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|  | | **Please read the checklist for submitting comments at the end of this form.** We cannot accept forms that are not filled in correctly.  We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.  In addition to your comments below on our guideline documents, we would like to hear your views on these questions:   1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) 4. The recommendations in this guideline were developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.   See [[Developing NICE guidance: how to get involved](http://www.nice.org.uk/process/pmg22/chapter/how-you-can-get-involved)](https://www.nice.org.uk/process/pmg20/resources/developing-nice-guidelines-how-to-get-involved-2722986687/chapter/commenting-on-a-draft-guideline) for suggestions of general points to think about when commenting. | | |
| Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank): | | Pelvic Partnership | | |
| Disclosure  Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry. | | N/A | | |
| Name of commentator person completing form: | | Sarah Fishburn (Chair) and Jen Campbell (co-ordinator) | | |
| Type | | [office use only] | | |
| **Comment number** | **Document**  **[guideline, evidence review A, B, C etc., methods or other (please specify which)]** | Page number  Or **‘general’** for comments on whole document | Line number  Or **‘general’** for comments on whole document | Comments Insert each comment in a new row.  Do not paste other tables into this table, because your comments could get lost – type directly into this table. |
| 1 | Guideline | 29 | 7-11 | **Response to Recommendation 1.4.12**  Thank you for inviting us to comment on this guideline.    We completely disagree with recommendation 1.4.12 which takes management of PGP back to the 1990s by disregarding the safe and effective treatment of PGP with hands-on manual therapy.  This would be a retrograde step to women’s healthcare services which now offer individualised care including manual therapy, and which support women to make a good recovery during pregnancy and postnatally. Early intervention, i.e. early assessment and treatment of PGP, also reduces the cost of early induction, maternal request caesarean birth, postnatal pain relief and antidepressant medication, and treatment for the physical and psychological consequences of pain, immobility and not being understood which follow the very outdated treatment regime of belts and crutches (as outlined in the [Irish CPG for management of pelvic girdle pain](https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/management-of-pelvic-girdle-pain-in-pregnancy-and-post-partum.pdf)).    Furthermore, a service which implemented individual assessment and treatment with manual therapy for joint and muscle imbalance in Norwich showed a 2/3 reduction in the need to provide crutches, reduction in antenatal bed-rest for immobility due to PGP, reduction in induction and caesarean birth, and very few women needing postnatal treatment beyond 3 months postnatally. This produced an overall cost saving to the service.    The proposed recommendations will perpetuate the outdated treatment, based on the outdated assumption that PGP is a hormonal condition rather than a biomechanical joint dysfunction, and result in significant physical and psychological consequences for women. They also contradict the RCOG guidance, the POGP guidance for healthcare professionals (Pelvic, Obstetric and Gynaecological Physiotherapy special interest group) and the NHS Long Term plan which is focussing on pelvic health including the pelvic floor and PGP.    We would suggest that the recommendation should read:    1.4.12  For women with pregnancy-related pelvic girdle pain, consider referral to physiotherapy services for individualised assessment and treatment including manual therapy, exercises and advice.  If the pain continues, consider providing aids including crutches and referral to an occupational therapist.  Consider psychological support for women with significant pain and immobility due to PGP.  Offer discussion about birth planning to take into account the woman’s immobility.  **Women with mild to moderate PGP**  We are very concerned that the review focused on women experiencing mild to moderate PGP only, therefore disregarding those women most impacted by this severe and painful condition. As per our attachment, testimonies from women with PGP underline the importance of ensuring the guidance reflects best practice in the treatment of PGP, i.e. a multidisciplinary and individualised treatment plan including manual therapy to treat the cause of the pain and psychological supports, rather than a “band aid approach”, as one healthcare professional referred to it when we consulted about the draft guidance (see statements below).  **Critical and important outcomes**  The outcomes selected only included symptoms during pregnancy, and did not take account of the fact that the majority of women do not recover postnatally, and 8.5% continue with significant symptoms 2 years postnatally [(Albert et al, 2001)](https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1034/j.1600-0412.2001.080006505.x).The evidence review lists pain intensity, pelvic disability/functionality and women’s experience and satisfaction as critical outcomes. The significant response to our social media posts on this draft guideline (reaching 3500 women in 5 days, with over 35 comments and emails) and the powerful testimonies listed below show that clear action needs to be taken to improve women’s experience and satisfaction.  Lost work days due to PGP was also listed as an important outcome: “women with a high degree of self-reported PGP have longer sick-leave duration than others, and these pain symptoms were in one study reported to bring about 80% of sick leaves during pregnancy. The authors argued that this makes PGP during pregnancy a major public health issue” in [Malmqvist et al (2015)](https://pubmed.ncbi.nlm.nih.gov/26437972/).  These factors point to the need to consider the significant mental health impact of PGP. Our own survey of 367 women in June 2018 found two thirds of respondents with PGP also experienced a mental health issue. Comments from healthcare practitioners (see attachment) supports this as the manual therapy is part of their multidisciplinary and individualised approach, supported by an understanding of the wider impact on a woman’s life of PGP. This is why we are calling for psychological support to be considered in the recommendation for women with PGP.  **Evidence for the benefits of manual therapy**  We are also disappointed that manual therapy was not included in the economic analysis, despite being listed as an intervention in the PICO. There was some comparison made about manual therapy in the context of chiropractic treatment, craniosacral therapy and foot manipulation, none of which are normally available on the NHS. We consider this a missed opportunity to assess the real benefit of mobilisation and manipulation of the joints using physiotherapy manual treatments along with muscle release techniques including trigger point and dry-needling treatments. The latter is the commonly accepted definition of manual therapy among healthcare professionals in the UK (as outlined in the various UK and Irish guidance listed below). Indeed, we are unaware of foot manipulation and craniosacral treatment being successfully used in the treatment of PGP in the UK even outside the NHS.  The evidence review cited limited evidence as a barrier to include manual therapy in the recommendation. Please see list of guidance recommending manual therapy to treat PGP below:   * [Royal College of Obstetricians & Gynaecologists information on pelvic girdle pain in pregnancy](https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-pelvic-girdle-pain-and-pregnancy.pdf) advice includes “manual therapy to the muscles and joints by a physiotherapist, osteopath or chiropractor who specialises in PGP in pregnancy. They will give you hands-on treatment to gently mobilise or move the joints to get them back into position, and help them move normally again. This should be painful.” * [Pelvic Obstetric & Gynaecological Physiotherapy guidance on pelvic girdle pain for women](https://pogp.csp.org.uk/system/files/publication_files/POGP-PGP%28Pat%29%28UL%29.pdf) includes assessment and treatment from a physiotherapist, e.g. exercises, advice and “manual therapy to make sure your spinal, pelvic and hip joints are moving normally or to correct their movement”, adding that PGP can be treated effectively in one or two sessions with a physiotherapist. * [Pelvic Obstetric & Gynaecological Physiotherapy guidance on pelvic girdle pain for healthcare professionals](https://pogp.csp.org.uk/system/files/publication_files/POGP-PGP%28Pros%29.pdf) includes assessment and treatment from “a physiotherapist who has appropriate training and expertise in PGP management and treatment” offering exercise, advice and “appropriate manual therapy as required, e.g. mobilisations, manipulation, muscle energy techniques, stretches. Manual therapy should be aimed at correcting any spinal pelvic and hip joint dysfunction including increasing hip join mobility”. * [Clinical Practice Guideline: Management of pelvic girdle pain in pregnancy and post-partum (Ireland):](https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/management-of-pelvic-girdle-pain-in-pregnancy-and-post-partum.pdf) includes “Physiotherapists trained in the assessment and treatment of PGP may use any or all of the following in the management of patients with PGP; advice and education, joint mobilisations, myofascial and trigger point techniques, muscle energy techniques, acupuncture, TENS, massage, specific individualised exercise programmes and pelvic belts”   **Multidisciplinary approach**  We promote manual therapy as part of a multidisciplinary and individualised approach to treating PGP, recognising that women experience PGP differently. Exercise and support belts when used in conjunction with manual therapy can help maintain the correct alignment of the pelvis, after assessment and treatment by a manual therapist. However, these approaches do not work in isolation, especially for moderate to severe cases of PGP.  