

UCLH Cancer Collaborative Patient Experience & User Involvement Steering Group

TERMS OF REFERENCE

1. Title of the Group

The group shall be called the UCLH Cancer Collaborative Patient Experience & User Involvement Steering Group; it will be part of the UCLH Cancer Collaborative and will be supported by the Patient Experience & 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. Steering Group members 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 co-design the UCLH Cancer Collaborative Patient Experience & User Involvement programme of work.

2. Aims of the Group:

- To foster and promote a partnership approach between UCLH Cancer Collaborative and people affected by cancer and ensure that their views are represented at the highest level through the Cancer Vanguard Board (CVB) and relevant Sustainability and Transformation Plan (STP) Cancer Boards and work stream meetings.
- To ensure all partners across the Collaborative engage and involve people affected by cancer to design and implement services to improve patient experience and clinical outcomes.
- To drive patient experience and user involvement across the UCLH Cancer Collaborative and help maintain standards through appropriate levels of discussion and challenge.
- To influence improvement initiatives in services by working collaboratively with partner organisations 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 Tumour Pathway Boards and Expert Reference Groups.
- To act as the platform for sharing and learning from quality improvement projects designed to enhance cancer patient experience and improve clinical outcomes.
- To help communicate the plans and achievements of the UCLH Cancer Collaborative partners with those affected by cancer in the wider community.
- To support, where required, focused project groups set up to address specific issues.

3. Membership of the Group

Membership of the group will be recruited through a selection process that is open to all interested and eligible persons.

Those eligible to apply for membership will include:

- People affected by cancer, as a patient, carer or relative, who live in the boroughs within the UCLH Cancer Collaborative or who have used the cancer services provided by one of the 17 hospitals within the UCLH Cancer Collaborative region. This will include people whose characteristics are protected by the Equality Act 2010. {The 9 characteristics are as follows: age, disability, gender reassignment, marriage and civil partnership status, pregnancy and maternity, race (including nationality and ethnic origin), religion or belief, sex and sexual orientation.}
- Members of voluntary and community sector services supporting people affected by cancer.

Joining and membership of the group:

- People affected by cancer will be invited to join the group following completion of an expression of interest form and a formal selection process.
- The group will be led by a chair, a co-chair (UCLH Cancer Divisional Manager) and a vice-chair.
- Members should ideally be people affected by cancer who have been in receipt of treatment within the last 5 years.
- 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.

4. Meetings

4.1. 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.

4.2. Meetings will take place once every two months 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.

4.3. Meetings will take place on fixed dates and times at one central location to allow ease of access to all attendees. These will be shared well in advance.

4.4. Where possible and necessary, the group will communicate by email, in between meetings. However, members who do not have access to an email will be sent all relevant meeting papers by post.

4.5. Members will be expected to attend in person, or by dialling in, to a minimum of 4 out of 6 meetings per annum. They must also contribute to a further 1 meeting by providing comments on specific topics or proposals by phone or email; this will be waived if the meetings clash with other UCLH Cancer Collaborative meetings or events. It will be expected that any comments for the meeting will be forwarded to the facilitator in this event.

4.6. Members who are unable to attend a meeting will be expected to send their apologies to the facilitator, in advance. They will also be expected to send their comments on the meeting's agenda and minutes before the meeting.

4.7. Regular attendance and commitment by all members will be critical to the success of the group. If members are not able to attend 2 or more meetings without reasonable explanation and prior discussion ahead of the meetings, they may be requested to step down from their role to allow other interested candidates to join the group.

4.8. Members agree to observe the following:

- Every member of the group will be inclusive and respectful when working together whilst adhering to our Ways of Working (see 'Ways of Working' document), and abiding by the [UCLH values](#).
- Members will represent not just their own personal experience but should also bring a wider perspective through links to other groups and organisations.
- Each member will have an opportunity to participate fully and no one member will dominate the discussions. Everyone will have an opportunity to speak and will be listened to.
- During discussions, the use of jargon and acronyms will be kept to a minimum and always explained. If something is unclear, clarification will be requested and provided.
- If a member wishes to raise a question during a meeting, this will be done via the facilitator or chairs.

- On occasion members may have different points of view and may disagree. It is expected that communication of differences of opinion will be conducted within the parameters set out above.
- Members will maintain a collaborative and constructive approach in undertaking the business of the meeting.
- All concerns and compliments will be shared with the facilitator and chairs of the meeting at the earliest opportunity, so that we can find a solution together and share success stories.
- Concerns about aspects of the meeting or conduct of members will be addressed by the facilitator and chairs. Any behaviour or style of communication deemed discriminatory, unfair or disrespectful will not be accepted and members involved may be asked to step down.
- All members will have their mobile phones on silent during each meeting.

4.9. Minutes of meetings will only include a summary of discussions and a list of actions.

4.10. Name cards will be provided, especially when new members join the Steering Group.

5. Resources

5.1. Members may claim travel and car parking expenses incurred through attendance at Steering Group meetings or any related activities. Expenses claims will not be processed unless a claim form has been duly completed and submitted, with relevant receipts. Members are expected to claim for their expenses no later than three months after the meeting date.

5.2. The Steering Group will receive appropriate levels of administrative and organisational support. The meeting agenda, associated papers and minutes will be distributed in a timely manner.

6. Confidentiality and Conflict of Interest

During the course of their duties as members of the Steering Group, members may have access to confidential information, which must not be divulged to any unauthorised person at any time. If in doubt, members will be expected to ask the facilitator for advice. Members will be expected to sign a confidentiality agreement and declare any conflict of interest ahead of meetings.