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NHS Improvement

National Cancer Survivorship Initiative Assessment and Care Planning Workstream 2008-2010

Contents

Title	Contents	Page
Executive Summary		3
Background		4
Assessment and Care Planning		6
	Test sites	8
	Evaluation	8
	Learning Events	9
	Screening Tools	9
	Levels of assessment	10
	Competencies	11
Touch Screens		11
Treatment Record Summary		12
Cancer Care Review		14
Transition to End of Treatment		16
Acknowledgments		19
References		20
Appendix		22

Executive Summary

It is the vision of the National Cancer Survivorship Initiative (NCSI) to ensure that “all cancer survivors get the care and support they need to lead as healthy and active life as possible, for as long as possible” (Vision 2010).

The Assessment and Care planning workstream was established to identify how to make this vision possible and defined four areas of work to contribute to developing care that would enable the vision.

The four areas included:

Assessment and Care Planning

Treatment Record Summary

Cancer Care Review

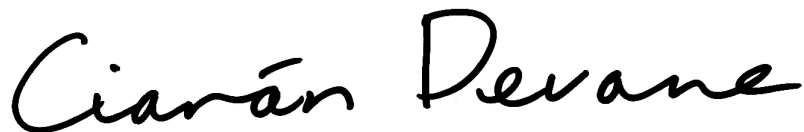
And post treatment aftercare.

All areas have been reviewed, researched, and theoretical models developed for testing and this report outlines these development. At the time of this report Macmillan Cancer Support and NHS Improvement have been commissioned to test these models of care and these will be evaluated in the autumn of 2010 and spring 2011.

The evaluation will enable the NCSI to identify the models of care that are appropriate to develop further and this will inform the future care of those living with and beyond cancer.

Further work is now ongoing to look at how these changes in the care process can be implemented in the future, how this will happen and what enablers will be required to make this possible.

As Chairman of the NCSI Assessment and Care Planning work stream I would like to thank all those who have given their time to contribute to the success of the project and to the test sites who are currently testing these new models of care.



Ciarán Devane

Chair of NCSI Assessment and Care Planning workstream

CEO Macmillan Cancer Support

Background

Since the Cancer Plan in 2000 the National Health Service (NHS) has invested in changing and developing the cancer services in England. The Cancer Plan recognised that each year 200,000 people in England were diagnosed with cancer and of those 120,000 would lose their lives to the disease. Cancer is therefore one of the biggest causes of death in the country. The Cancer Reform Strategy (2007) defined further plans for improving NHS cancer care. With the number of cancer survivors ever increasing, a key recommendation of the Cancer Reform Strategy was to create the “National Cancer Survivorship Initiative” (NCSI) with the aim of *“improving the services and support available for cancer survivors”*. The NCSI was developed in 2008 and is co-chaired by Professor Sir Mike Richards, Department of Health and Ciarán Devane from Macmillan Cancer Support and supported by NHS Improvement.

Two Million Reasons (2008) identified that there were 2 million survivors of cancer in the UK (1.6 million people in England), with 1 in 10 people over the age of 65 living with the disease. The National Cancer Survivorship Initiative (NCSI) was established to consider a range of approaches to survivorship care and how these could best be tailored to meet individual patient’s needs

The recent NCSI Vision (2010) acknowledges that survival rates are improving. Along with an increasing incidence, better survival rates and an ageing population it is thought that by 2030 there will be over 4 million people living with cancer. Long-term survivors of cancer however report poorer health and well-being than the general population and difficulties in returning to normal life (Macmillan 2008). There is both an economic and social need therefore to address the issues of survivorship and enable people living with and beyond cancer to have the best possible support and information to lead as active and normal lifestyles as possible.

A cancer survivor is someone living with or beyond cancer.

Someone who:

- Has completed initial cancer management and has no apparent evidence of active disease
- Is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life)
- Has had cancer in the past (Two Million Reasons 2008).

The NCSI *“are committed to taking steps to ensure that all cancer survivors get the care and support they need to lead as healthy and active a life as possible , for as long as possible”* (Vision 2010).

Seven workstreams were established in 2008 to develop the work of the NCSI in key areas:

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. Consequence of Treatment – 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. Supported 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 work stream)
7. Research – a cross-cutting strand to identify a future research programme and support other strands in commissioning research.

The main objectives of the workstreams were to look at best practice, recommend change and instigate new developments regarding care and planning for survivorship.

This report will focus on the work of the assessment and care planning and immediate post treatment workstream.

Assessment and Care Planning Workstream

The Assessment, Care Planning (ACP) and immediate post treatment workstream have four defined areas (subgroups) of work that include:

1. Assessment and Care Planning
2. Treatment Record Summary
3. Cancer Care Review
4. Immediate Post Treatment

Membership of the assessment and care planning group included cancer survivors, oncology clinicians, surgeons, clinical nurse specialists, and representation from Cancer Networks, cancer charities, National Cancer Action Team (NCAT), NHS Improvement and research teams. The workgroup was chaired by Ciarán Devane from Macmillan Cancer Support and supported initially by Alison Wetherall and Steve Hindle and since August 2008 by Noeline Young.

Work commenced in September 2008 with a remit to:

- Provide strategic direction to deliver the programme.
- To resolve strategic issues and provide specialist advice and support.
- To agree parameters for the projects and the testing and evaluation.
- To monitor progress against the project milestones.
- To establish channels of communication with test communities.
- Reference other NCSI workstream groups and other community forums.
- Formulate recommendations for the NCSI to inform the development and improvement of services associated with the NCSI agenda.
- To undertake work commissioned by the steering board to support the delivery of the NCSI programme.

1. Assessment and Care Planning

Initial work for the assessment and care planning workgroup involved a scoping exercise looking at what information was available, what screening tools were available and where they were used in the care pathway. Work was also undertaken to look at the Holistic Assessment Framework (2007) and Common Assessment Framework (2008). These frameworks are about providing quality and efficiency of care and support for adults and those requiring palliative care. The key focus relates

to improvements in the personalisation of care and support, earlier interventions and the development of self management (Putting People First, 2007).