We are concerned that by offering exercise advice or belts without a thorough assessment of the woman by a manual therapist, these approaches will do little to resolve the PGP and will lead to further issues later in pregnancy, during the birth and postnatally. This is supported by the findings of our June 2018 survey and feedback from our service users and healthcare practitioners, included below.  We call on the committee to review recommendation 1.4.12 and ensure the guidance reflects best practice, i.e. referral to physiotherapy services for individualised assessment and treatment of pelvic girdle pain, using manual therapy, exercises and advice, with additional referrals to psychological support and/or occupational therapy as needed.  Representatives from the Pelvic Partnership would also be happy to be co-opted onto this committee to assist with the review of the recommendation.  **Supporting statements from service users and healthcare professionals**  To support this submission we asked our online community of service users and healthcare professionals to respond to the NICE draft recommendations. We received 35 comments and 8 emails in four days. None agreed with the NICE draft guidance. All wrote supporting our position to change the recommendation, 14 of which we have shared below:   1. Woman with PGP: It did zero for me. I had a support belt, tubi grup covering my torso and crutches with my first. It just got progressively worse until I needed to sit in a wheelchair - which I struggled to sit in anyway. By the magic of manual therapy I needed nothing else in my other pregnancies! 2. Woman with PGP: Manual therapy (and mental health support) for all women needs to come as standard with a pelvic girdle pain (PGP) diagnosis. Exercises and support belts do not treat the underlying problem and in some cases, like mine, can significantly worsen the condition. For me, this resulted in an inability to function on a day to day basis (washing, dressing, feeding myself, walking etc) and an intolerable level of pain resulting in significant knock on effects for me physically, mentally and emotionally, to my family who had to watch me suffer, as well as the NHS in terms of subsequent costs. When I eventually got seen by an NHS physio, I was fobbed off and told I was “too severe” to treat which was rubbish because at the time I could actually walk (I later ended up in a wheelchair). I was told to exercise, use a support belt and crutches which did nothing but make everything worse (because I was pushing myself too hard and not listening to my pain as I later found out I should have been – a one size fits all set of guidelines is so dangerous and unhelpful with something as complex as PGP) and make me seriously depressed because I was doing everything I “could” and had been told to and the pain was increasing exponentially! Little did I know I had a problem which just needed to be treated with manual therapy. Luckily, I found a private practitioner via the Pelvic Partnership who saved me because at 30 weeks I was suicidal and done with pregnancy. My PGP traumatised me and I needed so much help both mentally and physically because I hadn’t had the right treatment soon enough and my issues dragged on for many months after (not helped by lockdown where, for some reason now, NHS physios are rarely treating patients face to face where private physios like mine are). Not to mention the fact that I had to have a c section as a result of my severe PGP. I appreciate physios are an expensive and high demand resource but the knock on effects and cost to the NHS of all my subsequent issues were FAR greater than the cost of a physio would have been. Your report completely underplays how debilitating PGP is or how severe it can become and how much it affects women mentally too. I had two years of hell and if I’d have just had the right treatment when I went to the NHS in the first place, it wouldn’t have been half as bad! It literally ruined my pregnancy and ruined my first 6+ months of life with my son, and I can never get that back! I very much hope you will reconsider. I wouldn’t wish my pain and suffering on my worst enemy but reading this just makes me wish that someone in your organisation knew what it was really like even if just for a few seconds so you would take it A LOT more seriously. Finally, for me, the scariest thing is that by making it sound like manual therapy doesn’t work, people wouldn’t know about it or bother to pursue it privately (if they can afford to (sadly many cannot) or get charity