

# The Status of Young Women in Scotland 2022-2023

Experiences of Accessing Healthcare



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#### **Foreword**

#### **Caitlin Stuart-Delavaine**

Working Group Member, Medical Student at The University of Glasgow

My main professional concerns, whilst studying medicine, have rarely centred on my performances in graded assessments or exam results achieved. Instead, my core fears have focussed on how my actions might impact those I am caring for. Will I do well by my patients? Have I appreciated and met all their needs? Have I allowed them to feel safe?

Unfortunately, this report has overwhelmingly reinforced such apprehensions, emphasising healthcare professionals' potential to cause harm. Patients left feeling unheard, unimportant and unfulfilled, are patients who have been systemically failed. And it is clear we are failing far too many.

So, although I was at first disheartened to see so many young women feel disregarded by the medical establishment, I now only see these findings as hopeful.

Young women have spoken, and they will no longer be silenced.

Their call for action is clear and changes must be implemented immediately. Nationally, healthcare accessibility must be improved. Equally, greater efforts must be made to better educate both patients and providers on what can and should be offered during all healthcare interactions. And it is clear many young women have already started down this path. I remain in awe of their own fierce self-advocacy as they cut down the jungle of bureaucracy and forge their own pathways to better their healthcare outcomes. Now it is time for those in positions of care to match their efforts and answer these cries.

I end on my own reflections. During clinical training, emphasis is often placed on finessing practical skills and optimising academic acumen, making it easy to forget that words exchanged, and attitudes adopted towards patients, have far more of a lasting impact than any prescriptions written. The time to be part of the change you wish to see is now, and I for one am excited to take these steps.



#### **Foreword**

#### **Emmagayle Harper**

Working Group Member, Journalist

The fact that so many respondents only found accessing healthcare just 'ok' or had negative experiences highlights a need for improvement. It is concerning that young women in Scotland face obstacles accessing healthcare due to their gender, age, disability or weight and is especially disheartening to see young women reaching out for help who are not taken seriously or are left feeling ignored. We must strive as a society to create an inclusive, compassionate, and responsive healthcare system.

As a young disabled woman, I have firsthand experience of facing challenges when trying to access healthcare due to inaccessible services and lack of education about disability. Ensuring those who can make a difference listen to the voices of all young women, especially of those who are often marginalised, to implement positive change and work to remove the barriers that prevent them from accessing the care they need has never been more important. Reports like this are just the first step to addressing the issue of healthcare inequality and we must all work together to ensure that long-term, positive change is made.



#### What we found

The Status of Young Women in Scotland 2022-2023 engaged with over 900 young women and people of marginalised genders aged 16-30 from across Scotland; with representation from every Scottish local authority and from all of the target ages. This research collected a wide range of findings on issues across the access to healthcare journey:

- The highest proportion of young women (40%) rated their experiences of accessing healthcare as "okay". Just under a fifth (17%) rated their experiences as mostly bad and a further 8% rated it as mostly awful.
- Young women struggled to access the healthcare they needed and deserved. The
  inaccessibility of appointment booking was the most common barrier to young
  women's ability to make the appointments they needed. We heard from young
  women who; are working, in education, have caring responsibilities, have long-term
  or mental health conditions meaning early mornings can be difficult, may struggle to
  communicate on the phone due to language or neurodivergence, about how these
  systems do not work for them.
- Limited NHS resources made appointments scarcer leading to respondents feeling guilt over asking for help. Reception staff were presented as gatekeepers to healthcare.
- Young women are not taken seriously in healthcare settings, they are often dismissed, and their experiences are minimised. Many told us they feel patronised and not believed by healthcare professionals. Young women were then often left with no further offer of support or follow-up.
- Age, gender, living in rural areas, being part of an ethnic minority, being disabled, being trans, and body type and weight, compounded issues of accessing healthcare.
- People with long-term health conditions had some of the worst experiences due to the one size fits all nature of treatment being inappropriate for them. This often meant having to start the access journey repeatedly with each referral.
- Young women have to tirelessly advocate for themselves in healthcare settings to get the support, treatment or follow-up care that they need.
- Under a third (30%) of young women said their experience of healthcare was mostly good. Being listened to, heard, believed and validated, were by far the most important features of a positive healthcare experience. Young women appreciated practitioners who showed empathy and genuine care.

#### What we found

- Young women make several recommendations relating to alternative ways to access healthcare, which are widespread and standardised across Scotland, covering waiting lists, better access to information and signposting, and improved communication between healthcare providers.
- Young women want to be heard, seen, listened to and validated. They want
  healthcare professionals to take them seriously. They no longer want to experience
  medical misogyny or gaslighting in healthcare settings. Young women and people of
  marginalised genders need to feel safe to access timely care. Especially in relation to
  abortion and reproductive services and gender-affirming healthcare.
- Improving training for medical professionals is essential, especially relating to sexual
  and menstrual health, also surrounding how conditions present differently in young
  women. The medical profession needs to practice anti-racism, dismantle ableism
  and operate intersectionally to consider the experiences of all young women and
  people of marginalised genders.
- Young women also wanted better education for themselves around accessing healthcare, they want to know their rights, and about how conditions might affect them differently, acknowledging that women's health is not widely discussed.
- There needs to be more women and people with marginalised genders in positions of power throughout the medical profession.
- Young women want more research into and understanding of women's health.
- Young women acknowledged the lack of funding and resource in the healthcare system. They want to see more staff and better pay for medical staff.
- They would like to be able to access healthcare through the NHS, acknowledging how unique our healthcare system is. If accessing private healthcare is necessary because of NHS failings, young women suggested they should receive personal healthcare budgets through the NHS.
- Young women wanted to see preventative care approaches being embedded, understanding that health is influenced by multiple societal and environmental factors.
- Young women want more choices and alternative types of support for menstrual health, instead of prescribing the pill as a default they want medical professionals to support them to explore alternative options.

