



International Patient Decision Aid Standards [IPDAS] Collaboration reaches consensus on indicators for judging the quality of patient decision aids

A O'Connor, G Elwyn, D Stacey, R Volk, R Thomson, A Barratt, M Barry, A Coulter, M Holmes-Rovner, H Llewellyn-Thomas, N Mounjid, T Whelan & IPDAS

27th Annual Meeting of the Society for Medical Decision Making
(October 21-24, 2005) San Francisco, CA, USA



Co Chairs: A O'Connor (CA) , G Elwyn (UK)

Steering Committee: A Barratt (AU), M Barry (US), A Coulter (UK), M Holmes-Rovner (US), H Llewellyn-Thomas (US), N Moumjid (FR) M O'Kane (US), D Stacey (CA), R Thomson (UK), T Whelan (CA)

Quality criteria panels: J Austoker (UK), A Barratt (AU), H Bekker (UK), J Belkora (US), C Braddock (US), P Butow (AU), E Chan (US), M Barry (US), A Charvet (Switz), A Clarke (UK), J Davison (CA), J Dolan (US), A Edwards (UK), V Entwistle (UK), A Fagerlin (US), D Feldman-Stewart (CA), J Fowler (US), D Frosch (US), P Hewitson (UK), T Hope (UK), MJ Jacobsen (CA), A Kennedy (Switz), S Knight (US), M Kupperman (US), B Ling (US), H Llewellyn Thomas, (US)T Marteau (UK), K McCaffery (AU), N Moumjid (FR), A Mulley (US), A O'Connor (CA), M O'Connor (US), E Ozanne (US), M Pignone (US), A Raffle (UK), C Ruland (NO), L Schwartz (US), K Sepucha (US), S Sheridan (US), S Stableford (US), D Stilwell (US), V Tait (CA), D Timmermans (NL), L Trevena (AU), T Whelan (CA), C Wills (US), S Woloshin (US), S Ziebland (UK)

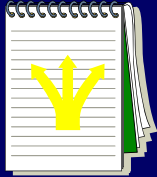
Stakeholder lead: A Coulter (UK)

Methods group: S Bernstein (US), P Shekelle (US), R Thomson (UK), R Volk (US)

Stakeholder 122 voters from 14 countries

Patient Decision Aids (PtDAs)

