A review of patient-reported measurement instruments about shared decision making for clinical practice

Kaat Verrezen, Laura Goetschalckx, Morgane Trop, KULeuven

Promotor: Bert Aertgeerts KULeuven

Co-promotor: Lien Mertens KULeuven

Master of Family Medicine
Masterproef Huisartsgeneeskunde
Academiejaar: 2022-2025

©Copyright by KU Leuven

This master's thesis is an examination document that has not been corrected for any errors that may have been identified. Except as permitted by law, no part of this publication may be reproduced, copied, used, or implemented without prior written permission from the author(s). For requests or information regarding the reproduction and/or use of parts of this publication, please contact KU Leuven, Faculty of Medicine, Campus Gasthuisberg O&N2, Herestraat 49 – box 400, 3000 Leuven, Belgium. Prior written permission from the supervisor(s) is also required for the use of the (original) methods, products, and programs described in this thesis for commercial purposes and for submitting this publication for scientific awards or competitions.

Deze masterproef is een examendocument dat niet werd gecorrigeerd voor eventueel vastgestelde fouten. Met uitzondering van het door de wet toegestaan gebruik, is zonder voorafgaande schriftelijke toestemming van de auteur(s) het overnemen, kopiëren, gebruiken of realiseren van deze uitgave of gedeelten ervan verboden. Voor aanvragen tot of informatie in verband met het overnemen en/of gebruik van gedeelten uit deze publicatie, wendt u zich tot de KU Leuven, Faculteit Geneeskunde, Campus Gasthuisberg O&N2, Herestraat 49 – bus 400, 3000 Leuven. Voorafgaande schriftelijke toestemming van de promotor(en) is eveneens vereist voor het aanwenden van de in dit afstudeerwerk beschreven (originele) methoden, producten en programma's voor commercieel nut en voor de inzending van deze publicatie ter deelname aan wetenschappelijke prijzen of wedstrijden

Contents

Abstract (English) 4
Abstract (Dutch) 5
Plain language summary 6
Open science 6
Introduction 7
Methods 9
Study design 9
Search strategy 9
Eligibility criteria 9
Data extraction and thematical analysis 10
Results 11
Included studies 11
Instrument characteristics 13
Thematical analysis 15
Discussion 18
Main findings 18
Strengths and limitations 21
Conclusion 22
Future research questions 22
References 23
Appendices: Measurement instruments 25
The Facilitation of Patient Involvement Scale 25
COMRADE 26
SDM-Q 27
SDM-Q-9 28
CollaboRate 29
SMDMQ 30
SDM Process Score 31
MADM 32
Dyadic OPTION 33

Abstract (English)

Background: Shared decision making (SDM) has become the golden standard as communication model in healthcare between physicians and patients promoting patient engagement and improved decision quality. Despite the well-known importance of the patient's perspective, it is not consistently included in rating the shared decision making process.

Objective: We aim to provide an updated overview of the existing patient-reported SDM measurement instruments as well as a content analysis. Further, we aim to align patient-reported barriers/facilitators with the existing SDM measurement instruments to assess the common elements and limitations.

Methods: A systematic review was conducted following PRISMA-COSMIN guidelines. Literature published between March 2019 and September 2024 was based on the following MeSH terms "Surveys and Questionnaires", "Decision Making, Shared" and "Patient Reported Outcome Measures". Key SDM themes were identified and refined by three researchers through a literature search, with disagreements resolved and theme prevalence calculated per instrument.

Results: Nine unique patient-reported or mixed-reported SDM instruments were included. Key themes identified were information (32.3% - 30/93 Q), choice/decision (22.6% - 21/93 Q), relationship (16.1% - 15/93 Q), participation (11.8% - 11/93 Q), time management (8.6% - 8/93 Q), communication (6.5% - 6/93 Q), and support (2.2% - 2/93 Q). Instruments varied in content, scoring system and level of patient involvement during development.

Conclusion: The analysis of patient-reported questionnaires identified seven key themes of shared decision-making (SDM), with information and choice/decision being the most frequently addressed. While these themes are central, important aspects such as discussing valid alternatives and social support remain underrepresented. A comprehensive SDM approach requires attention to all themes, but further research is needed to determine their relative importance across different contexts.

Abstract (Dutch)

Achtergrond: Gedeelde besluitvorming vormt de gouden standaard als communicatiemodel tussen arts en patiënt in de gezondheidszorg, dewelke de kwaliteit van besluitvorming en patiëntbetrokkenheid ten goede komt. Ondanks het gekend belang van het patiëntenperspectief wordt dit niet consistent opgenomen in de beoordeling van het gedeelde besluitvormingsproces.

Doelstelling: Het doel van deze studie is om een aanvullend overzicht te bieden van de bestaande patiënt-gerapporteerde meetinstrumenten met een bijhorende inhoudsanalyse. Daarnaast toetsen we de patiënt-gerapporteerde barrières en facilitatoren af met de bestaande meetinstrumenten om de gemeenschappelijke elementen te capteren en de beperkingen in kaart te brengen.

Methode: Een systematische review werd uitgevoerd volgens de PRISMA-COSMIN richtlijnen. Er werd gefocust op de literatuur die tussen maart 2019 en september 2024 werd gepubliceerd en de volgende MeSH-termen: "Surveys and Questionnaires", "Decision Making, Shared" en "Patient Reported Outcome Measures". Belangrijke SDM-thema's werden geïdentificeerd en verfijnd door drie onderzoekers via een literatuuronderzoek, waarbij meningsverschillen werden opgelost en de prevalentie van elk thema per instrument werd berekend.

Resultaten: Negen unieke patiënt- of gemengd gerapporteerde instrumenten werden opgenomen. Belangrijke thema's die werden geïdentificeerd, waren informatie (32,3% - 30/93 Q), keuze/besluitvorming (22,6% - 21/93 Q), relatie (16,1% - 15/93 Q), participatie (11,8% - 11/93 Q), tijdsbeheer (8,6% - 8/93 Q), communicatie (6,5% - 6/93 Q) en steun (2,2% - 2/93 Q). De instrumenten varieerden in inhoud, beoordelingssysteem en het niveau van patiëntbetrokkenheid tijdens de ontwikkeling.

Conclusie: De analyse van patiëntgerapporteerde vragenlijsten identificeerde zeven kernthema's van gedeelde besluitvorming, waarbij informatie en keuze/besluitvorming het vaakst aan bod kwamen. Hoewel deze thema's centraal staan, blijven belangrijke aspecten zoals het bespreken van geldige alternatieven en sociale steun onderbelicht. Een volledige SDM-benadering vereist aandacht voor alle thema's, maar verder onderzoek is nodig om het relatieve belang ervan in verschillende contexten te bepalen.

