ePPOC: Evolving from pilot to a national chronic pain registry

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Nine years ago a group of Pain Medicine Physicians and other interested parties attending the FPM refresher day /ANZCA ASM in Melbourne, Australia, put their heads together to complete surveys about outcome assessment tools they used and favoured in chronic pain in adults. A complicated spreadsheet was produced, but more importantly came the beginnings a consensus between a large group of professionals and researchers working in the field of chronic pain. From this point a steady process of collaboration and lobbying began. This covered a spectrum from clinicians and patients at the base, through to representative bodies (Australian Pain Society, New Zealand Pain Society, Faculty of Pain Medicine (ANZCA), the National Pain Summit, and the state governments. Paediatric services nationally were also keen and have now established a paediatric core data set.

The expertise of the Australian Health Services Research Institute (AHSRI) at the University of Wollongong chaired by a very capable Professor Kathy Eager, and their track record on outcome research aimed at quality improvement in Rehabilitation Medicine (AROC) and Palliative Care (PCOC), provided an interested organization with “registry experience. Their interest has included developing contemporary approaches in an outpatient population, for data collection with web based tools. The process of implementation has been inspiring, and has facilitated government support, primarily in NSW and now Victoria.

At December 31st 2014 ePPOC had data from 6361 patients in 21 services, mainly NSW(14), VIC (4) WA (1). Three paediatric services have commenced.

Many more services are progress: NSW(2), VIC(9), WA(2), QLD (1)and NZ(2).

There are many challenges as we move forward and roll out the collaboration nationally.

To be an outcome collaborative we need sufficient outcome and follow up reports with appropriate tools to measure change. In this workshop we will present and invite discussion on:

- Obtaining higher follow up rates, with data on our experience to date from a NSW centre, insights into logistics of follow up from the vicPPOP study, and discussion of some innovative approaches.
- Assessing function as an outcome. Is the BPI in ePPOC enough? And what about the vicPPOP experience using the Roland Morris Disability Questionnaire?

References: