NOTHING ABOUT US WITHOUT US

Amplifying the voice of grassroots women

Women's Health Strategy Survey Results

The Community Foundation Northern Ireland

Contents

Foreword

The 'Nothing About Us Without Us' co-design panel is proud to be part of a programme of works which places women at the heart of it, particularly when it comes to health. We have extensive experience and knowledge of the women's sector in Northern Ireland and, through our work, support grassroots women here to become more visible, vocal, and valued when it comes to issues that affect and matter to them.

The Community Foundation for Northern Ireland connected us together in the summer of 2022 with the purpose of designing a conference, specifically for women, focusing on the theme of health and wellbeing with a call to action on the need for a Women's Health Strategy. It was a sellout event with over 240 women attending and our event in March 2024, ahead of International Women's Day, was no different. At this event, we launched our health survey, and we are pleased to present our findings to you in this report.

These events, and our work since 2022, reaffirmed that women's health is a pressing and unifying issue for us all. Whilst we are pleased that the draft Programme for Government[1] highlights ending violence against women and girls as a priority for the Executive, we are disappointed that there is not also a focus on women's health. We have been shocked to learn how far behind Northern Ireland is on the issue of women's health and, when compared to other jurisdictions across the UK and Ireland, it is clear that we continue to be underserved compared to our peers.

Since we started this work in 2022, we have become increasingly aware of the countless health issues and misconducts that women in Northern Ireland continue to face. In October 2023, the cervical screening tests of more than 17,000 women in the Southern Trust had to be reviewed due to incorrect results,[2] leading to the preventable deaths of at least two women. Of 11,000 women who had vaginal mesh implants between 1998 and 2018, an estimated 5-10% have been adversely impacted, with years of pain awaiting mesh removal being the outcome for many[3].

We continue to see waiting times increase for breast cancer treatment and screening, a lack of perinatal mental health support, and no mother and baby unit despite campaigning that has spanned 20 years[4]. Abortion access remains an issue despite being decriminalised over four years ago and the subsequent regulations not being fully implemented. Despite a commitment from the Department of Health in 2020 and in the 'New Decade, New Approach' agreement, there remains a limited provision for assisted conception. All of this, alongside the societal context of women's health and the lived experiences you will read throughout this report, make the case even more compelling for the need of a coordinated and resourced Women's Health Strategy.

Too often women's health issues are considered 'taboo' and consequently, important conversations with other women, with our peers, and with professionals fail to take place. However, we know that these conversations need to happen if we want to see a real change.

Talking about our health in our 'safe spaces' with family, friends, or community groups is one example, and through the 'Nothing About Us Without Us' project, we have gone one step forward. We are delighted to have helped create regional safe spaces where these important conversations are happening openly between women from across NI and with a collective goal to aim for; a fully funded Women's Health Strategy that we all deserve.

We plan to continue in our efforts towards this and to collaborate with other organisations who join our call for better women's health outcomes in NI, including our engagement with Derry Well Women as they complete a public listening exercise on women's health, funded by the Department of Health and in partnership with Queen's University Belfast.

In closing, over the last 2 years we have learnt from and been inspired by the women who have joined us on this journey. We therefore want to give our sincere thanks to every individual that has attended an event, been involved in a discussion, filled out a postcard, or took the time to complete the survey. We have been humbled by the bravery that you have shown in sharing your health experiences with us and we hope that as you read this report, you feel truly represented.

With thanks,

Charmain Jones and Louise Coyle, Northern Ireland Rural Women's Network

Danielle Roberts, Reclaim the Agenda

Gosia O'Hagan, Building Communities Resource Centre

Ronda Rainey, The Carson Project

Susan McCrory, Falls Women's Centre

Amie Gallagher, Rachel Carlin, and Margaret Bonner, The Focus Project

Dawn Shackels, Lorraine Morrissey McCann, and Danielle Dawson, Community Foundation for Northern Ireland

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2. BBC News (2024) Some smear test scientists investigated over cervical screening. Available at: https://www.bbc. co.uk/news/articles/cyj4ylj1p89o (Accessed August 2024).

3. BBC News (2024) 'The pain was excruciating' after mesh implants. Available at: https://www.bbc.co.uk/news/articles/c623vpe3907o (Accessed August 2024).

4. Women's Resource and Development Agency (2024) Bold Women Blogging. Maternal Mental Health in Northern Ireland – a Feminist issue. Available at: https://wrda.net/2024/06/04/maternal-mental-health-in-northern-ireland-a-feminist-issue/ (Accessed August 2024).

Introduction

"I want better treatment for our daughters and granddaughters"

The following report and associated survey have been developed by the Community Foundation for Northern Ireland alongside the Nothing About Us Without Us co-design panel.

The Community Foundation for Northern Ireland is a local independent grant making trust, working hand in hand with communities to build a better future.

Since our formation in 1979 as the Northern Ireland Voluntary Trust we have awarded over £120m, distributing over 2,000 grants per year, with an average grant size of £8,500 in 2022. The Foundation wants to see a place where generosity and fairness change lives, communities flourish, and everyone feels they belong. The Foundation's vision is "a fair and equitable society for everyone".

The Foundation's 2023-2026 strategy set out the following strategic priorities:

Poverty	**invest in projects, campaigns and organisations addressing short- and long-term poverty**
Climate sustainability	**create opportunities to educate and learn, decarbonise our operations, commit resources and manage our investments through a climate justice lens**

Community Transformation	**build and develop opportunities in support of a stronger, more resilient and inclusive community and voluntary sector**
Digital inclusion	**commit resources and advocate for a digital strategy for Northern Ireland, an innovative approach to digital infrastructure and improve digital support and workforce development**
Social Justice	**broaden our human rights support and continue to advocate for and give greater voice to those most marginalised in our community**
Health	**develop funding, policy and programmes that address and enhanced mental, physical, economic, social and environmental well-being**

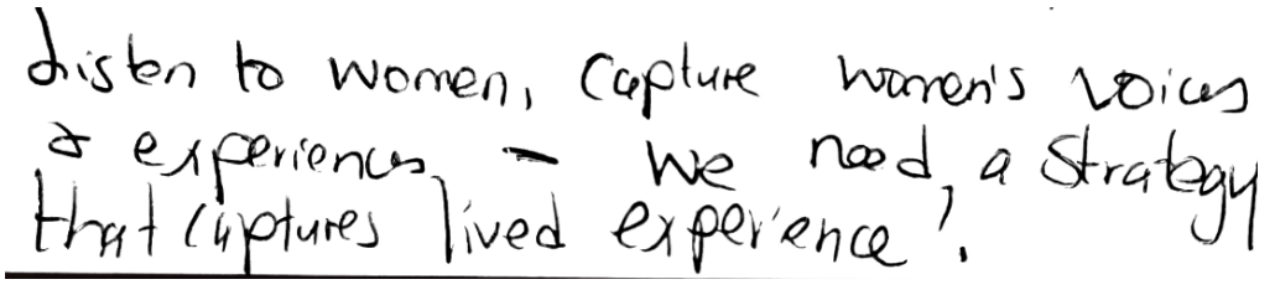
"NOTHING ABOUT US WITHOUT US"

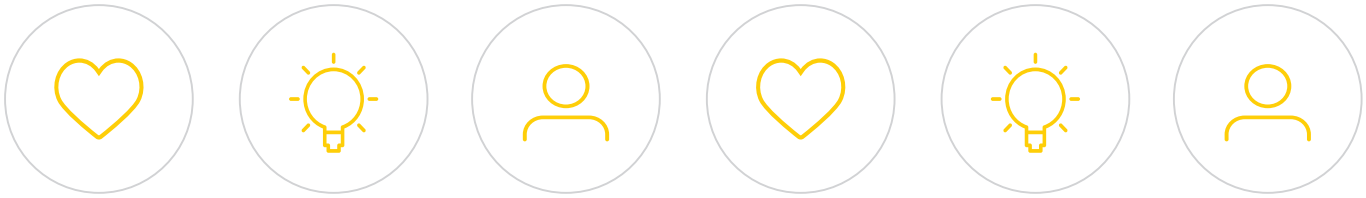
Amplifying the voice of grassroots women

The Foundations Mission is “to work hand in hand with communities to build a better future”. We will work collaboratively to influence policy, advocate for communities, and use impact and knowledge to inform practice and policy. We believe that increased and suitable investment into the VSCE sector will assist it to address need, sustain critical services, and support innovation.

The Nothing About Us Without Us group, supported by The Community Foundation for Northern Ireland, is a coalition of women from diverse backgrounds and experiences working within and across communities in Northern Ireland. The group focusses on supporting and enabling grassroots women to be more visible, vocal, and valued within and across their communities, the wider public space and consciousness. This is achieved through supporting grassroots women to identify and mobilise around key issues impacting on their lives including the need for a Women’s Health Strategy for Northern Ireland.

