



**HAL**  
open science

## Shared Decision Making among Patients with Chronic Conditions in France: A Cross-Sectional Survey in the ComPaRe E-Cohort

Yaël Busnel, France Légaré, Nora Moumjid, Laurie Panse, Annaëlle Testud, Viet-Thi Tran, Julie Haesebaert

### ► To cite this version:

Yaël Busnel, France Légaré, Nora Moumjid, Laurie Panse, Annaëlle Testud, et al.. Shared Decision Making among Patients with Chronic Conditions in France: A Cross-Sectional Survey in the ComPaRe E-Cohort. *Medical Decision Making*, 2026, Online ahead of print. <10.1177/0272989X251407617>. <hal-05538189>

**HAL Id: hal-05538189**

**<https://univ-lyon1.hal.science/hal-05538189v1>**

Submitted on 6 Mar 2026

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons CC BY-SA 4.0 - Attribution - ShareAlike - International License

# Shared Decision Making among Patients with Chronic Conditions in France: A Cross-Sectional Survey in the ComPaRe E-Cohort

Yaël Busnel , France Légaré , Nora Moumjid, Laurie Panse, Annaëlle Testud, Viet-Thi Tran , and Julie Haesebaert 

**Background.** Shared decision making (SDM) is a cornerstone of patient-centered care; however, little information is available on how SDM is practiced in routine care. We aimed to assess the level of SDM perceived by patients with chronic conditions for the most important health decision in the past 12 mo. **Methods.** This was a cross-sectional online survey among ComPaRe, a nationwide e-cohort of patients with chronic conditions in France. The survey asked participants about their perception of SDM using the 9-item Shared Decision-Making Questionnaire (SDM-Q-9) regarding their most important health decision in the past 12 mo. We weighted the sample to represent French patients with chronic conditions and conducted regression models to identify factors associated with higher SDM levels, adjusting for sociodemographic and clinical characteristics. **Results.** In total, 2,087 patients were analyzed (participation rate: 34.9%). In the weighted sample, 53.0% were women, the mean (SD) age was 51.0 (15) y, and the most frequent conditions were endometriosis (27.3%), inflammatory rheumatic diseases (20.7%), and high blood pressure (19.3%). The most important health decisions in the past 12 mo were mainly about drug treatments (36.5%) or surgery (20.5%). The mean (SD) SDM-Q-9 score was 63 (27)/100 (moderate level of SDM). The highest scores were observed for cancer (70 [26]) and depression (69 [26]), whereas the lowest scores were for long COVID (54 [28]) and endometriosis (58 [25]). Decisions about surgery (71 [25]) and with specialists (64 [27]) were associated with higher scores compared with medication decisions (60 [28]) or with general practitioners (62 [27]). Multivariate analysis confirmed that a higher SDM level was associated with being a man; having higher health literacy; making decisions relating to cancer, surgery, or medical devices; and specialist involvement. **Conclusions.** Patients with chronic conditions in France report moderate levels of SDM, with substantial variations by condition, decision type, and patient characteristics. Findings highlight the need for tailored strategies to foster SDM in chronic care.

## Highlights

- Shared decision making (SDM) is considered a key component of the chronic disease management model.
- This study provides the first nationwide assessment of perceived SDM levels among patients with chronic conditions in France.
- Patients have a moderate overall SDM score, but significant disparities exist. Patients with less recognized conditions such as long COVID or endometriosis, low health literacy, and high treatment burden reported significantly lower SDM scores as compared with others in their care decisions.
- These findings underscore the need for targeted interventions to improve SDM implementation.

## Corresponding Author

Julie Haesebaert, Laboratoire RESHAPE, 8 avenue Rockefeller, cedex 08, 69373, France; (julie.haesebaert01@chu-lyon.fr).

## Keywords

chronic disease, cohort, SDM-Q-9, shared decision making

Date received: February 5, 2025; accepted: October 19, 2025

## Introduction

Chronic conditions affect 40% to 60% of adults in Western countries.<sup>1</sup> Patients with chronic conditions frequently face health decision-making challenges, including choosing between treatment options (e.g., medication, surgery), lifestyle changes (e.g., diet, exercise), or management strategies.<sup>2</sup> Many of these decisions are complex, involving multiple options, limited evidence, or conflicting outcomes, and more than half of individuals report experiencing decisional conflict.<sup>3</sup> Shared decision making (SDM) is a decision-making process characterized by the sharing of information between clinicians and patients and/or families to build a consensus about the preferred treatment and reach an agreement on the decision.<sup>4,5</sup> By supporting patient agentivity and enabling informed, values-congruent choices, SDM contributes to high-value care.<sup>6</sup> As a result, SDM has been prioritized in health policy across Western countries and is central to many comprehensive care models.<sup>6,7</sup> In France, patient inclusion in health care decision making has been supported by regulatory measures and policies, with key milestones including the 2002 Patients' Rights Law<sup>8</sup> and guidelines from the Haute Autorité de Santé in 2013.<sup>9,10</sup>

Despite its central role in patient-centered care, data on the implementation of SDM in routine clinical practice remains limited, with most insights derived from experimental studies.<sup>11</sup> Few population-based studies have examined how SDM is implemented in real-world settings, particularly among patients with chronic

conditions, and existing data suggest substantial disparities across patient populations.<sup>12,13</sup> In this study, we described the level of SDM, as perceived by patients with chronic conditions, for what they considered the most important health decision in the past 12 mo. Then, we explored the factors associated with the perceived level of SDM.

