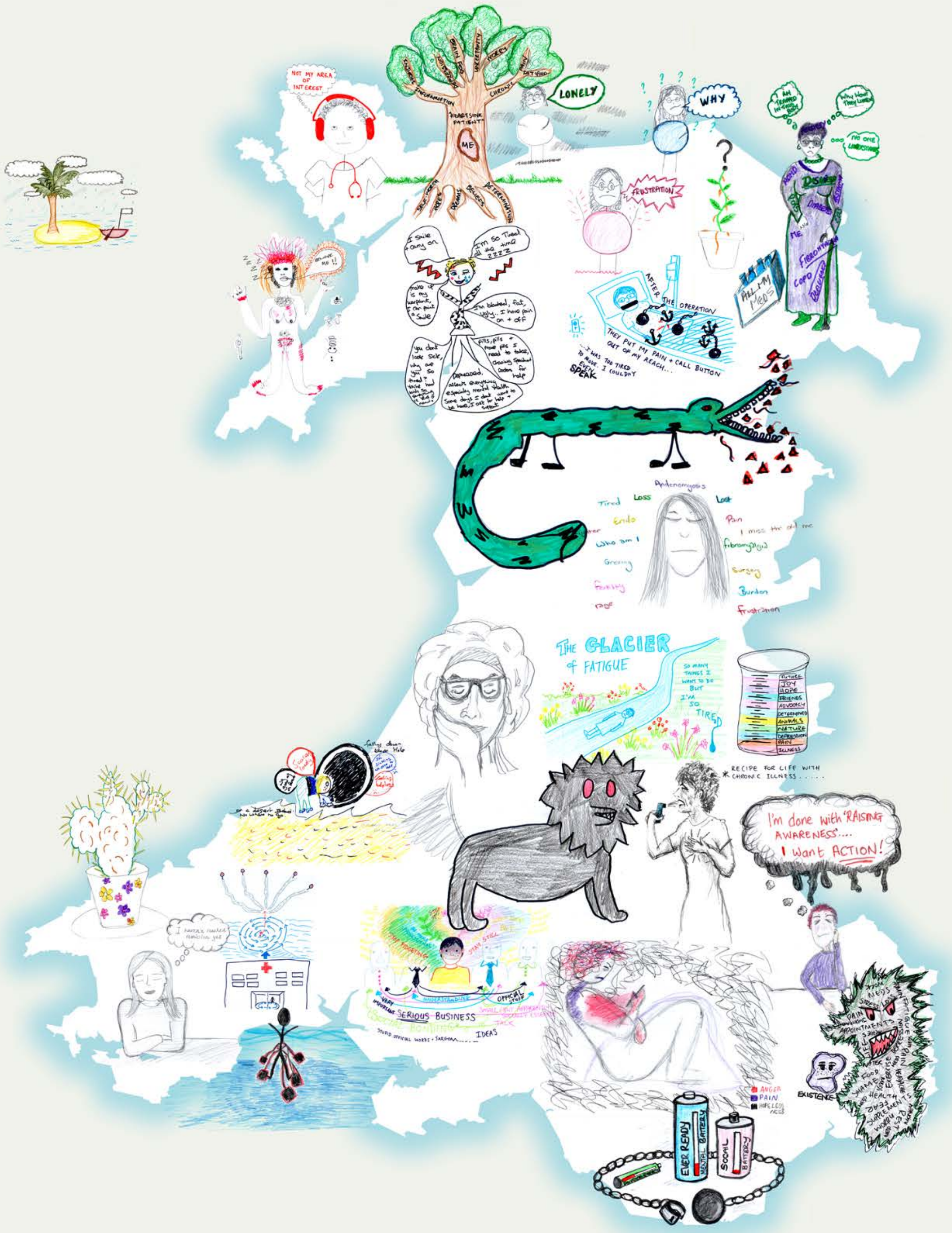
DrawingOut Long-Term Health Issues in Wales



FTWW DrawingOut CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD Women's Health Research Wales Ymchwil Iechyd Menywod Cymru ROSA THE UK FUND FOR WOMEN AND GIRLS CRONFA GYMUNEDOL COMMUNITY FUND

A project by FTWW in collaboration with Cardiff University & Women's Health Research Wales
Supported by the Rosa Fund and the National Lottery

FTWW

Executive Summary

DrawingOut Long-Term Health Issues in Wales

This executive summary presents the key findings, conclusions, and recommendations from DrawingOut Long-Term Health Issues in Wales, a project undertaken by FTWW (Fair Treatment for the Women of Wales), in partnership with Cardiff University & Women's Health Research Wales, and supported by the Rosa Fund. The project used the participatory DrawingOut methodology to gather drawings and stories based on the lived experiences of women and people assigned female at birth living with chronic and long-term health conditions across Wales.

Key Findings

Accessing Healthcare

Participants consistently reported significant barriers to accessing timely, appropriate, and specialist healthcare. Symptoms related to chronic pain, gynaecological conditions, neurodivergence, and fatigue were frequently minimised, normalised, or disbelieved. Gender stereotyping, ageism, and ableism were commonly perceived by participants to have a negative influence on how clinical services treated them, contributing to delayed diagnosis, fragmented care, and distrust. Regional inequities across Wales, and in comparison with England, further intensified participants' feelings of having been abandoned by healthcare providers and prompted some participants to seek private or overseas care at considerable personal cost.

Impact of Chronic Health Conditions

Chronic and long-term conditions were described as having considerable impacts across many aspects of participants' lives, which added up over time. These included declining mental wellbeing, loss of identity, reduced physical functioning, financial insecurity, and diminished employment prospects. The effects extended beyond individuals to their families and carers, lots of whom are also disabled or living with living chronic illness. Gendered inequalities, disability, caring responsibilities, and the gender pay gap were seen as coming together to compound disadvantage, putting people at increased risk of ill health as time passed.

Coping and Self-Management

Due to gaps in formal health and care provision, participants often developed their own coping and self-management strategies. These included pacing, lifestyle adaptations, symptom tracking, and avoidance of triggers. Peer support communities were valued as sources of knowledge and belonging, although self-management was widely recognised as demanding and not equally accessible to all. For some, diagnosis and peer connection fostered empowerment, solidarity, and a growing confidence in their ability to contribute meaningfully to society.

Recommendations

Participants and stakeholders emphasised the need for systemic change across healthcare and wider policy. Core recommendations include:

- Development of holistic, joined-up, person-centred care that addresses the needs of the whole person rather than isolated symptoms
- Improved continuity of care to reduce repetition, build trust, and support the management of long-term conditions
- Enhanced communication and relational care, ensuring patients are believed, listened to, and involved in shared decision-making when it comes to their health
- Training for health and care professionals to better enable care that is unbiased, gender-sensitive, trauma-informed, appreciative of the social model of disability, and supportive of shared decision-making
- Coordinated care pathways and improved access to specialist services, including equitable provision across regions
- Integration and resourcing of social and community support and advocacy within healthcare systems
- A cross-government commitment in Wales to prioritise women's health and address health inequities beyond the current NHS Wales 10-year Women's Health Plan.

Conclusion

The *DrawingOut Long-Term Health Issues in Wales* project demonstrates the value of co-produced, creative, and lived-experience-led approaches in enhancing participants' wellbeing whilst also identifying gaps, inequities, and opportunities for improvement within health systems. The project's findings align with broader national and international research, reinforcing the case for sustained investment in women's health, management of long-term conditions, and wider support. Addressing these issues is essential not only for individual health, but also for workforce sustainability, family resilience, economic productivity, and the future wellbeing of the population in Wales.

Introduction

Who delivered this project?

Fair Treatment for the Women of Wales (FTWW) is a pan-Wales patient-led charity and disabled people's organisation focused on highlighting and addressing health inequities experienced by women and people registered female at birth[1] who are disabled and / or living with long-term, chronic, recurrent and fluctuating health issues. These can be physical, mental, recurrent, or fluctuating in nature, or a combination of issues. Some of our members are also caring for people with long-term health conditions.

A key aim for FTWW is to support and empower our members to have their voices heard in policy and practice in Wales and the UK because, historically, disabled and unwell women have felt excluded and unheard, especially where symptoms are non-visible or considered 'taboo'.

It is vital for us that FTWW members have opportunities to get involved in activities to improve their wellbeing, develop skills, and grow in confidence so that they can more effectively advocate for themselves, ensuring that their lived expertise is understood, valued, and integrated fully into public services.

The *DrawingOut Long-Term Health Issues in Wales* project has been undertaken by FTWW to better understand and communicate the experiences of our members to other people and organisations, including policy-makers, healthcare professionals, and the wider public.

Project Team

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What is 'DrawingOut'?

The DrawingOut process involves taking part in facilitated workshops where participants create drawings which represent their lived experiences – something we call 'visual metaphors'. These workshops can be both healing and powerful spaces.

Healing because they involve bringing disabled and unwell women together to share their thoughts and experiences - reducing isolation, improving mental wellbeing, and growing confidence as participants learn they're not alone and feel validated in what they are describing;

Powerful because visual metaphors are a shared language that people from all walks of life, including power-holders, can really understand and which therefore have the potential to influence change.

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[1] This report will use the term 'women/woman' throughout but should be considered inclusive of those who might not identify as women but require access to women's health and reproductive services, including some transgender men, non-binary people, and intersex people or people with variations in sex characteristics.

The drawings, and participants' descriptions of what their drawings represent, are collated and analysed. This process enables the creation of a report like this one and a gallery of images which both explains people's feelings and experiences, and what needs to happen to improve the health, care, and lives, of those represented.

Why is this important?

UK law says that 'You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a "substantial" and "long-term" negative effect on your ability to do normal daily activities'. However, we know that not everyone living with a long-term health condition will describe themselves as disabled for various reasons, such as when health issues have been dismissed or not taken seriously by others, often for a long time.

Sometimes, people tolerate their symptoms and end up viewing them as 'normal', so they don't fully appreciate just how much of an impact they're having on daily life. For some people, this might be a positive thing, because it could demonstrate their having learned coping mechanisms, or having accessed the right amount of informal and social support to help them live alongside their symptoms. For others though, it might mean they don't seek medical help or personal support when they need and would benefit from it.

There are also lots of stereotypes about what being disabled 'looks like' so, when symptoms and health conditions aren't visible to others, this can mean people don't feel represented and so don't identify with how disability is portrayed. Another reason why some people don't use the term 'disabled' to describe themselves is because they fear prejudice and discrimination.

FTWW believes it is vital we raise awareness of gendered health and disability experiences, and associated injustice in Wales and the UK because there is widespread lack of understanding of disability and the different ways it can be experienced. It is particularly important to our charity because women live more years disabled or with chronic illness than men.

What is a 'long-term health condition'?

A long-term condition, also known as a chronic condition, is a 'health problem that requires ongoing management over a period of years or decades and is one that cannot currently be cured but can be controlled with the use of medication and/or other therapies'.[2]

Long-term health problems can be physical or mental, and symptoms can stay the same all the time, worsen, or they can be recurrent (happening again many times) or fluctuating (changing or varying a lot, especially up and down) in nature.

When thinking about management of a long-term condition, two important considerations will be how far it affects a person's ability to function across different areas of their lives, such as work, family, or social life, and the level of distress it causes.

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[2] https://www.datadictionary.nhs.uk/nhs_business_definitions/long_term_physical_health_condition.html

How many people are affected by long-term health conditions in Wales?

