

Annual report 2011 for Assessment and Care Planning, Treatment Summary and Cancer Care Review

Key Reports:

- **Holistic Needs Assessment for people with cancer: A practical guide for healthcare professionals (2011)**
- **Treatment Summary template and User Guide (2011)**
- **HSJ Cancer Survivorship Supplement April 2011**
- **Output Based Specification for Touch Screen Solution for assessment and Care Planning June 2011**

Key Projects:

- **Assessment and Care Planning**
- **Touch Screens for ACP**
- **Treatment Summary**
- **Cancer Care Review**

The National Cancer Survivorship Initiative (NCSI) was established in 2008 in response to The Cancer Reform Strategy (2007) and is led by the Department of Health, Macmillan Cancer Support and supported by NHS Improvement. This strategy recognised the needs of cancer patients, the lack of services available for people living with cancer and the side effects and long-term consequences of treatment.

The Improving Supportive and Palliative Care for Adults with Cancer (2004) guidelines identified the necessity to assess people's needs for physical, psychological, social, spiritual and financial support at key points in their care pathway. The document identified that the assessment should be uniform, systematic and able to be shared between health care professionals. It also acknowledged that the assessment was likely to be undertaken by nursing staff although other health care professionals could contribute. The report also identified the need for a formal assessment at the end of treatment and at recurrence. The later document the Cancer Reform Strategy (2007) identified the need to ensure that patients required high quality information and communication to enable them to take part in decision making and to address their individual needs. The National Cancer Survivorship Initiative Vision (2010) document focused on five key shifts to improve the quality of patient

care and this included a shift towards holistic assessment, information provision and personalised care planning.

Assessment and Care Planning (ACP)

The National Cancer Action Team (NCAT) document, Holistic Needs Assessment for people with cancer: A practical guide for healthcare professionals was published in 2011. This document encompasses the accumulated learning from NCAT and NCSI sites that have tested and implemented a holistic assessment process.

For those living with and beyond a diagnosis of cancer, care planning can help them navigate the complex health and social care systems and ensure that the full range of services agreed in the care plan are provided although the level of input will vary according to the level of need that a person has.

It is important that following the assessment people are given the opportunity to have a conversation with a health care professional to give them the opportunity to discuss their needs, goals and what is important to them. They are listened to, are given the information and signposting that they need at the right time and are supported to be more actively involved in their own care and self management.

Following testing at 11 NHS Improvement test communities' patients reported that they found the ACP process useful. It helped them to identify the concerns that they had and improved their relationship with health care professionals; it also made them feel cared for. Brennan et al (2011) identified several areas of concern using the Distress Thermometer, which further highlights the need for a structured approach to this process.

The assessment process informs the Treatment Summary which is sent to the patient and GP at the end of treatment.

Achievements during 2011

- ACP evaluation summary completed and published on NCSI website.
- Amended the ACP assessment tool from the learning from the test sites – Concerns Check List.
- ACP – triplicate pads developed for testing.
- Licence for use of the Distress Thermometer agreed with the National Comprehensive Cancer Network (NCCN) USA.
- Holistic Needs Assessment accepted as a Peer Review Measure.
- The ACP process to be included in the prototype sites with a simpler format for assessment and improved care plan. Integrated learning from previous test sites into

prototypes and co-ordinated information related to supportive services to the prototype sites.

- Contract for ACP training programme agreed.
- Contract for Motivational Interview training for prototype sites agreed.
- Established ACP and motivational training for prototype sites.
- HSJ Article including ACP during survivorship - published.
- Presented the value of ACP at a number of workshops and conferences.
- Contributed to the publication of the (NCAT) practical guide for holistic needs assessment.
- Hand Held Records– Macmillan Organiser that includes ACP, currently being tested.

Further work in 2012 includes

- Continue to work with NHS Improvement to test and develop ACP at prototype sites.
- Ongoing development and implementation of ACP with interested partners.
- Survey/audit for uptake.
- Development and testing of the concept of an electronic solution for ACP.
- Develop access to information and training on Macmillan Learnzone.
- Develop training programme for ACP and motivational interviewing.
- ACP to be recognised as part of job plans/job descriptions.
- ACP to be recognised as part of the commissioned care pathway for a quality service/best practice.

Touch Screens for Assessment and Care Planning

ACP and the tools for the process, when in use, have traditionally been completed on paper. These paper records would then be filed in the patient's record or in the nursing notes and are therefore not always accessible to other members of the multidisciplinary team (MDT). There can be no continual record or graph made from these paper records unless collated by hand.

