Pelvic pain: a pathway for care developed for both men and women by the British Pain Society

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Summary. This paper aims to explain the key points and highlight some of the controversies in the development of the British Pain Society's pelvic pain patient pathway map. Many clinicians lack experience and confidence with this group of patients, and this issue is highlighted. Additionally, the difficulties of classification and definitions in this area are discussed in detail. These are historical causes of disagreement among specialists which can lead to confused clinical care. This group of patients have multiple issues that cross many professional boundaries; they are best managed by the co-ordinated involvement of multiple teams. Patients suffer from significant distress and disability that often needs specialist assessment and intervention (interdisciplinary). This suggests that an integrated approach is required across the historic boundaries of primary and secondary care. A variety of interventions, including opioids and neuromodulation are recommended in the pathway and the controversies surrounding these inclusions are aired in detail.

Keywords: chronic pain; chronic pelvic pain syndrome; pelvic floor disorders; pelvic pain; urogenital pain

This paper aims to review the key points and controversies around the British Pain Society's (BPS's) chronic pelvic pain patient pathway map (for men and women).1 This pathway is one of an initial series of five, with the intention of improving and streamlining the delivery of timely, evidence-based and individualized care.2 –5 The pathways can be accessed through the BPS's website.

The principal focus of the pelvic pain pathway is on the initial non-specialist management of patients with pain perceived within the pelvis, and thereafter understanding pathways and timelines for onward referral to secondary and specialized tertiary care. To our knowledge, there are no comprehensive interdisciplinary and multispecialty guidelines of this sort for the generalist and as a consequence, we consider them as a major step forward in the management of this complex and potentially expensive to support group of patients.6 –9

Whereas this work is intended to be complimentary to other guidance such as the National Institute of Health and Clinical Excellence (NICE) and the Chronic Pelvic Pain guidelines of the European Association of Urology (EAU),10 –12 we feel that this pathway has the benefit of being truly between teams and multispecialty and having a clear evidence base. All the BPS pathways have been commissioned by an Executive Working Group of the BPS consisting of BPS council members and co-opted experts. The five initial pathways were chosen for the following reasons:

- High burden of disease volume of patients attending non-specialist and specialist clinics.
- Unwarranted variation in care, that is a lack of uniform approaches to assessment and initial management as evidenced by the variability of referrals to specialists.
- Uncertainty as to application of the evidence base; thus, best value for patients was unclear.

The pathway has been developed in collaboration between the Map of Medicine editorial team, representatives of the BPS, and independent reviewers. The pathway is based on well-reputed secondary evidence, as selected in accordance with the Map of Medicine's editorial methodology for developing care pathways. Practice-based knowledge has been added by clinicians.
nominate the best available figures suggest the number of women in the UK with chronic pelvic pain is 1 million (compared with 1.6 million adults with low back pain). Pelvic pain is thus an understated and major problem. A break down of prevalence for more specific terms is found in Table 1.17

### Practice point: care map information

In many ways, the supporting information behind the pathway tree (which is published as an integral part of the care map) is the most important part of the pelvic pain pathway as for most clinicians, the basic principles are unfamiliar. It is because of a lack of understanding of basic facts that treatment is often inappropriate.10 11 13–15 There is a potential point of confusion for this pathway because it has to provide the basic principles early on, but an in-depth discussion is also given later in the pathway.

### Discussion point: incidence and prevalence of chronic pelvic pain

In the literature figures around the incidence and prevalence of chronic pelvic pain are reported in an inconsistent manner which makes comparison and discussion difficult. The pathway highlights this:

(1) First, classifying pelvic pain has not been subject to a standard process for many years and this has only recently been fully addressed.10 16

(2) Secondly, much of what falls under the general heading of ‘chronic pelvic pain’ does not reach specialist care and is dealt with through self-management or with the support of primary care.17

(3) Thirdly, if specialist care is involved in the management, it is often spread between multiple specialties (urology, gynaecology, urogynaecology, colorectal services, pain medicine and even spinal services, rheumatology, and neurology). Patients may pass back and forth between different teams of the same speciality and between different specialities.

