North Central London
Health and Care
Integrated Care System

NHS
North Central London
Cancer Alliance

Patient and Carer Partner Role Description and Application Information

Patient Public Involvement Strategy Group

October 2024

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About this pack

Thank you for your interest in joining the North Central London Cancer Alliance as a patient or carer partner.

This pack contains a detailed role description that explains the purpose of the group, outlines the role responsibilities, and describes the support that the NCLCA provides to patients and carers. The role description also includes eligibility requirements and lists the skills and experience we're looking for.

How to apply

To apply, please complete a short Expression of Interest form. You can download it from our website as a Word document to fill out and email back. Alternatively, you can print the form and return it by post. If you'd prefer a printed copy, just let Fiona know your address. Fiona can also help you fill out the form over the phone if that’s more convenient. Please return your Expression of Interest by **5th December.**

Once we receive your completed form, here’s what you can expect next:

- **Confirmation of Receipt**: We’ll email you to confirm we received your application.
- **Application Review**: We’ll review your application based on the skills and experience outlined in the role description.
- **Informal Interview**: If you’re shortlisted, you will be invited to an informal interview with the Chair of the Group, along with a member of our patient participation team. This will be conducted via phone or Microsoft Teams, will last no longer than 30 minutes.
- **Application Outcome**: We’ll notify all applicants whether their application was successful or not.
- **Induction**: Successful applicants will participate in an induction in early 2025.

We look forward to receiving your application buy the **5th December.** If you have any questions about the role or the application process, please contact Fiona Martin, fiona.martin30@nhs.net or call 07929069134

About the role

The NHS North Central London Cancer Alliance (NCLCA) works to innovate, coordinate and transform cancer services to support the prevention, diagnosis and treatment of cancer for our local population. We cover the London boroughs of Barnet, Camden, Enfield, Haringey and Islington.

To achieve our aims, we consistently involve people affected by cancer in our working groups. The role of patient/carer partners on our Patient and Public Involvement Strategy Group is to support us to deliver the outcomes we aspire to achieve in patient experience and in clinical care that matters most to patients and their families and carers. Our patient/carer partners ensure we are embedding diverse and inclusive patient/carer voice in our work plans and help us to ensure our plans are inclusive and engaging with communities.

To achieve our aims, we consistently involve people affected by cancer in our work. We co-design services 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. Our patient and carer partners ensure we are embedding diverse and inclusive patient and carer voice in our work plans, provide oversight and help us to ensure our plans are inclusive and engaging with communities.

The purpose of the Patient and Public Involvement Strategy Group is to develop and oversee the patient and public involvement strategy. To embed the diverse voice of patients, carers and communities in North Central London and contribute to improvements in cancer services and patient experience.

Overview of the role

Type of role

Patient and Public Strategy Group

Time commitment

1 x 60 min Teams meeting every two months plus preparation time

Expenses

Expenses will be paid in line with NCLCA's Reward and Recognition policy

Duration of role

Maximum of 4 years

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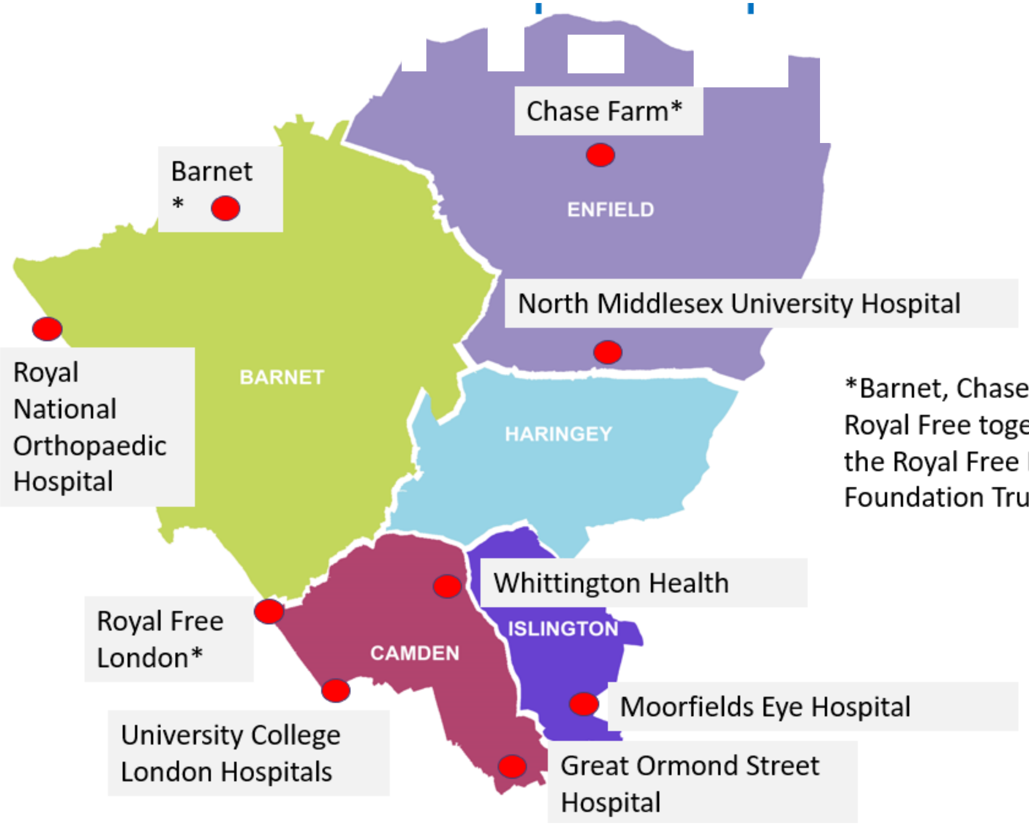
The Strategy Group's responsibilities include:

