Attendees

Monica Lennon MSP

Carol Mochan MSP

Rachel Hamilton MSP

Beatrice Wishart MSP

Jade Heffron (Secretariat)

Pat Menzies (Secretariat)

Rebecca Mason, Young Women's Movement

Emma Cox, Endometriosis UK

Holly Marr, West Lothian Warriors

Tara Bachoo, Cysters

Claire, EWWL

Dionne McFarlane

Dorothy-Grace Elder

Rueben Duffy

Rachael Duffy

Erin Colquhoun

Hannah Johnson

Isobel MacEwan

Jo Campion

Kirseen Campbell

Kirsten Kernaghan, PGR

Lynsey Harvey

Marie Kerguelen

Marion Graham, Endometriosis Grampian

Olivia Brooks

Endo Warriors West Lothian

Neelam Heera-Shergill, Cysters

Rachel Mclellan

Kate Sang

Elinor Sebire, PGR

Sinea Cook, NHS Grampian

Vicky Champman, Endometriosis UK Volunteer

Professor Alexandros Zangelidis

Hazel Gardiner

Apologies

Tess White MSP

Jackie Bailey MSP

Katy Clark MSP

Cross Party Group for Women's Health

Meeting Tuesday 12 March

18:00-19:15

Online via Microsoft Teams

<u>Context</u>

The theme of the meeting is '*Endometriosis Awareness Month - Endometriosis and Menstrual Education'*.

An essential part of the Scottish Government's Women's Health Plan, Endometriosis, is still a growing concern in Scotland, with diagnoses and care for patients getting worse, rather than better. 10% of the UK's population have endometriosis which means a considerable amount of people are suffering without the due care, support, and treatment that they need for many years at a time. March is Endometriosis Awareness Month, and we look forward to you coming along to this CPG to hear from a range of different speakers about the vital and important work that is ongoing, hearing personal experiences of those directly involved and engage in informative and helpful discussions.

Introduction

Monica thanked everyone for attending, with special thanks to the MSPs. Monica is the Chair of the Women's Cross-Party Group for Women's Health and is a Member of the Scottish Parliament for Central Scotland Region.

Monica provided a brief overview of what the Group is, which is a forum of MSPs and Stakeholders, which she recognised isn't the best word to use but essentially means anyone in the public who had an interest in the issue of women's health. The Group discusses how we can raise awareness of women's health and better inform the development of policy.

Monica is pleased to confirm the topic of this session which is endometriosis which is not by accident due to it being Endometriosis Awareness Month. There is already significant interest in this topic, and it is an issue that is returned to as often as possible.

She explained that endometriosis is an important part of the Scottish Government's Women's Health Plan and there are some important commitments in the acknowledging the many challenges around waiting times for diagnosis and for treatment. This is often heard about in this forum, and it does feel like it is getting harder for people, rather than better.

Approval of last meeting minutes

There is one small addition that needs to be amended of Helen Reilly from Queen's Nursing Institute Scotland who has been missed off the attendee list. Jade has confirmed that she will ensure this will be amended before formal distribution of the minutes. Carol Mochan MSP proposes the minutes and Sinead Cook seconds it.

Monica reminded the Group that if attendees are part of an existing organisation that is already a member of the group, people are welcome to join on their company's behalf. However, in the event of a vote, there will only be one vote per organistion.

Brittney Gibson is a volunteer for Endometriosis UK and a patient advocate for endometriosis and is a newly proposed member of the Group. She sent her apologies at the last minute, however, the Group agreed confirmed the acceptance of her joining in her absence.

18:05-18:15: Emma Cox, CEO of Endometriosis UK

Monica welcomed Emma Cox, CEO of Endometriosis UK who will be providing an overview of the Diagnosis Survey with a focus on the Scottish statistics. Emma thanked everyone on the call and for the invitation to speak and for having the theme as 'Action Month'. It was decided this year for the topic to be 'Action Month', not just 'Awareness Month' because although awareness is important, action is what is really needed.

Emma began by providing an insight into the Diagnosis survey. The first survey was done just before the pandemic and been repeated in 2023 so there are direct comparable, physical figures right from the beginning of 2020. It was decided for Action Month this year to look at diagnosis times and it is fully recognised that treatment is not great. Endometriosis UK acknowledged that there is a lot of aspect to this issue, but due to what they are hearing from across the UK, Scotland being absolutely no exception that there is people who were not getting access to diagnosis and it was feared that things had got worse, rather than better. Unfortunately, they were right. The aim of the report was to get people to start thinking 'could it be endometriosis'? The survey received the best part of 6000 responses, however for the report, the responses have been narrowed down to people who have a diagnosis in the UK by a healthcare professional, to ensure that the data was really tight which resulted in 4300 responses as part of the data for the report.

There were 400 responses from Scotland and once the data was reviewed, the results of England and Scotland were remarkably similar, which is interesting because the last time the survey was completed, the timescale for diagnosis was longer in Scotland, however at the current time it is the same.

Emma thanked everyone in the forum if they filled out the survey in as this important because Endometriosis UK cannot do any of the work without their input.

Unfortunately, since 2020 diagnosis times have increased to a UK average and Scotland average of eight years and 10 months. When the survey was done in 2020, the average for the UK and Scotland was eight years, therefore there has been an increase of 10 months. This is interesting because although it has increased in Scotland, it has increased by t he least amount compared to other nations in the UK and Emma said it was important to recognise that although we aren't there yet, the work that the Scottish Government are doing around trying to raise awareness and improve care of endometriosis should be considered.

