



Petitions Committee
**Support Yearly Screening for
Ovarian Cancer – Report on the
Consideration of a Petition**

February 2017



National Assembly for Wales
Petitions Committee

The National Assembly for Wales is the democratically elected body that represents the interests of Wales and its people, makes laws for Wales, agrees Welsh taxes and holds the Welsh Government to account.

An electronic copy of this report can be found on the National Assembly's website:
www.assembly.wales/SeneddPetitions

Copies of this report can also be obtained in accessible formats including Braille, large print; audio or hard copy from:

Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

Tel: **0300 200 6565**

Email: **SeneddPetitions@assembly.wales**

Twitter: **[@SeneddPetitions](https://twitter.com/SeneddPetitions)**

© National Assembly for Wales Commission Copyright 2017

The text of this document may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not used in a misleading or derogatory context. The material must be acknowledged as copyright of the National Assembly for Wales Commission and the title of the document specified.

Petitions Committee
**Support Yearly Screening for
Ovarian Cancer – Report on the
Consideration of a Petition**

February 2017



National Assembly for Wales
Petitions Committee

Petitions Committee

The Petitions Committee was established on 28 June 2016 to carry out the functions of the responsible committee set out in Standing Order 23.

Its role is to consider all admissible petitions that are submitted by the public. Petitions have to be about issues that the National Assembly had powers to take action on. The petitions process enables the public to highlight issues and directly influence the work of the National Assembly. Its specific functions are set out in Standing Order 23.

Current Committee membership:



Mike Hedges AM (Chair)
Welsh Labour
Swansea East



Gareth Bennett AM
UKIP Wales
South Wales Central



Janet Finch-Saunders AM
Welsh Conservative
Aberconwy



Neil McEvoy AM
Plaid Cymru
South Wales Central

The following Member attended as a substitute member during the course of this inquiry:



Suzy Davies AM
Welsh Conservative
South Wales West

Contents

The Committee's Recommendations	5
The Petition	6
Ovarian Cancer - Background	6
Consideration of the Petition by the Committee	7
Initial Committee consideration	7
Detailed evidence received.....	7
The Petitioners' ambition	7
Early diagnosis.....	7
A screening programme for ovarian cancer	8
Awareness amongst GPs and other health professionals	13
Public awareness.....	15
Conclusions	18
Annex A - List of Witnesses	19
Annex B - List of Written Evidence.....	20

The Committee's Recommendations

Recommendation 1. We recommend that the Welsh Government keeps the potential for a national screening programme for ovarian cancer under review and gives detailed consideration to any new evidence which comes forward. In particular, the Welsh Government should continue to closely consider advice produced by the UK National Screening Committee. Page 13

Recommendation 2. We recommend that the Welsh Government continues to work with GPs and other health professionals to ensure that women who have symptoms of ovarian cancer are referred for appropriate tests and are able to receive a timely diagnosis. As part of this, we recommend that the Welsh Government supports primary care cancer leads to use the learning from the current review of ovarian cancer cases to inform GP practice and cluster plans in each health board, with a view to improving early diagnosis. Page 15

Recommendation 3. We recommend that the Welsh Government does more to improve public awareness of ovarian cancer, including the common symptoms and when people should seek medical advice. We believe this should build upon the short campaign run in early 2016 by Velindre NHS Trust but should learn from other successful awareness-raising campaigns and seek to raise both general and specific awareness of ovarian cancer over a prolonged period of time. Page 17

The Petition

1. The following petition¹ was submitted using the National Assembly for Wales's online petitions system by Margaret Hutcheson, a retired palliative care nurse.

