

National Cancer Survivorship Initiative **Vision**



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Preface

by Professor Ann Keen, Parliamentary Under Secretary of State for Health

As a nurse, I am very aware that the significant investment and improvements the Government has made to the NHS over the past 10 years mean that cancer services are improving and cancer mortality is falling.

The dramatic improvements in survival rates mean that we need to challenge widespread beliefs about cancer. Cancer is increasingly an illness which might be cured or which might have the characteristics of a long term or chronic condition that people can live with for many years.

It is therefore very important that the increasing numbers of people living with and beyond cancer, their carers and their families have the support and services they need to resume as normal a life as they can following cancer treatment.

Through the National Cancer Survivorship Initiative we are committed to taking steps to ensure that all cancer survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Our vision is that people living with and beyond cancer have a personalised

assessment, information and care plan and are empowered to manage their condition, based on their needs and preferences. Our vision is for people to be informed and prepared for the long-term effects of living with and beyond cancer, and that health and care services are responsive to individual needs and ensure access to specialist care when needed.

Following cancer treatment some people will be left with physical or psychological problems which affect their health and well-being. There are some very practical actions we can take to make a difference to people following cancer treatment. Hair loss following cancer treatment can cause huge distress and anxiety – just at a time when people are recovering from their treatment and wanting to get back to as normal a life as possible. That is why the Department of Health is working with Trevor Sorbie's charity My New Hair to support cancer patients dealing with hair loss following cancer treatment. This is just one of the many things we can do to make a huge difference to individual patients.

I am delighted that there are now 38 test communities around the country piloting improvements for cancer survivors. We

must learn from these new service models and demonstrate that they offer better care for patients and best use of NHS resources. I congratulate all who have worked to make such a difference to this vital work.

A handwritten signature in black ink, appearing to read 'Ann Keen', with a stylized, cursive script.

**Ann Keen, Parliamentary Under Secretary
of State for Health**

Foreword

by Ciarán Devane and Mike Richards

Today over 1.6 million people living in England have had a diagnosis of cancer. An ageing population, the resulting increase in cancer incidence and improved survival means cancer prevalence will continue to grow at over 3% a year. By 2030 there are likely to be over 3 million people in England living with or beyond their cancer. Our first challenge is to understand the needs of those living with cancer today and to develop models of care which meet their needs. We need to design services which will accommodate the increasing numbers of cancer survivors in the future and we must do this in a way which ensures the sustainability of NHS services and increases the productivity of NHS resources. We believe this document identifies a vision which will achieve these aims.

For a proportion of the 1.6 million people living with and beyond cancer, we are neither identifying their needs, nor meeting them. We now have a range of evidence which suggests that current follow up arrangements do not address the full range of physical, psychological, social, spiritual, financial and information needs that cancer survivors may have following their treatment.

Our vision is that cancer survivors are supported to live as healthy and active

a life as possible for as long as possible. For some, cancer can be an 'acute illness' which can be cured by initial treatment. Being 'cured' however does not mean one is necessarily well. Chronic consequences of treatment may need to be managed over the following months and years, consequences which often have a devastating impact on daily life. For those with advanced disease, we want to support them to have as active and independent a life as possible. In short, we want to help these people live with their cancer.

Achieving the vision will require a personalised assessment and care plan for everyone and information and support to enable people to get back as normal a life as possible after cancer treatment. We will need to empower people to manage their condition based on their needs and preferences. It will require services which are responsive to individual needs and which ensure access to specialist care when needed. It will require coordination across primary and secondary care and across health and social care. Achieving the vision will also require the routine use of patient reported outcome measures to monitor problems for cancer survivors as defined by them.

In 2010, the National Cancer Survivorship Initiative (NCSI) will move from a development phase to building the evidence through both research and piloting. The focus of the initiative in 2010 will be to engage service users, clinicians and commissioners in defining the new models of aftercare for people affected by cancer and to establish the longer term survivorship research programme.

These new models will improve quality for cancer survivors and they will represent best use of NHS resources. Early evidence, which we will explore further in 2010 indicates that where care is coordinated and survivors are supported to self-manage, unplanned and emergency admissions can be reduced. Further, where people are well supported the number who can return to work is increased, with all that means for their self-esteem, finances and contribution to society.

The unmet needs of cancer survivors, the rising numbers, and the duty to use our resources efficiently all mean that through 2010 we must develop those critical interventions which will improve quality for patients. In December 2009, the Department of Health published a five year plan for the NHS to meet the challenge of delivering high quality health care in a tough financial environment.¹ The report describes the need to develop high impact changes in improved self care, care planning and making the best use of technology. These themes are picked up

in the shifts identified in the document. By publishing our vision for care and support for cancer survivors now we want to share the direction of the NCSI with service users, carers, clinicians and service commissioners. We want to prepare service providers and commissioners for tested models and principles for improved care and support that the NCSI will develop by the end of 2010. We want to show that as well as improved quality, survivorship represents a significant part of how the cancer community will respond to the quality and productivity challenge we all face.

This document is the work of many. We are grateful to the service users, carers, clinicians, commissioners, researchers, charities and many others who are working with us on the National Cancer Survivorship Initiative. We look forward to continuing to work together during the next stage of the initiative.



CIARÁN DEVANE
Chief Executive
Macmillan Cancer Support



MIKE RICHARDS
National Cancer Director

¹ NHS 2010–2015: from good to great. Preventative, people-centred, productive. Department of Health December 2009.

1. Executive Summary



1.1 The growing group of cancer survivors, their carers and families will need support and services, which help them to meet their needs over longer periods.

1.2 This document provides an update on the first year of the National Cancer Survivorship Initiative (NCSI) and describes our emerging vision for improved care and support for people living with and beyond cancer. More information about the NCSI is set out in the Annex to this document.

1.3 The NCSI has gathered a range of evidence about the current picture of care and support for cancer survivors which suggests that current follow up arrangements are not all meeting the needs of survivors. This evidence includes the Picker survey² of over 2,000 cancer survivors between June and September 2009, which found that 43% of respondents would have liked more information and advice, 75% did not have, or did not know if they had, a care plan and 75% reported not knowing who to contact for advice outside of office hours.

1.4 The vision of the NCSI is that by 2012, those living with and beyond cancer are supported to live as healthy and active a life as possible for as long as possible.

1.5 The NCSI has identified the need for five shifts in the approach to the care and support for people living with and beyond cancer. These shifts are:

- > a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment
- > a shift towards assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences
- > a shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences and with the appropriate clinical assessment, support and treatment
- > a shift from a single model of clinical follow up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease
- > a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

² The Summary Report of the Picker Survey is available at www.ncsi.org.uk

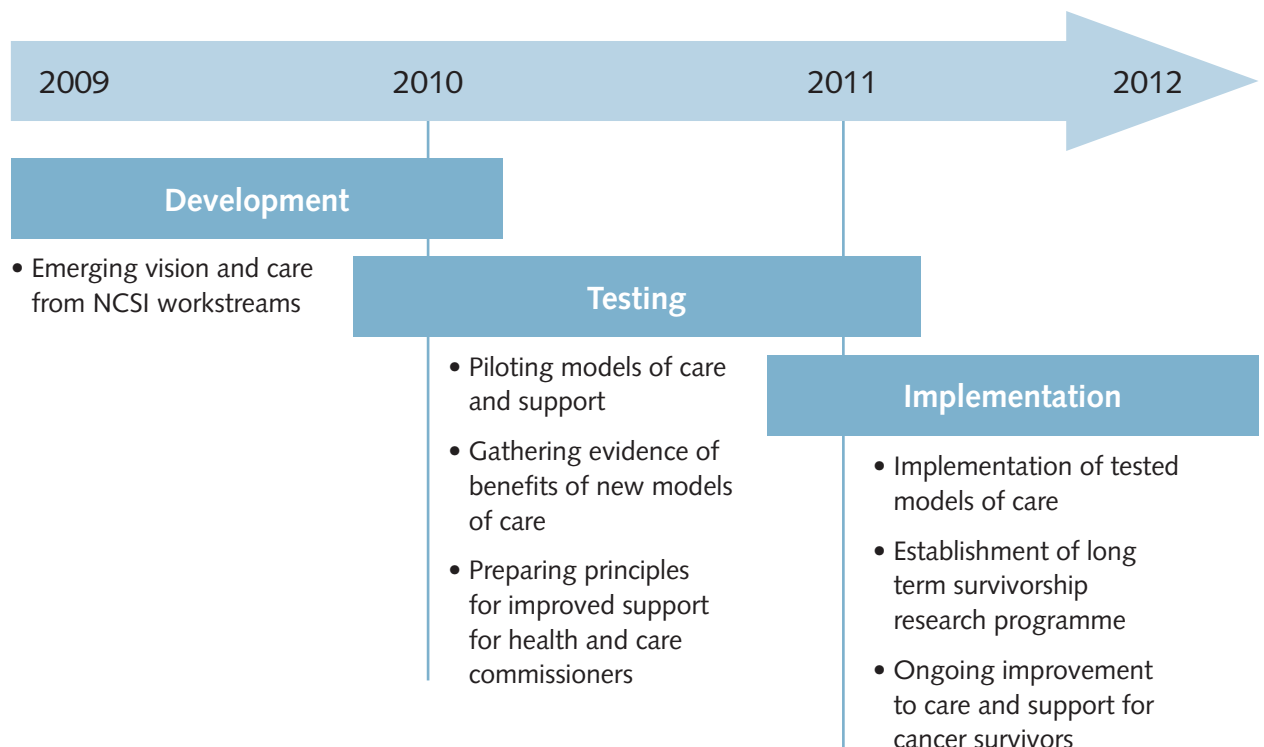
1.6 Changes to working practices will be needed to make this new model of survivorship care work effectively. Services need to be tailored to meet the needs of the individual, rather than the one size fits all model which has been the traditional pattern of follow up cancer care. Many of the changes that will be required are already in use in some areas and others are currently being piloted. It will be essential to evaluate new service models as they are developed and to learn from experience in other countries.

1.7 The NCSI considers that improving care and support for cancer survivors could improve the quality of life and experience of care of cancer survivors as well as securing the sustainability and efficiency

of healthcare services. The new approach to aftercare maximises health and well-being through supporting the prevention of ill health and early detection of further disease. A survivorship assessment and care plan can enable the early identification of possible consequences of treatment and help patients and healthcare professionals proactively manage these consequences to minimise their impact – preventing them becoming problems for the long term.

1.8 In 2010, the NCSI will move from a development phase to an evidence gathering and piloting phase. The main focus of the initiative in 2010 will be to engage service users, clinicians and commissioners in developing new models of aftercare and gathering evidence of

Timeline for phases of the National Cancer Survivorship Initiative



the benefits of tested models of care and support for cancer survivors. The NCSI will also be establishing a longer term research programme.

1.9 The next key milestone for the NCSI is the development of principles for service commissioners by the end of 2010, based on these tested models of care.

2. Background: Where are we now?



Numbers of Cancer Survivors

2.1 Today over 1.6 million people are living in England having had a diagnosis of cancer – 2 million across the United Kingdom. Nearly two thirds of these survivors are over 65 years old and around 3 out of 5 are women. Three cancer types (breast, prostate and colorectal cancer) account for over half of all survivors. We know that of the 2 million survivors in the UK 1.24 million people had an initial cancer diagnosis more than 5 years ago.

The number of cancer survivors is likely to grow by over 3% per year, reflecting the increasing incidence of cancer and better survival rates.

2.2 The significant improvements in cancer services over the past 10 years mean cancer survival is improving. Survival for breast, colorectal and prostate cancer have improved considerably. Today, five-year survival estimates for breast cancer are 86%; for colon cancer the figures are 53.4% and 52.7% for men and women; for rectal cancer the figures are 54.3% and

Numbers of people living in the UK and England who have had a cancer diagnosis³

	UK	%	England	%
Total	2,002,516	100	1,663,841	
Male	819,188	40.9	682,443	41
Female	1,183,328	59.1	981,398	59
Age 0-17	15,073	0.8	12,524	0.8*
18-64	729,181	36.4	605,858	36.4*
65+	1,258,262	62.8	1,045,459	62.8*
Breast	548,998	27.4	460,041	27.6
Colorectal	235,816	11.8	193,047	11.6
Prostate	253,436	12.7	215,654	13.0
Lung	63,522	3.2	51,668	3.1
Other	900,744	45	743,431	44.7
* Assumed to be the same as the UK				

³ Cancer prevalence in the United Kingdom: estimates for 2008 J Maddams, D Brewster, A Gavin, J Steward, J Elliott, M Utley & H Møller Br J Cancer 2009 101: 541-547

56% for men and women, and for prostate cancer the figure is 86.2%⁴.

2.3 Only one half of one per cent of cancer occurs in under 16 year olds and 1% of cancer in 15-29 year olds. However, 78% of children survive more than five years after cancer.⁵ Due to these high overall survival rates there are growing numbers of children, young people and adults who have been treated for childhood cancer.

Health and well-being of cancer survivors

2.4 The impact of cancer does not end after treatment. The 'Health and

Well Being Survey' by Macmillan Cancer Support in 2008⁶ found that cancer survivors reported poorer health and well-being than the general population. The health and well-being profile of the cancer survivor population (without active cancer) is comparable to the population of people with a chronic condition such as diabetes or arthritis. Much of this can be attributed to conditions related to the consequences of cancer treatment. The Macmillan survey showed 90% of cancer survivors had visited their GP in the last 12 months, compared to 68% of the wider population.