## Methods

We conducted a cross-sectional survey among patients with chronic conditions recruited in the Community of Patients for Research (ComPaRe; <http://compare.aphp.fr>), a nationwide e-cohort of 57,000 adults with chronic conditions, in France. ComPaRe received approval from the Comité de Protection des Personnes Ile de France 1 (IRB: 0008367), and all methods were performed in accordance with the relevant guidelines and regulations. The results of this survey are reported following the CHERRIES guideline for e-surveys.<sup>14</sup>

### Study Population

Participants were French adult patients (>18 y old) enrolled in the e-cohort ComPaRe who reported having at least 1 chronic condition, defined as any medical condition requiring health care for at least 6 mo. Patients provided informed consent at inclusion in the e-cohort. In addition, to participate in this survey, participants were required to be active in the e-cohort (i.e., they answered to a questionnaire in ComPaRe in the previous 6 mo), to live in France, and to report at least 1 health decision in the past 12 mo.

Eligible participants were invited to take part in the survey by e-mail, which included a link to the self-administered questionnaire (see additional file 1).

### Measures

The survey first asked participants to focus on the health-related decision they deemed most important in the past 12 mo. Importance was not predefined but rather assessed by the respondents, based on what they perceived to be most significant to them. Participants selected the type of decision from a predefined list

---

Research on Healthcare Performance (RESHAPE), INSERM U1290, University Lyon1, Lyon, France (YB, LP, AT, JH); Department of Family Medicine and Emergency Medicine, Université of Laval, Quebec, Canada (FL); Claude Bernard Lyon 1 University, Léon Bérard Cancer Centre, Lyon, France (NM); Center for Clinical Epidemiology, Hôtel-Dieu Hospital (AP-HP), Paris, France Université de Paris, CRESS, INSERM, INRA, Paris, France (V-TT); Hospices Civils de Lyon, Pôle Santé Publique, Service Recherche et Epidémiologie Cliniques, Lyon, France (JH). The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Financial support for this study was provided entirely by a contract with the Laboratory RESHAPE. The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

inspired by the DICTUM classification and could also provide a free-text description of their decision (drug-related decisions, planning a surgery, using a medical device, carrying out additional examinations, changing disease follow-up, other – social or health insurance issues).<sup>15,16</sup> This framing allowed the inclusion of a wide range of situations, including those not always recognized as decisions in clinical practice, such as renewing a treatment or undergoing follow-up. It aimed to capture the patient's perceived agency and their experience of meaningful choice in care. In addition, we collected the time elapsed since the decision had been made. We also collected data on the health professionals involved in the decision-making process, and the evolution of the patient's health status since the decision (improved/stabilized/deteriorated) were also collected.

Participants' perspectives on the level of SDM for the decision chosen were assessed using the French version of the 9-item Shared Decision-Making Questionnaire (SDM-Q-9).<sup>17</sup> The SDM-Q-9 is a self-administered questionnaire comprising 9 items on 6-point Likert-type scale summed into a 0 to 45 total score, which was scaled to a range of 0 to 100 points. Higher scores indicate a greater extent of SDM. In addition, participants were also asked whether the health professional respected their desired level of involvement and their preference regarding involvement in the decision-making process in health in general based on Strull's SDM scale.<sup>18</sup>

In addition to their answers to the survey, we used participants' most recent data available regarding their 1) sociodemographic characteristics (gender, age, marital status, occupation, level of education, and chronic conditions according to the categories of the ICD-10 classification)<sup>19</sup>; measures of burden of treatment related to all chronic conditions reported by the participant using the Treatment Burden Questionnaire (TBQ),<sup>20</sup> a self-administered questionnaire, with scores ranging from 0 (no burden) to 150 (high burden); and 3) measures of Health Literacy level using the French version of Functional, Communicative and Critical Health Literacy (Functional, Communicative and Critical Health Literacy scale; FCCHL) scale,<sup>21</sup> with scores ranging from 14 (lowest health literacy) to 70 (highest health literacy).

### Analysis

To obtain estimates representative of the French population of patients with chronic conditions, we used a weighted data set obtained by calibration on margins with weights for age categories, gender, and education level (low, middle school or equivalent, high school or equivalent, associate's degree, higher education). Weights were derived from

national census data describing the characteristics of the French population reporting chronic conditions.<sup>22</sup>

We described the mean SDM-Q-9 score on the whole sample and in subgroups according to sex, age category (18–34, 35–54, 55–74, and 75 y and older), chronic disease to which the decision referred (the 10 most frequent chronic conditions among respondents), professional involved in the decision process, and the type of decision. We also cross-tabulated the types of decisions with the health care professionals involved, to describe which professionals were most frequently associated with each decision type (Appendix Table A3). For each decision type, we further tested whether SDM-Q-9 scores differed significantly by health care professional using Kruskal–Wallis tests (Appendix Table 4). For the interpretation of SDM-Q-9 scores, since no formal thresholds are recognized, we categorized the level of SDM based on the theoretical range of the scale (0–100) as follows: low (0–25), moderate-low (26–50), moderate (51–75), and high (76–100).

We conducted univariable and multivariable regression linear analyses to examine factors associated with SDM-Q-9 score. Multivariable models included the SDM-Q-9 total score as dependent variable and the following independent variables: sociodemographic characteristics (gender male/female, age, level of education), level of health literacy (FCCHL total score); clinical factors (medical condition to which the decision referred, number of chronic conditions, and TBQ total score), and factors related to the decision making (type of decision, health care professionals implicated). Tests of collinearity (variance inflation factor) between the factors of the full linear regression model were performed. Results are presented using the Beta coefficients with their 95% confidence interval (CI).

We performed statistical analysis using R version 4.3.0 (<http://www.R-Project.org>, the R Foundation for Statistical Computing, Vienna, Austria). *P* values less than 0.05 were considered statistically significant.

