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How are patient-related characteristics associated with shared decision making about treatment? A scoping review of quantitative studies

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KEYWORDS

treatment decision making; SDM; systematic review; barriers and facilitators; patient involvement

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ABSTRACT

Objectives To identify what patient-related characteristics have been reported to be associated with the occurrence of SDM about treatment.

Design Scoping review.

Eligibility criteria Peer-reviewed articles in English or Dutch reporting on associations between patient-related characteristics and the occurrence of SDM for actual treatment decisions.

Information sources COCHRANE Library, Embase, MEDLINE, PsycInfo, PubMed, and Web of Science were systematically searched for articles published until March 25, 2019.

Results The search yielded 5289 hits of which 53 were retained. Multiple categories of patient characteristics were identified: 1) background characteristics (e.g., gender), 2) disease and decision characteristics (e.g., symptom severity), 3) preferences (e.g., for autonomy), 4) psychological, disease-related characteristics (e.g., adjustment), 5) general psychological characteristics (e.g., anxiety), and 6) clinician-patient relationship (e.g., trust). Many characteristics showed no association or unclear relationships with SDM occurrence. For example, for female gender positive, negative, and, most frequently, non-significant associations were seen.

Conclusions A large variety of patient-related characteristics have been studied, but for many the association with SDM occurrence remains unclear. The results will caution often-made assumptions about associations and provide a first step to target effective interventions to foster SDM with all patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We looked at a wide variety of treatment decisions, any patient-related characteristic that had been assessed, any year of publication, and any measure of SDM and were therefore able to provide an overview that cuts across clinical settings, study foci and study measures.
- We aimed to include studies that looked at a *specific* decision, not decision making experience in general, and decided to err on the side of inclusion in order to be comprehensive, but may have been too lenient in some cases.
- We did not put any restriction on how SDM should have been measured, allowing for constructs underlying the different SDM measures to differ and including studies that had used self-developed and unvalidated items, both making it more difficult to compare results across studies.

1. Introduction

Shared decision making (SDM) is recommended when patients face preference-sensitive decisions about treatment.[1 2] In clinical practice, the occurrence of SDM remains low.[3 4] Being an active participant in SDM can be difficult for patients, and potentially even more challenging for some patients than for others.[5 6] Previous research has suggested that e.g., those with higher age or lower education[7 8] are less likely to participate in SDM. Is it because they prefer to be less involved, because they struggle with certain aspects of SDM, such as understanding the information or expressing themselves,[6] or are clinicians less likely to involve patients in SDM whom they believe to have less desire or ability to participate?[8-10] Knowing about patient-related characteristics systematically associated with lower occurrence of SDM is an important step in identifying support needs for patients or educational or training needs for clinicians.

Associations between patient-related characteristics and actual occurrence of SDM have not been shown unambiguously. To our knowledge, no evidence-based overview exists on these associations. A scoping review is germane, as it allows answering broad and heterogenous research questions.[11] With this scoping review we aim to provide an overview of patient-related characteristics for which an association with the occurrence of SDM about treatment has been assessed. Our research question was: *What has been reported in the quantitative literature about the empirical relationships between patient-related characteristics and the occurrence of SDM about treatment?*

2. Methods

We based this scoping review on established frameworks,[11 12] and the protocol was registered at Open Science Framework (www.osf.io). The search strategy, developed with a librarian, included terms relating to SDM, patient-related characteristics, and others (e.g., distress, mental disorder) based on a simultaneous qualitative study on patient readiness for SDM about treatment.[6] The search was conducted on March 25, 2019 in: PubMed, MEDLINE, Embase, Web of Science, COCHRANE Library, and Psychinfo, from their inception (Appendix A). Abstracts and full-texts were screened independently and in duplicate. Disagreements were resolved in consensus meetings, consulting a third reviewer if necessary.

Peer-reviewed articles published in English or Dutch were included that reported on studies: 1) with an empirical, quantitative design, presenting new data or secondary analyses of existing data, in adult patients; that 2) involved a treatment decision for that patient; and 3) measured SDM occurrence and its association with patient-related characteristic. We defined patient-related characteristics as any characteristic of the person (e.g., age, attitude toward treatment) or condition (e.g., diagnosis). We excluded articles that 1) were case studies; 2) described decisions for children or about maternity care; 3) included patients who were not mentally capable of giving consent or not able to speak the relevant language; 4) involved decisions about screening, diagnostic testing, clinical trial participation, advance care planning/end-of life care, or general healthcare; or 5) assessed SDM occurrence after an SDM intervention. One researcher performed data charting (see Appendix B for the full data extraction chart), a second researcher checked it. Disagreements were resolved in consensus, or with a third researcher if needed. In agreement with common practice for scoping reviews, we did not conduct a quality assessment.[12]

The results regarding a characteristic were categorized as *mixed* when it had been assessed in different ways (e.g., variable analysed continuously versus categorically) and different results were found. The results were categorized as *unclear* when the direction or significance level was not clear from the article and the corresponding author did not respond to our request for clarification. In case both univariable and multivariable analyses had been conducted, we used the multivariable results for the categorization. A thematic categorization of the patient-related characteristics was made in consensus. The results are presented according to whether SDM was measured from patient, physician, or observer's perspective.

Patient and public involvement

This research was done without direct patient involvement, yet was based on input from patients from interviews held with the aim to inform the search strategy.[6] Patients were not invited to comment on

the study design and were not consulted to interpret the results. Patients were not invited to contribute to the writing or editing of this document.

3. Results

The search resulted in 5,289 articles, of which we included 53 in this review (Table 1). Figure 1 depicts the inclusion process.

[Insert Figure 1. Flowchart of included articles]

3.1 Article characteristics

The included articles were all written in English and published between 1989 and 2019, with the majority between 2010 and 2019 (n=44/53, Table 1). Sample sizes ranged from N=19 to N=5,383. The majority of included articles focused on patients with a somatic condition (n=42), mostly cancer (n=29). Ten focused on patients with a psychiatric condition, and one on a wider population including both somatic and psychiatric conditions. Most studies were conducted in the USA (n=21) followed by The Netherlands (n=7). Studies measured SDM from the perspective of the patient (n=42), an observer (n=8), both the patient and an observer (n=2), or the physician (n=1). The majority of studies (30/53) reported univariable analyses only for the characteristics relevant to this review (Table 1).

[Insert Table 1 about here]

3.2 Sociodemographic characteristics

The most frequently studied sociodemographic characteristics were age (n=45), gender (n=30), education level (n=31), and being in a committed relationship (n=16) (Table 2). For each characteristic, no significant associations with SDM occurrence were found in more than half of the studies (age: 31/45, gender: 21/30, education level: 26/31, being in a committee relationship: 11/16). In the remaining studies, more SDM was associated with lower age (9/45), female gender (4/30), male gender (4/30), and being committed in a relationship (3/16).

Region and insurance status are not included in Table 2. Region was studied in six studies. Two studies (in Sweden and Spain) found more SDM in patients who were from a more urban compared to a more rural area.[25 45] Three studies (Japan, Taiwan, the USA) found no associations between region and SDM occurrence.[42 56 65] In one other study from the USA, the specific study site was associated with SDM occurrence, but the results did not reveal a clear pattern for type of region.[37]

Insurance status was assessed in six studies. Of the five studies conducted in the USA, four found no significant associations (comparisons: insured vs. uninsured;[21] private vs public vs none;[13 38] private + Medicare vs Medicare vs Medicare + Medicaid[43]). One study found that patients with Medicare insurance were less involved in SDM than patients who were insured privately, through state programs, or other (controlling for age).[59] Insurance was also assessed in one study in South Korea, in which patients with private insurance were more involved in SDM than patients without private insurance.[28]

[Insert Table 2 about here}

3.3 General health and clinical characteristics

Ten studies assessed whether having (multiple) comorbidities compared to having no (or fewer) comorbidities was associated with SDM occurrence, and eight found no significant associations (Table 3). One study found a positive association between number of comorbidities and more SDM, in patients with inflammatory bowel disease or arthritis.[42] One study in patients with cancer[27] found a positive association between having more and/or more severe comorbidities and more SDM when SDM was measured from the perspective of the observer, but not when measured from the perspective of patients. Having a better general health was a positively associated with more SDM in three out of five studies among patients with cancer[37 52] or patients who take antidepressants.[59]

Conversely, a study among patients with inflammatory bowel disease or arthritis found a negative association.[42] One study among patients with cancer found no significant association.[56]

Three studies assessed depressive symptoms, of which two found no significant associations.[51 59] In a study on sleep apnea treatment, having lower compared to higher levels of depressive symptoms was associated with more SDM, but when depressive symptoms were analyzed as a continuous variable the association was non-significant.[16]

Sixteen studies assessed the association between diagnosis and SDM occurrence, of which seven focused on cancer (assessing either cancer type or primary cancer site), six on psychiatric conditions, and three on somatic conditions other than cancer. Six of the seven studies that looked at cancer found no significant associations.[22 35 37 38 57 64] One study found that more SDM occurred in patients with head and neck cancer compared to other cancer sites.[55] One study, using multiple SDM measures (from the perspective of the patient or observer), assessed whether there was a difference between patients with pancreatic compared to colorectal cancer. In the analyses of two of these measures, more SDM occurred among patients with pancreatic compared to colorectal cancer; this association was non-significant using any of the other measures.[27] In the same study, it was also reported that SDM occurred less with patients with benign compared to malignant tumors when measured with the SDM-Q-9; no associations were found using other measures of SDM.

Of the six studies that looked at psychiatric diagnoses, five studies found no significant associations.[18 26 29 44 64] One study found that more SDM was reported among patients with depression than patients with schizophrenia.[19]

Of the three studies looking at somatic conditions other than cancer, one found a significant association: SDM occurred less with patients with ulcerative colitis, Crohn's disease, and/or psoriatic arthritis compared to rheumatoid arthritis.[42] The two other studies (patients with gallstones[47] or vascular conditions[53]) found no significant associations.

Eleven studies assessed the association between SDM occurrence and cancer severity (Table 3); six studies found no association. Four studies found that more severe cancer was associated with less SDM. One found that overall, more severe cancer was associated with more SDM, except for patients with the highest stage of severity; for them, the greatest severity of cancer was associated with lower SDM.[56]

[Insert Table 3 about here]

3.4 Psychological characteristics and coping with illness

Having a positive attitude towards treatment was associated with more SDM in one study about sleep apnea treatment[16] and two studies about psychiatric treatment[19 31] (Table 4). All other factors were only studied once (Table 4).

Higher general perceived self-efficacy was found associated with more SDM in two studies (with seemingly partly overlapping samples) in mental health.[18 19] In the same studies, health locus of control was not significantly associated with SDM occurrence.

[Insert Table 4 about here]

3.5 SDM style or preference

Having a preference for involvement in decision making prior to making the decision, was assessed in two studies about cancer (Table 5). One study found a positive association with more SDM for decisions about surgery, but not for decisions about chemotherapy and adjuvant endocrine therapy.[54] The second study (adjuvant therapy after surgery[58]) found no significant association.

[Insert Table 5 about here]

4. Discussion

When a patient faces a decision between multiple treatment options, SDM is recommended.[1 2] Some patients may be less involved than others in decision making. We aimed to identify which patient-related characteristics have been studied in relation to the occurrence of SDM about treatment and summarize the findings.

Overall, the present review demonstrates many non-significant and mixed results regarding the association between patient-related characteristics with the occurrence of SDM. Importantly, the lack of evidence of associations between the characteristics studied and the occurrence of SDM is *not* evidence for no association. The heterogeneous nature of the studies (due to, for example, how the studied characteristics and occurrence of SDM were measured), and the sometimes small number of studies relating to a particular characteristic, provide insight into what has been studied and how often it has been studied. It does not provide conclusive evidence on associations that may exist with the occurrence of SDM. Focused systematic reviews and meta-analyses should provide additional information in this regard. Also, we have no indication of how often studies that showed null results were not published, so we should be mindful that possibly evidence on lack of association between patient-related characteristic and the occurrence of SDM may be under-reported.

We identified over seventy different patient-related characteristics of which the association with the occurrence with SDM had been assessed. SDM was assessed using 29 different measures (including self-developed items; Table 1), and most often from the patients' perspective. This perspective provides a relevant but incomplete view on the extent to which SDM occurred.[79] We categorized the characteristics into sociodemographic, health-related, or psychological characteristics, or decisional preferences. Most studies were conducted in relation to somatic conditions, which often was cancer, a minority in relation to psychiatric conditions. How frequently a particular patient-related characteristic had been studied differs greatly by characteristic – with sociodemographic characteristics having been studied most often and more psychological characteristics (such as coping with health and illness), and preference for involvement, least often. Of note, the latter has repeatedly been assessed but seldom such that preference for involvement was measured before engaging in the decision-making process. Overall, we found few clear determinants of SDM occurrence, even for characteristics that are commonly believed to be associated with less SDM, such as higher age, lower education, or ethnic minority background.

The most frequently studied characteristics were age, gender and education. For all three, more than two-third of the studies found no significant association, the associations that were found

were in either direction, or studies showed mixed results. The same holds true for other sociodemographic characteristics, such as being in a committed relationship and ethnicity, and for clinical characteristics such as diagnosis or comorbidity. Clearly, if characteristics such as e.g., age, ethnicity, or diagnosis were associated with SDM, this would allow for relatively practical ways for clinicians to identify patients who are likely to need additional support in order to become involved in treatment decision making. With clear associations lacking, on the contrary, caution should be taken to assume that SDM with patients of certain ages, gender, or education levels is more or less likely. Particularly for age, there are beliefs that elderly patients are less willing to be involved while many decisions elderly face are of a preference-sensitive nature and call for more SDM.

Fewer studies assessed psychological factors or preferences for involvement, in relation to SDM occurrence. Many of these characteristics can be considered to be states rather than traits and may change over time, in particular over the course of decision making. We excluded studies that had measured state-like characteristics *after* the decision had been made, and/or at the same time as when self-reported levels of SDM were assessed, because the participants' experiences with the decision-making process of interest could have influenced their responses to such questions. Still, these characteristics may be highly relevant in better understanding what makes one individual more likely than another to become involved in treatment decision making, or the same individual more "ready" to engage in SDM at a particular time than at other times. In order to be ready patients need, amongst others, to understand and apply the relevant information, and communicate effectively with their clinicians.[6] This could be more difficult for patients who experience emotional distress or have difficulties accepting their diagnosis. In our review, two articles reported a positive association between higher general self-efficacy and more SDM, though these articles reported on seemingly partly overlapping samples. If further research supports this finding, fostering general self-efficacy may be a factor that could benefit patients. To date, the number of studies is too small to draw conclusions about relevant psychological characteristics with regard to the occurrence of SDM. One exception may be that having a favorable attitude towards treatment seems associated with higher SDM occurrence. This could be due to clinicians generally tending towards treatment, and preference congruence facilitating a shared decision process.

