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# Addressing epistemic injustice in Shared Decision-Making: Learning from Underserved Patient Groups to Foster More Equitable Healthcare

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## Abstract

INTRODUCTION: Shared decision-making (SDM) is a hallmark of equitable, patient-centered care, yet inequitable practices and social disparities in patient participation remain. Underserved patients' perspectives can illuminate the differential impacts of SDM implementation on patient participation across strata of society and make the formats and conditions that hinder their participation more visible.

OBJECTIVE: This study explored underserved patients' experiences with SDM and their ideas for addressing the experienced drivers of exclusion, aiming to (1) identify factors excluding underserved groups from SDM participation and (2) uncover opportunities to reduce them.

METHODS: This qualitative study, part of a broader Targeted Intervention Planning (TIP) project, engaged fourteen underserved patients in a group brainstorming session combining patient journey mapping and the nominal group technique. Data included the recorded session, individual debriefing interviews, and written participant notes, analyzed using interpretive description and Braun and Clarke's thematic analysis.

RESULTS: Patients most frequently cited feeling dismissed ("the doctor does not take me seriously") and time pressure as drivers of exclusion. Six themes emerged: dismissiveness, system pressure, communicative misalignment, disrespectful behavior, assertiveness, and healing experiences. Findings pointed to epistemic injustice—patients' diminished credibility and interpretive gaps in patient-provider communication—as an underlying mechanism, compounded by structural pressures on healthcare systems.

CONCLUSION: Epistemic injustice, shaped by social identity, intersecting vulnerabilities, and systemic constraints, appears to be a key, underrecognized driver of underserved patients' exclusion from SDM. Addressing these epistemic and structural preconditions is essential for enabling equitable patient-provider communication and truly equitable SDM in clinical practice.

## 1. INTRODUCTION

1. **INTRODUCTION** (word count 607)
Health equity begins with the removal of inequity in health care, providing equal care for people in equal need of care(1)(2). The inclusion of health equity as an explicit goal of quality improvement in health care has been widely accepted as a priority aim(3)(4). Striving for equity requires actively identifying and eliminating barriers that lead to unequal distribution of, or access to, resources and opportunities among population (sub-)groups, with the aim of ensuring optimal treatment and equal support for all(5). An important determinant of equity in health care is equitable access to health care, which is – apart from other, out-of-clinic factors - importantly determined by patient-provider communication(6). Health care disparities have appeared to be most prevalent for processes that are affected by the quantity and quality of patient–provider communication, shared decision-making (SDM) and patient participation(7).

SDM considers a collaborative process between patient and HCP in which medical evidence, the HCP's expertise, and the values, preferences and context of patients are used to develop tailored treatment decisions for an individual patient(8). Robust evidence shows SDM improves the quality of care and clinical outcomes(9, 10)(11–13)(14)(15), can address issues of unequal access and foster greater equity in health care(16)(17)(18)(19)(20). SDM is recognized internationally as a hallmark of good clinical practice and an ethical imperative, increasingly reflected in national standards and legislation(21)(22–24)(25–29).

Yet, despite the strong policy and evidence base for SDM, a persistent gap exists between SDM theory and routine practice, with inequitable practices and persisting social disparities in patient participation(30–32)(33). These disparities are problematic, as they risk marginalizing underserved populations, worsening their long-term outcomes and exacerbating health inequities(17)(34, 35)(36). SDM researchers earlier agreed that SDM should have equity at its core(37) and that achieving greater equity in SDM should be a research priority(38). Luckily, recent years have already seen significant advances in SDM towards equity(39–45).

However, striving for equity in SDM – as outlined above – requires a "*full identification of barriers that lead to unequal distribution of, or access to, resources and opportunities*" that are needed for SDM. So far, the health literacy framework has provided a powerful framework for highlighting the barriers patients might face in accessing healthcare(46), and SDM more specifically(47–51). It could be questioned, though, whether this "ability-focused framing" fully covers the barriers at stake. Relational, organizational or structural explanations might play, placing some patients in participatory formats that are actually (too) difficult to navigate(52, 53). Before participation difficulties could be interpreted as problems solely relating to patient ability, we should question first whether the formats and conditions that hinder patient participation are already fully visible (53).

To further explore this, to evaluate SDM quality and to identify communication gaps, patients' perspectives are essential(54). Underserved patients' perspectives can illuminate the differential impacts of SDM implementation on patient participation across strata of society(55) and make the formats and conditions that hinder their participation more visible. Moreover, amplifying these patients' voices and ideas can directly inform more inclusive models of SDM and practical strategies to reduce barriers(56).

*Figure 1. Overview of study course. The numbers indicate the chronological flow of the different steps. Round 1, collecting underserved patients' experiences, ideas and reflections on underlying problems and solutions, served as a reflexive basis for subsequent, deepening analysis with physicians (round 2). The shared analytical output of patients and physicians finally served theory-building work with experts (round 3). Member checks ensured participants could check data on accuracy, completeness and recognizability before data were passed on to the next round. Feedback loops finally feedbacked the output of the experts to the earlier-engaged patients and physicians, giving the latter room for final input.*

Accordingly, we conducted a qualitative study exploring underserved patients' experiences with SDM, as well as their ideas to tackle the experienced drivers of exclusion from SDM. Our aims were to: (1) identify factors excluding these groups from participation in SDM, and (2) uncover opportunities to address

these factors. By centering underserved voices, we sought to inform theory and practice that advance both high-quality and equitable care—ensuring all patients have equal access to meaningful participation in decisions about their health and receive the high-quality health care to which they all have an equal right.

## 2. METHODOLOGY

## 2.1. Study Design

This qualitative study was part of a broader project following a 'Targeted Intervention Planning' (TIP) approach; a structured, participatory method that includes collective brainstorming techniques and co-creation principles, to analyze a problem with various stakeholders and identify possible solutions(57, 58). Underserved patients' exclusion from participation in SDM in the patient-physician interaction was defined as the analyzed problem in this project. Involved stakeholders included underserved patients, physicians from diverse disciplinary backgrounds and experts in SDM and sociology, who were consulted consecutively in three separate group brainstorming rounds (Fig. 1). This paper presents data collected during the initial brainstorming round, with underserved patients (round 1). We pursued main principles of inclusive co-creative research(59): reciprocity, equivalence and trust and, finally, maximal collaboration between the researchers and the different stakeholder groups interdependently.

