

Scottish Women's Convention response  
to the Scottish Government's  
Consultation on:

# Health: Long Term Conditions Framework



July 2025

## Premise

It has been estimated that 38% of Scotland's population live with a long term condition, impacting their personal and professional life. Currently, the Scottish Government have multiple strategies and policies which aim to improve care and support for a range of conditions. The approaches have a focus on safe, effective and person-centred care, and range from neurology to heart disease.

The purpose of this consultation is to assess whether the policy framework for long term conditions effectively provides support, recognising that condition-focused approaches may contribute to a complex policy landscape.

Responses gained will therefore identify improvement priorities for long term conditions at a national level, with priorities supporting the delivery of NHS reform and renewal work.



## **The Scottish Women's Convention (SWC)**

The SWC is funded to engage with women across Scotland to ensure that their views are represented in policy and decision-making processes. The SWC uses the views of women to respond to a variety of parliamentary, governmental, and organisational consultation papers at Scottish, UK and international levels.

The SWC gathers information using different methods, including roadshows, thematic conferences, surveys, and both in-person and online roundtable events. This submission presents the views of a range of women, reflecting their opinions, ideas and lived experience. Working together with many other equalities organisations and community groups, we use our broad network to ensure that women from a range of backgrounds are heard and acknowledged. We are continually reviewing innovative ways of engaging with women and developing our trauma-informed and culturally sensitive practice to support vital contributions from as many women as possible.

## **Our Response**

**Do you agree that the Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?**

Yes.

The reasons provided by the Scottish Government surrounding a joined approach are highly persuasive. Women have consistently pointed to poor collaboration between health departments, explaining that disjointed communication can create additional barriers to care. We therefore support a more holistic approach to long-term condition framing, however, emphasise that separate conditions must retain autonomous approaches.

**What would help people with a long term condition find relevant information and services more easily?**

As part of SWC activities, the SWC Team travel across Scotland to understand the issues facing women within local communities. Healthcare remains a consistent subject, dominating conversations. It can be said that issues such as access and quality of care are of particular importance to women, however, they have also stated that the reduction in localised, community-based care is often the root cause of these issues. Women have explained that this is largely related to centralisation to large hospitals, leaving many communities without sufficient care. This was noted to be a key issue due to the ageing demographic witnessed across Scottish communities, with long-term health conditions increasing in number causing a resultant strain on limited services.

- “Scotland has an ageing population, leading to a higher prevalence of chronic conditions and a greater need for healthcare services.”

The reduction in community-based care has also impacted the third sector. Through significant budgetary cuts and poor availability of long-term funding, the third sector are often placed in precarious positions. When this is combined with the wider erosion of community spaces, such as libraries and community halls, the overarching ideal of community cohesion is often not met. We would argue that community spaces provide key locations for support, particularly for those living with long-term conditions. Through free, easily accessible spaces, a wide range of individuals can fairly access improved information and services. Also, women have called for a singular online space which could provide additional information on vital services. This however must be balanced with physical platforms and materials, to ensure those with low digital literacy or no access to online spaces can access support.

- “I think there is a need for more care in the community and particularly social care. I have experience of this with my grandmother who died a few years back; care was very limited and the cost was very high.”

## What services outside of medical care do you think are helpful in managing long term conditions?

The key service which assists in managing long-term conditions is social care. Social care provides vital support, enabling daily activities, and improving general life quality. This care is generally provided by women, in both paid and unpaid capacities – women make up approximately 80% of adult social care staff in Scotland<sup>1</sup> and it has been estimated that 59% of unpaid carers are women<sup>2</sup>. The continued drive of women to provide invaluable care, works to prevent conditions from getting worse.

Yet, this can often be at personal cost, with women carers experiencing poor working conditions and pay. Of those who provide unpaid care, this is often unappreciated while also preventing them from entering the full-time employment market. We would like to emphasise the lack of inclusion of women's domestic labours throughout the Framework and would encourage the Scottish Government to work quickly to rectify this oversight.

