



# **Innovations in the use of the Palliative Outcome Measures**

8<sup>th</sup> – 9<sup>th</sup> February 2018 Workshop: Outcome Measures in  
Palliative Care: Sharing the POS Family of Measures

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# Outcome Measures in Palliative Care: Sharing the POS Family of Measures

This exciting workshop showcased the innovative ways in which the POS family of measures are being implemented. Over 115 participants attended from the US, the Philippines, Taiwan, Japan, Australia, Nepal, Poland, Cyprus, Brazil, Germany Iceland, Italy, the Netherlands and the UK, demonstrating the ever-increasing global interest in the measures. Attendees included specialist and generalist healthcare professionals, allied professions, students, managers, researchers and a patient organisation.

For the first time in these annual workshops, there was a Call for Abstracts in addition to the presentations by Cicely Saunders Institute staff. The number of abstracts submitted, and the breadth of topics covered, demonstrated the global appetite for using outcome measures in palliative care. There was a balance between using the measures for research and for clinical care, but all had improving care and the quality of life for patients and families at their centre. There was unanimous agreement on the value of the measures and recommendations for successful implementation and for overcoming any barriers.

The presentations and posters by organisations advancing the use of the measures led to a highly interactive two day. As well as interesting discussion, participants made informal links to share ideas and information going forward - and a few sceptics left converted.

This report summarises the new and diverse ways the participants are using the POS family of measures in their work. The measures are being used in a variety of settings and for different purposes, from education to research to improving care in an increasing number of conditions, with successful adaptations for different countries and cultures. The measures are an important tool for measuring impact, assisting organisations internally to improve their services, and in providing the robust evidence of impact increasingly required by commissioners of health services.

## Global adaptation and validation

Currently there are over 9,000 users of the POS measures in more than 120 countries. Adopters of the measures globally are continually innovating and refining them to different conditions, ways of working and cultural norms.

Diverse challenges were described to adapting the measures to cultural norms. In Nepal, **Dr Ruth Powy** of the **International Nepal Fellowship** explained illness was not traditionally discussed and **Dr Li-Lin Kuo** from Taipei City Hospital Taiwan put this in the context of in providing good palliative care in a culture where it is difficult to talk about dying. In some countries carers and family (rather than the patients) were the people given information about the illness, making the patient-completed POS more problematic to complete. There were countries where patient respect for the doctor might make them reluctant to say they had severe symptoms. For example, in testing the reliability and validity of the Japan IPOS with cancer patients, **Dr Hiroki Sakuri** noted the lower response rates on the questions of being able to share feelings and having sufficient information, which he felt could be attributed to patients' respect for doctors and patient concern for their families.

**Dr Jason Lee** discussed the considerations at Taipei City Hospital Taiwan about potential extra questions for the traditional Chinese version of the IPOS. For instance, Chinese people hope to die at their house or in their hometown; *'falling leaves return to their roots'* and filial piety is the most important virtue. Should these be covered by one or two further questions? The final decision was that the original UK version of the IPOS was sufficient.

In some cases, there was a need to change wording because the direct translation did not have the same meaning. For both Japan and Nepal, the question 'Have you felt at peace' presented difficulties because of its perceived religious connotations (although this item has been shown to be about individual wellbeing of any or no religion).

The adaptation of the MyPOS (for myeloma) for the German context by the **University Hospital in Munich** raised issues related to both the cultural context and the specific nature of the disease (for example the persistence of symptoms between treatments). A consultation identified a need for more elaborate answer options on information requirements, respect for those patients who wanted less information, and a measure to focus on continuity of care through all phases of the disease.

The highly successful African POS reflects the particular cultural and health needs of the continent, and there is innovation in how it is delivered. In Kenya, the Aga Khan University is taking advantage of the extensive mobile phones ownership and their existing use in healthcare. They have designed, developed and tested an App for patient reporting outcome measure based on the African POS. In a country with relatively few health professionals and many isolated rural areas, this has the potential to extend considerably the use of the outcome measures.

## **Ensuring the best patient care**

Use of the POS family of measures confirmed that it is essential to ask the patients about their symptoms and needs to ensure the best standard of care. An observational study carried out in nine centres in Portugal to ascertain the main palliative care needs of patients being treated in the palliative care services illuminated a mismatch between need and delivery of services.

*"In Portugal patients are referred late and staff are overwhelmed with dealing with physical symptoms. However, our study using the Portuguese IPOS, showed that the main palliative care needs were not physical, but psychological, family-related and spiritual. Clinical teams could use the IPOS systematically to track their progress in assisting patients and family with these needs. However, there is some resistance to addressing these issues and a shortage of psychologists in palliative care services. Younger doctors are often more willing to engage with these issues and the introduction of a mandatory palliative care module in the curriculum for medicine nursing and psychology should help create a more receptive culture".* **Dr Barbara Antunes: Faculty of Medicine, University of Porto Portugal**

In **Launceston General Hospital, Tasmania**, the POS- Renal and IPOS-Renal surveys were used in two separate studies to check whether staff and patient ratings of symptom severity for patients with dialysis were the same. The studies showed, like the Portuguese study, that staff assessment of patients' symptoms was inaccurate compared to patients' self-reports and that the latter were optimal for symptom recognition and management. Importantly, it changed clinical practice in the Unit studied.

