National Institute for Health and Clinical Excellence

Familial Breast Cancer
Scope Consultation Table
31st March – 28th April 2011

Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
SH	Association of Breast Surgery	13.00	General	The draft scope of the FBC Guideline is sensible and well thought out. It will build on the previously submitted guidance (CG14 & 41) and clearly identifies those areas in that guidance that need review and potential revision.	Thank you for your comments.
SH	Breakthrough Breast Cancer	4.00	General	This submission reflects the views of Breakthrough Breast Cancer, based on our experience of working with people with personal experience of, or who are concerned about, breast cancer. To inform our submission to this review, we have consulted with members of the Breakthrough Breast Cancer Genetics Reference Group (GRG), composed of people who have, or are interested in, a family history of breast cancer. GRG members play a vital role in informing Breakthrough on a wide range of issues, ensuring that our genetics and family history policy, campaigning and information activities continue to reflect the views of people with a family history of breast cancer.	Thank you for this information.
SH	National Patient Safety Agency (NPSA)	3.00	General	The NPSA welcomes the proposal to develop this guideline. The scope is comprehensive and appears to have covered the areas of importance. The key points in relation to patient safety are around the co-ordination of care across different care settings and the potential confusion this causes in advice and	Thank you for your comments, we agree.

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				also in the responsibility for ensuring that the pathway is completed appropriately.	
SH	NCRI/RCP/RCR/ACP/JCCO	14.00	General	The NCRI/RCP/RCR/ACP/JCCO is grateful for the opportunity to comment on the draft scope consultation. Overall, we believe that the scope is well balanced. The only concern of our experts is that it is important to ensure that surveillance is kept in the discussions for women 40-49 where the NHS BSP approach (draft protocol) is felt to disenfranchise a considerable proportion of women at risk.	We agree and we hope that the scope will address this group of patients. We will liaise closely with the NHSBSP during development of the guideline and any recommendations they make in their protocol will be taken into account by the GDG.
SH	NHS Direct	8.00	General	NHS Direct have considered the content and make no comment on the draft scope. NHS Direct welcome the guideline development.	Thank you.
SH	Royal College of General Practitioners	9.00	General	We support the scope consultation. The issues are pertinent and relevant to the management of these women (and men) - What we would like to see is some advice on the role of General Practice in these high risk populations.	Thank you for your comment. The role of GPs in managing the high risk population can be found in the existing guidance (CG14/41 http://www.nice.org.uk/guidance/CG41). NICE is currently developing clinical pathways for each of its clinical guidelines which we hope will allow easier access to this information for GP's.
SH	Royal College of Nursing	1.00	General	The Royal College of Nursing welcomes proposals to develop this guideline. The scope for this guideline is comprehensive and seems to have covered the importance areas of this topic.	Thank you for your comments.
SH	Royal College of Nursing	1.01	General	The scope seems right as there are still some unanswered questions needing guidance including guidance to those women with breast cancer and who are found to have a mutation. Also the use and costs of MRI surveillance should be covered.	Thank you for your comments. MRI surveillance is covered in the scope and will be considered as a topic for health economic evaluation.

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SH	Society and College of Radiographers	10.01	General	Positively the scope includes discussion about reviewing the need for genetic testing which is commonplace it seems in North America and Europe, for those at higher risk.	Thank you for your comments.
SH	Society and College of Radiographers	10.02	General	We welcome the proposed review and the scope being proposed.	Thank you.
SH	Target Ovarian Cancer	15.00	general	Target Ovarian cancer welcomes the opportunity to comment on the scope of this guideline, in the hope that more women, who have a family history of breast/ovarian cancer in their family are advised adequately about the risks, and actions that can be taken to mitigate risk, not just of breast cancer, but also ovarian cancer. Whilst this guideline is not about ovarian cancer, it represents an important opportunity to address an imbalance of responsible information. As an organisation we are aware of cases of women being diagnosed with late stage ovarian cancer, whilst under surveillance for familial breast cancer. They tell us that had they been aware of the risk, and of the potential symptoms, they would have acted a lot sooner on their symptoms. They have often expressed anger that they were not told of their potential to develop ovarian cancer.	Thank you for your comments. We agree that the provision of information to support discussion of risk is an important issue and will be considered when developing the new short clinical guideline.
SH	UCL Partners	16.03	General	Oophorectomy alone is not recommended in this group – the scope should say bilateral salpingo-oophorectomy	Thank you for your comment, we agree and have altered the scope to reflect this.
SH	UCL Partners	16.07	General	There may be further resource implications for surgery and for clinical psychology if the approach of offering early bilateral mastectomy is advocated in	Thank you for your comment. Where appropriate the GDG will seek expert advice from a surgeon with oncoplastic skills.

