



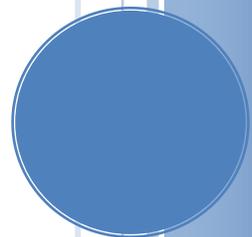
REPORT OF A WORKSHOP: PATIENT AND PROFESSIONAL PERSPECTIVES OF CHRONIC PELVIC PAIN

Workshop held as part of the Second World Congress on Abdominal and Chronic Pelvic Pain

The workshop aim was to facilitate discussion between people who experience chronic pelvic pain (via the International Pelvic Pain Partnership) and health professionals and researchers that specialize in chronic pelvic pain. Participants heard about Patient Reported Outcome Measures and Core Outcome Measures for clinical trials in chronic (pelvic) pain. Participants explored outcomes for chronic pelvic pain in day to day treatments, self management, and research. Smaller facilitated discussion groups shared views and experiences of specific outcomes then prioritized these. A whole group sharing session highlighted the differences and similarities across the small groups. There were some issues that generated robust debate, e.g. how we name and label outcomes, and the challenges of measuring outcomes. We concluded with a presentation and discussion about classification of chronic pelvic pain and the importance of involving people affected by chronic pelvic pain in these debates.

Declarations of interest: The venue was provided by the congress organizers. All speakers, participants and facilitators attended in a voluntary capacity. Grunenthal provided refreshments and assisted with travel for patient/patient representatives. Grunenthal had no input into the educational programme or the speakers/participants.

8/04/2015 Revised 04/04/2016



Report of a workshop: patient and professional perspectives of chronic pelvic pain

Workshop held as part of the Second World Congress on Abdominal and Pelvic Pain

Report written by Sally Crowe, with contributions from Judy Birch, Jenny Merriman, Andrew Horne, Jane Daniels, John Hughes, Jane Meijlink, Miznah Al-Abbadey and Katrin Neustadt

Workshop objectives:

- ▶ To review the progress (topics, types of studies) in Chronic Pelvic Pain research since the last congress in 2013 in Amsterdam
- ▶ To discuss Outcome Measures for Chronic Pelvic Pain research/services
- ▶ To consider standardization of language and coding for Chronic Pelvic Pain – and how patients can get involved
- ▶ To explore an ‘app’ for chronic pain and its’ relevance for Chronic Pelvic Pain

International Pelvic Pain Partnership (IPPP)

The IPPP is an informal partnership of organizations committed to substantially improving education, early and accurate diagnosis, effective treatment/management, and realistic prognosis for neuropathic chronic and visceral pelvic and perineal pain. A list of members is at the end of this report.

Workshop participants

Forty three people participated in the workshop, 21 of these were women experiencing CPP (with different causes and conditions) and 17 were health professionals or researchers, 2 were volunteers from the UK Pelvic Pain Support Network and 3 were from the workshop sponsor Grunenthal. Most of these were by prior invitation. On the day other health professionals (i.e. not invited) wanted to participate, the workshop team allowed some new participants but not so many that would upset the desired balance of the day.

Because of the size of the workshop we did a short introductions exercise, which encouraged participants to find and introduce themselves to someone that they didn’t know already.

Research presentation

The first presentation was from Judy Birch from the Pelvic Pain Support Network and Jane Daniels from Birmingham University (UK) who outlined some important published research as well as articles in press and new research in CPP.

Published:

- Cheong YC, Smotra G, Williams ACDC. Non-surgical interventions for the management of chronic pelvic pain. *Cochrane Database Syst Rev* 2014

- A meta-ethnography of patients' experiences of chronic pelvic pain: struggling to construct chronic pain as 'real' Francine Toye, Kate Seers and Karen Barker, JAN June 2014
- BMJ July 2014 Editorial T Fahey, Bebhinn Nicliam, Assembling the evidence for patient centred care - little evidence exists on patients' views, experiences, and preferences regarding interventions for chronic pelvic pain
- Prevalence of chronic pelvic pain among women: an updated review. Ahangari A. <http://www.ncbi.nlm.nih.gov/pubmed/24658485>
- [Actas Urol Esp.](#) 2014 Jun;38(5):298-303. doi: 10.1016/j.acuro.2013.09.006. Epub 2013 Oct 25. Prevalence and risk factors of pelvic pain.
- Chronic pelvic pain in Spanish women: prevalence and associated risk factors. A cross-sectional study. Díaz-Mohedo E1, Hita-Contreras F2, Luque-Suárez A3, Walker-Chao C4, Zarza-Luciáñez D5, Salinas-Casado J. <http://www.ncbi.nlm.nih.gov/pubmed/24992769>

