

# CPG for Women's Health Meeting Minutes

Wednesday 25th January 2022, 12.30-1.45pm by  
Microsoft Teams

## Agenda

### **1. Welcome & apologies**

- Monica Lennon welcomed all attendees and introduced the call.

### **2. Introduction**

- Monica explained who attends CPG meetings; a mixture of MSP colleagues, other stakeholders, people who might be part of a group or an organisation or individuals who have an interest. Monica invited MSPs to identify themselves in the meeting.

### **3. Matters arising**

- Monica welcomed Lizzie Smith of Endometriosis UK, who provide secretariat for the CPG for Women's Health; Lizzie introduced herself to the attendees.
- Survey to be circulated after the meeting: new members have joined and there has been interest in the group and how to join. The survey will capture key priorities, what people care about and give attendees a voice. Monica asked that attendees complete the survey if they are able.
- Minutes of the meeting 25 October 2022 proposed, approved and seconded by the meeting.

### **4. Cervical cancer prevention in Scotland**

- Monica introduced the topic of cervical cancer awareness week and speakers, Emma Keyes who is campaigning for cervical cancer to be higher up the political agenda and Iona Stoddart from Jo's Cervical Cancer Trust.

### **5. Speaker 1: Iona Stoddart, Jo's Cervical Cancer Trust**

- Iona introduced Cervical Cancer Prevention week 2023 and outlined Jo's Cervical Cancer Trust biggest ever campaign, to end cervical cancer.
- Iona described how Scotland has the tools to end cervical cancer; a wide-reaching HPV vaccination programme and effective cervical screening and colposcopy services, which can help prevent cervical cancer from ever developing.
- Iona detailed the barriers to the prevention programmes: screening being difficult for some due to anxiety and/or trauma, physical barriers such as pain or inaccessible GP practices or simply not having the information and/or time. School-based HPV programmes were impacted by the pandemic and the catch-up programmes have been effective but some inequalities persist.
- Screening and vaccination uptake is lower in the those living in the most deprived areas and there are disparities amongst different ethnicities and communities.
- Iona outlined how Jo's Cervical Cancer Trust are calling for government commitments to eliminate cervical cancer by tackling inequalities in cervical cancer prevention, ensuring there is appropriate workforce, technology and research to prevent cancer. HPV self-sampling could make cervical screening more accessible.
- Iona shared that in a recent survey by Jo's Cervical Cancer Trust, 70% of over 800 professionals working in and alongside cervical cancer prevention, felt HPV self-sampling was the biggest opportunity to eliminate cervical cancer in the UK. HPV self-sampling clinical accuracy is high but with a slightly reduced sensitivity for higher grade cervical cell changes, so it would be important that as many people as possible are still encouraged to attend clinical-led screening.
- Alongside government commitments, Iona noted that targeted interventions and engagement must continue and that Jo's Cervical Cancer Trust have been working with stakeholders across Scotland to provide training and awareness sessions on cervical health and to engage with women who are less likely to participate in cervical screening, to work with them and understand barriers they face.

## **6. Monica Lennon to introduce Emma Keyes**

- Monica introduced Emma Keyes, outlining her personal experience and involvement in campaigning work around cervical health and screening.

## **7. Speaker 2: Emma Keyes, Campaigning for at-home smear testing**

- Emma shared her experience of delaying her routine cervical screening due to common barriers, including a busy family life, work commitments and general accessibility. Emma also noted that as a young woman, she did not think her age group was especially at risk and felt that this information had never been made clear for her.
- Emma described later being seen at her local hospital where she was told any treatment would be undertaken on the day, however biopsies were taken which later confirmed a positive diagnosis for cervical cancer. Emma detailed her treatment, including a hysterectomy and how her experiences have led her to campaigning, specifically around the roll-out of HPV self-sampling as well as exploring some of the barriers women face in accessing cervical screening, including trauma, busy lives, disabilities and embarrassment in asking employers for time off.
- Emma advocated strongly for the roll out of HPV self-sampling to catch cervical cell changes early, before cancer develops, ultimately helping avoid the difficult decisions and harsh treatments that are part of a cervical cancer diagnosis.
- Monica thanked Emma for sharing her experiences and for her campaigning work.

