CONFERENCE REPORT
Saturday 29th January 2022
Glasgow Grosvenor Hotel

The Scottish Women's Convention

WOMEN'S HEALTH

Agnes Tolmie
SWC Chair

I am delighted to welcome women back to our first physical conference in over two years. The last two years have highlighted that women have been more adversely impacted by the pandemic. Inequalities have been exposed and exacerbated, and the challenges of balancing childcare, paid work and caring responsibilities with the uncertainties of the pandemic have been truly daunting for many women, and affected their health.

We wanted to hold this conference to highlight the issue of women's health, to look at the Scottish Government's Women's Health Plan, and to discuss what is to be done to improve the health of women in Scotland. The plan was introduced in August 2021 and, as a nation, we are the first country in the UK to have a women's health plan. We're also the first country in the world to have free period products.

The plan was set out to address the disadvantages women face, and ensure women have an equal right to high quality healthcare. Women's health is about more than just reproductive health, and the lack of women's inclusion in medical research has led to a society that sees women's health in the same terms as men's; this needs to change. While we welcome the plan, we will need to continually develop it, ensuring women's voices are central to driving forward the improvements needed to eradicate women's health inequalities.

5 Key Points

- Scotland's Women's Health Plan is the first of its kind in the UK, but it is only the start of the work needed to tackle women's health inequalities.
- Education for women and girls must be improved to empower them to make better-informed decisions about their health and treatment options.
- Staffing issues in the NHS need to be addressed since many women working in healthcare are leaving because they feel overworked and underappreciated.
- We cannot underestimate the long-term effects of the pandemic on women's physical and mental health because so many women went without treatment for chronic conditions, had surgeries delayed, and experienced isolation during that time.
- Women often feel ignored, dismissed or judged in relation to their health, and we need more constructive conversations about women's health to end this stigma.

Maree Todd MSP – Video

Maree was appointed Minister for Public Health, Women's Health and Sport in May 2021. A pharmacist by profession, she worked in NHS Highland for 20 years, mainly as a mental health pharmacist in a psychiatric hospital. She also contributed to SIGN guidance on perinatal mental health. She was previously the Minister for Children and Young People.

The Women's Health Plan was published in August 2021, the first of its kind in the UK.

- Its 66 actions aim to raise awareness of women's health, reduce inequalities in health outcomes and improve accessibility of services and information.

"We know that women and girls have specific health needs and risks at different stages of their lives… yet many women and girls describe feeling unprepared for the impact that these things have on their lives and sometimes feel like there is not enough information."

- The plan includes developing a platform on the NHS Inform website dedicated to women's health, appointing national women's health champions, and establishing women's health networks.
- A menopause platform has already been launched on NHS Inform, "busting menopause myths, and providing information on symptoms and treatment choices."

Women can experience health inequalities because of where they live, but also as a result of their childcare and other caring responsibilities.

- "Women tell us that juggling these competing priorities often makes it difficult to take care of your own health, and that's why women's health is a key priority for the Scottish Government."

"Engagement with women was absolutely central to the development of the women's health plan, and that's why we're working with the ALLIANCE to continue the experience group to ensure women are meaningfully involved in decision-making and priority-setting going forward."

"We don't underestimate the challenges that will come in implementing this plan, but this is an opportunity to tackle inequalities and build a fairer future where health outcomes are equitable right across the population of Scotland."

- An implementation board met for the first time in January 2022 to ensure that the plan is carried out.
- In Spring 2022, an implementation plan will be published with timelines setting out how they intend to make change happen, and the first progress report will be published in Autumn 2022.

Esther O'Hara

Esther is based in Glasgow as a Speech and Language Therapist specialising in cancers of the head and neck. She has been a staff-side rep for 29 years across 3 health boards, and the convenor for Unite GGC Health Branch for the last 3 years. Esther also sits on the Unite Women's Committee in Scotland, represents Unite on the Scottish Union Learning Board, and represents her Health Board on the Unite Industrial Sector (Health) Committee.

Discussing the Women's Health Plan, she began "I'm not an expert, but I am a woman, a Scot, and a frontline NHS worker, so I have a vested interest on all three counts."

- "The Scottish Government aspires to be a world leader in its approach to supporting women's and girls' health. This plan goes way beyond anything in place or planned for in the other UK nations, and so it does make me proud to be Scottish."

She reflected on the fact that health is about more than being physically well.

- "Any plan to improve the health of a population, and to eliminate inequalities in health has to look not only at the provision of healthcare, but also social and economic determinants of health such as educational opportunity, employment opportunity, housing, caring responsibilities, income and so on."