Conclusion

This review offers a comprehensive summary of studies that have assessed associations between one or more patient-related characteristics and the occurrence of SDM. From a practical standpoint, the results call for caution in making assumptions about whether SDM can or will occur with patients with particular characteristics. In fact, most if not all, patient-related characteristics studied do not

point towards a clear association with the occurrence of SDM. In other words, SDM, if truly attempted, may occur with any patient with any of these characteristics. The review points out to the need for further research to clarify which patient-related characteristics may be associated with the occurrence of SDM, and how, to inform effective interventions to foster SDM. Importantly, such characteristics may not be those that are readily determined (e.g., age, education), but rather less obvious psychological features. With reliable identification of support needs and the offer of adapted support, all patients could then have the best possible opportunity to contribute in the planning of their care.

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CONFLICT OF INTEREST

The authors declare none.

AUTHOR STATEMENT

AP, AMS and SK designed the study. AP, SK, JbB, SM and MK performed title and abstract screening. AP, SK, JdB, MK performed full-text screening. AP, SK, JdB, SM, and MK conducted the data extraction. SK wrote the first draft of the manuscript. SK, AP, AM, MK, EP, and WBdB were involved in interpreting the results. All authors have read the manuscript, made improvements of the content and wording, and have agreed to the final version. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

DATA AVAILABILITY STATEMENT

All data relevant to the study are included in the article or uploaded as supplementary information.

FIGURE LEGENDS

Figure 1. Flowchart of included articles.

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First author, year of publication, country, reference	Design, data collection method[a]	Health condition and decision specification	Sample characteristics: N, gender, age (in years)[b]	Perspective from which SDM was measured	SDM measurement	Multiple analyses (Yes/No); if yes, what
Barr, 2016, USA [13]	Cross-sectional Questionnaire	Depression Depression treatment	N=972 Female: 69.0% Age: M=43.2, SD=13.4	Patient	CollaboRATE	Yes Age analyzed as continuous and categorical variable
Barton, 2014, USA [14]	Cross-sectional Interview	Rheumatoid arthritis Rheumatoid arthritis treatment	N=509 - Rheumatoid Arthritis Panel (N=275): Female: 85.8% Age: M=64, SD=11 - University of California, San Francisco (UCSF) Rheumatoid Arthritis (RA) Cohort (N=234): Female: 84% Age: M=55, SD=14	Patient	Decision-making subscale of the Interpersonal Processes of Care survey, consisting of two items: "How often did you and your doctors work out a treatment plan together?" and "If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?" (Never to Always)	Yes Separate analyses for the rheumatoid arthritis panel and the UCSF RA cohort.
Berger, 2017, USA [15] *	Retrospective Questionnaire	Breast cancer Breast cancer treatment	N=873 Female: 100% Age: M=59.1, SD=12.1	Patient	CPS (actual)	No
Brostrom, 2018, Sweden [16] *	Cross-sectional Questionnaire, clinical examination	Obstructive sleep apnea Start of continuous positive airway pressure treatment	N=193 Female: 32.1% Age: M=59.7, SD=11.5	Patient	CollaboRATE	Yes CollaboRate analyzed as continuous and categorical (low, medium, high, very high) outcome

De las Cuevas, 2013, Spain [17] *	Cross-sectional Questionnaire	Psychiatric diagnosis Prescription of a new treatment or maintenance or change in dosage of current drug treatment	N=1111 Female: 67.4% Age: - Psychiatric outpatient (n=571): M=49.5, SD=16.4 - Primary care patients (n=540): M=44.7, SD=16.4	Patient	SDM-Q-9	No
De las Cuevas, 2014, Spain [18]	Cross-sectional Questionnaire, interview	Psychiatric diagnosis Psychiatric treatment	N=507 Female: 62.1% Age: M=48.4, SD=13.6	Patient	CPS (actual)	No
De las Cuevas, 2014, Spain [19]	Cross-sectional Questionnaire	Psychiatric diagnosis Psychiatric treatment	N=846 Female: 64.4% Age: M=49.9, SD=13.6, range=18–87	Patient	SDM-Q-9	No
Ekdahl, 2011, Sweden [20] *	Cross-sectional Interview	Older patients with comorbidities according to ICD-10 Acute admittance/hospitalization	N=156 Female: 50.6% Age: range=76-98	Patient	CPS (actual)	No
Ellis, 2016, USA [21] *	Cross-sectional Interview	Colorectal cancer Surgery, radiation therapy and/or chemotherapy	N=154 Female: 42.2% Age: - <65 years: n=79 - ≥65 years: n=75	Patient	CPS (actual)	No
Ernst, 2011, Germany [22] *	Cross-sectional Questionnaire	Haemato-oncological Chemotherapy, stem cell transplantation, other	N=108 (patients who completed CPS; total sample N=117) Female (n=117): 43.6% Age (n=117): M=57, Md=59; range 21-84	Patient	CPS (actual)	No
Fischer, 2006, The Netherlands [23] *	Prospective Questionnaire	Prostate cancer Prostate cancer treatment	N=126 Female: 0.0%	Patient	One question, to what degree they felt they had had the opportunity to	No

			Age: M=67, range 48-82		decide about their treatment, three response options (e.g., "I had no say in the decision, the doctor made the decision")	
Fowler, 2013, USA [24] *	Cross-sectional Questionnaire	Patients with hypertension or high cholesterol Blood pressure medication and cholesterol medication	N=2718 - Hypertension (n=1027): Female: 50.6% Age: >65: n=435 - High cholesterol (n=822): Female: 49.1% Age: >65 years: n=322	Patient	Four questions to assess the extent to which the healthcare provider informed and involved patients in decisions (e.g., "Did the health care provider(s) explain that you could choose whether or not to have ___?" Yes/No).	No
Frisell, 2016, Sweden [25] *	Retrospective Questionnaire, registry data	Breast cancer Immediate breast reconstruction after mastectomy	N=2217 (subsample of patients who completed questionnaire; total sample N=2929) Female: 100% female Age (n=2217): - No immediate reconstruction (N=2726): Md=66, range 21-97 - Immediate reconstruction (N=270): Md= 49, range 21-80	Patient	One item: "Did you feel involved in the decision-making process whether or not to perform breast reconstruction?" (Yes, Yes but not enough, No)	No
Fukui, 2014, USA [26]	Cross-sectional Audio-recorded consultations,	Psychiatric diagnosis Decisions during psychiatric visits	N=128 Female: 50.8% Age: M=43.4, SD=10.63	Observer	SDM scale	No

	information provided by clinician					
Geessink, 2018, The Netherlands [27]	Cross-sectional Observations, questionnaire	Colorectal or pancreatic cancer Cancer treatment	N= 80 Female: 45.0% Age: M=71.8, SD=5.2	Patient Observer	SDM-Q-9 and VAS-I OPTION-5, OPTION-12 and MAPPIN'SDM	Yes Multiple SDM measures
Gong, 2011, South Korea [28]	Prospective Information obtained during consultations, questionnaire	Carpal tunnel syndrome Surgery	N=78 Female: 91.0% Age: Md=57, range=27-81	Patient	CPS (actual)	No
Goss, 2008, Italy [29] *	Cross-sectional Audio-recorded consultations, questionnaire	Psychiatric diagnosis Treatment of main problem (most often anxiety or depression)	N=80 Female: 61.0% Age: M=43.6, SD=13, range=23–76	Observer	OPTION-12	No
Hamalainen, 2003, Finland [30]	Retrospective Questionnaire	Respiratory care Start of respiratory care therapy	N=3153 Female: 29.0% Age: M=61, range=16-95	Patient	One item: “Were you allowed to participate in decision-making when the home respiratory care was started?” (Not at all, Somewhat, A great deal, Can’t say)	No
Hamann, 2010, Germany [31] *	Cross-sectional Questionnaire	Schizophrenia Antipsychotic medication	N= 300 Female: 41.7% Age: M=39.7, SD=12.3	Physician	Physicians were asked whether the choice of medication was: 1. the doctor's preference; 2. the patient's preference; or 3. the result of a decision shared between doctor and patient.	No
Hamelinck, 2018, The Netherlands [32] *	Prospective Questionnaire	Breast cancer Type of surgery (breast-conserving or mastectomy), and for patients with invasive disease also adjuvant	N=74 Female: 100% Age: - Surgery (n=74): Md=60, range=42-80	Patient	CPS (actual)	Yes Separate analyses for decisions about surgery, adjuvant chemotherapy, and

		chemotherapy and/or adjuvant hormonal therapy	- Adjuvant chemotherapy (n=43): Md=60, range=42-76 - Adjuvant hormonal therapy (n=39): Md=60, range=42-86			adjuvant hormonal therapy
Hawley, 2007, USA [33]	Cross-sectional Questionnaire, Surveillance, Epidemiology, and End Results (SEER) record	Ductal carcinoma in situ (DCIS) or breast cancer Breast cancer surgery	N=1038 Female: 100% Age: M=59, range=29-79	Patient	CPS (actual)	Yes Age analyzed as continuous and categorical variable
Hawley, 2008, USA [34]	Cross-sectional Questionnaire	Breast cancer Breast cancer surgery	N=877 Female: 100% Age: M=59, range=29-79	Patient	CPS (actual)	No
Hou, 2014, China [35] *	Cross-sectional Questionnaire, medical record	Colorectal cancer Surgery	N=113 Female: 42.5% Age: M=62.8, SD=15.3, range=22-91	Patient	CPS (actual)	No
Kadmon, 2016, Israel [36]	Cross-sectional Questionnaire	Breast cancer Breast reconstruction surgery	N=70 Female: 100% Age: M=52.7, SD=10.2, Md=52	Patient	Two questions about level of involvement in decision making: 1. “What was the extent of your involvement in the decision-making process?” (Not involved, Slightly involved, Highly involved) 2. “How were decisions made about your breast reconstruction?” (The physician decided, The physician and I decided together, The physician decided after hearing my opinion, I	No

					decided after hearing the physician's opinion)	
Keating, 2010, USA [37]	Cross-sectional Computer-assisted telephone interview, registry data, medical record	Lung or colorectal cancer Surgery, radiation therapy, and/or chemotherapy	N=5383 Female: 46.6% Age: - 21-55 years: n=618 - 56-70 years: n=1963 - 71-80 years: n=1585 - ≥81 years: n=1217	Patient	CPS (actual)	No
Krok-Schoen, 2016, USA [38]	Cross-sectional Questionnaire	Cancer Cancer treatment	N=606 Female: 63.2% Age: - 18-39 years (n=227): M=30.8, SD=5.06 - 40-59 years (n=183): M=49.6, SD=5.75 - ≥60 years (n=169): M=68.6, SD=6.4	Patient	Six five-point Likert-type scale statements that measure the extent to which patients were involved. Categorized as Independent/isolated, Collaborative, Delegated, or Demanding roles.	No
Kunneman, 2014, The Netherlands [39] *	Cross-sectional Questionnaire	Endometrial cancer Vaginal brachytherapy	N=53 (relevant subsample patients who faced a decision; total sample: N=95) Female: 100% Age (N=95): Md=68; range=46-90	Patient	One question: "Do you feel you had a choice in the decision about whether or not to undergo VBT?" (No, Yes, I don't know)	No
Langseth, 2012, UK [40] *	Cross-sectional Audio recorded consultation, referral letter	Cardiac patients	N=49 Female: 47.0% Age: M=61	Observer	OPTION-12	No
Larsson, 1989, Sweden [41] *	Cross-sectional Questionnaire	Orthopedic patients Surgery	N=666 Female: not reported Age: M= 56.6, range=15-94	Patient	One question to indicate who they believed made the decision (Joint patient-doctor, Doctor, Patient, Others)	No

Lofland, 2017, USA [42] *	Cross-sectional Questionnaire, pharmacy and medical claims	Inflammatory bowel disease, rheumatoid arthritis or psoriatic arthritis Biologic therapy	N= 306 Female: 77.8% Age: - SDM (n=120): M=47.9, SD=11.6 - Non-SDM (n=237): M=48.0, SD=12.4	Patient	SDM-Q-9	No
Mandelblatt, 2006, USA [43]	Cross-sectional Patient interview, medical records	Breast cancer Surgery and/or adjuvant treatment	N=718 Female: 100% Age: M=75	Patient	Four five-point Likert scale items to measure domains of SDM (e.g.: "I asked my surgeon to explain breast cancer treatments and/or procedure(s) to me in greater detail" (Strongly agree to Strongly disagree)	No
Matthias, 2014, USA [44] *	Cross-sectional Audio-recorded consultations, questionnaire	Posttraumatic stress disorder (PTSD) Decisions during psychiatric appointments	N=63 (relevant subsample of patients who had faced a decision; total sample: N=79) Female (N=79): 14.0% Age (N=79): M=53, SD=10, range=23-71	Observer	SDM scale SDM-Min	Yes Separate analyses for the two SDM scales
Moral, 2014, Spain [45]	Cross-sectional Videotaped consultation, patient interview	Various (primary care), either psychological or somatic problem Specific treatment decision not reported	N=368 (relevant subsample; total sample: N=658) Female (N=658): 60.9% Age (n=658): M=52, range 18-88	Observer	CICAA-D	No
Morgan, 2015, UK [46] *	Cross-sectional Questionnaire	Breast cancer Surgery or primary endocrine therapy	N=729 Female: 100%	Patient	CPS (actual)	No

			Age: Md=77, range=70-96			
Mueck, 2018, USA [47] *	Cross-sectional Questionnaire	Gallstone disease Cholecystectomy	N=30 Female: 90.0% Age: M=46, SD=16	Patient	SDM-Q-9	No
Nguyen, 2014, France [illegible]	Cross-sectional Questionnaire	Breast cancer Treatment for early stage breast cancer	N=238 Female: 100% Age: M=56.3, SD=10.3, range=37-84	Patient	One question: "To what extent did you actually participate in deciding on your treatment?" (Not at all to To a great extent)	No
Ommen, 2011, Germany [49] *	Cross-sectional, retrospective Questionnaire	Inpatients of internal medicine or surgery wards Specific decision not reported	N=2197 Female: 26.3% Age: 18-30 years (n=454): 21.2% 31-65 years (n=1177): 55.0% 66-97 years (n=509): 23.8% range=18-97	Patient	Cologne Patient Questionnaire scale 'co-therapy' consisting of four items: e.g., "The doctors wanted me to be actively involved in the treatment process" (Strongly disagree to Strongly agree)	No
Palmer, 2013, USA [50] *	Cross-sectional, secondary analyses Questionnaire	Prostate cancer Surgery, radiation, watchful waiting, other	N=181 Female: 0.0% Age: M=61.3, SD=7.0, range=43-70	Patient	CPS (actual)	No
Phipps, 2008, USA [51] *	Cross-sectional Questionnaire	Cancer Second-line chemotherapy	N=26 Female: 50.0% Age: M=61, range=22-79	Patient	One question assessing participants' perception of involvement in decision making (I made final decision about which treatment I would receive to My doctor made all the decisions regarding my treatment)	No

