach that prepares and supports people when living with and beyond cancer.

In order to plan and deliver service provision cost effectively, commissioners and providers must better understand the needs of people living with and beyond cancer, as this population is growing and ageing. It is estimated that at least 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects their lives on a long-term basis. This includes chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems and lymphoedema. As a result, they may be unable to take part in activities that had been a normal part of their life before, such as going to school or college, working, shopping, socialising, being physically active, going on holiday, enjoying sexual intimacy and having children. This leads to a significant knock-on effect on family and friends, which in turn may cause the breakdown of relationships, mental health problems and further isolation. Psychosocial problems, such as fear of recurrence, are common, whether or not someone has physical consequences. Ongoing reassurance and support are vital.

Certain cancer treatments increase the risk of long-term conditions such as heart disease, osteoporosis or a second cancer, and can add to the other acute and chronic conditions common in older age, resulting in serious health and social care problems or premature death. These can also occur in young adults. The impact of these risks are currently under-recognised.

Problems such as these affect people’s lives more than is generally recognised, and are often poorly dealt with. Although many people return to a high level of wellbeing after cancer treatment, and do not report any problems, a significant minority have unmet needs that will increasingly impact on primary and secondary care unless action is taken.

Improvements for patients are achievable, but commissioners and providers need to better understand that there is a strong case for change:

- This is not a small-scale issue in the population, and the numbers will grow.
- The increase in need will largely come from older people with co-morbidities that may be exacerbated by cancer treatment.
- In terms of life-years at risk, people treated as children or young people also represent a population with significant health and social care needs.
- There is a socio-economic impact from children, young people and adults being unable to continue education or be economically active, due to ill health.
- Quality of life can be compromised for the people affected.
- There are significant costs being incurred by individuals, the NHS and the state.
- There are simple and inexpensive interventions.
- People with complex problems benefit from specialist multidisciplinary care.

Simple interventions include physical activity programmes, provision of information about self-management of problems, public toilet access schemes, dietary advice and monitoring for problems, all underpinned by a Recovery Package for every cancer patient after treatment that includes an Holistic Needs Assessment, a Care Plan, a Treatment Summary, a Cancer Care Review in primary care and access to a Health and Wellbeing Clinic (see the 2013 Department of Health report ‘Living With and Beyond Cancer: Taking Action to Improve Outcomes’). Commissioners and providers should design and commission pathways, services and new treatment methods that minimise the consequences of cancer and its treatment and address need.

National commissioning needs to address the inequitable and low level of provision of specialist services for severe, complex problems, in which specialist multidisciplinary teams can deliver holistic physical and psychosocial care. This is as important for newly treated patients as for long-term survivors.

More education and research is needed to improve knowledge and to establish the consequences of cancer and its treatment as a healthcare/academic field in its own right. For example, methods – such the stratification of patients and the use of biomarkers – need to be developed to predict the consequences of cancer and its treatment, and to guide further management. There is an urgent need to improve survivorship intelligence, particularly in developing a better understanding of the population who have unmet needs and how those needs can be addressed cost effectively.

It is estimated that at least 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects their lives on a long-term basis.

Key recommendations:

General recommendations to everyone involved in redesigning services and support for people living with and beyond cancer

- **Prevent** or minimise consequences of cancer and its treatment where possible, through healthier lifestyle choices, better surveillance, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
- **Inform** patients of potential consequences of cancer and its treatments, with simple strategies for self-management, and the value in taking early action and how to seek appropriate help.
- **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential consequences so they can be easily anticipated, recognised and monitored in primary care.
- **Assess** potential consequences through regular Holistic Needs Assessment, the use of 'power' questions and Patient-Reported Outcome Measure (PROM) tools at regular time points.
- **Support** patients through local care pathways for the consequences of cancer and its treatment, which include support for self-management and referral to appropriate specialist services.

Recommendations to organisations that influence or carry out cancer commissioning

General recommendations

Local implementation of the NCSI Recovery Package in England, or the equivalent in Wales, Scotland and Northern Ireland.

National commissioning of specialist services for complex problems arising from cancer treatment.

National quality and outcomes measurement should be embedded and further developed, including quality standards and PROMs for people living with and beyond cancer treatment, in order to monitor service delivery and cancer patient outcomes.

Inclusion in the cancer Maps of Medicine and Cancer Peer Review Programme of evidence-based management of consequences of cancer and its treatment.

Specific recommendations

National commissioning of specialist services for:

- 1** People with complex injuries resulting from radiation treatment for breast cancer. The Breast Radiation Injury Rehabilitation Service (BRIRS) should continue being nationally commissioned for England.
- 2** People with complex problems in adulthood as a result of child and young people's cancer treatments.
- 3** People with complex problems as a result of treatments for pelvic cancer, such as severe bowel, urinary and/or sexual dysfunction.

Continue and extend the current programme of survivorship PROM surveys in England.

Recommendations to cancer care professionals, other secondary care professionals, primary care professionals and social care professionals

General recommendations

Review patient information provision to ensure that appropriate information is available at multiple points (including at consent to cancer treatment) on risks of long-term consequences and how to seek help should problems arise.

Local implementation of the NCSI Recovery Package (or similar post-treatment package)².

Educate care providers by taking opportunities to increase their knowledge of how to identify and manage patients who have needs related to the consequences of cancer and its treatment.

Develop referral pathways between cancer teams and local or regional specialists in supporting and managing the consequences of cancer and its treatment.

Specific recommendations

Fully implement the NCSI Children and Young People service models and aftercare pathways as per the QIPP Quality and Productivity case study⁴.

Review the main pelvic cancer care pathways (NICE, Maps of Medicine etc) and ensure that they include signposting/referral pathways to local/regional specialists in supporting and managing the consequences of pelvic cancer and its treatment, such as:

Patient support groups, online communities, telephone support etc.

Specialists: Gastroenterology/endoscopy; Urology; Colorectal surgery; Biofeedback service; Dietetics; Psychosexual therapy and/or sexual medicine outpatient; Hyperbaric oxygen service; Community continence service; Lymphoedema service; Stomatherapy/stoma nursing service; Gynaecology; Menopause service; Fertility service; Orthopaedics; Pain clinic; Reconstructive surgery; Dermatology; Endocrinology; Counselling, psychology, psychiatry; Rehabilitation services, including physiotherapy (pelvic specialist), vocational rehabilitation, physical activity schemes e.g. exercise on referral schemes (or a walking scheme), services for management of fatigue, body image or memory loss, etc.

Primary care team for managing and monitoring for long-term conditions (as appropriate).

Complementary therapies such as acupuncture.

Stop smoking service.

Social services including carer support.

Financial advice service.

Recommendations to professional organisations and organisations who arrange training and education

General recommendations

Develop, publish and maintain clinical guidance on the management of the consequences of cancer and its treatment.

Set educational and skills standards and competences in relation to the consequences of cancer and its treatment.

Provide accessible education for professionals on the consequences of cancer and its treatments.

Undertake audits/research on the consequences of cancer and its treatment.

Specific recommendations

Prioritise clinical guidance development where need is seen to be greatest, for example in pelvic cancers and head and neck cancers, ensuring that psychosocial consequences are always considered alongside physical ones.

General recommendations to the research community

Extend, build on and ratify the evidence base for:

- Prevalence of consequences of cancer and its treatment
- Costs of managing consequences of cancer and its treatment
- Treatments for consequences of cancer and its treatment
- Methods to prevent or minimise consequences of cancer and its treatment
- Methods for monitoring for consequences of cancer and its treatment including the risk of developing long-term conditions
- Cost-effectiveness of new cancer follow up pathways.

General recommendations to the voluntary sector

- Raise awareness in individuals of the availability of post-treatment support through health and social care services, support groups, online community support, information etc.
- Raise the profile of consequences of cancer and its treatment as a health policy issue.



Introduction

The consequences of cancer and its treatment can affect people's lives in many ways.

However, they remain an under-researched area of healthcare in terms of:

- Describing the population that have health and social needs in relation to the consequences of cancer and its treatment;
- Effective ways to treat and support people who have consequences of cancer and its treatment;
- Effective ways to reduce/prevent damage to healthy tissues from cancer treatments; and
- Effective ways to reduce/prevent psychosocial problems.

Without better evidence and wider awareness, insufficient attention will be given to improving outcomes for people affected by the consequences of cancer and its treatment. This is particularly important given the increase in older people being treated for cancer, who are likely to have co-morbidities and social care needs that may be exacerbated by the treatment.

The 2013 NCSI report¹ 'Living With and Beyond Cancer: Taking Action to Improve Outcomes' calls upon commissioners and providers to design and commission pathways and services that minimise the consequences of cancer and its treatment and address need. It also describes the urgent need to improve

survivorship intelligence, particularly in developing a better understanding of the survivorship population, which is critical to improving outcomes and understanding the costs of meeting those unmet needs. The National Cancer Intelligence Network is working with Macmillan Cancer Support's Population Evidence Programme³ to improve epidemiological data such as incidence and prevalence of the consequences of cancer treatment.

To support this drive to improve outcomes for people affected or at risk, this report makes, for the first time, estimates of how many people are affected by specific long-term problems after cancer treatment in the UK. Some of these problems may also be relatively common in people unaffected by cancer, such as depression or female urinary incontinence. This report aims to show that, regardless of the baseline incidence in the population, those people affected by cancer, by virtue of their contact with health services, are in a unique position to be helped to more effectively self-manage, to minimise the risk of long-term health problems and to make healthy lifestyle choices. However, self-management is only part of the solution, and it does not take away the health service's responsibility to care for patients who may have been left with unexpected and possibly permanent side effects of their cancer treatment.

The estimates of prevalence give a vital picture of what kind of problems exist, and how many people are affected overall, but they still do not provide enough information to help health commissioners understand the degree of prioritisation of need within the population affected, or where inequalities exist. Should be selectively addressed? For example, there are opportunities to improve outcomes:

- For the small groups of people affected by very serious life-changing consequences of cancer and its treatment, in order to bring significant benefit to these individuals and their carers;
- For large groups of people affected by consequences of cancer and its treatment that have a lower, but still significant, impact on quality of life, in order to bring benefit to the largest number of people;
- For people affected by consequences decades after their cancer treatment ended, and who are likely to have lost contact with cancer care teams, but have a need for closer monitoring due to the risk of premature mortality.

The NCSI chose to focus its consequences of cancer and its treatment work on two main groups:

- People living after child or young people's cancer treatment (small number of people with high survival chances, but a high proportion affected long-term, many with complex conditions lasting decades).

- People living with the consequences of pelvic cancer treatment (large number of people with moderate survival chances, a significant minority affected long-term, with problems ranging from mild to very severe).

The Children and Young People cancer survivorship initiative, led by NHS Improvement, has tested and implemented service models and aftercare pathways to improve quality and the patient experience, with particular focus on the consequences of cancer and its treatment. The model has been accepted as a Quality, Innovation, Productivity, Prevention (QIPP) case study⁴, which indicates that it leads to modest savings from reduced consultant outpatient appointments. NHS Improving Quality is now taking forward the roll out of the recommendations to the 19 Children's Cancer Centres in England and Wales, followed by the 14 Teenage and Young Adult Centres by 2014. These improvements will benefit children and young people currently still under the care of a cancer centre.

Further challenges include:

- Developing transition services, so that young people are carefully transitioned to multi-disciplinary adult after care; and
- Targeting the group who were treated in the past and who have, or are at risk of, long-term complex problems, but are now unable to access the kind of co-ordinated monitoring and care that they need.

The NCSI project on the consequences of pelvic cancer treatment (e.g. colorectal, prostate, bladder, gynaecological), led by Macmillan Cancer Support, has aimed to improve outcomes for a large number of people with problems ranging from mild to severe that may affect bowel, bladder and sexual function, as well as with psychosocial issues. Work is ongoing on the development and evaluation of resources such as patient information to help support self-management, and clinical guidance for professionals on managing mild/moderate problems. Service models are being evaluated, and a business case for the creation of a small number of specialist multidisciplinary services for severe, complex cases is being developed.

However, the biggest barrier to widespread improvement is still the lack of awareness amongst health commissioners and professionals of the issues faced by people after cancer treatment. It is hoped that this document will increase awareness and lead to greater ownership of this agenda, and adequate assessment of population health needs. In anticipation of questions on how needs could be met, evidence and opinions were sought on the key ways in which local and national bodies could address the barriers to improving outcomes.

All challenges and questions about this report are welcomed. In preparing it, many limitations were found with the available data and hence it is emphasised that prevalence estimates are indicative, and should be used with caution. Although the literature strongly suggests that many long-term problems are caused or exacerbated by cancer treatment, there are not enough data recorded to prove this conclusively in all cases, or to indicate how long these problems might last.

Clinicians and the research community do not currently have robust, systematic methods to assess and record the incidence and severity of consequences of cancer and its treatment, to support both the clinical management of individuals and the measurement of outcomes in epidemiological studies and clinical trials. Health professionals and managers are therefore currently unable to plan effectively to meet the predicted increase in patient need that is accompanying improved survival rates, and unable to provide newly diagnosed patients with realistic predictions of the risks associated with their treatment.

The biggest barrier to widespread improvement is still the lack of awareness amongst health commissioners and professionals of the issues faced by people after cancer treatment.

What are the consequences of cancer and its treatment?

2a Definition

In this report, the terms 'consequences of cancer and its treatment' and 'consequences of treatment' mean the wide range of long-term physical and psychosocial changes that seem to be associated with cancer and its treatment, however long ago the diagnosis and treatment might have been given.

It is a difficult topic to define precisely because health professionals and researchers do not use a common terminology. 'Side effects', 'late effects', 'toxicity', 'adverse effects', 'long-term effects', 'chronic effects' and 'consequences of treatment' are all used. For simplicity, in this report the term used mainly is 'consequences', which aims to cover as broad a definition as possible, but with a focus on consequences that have the greatest long-term impact on patients' lives. The phrase 'long-term' covers not only chronic problems that arise soon after treatment, but also late-onset conditions that may arise decades later.

Although this report is not able to describe every consequence of cancer and its treatment on a person (including the consequences of someone being told that they have cancer, whether or not treatment is given – or the effect on family and friends), it is recognised that all consequences have the potential to affect quality of life. The particular issues faced by people in active treatment or at the end of life are

not covered in this report, as they are covered elsewhere^{5, 6}. Hence, it should be noted that the figures presented in this report, which are intended to provide a measure of how many people are affected by certain long-term consequences of cancer and its treatment, will probably not represent the totality of need in this population.

2b Types of consequences of cancer and its treatments

Cancer patients may receive surgery, radiotherapy, chemotherapy, biological therapy and hormone therapy, either alone or in combination depending on the stage of the disease and other factors. For each treatment option, there may be multiple physical and psychosocial consequences for a patient affecting different parts of the body, with some of them permanent. In general, the majority of patients will not experience consequences long term, but a significant minority do, and for some, the consequences may be very severe or even fatal⁷.

Figure 1 lists possible long-term effects for cancer patients. Further information about the possible long-term consequences of cancer and its treatments for individual cancer types can be found on the Macmillan Cancer Support website www.macmillan.org.uk.

Figure 1
Possible long-term consequences of cancer and its treatment
 Collated from the multiple references used in this document

Psychological and social consequences

Fear of cancer recurrence	Impact on family/friends	Unable to work or continue education
Fear of future HPV infection	Financial problems	Embarrassment or difficulty coping, which can affect relationships, work and day-to-day life in many ways
Body image issues	Isolation Anxiety	
Lack of confidence	Stress	
Memory/concentration problems	Depression	
	Change of outlook on life	

Physical consequences

Pain, arthralgia, numbness	Changes in bowel function*	Loss of fertility
Scarring	Bowel or bladder adhesions, strictures, fistulae	Eating difficulties^^
Facial or body disfigurement	Stoma [§]	Speaking difficulties^^
Persistent hair loss	Hernia	Oral and dental problems
Lymphoedema	Bleeding from the bowel or bladder	Hearing loss
Peripheral neuropathy	Changes in bladder function*	Breathing difficulties
Fatigue	Sexual difficulties#	Endocrine dysfunction
Nausea, vomiting	Early menopause	Cardiovascular disease
Weight loss, weight gain	Hot flushes	Pelvic necrosis
Sleep disturbance		Osteoporosis
		Second primary cancer

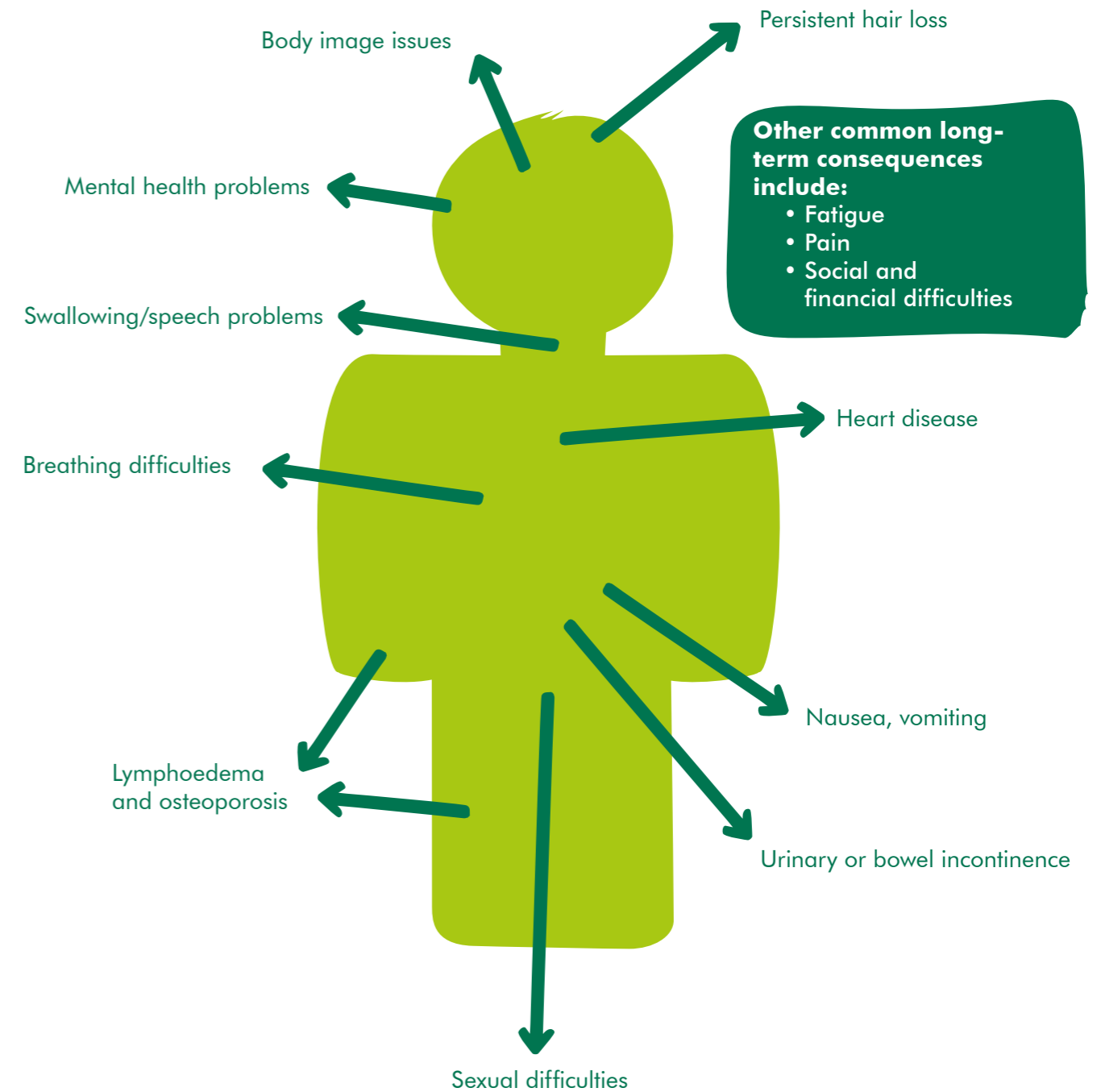
* Includes chronic incontinence, urgency, diarrhoea, constipation, leakage, flatulence.

Problems preventing a normal sex life, e.g. erectile dysfunction, penile shortening, vaginal dryness, stenosis and shortening, sexual pain and loss of sexual interest, psychosexual problems.

§ As a result of bowel adhesions, strictures, fistulae etc.

^^ Including being unable to speak or eat.

Examples of long-term consequences of cancer and its treatment



2c Impact on people

The consequences of cancer and its treatment may mean that people are unable to take part in activities that had been a normal part of their life before, such as going to school or college, shopping, working, socialising, being physically active, going on holiday and enjoying sexual intimacy. This leads to a significant knock-on effect on family and friends, which in turn may cause breakdown of relationships, mental health problems and further isolation. The impact on people's daily lives is best described in their own words. Several reports that include patient testimonies have been published (for example^{8,9,10,11}), with websites^{12,13} and patient forums^{14,15} also giving very good insight. See also case studies in Appendix 2.

There are many studies linking certain consequences of cancer and its treatment to reduced quality of life, e.g.^{16,17,18} although in general most people will not experience long-term problems after cancer treatment and report a good quality of life, and for some, certain changes may have a positive impact.

The following quotes are mostly taken from patients' free-text comments in the Department of Health survey of people living one to five years after a Hodgkin lymphoma, breast, prostate or colorectal cancer diagnosis¹⁹. Although more people gave positive comments than negative about their experience of living with and beyond cancer, a wide range of ongoing physical, psychological and social problems were reported by participants that were side effects of cancer treatment and that impacted greatly on their quality of life^{18,20}.

'I do have a fear of dying and [the] cancer returning (I've 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.'

Male, non-Hodgkin lymphoma, 1 year after diagnosis

'My anxiety has been affected in the sense that I never know when I will have [an] accident with my bowels. This can be a nightmare when driving or on public transport (sometimes I have very little warning and I can go 10 or 20 times or more in 2 hours). You never know when it's going to stop with the diarrhoea. [I] always have to think what I am eating i.e. about the fibre.'

Male, prostate cancer, 3 years after diagnosis

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

Male, colorectal cancer, 1 year after diagnosis

'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 later.'

Female, breast cancer, 5 years after diagnosis

'I had colorectal surgery, its side effects affected my life badly. I should have been warned/ advised about those side effects to decide. If I knew about them I would not [have] go[ne] ahead with surgery.'

Male, colorectal cancer, 3 years after diagnosis

'My problem is that I have one breast much larger therefore am having difficulty with underwear and clothes and certainly am too embarrassed to go swimming. I know this sound[s] trivial but it has made me quite depressed. I know my consultant is busy but they told me it wouldn't be long [before I could have breast reconstruction surgery]. I was offered an operation [...] but with one day's notice, which I just couldn't do.'

Female, breast cancer, 3 years after diagnosis

'It is now over 9 month[s] since my op and I am still paying for my own continence pads. [...] The pads cost £4.50 for a box of 10. I think patients should be given the information to contact the continence service before the operation so they have pads.'

Male, prostate cancer, 3 years after diagnosis

'I had a stem cell/bone marrow transplant a year ago but lately my depression has got so severe I have been to hospital many times on suicide watch. People need to realise that after all your cancer treatment your mind plays tricks on you. I have honestly been to hell and back. It is after treatment that you need care. I feel totally alone and have brought my 16 year old daughter up on my own. I have to stay strong so she can have a normal life. I hate it when I'm laid in bed crying and she doesn't know what to do!'

Female, non-Hodgkin lymphoma, 2 years after diagnosis



'Would have liked to know that the drugs which caused nerve damage could affect my balance and walking and that this could lead to back pain [sciatica]. Then I could have started preventative measures i.e. Pilates which I now do to prevent reoccurrences.'