funding). I implore you, at the very least, to acknowledge that it can be highly effective and even if the cost cannot be justified as part of your guidelines, women will know that there is something that can be done to help them and that they’re not destined to never be able to walk or function again without pain. Of course I wish that everyone who needs it could get specialist physio for free on the NHS but if they cannot (because in my opinion the wider implications and costs have not been fully considered), at least acknowledge the effectiveness of manual therapy and help to educate and inform them because that is free! PS I’m sure you’re well aware of information like this demonstrating how much sick leave is caused by PGP: <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-015-0667-0> 3. Chiropractor: This is such upsetting advice, and such a band aid approach root cause is being missed! Yes, exercise is helpful, as is some belt support, but misses the point! Mention in your reply that Research shows 72% of missed work days in pregnant women are due to PGP! 4. Osteopath: Absolutely, root cause individualised approach is key. Understanding each individual and their individual reasons for getting PGP. Please ensure that you advocate not just for physio, but for Osteopathy too. We know it works. This should be on the recommendations. Plus the importance of a multifaceted approach. Including stress management, and addressing fear and anxiety... previous birth trauma. The recommendation for improving access to Osteopathy for PGP means we can spend time signposting other services like these to help improve PGP and birth outcomes too if and when needed and necessary. 5. Physiotherapist: Manual therapy all the way 6. Physiotherapist: Manual therapy is so essential for the management of PGP 7. Exercise trainer: I shall be filling this out and sending in and also put this out to clients from XXXX. This lack of service and help needs to change. It's gone on long enough! 8. Woman with PGP: Hi there, I suffered from PGP in my first pregnancy from 16 weeks. No midwife would refer me for physio (because I could never get in touch with a midwife) and I had to go through my GP. It was so bad that I was offered a 4 week sick note to help me get some rest. I heard nothing back from the NHS, so assembled a team of a brilliant physio and a chiropractor. Women’s ante-natal care is a disgrace. If you’re low risk, it’s honestly like nobody really cares. The following pretty much sums up my journey of ante-natal care: No named midwife/contact A different midwife at every single appointment. On reflection, I was really anxious in my first pregnancy, but couldn’t share this with anyone as I never had the opportunity to build a relationship with someone who was a constant in my care. No physio provided through the NHS for PGP. I struggled with insomnia from 8-32 weeks and no support was provided apart from the suggestion that I should try to relax/use lavender. Refusal from GPs or anyone to prescribe anything to help with heartburn. My child was breech, but this wasn’t detected until 36 weeks because I felt the pattern of movements was off/he hadn’t dropped/family history of breech presentation. I had to really fight for a scan to check position. Being told by sonographers at the 36 week scan that even if he was the right way, he was an estimated weight of 9lb and that I wouldn’t have been able to give birth to him anyway. Medical staff need to make women aware that the margin of error on an ultrasound scans can be up to 750g either way. That’s a pound and a half. Scare mongering over size (unless there are genuine concerns/baby has fallen off the centile chart/identified problems with core blood flow and placenta) should not happen. Nutrition and management of women who are awaiting induction or Caesarian section. On the day of my section I was admitted at 7:30am and was not allowed to eat or drink until I had been out of theatre an hour. That was 6:30pm before I was allowed to drink anything. Then it was clear liquids for an hour before I was finally allowed to eat at 7:30pm. I had been nil by mouth with solids since 8pm the night before and wasn’t allowed any liquids past 6am on the morning of surgery. How can you be expected to recover from major abdominal surgery and care for a newborn with this inadequate nutrition and hydration? I also feel that sweeps should not be offered routinely due to increased infection risk and the whole idea of one intervention leading to further intervention. It should be a woman’s choice. I’ve addressed most of my personal concerns with the hospital involved, but it’s all symptomatic of maternity services that don’t actually put women’s needs at the heart of what they do. I know you’re just focusing on the PGP element of this, but honestly the chronic underfunding and litigious over managed culture of the NHS is making women’s lives a misery. The use of language needs to change