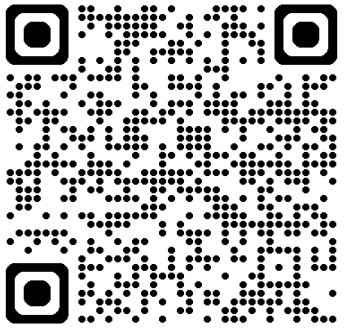


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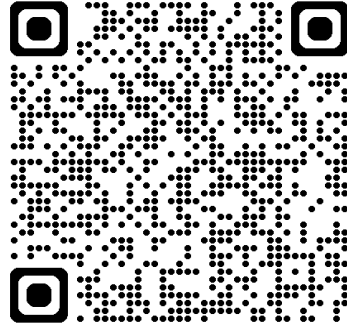


ISPOR

Special Interest
Group



Patient-Centered



Health Preference
Research

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Making Preferences Count: Patient-Engaged Values Clarification for Individual-Level Decision Making

May 19, 2026 | 12:15 – 1:15 PM EDT
ISPOR 2026, Philadelphia

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- The Antitrust policy is available on the ISPOR website.

Panelists and Moderator

- **Moderator** - Holly Peay, MS, PhD
- **Speaker #1** - Angie Botto-van Bemden, PhD
 - From co-design to clarity: What makes decision support tools genuinely patient-centered
- **Speaker #2** - Janine van Til, MSc, PhD
 - A systematic review of quantitative health preference methods to support value clarification and shared-decision making
- **Speaker #3** - Christine Poulos, PhD
 - How to develop, test, and evaluate health preference methods for use in individual-level decision support tools
- **Speaker #4** - Holly Peay, MS, PHD
 - Integrating evidence & recommendations cross-discipline

Objective: This session will provide experience and evidence for using preference methods to inform individual treatment decisions while also following best practices in developing patient-focused decision support tools.

Overlapping Disciplines

HEOR

Assesses value

Translating Evidence Into Patient-Relevant Context

Engagement Science

Advances patient centeredness

Clarifying Preferences & Priorities

Decision Science

Improves decision quality



Patient-Centered Outcomes

Context and definitions

Decision support tools...

- Enhance patient care by providing evidence-based, patient-specific information
 - Includes, but not limited to, patient decision aids

may incorporate values clarification

- Methods for user to evaluate desirability of options or option attributes in a specific context

to support informed decisions

- Often facilitated by shared decision making: collaborative process with healthcare providers and patients that balances evidence with patient values and preferences

**Context of use:
Individual or small group level**



What Is a Patient Decision Aid (PtDA)?

Decision aids help patients:

- Clarify the decision they face and why it matters
- Understand their options — including doing nothing
- Weigh benefits and risks against personal values
- Prepare to participate in decision making

Objective: Improve decision making that is congruent with informed and considered values

Guided by criteria from the International Patient Decision Aid Standards Collaboration

<https://decisionaid.ohri.ca/IPDAS/index.html>

1

Clarify the Decision

Describe the problem and clarify options

2

Understand Your Options

Describe positive and negative features, level of certainty, steps in process, and help imagine life impact

3

Clarify Personal Values

What positive and negative features matter most to you?

4

Participate in Decision

Decision intention and plan to move forward

Welcome!

You are thinking about taking part in an HIV remission clinical trial, also called a cure trial.

The goal of remission trials is to find ways to control the HIV virus in a person's body without taking ART.

Someday, clinical trials should lead to a cure for HIV. At this time, people who participate in a remission trial are very unlikely to be cured because the research is so new.

You may be excited about joining. You may want to help others with HIV. But, like other decisions, there's a lot to think about and you may have questions.

This web source, **Decision Partner**, will help you on your path to deciding whether joining the **HIV Example Trial** is the right choice for you.

You will go through a series of screens to learn key facts. Then you can decide on a next step. You may decide to meet with the clinical trial team to get more information, or you may decide that a clinical trial is not the right path for you.



Activity: What matters most to you when making a trial choice?

Here are some aspects of the trial that may be important to your decision. Review the list and select and drag one item into the "Matters most to my decision" side and one item into "Matters least to my decision". You can only select two items per screen. You will do this a total of 11 times. This may feel like a lot, but it allows Decision Partner to create your own unique priority list.

1/11

↑ The trial could give me hope about better future HIV treatments

↑ The trial team will closely monitor my health in the trial

↑ Transmission risk to sexual partners

↑ Others could learn of my HIV status

↑ My participation could help others living with HIV

<< BACK

NEXT >>

Matters most to my decision

Matters least to my decision

J AIDS and Behavior
https://doi.org/10.1007/s10461-025-04764-1

ORIGINAL PAPER



Development and Evaluation of Decision Partner: A Decision Aid for HIV Remission Clinical Trial Participation

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Accepted: 10 May 2025
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Abstract

HIV remission (or cure) clinical trials require potential participants to understand trial-related risks, approaches to minimize risks, potential benefits, procedures, and participation alternatives to make an informed decision. Decision aids (DAs) support preference-sensitive decisions. We report on the development and evaluation of a DA called Decision Partner, designed to support informed consent. We used an iterative, mixed-methods approach to develop and test Decision Partner. We conducted research and engagement activities among people living with HIV (PLWHIV), advocates, researchers, trialists, and clinicians which resulted in a product reflective of information required for informed choice. Among 20 PLWHIV, 90% rated that Decision Partner would be useful for decision-making. Decision conflict significantly decreased after using Decision Partner (37.3 to 16.8, $p=.007$) and knowledge significantly increased from pre to post ($z = -3.11$, $p<.01$). Our findings indicated that Decision Partner holds promise to augment the informed consent process, in HIV remission trials.

Keywords HIV remission clinical trials · Decision aid · Informed consent · Decision support

Weighing benefits, risks, and procedures of trial participation

Deciding whether to take part in a clinical trial involves understanding and thinking about the benefits, risks, and what is involved. People think about these factors differently based on what matters most to them and what is going on in their lives. Let's revisit with Anum, Angel, Remi, Henry, Ingrid, and Noa. These stories have been grouped together to show how people can have similar thoughts and feelings about trials, but different personal factors that are important to their decisions.

Resources

clinicaltrials.gov

Anum M. and Angel L.



Anum M. and Angel L. are excited about helping other people living with HIV, but they want to be realistic. They each worry about the trial's time commitment and how it would affect their day-to-day lives. Anum has flexibility in her schedule for the trial visits. Angel isn't sure about whether he can make all of the visits. Angel also wants to talk to the trial team about what would happen to his body. He wants details about the procedures at each visit. At this time, Anum is leaning toward trial participation and wants to meet with the trial team. Angel is not so sure, but he's willing to learn more.



Remi I. and Henry C.



Remi I. and Henry C. are curious about being able to stop taking ART for a brief time during the trial. Both think it would be nice to take a break while under the care of the trial team. They understand that there are risks of stopping ART. Remi worries about going off ART when it has kept them healthy, and doesn't want to put their long-term partner at additional risk or to abstain from sex. Henry is willing to accept the risks and feels prepared to abstain or talk to his partners about additional protection during sex. At this time, Remi is leaning away from trial participation. Henry is pretty confident that he will join the trial.



What's the next step on your path to deciding whether the HIV Example Trial is right for you?

Right now, you may be leaning one way or another with your decision. Or you just might not be sure yet, and that's okay.

As next steps, you can:

- Meet with your clinical trial team to learn more and ask questions.
- Talk with those close to you like your family, friends, or healthcare provider.
- Read and discuss the resources included in this decision aid tool and the informed consent form with your clinical trial team.

Summary of the Activities You Completed in the Decision Partner Resource

Things You Said Matter Most and Least to Your Clinical Trial Choice

Below is a list of the trial aspects you sorted as mattering most and least, to you. Please review your responses and think about how well your priorities match what would happen during the trial. You may also see any aspects you did not select at all.