"This is not a document about preferential care for women but about equity of care."

- She also highlighted that this is an inclusive document, making clear at the outset that it applies to anyone and everyone who requires access to women's health services including those who are transgender, non-binary or intersex.

She explained how medicine has historically been centred around male physiology.

- "Only in relatively recent years have we as a society, and to a certain extent within the medical professions, begun to openly discuss, debate and research the 'taboo' subjects of 'women's troubles' like menopause, endometriosis, miscarriage."
- It will ensure women scientists and health practitioners are involved in medical research and debates and seek women's opinions on health matters that affect them.

Emphasising that the Plan will be developed over time, she laid out its current ambitions:

- person-centred, joined up health and social care
- acknowledging other aspects that intersect with health
- consistent, accessible, and evidence-based information, empowering women to make informed decisions about their care
- properly funding and coordinating public sector services including the NHS, social care, and voluntary organisations to provide the best possible care
- menstrual health, abortion and contraception services, post-natal health, menopause, endometriosis, and tackling health inequalities are among the priorities
- the scope also extends to a range of other issues including violence against women and girls, the Mesh Survivors Charter, and screening for cancer and other conditions

Looking at how this will be implemented, she stressed that the disproportionate effect of the pandemic on women's mental and physical health cannot be overlooked.

- Women are usually the carers in the family unit, for children, elderly parents, and spouses, but many also have caring jobs, working long hours for little or no pay – "They were frontline staff, be it in health, social care, or retail, who were having to work flat out for ridiculous amounts of time and couldn't even be released for leave. The health toll of that will, I suspect, only really become apparent in future years."
- Being in caring and frontline roles, often with insufficient PPE, meant many women contracted COVID – "We do not yet know what the short- and long-term consequences of that will be. Even those without a long COVID diagnosis may well have unanticipated issues further down the line."
- Redundancy and loss of pay have been higher among women, the stress of which has many health implications.

She acknowledged that there will be challenges in delivering the plan.

- "It requires commitment, leadership and effort from all stakeholders, including those providing, supporting or receiving services, not just as the plan kicks in but in developing it. Only with full engagement of all parties can robust and more equitable healthcare be made available to women."
- Consideration must be given to women's changing health needs through their life.
- There are still barriers like the lack of female medical and associated practitioners, limited local services, and the recent drive towards developing centralised specialist health services rather than locally accessible and quality healthcare.

"Where there's a will, there's a way. The Scottish Government has demonstrated the will, now the women of Scotland have to step up and help develop the way."

Irene Oldfather – Video

Irene is Director at the ALLIANCE, leading on Strategic Partnerships and Engagement. As an MSP, she set up the Cross-Party Group on Alzheimer's and Dementia, drafting the Charter of Rights for People with Dementia and their Carers. Irene recently stood down as Chair of the National Dementia Carers Action Network (NDCAN), and she is involved in the European Patients' Academy (EUPATI) and represents Scotland's third sector on the European Economic and Social Committee (EESC).

Irene's contribution focused on the ALLIANCE's role in creating the Women's Health Plan.

- By working with a range of large charities and smaller community groups, they produced two reports: 'Hearing the Voices of Women in Scotland' and 'Scotland's First Women's Health Plan'.
- "It's been great to be leading on this in Europe and to know that Scotland is at the forefront in relation to women's health."

She explained how they gathered their information through a survey of over 400 women and a series of thematic online discussion events.

- They specifically tried to reach out to ethnic minority communities, inviting Sharpen-Her: The African Women's Network, and MECOPP, a charity who work with gypsy and traveller women.

Themes emerging from these revealed some best practice in women's healthcare.

- "The faster and more efficient the service, the happier the person who receives it."
- Women felt more positive when they were able to speak to women doctors.
- "Sometimes it's about having more than one appointment, because it's not just about diagnosing disease, it's about making sure women actually feel well."
- "On the whole, women were less concerned about which health professional they saw, and just more about having somebody to talk to who would listen and was able to give them appropriate information and advice."

However, the reports also demonstrated there are still shortcomings in current practice.

- Women did not always feel listened to, and some felt their treatment was not fully explained to them or that alternatives were not fully explored.
- It was common for the oral contraceptive pill to be given as a default – "Whenever you went in to talk about menstrual issues, the first line seemed to be prescribing the contraceptive pill, and that didn't always work."
- Stigma was a barrier, especially in ethnic minority communities – "Women often had difficulty talking about things as they felt they were being judged."