(4) Finally, there is no simple way of predicting or defining problematic pain.18

As a consequence of these issues, we do not have a true knowledge of the incidence or prevalence of chronic pelvic pain.

The pathway also emphasizes that whereas there will be some unique differences between male and female chronic pelvic pain, there are also many overlaps between in mechanisms and presentations,10 it is common to separate the conditions based on gender and the site of perceived pain, but this may be artificial.

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### Practice point: classification

To understand the pelvic pain pathway, it is important to understand the classification of pelvic pain and the significance of inappropriate classification. In particular, the pathway is about early recognition of ‘well-defined conditions’ that need to be separated from those categorized as ‘chronic pelvic pain syndrome’. Pain associated with well-defined conditions requires the underlying process to be investigated and treated: red flags must be identified early and referred to the appropriate speciality either as an emergency (immediate referral) or for an urgent appointment (seen within several weeks).

Failure to accept that a patient’s symptoms are primarily of a chronic pelvic pain syndrome may result in inappropriate investigations and treatment leading to a deterioration in the prognosis.10 13 This classification system, and hence the pelvic pain pathway, emphasizes the importance of assessing and managing not only the pain but also its impact on the patient (psychosocial, behavioural, and sexual) and assessing and managing the multisystem disorders often found in patients of both sexes with chronic pelvic pain.

### Practice point: psychosocial, behavioural, and sexual interactions and consequences

In addition to pain, this pathway emphasizes the evidence that these patients also suffer from psychological distress and concurrent negative behavioural and sexual consequences. This is introduced in the Care Map information box, but more details are presented in several of the subsequent key point boxes explaining that patients with pelvic pain often suffer with depression, anxiety, poor sleep, difficulty with work, and

### Table 1 Prevalence of some chronic pelvic pain conditions

<table>
<thead>
<tr>
<th>IASP syndrome</th>
<th>Prevalence</th>
<th>Notes</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic pelvic pain in women</td>
<td>1 million</td>
<td>women in the UK</td>
<td>17</td>
</tr>
<tr>
<td>Vulvar pain syndromes</td>
<td>3–18%</td>
<td>Main age 18–29 yr, decreasing by 44 yr. 50%</td>
<td>19–22</td>
</tr>
<tr>
<td>Female dyspareunia</td>
<td>15–20%</td>
<td>50% primary dyspareunia. Proved most commonly in</td>
<td>21, 23–25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>premenstrual women</td>
<td></td>
</tr>
<tr>
<td>Male chronic pelvic pain syndrome</td>
<td>8.2% (range</td>
<td>Increases with age (men aged 50–59 have a 3.1-fold</td>
<td>10, 26</td>
</tr>
<tr>
<td></td>
<td>2.2–9.7%)</td>
<td>greater risk than those aged 20–39)</td>
<td></td>
</tr>
<tr>
<td>Scrotal pain syndrome</td>
<td>Not known</td>
<td>After vasectomy surgery 2–20%. 2–6% have a visual</td>
<td>10, 27, 28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>analogue score &gt; 5 (1/10)</td>
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relationship issues. In common with many people with chronic pelvic pain, patients are often disabled by fear that activity will make things worse. Sexual issues may also pose a major problem and often have a significant adverse effect on relationships leading to further distress, anxiety, and low mood. Depression is strongly related to ‘catastrophizing’ (ruminating leading to negative amplification and subsequently helplessness) and these factors are associated with poor outcomes. It is important that those involved in supporting and managing these patients have the skills and experience in all of these fields both to evaluate and to involve other members of the team as indicated. It is essential to have the ability to ask tactfully about the details of sexual encounters and intimacy, and particularly to gather information about negative experiences or a reduction in frequency of intimacy, which is often very hard for patients to discuss.

