

# Endometriosis:

Lived Experience  
Insight Report 2023



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# Foreword by the Minister for Public Health and Women's Health



I welcome this Endometriosis Lived Experience Insight Report which provides valuable insight into the challenges faced by people living with endometriosis health.

I am pleased that one of the priority actions within the Women's Health Plan is to ensure that everyone with endometriosis receives the best possible care and treatment.

I am aware of the impact that endometriosis can have on a person's life and recognise that more needs to be done to support those with the condition.

That is why this report is so crucial to ensure the Scottish Government continues to create policy that meets the needs of those with endometriosis and those supporting them.

What we have heard from these experiences has shown that throughout Scotland there are examples of exemplary work that really do make a significant positive impact on the wellbeing of the people we care for.

It also highlights that there are opportunities to enhance practices to ensure that people are receiving the right information at the right time and that provides them with consistent and appropriate options suited to their needs.

While some of the findings in this report are challenging, the Scottish Government remains committed to progressing the actions in the Women's Health Plan and delivering services which meet the needs of all of those with endometriosis.

We will continue to engage with those with lived experience as we use the findings from this report to drive forward improvements.

A handwritten signature in black ink that reads "Jenni Minto". The signature is written in a cursive style with a large, sweeping initial 'J'.

**Jenni Minto MSP**  
Minister for Public Health and Women's Health

# What Is Endometriosis And Why Is This Project Necessary?



**1 in 10**



## What is endometriosis?

Endometriosis is a condition where tissue similar to the lining of the womb is found elsewhere in the body, and can be long-term. It's very common, affecting around **1 in 10** women and those assigned female at birth.<sup>1,2</sup> For some people, it can have a significant impact on their physical health, [emotional wellbeing](#), and daily routine.

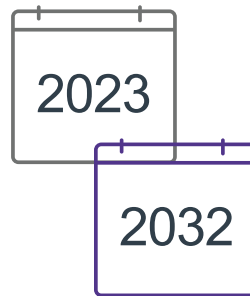
## Symptoms

The symptoms of endometriosis can vary from person to person but it is typically identified through significant pain which negatively impacts day-to-day life. The pain can range from lower abdomen to lower back or legs. Endometriosis can also be seen as symptoms such as bloating and having pain when going to the toilet.

## Diagnosis times

In a report from the All-Party Parliamentary Group on endometriosis it was noted that in the UK it took on average 8.5 years to receive a diagnosis of endometriosis.

Research has also shown that endometriosis costs the UK £8.2 billion per year in NHS costs and lost income.<sup>3</sup>



On average it takes **8.5 years** to get a diagnosis of endometriosis in the UK.

# Background

## Scottish Government policy background

In 2021 the Scottish Government published the Women's Health Plan to improve women's health inequalities by raising awareness around women's health and improving access to health care for women across their life course.

Enhancing care and support for people with endometriosis is one of the early priorities set out in the plan. It includes actions to improve access to appropriate support, speedy diagnosis and best treatment for endometriosis.

Lived experience has long been incorporated into the design of health initiatives in Scotland. In 2020, Healthcare Improvement Scotland published findings about the use of Experience-Based Co-Design in health services across Scotland.<sup>4</sup> This approach had led to improvements in the experience of care across different service areas across Scotland.



### Lived experience

A term that refers to the things that someone has experienced first-hand rather than through representations from others. This can be helpful in research to gain insights into how services work for people and the impact they have on them.

To deliver on the actions in the Women's Health Plan a quality improvement approach is being applied. In order to identify the systems currently in place and understand how the healthcare pathways work for people with endometriosis, a number of lived experience interviews were held to develop this knowledge.



# Overview

## Women's Health Plan actions

The Women's Health Plan identifies that there are aims and actions which sit under the endometriosis priority outcome.

### Priority

**Improve access for women to appropriate support, speedy diagnosis and best treatment for endometriosis.**

### Aims

1. Average diagnosis time for endometriosis will be reduced.
2. All women will be able to access the right support and effective treatment for endometriosis.
3. When required, all women will have access to a specialist endometriosis centre.

