FOI request- family history units

Please note – These questions relate specifically to people referred into a family history service from primary care based on their family history of cancer, not those who had been previously assessed and assigned a pathway by clinical genetics or were referred due to a personal diagnosis of breast cancer.

1. Does your trust have a familial cancer service or services (for example, as part of a breast care team, family history clinic, or breast clinic) that manage people who could be at an increased risk of breast cancer because of a history of the disease or related cancers in their family? (Yes/No)

   a) If no, please answer question 2
   b) If yes, please answer questions 3-5.

2. If your trust does not have a familial cancer service, where do you refer patients who need to have their familial breast cancer risk assessed?

3. If your trust does have a familial cancer service, could you please provide us with:

   a) The number of referrals your unit has received for assessment of possible familial breast cancer risk for each of the following periods:

Time period	Number of referrals
1st April 2021-31st March 2022	0
1st April 2022-31st March 2023	2
1st April 2023-31st March 2024	14

   b) How many patients were identified as moderate risk* of breast cancer for each of the following periods:

Time period	Number of moderate risk patients
1st April 2021-31st March 2022	0
1st April 2022-31st March 2023	1
1st April 2023-31st March 2024	7

   c) How many patients were identified as high risk** of breast cancer for each of the following periods:

Time period	Number of high-risk patients
1st April 2021-31st March 2022	0
1st April 2022-31st March 2023	0
1st April 2023-31st March 2024	3

* As defined by NICE in CG164 - Lifetime risk from age 20 of greater than 17% but less than 30%, or risk between ages 40 and 50 of between 3 to 8%

** As defined by NICE in CG164 - Lifetime risk from age 20 of greater than 30%, or risk between ages 40 and 50 of greater than 8%, or a 10% or greater chance of a gene mutation being harboured in the family

4. Which services do you offer to patients who are assessed as being at increased risk?

Please indicate with a **X** which risk management options are offered to individuals according to their age and calculated risk level by your service. Please leave related box **blank** if your service does not offer a particular service.

In regard to the provision of screening surveillance, please include any screening offered through the very high-risk programme and by your service for certain screening technologies that are only used under specific conditions (e.g. in the case of dense breast pattern)

	Moderate risk	**High risk**
Information about modifiable risk factors and behavioural changes to reduce risk	x	x
Chemoprevention	x	x
Risk reducing surgery		x

Screening surveillance	**Moderate risk**	**High risk**				
		<30% chance of BRCA/TP53 carrier	**>30% (>50%)chance of BRCA carrier**	**Known BRCA mutation**	**>30% chance of TP53 carrier**	**Known TP53 mutation**
Annual MRI						
20-29				25-30		x
30-39			x	x		x
40-49			x	x		x
50-59				X(assess breast density on mammo)		x
60-69				x(assess breast density on mammo		x
70+						X up to 71

Annual Mammography						
20-29						
30-39						
40-49	x		x	x		
50-59				x		
60-69				x		
70+						
Mammography as part of the population screening programme						
20-29						
30-39						
40-49						
50-59	x		x			
60-69	x		x			
70+						

Only a subset of those defined as high risk by NICE reach the VHR threshold used in NHSBSP.

After age 50ys testing is required to continue on VHR screening programme.

5. For people referred into your family history service, does your unit have any additional inclusion criteria it uses to determine who can receive different types of support, in addition to the eligibility criteria outlined in NICE CG164 guidance, and if so, what are those criteria for:

Undertaking an initial family history risk assessment	N/A
Access to risk-reduction interventions, both chemoprevention and mastectomy	N/A
Access to enhanced surveillance screening	N/A