There are several figures which Emma wanted to draw particular attention to from the report although she recognised that these would not be a shock to any of patients who are going through a diagnosis or have done in Scotland recently. The report finds that 74% of respondents had been to their GP 5 or more times and 47% been to their GP 10 or more times, with symptoms prior to a diagnosis which is a huge amount of NHS time that is being used, whilst people aren't receiving the information they need. 52% of those surveyed had visited A&E once.

However, it is not just in Primary Care settings where this is happening. It was also found that 20% of those people who had responded had seen a gyneacologist 10 or more times before getting diagnosis. This means that these are going through a long journey and are not even hearing the word endometriosis for all these visits. Emma acknowledged that she is preaching to the choir at this forum, but we know that we need to reduce diagnosis times because once somebody gets the diagnosis, they can make informed choices about their treatment and care. Also, until they get a diagnosis, they will be unable to access treatment and management and the disease may progress. It is known that endometriosis is a spectrum condition which affects everyone differently and some people might have mild symptoms, whereas others can have severe and debilitating symptoms. It is important to bear in mind that for some people, not getting a diagnosis could have a permanent impact on their long-term health going forward. This is heartbreaking, especially when hearing stories, particularly that of young people who have not been able to get through even to a medical professional which is of a particular concern.

One of the survey questions asked was how many people who later went on to get a diagnosis of endometriosis, had previously had a healthcare professional tell them they were making a fuss about nothing or similar, or were not believed. Endometriosis UK tried to ask this in the most neutral way possible and they also received advice from UCLH social science team about how to ask this. The data showed that 78% of respondents were at some point told that they were making a fuss or something similar, which has increased from 69% in 2020.

There is an understanding of the impact that COVID had on the NHS, and it is known that nobody is going to try and use the NHS when they don't need to, so the fact that people are going in and they are not being believed is especially worrying.

There are some positive data which has come out as a result of the survey. 10% of people had endometriosis mentioned in the first or second time they went to the GP, which is great. But what is needed is for this experience to be the majority, not the minority. One of the calls Endometriosis UK are asking from the Government is to commit to getting an average diagnosis time of a year or less by 2030. Emma recognised the Scottish Government have made by committing to drive down endometriosis diagnosis time, but a there needs to be a target to work to, which there is not currently.

Emma went on to discuss some of the reasons why diagnosis times are increasing. It is already known that COVID has had an impact, but it is also important to note that it is the non-cancer gynaecology list that grew the most by any percentage. In Scotland, Endometriosis UK are hearing that patients are receiving very different experiences based on where they live. Some of the specialist centres are able to keep all their operating time that they had before COVID, whereas other centres have had all work paused for many months, if not years. And that is assuming that patients can get access to a specialist centre. This shows that there is still a real issue about a post code lottery of care.

Endometriosis UK are calling for the NHS to wake up to the issue and recognise the severe detrimental impact that endometriosis can have and will give it due priority compared to any other condition that would also have the same impact. It is acknowledged that this can be difficult because endometriosis affects everyone differently, but Emma explained that it is absolutely imperative that those who have severe endometriosis or severe symptoms of endometriosis should get treated the way that other conditions are being treated.

Another important part of the report was the analysis of ages people got symptoms for their endometriosis. The respondents were asked: ‘Knowing what you know now, when did you first think you had something that wasn’t a normal period?’ and it was also asked: ‘Looking back, that now that you have a diagnosis of endometriosis, and you know what the symptoms are, when do you think now that you actually had symptoms of endometriosis?’. The results proved the that the myth that you can’t get endometriosis when you’re too young is still very much in place, with 30% of those with endometriosis first noticed their symptoms when they 16 or younger, and 50% felt that they had symptoms when they were 16 or younger. Emma acknowledged the absolute need to knock the head on the myth that you are can’t get endometriosis symptoms until you are older and this also reinforces the need to support young people, adolescents and teenagers with a diagnosis. By pulling this data out it will enable the change in narrative that young people are just ‘being dramatic’ and they are too young to understand their own body and symptoms.

Endometriosis are calling for the Government to commit to a diagnosis time of a year or less and for the NHS to recognise the volume of work that is needed to improve waiting times and to make plans to deliver that. There is not enough surgical time planned and increased access to appointments is also required. Emma says that people may say that the NHS is just too busy, however it can be argued that the number of appointments which are already unnecessarily wasted that we have seen from the data is not helping this improve. By streamlining the service, more time can be spent on people getting diagnosed with their treatment going forward. NHS Commissioners in different NHS Boards also need to recognise the impact endometriosis can have on individuals and therefore need to get the diagnosis times down.

There is also a huge task around awareness, particularly for healthcare practitioners. There is currently the NICE Guideline and Quality Standard which has been adopted by Scotland. These documents clearly states that all healthcare practitioners should recognise the symptoms of endometriosis and consider the possibility of it being endometriosis when seeing them. There is also work that needs to be done to make sure medical schools, professional bodies etc. are teaching mental health and endometriosis effectively to medics coming up through the system and are also doing so in a compulsory way. There are a few places where this is being done very well, but not everywhere.

Public awareness also needs to be improved. From the report, it shows that a lot of people often wait, with an average of just over three years before seeking help. It appears that a lot of people who are suffering question whether it is serious enough to seek help and often don't think their symptoms are worthy of bothering their doctor or even confiding with other people, such as family members, friends, or work colleagues. If people do not recognise the symptoms in the same way, they can often be downplayed, which is why much more public awareness is so vital.

Public awareness in educational settings such as schools also needs to be improved and is key in teaching menstrual health age appropriately in a way that doesn't scare anyone, but provides the tools needed. It will also teach young people to seek help if it is needed.

There are examples of people being diagnosed really prompted because the symptoms are recognised, but this needs to become the norm, not the exception.

