


## REVIEW

# Patients' preferred and perceived level of involvement in decision making for cancer treatment: A systematic review

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**Abstract**

**Objective:** Patient involvement in decision making is conditional for personalised treatment decisions. We aim to provide an up-to-date overview of patients' preferred and perceived level of involvement in decision making for cancer treatment.

**Methods:** A systematic search was performed in PubMed, EMBASE, PsycINFO and CINAHL for articles published between January 2009 and January 2020. Search terms were 'decision making', 'patient participation', 'oncology', 'perception' and 'treatment'. Inclusion criteria were: written in English, peer-reviewed, reporting patients' preferred and perceived level of involvement, including adult cancer patients and concerning decision making for cancer treatment. The percentages of patients preferring and perceiving an active, shared or passive decision role and the (dis) concordance are presented. Quality assessment was performed with a modified version of the New-Castle Ottawa Scale.

**Results:** 31 studies were included. The median percentage of patients preferring an active, shared or passive role in decision making was respectively 25%, 46%, and 27%. The median percentage of patients perceiving an active, shared or passive role was respectively 27%, 39%, and 34%. The median concordance in preferred and perceived role of all studies was 70%. Disconcordance was highest for a shared role; 42%.

**Conclusions:** Patients' preferences for involvement in cancer treatment decision vary widely. A significant number of patients perceived a decisional role other than preferred. Improvements in patient involvement have been observed in the last decade. However, there is still room for improvement and physicians should explore patients' preferences for involvement in decision making in order to truly deliver personalised cancer care.

**KEYWORDS**

decision making, medical oncology, neoplasms, patient participation, patient preference, psycho-oncology

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## 1 | BACKGROUND

As science continues to reveal the heterogeneity of tumors, the number of possible treatment options rises. This increases the potential for personalised cancer treatment and makes 'the best' treatment choice increasingly subject to preference. In the process of reviewing treatment options, evaluating them in the medical and psychosocial context of the patient and matching them with individual preferences and priorities is needed for personalised cancer care.<sup>1</sup> Patient involvement is therefore required to make a deliberate choice.<sup>2,3</sup> Through this process of shared decision making (SDM), patients are enabled to play an active role in composing their individual cancer care.<sup>4-7</sup>

Patient involvement in decision making for cancer treatment has been shown to improve patient's perception of quality of care,<sup>8</sup> physical functioning,<sup>9</sup> patient satisfaction,<sup>10</sup> and quality of life.<sup>11</sup> Hack et al.<sup>11</sup> showed that women experiencing active involvement in treatment decision for breast cancer reported a significantly higher quality of life than women experiencing passive involvement. Moreover, among these women, decision regret was reported significantly more by women who experienced less involvement in treatment decision than they would have preferred. A passive role in treatment decision making led to greater distress and lower quality of life among breast and prostate cancer patients.<sup>12</sup> Also, satisfaction with treatment decision was positively influenced by level of involvement, with greater patient involvement leading to higher decision satisfaction.<sup>10</sup> Furthermore, treatment adherence is higher for patients experiencing a level of involvement that corresponds to their preference in treatment decision for breast cancer.<sup>13</sup>

In the last two decades, research in decision making for cancer treatment increasingly underlined the mismatch between patients' preferred and perceived level of involvement in decision making. In a previous systematic review on this topic, Tariman et al.<sup>14</sup> concluded that there was discordance between the role that patients wanted to play in treatment decision making and the involvement they actually perceived. Hence, more attention for actively involving patients in the SDM process in clinical practice was recommended.

Since 2009, the number of possible treatment options has further increased, which results in even more complex treatment decisions for patients with cancer. In parallel, the rise of values such as autonomy and self-determination intensify the societal demand for patient involvement in medical decision making. Consequently, the call for more patient-centred care, boosts the uptake of shared decision making in health care policy.<sup>15</sup> Therefore, for this new era in which SDM seems more important, this systematic review aims to provide an up-to-date overview of patients' preferred and perceived level of involvement in decision making for cancer treatment, the concordance between preferred and perceived involvement and whether these outcomes have improved as compared to a decade ago.

## 2 | METHODS

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 checklist was used to report this systematic review.<sup>16</sup> This review was registered in the International Prospective Register of Systematic Reviews (registration number: CRD42020166925).

### 2.1 | Eligibility criteria

We included peer-reviewed articles published in English. Furthermore, studies needed to (i) include data on adult cancer patients, (ii) report both the preferred and perceived level of involvement in decision making, and (iii) concern decision making for cancer treatment. We excluded studies that performed a qualitative exploration of the role in decision making. If multiple publications were based on data of one study, we only included the publication that best reported the data of all participants.

### 2.2 | Sources and search strategy

A literature search was carried out in PubMed, EMBASE, PsycINFO and CINAHL for articles published between January 2009 and January 2020 (previous review included studies until January 2009). We based our search on the search performed by Tariman et al.<sup>14</sup> which included the medical subject heading terms 'decision making', 'patient participation' and 'oncology'. To further detail the search strategy, we added two search terms 'perception' and 'treatment'. Key words and relevant terminology were based on the search terms, index terms and relevant terminology in title/abstract used in so-called 'key publications'. These key publications were selected before constructing the search strategy, as publications that answer the research question and should be identifiable in the search results. We validated the final search (Supporting Information 1), by checking whether our 'key publications' would be identified in the results of the search. Finally, we performed backward and forward citation tracking to identify any potential relevant missed studies.

### 2.3 | Study selection

Two researchers (EN & LP) independently performed title/abstract screening for eligibility with the use of the online tool 'Rayyan'. Any discrepancies in the selection of eligible studies based on title/abstract were discussed with a third researcher (CH). Full-text screening of selected papers was done by two researchers (EN & CH).

### 2.4 | Data collection

The following data were extracted from the individual studies: (1) the percentage of participants preferring predefined levels of

involvement, (2) the percentage of participants perceiving these levels of involvement, and - if provided - (3) the percentage of participants with a (within-person) discordance between their preferred and perceived level of involvement.

## 2.5 | Level of involvement

The most commonly used scale in the included studies to measure the preferred and perceived level of involvement, is 'The Control Preference Scale' (CPS) designed by Degner et al.<sup>17</sup> The CPS asks patients to reflect on a specific decision and to select one of the five responses (A–E), which best corresponds with their preferred level of involvement (Table 1). These five responses are categorised into either an active, shared or passive decision role.