We, the undersigned, call upon the Welsh Government to support yearly screening for ovarian cancer (CA125 Blood Test)

2. The petition gathered 104 signatures online.

Ovarian Cancer - Background

3. Ovarian Cancer is one of the major causes of mortality of women in the UK. It is the sixth most common form of cancer diagnosed in women in Wales, with 365 cases diagnosed in 2014, and the fourth most common cause of cancer death for women in Wales, with 238 deaths in 2014.²

4. Information the Petitions Committee received from Target Ovarian Cancer indicated:

- 1 in 50 women will have ovarian cancer at some point in their life;
- Less than half of women with ovarian cancer are alive five years after diagnosis.

5. Survival in the UK is lower than the European average, which has been at least partly attributed to the disease being diagnosed at a later point in its progression. The early detection of ovarian cancer is critical for effective treatment. However, unfortunately, ovarian cancer is a disease with a complex diagnostic pathway and early stages of the disease are often symptomless.

6. Early stage ovarian cancer confined to the ovaries (Stage 1) has an extremely good outlook and can be successfully treated. Unfortunately, most ovarian cancers are not recognised at an early stage for a number of reasons. First, the cancer of the ovary usually develops after the menopause; when the ovaries are inactive and abnormal function of the ovary is not therefore easily noticed. Second, the ovaries are located deep inside the pelvis and are difficult to examine. Finally, even when symptoms do occur they are usually vague, non-specific symptoms, which could be due to a host of other causes.

7. For these reasons, by the time most women with ovarian cancer develop symptoms and their cancer is detected, it has spread outside the ovaries to the pelvis (Stage 2), the abdomen (Stage 3) or more distant sites (Stage 4) and is far more difficult to treat successfully.

8. The close link between early diagnosis and survival chances has long suggested that an effective method of screening to detect early stage ovarian cancer may help to save the lives of women who develop the cancer.

9. Ovarian cancer screening is not currently available on the NHS in Wales, or elsewhere in the UK.

¹ Petition reference number P-04-668

² Welsh Cancer Intelligence and Surveillance Unit (WCISU), <http://www.wcisu.wales.nhs.uk/cancer-in-wales-1>

Consideration of the Petition by the Committee

Initial Committee consideration

10. The petition was first considered by the Petitions Committee in the 4th Assembly on the 2 February 2016, when the Committee agreed to write to the Minister for Health and Social Services seeking his views on a series of detailed points submitted by the petitioner. Given the close proximity of the 2016 Assembly election, Members also recommended that their successor Petitions Committee should consider undertaking a short piece of work on the issue.

11. The new Petitions Committee in the 5th Assembly considered written evidence from the petitioner at their first meeting on 12 July 2016 and agreed to hold evidence sessions with the petitioner and the Cabinet Secretary for Health, Well-being and Sport during autumn 2016.

Detailed evidence received

12. During their consideration of the petition, the Committee received a range of written correspondence from the petitioner, Professor Mark Drakeford AM, the Minister for Health and Social Services (prior to June 2016), Rebecca Evans AM, the Minister for Social Services and Public Health (after June 2016), and several cancer charities.

13. The Committee held an oral evidence session with the petitioner Margaret Hutcheson and Jenny Chapman, a friend, on 13 September 2016, and with the Minister for Social Services and Public Health on 27 September 2016.

The Petitioners' ambition

14. Margaret Hutcheson (the petitioner) explained how she was inspired to start the petition after a number of her friends had been diagnosed with ovarian cancer. Two had themselves worked as chemotherapy nurses, and were therefore extremely familiar with cancer, but both were only diagnosed once their conditions had reached an advanced stage.

15. The petitioner described ovarian cancer as “a silent killer” and stated her ambition for:

- a national screening programme to be introduced for women aged over 50, using the CA125 blood test, because early diagnosis and treatment of ovarian cancer has a major bearing on the likelihood of successful treatment;
- increased awareness of ovarian cancer and its symptoms amongst General Practitioners (GPs) and other health professionals;
- increased public awareness of ovarian cancer and recognition of the common symptoms of the disease.