## **Our Approach**

The Status of Young Women in Scotland (SYWS) annual research is in its sixth iteration and has evolved and developed over the years. This project was the first to be entirely delivered by The Young Women's Movement research team, which was established in October 2021. Our approach weaved intersectional feminist principles throughout each stage of the project.

#### **Background research**

We conducted a review exploring key areas lacking data on young women's experiences and key focus areas for policy teams at The Scottish Government. This review, completed by the masters student, Eilidh Young from Glasgow Strathclyde university, recommended SYWS22 should focus on experiences of accessing healthcare, due to a lack of gender-disaggregated data on healthcare inequalities, and a lack of academic work focusing on the experiences of young women's access to healthcare, with most existing data surrounding reproductive or gynaecological health issues.

#### **Working group**

A working group was established comprised of young people, healthcare professionals, and experts from across the third-sector. The working group informed the research at each phase of the project, contributing to survey design, group discussion engagement, analysis and write-up. The group met three times between October 2022 and April 2023, young people were compensated for their time.

#### The survey

The survey ran for just over three months between October 2022 and January 2023. It gathered 887 respondents from across every Scottish local authority and all ages between 16 and 30. The survey gave the researchers a broad sense of how young women and other people with marginalised genders experienced accessing healthcare in Scotland.

#### **Group discussions**

Four group discussions took place online and in person in March 2023, engaging with a total of 26 young women and people of marginalised genders who were disabled or had long-term health conditions; who lived rurally; who were from ethnic minorities; and whose weight impacts their access to healthcare.

These focus areas were decided by the research team and working group based on an initial analysis of the survey, and gaps in demographics as well as themes that deserved a deeper dive. Although group discussion participants joined groups relevant to their identity or issue, we encouraged them to share whatever felt relevant to them in the discussion setting. Groups typically lasted 90 minutes, with all dialogue recorded and transcribed.

#### **Limitations**

Although the activity described above has many strengths, we acknowledge the limitations of the methodologies employed. The findings should not be considered representative of the experiences of all young women in Scotland;

## **Our Approach**

they shine a light on the lives and views of those who participated in this research. Although there were 887 survey respondents, the rate of response to the survey questions was not consistent. Given this when a percentage is stated it is representative of those who responded to the question, not the full sample.

This research briefly highlights issues faced by trans people and people from ethnic minorities but it does not fully capture the barriers they face when accessing healthcare in Scotland. We acknowledge the work of specialist organisations and researchers doing incredible work to campaign for better healthcare for these most marginalised groups, such as the Five x More campaign to improve black women and birthing people's maternal health outcomes in the UK, and Scottish Trans, from the Equality Network, and their Health CARE campaign, urging the Scottish Government and the NHS to improve healthcare for trans people in Scotland.

The researchers and participation principles

This research was led by Rhianna Mallia, Research and Policy Lead at The Young Women's Movement and Kirstie English, research consultant and PhD researcher with the University of Glasgow. We take this opportunity to acknowledge our privilege as white and able-bodied individuals, and the interplay of power dynamics these identities bring to this research project.

Throughout, we aimed to ensure the voices of those we were looking to represent in this research were engaged in the design of the project through our working group with representatives from organisations who work principally with people of marginalised identities. We would like to go further in future, building young women into the design and delivery of the research through peer research approaches. Resources did not allow for that kind of engagement in this project.

Young women working group members were compensated for their time, and we provided compensation in the form of a 'thank you' voucher for all group discussion participants. We also ensured there was a consistent feedback loop with all group discussion participants; sending the notes from the discussions back to them to ensure they felt representative of their experiences.

#### **Introduction**

We believe that all young women and girls should be able to access to safe, high quality and timely healthcare without fear of being dismissed and ignored. #SYWS23 fills an evidence gap that will work towards reducing health inequalities and meeting the needs of young women and girls, especially those experiencing compounding inequalities.

From registering with a medical centre, GP, or dentist, to making appointments, to experiences of being treated by and interacting with healthcare professionals, accessing healthcare is a journey. This report explores young women and people of marginalised genders' experiences throughout this journey and what needs to change to support young women to access the healthcare they need and deserve.

Young women and girls participate, codesign and lead in all areas of our work at The Young Women's Movement. This research centres the voices of young women, their quotes are embedded throughout the report to showcase and amplify the value, significance and diversity of young women's and girl's experiences.

At The Young Women's Movement we will continue to advocate fiercely for young women and girls and have recently launched a five-year strategy outlining our commitments, with this report we will drive forward change so that young women access the healthcare they deserve.

We will work with a group of young women and girls to co-design resources and campaigns that raise awareness and support young women and girls to feel more informed on accessing healthcare.

Young women want more research into and understanding of women's health. At the Young Women's Movement we have committed in our new strategic plan to enhance and develop our policy and influencing activity. The findings and insight from this report will be used to advocate and push for systemic change throughout Scotland's policy and practice.

I would urge everyone working in health care or with young women and girls, especially those in positions of decision-making, to demonstrate a commitment to thinking differently and meaningfully listening and including a diverse range of young women and girls' voices in the future of your work. This report can be used as a baseline to influence, inform and co-design health and wellbeing services that meet the needs of young women and girls.



## Who took part

The Status of Young Women in Scotland 2022-2023 engaged with over 900 young women and people of marginalised genders aged 16-30 from across Scotland; with representation from every Scottish local authority and from all of the target ages. The 16-18 and 25-27 age brackets were the most common, making up around 23% of respondents each.

This research highlights the barriers young women and young people of other marginalised genders face in accessing healthcare in Scotland. Trans people specifically face significant difficulties in accessing the care they need due to long waiting times, discrimination and a lack of understanding about their healthcare needs. We hope that these findings will highlight the issues faced by young trans people and inspire change so that young people of all genders can access timely, person-centred and compassionate care.

#### Ryan Butter,

Scottish Trans, Equality Network – Working Group Member

The term "people with marginalised genders' was used to recruit participants. Although this research was primarily to explore the experiences of young women (cis and trans alike), misogyny in healthcare does not only impact women, and we wanted to ensure everyone with relevant experiences, such as trans men or non-binary individuals, could participate if they wanted to.