The workgroup have defined assessment and care planning for survivorship as:

- A process of gathering and discussing information from the patient and/or carer in order to develop a deep understanding of what the person living with and beyond cancer knows, understands and needs. This holistic assessment deals with the whole person, in which their entire well-being is analysed—physical, emotional, spiritual, mental, social, and environmental factors, etc. The process culminates when the assessment results are used to inform a care plan.
- A plan, based on the diagnosis and holistic assessment of the patient. The essential components include identification of issues related to the diagnosis, the approach to solve those issues and goal setting and the likely benefit to the patient. The plan should include a statement of the specific actions and approach to achieve the goals specified. The assessment and care plan process should ensure that care is consistent with the patient's needs and progress toward supported self management.

An Assessment and Care Planning Framework was developed (available www.ncsi.org.uk) and this included a national template for assessment. The aims of testing the assessment framework were defined as:

- Identify the tools and techniques which support wide spread usability and application.
- Assess the feasibility of undertaking a structured approach to the assessment of needs and care planning set within the context of a busy clinical environment.
- Identify evidenced best practice for sharing across discipline and professional and organisational boundaries, developing good practice guidelines, frameworks to promote use in practice.
- Inform the content of the survivorship element of the Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer Framework.
- Assess the impact the introduction of a structured approach has upon the efficient utilisation of health and social care resources.
- Evaluate the impact the introduction of a structured approach to the assessment and planning of the management and care of people living beyond cancer has upon their experience, health, well being and outcomes.

It was not intended that the format for undertaking assessment and care planning would be prescriptive and a range of different assessment and care planning tools and techniques will be tested during the project by the test communities. It is,

however expected that the core principles / elements outlined within the framework are incorporated into the approach adopted by the test communities.

Test sites

Expressions of interest were circulated in late 2009 to cancer networks and included a nationally developed template for assessment and care planning (Appendix 1).

NHS Improvement are leading the testing within the NHS to:

Develop and test potential model(s) of care that will deliver an effective and relevant service for those living with and beyond cancer, this work includes;

- What does a successful assessment framework look like?
- What is unique to cancer and what is generic across long term conditions?
- What are the potential costs of new models in comparison to current model?

Of the current NHS Improvement test sites of which there are 28 in total, 11 are specifically testing and developing assessment and care planning, see Appendix 2

Evaluation of Assessment and Care Planning

Following Invites to Tender three companies were discussed by the workstream to evaluate this piece of testing to ensure a rigorous approach and neutrality. The Tribal Group www.tribalgroup.co.uk were contracted to take the work forward. The methodology for evaluation was Realistic Evaluation.

'Realistic Evaluation' is the theoretical framework which was recommended to underpin this study. The key question asked when using a realistic evaluation methodology is 'what works for whom in what circumstances'. A determining feature of this methodology is to understand 'how and under what conditions a given measure will produce its impact. (Pawson & Tilley 1997, 2000). The study will be exploring the change by the use of the surveys and case studies. This gives a deeper and richer picture of what people think is effective and how they feel about the change. The case study format seeks to evaluate how people have been affected, influenced or changed by their experience of assessment and care planning. It also seeks to determine whether, in fact, there has been any effective change or learning. The use of multi-faceted questioning was deemed an appropriate methodology to explore the nuances of care planning.

A full protocol for the evaluation including a time line was submitted to the workstream (copy available www.ncsi.org.uk) defining how the evaluation work would be carried out.

This includes surveys, focus groups and one to one interviews. Discussions took place re the content and structure of the surveys and focus groups and a baseline survey for all the test sites to use. The baseline survey was to be used before the assessment and care planning process (example available www.ncsi.org.uk).

The results of this testing work are expected in autumn 2010 and a full evaluation, report and recommendation for the testing of prototypes for assessment and care planning identified from the testing will follow from NHS Improvement.

Learning Events

Four learning events were planned for test site members to attend during the period of testing of assessment and care planning.

These events have enabled test sites to share experiences and develop new skills. The agenda for these events included learning about service development tools such as process mapping and the Plan Do See and Act (PDSA) process, assessment tools and the opportunity to develop new insight into future cancer services.

Screening Tools for Assessment

There are a multitude of validated screening tools available or being tested in different areas including quality of life, health behaviours, self efficacy, symptom management, treatment outcomes and patient centred interactions. The report by Davies 2009 outlines some of those available and their validity and acceptability. The initial tool developed by the workstream was derived from the Holistic Needs Assessment, however, early in testing, this was identified as being too time consuming and test sites have switched to test alternative tools. These include aide memoires such as the PEPSICOLA tool used in the West London Cancer Network and the Sheffield Profile Assessment and Referral to Care (SPARC) and self assessment tools such as the Distress Thermometer and Hospital Anxiety and Depression scale (HADs). For further details see Appendix 3.

There are few tools that have been developed specifically for survivorship in the UK however the Impact of Cancer Tool developed in America does cover all the areas (Domains) of survivorship. Unfortunately this is however designed for use in the American health service and not all relevant to the UK. The Distress Thermometer was also developed by the National Comprehensive Cancer Network (2007) <http://www.nccn.org/members/network.asp> in America and further adapted for use in The Sixth Vital Sign, Canada (2009) and also used in Australia, Japan and Europe. In the UK the Distress Thermometer has been adapted by Marie Curie for use in palliative care. <http://learningzone.mariecurie.org.uk/NR/rdonlyres/2187F2D2-51A8-4046-B5EE-55BFB66F7126/0/18JoeLowposter.pdf> and by Bristol University who are currently carrying out a Randomised Controlled Trial of the Distress Thermometer <http://clinicaltrials.gov/ct2/show/NCT00960466> . The team at Bristol have also developed a Distress Thermometer & Problem List Resource Directory for local use.