Macmillan Health and Well-being survey 2008⁷

	Cancer survivor	Wider Population
Use of the NHS in past 12 months		
> Primary care	90%	68%
> Specialist doctor	45%	15%
> A&E	20%	11%
Impact on work and relationships		
> Prevented by health from working in preferred occupation	25%	9%
> Health interferes with relationship with partner	29%	9%
Difficulty / inability in undertaking different activities:		
> Vigorous activities (running/sports)	56%	27%
> Housework, shopping, cooking	16%	2%
> Going out e.g. cinema, sporting events	18%	4%
> Social activities (e.g. visiting friends, clubs)	16%	4%
> Personal care (bathing, dressing, eating)	13%	2%

⁴ Cancer Reform Strategy 2nd Annual Report, November 2009, Department of Health

⁵ Childhood Cancer in Britain Incidence, Survival, Mortality Ed C Stiller Oxford University Press ISBN 978 019 852 0702

⁶ The sample for this survey included an even range of survivors diagnosed from one year to more than 10 years prior to the survey

⁷ Macmillan Cancer Support, Health and Well Being survey, 2008

2.5 Cancer survivors have a range of physical, psychological and social needs. In May 2009, the National Cancer Survivorship Initiative (NCSI) research work stream undertook a mapping exercise to identify the key aspects of the health and well-being, care and support needs and experiences of people living with and beyond cancer. The intention of the exercise was to map the 'survivorship journey' of people affected by cancer, both the more common and less common cancers, to understand what happens to survivors of cancer and the issues and challenges they face.

2.6 While the impact of issues will differ for individuals, the mapping exercise suggests that some of the key issues for survivors include:

- > psychosocial issues including anxiety, depression, isolation and negative impacts on self-identity or self-image
- > physical issues including fatigue, breathlessness and bowel problems, gynaecomastia (breast swelling in men), breast tissue removal and physical changes relating to the treatment of head and neck cancer which may also have significant psychological implications
- > effects on sexuality, including loss of libido, impotence and infertility

- > difficulties in the workplace as a result of lack of awareness amongst employers and colleagues
- > a lack of verbal and written information on areas such as diet, exercise and other potential beneficial lifestyle changes, financial assistance and contact information for support.⁸

2.7 There is a range of evidence available about the issues faced by cancer survivors. This evidence includes The Prostate Cancer Charity's Report 'Hampered by Hormones'. The Prostate Cancer Charity's Report describes the issues faced by men undergoing hormone therapy.⁹ It found that:

- > fatigue impacted on the lives of 70% of respondents to their survey of 332 men (affecting their ability to work, conduct household chores and pursue hobbies)
- > 80% experienced erectile dysfunction as a result of their treatment – with a quarter reporting that they found this difficult to cope with
- > 1 in 2 reported serious issues related to their mental well-being including feelings of depression, loss of confidence and cognitive problems.

2.8 Further evidence about the needs of cancer survivors is provided by analysis

⁸ Reports of the mapping exercises for the four common cancers and the less common cancers (by Cancer52) are available at www.ncsi.org.uk

⁹ Hampered by hormones? Addressing the needs of men with prostate cancer Campaign Report. The Prostate Cancer Charity, June 2009

of the Macmillan Cancer Support 'Health and Well Being Survey'. This shows that 84% of breast cancer survivors who responded to the survey said that they had experienced at least one physical health problem within the last 12 months.¹⁰ Fatigue, nerve damage, hot flushes, early menopause and lymphoedema are just some of the physical long-term problems that can affect breast cancer survivors.

2.9 A recent study of 1,152 people with breast, colorectal, haematological and gynaecological cancers treated at 66 UK cancer centres¹¹ suggested that 30% reported more than five moderate or severe unmet needs at the end of treatment and for 60% of these individuals, these had not improved six months after primary cancer treatment. The most common unmet needs were psychological needs and fear of recurrence.

2.10 Many survivors need support to deal with the consequences of treatment. Studies of patients after pelvic radiotherapy consistently suggest that 50% of all patients are left with bowel problems affecting quality of life and 30% state that these bowel problems have a moderate or severe impact. Studies suggest that

fewer than 1 in 5 of these patients is ever assessed by a specialist.¹²

2.11 CLIC Sargent have reviewed community based clinical care and support needed by children with cancer and their families¹³. The review identified the need for 'packages of care' for children and young people to address clinical care needs as well as emotional, educational, social, practical and financial needs. The review identified the special education and emotional needs of the siblings and families, friends and teachers of children and young people living with cancer.

The social and economic impact of cancer

2.12 More than nine out of ten (91%) of cancer patients' households suffer a loss of income and/or increased costs as a direct result of cancer.¹⁴ 90,000 people of working age are diagnosed with cancer each year in the UK.¹⁵ It is estimated that there are over 700,000 people of working age who have had a cancer diagnosis in the UK.¹⁶ Many people who have had cancer treatment want to go back to work when they feel fit and ready. However, the evidence suggests that some people are unable to return to work after a cancer

¹⁰ Macmillan Cancer Support, Health and Well Being Survey, 2008

¹¹ Armes PJ, Richardson A, Crowe M, Colbourne L, Morgan H, Oakley C, Palmer N, Ream E & Young A. Patients' supportive care needs beyond the end of treatment: a prospective and longitudinal survey. *J Clin Oncol* 27: 6172-6179 2009

¹² Widmark 1994, Kollmorgen 1994, Crook 1996, al Abany 2002, Henningssohn 2002, Bergmark 2002, Gami 2003, Fokdal 2004, Jephcott 2004, Olopade 2005, Andreyev 2007, Abayomi 2009, Barker 2009.

¹³ More than my illness – Delivering quality care for children with cancer. Clc Sargent 2009

¹⁴ Macmillan Cancer Support, Cancer Costs: The hidden price of getting treatment 2006

¹⁵ Office for National Statistics, 2003

¹⁶ Kings College London, Macmillan Cancer Support, and National Cancer Intelligence Network, Cancer prevalence in the UK, 2008

diagnosis. Recent international evidence suggests that 33% of cancer survivors were unemployed and that cancer survivors were 1.4 times more likely to be unemployed than people who have not had cancer.¹⁷ A UK study reported that 83% of cancer survivors returned to work, but over half of those returning had been off work for six months or more.¹⁸

2.13 Where people do return to work, most do so without medical or rehabilitation advice. In a recent study of cancer survivors' views about work, few said that they received any advice from their specialist cancer care team or from their own GPs about returning to work.¹⁹ A 2005 Cancerbackup survey of people affected by cancer found that less than half were advised by cancer doctors about the impact of treatment on their work. Support from employers is variable; 50% were not informed by employers of statutory rights and less than half were offered flexible working arrangements.²⁰

2.14 A survey of nearly 800 occupational health physicians (OHPs) in 2009²¹ suggested that there may be a role for OHPs to assist cancer survivors in their

return to work process. However, this study identified significant issues with respect to; timely access to occupational health services, communication between health professionals and employers, the knowledge base of OHPs in this area and the understanding of the potential assistance OHPs can provide. A survey of cancer survivors in 2008 found that just over a third of the sample returned to work after advice from an occupational health practitioner but this was restricted to those who worked in a large organisation.²²

2.15 In 2005 the Disability Discrimination Act was extended to apply to cancer patients from the point of diagnosis. The Act gives people living with cancer protection from discrimination in a range of areas including employment and education. Research by Cancerbackup, Working with Cancer, the Chartered Institute of Personnel and Development (2006) and the Department for Work and Pensions (2007) suggests that only one in five employers is aware that cancer is covered by the Act.^{23 24}

2.16 Provisional analysis for the Department of Health suggest that the

¹⁷ <http://jama.ama-assn.org/cgi/content/abstract/301/7/753>

¹⁸ Amir Z, Moran T, Walsh L, Iddenden R, Luker K. Return to paid work after cancer: a British experience. *J Cancer Surviv* 2007;1:129–136.

¹⁹ Amir Z, Neary D, Luker K. Cancer survivors' views of work 3 years post diagnosis: a UK perspective. *Eur J Oncol Nurs* 2008;12:190–197

²⁰ Cancerbackup, *Work and Cancer: How cancer affects working lives*, 2005

²¹ Amir Z, Wynn P, Whitaker S, Luker K (2009) Cancer survivorship and return to work: UK occupational physician experience. *Occupational Medicine* 59: 390–396.

²² Amir Z, Neary D, Luker K. Cancer survivors' views of work 3 years post diagnosis: a UK perspective. *Eur J Oncol Nurs* 2008;12:190–197

²³ Cancerbackup, CIPD, *Working with Cancer: Survey Report 2006*, 2006

²⁴ Simm C, Aston J, Williams C, Hill D, Bellis A, Meager N, *Organisations' Responses to the Disability Discrimination Act*, DWP Research Report 410 (2007)

annual costs to the economy in England of cancer survivors not returning to work could be as high as £1.5 billion. This figure is an estimate as the economic costs are dependent on whether jobs are filled by others when cancer survivors are unemployed and the assumptions in the calculation include that cancer survivors who are of working age, before cancer diagnosis and treatment, had the same full time work participation as the general working age population.

Experience of care of cancer survivors

2.17 The NCSI is working with the Picker Institute on a survey to get a national picture of the experience of care of adult cancer survivors. The first survey ran between June and September 2009 and involved over 2,000 people identified by the NCSI adult test communities. A further survey in the Summer of 2010 will enable the NCSI to track progress and measure the impact of the piloting work on the experience of survivors.

2.18 The findings of the baseline survey show that generally those surveyed felt positively about the care they had received from health professionals during their cancer care. 86% felt they had been given consistent advice all or most of the time and 96% felt they had been treated with

dignity and respect by health professionals all or most of the time.

2.19 However, the survey shows that the current system of follow up is not meeting all of survivors' needs. Some key findings are:

- > 65% of respondents said they knew who to contact during office hours, however, 75% did not know who to contact out of office hours if they had a concern
- > 75% reported that they did not have, or did not know if they have, a care plan
- > Access to information and advice was a particularly prominent issue; despite 80% reporting being given written information about their cancer, 43% of respondents said they would have liked more information and advice. Of those: 27% wanted more information and advice about the physical aspects of living with and after cancer and the side effects or signs of recurrence; 14% wanted information and advice about the psychological or emotional aspects of living with cancer; and, 15% wanted information about diet and exercise
- > 31% needed help with one or more physical concerns. Of those, 13% wanted more help with feeling tired, 11% wanted help with problems with

sleeping, 9% wanted help with bladder or urinary problems and 7% wanted help with bowel or digestive problems.²⁵

2.20 The NCSI children and young people work stream are planning to undertake an experience of care survey later in 2010.

2.21 To add to our understanding of the impact on health and care providers of providing services for cancer survivors, the Department of Health and the National Cancer Intelligence Network (NCIN) will work with the Nuffield Trust to understand the utilisation of social care services by cancer patients.

Current services for cancer survivors

2.22 Traditionally the focus of cancer services has been on cancer as an acute illness with an emphasis on the acute treatment phase. Care following treatment has been focused on monitoring, or surveillance of, individuals for signs of further disease or recurrence. These services have been called 'follow up'.

2.23 Follow up arrangements for people who have completed treatment usually involve regular out-patient appointments in an acute hospital and include a review of a patient's medical history and a physical examination. The main focus of follow up care has been to check for signs of

recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body).

2.24 There is some debate about the efficacy of current follow up strategies. Many recurrences are picked up through symptoms detected by patients themselves between scheduled clinic visits. For breast cancer this is the case for the large majority of recurrences.²⁶

2.25 Trajectories of cancer, that is how cancer unfolds over time for individuals, often differ from the traditional pattern of follow up care after treatment. Traditional follow up has been designed to 'screen' individuals for signs of cancer at regular intervals after completion for treatment. However, it has not been designed to manage the consequences of cancer treatment where symptoms can persist for many months or years, or provide adequate support or help to individuals experiencing recurrent cancer who may have to have repeated treatment, sometimes over many years.

2.26 In September 2009, NHS Improvement carried out a review of adult cancer follow up services. The review involved all the Cancer Networks in England and looked at what currently happens for patients following treatment for three cancer types – breast, colorectal and prostate cancer. The review found

²⁵ The summary report of the Picker survey is available at www.ncsi.org.uk

²⁶ Montgomery D.A. Krupa K. Cooke T.G. (2007) Alternative methods of follow up in breast cancer: a systematic review of the literature, *British Journal of Cancer*; 96; 1625-1632

that survivorship care usually means health professional led, clinically focused long-term follow up of cancer patients. Wide variation in follow up practice, including in the use of assessment tools and care plans was found.²⁷

2.27 Cancer treatment and follow up for children and young people is centralised into 18 centres in England. Life long surveillance and support for children and young people for the physical, psychological and social consequences of cancer is a component of the Children and Young People Improving Outcomes Guidance.²⁸ However, a study in 2004 suggested that more than 40% of long term survivors of childhood cancer in the UK had no contact with cancer services.²⁹

2.28 As cancer survivors are living longer they are spending more time in the community and requiring more support from their GP. Primary care has an important role to play in meeting the needs of people living with and beyond cancer. This might include providing ongoing treatment. For example, men on ongoing hormone therapy for prostate cancer often receive their treatment at their local GP practice. The Quality and Outcomes Framework for primary care includes incentives for GPs to invite patients for a review appointment within six months

of a diagnosis of cancer. This cancer care review enables GPs to understand the needs of cancer survivors and carers and provide information and support. In the future GPs will play a pivotal role in cancer survivorship and will need to be able to identify signs of recurrence or the consequences of treatment and refer and support patients and carers appropriately. However, it is also important to recognise that GPs are unlikely to have experience in assessment or managing the side effects of a wide variety of treatments.

2.29 Information about consequences of cancer treatment and signs and symptoms of recurrence is often not adequately communicated to primary care. The NCSI assessment and care planning work stream have identified that there is a wide variation in the quality and content of information about cancer treatment that is currently communicated to primary care.

2.30 A range of care and support is provided by Local Authorities for cancer survivors. Research for Macmillan Cancer Support³⁰ has described the social care needs of people with cancer and their carers, which can include: help with daily chores during treatment, formal domiciliary care, formal respite care, home adaptations and benefits assessment. The voluntary sector also provide services to support

²⁷ www.improvement.nhs.uk/cancer/

²⁸ Evidence on Cancer Services: Improving Outcomes in Children and Young People with Cancer NICE, 2005 ISBN 1846290678

²⁹ Taylor A, Hawkins M, Griffiths A, Davies H, Douglas C, Henney M, Wallace WH, Levitt G Long-term follow up of survivors of childhood cancer in the UK. *Pediatric Blood Cancer*. 2004 Feb; 42(2): 161-8.