Sainio, 2003, Finland [52] *	Cross-sectional Questionnaire	Cancer Cancer treatment	N=273 Female: 60.4% Age: M=49.7, SD=10.5, range=18-65	Patient	12 items (To a great extent, To some extent, Not at all)	No
Santema, 2016, The Netherlands [53] *	Cross-sectional Audio-recorded consultations	Vascular condition Vascular surgery	N=54 Female: 42.6% Age: M=69.1, SD= 15.2	Observer	OPTION-12	No
Seror, 2013, France [54]	Prospective Questionnaire, interview	Breast cancer Surgery, chemotherapy, and/or adjuvant endocrine therapy	N=415 Female: 100% Age: M=36.8, SD=3.8	Patient	CPS (actual)	Yes Separate analyses for decisions about surgery, chemotherapy, and adjuvant endocrine therapy
Shabason, 2014, USA [55] *	Cross-sectional Questionnaire	Cancer Radiation therapy	N=305 Female: 47.5% Age: M=59.8, SD=12.0, range=18-87	Patient	Three 5-point scale items to assess physicians' participatory decision style: e.g., "If there were a choice between treatments, would your radiation oncologist ask you to help him/her make the decision?" (Definitely yes to Definitely no)	No
Shen, 2019, Taiwan [56]	Cross-sectional Questionnaire, medical chart review	Breast cancer Breast cancer treatment (type of surgery and/or neo-adjuvant chemotherapy) or treatment of complications after breast cancer treatment (e.g., compression garments	N=511 Female: 100% Age: M=57.9, SD=11.1	Patient	SDM-Q-9	No

		or massage for lymphedema)				
Singh, 2010, Australia [57]	Prospective, observational Audio recording, questionnaire	Cancer Adjuvant treatment (chemotherapy and/or radiation	N=63 Female: 63.5% Age: M=54.9, SD=13.1, range=24-84	Observer	Self-developed coding system consisting of 20 behaviors: e.g., "Reason for consultation established" or "Multiple options presented" (Present or Not applicable, Absent)	No
Singh, 2010, USA & Canada [58] *	Pooled analysis Questionnaire, interview, medical chart review	Cancer Cancer treatment	N=2742 (relevant subsample of patients who reported actual decisional role, total sample N=3489) Female (N=3489): 67.7% Age (n=2144): <50: n=809 (37.7%) 50-64: n=35 (1.6%) >64: n=1300 (60.6%)	Patient	CPS (actual)	No
Solberg, 2014, USA [59]	Cross-sectional Questionnaire	Patients with a fill for antidepressant medication Depression treatment	N=1168 Female: 72.9% Age: M=44.2, - 18-34: n=344 (29.5%) - 35-49: n=391 (33.5%) - 50-64: n=347 (39.7%) - ≥65: n=86 (7.4%)	Patient	Six questions about SDM aspects of care: e.g., "During the past 6 months of depression treatment, were you asked for your ideas and preferences regarding your depression treatment?" (Yes/No)	No
Song, 2013, USA [60]	Prospective Questionnaire, medical record	Prostate cancer Prostate cancer treatment	N=788 Female: 0.0% Age: - <65 years: N=483 (63.3%) - ≥65 years: N=280 (36.7%)	Patient	One question: "Who was mostly responsible for deciding what to do about prostate cancer when you were first diagnosed?'' (Patient only, Shared, Physician only)	No

Suzuki, 2012, USA [61] *	Prospective Questionnaire, medical record	Head and neck cancer Head and neck cancer treatment	N=52 Female: 28.8% Age: M=58.3, SD=12.4	Patient	PICS	No
Vaillancourt, 2014, Canada [62] *	Observational, cross-sectional Audio recorded consultation, patient questionnaire	Diet-related health condition Nutritional treatment	N=19 Female: 57.9% Age: M=40.2, SD=25.2	Observer	OPTION-12	No
Van Stam, 2018, The Netherlands [63]	Prospective observational Questionnaire, medical record	Prostate cancer Prostate cancer treatment (active surveillance, radical prostatectomy, external beam radiotherapy, brachytherapy)	N=454 (relevant subsample of patients who completed the CPS for the actual decisional role, total sample N=474) Female: 0.0% Age: M=66.5, SD=6.1, range=48-87	Patient	CPS (actual)	No
Verwijmeren, 2018, The Netherlands [64]	Cross-sectional, real-time observation of consultation Questionnaire	Bipolar disorder Pharmacotherapy treatment	N=81 Female: 64.2% Age: M=52.0, SD=13.6	Patient Observer	SDM-Q-9 OPTION-12	No
Yamauchi, 2017, Japan [65] *	Cross-sectional Questionnaire	Breast cancer Breast cancer treatment	N=650 Female: 100% Age: - <50: N=202 (31.1%) - ≥50: N=448 (68.9%)	Patient	CPS (actual)	No

*[a] The study design and data collection as is relevant for our research; [b] Rounded to one decimal place where possible; * Study reporting only univariable analyses for the characteristics relevant to this review*

M=mean; SD=Standard deviation

References for the SDM measures in the table: CICAA-D;[45] CollaboRATE;[66] CPS (Control Preferences Scale) actua;l[67-69] MAPPIN'SDM;[70] OPTION-5;[71] OPTION-12,[72] PICS;[73] SDM-scale;[74 7] SDM-Q-9.[76 77]

Table 2. Associations between sociodemographic characteristics and occurrence of SDM, by measurement perspective

		Patient-reported					Observer-reported				Physician-reported			
Characteristic	**n**	**Positive**	**Negative**	**Mixed**	**Unclear**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**
Age, gender, ethnicity/nationality														
Older age	45[a]	2[46 49]	8[16 18 19 23 43 58 59 63]	4[14 33 54 78]	-	22[15 20 21 27 28 30 32 35-38 42 47 48 50 52 55 56 60 61 64 65]	1[27]	1[57]	-	8[26 29 40 44 45 53 62 64]	-	-	-	1[31]
Female	30[a]	4[13 18 35 42]	4[30 49 51 58]	1[27]	-	13[14 16 19-21 28 37 38 47 52 55 59 64]	-	-	1[27]	8[26 29 44 45 53 57 62 64]	-	-	-	1[31]
Ethnicity (white)	16	-	-	1[14]	1[37]	12[21 33 34 38 42 43 47 50 55 59 60 63]	-	-	-	2[26 44]	-	-	-	-
Minority status	1	-	-	-	-	1[15]	-	-	-	-	-	-	-	-
Country of birth	1	-	-	-	-	1[41]	-	-	-	-	-	-	-	-
Nationality (American compared to Canadian)	1	1[58]	-	-	-	-	-	-	-	-	-	-	-	-
Education and work														
Higher educated	31[a]	2[59 63]	1[30]	1[14]	1[50]	22[13 15 16 18 20 21 23 27 28 33 35 37-39 43 48 51 52 54-56 60]	-	-	1[27]	3[45 57 62]	-	-	-	1[31]
Higher health literacy	2	1[14]	-	1[56]	-	-	-	-	-	-	-	-	-	-
English language proficiency	1	1[14]	-	-	-	-	-	-	-	-	-	-	-	-
English as first language	2	-	-	-	-	1[47]	-	-	-	1[57]	-	-	-	-
Employed	8	1[59]	-	-	-	6[30 48 52 55 56 65]	-	-	-	1[62]	-	-	-	-
Higher income	7	2[30 38]	-	1[59]	-	4[15 37 48 51]	-	-	-	-	-	-	-	-
SES	1	-	-	-		1[49]	-	-	-	-	-	-	-	-

Involved in extra professional activities	1	-	-	-	-	1[48]	-	-	-	-	-	-	-	-
Involved in leisure activities	1	1[48]	-	-	-	-	-	-	-	-	-	-	-	-
Social situation														
Relationship status: married or in committed relationship	16	3[37 48 52]	-	-	1[50]	11[15 23 38 39 43 54-56 59 60 63]	-	-	-	1[45]	-	-	-	-
Having children	3	-	-	-		3[39 52 54]	-	-	-	-	-	-	-	-
Living alone	2	-	1[52]	-		1[21]	-	-	-	-	-	-	-	-
Having a caregiver	1	1[28]	-	-		-	-	-	-	-	-	-	-	-

[a] *One or more of these studies used both a patient- and observer-based PROM measurement; Not included in table: Insurance status and region.*

583 **Table 3. Associations between general health and clinical characteristics of condition or decision of interest and occurrence of SDM, by measurement**

584 **perspective**

		Patient-reported					Observer-reported				Physician-reported			
Characteristic	**n**	**Positive**	**Negative**	**Mixed**	**Unclear**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**
General health														
Comorbidities	10 [a]	1[42]	-	-	-	9[15 21 27 28 37 39 43 54 63]	1[27]	-	-	-	-	-	-	-
Better general health status	5	3[37 52 59]	1[42]	-	-	1[56]	-	-	-	-	-	-	-	-
Better physical functioning	1	-	-	-	-	1[43]	-	-	-	-	-	-	-	-
Quality of life	2 [a]	-	-	1[27]	-	1[61]	-	-	-	1[27]	-	-	-	-
Health related quality of life	1	-	-	-	-	1[63]	-	-	-		-	-	-	-
Frailty	1 [a]	-	1[27]	-	-	-	-	-	-	1[27]	-	-	-	-
BMI/weight	3	-	-	-	-	3[15 21 55]	-	-	-	-	-	-	-	-
Smoking	2	-	-	-	-	2[15 30]	-	-	-	-	-	-	-	-
Depressive symptoms	3	-	-	1[16]	-	2[51 59]	-	-	-	-	-	-	-	-
History of depression	1	-	-	-	-	1[63]	-	-	-	-	-	-	-	-
Anxiety	1	-	-	-	-	1[16]	-	-	-	-	-	-	-	-
Clinical characteristics of condition or decision of interest														
Cancer severity	11	-	4[23 58 60 65]	1[56]	-	6[15 33 43 54 55 63]	-	-	-	-	-	-	-	-
Symptom severity	4[a]	-	-	1[16]	1[64]	1[59]	-	-	-	1[64]	-	1[31]	-	-
Longer illness duration	2	-	-	-	-	1[14]	-	-	-	-				1[31]

Longer time since diagnosis	1	1[56]	-	-	-	-	-	-	-	-	-	-	-
Higher number of drugs	2 [a]	-	-	-	2[19 27]				1[27]	-	-	-	-
Prior treatment	2	1[59]	-	-	1[28]	-	-	-	-	-	-	-	-
Longer duration of total treatment by same mental health specialist	2 [a]	-	-	-	1[64]				2[44 64]	-	-	-	-
Positive family history of the disease	1	-	-	1[54]	-	-	-	-	-	-	-	-	-
Regular cancer screening prior to cancer diagnosis	1	-	-	-	1[54]	-	-	-	-	-	-	-	-
Risk of developing heart disease	1	-	-	-	1[24]	-	-	-	-	-	-	-	-

[a] *One or more of these studies used both a patient- and observer-based SDM measurement; Not in table: Diagnosis.*

Table 4. Associations between psychological and coping with illness-related characteristics and occurrence of SDM, by measurement perspective

		Patient-reported				Observer-reported				Physician-reported			
Characteristic	**n**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**
Decision-related													
Knowledge about the condition	1	-	-	-	1[28]	-	-	-	-	-	-	-	-
Accompanied to visit	1	1[43]	-	-	-	-	-	-	-	-	-	-	-
Pre-consultation anxiety	1	-	-	-	-	-	-	-	1[57]	-	-	-	-
Fear of financial burden	1	-	-	-	1[28]	-	-	-	-	-	-	-	-
Positive attitude towards treatment	3	2[16 19]	-	-	-	-	-	-	-	1[31]	-	-	-
Medication adherence	1	-	-	-	-	-	-	1[44]	-	-	-	-	-
Positive patient assessment of disease	1	-	-	1[14]	-	-	-	-	-	-	-	-	-
Illness insight	1	-	-	-	-	-	-	-	-	1[31]	-	-	-
Illness uncertainty	1	-	-	-	1[61]	-	-	-	-	-	-	-	-
Illness self-management	1	-	-	-	-	-	-	-	1[44]	-	-	-	-
Patient activation	1	-	-	-	-	-	-	-	1[44]	-	-	-	-
General													
General perceived self-efficacy	2	2[18 19]	-	-		-	-	-	-	-	-	-	-
Internal health locus of control	2	-	-	-	2[18 19]	-	-	-	-	-	-	-	-
Active coping	1	-	-	-	1[63]	-	-	-	-	-	-	-	-
Ability to cope with daily life	1	1[30]	-	-	-	-	-	-	-	-	-	-	-

Reactance proneness	1	-	-	-	1[19]	-	-	-	-	-	-	-	-	
Tendency to excuse	1	-	-	-	1[49]	-	-	-	-	-	-	-	-	
Religiosity[a]	1	-	1[51]	-	-	-	-	-	-	-	-	-	-	

[a]*Definition: The extent to which someone believes that their religion is part of all aspects of their life.*

Table 5. Associations between SDM style or preference and occurrence of SDM, by measurement perspective

		Patient-reported				Observer-reported				Physician-reported			
Characteristic	n	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.
Involved in previous decision about cancer treatment	1	1[54]	-	-	-	-	-	-	-	-	-	-	-
Preference for involvement	2	-	-	1[54]	-	-	-	-	1[57]	-	-	-	-
Desire for autonomy	1	-	-	-	1[47]	-	-	-	-	-	-	-	-
Avoiding or deferring decision-making style	1	-	1[36]	-	-	-	-	-	-	-	-	-	-