### Actions

- Implement and raise awareness of current national guidelines on endometriosis and develop and implement further pathways for care where these don't currently exist—for example, endometriosis outside the pelvis.
- Commission endometriosis research to find the cause of the condition, leading to the development of better treatment and management options, and a cure.
- Strengthen collaborative working between regional specialist endometriosis centres, territorial and special NHS boards, and primary care providers, to drive improvement in patient pathways and achieve equitable access to care and treatment.

# Overview

## Sample and methodology

Twenty interviews were conducted in January 2023 with people with lived and living experience of endometriosis. We worked with endometriosis support group networks across Scotland to gain a geographical spread of the type of care being provided for endometriosis. The interviews were hosted on Microsoft Teams and we had both phone calls and video calls.

For the process of considering participants we identified that we should not discriminate between those who had surgical diagnosis and those with a working diagnosis (a diagnosis without surgery) as an important part of the diagnosis journey is in primary care level.

Out of the twenty interviews, one participant was being treated under a working diagnosis.

We also created a lived experience survey which we circulated to Scottish Government staff to build upon the sample size. We received three further accounts of having endometriosis through this, including two further participants being treated under a working diagnosis.

The interviews and survey provided qualitative insight into people's experiences of endometriosis – their treatment, care and support.

Throughout this we worked with a Quality Improvement Advisor within the Scottish Government who interviewed the participants. We worked with our Improvement Advisor to design a set of key themes and questions which we planned to cover throughout the conversations.

We recognise that there are limitations within the study. The study predominantly focussed on those who were members of a lived experience group, which may have limited the types of experiences. In particular, hearing from those experiences where there hasn't been support from a support group.

Whilst there were a wide range of geographies represented by participants, we acknowledge there was a more limited range of socioeconomic groups and minority ethnic group participants. As we did not recruit to a sample frame or quota, but instead included all people who self-selected to participate, we were not able to specify socioeconomic group or ethnicity. For future we will explore other routes to recruiting from these groups to increase diversity of participants.



# Overview

## What did we want to find out?



### Endometriosis pathways and service delivery

It was important for us to understand how people with endometriosis were accessing services and what those services and treatments were. We wanted to develop a picture of the services currently being offered and how this compares to current NICE Guidelines and the new Endometriosis Referral Care Pathway for NHS Scotland. We also wanted to identify any key barriers to treatment or support which those with the condition felt they required.



### Living with endometriosis

We wanted to better understand the experiences of people living with or expected to have endometriosis; in particular, how the condition affected a person's quality of life and wellbeing.

A key aspect of this was to understand what kind of support resources people found helpful to manage their condition and to identify if people were using any self-management tools or techniques that had benefitted them.



### Listening to ideas

Listening, learning and understanding from those with endometriosis is vital to inform policy change. Through the conversations we felt it would be crucial to understand what people with lived experience felt would make a positive change in the diagnosis and management process. It was also important for us to get a sense of what their priorities were when speaking about support and treatment.



# Overview

## Insights summary

Throughout the interviews clear themes emerged from the conversations. In particular, the feeling of being **dismissed, unheard and not believed** when speaking to healthcare professionals throughout primary care, secondary and in A&E.

**“I never got anyone to take me seriously. Doctors told me painful periods were normal.”**

When people expressed positive communications with healthcare professionals this made a significant impact on mental health and wellbeing. It also helped rebuild trust with healthcare staff and develop more confidence in the advice being provided.

**“First time in years somebody actually listened to me.”**

During the interviews, participants expressed the **importance of peer support** through endometriosis support groups across Scotland. These groups aim to improve the lives of people affected by endometriosis in Scotland. They do this by offering advice, comfort and relevant resources, research and events for those with the condition or seeking more information about symptoms.

