Help us use a “teachable moment” to share advice about cancer prevention when it’s most effective

We are looking for two patient/carer representatives to join the Project Group for an exciting new cancer awareness project in North and East London. You’ll work with us to develop new cancer education events which reach people when they are more likely to be receptive to making healthy lifestyle changes, and to information about how to spot early cancer signs and symptoms.

**Length of role:** 4-6 months (until 31 March 2019)

**Background**

Nine out of ten people referred for urgent tests investigating possible cancer symptoms are given the ‘all clear’. We believe that there is an opportunity to enhance the experience that these people have in order to improve their future health outcomes. Research suggests that there are points in the cancer diagnostic process that create a “teachable moment” in people's lives.¹ A “teachable moment” is a period of time following a health event (such as a “cancer scare”) where people are more open than usual to new health information, and more prepared to make a lifestyle change which could have a positive impact on their health. For example, quitting smoking, eating a healthier diet, or increasing physical activity.

There is also evidence to suggest that if no information is given at this point, people who have been discharged without a diagnosis after a “cancer scare” are less likely to seek advice in future if they notice another possible symptom of cancer.²

**About the project**

Through this project, people across north and east London who have been recently discharged without a cancer diagnosis after an urgent (“2 week wait”) referral will receive:

- **a letter** giving them contact details for the Trust to which they were referred, explaining that they can ask questions about their result or pursue concerns if they feel this is necessary
- **an invitation to an awareness-raising event** where they will receive information about:
  - the importance of cancer prevention and screening
  - support and information related to healthy lifestyle choices
  - the continued need to be on the look out for cancer signs and symptoms
  - how to get back in contact with the hospital if they are concerned that something has been missed, or they start to feel more unwell following discharge.

This idea was piloted in a series of 5 events by Barts Health during March-May 2018, and the results will inform the work we do throughout this next phase.

We are currently setting up a Project Group to inform this work. Members of the group will include: clinicians and managers from hospitals in North and East London, who are directly involved with delivering these events, along with two patient/ public representatives. As part of this group, you’ll work with us to co-design invitations and events, and ensure they are accessible to people from different backgrounds across north and east London.

Your role

As a patient representative on the Project Group, your role will be to:

- Attend project group meetings, and contribute effectively by reviewing information sent in advance, listening and contributing to discussions, hearing different views and raising relevant issues from a patient perspective
- Broadly represent the diverse range of people who might be invited to these events (for example different ages, people with disabilities, and people with many different backgrounds and experiences), sharing ideas and perspectives which reflect the voice of local people
- Review and provide written comments to the project team on information materials/resources for patients and the public
- Draw on the views and experiences of other cancer support or community groups, so our work is informed by a broad range of perspectives
- Be collaborative, inclusive and respectful when working with other Project Group members, in line with our Ways of Working (see accompanying document).
- Tell us if you are asked to do something which you feel is outside your remit, beyond your skill or knowledge level, or would require a time commitment which you are unable to keep
- Discuss with us and let us know if any aspects of your involvement need adjusting
- Agree to disclose fully any potential conflict of interest that arises throughout the duration of the project

Who is eligible for this role?

We’re welcoming Expressions of Interest from anyone who either:

- Has a special interest in raising public awareness of cancer; or
- Has been urgently referred by their GP for cancer testing, whether or not this resulted in a cancer diagnosis (you might have been told you were on a “2 week wait” pathway); or
- Has attended a cancer education event, such as a “Health and Wellbeing” event

Please note that we can only accept Expressions of Interest from people who either currently live, or have been treated for cancer, in any of the areas we cover (see map).

We’re not able to accept Expressions of Interest from current clinical NHS employees or contractors (this includes honorary or unpaid medical or dental posts).

Time commitment

This project will run until 31 March 2019. The anticipated time commitment is below:

- Documents containing information about the project will be provided prior to meetings, at least 1 week in advance. You’ll need to set aside time to read through these documents and to make a note of any questions you have. A member of the project team will be available to answer your questions by phone or email ahead of the meeting, and in person at the meeting.
- The Project Group will initially meet monthly for the first 4 months of the project, then every other month until March 2019. You can choose whether to attend the meeting over the phone, or in person.
- As a general rule, we expect patient/carer representatives to attend a minimum of 4 out of 6 meetings in one calendar year. Of course we do understand that there may be times when your health or personal circumstances mean that you are unable to do this - we ask that you
let us know as far in advance as possible if you are not able to attend an upcoming meeting. This will enable us to inform the Chair and support you to contribute effectively.

**Skills and experience**

When we read your Expression of Interest form, we’ll be looking for whether you show:

- A keen interest in cancer prevention and the use of awareness raising events to share information about cancer screening and healthy living
- Confidence to communicate clearly and participate in group discussion with a range of people
- Ability to consider issues beyond your own experiences of services and anecdotes, and willing to provide objective input about the needs of people from a wide variety of different backgrounds and perspectives
- Good written communication skills
- Ability to listen, understand and respect different perspectives, display empathy and be open to other points of view
- Willing to adhere to our ‘Ways of Working’, conflict of interest and confidentiality agreements
- Reliable and able to meet the time commitment outlined above

**Training and support**

It’s really important to us that you have a positive experience when you work with us. When you get involved, we’ll make sure you’ll receive:

- An induction to prepare you for the role
- Briefings prior to each project meeting and debriefings afterwards with a key staff member, to enable you to participate effectively.
- Opportunities to participate in training provided by organisations such as Macmillan
- Ongoing support and guidance from the Patient Experience and User Involvement team.
- Opportunities to network with other people affected by cancer at various events
- Regular updates from the UCLH Cancer Collaborative on our work
- Reimbursement of reasonable travel expenses, in line with our Expenses Policy
- Meetings to be held in accessible venues. Please let us know if you have any accessibility needs, and we will explore how best to make reasonable adjustments.
- Transparency and honesty about what we can and cannot achieve
- Use of plain, jargon free language in meetings and an explanation of all acronyms
- Access to information, including meeting papers, in good time to allow you to prepare and raise questions
- Opportunities to discuss aspects of the Collaborative’s work with the team outside of the main meetings and make relevant contributions to the agenda
- Signposting to additional sources of support if you need it. We understand that talking about cancer can be difficult. Members can take a break at any point, if required.

**Our contact details**

If you’d like to discuss this role or find out more about other ways you can get involved with our work at the UCLH Cancer Collaborative, please don’t hesitate to contact us.

- **Email:** uclh.getinvolvedwithcancer1@nhs.net
- **Phone:** 07950 960168

A member of our team will get back to you as quickly as we can.

The UCLH Cancer Collaborative Patient Experience and User Involvement Team consists of:
Zoe Large, Macmillan Patient Experience and User Involvement Project Manager
Daisy Doncaster, Macmillan Project Coordinator

How to apply

If you would like to apply, please complete an Expression of Interest Form and email it to uclh.getinvolvedwithcancer1@nhs.net. The deadline is Monday 26th November 2018.

We will review your information and arrange a time to speak with you, either in person or over the phone. There will be a selection process to ensure we match the right person to each role, or other possible opportunities.

Thank you for your interest in this role.