


# GUIDELINES FOR THE ASSESSMENT AND MANAGEMENT OF WOMEN WHO HAVE A FAMILIAL MODERATE RISK OF BREAST CANCER, IN A DEDICATED NURSE LED CLINIC.

University Hospitals of Leicester   
NHS Trust

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## 1. Introduction

This document sets out the University Hospitals of Leicester (UHL) NHS Trusts Policy and Procedures for the nurse led clinic for the assessment and management guidelines for the patients who have a moderate risk of familial breast cancer.

The scope of the guideline is to cover all registered nurses within the department of breast surgery who intend to speak with patients who have been defined as have a moderate risk of breast cancer due the family history of breast and/or ovarian cancer. Nursing staff should have undergone a period of in-house training are deemed competent in speaking and advising this patient group. Any queries relating to the level of risk to the patient that is unclear will be discussed with the (UHL) Clinical Genetics team.

Once it has been identified that a woman has a moderate risk a telephone appointment will be offered to the patient to attend the virtual family history clinic. The group of women who are offered an appointment are those under the age of 50 years. If women do not wish to pursue or attend this appointment, no further action is required. Supporting literature will be sent via post to the patient.

## 2. Scope

At the telephone appointment the nurse will clarify the family history details within the questionnaire with the patient. Should there be any discrepancies the risk category will be re assessed and managed accordingly. For example if reassessed as low risk, will inform the women and discharge them. If assessed as high risk they will be referred to the clinical genetics team within UHL, which currently is based at Leicester Royal Infirmary, for further assessment. If there is any uncertainty regarding the risk the nurse should seek advice from the Clinical Genetics Team.

During the consultation process moderate risk patients will be made aware of the National Institute of Clinical Excellence (NICE) Guidelines -Familial breast cancer (2013) and the proposed management. Moderate risk women are offered annual mammograms from the age of 40-49. Women are then automatically entered into the National Breast Screening Programme that runs on a three yearly basis. A surveillance mammogram request form is completed (yellow form /Breast Screening form 12) with the relevant family history and women's appropriate past medical history.

Tamoxifen can be offered to moderate risk group who are pre menopausal from the age of 40 for 5 years. Side effects and the benefits will be discussed with women allowing them to make an informed decision. It is advised that women should discuss this further with their GP if they wish to consider Tamoxifen as preventative therapy. The GP is to prescribe the Tamoxifen. Tamoxifen leaflet should be provided to the women for their information. However if under the age of 50 and if there family is not complete/previous DVT – tamoxifen is not to be offered.

Post menopausal women with a uterus would be offered Raloxifene for 5 years.

Moderate risk women are not routinely gene tested (NICE Guidelines 2013). These women should be made aware of the rationale for not offering the gene test.

Breast awareness is advised at the consultation. Written information is offered. Should women notice any changes or new symptoms they will be advised to see their General Practitioners, and refer to appropriate clinic

Next Review: September 2024

Women are advised that should another close family member be diagnosed with breast and /or ovarian cancer, in the future, they should be reviewed by their GP and re-referred if appropriate.

No further appointments are necessary, following the consultation and they are therefore discharged back to the GP. Letter goes to the GP to confirm their patients status.

### 3. Legal Liability Guideline

Guidelines or Procedures issued and approved by the Trust are considered to represent best practice. Staff may only exceptionally depart from any relevant Trust guidelines or Procedures and always only providing that such departure is confined to the specific needs of individual circumstances. In healthcare delivery such departure shall only be undertaken where, in the judgement of the responsible healthcare professional' it is fully appropriate and justifiable - such decision to be fully recorded in the patient's notes

### 4. Supporting Documents and Key References

National Institute of Clinical Excellence (2013) Familial breast cancer: classification, care and managing breast and related risks in people with a family history of breast cancer. [CG164}

Nursing and Midwifery Council (NMC, 2023). The Code. Professional standards of practices and behaviour for nurses, midwives and nursing associates. London.

