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Improving healthcare decisions

FORUM:
Using Health Preference Methods for Value Clarification in Patient Decision Support: Current Use and Future Developments

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ISPOR Health Preference Research Special Interest Group

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Discussants

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1

Background of the Project

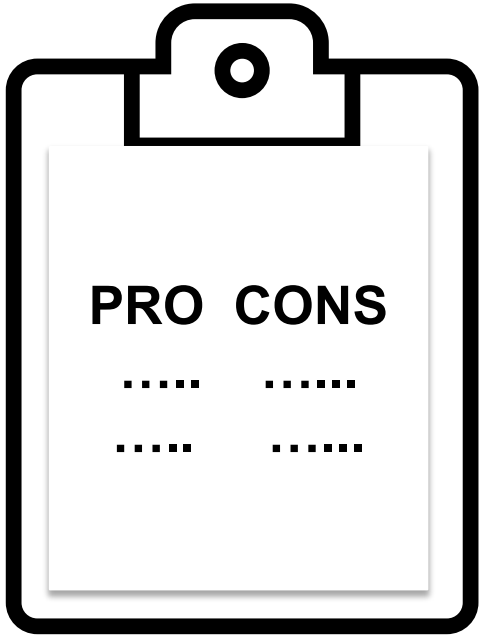
Janine van Til, PhD, Department of Health Technology and Services Research, University of Twente, Enschede, the Netherlands

Background

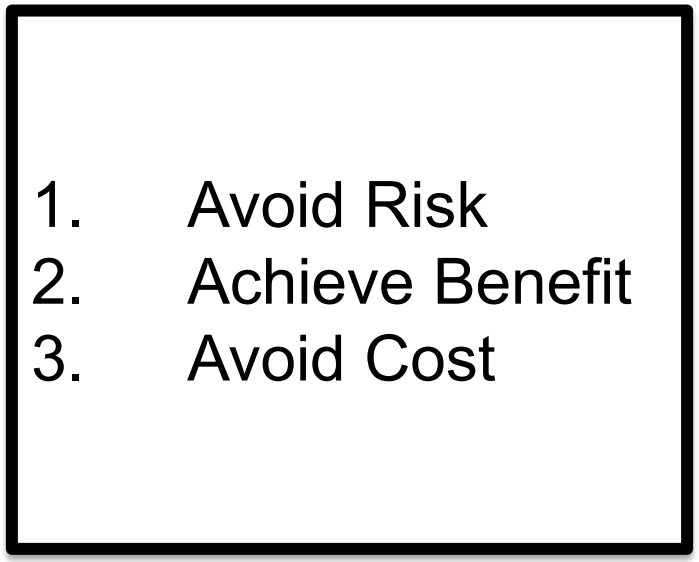
- The guidelines for development of patient Decision Aids recommend to include a value clarification method (Stacey et al., 2021)
- *Value clarification methods* (VCM) are strategies that are intended to help patients evaluate the desirability of **options** or **attributes of options** within a specific decision context, to identify which option [they] prefer (Fagerlin et al., 2013).
- There are no established best practices for values clarification in the context of informed or shared decision making (Witteman et al., 2016)

Value Clarification Methods

Talk with the health care provider



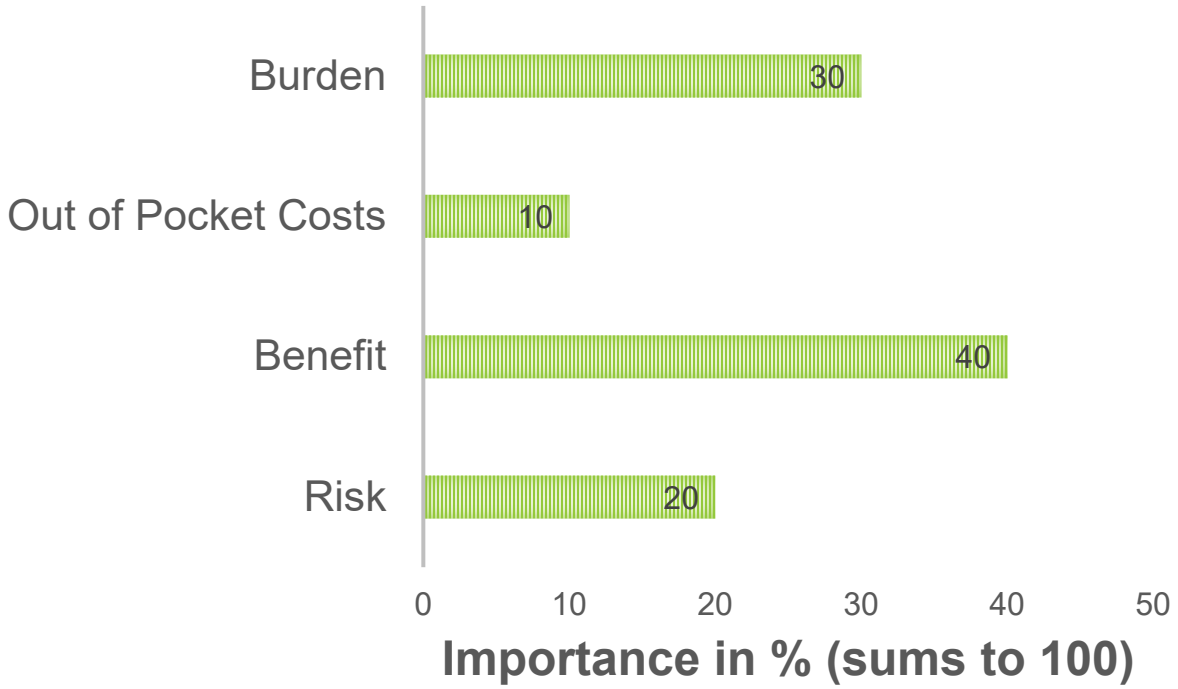
Pros and cons list



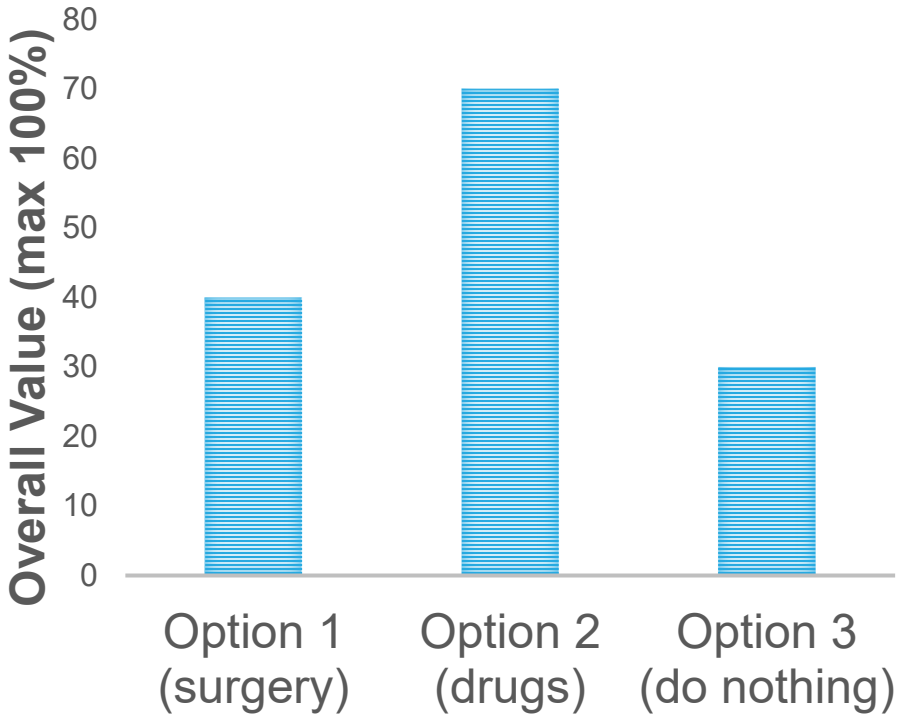
Priority Setting

Value Clarification Methods

RELATIVE IMPORTANCE OF TREATMENT ATTRIBUTES



PREFERENCE FOR REAL WORLD OPTIONS



Background

- In 2021, Witteman and others again reviewed existing VCM.
- They conclude that VCM that allow patients to see how different real-world options align with patients' values, show increased congruence between patient values and patient decisions (Witteman, 2021 #4).

Aligning preferences with real-world options

Understand the relative importance of the attributes of the real-world options to the individual patient

Outcome data for all options on each of the attributes

(Scientific evidence)

Combine relative importance of attributes with the value of outcomes to derive preferences for real world options

(mathematical or statistical process)

Guidelines

ISPOR TASK FORCE REPORT

Multiple Criteria Decision Analysis for Health Care Decision Making—An Introduction: Report 1 of the ISPOR MCDA Emerging Good Practices Task Force

Praveen Thokala, MASc, PhD[1,], Nancy Devlin, PhD[2], Kevin Marsh, PhD[3], Rob Baltussen, PhD[4], Meindert Boysen, MSc[5], Zoltan Kalo, PhD[6,7], Thomas Longrenn, MSc[8], Filip Mussen, PhD[9], Stuart Peacock, PhD[10,11], John Watkins, PharmD[12,13], Maarten Ijzerman, PhD[14]*

ISPOR TASK FORCE REPORT

Multiple Criteria Decision Analysis for Health Care Decision Making—Emerging Good Practices: Report 2 of the ISPOR MC Emerging Good Practices Task Force

Kevin Marsh, PhD[1,], Maarten IJzerman, PhD[2], Praveen Thokala, MASc, PhD[3], Rob Baltussen, PhD[4] Meindert Boysen, MSc[5], Zoltán Kaló, MSc, MD, PhD[6,7], Thomas Lönngren, MSc (Pharm)[8], Filip Mussen, MSc, PhD[9], Stuart Peacock, MSc, DPhil[10,11], John Watkins, PharmD, MPH, BCPS[12,13], Nancy Devlin, PhD[14]*

SCIENTIFIC REPORT

Conjoint Analysis Applications in Health—a Checklist: A Report of the ISPOR Good Research Practices for Conjoint Analysis Task Force

John F. P. Bridges, PhD[1,*], A. Brett Hauber, PhD[2], Deborah Marshall, PhD[3], Andrew Lloyd, DPhil[4], Lisa A. Prosser, PhD[5]

INTRODUCTION Open Access

Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids

Robert J Volk[1*], Hilary Llewellyn-Thomas[2,3], Dawn Stacey[4,5], Glyn Elwyn[6]

Medical Decision Making
2021, Vol. 41(7) 729–733

The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0

Dawn Stacey and Robert J. Volk, for the IPDAS Evidence Update Leads (Hilary Bekker, Karina Dahl Steffensen, Tammy C. Hoffmann, Kirsten McCaffery, Rachel Thompson, Richard Thomson, Lyndal Trevena, Trudy van der Weijden, and Holly Witteman)

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Constructing Experimental Designs for Discrete-Choice Experiments- Report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force