Round 1 involved a primary collaborative problem analysis – an analysis of the factors contributing to underserved patients' exclusion from participation in SDM - including a relevance-based factor ranking based on the nominal group technique (NGT)(60). To guide patients' reflections on the SDM process and the experienced hurdles, we made use of *patient journey mapping*(61). Patients were asked to identify, discuss and prioritize the 'pain points'(61) in their SDM journey, drawing inspiration from a newly developed SDM patient journey mapping framework(62) and from the barriers as identified in our previous reviews(63–65). After identification and prioritization of pain points, patients could brainstorm on possible solutions for the most highly ranked points. Further background on the study design can be found in the Appendix.

The Social and Societal Ethics Committee of the University of Leuven exempted this study from ethical approval at October 8 2025 (G-2025-9907), in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants. Consent for publication of photographic materials of the session was obtained separately.

## 2.2. Participants and recruitment

Eligible participants met the following criteria: 1) age > = 18, 2) Dutch-speaking, and 3) meeting at least one of the criteria used in published definitions of "socially disadvantaged groups"(66, 67)(Table 1) and/or 4) self-identifying as patient representative/advocate. Following latest destigmatizing language recommendations, participants are called "underserved" rather than "socially disadvantaged" in this paper(68). Equity-relevant data, characteristics contributing to inequities in health, were collected and analyzed, based on the criteria as defined in the PROGRESS-PLUS Framework(69). We limited inclusion to participants having at least basic linguistic affluency in Dutch as interpreter practices would have hampered the dynamics of a group discussion. Patient representatives/advocates were sought, to help bridge individual anecdotes with common patterns in population and broaden our perspective.

Table 1
Criteria of a socially disadvantaged group, according to published definitions(49, 50). To be defined as a socially disadvantaged group, one should meet at least 1 of the abovementioned criteria.

| |
|---|
| **1. People who are socially disadvantaged with respect to poverty or lower socioeconomic status** |
| 2. People who are socially disadvantaged as a result of their ethnicity or race |
| 3. People who have lower educational attainment (no college degree) |
| 4. People who have lower literacy and/or lower health literacy |
| 5. People who are socially disadvantaged with respect to geographical location (areas described as disadvantaged and/or medically underserved) |
| 6. People who are uninsured or on public health insurance |
| 7. People who have lower numeracy |
| 8. People who are socially disadvantaged as a result of speaking a primary language that differs from the official language of their country of residence |

Recruitment occurred through several ways. First, we identified eligible patients from the community health center where the main researcher (ML) is clinically active as a general practitioner and where participants were approached by ML either during visits or contacted by phone. Second, we partnered with a local neighborhood house and a volunteer organization for newcomers to expand recruitment. Third, we recruited through a social media announcement that was shared by a patient partner. Lastly, we contacted several Flemish patient organizations by email to recruit patient representatives/advocates.

Our sample size was guided by the principle of information power, which considers study aim, sample specificity, quality of dialogue, and analytic strategy(70). Given the focused aim and rich narratives collected, the final sample was deemed sufficient for reaching analytic depth.

## 2.3. Data collection

A live group brainstorming session was held on the evening of November 13, 2025, at a local neighborhood house. The session was led by VBP, an experienced moderator. ML, the lead researcher, supported the moderator by asking follow-up questions and providing logistical assistance. A social worker from the neighborhood house also assisted during the session and provided support to a participant with a disability and speech and writing difficulties in

expressing his thoughts, verbally as well as in written, during the session. Finally, a medical student (VHJ), assisting the lead researcher with data analysis, observed the session and took field notes on his overall impressions.

Beforehand, individual intake meetings had been organized by (video-)call or in person, each lasting 15–30 minutes and led by the lead researcher (ML), to get to know participants and build trust. These meetings were not recorded as we aimed to maximally support the spontaneity and safety of this initial contact. Field notes were taken, however, and used to prepare the session and tailor it as closely as possible to participants' needs and expectations, in line with the principles of equivalence and reciprocity. One to two weeks after the session, individual debriefing meetings were organized by (video-)call, to capture any final reflections and unheard voices.

The session lasted two hours, was audio- and videorecorded, transcribed verbatim, and de-identified. The debriefing meetings, lasting between 7 and 52 minutes, were processed in the same manner and added to the data. Finally, written notes of some participants, that they had prepared in advance of the session and that were considered of added value, were evenly added to the dataset.

Full description of the session, including the session guide, photographic impressions of the session, as well as more background on the pre- and post-brainstorm meetings, can be found in the Appendix.

## 2.4. Data analysis

For analysis of data, we used interpretive description, a qualitative method aimed at generating practice-relevant insights from patient experiences(71). For thematizing, we used thematic analysis according to Braun and Clarke(72). During the first phase, ML and VHJ familiarized themselves with the transcripts. In the second phase, they inductively and independently coded the transcript of the brainstorming session, using Nvivo15®. Codes were then discussed and reviewed until they reached consensus. The codebook was subsequently used for further independent coding of the debriefing phone calls and written notes by ML. In the third phase, ML developed initial themes and subthemes based on the codes and discussed these within the research group. Afterwards, the themes were further refined in the fourth phase by shifting codes between the themes. During the fifth phase, themes were defined and named. In the sixth phase ML reported the findings in narrative writing and illustrative quotes.

## 2.4. Positionality

The study team consisted of general practitioners, a postgraduate medical student (general practitioner trainee), an epidemiologist, and a medical-social scientist. The lead researcher (ML) has several years of clinical experience and remains clinically active as a general practitioner in a community health center that primarily serves underserved patient groups. She also has a strong affinity with issues of social injustice and discrimination, shaped by ideologic values passed down through her family. Coincidently, she became a patient herself during the writing of this paper. To mitigate the influence of our positionalities as white, Western and socially privileged researchers, and of our eventual ideological perspectives, we engaged in regular reflexive discussions throughout the research process. The involvement of a medical-social scientist with specific expertise in health equity helped to broaden our frames of reference. In addition, the social worker from the neighborhood house helped us anticipate challenges and needs related to engagement of participants and informally helped to contextualize the data. Throughout the analysis, we sought to remain grounded in participants' voices through member-checking, in order to reflect their lived experiences as accurately as possible.

# 3. RESULTS

## 3.1. Participant characteristics

Fifteen patients agreed to participate. All attended the session, except one due to illness. The participant characteristics are displayed in Table 2. Participants' ages were mixed, as were linguistic, ethnic, educational and employment status backgrounds. Almost half of the participants were off work because of illness or unemployment (n = 6/14; 43%) and more than half had (occasional) financial concerns (n = 9/14; 64%). Most participants suffered from multimorbidity (n = 9; 64%). Disease backgrounds varied greatly, yet mental health concerns were the most prevalent, followed by musculoskeletal pathologies, metabolic health problems and fatigue syndromes.

