



London Cancer: **Health and Wellbeing Event Implementation Guidance**

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1. Introduction

There are now approximately 200 000 individuals living in London who have been diagnosed with cancer. The number of cancer cases in London is increasing by over 3% per year so the total figure will rise to just over 400 000 by 2030 ⁽¹⁾.

Evidence shows that as many as 25% of individuals living with or beyond cancer have unmet physical or psychological needs - whilst others are experiencing difficulties living with the consequences of treatment that could either be avoided or minimised ⁽²⁾. Therefore, it is essential that we change the way in which we support individuals living after a cancer diagnosis to address these unmet needs and to meet the growing demands on NHS services as cancer incidence increases.

In order to improve patient outcomes and experience, *London Cancer* is supporting partner trusts to implement health and wellbeing events as part of the National Cancer Survivorship Initiative recommended 'recovery package'. The aim of this document is to provide information and guidance on the development and implementation of health and wellbeing events in order to embed them within cancer pathways.

2. Context – national and local

In 2013, the National Cancer Survivorship Initiative (NCSI) recommended implementation of the 'recovery package' within cancer pathways. The recovery package is a combination of interventions which, when delivered together, greatly improves the outcomes and co-ordination of care for people living with and beyond cancer.

The recovery package consists of 4 key elements:

- **Holistic Needs Assessment** - with copies provided to both the patient and GP
- **Treatment Summary** - with copies provided to both the patient and GP
- **Cancer Care Review** - conducted by GPs within 6 months of them receiving notification of the individual being diagnosed with cancer
- **A health and wellbeing event** – educational clinical events at end of treatment which support individuals to self-manage their condition. Participation in these events empowers people living with cancer (and their families) to actively participate in their recovery, giving them necessary information to promote and maintain positive lifestyle changes

In addition, NCSI recommended embedding stratified follow-up within cancer pathways. Stratified follow-up is an approach to steering individuals who have received their treatment onto the best pathway to address their specific clinical and individual needs. It has a focus on promoting wellbeing, recovery, and empowerment - and providing individuals with the information and confidence to have an active role in their recovery. The overall aims of stratified follow-up are to improve patient experience and the quality and effectiveness of care by tailoring aftercare and integrating supported self-management within the pathway.

Within London, the 5-year commissioning Strategy (NHS England, 2014) prioritised implementation of the recovery package and stratified pathways to improve the care and support for Londoners living beyond cancer.

The *London Cancer* Living with and Beyond Cancer Board is working collaboratively with pathway boards and trusts to implement the recovery package and stratified follow up. *London Cancer* is committed to improving the support mechanisms for individuals living with and beyond a cancer diagnosis. The primary aim of the Board is to action a transition from the current clinician-led and largely hospital-based model of care to the development of a collaborative model which recognises people as experts in their condition and focuses on recovery, health and wellbeing.

This includes providing support to plan and implement interventions such as the health and wellbeing event.

3. What is a health and wellbeing event?

Health and wellbeing events are patient education and support sessions (group or 1:1 clinic appointment) that provide individuals with the information and confidence they require to enable them to lead as normal and active life as possible after their cancer treatment.

4. Rationale for implementation

The National Cancer Survivorship Initiative piloted the introduction and evaluation of 14 Health and Wellbeing clinics for individuals with cancer between 2010 to March 2011. The pilots tested a range of models; tailored to the specific needs of the patient group. The evaluation found that the clinics enhanced quality of care, improved patient reported outcomes and reduced patients' use of health services⁽³⁾.

Other key findings from the NCSI evaluation include⁽³⁾:

- There was improvement to **quality of life** in terms of increased self-reported ability to manage emotional distress and participation in social activities
- There was improvement to patient-reported **physical wellbeing**. Individuals benefitted from advice on diet and exercise and referrals to physiotherapy/dietetic services, as well as receiving information about side effects (which led some patients to change medication, with positive effects)
- A reduction in patients' **self-reported use of health services** was evident following attendance at a clinic, particularly use of GP and district nursing services
- The major expense in delivering the clinics is staff time, which varies according to the model adopted
- The **informal atmosphere** of the clinics enhanced the delivery of health and wellbeing information
- The clinics may work well **earlier in the pathway**
- The clinics had a significant **'reassuring' role**. Individuals reported that they felt better knowing what services are open to them and how to access these
- Participants valued the **group discussions** - this assisted to alleviate isolation and confirm what is 'normal' to experience and feel for a person who has been diagnosed with cancer.
- Referral and attendance is supported through **engagement of the MDT, systematic referral processes and dedicated administrative time**

Components of the pilot sites that resulted in more effective provision⁽³⁾:

- Referral and attendance is supported through **engagement of the MDT, standardised referral processes and dedicated administrative time**.
- **Incorporation of market stalls into the day** – with a focus on wellbeing.
- **Involving volunteers** in the event. Participants especially valued hearing about personal cancer experiences.
- **Close working with local community groups** to encourage involvement of vulnerable groups, therefore maximising reach of the events.
- **Ensuring continued support for patients**. For example, offering them the opportunity to attend subsequent events as needed.