The tools used should be able to cover all the domains of care (Appendix 4) to enable the assessment to be holistic. This can be achieved by using either one single tool or a library of interacting tools to move the patient from one level of assessment to another if indicated

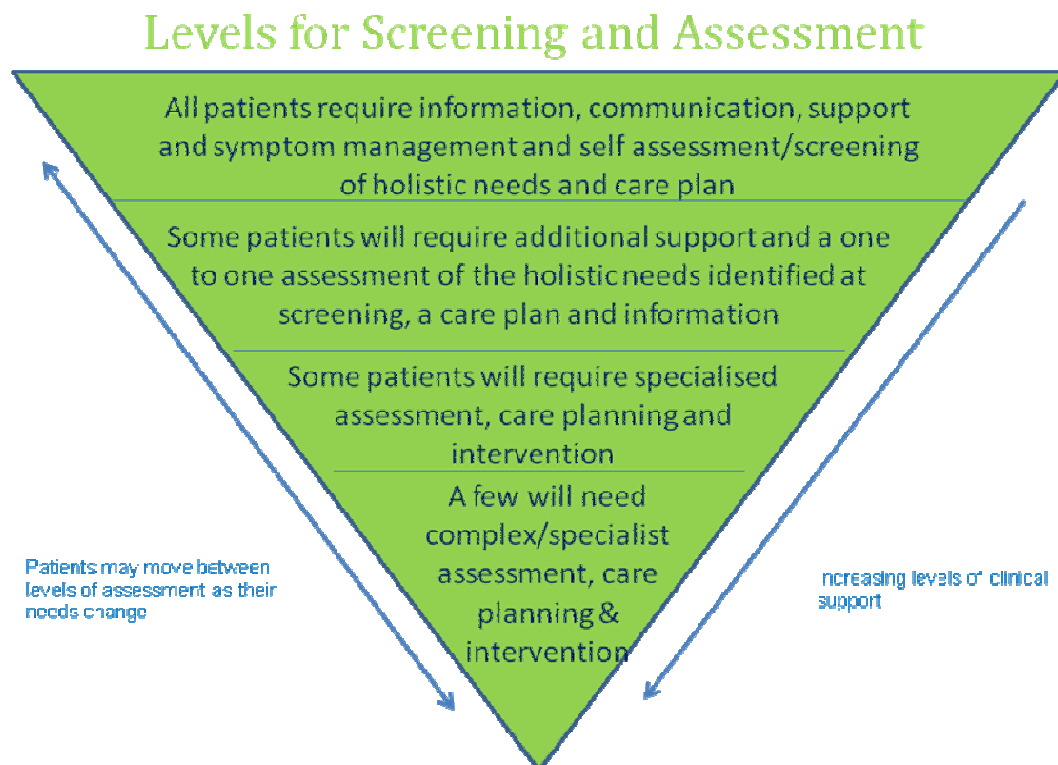
Levels of Assessment

The workstream defined the levels of involvement for assessment and care planning as:

- Self Assessment
- Contact Assessment a 1 to 1 consultation
- Specialist MDT assessment e.g. Dietician
- Complex specialist assessment e.g. psychologist/psychiatrist

These definitions align well with the Common Assessment Framework.

The assessment needs to take place at key points in the cancer journey and if any health or social circumstances change. It is recognised that patients may move between these levels for assessment and care planning according to personal need or a change in their physical or social health. Diagram 1 shows the levels of involvement self management and the support required at each level.



Competencies

Work is ongoing in many areas to develop competencies for health care professionals who undertake assessment and care planning. Some courses have already achieved recognition for their training programme, this includes Salisbury District Hospital who together with Wessex Cancer Trust (Jenkins et al 2010) have worked for the last three years to develop a training manual and a similar program at Bristol University (further details www.ncsi.org.uk).

Working in partnership with the Department of Health and the National End of Life Care Programme, the Association for Palliative Medicine and e-Learning for Health (e-LfH) are now about half way towards their goal of delivering more than 130 learning sessions, grouped into five courses for health care professionals.

The courses include:

- Assessment
- Advance care planning
- Communication skills and
- Symptom management
- The fifth course integrates learning through case studies.

As part of the e-learning for health programme, the End of Life module for assessment has been developed and is useful to all staff to develop their assessment and care planning skills. The modules can be accessed at

www.e-elca.org.uk or www.endoflifecareforall.com

Touch screens

Work is ongoing to look at the use of touch screens as part of the self assessment process. Work in Leeds for use of touch screens for assessment for clinical trials has proved successful (Velikova et al 2002) and further work to develop this for holistic assessment is now ongoing. Some screening tools lend themselves specifically to this use namely the Distress Thermometer, Social Difficulties Inventory (Podmore et al 2009) and the HADs or Mental Health Inventory- 5 (separate report available www.ncsi.org.uk).

2. Treatment Record Summary

The subgroup for this work comprises of oncology clinicians and GPs.

An interrogation of the GP Research Database (GPRD) by Peter Rose's team at Oxford University confirmed that in both the year following initial treatment and during the 5-6 years after diagnosis, breast, prostate and colorectal cancer survivors consulted their GP more frequently than their matched controls (Macmillan 2008).

As the majority of cancer survivors spend most of their time in the community rather than the hospital, the role of the GP and other members of the primary care team are becoming increasingly important in the coordination and delivery of cancer survivorship care. This is particularly the case for supporting the early detection, monitoring and management of the signs and symptoms and management of immediate or ongoing effects associated with the disease or its treatment.

Changes in follow up practice have also resulted in the involvement of a much wider range of health care professionals in the delivery of follow up management and care. It is not possible for primary care personnel to be aware of all the potential immediate and long term effects of treatment that may be required to enable the follow up, monitoring, management and care arrangements for the patient that may be required by the GP in the future.

Effective communication between the specialist cancer team and the patient, GP and primary care team is therefore of paramount importance in the delivery of high quality care and management to cancer survivors. There is wide variation in the quality and content of the information communicated to the GP, particularly in relation to the risks of future problems, ongoing follow up and management arrangements and / or the monitoring and management required by the primary care team.

A recent American study (Earle 2007) demonstrated that a standardised approach could result in an improvement in the early detection, intervention and management of recurrent disease and the effects of treatment. The content of an end of treatment summary from the specialist team to the patient's primary care physician needs to outline these areas. It is therefore essential to ensure that maximum benefits are realised from the consultations that are already occurring between cancer survivors and their GP. It was therefore recommended that high priority should be allotted within the NCSI programme to the development, testing and evaluation of an end of initial treatment record summary.

Approximately 30- 50% of the cancer survivor population will require some form of intervention to enable them to effectively manage the consequences of their disease or treatment on their health and well being.

Cancer survivors presently only receive very limited advice, information and support to manage the multitude of post treatment needs they encounter either immediately post treatment or in the following 2 – 5 year period phase.