Table 2
Participant characteristics (n = 14)

| ***Participant characteristics (n = 14)*** | ***n*** | ***%*** |
|---|---|---|
| *Gender* | | |
| *- Female* | *11* | *79%* |
| *- Male* | *3* | *21%* |
| *- Non-binary* | *0* | *0%* |
| *Age range (mean)* | *24–73 (52.7)* | |
| *- 20–40 years of age* | *3* | *21%* |
| *- 41–60 years of age* | *6* | *43%* |
| *- 61–80 years of age* | *5* | *36%* |
| *Mother tongue* | | |
| *- Dutch* | *10* | *71%* |
| *- Other** | *4* | *29%* |
| ** Turkish 2, Kirundi 1, Somali 1* | | |
| *Country of birth* | | |
| *- Belgium* | *10* | *71%* |
| *- Other** | *4* | *29%* |
| **Turkey 2, Burundi 1, Somalia 1* | | |
| *If migration history:* | *2–6 (4.4)* | |
| *Years since arrival in Belgium – range (mean)* | | |
| *Educational level* | | |
| *- Secondary - not finished* | *1* | *7%* |
| *- Secondary - finished* | *4* | *27%* |
| *- Postsecondary* | *9* | *60%* |
| *Employment status* | | |
| *- Sick leave / invalidity* | *4* | *27%* |
| *- Employed* | *3* | *21%* |
| *- Retired* | *3* | *21%* |
| *- Unemployed* | *2* | *14%* |
| *- Student (combined with work)* | *1* | *7%* |
| *- Other** | *1* | *7%* |
| ** 'career break': a Belgian employment scheme that allows employees to temporarily reduce or suspend their work while retaining certain employment rights and, in some cases, receiving a government benefit.* | | |
| *Literacy screening (self-affirmed)** | | |
| ** Screening question: "Can you read well texts in your mother tongue?"* | | |
| *- Okay ("usually, yes")* | *14* | *100%* |
| *- Not okay or doubtful ("usually, no" or "sometimes yes, sometimes no")* | *0* | *0%* |
| *Financial concerns** | | |
| ** Screening question: "Do you have any financial concerns?"* | | |
| *- Yes* | *4* | *27%* |
| *- Sometimes* | *5* | *36%* |
| *- No* | *5* | *36%* |
| *Disease background** | | |
| ** Several disease backgrounds per participant could be present* | | |

| *Participant characteristics (n = 14)* | *n* | *%* |
|---|---|---|
| *- Mental health concerns* | *7* | *50%* |
| *- Musculoskeletal pathologies* | *4* | *27%* |
| *- Metabolic health problems (diabetes mellitus, hypertension, hypercholesterolemia)* | *3* | *21%* |
| *- Fatigue syndromes (Long Fatigue Syndrome, Long COVID)* | *3* | *21%* |
| *- Oncologic conditions* | *2* | *14%* |
| *- Severe physical trauma in past (in need of ICU stay)* | *2* | *14%* |
| *- Gynecologic conditions* | *1* | *7%* |
| *- Chronic pain* | *1* | *7%* |
| *- Respiratory conditions (asthma)* | *1* | *7%* |
| *- Cognitive problems (memory problems)* | *1* | *7%* |
| *- Physical disability* | *1* | *7%* |
| *Recruitment* | | |
| *- Community health center* | *4* | *27%* |
| *- Neighborhood house* | *4* | *27%* |
| *- Volunteer organization for newcomers* | *4* | *27%* |
| *- Social media* | *1* | *7%* |
| *- Patient representative organization* | *1* | *7%* |

## 3.2. Themes

Six themes were identified: 1) Dismissiveness, 2) System pressure, 3) Communicative misalignment, 4) Disrespectful behavior, 5) Assertiveness, 6) Healing experiences. "*The doctor does not take me seriously*" appeared as the most highly ranked 'pain point' or factor of exclusion from SDM, followed by "*My doctor does not have sufficient time (to involve me)*" (Table 4, Appendix). Illustrative quotes can be found in Table 3.