Different research fields – Different terminology

Health Preference Research

- *Preferences* are defined as qualitative or quantitative statements of the relative desirability or acceptability of **attributes** that differ among alternative health interventions (MDIC, 2015)

Decision Aid Literature

- *Preferences* are inclinations toward or away from a given decision **option** (Witteman et al., 2016)
- *Values* refers to the extent to which decision **attributes** matter to in individual in making a health decision (Witteman et al., 2016)

Different research fields – Different terminology

Health Preference Research

- *Preferences* are defined as qualitative or quantitative statements of the relative desirability or acceptability of **attributes** that differ among alternative health interventions (MDIC, 2015)

Decision Aid Literature

- *Preferences* are the extent to which a decision **option** or **health state** is desirable or acceptable, either in the abstract or in comparison to other options or health states (from Witteman 2021 -> reference to MDIC, 2015)

- *Values* are what matters to an individual relevant to a health decision (from Witteman 2021 -> reference to Rocque 2020)

Aims of the Review

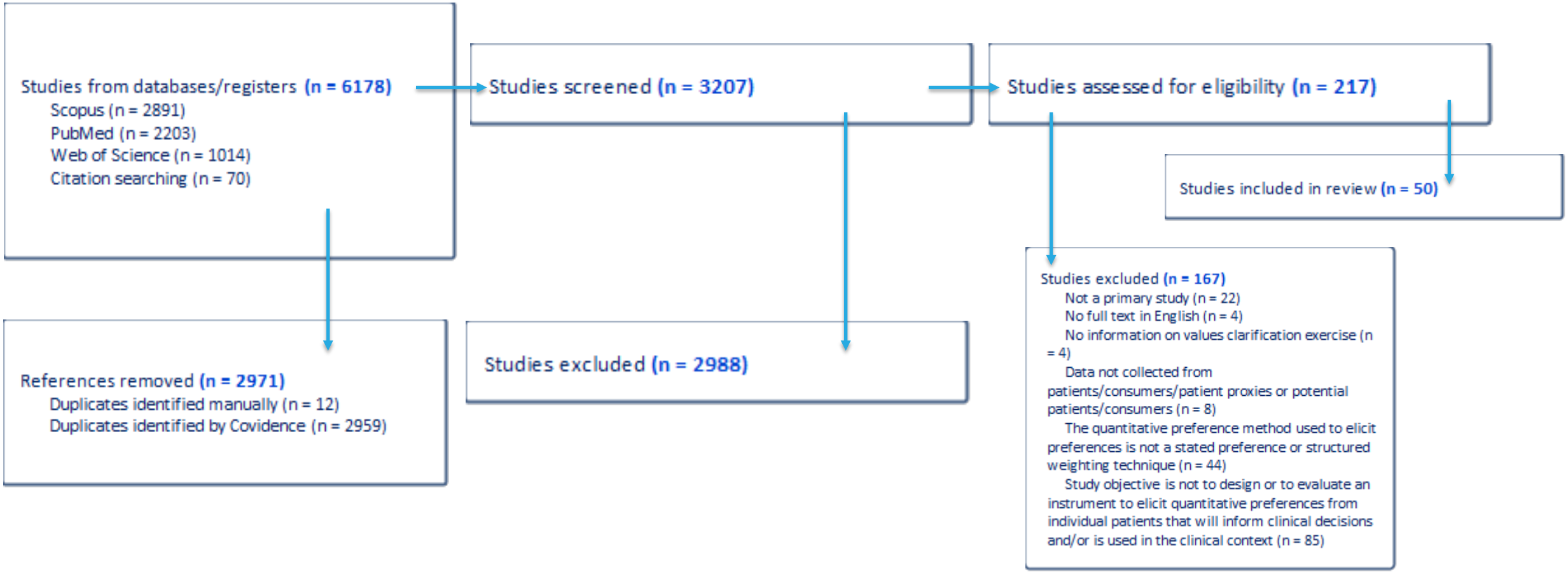
- To address a knowledge gap regarding current practices in the design and testing of preference based-VCM (Pb-VCM) to support individual value clarification to inform shared decision making.
- Design: Which Pb-VCM are used and how are they used?
- Testing: What is the feasibility and effectiveness of Pb-VCM?

Preference-based Methods included in the Review

Group	Method
Structured-weighting	• Simple direct weighting • Ranking exercises • Swing weighting • Point allocation • Analytic hierarchy process • Outranking methods
Health-state utility	• Time tradeoff • Standard gamble
Stated-preference	• Direct-assessment questions • Threshold technique • Conjoint analysis and discrete-choice experiments • Best-worst scaling exercises
Revealed-preference	• Patient-preference trials • Direct questions in clinical trials

- From: MEDICAL DEVICE INNOVATION CONSORTIUM (MDIC) PATIENT CENTERED BENEFIT-RISK PROJECT REPORT:
- A Framework for Incorporating Information on Patient Preferences Regarding Benefit and Risk into Regulatory Assessments of New Medical Technology By Medical Device Innovation Consortium (MDIC) (https://mdic.org/wp-content/uploads/2015/05/MDIC_PCBR_Framework_Web1.pdf)

Systematic Review Process



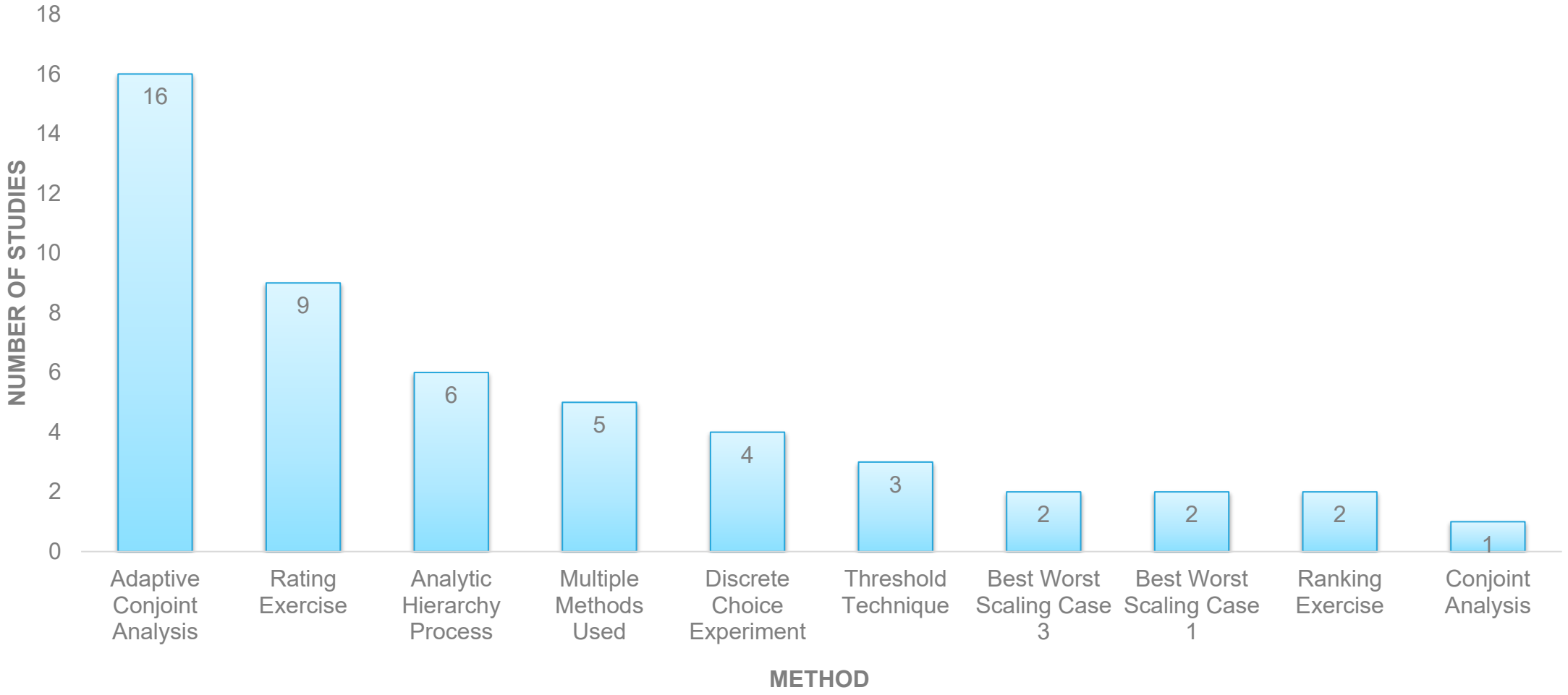
Publication trends

2

Methods Used for Individual Level Value Clarification

Caitlin Thomas, Evidera, UK

Adaptive Conjoint Analysis Most Frequently Used Method



Adaptive Conjoint Analysis - Most Used Method

- ACA combines rating and choice-based preference elicitation questions
- Based on the initial rating exercise, the ACA algorithm selects questions that are designed to refine the initial preference estimates and better understand the respondent's true preferences.

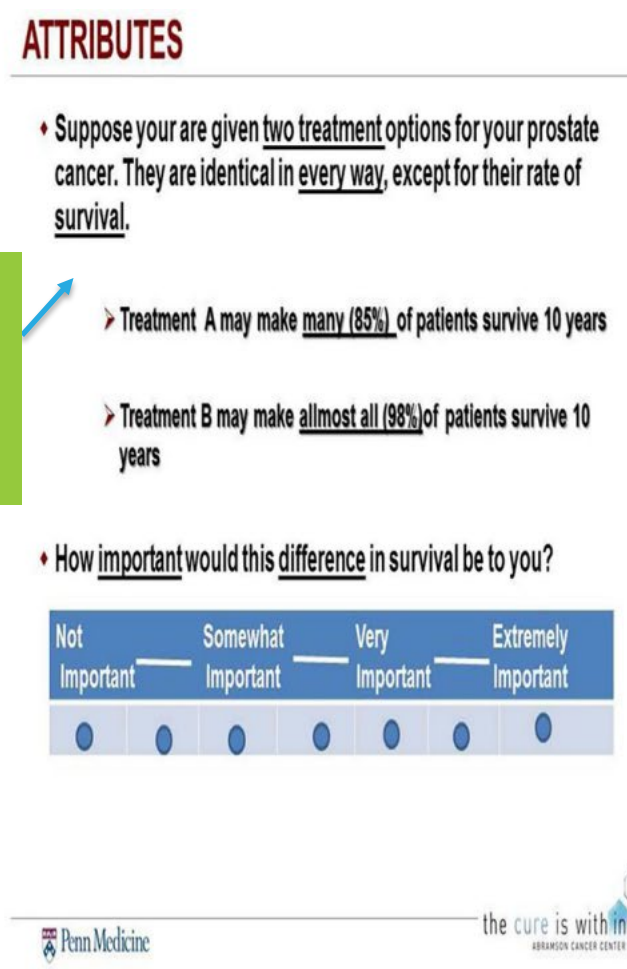
- **Pros**:
  - By focusing on the most important attributes, for a respondent, more precise data can be generated about individual preferences with fewer questions
  - A larger number of attributes can be considered than with other methods that involve trade-offs
  - Each survey is customised to what matters the most to an individual patient