To date, Northern Ireland is the only place across these islands not to have a dedicated Women’s Health Strategy or at the very least, a Women’s Health Action Plan. The Nothing About Us Without Us programme seeks to address this, and to ensure that any future Women’s Health Strategy for NI is sufficiently funded and reflects the experiences and needs of women from grassroots communities.





Whilst we welcome the Ministers commitment to develop an Action Plan for Women's Health, we believe that a long-term, cross-departmental strategy is the best approach to addressing the inequalities experienced by women in accessing the healthcare they need, when they need it.

This report is the result of questionnaires completed by 1,080 individuals and 74 Voluntary, Community, and Social Enterprise (VCSE) organisations from across Northern Ireland during March and April 2024.

The purpose of this survey was to better understand the experiences of women when accessing healthcare in Northern Ireland and to identify priorities for inclusion in a Women's Health Strategy for the region. Whilst this report presents data collected from the survey, we acknowledge that we have not been able to cover everything and issues such as the implementation of a gender-specific strategy, institutional misogyny, violence against women and girls, racism, ableism, and poverty still need addressed.

The Community Foundation for Northern Ireland and the Nothing About Us Without Us co-design panel, which includes Northern Ireland Women's Network (NIRWN), Falls Women's Centre, Reclaim the Agenda, Building Communities Resource Centre, The Carson Project, and The Focus Project would like to express our thanks to all those individuals and organisations who took part in this survey.

Content warning: Please be aware that some of the lived experiences shared within this report may make for difficult reading.

The Community Foundation Northern Ireland

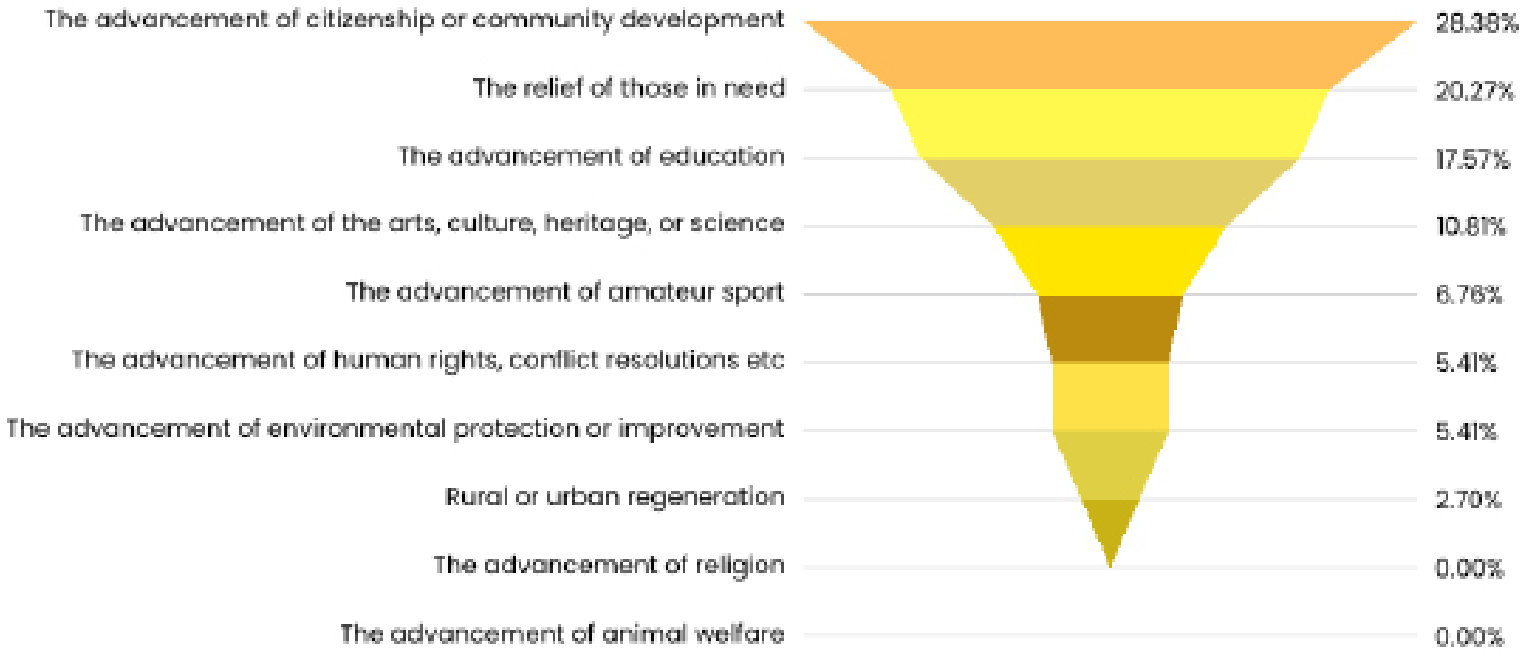
Demographics

This survey was open to both individuals and organisations from across Northern Ireland. A range of demographic questions were asked, the breakdown of which is available below. A total of 74 organisations and 1080 individuals completed the survey.

Demographics of Organisations

Charitable Purpose of Organisations

A total of 74 organisations responded to the survey. Organisations were asked to identify which of the charitable purposes, as set out by the Charity Commission for Northern Ireland, defines their purpose. Of these 44.59% (N=33) reported one of their charitable purposes as the 'The advancement of health or the saving of lives' and 28.38% (N=21) reported 'The advancement of citizenship or community development'. None of the respondents reported a charitable purpose of 'The advancement of religion' or 'The advancement of animal welfare'.



Health Related Support provided by organisations

Organisations were asked about the classification of services they provide. More than three quarters of respondents (75.68%) reported 'Mental health and wellbeing services' as a category of services provided to clients. This was followed by more than half (55.41%) of organisations who reported providing services around 'Social support including support groups'. More than a third of organisations (39.19%) reported providing services related to 'Physical health and wellbeing services'.

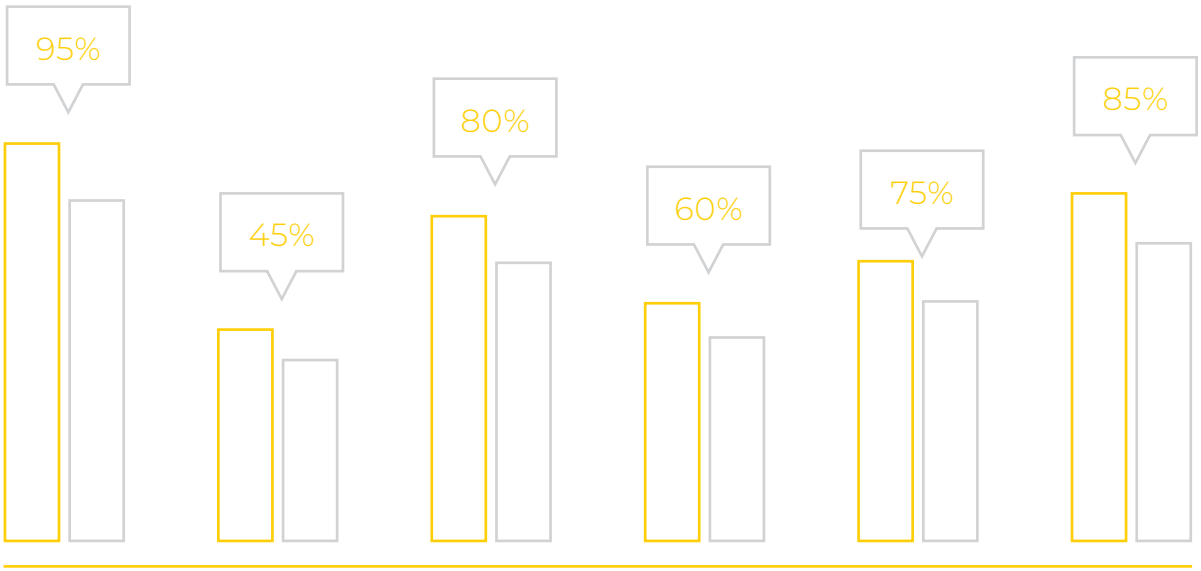
Which of the following classifications best defines the health-care related support you offer?	**% of orgs**	**No of orgs**
Mental health and wellbeing	75.68%	56
Social support including support	55.41%	41
Physical health and wellbeing services	39.19%	29
Sexual and/or reproductive health services	10.81%	8
Cancer diagnosis or support services	6.76%	5
Smoking cessation services	1.35%	1
None of the above	2.70%	2

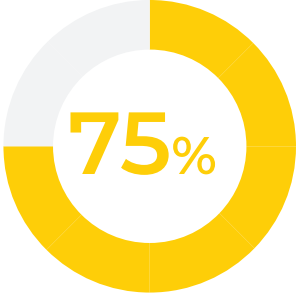
Information, Support and Advice Provided by Organisations

More than three quarters of organisations (78.38%) reported providing information on 'Mental health and emotional wellbeing' and more than half (56.76%) on 'Physical health and wellbeing'. The least common information provided was 'Specific health services available' at 4.05% (N=3), 'Gynaecological conditions' at 5.41% (N=4), 'Breastfeeding' at 5.41% (N=4), and 'Gynaecological cancers' at 6.76% (N=5).