*“Our positive findings on the validity, reliability and sensitivity to change of the IPOS Renal symptom survey changed clinical practice in our unit. All patients now bring completed symptoms IPOS to dialysis and supportive care clinics. However, integrating it more widely into busy dialysis units is a challenge. It requires constant outreach to senior nurses and doctors - they need to be convinced that using the tool will improve patient care.”* **Dr Rajesh Raj: University of Tasmania**

The University of Santa Caterina, Brazil, has used the POS-S Renal to assess symptoms and quality of life in patients in a Hemodialysis unit.

*“Currently palliative care is mainly only available to oncology patients in Brazil. One of the goals Nephrology is to incorporate the model of palliative medicine to dialysis units. We found that the POS-S Renal patient card was easily understood by patients and should be used routinely to establish measures that improve patients’ quality of life.”* **Dr Christine Dal Molin University of Southern Caterina**

A number of institutions used information from the IPOS to ensure patients were referred to specialist supportive care when appropriate. **Anna Hoffman, St George Hospital, New South Wales, Australia**, described how the IPOS-Renal was also used to identify dialysis patients with high symptom burden. However, the nephrologists were uncertain whether they could address these symptoms in their busy clinics, and so an automatic referral process to the Renal Supportive Care Service (RSC) was created. This automatic referral process was also initiated by the first RSC in Canberra.

The Royal Victoria Hospital, Scotland, used IPOS in an audit of symptom prevalence in patients with decompensated chronic liver disease (DCLD) to identify which prevalence of symptoms that might trigger referral to the Hospital Specialist Palliative Care Team. Again, a high burden of symptoms was identified, which did not appear to be recognised by the medical team. However, as **Dr Alana-Brown-Kerr**, pointed out, *“our palliative care unit does not have the resources to meet the need and so it is imperative that we empower our colleagues to be able to manage some of the palliative care needs in their patients.”*

### **Enhancing the quality of care across the whole patient journey: introducing IPOS measures into routine care and extending it to community settings**

Integrated care is recognised as increasingly important to quality care. The POS measures are now being used to monitor the standard of care throughout the whole patient journey, extending outcome measures into community and home settings.

Improving quality of life for patients is a key reason for ensuring palliative care is available throughout the patient journey and was described aptly by **Drs Luigi Maiorana and Giorgio Raniolo** as *“the litmus test for (our) daily work,”* Their organisation, SAMOT, Ragusa Onlus, providing palliative care to patients at home at home in Sicily, has undertaken a pilot study using IPOS to assess whether staff and patient views on patient quality of life were the same, to ensure staff are able to enhance the quality of care. The perception of both staff and patients was found to be similar and patients showed a good perception of their quality of life that improved over time.

This joining together of expertise across systems offers great potential for moving expert knowledge into clinical practice and ensuring that clinical practice contributes to the generation

of new knowledge. The Care Home Project Team, St Christopher's Hospice London UK looked at how the POS measures can be rolled out into care homes, a setting where the assessment and treatment of palliative care needs has not traditionally been available. Care homes do not routinely use outcome measures in practice and the team addressed this by establishing an innovative collaborative baseline audit between a research centre, a hospice and two care homes.

Dementia is a growing societal problem with ageing populations. NHS Walsall Clinical Commissioning Group is piloting IPOS-Dem as part of its whole commissioning approach to improving dementia care in Walsall in an acute hospital, mental health ward, nursing home, residential home voluntary organisations and supporting carers to use it soon after diagnosis. This will ensure that it captures all the possible settings where patients with dementia are managed.

Ardgowan Hospice in Scotland described a quality improvement project, introducing IPOS across general palliative care services including into primary consultations, to identify palliative care needs in the community setting, referral to local specialist palliative care services where appropriate and improve integrated working between services.

## **Increasing impact in other areas of palliative care activity**

Innovation in the use of the POS family of measures has not been limited to research and patient care. Contributors described some of its potential advantages in education, training and management.

In Taiwan the medical curriculum does not currently include palliative care. Taipei City Hospital introduced a palliative care module for first year medical students at National Yang-Ming University. One class involved an innovative palliative care scenario and simulation activity, including using the IPOS. Feedback showed this was one of the classes most liked by students, suggesting that the IPOS could be as important to cover as other aspects of palliative care. **Dr Li-Lin Kuo** remarked in her presentation *"IPOS helped a lot. It's just like a window. Through it (medical students) can see what patients might need and it's a very good tool for learning how to take care of patients."*

St Michael's Hospice Harrogate has undertaken a retrospective quantitative analysis of patients' symptom burden over a year in the in-patient unit with the analysis overlaid onto a training package map to identify gaps in provision. As a result the Hospice has increased its mandatory training package giving a special focus on dementia and are evolving the model of the day therapy unit.

St Gemma's Hospice, Leeds, UK is seeking to identify if Outcome Assessment and Complexity Collaborative (OACC) measures can assist in understanding when patients might have a longer stay in the in-patient unit and their likelihood of discharge. This could potentially reduce the time and resources currently used in discharge planning.