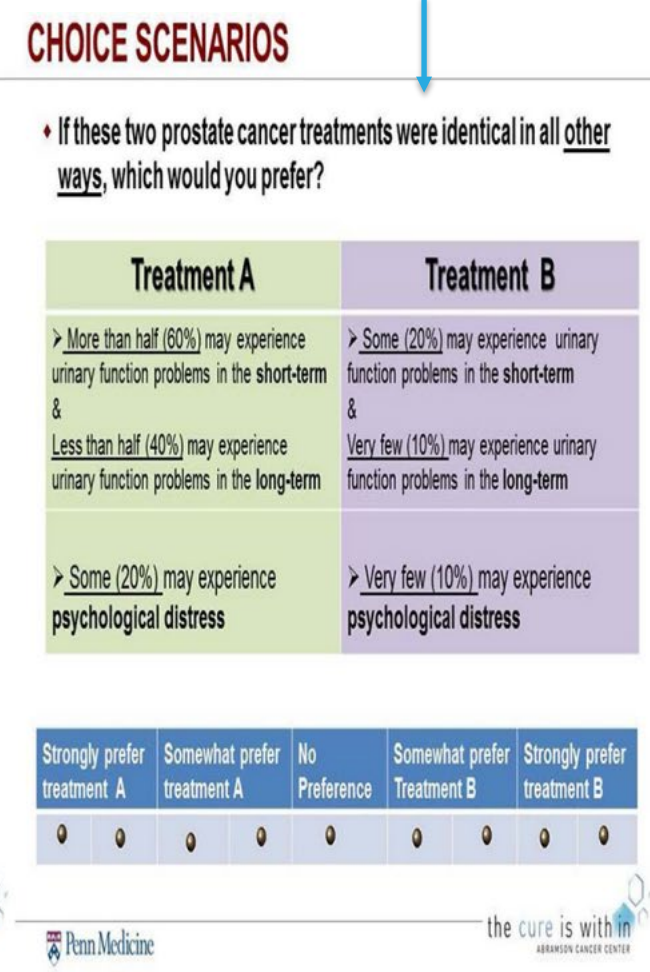
- **Considerations**:
  - Additional attributes increase the number of questions required
  - The initial rating section is very important
    - Any misunderstanding in the initial ratings can affect the subsequent adaptive process
  - The importance of lower rated attributes are not as well understood
  - Aggregating results for a larger sample is more challenging given varied designs

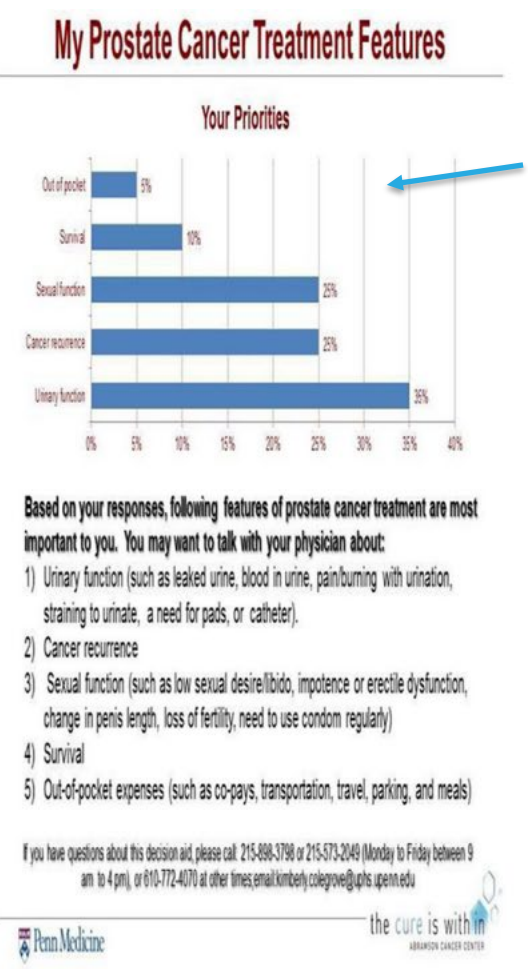
ACA Example – Prostate Cancer Care, Jayadevappa et al. (2019)

15 choice tasks with 3-5 attributes per task

Rating exercises for 15 attributes







The 5 most important attributes and their relative importance were presented to patients.

Patients encouraged to share with physician.

Jayadevappa, R., Chhatre, S., Gallo, J.J., Malkowicz, S.B., Schwartz, J.S. and Wittink, M.N., 2019. Patient-centered approach to develop the Patient's Preferences for Prostate Cancer Care (PreProCare) tool. *MDM policy & practice*, *4*(1), p.2381468319855375.

Rating Second Most Common Method
Fertility Preservation in Breast Cancer – Garvelink et al. (2013)

In this example patients were asked whether they thought an attribute was an advantage or a disadvantage and the extent of how important this is to their decision making.

Figure 1. Example of a statement in the value clarification exercise (cryopreservation of ovarian tissue). For each statement in the value clarification exercise, patient rate whether it is an advantage (green; right side of the figure) or disadvantage (red; left side of the figure) and the extent to which the statement is considered important in decision making about FP.

- **Pros**:
  - Rating is a simple exercise to implement
  - A larger number of attributes can be considered than with methods that involve trade-offs
  - Users can add their own attributes
  - Results could be aggregated across a larger sample

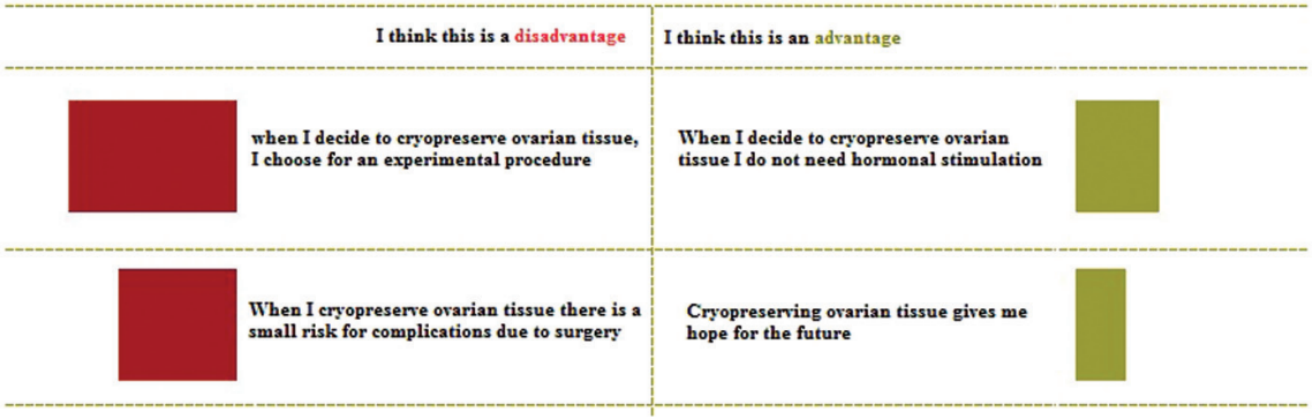


Figure 2. Example of the summary of given ratings (cryopreservation of ovarian tissue). The red boxes in the column with disadvantages (in red): (left side of the figure) represent the extent to which each rated disadvantage is important in the decision whether or not to opt for a certain FP option (in this case cryopreservation of ovarian tissue), as indicated by the patient herself in the previous step (Figure 1). The green boxes in the column with advantages (right side of the figure) represent the extent to which each rated advantage is important in the decision whether or not to opt for a certain FP option (in this case cryopreservation of ovarian tissue), as indicated by the patient herself in the previous step (Figure 1).

- **Considerations**:
  - The same importance score could be given to all attributes

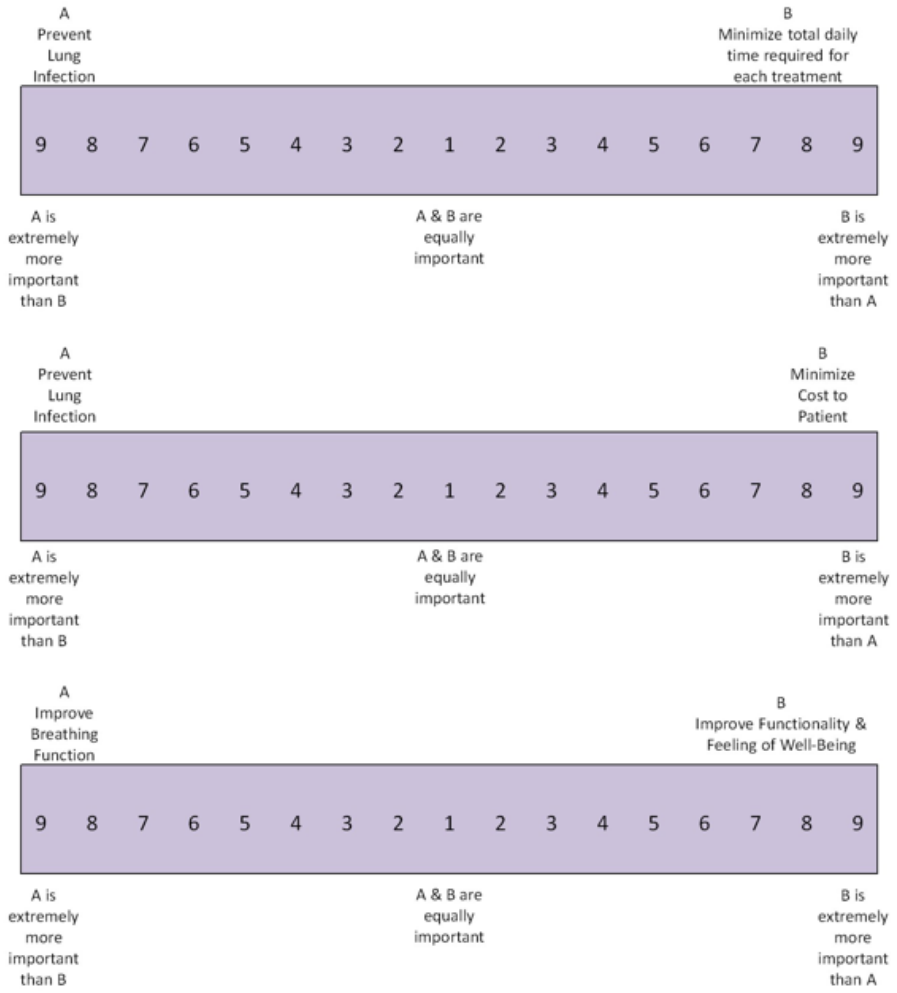
Garvelink, M.M., ter Kuile, M.M., Fischer, M.J., Louwé, L.A., Hilders, C.G., Kroep, J.R. and Stiggelbout, A.M., 2013. Development of a decision aid about fertility preservation for women with breast cancer in The Netherlands. *Journal of Psychosomatic Obstetrics & Gynecology*, *34*(4), pp.170-178.