Plain language summary

- SDM: Shared Decision Making
- PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses
- COSMIN: COnsensus-based Standards for the selection of health Measurement INstruments
- OMI: Outcome Measurement Instruments
- Q: Questions of the SDM measurement instruments
- FFP: Family, Friends and Peers
- IP: Interprofessional

Open science

The study was approved by the ethical committee of KU Leuven University (MP028900). No funding has been received for this paper. LG, MT, KV declare that they have no competing interests. All relevant data are in the paper and its supporting information files. LG, MT KV, BA and LM contributed to the study conception and design. LG, MT, KV were responsible for collecting the data and performed the data analysis. LG, MT, KV drafted the manuscript, and BA and LM carried out critical revisions on the paper.

Introduction

Communication in healthcare has become an important topic in the last decades. Shifting from the paternalistic decision-making model, where patients often play a passive role with minimal autonomy and responsibility, the golden standard has become Shared Decision Making (SDM) (1). SDM is a communication model between patient and health care professional. It contains four main fundamental properties: 1) creation of patients' medical choice awareness 2) clarification of the different options and outlining pros and contras 3) the exploration of patients' preferences 4) discussion and decision by mutual agreement (2,3).

SDM enhances the decision quality by boosting the patients' knowledge, improving adherence, fostering patient satisfaction, and promoting realistic expectations. It subsequently diminishes fears and reduces decisional conflict (1,4,5). It is important to put more emphasis on including the patient during the SDM process rather than making the actual decision (6). Nevertheless, SDM is still not consistently implemented in daily practice. Several research investigations indicate that a majority of patients refrain from vocalizing when a potentially harmful and/or preventable event could occur during their medical treatment. This phenomena, formerly termed "white-coat silence", is closely related to patients' perspectives on their participatory role in medical decision-making processes and their perceptions regarding the attributes of an ideal patient (7).

As this communication model can be implemented in different healthcare settings, for different healthcare providers and for different patients as well, it remains a well-known challenge to measure the process of SDM. When assessing the different SDM models, a clear definition of SDM is lacking, due to the broad interpretation of the communication method and the constant redefinition by authors. As a result, several SDM instruments exist without a universally accepted consensus on the definition (8).

SDM can be rated from different perspectives: the physician's, the observer's and the patient's perspective. Preceding studies demonstrate a remarkable difference between the observation of a SDM process either by a physician or by a patient. While multiple observer measures of SDM exist, the correlation between observed assessments of patient' involvement in SDM and concurrent patient reports about involvement, was limited (4,9). A recurring limitation of the existing SDM measurement instruments is a lack of evidence in measurement quality, in particular low content validity (10). Including the patient's view during item development, and so the correct end-user interpretation, could counter this problem (11,12).

As mentioned above, the patients' perspective in rating the SDM process has become more important. Understanding patients' perspective on the different factors (barriers and/or facilitators) influencing the process of SDM leads to better tailoring SDM approaches to the preferences of the target population (5,13).

This paper aims to provide an updated overview of the existing patient-reported SDM measurement instruments as well as a content analysis. Further, we aim to align patient-reported barriers/facilitators with the existing SDM measurement instruments to assess the common elements and limitations. The aim of this systematic review is to compare the existing patient reported SDM instruments to acquire insight in the different themes, their alignment to patients' needs in literature and the variety of facilitators and barriers.

Methods

Study design

For this systematic review, the researchers followed each item of the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) for Outcome Measurement Instruments (OMI) guideline that was published on the 9th of July 2024 (14).

Search strategy

To get an overview of the existing SDM measurement instruments, previous systematic reviews of Gärtner et al. and Ahmad et al. were consulted, which consisted of forty and seventeen instruments respectively (10,15). Gärtner et al. conducted a comprehensive analysis of forty different SDM measurement tools from different perspectives: sixteen patient-reported, eighteen observer-rated, four clinician-reported and two mixed instruments. These are the SDM measurement instruments developed before September 1st 2017. Ahmad et al. reported an additional search of SDM measures through November 2018 and updated on March 24th 2019.

An additional literature systematic search of articles starting from March 25th 2019 to September 1st 2024 was conducted. Search strategy consisted of three Mesh Terms "Surveys and Questionnaires"[Mesh]) AND "Decision Making, Shared"[Mesh] AND "Patient Reported Outcome Measures"[Mesh][2]. Screening by title and abstract was completed independently and in triplicate by LG, MT and KV using the software Rayyan.

Eligibility criteria

We defined criteria for three major characteristics, namely type of participants, type of outcome and type of studies. The type of participants included in this study were patients who seek healthcare. We excluded participants with intellectual disabilities, as well as parents, guardians, or surrogate decision-makers. Children aged eighteen years or younger were also excluded, along with patients concerned in advanced care planning. For the type of outcome, we considered studies that reported on the development process of measurement instruments, including patient-reported and mixed measurement instruments. Also, questionnaire tools used as study outcomes, with a particular focus on SDM were included. We excluded publications that measured decision-making in general, rather than specifically focusing on SDM, as well as those that emphasized perception rather than preference. Descriptive questionnaires were also excluded. Regarding the type of studies, we included studies that had both an abstract and a full text available, and that were published in English. We excluded studies that involved translations of measurement instruments, systematic reviews, editorials, commentaries, or opinion articles.

Data extraction and thematical analysis

The measurement instruments were first compared based on study characteristics. Two researchers independently extracted: author, publication year, country, target setting, measurement aim, development process, number of items, and scoring system. The item development process pointed towards the implementation of pilot study and patient involvement in item selection and/or adaptation.

To define the key themes in SDM measurement instruments, a manual literature search through snowballing, was fulfilled by the three researchers (LG, MT, KV) independently. These themes were finetuned while categorizing the different questions of the instruments into them. Disagreement was discussed within the group. The themes were calculated as a percentage for each instrument, to determine which theme outweighs the most.

Results

Included studies

Based on the systematic search of Ahmad et al. and Gärtner et al. only the patient-reported and mixed-reported questionnaires were withheld. Ahmad et al. listed seven instruments that were already included in Gärtner et al., this resulted in a total of eighteen unique instruments. After application of the in- and exclusion criteria, nine different instruments remained (*FPI, COMRADE, SDM-Q, dyadic option, SDM-Q9, Collaborate, SMDMQ, MADM, SDM Process Score*) (flowchart 1) (10,15).

The systematic search of the period between March 25, 2019 and September 1st, 2024, yielded 55 articles. The remaining four articles were assessed by full text screening by three reviewers (LG, MT, KV). Conflicts were resolved through discussion and resulted in inclusion of zero additional articles (flowchart 2).