Female, breast cancer, 2 years after diagnosis

'Although I was 65 when diagnosed, I was newlywed, the hormone treatment ruined our sex life and we found this extremely upsetting and difficult to live with especially my wife who still gets very upset. A less strong relationship could have split up.'

Male, prostate cancer, 2 years after diagnosis

'Well, I had to get all my teeth removed before the radiotherapy and I found that completely devastating. I wasn't prepared for it, it was just a case of, 'You're going to the dentist to get your teeth checked,' and I thought, 'Fine.' Then all of a sudden somebody said to me, 'Okay, all your teeth have to come out, cheerio.' I found that worse than being told I had cancer for some reason.'

Female, head and neck cancer, 2 years after diagnosis

These testimonies clearly show that, for some, the consequences of cancer and its treatment can have a very negative effect on quality of life.

It is also worth considering the scenarios of these same individuals some years later:

- How will their close relationships have been affected?
- Will they have developed other co-morbidities?
- Will they have a dependent partner but family who do not live near enough to provide support?

If the long-term effects of cancer treatment are well managed or are avoided in the first place, this could prevent GP visits, hospital admissions, a move into residential/nursing care (for cancer survivors themselves or a spouse) or a requirement for home help, or prevent a family member having to give up work to act as carer. All these have cost implications for health and social care, as well as for the individuals affected.

2d What causes the consequences of cancer and its treatment?

Although discussed as two sections below, the physical and psychosocial consequences of treatment cannot and should not be separated when considering health and social care services and support for people affected by cancer. Psychosocial and physical issues are so closely intertwined, each impacting on the other, that a holistic approach to needs assessment, support and treatment is vital. Equal weight should be given to developing psychological therapies and psychosocial support as should be given to interventions for physical symptoms after treatment.



Psychosocial consequences

Psychological morbidity, such as anxiety and depression, is a major problem that arises from the many significant changes experienced by individuals and the people around them resulting from a diagnosis of cancer and the effects of treatment. These psychosocial impacts can often be seen as 'adjustment disorders' as they represent a difficulty in adjusting to the functional and existential crisis that cancer represents. Psychosocial consequences are not just about emotions, but arise from the challenge of adapting to the physical and functional problems associated with cancer and its treatment. People with a pre-existing mental health diagnosis are at higher risk of psychosocial problems.

People are faced with the possibility of dying and have to cope with the extensive demands of cancer and its treatment. They may feel scared, uncertain, or angry. Numbness, confusion and difficulty concentrating are all common, as is loss of confidence, and feelings of shock, disbelief, fear, anxiety, guilt, sadness, grief and depression. There may be a sense of loss, as ways of coping with the new, unwanted changes in their life need to be found. These feelings may occur at the time of diagnosis, during treatment, or when people are recovering and adjusting to life after treatment. Distress during treatment can also lead to difficulties in long-term adjustment²¹. All types of cancer treatment can change the way the body looks, works or feels, which may cause embarrassment, loss of confidence and worry about the impact on family, friends and work colleagues. Intimate relationships may be adversely affected due to: feeling sexually unattractive; having no desire for sex; loss of sexual satisfaction; a partner distancing themselves; and functional changes in erectile capacity, vaginal anatomy and

physiology (which may cause sexual pain and changes in ejaculation and orgasm). Loss of fertility and the need to engage with reproductive technologies (sperm cryopreservation/egg freezing) at a time when you are also coming to terms with a cancer diagnosis can also be distressing. Friendships and support networks change, and some people may find themselves isolated. Psychosocial problems can affect a person's ability to self-manage, and cause greater reliance on other people or health and social services. Some treatments (e.g. chemotherapy and treatments for brain cancer) may lead to cognitive changes, which can affect the way people are able to live their lives. This is particularly the case for young people, who may not be able to leave home, find a job or go on to higher education²².

Some psychosocial consequences may be severe, resulting in persistent mental health difficulties. People living with and beyond cancer are considered to be at risk for post-traumatic stress disorder due to the shock and trauma of having a life-threatening disease and receiving treatment for cancer. Estimates of the prevalence of some psychosocial consequences are given in Chapter 3, Table 4B.

Such substantial changes to feelings, relationships, mental health and outlook on life are an understandable and common consequence of cancer, and therefore people's need for support and intervention should be assessed systematically and appropriate services provided, as it would be for a physical consequence of treatment.

Physical consequences

In order to destroy cancerous cells in the body, some healthy tissues will also be damaged^{24,25}. While the research community continues to develop more targeted cancer therapies to minimise such damage (e.g. biological therapies, interventional radiology (IR) and proton beam radiotherapy (PBT)), no current treatments can avoid damaging healthy cells. Whether this damage leads to long-term or late-onset consequences depends on a multitude of factors that are not yet well understood, but include:

- Cancer treatment type, dosages, frequency and/or combinations²⁶;
- Gender, age²⁶;
- Lifestyle choices (weight, smoking, diet, alcohol, physical activity)²⁷;
- Pre-existing conditions (e.g. diabetic neuropathy²⁸);
- Pre-existing medication (e.g. statins may have preventative effect²⁹);
- Post-treatment incidents (e.g. arm trauma triggering lymphoedema³⁰);
- Social deprivation³¹; and
- Genetic profile³².

Research into the mechanisms by which cancer treatments cause symptoms to arise is needed so that preventative or protective measures against healthy-tissue damage can start to be uncovered. Mechanisms of radiation damage are better understood³³ than other therapies. The impact of cancer treatments on pre-existing long-term conditions is not well understood.

A common and highly effective treatment for certain cancers is radiotherapy. The radiation is targeted as precisely as possible at the tumour, but it is inevitable that some

surrounding healthy tissue will be irradiated. For example, radiotherapy of a tumour in the pelvic region may affect the bowel, genitourinary organs, skin, blood vessels, lymphatic system, nerves or bone. Acute side effects (during or immediately after radiotherapy) will usually resolve quickly in tissues with rapid cell turnover. Chronic problems after pelvic radiotherapy are increasingly being termed 'pelvic radiation disease'³⁴. This is because subtle sub-cellular changes may develop gradually after cancer treatment has ended, leading to a cascade of adverse effects on tissues. For example, changes to small blood vessels may reduce tissue blood supply and cause an increase in fibrosis (scarring). Over time, this may lead to tissue inflexibility, internal adhesions, changes to physiological function and shrinkage of organs (e.g. bladder, bowel, vagina), resulting in problems such as loss of bowel or bladder control, or pain during sex.

These gradual changes, sometimes termed 'late effects', mean that some people do not experience symptoms until many months, years or even decades after treatment. Examples include heart failure after anthracycline chemotherapy for a range of cancers³⁵, and bone fractures due to osteoporosis caused by the effect of hormonal treatment on bone cells in breast or prostate cancer patients³⁶. There is a growing body of evidence implicating cancer treatments in increased risk of second primary cancers later in life, again due to a lengthy sequence of sub-cellular changes that currently cannot necessarily be prevented.

2e What can be done during treatment to prevent adverse consequences?

It is not the intention of this document to provide detailed information on all the methods currently in use or being researched for the prevention and clinical management of the consequences of cancer treatment. This section briefly outlines how strategies for cancer treatment continually develop and that future significant progress is possible on preventing consequences of treatment by modifying cancer treatment techniques. (Appendix 4 provides some links to information on the clinical management of consequences once they occur.)

The goal of research into any new cancer treatment is to find the most effective cancer-killing regime with the minimal level of toxicity during and after treatment. Scientists are constantly seeking treatments that target cancer cells as precisely as possible, e.g. robotic surgery, intensity modulated radiotherapy (IMRT), stereotactic ablative radiotherapy (SABR), PBT, IR and biological therapies, which damage normal tissue to a lesser extent than older treatments. However, as described in section 2d, each patient is likely to have a different response to the same treatment, and none of these methods can avoid causing any consequences. While researchers aim to develop new treatments that improve survival and minimise consequences of treatment, there is evidence that some new therapies may not achieve any reduction in the incidence or severity of consequences, or risk rare but serious complications^{7,37,38}. Hence, monitoring for consequences will always be necessary.

Therefore, increasingly, an additional goal of cancer research is to find ways to assess patients to predict their responses to treatment, thus allowing modification of the regime

to improve the chances of destroying the cancer with a lessened risk of damage to healthy tissue. For example, a pharmacogenomic approach aims to identify individuals with a high risk of toxicity from conventional doses of a chemotherapy drug, thus indicating reduced doses and a decreased risk of toxicity³⁹.

Biomarkers have the potential to predict the occurrence of consequences, such as anthracycline-induced cardiotoxicity, before the patient becomes symptomatic, thus allowing for early and potentially life-saving interventions⁴⁰. Biomarkers may also help to improve preoperative cancer staging, better inform treatment options, and improve the referral patterns of patients with urgently treatable cancers towards more appropriate modes of therapy⁴¹.

Research is also being undertaken into whether there are agents that can protect against or reduce the severity of certain consequences, without affecting the cancer-killing properties of the cancer treatment. These agents may have to be taken in advance, or alongside and after treatment. For example, several novel agents are being tested as drugs to prevent or reduce gastrointestinal radiation injury⁴². These drugs may also reduce injury after radiation exposure has occurred, but much more research is needed to confirm this.

To minimise psychosocial consequences, the concept of preparing people during treatment with simple strategies of how to proactively manage their physical, psychological and social recovery, and any long-term problems after cancer treatment ('prehabilitation') is recognised as an area that needs much more consideration⁴³. The Department of Health survivorship survey suggests that very few people are suitably prepared for what to expect when treatment finishes²⁰.

Gradual tissue changes mean that some people do not experience symptoms until years or even decades after cancer treatment.

There is a growing acknowledgement that healthy lifestyle choices can help to protect against some short- and long-term consequences of cancer and its treatment^{44,45}. A recent report⁴⁶ by Cancer Research UK highlights the acceptability to patients, family and friends of professionals offering lifestyle advice to cancer patients.

Again, much more evidence is needed to help professionals and patients make appropriate choices before, during and after cancer treatment, based on knowledge of the risks of both the physical and psychosocial consequences of cancer and its treatment, and whether the risks can be minimised.

2f Are the risks of consequences acceptable?

The risk of long-term and late-onset symptoms must be balanced against whether a particular treatment regime gives the optimal outcome in terms of cancer cure. However, at present, most newly diagnosed patients cannot be given realistic predictions of the long-term risks associated with their treatment⁴⁷.

There are many ethical and legal issues around the provision of information to patients on their treatment choices and on the risks of side effects (short and long term) that are discussed at the point of formal consent to treatment and subsequently. This document cannot cover these issues in detail. However, it is a fact that some people will unfortunately get unpleasant consequences or may even die as a result of their treatment^{5,48}, and these risks will not be eliminated in

the foreseeable future. Most people accept that it is worth taking the risk of developing side effects in order to get the most effective cure for their cancer⁴⁹. Good assessment of the information needs of patients, and the offer of personalised information, is vital to help people make an informed decision about their treatment. Some information on the potential long-term consequences of cancer and its treatment is needed so that they can be monitored for, and the minority of patients who do develop problems are better able to recognise that their cancer treatment may have been the cause, and to know how to seek help⁵⁰.

2g Information for patients about the risks of long-term consequences

A study carried out for Macmillan describes how there is a need to maintain some ambiguity about the future when providing information to cancer patients⁴⁷. This poses a difficult dilemma for healthcare professionals when assessing the information needs of their patients about the possible consequences of cancer and its treatment. It is impossible to define exactly what information patients want about the risks of consequences, and when to provide it, because every patient is unique and therefore information needs are highly variable. Healthcare professionals draw on their expertise in communicating risk associated with cancer treatments, but excessive information on this topic at the point of cancer diagnosis or treatment choice can be a burden to some patients, and knowledge of future risk may be a significant risk factor for later anxiety, depression and fear²⁶.

The desire for information may depend on the level of personal health literacy and motivation. However, a paternalistic approach to withholding information about the risk of side effects should be avoided. It has been argued that complete disclosure is needed⁵¹, but currently it is not known when the optimal time is or what the optimal approach is to discuss risks with a patient, and who is best placed to do this²⁶.

A recent evidence review⁵² found that “appropriate information provision led to an improved health competence, a better sense of control over cancer and better symptom management”, and that patients had less confidence to deal with health-related issues when they had had difficulty obtaining the information they wanted.

Although evidence shows that a majority of people are satisfied with the information they received about their treatment and side effects, these surveys tend to be focused on patients soon after treatment (e.g. the English 2011/12 National Cancer Patient Experience Survey⁵³). Given the crucial importance of information that helps support people in the long term to self-manage and avoid healthcare interventions, it is disappointing that in the 2011 Department of Health survivorship survey of people one to five years since diagnosis⁵⁴ 20 to 30% said that it would have been helpful to have had more advice or information on the physical aspects of living with and after cancer, the emotional aspects and diet/lifestyle.

When free-text comments in the 2011 Department of Health survivorship survey¹⁹ were analysed, five out of the six recommendations focused on improving the offer of information to individuals on preparing for the physical consequences of treatment and the ‘psychological aftermath’ of receiving a diagnosis of a potentially life threatening illness. The recommendations cover information about:

- Cancer diagnosis and treatment options;
- Potential physical effects of treatment;
- Self-management and coping strategies;
- Access to support services;
- Potential psychological impact of end of treatment and in the long-term; and
- Access to advice on social, work and financial issues.

Feedback from people who have received pelvic radiotherapy frequently mentions a lack of awareness of possible long-term effects on the bowel, bladder and sexual function^{55,56}, despite the fact that inexpensive interventions, such as providing a ‘toilet card’⁵⁷ and/or Radar key⁵⁸, doing pelvic exercises or moderating the intake of dietary fibre or fat⁵⁹, allow some people to better self-manage and potentially avoid more serious problems. In one study⁵⁵, less than half of pelvic radiotherapy patients reported receiving both verbal and written information on potential long-term effects of treatment. People may forget that they have been given information, so need to have it reiterated at multiple later time points (both verbally and written). In another study⁵⁶, 30 people who had had pelvic radiotherapy were asked for their views on a Macmillan booklet explaining possible consequences of pelvic radiotherapy⁶⁰, and 100% said they found it helpful. One response was: *“Having endured anal cancer treatment I am still coming to terms with after-effects a year later. I wish I had read [the booklet] earlier so that I could identify all my symptoms as being a direct result of radio/chemo. Most doctors, employers and [the] public are unaware of the effects on one’s life. This book made me feel less isolated.”*

Most newly diagnosed cancer patients cannot be given realistic predictions of the long-term risks associated with their treatment.

There are many other ways in which people can access information about life after treatment; for instance, talking to other patients who have already been through the treatment, through video stories such as provided by www.healthtalkonline.org and www.youthhealthtalk.org⁶¹ or reading personal experiences on online cancer patient forums.

Overall, there are clear shortfalls in information about the possible long-term consequences of cancer treatment. Patient feedback and other evidence strongly support better provision. Expert consensus is that there is a need to personalise this provision throughout the cancer diagnosis and treatment phase, and then to ensure that information about consequences is also proactively offered at later time points, especially when a patient is moving from treatment to follow up, or from follow up to self-management. However, healthcare professionals' views appear to be more reactive than proactive⁴⁷.

The Macmillan Listening Study found that people affected by cancer want researchers to give the highest priority to finding better ways to help with living with cancer⁶². This study also found that "research on treatment" was given equal ranking (7th out of 13) to research on "experience and management of side effects", whereas the current balance in UK cancer research effort and funding is heavily weighted towards research on treatments. There is therefore an urgent need for more research on the best strategies for communication about the risk of consequences of cancer and its treatment and their management, within an overall approach that prepares and supports people when living with and beyond cancer.

CHAPTER 2 SUMMARY

- Cancer treatment can cause a wide range of long-term physical, psychological and social consequences, some of which may not arise for many years or even decades afterwards.
- The consequences of cancer and its treatment can have a very negative effect on quality of life, although in general most people will not experience long-term problems after cancer treatment and report a good quality of life
- Strategies for cancer treatment are continually developing, and future progress is possible on preventing consequences of treatment by modifying cancer treatment techniques, but the risks of consequences of treatments can never be eliminated.
- Excessive information on consequences of cancer and its treatment at the point of cancer diagnosis or treatment choice can be a burden to some patients, so a proactive approach to personalised assessment of information needs and provision at multiple time points should be used.
- The provision of high-quality timely personalised information is a fundamental element of cancer care (including follow up in primary and community care) and one that can be improved at little or no cost, resulting in a better patient experience, fewer symptoms, fewer crises and better quality of life.
- There is an urgent need for more research on the best strategies for communication about the risk of consequences of cancer and its treatment and their management, within an overall approach that prepares and supports people when living with and beyond cancer.



Level of need relating to the consequences of cancer and its treatment

3a Overall prevalence of consequences of cancer and its treatment

i. Why it is important to quantify needs and demand for support with consequences of cancer and its treatment

The population of people living with and beyond cancer is growing and ageing, and has multiple needs. In order to plan and deliver service provision cost effectively, commissioners and providers must better understand these needs. This chapter provides estimates of the prevalence of particular consequences of cancer treatment in the UK as an indicator of the overall level of need for interventions such as support for self-management and specialist clinical services. The level of unmet need and demand is much more difficult to quantify, but there is clear evidence of unmet need and of rising demand, which will place further strain on primary and secondary care unless action is taken.

ii. How many people are treated for cancer?

If we assume that the majority of people diagnosed with cancer will receive some sort of treatment, then this amounts to approximately 300,000 – 325,000 people per year⁶³ who will have surgery, radiotherapy, chemotherapy or other treatments, either alone or in combination, at an annual cost to UK

health services of an estimated £5.5–5.8 billion⁶⁴. A large proportion of these will have treatment with curative intent, while some will have palliative treatment (e.g. to shrink an incurable tumour or for metastases). However, data are not yet easily available (from the UK's national repositories of cancer data) to give the full picture of how many people have each kind of cancer treatment for each cancer type in the UK each year. This makes it very difficult to assess with any accuracy what the potential impact of the consequences of each kind of treatment might be on the population.

For many patients, treatment is very successful. Around half of those diagnosed with cancer today will live for at least 10 years after diagnosis. For some cancers, such as melanoma and testicular cancer, the figure is higher than four in five⁶⁵. More than one in three people who have had cancer (35%) will now ultimately die from another cause, increasing to 38% by 2020⁶⁶.

The number of people living with and after a cancer diagnosis in the UK is currently estimated at two million⁶⁷. This number will continue to increase significantly for the foreseeable future (by about 3% per year, equivalent to one million per decade) so that, by 2030, the total will be four million. Of these, over two million will be at least five years beyond diagnosis (Figure 2). In addition, the age profile will change, and a greater proportion will be aged 65 and over (Figure 3). By 2030, one in five people over 65 will be living with a cancer diagnosis, and older people will account for 73% of the total number of people with a cancer diagnosis, an increase from 63% in 2010⁶⁸.

These increases will significantly impact on the quantity and nature of health and social care required, with a greater demand for rehabilitation and services to manage the long-term effects of cancer and its treatment¹, and greater needs likely amongst older people who will tend to have co-morbidities. Failing to meet these needs will have cost implications for the NHS and the wider economy, resulting in an increased use of health and social care resources, reduced economic activity and an increased dependency on state benefits.

Please see Appendix 3 for UK population figures split by different time phases after cancer diagnosis, split by cancer type, where available.

Fatigue

Fatigue related to cancer and its treatment can make even simple tasks feel exhausting. At its worst, fatigue can leave people bedridden. As many as 75% of people living with cancer feel fatigued at some point¹⁰². In a national survey of people living with breast, colorectal or prostate cancer or non-Hodgkin lymphoma, 43% of those diagnosed up to five years previously reported always feeling tired⁵⁴.

'I [don't] have the energy for [my] day-to-day lifestyle. Pre-cancer people seem to live life in the fast lane, whilst you feel as if you are on the outside looking in.'
Female, breast cancer, 5 years after diagnosis¹⁹.

Although fatigue affects a large number of people after cancer treatment, there are simple interventions that can reduce its impact. For example, a recent in-depth review of 22 studies showed that aerobic exercise, such as walking or cycling, can significantly reduce fatigue¹⁰³. Other research has shown that cognitive behavioural therapy that involves increasing activity in a planned, incremental way can help fatigue¹⁰⁴.

Figure 2
Number of people living with a cancer diagnosis by time since diagnosis in the UK

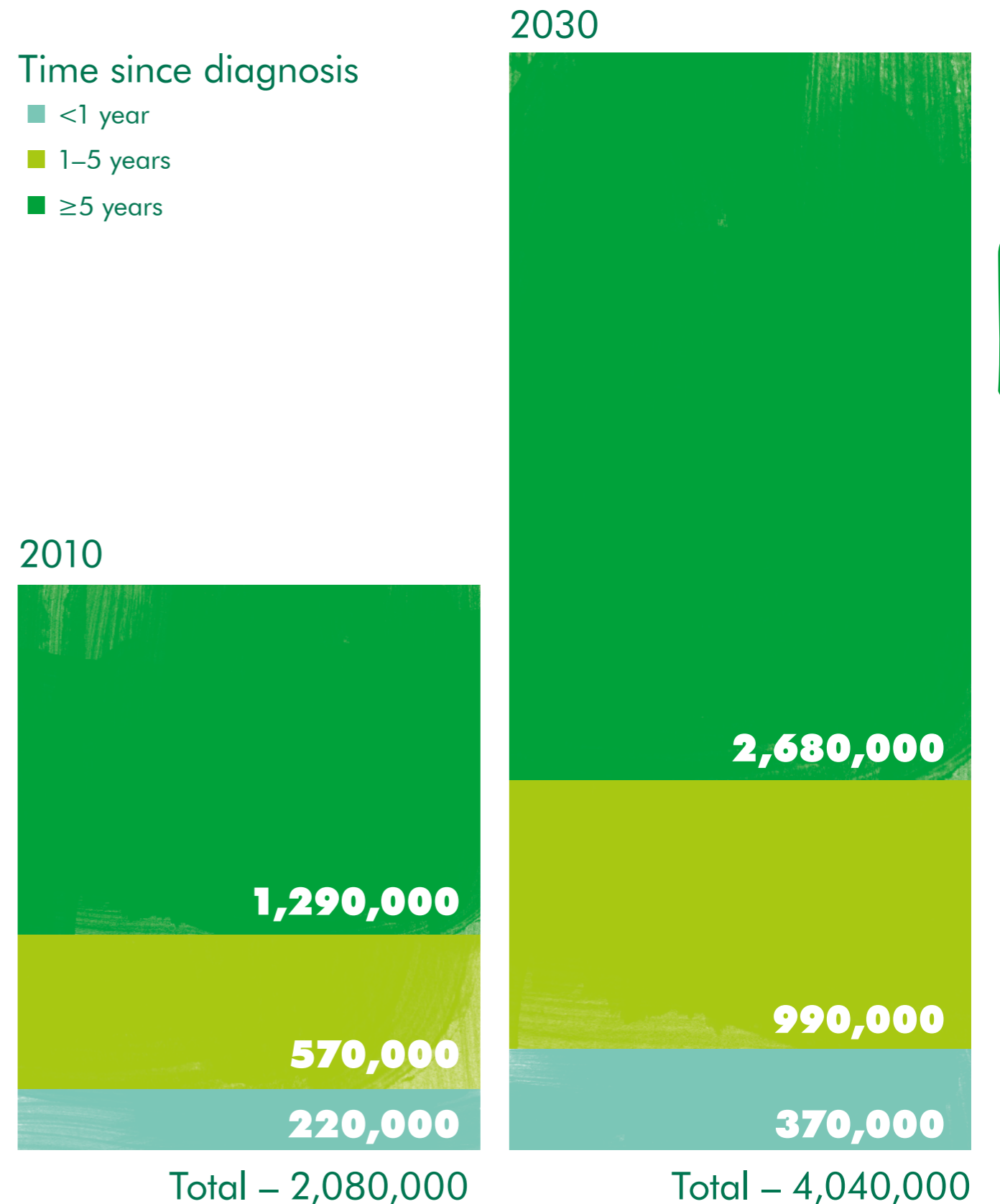
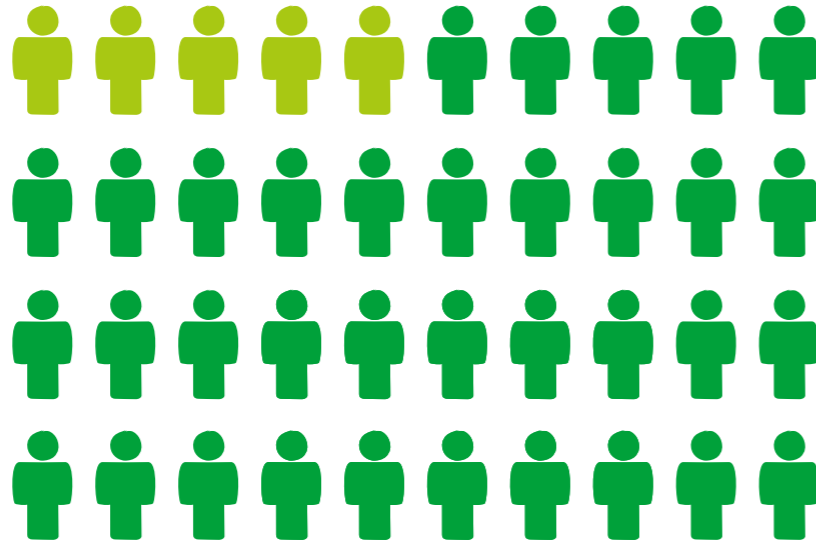


Figure 3
Proportion of older people (65 and over) living with a cancer diagnosis in the UK

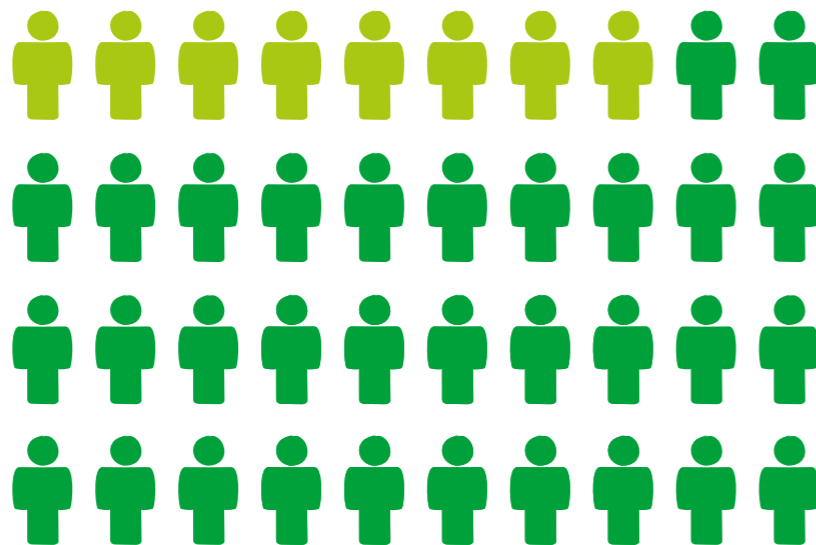
2010

1 in 8
 older people (65+) in the UK population lived with a cancer diagnosis.