Cancer survivors and the primary care team may not have been informed about the symptoms relating to the early signs of potential disease recurrence or the late effects of treatment. These symptoms should alert them to trigger a discussion or referral to the specialist cancer team. As well as resulting in the patient having to experience prolonged discomfort or symptoms, late presentation may impact upon the ability of the specialist cancer team to effectively retreat the cancer or manage the complications of recurrence or the consequences of treatment. This could have a detrimental effect on the patients' quality of life for example in the case of spinal cord compression following treatment for prostate cancer where a late intervention could lead to paraplegia.

It was therefore recommended that high priority should be allotted within the NCSI programme to the development, testing and evaluation of an end treatment record summary.

The work stream have carried out a mapping exercise with the Macmillan GP community and cancer survivors to identify the information required in the Treatment Record Summary to inform discussions and decisions.

Aim

The aim of testing a structured approach to communication between the specialist cancer team, GP and the patient in the form of a treatment record summary is to evaluate the impact upon the:

- Communication between health and social care involved in the delivery of care to patients, carers and their families.
- Confidence of the GP and the wider primary care team to make informed decisions about the patient and their family's care and management.
- Management and care of patients and their carers during the survivorship phase of their cancer pathway.
- Early detection, effective monitoring and initiation of interventions for patients who develop recurrence of their disease or late effects of treatment
- Timely entry onto the GP practice supportive care register
- Experience, health, well being and outcomes for people living with and beyond cancer to enable self management

- Satisfaction with the overall quality of care for cancer survivors and their families
- Evidence best practice for sharing across disciplines, professionals and organisational boundaries, developing good practice guidelines and frameworks.
- Introduction of a structured approach upon the efficient use of health and social care resources.

It is recognised that the treatment record/ letter summary format will require further development during the testing phase in a range of different formats and approaches. Some amendments have already taken place to make the wording more patient friendly (Appendix 5).

It is expected that the information items outlined in the proforma will be incorporated into the approach adopted by the test communities. These were deemed important for aiding and informing GPs and patients about their care. All patients have the right to be copied into correspondence between the treating clinician and their GP. The Treatment Record Summary is therefore being offered to patients and their views about the document will be sought at the focus groups.

Work has also taken place to develop an electronic template and this is being tested at some of the sites. This is a difficult change in practice to establish as it does not fit well into the current processes, therefore there have been different approaches at the test sites and these will be evaluated. Evaluation for this work is taking the form of surveys, focus groups and 1 to 1 interviews with patients and health care professionals. Tribal are evaluating this work as part of the assessment and care planning process.

3. Cancer Care Review

The work group for this comprises of oncologists, cancer survivors and GPs. GPs are increasingly playing a pivotal role in cancer survivorship care and there is a growing need to ensure that cancer survivors have access to a high quality cancer care review. GPs must be well informed and well equipped to deliver the information, advice, support, and management needed by their patients to manage this phase of the cancer journey.

The Quality and Outcomes Framework (QoF) now forms a major component of both general practice activity and income. One aim of QoF has been to improve the management of chronic disease and despite many initial opinions to the contrary it has been effective in providing more equitable high quality service provision for such patients. Cancer care has suffered from a low representation within the framework where other clinical domains (with a more robust evidence base) are represented up to nearly 10 fold higher.

Since 2003 it has been a measure for the Quality Outcomes Framework (QoF) that all patients diagnosed with cancer should be reviewed by their GP within six months of the practice receiving confirmation of their diagnosis.

Apart from some basic parameters, the scope and content of the cancer care review is presently left to the discretion of the individual GP. There is lack of clarity in the present QoF indicator, which states that the review is “an opportunity to cover the following issues” not that the review must cover the issues. This lack of a defined framework leaves the indicator open to broad interpretation. The extent to which the review is presently undertaken is widely variable.

To support GPs in conducting an effective cancer care review with their patients, the Macmillan GP community has taken forward several initiatives over the past few years including:

- Development of submissions to QOF to support the introduction of additional indicators and expansion of the content of the six month cancer care review.
- Working with the main GP IT system providers i.e. INPS and EMIS to develop cancer care review templates / patient information for downloading onto individual practice systems. The uptake of these additional support items across practices within England has been variable.
- Support for local education and training events on management of patients with cancer
- Recent further submission to QOF 9/10/09.

Over 200 GPs and more than 40 users were involved in the development of the QoF submission and subsequent template. It is not advocated as a ‘gold standard’ review but rather the level has been set, as is necessary within QOF that the process is 100% achievable by 100% of primary care. This is explicitly stated as a requirement for QoF indicators. Universal adoption of these suggestions would support the delivery of an enhanced level of care to a wide cohort of cancer patients. To date, the suggestions have not been adopted within the QoF process and the feedback has indicated that the evidence base is presently lacking to support the inclusion of the more robust review.

Test sites have therefore been identified to test the template and to take the development forward. This work is due to start in the spring of 2010 and will run for six months.

This work will also be evaluated as part of the assessment and care planning process by Tribal and the results evaluation will be available in the autumn.

As with the Treatment Record Summary this will require a change in current practice however this change should not only benefit the patient and carer but also the GP in their awareness of the individual patients needs for survivorship.

4. Transition at End of Treatment

The workstream discussed at length the issues that people face when they come to the end of their initial treatment and the obstacles people face on returning to normal social activities and work. Also, the feelings experienced, such as abandonment when they no longer have to attend the hospital on a regular basis for treatment. This patient's quote perhaps sums these feelings up very well and indicates for us not only the need for an assessment and care plan but also for a different kind of support at the end of treatment, when people affected by cancer are hungry for information and support 'a teachable moment'.

"I feel like my whole life has been thrown up into the air, chopped in a million pieces and is now on the floor in front of me. How do I make sense of this? Where do I start?" in Rankin (2008)

The process of assessment and care planning should help to answer the question "where do I start". As will the idea that everyone who had a cancer diagnosis and was living with cancer would have access to an innovative Health and Well Being clinic (Big Clinic), providing comprehensive and holistic support to enable them to lead as normal a life as possible.

It was envisaged that the clinic would be a one off event/initiative in the care pathway and would give a stepping off point for other forms of after care. This clinic will enable the patient and their carers to manage the transition between the treatment phase of their care and survivorship.