In Wales, around 21% of the population[3], or 669,900 people, describe themselves as living with at least one health condition that limits their daily lives. Data from the Office for National Statistics show that women are more likely than men to be living with a limiting health condition, with women living fewer years 'disability free' than their male counterparts as they age.

In 2022, NHS Wales undertook a survey to find out more about women's health needs and priorities. The survey received almost 4000 responses which became the 'Women's Health in Wales Discovery Report'. More than half (51%) of respondents reported having a 'long-standing illness', with 40% of them stating they felt limited in some way by their condition[4].

What are the wider impacts of living with a long-term health condition?

In 2024, the NHS Confederation published a report called 'Women's health economics: investing in the 51 percent'.[5] Whilst this report focused mainly on obstetric and gynaecology services in England, it helped to evidence the need for much greater investment in some of the most commonly reported long-term health issues for women which apply equally to Wales, including severe period pain and heavy periods, endometriosis, fibroids, and ovarian cysts.

The report found that the economic cost of sickness absence or unemployment due to these conditions was nearly £11 billion per year but, if an additional £1 per woman in England were invested in obstetrics and gynaecology services, there would be a return on investment (ROI) of £11.

The report goes on to show that 83 per cent of women living with any long-term physical or mental health condition reported the condition as having a negative impact on their ability to go to school, college or university; perform work for a family business; look for work; or look after the family and home. With nearly 80% of the NHS workforce in Wales being female[6], it's important to note the potential consequences for all our healthcare.

Indeed, it is clear both from the NHS Confederation's report – and FTWW's own work with women across Wales – that long-term health issues have a huge impact, not only on women's quality of life, their education, employment, family-life, and wider wellbeing, but also that of their families and the population at large.

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[3] https://www.gov.wales/disabled-peoples-outcomes-health-housing-education-and-economic-status-census-2021-html

[4] https://performanceandimprovement.nhs.wales/functions/networks-and-planning/womens-health/womens-health-documents/womens-health-in-wales/

[5] https://www.nhsconfed.org/publications/womens-health-economics p13

[6] https://heiw.nhs.wales/files/nhs-workforce-trends-march-2023/

What does research tell us about women's experiences of accessing healthcare for long-term health conditions?

NHS Wales's 'Women's Health in Wales Discovery Report' showed that the top priority for women, regardless of the health condition/s with which they were living, was to have their voices heard. This reflects a 2022 study undertaken by Merone et al[7] in which women reported that pain and suffering relating to chronic conditions was dismissed by healthcare staff.

More recently, a 2025 study by Peel et al showed that women felt dismissed, and their symptoms normalised by healthcare professionals and that there has been little change over 20 years of research.[8]

DrawingOut Long-Term Health Issues in Wales therefore enables participants to speak about their health and healthcare, the impact on their lives and wellbeing, and to share their experiences with others, both those in the room with them, and those in a position to facilitate change.

What are the aims of this project?

The overall aim of the *DrawingOut Long-Term Health Issues in Wales* project is to better understand and amplify the lived experience of women and people assigned female at birth managing long-term health conditions in Wales.

To help us achieve this aim, the project will:

- Give FTWW members the opportunity to share their experiences with each other to reduce isolation and improve confidence
- Better understand the impact and burden of long-term health issues on women in Wales
- Gain insights into how women in Wales manage their symptoms and health conditions themselves, and whether community support can help with this
- Learn more about how women and patients access and interact with healthcare services in Wales, and the impact this can have on health and wellbeing
- Gain knowledge of how long-term health conditions might be better-managed in Wales (chronic conditions differ to acute illness as they usually cannot be cured, only managed by a combination of medical treatments and therapies, lifestyle adjustments, and psychosocial support)
- Gather insights on how healthcare interactions and communication could be improved
- Share findings with service-providers, policy-makers, and the public in a creative and powerful way to improve awareness and understanding of the impact of long-term health issues on women and people assigned female at birth, and ensure that their experiences and needs are better supported in healthcare and beyond.

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[7] https://doi.org/10.1089/whr.2022.0052

[8] https://doi.org/10.1016/j.pec.2025.109225

Methods

Design

This study used two one-day DrawingOut workshops[9] to gather visual data, in the form of drawings, and textual data, transcribed from conversations had in the workshop, surrounding participants' experiences of long-term health conditions. DrawingOut is based on the principle that individuals may find it beneficial to express their experiences using visual metaphors.

Participant Eligibility

The inclusion criteria were being a woman or people assigned female at birth, being 18 years old or more, living with at least one long-term physical or mental health condition (defined as lasting for at least 6 months), being free to attend one of the two workshops listed above, and consenting to FTWW sharing the personal information they collected in their online expression of interest (whereby people reported interest in participating in the study) with the research team.

Procedures

Recruitment

The charity Fair Treatment for the Women of Wales (FTWW) collected information about people interested in participating in the study as per their standard procedures to organise events and activities. Specifically, information about the workshops was shared on the FTWW members-only private Facebook group, via their mailing list, and emailed directly to volunteers.

To ensure diversity of participants FTWW used a Microsoft Form to collect expressions of interest in which they asked for personal information, specifically: health board of region where people lived, age, ethnicity, sexual orientation, self-identification as disabled, long-term health issues people lived with and for how long (in years), and access and dietary requirements.

All participants who expressed interest in participating and were available were sent a study invitation email with a link to the participant information sheet, informed consent form, and contact details for organisation purposes. The informed consent form requested consent for participation and for FTWW to share the personal information they collected in their expression of interest with the research team.

Participants attended the workshop that was most convenient to them, based on date and location. No compensation was given; however, participants' travel expenses were reimbursed and they received lunch at the workshop.

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[9] https://drawingout.uk

Workshops

The workshops followed the structure recommended in Gameiro et al[10]., with minor deviations. The workshops ran all day, from 9:30am until 4:30pm, in South Wales, Cardiff, and North Wales, Llandudno Junction.

Participants were randomly spread onto four tables, and each table had two audio recorders to capture conversations. Each workshop had three moderators, comprising the Cardiff University research team members, and one FTWW staff member. One moderator directed the workshop and the other two facilitated as necessary and took notes on participants' drawings and the order in which they spoke to facilitate their identification in the audio recordings. The overall structure included introductions, introduction to drawing, drawing session, and debrief.

The introduction session began with arrival drinks, introductions from the facilitators, housekeeping, the workshop structure, and ground rules (respect, inclusivity, privacy). This was followed by an icebreaker activity.

The icebreaker activity involved participants being given small comics sheets and asked to find the person who had the matching sheet (same story and style). Once they found their pair they were invited to ask and answer the question 'If you were an animal, what would you be?', allowing them to get to know one another and become familiar with using metaphors to express themselves.

The introduction to drawing session aimed to put participants at ease with the idea of drawing and provided them with basic skills and tools for comics drawing. This consisted of two activities: the 'Everyone can draw' activity included simple drawing exercises to encourage participants to feel relaxed and promote their confidence, and the 'People, creatures, and objects' activity was designed to impart basic drawing skills and techniques to help them depict figures and simple objects.

The main drawing session of the workshop then began and was broken up into different activities:

1. Self Portrait: 'Draw yourself thinking or talking about your health issue'. Participants were asked to create a full-body drawing depicting how they feel when they think or talk about their health condition(s), with a speech/thought bubble. Participants then shared their drawings with the group, explaining how they feel when they think about their condition.
2. Drawing Thoughts and Feelings: 'If your health issue was: an object, creature or animal, place or situation, what would it be?'. In this section, participants were introduced to the idea of visual metaphors. They discussed examples of metaphors and were then asked to complete a drawing using the prompt above. This was followed by participants sharing their drawings and explaining what the metaphor represented and why they chose it.
3. Drawing Healthcare Experiences: 'How would you draw your relationship with healthcare staff'

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[10] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0203197

4. Final Piece: ‘Do a final drawing to express whatever you like about your disease experience. You can focus on a positive aspect of your disease experience’. Participants were given 30 minutes to complete drawings (iii) and (iv). The final sharing session of the day then commenced, and participants spoke about both their final drawings.
5. Debrief: Participants were given the opportunity to share any final thoughts about their health condition and/or the workshop and were asked to fill out a feedback form regarding the workshop. The aims of data collection were also reiterated to participants, and they were thanked for their time. Half an hour was reserved at the end of the workshop for decompression in recognition of the emotional and physical toll a full-day workshop can have on participants. Some participants chose to leave the venue straight after the workshop ended, whilst others stayed behind to chat with others.

Each drawing and sharing activity was followed by a break and there was also a longer break for lunch. Based on reflections from the South Wales workshop, less time was spent on the introduction to drawing session in the second workshop, to allow more time for the main drawing session and reduce participants’ fatigue.

Recording Procedures

There were two audio recorders on each table that were switched on at the beginning of the main drawing section of the workshop. They stayed on for the remaining duration of the workshop, including breaks and lunch, so that any relevant conversations could be included as part of the data.

In order to match participants’ drawings with their explanations, and identify them, we gave them a participant key with their name and a corresponding number.

Participants were asked to note their number on the back of their drawings. Additionally, two researchers recorded a brief description of the participant’s drawing and explanation so the participant identification numbers (PID) could be matched to their sections of the transcript. Furthermore, participants were asked to indicate on the back of the drawing if they did not want it to be shared beyond the research team.

Materials

The workshops were structured around the DrawingOut presentation, which was adapted to the current workshops. The workshop slides are included in the Appendix. Participants were given a range of art materials to create their drawings, including plain and coloured paper, coloured and normal pens and pencils, scissors, and glue. They could select whatever medium they felt would allow them to express their feelings best.

Audio recorders were used to capture participants’ explanations of their drawings and conversations.

Participants were offered a debrief and feedback form relating to their feelings about drawing and sharing before, during, and after the workshop which also asked them to rate how helpful the DrawingOut method had been in helping them explain their experiences.

Data Analysis

Prior to transcription the audio recordings were listened to and the sections deemed relevant to the research aims were recorded using timestamps. Additionally, the participants' PIDs were matched to their sections of the recordings to ensure the researcher team could correctly identify them. The timestamps were sent to the transcription company along with the audio recordings and they only transcribed within the timestamps.

The transcripts were analysed thematically in accordance with the methods described by Braun and Clarke (2006).[11] The anonymised transcripts were matched with the participants' drawings and then uploaded into NVivo 14. The two workshops were analysed separately to ensure possible differences between North and South Wales could be identified.

The South Wales transcripts were analysed first. WL coded the data. Any meaningful section of text was given a descriptive title and thereafter all mentions of that code were recoded under the same title. After all the South Wales transcripts were coded, similar codes were combined to ensure no repetition, and related codes were grouped into subthemes and then themes. This coding framework was exported into another file, where the North Wales transcripts were analysed.

Coding was still inductive, and new codes were created and sorted into themes, where relevant. Additionally, redundant code titles that did not appear were deleted. Regular meetings with SG and DW focused on discussion of codes, subthemes and themes emerging to ensure all members of the team agreed these represented the data. Once the themes and subthemes had been identified, the drawings were examined and matched with any themes they represented. This process was also done for illustrative quotes, with care being taken to ensure representation from both workshops.

In the results section we present themes and subthemes, along with a descriptive narrative of both, participants' drawings, and illustrative quotes. When presenting quotes we use "()" to add explanations, "[...]" to indicate omissions on non-directly relevant text, and [xxx] to indicate grammar and spelling corrections.