5. Health and wellbeing event development

The format of health and wellbeing events at trust level will depend on a variety of local and tumour pathway factors. The structure and content should be considered within the wider context of provision of interventions/programmes for individuals with other long term conditions within the locale. It is recommended that NHS England (specialist commissioning as appropriate) and local CCGs and Health and Wellbeing Boards are engaged early in the process of planning.

Local CCGs may already have health and wellbeing events in place for other long term conditions, so there may be opportunities to co-deliver events for cancer patients (with bolt-on modules for tumour specific information, for example). CCGs may have a view on the style of event that would support their local population. It would also be useful to liaise with local authorities as they have a role in health and wellbeing due to their public health responsibilities ⁽⁴⁾.

One of the first steps in the development of health and wellbeing support is identifying the intended audience. The NCSI advises delivering events which either have a generic focus or are tumour/treatment specific. A description of the options are as follows ⁽⁵⁾:

- **Generic**, covering topics that are relevant to a number of tumour sites. For instance nutrition, physical activity, returning to work, finance, emotional resilience.
- **Tumour specific** to impart information particular to the specialism. For example, information regarding stoma care after colorectal cancer, or bone health after breast cancer.
- **Subgroup specific** to convey messages to a particular subgroup. For example, information specific to particular treatments in order to provide information on side effects or consequences of treatment. For example maintaining a healthy lifestyle whilst on ongoing hormone treatments.

Other considerations in the development process ⁽⁶⁾:

- What existing health and wellbeing structures are in place?
- Who will provide the training? Health professionals and/or volunteers?
- Will it be delivered in-house or by an external organisation? Or both?
- What are the likely training needs of those involved in planning and delivering the event?
- How do you manage patient expectations? Ensure that participants will understand what will be available at the clinic, particularly if the focus is tumour specific.
- Who will manage and run the clinic or event? Who will provide administrative support?
- Where will the clinic or event be held? Consider logistics, diversity of the audience in a particular area, parking, participants with special requirements, length of the clinic - will refreshments be provided?
- How will you evaluate the event?
- How will you signpost to further sources of support? Consider speakers or information stalls from relevant local support groups
- How will costs for the events be covered? Consider options such as within existing budget, charitable organisations, CCG etc.

There are mixed approaches to the delivery of health and wellbeing events. They may be delivered as one or more of the following configurations:

- **1:1 appointments** conducted with individuals at the end of treatment
- **Rolling programmes** such as 6-weekly Macmillan HOPE events or Penny Brohn Living Well courses.
- **Group events** which are scheduled at regular intervals throughout the year – and which individuals may have an open invitation to attend if they choose to do so. Essentially, these are multidisciplinary meetings for patients and give opportunity for interaction between patients and carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapists. These might also include market stalls of local health promotion services or voluntary agencies.

Providing more than one type of health and wellbeing model is advantageous as it provides patients and carers with a choice to engage in the format which best meets their needs.

6. Content of health and wellbeing events

Health and wellbeing events provide an opportunity to inform and educate patients about the clinical and holistic aspects and the ongoing management of their health. They also serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families. Based on findings obtained from the national health and wellbeing clinic pilot sites in 2011 - and the 'Ten Things that Matter to our Patients' (Appendix A) - London *Cancer* recommends that the core and optional content of health and wellbeing events is as follows:

6.1 Core content

- Expert advice on **health promotion** - to minimise risk of recurrence and support healthy living. i.e. being physically active, nutrition, healthy weight management, smoking cessation. To include information/support to effect behavioural change.
- **Support** to ensure that individuals have the confidence and skills to manage their condition themselves – i.e. referral onward to rehabilitation and psychological support services as appropriate and signposting to local support groups or buddying services.
- **Information about complementary therapies** - how these therapies may help to facilitate wellbeing.
- Advice on **adjusting to life after treatment** – addressing fears of cancer recurrence.
- Information on **signs and symptoms of recurrence** and **potential consequences of treatment**. All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease.
- Information and access to **financial and benefits advice**.
- **Specific issues relevant to the individual's type of cancer**. For example colostomy care, prosthetic care, early detection and management of lymphoedema, body image & sexual functioning.
- **Vocational rehabilitation** – access to services for patients, information patients and carers can share with their employers.
- **Management of symptoms**. For example fatigue or physical discomfort.