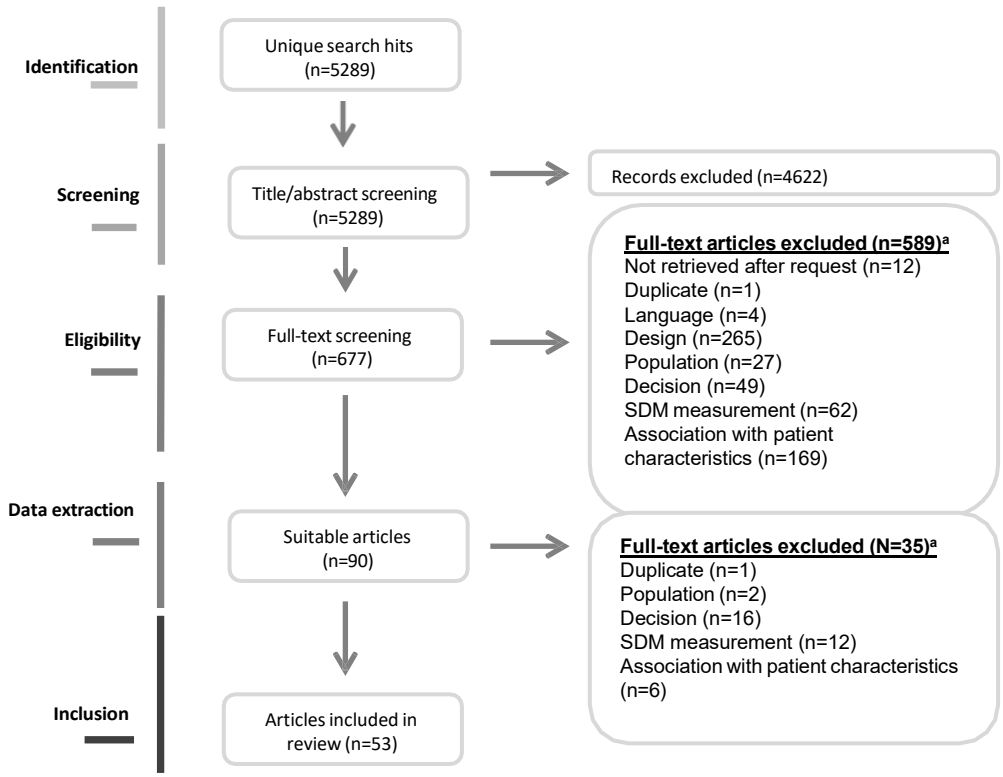

Figure 1.

a Reasons for exclusion are in hierarchical order; SDM, shared decision making

APPENDIX A: Search stragey in PubMed

(("understanding"[tiab] OR understand*[tiab] OR "Comprehension"[Mesh] OR "Comprehension"[tiab] OR "Time"[tiab] OR "Time Factors"[Mesh] OR "Time"[mesh:noexp] OR "Emotional distress"[tiab] OR "Emotional stress"[tiab] OR "Stress, Psychological"[Mesh:NoExp] OR "Psychological Stress"[tiab] OR "Psychological Distress"[tiab] OR "Depression"[Mesh] OR "Depression"[tiab] OR "Anxiety"[mesh:noexp] OR "anxiety"[tiab] OR "Fear"[mesh:noexp] OR "fear"[tiab] OR "Assertiveness"[Mesh] OR "Assertiveness"[tiab] OR unequal*[tiab] OR "Power (Psychology)"[Mesh] OR "Trust"[Mesh] OR "Trust"[tiab] OR "Trusting"[tiab] OR "Trusted"[tiab] OR trust*[tiab] OR "Confidence"[tiab] OR "confident"[tiab] OR confiden*[tiab] OR ("cognitive"[tiab] AND "overload"[tiab]) OR "cognitive load"[tiab] OR "Friends"[Mesh] OR "companion"[tiab] OR "companions"[tiab] OR "Caregivers"[Mesh] OR "Caregivers"[tiab] OR "Caregiver"[tiab] OR "Carers"[tiab] OR "Carer"[tiab] OR "information processing"[tiab] OR "Mental Processes"[mesh:noexp] OR (accept*[tiab] AND diagnos*[tiab]) OR ("Patient Participation"[majr] AND ("decision making"[tiab] OR "decisionmaking"[tiab] OR "shared decision"[tiab] OR "shared decisions"[tiab] OR "treatment decision making"[tiab] OR "therapy decision making"[tiab] OR "surgery decision making"[tiab] OR "Decision Making"[majr])) OR "Personal Autonomy"[Mesh] OR "Autonomy"[tiab] OR "feeling safe"[tiab] OR "feeling unsafe"[tiab] OR "atmosphere"[tiab] OR "patient query"[tiab] OR "patient question"[tiab] OR "patients query"[tiab] OR "patients question"[tiab] OR "patient's query"[tiab] OR "patient's question"[tiab] OR "patients' query"[tiab] OR "patients' question"[tiab] OR "patient queries"[tiab] OR "patient questions"[tiab] OR "patients queries"[tiab] OR "patients questions"[tiab] OR "patient's queries"[tiab] OR "patient's questions"[tiab] OR "patients' queries"[tiab] OR "patients' questions"[tiab] OR "Mental Disorders"[Mesh] OR "Mental Disorders"[tiab] OR "Mental Disorder"[tiab] OR "Mental Disease"[tiab] OR "Mental Diseases"[tiab] OR "convictions"[ti] OR "conviction"[ti] OR "Patient Satisfaction"[mesh] OR "Patient Satisfaction"[tw] OR "Patients Satisfaction"[tw] OR "Patient's Satisfaction"[tw] OR "attitude"[ti] OR "attitudes"[ti] OR attitude*[ti] OR "opinion"[ti] OR "opinions"[ti] OR "opine"[ti] OR "patient competency"[tw] OR "Cultural Competency"[mesh] OR "Attitude"[majr] OR patients conviction*[tw] OR patient attitude*[tw] OR patients attitude*[tw] OR patient's attitude*[tw] OR patient opinion*[tw] OR patients opinion*[tw] OR patient's opinion*[tw] OR patient competenc*[tw] OR patients competenc*[tw] OR patient's competenc*[tw] OR "Information Literacy"[mesh] OR "Health Literacy"[mesh] OR "literacy"[ti] OR "illiteracy"[ti] OR "literate"[ti] OR "illiterate"[ti] OR "numeracy"[ti] OR "patient health literacy"[tw] OR "patient literacy"[tw] OR "patient's health literacy"[tw] OR "deliberation"[ti] OR "deliberations"[ti] OR "considered"[ti] OR "considers"[ti] OR "consider"[ti] OR "consideration"[ti] OR "considerations"[ti] OR "weigh"[ti] OR "weighs"[ti] OR "weighing"[ti] OR "Social Values"[mesh] OR "value"[ti] OR "values"[ti] OR "goal"[ti] OR "goals"[ti] OR "Goals"[mesh] OR "Motivation"[mesh] OR "motivation"[ti] OR "deliberate"[ti] OR "deliberated"[ti] OR patient goal*[tw] OR patients goal*[tw] OR patient's goal*[tw] OR patient value*[tw] OR patients value*[tw] OR patient's value*[tw] OR patient motivat*[tw] OR patients motivat*[tw] OR patient's motivat*[tw] OR patient considerat*[tw] OR patients considerat*[tw] OR patient's considerat*[tw] OR "Communication"[mesh:noexp] OR "communication"[ti] OR "communications"[ti] OR "communicate"[ti] OR "communicated"[ti] OR "communicates"[ti] OR "communicating"[ti] OR "interaction"[ti] OR "interactions"[ti] OR "interacting"[ti] OR "interacted"[ti] OR "interact"[ti] OR "interacts"[ti] OR "encounter"[ti] OR

"encounters"[ti] OR "encountered"[ti] OR "encountering"[ti] OR "discuss"[ti] OR "discussed"[ti] OR "discussing"[ti] OR "discussion"[ti] OR "discussions"[ti] OR "discusses"[ti] OR "express"[ti] OR "expresses"[ti] OR "expressed"[ti] OR "expressing"[ti] OR "formulate"[ti] OR "formulating"[ti] OR "formulates"[ti] OR "formulated"[ti] OR "verbalize"[ti] OR "verbalise"[ti] OR "verbalizes"[ti] OR "verbalises"[ti] OR "verbalizing"[ti] OR "verbalising"[ti] OR "verbalized"[ti] OR "verbalised"[ti] OR "verbalize"[ti] OR "verbalise"[ti] OR "encounters"[ti] OR "verbalized"[ti] OR "verbalised"[ti] OR "utter"[ti] OR "utters"[ti] OR "uttered"[ti] OR "uttering"[ti]) AND ("shared decision making"[ti] OR "shared decisionmaking"[ti] OR "shared decision"[ti] OR "shared decisions"[ti] OR "treatment decision making"[ti] OR "therapy decision making"[ti] OR "surgery decision making"[ti] OR (("Patient Participation"[mesh] OR "shared"[ti] OR "share"[ti] OR "sharing"[ti]) AND ("Decision Making"[majr] OR "decision"[ti] OR "decisions"[ti])))

NOT

(("comment"[Publication Type] OR "editorial"[Publication Type] OR "letter"[Publication Type] OR "case reports"[Publication Type]) NOT ("Clinical Study"[Publication Type]))

AND

(dutch[la] OR english[la]))