Ardgowan Hospice, Scotland, has recognised the need to measure impact on the health and well-being of their patients and the efficacy of existing services, as their work moves out into the wider community. Patients at the peripheral supportive care clinics completed the IPOS at the first and last visit and significant improvements were found. These results were put into visual

representations and the use of a Spider chart was found to be the best way to demonstrate impact.

An innovative use of the outcome measures, including the IPOS, as a management tool has been developed by St Joseph's Hospice in London. It used the measures to create an Outcome Measures Dashboard as a meaningful but succinct way to track progress of outcome measures for the Hospice Clinical Governance Committee and the Board of Trustees. It included completion rates and missing data and measures of responsiveness and effectiveness, along with a short briefing document. The Hospice believes that the Dashboard could be one way of achieving buy-in to outcome measures at the highest level.

### **What is needed for successful introduction and implementation of the measures?**

This was succinctly summed up by Dove House Hospice UK as patience, persistence, communication and feedback, allowing enough time to embed the outcome measures, staff training and management support. Several organisations mention the need for an identified champion and that, where the measures are being implemented across a number of different services, there needs to be a champion in each clinical area. The role of the multi-disciplinary teams (MDT), where they exist, are important for success and several organisations comment on how the MDT meetings have become more focused and effective with the introduction of POS measures.

The location and working relationships between services can be important in how simple it is to introduce the IPOS. **Jill McKane** from Ardgowan Hospice said that the integration of IPOS in Ardgowan Hospice was relatively easy.

*"IPOS is now integrated within inpatient unit and the community palliative care clinic setting due to enthusiastic individuals driving this and being the 'first followers'. We use IPOS to complement our normal practice and blend within consultations. We used quality improvement methodology during the implementation and testing of the IPOS. We are in the process of introducing IPOS to general community services where we already have collaborative working established as we operate in a relatively small area."*

For an NHS specialist palliative care inpatient unit, Roxburghe House, Dundee, Scotland there are particular difficulties in introducing the patient-completed IPOS. One of the main issues is the frailty of the patients so that, in a pilot study, 23 of the 42 screened inpatients completed one IPOS, the others were too frail or cognitively unable to do so. Only 14 completed a second IPOS. These results informed the decision to use IPOS for baseline assessment within the admission document, with flexibility to use proxy ratings if necessary.

*"It is really important for us to be able to demonstrate to our Commissioners the impact we have on patient symptoms and quality of life and the patient score is vital to this. However, we have to balance the difficulties of obtaining these with the results we can show. It has been a long journey and, with no current IT capacity, simplicity is the key."*

**Dr Elinor Brabin Consultant in Palliative Medicine**

Ensuring that the IT systems are fit for purpose is essential, therefore IT teams need to be on board and systems (such as the patient electronic record) may need to be adapted. While use of the IPOS can increase the amount of useful data available it needs to be possible to analyse it effectively. This point was made in several of the abstracts. The Douglas Macmillan Hospice,

for example, noted the problems with the amount of data, its aggregation and the importance of consistency in collecting data. The Hospice believed that a specialist data analyst role was required to enable data to be scrutinised, and to understand why there were differences in service delivery between organisations.

## **Conclusion**

Participants at the workshop demonstrated that the POS family of measures are not only a robust validated form of measurement, but also a tool for innovation in research, patient care, education and palliative care management. They can play an important role in enabling health workers, who are not specialists to recognise and manage some symptoms in palliative care patients. The measures are adaptable and constantly evolving to work in many different illnesses and settings. They can serve both the needs of palliative care organisations globally and the needs of healthcare commissioners for proof of the impact of services. Further information is available on the POS website [www.pos-pal.org](http://www.pos-pal.org).

## APPENDIX 1

### What is the POS Family of Measures?

#### **The Palliative Care Scale Outcome Scale (POS) Family of Measures**

The (POS) family of measures are a set of free to use validated instruments to measure the physical symptoms, psychological, emotional and spiritual needs and provision of information and support for patients with progressive illnesses and end of life care. They are used in clinical care, audit, research and training to learn about the individual patient in real time, to improve performance, to demonstrate superior outcomes and to respond to 'payment by results' and outcome-driven healthcare.

The POS measures are specifically developed for use among people severely affected by diseases such as cancer, respiratory, heart, renal or liver failure and neurological diseases. The POS measures are widely used globally, including in Europe, Asia, Australia, Africa and America and are available in 12 languages. The POS family of measures are free to use and can be downloaded from the website [www.pos-pal.org](http://www.pos-pal.org). They are dynamic tools that are constantly evolving and adapting to need. The Integrated Palliative Outcome Scale (IPOS) is a new measure that incorporates the best of the POS, the POS-S (for symptoms) and the APCA African POS (designed for the African setting). Research is being undertaken through The Outcome Assessment and Complexity Collaborative (OACC) to agree on a standardised suite of outcome measures (including the IPOS), design training materials and support implementation, as well as establish feedback and reporting strategies that are nationally applicable.