



IAPO Member Case Study



Advocating for Patient Involvement in Clinical Guidelines: the Experience of the Pelvic Pain Support Network and the World Federation of Incontinent Patients

Introduction

This case study describes the work of the Pelvic Pain Support Network (PPSN) and the World Federation of Incontinent Patients (WFIP) in advocating for greater patient involvement in clinical guidelines and highlights their key achievements.

Background

The Pelvic Pain Support Network was founded in 2006 to provide support, information and advocacy for those with pelvic pain, their families and carers. PPSN communicates with health professionals and the public about issues of importance to patients and encourages research to improve knowledge and understanding of pelvic pain and its impact. It was founded in response to a lack of information and resources for patients with pelvic pain and to encourage an interdisciplinary approach to pelvic pain.

The World Federation of Incontinent Patients was founded in 2005 to act as an international umbrella for national continence associations worldwide. WFIP is dedicated to promoting the interests of patients suffering from incontinence and related pelvic floor disorders worldwide. WFIP provides its members with comprehensive scientific and patient-centred information, guidelines and educational resources. WFIP has an increasing global focus and seeks international co-operation and contact with official bodies and patient advocacy groups.

The 3rd Global Patients Congress

In 2008, PPSN and WFIP attended IAPO's 3rd Global Patients Congress in Budapest, Hungary. At the Congress, Judy Birch, Chief Executive of PPSN, and Lynne Van Poelgeest, then Vice-President of WFIP, spoke about the similarities between their organizations and decided to work

together through IAPO's Twinning Service. Twinning is a service where two or more IAPO members work together on an agreed project. It brings together the different experiences and expertise of the patient groups involved and is designed to enhance the skills and learning of IAPO members. To begin the project, Judy and Lynne outlined its key aim which was to gather evidence on patient involvement in clinical guidelines and to bring about a more interdisciplinary approach to the development of clinical guidelines.

Patient involvement in clinical guidelines

In the research that followed, Judy and Lynne identified a lack of patient involvement in the design and implementation of clinical guidelines. They researched patient involvement in clinical guidelines and the adherence



of professional bodies to the [European Appraisal of Guidelines for Research & Evaluation \(AGREE\) Instrument](#). The AGREE Instrument provides a framework for assessing the quality of clinical practice guidelines and its requirements state that: 'the guideline development group includes individuals from all relevant stakeholder and professional groups', which includes patient groups. After contacting patients' organizations in the fields of urology and gynaecology to ask if they wanted to put their names to a joint letter, Judy and Lynne wrote a letter on behalf of 13 of these organizations from eight countries. This letter was then sent to eight national, European and international healthcare professional bodies highlighting their concerns surrounding the quality of clinical guidelines and the lack of patient involvement in clinical guidelines. In this letter they included the AGREE Instrument as well as [IAPO Guidelines for Patient Involvement](#) which provide frameworks for multi-stakeholder involvement. Five of the bodies responded.

Since contacting these organizations, Judy and Lynne have been invited to speak at regional, national and international meetings and have been increasing awareness of the importance of an interdisciplinary

approach to clinical guidelines as well as raising awareness of pelvic pain and incontinence. Judy and Lynne have argued that as well as being a patients' rights issue, involving patients in decision-making processes is essential in bringing about better and more economical healthcare outcomes.

▶ In 2010, PPSN and WFIP shared their experiences of Twinning at IAPO's 4th Global Patients Congress in Istanbul, Turkey, which provided an opportunity to share their methodology and successes with other patients' organizations.

Outcomes and successes

Since Judy and Lynne began advocating for greater patient involvement in the development of clinical guidelines, professional bodies have been increasing their efforts to involve patients in the design and implementation of clinical guidelines in Europe. PPSN has run sessions on chronic pelvic pain as part of a university undergraduate curriculum for nurses to promote the importance of patient involvement. As part of the project, they have had several meetings with the [European Association of Urology \(EAU\)](#) which

resulted in a formal review of all the guidelines produced by the EAU. As a result of this policy change, patients' organizations are now involved in peer-reviewing EAU guidelines and WFIP are in the process of forming a partnership with EAU.

Judy has given presentations on patient-gathered data about endometriosis and chronic pelvic pain to clinicians and researchers at medical conferences and workshops at international level. Judy has also had input into the [National Institute of Clinical Excellence \(NICE\)](#) Health Technology Assessment (HTA) and European Union (EU) consultations.

Additionally, Judy is a member of the UK National Health Service (NHS) evidence accreditation committee, and an advisory committee member for Health First Europe. In 2011, Judy was elected to the board of the newly established umbrella patients' organization, Pain Alliance Europe.

Lynne is acting as the patient representative for the steering committee for the EU European Innovative Program for Chronic Conditions Management and the Active and Healthy Ageing Program whose target is to add two healthy life years by 2020 to the European population. In 2011, WFIP was

elected to the board of the [European Platform for Patients' Organisations, Science and Industry \(EPPOSI\)](#), a multi-stakeholder think tank which aims to improve healthcare outcomes. As a board member of EPPOSI, Lynne has closely monitored the findings of the [EU Patient Partner Program](#) which have been invaluable in helping to identify issues of importance to patients, such as patient involvement in clinical trials.

The WFIP has been invited to attend the EuroMeeting of the [Drug Information Association \(DIA\)](#), which will be held in March 2012. This event is a great opportunity to put forward the patient perspective.

► **By working together through the Twinning Service, Judy and Lynne have increased the voice of the patient in decision-making processes and have demonstrated the value of working together across disease areas and geographical boundaries to tackle broad issues. By raising awareness of these conditions, PPSN and WFIP hope that they have gone some way towards removing the stigma associated with pelvic pain and incontinence.**

PPSN's work on patient involvement has been recognised through an award. At the 5th European Patients' Rights Day in Brussels in April 2011, the Active Citizenship Network awarded PPSN a prize for Best Practices in Civic Participation in Health for their submission on patient involvement in HTA's and clinical guidelines.

PPSN has also won an award for best abstract at the International Pelvic Pain Society annual scientific meeting in Istanbul in May 2011.

Challenges

The approach of PPSN and WFIP was simple and cost-effective. Writing letters and networking did not require a large amount of financial resources yet it achieved wide-reaching outcomes and can be adapted by other patient groups to suit their healthcare contexts. However, the process was not without its challenges. It was a long process and both organizations have limited capacities. Producing materials, speaking at national and international gatherings and convincing the various stakeholders of the merits of an interdisciplinary approach was time-consuming and, at times, daunting.

Another challenge was changing organizational attitudes to patient engagement. Judy and Lynne encountered resistance from some professional bodies and clinicians who do not understand the value of an interdisciplinary approach and were reluctant to accept changing attitudes towards healthcare and patient involvement.

Judy and Lynne also found that patients can lack confidence and knowledge and need training and support to enable them to effectively advocate for patient-centred healthcare. Both Judy and Lynne have attended several training sessions which has given them the skills to enable them to work as equal partners with healthcare professionals.

Next steps

PPSN and WFIP continue to collaborate and are beginning to work across disease areas to increase the patients' voice. In May 2011, an open meeting was hosted by several professional societies involved in pelvic pain in Istanbul to facilitate the closer co-operation between professional bodies in the development of international guidelines for pelvic pain. Additionally,



at a recent event on the 'Societal Impact of Pain', which brought together policymakers and healthcare stakeholders in the European Parliament, chronic pelvic pain was included for the first time on the agenda. This event was endorsed by both PPSN and WFIP. This work demonstrates the increasing shift in Europe towards multi-stakeholder collaboration, where patient groups are regarded as equal partners.

In March 2012, PPSN will hold a meeting that will bring together patients' organizations from several countries working in the field of pelvic pain to develop a strategy for increasing involvement and awareness in the field of chronic pain. This meeting has been partly funded through the pilot of IAPO's Membership Support Fund.

How could IAPO further support this work?

IAPO could further support this work by providing PPSN and WFIP with further opportunities to speak at workshops and showcase their work. They would also like to be included in

IAPO projects where their experiences would be useful. IAPO could also develop further publications such as an advocacy toolkit to enable patients to strengthen the patient voice.

PPSN and WFIP would like to thank Ella Fearon-Low, IAPO's former Capacity Building Director, for the help and support she provided during the course of this project.

Further reading

- ▶ Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument
- ▶ Drug Information Association (DIA) EuroMeeting
- ▶ European Union (EU) Patient Partner Program
- ▶ European Association of Urology (EAU)
- ▶ European Platform for Patients' Organisations, Science and Industry (EPPOSI)
- ▶ IAPO Guidelines on Patient Involvement
- ▶ IAPO Policy Statement on Patient Involvement
- ▶ National Institute of Clinical Excellence (NICE)
- ▶ Pelvic Pain Support Network (PPSN)
- ▶ World Federation of Incontinent Patients (WFIP)