Title	First author	Year	Design[a]	Data collection method	Country	Study population: general	Study population Patients: diagnosis	Study population Professionals: specialty	Sampling procedure	SDM measurement	Perspective(s) of SDM measurement	When was SDM (self-report) measurement completed?	Patient-related characteristic of which the association was assessed with occurrence of SDM	Validated measurement instrument used to assess patient-related characteristic	Data Analysis	Decision specification	Patients (n)	Professionals (n)	Gender patients (female: n (%))	Gender providers (female: n (%))	Age patients (M/Md (SD); range)	Age providers	Results
Competing priorities in treatment decision-making: a US national survey of individuals with depression and clinicians who treat depression	Barr	2016	Cross-sectional	Questionnaire	USA	Consumers ≥18 years; ever diagnosed with, counselled about, or treated for depression; USA residents; proficient in English Clinicians who had counselled, diagnosed, or treated persons with depression in past 12 months; practise in USA; proficient in English Clinicians could inlude primary care	Depression	N/A	Convenience sampling through healthcare organisations and consumer advocacy groups and paid advertising to target male consumers due to low survey uptake	CollaboRATE Dichotomized into: 1=highest possible score (ie, Top score) vs 0 (all other scores)	Patient	Not reported	* Age (18-29, 30-39, 40-49, 50-59, 60+) · Gender · Education (≤high school, some college to Bachelor's degree, graduate/professional degree) · Treatment status (completed, ongoing, awaiting) · Treatments used (antidepressant medication only, medication and other treatment, non-medication treatment) · Health insurance status (private, public, no insurance) · Clinician most frequently seen (primary care physician, psychiatrist, therapist, other/not sure)	N/A	**Multiple logistic regression analysis**	Depression treatment (antidepressant, no medication, other treatment)	972	N/A	664 (69) Other: 8 (1)	N/A	M=43.17 (13.41)	N/A	Significant positive association with: female gender (OR 2.14, *P*=0.003), older age (40-49 years old or 60+ years vs those <30 years, *P*<.05)
English language proficiency, health literacy, and trust in physician are associated with shared decision-making in rheumatoid arthritis	Barton	2014	Cross-sectional	Interview	USA	Participants in one of two longitudinal, observational Rheumatoid Arthritis (RA) cohorts: the **RA Panel Study** or the **University of California, San Francisco (UCSF) RA Cohort**	Rheumatoid arthritis	N/A	**The RA Panel Study** was initiated in 1982 by enrolling all RA patients being treated over a 1-month period by random sample of Northern California rheumatologists **The UCSF RA Cohort** is a multi-site observational cohort consecutively enrolling from 2 outpatient clinics	2-item decision-making subscale of Interpersonal Processes of Care (IPC) survey: "How often did you and your doctors work out a treatment plan together?", "If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?" (never to always') Mean scores dichotomized into: optimal (mean scores 4-5) vs suboptimal (mean scores <4) communication	Patient	Up tot 12 months after consultation	**RA panel and UCSF RA cohort:** · Age · Gender · Education · Race/ethnicity · Disease duration · Patient global disease assessment **RA panel:** · Health literacy **UCSF RA cohort:** · English language proficiency	N/A	**Multivariable regression model** Cohorts analyzed separately	Treatment of rheumatoid arthritis (day vs in-patient; general vs local)	Total: 509 · **RA Panel:** 275 · **UCSF RA COHORT:** 234	N/A	**RA Panel:** 236 (86) **UCSF RA COHORT:** 198 (84)	N/A	**RA Panel:** M=64 (11) **UCSF RA COHORT:** M=55 (14)	N/A	**RA-Panel:** Significant negative association with: limited health literacy (adjusted OR 2.80, 95% CI 1.25–6.28, *P*<.05) **UCSF-Cohort:** Significant negative associations with: higher age (adjusted OR 1.28 per 10 years, 95% CI 1.01–1.62), limited English-proficiency (adjusted OR 5.11, 95% CI 1.56–16.7), *P* <.05)
Preferences and actual chemotherapy decision-making in the greater plains collaborative breast cancer study	Berger	2017	Retrospective	Questionnaire	USA	Women ≥18 years; confirmed primary diagnosis of breast cancer (in situ or invasive)	Breast cancer	N/A	Eight sites of a clinical data research network each identified a random sample of 250 eligible women who were mailed the survey in a 40-day period	CPS (actual role) Recoded into: 1 (CPS-score 1 or 5), 2 (CPS-score 2 or 4), 3 (CPS-score 3)	Patient	1 to 1.5 years after diagnosis	· Age · Education · Marital status · Minority status · Income · Weight · Smoking status · Arthritis · Hypertension · Cancer stage	N/A	**Non-parametric correlation**	Breast cancer treatment (Anaesthetic; date of surgery)	873	N/A	873 (100)	N/A	M=59.1 (12.1)	N/A	No significant association
Validation of CollaboRATE and SURE – two short questionnaires to measure shared decision making during CPAP initiation	Brostrom	2018	Prospective	Questionnaire, Data collected during face-to-face clinical examination	Sweden	Patients diagnosed with obstructive sleep apnea; no terminal disease, severe psychiatric disease, dementia, or alcohol/drug abuse; proficient in Swedish	Obstructive sleep apnea	N/A	Consecutive patients from two continuous positive airway pressure clinics at one university and one county hospital	CollaboRATE Recoded into: low, medium, high, very high SDM	Patient	At start study, after having undergone a clinical examination and an overnight respiratory polygraphy	· Age · Gender · Education · Depression · Anxiety · Insomnia · Daytime sleepiness · Sleep apnea · Attitudes to continuous positive airway pressure treatment	· Hospital Anxiety and Depression Scale · Attitudes to Continuous positive airway pressure Treatment Inventory · Minimal Insomnia Symptoms Scale · Epworth sleepiness scale · Apnea–hypopnea index	· **Correlation** (unspecified) · **Latent class analysis** to define groups with similar SDM-levels (low, medium, high, very high SDM) · **Chi-square analysis** (gender) or **ANOVA** (continuous variables) to assess differences across emergent classes	Start of continuous positive airway pressure treatment	193	N/A	62 (32.1)	N/A	M=59.7 (11.5)	N/A	**Univariable analysis, continuous outcome variable:** Significant association with attitudes to continuous positive airway pressure (-0.18, *P*<.05) **Univariable analysis, categorical outcome variable:** Significant positive association with: younger age (F=3.57; *P*=.015), lower depression levels (F=4.03; *P*=.002), positive attitudes to continuous positive airway pressure (F=5.41, *P*<.001), less daytime sleepiness (F=3.96, *P*=.009), less sleep apnea (F=4.99, *P*=.001)
To what extent psychiatric patients feel involved in decision making about their mental health care? Relationships with socio-demographic, clinical, and psychological variables	De las Cuevas	2014	Cross-sectional	Questionnaire	Spain	Psychiatric outpatients ≥18 years; diagnosis of schizophrenia, bipolar affective disorder, depression, or obsessive-compulsive disorder or other related disorder, according to the ICD-10 codes	Psychiatric diagnosis	N/A	Consecutive patients	SDM-Q-9 Recoded into: low (score≤25) vs high (score≥75); participant with scores between 25-75 diregarded	Patient	After consultation	· Age · Gender · Education · Diagnosis · Treatment duration at time of consultation · Number of drugs · Reactance proneness · Health Locus of Control · Self-efficacy · Drug Attitude	· Hong Psychological Reactance Scale · Multidimensional Health Locus of Control Form C scale · General Perceived Self-Efficacy Scale · Drug Attitude Inventory	**ANOVA with post-hoc Bonferroni test** (psychiatric diagnosis) **Logistic regression analysis** (other patient characteristics)	Psychiatric (drug) treatment	846	N/A	546 (64.4)	N/A	M=49.9 (13.6) range, 18–87	N/A	**ANOVA:** Significant difference between the four diagnostic groups (F=5.66, *P*=0.001; higher mean total SDM-Q-9 score in patients with depression vs schizophrenia, *P*≤0.001); the difference between patients with bipolar disorder vs schizophrenia was not significant (*P*≤0.07) **Logistic regression analysis:** Significant positive association with: lower age, being diagnosed with schizophrenia disorder, positive attitude towards drugs, higher perceived self-efficacy
Shared decision making in psychiatric practice and the primary care setting is unique, as measured using a 9-item Shared Decision Making Questionnaire (SDM-Q-9)	De las Cuevas	2013	Cross-sectional	Questionnaire	Spain	Psychiatric outpatients or Primary care patients not being treated by mental health facilities; scheduled or non-scheduled new or follow-up appointment	Psychiatric diagnosis	N/A	Consecutive patients	SDM-Q-9	Patient	Immediately after consultation	* Patient status (primary care vs psychiatric outpatient care)	N/A	**Student's t-test**	Drug treatment (new, continuing; modify dosage)	1111 · Psychiatric outpatients: 571 · Primary care patients: 540	N/A	749 (67.4) · Psychiatric outpatients: 371 (64.9) · Primary care patients: 378 (70)	N/A	· Psychiatric outpatients: M=49.5 (16.4) · Primary care patients: M=44.7 (16.4)	N/A	No significant association
Psychiatric patients' preferences and experiences in clinical decision-making: examining concordance and correlates of patients' preferences	De las Cuevas	2014	Cross-sectional	Questionnaire	Spain	Psychiatric outpatients ≥18 years; diagnosed with psychiatric condition according to ICD-10	Psychiatric diagnosis	N/A	Consecutive patients	CPS (actual role) (card-sorting version)	Patient	In waiting room before psychiatric consultation	* Age * Gender · Education * Diagnosis · Health locus of control * General self-efficacy	* Multidimensional Health Locus of Control Form C scale · General perceived self-efficacy scale	**Multiple regression analysis**	Psychiatric treatment	507	N/A	314 (62.1)	N/A	M=48.4 (13.6)	N/A	Significant positive association with: younger age (b=.007*), female gender (b=0.161*), higher self-efficacy (b=15.672*)
Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey	Ekdahl	2011	Cross-sectional	Interview	Sweden	Patients ≥75 years; ≥3 diagnoses according to the ICD-10; ≥3 hospitalisations in past year	Comorbidities according to ICD-10	N/A	Consecutive patients admitted to 1 of 3 hospitals with acute admissions (a small district hospital, a hospital in a medium-sized industrial city, a university hospital)	CPS (actual role) (modified)	Patient	Up to 12 months after hospitalization	* Age (≤79, 80-85, >85 years) · Gender · Education · Preferred decisional role	* CPS (preferences)	**Pearson's chi-square test** (age, gender, education) **Agreement by weighted kappa** (preferred decisional role)	Acute admittance /hospitalisation	156	N/A	79 (50.6)	N/A	range, 76-98	N/A	Moderate agreement (kappa statistic) between preferred and actual role (K=0.57; 95% CI: 0.45-0.69)
Patient-reported roles, preferences, and expectations regarding treatment of stage I rectal cancer in the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)	Ells	2016	Cohort study	Interview	USA	Patients diagnosed with stage I adenocarcinoma of rectum; ≥21 years; who have undergone local or total mesorectal excision	Colorectal cancer	N/A	Purposive sampling to obtain demographically representative cohort	CPS (actual role) (modified) Recoded into: patient-controlled, patient-physician shared, physician-controlled decision making	Patient	Not reported Mean time since ~~diagnosis~~ 8 months (range, 5-16 months)	· Age (<65 years, ≥65 years) · Gender · Race (white, non-white) · Education (≤12, >12 grades) · Lives alone (yes, no) · Insurance (yes, no) · Comorbidities (none/mild, moderate/severe) · BMI (<30, ≥30) · Study site (HMO, cancer registry, Veteran Affairs' health facility)	N/A	· **Student's t-test** · **Chi-square test** · **Fisher's Exact test**	Surgery, Radiation therapy and/or Chemotherapy	154	N/A	65 (42.2)	N/A	* <65 years: n=79 * ≥65 years: n=75	N/A	No significant association
Participation of haemato-oncological patients in medical decision making and their confidence in decisions	Ernst	2011	Cross-sectional	Questionnaire	Germany	In- and outpatients ≥18 years; new or recurrent haemato-oncological diagnosis; treated with curative intent; sufficient cognitive and physical functioning; proficient in German	Haemato-oncological cancer	N/A	Consecutive patients from hospital or haematological clinic	CPS (actual role) Recoded into: autonomous, passive, collaborative	Patient	3 months after start treatment	· Diagnosis (non-Hodgkin-lymphoma, leukaemia, plasmozytoma, other) · Treatment setting (in-, outpatient)	N/A	**Chi-square test**	Chemotherapy, Stem cell transplantation, Other	Total: 117 Results of CPS analyses: 108	N/A	51 (43.6)	N/A	M=57 Md=59 range, 21-84	N/A	No significant association
Treatment decision making in prostate cancer: Patients participation in complex decisions	Fischer	2006	Prospective	Questionnaire	The Netherlands	Patients diagnosed with prostate cancer; no other current or past type of cancer or serious illness; proficient in Dutch	Prostate cancer	N/A	Recruitment in co-operation with Dutch cancer patients' organization in 5 hospitals and during 4 educational patient meetings on prostate cancer	Perceived opportunity to decide about treatment: "I had no say in the decision, the doctor made the decision" (passive), "I have decided together with my doctor about my treatment" (collaborative), "The doctor left the decision up to me" (autonomous)	Patient	Up to 3 years after diagnosis	* Age (≤65 years, >65 years) * Education (lower, medium, higher) · Marital status * Cancer stage	N/A	**Chi-square test**	Prostate cancer treatment	126	N/A	0 (0)	N/A	M=67 range, 48-82	N/A	Significant positive association with: less advanced disease (χ^2=6.2, *P*<0.05), younger age (χ^2 = 10.9, *P*<0.01)
How patient centered are medical decisions? Results of a national survey	Fowler	2013	Cross-sectional	Questionnaire	USA	Probability sample from the Knowledge Panel; ≥40 years; made ≥1 of 10 target decisions in past 2 years (decision about: medication for hypertension, elevated cholesterol, or depression; screening for breast, prostate, or colon cancer; knee or hip replacement for osteoarthritis, or surgery for cataract or low back pain) In this review only analyses regarding **blood pressure and cholesterol** were relevant.	Decision about blood pressure or cholesterol medication	N/A	Sample recruited through random-digit dialing and address-based sampling	4 questions based on DECISIONS survey to characterize extent to which healthcare provider involved patients: "How much did you and the health care provider(s) discuss the reasons you might want ___?" (a lot, some, a little, not at all), "How much did you and the health care provider(s) discuss the reasons you might not want ___?" (*idem*), "Did the health care provider(s) explain that you could choose whether or not to have ___?" (yes/no), "Did the health care provider(s) ask you whether or not you wanted to have ___?" (yes/no) The 4 response options were recoded into: none/a little, some/a lot. A decision process score was calculated as the sum of 1 point for each positive response (some/a lot, yes), range score, 0-4.	Patient	Up tot 2 years after treatment decision	* Heart disease risk elevated (yes, no)	N/A	**Independent samples t test**	Blood pressure medication, Cholesterol medication	2718 · Blood pressure: 1027 · Cholesterol: 822 *Possible overlap between blood pressure and cholesterol samples*	N/A	· Blood pressure 520 (50.6) · Cholesterol 404 (49.1)	N/A	· Blood pressure: >65 years: n=435 (42.4%) · Cholesterol: >65 years n=322 (39.2%)	N/A	No significant association
National study of the impact of patient information and involvement in decision-making on immediate breast reconstruction rates	Frisell	2016	Retrospective	Questionnaire, Registry data	Sweden	Women diagnosed with primary breast cancer who underwent mastectomy	Breast cancer	N/A	*Questionnaire:* All women from the registry who were still alive *Registry:* All women who fulfilled inclusion criteria	1 item: "Did you feel involved in the decision-making process whether or not to perform breast reconstruction?" (yes, yes partly, no) Dichotomized into: yes/yes partly, no	Patient	Approximately 2 years after data were included in registry	* Healthcare region	N/A	**Chi-square test**	Immediate breast reconstruction after mastectomy	· Registry: 2929 · Questionnaire: 2217 (of 2906 alive of those 2929)	N/A	2929 (100) 2217 (100)	N/A	· No immediate reconstruction (n=2726): Md=66 range, 21-97 · Immediate reconstruction (n=270): Md=49 range, 21-80	N/A	Significant association with healthcare region (higher in Stockholm region)
Predictors of shared decision making and level of agreement between consumers and providers in psychiatric care	Fukui	2014	Cross-sectional	Audiorecorded consultation	USA	Psychiatric care consumers from one of three samples: observational study (samples 1 and 2), pre-intervention assessment of a randomized control trial of an SDM-intervention (sample 3)	Psychiatric diagnosis	N/A	Patients from 3 community mental health centers	SDM Scale	Observer	N/A	· Age · Gender · Race (white, other) · Diagnosis (schizophrenia, other) · Decision complexity (basic, intermediate/complex)	*Presumably:* Braddock's Informed Decision Making Scale	**Multilevel linear regression analysis**	Treatment, *unspecified*	128	8 · Psychiatrists: 5 · Nurse practitioners: 3	65 (50.8)	4 (50)	M=43.4 (10.63)	*Not reported*	Significant positive association with: higher decision complexity (*P*<.001)