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				early breast cancer management in those with a familial risk. The GDG does not specify a surgeon with oncoplastic skills which would be important	
SH	National Hereditary Breast Cancer Helpline	12.00	General/ scope	Moderate Risk Screening - please include in the Scope screening for those at increased risk of developing breast cancer.	Thank you for your comment - this is included in the scope.
SH	National Hereditary Breast Cancer Helpline	12.01	General/ scope	Ongoing support before and after diagnosis of faulty gene. All felt it essential to be furnished with phone numbers of helplines and support after receiving the news of a faulty gene inheritance. Ongoing access to psychological support helpful too. Decisions of this type are unusual; where the patient leads on their treatment - before symptoms are present. It can feel very isolating and the population as a whole do not really understand those difficult choices. It was felt essential to be put in touch with others who understand the situation from personal experience.	Thank you for your comment. We agree. However, the guideline will be unable to unable to make recommendations on which specific sites or patient helplines to access. Patient information, including access to psychological support, was covered in CG14/41 and in the accompanying 'Information for Patients' document.
SH	National Hereditary Breast Cancer Helpline	12.02	General/ scope	Options for surgical interventions- for discussion, concerns over surgeons- opportunities for choice with surgeon experienced in RR mastectomy, opportunity to see photographs of results.	Thank you for your comments. We agree that this is an important issue but risk reducing mastectomy for women unaffected with breast cancer will not be covered within the scope of this guideline.
SH	National Hereditary Breast Cancer Helpline	12.03	General/ scope	HRT and implications - clearer understanding and explanations of the pros and cons - which clearly even many GPs are unaware of.	Thank you for your comment. We agree that GP awareness should be raised and this issue will be addressed within the scope.
SH	Gloucestershire Hospitals NHS Trust	11.03	Section 4 (general)	Revision of clinical guidelines 80 and 41 welcomed to address existing internal variations.	Thank you for your comment.
SH	AstraZeneca UK Ltd	5.00		AstraZeneca would like to thank NICE for the opportunity to comment on the draft scope and have no comments to make.	Thank you.
SH	National Patient Safety Agency (NPSA)	3.01	3	The inclusion of men and women diagnosed with breast cancer who also have a family history of the	Thank you for your comment.

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				disease is welcomed but the scope gives no information on the clinical need for the inclusion of men in this guideline.	We have included men within the population for the update on the topics relating to risk thresholds (4.3.1a & 4.3.1b). For those recommendations in CG41 that are not being updated, the GDG will be asked to carry out an editorial review to ensure that they comply with NICE's duties under equalities legislation (for example, to determine whether the recommendations are also applicable to men).
SH	NHS Trafford	2.00	3.1 (a)	It may prove useful in the epidemiology section to provide a brief outline of what is considered to be an "unusually high number of family members affected …"	Thank you for your comment. We feel that this issue does not need defining in the scope but will be addressed in the background section of the full guideline.
SH	Target Ovarian Cancer	15.01	3.1 a)	We would like ovarian cancer to be included in this opening paragraph rather than just 'related cancer'. We would also like to see it mentioned specifically in the bullet points, with regard to the number of relatives and age of relatives when diagnosed	Thank you for your comment, we have amended the scope.
SH	Target Ovarian Cancer	15.02	3.1b) **3.1 c**	We think the risk should be quantified here, given the population risk is cited. Lifetime risk is up to 80% for a BRCA1/2 carrier in terms of breast cancer, but we would also like to see the up to 40% lifetime risk of ovarian cancer mentioned. Ovarian cancer survival rates are much much lower, so it is important women understand the range of risks they face as a result of having a familial cancer.	Thank you for comment. We feel that this issue does not need defining in the scope but will be addressed in the background section of the full guideline. Also, this topic has already been addressed in Clinical Guideline 14 Familial Breast Cancer and Clinical Guideline 41 Familial Breast cancer (update of CG14). http://guidance.nice.org.uk/CG41/Guidance
SH	Breakthrough Breast Cancer	4.01	3.1.c **3.1 d**	This section refers to "the care of women recently diagnosed with breast cancer". However, as the new short clinical guideline will cover both women and men diagnosed with breast cancer, the wording should refer to "the care of people recently diagnosed with breast cancer".	Thank you for your comment. The scope has been amended.
SH	UCL Partners	16.00	3.1.c,	No definite evidence that bilateral mastectomy	Thank you for your comment, the scope will address

