THE 2012 IPDAS BACKGROUND DOCUMENT:
AN INTRODUCTION

AUTHORS/AFFILIATIONS

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Summary

Ninety-two individuals from 9 countries used a systematic and standardized process to update the theoretical and empirical evidence for all of the 12 chapters in the 2005 Original IPDAS Background Document. In each updated chapter, transparency was ensured by specifically indicating which changes from the original chapter had been made, and by including the original chapter as an appendix. All of the documents relating to the original and the updating processes are available on the IPDAS website (http://ipdas.ohri.ca), for easy access by the various stakeholders who may be interested in learning more about quality indicators for the development, content, and evaluation of patient decision aids.

<u>What are Patient Decision Aids</u>?

Patient decision aids are tools designed to help people participate in decision making about two or more health care options. Patient decision aids explicitly point out that, in the particular situation under consideration, there is no single "best" action for all patients, and they help the patient to realize that there is an opportunity to be involved in choosing among the options. Patient decision aids provide information about the options, and help patients to clarify and communicate the personal values that they associate with different features of the options.

Therefore, patient decision aids are unlike general patient education materials that provide information about a recommended action in health care. Patient decision aids do not advise people to choose one option over another, nor are they meant to replace practitioner consultation. Instead, they prepare patients to make informed, values-based decisions with their practitioner.

<u>Why Patient Decision Aids</u>?

Patient decision aids are used for complex decisions that need more detailed information and more careful consideration. Complex decisions have multiple options with features that people value differently. Sometimes the scientific evidence about options is limited. Therefore, the best choice depends on the personal importance that the patient places on the benefits, harms, and scientific uncertainties.

The aim of patient decision aids is to improve the quality of decisions. Decision quality is the extent to which patients choose and/or receive health care interventions that are congruent with their informed and considered values. The features of options that patients value may include the health states that might be affected by the decision, their attitudes towards the chances associated with the relevant options, their willingness to make trade-offs over time, and other issues relevant to the decision, including attitudes about the acceptability of particular health care procedures and outcomes.

<u>What is IPDAS</u>?

The International Patient Decision Aid Standards (IPDAS) Collaboration is a group of researchers, practitioners, and stakeholders from around the world that was established in 2003. The IPDAS Collaboration is lead by professors Glyn Elwyn in the United Kingdom and Dawn Stacey in Canada.

IPDAS's overall purpose is to enhance the quality and effectiveness of patient decision aids by establishing a shared evidence-informed framework with a set of dimension-specific criteria for assessing and improving the content, development, implementation, and evaluation of patient decision aids.

Why are Standards Needed?

Hundreds of patient decision aids are available or are being developed by many different individuals and groups around the world. However, people may have difficulty knowing whether or not a decision aid is a source of reliable health information that can help in decision making.

Therefore, a standard set of criteria would be helpful to a wide variety of individuals and organizations that use and/or develop patient decision aids. For example:
- Patients or other individuals who are making a health decision;
- Practitioners guiding patients in making health decisions;
- Developers of patient decision aids;
- Researchers or evaluators of patient decision aids;
- Policy makers or payers of patient decision aids.

Such a set of criteria is provided in the IPDAS Checklist. To see the IPDAS Checklist, go to http://ipdas.ohri.ca/resources.html and click on "**2006 IPDAS Checklist for Judging the Quality of Patient Decision Aids"**. Note that the 2006 IPDAS Checklist consists of 12 quality dimensions (each of which incorporates several dimension-specific quality criteria).

Some History

The IPDAS Checklist's 12 quality dimensions (and the quality criteria within each dimension) were originally identified in 2005, using a Delphi voting process. To see how this Delphi voting process worked, go to http://ipdas.ohri.ca/resources.html and click on "**2005 First Round Voting Document"** & **"2005 Second Round Voting Document".**

The participants in this original Delphi process needed a knowledge base to inform their voting behavior. Accordingly, in 2005 an IPDAS Background Document was created. Each chapter in this Background Document fulfilled 4 functions:
a) Defined the relevant quality dimension;
b) Outlined the theoretical rationale for including the relevant dimension in the IPDAS Checklist;
c) Provided a summary of the relevant evidence base underlying that quality dimension; and
d) Listed the relevant theoretical and empirical references for that dimension.
To see the original 12-chapter IPDAS Background Document, go to http://ipdas.ohri.ca/resources.html and click on **"2005 Original IPDAS Background Document"**.

Current Motivation

New concepts and empirical evidence have accumulated since 2005, and consequently there was a need to update the 2005 Original IPDAS Background Document. The IPDAS Background Document Updating Group was charged with this effort.

Strategy

The IPDAS Background Document Updating Group consisted of 12 chapter-writing teams (i.e., one team for each of the 12 quality dimensions).

Volunteers who were interested in serving as team leaders, co-leaders, and/or members were identified using several strategies, including: a) postings on the listserves "Shared-L" and "SMDM-L"; b) advertisement at the 2009 International Shared Decision Making Conference in Boston, Massachusetts; c) reviewing the roster of participants from the 2005 Original IPDAS Background Document; and d) informal networking among the participants.

