

All-Party Parliamentary Group on Ovarian Cancer



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Diagnosing ovarian cancer sooner:

what more can be done?

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Secretariat provided by



The All-Party Parliamentary Group on Ovarian Cancer

The All-Party Parliamentary Group (APPG) on Ovarian Cancer was established in 2010 to facilitate greater understanding and awareness of ovarian cancer among parliamentarians. The APPG has focused much of its work on what can be done to improve early diagnosis of ovarian cancer.

APPG on Ovarian Cancer officers:

- **Chair:** Sharon Hodgson MP (Labour Party)
- **Vice Chair:** Lord Clement-Jones (Liberal Democrat Party)
- **Vice Chair:** Gordon Marsden MP (Labour Party)
- **Vice Chair:** Lee Rowley MP (Conservative Party)
- **Vice Chair:** Paula Sherriff MP (Labour Party)
- **Vice Chair:** Alison Thewliss MP (Scottish National Party)

The secretariat for the APPG on Ovarian Cancer is provided by Target Ovarian Cancer.

Methodology

The Inquiry was informed by desk research carried out by the APPG secretariat. The APPG then held two oral evidence sessions, full details of which are included in Appendix 1. This was accompanied by a call for written evidence. The information received across these channels, together with the views and experience of APPG members, have informed this report and its conclusions.

Thank you

We would like to thank all those who took the time to contribute to the Inquiry, in particular those who submitted evidence, either in person or through a written submission. We would also like to thank Ovarian Cancer Action for their support.

About ovarian cancer

Over 7,000 women are diagnosed with ovarian cancer across the UK each year.¹

The four key symptoms of ovarian cancer are:

- Persistent bloating
- Feeling full quickly and/or loss of appetite
- Pelvic or abdominal pain
- Urinary symptoms (needing to wee more urgently or more often than usual)

Other symptoms include changes in bowel habit, extreme fatigue and unexplained weight loss. Any woman experiencing these on a new and frequent basis (12 times a month or more) should go to see her GP.

UK survival rates are among the lowest in Europe and fewer than half of all women diagnosed with ovarian cancer survive five years or longer.^{2,3}

Over a quarter of women with ovarian cancer are diagnosed through an emergency presentation (for example, Accident and Emergency) and of these, just 45 per cent survive a year or more compared to over 80 per cent of women diagnosed following a GP referral.^{4,5}

The earlier a woman is diagnosed with ovarian cancer the greater her chances of surviving the disease.

Prevention

Approximately 15 per cent of women with ovarian cancer develop cancer as a result of a mutation in the BRCA1 or BRCA2 gene.⁶ Identifying women with ovarian cancer with a BRCA mutation opens up further treatment options. It also enables family members to be tested and, if found to carry the BRCA mutation, to make decisions about reducing their risk of developing ovarian cancer, including undergoing preventative surgery.

Achieving world-class cancer outcomes: a strategy for England 2015-2020 calls for all women with ovarian cancer to be offered access to genetic testing at the point of diagnosis.⁷ This follows National Institute for Health and Care Excellence (NICE) guidelines in 2013 and an NHS England Clinical Commissioning Policy in 2015 which require all women with a 10 per cent or higher risk of carrying a BRCA mutation (this is all women with non-mucinous ovarian cancer) to be offered genetic testing.^{8,9}

We have NICE guidance at the current point in time, which suggests that anyone with ovarian cancer or breast cancer, who has at least a 10 per cent chance of carrying a mutation, should be able to access testing. But the difficulty is that that is interpreted in many different ways around the country.

It ranges from some parts of the country, which have an age limit on it, so, for example, only women under the age of 60, with certain types of ovarian cancer can get testing. In some places, they'll only offer it to people who have a strong family history and ovarian cancer. And then, for example, in our hospital, everyone with endometrial ovarian cancer gets offered testing as part of their routine management.

So, the difficulty is, where a woman is in the country, currently makes a big difference as to how easily, or whether or not they can actually access testing at all.

Dr Angela George, Consultant in Oncogenetics and Clinical Lead for the Cancer Genetics Unit, The Royal Marsden Hospital

One of the reasons given for the current regional variation in access to genetic testing was how funding is currently provided.

At the moment, it's largely due to the way in which the funding is given, although this is going to change very soon because there is a nationwide genomics procurement going on. But, at the moment, each of the regional genetics centres is given a block of money to cover all testing. And it's then down to the individual centres to decide who meets that threshold.