2030

1 in 5
 older people (65+) in the UK population will be living with a cancer diagnosis.



Although the number of children and young people affected by cancer is much smaller than adults, childhood/young people's cancer treatment is highly successful, such that a much greater proportion of patients will live into middle and old age. Hence, for the first time, health and social services have to support a growing population of older people who may have long-standing or late-onset consequences from their cancer treatment as a child or young person, such as cardiac effects, second primary cancers, bone health problems, metabolic syndrome and fertility issues. Estimates give the number of five-year survivors of child and young people's cancer rising from 21,000 in 2001 to 42,000 by 2021¹.

When considering the long-term impact of consequences of cancer and its treatment on people's lives, clearly those with the greatest chances of living a long time with more serious risks and consequences are likely to require the greatest amount of health and social care over their lifetime. Children and young people automatically fall into the category of high chance of long survival (perhaps 60 to 70 life-years at stake) but are at high risk of serious consequences of treatment. Hence health service providers should consider how the needs of people living after child and young people's cancer treatment differ from those of people diagnosed much later in life, in whom only a few life-years might be at stake.

iii. Difficulties in estimating the number of people living with and after cancer who also experience consequences of cancer and its treatment

Obtaining the numbers of people affected by particular consequences (and how severely), or who are currently at risk of consequences, is very difficult. Whether people have consequences, and what their needs are, is not consistently recorded in patients' health records, and is not usually coded into hospital or GP IT systems, so information is almost impossible to retrieve and analyse with any confidence. Research on cancer treatments tends to focus on survival/recurrence and not on the side effects. For the estimates of prevalence in this document, we have had to rely largely on published articles, and have also used studies commissioned for the NCSI and Macmillan Cancer Support.

A number of innovative studies have aimed to quantify and describe the number of people living with the consequences of cancer and its treatment. Although these sources have helpfully increased the evidence of what a survivorship journey may look like, not all of them can be used as proof that morbidities after cancer treatment can be directly attributable to a specific cancer treatment. Examples include:

- The study by Elliott et al.⁶⁹, quoted below, shows the widespread incidence of problems after a cancer diagnosis, but presents no evidence about how these may be related to treatment.

- Macmillan's Routes from Diagnosis programme⁷⁰, which uses routinely collected data (Cancer Registry Data, Hospital Episode Statistics for inpatients), identifies clinical outcomes including recurrence, metastatic, second primary cancers and other health-related morbidities. The pilot study showed a high level of cardiovascular morbidity (requiring hospital admission) in people after a colorectal cancer diagnosis, but did not include an age-matched population, so it cannot be concluded that the cardiovascular problems were due to cancer treatment and therefore cannot attribute causal links. In future, the programme will include a control population, allowing comparison with the 'normal population' thus supporting conversations about whether any increased use of health resources is due to cancer and its treatment. In addition, it will address the level of health-resource use in non-inpatient settings such as outpatients, diagnostic tests and A&E.
- The Southampton CREW study (a prospective cohort study on the recovery of health and wellbeing following colorectal cancer)⁷¹ which captures patient reported data before surgery and at regular points during and after treatment as well as medical data. CREW will help to inform healthcare providers about what helps or hinders rapid and effective recovery from cancer, who is most at risk of problems, and identify areas for the development of interventions to aid this process.
- Khan et al.²⁵ show that the risk of certain long-term conditions after cancer treatment is increased compared to an age-matched population but, again, without information on what treatments may have caused these increased risks.

We also have to apply caution when looking at the results of cross-sectional surveys, i.e. questionnaires that are

sent to a section of the population to get a snapshot of their views and experiences. Although these surveys can be very useful in obtaining information from people many years/decades after treatment, a well-known limitation of these surveys is that people with problems are more likely to respond than those without problems, and therefore the results may overestimate prevalence of problems.

Prospective studies, such as observational studies, randomised controlled trials of cancer treatments and epidemiological cohort studies, should provide much more reliable data as they follow a defined group of people who have had known treatments. However, they often do so only for a relatively short time (approximately three years), and also suffer from high dropout rates, meaning that insufficient responses may prevent firm conclusions about consequences of cancer and its treatment at later time points³⁷.

Given the expected significant rise in the population living with and beyond cancer, the epidemiology of the consequences of cancer and its treatment deserves much greater attention, and better research techniques than have been used historically¹⁷¹. The research community should adopt new methods to assess the incidence and severity of consequences of cancer and its treatment in large groups of patients. If not, health professionals and managers will remain unable to plan effectively for the predicted increase in patient demand, and unable to provide newly diagnosed patients with realistic predictions of the risks associated with their treatment. Macmillan's Routes from Diagnosis is an approach that links and analyses routinely collected data and allows the cancer journey to be mapped from diagnosis to death, describing the health outcomes that patients experience. This is one step towards describing the survivorship journey at a population level.

Sexual difficulties

Cancer treatment can make it physically and psychologically difficult to have sex, or leave people with reduced confidence or a poor body image. Fifty-three percent of men and 24% of women who received radiotherapy to their pelvic area report issues with maintaining a sexual relationship, with the effects persisting up to at least 11 years after treatment. Fifty-eight percent of men diagnosed with prostate cancer up to five years previously are unable to have a full sex life as they are completely unable to get an erection, with a further 11% reporting difficulties with having or maintaining an erection.

'After I was diagnosed with womb cancer in 2011, I found it exceptionally difficult to get information on how the treatment might affect my future sexual relationships. I experienced a range of side effects from pelvic radiotherapy, including hot flushes and premature menopause, and for several months afterwards I wasn't able to have an orgasm. Before I was diagnosed I felt comfortable talking about sex, but having cancer changed that. It made me suddenly very protective of my sexual identity and of my body, and I found it a very isolating experience.'

Vanessa, 42, south-west England

Depending on the issues involved, there are several ways people living with cancer and their partners can help themselves cope with sexual difficulties. This can include adjusting the way they approach sex, using medication or devices to combat vaginal dryness or erectile dysfunction, or taking simple steps to reduce the impact of bowel or urinary incontinence during sex.

iv. Overall estimates of the number of people affected by consequences of cancer and its treatment

Overall, the expert consensus view⁷² is that at least 25% of the two million people living with and after cancer in the UK will have one or more physical or psychosocial consequences of their cancer or its treatment that affects their lives to a greater or lesser degree on a long-term basis.

For adults living after child or young people’s cancer treatment, this figure is higher: 60% are affected to some degree, of which 25% will have more severe long-term effects⁷³.

Hence, at least 500,000 people in the UK today have had their lives affected long term following a diagnosis of cancer and receiving treatment.

Several studies back up this figure:

- 53% of people surveyed 6 months after cancer treatment had ≥1 moderate or severe unmet needs⁷⁴.
- 25% of people (surveyed 2–15 years after cancer diagnosis) reported unmet needs for ‘care coordination’ and 21% for ‘help to manage anxiety and recurrence concerns related to cancer’. In the same study, 8% of people reported severe ‘late effects’ of treatment, 12% moderate and 18% mild⁷⁵.
- People in Scotland diagnosed with cancer 6 or more years previously were surveyed⁷⁶ and 43% said that their health was very bad, bad or fair, compared with 23% of those who had not had cancer.
- In a review, 20–30% of survivors consistently reported problems associated with cancer and its treatment, including physical problems, poorer quality of life, psychological distress, sexual problems, problems with social relationships and financial concerns¹⁶.

- Quality of life scores amongst breast, colorectal, prostate and non-Hodgkin lymphoma survivors who were surveyed 1–5 years from diagnosis were lower than those from the general population. 47% of patients reported fear of recurrence, while 20% reported moderate or severe difficulties with mobility or usual activities¹⁸.
- In a survey in Northern Ireland, 41% of people living with and beyond cancer reported ‘late effects’⁷⁷ with a significantly greater number of co-morbidities, lower physical and mental health scores, greater overall health service use and more unmet needs.
- 10–20% of people living with and beyond cancer with no other chronic condition may have serious ongoing poor health and disability, and for those with an additional chronic condition this figure may be as high as 25–30%⁶⁹. This study reported that people living with and beyond cancer were significantly more likely to report difficulties compared to healthy people (Table 1).

This latter study⁶⁹ also concluded that the profiles of people living with and beyond cancer in their study were remarkably similar to individuals with chronic or long-term health conditions, but that there has been little progress in designing models of cancer follow-up care that might be better tailored to meet individuals’ long-term needs related to the consequences of cancer and its treatment and a range of co-morbidities. These needs include support for psychological and social problems. There is clear evidence that this group of people are at increased risk of a variety of long-term conditions such as osteoporosis, heart failure, coronary artery disease, hypothyroidism and dementia, as a consequence of their cancer treatment, which may contribute to premature death^{25,73,78}.

Table 1
Proportion of survey participants who reported the health outcomes listed⁶⁹

	Healthy People	People living with and beyond cancer	
		with no chronic condition	with ≥1 chronic condition
Being in average or poor general health	17%	33%	63%
Vigorous activities very difficult or not able to do them at all	12%	27%	56%
Find performing physical activities, e.g. personal care or housework, very difficult	3%	10%	23%
Report aches and pains as a problem	44%	55%	76%
Poor emotional wellbeing	18%	23%	23%
Poor cognitive functioning	2%	1%	4%
Agreed strongly that health had prevented working in their preferred occupation	5%	12%	27%
Visited a doctor or other healthcare professional ≥10 times over the past year	4%	9%	25%

Mental health problems

Mental health problems such as anxiety and depression are common conditions that can be triggered by difficult events, such as a cancer diagnosis or having treatment for cancer. Around a third of people diagnosed with breast, colorectal or prostate cancer or non-Hodgkin lymphoma five years previously experience anxiety or depression. More than one in eight of those diagnosed up to five years previously report moderate to extreme anxiety and depression⁵⁴.

Some psychosocial consequences may be particularly severe, resulting in persistent mental health difficulties. People living with and beyond cancer are considered to be at risk for post-traumatic stress disorder due to the shock and trauma of being diagnosed with a life-threatening disease and receiving treatment that can be both physically and mentally gruelling¹⁶⁵.

'For me, it is the psychological and emotional effects of the cancer that has affected me the most. I was diagnosed when my son was 7 months old and my nights were spent crying in bed that I was going to die and he would never know me and that my husband would be left alone to cope.'

Female, breast cancer, 5 years after diagnosis

Some mental health problems associated with cancer and its treatment can be managed by the patient, but more severe problems may require professional help.

Cancer patients are also at higher risk of developing a second primary cancer, although not all of these will be as a consequence of treatment for their first primary cancer^{79,80} e.g. if they have a history of smoking or an inherited genetic risk. For more details, see section 3e.

3b Sources of evidence on the prevalence of various consequences of cancer and its treatment

Our estimates of the prevalence of different types of consequence of cancer and its treatment in the UK are based on three main data sources:

- Clinical trials of cancer treatments;
- Studies of routinely collected NHS and audit data; and
- Surveys of people with a cancer diagnosis, or history of cancer treatment.

The type of data available from these sources is described in Appendix 3, and some of the difficulties in using the data are shown in Table 2. Although clinical trial data can be very compelling, there are several difficulties in extrapolating results in order to estimate prevalence in the population.

Another method is to obtain and combine datasets already collected by the NHS or researchers – this has very significant potential, but is yet to be widely carried out or published. Macmillan is highly supportive of the Department of Health's recent approach to use PROMs population surveys, as these types of cross-sectional surveys offer rich qualitative and quantitative data from very large numbers of people, and will enable better understanding of the population as well as helping to prioritise service improvements. Cohort, longitudinal or observational studies are also very informative, as they have led to important findings such as the increased incidence of cancer and myocardial infarction after treatments for Hodgkin lymphoma^{166, 167}, and the incidence of androgen deficiency in young men after treatment for testicular cancer¹⁶⁸.

Table 2
Advantages and disadvantages of using different data sources in estimating the prevalence of consequences of cancer and its treatment

Advantages	Disadvantages
Clinical trials of cancer treatments	
Detailed study of many aspects of symptoms, quality of life etc. at frequent time points including prior to treatment.	<p>Difficulty in recruiting patients to clinical trials.</p> <p>Some assessment tools are not ideal⁵⁰ – they are often too global to tackle the intricacies of specific consequences of cancer and its treatment.</p> <p>Reliable data on long-term effects are not often available⁸¹.</p> <p>Problems extrapolating clinical trial results to a general population.</p> <p>Great variation in how consequences of cancer and its treatment are defined, measured and recorded between different trials.</p> <p>Some long-term and late-onset (decades) effects are simply not yet known because the drugs and techniques are so new, and so are unlikely to be monitored for.</p> <p>Quality of life analysis may not take account of ‘response shift’⁸², in which patients may learn to cope with the problems and the symptoms they experience, and therefore adjust their own internal values and standards.</p>
Studies of routinely collected NHS data	
<p>Have the potential to provide new insights into what care is provided for what problems after cancer treatment, the outcomes and the costs.</p> <p>It is worth testing methodologies now because future availability of data will improve, with national radiotherapy and chemotherapy datasets now online and collecting data^{83,84}.</p>	<p>Existing published results currently do not provide sufficient detailed information on specific consequences, whether physical or psychosocial.</p> <p>Data on the treatment mode and combinations of treatment given to patients are not readily available in national reporting aside from audits (e.g. Ref 150).</p> <p>NHS outpatient data are almost completely lacking in diagnostic and treatment information.</p> <p>Generally there is poor record keeping, data entry and coding of cancer treatment and consequences, or risk of consequences.</p>

Advantages

Disadvantages

Surveys of people with a cancer diagnosis, or history of cancer treatment

Large-scale surveys are feasible and acceptable¹⁸.

Results are strongly indicative of where significant problems exist for people living with and after cancer.

Often limited to common cancer types, and hence cannot always be extrapolated to all cancers.

May overlook issues that are specific to certain rarer cancers.

Response rates vary by cancer group, deprivation category and age, which could result in selection bias when generalising results.

Treatments may change over the 1 to 5-year period used to select study participants and it is therefore possible that results reflect these changes.

A weakness of most longitudinal studies of life after cancer is that it is not possible to gain a baseline of health prior to cancer diagnosis.

Evidence from the different types of data sources listed in Table 2 have been analysed (see Appendix 3 for details) to provide, where possible, estimates of the prevalence of a range of consequences. Owing to the difficulties in extrapolating results from clinical trials or using existing datasets, the prevalence estimates in this document have tended to be based on results from PROMs, using large-scale surveys where available, as it was felt that these give the most meaningful results in terms of the scope and scale of the problems that people are experiencing in everyday life, regardless of what cancer treatment they had and when it was given. Other key sources are published literature reviews. These results were then applied to data generated by Macmillan on the prevalence of people living more than one year after a cancer diagnosis⁸⁵.

The consequences of cancer and its treatment prevalence estimates are grouped into three categories (as per Table 3):

- 1** Common consequences of cancer and its treatment (in essence, a breakdown of the estimated 500,000 with consequences)
 - Physical consequences
 - Psychosocial consequences
- 2** Rare or complex consequences of cancer and its treatment
- 3** Risks for long-term or late-onset conditions.

Table 3
Grouping of consequences of cancer and its treatment for estimation of prevalence

(Note that these categories are not mutually exclusive or exhaustive)

Category		Impact	Timing
Common Large numbers affected – in total around 500,000	Section 3c Table 4A and 4B	Physical and psychosocial effects ranging from mild to severe. Interventions range from simple to complex.	Usually either immediately on treatment (and not resolving) or occurs within 2–3 years of end of treatment. Sometimes remain lifelong.
Rare/complex Small numbers affected	Section 3d Table 5	Often severe, potentially life threatening, requiring complex, expensive treatment.	Usually either immediately on treatment (and not resolving) or occurs within 2–3 years of end of treatment and often remains lifelong.
Risks of long-term conditions Significant numbers at increased risk (hundreds of thousands)	Section 3e Table 6	People are affected by the possibility of future problems although not all will develop them; may need preventative care, including monitoring. Can have a significant impact on wellbeing and can range from mild to severe.	Usually 5 years+ (lifetime risk).

Note: There are many more consequences that are not included in this report, especially rarer ones, but which may have a profound impact on people’s health and wellbeing, or place people at greater risk of problems later in life.

Pain

Pain can persist after the end of cancer treatment for many reasons. For example, radiotherapy and chemotherapy can cause nerve damage that leads to neuropathic pain¹⁰⁶ while surgery or radiotherapy in the pelvic area can lead to parts of the bowel sticking together¹⁰⁷.

‘I’m thankful the surgery allowed me to live. I try to remember that when debilitating pain makes me want to die.’
Male, prostate cancer, 5 years after diagnosis

One in three (33%) people who have completed treatment intended to cure their cancer report some degree of pain¹⁰⁸. Around one in five of those diagnosed with breast, colorectal or prostate cancer or non-Hodgkin lymphoma up to five years previously report moderate to extreme pain or discomfort after completing treatment⁵⁴.

3c Common consequences of cancer and its treatment

Tables 4A and 4B show that there is a very broad range of consequences of cancer and its treatment, and that many hundreds of thousands of people are affected, often with multiple problems. In many cases, it is thought that there is a significant level of unmet need, as there is little evidence that health services are designed to meet these needs, and people experiencing these problems often report unmet needs^{74,77}. As described in Chapter 2, patient survey results and individual testimonies describe the gaps in information, support and treatment.

Note: All figures in Tables 4A and 4B are indicative. For information on how these estimates were made, please see Appendix 3. Figures in this table must not be interpreted to mean that these groups of people all had their problems caused directly by cancer treatment. Some people may have pre-existing conditions, and will report them as problems post-cancer, and are therefore within the scope of our estimate of the number of people who have needs post-cancer.

Table 4A
Estimated prevalence of common physical consequences of cancer and its treatment

Consequence of cancer and its treatment	Main cancer types/main causes of the consequences	Prevalence estimates (UK)
<p>Chronic changes in lower gastrointestinal function including diarrhoea, faecal incontinence, urgency, flatulence, bleeding, hernia, adhesions, strictures, pain, fistula (see Table 5)</p> <p>Treatments/services that may manage/alleviate symptoms include: lifestyle changes, medication, surgery including stoma formation, hyperbaric oxygen therapy, biofeedback, dietary changes, continence products, pelvic floor exercises.</p>	<p>Pelvic</p> <p>RT, S</p>	<p>90,000</p>
<p>Chronic changes in upper gastrointestinal function including swallowing, voice dysfunction, tube feeding, trismus, nausea, weight loss</p> <p>Treatments/services that may manage/alleviate symptoms include: medication, surgery, parenteral nutrition, speech and swallowing therapy, dietetic intervention, dental input.</p>	<p>Head and neck; upper gastrointestinal</p> <p>RT, S, CT</p>	<p>Up to 50,000</p>
<p>Chronic dental/oral problems including neurosensory changes; saliva, taste and functional changes; oral and dental infection; and tooth loss and damage</p> <p>Treatments/services that may manage/alleviate symptoms include: medication, dental surgery, self-management (dental hygiene).</p>	<p>Various (mostly head and neck)</p> <p>RT, CT, S</p>	<p>Could not be estimated</p>
<p>Chronic changes in urinary function including incontinence, urgency, decreased capacity, frequency, nocturia, ulcer, telangiectasia, haematuria, fistula (see Table 5)</p> <p>Treatments/services that may manage/alleviate symptoms include: lifestyle changes, medication, surgery, artificial urinary sphincter, sacral neuromodulation, intravesical instillations, continence products.</p>	<p>Pelvic</p> <p>RT, S</p>	<p>150,000</p>

Consequence of cancer and its treatment	Main cancer types/main causes of the consequences	Prevalence estimates (UK)
<p>Sexual difficulties including problems preventing a normal sex life, e.g. erectile dysfunction; penile shortening; vaginal dryness; stenosis and shortening; sexual pain and loss of sexual interest; and psychosexual problems</p> <p>Treatments/services that may manage/alleviate symptoms include: medication, surgery, vaginal dilators, vacuum erection devices, penile prosthesis, counselling.</p>	<p>All</p> <p>RT, S, CT</p>	<p>350,000</p>
<p>Menopausal and hormonal symptoms including hot flushes and sleep disturbance (in men and women), vaginal dryness, early menopause</p> <p>Treatments/services that may manage/alleviate symptoms include: medication, lifestyle changes.</p>	<p>Various</p> <p>RT, CT, S, H</p>	<p>At least 80,000 men and women</p>
<p>Loss of fertility – around 11,000 patients in the age group 15–40 years are diagnosed with cancer each year in the UK⁸⁶. The probability of parenting a first child is reduced by approximately 50% after treatment⁸⁷</p> <p>Treatments/services that may manage/alleviate problem include: pre-treatment collection of sperm or ova, IVF, egg donation, sperm donation, adoption, surrogacy, hormone replacement.</p>	<p>Various</p> <p>RT, CT, S, RI</p>	<p>Could not be estimated</p>
<p>Stoma within 5 years of diagnosis excluding those whose stoma has been reversed</p> <p>Treatments/services that may manage/alleviate problem include: stoma reversal, self-management, stoma nursing.</p>	<p>Colorectal, other pelvic</p> <p>S, RT</p>	<p>At least 14,000</p>
<p>Cancer-related lymphoedema Treatments/services that may manage/alleviate problem include: self-management, lymphoedema services, lymphovaticovenous anastomosis surgery.</p>	<p>Breast, pelvic, head and neck</p> <p>S, RT</p>	<p>21,000 to 63,000</p>

Consequence of cancer and its treatment	Main cancer types/main causes of the consequences	Prevalence estimates (UK)
<p>Peripheral neuropathy Treatments/services that may manage/alleviate problem include: physiotherapy, pain management, self-management e.g. protecting hands and feet from damage.</p>	<p>Various CT</p>	Total could not be estimated
<p>Chronic fatigue Treatments/services that may manage/alleviate problem include: medication, blood transfusion, self-management e.g. improve physical activity, sleep, diet etc.</p>	<p>Various RT, CT</p>	350,000
<p>Endocrine system disorders – around 33,000 people living with and beyond child and young people’s cancer are at risk of endocrine disorders⁸⁸, including complex hormone dysfunction, thyroid dysfunction, androgen deficiency, metabolic syndrome, growth hormone deficiency, and primary ovarian failure Treatments/services that may manage/alleviate problem include: medication.</p>	<p>Brain and central nervous system, child and young people’s cancers, head and neck RT</p>	Total could not be estimated
<p>Chronic moderate to severe pain Treatments/services that may manage/alleviate include: medication</p>	<p>Various S, RT</p>	200,000

CT, chemotherapy; S, surgery; RT, radiotherapy; RI, radioactive iodine; H, hormonal treatment.

