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Pelvic Partnership

Organisation response to the NHS 10 Year Health Plan

1. What does your organisation want to see included in the 10 Year Health Plan and why?

What is pelvic girdle pain?

Pregnancy-related pelvic girdle pain is a pelvic joint problem affecting up to half of all women and birthing people during and/or after pregnancy[1]. Pelvic girdle pain can be severe causing physical immobility and leading to associated mental health impacts during and/or after pregnancy. Left untreated, it can continue for months or even years postnatally, with research noting 10% experience pain more than 3 months postnatally[2]. This supports findings from our own 2024 survey of women with pelvic girdle pain, of which 40.5% had been in pain for more than 12 months[3].

The impacts of pelvic girdle pain are considerable. With limited support from healthcare professionals, women are often left to manage this pain themselves, affecting their ability to walk, sit or stand for long periods, get dressed, climb the stairs, work and care for their families. According to our 2024 survey, less than 1% of respondents could walk normally without pain, while 27.1% needed to use mobility aids to get around and 3.5% were bedbound[4].

"In my final trimester I could barely walk or go upstairs, was on crutches, couldn't drive, struggled to get in and out of the car as a passenger and I couldn't dress myself properly or put on shoes due to the pain. I had to work from home entirely." Sophie, service user

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[1] Ceprnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)
[2] Gutke A, Lundberg M, Östgaard HC, Öberg B. Impact of postpartum lumbopelvic pain on disability, pain intensity, health-related quality of life, activity level, kinesiophobia, and depressive symptoms. Eur Spine J. 2011;20(3):440-448. doi:10.1007/s00586-010-1487-6
[3] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/
[4] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/

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Challenges and their impact

1. Knowledge of practitioners, lack of support and medical gaslighting

On our support services, we hear from too many women who feel ignored, dismissed and disbelieved by their healthcare practitioners when they report symptoms of pain during and/or after pregnancy. In our 2024 survey, only 18.4% of respondents felt supported by their GP or midwife[5].

We consider this is due to a lack of appropriate knowledge and understanding of pregnancy-related pelvic girdle pain and its impact on a woman's physical and mental health during and/or after pregnancy, as reinforced by feedback from our service users:

"It made me feel so much worse that the health professionals didn't' seem to have any true understanding of the condition and how awful it was." – Service user

"One of the most frustrating aspects was that I was experiencing PGP prior to birth but it was not picked up by my midwife/GP. Despite saying the pain I was in and the fact I was struggling to walk, nothing was done about it." - Service user

"I feel it would be really helpful if midwives spoke to you in your booking appointment about PGP symptoms, preventative/reductive actions (e.g. how to get in and out of bed, not opening legs wide), to take the pain seriously to avoid deterioration, and when and where to seek help. I really don't think my PGP would have got as bad as it did if I hadn't have thought it was just general pregnancy pain and I should push through it." – Service user

As suggested above, the booking appointment with the midwife is a clear intervention point where pelvic girdle pain can be raised, to share key strategies to manage any symptoms and refer to ongoing treatment as required, in partnership with pelvic health midwives. Early intervention is crucial with pregnancy-related pelvic girdle pain to ensure appropriate management and effective treatment during pregnancy, to reduce the physical and mental health impacts during pregnancy and expedite postnatal recovery for those for whom symptoms can continue postnatally – which we will explore more in Q4.

If ongoing gaps in knowledge and understanding continue, this will leave more and more women in pain during and/or after pregnancy, with ongoing impacts on women's willingness to report other healthcare symptoms and therefore impact on their health issues. We discuss the impact of this medical gaslighting in our award winning essay for the Heather Trickey Prize.

2. Insufficient treatment options on the NHS

[5] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/

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Pregnancy-related pelvic girdle pain can be safely and effectively treated with hands-on treatment from a physiotherapist, osteopath or chiropractor using a range of hands-on techniques, including manual therapy, to treat the cause of their pain. When women reach out to us in pain, we encourage them to go to the GP or midwife, describe their pain and how it is affecting them and ask for a referral for NHS physiotherapy to treat the cause of their pain (as well as pain relief and mental health support if needed)[6].

While many NHS physiotherapists have the skills and experience to treat pregnancy-related pelvic girdle pain during and after pregnancy using hands-on manipulation and mobilisation of the pelvic joints, we hear from too many women that they are unable to get the treatment they need on the NHS due to a range of factors:

i. Local policy enables women to only access group classes or telephone or video physiotherapy appointments, which offer generic advice and exercises only.