Shared decision-making in older patients with colorectal or pancreatic cancer: Determinants of patients' and observers' perceptions	Geessink	2018	Cross-sectional	Direct observation, Questionnaire	The Netherlands	Patients ≥65 years; newly-diagnosed with colorectal or pancreatic cancer; initially considered for surgery based on referral information	Colorectal or pancreatic cancer	N/A	Consecutive patients from surgical outpatient clinic	**Patient perceptions:** SDM-Q-9, visual analog scale **Observer perspectives:** OPTION-5, OPTION-12, MAPPIN'SDM	Patient Observer	**Patient perceptions:** After consultation	· Age · Gender · Education · Cancer diagnosis · Functional status · Comorbidities · Frailty · Quality of life · Total number of medications	· KATZ index of independence in activities and instrumental activities in daily living, 15 items · Older Persons and Informal Caregivers Survey Minimum Dataset Frailty Index, 45 items · Modified Cantril's Self Anchoring ladder · EuroQol-5D · Cumulative Illness Rating Scale	**Multivariable linear regression analysis** per outcome	Colorectal or pancreatic cancer treatment	80 · Colorectal cancer: 58 · Pancreatic cancer: 22	N/A	36 (45)	N/A	M=71.8 (5.2)	N/A	Significant positive association of patient-reported involvement with: female gender, better quality of life (EuroQol-5D), a pancreatic cancer diagnosis Significant positive association of observed patient involvement with: lower education (MAPPIN' doctor), male physician gender (OPTION-5)
Patients' preferred and retrospectively perceived levels of involvement during decision-making regarding carpal tunnel release	Gong	2011	Retrospective	Questionnaire	South Korea	Patients referred for carpal tunnel syndrome surgery; no Workers' Compensation issue; no condition requiring additional surgery	Carpal tunnel syndrome	N/A	Consecutive patients from urban tertiary referral hospital	CPS (actual role)	Patient	Median of 4 weeks after treatment decision	· Age · Gender · Education <high school (yes, no) · Private insurance · Prior operation · Caregiver available · Family member's opinion important · Knowledge about condition · Fear of burden imposed by medical costs · Comorbidities · Extent of disabilities of arm, shoulder, hand	* Disabilities of the Arm, Shoulder and Hand questionnaire	**Multivariate analysis**	Treatment, *unspecified*	78	N/A	71 (91)	N/A	Md=57 range, 27-81	N/A	Significant positive association with: private insurance, having caregiver (*P* ≤0.05)
Involving patients in decisions during psychiatric consultations	Goss	2008	Cross-sectional	Audiorecorded consultation, Questionnaire	Italy	Psychiatric outpatients; newly-diagnosed or with new illness episode; scheduled for first contact appointment with psychiatrist	Psychiatric diagnosis	N/A	Consecutive patients from community health service	OPTION-12	Observer	N/A	* Age * Gender * Index problem (=main problem reported by patient during consultation; most often anxiety, 55% or depression, 39%)	N/A	**Pearson's correlation coefficient** (age) **Independent samples t-test** (gender) **ANOVA**	Treatment of index problem	80	16	49 (61)	Not reported	M=43.6 (13) range, 23–76	*Not reported*	No significant association
Patient participation in decision-making on the introduction of home respiratory care: Who does not participate?	Hamalainen	2003	Cross-sectional	Questionnaire	Finland	Respiratory care patients	Respiratory care	N/A	Patients from the pulmonology departments of 5 university hospitals in Finland, the central hospital of Lapland, and from 7 other, randomly-chosen hospitals	1 item: "Were you allowed to participate in decision-making when the home respiratory care was started?" (not at all, somewhat, a great deal, can't say) Dichotomized into: non-participation (score 'not at all'), participation (other scores)	Patient	Not reported	· Age · Sex · Education · Employment · Income group · Smoking status · Treatment duration (years) · Ability to cope with daily life (measured as a sum of five activities; 0-1 vs 2-5 vs 6-20 points)	N/A	**Stepwise logistic regression analysis**	Start respiratory care therapy	3153	N/A	914 (29)	N/A	M=61 range, 16-95	N/A	Negative significant association with: older age (>70 years; OR=1.31, *P*=0.12), high education (OR=1.55, *P*=0.02), low income (OR=2.30, *P*=0.0002), increased score on difficulties with coping with daily life (2–5 points, OR=1.88, *P*=0.002; 6–20 points, OR=2.56, *P* < 0.0001) *Gender was strongly associated with other background variables and was left out of the model*
Patient participation in antipsychotic drug choice decisions	Hamann	2010	Cross-sectional	Questionnaire	Germany	Inpatients 18-80 years; diagnosed with schizophrenia; ≥1 relapse	Schizophrenia	N/A	All eligible inpatients of participating wards in psychiatric hospitals, scheduled to be discharged within next 3 days were approached	1 item asking whose choice the current antipsychotic medication was (doctor's preference, patient's preference, result of decision shared between doctor and patient) Dichotomized into: patients having vs not having participated in medication decision	Physician	Up to 2 days before discharge	· Age · Gender · Education · Duration of illness · Therapeutic alliance (patient) · Psychiatric symptoms · Illness insight · Drug attitudes · Preferences for participation	· Questionnaire on Therapeutic Alliance · Brief Psychiatric Rating Scale · Insight Scale · Drug Attitude Inventory	· **Pearson's correlation coefficient** · **Kruskal–Wallis test** · **Path analysis**	Antipsychotic medication	300	N/A	125 (41.7)	N/A	M=39.7 (12.3)	N/A	Significant positive association with: lower psychiatric symptoms, better illness insight, more positive drug attitudes
Preferred and perceived participation of younger and older patients in decision making about treatment for early breast cancer: A prospective study	Hamelinck	2018	Prospective	Questionnaire	The Netherlands	Patients ≥40 years; diagnosed with primary DCIS or invasive tumor (clinical T1-2) in one breast; eligible for both breast-conserving surgery + radiotherapy and mastectomy; no BRCA1/2 mutation; not diagnosed with a malignancy in past 5 years; no mental or cognitive problems; proficient in Dutch	Breast cancer	N/A	Consecutive patients approached during first surgical consultation	CPS (actual role) (modified)	Patient	**Role in surgery decision:** Median of 60 days after surgery consultation (range, 45-115 days) **Role in adjuvant chemotherapy decision:** Average of 29 days (range, 9-89 days) after consultation with medical oncologist	* Age (40-64, ≥65 years) * Preferences for decision-making role	* CPS (preferences)	· **Chi-square test** · **Fisher exact test** For each decision, only participants who filled in both their preferred and perceived role were included	Surgery type (breast-conserving vs mastectomy), Adjuvant chemotherapy and/or adjuvant hormonal therapy	· Surgery: 74 · Adjuvant chemotherapy: 43 · Adjuvant hormonal therapy: 39	N/A	· Surgery: 74 (100) · Adjuvant chemotherapy: 43 (100) · Adjuvant hormonal therapy: 39 (100)	N/A	· Surgery: Md=60 range, 42-80 · Adjuvant chemotherapy: Md=60 range, 42-76 · Adjuvant hormonal therapy: Md=60 range, 42-86	N/A	No significant association
Latina patient perspectives about informed treatment decision making for breast cancer	Hawley	2008	Cross-sectional	Questionnaire	USA	(Latina) breast cancer patient	Breast cancer	N/A	Eligible patients identified shortly after diagnosis on monthly basis as they were reported to SEER Cancer Registry for Los Angeles County	CPS (actual role) Recoded into: doctor-based, shared, patient-based	Patient	Average of 9 months after surgery	* Ethnicity/race (Latina-Spanish preferent, Latina-English preferent, African American, Caucasian)	* Short Acculturation Scale for Hispanics (SASH)	**Multinomial logistic regression** Reference category: shared decision	Breast cancer surgery	877 (N=925-48 who did not indicate ethnicity and were excluded from the analyses)	N/A	877 (100)	N/A	M=59 range, 29-79	N/A	No significant association
Factors associated with patient involvement in surgical treatment decision making for breast cancer	Hawley	2007	Cross-sectional	Questionnaire, Surveillance, Epidemiology, and End Results (SEER) record	USA	Women diagnosed with documented DCIS or localized stage I, II or III breast cancer in the SEER Cancer Registry; eligible for both breast-conserving surgery + radiotherapy and mastectomy	DCIS or breast cancer	N/A	All women registered in SEER databases with DCIS were approached and an approximate 20% random sample with invasive disease were accrued during study period; African American women were oversampled	CPS (actual role) Recoded into: doctor-based, shared/collaborative, patient-based	Patient	An average of 6.9 months after surgery	· Age (continuous vs categorical variable: 29–44, 45–64, 65–79 years) · Race/ethnicity (white, non-white) · Education (≤high school graduate, ≥some college) · Tumor size · Tumor behavior (DCIS, invasive) · Cancer program (National Cancer Institute-designated cancer center, American College of Surgeons cancer program, no specific program)	N/A	**Multinomial logistic regression** Reference category: shared decision	Breast cancer surgery	1038	N/A	1038 (100)	N/A	M=59 range, 29-79	N/A	Significant association with: age (OR 1.73, 95% CI: 1.19–2.51 for women 45–64 years vs 65–79 years)
Preferred and actual participation roles in operation treatment decision making of patients with colorectal cancer	Hou	2014	Cross-sectional	Questionnaire, Patient medical record abstraction	China	Inpatients ≥18 years; diagnosed with colorectal cancer; hospitalized in general surgical ward after operation; no mental disorder, impaired cognitive function, or other serious somatic disease	Colorectal cancer	N/A	Inpatients from a general surgical ward of 2 upper first-class hospitals in Beijing	CPS (actual role) added category: 'family plenipotentiary' Recoded into: patient not involved (=category 'family plenipotentiary'), passive patient role, shared role, active patient role	Patient	On day of discharge or 1 day earlier	· Age · Gender · Education (≤primary school, high school, ≥college) · Cancer diagnosis (colon, rectal)	N/A	· **Chi-square test** · **ANOVA**	Colorectal cancer surgery	113	N/A	48 (42.5)	N/A	M=62.8 (15.3) range, 22-91	N/A	Significant positive association with: female gender (χ^2=9.854, *P*<0.05)
Decision-making styles and levels of involvement concerning breast reconstructive surgery: An Israeli study	Kadmon	2016	Cross-sectional	Questionnaire	Israel	Israeli women >18 years; diagnosed with breast cancer; undergone breast reconstruction within past five years; proficient in Hebrew	Breast cancer	N/A	Purposive sampling; eligible patients identified from medical records, from women attending plastic surgery clinic, and from women in plastic surgery ward after undergoing reconstructive surgery	2 items: "What was the extent of your involvement in the decision-making process?" (not involved, slightly involved, highly involved), "How were decisions made about your breast reconstruction?" (physician decided, physician and I decided together, physician decided after hearing my opinion, I decided after hearing physician's opinion)	Patient	Up tot 5 years after breast reconstruction	· Age · Decision making style	* Michigan Assessment of Decision Style Questionnaire (MADS)	**Logistic regression** (age) **ANOVA** (decision-making style)	Breast reconstruction surgery	70	N/A	70 (100)	N/A	M=52.7 (10.2) Md=52	N/A	Significant association with: patient decision-making style (less participation significantly associated with higher avoidance or deferred responsibility score, *P*=0.0001; same strength of correlation with deferred responsibility), women possessing avoidance and deferred responsibility decision making styles significantly more likely to have the physician decide, with or without having their concerns heard (*P* =0.02)
Cancer patients' roles in treatment decisions: Do characteristics of the decision influence roles?	Keating	2010	Cross-sectional	Interview	USA	Patients ≥21 years; diagnosed with lung or colorectal cancer; who discussed ≥1 treatment decision (ie, about surgery, radiation therapy, and/or chemotherapy) with a clinician	Lung or colorectal cancer	N/A	Not specified Population-based and health system-based cohorts included in a national study on variations in care and outcomes	CPS (actual role) Recoded into: patient-controlled, shared control, physician-controlled	Patient	3 to 6 months after diagnosis	* Age (21-55, 56-70, 71-80, >80 years) · Sex · Ethnicity (white, black, hispanic, asian, other) · Education (<high school, high school graduate or some college, ≥college degree) · Marital status · Income, $ (<$20.000, $20.000 to <$40.000, $40.000 to <$60.000, ≥$60.000) · Comorbidities (0, 1, 2, ≥3) · Pre-diagnosis health status · Cancer diagnosis (colorectal, lung) · Treatment modality (surgery, radiation, chemotherapy) · Study site	* Short Form health survey, 12 items	**Multinomial logit regression** Unit of analysis: decision, including ≤3 types of treatment modalities that a patient may have discussed	Surgery, Radiation therapy, and/or Chemotherapy	5383 n=10,939 decisions	N/A	2530 (47)	N/A	* 21-55 years: n=618 * 56-70 years: n=1963 * 71-80 years: n=1585 ≥81 years: n=1217	N/A	**Multinomial logit accounting for clustering by patients:** Significant association with: age, ethnicity, marital status, pre diagnosis health status, treatment modality **Adjusted associations:** Significant positive association with: being married, better pre-diagnosis health, treatment modality (decisions about chemotherapy vs surgery: more likely patient controlled; decisions about radiation: least likely patient-controlled)
Age differences in cancer treatment decision making and social support	Krok-Schoen	2016	Cross-sectional	Questionnaire	USA	USA residents ≥18 years; diagnosis with cancer in past 2 years; current participants in Qualtrics survey network	Cancer	N/A	All eligible patients participating in survey network were approached	Six statements assessing extent to which patient was involved Recoded into: independent/isolated decision making, collaborative with doctor, collaborative with family, delegated to doctor, delegated to family, demanding (family-controlled)	Patient	Up to 2 years after diagnosis	**Covariates in Step 1 of linear regression analysis:** * Age (18-39, 40-59, ≥60 years) · Gender · Race (white, black, asian, other) · Education (<high school, high school, some college, college graduate/graduate school) · Marital status · Income (≤$30.000, $30.001-$75.000, ≥$75.001) · Health insurance (private, public, uninsured) **Covariates in Step 2 of linear regression analysis:** · Cancer diagnosis (breast, prostate, lung, colorectal) · Survival prognosis (<50%, ≥50%)	N/A	**Multivariable linear regression analysis**	Cancer treatment	606	N/A	383 (63.2)	N/A	· 18-39 years (n=227): M=30.8 (5.06) · 40-59 years (n=183): M=49.6 (5.75) · ≥60 years (n=169): M=68.6 (6.4)	N/A	Significant positive association with: higher income (β=0.06, *P*<.05)
Treatment preferences and involvement in treatment decision making of patients with endometrial cancer and clinicians	Kunneman	2014	Cross-sectional	Questionnaire	The Netherlands	*Questionnaire about perceived involvement in decision making: Patients <90 years; diagnosed between 2007-2013 with endometrial cancer; undergone surgery with vaginal brachytherapy; no history of other malignancies	Endometrial cancer	N/A	Random selection of patients from hospital databases	3 items: "To what extent did you have space to (1) think about benefits and harms of VBT and (2) give your opinion on the benefits and harms of VBT" (not at all to a lot), "Do you feel you had a choice in the decision about whether or not to undergo VBT?" (no, yes, I don't know) Response on each item were recoded into: score 1-3, 4, 5-7	Patient	Not reported	· Age · Educational level (low vs. intermediate vs. high) · Relational status (partner yes vs. no) · Having children (yes vs. no) · Comorbidity (≤1 vs. >1)	N/A	**Chi-square test**	Vaginal brachytherapy	53 (of 95) who had faced decision	N/A	95 (100)	N/A	*Not reported for subsample* Total sample: Md=68 range, 46-90	N/A	No significant association
Quality of decision making is related to decision outcome for patients with cardiac arrhythmia	Langseth	2012	Cross-sectional	Audiorecorded consultation, Referral letter	UK	Patients referred to cardiologist to consider invasive treatment of suspected or confirmed arrhythmia (i.e. ablation), or for device implantation	Electrophysiological disease	N/A	Consecutive patients referred from secondary care	OPTION-12	Observer	N/A	* Age	N/A	**Pearson's correlation coefficient**	Ablation, Implantable device, or Pharmacological treatment	49	N/A	23 (47)	N/A	M=61	N/A	No significant association
Patient involvement in decision-making in surgical and orthopaedic practice: the Project Perioperative Risk	Larsson	1989	Cross-sectional	Questionnaire	Sweden	Orthopaedic inpatients ≥18 years; admitted for elective surgery	Eligible for orthopaedic elective surgery	N/A	All eligible patients were approached	Questionnaire on how decision was made	Patient	Before surgery	* Country of birth (Sweden, other Scandinavian countries, other European countries, other)	N/A	· **Pitman's non-parametric permutation test** · **Pearson's correlation coefficient**	Surgery (*minor*: surgery for varices, inguinal hernias; *intermediate*: surgery for knee-joint disorders, prostate hypertrophy; *major*: cholecystectomies, osteosynthesis of collumfemor)	666	N/A	*Not reported*	N/A	M=56.6 range, 15-94 *Note: Patients were eligible if ≥18 years, the reported age range may be a typo or ≥1 younger patients have nevertheless been included.*	N/A	No significant association

