

NATIONAL CANCER SURVIVORSHIP INITIATIVE NEWSLETTER August 2009, Issue 3

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Welcome to the third newsletter from the National Cancer Survivorship Initiative.

The newsletter provides an update on the work of the initiative, for people with an interest in the care of those living with and beyond cancer as well as those actively involved in the initiative.

A year on into the National Cancer Survivorship Initiative

Looking back over the past twelve months, a great deal of progress has been made in the National Cancer Survivorship Initiative. Over this period the NCSI workstream and test communities have been establishing what is known about each step in the survivorship pathway and planning piloting work. During the next period, workstreams will develop principles and models of improved care and support for those living with and beyond cancer and test communities will begin their piloting work.

At the last NCSI Steering Group in July, the seven NCSI workstreams reported good progress and mapped out key milestones for the next quarter.

The seven NCSI workstreams

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

The Evidence Review is now underway, which will establish existing research and priority areas for future survivorship research. This work is being led by the Research Workstream and will be complete in October 2009. To inform this work, the Research workstream have also completed a mapping exercise of the issues for survivors.

The assessment and care planning workstream have produced a draft assessment and care-planning framework, which will be piloted by new NCSI test communities. A call for expressions of interest in becoming an NCSI test community went out at the end of July to NHS provider organisations. These new test communities will test approaches to:

- assessment and care planning that can be applied at key points across the patient pathway and is flexible enough to be triggered by patient self assessed need and
- end of treatment record summaries, for sharing information between hospital and the community including local authorities.

We are looking for test communities to test innovative approaches that will improve the quality of the current assessment and care planning provision which meet patients' needs. The new test communities will be led and supported by NHS Improvement and externally evaluated by Tribal Health Care. Interested parties should contact Gilmour.Frew@improvement.nhs.uk for further details.

The workstream looking at the consequences of treatment have issued a call for expressions of interest to build a community of people with expertise in this field to develop and promote the research and thinking about consequences of cancer treatment. Responses were requested by the end of August. Contact csteele@macmillan.org.uk for further details.

NHS Improvement is leading a review of cancer follow-up within the NHS in England. The aim of the review is to provide a clear picture about follow-up/survivorship services today following treatment for three high volume tumour sites (breast, colorectal and prostate cancer). The review will also identify innovative approaches currently in place and share these with cancer networks across England.

All the NCSI workstreams have been busy identifying principles for survivorship care and support. These principles will be developed by workstreams in preparation for workshop sessions at the NCSI conference on 21st September where emerging principles will be presented and tested – see below for more information.

The NCSI workstreams are supported by 27 test communities who are testing models of survivorship care and support. NHS Improvement is working with these communities. There are currently 17 test communities looking at care and support for adults and 10 sites testing models of care for children. For more information about the test communities contact: Nina Webb
Nina.Webb@improvement.nhs.uk

As part of the evaluation of the test communities, the NCSI is working with the Picker Institute to develop and run a patient reported experience of care survey across the test communities. Results of the baseline survey will be available in November 2009. A follow up survey will be completed in 2010. The NCSI is also considering patient reported quality of life outcome measures for survivorship.

In the Project Office we are developing an NCSI communications and engagement strategy, which will identify and prioritise key audiences, messages and engagement activities.

Vision and Implementation Plan

The NCSI will publish a Vision and Implementation Plan for the initiative in December 2009. NCSI workstreams have contributed to an outline draft of this document, which is intended to set out a clear vision for the initiative and the next steps up to 2012.

Coming Up: NCSI Conference

On Monday 21st September 2009, we will celebrate year one of the National Cancer Survivorship Initiative with our conference at Central Hall Westminster, London. If you have received an invitation by e-mail, don't forget to confirm your attendance on-line! For assistance please contact Nneka.Chukwurah@dh.gsi.gov.uk

The conference is an opportunity for those involved in the initiative and others with an interest in survivorship care to:

- get up to date on the work of the NCSI workstreams and test communities;
- share findings, make links and provide challenge;
- develop the emerging principles for new models of care for those living with and beyond cancer; and
- inform the NCSI Vision and Implementation Plan.

NCSI test community representatives, workstream members, patient and carer representatives and colleagues from Cancer Networks will be joining us for what we hope will be an active and enjoyable

event. We look forward to seeing all those with an interest or an active involvement in the initiative there.

Further Information

Further information about the NCSI workstreams and test communities is available on the NHS Improvement website, www.improvement.nhs.uk/cancer/survivorship.html

The Project Office is developing a dedicated website for the NCSI and more details will be available soon and will be available at www.ncsi.org.uk

The Project Office consists of Claire Bache Claire.Bache@dh.gsi.gov.uk, Nneka Chukwurah Nneka.Chukwurah@dh.gsi.gov.uk who joined the Department of Health at the end of April 2009, Steve Hindle shindle@macmillan.org.uk and Steven Wibberley swibberley@macmillan.org.uk