Familial breast cancer (standing committee update)

Consultation on draft guideline - Stakeholder comments table
29/11/2016 - 05/01/2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

ID	Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
5	Association of Breast Surgery	General	General	General	The ABS considers these amendments to be very sensible and well referenced and we support them.	Thank you for your comment.
6	Association of Breast Surgery	General	General	General	The recommendations will increase breast/ genetics workload and there will be capacity issues. It will need to be commissioned.	Thank you for your comment. We will pass this information to our resource impact team. Resource impact analysis has shown that the additional number of tests and expenditure is likely to be of a manageable magnitude: there is an estimated annual incidence of 6,733 cases of triple negative breast cancer in women age 40-49 with no family history across England, for whom testing would incur a cost of £671,600. However, as many centres are already testing women of this age range, the resource impact is likely to be considerably lower in practice. Moreover, providing testing to these women is likely to be a cost effective use of resources, in that future costs of treating breast cancer are avoided, therefore justifying the additional spend.
12	Association of Breast Surgery	Short	General	1.5.17	BRCA 1/2 testing is recommended for all triple negative cancers that develop < 50years. Is it correct that no other genetic tests eg TP53 are funded in this situation unless indicated by family history?	Thank you for your comment. This question was specifically restricted to triple negative breast cancer and the BRCA1/2 mutations to reflect the new evidence identified by surveillance; other breast cancer associated genes were not prioritised by the topic experts for this update and so the evidence for these have not been reviewed as they are outside the scope of the update. We will however pass

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						this comment onto the surveillance team for consideration in the next update of this guideline.
13	Association of Breast Surgery	Short	General	1.7.20	All chemoprevention discussions need to take place in secondary care (breast or genetics units). There will be funding and capacity implications which need to be addressed.	Thank you for your comment. We will pass this information to our resource impact team. The previous version of this guideline also recommended discussion of choice of chemoprevention within a specialist genetic clinic, indicating no substantial change to current practice in this aspect of treatment, and therefore no major impact on resource usage. Moreover, economic analysis has shown that the overall process of providing chemoprevention to high and moderate risk women is cost effective, and therefore any additional resource usage is worthwhile.
11	AstraZeneca UK	Short	General	General	There is the potential for confusion about the focus of these guidelines. On page 41 of the short guidelines, it is stated that it covers "*people with a diagnosis of breast cancer and a family history of breast, ovarian or a related cancer"* as well as people at risk of familial breast cancer. However, recommendation 1.5.13 (p18) recommends offering genetic testing to a person with breast or ovarian cancer if their combined BRCA1 and BRCA2 mutation carrier probability is 10% or more. Whilst any recommendation for genetic testing of people with ovarian cancer is to be welcomed, their inclusion in these guidelines has the potential to cause confusion and	Thank you for your comment. However, where recommendations are shaded in grey the evidence has not been reviewed for the current update – these recommendations were outside the scope of this update

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					should be properly addressed in guidelines specific for ovarian cancer.	
1	BASO – The Association for Cancer Surgery	Addendum 1 - chemopreventi on	General		The recommendation about use of anastrozole is very sensible and reflects the newly available research evidence for the role of aromatase inhibitors in chemoprevention. I am unsure why exemestane hasn't been included for the evidence is also supportive of this. However this is a minor point.	Thank you for your comment. The committee decided it was not appropriate to make a broad recommendation to include exemestane for the following reasons: - evidence on exemestane was lacking in those with a family history - although exemestane and anastrozole are third generation aromatase inhibitors, they are not from an identical class and may therefore have different modes of action.
4	BASO – The Association for Cancer Surgery	Addendum 2 – genetic testing	General		Re testing of all TNP cancers for BRCA mutations if under age 50 is also sensible and simplifies referral guidelines. However there is now a lot more evidence about different types of TNP cancer which may have 5 or 6 subgroups and only the basal types are linked to BRCA. It might be of value to refine the criteria to state that basal subtype TNP cancers are eligible and encourage national pathologies standards to better define TNPs with cytokeratin testing as routine if HR and HER2 testing is negative. At present there is a lot of confusion and no standardisation of TN cancers in the pathology itemised reporting proformas. It might also be helpful to suggest that the path report has an item to report	Thank you for your comment, however, please note this is outside of the scope of this update. Also, as no references have been provided, it is not possible to access this evidence base suggested. We will however pass on this comment to the surveillance for consideration in the next update. The committee have however made a research recommendation examining the prevalence of BRCA1 mutations in unselected basal phenotype breast cancer. Please refer to section 2.8 of the addendum 164.2 for more information on this.

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					cytokeratins and if basal type, flags the potential link to BRCA so teams are reminded about the option to refer.	
7	Department of Health	General	General	General	Thank you for the opportunity to comment on the draft addenda to the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
8	NHS England	General	General	General	Thank you for the opportunity to comment on the above Clinical Guideline. We can confirm that there are no comments to be made on behalf of NHS England.	Thank you for your comment.
9	Royal College of Nursing	General	General	General	This is to inform you that the Royal College of Nursing has no comments to submit to inform on the above consultation at this time. Thank you for the opportunity.	Thank you for your comment.
10	Royal College of Physicians and Surgeons of Glasgow	General	General	General	The College welcomes this guideline and supports its recommendations. We would encourage an active plan of distribution of the guideline to breast clinicians and nurses who participate in family history clinics. We have noted that the uptake of chemoprevention has been low in higher risk groups and welcome further moves to encourage the full discussion of the options for chemoprevention and balance of risk/ benefits for patients.	Thank you for your response. Your comments will be considered by NICE and where relevant support activity is being planned. In order to encourage the full discussion of options for chemoprevention and balance the risks/benefits for patients, NICE has developed a patient decision aid to be published alongside this guideline.

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19	Royal College of Physicians and Surgeons of Glasgow	Short	27	16	Footnote 8 should be part of the text so making clearer the need for monitoring and maintenance of bone health with AI use	Thank you for your comment. It was outside the scope of this update to provide guidance on this area and it has therefore been decided to maintain the footnote as it is.
25	Royal College of Physicians and Surgeons of Glasgow	Short	28	10	Footnote 13 should be part of the text, as above	Thank you for your comment. The committee decided it was outside the scope of this update to provide guidance on this area and have therefore decided to maintain the footnote as it is.

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

Registered stakeholders