

NATIONAL CANCER SURVIVORSHIP INITIATIVE NEWSLETTER

March 2009, Issue 2

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Welcome to the second newsletter from the National Cancer Survivorship Initiative. These newsletters will be published every three or four months, and they will be provide an overview of the initiative, informed by the progress of the seven work streams, for people with an interest in care and support for those living with and beyond cancer, as well as those actively involved in the initiative. Further information is also available from www.improvement.nhs.uk/cancer/survivorship.html.

In case you missed it, the first edition of the newsletter is available from the Department of Health website at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088879

A message from joint chairs, Mike Richards & Ciarán Devane

We are delighted with the progress so far of the National Cancer Survivorship Initiative. The work streams have made great strides in establishing their early work programmes, and have already delivered some pieces of work. The first quarterly reports made impressive reading.

We have now started to set out a clear vision for the initiative, with a supporting implementation plan. Although still at an early stage, this document is a good starting point for a publication in the autumn setting out the vision and implementation plan. More details of this are set out below.

We have also started thinking about the cross-cutting strands of work – information for patients/survivors and their carers, workforce issues and commissioning – and how best to take work forward on these areas. Watch this space for more information...

We remain committed to moving forward quickly so that the goal of the initiative – to optimise the quality and length of life following primary treatment for people who have received a diagnosis of cancer – can be achieved within the timescale for the initiative.

PLEASE HELP US!

This initiative aims to improve care, advice and support for people living with and beyond cancer. However, we know that there is already some very good practice out there. If you have a good story to tell us please get in touch with Claire Bache (claire.bache@dh.gsi.gov.uk)

What has been happening in the National Cancer Survivorship Initiative?

The main focus of the NCSI over the last quarter has been to develop a clear vision for the care and services needed to support those living with and beyond cancer, and to ensure that the work programme of the seven work streams will deliver that vision. Updates on the vision and the work streams are included later.

The seven work streams

1. Assessment, care planning and immediate post treatment approaches to care - to ensure that survivors' needs are identified and plans made to meet them from an early stage.
2. Managing active and advanced disease – to address the key issues for those living with active cancer
3. Late effects – to consider and address the management of the long-term effects of cancer and its treatment.
4. Children and Young People – to address the specific needs of survivors of childhood cancers
5. Self-care and self-management – a cross-cutting strand covering all cancer survivors, whether with active disease or not
6. Work and Finance – to consider issues around employment and finance for cancer survivors (the issue of continuing education for young cancer survivors is being addressed by the Children and Young People stream)
7. Research – a cross-cutting strand to identify a future research programme and support other strands in commissioning research

All the work streams have strong user and carer involvement to ensure they address the needs of cancer survivors.

The Project Office is now set up, and Claire Bache (claire.bache@dh.gsi.gov.uk) started work on 16th February. Melissa Leffler started her maternity leave at the end of February, and May Bullen will also be leaving the project office in mid-March 2009. We are extremely grateful to May and Melissa for all the work they have put in on the initiative.

An overview of the National Cancer Survivorship Initiative – living with and beyond cancer

The overall goal of the initiative is to enable people who have been diagnosed with cancer to lead as healthy and active a life as possible, for as long as possible. To achieve this, survivors are likely to require integrated care and support from a wide range of services, particularly statutory health and social care services and the voluntary sector, but also from other sources, such as employers and education services. In addition, carers are likely to want to know that professionals will actively consider their needs, and that they will also receive high quality information, advice and support.

Success will be assessed in terms of whether survivors are receiving the care and support that they want and need. Work is underway on the metrics to be used, but in general terms we see success in terms of survivors:

- * knowing that they have received (or are continuing to receive) the best possible treatment for their condition to minimise their risk of recurrence/death.
- * getting back to as normal a life as possible (but not necessarily the same as before).
- * knowing they have easy access to reliable information, expert advice, support and care tailored to their particular needs and preferences.
- * knowing that they and their families will be financially secure.
- * knowing that any recurrence of cancer or any long term effects of treatment will be dealt with without delay and as effectively as possible.
- * knowing that they will be involved in decision making to the extent that they wish.
- * knowing they have the confidence and skills to manage their condition themselves as far as possible.
- for children and young people, getting flexible education services to meet their needs.

