

## **Pathway Boards and Expert Reference Groups**

### **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, with a specific focus on improving patients' experience of care and clinical outcomes.

### **Patient and Carer Involvement Opportunity:**

#### **What is the role of people affected by cancer on a Pathway Board or Expert Reference Group?**

In order to achieve our aims we consistently involve people affected by cancer in our Pathway Boards, Expert Reference Groups and within specific projects designed to improve services. Co-designing services continues to help us deliver the outcomes we aspire to achieve - both in patient experience and in clinical care that matters most to patients and their families and carers.

As a patient / carer representative you will:

- Broadly represent the diverse range of people affected by cancer who use health services in the UCLH Cancer Collaborative area (see map on page xx)
- 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)

#### **Please note:**

We have a number of vacancies on our various Pathway Boards and Expert Reference Groups. Please see 'Pathway Boards and ERG vacancy list' document for a complete list, to decide which one would be most relevant and interesting for you.

“Using my own experiences as a patient and carer to contribute positively to developing training films 'Telling your child you have cancer' and 'Supporting families and carers of people with cancer' has felt worthwhile and hopefully will be useful to others. I have also learnt a lot thanks to the support of the Chair and other members of the group.”

**Daphne Earl, patient representative on the Psychosocial Expert Reference Group and the Living with and beyond Cancer Expert Reference Group.**

“I really did not know what to expect. But all the Haematology Pathway Board members have been very welcoming and clearly value the input of my fellow patient reps. We’ve been involved in a range of projects - big and small, some general and others quite specialized. It’s been fun, always interesting and a great way to help the boards improve patient care.”

**Declan Sheehan, patient representative on the Haematology Pathway Board.**

### **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.

### **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).

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

Typically, each Pathway Board or Expert Reference Group holds three or four meetings per year. The exact duration and frequency of meetings for each group is determined by the Pathway Director or Chair. We will share meeting dates as far in advance as possible.

You will need to allow yourself time to prepare for the meetings, including participating in pre-meeting briefings with our team, 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.

Patient and carer representatives will be expected to attend a minimum of 75% of meetings in any 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 Pathway Director or Chair and/or 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 have an informal discussion about your experience, skills and interests, to assess whether this role would be a good fit for you.

You can then fill out 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, the relevant Pathway Director or Chair, and a Project Manager for the Pathway Board or Expert Reference Group.

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

The length of tenure for each patient / carer representative will be 2 years with a review at the end of the first year in the role. Patient / carer representatives may step down at any point in their tenure, should their circumstances and ability to participate change. Patient / carer representatives 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, the Director / Chair and Project Manager of the Pathway Board or Expert Reference Group.
- 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 Pathway Boards' and Expert Reference Groups' work with the Project Managers 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. Patient / carer representatives 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 services 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 Pathway Director or Chair 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: 07950 960 159 or 020 3447 2787.

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.

## Appendix 1: Map of the area covered by the UCLH Cancer Collaborative

Please note that in order to be a patient representative, you (or the person you care for) must have received your treatment at one of the hospitals on this map.



### Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT)

- 1** King George Hospital
- 2** Queen's Hospital

### Barts Health NHS Trust (Barts Health)

- 3** Newham University Hospital
- 4** The Royal London Hospital
- 5** St Bartholomew's Hospital
- 6** Whipps Cross University Hospital
- 7** Great Ormond Street Hospital for Children NHS Foundation Trust
- 8** Homerton University Hospital NHS Foundation Trust

- 9** Moorfields Eye Hospital NHS Foundation Trust

- 10** North Middlesex University Hospital NHS Trust

- 11** Princess Alexandra Hospital NHS Trust

### Royal Free London NHS Foundation Trust

- 12** Barnet Hospital
- 13** Chase Farm Hospital
- 14** Royal Free Hospital

- 15** Royal National Orthopaedic Hospital NHS Trust

- 16** University College London Hospitals NHS Foundation Trust (UCLH)

- 17** Whittington Hospital NHS Trust