

Familial Breast Cancer SM1 minutes

Familial Breast Cancer update – Scoping meeting 1 minutes

Date: 26/08/2025

Location: Virtual

Minutes: Final

Committee members present:		
Alison Cameron	Chair	Present for items 1-11
Helen Hanson	Clinical Geneticist	Present for items 5-11
Zoe Kemp	Clinical Geneticist	Present for items 1-11
Sarah Pugh	Genetic Counsellor	Present for items 1-11
Kathryn Rigby	Breast Surgeon	Present for items 1-11
Liz Sherwin	Clinical Oncologist	Present for items 1-11

In attendance NICE:		
Sarah Boyce	Senior Technical Analyst	Present for items 1-11
Jeremy Braybrooke	Clinical Adviser	Present for items 1-7
Victoria Carter	Implementation Lead	Present for items 1-11
Danielle Conroy	Project Manager	Present for items 1-11
Gareth Haman	Senior Guidance Content Designer	Present for items 1-11
Marie Harrisingh	Topic Lead	Present for items 1-11
Tzujung Lai	Health Economist	Present for items 1-11
Sarah Matthews	Technical Analyst	Present for items 1-11
Lina Manounah	Technical Analyst	Present for items 1-11
Eric Slade	Health Economics Adviser	Present for items 1-11
Daniel Tuvey	Information Specialist	Present for items 1-11
Magda Watras	Pharmacist Clinical Adviser	Present for items 1-11

Apologies:		
Sarah Case-Scott	PCIE Lead, NICE	
Kay Davies-Crowley	Advanced Nurse Specialist, Committee	
Rachael Griffin	Co-opted Lay member, Committee	
Sadaf Haque	General Practitioner, Committee	
Ashley Hurst	Lay member, Committee	
Tamsin Sargeant	Lay member, Committee	

Hannah Seabrook	Clinical Psychologist, Committee
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1. Welcome, Introductions and apologies

The Chair, Alison Cameron (AC) welcomed the committee members and NICE attendees to scoping meeting 1 for the NICE Familial Breast Cancer guideline update which will focus on initial assessment and genetic testing.

Apologies were noted and the group introduced themselves.

2. Aims of meeting and overall project

The Chair introduced Marie Harrisingh (MH), Topic Lead who outlined the aims of the project which are to update the evidence reviews and related recommendations in the 2013 familial breast cancer guideline and to identify areas that are affected by these updates and make necessary changes.

MH then ran through the aims of the day's meeting which were to discus and agree topics for inclusion in the scope of the update and how they will be updated, and to review the equality and health inequalities assessment to identify any missing issues.

AC thanked MH for her contribution.

3. Overview of scoping process

The Chair introduced Sarah Boyce (SB), Senior Technical Analyst who provided an overview of the NICE scoping process including what scoping is and why it is necessary.

The committee had the opportunity to ask questions.

AC thanked SB for her contribution.

4. Reminder of guideline scope

MH then presented the scope of the guideline to the committee focusing on the populations and settings to be covered.

The committee provided their input on possible amendments to these areas.

AC thanked the committee for their input.

5. Scope of the guideline – areas for discussion:

- Carrier probability
 - Tools for calculating this
 - Thresholds for referral
- Genetic testing (NGTD)

The Chair introduced Sarah Matthews (SM), Technical Analyst, who presented several areas identified by surveillance for possible update for committee consideration. Some of these would be updated with or without an evidence review.

This included differences between NICE's familial breast cancer and familial ovarian cancer regarding genetic testing. The committee considered carrier probability and which genes are currently tested as part of the National Genomic Testing Directory.

The committee had the opportunity to discuss as a group, helped answer specific questions from the NICE team and advised which recommendations they would like to update.

6. Scope of the guideline - areas for discussion (continued):

- Predicting the risk of developing breast cancer
- Surveillance
- Risk reducing surgery

The Chair introduced Lina Manounah (LM), Technical Analyst, who presented further scoping areas for committee consideration.

This included tools for predicting the risk of developing breast cancer, surveillance strategies for detection of breast cancer and risk reducing surgery.

The committee considered which areas would benefit from an evidence review and offered their opinion on the proposed approach to take from the NICE team.

The Chair thanked the committee for their input.

7. Scope of the guideline – areas for discussion (continued):

- Chemoprevention
- HRT

The committee continued to discuss the scope in relation to chemoprevention and hormone replacement therapy and whether an update was required in these areas.

The Chair thanked the committee for their input and SM and LM for their contributions.

8. Equality and health inequalities assessment

MH explained the purpose of NICE's equality and health inequalities assessment and presented the areas currently captured for committee input on any missing issues or inaccuracies.

The committee had the opportunity to discuss as a group and considered factors such as age, ethnicity, disability, sexual orientation and gender reassignment and geographical location in relation to familial breast cancer and breast cancer services.

The Chair thanked the committee for their input.

9. Proposed guideline committee composition

MH confirmed the current lay and professional roles recruited to the committee and asked members for their input on whether any additional expertise is required for this guideline update based on the areas covered by the scope.

The committee gave their opinion on possible other roles which may be helpful which the NICE team will take away for consideration. This will be revisited once the review questions are confirmed.

The Chair thanked the committee for their input.

10. Future timelines and meetings

The Chair introduced Danielle Conroy (DC), Project Manager, who explained that the NICE technical team will revise the draft scope and equality and health equalities assessment based on today's discussion and these will be circulated for further committee input prior to going out for a 2-week public consultation on 22nd September.

The Committee will meet again on 21st October to respond to consultation feedback and make any necessary amendments to the scope and equality and health inequalities assessment prior to publication on 19th November.

DC confirmed the subsequent committee meeting dates and current proposed dates for consultation of the draft guideline and publication. These will be confirmed in due course.

11. AOB and close

AC summarised the main actions from the day and asked for items of any other business. As there was no further business to discuss, AC brought the meeting to a close.

Date of next meeting: 21st October 2025

Location of next meeting: Virtual