

# Cultural adaptation of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) for the Swiss context: a focus-interview study with relatives, district nurses and acute care nurses

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## Background

There is an increasing number of people living with dementia in the near future<sup>1</sup>. People with advanced dementia (PwD) are affected by symptoms and needs which are challenging for nurses and relatives to elicit. Assessment in acute and community care settings is not guided by a person-centred outcome measure thus debilitating symptoms are often not recognized<sup>2,3</sup>. The Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem), developed in England and translated into German, is a comprehensive, person-centred measure to aid caregivers identify symptoms and needs<sup>4</sup>. No global person-centred outcome measure for PwD in acute and community care settings is available in Switzerland<sup>4</sup>. Cultural adaptation to the Swiss primary care context is needed before use.

## Aim

To culturally adapt the IPOS-Dem for a Swiss context, evaluation of clinical utility, and inform implementation for future use.

## Methods

Semi-structured, online focus-group interviews with district nurses (DNs), acute care nurses (ACNs), and relatives (R). Discussions focused on comprehension and clinical utility (value, scope, content) of the IPOS-Dem when caring for a PwD. Focus groups were recorded and transcribed verbatim. Thematic content analysis using an inductive approach was performed. Two researchers coded 50% of the transcripts independently and discrepancies solved by consensus.

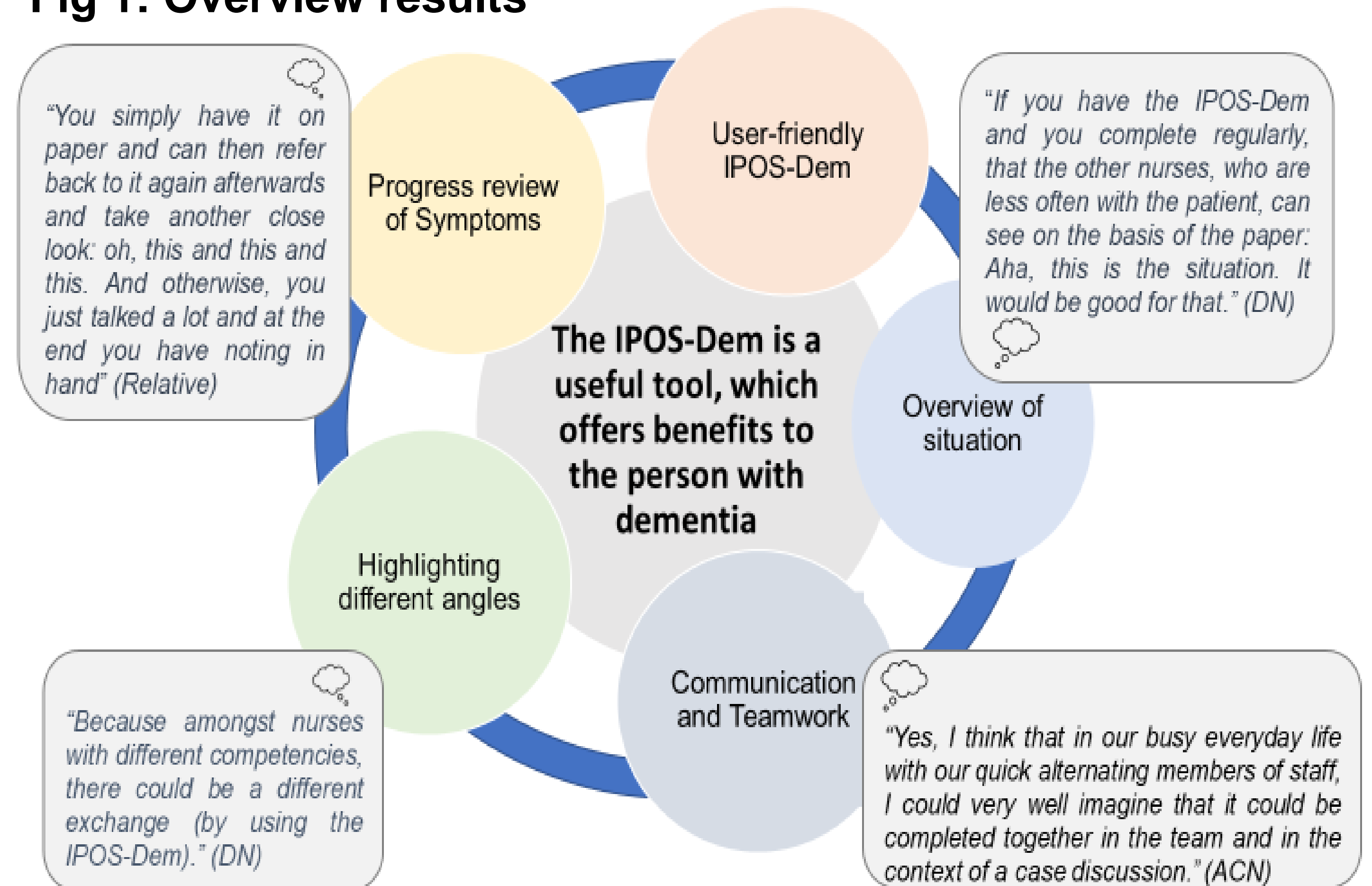
## Results I

Three focus-groups with DN (n=6), ACN (n=5), and relatives (n=4) were conducted. IPOS-Dem was reported as a valuable and important tool for use in the Swiss primary care context, as it takes the view of the PwD in a process guided environment (Fig 1). 1) DN felt it provided an overview of the current situation for targeted interventions but recommended "physical contact" be added. 2) Relatives recommended use earlier in the dementia course to help preparedness for future care planning and recommended its use to facilitate focused communication with health care professionals. 3) ACNs determined IPOS-Dem would be of value in interdisciplinary discussions but needed to know the PwD well to complete to support discharge planning.