There is an opportunity for the NCSI to be instrumental in facilitating a major improvement across the NHS in the assessment of the needs of people affected by cancer. The use of technology could assist in overcoming the challenges, by building on existing work and tools to develop software, that can enable the systematic introduction of touch screen assessment. This would be helpful in ensuring that every person affected by cancer has an assessment centred on their own defined needs, enabling the provision of a care plan to meet those needs, throughout their cancer journey and survivorship. Touch screen computers can be used for completion of the screening tools for self assessment. Appropriate software can analyse the assessment and the data can inform the care planning. This analysis and care plan can then be held on the patients' electronic records or the cancer information system. The file can be accessed by members of the MDT as appropriate and a paper copy retained by the patient.

Achievements during 2011

- Funding for electronic solutions using touch screen technology agreed.
- Touch Screen technical specification completed by Leeds University.
- Project Manager for development of ACP in electronic format appointed.
- Invites to tender circulated to 6 companies 2 selected for interview.
- Health Unlocked selected to test the concept of ACP in an electronic format for use on touch screens.
- Good response to Expression of Interest for Test Sites. 4 sites appointed.
- Touch Screen test site hand books completed.
- Invites to Tender circulated for evaluation of the touch screen project to 6 companies, 2 selected for interview and Ipsos Mori appointed.
- Hardware identified and purchased

Further work in 2012 includes

- Developing software for ACP for touch screen use.
- Testing software for ACP in touch screen format.
- Evaluation of the use of ACP in a touch screen format.
- End of project report.

Treatment Summary

The Treatment Summary has been developed to support improved communication between cancer services and primary care. Work with Macmillan GP Advisors identified a multiplicity of information from secondary care but the lack of a simple summary of the patients' cancer diagnosis treatment and ongoing management plan. Clinic letters failed to provide sufficient information to enable patients to be fully managed in the community, resulting in unnecessary delays and referrals back to secondary care. In spring 2009 a group of Macmillan GP advisors identified the information that would be helpful at the end of first line treatment. A template was designed and subsequently tested in 11 NHS test communities across several tumour groups using a variety of methodologies and was positively evaluated by GPs, patients and oncology clinicians.

An updated version of the Treatment Summary based on this learning was developed along with a User Guide and these are available at www.ncsi.org.uk for wider use. There are no copyright issues so the template can be adapted for local use however it is important to keep the key headings, GP READ Codes and NCSI acknowledgements. The Treatment Summary is given to the patient with a copy to their GP and this document is useful for emergency admissions, holiday insurance or admission to hospice as it summarises the care that the patient has had.

The READ codes in this document inform the GP data base and the Cancer Care Review.

Achievements during 2011

- Developed Treatment Summary template and user guide for roll out to prototype sites and other interested parties. Available on the NCSI, and NHS Improvement websites.
- Treatment Summary marketing plan developed.
- Speakers at conferences and learn and share days, extolling the benefits of the Treatment Summary.
- Treatment Summary article published in Mac Voice and HSJ.
- Poster accepted for Cancer Care Congress.
- Treatment Summary: Highly Commended Pfizer Oncology Award.
- Currently negotiating to have the template added to cancer information systems, Somerset and Infoflex.
- Submitted as a Peer Review Measure.

Further work in 2012 includes:

- Support NCSI prototype using the Treatment Summary.
- Develop and test the electronic format with Somerset and Infoflex cancer information systems.
- Continue to promote, publicise and extol the virtues of the Treatment Summary.
- Peer Review Measure.
- Survey/audit for uptake.
- ACP as a recognised part of the care pathway and commissioning process.
- Scope further electronic solutions/systems for Treatment Summary.
- Ensure that the Treatment Summary continues to inform the Cancer Care Review.

Cancer Care Review

Since 2002 GPs have been required to carry out a Cancer Care Review with their patients 6 months after a diagnosis of cancer. The current Cancer Care Review is relatively imprecise and the Quality Outcome Framework (QoF) states simply that it is 'an opportunity to cover the following issues'. This lack of enforcement has resulted in a situation where it is unclear what GPs actually cover in their cancer care reviews and so they vary a lot.

The Macmillan primary care community has been proactive in expanding and testing the content of the six month Cancer Care Review by introducing a template (in line with other chronic disease templates). They have worked with the main GP IT system providers, INPS and EMIS, to develop cancer care templates which will ensure consistency in quality.

During 2010 Macmillan Cancer Support tested the use of the new templates. They looked specifically at how the templates were used by GPs, how they could be used more effectively and asked how helpful the review was for patients. This work has been evaluated. There was a wide range of topics covered by the Cancer Care Review and these varied from over half being for medication review to 12% related to information related to benefits. 88% of GPs found it useful to have access to Macmillan's information resources during the consultation. However 49% of GPs did not use (print) the resources available on line although the Macmillan GPs were more likely to use these.