- Overseeing the three strategy work streams which focus on the support for patient and carer partners, quality and improvement and increasing diversity of our patient partnership community.
- Ensure that projects, groups and work streams across the Alliance and partners, engage and involve people with lived experience of cancer. When designing and implementing services to improve patient experience and clinical outcomes.
- Link patient experience and user involvement work to local support groups and communities to ensure engagement with a diverse range of groups and communities across North Central London.
- Drive patient experience and user involvement across the North Central London Cancer Alliance and help maintain standards through appropriate levels of discussion and challenge.

North Central London
Cancer Alliance

Eligibility for the role

- Individuals who have been diagnosed with cancer and/or received cancer treatment/support within north central London within the last 5 years.
- Individuals who have cared for someone, in a personal capacity, who has been diagnosed with cancer and/or received cancer treatment/support within north central London within the last 5 years.



*Barnet, Chase Farm and Royal Free together form the Royal Free London NHS Foundation Trust

Skills, experience and personal qualities

- Ability to bring personal experience, advice and perspective into the Delivery Group. By doing so, patient/carer partner representatives will be actively contributing to the design of services, policies, and procedures and helping us to meet the needs of people living in NCL or being treated in an NCL hospital.
- Have experience of championing health improvements.
- Be connected to related patient and public voice networks within north central London.
- Understand and evaluate a range of information, data and evidence to support different approaches to service delivery.
- Offer respectful challenge as appropriate to other members of the group and wider stakeholders and Cancer Alliance team.
- Be passionate about supporting us through a positive dialogue and a collaborative approach.
- Consider issues beyond own experience of services and anecdotes.
- Provide objective input about the needs of people affected by cancer.
- Communicate ideas to a wide range of people, including senior healthcare professionals.
- Be confident about participating in group discussions and presenting views.
- Listen to, and respect, different perspectives. Display empathy and be open to other points of view.
- Have an awareness of, and commitment to, equality and diversity.
- Be reliable and able to meet the time commitments for the role, including preparing for meetings.

In this role, patient/carer partner representatives will need to:

- Attend every meeting and actively participate by reviewing any information provided beforehand.
- Engage in discussions, listening to others' perspectives, and bringing up important issues from the viewpoint of an expert by lived experience.
- Sign up and adhere to our Ways of Working, Conflict of Interest process and, where necessary a Confidentiality Agreement.
- Approach collaborations with a spirit of inclusivity and respect, while adhering to the guidelines outlined in our Ways of Working document.
- To work within our values of teamwork, safety, kindness and improving.
- Avoid behaviours or communication styles that could be interpreted as discriminatory, unfair, or unhelpful to fellow group members.
- Agree to maintain confidentiality regarding certain aspects of the meetings, as indicated by the Co-chairs.
- Ask questions to understand how our plans and projects will affect the accessibility of healthcare for different patient groups.
- Take into account the diverse needs of various communities affected by cancer within north central London when contributing to the development of services.
- Offer insights on how proposed ideas might impact individuals affected by cancer and be willing to constructively challenge healthcare professionals' perspectives when necessary.
- Provide feedback on various documents, such as patient information leaflets or communication plans, via email between meetings as needed.
- Disclose any potential conflicts of interest as they arise and discuss any necessary adjustments to our arrangements with us.
- Let us know any relevant accessibility needs.

Patient/carer partners can expect us to provide:

A letter of appointment along with a welcome pack and induction to prepare for the role.

- A briefing with the Patient Partnership Manager and the Chair prior to the first Delivery Group meeting.
- Induction and appropriate training to enable individuals to carry out their role confidently and effectively.
- Regular meetings with Cancer Alliance team and annual review meeting with Chair of the Delivery Group to discuss any learning needs/reflections
- Support to answer any questions/address any concerns
- Access to information, including meeting papers, in good time to allow for preparation and raising questions.
- Plain, jargon free language in meetings and an explanation of all acronyms.
- Transparency and honesty about what we can and cannot achieve.
- Signposting to additional sources of support if needed. We understand that talking about cancer can be difficult. Patient partner representatives can take a break at any point during a meeting, if required.
- Reimbursement of reasonable travel expenses, in line with the NCLCA Reward and Recognition policy
- Accessible venues if meetings need to be held face to face. We will work with our patient/carer partners to explore how best to make reasonable adjustments as needed