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This table is used to track the development and approval of the document and any changes made on revised / reviewed versions

DEVELOPMENT AND APPROVAL RECORD FOR THIS DOCUMENT			
<b>Author / Lead Officer:</b>	Sue Orgill/Jill Hardman-Smith		<b>Job Title:</b> Breast Care Nurse/Lead Advanced Clinical Practitioner
<b>Reviewed by:</b>	Sue Orgill , Janice Brown, K Valassiadou		
<b>Approved by:</b>			<b>Date Approved:</b>
REVIEW RECORD			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
April 2019	2		Additional information on tamoxifen and who to offer it to. Confirm letter to GP once attended moderate risk appointment. Update of NMC Code version
October 2020	3	Jill Hardman-Smith	Addition of alteration to service due to Covid 19
May 2023	4	Janice Brown/ Sue Orgill	Removal of covid-19 descriptor Addition od appendix 1 competency training programme for Nurses undertaking Family History assessment and clinics
DISTRIBUTION RECORD:			
Date	Name	Dept	Received

<b><u>Training Program</u></b> <b><u>Genetic/Family History Training</u></b>		
Phase 1 – 0-3 months Clinical standards to be met		
<b><u>Essential Knowledge</u></b>	<b><u>Achieved by</u></b>	<b><u>Date of Attainment</u></b>
<b>1. <u>Be aware of and understand Trust guidelines in relation to the Family History pathway</u></b>	Read Trust guidelines and discuss with Lead Nurse for moderate family history Spend a session with genetic counselling team.	
<b>2. <u>Understand Manchester Scoring System</u></b>	Read guidelines and discuss with Lead Nurse for Family history who will assess.  Demonstrate an ability to use the Manchester scoring system to calculate risk using 10 pedigrees.	
<b>3. <u>Knowledge of BRCA1 and BRCA2</u></b>	Demonstrate an understanding of the percentage risk of carrying the gene and the percentage risk of developing breast and/ or ovarian cancer.  All relevant genes, check with genetics, demonstrate understanding of threshold for testing eligibility, uninformative result possibility, discussing risk of breast or ovarian cancer as proportion/percentage and /or grid (autism/ADHD friendly versions can be used)	
<b>4. <u>Knowledge of differentiation of low, moderate and high risk</u></b>	Assess a minimum of 15 completed patient questionnaire referrals with Lead Nurse for Family history  Assessing the documented family history and calculating their risk in accordance with UHL/Nice guidelines.  Express risk as % of chance of developing breast cancer within the next 10 years, or remaining lifetime risk	

**Training Program**  
**Genetic/Family History Training**

Phase 2 – 3-5 months  
Clinical standards to be met

<b><u>Essential Knowledge</u></b>	<b><u>Achieved by</u></b>	<b><u>Date of Attainment</u></b>
<p>1. <b><u>Be able to understand and consent patients already diagnosed with breast cancer for Mainstream Genetic Testing following Trust guidelines</u></b></p>	<p>Seeing patients who are referred to genetics or have been referred from genetics in breast clinics alongside the consultant.</p> <p>Do consent training with genetics counsellor.</p> <p>Do Marsden/Mainstreaming training with genetics.</p>	
<p>2. <b><u>Have knowledge of and be able to run and advise patients in the virtual moderate family history clinics</u></b></p>	<p>Demonstrate the ability to support moderate risk family history patients in the virtual clinic</p> <p>Be able to advise women on the risks and benefits of screening, chemo prevention</p>	
<p>3. <b><u>Have knowledge and be able to advise patients and other health care professionals on the use of contraceptives in women with a history of breast cancer</u></b></p>	<p>Please discuss newest guideline with the team.</p> <p>Use ABS or NICE guidelines</p>	
<p>4. <b><u>Have knowledge and ability to request mammographic imaging for patients who are assessed as Moderate/ high, and very high risk for developing breast Cancer</u></b></p>	<p>Complete Non- medical referrers training as per UHL policy.</p> <p>Discuss with radiology head of family history screening completion of imaging requests and who will authorise medically.</p> <p>Ensure admin team are aware of pathway for requesting imaging</p>	