Consequently, women expressed what they would like to see from their services:

- information that was accessible and understandable, available in different languages
- proactive conversations about things like the menopause – "It's not just about identifying an illness or a disease, because the menopause is not an illness or a disease. It's about what appropriate advice can we give to women that will help them through these difficult times in their lives."
- producing information in a range of formats, such as videos on social media
- easy access to women GPs – "Having to explain to receptionists and other staff was a bit off-putting. It meant they had to talk a bit about what the appointment was about, and shouldn't it just be the case that if women want to see a woman GP, they should be able to ask for it. Let's just keep things simple."
- services that accommodate childcare and other caring responsibilities – "If you do have an appointment that is outwith school hours and you do have to take the kids with you, that shouldn't be a negative or a barrier."
- avoiding negative language relating to women's health, like 'the curse'

Irene emphasised that we all have a role to play in implementing the Women's Health Plan.

- "I don't think that it's something out there for statutory services to deliver, I think it's something that's everybody's business."
- "Gone are the days where women should have to hide any talk about the menopause, or periods, or contraception. As a society we should be able to speak about this openly, and women should get the time they need to be able to deal with situations that arise as a result of menopause or other issues that relate to their employment."
- "I hope the Women's Health Plan is just the very start of things. There's a huge amount to do, and I'd love to come back to you at a later date to tell you about the progress we're making in putting women at the heart of everything we do."

Jasbir Singh

Jasbir has worked with Sikh Sanjog since 2011 as a Community Development worker. She co-ordinates the Health and Wellbeing group for senior women which has been running for over 10 years, focusing on socially inclusive activities to promote health and wellbeing for women from Sikh and other ethnic minority communities.

Jasbir began by talking about the Health and Wellbeing group that she runs and how it was affected by the pandemic.

- Consisting of 20 women, the weekly group was set up to respect the cultural barriers that ethnic minority women face by giving them a safe space away from men.
- She runs exercise classes, health workshops, walking groups, music groups, gardening projects and regular trips out to help the women's broader wellbeing.
- "The women relied on the group each week as we'd been meeting regularly for years. For a lot of women, the group was their only way of social interaction."
- She explained the challenges she faced trying to move the sessions onto Zoom, but warmly shared that "Seeing other women again after so long, just being able to talk, and just to see their faces, engaging in conversation, it was amazing."

Another service that Sikh Sanjog were able to offer was an in-house counsellor.

- "When COVID hit, a lot of women benefitted from the counsellor because they just found it very challenging being in the house and having no access to the outside world."
- "There are a lot of barriers within the Asian community and a lot of women tend not to talk about the difficulties they've been through, so they could have these one-to-ones and just offload."

During the lockdown, she unfortunately experienced several health issues of her own. In March 2020, she went into hospital for a routine biopsy, but it went wrong, leaving her with a whole in her womb.

- "I had to stay in hospital for three days. It was a lot to deal with as I didn't have any of my family around me."
- "After that I had a lot of nerve problems and I couldn't explain exactly what was wrong, but it wasn't easy to speak to a doctor as you couldn't just go to your GP surgery in the lockdown. Also, I wanted to talk to a female doctor which was difficult as well."
- "I wish there was support in the hospital at that time. It was just a 'sorry' from the surgeon that something had gone wrong, but they gave me no support to deal with it."

Four months later, after a scheduled check-up, she found out that she had cancer.

- "Because of COVID, my surgery date was delayed, and every day seemed like a year for me because I just wanted it over and done with. I was meant to have the surgery within 3 weeks but, about 6 or 7 weeks later, I finally got a date."
- "It was just horrific for me as I had no one to talk to when I went in for my surgery. The nurses would only come round every so often to check my blood pressure, but it wasn't like a chat or anything, and they were all in their PPE so they would just quickly leave."

She shared that she had used Sikh Sanjog's counselling service herself after her failed operation but, to her disappointment, the funding had stopped before her cancer treatment.

- "You put all these things inside you, you put on this face, and you get on with things. But I actually needed that help, so I took the counselling which really benefitted me. Eventually those sessions had to stop, and I didn't know what I was in for next, and there were many women who had that same experience."
- "The build-up of all that over the year meant I felt like I still needed more counselling, I needed to talk to somebody. I contacted another organisation, and they had a waiting list of six months, but I wanted to speak to somebody now, I didn't want to speak to somebody in six months' time. I struggled so hard."

Looking to the future, she reflected on what her experiences during the lockdown had taught her and how she was going to take those forwards in her work.