Time commitment and duration

- Membership of the Patient and Public Involvement Strategy Group will be 12 months initially at which point membership will be reviewed and by mutual agreement may be extended to a maximum term of four years.
- The Strategy Group meets 6x per year. It is expected that patient/carer partners attend a minimum of 6x per year. We understand that there may be times when health or personal circumstances might make attending a meeting difficult; so we ask that patient/carer partners let us know as far in advance as possible if not able to attend an upcoming meeting. This will enable us to inform the Chair and provide support to enable effective contribution to the agenda where possible.
- The meetings will be held online via Microsoft Teams and last 60 minutes.
- Patient/carer partners representatives will need to prepare for meetings by reading documentation in advance. In addition, there may be virtual involvement via email in between meetings. Opportunities will be offered to meet with the Chair of the Strategy Group before and after the meetings to answer questions or to discuss any content of the meeting.

Confidentiality

- Some of the information shared in the Strategy Group meetings may be confidential. Where this is the case, patient partner representatives will be told in advance and asked to sign a confidentiality agreement and agree not share information with any individual or organisation.

Equal opportunities and diversity

- NCLCA is committed to embedding equality of opportunity in everything we do. We recognise that the experiences and needs of individuals are unique and strive to respect and value the diversity of our patients, carers, and staff, regardless of age, disability, gender identity, marital status, pregnancy or maternity status, race, religion, or belief (including non-belief) sex or sexual orientation. We actively encourage involvement from people of all backgrounds and cultures.

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Appendix
Role detail

About the role

Q. What is the time commitment of this role?

A. Regular meetings and preparation time as specified in the main body of the role description

Q. How long will I be a member of the group?

A. You will be a member of the group for 12 months at first. Then, we'll review together, with the option to extend up to a total of four years.

Q. What skills and experiences are needed for this role?

A. When you start the role, you must have been diagnosed with cancer and/or received cancer treatment/support within north central London within the last 5 years. Or, you must have cared for someone, in a personal capacity, who has been diagnosed with cancer and/or received cancer treatment/support within north central London within the last 5 years.

We're looking for people with experience in promoting health improvements, who can offer respectful and helpful feedback when needed. It's also important to feel comfortable understanding and evaluating different types of information, and to have connections with public and patient voice networks. You don’t need to be an expert in the NHS or cancer services to be a member of the group.

Q. Are travel expenses reimbursed in this role?

A. Yes, Reasonable travel expenses will be paid in line with our Reward and Recognition policy.

Q. Will I be given any training?

A. When you start your role as a patient or carer representative, you'll be warmly invited to an induction meeting. We'll take the time to discuss and plan any specific training you might need, tailored just for you. You'll also receive a Welcome Pack with helpful information about the Cancer Alliance and the groups you'll be involved with.

Q. Can I be involved with multiple groups?

A. Yes, you are welcome to be a member of multiple North Central London Cancer Alliance groups. but usually no more than 5 roles held simultaneously (to encourage diversity of patient and carer voice)

The application process

Q. Is an application process needed?

A. Yes, there's an application process for this role. You'll just need to complete a short expression of interest form, followed by an informal interview with the Chair and someone from the patient and public involvement team.

Q. Are references required?

A. No, references are not required for this role.

Q. Is a DBS required for the role?

A. No, a DBS is not required for this role.

Q. Is a declaration of interest form required?

A. No, a declaration of interest form is not required for this role

Q. Will my name be published in minutes/documents?

A. Yes, names of all group members are published in meeting minutes and related documents. If there is a concern regarding a patient or carer representative's name being published, this can be discussed on an individual basis.

Q. Will I need to sign a confidentiality agreement?

A. In some circumstances, you may be asked to sign a confidentiality agreement. In most cases, groups will be reviewing non-sensitive material, but in some cases the groups will be presented with restricted material e.g. draft documents. If this is a regular requirement for the group, then a confidentiality agreement will be required.

NHS
North Central London
Cancer Alliance

Working with the North Central London Cancer Alliance

Q. Do you have terms of reference and ways of working for the group?

A. Yes, each NCLCA group has its own terms of reference which will be shared with you. We also have a ways of working document to help all members of the group to understand what behaviours are encouraged and discouraged in our work together.

Q. Will I get regular support from the Cancer Alliance team

A. Yes, you will be offered regular one to one meetings with the patient and public involvement team at North Central London Cancer Alliance. You will also have access to the – frequency to be negotiated between patient partner and Public and Patient Involvement Team

Q. As a member of a group, will I have access to emotional support?

A. As a member of the group, we want you to know that your well-being is important to us. While we don’t provide ongoing emotional support directly, we encourage you to reach out if you need support in order to carry out your role. We’re committed to working with you to find the right resources and support to meet your individual needs. Your comfort and ability to perform effectively are our priorities, and we're here to help however we can.

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Q. How will you process and store my personal data?

A. The personal data you share with us during the application process will be stored on the North Central London Cancer Alliance Patient and Carer voice database which is managed in accordance with UCLH Information Governance Policy and Data protection law