Monica thanked Emma for an excellent start to the session and really loved the idea of 'Action Month', rather than 'Awareness Month' which will be important and hopefully result in a few calls to actions. She acknowledged the concerning statistics that have come out the result, but appreciated how great it is that people took part in the survey to share their own experience. But the fact that women are still not being believed and being told it is all in their heads whilst wasting peoples time is unacceptable.

18:15-18:25: Livvi Brooks, Bloody Amazing

Livvi has a diagnosis of Stage 2 endometriosis and found the Endometriosis Diagnosis Report triggering as it has been her exact experience in dealing with the NHS. Livvi got her first period when she was 12 years old on Christmas Eve. She didn't tell her parents for a couple of months as she didn't have any idea what was going on, however upon her parents washing her clothes the issue was brought up. It resulted in her Mum being slightly in denial that she started her period, and her Dad taking her to Tesco where they were standing in the period product isle, hoping for a female employee to guide them in the right direction. Livvi having a period wasn't spoken about with her parents.

It wasn't until Livvi was 14 that she started to experience debilitating symptoms to do with endometriosis. She didn't know what was wrong at the time but the symptoms she suffered from was very heavy bleeding. It wasn't until she was 14 and realised that her friends were able to do activities such as cycling, play tennis and wear white shorts that she wasn't able to have that experience that there was something wrong.

Livvi was diagnosed at age 19 privately with Stage 2 endometriosis. She went privately because her experiences with the NHS included being told she was being dramatic and that everyone had heavy periods. In one appointment, the GP got a tablespoon from a drawer, poured some water in it and said that this is actually how much she was bleeding, and that she was overstating how much she was actually bleeding. She also was reluctant to go on the pill at age 14 as advised, so therefore her options within the NHS were limited.

Despite having a private diagnosis of endometriosis, the NHS still won't accept this as a formal diagnosis. Livvi was given a laparoscopy and in her surgical report, they found adhesions in her womb and bladder but that still supposedly isn't enough to merit a diagnosis. She was told by her GP to seek a second opinion from a second gyneacologist. The original gyneacologist ended up writing back to Livvi and told her that they had spoken to everyone who was relevant and to not bother getting a second opinion because they wouldn't ultimately do another surgery as they have already decided what is wrong with Livvi. Because of this she is being bounced around various departments within the NHS whilst trying to be taken seriously.

Livvi then went on to share some more information about Bloody Amazing. Bloody Amazing is a teacher led enterprise who is made up of five teachers and their mission is to foster a main arc (first period) and menopause literacy across Scotland. They target schools and workplaces and as they have seen this is where they get the most impact. They aim to teach clarity and connection because it's important to understand it is not just about having a period and having a bleed.

51% of the world's population is impacted in some way by having a period and the whole world is arguably also indirectly impacted. Bloody Amazing's aim is to teach in an inclusive manner, so they include people from all gender diversities and additional support needs. Livvi herself is an additional support needs teacher and has firsthand seen how periods can impact autistic people in a particular way who have sensory issues. They also aim to teach about sustainability because although there is period product provision in Scotland, there is still an environmental impact about too much disposable waste being sent to landfill.

It is also known that periods impact every aspect of education, and that menstrual health has not always been delivered. However, in most settings, the education has been in Primary settings and S2 grade, however the way it is delivered is often chauvinistic. The lessons only usually happen once in education and it is mainly focused on the female anatomy and just that bleeding will happen for a week once a month, but with the outcome that usually it will all be okay.

Bloody Amazing believe that it is important that education on menstrual health is provided because it isn't just children in developing countries that are not able to access school because of lack of period products which brings a sense of shame about periods. Although period products are free in Scotland, it isn't always accessible and it is only through period education that young people can make full use of the range of products that are available, where to get them, learning their benefits and drawbacks and most importantly, how to use them. It is important not to assume parents are going to show young people how to use period products.

Livvi went on to say that period education needs to look different for transgender and non-binary young people, who are just as likely to be impacted by periods but who also have different struggles as period education improves health outcomes.

It is important to ensure young people are understanding of their entire cycle, or just that a bleed happens as this will improve better knowledge about pregnancy prevention, improved body image, self-esteem, and improved ability to look after oneself throughout the whole cycle. Better education will also improve practical elements such as better hygiene, less UTIs and toxic shock syndrome, which is also very important.

Livvi stressed the important that young people know what a normal and abnormal menstrual cycle looks like, and how to advocate for themselves in a country where you can expect to visit a doctor five times with the same symptoms to only be offered the pill or nothing.

It is also known that periods are still a taboo subject which is rife in shame, especially in some religions and cultures. Bloody Amazing have been doing some work with local mosques to deliver Relationships, Sexual Health, and Parenthood (RSPH) education as there have been instances of students being pulled out of RSPH education in schools, due to fear of what will come out as a result of the education which means some students aren't getting knowledge of periods at all.

Everyone who Livvi has spoken to has said how much Bloody Amazing is needed, but the amount of people who expect the service to be delivered for free isn't great. Livvi wishes she could deliver it for free, however it isn't practical given the climate of diminishing budgets and cluttered curriculum at school. Livvi works in a variety of schools including Primary, Secondary and Provisions and she can see that the schools do not have the resource to take this in. Bloody Amazing have found that their emails and other communication often go ignored, because schools are dealing with so many enquiries and complaints from parents already. Livvi has a friend called Julie who works for Unicorn Cup, who are the leading provider of menstrual cups in Glasgow at the moment. Julie found that only seven out of 32 of those took her up on the offer because they either didn't get an email or were unable to open it. Often, Unicorn Cup and Bloody Amazing come against the attitude that it is not important, or that this type of thing should be taught by parents. However, it is known that many people grow up disadvantaged in Scotland and therefore talking about periods are not top of peoples to do lists.

