Gynaecological cancer surveillance for women with Lynch syndrome: systematic review and cost-effectiveness evaluation

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Plain language summary

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Plain language summary

Lynch syndrome is an inherited condition which puts people at a higher risk of getting bowel cancer, womb cancer and ovarian cancer. Although people with Lynch syndrome are more likely to get these cancers, they are more likely to survive cancer if they get it.

People diagnosed with Lynch syndrome get regular testing (surveillance) using a camera to check for bowel cancer or polyps. For womb and ovarian cancer, surveillance may also be an option, but it is less well studied in these cancers. This means that many women are not offered surveillance. Women with Lynch syndrome are recommended to have risk-reducing surgery when their risk starts rising, if they do not want any more children.

We wanted to find out whether surveillance for womb and ovarian cancer would work and would be good value for money. Doctors and patients have said that these are important research questions.

We searched for published research on this subject and found a lot of studies, but these studies were often small or not well designed, so they could only tell us a limited amount. Studies did not always measure the things that patients want to know.

There was some evidence that people having surveillance might live longer than people not having surveillance, but there was also some evidence that risk-reducing surgery is better than surveillance. Surveillance has detected some cancers which had no symptoms, but there are also cancers diagnosed soon after a surveillance visit where nothing was found. People often find surveillance painful, but experiences vary.

Our work shows that surveillance and surgery could be good value for money for many women with Lynch syndrome.

We need better research to help patients and doctors decide whether surveillance is right for them.

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