

Report of Workshop

Report of a workshop at the 1st World Congress on
Abdominal and Pelvic Pain

Amsterdam 31 May 2013

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International Pelvic Pain Partnership

WORKSHOP SUMMARY: Members of the International Pelvic Pain Partnership (patient organisations with a common aim) worked with clinicians and researchers to discuss and explore uncertainties in the diagnosis, treatment and management of chronic abdominal and pelvic pain. Following some input on research methods relevant to persistent abdominal and pelvic pain, small discussion groups used the Map of Medicine Pathway (UK) to help structure dialogue and keep focus. The atmosphere in the workshop was collaborative and respectful with participants debating the relative merit of research ideas to address issues such as the initial presentation/primary care, especially how to ensure that this first contact with services is useful for both health professional and patient; diagnosis, in particular how to improve communication between patient and clinician, and how to reduce duplicated or unnecessary investigations; personalising treatments, phenotyping, dealing with side effects, managing expectations when treatments don't work; and improving multidisciplinary team working so that patients are not part of a 'pinball' experience of services.

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Introduction

This workshop was part of a larger and important Congress on Abdominal and Pelvic Pain, the first major international congress of its kind.

The title of the workshop was **“What are the research gaps and priorities in abdominal and pelvic pain diagnosis, treatment and management? Patient and Professional Perspectives”** and it ran on Friday 31st May concurrently with the main programme. The workshop was sponsored by Grünenthal GmbH and the Pelvic Pain Support Network enabling several patient organization members to participate (the registration and travel costs being too prohibitive for many IPPP members) and for a professional facilitator to plan and run the workshop.

Workshop Objectives

- To consider areas in pelvic pain where there is ongoing uncertainty in diagnosis, management and treatment, from patient and professional perspectives;
- To ‘map’ these research uncertainties using a recognized pathway of diagnosis, treatment, management and prognosis, and
- To initiate a discussion about the relative priorities on this map.

Workshop participants

People representing relevant patient organisations and with lived experience of pelvic pain, health professionals that treat

What workshop participants said

Patients need a “pelvic pain passport” to show professionals the investigations and pathways that they have already travelled. Too often they experience a ‘pinball’ effect of referrals, and investigations.

Pain Consultant

I want professionals to stop treating me as a set of symptoms... I am a person with a particular set of needs in relation to pelvic pain – I want to keep my dignity and I want to get better...

Patient

It is vital that patients are involved in developing things like symptom questionnaires to ensure effectiveness and relevancy

IPPP member

and care for people with chronic abdominal pelvic pain, and researchers interested and active in this area. There were also four workshop observers from the sponsor organization. A full list of workshop participants is available in Appendix 3.

About the International Pelvic Pain Partnership (IPPP)

The partnership started in March 2012 with a meeting in London of representatives interested in collaborating on research and services for chronic pelvic pain. These groups already showed a high degree of communication and interaction but the partnership attempted to put this work on a more formal and recognizable footing and agree priorities for shared activity.

“The IPPP is committed to substantially improving education, early and accurate diagnosis, effective treatment/management, and realistic prognosis for neuropathic chronic and visceral pelvic and perineal pain. We intend to increase the participation of people in research and services development, so that these objectives are achieved in the next decade.”

Key aspirations of the IPPP are:

- ▶ Better awareness education, understanding and experience of physicians to take chronic pain seriously, diagnose effectively and treat effectively;
- ▶ Better access to (integrative/interdisciplinary) pain management;
- ▶ Improving quality of life and comfort, with more respect for the condition;
- ▶ Empowering more women and men to ask for better treatment and care (self management);
- ▶ Less confusion regarding terminology and definitions; and
- ▶ Better research to underpin all of the above.

A full list of the partners is in Appendix 2.

Workshop process and activity

Overview

The workshop was designed as a first exploratory step in patient representatives working with researchers and clinicians on areas of shared interest. After some scene-setting presentations, including the background to the IPPP and some information about types of research needed in chronic pelvic and abdominal pain, participants split into smaller discussion groups – loosely based on the components of the Map of Medicine® pathway of care and treatment for chronic pelvic pain. Groups fed back highlights from their discussion and everyone was invited to contribute views and perspectives on the ideas presented.

