WE ARE MACMILLAN. CANCER SUPPORT

Project Initiation Document

National Cancer Survivorship Initiative

Health and Wellbeing Clinic

Contents

	Page Number
Introduction	3
Background	3
Project Definition	4
Project Objectives	4
Project Scope	6
Exclusion	7
Expected Outcomes	7
Challenges	8
Interfaces	8
Project Approach	9
Project Risks	9
Impact of Failure	9

Introduction

Purpose of the document

The purpose of this document is to define the project, to form the basis for its ongoing management and the assessment of overall success. It also provides a statement of how and when the project objectives are to be achieved, by showing the major activities and resources required.

Background

Around 2 million people are currently alive in the UK having had a diagnosis of cancer (1.63m in England). This number is likely to grow by over 3% per annum, reflecting the increasing incidence of cancer and better survival rates. Long-term survivors of cancer report poorer health and well-being than the general population.

The National Survivorship Initiative (NCSI) has therefore been set up, as set out in the Cancer Reform Strategy (2007) to take forward the development of services needed by survivors of cancer. Whilst it is acknowledged that the National Cancer Survivorship Initiative is an England only initiative, the development of Health and Wellbeing Clinics will be UK wide.

The NCSI consists of 7 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. 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.

These work streams are looking in detail at best practice regarding care and planning for survivorship.

Project Definition

The assessment, care planning and immediate post treatment work stream have three defined areas of work that include:

- Assessment and care planning
- Treatment Record Summary & Cancer Care Review
- Follow-up care

This document is related to the follow-up care aspect of the work stream.

Vision

Macmillan Cancer Support has a vision that everyone who has had a cancer diagnosis and is living with cancer will have access to an innovative Health and Wellbeing Clinic, providing comprehensive and holistic support to enable them to lead as normal a life as possible.

It is envisaged that the clinic will be a one off event/initiative and will give a stepping off point for other forms of follow up care. It will enable the patient and their carers to manage the transition between the treatment phase of their care and survivorship.

Key to the success of these health and wellbeing clinics will be the involvement of a cohort of regular and senior volunteers, providing a holistic range of services such as coordination of the clinic, buddying, information and support, financial advice.

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:

- Test the ideas of an innovative post treatment multi- disciplinary clinic which will be supported by volunteers across all aspects of the service, and are seen as integral to the health and wellbeing clinic function.

- Test the Health and Wellbeing clinic for different tumour sites. The tumour sites that will be the focus of this work are colorectal, lung,

breast, prostate, gynaecology and haematology. Other tumour groups will be considered if appropriate.

It is anticipated that the Health and Wellbeing Clinic will offer:

- 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
- 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.
- The health and wellbeing clinic will also meet the needs of the carers.

A Health and wellbeing clinic would provide the opportunity to inform and educate patients 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.

There would also be the opportunity to cover issues specific to the disease type for example colostomy care, prosthetic care, lymphoedema and body image & sexuality (Macmillan have excellent resources on the Learnzone to support this). Importantly survivorship issues that will help in the rehabilitation such as information related to work & welfare benefits, lifestyle & diet and support groups would also be discussed and displays or information stands could also be available.

In affect the Health and Wellbeing Clinic is a multidisciplinary meeting for patients and the chance to interact with other patients and carers, clinicians, clinical nurse specialists, allied health professionals, complimentary therapists and the voluntary sector.

There is the possibility of offering the Health and Wellbeing clinic in venues not traditionally used in secondary or primary care

Facilities would need to be available to ensure that the clinicians in the clinic were able to make referrals directly to other professionals e.g. GP or other consultants, ward, clinic, investigations or other services such as support

groups/charities. This would therefore become a one stop clinic and avoid duplication or the need for a further clinic appointment.

Project Scope

Identification of a Health and Wellbeing clinic framework that incorporates the care and support that is required during survivorship

- To enable this we need to
    - establish a clear baseline (i.e. what do we know and what don't we know) across areas in the UK.
    - agree what benefits and deficiencies exist in the current care models
    - determine what benefits should be achievable for cancer survivors;
    - decide what testing/evaluation can be undertaken now, and what issues need more formal development or research
    - determine how Health and Wellbeing clinics will be supported
    - determine what specific information needs are required
    - understand how successful models can be implemented UK wide.
    - understand when to offer a Health and Wellbeing clinic in the care pathway and which (if not all) cancer survivors would benefit from this form of clinic
    - Understand the valuable contributions that volunteers/ peer support and advocacy could make to the project
    - Understand how and when assessment and care planning should take place in relation to the clinic.
- Identification of suitable test communities to test new approaches to managing the issues affecting cancer survivors and their carers;
- Development of new tool kit/guidance to support management of services for cancer survivors and their carers
- Include guidelines for Macmillan volunteers within the new tool kit/guidance as support/assistance in the clinic
- Support of the test communities
- Evaluation of new approaches to managing services for cancer survivors and their carers
- Management of key communication messages between work streams, test communities and wider stakeholders, including the general public

- Rollout of new tools, approaches etc to the wider NHS and beyond, once agreed to be helpful and appropriate
- Making links with other initiatives, programmes and strategies which affect the survivorship initiative, for example, the self management programme.