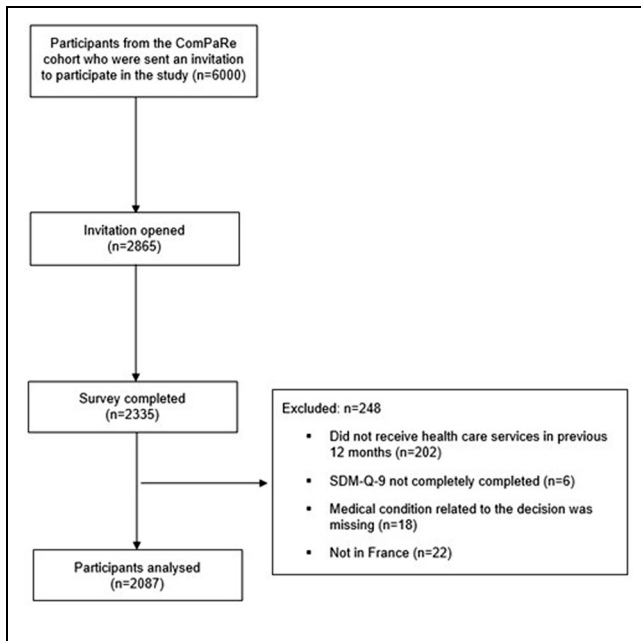
### Patient and Public Involvement

A patient partner (L.P.) affiliated with our research team contributed to the elaboration of the protocol by discussing choices of outcomes and questionnaires and to the interpretation of results. She also critically revised the manuscript and was associated as coauthor in this publication.

## Results

### Participants' Characteristics

From April 6 to May 18, 2023, 6,000 participants from the ComPaRe e-cohort were invited to participate by e-



**Figure 1** Flowchart of patient selection.

mail; 2,335 patients (38.9%) volunteered to participate, and 2,087 were analyzed (Figure 1). After weighting, 53.0% were women, the mean (SD) age was 51.0 y (15.0), and 68.9 lived in an urban area. Most participants in the study suffered from endometriosis (27.3%), inflammatory rheumatic diseases (20.7%), and high blood pressure (19.3%). The mean (SD) health literacy level was of 55 (7)/70, and the mean (SD) treatment burden was 56 (33)/150. The characteristics of the patients are presented in Table 1.

### Health-Related Decisions

The health-related decisions participants deemed most important in the past 12 mo were mainly related to drug treatments (36.5%) and planning a surgery (20.5%). Chronic conditions involved were diabetes (170 [8.1%]), endometriosis (168 [8.0%]), and inflammatory rheumatic diseases (145 [6.9%]). Decisions were made with medical specialists in 63.1% of responses. The average time elapsed since the decision was  $4 \pm 3$  mo. The characteristics of the most important decision deemed by patients during the 12 mo are presented in Table 2.

### Perceived Level of SDM

The overall mean (SD) SDM-Q-9 score was 63 (27), reflecting a moderate perceived level of SDM. The item

**Table 1** Sociodemographic Characteristics of the Respondents in the Weighted Sample<sup>a</sup> ( $N = 2,087$ )

Characteristic	Weighted Sample
Total $n$	2,087
Age, y, $n$ (%)	
[18; 34]	313 (15.0)
[35; 54]	615 (29.5)
[55; 74]	837 (40.1)
[75; 100]	322 (15.4)
Sex, $n$ (%)	
Female	1,105 (53.0)
Education level, $n$ (%)	
Lower education	188 (9.1)
Middle school or equivalent	1,178 (56.5)
High school or equivalent	289 (13.9)
Associate's degree	185 (8.9)
Undergraduate or graduate degree	237 (11.4)
Missing data	5(0.20)
Self-reported diagnosis <sup>b</sup>	
Endometriosis	569 (27.3)
Inflammatory rheumatic diseases	433 (20.7)
High blood pressure	402 (19.3)
Depression	398 (19.1)
Long COVID	396 (19.0)
Asthma	318 (15.2)
Thyroid disorders	279 (13.4)
Diabetes	261 (12.5)
Cancer	95 (4.6)
No. of chronic conditions, $n$ (%)	
1	615 (29.9)
2	399 (19.0)
3+	1,076 (51.5)
Level of health literacy (FCCHL) (0–70), mean (SD)	55 (7)
Treatment burden (TBQ) (0–150), mean (SD)	56 (33)

FCCHL, Functional, Communicative and Critical Health Literacy scale; TBQ, Treatment Burden Questionnaire.

<sup>a</sup>Weighted data were obtained after calibration on margins for sex, age, and educational level by using data from a national census describing the French population with chronic conditions.

<sup>b</sup>Nonexhaustive list. List of the most frequently reported conditions by respondents. Total percentage might exceed 100% since some participants reported multiple conditions ( $N = 8,404$  declared conditions among 2,087 respondents).

with the highest average agreement was “my doctor made it clear that a decision had to be made,” and the item with the lowest level of agreement was “he/she presented me with the pros and cons of each treatment option” (online Appendix 1). The desire to be actively involved in decisions concerning their health was expressed by 86.4% of participants. In total, 78.6% participants declared that the health professionals respected their

**Table 2** Characteristics of the Most Important Decision Lived by Patients during the Past 12 mo and for Which They Evaluated Their Shared Decision-Making Level

Characteristic	Weighted Sample (N = 2,087)
Type of decision, n (%)	
Drug-related decisions	762 (36.5)
Planning or performing a surgery	429 (20.5)
Using a medical device	212 (10.2)
Carrying out additional examinations	343 (16.4)
Changing follow-up	248 (11.9)
Social and health insurance related	93 (4.5)
Health-care professionals involved, n (%)	
General practitioner	693 (33.2)
Specialist	1,317 (63.1)
Other health professional	77 (3.7)
Chronic condition involved, n (%) <sup>a</sup>	
Diabetes (type 1 or 2)	170 (8.1)
Endometriosis	168 (8.0)
Inflammatory rheumatic diseases <sup>b</sup>	145 (6.9)
Cancer	142 (6.8)
Chronic pain	131 (6.3)
Depression, anxiety	98 (4.7)
Long COVID	80 (3.8)
Cardiovascular diseases <sup>c</sup>	75 (3.6)
Thyroid disorders	71 (3.4)
Respiratory disease <sup>d</sup>	68 (3.3)
High blood pressure	51 (2.4)
Inflammatory bowel disease	38 (1.8)

<sup>a</sup>List of the most frequently reported conditions to which the decision refers.