**“The endometriosis support group page got me through this; I don’t think I could’ve done it without them.”**



# Key Themes

## Symptoms

This section focusses on the types of symptoms mentioned and how they presented in the people we spoke with.

Endometriosis can present in a variety of ways which can often delay a diagnosis.

Throughout the conversations the symptoms reported were consistent with the description of endometriosis as a condition in which symptoms vary from person to person.

It was clear that endometriosis-associated pain did not always follow a specific pattern, resulting in “flare ups”, which for many were outwith their period.

We know that suffering with chronic pain can be associated with poorer mental health.<sup>5</sup> People with chronic pain are also more likely to report lower life satisfaction and poorer quality of life compared to those without chronic pain.<sup>6,7</sup>

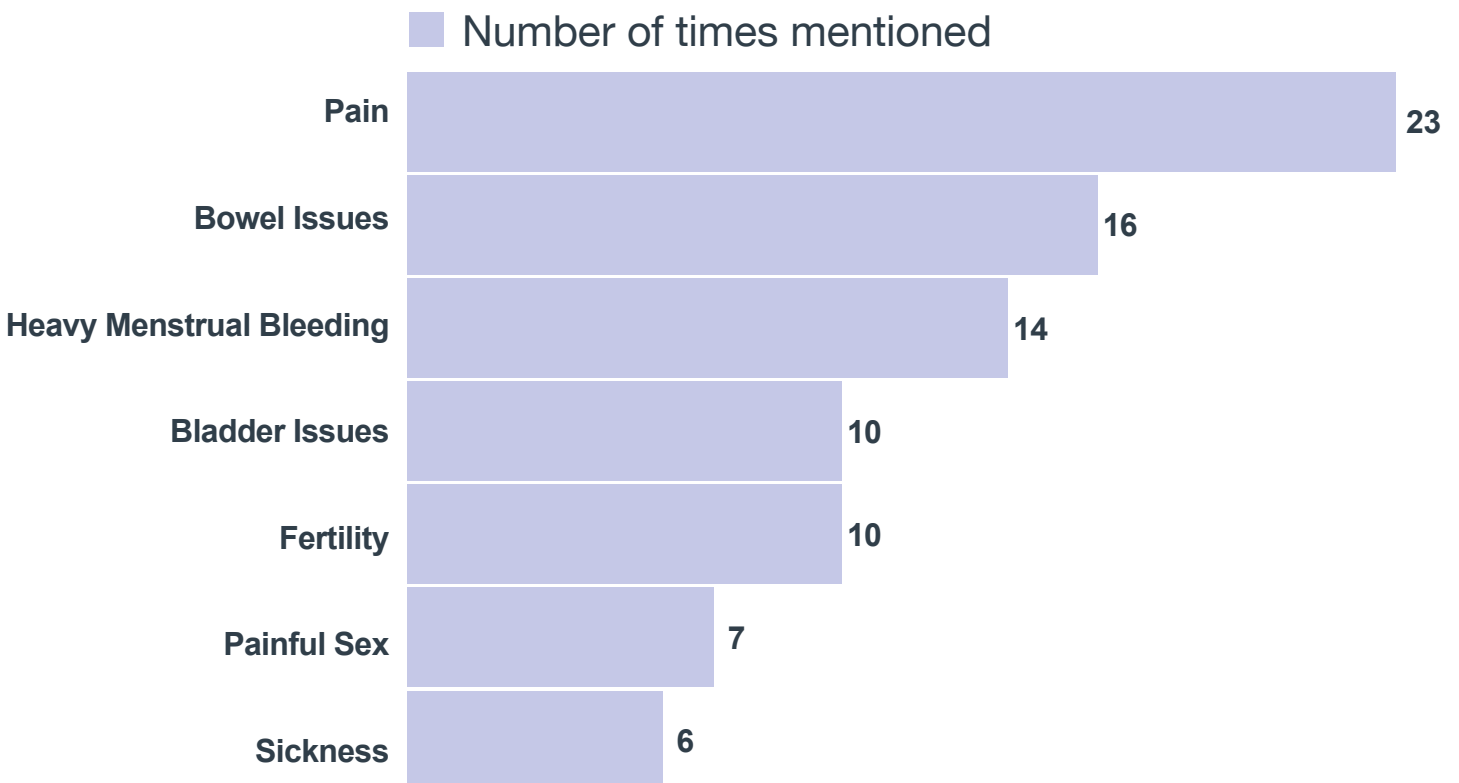


### Lived experience

Endometriosis is typically associated with symptoms such as chronic pelvic pain, pain with sex, pain opening bowels or urinating and, sometimes, difficulty getting pregnant.

One of the symptoms not commonly spoken about is the fatigue associated with endometriosis. There are no current treatment pathways within the NICE guidelines on endometriosis to support management of fatigue.

## Symptoms



## Key Themes

### Challenges with diagnosis and symptom dismissal

This section will focus on the information and types of diagnosis provided by healthcare professionals when the people we spoke with presented with symptoms of endometriosis.

The questions used to capture this information allowed us to explore with the participants what conditions are considered alongside endometriosis and how often those conditions are treated first before any investigations into endometriosis.

**“It felt like when the GP had their mind set on a diagnosis, like gastric issues, there was no way of convincing them otherwise. More openness to consider other things would have been a better alternative.”**

We found that many of the people we spoke to mentioned that a healthcare professional had suggested that heavy and/or painful periods were a normal part of life.

The same number of people were prescribed a form of contraceptive pill to treat and manage the symptoms, however, there wasn't a conversation or investigation into the cause of the symptoms.

We spoke with 16 people who mentioned they had bowel issues associated with their endometriosis and out of the 16 there were 9 people who were treated for Irritable Bowel Syndrome (IBS) before endometriosis was considered.