Which of the following areas does your organisation provide information, support, or advice on?	**% of orgs**	**No of orgs**
Mental health & emotional wellbeing	78.38%	58
Physical health & wellbeing	56.76%	42
How to prevent ill-health or maintain your health	28.38%	21
General physical health concerns e.g. diabetes, heart disease	21.62%	16
Disabilities	20.27%	15
Menopause	18.92%	14
Menstrual wellbeing e.g., period pain, heavy menstrual bleeding	13.51%	10

How to prepare for or prevent pregnancy	12.16%	9
Gynaecological cancers	6.76%	5
Breastfeeding	5.41%	4
Gynaecological conditions e.g., endometritis, fibroids	5.41%	4
Specific health services available	4.05%	3
Other	14.86%	11
None of the above	8.11%	6





Demographics of Respondents

Council Area of Respondents

More than 1 in 10 of individual respondents were from the 'Belfast City Council' area. The lowest representation was from the 'Mid and East Antrim Borough Council'. All 11 Councils across Northern Ireland were included in the responses to the survey and accounted for 6% or more of all responses.

Please indicate the council area where you live?	% of respondents	No of respondents
Belfast City Council	14.07%	152
Armagh City, Banbridge and Craigavon Borough Council	10.19%	110
Antrim and Newtownabbey Borough	9.63%	104
Derry City and Strabane District Council	9.44%	102
Causeway Coast and Glens Borough	9.35%	101
Ards and North Down Borough Council	8.89%	96
Fermanagh and Omagh District Council	8.61%	93
Mid Ulster District Council	7.87%	85
Newry, Mourne and Down District	7.87%	85
Lisburn and Castlereagh City Council	7.78%	84
Mid and East Antrim Borough Council	6.30%	68

Age Categories of Respondents

Respondents reflected a broad range of age categories. The largest response rate was from the '30-39 years old' age category accounting for 23.24% (N=251) of responses. The lowest response rates were from the '16-19 years old' category (1.02%) and the '80 years and above' category (0.09%).

What age are you?	% of respondents	No of respondents
16-19 years old	1.02%	11
20-24 years old	12.13%	131
25-29 years old	16.67%	180
30-39 years old	23.24%	251
40-49 years old	17.87%	193
50-59 years old	18.33%	198
60-69 years old	8.98%	97
70-79 years old	1.67%	18
80 years old or above	0.09%	1

Gender and Gender Identity of Respondents

The vast majority of respondents identified as 'Female' at 80.37% (N=868) while 19.54% (N=211) of respondents identified as 'Male'. One respondent identified as 'Other'. 3.71% (N=40) of respondents identified as 'Transgender', this included 25 respondents who identified as female and 15 respondents who identified as male.

Gender	% of respondents	No of respondents
Female (including transgender)	80.37%	868
Male (including transgender)	19.54%	211
Other i.e non-binary, gender neutral etc (please state)	0.09%	1

Do you identify as Transgender?	% of respondents	No of respondents
Yes	3.71%	40
No	95.92%	1034
Prefer not to answer	0.37%	6

Sexual Orientation

The vast majority of respondents identified as 'Heterosexual/Straight' at 92.13% (N=995). 6.58% (N=71) of respondents identified as another sexual orientation and 14 respondents preferred not to answer this question.

What is your sexual orientation?	% of respondents	No of respondents
Lesbian/gay woman	2.69%	29
Heterosexual/ Straight	92.13%	995
Bisexual	3.06%	33
Gay man	0.46%	5
Prefer not to say	1.30%	14
Other (please state)	0.37%	4

Community Background

45.74% (N=494) of respondents identified their community background as being a member of the 'Catholic community' while 39.07% (N=422) identified as being a member of the 'Protestant community'. More than one in ten (11.2%) of respondents identified as being a member of 'neither community' and a small number of respondents (N=43) chose 'Prefer not to say'.

In Northern Ireland, many of us are perceived to belong to either of the two main communities. Which best describes you?	% of respondents	No of respondents
I am a member of the Protestant community	39.07%	422
I am a member of the Catholic community	45.74%	494
I am a member of neither community	11.20%	121
Prefer not to say	3.98%	43

Ethnicity

The majority of respondents identified their ethnicity as 'White' at 92.5% (N=999). 2.04% (N=22) of respondents identified as either 'Black African' or 'Black Caribbean'. 7.05% (N=76) identified as an ethnicity other than White, while 5 respondents chose not to answer.

What is your ethnicity?	% of respondents	No of respondents
Bangladeshi	1.39%	15
Black African	1.48%	16
Black Caribbean	0.56%	6
Irish Traveller	0.65%	7
Central European	1.20%	13
Eastern European	0.19%	2
Indian	0.28%	3
Pakistani	0.28%	3
Chinese	0.00%	0
White	92.50%	999
Mixed Ethnicity	0.93%	10
Prefer not to answer	0.46%	5
Other (please specify)	0.09%	1

Caring Responsibility

The highest level of caring responsibility was for a 'Child/Children' with a total of 65.37% (N=685) of respondents having either shared or sole responsibility for a 'Child/Children' compared to 56.45% (N=560) having responsibility for the care of an 'Older person' and 49.8% (N=497) having responsibility for the care of a 'Person with a disability'. In terms of sole caring responsibility there were an almost equal number of people who had responsibility for the care of an 'Older person' (40.12%) or a 'Person with a disability' (40.18%).

Please tell us if you have any responsibility for the care of	None		Shared		Sole	
	%	Num	%	Num	%	Num
Child/Children	34.64%	363	57.16%	599	8.21%	86
Older person	43.55%	432	16.33%	162	40.12%	398
Person with a disability	50.20%	501	9.62%	96	40.18%	401

Employment

The majority of respondents (85%) were employed with 35% (N=378) 'Working full time', 43.52% (N=470) 'Working part-time' and 6.48% (N=70) being 'Self-employed'. 2.87% (N=31) of respondents were 'Not working at present' and 6.02% (N=65) were retired. A small number of respondents were 'Carers' (1.94%), 'Homemakers' (1.2%) and 'Students' (1.78%).

Which of the following best describes your employment status?	% of respondents	No of respondents
Working full-time	35.00%	378
Working part-time	43.52%	470
Self-employed	6.48%	70
Not working at present	2.87%	31
Carer	1.94%	21
Homemaker	1.20%	13
Retired	6.02%	65
Student	1.76%	19
Other (please specify)	1.20%	13

People Living with a Disability

49.07% (N=530) of respondents reported living with a disability, while 49.44% (N=534) reported not living with a disability. The most common form of disability experienced by respondents was a 'Mental health condition' at 77.99% (N=411). Experiences of a 'Mental health condition' were more than 3 times as common than any other form of disability with 16.51% (N=87) having a 'Physical disability' and 9.87% (N=52) having a 'Long standing illness'.

Are you living with a disability?	**% of respondents**	**No of respondents**
Yes	49.07%	530
No	49.44%	534
Prefer not to say	1.48%	16

Type of disability	**% of respondents**	**No of respondents**
Physical - such as difficulty using arms or mobility requiring the use of a wheelchair or crutches	16.51%	87
Sensory - such as blind/visual impairment or deaf/hearing impairment	5.69%	30
Mental health condition, such as depression or schizophrenia	77.99%	411
Learning - such as Down's Syndrome, Dyslexia or Cognitive Impairment such as Autism	4.93%	26
Long standing illness - such as cancer, diabetes, chronic heart disease or epilepsy, HIV	9.87%	52
Other (please specify)	7.59%	40

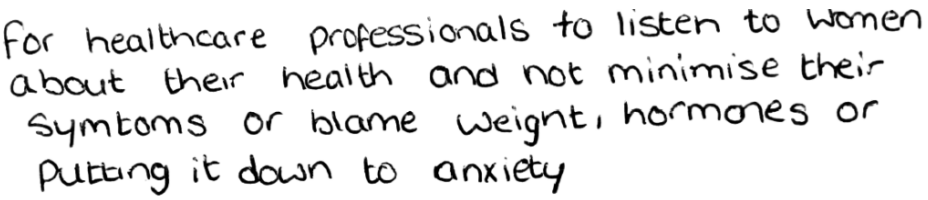
Talking About Health

It's crucial to have safe and accessible opportunities to discuss health topics. By talking openly about their health in safe and accessible ways, women can learn about preventive measures, early detection of diseases, and available treatment options. Discussing health empowers women to take control of their bodies, make informed decisions about their health, and seek necessary medical care when needed. Open conversations about women's health breaks the stigma surrounding certain conditions, encourages support networks, promotes overall wellbeing and improves quality of life.