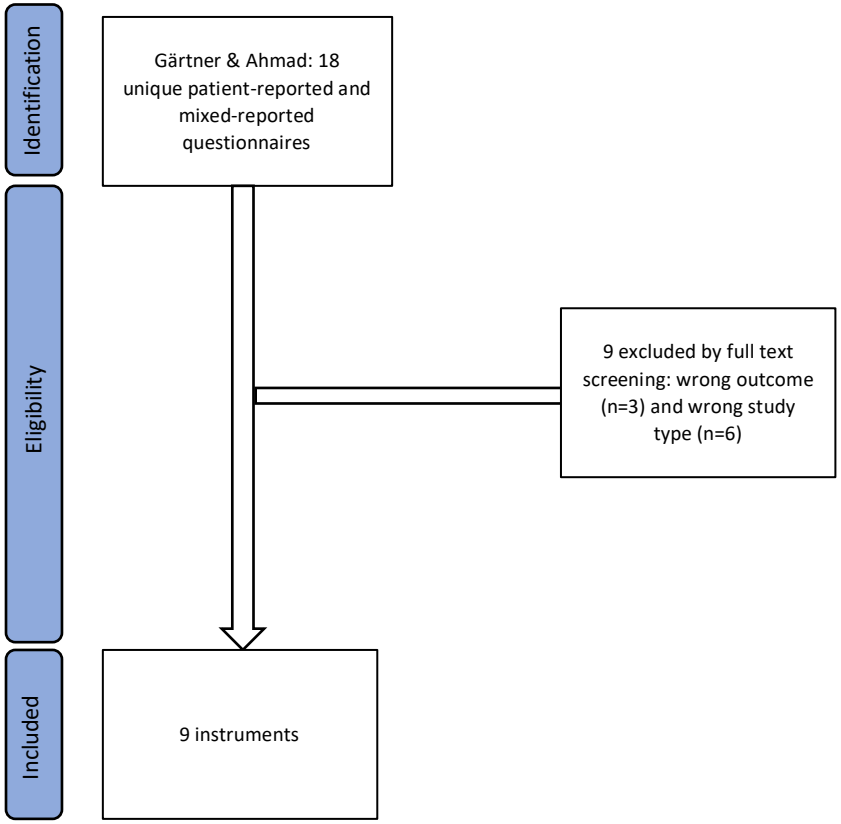


FIGURE 1. Flow diagram of the previous instrument selection

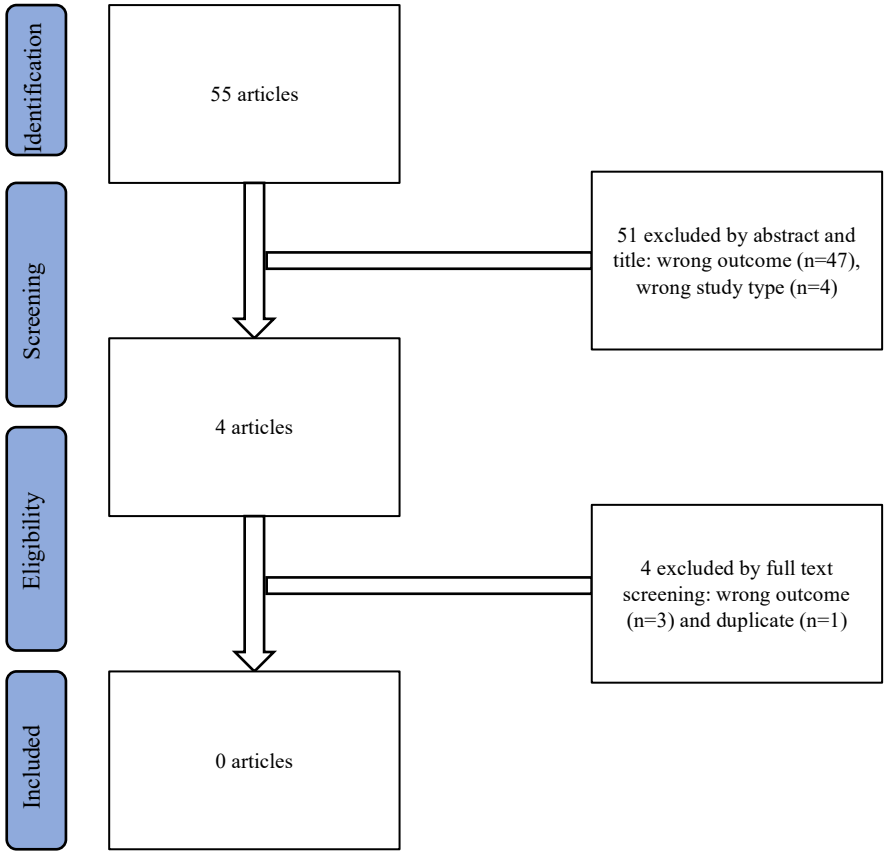


FIGURE 2. Flow diagram of the additional search

Instrument characteristics

The target population was generic. This means not limited to a specific healthcare setting or sociocultural group. The MADM was the only exception as the patient samples were specified in primary maternity care. As mentioned in the table, a variety of aims were detected. The FPI and Dyadic Option aimed to capture the active involvement of the patient in SDM while the other instruments assessed the whole process of SDM.

It is very interesting whether or not patients' opinions were taken into account in the development process of the SDM measurement instrument. All instruments used pilot testing except SMDMQ and SDM-Q-9. FPI did not incorporate pilot testing nor patient involvement during the development process.

There was a clear variation in the number of items and their scoring system. As mentioned in table 1, SDM Process Score includes six items, while only four questions were used in application. This instrument consisted of four questions where question number four could be tailored to three specific situations regarding intervention or treatment (cfr. Appendix). As those items explored different aspects of SDM, we decided to assess these items separately.

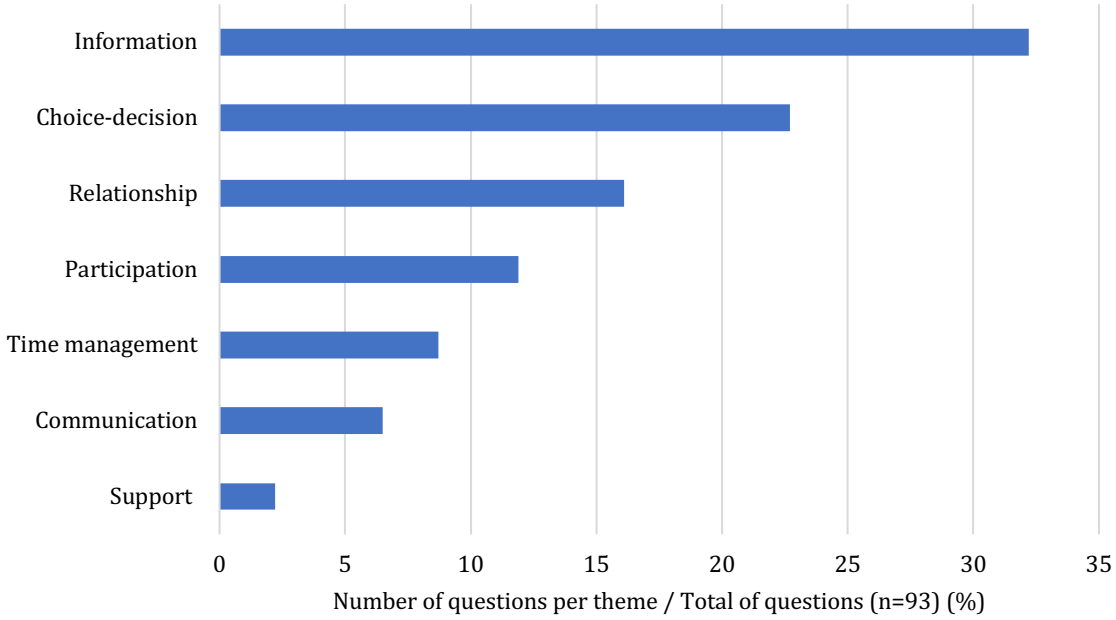
Most of the instruments used a Likert-type response format and one instrument did not report a clear scoring system of items. The questionnaire SDM-Q9 was the revised version of SDM-Q.