**“I was told from a young age that I had IBS; I was told it was only IBS.”**

# Key Themes

## Case study – diagnosis

**One participant was diagnosed with stage four endometriosis and a frozen pelvis after years of being treated for IBS. They said their main reason for speaking with us was because they want to make sure people have more knowledge of the symptoms of endometriosis, be more aware of their bodies and be able to ask for support and help when needed.**

“From a teenager I had really, really heavy periods where I would bleed for 10 days. I was put on the contraceptive pill at 15 to reduce the bleeding. That was quite successful: I then would only bleed for 5 days but still quite heavy. They said it could be down to genetics and to ask my family if there was a history of heavy periods.

“In my early twenties I then had severe bloating just before my period came. The doctor blamed it on me being a vegetarian, told me I was anaemic, that I had low blood count and that I obviously had heavy periods and IBS. I was told that lack of fibre was causing me to have bowel problems.

“I took the word of the GP.

“I was then treated for IBS and given painkillers from a young age to take the week before my period and during my period. I just had to live with IBS from a very young age.

“In 2018 I went back to the doctor because my IBS had got worse. I had bad bloating all the time and getting bad heartburn.

“They checked me for Helicobacter virus but I was told it was probably what I was eating and to keep taking Movicol sachets that I had for IBS.

“At that point I was also getting really bad sickness, diarrhoea and lower back pain to the point I was taking a hot water bottle to work.

“I am a lecturer in a college and I would have to take time out of class to sit down and put the hot water bottle on me.

“I went back to the doctor and told them I couldn't go on like this, I have a full time job, I have a busy life and there is definitely something not right.

“The doctor then sent me for an ultrasound scan and they found two ovarian cysts and that I would need an operation to remove them. There was no mention of endometriosis it was just cysts at this point.

“I was taken into hospital quite quickly, within six months, and I had keyhole surgery. They found that I had a frozen pelvis and stage four endometriosis. I had no clue prior to this.”



# Key Themes

## Understanding the wellbeing impact of accessing care

We wanted to focus on our participants' experiences interacting with the healthcare system, and the impact this had, throughout all stages of diagnosis and management.