The majority of respondents were young women and will be discussed as such while acknowledging that not all participants identified as women. Quotes have remained anonymous throughout to protect participants.

- 92% of the survey respondents who specified their gender were cis or trans women, with the rest being trans men (1%) or non-binary people (10%).
- Some participants selected more than one gender, for example, 20 women also indicated they were non-binary.
- Overall, 9% of survey respondents were trans. 2 of the 26 discussion group participants were trans one being non-binary and the other undefined.
- Given its relevance to experiences of healthcare, we also asked if any respondents had variations of sex characters (also known as being intersex), and 7 indicated they did.

## Who took part

#### **Sexuality**

• Almost half of the survey respondents were straight (48%). The next most common sexual orientation was bisexual (31%), then queer (13%) and lesbian (9%).

#### **Ethnicity**

- 88% of the survey respondents were white and mostly from the UK. 5% were of Asian ethnicity, primarily Pakistani, Chinese or Indian. 4% had mixed or multiple ethnicities.
   2% were Black, mostly Black African. The rest of the sample indicated they had an Arab ethnicity (1%) or an ethnicity not listed.
- 8% of survey respondents were not UK citizens which could have created additional barriers to their access to healthcare.

Given the discussion of experiences of racism and xenophobia in the survey responses, we decided to explore this further with a discussion group on how being part of an ethnic minority, related to experiences of accessing healthcare. Across the four focus groups 9 of the respondents were white and from the UK and 15 were women of colour, primarily from Asian backgrounds.

#### Disability and long-term health conditions

- Mental health and neurodiversity were mentioned throughout this research. 67% of respondents stated they had a long-term health condition; mental health (49%) conditions and being neurodivergent (26%) were the most common responses.
- Although only 26% of survey respondents identified as disabled. Eight of the discussion group participants were also disabled.

#### Other demographics

Through these we found that most of the survey respondents were not religious (79%), were university educated (55%) and did not have care responsibilities (83%). 5% of participants stated they had experience of the criminal justice system. When asked to self-define their economic class around half of the respondents indicated they were working class and half middle class.

To recognise any potential impact being looked after could have on access to healthcare we asked the participants if they were care experienced, 10% of the survey respondents were and a further 3 of the discussion group participants.

## In the beginning:

## experiences of registering with healthcare services

This section explores the very first stage in the accessing healthcare journey; registering with a service. We found that most respondents were registered with an NHS GP and dentist. However, fewer young women were registered with an NHS dentist (27% were not registered) than they were with a GP (2% were not registered).

When young women talked about their positive experiences of registering with a service, they said there were <u>enough</u> services in their local area and that they had a <u>choice</u> of which GP, dentist, or medical centre to register with.

Positive experiences highlighted an <u>easy</u> registration process, that was <u>flexible</u> about how and when young women could register and offered different ways of filling in forms, for example, through <u>digital</u> forms. Finally, positive registration experiences included forms, letters and other communications that were <u>accessible</u> and easy to read.

Having <u>visible</u> services supported young women to register easily with their GP, some participants talked about representatives from local medical centres having stalls at university and college matriculation days.

#### **Barriers**

I've been trying every two months for two years to join an NHS dentist and every time they say there are no spaces; [accessing emergency dental care] was all just really confusing and it felt like I was being such a burden and a pain [they were] acting like I was a complete nuisance and I'd done everything wrong and why was I calling?!, I ended up getting a same day appointment for the next hour so had to leave early, to get to that point was very stressful.

[group discussion participant, living rurally]

Participants who struggled to register with a healthcare service talked about a lack of services in their local area that were open to new registrations. Some described unclear or confusing processes. Examples were given of services that only had specific windows of time for returning paper forms, and that this made registering impossible because of work, education or caring commitments.

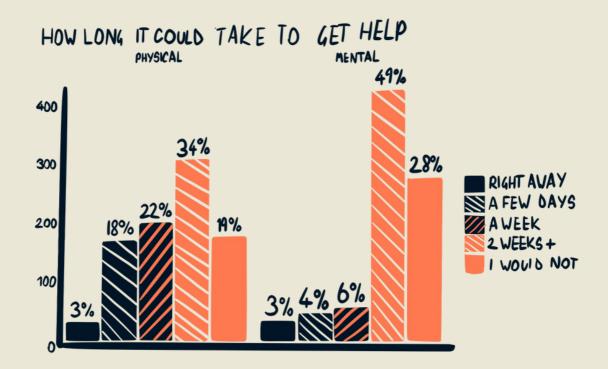
Registering in a new area can be difficult, a few participants talked about waiting long periods for records to be transferred. Having a negative experience of registering with healthcare services, prevented some young women from accessing further support.

Negative experiences begin just from the inability to register with a GP practice following a move, the most recent registration took over 8 months and I'm still not sure I'm registered because the communication is so poor. That then puts you off contacting your GP when you need them.

[survey respondent]

## **Continuing the journey:** making appointments

We found that in general, young women struggled to make appointments with healthcare services. They told us it took two weeks or more to get help after recognising a mental health issue or minor physical health issues like a persistent cough or headache.



#### **Barriers**

The <u>inaccessibility of appointment</u> booking was the most common barrier to young women's ability to make the appointments they needed. Young women talked about struggling with the <u>small windows of time</u> for calling the GP to make appointments, which are often early in the morning. They described <u>waiting on hold</u> for long periods or having to call back multiple times because of a busy line. Oftentimes, these systems mean that a healthcare professional may call back at any time of the day.

<u>These systems are inaccessible</u> for many and for a multitude of reasons. We heard from young women who; are <u>working</u>, in <u>education</u>, have <u>caring responsibilities</u>, have <u>long-term or mental health conditions</u> meaning early mornings can be difficult, may struggle to communicate on the phone due to <u>language</u> or <u>neurodivergence</u>, about how these systems do not work for them.

