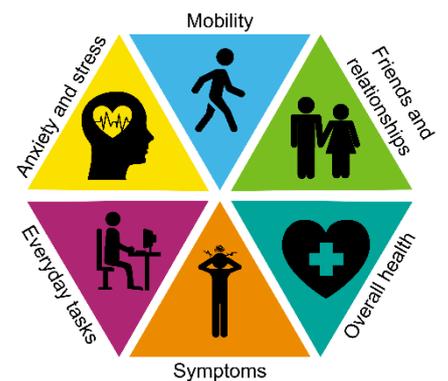


Cancer Quality of Life Survey Local Champions

Role profile



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Introduction

1. Public Health England, NHS England and NHS Improvement are leading the way in cancer care by recognising that quality of life (QoL) outcomes are as important to patients as survival.

We launched a nationwide QoL survey in September 2020. We would like to understand how cancer may have changed people's quality of life. This will help us to improve services. The NHS wants to support people to live as long and as well as possible.

2. Initially we will survey people who have been diagnosed with breast, prostate or colorectal cancer. People with all other cancer types will be included from 2021 onwards. People will be sent a survey 18 months after their diagnosis to assess their QoL. The information collected from the survey will be used to work out how best to support the growing number of people living with and beyond cancer. This is an ambitious programme with a scale and depth that isn't being matched anywhere else in the world.
3. We want to encourage as many people as possible to complete the survey so that the information collected fully represents our cancer population. In order to do that, we need people to act as 'local champions' and promote the survey locally.
4. This role profile sets out the purpose of local champions, ways to promote the survey and how we will support local champions to deliver local awareness raising activity.
5. If you are interested in becoming a local champion for the QoL survey, please read this role profile and contact Erin.Barton@nhs.net



Purpose

1. The role of the local champion is to:
 - i) **Promote uptake of the survey** so that we achieve a good response rate. We want people to understand why the survey is important and how their response will help us to improve support for people who have had a diagnosis of cancer.
 - ii) **Improve our reach** by encouraging underrepresented groups to complete the survey and engage with the findings.
 - iii) **Spread awareness of the survey** more generally so that the Cancer Quality of Life Survey is recognisable and trusted.
 - iv) **Foster support for the project** and encourage a shift towards recognising that quality of life is as important to patients as survival.
 - v) **Increase engagement with the findings.** When data becomes available, it is important that patients, clinicians and the wider cancer community are enthusiastic about using the data to improve quality of life.



Ways to promote the survey

1. There are various ways to promote the survey including, but not limited to:
 - i) **Posting on social media** – Tweeting and re-tweeting about the survey. Sharing posts on LinkedIn, Instagram and Facebook, including any closed patient support groups or advocacy groups.
 - ii) **Talking to patients about the survey** – This could be at local support groups or patient advisory groups, by sharing the patient information leaflet and locally printable posters, or by posting on forums.
 - iii) **Talking to clinicians about the survey** and ensuring local GP practices know about the survey.
 - iv) **Talking to local charities about the survey** – to make them aware and to ask if they can promote the survey too.
 - v) **Delivering presentations** – There will be opportunities to present to different audiences including patients and clinicians. Hearing about why the survey is important from a patients' perspective can be very powerful.
 - vi) **Writing blog posts** about why quality of life outcomes are important to patients and why people should complete the survey, or encouraging other bloggers or influencers within the cancer community to write about the survey.
 - vii) **Using the workspace discussion forum** – Parts of the FutureNHS Collaboration platform can be accessed by healthcare professionals working within a Cancer Alliance and members of the Patient and Public Voices Forum. Those with access to the platform can use it to start a discussion about the survey.
 - viii) **Identifying opportunities** – Acting as our 'eyes and ears' and letting us know of any other opportunities to promote the survey. This could include inviting us to deliver a presentation.



Support for local champions

1. We will convene regularly as a group to discuss progress and share ideas. Initially, we will meet virtually via Microsoft Teams every other month. The location, format and timing of meetings will be reviewed based on feedback from the group, as the project progresses and as the situation with COVID-19 changes.
2. The total time commitment depends on the number and type of awareness raising activities delivered by each individual. There is no minimum level of activity required.
3. The local champion role is an unpaid voluntary position. However, local champions will be reimbursed reasonable out-of-pocket expenses incurred in line with NHS England's PPV Partners Expenses and Involvement Payments Policy. Expenses usually cover travel and any subsistence requirements that arise, as well as used of broadband to attend meetings or events.
4. The Cancer Quality of Life team at NHS England will be available via email or telephone should local champions have any questions, concerns or ideas that they would like to share.
5. The Cancer Quality of Life team will provide a toolkit of resources that can be used to deliver local awareness raising activity, including:
 - i) Key messages
 - ii) Frequently Asked Questions
 - iii) A slide set and slide template for presentations
 - iv) Social media suggestions
 - v) Locally printable patient information leaflet and poster
 - vi) The patient facing website – www.CancerQoL.england.nhs.uk
6. The Cancer Quality of Life team will hold an induction session with new local champions to explain the role and the support available, and to ensure champions are confident to deliver key messages.



Evaluation

1. Local champions should record their recently delivered activities. It would be helpful for us to know numbers – for example, how many people attended a meeting or how many leaflets were shared. It would also be helpful to know more detailed feedback from the people you talk to about the survey, and if they had any questions or concerns.
2. This information should be recorded in a short template which will be sent around ahead of the monthly meeting. This should take no longer than 5 minutes to complete and will help us to understand how effective our communications plan is. We will then collate this information and share it at the next group meeting.
3. Local champions may be asked how the Cancer Quality of Life Survey differs from other surveys run by NHS England, including the National Cancer Patient Experience Survey. We encourage local champions to collect feedback about other NHS surveys and services and feed this back to the National team as part of our efforts to make continuous improvements in all areas.



Membership

1. Local champions must be passionate about promoting the Cancer Quality of Life Survey. The role is open to people who have had a diagnosis of cancer; carers of people with cancer; anybody involved in the delivery of care to cancer patients; and anybody who has a special interest in improving the lives of people living with and beyond cancer. If you are interested in becoming a local champion, you can email Erin Barton for more information – Erin.Barton@nhs.net
2. We will aim to have at least one local champion from each Cancer Alliance Geography.
3. We will encourage local champions to form a relationship with the Patient Experience and Engagement Lead within their local Cancer Alliance.
4. Initial engagement of local champions will be for one year, with the option of renewal by mutual agreement. Local champions may resign their role at any time by informing Erin Barton, Project Manager for the Cancer Quality of Life Survey – Erin.Barton@nhs.net