Dr Angela George, Consultant in Oncogenetics and Clinical Lead for the Cancer Genetics Unit, The Royal Marsden Hospital

As genetic testing is further rolled out to family members of women found to carry a BRCA1 or BRCA2 mutation there is the opportunity to prevent future cases of ovarian and breast cancer and reduce the number of women diagnosed with these diseases. Not only does this save lives, but there are significant cost benefits to the NHS of preventing cancer from occurring in the first place.

With regards to ovarian cancer we did a formal cost-effectiveness analysis and if we offered BRCA testing to every woman in the UK with ovarian cancer, we found that it was highly cost-effective.

Because, once you identify the family members who are also carriers, you have the opportunity to prevent them ever getting cancer in the first place, either through screening or risk-reducing strategies.

Dr Angela George, Consultant in Oncogenetics and Clinical Lead for the Cancer Genetics Unit, The Royal Marsden Hospital

However, one potential barrier to the further roll-out of genetic testing is lack of certainty over protection from those who have undergone genetic testing and found they carry a genetic mutation, and thus have a heightened risk of developing cancer, from future increases in life and critical illness insurance costs.¹⁰

At this moment in time, there is a moratorium that the insurance companies have all signed up to, which is reviewed on a five-yearly basis and is due to next be reviewed in another year or so.

At the current point in time, they differentiate between people who have a diagnostic test, which means people who have had one of the associated cancers and who do have to disclose that they've had genetic testing if they are taking out new life insurance or health insurance.

If a BRCA mutation is identified in a family, and their family members are undergoing testing to see if they also carry the mutation to determine, or clarify, their cancer risk for the future, they have a different set of rules. Under the current guidelines, if you've had a predictive test and you've not had one of the cancers, you do not have to disclose that you've had genetic testing. And with the current moratorium, the insurance companies are not allowed to ask you, if you've not had one of the associated cancers.

They are allowed to ask you if any of your family members who have had cancer have had genetic testing, and what the results are, but they are not then allowed to come back and ask you if you've had genetic testing and what your results are.

Dr Angela George, Consultant in Oncogenetics and Clinical Lead for the Cancer Genetics Unit, The Royal Marsden Hospital

Conclusion

The increased use of genetic testing offers huge potential to prevent future cases of ovarian, and other cancers occurring. However, at the moment this is hampered by slow roll-out of NICE guidelines. There is also uncertainty over the long-term financial implications for relatives of women with a BRCA1 or BRCA2 mutation who have life or private health insurance and choose to undergo genetic testing to see if they too are at risk.

On this basis the APPG on Ovarian Cancer makes the following recommendations:

- NHS England to ensure current guidelines on genetic testing for women with ovarian cancer are fully implemented with the appropriate funding in place.
- NHS England to report on BRCA testing for women with ovarian cancer, specifically the percentage of eligible women being offered and accessing testing.
- The Department of Health to work with the insurance industry to renegotiate the Concordat and Moratorium on Genetics and insurance when it expires and provide greater certainty for cancer patients and their families undergoing genetic testing.

Screening

While screening programmes exist for other women's cancers such as breast and cervical, there is currently no screening programme for ovarian cancer, either for women in the general population or women who know they are at an increased risk of developing ovarian cancer due to a genetic mutation or their family history.

The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) looked at the possibility of an ovarian cancer screening programme. It took two approaches, the first involved annual blood tests looking for changes in levels of the CA125 protein, followed by ultrasound if levels rose (multi-modal arm). The other relied on an annual ultrasound. This was all compared against a control group which received no screening.

UKCTOCS reported in December 2015.¹¹ The multi-modal arm had succeeded in diagnosing women earlier and reducing mortality rates as a consequence, although not to the extent that a full screening programme could be rolled out.

There was a 15 per cent decrease in deaths due to ovarian cancer. But it was not significant. So, we still don't know whether that was just because of chance, or if that was true.

Professor Usha Menon, Principal Investigator, UKCTOCS and co-investigator, UKFOCSS

These women are now being followed up further to help give a clearer indication of the extent to which screening in UKCTOCS reduced the number of deaths due to ovarian cancer.

The National Institute for Health Research Health Technology Assessment programme, Cancer Research UK and The Eve Appeal, has supported further follow-up until December 2018. We will look at the data again next year and have results available by the end of 2019.

Professor Usha Menon, Principal Investigator, UKCTOCS and co-investigator, UKFOCSS

A separate study, the UK Familial Ovarian Cancer Screening Study (UKFOCSS) has also been taking place looking at the potential for a screening programme for women at high risk of ovarian cancer aged 35 or over, who choose not to undergo risk reducing surgery or who wish to delay this in order to complete their family.

What we recommend is that women at a high risk of developing ovarian cancer consider having their fallopian tubes and ovaries removed. Women who took part in the study were those who did not want to follow that recommendation. They did not want to have their tubes and ovaries removed or wished to delay surgery.