Shared decision-making for biologic treatment of autoimmune disease: Influence on adherence, persistence, satisfaction, and health care costs	Lofland	2017	Cross-sectional	Questionnaire, Pharmacy and medical claim data	USA	Patients ≥18 years; diagnosed with inflammatory bowel disease (IBD) or rheumatoid or psoriatic arthritis; with ≥1 pharmacy or medical claim for new initiation of 1 biologic agent (drug index date); ≥2 medical claims ≥30 days apart within 6 months before drug index date; continuously enrolled in health plan for 6 months prior and 6 months after drug index date	Inflammatory bowel disease, or rheumatoid or psoriatic arthritis	N/A	Eligibale patients identified on rolling basis using medical claims, pharmacy claims, and enrollment data from a proprietary research claims database (Optum Research Database)	SDM-Q-9 Dichotomized into: SDM (total score≥80) vs non-SDM (total score<80)	Patient	Approximately 8 weeks after drug index date	· Age · Gender · Race/ethnicity (American Indian or Alaskan Native, Asian, Black or African-American, Native Hawaiian or Pacific Islander, White, Other race, Hispanic) · Geograpic region (Northeast, Midwest, South, West) · Autoimmune diagnosis (ulcerative colitis, Crohn's disease, rheumatoid arthritis, psoriatic arthritis) · Comorbidity score · Number of comorbidities (0, 1-2, 3-4, ≥5) · Health status · Provider specialty (Rheumatology, Gastroenterology, Dermatology, Internal medicine)	· 1-item General self-rated health status scale · Quan-Charlson comorbidity index	**Bivariate analysis** (e.g., Independent samples t-test, Mann-Whitney U test, Chi-square test)	Biologic therapy	306 · Rheumatoid arthritis/Psoriatic arthritis: 204 · Inflammatory bowel disease: 102	N/A	238 (77.8) * SDM (n=120): 90 (75.0) * Non-SDM (n=237): 148 (62.5)	N/A	* SDM (n=120): M=47.9 (11.6) * Non-SDM (n=237): M=48.0 (12.4)	N/A	Significant positive association with: female gender (*P*=.018), lower health status (*P*=.005), autoimmune condition (less patients with ulcerative colitis, Crohn's disease and/or psoriatic arthritis in SDM group, *P*<.05), number of comorbid conditions (SDM more likely with patients reporting 1-2 comorbid conditions, *P*=.003), higher comorbid score (*P*=.035)
What is the impact of shared decision making on treatment and outcomes for older women with breast cancer?	Mandelblatt	2006	Cross-sectional	Interview, Patient medical record abstraction, Physician questionnaire	USA	Women ≥67 years; diagnosed with primary T1 or T2, No, N1, or Nx, or Mo invasive breast cancer; community dwelling; proficient in English	Breast cancer	N/A	All eligible patients whom physician consented that they could be contacted were approached	4 items: "I asked my surgeon to explain breast cancer treatments and/or procedure(s) to me in greater detail", "I asked my surgeon a lot of questions about my breast cancer treatment options", "My surgeon asked me about my worries about breast cancer", "My surgeon encouraged me to give my opinions about my breast cancer" (strongly agree to strongly disagree)	Patient	6 to 24 weeks (mean, 18 weeks) after surgery	* Age (67-74, ≥75 years) * Race (white, black) * Education (<high school, ≥high school) * Marital status * Insurance (private + Medicare, Medicare only, Medicare + Medicaid) * Care setting (HMO, non-HMO) * Comorbidity (≤2, >2) * Physical function (high, low) * Accompanied to visit * Cancer stage (1, 2a, 2b)	* Physical function subscale of the Short Form health survey, 36 items	*** Linear regression model** *** Linear mixed model with surgeon random effects** controlling for region and stage	Breast cancer surgery and/or Adjuvant breast cancer treatment	718	N/A	718 (100)	N/A	M=75	N/A	Significant positive association with: lower age (b=-0.66, *P*=.001), being accompanied (b=7.19, *P*<.001)
Consumer and relationship factors associated with shared decision making in mental health consultations	Matthias	2014	Cross-sectional	Audiorecorded consultation, Questionnaire	USA	Consumers seeing one of the three consenting providers of a psychiatric clinic during the study period; no PTSD-related symptom exacerbations	Post Traumatic Stress Disorder	N/A	Consecutive patients	**Overall SDM:** SDM scale (overall score, range 0-18) **Minimum level of SDM (SDM-Min)** varied by decision complexity (basic, intermediate, or complex) SDM-Min dichotomized into: 0=absence of minimum SDM vs 1=minimum SDM	Observer	N/A	· Age · Gender · Race · Illness self-management · Medication adherence behavior · Patient activation · Length of relationship with provider	· Morisky Scale of 10-item Medication Adherence Rating Scale · Mental Health Version of Patient Activation Measure * Illness management and Recovery Scale, client version	**Pearson correlation coefficient** (continuous variables) **Point-biserial correlation** (dichotomous variables)	Treatment, *unspecified*	63 (of 79) who had a treatment decision	N/A	9 (14)	N/A	M=53 (10) range, 23-71	N/A	**Overall SDM score:** No significant association **SDM-Min score:** Significant association with: medication adherence (*r*=-.32, *P*<.05)
Patient participation in the discussions of options in Spanish primary care consultations	Moral	2014	Cross-sectional	Videorecorded consultation, Interview	Spain	Patients diagnosed with a chronic condition or having new health problem; seeing one of 96 primary care doctors with >5 years of clinical experience and worked in a clinic from one of 5 different regions in Spain	Various chronic conditions or new health problem, either psychological or somatic	N/A	Systematic selection of 6–8 patients per doctor (not further specified)	3-point item 8 of CICAA (Conector Identificar Comprender Acordar Ayudar)-D scale ("To what extent did the provider give the patient opportunities to participate in the decision- making process and encourage them to do so?") (0=conduct absent, 1=probably present, 2=definitively present) Clinical encounters scoring 1 or 2 on item 8 plus random selection of those scoring 0 on item 8 were assessed using full 17-item CICAA-D scale	Observer	N/A	· Age · Gender · Education (no studies, primary, high school, university) · Marital status · From urban or rural area · Health problem (neurological, skin diseases, cardio circulatory problems, nose/throat/ear-related problems, digestive, emotional/psychological, metabolic, breathing problems)	* International Classification of Primary Care	**Stepwise multiple logistic regression** **Multiple linear regression**	Treatment, *unspecified*	Relevant subsample: 368 · Patients rated with the CICAA-D scale (13 items): n=278 (117+161) · Patients Rated with CICAA-D scale (17 items): 90	N/A	*Not reported for subsample* Total sample: 401/658 (62)	N/A	*Not reported for subsample* Total sample: M=52 range, 18-88	N/A	No significant association
The balance of clinician and patient input into treatment decision-making in older women with operable breast cancer	Morgan	2015	Cross-sectional	Questionnaire	UK	Women >70 years; diagnosed with operable primary breast cancer in 1 of 43 UK units	Breast cancer	N/A	UK cohort study of older women with breast cancer (the Bridging the Age Gap in Breast Cancer study)	CPS (actual role) Recoded into: patient-centred, shared, doctor-centred	Patient	Up to 4 weeks after diagnosis and prior to treatment	* Age	N/A	**Chi-square test**	Surgery or Primary endocrine therapy	729	N/A	729 (100)	N/A	Md=77 range, 70-96	N/A	Significant positive association with: higher age (*P* <0.001)
Shared decision-making during surgical consultation for gallstones at a safety-net hospital	Mueck	2018	Cross-sectional	Questionnaire	USA	Vulnerable patients seeking care for gallstone disease at safety-net hospital	Gallstone disease	N/A	Purposive sampling of outpatients being evaluated in a general surgery clinic	SDM-Q-9, interviews	Patient	Prior to treatment	* Age * Sex * Race/ethnicity * Primary language (Spanish, English) * Diagnosis * Desire for autonomy	* Autonomy Preferences Scale	*** Chi-square test** *** Independent samples t-test** *** Mann-Whitney U test**	Gallstone treatment	30	N/A	27 (90)	N/A	M=46 (16)	N/A	No significant association
Treatment decision-making in the medical encounter: Comparing the attitudes of French surgeons and their patients in breast cancer care	Nguyen	2014	Cross-sectional	Questionnaire	France	French surgeons and their patients Patients diagnosed with stage I or II localized breast cancer; treated by lumpectomy or mastectomy	Breast cancer	N/A	Radiation oncologists at cancer care network were asked to recruit patients they had treated, once treatment was completed	One item asking patients whether they had actually participated in treatment decision making (not at all to a great extent)	Patient	Not reported	* Age (<60, ≥60 years) * Marital status * Education <high school, (≥high school) * Income (<€22.867, ≥€22.867) * Employment status * Leisure activities	N/A	**Multilevel regression analysis**	Treatment for early stage breast cancer, not further specifed	238	N/A	238 (100)	N/A	M=56.3 (10.3) range, 37-84	N/A	Significant positive association with: being married, being involved in leisure activities
The relationship between social support, shared decision-making and patient's trust in doctors: A cross-sectional survey of 2,197 inpatients using the Cologne Patient Questionnaire	Ommen	2011	Cross- sectional	Questionnaire	Germany	Inpatients ≥18 years; admitted to internal medicine or surgical wards of 1 of 6 hospitals	Inpatients of internal medicine or surgery	N/A	Purposive sampling; 50% random sample was drawn from patient registers of 3 urban and 3 rural hospitals with different sizes and from different regions	Cologne Patient Questionnaire 4-item scale 'co-therapy'	Patient	Not reported	* Age (18-30, 31-65, 66-97 years) * Gender * Socio-economic status * Tendency to excuse	N/A	**Pearson correlation coefficient**	Treatment, *unspecified*	2197	N/A	577 (26.3)	N/A	M=50 range, 18-97 * 18-30 years: n=454 (21.2%) * 31-65 years: n=1177 (55%) * 66-97 years: n=509 (23.8%)	N/A	Significant positive association with: higher age (r=0.116, *P*<.01), male gender (r= -0.050, *P*<.05)
African American prostate cancer survivors' treatment decision-making and quality of life	Palmer	2013	Secondary analyses of cross-sectional, case-control study	Interview	USA	Men 40–75 years; diagnosed with prostate cancer within past 6 months; African American race; residing in 1 of 15 counties surrounding Winston-Salem, North Carolina	Prostate cancer	N/A	Patients identified using rapid case ascertainment of the North Carolina Central Cancer Registry (NCCCR), for whom physicians authorized or did not object to researchers contacting them	CPS (actual role) Recoded into: active, collaborative, passive	Patient	Not reported (approached within 6 months after diagnosis, interviews scheduled at convenience)	· Year of birth · Race/ethnicity · Education (<high school, high school, ≥college) · Marital status · Cancer severity (Gleason score) · Whether a second opinion about prostate cancer treatment took place and if so, physician's speciality · Sources of information consulted about prostate cancer · Perceived severity of prostate cancer · Distress while making treatment decision	N/A	**Chi-square test, Fisher's Exact test** (education, marital status, sources of information used, second opinion, perceived severity, distress) **ANOVA with post-hoc Tukey's Honest Significant Difference test** (age)	Prostatectomy, Hormonal therapy, Brachytherapy, Chemotherapy, External beam radiation, Internal radiation therapy, Eatchful waiting, Other	181	N/A	0 (0)	N/A	M=61.3 (7.0) range, 43-70	N/A	Significant association with: marital status (χ2=7.8, *P* =0.020), education (χ2=16.6, *P* =0.002)
The importance of patient participation in second-line chemotherapy decisions: Perspectives of African-American patients	Phipps	2008	Cross-sectional	Interview	USA	Patients diagnosed with cancer; treated previously with first-line chemotherapy and recently consented to second-line chemotherapy; African-American	Cancer	N/A	Eligible patients identified via treating physician	Patient Perception of Role in Decision (adapted) Recoded into: patient-based decision making (scores 1-2), SDM-based (score 3), physician-based decision making (responses 4-5)	Patient	Up to 1 month after documented consent to second-line chemotherapy	* Gender * Education (<high school, high school, some college) * Income (<$12.000, $12.000-$25.000, $25.000-$55.000, >$55.000) * Intrinsic religion / spirituality * Depression	* Durel score * Center for Epidemiological Studies – Depression	*** Chi-square test** *** ANOVA** *** Pearson correlation coefficient** *** Spearman rho correlation**	Second-line chemotherapy	26	N/A	13 (50)	N/A	M=61 range, 22-79	N/A	Significant positive association with: male gender (8% vs 46% 8% reported the doctor to have made the decision, *P*=0.06), lower intrinsic religiosity (IR; SDM-decision makers had lower IR mean scores compared with physician-based decision makers, *P*=.02)
Cancer patients' decision-making regarding treatment and nursing care	Sainio	2003	Cross-sectional	Questionnaire	Finland	Patients 18-65 years; diagnosed with cancer ≥2 months earlier; able physically and mentally to complete questionnaire	Cancer	N/A	Consecutive patients	12 items to assess participation in treatment decision-making (to a great extent, to some extent, not at all)	Patient	2 months to 15 years (mean=29 months, SD=40 months) after diagnosis; >40% had been diagnosed <6 months before	* Age (<45, 45-52, 53-56, >56 years) · Gender · Marital status · Having underage children · Education (none, school degree, college degree, academic) · Employment status · Physical condition	N/A	· **Mann–Whitney U-test** · **Kruskall–Wallis test**	Cancer treatment	273	N/A	165 (60)	N/A	M=49.67 (10.51)	N/A	Significant positive assocation with: being married (*P*=0.025), being in good physicial condition (*P*=0.002)
Shared decision making in vascular surgery: An exploratory study	Santema	2016	Cross-sectional	Audiorecorded consultation	The Netherlands	Patients with a disorder requiring a visit at the vascular surgery outpatient clinic; facing treatment decision with >1 legitimate treatment option; able to give informed consent and to complete questionnaire	Eligible for vascular surgery	Vascular surgeons	Consecutive patients recruited at 3 university and 1 teaching hospital	OPTION-12	Observer	N/A	* Age * Gender * Diagnosis (abdominal aortic aneurysm, peripheral arterial disease, venous disease, other)	N/A	**Univariable linear regression analysis**	Vascular surgery	54	12	23 (42.6)	Not reported	M=69.1 (15.2)	*Not reported*	No significant association
Young breast cancer patients' involvement in treatment decisions: The major role played by decision making about surgery	Seror	2013	Prospective	Questionnaire, Interview	France	Consecutive female patients aged 18–40 years; diagnosed with primary localized breast cancer; valid address in southeastern France	Breast cancer	N/A	Consecutive patients	CPS (actual role) Dichotomized into: fully passive vs. other	Patient	Not reported Interview took place 10 months after diagnosis	* Age (≤35, >35 years) · Education (≤high school, >high school) · Marital status · Children (0, ≥1) · Tumor stage (I, >I) · Comorbidities · Family history of breast/ovarian cancer · Regular breast surveillance up to diagnosis (yes, no) · Preferred role in decision making (fully vs not fully passive) · Announcement of diagnosis (too vs not too bluntly) · Understanding of breast cancer information (yes, no, N/A) · Satisfaction about treatment information received* · Complete mastectomy (yes, no)** · Role in surgery decision (fully vs not fully passive)** · Role in chemotherapy decision (fully vs not fully passive)*** *=Information about surgery assessed for decision about surgery, chemotherapy and endocrine therapy; information about chemotherapy assessed for decision about chemotherapy and endocrine therapy; information about endocrine therapy assessed for decision about endocrine therapy **=relevant for role in decision about chemotherapy and endocrine therapy ***relevant for role in decision about endocrine therapy	N/A	**Multivariable regression analysis**	Breast cancer surgery, Chemotherapy, and/or Adjuvant endocrine therapy	415 · Surgery: 404 · Chemotherapy: 317 · Adjuvant endocrine therapy: 224	N/A	415 (100)	N/A	M=36.8 (3.8) *At enrollment (ie 10 months before interview)*	N/A	**Surgery decision:** Significant negative association with: preferring a fully passive role (*P*<0.01) **Chemotherapy decision:** Significant negative association with: preferring a fully passive role (*P*<0.001) **Endocrine therapy decision:** Significant negative association with: being ≥36 years (*P*<0.05), with reporting fully passive role in deciding about surgery (*P*<0.001)