- “Just on carers, I wanted to add that it's not just about increasing pay for carers, it's about improving their conditions. The conditions they work in are terrible”
- “It's so common that women take up the slack, you now, women take on everything”

## What barriers, if any, do you think people face accessing these (non-medical) services?

When discussing social care with women in rural areas, they have highlighted the reduced availability of services. They explained that a reduction in young people across remote and rural locales has caused staff shortages. This youth scarcity has been largely caused by the centralisation of key services, eroding local economies. Also, there is low availability of low-cost housing for first-time buyers, forcing many young people to move elsewhere. SWC Roadshows have regularly reported on the negative impacts of centralisation across rural Scotland, calling for reversals<sup>3</sup>. Low staff availability has been widely acknowledged across Scottish social care, with 81% of providers witnessing recruitment struggles<sup>4</sup>. This has led to significant burn-out for existing staff and a decline in service quality.

- “I know someone who lived very rurally, they won't go to a care home, they can't get carers to go out to their 80-year-old mother”

<sup>1</sup> Scottish Government. (2022). The Adult Social Care Workforce in Scotland. Available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2022/06/national-care-service-adult-social-care-workforce-scotland/documents/adult-social-care-workforce-scotland/adult-social-care-workforce-scotland/govscot%3Adocument/adult-social-care-workforce-scotland.pdf>

<sup>2</sup> Cares UK. (2024). Women and Unpaid Caring in Scotland. Available at: <https://www.carersuk.org/briefings/women-and-unpaid-caring-in-scotland/>

<sup>3</sup> Scottish Women's Convention. (2025). Roadshows. Available at: <https://www.scottishwomensconvention.org/roadshows/>

<sup>4</sup> Coalition of Care and Support Providers in Scotland. (2024). Staffing Crisis Deepens as 81% of Providers Report Recruitment Needs as Higher or Same as Previous Year. Available at: <https://www.ccpsscotland.org/ccps-news/social-care-staffing-crisis-deepens-with-81-of-providers-reporting-recruitment-needs-as-higher-or-same-as-previous-year/>

- “...my oldest friend who is about 91...her eyesight is gone, so she can't drive, and she is in her own home. Her family are always worried, because her care, it's not easy, I mean, the people who do come are super...it's just that there isn't enough of them.”

In relation to social care, access has been reported as a key barrier. A reduction in care homes and sheltered housing has resulted in those requiring social care to travel longer distances for essential services. This issue is magnified in rural locations, forcing many with long-term conditions to move away from their home and local community. The additional stress and diminished access to friends and family, can ultimately worsen wellbeing and health.

- “There's a distinct lack of care homes, there's only one...if you get into the main one, you have to go [far away from home], so you're away from your family. It's just appalling.”
- “Some people can be told to [move away], they've maybe lived [on the island] all their lives, and sometimes a couple can be separated, very far from each other, they're split up during the final years of their lives. That happens everywhere, they just put you anywhere they can fit you; it doesn't matter where you go.”

An additional barrier to women accessing non-medical services, is a lack of joined-up processes across service-provision. Women have explained that due to continued siloing of health and social care services, they often struggle to access an appropriate level of care. This tends to be worsened when attempting to negotiate between services, with the effectiveness of health and social care partnerships varying by local authority. The lack of communication between internal local authority services, also extends to external services. Despite providing essential care, third sector organisations are not viewed as equal partners in supporting those with long-term conditions. This results in poor communication between statutory and third sector organisations, preventing many from accessing vital information and services.

- “...unless there's a more joined-up approach between local government and a higher level and local groups”
- “...there are no services being joined up”
- “...[there is a] lack of communication, this department doesn't talk to this one. They work in silos and they don't talk to each other.”

### **What barriers to people face making healthy decisions in preventing or slowing the progress of long term conditions?**

Poverty remains the key barrier to people making healthy decisions in preventing or slowing the progress of long-term conditions. Through limited financial means, women are prevented from purchasing good quality produce, contributing to poor health outcomes. This has been worsened as a result of high living costs, with increased prices limiting women's capacity to purchase fruit and vegetables. Instead, women have

stated that they often buy frozen items with little nutritional value to mitigate high costs. Alternatively, a growing number of women are turning to foodbanks for sustenance. The Trussell Trust reported that emergency food parcel output in Scotland has doubled in the past decade<sup>5</sup> (Trussell Trust, 2025). While foodbank provision is an essential service, the quality of food is variable and rarely includes fresh food. Having access to good quality food improves health and wellbeing, allowing individuals to live positive lifestyles.

