

Cross-Party Group on Women's Health

22.03.2023 12:30-1:45

Minute

Present

MSPs

Monica Lennon MSP

Rhoda Grant MSP

Tess White MSP

Beatrice Wishart MSP

Invited guests

Professor Anna Glasier MBE

Emma Cox

Candice Mckenzie

Marion Graham

Lorna Taylor

Kirsteen Campbell

Non-MSP Group Members

Sinead Cook

Professor Anna Glasier

Pat Menzies

Alice Murray

Lorna Macfarlane

Dorothy Grace Elder

Philippa Balshaw

Rosie Ilett

Jonathan Sher

Professor Alexandros Zangelidis

Ms Brooks

Catia Montagna

Jackie Maybin

Hannah Wright

Siobhan Fergusson

Gillian Forbes

Marie Kerguelen

Lucy Grieve

Danielle Le Poidevin

Rebekah McNerney

Eileen Cawley

Jennifer Stewart

Susan Mckellar

Lucky Saraswat

Kirsty Kerr

Lynsey Mcluckie

Kirsten Kernaghan

Gillian McElroy

Christine Craig

Rachel Mclellan

Emma Cox

Sophie Baldwin

Heather Denham

Catherine Hughes

Miss Gardiner

Hannah Bardell

Apologies

Collette Stevenson MSP

Rachael Hamilton MSP

Emma Roddick MSP

Agenda item 1 Welcome

Welcome from chair Monica Lennon.

- Screenshot photo taken for CPG twitter account.

Minutes approved from January meeting

- Monica gives thanks to those who completed the recent survey circulated to members, the content will influence the topics to be addressed in these meeting sand areas to be worked on.

- Monica introduces meeting theme as endometriosis, discusses recent parliament Reiterated Women's Health plan has short & long term actions on endometriosis care

Agenda item 2 Professor Anna Glasier

Anna introduces herself to group and is delighted at being appointed and gave an overview of her new role. Explains clinical history as a Consultant in Obstetrics & Gynecology in Edinburgh. Since retiring from the NHS has continued to work in research in reproductive medicine.

- Priorities are to progress the actions set out in the Women's Health plan but emphasized she is realistic and has limited time so is going to concentrate on 3 areas and keen to focus on "Doing rather than Talking"

- Focus on

Menstrual health: PCOS, Endometriosis, Heavy Bleeding & Fibroids

Menopause &HRT

Women's Cardiac Health: prevent & Protect explore links eg PCOS and heart disease in later life.

- She has been in the post 7 weeks and will take the first 3 months to listen then from May 2023 will start as a "legitimate dissenter" and start asking the why questions, seeking to make real changes.

Agenda item 3 Emma Cox, CEO Endometriosis UK

Thanks for the opportunity to address the audience. Encouraged the meeting to continue to see Scotland setting targets for differences that would be put into practice especially in the areas of

➤ reducing diagnostic waiting times for endometriosis, she was heartened to see the call to reduce times from the 8 year average and hoping to see a real difference in the future.

➤ There is a real need to address the postcode lottery across Scotland for access to services and specialist help and intervention.

➤ Increase in treatment intervention for endometriosis sufferers, seeing it raised in priority alongside other conditions

➤ Commended the commitment from Scottish Government to address menstrual health and education in schools for all genders to empower and help earlier, aim for optimism for the future.

- Summary: Whilst there is a long way to go, she acknowledged the working together of all involved in raising awareness and seeking action, despite the difficulties, has got us this far and we can aim for more action in future. We must continue to push for better care and diagnosis for endometriosis sufferers in Scotland

Agenda item 4 Lived Experience Panel

Note: As many personal stories were shared, full speaker notes will not be included in the minutes but there is a summary of discussion below.

Each speaker in turn shared their lived experience journey.

- Candice McKenzie Endo Warriors West Lothian
- Marion Graham Endometriosis UK
- Lorna Taylor Endometriosis UK
- Kirsteen Campbell North Highland Womens Wellbeing Hub NHWWH

Very powerful stories were shared by speakers of their journeys from diagnosis and through many and often lonely and harrowing interventions, sadly and repeatedly of not good experiences from and within both primary and secondary health services. Living with unnecessary grief that often ends up with people paying for private medical diagnosis & care. The inequality of service provision for women across regional areas in Scotland was evident.

Themes called for from their personal perspective and experiences were

- Recognition of gender injustice faced by women in healthcare in Scotland.
- Communications between different parts of the health service and where there is crossover of treatment.
- Address follow up from services in Gynecology eg. no written information or pointers to support following confirmation surgery. Patient left with diagnosis of incurable condition.
- Acknowledgment that common issues still faced 10 years on by most women. Call for real changes to be made on the back of Women's Health Plan.
- Call for better teenage health education and also impact of GP visits at that age that may have lasting effects by being "gaslighted" / dismissed with symptoms.
- Acknowledgement of impact of living with this condition on education, work and family life.
- Employment work adjustments acknowledging Endometriosis is a long-term chronic pain condition.

Agenda Item 4: Group discussion

- Christine Craig: Request for targeting support, reducing postcode lottery and financial privilege. Acknowledge rural services and the effect of centralizing services.
- Professor Anna Glasier: recognizes that those living in rural communities are limited in gynecologist options, especially for specialized treatment. We are trying to put together a national clinical forum for menstrual health problems, which will include endometriosis so that throughout Scotland, every health board we can identify someone who will take the lead on menstrual conditions.
- Lucky Saraswat, Aberdeen Specialist service: There is hope through more awareness

and research is being undertaken. We have just developed an endometriosis integrated referral care pathway, primary secondary to streamline care so it is not postcode lottery. There is increased training within our curriculum for obs and gynae doctors. What we need is also for GP's and other healthcare professionals to recognize the symptoms. We are also looking into extra pelvic endometriosis.

- Hazel Gardiner, NASUWT & Endo West Coast & Arran: Request for international dialogue and best practice. Suggested an annual conference. Address absence of management of endometriosis in the workplace. We still don't know what causes endometriosis which is big issue.
- Dorothy-Grace Elder: explains link to chronic pain CPG, the majority of this group are females and many endometriosis sufferers. There is a lack of openness in Scottish Health. Shares concerns over health officials recruiting via Facebook for paid patients panels. Raises link of women's health and mesh women who are still going through years of delay.
- Professor Anna Glasier: responds briefly to Hazel Gardiner and says that sadly there are many conditions in medicine we don't know what causes them; gives example of schizophrenia, preeclampsia. Both of these conditions are recognized and have been recognized for longer than endometriosis, so we may never know what causes endometriosis. But we need to know how to treat it. There are studies ongoing at University of Edinburgh to do controlled trials of non-hormonal treatment on endometriosis. As you will know, there are long waiting lists for procedures. But as Lucky said, there is glimmers of hope.
- Hannah Bardell: Thanks all speakers for the amazing work they do, explains that at Westminster they want to do everything they can and work with Scotland to pursue issues. We need to do more and should be doing more at party level. It has to be an effort guided and led by experts but also from sufferers and those who have experienced endometriosis. Agrees with Hazel's idea of a international conference and that this could potentially be hosted in Scotland. We need to work more across legislatures.
- Tess White MSP: Thank you all for coming and for all speakers today. The next meeting is on the 21st June at 12.30pm and details to follow.