The Cancer Care Review was seen as quite different to reviews for other long term conditions as cancer patients were seen as more psychologically frail.

Achievements during 2011

- Cancer Care Review evaluation completed
- Cancer Care Review Report Completed

Further work in 2012 includes:

- Create a Macmillan endorsed document that shares the findings from all recommendations and provides background information on the evidence base for the Cancer Care Review
- Publicise the final report and add summary to NCSI website
- Link in with key messages from the Survivorship Agenda
- Develop a marketing plan
- Promote, publicise and extol the virtues of the Cancer Care Review
- Survey/audit for uptake
- Plan and hold an engagement event in the spring of 2012 that will target commissioners to promote the importance of structured Cancer Care Reviews within patient pathways of care.

References:

Brennan, J. Gingell, P. Brant, H. and Hollingworth, W. (2011). Refinement of the distress problem list as a basis for holistic therapeutic conversation among UK patients with cancer. *Psycho- Oncology (wileyonlinelibrary.com)*. DOI: 10.1002/pon.2045

Cancer Reform Strategy (2007) *Department of Health*

Holistic Needs Assessment for people with cancer: A practical guide for healthcare professionals (2011) *National Cancer Action Team*.

Improving Supportive and Palliative Care for Adults with Cancer (2004) *National Institute for Clinical Excellence*

National Cancer Survivorship Initiative Vision (2010) *Department of Health*

Assessment and Care Planning work/ steering group:

Member	Title/Organisation	ACP/Touch Screens Projects
Ciaran Devane	Project Sponsor	ACP/Touch Screens
Noeline Young	NCSI Project Manager	ACP/Touch Screens
Anne Wilkinson	NHS Improvement	ACP/Touch Screens
Vanessa Brown	NHS Improvement	ACP
*Gilmour Frew	NHS Improvement	ACP
Claire Morris	NCAT	ACP/Touch Screens
Alistair Smith	Consultant Haematologist	ACP/Touch Screens
Adam Glaser	NCSI Director for Survivorship	Touch Screens - Project Sponsor
Amanda Watson	Macmillan Cancer Support	Touch Screens - Project Manager
Galina Velikova	Leeds University	Touch Screens
Penny Wright	Leeds University	Touch Screens
# Andrew Sowden	Macmillan Cancer Support	Touch Screens
Richard Ball	Macmillan Cancer Support	Touch Screens
Richard Else	Macmillan Cancer Support	Touch Screens
Casper Below	Macmillan Cancer Support	Touch Screens
# Jackie Graves	Macmillan Cancer Support	Touch Screens
Neal Southwick	Macmillan Cancer Support	Touch Screens
Stephen Edwards	Macmillan Cancer Support	Touch Screens
Steve Hindle	Macmillan Cancer Support	Touch Screens
Stephen Wibberley	Macmillan Cancer Support	Touch Screens
Chris Urwin	NHS.Net	Touch Screens
Graham Waring	User representative	Touch Screens
# Neal Murphy	NHS Connecting for Health	Touch Screens
Nneka Chukwurah	Department of Health	Touch Screens
Greg Hartwell	Department of Health	Touch Screens

*For information only # has left the group

Treatment Summary Steering Group

Member	Title/Organisation
Lucy Thompson (Co- chair)	Macmillan GP Advisor
Terry Bowley (Co- chair)	Macmillan GP Advisor
Rosie Loftus	Macmillan GP Advisor
Nicola Harper	Macmillan GP Advisor
Alastair Smith	Consultant Haematologist
Anne Wilkinson	NHS Improvement
*Gilmour Frew	NHS Improvement
Claire Morris	NCAT
Greg Hartwell	Department of Health
Noeline Young	NCSI Project Manager
Lorraine Sloan	Macmillan Cancer Support, Healthcare
Stephanie Peart	Macmillan Cancer Support, Healthcare

# Christine Denmark	Macmillan Cancer Support, Marketing
Sonia Peart	Macmillan Cancer Support
*Steve Hindle	Macmillan Cancer Support

*For information only # has left the group

Cancer Care Review Steering Group

Member	Title/Organisation
David Plume (Chair)	Macmillan GP Advisor
Rosie Loftus	Macmillan GP Advisor
Lorraine Slone	Macmillan Cancer Support
Stephanie Peart	Macmillan Cancer Support
*Steve Hindle	Macmillan Cancer Support
# Tasia Malinowski	Macmillan Cancer Support
Noeline Young	NCSI Project Manager
Alastair Smith	Consultant Haematologist
Greg Hartwell	Department of Health

*For information only # has left the group