“This year celebrates the 70th anniversary since the establishment of the NHS. We thank the dedicated nurses and doctors who work tirelessly to ensure that healthcare issues are dealt with quickly and efficiently.

The work which the SWC has undertaken focusses on women’s health. We have heard from women throughout Scotland about their experiences with health services and professionals - some good and others not so good.

We all must work together to ensure that women’s health is given priority. Illnesses and diseases which are personalised to women must be recognised and managed with care and sensitivity.”

Agnes Tolmie  
Chair, SWC  
July 2018
Who We Are

The Scottish Women’s Convention (SWC) is funded by the Scottish Government to consult with women in Scotland to influence public policy.

Roadshows, roundtables, conferences and thematic events allow women from throughout Scotland to engage with the SWC and have their voices heard. The organisation uses information gathered from these events to respond to Scottish and UK Government consultations. This ensures that women’s voices are heard at the heart of the decision making process.

What We Did

In order to focus on key areas of women’s health, the SWC worked with health professionals to identify key priorities - breast and cervical screening; mesh implants; thyroid health; mental health.

Prior to holding a conference to discuss these issues, the organisation decided to explore some of the main concerns around these five key areas. By holding local roundtables and launching an online survey, the SWC was able to engage informally with key stakeholders.

Roundtable Discussions
Five roundtable discussions were held with various groups of women throughout Scotland.
- Kelloholm (rural women)
- Breast screening, Glasgow
- Community group, Govan
- BME women, Edinburgh
- Mental health, Glasgow

The notes taken from these discussions form part of this report.

Online Survey
While not a preferred method of engagement, the SWC had responses from over 1,300 women. Information came from each local authority area in Scotland and the SWC was able to gauge the key issues for women around health.

The survey responses have been analysed and are included throughout this report.

Conference
The SWC held a conference in Glasgow on Saturday 21 July to engage with women around health in Scotland. Information analysed from previous activities formed the basis for roundtable discussions. Speakers were women who had undergone diagnosis and treatment for major health concerns.

Feedback confirms that health is a major problem for women throughout Scotland. Some have indicated suggestions for change which may improve their healthcare experience while others are content with the service received.

The SWC would like to thank all of the women who participated in this piece of work. Your valuable contribution has been much appreciated.
Report on Women’s Health in Scotland

The SWC Conference allowed the organisation to invite women from throughout Scotland to attend this important discussion.

Speakers
Elaine Holmes and Olive Mclroy discussed the life changing impact of mesh implants.

Elaine and Olive live with the constant pain and crippling side effects of surgery that was intended to 'change their lives'. They launched a campaign for Scottish Mesh Survivors called 'Hear Our Voice'. Hundreds of women have joined to talk about suffering the effects of polypropylene mesh implant surgery, and the need to change the way the NHS seeks consent from patients. Not only have women empowered themselves, their relentless campaign has led to the procedures being suspended pending a safety inquiry. For the first time, the NHS in Scotland is also required to seek informed consent from every new patient, telling them every side effect of the surgery.

Since the conference, the Scottish Parliament’s Public Petitions Committee has issued a report urging Ministers to take stronger action to support women. A copy of the report can be found here


Wendy McDougall is a volunteer for See Me Scotland - a programme which aims to tackle mental health stigma and discrimination. She is a Community Champion and plays a lead role in challenging the stigma of mental health in her local community.

Wendy spoke openly about her battles with mental health issues as well as the support she has received from family, friends and the See Me Scotland project.

Lorraine Cleaver has been a thyroid sufferer for over twelve years. She was first diagnosed with hyperthyroidism and then hypothyroidism after surgery. Her battle to get a diagnosis and adequate treatment led Lorraine to petition the Scottish Parliament for improved thyroid care over six years ago.

Lorraine spoke about her struggle to regain her health, how she overcame those issues and how patients can take control of their health.

Copies of speakers presentations are available from the SWC website - www.scottishwomensconvention.org
Breast Screening and Cancer Detection

**Early Detection**

Despite the recognition that self checking of breasts for lumps or changes should be regularly undertaken, women are still unsure as to how this should be done.

