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Bekker, H orcid.org/0000-0003-1978-5795, Stiggelbout, A, Kunneman, M et al. (2 more authors) (2019) Psychometric Testing of SHARED - a patient reported outcome measure of shared decision making. In: 10th International Shared Decision Making Conference, 07-10 Jul 2019, Quebec, Canada.

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SHARED – A Patient Experience of Shared Decision Making Questionnaire

What was your experience of making this treatment decision with your [health professional/s] – for each statement, tick the box that matches best how much you agree with it:

		Disagree Strongly	Disagree	Not Sure	Agree	Agree Strongly
The [health] professional...						
1	talked about other options from the one I chose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	talked about whether or not there was a medically best option for my [health problem]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	gave their views about the options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	asked for my views about the options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talked about...						
5	what was important to me about this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	why one option suited me better than another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	the risks and benefits of the options for me and my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt...						
8	it would be OK to choose any option we talked about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	the decision made was the best one for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	the [health] professional and I agreed which option was the best one for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NOTES FOR USE

Replace [Health Professional] with a professional or team, such as cancer/ kidney/ and doctor/ nurse/ etc

Replace [Health Problem] with specific problem, such as prostate cancer/ kidney disease, etc.

Add all the treatment or care plan options available for the health problem to capture the choice made, including a non-medical intervention option, for example: a) monitor/ check-up X, b) further tests/ procedures X, c) medication X, d) surgery X, etc.

NOTES FOR SCORING

Each item is rated on a five-point scale (strongly disagree, disagree, not sure, agree, strongly agree; 1-5).

Scores can be used without transforming, or changed to binary scores of SDM item being present (1 for agree/ strongly agree) or absent (0 for not sure/ disagree/ strongly disagree).

Using the five-point rating is useful for validation analyses; using the binary summaries per item or section is useful for quality improvement projects, SDM training and SDM implementation.

CONTACT

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Summary of the development and testing process for SHARED – a patient reported outcome measure of shared decision making.

SHARED is a patient reported outcome measure of shared decision making (SDM) for use in quality improvement, audit and research [1]. SDM is defined as “a two-way exchange of information, both the doctor and patient reveal treatment preferences, and both agree on the decision to implement”. [2]

SHARED is a ten-item, multi-construct measure assessing patient’s experience of the patient and professional discussing the following during healthcare: treatment options, health professional and patient preferences, reasoning, and reaching mutual agreement [1-10]. See appendix 1 for summary of theoretical background and components in informed, shared and evidence-based decision making.

SHARED was developed for use within the NHS Right Care Shared Decision Making quality improvement programmes (2012-2013) [1, 11-14]: staff training about SDM (33 musculoskeletal, renal, maternity teams; n=351 consultations); developing and implementing digital patient decision aids (PtDAs); audit of Chronic Kidney Disease PtDA (27 renal teams; n= 492 consultations) [15]. Findings showed SHARED was integrated into usual care, had good content validity, was responsive to SDM initiatives, and assessed more about the patient-professional partnership than informed decision making measures [12, 15-18].

SHARED was translated into Dutch, and underwent reliability and construct validity testing [19]. The internal consistency of SHARED was good for both the 1-5 rating scale (Cronbach’s α 0.88) and transformed binary scale (Cronbach’s α 0.81); all items correlated well with the item-deleted total (0.85-0.89). The principle components analysis extracted two dimensions explaining 63.7% of the total variance.

SHARED is currently being used in research projects investigating shared decision making in everyday clinical practice, in the UK [18] and Denmark. See appendix 2 for SHARED questionnaires during development (2012-2019).