Professor Usha Menon, Principal Investigator, UKCTOCS and co-investigator, UKFOCSS

Initial results suggest that four monthly screening, using the same multimodal screening method as in UKCTOCS (blood tests looking for changes in CA125 levels, followed up by ultrasound as necessary) may be a better option for these women than no screening until they decide to undergo surgery.¹²

The study found that screening in this group resulted in a significant stage shift, with more cancers diagnosed at stage one and stage two. After the end of screening there were significantly more women diagnosed with the advanced stage cancer.

Professor Usha Menon, Principal Investigator, UKCTOCS and co-investigator, UKFOCSS

It needs to be noted that unlike UKCTOCS, UKFOCSS is a single arm trial, meaning there is no control group to compare findings against so instead researchers have compared outcomes for the group during the trial with those for the same group after the end of screening. In addition, some women with ovarian cancer caused by a genetic mutation can have better short-term survival.

Once UKCTOCS has concluded, Public Health England are responsible for taking the decision on whether there is sufficient evidence for a screening programme to be rolled out using well-established criteria.

In the 1960s, it became apparent that quite a lot of people were being screened for quite a lot of things. So, a pair of people, called Wilson and Jungner set out a list of questions, and said if a screening programme meets these, the chances are that it will do more good than harm, at reasonable cost. And while they might be old, they've have stood the test of time.

UKCTOCS is a large well designed controlled trial, which you very rarely get in screening. If that trial demonstrates that there's a significant reduction in mortality and that screening is cost-effective, and it's acceptable, then the chances are we would make a recommendation that it be implemented.

Professor Anne Mackie, Director of Screening, Public Health England

If UKCTOCS proves to be effective in reducing mortality it is estimated, it would take roughly five years to roll out a screening programme. However, a major challenge is posed by the need for a suitably trained sonographer workforce. As UKCTOCS relies on women with any change in their CA125 levels being referred for ultrasound, it cannot work without an adequate number of trained staff to carry out the necessary ultrasounds.

The workforce issues in the NHS are such, that laying our hands on highly skilled diagnosticians is quite difficult. And that's an issue across quite a lot of screening programmes.

So, if it looks like UKCTOCS is likely to be a good thing, we need to be imaginative and explore every way we can to increase ultrasonography capacity. Including assessing whether artificial intelligence might be able to contribute.

Professor Anne Mackie, Director of Screening, Public Health England]

Without the sonographer workforce UKCTOCS cannot be effective as it relies on a referral pathway to ultrasound for women found to have raised levels of the CA125 protein in their blood. If rolled out it is estimated 12.5 million women would be included in the screening programme (if this applied to all women over 50) and it would be expected that two per cent of these women would require referrals for ultrasound due to changes in CA125 levels.

Conclusion

It is to be commended that two such high-calibre studies into screening for ovarian cancer have taken place although it is disappointing that UKCTOCS has not yet been able to conclude conclusively in favour of a screening programme for women in the general population. In those at a heightened risk of developing ovarian cancer, UKFOCSS findings need to be evaluated together with similar studies from the US, with a view to deciding on next steps in offering screening for this group.

The Inquiry welcomes the positive commitment made by Public Health England should final results for the two studies demonstrate a positive impact on mortality, while also noting the potential challenges.

On this basis the APPG on Ovarian Cancer makes the following recommendation:

- For NHS England and Health Education England to factor a potential increase in demand for sonographers in their workforce planning.

Awareness

Awareness of the symptoms of ovarian cancer remains low, with just 20 per cent of women able to name the symptoms of bloating or tummy pain and just a few per cent able to name symptoms such as needing to wee more often or urgently or loss of appetite.¹³

The four classic symptoms: abdominal pain, bloating, feeling full quickly and wanting to wee more, must become common knowledge. They are still not widely known.

Woman with ovarian cancer, written submission

As part of efforts to increase awareness of the symptoms of ovarian cancer, Public Health England has run a regional pilot for ovarian cancer as part of the wider Be Clear on Cancer campaign. Be Clear on Cancer was first introduced in 2011 and aims to improve awareness of the symptoms of cancer to ensure more people are diagnosed sooner. National awareness campaigns to date have included campaigns for bowel, lung, breast (in women over 70), bladder, kidney and oesophago-gastric cancer.¹⁴

The ovarian cancer pilot ran first as a local pilot in 2013 and then a regional pilot followed the year after. These used a range of channels including television, radio, press, online, face to face events in shopping centres and leaflets in GP surgeries.

