Citizen Participation and Public Petitions Committee Wednesday 21 May 2025 9th Meeting, 2025 (Session 6)

PE2088: Help eliminate cervical cancer through improved and at home HPV testing

Introduction

- Petitioner Emma Keyes
- **Petition summary** Calling on the Scottish Parliament to urge the Scottish Government to help eliminate cervical cancer for woman and those with a cervix in Scotland by introducing at home HPV (human papillomavirus) self-sampling to enhance the smear testing programme, helping to increase the uptake and accessibility of smear testing.
- Webpage <u>https://petitions.parliament.scot/petitions/PE2088</u>
- 1. <u>The Committee last considered this petition at its meeting on 12 June 2024.</u> At that meeting, the Committee agreed to write to the UK National Screening Committee, and the Scottish Government.
- 2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
- The Committee has received new written submissions from the UK National Screening Committee and the Scottish Government, which are set out in Annexe C.
- 4. <u>Written submissions received prior to the Committee's last consideration can be</u> <u>found on the petition's webpage.</u>
- 5. <u>Further background information about this petition can be found in the SPICe</u> <u>briefing</u> for this petition.
- 6. The Scottish Government gave its initial response to the petition on 2 April 2024.
- 7. Every petition collects signatures while it remains under consideration. At the time of writing, 1860 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee May 2025

Annexe A: Summary of petition

PE2088: Help eliminate cervical cancer through improved and at home HPV testing

Petitioner

Emma Keyes

Date Lodged

5 March 2024

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to help eliminate cervical cancer for woman and those with a cervix in Scotland by introducing at home HPV (human papillomavirus) self-sampling to enhance the smear testing programme, helping to increase the uptake and accessibility of smear testing.

Background information

While I was going through treatment for cervical cancer, I started to look into the smear programme and how we could improve it in Scotland to make smear testing easier and more accessible.

The uptake is at an all-time low and we need a testing programme that catches the disease at a pre-cancerous stage, helping woman and those with a cervix avoid harsh, life-changing cancer treatments. The Minister for Public Health & Women's Health Jenni Minto supports this.

I previously started a petition on change.org, which has gained over 2200 signatures.

Monica Lennon MSP shared my story during a debate on Cervical Cancer Prevention Week 2023.

I contributed to the discussion on cervical cancer prevention at the CPG on Women's Health meeting on 25 January 2023.

Annexe B: Extract from Official Report of last consideration of PE2088 on 12 June 2024

The Convener: That brings us to PE2088, our next new petition, which calls on the Scottish Parliament to urge the Scottish Government to help eliminate cervical cancer for women and those with a cervix in Scotland by introducing at-home human papillomavirus self-sampling to enhance the smear test programme, helping to increase the uptake and accessibility of smear testing. The petition was lodged by Emma Keyes, and I believe that she and supporters of the petition are present in the public gallery.

We are also joined by one of our faithful attendees from among our MSP colleagues, Monica Lennon. Good morning, Monica. I will invite you to address the committee in a moment.

As referenced in the SPICe briefing, the Public Health Scotland cancer incidence report notes that the drop in early detection of cervical cancers in 2020 is most likely due to the pause in screening services during the pandemic. The briefing also highlights that women from deprived backgrounds are less likely to participate in screening, and notes that self-testing is seen as a way of getting around some of the barriers to smear testing, and that self-testing has been trialled in some areas of England and in Dumfries and Galloway.

In response to the petition, the Scottish Government states that it relies on advice from the United Kingdom National Screening Committee. Although that committee recognises the potential benefits of self-sampling, it has previously concluded that there is insufficient evidence to recommend implementation. The Scottish Government notes that studies that are under way to gather further evidence are expected to conclude shortly, if they have not already done so.

The Scottish Government acknowledges the potential of self-sampling to increase uptake levels and reduce barriers to cervical screening. As such, a working group has been convened to assess potential models and understand any changes to the screening programme that might be required to support an initial roll-out of selftesting, following emerging evidence from global studies, including the one that took place in Dumfries and Galloway.

Monica Lennon, I welcome any comments that you might want to share with the committee.

Monica Lennon (Central Scotland) (Lab): It is always a pleasure to attend the Citizen Participation and Public Petitions Committee, and I am pleased that I can speak today in support of the petition by Emma Keyes. A lot of work has gone into getting the petition to this point, and I am grateful to SPICe for its excellent briefing, which sets out that self-sampling is already common in countries such as the Netherlands and Australia, so, in addition to the work that is being done in England and elsewhere in the UK, we have international experience to learn from.

