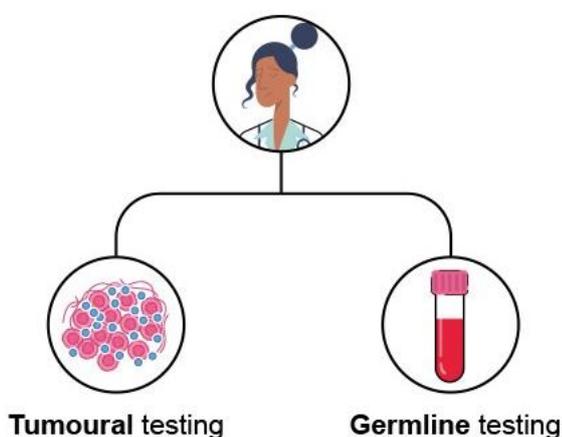


## The Questions- Reflex cancer/ tumour testing for ovarian cancer?

Please read the following background information, and write down any questions you might have about this background information (e.g. any words that you are unsure about).

There are two main types of genetic testing being offered to patients after their cancer diagnosis:

1. Testing your cancer cells. This is normally done on the sample we took during your diagnosis. This is called '**somatic testing**' or '**tumoural testing**'.
2. Testing your blood or saliva to find out whether you were born with a higher chance of getting cancer than most other people. This is called '**germline testing**'. This test may give information that could affect your family.



**In endometrial (womb) cancer, doctors do not need to ask for your permission first before they perform tumoural testing. Tumours are automatically tested for gene changes.**

**Tumoural testing** is done because it may allow new treatments to be given (e.g. immunotherapies)

Around **3 in 10** patients with womb cancer have tumoural test results that are suggestive of a germline gene change. It means that these patients may have gene changes in their normal cells that are linked with higher chances of getting cancers in their families.

These 3 patients will then be offered the choice whether to be tested for gene changes in their normal cells, also known as **germline testing**, to find out whether their families have higher chances of getting cancers. This is only performed if these 3 patients agree to germline testing.

Just over **1 in 10** (12 in 100) in this group (the 3 patients offered germline testing, which is a blood or saliva test) will be confirmed to have higher chances of getting cancers in their family.

**In ovarian cancer, doctors need to ask for your permission before they perform tumoural testing.**

After having a biopsy confirming the ovarian cancer diagnosis, a trained doctor or nurse will ask patients for permission first (e.g. at a clinic or over the telephone) before they feedback to the laboratory for testing.

**Tumoural testing** is done because it may allow new treatments to be given (e.g. PARP inhibitors) or inform doctors how likely a treatment is going to work for their patients.

Around **2 in 10** patients with ovarian cancer will have tumoural test results that are suggestive of a germline gene change. It means that these patients may have gene changes in their normal cells that are linked with higher chances of getting cancers in their families.

These 2 patients will then be offered the choice whether to be tested for gene changes in their normal cells, also known as **germline testing**, to find out whether their families have higher chances of getting cancers. This is only performed if these 2 patients agree to germline testing.

In almost **7 in 10** in this group (the 2 patients offered germline testing, which is a blood or saliva test) will be confirmed to have higher chances of getting cancers in their family.

Why are we discussing the following questions?

Because of the need for asking patients with ovarian cancer for permission first before testing the tumours (the cancer cells), there are often delays or sometimes missed tumour testing in this group.

Without the tumour testing results, it could mean doctors are less certain about which treatments may be best for their patients (e.g. less information about whether it would work) or, sometimes, limit their access to certain new treatments.

Doctors are now asking whether it would be acceptable to you and other patients with ovarian cancer to test the cancer cells for gene changes without asking for your permission first, like what they do for patients with endometrial (womb) cancer.

**After reading the above background information**, please consider your answers to the following questions for discussion during the PPI group:

- Can you please tell us if it would have been acceptable to you to test your cancer cells for potential gene changes without asking you separately first?
- It would also be helpful for us to know how you have decided that?
- If you think *reflex* testing (i.e. without asking you first) is **NOT** acceptable at the moment, is there anything that doctors and nurses could do to make it more acceptable to you?

## Results summary (Cambridge and Birmingham)

### Cambridge (Virtual; 22 of 30 volunteers responded)

All (22/22) patients found reflex tumour testing acceptable.