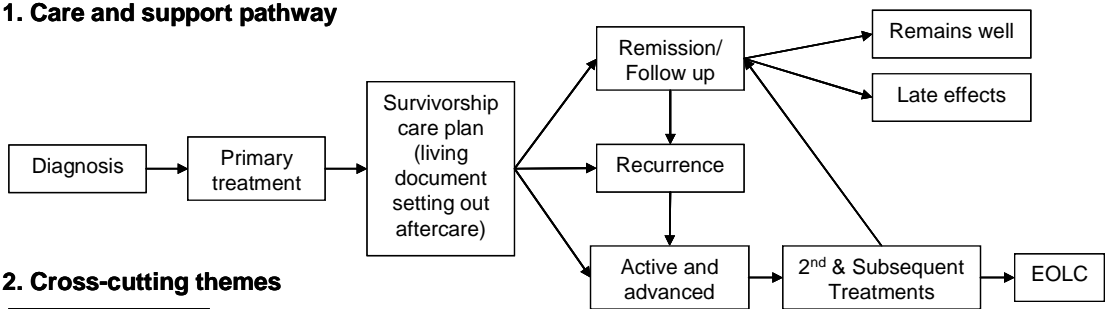
In addition, carers are likely to want to know that professionals will actively consider their needs throughout the survivorship care and support pathway, and that they will receive high quality information, advice and support across all their needs.

In order to identify priorities, and as a basis for developing new models of care, a generalised survivorship framework with a 'care and support pathway' has been defined, with the key stages laid out from diagnosis through primary treatment and care planning, covering remission, recurrence and active and advanced disease, long-term consequences of treatment, and, in some cases, end of life care. Each individual will have their own care pathway, but this generalised format will enable us to ensure that the workstreams are focusing on the right areas, and that the cross-cutting workstreams (such as research and work and finance) are covering the needs and wants of all survivors. A diagram of the framework is on the next page.

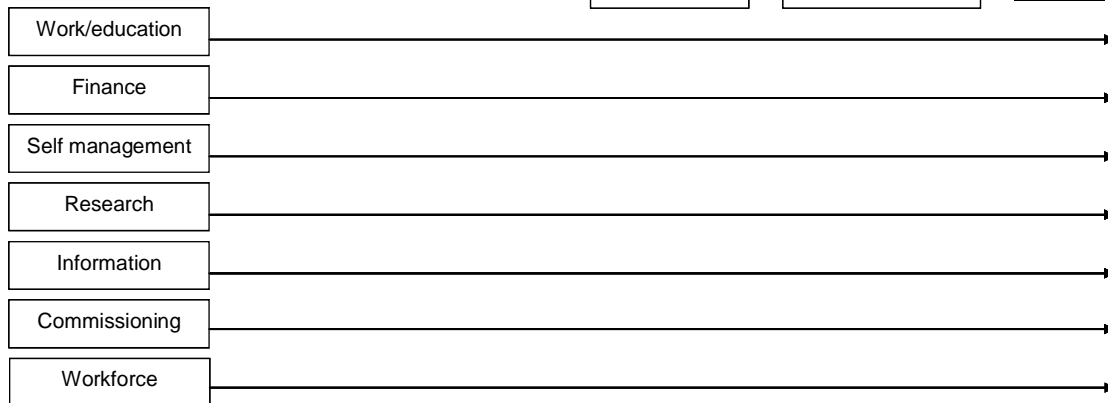
In this first year, we plan to focus on establishing a baseline of what we know and what we don't know. This will not only tell us where future work and research are necessary, but also where the initiative should focus. The full vision and implementation plan will be published in the autumn.

The survivorship framework

1. Care and support pathway



2. Cross-cutting themes



3. Factors which impact on survivorship



COMMENTS

If you have any comments on the vision set out here, and on the survivorship framework, or on this newsletter or the initiative more generally, please email Claire Bache (claire.bache@dh.gsi.gov.uk). We appreciate all comments, as they will help us ensure the initiative meets the needs of those living with and beyond cancer, and also that the newsletter is useful to its recipients.

Updates from the work streams

Assessment, Care Planning and Immediate Post Treatment Approaches to Care

Chaired by Ciarán Devane, Chief Executive Macmillan Cancer Support

This work stream has focused on two main areas this quarter:

- * Development of a treatment summary record framework; and
- * Development of a survivorship assessment framework for adults.

Both of these are in an advanced stage of drafting, with comments currently being sought from key groups, including the test sites, GPs and other professionals. The drafts will be reviewed to ensure that they are absolutely consistent with the new vision. Once the initial draft of each has been agreed, they will be released to the test sites for piloting, with full and rigorous evaluation planned.

