NAoPri Patient and Public Involvement (PPI) Forum
Membership and Terms of Reference

Purpose

The National Audit of Primary Breast Cancer (NAoPri) Patient and Public Involvement (PPI) Forum will act as a consultative group to the NAoPri Project Team (PT) (Appendix). It will provide advisory support across the entire scope of the NAoPri's work, with the aim of ensuring that the voice of patients is reflected in the direction and delivery of the Audit. Specifically, PPI Forum members are (a) invited to provide insight from a patient perspective on strategic aims and specific audit priorities; and (b) actively participate in the production of audit outputs, and the development of each audit's Quality Improvement initiatives by ensuring the work is relevant from a patient perspective.

Objectives

The NAoPri PPI Forum will:

- Represent the views of patients (via patients, carers, or those with a close relationship to someone with primary breast cancer) and act as a consultative group to the NAoPri PT.
- Provide insight on all aspects of the NAoPri scope of work, including the intended aims, priorities, and important questions to be addressed from a patient perspective.
- Support the NAoPri team in the ongoing selection and review of the NAoPri performance indicators, including the direction of future performance indicators.
- Input into the interpretation of any NAoPri results, including highlighting what is important and relevant to patients, as well as advising how best to make these accessible to lay audiences.
- Be active participants in the production of audit outputs including:
    - the development and review of any patient and public information materials,
    - patient summaries of the "State of the Nation" annual reports,
    - the content and design of Audit infographics to aid dissemination of key information and results, and
    - co-development and co-authorship of scientific papers that explore NAoPri results.
- Undertake a key advisory role to the NAoPri PT in developing the design and function of the NAoPri webpages to ensure that patients and the public can easily find relevant results together with appropriate explanatory information.
- Direct and drive the development of the NAoPri's quality improvement (QI) goals, activities, and outputs by ensuring this work is relevant from a patient perspective.

Membership and representation

The NAoPri PPI forum membership will be based upon the following:

- Membership is open to all patients diagnosed with primary breast cancer, as well as family members, friends, or carers of patients.
- The Forum will include around 15 members at any one time.
- The Forum will aim to embrace the diversity of patients affected by primary breast cancer within England and Wales. This will involve striving for inclusion of members from across important patient demographics (e.g., gender, age, ethnicity, geographical location), as well as coverage

across different breast cancer types (e.g., HER2-positive, triple negative), stages, and treatment pathways (e.g., different types of surgery, neo-adjuvant chemotherapy, radiotherapy).

- The Forum will also comprise:
    - Clinical and methodological representatives from the NAoPri PT.
    - Representation from breast cancer charities including, but not limited to, Breast Cancer Now and Macmillan.
- Individuals will be recruited directly by the NAoPri PT via a national advertisement, as well as with the support of the breast cancer charities.
- Members of the PPI Forum should include those with a personal experience of primary breast cancer and who:
    - are prepared to discuss treatment, side effects, and other issues from a patient's perspective,
    - respect different viewpoints and are happy to engage with a diverse group including health professionals, researchers, and charity professionals,
    - are flexible and available to join virtual meetings with the possibility of face-to-face meetings, and
    - have internet access and confidence in using IT software including e-mail, Microsoft packages such as Word and PowerPoint, PDFs, and virtual meeting applications such as Microsoft Teams and Zoom.
- Individuals will be appointed to the group through expressions of interest indicating relevant experience.
- All members will be provided with an introductory pack with information about the NAoPri.
- A member may change their level of involvement or give up their membership at any time.
- Membership will include an initial commitment of at least one year with the likelihood of extending up to two or three years.

Chairing arrangements

- The Chair will be an individual who is one of the group members, and the appointed individual will be revisited on an annual basis.
- The Chair will be supported by the NAoPri PT who will be responsible for the administration of the Forum.
- The main responsibilities of the Chair will include:
    - Liaising with the NAoPri PT to agree priorities for upcoming meetings,
    - Welcoming members to each meeting and providing introductions where required,
    - Ensuring everyone is given an equal opportunity to contribute to discussions, and
    - Keeping time for meetings to ensure all proposed agenda items are covered.