³⁰ 'Social Care for Cancer – Do social care services meet the needs of people affected by cancer?' by Macmillan Cancer Support (April 2009)

people affected by cancer, either in their role as service providers for Local Authorities or Primary Care Trusts or directly through their charitable objectives.

3. Vision and five key shifts



The Scope of Survivorship

3.1 There are different definitions of cancer survivorship. Anyone who is living following a diagnosis of cancer can be described as a 'survivor', though many people prefer to think about this in terms of 'living with and beyond cancer'. Survivorship therefore encompasses those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease.

3.2 While many aspects of longer-term care and support need to be in place from the point of cancer diagnosis, the focus of the National Cancer Survivorship Initiative (NCSI) is on the assessment, care and support given to people from the end of primary treatment onwards. While this document refers to the needs of cancer survivors, this should be read as including the needs of their carers and families.

3.3 The NCSI addresses the full range of issues – including health care, specialist services, social care, self-care, family care, psychological and emotional, financial, employment, education and spiritual issues – which affect the quality and length of the life of a person living with cancer. Additionally, for children and young people, the NCSI is considering issues around future autonomy and the ability to live independently.

A Patient Perspective

3.4 No two people with cancer will have exactly the same priorities and needs. However, following a diagnosis of cancer most people are likely to want to:

- > have the maximum chance of being cured
- > return to as normal a life as possible (though their priorities may change and they may develop a 'new normal')
- > be empowered to take as much control of their own care as they wish
- > be given the information they require to help them make informed decisions
- > know what to expect and what to look out for
- > know who to contact should the need arise
- > know that the importance of side effects such as hair loss will be recognised and help given with them
- > know that any further disease or consequence of cancer treatment will be detected at an early stage
- > be offered and given the best treatments should they experience further disease or consequences of treatment
- > know that they can re-access specialist advice and care without delay should they so need

- > know that their anxieties and fears will be taken seriously and that they will have access to emotional support if they want it
- > know that they will be given advice on financial benefits and on returning to work, education or training should they need this
- > know that health and social care teams will work effectively together, so that their care is seamless and well coordinated
- > know that care will be given as close to home as possible, recognising that some specialist services cannot be provided in all locations
- > know that they will be given advice on living healthily to maximise their chance of remaining well for as long as possible.

3.5 People affected by cancer will rightly expect that health and social care professionals will help them to achieve these goals and that services will be organised to maximise their safety and convenience and to minimise their problems and concerns. People will want to know that the services which they access will:

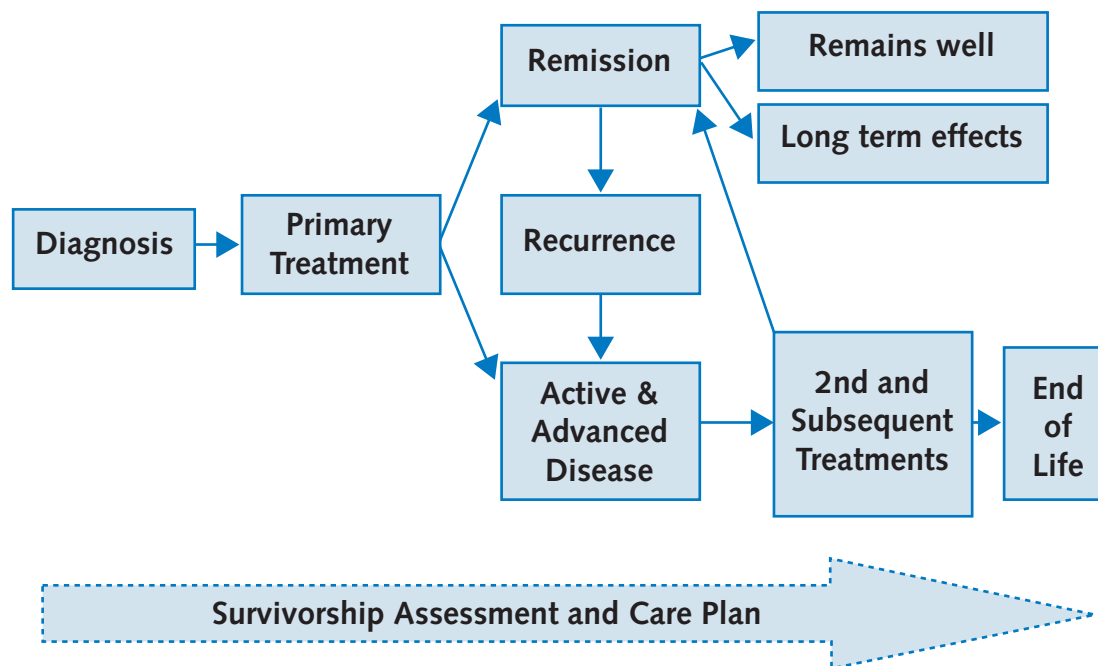
- > care for them and treat them as individuals
- > provide information at each step in the care pathway so that they are empowered to make informed decisions

- > have all the necessary expertise and facilities to deliver high quality care
- > signpost them to other services as and when they need them
- > coordinate care effectively both within a service and across organisational boundaries.

3.6 People will expect services to be well organised to deliver personalised care for as long as they may need it.

The Survivorship Pathway

3.7 The NCSI has defined a 'survivorship pathway' to describe different phases of health or illness that a person with cancer may experience from diagnosis onwards. This pathway may help to clarify thinking about the different services and support that individuals may need at different times after a cancer diagnosis.



3.8 Many cancer survivors have all evidence of cancer eliminated following primary treatment, enter remission and are cured. The proportion varies from cancer to cancer. For example, the vast majority of people with testicular cancer will have no evidence of disease following treatment and do not experience any subsequent recurrence of disease. Many people with breast and prostate cancer also have no evidence of disease after primary treatment, though some will experience a recurrence months or years later. They may then achieve a second remission or live a productive life for years without cancer.

3.9 For other types of cancer only a minority of patients will be free of disease at the end of primary treatment. Lung cancer and pancreatic cancer are typical examples.

3.10 Some people with active or advanced cancer may die from their cancer within a matter of weeks or months. However, others will live with 'chronic' cancer for many years without it giving rise to significant symptoms – they might die 'with' cancer but 'from' another cause.

3.11 In between these extremes, many people have cancer, which responds to treatment for a period of months or years and then relapses. In some cases, the cancer may respond to a second or subsequent treatment. Typically, however, cancers become less responsive to treatment over time.

3.12 Although all evidence of cancer may be eliminated following treatment, people can be left with short or long-term consequences either of the cancer itself or from the treatments used to eradicate it. These effects can develop immediately or

only become apparent many years later, for example cardio-toxicity or sub-fertility. Surgery, radiotherapy, chemotherapy and novel targeted treatments such as Herceptin can all have short or long-term consequences. Examples of the impact that this can have include:

- > problems with urine, bowel, rectum and sexuality in survivors who have had cancers of the cervix, womb, rectum, bladder or prostate
- > problems with insufficient hormone production in people who have had cancers of the lymph glands or the brain
- > increase in incidence of heart disease in people who have had breast or prostate cancer
- > bone fractures for those with prostate cancer.

A Service Perspective on Future Survivorship Care

3.13 Each year more people will be alive having had a diagnosis of cancer. These people will have very different levels of need and for individuals levels of need are likely to change over time.

3.14 Services will therefore need to be tailored to meet the needs of the individual, rather than the one size fits all model which has been the traditional pattern of follow up cancer care. Care should be tailored to the needs of the individual and should be delivered as close to home as is compatible

with safety and quality. Many people will receive care from a combination of their primary care team and from a range of specialists based in secondary or tertiary care. Effective coordination and communication between these services will be vital.

3.15 Many 'routine' follow up appointments serve little purpose in terms of detection of disease recurrence. In practice the large majority of recurrences are detected either by patients themselves or on investigations which can be planned without a patient having to attend a clinic. In addition, patients may see different clinicians on each occasion making it difficult to provide continuity of care. These attendances tend to focus on the medical aspects of follow up. Patients frequently report that their psychological or other concerns are not adequately addressed.

3.16 A patient's survivorship care plan should contain details of the tests required to monitor for any evidence of recurrence and the intervals at which these tests are needed. In the future it is envisaged that the ordering of tests will be automated (allowing people to choose convenient times) and that tests will be delivered more locally. This will remove the need for patients to come to an outpatient clinic, have a request form written and then return on another day for the test.

3.17 Several alternatives to routine medical follow up have been tested. These include nurse-led follow up and telephone follow up. Clinicians and patients who have

experienced these alternative models have in general been very positive about them. Clinicians and patients without such experience generally express reservations. These and other models (e.g. the use of e-mail between clinicians and patients) need further testing and evaluation. Slavish adherence to 'routine follow up' should, however, be challenged.

3.18 Clinicians are increasingly seeing patients as partners in decision making about care. In future patients will also, subject to informed choice, take as much control of their own management as they wish. Patients will, however, need to be assured that they can access specialist advice and support as and when they need it.

3.19 Substantial changes to working practices will be needed to make this new model of survivorship care work effectively. These changes will affect:

- > Assessment and reassessment of individual's needs
- > Provision of information
- > Care planning
- > Support for self-management
- > Coordination of care
- > Ability to enable rapid re-entry to specialist services
- > Surveillance during remission
- > Support during remission

- > Support for those with medium and long-term consequences of cancer treatment
- > Support for those with active and advanced disease
- > Transition to end of life care
- > Communication between health professionals.

3.20 Throughout their care pathway, people wish to know that their care is well coordinated. This will reduce fear, uncertainty, duplication of effort and use of resources.

3.21 Surveys have indicated that people affected by cancer value the concept of a 'key worker' very highly. The challenge is to turn the concept into a reality, given that no individual works 24/7 without holidays. There is therefore a need to pilot and evaluate different 'key worker' models which allow for this. In practice the position of key worker may well change over time. A clinical nurse specialist may take on the role around diagnosis and then hand over the relay-baton to a chemotherapy nurse specialist if and when a patient starts chemotherapy. Later the GP may take on this role. What is important is that the patient should know who is their first point of contact both within and outside normal working hours and that the person who is the point of contact responds quickly and appropriately.

3.22 Many of the changes that will be required are already in use in some areas and others are currently being piloted. It will be essential to evaluate new service models as they are developed and to learn from experience in other countries.

Five shifts

3.23 The NCSI has identified five shifts which are needed in the approach to the care and support for people living with and beyond cancer.

The NCSI Vision for future survivorship care

Shift one – A cultural shift in the approach to care and support for people affected by cancer

3.24 The first of these shifts is a cultural or attitudinal shift in the care and support for people affected by cancer. This is a shift from a predominant focus on cancer as an acute illness treated in the acute sector to a greater focus on recovery, health, well-being and return to work after cancer treatment. This shift will enable people affected by cancer to be prepared for the long term – for living with and beyond cancer.

Five shifts in care and support for people living with and beyond cancer:

1. a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.
2. a shift towards holistic assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences.
3. a shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences. This approach empowers individuals to take on responsibility for their condition supported by the appropriate clinical assessment, support and treatment.
4. a shift from a single model of clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease as well as tailored support for those with advanced disease.
5. a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

3.25 This is a shift in widely held beliefs about cancer. Achieving the NCSI vision for improved care and support for cancer survivors will require a shift towards a wider understanding that cancer is a complex range of different conditions with a variety of illness trajectories. Cancer is an illness which might be cured or which might have the characteristics of a long term or chronic condition that people can live with for many years. Different aspects of that chronic illness will require specialist diagnosis and treatment.

3.26 This approach will improve quality of life for people living with cancer and enable them to live a healthy and active life and resume everyday activities, including returning to work. For children and young people, this shift will enhance future autonomy and access to education and employment.

3.27 Through this shift, cancer survivors will be supported by aftercare services that are focused on maximising health and well-being and minimising the long-term physical, emotional or social consequences of cancer and cancer treatment.

3.28 Underpinning this shift is moving from traditional medically led follow up services that have traditionally focused on surveillance tests and investigations to identify whether there are signs of cancer recurrence, towards aftercare services, which link acute specialist, primary care, palliative care,³¹ rehabilitation and support services.

³¹ Active holistic care of patients with advanced progressive illness, focusing on management of pain and other symptoms and provision of psychological, social and spiritual support.

Shift Two – Assessment, information provision and care planning

3.29 The second shift is towards assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised information and care planning based on assessment of individual risks, needs and preferences.

3.30 Care planning will start at the point of diagnosis. Assessment for the survivorship phase of care will be carried out at the point of completing active treatment and at any subsequent 'transition' points, for example if there is further disease or a move towards end of life care. The assessment will identify individuals at low, moderate or high risk of consequences of treatment, further disease, co-morbidities, psychological problems or disabilities.

3.31 This assessment will shape decisions over the information and support that an individual will require and a care plan and information prescription is developed in partnership with the individual and their carer if appropriate.

3.32 Follow up care of cancer patients has traditionally been focused heavily on the detection and treatment of recurrent or progressive disease. Clinicians have frequently not taken a holistic approach to needs assessment, either because of a lack of training or because of a lack of time in busy clinics.

3.33 To make holistic assessment feasible on a repeated basis involvement of patients in the process will almost certainly become essential. Experience in individual centres in the UK and USA has shown that the vast majority of people are happy to complete questionnaires about their current problems and concerns using modern digital technology (e.g. touch screen tablets). The information can then be made available to the clinician in a format which can help to shape the consultation and to identify domains which require further assessment from an expert (e.g. a financial benefits expert or an expert in psychological problems).