**Practice point: multisystem disorders including, sexual, bowel, urinary, gynaecological, and musculoskeletal symptoms**

The term pelvic pain is an enigma as it does not give a clear indication of the mechanism of the pain and does not take into account that many of the symptoms and signs may be outside of the anatomical pelvis. The pelvic pain pathway highlights that, in addition to pain, there may be multiple functional abnormalities both within and outside the pelvis. These need to be assessed and managed as well as any pain perceived within the pelvis.

**Discussion point: when is pelvic pain a chronic pelvic pain syndrome**

The pelvic pain pathway aims to separate out pain associated with a well-defined process (such as cancer or infection) from the chronic pelvic pain syndrome (where there is no proven infection or other obvious local pathology that may account for the pain). Red flags are always a concern and the pelvic pain pathway working group have clearly stated when urgent referral should occur.

If a well-defined pelvic condition continues to produce pain despite standard management, then the pathway recommends a multidisciplinary and multi-professional approach with interdisciplinary and multispecialty assessment. Confusingly, a patient may have a well-defined pelvic condition concurrently with chronic pelvic pain syndrome. Some patients in this category that do not require specialist medical management could be managed by primary care acting as a co-ordinator of professionals. A case management approach may be the most effective although there is insufficient evidence on appropriate models in pain medicine from which to determine practice. Further research is needed.

**Practice point: information for patients**

In chronic pelvic pain syndrome, there is a significant amount of information that needs to be assimilated and dedicated time and support needs to be available to develop this approach. In primary care, the constructive interview approach may be facilitated by a questionnaire such as the International Pelvic Pain Society web-based form—History and Physical Form; 2008. In secondary care, the team approach is essential. Active patient participation allowing time for this information to be processed and assimilated is necessary.

**Practice point: physical therapy interventions in primary and secondary care**

Evidence-based medicine has both its advocates and detractors. Many of the published guidelines focus on individual, evidence-based interventions only: the pelvic pain pathway attempts to provide a whole patient approach which incorporates multiple interventions. As part of this pragmatism, there is a strong emphasis on both a pain management approach and a hands-on approach to physical therapy in the guidelines. The group strongly supports basic ‘common sense advice’ of reassurance, maintenance of activity, and general physiotherapy despite there being limited direct evidence for that approach in terms of research.

The pelvic pain working group also advocate an early assessment and management by a specialist physical therapist. If the presentation is with predominantly urological symptoms rather than pain, then women’s physiotherapy may be more appropriate—the exact access to appropriate physiotherapists will depend on local systems and may require referral to specialist care. The pelvic pain pathway is one of the first documents to discuss these different approaches and to place them in a workable framework.

The importance of a specialist physical therapist is emphasized and it is reinforced that this should be in accordance with International Association for the study of Pain (IASP) competencies to ensure that well-recognized and standardized approaches are utilized in the absence of clear research supporting alternative approaches.

In the secondary care situation, the importance of integrated working is emphasized which is in keeping with best practice. In the more complex patient, the role of specialized physical therapy techniques is emphasized as a key management approach. There will always have to be a balance between ‘hands-on’ physical therapy and ‘hands-off’ behavioural physical therapy approaches and the decision around that balance will be a joint decision between the patient and the team supporting the patient. Further research is needed in this area to ensure that interventions are matched to patient need.

**Practice point: the role of opioids**

It is well established that opioids may be beneficial for a proportion of patients with chronic non-malignant pain. However, their role in supporting patient with pelvic pain is less clear. The pelvic pain pathway supports the several publications providing guidance for both patient and professionals. The pathway indicates that opioids should only be prescribed in a co-ordinated fashion with regular review looking at both the benefits and side-effects. At a clinical level, they should only...
be used in conjunction with a management plan and with consultation between clinicians experienced in their use (the involvement of a Pain Management Centre may be beneficial). Patients should be reviewed regularly with assessments for functional improvement along with analgesia. Often patients stop taking oral opioids because of side-effects or insufficient analgesia and hence the pathway emphasizes that assessing compliance is important.