Variables you selected as mattering most

Transmission risk to sexual partners

Having to talk with partner(s) about transmission risk

Possible risks/side effects to my health

My participation could help others living with HIV

Variables you selected as mattering least

I could learn more about my health in the trial

Others could learn of my HIV status

The time required for me to be in a trial

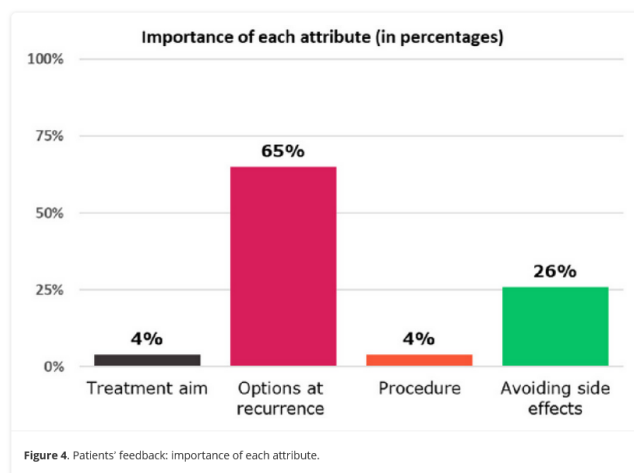
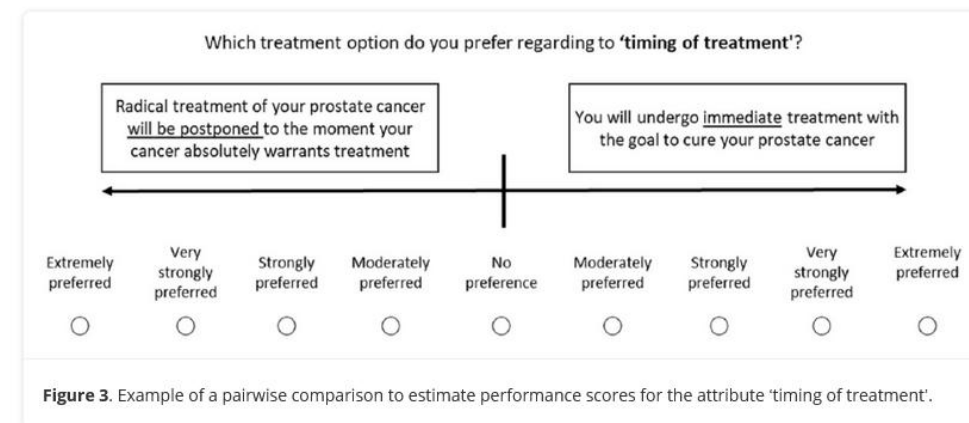
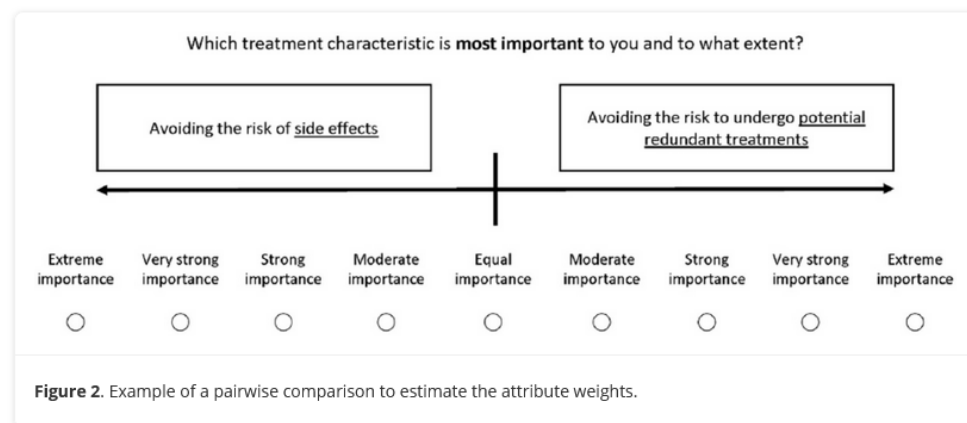
The trial could cause me a lot of stress

Variables you never selected

The procedures may be uncomfortable for me

The trial team will closely monitor my health in the trial

The trial could give me hope about better future HIV treatments



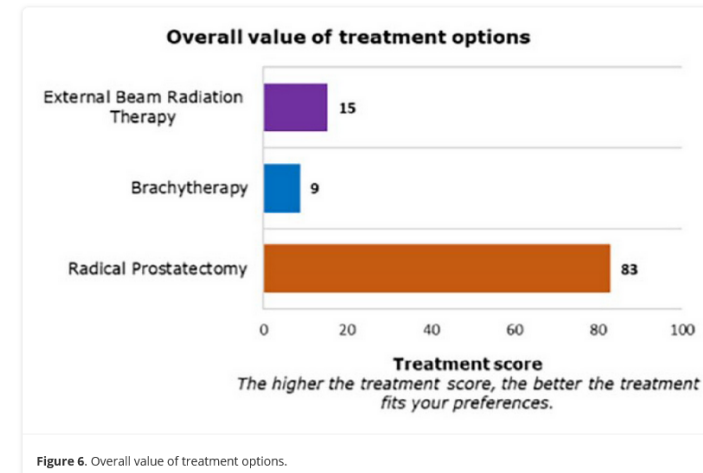
Health Informatics Journal
Volume 26, Issue 1, March 2020, Pages 486-498
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<https://doi.org/10.1177/1460458219832055>



Regular Article

Development and usability testing of a multi-criteria value clarification methods for patients with localized prostate cancer

Isabel B de Angst^{1,*}, Marieke GM Weernink^{2,*}, Paul JM Kil³, Janine A van Til⁴, Erik B Cornel⁵, and Johanna JM Takkenberg⁶



From Co-Design to Clarity:

What Makes Decision Aids Genuinely Patient-Centred

A Patient Perspective | ISPOR 2026 · Patient-Centered SIG

Joint Forum: Health Preference Research & Patient Focused SIGs

'Making Preferences Count: Patient-Engaged Values Clarification for Shared Decision Making'

Angie Botto-van Bemden

Patient Partner · EUPATI Fellow



The Gap Between Promise & Practice

817+

Patient Decision Aids
exist today (DALI, 2024)



Up from 145 in 2010

~50%

developed without
meaningful patient input



Witteman et al.; IPDAS review

70%

of DA evidence based
on low-quality data



Danner et al., 2022

"It is no longer sufficient to curate great science; it is equally necessary to translate that science into plain language and present it to decision makers in a way that enhances understanding and use." — ISPOR Strategic Plan 2030

Decision Coaching in Practice: The OPDG in Action

Sample Coaching Language

Ottawa Decision Coaching Script, 2025

Step 1

"Tell me about the decision you are facing."

Step 2

"Which benefits are most important to you? Which risks do you most want to avoid?"

Step 3

"Who else is involved? Are you feeling pressure to choose a specific option?"

Step 4 (SURE)

"Do you feel sure about the best choice for you?"

The SURE Scale

*4-item decisional conflict screener
(O'Connor & Légaré, 2008)*

S – Sure of the best choice?

U – Understand information?

R – Right decision for your values?

E – Enough support from others?

Key Principle

Decision coaching does not tell patients what to decide — it **builds the skills, confidence, and clarity they need to decide for themselves.**

Two-person coaching: let the more vulnerable voice speak first.

What Decision Aids Can Achieve

Cochrane Systematic Review 2024 | Ottawa DALI | 105 randomised trials, 31,043 participants

94%

Increased
Knowledge

88%

Improved Patient–
Clinician Communication

82%

Values Aligned
with Care Choices

79%

Reduced
Decisional Conflict

71%

Fewer
Undecided Patients

68%

Less
Decision Regret

These outcomes depend on tools built WITH — not just FOR — patients.

What Makes a PtDA Genuinely Patient-Centered?

A patient perspective | Ayre et al. 2025 · Cochrane 2024 · IPDAS



It reflects MY values, not assumed ones

Interactive VCMs help patients surface what actually matters to them — not what clinicians assume should matter. Health-literate design embeds personal autonomy.



It speaks my language

Plain language, plain statistics, and visual formats reduce cognitive load. Low health literacy is the rule, not the exception — design for it from the start. Ensure cultural adaptation.



It was built with people like me

Co-design from the start — not 'patient review' at the end. Patients evaluate usability, emotional tone, and trustworthiness in ways experts cannot predict. Consider heterogeneous aspects.