Table 1 Instrument characteristics: a chronological overview of the included SDM measurement instruments.

Instrument	Author	Publication year	Country	Population	Interest	Development process: Pilot Study	Development process: Patient involvement	Number of items	Scoring system
FPI	Martin et al.	2001	United States of America	Generic	The degree to which patients perceive that their physicians actively facilitate or encourage their involvement in their own healthcare	No	No	9	6-point Likert-type scale
COMRADE	Edwards et al.	2003	United Kingdom	Generic	Effectiveness of risk communication and treatment decision making in consultations	Yes	Yes	20	5-point Likert-type scale
SDM-Q	Simon et al.	2006	Germany	Generic	The process of SDM in clinical encounters	Yes	Yes	11	4-point Likert-like scale
Dyadic Option	Mebourne et al.	2010	United Kingdom	Generic	The extent to which patients have been involved in SDM from two viewpoints (those of the patient and of the clinician)	Yes	Yes	12	4-point Likert-type scale
SDM-Q-9	Kriston et al.	2010	Germany	Generic	The process of SDM in clinical encounters from the patients' perspective	No	Yes	9	6-point Likert-type scale
CollaboRATE	Elwyn et al.	2013	United States of America	Generic	The extent of SDM in clinical encounters and all conditions, as well as brief enough to routine use	Yes	Yes	3	10-point Likert-type scale
SMDMQ	Chang et al.	2014	Taiwan	Generic	The SDM process	No	Yes	15	Not mentioned
MADM	Vedam et al.	2017	Australia	Primary maternity care	Women's autonomy and role in decision making during maternity care	Yes	Yes	7	6-point Likert-type scale
SDM Process Score	Fowler et al.	2021	United States of America	Generic	The extent to which there was an interaction between provider and patient that would meet standard for SDM	Yes	Yes	6	4-point Likert-type scale (2 questions) and dichotomous (4 questions)

Thematical analysis

FIGURE 3: Barplot of themes: overview of different themes occurring in the SDM instruments, from top to bottom in a decreasing frequency.



The information theme (32,3% - 30/93 Q) was categorized into four subdivisions, namely 'sufficiency', 'information provision by different sources', 'overview of the different treatment options' and the 'information input by the patient'. CollaboRATE is the only instrument that did not gauge the information theme. The subtheme 'sufficiency' included content information provided by the doctor, about diagnosis and any further procedures. The second subtheme surveyed the use of various sources of information, for example photos, brochures, videos… The Dyadic Option was the only questionnaire that surveyed this. The overview of different treatment options must be provided by the doctor and included mentioning the advantages, the disadvantages and the consequences of the different treatment options. The last subtheme, 'active information input by the patient', was only probed in the SMDMQ.

The section choice/decision (22,6% - 21/93 Q) included 'the clarification of the choice to be made', 'the ability of doing nothing as a treatment option', 'feeling well equipped to make a decision', 'the mutual agreement between the doctor and the patient' and 'the satisfaction of the decision (making process)'. Creating awareness of the choice that needed to be made aroused the patient to think about participation. Patients' feeling of being well equipped reflected their readiness, confidence, and sense of being prepared to make a decision. This theme emerged as the second most frequently addressed, following information.

The theme relationship (16,1% - 15/93 Q) assessed the extent to which patients felt taken into account or not, by their physician. Feelings of trust, safety and respect during the process of decision are evaluated here as well as the doctor's listening behaviour and empathy. This theme is addressed in every instrument by one, two or three separated questions.

Participation (11,8% - 11/93 Q) meant being able to take part in the decision-making process. The first subcategory was the 'patients' wish/need to participate,' which came from the patient themselves expressing the desire to participate. The second subcategory, 'dis- or encouragement to participate,' referred to the proposition from the doctor and others, including everyone involved in the decision-making process.

Time management (8.6% - 8/93 Q) referred to the time available during the consultation to ask questions, as well as the potential additional time to reflect on or make the decision. The subsection 'time to think/make the decision' is questioned in two of nine questionnaires. The other subsection 'enough time and room for asking questions' appeared in five out of nine instruments.

The communication (6,5% - 6/93 Q) section referred to the correct wording towards the patient and the assurance that the information is clearly understood. These questions aimed to avoid misinterpretation. Six out of nine questionnaires specifically asked about this theme.

Support (2,2% - 2/93 Q) consisted of second expert opinions as well as the network of the patient. SMDMQ is the only scale that highlighted this theme.

TABLE 2 Thematical analysis: The nine scales, each with their respective questions, were divided into six main themes: Information, relationship, participation, choice/decision, time management and support.

Themes	**Instruments**										
	FPI	**COMRADE**	**SDM-Q**	**Dyadic OPTION**	**SDM-Q-9 revision**	**CollaboRATE**	**SMDMQ**	**MADM**	**SDM Process Score**	**Total**	
Number of questions (Q)	n = 9	n = 20	n = 11	n = 12	n = 9	n = 3	n = 16	n = 7	n = 6	**n = 93 Q**	
Information										**32.3 %**	**30**
Sufficiency	1	1					2			4.3 %	4
Information provision by different sources				1						1.1 %	1
Overview of different treatment options	1	6	4	3	3		3	2	2	25.8 %	24
Information input by the patient							1			1.1 %	1
Choice / Decision										**22,6 %**	**21**
Clarification of choice to be made				1	1					2,2 %	2
Ability of doing nothing									1	1,1 %	1
Feeling well equipped		2	1				1	1		5,4 %	5
Mutual agreement		1	2	1	2		2		1	9,7 %	9
Satisfaction of the decision / decision making process		4								4,3 %	4
Relationship										**16,1 %**	**15**
(Not) being taken into account	1	1	3	2	1	2	2	1	2	16,1 %	15
Participation										**11,8 %**	**11**
Patients' wish / need to participate				1			1			2,2 %	2
Dis- of encouragement to participate	4	2			1		1	1		9,7 %	9
Time management										**8,6 %**	**8**
Enough time and room for asking questions	2	2	1	1						6,5 %	6
Time to think / to make the decision				1				1		2,2 %	2
Communication										**6.5 %**	**6**
Correct wording		1		1	1	1	1	1		6,5 %	6
Support										**2,2 %**	**2**
Support of others							2			2,2%	2

Discussion

Main findings

The two themes that were most frequently addressed in the questionnaires were information and choice/decision.