Ongoing studies

- The SUPPORT trial: Randomized trial of a self help guide for women with persistent pelvic pain in primary care. Manchester
- Pelvic Congestion Syndrome Systematic Review: Champaneria et al 2015 *Health Tech Assess* in press (this means it is in the process of being published)
 - Is there an association between dilating/ refluxing/ incompetent pelvic veins (PVI) and chronic pelvic pain?
 - Can we make a diagnosis of pelvic congestion syndrome?
 - Does occlusion of incompetent pelvic veins improve pelvic pain?
 - Trials/Studies starting to recruit before end of 2015
- GaPP 2 Multi centre RCT funded by NIHR EME: 300 women with CPP and no obvious pathology at laparoscopy: Gabapentin (up to 2700mg/day) or placebo
 - Primary outcome: worst and average pain over 4wks after 8wks stable treatment
 - fMRI sub-study at Edinburgh
- NIHR funded RCT of pelvic vein occlusion *Manchester group*
- NIHR funded RCT of a mindfulness phone app *Dr Lisa Ball, Barts and the London Hospital*

The importance of recognizing qualitative research was emphasized. There was a short discussion about these items and we heard about other relevant research.

The following websites are useful sources of information about ongoing research:

United Kingdom

<http://public.ukcrn.org.uk/>

Europe

<http://cordis.europa.eu/>

Worldwide

<https://clinicaltrials.gov/>

<http://apps.who.int/trialsearch/>

<https://www.clinicaltrialsregister>

Focusing on outcomes in Chronic Pelvic Pain

Sally Crowe, workshop facilitator outlined the next part of the workshop which was to focus on outcomes (results) of research and/or treatments and care for chronic pelvic pain.



Presentation Patient Reported Outcome Measure for Chronic Pelvic Pain

The first presenter on this topic was Miznah Al-Abbadey from the UK who outlined her PhD project on a Patient Reported Outcome Measure (PROM) for Chronic Pelvic Pain. A PROM is a tool that patients use to record outcomes (such as pain levels); the data can be used for research and/or for consultations with health professionals and even for self management. Miznah wanted to develop a PROM that works for women who experience any sort of chronic pelvic pain, regardless of their underlying cause or condition.

The development of the PROM was based on findings of a study that explored the impact of CPP on women's lives. A total of 25 women took part and were interviewed individually to share and discuss their experiences with CPP. Important themes included the impact of chronic pelvic pain on relationships, changed self and emotional wellbeing. The PROM was then piloted; asking for women's feedback on the items. This is an ongoing study and

the PROM is currently available online to be filled in by a large number of women with CPP for its last stage of development. Miznah's presentation generated a lot of questions about her PROM in particular, PROMS for chronic pain more generally and how much this approach can be used in research and in long term management. The length and complexity of questionnaires used is a problem, perhaps it is appropriate to use longer tools for research purposes and shorter ones for clinical and day to day use?

Miznah's slides are available here: https://prezi.com/swl2ixfu9nik/a-patient-reported-outcome-measures-project/?utm_campaign=share&utm_medium=copy



Miznah Al-Abbadey

Small Group work:1

The large group then dispersed into pre allocated small groups around the hall, these were facilitated by John Hughes, Jenny Merriman, Andrew Horne and Jane Daniels. The purpose of these groups was to discuss a nominal list of outcomes drawn up by the workshop team (using actual research studies and clinical and patient experience). These outcomes were printed onto A4 cards (a different colour for each group). The facilitators ensured that everyone introduced themselves (each group was a careful mix of patients, researchers and health professionals), and set out the discussion task. Generally each participant took it in turns to talk about one of the outcomes; participants were encouraged to write comments on the outcome cards suggesting rewording or key issues in the discussion.

Most small groups managed to discuss all the outcomes and get a sense of which ones mattered and for which groups of women, for example fertility would matter to women of childbearing age as a functional outcome, but for older women it might be a more psychological outcome if they were infertile due to their health condition. Each group gave some highlights of their discussion and there were a couple of outcomes that generated a lot of views. One of these was 'Pain Catastrophising', for some in the room this felt like a very hostile, difficult and threatening phrase. Using it may be counterproductive, as some participants felt that it may be interpreted as "*all in your mind love*" but for researchers "*it's just a word*" with no associated issues. We concluded that it may be helpful to have more information about this outcome, as it is used in clinical trials. More information about it here <http://sullivan-painresearch.mcgill.ca/pcs.php>

Fatigue and tiredness was an outcome that several groups talked about as a 'silent' symptom of CPP and often as difficult to manage as pain relief.