Health and Well Being Clinics - Project Objectives

The objective 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 health and social care services and the voluntary sector, but also from other sources such as employers and education services.

The objectives of the clinics will be to offer:

- Those living with cancer the information and confidence to self manage their disease.
- Expert advice on the best possible personal health care and lifestyle to minimise their risk of recurrence.

- Access to volunteer led support groups and/or buddying services (from other people who have had a cancer experience)
- Access to reliable information, expert advice, support and care tailored to their particular needs and preferences
- Access to financial benefits and support
- Information on recurrence of cancer or any long-term effects of treatment as appropriate
- Involvement in decision-making to the extent that they wish
- Support to ensure they have the confidence and skills to manage their condition themselves as far as possible, and that supported self management will be available when it is needed.
- A supportive network that meets the needs of the carers.

The clinic would provide the opportunity to inform and educate patients and carers about the clinical and holistic aspects and the ongoing management of their disease. It would also aim to make them aware of the local facilities, supportive care and opportunities that are available to them and their families.

This concept has been taken forward by Macmillan Cancer Support as the Health and Well Being Clinic and a new steering group has been developed to test the work, with project sponsor Maureen Rutter and Managers Fay Scullion and Jane Rudge. The steering group consists of senior service development managers, voluntary support and clinicians.

Expressions of Interest for test sites were circulated in the autumn of 2009 and Macmillan received a big response to this invite to test, perhaps indicating the popularity of the idea in secondary care. Test sites appointed (Appendix 6) will commence testing from April 2010. (Project Initiation Document, handbook and a one page summary are available www.ncsi.org.uk).

As with the assessment and care planning testing, learn and share workshops have been set up across the year of testing. The testing and evaluation work will complete in April 2011.

Invites to Tender were sent out to seven companies offering evaluation services and OPM <http://www.opm.co.uk/> have been appointed to evaluate this work.

The evaluation will (like ACP test sites) involve surveys, focus groups and telephone interviews.

All of these elements of care in the immediate period at or following the end of treatment contribute to an integrated approach to care (Appendix 7) and together will contribute to the individualised care of people living with and beyond a cancer

diagnosis. There have been a significant number of papers calling for models of personalised care and people centred care, these include:

- Improving the life chances of disabled people (2005)
- Independence, well being and choice (2005)
- Our health, our care, our say (2006)
- Independent living strategy (2008)
- NHS 2010-2015 From good to great (2009)
- Reducing cancer inequalities: evidence, progress and making it happen (2010)
- NCSI Vision (2010)

The development of this integrated approach to cancer care should enable us to reach our goal of personalised and patient centred care for cancer patients.

To Summarise:

The Assessment and Care Planning work stream aims were to:

- Provide strategic direction to deliver the programme.
- To resolve strategic issues and provide specialist advice and support.
- To agree parameters for the projects and the testing and evaluation.
- To monitor progress against the project milestones.
- To establish channels of communication with test communities.
- Reference other NCSI workstream groups and other community forums.
- Formulate recommendations for the NCSI to inform the development and improvement of services associated with the NCSI agenda.
- To undertake work commissioned by the steering board to support the delivery of the NCSI programme.

On the whole the initial aims for the work stream have been achieved, however there are some elements still in the testing phase with NHS Improvement and Macmillan Cancer Support and others where further development is required.

This work will now continue as either separate dedicated project groups or as NHS Improvement or Macmillan Cancer Support test sites and the outcomes from this work will report directly into the NCSI Steering board.

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Self Assessment Template

You are nearing the end of the main treatment phase for your cancer. (Add in relevant statement for late effects or active disease patients and carers)

At this stage you may still be experiencing some of the effects of your treatment.

We would like to help you plan the ongoing care and support that you feel you, your partner or family needs once your treatment is finished. This may be about the practical help or support you will need or any anxieties that you may be feeling.

To help you with this we have listed some issues that are raised by patients or carers when they reach this stage of their treatment. You may have none or some of these issues or there may be other concerns that you would like to discuss directly with the person that has arranged to meet with you to discuss this next stage of your care.

Please use the sections below if you wish to make any notes about the items you would like to discuss during the meeting to plan the next stage of your care.

What are the issues that concern you most about completing your treatment?
Do they relate to:
Continuing to feel symptoms that you feel are due to your cancer or its treatment/ For example these might include - fatigue, pain, sleep disturbance, breathlessness, hot flushes, diet, feeling or being sick etc.
Emotional Support that you may need? E.g. if you are feeling tense, worried, irritable or depressed etc.
Practical Support that you may need? E.g. Help with house work, shopping, personal care gardening, travel etc.
Information, advice, help or support to return to work, seek alternative employment or early retirement?
Information, advice, help or guidance in managing the household finances
Information, advice, help or support with benefit claims?
Fears that the cancer may return or that you may not feel any better than you do now?

Any concerns you may have about how your family or friends are coping with your cancer or the help and support they need.

Your relationships with your family and friends?

The commitments you have and whether you will still be able to cope with them all?

How you will re - establish your social life if it has been difficult to maintain during your treatment?

Other Issues/ Concerns not addressed by the above questions.

What would you most like to change about the issues/ concerns/ difficulties that you have identified?

What are you most looking forward to being able to do once you have completed your initial treatment for your cancer?

What help and support might be needed to help you to do this?

Considering your answers and the things you feel you are most looking forward to doing - What are the first 3 goals you would set yourself and when would you like to achieve them?

1.

2.

3.

Please add some more goals if you want to:

Do you have any initial thoughts as to how you might achieve these goals?