Other methods used in included studies to measure the level of involvement in decision making are the Shared Decision Making Questionnaire (SDM-Q-9),<sup>18</sup> the Patient Perception Scale (PPS)<sup>19</sup> and the Treatment Decision Making (TDM) examples, designed by Charles et al.<sup>20,21</sup> These measurements also allow making a distinction between an active, shared or passive role in decision making.

## 2.6 | Data analysis

From the included individual studies the following data were extracted: the percentage of patients preferring and perceiving an active, shared or passive role and the percentage of (dis)concordance. For studies presenting the percentages for the levels of involvement in five categories (A–E, see Table 1), we calculated the percentage of A plus B for an active decision role, and of D plus E for a passive decisional role. Additionally, if the percentage of (dis)concordance was not provided and if the data allowed, we calculated the overall (dis)concordance and the discordance separately for the three levels of involvement. Supporting information 2 shows the presentation of the data of individual studies that allow and do not allow for calculation of the (dis)concordance. Also, if individual studies presented their data in subgroups (such as for different age groups or different types of treatment), we calculated the overall percentages.

Subsequently, we calculated the median percentage and interquartile range of all studies for the: (1) percentage preferred, (2) percentage perceived and (3) percentage discordance between

preferred and perceived for an active, shared and passive role and 4) the percentage of overall (dis)concordance. We present these medians and interquartile ranges for all included studies together and for the following subgroups: cancer diagnoses (breast, haematologic, lung, (colo) rectal, prostate cancer), culture (Western, Asian), and stage of cancer (early, advanced).

## 2.7 | Quality assessment

For all included studies the quality was independently assessed by two researchers (EN, LP). To assess the risk of bias we used the Newcastle-Ottawa Scale (NOS).<sup>22</sup> The NOS was originally designed to assess the risk of bias on outcome and study level for cohort and case-control studies. Previous studies tested<sup>23</sup> and used<sup>24,25</sup> a modified version of the NOS to fit cross-sectional studies. We modified these scales to fit our research (Supporting Information 3). We used the modified version of the NOS for all included studies, as the measurement of the variables of interest (irrespective of study design) was comparable. Quality of studies was scored for the topics 'selection of participants' and 'definition and assessment of the outcome'. Scores could range from 0–9 stars, with 0–3 stars corresponding with a poor quality, 4–6 with a fair quality and 7–9 with a good quality.

## 2.8 | Comparison with Tariman et al.

The steps as described in the data collection and data analysis section were also performed for the individual studies included in the review by Tariman et al. The differences in median percentages of the present review and the review by Tariman et al. were tested for significance with a (non-parametric) median test for two independent medians. All analyses were performed with IBM SPSS 26.0.0.1 and a *p*-value < 0.05 was considered as statistically significant.

## 3 | RESULTS

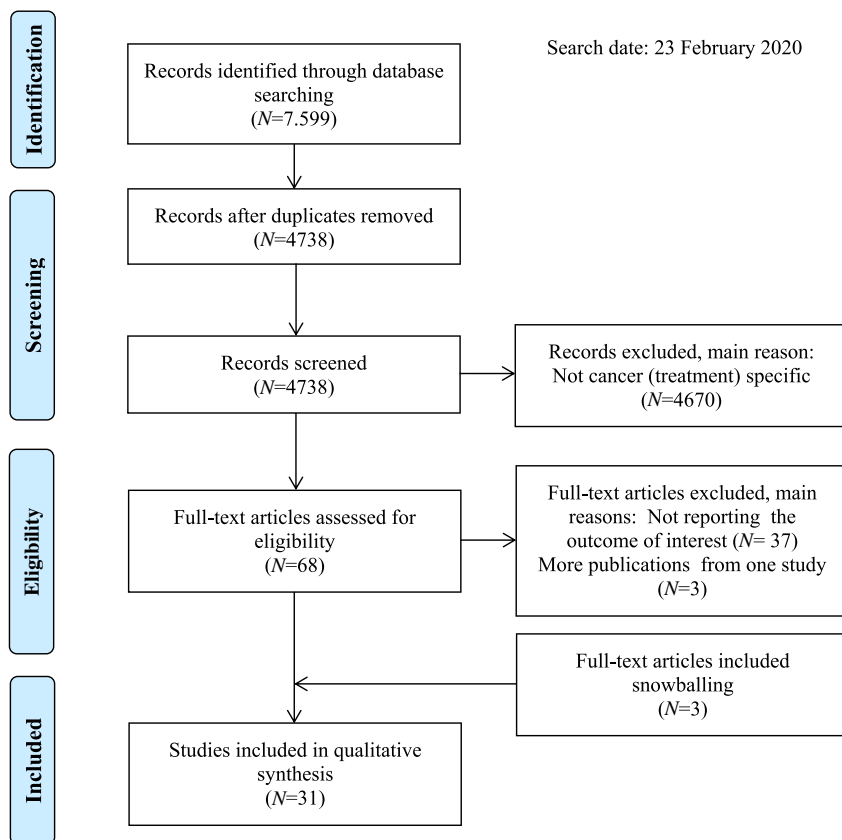
### 3.1 | Study selection

After removal of duplicates, 4,738 records were identified and screened on title and abstract (Figure 1). Sixty-eight studies were

TABLE 1 The control preference scale and the translation to decision roles<sup>17</sup>

Response	Control preference scale	Decision role
A	I prefer to make the final selection about which treatment I will receive	Active
B	I prefer to make the final selection of my treatment after seriously considering my doctor's opinion	Active
C	I prefer that my doctor and I share responsibility for deciding which treatment is best for me	Shared
D	I prefer that my doctor makes the final decision about which treatment, but seriously considers my opinion	Passive
E	I prefer to leave all decisions regarding treatment to my doctor	Passive

Abbreviation: CPS, control preference scale.



**FIGURE 1** Flowchart for the selection of studies, based on preferred reporting items for systematic reviews and meta-analyses<sup>16</sup>

screened full-text, of which 28 were eligible. Backward and forward citation tracking yielded three additional studies, resulting in 31 studies for analysis. The main reasons for exclusion was the focus on a diagnosis other than cancer and a focus on decision-making for cancer care in general instead of cancer treatment specifically.