Groups were also encouraged to think about and discuss the wording of the outcomes under focus. This generated some fascinating insights for example; sexual function/activity is very personal and may cover a wide range of activity and that may include sexuality, intimacy and sexual orientation.

There were some similarities across groups but also interesting differences in these discussions. However the main point of this exercise was for people to feel comfortable talking about a range of outcomes and be familiar with this material for the next exercise.

Small Groups



Presentation: Core Outcomes in Chronic Pain

The next presentation was from Katrin Neustadt who is part of a group at the University of Dresden, Germany that is developing a set of core outcomes for use in effectiveness studies of multidisciplinary pain therapy. Core Outcome Sets often called COS for short are the minimum that should be measured and reported in all clinical trials of a specific condition or therapy setting, and are also suitable for use in clinical audit. This work is funded by the German Government and part of the COMET programme for developing patient reported outcomes for research in chronic pain.

Katrin described the comprehensive ways that the VAPAIN project has involved a range people in developing the core outcomes over a 4 step process. This began with reviewing the existing research in this area (chronic pain), consensus meetings, focus groups and a large survey. She focused on the focus group results, highlighting the tensions in using language to explain outcomes that people might interpret differently, and the challenges of using scores again which might be used differently. She concluded that the experience of involving people living with chronic pain was enriching, gave interesting insights, helped to test out ideas and was a pleasurable experience for all involved.



Katrin Neustadt

Following lunch the group reconvened to start the second small group task.

Small Group Work:2

In the same small facilitated groups participants were asked to order the A4 outcome cards into an order of importance that they could agree on. The four groups approached the task in slightly different ways, which was really interesting.

Some moved into a linear model of lining up the cards in order of importance, another group decided on grouping outcomes into key themes which were then prioritized, another group 'took a knife' to the outcomes removing those that they didn't agree with (or merited more detailed discussion and understanding), and finally a group went with a diamond approach with a few clear 'winners' at the top, a few clear 'losers' at the bottom and a crowded middle.

In addition groups were allowed to introduce new ideas for outcomes, some groups substantially reworded some outcomes, others removed outcomes that they thought were unobtainable (complete relief of pain, cure) or where they thought the item was more of a target or goal of treatment and self care rather than an outcome.



Small Groups



Once the task was completed everyone appraised each other's important outcomes and each group was invited to contribute comments about their process and important outcomes.

It felt important at this workshop to allow the groups some flexibility in how small groups undertook this exercise, and it was also important for all the views to emerge. However this does mean that combining the work is more complex.

Analysis method

- All cards were collected in order and numbered manually
- Photos were taken of each of the small group card order for reference
- Group placing of each card were noted and entered into a spreadsheet
- A comments section allowed notes to be made about the particular outcome such as word changes, or comments recorded by the small group.
- Similarity of outcome card placing was noted across the four groups
- Where an outcome achieved a **placing of Top 5 in all four groups** this was considered an important shared outcome from the process.

Results of small group prioritization exercise

The table below represents the voting preferences of the four groups combined:

Outcome area	Blue Group	Green Group	Yellow Group	Pink Group	Comments
Areas of high consensus					
Quality of life	2	3	1	1	Green - more positive framing – e.g. capabilities, freedom, better processes to measure
Psychological	2	3	1	2	Blue would put this as part of QoL. Yellow suggested global plus personal measurement tools. Green include it in bundle with QoL, sexuality, ability to work etc.
Fatigue and tiredness	2	3	2	5	
Areas of some consensus					
Social activities	2	3	4	6	E.g. pursuing hobbies
Pain	3	2	8	4	Better pain measures needed
Adverse effects of treatments	7	2	8	3	Green – dependent on treatment type
Sexual activity	4	3	5	6	Green - Suggest reword to sexuality and relationships
Work productivity	2	3	3	6	Yellow and Green – better and broader definition
Fertility	4	3	8	6	Age dependent
Areas of much less consensus					
Pain catastrophising	5	2	7	Removed	Some groups wanted to reword this as it is negative; e.g. pain belief, coping mechanisms, management were preferred terms. Yellow group wanted more debate
Symptom improvement	1	2	4	Target not an	Use measure yourself medical outcome MYMOP