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APPENDIX 1

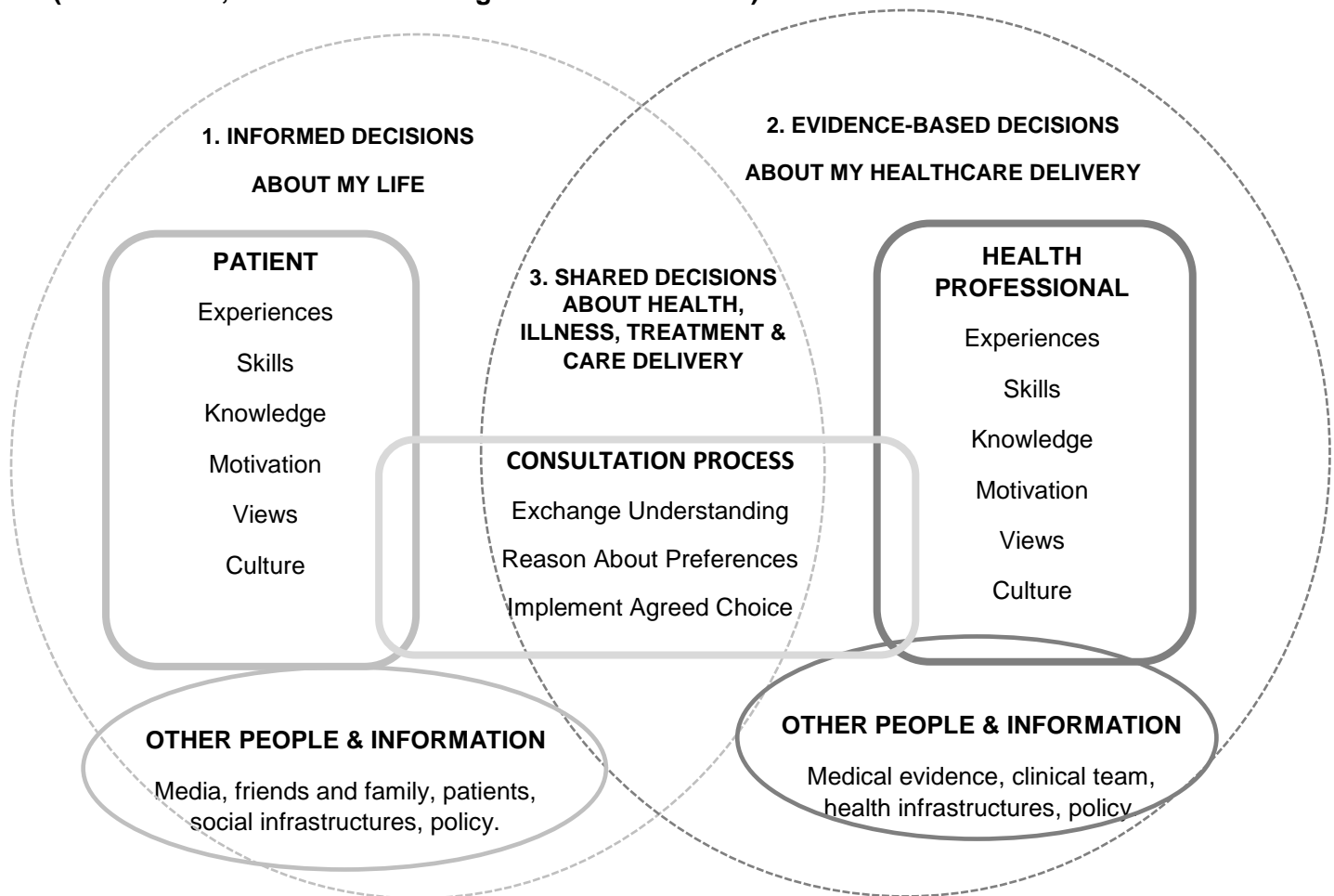
Decision Aids and Shared Decision Making in healthcare (NOTE: summary from publications below)

Decision aids use decision science to structure the healthcare problem in a way that supports people's ability to make reasoned decisions. Decision aids encourage people to consider accurate information about all options and their consequences without bias, evaluate this information with their values, make a decision on trade-offs between evaluations, and, in the healthcare context, discuss their reasoning with others to implement an agreed choice. Decision aids include different components to facilitate (see figure 1): patients making reasoned decisions between options; professionals making accurate treatment choices; patients and professionals collaborating more effectively in the process of choosing healthcare within consultations.

Measures used to assess decision making outcomes are predominantly self-report questionnaires designed to evaluate a decision support intervention's effectiveness and/or screen for decisional outcomes within usual care. The substantial number of measures reflects the complexity of these interventions in terms of their impact on different people within the process of delivering care and components needed to enhance people's active reasoning and engagement with others. Measures by type of intervention include:

- Patient Decision Aids enabling people to make informed decisions between options by consideration of accurate information about all options and their consequences without bias, evaluation of this information with their values, and making a decision on trade-offs between evaluations. There are several patient-reported informed decision outcome measures (e.g. decisional conflict scale). Alternatively, proxy outcomes may be used to assess an aid's impact by capturing people's knowledge, risk perception, values, involvement, activation, usefulness intervention, value-choice consistency, decision quality.
- Professional Decision Support enabling professionals to make evidence-based choices by using the best evidence available, and in consultation with the patient, to decide upon the option which best meets the needs of the patient (e.g. accurate or evidence-based choice).
- Shared Decision Making Support within patient-professional consultations enabling the process of choosing healthcare collaboratively by exchanging information, preferences and values about treatments, explicit reasoning about choices, and agreeing a choice and implementation plan. Some measures assess patient-reported experience of shared decision making in healthcare (e.g. SHARED). Proxy outcomes assess an aid's impact on the professional (e.g. provided option information, elicited values, awareness of patient experience, etc.), the patient (e.g. asked questions, provided values, awareness of professional viewpoint, etc.) and/or the concordance between patient-professional factors (e.g. SDM-Q-9; decisional conflict scale for patient and professional).

Figure 1: Representation of Making Health Decisions Individually (1,2) and Together (3) (Bekker 2015; Danish and Norwegian versions in 2018).