### 3.2 | Study characteristics

In total, we included 31 studies, with 13,247 cancer patients participating. These patients reflected on 16,537 cancer treatment decisions. Table 2 provides an overview of the included studies. Most studies ( $N = 13$ ) included breast cancer patients,<sup>26-38</sup> two studies included patients with haematologic cancer,<sup>39,40</sup> two studies lung cancer patients,<sup>41,42</sup> one study colorectal cancer patients,<sup>43</sup> two studies prostate cancer patients<sup>44,45</sup> and others included various cancers.<sup>9,46-54</sup> More studies were performed in Western countries,<sup>9,27-31,33,35,36,39,40,42,44,45,47-54</sup> as compared to Asian countries.<sup>26,32,34,37,38,41,43,46</sup> Most studies included early stage cancer patients.<sup>26-33,36,37,42,44</sup> Five studies included advanced stage cancer patients,<sup>35,41,46,48,51</sup> eight studies included all stages,<sup>9,34,38,47,52-54</sup> and for six studies cancer stage was not reported.<sup>39,40,43,45,49,50</sup> Most studies used a cross-sectional design in which patients' preferred and perceived decision role were measured after treatment decision.<sup>9,26,27,29,30,32,33,35,37-43,45-54</sup> Five studies used a prospective

study design and measured patients' preferred decision role before treatment decision and their perceived role afterwards.<sup>28,31,34,36,44</sup> Study characteristics of the studies included by Tariman et al. can be found in the original publication.<sup>14</sup>

### 3.3 | Quality of studies

Quality of the included studies ranged from four to eight stars, with 12 studies having a good, 19 a fair and 0 a poor quality (Table 3). Most studies included a selected group of patients, lacked a sample size calculation and a description of the response rate and/or comparability with non-responders. Also, in some studies the sample was not described clearly, in these cases cancer stage was not reported. Furthermore, in three studies timing of the measurement of patients' preferred and perceived level of involvement was unclear. For retrospective studies, potential recall bias should be kept in mind.

### 3.4 | Preferred level of involvement

The median percentage of patients preferring a shared role for all studies was 46%, 25% for an active role and 27% for a passive role (Table 4 and Supporting Information 4). Subgroup analyses showed minor differences (Table 4). In both studies including

TABLE 2 Overview of the included studies, presenting study characteristics, the reported level of preferred, perceived involvement and discordance between the preferred and perceived level of involvement

Reference	Research design	Study population	Decision, moment, measurement	Preferred level of involvement	Perceived level of involvement	Discordance between preferred and perceived level of involvement	Discordance per level
		<i>N</i> = number of participants, age, type of cancer, stage cancer, country	Type of treatment decision Moment of measurement Questionnaire	<i>N</i> = number of decisions evaluated % of patient preferring an active, shared or passive role	<i>N</i> = number of decisions evaluated % of patient perceiving an active, shared or passive role		
Aminataie, 2019 <sup>26</sup>	Cross-sectional study	<i>N</i> = 328, mean 46 years, breast cancer, stage I-II, Iran	Surgery Post decision CPS & SDM Q9	<i>N</i> = 328 Active: 1% Shared: 8% Passive: 91%	<i>N</i> = 328 Active: 8% Shared: 78% Passive: 14%	Not reported	
Atherton, 2013 <sup>9</sup>	Cross-sectional study	<i>N</i> = 594, mostly >60 years, various cancer, stage I-IV, US	Treatment Post decision CPS	<i>N</i> = 594 Active: 35% Shared: 53% Passive: 13%	<i>N</i> = 594 Active: 33% Shared: 50% Passive: 17%	Discordance: 12%	
Berger, 2018 <sup>27</sup>	Cross-sectional study	<i>N</i> = 873, mean 59 years, breast cancer, stage I-III, US	Adj. chemotherapy Post decision Modified version CPS	<i>N</i> = 868 Active: 31% Shared: 51% Passive: 19%	<i>N</i> = 873 Active: 28% Shared: 41% Passive: 31%	Discordance: 53%	
Bieber, 2018 <sup>53</sup>	RCT	<i>N</i> = 107, mean 64 years, breast & colon cancer, stage I-IV, Germany	Treatment Post decision CPS & PPS	<i>N</i> = 96 Active: 19% Shared: 60% Passive: 21%	<i>N</i> = 96 Active: 25% Shared: 51% Passive: 24%	Discordance: 28%	Active: 28% Shared: 26% Passive: 35%
Brown, 2012 <sup>28</sup>	RCT	<i>N</i> = 683, mean 54 years/57 years, breast cancer, early stage, Australia, New Zealand, & Switzerland, Germany, Austria	Adjuvant therapy 2w pre & 2w post consult CPS	<i>N</i> = 683 Active: 24% Shared: 48% Passive: 28%	<i>N</i> = 683 Patient: 28% Shared: 26% Passive: 46%	Discordance: 63%	Active: 69% Shared: 64% Passive: 57%
Burton, 2017 <sup>29</sup>	Cross-sectional study	<i>N</i> = 104, included ≥75 years, breast cancer, early stage, UK	Surgery versus endocrine, post decision CPS	<i>N</i> = 93 Active: 39% Shared: 24% Passive: 38%	<i>N</i> = 93 Active: 41% Shared: 14% Passive: 45%	Discordance: 26%	Active: 19% Shared: 59% Passive: 11%
Carey, 2012 <sup>39</sup>	Cross-sectional study	<i>N</i> = 268, mean 60 years, haematologic cancer, stage unknown, Australia	Last important decision Post decision Modified version CPS	<i>N</i> = 235 Active: 25% Shared: 30% Passive: 46%	<i>N</i> = 235 Active: 20% Shared: 22% Passive: 58%	Discordance: 23%	Active: 28% Shared: 44% Passive: 8%

(Continues)

TABLE 2 (Continued)

