Patient / Carer Representative Role Description

Title: Patient Representative

Time commitment: The duration and frequency of meetings are at the discretion of the Pathway Director. Meetings are typically held between every month and every three months. Prior to committing to join a Pathway Board or Expert Reference Group, patients are welcome to discuss the associated time commitment with the relevant Pathway Manager.

Venue: The majority of meetings are held at London Cancer Offices, 3rd Floor, 170 Tottenham Court Road, London, W1T 7HA

Expenses: Out-of-pocket expenses for travel only

Accountable to: Pathway Director

Supported by: Pathway Director, nominated Pathway Board member, London Cancer Project Manager for Patient Experience and User Involvement

Tenure of Office: 1 Year (extension/renewal will be through mutual agreement with the Pathway Director)

London Cancer values the role that patient representatives play in bringing a unique perspective to our Boards, and Groups. People who have experience of life-changing diseases or injury or disability find ways to adjust to what life throws at them. They look for creative solutions to challenges and identify opportunities for improvement. They are experts by experience. We believe these experiences, both good and bad, empower patients to be meaningfully engaged in discussions around quality, and service and system improvement.

London Cancer has four key guiding principles:

- Being patient-focused through listening, communication, involvement, information, education, choice, and personalisation
- Optimising care along a co-ordinated pathway through earlier diagnosis, excellent treatment for all, local treatment where appropriate, compassionate aftercare and empowering and supporting patient self-management
- Embedding research for personalised care, equitable access to trials, the discovery of new treatments and evaluating new ways of working together with patients
- Increasing value through superior outcomes for patients per pound invested, with continual improvement over time against our previous performance

We believe patients, carers and families can help us to deliver on all of these.
1. **Formal London Cancer Patient Representatives Roles**

Patient Representatives are included at all levels of the formal governance structure of *London Cancer*. These include membership of:

- The *London Cancer* Board
- The Patient Experience Action Community
- The Cancer Pathway Boards and Expert Reference Groups
- The Cancer Partnership Group

Further information relating to the roles and responsibilities of these groups can be found on our website ([www.londoncancer.org](http://www.londoncancer.org)) or by contacting Fiona McKenzie, our Patient Experience and User Involvement Project Manager (fiona.mckenzie@londoncancer.org; 0207 679 9525).

2. **Specific Roles and Responsibilities for Patient Representatives**

The role of Patient Representatives on Pathway Boards and Expert Reference Groups is to ensure that the views of patients, carers and families are taken into consideration during relevant discussions and heard throughout *London Cancer* as a wider organisation, whenever decisions that affect patient care are made. Patient Representatives who serve on these groups are expected to contribute to this decision making process. Patient Representatives are valued members of the Board or Group and have the full support of the Director or Chair, who will be happy to meet with any incumbent or potential Patient Representative as they may require to help inform them about the role and remit of the Board or Group.

Patient Representatives will work to:

- Contribute to relevant meetings in a constructive manner, offering ideas and opinions which reflect the voice of patients, carers and their families
- Where appropriate and applicable, Patient Representatives should seek views and feedback from other patient groups on the work of *London Cancer*. Such groups include, but are not limited to, the Cancer Partnership Group, *London Cancer*’s Patient Experience Action Community, Healthwatch, Councils for Voluntary Services, local support groups and personal contacts
- Keep abreast of local and national news and developments with regards to healthcare policy and patient experience, and consider the impact of this on the activities of their Group or Board
- Seek to attend training from *London Cancer* when offered, if considered useful and applicable
- Work on projects which have been identified as an area of focus by the membership, and agreed by the Pathway Director or Clinical Chair. This may sometimes require collaborative working with other Board or Group members and at other times working autonomously
- Provide a commitment to the Board or Group, attending as many meetings as they are able, and acting as a representative of the Board or Group when required
• Patient Representatives should not agree to take on projects, which they feel are outside of their remit, beyond their skill or knowledge level, or would require a time commitment which they are unable to keep.

If Patient Representatives have any queries relating to their role and responsibilities, they should contact the Patient Experience and User Involvement Project Manager (details below), the Pathway Manager or Pathway Director, or the Patient Advocate, as they feel appropriate. Patient Representatives will be asked to sign a confidentiality agreement.

We strive to ensure that all Boards and Groups have a Patient Advocate who acts to support Patient Representatives through providing them with any necessary information or interpretation during meetings and ensuring their voice is heard and their viewpoints considered. If a Patient Representative has any concerns relating to the activity of their Board or Group and feel unable to raise this at the relevant meeting, they should contact their corresponding Patient Advocate in the first instance. Contact details for all of the Pathway Board Patient Advocates can be found on the London Cancer website, under the ‘Pathway Board Constitution’ section, or alternatively by contacting the Patient Experience and User Involvement Project Manager, Fiona McKenzie (fiona.mckenzie@londoncancer.org or 0207 679 9525).
# Patient Representative Person Specification

## Experience
- Be either:
  - a current or previous user of cancer services at either one or more of the trusts within the London Cancer system or elsewhere.
  - a carer for patients who have accessed such services

*Some Clinical Pathway Directors or Chairs of Expert Reference Groups may seek individuals who have experience of acting as Patient Representatives. Others will require more recent service users who will present a more up-to-date view of current provision and issues. This will need to be looked at on a case-by-case basis, but in general no specific experience of being a member of a committee previously is required.*

## Skills and aptitude
- Good communication and influencing skills
- Ability to present reports verbally and in writing
- Ability to form and maintain working relationships in challenging circumstances
- Ability to distinguish between personal and patient views
- Good time management skills

## Personal qualities
- Assertiveness and confidence to raise issues in meetings
- Sensitivity
- Reliability
- Flexibility
- Resilience and tenacity
- Openness and transparency
- Ability to consider the majority view
- A commitment to connecting with local user groups, such as Healthwatch, where appropriate

## Knowledge
- Awareness of national health and social care issues
- Elements of the cancer pathway as experienced by patients
- Appreciation of the complexity of working across organisational boundaries and joint working
- Knowledge of London Cancer and our aims and objectives
Commitment to London Cancer Patient Representatives

The London Cancer core team, Pathway Directors and Group Chairs have all signed the following commitment.

London Cancer seeks to engage service users in clinical pathway design, decision making, and the diffusion of best practice. Patients or care givers are considered vocal partners in the governance and working parties of London Cancer, and advise on the quality and redesign of services from their personal experience. The organisation recognises the importance of learning from experience, and will seek to use patients as sources of expert knowledge for consultation.

London Cancer aims to embed user engagement into its organisational culture, governance structure and everyday work, as a means to improve value by driving up outcomes that matter to patients, and the betterment of patient experience. This is in line with the UCL Partners partnership approach, working collaboratively rather than mandating change.

In return for their valuable contribution, London Cancer Pathway Board Directors, Expert Reference Group Chairs, and the London Cancer core team, commit to the following;

- To invite and welcome open and honest feedback from our patient representatives
- Giving patients the opportunity and the time to contribute to decision making
- To consider patient representatives as full members of any meetings for which they are on the membership list
- To ensure meetings are held at accessible locations, with adequate refreshments. Meetings will be arranged at the most convenient time for the entire membership
- To reimburse any travel expenses accrued getting to and from London Cancer meetings, in line with the expenses policy
- To ensure the language used in meetings is as accessible as possible. Where necessary, medical terms will be explained
- To provide training as and when Patient Representatives identify the need, be this formally or through informal shadowing and observation
- To respond to queries and requests from Patient Representatives in a fast, efficient manner

www.londoncancer.org