Exclusions

The project does not cover:

- other forms of follow up care that have been considered by the Assessment and Care planning Work stream i.e. Telephone follow up care
- issues related to follow-up care covered by the self-care and self-management work stream
- issues about screening, diagnosis of cancer etc (covered by other work streams within the Cancer Reform Strategy)
- any inpatient care following a diagnosis of cancer (covered by work on Inpatient Care led by NHS Improvement).

Expected Outcomes

Rehabilitation is about helping people to maximise their potential within the limits of their disease and in terms of their physical, emotional, social and economic potential. Following a visit to the Health and Wellbeing clinic the cancer survivors and their families would be more informed about their disease and treatment and therefore better able to cope with the experience and the challenges of returning to as normal a lifestyle as possible. For some this may mean returning to work, for others being able to support their family and for others enjoying their retirement.

The expected outcomes would therefore include:

- awareness of Macmillan and wider services
- better informed and supported cancer survivors
- Improvement of quality of patient experience
- better social integration
- improved self management of the side effects of treatment
- better access to the appropriate services
- improved well being and self confidence
- less reliance/need for follow-up appointments
- prevention of unnecessary loss of function, nutritional deficiencies
- enable the achievement of realistic goals
- access to voluntary/self help and support - buddies
- less social stigma related to a diagnosis of cancer
- efficient use of clinicians time.

- an opportunity in the future to have the Health and Wellbeing clinic as a recognised service and included in the Cancer Measures and therefore in the Measures for Cancer Peer Review.

Challenges

In the current climate of change and financial constraint the implementation of a sustainable Health and Wellbeing clinic in a secondary or primary care setting will require some changes in current clinical practice and organisational processes.

Constraints identified include issues related to Clinical Governance and confidentiality in terms of suitable venues and appropriate workforce.

Changes to the workplans of clinicians and nursing staff.

Availability of staff to work off site, i.e. away from secondary care if venues are selected that are not in a hospital environment.

In the current financial climate the resources required to make the initial changes in the structure of facilities, change in processes and workforce.

Commissioning of services that may not initially offer a cost benefit.

Loss of follow-up income under current payment systems.

The format would need to be sustainable and therefore a funding stream would need to be identified within the Primary Care Trust and Secondary Care budget. A disinvestment in routine follow-up appointments would, following initial investment enable the Health and Wellbeing clinic to be sustainable.

The clinic format would have to be compliant with clinical governance and confidentiality guidelines within primary and secondary care

Interfaces

The key interfaces are:

- other elements of the Cancer Reform Strategy work streams
- Welsh, Scottish and Northern Ireland Cancer Strategies.
- other long-term conditions to learn from their examples of group follow-up
- the common assessment framework development
- work on improving mental health
- the End of Life Care Strategy

- work in Macmillan, especially linked to commissioning, the healthcare strategy, and workforce, as well as user involvement and the use of volunteers
- Work ongoing within the nations
- other NCRI Partners in respect of the research work stream
- commissioning.

Project Approach

- Project Managers Jane Rudge and Fay Scullion have been appointed as a job share each doing two days a week for 18 months until end of April 2011.
- Maureen Rutter, Director, is project sponsor.
- A minimum of 10 Pilot sites to be selected by January 2010 and launch by April 2010 and piloted for 1 year until end of March 2011
- External evaluation will be included within the project which will include a baseline assessment, and ongoing evaluation with interim findings by September 2010 and a full report in April 2011.

Project Risks

Developing a programme that is either not able to be resourced in the current financial climate or that is not sustainable within the secondary or primary care structures/processes.

Patients may assume that the proposed changes as being driven by cost savings and not as a benefit to them.

Patients may not attend as they think it does not apply or is not relevant to them.

Patients who are less able to attend due to age, language skills, work/social commitments, transport issues may be disadvantaged.

Not all tumour sites offer the service therefore creating inequality of care

There is no change in the delivery of care and after treatment support for people living with and beyond cancer.

Impact of Failure

- inadequate or no change to current follow-up care
- processes put in place that do not create the care and support that people affected by cancer require
- treatment outcomes are affected by inadequate follow-up care

or

- Offer stand alone Macmillan supported and funded survivorship conferences that are not part of the formal clinic setting – as is the current practice of some support groups.