- “I can’t afford healthy food and we have gained a lot of weight because junk food is cheaper and more accessible.”
- “...women take on the key role in caring for their family, their children, older family members or others, which places additional pressures on them in times of food insecurity, and maybe women try and prioritise feeding their children over themselves”
- “Since graduating, I’ve been lucky to find work that pays well, but there is a long-term impact of poverty. I still find myself putting things like fresh fruit back in the supermarkets, because it feels like a luxury I can’t afford, and I still find myself skipping meals on days when I’m home alone.”
- “I think it’s not just about accessing food, it’s about accessing good food, and I think that’s a major issue. People will buy what’s cheap and not necessarily something that’s nutritious.”

In addition, women have explained that rising living costs have also impacted household bills – particularly heating costs. Due to incredible rises, many women are forced to choose either to “heat or eat” in the winter months. This situation is made more difficult when children are included, with mothers often going without, to feed, clothe, and heat others. For those living with long-term health conditions, standard living costs also tend to be high. Women have explained that the cost of specialised equipment and/or more time spent within the home, result in high household bills<sup>6</sup>. It can be observed that living in a poorly heated home negatively impacts health outcomes, contributing to health conditions such as asthma<sup>7</sup>.

- “I think a lot of the cost of living...there’s going to be a lot of long-term fall-out from people not turning on their heating, both from the point of view of the fabric of the housing, but also the physical health side. You know, like chest infections and things are likely to increase”

We would therefore argue that poverty continues to limit the lives of women and children across Scotland; simultaneously creating and maintaining health inequalities.

<sup>5</sup> The Trussell Trust. (2025). End of Year Food Bank Stats. Available at: <https://www.trussell.org.uk/news-and-research/latest-stats/end-of-year-stats>

<sup>6</sup> Inclusion Scotland. (2022). Disabled People, Poverty, and the Cost-of-Living Crisis. Available at: <https://inclusionScotland.org/wp-content/uploads/2023/02/Inclusion-Scotland-Briefing-Disabled-People-Poverty-and-the-Cost-of-Living-Crisis-Version-1-November-22nd.pdf>

<sup>7</sup> Institute of Health Equity. (2024). Left Out in the Cold: The Hidden Impact of Cold Homes. Available at: <https://www.instituteofhealthequity.org/in-the-news/press-releases-and-briefings/left-out-in-the-cold-the-hidden-impact-of-cold-homes>

Eliminating child poverty has been a key commitment of the Scottish Government for many years, with the expected positive effects encompassing improved health levels. SWC work in this area concludes that through a direct focus on women's poverty, child poverty can be effectively reduced<sup>8</sup>.

## **Are there additional important considerations for people with long term conditions?**

We must emphasise our disappointment at the total lack of consideration of women's experiences in the Long-Term Health Conditions Framework. Women are more likely to experience long-term health conditions than men – 50.1% of women compared to 45.7% of men<sup>9</sup>. Women are also more likely to live longer than men, often in poor health, with additional considerations such as poverty and rurality further worsening life experiences<sup>10</sup>. It can also be noted that due to women's continuous labour within the home, they are more likely to be the primary carer for a family member or friend who lives with a long-term health condition<sup>11</sup>. The combination of these factors must be effectively centred throughout Framework creation, taking a gendered lens to health and social care provision. This work is made more important by the lack of proper consideration given to long-term health conditions in the Women's Health Plan.

Women with long-term health conditions, such as endometriosis, have provided the SWC with their difficulties accessing diagnosis and care. Barriers include rurality, medical misogyny, and poverty. For those who live in remote locations across Scotland, the increase in centralised medical models has significantly limited their ability to access healthcare. The reduction in localised service has forced many women to travel long distances to access essential care – for example, women in Wick must travel approximately two hours to Raigmore Hospital in Inverness when seeking an official diagnosis for endometriosis<sup>12</sup>. The additional cost and time taken to carry out these trips creates hardship for many, limiting women on low incomes ability to seek their right to healthcare. This has been acknowledged by the Scottish Human Rights Commission, who have reported gaps in human rights access across rural Scotland<sup>13</sup>.