Information is one of the most important themes for patients, as they consider it crucial for developing decision-making abilities (13). SDM-Q(-9) highlighted this by dedicating one third of their questions to this section, unlike the CollaboRATE scale. All participants of the CollaboRATE study indicated 'good understanding' above 'information provision' after two stages of cognitive interviews (12). The understandability of the information is evaluated in the theme communication as 'correct wording'.

'Overview of different treatment options' is one of the four subcategories within the broader theme of information. This subcategory contains the highest number of questions across all measurement instruments, accounting for one-quarter of all questions. SDM authors define a SDM appropriate decision if several treatment options and uncertainty around possible outcomes are decision characteristics (16). Notwithstanding the fact that the additional use of different sources is only mentioned in the Dyadic Option. The added value of extra information in written format, offline as well as online, is demonstrated. This arises from a higher patients' commitment in decision-making by seeking high-quality information themselves (13,17).

The second most prevalent theme is choice/decision. This theme is in line with the 'decision talk phase' of the three-talk model of Glyn Elwyn. His model divides the SDM process in interactive team talk (work together, describe choices, offer support and ask about goals), option talk (discuss alternatives, using risk communication principles) and decision talk (get to informed preferences, make preference-based decisions)(18).

The clarification of a choice to be made facilitates the SDM process and was mentioned in two scales, The Dyadic Option and SDM-Q-9 (5). '*My doctor made clear that a decision needs to be made*' (SDMQ9) marks a notification towards the patient and differs from the patients' wish or need to participate as meant in '*I will express my preference about treatment option to my doctor*' (SMDMQ).

The subtheme 'overview of different treatment options' serves as an intersection between the themes of 'information' and 'choice,' though it differs from 'mutual agreement,' which involves a dynamic exchange of knowledge that has already been established. Mutual agreement stands out as the largest and most significant component within the broader theme of decision. It is crucial

that patients' feel their voices are heard and valued during the decision-making process. When patients' preferences differ from those of the doctor, the doctor's openness to disagreement plays a key role in helping the patient feel comfortable accepting these differences. Throughout the deliberation process, it is essential for doctors to take patients' views seriously. This approach not only fosters a sense of safety but also sends an implicit message that the patient's input truly matters, thereby strengthening the collaborative relationship between doctor and patient (3,13).

Ability of doing nothing is a subdivision of the choice/decision theme and is queried in one of the nine questionnaires, which seems quite limited. The question *'Did any of your doctors (or health care providers) explain that you could choose whether or not to have intervention?'* reflects this. However, this represents a crucial yet often overlooked aspect of SDM, as patients may not view it as an equally meaningful option, particularly because it may limit their sense of control over their illness (19).

The subtheme 'being taken into account' belongs to the relationship category and was, as the only theme, addressed in every questionnaire. Remarkably, CollaboRATE has only three questions where two out of three are categorised within this theme. A patient desires to feel understood and valued by the physician, reflects in a question such as '*I felt included in the treatment' (SDMQ)*. The doctors' listening behaviour and empathy is very important as mentioned above and noted in literature before therefore the doctors need to be good listeners (13). The feeling of trust with your physician can have a positive or negative impact on the SDM process (5). Besides, questions like *'The doctor gave me a chance to decide which treatment I thought was best for me*' (COMRADE) and *'in the selection of the treatment method, my thoughts were taken into account just as much as the considerations of my doctor' (SDMQ)* also takes part in this theme. These questions highlight that the patients' input is an important additional element to the information conveyed by the doctor. Unfortunately, this is not generally recognised by the patient as they believe 'doctor knows best' while personal contributions facilitate SDM in a strong way (5).

We divided participation into two different perspectives, namely the patients' view and the doctors' view. The question '*The preference to take part in the decision (or not) was respected*' refers to the active involvement directly by the patient, on the other hand *'my doctor strongly encourages me to express all of my concerns about the prescribed treatment'* points towards the encouragement for participation actively expressed by the doctor. In literature, the patients' wish or need to participate strongly depends on the patients' characteristics such as age, ethnic background, level of education and other pre-disposing factors (1,20). This is in line with the hypothesis of increasing assertiveness seen in Western oriented population as a culture-specific

phenomenon (13). Despite the fact that not all these characteristics are modifiable, individual patient-centred adjustments in the doctors' approach could change their will or need to participate (21). For the patient, the perceived acceptability of asking questions and express their opinion by the doctors' explicit encouragement acts as an important facilitator for SDM (5). More so, previous literature has shown that SDM is possible for any patient with any characteristic, if the physician's communication style and attitude toward the patient are adequate and supportive (13,20,22). This could be encouraged by the explicit expression of the opportunity whether or not to participate in the decision rather than participation in the actual SDM process (5).

Patient participation goes together with increasing knowledge and understanding of their health. The challenges of low individual health literacy can be reduced by involving the patients' social network, using simple language in medical discussions, and ensuring consistency in care by assigning the same healthcare provider for each visit (2). Clinicians play a key role in encouraging patient participation and should be mindful of social and personal factors that may hinder active engagement in their healthcare (21). This can lead to a constructive dialogue between two equals (23).

The subsection time to think/to make the decision of time management is only mentioned in two questionnaires, however this is considered as a facilitator of patient involvement (5). The opportunity to come back to the decision was considered useful, especially in the limited health literacy population (24). Patients seem to appreciate the option to go away and think about the decision and to discuss the options with family, friends and peers (FFP) (25). Enough time and room for asking questions is not considered as evidently during a consultation as the patient might feel guilty about taking up the clinician's time (26). A shortage of time can cause physicians to feel stressed, which may in turn limit the amount of information they share and discourage patients from asking questions (26).

Correct wording is a subtheme of communication and appears in six out of nine questionnaires. Since SDM is a communication technique, it seems obvious that communication should be considered important and essential. However, it's not just the content of the information that matters, but also the way it is communicated to make it understandable for the patient. Therefore, questions like *'The information given to me was easy to understand'* and *'My doctor helped me understand all the information'* seem useful to us to include in a patient-reported SDM questionnaire.

Many medical specialist trainings lack coaching in communication skills. In contrast, technical skills are systematically supervised, while physicians are rarely observed during patient interactions. Consequently, the acquisition of essential professional attributes by junior doctors largely depends on the quality of mentorship they happen to receive. Additionally, excessive reliance on medical jargon continues to hinder effective information transfer, leading to significant loss of critical details (3).