Early diagnosis

16. All the evidence the Committee received emphasised the importance of early diagnosis of ovarian cancer. For example, Ovarian Cancer Action stated:

“Ovarian cancer is the UK’s biggest gynaecological killer, killing a woman every two hours. Women who are diagnosed early have a much greater chance of survival, and far too many women are still diagnosed at stage 3 of the disease.”

17. The stark differences in survival rates between women diagnosed in the initial stages of the disease and those who are diagnosed at a later point, are demonstrated by figures from Cancer Research UK. For England and Wales, the five-year ovarian cancer survival rate is 46 per cent but, if diagnosed at the earliest stage, up to 90 per cent of women with ovarian cancer would survive for five years or more.³

18. With regards to the specific situation in Wales, the Minister for Social Services and Public Health told the Committee that some progress has been made over the past decade in relation to survival rates for women diagnosed with ovarian cancer:

“The latest figures do show that things are improving. For example, 70 per cent of women living in Wales who are diagnosed with ovarian cancer survive at least one year, and almost 38 per cent survive five years. And those figures have actually improved by 4.3 per cent and 0.2 per cent respectively since 2004. So, there is an improvement, albeit slow, and obviously we want to seek to continue to move in this direction.”

19. However, the Committee is concerned that this seems to indicate that Wales’s performance in respect of the overall five-year survival rate is behind that in England.

20. Mr Irfon Rees, deputy director for public health for the Welsh Government, outlined the Government’s overall aims in relation to continuing to improve performance on the diagnosis and treatment of ovarian cancer during the Committee’s evidence session with the Minister:

“...we want earlier diagnosis, and that’s better awareness amongst the population, better referral, GPs better equipped to recognise, and better links between primary care and secondary care. And, finally, better access and speedier access to further diagnostics and treatment.”

A screening programme for ovarian cancer

21. The petitioner’s primary objective is for a national screening programme to be introduced for ovarian cancer. This would involve women receiving an annual blood test aimed at detecting early stage ovarian cancer. In subsequent evidence to the Committee, the petitioner stated her view that this programme should target women aged 50 and over.

22. Cancer screening involves testing apparently healthy people for signs that could show that a cancer is developing. Current cancer population screening in the UK includes breast, cervix and bowel cancer screens. At present, there is no routine screening programme for ovarian cancer in any part of the UK.

23. The Committee learned that studies to find a general population screening test for ovarian cancer are ongoing. These have focused on 2 main tests: the CA125 blood test and transvaginal ultrasound.

The CA125 blood test

24. CA125 is a protein found in the blood that is currently used as a tumour marker for ovarian cancer. It is given off by cancer cells and circulates in the bloodstream and therefore women with

³ <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer#heading-Two>

ovarian cancer tend to have higher levels of CA125 in their blood than women who do not have ovarian cancer.

25. The CA125 test is easily and quickly performed on a small blood sample sent to a laboratory. Guidelines produced by the National Institute for Health and Care Excellence (NICE) recommend that it is the first test GPs carry out if they suspect ovarian cancer. It is also used to monitor women during and after treatment of ovarian cancer.

26. However, levels of CA125 can be raised for a number of reasons, including other non-cancerous reasons. In a letter to the Committee, the charity Ovarian Cancer Action confirmed its limitations:

“...to date, it has not been shown to be effective at picking up early stage ovarian cancer, and levels of CA125 can be raised by normal tissues or other conditions, such as endometriosis. Different women have naturally varying levels of CA125, so the same reading could mean different results across patients.”

27. The Committee heard that a relatively new method of calculating ovarian cancer risk based on changing levels of the CA125 protein in the blood over time, as opposed to a reading at a fixed point, has the potential to provide a more accurate prediction of ovarian cancer than was previously available.⁴ This was considered as part of the UKCTOCS trial (below).