Reflexivity

WL related to the participants because she also identifies as a woman, however, she does not have personal experience as a patient with a chronic health condition. This allowed all focus to be on the participants' descriptions of their own experience without risk of unconscious bias.

Additionally, being a recent psychology graduate, WL had some experience with qualitative data.

Being present during the workshops and hearing first-hand the participants' discussions provoked feelings of empathy. To ensure the coding and descriptions of themes remained true to the data, regular meetings took place with SG and DW, both health psychologists with personal experience of chronic illness to discuss the findings and gather feedback on the analysis. The team remained reflexive throughout all stages of the analysis to honour the data and participants' experiences.

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[11] https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa

Results

The final sample consisted of 20 women living in Wales with 9 attending the South Wales workshop and 11 the North Wales workshop. All 29 participants who completed an expression of interest were accepted onto the study, but 9 had to drop out before the workshops due to health flare ups, travel time, or health appointments. Additionally, one participant in the South Wales workshop left early, after the Drawing Thoughts and Feelings section, due to a pre-existing commitment. Participants' socio-demographic information is presented in Table 1. Most participants were White British and identified as Heterosexual. Participants in the South Wales workshop were from a variety of health boards, whereas those from North Wales were from one. Most participants identified as disabled and were representing themselves, with two participants speaking about their child's experiences

Table 1: Sociodemographic Characteristics

Sociodemographic Characteristics of Participants Across Both Workshops

		n	%
Age	25-34	3	15%
	35-44	7	35%
	45-54	2	35%
	55-64	1	10%
	75+	1	5%
Ethnicity	Mixed White and Black Caribbean	1	5%
	White Welsh, English, Scottish, Northern Irish or British	17	85%
	Any other Mixed or Multiple ethnic background	1	5%
	Any other White background	1	5%
Sexual Orientation	Bisexual	3	15%
	Heterosexual	15	75%
	Pansexual	1	5%
	Unspecified	1	5%
Disabled	Yes	13	65%
	No	4	20%
	Unsure	3	15%
University Health Board	Aneurin Bevan	1	5%
	Betsi Cadwaladr	11	55%
	Cardiff and Vale	4	20%
	Cwm Taf Morgannwg	3	15%
	Swansea Bay	1	5%
Representing	Self	18	90%
	Their child	2	10%

Table 2: Self-reported Health Conditions

Participants' Self-reported Health Conditions, Categorised Using the ICD-11.

	n	%
Chronic pain	3	15%
Developmental anomalies	3	15%
Diseases of the blood or blood-forming organs	2	10%
Diseases of the circulatory system	2	10%
Diseases of the digestive system	3	15%
Disease of the genitourinary system	7	35%
Diseases of the immune system	2	10%
Diseases of the musculoskeletal system or connective tissue	1	5%
Disease of the nervous system	8	40%
Diseases of the respiratory system	3	15%
Disorders of the autonomic nervous system	1	5%
Endocrine, nutritional or metabolic diseases	7	35%
Factors influencing health status or contact with health services	2	10%
Mental, behavioural, or neurodevelopmental disorders	8	40%
Neoplasms	2	10%

Note. All 20 participants reported a description of their conditions. The content of the descriptions was coded into categories using the ICD-11 for mortality and morbidity statistics.

Table 3: Themes and Subthemes

Themes and Subthemes Categorised from the DrawingOut Workshops, and number of codes within each theme and subtheme.

SW = South Wales workshop
NW = North Wales workshop

Theme	Subtheme	SW	NW	Total
Lost faith in NHS Wales	Sub-optimal healthcare interactions	63	68	131
	Negative views of the healthcare system	29	12	41
	Positive healthcare experiences	12	6	18
	Barriers to accessing healthcare	6	6	12
	Total	**110**	**92**	**202**
Chronic illness dominates life	Psychological impact	46	38	84
	Physical impact	31	23	54
	Disruption to daily life	11	10	21
	Total	**90**	**72**	**162**
Growth and empowerment in the face of adversity	Community support	22	11	33
	Empowerment through advocacy	10	19	29
	Adaptation and resilience	10	17	26
	Positivity in face of adversity	17	0	17
	Total	**60**	**48**	**108**
Alone with one's illness	Lack of understanding and support from others	20	16	36
	Isolation and disconnect	10	7	17
	Internalised pressure to meet societal expectations	6	9	15
	Total	**36**	**32**	**68**

Themes

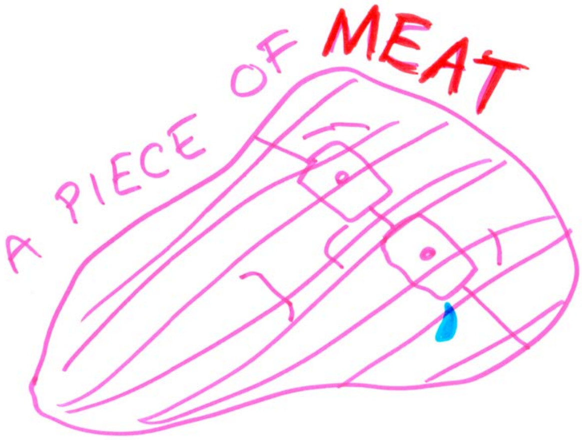
Lost faith in NHS Wales

This was a theme visited by a significant majority of participants during both workshops. Participants discussed their suboptimal healthcare experiences and the barriers they have faced when trying to access healthcare. In some cases, this led participants to share frustration towards the healthcare system, particularly towards NHS Wales. Some participants also reflected on positive experiences they have had. There was an overall sense that healthcare interactions, positive and negative, had a direct impact on participants' ability to manage their condition. This theme was further categorised into 4 sub-themes, depicted via description, illustrative quotations, and participants' drawings.

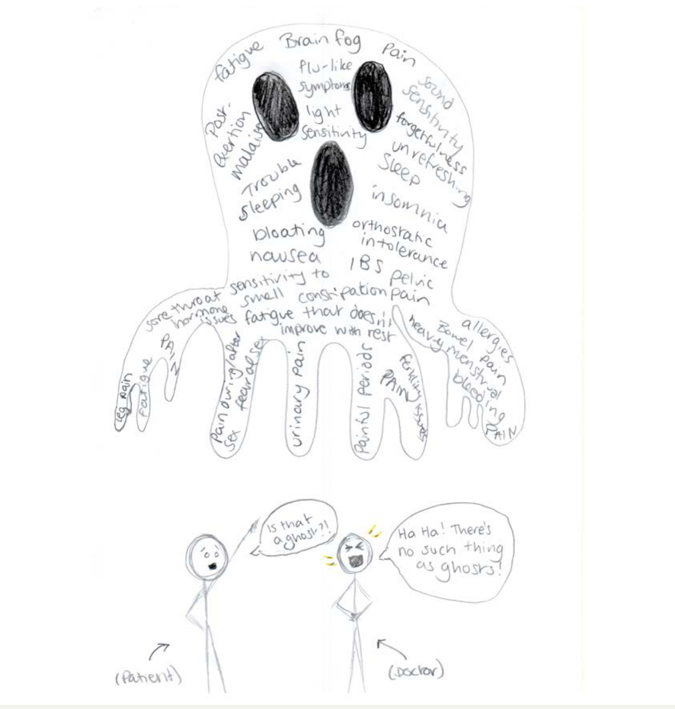
Sub-optimal healthcare interactions were repeatedly described by most participants. Participants shared experiences of inadequate care, often marked by delayed responses, a lack of holistic approaches, and the dismissal of their symptoms by healthcare professionals. Many described feeling disempowered, stemming from not being listened to or involved in decisions about their treatment. This sense of exclusion was compounded by perceived power imbalances and feelings of being dehumanised by clinicians. Collectively, these experiences contributed to a breakdown in trust and communication between patients and healthcare staff.

> "And then that led to that where I was like a piece of meat, basically, [...] I feel like the medical system treats you like a body, and that's it. It just meat without any feelings."
> –SW10

> "I felt butchered, actually, because this was in the context of having had surgery outside of my consent, which has had life-changing consequences for me, and being told they did it because I was a woman of a certain age who didn't need all her, you know [reproductive organs]. And I was told, literally by the doctor [...] 'basically, we castrated you'. That was the language they used."
> –NW4 "So lots of symptoms listed, not all

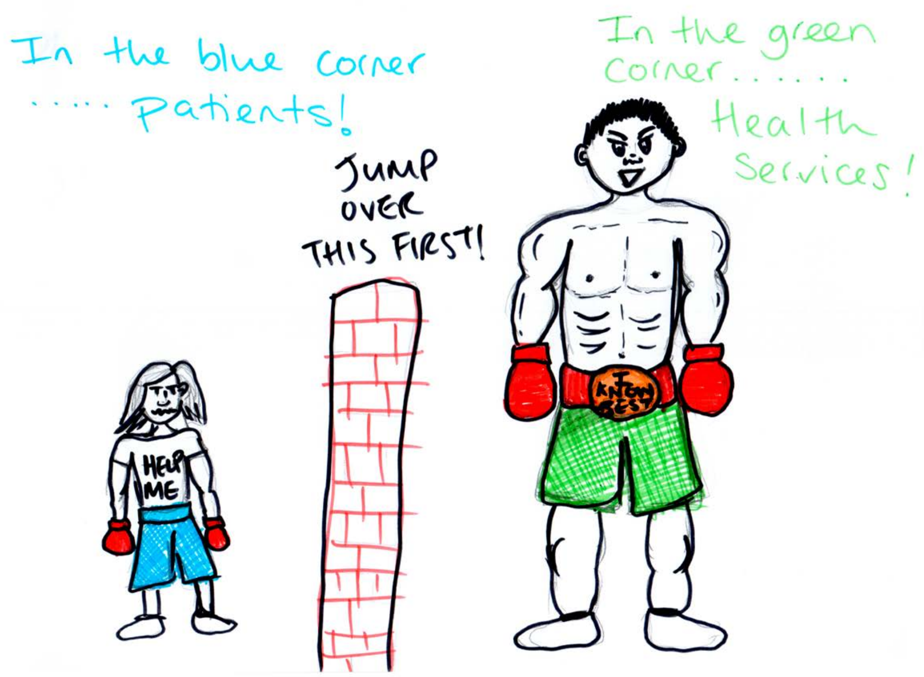


SW10



> of them, but the most sort of prominent ones and then [...] that's a patient, going, is that a ghost? And the doctors just pissing themselves laughing, saying 'Ah, there's no such thing as ghosts'."
> –SW3

> "I had become quite severely anaemic, and I was telling them how much I was bleeding and [they were] not taking any notice. I don't think they took me seriously."
> –NW5



NW10

> "I've been told since that they probably won't prescribe it for me [oxygen] anyway because I haven't actually got COPD and you've got to be really, really desperate, and yet you can go and buy your way into an oxygen tank."
> –NW8