*I cannot physically call at 8 o'clock because I am rushing to get to school.*[group discussion participant, ethnic minority]

#### making appointments

I have not found a single doctor in the UK who seems to work with autistic people, who recognises autistic communication requires directness. Furthermore, all appointments require phone calls to book, so despite bleeding that won't stop, recurrent pain and other issues I have not gone to the doctor as I cannot manage a phone call.

[survey respondent]

Many young women described how their privilege and circumstance made accessing healthcare easier for them. 72% said that access to the internet supported them to access the healthcare they needed, 27% identified their economic class as having a positive impact on their access to healthcare. Some specifically stated their employment had an impact.

My level of employment, I have a permanent and full-time contract, allows me to accept an appointment at any time without fear of missing wages.

[survey respondent]

Reception staff were often described as being <u>rude</u>, or <u>discriminatory</u> towards young women. Some described experiences of <u>feeling pressured</u> to share their reasons for wishing to make appointments. They also described feeling like reception staff were <u>gatekeepers</u>, deciding whether their issue was <u>severe enough</u> to be referred for an appointment.



They are [reception staff] the decision makers of whether you deserve an appointment or not and I think that's really unfortunate [...] you're having to talk to somebody who's not qualified as a GP to say whether your condition or your situation requires to see a doctor and that's impacting your confidence, and how you're feeling and you're having to explain all this to someone who's not very nice.

[group discussion participant, body type and weight]

Sometimes it's like 50 calls and by the time you get through the receptionist can be really rude... or they want to know what the appointment's regarding and I'm like it's none of your business, you're not my doctor.

[group discussion participant, living rurally]

Young women often felt <u>frustrated</u> that there was a <u>lack of information</u> upfront about how to access their local healthcare services. They talked about how different services have their own <u>websites</u> which can often be i<u>naccessible</u> and difficult to <u>navigate</u>.



Since covid access to GP services has been incredibly difficult. It takes at least 40 minutes on hold before speaking with a receptionist who tells you there are either no appointments left and to call again on a certain date or gives you an appointment in several weeks.

### making appointments

It's hard to find the right phone numbers to call, websites sometimes don't look like official websites and even getting there in the first place is so complicated and confusing.

[group discussion participant, living rurally]

Nothing is standardised, depending where you live, depends on how you can book appointments, what time to call, there are different rules and regulations, when you move to a new area it's not easy to find this all out, it's crazy to me that it can be so wildly different and there seems to be no regulation on like the most basic of things. [group discussion participant, living rurally]

Attending appointments was often a struggle for young women due to their circumstances, and location. A few participants shared experiences of being penalised for not attending appointments, by being de-registered from their healthcare service.

Travel's a huge issue especially in rural areas ... I can't drive and the buses don't go straight there so I have to get the bus in town and wait hours for another bus, or I've got to rely on my parents to give me a lift in [group discussion participant, living rurally]

Some young women with long-term conditions <u>struggled to manage referrals</u>, this was particularly difficult if they have more than one condition, or if they were relocating while on waiting lists. They talked about how communication between healthcare providers, including GPs to pharmacies, often left them not accessing the healthcare they needed.

If you have comorbid conditions, every single part needs a new referral. If you need one symptom looked at for something slightly different you need to go on a new waiting list. Even if it was related to the first thing... no one speaks to each other.

[group discussion participant, living rurally]

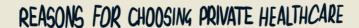
I was trying to access NHS mental health support and I had just finished up a block of counselling in one area and then I moved. When I moved I was like I'm already getting support but would like to change the councillor but they said because I have moved area I would need to re-refer myself to the other mental health team and wait again. I had previously waited 9 months and would have to do it all over again. So at that point, I went private for counselling because I really needed it...it was a stupid system to be honest, there was no continuity of care.

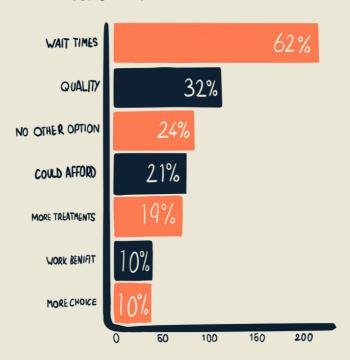
[group discussion participant, disabled or long-term condition]

Waiting times were mentioned throughout this research. In relation to appointments, young women talked about often waiting weeks to see a GP. Most commonly though, young women talked about the impacts of having to wait for referrals for specialist care, tests or scans or mental health support. A few young women specifically mentioned long wait lists for sexual and reproductive health support. One young woman waited eighteen months for her implant to be removed rendering it out of date.

## making appointments

Many young women turned to private healthcare due to long wait times. 43% of survey respondents had accessed private healthcare at some point. Wait times (62%) was the most common reason for going private.





#### **Helpers**

<u>Easy to access information and flexibility</u> made accessing healthcare easier for young women. Some described <u>digital services</u> employed by their local healthcare service, such as e-consultations and digital appointment scheduling.

Since Covid, my GP has an e-consultation option which means you can describe what your issue is and they get back to you within 48 hours, it's easy to fill in the forms and helps to give a clearer picture, all in just one place, there are lots of questions which could be frustrating for some but were really helpful for me.

[group discussion participant, body type and weight]

Many young women mentioned the <u>NHS Inform website</u> as being <u>helpful and supportive</u> in giving them information about health conditions and what kind of intervention they might need. A few specifically mentioned how the website <u>met their accessibility needs</u>.

Some participants did experience more flexible healthcare services, who operated longer windows for call times. Some also mentioned positive experiences with reception staff. The <a href="https://www.new.numer.com/NHS 111 service">NHS 111 service</a> was also <a href="https://www.numer.com/numer

#### The destination:

## experiences of receiving healthcare

We asked survey respondents how they would rate their experiences of healthcare; the highest proportion of young women (40%) rated their experiences as "okay". Just under a fifth (17%) rated their experiences as mostly bad and a further 8% rated their experiences as mostly awful.

Across every theme we explored within experiences of accessing healthcare, young women told us that they are <u>not taken seriously</u> in healthcare settings, they are <u>often dismissed</u>, and <u>their experiences are minimised</u>. Many told us they <u>feel patronised</u> and <u>not believed</u> by healthcare professionals. Young women were then often left with no further offer of support or follow-up.