Analytic Hierarchy Process Third Most Common Method

- AHP involves pairwise comparisons between treatment attributes – for 5 attributes, 10 pairwise comparisons are required
- Respondents report which item in the comparison is more important and rate this using a scale e.g. from 1 (equally important) to 9 (extremely more important).
- Relative weights for attributes are then calculated

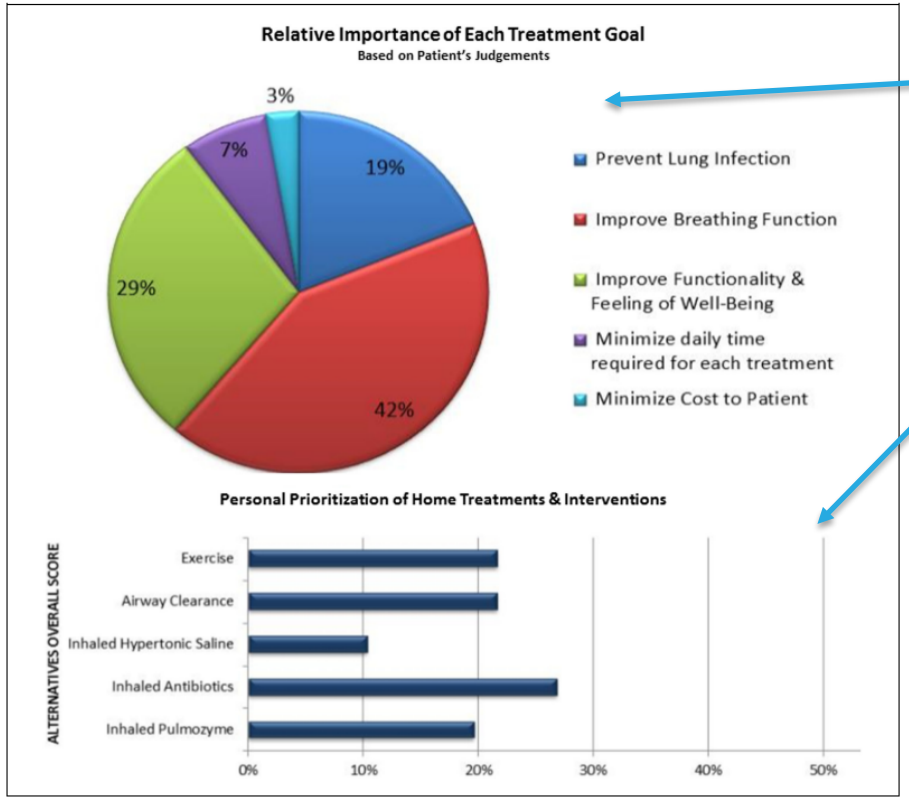
- **Pros**:
  - Simple to design
  - Results can be aggregated across a larger sample

- **Considerations**:
  - Additional attributes increase the number of pairwise comparisons required
  - Does not show level range for attributes (e.g. how much breathing function improves)

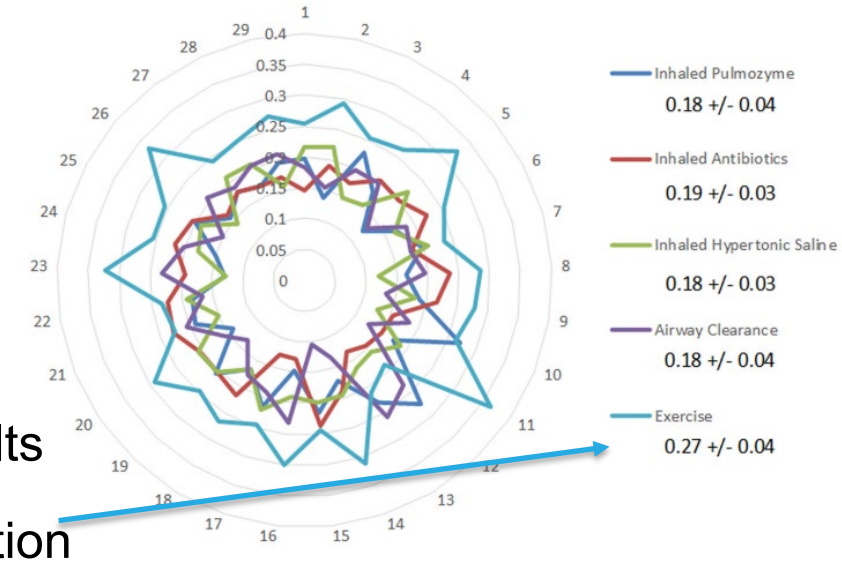


Eckman, M.H., Kopras, E.J., Montag-Leifling, K., Kirby, L.P., Burns, L., Indihar, V.M. and Joseph, P.M., 2017. Shared decision-making tool for self-management of home therapies for patients with cystic fibrosis. *MDM Policy & Practice*, *2*(1), p.2381468317715621.

Analytic Hierarchy Process Third Most Common Cystic Fibrosis – Eckman et al. (2017)



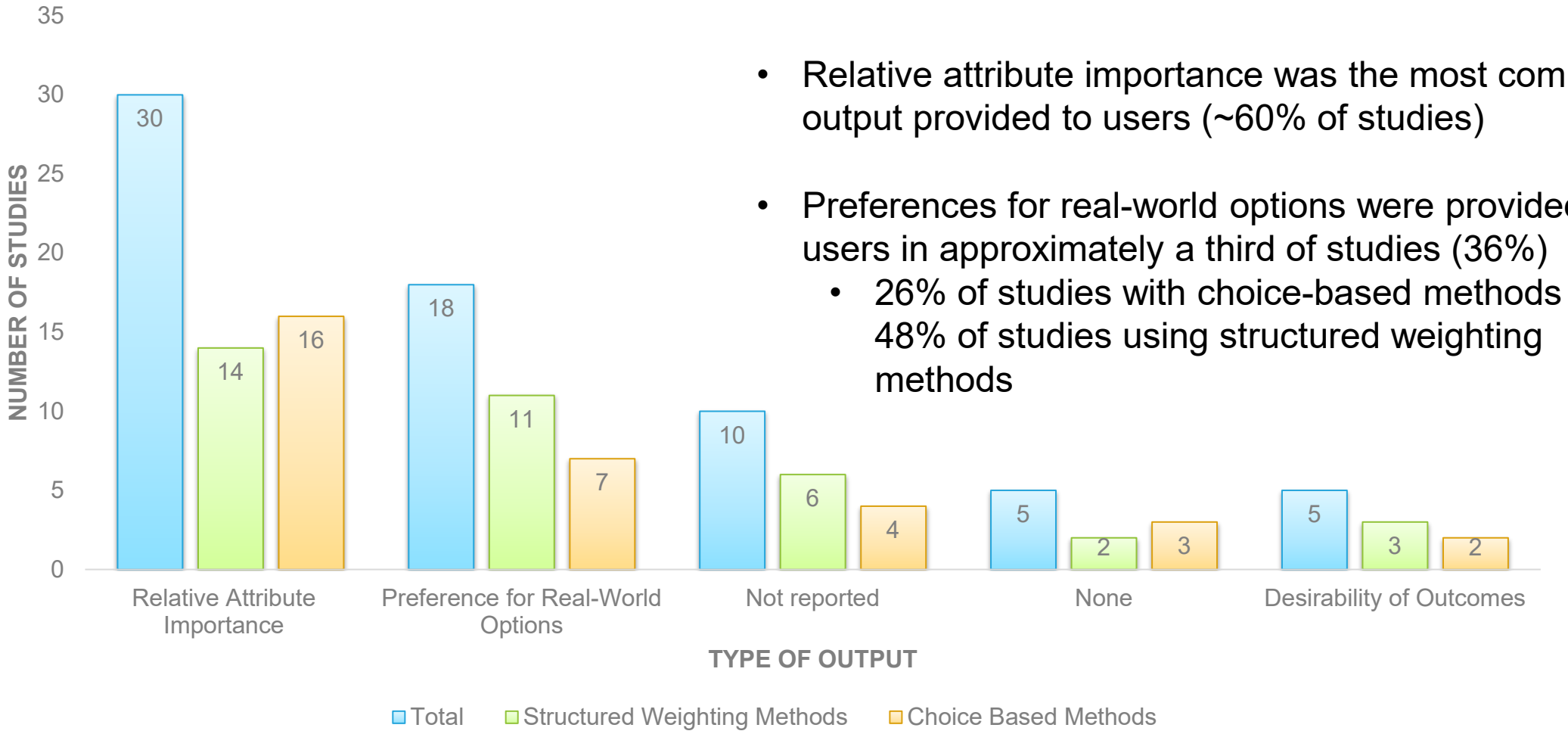
- In this example, patients were shown the relative importance of treatment attributes (goals)
- They were also shown their personal prioritisation of treatment/intervention options (combination of treatment or intervention performance and attribute importance)
- It is possible to aggregate results across a population. In this example, the exercise intervention had the highest priority score on average.



Each number on the circle represents a patient in the study

Eckman, M.H., Kopras, E.J., Montag-Leifling, K., Kirby, L.P., Burns, L., Indihar, V.M. and Joseph, P.M., 2017. Shared decision-making tool for self-management of home therapies for patients with cystic fibrosis. *MDM Policy & Practice*, *2*(1), p.2381468317715621.

Preference Insights (Outputs) Shared With the User



- Relative attribute importance was the most common output provided to users (~60% of studies)
- Preferences for real-world options were provided to users in approximately a third of studies (36%)
  - 26% of studies with choice-based methods and 48% of studies using structured weighting methods

Novel Approaches/Methods

Multi-dimensional thresholding (MDT) is a novel method that involves an attribute ranking exercise (over scale swings) followed by a series of pairwise thresholding exercises (Heidenreich et al., 2024)

- **Pros:**
  - Involves trade-offs and elicits preferences at individual level
  - Accommodates several attributes
  - Results could be aggregated across a larger sample
- **Considerations:**
  - Additional attributes increase the number of thresholding exercises required
  - Initial ranking exercise is important as it impacts the subsequent series of thresholding exercises
  - MDT works best with continuous attributes, and inclusion of categorical attributes, while feasible, does impact precision.
    - If several categorical attributes are required, this method may not be the most suitable.

Preference Diagnostic Tool – this approach proposed by Gonzalez et al., (2023) uses a small number of choice tasks to determine a patient's likely membership to previously identified clinically relevant preference groups.