The pelvic pain pathway also refers to the recent research evidence around the understanding of opioid-induced hyperalgesia, a situation where paradoxically patients taking opioids become more sensitive to certain painful stimuli. This is something that is often poorly appreciated by the non-specialist. Opioids can also have a significant impact on the endocrine system, with lowered sex hormones, and the pathway highlights the need to consider this and gives guidance on its investigation and management, in accordance with established advice. Similarly, immunosuppression is also a potential risk, which is clear at cellular level but less so clinically. In order to better appreciate the clinical relevance of these issues, further research in the area is required.

Practice point: review, when and where to refer

It is recognized that in England it can take several years for a patient’s persistent chronic pain condition to be recognized and even longer before management is provided in a secondary care setting. Accordingly, the pelvic pain pathway working group was keen to empower the patient and their primary or community caregivers. As a consequence, it was agreed by the executive committee that all pathways should advocate early review and if appropriate referral. This suggestion is taken up in the pelvic pain pathway. At the first visit to a primary care specialist, the main emphasis will be on ensuring that there are no red flags, treatable conditions are identified, simple analgesia and continued movement is encouraged; and for the second consultation, a more specific management plan needs to be agreed on. This plan should be followed through and reviewed on a regular basis in primary care. If there is a lack of progress in the plan, referral to secondary care should be considered no later than 6 months after presentation. This ‘line in the sand’ should be a part of the initial management plan.

The pelvic pain pathway also supports that patient care should be local to where the patient lives and, in the first instance, a local pain management service referral should be made. For the first time, the pathway has defined what such a secondary care service should look like. Such a centre should be able to provide the specific services which are clearly set out. The National Pain Audit found that less than half of services had the required personnel to deliver such services to a minimum standard (i.e. lack of appropriately trained physicians, psychologists, or physiotherapists). Clearer specification of the service is needed and its necessary inter-relationships thoroughly described.

According to the National Health Service (NHS) Commissioning Board guidelines for specialized services, referral to one of the few National Centres for Urogenital and Pelvic Pain should originate from secondary care in most cases. The pelvic pain pathway is acknowledged in the service specification for Specialised Services for Pain in England as being an example of best practice.

Discussion: the role of interventional pain therapies

Is there a role for injection treatment and neuromodulation in the management of chronic pelvic pain? This debate is ongoing and is often a key area of controversy. Most injections will be undertaken in secondary or tertiary care by clinicians that are trained to perform the procedures and have the skills to ensure that appropriate diagnosis and indications are adhered to. There must be appropriate equipment to ensuring maximum accuracy and as a result maximize efficacy and also adequate facilities to manage any complication.

For the clinicians that perform the interventions in the above manner, there is evidence from parallel conditions that they have an important role. However, timing of the intervention and diagnosis are considered key and the pathway goes on to define this, but also emphasize that patient expectations are important and need to be managed.

Well-targeted injections may guide other treatment options in addition to being therapeutic in their own right. They may have a role in the investigation and management of muscle-related pain or of pain associated with nerve injury. The diagnostic situation may be improved by other techniques.

In many patients, nerve blocks rarely provide long-term benefit on their own, and consideration should be given to multidisciplinary team involvement to maximize outcomes. The pathway goes on to discuss the frequency of repeat injections, indicating that the duration of benefit and potential complications (e.g. repeat steroid use and the cumulative dangers of X-rays) need to be considered. Currently, for some injections the procedure can be performed only with Computer Tomography (CT) guidance, even with modern scanners a significant radiation dose to the pelvis is required. In a secondary care setting, interventions need to be supported by physiotherapy, graded activity, explanation, education, and self-management.

Implantable neuromodulation for pain perceived in the pelvis should be performed in a specialized centre to ensure the safety, consistency, and appropriate audit that comes with doing larger numbers of patients. Those that implant such devices agree that there are three important factors for neuromodulation to be successful:

1. Appropriate diagnosis.
2. Stimulation perceived in the site of perceived pain.
3. Realistic patient expectations.

NICE guidelines for pain and neuromodulation relate to spinal dorsal horn stimulation. Unfortunately, most of the work around neuromodulation and pain perceived in the pelvis has not, until more recently, taken into account this...
diagnostic approach or the fact that to obtain stimulation in the pelvis through dorsal horn stimulation is problematic. As a result, publications are few and the pelvic pain pathway is limited in its guidance or recommendation of these expensive interventions. There is, however, growing literature to suggest that sacral root stimulation, pudendal nerve stimulation, and even tibial nerve stimulation despite having different mechanisms of action to dorsal horn stimulation, may be beneficial. Sacral root stimulation has NICE guidelines for functional bowel and bladder issues.