Respondents were asked how comfortable they felt talking about health-related issues with a range of people. Respondents were most comfortable talking about health issues with a 'Female health professional' with 71.9% (N=777) stating they felt 'Very comfortable' or 'Comfortable' talking to them about health-related issues. This was followed by 'Friends' at 67.22% (N=726) and 'Partner/spouse' at 63.05% (N=681).

46.5% (N=524) of respondents reported feeling 'Very comfortable' or 'Comfortable' talking to male health professionals, with some comments shared highlighting that lower number may be the result of a reluctance by male health professionals to offer support and advice as opposed to women feeling uncomfortable discussing their issues with them in the first instance.

"I was told by a male GP that I would be 'better talking to one of the lady doctors' as he didn't know much about menopause or menopausal symptoms."

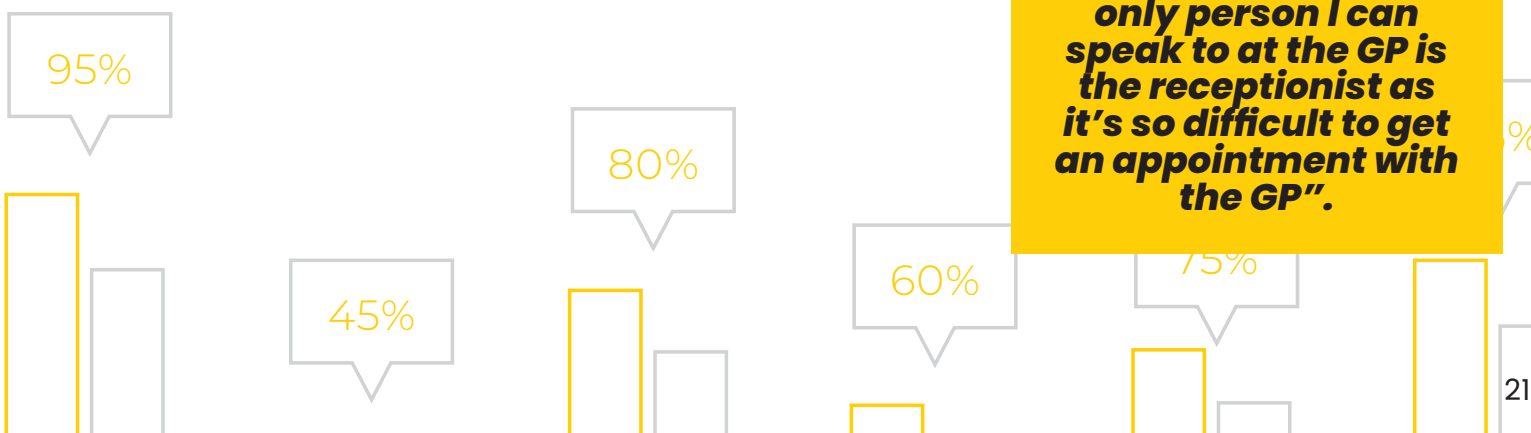


How comfortable are you talking about health issues with:	Very Comfortable	Comfortable	Neither	Uncomfortable	Very Uncomfortable
Female health professionals	41.85%	30.09%	13.06%	6.94%	7.96%
Male health professionals	17.59%	28.98%	23.52%	19.44%	10.37%
Colleagues	17.69%	29.91%	25.37%	16.94%	8.43%
Friends	31.85%	35.37%	14.44%	10.56%	7.59%
Partner/ Spouse	35.83%	27.22%	14.17%	9.63%	6.48%

A large percentage of respondents (79.3%) stated that there have been incidents where they have not been listened to by a health professional. The most common occurrence was in 'Discussing symptoms' at 50.25% (N=436), followed by 'Discussing treatment options' at 38.12%, 'Seeking referral to a specialist' at 35.11%, 'Asking for more information about an issue or a condition' at 32.79% and 'Follow up care' at 31.75%.

"I am fed-up as a woman with being ignored, belittled and expected to put up with things that the male cohort would not be expected to contend with... Women should feel empowered by their health workers not dismissed and less-than because they are/identify as a woman."

"I feel increasingly isolated from health and social care services. It is near impossible to get talking to a GP these days, with local GPs expecting us to self-diagnose, often the only person I can speak to at the GP is the receptionist as it's so difficult to get an appointment with the GP".

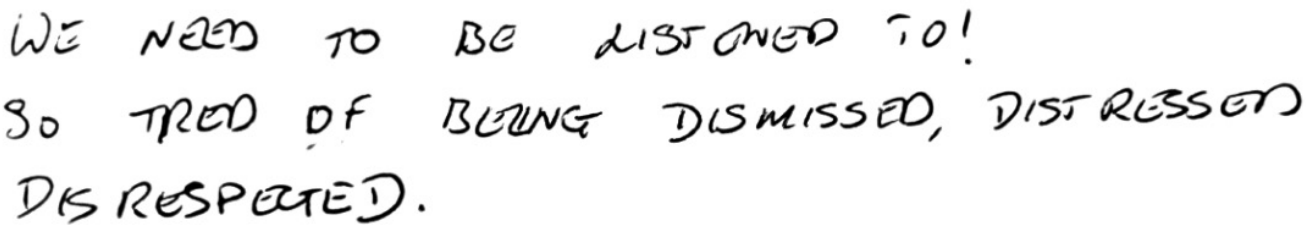


"I suffered severe pain in my teens and twenties during first few days of my period every month. I couldn't go to school or work; it affected my life every month. My GP prescribed painkillers and that was it. I was never checked out for gynae issues, never referred, just expected to get on with it."

Have there been any incidents where you feel you have not been listened to by health professionals?	% of respondents	No of respondents
Yes	79.72%	861
No	19.07%	206
Prefer not to say	1.20%	13

What was the nature of the discussion?	% of respondents	No of respondents
Discussing symptoms	50.52%	436
Discussing treatment options	38.12%	329
Seeking referral to a specialist	35.11%	303
Asking for more information about an issue or condition	32.79%	283
Follow-up care	31.75%	274
Discussing diagnosis of a condition or disability	27.00%	233
Raising concerns or a complaint	20.51%	177
Being asked for consent to a procedure or course of action	16.80%	145
Seeking informed consent	14.25%	123
Other (please specify)	3.82%	33

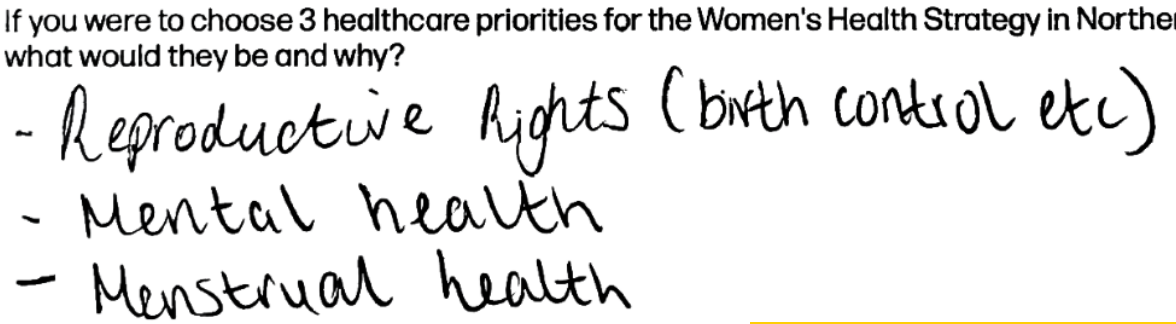
Many survey respondents shared their experiences of not being listened to, feeling dismissed, having their symptoms downplayed, and – despite voicing their own intuition – having symptoms viewed disparately rather than holistically.



"A gynaecologist was trying to persuade me to have a Mirena coil fitted to reduce probability of further uterine polyps. I had a previous horrendous experience with a coil, as had my female siblings so I refused prior to surgery. After surgery, it was raised again although I had been adamant in my refusal and had clearly articulated my rationale prior to surgery. My response was met with evident displeasure on both occasions."

Amongst many examples of women's opinions being disregarded, a collection of women reported their experiences of this with regards to contraception and their reproductive autonomy.

"I had a doctor literally laugh at me down the phone for asking for sterilisation."



Survey respondents also reported the discrimination they experienced due to their weight, with their body mass index being "constantly mentioned", even when discussing unrelated health concerns.

"[I have a] PCOS diagnosis [and] have been told multiple times it's just my cycle and to deal with it, or the only treatment is to lose weight...There has to be...more support. Heavier people have normal cycles, and lighter people have the same condition - but nobody listens."

Many women reflected the pressure they felt to be agreeable, "not wanting to add to time pressure", "be a burden", or be "a nuisance". The Foundation has hosted two large scale events to engage women in discussions about their health. Overwhelmingly, the women present at those events reported that their opinions were often disregarded and/or they lacked confidence to make their valid opinions heard, which was often compounded by fear that their views would not be taken seriously.

"I've had varying responses from different doctors over the years, ranging from the sympathetic-but-little-to-be-done, to the fully abrupt and dismissive, which genuinely made me feel like the problem was me not trying hard enough to make it go away. That was pretty soul-crushing especially since I am naturally non-confrontational and pretty anxious, so I don't tend to push back."