For full text, and referencing, see publications:

Bekker HL (2015) Representation of Making Health Decisions Individually, and Together published in:

1. Breckenridge K, Bekker HL, van der Veer SN, Gibbons E, , Abbott D, Briançon S, Cullen R, Garneata L, Jager KJ, Lønning K, Metcalfe W, Morton R, Murtagh FM, Prutz K, Robertson S, Rychlik I, Schon S, Sharp L, Speyer E, Tentori F, Caskey FJ. NDT Perspectives - How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant*. 2015; 30: 1605-1614.
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Informed by:

3. **Bekker HL**. The loss of reason in patient decision aid research: do checklists affect the validity of informed choice interventions? *Patient Education and Counseling* 2010; 78:357-364.
4. **Bekker HL**. Genetic screening: facilitating informed choices. (p. 926-930). In (Eds) Cooper DN, Thomas N. *Nature Encyclopaedia of the Human Genome*. (2003). New York: Nature Publishing Group - Macmillan Publishers Ltd.
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APPENDIX 2

SHARED - Patient Experience of Shared Decision Making Questionnaire (Dutch - 2013)

Wij willen graag uw mening horen over het nemen van de beslissing met uw (bestralings-) arts over het wel of niet ondergaan van bestraling. We vragen u alle 10 onderstaande uitspraken te beoordelen. Wilt u achter elke uitspraak het hokje aankruisen dat het beste weergeeft in hoeverre u het er mee eens bent.

		helemaal mee oneens	mee oneens	niet mee oneens, niet mee eens	mee eens	helemaal mee eens
1	De arts heeft andere mogelijkheden besproken dan degene die we hebben gekozen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	De arts heeft besproken of er al dan niet een mogelijkheid is die het meest doeltreffend is voor mijn ziekte.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	De arts gaf zijn of haar mening over de mogelijkheden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	De arts vroeg naar mijn mening over de mogelijkheden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Ik heb besproken wat er voor mij belangrijk was bij deze beslissing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Ik heb besproken waarom de ene mogelijkheid beter bij me past dan de andere.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Ik heb de voor- en nadelen van de mogelijkheden voor mij en mijn gezondheid besproken.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Ik voelde me vrij om te kiezen uit de mogelijkheden die we besproken hadden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Ik had het gevoel dat de beslissing die is genomen voor mij de beste was.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Ik had het gevoel dat de arts en ik het eens waren over welke mogelijkheid voor mij de beste was.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Authors: Bekker, Légaré, Walker, Nye, 2012; Translated by Stiggelbout, Pieterse, 2013

Presented at: Bekker HL, Stiggelbout AM, Kunneman M, Engelhardt E, Pieterse A. Psychometric Testing of SHARED - a patient reported outcome measure of shared decision making. Abstract - International Shared Decision Making Bi-Annual Conference, June 2019; paper under review.

SHARED - Patient Experience of Shared Decision Making Questionnaire (May 2013).

We are interested in your views about making healthcare decisions with the health professionals. We use the word option to mean the treatment or testing choices you talked about for a health problem. Options can be choosing to take medicines, have operations and therapy, change your lifestyle or they can be choosing to monitor your health, do nothing different from what you do already, cope with illness symptoms only, not have a test. Please answer all 10 questions below.

Write down below the decision you are making about your health problem:

I am making a decision about

for this health problem

For each statement below, tick a box that matches best how much you agree with it:

		Disagree Strongly	Disagree	Not Sure	Agree	Agree Strongly
1	The health professional talked about other options from the one we chose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	The health professional talked about whether or not there was a medically best option for this health problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The health professional gave his or her views about the options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The health professional asked for my views about the options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I talked about what was important to me about this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I talked about why one option suited me better than another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	I talked about the risks and benefits of the options for me and my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	I felt it would be OK to choose any option we talked about.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	I felt the decision made was the best one for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	I felt the health professional and I agreed on which option was the best one for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Authors: Bekker, Légaré, Walker, Nye, 2012

Published in: Durand M-A, Bekker HL, Casula A, Elias R...Tomson CRV. Can we routinely measure patient involvement in treatment decision making in chronic kidney care? A service evaluation in 27 renal units in the UK. Clinical Kidney Journal. 2016; 1-8.

SHARED - Patient Experience of Shared Decision Making Questionnaire (April 2012)

You are making a decision about treatment or tests for

We are interested in your experiences of making this decision with the health professional you met today. In the questions below, the word option means the treatment or test choices you talked about for this healthcare problem.

Your views will help us improve the care we give to patients making this decision.

- ❖ Please answer the 8 questions below. Tick the answer that best fits your experience, either **agree strongly**, **agree**, **disagree** or **disagree strongly**.
- ❖ Your answers are confidential. Do not put your name on this form.

	How much do you agree with the following:	Agree Strongly	Agree	Disagree	Disagree Strongly
1	The health professional talked about other options from the one we chose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	I felt the health professional thought one option was better for me than another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	I felt it was OK to choose an option that was different from the health professional's choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I felt the health professional gave me the support and advice I needed to make the best decision for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I was able to tell the health professional what was important to me about this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I am clear about the benefits and risks of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	I am clear which benefits and risks matter most to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	I am sure the option we chose is the best one for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Authors: Bekker, Légaré, Walker, Nye, 2012

Thank you for answering these questions.

Please return the form to

Published in: NHS RightCare.Your Health, Your Decision - Evaluation & Output Report of the AQuA Workstream within the National Shared Decision Making Programme. National Health Service, Department of Health (2013).