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			general **3.1 d**	improves survival in women with recently diagnosed breast cancer and a family history although it does reduce the incidence of a second new breast primary	this issue.
SH	NHS Trafford	2.01	3.2 (b) **3.2 i**	Comment as above what is considered to be a strong family history. Will the guideline also include a differential diagnosis tool to also cover what should happen to patients with a family history which is not considered strong.	Thank you for your comment. We have amended the scope and removed the word 'strong'.
SH	UCL Partners	16.01	3.2.b **3.2 i**	Additional funding will need to be made available if the threshold for offering BRCA1 and 2 screening is lowered to 10%, although there may be some cost saving with the newer technologies	Thank you for your comment. This topic will be considered for health economic evaluation by the GDG.
SH	UCL Partners	16.02	3.2.b **3.2 i** and 4.3.1d	We support the recommendation that women with BRCA1 and BRCA2 mutations should use HRT until 50 if they have early bilateral salpingo-oophorectomy and do not have breast cancer	Thank you for your comment. We will be addressing this issue and once the evidence has been reviewed the GDG will make an appropriate recommendation.
SH	Breakthrough Breast Cancer	4.02	3.2.b,f,g,h **3.2 i,e,f,g**	As above, these sections should refer to "people" rather than "women" to reflect the remit of the new short clinical guideline.	Thank you for your comments. The scope has been amended.
SH	UCL Partners	16.04	3.2.c, 4.3.1f **3.2 a**	If genetic testing for BRCA1 and BRCA2 is to influence decisions about surgery for women with breast cancer turnaround times for testing will need to be shorter. There will need to be mechanisms in place for rapid referral to clinical genetics services. The majority of tests in the UK for BRCA1 and BRCA2 are currently carried out in clinical genetics not oncology. If this situation were to change it would have significant implications for service provision and training. There is limited data regarding the psychological impact of this rapid genetic testing.	Thank you for your comment. We will be addressing these issues when developing the guideline.

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SH	Target Ovarian Cancer	15.03	3.2c) **3.2 b**	We would welcome the lowering of thresholds, and would also welcome the option of testing of high risk women even if they do not have an affected family member who can be tested.	Thank you for your comment. We will be addressing this issue and once the evidence has been reviewed, the GDG will make an appropriate recommendation.
SH	National Patient Safety Agency (NPSA)	3.02	3.2.e **3.2 d**	The potential use of HRT under the age of 50 causes great confusion and disparity of care across the service; it is a welcomed area for review and clear recommendation.	Thank you for your comment.
SH	Target Ovarian Cancer	15.04	3.2e) **3.2 d**	We would welcome greater clarity on this matter, also in relation to risk of ovarian cancer	Thank you for your comment. We hope to provide greater clarity in the final guideline.
SH	Target Ovarian Cancer	15.05	3.2g) **3.2 f**	We agree that the discussion of second cancer risks is patchy, in relation to ovarian cancer (not just second breast tumours)	Thank you for your comment.
SH	Target Ovarian Cancer	15.06	3.2h) **3.2 g**	We support women having genetic testing when it can help with management decisions. This is also important if a woman develops ovarian cancer. Having a confirmed BRCA status may mean she is able to access treatment with PARP inhibitors, which are proving useful for BRCA ovarian tumours.	Thank you for your comment.
SH	Breakthrough Breast Cancer	4.03	4.1	Breakthrough asked the GRG whether they thought the proposed population groups were the appropriate groups to be covered / not covered by the guidelines. Six of 15 members responding to this question independently stated that men without breast cancer but with a family history of the disease should not be excluded from the update of CG41. Comments included: *"I think adult men without breast cancer but with a family history of it should be included in the guidelines. Surely, inheriting the faulty gene gives them the same concerns as women have? My niece has just had her ovaries removed and cancer was found; my nephew, also with the faulty gene, must*	Thank you for your comment. We have included men within the population for the update on the topics relating to risk thresholds (4.3.1a & 4.3.1b). For those recommendations in CG41 that are not being updated, the GDG will be asked to carry out an editorial review to ensure that they comply with NICE's duties under equalities legislation (for example, to determine whether the recommendations are also applicable to men).