Findings for the larger, regional campaign showed significant improvements in women's awareness of the symptoms of ovarian cancer and propensity to visit their GP to discuss concerns, although did not lead to a subsequent increase in diagnoses or improvement in stage at diagnosis within the three month window included in the evaluation.¹⁵

We measure how many people go to the GP with a certain symptom, we measure whether they have CA125 tests and whether there's been an increase in those. Then we measure whether the GP refers people urgently to hospital. We measure the tests they have and we measure whether they are then diagnosed, whether there are more diagnoses and whether they're at an earlier stage, and then we measure survival.

On seeing the campaign women went to the GP. There was an increase in the referrals that the GPs then made to secondary care. The right kind of people were going to see the GP and were referred on but we didn't then see an increase in cancers being picked up in secondary care or any stage shift in terms of more people presenting earlier.

Lucy Elliss-Brookes, Head of Cancer Analysis, National Cancer Registration and Analysis Service

In terms of the results, we had very, very high awareness and we had very high levels of reported propensity to act. But all of our campaigns are evaluated through to the next stages and the top line of that was that in terms of the diagnostics evaluation, we didn't see any sort of follow-through there.

Alexia Clifford, Deputy Director, Marketing Activation, Public Health England (Be Clear on Cancer)

In February and March 2017 a further regional pilot was launched focusing on abdominal symptoms, including bloating. The intention of this campaign was to raise awareness of symptoms that could be linked to a number of cancers. Initial findings show the campaign led to an increase in the number of urgent GP referrals for suspected cancer but further data is needed before a full evaluation can take place.¹⁶

We're trying to get the highest impact for what is a discrete level of spend which is about five million pounds a year. We're looking at the symptoms that we can cluster and that could be indicative of a number of cancers and that was the approach that we used in a local pilot in March last year. This brought together some of the symptoms that could be a sign of ovarian cancer among other cancers. So, that was diarrhoea, bloating, discomfort or anything else that just doesn't feel right.

Alexia Clifford, Deputy Director, Marketing Activation, Public Health England (Be Clear on Cancer)

At the oral evidence sessions, it was discussed whether stage shift in the diagnosis of cancer should be the primary goal of awareness campaigns, or whether improved symptoms awareness could be judged sufficient.

For symptom awareness, we may not get a stage shift but what we will get is patients coming less through A&E and having an emergency presentation; in too many cases we cannot operate because they are so far advanced.

Professor Usha Menon, Principal Investigator, UKTOCS and co-investigator, UKFOCSS

It was also discussed how important knowledge of the symptoms was in ensuring women knew to take them seriously and present to their GP.

One of the issues with ovarian cancer is that women actually can often be quite well. I'd just been on a water sports holiday, I'd been hiking in the summer, but I did have symptoms.

If a Be Clear On Cancer campaign had put the symptoms on the television, I probably would have seen my GP because they're such a mixture of things, they don't necessarily raise an alarm bell as much as they should do.

Hilary Morrison, patient advocate and former GP

Ongoing public information and awareness through leaflets, TV ads, interviews and talks by those who have experienced this, any publicity, so that every woman knows the signs and symptoms as well as she knows those for breast cancer.

Woman with ovarian cancer, written submission – in response to question asking what could be done to speed up the time taken to diagnose ovarian cancer

Conclusion

It is clear that relatively few women know the symptoms of ovarian cancer and, based on the experience of those that gave evidence, this can risk women delaying going to their GP. The Inquiry heard with interest the work of Public Health England and its efforts to improve awareness of cancer symptoms through awareness campaigns, coupled with the need to ensure all its work has maximum impact.

On this basis the APPG on Ovarian Cancer makes the following recommendation:

- For Public Health England to run a national Be Clear on Cancer campaign which, whether focusing entirely on ovarian cancer or a cluster of cancers, includes the key symptoms of ovarian cancer.

The diagnostic pathway

Once a woman approaches her GP with symptoms that could be ovarian cancer, it is important she is referred promptly for tests.

The current GP referral process, as set out in National Institute for Health and Care Excellence (NICE) guidelines, for women in England displaying symptoms that might be ovarian cancer is:

- 1) Referral for a CA125 blood test.
- 2) If CA125 is found to be 35 IU/ml or greater, referral for an ultrasound of the abdomen or pelvis.
- 3) If ultrasound suggests ovarian cancer, an urgent referral (two-week wait) for further investigation.

The exception is if upon examination a woman's GP discovers a physical mass or ascites, in which case women receive an urgent (two-week wait) referral.¹⁷

Delays in diagnosis

Many women report experiencing delays in diagnosis, with 45 per cent of women reporting it taking three months or longer to receive a diagnosis from first approaching their GP with symptoms.¹⁸

I received my diagnosis after three visits to my GP and getting referred for an ultrasound. Fortunately I had an early diagnosis.