Reference	Research design	Study population	Decision, moment, measurement	Preferred level of involvement	Perceived level of involvement	Disconcordance between preferred and perceived level of involvement	Disconcordance per level
Engelhardt, 2020 <sup>30</sup>	Multicenter observational study	N = 101, mean 61 years, breast cancer, stage I-III, The Netherlands	Adj. systemic treatment Post decision CPS & open question	N = 101 Active: 38% Shared: 40% Passive: 23%	N = 101 Active: 56% Shared: 9% Passive: 36%	Disconcordance: 51%	Active: 23% Shared: 83% Passive: 41%
Ghoshal, 2019 <sup>46</sup>	Cross-sectional study	N = 150, median 47 years, various cancer, advanced stage, India	Treatment Post decision Modified version CPS	N = 150 Active: 27% Shared: 21% Passive: 53%	N = 150 Active: 21% Shared: 19% Passive: 59%	Not reported	
Hamelinck, 2018 <sup>31</sup>	Prospective study	N = 122, mean 60 years, breast cancer, early stage, The Netherlands	BCS + RT versus mastectomy Pre & post decision Modified version CPS	N = 156 Active: 34% Shared: 51% Passive: 15%	N = 156 Active: 45% Shared: 33% Passive: 22%	Disconcordance: 60%	Active: 47% Shared: 65% Passive: 71%
Herrmann, 2018 <sup>47</sup>	Cross-sectional study	N = 423, mean 64 years, various cancer, early & advanced stage, Australia	Last important decision Post decision Modified version CPS	N = 416 Active: 31% Shared: 39% Passive: 30%	N = 416 Active: 28% Shared: 36% Passive: 37%	Disconcordance: 20%	Active: 23% Shared: 27% Passive: 7%
Hitz, 2013 <sup>48</sup>	Cross-sectional study	N = 480, median 67 years, various cancer, advanced, Switzerland	New line palliative treatment Post decision CPS	N = 463 Active: 11% Shared: 45% Passive: 44%	N = 463 Active: 13% Shared: 38% Passive: 50%	Disconcordance: 29%	Active: 42% Shared: 37% Passive: 18%
Hotta, 2010 <sup>41</sup>	Substudy of RCT	N = 28, median 67 years, lung cancer, stage IIIb/IV, Japan	Chemotherapy Post decision Pre + Per: CPS	N = 28 Active: 14% Shared: 61% Passive: 25%	N = 28 Active: 29% Shared: 46% Passive: 25%	Disconcordance: 32%	Active: 25% Shared: 35% Passive: 29%
Hou, 2014 <sup>43</sup>	Cross-sectional study	N = 113, mean 63 years, colorectal cancer, stage unknown, China	Surgery Post decision Modified version CPS	N = 113 Active: 10% Shared: 35% Passive: 54%	N = 113 Active: 24% Shared: 18% Passive: 59%	Disconcordance: 28%	Active: 14% Shared: 54% Passive: 14%
Kehl, 2015 <sup>53</sup>	Cross-sectional study	N = 5315, included 18+, colon & lung cancer, stage I-IV, US	Surgery, CT, RT Post decision CPS	N = 8191 decision by 5170 patients Active: 36% Shared: 59% Passive: 6%	N = 8191 decision by 5170 patients Active: 40% Shared: 47% Passive: 13%	Disconcordance: 40%	Active: 38% Shared: 39% Passive: 52%
Mack, 2019 <sup>49</sup>	Cross-sectional study	N = 203, included 15-29 years*, various cancer, stage unknown, US	Treatment Post decision CPS	N = 150 Active: 18% Shared: 63% Passive: 19%	N = 148 Active: 24% Shared: 42% Passive: 34%	Disconcordance: 34%	

TABLE 2 (Continued)

Reference	Research design	Study population	Decision, moment, measurement	Preferred level of involvement	Perceived level of involvement	Disconcordance between preferred and perceived level of involvement	Disconcordance per level
Mansfield, 2019 <sup>50</sup>	Cross-sectional study	N = 355, mean 61 years, various cancer, stage unknown, Australia	Last important decision Post decision Modified version CPS	N = 341 Active: 36% Shared: 32% Passive: 32%	N = 341 Active: 33% Shared: 27% Passive: 40%	Disconcordance: 30%	Active: 25% Shared: 42% Passive: 23%
Moth, 2016 <sup>42</sup>	Observational cohort	N = 98, median 64 years, lung cancer, I-IIIb, Australia & New Zealand	Adj, chemo Post decision CPS	N = 98 Active: 27% Shared: 47% Passive: 27%	N = 98 Active: 24% Shared: 48% Passive: 28%	Disconcordance: 19%	Active: 27% Shared: 15% Passive: 19%
Moth, 2019 <sup>51</sup>	Cross-sectional study	N = 179, median 74 years, various cancer, advanced stage, Australia	Palliative chemotherapy Post decision CPS	N = 172 Active: 39% Shared: 26% Passive: 35%	N = 172 Active: 42% Shared: 22% Passive: 36%	Disconcordance: 25%	Active: 18% Shared: 42% Passive: 20%
Nakashima, 2012 <sup>32</sup>	Cross-sectional study	N = 104, majority > 50 years, breast cancer, stage 0-III, Japan	Treatment Post decision CPS	N = 104 Active: 18% Shared: 69% Passive: 13%	N = 104 Active: 27% Shared: 43% Passive: 30%	Disconcordance: 41%	Active: 37% Shared: 46% Passive: 23%
Nguyen, 2014 <sup>33</sup>	Cross-sectional Study	N = 238, mean 56 years, breast cancer, stage I-II, France	Treatment Post decision TDM examples	N = 216 Active: 3% Shared: 30% Passive: 67%	N = 238 Active: 2% Shared: 10% Passive: 88%	Not reported	
Nicolai, 2016 <sup>54</sup>	Prospective parallel-group cluster-randomised controlled trial	N = 71, mean 64 years, breast & colon cancer, stage I-IV, Germany	Treatment Post decision CPS & PPS	N = 71 Active: 21% Shared: 65% Passive: 14%	N = 71 Active: 27% Shared: 52% Passive: 21%	Disconcordance: 34%	
Nies, 2017 <sup>34</sup>	Cross-sectional study	N = 204, mean 54 years, breast cancer, all stages, Malaysia	Treatment Pre + post decision CPS + PPS	N = 204 Active: 10% Shared: 48% Passive: 43%	N = 204 Active: 9% Shared: 52% Passive: 39%	Disconcordance: 9%	Active: 10% Shared: 4% Passive: 14%
Palmer, 2013 <sup>45</sup>	Cross-sectional study	N = 181, mean 61 years, prostate cancer, stage unknown, US	Treatment Post decision Modified version CPS	N = 181 Active: 45% Shared: 39% Passive: 16%	N = 181 Active: 46% Shared: 39% Passive: 15%	Disconcordance: 3%	Active: 1% Shared: 3% Passive: 10%
Sepucha, 2009 <sup>35</sup>	Pilot intervention study	N = 32, median 55 years, breast cancer, advanced stage, US	Treatment Post decision Modified version CPS	N = 32 Active: 7% Shared: 72% Passive: 21%	N = 24 Active: 13% Shared: 42% Passive: 46%	Disconcordance: 62%	