Complex conditions like pelvic girdle pain require individualised hands-on assessment and treatment. A hands-off, generic approach would not treat the cause of their pelvic girdle pain and risks dismissing their pain and/or aggravating it further. According to our 2024 survey, 81.9% of respondents were not offered hands-on treatment on the NHS[7].

ii. Long waiting lists for treatment

For women who have been able to get an appointment, some have experienced such long waiting lists that they have either had to seek private treatment, have accessed more acute healthcare services due to the pain. For others they have only been offered appointments after their due date. They have reported to us that waiting lists can be so long that their symptoms would have worsened so they may have sought alternatives or accessed more acute healthcare services, or it will have been after their due date.

iii. Many Trusts also have policies in place that separate the treatment of pelvic girdle pain from incontinence, overactive pelvic floors and other pelvic floor dysfunctions.

In practice, treatment for pelvic floor dysfunction is normally offered by women's health physiotherapists, occasionally through the new pelvic health services, focusing on early intervention and prevention, while pelvic girdle pain is treated by the musculoskeletal (MSK) physiotherapists. In practice we find that MSK physiotherapists have different referral and monitoring methods, less focus on early intervention and less engagement with the midwifery and antenatal teams. While they have the skills to treat pelvic girdle pain, a more joined-up

[6] See our free Pelvic Partnership toolkit to help you describe your PGP, available on our website: https://pelvicpartnership.org.uk/who-we-are/resources/
[7] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/

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and collaborative approach in treating pelvic girdle pain and pelvic floor problems would make clinical sense, given how many women may experience pelvic girdle pain and pelvic floor dysfunction concurrently.

iv. Inconsistent self-referral models across NHS England

Women have reported to us that they find it challenging to know how to access physiotherapy treatment due to leading to confusion about how to ask for a referral or self-refer for physiotherapy treatment and if women can self-refer or ask for a referral for other healthcare practitioners, such as osteopaths or chiropractors.

v. Policy failure pushing women to pay for private treatment

Due to limited access to treatment on the NHS, women are being forced to look elsewhere. In a cost of living crisis, it is becoming increasingly hard for some women who are pregnant or have young children to budget for this. As a result, too often it is only women who can afford to pay for private treatment who are able to become pain-free. In our survey, of those who hadn't had private treatment, 77.5% of respondents shared that this was because they couldn't afford the cost of private treatment[8].

"Training needed for NHS physios regarding manual therapy. Women should not have to pay for effective treatment which can only be provided by private sector!" – Healthcare practitioner

"I also strongly feel that appropriate treatment should be on the NHS. It's not reasonable that we should all have to seek help at a huge cost to us when any other condition would be treated properly via the NHS. The overwhelming feeling I have is being let down in my hour of need." – Service user

3. Perinatal mental health support doesn't acknowledge mental health impacts of pregnancy-related pelvic girdle pain

Women with pregnancy-related pelvic girdle pain have a higher reported risk of developing a perinatal mental health condition[9] and given the physical and emotional toll of living with severe pain, this is not surprising. This also correlates with feedback from our service users, who are feeling the impact of living with pain, feeling isolated and not getting the care, support and treatment they need. In our 2024 survey, 60.5% of respondents shared that they had experienced a problem with their mental health during or after pregnancy associated with their pelvic girdle pain[10].

[8] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/
[9] Gutke A, Josefsson A, Öberg B. Pelvic girdle pain and lumbar pain in relation to postpartum depressive symptoms. Spine. 2007;32(13): 1430-1436. doi:10.1097/BRS.0b013e318060a673
[10] Pelvic Partnership 2024 Survey, Available here: https://pelvicpartnership.org.uk/who-we-are/reports/

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" I struggled mentally with living with daily pain and not being able to live normally and do things with my toddler." – Service user

Our volunteer peer supporters spend much of their time addressing the initial mental health impacts of pelvic girdle pain, to give women the tools and confidence to get the treatment they need. Without acknowledging and treating the mental health impacts of pelvic girdle pain, it is hard for many women to make a full recovery.

Solutions to include in the 10 Year Health Plan

In summary, we consider the below policy solutions should be included in the 10 Year Health Plan.

1. Improved knowledge and understanding of pregnancy-related pelvic girdle pain among healthcare practitioners to combat medical gaslighting by offering ongoing training and skills development so signs and symptoms can be recognised early

2. Improved in-person treatment options for pregnancy-related pelvic girdle pain on the NHS, where women are able to be seen quicker for in-person and hands-on treatment with an experienced practitioner as soon as symptoms start (e.g. giving women access to physiotherapy like you get access to free prescriptions when pregnant)

3. Broadening of perinatal mental health support to acknowledge the mental health impacts of pregnancy-related pelvic girdle pain

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2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

What is pelvic girdle pain?