Assessment Record

Patient Demographics (name, address, date of birth, record number, contact details)					
Family Carer Contact Details			Professional Carer Contact Details		
Social Circumstances (eg live on own, dependent children and / or family member)					
Assessment completed by:					
Name:		Title:		Contact Details:	
Assessment					
What are the patient and their carer hoping for in the near and long term?					
Physiological:					
Diagnosis:			Histology/ Staging/ Grade:		
Disease Status: (Tick appropriate box)	New Diagnosis	Remission	Progressive	Recurrent	Metastatic
Prognosis:					
Likely Risk of Recurrence:			High	Medium	Low
Initial Treatment Summary:					
Symptom Profile/ Impact of Current Treatment: (Include fatigue, pain breathlessness, balance, sleep disturbance etc)					
Functional Status:					
Functional independence	Impairment	Disability	Cognitive ability		
Nutritional Status: (include special diets eg vegetarian or specific food intolerances / allergies etc)					

Lifestyle Behaviours e.g. alcohol consumption, smoking, weight, exercise, time for self:		
Patients Name:		Record Number:
Psychological:		
The hope the patient/ carer has for their life and the strengths they can employ to achieve them:		
Beliefs, values, spiritual and cultural systems:		
Dynamics and relationships with others eg family, friends and colleagues:		
Patient and Carers Perception of:		
Illness:		Quality of Life:
History of coping patterns i.e. reaction to previous stressful events and crisis management:		
Patients Strengths:		
Strategy agreed with Patient and Carer for Managing Concerns, Fears and Achieving Life Goals		
Social:		
Support Systems Currently in Place:		
Support System Interventions agreed with Patient and or Carer:		
Employment History and Flexibility of Employment:		
Financial Concerns:		
Benefits advice, information, support given:		Yes: (Please Specify) No:
Patient able to Live:	Independently:	Independently with Support Services:
	With Carer Support:	With Carer Support and Support Services:
Equipment Requirements:		
Ability of Family Carer to Manage Care ie Is Carers own health compromised?		
Availability of others to support care burden:		

Patients Name:			Record Number:		
Interventions:					
Respite Care offered to Carer / Family		Yes: (Please Specify)		No:	
Guardianship Arrangements for Dependent Children:					
End of Life Preferences (if applicable)					
Do Not Resuscitate Wishes/ Decision Discussed: (if applicable)					
Patient Requires Access To					
Residential Care	Nursing Home:	Sheltered Accommodation:		Long Term Care:	
Community Hospital Convalescence Place:	Hospice In Patient:	Hospice Respite:		Day Care:	
Specialist Palliative Care Team Support:			Community End of Life Care Team Support:		
Referrals made to Services:					
GP:	Practice Nurse:	Dietician:	Physiotherapist:	Occupational Therapist:	Speech & Language Therapist:
Specialist Service eg Stoma, Fertility clinic etc:	Counsellor:	Bereavement Counsellor:	Community Mental Health Team:	Psychologist:	Psychiatrist:
Social Worker:	Financial/ Benefits Advice Service:	Buddying/ Befriending Scheme	Local Self Help & Support Group	Healthy Life style Initiative Services within locality:	Specialist Palliative Care Team:

Holistic/ Complementary Therapy Services:	Information Services:	Other:	
Self Management Programmes Referrals:			
Information:	On Line Tools:	Face to Face:	
Additional Comments:			
Assessment Summary:			
Planned Follow Up/ Supportive Management Plan:			

Management and Support Plan

Patient Demographics (name, address, date of birth, record number, contact details)		
Carer Contact Details		
Assessment completed by:		
Name:	Title:	Contact Details:
<p><i>This Management and Support Plan has been developed in conjunction with yourself and / or your carer. It provides a summary of the information about your diagnosis, treatment and your ongoing follow up and supportive care requirements. The plan also provides information on the symptoms you should be aware of and act upon as well as steps that you can take to stay healthy. You should show this plan to the doctors, nurses and other professionals involved in your care so that they are aware of the care you are receiving or require and can update the information with your agreement if necessary.</i></p>		
You have agreed that the information within this care plan can be shared with:		
The following members of your family:		The following care providers:
If you require access to a professional for general queries, advice or support; you should contact:		
If you require access to a member of the specialist team involved in your cancer care; you should contact:		
Normal working hours:		Out of Normal Working Hours:
Initial Treatment and Management Plan Summary:		
You have identified the following key concerns, care needs or goals that you would like to see addressed, improved or achieved. (Please specify):		
1.		
2.		
3.		
4.		
5.		

As an outcome of the discussion relating to the care needs and concerns you identified and those discussed relating to your ongoing care, support and the goals you wish to achieve it was agreed:	
Management and Support Plan	
Name:	Record Number:
Your Follow Up / Monitoring Requirements:	
Your Likely course of Recovery from Treatment :	
Ongoing Services or treatment that you will be receiving:	
The medicines that you have been prescribed need to be reviewed by: (Please Tick appropriate Box)	Within the following specified period or stated date:
Your Consultant:	Your GP:
Services you have been referred to:	
Self Management Programmes that you have been advised to access to assist your recovery:	
Healthy Lifestyle Advice that has been given to you: (include virus protection, sunscreen advice, nutrition, exercise etc as appropriate)	
Signs and Symptoms to look out for and seek advice on:	
Information given to you (include verbal and written information)	
Copy of this plan has been given or will be sent to (eg GP, district nurse, dietician):	
Date of Next Review	
Signature of Patient/ Carer:	Signature of Professional:

Test Communities for Assessment and Care Planning

Test Community	Tumour Groups	Contact
Ipswich NHS Trust Suffolk	Head & Neck Myeloma	Donna Cathmoir donna.cathmoir@suffolkpct.nhs.uk
Central South Coast Cancer Network	Head & Neck Myeloma Colorectal Lung	Sally Stanley sally.stanley@cscn.nhs.uk
Brighton and Sussex University Hospitals NHS Trust and Brighton and Hove Local Authority	Brighton and Sussex University Hospitals NHS Trust and Brighton and Hove Local Authority Lung Dr Sarah Doffman sarah.doffman@bsuh.nhs.uk	Dr Sarah Doffman sarah.doffman@bsuh.nhs.uk
Hull & East Yorkshire NHS trust	Lung	Dr Gavin Anderson gavin.anderson@hey.nhs.uk
North West London	Myeloma	Reggie Haynes Reggie.Haynes@imperial.nhs.uk
Hillingdon NHS Trust	Lung	Johanna Lynch johanna.lynch@thh.nhs.uk
Sandwell & West Birmingham NHS Trust	Lung, Myeloma	Bernie County bernie.county@westmidlands.nhs.uk
Royal Marsden NHS FT	Colorectal	Natalie Doyle natalie.doyle@rmh.nhs.uk
Great Western NHS Foundation Trust	Lung Myeloma	Alison Koster alison.Koster@gwh.nhs.uk
Taunton & Somerset NHS Foundation Trust	Colorectal	Nicky Forsyth nicola.Forsyth@tst.nhs.uk
Poole Hospital NHS Foundation Trust	Head & Neck Colorectal	Andrea Moxham andrea.moxham@poole.nhs.uk

