

Survivorship programme – Workshop overview

The survivorship workshop was an opportunity to update participants on survivorship work and specifically to introduce the Oncolink approach to care planning.

Steven Wibberley introduced the workshop and gave an overview of the National Cancer Survivorship Initiative. NCSI is a five year programme focussed on enabling “people who have been diagnosed with cancer to lead as healthy and active a life as possible, for as long as possible.” There are seven NCSI workstreams; all the workstreams have Cancer Voices or other service users in the groups. The workstreams are:

- Assessment and Care Planning
- Consequences of Treatment
- Active and Advanced disease
- Work and Finance
- Supported Self Management
- Children & Young People
- Research

The workstreams are developing new ways of working to support cancer survivors. These are being tested out through a range of pilots and test communities across England. There is more detail on all of this work on the NCSI website www.ncsi.org.uk.

Carolyn Vachani presented the work of Oncolink (www.oncolink.org). This is an on-line cancer information resource. The unique feature is the Survivorship Care Plan that users can produce. Cancer survivors can put in the details of their treatment and any side effects. A personalised care plan is generated; this lists the specific late effects and follow-up care. Macmillan are considering how Oncolink could be adapted for use in the UK and is testing this out through the “thousand people project” with cancer survivors reviewing Oncolink and the care plans.

The workshops ended with a group discussion. These focused on people’s experiences of accessing services for consequences of their cancer treatment, for recurrence or to support well-being. Key messages that came out are:

There was real variation in experiences of accessing support

“secondary – what’s that? I had no idea...”

“Most people don’t know who or where to go”

“Went round and round....”

“GP.... Could not pinpoint a specialist to refer me to”

But some people reported a better experience:

“Spoke to breast nurse about hot flushes...she organised acupuncture”

“Rang up at lunchtime and told to come in at 4pm”

“Emailed oncologist and self referred”

The groups suggested a number of possible improvements to the current system:

“Make sure discharge information contains as much information as possible”

“Listen to survivors – they know most!”

“Train health professionals”

“More GP awareness”

“Survivorship care plan. Thank you Oncolink!”