(Continues)

TABLE 2 (Continued)

Reference	Research design	Study population	Decision, moment, measurement	Preferred level of involvement	Perceived level of involvement	Disconcordance between preferred and perceived level of involvement	Disconcordance per level
Seror, 2013 <sup>36</sup>	Cohort study	N = 415, mean 39 years, breast cancer, stage 0-III, France	Surgery, chemo-therapy, adjuvant endocrine therapy Pre + post start treatment CPS	N = 945 decision Active: 14% Shared: 27% Passive: 59%	N = 945 decision Active: 2% Shared: 19% Passive: 79%	Disconcordance: 46%	Active: 95% Shared: 77% Passive: 21%
Stacey, 2010 <sup>52</sup>	Descriptive study	N = 192, mean 60 years, various cancer and stages, Canada	Chemotherapy, radiotherapy Post decision Modified version CPS	N = 192 Active: 51% Shared: 33% Passive: 17%	N = 192 Active: 55% Shared: 35% Passive: 10%	Not reported	
Van Stam, 2018 <sup>44</sup>	Prospective, multicenter, observational study	N = 454, mean 67 years, prostate cancer, cT1-cT2, Netherlands	Treatment options: AS, RP, external beam RT and Brachy Pre + post treatment CPS	N = 454 Active: 89% Passive: 11%	N = 454 Active: 87% Passive: 13%	Disconcordance: 17%	Active: 11% Shared: - Passive: 67%
Wang, 2018 <sup>37</sup>	Cross-sectional study	N = 154, mean 47 years, breast cancer, stage 0-II, Taiwan	Surgery Post decision Self-developed CPS	N = 154 Active: 18% Shared: 55% Passive: 27%	N = 154 Active: 12% Shared: 63% Passive: 25%	Disconcordance: 31%	Active: 59% Shared: 20% Passive: 36%
Yamauchi, 2017 <sup>38</sup>	Cross-sectional study	N = 650, included 20-69 years, breast cancer, stage 0-IV, Japan	Treatment Post decision CPS	N = 650 Active: 37% Shared: 50% Passive: 13%	N = 650 Active: 48% Shared: 30% Passive: 22%	Disconcordance: 43%	
Yogaparan, 2009 <sup>40</sup>	Cross-sectional study	N = 31, mean 64 years, acute myeloid leukaemia, stage unknown, Canada	Treatment Post decision CPS	N = 31 Active: 16% Shared: 32% Passive: 52%	N = 31 Active: 23% Shared: 39% Shared: 39%	Not reported	

Abbreviations: BCS, breast conserving surgery; CPS, control preference scale; CT, chemotherapy; PPS, patient perception scale; RT, radiotherapy; TDM, treatment decision making; SDM, shared decision making.

\*We only use data 18+.



TABLE 3 Quality assessment of the individual study, based on a modified version of the NOS

	Selection				Outcome		Total stars
	1 <i>Clear description sample</i>	2 <i>Representativeness sample</i>	3 <i>Sample size</i>	4 <i>Non responders</i>	5 <i>Clear variables</i>	6 <i>Outcome assessment</i>	
Aminiae	2	0	0	0	2	2	6
Atherton	2	1	1	0	2	2	8
Berger	2	1	0	0	2	2	7
Bieber	2	0	0	0	2	2	6
Brown	2	0	0	0	2	2	6
Burton	2	0	0	0	2	2	6
Carey	1	1	0	0	2	2	6
Engelhardt	2	0	1	0	2	1	6
Ghoshal	1	0	1	0	1	2	5
Hamelinck	2	0	0	0	2	2	6
Herrmann	2	0	0	1	2	2	7
Hitz	2	1	1	0	2	2	8
Hotta	1	0	0	0	2	2	5
Hou	1	0	0	0	1	2	4
Kehl	2	1	0	0	2	2	7
Mack	1	0	1	0	2	2	6
Mansfield	1	0	1	1	2	2	7
Moth 2016	2	1	0	0	2	2	7
Moth 2019	2	1	0	0	2	2	7
Nakashima	2	0	0	0	2	2	6
Nguyen	2	0	0	0	1	1	4
Nicolai	2	0	0	0	2	2	6
Nies	2	1	0	0	2	2	7
Palmer	2	1	0	0	2	2	7
Sepucha	2	0	0	0	2	2	6
Seror	2	1	0	0	2	2	7
Stacey	1	0	0	0	2	2	5
van Stam	2	1	0	1	2	2	8
Wang	2	0	0	0	2	1	5
Yamauchi	2	0	0	0	2	2	6
Yogaparan	1	0	0	0	2	2	5

Note: Number of stars for 'selection of participants' and 'definition and assessment of the outcome'. Maximum number of stars for selection = 5; Maximum number of stars for outcome = 4. Number of stars 0-3: poor quality, 4-6: fair quality, 7-9: good quality (note that this is based on an adapted scoring from the NOS).

Abbreviation: NOS, Newcastle-Ottawa scale.

haematologic cancer patients, the percentage of patients with a preference for a passive role was higher than for an active or shared role. For prostate cancer patients, the percentage of patients preferring active involvement was higher than for shared and passive involvement. The median percentage of patients

preferring an active role was lower for Asian cancer patients (16%) than for Western cancer patients (31%). Patients with advanced cancer less often preferred an active role as compared to early stage cancer patients (median 14%, and 26%, respectively).