Livvi spoke about getting emails from male teachers who are frightened about talking about periods because they do not have all the facts or are generally just scared to talk about it as they won't deliver it properly. It is also known that some parents will just blanket withdrawal from RSHP altogether.

Bloody Amazing are doing a lot of work currently. Some examples include having done whole day school workshops that have been viewed by the Period Dignity Officer in Glasgow City Council who advises that they were fantastic resources, and she only wishes that it could be afforded for the whole authority. Bloody Amazing have also created resources and partnerships with Muslim organisations and families who can help protect their disadvantage in obtain this knowledge in their community due to the sense of shame when speak about these issues in a public place. They have successfully recruited someone on their Board to hopefully bring as much diversity as they can. They also offer school and parental twilight sessions for anybody, from Primary to Secondary schools and Livvi has delivered training on social stories which are appropriate for children who have got autism or any additional needs.

Monica thanks Livvi for firstly sharing her experiences and is very sorry for the barriers that she has faced in terms of a diagnosis and treatment. She went on to say that the work she is doing with young people is really inspiring and for several years, this Group and many others, including Emma from Endometriosis UK worked to try and get this on the curriculum to ensure that where anyone is in Scotland, students are receiving accurate information. She said it was right to mention that there is legislation on free period products that provides options and access and was pleased to hear of the growing demand for reusable period products. She seconded Livvi's point regarding the lack of time and capacity for this all develop.

18:25-18:35: Rebecca Mason, Research and Policy Lead for The Young Women's Movement

Rebecca introduced herself as their Research and Policy Lead for The Young Women's Movement, which is Scotland's national organsation for Young Women's feminist leadership and collective action against gender inequality. Their work is very much led by young women, and it is for young women. Every year, they publish a large-scale research project that focuses on a particular issue that matters to young women at that moment in time. It was noted that in their most recent status of young women in Scotland's report on accessing healthcare that young women face substantial obstacles when they are accessing healthcare, especially reproductive and sexual healthcare. They believe as an organsation that all women should be able to access safe, high quality and timely healthcare without fear of being dismissed or ignored by healthcare staff and that young women deserve to be listened to and meaningfully heard when describing the worries, or their symptoms to GP and hospital staff. Their report engaged with over 1000 young women in Scotland, who expressed that they felt ignored and their concerns had been dismissed when accessing healthcare. Since the publication of the report, The Young Women's Movement have continued to work very closely with young women to better understand how they can have a more positive experience within their local communities.

EmBody to EmPower came as a result from this report and it is a resource for young women, made by young women, to support them, to feel confident and advocate for themselves in healthcare settings. Rebecca said that Livvi's story really resonated with her as this is something young women have told them that they really do not feel like do know their rights and they don't know how they can push for themselves in healthcare, and they wanted an overall understanding of the system in more detail. This included registering with a medical centre, a doctor, or a dentist and how to make these appointments, or more information about having treatments. Healthcare for young women is a journey.

The project consisted of a group of young women who co-designed three digital and physical resources to help create a more inclusive understanding of what a positive experience of accessing healthcare is, what it looks like and how young women can build the skills and the confidence to self-advocate within the healthcare settings.

For the Young Women's Movement, it's important to amplify and empower young women's voices, ensuring that they are being proactive in removing barriers to their participation. They wanted to create a resource that is reflective of their experiences, is helpful to young women and is also helpful to other people who perhaps are alienated or margianlised by the system. As a movement, it is incredibly important to listen to young women about the barriers they are facing every day, as well as listening to the people who are most affected by the existing gaps and barriers to accessing healthcare. Without implementing changes based on their experience, the situation will not ever change.

As a small charity, The Young Women's Movement can only do so much, but their report findings embolden us do something to improve the situation for young women and people of margianlised agendas today. In the report, young women made several recommendations relating to alternative ways to accessing healthcare which could be widespread and standardised across Scotland. This covered topics such as waiting lists, better access to information, signposting, and improved communication between healthcare providers. They also asked for better education for themselves around how they can access healthcare, their rights to healthcare and how conditions might affect them differently, as well as acknowledging that women's health is not a topic that is widely researched or discussed.

The right to health in Scotland is a universal right, but it should not assume that everyone automatically knows their rights, or how to access information on the right to health. From the work The Young Women's Movement have been doing, it has become clear that there is a real lack of understanding within the public of both the right to health, and how to access information that is safe on the right to health, these issues being structural.

Appointment booking was the most common barrier to young women's ability to make the appointments that they needed, and they heard from young women who were working, in education, had occurring responsibilities, and/or had long term or mental health conditions, which meant that early morning can be difficult, or they may struggle to communicate on the phone due to language barriers, or because of neurodivergence. Overall, they said that the system does not work for them.

The EmBody to EmPower resource includes tips and tricks for young women to advocate for themselves in healthcare settings and young women with disabilities or long-term illnesses were intrinsically involved in its design. This ensured that it is easily understood and accessible to all, no matter their health or their experience of accessing healthcare. This may appear quite simple, but it is a power document that brings young women through the process of understanding symptoms, keeping a log of interactions with healthcare providers and young women.

The young women told The Young Women's Movement that menstrual or health surrounding the reproductive system, including endometriosis was a real barrier and it does not surprise Rebecca to hear that many young women experience symptoms of quite a young age, or that it took up to 10 appointments. Young women said that they had to push to be able to not only speak face to face to a healthcare provider, but also to feel confident enough to articulate their symptoms.