<sup>b</sup>Inflammatory rheumatic diseases include arthritis, arthrosis, osteoporosis, and rheumatism.

<sup>c</sup>Cardiovascular diseases include acute myocardial infection and stroke.

<sup>d</sup>Respiratory diseases include asthma and chronic obstructive pulmonary disease.

desired level of involvement in the decision-making process.

As shown in Table 3, SDM-Q-9 scores varied across sociodemographic groups, conditions, and types of decisions. Men reported higher scores than women did (68 [26] v. 61 [27]), and patients with higher education levels had slightly better scores compared with those with lower education (63 [26] v. 59 [27]). SDM scores increased across age categories, ranging from 62 (25) to 69 (27).

Results also showed disparities across conditions associated with the decision reported by the participant. Figure 2 highlights that patients with long COVID (54 [28]) and endometriosis (58 [25]) had the lowest SDM-Q-9 scores, while those with cancer (70 [26]) and depression/anxiety (69 [26]) reported the highest. Decision types also

influenced SDM perceptions: decisions involving surgeries (71 [25]) or medical devices (70 [22]) received the highest scores, while those related to social and health insurance issues had lower scores (59 [27]). Finally, decisions involving specialists (64 [27]) were rated higher than those involving general practitioners (62 [27]) or other health care professionals such as pharmacists or nurses (58 [30]).

#### *Factors associated with the Perceived Level of SDM*

The multivariate analysis, as presented in Table 3, underscore the multifactorial nature of SDM, highlighting the influence of patient characteristics, health care contexts, and decision types. Findings confirmed several factors independently associated with SDM-Q-9 scores. Factors associated with higher perceived SDM were being male, patients with higher health literacy levels, decisions relating to cancer or cardiovascular diseases, decisions related to surgeries and medical devices, and decisions made with specialists.

## Discussion

In this study of 2,087 patients weighted to represent the French population of patients with chronic conditions, we observed a moderate perceived level of SDM as measured with the SDM-Q-9 score. Participants declared lower SDM scores for decisions relating to long COVID and endometriosis, targeting drug or changing follow-up changes, made with general practitioners, among women, with low educational level, low literacy level, and high treatment burden.

In comparison with a 2017 systematic review of intervention studies using the SDM-Q-9 questionnaire, with mean scores ranging from 42 to 75 in a variety of health care settings, mainly in Europe, our overall SDM-Q-9 score of 63 is in the higher range noted in this review.<sup>23</sup> Several factors might explain this, including recent efforts to promote patient participation in the health care system, notably in France.<sup>9</sup> While many studies in the review involved chronic conditions, several also focused on acute or preventive decisions (cancer screening, elective surgery), often assessed in the context of controlled interventions. In contrast, our study focused exclusively on patients with chronic conditions, asking them to reflect on what they considered the most important health decision made in the past 12 mo. This framing may have influenced how patients perceived and recalled their SDM experience while also allowing for meaningful comparisons with previous findings. These findings should be interpreted in light of the differences