Table 3
Illustrative quotes

| Themes | Subthemes | | Illustrative quotes |
|---|---|---|---|
| Theme 1: Dismissiveness | Dismissiveness related to diagnostic or treatment processes | Q1 | *"And when I went to the emergency room, the doctor... didn't examine me; he said... "Why are you here?"* |
| | | Q2 | *"[…] that [doctor]... kept saying every time: 'Take painkillers, let your hands rest a bit,' and nothing else. But I did that, and things just stayed the same."* |
| | | Q3 | *"It often takes far too long before they actually help you."* |
| | Dismissiveness related to information provision | Q4 | *"I've… had nine operations, and a doctor never came to me to… to say… […] what the purpose of the operation was. They never said that. Just… that […] nurse came and said: 'Right, you're having an operation. You have to [go]…'"* |
| | | Q5 | *"I often felt powerless and afraid, because I didn't know what would happen to me and because no one explained it to me properly."* |
| | | Q6 | *"Regarding my gallbladder surgery, the doctor only offered the option of surgery. I didn't know if I could have been treated with medication. I didn't know if I could have put it off a little longer. I didn't know if there were other options. I didn't know."* |
| | Dismissiveness due to social traits | Q7 | *"And yes, I think it's important to investigate these things rather than just saying, well, women are 'inferior beings' or women are just 'imagining things'—you know, things like that."* |
| | | Q8 | *"[…] And then the doctor said: 'You're getting a bit older too, you know.'."* |
| | Dismissiveness due to disease traits | Q9 | *"[…] because I'm on sick leave, I was treated as if I were mentally disabled. But I'm not mentally disabled at all! And that is my biggest frustration."* |
| | | Q10 | *"[…] once you've had mental health issues, it's very difficult. […] If you have a physical complaint, it's very quickly dismissed with: 'it's probably mental.' So sometimes… once you have that mental health label stamped on your forehead, everything you say is taken far less [seriously]…"* |
| | | Q11 | *"It's the same with chronic conditions, you know. Once you have chronic complaints, everything is… a result of that."* |
| Theme 2: System pressure | Pressure on (underserved) patients | Q12 | *"For me, the most important thing is that you clearly notice the doctor doesn't have time to engage in a high-quality interaction with the patient..."* |
| | | Q13 | *"Yes, well, I think that politically, it's always just cuts, cuts, cuts—at the expense of the vulnerable. And I find that such a shame. They are the ones who immediately end up bearing the brunt of it."* |
| | | Q14 | *"What I think is also becoming a problem these days… is the fact that… if you qualify for the increased reimbursement scheme, certain doctors, physiotherapists, and so on… simply won't take you on anymore."* |
| | Pressure on physicians | Q15 | *"Um, well, doctors also have very little time. Which is a shame […] … there isn't always the opportunity to explain everything due to a lack of time. [….] That [the lack of time] is the big problem. It is not the fault of the doctor either."* |
| | | Q17 | *"I don't think it [working with a bias] always stems from a lack of understanding. Sometimes it's just... well, very human. Moving too fast. Wanting to be too quick about things, I think."* |
| | | Q16 | *"I think that… it's not easy these days, with… the overburdened doctors… […] I think everyone is looking out for themselves… […] but ultimately, it's the doctors who have to solve it, right?"* |
| | Need for support and political action | Q17 | *"[...] structural matters, such as [...] how to give healthcare providers more time in certain ways—it comes down to... that [...] idea of nurses potentially taking over some of the tasks."* |
| | | Q18 | *"A hint to the politicians: they really need to do something about this urgently. Because who pays the price? The patient. And I find that scandalous. For a country that is so wealthy... […] I consider those waiting lists a real disgrace. Things like that... they put doctors under pressure. But who has to bear the brunt of it? The patient."* |
| Theme 3: Communicative misalignment | Patients towards physicians | Q19 | *"[…] when I had Sudeck's […] It's so unpredictable… you might get up in the morning… no pain, and an hour later you're in agony. You're sitting there crying. And just try explaining that. It's incredibly difficult."* |
| | Physicians towards patients | Q20 | *"The explanation given by most [doctors] is… really complicated, you know."* |
| | Hierarchy in sense-making | Q21 | *"You come across plenty of people […] who really act as if they own the place. […] it's like, "I might not have a degree, but don't you go acting all superior with me!" [laughs] Because... well, my immediate reaction is: I never want to see that person again."* |
| | | Q22 | *"I was never able to finish school because of my home situation. […] I had to… Well, I didn't grow up in good circumstances; I didn't have parents who had my back. […] That's why, for me… if a doctor —or anyone, really—acts condescending… I just think: no, don't do that!" [laughs]* |
| Theme 4: Disrespectul behavior | Shouting | Q23 | *"Some nurses said I had already received enough [pain] medication and started shouting at me."* |
| | Bullying | Q24 | *"Everyone has a call button for the nurses… […] for when I need something. And, you know, the worst pain always hits in the evening—lasting all night long, right up until morning. I'm in pain. […] And after she [the nurse] administers medication two or three times, she doesn't say anything else. […] But if I ring the bell again, she just starts shouting. […] … she just yells and puts the button up a* |

| Themes | Subthemes | | Illustrative quotes |
|---|---|---|---|
| | | | *bit… so I won't ring it again… And so the whole [night]… Yeah […] I had to spend the entire night… in pain."* |
| | Mocking, gossiping | Q25 | *"I woke up once while being transported after surgery and heard nurses talking about me as if I weren't there. That was very painful and humiliating."* |
| | Trauma and mistrust | Q26 | *"I think that… the main thing is that… with that first negative experience I had, I developed a deep distrust of the medical profession."* |
| | | Q27 | "*There were nights when I was in a lot of pain, but no one came—you don't forget that feeling*." |
| | | Q28 | "*For sure, I am very trauma[tised]… I am very afraid…"* |
| | Importance of respectful care | Q29 | *"Because of what I have been through, I now realize how important respectful care is."* |
| Theme 5: Assertiveness | Relevance of assertiveness | Q30 | *"I think... that the patient themselves should take more initiative. In the sense that: if you do not agree, either you argue against it, or you go ask someone else for advice."* |
| | | Q31 | *"I didn't know there was a choice [...] until I asked myself if there were alternatives."* |
| | | Q32 | *"The times I have been assertive, I was actually glad afterwards that I did it."* |
| | Difficulty because of illness | Q33 | *"As a chronic patient, you don't know in advance when you'll be 'well enough' to be assertive enough for an appointment."* |
| | | Q34 | *"The times when you aren't physically well enough to be able to be assertive—that frustrates you enormously. Well, it certainly frustrates me enormously!"* |
| | | Q35 | *"Because I'm not feeling well today either… and… [pauses to think] you can't show [assertiveness] those moments—what you'd actually like to show."* |
| | Difficulty because of prior negative responses | Q36 | *"if you suggest options yourself... ...that isn't always appreciated either..."* |
| | Difficulty because of lower social or educational status | Q37 | *"It is an unequal relationship. No matter how you look at it, there is a hierarchy. You cannot simply assume that the person who… is actually, so to speak, 'a little lower down'… is going to be assertive regarding the circumstances."* |
| | | Q38 | *"[…] that [physician] is a person who has studied for so long, so you assume that he knows a lot... so I very quickly feel, I may put it that way […] ...'inferior 'or 'small' compared to him.. so I hardly dare to contradict him..."* |
| | | Q39 | *"Yes, we are… you feel 'inferior' because you are with people who have studied… it is not, so […] easy… you say not easy… […] you have things like… That person studied for that. I cannot argue with that, I cannot contradict that. Because… you assume that the physician knows the subject better than you do."* |
| | Difficulty because of time pressure | Q40 | *"And as a patient, you sense that [time pressure] too, so you stop asking questions or stop… well, yeah, you just think: okay, I'm not going to…"* |
| Theme 6: Healing experiences | Novelty and power of healing experiences | Q41 | *"I'm telling you, I've never experienced anything like that, a doctor coming to my house […] Well, he did stop by for a bit and sat talking to me for half an hour. […] sitting there, talking at my place like that… When a doctor used to come to my place, he examined me and then left. But that doctor would sit there talking to me, well, also because they were worried and – I'm telling you – that, I have never experienced anything like that."* |
| | | Q42 | *"When a nurse was kind, it gave me the strength to carry on."* |
| | | Q43 | *"Through recent experiences… with positive people, the positive ones… that they helped me through it a bit. Now anyway… I am more able to take that step to go [to the doctor]… if there is anything."* |
| | Feeling welcomed | Q44 | *"Fortunately, we met another Turkish doctor at [name of hospital], and thanks to her, this topic could be discussed again."* |
| | Sensing shared humanity | Q45 | *"Respect and humanity are just as important as good treatment."* |
| | | Q46 | *"A simple explanation or a little empathy can make the difference for a patient."* |

## 3.3. Theme 1: Dismissiveness

## 3.3.1. Dismissiveness related to diagnostic or treatment processes

Many patients felt dismissed by their physician, as reflected in the most highly ranked exclusion factor: "The doctor does not take me seriously". This dismissiveness was often tied to the diagnostic or therapeutic process: patients felt they had not been thoroughly examined or listened to, had their symptoms normalized or downplayed, or were told to wait or continue ineffective treatment. Delayed diagnostic or therapeutic action left patients feeling unheard, deprioritized and excluded from meaningful participation in diagnostic or therapeutic decisions.