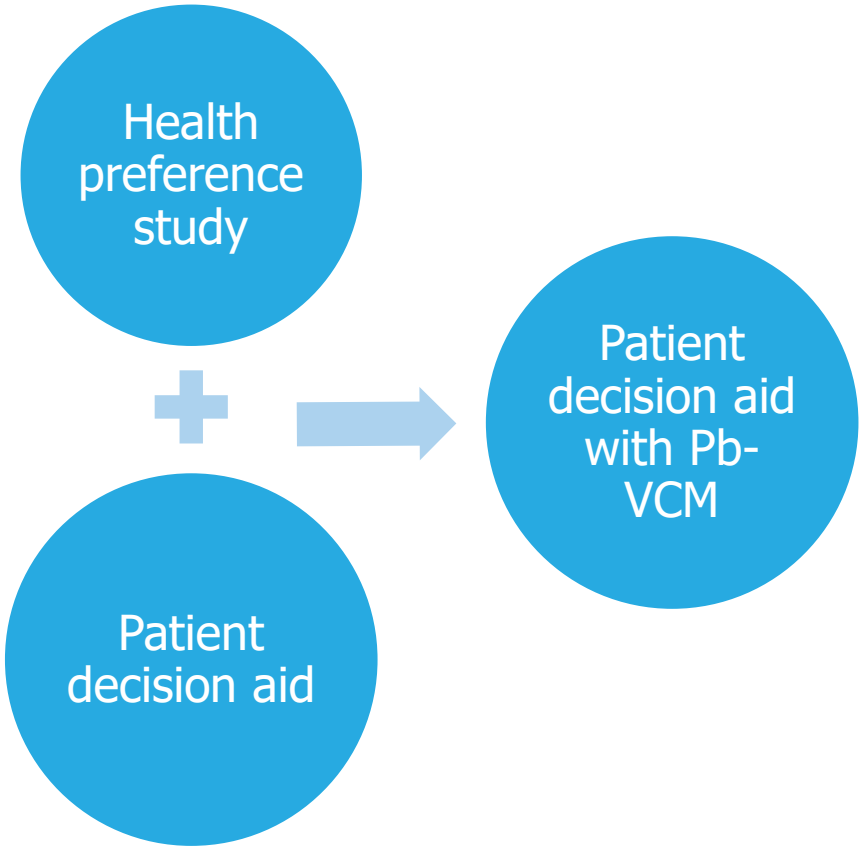
- **Pros:**
  - Quick to complete in clinical setting
- **Considerations:**
  - Need to determine clinically relevant preference groups e.g. conduct larger preference elicitation study first
  - Assumes patients within each group have homogenous preferences
  - Authors note validation work required

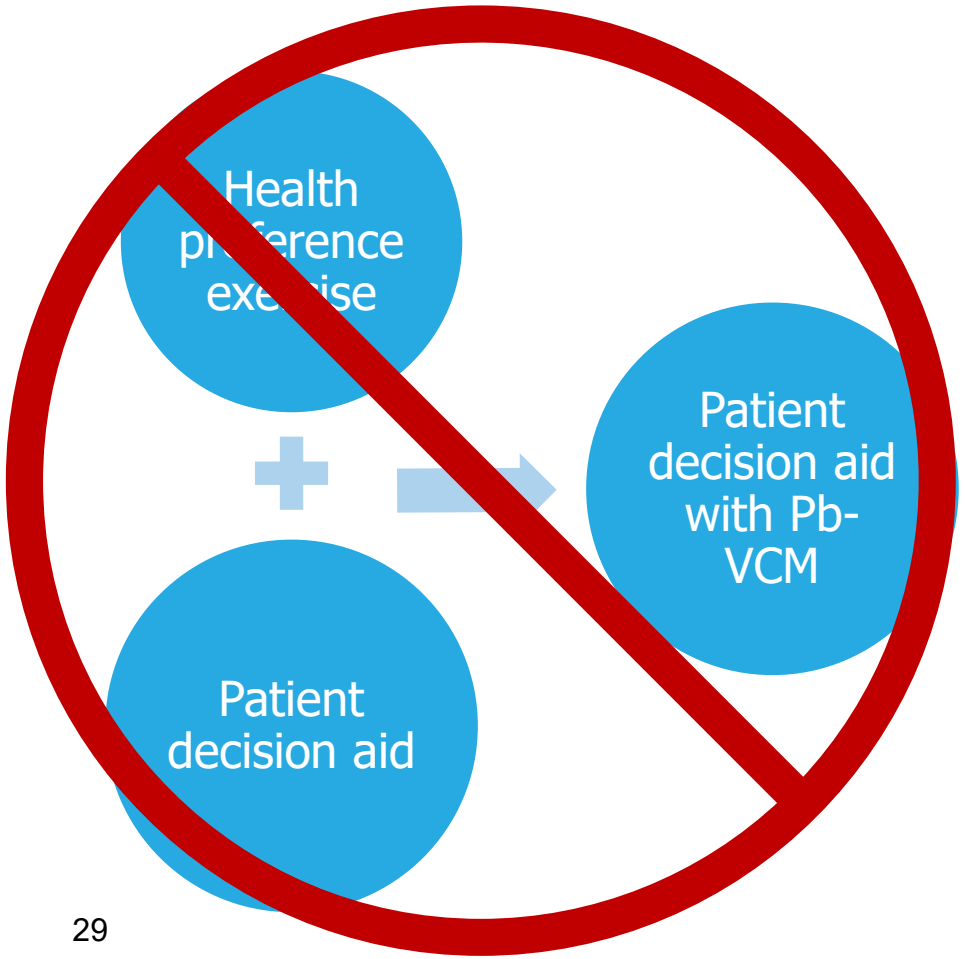
Heidenreich, S., Postmus, D. and Tervonen, T., 2024. Multidimensional Thresholding for Individual-Level Preference Elicitation. Value in Health; Gonzalez Sepulveda, J.M., Johnson, F.R., Reed, S.D., Muiruri, C., Hutyra, C.A. and Mather III, R.C., 2023. Patient-preference diagnostics: adapting stated-preference methods to inform effective shared decision making. Medical Decision Making, 43(2), pp.214-226.

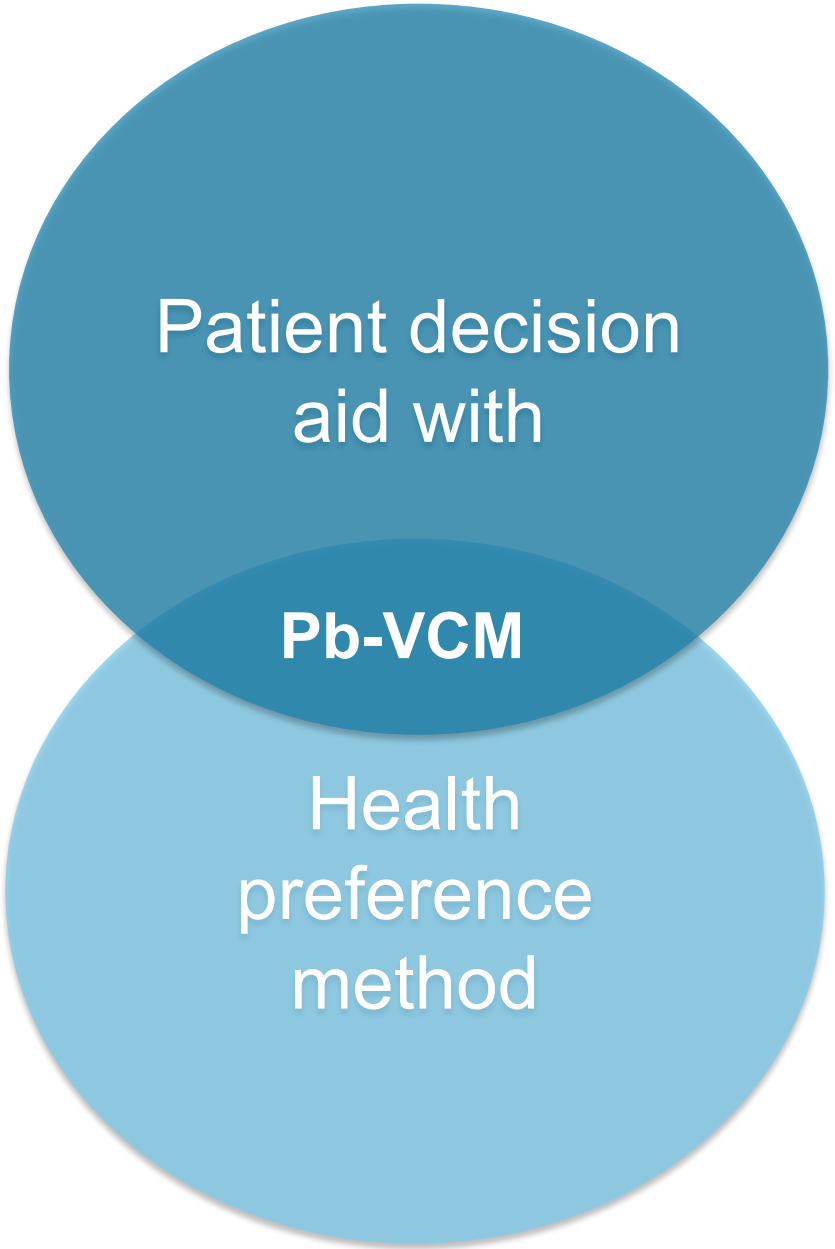
3

Development of a Preference-Based VCM for a Decision Aid: Treatments for Primary Immunodeficiency Diseases

Christine Poulos, RTI Health Solutions, US


Health preference study
Patient decision aid
Patient decision aid with Pb-VCM


Health preference exercise
Patient decision aid
Patient decision aid with Pb-VCM

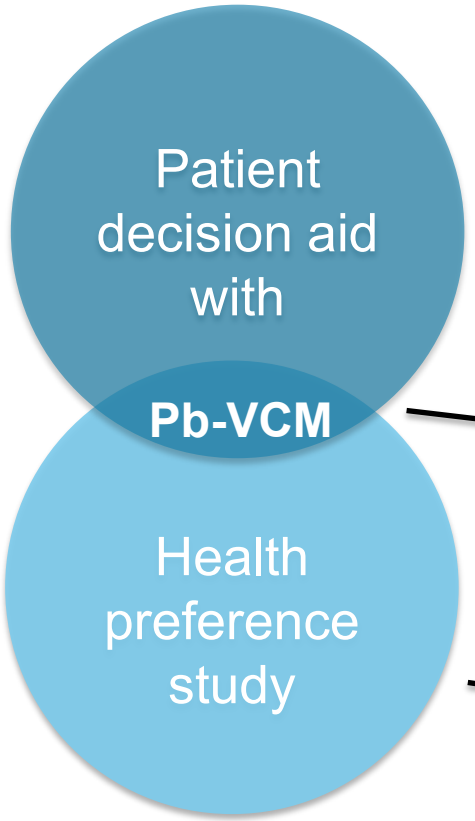

Patient decision aid with
Pb-VCM
Health preference method

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

Decision aid for adults with PID considering IGRT

- Primary immunodeficiency disease (PID) often requires lifelong immunoglobulin replacement therapy (IGRT)
- Unmet need for decision support identified by targeted literature TLR and clinical experts
- Objective: Develop a patient–centered tool to support shared decision making between adults with PID considering initiating or switching IGRTs and health care providers
- Formative research study led to development of beta version of decision aid with preference-based VCM