Pregnancy-related pelvic girdle pain is a pelvic joint problem affecting up to half of all women and birthing people during and/or after pregnancy[11]. Pelvic girdle pain can be severe causing physical immobility and leading to associated mental health impacts during and/or after pregnancy. Left untreated, it can continue for months or even years postnatally, with research noting 10% experience pain more than 3 months postnatally[12]. This supports findings from our own 2024 survey of women with pelvic girdle pain, of which 40.5% had been in pain for more than 12 months[13].

The impacts of pelvic girdle pain are considerable. With limited support from healthcare professionals, women are often left to manage this pain themselves, affecting their ability to walk, sit or stand for long periods, get dressed, climb the stairs, work and care for their families. According to our 2024 survey, less than 1% of respondents could walk normally without pain, while 27.1% needed to use mobility aids to get around and 3.5% were bedbound[14].

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Shift 1: Challenges and Enablers

1. Insufficient capacity in the community (primary healthcare appointments, physiotherapy appointments, limited access to specialist midwives)

[11] Ceprnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)
[12] Gutke A, Lundberg M, Östgaard HC, Öberg B. Impact of postpartum lumbopelvic pain on disability, pain intensity, health-related quality of life, activity level, kinesiophobia, and depressive symptoms. Eur Spine J. 2011;20(3):440-448. doi:10.1007/s00586-010-1487-6
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Women report to us that they experience challenges accessing healthcare appointments, with long waiting lists for physiotherapy, access to specialist midwives including pelvic health and mental health midwives and even GP appointments and mental health support. If more healthcare is to be effectively delivered in the community, it requires significant investment to build capacity in the short and medium term.

2. Lack of understanding and awareness of pelvic girdle pain among healthcare practitioners

On our support services, women have reported to us time and again that they are fobbed off, dismissed and ignored when reporting signs and symptoms of pregnancy-related pelvic girdle pain. We consider that this is due to a lack of understanding and awareness of the pelvic girdle pain, its impact on women's physical and mental health and the effective treatment and referral pathways within the NHS (e.g. women's health physiotherapists and MSK physiotherapists). However, it's also a sign of medical gaslighting, which we explain in more detail in award winning essay for the Heather Trickey Prize.

If conditions like pelvic girdle pain are treated effectively in the community, we first need to ensure that all healthcare practitioners understand the signs and symptoms of pelvic girdle pain, and have a willingness to support women to get the care, support and treatment they need. Without this base understanding and supportive approach among healthcare practitioners, we risk women disengaging from community healthcare during and after pregnancy, leading to worse outcomes for many conditions and greater use of more acute healthcare services such as A&E.

"I asked for a physiotherapy referral at my booking appointment and shared my history of pelvic girdle pain and said I was already experiencing some pain, I was told I wasn't in enough pain to be put on the waiting list." Jen, service user

Women have reported to us that in some parts of the UK the new pelvic health pilots are proving effective and pelvic health midwives are working to up-skill other midwives and ensure pelvic health issues and pelvic girdle pain are covered in appointments. This needs to be implemented consistently however, and monitored at different intervention points like perinatal mental health.

3. Lack of community awareness of pelvic girdle pain and other pregnancy-related conditions and what support is available in the community

If we want people to access community healthcare services, there needs to be a broad information and awareness raising campaign to accompany this shift, so that people know what community healthcare services are available, how they can engage and what signs and symptoms to look out for. Too often, women report to us that either they don't want to waste time given capacity issues within the NHS, they don't know how to engage with healthcare

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services (e.g. self-referral) or they aren't aware that their condition isn't normal (e.g. counteracting the myths that pain isn't a normal part of pregnancy and that pelvic girdle pain doesn't always disappear at birth).

Without addressing these challenges, there is a risk that people will continue to not engage effectively with community healthcare. As a result they risk only reaching out when symptoms become unbearable and will then engage with more acute healthcare services, such as A&E at greater cost to the NHS.