I tried to access mental healthcare so many times before I was finally able to see a specialist. It took YEARS for me to get life-saving healthcare and medication. The first time I went to see my GP despite pretty severe symptoms I was told to do a worksheet and try not to think about it. I get angry thinking about how much easier my life could have been if I'd been taken seriously when I was a teenager, especially because I don't think they would have reacted that way if I hadn't been a brown teenage girl.



When at an appointment with a specialist I was patronised, dismissed and spoken down to by a male doctor. The way he spoke to me made me feel like I had made up how bad my problem actually was and that I was making things up. He spoke to me like I was a small child and not a young adult.

[survey respondent]

Recently, the British Medical Journal highlighted that women are more likely than men to experience what's known as medical gaslighting, when a medical professional can wrongly attribute a patient's symptoms to psychological factors such as stress or anxiety or downplays a patient's symptoms. A small sample of participants explicitly used the term 'gaslighting' to describe their experiences of accessing healthcare, however, a large majority of young women who engaged with this research described experiences that could be considered gaslighting.

Commonly, for young women who were presenting with any symptoms, mental or physical, medical professionals would suggest hormonal or menstrual issues were the likely cause.

When I have sought advice and help from my GP for depression, excessive menstrual symptoms or migraines, my GP has talked to me as if this is unavoidable due to hormones and there is no further discussion.

[survey respondent]

Young women with a diagnosed mental health condition, who were presenting with physical symptoms felt that medical professionals did not take their physical symptoms seriously, due to their diagnosis.

She [medical professional] said everything is because of your anxiety. I say I want to do blood tests she said no because I have anxiety. She asks why call for an emergency appointment I said because I was having so much chest pain and pain in my arm and she said to stop searching on Google.

[group discussion participant, ethnic minority]

Growing up I suffered from chronic migraines which is a family trait. At the GP I was told it was because I was stressed or because of my weight. They gave me no other option apart from painkillers.

[survey respondent]

I went to the doctor once to discuss severe tummy issues and being sick every day and it was dismissed as being just anxiety. However, when I asked about what the doctor could do to help my anxiety, he said it wasn't bad enough to warrant a referral to the mental health service.

<sup>1 [</sup>https://www.bmj.com/content/378/bmj.o1974.full

Young women who sought medical care for menstrual or hormonal issues, such as excessive bleeding and pain or irregular periods, were also dismissed resulting in <u>delayed diagnoses</u> or <u>debilitating physical</u> and <u>mental health impacts</u> for some.

I've had debilitatingly bad periods since I was a teen and almost collapsed due to the levels of bleeding at work. Doctors did not perform an ultrasound as they are supposed to, looking for fibroids, endometriosis, or anything like that, and have relentlessly pedalled hormonal contraceptives despite me explaining that any time I take them I relapse into self-harm, or have suicidal thoughts.

[survey respondent]

It turns out I had been living with PCOS for years undiagnosed because doctors wouldn't take me seriously – telling me my horrendous periods were due to my age.
[group discussion participant, ethnic minority]

Many young women shared experiences of engaging with healthcare professionals who lacked empathy, compassion or kindness. Young women often feel rushed, and they are not given focused time and space to explore their concerns. Many participants also shared that medical professionals do not actively listen to their concerns.

My most negative experience was a referral to a gynaecologist at a hospital. I felt rushed, I did not feel heard, I felt judged about choosing not to take contraception as (it really negatively affected my mental health in my teenage years,) they were really stressed and not listening. She also said; "what's wrong with hormonal contraception, if it makes you a bit crazy lady, just come off it". I was prescribed hormonal contraception and referred for more invasive examinations. I decided not to proceed with them because of how awful that experience was.

[survey respondent]

Feeling not being listened to by the doctor or taken seriously. Being dismissed when I have raised things that I have been experiencing over a period time. Then feeling like I was being an inconvenience and wasting the time GPs time as there was nothing they could do. Not being made to feel calm or reassured about what I was raising.

Survey respondents told us which of <u>their characteristics</u> they thought contributed to having negative experiences of accessing healthcare. They felt strongly that their negative experiences were because they were young (55%) and because of their gender (62%).

This sentiment of discrimination and bias due to characteristics was echoed by young women with intersecting identities and experiences.

Young women with long-term health conditions, including mental health diagnoses and neurodivergence, were 49% more likely to rate their experiences of accessing healthcare negatively. 65% of disabled respondents stated that having a disability was associated with poorer access to healthcare. These participants highlighted a lack of consistency in medical providers, a lack of understanding or ability to treat multiple conditions holistically, or through bias and discrimination.

I have had appointments with various GP's who have been very unsupportive and condescending with attempting to diagnose my long-term illness. As I don't have a regular GP, having to meet with a new doctor each time I had a problem meant I had to constantly repeat and highlight my issues and removed the familiarity I think diagnosing a long-term illness needs. Some doctors were very quick to dismiss my pain due to my young age, and eager to treat the symptoms but not diagnose the cause.

I've not disclosed to my GP and other healthcare professionals that I'm autistic because I have no faith that it'll actually help my care, I think it'll hinder the already poor quality healthcare I'm getting for my physical health so I've made an active decision not to disclose that, I think there'll be a lot of stereotypes and stigmas around autism if I disclose that to a GP and I don't want that, I don't want my physical health needs to be overshadowed by that (based on experience with a health care practitioner during application for a blue badge).

[group discussion participant, disability or long term condition]

I think that medical professionals have infantilised me due to my disability, I have been spoken down to and treated like I am stupid by people in the medical field when trying to access healthcare and often my partner who is non-disabled and a cis man has to step in to advocate for me in these situations as he will be listened to more than I will even though it is my healthcare that is being discussed.

[survey respondent]

Young women also associated their weight (34%) with having negative experiences of accessing healthcare. They suggested that their <u>weight</u> was often used as a '<u>scapegoat</u>' for their symptoms and that this contributed to feeling like their concerns were not taken seriously.