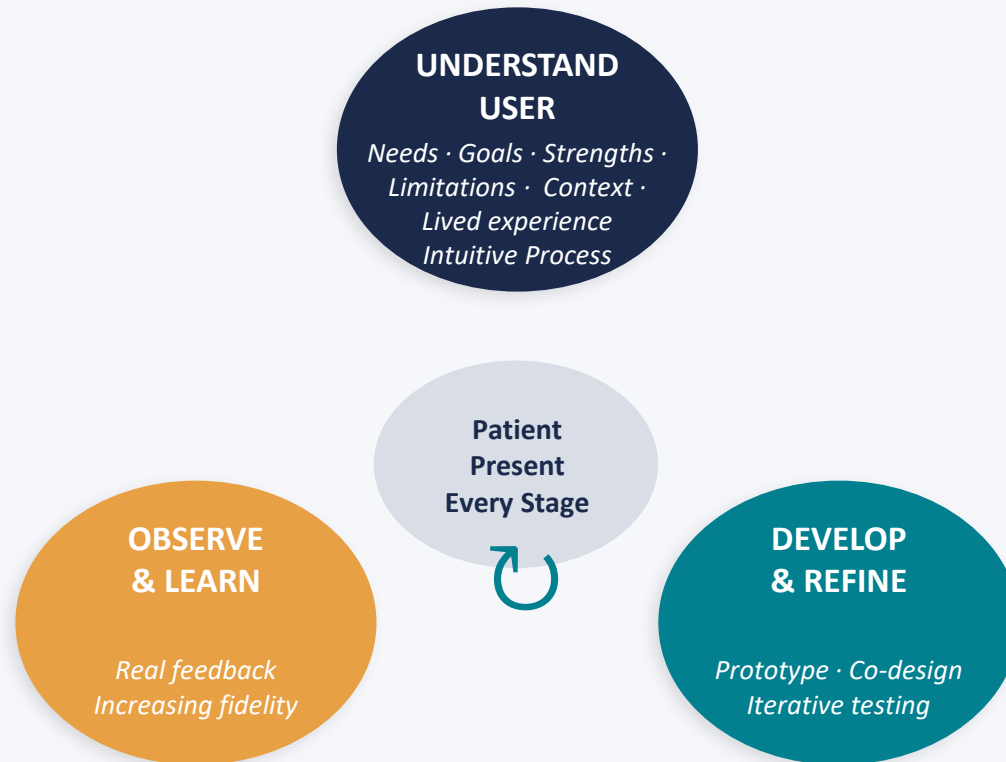


It supports — not replaces — the conversation

The best DAs scaffold shared decision-making discussions. They prepare patients to ask better questions and engage as informed, empowered partners.

Co-Design with Users/Patients: The Development Cycle That Works

Witteman et al., 2015 · IPDAS Collaboration · Nature npj Digital Medicine 2025



✓ What's Working

- Co-design identifies usability issues experts routinely miss
- Improves relevance, uptake, and sustained use of interventions
- Builds trust between researchers, designers, and end-users

⚠ What Needs to Change

- Power imbalances: clinician/researcher voices still dominate
- Time & resource constraints exclude marginalized patients
- Engagement starting after design phase limits impact
- Inconsistent reporting makes cross-study learning difficult

Funding · Remuneration · Early involvement = the three most consistent enablers

User/patient-centered Co-Design:

Co-design is a commitment to patients & quality assurance.

We know what it feels like to face a decision without the right support. You, HEOR researchers know what it takes to build support with rigour.

This forum is our opportunity to think as developers in co-design and make preferences count, not just on paper, but in practice.

Thank you | Questions welcome | Connect with the Patient-Centered SIG

Angie Botto-van Bemden | ISPOR 2026, Philadelphia

What This Forum Asks of All of Us

Actionable guidance for researchers, clinicians, and industry

01

Involve patients from day one

Map PPI opportunities at every stage of the DA lifecycle — not as reviewers, but as co-investigators.

02

Choose VCMs for this patient, this decision

No single method is best. Ground selection in health preference research and co-design evidence together.

03

Design for health literacy first

Plain language, balanced information, and interactive clarification tools are not 'nice to have' — they are equity.

04

Name and address power imbalances

Build remuneration, time, and genuine authority for patient partners into project budgets and governance.

05

Evaluate. Report. Share what didn't work.

Consistent reporting of co-design processes is how the field advances. Negative findings matter.

Janine van Til

A SYSTEMATIC REVIEW OF QUANTITATIVE HEALTH PREFERENCE METHODS TO SUPPORT VALUE CLARIFICATION AND SHARED-DECISION MAKING

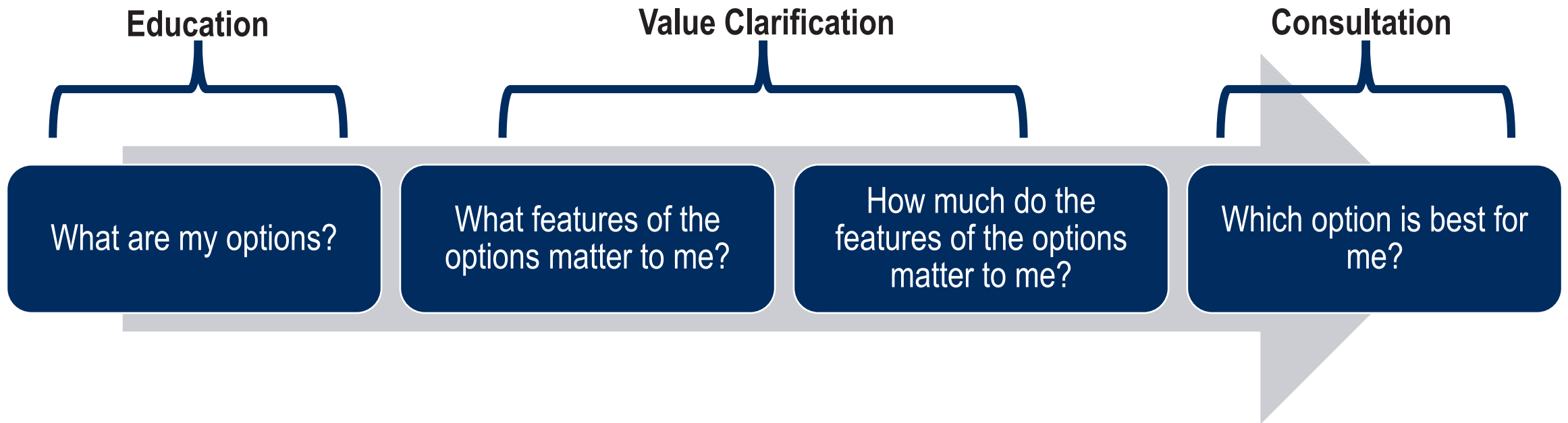
**A REPORT OF THE ISPOR HEALTH
PREFERENCE SPECIAL INTEREST GROUP**



**UNIVERSITY
OF TWENTE.**

WHAT ARE VALUE CLARIFICATION METHODS?

“Patient decision aids are tools designed to help people participate in decision making about health care options. They provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options.” ([International Patient Decision Aids Standards Collaboration, 2024](#))



IMPLICIT AND EXPLICIT VCM

“Value clarification methods (VCM) are strategies that help patients evaluate the desirability of their options or attributes of their options within a specific decision context, to identify which option is “best” for this individual patient.” ([Fagerlin et al., 2013](#)).

Implicit value clarification

- Detailed information about the options and their outcomes, which helps to promote understanding of what it means to undergo the procedures involved

Social matching

- Considering how others value features of options and then decide which of the others is most like you

Explicit value clarification

- Rating, ranking or trading options or features of options, which may give insight into one’s personal values and/or the tradeoffs underlying the choice for one versus other options

WORKING GROUP PROJECT SPECIAL INTEREST GROUP HEALTH PREFERENCE RESEARCH

- Rationale:
 - VCM methods often have no theory, framework, model or mechanism to explain their effect ([Fagerlin et al., 2013](#))
 - Even if the exercise is explicit, many VCM don't show the result of the VCM to participants, which keeps preferences implicit ([Fagerlin et al., 2013](#))
 - Preference based methods, or multi-criteria decision methods, allow for the estimation of relative importance of features, and the estimation of preferences for real-world options.
- Aims of the systematic literature review
 - To explore the design and outcomes of preference-based value clarification methods (Pb-VCM) used to support clinical decision making
 - To understand which guidance is used to design Pb-VCM
 - Identify effective components of Pb-VCM

GUIDANCE FROM PREFERENCE LITERATURE

1. Bridges JF, Hauber AB, Marshall D, Lloyd A, Prosser LA, Regier DA, et al. Conjoint analysis applications in health--a checklist: a report of the ISPOR Good Research Practices for Conjoint Analysis Task Force. Value Health. 2011;14(4):403-13.
2. Marsh K, M IJ, Thokala P, Baltussen R, Boysen M, Kaló Z, et al. Multiple Criteria Decision Analysis for Health Care Decision Making--Emerging Good Practices: Report 2 of the ISPOR MCDA Emerging Good Practices Task Force. Value Health. 2016;19(2):125-37.
3. Thokala P, Devlin N, Marsh K, Baltussen R, Boysen M, Kalo Z, et al. Multiple Criteria Decision Analysis for Health Care Decision Making--An Introduction: Report 1 of the ISPOR MCDA Emerging Good Practices Task Force. Value Health. 2016;19(1):1-13.