adjuncts to counseling



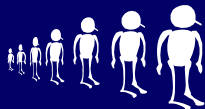
- **information:** options, outcomes



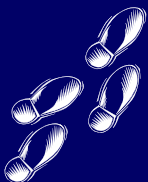
- outcome probabilities



- values clarification



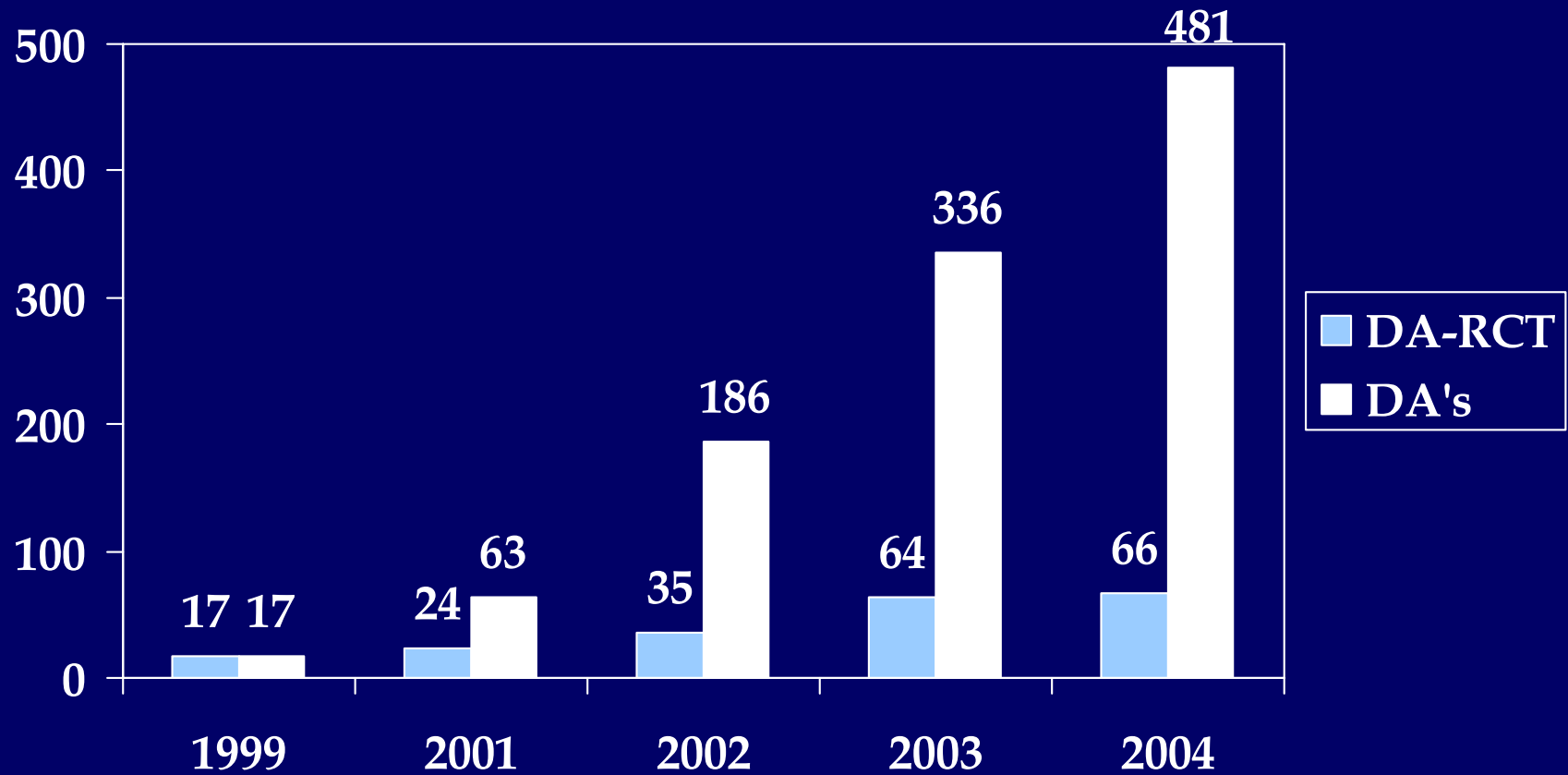
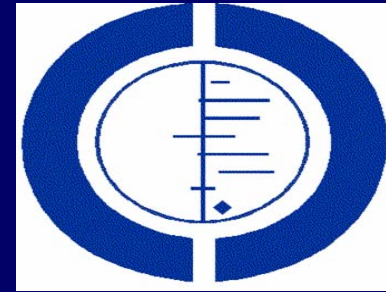
- patients' stories



- guidance/coaching



Exponential growth





Home

What are
Patient Decision
Aids?

Who's Involved?

Contact Us

International Patient Decision Aid Standards (IPDAS) Collaboration

Objective

- **To establish an internationally approved set of indicators for judging the quality of the development and evaluation of patient decision aids [PtDAs]**
- **For use by:**
 - Developers
 - Users (patients & practitioners)
 - Providers and policy makers



Methods

Launched 2003 conferences:

ISDM; SMDM; Ix

Committees formed:

1. Steering 2. Quality Criteria 3. Methods;
4. Stakeholder

Background evidence document:

12 quality domains

Discussed on SDM list serve



Methods

- nominated sample [familiar with PtDAs]
- 4 stakeholder groups:
 - researcher, practitioner, consumer, policy maker
- 2-stage 'evidence-informed' Delphi consensus method; feedback 2nd round
- online voting document
 - 83 indicators in 12 quality domains
 - background summaries



Methods

‘Equi-median’ scores [1-9 importance scale]

- equalised effect of different numbers in stakeholder groups

Indicators classified according to scores

- Important: 7-9
- Equivocal: 4-6 without disagreement
- Invalid: 1-3 or disagreement
[30% scores bottom/top terciles]

I. Using a systematic development process

What is this criterion? The logical steps taken to build a patient decision aid.