## **8. Discussions from members and questions for speakers**

- Monica first invited MSPs to comment or pose questions.
- Jackie Bailie MSP thanked Iona and Emma for their presentations and asked for the copy Iona shared in her presentation to use for a first ministers' question on the subject of cervical cancer. Jackie detailed experiences of her constituents facing lengthy waiting times for colposcopies following an abnormal cervical screening result and the impact that can have on the individual. She hoped to underline the importance of deploying the resources Scotland has to prevent cervical cancer, as detailed by Iona, to help make cervical cancer a thing of the past. Iona responded that she would share the copy and detailed how the Jo's Cervical Cancer Trust

helpline has noted colposcopy delays being a 'hot topic' for women in Scotland at present.

- Carol Mochan MSP thanked the speakers and shared her interest and prior experience in women's health, specifically cervical screening inequalities. Carol has previously raised the subject of HPV self-sampling to the Minister for Women's health (Maree Todd MSP) in March 2022 and was told the government were awaiting further evidence, which now seems to have been acquired: Carol expressed her support for the self-sampling initiative to be pushed. Carol also shared information in the meeting chat of an event in parliament on January 26th for MSPs to learn more about a recent report on cervical screening and figures on screening and vaccination statistics in different constituencies.
- Monica commented on the importance of distinguishing between the HPV self-sampling process and cervical screening in a clinical setting and referenced the Dumfries and Galloway pilot scheme on HPV self-sampling. Emma emphasised the importance of the government's role in improving education on cervical health, explaining and signposting the different testing options available to women and recognising that making the cervical screening options more accessible and better understood would ultimately save lives and resources, by avoiding the necessity for costly cancer treatments.
- Monica asked if Iona was aware of any progression or issues with the Dumfries and Galloway pilot scheme: Iona explained that Jo's Cervical Cancer Trust are calling for the government to back the HPV self-sampling initiative but that it falls to the National Screening Committee to make a formal recommendation before the initiative can be rolled out. Further research on the specific swab type to be used is currently being waited on before progress can be made. Iona shared that similar HPV self-sampling initiatives have been successfully implemented in other countries, including Australia, the Netherlands and Sweden.
- Emma Roddick MSP thanked Emma and Iona and asked that they share their key resources and asks to MSPs.
- Monica acknowledged the meeting chat where requests had been made for Emma's social media handles to be shared so attendees could support her campaign work.

- Fiona Robinson thanked the speakers and emphasised the importance of recognising that trauma and pain experiences can be a significant barrier to many who are invited to attend a cervical screening appointment. Fiona felt that the barriers of trauma and pain are often not acknowledged, with a greater focus on 'forgetting or embarrassment' and that acknowledging the experiences of trauma and pain in cervical screening campaigns would be beneficial. Fiona also highlighted the increased prevalence of these barriers for those from marginalised or minority groups. Monica thanked Fiona for sharing these points and referenced previous meetings where the 'My Body Back' project had been discussed and Dr Audrey Brown had attended to speak about support for those who have experienced sexual trauma and/or violence.
- Dr Jonathan Sher from the Queen's Nursing Institute Scotland, is currently leading a programme called 'healthier pregnancies, better lives' and queried if another way of addressing the issue of cervical screening uptake, in addition to the HPV self-sampling initiative, is to promote the idea of medical appointments having multiple purposes. So when an individual attends for one reason, they are offered the opportunity to have a variety of tests and screenings at the same time, similarly to the screening processes outlined within the 'healthier pregnancies, better lives' programme or in the style of 'well woman' clinics. Jonathan acknowledged that one of the barriers to cervical screening is that it is a separate, 'special' screening and that if it were integrated into other appointments, it may be improve cervical screening uptake.
- In reference to Fiona's point on trauma and pain as barriers to cervical screening, Iona detailed research undertaken by Jo's Cervical Cancer Trust that identified multiple barriers, including trauma, emotional barriers and cultural beliefs. In Scotland, Jo's Cervical Cancer Trust is piloting a clinic with Ayrshire and Arran, to hold cervical screenings for those who need additional support. Jo's Cervical Cancer Trust are also involved in sample taker training in some locations, which involves sharing information on barriers to support healthcare professionals in adapting their practice. Jo's Cervical Cancer Trust is also in the process of creating their new five year strategy, in which those with a physical disability are focused upon. Iona also acknowledged Jonathan's suggestion as a good idea to remove barriers.

