

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

Purpose

The National Audit of Metastatic Breast Cancer (NAoMe) Patient and Public Involvement (PPI) Forum will act as a consultative group to the NAoMe Project Team (PT) (Appendix). It will provide advisory support across the entire scope of the NAoMe'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 NAoMe PPI Forum will:

- Represent the views of patients (via patients, carers, or those with a close relationship to someone with metastatic breast cancer) and act as a consultative group to the NAoMe PT.
- Provide insight on all aspects of the NAoMe scope of work, including the intended aims, priorities, and important questions to be addressed from a patient perspective.
- Support the NAoMe team in the ongoing selection and review of the NAoMe performance indicators, including the direction of future performance indicators.
- Input into the interpretation of any NAoMe 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 NAoMe results.
- Undertake a key advisory role to the NAoMe PT in developing the design and function of the NAoMe 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 NAoMe's quality improvement (QI) goals, activities, and outputs by ensuring this work is relevant from a patient perspective.

Membership and representation

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

- Membership is open to all patients diagnosed with metastatic 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 metastatic 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), and treatment pathways (e.g., different systemic treatments).

- The Forum will also comprise:
 - Clinical and methodological representatives from the NAOme PT.
 - Representation from breast cancer charities including, but not limited to, Breast Cancer Now, Macmillan, METUPUK.
- Individuals will be recruited directly by the NAOme 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 metastatic 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 NAOme.
- A member may change their level of involvement or give up their membership at any time.

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 NAOme PT who will be responsible for the administration of the Forum.
- The main responsibilities of the Chair will include:
 - Liaising with the NAOme 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 NAOme Audit Advisory Committee (AAC) to strengthen the patient's voice in the Audit. They will relay advice and recommendations from the NAOme PPI Forum with support from the NAOme PT.

Frequency and operation of meetings

- Meetings will be held at least twice a year, with additional virtual meetings scheduled on an ad-hoc basis determined by 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 held by the forum: Under circumstances where members are unable to attend a meeting, they are requested to send any comments on relevant papers for discussion during the meeting.
- A summary of minutes and action points will be circulated electronically after the meeting. This will be the responsibility of the NAoMe PT.

Method of communication

- Discussions within the NAoMe 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 Chatham House rule meaning that all opinions that go on to support or be used in our work will not be attributed to any individual allowing members to share openly without fear of identification.
- Communication between the NAoMe PPI Forum and the NAoMe PT will be by e-mail.
- Electronic documents will be circulated as required for review.
- The NAoMe PT will explore the potential for online NAoMe PPI Forum events such as webcasts and webinars on the NAoMe webpages.
- The NAoMe PT will ensure that all documents and presentations are in a lay-friendly format.
- The NAoMe 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 the meetings and by e-mail in between.

Expenses

- In the event of attendance at face-to-face meetings of the NAoMe 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 NAoMe PPI Forum and then as required during the time period of the project to ensure the group's purpose and objectives remain current with the needs of the NAoMe.

Appendix - Membership:

This section will be updated as appropriate:

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

NAoMe Project Team		
Name	Organisation	Role
Dr David Dodwell	University of Oxford	Clinical Lead (Clinical Oncology) Consultant Clinical Oncologist
Dr Mark Verrill	Northern Centre for Cancer Care, Newcastle upon Tyne NHS Hospital	Clinical Lead (Medical Oncology) Consultant Medical Oncologist
Prof. Kieran Horgan	Leeds Teaching Hospitals NHS Trust Association of Breast Surgery	Clinical Lead (Surgery) Consultant Breast Surgeon
Prof. David Cromwell	Clinical Effectiveness Unit, RCS	Director/Senior Methodologist
Ms Jibby Medina	Clinical Effectiveness Unit, RCS	Programme Manager
Ms Melissa Gannon	Clinical Effectiveness Unit, RCS	Methodologist
Dr Jemma Boyle	Clinical Effectiveness Unit, RCS	Clinical Research Fellow
Dr Christine Delon	Clinical Effectiveness Unit, RCS	Data Scientist
Dr Sarah Blacker	Clinical Effectiveness Unit, RCS	Clinical Research Fellow (from Feb'24)
Ms Ridwana Siddika	Clinical Effectiveness Unit, RCS	CEU Research Co-ordinator