Transvaginal ultrasound

28. This is an ultrasound examination done by putting the ultrasound probe into the vagina to identify lumps or a change in the ovaries. However it can still be difficult to tell whether there is a cancer on the ovary or just a harmless cyst. Under current guidelines, women are usually referred for an ultrasound if they have raised levels of the CA125 protein.

The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) trial

29. The UKCTOCS trial, which commenced in 2001, involves 200,000 women aged 50-74 years. It is a randomised trial in which women taking part are allocated randomly for screening with either CA125 or ultrasound, or to a control group who are followed up without screening.

30. The results of the UKCTOCS trial were published in December 2015. They indicated that screening based on an annual blood test may help reduce the number of women dying from ovarian cancer by around 20 per cent. The result was similar for women who received an ultrasound.

31. However, the results included a large ‘confidence interval’ – effectively the size of the uncertainty in the result. This was due to the low numbers of women who have so far developed and died from ovarian cancer in the trial – about 650 out of 200,000 – and means that the range of possible benefit could be anywhere between 0 and 40 per cent.

32. Therefore, the study concluded that longer follow-up is needed to establish more certain estimates of how many deaths from ovarian cancer could be prevented by screening. As a result it will continue to run for another 3 years.

33. In her evidence to the Committee, the petitioner acknowledged that:

⁴ <http://scienceblog.cancerresearchuk.org/2015/05/05/new-ovarian-cancer-blood-test-is-promising-but-screening-still-a-way-off/>

“A CA125 blood test may not be perfect, but I feel it’s better than nothing, which is what we’ve got at present.”

34. The Minister for Social Services and Public Health stated that, in order for a screening test to be made available on the NHS, it has to be proven to be accurate and safe. The Welsh Government takes its advice from the UK National Screening Committee (UK NSC), which provides independent expert advice on population-based screening to all UK Ministers:

“The UK NSC reviews conditions against set criteria in order to appraise the viability, effectiveness and appropriateness of a population screening programme. There are 20 points to the established criteria covering the condition, the test, the intervention, the screening programme and implementation...

...The UK NSC has recently reviewed its recommendation about ovarian cancer screening and their existing recommendation remains for no population screening at this stage but this decision will be reviewed if new evidence becomes available. The UK NSC requires the highest-quality evidence about population benefits before a new programme is recommended. This is vitally important to ensure screening programmes do more good than harm and to ensure NHS funding and staff resources are used in the most effective way possible.”

35. The Minister outlined that although screening with CA125 and/or ultrasound can detect ovarian cancer early, this does not necessarily mean that screening will save lives. Screening will only be worthwhile if it detects ovarian cancer sufficiently early to make treatment more effective.

36. Dr Rosemary Fox, Director of Screening Division at Public Health Wales, attending alongside the Minister, expressed her view that the findings of the UKCTOCS study had so far not provided the evidence for the value of screening for ovarian cancer that had been anticipated:

“And, I must say, on a personal basis, as somebody who’s worked in screening for the last 10 years, that was quite a surprise. I think everybody had been expecting that the [UKCTOCS] trial would show that there was a benefit from screening. The fact that it hasn’t shown that means that we need to be very careful not to allow enthusiasm to do good to overcome looking at the actual evidence to see whether we will do more good than harm.”

Accuracy of results

37. In the absence of a screening programme, the CA125 blood test is currently undertaken when a patient presents with symptoms which could be caused by ovarian cancer. In a follow up letter to the Committee, the Minister provided further information on the most recent evidence review carried out by NICE⁵ on current practice in this area:

“The National Institute for Health and Care Excellence (NICE) has reviewed the evidence and developed guidelines on ovarian cancer recognition and initial management. This review concluded that around 1 in 100 women referred to

⁵ <https://www.nice.org.uk/guidance/cg122/evidence>

secondary care following a positive CA125 blood test would have ovarian cancer. A ‘false positive’ is a test result which wrongly indicates that a particular condition or attribute is present - for this test that is 99 out of every 100 women.”

