

Patient Perspectives on National Standards for the Certification of Patient Decision Aids

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Background and Aims

In late 2016, the National Quality Forum in the United States published National Standards for the Certification of Patient Decision Aids. These standards propose seven screening criteria for determining whether a patient decision aid (DA) is eligible for certification and twelve certifying criteria for determining the level to which a DA facilitates decision-making, with some of these certifying criteria optionally met by either the DA itself or a supporting document. While these screening and certifying criteria emerged from the recommendations of a multi-stakeholder expert panel, there was only minimal involvement of patients. We set out to explore patient perspectives on some of the proposed criteria and other potential DA content as part of the process of developing a DA on postpartum contraception.

Methods

We administered an online patient survey using a commercial panel service. Eligible participants were currently pregnant and/or ≤ 24 months postpartum, could read and write English, and resided in the United States. As part of the survey, we presented participants with a list of thirteen DA elements and asked whether each should be included in or excluded from the DA. We then presented participants with a list of six pieces of information, five of which were related to certifying criteria that could be met by either the DA or a supporting document, and asked where each should be included. Before responding, participants were advised that “we want to make sure that the guide is as short as possible but still includes all the information that people need”.

Results

Altogether, 286 eligible participants completed the survey. A majority thought that each of the thirteen DA elements should be included. The least popular element was “other people’s stories about making birth control decisions after having a baby” (64% recommended inclusion) and the most popular was “a list of birth control methods that can be used after having a baby” (93% recommended inclusion). Among the five pieces of information that were related to certifying criteria that could be met by either the DA or a supporting document, the sample slightly favoured three for inclusion in the DA itself (i.e., information about development process and user testing, information about evidence sources, information about update policy and next expected update). The sample slightly favoured the other two for inclusion in a supporting document (i.e., information about competing interests and/or policy, information about readability levels). The remaining piece of information assessed – information on DA authors and their qualifications – was not a proposed screening or certifying criterion but was favoured for inclusion in the DA by 64% of the sample.

Conclusions

The findings of our exploration of patient perspectives on the newly-developed National Standards for the Certification of Patient Decision Aids are relevant to both DA developers and those working in DA certification. Although patients reported fairly extensive information needs, introducing challenges for the development of concise DAs, some of these may acceptably be addressed in ancillary materials.