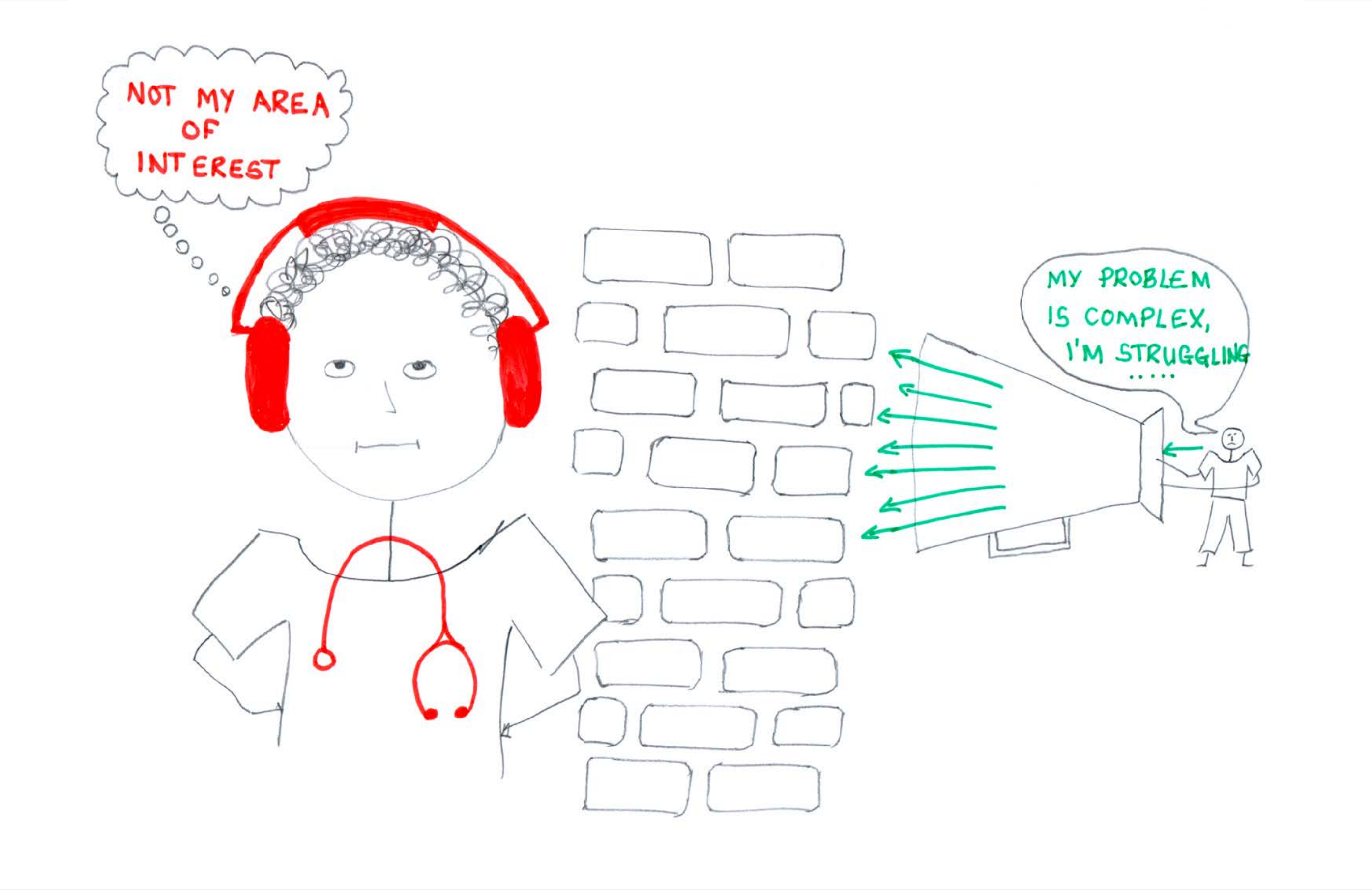
> "Whereas I know in other countries, things are different, even in England, things are different, and it's the way they talk about it here is very different to the way that London speak about it because they've got more experience."
> –SW8

> “So, this is me, and that’s a doctor, and that’s how I’m made to feel, very small, very insignificant, a little bit like I’m not there.”
> –NW3

> “Because I’m a woman, I feel as though I’ve been ignored. And I’m an old woman, which makes it twice as bad.”
> –NW8

> “I’ve gone to Greece for surgery. I’ve gone to Poland for surgery. I don’t trust our systems. I don’t trust our NHS.”
> –NW11

Furthermore, some participants described barriers to accessing healthcare, the two primary ones being the location of their health board and the financial burden of seeking private healthcare. Many perceived services outside NHS Wales—particularly in NHS England and overseas—as superior. Some reported that private care was the only viable option for receiving timely and effective treatment. However, while a few were able to pursue this route, several shared that doing so placed them in significant financial hardship and that public and private care did not communicate well, which made it hard to transition between care services.



> “There's an arrow to the help with a price tag of £20,000, which is probably about what I'd spent on my healthcare, which I always do the disclaimer, I recognise I'm in a really privileged position that I've been able to do that […] I shouldn't have had to do that. Yeah, I should have now been able to have financial security that I don't have any more from working my ass off and things like that.”
> –SW3

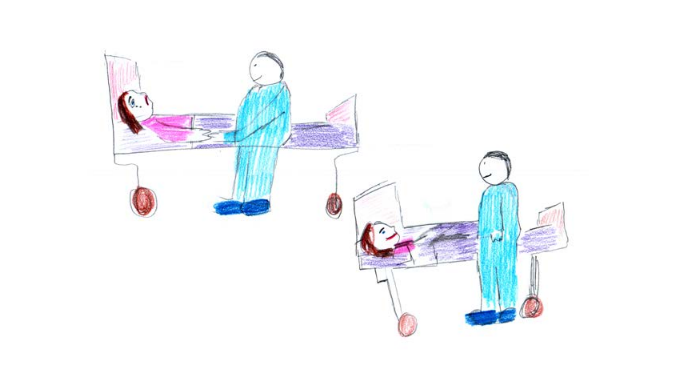
> “We’re just so behind in South Wales, you know, it’s scary, really, and it’s sad that we have to pay and go somewhere else to get the answers that we want.”
> –SW6

> “I feel really angry with the NHS in Wales”
> –SW8

Negative views of the healthcare system were frequently voiced, often accompanied by lingering emotional responses—most notably frustration with systemic issues within the NHS. These feelings of frustration and anger were commonly triggered by hearing or sharing stories of inadequate care and persistent barriers. Some participants also reflected on personal experiences that had fostered a sense of distrust, subsequently shaping their attitudes toward other healthcare professionals.

> “I think that experience as well, I don’t know, if anyone else has seen, for me, even if I do go and see people that are good at their job now, they know what they’re talking about, I already have my walls up, and I don’t engage with the nice ones as much as I should because all I’ve got in my head are the times that it’s gone horribly wrong.”
> –NW Participant

Finally, while some participants shared positive healthcare experiences, these were generally described as rare and unexpected, indicating that such encounters were not typical among workshop attendees. In contrast, other participants sought to reframe negative experiences by emphasising the commitment and dedication of many NHS staff, suggesting that individual efforts stood out and make a difference despite systemic challenges.



NW11

> “And I know, I got my first diagnosis very quickly, which is very unusual. Normally it took back then ten years to get a POTS diagnosis.”
> –NW1

> “Okay, so I’m one these rare, rare creatures where my GP is absolutely amazing. I know. I know. I know. I ring her up, and she will give me a call back. We have a chat on the phone. She diagnosed my fibro on the phone because she believed me when I told her"
> –SW2

> “I tried to reflect that I don’t think it’s all bad because I think it’s really easy to bash the NHS, but there are people there that are doing the best that they can with what they can, and I do see that.”
> –SW8

Chronic Conditions Dominate Life

This theme emerged consistently across both workshops, with participants describing the widespread negative impact their conditions had on all aspects of their lives. It was further broken down into three interrelated subthemes, which captured how the physical burden of unmanaged symptoms affected mental health and overall quality of life. Together, these factors contributed to significant disruption in daily living. The psychological impact of living with chronic conditions was marked by emotional distress and a profound sense of lost control. Participants described a wide range of negative emotions—including hopelessness, sadness, frustration, insecurity, and feeling overwhelmed—often in response to the demands of everyday life. Additionally, some shared how the unpredictable nature of their conditions, along with fears about the future, contributed to ongoing emotional strain.

SW4

> "the black is the hopelessness [...] I realised that despite the pain, despite the anger, it is the hopelessness that affects me more because it makes you, because you when you're fighting all the time and you're running against the wall, you think [...], what is the point? What am I going to do? And no one listens. That's the [...] hard one."
> –SW4

> "So I did the question mark because we don't know what, if the gun is going to go off and the bullets say different things. So it's life, death, hope, loss, but it's got a lot of fear on the gun that's always there"
> –SW8 (carer)

> "Why me all the time? And why did I get ill? Why was it me and not, like, my friend? Why was it me and not somebody else? And it's like, why was I the one who had to give up my life? Because it is very much giving up your life, and not through choice."
> –SW9

SW8 (CARER)

> “Because I think when I was first trying to get diagnosed with Endo, like, God, well, over 20 years ago now, that was horrendous, and I just remember, like, finding forums and everything, just being so miserable to the point where I was suicidal.”
> –SW3

> “[...] a loss of control, not knowing what you’re going to do in the future, feeling like, oh, I’ve wasted a lot of the time that I’ve already lived”
> –NW5

The physical impacts described by participants centred on how unmanaged symptoms—most commonly pain and fatigue—disrupted their lives. Many spoke of the relentless nature of these symptoms and the toll they took on daily functioning, ultimately diminishing their overall quality of life.

NW9

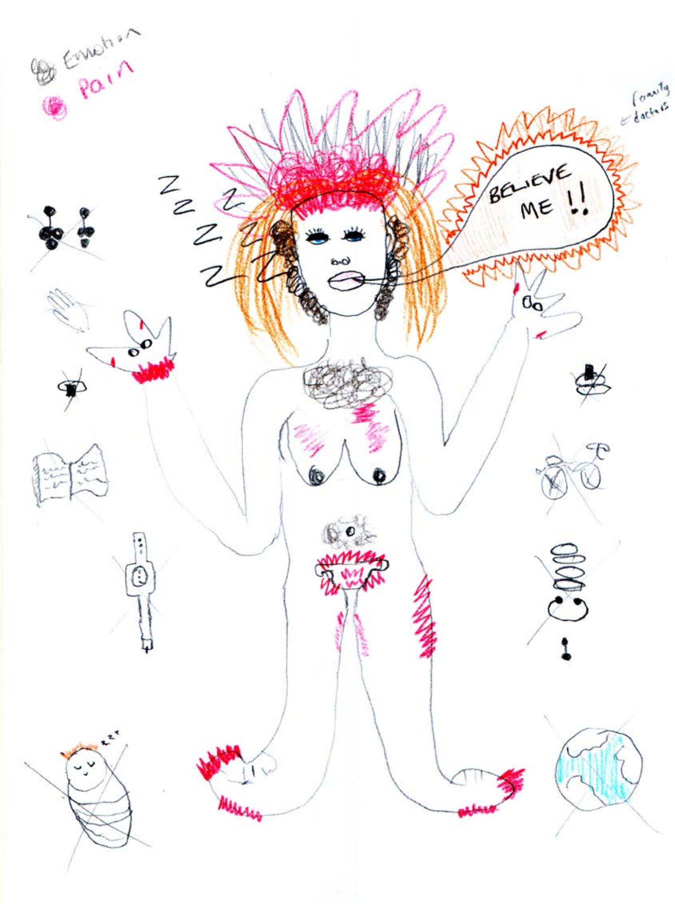
> “So like with the gynae pain I feel it’s like a dragon or a crocodile licking its lips ready to cause a lot of pain and blood, and, yeah, just that sharp, dragging pain. And then everywhere else, it looks just like sunshine, and ready to take your day down.”
> –NW9