TABLE 4 Comparison of the overall median of the included studies in the review of Tariman et al. and this review, concerning the percentage preferred and perceived active, shared and passive involvement for all studies and for subgroups<sup>14</sup>

		Previous Review by Tariman et al.			Present review by Noteboom et al.		
		Preferred	Perceived		Preferred	Perceived	
		N = number of studies, participants, decisions	Median % (IQR)	N = number of studies, participants, decisions	Median % (IQR)	N = number of studies, participants, decisions	Median % (IQR)
<b>Active involvement in decision making</b>							
<b>All</b>	N = 19, 5294, 5294	24 (19–39)	32 (22–46)	N = 18, 6079, 6332	25 (14–36)	N = 31, 13247, 16537	27 (20–41)
<b>Breast</b>	N = 11, 3830, 3830	24 (20–35)	35 (24–51)	N = 10, 4667, 4667	18 (9–36)	N = 13, 4005, 4561	27 (9–43)
<b>Lung</b>	N = 1 <sup>a</sup> , 2, 22	19	14	N = 1 <sup>a</sup> , 22, 22	1427	N = 2 <sup>a</sup> , 126, 126	29
<b>Haematologic</b>	N = 0	-	-	N = 0	25	N = 2 <sup>a</sup> , 299, 266	20
<b>Colorectal</b>	N = 1 <sup>a</sup> , 55, 55	18	6	N = 1 <sup>a</sup> , 55, 55	16	N = 1 <sup>a</sup> , 113, 113	23
<b>Prostate</b>	N = 4, 853, 853	41 (27–53)	57 (35–78)	N = 4, 853, 853	10	N = 2 <sup>a</sup> , 635, 635	24
<b>Western</b>	N = 19, 5294, 5294	24 (19–39)	32 (22–46)	N = 18, 6079, 6332	89	N = 2 <sup>a</sup> , 635, 635	87
<b>Asian</b>	N = 0	-	-	N = 0	45	N = 5, 869, 845	39
<b>Early</b>	N = 7, 2090, 2090	40 (31–53)	62 (39–77)	N = 7, 3076, 3076	31 (18–38)	N = 23, 11516, 14806	28 (23–42)
<b>Advanced</b>	N = 1 <sup>a</sup> , 22, 22	19	14	N = 1 <sup>a</sup> , 22, 22	16 (10–25)	N = 8, 1731, 1731	23 (10–29)
<b>Shared involvement in decision making</b>							
<b>All</b>	N = 19, 5294, 5294	42 (28–47)	21 (17–34)	N = 18, 6079, 6332	46 (32–56)	N = 30, 12793, 16083	39 (22–47)
<b>Breast</b>	N = 11, 3830, 3830	42 (29–49)	30 (18–36)	N = 10, 4667, 4667	48 (29–53)	N = 13, 4005, 4561	33 (17–48)
<b>Lung</b>	N = 1 <sup>a</sup> , 2, 22	24	9	N = 1 <sup>a</sup> , 22, 22	61	N = 2 <sup>a</sup> , 126, 126	46
<b>Haematologic</b>	N = 0	-	-	N = 0	47	N = 2 <sup>a</sup> , 299, 266	48
<b>Colorectal</b>	N = 1 <sup>a</sup> , 55, 55	47	18	N = 1 <sup>a</sup> , 55, 55	30	N = 2 <sup>a</sup> , 299, 266	22
<b>Prostate</b>	N = 4, 853, 853	43 (38–48)	30 (15–43)	N = 4, 853, 853	32	N = 1 <sup>a</sup> , 113, 113	39
<b>Western</b>	N = 19, 5294, 5294	42 (28–47)	21 (17–34)	N = 18, 6079, 6332	43 (32–55)	N = 22, 11062, 13632	37 (22–43)
<b>Asian</b>	N = 0	-	-	N = 0	49 (25–60)	N = 8, 1731, 1731	45 (22–60)
<b>Early</b>	N = 7, 2090, 2090	42 (29–48)	17 (14–33)	N = 7, 3076, 3076	47 (27–51)	N = 12, 3671, 4227	33 (14–48)
<b>Advanced</b>	N = 1 <sup>a</sup> , 22, 22	24	9	N = 1 <sup>a</sup> , 22, 22	45 (24–67)	N = 5, 869, 845	38 (21–44)

TABLE 4 (Continued)

	Previous Review by Tariman et al.			Present review by Noteboom et al.		
	Preferred		Perceived	Preferred		Perceived
	N = number of studies, participants, decisions	Median % (IQR)	N = number of studies, participants, decisions	N = number of studies, participants, decisions	Median % (IQR)	N = number of studies, participants, decisions
<b>Passive involvement in decision making</b>						
<b>All</b>	N = 19, 5294, 5294	34 (13-47)	N = 18, 6079, 6332	39 (21-76)	27 (16-44)	N = 31, 13247, 16537
<b>Breast</b>	N = 11, 3830, 3830	34 (15-48)	N = 10, 4667, 4667	29 (20-55)	27 (17-51)	N = 13, 4005, 4561
<b>Lung</b>	N = 1 <sup>a</sup> , 2, 22	57	N = 1 <sup>a</sup> , 22, 22	76	25	N = 2 <sup>a</sup> , 126, 126
<b>Haematologic</b>	N = 0, 0, 0	-	N = 0, 0, 0	-	46	N = 2 <sup>a</sup> , 299, 266
<b>Colorectal</b>	N = 1 <sup>a</sup> , 55, 55	35	N = 1 <sup>a</sup> , 55, 55	76	54	N = 1 <sup>a</sup> , 113, 113
<b>Prostate</b>	N = 4, 853, 853	16 (8-29)	N = 4, 853, 853	15 (7-23)	11	N = 2 <sup>a</sup> , 635, 635
<b>Western</b>	N = 19, 5294, 5294	34 (13-47)	N = 18, 6079, 6332	39 (21-76)	23 (16-38)	N = 23, 11516, 14806
<b>Asian</b>	N = 0	-	N = 0	-	35 (16-54)	N = 8, 1731, 1731
<b>Early</b>	N = 7, 2090, 2090	12 (10-17)	N = 7, 3076, 3076	18 (8-27)	27 (16-54)	N = 12, 3671, 4227
<b>Advanced</b>	N = 1 <sup>a</sup> , 22, 22	57	N = 1 <sup>a</sup> , 22, 22	76	35 (23-49)	N = 5, 869, 845

<sup>a</sup>For subgroups that include 1 or 2 studies, the individual percentage(s) is presented.