- "After everything that has happened to me, it has actually made me feel stronger… now I'm starting to question health professionals myself and say 'no, I can ask questions.'"
- "When my operation went wrong, there should have been support there, someone to talk to me. So, I feel I want this to be on the health plan moving forward."
- "The present focus for Sikh Sanjog is we would like to get an inhouse counsellor or permanent service that is bilingual for all of our service users, and that understands all the issues that Asian women face."

Discussion

Osteoporosis

One woman raised concerns that osteoporosis was not identified as a priority in the plan and recounted her experience of living with the condition.

- She explained that 50% of women over the age of 50 have some level of bone density loss and will have at least one fracture within their lifetime, costing the NHS millions.
- Having been without medication or physiotherapy for more than two years during the lockdown, she was worried about the long-term and potentially irreversible effects on her and other women.
- She implored the Government to support more work into developing medication for the condition as currently only 30% of women using the drugs will still be taking them after 2 years because the side effects are so severe.

Endometriosis

The Glasgow support leader for Endometriosis UK recalled her journey to diagnosis and highlighted the barriers many women are facing.

- Despite having first presented with severe symptoms at the age of 15, she did not receive a diagnosis until a month before her 30th birthday.
- "These are conditions that have impacted on my quality of life, have changed the way in which I have to function day-to-day, and have impacted on my fertility… it's a lot to take on in your twenties to know that your fertility is not going to be as you had planned."
- Although she welcomed the inclusion of endometriosis on the priority list, she asked for clarity on precisely which procedures are covered in the plans.
- "COVID has obviously delayed surgeries and, in our group, we have women who have been waiting for diagnostic surgery or surgery to actually remove the endometriosis for more than two years. How is that going to be managed and not just seen as elective surgery because, at the end of the day, it's not really elective anymore?"
- When left untreated, complications from endometriosis can mean women are left with no option but a hysterectomy - "These are the worst cases, but these cases are starting to present on a more regular basis because that preventative care isn't being done at the moment."

A woman running an endometriosis support group in the Highlands shared these grievances.

- "There are a lot of people who are suffering and waiting far too long. Endometriosis is such a common illness; it's the same as diabetes or asthma if you look at the numbers, but so few people are aware of the condition or some of the symptoms."

Maternity and Fertility

A retired midwife of 45 years addressed the challenges midwives are currently facing.

- "The midwifery crisis is really scary for women of childbearing age. In Scotland, midwives are just leaving because they're so exhausted… I don't see any real movement towards supporting staff."

She also spoke about miscarriage, highlighting the detrimental effect that stigma around this issue has on women's mental health.

- Now pregnancy tests can show up positive within a couple of days, even though a lot of embryos are lost in the very early stages, "but to that girl, as soon as she sees that stick, she was pregnant. That was a baby to her."
- She spoke about the societal norm that "you don't tell anyone until after 12 weeks" and how this leads to many women carrying the grief of losing a baby without being able to share their pain or reach out for support – "the depression, the mental illness, the anguish that comes with that: it all goes unrecognised."

A fertility coach expressed her disappointment that infertility was not covered in the plan.

- "I had an ectopic pregnancy, I had miscarriages, I had failed IVF, I've had successful IVF because I went abroad due to the lack of care in Scotland."
- "1 in 7 couples is affected by this so I just think it is something that should be getting highlighted, and I think it is taboo because it affects women."

Menopause

As a menopausal nurse, one woman argued that employers need to be better at listening to women's needs at work.

- She explained that there are no fans in the building where she works, and she has to hide her hand-held fan from her boss for fear of disciplinary action.
- "I can't breathe in those uniforms. Maybe they could ask us nurses who are menopausal about what uniforms would be suitable… I know we need outfits that are environmentally-friendly, but we also need them to be menopause-friendly."

Esther brought attention to NHS Greater Glasgow & Clyde's menopause policy that was developed by menopausal or post-menopausal trade union reps. It is available online for anyone to see, and she encouraged women to use it as a guide for their own workplaces to adopt something similar.

Rare Diseases and Chronic Pain

Now diagnosed with hyperthyroidism, one woman recalled a male doctor's dismissive behaviour.

- "One time I went to the doctor, and he told me that kidney infections were basically just a poor design of the female body and I accepted that. It wasn't until years later and I got my diagnosis that I realised."

Sickle cell anaemia is a condition that mostly affects people from the African community, and one woman wanted to raise awareness of the systemic negligence of this condition.