One real issue with endometriosis that came from the research was that young women who perhaps do not present with the most common symptoms were less believed and healthcare providers would say that they were probably just experiencing heavy periods to take paracetamol and to get on with it. One of the most shocking things that young women told them was that even if they did have a diagnosis of endometriosis, their GP told them that nothing could be done for them, and it was something that they would have to manage on their own.

For The Young Women's Movement, it is really important that young women can understand what a positive experience of healthcare can look like, they can go into a situation not feeling dismissed, and they can also ask for further advice, and read further resources when engaging with the system.

Rebecca shared that if attendees of the Group wanted to have a look at the resource themselves, or download or order a free copy, it can be accessed on their website. Rebecca explained that The Young Women's Movement are hoping to go into schools and other kind of settings to talk to young people about this issue, therefore if anyone wanted to reach out to Rebecca to discuss this further, or if anyone had any further questions, to contact her on:

Monica thanks Rebecca for all the work happening at The Young Women's Movement and for coming here tonight to explain it in detail. She noted that she had made a note specifically about GPs and Primary Care.

18:35-18:45: Holly Marr, West Lothian Warriors - Personal experience

Holly began by providing an outline of her own story with endometriosis. Holly's journey started when she was 16, when she was experiencing very heavy and painful periods every month. She would be scared to attend school due to leaking, painful cramps, and anxiety which she imagines resonates with a lot of people in the Group today.

Holly's symptoms encouraged her to go to the GP, who explained that the pill would solve all her problems. As a young girl, she never thought to question anything that the doctor recommended, so agreed to take the pill as most women do. The pill masked Holly's symptoms for quite a while by stopping her cycles, as the GP said it would and she carried on as normal.

Holly was a fairly active teenager, where she played hockey and attended running clubs, and used to run every single day, which is something she loved and enjoyed. However, when she was 17, this all changed and she could no longer run outside due to crippling pain in her stomach and Holly would have to walk home from rural areas in agony. Instead, she started to run indoors, but this did not help. Holly sought help from her GP who was told that it was most likely IBS and to keep a diary tracking her foods and pain.

Later on that year, Holly was referred to A&E with acute pain with suspected appendicitis. She was told by a surgical team that her pain was not consistent with appendicitis because the pain had radiated across her whole stomach. Holly was discharged with no pain relief, but the following day was diagnosed as having a ruptured ovarian cyst with an ultrasound scan, with smaller cysts on both ovaries.

Holly ended up going to the GP every month with the pain becoming an intense part of her life. Despite her pain being the same levels as before, they used this to undermine her symptoms as not being critical, as they were not labelled acute. Holly was advised to desensitize herself from the pain to be able to move on with her life and to accept that ultimately, there were minimal options that the GP could do. For Holly, this was reoccurring day-to-day appointments at her GP Practice when she was finally permitted a referral for an ultrasound. The ultrasound, however, showed that there were no cysts on her ovaries. The ultrasound technologist at this appointment was the only person who said to Holly that he understands in this situation, that no news is not good news. He was also the first person to ever mention the word endometriosis to her.

At age 18, Holly had no idea what endometriosis was which left her franticly trying to search for various articles online to understand the condition, as well as to go back to her GP to discuss what endometriosis is and what to do next.

For Holly, it is extremely important to reflect on the inadequate level of education she received about reproductive health. At school, she was again told that they would lose around a tablespoon of blood per period which not only highly inaccurate, but it also meant that young girls are then scared if they grew up experiencing different from what they had been told was meant to happen, with nobody to turn to for support and guidance. The stigma on reproductive health in high schools are so bad that young girls are shamed into self-silencing about this from the ages of 12 and 13. They don’t talk to their peers or family members about this, but instead just suffer alone.

Holly went on to say that there isn't any early intervention in place or secure education about periods that can support young girls with topics such as PCOS, endometriosis, UTIs, STIs, PMS, sexual violence, or access to safe abortion. All these things are highly untouched in educational settings and by doing this, they are shaping the mindsets of young girls into self-silencing, without safeguarding their access to adequate education on their own bodies.

An example of this was when in her year group at school which was S5, Holly received a program delivered by a third-party charity on sexual violence. Although this may be considered a good thing, which for the most part it was, already half the girls in her year group had already been victims of sexual harassment or assault by age 16. The intervention was far too late in its delivery, and although this is reflective of different and extreme wider societal issues, the principles I really key in understanding the extent of neglect young people suffer and how this affects their skills, which is something Holly is extremely passionate about.

Holly goes on to say that these young women are not equipped with the knowledge to challenge medical professionals, much like herself, who was put on the pill and left to deal with the symptoms. She believes that they do not have an understanding of young women's bodies and they don't have the knowledge to challenge and have conversations with medical providers. Many of Holly's own friends at the age of 20 are still scared to go to their GP because of the level of gaslighting they receive. Even with Holly's own self educating knowledge of endometriosis, she still regularly experiences medical gaslighting very regularly.

Holly waited one year to be seen by the Royal by a gyneacologist consultant and she has also written a complaint to the NHS about her experience, telling them how bad her symptoms were progressing. She explained that she was in a crisis situation between receiving no help from her GP whilst waiting for a consultant, being in a free-floating space left in isolation. After her appointment, Holly was left with naivety, and was told that her symptoms were not consistent with endometriosis, and that she was also too young to have endometriosis. Holly wanted the consultant to rule out that she had PCOS, where she was laughed due to it being obvious if that was the case. Holly made her consultant pull up the scan of her ovaries to prove to her that her ovaries were not polycystic, only for the consultant when they did pull up the scans to be hesitant to provide Holly an answer as they seemed unsure. Holly then thought to herself that if she couldn't trust them, who could she trust and who is she left to turn to for her information?