The least queried theme is support, appearing in only one of nine scales, the Taiwanese SMDMQ. Besides this is the only non-Western questionnaire in our study and reflects to a potential culture-specific facilitator of SDM (13). Of the ninety questions across all questionnaires, only two refer to support of others: *'I know I have the right to appoint an agent regarding my treatment decision'* and *'I will ask for a second opinion to confirm my expectations about treatment options.'* Notable is that literature often emphasizes the importance of social support in SDM, which is a concept that has gained more importance over the last years (5). FFP are thought to contribute to a variety of dimensions of support (informational, conversational, decisional, emotional, and sociocultural) during the decision-making process (13). Besides, support could be extended to the infrastructural barriers such as noisy environment and lack of privacy (5). The new interprofessional (IP)-SDM model for primary care underlines a beneficial influence of FFP in healthcare decision-making (22). This is a clear gap in the questionnaires and should certainly be addressed in the future to create a more comprehensive SDM patient-reported questionnaire.

Strengths and limitations

To the best of our knowledge, this is the first systematic review that specifically delves into the content analysis of SDM instruments. This contributed to a deeper understanding of the structure and components of these tools. The selection process was conducted systematically at three levels - title, abstract, and full text - by three independent researchers, ensuring a rigorous and unbiased selection of studies. Additionally, the discussion and development of the analysis table were consistently carried out in a collaborative setting, involving the same three researchers. This ensured a well-founded and consensus-based interpretation of the findings. Furthermore, our research adheres to the widely accepted, recently updated COSMIN standards.

Despite its strengths, our study also has some limitations. First, the search process was restricted to only one database, PubMed. As a result, relevant studies indexed in other databases may have been overlooked. Second, the inclusion of studies was limited to those published in English, so we could have failed to notice instruments in other languages. Third, there is a general lack of strong evidence and uniform validation of SDM instruments, making it challenging to draw definitive

conclusions about their effectiveness and applicability. Finally, for an article to be included in this review, it had to explicitly describe the development or validation of an SDM-process instrument. Consequently, we may have missed relevant studies if these aspects were not explicitly mentioned in the title or abstract.

Conclusion

The content analysis of the patient-reported questionnaires clearly shows a variety of topics. We were able to list seven themes of SDM and to score their weights in the existing SDM instruments. Information and choice/decision emerged as the most frequently addressed themes across SDM questionnaires, with clear and understandable information being central to effective SDM. Despite this emphasis, gaps remain, such as the limited attention to valid alternatives like doing nothing, and the underrepresentation of social support, time to decide, and correct wording. Trust, mutual respect, and encouragement from doctors are essential elements in fostering active participation. As patients face different challenges, barriers and facilitators, the emphasis on each theme may vary depending on the specific setting and purpose of the SDM process. While all themes should be incorporated into a comprehensive SDM instrument, we are unable to draw conclusions about the relative weight of each theme within different patient groups or healthcare settings, as this was beyond the scope of our current analysis.

Future research questions

Research is needed to train well-versed healthcare professionals and patients who master effective implementation of SDM by understanding its essence and knowing when to apply it. Even though authors tried to define decision characteristics for which SDM was considered appropriate, when to apply SDM is no exact science (16). Advancing the integration of SDM in a clinical spectrum and divers patient populations could be more valuable (27). Future research could differentiate between different patient groups in order to retrieve the most appropriate SDM instrument for a select setting or focus on the challenges in implementation of SDM in different contexts which contain different needs. By doing so, we aspire to enhance the practical applicability of SDM in everyday healthcare practice. Besides, expanding the search across multiple databases and including studies in additional languages could contribute to a more comprehensive overview. Additionally, efforts should be made to improve the validation and standardization of these instruments to enhance their reliability and usability in clinical practice.

References

1. Büdenbender B, Köther AK, Grüne B, Michel MS, Kriegmair MC, Alpers GW. When attitudes and beliefs get in the way of shared decision-making: A mediation analysis of participation preference. Health Expectations. 2023 Apr 1;26(2):740–51.
2. Stiggelbout AM, Van Der Weijden T, De Wit MPT, Frosch D, Légaré F, Montori VM, et al. Shared decision making: Really putting patients at the centre of healthcare. Vol. 344, BMJ (Online). 2012.
3. Pieterse AH, Gulbrandsen P, Ofstad EH, Menichetti J. What does shared decision making ask from doctors? Uncovering suppressed qualities that could improve person-centered care. Vol. 114, Patient Education and Counseling. Elsevier Ireland Ltd; 2023.
4. Kasper J, Heesen C, Köpke S, Fulcher G, Geiger F. Patients' and observers' perceptions of involvement differ. Validation study on inter-relating measures for shared decision making. PLoS One. 2011 Oct 17;6(10).
5. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Vol. 94, Patient Education and Counseling. 2014. p. 291–309.
6. Edwards A, Elwyn G. Inside the black box of shared decision making: Distinguishing between the process of involvement and who makes the decision. Health Expectations. 2006 Dec;9(4):307–20.
7. Judson TJ, Detsky AS, Press MJ. Encouraging Patients to Ask Questions How to Overcome "White-Coat Silence" [Internet]. Available from: http://www.jointcommission.org/speakup.aspx
8. Shunnmugam B, Ng CJ, Aishah Mohd Taib N, Chinna K. Validation of the Malay, English, and Chinese Translations of the 9-Item Shared Decision Making Questionnaire (SDM-Q-9) in Breast Cancer Patients Making Treatment Decisions. Asia Pac J Public Health. 2021 Nov 1;33(8):914–22.
9. Saba GW, Wong ST, Schillinger D, Fernandez A, Somkin CP, Wilson CC, et al. Shared decision making and the experience of partnership in primary care. Ann Fam Med. 2006 Jan;4(1):54–62.
10. Gärtner FR, Bomhof-Roordink H, Smith IP, Scholl I, Stiggelbout AM, Pieterse AH. The quality of instruments to assess the process of shared decision making: A systematic review. Vol. 13, PLoS ONE. Public Library of Science; 2018.
11. Scholl I, Loon MK Van, Sepucha K, Elwyn G, Légaré F, Härter M, et al. Measurement of shared decision making - A review of instruments. Z Evid Fortbild Qual Gesundhwes. 2011;105(4):313–24.
12. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: A model for clinical practice. Vol. 27, Journal of General Internal Medicine. 2012. p. 1361–7.
13. Mertens L, Kasmi T, Bekkering GE, Hannes K, Vermandere M, Delvaux N, et al. Shared challenges and opportunities: Uncovering common ground in patient participation across different healthcare settings and patient groups. A qualitative meta-summary on patient-reported barriers and facilitators to participation in shared decision-making. Vol. 130, Patient Education and Counseling. Elsevier Ireland Ltd; 2025.
14. Elsman EBM, Mokkink LB, Terwee CB, Beaton D, Gagnier JJ, Tricco AC, et al. Guideline for reporting systematic reviews of outcome measurement instruments (OMIs): PRISMA-COSMIN for OMIs 2024. Quality of Life Research. 2024 Aug 1;33(8):2029–46.