- "Glasgow is experiencing a rise in people from diverse cultures and one of the effects of this is people with different diseases… people from the West have a different version of the disease call haemophilia or thrombosis and the health service is doing a good job of taking care of those, but there is not even one unit here that takes care of people with sickle cell anaemia patients, even though there are about 400 patients in Scotland."
- She also explained that a new drug has been developed and approved for sickle cell anaemia, but Scotland has refused to accept it, so she urged the Minister to explain and reconsider this decision.

Describing herself as a "rare disease warrior", one woman shared her experiences of living with and losing her daughter to a rare disease.

- "The criminal neglect of rare disease patients in this country is phenomenal."
- "The transition from paediatrics into adult care for women is absolutely horrific. Not only do you get transferred, but you also get rediagnosed… your consultants will tell you 'We don't have the specialist knowledge about that in Glasgow' or the doctors just won't believe the test results they see."
- "We don't get care; we get side-lined from care… you're labelled as 'challenging' just because you ask a question."

One woman living with chronic pain emphasised the continuous struggles women with long-term conditions face to be heard and how many women tragically lose that battle.

- "I've had several friends who have sadly passed away because they have committed suicide because they couldn't live with the pain and obviously no one listened to them when they were complaining."
- "We need to do much more to highlight that chronic conditions are real for many women and most women are tired of calling their GPs and not getting answers."
- "So many women suffer from things for a very long time, and yet I find it difficult to contact my GP over and over again for the same thing. You find that you become almost a bit of a problem, having to complain all the time."

Advocacy

One woman suggested that the best way to empower women in accessing health services is to invest in advocacy for all women, in addition to translators and interpreters.

- "We need mental and physical health advocates because, I know myself, I find it difficult on my own when I'm going to see doctors, and my first language is English."

Education

Several women reflected on the need for better education from an early age for girls and women to know their own bodies and feel confident asking for the support they need.

- "I think we should be empowering girls. It's so important because we talk to girls about their periods, but we don't talk about it through their whole life scale. That's really important, having that when they're young. We need to start sharing our stories and telling the young girls these things right away."
- "Our motto should be to educate girls young. Where you have well women sessions in doctors' surgeries, there should be something similar for young girls in schools so things like endometriosis and cervical cancer can be picked up. They should be part of the curriculum or put into workshops where girls have the opportunity to take part, because often these subjects are very taboo in the household."
- "Very few girls think about how their diet might affect conditions later in life, like osteoporosis. These things could be addressed a lot earlier if the support in schools was a bit better."

It was also suggested that, if there is a genuine commitment to improvement, doctors should be given protected time within their working hours for education.

- "I couldn't see much in the plan about education for doctors. A lot of the education seems to come from the third sector, and it seems to be voluntary; they have to go out and find a course. No doctor has the time to not be paid and go out for an afternoon for a course, so I think that would be really beneficial."

Effects of the Pandemic

Women working in healthcare discussed the challenges facing the NHS coming out of the pandemic, especially in relation to staffing.

- "Staffing in the NHS is appalling at the moment. During the most recent outbreak, we had 2,000 staff off, either isolating or off with COVID-related circumstances. The reality for the staff that are left is absolutely unbelievable."
- "I'm still sitting with 21 days of annual leave to take from last year and I'm not going to be able to take it. So, the Government's response is you can carry 10 of those days over or you can get paid for them, but they're not recognising that what people need is the time off and, actually, what they needed was the time off back then because people were pulling 14- or 15-hour shifts."
- "It's bred into us as NHS people, you just don't walk away from a patient, so you just work on."
- "A lot of workers are retiring because of the conditions, and we're losing the most experienced staff that can get it done and support other staff. They're all going to disappear."

Looking more broadly, women reiterated the need to address the long-term effects of the pandemic on the general population's mental health.

- "I think there has to be more work from the Government looking at the impact that isolation has on families. Even though we're sort of coming out of this period of pandemic, we don't know what's round the corner. It's going to take people a while to readapt to society again, so we really need to look at an in-depth analysis of what that isolation has done to people and how we can help."

Implementation of the Women's Health Plan

Questions were asked about what will be done at a local authority level to ensure that the plan is fully realised on the ground.

- "They make all the plans and recommendations, but then every five years or so, they make a new plan. Last time, there were around 40 recommendations but only 20 were implemented. What happens about the other 20?"
- "It's at a local authority level that these things are going to happen, so something needs to happen at the government level."

Thank You!

The Scottish Women's Convention would like to thank all of those who attended our conference, as well as those who contributed via email. We would also like to thank our speakers for providing their wealth of knowledge and experience, as well as brilliantly contributing to our broader discussion. The SWC will use all the voices gathered to feed back to policy makers regarding this timely and vitally important subject.

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