Holly has now been on a wait list for a laparoscopy for around eight months, and during this time she has again been completely isolated with no support. She still does not have a diagnosis and is battling to get one. She has written letters to her GP's practice complaining about the attitude she has received during her journey and has also asked for a second opinion on her MRI scans because she does not know who she can trust in this process. She doesn't feel like anyone has her back, nobody listened, and nobody communicates with her.

One of the most frustrating things Holly has found during her journey is the lack of consistency in regional care, feeling it is a postcode lottery within the NHS service. There is a two-year waiting period to be seen in one area, women are being privately seen under the NHS in other areas and there are also other women who aren't even on a list because their healthcare providers are too busy safeguarding the length of wait lists to accept patients onto them. She goes onto say that every woman's story is different, and that this should not be the case when it comes to access in their area for healthcare, which is an incredibly frustrating and infuriating process that has made Holly herself feel insecure about her future in regards to what to expect and when to expect it, if she able to expect anything. There is no baseline of care and no repercussions for this at the provider level.

Holly has often been left feeling 'how can they talk to me like that, how is the standard in the level of care that I am receiving?', and though this, she has been left feeling that there are no repercussions in the way that medical professionals speak to patients and women are left with no protection in the healthcare system, and no voice to project our concerns. When these are voiced, women are ultimately felt very ignored.

Holly wants to say that her journey changed very drastically when she found Endo Warriors, and never has she had access to a community that has provided such a high level of support. The difference between NHS care and support groups is massive because the groups listen, understand, and help each other, and this group has become a safe haven for Holly. She doesn't feel like she can confide in her family, friend, or GP because although they have good intentions, they just don't understand. They don't share the same experiences which is so crucial to Holly. She explained her need to feel acknowledged and heard and one aspect of endometriosis is being ignored and the isolation that comes with it. Holly often feels that she is completely alone with nobody to turn to with help, or guidance. When she was referred to the pelvic pain psychologist, she communicated how much her mental health was impacted and although Holly was met with the upmost sympathy and the staff being the most genuine and caring people that you can experience and have contact with, they are lacking the resources to help women with chronic pain in terms of mental health. She wasn't offered any 1-1 support, which would be beneficial. Ultimately, what happens is you are categorised into a low risk group and left idle because of the resources they have offered and are available to them. Often, Holly feels that it becomes the lost case to communication her emotions with medical providers, and therefore she only feels comfortable in doing so with other women and Endo Warriors.

Holly knows that she won't be left alone in her support group, but she knows she will be ignored by the healthcare system, because that is ultimately what it came to for her experience and the way she views this system. Holly feels the most trust towards women in likeminded positions because it they share the same intentions and emotions, and the ability to trust someone is such an undervalued thing. Ultimately, Holly believes that local support groups are the only channel that have really mastered this.

As a young person, Holly wants to be optimistic that the future is bright, but it is extremely hard to do so when she has been met with some of the realities she has spoken about. Holly ultimately hopes that a healthcare system can be developed that values women in their positions. However, she believes that women's stories need to be taken forward and adapted into reform because female reform care is something that is missing in Scotland. Women need to be given the voice to shape the change that we want to see. Women with endometriosis have become experts in their own rights and in their own area and we all need to be part of that alteration.

Holly concludes her talk by thanking Candace Sinclair for allowing her to speak today on the Endo Warriors Groups' behalf, alongside Jade and Pat for organising the talk. Despite Holly's position of being undiagnosed, she hopes that her journey and her position as a young person has provided some valuable insight into the realities of many young girls in the system today.

Monica thanked Holly for her honesty and courage while sharing her story for which she has been left speechless. She is glad to hear of the support that she found with Endo Warriors and echoed how voices really do matter.

Monica discussed the actions following the panel which included writing letters to the Scottish Government about the concerns raised here and will liaise with Jade and Pat after the meeting to get this done. Monica will also liaise with the MSPs to ensure they also make an impact.

18:45-19:05: Group discussion and Q&A

Tara Bachoo began by saying it was an inspiring evening that that she was proud and glad to be a part of. Tara has been working with Neelam and Cysters for around four years who is also a biomedical scientist, who is not too far off graduating as a doctor. Tara has been a patient of endometriosis and therefore has the benefit of both medical knowledge and patient experience. Tara got her endometriosis diagnosis during COVID and wanted to highlight is that women are often pushed to the point of crisis before they are taken seriously. For her, it was a life and death situation as her ovary had burst due to scar tissue which ruptured nearby blood vessels which led to an internal hemorrhage. Tara doesn't like to think about what might have happened if she didn't have the operation and this situation is replicated in so many women who are pushed almost to death, whether it be psychological or physical, or a combination of both. From her own experience professionally as a scientist, gyneacologist research has been the forefront of her priorities since Tara was diagnosed herself. She explained that women's health is a discipline and that they have very elaborate clinical descriptions to help diagnose patients. For example, women may present with symptoms such as a stabbing pain, firework pain, boxing glove pain or pain that feels like barbed wire. But when looking into scientific literature, molecular detail is incredibly sparse, which is a prime example that female anatomy and physiology is not actually understood. When looking at scientific research papers, the first thing that comes up for endometriosis is that it is a benign inflammatory disease that causes infertility and that's all. People cannot be told whether it is genetic, or auto immune, or what links it has to cancers such as breast or ovarian cancer for example. If the answers to these scientific questions were known, treatments could be started such as prophylactic treatment which could save the patient intensive alternative treatments that patients receive when they are older. This is putting women at risk from such an early stage. The final point that Tara highlighted was the general consensus of using metformin to treat those with PCOS. Metformin is used to treat type 1 diabetics which is autoimmune, and PCOS is a metabolic disorder. There is no link that has been proven so far that insulin resistance is caused by the same pathway when looking at it molecularly. The problem is that metformin has now been labelled as an off-label drug, so it is not actually licensed to be used for PCOS patients in the UK which is very concerning. Patients are being given a drug that is very strong and there is not enough evidence to show what cross reactions, side effects or potential tissue damage this could be causing to patients. Therefore, it is understandable that patients are not compliant with using metformin due to the side effects they are having. Tara explained that this is a damning reflection that healthcare, certainly in these aspects, is pretty much guesswork, and that there is very little scientific evidence to back up these decisions which is very worrying.