THREE TYPES OF PREFERENCE BASED VCM

Prioritization

- Ranking features (attributes) of options

Scoring

- Rating features (attributes) of options
- Rating options

Valuation

- Part-worth utility of features (attribute-levels) of options
- Utility of options

[Fagerlin et al., 2013](#)

Ranking methods

- Full ranking exercises
- Best Worst Scaling case 1

Rating methods

- Rating exercises
- Swing weighting
- Point allocation
- Analytic Hierarchy Process

Choice-based methods

- Threshold Technique
- Conjoint Analysis
- Discrete Choice Experiments
- Best Worst Scaling Case 2 and 3

[MDIC Framework](#)

[Soekhai et al., 2019](#)

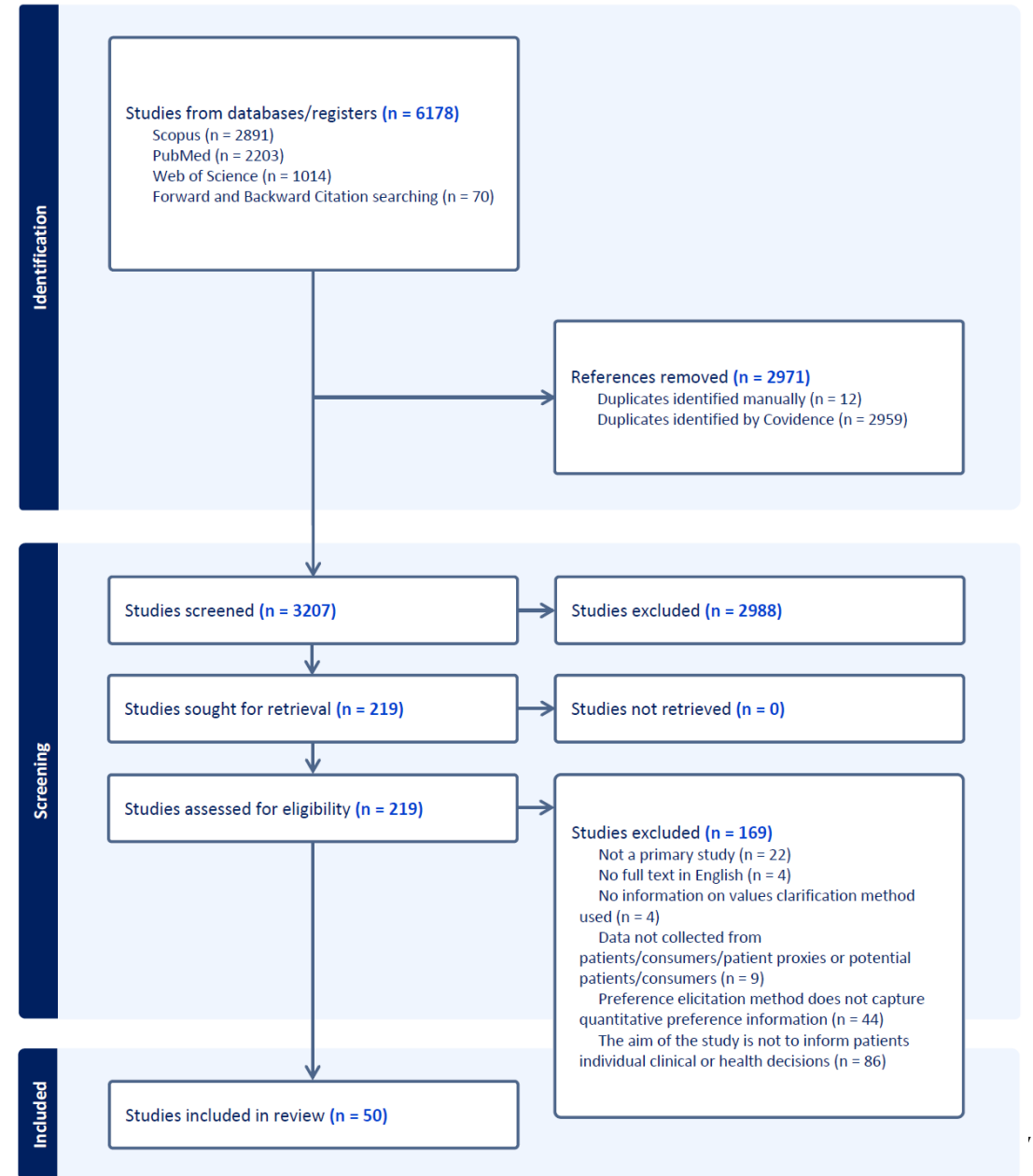
METHODS

To be eligible, the method must:

- 1) elicit quantitative preference information (through ranking, rating or choice-based);
- 2) accommodate health, non-health, and process attributes

Only primary studies that elicited preference information from patients, patient proxies or health subjects asked to make a salient choice (i.e. prevention/screening) were included.

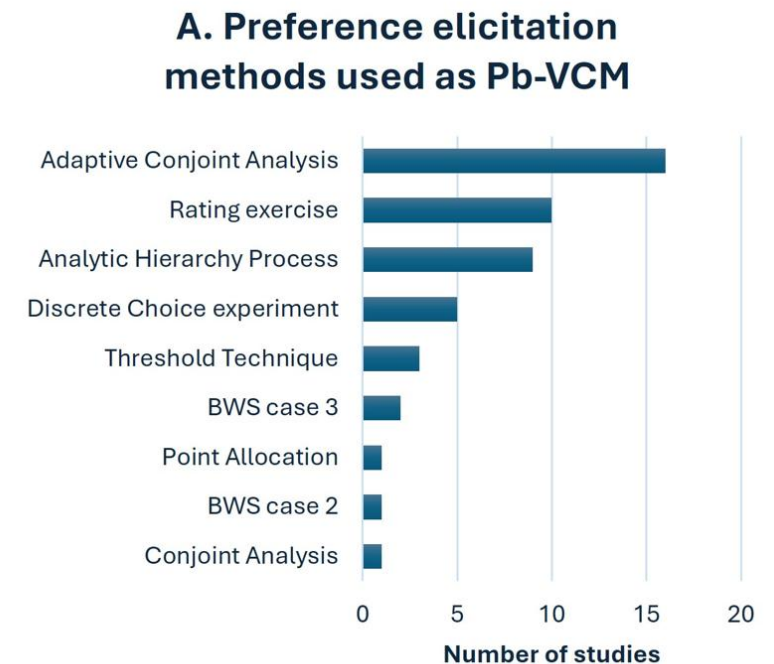
Eligible methods include rating and ranking, SWING weighting, Point Allocation, Analytical Hierarchy Process, (Adaptive) Conjoint Analysis, Discrete Choice Experiments, Best Worst Scaling (case 1, 2 and 3) and threshold technique (as described in MDIC classification).