				outcome	
Cure	3	1	A target not an outcome	Removed	
Need for pain medications	6	2	4	Target not an outcome	Include use of other treatments such as services and non medicinal treatments
Complete relief of pain	3	2	Removed	Target not an outcome	
General health	2	3	7	Removed	Green group linked this to physical activity. Blue group put this as part of QoL
Suggestions for new outcome areas					
Quality of relationships, partners and friends					New outcome area suggested by Blue Group
Best possible relief of pain					New outcome area suggested by Green Group
Empowerment					New outcome area suggested by Green Group –could influence other outcomes e.g. self management
Support empathy and understanding					New outcome suggested by Pink Group

Discussion

Outcomes that appeared in the top five placing of all four groups include; quality of life, psychological outcomes and fatigue and tiredness. Comments about these outcomes included the challenges of measuring quality of life but the tendency to frame it in negative terms i.e. people wanted it framed in more positive terms such as capability to live life to the full, freedom to live life to the full etc. There were differing views about psychological outcomes some felt it could be part of quality of life measurement, others were clear that it merited its own measurement, this may be dictated by the sort of intervention that is being measured e.g. mindfulness. Fatigue and tiredness was felt to be an important outcome as it was more difficult to manage and was potentially more debilitating than pain. There were a range of comments around work, and productivity. For some it is caring for a family or loved one, for others it is volunteering and for others it is paid employment, and for some it is all three!

Some outcomes were more difficult to talk about in the workshop, such as psychological and sexual, and talking about pain can be painful! There were a lot of points about how to measure pain – how often, intensity, affecting daily living, out of normal patterns (for some pain in background is the norm and it is the extra that causes problems) and how often have you forgotten about your pain?

Everyone agreed that the discussion showed how interconnected outcomes are and it could be challenging to interpret them in isolation, for example the relationship of being socially well and having better self management.

Presentation: Standardization: why patients need to be involved

Jane Meijlink (International Painful Bladder Foundation) presented an overview of why patients need to be involved in standardization of terminology, definitions, taxonomies and guidelines and what role patient advocates and support groups can and should play. Healthcare is a chain with multiple links, and standardization of terminology and definitions can have an impact on every link in the chain and therefore a major impact on the patient, the patient's healthcare and ultimately the patient's whole family. It goes without saying that new or changed terms or definitions should help the patient, not form a hindrance, and should never actually cause harm to the patient, whether medically, financially or otherwise. Patient organizations and their representatives can provide standardization committees with supplementary information and insight, helping to create a comprehensive picture of each condition and everything this involves along the entire healthcare chain.

Patients can ensure that all aspects of a condition are covered, that no patients or symptoms are excluded and that there is no adverse impact on the patient in practical terms following implementation. Particularly important for the patient is that official recognition of the name of the condition means eligibility to receive reimbursement of treatment, unemployment benefits, disability benefits and social services and care. In the past, standardization, taxonomy and guideline committees have tended to go over the heads of patients and have looked at terminology issues from research and clinical points of view, but failed to look further along the chain at the potential impact on the patient in practical terms when implemented.

Jane emphasized that we need to find some way of training patients to enable them to participate fully in standardization and guidelines.



Jane Meijlink

Final presentation: What are the implications of the current International Classification of Disease 11 coding for chronic pelvic pain?

Judy Birch gave an overview of the process whereby disease is classified and how this affects services, benefits and self management. The International Classification of Disease ICD is the standard diagnostic tool health population and clinical purposes. ICD is used by physicians, nurses, other providers, researchers, health information managers and coders, health information technology workers, policy-makers, insurers and patient organizations to classify diseases and other health problems recorded on many types of health and vital records, including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States. ICD is used for reimbursement and resource allocation decision-making by countries.

Key points from Judy's presentation included:

- Goal : to create a classification system that is applicable in primary care as well as in specialized settings
- Using multiple-parenting. Each diagnosis has a primary parent, but is cross-referenced to other categories that function as secondary parents
- Chronic pain is defined as persistent or recurrent pain lasting longer than 3 months
- For each diagnosis, pain intensity and disability will be reflected
- Psychosocial factors can be recorded for each diagnosis
- Challenge: to ensure that conditions in our field are adequately included

There is a concern that there is a lack of expertise in the field of chronic pelvic pain represented on the TAG (Topic Advisory Group) for Reproductive and Urogenital health that is responsible for developing the coding for chronic pelvic pain conditions. Judy appealed to anyone in the audience to consider getting involved in this.

