

## Minutes of the Women's Health Cross-Party Group

18 February, 18:00 – 19:00, Online Meeting

### Attendees:

#### MSPs:

- Carol Mochan
- Elena Whitham

#### Non-MSP Attendees:

- Kate Sang (*member*)
- Pat Menzies, Endometriosis UK (*member*)
- Reuben Duffy, Office of Monica Lennon MSP (*member*)
- Hazel Gardiner (*member*)
- Audrey Brown, Abortion Rights Scotland (*member*)
- Dorothy-Grace Elder (*member*)
- Iona Roxburgh (*invited attendee*)
- Chiara Cocco (*member*)
- Mhairi Campbell (*invited attendee*)
- Lynsey Matthews (*member*)
- Eileen Cawley, Scottish Pensioners Forum (*member*)
- Kellie King, Royal Pharmaceutical Society (*member*)
- Wendy Knoop (*invited attendee*)
- Jonathan Sher (*member*)
- Susan McKellar, Scottish Women's Convention (*member*)
- Tara Bachoo (*member*)
- Dr Sinead Cook (*member*)
- Dr Rosie Ilett, Faculty of Sexual and Reproductive Health (*member*)
- Jill Wood, Engender (*member*)
- Jaki Lambert, Royal College of Midwives (*member*)

### Speakers:

- Chand Kaur, Founder and CE of PCOS Relief (*member*)
- Neelam Heera-Shergill, Founder of Cysters (*member*)
- Carrie, Endometriosis UK Forth Valley Support Group Leader (*invited attendee*)
- Anji Sandhu, Unlipping PCOS (*invited attendee*)

**Apologies:** Monica Lennon MSP

### 1. Welcome

1.1 Carol Mochan MSP shared apologies from the Chair Monica Lennon MSP and noted she would be chairing this meeting.

1.2 Minutes of the previous meeting were approved:

- Proposed: Eileen Cawley
- Seconded: Hazel Gardiner

## **2. Speaker - Chand Kaur, Founder and CE of PCOS Relief**

- Chand gave an overview of polycystic ovary syndrome and its symptoms. Approximately 70% of PCOS goes undiagnosed worldwide.
- PCOS Relief focuses on health, education and supporting those from ethnic minority groups. PCOS is often stigmatised within Asian communities due to associations with infertility – PCOS Relief look to provide in-confidence support to women within ethnic minority communities, in several languages, alongside other support services. They also work to raise awareness of PCOS within Scottish Parliament.
- PCOS Relief are currently supporting 2500 women nationwide and want to expand their support to international audiences.

## **3. Speaker - Neelam Heera-Shergill, Cysters**

- Cysters has been active for around 10 years. They take a grassroots, intersectional and decolonised approach, combining faith, community and culture to ensure people are getting the best care across menstrual health, maternal health, menopause and mental health. This is needed due to the one-size fits all approach under the current NHS.
- Neelam reaffirmed Chand's point on stigma around PCOS within South Asian, Black and Chinese communities, given a high cultural emphasis upon fertility.
- Cysters is leading community-focused events, such as running sessions that harness holy scripture within Sikh communities, and Paint and Sip evenings discussing women's health research.
- As their work sits across different levels of intersectionality and oppression, Cysters must approach their work from a place of empathy.
- Cysters have been engaging in community-led research, teaming up with other organisations to take an intersectional inquiry on why women are being failed across the health system. Neelam noted that community-centred approaches can positively benefit the trajectory and dissemination of research, and Cysters are happy to work with researchers at the meeting on their PPI.
- They are also working with trans and non-binary communities, where they are learning lessons on how to work better and centralise the most marginalised voices.

## **4. Speaker – Carrie, Forth Valley Endometriosis UK Support Group Leader**

- Carrie provided a patient perspective on her experience of PCOS. She experienced symptoms from a young age, prompting issues with her education. Her pain became completely normalised, and she only realised that she may also have endometriosis following her nursing training. She has since struggled with the various symptoms of hormonal treatments for her PCOS and endometriosis.

## **5. Speaker - Anji Sandhu, Unlipping PCOS**

- Anji noted the social stigma in the UK against speaking on health, particularly women's health.
- Within her work, she looks to inspire open, honest conversations about PCOS, including through the half-lip selfie challenge. She has also worked to develop the PCOS Buddy App, to enable women to track their symptoms and empower them in their interactions with healthcare providers.
- Anji noted that women with PCOS often suffer in silence, impacting mental wellbeing and self-confidence.

## **6. General discussion**

**6.1** Lynsay Matthews asked for confirmation on if PCOS has a higher prevalence within minority populations. Neelam confirmed it does have a higher prevalence within South Asian communities, and that there is current research in this space. This includes high prevalence within the Arabic community, to an extent where PCOS has become normalised within this community.

**6.2** Elena Whitham MSP asked what was missing within the current triage process from GPs to provide appropriate care, noting Carrie's story of dealing with significant menstrual health issues at a young age.

- Carrie shared that after she was diagnosed with PCOS, there was no further conversation around additional conditions – she had to go back and forth with her GP 10 times before being referred to a gynaecologist for investigation of endometriosis. She had a specific moment where she had to request a second specialist opinion from her GP. She now works with patients within her Forth Valley support group to help them advocate for themselves.
- Neelam noted that GPs don't have a lot of time at each appointment – to better support them, she takes notes and tracks her symptoms. Doctors are also likely to tell people to lose weight if they are over a certain BMI, without further investigation into symptoms and treatment.

**6.3** Kellie King noted that focus should be placed upon advocating for more joined-up care across GPs and pharmacists. How do we engage to improve education and contact time to lift the PCOS diagnosis statistics?

- Chand noted that pharmacists can work with organisations like PCOS Relief, who can inform pharmacists on lived experience. Pharmacies can also work to educate and inform on hormonal medication/contraception. There are particular anxieties around this within ethnic communities, where medication relates to fertility.
- Carrie noted that nationally there are difficulties in getting certain contraception medications – a postcode lottery.

**6.4** Dorothy-Grace Elder noted that significant pressure is being placed upon community care, primary care providers and patients, given the long waiting lists for secondary care. Patients often don't know that they can ask to be referred on to specialist services. Certain treatments are being cut or phased out that can only be done by specialists. She also noted that there is a meeting on the 12 March on the upcoming Scottish Government health consultation.

**6.5** Audrey Brown noted that gynaecological services and waiting lists are disproportionately affected amidst the recovery from Covid. She commented on practitioners' emphasis on fertility – gynaecologists occasionally forget that not everyone with PCOS is infertile. Patients may then go on to not use contraception. It is important that patients know to discuss fertility and contraception. GPs must be encouraged to consider interaction and risks with other chronic diseases, e.g. diabetes.

- Chand noted that GPs are the first point of contact for those with PCOS. Most of PCOS Relief's members have had GPs tell them they are infertile. PCOS Relief are currently working to change this with 19 GP practices across Scotland. She noted that terminology around PCOS is often linked with infertility within primary care settings, and this is a particular issue for South Asian communities. People aren't getting the opportunity to then go on to secondary care for fertility considerations. There is a need to improve education for primary care practitioners.