3.34 Verbal information sharing will remain of paramount importance, but this will need to be supplemented more effectively with tailored or personalised written information. At present the provision of written information is very variable, despite the existence of high quality materials. A major cancer patient information programme to improve the provision of information for people affected by cancer is currently underway. This involves a partnership between Macmillan Cancer Support, Cancer Research UK, the National Cancer Action Team, NHS Choices, Cancer Networks and local multidisciplinary teams.

3.35 The vision for the future is that high quality information materials will be available electronically and will be personalised to be relevant to individuals. Clinicians will be able to write an 'information prescription' which will then

be dispensed either in the clinic setting or from an information centre.

3.36 Care planning is not a one-off event. It will be needed at diagnosis, at different stages of treatment, at the end of treatment and at subsequent key points in the care pathway. These may include the point of recurrence or progression, the development of long term consequences or the transition to end of life care.

3.37 Care planning will be accompanied by careful assessment and provision of information. Care planning should cover advice on:

- > Management of current physical, psychological, social and spiritual problems and concerns
- > Financial benefits (where appropriate)
- > Return to work (where appropriate)
- > Lifestyle (e.g. smoking, diet and exercise)
- > Access to support groups and self-management training programmes
- > Risks and signs of recurrence and planned surveillance tests
- > Risks of future psychological problems, including fear of recurrence
- > Risks and signs of consequences of treatment

- > Who to contact about problems and concerns both within and outside normal working hours.

3.38 There is still much to learn about how care planning can best be done. One model to be tested by the NCSI is that of a 'health and well-being clinic' at the end of treatment where patients would receive information and support from a doctor, nurse and have access to a range of other experts (e.g. counsellors, welfare officers, physiotherapists and occupational therapists) at a single visit.

Shift Three – Support for self-management

3.39 Where possible there should be a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences with appropriate clinical support.

3.40 This shift draws on the supported self-management approach, which has worked successfully for those with other long term conditions. This shift starts at the point of diagnosis, with a new relationship between healthcare professionals and patients. This new relationship of collaborative interaction supports and empowers individuals to take on responsibility for their condition, supported by the appropriate clinical assessment to ensure that physical or other issues requiring specialist diagnosis and management are dealt with.

3.41 This shift can be facilitated in a number of ways, including using support through telephone, text and e-technology.

For young people this shift includes care and support which empowers them to become increasingly independent and to live autonomously.

3.42 If people are to become empowered to take the level of control of their condition to the extent that they wish, they will need access to education and support in addition to assessment and care planning. Such education and support can be given in several different ways. Clinical nurse specialists already have a considerable role in this area, but cannot currently be expected to have expertise or time to cover all aspects of survivorship without further training or capacity.

3.43 Several models of education and training for people affected by cancer have been developed, aimed at different points on the care pathway. Maggie's Cancer Caring Centres have developed a 'Getting started with cancer treatment' workshop for people affected by cancer to better understand cancer treatment, side effects and wellbeing. Macmillan Cancer Support run 'New Perspectives' – a self-management course for people living with cancer facilitated by people living with cancer. There are also several initiatives across England that aim to support people at the transition point of moving from treatment to aftercare. A good example of this is in South Devon Healthcare Trust, where the charity-funded 'Moving On' Programme helps women who have finished treatment for breast cancer and are 'moving on' to the post-treatment phase.

It aims to teach them skills and strategies to help manage the situations they may face more effectively, using mutual support from all the women attendees. Other courses are run from Cancer Information centres, such as the 'Moving on' course at Buckinghamshire Hospitals NHS Trust. This is a 6-week programme for patients at the end of active treatment – run by the Macmillan Cancer Information and Support Service. Each week is themed and tackles the various rehabilitation issues that people might face, focusing on emotional and practical support but adapting to each cohorts' needs.

Shift Four – Tailored support for potential consequences of treatment or further disease

3.44 The fourth shift is a shift from one-size fits all clinical follow up to a more personalised approach enabling people to prepare for the consequences of treatment and to encourage early recognition of signs and symptoms of further disease. This approach will be 'risk-adapted' – with more intense surveillance being available to those who are at particular risk of developing further disease or experiencing adverse longer-term consequences of treatment.

3.45 This shift will mean that people affected by cancer know what might happen, what to do and who to contact. It will mean the healthcare system acts appropriately, rapidly and responsively to individuals who have concerns.

3.46 The shift is underpinned by risk assessment, awareness, preparation and infrastructure to support the early recognition of signs and symptoms of further disease or adverse consequences of treatment. It also requires systems to be in place for rapid access to specialist services.

3.47 People who have received treatment for cancer may be at risk of developing problems related to the treatment several years later. The risk of such an occurrence will depend on the nature of the treatment (e.g. surgery, radiotherapy, chemotherapy etc.) and, in the case of radiotherapy the particular organs that will have received a dose of radiation.

3.48 The first step in managing these consequences of cancer treatments is to make the patient aware of the risks and the likely time course (e.g. months or years after treatment) for such consequences to occur. Potential consequences of treatment should be discussed prior to consent to cancer treatment. Patients should be informed about what signs to look out for and what tests, if any, can be done to detect problems at an early stage. These potential consequences of treatment should also be discussed at the assessment and care planning session at the end of treatment. The reporting and analysis of consequences of cancer treatment should become embedded in routine clinical practice.

3.49 Patients may have ongoing active disease from the time of first diagnosis.

Alternatively they may experience a recurrence or spread of their cancer following an initial period in remission. The clinical pattern of active/advanced disease varies widely. Although predictions can be made by experienced clinicians of the likely pattern of disease for an individual patient (based on the type of cancer, the extent of spread and other factors), it is impossible to be certain about the disease course for an individual patient.

3.50 Individuals will differ in the amount of information they wish to receive about their condition and the likely prognosis. However, increasingly people do want to be active partners in decision making throughout their illness. Patients should know that they have ready access to information and expert advice whenever the clinical situation changes and that they will have access to the wide range of services which they may need.

3.51 These may, for example, include:

- > Diagnostics
- > Surgery, radiotherapy, chemotherapy
- > Novel drug or other treatments
- > Nursing and supportive care
- > Rehabilitation services (e.g. physiotherapy, occupational therapy, dietetics, speech and language therapy)
- > Counselling services
- > Financial/benefits advice

> Social care services

> Specialist palliative care services.

3.52 Models for optimising treatment recommendations and for continuity of care for those with active/advanced disease are less well developed than those with newly diagnosed cancer (or for those being followed up in remission). Given the variable and changing clinical course of active/advanced disease, traditional multidisciplinary team meetings may not provide a practical way forward.

3.53 During 2010, the NCSI will work to develop new models of care for people with active/advanced cancer. These may include 'virtual' teams linked by modern technology, with the option to call case conferences as and when necessary.

Shift Five – Measuring outcomes and experience

3.54 The final shift in the approach to care and support of cancer survivors is a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience, concerns and outcomes for cancer survivors. This shift reflects the importance of understanding the current concerns and needs of survivors. It is a new emphasis on monitoring outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services. It is also a shift to measuring survivors' experience of care, including through survivorship questions being included in the National Cancer Patient Experience Survey Programme.

4. Personalised assessment, information provision and care planning



'Our vision is that during initial cancer treatment patients will self-assess their needs against a holistic set of issues (medical, emotional, financial, practical and spiritual). Issues which they flag will be further assessed in depth, a care plan will be developed with them, and they will be signposted to information and services to meet those needs. There will be reassessment of needs at key transition points.'

Ciarán Devane, Chief Executive, Macmillan Cancer Support and Chair of the NCSI Assessment and Care Planning Work Stream

Case study

Fran, 57, London, diagnosed with cancer of the retina in 2006.

'Once my treatment was over, I was abandoned. There was no system to support me, no one asked me how I would cope emotionally, and when I started suffering side effects, I felt like I was making a fuss about nothing. The absolute silence of support was deafening. Two years on and I'm still lacking in energy and I experience flashing lights so do I still have cancer? Has it been cured? Is it going to return? No one is there to ask my questions and I don't know who to turn to for the answers.'

opportunity to discuss and access support for the needs that they may have following their treatment. While many patients want to take greater control of their own health and wellbeing, they can only do so effectively if they have access to the appropriate information and support.

4.3 Individuals' needs will change over time. Care planning will start at the point of diagnosis. The NCSI vision is that assessment for the survivorship phase of care will be carried out at the point of completing cancer treatment and at any subsequent 'transition' points. These transition points might include the development of consequences of treatment which need expert assessment and management or when there is further disease or a move towards end of life care.

4.1 The National Cancer Survivorship Initiative (NCSI) has identified a shift towards assessment, information provision and care planning as crucial to improving care and support for cancer survivors.

4.2 At the end of treatment cancer survivors do not routinely have an

4.4 The NCSI vision is that this assessment covers the full range of needs of individuals, including physical and lifestyle needs, social, financial advice and occupational support needs, psychological wellbeing and spiritual needs. The assessment will identify individuals at low,

moderate or high risk of consequences of treatment or further disease.

4.5 The assessment might involve people providing specific information about their problems and concerns (e.g. via touch screen technology) to identify areas requiring more detailed assessment and discussion with a healthcare professional.

4.6 The NCSI assessment and care planning work stream is proposing to pilot a post-treatment, or 'health and wellbeing' clinic in early 2010. The clinic is effectively a meeting for patients with a range of health care professionals, complementary therapists and the voluntary sector and a chance to interact with other patients and carers. The proposal is that a post-treatment clinic would be available to people at the end of cancer treatment. The clinic could provide an opportunity to inform and prepare patients for the long term, living with and beyond cancer. The preparations will include what to look for in terms of late effects or recurrence and psychological impact. The clinic will develop a new range of referral pathways for those patients with late effects of cancer treatment requiring specialist evaluation. There would be the opportunity to cover specific issues, for example colostomy care, prosthetic care, lymphoedema, body image and sexuality. The clinic would inform cancer survivors and their families and carers about the ongoing support and care that is available to them. The clinic would provide an

opportunity to access information to support survivors to return to as normal a life as possible, including information related to work and welfare benefits, lifestyle and diet and support groups.

4.7 This assessment shapes decisions over the level of future support that an individual will require and a care plan will be developed in partnership with the individual and their carer. This care plan will include information about sources of support and who to contact if an individual has concerns.

4.8 A personalised approach to aftercare will ensure that the needs of all groups are met and help address inequalities in access and outcomes. People with specific needs such as children and young people, or those who find it difficult to engage with the current system of follow up, will have an opportunity to consider the whole range of their needs and ensure aftercare services are tailored to their needs.

4.9 The experience of using personalised care planning for people with long term conditions shows that the approach can lead to a range of benefits for individuals, commissioners, providers of services and the health and social care workforce. These benefits were described in the Department of Health's guidance for commissioners 'Supporting People with Long Term Conditions'³² and include enabling people to stay healthier for longer by promoting health through information and self care and enabling independence and achievement

³² Department of Health. Supporting People with Long Term Conditions. Commissioning Personalised Care Planning. A guide for commissioners. London 2009

of goals such as returning to work. The End of life Care Strategy³³ also emphasises the importance of personalised care planning, including advance care planning.

4.10 This shift is consistent with the NICE guidance on supportive and palliative care.³⁴ In January 2007, the National Cancer Action Team published a specification for the holistic common assessment of supportive and palliative care needs for adults with cancer.³⁵ This guidance included the holistic assessment of the range of needs of adult cancer patients.

4.11 The NCSI assessment and care planning work stream has developed an assessment and care-planning framework for those living with and beyond cancer. The framework ensures that, at key points across the patient pathway, post-treatment care is holistically assessed. This framework is being piloted in twelve test communities, who are looking at its effectiveness for patients with colorectal, lung, head and neck cancer and myeloma at different stages in the patient pathway, including with patients with advanced disease. Evaluation of this piloting work will be complete by September 2010.

4.12 The NCSI children and young people work stream are piloting personalised care plans and patient information provision for children and young people. The care

plan was launched in September 2009 for piloting by children and young people test communities to ensure it is practical to implement locally.

4.13 A holistic assessment will identify individual information needs. These needs can be met through a discussion with a healthcare professional and they might be met through a tailored information prescription which signposts individuals to high-quality information and support.

4.14 The shift towards tailored support for early recognition of recurrence and consequences of treatment is underpinned by awareness, preparation and systems in primary and secondary care services for recognising early, potential signs of further disease and consequences of treatment. The NCSI assessment and care planning work stream have developed a framework for an end of treatment summary record. The intention is that the end of treatment record would provide clearly identifiable information that will enable health professionals in primary care to inform and support survivors and their carers in their aftercare. Twelve test communities are testing the application of the framework to see whether this improves the provision of information to primary care and what impact the end of treatment summary makes to the experience and health and wellbeing outcomes for cancer survivors.

³³ End of Life Care Strategy, Department of Health, July 2008.

³⁴ National Institute for Health and Clinical Excellence. Guidance on cancer services: improving supportive and palliative care for adults with cancer. (2004)

³⁵ Cancer Action Team (2007) Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance.

Example: Sheffield Profile for Assessment and Referral to Care

The University of Sheffield has designed an assessment tool 'Sheffield Profile for Assessment and Referral to Care' (SPARC), in collaboration with clinicians within North Trent, and the Network Supportive and Palliative Care Group (NSPCG). This tool is designed to be completed by the patient (with support from carers if needed) and forms the starting point for the holistic needs assessment process. SPARC is a screening questionnaire that explores a variety of issues and may help the patient and carers to reflect on their needs.

The issues covered in the questionnaire fall into the following domains:

- > physical
- > psychological
- > religious/spiritual
- > independence/activity
- > family/social
- > treatment
- > information
- > communication

Use of the SPARC tool provides the professional making the assessment with an opportunity to ask the patient "what is concerning you most" in the knowledge that they will have been encouraged to think about this question through the questionnaire. This is intended to enable a conversation that will have the person's concerns at the centre.