DEVELOPMENT OF THE VCM

Recommendation	Source
Report and justify the preference elicitation format (methods used for weighting attribute importance)	(1, 2)

- All studies report the preference elicitation format = eligibility criterion
- The most used preference elicitation methods were Adaptive Conjoint Analysis (ACA) (n=16, rating (n=10) and the Analytic Hierarchy Process (AHP) (n=9)
- Justification of the use of a quantitative preference elicitation method is limited. Arguments include ability to understand trade-offs or patient priorities, and cognitive burden

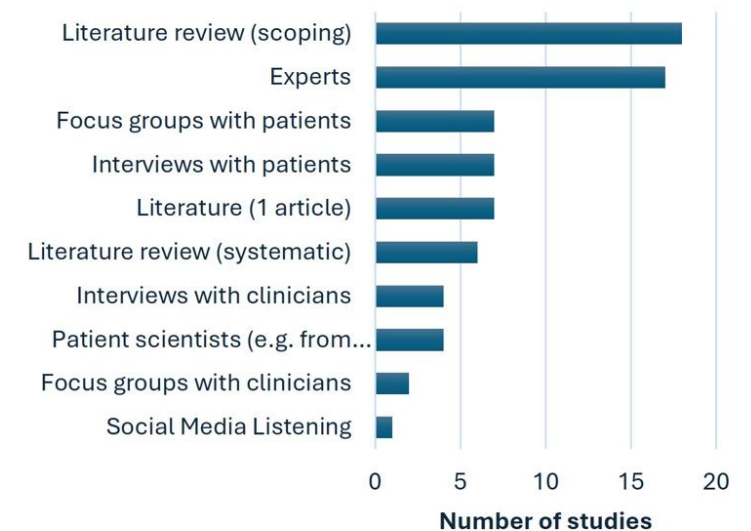


DEVELOPMENT OF THE VCM

Recommendation	Source
Report and justify the methods used to identify criteria	(1, 2, 3)
Attribute set should be consistent with decision theory (complete, non-redundant, non-overlapping and preferential independent)	(1, 2)

- Most studies report at least on method used to identify criteria, many report multiple.
- Most used methods are scoping review (n=18), expert elicitation (n=14), and focus groups (n=7) or interviews (n=7) with patients.
- Most studies provide no justification for why the method used to identify criteria was chosen.
- 18 studies report on some properties of the attribute set.
 - The relevance of the attribute to the decision (n=13) was mentioned as a reason to include an attribute
 - Overlap between attributes (n=4), preferential dependence (n=4) and redundancy (n=1) were sometimes used as arguments to remove attributes or adjust attribute set

B. Methods for Attribute Identification

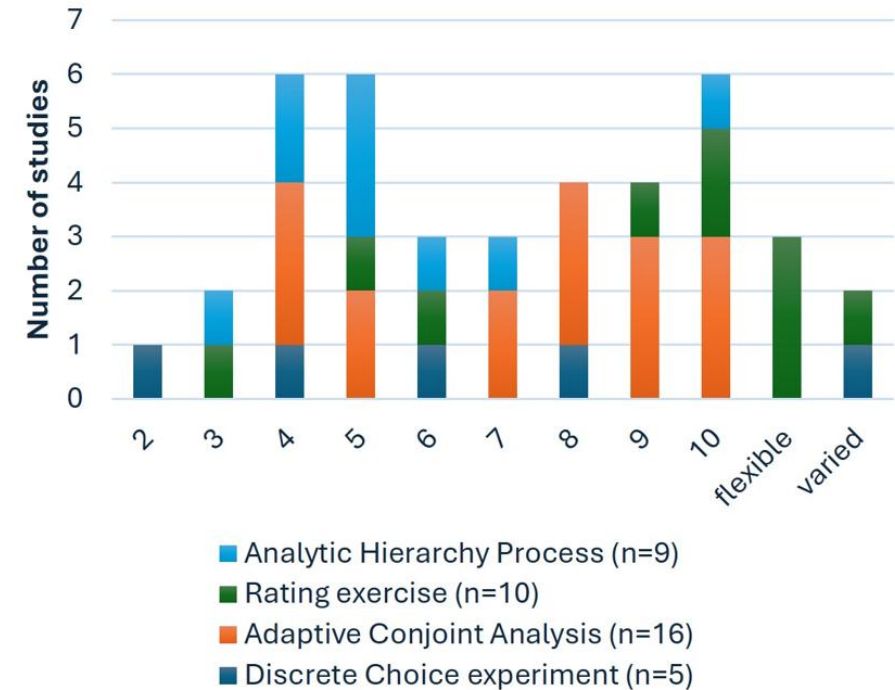


DESIGN OF THE PB-VCM

No guidance available

- Existing reviews of different methods suggest between 4-8 attributes for choice-based methods is optimal
- Rating methods (rating, AHP) capture preferences on the individual level. Increasing the number of attributes increases the number of tasks, but burden remains low
- Choice based methods (ACA; DCE) capture preferences on the group level. Increasing the number of attributes requires increasing the number of tasks or the number of study participants
- No relationship between number of attributes and preference-elicitation method

E. Number of Attributes in the Pb-VCM

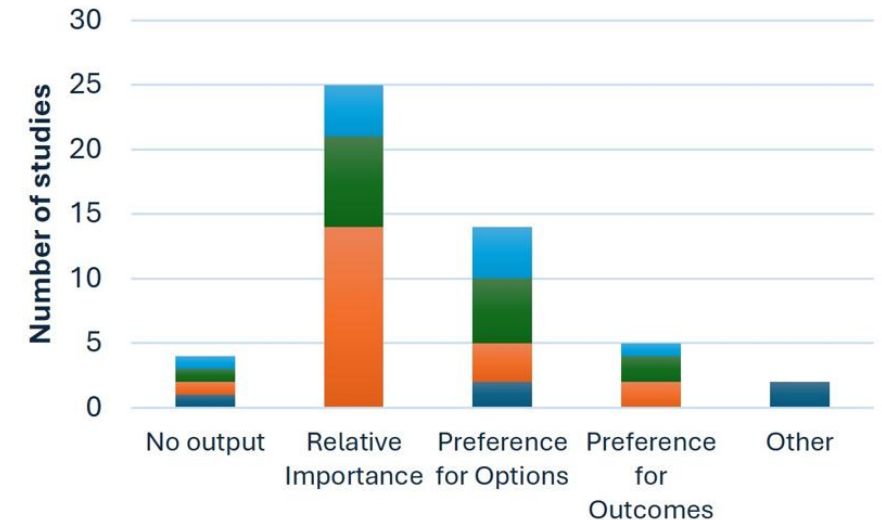


PERSONALIZED PREFERENCE INFORMATION

Recommendation for evaluation of quality of the Pb-VCM	Source
Examine the quality of responses to the Pb-VCM (rationality, validity, reliability)	(1)
Account for uncertainty of preference estimations in predicting the “best” option (perform sensitivity analysis)	(1,3)

- Personalized preference information available to users in 45/50 studies
 - 25 studies showed attribute importance
 - 5 studies showed preferences for specific outcomes (f.i. preference for IV over pill for mode of administration)
 - 14 studies showed preferences for options
- No relationship between method for preference elicitation and which preference information was shown
- Only few studies, mostly the DCE, examine quality of the responses
- No studies performed sensitivity analysis of estimates

F: Personalized Preference Information



■ Analytic Hierarchy Process (n=9)
 ■ Rating exercise (n=10)
 ■ Adaptive Conjoint Analysis (n=16)
 ■ Discrete Choice experiment (n=5)

FEASIBILITY OF PB-VCMS

Recommendation for use in clinical practice / as part of a Patient Decision Aid	Source
Report on the educational materials used to explain the decision problem to patients	(1)
Explain how attribute definitions and performance of options were explained to patients	(1)
Report on the information that precedes the Pb-VCM	(1)
Report and justify the level of burden to the participant	(1)
Report and justify the mode of administration of the Pb-VCM	(1)

Reporting on actual use of Pb-VCM in clinical practice was poor

- Whether Pb-VCM was intended as a stand-alone tool or as part a Pt-DA
- Whether and how information about disease, options, and features of options (attributes) were explained to patients
- Whether the “educational information” was evaluated together with the “value clarification part”

FEASIBILITY OF PB-VCMS

36 studies presented some data on feasibility

- Feasibility is reported in terms of completion time for the Pb-VCM, completion rate, whether assistance is required during the task
- Completion times varied between 3 and 30 minutes, but most concluded that Pb-VCM were feasible

User experiences were elicited using qualitative and quantitative study methods, including:

- the extent to which the process of using the Pb-VCM was seen as beneficial, helpful, useful, providing insight, helps decision making, or stimulating.
- User comprehension, understanding, ease of use of the task itself

Iterative improvements to design were reported by some studies.

Strategies for improving Pb-VCM included: 1) clearer instructions, 2) limiting and simplifying attributes, 3) allowing participants to add new attributes, 4) reducing and simplifying numerical information, 5) simplifying and layering educational content that introduces the decision and the attributes, and 6) improving the layout or user interface.

EFFECTIVENESS OF PB-VCMS

23 studies assessed the effect of the Pb-VCM on the decision-making process and outcomes.

