NICE National Institute for Health and Care Excellence

Appendix A: Stakeholder consultation comments table

2022-2023 surveillance of CG164 Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer

Consultation dates: 17th December 2021 to 12th January 2022

1. Do you agree with the proposal to withdraw recommendation 1.1.2 from CG164 Familial Breast Cancer?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
UK Cancer Genetics Group	Yes	Agree to remove the statement. We feel it is important to actively seek to identify people with a family history of breast cancer.	Thank you for your comments. Following the current surveillance check, we plan to withdraw recommendation 1.1.2.
Breast Cancer Now	Yes	Yes, we support the withdrawal of recommendation 1.1.2 from the CG164 Guideline. It is well established that a family history of breast cancer, especially amongst first degree relatives, can significantly increase an individual's risk of developing breast cancer. [1] Current guidance also recommends that a family history of breast cancer should be factored into certain treatment decisions, such as the use of oral contraceptives, and that individuals who are at increased risk of breast cancer based on family history should be offered risk-reducing treatments such as	Thank you for your comments. Thank you also for the additional information and citations. The focus of the current surveillance check was limited to withdrawal of recommendation 1.1.2. Following the current surveillance check, we plan to withdraw recommendation 1.1.2. We have noted your comments about other aspects of the guideline. The NICE 5-year strategy is currently

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		chemoprevention. [2] It is therefore important that the guidance given to primary care clinicians on this topic facilitates the identification and management of people with a family history of breast cancer as effectively as possible. Recommendation 1.1.2 in the current NICE guidance has the potential to limit the role of primary healthcare professionals in identifying people who might be at an elevated risk of breast cancer by stating that healthcare professionals 'should not, in most instances, actively seek to identify people with a family history of breast cancer. [2] For most people primary healthcare professionals, namely GPs, are their main point of contact with the health service and are a trusted source of advice. [3] They are therefore well placed to have potentially sensitive conversations with patients about family history and help manage any anxiety people may have about the topic. While active, systematic case finding in primary care settings may not always be a practical or suitable solution for identifying people with a family history of breast cancer, clinical guidance should not dissuade primary healthcare professionals from seeking to proactively identify patients with a family history. Furthermore, the current NICE guideline 'Early and locally advanced breast cancer: diagnosis and management' (NG101) recommends that information on family history is taken to help determine the need for genetic testing. [4] However, insights from breast cancer patients suggest that the collection of this information is not always carried out during diagnosis and treatment. Furthermore, both the range of genetic tests available and the family history criteria used to determine an individual's risk level have evolved significantly over time. It is therefore appropriate for a previous diagnosis of breast cancer to be added to Recommendation 1.1.3 in the updated version of this clinical guideline on familial breast cancer (CG164), as a circumstance where it may be clinically relevant to ask a patient about their family history, to ensure	prioritising which parts of the guidelines portfolio will be actively maintained. This work will determine how the CG164 guideline is updated in the future.

		individuals with a personal history of breast cancer who remain at increased risk post-treatment are suitably surveilled in the long-term. References [1] Brewer, H R., et al. Family history and risk of breast cancer: an analysis accounting for family structure." Breast cancer research and treatment 165.1 (2017): 193-200. [2] National Institute for Health and Care Excellence. Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer (2013). Available: https://www.nice.org.uk/guidance/cg164 [3] NHS England. GP Patient Survey 2021 (2021). Available: https://www.england.nhs.uk/statistics/2021/07/08/gp-patient-survey-2021/ [4] National Institute for Health and Care Excellence. Early and locally advanced breast cancer: diagnosis and management (2018). Available: https://www.nice.org.uk/guidance/ng101	
NHSE National Cancer Programme	Yes	The NHSE/I National Cancer Programme agrees with the proposal to withdraw recommendation 1.1.2 from CG164 Familial Breast Cancer. It is an important change to allow the proactive identification of women at increased risk of breast cancer who would benefit from being on appropriate surveillance pathways and offered risk-reducing treatments.	Thank you for your comments. Following the current surveillance check, we plan to withdraw recommendation 1.1.2.
Royal College of Nursing	No comment	No comment	
National Hereditary Breast Cancer Helpline	Yes	Recommended 1.1.2 Familial Breast Cancer CG 164 I strongly approve of the removal of this recommendation. There is robust evidence that identifying people with a family of history cancer is	Thank you for your comments. Following the current surveillance check, we plan to withdraw recommendation 1.1.2.