15. Ahmad M, Abu Tabar N, Othman EH, Abdelrahim Z. Shared Decision-Making Measures: A Systematic Review. Vol. 29, Quality Management in Health Care. Lippincott Williams and Wilkins; 2020. p. 54–66.
16. van der Horst DEM, Garvelink MM, Bos WJW, Stiggelbout AM, Pieterse AH. For which decisions is Shared Decision Making considered appropriate? – A systematic review. Vol. 106, Patient Education and Counseling. Elsevier Ireland Ltd; 2023. p. 3–16.
17. Reychav I, Najami I, Raban DR, McHaney R, Azuri J. The impact of media type on shared decision processes in third-age populations. Int J Med Inform. 2018 Apr 1;112:45–58.
18. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision making: Multistage consultation process. BMJ (Online). 2017;359.
19. Charles C, Redko C, Whelan T, Gafni A, Reyno L. Doing nothing is no choice: Lay constructions of treatment decision-making among women with early-stage breast cancer. Sociol Health Illn. 1998;20(1):71–95.
20. Street RL, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient Participation in Medical Consultations Why Some Patients are More Involved Than Others. 2005.
21. Protheroe J, Brooks H, Chew-Graham C, Gardner C, Rogers A. "Permission to participate?" A qualitative study of participation in patients from differing socio-economic backgrounds. J Health Psychol. 2013 Aug;18(8):1046–55.
22. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. Vol. 73, Patient Education and Counseling. 2008. p. 526–35.
23. Chang CC. Developing the First Validity of Shared Medical Decision-Making Questionnaire in Taiwan DevelopingtheFirstValidityofSharedMedicalDecision-MakingQuestionnaireinTaiwan Developing the First Validity of Shared Medical Decision-Making Questionnaire in Taiwan. Type: Double Blind Peer Reviewed International Research Journal Publisher: Global Journals Inc. 2014;14.
24. Oosterveld M, Noordman J, Kennisvraag JR. Samen beslissen in de spreekkamer [Internet]. 2019. Available from: www.nivel.nl
25. Skea Z, Harry V, Bhattacharya S, Entwistle V, Williams B, MacLennan G, et al. Women's perceptions of decision-making about hysterectomy. BJOG. 2004 Feb;111(2):133–42.
26. Zagt AC, Bos N, Bakker M, de Boer D, Friele RD, de Jong JD. A scoping review into the explanations for differences in the degrees of shared decision making experienced by patients. Vol. 118, Patient Education and Counseling. Elsevier Ireland Ltd; 2024.
27. Opel DJ, Gerstein MT, Carle AC, Fournier AK, Hargraves I, Lafata JE, et al. Saving Shared Decision-Making. J Gen Intern Med. 2025;

Appendices: Measurement instruments

The Facilitation of Patient Involvement Scale

The Facilitation of Patient Involvement Scale

Directions: Please indicate how often your physician typically does the following things, using these responses: *none of the time* (1); *a little of the time* (2); *some of the time* (3); *a good bit of the time* (4); *most of the time* (5); *all of the time* (6).

1. My doctor gives me all the information that I need to make the decisions that are right for me.
2. My doctor ignores my opinion about treatment options. (–)
3. When prescribing a new medication, my doctor asks if I have any questions about the medication(s) and possible side effects.
4. My doctor discourages my questions. (–)
5. My doctor explains all the treatment options to me so that I can make an informed choice.
6. My doctor strongly encourages me to express all of my concerns about the prescribed treatment.
7. My doctor discourages me from expressing my personal opinion about my medical condition. (–)
8. My doctor's office staff makes it hard for me to be involved in my own medical care. (–)
9. My doctor makes it difficult for me to communicate my concerns about treatment decisions. (–)

B.1. Satisfaction with communication

1. The doctor made me aware of the different treatments available (Q8).
2. The doctor gave me the chance to express my opinions about the different treatments available (Q9).
3. The doctor gave me the chance to ask for as much information as I needed about the different treatment choices (Q10).
4. The doctor gave me enough information about the treatment choices available (Q11).
5. The doctor gave enough explanation of the information about treatment choices (Q12).
6. The information given to me was easy to understand (Q14).
7. I know the advantages of treatment or not having treatment (Q15).
8. I know the disadvantages of treatment or not having treatment (Q16).
9. The doctor gave me a chance to decide which treatment I thought was best for me (Q28).
10. The doctor gave me a chance to be involved in the decisions during the consultation (Q30).

B.2. Confidence in decision

1. Overall, I am satisfied with the information I was given (Q27).
2. My doctor and I agreed about which treatment (or no treatment) was best for me (Q32).
3. I can easily discuss my condition again with my doctor (Q33)
4. I am satisfied with the way in which the decision was made in the consultation (Q34).
5. I am sure that the decision made was the right one for me personally (Q35).
6. I am satisfied that I am adequately informed about the issues important to the decision (Q36).
7. It is clear which choice is best for me (Q43).
8. I am aware of the treatment choices I have (Q44).
9. I feel an informed choice has been made (Q45).
10. The decision shows what is most important to me (Q46).

SDM-Q

	Items	Strongly agree	Agree	Disagree	Strongly disagree	Item-infit	Item difficulty	Step in the SDM process
1	In the selection of the treatment method, my thoughts were taken into account just as much as the considerations of my doctor	☐	☐	☐	☐	1.06	0.15	7
2	There was enough time for questions	☐	☐	☐	☐	1.10	−0.78	5
3	My doctor and I weighed up the different treatment options thoroughly	☐	☐	☐	☐	1.05	0.59	7
4	I was able to discuss the different treatment options with my doctor in detail	☐	☐	☐	☐	0.92	−0.18	7
5	My doctor and I selected a treatment option together	☐	☐	☐	☐	0.96	0.27	8
6	I now know the advantages of the individual treatment options	☐	☐	☐	☐	0.95	0.05	4
7	I now know which treatment option is the best one for me	☐	☐	☐	☐	1.03	−0.08	4
8	During the consultation, I felt included in the treatment decision	☐	☐	☐	☐	0.78	−0.27	8
9	Through the consultation with the doctor, I felt jointly responsible for my further treatment	☐	☐	☐	☐	0.99	−0.12	9
10	My doctor and I discussed the next steps of the treatment plan in detail	☐	☐	☐	☐	1.07	0.08	9
11	My doctor and I reached an agreement as to how we will proceed	☐	☐	☐	☐	1.14	0.28	9

SDM-Q-9

The 9-item Shared Decision Making Questionnaire (SDM-Q-9)

[Example] **Please indicate which health complaint/problem/illness the consultation was about:**

[Example] **Please indicate which decision was made:**

Nine statements related to the decision-making in your consultation are listed below. For each statement please indicate how much you agree or disagree.

