

## IPOS in the UK and Germany: How Interviewing Patients Can Shape Research

### New findings from research at the Cicely Saunders Institute, King's College London

- In response to patient and clinician demands, we have developed the IPOS (Integrated Palliative care Outcome Scale) measure, which has been shaped to reflect the main symptoms and concerns of people with advanced illness.
- This study demonstrates the importance of interviewing people with advanced illness about the measures which are being used to assess and review their individual symptoms and concerns.
- The use of interviewing in two languages – for the first time in palliative care – provided important additional information. This enabled our team to create a measure which was as relevant and useful as possible for people with advanced illness, and for the professionals caring for them.

### Summary of policy recommendations

- IPOS is now available for clinical use; it is one of the few brief measures tested in this population that covers all relevant areas.
- The refined version of the IPOS is currently undergoing further testing to ensure it works well.
- The use of cognitive interviewing is a crucial part of refining measures in order to gather a wide range of perspectives from those with advanced illness themselves. Conducting interviews in two languages deepens this understanding.
- People with advanced illness did not find it distressing or burdensome to complete the questionnaire.

### Introduction

Outcome measures are a vital part of ensuring that patients' symptoms and concerns are being considered and treated by clinical teams<sup>1</sup>. It is important that these measures are specifically developed in palliative care to reflect the concerns of patients with advanced illness. These tools must also be brief to minimise the burden of completing the measures.

### Summary of Research

The IPOS consists of 10 questions which cover patients' main concerns, common symptoms, patient and family distress, well-being, sharing feelings with family, information received and other practical concerns. The IPOS measure was tested with people in advanced illness to see if it was understandable and relevant to them and their needs, and as a result it was refined further.

We interviewed 25 people with advanced illness from palliative care units, general hospital wards and in the community. The study used 'think aloud' and probing techniques to encourage people to share their opinions on the measure as freely as possible<sup>2</sup>. These methods allow different cultural contexts of patients to be explained and ensure in-depth investigation into the effectiveness of the measure<sup>3</sup>.

### Research Findings

The cognitive interviews conducted simultaneously in the UK

and Germany showed that most of the IPOS questions worked very well and accurately reflected symptoms and concerns. People with advanced illness did not find it distressing or burdensome to complete the questionnaire, and wanted to retain all the questions. Some patients suggested a longer time frame, so both a 3-day and a 7-day version of IPOS are also now available.

'Well I think it's a good questionnaire I really do... staff [have] only got to look at it and they know how you feel.' (Female aged 74 years, UK)

Some difficulties with the wording and comprehension of the questions were identified in both countries and, as a result, questions were amended to ensure the most concise and clear phrasing in both languages.

Although any questionnaire is only one part of a clinical assessment<sup>4</sup>, research shows the clear benefits of outcome measures for patient welfare and well-being.

Cognitive interviewing of people with advanced illness helped to ensure that IPOS is a valid and reliable tool in the palliative care setting and captures the most relevant issues. A limitation of this study is its relatively small sample size and a future study could involve a larger sample of people with advanced illness with a more diverse range of conditions.<sup>3</sup>

## Policy Recommendations

In order to ensure that the most effective care is provided to people with advanced illness, and that these people and their families feel listened to, we recommend that policymakers ensure:

### 1) Training and resources for routine use of IPOS are provided

IPOS has been developed in response to patient and clinician recommendations, and is now available for clinical teams to implement into routine practice. The relevant training, resources and support for staff should be provided to maximise the use of the measures to their full potential.

### 2) Patient involvement to guide research is encouraged

This study shows that palliative care patients did not find it distressing or burdensome to complete the questionnaire. They wanted to retain all of the content because they felt that the questions were important in capturing their main concerns. It is important to consider the perspectives of people with advanced illness when producing guidelines and resources which are designed to improve care.

### 3) The use of interviewing in multiple languages is supported

Interviewing in two languages has not often been used in palliative care research but this study proves it is a useful way to capture patient needs and concerns from a range of cultural backgrounds. How to word the questionnaires used by patients requires careful consideration to ensure that they are as acceptable and understandable as possible for people with advanced illness. Using the findings from interviews in two languages made the acceptability and comprehensibility better overall.

## References

1. Dawson J, Doll H, Fitzpatrick R, et al. The routine use of patient reported outcome measures in healthcare settings. *BMJ* 2010; 340: c186.
2. Willis GB. *Cognitive interviewing: a tool for improving questionnaire design*. 2005. Thousand Oaks, CA: SAGE.
3. Lee J. Conducting cognitive interviews in cross-national settings. *Assessment* 2012; 21: 227–240.
4. Watanabe S, Nekolaichuk C, Beaumont C, et al. The Edmonton symptom assessment system – what do patients think? *Support Care Cancer* 2009; 17: 675–683.

This brief was produced by the C-CHANGE team from the Cicely Saunders Institute, led by Dr Fliss Murtagh who can be contacted at [pa\\_flissmurtagh@kcl.ac.uk](mailto:pa_flissmurtagh@kcl.ac.uk).

Please reference the review as:

Schildmann EK, Groeneveld IE, Denzel J, Brown A, Bernhardt F, Bailey K, Guo P, Ramsenthaler C, Lovell N, Higginson IJ, Bausewein C and Murtagh FEM: **Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the Integrated Palliative care Outcome Scale**. *Palliative Medicine*. 2015 September. DOI:10.1177/0269216315608348  
Article freely available at: <http://pmj.sagepub.com/content/early/2015/09/29/0269216315608348.full>

### Acknowledgements and funding:

This policy brief presents independent research funded by the National Institute for Health Research under the Programme Grants for Applied Research scheme (project number RP-PG-1210-12015).

The views and opinions expressed by authors are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the NIHR Programme Grants for Applied Research programme or the Department of Health.



THE CICELY SAUNDERS INSTITUTE | KING'S COLLEGE LONDON | BESSEMER ROAD LONDON  
SE59PJ | [www.csi.kcl.ac.uk](http://www.csi.kcl.ac.uk) | +44 (0)20 7848 5516

Twitter: @CSI\_KCL | Youtube: [www.youtube.com/CSIKCL](http://www.youtube.com/CSIKCL) | Facebook.com/CicelySaundersInstitute