> “It’s like a glacier of fatigue, so I’m stuck in it, and [...] I feel frozen. There’s lots of things, like everything’s happening outside and it’s all colourful and sunny, and there [were] things I want to do, and I am so tired. And I am just like, stuck there.”
> –SW10

> “So surely, the tiredness is the worst thing, and sleeping all the time, I can’t do anything, I can’t make any plans because, you know, I’m exhausted, and then, like you, with the hopelessness, you know, I’ve been feeling hopeless.”
> –SW6

> "I can't remember what it's like to not have a headache and not worry about, if I do this, am I going to set off, like a horrific kind of and like you can do everything right, and you can still have, like, all of this pain."
> –NW10

> "The most impactful things for me from that point is that when I got out of the surgery, they gave me like the little button for the morphine, and I used it twice because the pain of the surgery was nowhere near what I've been feeling for years, and that's when it hit me just how much pain I've been living with."
> –SW4

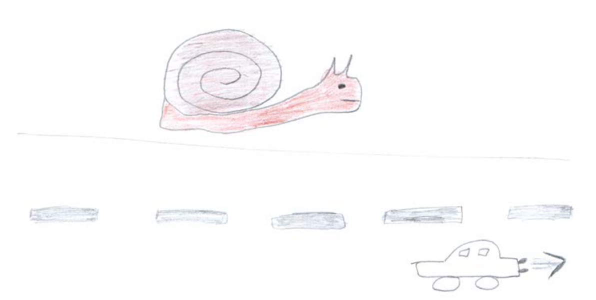


SW6

In addition to these psychological and physical challenges, participants also spoke about broader disruptions to daily life. These included strained personal relationships, limitations in pursuing professional careers, and a general inability to engage in activities they valued or desired. Together, these impacts reflected the pervasive and interconnected nature of living with chronic illness.

> "And also these are the things that I can't do, because I'm a cake decorator, I decorate cakes, and I can't really do that anymore because I can't stand up for long enough and it takes too much energy. And I also make, this is just a craft, this is a wreath. Because I […] do a lot of crafty things. I can't do that anymore"
> –SW 6

> "And it's kind of sometimes the small things that people take for granted, it's like I can't drive anymore, so then that makes, like, life loads more difficult."
> –NW7



SW6

> "And it's like, in the back of my mind, I'm going, how are we going to afford a wedding when I can't work full-time, you know? And how are we going to afford things when I can't work full-time. You know, I work three jobs, all ad hoc because I can't have a full-time job."
> –SW9

Alone with one’s illness

This theme captured the deep sense of isolation and disconnection that many participants felt in relation to those around them. A lack of understanding and negative comments from people in their everyday lives left some feeling misunderstood and alone in managing their conditions (excluding those who work in healthcare; this is covered in healthcare experiences). Several participants also described the internal pressure to meet societal expectations and appear “normal,” despite experiencing significant suffering. Lack of understanding and support from the world captured experiences where others failed to grasp or believe the severity of what they were going through. Some recounted unkind or dismissive remarks, which further contributed to feelings of invisibility and invalidation. Others expressed frustration at being seen solely through the lens of their condition, when they longed to be recognised as whole individuals beyond their illness.

> “Have you tried yoga? Have you tried this quack cure? And then with a banner over the top that says disabled but not disabled enough.”
> –NW12

> “I'm actually really quite easy to get close to. If you know how to handle the cactus, and it's those who don't know how to handle the cactus that find me prickly, that find me aggressive […]. See me as the pot, and not the cactus, not the thing that's being held in the pot […] here's also so much more to me than my impairments.”
> –SW2

> “It isn’t just a painful period. It affects all parts of you, all parts of your body or parts of your life.”
> –SW6

> “One of my colleagues said 'just have a baby and the endometriosis will go away'. This was a senior male colleague. 'It’s just a bad period. We all have periods.' That was a sister in the hospital and HR.”
> –NW9

Participants described how their conditions had a detrimental impact on their social lives, often leading to the loss of relationships and a sense of isolation and disconnect from others. This isolation was frequently attributed to a lack of energy to maintain regular contact, as well as others’ inability to understand what they were going through. A few participants also spoke about the unique isolation they felt as neurodiverse individuals navigating predominantly neurotypical environments, highlighting the added layer of social exclusion and misunderstanding.

> “Then we’ve got a social situation, probably mostly with neurotypical […] and they’re all over there, and they’re all in a group and chit chatting and multi way conversation. And I’m stuck on my own, and I feel like I’m surrounded by barbed wire because I can’t say the right thing […it’s] difficult to find how you can feel so alone in a group”
> –NW1

> “I lost a lot of my friends […] so there’s just like this big bubble of isolation, and then just like this tiny little drawbridge with loads of spikes. Because it’s like, I feel like people have to really work to get close to me”
> –SW9

> “So we’re sort of hidden away from society.”
> –SW3

SW9

Some participants described the internalised pressure to meet societal expectations, often feeling compelled to mask their pain and push themselves to carry on despite significant struggles. This pressure was rooted in long-standing messages they had received—being told to persevere and that what they were experiencing was “normal.” As a result, many felt obligated to present a façade of wellness, even when suffering, reinforcing feelings of isolation and emotional exhaustion.

This is me in work hoovering, the day
after what I now believe was either
an ovarian torsion or a burst endometrioma.
The night before this I was in excruciating pain,
but I just took ibuprofen + went to bed because
I'd been told "Period pain is normal"

> “What’s wrong with me? Pull yourself together because you know what this is, so why aren’t you getting on top of it and sort of getting a grip? […] So I even painted my little red nails there because […] I go through all the fakery of putting my makeup on, doing my hair, getting my nails done, to sort of give this mask of competence and the mask of having it all together.”
> –NW4

> “So I spent decades trying to fit in and trying to do everything that everyone else is doing because they can all manage it. Why can’t I? Feeling like a complete failure of a human and all of those horrible negative words”
> –SW3

Growth and empowerment in the face of adversity

Despite the discomfort and disruption caused by chronic health conditions, many participants shared how they had found personal strength and a sense of empowerment. This theme was consistent across both North and South Wales workshops, with several participants highlighting the importance of community and a shared drive to advocate for change—both of which, for many, had been facilitated by FTWW.

In South Wales, discussions often centred around finding positivity in the face of adversity and the use of positive language, reflecting a focus on growth and meaning making. In contrast, participants in North Wales spoke more about the resilience they had to cultivate simply to survive, underscoring the emotional and practical challenges they faced.

Community support emerged as a vital lifeline for many. Participants described the empowerment and sense of value they felt from connecting with others who shared similar experiences. FTWW was frequently mentioned as a central force in enabling these connections, providing not only a platform for shared understanding but also a source of strength and solidarity.

> "So it's, it's just, it's really inspiring to see you guys and how everything you've dealt with, and just understanding that, if, you know, if she did have something in the future, you know, she still can have a full life."
> –SW8 (carer)

> "I did talk to myself as if I was the worst person on earth until I found other disabled people"
> –SW3

> "I was unwell, I was alone, I was struggling, and I was unheard. And then I found FTWW"
> –NW1

> “And then [someone] I worked with saw about FTWW, and I came to watch the video, and it was a lifeline. So that was meant to be like a dinghy or something. So, the positive, there are people […] that help navigate the health system and support you on this fight, jumping through hoops. You’re not alone because I did feel very alone. There are events like the march, which those things have really helped. You are valued, community and somebody listening, you know, meeting them is just, you know, I can’t express how grateful for the work that they do, but it has been a lifeline.”
> –NW9

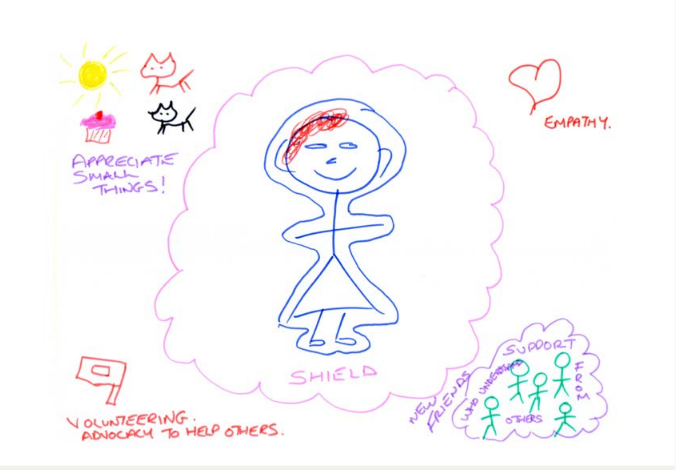
SW10

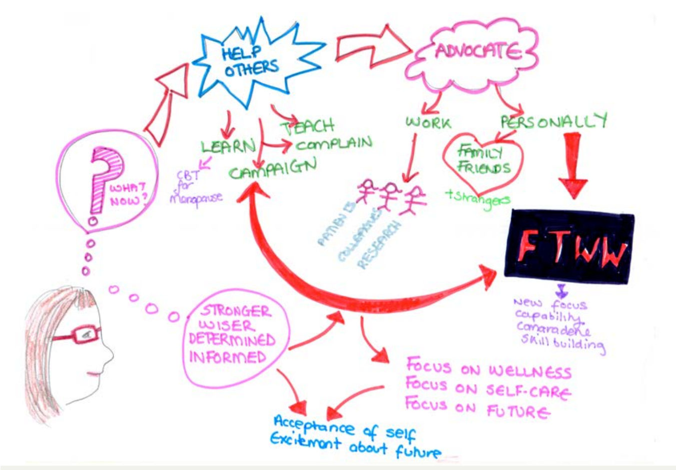
Additionally, some participants demonstrated the support a community can provide during the workshop; they used the space to support and validate the experiences of others.

> “You’re not on your own on this, you know. And […] we’ve had this before, where there’s been women who have gone, oh, well, it’s not me, it’s my kids. So don’t really belong here. Yeah, you do.”
> –SW2

Some participants spoke about building empowerment through advocacy, describing how having a voice, contributing to change, and supporting others gave them a renewed sense of purpose. They shared how opportunities to speak from their perspective as disabled individuals allowed them to challenge misconceptions and confront stigma, fostering both personal growth and broader social awareness.

> “[…] what can I do to make sure other people don’t go through what I’d gone through because what I’ve gone through was so significant. I thought there has to be a way to do that. So I started reading a bit. So broadly what that has done, I’ve learned a lot more about all the things that I’ve been through, or women go through. I thought I’d have to learn more.”
> –NW4





NW4

> "My niece is the same, you know, I'm doing it for them because I don't want them to see them have to go through what I've been through."
> –SW6

> "I'm contributing again. Might only be a little bit, but I actually do feel like I'm contributing, and I can make a difference. And the way that's boosted up my self-esteem, which had been on rock bottom it's really important, and it's made me feel I might not be doing my paid job, but I can do something."
> –NW1

Adaptation and resilience captured journeys of adapting to a new normal, often through practical strategies such as pacing and symptom management. These tools helped participants navigate daily life more effectively. Additionally, several of them reflected on how their experiences had made them feel stronger and more resilient, highlighting a sense of personal growth that emerged from enduring and overcoming ongoing challenges.