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It is important to take a moment to remember why we are here and why the petition is necessary. We know that hundreds of people in Scotland are diagnosed with cervical cancer every year and that, sadly, many of those diagnosed lose their lives. Figures from Jo's Cervical Cancer Trust show that around 95 people died of the disease in 2023. I take this opportunity to pay tribute to the trust and note that, sadly, the charity has recently had to wind down for reasons that we will not go into today. I know that colleagues know how much it has done to raise awareness of the symptoms as well as of the treatments and the potential that we have to prevent the disease. That is a message of hope today.

The World Health Organization has called for countries to come together to eliminate the disease, and, last year, I was pleased to hear NHS England pledge to eliminate cervical cancer by 2040. Setting out how that could be done, the NHS England chief executive, Amanda Pritchard, outlined how the health service can help to achieve the goal of elimination by making it as easy as possible for people to get the life-saving HPV vaccination and by increasing cervical cancer screening uptake.

That is an important step, because we know that HPV causes up to 99 per cent of cervical cancers. An approach that involves vaccination plus screening plus self-sampling gives us an array of tools that we can use. In England, self-sampling is being trialled to determine whether it should be part of a national screening programme, and the message that campaigners want to send is that, if you get that invitation or opportunity to have that screening, you should take it without delay, as it could save your life. We also know that, for women and people with a cervix who do not take up that offer of screening, the opportunity can be missed, because cervical cancer often has no symptoms in its early stages.

Self-sampling has been identified as a factor that could support the realisation of the World Health Organization's cervical cancer elimination goals.

As ever, there is always a human story behind petitions, and I pay tribute to my constituent, Emma Keyes, who is sitting behind me in the gallery today. Emma is a young mum from Uddingston in Lanarkshire, and she experienced a shock cervical cancer diagnosis at the age of 29. That would have been debilitating and shocking for many people, but Emma has chosen to use her experience to raise awareness, help women and save lives.

Emma's message is that cervical cancer is preventable. She has become a bit of an icon online and is known on social media as Mrs Smear. We politicians sometimes think that we are the best message carriers, but Emma can speak to an audience in our community whose attention we cannot always get. She has got not only women talking, but partners, employers, friends, neighbours and families. Such communication is really important, because there are many barriers.

However, the petition is about much more than raising awareness; it is about making sure that our healthcare systems are fit for purpose and that we eliminate barriers to healthcare. The HPV self-sampling trial in Dumfries and Galloway went very well. I know that one of the MSPs in that region, Emma—I have blanked on her name. Emma Harper! I apologise to her—that will now be on the record, so I will say it

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again: Emma Harper. I know that, as a result of her background in nursing, she was passionate about the subject.

Emma Keyes and I have met two different public health and women's health ministers, and I thank Maree Todd and Jenny Minto for those meetings. It is really good that the Scottish Government is looking to take advice from the UK National Screening Committee, which was mentioned earlier. However, we also need to work at pace on this. Again, we should look at the experience not just in the UK but around the world.

The pilot scheme that has been mentioned was really important. I know that the pandemic set back a number of initiatives. The convener talked about the year during the pandemic when the number of cases being diagnosed went down because of a lack of screening.

This committee has a strong record on championing women's health. That is best evidenced in the committee's role in advancing truth and justice for mesh-injured women. We now have a real opportunity in Parliament to pick up the challenge that has been set by the World Health Organization and to show that Scotland has the necessary expertise and knowledge to do so, and we must not sit back and wait to get the wheels in motion.

I will end by reiterating my support for Emma Keyes's petition and her campaign. I know that Emma, who is a cervical cancer survivor, at one point feared that she would not live to see her three children grow up. Thankfully, due to our amazing NHS and Emma's tenacity, she is here to fight and to show others that, even with a dark diagnosis, there is hope. Emma has taught us that we can prevent and eliminate cervical cancer if we use all the tools that are available to us, and that is what the petition is about.

I thank the committee for looking at the petition, and I hope that we can discuss it again in the future.

The Convener: I thank Monica Lennon for her contribution to the aims of the petition. You gave a heartfelt tribute on behalf of your constituent, who is the petitioner. You are quite right that over the years, the committee has been fortunate in the number of courageous people who have come forward to lodge a petition on the back of their experience. The committee has been able to give additional voice to the aims of those petitions, profile them and take them forward. Of the long list, you alluded to Elaine Holmes and Olive McIlroy on transvaginal mesh, but we should also acknowledge Amanda Kopel, who was successful in lobbying for changes to legislation in support of those who are diagnosed early with dementia, and our former colleague Elaine Smith, who was proactive on issues relating to women's health and took those issues forward with the committee.

The petitioner is in the excellent company of women who have been at the forefront of ensuring that we are able to advance issues that have resulted in a material change in the way that the Scottish Government and Scottish public life approaches them. In light of that, we should write to the United Kingdom National Screening Committee to seek an update on its work to gather further evidence on the benefits of HPV self-sampling, including work to assess and validate a test for HPV selfsampling in the UK. Are there any other suggestions from colleagues?