Accessibility of health services and information

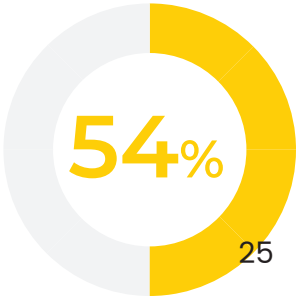
Women need appropriate resources to make well-informed decisions regarding their wellbeing. When health services and information are readily available, women can effectively manage their health, seek prompt medical assistance, and address any health-related concerns they may have. Accessible health services play a pivotal role in preventative care, early detection of illnesses, and overall wellness for women. By providing convenient access to healthcare resources and services, women can take proactive steps towards managing their health and leading healthier lives.

Sources of information

Respondents were asked about what sources they use for health-related information. More than half of respondents reported using 'Online' sources at 55.83% (N=603) and 'GP/Health or Care professional' at 51.57% (N=557).

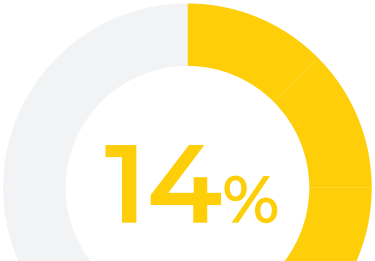
"I have found more support in social media groups by women that are going through similar situations than the GPs, who in most cases are not specialising in women's health."

Which of the following do you use as sources for health information?	% of respondents	No of respondents
Online including blogs and search engines	55.83%	603
GP/Health or Care professional	51.57%	557
Family or friends	46.39%	501
NHS including 111 and NHS website	36.48%	394
Social media (e.g. Instagram, Facebook, YouTube, TikTok or Twitter)	32.87%	355
Charities	30.74%	332
Leaflets at GP/Pharmacy/Hospital	26.76%	289
Magazines Academic or Medical journal articles	21.30%	230
Work	13.80%	149
Helplines	13.33%	144
Libraries	9.35%	101
School	9.07%	98
Youth club	7.87%	85
Other (please specify)	2.96%	32



The most common source of information across all age categories was 'Online including blogs and search engines', however this was more common among those aged over 30 than those aged under 30. The second most common source of information was 'GP/Health care professional' followed by 'Family or friends'.

Which of the following do you use as sources for health information?	**16-29 year olds**		**30 - 39 year olds**		**50+**	
	%	**Num**	**%**	**Num**	**%**	**Num**
Family or friends	28.57%	92	50.68%	225	58.60%	184
Online including blogs and search engines	33.85%	109	60.36%	268	71.97%	226
GP/Health or Care professional	33.85%	109	54.28%	241	65.92%	207
NHS including 111 and NHS website	24.84%	80	39.64%	176	43.95%	138
Social media (e.g. Instagram, Facebook, YouTube, TikTok or Twitter)	31.68%	102	36.49%	162	28.98%	91
Leaflets at GP/Pharmacy/Hospital	24.22%	78	22.30%	99	35.67%	112
Charities	21.74%	70	33.11%	147	36.62%	115
Magazines Academic or Medical journal articles	19.88%	64	19.14%	85	25.80%	81
Helplines	17.08%	55	13.51%	60	9.24%	29
Work	16.77%	54	15.77%	70	7.96%	25
School	18.32%	59	8.33%	37	0.64%	2
Libraries	14.91%	48	8.11%	36	5.41%	17
Youth club	18.32%	59	5.63%	25	0.32%	1
Other (please specify)	0.62%	2	2.93%	13	5.41%	17



"To receive menopause support I have had to pay privately as the GP doesn't have the necessary training to give proper advice."

Alongside a lack of specialist training for medical health professionals, delays in diagnosis and long waiting lists have left many women with no choice but to turn to private care for effective support. From survey responses, this is particularly evident when it comes to women seeking advice and treatment for menopause.

"HRT has given me back my life, but I should not need to pay for it. What about all those who are really struggling & don't have the knowledge or the money to do what I did and end up suicidal as a result?"

A further issue raised by survey respondents concerns the inaccessibility of effective treatment. Many survey respondents outlined attending a private specialist to get an initial prescription for Hormone Replacement Therapy (HRT) and testosterone, for the prescription to then be stopped without an explanation from their local surgery. The result being that women must continue to pay for private treatment.

"I had to go privately to a gynaecologist with specific specialism in HRT when my [doctor's] surgery stopped my HRT with no discussion or reason."

Accessibility of Information

In relation to the accessibility of information in Northern Ireland related to women's health, respondents reported information related to 'Diabetes' to be the most accessible with a score of 3.31 out of 5, where 5 is very accessible and 1 is not accessible at all. The least accessible information was reported as 'Research into health issues or medical conditions that affect women' at 2.7 out of 5, and 'Health impacts of violence against women and girls' at 2.71 out of 5.

"Ever since my [endometriosis] operation, I've had no follow up appointments or support or any advice on how to manage things e.g. with diet / lifestyle. I've had to do it all myself using social media and finding out how I can prevent flare ups / prevent it from returning."

How accessible do you believe the following health related information is for women in Northern Ireland?	Score out of 5
Diabetes	3.31
Sexual health including contraception	3.3
Heart disease and stroke	3.24
Other cancers, for example lung cancer	3.23
Health behaviours, for example tackling obesity, tobacco	3.16
Screening services	3.09
Neurological conditions for example dementia, multiple sclerosis	3.09
Alcohol, drugs, and addiction	3.06
Disability	3.02
Musculoskeletal conditions for example arthritis	3.02
Fertility, pregnancy, pregnancy loss and post-natal	2.99
Healthy ageing	2.98
Mental health	2.96
Womb, ovarian, cervical, vulval and vaginal cancers	2.92
Pelvic floor health	2.87
Gynecological conditions for example endometriosis, fibroids	2.86
Carers	2.86
Menopause	2.85
Autism and neurodiversity	2.84
Menstrual health, for example period pain, heavy menstrual bleeding	2.83
Health impacts of violence against women and girls	2.71
Research into health issues or medical conditions that affect women	2.7

Accessibility of Services

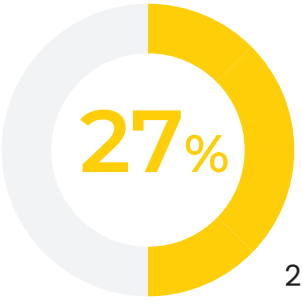
Respondents were asked about the accessibility of services they need in terms of location. Two in five respondents (42.68%) reported services they need as 'Accessible' or 'Very Accessible'. 30.55% (N=330) of respondents reported services they need as 'Inaccessible' or 'Very inaccessible'. In terms of local council areas, 'Antrim and Newtownabbey Borough Council' area was reported as having the most accessible services at 3.4 out of 5 compared to the least accessible services being reported in the 'Newry, Mourne and Down District Council' area with a score of 2.7 out of 5.

"Virtually impossible to get, require an hour of time to constantly call to get through for open surgery then no appointments left."

"Difficulty in securing initial appoint with GP. Try again tomorrow."

"Stressful amount of redials before even getting in queue."

How would you score the accessibility of the services you need in terms of location?	% of respondents	No of respondents
Very accessible	13.61%	147
Accessible	29.07%	314
Neither Accessible nor inaccessible	26.39%	285
Inaccessible	20.74%	224
Very inaccessible	9.81%	106
Prefer not to answer	0.37%	4



How would you score the accessibility of the services you need in terms of location?	Score out of 5
Antrim and Newtownabbey Borough Council	3.40
Ards and North Down Borough Council	3.28
Armagh City, Banbridge and Craigavon Borough Council	3.25
Belfast City Council	3.24
Mid and East Antrim Borough Council	3.24
Derry City and Strabane District Council	3.23
Causeway Coast and Glens Borough Council	3.18
Lisburn and Castlereagh City Council	3.15
Mid Ulster District Council	3.05
Fermanagh and Omagh District Council	2.90
Newry, Mourne and Down District Council	2.70

Barriers to Healthcare

How should the healthcare experiences of grassroots women be improved?

better access - unaccessible for rural women - even urban women outside Belfast. abortion access

Respondents were asked about barriers they face in accessing the healthcare services they need. More than half of respondents (58.7%) reported the 'Availability of appointment' as being a barrier to accessing the services they need, while 44.54% (N=481) reported 'Ability to be referred by GP or another medical professional' as a barrier. Transport and location was also highlighted by a number of respondents with 29.91% (N=323) reporting 'Living rurally or lack of access to services in a rural setting' as a barrier, 27.59% (N=298) reporting 'Distance to travel to access', 22.78% (N=246) reporting 'Public transport accessibility' and 17.78% (N=192) reporting 'Lack of personal transport'.

"I am disabled and was due to attend Musgrave Park limb fitting centre. I was unable to attend as the ambulance service from Enniskillen was suspended leaving me without a way to attend Musgrave for the past 5 years, making my disability more painful and severe."

