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BJOG An International Journal of Obstetrics and Gynaecology
Royal College of Obstetricians & Gynaecologists

Patient voice in core outcome sets: are we hearing but not listening?

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Linked article: This is a mini commentary on O Kgosidialwa et al., pp. 1855–1868 in this issue. To view this article visit https://doi.org/10.1111/1471-0528.16825

The article by Kgosidialwa et al. is a good example of the process of uniformisation of research (Kgosidialwa et al. BJOG 2021; 128:1855–1868). In the absence of unambiguous empirical evidence, a (modified) Delphi consensus procedure is the method of choice to develop agreement on definitions, core outcome sets and other sets of relevant items. The Delphi procedure taps into the contemporary knowledge and values of individual participants, including lay experts and patient representatives. (Williamson et al. Trials 2017;18 (Suppl 3):280). Patient involvement is advocated because they are the primary stakeholders and are best informed about what outcomes are most important to them. An example: the perception of the importance of breastfeeding as an outcome of obstetric intervention studies may differ between patients and healthcare providers.

The COMET initiative provides tools for COS development, and has initiated a working group for patient involvement ('People and Patient Participation, Involvement and Engagement (PoPPIE)'). A full understanding of the concept of the COS itself for all stakeholders and particularly for patients is of paramount importance and has been promoted by a video explaining the COS concept for patients and other stakeholders (COMET. The COMET initiative's guide to selecting outcomes in clinical trials. 2018; https://youtu.be/Hpmtk4v5xpA).

It is important to counteract actively the effects of biases such as heterogeneity in knowledge and numbers among stakeholder groups and carefully to balance participants between stakeholder groups in order to allow for minority opinions and prevent attrition bias (thereby overestimating agreement).

In our own experience in COS development procedures, several issues complicate patient involvement. This is seen in many studies, including the one by Kgosidialwa et al.:

1. The patient group is typically smaller than the group of professional experts. In the current study, 46/205 (22%) participants were patients in the first round and 2/26 (8%) of the participants were in the consensus meeting. Also, no stratified responses were analysed (which would also pose challenges for semi-anonymity). Thus, the patient voice may not be sufficiently heard among other stakeholders. We wonder: should the patient have a stronger voice than the other stakeholders? The COMET methodology does not give guidance on prioritised inclusion of outcomes that have a very high percentage agreement (for example >90%) in specific predefined stakeholder groups (such as patients). To illustrate the point: of 21 outcomes scoring >90% among patients in the first round, only five were included in the COS, and of 20 outcomes scoring >90% by the professionals, 16 were included in the COS: patient preferences are numerically undervalued.
2. In a consensus meeting, individuals from professional stakeholder groups are all highly educated and experienced caregivers or researchers. Patient participants, often recruited from patient organisations, also have a tendency towards higher education, but their experience of the condition is usually personal. Given the obvious difference in medical expertise, means that patients will be influenced by the professional stakeholders. In the example above, 14 of 21 outcomes that scored >90% in the patient group were excluded during the consensus meeting.

Consensus procedures clearly have the potential to bring research forward in many areas. This has increased uniformity and fostered collaboration. We applaud that it has become self-evident that involvement of the primary stakeholders is key. However, in our view this needs to be more than a pretence: it is time to evaluate whether the mechanics of these procedures adequately allow the perspective of what patients find valuable to be incorporated.

Disclosures of interest

None declared. Completed disclosure of interest forms are available to view online as supporting information.

Data availability

Data sharing is not applicable to this article as no new data were created or analysed in this study. ■