Urinary and gastrointestinal problems

Having surgery or radiotherapy in the pelvic area often leads to changes in the way the bowel and bladder function. These can include diarrhoea, frequency, urgency and sometimes incontinence.

More than one in three men (39%) diagnosed with prostate cancer up to five years previously report some degree of urinary leakage¹⁸ More than a third of women (38%) who received radiotherapy to their pelvic area report urinary incontinence up to 11 years after treatment, and more than one in 10 people (12%) who received radiotherapy to their pelvic area report bowel incontinence⁵⁵. Up to one in six (17%) of those who have had surgery for colorectal cancer several years previously may still need to wear a protective incontinence pad at all times¹⁷.

‘I was diagnosed with anal cancer in 2007, and had chemotherapy and radiotherapy. I felt like I had been burnt to a crisp inside and out and was in agony for months afterwards. Using the lavatory became a nightmare. Then I was hit with bowel incontinence – although it’s more controlled now, I still suffer from periodic bowel incontinence six years later. Having changed my own children’s nappies, it’s ironic that at 68 I’m now the one who needs nappies.’
Richard, 68, London

People experiencing these issues may be able to manage many of the symptoms themselves with the right support. For example, guided changes to diet and strengthening the muscles used for bowel control can reduce the severity of some gastrointestinal problems.

Table 4B
Estimated prevalence of common psychosocial consequences of cancer and its treatment

Treatments/services that may manage or alleviate problems include: self-management, mental health care, psychological therapies, counselling and vocational rehabilitation.

Consequence of cancer and its treatment	Main cancer types/main causes of the consequences	Prevalence estimates (UK)
Mental health problems Including depression, anxiety, post-traumatic stress disorder	All All treatments	240,000
Fear of cancer recurrence, fear of dying	All All treatments	125,000 – fear of dying 240,000 – fear of recurrence
Cognitive dysfunction including neurodisability, neurocognitive problems, 'chemo brain'	Various (adult), brain (child and young people) RT, CT	Total could not be estimated
Psychosexual problems including psychological distress, mood changes, reduction in libido, body image issues, relationship changes etc	Various S, RT, CT, H	Included in sexual difficulties in Table 4A
Body image issues including coming to term with changes in body appearance, functions and sensations; feelings of embarrassment; loss of confidence; impact on relationships and sexuality Often associated with loss of a limb, lumpectomy, mastectomy, stoma, lymphoedema, excision of head/face/neck bone and tissue, scarring/disfigurement, long-term hair loss	Various S, CT, RT	Total could not be estimated

Consequence of cancer and its treatment

Main cancer types/main causes of the consequences

Prevalence estimates (UK)

Difficulties with education, employment and finances

including: reduced income; increased costs (e.g. heating, clothing, travel to appointments, other health costs); difficulty returning to work or education; discrimination at work; impact on carers' financial situation.

All

 All treatments

Total could not be estimated; likely to be many hundreds of thousands

Up to 700,000 people of working age are living with cancer in the UK⁸⁹

CT, chemotherapy; RT, radiotherapy; S, surgery; H, hormonal treatment. Further details in Appendix 3

Speech and swallowing problems

Surgery and radiotherapy to the head and neck area may interfere with some of the actions or movements of the mouth, tongue or throat, making it more difficult to eat or drink. Any change to the lips, teeth, tongue or soft palate is likely to make speech sound different. It is estimated that 40 to 50% of head and neck and oesophago-gastric cancer patients will experience dysphagia, speech difficulties or other upper gastrointestinal problems^{59,111}. A recent cross-sectional survey of people who had been treated for head and neck cancer within the last five years identified that between 40 and 50% reported concerns/problems with swallowing, chewing/eating or dry mouth¹¹².

'You can't go out with your friends for a lunch. You're self-conscious in a public place because you might choke and all of a sudden, you've got to go, excuse yourself to go to a bathroom and you're wondering am I going to cough this up.'
Head and neck cancer patient, Scotland

Rehabilitation for the functional, psychological, social and physical aspects of eating, drinking^{113,114} and speaking is increasingly complex¹¹⁵, and it is important to ensure that good long-term nutritional status is maintained.

3d Rare or complex consequences of cancer treatment

It is very difficult to estimate prevalence for these consequences due to their rarity. Only radiation-induced brachial plexus (RIBP) nerve injury prevalence is known with reasonable accuracy owing to the Radiotherapy Action Group Exposure (RAGE) action group⁹, comprising people who have lived for several decades with extensive and disabling unmet needs. Annual incidence of some consequences can be estimated, e.g. chronic graft versus host disease is estimated at least 250 cases per year^{90,91}.

Owing to the seriousness of the types of consequences listed in Table 5, it is likely that these needs are being met, at least in part, as people will be very unwell and will almost certainly require hospital admission, possibly as an emergency. Although the number affected is small in comparison to those described in Tables 4A and B, these groups should be considered in local and national commissioning plans, owing to the risk of mortality and the high expense and complexity of interventions (e.g. complex surgery or bone marrow transplants requiring lengthy inpatient stays). The rarity of the conditions and the complexity of the interventions raise questions such as:

- Whether services should be concentrated in a small number of expert centres;
- Whether earlier detection of problems may reduce the complexity of interventions needed, or indeed whether prevention may be possible; and

- Whether data are being collected and compiled routinely about consequences of cancer and its treatment, allowing rare but serious conditions caused by new treatments³⁸ to be identified and, if possible, mitigated against or appropriately treated.

Like many areas relating to the consequences of cancer and its treatment, these issues are very under-researched.

The lessons from the RIBP/RAGE group of women are that, despite having an action group and a 'voice', it took decades for the establishment to acknowledge the multiple needs of this group of people and address them through specialist commissioning (in England – the BRIRS^{92,93}). This service offers a model for how people with rare but severe consequences of treatment can be helped through specialist centres with multidisciplinary expertise.

Table 5
Examples of rare or complex consequences of cancer and its treatment

Consequence of treatment	Main cancer types/main causes of the consequences	Prevalence estimates (UK)
Radiation-induced brachial plexus (RIBP) nerve injuries Treatments/services that may manage/alleviate symptoms: Breast Radiation Injury Rehabilitation Service (BRIRS).	Breast RT	300–400
Fistulae involving urinary tract, lower gastrointestinal tract and/or vagina Treatments/services that may manage/alleviate problem: complex surgery, stoma.	Pelvic RT, S	
Osteonecrosis – hip, knee, jaw Treatments/services that may manage/alleviate problem: complex surgery, hyperbaric oxygen therapy.	Head and neck, multiple myeloma, breast RT, CT, BP	Could not be estimated but likely to be many hundreds with each problem
Myelodysplastic syndrome, acute myelocytic leukaemia Treatments/services which may manage/alleviate problem: CT, RT, BMT.	Haematological, breast RT, CT	
Chronic graft versus host disease (following bone marrow transplant) leading to long-term health problems such as with skin and mouth, lungs, fasciitis and joint contractures Treatments/services that may manage/alleviate problem include: medication.	Haematological BMT	
Loss of limb including phantom sensations and pain Treatments/services that man manage/alleviate symptoms include: rehabilitation, artificial limb.	Bone, soft tissue S	Could not be estimated but likely to be small numbers

BP, bisphosphonates; BMT, bone marrow transplant; CT, chemotherapy; RT, radiotherapy; S, surgery. For further details and references see Appendix 3.

Lymphoedema

Lymphoedema can develop when lymph nodes or vessels are removed, damaged or blocked. This leads to a build-up of fluid in the affected area. Radiotherapy to the lymph nodes can cause scar tissue that also blocks the flow¹⁰⁹. The condition is chronic, which means it cannot be cured but can be managed. As well as causing physical and psychosocial difficulties, lymphoedema can also increase the risk of infections in the affected area.

'Being diagnosed with breast cancer in 2001 completely changed my life. After the surgery, I had chemotherapy and then radiotherapy. I had a lot of unpleasant side effects at the time, such as anaemia, hair loss, severe fatigue, depression and lymphoedema. The lymphoedema has led to restricted movement in one of my arms, which causes me physical difficulties. It's hard to find clothes that fit and it's difficult to exercise. I also have problems raising the arm, which then hinders many day-to-day activities. The doctors say it may never go away and I will just have to learn to live with it for the rest of my life.'

Asma, 50, Middlesex

There are several ways patients can help treat lymphoedema themselves, including using compression garments and techniques to relieve the swelling, such as simple lymphatic drainage.

The NHS saves an estimated £100 in reduced hospital admissions for every £1 spent on lymphoedema treatments that limit swelling and prevent damage and infection¹¹⁰.

3e Risks of developing long-term conditions after cancer treatment

Some people will have an elevated statistical risk of developing certain long-term conditions many years after treatment for cancer. As with other, more immediate, consequences of treatment, the level of risk depends on a wide range of factors including type of cancer, type of treatment, lifestyle and any co-morbidities. The most serious long-term risk is the development of a second primary cancer, which is uncommon^{94,95} but many patients live with the knowledge that they are at increased risk of this (alongside the fear of recurrence of the original cancer). Other conditions such as endocrine disorders, osteoporosis and heart disease are also associated with risk of premature mortality.

Many of the following examples are common conditions in the general population and therefore it is not possible to say with certainty that any one person's long-term condition was caused by their cancer treatment. Nevertheless, there is clear evidence (Table 6) that cancer treatment increases the risk of developing these conditions, and therefore suitable monitoring or preventative measures are required⁸⁸, e.g. identifying a prior risk of osteoporosis by bone mineral density scanning for men living with and beyond prostate cancer²⁵. In addition, it is vital to empower patients with information to help them make good lifestyle choices, including increasing physical activity, stopping smoking, sensible dietary/alcohol advice and the value of any dietary supplements^{44,45}.

Table 6
Risks of developing long-term conditions after cancer treatment

Long-term conditions	Cancer types/causes	Increased risk compared to population without cancer diagnosis (selected examples)
Second primary cancer (caused by treatment of first cancer)	Child and young people's cancers, breast, haematological, prostate	Young people after radiotherapy for Hodgkin lymphoma were 5 times more likely to develop oestrogen (ER) – and progesterone (PR)-positive breast cancer and 9 times more likely to develop ER- and PR-negative breast cancer ⁹⁶ .
	RT, CT	People living after child and young people's cancer treatments are 4 times more likely to develop a subsequent primary neoplasm ⁹⁵ .
Osteoporosis	Prostate, breast, colorectal RT, H	Hazard ratios*: <ul style="list-style-type: none"> • After breast cancer²⁵ 1.26 • After colorectal cancer²⁵ 1.41 • After prostate cancer²⁵ 2.49

Long-term conditions	Cancer types/causes	Increased risk compared to population without cancer diagnosis (selected examples)
Cardiovascular	Cardiovascular Breast, testicular, haematological, child and young people's cancers RT, CT, BT	Hazard ratios*: <ul style="list-style-type: none"> • After breast cancer²⁵ For heart failure 1.95 For coronary heart disease 1.27 • For people living after child and young people's cancer treatments compared to siblings⁹⁷: For congestive heart failure 5.9 For myocardial infarction 5.0 For pericardial disease 6.3 For valvular abnormalities 4.8
Diabetes	Colorectal, child and young people's cancers RT, steroids	Hazard ratio*: <ul style="list-style-type: none"> • After colorectal cancer²⁵ 1.39 Odds ratio*: <ul style="list-style-type: none"> • After child and young people's cancer⁹⁸ 1.8
Hypothyroidism	Breast, Hodgkin lymphoma, head and neck RT, CT	Hazard ratio*: <ul style="list-style-type: none"> • After breast cancer²⁵ 1.26 For people living after childhood cancer treatments: 7.7% of a cohort ⁹⁹ reported hypothyroidism with the highest risk among patients treated for Hodgkin lymphoma (19.9%), central nervous system neoplasms (15.3%), non-Hodgkin lymphoma (6.2%) and leukaemia (5.2%). For people living after radiotherapy for head and neck cancers, the incidence of hypothyroidism was much higher (23–53%) than would be expected in a non-irradiated cohort ¹⁰⁰ .
Cognitive dysfunction/dementia	Central nervous system, colorectal RT, CT	Hazard ratio*: <ul style="list-style-type: none"> • After colorectal cancer²⁵ 1.68 Odds ratio*: <ul style="list-style-type: none"> • After various cancers¹⁰¹ 2.1

BP, bisphosphonates; BMT, bone marrow transplant; CT, chemotherapy; RT, radiotherapy; S, surgery. For further details and references see Appendix 3.

*The hazard ratio is an expression of the hazard or chance of events occurring in the 'with cancer' group as a ratio of the hazard of the events occurring in the 'no cancer' group. For example, a hazard ratio of 2.49 for osteoporosis after prostate cancer means, in the quoted study, prostate patients were 2.49 times more likely to develop osteoporosis than men who have never had prostate cancer.

The odds ratio represents the odds that an outcome will occur given a particular exposure, compared with the odds of the outcome occurring in the absence of that exposure.

CHAPTER 3 SUMMARY

- In order to plan and deliver service provision cost effectively, commissioners and providers must better understand the needs and demands of people living with and beyond cancer, as this population is growing and ageing.
- It is estimated that around 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects their lives on a long-term basis.
- The prevalence of consequences of cancer and its treatment in the UK provides an indicator of the level of need for interventions, such as support for self-management and specialist clinical services. Examples include:
 - Gastrointestinal problems: 90,000 people
 - Urinary problems: 150,000 people
 - Sexual difficulties: 350,000 people
 - Mental health problems: 240,000 people
 - Chronic fatigue: 350,000 people
 - Lymphoedema: up to 63,000 people
 - Rare and complex complications, e.g. chronic graft versus host disease, myelodysplastic syndrome, fistulae: probably a few hundred new cases of each per year
- People living with and beyond cancer are likely to be at increased risk of second primary cancer and other common long-term conditions. These risks are particularly high amongst people living after child and young people's cancer treatment.
- There is clear evidence of unmet need, which will increasingly impact on primary and secondary care unless action is taken.



Improving outcomes for people affected by the consequences of cancer and its treatment

4a The case for change — addressing the barriers to improving outcomes

Chapter 3 outlined the clinical case for change – proof of a significant prevalence of consequences of cancer and its treatment, and a level of unmet need that could affect around 500,000 people, preventing them from living as healthy and active a life as possible. Many of these people could be helped with simple interventions and support for self-management, but a significant minority will need more complex support and treatment. The immediate question is: how much will it cost to provide these interventions, and will they save any money elsewhere in the system?

The lack of robust economic evidence that addressing the consequences of cancer and its treatment is worthwhile is one of the most significant barriers to change in the current financial and commissioning climate. Again, a low level of research (in this case into understanding the drivers of costs of caring for people after their cancer treatment has ended) is severely hampering efforts to improve outcomes for people living with and beyond cancer.

Chapter 4 looks at the current economic evidence, and examines some of the other barriers to change, some of which could be tackled at little or no cost to the NHS.

4b Economic evidence

i. Costs of consequences of cancer and its treatment

Chapter 4 of the 2013 NCSI report¹ describes how failing to meet the needs of people living with and beyond cancer has very significant cost implications for the NHS and wider economy. It is 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 people living with and beyond cancer⁶⁴. Cancer diagnosis and treatment are expensive, but what is much less well understood is the high healthcare and personal costs incurred after people have completed treatment. Many long-term consequences of cancer and its treatment affect people's (including carers') ability to work and take part in normal activities. This not only contributes significantly to the cost burden on health services and other state support such as benefits and social services, but also causes a reduction in tax revenue. Therefore the health economics of the consequences of cancer and its treatment should play a major part in the rationale for change.

What is equally important to consider is the cost burden to the person affected by cancer, their family and friends. For example, people may have a reduced income due to an inability to work or a reduction in hours, need to purchase continence products or new clothing owing to swollen limbs, or pay for private healthcare or complementary therapies because they cannot find the help they need in the NHS. These financial pressures often have a knock-on effect on mental health by placing continuing strain on people who may have run up debts during their treatment – the latest research shows that 83% of cancer patients who have recently had treatment are on average £570 per month worse off¹¹⁶.

ii. Potential areas for more cost-effective use of resources

The NCSI has shown how outpatient capacity can be released by changing from traditional ‘one size fits all’ post-treatment follow-up services, to stratified pathways of care, allowing resources to be reinvested in survivorship services¹⁶⁹. Alongside savings from fewer low-cost/high-volume cancer follow-up consultations with professionals by providing better support for self-management, there is also the potential to reduce the costs of high-cost/low-volume episodes such as complex consequences of treatment that require intensive hospital care (including complex surgery) and lengthy rehabilitation.

Figure 4 details some of the findings of the Macmillan Routes from Diagnosis study, which describes the inpatient activity of colorectal cancer patients within North Trent between 2006 and 2008¹¹⁷. Across eight different patient groupings (‘pathways’), the ‘survivorship’ costs varied from £1,000 (those surviving less than a year after diagnosis) to £15,000 (those surviving one to five years after diagnosis

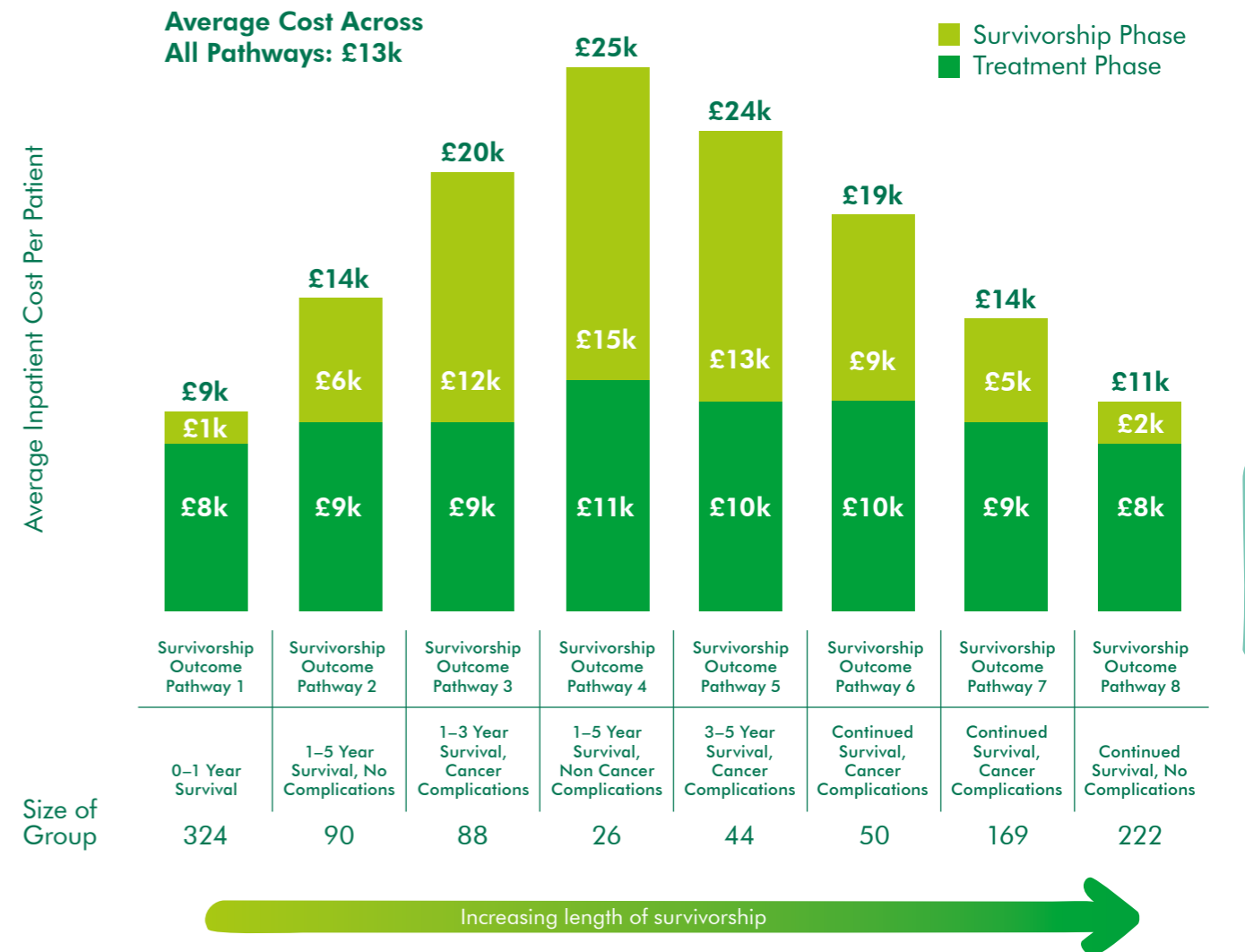
with non-cancer complications, i.e. morbidities such as cardiovascular disease or intestinal issues and not including additional primary, metastatic cancer or a recurrence) per person according to the nature of the person’s needs.

This insight offers the opportunity to explore whether there are ways to manage cancer treatment that avoid potential complications for each group and thus the subsequent healthcare costs. For example:

- Those with non-cancer complications may benefit from increased primary care involvement,
- Those with cancer complications (i.e. additional primary, metastatic cancer or a recurrence) may benefit from better cancer care team support, and
- Those with no complications (i.e. no morbidities or cancer complications identified through the study) may benefit from being on a stratified care pathway that does not involve routine hospital follow-up appointments, but instead has support for self-management with rapid re-access to professionals when needed.

Figure 4
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). All costs have been rounded to the nearest thousand, so the figures shown in the table do not add up exactly. Totals shown are actual totals rounded up or down, rather than a sum of the adjusted figures.