Shared decision-making and patient control in radiation oncology: Implications for patient satisfaction	Shabason	2014	Cross-sectional	Questionnaire	USA	Patients ≥18 years; diagnosed with cancer; Karnofsky performance status of 60; undergoing radiotherapy with curative intent; no known brain tumor or abnormal neurologic function; able to understand study requirements	Cancer	N/A	Eligible patients identified from medical records were approached during their final week of radiotherapy	3 items: "If there were a choice between treatments, would your radiation oncologist ask you to help him/her make the decision?" (definitely yes to definitely no), "How often does your radiation oncologist make an effort to give you some control over your treatment?" (very often to never), "How often does your radiation oncologist ask you to take some of the responsibility for your treatment?" (very often to not at all) Dichotomized into: SDM yes vs no, using 70/100 as cutoff score	Patient	During final week of treatment	* Age (<55, 55-65, >65 years) · Gender · Race/ethnicity (white, non-white) · Education (≤high school, some college, ≥college) · Marital status · Employment status · BMI (normal, overweight, obese) · Cancer diagnosis (prostate, breast, head/neck, gastrointestinal, lung, genitourinary/skin/other) · Disease stage (I, II, III, M) · Had surgery · Received chemotherapy · Received hormonal therapy	N/A	**Chi-square test**	Radiation therapy	305	N/A	145 (47.5)	N/A	M=59.8 (12.0) range, 18-87	N/A	Significant positive association with: having had head/neck malignancy vs other disease sites (*P*=.028)
The relationship between health literacy and perceived shared decision making in patients with breast cancer	Shen	2019	Cross-sectional	Questionnaire, Patient medical record abstraction	Taiwan	Patients ≥20 years; diagnosed with breast cancer; no cognitive impairment or brain metastasis	Breast cancer	N/A	Convenience sampling; eligible patients referred through surgeons post-consultation	SDM-Q-9	Patient	After surgical consultation	* Age (<60, ≥60 years) · Education (≤12, >12 years) · Marital status · Employment status · Urbanized level of residence (urban, non-urban) · Time since diagnosis (≤6, 7-23, 24-59, ≥60 months) · Cancer stage (0-I, II, III, M) · Health literacy: healthcare, disease prevention, health promotion · Self-rated health status	· Health Literacy Survey European Questionnaire, 47-items · EuroQol Visual Analogue Scale · American Joint Committee on Cancer	· **Multiple regression analysis** · **Sequential linear regression analysis** (1st factor: domains of health literacy)	*Newly-diagnosed patients*: typical decisions included lumpectomy+radiation vs mastectomy, or surgery vs neoadjuvant chemotherapy *Follow-up appointment*: typical decision related to treatment for lymphedema	511	N/A	511 (100)	N/A	M=57.9 (11.13)	N/A	**Sequential regression analysis:** Significant positive association with: age <60 years (*P*=.002), >12 years of education (*P*=.002), being single/widow vs married (P=.003), living in urban area (P=.049), longer time since diagnosis (P<.001), more advanced stage (except stage IV, *P*<.001) **Multiple regression analysis:** Significant association with: health literacy (healthcare: β=.951, P<.001; disease prevention: β=.787, P=.001; health promotion: β=-.507, P=.016), time since diagnosis (β=.045, *P*=.023), cancer stage (reference category: stage 0-I; Stage III higher SDM, β=8.53, *P*=.006, stage IV: lower SDM, β=-33.6, *P*<.001)
Shared decision making in oncology: Assessing oncologist behaviour in consultations in which adjuvant therapy is considered after primary surgical treatment	Singh	2010	Cross-sectional	Audiorecorded consultation, Questionnaire	Australia	Patients diagnosed with solid tumour primary cancer; scheduled for consultation to consider adjuvant therapy after surgery	Cancer	N/A	Secondary analysis and purposive selection from consecutively sampled patients	18-item coding system to assess cancer specialist behaviours (1=present or behaviour N/A, 0=absent; range total scores, 0-18)	Observer	N/A	* Age * Gender * Education (≤high school, any tertiary degree) * English as first language * Site of primary cancer (breast cancer, other) * Observer-based preferred decisional role (passive, active/shared) * Pre-consultation anxiety	* CPS (preference) * State version of State-Trait Anxiety Inventory, 20 items	**Multiple linear regression**	Adjuvant treatment (Chemotherapy and/or Radiation; if so, what type)	63	N/A	40 (64)	N/A	M=54.9 (13.1) range, 24-84	N/A	Significant positive association with: younger age (b=-0.08, *P*=0.04), female vs male breast cancer patients (b=2.4, *P*=0.03)
Preferred roles in treatment decision making among patients with cancer: A pooled analysis of studies using the Control Preferences Scale	Singh	2010	Pooled analysis of 6 studies *Note: Degner & Sloan (1992) assessed role preference, not actual role, but was included in the results.*	Questionnaire (5/6) or Interview (1/6)	USA, Canada	Patients diagnosed with cancer (breast, protate or other); enrolled in 1 of 6 different cancer treatment trials	Cancer	N/A	Depends on design of original study: prospective longitudinal study, (block) randomized study, consecutive sample	CPS (actual role)	Patient	Varied per study; ranged from immediately after treatment decision to 12 months after diagnosis	* Age (<50, ≥50 years) * Gender * Nationality (Canadian, US citizen) * Education (grade school, high school, >high school) * Tumor stage (0-2, 3-5)	N/A	**Fisher's Exact test**	Treatment (Cancer treatment or treatment not further specified depending on study)	3491 *No data CPS data from 1 study (N=749)*	N/A	2363 (67.7)	N/A	* <50 years: n=809 (37.7%) * 50-64 years: n=35 (1.6%) * >64 years: n=1300 (60.6%)	N/A	Significant positive association with: younger age (30 vs 38% reporting passive role, P<.001; 34% vs 29% reported active role, P=.02), male gender (24% vs 40% reporting passive role, *P*<.001), US vs Canadian nationality (18 vs 42% reporting passive role, *P*<.001), being American male or female vs Canadian male or female (*P*<.001), higher vs high school vs grade school education (23% vs 35% vs 64% reporting passive role, P<.001), tumor stages 0-2 vs ≥3 (30% vs 22% reporting active role, *P*=.02)
How much shared decision making occurs in usual primary care of depression?	Solberg	2014	Cross-sectional	Interview	USA	Patients ≥18 years; with a fill for antidepressant medication; who could be contacted within 21 days of that fill; from 1 of 88 participating clinics; scoring ≥7 on 9-item Patient Health Questionnaire (PHQ-9) assessment for depression severity; with continuous insurance coverage in past 4 months; received antidepressant treatment in past 4 months	Depression	N/A	Eligible patients idenfied on a weekly basis via claims data of 6 main health plans in the state and the Minnesota Department of Human Services	6 questions to assess SDM aspects of care Composite score calculated as the proportion of the 6 components that patients reported receiving (range scores, 0-100%)	Patient	Up tot 30 days after treatment decision	* Age (18-34, 35-49, 50-64, ≥65) · Sex · Ethnicity (non-hispanic white/hispanic/any race, non-hispanic, non-White) · Education (≤high school, some college/trade school, ≥college degree) · Marital status · Employment status · Income (<2x poverty level, >2x poverty level) · Insurance type (Commercial, State programs, Medicare, Other) · Depressive symptoms · Length of treatment (0-5, ≥6 weeks) · Other depression treatment in past 6 months · General health	* Patient Health Questionnaire, 9 items	**Univariate general lineair model analysis** (education, marital status, employment status, insurance type) **Multivariate general lineair model analysis** 1 model estimated main effects of all the retained set of patient characteristics. The second estimated main and 2-way interactions	Depression treatment	1168	N/A	851 (72.9)	N/A	M=44.2 * 18-34 years: n=344 (29.5%) * 35-49 years: n=391 (33.5%) * 50-64 years: n=347 (39.7%) * >65 years: n=86 (7.4%)	N/A	**Univariable analysis:** Significant positive association with: higher education, employed, not insured through Medicare **Multivariable analysis, main effects only:** Significant positive association with: younger age (patients 50 64 (*P*=.001) and >= 65 (*P*<.001) years old reporting SDM lower scores than patients 35-49 years old (reference)), higher income (*P*=.04), shorter treatment length (*P*<.001), better health (*P*<.001) **Multivariable analysis, main effects + interactions:** Same significant associations
Who makes the decision regarding the treatment of clinically localized prostate cancer - the patient or physician? Results from a population-based study	Song	2013	Cross-sectional	Interview, Patient medical record abstraction	USA	Patients diagnosed with localized prostate cancer (T1 or T2); self-identified as African American/black or Caucasian-American	Prostate cancer	N/A	All patients from first follow-up of Health Access and Prostate Cancer Treatment in North Carolina (HCaP-NC) study	1 item: "Who was mostly responsible for deciding what to do about prostate cancer when you were first diagnosed?" Recoded into: patient-only, patient-physician shared, physician-only decision-making and results extracted for patient-physician shared vs physician-only	Patient	Not reported	* Age (<65, ≥65 years) * Race (African-American, Caucasian-American/white) * Education (≤high school, ≥some college) * Marital status * Cancer aggressiveness (low, intermediate, high)	N/A	**Multinomial logistic regression**	Prostate cancer treatment	788	N/A	0 (0)	N/A	* <65 years: n=483 (63%) * ≥65 years: n=280 (37%)	N/A	Significant association with: high vs low cancer agressiveness (OR 0.45)
Quality of life, uncertainty, and perceived involvement in decision making in patients with head and neck cancer	Suzuki	2012	Prospective	Questionnaire	USA	Patients ≥18 years; newly-diagnosed with head and neck cancer; as of yet untreated; no history of other cancers	Head and neck cancer	N/A	Convenience sample recruited at outpatient clinics through 4 physicians in 6 hospitals in New York metropolitan area	13-item PICS (Perceived Involvement in Care Scale)	Patient	Immediately after treatment decision (Time 1, pretreatment) and 6 weeks after treatment was completed (Time 2)	* Age * Education * Income (at Time 1, 2) * Perceived involvement in care (at Time 1, 2) * Uncertainty (at Time 1) * Quality of life (at Time 1)	* Mishel Uncertainty in Illness Scale (Adult) * Functional Assessment of Cancer Therapy - Head & Neck	**Bivariate correlation**	Head and neck cancer treatment	52	N/A	15 (28.8)	N/A	M=58.3 (12.4)	N/A	No significant association
Assessing patients involvement in decision making during the nutritional consultation with a dietitian	Vaillancourt	2014	Cross-sectional	Audiorecorded consultation, Patient and physician Questionnaire	Canada	Members of the Professional Order of Dieticians of Quebec consulting with a patient with a diet-related health condition (all ages) requiring a value-sensitive treatment decision. For patients <18 years, parents were included	Diet-related health condition	Dietitians	All eligible healhcare professionals were approached; participants each selected 1 patient encounter	OPTION-12	Observer	N/A	**Covariates in Step 1 of linear regression analysis:** · Age · Gender · Race (white, black, asian, other) · Education (<high school, high school, some college, college graduate/graduate school) · Marital status	N/A	**Spearman rho correlation**	Nutritional treatment	19	19	11 (58)	19 (100)	M=40.2 (25.2)	M=39.3 (11.0)	No significant association
Shared decision making in prostate cancer care - Encouraging every patient to be actively involved in decision making or ensuring the patient preferred level of involvement?	Van Stam	2018	Prospective	Questionnaire, Patient medical record abstraction	The Netherlands	Patients newly-diagnosed with localized prostate cancer (cT1-cT2 OR Gleason ≤7 OR prostate-specific antigen ≤20 ng/ml)	Prostate cancer	N/A	Eligible patients recruited by urologist or clinical nurse specialist after being informed was about treatment options	CPS (actual role) Dichotomized into: active (score 1-3) vs passive (score 4-5)	Patient	3 months after treatment	· Age · Education (<high school, high school, some higher education) · Marital status · Nationality (Dutch, non-Dutch) · cT status (cT1, cT2) · Gleason score (6, 7) · Prostate-specific antigen (PSA) in ng/ml (0-4, 5-9, >9) · Cancer risk group (low, intermediate, high) · Comorbidities (0, 1, >1) · History of depression · Baseline health-related quality of life · Active coping	* European Organisation for Research and Treatment of Cancer Quality of Life Questionniare - Cancer 30 items	**ANOVA**	Prostate cancer treatment (Active surveillance, Radical prostatectimy, External beam radiotherapy, Brachytherapy)	474 (at baseline; 96% at 3 months)	N/A	474 (0)	N/A	M=66.5 (6.1)	N/A	**Multivariable analysis:** Significant positive association with: higher education (*P*=.005)
Shared decision making in pharmacotherapy decisions, perceived by patients with bipolar disorder	Verwijmeren	2018	Cross-sectional	Direct observation, Questionnaire	The Netherlands	Patients >18 years; diagnosed with bipolar disorder I, II or 'not otherwise specified' (NOS) according to DSM-IV (Diagnostic and Statistical Manual of Mental Disorders); scheduled for consultation to consider pharmacotherapy decision	Bipolar disorder	N/A	Not specified Consultations with psychiatrist, resident or nurse practitioner in 2 specialised outpatient clinics for bipolar disorder	SDM-Q-9, OPTION-12	Patient Observer	**Patient perceptions:** After consultation	* Age * Gender * Diagnosis * Decision making self-efficacy * Severity of bipolar symptoms * Duration of total treatment by same clinician	* WHO Disability Assessment Schedule 20 * Decision Self-Efficacy scale	**ANOVA**	Pharmacotherapeutic treatment of bipolar disorder	81	N/A	52 (64.2)	N/A	M=52.0 (13.6)	N/A	**SDM-Q-9** Significant association with: decision self-efficacy (P=0.035; lowest vs highest score differed, P=.02) **OPTION-12** No significant association
Congruence between preferred and actual participation roles increases satistaction with treatment decision making among Japanese women with breast cancer	Yamauchi	2017	Cross-sectional	Questionnaire	Japan	Women registered with marketing research company as breast cancer survivors; diagnosed with breast cancer between ages 20-69; had breast cancer-related surgery and/or treatments in Japan	Breast cancer	N/A	Purposive sampling; eligible participants from variety of sociodemographic backgrounds and places of residence in Japan	CPS (actual role)	Patient	Up to 5 years after diagnosis (N=321); >5 years after diagnosis (N=329)	*Age (≤40 years, 41-50 years, ≥51 years) * Residential area (≥5 million inhabitants, <5 million inhabitants) * Employment status * Cancer stage (0-II, III-IV, don't know)	N/A	**Chi-square test** Only participants with complete data used	Breast cancer	650	N/A	650 (100)	N/A	* <50 years: n=202 (31%) * >50 years: n=448 (69%)	N/A	Significant positive association with: lower cancer stage (*P*=.02)

ˆDesign is reported with respect to patient-related characteristics reported
N/A, Not applicable

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	5
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix A
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	5

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	7 Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Tables 1-5 7-10
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1 Appendix B
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	7-10
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	11-12
Limitations	20	Discuss the limitations of the scoping review process.	3
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	12-13
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	13

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

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