### 3.5 | Perceived level of involvement

The median percentage of patients perceiving a shared role for all studies was 39%, 27% for an active role and 34% for a passive role (Table 4 and Supporting Information 4). Subgroup analyses showed minor differences (Table 4). For haematologic cancer patients, both studies showed that the percentage of patients perceiving a passive role was higher than those perceiving an active or shared role. In addition, the median percentage of cancer patients perceiving a passive role is somewhat higher for Western patients (36%) as compared to Asians (28%). Also, advanced stage cancer patients perceived a passive role more often when compared to early stage cancer patients (median 46% vs. 31%).

### 3.6 | Concordance between the preferred and perceived level of involvement

Combining all studies, the median percentage of overall concordance between patients' preferred and perceived level of involvement in decision making for cancer treatment was 70%. Discordance was highest for patients preferring a shared role (median 42%), as compared to patients preferring an active (median 26%) or a passive role (median 22%) (Table 5). In subgroup analyses, the overall discordance levels were the highest for studies in patients with early stage (44%) and breast cancer (46%).

### 3.7 | Comparison with Tariman et al.

Table 6 shows the difference in outcomes between the review by Tariman et al. and the present review. This table shows that compared to a decade ago the preference for active and shared involvement has somewhat increased, while the preference for passive involvement decreased. The perceived level of shared involvement is significantly higher than a decade ago (median review Tariman et al. 21%, median present review 39%,  $p = 0.036$ ). The discordance between the preferred and perceived level of involvement decreased for all levels of involvement. Presently, the discordance in shared involvement is significantly lower than a decade ago (median review Tariman et al. 67%, median present review 42%,  $p = 0.005$ ).

## 4 | DISCUSSION

This systematic review presents an overview of studies exploring cancer patients' preferred and perceived level of involvement in decision making for cancer treatment and the (dis-) concordance between these levels. Pooled results demonstrate that patients' preferences for and perceptions of their decision role vary, but a majority of the patients preferred and

perceived a shared role in decision making. About one in three patients perceived a decision role other than they preferred. Although the majority of cancer patients preferred a shared role in decision making, half of these patients perceived either an active or passive role.

In line with the previous systematic review, we found that patients' preferences and perceptions for involvement in decision making vary and that discordance between preference and perception occurs frequently.<sup>14</sup> Tariman et al.<sup>14</sup> showed that the percentage of patients with prostate and breast cancer preferring a shared or active role is higher than for other cancer types (colorectal, lung, gynaecological). 10 years later this is still the case for breast and prostate cancer patients. For lung cancer, the limited number of new studies suggests a minor shift from both preference for and perception of a passive role, to a more active role. In addition, for breast cancer patients, it seems that the percentage of patients preferring and perceiving passive involvement has decreased. Also, for prostate cancer patients, the percentage of patients perceiving a passive role is now somewhat lower. This is likely to be due to the increased attention for SDM in this field, which together with the rising number of treatment options available with comparable efficacy, urges for more patient involvement in individual treatment decisions.<sup>55,56</sup>

In summary, compared to the findings of Tariman et al., our review suggests that some progress in patient involvement has been made in the last decade. Patients are more involved in decision making than a decade ago and the discordance between the preferred and perceived level of involvement has decreased. Furthermore, although Tariman et al.<sup>14</sup> recommended to perform studies including patients with cancers other than breast cancer and to use a longitudinal design to measure patients' level of involvement, the majority of studies in our review included breast cancer patients and used a cross-sectional design. Hence, still longitudinal exploration of patients' preferences and perceptions of involvement is needed, as preferences for involvement may change over time and since a prospective approach minimises the influence of recall bias on findings.<sup>57</sup> Also, studies should include more patients diagnosed with cancer other than breast cancer.

Our review highlights that even though most patients prefer shared or active involvement, some prefer a passive role more often. Haematologic cancer patients seem to be more likely to prefer and perceive a passive role in treatment decision making as compared to patients with other types of cancer. Ernst et al.<sup>58</sup> suggest that for haematologic cancer this might be due to the complex treatment plan and the perception of the physician as the expert, both impeding patient involvement.

Furthermore, in our results, the majority of the Asian cancer patients preferred and perceived a shared role. This is in contrast with the results of a review by Yilmaz et al.<sup>59</sup> which concluded that most studies including Asian cancer patients (living in Western countries) reported that these patients preferred a passive role in

**TABLE 5** Comparison of the overall median of the included studies in the review of Tariman et al. and this review, concerning the percentage discordance and the discordance per level presented for all studies and for subgroups<sup>14</sup>

Discordance	Previous review by Tariman et al.						Present review by Noteboom et al.					
	Overall			Active			Shared			Passive		
	<i>N</i> = number of studies, participants, decisions <sup>a</sup>	Median % (IQR)	Median % (IQR)	<i>N</i> = number of studies, participants, decisions <sup>a</sup>	Median % (IQR)	Median % (IQR)	<i>N</i> = number of studies, participants, decisions <sup>a</sup>	Median % (IQR)	Median % (IQR)	<i>N</i> = number of studies, participants, decisions <sup>a</sup>	Median % (IQR)	Median % (IQR)
All	<i>N</i> = 14, 5054, 5255	38 (25-52)	39 (22-63)	67 (63-75)	37 (27-56)	31 (22-44)	<i>N</i> = 26, 12308, 15598	26 (18-41)	42 (26-59)	22 (14-40)		
Breast	<i>N</i> = 10, 4443, 4644	38 (30-49)	30 (13-41)	65 (60-70)	41 (19-85)	46 (31-60)	<i>N</i> = 11, 3439, 3995	42 (20-67)	62 (27-74)	30 (16-53)		
Lung	<i>N</i> = 1 <sup>b</sup> , 22, 22	29	-	-	-	32	<i>N</i> = 2 <sup>b</sup> , 126, 126	25	35	29		
Haematologic	<i>N</i> = 0	-	-	-	-	23	<i>N</i> = 1 <sup>b</sup> , 268, 235	28	44	8		
Colorectal	<i>N</i> = 1 <sup>b</sup> , 55, 55	69	100	85	32	28	<i>N</i> = 1 <sup>b</sup> , 113, 113	14	54	14		
Prostate	<i>N</i> = 0	-	-	-	-	17	<i>N</i> = 2 <sup>b</sup> , 635, 635	11	-	67		
Western	<i>N</i> = 14, 5054, 5255	38 (25-52)	39 (22-63)	67 (63-75)	37 (27-56)	30 (21-50)	<i>N</i> = 20, 11055, 14345	27 (19-42)	42 (27-64)	21 (11-52)		
Asian	<i>N</i> = 0	-	-	-	-	32 (23-42)	<i>N</i> = 6, 1253, 1253	25 (12-48)	35 (12-50)	23 (14-33)		
Early	<i>N</i> = 6, 2760, 2760	38 (31-51)	26 (range 9-34)	64 (range 58-66)	41 (range 40-100)	44 (24-55)	<i>N</i> = 10, 3105, 3661	37 (21-64)	62 (27-74)	36 (20-62)		
Advanced	<i>N</i> = 1 <sup>b</sup> , 22, 22	29	-	-	-	31 (26-55)	<i>N</i> = 4, 719, 695	25	37	20		