Following a refreshment break, participants revisited the parts of the pathway that they were particularly interested in, and reconvened discussions. It was noted that the diagnostic and investigations part of the pathway was very popular at this stage of the workshop. This discussion session ended with some further large group discussion. Participants were then encouraged to use stickers provided to indicate which parts of the pathway merited the **most research**, and also which questions that had been generated merited **further investigation**. This was not meant to be a sophisticated process but a pragmatic way of assessing the preferences of the workshop participants about the issues under discussion.

A full workshop programme is in Appendix 1.



Research issues highlighted in small group discussions

<i>Stages of the pathway</i>	Research needed – the statements in bold were ranked highly by workshop participants, and are in order of their rank
<p><i>First consultation in primary care setting</i></p> <p><i>Investigations</i></p>	<ol style="list-style-type: none"> 1. What is the effectiveness of a 'tool' for patients to focus on their own awareness of signs and symptoms? 2. Need to understand the perspectives of teenagers and adolescents with CPP. 3. How do we increase awareness of primary care staff of CPP? 4. What is the best way to triage (asses quickly) patients in first consultations? 5. Are pre-consultation questionnaires, assessments (computer based) useful? Use of the IPPS questionnaire is encouraged in secondary care. 6. Is there an evidence based 'app' for self diagnosis? 7. Should primary care have a specialized person (of any background) to help assess? 8. How to encourage follow-up by physician and team in a timely manner? 9. How do we achieve quicker referrals to specialists? <ul style="list-style-type: none"> - How can we utilize other health care professionals to speed up the consultation process? - How do we recognize co-morbidities in society? - Diagnostics algorithm needed. - Should local doctors manage patients in conjunction with secondary/tertiary care teams? - Should it be easier for patients to get a second opinion?
<p><i>Referral to specialist care</i></p> <p><i>Diagnosis, including – well defined conditions, chronic pelvic pain syndrome, no well defined condition, consider other</i></p>	<ol style="list-style-type: none"> 1. What is the effectiveness of a symptom questionnaire for patients to use before the first referral consultation? 2. How can we develop a record or 'pelvic pain passport' to stop the revolving door of referral and investigative activity? 3. How do we develop better listening/hearing for better history taking (and ask about quality of life as well as pain)? 4. Can we develop a CPP 'triage' application for smart phones? 5. What % of patients is appropriately referred? 6. How can we prove the hypothesis that time spent in the initial consultation is time well spent?

<p><i>diagnosis</i></p>	<ol style="list-style-type: none"> 7. How can primary care practitioners maximize the reduced time available for the initial consultation? 8. What is the best way to gain the trust of the patient in the therapeutic relationship? <ul style="list-style-type: none"> - What is the role of standardized history taking in the first encounter with health services? - Can the diagnosis be multidisciplinary? - How to target symptom questions to women and men? - How to break through the specialties – to a broader assessment of needs? - How can the Map of Medicine® be adopted or embedded by GPs?
<p><i>Treatments including physical, psychological, pharmacological, complementary, and alternative</i></p> <p><i>Review of treatments and reassessment</i></p>	<ol style="list-style-type: none"> 1. How to best tailor treatments to individual patient? 2. What is the role of phenotyping (expression of genes) in reducing trial and error in treating CPP? 3. What are the treatment challenges when ‘different’ conditions overlap? 4. What is the best way to set realistic goals and expectations with clinicians and patients? 5. More quality of life evaluation. 6. What are the best management options when no effective treatments are available? 7. How do we improve better listening and hearing (to patients) for better treatment and care? 8. How best to manage drug intolerance? 9. How to minimize harm? 10. More research into non interventional treatments. 11. What will be the situation re treatment in 10 – 20 years time? <ul style="list-style-type: none"> - Drug interactions, side effects and intolerance. - Tackling adherence to treatments. - Achieving trust and transparency in the therapeutic relationship between patient and clinician. - How can more treatments be more available and affordable? - How to get the best treatment across several CPP services (especially when they aren’t working together very well). - What should be leading the treatment – biomarkers, symptoms, genetics?