> "I found a lot of inner strength. So even though I'm not strong physically, there's a lot of things that I am strong at. And I've realised that there's a lot of things I can get through now that I probably couldn't have got through ten years ago, but I've had to get through them. So I don't know whether that's a strength, but I have to kind of see it as a bit of a superpower."
> –NW3

> "So although it's not what you choose, it definitely makes you stronger."
> –NW7

> "So you have to just keep finding those glimmers of hope and light, don't you?"
> –SW3

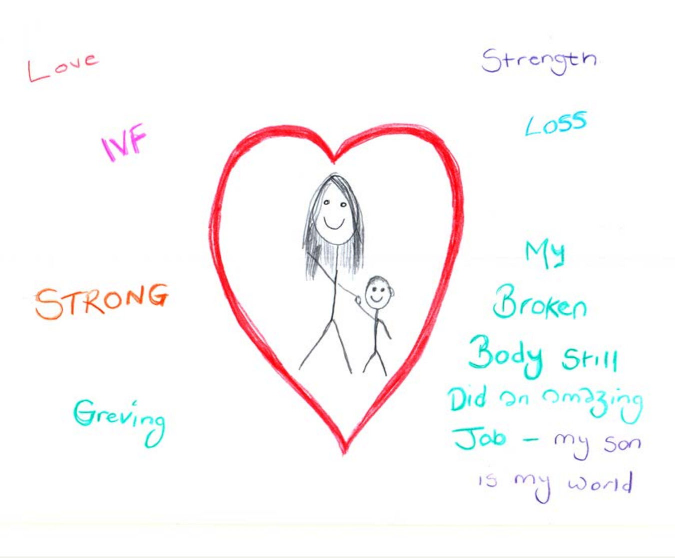
Finally, positivity in face of adversity was a theme that emerged in the South Wales workshop. In this workshop a small number of participants discussed how they had found personal meaning and benefits in living with their condition. They spoke about how their experiences made them feel unique and contributed to a sense of pride and self-love. These reflections were framed in a notably positive light, highlighting how some individuals were able to reframe their condition as a source of strength and identity.

> “The benefits of being neurodivergent, as I see them. So like there’s little shells, like I notice all the tiny details, like of everything […] I can’t ignore injustice. And if it’s just the way things are, then why can’t we just change the things? And a little bug, so I never, never squish bugs. I let things grow. Like it physically, like, it really hurts me seeing people hurt each other […] And I said, wouldn’t the world be nicer if it was filled with people who care about things as much as we do? […] A little hammer and a crochet hook and spinning wheel. And I wrote, a great ally in an apocalypse because I have so many skills.”
> –SW10

> “So I always say sorry, especially to my little tummy because I used to be so horrible to her and call her broken. And now I realise how hard she's been trying to keep me alive. So I'm very proud of her.”
> –SW3

> “I’m really proud of myself, and I’m proud of all of you. I’m proud of our community”
> –SW3

SW10



SW5

> “I deserve to have a full life, not just survive.”
> –SW4

Discussion - Our Findings

There is much learning to be had from the *DrawingOut Long-Term Health Issues in Wales* project. However, generally-speaking, participants' contributions led to three main findings:

1. Difficulties accessing and receiving healthcare
2. The many ways chronic health conditions can impact people over time
3. Coping with long-term health issues

1. Difficulties accessing and receiving healthcare

The report shows that women's chronic pain and long-term health concerns are often minimised, disbelieved, or 'normalised', a finding which is reflected in other recent academic studies.[12][13]

The term 'normalised' is used here to how symptoms can be perceived both by the sufferer and those around them as a 'normal' part of life, something that they should tolerate or 'put up with'. One of our workshop participants described their experience of telling work colleagues about their endometriosis, 'It's just a bad period. We all have periods. That was a Sister in the hospital and Human Resources'.

Often, symptoms like heavy or painful periods, hot flushes, brain fog, or fatigue. are attributed to normal female physiology or bodily functions, irrespective of how severely they are impacting the person. The participants in our *DrawingOut Long-Term Health Issues in Wales* workshops felt strongly that gender stereotyping, ageism and ableism[14] led to their symptoms being dismissed, and that prejudices like these often fuelled the difficulties they had in accessing support or healthcare. These perceptions align very closely with broader literature on women's unequal healthcare experiences and diagnostic delays.

Participants in our *DrawingOut Long-Term Health Issues in Wales* project also spoke about how, when they did manage to access healthcare, services either weren't of the type they wanted or weren't sufficiently specialised. They described a lack of communication or follow-up from their healthcare providers which resulted in care which didn't join up. For many, this meant that their symptoms got worse over time.

Participants perceived stark regional inequities, especially between Wales and England, contributing to feelings of abandonment and mistrust. Several told of how they had turned to private or overseas care due to long waits or lack of specialist provision, often at substantial personal cost.

We know from FTWW's members that living in Wales can pose additional challenges to accessing specialist healthcare where it isn't available locally. Aside from this, however, the literature suggests that both women in England and Wales face similar societal barriers to healthcare for gynaecological conditions, such as symptoms being dismissed or underplayed.[15]

Overall, the findings from our *DrawingOut Long-Term Health Issues in Wales* project are very similar to those from other UK-wide research studies looking at women's experiences of healthcare, especially around the lack of person-centred communication, often resulting in women's symptoms, chronic pain, and long-term health conditions being minimised.

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[12] https://journals.sagepub.com/doi/full/10.1089/whr.2021.0083

[13] https://www.sciencedirect.com/science/article/pii/S0738399125005920?via%3Dihub

[14] https://pmc.ncbi.nlm.nih.gov/articles/PMC11061527/

[15] https://www.sciencedirect.com/science/article/pii/S0738399125005920?via%3Dihub

2. The many ways chronic health conditions can impact people over time

The *DrawingOut Long-Term Health Issues in Wales* report shows how chronic conditions can have pervasive impacts on different aspects of people's lives. By this we mean that lots of different parts of a person's life can be affected, in a noticeable and often negative way. For our workshop participants, the wider impacts of living with chronic illness included:

- **Poor psychological wellbeing**, for example, feeling a lack of hope about the future, fear about what will happen to them, or experiencing a loss of identity as everything becomes concentrated around their symptoms and prognosis
- **Reduced physical functioning**, for example, if they experience pain or fatigue all the time, or lose their mobility
- **Declining socioeconomic status or financial security**, for example, if they find themselves unable to work or experiencing financial difficulties as a result of their symptoms or healthcare needs.

These impacts are reflected in other academic studies and also in the conversations FTWW has with members and wider networks.

We also learned that, sometimes, it isn't just the person living with chronic health conditions that is affected by these difficulties but also the people around them, such as family members or carers. Evidence suggests that around 70% of carers in the UK are disabled or living with a long-term health condition themselves, with almost half of all current carers reporting worsening health since taking on a caring responsibility for another person.[16]

Financial hardship, worries about daily living, and physical and emotional struggles can impact on entire families and this can be made worse where there are challenges accessing healthcare. If a person's health needs aren't being met, their symptoms can worsen, causing more distress and creating a cycle of deteriorating wellbeing, both for the sufferer and those around them.

We know that the majority of those living with chronic health conditions will be female[17] and that there are conditions which uniquely, disproportionately, or differently impact them compared to men[18]. We also know that women make up the majority of unpaid carers in Wales[19] and that women experience what is called the 'gender pay gap', where their job prospects and earning potential are worse than men. This is an issue which can be amplified both by roles and responsibilities outside of formal, paid work and / or being disabled or living with a long-term health issue.

Research undertaken by the House of Commons reports that median pay of women is consistently lower than that of men and that the largest disparity is between non-disabled men and disabled women which, in 2023, stood at 23.2%.[20] These multi-layered issues – sometimes called 'intersections' – can further impact on women's health and wellbeing, creating more disadvantage, stress, and risk of illness.[21]

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[16] https://carers.org/news-and-media/news/post/500-nearly-half-of-uk-adults-with-caring-responsibilities-say-their-health-has-been-impacted-since-caring-reporting-new-or-worsening-conditions

[17] https://www.bmj.com/content/385/bmj.q999.full

[18] https://www.ncbi.nlm.nih.gov/books/NBK607720/

[19] https://www.carersuk.org/media/oiebqs4k/full-report-care-policy-scorecard-for-wales-final.pdf

[20] https://researchbriefings.files.parliament.uk/documents/CBP-9602/CBP-9602.pdf

[21] https://wenwales.org.uk/wp-content/uploads/2024/11/Feminist-Scorecard-Report-2024_ENG_DIGITAL.1.2.pdf

3. Coping with Long-Term Health Issues

The *DrawingOut Long-Term Health Issues in Wales* report shows how participants often had to create their own coping strategies, or ways to manage, deal with, and live alongside their health issues, because the formal health and care services they were offered weren't sufficient or 'holistic' enough.

This echoes what we hear from FTWW members, who often report healthcare being 'siloed' or focused on just one set of symptoms, with services tending to be short-term in nature. This means that people often have to learn how to self-manage the many and varied longer-term impacts chronic conditions have on their lives outside of healthcare appointments.

The *DrawingOut Long-Term Health Issues in Wales* report shows how women often rely heavily on self-directed coping strategies, including making practical adaptations to how they live, to help them deal with the day-to-day impact of chronic illness. Amongst the strategies discussed were things like:

- **Pacing**, which is where they learn how to save and use energy more effectively, taking regular rest-breaks or saying 'no' to activities which they know will cause symptoms to get worse
- **Avoiding triggers for pain or distress**, whether that's stressful situations, certain physical movements, or particular foods
- **Adjusting lifestyle routines**, such as changing their diets, sleep patterns, or working hours
- **Crafting personalised symptom-management systems**, including using symptom diaries, apps, and embedding approaches they found helpful into their daily lives, such as supplements or wellbeing activities.

Some of the participants spoke positively of drawing on peer-support and knowledge, such as online forums and advocacy groups, to make up for gaps in clinical guidance. Whilst participants found these helpful, there is a lot of research to show that, in reality, self-management of long-term health issues can be difficult. One 2024 study described how this is because people need to be capable, motivated, and have opportunity to embed self-management approaches into their lives and this isn't always possible for some groups or individual circumstances.[22]

Some of our participants described how being diagnosed with a long-term health issue had enabled them to find a community of women or people in similar circumstances and that this had created a sense of belonging and solidarity. Being able to take up opportunities to share their experiences and knowledge had given meaning to their struggles and helped them grow confidence in their ability to contribute positively to society.

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[22] https://bmjopen.bmj.com/content/bmjopen/14/11/e088568.full.pdf

Recommendations

The following recommendations for action are based upon what both participants in the DrawingOut Long-Term Health Issues in Wales workshops, and FTWW's wider membership, told us would help to improve their health-related experiences, outcomes, and lives.

1. Healthcare provision which moves beyond focusing on one set of symptoms or 'body part' to 'whole person support', via holistic, joined-up, and person-centred care
2. Better communication in and across healthcare settings, with a focus on improving 'relational care' between clinician and patient
3. All policy areas in Wales to make addressing health inequities a priority.