Woman with ovarian cancer, written submission

Under the current system GPs are expected to identify the cancer they suspect and then refer patients down this pathway.

The trouble is you have specific symptoms for a particular cancer and you put someone on that pathway. I've had patients go along the gastro route and then come back and you have to start all over again and it's terrible. Because you know deep down that they've got cancer somewhere.

Dr Alison Wint, Macmillan Cancer Lead, South Gloucestershire CCG

This challenge is something *Achieving world-class cancer outcomes: a strategy for England 2015-2020* aims to address and recommendation 21 calls for a pilot of multi-disciplinary diagnostic centres for vague or unclear symptoms. These should have the capability to carry out several tests on the same day.

Multi-disciplinary centres broadly come out of some of the experience from Denmark and look at three groups of patients. Patients who have very clear symptoms of a particular cancer, who meet the NICE guidance criteria for referral, a second group of patients who have quite specific symptoms who require a specific test to be available for the GP. And then the third group of patients who have less specific symptoms, maybe a combination of things, not typical. It is providing a referral route for GPs for those sorts of patients, who the GP has a high suspicion that there might be a cancer diagnosis.

Professor Chris Harrison, National Clinical Director for Cancer

If the current pilots prove effective, this new ‘third’ pathway for vague or less specific symptoms will be rolled out further.

In part it depends on what the data shows and the question will be what the scale would need to be to have the maximum impact, but in principle there’s no reason why we wouldn’t roll out the new pathway from next year. That’s already signalled in the various NHS planning guidance five-year forward view, etc, and the question now is homing down on exactly what scale it’s going to have.

Professor Chris Harrison, National Clinical Director for Cancer

The Inquiry also considered whether lessons could be learnt from breast cancer where survival rates vastly exceed those for ovarian cancer; one-year survival for breast cancer is currently 96 per cent, compared to 71 per cent for ovarian cancer.¹⁹

What we have in breast cancer is if a woman presents at her GP with a breast symptom that they can’t explain, even if they don’t suspect breast cancer they currently have to be seen within two weeks. So, while the breast cancer pathway is split into suspected cancer and breast symptoms not suspected, in reality all patients should be seen within two weeks. We call it urgent and non-urgent but it’s not urgent and non-urgent in the way that this applies to other cancers.

Sally Greenbrook, Policy Manager, Breast Cancer Now

At the same time, any move to lower the threshold at which patients are referred for testing has resource implications for the NHS and can impact on individual patients in terms of the anxiety this may cause.

We’ve seen a massive increase over the last four or five years in women being referred with suspected breast cancer, an increase of 119,000 women since 2012-13.

Sally Greenbrook, Policy Manager, Breast Cancer Now

Ensuring no cancer is missed

The Inquiry heard about smart ways of ensuring no cancer diagnosis is missed, including the ‘three strikes’ campaign by the Teenage Cancer Trust which calls for young people returning to their GP three times with the same symptoms to be referred automatically for testing for cancer.

Something that the Teenage Cancer Trust have been campaigning for is that if you go back with the same symptoms three times, you get referred for tests.

Sally Greenbrook, Policy Manager, Breast Cancer Now

We have a golden rule in our practice - someone comes back the third time with the same thing, you do something.

Dr Alison Wint, Macmillan Cancer Lead, South Gloucestershire CCG

The Inquiry also heard about challenges with the current diagnostic tests for ovarian cancer and the importance therefore of ensuring women with persistent symptoms return to see their GP, even if initial testing has proved negative for ovarian cancer.

The CA125 ultrasound route will only pick up 66 per cent of ovarian cancers and 34 per cent of cancers found in this group will have a normal CA125 and a normal ultrasound scan; in other words, they’ll be negative for both tests.

Dr Alison Wint, Macmillan Cancer Lead, South Gloucestershire CCG]

Current NICE guidelines are clear that women should be advised to return to see their GP if symptoms persist, despite negative test results.

And so the advice is about safety netting. It's about saying if a woman's symptoms persist, then they need to be reinvestigated and not to have false reassurance by a negative test.

Dr Alison Wint, Macmillan Cancer Lead, South Gloucestershire CCG

Diagnosing ovarian cancer more quickly

Recommendation 24 of the cancer strategy calls for the introduction of a new four-week target for cancer to be diagnosed or ruled out following a GP referral.

We've got a number of pilot approaches to the 28-day target and we are in the process of setting out the implementation process over the next three years. A number of the pilots that have been taking place do include gynaecological cancers, including ovarian cancer. So, we have got some learning from that to apply.