What barriers, if any, do you face in accessing the healthcare services you need?	% of respondents	No of respondents
Availability of appointments	58.70%	634
Ability to be referred by GP or another medical professional	44.54%	481
Ability to complete self-referral	34.07%	368
Timing of services	32.22%	348
Living rurally or lack of access to services and support in a rural setting	29.91%	323
Distance to travel to access	27.59%	298
Public transport accessibility	22.78%	246
Lack of personal transport i.e. a car	17.78%	192
Other (please specify)	6.57%	71
None of the above	2.31%	25

Experience of Healthcare for those Living with a Disability

Respondents who reported living with a long-term condition or disability were asked about the quality of support provided to them. 41.65% (N=217) of respondents reported the support provided to them as 'Excellent' or 'Good'. 15.16% (N=79) of respondents reported the support provided to them, as 'Bad' or 'Very bad'. The largest percentage of respondents (42.61%) reported the support provided to them as 'Neither good nor bad'.

If you are living with a long-term condition or disability, how would you score the support provided to you?	**% of respondents**	**No of respondents**
Excellent	4.99%	26
Good	36.66%	191
Neither good nor bad	42.61%	222
Bad	8.25%	43
Very bad	6.91%	36
Prefer not to say	0.58%	3

Health and the workplace

In recent times, the focus by many employers on health and wellbeing policies in the workplace is a welcome development. Women make a significant contribution to the economy, including those from disadvantaged backgrounds who face greater health inequalities because of their postcode. To support the wellbeing of women and maximise the value they bring to the workplace, employers need to take more positive action. By fostering discussions on women's health within the workplace, organisations can create a supportive environment that prioritises the unique health needs of women. This can lead to the implementation of tailored health programmes, access to necessary healthcare resources, and the promotion of work-life balance. Ultimately, promoting women's health in the workplace not only enhances individual employees' health outcomes but also contributes to a more inclusive and thriving work culture.

Organisations were asked about any policies and support they had in place and were provided with the options in the table below. The most common policy in place was 'Flexible working' with 58.11% (N=43) of organisations noting this was in place. The least common practice in place was 'Training and support for managers to better understand women's health' at 20.27% (N=15). One in five organisations noted than none of these policies or support were in place.

Does your organisation provide any of the following policies or support?	% of respondents	No of respondents
Flexible working	58.11%	43
Open discussion of sensitive/taboo topics	48.65%	36
Statutory minimum sick pay	44.59%	33
Workplace adjustments Workplace policies for health	36.49%	27
Support for carers	28.38%	21
Above statutory sick pay	25.68%	19
Policies/Protection regarding domestic abuse	25.68%	19
Occupational Health	24.32%	18
Training and support for managers to better understand women's health	20.27%	15
None of the above	20.27%	15
Other	6.76%	5

More than half of respondents (57.87%) reported feeling 'Very comfortable' or 'Comfortable' talking about women's health issues in the workplace. 18.42% of respondents stated that they felt 'Uncomfortable' or 'Very uncomfortable' speaking about health-related issues in the workplace. Just over half of respondents (50.28%) stated that they felt that their workplace had been 'Very supportive' or 'Supportive' on women's health issues. Just under one in five respondents (19.26%) stated that their workplace had been 'Unsupportive' or 'Very unsupportive'.

How do you feel talking about women's health issues in the workplace?	% of respondents	No of respondents
Very comfortable	22.78%	246
Comfortable	35.09%	379
Neither comfortable or uncomfortable	22.31%	241
Uncomfortable	16.11%	174
Very uncomfortable	2.31%	25
Prefer not to say	1.39%	15

How supportive has your current or previous workplace been on women's health issues?	% of respondents	No of respondents
Very supportive	21.67%	234
Supportive	28.61%	309
Neither supportive or unsupportive	27.41%	296
Unsupportive	15.83%	171
Very unsupportive	3.43%	37
Prefer not to say	3.06%	33

Two out of three respondents (67.59%) stated that a health condition or disability had impacted on their experience in the workplace. The most common impact was 'Increased stress levels' at 61.65% (N=463) followed by 'Impacted my mental health' at 56.89% (N=427), 'Impacted productivity' at 46.07% (N=346), 'Work relationships impacted earnings' at 33.56% (N=252), 'Opportunities for employment' at 31.42% (N=236) and 'Stopped working earlier than planned' at 32.89% (N=247).

"It's the menopause thing! No one really walks you through it. [I am] starting to feel like I need to give up work - and I'm only [in my] mid 50's. It's not talked about or understood. Just look at the older generation of women with so many health issues which set in post-menopause – this is a totally neglected area."

Has a health condition or disability impacted on your experience in the workplace?	% of respondents	No of respondents
Yes	67.59%	730
No	28.24%	305
NA / Prefer not to say	4.17%	45

In which ways has your health condition or disability impacted your experience in the workplace?	% of respondents	No of respondents
Increased stress levels	61.65%	463
Impacted mental health	56.86%	427
Impacted productivity	46.07%	346
Work relationships Impacted earnings	33.56%	252
Opportunities for promotion	31.42%	236
Stopped working earlier than planned	32.89%	247
None of the above	1.33%	10
Don't know	0.67%	5
Prefer not to say	0.27%	2

Priorities for a Northern Ireland Women's Health Strategy

To date, Northern Ireland is the only place across these islands not to have a dedicated Women's Health Strategy or, at the very least, a Women's Health Action Plan. The Nothing About Us Without Us programme seeks to lobby for a fully funded Women's Health Strategy for NI which reflects the experiences and needs of women from grassroots communities.

Which of the following conditions/ women's health issues do you feel a Women's Health Strategy should cover?	% of resp	No of resp	% of orgs	No of resp
Alcohol, drugs, and addiction	30.28%	327	60.81%	45
Autism and neurodiversity	31.76%	343	55.41%	41
Carers	34.17%	369	72.97%	54
Diabetes	27.69%	299	47.30%	35
Disability	31.30%	338	60.81%	45
Fertility, pregnancy, pregnancy loss and post-natal support	53.52%	578	75.68%	56
Gynaecological conditions for example endometriosis, fibroids	62.87%	679	81.08%	60
Health behaviours, for example tackling obesity, tobacco	34.44%	372	60.81%	45
Health impacts of violence against women and girls	50.46%	545	81.08%	60
Healthy ageing	42.69%	461	70.27%	52
Heart disease and stroke	37.78%	408	66.22%	49
Menopause	60.19%	650	83.78%	62

Menstrual health, for example period pain, heavy menstrual bleeding	53.89%	582	79.73%	59
Mental health	55.46%	599	86.49%	64
Musculoskeletal conditions for example arthritis	38.15%	412	54.05%	40
Neurological conditions for example dementia, multiple sclerosis	37.41%	404	70.27%	52
Other cancers, for example lung cancer	24.54%	265	45.95%	34
Pelvic floor health	47.13%	509	59.46%	44
Research into health issues or medical conditions that affect women	53.33%	576	74.32%	55
Screening services	48.80%	527	72.97%	54
Sexual health including contraception	44.17%	477	71.62%	53
Womb, ovarian, cervical, vulval and vaginal cancers	57.96%	626	77.03%	57
Other (please specify)	4.63%	50	10.81%	8

Organisations were asked to choose their top 10 categories for inclusion in the Women's Health Strategy. The most common choice was 'Mental health' at 70.27% (N=52). Other categories included 'Menopause' (68.92%), 'Womb, ovarian, cervical, vulval and vaginal cancers' (66.22%), 'Research into health issues or medical conditions that affect women' (63.51%), 'Gynaecological conditions for example endometriosis, fibroids' (62.16%).

Individual respondents were asked to identify their top 10 health priorities for inclusion in the Women's Health Strategy. The most common priority was 'Gynaecological conditions' at 58.52% (N=632) and 'Menopause' at 56.67% (N=612), 'Womb, ovarian, cervical, vulval and vaginal cancers' at 50.46% (N=545), 'Fertility, pregnancy, pregnancy loss and post-natal support' at 49.17% (N=531), and 'Menstrual health, for example period pain, heavy menstrual bleeding' at 47.13% (N=509).

Despite a difference in percentage of organisational responses and individual respondents against each of the categories, the same 10 key priorities were chosen by both groups as outlined below.