Assessment Tools

Tool	Availability	Validated	Licence	Domains
Health Related Quality of Life HRQOL	Free http://prc.coh.org/qol-cs.pdf	√	X	Physical, Psychological Social, Spiritual
The General Practice Physical Activity Questionnaire (GPPAQ)	Free http://www.dh.gov.uk/en/publicationsandstatistics/publications/policyandguidance/dh_063812	√	X	Four level index of physical activity. Work and recreation. Recommended by NICE
Lorig's 6 item Self-efficacy	Free http://patienteducation.stanford.edu/research/secd6.pdf	√	X	Symptom Control, role function, emotional functioning and communicating
Physician Achievement Review PAR	http://www.par-program.org/ep_patient%20form.pdf	√	Free for research and study	For physicians performance, clinical knowledge and skills, communication skills, psychosocial management and office management

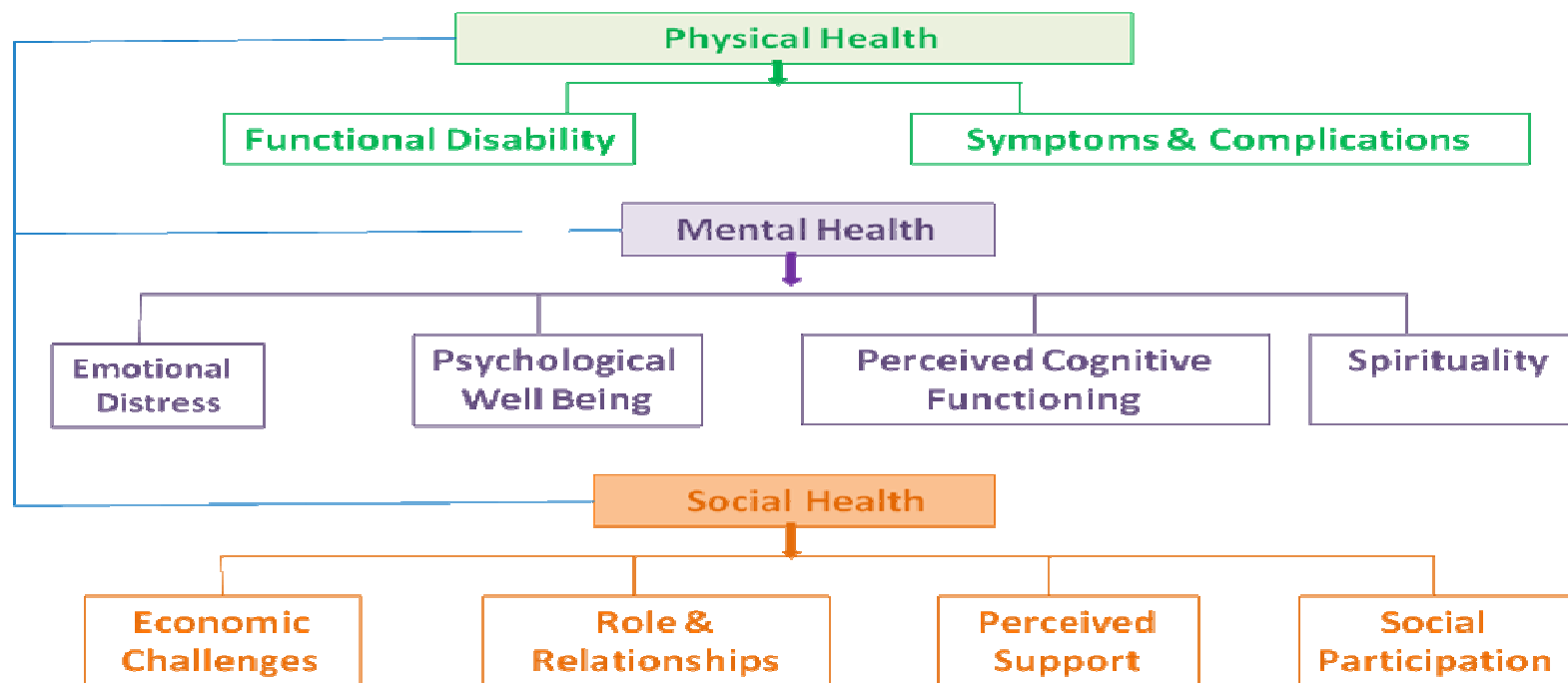
Distress Thermometer	http://www.epi.bris.ac.uk/ditit/pdf/3_DT%20Tool%20Revised.pdf http://learningzone.mariecurie.org.uk/NR/rdonlyres/2187F2D2-51A8-4046-B5EE-55BFB66F7126/0/18JoeLowposter.pdf H:\Assessment\Assessment Tools\DT\Distress Thermometer Intervention Trial (DiTIT).mht	√	X	Patients are asked to quantify on a scale of 0-10 their level of distress during the past week, including the day the screen is done. A score of 5 or higher for any item flags a significant level of distress that should be referred for appropriate support
SPARC	Free - contact for more information nyoung@macmillan.org.uk	√	√	(SPARC) covers a variety of physical, psychological, social, spiritual and information needs. A healthcare professional uses the questionnaire to help inform a discussion with the patient about their concerns and then formulates an action plan which may involve signposting, referral or dealing with an issue

				directly where appropriate. It is carried out at key points on the cancer journey and this may vary between cancer sites
Hospital anxiety and depression (HAD)	http://www.gi-assessment.co.uk/health_and_psychology/resources/hospital_anxiety_scale/hospital_anxiety_scale.asp	√	√	Hospital Anxiety and Depression Scale (HADS) is a rapid self-report questionnaire which measures depression and generalised anxiety. It is equally useful in hospital, out-patient and community settings.
Pepsi-cola	http://www.goldstandardsframework.nhs.uk/OneStopCMS/Core/CrawlerResourceServer.aspx?resource=2E9DA6B2-5D8D-4D3B-8315-C0FA90181045&mode=link&guid=4913518d1abe4b2d976d500829f54c5b	√	X	The aide memoire encompasses all the domains of a holistic assessment through the acronym PEPSI COLA : P – Physical E – Emotional P – Personal S – Social support I - information and communication C – Control and