Beatrice Wishart MSP thanked all the speakers and said that she was almost in tears listening to Hollys' journey. Beatrice has been in touch with a young person in her constituency who is still in school and has recently been diagnosed with endometriosis, asking what it is she would like to say. The young person said her main question was if they are doing anything to change the way Doctors learn about women's health, particularly endometriosis. She experienced Doctors giving her misinformation and she also wanted to know if there is anything that can be done about education at schools for both pupils and teachers. The young woman said that she had been in a situation where she went to a pupil support teacher to help her deal with endometriosis during her exams and the school was unsure about how to help with this. Beatrice asked the group if anyone could help with these queries. Beatrice also went on to say that she does believe there is an issue in making sure that teaching staff are aware and can be as supportive as possible.

Monica thanked Beatrice for raising these questions on behalf of her constituent and noted that it really connected with what has already been spoken about this evening, especially with the work that Bloody Amazing are doing.

Neelam Heera-Shergill from Cysters explained that the work they do is essentially around menstrual justice and ensuring that the most marginalised person is centered in those conversations. She mentioned that the stories and statistics that have been shared doesn't surprise her. Neelam raised a point that she noted she has already raised in previous Groups, where she is disappointed to have to bring up again the lack of diversity on the panel. She explained that there is never people of colour in these panels all the time, which is a concern especially as it has been brought it the Group's attention on three separate occasions. Neelam clarified that it is not a case that people of colour are not affected by this condition, but they are more likely to be affected with diagnosis times more likely to be longer. Yet, when in rooms such as this, people of colour are still not in this space. Neelam is not saying that she wants a person of colour as a speaker at every event, but there are plenty of people in the space that are actively being ignored and dismissed even more so than what has been heard already. For Neelam, it is disappointing that again this is what she must speak about because if she hadn't attended the meeting, it is likely that no one else would have raised or even noticed this as an issue. Neelam urged everyone in the room who are working for advocacy in women's health to be mindful of centering marginalised people within these conversations, because otherwise, they will continue to be left out of the conversation and this work will have to be done for free as well as continuously just not be present or doing enough for all of the hard to reach community, which they are absolutely not. Neelam apologized for bringing the tone down of the meeting but stressed the importance of mentioning the issue because if she does not do this, people of colour will be another footnote in history again.

Monica thanked Neelam and assured her not to apologise. She went on to say that she was glad that this issue had been raised and apologised to Neelam that she had to say it again. Monica promised to take this away and to speak with the other Cross-Party Group members as well as the Secretary team and won't try and make excuses, but just to promise to do better.

Monica handed back to panel to see if they had any additional thoughts on the issues raised before returning to further questions. Emma from Endometriosis UK said that one of points that is being raised in the group is a historic lack of research into women's health. It is also important to reflect that not all women are the same, and to recognise diversity. Emma questioned when as a society we are going to wake up to doing more research that meets the needs of different people. Emma was very sorry to hear of Holly's journey and stated that a huge factor in these journeys is that there are in place pathways of care and processes that are not being followed. Emma went on to recognise that colleagues we work with in the NHS often go into that career path because they want to help people, so how is it that we can ensure they are making a difference. Emma asked if Monica and the other MSPs on the call if there was something they could do together to look at how they can get menstrual health conditions and endometriosis raised within the NHS. Monica responded to Emma by confirming that this can be done and there will be a range of actions that will come out because of this meeting to follow up on. Monica then handed back to the audience for any further questions.

Vicky Chapman had two points that she wanted to raise. The first was in relation to the waiting times within NHS Teeside which she wanted to flag up on behalf of Members. Whilst patients have been told of their waiting times, which at the end of the year was 47 weeks, there are now members being told that this has increased to 97 weeks and there is no information as to how this has happened. Vicky confirmed that she is going to raise the issue that she raised last year in Parliament, that NHS Teeside are not willing to engage with the local support group that she runs. Every time the Group try and contact them, the hospital do not engage. Tess White MSP is also trying to open up that conversation and Vicky explained that she is very grateful for doing that, and for inviting herself and others and Tess was unable to attend this session. The second point Vicky raised was in relation to a drug that was recommended to her last June. Vicky is under the care of the Grampian Centre in Aberdeen. She is unable to get the drug because NHS Teeside are unwilling to sign it off due to it not being on the formulary list. Vicky explained that this is another example of the postcode lottery of care that is happening because if you are in certain parts of Scotland, you can get the drug. Lots of people have asked Vicky why she doesn't just go private as the drug can be bought for £28 for a box of 28 tablets. However, Vicky questioned why it is she should go private when she is aware that other patients are receiving this drug via the NHS. Vicky also raised the issue of patients who already have a diagnosis and how they are sometimes forgotten about, and the importance of managing care going forward. She has had a recommendation made by a specialist, yet she is still unable to access the treatment she needs. Vicky has now decided to try something else because she is unable to access the drug recommended and stated how poor it is that other people can access the same treatment. There are also members in her support group who are trying to access the drug and Vicky does not know how to help them or support them to gain access to it.

