

**UCLH Cancer Collaborative**  
**Patient Experience and User Involvement Steering Group**  
**Member's Role Description: People affected by cancer**

This is an opportunity for people affected by cancer to have a significant role in helping us shape and improve cancer services in north central and east London and west Essex, driving the co-design and delivery of our patient experience and user involvement programme of work.

**Patient and Carer Involvement Opportunity:**

**What is the role of the Patient Experience & User Involvement Steering Group?**

It is part of UCLH Cancer Collaborative and supported by the Patient Experience and User Involvement Team. The group will work with the Pathway Boards, Expert Reference groups, project teams, wider patient experience teams and cancer leads within the Trusts. They will foster links with relevant community and voluntary sector groups supporting people affected by cancer and they will work in alliance with all key stakeholders to help support the co-design and delivery of the UCLH Cancer Collaborative patient experience and user involvement programme of work.

Its aim is to foster and promote a collaborative approach between the UCLH Cancer Collaborative and people affected by cancer and ensure that all partner organisations (including Trusts and CCGs) engage and involve people affected by cancer to design and improve services to deliver positive patient experience.

**The Steering Group:**

- will be co-chaired by an appointed chair who is a person affected by cancer and a co-chair who is the UCLH Cancer Divisional Manager. The co-chairs will preside over the meeting to ensure that participants are following the conventions of the meeting and represent the Steering Group to the public and other relevant meetings
- will have an appointed vice-chair who will deputise in the absence of one of the co-chairs and lead on specific identified projects or work streams
- will have a facilitator from the UCLH Cancer Collaborative Patient Experience and User Involvement Team. The facilitator will coordinate recruitment, induction and support arrangements for members, set the dates for the meeting, work with the Collaborative and Steering Group members to set the agenda for each meeting, take minutes, and maintain the action log. They will support the group's relationship with the Pathway Boards, Expert Reference Groups and the Cancer Vanguard Board. They will be available for discussions with members about the work of the Steering Group. The facilitator will support the chair and the vice-chair to carry out the business of the Steering Group effectively and respond to queries which may arise.

### **Aims of the Steering Group:**

- To drive patient experience and user involvement work across the UCLH Cancer Collaborative.
- To influence improvement initiatives in cancer services by working with partner organisations in the UCLH Cancer Collaborative and helping them respond to patient and carer insight.
- To support new and existing patient experience projects and user involvement opportunities within UCLH Cancer Collaborative.
- To link patient experience and user involvement work to local support groups and learning communities to ensure engagement with diverse groups.
- To act as the communication and information sharing hub for people affected by cancer who sit on the UCLH Cancer Collaborative Cancer clinical Pathway Boards and Expert Reference Groups.
- To act as the platform for sharing and learning from quality improvement projects designed to improve cancer patient experience and wider outcomes.
- To help communicate the plans and achievements of the UCLH Cancer Collaborative partners with people affected by cancer within community groups.
- To support, where required, focused project groups set up to address specific issues.

As a Steering Group member you will:

- Broadly represent the diverse range of people affected by cancer who use health services in the UCLH Cancer Collaborative area (see map in Appendix 1)
- Actively seek to improve the quality of services for people affected by cancer
- Use your experience and knowledge to provide advice on how proposals may impact on people affected by cancer, and constructively challenge the thinking of healthcare professionals when necessary
- Draw on the views and experiences of other cancer support or community groups (if you are a current member of any other relevant groups), so that our work is informed by a broad range of perspectives
- Advise healthcare professionals and managers on how people affected by cancer should be involved in work to improve health services (patient and public involvement)

### **Who is eligible for this role?**

You are eligible for this role if:

- You have been treated for cancer, or have cared for someone who has received treatment for cancer, within the past 5 years. If you are a carer, this must be in a personal and unpaid capacity, rather than as a professional.
- You have received (or the person you care for has received) treatment for cancer at an NHS hospital in the UCLH Cancer Collaborative area. This covers 17 hospitals – please see our map in Appendix 1.
- You are a member of a voluntary and community sector service supporting people affected by cancer.