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				be panicking." *"I believe men should be included. I worry about my son as myself and both his grandmothers have/had breast cancer."* *"I do not understand why adult men with an increased risk of developing cancer would not be included, I think that they should be. How else will they be guided?"* *"I do think that adult men - with a family history of breast cancer - should be included. My reason for this is that my husband's first cousin actually had breast cancer in both breasts. I know the incidence of men getting this is very small but it does happen especially with a family history."* However, one respondent specifically stated that men should be excluded from the guideline as *"men without breast cancer (but at increased risk) may need a different approach which addresses their specific issues"*. These comments were not surprising to Breakthrough, as many people with a family history of breast cancer have told Breakthrough that they view familial breast cancer as having implications for all family members regardless of gender. NICE has asked stakeholders to specifically consider whether the draft scope could be changed to promote equality of opportunity, including in relation to gender. Gender equality would be	

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				promoted by expanding the scope to ensure that men with a family history of breast cancer are informed about their own risk and receive genetic counselling and genetic testing where relevant. Effective management of the care of men with a family history of breast cancer would allow men to make informed healthcare decisions and to pass on important information to daughters and other female relatives who may be at risk.	
SH	UCL Partners	16.05	4.1.1.b & 4.1.1d	This may need to be extended to other ethnic groups where there is a significant proportion of founder mutations in BRCA1 and BRCA2 eg those of Polish ancestry	Thank you for your comment. The scope will give specific consideration to those populations with a particularly high prevalence of BRCA1 and BRCA2 mutations.
SH	Association of Breast Surgery	13.01	4.1.1 c	It is essential that the scope includes (as proposed) guidance for the management of individuals with a recent diagnosis of breast cancer who have a family history of breast or ovarian cancer as there is a lack of any clear guidance in this area currently.	Thank you for your comment. This important topic is now included in the revised scope.
SH	Breast Cancer Care	6.00	4.1.1C	Should this also include a history of other relevant, early onset cancers e.g pancreatic & prostate	Thank you for your comment. We have amended the scope to include those 'with a family history of breast, ovarian or a related cancer'.
SH	Breakthrough Breast Cancer	4.04	4.1.2 a 4.1.2 c	Four GRG members commented on point 4.1.2.a and 4.1.2.c (which exclude children from the update of CG41 and the new short clinical guideline). Three of these agreed with this exclusion, with one stating: *"I agree it should not cover children younger than 18 as I feel you need to be an adult to be able to cope with the knowledge involved and decisions to be made."* However, one disagreed, preferring a more flexible approach taking into account each individual's risk:	Thank you for your comment. Children (younger than 18) will not be included in either the update or the short clinical guideline.

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				"Why have strict age boundaries? Why not base the guidelines on sensible factors such as the age of the earliest breast cancer patient in the family tree? After all, these are guidelines based on the risk of familial breast cancer - individual to the patient not to the population as a whole." Breakthrough feels that it would not be appropriate to include children under 18 in the guideline as there is very little to be done at such a young age to manage a person's risk of developing breast cancer. Even where breast cancer has occurred in family members in their 20s, evaluation of genetic risk at age 18 would allow for relevant management decisions to be made before this age was reached. Children under 18 may not yet have the maturity required to make important and complex decisions about risk management, and it would not be appropriate for parents or guardians to make these decisions on behalf of their children.	
SH	NHS Trafford	2.02	4.1.2 (b)	What is the rationale for not including men aged 18 years and older who may be at increased risk of developing breast cancer because of family history of breast or ovarian cancer?	Thank you for your comment. We have included men within the population for the update on the topics relating to risk thresholds (4.3.1a & 4.3.1b). For those recommendations in CG41 that are not being updated, the GDG will be asked to carry out an editorial review to ensure that they comply with NICE's duties under equalities legislation (for example, to determine whether the recommendations are also applicable to men).
SH	Society and College of Radiographers	10.00	4.1.2 (b)	The rational for this is not clear (although it is presumably the low number of men who	Thank you for your comment