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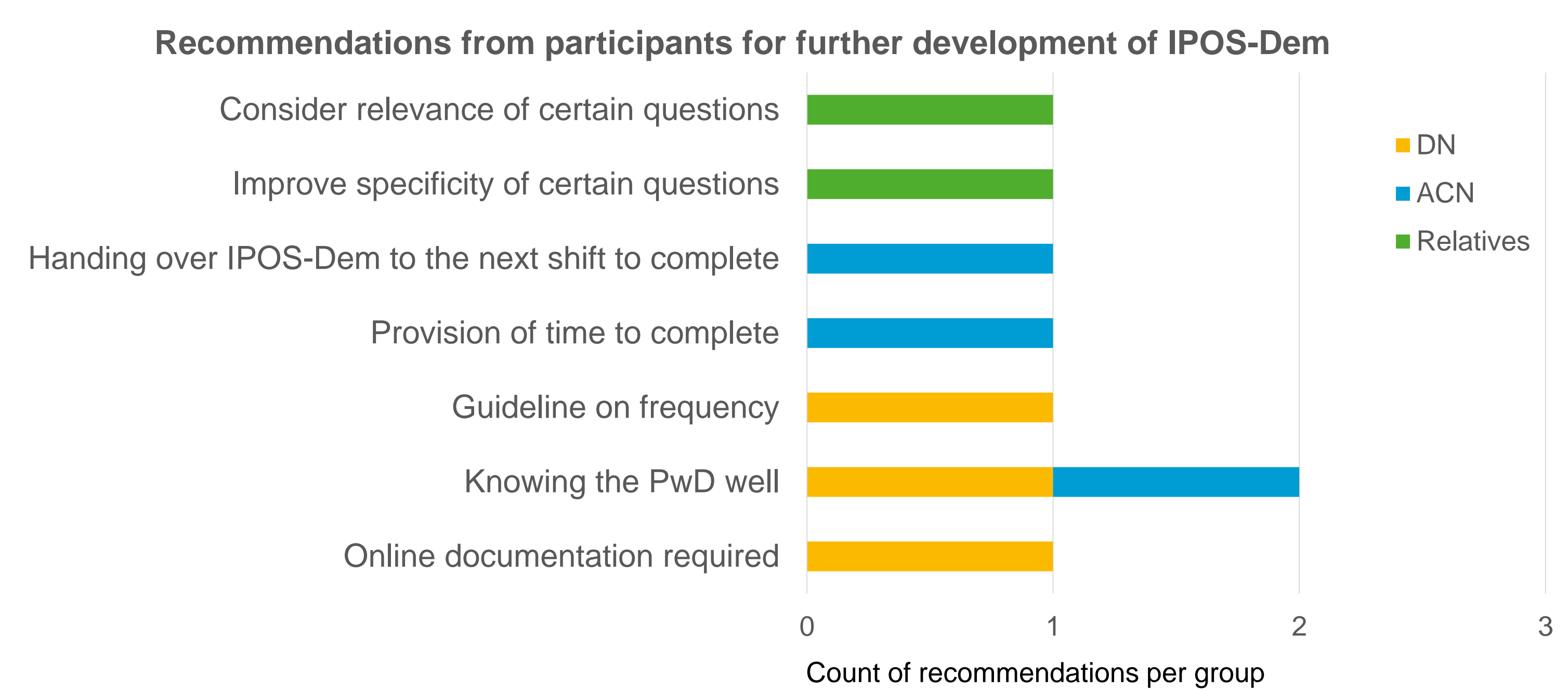
**References:** <sup>1</sup>Husebø et al 2019 J Am Med Dir Assoc.; <sup>2</sup>Singh et al 2019 Geriatrics (Basel); <sup>3</sup>Erickson et al 2019 Med Sci Sports Exerc.; <sup>4</sup>Ellis-Smith et al 2016 Palliat Med.

**Fig 1: Overview results**



## Results II

**Fig 2: Recommendations from Participants**



Participants felt that the IPOS-Dem, as it stands, has also scope for improvement in thinking about practical challenges and the wording of some IPOS-Dem items (see Fig 2).

We have added physical touch in one item as all participants felt that by taking someone's hand or touching a shoulder, a different quality in communicating with PwD can be added:

*He still had was a strong handshake actually - as a widower. And he still felt that, he appreciated that. And afterwards, because of Corona[virus], that simple touch was off limits. And that's what bothered me, when he was in the hospital at the end. He had nothing at all anymore." (Relative)*

## Conclusion

IPOS-Dem was recognised as a valuable addition to the assessments already in use by all groups. IPOS-Dem was reported to be readily adapted by nurses and relatives, with mutual benefit of helping to maintain communication with key players throughout the advanced dementia trajectory. The IPOS-Dem (CH) is now ready for cognitive interviewing.