4. Community healthcare needs to be appropriate for service users

When moving care to the community, services need to be appropriate for all service users to promote greater engagement with healthcare services. Women with pelvic girdle pain have reported to us that they have experienced challenges accessing healthcare services for accessibility reasons, which in some cases has meant that they have not been able to attend the appointments:

"I remember being in agony accessing my physio sessions when on crutches. I wasn't entitled to a disabled bay, so had to park far away […] I was in agony before I got there." Abi – service user

"I couldn't take my daughter for her jabs as I couldn't carry her to GP or push her pram so I had to arrange for nurse to do a home visit, also any appointments with my midwife I had to ring ahead to tell them to knock and enter as getting up to answer the door was too painful. Also couldn't access breastfeeding support group and actually wasn't fed breakfast in hospital as that was self-service and stopped going to physio in the end as pain of doing it (parking, getting to appointments, waiting) to be told to do exercises wasn't worth it when weighing it all up." Jenni – service user

In summary, the Pelvic Partnership supports the shift from hospital to community care, if is not done in isolation but accompanied by the below policy changes:

- Investing in building capacity of community healthcare so that women can get an appointment with their midwife, physiotherapist, GP or access to mental health support as soon as they need it

- Offering greater education and training about pregnancy-related girdle pain to healthcare professionals to ensure that more women have their symptoms recognised sooner and they are taken seriously when reporting this and any other symptom
- Raising awareness about pregnancy-related pelvic girdle pain and what support is available for them in the community, e.g. recognising the early signs of pelvic girdle pain and self-referring to hands-on physiotherapy appointments early

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- Actions to ensure community healthcare is appropriate for service users, e.g. taking into account accessibility issues for women with pelvic girdle pain by offering bookable parking spaces closer to the healthcare centre or offering temporary blue badges

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3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

What is pelvic girdle pain?

Pregnancy-related pelvic girdle pain is a pelvic joint problem affecting up to half of all women and birthing people during and/or after pregnancy[15]. Pelvic girdle pain can be severe causing physical immobility and leading to associated mental health impacts during and/or after pregnancy. Left untreated, it can continue for months or even years postnatally, with research noting 10% experience pain more than 3 months postnatally[16]. This supports findings from our own 2024 survey of women with pelvic girdle pain, of which 40.5% had been in pain for more than 12 months[17].

The impacts of pelvic girdle pain are considerable. With limited support from healthcare professionals, women are often left to manage this pain themselves, affecting their ability to walk, sit or stand for long periods, get dressed, climb the stairs, work and care for their families. According to our 2024 survey, less than 1% of respondents could walk normally without pain, while 27.1% needed to use mobility aids to get around and 3.5% were bedbound[18].

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Shift 2: Challenges and Enablers

1. Risk of adopting a one-size-fits-all approach for all health conditions

Digital technology should only be an enabler of a solution, not the solution itself, and should only be used if it meets defined needs. In the case of pregnancy-related pelvic girdle pain,

[15] Ceprnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)
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women report to us that they are being referred for telephone and video physiotherapy appointments, rather than seeing a physiotherapist in-person for hands-on treatment, as part of a course of treatment if needed. Pelvic girdle pain can present differently for different women, and as a result they require individualised hands-on treatment rather than a generic approach. According to our 2024 survey, 81.9% of respondents were not offered hands-on treatment on the NHS[19].

This policy was implemented during COVID as a short term measure and we are really concerned that this policy remains in place to this day. This results in ineffective treatment because pelvic girdle pain cannot be effectively assessed for and treated without a hands-on approach.

Furthermore, women have shared with us that it is difficult to convey the nature and impact of their pain without seeing someone in person, especially if the healthcare practitioner is not open and willing to consider the broad physical and mental health impacts of the condition (given risk of medical gaslighting outlined in our response to Question 1). Use of technology in this way is not fit for purpose, and ensures that women with pelvic girdle pain are not given the treatment they need and are left to manage their worsening pain alone. Some women can afford to pay for private treatment, but given the cost of living crisis, this is often out of reach for many women. In our survey, of those who hadn't had private treatment, 77.5% of respondents shared that this was because they couldn't afford the cost of private treatment[20].

2. Use of technology in raising community awareness for less well-known conditions, such as pregnancy-related pelvic girdle pain

While we don't think technological solutions should be used in treating pregnancy-related pelvic girdle pain, there is a strong case for adopting digital technology as a means of educating and raising community awareness for less well-known conditions, such as pregnancy-related pelvic girdle pain. As outlined in our response to Question 2 and 4, we consider the shift to more community healthcare and early intervention needs to be accompanied by a comprehensive education campaign about different health conditions, what symptoms to be aware of and what healthcare services can be accessed in the community, so people know what support is available and when to access that support.
By utilising digital technology and online media, the NHS can deliver a cost-effective awareness raising campaign to support the implementation of the neighbourhood health service, ensuring people have the knowledge and skills to access community healthcare early, before conditions worsen and require more intensive healthcare interventions. Furthermore, the NHS could utilise digital solutions to support women when managing their conditions, e.g. symptom tracking and communicating with healthcare practitioners.

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4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

What is pelvic girdle pain?