David Torrance: I wonder whether we could write to the Scottish Government to seek an update on the working group that has been established to assess potential models and understand any required changes to the screening programme to support the initial roll-out of HPV self-sampling. Monica Lennon has highlighted that that is really important, and my better half just lost a cousin at the age of 39 last Friday to the illness, so I know how important it is to get sampling done and to get tested.

The Convener: Thank you very much to the petitioner and to Monica Lennon. Are members content with the suggested action, and for the petition to be held open and for the committee to advance its aims?

Foysol Choudhury: Can we also try to find out what the barriers are that prevent women from various communities taking up cervical screening? Is there a way that we can ask for that data?

The Convener: We will incorporate that into the request of the Scottish Government and see whether it can give further insight into the best body to ask for that information. With the addition of Mr Choudhury's suggestion that we seek to establish what barriers people face, are members content to proceed as suggested?

Members indicated agreement.

Annexe C: Written submissions

UK National Screening Committee written submission, 8 July 2024

PE2088/B: Help eliminate cervical cancer through improved and at home HPV testing

The UK National Screening Committee (UK NSC) is an independent Scientific Advisory Committee that advises Ministers across the UK on all aspects of screening. The Committee reviewed the evidence on the use of human papillomavirus (HPV) self-sampling as a programme modification within the NHS Cervical Screening Programme in February 2019. Self-sampling might lead to an increase in uptake as it may reduce some of the barriers that prevent people from engaging with the screening offer, including availability of appointments, physical disability, and past trauma. The Committee recognised that HPV self-sampling offered a promising test, but that further work was required to ensure its feasibility and value in the current screening programme. Pieces of work are underway:

Self-sampling for non-attenders (those who have not attended at least 6 months after their appointment, or have never attended)

YouScreen is a research programme that investigated the end-to-end pathways for introducing self-sampling for non-attenders in the NHS Cervical Screening Programme. GP practices across North Central and North East London were given the opportunity to take part in the YouScreen study offering HPV self-sampling to non-attenders aged 25-64 and those at least 6 months overdue for cervical screening. The research has finished but is yet to be published.

The UK NSC have commissioned an evidence review to collate and assess the evidence of the acceptability and effectiveness of introducing self-sampling for non-attenders, including findings from YouScreen.

Self-sampling for women who attend for cervical screening

UK NSC, NHS England (NHSE) and the National Institute for Health and Care Research (NIHR) have designed an in-service evaluation which will provide evidence on the effectiveness and feasibility of introducing self-sampling to all eligible participants.

To identify appropriate self-sampling devices for the evaluation the UK NSC and NHSE carried out a study to see how accurate self-samples were compared with clinician-taken samples. This study, called HPValidate, has been completed.

The study evaluated 5 self-collection tests. These were combinations of 3 different self-sampling kits:

- Copan Diagnostic's FLOQswab
- Rovers Medical Devices' Evalyn brush
- Hologic's Multitest Swab Specimen Collection Kit

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and the 2 human papillomavirus (HPV) assays used in the NHS Cervical Screening Programme at present:

- Roche's cobas 6800/8800
- Hologic's APTIMA Panther

The companies have received their results and an academic publication is awaited.

All these projects will inform UK NSC recommendations. Given the timings of the work the committee will first consider self-sampling for non-attenders, then consider its use for all participants once evidence is reviewed from the ISE.

Self-sampling has increased the uptake in the bowel screening programme. It is hoped that this could lead to a similar increase in people being screened for cervical cancer as it will reduce some of the barriers that prevent people from attending.

Scottish Government written submission, 12 July 2024

PE2088/C: Help eliminate cervical cancer through improved and at home HPV testing

As previously advised, the Scottish Government, along with the other UK Nations, relies on advice from the UK National Screening Committee (UK NSC), an independent expert advisory group which informs decisions taken across the UK on screening programmes. The UK NSC is expected to make a recommendation on the use of self-sampling within the cervical screening programme later this year, or early in 2025.

The working group that was established as part of the scoping work for a business case for cervical self-sampling stands ready to resume this work upon a positive recommendation from the UK NSC.

The Scottish Government remains committed to reducing inequalities in both access to and uptake of all of the national screening programmes, including cervical screening, and acknowledges that more work is required to improve in these areas. As part of this work, we commit £1 million annually to tackle inequalities within the cancer screening programmes, and in July 2023, published the Scottish Equity in Screening Strategy with Screening Oversight and Assurance Scotland, providing direction and focus to tackling screening inequalities.

Further to this, we continue to explore other avenues alongside self-sampling, that may improve uptake of the cervical screening programme, including the consideration of better use of digital technology or more personalised communications with eligible participants.

Public Health Capabilities