**Table 3** Factors associated with Shared Decision Making, Multivariate Linear Regression Results

Characteristic	SDM-Q-9, Mean (SD)	Model 1 <sup>a</sup>		Model 2 <sup>b</sup>	
		$\beta$	<i>P</i>	$\beta$	<i>P</i>
Total	63 (27)				
Age, y					
Ref: [18; 34]	62 (25)	—	—	—	—
[35; 54]	62 (27)	0.87 [−2.7, 4.5]	0.6	8.1 [3.5, 13]	<0.001
[55; 74]	66 (27)	−2.0 [−5.7, 1.7]	0.3	3.4 [−1.7, 8.6]	0.2
[75; 100]	69 (27)	−5.0 [−9.6, −0.41]	<b>0.033</b>	−1.6 [−8.5, 5.2]	0.6
Sex					
Male	68 (26)	8.9 [6.3, 11]	< <b>0.001</b>	3.9 [0.44, 7.4]	<b>0.027</b>
Education level					
Ref: Low	59 (27)	—	—	—	—
High school	65 (27)	−2.3 [−5.0, 0.39]	0.093	6.0 [2.1, 9.9]	<b>0.003</b>
Higher education	63 (26)	−1.1 [−1.4, −0.70]	< <b>0.001</b>	−1.1 [−4.4, 2.1]	0.5
Level of health literacy (FCCHL) (0-70) <sup>c</sup>	—	4.7 [3.1, 6.3]	< <b>0.001</b>	4.8 [2.9, 6.7]	< <b>0.001</b>
Treatment burden (TBQ) <sup>c</sup>	—	−1.1 [−1.4, −0.70]	< <b>0.001</b>	−0.35 [−0.80, 0.10]	0.13
No. of chronic conditions					
Ref: 1	63 (27)	—	—	—	—
2+	63 (27)	−2.3 [−5.0, 0.39]	0.093	−1.1 [−4.6, 2.5]	0.6
Decision					
Ref: Drug related	60 (28)	—	—	—	—
Performing a surgery	71 (25)	16 [12, 19]	< <b>0.001</b>	8.0 [3.6, 13]	< <b>0.001</b>
Using a medical device	70 (22)	4.5 [0.32, 8.7]	< <b>0.001</b>	9.8 [3.1, 16]	<b>0.004</b>
Changing follow-up	63 (28)	2.0 [−1.8, 5.8]	0.3	5.1 [0.49, 9.8]	<b>0.030</b>
Social and health insurance related <sup>d</sup>	59 (27)	24 [18, 29]	< <b>0.001</b>	17 [11, 23]	< <b>0.001</b>
Health care professionals					
Ref: Specialists	64 (27)	—	—	—	—
Generalists	62 (27)	−6.9 [−9.4, −4.3]	< <b>0.001</b>	−8.6 [−12, −5.4]	< <b>0.001</b>
Other <sup>e</sup>	58 (30)	−9.6 [−15, −4.3]	< <b>0.001</b>	−26 [−32, −19]	< <b>0.001</b>
Disease					
Ref: Cancer	70 (26)	—	—	—	—
Diabetes (type 1 or 2)	68 (26)	—	—	−16 [−22, −9.6]	< <b>0.001</b>
Endometriosis	58 (25)	—	—	−6.3 [−13, 0.77]	0.081
Inflammatory rheumatic diseases	65 (26)	—	—	−9.1 [−15, −3.2]	<b>0.003</b>
Chronic pain	62 (28)	—	—	−11 [−17, −3.9]	<b>0.002</b>
Depression, Anxiety	69 (26)	—	—	3.8 [−3.1, 11]	0.3
Long COVID	54 (28)	—	—	−16 [−23, −7.9]	< <b>0.001</b>
Cardiovascular diseases (stroke, acute myocardial infarction)	60 (29)	—	—	21 [12, 29]	< <b>0.001</b>
Thyroid disorders	65 (28)	—	—	−17 [−24, −9.4]	< <b>0.001</b>
Respiratory disease	68 (25)	—	—	−17 [−25, −9.5]	< <b>0.001</b>
High blood pressure	58 (25)	—	—	−13 [−21, −5.1]	<b>0.001</b>
Inflammatory bowel	64 (23)	—	—	−16 [−25, −6.7]	< <b>0.001</b>

FCCHL, Functional, Communicative and Critical Health Literacy scale; SD, standard deviation; SDM-Q-9, 9-item Shared Decision-Making Questionnaire; TBQ, Treatment Burden Questionnaire.

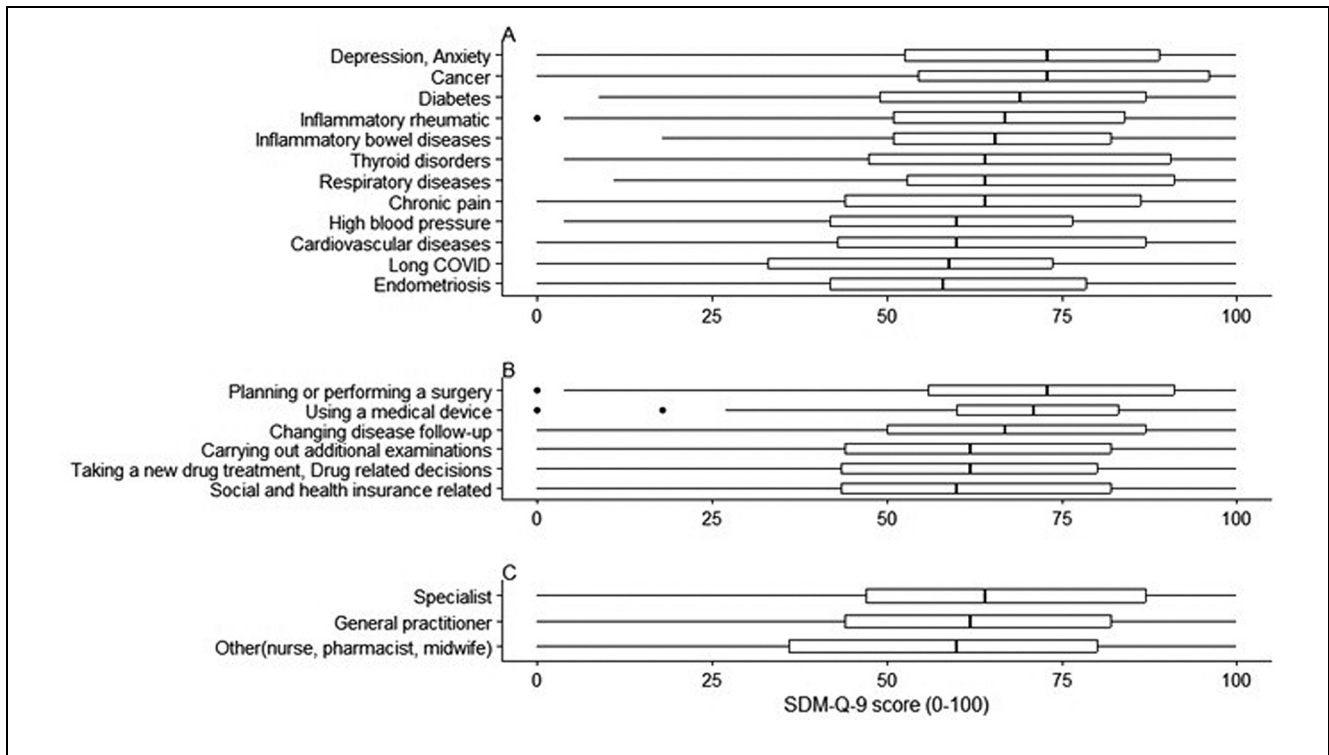
<sup>a</sup>Model 1, *N* = 2,087, factors associated with SDM level adjusted for age, sex, education level, health literacy level, treatment burden level, number of chronic conditions, type of the most decision for patients and health care professionals involved in the decision.