38. The Minister outlined the risks which can arise from ‘false positives’ as a result of population screening programmes:

“...for every ovarian cancer case detected by the screening, two additional women in the multimodal group and 10 in the ultrasound group had unnecessary surgery, where the ovaries had benign lesions or were normal, and around 3 per cent of the women who had the unnecessary surgery had a major complication with that as well. So, this is very much what must be considered when we’re balancing doing more good than harm.”

39. In her subsequent letter to the Committee, the Minister also raised the issue of ‘false negatives’:

“[The NICE evidence review] also reported that around 1 in every 2,000 women with a negative test result would turn out to have ovarian cancer - this is termed a ‘false negative’. False negative results may provide inappropriate reassurance and it is important that a holistic assessment is undertaken which makes use of, but does not rely on, a single test.”

The cost of a screening programme

40. The Committee sought information on the likely cost of introducing a screening programme. The petitioner informed Members that in her experience the unit cost of administering a single CA125 blood test was in the region of £25 - £30, but that organising a test from a private provider frequently meant paying several hundred pounds. The petitioner was also aware of an occasion when even this was not available without a referral letter from a GP.

41. The Committee questioned the Minister about what calculations had been made as to the cost of introducing a screening programme for ovarian cancer. The Minister stated that an economic evaluation would only be undertaken if there was evidence that the population screening would be beneficial to patients and that the UK NSC had not recommended that at this point in time.

42. In subsequent correspondence to the Committee, the Minister stated that the review carried out by NICE⁶ had identified that the CA125 blood test had:

“...a total cost of just over £1,500 per patient (within this figure the unit cost of a CA125 blood test was estimated to be £23).”

The Welsh Government’s position

43. In a letter to the Committee on 20 March 2016, the previous Minister stated the Welsh Government’s view that there is not currently enough evidence for NHS Wales to introduce a national screening programme.

⁶ <https://www.nice.org.uk/guidance/cg122/evidence>

“Early diagnosis of ovarian cancer is both desirable and needed, however, the evidence recently published from the large UKCTOCS trial indicates that the data to date are not sufficient to recommend a national population screening programme in women with no symptoms or relevant family history.”

44. The Minister for Social Services and Public Health expanded on the Welsh Government’s position in her evidence session with the Committee:

“Screening programmes should only be offered when there is robust, high-quality evidence that screening will actually do more good than harm and also be cost-effective within the Welsh NHS budget. We take our advice from the UK National Screening Committee and they provide independent expert advice on population-based screening to all UK Ministers. It’s a world leader in its field and the screening programmes in the UK, I think, are amongst the most respected internationally. The screening committee does not currently recommend population screening for ovarian cancer.”

Our conclusion

45. The introduction of a screening programme was the primary purpose of the petition and we gave detailed consideration to the range of evidence we received.

46. On balance, whilst the petitioner provided powerful evidence of the importance of early diagnosis and treatment of ovarian cancer, we recognise that current evidence does not support the introduction of a population screening programme, using either the CA125 blood test or an alternative method.

47. This is supported by the charities who provided evidence to the Committee, including Cancer Research UK who wrote:

“...we do not recommend the introduction of a national screening programme for ovarian cancer, as the evidence to date has not shown that it can reduce deaths from ovarian cancer.”

48. We believe that the current situation was succinctly summarised in the evidence submitted by Ovarian Cancer Action:

“Screening tests can have a range of unintended consequences from anxiety to unnecessary surgery in extreme cases. We believe that currently testing levels of CA125 is not yet specific or accurate enough to risk being used as a national screening tool. Funding would be better spend at this time on a national symptoms public awareness campaign.”

49. However, given that the UKCTOCS study is still underway and will report further findings in the coming years, we believe that the Welsh Government should keep the situation under close review and give detailed consideration to any new evidence in relation to a national screening programme.