Tzivelekis S, et al. *Immunotherapy.* 15 (9) 2023, Pages 647-656

Formative Research Process

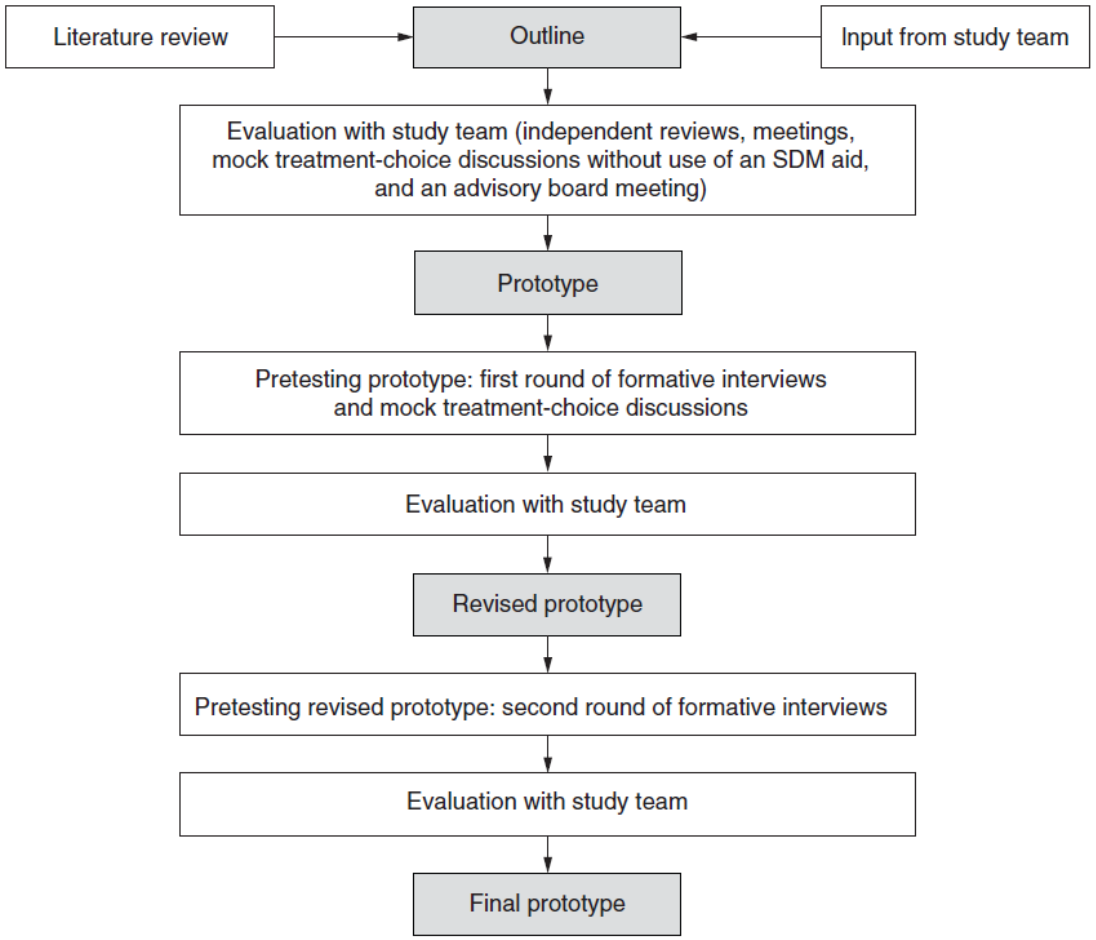


Figure 2. Summary of formative research and shared decision-making prototype aid development activities.
SDM: Shared decision making.

Tzivelekis S, Orange J, Poulos C, Meckley LM, Peay H, Sutphin J, Hernandez-Trujillo VP, Wasserman RL. Development of a novel shared decision making aid for primary immunodeficiency diseases. Immunotherapy. 2023 Jun;15(9):647-656. doi: 10.2217/imt-2022-0193.

Preference-based values clarification

- Case 1 Best-Worst Scaling

Table 1. Features of modalities of administration of immunoglobulin replacement therapy in the best–worst scaling preference assessment exercises used in the two rounds of interviews.

Features used in the first round of pretest interviews	Features used in the second round of pretest interviews
1. Given at home by you or a family member	1. Given at home by you or a family member
2. Given at home by a healthcare provider	2. Given at home by a healthcare provider
3. Given at a hospital, clinic or doctor's office by a healthcare provider	3. Given at a hospital, clinic or doctor's office by a healthcare provider
4. One needle used each time	4. One needle used each time
5. More than one needle used each time	5. More than one needle used each time
6. Given monthly for about 4 h or more each time	6. Given monthly
7. Given monthly for about 2–3 h each time	7. Given every other week
8. Given every other week for about 1–2 h each time	8. Given weekly
9. Given weekly for about 1 h each time	9. Given for about 4 h or more each time
	10. Given for about 2–3 h each time
	11. Given for about 1–2 h each time
	12. Given for about 1 h each time

Tzivelekis S, et al. *Immunotherapy.* 15 (9) 2023, Pages 647-656

Preference-based VCM

- Other design considerations

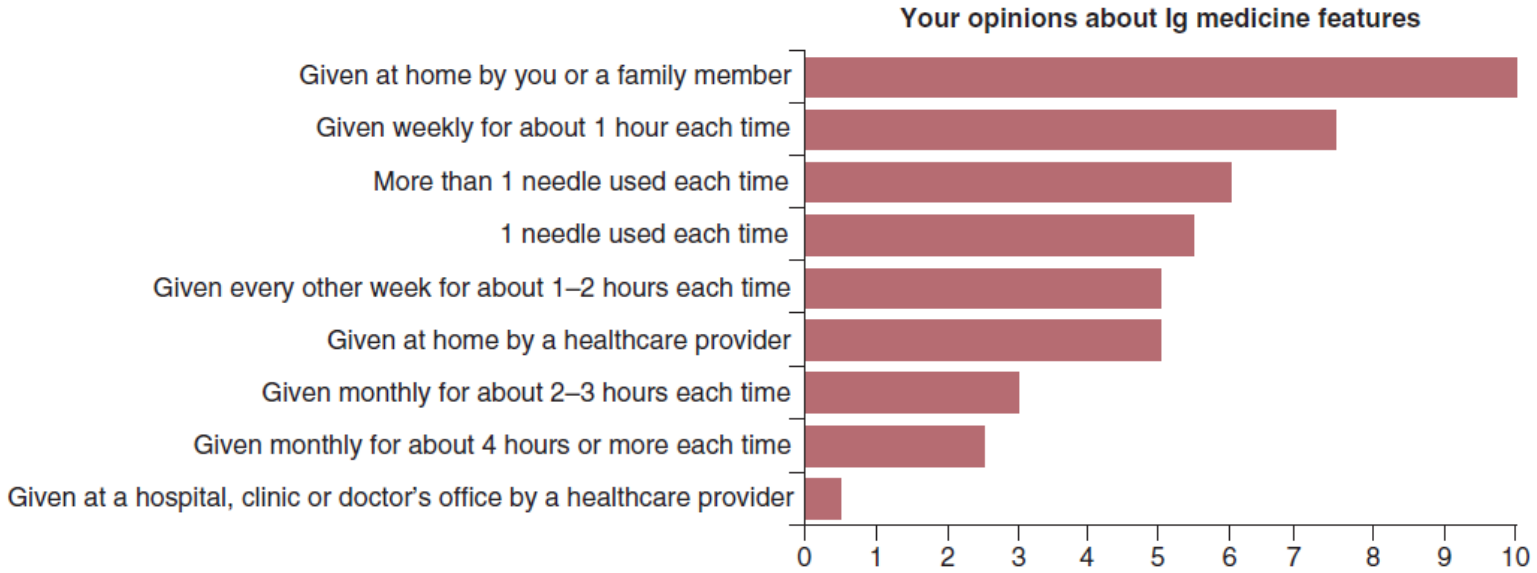
I like this the most (Please check one)	Things you could choose about the treatment	I like this the least (Please check one)
○	Given at home by you or a family member	○
○	Given for about 4 hours or more each time	○
○	Given for about 2-3 hours each time	○
○	Given at home by a health care provider	○
○	Given weekly	○

Next

Tzivelekis S, et al. *Immunotherapy.* 15 (9) 2023, Pages 647-656

Preference-based VCM: User's Preference Information

You answered all of the questions. We have used your answers to create the personalized results below.



Longer bars = you like it more; Shorter bars = you liked it less; No bar = you liked the least; Same length bars = liked same amount

Based on your choices, you may prefer the features with the longer bars. The features with shorter bars are the features you liked less.

Take some time to look over the results. You can print or save the results by [insert instructions for downloading or printing results].

You also said that:

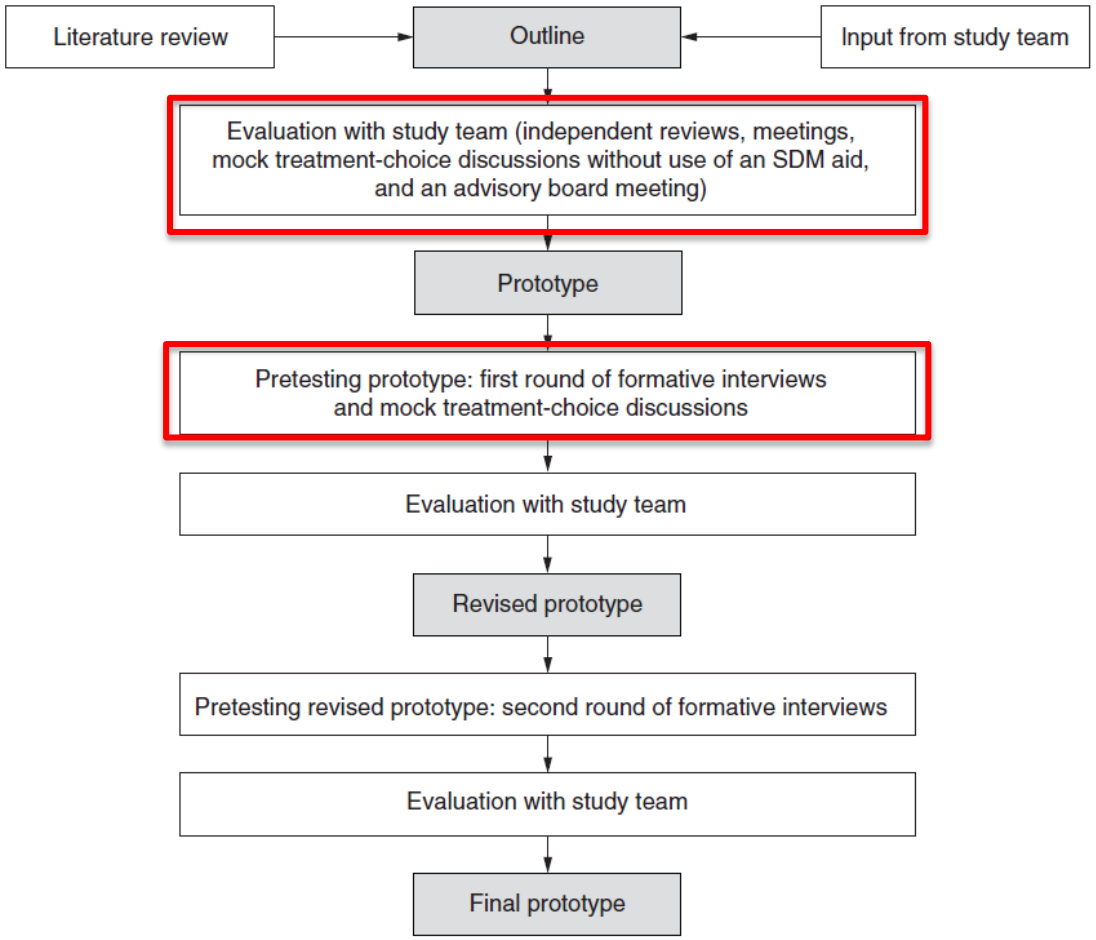
- You feel very comfortable being completely responsible for giving yourself your Ig medicine.
- Being able to get your Ig medicine when it works best in your schedule is extremely important to you.