This analysis highlights the higher cost per patient of the group with non-cancer-related morbidities after colorectal cancer treatment and who die 1 to 5 years after diagnosis (Pathway 4 on Figure 4). We know from this analysis that pre-diagnosis these individuals have a high percentage of unplanned admissions mainly due to non-cancer related problems, so these individuals may already be debilitated by bowel problems and poor general health. We also know 2-3 years after diagnosis and then major surgery, intense chemotherapy and/or radiotherapy, this group experience a high frequency of unplanned admissions for non-cancer related issues. Treatment for these non-cancer problems may involve lengthy hospital stays and additional costs for rehabilitation, counselling and support. 50% of the Pathway 4 group die of a non-cancer related cause, compared to an average of 6% amongst the other pathways. It may be possible to prevent or reduce such non-cancer morbidities with earlier intervention, but this is unproven. Management of complex cases such as these requires a high degree of team work between different cancer and non-cancer specialty teams and between secondary and tertiary care, and therefore protocols that streamline referral, decision-making and treatment are likely to improve efficiency and outcomes.

People with long-term mild/moderate problems as a consequence of cancer or its treatment who do not need major interventions often struggle on, but are known to visit health professionals much more frequently than non-cancer patients^{69,75}. They may also be at risk of their condition deteriorating to the point of requiring inpatient care.

There is potential for this use of resources to be reduced if:

- Professionals and patients have the knowledge that post-treatment symptoms and difficulties may be a result of the cancer treatment and that effective interventions exist (facilitating the recovery of health and wellbeing through self-management, including restoration of self-confidence and confidence to self-manage cancer-related problems¹¹, and/or earlier referral to specialists in consequences of cancer and its treatment); and
- Patients at risk of future problems are educated to avoid risk factors (e.g. avoid skin damage to limbs if at risk of lymphoedema) and are encouraged to adopt a healthier lifestyle (e.g. increased physical activity, stop smoking), and therefore can prevent problems occurring in the first place, thus reducing the demand on health and social care.

Patient engagement in healthcare via self-management is widely recognised as crucial to improved outcomes for people with long-term chronic conditions, although cost-effectiveness evidence in relation to cancer has been scarce¹¹⁸. The hypothesis that self-management as part of stratified cancer follow-up pathways will result in greater efficiency has yet to be fully proven, but NHS Improvement test sites are already achieving reductions in oncology follow-up outpatient attendances, number of hospital readmissions and use of bed days¹¹⁹.

A study in Manchester¹²⁰ 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. Please see the NCSI report¹ for more information.

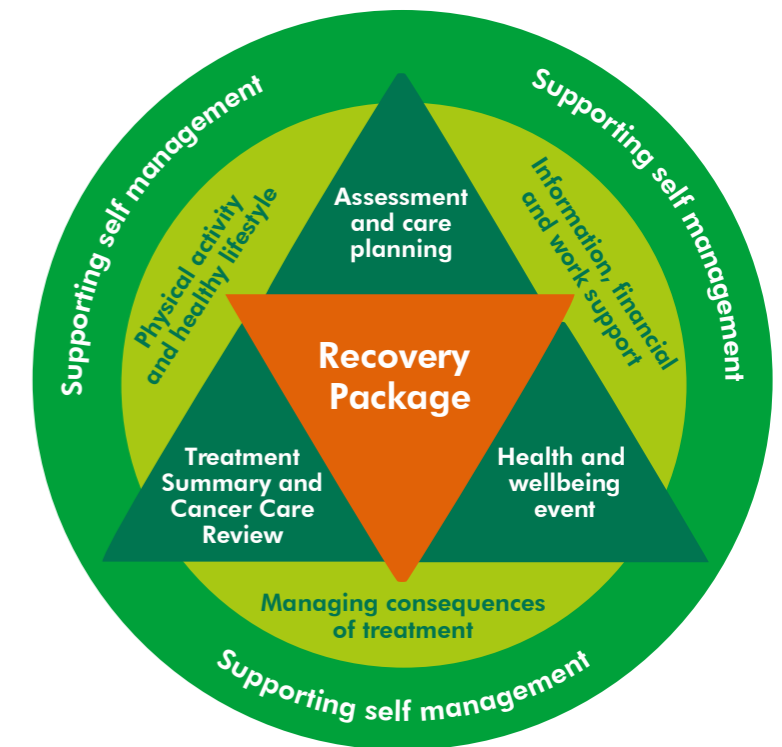
A review¹²¹ of evidence on self-management for prostate patients post-treatment found that “it is a viable and appropriate way of providing healthcare solutions to ameliorate men’s functional and emotional problems” but that “economic viability will be difficult to assess since cost comparison with current provision is not straightforward”.

The NCSI has concluded that as a minimum there should be a Recovery Package of interventions (Figure 5), which could play a significant role in moving patients into greater self-efficacy and help to reduce the impact of consequences of cancer and its treatment¹.

Through the Recovery Package, it is intended that people will be helped to minimise any effects of the consequences of cancer and its treatment on their life:

- **Holistic Needs Assessment and Care Plan:** to be carried out at or near diagnosis, and at the end of treatment, and any other time needs change, using a standardised assessment tool, resulting in a written Care Plan outlining the actions to be taken to address identified needs.
- **Treatment Summary:** from the hospital team using a structured format, to be shared with the patient and their GP.

Figure 5
The Recovery Package



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- **Cancer Care Review:** to be carried out by the patient’s GP practice three months post-diagnosis, which includes discussion of potential long-term effects of their cancer and treatment.
- **Health and Wellbeing Clinic:** to help prepare the person and their carers for supported self-management. It will include what signs and symptoms they need to look out for, what resources are available to help them, what to do if they are worried, and will include advice on healthy lifestyles, including physical activity, and work and financial issues.

iii. Additional costs of addressing unmet needs relating to the consequences of cancer and its treatment

It is clear that new costs will be incurred if unmet needs relating to the consequences of cancer and its treatment are to be met. Currently, owing to the lack of a detailed understanding of the level of need or what interventions and services are most appropriate for which consequences, it is not possible to forecast what level of funding might be needed. However, when compared to health economic analyses of the cost–benefit of new treatments to reduce mortality and improve quality of life, the costs of services for the consequences of cancer and its treatment are likely to be very modest and well within accepted limits (i.e. cost effective at less than £20–30,000 per Quality of Life Year (QALY) gained¹²²).

As described earlier, simple and inexpensive interventions for many problems are available, including the provision of information and supporting people to self-manage and to take preventative measures. The costs of implementing these are likely to be largely around ‘pump priming’ in terms of short-term project costs and staff training. Recurring costs will be minimal. Voluntary sector involvement is also possible.

The costs of implementing the Recovery Package will depend on local implementation – reductions in cancer follow-up (through stratified pathways and remote surveillance) can support the development of the Recovery Package. 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.

Local management of most mild/moderate consequences of cancer and its treatment is possible and effective (e.g. ^{103,123,124,125,126}) but referral pathways do not always exist from cancer care teams to local services, such as for lymphoedema, fatigue, pain management, counselling, or cancer-related sexual dysfunction, urinary problems and gastrointestinal dysfunction. Establishing these pathways will probably result in a small increase in referrals to secondary care, but it is likely that costs are already being incurred in terms of other consultations with GPs and secondary care that result in unnecessary investigations or ineffective treatments (due to the lack of awareness of local services or of the best clinical practice for consequences of cancer and its treatment).

The small proportion of people who experience serious consequences of cancer and its treatment need specialist health service care and treatment. Like the BRIRS (Chapter 3), regional centres for other complex consequences of treatment are needed in order to provide equitable access to high-quality care and treatment from multidisciplinary expert teams. These centres can also help to fill the gaps in research and education on the consequences of cancer and its treatment. Currently, there is only one dedicated multidisciplinary service in the UK for gastrointestinal

consequences of cancer treatments, at the Royal Marsden Hospital in London, and it is estimated that approximately four more are needed because the majority of people who would benefit from the service cannot access it owing to the travel distance. Specialist multidisciplinary teams are also needed to support people living with complex long-term consequences of child and young people’s cancer treatment, many of whom are lost to follow up and at risk of serious health problems if not helped. The cost of such specialist services has yet to be fully calculated, but as they will be largely outpatient based and usually do not involve high-cost drugs or therapies, it is very likely that they will cost much less per QALY gained than the £20–30,000 threshold.

4c Addressing the barriers to change

i. The main barriers to change and possible solutions

This section outlines some of the main barriers that exist to patients receiving optimal care for long-term problems after cancer and its treatment, around:

- The healthcare system (4c ii),
- Healthcare and research professionals (4c iii), and
- People affected by cancer (4c iv).

Some solutions are suggested in this section in order to stimulate further debate and action on strategies for which there is good evidence and that can be easily and inexpensively implemented now, and strategies that need further research or resources.

Although some consequences are widely understood to be caused by cancer treatment and may already have dedicated local services, other consequences are still at a low level of awareness and have poor provision^{127,128}. It is therefore acknowledged that health service staff and researchers are largely still at the early stages of developing and

testing potential solutions¹²⁹ including what could be achieved through supported self-management¹⁹, and how the stratification of cancer follow up and devolvement of care to primary/community teams could be designed to ensure that long-term problems and risks are properly recognised and minimised.

ii. Barriers and some potential solutions for the healthcare system

Often, the biggest barriers to improvements in healthcare are around the way that NHS services are funded, incentivised, provided and monitored, which can often seem to create too many time-consuming hurdles for professionals and service managers who are keen to make improvements.

National or local targets for cancer care improvement have focused on major issues such as early diagnosis, enhanced recovery from surgery, waiting times for diagnosis and treatment, provision of more and better radiotherapy, and unscheduled care for cancer patients. As a result, there has not been much space as yet to consider survivorship as a whole, although as of March 2013, commissioners and providers in England are now expected to follow the guidance in the 2013 NCSI document¹, including implementation of the Recovery Package (Figure 5).

There is growing recognition of the value of redesigning cancer follow up, and it is expected that stratified follow-up pathways will roll out across the NHS in the next few years^{119,169}, thus freeing up valuable resources that can be better targeted at people with the highest need, including those with long-term problems after treatment. This system redesign in the coming years offers considerable opportunity for addressing the needs of people relating to the consequences of cancer and its treatment (Figure 6), as long as it is done in a whole-system patient-centred way.

Costs of services for the consequences of cancer and its treatment are likely to be very modest and well within accepted limits i.e. cost effective at less than £20–30,000 per Quality Adjusted Life Year (QALY) gained.

Figure 6
Example of greater use of local support services by redesigning cancer follow up¹¹⁹

Greater use has been made of local support services as a result of the redesign of breast cancer follow up at the NHS Improvement stratified pathway test sites. Breast cancer teams referred more patients to services for:

- Lymphoedema
- Physiotherapy
- Menopause clinics
- Psychological support services Level 3 and 4
- Complementary therapies
- Support groups

'The most surprising and pleasing thing about this project was discovering what facilities already exist in the community and that by working with providers we could greatly enhance our service simply by being aware of them and using them appropriately.'
Healthcare professional

Table 7
Barriers to improvement related to the healthcare system, and suggested solutions for health commissioners and providers

Barriers relating to the healthcare system	Suggested solutions	
National guidance	National guidance and quality standards generally do not include management of consequences of cancer and its treatment as part of the cancer care pathway	The relevant decision-making bodies should ensure that quality standards and measures are updated to include evidence-based best practice for the management of consequences of cancer and its treatment, e.g. NHS England Service Specifications, NICE cancer guidelines, Map of Medicine, Cancer IOG Peer Review standards and any other relevant cancer care quality standards such as for gastrointestinal problems ⁵⁹ , lymphoedema ³⁰ and vaginal problems ³¹ .
Services for consequences of cancer and its treatment	There is not enough capacity and infrastructure to adequately agree responsibility for and deal with complex consequences of cancer and its treatment	Assess level of need for services (at local and national level) and address inequalities in provision. National commissioning of specialist services for complex consequences of cancer and its treatment. Develop competences for professionals so that providers know the range of skills and services required.
Cancer treatments with reduced risk of consequences	Current treatment regimes and equipment do not always maximise the methods that offer the least risk of consequences of treatment	Commissioning of innovative treatments where these have been shown to be safe and effective (e.g. laparoscopic surgery, IMRT, Image Guided Radiotherapy (IGRT)).

Barriers relating to the healthcare system

Suggested solutions

Co-ordinated local pathways that include consequences of cancer and its treatment

Health service provider processes, pathways and referral mechanisms hamper effective identification and treatment

Ongoing improvements in multidisciplinary care, communication between teams/professionals and with the patient.

Improving post-treatment pathways so that problems are identified early and appropriate signposting/referral is made (based on research such as Routes from Diagnosis).

Focussing attention on key transition points e.g. from treatment to follow up, and at discharge from follow up.

Engage private cancer care providers in local cancer commissioning discussions.

Integrating checks/scans for consequences of cancer and its treatment with existing checks/scans for cancer recurrence and other conditions/age-related check-ups.

Innovations such as virtual multidisciplinary teams, nurse-led late-effects clinics, radiographer-led phone follow up.

Data/intelligence

Poor record keeping, data entry or coding of cancer treatment and consequences/risk of consequences

Secondary care records contain coded diagnostic information about consequences of cancer and its treatment.

Treatment Summary from cancer care team to primary care includes READ codes for cancer treatment and consequences/risk of consequences.

Patient information

Information is not always personalised, does not always have a 'minimum standard' or is not given enough importance in measurement of service quality

Personalisation of the information and support offered to meet a person's holistic needs.

Use NHS Information Prescriptions.

Consent forms and Care Plans should include list of information resources provided to patients.

Follow NICE guidance and cancer service peer review standards.

Barriers relating to the healthcare system

Suggested solutions

Outcome measurement

Patient-reported outcomes not given enough importance in quality monitoring

Assess all patients for the emergence of consequences of treatment through the routine use of PROMs, which are tailored to their specific risks, based on their diagnosis and treatments provided. Methods for doing this in clinical practice need to be developed and evaluated.

Access to effective medication

New medication for consequences of treatment may be 'off licence'/'off label'

Policy decisions about the use of new drugs.

Commissioning focus on long-term care needs of cancer patients

Cancer care services are incentivised to provide early diagnosis and treatment, not long-term support and care

A culture shift in commissioning of cancer care, helped by policy/financial incentives that encourage the provision of long-term care and support, including supported self-management.

Planning blight

NHS reorganisation in England — major changes to commissioning and cancer networks

Cancer commissioning 're-boot' in England is opportunity to give due attention to post-treatment patient needs — commissioners should implement the recommendations of the NCSI, particularly the Recovery Package.

See also Appendix 4.

iii. Barriers and possible solutions for healthcare and research professionals

There is a wide range of issues that prevent health and social care professionals from improving outcomes for patients with long-term unmet needs. Underlying these is the fact that cancer care is a complex and rapidly changing field of medicine. It is a challenge for professionals outside the cancer care team to keep up to date with these regimes and what effects they may have on patients in the long term. Some may not even realise that a problem has been caused by cancer treatment. Even for cancer professionals, correctly diagnosing consequences of cancer treatment can be complex and challenging, and there can be confusion with symptoms

of recurrent cancer or of other chronic illnesses/co-morbidities. Cancer professionals cannot be prepared for every eventuality because patients have simply not yet lived long enough after being given the newest treatments for researchers to be able to pin point all problematic consequences. Research on improving outcomes for the consequences of established (or discontinued) treatment regimes is also limited, because it is hard to engage current clinicians with problems that might be seen as 'old news'.

Hence, although survivorship issues have come a long way up the agenda of health professionals, there remains a lot to do. Table 8 lists some barriers to change and possible solutions for healthcare professionals.

Table 8
Barriers to improvement related to health and social care/research professionals, and suggested solutions

Barriers relating to health and social care/research professionals		Suggested solutions
Time	Multiple competing priorities for professionals' time	Whole team/pathway system redesign that releases professionals' time from routine follow up.
Awareness	Health and social care professionals, especially those outside of cancer care teams, lack awareness of the problems that consequences of cancer and its treatment can cause	Read/attend conference presentations, study days, journal articles etc. Improve primary care awareness by secondary care providing clear post-treatment letters to primary care and patients that include READ coding for cancer treatment (e.g. using the NCSI Treatment Summary template ¹³²).

Barriers relating to health and social care/research professionals

Suggested solutions

Formal education

There is little formal education on offer for screening, identification and clinical management of consequences of cancer and its treatment or on how to support people to self-manage physical or psychosocial problems

Professional associations and educational institutes develop information and educational resources (e.g. clinical guidance, clinical tools, e-learning, textbooks; see Appendix 4) to (a) improve correct diagnosis and management of consequences, and (b) improve ability of cancer care teams to prepare people for possible consequences with self-management strategies.

Professional associations develop and promote competency frameworks and professional curricula for continuing professional development, which includes skills for assessing the information and support needs of patients, and improving level 2 skills in psychological assessment and support¹³³.

Education of primary care teams regarding long-term conditions exacerbated/caused by cancer treatment, such as osteoporosis and cardiovascular problems.

Education of community pharmacists.

Confidence and ownership

Some professionals express lack of ownership and/or lack of confidence in identifying and managing the consequences of cancer and its treatment

Adopt recognised assessment tools (e.g. Holistic Needs Assessment) and develop Care Plans¹³⁴. Use the Treatment Summary process to identify possible consequences.

Use other structured questions when discussing post-treatment issues with patients.

Offer and support practical experience opportunities in managing consequences of cancer and its treatments.

Clinical expertise

Consequences of cancer and its treatment are not seen as a career-making area of healthcare – few choose to develop in-depth expertise

Establish consequences of cancer and its treatment as a medical/academic field in its own right.

Test whether 'virtual' expert teams can facilitate multidisciplinary discussion of complex cases.

Barriers relating to health and social care/research professionals

Suggested solutions

Research and scientific knowledge

There is limited research into ways to predict, avoid, minimise and treat consequences of cancer and its treatment

Survivorship research strategy¹³⁵.

Research into the mechanisms of consequences of cancer and its treatment, their prevalence and trajectory, and ways to prevent, minimise and manage them.

Increase publication of articles about consequences.

Improve the identification and ongoing measurement of consequences, including PROMs.

More detailed PROMS/assessments designed for specific aspects of morbidity (e.g. bowel, urinary, sexual) are needed to give accurate data on the scope and severity of impact.

National survivorship surveys.

Monitor groups of patients for increased risk of late-onset consequences, including through the long-term follow up of patients in clinical trials, observational studies, prospective longitudinal cohort studies 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 should be developed for monitoring and surveillance.

See also Appendix 4.

iv. Barriers and possible solutions relating to people affected by cancer

Reference has already been made to the importance of empowering people undergoing treatment and their families so that they are prepared for the possible physical and psychosocial consequences of cancer and its treatment. There needs to be much better understanding of the difficulties that people encounter, and what

self-management, coping strategies and other solutions there could be. Table 9 provides some suggestions. Addressing barriers to self-efficacy could result in a significant improvement in how soon people are able to return to living as normal a life as possible after a cancer diagnosis, and how much they might need health and social care services in future.

Table 9
Barriers to improvement related to people affected by cancer, and suggested solutions

Barriers relating to people affected by cancer

Suggested solutions

Knowledge

Patients and carers lack knowledge about their condition or level of risk, and are not prepared for the physical, psychosocial or financial impact of cancer and its treatment

Offer people information and education (repeated at several time points) about which consequences of cancer and its treatment might arise and why (taking into account language barriers, cognitive difficulties or learning difficulties etc) with advice on coping strategies.

Help patients to better understand risks, how to self-manage and how to get back into the cancer care system or into post-treatment services.

Provide advice on work-related and financial issues early in diagnosis/treatment phase (as well as later on).

Ensure patients' family and friends are aware of potential problems – as appropriate/desired.

Effective transition to adult services of people living after child or young people's cancer treatments.

Barriers relating to people affected by cancer

Suggested solutions

Reluctance to raise problems with a professional

e.g. due to embarrassment, feelings of isolation, cultural taboos, not wanting further invasive treatment, or feeling that nothing can or will be done

Reluctance in talking to health professionals or with family or friends; reluctance to attend healthcare appointments for fear of personal accidents or not wanting to be seen in public

Reassurance to patient of healthcare team contact details and availability including who to contact out-of-hours.

Telephone, written or online communication with patient.

Topic is raised by health professional, using structured questions.

Patient completes a questionnaire (e.g. PROM) prior to appointment.

Patient completes a bowel diary, food diary etc prior to appointment.

Signpost patient to support services, charities, groups, online communities including those dedicated to cultural, ethnic or religious groups.

Public campaign that something can be done.

Give patient information that these are normal feelings or symptoms and should be discussed.

Delay in raising problems with a professional

(including signs of recurrence)

Waiting until annual cancer follow-up appointment to mention the problem

Open access 'patient-triggered' follow up (i.e. patient able to contact cancer team as soon as problems arise).

Primary care team understand risk of consequences via the Treatment Summary.

Lifestyle factors

Range of barriers to making healthy lifestyle choices

Reduction in severity of consequences through healthier lifestyle choices on diet, smoking, weight, physical activity, alcohol.

Prevention of commonly associated chronic illnesses through healthier lifestyle choices as above.

CHAPTER 4 SUMMARY

- There is an economic rationale for changing how consequences of cancer and its treatment are identified and managed.
- There are simple and effective changes that can be implemented at little or no cost, such as:
 - Better patient information about consequences of cancer and its treatment and who to go to for help, including use of the Treatment Summary as the keystone to communication with the patient and primary care.
 - Advice on healthier lifestyle choices.
 - Use of structured questions to identify people with problems.
 - Increasing professionals' awareness through education events and publication of guidance.
 - Co-ordinated pathways from cancer care teams to existing local specialists in managing consequences of cancer and its treatment.
- **The key principles of service redesign are:**
 - **Prevent** or minimise consequences where possible, through healthier lifestyle choices, better surveillance, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
 - **Inform** patients of potential consequences of cancer and its treatments, with simple strategies for self-management, and the value in taking early action and how to seek appropriate help.
 - **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential consequences so that they can be easily anticipated, recognised and monitored in primary care.
 - **Assess** potential consequences through regular Holistic Needs Assessment, the use of 'power' questions and PROM tools at regular time points.
 - **Support** patients through local care pathways for consequences of cancer and its treatment, which include support for self-management and referral to appropriate specialist services.
- More education and research is needed in order to improve knowledge and to establish the consequences of cancer and its treatment as a healthcare/academic field in its own right. For example, in developing tools to predict the consequences of cancer and its treatment, identifying biomarkers, and using risk stratification of patients to guide further management.

See also Appendix 4.



Conclusions and recommendations

Faced with a growing population of people living with and beyond cancer, due to increasing numbers of diagnoses and better survival rates, the commissioners and public health teams who are tasked with assessing the needs of the population must take account of the long-term consequences of cancer and its treatment.

The majority of people affected will be in older age, but in terms of life-years at risk, people treated as children and young people also represent a population with significant needs. Health commissioners and providers need a 'case for change' which not only shows the many benefits for people affected by cancer and the financial benefits to the system, but also that changes are achievable.

This report complements the 2013 Department of Health report 'Living With and Beyond Cancer: Taking Action to Improve Outcomes' (2013) by providing a more in-depth description of the scale and scope of long-term problems affecting people as a result of cancer treatment.

It is intended to assist health service professionals, managers and commissioners to develop and take forward plans to deliver cost-effective service provision that improves outcomes for this population, which is growing and ageing and whose needs are currently poorly met. There is a clear rationale for change in terms of addressing unmet need, improving patient outcomes and reducing the impact on the economy and health services.

It is estimated that around 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects the quality of their lives on a long-term basis. The prevalence of consequences of cancer and its treatment provides an indicator of the level of need for interventions, such as support for self-management and specialist clinical services. Our estimates include:

- Gastrointestinal problems: 90,000 people affected
- Urinary problems: 150,000 people
- Sexual difficulties: 350,000 people
- Mental health problems: 240,000 people
- Chronic fatigue: 350,000 people
- Lymphoedema: up to 63,000 people
- Rare and complex complications, e.g. chronic graft versus host disease, myelodysplastic syndrome, fistulae: probably a few hundred new cases of each per year.