Recommendation 1. We recommend that the Welsh Government keeps the potential for a national screening programme for ovarian cancer under review and gives detailed consideration to any new evidence which comes forward. In particular, the Welsh Government should continue to closely consider advice produced by the UK National Screening Committee.

Awareness amongst GPs and other health professionals

50. The Committee heard how it is vitally important that women receive the appropriate support and diagnostic tests when ovarian cancer is a possibility. Cancer Research UK stated:

“It is important to remember that screening programmes are meant for people who don’t have symptoms: this is different to having a diagnostic test if you have symptoms. We advise people of any age who notice an unusual or persistent change to their body to tell their doctor.

We want women who present with ovarian cancer symptoms to be able to access the appropriate diagnostic tests quickly, so that optimal treatment is available to them. Cancer Research UK works closely with GPs and other healthcare professionals to ensure they are aware of the symptoms of ovarian cancer and know when and how to refer women for tests to increase the chances of early diagnosis.”

51. The evidence the Committee received was clear about the importance of a high degree of awareness of ovarian cancer amongst health professionals. In particular, given that GPs are most people’s first line of contact with the NHS, it is crucial that they are consistently able to recognise the symptoms of ovarian cancer and appropriately refer people on for diagnostic tests.

52. The Committee received evidence from the petitioner which indicated that the experience of women seeking advice and diagnostic tests may not be consistent:

“A dear friend, another retired nurse, was diagnosed aged 69 in July 2015 with stage 3 advanced ovarian cancer. Her daughter, in her late 40’s went to the GP and asked if she could have a CA125 blood test, in view of her mother’s diagnosis. The GP then stated that ‘Your mother has to die of something’. She was denied the test and advised to pay privately to have it done. The GP did not make it easy for her to do by not giving her a letter of referral.

“Her other daughter, in her early 40’s went to her own GP but was given the test. The result was 55, the cut off being 35 – she was then given an ultrasound scan. What a difference in GP attitudes.”

53. However, the Committee heard that work is ongoing in relation to GP awareness. Correspondence from the then Minister for Health and Social Services, Mark Drakeford AM, in March 2016 referred to the awareness raising campaign run by Velindre NHS Trust in early 2016 and wider work on this subject:

“The campaign will support women to recognise symptoms and to seek help from their GP, as well as supporting GPs to consider the possibility of ovarian

cancer and to undertake appropriate investigations. It will add to the wider work being done by the NHS to implement the new National Institute for Health and Care Excellence suspected cancer referral guidelines and the inclusion of cancer as a national priority area in the GP contract to review cases of lung, gastrointestinal and ovarian cancer to identify opportunities to improve practice.

More widely, the Cancer Implementation Group has prioritised better access to diagnostics; the development of primary care oncology; improving patient experience and innovation of cancer pathways in Wales. The group is investing £1m a year to support these national priorities.”

54. The current Minister confirmed her willingness to continue to work to improve the understanding of symptoms and early diagnosis of ovarian cancer by clinicians. Following questions from the Committee as to why some other parts of Europe have better survival rates than Wales, the Minister stated:

“I think there’s certainly more that we can learn in terms of international practice for survival rates...We do participate in some key international partnerships studies, such as the International Cancer Benchmarking Partnership, which is enabling us to scrutinise what we do. The studies do point us in the direction of some of the answers to the question that you asked, and, so far, they’ve indicated that we’ve got some issues with data completeness, but also that some women are less likely here to recognise their symptoms and to seek help, and that GPs may be less willing here than in other countries to refer patients for testing, or certainly that has been the case in the past.”

55. Mr Rees outlined some of the steps the Welsh Government has been taking to improve awareness amongst GPs in Wales:

“...there are a number of factors where we are wanting to do better. Some of those factors, as the Minister said, are patient behaviour and some of those are doctor behaviours and doctors’ capacity to identify, perhaps, what is a very rare condition when we think of the day-to-day activities of a GP and the numbers of ovarian cancer cases in Wales. Therefore, it’s those areas that we are focusing on improving, both through awareness campaigns, but significant work with primary care, to improve earlier diagnosis. To give an example of that, this has been identified as a priority area in the GP contract, and GPs are now asked to review, as part of that, every case of ovarian cancer in 2015, to understand whether there are any lessons that could be learned in terms of practice around diagnosis and referral.”