Next

Tzivelekis S, et al. *Immunotherapy.* 15 (9) 2023, Pages 647-656

Formative Research Process

- Input from clinicians:
  - 3 clinicians on study team
  - 2 advisory panels
  - Observation of mock treatment discussion in development stage
  - Observation of mock treatment discussions using output of decision aid



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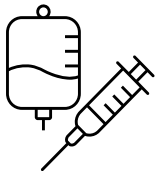
Feasibility considerations


Location where tool is completed


How to share output with 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

Formative Research Process

- Input from patients:
  - 2 rounds of user tests of prototype
  - Observation of mock treatment discussions using output of decision aid

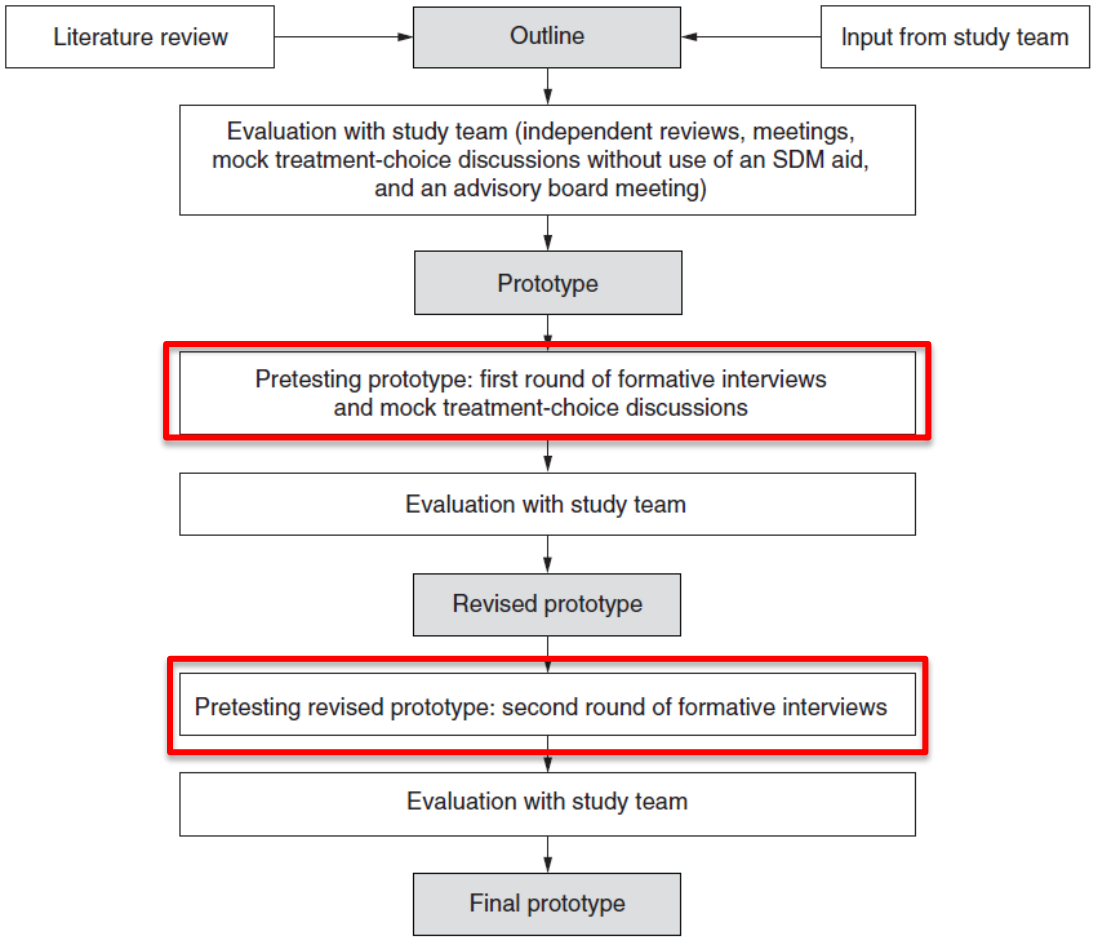


Figure 2. Summary of formative research and shared decision-making prototype aid development activities.
SDM: Shared decision making.

Tzivelekis S, Orange J, Poulos C, Meckley LM, Peay H, Sutphin J, Hernandez-Trujillo VP, Wasserman RL. Development of a novel shared decision making aid for primary immunodeficiency diseases. Immunotherapy. 2023 Jun;15(9):647-656. doi: 10.2217/imt-2022-0193.

Acceptability to Patients

Content

Burden

Perceptions of impact / utility

Intention to use

Discussion

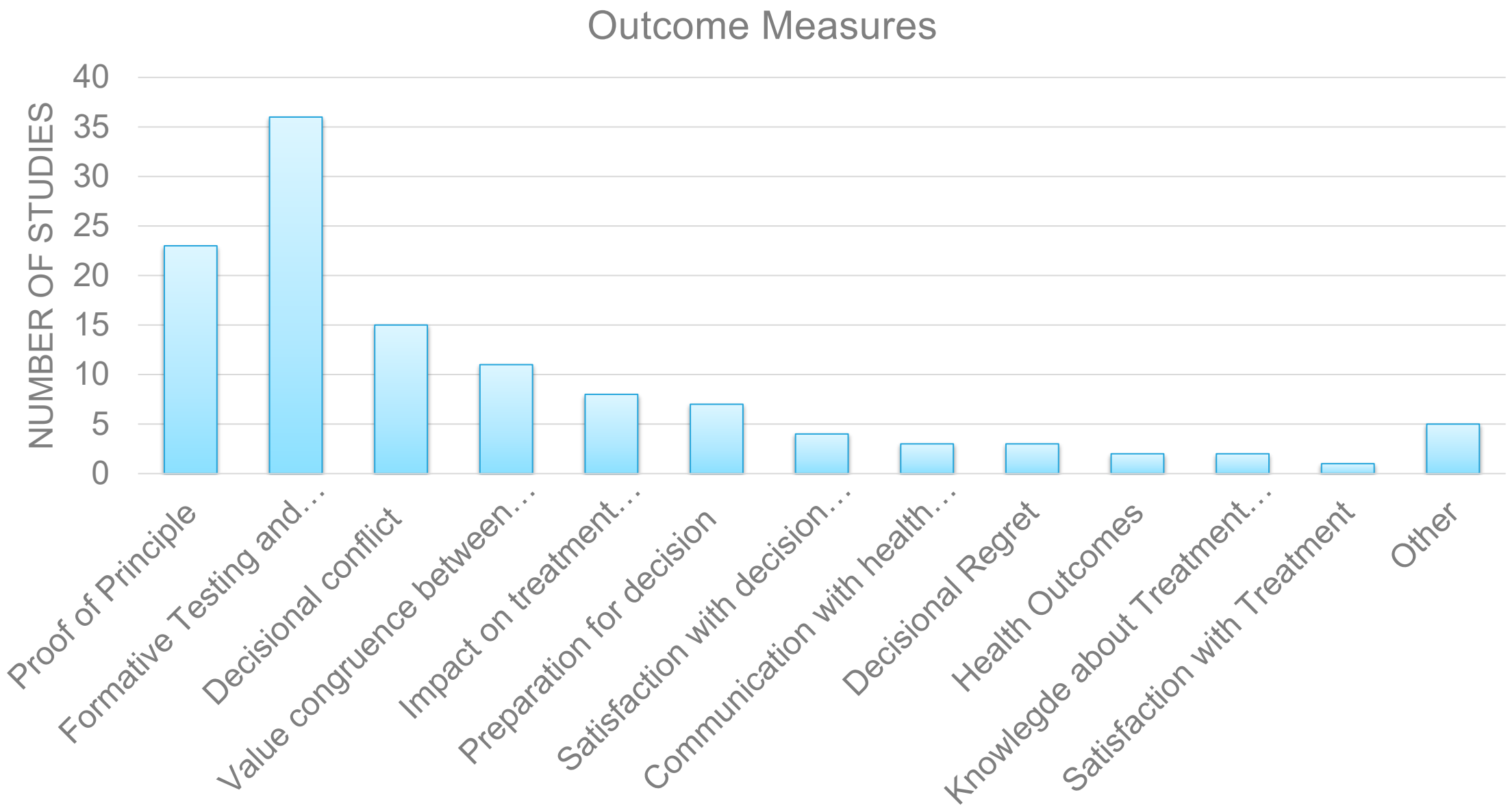
- Gaps
- Acceptability of prototype
  - Patients: Helpful, better for newly diagnosed
  - Clinicians: Mixed reactions
- Unfinished business:
  - Web design and user testing
  - Survey-based evaluation of decision outcomes (e.g., knowledge, value congruence, satisfaction), feasibility, acceptability

