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Pelvic Partnership submission to ARMA Health Inequalities Inquiry Call for Evidence

The Pelvic Partnership is a small charity offering support and information to women and birthing people experiencing pregnancy-related pelvic girdle pain (PGP). Initially formed as a local support group for women with lived experience of PGP, we are now a national charity supporting thousands of women each year. We draw on our own experience and those of our supporters to give others the tools and confidence to get the care, support and treatment they need to become pain-free.

PGP is a pelvic joint problem affecting up to half of all women during and/or after pregnancy[1], causing pain, immobility and leading to associated mental health impacts. Fortunately, PGP can be safely and effectively treated with hands-on individualised treatment including manual therapy, such as physiotherapy, osteopathy and chiropractic care.

In this submission we will explore challenges around access to appropriate care, support and treatment for women experiencing PGP including those from different cultural and ethnic backgrounds on the NHS and privately. We consider challenges around access to appropriate care, support and treatment on the NHS mean that women can only consider private treatment options, which for some is impossible due to the significant financial implications, especially in the cost of living crisis.

Impact of PGP

Pregnancy-related PGP can be a severe and debilitating condition for women, starting during or following pregnancy and causing physical and mental health implications for women and their families.

PGP can affect different women in different ways. To better understand how PGP can affect women's lives, we surveyed our service users in 2022 and asked how PGP affected them physically: only 6% of respondents could work normally without pain, while the vast majority could walk with some pain, 12.8% had to use a mobility aid (crutches or a wheelchair) and 2% were bedbound due to their PGP[2]. As such, the impact of this condition on women's lives starts to become clear, impacting their capacity to carry on daily tasks, work and caring responsibilities.

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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] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

The Pelvic Partnership provides information and support for women with Pelvic Girdle Pain
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There is also a growing recognition of the impact of living with pain on our mental health and wellbeing and this shapes the support we offer to women with PGP. Indeed, 63% of respondents to our 2022 survey shared that they had experienced a mental health problem during or after pregnancy, with many noting that PGP was a causal factor[3]. In response, as a charity we offer peer support on social media and on our telephone helpline, listening to women's concerns, walking the path with them and signposting to further care, support and treatment.

Coupled with these health impacts, we hear from many women who have felt fobbed off or ignored when reporting their symptoms to healthcare practitioners and asking for treatment. This was confirmed in our latest survey, in which 82% of respondents shared that they did not feel supported or had mixed feelings about the support offered by their GP or midwife[4]. This medical gaslighting can lead to inconsistent access to appropriate treatment and support for women with PGP, leaving too many women with worsening symptoms that could have been avoided.

Access to treatment on the NHS

PGP can be safely and effectively treated with hands-on individualised treatment, including manual therapy. As a charity, we strongly encourage women experiencing pain in and around their hips, lower back and pelvis during and/or after pregnancy to see a manual therapist as soon as symptoms commence. As well as offering relief from pain and reducing the severity of their symptoms, manual therapy can treat the cause of their pain and quicken their postnatal recovery.

Before the pandemic, it was reported to us that there was inconsistent access to face to face treatment from NHS physiotherapy across the UK: with some women able to access appropriate treatment for their pain, while others were only given generic exercises and advice which would not treat the cause of their pain. We worked with women with PGP to give them the tools and confidence to ask for face to face individualised treatment, including manual therapy. While for some this approach was successful, too many women were unable to get the care, support and treatment they needed.

From March 2020, NHS and private face to face appointments were put on hold at the start of the pandemic. We experienced a significant uplift in calls for support from our service users at this time, as women were left without care, support and importantly treatment options for

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[3] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

[4] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

their pain. Since most in-person services have opened up again, it has been reported to us that many NHS physiotherapy services are no longer offering face to face treatment options, preferring instead to retain telephone and video physiotherapy for women with PGP, rather than hands-on manual therapy to treat the cause of the pain. This is supported by our 2022 survey of women with recent experience of PGP, in which only 19.2% of respondents had been offered hands-on manual therapy on the NHS[5]. We have also heard from many women with PGP that in some Trusts there are significant waiting lists for appointments, with the result that they are waiting weeks or even months for an appointment. Even then, it has been reported to us that some women only get a telephone or video appointment with generic exercises and advice offered, rather than individualised and hands-on treatment.