- Decisional conflict (n=15)
 - Decrease in decisional conflict after Pb-VCM (n=3)
 - No evidence for a difference between Pb-VCM and comparator (implicit VCM; education only)
 - No evidence for difference between Pb-VCMS in reduction in decisional conflict
- Value congruence (n=11)
 - One study using rating found high congruence between predicted preferences and intended treatment choice without showing preference information
 - One study using rating found increased congruence between predicted preference and actual treatment choice after showing preferences for real-world options to users, compared to not showing this information

CONCLUSIONS

Substantial variation in Pb-VCM designs

- No clear link between method choice and number or type of attributes
- Few studies compare multiple methods → selection often based on familiarity

Limited evidence on comparative performance

- No strong evidence that some Pb-VCMs are more feasible or effective than others

Unclear added value of presenting preference output to users

- Showing personalized preferences may not be more beneficial than completing the exercise itself

Large variation in development and reporting practices

Need for additional guidance to

- Improve comparability across Pb-VCMs and other VCMs
- Identify effective components of Pb-VCMs

RECOMMENDATIONS FOR DESIGN

Justify the use of a quantitative Pb-VCM

- Choice of preference elicitation method
- Theoretical strengths
- Attribute balance across options
- User burden relative to the number and type of attribute

Streamline and layer educational content within the PtDA and Pb-VCM

- Align with clinicians' roles in informing and discussing values
- Follow IPDAS guidance

Apply an **iterative, user-centred design** process

- Minimize patient and clinician burden
- Ensure understanding of attributes and tasks
- Align preference outputs with user needs
- Report improvements from feasibility testing

Understand the **quality and comparability of clinical evidence** before deciding on estimating preferences for real-world options

RECOMMENDATIONS FOR EVALUATION

Theoretical rationale for benefit of preference-based value clarification methods over implicit VCM

Conduct **randomized studies** to:

- Compare Pb-VCMs with implicit VCMs
- Directly compare different Pb-VCM approaches

Use **validated outcome measures**, such as:

- Decisional conflict
- Participation in decision making
- Decision regret
- Value congruence (alignment between predicted and actual choices)

Report the **type of personalized preference information** presented to users

- Identify which outputs are most effective

RECOMMENDATIONS FOR GUIDANCE

Assess the **feasibility** of different preference-based methods

- Align choice of preference method with number of attributes and attribute levels

Determine the **performance** of these methods

- Generate reliable individual-level estimates of attribute importance and patient preferences for real-world options at the individual level

Provide guidance for **standardized reporting**

- Improve consistency in reporting Pb-VCMs in publications

Methods for use in individual-level decision support tools

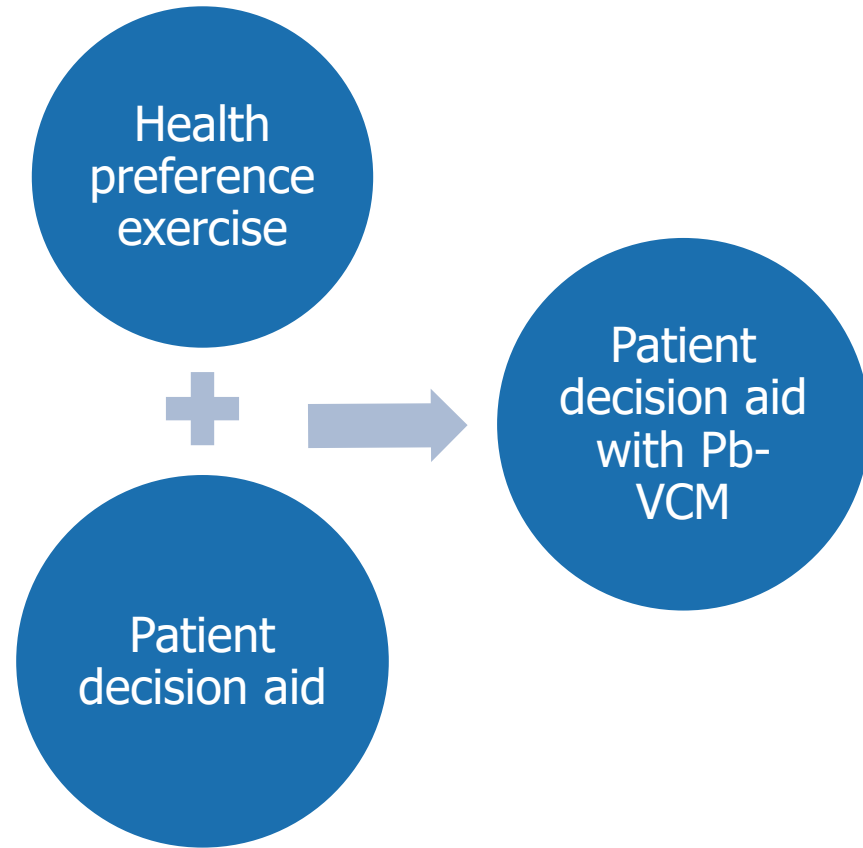
Christine Poulos, PhD

Senior Economist and Vice President

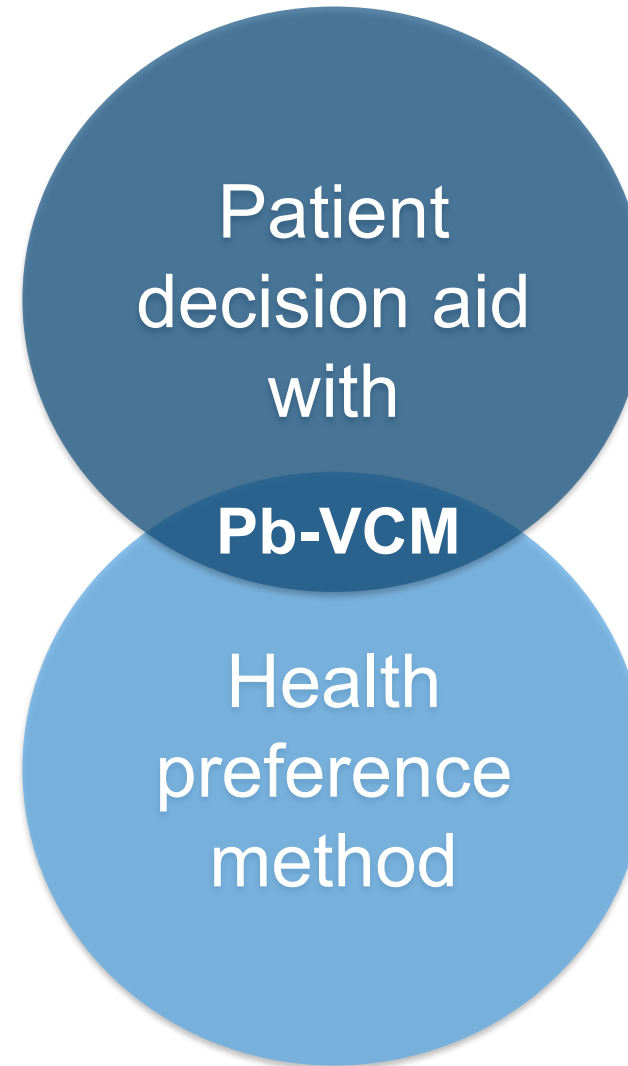
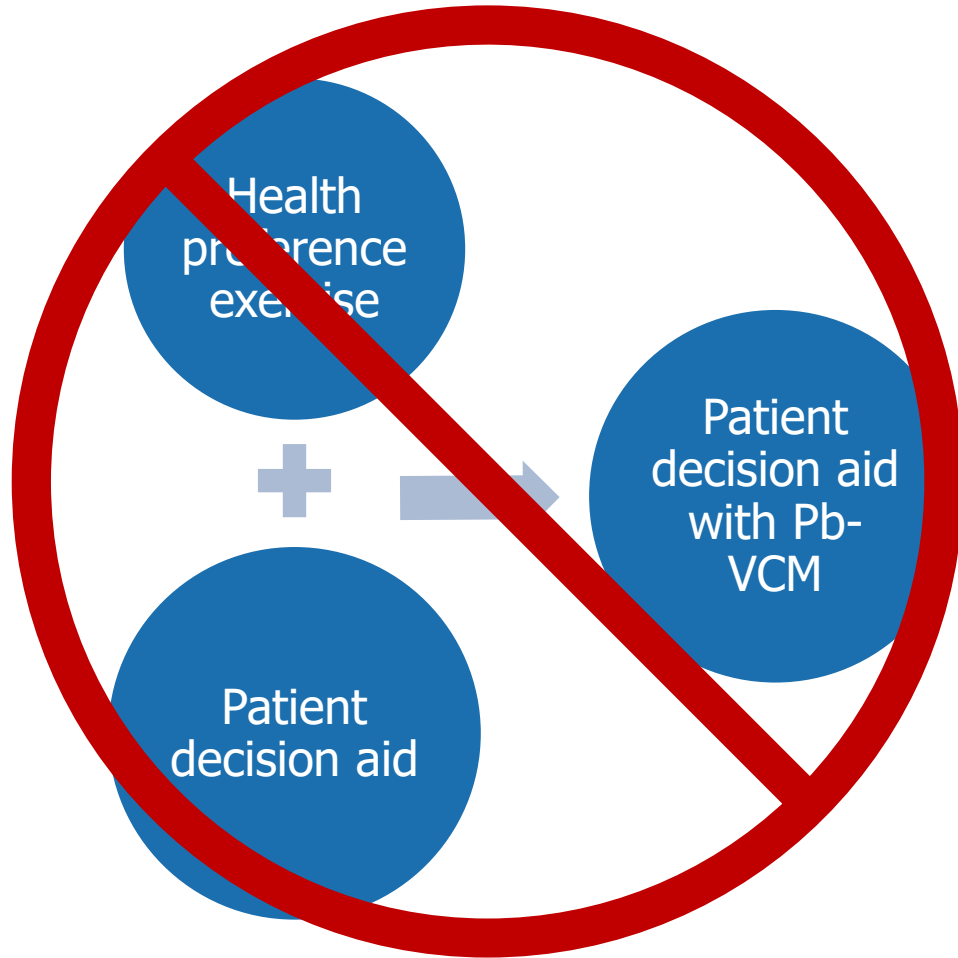
Health Preference Assessment