4

Conclusion & Discussion

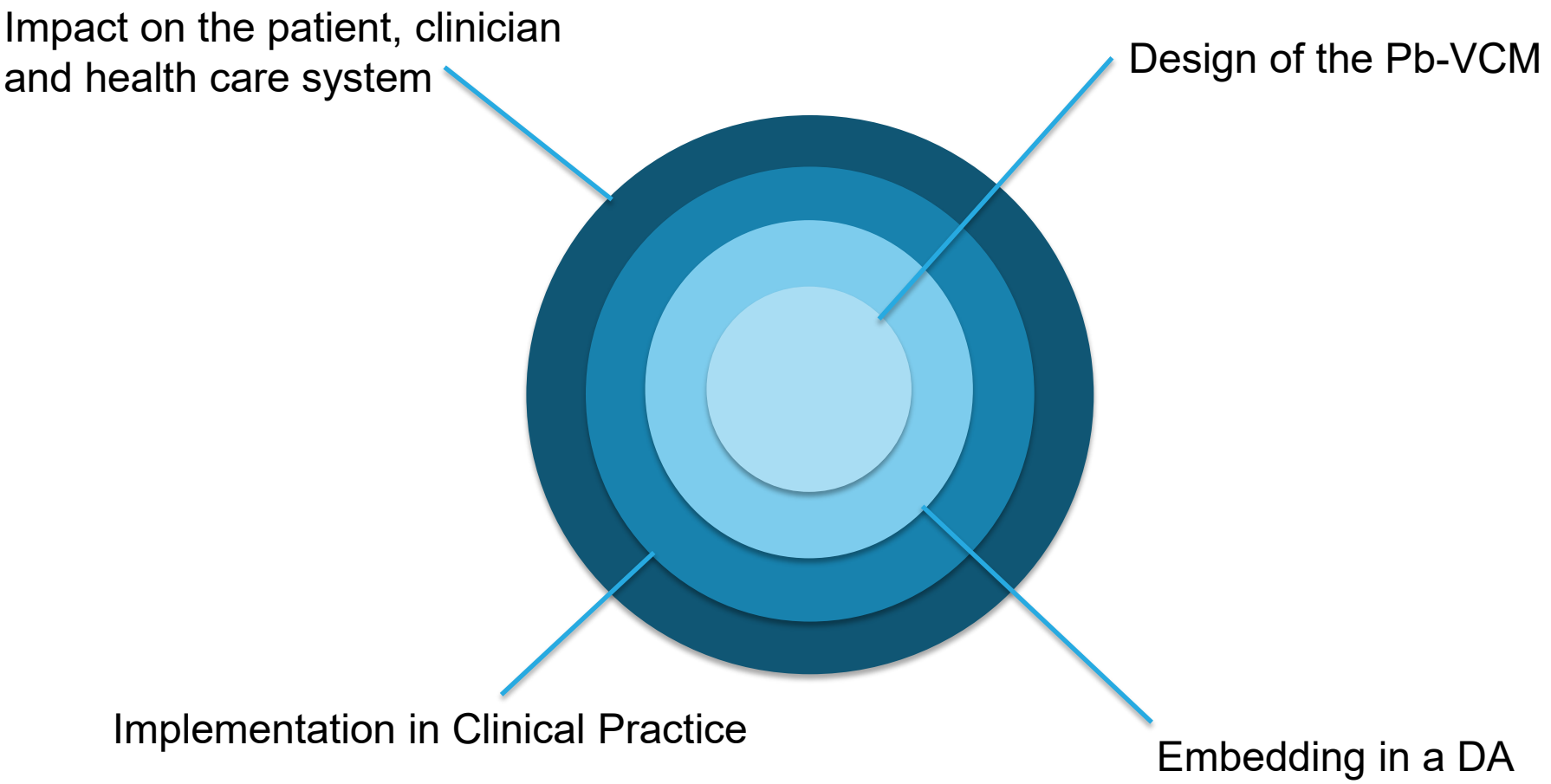
Conclusion from the SLR

- Design: Significant variation in Pb-VCM, including within-group differences.


Outcome Measures
NUMBER OF STUDIES
40
35
30
25
20
15
10
5
0
Proof of Principle
Formative Testing and…
Decisional conflict
Value congruence between…
Impact on treatment…
Preparation for decision
Satisfaction with decision…
Communication with health…
Decisional Regret
Health Outcomes
Knowlegde about Treatment…
Satisfaction with Treatment
Other

Conclusion from the SLR

- Design: Significant variation in Pb-VCM, including within-group differences.
- Testing:
  - Wide variability in outcome measures
  - Use of diverse study designs
- Issues with reporting
- Insufficient evidence for guidelines, but enough for good practices?


Impact on the patient, clinician and health care system
Design of the Pb-VCM
Implementation in Clinical Practice
Embedding in a DA

Your Questions...

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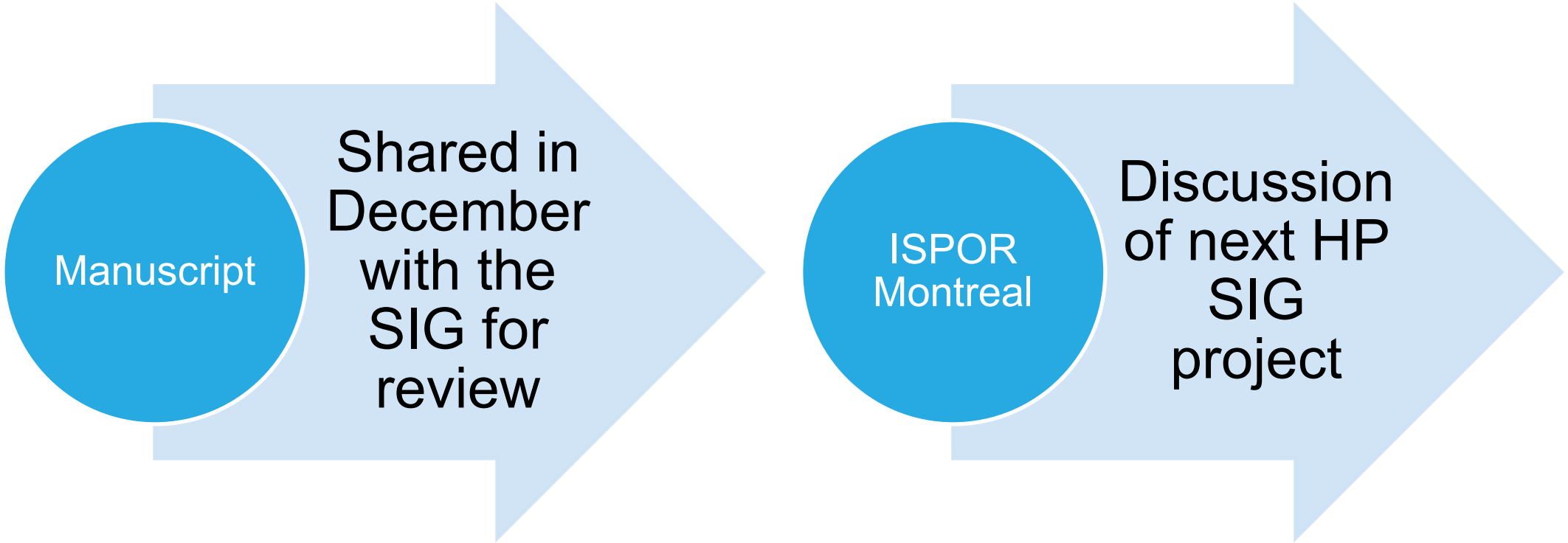
Improving healthcare decisions

Thank you!

For questions:

HealthPreferenceSIG@ispor.org

HP SIG Next Steps



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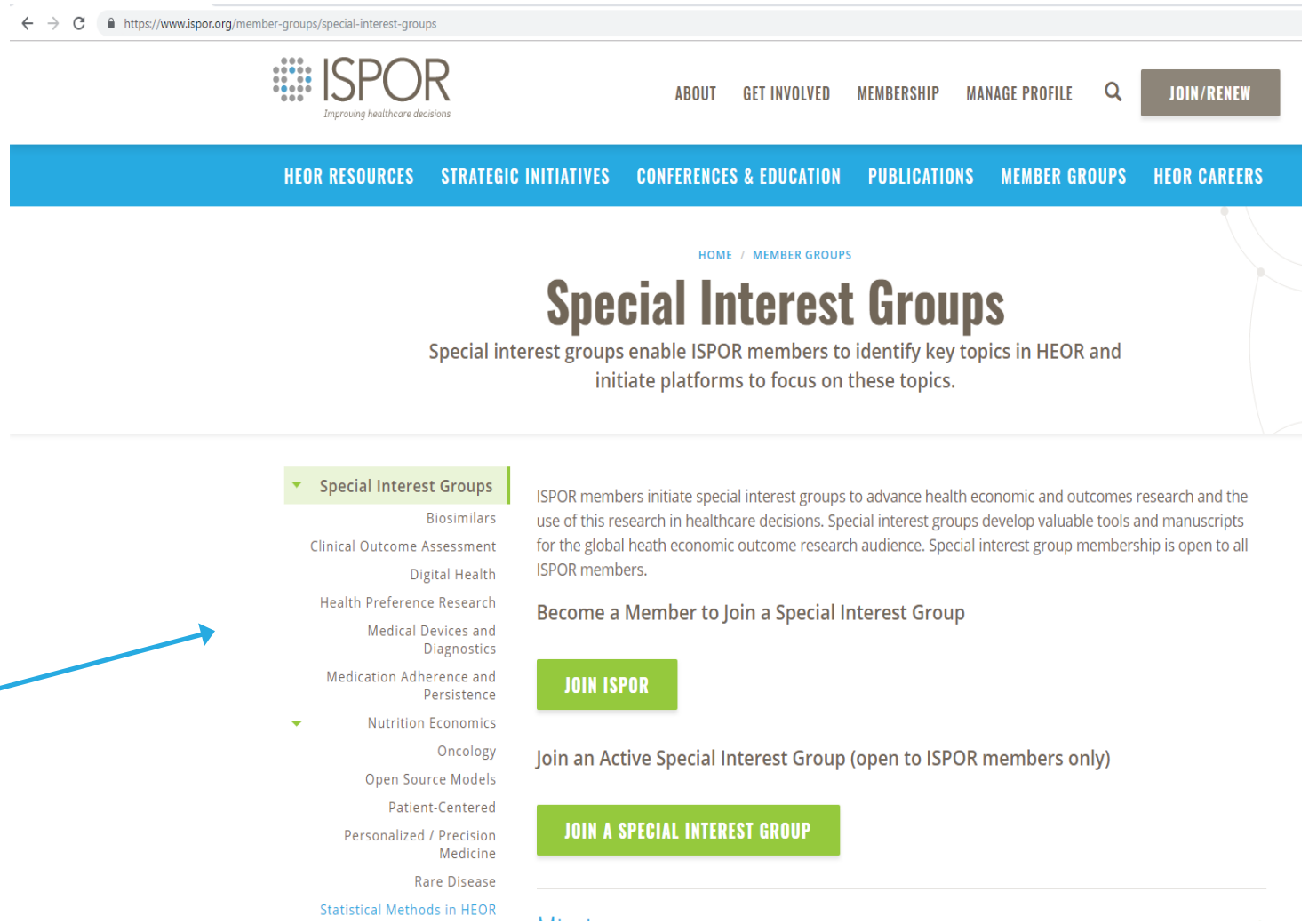
You must be an ISPOR member to join a Special Interest Group



More Preference Sessions Later Today!

13:45 - 14:45 How Can We Move From Generating Robust Patient Preference Information to Producing Decision-Ready Outputs?

16:00 - 19:00 Patient-Centered Research Poster Session 4