Using a Delphi Panel to Establish Content for a Breast Cancer Screening Decision Aid Inclusive of Women with Limited Health Literacy

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BACKGROUND

- Breast cancer screening **decision aids (DAs)** that help women understand their risk for cancer and available screening options can improve decision-making quality for women in their 40s

- Existing DAs do not address the needs of women with **limited health literacy (LHL)**

OBJECTIVE

To establish consensus about breast cancer screening decision aid content for women ages 40-54 who have LHL among a panel of breast cancer screening and decision science experts

METHODS

- 3-round, modified **Delphi panel** administered via online May – July 2020
- Eligibility criteria: advanced degree, 3+ years of experience, and content expertise
- Statements covered domains associated with International Patient Decision Aid Standards
- Panelists rated importance of statements on a scale of 1-9, and provided comments explaining ratings
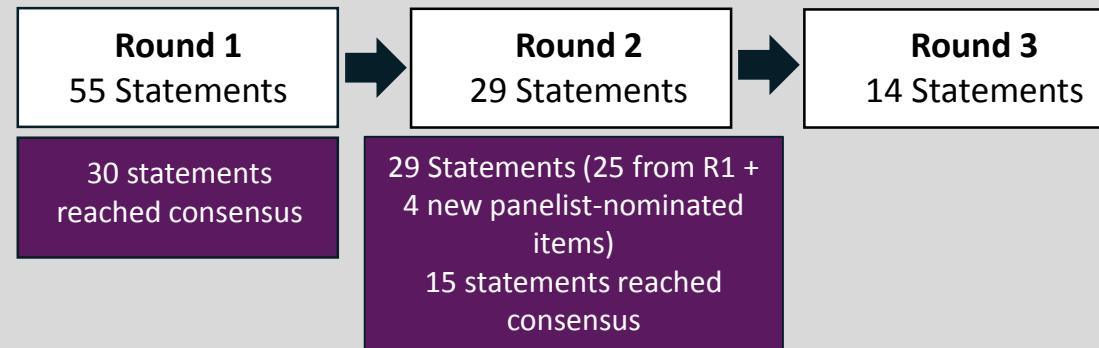
ANALYSIS

- 30th - 70th percentile range, central point, and asymmetry index were calculated for each item

- Disagreement Index: value >1: item moved to the next round; value < 1: consensus was established and item omitted from future rounds

- Between rounds, experts received a summary of their rating for each item relative to others and all open-ended explanations

- Process was repeated for Rounds 2 and 3

RESULTS

Expert Panel (N=8)
- All female
- Mean age: 53
- 7 white; 2 Asian
- 5 held MDs; 3 had PhDs

Of 59 statements, 46 achieved consensus, 4 items were found consensus as uncertain, and 9 did not reach consensus

Round 1
55 Statements

Round 2
29 Statements

Round 3
14 Statements

30 statements reached consensus

29 Statements (25 from R1 + 4 new panelist-nominated items)
15 statements reached consensus

Experts Agreed On:

- Importance of defining breast cancer
- Describing screening as a choice
- Sharing potential benefits and harms
- Describing the mammography process
- Including an interactive element or planning tool

Experts Disagreed On:

- Inclusion of breast cancer risk factor information
- Whether multiple imaging modalities (MRI, ultrasound, tomosynthesis) should be included

Explanations for disagreement revolved around balancing an ethical imperative to provide information and avoid paternalism, while limiting extraneous information

CONCLUSIONS

- While guidelines suggest risk assessment is key to mammography decisions for women in their 40s, experts **did not agree** about the inclusion of **risk factor information** in a breast cancer screening decision aid for women with LHL

- In prior work, we found that women identified other elements, like **knowing what happens during a mammogram**, as central to decision-making, which was **at odds** with these expert opinions

Balancing detail with simplicity remains a challenge in determining content for decision support tools that seek to include a range of literacy levels

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