Cross-Party Group on Women's Health 22/06/2023

12.30-13.45

Present

MSPs

Monica Lennon MSP

Beatrice Wishart MSP

Carol Mochan MSP

Invited guests

Bethany Ivison MSYP Neelam Heera-Shergill Rhianna Mallia

Non-MSP Group Members

Lucy Grieve J. Vonpierre Brittnee Levsen Philippa Bradshaw Helen Reily **Frances Johnston** Jessica Potter Gen Mincher Fiona Robertson Anna Tully Marie Cas **Dorothy-Grace Elder** Kayleigh Lindsay Susan Mckellar **Kimberley Somerside** Sophie Bridger Miss Gardener Sinead Cook Mohammed Abdel-Fattah Pat Menzies Alice Murray Emma Cox

Alexandros Zangelidis Sharon Hanley Olivia Brooks Catia Montagna Marie-Clair Munro Kirsteen Campbell Charlene Busalli Kirsty Kerr

Apologies

Tess White MSP Rachael Hamilton MSP

Agenda item 1 : Introduction by Monica Lennon MSP

The Chair Monica Lennon MSP, welcomed participants to the Cross-Party Group for Women's Health with the theme of this Group being on Gender Inequality.

Approval of March meeting minutes

The previous minutes were circulated to attendees via email. They were approved by the Cross-Party Group and seconded by Susan McKellar.

Discussion of the response from the Minster for Women's Health regarding Endometriosis

The response from the Minister for Women's Health came through 22 May 2023, there were no further comments from the participants

Scottish Employment Injuries Advisory Council Bill Correspondence was received from Mark Griffin MSP in regard to the current work which is being led by Mark's Office. The CPG was invited to comment on the sections relevant to Women's Health and the gender pay gap in the Scottish Employment Injuries Advisory Council Bill. Monica Lennon MSP commented that it was a positive step that Mark reached out to us for our comments. There were no further comments from the Group in regard to the Bill.

Agenda item 2: "Experiences of Accessing Healthcare".

The Young Women's Movement discusses their new research - Rhianna Mallia, The Young Women's Movement and Bethany Ivison MSYP Monica welcomed Rhianna Mallia who currently works as the Policy and Research Lead for the Young Women's Movement and Bethany Ivison who is a Member of the Scottish Youth Parliament and has assisted Rhianna with the new research report, "The Status of Young Women in Scotland, Experiences in Accessing Healthcare 2022-2023". The report came out at the end of April and is available to access via their website and their decision for the report to be focused on healthcare was due to the fantastic ongoing work which is happening with the Women's Health Plan and their team and also the wider focus on Women's Health currently. Rhianna explained the initial approach into the report, including a background review to find out where there were gaps. To do this, three working groups were created with young women, practitioners, those from the third sector and healthcare professionals which provided a key insight into healthcare, an online survey which had over 900 responses and four discussion groups which consisted of the following:

- 1. Discussion Group for those in Rural Areas
- 2. Discussion Group for those with negative experiences in weight or body type
- 3. Discussion group for women of colour

4. Discussion group for people with long term condition. The report is an exploratory look into young women's journeys in accessing healthcare, from the initial GP appointment to the follow up appointments. Barriers that were noted by participants in the report included: - Issues with registering and making appointments - Not having enough services in their area - Confusing and rigid processes in place - The drastic change in processes since the pandemic - Inaccessibility generally and especially with phone conversations - The varied level of experience depending on where you are located in Scotland Good experiences that were noted by participants in the report included: - A variety and choice of healthcare options in their areas which were visible and easy to go to - Flexible options including digital options, for example: booking and accessing appointments online - Social and economic facts helped patients feel confident about making informed choices Statistics of young women's experience receiving healthcare were: - 40% of participants noted that their experience was just okay - 17% of participants noted that their experience was mostly bad - 8% of participants noted that their experience was mostly awful. It was also noted in the report that young women with intersecting identities experienced healthcare differently, with transgender respondents 57% more likely to relate their experiences negatively. Long term people with long term conditions also experienced much worse access to healthcare than others. The overall findings from the report showed that young women are not being taken seriously in healthcare settings, often being dismissed and their experiences or symptoms being minimised as "hormonal" or "normal". Young women experienced a lack of empathy from healthcare professions, as well as being rushed and not listened to during their appointments. An unexpected outcome that came the report was the level of selfadvocacy that young women felt they had to have in order to be able to attend their appointment. Women cited that they needed to feel "armed", strong, resilient and ready to fight for what they needed from healthcare professionals. An additional point raised was the UK wide issue of waiting times for appointments across the NHS and the lack of support for patients during the long interim. Patients that cited having good experiences with healthcare professionals included being listened to, heard, validated and believed in their appointments as the most important part of a positive appointment. Rhianna went on to explain the key four changes that need to happen in the healthcare sector in order for experiences to improve: - Access - it needs to be timely and flexible with an understanding that no one size fits all - Attitude and culture – systematic changes need to change misogynistic mindsets in the education of healthcare professionals Bethany then talked about the next project which she is working on as a result of findings from the report. She described that as one of the participants for the Discussion for Rural Areas working group, she really understood the lack of access, knowledge and limited choice in Clydesdale, as just one example