	<ul style="list-style-type: none"> - What is the best way to treat women with CPP when they want to get pregnant?
<p><i>Management: interdisciplinary and multidisciplinary team working</i></p> <p><i>Self management</i></p>	<ol style="list-style-type: none"> 1. Is adherence to treatment an effective part of self management of CPP? 2. How do we effectively involve family members in management of CPP? 3. What is the most effect model of multidisciplinary coordination and management of CPP? 4. How do we improve multidisciplinary working for better outcomes in CPP? 5. How can patients be involved effectively in agreeing wording of medication and treatment leaflets? 6. How do multidisciplinary teams integrate their skills for patient benefit as well as collaborate and share information? <ul style="list-style-type: none"> - Management for individuals. - What is the role of e-health and media for knowledge and self management? - How aware is the health system of the possibilities of self management in CPP? - What is the role of involving family members in the management of CPP? - What are the cultural aspects of self management? - What is self management? Needs a clear definition! - What is the role of medical devices in managing CPP? - How do we keep the momentum going in EUCOMED on self management issues? - How do we keep international groups aware of what is developing in CPP management?

These ideas generated some interesting discussion points in the group. Some participants were keen on a pre-consultation questionnaire (as long as patients were involved in developing it) and others thought that it might detract from working with the patient on their terms, i.e. the patient being able to tell their own story/narrative. With diagnosis there was a great deal of consensus about the challenges of getting this part of the process right for patient and clinical benefit.

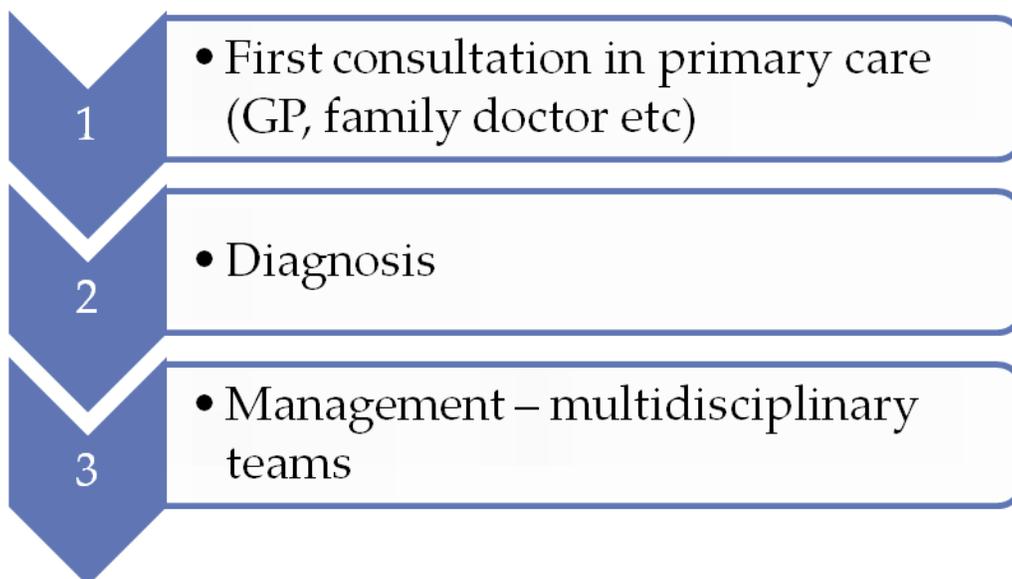
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For treatments, the main area of discussion was the challenge of ‘personalising’ treatments for patients, especially where there were treatments that were ineffective or had significant side effects. From a management point of view a key challenge was not the question why the patient needs to be at the centre of the process, but how to ensure that they are. The different health systems and practices were highlighted in all the small groups, making the collaboration of groups across Europe and internationally so important in coming to consensus about best ways forward.



What are the most important parts of the pathway to research?