After the physical therapy, I went back to my doctor and said that the pain hadn't gone away. But he just told me to keep doing the exercises at home.

## 3.3.2. Dismissiveness related to information provision

A second, more direct form of dismissiveness occurred in the informational domain of SDM: unclear explanations and omission of treatment alternatives. Information was often delivered in jargon or without interpreter support, and many patients felt the physician had simply decided for them — alternatives only surfaced later, from another provider. Some received no explanation at all, leaving them uninformed, anxious and powerless to participate in decisions about their own care.

The doctors often made decisions without properly explaining to me exactly what was going to happen. […] Sometimes I was even taken to the operating room without knowing what was going to happen.

### 3.3.3. Dismissiveness due to social traits

Many patients raised concerns that assumptions about their (female) gender, social, educational and insurance status had influenced how their physician treated them, and how much credibility they were given. They often felt treated 'differently' or felt their symptoms had been dismissed, normalized, downplayed, or undervalued - and explicitly wondered whether this was because of their social identity.

[…] sometimes I wonder… People who go to the doctor with [increased reimbursement scheme] —are they viewed differently, I mean, do they get less help than someone who pays? […] I [suspected that I] was treated differently than anyone else, really.

### 3.3.4. Dismissiveness due to disease traits

Being a patient, or carrying certain diagnoses, was experienced as another, or complementing, reason to be judged less capable of understanding or deciding. This was especially pronounced for patients with a mental health history, whose current symptoms were often reinterpreted through that diagnosis, and for those with contested or unexplained conditions (e.g., fatigue syndromes, chronic pain), whose symptoms were discounted despite clear functional limitations — narrowing the space for shared decisions in both groups.

Some things in your medical record aren't always relevant to the reason you're visiting the doctor. This is especially true regarding mental health problems; if you have a few 'beautiful" diagnoses on your record, you're inevitably viewed differently.

## 3.4. Theme 2: System pressure

### 3.4.1. Pressure on (underserved) patients

Patients often linked structural time pressure directly to their exclusion from SDM: "*My doctor does not have sufficient time (to involve me).*" Rushed consultations left no room for explanation, questions, or patient narratives. Non-native speakers and other vulnerable groups were seen as bearing the brunt of this first, since they typically need more time and support to be meaningfully involved. Some worried that this time pressure would even imply that "*certain doctors […] simply won't take you on anymore*", if you are part of one of these groups.

[…] what really struck me was that with non-native speakers […] it requires so much extra effort to get their story across. For doctors […] they only have a certain amount of time to let them finish speaking, and then to provide an explanation and ensure they've actually understood it...[…] Yeah, that is not easy.

### 3.4.2. Pressure on physicians

Most patients did not blame physicians personally, but attributed the lack of time — and, by extension, the lack of involvement — to systemic causes rather than individual unwillingness. Patients even explicitly empathized with the difficult circumstances in which physicians must work today, seeing physicians – just as much as patients - as "*victims*" of these systemic changes. Some thought that the structural lack of time could even help explain clinicians' biases, stereotypes, and prejudices towards patients, as well as the tendency to not take patients seriously and to exclude them from SDM.

[…] then my question is, regarding 'not being taken seriously' […] what is the reason for that? […] I think it's time. That they [the physicians] say: if I let this lady ramble on completely now, half an hour will have passed and I only have ten minutes.

The (growing) pressure under which physicians have to work made some patients worry about physicians' mental wellbeing, and the inevitable impact on their abilities to truly connect and collaborate with patients.

[…] where you can see that the doctor is actually burnt out. They're at the end of their rope; they've really lost interest in the job. They're just living day to day, just to earn some money... That can be a problem, too.

### 3.4.3. Need for support and political action

Suggested remedies aimed at freeing up physician time and continuity for SDM specifically considered: more support from nurses, and a stronger central role for general practitioners to guarantee continuity of care. Patients felt that this domain is clearly a political responsibility, but that patients and physicians could - because of shared interests – benefit from uniting in one 'team', or one front, to reach for change.

After all, they often frame it as an 'us-versus-them' situation, but when it comes to the system itself, we're actually—well, we really ought to be acting as a team, in the sense that... we all bear the consequences of the pressure to cut costs and the reorganizations. And naturally, that carries over into shared decision-making, too.

## 3.5. Theme 3: Communicative misalignment

Many patients experienced forms of communicative misalignment with their physician. Patients found it hard to translate their illness experience into medically recognized terms, resulting in misunderstandings of their narratives and difficulties in co-constructing meaning with physicians.

[…] That you aren't properly understood. That […] there's a breakdown in communication. He [the doctor] simply doesn't understand... what I'm trying to say. […] Yes, I [...] find it difficult to explain my symptoms. […] that you can't get the message across.

Conversely, physicians' jargon often excluded patients from understanding their own explanations, increasing their frustrations: *"Some of them [physicians] really speak Latin, you know. [sighs]"*. In summary, both patients and physicians struggled to understand each other, complicating the co-construction of meaning that SDM requires.

Also, many experienced a hierarchy in this collaborative sense-making, and the following dynamics. They felt physicians acted as though they "knew better" or were positioned "higher" than them. This often strongly irritated patients and discouraged them from raising concerns a second time — directly limiting their participation.

[...] there is still a... […] certain number of doctors... […] I'm just 'Doctor with the Diploma' here... someone who places themselves above the patient. […] you [the patient] mention it, but then you don't dare bring it up a second time because you know it's not getting through anyway.

## 3.6. Theme 4: Disrespectful behavior

In some cases, patients shared more severe toxic dynamics - rudeness, disproportionate anger or shouting, bullying, mocking or gossiping from clinicians - that left them feeling powerless and unable to act, let alone participate as partners in decisions.

I woke up once while being transported after surgery and heard nurses talking about me as if I weren't there. That was very painful and humiliating.