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				develop breast cancer). However, the consultation does ask for considerations from the equality perspective, so greater clarity here would be appreciated.	We have included men within the population for the update on the topics relating to risk thresholds (4.3.1a & 4.3.1b). For those recommendations in CG41 that are not being updated, the GDG will be asked to carry out an editorial review to ensure that they comply with NICE's duties under equalities legislation (for example, to determine whether the recommendations are also applicable to men).
SH	Association of Clinical Pathologists	7.00	4.3.1	Item h: It would be useful also to consider access to, and the process of, requesting genetic testing, and which professionals should be able to do so; the current requesting procedure is inconsistent and in some parts of the country the process is particularly difficult.	Thank you for your comment. However, we are not updating this topic. Recommendations on this topic were addressed in the original guideline (CG14/41). http://www.nice.org.uk/guidance/CG41 The issue of rapid testing for affected men/women is in the scope and will be discussed by the GDG.
SH	Target Ovarian Cancer	15.07	4.3.1	In addition to the outlined areas we would like to see specific mention of the information needs of those women who have a family history of breast/ovarian cancer, and that this should include symptom information about ovarian cancer (Newly published NICE Guideline CG122 on the recognition and initial management of ovarian cancer). This should be included in both the CG41 and the new short clinical guideline	Thank you for your comment. We can cross reference CG122 within both the update and new short clinical guideline.
SH	National Patient Safety Agency (NPSA)	3.03	4.3.1.b	Reference to genetic testing should include a recommended timeframe for this to be carried out and completed through to the results being given to the patient. How this process is completed is an important consideration in making it safer and ensuring that high risk patients are not waiting for investigations and results while their cancer is developing.	Thank you for your comments. We will be considering rapid testing in the scope.

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SH	Breast Cancer Care	6.01	4.3.1B	As well as the risk threshold (once confirmed as high) Should the number of other 1st degree relatives (to the affected deceased relative) be considered when discussing indirect testing? And if so how will the management of the reporting/disseminating of the results be given (especially when more than 1 regional genetic centre is involved) to the individuals concerned?	Thank you for your comments. This topic is in the scope and these issues will be considered by the GDG.
SH	Breast Cancer Care	6.02	4.3.1D	Now that the surveillance management is under the NHS BSP, should this point acknowledge that once the NHS BSP surveillance management guidelines/recommendations are completed they will replace this guidance.	Thank you for your comments. We will liase closely with the NHSBSP during development of the guideline and any recommendations made by them will be taken into account by the GDG.
SH	Target Ovarian Cancer	15.08	4.3.1d)	We believe that in addition to surveillance for women for breast cancer, that they are given information about the risk and symptoms of ovarian cancer, as until the UKCTOCs familial screening study trial is published, this is the best information available.	Thank you for your comment. We can cross reference CG122 within both the update and new short clinical guideline.
SH	UCL Partners	16.08	4.3.1d, general	We have significant concerns about breast surveillance provision. Provision of MRI in high risk women as specified by CG41 is variable throughout the UK. We also have concerns that some women with a moderate breast family history who are currently receiving surveillance according to CG14/41 would not if the thresholds suggested by the national screening programme are adopted. Would these women continue to receive screening outside of the national screening programme? If so how should that be organised? We feel it is essential NICE addresses this.	Thank you for your comment. This topic is in the scope and will be addressed by the GDG during development of the guideline.
SH	National Patient Safety Agency (NPSA)	3.04	4.3.1.d	The specific surveillance requirements should include the responsible clinician/clinical service for ensuring this takes place.	Thank you for your comment. This topic is in the scope and will be addressed by the GDG during development of the guideline.
SH	Gloucestershire Hospitals	11.00	4.3.1	Should address the surveillance	Thank you for your comment. This topic is in the