	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
1. My doctor made clear that a decision needs to be made.	☐	☐	☐	☐	☐	☐
2. My doctor wanted to know exactly how I want to be involved in making the decision.	☐	☐	☐	☐	☐	☐
3. My doctor told me that there are different options for treating my medical condition.	☐	☐	☐	☐	☐	☐
4. My doctor precisely explained the advantages and disadvantages of the treatment options.	☐	☐	☐	☐	☐	☐
5. My doctor helped me understand all the information.	☐	☐	☐	☐	☐	☐
6. My doctor asked me which treatment option I prefer.	☐	☐	☐	☐	☐	☐
7. My doctor and I thoroughly weighed the different treatment options.	☐	☐	☐	☐	☐	☐
8. My doctor and I selected a treatment option together.	☐	☐	☐	☐	☐	☐
9. My doctor and I reached an agreement on how to proceed.	☐	☐	☐	☐	☐	☐

Item progression over three stages of development.

	Stage one Cognitive interviews: item refinement (iteration 1)	Stage two Cognitive interviews: item refinement (iteration 2)	Stage three Pilot: final items
Explanation	Today, how much effort do you feel your healthcare provider (e.g. doctor, nurse, midwife, pharmacist) made to a) explain your problem to you? b) help you understand your health issues? c) give you information about your problem?	How much effort did your provider make to help you understand your health issues?	How much effort was made to help you understand your health issues?
Preference elicitation	Today, how much effort do you feel your healthcare provider made to a) understand your worries and concerns b) consider carefully what matters most to you c) pay attention to what is most important to you?	How much effort did your provider make to a) consider/listen to your thoughts or opinions about your health issues? b) consider/listen to your preferences about your health issues? c) consider/listen to the things that matter most to you about your health issues?	How much effort was made to listen to the things that matter most to you about your health issues?
Preference integration	No item in first round of interviews.	How much effort did your provider make to a) work with you to decide/choose the way forward? b) involve you in deciding/choosing what to do next? c) include what matter most to you/your preferences in deciding/choosing what to do next?	How much effort was made to include what matters most to you in choosing what to do next?

SMDMQ

No	Item
1	I will express my preference about treatment option to my doctor
2	I will inform my doctor of my family health record
3	I was able to discuss the different treatment options with my doctor in detail
4	I know I have a right to appoint agent about my treatment decision
5	I will ask the second opinion to conform with my expectation about treatment option
6	I now know which treatment option is the best one for me
7	My doctor and I weighed up the different treatment options thoroughly and selected a treatment option together
8	Through the consultation with the doctor, I felt jointly responsible for my further treatment
9	My doctor encourage my question about the tests or treatment
10	During the consultation, I felt included in the treatment decision
11	When I had important questions to ask my doctor, I can get answers that I could understand
12	My doctor is willing to explain the treatment or procedure to me in greater detail
13	My doctor has explain the purpose of any laboratory tests
14	My doctor has tell me any risk about treatment in detail
15	My doctor and I discussed the prognostic plan with me together
16	My doctor and I reached an agreement as to how we will proceed

SDM Process Score

The SDM Process score consists of 4 questions that can be tailored to a specific intervention or treatment:

1. How much did a doctor (or health care provider) talk with you about the reasons you might want to (HAVE INTERVENTION)? with responses of a lot, some, a little, or not at all.

2. How much did a doctor (or other health care provider) talk with you about reasons you might not want to (HAVE INTERVENTION)? with responses of a lot, some, a little or not at all.
3. Did any of your doctors (or health care providers) ask you if you wanted to (HAVE INTERVENTION)? with responses of yes or no.

a. Did any of your doctors (or health care providers) explain that you could choose whether or not to (HAVE INTERVENTION)? with responses of yes or no.

OR

b. Did any of your doctors (or health care providers) explain that there were choices in what you could do to treat your [condition]? with responses of yes or no.

OR

c. Did any of your doctors (or health care providers) talk about (ALTERNATIVE INTERVENTION) as an option for you? with responses of yes or no.

MADM

Table 1. Scale items—Mothers Autonomy in Decision Making (MADM)[1].

Please describe your experiences when making decisions and choosing options for care during this pregnancy. (*Auto-populated with provider type*)
My _____ asked me how involved in decision making I wanted to be
My _____ told me that there are different options for my maternity care
My _____ explained the advantages and disadvantages of the maternity care options
My _____ helped me understand all the information
I was given enough time to thoroughly consider the different maternity care options
I was able to choose what I considered to be the best care options
My _____ respected that choice

[1].Response options are (1) Completely disagree; (2) Strongly disagree; (3) Somewhat disagree; (4) Somewhat agree; (5) Strongly agree; (6) Completely agree

doi:10.1371/journal.pone.0171804.t001

Dyadic OPTION

The dyadic OPTION instrument (December 2008).

Most encounters about health problems lead to decisions of one sort or another. These questions ask about the idea of being or feeling involved in decisions, for example, having an opinion or deciding whether to take medication, and if so which one, or what to do next. Answer the questions from your point of view by putting a tick in one box for each question. Please answer every question.				
What was the main problem you talked about? Please describe it in a few words...				
1. A health problem was identified, where it was made clear that a decision was needed.	Strongly agree	Agree	Disagree	Strongly disagree
2. More than one way to manage the health problem was described.	Strongly agree	Agree	Disagree	Strongly disagree
3. Different sources of information (e.g. leaflets, websites, contact with other people) to help make the decision were offered.	Strongly agree	Agree	Disagree	Strongly disagree
4. Different options (including the possibility of doing nothing) were discussed.	Strongly agree	Agree	Disagree	Strongly disagree
5. The advantages, disadvantages and possible outcomes of options were discussed.	Strongly agree	Agree	Disagree	Strongly disagree
6. Ideas or expectations about managing the health problem were discussed.	Strongly agree	Agree	Disagree	Strongly disagree
7. Concerns or worries about managing the health problem were discussed.	Strongly agree	Agree	Disagree	Strongly disagree
8. It was made sure that information had been understood.	Strongly agree	Agree	Disagree	Strongly disagree
9. There were opportunities to ask questions.	Strongly agree	Agree	Disagree	Strongly disagree
10. The preference to take part in the decision (or not) was respected.	Strongly agree	Agree	Disagree	Strongly disagree
11. During the consultation, a decision was made; or there was an agreement to postpone making the decision.	Strongly agree	Agree	Disagree	Strongly disagree
12. The possibility of coming back to the decision was discussed.	Strongly agree	Agree	Disagree	Strongly disagree