

Cancer patient and carer involvement handbook



Welcome!

To Barts Health NHS Trust

We welcome and need your experience and knowledge from a patient and/or carer point of view.

Introduction:

Barts Health Trust is one of the largest and most respected teaching hospital trusts in the country.

It incorporates the following hospitals:

- **St Bartholomew's Hospital** in West Smithfield (Founded in 1123)
- **The Royal London Hospital** in Whitechapel (Founded in 1740)
- **Mile End Hospital** in Stepney Green (Founded in 1748)
- **Whipps Cross Hospital** in Leytonstone (Founded in 1889)
- **Newham University Hospital** in Plaistow (Founded in 1983)



St Bartholomew's
Hospital



The Royal London
Hospital



Mile End Hospital



Whipps Cross
University
Hospital



Newham
University
Hospital



Our Vision and Values

We will work together towards our vision and show that WeCare



WELCOMING



ENGAGING



COLLABORATIVE



ACCOUNTABLE



RESPECTFUL



EQUITABLE

Our **WeCare** values shape everything that we do, every single day. They are visible in every interaction we have with each other, our patients, their families and our partners. **WeCare** about everything from the appointment letters our patients receive, to the state of our facilities when they walk through the door, to the care and compassion they receive up to when they are discharged.

Our vision: To be a high performing group of NHS hospitals, renowned for excellence and innovation and providing safe and compassionate care to our patients in East London and beyond.



Patient & carer involvement

What is it?

The involvement of patients and carers means to actively work in partnership with staff at the hospital. This could be by participating in board meetings, attending focus groups, providing a review on written documentation, supporting improvement projects and research, patient panel membership and recruitment panels.

How does it benefit the organisation?

The organisation carries out improvements that really matter to our patients. Changes are made with and by our patients rather than for our patients.

How does it benefit the patient/carer?

Patient and carers will personally find the experience rewarding, knowing that they have contributed in improving better cancer services in terms of quality of care.



Person Specification

Essential:

- You need to have experience of either living with, being treated for, recovered from cancer or caring for someone with cancer within one of our hospitals:
 - The Royal London and/or Mile End
 - St Bartholomew's
 - Whipps Cross
 - Newham University Hospital
- A passion for understanding the needs of people affected by cancer and to represent the diverse range of people treated in North East London.
- Able to listen to and respect different perspectives, display empathy, and be open to other points of view.
- Reliable, honest and trustworthy.
- Willing to sign up and adhere to our Ways of Working, Conflict of Interest and Confidentiality Agreement.
- Have an awareness of and commitment to equality and diversity.

Desirable:

- Willing to take part in group discussions.
- Able to communicate your ideas to a wide range of people, including senior healthcare professionals.
- Have an interest in learning more about different approaches to improving services along with some basic understanding of the health and care system.



Expected time commitment

The time commitment you can expect will be dependent on the level of involvement you choose.

If you choose to work with staff on a particular project it is likely there will be monthly meetings with reading documents in between. The project will be run over a period of time which will be made clear to you at the beginning of each session.

If you choose to be a member of our cancer board there is a separate information sheet to explain the role in more detail with expected time commitment.

Other involvement such as reviewing documents or surveys will be on an ad hoc basis.

Do not worry if you have committed to something but, due to personal circumstances you, can no longer participate. Just inform a member of staff you are working with.

We will support you with whatever involvement you choose.



Policy & Procedures

Barts Health is committed to providing a first class cancer patient involvement programme that operates at the highest level of good practice. We want to ensure that you feel valued and supported while working with the Trust. We recognise how important it is for you to receive refreshments and out of pockets expenses and this policy will outline your entitlement and what you can expect.

Travel expenses

You are entitled to reimbursement of travel expenses up to a maximum return fare of **£6 per session**. Reimbursements can only be made on submission of travel tickets/receipts/oyster card online statement. Please note top-up receipts are not acceptable as we need proof of what you paid for your journey. We cannot reimburse part of a weekly or monthly travel card as this would not be deemed an “out-of-pocket” expense as you would be purchasing this anyway. In order to claim you need to complete a claim form which can be obtained from the Macmillan Patient Experience and Engagement Lead for Cancer.

