ovarian cancer action

Acting on BRCA: the opportunity for a cancer prevention strategy

Setting the scene

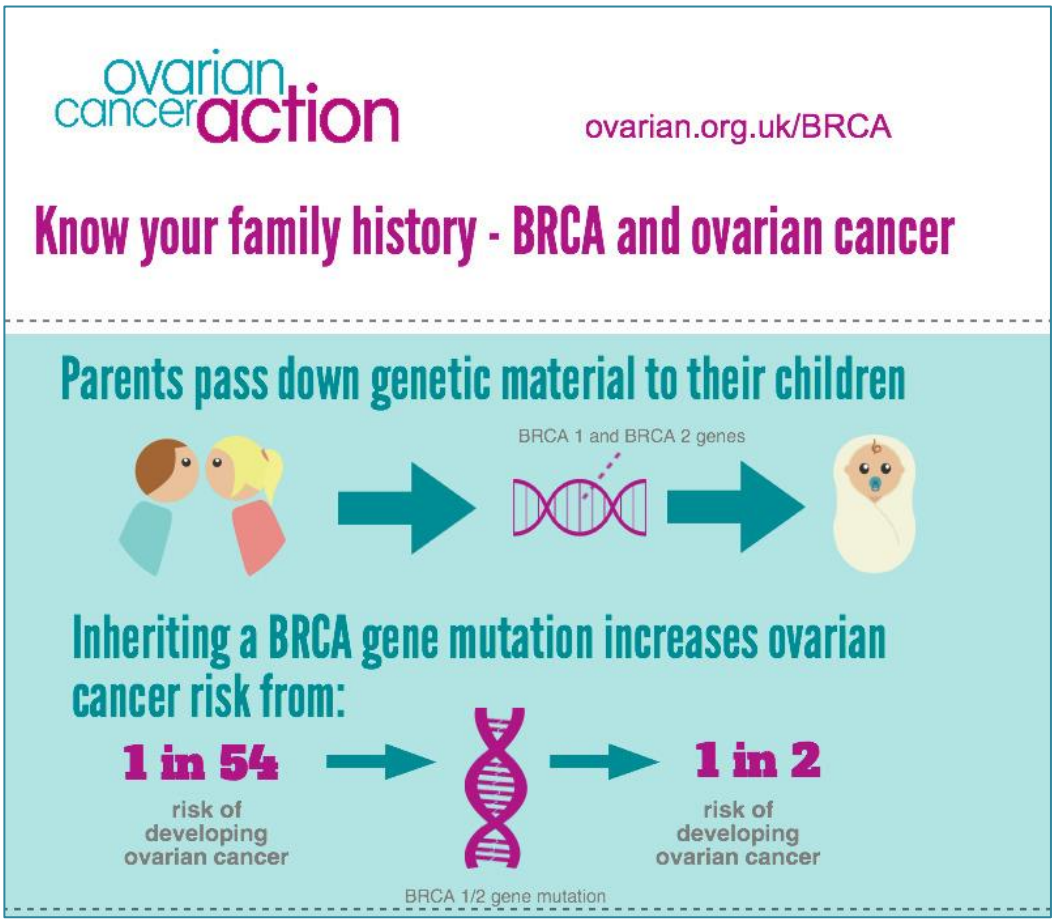
There are many genetic and hereditary elements to cancer. This means that building a picture of family history is vital in helping identify increased risk.

BRCA1/2 gene mutations are the most important genetic mutations to be discovered in cancer. Those who have a mutation in one of these genes have an increased risk of breast, ovarian, prostate and pancreatic cancer. The mutations are passed through both mother and father, and children have a 50% chance of inheriting it.

Women with a BRCA1/2 gene mutation have an 80% chance of developing breast cancer and a 35%-60% chance of developing ovarian cancer, in their lifetime.

Around 17% of women with ovarian cancer carry a BRCA1/2 gene mutation. Family history is very important in identifying BRCA1/2 gene mutations but, in modern times, tracing family members is not always easy or possible.

Further complicating the matter is the fact that as many as half of women diagnosed with ovarian cancer, that have a BRCA1/2 gene mutation, may have no known family history of breast or ovarian cancer.



The story so far: increasing access to BRCA testing in the NHS

Since 2013, Ovarian Cancer Action has been campaigning for all women with non-mucinous epithelial ovarian cancer to be offered testing for the BRCA1/2 gene mutation at the point of diagnosis. This is to ensure the best possible outcome for patients and their families.

In recent years parts of the NHS in England have pioneered new models of access to BRCA testing for women diagnosed with ovarian cancer. However, variation in access to BRCA testing has remained a problem.

In July 2015 our campaign had success with the introduction of new NHS England Commissioning Policy enabling women with ovarian cancer to be offered testing. Ovarian Cancer Action welcomes this policy and has strong hopes that it should contribute to a uniform approach to offering testing at a 10% carrier probability threshold across the NHS in England.

Sadly this won't address variation across the UK, particularly in Wales. This is an issue we remain concerned about; and one we highlighted in our report in 2014 on the UK picture (OCA 2014).

We do, however, anticipate that more BRCA testing will take place in England as this Commissioning Policy is rolled out. This will help inform women diagnosed with ovarian cancer about their BRCA status as well as helping to ensure access to the most relevant treatment for women diagnosed with ovarian cancer. It will also open up the potential for more family members to learn more about their own risk and what measures they can take if they too have a BRCA1/2 gene mutation.

