

GO Hildas

a women's cancer co-production group

Terms of Reference

1 Vision statement

We can promote fair and equitable gynaecological cancer care and research through co-production with people from diverse backgrounds.

Gynaecology or gynaecological cancers are cancers that start in female reproductive organs, such as the womb (uterus), tube (fallopian tube) and ovary, neck of the womb (cervix) and birth canal (vagina or vulva).

2 Our aims

- To influence decisions made by health and social care providers for patients with gynaecological cancer.
- To shape the research questions and how they are answered with researchers in gynaecological cancers and women's health.
- To raise awareness and educate about gynaecological cancer to promote fair and equitable care.
- To engage with people from different underserved groups to achieve our vision by working with non-government organisations, including charities and community and faith groups.
- To provide opportunities to learn and understand the benefits of working together (co-production), and to develop skills and tools for working in this way.

2.1 What co-production means to us?

Co-production to us means finding shared solutions together as equal partners from the start until our vision is achieved. We will try our best to ensure the power and influence of this group is fairly shared with our members.

2.2 Our key values are:

- Respect, kindness and compassion
- Building Trust

- Empowerment
- Inclusiveness
- Collaboration

3 The principles for how we work together.

- We respect everyone's skills, knowledge, experience, interests, views and wishes.
- We trust that we can make use of these differences to help us achieve our vision and aims together.
- We will make time to listen and respond with kindness when we communicate.
- We will try our best to ensure we use language, written information and other kinds of communication that will work for everyone.
- We know we may not get everything right, but we will learn and change together during the process.

4 Who are we?

We are a subgroup of the Hildas supported by the Dame Hilda Lloyd Network at the University of Birmingham (<https://www.dhlnetwork.com/>) focusing on women's cancer care and research.

Our members include:

- People with lived experience of gynaecological cancers, including patients, their families and carers/supporters.
- People at higher risks of having gynaecological cancers.
- Representatives from non-government organisations, which have members with lived experiences or at higher risks of gynaecological cancers or involved with supporting them.
- Health and social care providers for those affected by gynaecological cancers.
- Researchers conducting research to improve gynaecological cancer care.

5 What do we do?

Core activities:

- We keep each other up-to-date about groups and events related to promoting fair and equitable gynaecological cancer care and research.
- We support patient and public involvement and engagement (PPIE) work that follows the UK Standards for Public Involvement in Research and related recommendations set by the National Institute for Health and Care Research (NIHR).

- We co-design with clinicians and researchers to plan work that could promote fair and equitable gynaecological cancer care and research, including funding applications.
- To share our experiences of co-production and support joint-learning to work in this way.

Of note:

- We are not a peer-support group.
- We understand the challenges faced by teams that have fewer resources to follow the recommended PPIE guidance. If this applies to your team, please contact us at dhlnetwork@contacts.bham.ac.uk with GO Hildas in the title to discuss.
- We believe there are common barriers to equitable healthcare. Thus, we focus on ensuring diversity, rather than targeting specific underserved groups.
- We promote collaborations for learning better ways to work together as equal, and we challenge poor co-production when we see it.
- We are committed to shared decision-making with people from different backgrounds when we decide which clinical and research teams or initiatives we support.

6 How do we work together?

- We meet every 2-4 months for co-production workshops to review our work and develop additional skills and tools for co-production.
- When possible, we will support both in-person and virtual attendance. Virtual participation may be limited for skill development and training sessions.
- Our co-lead(s) may host informal meetings below to share stories, news and ideas to support the planning of our work for different groups.
 - Those with lived experiences and their carers/families (1-2 times per year based on preferences of this group).
 - Professional/community organisations (3-4 times per year; 1-hour and virtual).
- In between meetings we will keep in touch via emails, WhatsApp, telephone and virtual meeting/calls as preferred.

7 What is expected of all members?

- To recognise everyone's contribution is important to the group.
- To respect different views and to understand we will not always agree and that this is ok.

- To be open and honest and include everyone in our decisions as much as we can.
- To attend meetings or send apologies if they cannot attend.

8 What is expected of the co-leads?

- Jointly process PPIE and co-production invitations and opportunities.
- Jointly manage our mailing list and administrative tasks.
- Contribute to the preparation and hosting of regular meetings.
- Co-chair meetings to ensure different voices are heard.
- Optional: lead on additional patient and public meet-ups (voluntary).

9 Who are our current co-leads and what do they do?

The group is currently co-chaired by Jaki Mills (patient co-lead) and Elaine Leung (clinician co-lead).

10 What support do people receive?

- We offer tokens of appreciation (£25/hour as shopping vouchers or equivalent) for the work of our patient and public partners attending our co-production workshops.
- The group will seek additional funding to support our co-production activities, which may include training on advocacy and providing appropriate technical support.
- Although we are not a peer-support group, some members find the group interactions helpful for their wellbeing.
- Whenever possible, we will make reasonable adjustments to support members who experience barriers to participate in this group.

11 How are we going to manage our shared data?

- The shared contact information, including our mailing list, is kept within a secure online drive at the University of Birmingham. Only the organisers of this group (including the co-leads) have access to the database.
- Stories and ideas summarised at our meetings may be published in writing and presented at meetings. We will acknowledge everyone as a group.
- Co-leads may put this group forward for relevant awards for recognition of our work. Any financial awards will then be donated to support this group's work.
- We do not publish details that could identify you without your permission.

12 What if any members of this group had concerns?

Some of our activities may lead to emotional challenges. We are pleased to collaborate with MacMillan Cancer Support, which has worked with Bupa, to provide up to 6 complimentary counselling sessions to anyone experiencing emotional challenges due to cancers. For help and support, please reach out to the MacMillan helpline at 0800 808 00 00, available 7 days a week from 8 am to 8 pm.

If you have any other concerns about your experiences with this group, please contact Dr Rachel McNeil (r.mcneill.1@bham.ac.uk; +44 1213718190; Programme Manager in Global Women's Health Research), who provides oversight of activities related to the Hildas of the DHL network.

13 What if I want to be removed from our mailing list?

If you want to be removed from our mailing list, please contact either one of our co-leads or Dr Rachel McNeil (r.mcneill.1@bham.ac.uk; +44 1213718190; Programme Manager in Global Women's Health Research).

14 What do the following words mean?

- **Patient and public involvement and engagement (PPIE):** Working with the public and communities to improve care and research that affect them.
- **Underserved groups:** Groups that are not provided with enough help or services, or not given services that are of high quality.
- **Non-Government Organisation (NGO):** a non-profit entity that is not part of a government. For example, religious organisations, charities and rights groups.
- **Inclusiveness:** including different groups of people and treating them fairly; actively including everyone so they feel safe, valued and heard.
- **Empowerment:** the process of becoming stronger and more confident to control what happens to you and do what you want. This may involve participation in educational, skill training and other knowledge-exchange events.
- **Dame Hilda Lloyd Network (DHL network):** a women's health research network named in the memory of Dame Hilda Lloyd, a doctor whose work reduced inequality experienced by underserved women. Dame Lloyd was also the first female president of the Royal College of Obstetricians and Gynaecologists.

- **National Institute for Health and Care Research (NIHR):** a major governmental organisation providing funding for research in Britain with the mission to improve the health of the nation through research.

15 When are we going to review these Terms of Reference?

We review our Terms of Reference every 18 months from the time of each agreed version.