If you need to use your **car** rather than public transport to travel to the hospital you may claim petrol money provided you keep a record of your mileage. The allowance for petrol is **24p per mile**.

Please claim once a month or when your total is no more than £20.

Refreshments

The general principle is as follows:

- If you are on hospital grounds working with us for more than **4.5 hours** you will be entitled to a lunch voucher to the value of **£3.50** which you can use in the Canteen.
- Wards usually have a staff kitchen or area where you can have a hot drink.
- Water can be obtained from drinking points around the hospital or in the Café or restaurant.



Please note that change is not given from the voucher(s).

Keeping Records

Your details are registered on our volunteer database called “**Better Impact (My Volunteer Page).**”

The database is an important tool to help us organise the programme efficiently and keep you informed. It makes it easier to notify you of new events, opportunities and training and keeping track of your attendance and progress.

You can obtain access to your personal records at any time. Please contact the Macmillan Patient Experience and Engagement Lead for Cancer if you wish to look at your personal record.

Consent for holding of Data

In order to for you to work safely with us we need to be able to contact you by email, post or by telephone.

Information on our database is strictly confidential and we do not pass on any personal data about you to outside organisations and/or individuals without your express personal consent. The only exception to this might be if there is a crisis and the emergency services need to be given appropriate information.

Personal data will be processed in a manner compliant with the Information Commissioner's Office and General Data Protection Regulation. It will be stored in Canada, one of twelve countries outside the EU that the European Commission has determined favourable for data storage.

You have the right to withdraw at any time. Please contact a member of the cancer team if you would like to speak to someone about removing your information.



Code of Practice

It is important that patient representatives represent Barts Health positively and that they enjoy their experiences. This Code of Practice outlines what is expected of anybody acting as a volunteer for Barts Health and what you can expect in return.

The Code of Practice is based on a non-contractual agreement between Barts Health Trust and individual volunteers. This Code of Practice establishes a set of standards designed to help all to understand the requirements.

The Code of Practice does not indicate a contractual relationship between you and Bart's Health NHS Trust.

The following standards should be applied at all times:

Barts' Health NHS Trust patient and carer representatives can expect:

- Clarity with regard to their activities.
- Appropriate training for their role.
- Appropriate supervision with a named contact person at each activity.
- A healthy and safe environment.
- Equality of opportunity.
- Reimbursement of expenses.
- Respect, honesty and integrity.
- Regular communications including social events.

Whilst representing Bart's Health NHS Trust patient and carer representatives:

Should:

- Uphold the Vision and Values for the Trust at all times.
- Abide by relevant policies and procedures at all times when working with Barts Health Trust.
- Attend appropriate training where required.
- Take responsibility for your own health and safety, reporting any concerns to the cancer team.
- Uphold confidentiality.



You should not:

- Speak to members of the Press unless you have spoken first to a member of staff.
- Smoke within or on hospital grounds.
- Take risks with your personal safety.
- Use offensive language or make inappropriate remarks or jokes.
- Break confidentiality including not taking home any literature or documentation relating to patients or visitors.
- Engage or intervene in any public order offence or criminal activity.
- Cross boundaries between non-clinical and clinical care with patients. Even if you have a medical background you must never provide any form of clinical care.
- Divulge any patient or other information you are privy to as a result of your placement with the Trust. This level of confidentiality continues after your volunteer placement has ended. Any breach of confidentiality would be of a breach of both the General Data Protection Regulation (GDPR) and the Trust's Confidentiality Code of Practice.
- You must not tell anybody outside the specific area in which you work:
 - The name of any patient of the Trust's hospitals.
 - Any information relating to the diagnosis, treatment or care of any patient.
 - Any aspect of patient or staff records.
 - Any details of the Trust's commercial business, including information for contract specifications.

Please note that this list is by no means exhaustive. If you do not understand any of the above please contact the Macmillan Patient Experience and Engagement Lead for Cancer.

**Finally, we look forward to working with you and
would like to thank you for your passion and
engagement.**