Understanding how people felt at each stage provided us with an opportunity to identify patient needs throughout their journey and help support a patient-centred approach to care for endometriosis.

In speaking with people about their experiences of healthcare we heard many journeys, with both positive and negative impacts on how people felt they could interact with health care professionals.

Throughout conversations we heard some consistent ways of phrasing the negative emotions people felt when speaking with their healthcare practitioners. In particular, a significant proportion of the people spoke about feeling like they had been gaslit by a health care practitioner during a period of the diagnosis journey.



Realistic Medicine is for people using healthcare services and their families to feel empowered to discuss their treatment fully with healthcare professionals. Everyone should feel able to ask their healthcare professional why they have suggested a test, treatment or procedure, and all decisions about a person's care should be made jointly between the individual and their healthcare team.



**“I was told by my GP I had health anxiety and that it was all in my head.”**



## Key Themes

### Understanding the wellbeing impact of accessing care

We also heard a number of positive interactions with Healthcare Professionals, with several people mentioning that their GP provided support, listened and offered options for treatment or referral.

There were also examples of good practice from consultant gynaecologists in hospital settings in particular, providing clear information and next steps in their care pathway.

**“First time in years that somebody actually listened to me.”**

Many of the examples participants classed as a good experience had a focus on Healthcare Professionals offering a clear treatment pathway, using active listening and making sure there was time to ask questions.

We found that when people experienced positive communication after having any negative experiences with Healthcare Professionals it allowed them to rebuild trust and feel more positively about their future and their treatment pathway.

**“They were fantastic, I felt validated, like I wasn’t just imagining things.”**

In particular, we heard some excellent feedback from participants around the clinicians working in the endometriosis specialist centres across Scotland. There was clear positivity around the role of the endometriosis nurse specialist and the support and reassurance this provided to those with complex endometriosis.

**“One of the few that has actually treated me like a human being, in a long, long time.”**

# Key Themes

## Lifestyle impact of endometriosis

Endometriosis has a significant impact on physical health but it can also affect a person's lifestyle and wellbeing.

We learned from participants that endometriosis is often spoken about as an "invisible" illness which can lead to a lack of understanding from people around those with the condition.

We heard from participants that endometriosis impacted their life in a multitude of ways, with some having serious implications on their career path and opportunities and their social lives.

These areas impact on a person's overall quality of life which adds to the negative impact on mental health.

**"I'm more isolated than I've ever been before."**

Several people spoke to us about the impact endometriosis has had on their career. Some had to drop out of university due to the condition and some had missed out on career progression.

We also spoke with two people who due to endometriosis decided to change their career paths and have retrained to become Healthcare professionals within Obstetrics and Gynaecology as they felt they could make a difference and make sure people feel listened to.

**"Maybe I should act like I'm ill so people believe me."**

Many people spoke to us about how endometriosis made them feel like they were unable to go out and take part in activities or even do simple day-to-day tasks.

We also heard that some had to give up their hobbies due to pain and fatigue.



# Key Themes

## Case study – a journey to feeling heard

**One participant highlighted the difficulties they had communicating with their GP and feeling unsupported with their symptoms. It was when they moved to a new GP that they felt heard and didn't feel dismissed with the problems they were raising. They said their main reason for speaking with us was to raise awareness of the condition and how it impacts on people's lives.**

"I started my period at 11 which was very heavy and painful. Over the years I was on various different painkillers and when I was 15 I was put on the contraceptive pill as nothing else was helping.

"The pill reduced bleeding and pain but masked everything for 10 years. The severe pain was my most prominent symptom as well as nausea and vomiting. Every day of summer 2018 I was vomiting. This made me go back to GP and get tests done.

"I also decided to get a private allergen test which showed dairy intolerance and I stopped vomiting every day but it didn't stop the pain.

"In my teens, I didn't just have pelvic pain but leg pain but I was told by GPs that this was a normal part of being a woman.

