

NATIONAL CANCER SURVIVORSHIP INITIATIVE NEWSLETTER
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Welcome to the first newsletter from the National Cancer Survivorship Initiative.

The newsletter will provide updates on the work of the initiative's seven work streams, for people with an interest in survivor care as well as those actively involved in the initiative.

Further information will also be available throughout the year either from the individual working groups or from May Bullen [May.Bullen@googlemail.com].

What is the National Cancer Survivorship Initiative about?

The National Cancer Survivorship Initiative, a partnership between the Department of Health and Macmillan Cancer Support, was formally launched at our conference in London on 11 September.

Following the Cancer Reform Strategy's commitment to improve patients' experience of living with and beyond cancer, the initiative has been established to consider a range of approaches to survivorship care and how these can be best tailored to meet individual patients' needs.

A Think Tank event and user workshops held earlier this year highlighted that survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs. The feedback from these events has helped us to identify and shape the initiative's seven work streams.

The seven work streams

1. Assessment, care planning and immediate post treatment approaches to care
2. Managing active and advanced disease
3. Late effects
4. Children and Young People
5. Self-care and self-management
6. Work and Finance
7. Research

A message from joint chairs, Mike Richards & Ciaran Devane

A cancer survivor is someone who is living with cancer or who has had cancer. Some have active disease, some are living with the consequences of their disease, and some can truly be said to be living beyond their cancer. At present, there are 2 million such people in the UK.

There is an enormous range of needs among these survivors. For example, many of those not in active treatment need emotional support; some cancer survivors are hit hard financially; some may not have active disease but are still not well.

We have done so much to improve diagnosis and treatment of cancer, and we must now expand our efforts to meet the longer term needs of cancer survivors.

We are confident that the 7 work streams that we have initially developed will cover the wide range of different aspects of survivor care – what we must ensure, though, is that they work together and with a wide range of other more general initiatives which are also relevant.

Our key criteria for success must be demonstrable improvements in outcomes for patients, carers and families and improvements in the processes for delivering care. We must ensure that the working groups move forward as quickly as possible so that we can deliver these improvements within the timescale of the initiative.

National Cancer Survivorship Initiative work streams update

Assessment, Care Planning and Immediate Post Treatment Approaches to Care

Chaired by Ciaran Devane, Chief Executive
Macmillan Cancer Support

The overall aim of this work stream is to deliver four approaches to assessment, care planning and immediate post treatment care which can be implemented on a sustainable and practical basis:

- ❖ an Assessment and Care Planning Framework to ensure that post-treatment care is correctly and holistically assessed, and that clarity exists on delivering that care
- ❖ a Treatment Record Framework to ensure a single record which is intelligible to the patient exists and which is the basis of conversations about the patient's care
- ❖ a GP Review and Recall System which ensures appropriate, patient- specific, primary care oversight of cancer survivors
- ❖ models of care for immediate post-treatment, tailored to the individual patient need.

The mantra for the workstream is "keep it simple and get it used".

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Managing active and advanced disease

Chaired by Roger Wilson, Director Sarcoma UK

Cancer patients surviving with active or advanced disease present a very wide spectrum of needs. The aim is to have a responsive service which takes account of the individual health and wellbeing needs of patients and carers. The initial view is that the work stream will cover:

- ❖ follow up
- ❖ rehabilitation
- ❖ easy rapid access to all care and support
- ❖ the role of professionals, patients and carers
- ❖ the role and interrelation of services and organisations
- ❖ cultural/ethnic diversity
- ❖ age
- ❖ treatment "rationing".

This is not an exhaustive list and horizon scanning will shape it further.

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National Cancer Survivorship Initiative work streams update

Late Effects

Chaired by Jane Maher, Chief Medical Officer, Macmillan Cancer Support

Many “cancer survivors” are getting on with their lives, with cancer treatment a thing of the past, but there is a higher incidence of chronic illness and disability in cancer survivors compared with those without a cancer diagnosis. Unrecognised effects of cancer treatments may explain at least part of this.