56. The Committee sought further information from the Minister on how this review was operating and how lessons from this would be adopted. In her letter of 25 October 2016, the Minister provided detail:

“I can confirm the review of ovarian cancer cases was introduced into the 2015/16 GP contract and is continuing. The 2015 analyses were summarised by

April 2016 and informed the development of practice and cluster plans this autumn. The ongoing work will update GP practice and cluster plans where appropriate. Through our collaboration with Macmillan we now have primary care cancer leads in health boards and each has a specific objective to support the collation of the learning themes to inform health board actions to improve early diagnosis. The work is also shared with the Cancer Delivery Group, which is supporting specific projects relating to pathways of care and access to diagnostics which were issues raised through the GP analysis.”

57. The Minister also informed the Committee that:

“NICE has introduced new referral guidelines for suspected cancer. That lowers the threshold of suspicion, and hopefully that will encourage more referrals to come forward in a more timely fashion as well.”

Our conclusion

58. We support the work that is currently ongoing in relation to ensuring that GPs and other health professionals have a high degree of awareness of ovarian cancer, its common symptoms and the importance of early referral for diagnostic tests and investigation.

59. In particular, we are encouraged that awareness and appropriate treatment of ovarian cancer amongst GPs is being prioritised in this way, given the close correlation between early diagnosis and treatment of the disease and survival rates.

60. We believe that it is vital that the Welsh Government continues to monitor and improve practice in this field.

Recommendation 2. We recommend that the Welsh Government continues to work with GPs and other health professionals to ensure that women who have symptoms of ovarian cancer are referred for appropriate tests and are able to receive a timely diagnosis. As part of this, we recommend that the Welsh Government supports primary care cancer leads to use the learning from the current review of ovarian cancer cases to inform GP practice and cluster plans in each health board, with a view to improving early diagnosis.

Public awareness

61. The subject of general public awareness of ovarian cancer, and particularly awareness amongst women aged 50 and over, was frequently raised with the Committee. The petitioner expressed her concern that public awareness of the condition is extremely low and linked this to the problem of late diagnosis. For this reason, the petitioner described ovarian cancer as a “silent killer” on a number of occasions and stated that:

“Women are not aware of ovarian cancer. The message is not out there in the public.”

62. The Committee heard that a leaflet on ovarian cancer, including the common symptoms of the disease, has been produced and is available in GP surgeries. In March 2016, the Minister for Health and Social Services confirmed to the Committee that he had:

“...asked Velindre NHS Trust to develop an awareness campaign for ovarian cancer. This was launched on 9 March to coincide with ovarian cancer month and includes the dissemination of symptom awareness leaflets and posters to all GP surgeries in Wales.”

63. In response to questions from the Committee, the Minister for Social Services and Public Health confirmed further details about this following her evidence to the Committee:

“...I can report the ovarian cancer awareness campaign undertaken in March 2016 cost Velindre NHS Trust approximately £4,700 but the production and distribution of the GP information packs was funded separately by Target Ovarian Cancer.”

64. This was considered to be a positive step by the petitioner. However, she also argued that more should be done proactively to increase awareness of ovarian cancer and the importance of raising concerns at an early opportunity amongst women:

“But the thing is, you see, women are not aware of ovarian cancer, and this is the problem. The message just isn’t out there in the media. To think it’s acceptable just to put [a leaflet] in a doctor’s surgery, or it could be in supermarkets or something—get real, it’s not going to happen.”