<sup>b</sup>Model 2, *N* = 1,266; model 1 also including the most frequent conditions to which the decision referred.

<sup>c</sup>Regression for a 10-unit increase.

<sup>d</sup>Disability forms, out long-term illness forms, certificates.

<sup>e</sup>Midwife, physiotherapist, pharmacist.



**Figure 2** Distribution of overall SDM-Q-9 scores (0–100) among chronic conditions that the decision referred (A), type of decisions made (B), and health care professionals met for the decision (C) ( $N = 2,087$ ).

in study context and decision types. Reported SDM-Q-9 scores vary depending on whether decisions are assessed in real-life settings or in controlled interventions and on the nature of the decision.<sup>24</sup> Acute decisions are often made in a single encounter, under time constraints, and often focus on resolving a specific health issue such as upper respiratory tract infection, mild diverticulitis, and so forth. In contrast, chronic care decisions are usually distributed over time, revisit tradeoffs, and integrate broader life considerations such as long-term management and lifestyle compatibility. Thus, balancing options based on their evidence and the values and preferences of individuals will differ depending of the types of decision and thus in terms of engagement.<sup>25</sup> These differences that are so multidimensional in decision-making contexts may partly explain the variability in perceived SDM scores between studies. Our lower scores may also be explained by the fact that decisions reported in our sample concerned chronic care, often involving complexity, uncertainty, or emotional burden.

Our results can also be compared with population-level studies conducted in other countries. For example, the DECISIONS study conducted in the United States

regarding recent medical decisions found that the level of patient involvement varied greatly across decision types (surgery, screening, medication) and that sociodemographic characteristics, such as gender and education, influenced the extent of SDM.<sup>26</sup> Despite differences in instruments and settings, these results align with our findings, notably the lower perceived SDM in certain groups (patients with low literacy) and the variability according to decision types. These findings are also echoed in the recent 2025 OECD PaRIS report, which identified significant inequalities in patient engagement and perceived autonomy across countries and within populations, particularly by gender, education level, and health literacy.<sup>27</sup> These international findings further support the need for tailored SDM strategies adapted to the diversity of patient profiles and health system contexts.

Despite these encouraging results, disparities pointed out in our results show that SDM is still not yet totally and systematically integrated in clinical practice. Also, according to patients' perceptions, the SDM model process is not fully deployed with some components that are not implemented, such as pro-and-con discussions or patients' preferences inquiry. A previous study showed

that clinicians found it inappropriate to ask these 2 questions during a consultation.<sup>28</sup> Several studies also indicate that most clinicians mistakenly believe that they know the patient's preferred level of involvement without asking them.<sup>28,29</sup> This preference should itself be informed rather than based on a clinician's presumption about the patient's wishes.

It is also important to consider whether the observed variations in SDM may reflect not only differences in implementation but also the appropriateness and feasibility of SDM depending on the clinical context, the capacity to single out one of few decision points, and the type of decision.<sup>30,31</sup> For instance, preference-sensitive decisions such as surgery may seem more conducive to shared deliberation, whereas time-constrained or protocol-driven decisions (e.g., renewing a prescription) may leave less room for patient involvement or even the consideration that there is a decision point: renew or not.<sup>16</sup> Therefore, part of the variation we observed could relate to contextual differences in how suitable SDM is perceived by professionals for each clinical decision. However, involving patients in each decision, including primary care, is crucial since it can set out the trajectory of future decision points and contributes to building agentivity and decisional autonomy. In fact, the only way to clearly determine what is important to patients is to clarify the decision points and outcomes of options laid out. Professionals' beliefs about the appropriateness of SDM in certain situations may act as a barrier, reinforcing the need to address misconceptions.<sup>29</sup> This may also explain the lower SDM scores reported for decisions made with GPs. These results should not be interpreted as a reflection of GPs' willingness or skills to engage in SDM but rather as a consequence of the type of decisions typically handled in primary care. In our study, patients were asked to report the most important health decision they made in the past 12 mo, many of which related to significant interventions or treatment changes more commonly managed in specialist care. This difference in clinical context likely influenced the type and depth of shared deliberation observed across provider types.

Variations observed in SDM scores in our results provide valuable insights for future research, considering specific medical conditions and patient profiles. The highest levels of SDM reported by cancer patients reflect oncology's leadership in improving patient pathways and care experiences in France and internationally. Conversely, patients with long COVID and endometriosis reported lower SDM scores. Despite their different medical underpinnings, these conditions share common challenges such as clinical uncertainty, notably due to misdiagnosis,<sup>32,33</sup> widespread impairing symptoms,<sup>34,35</sup>

and the absence of effective curative treatments.<sup>34,36</sup> The low SDM scores in these cases might be attributed to physicians' difficulties in their own decision-making process, perceiving patient involvement in the decision as too costly, given that clinicians' self-efficacy and knowledge are essential for SDM. However, by involving patients and sharing responsibilities, applying SDM in situations of uncertainty might be even more beneficial. Limited literature exists on SDM in long COVID and endometriosis care, but patients with endometriosis express willingness to be involved in decisions and disease management.<sup>37,38</sup>