Risk Stratification

4.15 The NCSI research work stream is working with the National Cancer Intelligence Network (NCIN) to develop a systematic approach to risk stratification to enable a personalised approach to assessment and care planning.

4.16 The aim of the work is to develop a tool or framework which will enable the aftercare of cancer survivors to be planned based on likely or predicted need. Events or stages along the survivorship journey will be identified that are important to patients with particular cancers. The likelihood of these occurring will be based on a range of factors relating to cancer type, treatment, demographic and lifestyle factors and co-morbid conditions. A range of methodological approaches will be used to quantify the likelihood of events occurring and from that a predictive model can be developed over time for each cancer type. The work will start with cancers where there are the most data available and where the relevant research has already been undertaken.

4.17 The NCSI children and young people work stream has also commissioned a risk stratification tool that will enable the classification of children and young people who are at high, medium and low risk for adverse health outcomes, following cancer treatment. The work stream is working with the University of Birmingham to develop the tool, which will be based on data available from the British Childhood Cancer Survivor Study.

5. Supported self-management



'Our vision is of a transformed approach to cancer from treating it as an acute or end of life care condition to one where cancer is managed by people in partnership with the clinical team and where current follow up services are replaced by after care services based on a model of supported self-management tailored to individual need.'

Jessica Corner, Chief Clinician, Macmillan and Chair of the NCSI Self-Management Work Stream

Case Study

Dave, 59, diagnosed with non Hodgkin's lymphoma in 2007.

'Three things were lifesavers for me. My specialist nurse who 'held my hand' from diagnosis to completion of treatment; Cancerbackup's telephone service (now merged with Macmillan) who helped me on numerous occasions to deal with every aspect of having and living with cancer, and the Macmillan 'Living with Cancer' course which I saw advertised in my doctor's surgery. This course gave me the practical and emotional tools to face up to my situation, to restore confidence and rebuild my life. The course members were a constant source of support to each other and those of us who are left continue to meet socially.'

5.1 Patient engagement in health and in particular self-management is widely recognised as crucial to improvement in care and outcomes for people with long-term conditions.^{36 37 38 39} Supported self-management is a philosophy and approach defined as: 'what health services do in order to aid and encourage people living with a long term condition to make daily decisions that improve health related behaviours and clinical and other outcomes'.⁴⁰ Self-management support enables people to make informed choices, to apply skills to new problems as they arise and to practice new health and lifestyle behaviours.

5.2 The National Cancer Survivorship Initiative (NCSI) has identified the need for a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences.

³⁶ Skills for Health, Skills for Care, Common Core Principles to Support Self Care. 2008

³⁷ Department of Health, Supporting People with Long Term Conditions, 2005)

³⁸ Department of Health, Supporting People with Long Term Conditions to Self Care, 2006

³⁹ Department of Health, Generic Choice Model for Long Term Conditions, 2007

⁴⁰ Adapted from The Health Foundation, Co-creating Health Programme 2008

5.3 This shift draws on the supported self-management approach, which has worked successfully for those with other long term conditions. This shift starts at the point of diagnosis, with a new relationship between healthcare professionals and patients. This new relationship of collaborative interaction supports and empowers individuals to take on responsibility for their condition, following appropriate clinical assessment to ensure that physical or other issues requiring specialist diagnosis and management are dealt with. This shift can be facilitated in a number of ways, including using support through telephone and digital technology. For young people this shift includes care and support which empowers them to become increasingly independent and to live autonomously.

5.4 The NCSI self-management work stream has identified three enablers for supported self-management:

- > Self-management education and training programmes
- > Skills development programmes for professionals
- > Institutional support for service redesign.

5.5 Self-management training and education might be via group, one-to-one training or peer support networks. The training is intended to build self-management skills such as agenda setting, goal setting and action planning. Sessions most positively rated by a range of cancer

survivors who were participants in 29 self-management programmes nationwide included action planning and positive thinking.⁴¹

5.6 Supported self-management requires training, support and development for professionals providing care and re-organisation of services so that they are based on empowering and supporting individuals to take on full responsibility for their condition. The second enabler, therefore, is the provision of skills development programmes, which provide support for professionals to reflect on their consulting styles, to build on what works well, to stop what does not work well and build new skills.

5.7 The third enabler is the support required by organisations to redesign their systems and services. This might include the use of technologies including the telephone and internet.

5.8 Self-management might include an individual engaging in activities which protect and promote their health and well being, activities to monitor symptoms of further disease or the consequences of treatment, as well as monitoring the impact of the condition on functioning, emotions and relationships. The appropriateness and success of a supported self-management approach will depend upon how each person values and understands their own role and abilities to contribute to the management of their care. Through

⁴¹ Macmillan Cancer Support, 'Living with Cancer', Report 2008

assessment and skilled communication, health professionals can assess a person's readiness for supported self-management.

5.9 Those who survive cancer are more likely than the healthy population to develop a second cancer and have a significantly higher chance of developing heart disease or bone fractures. This could be reduced by lifestyle change, for example, exercise, but significant numbers of cancer survivors are unaware of the importance of lifestyle factors following their treatment for cancer. 35% of respondents to the Macmillan Health and Well Being Survey were unaware of the increased importance of a healthy lifestyle, 33% did not have all the information and 42% wanted more information to make decisions about their lifestyle, including more information on diet, weight management, stress management and exercise.⁴²

5.10 The NCSI self-management work stream has been looking at the impact of support for health and wellbeing for cancer survivors. There is emerging evidence to show that lifestyle factors including physical activity and diet, can influence the rate

of cancer progression, improve quality of life, reduce side effects during treatment, reduce the incidence of relapse, and improve overall survival.^{43 44 45 46} A range of studies looking at diet and lifestyle after a breast cancer diagnosis support the concept that diet and lifestyle choices can make a difference to breast cancer survival as well as helping women feel better.⁴⁷ Resistance exercise has been advised by the National Institute for Health and Clinical Excellence to help combat fatigue in men with prostate cancer.⁴⁸ However, The Prostate Cancer Charity's survey of men with prostate cancer found that 86% of men who experienced fatigue were not told about these resistance exercises.⁴⁹

5.11 Assessment and planning for lifestyle change and support should become part of routine care during treatment and aftercare for all cancer survivors. Cancer services could learn from rehabilitation programmes for example in cardiology, where systematic lifestyle assessment and lifestyle planning occurs. This could be achieved through specific clinics or in community settings and with leisure services, and could be staffed with activity and nutrition professionals.⁵⁰

⁴² It's No Life. Follow up to Macmillan Cancer Support, Health and Well Being Survey, 2008

⁴³ Irwin M.L. et al(2008) Influence of pre and post diagnosis physical activity on mortality in breast cancer survivors: The Health, Eating, Activity and Lifestyle Study, *Journal of Clinical Oncology*, (26), 24, 3958-3964.

⁴⁴ Thomas R. Davies N.(2007) Lifestyle during and after cancer treatment, *Clinical Oncology*; 19; 616-627

⁴⁵ Meyerhardt J.A. et al(2006) Impact of physical activity on cancer recurrence and survival in patients with stage III colon cancer; findings from CALGB 89803. *J clin Oncology*, 24; 3535-3541

⁴⁶ Holmes M.D. et al(2005) Physical activity and survival after breast cancer, *J Am Med Assoc*, 293; 2479-2486

⁴⁷ Brown C.H. Baidas S. M. Hajdenberg J.J.(2009) Lifestyle interventions in the Prevention and Treatment of Cancer, *American Journal of Lifestyle Medicine*, 3; (5) 337-348

⁴⁸ Prostate Cancer: Diagnosis and Treatment (full guideline). NICE. Feb 2008

⁴⁹ Hampered by hormones? Addressing the needs of men with prostate cancer. The Prostate Cancer Charity. June 2009.

⁵⁰ Rabin C.(2009) Promoting lifestyle change among cancer survivors: when is the teachable moment? *American J of Lifestyle Medicine*, 3;(5) 369-378

Evidence is continuing to emerge as to when the 'teachable moment' is for assessing and supporting lifestyle change, but there is increasing clarity as to the need for some ongoing coaching for patients so

that attitudes and behaviours can change for the long term.⁵¹

Example: A new aftercare and support service for breast cancer patients at Good Hope Hospital.⁵²

This test community has redesigned the care and support pathway for breast cancer patients who have completed treatment for primary breast cancer.

The test community has redesigned aftercare services so that it is providing (i) a telephone based support service by trained cancer nurses, (ii) a service which provides practical home based support, (iii) a home based care management service for complex needs and (iv) a tailored self-management programme for patients. Services will be accessed by patients following individual assessment and a tailored survivorship care plan. All patients will be offered participation in a new self-management programme which is integrated within the new aftercare pathway.

The self-management programme is based on a course developed at Coventry University called HOPE (Helping Overcome Problems Effectively) and is integrated as part of the aftercare pathway.

The evaluation is looking at patient reported quality of life, changes in lifestyle factors, confidence and motivation to self manage, patterns of health care utilisation, and feelings of hope and gratitude. These are being measured immediately, before and after the course, and at 6 and 12 months after the course.

In addition a skills training programme for professionals in the pathway is being tested and evaluated through patient reported experience of consultation styles. The results of this programme will be available by May 2010.

The results are expected from November 2010.

⁵¹ Thomas R. et al (2009) Life after cancer – rehabilitation at home can improve well being and survival. British Journal of Healthcare, 5(1);10-12. And see Thomas & Davies 2007 4

⁵² NHS Birmingham East and North, Pan Birmingham Cancer Network, Heart of England NHS Trust, National Cancer Survivorship Initiative, NCSI Test community survivorship improvement project ongoing. Macmillan Cancer Support, 'Living with Cancer', Report 2008

Example: Macmillan's 'New Perspectives' programme

New Perspectives – a course for people living with cancer facilitated by people living with cancer – is a six-week self-management course specifically developed by Macmillan Cancer Support.

The course is a cancer specific version of the Chronic Disease Self-management Programme originating from Stanford University in the United States, which the Expert Patients Programme (EPP)⁵³ is based on. A national evaluation of the EPP found that such courses are a useful addition to the current services for the management of long term conditions, and are likely to be cost effective.

The New Perspectives course aims to improve the skills and confidence of participants to manage the day-to-day challenges faced when living with a cancer diagnosis through activities such as facilitated discussion and problem-solving.

The course, which is available throughout the UK, is facilitated by two trainers who themselves have experienced cancer which helps to develop an atmosphere of shared support and understanding.

Course evaluation has shown that participants particularly respond to the emphasis on positive thinking and action planning, with many reporting many important lifestyle changes following attendance. As one participant remarked, *'The course has helped me to re-evaluate how to move forward with life and given me new perspectives of what is achievable'*.

⁵³ National Primary Care Research and Development Centre, National Evaluation of the Expert Patients Programme, Executive Summary 44, March 2007; Key Findings (Research into Expert Patients – Outcomes in a Randomised Trial)

Example: Maggie's Cancer Caring Centres 'Where now?' programme:

Maggie's programme of professional, emotional and psychological support can transform the way that people live with cancer.

"Where now?" is a series of six workshops which has been developed to help people affected by cancer make the adjustment between completing treatment and moving on to follow up. The workshops give the opportunity for people to make lifestyle changes, adjust to living with uncertainty and fears of cancer recurrence and take a fresh look at their priorities in work, home-life and relationships.

"Where now?" comprises the following topics:

- > Exercise
 - Using exercise to combat fatigue, build confidence and become part of everyday living beyond cancer
- > Healthy eating
- > Relaxation and stress management
 - Managing stress in family and work life
- > Emotional well-being
 - Living with uncertainty and the fear of cancer recurrence
 - Looking afresh at relationships and what you want out of life
- > Being a partner in your long term medical management
 - Communicating with your medical team
 - Short and long term health risks after cancer
 - Follow up care
 - Genetic implications of cancer

People who have participated in Maggie's "Where now?" programme have reported positive changes in health related quality of life and lifestyle change.

"Wow....I can't believe I've actually done a sit up!...I've been so tired, no energy..."
55yr old woman 4 months after breast cancer treatment

"The group understands that my life is not the same...I'm different...now I have to help my family see I'm different..that's the hard bit" 49 yr old man after treatment for prostate cancer

Example: Yorkshire Cancer Network Test Community

This test community aims to develop a web-based information system to allow both patients, and authorised clinical or social services staff, to access and share the core information that is required to efficiently and effectively meet their health needs.

By using a web-based electronic-platform, patients will be able to share agreed levels of information with health and social services professionals as they feel appropriate. A web-based system will facilitate a radical change in how such patients will be managed within the Yorkshire Cancer Network (YCN).

This IT initiative is an essential component of a wider YCN project that aims to transform the management of late effects of cancer treatment for those treated as children and young adults.

For the patient this IT initiative will ensure greater patient empowerment via:

- > choice as to where they wish to have their late effects managed (community or tertiary)
- > provision of a rapid access route to their key-worker within the tertiary Late Effects Team
- > access to their own treatment history and future planned care (Cancer Survivor Care Plan)
- > greater knowledge provided via a comprehensive range of supporting information/ sources of advice
- > ensuring control and certainty through e-mail alerts to ensure planned interventions/monitoring is undertaken on schedule
- > availability of information that the patient can choose to share with health, social care and education professionals as the patient feels appropriate
- > peer support via a secure web-based forum.

5.12 Piloting work being undertaken for the NCSI children and young people work stream includes testing the impact of physical activity for children and young people survivors.

5.13 The NCSI children and young people work stream test communities include work to pilot using technology to share and provide information to patients, carers and practitioners. It is envisaged that moving from parental control of care to self-management of care is part of the shift that allows empowerment for young adults. Allowing children and young adults greater access to, and sharing of, information related to their cancer treatment and late effects will enable young people to have self managed care and the confidence to be autonomous.

Example: NHS Cambridge Test Community

Testing will identify the impact of introducing an exercise programme on the quality of life and other measures in children and young people survivors.