“I do check now and again but I’m unsure what I’m really looking or feeling for. I suppose anything bumpy would be obvious if it’s painful or significant but I know that’s not always the case.”

“Perhaps the earlier we introduce this subject to young women, it will become more normalised, so they will feel informed and comfortable with checking themselves regularly.”

Many women are fearful that they may find something which could require further investigation. While it is acknowledged that this attitude is not a good one to have, it remains a key reason for not examining their breasts at regular intervals.

“I get anxious when I go to do it, convincing myself that I am going to find something.”

Women report a lack of centralised, clear and concise information about instances of breast cancer, as well as diagnosis and treatment. Being aware of the importance of early diagnosis and the range of options for treatment could go some way to encouraging more women to take responsibility for checking themselves.

Suggestions were put forward as to what could be done to encourage regular, confident self-checking.

“I used to have a card which you could hang in the shower. It showed you how to examine yourself and noted what was ‘normal’ and what wasn’t. It also had little circles for each month of the year, which you popped out once you had checked your boobs.”

“A monthly reminder sent out via social media or email would be good.”

Women between the ages of 50-70 who are routinely invited to attend a mammogram screening welcome the service and recognise the value of being checked. Although often sore or uncomfortable, the majority do attend. Some raised concerns about exposure to radiation and previous unpleasant experiences.

“I go, but it’s awful. You feel as if your breast is going to explode.”

Appointments can be off-putting for women who have transport or employment issues. Location can also be a barrier, particularly for those who live outwith main towns. The cost of transport and caring responsibilities can all impact on a woman’s ability to attend these types of arrangements.

“The facility that carries out the scans is far away from where I live and the bus service is quite limited. I can’t really afford taxis there and back. Add to that the fact that I am a carer, as well as being disabled myself. The barriers I face outweigh the benefits of going.”
Diagnosis and Treatment

Women who have contributed to the SWC discussions have mixed experiences of diagnosis and treatment. It should be noted, however, the majority value the NHS as a healthcare service which is free to all at the point of access. The importance of investment in the NHS cannot be underestimated.

Staff at breast clinics are commended for their knowledge, understanding and professional outlook and attitude. Women’s experiences can be made much easier and they can be made to feel much more supported if they have sympathetic, caring staff looking after them.

“I attended a breast screening clinic in Glasgow. I was very nervous, however, from the moment I arrived I was put at ease. I was greeted with a smile from the receptionist and shown to a comfortable waiting room. Being able to sit and have a coffee before I went in made a big difference. All staff I came into contact with explained, in detail, what they were doing and asked if I understood everything. I also felt much more comfortable as all the members of staff on duty were women.”

“I was appointed to a nurse to whom I could ask anything however trivial it may seem but to me was huge. The fantastic sense of humour of the surgeons in particular also helped lighten the experience.”

Women have also reported, however, that they feel unsupported, anxious and ‘just another number’ when they are being given life changing information.

“I was told, with little emotion, that I had breast cancer and my only option was a mastectomy. I had nobody with me and was offered no comfort from the doctor who gave me the news.”

There are also cultural sensitivities around who should examine a woman attending these types of appointment. Whilst it is not always possible for a female member of staff to be on duty, it should be an option available to women who are attending a clinic or hospital.

“When I was examined there were two male doctors in the room. They spoke to each other but not to me. I was feeling anxious and the lack of communication set me even more on edge.”

Practical Suggestions For Change:

- More information about self-examination in places where women congregate eg GP surgeries, nurseries, schools, libraries etc
- More information about diagnosis and treatment in an easy to understand format.
- Flexible appointments which allow women to attend eg evening and weekend.
- Presence of woman practitioner when examinations are taking place.
Early Detection

The majority of women who spoke to the SWC confirmed that they do attend cervical screening (smear) tests when they are invited to make the appointment. Although the procedure is seen as uncomfortable, the benefits of being checked far outweigh the negative aspects of a smear.

“It just seems the responsible thing to do. It isn’t very pleasant, but it’s a great deal better than finding out you’ve got cervical cancer when it’s too late to do anything about it.”