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	NHS Trust		(d)	recommendations for women in these categories who reach the age of 50 (currently annual mammograms from 40 to 50 (or 'screening age', now 47 in Gloucestershire, so an ambiguous description), which means a dramatic and sudden reduction in the frequency of surveillance which most patients find hard to understand.	scope and will be addressed by the GDG during development of the guideline.
SH	Association of Breast Surgery	13.02	4.3.1 d	Surveillance requirements clearly need review. However, it would be desirable that this review takes into account the current service developments within the NHS. The NHS Breast Screening Programme is currently in the process of taking over the delivery of surveillance for women identified as being at high risk due to their family history as detailed in the Cancer Reform Strategy. It would be beneficial if the review of surveillance requirements by both the NHSBSP and NICE adopted a consistency of approach in particular in relation to the definition of levels of risk, and the evaluation of the efficacy and cost effectiveness of different surveillance strategies. NICE may not have a role in the implementation of the guidance it issues, but if 2 different surveillance strategies with differing definitions of 'high risk' are proposed simultaneously by the NHSBSP and NICE this will cause confusion for patients, providers and commissioners and the 'postcode lottery' will continue.	Thank you for your comment. This topic is in the scope and will be addressed by the GDG during development of the guideline.
SH	UCL Partners	16.06	4.3.1f	We need to be specific about what these outcomes are. Are they choices about primary treatment or impact of treatment on survival/risk of a second primary breast cancer (see comment on 3.1.c)	Thank you for your comment. This topic is in the scope and will be addressed by the GDG during development of the guideline.

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					The outcomes for each topic included in the scope will be discussed and agreed by the GDG.
SH	Association of Breast Surgery	13.03	4.3.1 h	Genetic testing at the time of diagnosis for BRCA1 & 2 and TP53 within 4 weeks may be advantageous in potentially informing management decisions (mastectomy / breast conserving surgery, contralateral mastectomy). However, in the proposed 4 week timescale (currently shorter timescales in Europe, North America and UK private sector), it will also cause a delay in treatment, inevitably breaching the current 62 day breast cancer treatment target. An additional question to pose could be: 'Does a delay in breast cancer treatment to facilitate genetic testing at the time of diagnosis affect outcome?' – this could be positive (wrong treatment decision without genetic information) or negative (delay worsens prognosis).	Thank you for your comment. This issue of rapid genetic testing will be addressed in the guideline. We feel that the topic included in the scope adequately covers this issue.
SH	National Patient Safety Agency (NPSA)	3.05	4.3.1.h	As mentioned above (point 4.3.1.d) 'who should discuss the outcome…' should include who should be responsible for ensuring the process has taken place.	Thank you for your comment. This topic is in the scope and will be addressed by the GDG during development of the guideline.
SH	Gloucestershire Hospitals NHS Trust	11.01	4.3.1 (i) first bullet point	Any recommendation should not be so prescriptive that it disallows the prospect of individual patient choice: there is a natural variation in the thresholds of different individuals.	Thank you for your comment. We agree.
SH	Gloucestershire Hospitals NHS Trust	11.02	4.3.1 (j)	Clarification in this area would be welcome.	Thank you for your comment. We agree, and this will be addressed in the guideline.
SH	Breakthrough Breast Cancer	4.05	4.4.c	Breakthrough asked the GRG whether there were specific aspects of quality of life that could be improved by having clear guidelines on the care of people with a family history of breast cancer, and	Thank you for your comment. We have amended the scope in section 4.4c to include 'health related quality of life'.