Professor Chris Harrison, National Clinical Director for Cancer

The Inquiry heard how the referral pathway in Scotland is now shorter, with GPs able to refer women for a CA125 blood test and ultrasound at the same time, rather than having to complete these tests one after another as in England.²⁰

The Scottish guidelines are if you suspect ovarian cancer, you actually do your CA125 and your ultrasound together and that would probably catch a bigger number of diagnoses.

Hilary Morrison, patient advocate and former GP

Ultrasound and CA125 ordered at the same time helped me and seems a simple thing to implement. Initial misdiagnosis was a problem for me which was sorted out fairly quickly but I know longer delays can have more serious consequences.

Woman with ovarian cancer, written submission

Measuring improvement

The first recommendation of *Achieving world-class cancer outcomes: a strategy for England 2015-2020* calls for the development of a cancer dashboard of metrics at the Clinical Commissioning Group (CCG) and provider level, to be reported and reviewed regularly by Cancer Alliances.²¹ This is to include a wide range of data at CCG level including one-year survival and stage at diagnosis. Although some of this data in relation to ovarian cancer is already published by the National Cancer Registration and Analysis Service, it is not yet available as part of the cancer dashboard.

The Inquiry asked when the cancer dashboard could be expected to be extended to include ovarian cancer.

The cancer dashboard's in development. The first iteration was produced and there are further iterations being developed.

Professor Chris Harrison, National Clinical Director for Cancer

We have been working on making more data available for less common cancers and in December we launched a new set of data on brain cancers. It is a pilot to see whether we could make more data available because there a number of issues with small numbers. The next wave will probably include pancreatic and ovarian cancer. So, you should see something in the next six months with more data on less common cancers coming out from us in the future.

Lucy Elliss-Brookes, Head of Cancer Analysis, National Cancer Registration and Analysis Service

The Inquiry asked witnesses whether there was regional variation in the diagnosis of ovarian cancer and heard about the benefits offered by national clinical audits.

We see in other cancer sites, where there's been a national audit, lung in particular has been going for many years, that publishes data comparing trusts, comparing pathways and exposes some of those variations which are then acted on. We've seen some real improvements in lung in particular, on surgical resection rates and some of the referral times in the pathways and actually survival has increased quite dramatically in lung over time.

We're privileged in this country to have fantastic cancer data from the patients that we care for and that we hold in Public Health England securely and we need to use that better to understand where the variation is and then understand why that's happening and how we can reduce that and improve outcomes all around.

The charities have been really, really pushing for an ovarian cancer audit for a long time and I think that might well show some areas where we can make improvements that maybe we don't know about already.

Lucy Elliss-Brookes, Head of Cancer Analysis, National Cancer Registration and Analysis Service

Conclusion

The evidence received presented four separate issues. The first was challenges within the existing diagnostic pathway. Here the opportunities offered by creating a referral pathway, through multi-disciplinary diagnostic centres, where symptoms could indicate a range of cancers, were clear. As these are rolled out more fully in will be important to ensure equal access across the country.

The second issue concerned ensuring no diagnosis was missed. Here it was apparent that appropriate safety netting is key, both in ensuring patients are referred for diagnostic tests in the first place but also in that ensuring no cancer is missed if initial tests are negative.

The third was whether ovarian cancer could be diagnosed more quickly and here it seemed that evidence from Scotland was particularly significant, especially given the target contained within the cancer strategy for cancer to be diagnosed or ruled out within 28 days.

The fourth issue concerned access to reliable data to identify areas where improvement is needed. Here, ovarian cancer's absence from the cancer dashboard is a concern although the Inquiry was pleased to learn of work by charities to take forward an audit in this area.

On this basis the APPG on Ovarian Cancer makes the following recommendations:

- NHS England to ensure that multi-disciplinary diagnostic centres are accessible to all patients with vague or less specific symptoms across the country.
- NHS England to work with GPs to raise awareness of guidelines on safety netting to ensure no cancer diagnosis is missed.
- NICE and NHS England to review the referral pathway for ovarian cancer, incorporating any learning from the introduction of the shortened pathway in Scotland, so CA125 and ultrasound can be carried out at the same time.
- NHS England and Public Health England to commit to include ovarian cancer data within the cancer dashboard.
- Public Health England to support work to initiate an ovarian cancer clinical audit to address issues in regional variation.

Final thoughts

Clear progress has been made in the diagnosis of ovarian cancer in recent years. A decade ago many GPs lacked direct access to diagnostic tests and there were no clear guidelines for diagnosing the disease. Both of these have now changed and we can see the benefits as each year survival rates for ovarian cancer increase.