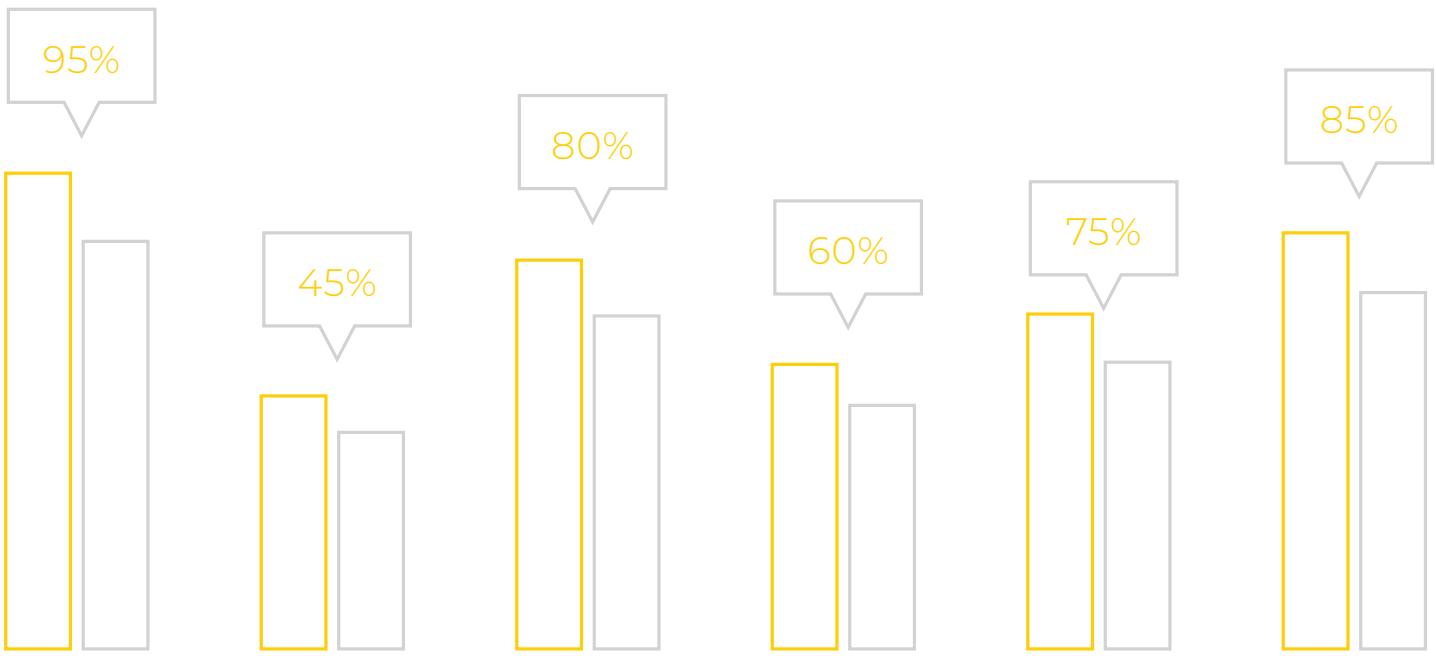
Which of the following conditions/ women's health issues do you feel a Women's Health Strategy should cover?	% of resp	No of resp	% of orgs	No of resp
Gynaecological conditions for example endometriosis, fibroids	58.52%	632	62.16%	46
Menopause	56.67%	612	68.92%	51
Womb, ovarian, cervical, vulval and vaginal cancers	50.46%	545	66.22%	49
Fertility, pregnancy, pregnancy loss and post-natal support	49.17%	531	62.16%	46
Menstrual health, for example period pain, heavy menstrual bleeding	47.13%	509	56.76%	42
Research into health issues or medical conditions that affect women	46.57%	503	63.51%	47
Mental health	46.48%	502	70.27%	52
Health impacts of violence against women and girls	39.17%	423	51.35%	38
Screening services	35.00%	378	51.35%	38
Sexual health including contraception	30.56%	330	47.30%	35

"I was emotional on one occasion in a meeting with my GP... I explained that the emotion was natural as I had just received notice that week from the PPS, that a prior sexual assault (historical) was not going to go to trial. I shared this and was a tad emotional whilst sharing. The immediate reaction was to offer antidepressants. I was shocked and annoyed at this reaction. It was like tears were not natural and I should consider how to repress those instead of a listening ear."

Many respondents mentioned medical professionals' rush to medicate symptoms as opposed to discussing underlying causes, especially when it comes to issues surrounding mental health and trauma.

"I feel that health providers are just keen to medicate and send you off instead of looking further into the diagnosis."

"The state of play is to heavily medicate and take little, if any, time to hear of traumatic experiences. No counselling - just meds is the only options it seems."



Impact of Covid-19

It is important to understand the impact of Covid-19 on women's health and to highlight any distinct challenges that women have encountered. From heightened caregiving responsibilities to disruptions in accessing healthcare services, women have bore a substantial burden throughout this period.

Respondents were asked about what impact they felt the Covid-19 pandemic has had on women's health. More than four out of five individual respondents (82.78%) felt that the pandemic had a 'Negative' or 'Very negative' impact on women's health.

"I had a 6-week post birth appointment and noted a number of concerns I had. These were quickly dismissed by the doctor. The doctor wouldn't see me in person to review my wound / check blood pressure etc, instead the appointment was a 10-minute phone call appointment. This was after a labour with a number of complications after, including a major haemorrhage"

Organisations were asked for their assessment on the impact of the Covid-19 pandemic on women's health. 90.28% of organisations felt that the pandemic had had a 'Negative' or 'Very negative' impact on women's health. Only one organisation felt that the pandemic had had a 'Very positive' response on women's health.

Do you feel the Covid 19 pandemic has had a positive or negative impact on women's health?	% of resp	No of resp	% of orgs	No of resp
Very positive	2.22%	24	1.39%	1
Positive	2.69%	29	0.00%	0
Neutral	8.80%	95	6.94%	5
Negative	45.28%	489	62.50%	45
Very negative	37.50%	405	27.78%	20
Don't know/ Prefer not to answer	3.52%	38	1.39%	1

Conclusions and Recommendations

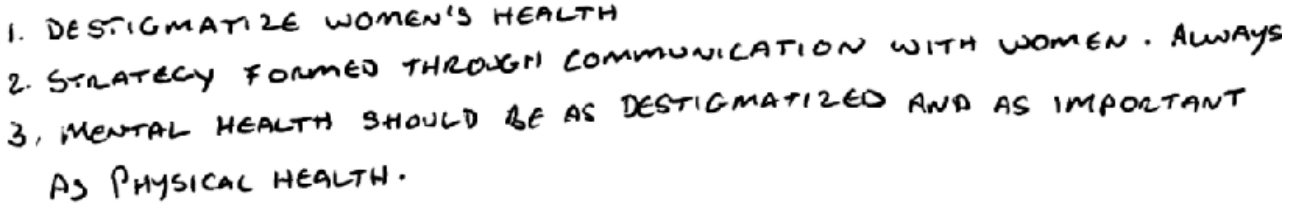
The following conclusions and recommendations have been compiled from the data collected in CFNI's Women's Health Strategy survey. Each recommendation should be considered alongside the foundational recommendation of centering the voices of grassroots women in Northern Ireland. After all, there should be **Nothing About Us Without Us.**

Talking about health

Respondents reported feeling most comfortable speaking with female health professionals about health issues, followed by friends and partners/spouses. Respondents reported feeling least comfortable talking about health issues with male health professionals.

Recommendation 1: A Women's Health Strategy for Northern Ireland should identify models of best practice in communicating both gender-specific and gender non-specific health issues with women across NI, taking into consideration age, rurality, gender identity, language, and culture.

Underpinning this recommendation is the need for increased education and training of healthcare professionals to ensure consistent and empathetic messaging that does not sustain unhelpful stigmas and stereotypes. Furthermore, a willingness from healthcare professionals to initiate conversations around women's health could help alleviate some of the discomfort that women encounter when discussing their healthcare concerns.



Access to information

It is imperative to ensure that women have the necessary resources to make well-informed decisions regarding their wellbeing. When health services and information are readily available, women can effectively manage their health, seek prompt medical assistance, and address any health-related concerns they may have.

One in every two respondents reported using online sources to access information on health. Online sources were the most common source of information across all age categories, and particularly high for over 50's where seven in ten used online sources for healthcare information. The next most common source of information across all age categories were GPs/health professionals followed by family and friends.

Recommendation 2: A Women's Health Strategy for Northern Ireland should prioritise creating and promoting evidence-based and reliable information that is provided in a user-friendly and accessible format.

This approach would assist in increasing women's understanding of their bodies; enabling them to advocate for their health and wellbeing. The information should be research-based and available in different formats, and languages acknowledging that not all women will have access to the internet or have English as their first language. Furthermore, options to make the information accessible for blind and visually impaired women should be implemented, as well as providing easy-read information to increase accessibility for women with learning difficulties and/or varying literacy levels. Information should also promote diverse messaging to be inclusive of culturally specific health requirements.

Access to services

Supporting women to access the care they need, when they need it, is paramount to addressing the health inequalities those women from disadvantaged backgrounds are far more likely to experience, including disabled and Black and minoritised women. At present, a postcode lottery appears to exist in terms of the advice, support, and treatment available to women in NI.