- "...I mean we have to go to Inverness for most things and the public transport is not particularly reliable. So, if you get an early appointment, you have to go down

<sup>8</sup> Scottish Women's Convention. (2024). The Impact of Poverty on Women. Available at: <https://www.scottishwomensconvention.org/resources/poverty-full-report-2024.pdf>

<sup>9</sup> Office for National Statistics. (2022). UK Health Indicators: 2019 to 2020. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/ukhealthindicators/2019to2020>

<sup>10</sup> Scottish Government. (2024). Women's Health Plan 2021 to 2024: Data Landscape Review. Available at: <https://www.gov.scot/publications/womens-health-plan-review-data-landscape/>

<sup>11</sup> Carers UK. (2024). Women and Unpaid Caring in Scotland. Available at: <https://www.carersuk.org/briefings/women-and-unpaid-caring-in-scotland/#:~:text=Unpaid%20caring%20has%20a%20gendered%20dimension%20with%20women,who%20took%20part%20in%20State%20of%20Caring%202023>

<sup>12</sup> Scottish Women's Convention. (2024). Wick. Available at: <https://www.scottishwomensconvention.org/resources/wick-report.pdf>

<sup>13</sup> Scottish Human Rights Commission. (2024). Economic, Social and Cultural Rights in the Highlands. Available at: [https://www.scottishhumanrights.com/media/2880/executive-summary\\_economic-social-and-cultural-rights-in-the-highlands-and-islands.pdf](https://www.scottishhumanrights.com/media/2880/executive-summary_economic-social-and-cultural-rights-in-the-highlands-and-islands.pdf)



the day before, but they don't take that into consideration when they're making appointments for you."

- "The journey [to Raigmore] makes me feel terrified, anxious, frightened, scared, nervous, overwhelmed, uncomfortable"
- "I know that my bairns, when they go down south [for hospital appointments], I'm the one who has to help out because they don't have the finances to do that, and I'm not the only mum or grandparent in my area who is helping their children or grandchildren get healthcare."

The link between healthcare and financial security can also be witnessed in areas of low affluence. Women experiencing poverty are less likely to have good quality health, resulting in comorbidities and premature death<sup>14</sup>. As women are more likely to experience poverty than men in Scotland, considering poverty and the link with long-term health conditions through a gendered lens is imperative. With women's poverty directly resulting in children's poverty, and the inevitable furthering of health inequalities, the importance of tackling this issue cannot be stressed enough.

- "...it's the cost that's attached to that, or you're someone from a minority ethnic background or you're an asylum seeker, you're not going to take an appointment which is far away. We need to look at where services are based, making them accessible"
- "When you're living in poverty, you have a propensity to be in diverse health challenges, especially when it comes to mental health; the anxiety around not having your essentials, that is going to drag down the quality of your health."
- "...if you're poor, you have no access to the things that allow you to access opportunities around you. If you're hungry, you're watching your children go without the essential things they need, that would also drag down your own health."

Additionally, women have reported considerable misogyny across medical fields, with their views and conditions not being taken seriously by professionals. Women have explained that seeking diagnosis for conditions such as endometriosis can take a sizable length of time – recent estimates state that it can take approximately eight years and 10 months to receive a diagnosis in Scotland<sup>15</sup>. From their experiences, women stated that this wait is largely due to poor understanding of women's health conditions by GPs and direct misogynistic attitudes. They have called for improved training surrounding bias and women's health for primary medical professionals.

- "...young women are telling us as well that the amount of gaslighting that's happening when they're going with pains, like endometriosis pain and period pain...they're being told to go on the pill. They're going on contraception because

<sup>14</sup> Scottish Health Equity Unit. (2024). 2024 Inequality Landscape: Health and Socioeconomic Divides in Scotland. Available at: <https://scothealthequity.org/wp-content/uploads/2024/09/FINAL-for-website.pdf>

<sup>15</sup> Endometriosis UK. (2024). Years of Being 'Dismissed, Ignored and Belittled': Endometriosis UK Urges Improvement to Deteriorating Diagnosis Times. Available at: <https://www.endometriosis-uk.org/diagnosis-report>



that's what the doctors are suggesting that they do rather than actually listen to them."