(For further detail, see Appendix 3.)

People living with and beyond cancer are also likely to be at increased risk of second primary cancers, and long-term conditions including osteoporosis and cardiovascular problems.

In recent years, a range of evidence has become available on what actions can be taken to improve outcomes. Some examples of what can be achieved at little or no cost at a local level include:

- Provision of good quality patient information that supports self-management, including healthier lifestyle choices.
- Education for professionals on symptoms of consequences of cancer and its treatment and the risk of long-term conditions.
- Better identification of patients with problems through the use of structured questions to overcome embarrassment.
- Co-ordinated pathways from cancer care teams to existing local specialists in managing the consequences of cancer and its treatment.

(For further information, see Chapter 4 and Appendix 4.)

National specialist commissioning needs to address the inequitable and low level of provision of specialist services for rare, severe, complex problems, for which multidisciplinary teams can deliver expert holistic physical and psychosocial care.

If health commissioners and providers ignore the evidence, they will be unable to plan effectively for the inevitable rise in demand from people living with and beyond cancer, especially from older people with co-morbidities, whose needs for health and social care will only increase or result in premature death if the consequences of their cancer treatment are poorly managed.

This report is also intended to stimulate debate about available intelligence on the consequences of cancer and its treatment and on patients' experiences of living long term after a cancer diagnosis. Challenges and questions

about this report are welcomed (survivorship@macmillan.org.uk). In preparing it, many limitations were found with the available data and it is emphasised that the estimates of prevalence of consequences of cancer and its treatment (Chapter 3) are indicative only. If intelligence is to improve, then data collection and analysis need a step change. Better information on acute and long-term outcomes and experiences will help professionals to provide better personalised and targeted care for their patients. It will also allow commissioners and cancer service managers to measure how well a local health system is helping people to live as healthy and active a life as possible after a cancer diagnosis. Macmillan and the National Cancer Intelligence Network are starting to tackle this through the Cancer Population Evidence Programme³, which includes studies such as Routes from Diagnosis⁷⁰, which is now being extended. Macmillan is calling on NHS England to ensure that their pilot cancer survivorship survey is rolled out at a national level, and to work with Macmillan to develop a process for using the results as a driver for service improvement.

In conclusion, the consequences of cancer and its treatment remain a significantly under-recognised aspect of cancer care, with hundreds of thousands of people having long-term unmet needs that affect their health and quality of life, and that of their carers, and which have a serious impact on health and social care, and on the economy.

Box 1 Recommendations

General recommendations to everyone involved in redesigning services and support for people living with and beyond cancer

- **Prevent** or minimise consequences of cancer and its treatment where possible, through better surveillance, healthier lifestyle choices, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
- **Inform** patients of potential consequences of cancer and its treatments, with simple strategies for self-management and value of taking early action to seek help.
- **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential consequences so that they can be easily anticipated, recognised and monitored in primary care.
- **Assess** potential consequences through regular Holistic Needs Assessment, the use of 'power' questions and PROM tools at regular time points.
- **Support** patients through local care pathways for the consequences of cancer and its treatment, which include support for self-management and referral to appropriate specialist services.

Recommendations to organisations that influence or carry out cancer commissioning

General recommendations

Local implementation of the NCSI Recovery Package in England, or the equivalent in Wales, Scotland and Northern Ireland.

National commissioning of specialist services for complex problems arising from cancer treatment.

National quality and outcomes measurement should be embedded and further developed, including quality standards and PROMs for people living with and beyond cancer treatment in order to monitor service delivery and cancer patient outcomes.

Inclusion in the cancer Maps of Medicine and Cancer Peer Review Programme of evidence-based management of the consequences of cancer and its treatment.

Specific recommendations*

National commissioning of specialist services for:

- 1** People with complex injuries resulting from radiation treatment for breast cancer. The Breast Radiation Injury Rehabilitation Service (BRIRS) should continue being nationally commissioned for England
- 2** People with complex problems in adulthood as a result of child and young people cancer treatments.
- 3** People with complex problems as a result of treatments for pelvic cancer, such as severe bowel, urinary and/or sexual dysfunction.

Continue and extend the current programme of survivorship PROM surveys in England.

Recommendations to cancer care professionals, other secondary care professionals, primary care professionals and social care professionals

General recommendations

Review patient information provision to ensure that appropriate information is available at multiple points (including at consent to cancer treatment) on risks of long-term consequences and how to seek help should problems arise.

Local implementation of the NCSI Recovery Package (or similar post-treatment package)².

Educate care providers by taking opportunities to increase their knowledge of how to identify and manage patients who have needs in relation to the consequences of cancer and its treatment.

Develop referral pathways between cancer teams and local or regional specialists in supporting and managing the consequences of cancer and its treatment.

Specific recommendations*

Fully implement the NCSI Children and Young People service models and aftercare pathways as per the QIPP Quality and Productivity case study⁴.

Review the main pelvic cancer care pathways (NICE, Maps of Medicine etc) and ensure that they include signposting/referral pathways to local/regional specialists in supporting and managing the consequences of pelvic cancer and its treatment, such as:

Patient support groups, online communities, telephone support etc.

Specialists: Gastroenterology/endoscopy; Urology; Colorectal surgery; Biofeedback service; Dietetics; Psychosexual therapy and/or sexual medicine outpatient ; Hyperbaric oxygen service; Community continence service; Lymphoedema service; Stomatherapy/stoma nursing service; Gynaecology ; Menopause service; Fertility service; Orthopaedics; Pain clinic; Reconstructive surgery; Dermatology; Endocrinology ; Counselling, psychology, psychiatry; Rehabilitation services, including physiotherapy (pelvic specialist), vocational rehabilitation, physical activity schemes e.g. exercise on referral schemes (or a walking scheme), services for management of fatigue, body image or memory loss, etc

Primary care team for managing and monitoring for long-term conditions (as appropriate).

Complementary therapies such as acupuncture.

Stop smoking service.

Social services including carer support.

Financial advice service.

Recommendations to professional organisations and organisations who arrange training and education

General recommendations

Develop, publish and maintain clinical guidance on the management of the consequences of cancer and its treatment.

Set educational and skills standards and competences in relation to the consequences of cancer and its treatment.

Provide accessible education for professionals on the consequences of cancer and its treatment

Undertake audits/research on the consequences of cancer and its treatment.

Specific recommendations*

Prioritise clinical guidance development where need is seen to be greatest, for example in pelvic cancers and head and neck cancers, ensuring that psychosocial consequences are always considered alongside physical ones.

*Specific recommendations to urgently address consequences of cancer and its treatment that are highly prevalent and/or have a particularly negative effect on quality of life.

General recommendations to the research community

Extend, build on and ratify the evidence base for:

- Prevalence of consequences of cancer and its treatment.
- Costs of managing consequences of cancer and its treatment.
- Treatments for consequences of cancer and its treatment.
- Methods to prevent or minimise consequences of cancer and its treatment.
- Methods for monitoring for consequences of cancer and its treatment including the risk of developing long-term conditions.
- Cost-effectiveness of new cancer follow up pathways.

General recommendations to the voluntary sector

- Raise awareness in individuals of the availability of post-treatment support through health and social services, support groups, online community support, information etc.
- Raise the profile of consequences of cancer and its treatment as a health policy issue.

For further information please contact Lesley Smith, Programme Manager for Consequences of Treatment: lsmith2@macmillan.org.uk or survivorship@macmillan.org.uk.

Appendix 1: Glossary of terms

Term	Definition
Acute myelocytic leukaemia	A quickly progressing malignancy arising in the bone marrow that causes the production of cancerous white blood cells that are released into the blood.
Anthracycline	A group of antibiotics originating in <i>Streptomyces</i> bacteria that are used to damage the DNA in cancer cells leading to cancer cell death.
Arthralgia	Joint pain or ache.
Artificial urinary sphincter	A device that is fitted to treat male urinary incontinence by preventing involuntary opening of the urethra.
Biofeedback	A treatment method that allows patients to monitor body functions that are usually automatic, so that they can learn to control the functions voluntarily (e.g. blood pressure and body temperature).
Biological therapy	Unlike chemotherapy, biological therapies do not directly damage the DNA of cancer cells. Biological agents can act to modify the immune system or to reprogram abnormal cellular pathways and so eliminate cancer cells by more indirect routes than with traditional forms of chemotherapy.
Biomarkers or Biological marker	A substance used as an indicator of a biological process. For example, an antibody can be a biomarker of infection. In genetics a biomarker is a specific DNA sequence known to relate to the susceptibility of a certain disease. Biomarkers can also be introduced into the body to examine organ function, or used to measure the therapeutic response to a treatment.
Bisphosphonates	A type of drug that prevents the loss of bone mass and is used to treat osteoporosis.
Bone marrow transplant	A surgical procedure that substitutes damaged or diseased bone marrow with a healthy replacement.
Bone mineral density scanning	A measurement of the amount of calcium and other minerals in areas of bone. The test is usually associated with the diagnosis and management of osteoporosis.
Boots Macmillan Information Pharmacists	Macmillan-trained pharmacists available in some Boots stores to offer information and support to cancer sufferers.
Bowel adhesions	Part of a healing process that results in fibrous bands of connective scar tissue that affect the normal function of the bowel. This can lead to obstructions within the bowel.

Term	Definition
Brachial plexopathy	The loss of sensation, movement or an increase in pain in the arm or shoulder. This is due to a nerve problem.
Cancer Care Review	A meeting between a patient and their GP within six months of cancer diagnosis to allow patients to discuss their condition, treatment and required support.
Cancer IOG Peer Review standards	Standards assessed by external peers to ensure local cancer services meet national quality requirements.
Cardiovascular disease	An umbrella term for all disease relating to the heart or circulatory system.
Care Plan	A patient-specific document outlining patient needs and ways of meeting them during their course of care.
Chemotherapy	The treatment of disease using chemicals inserted into the body intravenously or orally. These chemicals are chosen to specifically harm cancer cells and thereby prevent or slow further growth or spread. This can be administered simultaneously with radiation therapy, which is known as chemoradiation.
Chronic graft versus host disease	An illness caused by a stem cell or bone marrow transplant, in which transplanted donor cells start to attack the recipient's body more than three months after transplantation.
Clinical networks for cancer	A network that provides services to support cancer patients by linking health and social care providers.
Clinical trials	Research involving a comparison of two clinical treatments. This can involve the use of healthy people and/or patients.
Co-morbid condition	A medical condition that exists alongside with the condition of primary interest. These conditions are usually independent of each other, but not always. Multimorbidity is the existence of multiple synchronous medical problems (e.g. cancer, heart disease and dementia in the same patient).
Cognitive	An umbrella term relating to the neurological processes involved in knowing, perceiving, remembering, awareness etc.
Competences	An individual's skills that make them well qualified and capable of performing a task.
Cross-sectional surveys	A type of study that focuses on collecting details related to either a singular point in time, or a very short period in time. For studies over a longer time period, see longitudinal studies.
Diabetic neuropathy	A long-term complication of diabetes thought to be worsened by poor blood glucose control, which is known to lead to nerve damage. This nerve damage can affect the sensory, autonomic and motor systems, leading to a variety of symptoms.

Term	Definition
Early menopause	The occurrence of menopause before 40–45 years of age. This can be due to premature ovarian failure, or result from damage to the ovaries during chemotherapy or radiotherapy, or the surgical removal of the ovaries.
Egg freezing	Also known as human oocyte cryopreservation. The process by which eggs are frozen for use at a later date. This is commonly done when women wish to start families later in life, when there are fertility issues, or prior to some cancer treatments.
Endocrine dysfunction	The abnormal functioning of glands that secrete substances directly into the bloodstream for passage around the body. Common endocrine dysfunctions include diabetes and hypo- or hyperthyroidism.
Endocrine system disorders	Conditions which affect the body's hormone balance.
Epidemiology	The study of disease patterns and their causes within a defined population.
Erectile dysfunction (ED)	The inability to get or maintain an erection that is sufficient for sexual intercourse.
Fasciitis	Painful inflammation of the membrane that surrounds muscles and organs.
Fatigue	A physical and/or mental state causing decreased motivation, tiredness and lethargy. This is not to be confused with drowsiness or the need to sleep.
Fistulae	A passageway within the body that is anatomically abnormal. This can be the result of an operation or injury, and can involve passage between two organs (e.g. between bowel and bladder) or one organ with the body's exterior (between bowel and skin).
Genetic profile	A person's genetic fingerprint. This can be used to test if a person is likely to develop a certain cancer (in familial strains), or to assist in diagnosis and predict the response of a cancer to treatments.
Genitourinary organs	The organs that together form the genitals and urinary system.
Haematuria	The presence of red blood cells in the urine.
Hazard ratio	A method used in clinical trials to measure the outcomes of a particular event in one group of patients compared to another.
Hernia	Formed when an internal organ protrudes through the abdominal muscle wall. This can be due to a previous surgery or other weakness of the muscle wall. The most common hernia is the inguinal hernia caused by the protrusion of the bowel through the lower abdomen close to the groin.
Holistic treatment	Holistic treatment is the treatment of the person as a whole, including mental, social and physical factors.

Term	Definition
Holistic Needs Assessment	A discussion between patient and doctor to ensure the patient's physical, emotional and social needs are being supported alongside their cancer treatment.
Hormone therapy	The treatment of cancer by manipulating the endocrine system – some tumours are hormone dependent and can be treated using antagonists (e.g. the anti-oestrogen tamoxifen). Also known as endocrine therapy.
HPV	Human papilloma virus. A large family of more than 50 viruses, some of which are known to lead to cancerous and precancerous states in some instances.
Hyperbaric oxygen therapy	A treatment involving breathing 100% oxygen in a sealed pressurised chamber. This technique increases the levels of oxygen in the blood, which can increase rates of healing in the body.
Hypothyroidism	A condition in which there are inadequate amounts of thyroid hormone in the body. This causes weight gain, dry skin, fatigue and a general slowing down.
Image guided radiotherapy (IGRT)	The process of frequent two and three-dimensional imaging, during a course of radiation treatment, used to direct radiation therapy.
Intensity modulated radiotherapy (IMRT)	A treatment that focuses on shaping radiotherapy beams to give treatment from multiple angles and fit the tumour outline more accurately. This treatment also allows varying doses to be administered to different parts of the tumour.
Interventional Radiology (IR)	Minimally invasive image-guided procedures. In cancer care, these include transarterial chemoembolisation, radiofrequency ablation, cryoablation and high intensity focused ultrasound.
Intravesical instillations	The administration of drugs directly into the bladder to treat disease.
Joint contractures	Stiffening of the muscles and joints that prevents full joint extension.
Laparoscopic surgery	A form of surgery using specialised equipment that allows access to the body using limited surgical incisions and is often combined with video imaging to visualise internal structures and organs. Also known as keyhole surgery.
Longitudinal studies	A research study that involves repeat observations from the same patient over a long period of time.
Lymphoedema	The chronic swelling of tissues, usually in the arms or legs. This occurs when lymph fluid cannot be drained away due to the damage or blockage of lymph nodes or vessels. This condition can be intractable.
Lymphoedema practitioner	A clinically trained professional that helps to alleviate the symptoms of lymphoedema through special techniques.

Term	Definition
Lymphovaticovenous anastomosis surgery	Surgery that connects one lymph vessel to another to bypass a blockage.
Map of Medicine	A comprehensive care map (www.mapofmedicine.com/) that outlines up-to-date clinical knowledge of a variety of conditions. The map helps clinicians devise the optimum care pathway to treat illnesses and make clinical decisions.
Metabolic syndrome	The synchronous occurrence of diabetes, high blood pressure and obesity. Together these factors can lead to a much greater risk of heart disease, stroke and blood vessel conditions including deep vein thrombosis.
Metastases	A metastasis is a secondary cancerous tumour or growth. Metastases result from the spread of cancer cells from a primary tumour — the cells disseminate via the blood or lymphatic systems or, occasionally, across body cavities.
Monoclonal antibodies	Antibodies assist in the ‘tagging’ of foreign bodies or cells for destruction by the immune system. Monoclonal antibody therapy can be used to treat certain forms of cancer (e.g. rituximab for lymphoma).
Morbidities	The disease state of an individual. This can also refer to the prevalence of a disease within a population.
Myelodysplastic syndrome	A condition affecting the bone marrow that prevents individuals from producing sufficient healthy blood cells.
Needs assessment	A tool or approach that assists in defining the support and care needs of the individual patient with consistency.
NHS England Service Specifications	Standards set by the NHS to ensure services across the country meet specific requirements.
NHS Improvement	An NHS organisation now superseded by NHS IQ (NHS Improving Quality) and hosted by NHS England.
NHS Improving Quality	An improvement organisation (www.england.nhs.uk/ourwork/qual-clin-lead/nhsiq/) hosted by NHS England that is in alignment with the needs and challenges of the NHS.
NHS Information Prescriptions	Documents and online information that guide people to sources of reliable information on their condition.
NHS Outcomes Framework	Targets and directions set to guide the NHS to improve future outcomes.
NICE cancer guidelines	Guidelines set by the National Institute for Health and Care Excellence to ensure cancer care and treatments meet quality requirements.
Nocturia	A condition in which sufferers frequently need go to the toilet to pass urine during the night.
Odds ratio	A method used in studies to compare the odds of an event occurring in one group with the odds of the event occurring in a different group (classically the comparison is between an experimental group and a control group).

Term	Definition
Off-licence/off-label	When a drug is prescribed for a condition that is not included in the list of conditions that the drug is licenced for by the Medicines and Healthcare Products Regulatory Agency. Off-label prescriptions are judged by the prescriber to be in the best interest of the patient on the basis of available evidence (www.mhra.gov.uk/Safetyinformation/DrugSafetyUpdate/CON087990).
Osteonecrosis	A process in which blood flow to the bones is reduced and which can cause fractures and chronic pain.
Osteoporosis	A condition leading to weak and fragile bones due to a decrease in bone density. This condition can lead to fractures following minor falls or trauma.
Palliative treatment	In cancer, palliative treatment can be used at any stage to alleviate symptoms. The main aim of palliative treatment is to lengthen life while making it more comfortable. This can include a range of treatments for symptom and disease control including radiation and chemotherapy.
Parenteral nutrition	Feeding a person by a drip directly into their blood.
Patient-reported outcome measures (PROMs)	Structured information provided by patients, which can include specific symptoms, general quality of life and opinions on quality of care.
Pelvic floor exercises	Self-controlled contraction and relaxation of the pelvic floor muscles to increase their strength and prevent incontinence.
Pelvic necrosis	Necrosis is the premature death of cells caused by a lack of blood flow to the tissues. This can be due to infection, trauma or toxins, and is detrimental and occasionally fatal to the person.
Pelvic radiation disease	The occurrence of pelvic symptoms following radiation therapy. These problems can develop immediately, or may appear years later.
Periodontitis	A bacterial infection of the gums and bone surrounding the teeth.
Peripheral neuropathy	Damage to the peripheral nervous system known to cause numbness or tingling in the extremities, burning, stabbing or shooting pains, muscle weakness or loss of coordination. This is a common condition, and is commonly associated with diabetes and some cytotoxic drugs.
Phantom sensations	Perceived feeling in a limb or organ that is not caused by a physical stimuli, such as the sense of feeling in a limb that is not physically attached to the body.
Pharmacogenomics	A relatively new field used to predict how an individual’s genetic make-up will determine their response to specific drugs. See also genetic profile.

Term	Definition
Post-traumatic stress disorder	An anxiety disorder that develops following a frightening or stressful event. The time between occurrence of the incident and the onset of symptoms can vary dramatically from immediately to years later.
Premature mortality	A measure of the deaths occurring before the age of 75 (as defined by the European age-standardised mortality rate).
Prevalence	An epidemiological term used to define the number of cases of a disease within a population at a specific time. This is different from incidence (the number of new cases of a disease occurring within a specified time interval in a defined population).
Primary ovarian failure	Premature failure of the ovaries before a woman reaches natural menopause.
Prospective studies	A study that is conducted forwards in time. A specific group of patients (or members of the population) are tracked over time.
Proton beam radiotherapy (PBT)	A type of radiotherapy that utilises high-energy beams of protons instead of x-rays. Protons treat to a defined depth that is dictated by the energy of the beam. This confers advantages over conventional radiotherapy for treating tumours close to the skull or spine.
Quality, Innovation, Productivity, Prevention (QIPP)	A resource for the NHS, public health and social care for making decisions about patient care or the use of resources (www.evidence.nhs.uk/qipp).
Psychosexual	Mental and emotional aspects of sexuality.
Psychosocial	The interrelation of social factors and individual thought and behaviour.
Quality of life	In healthcare, the term 'quality of life' relates to patient wellbeing following a disease diagnosis. Quality of life encompasses the physical, social and psychological wellbeing of patients, and can be used as a measure of determining the impact of disease, as well as the best treatments.
Quality Adjusted Life Year (QALY)	A measure of how many extra months or years of life of a reasonable quality a person might gain as a result of treatment (particularly important when considering treatments for chronic conditions).
Radioactive iodine	A radioactive form of iodine that is commonly used in diagnostic imaging or as a treatment for hyperthyroidism or thyroid cancer.
Radiotherapy	The treatment of disease by exposure to radiation via a beam (external beam treatment) or a radioactive element inserted into the tissues (brachytherapy) or the use of a systemically administered radioisotope.

Term	Definition
RAGE action group	A group of women who drew attention to the problems caused by brachial plexus damage following radiotherapy for breast cancer.
READ codes	A coding for clinical terminology used primarily in general practice.
Recovery Package	A set of interventions developed to help people diagnosed with cancer prepare for the future, identify their needs and manage their transition back to work.
Response shift	A phenomenon relating to the change that individuals undergo over time, thereby also changing the way that they view or make quality of life judgements (expectations may be lowered if general health is impaired).
Robotic surgery	A surgical technique in which a surgeon uses a computer to control instruments attached to a robot.
Routes from Diagnosis	A Macmillan research program in which data from different sources is linked to describe patient journeys from cancer diagnosis to health outcomes. The program aims to provide information on how cancer diagnosis affects individuals and how they use the healthcare system, to improve the implementation of cancer services in the future.
Sacral neuromodulation	A treatment method for urinary and faecal incontinence that involves the installation of a small pacemaker-like device under the skin to stimulate dysfunctional nerves at the base of the spine
Second primary cancer	A cancer that has developed independently of previously diagnosed cancers.
Selection bias	A bias that occurs when selecting patients or groups to participate within a study. Researchers aim to minimize this bias as much as possible.
Self-efficacy	An individual's belief in their ability to complete tasks and achieve goals.
Self-management	A current healthcare intervention to promote independence, whereby patients are encouraged to take control of the day-to-day care of their chronic conditions with the assistance and support of healthcare professionals.
Sperm cryopreservation	The process by which fresh sperm can be frozen for use at a later date. This is commonly done when there is a danger of fertility being impaired or lost.
Statins	A drug group that lowers low-density lipoproteins ('bad' cholesterol) in the blood, thereby lessening the risk of heart attack, stroke and coronary artery disease.
Stenosis	The abnormal narrowing of a passage within the body, including vessels. See also stricture.