				autonomy O – Out of Hours L - Living with your illness A – Aftercare
European Organisation for Research and Treatment of Cancer EORTC	http://groups.eortc.be/qol/	√	√	Quality of Life assessment used in cancer clinical trials to provide a more accurate evaluation of the well-being of individuals or groups of patients and of the benefits and side-effects that may result from medical intervention
Cancer Survivors unmet Needs CuSAN		√	X	Essential survivorship, comprehensive cancer care, information, Quality of Life and relationships
Cancer Survivors Partners unmet Needs (CaSPUN)		√	X	For carers
Impact of Cancer	Free from	√	X	Health Awareness, body changes, health worries, self evaluation, positive

IOC	http://accc-cancer.org/education/pdf/zebrack_cancerscaletool.pdf			outlook, relationships and meaning of cancer
Quality of Life – Cancer Survivors QOL-CS	Free http://prc.coh.org/QOL-CS.pdf	√	X	Physical, psychological, social and spiritual
Functional Assessment of Chronic Illness Therapy FACIT	http://www.facit.org/	√	√ Requires registration	Range of questionnaires for health-related and quality of life measure for people with chronic illnesses. The Functional Assessment of Cancer Therapy -General (FACT-G), was developed and validated over 10 years used worldwide.

Domains of Care



Michael Feuerstein (2007)

Treatment Record Summary Template

Appendix 5

GP Contact Details Address

Dear Dr X

Re: Add in patient name, address, date of birth and record number

Your patient Mr/ Ms Bloggs has now completed the first part of their treatment management plan for their cancer. A summary of the treatment they have received to date and the ongoing treatment / management plan for them is outlined below. (pts name) is aware that this letter is being sent to you and has their own copy /does not have their own copy.

Diagnosis:	Significant Clinical Findings: (NB include secondaries)	Histology/ Staging/ Grade:
Date of Diagnosis:		
Summary of Initial Phase Treatment Delivered:		Treatment Aim: (Please specify whether curative, disease/ symptom control or palliation)
Possible treatment toxicities and / or late effects: <i>Need to stipulate which toxicities and / or late effects and appropriate action.</i>		Treatment result (Please specify eg complete remission/ residual disease etc)
Alert Symptoms that need to be discussed or referred back to the specialist team: (include likelihood and signs of recurrence, progression of disease, complications and late treatment effects)		Recommendation that patient is entered onto primary care palliative or supportive care register Yes / NO
		Specialist Team Fast Track Re-entry Referral Service Contact Details/ Process: <i>This will depend on local arrangements</i>
		Out of Hours Emergency Specialist Service Contact Details: <i>This will depend on local arrangements</i>
Ongoing Management Plan: (include , Investigations and tests required during this period, outline of ongoing treatment planned and likely duration of treatment) Include frequency of follow up appointments .		Referrals made to other services: : <input type="checkbox"/> District Nurse <input type="checkbox"/> AHP <input type="checkbox"/> Social Worker <input type="checkbox"/> Other <input type="checkbox"/> Clinical Nurse Specialist

Actions needed by the GP: (include symptom management, screening / monitoring, investigations, place on osteoporosis pathway etc)	
Infection Risk:	
Specialist Medication Prescribing Arrangements	Medication Review Requirements by GP: (include scheduled date for review, dosage alterations/ discontinuation, investigations etc)
Summary of information communicated to the patient and / or their carer/ family: (and / or attach / enclose copy of patient information sheet/ survivorship care plan plus benefits / financial advice information given to the patient as appropriate. Please also state whether a DS1500 has been completed or a prescription charge exemption certificate has been given or is needed.)	
Free text box for additional information (include healthy living, 'exercise', emotional support that would be beneficial for the patient plus any tumour specific website information that may facilitate management of the patient by the GP)	

Please ensure this patient is on the Cancer Care Register and has had a Cancer Care Review.

(Read Codes for this information can be found on the reverse).

Completing Drs Signature.....(Please also print name and include contact details)

GPs Please let us know your views on this summary method. Feedback via www.----- or using the attached letter and SAE. You only need to complete this survey once. Thank you for your help.

Health and Wellbeing Test Communities

Test Community	Tumour Group/s	Contact	Macmillan Regional Contact	Project Manager
Aintree	Lung	joanne.bayly@aintree.nhs.uk	Jez Such	FScullion
Barts and the London	Breast and Gynaecology	nichola.kane@bartsandthelondon.nhs.uk	Linda Nixon	JRudge
Belfast	Urology	sally.campalini@belfasttrust.hscni.net	Heather Monteverde	FScullion
Blackpool	Urology	Joanne.ashton@bf.nhs.uk	Jez Such	FScullion
Derbyshire County PCT	Prostate	bali.mamam@ntcn.nhs.uk	Sandra Clarkson	JRudge
Kilmarnock	All	sandra.white@aapct.scot.nhs.uk	Janice Preston	FScullion
Lincolnshire	Prostate	Jennifer.hinchliffe@ulh.nhs.uk	Kathy Blythe	JRudge
Milton Keynes	Haematology	nancy.hopewell@mkhospital.nhs.uk	Christine Refausse	JRudge
North Tyneside	All	lorraine.lentell@northtyneside.nhs.uk	Pam Ramaswamy	FScullion
Portsmouth	Breast	carmel.sheppard@porthosp.nhs.uk	Fran Williams	JRudge
Rotherham	Womens Health	janine.birley@rothgen.nhs.uk	Maxine Astley-Pepper	JRudge
Royal Liverpool	Gynaecology	jan.ablett@liverpool.ac.uk	Jez Such	FScullion
Ulster	Breast	wilma.boydcarson@setrust.hscni.net	Heather Monteverde	FScullion
Velindre	CNS tumours	Lisa.miller@wales.nhs.uk	Alun Tandy	FScullion
Velindre	All	Sue.acreman@velindre-tr.wales.nhs.uk	Alun Tandy	FScullion

Linking initiatives which support patient experience

Appendix 7