Steps may include:

- To form groups to develop decision aids (decision experts, patient users, practitioner users);
- To identify the needs of potential users;
- To draft, review, field test, and revise the decision aid;

- To have the decision aid reviewed by outside experts who were not involved in its development and field testing.

How might this affect the quality of decision making? In theory, decision aids may lead to poor decisions if they are developed by people who do not have the knowledge and skills to understand the decision situation and to help patients make decisions. Even qualified people may not design a good decision aid, if they do not take the time to develop it to meet the needs of the patients who face the specific decision and the practitioners who counsel them about the options. Outside experts may also help to identify things that were missed during development.

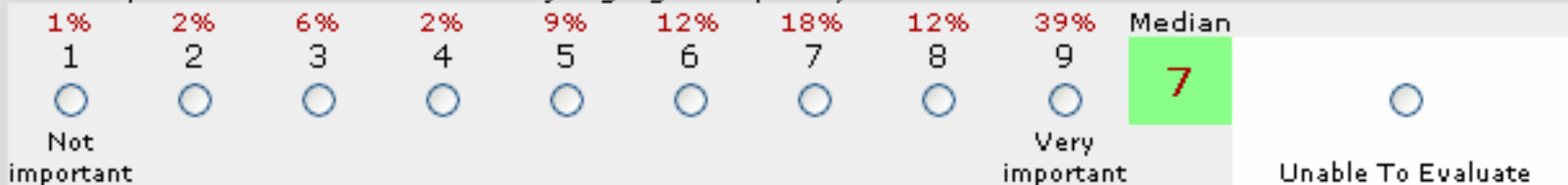
What is the evidence to support including or excluding this criterion? The Cochrane Collaboration review team examined the way 19 decision aids were developed. Of these, 17 reported the credentials of the developers (e.g. MD, RN, PhD), and 11 reported on the steps taken to develop the decision aid. There were no studies comparing different ways of developing patient decision aids.



Voting Site Layout: 2nd round

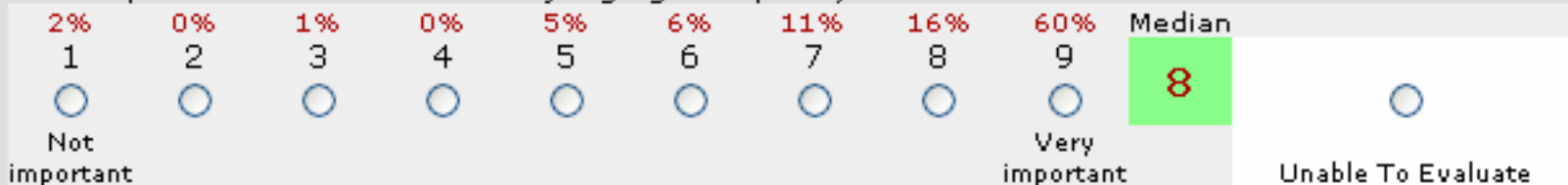
1. The patient decision aid has information about the credentials of the people who developed it.

How important is this criterion in judging the quality of a decision aid?



2. Patients were asked what they need to prepare them to discuss a specific decision.

How important is this criterion in judging the quality of a decision aid?