However, overall survival rates for ovarian cancer continue to lag behind those for other cancers and there are still too many stories of missed or late diagnoses and GPs trying to refer women through a system that at times can feel stacked against them. This Inquiry has therefore focused on what comes next, what delivers the next big step change in ensuring more women are diagnosed sooner and what more can be done to match the survival rates seen in other cancers.

The Inquiry was impressed at the range and breadth of work currently taking place and hugely grateful to the expert witnesses who shared their knowledge with us. We have considered four of the most significant issues in relation to what more can be done to diagnose ovarian cancer sooner and drawn the following conclusions:

- In relation to prevention, we heard that with genetic testing there is the opportunity for more and more cases of ovarian cancer to be avoided; based on current evidence, this could result in 15 per cent fewer cases of ovarian cancer each year.
- We learnt that screening has not yet produced sufficient evidence for the introduction of a national programme, although we remain hopeful that this will change in the future.
- When it came to awareness we heard how few women know the symptoms to look out for and the work underway to address this.
- Finally, looking at the diagnostic pathway itself we saw how action to address referrals, to shorten the pathway and to improve the data available all had great potential to quicken the time taken to diagnose ovarian cancer and reduce regional variation.

It is our hope that action on prevention, with the full roll-out of genetic testing, will see many women spared an ovarian cancer diagnosis. Turning to those women for whom prevention is not yet a possibility, we must see investment in awareness raising and for the cancer strategy to deliver on improvements to the diagnostic pathway. Only then will we see more women diagnosed sooner and as a result, more women surviving ovarian cancer.

Recommendations

NHS England to ensure current guidelines on genetic testing for women with ovarian cancer are fully implemented with the appropriate funding in place.

NHS England to report on BRCA testing for women with ovarian cancer, specifically the percentage of eligible women being offered and accessing testing.

The Department of Health to work with the insurance industry to renegotiate the Concordat and Moratorium on Genetics and insurance when it expires and provide greater certainty for cancer patients and their families undergoing genetic testing.

For NHS England and Health Education England to factor a potential increase in demand for sonographers in their workforce planning.

For Public Health England to run a national Be Clear on Cancer campaign which, whether focusing entirely on ovarian cancer or a cluster of cancers, includes the key symptoms of ovarian cancer.

NHS England to ensure that multi-disciplinary diagnostic centres are accessible to all patients with vague or less specific symptoms across the country.

NHS England to work with GPs to raise awareness of guidelines on safety netting to ensure no cancer diagnosis is missed.

NICE and NHS England to review the referral pathway for ovarian cancer, incorporating any learning from the introduction of the shortened pathway in Scotland, so CA125 and ultrasound can be carried out at the same time.

NHS England and Public Health England to commit to include ovarian cancer data within the cancer dashboard.

Public Health England to support work to initiate an ovarian cancer clinical audit to address issues in regional variation.

Appendix 1

The APPG on Ovarian Cancer held two oral evidence sessions on Tuesday 20 February 2018.

Session one: Prevention, screening and awareness

Chair: Sharon Hodgson MP

Witnesses:

- Dr Angela George, Consultant in Oncogenetics and Clinical Lead for the Cancer Genetics Unit, The Royal Marsden Hospital
- Professor Anne Mackie, Director of Screening, Public Health England
- Professor Usha Menon, Principal Investigator, UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) and co-investigator, UK Familial Ovarian Cancer Screening Study (UKFOCSS)
- Professor Chris Harrison, National Clinical Director for Cancer*
- Lucy Elliss-Brookes, Head of Cancer Analysis, National Cancer Registration and Analysis Service*
- Alexia Clifford, Deputy Director, Marketing Activation, Public Health England (Be Clear on Cancer)

Session two: Diagnosing ovarian cancer

Chair: Lee Rowley MP

Witnesses:

- Hilary Morrison, patient advocate and former GP
- Dr Alison Wint, Macmillan Cancer Lead, South Gloucestershire CCG
- Sally Greenbrook, Policy Manager, Breast Cancer Now (to enable comparisons with the breast cancer pathway)

* Professor Chris Harrison and Lucy Elliss-Brookes took part in both oral evidence sessions.

Declarations of interest:

Professor Usha Menon, Principal Investigator, UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS)

Stocks awarded by UCL in Abcodia Pvt Ltd, UCL spin-out. Abcodia has

- 1) the license from Massachusetts General Hospital to commercial use of the 'Risk of Ovarian Cancer Algorithm'. ROCA is part of the multimodal screening strategy.
- 2) an interest in discovery and validation of cancer biomarkers using the UKCTOCS Biobank samples.