6.2 Optional content

- Access to complementary therapies
- Mindfulness

7. Who should receive a health and wellbeing event?

Every individual with cancer should be offered the opportunity to attend a health and wellbeing event at the end of treatment: it is an integral part of the cancer pathway. Evidence from the national pilot project revealed that the events were well received by patients. The main reasons cited for non-attendance at the clinics were practical rather than objections to the format or content. For example, patients cited feeling unwell on the day, or having too many other appointments to attend at the time that a clinic was being held⁽³⁾.

The individualised needs of the patient will determine the type of health and wellbeing event most appropriate for them. Some may prefer or require a 1:1 session whilst others prefer the group format.

It is also recommended that health and wellbeing support be made available to carers as it is essential that their need for information, advice and support are addressed. Palin et al (2011) demonstrated that carers and family members experienced multiple benefits from attending health and wellbeing clinics. These benefits include peer support, empowerment, and signposting to relevant services.

8. Progress with developing health and wellbeing events across *London Cancer*

In October 2014, the Living with and Beyond Cancer Lead for *London Cancer*, scoped the current provision of health and wellbeing events being delivered at our local trusts. The results revealed that:

- 64% of our hospital sites provide their own health and wellbeing events (to one or more tumour site) and;
- 18% of hospital sites signpost patients to voluntary services (CYANA, The Haven or Cancerkin);
- 18% of sites have commissioned the running of health and wellbeing events via an external provider.

9. Useful contacts to support planning and implementation

The Macmillan Lead for Living with and Beyond Cancer and AHPs for *London Cancer*, **Sharon Cavanagh**, is supporting our partner trusts to plan and implement health and wellbeing events as part of the National Cancer Survivorship Initiative Recovery Package. Email: Sharon.cavanagh@londoncancer.org

Local cancer commissioning managers regularly meet with Trust cancer managers and they will be able to advise on who to speak to within CCGs. These are:

- **Kate Kavanagh** - Barking & Dagenham, Havering, Redbridge and West Essex
Email: katherine.kavanagh@nelcsu.nhs.uk
- **Tony Lawlor** – City & Hackney, Newham, Tower Hamlets and Waltham Forest
Email: Tony.Lawlor@nelcsu.nhs.uk.
- **Michael Yare** – Barnet, Camden Enfield, Haringey and Islington
Email: Michael.Yare@nelcsu.nhs.uk

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Appendix A Ten things that matter to patients: What great care looks like

In 2010, during the early phase of the formation of *London Cancer*, UCLPartners (a partnership of health care providers and universities in North Central London), began a collaboration with local commissioners that aimed to think about cancer care and diagnosis differently, in order to improve patient experience and outcomes. Recognising that good patient experience can only be delivered by putting patients first and working together along the journey from symptoms to recovery, a focus was placed on understanding what mattered most to patients, organising how this could be achieved, and how *London Cancer* could measure success around this. Co-designed by conversations and contributions from 1,000 clinicians and over 200 patients within *London Cancer's* footprint within North Central London and West Essex, the 'Ten Things that Matter to Patients' were identified⁽⁷⁾. Outlined below, these have been, and remain, a cornerstone in the continuing work of *London Cancer*.

- 1) **Early Diagnosis:** Patients are diagnosed at an earlier stage
- 2) **Ethos:** Patients are treated holistically as individuals, and with dignity, sensitivity and respect
- 3) **Communications:** Written and verbal information about diagnosis, all treatment options including side effects and quality of life implications
- 4) **Choice:** Patients/ carers fully involved in choice of hospital and treatment options
- 5) **Supports:** Support groups, benefit entitlement, offered emotional/psychosocial support, information about complementary therapies
- 6) **Carers:** Fully involved and supported throughout pathway
- 7) **Holistic Assessment:** At appropriate stages throughout the pathway, with action as a result to meet their needs
- 8) **Seamless Care:** All patients assigned a CNS when diagnosed and community keyworker on discharge
- 9) **Transport:** Patients given information on hospital parking and costs
- 10) **Discharge:** Patients and GP provided with discharge information and follow up advice.