

**Title:** Patient/carer representative role description

**Lay title:** Using self-sampling kits to increase early detection of cervical cancer

**Full project title:** The Alliance feasibility study of an HPV self-sampling service in North and East London

**Accountable to:** Tbc. - Steering Group Chair is currently being recruited

**Tenure of office:** 18 Months

## 1. Project Summary

### Background

We know that when cervical cancer is detected at an early stage, treatment is less invasive and patients are likely to have a better quality of life in the long term. However cervical cancer screening uptake in London is the poorest in the UK, with some patches of North East London having some of the lowest rates of all. The reasons for this are often pragmatic: when asked why they do not take up an appointment, many women say they haven't been able to find the time due to personal stresses or conflicting priorities.

Research in the Netherlands and America has shown that screening uptake is increased when women are offered the chance to take a screening sample themselves - in private and at a time of their choice - using a kit which tests for the human papillomavirus (or HPV). This could have particularly high impact in London, where busy lifestyles pose a significant screening barrier for many women.

This project will be introducing the use of self-sampling HPV kits in GP Practices across North East London. By testing this new method of service delivery we hope to generate learning which will support self-sampling to be offered across a far larger area.

### About HPV and Cervical Cancer

HPV is the name given to a very common group of viruses, some of which are called "high risk" because they're linked to the development of cancers. Nearly all cervical cancers (99.7%) are caused by infection with a high-risk type of HPV. HPV infections do not usually cause any symptoms, and most people will not know they're infected.

[Read more](#) about HPV on the NHS Choices website.

### About the Steering Group

We are setting up a project Steering Group to oversee all aspects of this new project's design and delivery.

The membership of the Steering Group will consist of:

- London Cancer Gynaecology Pathway Director
- HPV Self Sampling Programme Manager
- Research Leads from Kings College London
- Representatives from Public Health England

- Representatives from Voluntary Sector Organisations
- Representatives from Sustainability and Transformation Plans (STPs)
- 2 x Patient / Carer Representatives
- NHS Contractors

As one of two patient / carer representative on the steering group, you will make a difference by:

- Ensuring that the approach is centred on the needs of people with cancer, and enabling us to think through processes from a patient perspective
- Critically discussing options from the perspective of patients with different needs
- Advising on development of appropriate and accessible patient information
- Advising on wider engagement that may be required

## 2. Responsibilities

Patient/carers representatives will be expected to:

- Attend monthly Steering 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/carers perspective
- Broadly represent the diverse range of people invited to cervical screenings or affected by cervical cancer in our area, offering ideas and perspectives which reflect the voice of local patients
- Use your experience and knowledge to provide advice on how proposals may affect people invited to cervical screenings and affected by cervical cancer, and ask questions about how proposals will impact on different people
- Review and provide written comments to the project team on information leaflets for patients and the public
- Draw on the views and experiences of other cancer support or community groups, so that our work is informed by a broad range of perspectives
- To be collaborative, inclusive and respectful when working with us and other people affected by cancer with a commitment to our 'Ways of Working' (see accompanying document).
- Discuss with us and let us know whether aspects of the arrangement need reviewing and adjusting.
- Sign up and adhere to our Ways of Working, Conflict of Interest and Confidentiality Agreement.

### Who is eligible for this role?

You are eligible for this role if you: 1) live in the UCLH Cancer Collaborative area **or** 2) have used/ cared who someone who has used GP or hospital services in the UCLH Cancer Collaborative area – either for cervical screening, follow up or treatment. **Please [see our map](#).**

In addition to the above, your experience should match **at least one** of the criteria below:

- You have been invited to a cervical screening within the past two years (whether or not you attended).
- You have experienced treatment for cervical changes, for example the removal of cell abnormalities (either with your GP or in hospital)
- You have experienced treatment for cervical cancer

- You have cared within the past 5 years for someone who has been treated for cervical changes or cervical cancer. (If you are a carer, this must be in a personal and unpaid capacity, rather than as a professional.)

### **Who is not eligible for this role?**

You are not eligible for this role if:

- You are a current clinical NHS employee or contractor (this includes honorary or unpaid medical or dental posts).

### **3. Time commitment**

This project will run for 12-18 months. The anticipated time commitment is as follows:

- Several documents will be provided prior to meetings, at least 1 week in advance. These will contain information about progress of the project. It is important that you 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.
- You will be asked to join a monthly Steering Group (1-2 hours). You can either dial into meetings by phone, or attend in person.
- You will be expected to attend a minimum of 8 out of 12 meetings in one calendar year. We understand that there may be times when your health or personal circumstances may make this difficult; so 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.
- You will be invited to join the rest of the Steering Group at meetings with wider UCLH Cancer Collaborative staff, and contribute to the creation of presentations about the project where relevant. We will send you the dates for any meetings as soon as possible. You and the other Patient Rep may wish to share these opportunities between you.

### **4. Skills, experience and attributes required**

For this role, it's essential that you have:

- 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 women invited for cervical screening, or being treated for cervical changes
- Good written communication skills
- Ability to listen, understand and respect different perspectives, display empathy and be open to other points of view
- Ability to form and maintain working relationships in challenging circumstances
- Willing to adhere to our 'Ways of Working', conflict of interest and confidentiality agreements
- Reliable and able to meet the time commitment outlined above.

For this role, it's desirable that you:

- Belong to, or are willing to join, a cancer support group or a community group. As well as cancer-specific groups, this could also include a patient participation group, local Healthwatch, a peer support group, a faith or cultural group. This will help enable you to bring a wider perspective to the discussions.

## 5. What can you expect from us?

- 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 the progress of our programmes of 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.
- Opportunity 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 would like to discuss this role, or 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](mailto:uclh.getinvolvedwithcancer1@nhs.net)

Phone: 020 3447 2779 or 07950 960168

A member of our team will get back to you. The UCLH Cancer Collaborative Patient Experience and User Involvement Team consists of:

- Becky Driscoll, Macmillan Patient Experience and User Involvement Project Lead
- Zoe Large, Macmillan Patient Experience and User Involvement Project Manager
- Daisy Doncaster, Macmillan Project Coordinator
- Hasmita Gorasia, office volunteer

## How to apply

If you would like to apply, please complete an Expression of Interest Form and email it to [uclh.getinvolvedwithcancer1@nhs.net](mailto:uclh.getinvolvedwithcancer1@nhs.net). The deadline is **Monday 24<sup>th</sup> September 2018**.

We will arrange a time to speak with you, either in person or over the phone. There will be an informal selection process to ensure we match the right person to each role, or other possible opportunities. Thank you for your interest in this role.