Results

Response to invitation to serve on voter panel

	# invited on voting panel	# (%) agreeing to be on voting panel
policy makers / health plan administrators	26	14 (54%)
patient / consumers	43	21 (49%)
health professionals	18	10 (56%)
Researchers/developers	125	77 (62%)
Total	212	122 (58%)



Results

1st round voters participating in 2nd round

			%
	Policy maker	9/14	64%
	Patient	19/21	90%
	Health Professional	9/10	90%
	Researcher	66/77	85%
		103/122	85%



Results after two votes

	N
Equimedian = 9	41
Equimedian = 8	26
Equimedian = 7	7
Equimedian = 4to6 without disagreement	8
Equimedian = 3 or less	0
Disagreement : 30% bottom/top terciles	1
Total	83

Consensus: highlights

Development process

Providing information about options

Probabilities

Values clarification

Guiding/Coaching

Disclosure

Delivery on Internet

Balance

Plain language

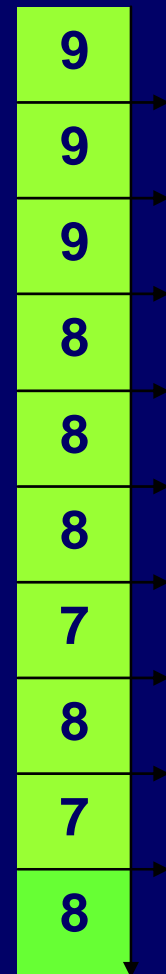
Up-to-date scientific evidence

Effectiveness

Presenting probabilities

- event rates, specific pop'n, time period
- compare same denominator
- compare same period of time, scales
- uncertainty e.g. our best estimate
- visual diagrams e.g. faces, stick figures, bar charts
- > one method e.g. words numbers diagrams
- patient can select method
- tailored to patient e.g. age
- in context e.g. chances other diseases
- both positive & negative frames

Median





Clarifying & expressing values

Median

describes option features to help patients imagine what it is like to experience ...physical, emotional, social effects

asks patients to consider which positive & negative features matter most to them

suggests ways to share what matters most to them with others

8

9

7

Establishing effectiveness

DECISION PROCESS

recognize ...a decision needs to be made

know available options

know different features of options

understand ...values affect decision

clear ...which features matter most to them

discuss values with health practitioners

become involved in dm...in ways they prefer

DECISION QUALITY

improves ..match between features that matter most to the informed patient & chosen option