Many, however, admit to ‘putting off’ phoning their GP surgery or sexual health clinic to make an appointment. In most cases, this is due to securing time off work, arranging childcare, or because they receive the letter during their period and so have to wait until a more suitable time. Women’s busy working lives means that this task can be “put to the bottom of a very long list.”

Some reasons given for not attending include:

- Experience of rape or sexual assault
  “I was sexually abused as a child and struggle with intimate examinations.”

- Availability of appointments
  “Most people work 9 - 5 and won’t take time off unless they really need to.”

- Time off work / childcare
  “Working women can’t always get away early, especially those on zero hours contracts.”

- Want to see a female practitioner
  “There’s just something more comfortable about having a woman do it.”

Women have reported positive experiences with NHS staff who have performed smear tests.

Diagnosis and Treatment

A lack of reluctance amongst women to discuss this aspect of health, however, means that some who are advised that they require further tests can often feel isolated and left fearing the worst after a diagnosis.

“I was so scared. Then I started mentioning it to other women and it turned out that loads of them had had the same thing. I instantly felt better knowing that I wasn’t alone. Maybe having a wee leaflet with real women’s stories would be a useful thing.”

Throughout consultation on this issue, women who have undergone further tests and treatment have commented on the positive support they received from NHS staff across a variety of Health Boards throughout the country.

“Having another woman there, chatting away and holding my hand was honestly invaluable. The whole experience was made more bearable knowing that she was there to support me.”
Practical Suggestions For Change:

- More information about the examination process in places where women congregate eg GP surgeries, nurseries, schools, libraries etc
- More information about diagnosis and treatment in an easy to understand format.
- Flexible appointments which allow women to attend eg evening and weekend.
- Presence of woman practitioner when examinations are taking place.

Awareness

Although there is an awareness amongst women of the use of transvaginal mesh implants, there is less understanding of the debilitating effect that mesh can have on the lives of its patients.

Most women who spoke with the SWC do not have direct experience of this type of procedure. Those who do, however, have had their lives changed completely. What was claimed to be a simple and effective procedure has resulted in over two thirds of women having had negative experiences which have significantly impacted on their daily lives.

Living with Mesh

The surgery associated with mesh implants aims to improve the lives of those who are living with incontinence, which can reduce an individual's ability to live a ‘normal life’ and can be embarrassing. It is also used to assist with pelvic organ prolapse, which can cause pain and discomfort.

It has been reported that little to no information about the devastating impact of this treatment is given to patients prior to surgery. Potential risks and side effects are not clearly outlined. Women have been told by doctors across various health boards that the surgery will make a positive change to their current conditions.

For many, this has not been the case. Constant pain, skin lesions, difficulty in standing and in some cases permanent disability are common amongst those who have undergone mesh surgery.

“I'm in chronic pain in my groin, hip and lower back. I have auto-immune problems. I am being poisoned from the inside out by highly toxic polypropylene. The material used to make mesh is the same as what’s used to make plastic bottles. It has utterly ruined my life.”

As well as a lack of information prior to the surgery, women have commented that they have received very little following the procedure, and even less after-care and support. Patients have not been advised what to expect as their body heals, and how they will adapt to the mesh.
While mesh can be removed, it can be difficult and has been likened to “removing chewing gum from hair”. Doctors seem extremely reluctant to progress a request for removal, which is extremely frustrating for those who live with daily pain and struggle.

“I’ve been told that the operation to take it out would be extremely high risk. That the pain may reduce, but the incontinence will potentially be worse than ever. At this point, I would take the worry and embarrassment of wetting myself in public above the hell that I’ve been living through since this poison was put into my body.”

Some women have shown a reluctance to undergo this surgery, despite it being recommended by their healthcare professional, due to the negative publicity surrounding the procedure.

Similarly, those who have had mesh implanted, but who have not yet experienced any side effects, are worried that they will end up suffering more than they did prior to the operation.

Practical Suggestions For Change:

- More information about the mesh procedure prior to surgery.
- More information about the mesh procedure after surgery.
- Support for women who experience negative conditions post surgery.
- Medical and legal review of the procedure.