Access to private treatment

We hear from many women each week who are unable to access appropriate care, support and treatment on the NHS. As well as encouraging them to go back and get a second opinion, we ask if they have the option of paying for private treatment from a private physiotherapist, osteopath or chiropractor and signpost to our list of recommended practitioners.

We have over 200 private physiotherapists, osteopaths or chiropractors on our website, all of whom have been recommended by at least two women with PGP. We know that for those who can afford to pay for private treatment, this can be an effective mechanism for treating the cause of their pain during and/or after pregnancy: in our 2022 survey, 59.3% of respondents had had manual therapy with a private physiotherapist, osteopath or chiropractor and of those, over fifty per cent were either very or fairly confident that this treatment had improved their condition[6].

As noted above, the cost of private manual therapy can be prohibitive for many women with PGP, especially when they are expecting a new addition to their family. At between £50-80 per session, treatment can come at a significant cost for many families and while we are aware of one grant organisation who can help[7], we hear from many women for whom they just can’t consider private treatment and so are left in pain.

In response to anecdotal evidence from our service users, we also explored challenges around affordability in our 2022 survey and found that of those who hadn’t had private manual therapy, 76% cited affordability issues as the reason. The high proportion of women not having private treatment due to cost also aligns with the feedback we have directly from

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[5] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

[6] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

[7] The Frederick Andrew Trust: https://www.frederickandrewtrust.org/

women on our support services[8]. As a charity we are very concerned about the long term impacts when treatment is only available for those with the capacity to pay for private treatment.

Access to healthcare from women of different cultural and ethnic backgrounds

When discussing healthcare inequalities, it is also essential to discuss the different experiences in healthcare of women from different cultural and ethnic backgrounds, especially in the perinatal period. As campaigns like Fivexmore[9] have so adeptly explained, women from different cultural and ethnic backgrounds are less likely to be given the care, support and treatment they need during the perinatal period. Indeed, “Black women are 3.7x more likely to die than white women” when giving birth and “Asian women were 1.8x more likely to die than white women” when giving birth[10]. These figures indicate the discrepancies in care provided in healthcare for women from different backgrounds that, especially when coupled with more general medical gaslighting outlined above, could lead to a lack of trust and possibly a disengagement from healthcare. In turn, this may encourage women experiencing pregnancy-related PGP to not consult with healthcare practitioners and therefore not get the care, support and treatment they need.

While the majority of our survey respondents identified as being White (91.2%)[11], we hear from many women from different cultural and ethnic backgrounds on our support services, especially our telephone helpline. Many of these women’s first language is not English and too often they are struggling to navigate the often complex healthcare landscape to get the treatment that they need. In an environment where women often have to advocate for themselves and push back to get the right care, support and treatment they need for PGP, this is clearly problematic when the women do not have English as a first language or are not familiar with what is available on the NHS. Greater understanding and support for women from different cultural and ethnic backgrounds is essential, especially when experiencing more complex healthcare conditions, including MSK conditions.

Inequalities in MSK health

We consider that the inconsistent access to appropriate care, support and treatment on the NHS has created inequalities in the treatment of PGP across the UK. The postcode lottery of manual therapy on the NHS is forcing many women to pay for private manual therapy, which is out of reach for many women in a cost of living crisis. For women from different cultural

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[8] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf
[9] Fivexmore Campaign, https://www.fivexmore.com/
[10] MBRRACE-UK – Saving Lives, Improving Mothers’ Care 2022, https://www.npeu.ox.ac.uk/mbrrace-uk/reports
[11] Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf

and ethnic backgrounds, issues relating to race further exacerbates the challenges around inadequate access and requires further exploration to see how much women from these communities are affected by MSK disorders, like PGP.

To address this ongoing inequality in access to treatment, we are calling for more effective resourcing of NHS physiotherapy across the UK and better information sharing among healthcare practitioners around PGP and its treatment so that women can access the right care, support and treatment as soon as their symptoms start.