1. Holistic, joined-up, person-centred care

Participants' recommendations include:

- A focus on enabling clinical settings and personnel to better meet the needs of women living with chronic health conditions through co-production. This might include creating 'hubs' which focus on managing long-term health issues, with specific teams and longer appointment times.
- Improved communications between providers, professionals, and patients so that all letters and communiques are seamlessly transferred, discussed, and agreed between teams and the patient and / or their carer.
- Coordinated care across sectors, including the potential for developing 'care coordinator' roles so that the burden of navigating various healthcare providers and facilitating various appointments, communications, and treatments doesn't necessarily fall to the unwell patient, unless this is their choice
- Continuity of care, where patients have a designated person or team providing care so that they don't have to 're-tell' their stories repeatedly.
- Timely access to specialists, including where they aren't available in local health board areas, to prevent symptom escalation or disease progression, and enable earlier action and better outcomes for patients. This could include patient advocates working with NHS Wales Health Boards and Joint Commissioning Committee to map patient needs and develop equitable pathways for less well-served chronic health conditions.
- Integrating social and community support into care offered through better understanding women's needs, ensuring healthcare professionals have the means and information at their fingertips to signpost patients appropriately, and resourcing the services that help patients cope or self-manage health conditions outside of healthcare appointments.

2. Better communication in and across healthcare settings, with a focus on improving ‘relational care’ between clinicians and patients

‘Relational care’ looks at how healthcare professionals and patients relate and communicate with one another. Recommendations for improvement in this area include:

- The importance of the patient being believed when reporting symptoms or issues. This often necessitates the healthcare provider having training and support to identify and address any unconscious biases which could hamper their ability to work effectively with certain patient groups so that they are able to listen to patients and validate their symptoms without prejudice or assumptions.
- Investing in services which focus on continuity of care for those living with long-term health conditions. Mutual trust and respect between healthcare professional and patient is vital to enabling effective management of chronic illness but it takes time to build. Trust and respect are more likely to develop where the patient’s needs are known to the healthcare professional and where they don’t have to repeat themselves and potentially encounter attitudinal barriers multiple times. These are things that can eventually deter people from seeking help or following medical advice.
- Recognition of the impact of fluctuating and non-visible impairments, neurodivergence, mental illness, and chronic pain, including how both symptoms and healthcare environments can ‘disable’ people. It is important that the NHS understands and receives training, led by those with lived experience, on the social model of disability so that providers don’t create barriers to seeking or receiving effective healthcare. These barriers can include misconceptions or stereotypes about people with non-visible or fluctuating conditions and how they might ‘present’ or communicate, as well as places and spaces that aren’t accessible, difficult to contact, enter, or use.
- The importance of training and support to embed person-centred care which is open, empathetic, equitable, and focused on listening. This includes being trauma-informed, where providers understand how people’s past experiences can make receiving healthcare more difficult or upsetting and seek to ensure they don’t trigger distressing feelings or make them worse; gender-sensitive communication which avoids making assumptions or stereotyping individuals and which ensures patients’ preferences and needs are heard, understood and accommodated; shared decision-making, as is set out in NICE guidance[23], to correct the typical power imbalance in healthcare where women don’t feel like their voices are heard when it comes to treatment options or referrals.

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[23] https://www.nice.org.uk/guidance/ng197

3. All policy areas in Wales to make addressing health inequities a priority

Many of the gender health inequities outlined in this report can be attributed to a lack of understanding or investment in the health and wellbeing-related issues and needs affecting women, ranging from inadequate clinical research and health service provision, to other areas of policy and decision-making. To address these problems and gaps, the following recommendations are made:

- Make 'women's health and wellbeing' a priority across all policy areas, in recognition of how long-term health issues experienced by this population group have wide and varied impacts across different aspects of life, including education, employment, social care, infrastructure, and the economy.
- Invest in and roll-out evidence-based training for health and care professionals, educators, and employers, co-designed and delivered by people with lived experience, so that there is a fuller appreciation of women's health needs throughout their lives.
- Address regional variations in care ('postcode lotteries') by investing in the development of equitable pathways for various long-term health conditions across Wales and into other nations, where appropriate. This should include making sure those pathways are known to both patients and their healthcare professionals, for example on a new Wales Women's Health Website.
- Maintain a NHS Wales commitment to women's health beyond the current ten-year Women's Health Plan (2025-2035)[24].

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[24] https://womenshealth.nhs.wales/files/health-reports/nhs-wales-womens-health-plan

Strengths, limitations, and diversity of the project

Strengths

The workshop approach and DrawingOut method helped researchers collect first-person narratives and experiences from participants without having to lead discussion or direct a particular line of questioning. Participants were able to choose for themselves what experiences of long-term health issues to share which helped overcome the power-imbalance which people sometimes describe when taking part in research studies. Instead, the DrawingOut method fostered a collaborative approach to activities, where participants' contributions led the discussion, with only minimal prompts to guide activities from the researchers.

The workshops themselves were set up by FTWW, a peer-led organisation, which created a more supportive and relatable environment than one set up by external partners. This meant that participants felt comfortable and more confident to share their personal lived experiences. It also meant that participants were able to offer support, encouragement, and validation to one another throughout the day.

The DrawingOut method enabled participants to share and capture their experiences in multiple ways, including story-telling, visual images, and visual textual data (words written alongside their drawings). This meant that even if a person was less confident in their drawing skills, their written descriptions could help explain the drawings' meaning and vice versa, whilst their verbal contributions could still be captured on the audio recording for use in the report.

The workshops captured geographically diverse views of healthcare experiences by spanning both South and North Wales. Out of seven health board regions in Wales, five were represented, with only two (Powys, and Hywel Dda – mid and West Wales) not represented, which could be addressed in any future iterations of the activity.

Involving FTWW staff with lived experience throughout the writing of the report strengthened the research team's interpretation of the findings because they were able to connect those findings to what the organisation says about its members' experiences.

Limitations

Although this project captured a wide range of experiences from South and North Wales, we can't be certain of how far findings would be applicable to all women and people assigned female at birth because of how participants were recruited. For example, all participants had to be members of FTWW, were required to put themselves forward to take part, and it was a small sample size (number of people) overall.

Whilst the peer-led approach to the workshops enabled open discussion, and the researchers worked to ensure that all participants had the opportunity to reflect on their personal experiences and share their own truths, a group workshop format of this type can risk amplifying certain types of story (for example, negative healthcare experiences). The workshops were held through the medium of English, and it was anticipated that participants would have a UK average reading age of around 10 years. This could have been a potential barrier to participation for those whose first language wasn't English or who might feel less confident or scrutinised in a group setting. It would certainly be possible to run the activity in different languages, such as Welsh, and adapt content for a range of learning needs. In the meantime, it would be fair to assume that some of the challenges in accessing healthcare described by participants would be more pronounced for these groups.

Diversity Measures

In terms of diversity amongst workshop participants, the majority of attendees identified as Welsh, English, Scottish, Northern Irish or British, with 89% describing themselves as white, compared to 94% of Wales's population. Broadly speaking, these figures indicate that the workshops had a slightly greater degree of ethnic diversity than is reflected in the population of Wales as a whole.

The majority of workshop participants identified as Straight or Heterosexual (74%), with the remaining 26% identifying with other sexual orientations or identities, compared to 89% and 11% of respondents to the 2021 England and Wales Census respectively. In terms of disability, 68% of workshop attendees described themselves as disabled, with 16% unsure, and a further 16% who would not describe themselves as disabled. As would be expected of an activity focused on long-term health conditions, this far exceeded the proportion of Wales's population who identify as disabled (21%).

The most commonly reported long-term health issues amongst participants were endometriosis, ADHD and autism, ME or Chronic Fatigue, and Fibromyalgia. Other frequently mentioned conditions included depression, anxiety, Ehlers-Danlos Syndrome (EDS), PCOS, Adenomyosis, and a range of chronic pain, hormone-mediated, and neurodevelopmental conditions. In total, 50 distinct health conditions were identified, reflecting the wide diversity and complexity of the health challenges experienced by participants.

On balance

Overall, whilst the findings from the *DrawingOut Long-Term Health Issues in Wales* project are highly credible and rich, they tend to reflect the experiences of a particularly engaged group, likely those most burdened by chronic conditions and systemic inequities who felt sufficiently motivated and able to share their experiences.

Furthermore, whilst the project's broad focus on women's experiences of various and multiple long-term health issues enables us to understand common themes, it also means that recommendations remain general rather than concentrated on a particular health condition or sub-section of the female population.

Undertaking much more focused work, so that advice can be tailored to specific needs and clinical areas, will always be needed.

Conclusion

Increasingly in the UK and Wales, healthcare providers describe the value of lived experience in helping evaluate and design health service design. Often, this is called ‘coproduction’ and it can be seen in NHS Wales’s first principle of ‘Prudent Healthcare’. Embedding service users’ expertise in this way is seen as an important way to make sure that healthcare is better able to meet people’s needs, improving patient outcomes and the efficiency of services.

Coproduction is also seen as an important way to help prevent discriminatory practices or barriers to health and care, so it aligns with UK-wide legislation like the Equality Act 2010, and Welsh legislation which followed, such as the Social Services and Wellbeing Act, and the Wellbeing of Future Generations Act. Both of these Acts highlight the fundamental role of giving diverse citizens and service-users ‘voice, choice, and control’.

The *DrawingOut Long-Term Health Issues in Wales* project very much centres around giving participants the opportunity to have their voices heard.

Furthermore, the various outputs from the activity, such as this report, a poster, booklet, and gallery also ensure that their expertise can be viewed and shared widely to highlight what is needed to make health services work better for women and people assigned female at birth affected by chronic conditions.

Overall, findings from the *DrawingOut Long-Term Health Issues in Wales* project are consistent with a wide body of research into chronic health conditions. Together, they tell us that sustained investment in women's health and long-term health conditions is crucial and likely to yield benefits not only for those individuals affected but also for workforce sustainability, family wellbeing, economic productivity, and the wider population in Wales, now and into the future.

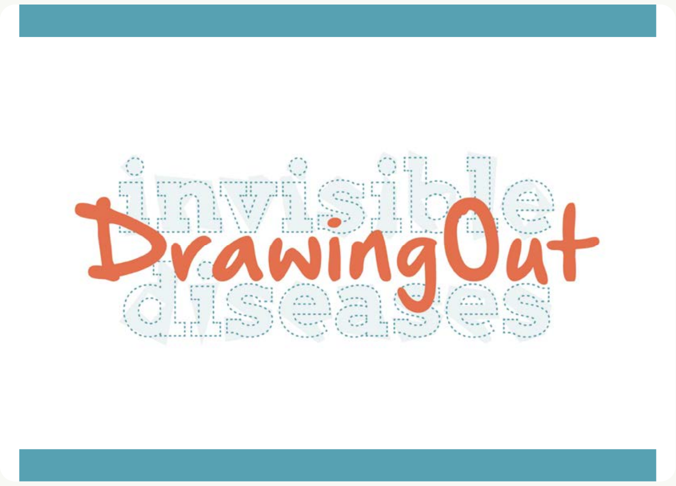
Thank you for reading.