Median

8

9

9

9

9

7

9

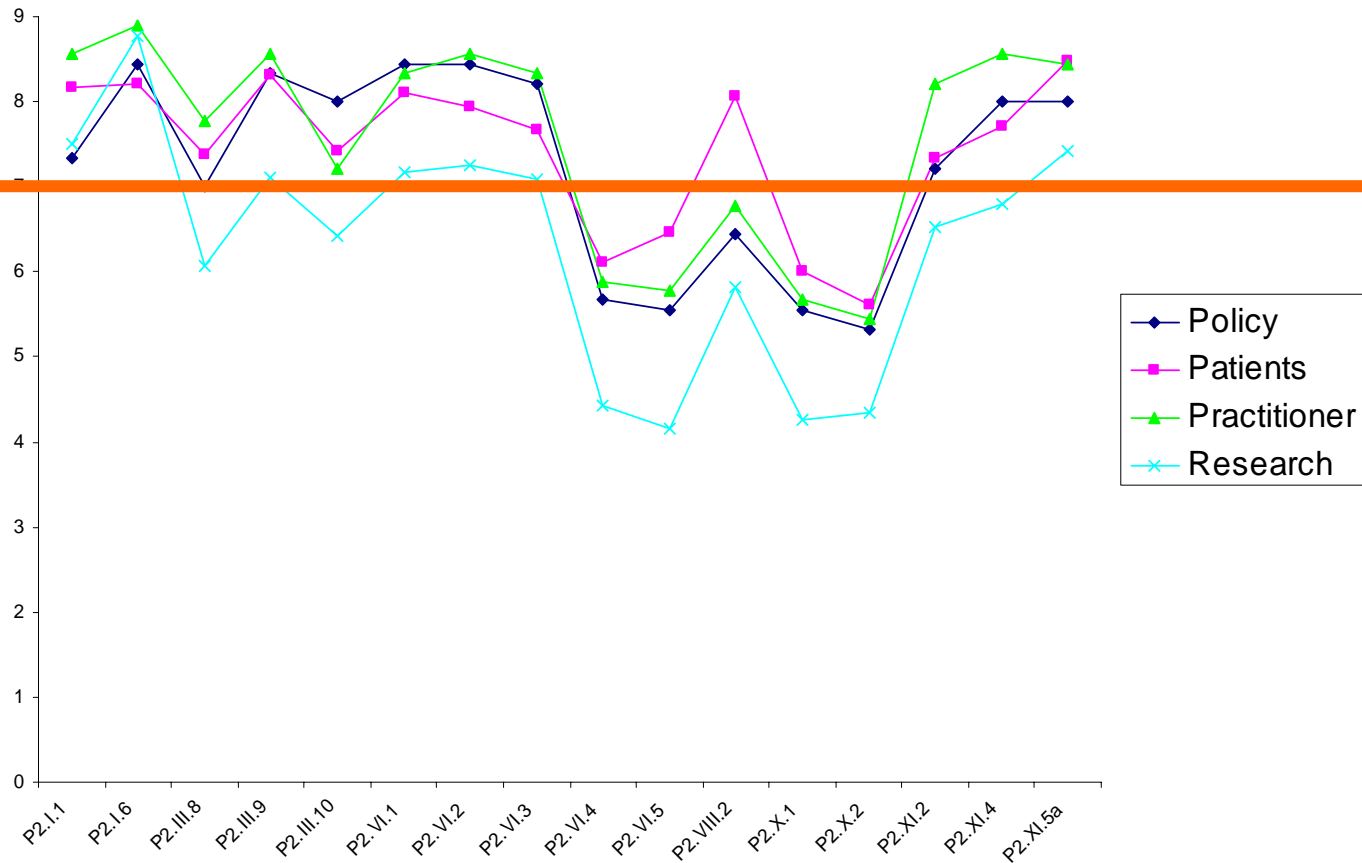
9

Excluded indicators

- **Content of PtDAs**
 - including stories
 - offering option of trained coaches
- **Documentation evidence/tools**
 - estimate probabilities
 - establish plain language
 - select stories

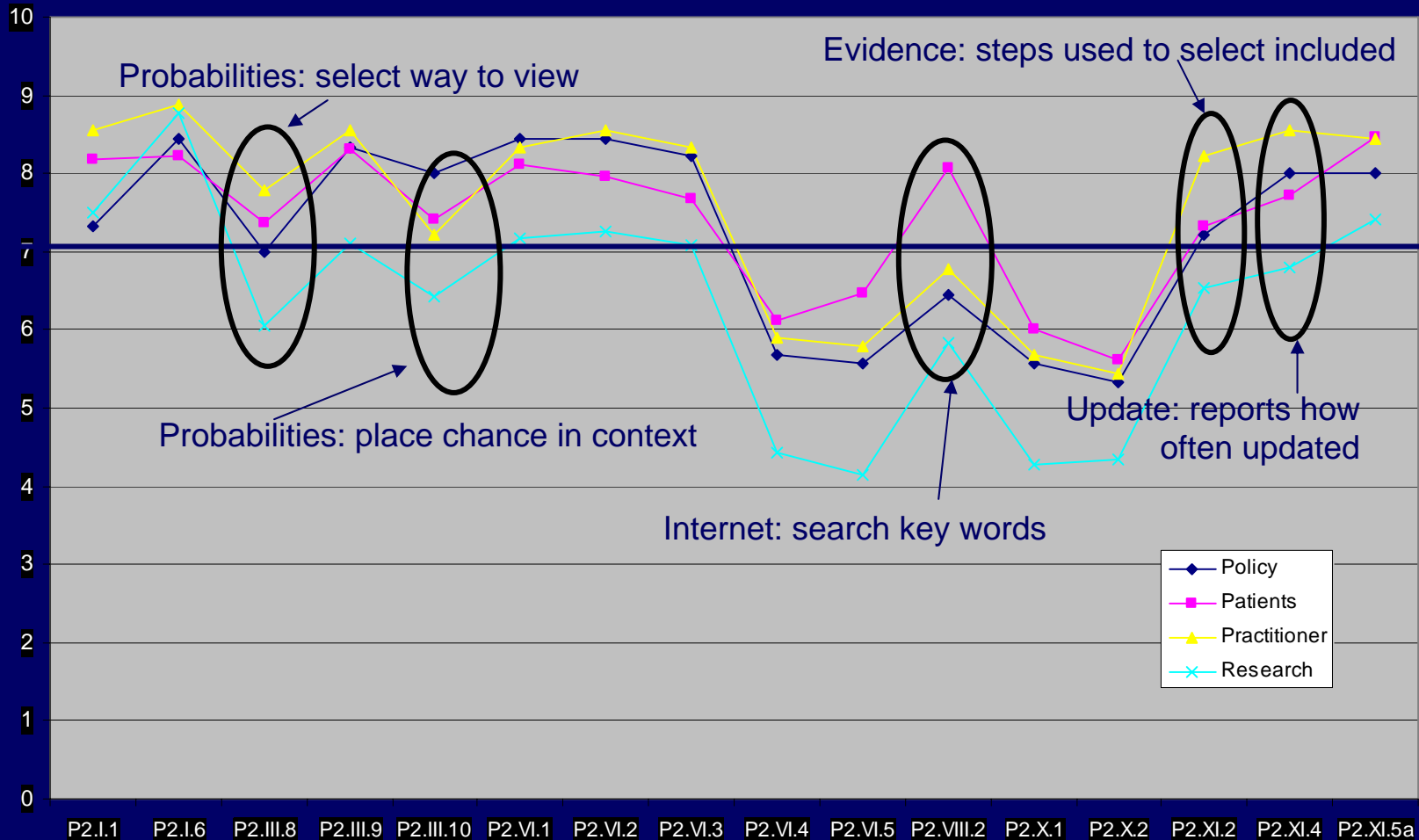
Is there a stakeholder effect?

