London Cancer Alliance
Survivorship Group (LCA SG)
Constitution
CONTENTS

Background and introduction p.3
Overview p.3
Pathway p.5
Critical components and priorities p.6
  Holistic needs Assessment p.7
  Rehabilitation p.7
  Stratified follow up p.8
Metrics and Outcomes p.8
Role and function p.9
Membership p.10
Background and Introduction

In 2009, Commissioning Support for London was asked to review how cancer services were being provided in the Capital. The resulting ‘A case for Change’ report (2009) provided compelling evidence of the need for change. As a result, ‘A model of care for cancer services’ was produced in 2010. This is was a clinically-led project with input from multiple professions and professionals which sets out the areas for improvement in service delivery. At present five Cancer Networks, which were established in 2000 following the publication of ‘NHS Cancer Plan’, exist within London. They aim to facilitate seamless care across organisational boundaries and plan a role in both provider and commissioning of cancer services. However, ‘The case for change’ showed that variation still exists across London and that the constraints of the system in which the Networks were working had prevented them closing the gap. ‘A model of care for cancer services’ sets out the formation of Integrated Cancer Systems; the joining up of cancer services across providers to form systems allowing patients to flow seamlessly between providers, accessing world-class care and so helping to achieve earlier diagnosis and increased 5-year survival rates. These new systems are currently in the set-up phase with the aim of being fully implemented in the near future.

The London Cancer Alliance (LCA) is the Integrated Cancer System for south and west London. It aims to:

- Improve cancer patients’ experiences, outcomes and quality of life through the delivery of excellence in clinical care, research, innovation and education
- Ensure equitable access to integrated pathways across primary, secondary, tertiary, community and third sectors
- Promote prevention and early detection of cancers by influencing public health messages

Key themes identified within ‘A model of care…’ include

- Supportive care and palliation services would be brought in line with the National Institute for Health and clinical effectiveness (NICE) guidelines
- Addressing unnecessary follow-up attendances which are often being delivered in non-optimal settings

These themes are raised throughout the document and have obvious impact onto the survivorship agenda within the LCA.


Overview

A cancer survivor is anyone who is living with or beyond a cancer diagnosis.

Survivorship can be defined as:
“...cover[ing] the physical, psychosocial and economic issues of cancer, from diagnosis until end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late
effects of treatment, second cancer and quality of life. Family members, friends and caregivers are also part of the survivorship experience.”

National Cancer Institute, accessed 18/04/2012

Currently within the UK:
- 50% of people diagnosed with cancer survive their disease for at least five years (CRUK 2011)
- 2 million people alive in the UK today are cancer survivors (NCSI 2010)
- 60% of all cancer diagnoses occur in people over 65 (Roth 2008)
- 51% of these diagnoses occur in people over 70 (DH 2007)
- It is predicted that, by 2030, there will be 4 million cancer survivors, a rise of 3% per annum (Macmillan 2012)
- Cancer survivorship often have unmet needs (Armes et al 2009)

‘A model of care...’ discusses the need to move away from traditional follow-up which has not shown to be cost effect or patient focused, as well as the increasing number of people living with ‘chronic cancer’. These people are living longer, experiencing long-term side effects of cancer and its treatment. It requires a shift in follow-up service provision towards that laid-out in the National Cancer Survivorship Initiative (NCSI) vision document. The NCSI vision, and therefore that of the LCA is to take the necessary steps to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.


It is essential that the focus of treatment and care is not just on survival, but on ensuring that cancer survivors have as good a quality of life as possible. The NCSI has identified a range of service developments which are likely to improve the health and well being of cancer survivors. These developments may reduce the overall costs of survivorship care to the NHS; some of this cost saving will need to be re-distributed to facilitate associated change to service provision.
The Survivorship pathway

The following diagram shows the framework encompassing the patient pathway, the cross cutting themes and impacting factors. The critical components (see...) underpin the pathway ensuring successful survivorship outcomes.

An interactive pathway will be available at:
The main processes within the survivorship pathway are:

- Holistic Needs Assessment
- Individualised care planning
- Coordination of care
- Risk stratified follow up

In 2004, the NICE Supportive and Palliative Care Improving Outcomes Guidance was published. It set out the National requirements for supportive and palliative care; there are now several peer review measures associated with its recommendations, including; rehabilitation, palliative care and complementary therapies. Supportive care has been defined as:

“help[ing] the patient and their family to cope with cancer and treatment of it—from pre-treatment through the process for diagnosis and treatment to cure, continuing illness of death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects for the disease. It is given equal priority alongside diagnosis and treatment” NCHSPCS 2002 In: NICE 2004

This definition encompasses the survivorship pathway, and so the critical components of supportive care must be mirrored by the survivorship pathway.