65. The petitioner was also clear in her statement that an information leaflet on its own is not sufficient:

“To the best of my knowledge, the only awareness campaign at present is a leaflet put in general practitioner surgeries, which you’ve got, and possibly in other places I haven’t seen them. But I question how many women actually see them, because I know recently I had an appointment in my surgery and I had to really look for it, because I was told there was one there. It’s not very well set out; the symptoms are not as well set out in the surgery one as they are in the ones I’ve handed out. Anyway, by the time the symptoms become apparent, which are listed down there, it’s invariably a late diagnosis and a very poor prognosis. This has been the case with several of my friends. The symptoms in the leaflet are common in other conditions, which is why I feel that the sooner screening is set up, the more lives it could possibly save.”

66. The Committee also considered that there was generally confusion in this area and that some women may be wrongly under the impression that routine smear tests can help to identify ovarian cancer.

67. The petitioner made the comparison between the low awareness of ovarian cancer when compared with more common cancers, which have a significantly higher profile with the public:

“You never see television programmes about it. Breast cancer is just—. Obviously, there are so many more people diagnosed with breast cancer. But, over the years, because so much money has been spent on research and treatment and...they have a much better prognosis, whereas ovarian cancer women don’t.”

68. In terms of the most effective methods of raising awareness, the Minister for Social Services and Public Health also outlined the importance of ongoing activity as compared with one-off campaigns:

“We do see when we have awareness-raising campaigns that, actually, there is a small increase of people seeking diagnosis when an awareness-raising campaign is ongoing. But, then, we do see that falling off over time as people become less engaged with those—or looking for those symptoms.”

Our conclusion

69. We concluded that, given the close correlation between early diagnosis of ovarian cancer and survival prospects, it is essential that more is done to raise awareness amongst the general population, and women in particular, about ovarian cancer. We believe that, where possible, this should be done on an ongoing basis, particularly given the learning from previous awareness-raising campaigns.

Recommendation 3. We recommend that the Welsh Government does more to improve public awareness of ovarian cancer, including the common symptoms and when people should seek medical advice. We believe this should build upon the short campaign run in early 2016 by Velindre NHS Trust but should learn from other successful awareness-raising campaigns and seek to raise both general and specific awareness of ovarian cancer over a prolonged period of time.

Conclusions

70. We would like to thank the petitioner for her hard work and dedication and for drawing our attention to this important issue.

71. We would also like to place on record our thanks to all those who provided evidence to the Committee, including the petitioner, the Minister and her officials, and to those who responded to our request for information.

Annex A - List of Witnesses

The following witnesses provided oral evidence to the Committee on the dates noted below.

Transcripts of all oral evidence sessions can be viewed in full at

<http://senedd.assembly.wales/mgIssueHistoryHome.aspx?Ild=15162>

13 September 2016

Name	Organisation
Margaret Hutcheson	Lead Petitioner
Jenny Chapman	

27 September 2016

Name	Organisation
Rebecca Evans AM	Minister for Social Services and Public Health
Irfon Rees	Deputy Director, Public Health, Welsh Government
Dr Rosemary Fox	Director of Screening Division, Public Health Wales

Annex B - List of Written Evidence

The following people and organisations provided written evidence to the Committee. All written evidence can be viewed at

<http://www.senedd.assembly.wales/ielssueDetails.aspx?IId=14394&Opt=3>

Organisation	Meeting Considered
Mark Drakeford AM, Minister for Health and Social Services	2 February 2016
Margaret Hutcheson (Petitioner)	2 February 2016
Mark Drakeford AM, Minister for Health and Social Services	12 July 2016
Margaret Hutcheson (Petitioner)	12 July 2016
Rebecca Evans AM, Minister for Social Services and Public Health	27 September 2016
Rebecca Evans AM, Minister for Social Services and Public Health	29 November 2016
Ovarian Cancer Action	29 November 2016
Cancer Research UK	29 November 2016
Target Ovarian Cancer	29 November 2016