Detailed comments when provided:

***The desire to have the best available treatments to prolong life, and tumour testing should be considered as an essential part of treatment planning***

- If tumour is being removed and disposed of, any information the doctors can gain from it is a positive. My personal feelings are permission should not be required to test tumours. This only holds up the process of getting the correct treatment to patient, and giving the patient too many things to think about after being diagnosed is just a waste of precious time.
- I have no objection to the cancer cell test being done without permission as ultimately as a patient you want the best available treatment.
- I read the questions. I feel it is totally acceptable and possibly essential for automatic testing without permission/ This would then allow the best and right treatment possible for each person.
- If one considers that a blood test to establish cancer antigens is undertaken without the patient being aware of this, then to me that is a similar situation - identifying the parameters of the disease as early as possible by conducting the most in-depth analysis possible. Moreover, if a biopsy has been undertaken in any case, it would seem sensible to undertake as extensive a range of tests on the cancer cells as possible. Further, if deficient genes are identified, I understand that future treatment options such as PARP inhibitors/other new treatments which might be given prior to the conventional route of neoadjuvant treatments or surgery/chemotherapy. This could, as I understand, be of specific benefit to patients with genetic mutations. It might ultimately extend their progression free survival.
- For patients who might be resistant to automatic testing, there might be a need to explain the logic - and statistics. It would help if the treatment options and potential benefits were explained.
- I would have had no objection to my cancer cells being tested for anything without questioning, permission requests or delays that links my family and helps me inform my sisters and daughter for the future and informs the doctors of the best treatment for going forward. I gave permission for testing of my tissue early in 2020 for BRCA 1 and 2 but nothing since which is disappointing. I would like to see up to date testing freely offered, or carried out as a matter of course as progress is made, for people with continuous recurrences like myself.

***The preference for tailored information provision over time***

- I 'feel' that I had very basic information regarding ANY testing that was done initially. I'm sure that although I know it would have been explained. I was so

shell-shocked, that I could not possibly properly comprehend / retain this information. And, as a result, feel the need NOW to ask lots of questions with any new development stage of my treatment. I didn't feel in control about initial treatment, because the inference is that I wasn't 'listening' or 'paying attention' to what I was being told. I believe that because initially there is a feeling of being over-whelmed, and lack of knowledge to influence your decisions - that such testing SHOULD be done as standard, then at least should this issue become relevant in the future... the information has already been gathered.

- I feel personally that testing as standard would negate having TOO much information thrust at a person, when not ready to receive or understand it. But obviously that won't be everyone's view... but giving patients time first, - when reluctant to testing, letting them absorb their diagnosis, and consider what testing will ultimately mean for the individual. Fully armed with relative information when receptive to that, gives a much more informed decision.

### **Birmingham (Hybrid focus group meeting- 1 virtual and 4 face-to-face patient volunteers)**

#### **Four of 5 patients found reflex tumour testing acceptable.**

Key points summarised with the group:

- Being diagnosed with cancer was a stressful time- the high volume of information being presented at diagnosis was overwhelming
- In the ideal situation, identifying patient preferences of the amount of information they would like to receive during their journeys would be helpful.
- Similarly, if explicit consent is required, obtaining it at the time of diagnostic biopsy being organised or taken as part of the routine consent process by the clinician offering/requesting the test or obtaining the biopsy would be helpful.

Patient 1: overall the idea of reflex testing was acceptable, but initially had reservations about the high chance of potentially relevant germline mutation in the small group that tested positive. However, in the context of parallel testing being recommended and after group discussion, she decided that reflex somatic testing would be acceptable.

Patient 2: although being told the diagnosis was overwhelming and she would have accepted any tests that were offered to her, having control over tests and treatments given to her was important. To her, reflex somatic testing would not be acceptable.

Patient 3: believed that somatic testing should be presented as part of the work-up for treatment planning and therefore explicit consent would not be required. In addition, she suggested that would reduce the burden of needing to decide and the associated guilt. She also suggested that if one had wanted more information, there should be an option to be given more information in different formats if required. Ideally, there should be ways to tailor the amount of information a patient wanted to have early in their patients' journey. More importantly, there should be mechanisms to accommodate those who want to entrust health professionals in decision making without being presented with an unacceptable amount of information for gold-standard informed consent.

Patient 4: believed that somatic testing should be performed without explicit consent to reduce the burden of needing to choose between better information for her, versus the potential burden of knowing about a gene change that runs in her family.

Patient 5: although she would agree to reflex somatic testing herself, she was concerned that some patients would like the choice or control whether the test should be performed. In her opinion, some methods to identify patients' preferences about health decision making (e.g. the amount of information one would like to receive) before reflex somatic testing would be helpful.