The critical components within the Survivorship pathway are

![Diagram of Survivorship pathway]

The three priority areas for the LCA Survivorship Group (SG) based on the ‘A model of care...’ recommendations are implementation of:

- Holistic Needs assessment
- Rehabilitation pathways (starting with NCAT pathways)
- Risk stratified follow up
Holistic Needs Assessment

Holistic needs assessment (HNA) should be part of every cancer patient’s care in order to improve their overall experience. It can be used to identify a patient’s top three to four areas of concern. It is vital that these are discussed with the patient and used to develop an individualised care plan with on-ward referrals made as required. This process allows for greater control and choice and supports people to self manage their condition. There is no “one size fits all” solution and there are various holistic needs assessment tools available. The specific tool is not as important as the process. Supported self-management leads to more efficient use of NHS resources (NHS Confederation 2010). LCA has agreed to 19 metrics, as mandated by LHP, which include percentage completing HNA. A CQuIN (Commissioning for Quality and Innovation) may be developed to encourage its wide-spread roll-out.


Rehabilitation

Cancer Rehabilitation

“Involve helping a person with cancer to help him or herself to obtain maximum physical, social, psychological, and vocational functioning within the limits imposed by disease and its treatment.”

_Cromes 1978, In; Fialka-Moser et al 2003_

Physical activity has been shown to be an essential component of rehabilitation. Evidence supports the use of information sessions covering e.g. diet, lifestyle change, and body-image alongside physical activity as an effective way of achieving physical activity for health benefits for cancer survivors. Studies have shown a clear cost benefit of this type of intervention, costing around £400 per person to run, but saving around £1500 per person in reduced GP attendance, hospital admissions, CNS time etc.

Specialist rehabilitation services should be available to all patients based on clinical need assessed by informed professionals and the patient. Services should be compliant with the National Cancer Rehabilitation Pathways and Rehabilitation Peer Review requirements. [http://ncat.nhs.uk/sites/default/files/Gateway_11008_DEC_rehab_20081117_0.pdf](http://ncat.nhs.uk/sites/default/files/Gateway_11008_DEC_rehab_20081117_0.pdf)

Follow-up Services based upon evidenced stratified risk

Follow up after cancer treatment should be developed using evidence-based risk stratification as described by the National Cancer Survivorship Initiative. A patient’s
level of risk of recurrence, risk of developing consequences of being diagnosed and treated for cancer and risk of psycho-social morbidity should be assessed. This will fit within the model below. There is emerging data and evidence on the numbers of patients which fit within this model by tumour type, and the realities and practicalities of risk-stratification. It will be published at http://www.improvement.nhs.uk/cancer/Default.aspx?alias=www.improvement.nhs.uk/cancer/survivorship

Risk-stratification will happen at the end of treatment consultation. For self-management to become a reality, robust remote monitoring solutions need to be in place. As such, close liaison with the LCA information team and their strategy is vital.

Outcomes and metrics
The effects of any change as a result of the LCA SG work-streams need to be measured. The Survivorship group will review performance against existing metrics contained within peer review and the NICE supportive and palliative care recommendations. Further metrics will be developed by the Group, where appropriate alongside LHP and National Groups and Forums. Relevant outcome measures, including patient reported outcome measures will be identified, promoted and if necessary developed to show effect on the patients themselves, rather than just effect on service provision. Learning from NCSI test communities and local service initiative will be used to inform this work.

Role and function of the LCA Survivorship Group (SG)
The format and function of the Survivorship Group is reliant on the final form of the governance model for the LCA and is likely to be a development of the following.

The purpose of the Survivorship Group is to be the clinical scrutiny and standard setting group for the provision of survivorship services across the LCA. The LCA SG will agree priorities and work plan. The membership will be composed of a multi-professional group with representatives from each of the 16 providers who either currently deliver or have an interest in delivering Survivorship services. The LCA SG needs to work in close collaboration with the other priority pathway groups to ensure that survivorship needs identified by them are addressed in a cohesive and logical manner.

The standards and guidance set by the LCA SG will be ratified by the Interim Clinical Board before being disseminated through the relevant groups for wide-spread use and implementation. Relationships will need to be built to ensure that the service providers fully understand the purpose of the LCA SG to enable optimal collaboration and utilisation of the standards and guidance.