The power of **knowledge**.
The value of **understanding**.

PtDA with PbVCM



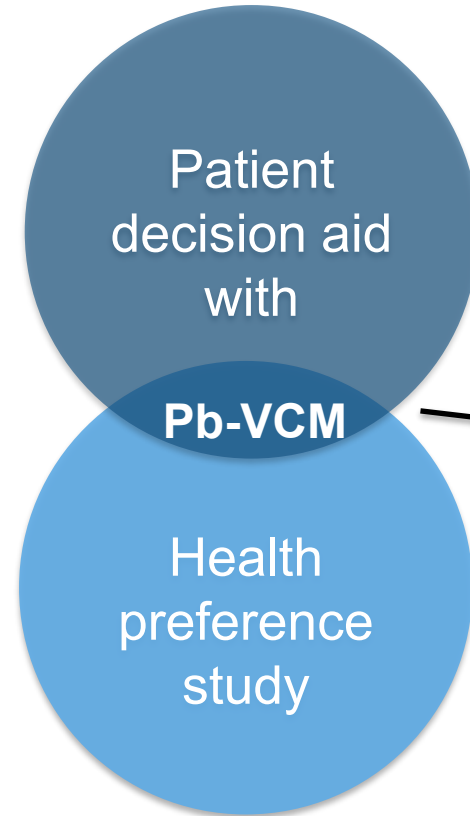
PtDA with PbVCM



Comparing qualities of preference applications

Similar Qualities

- Patient-centered
- Balanced
- Not burdensome
- Good preference research practices (including attribute properties)



Different Qualities

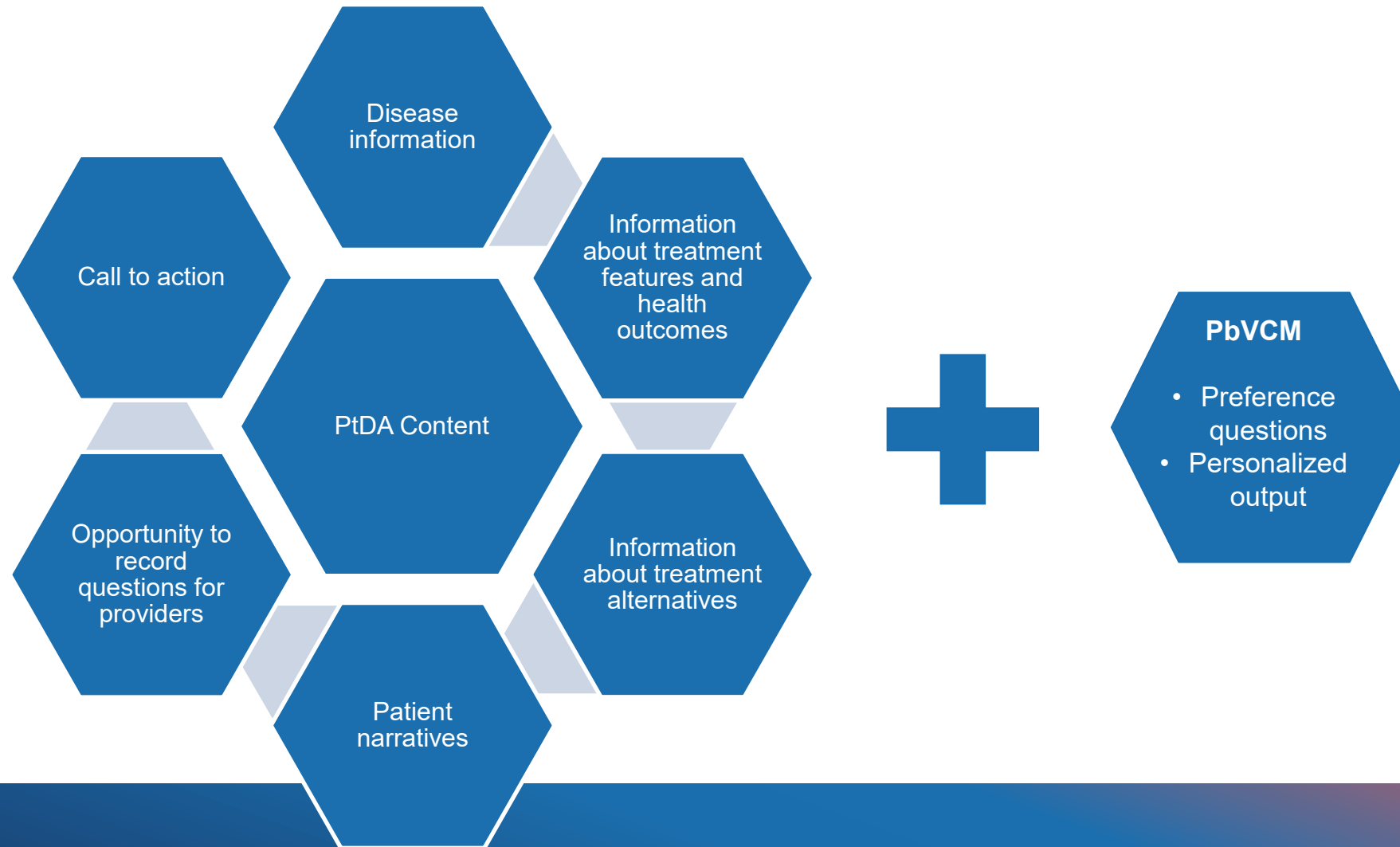
- Feasible
- Acceptable
- Improve decision-related outcomes
- Design considerations when N=1
- Other design issues including experimental design, analysis

Selecting a method for PbVCM

- Available guidance (e.g., MDIC catalog) focused on health preference applications.
- Key factor for choice in PtDA is the type of preference information sought
- Based on formative research
 - Preference sensitive choice
 - Patient-centered information
 - Relevant to the choice and clinical encounter

Type of Information	Method
What matters (Attributes)	• Qualitative methods (concept elicitation) • Ranking
What matters most (Relative importance)	• Simple direct weighting • Ranking (if converted to relative importance scores) • Outranking • Time tradeoff • Standard gamble • Ranking questions • Best-worst scaling (case 1) • Best-worst scaling (case 2)
Acceptable tradeoffs	• Swing weighting • Analytical hierarchy process • Threshold technique*
Treatment acceptability (preference-weighted performance of alternatives*)	• Conjoint analysis and discrete choice experiment* • Best-worst scaling (case 3)*

Selecting a Method, continued



Selecting and Refining a PtDA and Pb-VCM: Acceptability Considerations



Content – is PbVCM supportive and relevant



Burden – PbVCM should not be too long, complex, or burdensome



Perceptions of impact / utility – PbVCM should be perceived to be useful



Intention to use

Selecting and Refining a PtDA and Pb-VCM: Feasibility considerations



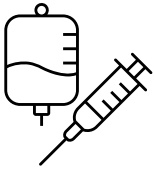
Location where tool is completed



How to share output with user and provider



Aligning content and personalized output with provider and patient discussion



Treatments and their features



Objectivity and access



Longevity of the tool / ability to update and maintain / not too complex

Summary

- The selection of a preference method to include in a PtDA balances a range of factors and is context-specific
 - Preference sensitive decisions
 - Clinical setting factors
 - Patient factors
 - Treatment features and alternatives
- The next section describes additional context related to decision making

ISPOR 2026

Integrating Evidence & Recommendations Cross-Discipline

Holly Peay, PhD

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Integration, Not Co-Invention

- Heuristics
- Numeracy
- Use of narratives
- Alignment of preference and behavior
- Comparing models based on attributes



Heuristics & Cognitive Bias

Decision aids use **evidence-based best practices** to anticipate and manage heuristics and cognitive biases.