Governance

- The Chair will sit on the NAoPri Audit Advisory Committee (AAC) to strengthen the patient's voice in the Audit. They will relay advice and recommendations from the NAoPri PPI Forum with support from the NAoPri PT.

Frequency and operation of meetings

- Meetings will be held at least twice a year. Additional virtual meetings may be scheduled on an ad-hoc basis dependent on the needs of the PPI Forum.

- Doodle polls will be circulated in advance to ensure that meeting dates work for most members.
- Meetings will be held virtually via Microsoft Teams or Zoom with the possibility of face-to-face meetings once a year at the Royal College of Surgeons of England (RCSEng) in London.
- When meetings are held face-to-face, there will be the flexibility to attend via Microsoft Teams or Zoom if most convenient.
- Refreshments will be provided by the RCSEng in the event of face-to-face meetings.
- A proposed agenda and meeting papers will be circulated electronically at least one week in advance of any meetings.
- Understanding that not all members will be available to attend every meeting, those unable to attend are requested to send any comments on relevant papers for discussion.
- A summary of minutes and action points will be circulated electronically after the meeting. This will be the responsibility of the NAoPri PT.

Method of Communication

- Discussions within the NAoPri PPI Forum are considered **confidential** unless otherwise indicated.
- In line with GDPR regulations, **no personal information will be shared** with third parties or any other bodies.
- Each PPI Forum meeting will abide by the **Chatham House rule**, meaning that all opinions used in our work will not be attributed to any individual, allowing members to share openly without fear of identification.
- Communication between the NAoPri PPI Forum and the NAoPri PT will be **by email**.
- Emails will be sent as CC unless explicitly requested otherwise.
- Any other unsolicited group communication without the permission of the Chair and/or RCS is not allowed.
- Electronic documents will be circulated as required for review.
- The NAoPri PT will explore the potential for online NAoPri PPI Forum events, such as webcasts and webinars, on the NAoPri webpages.
- The NAoPri PT will ensure that all documents and presentations are in a lay-friendly format.
- The NAoPri PPI Forum will always be given the opportunity to ask the PT for clarification on audit methods or clinical issues that are unclear, both during meetings and by email in between.

Expenses

- In the event of attendance at face-to-face meetings of the NAoPri PPI Forum, standard class travel will be booked and paid for in advance.

Reviewing the Terms of Reference

- The Terms of Reference will be reviewed by its members at the first meeting of the NAoPri PPI Forum and then as required during the lifetime of the project to ensure the group's purpose and objectives remain current with the needs of the NAoPri.

Appendix - Membership:

This section will be updated as appropriate:

Patient and Public Involvement Forum (excluding the NAoPri Project Team)		
Name	**Organisation**	**Role**

NAoPri Project Team		
Name	**Organisation**	**Role**
Dr Sarah Blacker	Clinical Effectiveness Unit, RCS	Clinical Research Fellow
Dr Jemma Boyle	Clinical Effectiveness Unit, RCS	Clinical Research Fellow
Prof. David Cromwell	Clinical Effectiveness Unit, RCS	Director / Senior Methodologist
Dr Christine Delon	Clinical Effectiveness Unit, RCS	Data Scientist
Prof. David Dodwell	University of Oxford	Clinical Lead (Clinical Oncology); Consultant Clinical Oncologist
Mr Robert Douce	Clinical Effectiveness Unit, RCS	Programme Manager
Dr Georgina Hanbury	Clinical Effectiveness Unit, RCS	Clinical Research Fellow
Prof. Kieran Horgan	Leeds Teaching Hospitals NHS Trust; Association of Breast Surgery	Clinical Lead (Surgery); Consultant Breast Surgeon
Mr Augusto Nembrini	Clinical Effectiveness Unit, RCS	CEU Research Co-ordinator
Dr Mark Verrill	Northern Centre for Cancer Care, Newcastle upon Tyne NHS Hospital	Clinical Lead (Medical Oncology); Consultant Medical Oncologist
Dr Liyang Wang	Clinical Effectiveness Unit, RCS	Clinical Research Fellow