Each chapter-writing team leader was identified from senior individuals who had indicated an interest in serving as a team leader and had conducted relevant research in the area addressed by the specific chapter.

Each confirmed team leader was provided with: a) an outline of the updating processes (see below) that their team should follow; b) lists of the names of potential co-leaders and team members who had volunteered through the recruitment strategies described above; and c) the names and contact information of any individuals—including any of those who had co-authored the original 2005 chapters—who had not directly volunteered but were experts in the field and who might be interested in being involved.

Team leaders selected their co-leaders, and then together the leaders and co-leaders selected the members for their teams. In doing so, they were instructed to consider a) the diversity of their team (e.g., a mix of basic scientists, decision aid developers, and clinicians), and b) the importance of international representation on the teams. Final decisions about team membership were made by the individual leaders and co-leaders.

Taken together, these teams involved 92 co-authors from 9 countries.

Updating Processes

Each of the 12 chapter-writing teams was charged with creating an updated chapter consisting of 7 major sections:
1.   Current Authors & Affiliations
2.   A Chapter Summary
3.   Updated Definition (conceptual/operational) of the Quality Dimension
4.   Updated Theoretical Rationale for Inclusion of the Quality Dimension
5.   Updated Evidence Base Underlying the Quality Dimension
6.   Updated References
7.   Appendices, including a) supporting materials (if needed), and b) the relevant 2005 Original Background Document Chapter.

Sections 3, 4, and 5 required the most work on the part of a writing team. Within each of these sections, a team's search, retrieval, and appraisal of the relevant theoretical and empirical literature focused primarily on: a) high-quality publications that are squarely in the field of

patients' decision aids / patients' decision making; and b) high-quality publications that are clearly in the larger *field of health care in general*. Within each of these sections, a team could also identify particularly important relevant publications in *other non-health-related fields* (e.g., psychology, business, adult education); the points raised by these publications could then be outlined in the "emerging issues / future research" sub-sections of the chapter.

Each team followed established writing guidelines and used a common writing format, as they considered, summarized, and presented the theoretical and evidentiary literature relevant to the quality dimension addressed by their chapter. However, each writing team necessarily worked out its own procedures for dividing up the team's work, circulating initial drafts among its members, resolving points of discussion via e-mail and/or conference call, and preparing the final submitted version of their updated chapter.

A Note about Funding

This updated 2012 IPDAS Background Document was prepared without centralized financial support. Individual chapter leads/co-leads/members indirectly were supported by their affiliation sites while they worked as volunteers on this project, and administrative support for the entire update process was provided as "gifts in kind".

Conclusion

The teams' updating work is reported in the following 2012 chapters:

A. Using a Systematic Development Process

B. Providing Information About Options

C. Presenting Probabilities

D. Clarifying and Expressing Values

E. Using Personal Stories

F. Coaching/Guidance in Deliberation and Communication (formerly "Guiding/Coaching in Deliberation and Communication")

G. Disclosing Conflicts of Interest

H. Delivering Decision Aids on the Internet

I. Balancing the Presentation of Information and Options (formerly "Balancing the Presentation of Options")

J. Addressing Health Literacy (formerly "Using Plain Language")

K. Basing Information on Comprehensive, Critically Appraised, and Up-To-Date Syntheses of the Scientific Evidence (formerly "Basing Information on Up-To-Date Scientific Evidence")

L. Establishing the Effectiveness

Note that each of these updated chapters includes, as an appendix, the comparable chapter from the 2005 Original IPDAS Background Document.   This has been done so that the reader is provided with an overview of the evolution of thinking in each of the 12 IPDAS quality dimensions.

Next Steps

Two further points should be noted.

Point 1. This updated 2012 IPDAS Background Document focuses on the theoretical and evidentiary literature relevant to each of the IPDAS Checklist's *current* 12 quality dimensions. This is in accordance with the mandate undertaken by the updating editors. However:

a) The International Patient Decision Aids Standards collaboration realizes that, in the future, new quality dimensions may need to be added to the IPDAS Checklist (and, by corollary, that new dimension-specific criteria would need to be added to the IPDAS Checklist).

b) Furthermore, even if the current 12 quality dimensions remain intact, the International Patient Decision Aids Standards collaboration realizes that some of the IPDAS Checklist's criteria, which are nested within these dimensions, may need to be dropped, modified, or added.

Therefore, the International Patient Decision Aids Standards collaboration is formulating a proposal about how to proceed systematically with identifying new dimensions (if needed) and identifying new criteria (if needed).

Point 2. Given the logical link between the IPDAS Checklist and the IPDAS Background Document, this update is necessarily confined to these 12 current quality dimensions. At the same time, the International Patient Decision Aids Standards collaboration is well aware of relevant work that is crucially important for moving forward the field of patient decision support/patient decision aids, in general.

For example, there is a cumulative body of evidence about the implementation of patient decision aids; this evidence could lead to the development of implementation guidelines that may be particularly useful to researchers and implementers.

Therefore, the International Patient Decision Aids Standards collaboration is planning to add an "implementation resource" to the IPDAS website, where readers can access manuscripts such as Elwyn et al.'s "The Implementation of Patient Decision Support Interventions Into Routine Clinical Practice: A Systematic Review" (manuscript under review).