It is envisaged that introducing exercise programmes as part of treatment (either during or after treatment finishes) reduces chronic fatigue, increases the ability to do more activity, reduces obesity, improves concentration and improves other physiological measurements.

A structured exercise programme is offered either at the beginning or end of treatment. Exercise would include either a structured number of exercises, which could be performed at home or at a gym. A DVD is also being produced as a means of exercise instruction and additional support.

6. Tailored support for patients in remission, those with consequences of treatment and those with active and advanced disease



Case study

Sue, 57, Tyne & Wear, diagnosed with breast cancer in 2002

'Going back to work after treatment was tough as I felt tired constantly and my joints ached. I tried managing by cutting back to a three day week but then suffered bouts of depression. Both managers and colleagues expect cancer survivors to be back to 'normal' when they hear treatment was 'successful' but I've struggled for six years, I've tried to get the Occupational Health team to understand that my problems are because I had cancer, but I've failed to get the message across. I've decided to call it a day.'

Tailored support for patients in remission

6.1 For patients who are in remission following cancer treatment, the focus of follow up care is currently on monitoring for signs of further disease or recurrence, rather than addressing the wider range of needs that people may have at this stage. As we have described earlier in this document, despite being resource intensive for the NHS, this approach appears to offer little benefit for many patients, especially as recurrences are most frequently detected by patients between clinic visits. The

National Cancer Survivorship Initiative (NCSI) vision for future survivorship care is that it should not be necessary for survivors to attend an out-patient appointment at clinic simply to have a surveillance test ordered. This could and should be done through automated call and recall processes (as in the cancer screening programmes) involving blood tests and imaging without routine follow up appointments.

6.2 In 2007, NHS Improvement completed a survey of perceptions and preferences for follow up cancer care. Around 3000 clinicians and service users replied. Responses to this survey suggest that clinicians and service users consider that the key reasons for follow up are; monitoring for early complications following treatment, detecting recurrence and detecting late effects of treatment.⁵⁴ Those surveyed had some experience in the use of different models, including patient triggered follow up, nurse led, group, telephone and postal follow up. Those who had experienced these services were positive about them but those who had not experienced a different model expressed a preference for hospital based follow up. Nurse-led follow up services have been positively evaluated by breast and prostate cancer survivors.⁵⁵

⁵⁴ www.improvement.nhs.uk/cancer/

⁵⁵ Faithful, S, Corner, J, Myer, L, Huddart, R and Deranaley, D (2001) Evaluation of nurse-led care for men undergoing pelvic radiotherapy. *British Journal of Cancer* 85(12) 1853-1864

Example: Birmingham Children's Hospital NHS Foundation Trust and University Hospital Birmingham NHS Foundation Trust Test Community

This test site is developing a risk stratified model of care for the tailored long term follow up of childhood cancer survivors through acute surveillance for early recurrence at Birmingham Children's Hospital to adult based long term follow up services at Selly Oak Hospital.

The three models to be developed are:

- > Postal / telephone survey in conjunction with the West Midlands Regional Children's Tumour Registry for low risk patients
- > Nurse led follow up clinics will be run in parallel with medical long term follow up clinics, for medium risk patients
- > Consultant led follow up clinics – development of current practice to allow consultant-led follow up for patients predicted to have the greatest need.

This model of care is intended to provide:

- > access for patients to robust, sustainable and reliable levels of follow up which are appropriate to the patients' needs with ease of transfer of patients between levels of care depending upon patient need
- > a regular postal follow up questionnaire to GPs of childhood cancer survivors which provides accurate, reliable data which contributes to the patients' clinical care
- > continuity of care from completion of therapy through to adult based services
- > patient / parent involvement in the development of their individual care pathway.

Staying at or returning to work

'Our vision is that people with cancer will be enabled to remain in or return to work after a cancer diagnosis if they want to and if this is appropriate for them. People with cancer are routinely given the information, advice and support they need to do so as well as routinely offered financial information and advice.'

Maureen Dowling, Cancer Network Lead Allied Health Professional and Chair of the NCSI Work and Finance Work Stream

6.3 A shift towards tailored support for people affected by cancer includes improved information and support for cancer survivors and employers to enable those cancer survivors who want to, to get back to work. The NCSI work and finance work stream has developed a model of support for those living with cancer who want to, return to, or remain in work. The model proposes four tiers of vocational support for people living with cancer:

- > Level 1 – Information and Support provided through electronic and printed media
- > Level 2 – One to one support and signposting through telephone help lines and digital media
- > Level 3 – Self-management programmes accessed during or following treatment
- > Level 4 – Specialist Vocational Rehabilitation service.

6.4 The model is underpinned with the values of dignity, empathy, respect, humanity and normality. The intention is that the model supports both the individual diagnosed with cancer and the employer. This vocational rehabilitation model will be piloted during 2010.

Meeting the long term needs of children and young people

'Our vision is that children and young people surviving cancer have consistent, holistic, seamless and appropriate care and information to enable each individual to lead fulfilling lives beyond their cancer treatment.'

Faith Gibson. Senior Lecturer, Great Ormond Street Hospital and Chair of the NCSI Children and Young People Work Stream

6.5 The children and young people work stream are working with NHS Improvement to test a number of approaches to after care for children and young people. The children and young people test communities are piloting improved information exchange between patients and parents and health care professionals via survivorship care plans. The work includes piloting a risk stratified methodology of follow up care and planning for ongoing care and potential late effects. The intention is to meet the holistic needs of this group of survivors and reduce the number of patients who have the potential to become 'lost' to follow up.

6.6 Children and young people surviving cancer have a range of needs including education, employment and psychological support. It is particularly important for the overall wellbeing and future lives of this group of survivors that they are able to maintain continuity at school and have support for successful entry into their first employment. As part of the NCSI children and young people work stream, CLIC Sargent are undertaking a review of the existing guidance and policies that currently support these areas. Outcomes from this work will help to inform future care and provision for young cancer survivors. An initial report will be available in March 2010.

Tailored support for people with consequences of cancer treatment

'Our vision is that consequences of cancer treatment are acknowledged and therefore described, measured, coded, enumerated and reported routinely by the NHS. Preventable consequences are avoided through universal access to the safest and most effective treatments for cancer. Where adverse consequences cannot be prevented, effective and accessible services are available for all patients in order to reduce functional impairment and to alleviate distress, whether physical or psychological. The nature and content of the services provided is matched to need using stratified assessment tools. There is a continuing research and development programme to improve our understanding of the consequences of cancer and its treatment, and this research programme is seamlessly integrated into mainstream research into the treatment of cancer.'

Jane Maher, Chief Medical Officer, Macmillan and Chair of the NCSI Consequences of Treatment Work Stream

Case study

G, 31, South Coast, with a small son, diagnosed with cancer of the cervix.

G was cured by surgery and radiotherapy but she was left with severe bowel problems. She would have diarrhoea up to 12 times a day, would repeatedly soil herself and her weight dropped from 11 to 7 stone. She had sub acute obstructive symptoms every 6 weeks. G found it impossible to work regularly. Her doctors locally repeatedly said that nothing could be done. After seven years, G was referred to a specialist service in London. Three simple conditions were diagnosed and appropriate treatment instituted after a single clinic visit. Three weeks later bowel function was normal. 'It's like a miracle' she said. 'Thank you for giving me my life back.'

6.7 The NCSI has identified the need for a shift towards supporting cancer survivors through personalised information and specialist support to enable them to prepare for and deal with consequences of treatment and to ensure early recognition of signs and symptoms of further disease. This shift will mean that patients know what might happen, what to do and whom to contact.

6.8 Implicit within the principle of successful treatment of cancer is an acceptance that there is a real potential for some degree of damage to normal tissues. The consequences of cancer or its treatment can be defined as symptoms and/or changes in function – whether physical or psychological – which develop following treatment for cancer. This definition embraces a wide variety of problems, the nature of which will depend both upon the primary site of the original cancer and the treatments deployed. These problems might be persistent or develop months or years later, after a period of normal health, and when neither the patient or healthcare professional links them to previous cancer treatment. In some cases, the consequences of cancer or its treatment will take the form of a new long term or chronic condition or an exacerbation of an established co-morbidity.

6.9 The NCSI consequences of treatment work stream estimate that between one quarter and one fifth of people treated for cancer (up to 500,000 people in the UK as a whole) are currently experiencing a consequence of cancer which has an adverse impact on the quality of their life.⁵⁶ This number is expected to increase to 600,000 by 2020.⁵⁷

⁵⁶ Based on levels of need identified in: Armes PJ, Richardson A, Crowe M, Colbourne L, Morgan H, Oakley C, Palmer N, Ream E & Young A. Patients' supportive care needs beyond the end of treatment: a prospective and longitudinal survey. *J Clin Oncol* 27: 6172-6179 2009

⁵⁷ Based on rate of increase in survivorship prevalence identified in: Cancer prevalence in the United Kingdom: estimates for 2008 J Maddams, D Brewster, A Gavin, J Steward, J Elliott, M Utley & H Møller *Br J Cancer* 2009 101: 541-547

6.10 Cancer treatments in young people can have lasting effects on physical and mental health leading to increased morbidity and mortality. The effects can have a significant impact on achieving autonomy. Consequences of treatment for this group include effects on growth and development; vital organ function; fertility and reproduction; and secondary tumours. 67% of childhood cancer survivors go on to develop one or more late morbidities. The morbidity burden increases with time from completion of treatment.⁵⁸

6.11 There is little awareness of the consequences of cancer and its treatment among the public, primary healthcare professionals and cancer survivors. A Macmillan survey of survivors found that 40% were unaware of the long-term consequences of cancer and its treatment and among those who were aware, some did not know which effects might affect them personally. A poll of 60 GPs with an interest in cancer found that the majority (64%) had not received any training or education about the long-term consequences of cancer and its treatment.⁵⁹

6.12 Awareness among secondary or specialist healthcare professionals is higher.⁶⁰ However secondary care doctors, specialist nurses and therapeutic radiographers often do not feel confident to discuss consequences of treatment

without inappropriately worrying their patients. Cancer specialists may not have the appropriate skills to deal with chronic treatment related problems, for example, chronic bowel conditions after the treatment of pelvic cancers or cardiac problems related to chemotherapy for breast cancer.

6.13 Many consequences of cancer and its treatment can be embarrassing for the patient, which means they may not raise the issue with their GP or specialist. This is a particular issue in relation to faecal and urinary incontinence and sexual and relationship issues after treatment of pelvic cancers.

6.14 Although supported self-management will have an important role to play in helping patients to deal with the adverse consequences of treatment for cancer, it will not be the entire solution. The shift towards support for consequences of treatment is from passive to active and involves taking steps to assess more accurately the scale and impact of the consequences of treatment. It also involves devising interventions that prevent or mitigate these effects – reducing the risk of them becoming problems for the long term.

6.15 We do not yet know what the long-term consequences of many contemporary cancer treatments are likely

⁵⁸ Oeffinger K, Martens A, Sklar C Chronic Health Conditions in Adult Survivors of Childhood Cancer N Eng J Med 2006 Vol 355, 1572 – 1582

⁵⁹ Cancer Survivor: Health & Well Being Follow up Survey Oct 2008

⁶⁰ Cancer Survivor: Health & Well Being Follow up Survey Oct 2008

to be and need to define the nature and extent of the problems that patients are likely to face. This will be a continuing process – as treatments evolve, so do their consequences. Case-finding and understanding effects are pre-requisites for effective management of consequences of treatment. It requires expertise to map symptoms to the treatment that was given to each individual and to look for patterns. This requires better understanding of the short, medium and long-term consequences of cancer treatment in acute and primary care – so that aftercare services can anticipate future problems and provide early support, intervention and specialist services where necessary.

6.16 Most consequences of cancer treatment do not have to be disabling, but after appropriate specialist assessment and diagnosis, can be managed effectively, often by patients themselves. However, a minority will have more complex problems requiring specialist multi-disciplinary management. Recent estimates, based on literature and discussion with senior health professionals and patients suggest this may involve 5-10% of those with common cancer types over a 20-year period.⁶¹

Level of need	Estimated number of patients involved (percentages will vary according to cancer)
Level 1 – supported self-care with quick access back into the system if and when needed to improve early detection and management.	c70%
Level 2 – level of requirement requiring low levels of secondary and/or primary care input after specialist assessment, diagnosis and care planning.	c25%
Level 3 – highly complex consequences of treatment requiring case management by an assigned key worker (often a Clinical Nurse Specialist) with multi-disciplinary support.	c5%

⁶¹ Life after cancer treatment -- a spectrum of chronic survivorship conditions Denton et al : Clin Oncol (R Coll Radiol). 2007 Dec;19(10):743-5. Epub 2007 Oct 25

6.17 We should expect that increased use of regimens that combine radiotherapy and chemotherapy, which are associated with significant improvements in survival, will result in an increase in the late consequences of treatment.

6.18 The NCSI consequences of treatment work stream is working with the National Cancer Intelligence Network (NCIN) to understand prevalence of consequences of cancer treatment. It will start with the NCIN clinical reference groups for breast and prostate cancer examining the prevalence of cardiac and bone complications and second and subsequent malignancy after treatment. This work will be complete in late 2010. This work could be extended to include analysis of factors that predict an increased probability of developing late effects.

