Target Ovarian Cancer is the national ovarian cancer charity working to save lives and help women diagnosed live their lives to the full, wherever they are in the UK. We do this by improving early diagnosis, finding new treatments and providing support for women.

This position statement sets out Target Ovarian Cancer’s position on women with ovarian cancer’s access to genetic testing.

Approximately one in eight women with ovarian cancer have a BRCA 1 or BRCA 2 gene mutation.\(^1\) Recently refreshed NICE and SIGN guidelines mean that all women with ovarian cancer living in the UK are now eligible for genetic testing to find out whether they have a gene mutation.\(^2\),\(^3\),\(^4\),\(^5\) Target Ovarian Cancer believes that the NICE and SIGN guidelines need to be fully implemented with genetic testing made available to all women across the UK with ovarian cancer.

Genetic testing has strong emotional implications for women and their families, so all women should have access to counselling, overseen by genetic services, in order to make a truly informed decision on whether to be tested. Target Ovarian Cancer believes that:

- Consent should not be sought at the immediate point of diagnosis as patients are often emotionally vulnerable and overwhelmed by a cancer diagnosis.
- Genetic testing has implications for a woman’s family, and all women diagnosed with high-grade serous ovarian cancer should have access to genetic counselling prior to testing.
- There must be a cooling off period between being offered the test and consenting to allow women time to reflect on the possible implications of the results for themselves and their family.

Trials are currently taking place for new treatments, called PARP inhibitors, designed for women with a BRCA 1 or BRCA 2 mutation. This would mean that genetic testing would

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\(^2\) Genetic testing is available to all women with non-mucinous epithelial ovarian cancer. This includes high grade serous, low grade serous, endometrioid, clear cell and undifferentiated/unclassified ovarian cancers which between them account for nearly 90% of ovarian cancer diagnosed.


\(^4\) The Northern Ireland Department of Health, Social Services and Public Safety endorsed NICE clinical guideline 164 in August 2013.

have implications not just for a woman’s wider family, but could also determine her treatment. Target Ovarian Cancer believes that:

- The approval and ongoing trials for PARP inhibitors are for use at first recurrence, not currently as a first line therapy. This means that women can be given time to decide whether to be tested and to receive appropriate counselling and support.

- Currently there is no peer reviewed evidence on the acceptability, cost effectiveness and feasibility of a more streamlined approach to testing.

- With no PARP inhibitor currently available on the NHS and with the Genetic Testing in Epithelial Ovarian Cancer (GTEOC) trial ongoing there is time to review the evidence before deciding on the best approach for the women concerned.

*Please note, this position statement has been prepared for policy makers, journalists and clinicians. It does not form part of our health information for women, which can be found here: [www.targetovariancancer.org.uk/ovariancancerinfamilies](http://www.targetovariancancer.org.uk/ovariancancerinfamilies)*