Monica thanked Vicky for raising those two points and was pleased to hear that she is working closely with Tess White MSP. She noted that there are a few MSPs who do attend this group but suggested that if the are patients who are not in touch with their local or regional MSP to really encourage them to do so. She wasn't sure if Holly was receiving support for her journey locally but believed that by people reaching out to them MSPs, it provides opportunity to piece together what is happening in different parts of the country. Monica acknowledged that they do have a very unequal Scotland when it comes to accessing healthcare for endometriosis and many other conditions.

Dorothy-Grace Elder thanked the superb speakers at the Group and how fantastic it would be if everyone was able to speak up like that, especially with some being so young. She also wanted to follow up Neelam's point of diversity which she noted as being terribly important. She recognised that Cysters is a voluntary group, where people have worked hard to bring together but the exclusion is of people is happening from paid people in quite a lot of places. Only a few months ago, Dorothy complained about the issue with a meeting she attended where there was a panel of 16 which was created via a marketing firm. There was no one on the panel who required a translator and there also wasn't an option for one, which horrified her as this is creating a language barrier. It also likely means that it is cutting out somebody with a disability problem in relation to speaking as well. She noted the importance of this issue because as Neelam mentioned, it is likely that these people are most affected by these issues. Any condition if it is predominantly female will be found at the bottom ladder which is known and Dorothy would also include chronic pain in that, which both herself and Monica are on Cross Party Group for Chronic Pain, with the patients suffering being predominantly female. Dorothy explained that it appears that almost nothing is being done with the issues continuing year after year. Dorothy is a volunteer for this, as are others, and finds it exhausting to continue working to make a difference and still making a breakthrough. Dorothy also referenced the terrible of what has happened to women who received mesh treatment who received an official letter which explained that if they were to be compensated, the rest of the NHS would suffer. Dorothy would like a letter or action to be done as a result of this issue to help the mesh survivors.

Monica thanked Dorothy-Grace for raising the issue regarding the mesh survivors and agreed that the situation is awful. Monica agreed that is pointed to the issue about medical gaslighting and constant injustices that are happening. She noted that it is great that Marie who is a journalist who is in the Group but that more people like Marie are needed to help bring these issues to light.

Rebecca from NHWWH raised that she highly disagreed with heavy bleeding being taking off Endometriosis UK's symptom list and that the research does not show that it should be removed. Every single woman that Rebecca has spoken to with lived experience of endometriosis has had heavy and painful periods. Rebecca went on to say that a lot of people are quick to criticise doctors who are not sure how to address endometriosis but if the guidance and symptoms are not consistent, this makes it harder to diagnose. It is already quite a difficult issue because heavy bleeding overlaps with other conditions and although Rebecca is not excusing delays in any way, if the goal posts keep moving and national charities are not sitting with the guidance, that is confusing. Rebecca has also noticed a deep sexism within the NICE Guidelines, where there are a lot of conditions which are covered for men, but not for women. Rebecca noticed that in her local hospitals they are able to do a repair od a testicular torsion, but are not able to do an ovarian torsion and part of the reason for this is that there is no NICE Guidelines for ovarian torsion, but there is for testicular. If there was a NICE Guideline in place, Rebecca's local hospital wouldn't be deemed safe due to not having scanning and no access to emergency surgeries. The nearest emergency gynaecology surgery is around three and a half hours away which again comes back to the issue of treatment being a postcode lottery. On the point of schools and education, NHWWH have also experienced similar issues to Livvi where they have put on amazing community courses for young adults from 16 to 22 years of age women, yet the schools have refused to share them because they do not trust that their information is accurate. But they are also not looking for their own information to make sure that the gap is filled. Rebecca went on to say that education settings believe that the PSE they are teaching covers enough, and what they are hearing is that it isn't the case.

Monica thanked Rebecca and recognised that Emma from Endometriosis UK has had to leave her building so she will be unable to answer the specific point on heavy menstrual bleeding being taken off Endometriosis UK's symptoms list and asked if anyone can answer Rebecca's query in Emma's absence. Jo Campaign introduced herself as the new Public Affairs Advisor for Endometriosis UK. She explained that she was too new to provide an informed answer but will make sure that this is responded to and thanked Rebecca for raising the issue. Monica raised that she would also like to see the response which Jo confirmed will happen.

Monica recogised the engagement from the Group in the chat and again thanked Emma, Livvi, Rebecca and Holly for the contributions to the meeting and thinks that everyone has appreciated it. She hoped that people felt they got something out of the session and recognised it had been a really powerful and moving session with a lot of actions to follow up on.

19:05-19:10: Details of next meeting, Monica Lennon MSP

Monica raised details of the next Cross Party Group for Women's Health which will take place on Tuesday 11 June 18:00-19:30. There is no topic lined up currently and explained that she is keen to platform speakers that have not been heard from before. She noted that there is plenty of time until the next meeting to take on board what Neelam said regarding the diversity of the panel which she agreed was very important to do and will ensure herself and the Secretariat will do they very best to ensure that there is a diverse panel which will reflect the communities and hear the voices that keep her and the other MSPs informed as parlaimentarians. She thanked again the volunteers in the back to make these meetings happen and for the MSPs who turned up to tonight's sessions as it wouldn't be possible to have a quorum meeting without them as well.

Monica noted the topic of UTI which has already been suggested and she has also had people get int touch with her via social media regarding chronic UTI's, so that is something that is already on her mind.

Monica asks for any suggestions for the next topic of the meeting to be emailed to cpgwomenshealth@gmail.com. Monica said that both her and the Secretariat to come up with a panel as exciting but recognised that it will be really hard to follow the standard of what was heard at this Group. She spoke on how impressed everyone had been on the contributions that have been had.