of a rural area. Bethany is working on a resource pack for both healthcare professions and young women to help them better understand what healthcare is and to ensure young people are able to advocate for themselves, regardless of their background. The initial consultation has been done and for the next phase, Bethany will be working with thirteen other young people over the summer to create self-advocacy resources. Both Bethany and Rhianna emphasised that for people to self-advocate, it often requires confidence, education and privilege which so many young people do not have.

Monica thanked both Rhianna and Bethany for the work that they have done and are doing and invited questions and comments from the audience. Fiona Robertson said that it was encouraging to hear about the work that is being done, and went on to describe the work she is creating which is a self-help guide to help those who had recently been diagnosed as disabled to self-advocate with Doctors in appointments. Rhianna agreed the way in which young women had to adapt themselves in order to get what they required came up a lot during the research. Fiona and Rhianna agreed to share their documents with each other. Emma Cox, CEO of Endometriosis UK spoke of how she also hears many stories from many young women and those with endometriosis, and that it isn't just limited to young women but people of all ages in their healthcare journeys. Emma offers any support that Endometriosis UK can provide in order to support the Young Women's Movement on their research. Kayleigh Lindsay asked if women's experiences differed compared to whether they had a GP appointment or a hospital appointment. Rhianna answered that young women had more positive experiences in hospitals than in GPs. This appeared to be because they were speaking to more relatable people to such as nurses, and this made their appointments more impactful

Agenda item 3: Health Inequalities for Marginalised Groups - Neelam Heera-Shergill, Founder of Cysters

Neelam Herra-Shergill introduced herself by explaining that the organisation Cysters was started by accident. This was simply because she had nowhere to turn for support and there was nowhere that understood the level of intersect of people of colour and people that are queer and wanted to bridge the gap of people becoming their own advocate. Neelam described that she currently has, amongst other health conditions, endometriosis. In addition to this, Neelam is South Asian and described her experience with systematic racism within the NHS and the patriarchal issues with heritage that often comes alongside people of certain backgrounds and religions, especially with menstrual problems. Menstrual problems can be seen within certain communities as a problem that is caused because the sufferer has done something wrong, either in a past life or they are receiving some sort of karma. Neelam noted that there are different statistics of white women's health, compared to other women's health and that white females are the majority of statistics. One of the reasons for this is because people of an ethnic minority or heritage are so disenfranchised with their experiences in healthcare that they do not want to engage with policy makers and researchers and they want to what has happened with the comments they have provided. Cysters has flipped the lid on research and they are now undertaking community research who are doing it themselves and is led by the