On 6th September 2018, it was reported that ‘mesh implant listed as ‘cause of death’ for the first time’ (https://www.bbc.co.uk/news/uk-scotland-edinburgh-east-fife-45430625

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**Thyroid Health**

**Awareness**

Of the women who spoke with the SWC, the majority have an awareness of thyroid health issues. Some have reported difficulties in obtaining a diagnosis while others talk about the challenges in receiving adequate treatment. This has had a significant impact on the lives of individuals and their families.

**Living with Thyroid Issues**

Women report that one of the main reasons for the rare diagnosis and treatment of thyroid conditions is a lack of knowledge and understanding by professionals. Medical specialists must abide by guidelines for testing, with many not looking at other issues.

“Doctors hold no sway over lifestyle and diet changes, preferring to medicate or remove the thyroid altogether.”

Little information is provided to patients, both prior to and post diagnosis. There is a tendency to treat other illnesses and conditions – most commonly depression and anxiety – rather than refer individuals on for further tests according to those who attended SWC events.
“I attended a nutritionist due to symptoms, which I believed may be related to nutrient deficiencies. She suspected thyroid disease due to family history and pushed me to pay for a private blood test, which eventually I did as I was really struggling. This flagged that I have Hashimoto’s disease.”

“I was diagnosed with an underactive thyroid in February 2017. I have learned how to best manage my condition through my own efforts and research. Medication has not helped.”

The SWC has been informed that the treatment available does not manage all of the side effects and symptoms which come from having an overactive or underactive thyroid. The medication offered does not mitigate the weight gain and the accompanying difficulty in losing it, fertility issues, general aches and pains, lethargy, poor mental health, hair loss and brain fog.

Women have commented on the inefficiency of the methods of testing used in diagnosis. Emphasis continues to be placed upon results, with little regard paid to patient symptoms. Too many are forced to seek private testing and treatment.

Some women have spoken about accessing ‘dessicated thyroid’ privately. This method of thyroid treatment has been reported as effective in managing thyroid symptoms. It is, however, costly for patients. Many say that the benefits far outweigh the necessary financial outlay.

“I am certainly not living a full life, but because I am buying treatment myself online I am so much better than I was before. I’m not 100% yet but things are definitely on the up.”

Practical Suggestions For Change:

- Women who suspect they have thyroid issues must be given the confidence and support to push for further testing and treatment.
- Recognition that a combination of drugs may improve health.
- Availability of specialist thyroid nurses.

### Mental Health

#### Support and Assistance

The majority of women with experience of mental ill health have sought some form of assistance and support to deal with their condition. This has been primarily via their GP, however a significant number have seen a counsellor. Waiting times, treatment, linkage with physical health, lack of resources and staff issues are some of the key areas in which women have commented.

Patients have reported waiting months to be referred on to dedicated mental health services. Having to wait this long does little to help anyone who is struggling to cope with their situation, causing many to suffer more as a result.

“I was offered counselling, but it took four months for my first appointment to come through. I would have liked that support earlier as I was having a difficult time which pills alone did not help.”
Difficulty in accessing specialist services can lead to seeking help privately. This is unjust, especially given mental health issues are more prevalent in areas of deprivation. Also, some specialist services are accessed via self-referral. This can be extremely difficult for someone who is suffering from mental ill health to be able to make a telephone call or fill in a form.

“If you can’t even get out of bed to have a shower, then how can you be expected to refer yourself to then have to cope for months before you even get an appointment?”

When women attend their GP seeking support and assistance with a mental health issue, they are almost always offered medication as the initial form of treatment. For some, this is exactly what they require in order to manage their condition in a way that suits them.

“I’m currently on an anti-depressant for stress and anxiety. I feel that the medication has helped me over the last few occasions when I’ve had to ask the doctor for help.”

Others, however, do not wish to begin this type of treatment due to concerns about being reliant on drugs. It often does not treat the root cause of mental illness.

“I think that the doctor was too quick to prescribe pills rather than giving me an opportunity to talk through issues and potential ways to handle them.”