These events had often been traumatizing, and finding acceptance was difficult. Most patients became emotional while recounting them. These experiences created lasting mistrust of physicians and the healthcare system, a mistrust patients described as a long-lasting barrier to re-engaging in collaborative care.

*My trust was completely gone. I waited a long time before taking the step to go to [the community health center], wondering all the while... which doctor should I go to?*

Patients had often felt powerless to act upon these events at the time they occurred or even afterward. However, they were acutely aware that what they had been through was unacceptable and expressed strong indignation that this could happen in healthcare. The experiences had heightened their awareness of the importance of respectful care.

*"Yes, you remain with the sorrow, with the pain. But you cannot do anything. Losing time on going to court or doing… We just… accept it. Things like that. But it should not happen to other people." [silence]*

## 3.7. Theme 5: Assertiveness

Assertiveness was experienced by many as a necessity to get heard, to 'get things done' and to receive the same chances as other patients, in terms of SDM and quality of care: insisting on their complaints, 'begging' –repeatedly trying to convince providers that their symptoms warrant further action, actively asking for alternative options or searching a second opinion to identify these. Most patients felt this assertiveness should not be necessary and thought that *"the quality of care should not depend on the assertiveness of the patient*". Yet, some had internalized it as a responsibility - "*You have to insist or no change will come.*" – and were positive about its experienced beneficial effects on real participation in shaping their own care.

Personally, I have had a positive experience where I was able to realize my ideas through dialogue with the doctors. […] by expressing my idea. […] I think they [the doctors] were also happy in hindsight that it turned out well.

Most patients, however, recognized that speaking up was often difficult: the inherent hierarchy of the relationship, illness itself as well as physicians' previous behavioral disliking of patient assertiveness often discouraged them from trying (again) — an effect amplified for those with lower social or educational status or when time pressure was experienced.

Someone with a long academic background... ...and here I am—poor me, sitting here... what do I have to say about that? ... […] that... sometimes holds you back from being assertive.

## 3.8. Theme 6: Healing experiences

In contrast, patients evenly described strong healing encounters that had actively enabled participation. These were often described as intense counter-experiences; as experiences that were completely 'new' yet refreshing and healing for them, after having lived years of cumulative negative experiences. These helped to rebuild trust in healthcare and their providers, which they had often lost over the years. Furthermore, they helped to build resilience and 'the strength to carry on' in their disease trajectory. These experiences often differentiated from other experiences in aspects of 'feeling welcomed', sensing shared humanity and physicians' flexibility in thinking broad.

No, I really never, never have that happened. […] the doctor saying: we are concerned about you. […] Yeah, that gave a totally different feeling… […] I've actually never experienced that, that was new to me.

### 3.8.1. Feeling welcomed

Feeling welcomed as an equal, having assertiveness received openly, and being linguistically understood — helped patients speak up in the first place. For non-native speakers, 'linguistic hospitality' through (the presence of) linguistically concordant physicians specifically helped in feeling linguistically welcomed

and enabled to speak up. For patients having greater difficulties in explaining their symptoms or in building trust, having a good rapport was especially determining in their abilities to become empowered – linguistically and emotionally – to speak up.

I also find it difficult to explain my symptoms. And when I don't feel a sense of trust with the doctor, explaining them becomes even harder. […] there's a good rapport, or there isn't.

### 3.8.2. Sensing shared humanity

By connecting through a sense of 'shared humanity' - physicians who engaged in longer, more personal conversations, who showed small humanizing acts such as calling patients by their surname or showing empathy, or who saw 'the person behind the illness' - made patients feel recognized as partners rather than cases.

Yes, I think it's mainly about starting from a sense of shared humanity—from genuine engagement, really. […] From a more equal, more human kind of connection. Rather than focusing on 'the level' or the clinical aspect, but simply... […] person to person.

### 3.8.3. Physicians' flexibility in thinking broad

Lastly, physicians who took a holistic view, by looking at the patient in their contextual, social entirety and by looking further than their own specialty, helped to reach more fruitful collaboration.

I think it is more important to truly look at the patient as a whole […] look at the patient in their entirety, at their story—how it began, how it unfolded—and then ask, and discuss together: where do you want to go from here?

### 3.8.4. Changing physicians through medical education

Changes in medical education, such as the more systematic integration of patient stories as well as deep dive experiences in patients' world, were suggested to help train physicians in these warranted communicative and social awarenesses and skills, enabling them to build more connective experiences with (underserved) patients.

Because then [when encountering patient stories] they [the medical students] can see... okay, maybe that person can't explain it well, or explains it a bit oddly, but you still have to take them seriously—because with some people, you have to dig a little deeper than with others. [...] encountering a number of those real-life stories regularly during your training could... well, give you a better feel for it.

## 4. DISCUSSION

### 4.1. Key findings

Underserved patients frequently experience dismissiveness, communicative misalignment, and sometimes disrespect in healthcare interactions, limiting their ability to participate in SDM. System pressure amplifies the interactional challenges, while assertiveness helps patients navigate them, and healing experiences - through warm, welcoming interactions - help restore trust. The most recurring barriers to participation were credibility deficits ("The doctor does not take me seriously") and time pressure ("My doctor does not have sufficient time").

### 4.2. Comparison with existing literature

Participants described different forms of injustice, resulting in their disempowerment as knowers and partners in SDM. Underlying these findings seems to be the phenomenon of epistemic injustice, compounded by growing structural pressure on the healthcare system.

"Epistemic injustice" was defined by Fricker as "the unfair treatment of individuals in their capacity as knowers", undermining their credibility, authority, and ability to understand their own experiences(73). First, participants described experiences of "testimonial injustice", occurring when a person's account is unfairly discounted due to identity-based prejudice(73). Participants described diminished credibility linked to gender, ethnicity, class, mental illness, or social hierarchy—an effect also experienced with biomedically contested diagnoses like chronic fatigue syndrome or chronic pain. Consistent with prior literature(37)(74), patients' knowledge of their own bodies is often outweighed by "objective" test results; when those tests appear normal, the patient's experience is dismissed. Multiply marginalized patients—such as a Black woman with chronic pain in our sample—often face compounding prejudices that sometimes intensified toxic dynamics, as described in earlier literature(75). Secondly, participants in this study recognized that they often struggled to express their illness experience in medically recognized terms, while physicians' jargon similarly excluded them from understanding and further involvement. This closely aligns with descriptions of the phenomenon of "hermeneutical injustice", the second form of epistemic injustice, "arising when gaps in shared interpretive resources leave someone unable to make sense of their experience"(76). As described earlier, healthcare is built on a particular idea of what counts as knowledge or interpretive framework. While "episteme" and "techne" are broadly recognized, healthcare still lacks a framework for recognizing "phronesis"; patients' interpretive resource, built on illness experience and practical wisdom(77). Patients and HCPs thus often face communication barriers that are rooted in this interpretive resource gap, or – moreover - in the failure to recognize patients' distinct form of knowledge(78)(77).