communities. In this way, the community are upskilled and also have the chance to advocate for themselves. Neelam noted that she no longer wants the exhausting task of often being the only person of colour sitting in a room advocating for these matters. An important note to take forward is that there isn't only a gender pay gap. but there are also a people of colour pay gap. Neelam advocated for stopping the use of "hard to reach communities" or "BAME" when it comes to having conversations around marginalised communities. It is not that they are hard to reach but that they are often not invited to join these conversations and therefore unable to produce equitable change. She observed that there are many conversations about how privileged people can use their privilege to make equitable changes happening, but it is vital in ensuring that marginalised voices are also heard. Monica thanked Neelam for coming today and invited participants to make comments or ask questions. Fiona Robertson asked what can be done to provide greater levels of support, including peer support, to people of colour who have recently been diagnosed as disabled? Neelam answered by suggesting that support networks do not have to work on their own to provide this support and urges other organisations and groups within the third sector to join together and collaborate. Dorothy-Grace Elder is the voluntary secretary for CPG on Chronic Pain. She spoke about a recent Scottish Government report which has just been released which mentioned the difficulty in reaching "hard to reach communities". The report cost taxpayers £40,000 and has a number of flaws. FOI documents obtained by Elder showed that recruitment to a pain patient panel, which formed part of the report, had stipulated that anyone who required a translator should not be accepted . Instructions to recruiters obtained under FOI were marked "thank and close". She objected strongly to this. These were surely the most "hard to reach" of all patients being excluded from even one needing an interpreter and this should not have happened. People with language difficulties would therefore not be on any kind of group or register to help manage their pain. Often people who required a translator were not asked about their pain at all due to the costs of procuring a translator. Neelam answered but saying that this is sadly not something she hasn't heard before, but what does help is hearing a person like Dorothy-Grace speak about the issue openly. The queer and trans communities also suffer in these particular areas, and it is an overarching problem in intersectional decolonisation that there is an ongoing history in gynaecology that needs to be addressed. Monica raised the question to the group of who is missing from this group, and what voices do we need to hear more from. Kimberley Somerside works as the Policy Lead for Voluntary Health Scotland and spoke of her recent work on radicalised health inequalities where a lot of the topics spoke about in this meeting has also come up. In their work, it is looking at the impact that racism has in the health and social care sector and that often communities feel that they are being constantly researched into. Kimberley recently did a presentation for the CPG on Health Inequality and will share the presentation with Neelam. Mohammed Abdel-Fattah is the Co-Director of Aberdeen Centre for Women's Health Research and School Medicine, Medical Sciences and Nutrition at University of Aberdeen. He spoke about the recent positive step of providing free sanitary ware to all people who are menstruating in Scotland. Mohammed is currently doing a report in his work about health inequalities and references the phrase "hard to reach communities" quite often and asked Neelam what the alternative phrase should be used if it is deemed as inappropriate. Neelam suggested the phrase "systemic erasure" or "not as typicaly sort out communities". Tata Batchu runs some of the Cysters Support Groups and wats to link up with

Mohammed to discuss ongoing work that is happening on the ground and see how they can get involved. Professor Alexandros Zangelids is the Professor of Economics at Aberdeen University and recently did a survey about women's voices being heard and 1/3 of the respondents stated that they did not feel cared for or empowered by a GP or Consultant. Alexandros stated if women are not engaged with these processes, you do see an adverse in their wellbeing following any treatment. He also explained the importance of patients journeys not ending when they have had a diagnosis, but it continues, and they are not heard enough. Beatrice Wishart MSP attended the CPG on Mental Health yesterday where the topic was looking at the impact of the cost-of-living crisis and how this is impacting Ukrainian refugees. There is a lot of information on how the health system is working, and the information appears that the people aren't to reach but it is the systems that are hard to reach. Monica Lennon MSP also expressed concerns over information that it is currently easier for refugees to go back to Kiev or Poland to get health treatment than in the UK.

Agenda item 4: AOB

There is currently no date booked in for the next meeting. Recess is next week and parliament will re-start in September so future dates for the next CPG will be shared soon. Monica Lennon MSP also wanted to share the good news that the North Highland Women's Hub recently released a public survey into the current healthcare situation in the highlands and also did a petition. These are a big push on the issue of endometriosis care but it does also go wider than just endometriosis. Kirsteen Campbell thanked Monica and said that it has been a very busy year so far and the Hub has only just turned one. Monica promised to share the survey on various platforms to provide more opportunities for the survey to be completed. Monica reminded the group that there although things will be quiet during recess, there will be information and resources shared on the Women's Health CPG Twitter platform that people can access. Monica finished the CPG by thanking all for attending the session with particular thanks to the speakers and those who made contributions.