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Managing active and advanced disease

Chaired by Roger Wilson, Director, Sarcoma UK

This work stream has focused on developing a work programme and has identified priorities for future work as:

- * Roles and responsibilities of multi-disciplinary teams in active and advanced disease;
- * Supporting GPs in management of referral for suspected recurrence
- * Transitions from active disease to end of life care;
- * Role of keyworkers and co-ordinators
- * Patient-centred practice and in particular, developing a working definition;
- * Information needs and information prescriptions;
- * Future trends in treatment and care;
- * Improving well-being;
- * Defining different patterns and phases of active and advanced disease; and
- * Defining the likely needs for care of patients at different phases of disease.

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Long-term consequences of cancer and its treatment

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

This work stream has identified priority outcomes for their work to be:

- * The incidence, prevalence and natural history of the long-term consequences of cancer and its treatment are known for common cancers and rare cancers where consequences are particularly severe.
- * This will mean that cancer patients and healthcare professionals are aware and informed about the incidence, prevalence and risk of the long-term consequences of cancer and its treatment.
- * On completion of treatment, cancer patients are given information about the symptoms of long-term consequences assessed and given a long term care plan including management of long term consequences of treatment (including self-management).

The group is working closely with both test sites and the Children and Young People work stream.

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Children and Young People

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

The group's objective is to improve the provision of care and support for children and young people surviving cancer; and the support to parents and carers. To achieve this, it will test models of care for clinical and non-clinical services and support, around these priorities:

- * Development of Survivorship Treatment Plans
- * The development of Survivor Pathways with a particular focus on key stages, namely transition
- * Appropriate follow-up models – including shared care and nurse led follow-up
- * Identifying patients at low, medium and high risk of late effects following treatment
- * Continuing support throughout care in terms of education needs
- * Dealing with non-clinical issues to ensure a 'normal' life following cancer diagnosis and treatment.

The group has agreed that it will have a Survivorship Treatment Plan and risk stratification tool produced by January 2010, and work has already started on both these.

In addition, 10 further test sites have been identified to focus on issues affecting children and young people, and will formally start work later in 2009. These are the Christie NHS Foundation Trust – Manchester, Birmingham Children Hospital NHS Foundation Trust, The Royal Marsden NHS Foundation Trust, Yorkshire Cancer Network/St James Leeds (2 projects), Great Ormond Street Hospital, Sheffield, Cambridge, Brighton & Sussex, and Bristol University Children's Hospital.

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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 has focused this quarter on four main deliverables:

- we have agreed the final version of the self management evidence review: “Self management support: a review of the evidence” This report will be made available to all the workstreams and the test communities, and will inform the general evidence review being commissioned by the research workstream
- we have commissioned the production of a “framework for commissioning self management support” which will be a resource to support both providers and commissioners of services
- we have commissioned a review and analysis of outcomes measures for self management support interventions. This work will inform the design of the evaluation of the self management support interventions to be tested in health communities.
- and we are currently planning for collaborating with at least one of the NHS Improvement test communities to introduce a ‘whole systems’ approach to the implementation of self management support.

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Work and Finance

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

This group has developed and embarked upon a detailed work programme. A literature review has already been completed with a view to beginning to identify the key issues for cancer survivors. In the meantime, the main priorities for the group are developing a system of vocational rehabilitation, ensuring that cancer survivors receive information about work and financial issues and providing support for employers.

The group is also working with the Research work stream to identify large-scale research projects on work and financial issues that should be taken forward within the main research programme. An early candidate is a large scale population study on cancer and work.

Finally, although many cancer survivors experience difficulties navigating the benefits system, and we aim to provide more timely information and advice on this subject, it is recognised that changing this more fundamentally will be a long-term project

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Research

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

The group has agreed an invitation to tender for a full review of evidence (both published and non-published) on the current situation with respect to cancer survivors. This has been issued, and responses are awaited. The evidence review will feed into all the workstreams, all of whom have been consulted in the preparation of the invitation to tender.

The group, with the helpful input of a number of charities, has also begun work to map the 'survivorship journey' for the four most common cancers – breast, prostate, lung and colorectal. This work will be extended to identify any specific issues to be taken into account for the rarer cancers.

A model has been developed by the Research work stream for mapping the survivorship journey and this has been circulated to the other workstreams to facilitate their identification of key issues. This model is being fused into a version discussed recently by the steering group of all the survivorship chairs and supports.

A meeting is currently being organised with potential research funders to test early interest in funding the new programme of survivorship research which will be commissioned once the evidence review is complete and priorities have been agreed.

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Adult test sites

The diagram on the next page shows how the adult test sites relate to the survivorship 'journey' and where the test sites are located geographically.

For more information contact Gilmour Frew on gilmour.frew@improvement.nhs.uk