"I was fatigued and thought I had depression as getting out of bed in the morning was difficult. I had Cognitive Behavioural Therapy as a result but I now believe it could have been a symptom of my endometriosis.

"After being dismissed I carried out my own research. I questioned the GP time and time again if it could be endometriosis but was told that it was unlikely and I was consistently dismissed. After the dairy diagnosis things did get better but I then had COVID which triggered everything again.

"At this point there was a new doctor at the surgery and I felt listened to and heard for first time. Thanks to him I was able to get on my path to diagnosis and I was referred to gynaecology."





## Key Themes

### Impact on behaviour from living with endometriosis

When we spoke to participants about their journey and the impact endometriosis has on their life we noted how it had completely changed their behaviours, views and life goals.

The endometriosis management and treatment journey had in some cases altered aspects of their personalities to allow people to ensure they were getting the best treatment for their condition.

**“It’s changed who I am as a person.”**

In particular we heard from some participants about the importance of learning how to self-advocate and be clear when they felt options were not appropriate.

In addition, some participants spoke about developing research skills and being able to present findings to Healthcare Professionals on what treatments they would like to use in managing their endometriosis.

We recognise that being well informed about your condition can help people to express and describe their symptoms more easily but it is important that information and support is also passed to patients at the appropriate time throughout any diagnosis or treatment process.

We heard how some participants had learned to self-manage their condition gaining insight and advice from members of support groups into potential self-management options.

**“I don’t have any trust in the medical profession. I do my own research; I don’t trust you.”**

Support groups were a central part of how people shared experiences, tools and knowledge on endometriosis management. The groups importantly provided a safe and inclusive space which helped support emotional wellbeing when struggling with aspects of the condition.

We also heard from a small number of participants who worked within the NHS who have used their experiences to learn from them to provide better care for their own patients.



# Key Themes

## Financial impact and resources

Throughout our conversations we noted that participants were seeking other management options to better understand their condition and find different ways which would support their treatment pathways.

This included using management tools such as TENS machines, hot water bottles or following different diets to see if it impacted on symptoms.

When speaking about these resources we heard about the negative financial impact of seeking alternative options for management had and how alternatives were sought due to feeling dismissed by their HealthCare Professionals.

Speaking about the financial impact also led to conversations about seeking private healthcare they felt they didn't or wouldn't receive from NHS Scotland, ranging from mental health support to surgery. Overall a total of **9 out of 23 women mentioned that they had sought some form of private treatment.**

**“It’s financially had a massive impact on us. Its eaten away at our savings, being off and not at work.”**

Another important resource and area where those with the condition go to seek advice and support is from the endometriosis support groups across Scotland.

The groups provide a signposting service to further resources and support and also provide a non-judgemental space to gain advice.

**“Support group is fantastic ... I don’t think I could’ve done it without them.”**

There were also people throughout the conversations who had been able to see other specialists in areas such as urology, gastroenterology or pain management. This, however, was uncommon, which suggested that there were inconsistencies in treatment plans for those with the condition.

Where these referrals positively impacted on patients it provided insight into the success of how a more multi-disciplinary approach to endometriosis from the outset can be a more supportive treatment pathway.

# Key Themes

## Case studies – self-management and career impact

**One of the participants spoke about how the condition impacts on how they manage their work life to allow for time to recover from days which may be more strenuous.**

“It’s only the last year that I have set boundaries for myself. I am going to paint a mural for someone so I know I have to work from home the following day to make up for that. I can plan around myself.

“I have a studio about 30 minutes’ walk away. I used to walk it a lot but I can’t do that anymore. I have managed to find a bus route to take me there even though I have taken a hit financially, it means I can get there. If I walked to the studio I would have less energy to do stuff when I’m there.

“I also do a lot of markets and I need to make sure the next day I am off. When I am doing a market I need to make sure they are accommodating, make sure they have chairs; a kettle nearby so I can do a hot water bottle for my joints. I have to pace myself.

“The good thing about markets is that you meet other chronic ill and disabled people who have tips to help me.