		life saving, beneficial to the health service in saving treatments and identifying those most at risk. Nothing should be done to discourage GPs from taking family history.	
Prevent Breast Cancer	Yes	Yes, we support the withdrawal of recommendation 1.1.2 from the CG164 Guideline. The problem with this clause - that healthcare professionals 'should not, in most instances, actively seek to identify people with a family history of breast cancer' - is that it can dissuade doctors in primary and secondary care settings from taking the initiative to identify individuals with a significant family history of cancer. Several relevant factors have changed since these guidelines were first written. 1. Preventative strategies for women carrying a gene mutation have been shown to be effective in reducing breast cancer mortality. 2. A highly effective future strategy for preventing more breast cancer diagnoses and deaths would be to identify as many women as possible carrying high risk mutations, as they account for a disproportionately high number of cases within the population. 3. Public awareness of the inherited risk of breast cancer is more widespread 4. Awareness of the inherited risk of breast cancer is however less prevalent in ethnic minority communities and areas of social deprivation, and a more proactive approach to reaching these communities is required.	Thank you for your comments. Thank you also for the additional information. The focus of the current surveillance check was limited to withdrawal of recommendation 1.1.2. Following the current surveillance check, we plan to withdraw recommendation 1.1.2. Proactive collection of family history was beyond the scope of the current surveillance check. However, we have noted your comments about the benefits of a proactive approach. The NICE 5-year strategy is currently prioritising which parts of the guidelines portfolio will be actively maintained. This work will determine how the CG164 guideline is updated in the future.

		5. The cost of genetic testing has fallen dramatically, and it is more effective, with several more high risk genes have been identified. A proactive approach to identifying as many individuals as possible who might carry a high or intermediate risk gene could save hundreds of lives. We support the withdrawal of recommendation 1.1.2	
UK National Screening Committee	Yes	We agree with this on the understanding that it does not imply that the health service should routinely and proactively seek people with a history of breast cancer.	Thank you for your comments. Following the current surveillance check, we plan to withdraw recommendation 1.1.2. This means that the guideline will remove any reference actively seeking to identify will be neutral about people with a family history of breast cancer; the guideline will therefore be neutral on this point.

2. Do you have any comments on equalities issues that relate to this proposal?

Stakeholder	Overall response	Comments	NICE response
UK Cancer Genetics Group	Yes	Health inequalities will arise if active identification of patients at increased familial risk of breast cancer are not uniform across the UK. The UK Cancer Genetics Group would be happy to work together with other national bodies to ensure equity of access to assessment of familial cancer risk.	Thank you for your comments.
Breast Cancer Now	Yes	The current process of identifying people with an increased risk based on family history relies on individuals who are concerned about their family history or have breast symptoms seeking out support and being able to provide detailed personal information to their healthcare professionals.	Thank you for your comments. Thank you also for the additional information and citations. The focus of the current surveillance check was limited to the withdrawal of recommendation 1.1.2.

		This system has the potential to create indirect barriers to identification and appropriate management of certain groups, for example those who are in contact with the health system less frequently or feel less confident raising their concerns with healthcare professionals. Demographic-based health inequalities are present in the identification and testing system, with research showing that referrals and uptake of cancer genetics services are also influence by factors like ethnicity and socioeconomic deprivation. [5,6,7] Recent analysis also suggests that regional variation in the implementation of current surveillance guidelines, and the resulting inconsistencies in screening provision across the UK for those at an increased risk, causes up to 73 preventable breast cancer deaths annually. [8] A wide range of solutions have been proposed to help address these disparities, which were highlighted in the NICE needs assessment report for this guideline, including routine systematic enquiries about family history of cancers in primary care amongst specific groups. [9] There is also ongoing research into the viability of digital innovations such as online questionnaire platforms to improve the identification of individuals at an elevated risk through automated risk stratification. Removing this recommendation will help systems pilot new models of identifying individuals at increased risk in both community and primary care. NICE should also consider whether an additional research recommendation should be included on how the process for identifying individuals at increased risk because of a familial history of breast cancer can be improved, and how inequalities in the utilisation of cancer genetic services can be addressed. References [5] Martin, A. P., Pedra, G., Downing, J., Collins, B., Godman, B., Alfirevic, A.,... & Greenhalgh, K. L. (2019). Trends in BRCA testing and	We have noted your comments about other aspects of the guideline and surveillance of people with familial cancer. The NICE 5-year strategy is currently prioritising which parts of the guidelines portfolio will be actively maintained. This work will determine how the CG164 guideline is updated in the future.

		socioeconomic deprivation. European Journal of Human Genetics, 27(9), 1351-1360. [6] Hopwood, P., Wonderling, D., Watson, M., Cull, A., Douglas, F., Cole, T.,... & McPherson, K. (2004). A randomised comparison of UK genetic risk counselling services for familial cancer: psychosocial outcomes. British journal of cancer, 91(5), 884-892. [7] Allford, A., Qureshi, N., Barwell, J., Lewis, C., & Kai, J. (2014). What hinders minority ethnic access to cancer genetics services and what may help? European Journal of Human Genetics, 22(7), 866-874. [8] Evans, D. G., Edwards, M., Duffy, S. W., & Tischkowitz, M. (2020). Sporadic implementation of UK familial mammographic surveillance guidelines 15 years after original publication. British journal of cancer, 122(3), 329-332. [9] Solomons, J. National Institute for Health and Care Excellence. Familial breast cancer: Classification and care of women at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer. - An assessment of need. Available: https://www.nice.org.uk/guidance/cg164/evidence/needs-assessment-pdf-190130945	
NHSE National Cancer Programme	Not answered.		
Royal College of Nursing	No Comment	No comment	
National Hereditary Breast Cancer Helpline	Not answered.		

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Prevent Breast Cancer	Not answered.		
UK National Screening Committee	Not answered		