- Monica recognised the work of Jo's Cervical Cancer Trust in being inclusive, setting the agenda for women and those with a cervix, as well as for people with neurodivergence and people with learning disabilities.
- In response to Jonathan's references to 'well woman' clinics, an attendee, Michelle, shared her experience of attending a clinic of this type whilst living in the USA and how a cervical screening at the age of 22 led to her being diagnosed with and treated for precancerous cervical cells. Michelle was advised to have yearly cervical screenings for monitoring purposes whilst in the USA but upon her return to the UK, as she was below the age of having routine cervical screening, she was denied the yearly screening. Monica detailed how in a meeting with Maree Todd MSP, she queried which other countries' models of practice the Scottish government are reviewing and assured meeting attendees that any ideas or suggestions of good practice they have that could be used to develop the Women's Health Plan currently under review should be shared and Monica will write a letter to Maree Todd MSP.
- Emma shared that she felt Fiona's point about trauma and pain being a barrier to clinical cervical screening further supported the need for HPV self-screening to be made available, in addition to a recent experience shared with Emma where a lady with a learning disability had a traumatic experience as she wasn't able to understand the procedure.
- Fiona Robinson reiterated her support for the HPV self-screening and queried if there is any action to be taken by the CPG for women's health and interested stakeholders to maintain the pressure and emphasise the need for the HPV self-screening programme to be approved and implemented. Fiona shared a report in the meeting chat in which Jo's Cervical Cancer Trust uses evidence gathered from healthcare professionals to call for the introduction of HPV self-screening programmes (We can end cervical cancer: The opportunities and challenges to eliminating cervical cancer in the UK ([jostrust.org.uk](http://jostrust.org.uk)) and encouraged interested parties to continue asking the government for updates and keep the conversation going.
- Dorothy Grace, secretary of the CPG on chronic pain, thanked previous speakers for their contributions and ongoing work and shared her experiences of over 20 years of consultations that did

not ultimately enact change. Dorothy Grace noted that a significant proportion of the issues not addressed were in relation to concerns facing women and how chronic pain is an issue that disproportionately impacts women, hence her involvement in the CPG on women's health. Monica commented on the importance of tackling societal misogyny as well as medical misogyny.

- Iona thanked attendees for their comments and questions and reiterated Jo's Cervical Cancer Trust's goal to bring an end to cervical cancer, in line with the ongoing global strategy, which currently, the UK has not committed to.
- Emma thanked attendees for their support and noted her ambition to increase understanding of cervical cancer and the preventative strategies available to all ages, including school age girls being offered the HPV vaccine, in addition to her campaigning for the roll-out of the HPV self-sampling. Emma also shared her Instagram handle: @mrs\_smear.
- Monica thanked all contributors and shared her action to write to the Women's Health Minister and the Cabinet Secretary.

#### **9. Date of next meeting**

- A virtual meeting on Wednesday 22<sup>nd</sup> March, 12.30pm – 1.45pm, on the topic of Endometriosis, as March is Endometriosis Action Month.
- Monica invited any attendees who wish to comment on anything relating to the topic of the next meeting to email the CPG mailbox - [alice.murray@parliament.scot](mailto:alice.murray@parliament.scot).

#### **10. Any other business arising**

- Monica shared her hopes that by the next meeting, a women's health champion for Scotland will have been appointed.
- Monica reiterated her call for attendees to respond to the survey, to ensure the CPG on women's health can be proactive and address key issues.

**Meeting closed.**