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				how these improvements could be measured. Most respondents mentioned psychological outcomes such as reduced fear and anxiety and improved peace of mind associated with receiving appropriate information and risk management options. *"I would say it takes the worry from them. And hopefully it helps them to lead a worry free life not thinking 'I've got a lump here or I've got a lump there'. It takes that fear away."* *"Providing reassurance that the possibility of contracting breast cancer is being managed in the most appropriate way. In the long-term, if the guidelines are not right, the loss of a young mother to breast cancer impacts the quality of life of many generations in that one family."* *"To be able to make an informed decision and have appropriate support from other people who are in the same position and support from professionals. The possibility of having a life without the fear of breast cancer."* *"Clear guidelines would give peace of mind to young people in families with a high incidence of breast cancer."* *"Reduced anxiety due to clearer advice on the options available based on clearer information on risk."* *"With 8 out of 8 of [the women in our family]*	

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				inheriting the faulty BRCA2 gene, reassurance is everything." Unfortunately, measuring improvements in these psychological outcomes would be extremely difficult. It would require the systematic collection and recording of data on psychological state both before and after intervention by genetics and family history services. As one GRG member pointed out, standardised measures of anxiety could be used, but the issues associated with familial breast cancer may be more specific (for example, concern for the health of children and other relatives). A proxy measure could be satisfaction with the individual management plan, although where management options are limited (e.g. for very young women, women without a sufficiently strong family history or men) satisfaction may be low. Other appropriate measures or proxy measures of improvements in psychological outcomes should be considered during the update of the Familial Breast Cancer guidelines.	

These organisations were approached but did not respond:

Abbott Laboratories Limited
African Health Policy Network
Association for Clinical Biochemistry
Association of Cancer Physicians
Association of Clinical Pathologists
Association of Genetic Nurses and Counsellors
Bard Limited
Birmingham Womens NHS Foundation Trust
BMJ

Breast Cancer Campaign
Breast Test Wales
British Dietetic Association
British Medical Association (BMA)
British National Formulary (BNF)
British Psychological Society, The
Cambridge University Hospitals NHS Foundation Trust (Addenbrookes)
Cancer Genetics Group
Cancer Research UK
Care Quality Commission (CQC)
Central South Coast Cancer Network
CLIC Sargent
Connecting for Health
Department for Communities and Local Government
Department of Health
Department of Health Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI)
Department of Health, Social Services & Public Safety, Northern Ireland (DHSSPSNI)
Dudley Group of Hospitals NHS Trust
Energy Therapy World-Wide Net
Great Western Hospitals NHS Foundation Trust
Healthcare Improvement Scotland
Healthcare Quality Improvement Partnership
Joint Collegiate Council for Oncology
Kent & Medway Cancer Network
Luton & Dunstable Hospital NHS Foundation Trust
Luton & Dunstable Hospital NHS Foundation Trust
Macmillan Cancer Support
Medicines and Healthcare Products Regulatory Agency (MHRA)
Ministry of Defence (MoD)
National Council for Palliative Care
National Treatment Agency for Substance Misuse
NCC - Cancer
NCC - Mental Health
NCC - National Clinical Guideline Centre (NCGC)
NCC - Women & Children
NETSCC, Health Technology Assessment
NHS Cancer Screening Programmes
NHS Clinical Knowledge Summaries Service (SCHIN)

NHS East Sussex Downs & Weald and NHS Hastings & Rother
NHS Hertfordshire
NHS Oxfordshire
NHS Plus
NHS Western Cheshire
NICE - CHTE for info
NICE - CPHE
NICE - CPHE Methodology - Simon for info
NICE - Guidelines - GC, HE, Tech Lead
NICE - Guidelines HE for info
NICE - IMPLEMENTATION CONSULTANTS (ALL)
NICE - IMPLEMENTATION CO-ORDINATION for info
NICE - PPIP
NICE - R&D for info
Northern Ireland Regional Genetics Service
Public Health Wales
QResearch
Roche Diagnostics
Roche Products Limited
Rotherham NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Surgeons of England
Royal Pharmaceutical Society of Great Britain
Royal Society of Medicine
Royal Society of Medicine
Sanofi-Aventis
Scottish Intercollegiate Guidelines Network (SIGN)
Sheffield Teaching Hospitals NHS Foundation Trust
Social Care Institute for Excellence (SCIE)
Solent Healthcare
South Wales Cancer Network

Step4Ward Adult Mental Health
Sussex Cancer Network
Sussex Cancer Network
The Society and College of Radiographers
UK Clinical Pharmacy Association (UKCPA)
Warwickshire, Solihull and Coventry Breast Screening Unit
Welsh Assembly Government
Welsh Scientific Advisory Committee (WSAC)
York Teaching Hospital NHS Foundation Trust
Yorkshire Ambulance Service