Our results also emphasize the need for caution in SDM practices to avoid reinforcing existing social health inequities.<sup>13,39,40</sup> We found that patients with lower literacy were less involved in decisions, which is contrary to the equity goal of SDM. To address this, SDM interventions designed for vulnerable populations have shown effectiveness in reducing health inequities.<sup>41</sup> These interventions counter professionals' perceptions of vulnerable patients' reduced capabilities or unwillingness to participate.<sup>42</sup>

Our findings advocate going beyond regulatory incentives and national guidelines in France to work toward more inclusive and effective SDM practices that benefit all patients and root SDM in daily clinical practices in France. The roll out of structured, multifaced SDM implementation programs including organizational and individual interventions would support health professionals and foster SDM implementation at all health system levels and support, as did the MAGIC program in the United Kingdom.<sup>43</sup>

### *Strengths and Limitations*

Our study is the first nationwide survey to evaluate the level of SDM perceived by patients with chronic conditions in France, conducted in daily practices. One of our strengths is to link patients' perception of SDM to the decision made and the professional encountered. Nevertheless, we acknowledge some limitations. Primarily, participants were drawn from an electronic patient e-cohort, who may be more engaged in their care and motivated to participate in research or to convey a specific message. The sample may include individuals who are particularly engaged in their health care and more inclined to value participation in medical decision making. Although, after weighting, the sample reflects the lower formal educational attainment of the chronic disease population in France, participants in our e-cohort still reported higher scores on the FCCHL scale, reflecting greater health literacy and engagement than the general population.

This could have led to an overestimation of SDM levels compared with the general population of patients with chronic conditions. However, weighting allows us to adjust our sample to reflect the characteristics of the French population suffering from chronic conditions. Another limitation is the inherent subjectivity in how participants interpreted what constituted a decision. The categorization of “type of decision” is complicated by whether or not the patient conceptualized an interaction as a decision, and this ambiguity may have influenced how participants reported their most important decision. According to foundational and recent models of SDM, however, it is the clinician’s responsibility to clearly signal to the patient when a decision is being faced and thus need to be made in order to enable their meaningful involvement in the process.<sup>4,44</sup> Finally, our questionnaire assesses the perceived level of patient health care decision making over the previous 12 mo; thus, our data may be susceptible to recall bias, even though this might be limited since the average time since the decision was 4 mo.

## Conclusion

The perceived level of SDM among patients with chronic conditions in France is moderate, but disparities persist, influenced by sociodemographic factors, health literacy level, type of disease, and decision taken. To address these disparities, intensified efforts are essential to enhance the implementation of SDM in routine clinical practice in France, notably toward vulnerable patients.

## Acknowledgments

We would like to thank the cohort ComPaRe team for their collaboration in collecting the data and the respondents for participating to the survey.





## Ethical Considerations

The study received approval from the Comité de Protection des Personnes Ile de France I (IRB: 0008367), and all methods were performed in accordance with the relevant guidelines and regulations.

## Consent to Participate

Patients provided informed consent at inclusion in the e-cohort.

## ORCID iDs

Yaël Busnel  <https://orcid.org/0009-0007-5321-1492>  
 France Légaré  <https://orcid.org/0000-0002-2296-6696>  
 Viet-Thi Tran  <https://orcid.org/0000-0003-1863-6739>  
 Julie Haesebaert  <https://orcid.org/0000-0001-9109-5604>

## Data Availability

Data not available.

## Supplemental Material

Supplementary material for this article is available online at <https://doi.org/10.1177/0272989X251407617>

## References

- Boersma P, Black LI, Ward BW. Prevalence of multiple chronic conditions among US adults, 2018. *Prev Chronic Dis.* 2020;17:E106.
- Muth C, van den Akker M, Blom JW, et al. The Ariadne principles: how to handle multimorbidity in primary care consultations. *BMC Med.* 2014;12(1):223.
- O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expect.* 2003;6(2):97–109.
- Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med.* 1997;44(5):681–92.
- Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns.* 2006;60(3):301–12.
- Stiggelbout AM, Van der Weijden T, De Wit MPT, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ.* 2012;344:e256.
- Weston WW. Informed and shared decision-making: the crux of patient-centred care. *CMAJ.* 2001;165(4):438–9.
- France. Loi n° 2002–303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé. *Journal officiel de la République française.* 5 mars 2002.
- Haute Autorité de Santé. Patient et professionnels de santé: décider ensemble. Disponible sur; 2025. Available from: [https://www.has-sante.fr/jcms/c\\_1671523/fr/patient-et-professionnels-de-sante-decider-ensemble](https://www.has-sante.fr/jcms/c_1671523/fr/patient-et-professionnels-de-sante-decider-ensemble)
- Moumjid N, Durand MA, Carretier J, et al. Implementation of shared decision-making and patient-centered care in France: towards a wider uptake in 2022. *Z Für Evidenz For- t bild Qual Im Gesundheitswesen.* 2022;171:42–8.
- Légaré F, Adekpedjou R, Stacey D, et al. Interventions for increasing the use of shared decision making by healthcare professionals - Légaré, F - 2018 | Cochrane Library. *Dis- ponible sur; 2024.* Available from: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006732.pub4/full>
- Driever EM, Stiggelbout AM, Brand PLP. Shared decision-making in different types of decisions in medical specialist consultations. *J Gen Intern Med.* 2022;37(12):2966–72.
- Haesebaert J, Adekpedjou R, Croteau J, Robitaille H, Légaré F. Shared decision-making experienced by Canadians facing health care decisions: a Web-based survey. *CMAJ Open.* 2019;7(2):E210–6.

14. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-surveys (CHERRIES). *J Med Internet Res*. 2004;6(3):e34.
15. Sundling V, Stene HA, Eide H, Hugaas Ofstad E. Identifying decisions in optometry: a validation study of the decision identification and classification taxonomy for use in medicine (DICTUM) in optometric consultations. *Patient Educ Couns*. 2019;102(7):1288–95.
16. Braddock CH, Fihn SD, Levinson W, Jonsen AR, Pearlman RA. How doctors and patients discuss routine clinical decisions. *J Gen Intern Med*. 1997;12(6):339–45.
17. Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns*. 2010;80(1):94–9.
18. Strull WM. Do patients want to participate in medical decision making? *JAMA J Am Med Assoc*. 1984;252(21):2990.
19. World Health Organization. ICD-10. International statistical classification of diseases and related health problems: tenth revision 1992, volume 1 = CIM-10. Classification statistique internationale des maladies et des problèmes de santé connexes : dixième révision 1992, Volume 1. *Wkly Epidemiol Rec Relevé Épidémiologique Hebd*. 1992;67(27):203–4.
20. Tran VT, Harrington M, Montori VM, Barnes C, Wicks P, Ravaud P. Adaptation and validation of the Treatment Burden Questionnaire (TBQ) in English using an internet platform. *BMC Med*. 2014;12:109.
21. Ousseine YM, Rouquette A, Bouhnik AD, et al. Validation of the French version of the Functional, Communicative and Critical Health Literacy scale (FCCHL). *J Patient-Rep Outcomes*. 2018;2(1):3.
22. Direction de la recherche, des études de l'évaluation et des statistiques [Internet]. L'état de santé de la population en France - Rapport 2017. Disponible sur; 2024. Available from: <https://drees.solidarites-sante.gouv.fr/publications-documents-de-reference/rapports/letat-de-sante-de-la-population-en-france-rapport-2017>
23. Doherr H, Christalle E, Kriston L, Härter M, Scholl I. Use of the 9-item Shared Decision Making Questionnaire (SDM-Q-9 and SDM-Q-Doc) in intervention studies—a systematic review. *PLoS One*. 2017;12(3):e0173904.
24. Watt S. Clinical decision-making in the context of chronic illness. *Health Expect*. 2000;3(1):6–16.
25. Stacey D, Légaré F, Boland L, et al. 20th anniversary Ottawa decision support framework: part 3 overview of systematic reviews and updated framework. *Med Decis Making*. 2020;40(3):379–98.
26. Zikmund-Fisher BJ, Couper MP, Singer E, et al. The DECISIONS study: a nationwide survey of United States adults regarding 9 common medical decisions. *Med Decis Making*. 2010;30(5 suppl):20S–34S.
27. OECD. Does healthcare deliver? Disponible sur; 2025. Available from: [https://www.oecd.org/en/publications/does-healthcare-deliver\\_c8af05a5-en.html](https://www.oecd.org/en/publications/does-healthcare-deliver_c8af05a5-en.html)
28. Goossensen A, Zijlstra P, Koopmanschap M. Measuring shared decision making processes in psychiatry: skills versus patient satisfaction. *Patient Educ Couns*. 2007;67(1–2):50–6.
29. Couët N, Desroches S, Robitaille H, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expect*. 2015;18(4):542–61.
30. Ofstad EH, Frich JC, Schei E, Frankel RM, Gulbrandsen P. What is a medical decision? A taxonomy based on physician statements in hospital encounters: a qualitative study. *BMJ Open*. 2016;6(2):e010098.
31. Légaré F, O'Connor AM, Graham ID, Wells GA, Tremblay S. Impact of the Ottawa decision support framework on the agreement and the difference between patients' and physicians' decisional conflict. *Med Decis Making*. 2006;26(4):373–90.
32. Aiyegbusi OL, Hughes SE, Turner G, et al. Symptoms, complications and management of long COVID: a review. *J R Soc Med*. 2021;114(9):428–42.
33. Nnoaham KE, Hummelshoj L, Webster P, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril*. 2011;96(2):366–373.e8.
34. Vercellini P, Viganò P, Somigliana E, Fedele L. Endometriosis: pathogenesis and treatment. *Nat Rev Endocrinol*. 2014;10(5):261–75.
35. Crook H, Raza S, Nowell J, Young M, Edison P. Long COVID—mechanisms, risk factors, and management. *BMJ*. 2021;374:n1648.
36. Davis HE, Assaf GS, McCorkell L, et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*. 2021;38:101019.
37. Gouesbet S, Kvaskoff M, Riveros C, et al. Patients' perspectives on how to improve endometriosis care: a large qualitative study within the ComPaRe-Endometriosis e-cohort. *J Womens Health*. 2023;32(4):1–18.
38. Metzemaekers J, Slotboom S, Sampat J, et al. Crossroad decisions in deep endometriosis treatment options: a qualitative study among patients. *Fertil Steril*. 2021;115(3):702–14.
39. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient Educ Couns*. 2006;60(2):102–14.
40. Moreno CC, Weiss PS, Jarrett TL, Roberts DL, Mittal PK, Votaw JR. Patient preferences regarding colorectal cancer screening: test features and cost willing to pay out of pocket. *Curr Probl Diagn Radiol*. 2016;45(3):189–92.
41. Durand MA, Carpenter L, Dolan H, et al. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS One*. 2014;9(4):e94670.
42. Pollard S, Bansback N, Bryan S. Physician attitudes toward shared decision making: a systematic review. *Patient Educ Couns*. 2015;98(9):1046–57.
43. Joseph-Williams N, Lloyd A, Edwards A, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ*. 2017;357:j1744.
44. Stacey D, Volk RJ, Smith M, Lewis KB, Carley M for the IPDAS Steering Committee. Policy brief: IPDAS 5.0. 2025. Available from: <https://decisionaid.ohri.ca/ipdas>