Others talked about how healthcare professionals did not address their weight appropriately as a health concern and would have liked to have a healthy conversation with their doctor about their weight.

1] https://www.fivexmore.com, (mbrrace, 2021).

I am constantly undermined and told I'm making things up about my symptoms because I'm an obese individual and that everything would be better and go away if I were to lose weight, which is difficult as I also have an eating disorder.

[survey respondent]

If you're gonna talk about my weight, talk about it properly, look at my health chart, look at the fact that I've been diagnosed with PCOS, look at the fact that I am a woman [...] and also watch how you speak to me because I might be really emotional that day [...] and how you present yourself will definitely change my narrative on how much I share with you.

[group discussion participant, weight and body type]

9% of respondents associated ethnicity with negative experiences. This included all the respondents of mixed or multiple ethnicities, the majority of black respondents and around half of the Asian and Arab respondents.

Years of research has consistently shown that Black, Asian and minority ethnic women report negative interactions with healthcare professionals more often than white women and that these interactions, often grounded in racial biases, negatively impact their experiences of healthcare. Further, black women in the UK are four times more likely to die in pregnancy & childbirth.

Young women from ethnic minorities described situations where professionals had made assumptions about their language, or level of education, which left them feeling patronised. A few said there was a need for medical professionals to be more culturally competent. Others talked about experiences of racism and xenophobia in healthcare settings.

During a gynaecological exam a nurse asked me if I have had sex abroad and assumed because of my race and ethnicity that I was at a greater risk of HIV infection.

[survey respondent]

I have beta thalassemia trait and doctors never understand it because it's an issue that doesn't tend to affect white people and so their knowledge of it is limited.

[survey respondent]

Some ethnic minority young women shared that they not only struggle to access healthcare for themselves but for their families too, as they are often the only English speaker in their families.

They do that a lot, assume based on your background. For example, for Muslims, they assume a lot about you. They assume you can't speak English and it sounds so bizarre but they assume you're stupid if your English isn't good and that you don't know anything.

[group discussion participant, ethnic minority]

It's frustrating when I'm with my mum and she is describing a pain and he [the interpreter] is describing something else. So I needed to translate for them. I shouldn't even have to be here. I have to go with her to take time out of my studies to translate.

[group discussion participant, ethnic minority]

Participants also faced bias due to their sexuality, they talked about having assumptions made about their sexuality, commonly experiencing heteronormative assumptions.

There is a lack of understanding about queer sex and the risks of unprotected sex between two cis women. Once a doctor told me they didn't know if I could contract chlamydia from another cis woman. Upon hearing I'd only had sex with other cis women a doctor once started referring to me as not sexually active.

[survey respondent]

60% of trans respondents stated being trans was linked to negative experiences of accessing healthcare. Trans respondents were 57% more likely to rate their experience of accessing healthcare negatively compared to cis women. Lack of understanding, misgendering and poor access to making private healthcare a requirement were all issues trans respondents shared. One participant's poor experiences of accessing healthcare were due to intersecting experiences of being trans, young, living in a rural area and having mental health issues:

Little to no understanding of trans healthcare outside the big cities as well as queer healthcare – I'm afraid to even say anything to my GP. A limited understanding of mental illness and disability in young people means I feel like I've never been taken seriously.

[survey respondent]

The principles of trauma-informed practice are; <u>safety, trust, choice, collaboration, and empowerment</u><sup>2</sup>. These principles <u>were lacking</u> in many participants' negative experiences of accessing healthcare. Some described their experiences as being compounded by having a lack of choice, not feeling safe, or having painful or invasive procedures that they were not properly prepared for or supported through.

I wish I had known the choices, I probably wouldn't have come off the medication the way I did, but I wouldn't have opted for the higher dosage had I known I'd be stuck on it for 6 months.. it's about choice but do you have a choice if you don't have all the information?

[group discussion participant, body type and weight]

I needed a vaginal exam because of pain, and it was extremely painful and I was not told what was going to happen. She didn't warn me about what she was doing. There was no offer of a chaperone.

This was only in 2024.

This was only in 2021! [survey respondent]

When depressed brushing my teeth is the first thing to go, the dental hygienist laughed to their assistant and said 'surely you just feel more depressed if your teeth are gross' I live in a really small town [...] I know there's only one hygienist.. that conflicted feeling of I wish I'd complained at the time but I felt so ashamed.

[group discussion participant, living rurally]

Having consistent negative experiences of accessing health made young women feel <u>frustrated</u> and <u>belittled</u>. Others described more <u>severe mental health impacts</u> of receiving poor healthcare, like feeling <u>traumatised</u>. These participants suggested their experiences had put them off accessing further healthcare treatment.

Some young women felt <u>guilty</u> for accessing healthcare, knowing how much pressure is facing the NHS, especially throughout and since the Covid-19 pandemic.

Some participants also talked about the financial impacts of having to access private healthcare after struggling to access needed treatment through the NHS.

I also had to pay for a mental health assessment. Before moving I had been referred by a previous mental health team but it seemed like they just threw that in the bin. So I had to go private and now I'm in a lot of financial difficulties because of that.

[group discussion participant, disabled or long-term condition]

https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/pages/4/



The guilt puts me off trying to access things as does all the bad experiences that my friends have had as does all the news stories about how broken everything is [...] it feels like such a big task that I don't have the energy for [...] it feels like too big of a thing to tackle, trying to access healthcare.

[group discussion participant, living rurally]

Some participants who had experienced long waiting times experienced falling through the gaps of youth services and adult services, and often severe mental and physical health impacts. Some participants shared the sentiment that seeing their GP about their mental health was 'pointless' because they understood how long they would have to wait to get referrals.

I had to wait something like seven months to get therapy from CAMHS, and because of this my condition worsened significantly. When I eventually got therapy, it was useless, and I was signed off after a few months because I turned 18. Now I've been left alone with no support.