While epistemic injustice is well-studied in patient-provider interactions generally(37, 78, 79)(74, 80), it has remained underused as a lens for understanding SDM dynamics specifically(37, 81, 82). The framework of epistemic (in)justice could, however, be valuable to complement SDM as it illuminates "the prior epistemic conditions that determine whether patients are recognized as credible informants in the first place"(52). SDM primarily requires that physicians treat patients as "equal partners" with equal communication rights(83)(84). Is it acceptable to communicate for both partners, and if so, what can be said and to whom(37)? Epistemic injustice may undermine this equality in communication rights and thus, the SDM core principle of "equity of contributions"(37).

For underserved patients, the phenomenon of epistemic injustice is probably all the more relevant. Underserved patients are known to face not only intersecting vulnerabilities and accumulated identity prejudices(85) but also historical exclusion from dominant interpretive frameworks(73, 76). While SDM emphasizes "individual uniqueness", it should be acknowledged too that this uniqueness also reflects patients' position within systems of power that can limit their participation(85)(86–88). Moreover, coloniality in knowledge production has historically deprived specific population groups systematically from participating in defining the terms used to discuss SDM and other interpretive frameworks(85). Healthcare is fundamentally a social practice embedded in power structures and SDM rests on social and communicative foundations as much as clinical ones(37). As SDM is founded on the notion that "the accounts and knowledges of those who participate should be explicitly acknowledged"(37), the structural preconditions needed therefore should be equitably met for SDM to function equitably(52). This study suggests however that, for some groups more than for others, these structural preconditions are still to be met.

Nevertheless, it is worth adding that this study also offers further strong evidence for the power of good HCP-patient relationships - particularly when engaging with underserved patients, whose relationship may be more prone to strain. Just as vividly as participants shared their negative experiences, they emphasized the strength and empowerment they drew from warm, connective experiences. This supports earlier research underlining that patients, even when lacking knowledge, skills and/or competencies, can become empowered if they are appropriately supported and have a good HCP-patient relationship. Empowerment and disempowerment are contextual and largely come into existence through interactions(89).

## 4.3. Strengths and limitations

This qualitative study provides unique insight into underserved patients' experiences with SDM, as well as their ideas for greater equity in SDM. Patients with underserved backgrounds were purposefully sampled as '*critical cases*'; 'cases of particular interest and with strategic content in relation to the research questions investigated'(90), helping to make broader generalizations and falsify or verify existing theory(91). The imperative to engage "the people concerned" was clearly a priority in this work and is also increasingly been recognized in developments, both in healthcare and in the drafting or implementation of policy and in research(92–97)(98, 99).

Our choice of methodologies served the study's aims and guiding principles. TIP enabled "those experiencing the problem" – the problem stakeholders – to drive the creative process(57, 58). Consulting stakeholder groups sequentially rather than collectively, unlike typical TIP practice, gave each group emotional safety to voice their views without fear of judgment, while also limiting social or educational hierarchy effects. Lastly, by deliberately consulting underserved patients first, their ideas could be prioritized and the risk of reproducing power asymmetries within the research process could be minimized. *Patient journey mapping*, valuable for surfacing insights in complex care processes(61) such as SDM, made the SDM process tangible and discussable, and helped identify "*pain points*" central to designing better (SDM) experiences(61). NGT prevented any single participant from dominating discussion(60), and helped prioritize and narrow the focus of the later project phases.

Most participants felt great intrinsic affinity for the project and felt genuinely engaged. The presence of zero no-shows suggests participants hold great trust and motivation. Several expressed activist hopes that the research would amplify patient voices. As one participant put it: *"I want other patients to be heard and treated better than I was back then. […] Through participation, I want to change that."*.

However, this study also has several limitations. First, the brainstorming session was more crowded than anticipated, complicating moderation and leaving some participants intimidated and/or unable to speak – particularly for non-native speakers, who faced greater participation difficulties than we had expected. Individual debriefings after the session helped address this by giving patients space to share anything they had not yet been able to express during the group discussion and to deepen desired topics.

Despite an introductory video(100) and presentation on SDM at the start of the session, we experienced some difficulties in keeping the participants "on topic" during the discussion. Participants often drifted toward broader healthcare experiences rather than SDM specifically. We could hypothesize, however, that this happened because SDM is the "pinnacle" of qualitative, patient-centred care(21) and necessitates structural, epistemic preconditions to be met to take place(52). Our participants' history of a recurring lack of these structural, epistemic preconditions, as apparent in our data, probably prevented them from building up meaningful experiences with SDM in the past and, thus, making focused reflections on this process during the session.

The study was also limited to a small sample of underserved patients, who may have been more interested, empowered, or willing to engage in shared decision-making than others, introducing bias. Many also had mental health conditions or medically unexplained illnesses like chronic pain or fatigue, which earlier literature links to being disbelieved by clinicians(65, 75). We therefore cannot determine whether these findings evenly apply to other underserved patients without such diagnoses, or reflect issues specific to this group versus broader systemic patterns. Prior work(86–88), however, shows SDM participation is often shaped by intersecting oppressions — sexism, racism, and other structural discrimination — that compound for multiply marginalized patients(75). Our findings nonetheless align with earlier work on inequitable SDM practices and comparable underserved patient experiences(1, 33, 101–105)(106), suggesting that (even) this small, selective sample is signalizing relevant phenomena in this group.

## 5. CONCLUSION

This paper examined the mechanisms behind inequities in patient participation in SDM, through a participatory study with underserved patients. Through collaborative discussion with the people concerned, the formats and conditions that can hinder underserved patients' participation were intended to become more visible. The study results suggest that underserved patients frequently experience dismissiveness, communicative misalignment, and sometimes disrespect in healthcare interactions, limiting their ability to participate in SDM. The socially stratified effect of epistemic injustice, "the prior epistemic conditions that determine whether patients are recognized as credible informants in the first place", was recognized in our data as a determining factor of exclusion in underserved groups. SDM acknowledges patients' right to participate, yet this study confirms how social determinants, as well as intersecting

vulnerabilities and accumulated identity prejudices, can threaten this right. The results highlight that decolonizing the health care service process implies an active acknowledgement of historically entrenched forms of epistemic injustice in healthcare. It invites care practitioners and managers to invest in the co-creation of conditions in which diverse ways of knowing, experiencing, and compliance are recognized as legitimate and able to shape care. There remains a need to further strive for clinical practice that promote epistemically equitable patient-provider communication, in which all voices are recognized and respected and SDM might function truly equitably.