References

1. Cancer Research UK website. Available at: www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/incidence [Accessed 30 March 2018]
2. De Angelis et al. (2014) Cancer survival in Europe 1999–2007 by country and age: results of EUROCORE-5 – a population-based study. *The Lancet Oncology* (15):23-34. Available at: [www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70546-1/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext) [Accessed 30 March 2018]
3. Office for National Statistics (2017) Cancer Survival in England- Adults Diagnosed: 2011 to 2015, followed up to 2016. Available at: www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016/relateddata [Accessed 30 March 2018]
4. National Cancer Registration and Analysis Service (2017) Routes to diagnosis 2006-2015. Available at: www.ncin.org.uk/publications/routes_to_diagnosis [Accessed 30 March 2018]
5. National Cancer Registration and Analysis Service (2017) Routes to diagnosis 2006-2015. Available at: www.ncin.org.uk/publications/routes_to_diagnosis [Accessed 30 March 2018]
6. Zhang, S. et al (2011) Frequencies of BRCA1 and BRCA2 mutations among 1,342 unselected patients with invasive ovarian cancer. *Gynecologic Oncology*, 121(2):353–357. Available at: www.ncbi.nlm.nih.gov/pubmed/21324516 [Accessed 30 March 2018]
7. Independent Cancer Taskforce (2011) Achieving world-class cancer outcomes: a strategy for England 2015-2020. Available at: www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf [Accessed 30 March 2018]
8. National Institute for Health and Care Excellence (2013) Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer. Available at: www.nice.org.uk/guidance/cg164/chapter/Recommendations [Accessed 30 March 2018]
9. NHS England (2015) Clinical Commissioning Policy: genetic testing for BRCA1 and BRCA2 mutations. Available at: www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e01/ [Accessed 30 March 2018]
10. HM Government and Association of British Insurers (2014) Concordat and Moratorium on Genetics and Insurance. Available at <https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/genetics/concordat-and-moratorium-on-genetics-and-insurance.pdf> [Accessed 1 May 2018]
11. Jacobs, I., Menon, U. et al (2015) Ovarian cancer screening and mortality in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS): a randomised controlled trial. *The Lancet* (387) 10022: 945-956. Available at: [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01224-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01224-6/fulltext) [Accessed 30 March 2018]
12. Rosenthal et al (2017) Evidence of stage shift in women diagnosed with ovarian cancer during phase II of the United Kingdom Familial Ovarian Cancer Screening Study. *Journal of Clinical Oncology* (35) 13: 1411-1420. Available at: <http://ascopubs.org/doi/abs/10.1200/jco.2016.69.9330> [Accessed 30 March 2018]
13. Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 30 March 2018]
14. Public Health England website. Available at: <https://campaignresources.phe.gov.uk/resources/campaigns/16-be-clear-on-cancer/overview> [Accessed 30 March 2018]
15. National Cancer Intelligence Network [now National Cancer Registration and Analysis Service] (2015) Be Clear on Cancer: ovarian cancer awareness regional pilot campaign. Available at: www.ncin.org.uk/view?rid=2907 [Accessed 30 March 2018] and National Cancer Registration and Analysis Service website. Ovarian cancer awareness campaign – evaluation results. Available at: http://ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/be_clear_on_cancer/ovariancancerevaluationresults [Accessed 30 March 2018]
16. National Cancer Registration and Analysis Service website. Abdominal symptoms campaign – evaluation results. Available at: http://ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/be_clear_on_cancer/abdominalsymptomsevaluationresults [Accessed 30 March 2018]

17. National Institute for Health and Care Excellence (2011) Ovarian cancer: recognition and initial management. Clinical guideline 122. Available at: www.nice.org.uk/guidance/cg122 [Accessed 30 March 2018]
18. Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 30 March 2018]
19. Office for National Statistics (2017) Cancer Survival in England- Adults Diagnosed: 2011 to 2015, followed up to 2016. Available at: www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016/relateddata [Accessed 30 March 2018]
20. Scottish Intercollegiate Guidelines Network (2013) Management of epithelial ovarian cancer. Available at: www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html [Accessed 30 March 2018]
21. Independent Cancer Taskforce (2011) Achieving world-class cancer outcomes: a strategy for England 2015-2020. Available at: www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf [Accessed 30 March 2018]

Target Ovarian Cancer provides the secretariat to the All Party Parliamentary Group on Ovarian Cancer

www.targetovariancancer.org.uk/our-campaigns/all-party-parliamentary-group-ovarian-cancer
appg@targetovariancancer.org.uk

0207 923 5473



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