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The impacts of pelvic girdle pain are considerable. With limited support from healthcare professionals, women are often left to manage this pain themselves, affecting their ability to walk, sit or stand for long periods, get dressed, climb the stairs, work and care for their families. According to our 2024 survey, less than 1% of respondents could walk normally without pain, while 27.1% needed to use mobility aids to get around and 3.5% were bedbound[24].

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Shift 3: Challenges and Enablers

We strongly support the shift to recognise and treat illnesses earlier, ensuring symptoms don't worsen, improving healthcare outcomes and reducing the cost to the NHS in the long term. As well as stressing the benefits of early intervention in treating pregnancy-related pelvic girdle pain to healthcare practitioners, we have consistently sought to raise awareness about

[21] Ceprnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)
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the early signs of pelvic girdle pain and giving women the tools and confidence to access treatment early.

In the case of pelvic girdle pain, understanding the condition, taking steps to manage it and accessing hands-on treatment early can make a big difference to physical symptoms during pregnancy, postnatal recovery and a woman's mental health during and after pregnancy.

"The sooner manual therapy is offered in a pregnancy, the better the outcome." – Service user

"Third pregnancy I had manual therapy privately from the start and it stopped me getting it badly and not at all postpartum." – Service user

With no access to early treatment, women's symptoms can worsen and they may require extra support through acute healthcare, e.g. A&E and greater interventions during birth, at significant cost to the NHS. Treating pelvic girdle pain early makes clinical sense for the woman, and financial sense for the NHS.

To encourage early recognition of a condition and early access to treatment, there are several supply-side issues to address:

1. Insufficient understanding of different healthcare conditions and what signs and symptoms to look out for and when to ask for help, both in the community and among healthcare practitioners. Technology could offer a mechanism to address this lack of understanding (as outlined in our response to Question 3).

2. Insufficient supply of and access to appointments and treatment options, so that women with pelvic girdle pain can access a physiotherapy appointment, after recognising the signs. This will need significant investment to ensure women can access appointments as soon as their symptoms start, rather than making women battle against long waiting lists and virtual appointments which risk aggravating their condition and ensure they will then need further medical interventions at a greater cost.

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5. **Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:**
    a. **Quick to do, that is in the next year or so**
    b. **In the middle, that is in the next 2-5 years**
    c. **Long term change, that will take more than 5 years**

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"In my final trimester I could barely walk or go upstairs, was on crutches, couldn't drive, struggled to get in and out of the car as a passenger and I couldn't dress myself properly or put on shoes due to the pain. I had to work from home entirely." Sophie, service user

The Pelvic Partnership is a small charity offering support and information to women experiencing pregnancy-related pelvic girdle pain, giving them the tools and confidence to access treatment. Led by women with lived experience of pregnancy-related pelvic girdle pain, we offer a range of peer support services, on which we hear from hundreds of women across the UK each year, who are unable to access the care, support and treatment they need.

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Please see our responses to Q1-4 for more detailed exploration of the issues facing women with pregnancy-related pelvic girdle pain.

Short term policy recommendations

1. Fast-track in-person appointments for women with pelvic girdle pain currently waiting for physiotherapy appointments
2. Reduce waiting lists for women with pelvic girdle pain currently waiting for physiotherapy appointments
3. Ensure midwives check for signs of pelvic girdle pain at the booking appointment
4. Ensure pelvic health services support women with pelvic girdle pain alongside pelvic floor dysfunction, with pelvic health midwives empowered to work with MSK physiotherapists to ensure rapid treatment for pelvic girdle pain and train other midwives in the signs and symptoms of pelvic girdle pain
5. Broaden perinatal mental health checks to acknowledge mental health impacts of pelvic girdle pain and other pain conditions

Medium term policy recommendations

6. Ensure policies recognise the physical and mental health impacts of pelvic girdle pain, so women are given the care support and treatment they need
7. Offer a course of in-person, hands-on treatment to all women with pregnancy-related pelvic girdle pain during and/or after pregnancy, as long as needed
8. Adopt digital solutions to raise awareness about lesser known conditions such as pelvic girdle pain, tracking symptoms and accessing treatment
9. Offer targeted training to midwives on pregnancy-related pelvic girdle pain, its symptoms and treatment options
10. Improve accessibility for women with pelvic girdle pain, by offering bookable parking spaces at healthcare appointments or temporary blue badges

Long term policy recommendations

11. Ensure women with pelvic girdle pain are given the tools and confidence to access treatment easily as soon as symptoms start
12. Embed pelvic girdle pain into the education and training plans of midwives, GPs and physiotherapists working in the NHS with a focus on supporting women with difficult conditions to get the care, support and treatment they need