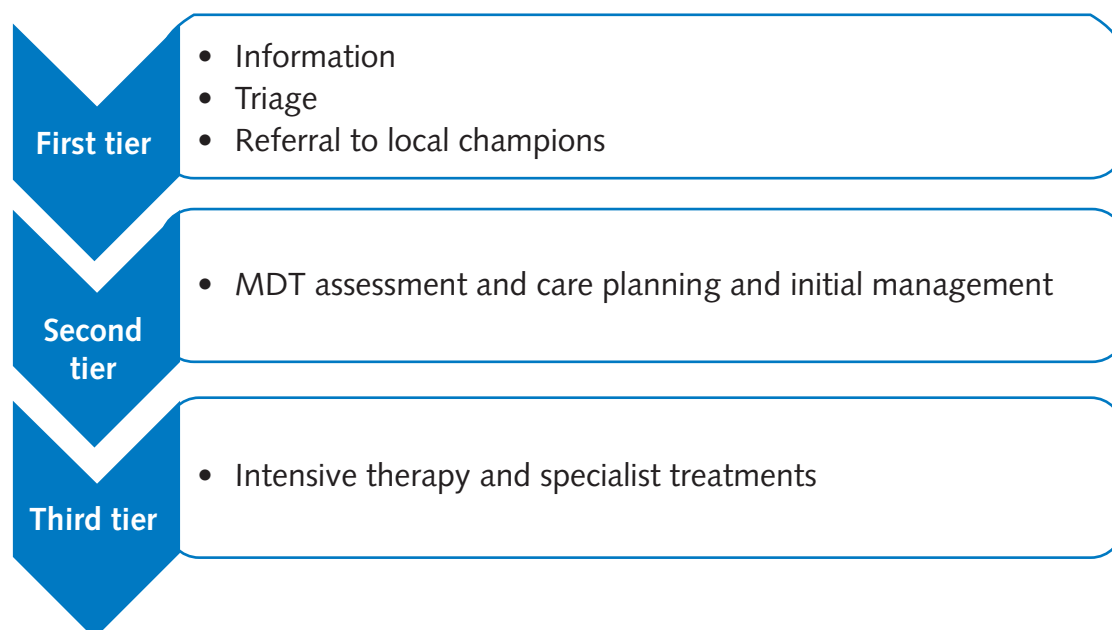
6.19 The Royal College of Radiologists is also undertaking a repeat of an audit in 2000 of the late consequences of pelvic radiotherapy and chemotherapy for cancer of the cervix. The consequences of treatment work stream is considering how to build on this work to identify patterns of health service resource utilisation associated with different levels of consequences of cancer treatment. The work stream is considering how to extend current piloting work related to the creation of specialist clinics, symptom measurement and risk stratification with this group of patients. This work will improve understanding and awareness of consequences of cancer and treatment and complement the work of the

NCSI research work stream to develop a systematic approach to risk stratification of cancer survivors.

6.20 The Department of Health and the NCSI consequences of treatment work stream have commissioned the British Society of Gastroenterologists and the Royal College of Physicians to produce practice guidance on the diagnosis and management of bowel problems related to consequences of cancer treatment. This guidance is expected to be available in March 2010. This work could be used as a model for approaching other problems such as neurological dysfunction (including cognitive problems), bladder problems, endocrinological disturbance and psycho-sexual problems.

6.21 The NCSI consequences of treatment work stream is establishing a community of clinical leaders with expertise in the consequences of cancer treatment. Twelve nurses and allied health professionals have been identified by the NCSI to work together over a 2-3 year period to develop an influential programme of research and service development. The community aims to develop and improve services to enable informed, well-supported patients, flexible, responsive services; and, more productive conversations between healthcare professionals and patients.

6.22 The NCSI consequences of treatment work stream highlight a proposed model for specialist services for those with moderate and severe consequences of



treatment (levels one, two and three identified above).

6.23 This model incorporates the idea of ‘local champions’ for specialist clinics. Providing support and specialist services for those with moderate or severe consequences of treatment is a particular challenge and the consequences of treatment work stream have reviewed models of care for this group of survivors. These include specialist services for the management of bowel consequences at the Royal Marsden Hospital and a model developed for patients with severe complex problems after radiotherapy for breast cancer – the RAGE model.

Tailored support for people with active and advanced disease

‘Our vision is that cancer survivors have a personalised assessment and care plan. Survivors have easy access to support and rehabilitation services. There are prompt and sensitive pathways back into the system for side-effects of treatment, recurrence or secondary cancer. The model of care for recurrent or secondary cancer delivers clinical and care standards comparable to that of primary treatment. End of Life Care decisions are made together by patients and professionals.’

Roger Wilson, Chief Executive,
Sarcoma UK and Chair of the NCSI
Active and Advanced Disease Work
Stream

6.24 Some people will live with advanced cancer as a long term illness and have a number of treatments. The NCSI active and advanced disease work stream has worked with cancer survivors and clinicians to

describe the patterns of advanced disease, to identify the needs of patients with active and advanced disease and the services that are needed to support this group of patients. Specialist palliative care and

Example: Specialist Support Services: Radiotherapy Action Group Exposure (RAGE) Intervention Pilot Programme

R.A.G.E. is a group of women who are living with the long-term effects of radiotherapy that was given to treat breast cancer.

R.A.G.E., Macmillan Cancer Support and the National Cancer Action Team designed a programme of intervention aimed at helping R.A.G.E. members access the services and support they need.⁶²

The programme is testing a number of interventions for this group including:

- > initial identification through membership of a national self-help group
- > matching MDT membership to needs identified through telephone contact
- > inviting cancer centres to assemble appropriate teams to assess small numbers of patients
- > education and awareness-raising
- > auditing how easy it is for care plans to be implemented locally
- > auditing the impact of a patient held budget

240 patients were identified and invited to complete self report questionnaires.

126 women accepted an invitation to attend a multi-disciplinary assessment.

158 women received grants and were sent a follow-up form to solicit information of how grants were actually spent.

A final report will be available in June 2010.

⁶² This built on the recommendations made by the Maher Committee, the Hanley and Staley (2006) report, as well as consultations with R.A.G.E. members.

end of life care services do not generally address the needs of people living with active cancer who are not thought to be 'dying'.

6.25 Breast Cancer Care's Secondary Breast Cancer Taskforce has done valuable work to understand the needs of those with metastatic (secondary) breast cancer diagnosis. Breast Cancer Care have found that this group of survivors often feel isolated and lack adequate coordination of care and support. In particular in comparison to the care and support they received at their primary diagnosis.⁶³

6.26 The NCSI has identified the need to develop new models of care for people with active and advanced disease, which include the involvement of a multi-disciplinary team. In 2010 the NCSI will focus on developing models of care for this group of survivors.

6.27 The NCSI active and advanced disease work stream have commissioned a review of the evidence of the benefits of keeping well for those with active and advanced disease as well as examining current good practice in this area.

6.28 Some patients with active and advanced disease will go on to need palliative and end of life care services. The End of Life Care Strategy⁶⁴, which centres on personal care planning including advance care planning, is working to address this for everyone approaching the end of life, including cancer survivors. In 2010 the active and advanced work stream will develop principles for best practice in the transition to end of life care.

⁶³ Breast Cancer Care, Secondary Breast Cancer Taskforce, Improving the care of people with metastatic breast cancer, Final Report, November 2008.

⁶⁴ End of Life Care Strategy, Department of Health, July 2008.

7. Measuring outcomes for survivors



7.1 The National Cancer Survivorship Initiative (NCSI) has identified a need for a new emphasis on understanding and monitoring the concerns and outcomes for cancer survivors through the routine use of Patient Reported Outcome Measures (PROMs) in aftercare services.

7.2 This measurement of concerns and outcomes is important to:

- > identify how quality of life can be improved for individuals and to help plan care for individual patients
- > assess quality of care in individual services
- > measure progress on survivorship care across the country.

7.3 This measurement can be achieved through patients recording current problems and concerns, as a prompt for more detailed discussions with healthcare professionals (as described in chapter 4). It may also be achieved through sending questionnaires to patients at defined points (e.g. 1, 5 and 10 years after diagnosis) to assess health related quality of life: allowing for comparisons across the country and to detect progress on survivorship over time. Measurements might also be taken by integrating PROMS measures into broader patient experience surveys where feasible to do so which enable assessments to be made about quality of care.

7.4 This is a new emphasis on measuring outcomes for cancer survivors across the whole range of health and quality of life domains – physical, psychological, social and emotional as well as in relation to quality of care.

7.5 A range of questionnaires have been developed and are being used as PROMs with cancer survivors. In 2010, the NCSI will do further work to test the routine use of PROMs in aftercare to track progress in improving care and support for cancer survivors.

7.6 To date, the NCSI has identified a selection of PROMs questionnaires that are used for understanding quality of life issues for cancer survivors. In addition, the Department of Health has commissioned the Patient-reported Outcome Measurement Group at the University of Oxford to review the evidence for PROMs for breast, lung, colorectal and prostate cancers. This work is expected to be complete later in 2010.

7.7 The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)⁶⁵ and the EuroQoL (EQ-5D)⁶⁶ questionnaires are being used for comparison of outcomes for groups of patients and with patients with other disease types.

⁶⁵ Ware JE, Sherbourne CD. The MOS 36-item short form health survey (SF-36). Conceptual framework and item selection. *Med Care* 1992; 30:473-483.

⁶⁶ EuroQol Group. EuroQol-A new facility for the measurement of health-related quality of life. *Health Policy*. 1990; 16: 199-208.

7.8 The Quality of Life in Cancer Survivors (QLACS)⁶⁷ and the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire – C30 (EORTC QLQ-C30)⁶⁸ questionnaires are used for understanding outcomes for individuals.

7.9 The value of using a 'screening' measure prior to providing patients with longer and more detailed questionnaires has also been considered, with the Social Difficulties Inventory⁶⁹ offering potential for this.

7.10 The ease of providing and analysing data from PROMs will be crucial to uptake and use in cancer aftercare services. The NCSI consider that an IT based, rather than a paper based, system is most likely to be effective.

7.11 This shift is towards better measurement of survivors' experience of care, including through survivorship questions being included in the National Cancer Patient Experience Survey Programme. The Cancer Reform Strategy commitment to develop and implement a Cancer Patient Experience Survey Programme provides an opportunity to assess the quality of survivorship care (as well as assessing patients' perceptions of diagnosis and primary treatment). The first survey is due to take place in Spring 2010, with results available by Summer 2010.

⁶⁷ Avis NE, Smith K, McGraw S, Smith RG, Petronis VM, Carver CS. Assessing quality of life in adult cancer survivors (QLACS). *Qual Life Res* 2005; 14(4): 1007–1023.

⁶⁸ Aaronson N.K., Ahmedzai S., Bullinger M. et al (1987) The EORTC core quality of life questionnaire: Interim results of an international field study. In: Osoba D. ed. *Effect of Cancer on Quality of Life*. Boca Raton, FL: CRC Press 1991: 185-203.

⁶⁹ Wright EP, Kiely M, Johnston, C, Smith, AB Cull, A. and Selby PJ. (2004) Development and evaluation of an instrument to assess social difficulties in routine oncology practice *Qual Life Res* (2005) 14: 373–386

Advantages and Disadvantages of two cancer specific PROMs for cancer survivors:

Measure	Advantage	Disadvantage
EORTC QLQ-C30	<ul style="list-style-type: none"> > evidence based and shown to be effective in understanding concerns of survivors > demonstrated to be used by doctors > can be used with touch screen technology 	<ul style="list-style-type: none"> > originally designed for clinical trials and so might not be responsive to the needs of cancer survivors > may not be sensitive enough to show change in outcomes for survivors > does not cover all aspects of survivorship experience – e.g. financial, social, family issues only mentioned briefly
QLACS	<ul style="list-style-type: none"> > survivor-specific as well as cancer-specific > measures both generic and cancer-specific quality of life, considering the survivor in the wider context of the patient experience > very broad – picking up a range of survivorship issues, including financial and family concerns 	<ul style="list-style-type: none"> > may not be sensitive enough to show changes in outcomes

A close-up photograph of a middle-aged man with a shaved head and glasses. He is wearing a light-colored shirt with thin vertical stripes in blue and yellow. He is resting his chin on his clasped hands, looking off to the side with a thoughtful expression. The background is blurred, suggesting an office or laboratory setting.

8. Research

'Our vision is that there is a strategic programme of new research to answer the priority areas of uncertainty in cancer survivorship – with a strong emphasis on practical interventions to improve the experience, health and wellbeing of people living with cancer. This programme will include the development of tools for assessing the likelihood and significance of different events occurring in the experience of people living with cancer, enabling timely, relevant and effective support to be provided. A longer term vision is to achieve a national portfolio of research trials open to patients at all stages of the survivorship pathway (not just those undergoing treatment). The trials would include a particular focus on practical support interventions for cancer survivors.'

John Neate, Chief Executive, The Prostate Cancer Charity and Chair of the NCSI Research Work Stream

8.1 One of the aims of the National Cancer Survivorship Initiative (NCSI) is to identify what is known and not known about the issues that affect people living with cancer and about care and support for cancer survivors. In June 2009, the NCSI research work stream commissioned a comprehensive review of existing literature and evidence about care and support for adults following cancer treatment. The intention of the review was to identify gaps in knowledge about survivorship to inform a future, long-term survivorship research programme.

8.2 The review included published literature and unpublished reports and studies, ongoing research and studies and collections of data. The review was completed by the National Cancer Research Institute (NCRI) Supportive and Palliative

Care Research Collaboratives, COMPASS and CECa (the Cancer Experiences Collaborative).⁷⁰ The review covered the psychosocial, physical and practical aspects of survivorship and interventions aimed at improving the health and wellbeing of cancer survivors.

8.3 The research work stream went on to complete a consultation with researchers, clinicians and people affected by cancer on their priorities for future research.

8.4 A review of the evidence about models of care for children and young people following cancer treatment is underway and initial results will be available by April 2010.

8.5 The NCSI research work stream is currently gathering information from its work in 2009 to identify a set of research

⁷⁰ The supportive and palliative care research collaboratives are supported by six NCRI partners, including Cancer Research UK, the Economic and Social Research Council and the Department of Health. They are working to bring together researchers to address the aims of the NCRI's Report on Supportive and Palliative Care in the UK (2004).

priorities to be published at the beginning of 2010. These research priorities will be developed into a programme of research on cancer survivorship that will be taken forward in two ways, both in close collaboration with the National Cancer Research Institute (NCRI).

8.6 The first will be to target and maximise the use by researchers of existing relevant sources of research funding, including the National Institute for Health Research (NIHR) and Medical Research Council.