- "Thinking now with my condition, endometriosis, I mean, things have never been so bad, and it features so heavily in the Women's Health Plan, these big ambitious goals to take diagnosis times down, and it's actually gone up in Scotland...You're waiting two years to be seen by gynae...You're spending your whole life on a list"
- "...the waiting times, but also women tend to have to go back more than once for the same issue because they're not believed. Like take endometriosis, that runs in my family, but my mum, even after diagnosis by a doctor, when she was telling them about her pain, they told her 'It's just a period dear'. It was just like, that shouldn't ever be coming out of a doctor's mouth, but we're not believed when it comes to pain"
- "...for my youngest daughter, who is 17, she started her period during lockdown and it was really, really heavy for her, and that was when we first started talking to the GP about it, and it was about three years before she got an appointment to a gynaecologist. She would tell them about going into school, flooding her trousers and then having to go home, and it was a female gynaecologist who said to her 'Can you not double pad?'."

Alternatively, while the focus of this work remains pointed at improving outcomes for those with long-term conditions, we propose that this is impossible without discussion with women providing care. Women manage the majority of caring responsibilities within and outside of the home, providing care through paid and unpaid methods. The lack of support for women is widely acknowledged, placing incredible strain on women across Scotland. Women have reported worsened physical and mental health as a result of the increased workload. This ultimately places more people at risk of long-term conditions and worsens the quality of care received by those in need. We would suggest improved collaboration with care providers, including both paid and unpaid carers.

- "More [women are] becoming sandwich carers – caring for disabled children and elderly parents. They are exhausted and have no fight left to challenge services and systems, it's about survival for many. They do what they have to do to get through the day. Who cares for the carers?"
- "But women are still sandwiched between looking after children, helping their ageing parents. So, they have a lot of juggling to do and I don't think that that is facilitated."
- "Women still bear the brunt of responsibility for domestic tasks and so it is often left to them to figure out how to stretch their limited resources to look after themselves and their families."
- "[Social care] is in absolute crisis. I don't know how people are managing, and they're bringing children up, while also caring for the most vulnerable people, of

whatever age category, in our society and all of those people have got as many rights as we have. They are entitled to respect, autonomy, decision-making”

Overall, we would strongly recommend reconsideration of priorities outlined within the Framework. This should include proper mention of women's experiences as those experiencing long-term health conditions and as those providing support for individuals with long-term health conditions. Without a full investigation into the impact of long-term health conditions on women's lives, the Scottish Government cannot effectively modernise long-term condition approaches.

### **Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?**

While investigating women's experiences of maternity care in Scotland, the SWC heard a range of experiences, including the unequal access to healthcare afforded to ethnic minority women<sup>16</sup>. Ethnic minority women stated that they would often face a mixture of indirect and direct racism from health professionals. For example, women explained that assumptions were made surrounding their English language skills, taking away their ability to self-advocate. Similar issues are present for ethnic minority women with long-term health conditions, with stigmatising assumptions worsening healthcare access.

- “...they spoke to me so slowly, doing animations, and I mean, I told them that they could speak normally to me, I could hear them, I could understand them. It was literally someone looking at me and making an assumption.”
- “I am speaking as a person of colour...people are looking down on you...It's very tough when you're dealing with a system that is under strain...there is also that systemic racism...your rights are always being undermined.”

When asked what would improve the quality of care for ethnic minority women, they highlighted improved training for medical staff. This training should be practical, taking into account the considerable workload already placed upon healthcare employees. Women highlighted that this training should focus on cultural safety, enabling a wider range of NHS Scotland staff to feel confident providing culturally sensitive care.

- “On training... [The phrase] cultural competency tends to be used a lot, but they are not competent in Scotland, you can't be competent in my culture. I wouldn't expect a midwife to be competent in my entire culture, but if you look at cultural safety, that addresses that idea around power”

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<sup>16</sup> Scottish Women's Convention. (2025). Your Maternity Journey, Your Voice: Women's Experiences in Scotland. Available at: <https://www.scottishwomensconvention.org/resources/maternity-full-report.pdf>

## Conclusion

Having listened to women, our three key recommendations on this topic are:

- A re-evaluation of the Framework must be carried out, centring women's needs.
- Consult with women providing unpaid care to those with long term conditions; to understand the impact this has on their wellbeing.
- Embed cultural sensitivity training across NHS roles.

The SWC is grateful for the opportunity to respond to the Scottish Government's consultation on **Health: Long Term Conditions Framework**. As an organisation, we will continue to work with women from across Scotland to gather voices and experiences relating to this topic and its effects on women's equality.

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