“This is the career I always wanted but I know for a lot of people it’s not the case so I am very lucky.”

**Another participant spoke about how learning about and understanding their condition led them to a new career path.**

“If it wasn’t for my condition I probably wouldn’t be on route to becoming an embryologist. I love the idea of being able to help people. I am a qualified chef to trade but I had to give it up because of the pain. I then went back to university to retrain as a nutritionist and I ended up transferring into human biology.

“It wasn’t until my BSc that I wanted to really learn about endometriosis – I didn’t get diagnosed until after my degree. It had been a buzzword in my records. In my BSc I decided I needed to learn about endometriosis and how to approach doctors about it and understand what they’re trying to tell me. It was at the same time I found something I was really passionate about and I turned it into my career.”



# Change Ideas

Through the conversations we heard a number of different areas where people with endometriosis would like to see improvements.

We collated the data and drew together a set of changes which those with lived experience would like to see.



## Accessing Care and Treatment

- Increased use of technology such as Near Me, where appropriate
- More non-medicinal management options offered as treatment
- Ensure there are after surgery care plans that are patient-centred
- Improved education for Health Care Professionals



Change Ideas from those with lived experience



## Raising Awareness and Improving Information

- Improved public awareness of the condition
- More information and signposting in Primary Care
- Improvements in medical education
- Improvements to post-surgery consultations



## Research

More investment into endometriosis research

# Progress So Far

The Scottish Government is committed to improving endometriosis care and has been working to deliver on the actions in the Women's Health Plan.

## Awareness

We recognise that the public needed to understand the condition better and be able to recognise the symptoms of this common condition.

To support this we have:

- launched an updated and informative endometriosis page on NHS Inform.
- worked with Parent Club, the ALLIANCE and Young Scot to share information on a wider scale and start discussions.
- worked with Relationships, Sexual Health and Parenthood to provide further ways for teachers to speak with their pupils about the condition.

## Research

It is known that women's health research is underfunded and it is important to develop research into women's health conditions to ensure the most effective treatment options and support are being provided.

To support this we have:

- jointly funded a £250,000 endometriosis research project with charity Wellbeing of Women which aims to find a non-hormonal treatment option for endometriosis-associated pain.
- funded the ENDOCAN project, which aims to investigate whether a cannabinoid will reduce endometriosis-associated pain.

## Pathways and Building Relationships

We know that to support improvements for endometriosis care it is important that there are clear treatment pathways to follow and we are continuously hearing from those with lived experience and clinicians.

To support this we have:

- supported the Modernising Patient Pathways Programme to raise awareness of the Endometriosis Referral Care Pathway for NHS Scotland.
- continued to work with our Endometriosis Lived Experience Forum to understand where there are things going well and where things could be improved.
- developed an Endometriosis Advisory Group made up of clinicians and service managers to understand barriers to service delivery, share best practice and advice on policy development.

## Next Steps

Firstly, we want to thank all of those involved in the process for sharing your experiences with us and for providing such honest and thoughtful accounts.

Conducting this research and speaking to the participants has provided an insight into how patients experience services that currently operate, where things are working well and where improvements could be made.

The information gathered will be used to evidence the need for change and continue to build on conversations with people across the healthcare system. We hope to use the data to develop ideas and highlight best practice to ensure that patients have access to the best, most appropriate and consistent endometriosis care across Scotland.

This work has helped to identify key priorities that should be considered for the following year. The key themes found in the report will inform what types of projects are required and the groups that we need to engage with those projects.

The report will also help to inform our response to the NICE Endometriosis Guideline review consultation and any further endometriosis pathway reviews.

We will also engage with our Endometriosis Advisory Group (EAG) on the report to help develop ideas for change to address some of the key improvement ideas highlighted throughout the lived experience conversations.



# Resources

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2. All-Party Parliamentary Group (APPG) (2020), [Endometriosis in the UK: time for change, APPG on Endometriosis Inquiry Report 2020](#)
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# Endnotes

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