16/83 items but only **5/83** cross **threshold**





5 Differences affect Threshold





Limitations

- 58% participation (e.g. not available within 3 week time frame; thought we were SPAM)
- nominated sampling
- positive rating bias
- minimum versus gold standards → feasibility



Conclusions

- **Users now have a checklist version 2005.1 to assess quality**
- **Strong endorsement among stakeholders**
- **Content elements not endorsed had weakest evidence**

Research Agenda

- **Effects of stories & coaching on decision quality**
- **Application of indicators in quality measurement tool**

www.ipdas.ohri.ca



Co Chairs: A O'Connor (CA) , G Elwyn (UK)

Steering Committee: A Barratt (AU), M Barry (US), A Coulter (UK), M Holmes-Rovner (US), H Llewellyn-Thomas (US), N Moumjid (FR) M O'Kane (US), D Stacey (CA), R Thomson (UK), T Whelan (CA)

Quality criteria panels: J Austoker (UK), A Barratt (AU), H Bekker (UK), J Belkora (US), C Braddock (US), P Butow (AU), E Chan (US), M Barry (US), A Charvet (Switz), A Clarke (UK), J Davison (CA), J Dolan (US), A Edwards (UK), V Entwistle (UK), A Fagerlin (US), D Feldman-Stewart (CA), J Fowler (US), D Frosch (US), P Hewitson (UK), T Hope (UK), MJ Jacobsen (CA), A Kennedy (Switz), S Knight (US), M Kupperman (US), B Ling (US), H Llewellyn Thomas, (US)T Marteau (UK), K McCaffery (AU), N Moumjid (FR), A Mulley (US), A O'Connor (CA), M O'Connor (US), E Ozanne (US), M Pignone (US), A Raffle (UK), C Ruland (NO), L Schwartz (US), K Sepucha (US), S Sheridan (US), S Stableford (US), D Stilwell (US), V Tait (CA), D Timmermans (NL), L Trevena (AU), T Whelan (CA), C Wills (US), S Woloshin (US), S Ziebland (UK)

Stakeholder lead: A Coulter (UK)

Methods group: S Bernstein(US), P Shekelle(US), R Thomson(UK), R Volk(US)