Women have spoken about being treated as an individual by professionals rather than adopting a ‘one size fits all’ approach to support. Some of the ways in which mental health can be improved, for example via exercise, can be appropriate, but not for all patients.

“We’re always told that poor mental health is ‘associated’ with other times in a woman’s life – it’s always because of your periods, or because you’re pregnant, or post-natal, or starting the change, as opposed to actually being recognised for what it is.”

When it comes to living with mental ill health, many struggle on a daily basis to cope with everyday activities. It has a detrimental impact on their lives.

“My depression has made me unable to deal with large crowds and noises. It manifests as anger and me shutting down and being unable to function. I don’t feel like I am able to hold down a job and our family life struggles.”

Women who have experienced violence – such as rape and sexual assault, domestic abuse and childhood sexual abuse – are likely to suffer from mental ill health as a result of these experiences. Many women in this situation are unable to work, which means they rely on social security to survive. It is difficult for them to claim benefits they are entitled to because of the illness. Assessments only appear to support physical impairments.

“I’m a previous victim of abuse, violence and attempted rape. I had dealt with this for over 30 years until the Department for Work and Pensions forced me onto a work programme with violent male offenders serving out the end of their service via community service. I was terrified at having to go to work. During this time I had to fight an appeal as my benefits were stopped due to non-attendance.”
Women have expressed that there is still a strong stigma around mental health issues. This, coupled with a perceived lack of services and support mechanisms is leading to what has been described as a “mental health epidemic” in Scotland.

“I don’t think people want to talk about mental health because they’re embarrassed. If the stigma around this type of ill health was removed, women would be more open to discussing things. The more people who know about and understand mental health issues, the more ‘normalised’ they will become.”

“Nobody bats an eye if an individual needs treatment for a broken leg. But you are seen as weird or unproductive if you need support and assistance for a mental illness.”

Despite a ten year governmental strategy, admitting to living with poor mental health is still considered by many as a weakness. Women have been told to “give themselves a shake” and “get on with things”, with little to no importance placed on the issues that they are struggling with.

Too many employers have limited understanding of what it means when members of their workforce have mental health issues. Women are extremely hesitant to tell their employers if they are suffering, for the fear that they will lose their job.

“Oh my return to work my employer didn’t fully understand or acknowledge my depression as a serious condition. I fear for losing my job, but I’m also worried that the pressure of all of this will trigger a depressive episode. It’s a daily struggle.”

Women have commented on the importance of having mental health training in workplaces, so that employers have a greater knowledge and understanding of the issue.

Practical Suggestions For Change:

- Awareness raising of the causes and consequences of mental ill health.
- Easy to read information ready available for those who might be struggling.
- Self help therapies eg exercise, change of diet, which may help some women rather than medication.
- Workplace recognition and support for those suffering from mental ill health.

**Feedback from the Event**

- All the presentations were excellent
- Very emotional
- Thought provoking and lots of food for thought
- Speakers were very good and empowering
- Thank you all so much for a fantastic morning

Huge thank you to SWC for understanding the numerous needs of women, for bringing them together, to help raise awareness and share and learn new knowledge.
Those who completed the health survey and took part in roundtables discussed a number of other conditions which impact on women.

**Gynaecological Conditions**

There appears to be a lack of understanding of the range of gynaecological conditions that women face. Issues such as endometriosis and polycystic ovary syndrome (PCOS) can seriously impact on women’s lives. Often, these conditions are “written off” as nothing more than heavy, painful periods.

“Because my condition isn’t life threatening, it’s not really considered a issue. I have had to learn to live with the serious emotional and psychological effects.”

While endometriosis is considered a common gynaecological illness, women report barriers in diagnosis and adequate treatment. The condition is debilitating, causing women to have heavy periods and often constant pain.

“I was told period pain was normal and I would just have to learn to live with it.”

Women who live with this condition have stressed the importance of raising awareness and understanding. When young women are learning about their bodies at school, this type of condition is rarely mentioned. More education, from a young age, is extremely important.

