

PRESS RELEASE

New NHS guideline will help identify and care for women at risk of “familial” breast cancer

A new guideline published today by the National Institute for Clinical Excellence (NICE) and the National Collaborating Centre for Primary Care (NCCPC) sets out how health professionals should identify and care for women who are at risk of developing breast cancer because of a history of the condition in their family (familial breast cancer).

Key recommendations in the guideline include:

- Taking a family history in primary care because this allows appropriate classification and care.
- Recognising that access to psychological support and assessment is a key part of the package of care needed for many women covered by the guideline.
- Only carrying out mammograms after giving women information about its potential advantages and disadvantages for the early detection of breast cancer
- Recognising that genetic testing is appropriate only for a small proportion of women who are from high-risk families.
- Recognising that risk-reducing surgery is appropriate only for a small proportion of women and should be managed by a multidisciplinary team.
- Offering women standard written information to provide consistent advice alongside individually tailored information that outlines sources of support (including local and national organisations).
- Giving patients the opportunity to make informed choices and share in decision making.

The guideline highlights some key messages that should be shared with women who have concerns about developing breast cancer because of a history in their family.

These include telling women that:

- Most women do not develop breast cancer, and of those who do, most will not have a known family history of the disease.
- For most women, increasing age is the greatest risk factor.
- The great majority of women with a family history of breast cancer do not fall into a high-risk category and do not develop breast cancer.
- The great majority of women with a relative with breast cancer are not at substantially increased risk of breast cancer themselves.

Professor Peter Littlejohns, Clinical Director at NICE, said: “I would like to thank the National Collaborating Centre for Primary Care and the Guideline Development Group for all their hard work on this important guideline. The worry caused to women by having a history of breast cancer in their family should not be underestimated. These guidelines will go a long way to allaying fears and giving women a realistic idea of the risk they face and evidence based information about the choices for care that are available to them.”

Prof Gareth Evans, chair of the guideline development group and Consultant Clinical Geneticist said: “It is only relatively recently that health professionals have begun to understand the role genes can play in the development of disease. Whilst many women who develop breast cancer do not do so because of a genetic link, it is important that we identify those who are at risk because of their family history in order that they can be offered appropriate monitoring and care.”

Dr Penny Hopwood, Consultant Psychiatrists and Psycho-Oncologist, said: “Women with an increased risk of breast cancer because of a family history need to know what they can do to protect their health and reduce their worries. By offering women appropriate risk assessment, information and support, health professionals can help them to understand the level of risk they face and make informed decisions about the healthcare choices that are available.”

Mr Mark Sibbering, Consultant Breast Surgeon, said: “Making the decision to have a mastectomy when you don’t have cancer is extremely difficult and not something that any woman enters into lightly. There are circumstances when it is advisable for a woman to have seemingly healthy breasts removed, but these are

rare. This guideline identifies when this should be offered as an option and will standardise practice across the NHS in England and Wales.”

Dr Michelle Barclay from the UK’s leading breast cancer charity, Breakthrough Breast Cancer, said: "Breakthrough welcomes the guidance published today as a positive step forward for women concerned about familial breast cancer.

We are encouraged to see that the guidelines recommend that all women from age 40 and with a significant family history of the disease should now be offered annual breast screening and that the importance of reliable support and information has been highlighted. Women concerned about hereditary breast cancer tell us how vital access to clear and accurate information is for both themselves and their families."

Ms Wendy Watson, Patient Representative and Director of Hereditary Breast Cancer Helpline, said: “The publication of this guideline is the culmination of a vision I had 12 years ago when I experienced difficulty getting recognition that breast cancer could be hereditary. I was one of the first women to have preventative surgery, and since then I have been working to ensure that full information and support is made available to patients no matter what they chose. This guideline is a colossal step forward and fulfils my vision.”

Dr Jon Emery, General Practitioner, said: “By taking a consistent approach to assessing a woman’s risk of developing breast cancer, as set out in the guideline, GPs will play a vital part in the implementation of this guideline. The guideline also highlights the importance of local NHS organisations working together effectively and ensuring that those working at primary care have access to advice from specialists where they are uncertain about an individual patient’s risk.”

Ends

For more information call Lucy Betterton on 020 7067 5903 and 07747 865 562

Notes to Editors

About the clinical guideline and the National Collaborating Centre for Primary Care

1. Further information on the familial breast cancer guideline is available from www.nice.org.uk/CG014.
2. Clinical guidelines are recommendations on the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales. They sit alongside, but do not replace, the knowledge and skills of experienced health professionals.
3. NICE clinical guidelines are developed by independent groups that include healthcare professionals working in the NHS, patients and people who are familiar with the issues affecting patients and carers. Professional and patient/carer groups whose members are

likely to be affected by the guideline are able to submit information and comment on the recommendations before they are finalised.

4. The National Collaborating Centre for Primary Care is based at the Royal College of General Practitioners, and involves the following partners:
 - Royal College of General Practitioners
 - Royal Pharmaceutical Society of Great Britain
 - Community Practitioners and Health Visitors Association
 - School of Health and Related Research, Sheffield University
 - Clinical Governance Research and Development Unit, Department of General Practice and Primary Health Care, University of Leicester.
5. The guideline asks local health communities to review their existing management of familial breast cancer against this guideline. The review should consider the resources required to implement the recommendations set out in the guideline, the people and processes involved, and the timeline over which full implementation is envisaged. It is in the interests of patients that the implementation timeline is as rapid as possible. Relevant local clinical guidelines, care pathways and protocols should be reviewed in the light of this guidance and revised accordingly.

About NICE

6. NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patients and their carers to help them make decisions about treatment and healthcare. For further information about NICE you can visit www.nice.org.uk.
7. NICE produces guidance in three areas of health:
 - the use of new and existing medicines and treatments within the NHS in England and Wales – technology appraisals
 - the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales – clinical guidelines.
 - whether interventional procedures used for diagnosis or treatment are safe enough and work well enough for routine use – interventional procedures.

NICE also funds three enquiries that undertake research into the way patients are treated to identify ways of improving the quality of care (the investigations are known as confidential enquiries).
8. NICE guidance and recommendations are prepared by independent groups that include professionals working in the NHS and people who are familiar with the issues affecting patients and carers.