Ideally, we would like to appoint 2 members from each of the 11 NHS Trusts in the UCLH Cancer Collaborative area, and will take this into consideration during the selection process.

### **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).
- You are already a member of a Pathway Board or Expert Reference Group within the UCLH Cancer Collaborative.

### **What is the time commitment?**

Meetings will take place once every two months for 1.5 - 2 hours ahead of the Cancer Vanguard Board, so that the chair and vice-chair are able to attend the Board and report on progress. This arrangement will be reviewed and adjusted if deemed appropriate. We will share meeting dates as far in advance as possible.

You will need to allow yourself time to prepare for the meetings, including reading and digesting the meeting papers, and discussing key issues with your own networks (e.g. a support group or patient / carer forum you attend) as appropriate.

In addition, there may be occasional project work and virtual involvement via email in between meetings.

Steering Group members will be expected to attend in person or dialling in to a minimum of 4 out of 6 meetings in any one calendar year. Members must also contribute to a further 2 meetings by providing comments on specific topics or proposals; this will be waived if the meetings clash with other events organised by the UCLH Cancer Collaborative. 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.

### **What is the selection process?**

If you are interested, please review all the information provided carefully and contact us to arrange an informal discussion about your experience, skills and interests, to assess whether this role would be a good fit for you.

You will need to complete the Expression of Interest Form. All forms should be sent by midnight Sunday 29 April 2018.

Shortlisted applicants will be invited to meet with a selection panel which will include the Patient Experience and User Involvement team, and the senior leadership of the UCLH Cancer Collaborative.

### **What is the term of office?**

The length of tenure for each member will be 2 years with a review at the end of the first year in the role. All members may step down at any point in their tenure, should their circumstances and ability to participate change. Members will be encouraged to raise any issues in between meetings, so that we can provide effective support.

### **What can you expect from us?**

- An induction day to prepare you for the role
- 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 our programmes of work in our area
- 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 relevant teams 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.

### **What will we expect from you?**

- To attend each meeting and contribute effectively by reviewing the information sent in advance, listening and contributing to discussions, hearing other's views and raising key, relevant issues from a wider patient and carer perspective.
- To ask questions and enquire how our plans and programmes of work will impact on the way different patient groups access and use the service being designed.
- To consider the needs of different communities of people affected by cancer living in our sector when helping us shape services.
- To be collaborative, inclusive and respectful when working with us and other people affected by cancer whilst adhering to our Ways of Working (see document), and abiding by the [UCLH values](#).
- To refrain from behaviours and style of communication which may be perceived as, discriminatory, unfair or unconstructive to the members of the group.
- To respond to email requests promptly and to let us know in advance if you are not able to attend meetings or other key events.
- To sign a confidentiality agreement and respect the confidential nature of some aspects of the meetings (the Co-chairs will make clear when confidentiality applies).
- To declare any potential conflicts of interest as they arise.

- To discuss with us and let us know whether aspects of the arrangement need reviewing and adjusting.

### **What skills, experience and personal qualities do you need?**

For this role, it's essential that you:

- Are passionate about supporting us through a positive dialogue and a collaborative approach.
- Are able to consider issues beyond your own experience of services and anecdotes.
- Are willing to provide objective input about the needs of people affected by cancer, and to represent the diverse range of people treated in the UCLH Cancer Collaborative.
- Are able to communicate your ideas to a wide range of people, including senior healthcare professionals.
- Are confident about participating in group discussions and presenting the views of people affected by cancer.
- Are able to offer constructive challenge to senior professionals when necessary.
- Are able to listen to and respect different perspectives, display empathy, and be open to other points of view.
- Are able to understand and evaluate a range of information and evidence to support different approaches to service delivery.
- Have an awareness of and commitment to equality and diversity.
- Are reliable and able to meet the time commitment outlined above, including preparing for meetings.
- Are willing to sign up and adhere to our Ways of Working, Conflict of Interest and Confidentiality Agreement.

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.

### **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 2787 or 07950 960 159.

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
- Vacant position – Macmillan Patient Experience and User Involvement Project Manager

- 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 midnight Sunday 29 April 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.

If you are selected for this role, you will be invited to an Induction Day in June 2018.