Some problems start during treatment and are time limited, others begin during treatment and persist and still others may not appear until months or years later. Treatment can affect health in a range of ways, and the range of treatment effects can span minor changes (in the majority) to catastrophic complex problems (in a small but significant minority).

Currently, long-term treatment effects are not systematically identified or recorded; there are few diagnostic or integrated care pathways linking changes in health resulting from the consequences of cancer treatments to help to reduce disability and few specialist services are available even for those with complex needs. This is the challenge for the late effects work stream, which aims to develop a framework for the identification and management of late consequences of cancer treatment.

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Children and Young People

Chaired by Carole Easton, Chief Executive, CLIC Sargent cancer Care for Children

Survivorship is a particularly significant issue for children and young people with cancer, with more and more children surviving cancer. When cancer hits at a younger age, people can find their lives are hugely impacted in terms of education, employment, financial wellbeing, as well as physical, growth and hormonal affects.

The Children and Young People’s Work stream will seek to ensure that children and young people who have or have had cancer have equal opportunities to achieve the five Every Child Matters outcomes:

- ❖ be healthy
- ❖ stay safe
- ❖ enjoy and achieve
- ❖ make a positive contribution
- ❖ achieve economic wellbeing

The Children and Young People’s work stream values the voice of children and young people in developing models for future priorities and services, and will be working directly with young people who have their own experience of cancer.

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National Cancer Survivorship Initiative work streams update

Self care and self-management

Chaired by Jessica Corner, Chief Clinician, Macmillan Cancer Support and Head of the School of Health Sciences, University of Southampton

This work stream brings together individuals from a range of settings within and beyond the cancer field who have expertise and experience of developing initiatives in self-care and self-management. Cancer survivors will bring user perspectives, and people working directly in cancer services will ensure attention is made to grounding the work in service delivery.

Five broad aims have been identified for the work stream:

- ❖ review the evidence for self-management support and to map the current extent of self-management support services
- ❖ develop models for self-management support
- ❖ initiate and evaluate pilot models of self-management support
- ❖ make recommendations for cancer policy and for commissioners of cancer services
- ❖ review and make recommendations related to the cancer workforce learning and development needs in order that professionals can deliver effective self-management support with cancer survivors.

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Work and Finance

Chaired by Barbara Wilson, Co-Founder, Working with Cancer

The purpose of this work stream is to consider:

- ❖ the roles that employers, NHS professionals, occupational health, rehabilitation specialists and Jobcentre Plus services and other groups should play in supporting people return to work after cancer and
- ❖ the role that the NHS should play in ensuring that patients are given information and advice about benefits and financial issues.

In undertaking the work the following questions will be addressed:

Work

- what is specific to cancer in terms of vocational rehabilitation needs?
- what role should health professionals play in helping people return to work?
- what are the best models of vocational rehabilitation for cancer patients?
- what forms of information and support should be provided and how to those affected by cancer who work, including carers of cancer survivors, the self employed, and young people about to enter the world of work?

Finance

- how can financial information and advice be built into the key stages of the cancer journey?
- how can health professionals be supported to identify potential entitlement and signpost effectively; what training do they need?
- how can NHS levers (e.g. Payment by Results, Quality and Outcomes Framework) support the provision of benefit information and advice?

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National Cancer Survivorship Initiative work streams update

Research

Chaired by John Neate, Chief Executive, The Prostate Cancer Charity

The task faced by this work stream is to map the survivorship journey and, for each point on that journey, to identify what is, and what is not, known from established research. Other survivorship work streams will contribute in helping to identify the future research agenda.

It is broadly anticipated that there will be three phases to the work of the Research Work stream. Year 1 will be concerned with identifying the research agenda. Year 2 will focus on identifying funding for the research and Year 3 will involve commissioning the research. This timescale will be shortened if possible – the aim will be to achieve both scientific rigour and speedy action.

The Research Work stream will be working closely with the National Cancer Research Institute (NCRI) to produce co-ordinated outputs from the process.

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NHS Improvement Test Sites

Linked to the work of some of work streams NHS Improvement is setting up test sites – further information is available from

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