8.7 The second will be to develop a new, joint research funding budget with contributions from organisations with a particular interest in the area.

8.8 There are five broad areas of work that are being brought together to create the research priority areas:

- > the mapping exercise carried out to identify key issues faced by cancer survivors
- > the comprehensive review of the evidence base for cancer survivorship undertaken by the NCRI Supportive and Palliative Care Research Collaboratives
- > the consultation exercise with stakeholders on their views of the most important areas for future research

> output from the NCRI Rapid Review of Research into Survivorship after Cancer and End of Life Care, undertaken to set a clear future direction, from the perspective of organisations who fund research in these areas. The review has identified a number of actions which will be taken forward during 2010, including the promulgation of existing funding sources, targeted new funding streams, and promotion of already funded studies to increase uptake in the cancer networks

> research needs and key questions identified by the six other NCSI work streams, which will be tested against the findings from the evidence review to clarify which questions have already been answered and which will need to be met through new research.

8.9 Suggested criteria are being developed to help determine the research priorities. A key requirement is that new research should make a significant difference to the lives of people living with cancer as rapidly as possible.

8.10 Research already underway that is relevant to the future research agenda – including a project to further understand and model cancer prevalence and work on risk stratification – will all be taken into account in drawing together the priority areas and developing the new research programme.

8.11 The full report of the research work stream is expected to be published later in 2010 and is designed to provide a practical tool for researchers, research funders, health service providers and commissioners, cancer survivors and policy makers in driving improvements in survivorship research and the practical experiences of cancer survivors.

9. Next steps



9.1 This chapter sets out some of the next steps for the National Cancer Survivorship Initiative (NCSI). These include how the NCSI will focus on piloting models of care to achieve the vision for improved care and support, developing the longer-term research programme for survivorship and supporting the health and care workforce to improve care and support for cancer survivors.

9.2 During 2010, the NCSI will focus on gathering evidence of the quality and productivity benefits of evaluated models of survivorship care and support.

Test communities

9.3 NHS Improvement is supporting the NCSI through piloting new approaches to care and support for cancer survivors. There are now 38 test communities; 28 piloting approaches to care and support for adults and 10 communities piloting approaches for children and young people. The aims of the testing work are to:

- > develop and evaluate effective pathways which provide measurable improvements in the health, wellbeing and experience of care of cancer survivors
- > build principles for post treatment care and support that will inform commissioning, workforce and providers of care.

9.4 There are 16 adult test communities who are piloting new approaches to

care based on effective management of the patient pathway. The communities are looking at the care and support for patients with a range of cancers. All of these communities are now in the testing phase and this will continue through to late summer 2010.

9.5 The Picker Institute experience of care survey provides a baseline showing where experience of care can be improved in these 16 adult test communities. A second survey will be conducted during the summer of 2010 to provide evidence about the national and local impact of the testing work.

9.6 Twelve test communities have also been commissioned to pilot the NCSI assessment and care planning framework and summary treatment record. These will be tested with patients who have lung, colorectal, head and neck cancer or myeloma. The test communities will pilot the assessment and care planning framework at different trigger points in the survivorship pathway. This piloting work will get underway in January 2010 and will be completed in Summer 2010. The impact on quality of life for cancer survivors in these test communities will be evaluated using both qualitative and quantitative methods.

9.7 There are 10 test communities piloting a range of models of care and support for children and young people, these include; assessment and care planning, models of care for the transition

to adult services for young people, using IT as part of supported self-management for aftercare, nurse led follow up clinics and maintaining contact with long term survivors.

9.8 The location of all of the NCSI test communities can be seen below.

9.9 During 2010, NHS Improvement will pull together learning from the testing work around the country to inform principles for commissioning new models of care and support.

Workforce

9.10 The NCSI has reviewed the emerging implications for the health and care workforce of the shifts that are needed to improve care and support for cancer survivors. Key themes are:

NCSI Test Communities

- Models of Care
- Children and Young People
- Assessment and Care Planning



- > The current cancer workforce needs to adapt to the changing emphasis of care and support and the role of a key worker needs to become embedded into practice
- > Cancer patients are increasingly supported in the community. With more emphasis on after care, ongoing support and the management of the consequences of treatment, primary care will need to play a greater part in the continuing care of people with cancer. Therefore, key primary care staff (particularly GPs, practice nurses, district nurses, specialist nurses and allied health professionals) will be required to develop existing and new skills
- > If the holistic needs of people with cancer are to be addressed then social care skills and competencies must be considered across the workforce
- > There is a need to develop the role of the volunteer workforce to co-deliver care and support
- > The incidence of co-morbidities is going to increase and so the workforce will need to be aware of the possible interactions of conditions
- > New roles, such as case managers and cancer supporters, need to be identified and models defined
- > Need to develop skills in assessment and managing consequences of cancer treatment in the specialist cancer

workforce to support those with complex needs

- > Need to develop skills and ways of working to care for patients with advanced cancer
- > Working patterns to be organised to facilitate tailored follow up and rapid access to specialist services when needed.

9.11 The NCSI has also started to identify the generic skills required across the workforce, these include:

- > **Holistic needs assessment skills** – to work in partnership to facilitate a patient-led assessment on an ongoing basis on the emotional, financial, physical, social, information, spiritual, psychosexual and practical needs that people living with cancer face utilising the skill of narrative assessment and enabling patient completed screening tools
- > **Navigation skills** – to identify and understand individual need, enable care that is personalised, sign-post to other services (including non-health) and enable people to access, identify, appraise and interpret information that allows them to determine their future
- > **Coordination skills** – to act as a key worker and coordinate the 'virtual' multi-disciplinary team that are involved in supporting the after care pathway, as the breadth of the team supporting

people is likely to increase in the future and be across traditional service boundaries

- > **Risk stratification skills** – to ensure that there is knowledge of the likely consequences of treatment, that care planning is personalised and that resources are appropriately directed. Including assessing the risk to vulnerable people who are open to financial and other abuse
- > **Skills to enable self-management:**
 - Working in partnership with the patient to support health and well-being
 - Facilitative skills – including effective communication, goal setting, motivational interviewing, coaching and behaviour change techniques
 - Promotion of health and healthy lifestyles
 - Enable and encourage self-assessment on an ongoing basis, including recognition of consequences of treatment
 - Enable recognition of the signs of recurrence and the need for rapid re-entry into services and mechanisms for re-entry
 - **Outcome measurement skills** – to collect and record the experience of care and also evidence the efficacy of care

- **Telecare/telehealth skills** – increasing use of telephone care and e-medicine management for specialist follow up and aftercare is currently burgeoning, without effective workforce development. Online support and assistive technologies are also rising
- **IT skills** – will underpin all the skills identified above.

9.12 Other specific skills include:

- > Skills and knowledge to understand and support the management of the consequences of cancer treatment
- > Highly developed communications skills, both in breaking bad news and exploring partnership working
- > Psychological and emotional support – this will include assessment and support within the level of competence for each individual clinician and the knowledge of when and how to refer onto specialist support services
- > Specialist knowledge e.g. consequences of cancer, understanding the interrelated effects of co-morbidities; financial and practical support; employment rights or practices; benefits; psychosexual and fertility
- > Interventional management through specialist training, psychosexual counsellors, physiotherapists and clinical nurse specialists

- > Vocational rehabilitation including occupational health advice and therapy
- > Support people to broker, employ and manage care givers using money from personalised budgets.

Implications for workforce development

9.13 There is an urgent need to prepare and develop both the current and the future cancer workforce with the skills identified, in particular, the skills to support patients in the transition to becoming a partner in care. The generalist workforce will also need to be enabled to develop some of the skills outlined, in order to provide continuing care for people living with and beyond cancer in every care setting.

9.14 Below, the workforce is divided into three distinct groups in order for workforce

development to be focused, with the priority being Group A and B.⁷¹ 'Staff' is used in the broadest context to mean nurses, doctors, allied health professionals, support workers, information staff and the social care workforce.

The way forward

9.15 There are already in existence a plethora of sources of supporting work, for example, pre-existing competence frameworks, learning materials from a wide range of organisations/Universities and bodies of evidence which list existing and relevant competencies. The NCSI will commission work to cross-reference all the existing sources that are relevant against the themes and skills that have been identified and develop new competencies if there are gaps. This will include analysis of the competencies for those providing management for long term consequences

Group Definition	Minimum Skill and Knowledge
Group A: Specialist staff, whose work focus is enabling people to live with and beyond cancer	Highest levels, through specialist training. To include all common core competencies
Group B: Generic staff who frequently deal with enabling people to live with a long term condition	Need to be enabled to develop or apply existing skills and knowledge to the principles and competencies. May require additional training in cancer specifics
Group C: Staff working in other services who are infrequently involved with enabling people to live with a long-term condition	Good basic grounding in the principles and competencies; alongside knowledge of where and how to seek expert advice or refer on

⁷¹ Adapted from the 'Common Core Competencies and Principles for health and social care workers working with adults at the end of life, June 2009)

of treatment – to identify additional training needs. Some of the key sources already identified are highlighted below:

- > Skills for Health – www.skillsforhealth.org.uk working with Skills for Care – www.skillsforcare.org.uk have produced 'Common Core Principles to Support Self Care' (2008) as part of the work on Long Term Conditions
- > Breast Cancer Care have developed a set of core competencies for key workers caring for secondary (metastatic) breast cancer patients 'Guide for Commissioners: meeting the nursing needs of metastatic breast cancer patients' Breast Cancer Care, November 2008 www.breastcancercare.org.uk
- > eLearning for Healthcare Projects – www.e-lfh.org.uk – elearning for end of life care around communication skills, advance care planning, care planning and assessment, and symptom management are being developed as well as elearning to support Long term Neurological Conditions learning for non-specialist staff
- > Skills for Health have also developed competencies related to Long Term Conditions Case Management and as part of the Integrated Cancer Care programme competencies were also identified for a supporting Care Tracker Role

- > Long Term Conditions 'Workforce Development Resource Pack' www.healthcareworkforce.nhs.uk

- > National Diabetes Support Team, Partners in Care: A guide to implementing a care planning approach to diabetes care.

9.16 Skills to enable partnership working and self-management are a key priority and developments focusing on these areas may be able to draw on and be incorporated into existing work. Training such as the Advanced Communications Skills Training for adults with cancer already exists and will be important to the delivery of the learning portfolio required.

9.17 Local commissioners and services are encouraged to undertake an audit of their workforce skills to meet the survivorship agenda and identify gaps in services and roles (new roles or services may be required or existing roles and services redesigned). For adult survivors of childhood cancer, workforce guidance is provided by the Children and Young People Improving Outcomes Guidance.⁷² The NCSI consequences of treatment work stream project on mapping training needs in relation to long term consequences of treatment will feed into this mapping. Using the sources identified by the NCSI, local commissioners and services will then be able to determine workforce development plans. The National Training

⁷² Evidence on Cancer Services: Improving Outcomes in Children and Young People with Cancer NICE, 2005 ISBN 1846290678

Needs Analysis Template, currently being developed in relation to the End of Life Care Communication Skills pilots, could aid local planning if positively tested and could support survivorship workforce development.

Next steps for 2010

9.18 During 2010, the NCSI will:

- > identify an effective model for the key worker function that transcends the care pathway
- > tease out and define the currently identified new functions of the case-manager and cancer supporter
- > commission work to cross-reference all the existing competencies that are relevant against the themes and skills that have been identified and develop new competencies if there are gaps
- > develop a National Training Needs Analysis template, to identify existing capacity and scope future requirements, challenges and potential changes in workforce
- > influence education to be more focused on assessment, communication and the acceptance of cancer as a chronic illness
- > develop tumour and treatment specific work based packages on late effects to be freely accessible across disciplines to raise knowledge and awareness.

Annex

About the National Cancer Survivorship Initiative

1 The National Cancer Survivorship Initiative (NCSI) was announced in the Cancer Reform Strategy⁷³ and was formally launched in September 2008. The aim of the NCSI is, by 2012, to have taken the necessary steps to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible. The NCSI is led by the Department of Health and Macmillan Cancer Support and is co-chaired by the National Cancer Director, Professor Sir Mike Richards, and the Chief Executive of Macmillan Cancer Support, Ciarán Devane.

2 Seven NCSI work streams were established, made up of cancer survivors, carers of survivors, representatives from cancer charities, health and social care staff and researchers.⁷⁴ The work streams were asked to assist the development of improved models of care and support for those living with and beyond cancer. Three of the seven work streams dealt specifically with steps in the survivorship pathway.

These were assessment and care planning, consequences of cancer and treatment and active and advanced disease. A further three work streams were cross cutting, covering the whole survivorship pathway and are generic (i.e. not confined to a specific tumour type or age group). These were work and finance, self-management and research. The work stream on survivors of childhood and young peoples' cancer also covers the whole survivorship pathway, but for a particular group. This work stream is focusing on the holistic needs of children and young people living with and beyond cancer. Each work stream was asked to consider issues relating to patient information, commissioning and workforce.

3 NHS Improvement are supporting the delivery of the NCSI through piloting models of improved care and support for adult and children and young people survivors. There are currently ten children and young people test communities and 28 adult test communities.

⁷³ Cancer Reform Strategy, Department of Health, 3 December 2007

⁷⁴ More information about the NCSI work streams, including the contact details for the work stream chairs and supports is available at www.ncsi.org.uk

- 4 The NCSI is committed to delivering the following outputs:
- > a document describing the vision for the care and support of people living with or beyond cancer
 - > principles for effective models of care and support
 - > acceptance of 'survivorship' as a priority for people with cancer
 - > beginning the translation of the vision into action at a local level
 - > a community of interested people who will continue to lead this agenda
 - > guidance for commissioners on new models of care and support for cancer survivors
 - > development of specialist services for those suffering from the late effects of cancer treatment
 - > guidance on workforce capacity development and training needs analysis
 - > a new longer term research programme designed to answer priority questions on survivorship.

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