“You’re told that your health is your wealth, and it’s important to take responsibility for keeping yourself fit and well. That’s not possible if you’re not told about a condition like this, which only effects women, and which can have a real impact on your life.”

**Menopause**

Every woman will have to go through menopause. It will, however, manifest itself in a variety of ways, and can impact on individual’s life overall. Despite this, there is little information available.

Women can experience a variety of symptoms including excessive flushes and night sweats, reduced concentration, mood swings, insomnia, irregular periods and weight gain. While these changes occur women have to carry out their normal day to day activities with little support or adjustment.

Employers, whose lack of understanding and empathy, often make it difficult for women to do their job effectively.

“Women are a large sector of the working population, particularly in certain sectors and professions. They are having to work longer because of the changes to pension age, so menopause is more likely to impact on them in their workplace.”

Women have called for all employers to adopt a menopause policy, accompanied with training for staff. This will not only raise awareness and understanding, but will also protect women in the workplace who are at risk of discrimination because of the menopause.
**Fertility, Pregnancy and Maternity**

Young people are taught about the female reproductive system and biologically of how a woman will fall pregnant. There is, however, little education as to the difficulties that couples may face when they decide to have a baby. Often it is not until a woman tries to become pregnant that fertility issues present.

“There’s so little support for couples who have to go through this. We have recently been through a fertility journey and it has been emotional, in some cases embarrassing, and overall extremely difficult.”

For women who do become pregnant, maternity services have been praised. The levels of care at all times during a woman’s pregnancy journey are commended by the majority.

“I’ve been so impressed with services available to me as a pregnant woman. Everything from antenatal appointments, parenting and breastfeeding classes. The NHS is an amazing thing!”

Where women suffer a loss during pregnancy, however, there is little support available.

“I found it very distressing being placed on the maternity ward while I was miscarrying.”

Once the baby has been delivered, women comment on the lack of information available to support them through the first few weeks of a baby’s life. Pressure on maternity units means that some women are in and out of hospital on the same day as giving birth.

“Hormones are all over the place, but the stretch on resources means there just aren’t enough staff to offer the help that women need.”

**Pelvic Health**

Many consider pelvic floor weakness as “part and parcel of being a woman”. Discussing pelvic health can be embarrassing, and as such it is something which few women are likely to seek medical assistance with, despite the impact it has on their daily lives. They are often unaware of the existence of specialist pelvic floor physiotherapists and incontinence nurses, who can provide support, guidance and treatment for this type of condition.

“I am a very active person and this problem has really limited my ability to participate in exercise classes, which I love. It’s really knocked my confidence.”

The benefits associated with seeking treatment are seen to far outweigh any shame or reticence which women previously felt in seeking help for their condition.

“I haven’t looked back since I saw a dedicated incontinence nurse. I have received one to one support and have been given excellent strategies to cope with and overcome the condition. This has led to a reduction in urinary infections. Excellent service!”
Conclusions

The SWC has been overwhelmed by the level of engagement from women on the health issues outlined in this report. We have had the pleasure of meeting with healthcare professionals and practitioners, as well as others working across the NHS, who have shared their knowledge and expertise. This information has helped to inform much of the work undertaken.

The organisation is grateful to the women who have completed the survey as well as those who attended the roundtable discussions and conference. The experiences are emotional and brutally honest. The SWC acknowledges that women feel comfortable enough to share the most personal aspects of their lives with us.

The information contained in this report, which is based solely on women’s experiences, will be put forward at every opportunity by the SWC. The document will be distributed to politicians, Scottish Parliament Committees and Scottish Government departments, as well as our mailing list. It will also be used by the SWC to respond to consultations, calls for evidence and international reports. The SWC will ensure that women’s voices are heard at all relevant levels of policy and decision making relating to health in Scotland.

Further information on
- Case studies,
- Speakers presentations
- Information and advice
- Reports from roundtables

can be found on the health page of our website - www.scottishwomensconvention.org

You can keep up to date with the work of the Scottish Women’s Convention in a number of ways.

Visit www.scottishwomensconvention.org to read our reports, consultation responses and other relevant documents. You can also sign up to our mailing list via the website.

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