and women need to be empowered to know that they actually have choices in their medical care. I’m very early in my second pregnancy and already the problems have started. I am a primary school teacher and in my area there is a project to let keyworkers have leftover covid vaccines. I also have risk factors which make me more vulnerable to complications. I spent hours trying to contact a midwife this week and was passed from pillar to post. I’ve been told that if I request this at my booking appointment and the midwife agrees, at some point in the future, I’ll hopefully be able to have a video consultation with an obstetric consultant who will then do a risk assessment for me. Then that obstetric consultant will decide if I am allowed to be offered a vaccine. I find this bizarre. Anyway, I’m completing this and sending it because this is important. 9. Woman with PGP: Gosh they're not making it easy with this documentation are they?! I will definitely complete and send on though. The current 'support' from the NHS is truly awful and things must change. 10. Chiropractor: Thanks for flagging upcoming changes in NICE guideline re PGP. Worrying. I recently listened to the back pain podcast episodes with Physio Sarah Fellows. Really good and worth a listen. So much of what we do as manual therapist foes beyong the hands on mechanical effect on joints, it is about listening, reassuring, calming the system which can be done with the laying on of hands. Good care is about providing an appropriate mutlifaceted approach to care... not just dishing out belts! Also about providing good quality physical examination and assessment to determine if indeed the diagnosis is PGP. 11. Woman with PGP: Whom it may concern,I have recently seen an advert with the pelvic partnership charity about getting manual therapy recognised by NICE. I just wanted to share with you my story. At 26 weeks pregnant I started with the worst pelvic pain, I was referred to NHS physio and advised to loose weight (I have a high BMI) and wear a support band on my bump. I ended up finishing work at 32 weeks pregnant as I couldn't work with the pain. After giving birth the pain was still there. After 4 months I rung the DR's I was prescribed Naproxen, referred to physio and told to exercise. Three months later I was seen by physio who had no experience or knowledge on PGP and gave me an exercise program. However, after a few weeks of following the exercises, I found my pain had become unbearable and was now requiring amitriptyline at night time. Again Dr's and physio where telling me to continue exercising and loosing weight. I discovered to pelvic partnership charity and wrote to them with my symptoms and they recommended seeing an osteopath. My first meeting with the osteopath he told me the advice from the Dr's and physio to exercise is what had made my PGP worse; My pelvis coupsnt withstand the numerous squats and lunges. After 2 months of seeing an osteopath weekly, and following some appropriate light stretches daily, I can now sit on the floor and play with my child. I can walk upstairs without crying. I can work without having to sign of sick for days following a shift. I can enjoy family walks. My daughter is 14 months old, I suffered miserably for 17 months with PGP being wrongly advised by professionals. I urge you to make the change and recommend manual therapy to ladies pre and postpartum that suffer with PGP. It IS treatable. Unfortunately like me, who is a nurse and works of evidence based practise I was very against paying for something that wasn't recommended, and I'm certain there will be ladies out there suffering because they had the same mind set as me. 12. Woman with PGP: Hi, I am very concerned about the guidance for pelvic girdle pain. I have had PGP since 14 weeks pregnant and was referred to an NHS physio. Only offered exercise advice and support belts which has not helped and was told to limit my movement if exercises made the pain worse. I’ve been unable to walk or get any exercise throughout my entire pregnancy. My pain and mobility has steadily increased and from 35 weeks pregnant I couldn’t move without crutches - couldn’t sleep as the hip pain was so bad. Evidence shows that manual therapy should be standard practice. This needs to be offered to all women. The impact on my physical health and mental health has been awful. Pelvic girdle pain For women with pregnancy-related pelvic girdle pain, consider referral to physiotherapy services for: • exercise advice and/or • a non-rigid lumbopelvic belt. 13. Woman with PGP: Hello I would just like to add my comments to your comments that will be submitted to NICE. I have had problems with my hips since the start of pregnancy my GP and Midwife put it down to just being pregnant. At 33 weeks pregnant I was then unable to walk, I could just about get around my house. A referral was sent for physiotherapy but manual therapy was not offered, the exercises seemed to