<sup>a</sup>Numbers are based on the overall discordance, numbers of studies, participants and decisions for the discordance of the active, shared or passive role might deviate from the numbers for the overall discordance, due to the incompleteness of the reported data in the individual studies.

<sup>b</sup>For subgroups that include 1 or 2 studies, the individual percentage(s) is presented.

**TABLE 6** Differences of the overall median of the included studies in the review of Tariman et al. and the present review, concerning the percentage preferred and perceived active, shared and passive involvement for all studies and whether this difference is statistically significant<sup>14</sup>

		Previous review by Tariman et al.	Present review by Noteboom et al.	Difference (p-value)
	Involvement	Median % (IQR)	Median % (IQR)	
<b>Preferred</b>	Active	24 (19–39)	25 (14–36)	+1 (1.0)
	Shared	42 (28–47)	46 (32–56)	+4 (0.561)
	Passive	34 (13–47)	27 (16–44)	–7 (0.561)
<b>Perceived</b>	Active	32 (22–46)	27 (20–41)	–5 (0.372)
	Shared	21 (17–34)	39 (22–47)	+18 (0.036) <sup>a</sup>
	Passive	39 (21–76)	34 (22–46)	–5 (1.0)
<b>Disconcordance</b>	Overall	38 (25–52)	31 (22–44)	–7 (0.198)
	Active	39 (22–63)	26 (18–41)	–13 (0.645)
	Shared	67 (63–75)	42 (26–59)	–25 (0.005) <sup>a</sup>
	Passive	37 (27–56)	22 (14–40)	–15 (0.160)

<sup>a</sup>p-value < 0.05 was considered as statistically significant.

decision making. The difference in cultures between Asian countries might explain this difference, since our review included more Asian patients from Japan, whereas the review of Yilmaz et al.<sup>59</sup> included mostly patients of Chinese origin.

Although it seems that, in the past decade, some progress has been made in actively involving cancer patients in treatment decisions, the suboptimal concordance between patients' preferred and perceived decision role shows that it remains challenging to involve patients to the level of their preference. Several potential explanations for the disconcordance between patients' preferred and perceived level of involvement are described in literature. Insufficient creation of awareness among cancer patients that they do have choice<sup>7</sup> and inadequate exploration of patients' values and preferences by physicians are mentioned as barriers for involvement in SDM.<sup>60</sup> Creating awareness of choice is difficult, since it has been reported that even when a choice in treatment is offered, cancer patients do not always experience having a treatment choice.<sup>61</sup> It is also suggested that physicians incorrectly estimate to what extent their cancer patients want to be involved in treatment decision making, without explicitly asking them.<sup>62</sup> This is further complicated by potential differences in the perception of the extent of involvement between cancer patients and physicians.<sup>41</sup> External factors might also influence the level of involvement. Keating et al.<sup>63</sup> showed that the more evidence based a specific treatment was, the more likely it was that decisions were shared. Also, lack of time during consultations is mentioned by physicians as a barrier for patient involvement.<sup>64,65</sup>

All these internal and external factors could lead to the involvement of patients in decision making for cancer treatment at a level other than preferred.

#### 4.1 | Study limitations

This review has its strengths and limitations. A strength of this review is the large number of studies included and the completeness of the data we retrieved from the studies. A limitation of this review, similar to the review of Tariman et al.<sup>14</sup> is that the majority of the studies in our review included breast cancer patients. Therefore, the overall trends we show in our data might not be generalisable to other cancer diagnosis. In addition, even though the results of randomised trials showed similar results to those with a retrospective design, it should be taken into account that trials may have targeted level of decision involvement with an intervention which could influence results. Also, the data in the included studies does not allow to show the influence of important patient characteristics, such as socioeconomic status, race and health literacy.

#### 4.2 | Clinical implications

That said, our findings highlight the variety in preferences for involvement in treatment decision making and challenges of attempting to match the preferred with the perceived level of involvement. Consequently, the main implication for practice is that more actively tailoring of patient involvement to individual preference is needed. This active exploration of preference should be performed at an early stage of the treatment decision process, to enable patients to take their preferred roles in shaping their personalised cancer care. Attempts to create awareness of this among physicians have resulted in improvement, but still more effort is needed. The implementation of tools, such as the three question model,<sup>66</sup> could support physicians in exploring patients' preferences and enable them to meet these preferences for involvement.

### 5 | CONCLUSION

Patients' preferences for involvement in cancer treatment decision making vary, but the majority of patients prefers to be involved. A significant number of patients perceive a decisional role other than preferred, especially when patients prefer a shared role. Improvements in patient involvement have been observed in the last decade. However, there is still room for improvement and physicians should be made more aware of the importance of exploring patients' preferences for involvement in decision making to truly deliver personalised cancer care.

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to declare that are relevant to the content of this article.

## ETHICS STATEMENT

This is a systematic review. Ethics approval is not applicable.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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