Term	Definition
Stereotactic ablative radiotherapy	A treatment that utilises high-energy x-ray radiation more precisely than older treatments. This technique permits higher radiation dose, fewer side effects and a shorter treatment time.
Stoma	A surgically created passageway through which waste can be excreted from the damaged organs or tracts. Waste can be either urine or faeces via a urostomy, colostomy or ileostomy.
Stratified pathways of care	A process in which patients and clinicians agree on a cancer aftercare pathway that is most suited to individual patient needs.
Stricture	A narrowing of a passage within the body. This can be caused by inflammation and scar tissue formation as well as cancer.
Surgery	A medical procedure involving incision used to treat deformity or injury to the body. This procedure is usually performed by a surgeon, but not always.
Survival rates	The percentage of patients still living at a certain time interval following their diagnosis. In terms of cancer, a five-year survival rate is usually given.
Survivorship	Macmillan Cancer Support has defined survivorship as those not undergoing active treatment, and not within the terminal stages of cancer.
Telangiectasia	Small visible blood vessels near the surface of the skin
Treatment Summary	A summary of cancer treatments received by a patient, completed by the hospital and sent to a patient's GP and the patient at the end of primary cancer treatment.
Trismus	Difficulty opening the mouth due to defects in the jaw muscles.
Vaginal dilators	A device that is used to stretch the muscles of the vagina.
Virtual MDTs	A multidisciplinary team that uses electronic systems to communicate, as team members are usually geographically dispersed.
Vocational rehabilitation	A process that gives individuals with an illness or disability assistance in gaining employment or occupational pastimes.

Appendix 2: Case Studies

1. Case study of problems after pelvic cancer treatment

(with thanks to the Gastrointestinal and Nutrition team, Royal Marsden Hospital, London)

This case is typical of those seen by the team and involves multiple problems after pelvic cancer treatment. Bowel urgency and faecal leakage are the most troublesome and common symptoms in patients who have undergone pelvic radiotherapy or colorectal surgery. These symptoms often occur in conjunction with urinary and sexual problems and often have a severe impact on quality of life. Financial implications of faecal leakage or incontinence as well as the psychological and emotional impact of being incontinent in public, or the fear of being incontinent, can be enormous.

Fiona (not her real name), aged 38, was diagnosed with cervical cancer. She had radical surgery, then 18 months later she experienced pelvic and para-aortic lymph node relapse and small bowel obstruction. She underwent further surgery during which 35cm of the terminal ileum was resected, and was given chemotherapy and pelvic and para-aortic lymph node irradiation.

Symptoms on referral

- Bowel frequency: 3–6 times per day
- Stool consistency: type 1–7 Bristol Stool Chart (i.e. ranging from liquid to very hard)
- Daily urgency of defaecation
- Faecal leakage weekly
- Nocturnal defaecation 3 times per week
- Severe abdominal pain daily
- Frequent painful bloating
- Steatorrhoea 2 times per week
- Urinary frequency and leakage
- Sexual problems
- Fatigue
- Financial concerns
- Social isolation and low mood

Differential diagnoses for Fiona's symptoms included:

- Development of small bowel bacterial overgrowth
- Bile acid malabsorption
- Pancreatic insufficiency
- Underlying gastrointestinal disease unrelated to previous cancer or radiotherapy (i.e. coeliac disease, new-onset inflammatory bowel disease)
- Excess fibre intake (dietary assessment)
- Recurrent pelvic malignancy
- Damaged anal sphincters from previous childbirth

Test results (as per the Marsden bowel algorithm and published guidance for managing gastrointestinal symptoms after radiotherapy) (See Appendix 4):

- Raised CRP (140 and low vitamin B12 (157pg/ml) (See Appendix 4)
- Glucose/hydrogen methane breath test: positive for methane and hydrogen after 40 minutes
- Upper gastrointestinal endoscopy with duodenal aspirate and biopsies – positive for *Escherichia coli* and *Streptococcus* bacteria, both sensitive to ciprofloxacin, biopsies did not show inflammation, dysplasia or malignancy
- SeHCAT scan (selenium homocholic acid taurine – a clinical test to diagnose bile acid malabsorption – 7-day retention of 3.2% indicating severe bile acid malabsorption
- Flexible sigmoidoscopy – biopsies did not show any organic cause for symptoms i.e. no cancer or non-malignant GI disease
- Physical examination and anorectal physiology – weak sphincter muscle tone and anterior sphincter trauma
- Endoanal ultrasound and anorectal manometry – anterior internal sphincter trauma confirmed but not requiring surgical intervention
- CT scan abdomen and pelvis – no recurrent cancer, no gall bladder disease
- 7-day food diary – fibre intake 15g per day, fat intake 80g per day
- Trial of lactose-free diet – no benefit

Multidisciplinary aspects of Fiona's management:

- Course of ciprofloxacin to treat small intestine bacterial overgrowth
- Management of bile acid malabsorption with colestevlam 2 tablets TDS and referral to a registered dietitian (see below)
- Annual check of vitamin B12 and CRP levels in addition to serum fat-soluble vitamin levels and trace elements
- Pelvic floor and toileting exercises
- Introduction of gentle exercise as symptoms improve

- Dietetic assessment and advice included:
 - Obtaining a weight, height, BMI and percentage weight loss
 - Analysis of 7-day dietary food diary or diet history (to facilitate the calculation of the patient's dietary fat intake and to assess pattern of eating and dietary adequacy)
 - Review of vitamin and mineral levels (e.g. vitamin A, D, E, B12, folate, zinc, selenium) to identify any potential deficiencies
 - A diet that provided 20% of her energy intake from fat was discussed i.e. 45g of dietary fat per day based on an intake of 2,000 calories per day
 - Supportive literature given and explained, including discussing meal plans, reading food labels and eating out
 - Forceval and Calcichew D3 were commenced subsequently to colestevlam to enable a staged approach.

Fiona's symptoms after 5 visits to the Royal Marsden Gastrointestinal and Nutrition team service

- Bowel frequency 2 times per day
- Bristol Stool Chart type 4–5 stool (i.e. consistent normal type)
- Daily urgency resolved
- Faecal and urinary leakage resolved
- No nocturnal defaecation
- No abdominal pain
- Bloating resolved
- Steatorrhoea resolved
- Able to participate in social activities
- Fatigue improved with reintroduction of gentle exercise
- Financial burden of faecal and urinary incontinence diminished
- Mood improved – “feels much better in herself”.

With thanks to Ann Muls, Macmillan Nurse Consultant in Gastrointestinal Consequences of Cancer Treatment, Royal Marsden Hospital NHS Foundation Trust.

2. Case study of problems in adulthood after childhood cancer treatment

Ellie (not her real name) was diagnosed with acute lymphoblastic leukaemia (ALL) at the age of 6 years.

She had a high blast count and was treated according to the clinical trial protocol UKALLX.

She was treated with daunorubicin (an anthracycline) at 180 mg/m² and received cranial radiotherapy (18 Gy).

Subsequently, she had two bone marrow relapses (disease recurrence) and received further chemotherapy

(including anthracyclines) and total body radiation. This was followed by an allogeneic bone marrow transplant.

At follow up as a young adult Ellie has many treatment-related complex chronic diseases as listed below, involving many specialities that may not be all on one site or provide continuity of care from consultants with full knowledge of cancer-treatment-related diseases. In addition, primary care support is essential.

Part of body affected	Diagnosis	Specialty expertise involvement required
Endocrine system	Endocrine growth disorder Gonadal failure and infertility Diabetes Adult growth hormone disorder syndrome Metabolic syndrome	Endocrinology
Heart	Cardiotoxicity	Cardiology
Bone	Avascular necrosis and osteoporosis	Orthopaedics
Kidney	Nephrotoxicity and hypertension	Nephrology
Eyes	Cataracts	Ophthalmology
Lung	Chronic graft versus host disease causing obliterative bronchiolitis	Respiratory medicine
Psychological	Psychosocial problems	Psychology
Whole body	Potential for second primary cancers, with high risk of brain tumours	Oncology (screening)

Appendix 3: Methodology notes

Methodology notes and data tables for the prevalence of consequences of treatment

Section 1 Methodology notes
 Section 2 Cancer prevalence (Table 11)
 Section 3 Prevalence of consequences of cancer and its treatment (Table 12)

Section 1 Methodology notes

There are two main parts to the document and different methodologies were used for each:

1. Evidence on the prevalence of the main consequences of cancer and its treatment for the more common cancers were sought, and applied to estimates of the size of the population who are living with and after cancer.
2. Given the level of prevalence and unmet need, evidence and opinion on how improvements to patient outcomes could be achieved was sought.

The chief sources of evidence on prevalence were gathered by the University of Dundee and Macmillan Cancer Support from a variety of sources including research articles, publications, conference proceedings, publically available statistics, focus groups, personal communication from people affected by cancer and from experts, plus Macmillan-funded research and evaluation studies. Wherever possible, UK-based studies were used.

If this document had tried to cover all relevant sources and all consequences of all cancer treatments, the result would have been far too long and detailed to be of value to the intended audience. It is therefore not an exhaustive systematic review that follows strict scientific community rules governing such types of review. Furthermore, the heterogeneity of the evidence precluded meta-analysis. Hence, the quality of the evidence has not been formally assessed according to standard criteria¹³⁶ but used broad quality criteria and review by experts to ensure that the information presented in this document is largely representative and unbiased.

Limitations and assumptions

The number of people living with different consequences of cancer and its treatments cannot be directly measured at this time due to limitations in the availability and granularity of data. As such our estimates are indicative only and here we explain key limitations and assumptions used to generate these estimates. As more information becomes available we will refine our figures.

A number of factors have led to difficulties in presenting the consequences of cancer and its treatment prevalence statistics in a coherent way that is relevant to how the care of patients living with and after cancer in England, Wales, Scotland and Northern Ireland is currently organised.

These factors include:

- Consequences of cancer and its treatment are not routinely collected and reported in health records or linked between primary, secondary or community care making it difficult to report the level and extent and the impact on people lives. In particular the lack of routinely available data means that we cannot identify the proportion of people with multiple compared to single consequences.
- Academic articles about consequences of frequently differ in their perspective (such as whether they are from the perspective of the tumour type, the treatment type or the type of consequence of treatment). Therefore it is very difficult to find studies that have looked at similar cohorts of patients at similar time points after similar treatments.
- Definitions/diagnostic criteria for consequences of cancer and its treatments are variable¹³⁷.
- Modern cancer treatment, often involving combinations of treatments, is continually evolving. Therefore the pattern of consequences of will also change over time. Thus it is uncertain whether the results from any research study on consequences can be extrapolated to the current population who are living with and beyond cancer. Some articles deal specifically with novel treatments for cancer and these techniques may never be adopted into routine clinical use, therefore the results have to be treated with particular caution.
- There is a lack of comparison of problems experienced by patients who are living with and beyond cancer with problems experienced by patients without a cancer diagnosis. In a patient who is living with and beyond cancer, it would be unreasonable to attribute every health problem to their cancer or its treatment. However, studies that include control groups (i.e. patients without a diagnosis of cancer) are difficult to find.
- It is possible that studies systematically underestimate the potential risk of consequences of treatment. If survival rates improve as a result of a change in treatment, then there may be an increase in the number of people living with and beyond cancer who have consequences.
- Often, relatively small series of patients are studied in order to obtain estimates of the likelihood of rare events. Most cancer treatment schedules have been calibrated so that only a small proportion of patients might suffer severe consequences and so the estimates of event rates are unlikely to be reliable.
- Data from clinical trials will tend to report consequences that affect those people who have had treatment, but consequences such as pain, fatigue and psychosocial problems will affect people living with and beyond cancer who are not receiving treatment. Data are not yet easily available (from the UK's national repositories of cancer data) that would give the full picture of how many people have each kind of cancer treatment (or no treatment) for each cancer type in the UK each year. This makes it very difficult to assess with any accuracy what the potential impact of the consequences of each kind of treatment (or no treatment) might be on the population.
- Long term follow up of people living with cancer in many studies is limited to 5 years and very few studies follow up beyond 10 years after diagnosis.

There are a number of factors that may have caused under- or overestimation of the prevalence of consequences of cancer and its treatment in this report.

Factors that may cause underestimation:

- The number of people living with and beyond cancer has increased by 3% per year since 2010, which is the latest data for the cancer population estimates.
- Percentage prevalence figures were applied only to certain main cancer types
- Percentage prevalence figures may only relate to one form of treatment e.g. radiotherapy, thus excluding those with consequences after other treatments such as surgery or chemotherapy.
- Issues relating to outcome measures in cancer treatment clinical trials:
 - Patient-reported outcome tools and clinician-rated outcome tools may not ask about all potential consequences.
 - Clinician-rated outcome tools tend to group outcomes into grades of toxicity, and then judge only 'high' severity as representing toxicity, thus potentially ignoring lower-grade toxicity that still might cause significant reduction in quality of life for the patient.

Factors that may cause overestimation:

- Response bias in surveys — those people with health problems being more likely to respond.
- Calculations were based on an assumption that all people with a cancer diagnosis will receive treatment (whether curative or palliative) and that this occurs within a year of diagnosis.
- Calculations were based on an assumption that consequences only affect those from one year or more after diagnosis but evidence beyond 10 years after diagnosis in particular is limited.

Our estimates broadly assume that consequences are uniformly applied to the population living with cancer and have not been refined to take into account different outcomes for different demographic groups, cancer types or treatment types and combinations as this level of detail are not available uniformly in the evidence. We acknowledge that different groups in the population will experience different outcomes. Where we know consequences are only applicable to certain cancer types or treatments and have data which can help us distinguish these groups we have adjusted the estimates accordingly.

Calculations were based on an assumption that consequences experienced at one year (or one to five years) after diagnosis will stay at the same prevalence however long ago the treatment was. There is good evidence that many chronic physical consequences of treatment do not improve over time unless treated. However, some consequences such as fear of recurrence or hot flushes may reduce over time. Where evidence suggests consequences diminish over time we have restricted the population affected accordingly, for example to the one to five years after diagnosis population group.

Where evidence is only available for a subset of the population such as certain localities (region or nation) we assume that the observed prevalence persists across the UK.

Where evidence is only available for certain cancer types we assume these consequences apply to all cancer types only where we have further evidence that consequences are likely to be an issue for people with any cancer type. This is partly because we know more about the potential long-term consequences of certain cancers and treatments than others.

Section 2 Cancer prevalence

Table 11
UK cancer population figures split by time period after cancer diagnosis and cancer type, at the end of 2010 (Excludes non-melanoma skin cancer)

Cancer type	Total UK prevalence in 2010	0–1 year after diagnosis	>1 year after diagnosis*	1–5 years diagnosis*
Breast	569,883	45,892	523,991	143,834
Colorectal	243,516	29,423	214,093	73,109
Lung	64,476	17,366	47,110	15,041
Prostate	255,432	33,373	222,059	106,161
Other	945,417	95,661	849,756	228,964
Total	2,078,723	221,714	1,857,009	567,109

Source: ref.138

Some figures do not add exactly due to rounding.

*The figures were used as the basis for consequences of cancer and its treatment calculations. Therefore people with side effects during treatment or within 6 months of completing treatment are excluded in the consequences of cancer and its treatment prevalence calculations, as these side effects would normally (in the majority of people) be expected to resolve by 1 year since diagnosis. Any side effects lasting more than 1 year from diagnosis are assumed to be chronic, i.e. long lasting, although it is recognised that some will resolve over a longer period of time. However, the evidence does not support significant resolution over a longer timescale for some of the most debilitating consequences of cancer and its treatment, such as bowel, urinary and sexual problems and serious mental health issues.

The number of people living with 'Other' cancers has been further disaggregated to allow estimation for consequences which affect only certain cancer types. For example we have estimated the total number of people living with other pelvic cancers using the best currently available data of known 20-year prevalence in England and 1-year prevalence for the UK for 22 cancer types at the end of 2006 and applying these figures to the UK total for 'Other' cancers. Estimated cancer population figures are given in the table below. Further work to refine these estimates is underway.

Reference: 138 above; National Cancer Intelligence Network. One, Five and Ten-Year Cancer Prevalence, UK, 2006

Table 12
Prevalence of consequences of cancer and its treatment – sources of evidence
 Note: this list does not include all consequences of every cancer treatment

Sources used for the calculation	Assumptions/limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Chronic changes in lower gastrointestinal function Total = 90,000			
<p>Source 1: Glaser et al. 2013¹⁸. Do you have any difficulty in controlling your bowels?</p> <p>19% of colorectal patients >1 year after diagnosis = ~41,000.</p> <p>13% of prostate patients >1 year after diagnosis = ~29,000.</p>	<p>May exclude people who have other bowel problems such as urgency, constipation, flatulence, bleeding etc. Assume that problems prevalent at 1–5 years after diagnosis remain at similar prevalence after this time⁵⁵.</p>	<p>In colorectal cancer 15–66% have chronic gastrointestinal problems after various types of treatment. In urological cancer 30% have chronic gastrointestinal problems after RT⁵⁹.</p> <p>58.7% of women and 45.1% of men after pelvic RT reported bowel urgency 1–11 years after RT⁵⁵.</p>	<p>Glaser et al. 2013¹⁸.</p>
<p>Source 2: Andreyev et al. 2012⁵⁹. Chronic gastrointestinal problems affecting quality of life after curative treatment, 16% of 120,000 cervix + uterine patients >1 year after diagnosis = ~19,000.</p> <p>2.4% of 91,700 bladder patients living >1 year after diagnosis = ~2,000.</p>	<p>Estimate 40%¹⁴⁰ of cervical and uterine patients have RT of which estimate that 40%⁵⁹ of those will have gastrointestinal problems = 16%.</p> <p>Exclude ovarian as RT rarely used.</p> <p>Estimate 8%¹⁴⁰ of bladder patients have RT, of which estimate that 30%⁵⁹ have gastrointestinal problems = 2.4%.</p> <p>Excludes non-pelvic cancers although it is known that gastrointestinal problems occur in other cancers, e.g. chronic graft versus host disease in people treated with bone marrow transplants.</p>		

Sources used for the calculation	Assumptions/limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Chronic changes in upper gastrointestinal function Total = up to 50,000			
<p>Source: Andreyev et al. 2012⁵⁹. Up to 50% of 100,000 head and neck, oesophago-gastric, liver, stomach and pancreatic cancer patients living >1 year after diagnosis = ~50,000</p>	<p>Excludes other cancers although it is known that upper gastrointestinal problems occur in other cancers, e.g. chronic graft versus host disease in people treated with bone marrow transplants.</p>	<p>The long-term side effects of treatment for head and neck cancer are often severe, with the majority of people being left with impairment in vital functions such as eating and drinking¹¹³.</p>	<p>Cousins et al. 2013¹¹³. Taylor and Morgan 2011¹⁷⁰</p>
Chronic dental/oral problems Total could not be estimated			
	<p>Overall prevalence of chronic problems could not be estimated due to lack of studies, but are common in the first year after treatment, which may lead to permanent tooth loss.</p>	<p>Chronic periodontitis may affect 70% of people who receive RT to the jaw¹⁴¹. Dental caries affects 28% of all cancer patients¹⁴².</p>	<p>Atri et al. 2007¹⁴³.</p>
Chronic changes to urinary function Total = 150,000			
<p>Source 1: Glaser et al. 2013¹⁸. Percentage of respondents reporting urinary leakage:</p> <p>23.5% of colorectal patients >1 year after diagnosis = ~50,000</p> <p>38.5% of prostate patients >1 year after diagnosis = ~85,000.</p>	<p>May exclude people who have other urinary problems such as urgency, bleeding etc.</p> <p>Assume that problems prevalent at 1–5 years after diagnosis remain at similar prevalence after this time⁵⁵.</p>	<p>For prostate cancer, 37% of patients will receive RT during the first 6 months after diagnosis. Low – and high-grade ‘adverse events’ are reported to occur in 20–43% and 5–13%, respectively, with a median follow up of ~60 months¹⁴⁰.</p> <p>49.3% of women and 46.2% of men after pelvic RT reported urine urgency 1–11 years after RT⁵⁵.</p>	<p>Glaser et al. 2013¹⁸.</p>

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Chronic changes to urinary function Total = 150,000 (continued)			
<p>Source 2: Elliott and Malaeb 2011¹⁴⁰</p> <p>After RT, grade 2 and 3 'late adverse events' affect 24–44% bladder patients, 8–42% cervical patients and 11–16% uterine patients (the latter an underestimate due to lack of data). Based on estimates for the proportion of patients receiving RT (bladder 8%, cervical 53%, uterine 23%), this results in upper estimate totals of bladder ~3,000, cervical ~11,000 and uterine ~3,000 people affected = 17,000, rounded down to 15,000.</p>	<p>May exclude urinary effects of people treated with surgery ± chemotherapy. For example, people having bladder surgery (e.g. creation of a neobladder) are likely to have urinary side effects, but are not included here.</p> <p>Evidence suggests that after RT, urinary effects increase over time.</p> <p>The percentage of patients receiving RT is likely to have increased from 2006.</p> <p>Assume that the percentage receiving RT (USA data) is the same in the UK.</p> <p>Other gynaecological cancers and testicular cancer are not included.</p>	<p>Urinary incontinence, with an occurrence rate of more than 50%, represents the most common side effect after surgery and RT for Stage I endometrial carcinoma. Depending on the type of RT, a stress incontinence rate of 24.4% and an urge incontinence rate of 29.2% is possible¹⁴⁴.</p>	

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Sexual difficulties Total = 350,000			
<p>Source: Department of Health PROMS survey 2012⁵⁴. The percentage reporting sexual difficulties "quite a bit" or "very much": 27% of the 70% (= 18.9%) who said the question "Have you had any difficulty concerning sexual matters?" applied to them of all cancer patients living >1 year after diagnosis = ~350,000.</p>	<p>Extrapolating the Department of Health PROMs results from non-Hodgkin lymphoma, colorectal, prostate and breast cancer to all people living >1 year after a cancer diagnosis of any type. Assume that problems prevalent at 1–5 years after diagnosis remain at similar prevalence after this time.</p>	<p>For prostate cancer, post-operative incidence of ED over varying periods of time ranged from 24–82%. Post-EBRT 60–70% ED. Post-brachytherapy 5–51% ED. For colorectal cancer, in a recent comparison, 86% of survivors of rectal tumours had sexual dysfunction compared with 39% of colon cancer survivors. For breast and gynaecological cancers, approximately one half of women who have been treated for breast and gynaecological cancers experience long-term sexual dysfunction¹⁴⁵.</p> <p>23.8% of women and 53.3% of men after pelvic RT reported sexual relationships affected 1–11 years after RT⁵⁵.</p>	<p>Glaser et al. 2013¹⁸.</p>

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Menopausal and hormonal symptoms Total = at least 80,000			
Source 1 (women): Carpenter et al. 1998¹⁴⁶. 65% of postmenopausal women report hot flushes after breast cancer treatment. We assume that 50% of the 144,000 1–5-year post-diagnosis breast cancer population are under 65 = ~46,000, rounded down to 45,000 .	Estimate for women based on assumption (to be conservative) that menopausal symptoms will only affect under 65 breast cancer patients and only affect this group 1–5 years post-diagnosis. Excludes other female cancers, e.g. ovarian.	The prevalence of symptoms among the postmenopausal women was as follows: hot flushes, 65%; night sweats, 44%; vaginal dryness, 48%; dyspareunia, 26%; difficulty sleeping, 44%; and feeling depressed, 44% ¹⁴⁷ .	Carpenter et al. 1998 ¹⁴⁶ .
Source 2 (men): several sources used. Assume 50% of men diagnosed with prostate cancer living 1–5 years after diagnosis are receiving androgen deprivation therapy and 70% of these experience hormonal symptoms including hot flushes = 35% of 106,000 = ~37,000, rounded down to = ~35,000 .	Estimate for men based on conservative assumption that symptoms only affect men 1–5 years post-diagnosis. 70% experiencing hot flushes is a consensus view from the literature and clinical experts.	Retrospective and cross-sectional studies have shown that the incidence of hot flushes in men subjected to castration is about 75%. Some patients treated for prostate cancer report that hot flushes are the most distressing side effect of treatment ¹⁴⁸ .	Spetz et al. 2004 ¹⁴⁸ .
Loss of fertility Total = could not be estimated			
	Overall prevalence of chronic problems could not be estimated due to lack of studies.	Around 11,000 patients in the age group 15–40 years are diagnosed with cancer each year in the UK ⁸⁶ . The probability of parenting a first child is reduced by approx 50% after treatment ⁸⁷ .	Several references in Adams et al. 2013 ¹⁴⁹ .