Response to heuristics is one of the **primary drivers** for use of values clarification activities.

Heuristics

- Anchoring
- Availability
- Framing effects
- Present bias / immediacy bias
- Status quo bias
- Confirmation bias

Nielsen Norman Group Heuristic Evaluation Workbook

Use this workbook to conduct your own heuristic evaluation.

For each of Jakob's 10 Usability Heuristics, look for specific places where the interface fails to adhere to the guideline. Write your recommendations for how to fix those usability issues.

<https://www.nngroup.com/articles/ten-usability-heuristics/>

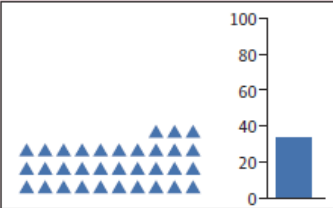
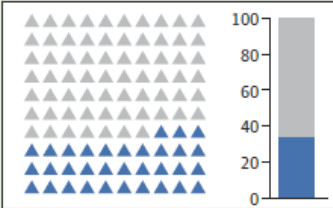
For web-based products, there is an entire industry around product development and evaluation for virtual interfaces based on usability heuristics

Nielsen Norman Group: nngroup.com

Numeracy

Reference:
Zikmund-Fisher, Thorpe, and Fagerlin. JAMA 2025

Figure. Guidance for Communicating With Patients About Medical Numbers

<i>Recommendation</i>	<i>Potentially problematic communication</i>	<i>Preferred communication</i>
Use numbers to convey risk even when approximate	"Common" "Very rare" "Unlikely"	"35%" or "60%" "4 in every 1000" "5% to 10%"
Adjust numerators and use consistent and round denominators	"1 in 12" "1 in 384"	"8% of women" "About 3 in 1000 people"
Communicate changes in probability (eg, beneficial effects) with absolute differences, not relative change or odds ratios	"Reduces the 10-year risk by 25%"	"Reduces the 10-year risk from 8% to 6%"
Use part-to-whole visualizations such as icon arrays or stack bars when showing risk graphically		
Provide contextual and interpretive information	"Your platelet count is $75 \times 10^9/\text{L}$. Normal is 150 to $400 \times 10^9/\text{L}$." "Your $\text{HbA}_{1\text{C}}$ is 8.3%. Normal is 4.0% to 5.6%."	"Your platelet count is $75 \times 10^9/\text{L}$. Normal is 150 to $400 \times 10^9/\text{L}$. We'll need to cancel the procedure if it gets to $50 \times 10^9/\text{L}$." "Your $\text{HbA}_{1\text{C}}$ is 8.3%. For you, our target is below 7%, and even a 0.5% change is significant."

Numeracy

Reference:
Zikmund-Fisher, Thorpe, and Fagerlin. JAMA 2025

Figure. Guidance for Communicating With Patients About Medical Numbers

Recommendation	Potentially problematic communication	Preferred communication
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Adjust numerators and use consistent denominators	"1 in 12"	"8% of women"
Communicate risk in context (eg, 1 in 1000 is different from 1 in 100 odds)		
Use percentages such as 10% when appropriate		
Provide interpretation of numbers	150 to 400 x 10⁹/L." "Your HbA_{1c} is 8.3%. Normal is 4.0% to 5.6%."	We'll need to cancel the procedure if it gets to 50 x 10⁹/L." "Your HbA_{1c} is 8.3%. For you, our target is below 7%, and even a 0.5% change is significant."

Systematic Review:

People interpreted "rare" to range from 0% to 80%, while "common" ranged from 10% to 100% Caveat: Nonnumeric communication may be appropriate when goal is to represent a risk category

Use of Narratives



Pro: Users like them

- Increased engagement
- Improved information recall
- Generate fewer counter-arguments
- Enhanced emotional connection
- Effective at persuasion



Con: May bias decisions

- Alter preferences and intentions in unexpected ways
- Narratives overshadow data
- Concerns about unrepresentative experiences



Considerations: Caution!

- Multifaceted construct
- Focus on decision process and experience
- Pair with statistical information
- Extend beyond patients to healthcare providers, caregivers
- Not (yet) a recommended element of PtDAs

Reference: Shaffer et al., 2021
DOI: 10.1177/0272989X211011100



Alignment of Preferences & Behavior

- PtDAs increase congruence between informed values and healthcare choice, with moderate-certainty evidence.
- There is indirect evidence that PtDAs may improve adherence to the selected treatment.

Reference: Stacey et al., 2024 DOI: 10.1002/14651858.CD001431.pub6



Table 2 Content Elements for PtDA used Preconsultation versus During Consultation

Content Element	Preconsultation (n = 123)	During Consultation (n = 26)
Values clarification methods		
Explicit	93 (76%)	8 (31%)
Implicit	30 (24%)	18 (69%)
Use of probabilities		
Yes	107 (87%)	25 (96%)
No/unable to ascertain	16 (13%)	1 (4%)
Presenting information side by side		
Yes	70 (57%)	15 (58%)
No	29 (24%)	10 (37%)
Unable to ascertain	24 (20%)	1 (4%)
Guidance in decision making step by step		
Yes	78 (63%)	24 (92%)
No	30 (24%)	2 (8%)
Unable to ascertain	15 (12%)	0 (0%)
Personal summary to facilitate communication		
Worksheet	44 (36%)	2 (8%)
Automated summary	37 (30%)	6 (23%)
No	42 (34%)	18 (69%)
List of questions to discuss decision		
Yes	15 (12%)	0 (0%)
No	91 (74%)	26 (100%)
Unable to ascertain	17 (14%)	0 (0%)
Encourage to discuss decision		
Yes	88 (72%)	26 (100%)
No	22 (18%)	0 (0%)
Unable to ascertain	13 (11%)	0 (0%)
User involvement in development		
No users/not reported	37 (30%)	3 (12%)
HCP	13 (11%)	6 (23%)
Patient/consumer	7 (6%)	0 (0%)
HCP and patient/consumer	66 (54%)	17 (65%)
User involvement in testing		
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Use of a theoretical or conceptual framework		
IPDAS	30 (24%)	9 (35%)
Other frameworks with or without IPDAS	57 (46%)	2 (8%)
No	36 (29%)	15 (58%)

HCP, health care provider; IPDAS, International Patient Decision Aid Standards Collaboration; PtDA, patient decision aid.

Meta-analysis of the effect of PtDA attributes on patient outcomes

Reference: Stacey et al., 2025
DOI: 10.1177/0272989X251318640



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Implicit vs explicit values clarification:

PtDAs with either type of VCM were significantly better than usual care. No significant difference in comparison of PtDAs with explicit vs implicit VCMs.

Reference: Stacey et al., 2025
DOI: 10.1177/0272989X251318640



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Use of probabilities:

With or without probabilities, PtDAs were significantly better than usual care. Those using probabilities resulted in improved knowledge vs those without.

Reference: Stacey et al., 2025
DOI: 10.1177/0272989X251318640



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Personalized summary

With or without summary, PtDAs were significantly better than usual care. No meaningful significant difference with summary vs without.

Reference: Stacey et al., 2025
DOI: 10.1177/0272989X251318640



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User involvement in development and testing:

Significant improvements in knowledge when patients involved in development over HCP alone

Reference: Stacey et al., 2025
DOI: 10.1177/0272989X251318640



Priorities

Improved models for use of health preference methods for N=1 decision support that build on evidence and recommendations from:

- Economics
- Decision science
- Engagement science
- Psychology and behavioral science
- Evaluation of outcomes
- Recommendations for best practices





ISPOR 2026

Thank You.

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Senior Director

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Discussion/Audience Q&A

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ISPOR's community of more than 20,000 individual and chapter members from 120+ countries includes a wide variety of healthcare stakeholders, including researchers, academicians, regulators and assessors, public and private payers, healthcare providers, industry, and patient representatives. The Society's leadership has served as an unbiased resource and catalyst for innovation in the field for more than 20 years.

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