**Aims and objectives**

The overarching aim of the Survivorship Group is to ensure that there is a consistent and robust Survivorship pathway for all patients living with and beyond cancer

The objectives are:

- To develop and implement a Survivorship pathway across the LCA in line with the LCA SG key priorities
- To raise awareness of Survivorship issues for people living with and beyond cancer
- To act as a resource across the LCA providing support, increased awareness and knowledge about Survivorship issues
- To identify and suggest strategies to address the training and education needs associated with the successful implementation of the survivorship pathway
- To contribute to National and International Survivorship initiatives, increasing the evidence base where possible
• To ensure improved experience for patients using the evidence of the national cancer experience and national cancer survivorship surveys
• To feed into pan-London and National monitoring work, including the development of survivorship metrics and key performance indicators

Outcomes
• Survivorship pathway established for use in all tumour types
• Survivorship pathway integrated into each priority pathway
• The LCA able to evidence international best practice standards in Survivorship services
• All Londoners in the LCA to be able to access a Survivorship care plan individually tailored to their needs.

Membership

The interim Chairs for the Survivorship Group are Nick Hyde and Natalie Doyle. As the LCA enters the implementation phase, these posts will be recruited to as per the CEO Group agreed process.

The following are the current members – this is subject to review to ensure that each organisation and professional group is evenly represented with skills and knowledge relevant to the critical components.

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Provider Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nick Hyde</td>
<td>Clinical Director</td>
<td>St. George’s NHS Trust</td>
</tr>
<tr>
<td>Natalie Doyle</td>
<td>Nurse Consultant</td>
<td>The Royal Marsden NHS Foundation Trust</td>
</tr>
<tr>
<td>Janine Mansi</td>
<td>Medical Oncology Consultant</td>
<td>Clinical Lead for Survivorship for Kings Health Partners</td>
</tr>
<tr>
<td>Amanda Shrewbridge</td>
<td>Nurse Consultant for Breast</td>
<td>Guy’s and St Thomas’ Foundation Trust</td>
</tr>
<tr>
<td>Nicky Easton</td>
<td>Survivorship project manager</td>
<td>KHP Integrated Cancer Centre</td>
</tr>
<tr>
<td>Maureen Dowling</td>
<td>Network Lead AHP</td>
<td>SWLCN</td>
</tr>
<tr>
<td>Cathy Wilson</td>
<td>Head of School</td>
<td>The Royal Marsden NHS Foundation Trust</td>
</tr>
<tr>
<td>Nicola Glover</td>
<td>Survivorship Project Manager &amp; AHP Lead</td>
<td>London Cancer Alliance</td>
</tr>
<tr>
<td>Bernie Byrne</td>
<td>Centre Manager</td>
<td>Maggie’s London, Charing Cross Hospital</td>
</tr>
<tr>
<td>Claire Taylor</td>
<td>Colorectal Lead CNS</td>
<td>North-West London Trust</td>
</tr>
<tr>
<td>Sam Tordesillas</td>
<td>Team Lead for Community Head &amp; Neck Cancer Team</td>
<td>Lewisham Healthcare NHS Trust</td>
</tr>
<tr>
<td>Julie Baker</td>
<td>Lead Nurse for Cancer</td>
<td>Lewisham Healthcare NHS Trust</td>
</tr>
<tr>
<td>Ann Muls</td>
<td>Macmillan Nurse Consultant (Cancer Late Effects)</td>
<td>The Royal Marsden Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>Theresa Wiseman</td>
<td>Strategic Lead for Health Research</td>
<td>The Royal Marsden NHS Foundation trust</td>
</tr>
<tr>
<td>Steve Marshall</td>
<td>Social Worker</td>
<td>St Christopher's Hospice</td>
</tr>
<tr>
<td>Donal Gallagher</td>
<td>Macmillan Development</td>
<td>Macmillan Cancer Support</td>
</tr>
</tbody>
</table>
User involvement – user involvement has been requested through the user representatives on the Interim Clinical Board.

Accountability
The group is accountable to the LCA Interim Clinical Board with future accountability dependent on the final LCA governance structure. A highlight report will be submitted on a monthly basis, with feedback from a co-Chair or the Project Manager as agreed.

Attendance
Members of the group are expected to attend all meetings or to nominate a fully briefed deputy in the event that they are unable to attend. If members are unable to attend they should give at least one week’s notice other than in exceptional circumstances. If members are consistently unable to attend, they should consider their suitability for the Group.

A quorum would consist of the Chair (or nominated deputy) and at least four others.

Frequency of Meetings
Throughout the interim development phase the group will meet on a monthly basis, with significant email correspondence and other communication in between as required. This may be reviewed once the project moves into the implementation phase.

Extraordinary meetings may be called at the request of the Chair.

Administration
The Project Manager for the LCA will administer this committee in liaison with the Chair.
Minutes of the meeting will be circulated to the Interim Clinical Board