Finally Judy outlined ongoing work with developing 'Apps' software for use with smart phones and tablets that collected user (patient) generated data for use in clinical consultations and research. She suggested that apps can potentially save both doctor and patient time, describing what happened (sequence of events, patterns, trends) with pain and other symptoms. Apps may also help save unnecessary hospital and clinic journeys, reduce 'white coat' syndrome (i.e. doctor induced anxiety), reduce recall error (this is where in a consultation it can be difficult to remember details about pain over time, and app data can provide a picture of data over time. Generally apps are proving popular as they may contribute to reporting better evidence and get better care (right treatment, right person, right time).

Several participants then tested the two pain clinic apps at the end of the workshop and provided some general feedback for the developer.



Feedback from the workshop

People were asked to tell us how the workshop was for them and here is what people said:

- Many thanks for a very enjoyable educational and maturational day
- Good opportunity to network and share experiences
- Fantastic opportunity to meet with other groups thanks for inviting us
- Thanks for inviting me – changed my practice
- Very informative
- Great group work and atmosphere
- Many thanks to everyone (several of these)
- Thanks from ACACI Spain for all your work and encouragement
- This is just the beginning!

Appendix 1: Workshop programme

10.30	<ul style="list-style-type: none"> • Welcome to workshop, role of IPPP • Introductions exercise • Workshop objectives and process 	Judy Birch, Co Founder of Pelvic Pain Support Network (UK) Sally Crowe, IPPP Member
10.45	Overview of ongoing and completed research since the last Congress	Judy Birch and Jane Daniels Research Fellow/ Coordinator of the Birmingham Clinical Trials Unit, UK
11.00	What are outcomes in Chronic Pelvic Pain? Group exercise	Group Facilitators
11.50	Developing a Patient Reported Outcome Measure - project	Miznah Al-Abbadey Centre for Applications of Health Psychology (CAHP), University of Southampton, UK
12.10	Core research outcomes for chronic pain - VAPAIN Project	Katrin Neustadt, Research Assistant, VAPAIN Project, Dresden University, Germany
12.30	<i>Lunch Break</i>	
13.15	Small group discussions <ul style="list-style-type: none"> • Which outcomes really matter? • What are the important outcomes patients can measure for self management? (e.g. Apps) 	Group Facilitators
14.15	Standardization: why patients need to be involved Update and progress on standardization of medical terminology and definition ICD 11 Update	Jane Meijlink, Chair International Painful Bladder Foundation Judy Birch
14.50	Summing up and next steps	Sally Crowe
15.00	<i>Workshop closes</i>	
	Demonstration of a chronic pain App - optional	Judy Birch

Appendix 2: Participants List**S = speaker, F = Facilitator**

Patients
Judy Birch (S), Donna Timms, Carolyn Martindale, Julia Hough, Kathie Berger, Nicole Honegger, Martine Jacquot, Claudine Bosi, Nicole Briand, Henriette Van Bellen, Gloria Romanello, Asuncion Caravaca, Jacqueline Veit, Jane Meijlink (S), Laurel Burton Talley, Mary Heslin, Shauna Heslin, Sally Crowe (F), Nicole Briand, Unguild Utrehus, PamelaDehne
Patient Association Trustees and staff
Winona Harrod, Jenny Merriman (F)
Health professionals/researchers
Katrin Neustadt (S), Maeve Whelan (PM only), Andrew Horne (F), John Hughes (F), Jane Daniels (S and F), S Brown, Katy Vincent, Miznah Al-Abbadey (S), Tracy Miles, Katrine Petersen, Bert Messelink, Johanna Sverrisdottir, Katrinka Hauge, Gareth Greenslade, William Rea, Beta Vadodaria, Micheline Moyal Barraco, Fetske Hogen Esch
Sponsors: Grunenthal
Emilio Quetglas, Katrin Seemeyer, Wolfgang Schroder

Appendix 3: Information about IPPP

"The International Pelvic Pain Partnership 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 the International Pelvic Pain Partnership in research and services development, so that these objectives are achieved in the next decade" For the IPPP it is all about expert patients talking and working with specialist clinicians.

Partner organizations include:

Pelvic Pain Support Network (UK), Netherlands Interstitial Cystitis Patients' Organization, Vulval Pain Society (UK), Endometriosis Association of Ireland, AFCI (Association Francaise de la Cystite Interstitielle), 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)