[survey respondent]

I feel like I'm being pushed to either go private or self-medicate on this gender clinic waiting list. I can't afford to go private so I'm having to look at illegaly purchasing testosterone. Knowing who you are as an adult and being unable to do anything meaningful about it makes you feel like half of a human being.

[survey respondent]

#### **Navigating the healthcare journey**

Having access to the Internet (72%), education (36%) and economic class (27%) were the most common factors tied to having positive experiences. We explored this in more depth in our group discussions. Young women told us about how tirelessly they had to advocate for themselves in healthcare settings to get the support, treatment or follow-up care that they needed.

Participants acknowledged the privilege of time, resources, education, access to information, and understanding their rights supported and empowered to self-advocate, and that not every young person has these privileges.

My diagnoses took two years though, of my own persistence after being dismissed and misdiagnosed and my ability to call and hassle my GP's surgery, to be able to call within the triage window because I work from home, which not everyone has the ability to do. I also think because I had spent so long trying to advocate for myself, I knew how to 'work the system' and how to ask for the care I needed.

[survey respondent]

Young women acknowledged the <u>injustice</u> of this and described feeling <u>exhausted</u> by having to <u>self-advocate</u>, and hoped for a future where self-advocacy was not as essential to receive adequate support and treatment.

One thing that hinders care is if you go in uninformed essentially... with type 1 diabetes there's so many different treatment options and some are more expensive than others so the teams won't give you the options ... so you have to go in knowing all the different treatment options for yourself because you won't be offered them unless you bring them up and you have to be really good at advocating for yourself or you won't get the care you deserve... it's not fair, I have to advocate for myself for my own care, but someone who's not confident enough to do that would have just lost the funding.

[discussion group, disability or long-term condition]



I spent years working to get an ADHD diagnosis. I felt like my experience and symptoms were ignored because they didn't fit well with the diagnostic criteria which is based on the behaviour of disruptive boys. I was pushed to investigate anxiety and depression and had to restart the process four times, with total of 5 different doctors, before finally being taken seriously and receiving a diagnosis and medication that has hugely improved my life.

[group discussion participant, living rurally]

<u>30% of young women</u> we surveyed said their experience of healthcare was <u>mostly</u> <u>good</u>. Being <u>listened to, heard, believed and validated,</u> were by far the most important <u>features</u> of a positive healthcare experience. Young women <u>appreciated</u> practitioners <u>who showed empathy</u> and <u>genuine care</u>.

Positive experiences are ones where I have been listened to and allowed to have the initiative in my care. Where I have been made aware of all my options, and providers have been honest with me when they are unable to provide care.

[survey respondent]

I felt really listened to, my doctor recognised my experiences and offered a variety of other viewpoints in a helpful way but ultimately trusted me.

[survey respondent]

The doctor read my notes ahead of my procedure and knew because of my autism, I needed to be told what was happening all the time. It probably didn't take much out of their day or anything just really helped me to keep calm ... I was so grateful ... it shouldn't have stood out as a really positive experience because that's what healthcare should be.

[survey respondent]

There is a lovely doctor at my surgery who listens to what I have to say and actually seems to care about my health and wellbeing. She is always reassuring and talks me through her theories and plans for the future. Many other doctors seem to try and rush me out of their office as fast as possible, whereas she genuinely seems to want to help me.

[group discussion participant, living rurally]

<u>Safety, choice and follow-up</u> support were key for young women who had positive experiences of accessing healthcare. Having <u>a plan</u> or <u>clear</u> next steps was crucial for young women to have a positive experience.

I have had positive experiences in healthcare where I have been believed and supported to access medication or interventions I really needed. This often came from professionals who took the time to listen, offered different options and were really speedy in how they then responded.



66

I have had a positive experience with a GP who was very supportive and understanding when I asked for help with my mental health. He took the time to listen, ask appropriate and compassionate questions, empathised, checked in with me, explained my options, asked me what I needed and did what he could do to support, he prescribed medication, signed me off from work, proactively checked in with me over the phone to see how I was doing.

<u>Transparency</u> and <u>honesty</u> about next steps, timings, and procedures were really important for young women to have positive experiences. They talked about professionals who explained things <u>clearly</u> and often <u>provided</u> written follow-ups.

A lot of people that you come across in the healthcare profession are very empathetic and want to help but they're held back by the policies in place, I've had nurses and drs say in a perfect world this is what we'd give you but... they don't have the funding or the time to give you the proper care, no matter how much they care they just don't have the resources to give you the care they want... it's the bureaucracy and the lack of funding overarching it that makes accessing healthcare harder.

[group discussion participant, disability and long term condition]

Interestingly, many young women's positive experiences took place in a hospital setting, they described nurses and doctors who provided exceptional care in more extreme circumstances.

Further, some young women explicitly mentioned better care from healthcare professionals who were representative of their identities, whether through gender, ethnicity or class.

[nurse] checked up on me... she reached out to me to make sure I was okay, which is very rare because everyone is so busy so that meant a lot because when you have long-term healthcare you feel like you're a burden already because you're taking up a lot of resources...

she was like you're not a burden.

[group discussion participant, disability and long term condition]

Almost every interaction I have had with nurses within the hospital setting has been positive - they have been compassionate, considerate and have often gone out of their way to make me feel comfortable and at ease at as a young woman. One nurse advocated on my behalf when she could see that I was uncomfortable with how the (all male and substantially older) medical team were approaching me/my case. It is not wasted on me that 99% of the time it has been women of a similar social class to myself who have stepped in also.

[survey respondent]

Young women who had ongoing relationships with their healthcare provider described this as positive, building a relationship and mutual understanding led them to access the healthcare they needed.

## What needs to change:

## for all young women and people of marginalised genders to receive the healthcare they deserve

Participants told us what they think needs to change for all young women and people of marginalised genders to access the healthcare they need and deserve in Scotland. Alongside these actions, The Young Women's Movement would urge policymakers, healthcare practitioners, and institutions in positions of power that can implement change in young women's access to healthcare to consider the findings and recommendations of the <u>Better for Women report</u>, by the Royal College of Gynaecologists and Obstetricians and the <u>actions of the Scottish Government's Women's</u> Health Plan.