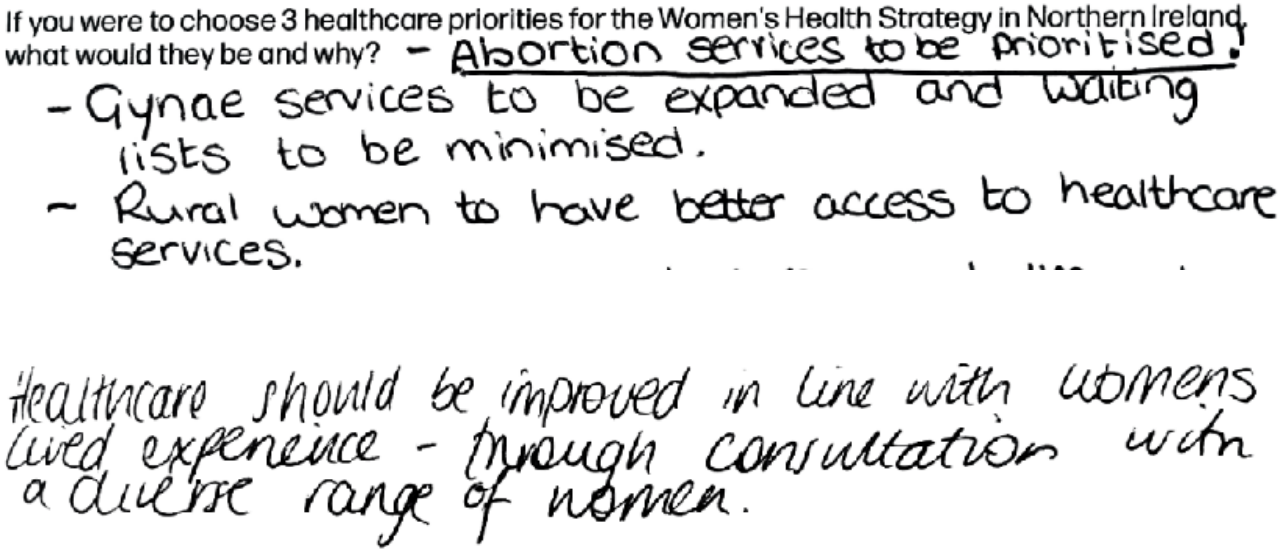
Four in every five respondents to this survey reported that there were times when they felt they were not listened to by health professionals, most commonly when discussing symptoms but also when discussing treatment options, seeking referrals to specialist services, follow up care and more.

Location of services is also impacting the accessibility of services. Two in every ten respondents reported that the services they needed were inaccessible based on location, and one in ten reported them to be very inaccessible. This was particularly high for rural council areas such as Newry, Mourne and Down District council area, Fermanagh and Omagh District Council area, and Mid Ulster District council area. Additionally, three in every ten respondents to the survey noted 'living rurally' or 'lack of access to services and support in a rural setting' as a barrier to accessing the healthcare services they need.

Recommendation 3: The process of developing a Women's Health Strategy for Northern Ireland should include a co-design process which ensures that the diverse lived experiences of women in Northern Ireland and the unique barriers experienced by communities are understood and used to inform the development of the strategy. Meaningfully involving women at every stage, including a review of current services, will ensure that a Strategy is fit for purpose and can realistically work in practice.

The vision of the Nothing About Us Without Us project is to create a society in NI where women are visible, vocal, and valued. The co-design panel have developed a model of engagement best practice which outlines how to effectively engage with grassroots women on decisions that affect and matter to them (Appendix 1).

Meaningful engagement means women being equitably involved in decision making on both regional levels e.g. being effectively engaged during the design and implementation of a Women's Health Strategy, and personal levels e.g. being effectively engaged and consulted about their own bodies when interacting with medical professionals.


If you were to choose 3 healthcare priorities for the Women's Health Strategy in Northern Ireland, what would they be and why? - Abortion services to be prioritised.
- Gynae services to be expanded and waiting lists to be minimised.
- Rural women to have better access to healthcare services.

Healthcare should be improved in line with womens lived experience - through consultation with a diverse range of women.

Health and the workplace

More than half of respondents felt comfortable or very comfortable talking about women's health issues within the workplace. One in every two respondents reported feeling supported or very supported within the workplace around women's health issues. Additionally, three in every five respondents reported a health condition or disability impacting on their experience within the workplace resulting in increased stress levels, their mental health being impacted, impacts on their productivity and on their income, opportunities to advance and ability to continue to work.

Recommendation 4: A Women's Health Strategy for Northern Ireland should identify opportunities to support employers on increasing the support available to women in the workplace related to their health and wellbeing and to encourage better understanding of the inequalities and unique experiences of women within the workplace.

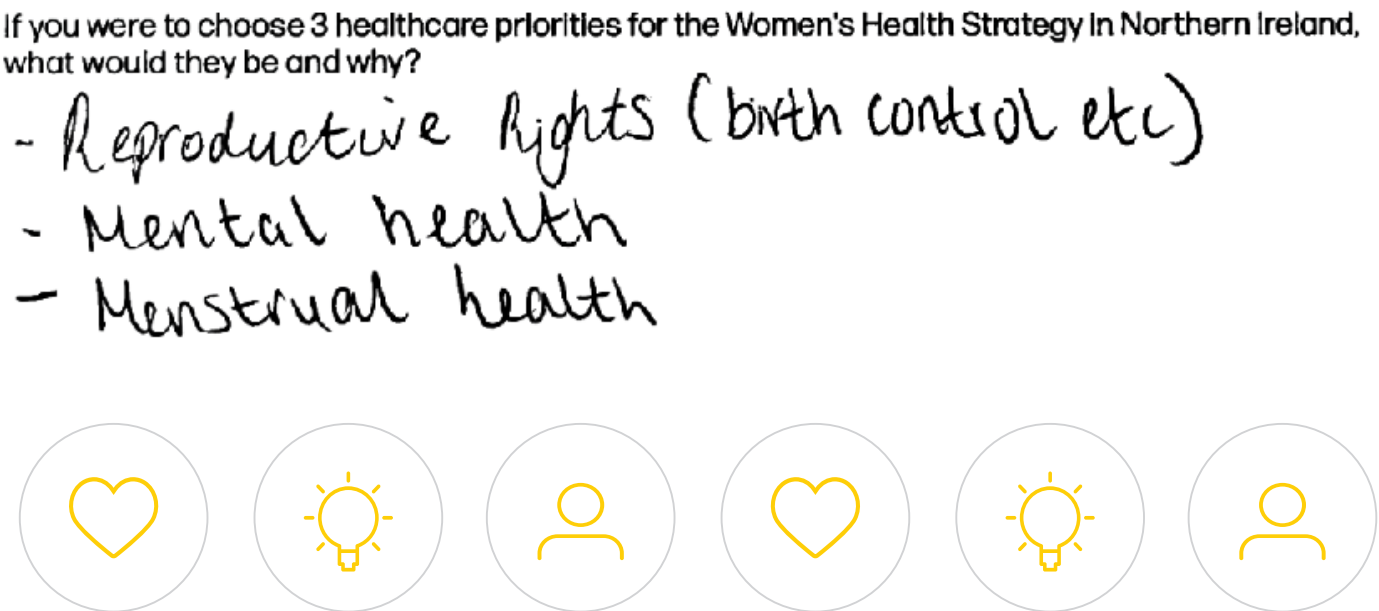
Priorities for a Women's Health Strategy

This survey highlights the need for a co-designed, resourced, and outcome-based Women's Health Strategy for Northern Ireland.

Recommendation 5: A thorough and well-informed Strategy will fall short of addressing the health and wellbeing needs of women without long-term sufficient investment. Gender-responsive budgeting should be considered for decisions relating to the allocation of Department of Health budgets, thus reflecting the needs of women in NI.

Recommendation 6: The following areas should be prioritised in the development of a Women's Health Strategy for Northern Ireland:

- Gynaecological conditions
- Menopause
- Womb, ovarian, cervical, vulval and vaginal cancers
- Fertility, pregnancy, pregnancy loss and post-natal support
- Menstrual health, for example period pain, heavy menstrual bleeding
- Research into health issues or medical conditions that affect women
- Mental health
- Health impacts of violence against women and girls
- Screening services
- Sexual health including contraception



VISIBLE, VOCAL, VALUED

A Five Pillar Model to Effectively Engage Women from Grassroots Communities in Northern Ireland in Decisions that Affect & Matter to Them

The Community Foundation for Northern Ireland and the Nothing About Us Without Us co-design panel which includes Northern Ireland Rural Women's Network (NIRWN), Falls Women's Centre, Reclaim the Agenda, Building Communities Resource Centre, The Carson Project, and The Focus Project, would like to express our thanks to all the individuals and organisations who took part in the survey.

The Community Foundation Northern Ireland

"NOTHING ABOUT US WITHOUT US"
Amplifying the voice of grassroots women

Contact Us

Community House
City Link Business Park
6a Albert Street
Belfast BT12 4HQ

T : +44 (0) 28 9024 5927

info@communityfoundationni.org
Charity Number: NIC105105