be impossible to do in my immobile condition. I had to seek out private manual therapy from a PGP therapist, after one session of manual therapy she told me my right hip was two inches higher then my left, putting considerable pressure everywhere and making me immobile. Two days later I am able to walk pain free. I am a fit, healthy NHS specialist nurse, I find the fact that a physiotherapist does not have to physically assess you quite shocking. In my profession I would not be able to assess a patient without seeing them. I also worry that many women are being left untreated, I am lucky I had the knowledge and money to seek private help, however I do believe that it should be mandatory for manual therapy to be gold standard in regard to this condition. Without the manual therapy I would have slipped into a very depressive state. 14. Woman with PGP: Last year I had my baby in April, so mostly pregnant pre Covid, during my pregnancy I suffered with severe PGP that resulted in me being bed bound at 30 weeks. I was referred to the physio in my area by my consultant. It was a group therapy session with absolutely no physical or personal assessment done. I was then advised to do pelvic floor exercises religiously, as it happens I have been doing these for 20 years and have since been told by my private womens health physio that my pelvic floor is 5/5 and one of the strongest she has ever examined. My point is that clearly the pelvic floor was not the issue and the NHS physio was hugely lacking in knowledge on PGP. After the group session I took the physio aside to ask where we went from here, she said she would strongly recommend crutches and she would happily teach me how to use them. She still hadn't done any assessment of my personal symptoms. I asked about manual therapy and was told that that was not something she would do, that that wasn't suitable. I went home and cried for 2 days, the pain was horrific and I couldn't even move around my house without help, and now I had no hope. Next I started googling and found a pregnancy chiropractor 60miles away who I rang and spoke at length to. She said absolutely she could help me. And she did. With manual therapy. The relief was instant, I still walked like an old lady but the pain was greatly reduced. Due to not receiving treatment sooner I had to have twice weekly sessions until lockdown put a stop to that and I was once again bed bound for the last 5 weeks of my pregnancy. After the birth I was relatively pain free until 8 weeks postpartum when I had a relapse, luckily chiropractors were open again and I got help. To date, since the birth, I've had over 20 appointments with my chiropractor and 4 with a womens health physio and I'm having a much better quality of life although I still have to get adjusted every 3 weeks. PGP needs to be understood by the people whose job it is to care for pregnant women, the mental health element of being unable to take even 2 steps without agonising pain is unacceptable when treatment is available and so very simple. Thank you for listening. |
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| **Checklist for submitting comments**   * Use this comment form and submit it as a **Word document (not a PDF)**. * Complete the disclosure about links with, or funding from, the tobacco industry. * Include **page and line number (not section number)** of the text each comment is about. * Combine all comments from your organisation into 1 response. **We cannot accept more than 1 response from each organisation**. * Do not paste other tables into this table – type directly into the table. * Ensure each comment stands alone; do not cross-refer within one comment to another comment. * **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.** * **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted. * Spell out any abbreviations you use * For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline. * **We do not accept comments submitted after the deadline stated for close of consultation.**   You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](http://pathways.nice.org.uk/).  **Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.  Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.  **Data protection**  The information you submit on this form will be retained and used by NICE and its advisers for the purpose of developing its guidance and may be passed to other approved third parties.Please do not name or identify any individual patient or refer to their medical condition in your comments as all such data will be deleted or redacted. The information may appear on the NICE website in due course in which case all personal data will be removed in accordance with NICE policies.  By submitting your data via this form you are confirming that you have read and understood this statement.  For more information about how we process your data, please see our [privacy notice](https://www.nice.org.uk/privacy-notice). |