The real impact of BRCA testing: the patient view

Ann Chillingworth says that knowing her BRCA status after being diagnosed with ovarian cancer meant: "the information, the knowledge about BRCA is out there in the family. My siblings, cousins, are all taking measures to protect themselves. It puts them in a strong position of control."
And for her daughter, who does not have the mutation, it has meant: "she's able to move on from the anxiety of not knowing".

Niki Orchard has a BRCA gene mutation and has had preventative surgery, after losing her mother to ovarian cancer. She says: "knowledge is power, and each individual person can choose what to do with that knowledge."

After being diagnosed with ovarian cancer, Angela Walker told us: "knowing I had the BRCA2 gene mutation helped me greatly because my children were little. I didn't want anyone to fall through a loophole. It means we know what to look for in my daughter, and she can be monitored in the future."

Caroline Presho is has a BRCA2 gene mutation and has opted for risk reducing surgery. She says: "I realised I could not live with the worry and anxiety. After surgery I felt so happy, so relieved. I felt vulnerable not knowing my BRCA status given my family history of cancer. Now I have taken away another risk for breast and ovarian cancer"

What's next? Opportunities for cancer prevention

The cancers associated with a BRCA1/2 gene mutation have high mortality and are hard to detect in the general public. However, testing for BRCA1/2 gene mutation provides a significant opportunity for preventing future cases of cancer.

Theoretically we could reduce the number with ovarian cancer by around 17%. That means potentially saving the lives of around 1,000 women a year in the UK.

Unlike many other hereditary diseases, women with a BRCA1/2 gene mutation can take action to reduce their risk of developing cancer. Through preventative surgery they can reduce their risk of developing breast and/or ovarian cancer by up to 95%.

Prevention has been identified as a key opportunity for the NHS over the next five years as part of the Five Year Forward View (NHS 2014) and this focus has been reiterated in *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*.

The Strategy identifies BRCA as one of the areas where knowledge is now advanced enough to offer the potential to implement active surveillance for those at high risk.

NHS England has also identified improved prevention, based on underlying predisposition, in its emerging strategy for personalised medicine (NHSE 2015b).

Families with the mutation need to be supported by the NHS and other bodies to be empowered to understand the condition and all the options available to them to reduce their risk of cancer. If this is done properly, we believe it can become a highly effective part of delivering on ambitions for cancer prevention.

There remain challenges to be overcome as the NHS builds on its ambitions for cancer prevention. In the context of BRCA1/2 gene mutations, it needs to be decided whether it is the individuals' responsibility to contact the NHS or whether the NHS will seek them out – either through genetics services or local GPs.

Awareness of the BRCA1/2 gene mutation is growing amongst the general public, in part owing to the 'Angelina effect' of her highly discussed preventative surgery. At the same time, costs for genetic sequencing are continuing to fall; making provision quicker and less expensive.

The time is now to address the growing need and the unanswered questions around provision and support for families impacted by BRCA1/2 gene mutations.

What does Ovarian Cancer Action want?

BRCA1/2 gene mutations were discovered 21 years ago.

The NHS is now making headway in offering BRCA1/2 gene testing to women newly diagnosed with ovarian cancer, and their family members.

However, over the next few years there will be an increasing number of second, third and fourth generation families carrying a mutation, many of whom may not know their family has been affected.

- We want all families with a BRCA1/2 gene mutation to have a clear and easy to use care pathway. This should include not only testing, but relevant advice and guidance. We want the NHS to find a mechanism to reach out to individuals who may be unaware of their BRCA status, in order to maximise cancer prevention opportunities.

- We want BRCA affected families to have, world-class information, advice and guidance on cancer risk reduction and prevention so that they can be empowered to make the best decision for themselves. We want this information pathway to be available across the UK, not just in selected nations. The advice should include:

    - The right to know/not know BRCA status
    - The impact of other family members' decision to know, or not
    - The age to tell/test children
    - Risk of cancer relating to individuals' BRCA status and age
    - Different options for preventative surgery and the impact on risk
    - Effectiveness of ongoing cancer monitoring
    - Risk/benefits of contraceptive pill
    - Options for IVF and embryo screening

- We want the NHS to demonstrate its commitment to delivering on its ambitions for cancer prevention. This means active monitoring of the take up of BRCA1/2 testing across the country, via an audit of Genetics Centres, and quickly identifying and remedying any barriers to BRCA1/2 testing. Data on uptake will also help the NHS to identify demand and plan for the future.

What will we do?

- We will develop and provide patient guide materials to help family members' access existing genetic services and cancer prevention options.
- We will lobby the government, and the devolved assemblies and parliaments, to deliver a life-saving cancer prevention strategy across the UK as a whole.
- We will monitor international advice and protocols through our extensive global connections from supporting international forums.
- We will monitor the roll out of the current NHS England commissioning policy to ensure consistent and high quality services are available to all BRCA families in England.
- We will help women understand their BRCA risk through our online risk tool.

Acting on BRCA

The BRCA1 gene mutation was discovered in 1994 and in the intervening 21 years our understanding of BRCA1/2 gene mutations has 'come of age'. Women and families affected by this potentially fatal genetic alteration now have the opportunity, as never before, to take action to protect themselves from cancer.

However, this cannot happen without the active support of the NHS in providing advice and services around cancer prevention. The first steps have been taken with NHS commissioning recognising the importance of testing women with ovarian cancer.

There now needs to be concerted effort by the NHS to embrace BRCA as a cancer prevention strategy before information is lost between generations and more women continue to die from preventable diseases.

Ovarian Cancer Action will continue to campaign on this matter and to inform those affected by BRCA1/2 gene mutations with accurate information on their options and rights.

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