#### **Access**

<u>Alternative</u> ways to <u>access</u> healthcare need to be more <u>widespread</u> and <u>standardised</u> across Scotland. Young women want to be able to engage <u>digitally</u>, such as through <u>econsultation and online registration</u>, or making appointments <u>online</u>.

Why is it easier to book a train ticket than a GP appointment?
[group discussion participant, disability and long-term condition]

<u>Better management of waiting lists.</u> Young women are understanding of the pressures facing the NHS but would like to see the triaging of waiting lists to ensure those who are in most urgent need of care are seen first. They would also like the standardisation of being kept up-to-date about their position on waiting lists for referrals.

<u>Better access to information and signposting.</u> Young women and people of marginalised genders want to see up-to-date websites and accessible information about local healthcare services. They want information that has been tailored to meet their needs.

Better organised and more accessible information would just make so much sense and I just don't understand why we don't have that.

[group discussion participant, disability and long-term condition]

Young women want <u>better communication between healthcare providers</u>, including improved record transfer.

#### **Attitudes and culture**

<u>Young women want to be heard, seen, listened to and validated.</u> They want healthcare professionals to take them seriously. They no longer want to experience medical misogyny or feel gaslit in healthcare settings.

## for all young women and people of marginalised genders to receive the healthcare they deserve

The system does not acknowledge that people really know their bodies and if I'm telling you something is wrong, I know that because I'm living in this body 24/7 and you just need to believe me.

[group discussion participant, living rurally]

There needs to be more <u>compassion</u> and <u>empathy</u> from healthcare professionals across the board. They deserve to feel at ease and cared for in a vulnerable healthcare setting.

I think there needs to be more acknowledgement of how uncomfortable and nervous young woman may feel in the general setting of a doctor's office.

[survey respondent]

Young women and people of marginalised genders need to <u>feel safe</u> to access <u>timely care</u>. Especially in relation to abortion and reproductive services, gender-affirming healthcare, and mental health support.

#### **Education**

Improving training for medical professionals is essential, especially relating to <u>sexual</u> and <u>menstrual</u> health, also surrounding <u>how conditions present differently</u> in young women. The medical profession needs to practice <u>anti-racism, dismantle ableism</u> and <u>operate intersectionally</u> to consider the experiences of all young women and people of marginalised genders.

In an ideal world, there would be no biases... there should never be a 'look'... whatever your identity is, you deserve the same healthcare... there's so much bias and stigma around it.

[survey respondent]

Healthcare professionals should receive sexuality and gender diversity training, to help combat harmful misconceptions, preconceptions, prejudice and presumption.
[survey respondent]

Young women also wanted <u>better education</u> for themselves around accessing healthcare, they want to <u>know their rights</u>, and <u>about how conditions might</u> affect them differently, acknowledging that women's health is not widely discussed.

Young women want <u>more research into and understanding of women's health.</u> Currently, less than 2.5% of publicly funded research in the UK is dedicated to reproductive health, despite one in three British women suffering from a chronic gynaecological problem<sup>3</sup>

<sup>&</sup>lt;sup>3</sup>[https://www.refinery29.com/en-gb/2020/09/10005515/exploring-the-gender-health-gap

## for all young women and people of marginalised genders to receive the healthcare they deserve

#### Systemic change

Young women acknowledged the lack of funding and resource in the healthcare system. They want to see more NHS staff and better pay for medical professionals.

They would like to be able to <u>access healthcare through the NHS</u>, acknowledging how unique our healthcare system is. If accessing private healthcare is necessary because of NHS failings, young women suggested they should receive personal healthcare budgets through the NHS.

Young women wanted to see <u>preventative care approaches</u> being embedded, understanding that health is influenced by multiple societal and environmental factors.

Healthcare is a human right, and it is vital that no more of the NHS is privatised. Furthermore, preventative care is the most cost-effective and most humane way to approach public health. This means people living in security - without fear of destitution. That means accommodation, with proper insulation, and the money to put on their heating and eat enough food with no questions asked - no hoops to jump through. This would change the lives of thousands of people, and prevent a huge range of conditions.

#### [survey respondent]

Young women want more choices and alternative types of support for menstrual health, instead of prescribing the pill as a default they want medical professionals to support them to explore alternative options.

They want more choices about the type of mental health support available through the NHS. Some specifically discussed peer-led support and alternatives to CBT.

There needs to be more women and people with marginalised genders in positions of power throughout the medical profession.

Fundamentally we just do not have enough women and people with marginalised genders at the decision-making tables - deciding what services should receive funding and which are the priority or even deciding the curriculums in medical schools (it's only in the last few years that a women's health module has become mandatory in Scottish medical schools!)

## Thank you

Thank you to every young person who took part in this research, and shared honestly and vulnerably, without you this work would not have been possible.

To our working group members, who were critical friends at each stage of this project and supported us with reach and engagement:

Annabelle Lamont
Caitlin Stuart-Delavaine
Donna Nicholas, Who Cares? Scotland
Emmagayle Harper
Jennifer Stewart, Alliance Scotland
Kimberley Somerside, Voluntary Health Scotland
Rachel Barr, NHS Lothian
Rebecca Hoffman, LGBT Health and Wellbeing
Ruth Pearce, University of Glasgow
Ryan Butter, Scottish Trans, Equality Network
Vic Valentine, Scottish Trans, Equality Network

Thank you to Eilidh Young and Glasgow Strathclyde University for supporting the background research for this project.

Thank you to all organisations who supported us to facilitate group discussions. Particularly, Aileas Pringle at Govanhill Community Project.

Thank you to the Esmee Fairburn Foundation who provided The Young Women's Movement with the funds to be able to dedicate staff time to this important research.

Thank you so the TRIUMPH network, for providing the budget for young people's participation in the group discussions.







@youngwomenscot



www.youngwomenscot.org

If you would like more information about the research, or to give feedback about this report, please contact hello@youngwomenscot.org