Participants were asked to use stickers provided to indicate where in the pathway they thought the focus of research should be, and these are the top three areas that emerged:



Next steps

The final few minutes of the workshop were spent in discussing how to take forward some of the ideas from the session, and to promote the role of patient engagement in making decisions about abdominal-pelvic chronic pain research.

Actions:

- Sally to draft a report of the workshop with input from IPPP and other participants
- IPPP to contribute to the book from the congress – the workshop report and experiences from workshop participants could be developed (by the end of September 2013).
- Bert agreed to talk about the workshop a little in his summing up of the congress.
- Bert made a short video of Sally talking about the experience of the workshop, this will be uploaded to the congress website
- IPPP members that have taken photos of the workshop to share these with congress media
- Sally and IPPP to share their prioritised research ideas with UK NETSCC as they have an imminent chronic pain call for research ideas

Appendix 1

Workshop programme

Time	Activity	Facilitator/speaker
08.30	Registration and networking	
09.15	Welcome to workshop, role of IPPP Introductions, workshop rationale, objectives and process	Judy Birch, Pelvic Pain Support Network Sally Crowe, Crowe Associates Ltd
09.30	The role of evidence in pelvic pain diagnosis, treatment and management	Jane Daniels, Birmingham Clinical Trials Unit, Birmingham University
09.45	What are the ongoing uncertainty in diagnosis, management and treatment, from patient and professional perspectives?	Small group activity
10.30	Break	
10.50	<ul style="list-style-type: none"> Review the areas of ongoing uncertainty – issues to add? Discussion 	Large group activity
11.30	Identifying priority areas for consideration	Large group activity
12.15	<ul style="list-style-type: none"> Where are there areas of consensus? How does the group want to represent this activity to the wider pelvic pain community of interest? Summary and evaluation 	Large group activity Sally Crowe
12.30	Workshop closes – lunch at congress	

Appendix 2

International Pelvic Pain Partners

Pelvic Pain Support Network (UK)

Netherlands Interstitial Cystitis Patients' Organization

Vulval Pain Society (UK)

Endometriosis Association of Ireland

AFCI (Association Francaise de la Cystite Intersitielle)

MICA (Multi- national IC Association)

International Painful Bladder Foundation

Associazione Italiana Endometriosi

ACACi (Spain Interstitial Cystitis Association)

AeAP-NP (Spanish Association for Pelvi-Perineal pain)

Endometriosis Association Iceland

Endometriosis Association Norway

Endometriosis Association Netherlands

AICI (Italy Interstitial Cystitis Association)

Appendix 3

Workshop participants

First name	Last name	Country	Organisation/establishment
Judy	Birch	United Kingdom	Pelvic Pain Support Network
Jenny	Birch	United Kingdom	Pelvic Pain Support Network
Bebhinn	Nicliam	Ireland	Endometriosis Association Ireland
Jane	Meijlink	Netherlands	International Painful Bladder Foundation
Francoise	Watel	France	AFCI
Andrew	Horne	United Kingdom	University of Edinburgh
Anushka	Tirlapur	United Kingdom	Queen Mary, University of London
	Van Poelgeest-		Netherlands Interstitial Cystitis Patients
Lynne	Pomfret	Netherlands	Organization-ICP
Ying	Cheong	United Kingdom	University of Southampton
Gareth	Greenslade	United Kingdom	North Bristol NHS Trust Pain Service
Susana	Sancho	Spain	AEAP-NP
Gloria	Romanello	Spain	ACACI
Jane	Daniels	United Kingdom	University of Birmingham
Bjork	Felixdottir	Iceland	Icelandic Endometriosis Association
Wolfgang	Schroeder	Germany	Grünenthal GmbH
Emilio	G. Quetglas	Spain	Grünenthal GmbH
Märta	Segerdahl Storck	Germany	Grünenthal GmbH
John	Hughes	United Kingdom	The James Cook University Hospital
Bert	Messelink	Netherlands	University Medical Centre Gronigen Netherlands
Klaus	Schiene	Germany	Grünenthal GmbH
JeanJacques	Labat	France	CHU, Nantes
Lorena	Fernandez	Spain	Grünenthal GmbH
Oriel	Porta	Spain	Sant Pau Hospital