For more information about *DrawingOut Long-Term Health Issues in Wales*: ftww.org.uk/drawing-out

To learn more about the ‘DrawingOut’ methodology: drawingout.uk

Appendix: Workshop Presentation

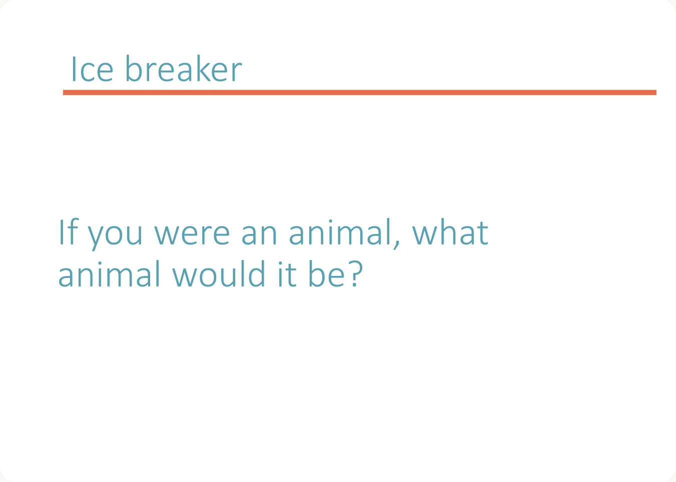
Please note that for the DrawingOut Long-Term Health Issues in Wales project, workshops were held through the medium of English using the slides below.



invisible DrawingOut diseases

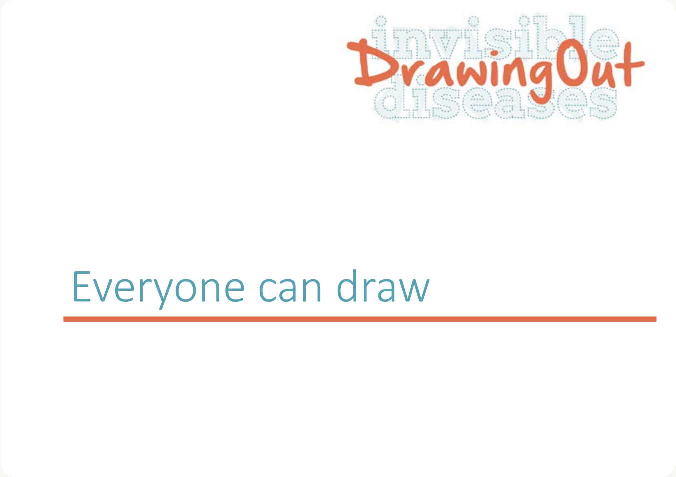
invisible DrawingOut diseases

Welcome to our workshop!



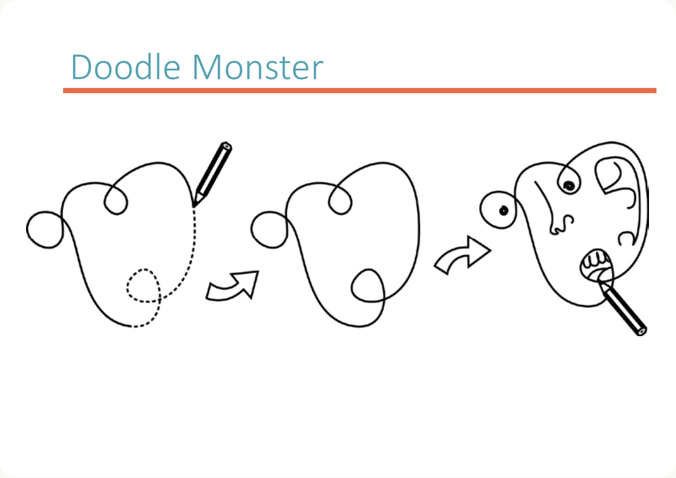
Ice breaker

If you were an animal, what animal would it be?

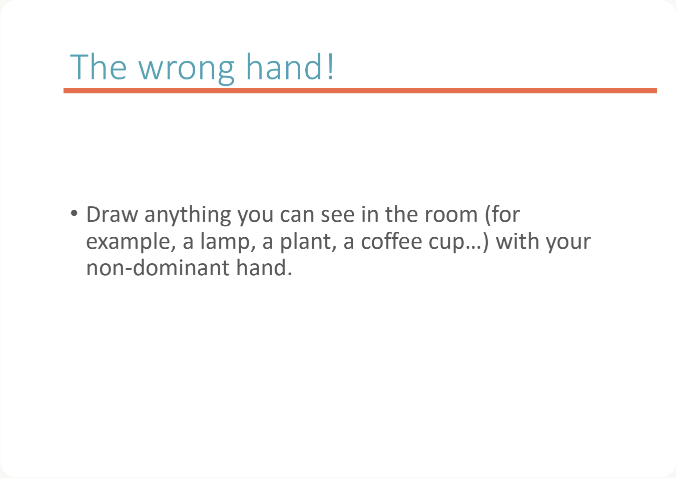


invisible DrawingOut diseases

Everyone can draw



Doodle Monster



The wrong hand!

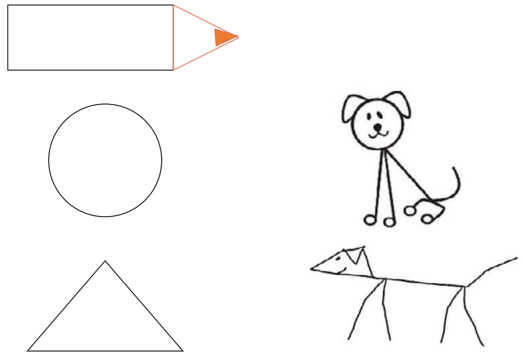
- Draw anything you can see in the room (for example, a lamp, a plant, a coffee cup…) with your non-dominant hand.

No peeking!

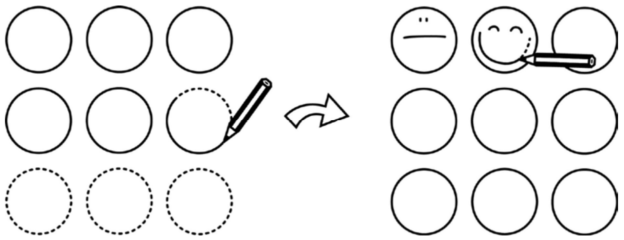
- Draw anything you can see in the room without looking at the paper and without lifting your pen off the page.

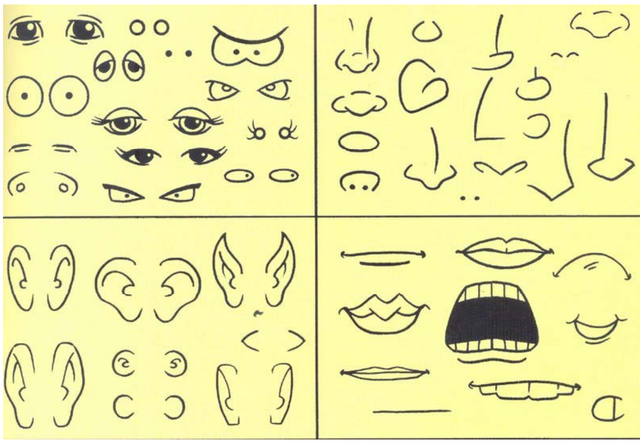
People, creatures and objects 1

Objects and creatures

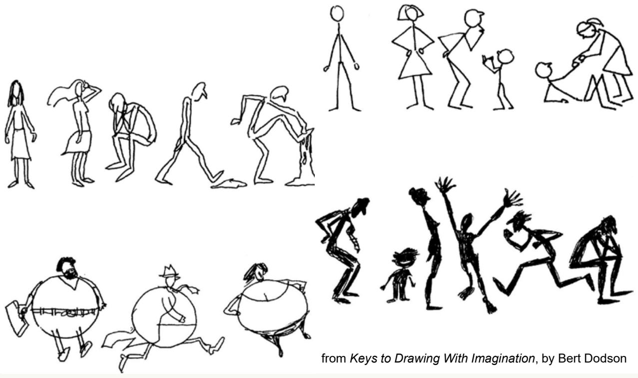


Nine faces





Drawing figures



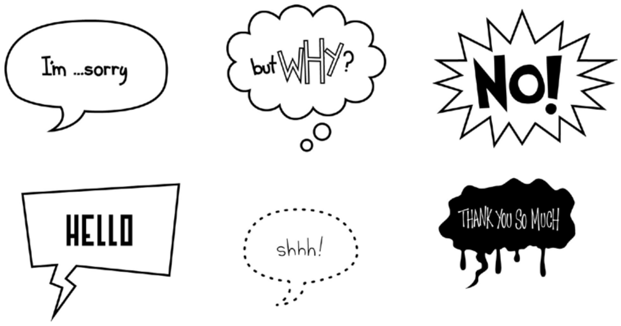
from *Keys to Drawing With Imagination*, by Bert Dodson

People, creatures and objects 2

Using words

David Mazzucchelli (2009) *Asterios Polyp.*

Using words



Self-portrait

Draw yourself thinking or talking about your health issue

invisible DrawingOut diseases

Sharing with the group

invisible DrawingOut diseases

Drawing thoughts and feelings

Visual metaphor – example 1

Frederik Peeters (2008) *Blue Pills*

Visual metaphor – example 2

Marjane Satrapi (2006) *Persepolis*

Visual metaphor

uses something visible (e.g. a monster, place, or situation)

to show something invisible (e.g. a thought or feeling)

What if...

If your health issue was an object, creature or animal, or weather, what would it be?

Sharing with the group

What if

How would you draw your relationship with healthcare staff?

Create a final piece

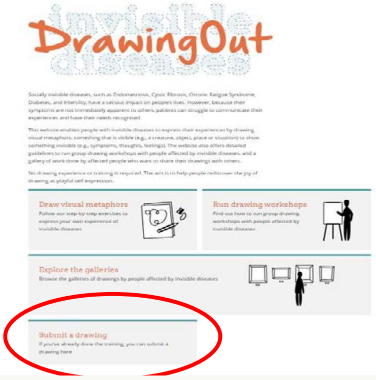
- Do a final drawing to express whatever you like about your disease experience.
- You may also want to experiment with collage?
- Perhaps you would like to focus on a positive aspect of your disease experience
  - Has your disease helped you discover new things about yourself/other people?
  - Has it made you stronger, or helped you grow as a person?
  - How do you imagine a happy future life? It is completely up to you to decide what you want to draw about.

Decompressing and wrap up

Share your work with others

Website:
www.drawingout.uk

Press this button



Socially invisible diseases, such as Endometriosis, Cystic Fibrosis, Chronic Fatigue Syndrome, Diabetes, and Infertility, have a serious impact on people's lives. However, because their symptoms are not immediately apparent to others, patients can struggle to communicate their experiences and have their needs recognised.

This website enables people with invisible diseases to express their experiences by drawing visual metaphors: something that is visible (e.g., a creature, object, place or situation) to show something invisible (e.g., symptoms, thoughts, feelings). The website also offers detailed guidelines to run group drawing workshops with people affected by invisible diseases, and a gallery of work done by affected people who want to share their drawings with others.

No drawing experience or training is required. The aim is to help people rediscover the joy of drawing as playful self-expression.

Draw visual metaphors
Follow our step-by-step exercises to express your own experience of invisible diseases

Run drawing workshops
Find out how to run group drawing workshops with people affected by invisible diseases

Explore the galleries
Browse the galleries of drawings by people affected by invisible diseases

Submit a drawing
If you've already done the training, you can submit a drawing here

Thanks for your participation!

FTWW

fтww.org.uk

FTWW
DrawingOut
Cardiff University
Prifysgol Caerdydd
Women's Health Research Wales
Ymchwil Iechyd Menywod Cymru
ROSA
THE UK FUND FOR WOMEN AND GIRLS
CRONFA GYMUNEDOL
COMMUNITY FUND