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Stoma Total = 14,000			
Source: Glaser et al. 2013¹⁸. The percentage reporting having a stoma 1–5 years after colorectal cancer diagnosis = 19.2% of 73,000 = ~14,000 .	Excludes stoma as a complication of other surgery/RT for non-colorectal cancers. Excludes permanent stoma more than 5 years after diagnosis.	57% of rectal cancer patients having a major resection had a stoma 12 months later ¹⁵⁰ . National estimates for people living with stoma in total (due to any cause) = 100,000 ¹⁵¹ .	Overall evidence appears to be contradictory — more research needed ¹⁵² .
Cancer-related lymphoedema Total = 21,000 to 63,000			
Source: 2013 National Cancer Action Team report (not yet published but data confirmed by British Lymphology Society). Recent prevalence studies in Wandsworth and Derby City found a total prevalence of lymphoedema of between 1.33 and 3.99 per 1,000 population, respectively. Cancer-related lymphoedema accounts for 25% of these figures. For UK population of 63.2 million, cancer-related lymphoedema prevalence therefore ranges from 25% of 1.33 x 63,200 = ~21,000 to 25% of 3.99 x 63,200 = ~63,000	Lymphoedema is a permanent condition and cannot be cured.	In a breast cancer study, 8% of the women had diagnosed lymphoedema and 37% had arm symptoms without diagnosed lymphoedema ¹⁵³ . In gynaecological cancers, 10% of participants reported being diagnosed with lymphoedema, and a further 15% reported undiagnosed “symptomatic” lower limb swelling ¹⁵⁴ .	Macmillan Cancer Support ¹⁵⁵ .

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Chronic peripheral neuropathy Total = could not be estimated			
	Overall prevalence of chronic problems could not be estimated due to lack of studies on long-lasting problems. Is common during certain chemotherapy treatments but usually resolves.	Radiation induced peripheral neuropathy ¹⁵⁶ .	Weickhardt et al. 2011 ¹⁵⁷ .
Chronic fatigue Total = 350,000			
Source: Prue et al. 2006¹⁵⁸. Substantial or severe fatigue after anti-cancer therapy affects 19–38%. 19% of all cancer patients living >1 year after diagnosis = ~350,000.	Assumed to extrapolate to all cancer types. The lower figure of 19% was taken to allow for fatigue that does not persist.	In the Department of Health PROMS survey 2012, 14% strongly agreed and 29% agreed with the statement “I always feel tired” (in the past month), i.e. total over 40% of people reporting always feeling tired (1–5 years after diagnosis) ⁵⁴ .	Prue et al. 2006 ¹⁵⁸ .
Endocrine system disorders Total = could not be estimated			
	Overall prevalence of specific problems could not be estimated, but the 33,000 people living with and beyond child and young people’s cancer treatment are at risk ¹⁵⁹ as are thyroid cancer patients.	Head and neck cancer: the incidence of hypothyroidism was much higher (23–53%) than would be expected in a non-irradiated cohort ¹⁰⁰ .	References in Oeffinger et al. 2007 ⁷³ .

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Chronic moderate to severe pain Total = 200,000			
Source: van den Beuken 2007¹⁰⁸. 33% prevalence of pain in patients after curative treatment of which one third assumed to be in moderate/severe pain = 11% of all cancer patients living >1 year after diagnosis = ~200,000.	Excludes the higher percentage prevalence of pain occurring in people undergoing treatment, in rehabilitation or with metastatic disease.	“No single survey identified a prevalence of any type of pain below 14% ¹⁶⁰ . 13% had moderate pain or discomfort, 5% had severe pain or discomfort and 1% had extreme pain or discomfort (1–5 years after diagnosis with non-Hodgkin lymphoma, colorectal, prostate or breast cancer) ⁵⁴ . Two-thirds of breast cancer patients reported some degree of pain (1–5 years after diagnosis) ¹⁸ .	Green et al. 2010 ¹⁶¹ .
Mental health problems Total = 240,000			
Source: Department of Health PROMS 2012⁵⁴ In answer to a question about their health today, answering that they were “moderately, severely or extremely” anxious or depressed (10% were moderately anxious or depressed, 2% were severely anxious or depressed, and 1% were extremely anxious or depressed = 13%). 13% of all cancer patients living >1 year after diagnosis = ~240,000.	Extrapolating the Department of Health PROMS results from non-Hodgkin lymphoma, colorectal, prostate and breast cancer to all people living >1 year after a cancer diagnosis of any type. Assume that problems prevalent at 1–5 years after diagnosis remain at similar prevalence after this time.	The prevalence of depression was 11.6% (10.2% in healthy controls). The prevalence of anxiety was 17.9% (13.9% in healthy controls) ¹⁶² . More than 5 years after diagnosis with cancer, a substantial minority (around 20–30%) consistently reported long-term psychological problems including depression and anxiety. Symptoms of post-traumatic stress disorder have been reported among 15–18% of female survivors of breast cancer. Of lung cancer survivors, 31% were clinically depressed ¹⁶ .	“How health-related quality-of-life changes with time in relation to anxiety and depression is unclear. [...] results suggest that emotional wellbeing is mixed in long-term cancer survivors, which might be affected by cancer type and concomitant physical complications.” ¹⁶² .

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Fear of recurrence Total = 240,000 Fear of dying Total = 125,000			
<p>Source: Department of Health PROMS survey 2012⁵⁴. Fear of recurrence: 42.5% of all cancer patients living 1–5 years after diagnosis = ~240,000.</p> <p>Fear of dying: 22% of all cancer patients 1–5 years after diagnosis = ~125,000.</p>	<p>Extrapolating the Department of Health PROMs results from non-Hodgkin lymphoma, colorectal, prostate and breast cancer patient at 5 years after diagnosis (to be conservative), to all people living 1–5 years after a cancer diagnosis.</p> <p>Owing to the decline in fear of recurrence and fear of dying by 5 years after diagnosis in the Department of Health PROMS survey, we are assuming that the percentage applies to the 1–5 year population only, although we do know that fear of recurrence and fear of dying will persist after 5 years but we do not have data to verify if the prevalence is maintained beyond 5 years.</p>	<p>The majority of cancer survivors reported low to moderate levels of fear of cancer recurrence, and considered it to be one of the top five greatest concerns and the most frequently endorsed needs. More precisely, across different cancer sites, 39–97% of cancer survivors reported some degree of fear of recurrence, 22–87% reported moderate to high degree and 0–15% reported high levels³⁷.</p>	<p>Simard et al. 2013¹³⁷.</p>
Cognitive function Total = could not be estimated			
	<p>Overall prevalence of chronic problems could not be estimated due to lack of data that could be extrapolated.</p>	<p>The reported incidence of chemotherapy-related cognitive dysfunction is in the range of 15%–70% and for radiotherapy is in the range of 0%–86%¹⁶³.</p>	<p>Dietrich et al. 2008¹⁶³.</p>

Sources used for the calculation	Assumptions/ limitations	Other sources for comparison	Evidence that the problem affects quality of life (examples)
Body image issues Total = could not be estimated			
	<p>Overall prevalence of chronic problems could not be estimated due to lack of data that could be extrapolated.</p>	<p>69% of patients said they had no difficulty concerning their appearance or body image; 19% had a little difficulty, 7% said quite a bit, 5% said very much, 8% said this did not apply to them⁵⁴.</p>	<p>Falk-Dhal et al. 2010¹⁶⁴.</p>
Difficulties with education, employment and finances Total = could not be estimated			
	<p>37% of people who return to work after cancer treatment say that they experience some kind of discrimination from their employer or colleagues.¹⁷² Could not estimate total prevalence as it is not known how long the work difficulties last for – the 37% applies to people fairly recently diagnosed/ treated.</p>		<p>Macmillan Cancer Support 2010⁸⁹.</p>

EBRT, External Beam Radiotherapy ; ED, Erectile Dysfunction; RT, radiotherapy.

Appendix 4: Resources for people affected by cancer, professionals and commissioners

Important note: Resources listed here are not all tested and endorsed by Macmillan Cancer Support.

This list is by no means exhaustive, and comments about what resources are included, and suggestions for additions are welcomed. Please email survivorship@macmillan.org.uk

The full range of Macmillan Cancer Support booklets & resources included below are available to order free of charge at www.be.macmillan.org.uk and as PDF downloads.

General resources on Survivorship living with and beyond cancer

What To Do When Treatment Ends: Ten Top Tips Macmillan booklet* MAC13615
www.be.macmillan.org.uk/be/p-20338-what-to-do-after-cancer-treatment-ends-10-top-tips.aspx

Life After Cancer Macmillan booklet* MAC11661
www.be.macmillan.org.uk/be/p-18826-life-after-cancer-treatment.aspx

Assessment And Care Planning For People With Cancer Macmillan booklet* MAC12957
www.be.macmillan.org.uk/be/p-19300-assessment-and-care-planning-for-people-with-cancer.aspx

Courses, events and meetings for people after treatment – provision varies in different parts of the UK.

Examples include:

HOPE

Health and Well Being Clinics

Moving Forward

Cancer Transitions

Mi Wellbeing (online facilitated course) www.learnzone.org.uk/courses/course.php?id=74

Sources of information about courses and events include:

Macmillan Support Line 080 8808 0000

Macmillan Information Centres www.macmillan.org.uk/HowWeCanHelp/LocalInformationCentres/

Local Support Groups

www.macmillan.org.uk/HowWeCanHelp/CancerSupportGroups/CancerSupportGroups.aspx

Survivorship support in Northern Ireland

www.survivorship.cancerni.net/

Moving Forward (Breast Cancer)

www.breastcancercare.org.uk/breast-cancer-services/information-and-support-sessions/improving-wellbeing/moving-forward-programme

Wide selection of information and resources on physical activity including resources for commissioners

www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Physicalactivity/Physicalactivity.aspx

Wide selection of information and resources on financial issues

www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Financialissues/Financialissues.aspx

Wide selection of information resources on work and cancer

www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Workandcancer/Workandcancer.aspx

Macmillan online course for professionals on Vocational Rehabilitation.

www.learnzone.org.uk/courses/course.php?id=102

Macmillan online course for public and professionals on Working With Cancer.

www.learnzone.org.uk/courses/course.php?id=29

Living With And Beyond Cancer: Taking Action To Improve Outcomes. Department of Health 2013.

www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf

After Cancer Treatment: Guide for professionals. Macmillan August 2013

www.ncsi.org.uk

Macmillan online course for professionals on Survivorship

www.learnzone.org.uk/courses/course.php?id=96

Holistic Needs Assessment For People With Cancer. A Guide For Healthcare Professionals. National Cancer Action Team 2010.

www.ncsi.org.uk/wp-content/uploads/Holistic-Needs-Assessment-practical-guide.pdf

Holistic Needs Assessment And Care Planning. A Practical Guide. Macmillan 2012

www.ncsi.org.uk/wp-content/uploads/HNA-and-CP-Sharing-Good-Practice.pdf

Treatment Summary – A Tool To Improve Communication Between Cancer Services And Primary Care. Macmillan 2011

www.ncsi.org.uk/wp-content/uploads/Treatment-Summary-Sharing-Good-Practice.pdf

Treatment Summary User Guide. Macmillan 2012

www.ncsi.org.uk/wp-content/uploads/NCSI-treatment-summary-2.pdf

Evaluation Of Macmillan's Cancer Care Review Template. Macmillan

www.ncsi.org.uk/wp-content/uploads/EvaluationofMacmillansCancerCareReviewPDF.pdf

Cancer Care Review – A Patient Who Has Completed Primary Treatment for Cancer. InnovAiT: The RCGP Journal for Associates in Training March 2011 4: 177-178. C. Campion-Smith
InnovAiT March 2011 vol. 4 no. 3 177-178 (NB subscription required)

Evaluation Of Health And Well Being Clinics. Office for Public Management & Macmillan 2011
www.ncsi.org.uk/wp-content/uploads/HWC-Final-report-.pdf

From Concept To Innovation. NHS Improvement 2012 (report on Stratified Pathways of Care in adult cancer)
www.improvement.nhs.uk/documents/Concept_to_Innovation.pdf

Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A ‘how to guide’. NHS Improvement 2013.
www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf

Children And Young People Living With And Beyond Cancer. Designing And Implementing Pathways To Benefit Patient Aftercare: Continuing To Build The Evidence. NHS Improvement 2011
www.ncsi.org.uk/wp-content/uploads/CYP-October-Publication.pdf

NHS Evidence QIPP Quality And Productivity Case Study. Children And Young People Cancer Survivorship Initiative: Improving Quality And The Patient Experience. NHS Improvement 2012
<https://www.evidence.nhs.uk/search?q=children%20and%20young%20people%20cancer&om=%5B%7B%22srn%22%3A%5B%22%20qipp%20%22%5D%7D%5D>

Teenage And Young Adult Aftercare Pathway NHS Improvement 2012
www.improvement.nhs.uk/cancer/survivorship/pathway/

The Cancer Pathway And The Role Of Primary Care – In Association With The Department Of Health. BMJ Learning Module (NB subscription required)
www.learning.bmj.com/learning/module-intro/cancer-pathway-primary-cae-.html?locale=en_GB&moduleId=10043291

General resources on consequences of cancer and its treatment

Long Term Follow Up Of Survivors Of Childhood Cancer. A National Clinical Guideline SIGN 132. Scottish Intercollegiate Guidelines Network 2013.

This guideline covers: subsequent primary cancers, fertility issues, cardiac effects, bone health, metabolic syndrome, cognitive and psychosocial outcomes, growth problems, obesity, dental and facial problems and thyroid dysfunction.

www.sign.ac.uk/pdf/sign132.pdf
www.bmj.com/content/346/bmj.f1190.pdf%2Bhtml

Competences: 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 Cancer. Royal College of Nursing 2011
www.rcn.org.uk/___data/assets/pdf_file/0005/408254/004172.pdf

A similar competence document for nurses working with adults with consequences of cancer and its treatment is under development by Macmillan CCaT.
Please email survivorship@macmillan.org.uk for information

Module 5: Awareness of late effects of cancer and its treatment. In ‘Improving The Quality Of Cancer Care In Primary Care’. 2nd edition. Macmillan Cancer Support 2012.
www.macmillan.org.uk/Documents/AboutUs/Health_professionals/RevalidationToolkit.pdf

Macmillan online course for professionals on Late Effects.
www.learnzone.org.uk/courses/course.php?id=98

Macmillan online course for professionals on Nutrition for survivors beyond cancer.
www.learnzone.org.uk/courses/course.php?id=92

Gastrointestinal problems

Pelvic Radiotherapy In Men/Women – Managing Side Effects During Treatment. Macmillan booklets* MAC13943 (men) MAC13944 (women)
www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC13943Pelvicradiomen-E1.pdf (men)

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC13944Pelvicradiowomen-E1.pdf (women)

Managing The Late Effects Of Pelvic Radiotherapy. Macmillan booklets* MAC13825 (men) and MAC13826 (women)
www.be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC13825MalePelvicRT-E1.pdf

<http://be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC13826FemalepelvicRT-E1.pdf>

Managing The Late Effects Of Bowel Cancer Treatment. Macmillan booklet* MAC 12162
www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12162Managingthelateeffectsofbowelcancertreatment-E2.pdf

Pelvic Radiation Disease Association (registered charity) www.prda.org.uk

Practice Guidance On The Management Of Acute And Chronic Gastrointestinal Problems Arising As A Result Of Treatment For Cancer. British Society of Gastroenterology Guidance 2012
Article: www.gut.bmj.com/content/61/2/179.full
Podcast: www.gut.bmj.com/content/61/2/179/suppl/DC1

Royal Marsden Guide (Algorithm) To Managing Pelvic Radiation Disease (PRD). (under peer review).
Previous draft (version 7) can be obtained at this link.
www.ncsi.org.uk/wp-content/uploads/RMH-Bowel-Algorithm-v7-2011.pdf

British Society of Gastroenterology (BSG) Commissioning Guidance and NCSI/BSG Resource Pack
www.bsg.org.uk/clinical/commissioning-report/chronic-gi-morbidity-after-cancer-treatment.html
www.ncsi.org.uk/wp-content/uploads/GI-effects-cancer-tment-resource-pack-BSG-leads-final-24Oct12.pdf

Simple Guide To Managing Chronic Gastrointestinal Consequences Of Cancer Treatment.

(forthcoming publication by Macmillan)

Please email survivorship@macmillan.org.uk for information**NICE guidance on Prostate Cancer 2008 Section 1.4 – Adverse effects of treatment**www.nice.org.uk/guidance/CG58/NICEGuidance**NICE guidance on Colorectal cancer 2011 Section 1.4.2 – Information on bowel function**<http://guidance.nice.org.uk/CG131>**NICE guidance on faecal incontinence 2007** (NB not cancer-specific)www.nice.org.uk/nicemedia/live/11012/30548/30548.pdf**Rehabilitation Pathway For Continence. National Cancer Action Team 2009**www.ncat.nhs.uk/sites/default/files/NCAT_Rehab_SyS_Continence.pdf**Urinary problems**

Macmillan booklets on Pelvic Radiotherapy & Bowel Cancer late effects

(see Gastrointestinal resources above)

The Radar National Key Scheme (NKS) offers disabled people independent access to locked public toilets

Key £4, Guide £13.99, App £4.99

www.radar-shop.org.uk/Detail.aspx?id=0**'Can't Wait' toilet card from Bladder and Bowel Foundation** (£5)www.bladderandbowelfoundation.org/resources/toilet-card.asp**Rehabilitation Pathway For Continence. National Cancer Action Team 2009**www.ncat.nhs.uk/sites/default/files/NCAT_Rehab_SyS_Continence.pdf**Guide To Managing Chronic Male Lower Urinary Tract Symptoms After Cancer Treatment**

(forthcoming publication by Macmillan)

Please email survivorship@macmillan.org.uk for information**Guidelines on Urinary Incontinence.**

European Association of Urology 2010 (NB not cancer-specific)

www.uroweb.org/gls/pdf/Urinary%20Incontinence%202010.pdf**NICE Guidelines on management of urinary incontinence in women. NICE 2006**

(NB not cancer-specific)

www.nice.org.uk/CG40**Sexual difficulties**

Sexuality And Cancer Macmillan booklet* MAC11644www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC11644SexualityandcancerE72011.pdf**Macmillan booklets on Pelvic Radiotherapy & Bowel Cancer late effects**

(see Gastrointestinal resources above)

Macmillan online course for professionals on Sexual Relationships and Cancer.<http://learnzone.org.uk/courses/course.php?id=68>**Guides To Managing Erectile Dysfunction In Prostate Cancer**

(forthcoming publications from Prostate Cancer UK/Macmillan)

Please email survivorship@macmillan.org.uk for information**Guidelines On The Management Of Erectile Dysfunction. British Society for Sexual Medicine 2007/2009.** (NB not cancer-specific)www.bssm.org.uk/downloads/BSSM_ED_Management_Guidelines_2009.pdf**International Guidelines On Vaginal Dilation After Pelvic Radiotherapy. International Clinical Guideline Group, chaired by Dr Tracie Miles, President, National Forum of Gynaecological Oncology Nurses 2012**www.ncsi.org.uk/wp-content/uploads/Inter-Best-Practice-Guide-Vaginal-Dilators-July-2012.pdf**Fertility**

Cancer Treatment and Fertility – Information for Women. Macmillan booklet * MAC 12156www.be.macmillan.org.uk/be/p-691-cancer-treatment-and-fertility-information-for-women.aspx**Cancer Treatment and Fertility – Information for Men. Macmillan booklet * MAC 12155**www.be.macmillan.org.uk/be/p-690-cancer-treatment-and-fertility-information-for-men.aspx**The Effects Of Cancer Treatment On Reproductive Functions. Guidance On Management. Royal College of Physicians, The Royal College of Radiologists, Royal College of Obstetricians and Gynaecologists. Report of a Working Party 2007**www.rcplondon.ac.uk/sites/default/files/documents/effects-of-cancer-treatment-reproductive-functions.pdf**Fertility. Assessment And Treatment For People With Fertility Problems. CG156 NICE 2013**www.nice.org.uk/CG156**Lymphoedema**

Understanding Lymphoedema Macmillan booklet * MAC11651www.be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC11651Lymphoedema-E13.pdf**Top Tips for the Self-Management of Lymphoedema – A Guide. The Lymphoedema Project for Scotland 2012.**http://www.alliance-scotland.org.uk/download/library/lib_50b72eccba4b/**Lymphoedema Support Network** (registered charity)www.lymphoedema.org/**Lymphoedema alert bracelets**www.lymphoedema.org/Menu5/Index.asp**Chronic Oedema and Lymphoedema.**

In association with the Lymphoedema Support Network. BMJ Learning Module (£)

www.learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385**Best Practice guidance documents by the International Lymphoedema Framework**<http://www.lympho.org/resources.php>

Reducing The Risk Of Upper Limb Lymphoedema. Guidance For Nurses In Acute And Community Settings. Royal College of Nursing 2011

http://www.rcn.org.uk/__data/assets/pdf_file/0003/403716/004138.pdf

Diary of education courses for professionals

www.thebls.com/education/index.php

Stoma care

Colostomy Association (registered charity)

www.colostomyassociation.org.uk/index.php

IA – The Ileostomy and Internal Pouch Support Group (registered charity)

www.iasupport.org/

Urostomy Association (registered charity)

www.urostomyassociation.org.uk/

Clinical Nurse Specialists – Stoma Care. Royal College of Nursing 2009

www.rcn.org.uk/__data/assets/pdf_file/0010/272854/003520.pdf

Body image changes

Body Image and Cancer. Macmillan booklet* MAC 14192

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC14192Bodyimage-E2.pdf

Look Good, Feel Better. (registered charity)

www.lookgoodfeelbetter.co.uk/site/index.cfm

Weight Management After Cancer Treatment. Macmillan booklet* MAC12167

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12167Weightmanagement20120801.pdf

Macmillan online course for professionals on Body Image and Cancer.

www.learnzone.org.uk/courses/course.php?id=37

Head, neck, mouth changes

Managing The Late Effects of Head And Neck Cancer Treatment.

Macmillan booklet – due for publication in late 2013

Please email survivorship@macmillan.org.uk for information

A number of local support groups and charities support people living with changes to speech, swallowing etc after head and neck cancer. Local Support Groups directory

www.macmillan.org.uk/HowWeCanHelp/CancerSupportGroups/CancerSupportGroups.aspx

Improving Outcomes In Head And Neck Cancers – The Manual. NICE 2004.

(Section on Aftercare And Rehabilitation)

www.nice.org.uk/nicemedia/live/10897/28851/28851.pdf

Macmillan online course for public and professionals on Laryngectomy.

www.learnzone.org.uk/courses/course.php?id=47

Breast cancer treatment consequences

Managing The Late Effects of Breast Cancer Treatment. Macmillan booklet* MAC12161

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12161Lateeffectsbreast-E2.pdf

Management Of Adverse Effects Following Breast Radiotherapy. Royal College of Radiologists 1995

www.rcr.ac.uk/docs/oncology/pdf/maher.pdf

Psychosocial problems

Your Feelings After Cancer Treatment. Macmillan Booklet* MAC12517

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12517Yourfeelingsaftercancertreatment-E2.pdf

Fear of recurrence (working title)

Macmillan booklet – publication due in 2013

Fatigue

Coping With Fatigue. Macmillan booklet* MAC11664

www.be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC11664Copingwithfatigue-E5.pdf

Pain

Controlling Cancer Pain. Macmillan booklet* MAC 11670

<http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC11670Controllingcancerpain-E9.pdf>

Cancer Pain Management. British Pain Society 2010

www.britishpainsociety.org/book_cancer_pain.pdf

Bone

Bone Health. Macmillan booklet* MAC 12169

<http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12169Bonehealth-E1.pdf>

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