Again, comparative effectiveness studies are needed against other therapies in the pathway such as specialist Cognitive Behavioural Therapy (CBT) for pain, combination medicines management, and specialist pelvic floor physical therapies.

The pathway also mentions both interdisciplinary and multidisciplinary care. Both interventions require further clarification and research.

Summary
The BPS pelvic pain pathway is an important step forward because it highlights the high prevalence of a condition which often goes under recognized despite its high impact on the life of the patient and our society and its complexity involving multiple symptoms other than pain. The pathway educates around these issues but also empowers those in primary care to explore these concerns with patients in a way that is both practical and efficacious. The pathway supports a multi-speciality approach alongside the collaboration of different teams in the management of care at all levels.

Recently, the Right Care Team has brought together stakeholders in a series of workshops to define a population specification. This confirmed the acceptance of the new pelvic pain pathway to stakeholders, but also identified significant challenges in implementation. Shared decision tools and approaches may work well in conveying the trade-offs between risks, benefits, and personal needs. However, no such decision tools exist for chronic pelvic pain at present. In order to achieve this comparative effectiveness, studies are needed. A significant amount of investment in both primary and secondary clinical research is needed to ensure that patients and referrers are fully informed about the effectiveness of interventions in the right context.

Authors’ contributions
All the authors contributed equally to this paper with involvement at all stages of preparation.

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Declaration of interest
C.P. has received industry support for attendance at the World Congress of Pain 2012 from Napp UK and travel costs for a European-wide consensus meeting on Outcome indicators for Pain in 2013 from Grunenthal. C.P. is a Member of the editorial board for the British Pain Society Persistent Pain Pathways, Consultant Advisor for the National Institutes of Health Research Evaluation and Trials Co-ordinating Centre and Clinical Director Southampton City Clinical Commissioning Group. J.H. has received occasional support for meetings and delivering lectures from: Pfizer, Mundipharma, Prostrakan. J.H. is employed by South Tees Acute Hospitals Foundation NHS Trust. (Clinical lead Pain Management); is a Chair of the British Pain Society Chronic Pelvic Pain Patient Pathway Working Group; Member of Pelvic Pain Guidelines Committee, The European Association for Urology (EAU covers expenses); Member of the Board Faculty of Pain Medicine of Royal College Anaesthetists; Senate member of the Clinical Reference Group Specialised Pain Services, North England; Member of the Educational Working Group of International Association for the Study of Pain; and has written multiple chapters, articles written some with honorarium. A.P.B. is employed by the UCLH NHS Foundation Trust; Clinical Lead Pain Management Centre, UCLH; is the Chairman of The Taxonomy Committee, Pain of Urogenital Origin (PUGO), Special Interest Group of IASP; is a Committee member, Pelvic Pain Guidelines Committee, The European Association for Urology (EAU covers expenses); is Honorary Treasurer, British Pain Society; Chairman NHSCB, Clinical Reference Group Specialised Pain Services, England; Consultant for Mundipharma Research GmbH & Co. (this covers expenses incurred around his involvement in Mundipharma); is an Invited Speaker for multiple organisations from time to time, for which expenses are paid; and has published multiple chapters and publications. J.L. is a member of the medical charity SPIN (Specialists in Pain International Network) and a member of the British Pain Society.
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Appendix

Map of Medicine®

The Pelvic pain care map1 which can be found at www.mapofmedicine.com, and of which an extract is included in this article, is published with the authorization of Map of Medicine Limited, who owns the copyright.

British Pain Society Pain Patient Pathway Maps Executive Committee

- Andrew Baranowski (chair)