

CONFERENCE ABSTRACT

Patient reported outcome measures for minority languages: closing the gap for improving health monitoring in bilingual settings

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Introduction: Patient Reported Outcome Measures (PROMs) are measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life. The use of PROMs improves patient-clinician communication, emotional well-being of patients and clinical management, as well as patient satisfaction with care.

The Basque Country straddles the boundary between France and Spain, under different administrations. The Basque Autonomous Community is a bilingual setting, with a population of approximately 2,100,000 people and two official languages (Spanish and Basque). The Basque Health Service Osakidetza adopts an integrated approach merging hospitals and primary care units, organized in 13 Integrated Health Organizations (IHOs).

Objectives: to study the use of PROMs in Osakidetza, and the availability of validated PROMs in both official languages, exploring the potential gaps in research and health assessments in a bilingual context.

Methods: a descriptive study was undertaken to: i) identify the integrated care units and departments of Osakidetza in which PROMs are being systematically used (this information was obtained through the Directorate of Health Assistance) ii) explore the scope of the PROMs and the importance of having them available in local languages; and iii) identify the languages in which the PROMs are being offered, by asking the program managers.

Results: the systematic use of PROMs in clinical care and research is confined to the Departments of Neurology, Urology and Radiotherapy Oncology of the Ezkerraldea-Enkarterri-Gurutzeta IHO. In this case they are administered to those patients with localized prostate cancer and stroke, who are registered in 'My quality of life' program delivered by Osakidetza since 2017 in partnership with the International Consortium for Health Outcomes Measurement. The PROMs used are the PROMIS Global-10, EPIC 26, and EORT QLQ-PR-25. No information has been collected from mental health units. Validated Basque versions of these instruments are not currently in use.

Conclusions: This study shows that in Osakidetza the systematic use of PROMs is not common in clinical care, and there are not validated versions available in Basque. PROMs offer the opportunity of putting the patient at the core of the evidence, reflecting person centred care and a shared decision model. Linguistic minorities should be considered at every step of clinical research or care assessment, so PROMs require a process of translation and cultural adaptation to different languages, in order to ensure the feasibility, validity and reliability. In bilingual settings like the Basque Country, PROMs should be available in both languages. We suggest fostering the

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translation and validation of PROMs in both official languages, and to extend their use to close the gap for improving health research and monitoring health outcomes from an individual and community perspective. With this purpose, we propose that Osakidetza's Basque language schemes should reflect these needs and promote validated questionnaires through collaborative work, in partnership with the basque universities.

Keywords: bilingual setting; health monitoring; Patient Reported Outcome Measure; minority language; patient-centred