## Abbreviations

SDM: shared decision making

HCP: Health care provider

TIP: Targeted Intervention Planning

NGT: Nominal Group Technique

## Declarations

**Ethics approval and consent to participate**

The Social and Societal Ethics Committee of the University of Leuven exempted this study from ethical approval at October 8 2025 (G-2025-9907), in accordance with the Declaration of Helsinki. Further information and documentation to support the approval is available on request.

**Consent for publication**

Written informed consent for publication of photographic materials was obtained from all participants. Participants that did not give their consent were anonymized on the materials. Written informed consent for publication was equally obtained.

**Availability of data and materials**

All materials described in the manuscript, including all relevant raw data, are available on request to any scientist wishing to use them for non-commercial purposes, without breaching participant confidentiality.

**Authors' contributions**

**Lien Mertens:** Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Karin Hannes:** Methodology, Investigation, Conceptualization, Writing – review and editing. **Pieter Van Bostraeten:** Investigation,Writing – review and editing. **Jasmien Jaeken:** Writing – review and editing. **Geertruida Bekkering:** Writing – review and editing. **Nicolas Delvaux:** Writing – review and editing. **Hendrik-Jan Verhaegen:** Formal analysis, Writing – review and editing. **Bert Aertgeerts:** Supervision, Investigation, Conceptualization, Writing – review and editing.

**Declaration of Generative AI and AI-assisted technologies in the writing process**

During the preparation of this work the author(s) used Claude AI® in order to improve the readability of certain sentences. After using this tool/service, the author(s) reviewed and edited the content as needed and take full responsibility for the content of the published article.

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**Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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**Appendix A. Supporting information**

Supplementary data associated with this article can be found in the online version at ###

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## Figures

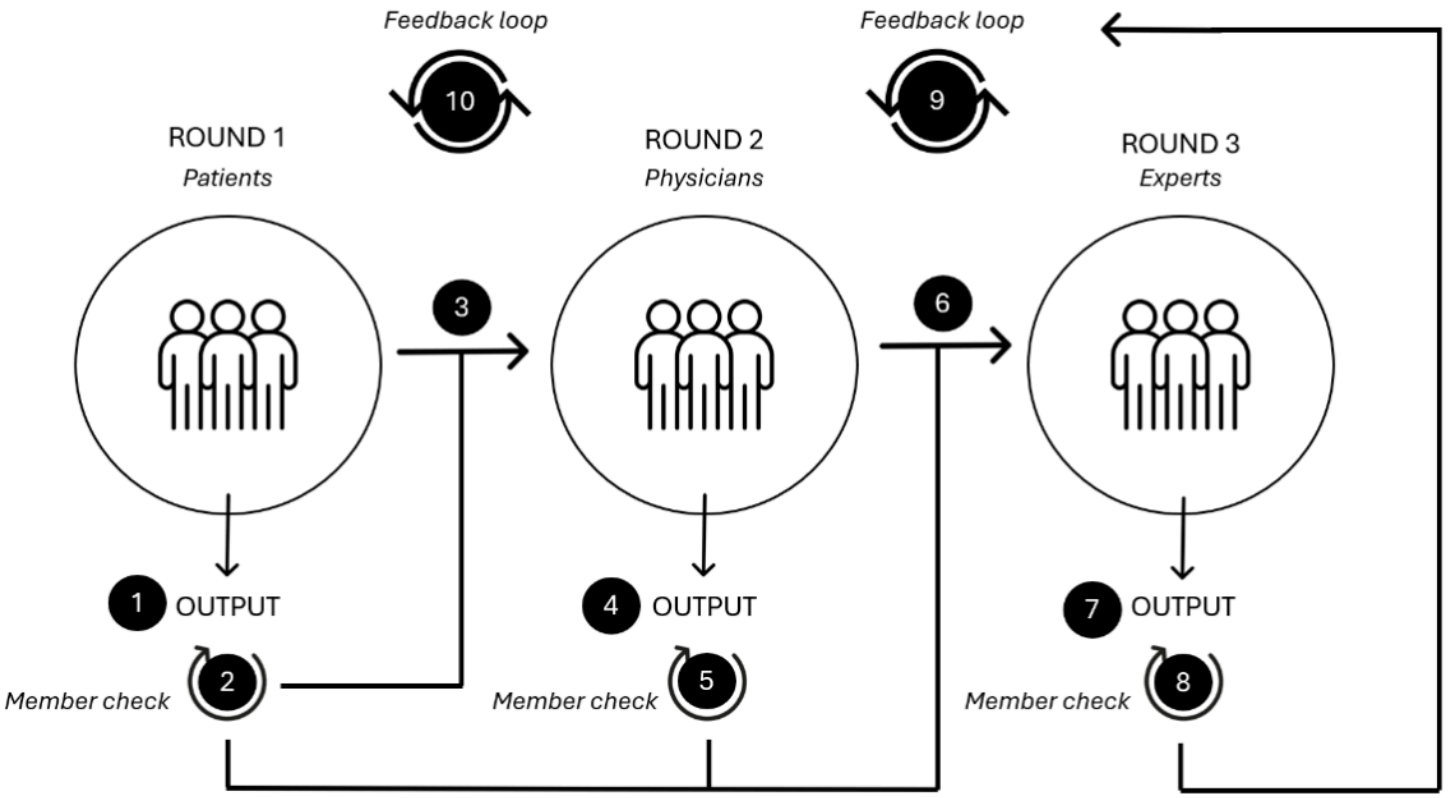



**Figure 1**

*Overview of study course. The numbers indicate the chronological flow of the different steps. Round 1, collecting underserved patients' experiences, ideas and reflections on underlying problems and solutions, served as a reflexive basis for subsequent, deepening analysis with physicians (round 2). The shared analytical output of patients and physicians finally served theory-building work with experts (round 3). Member checks ensured participants could check data on accuracy, completeness and recognizability before data were passed on to the next round. Feedback loops finally feedbacked the output of the experts to the earlier-engaged patients and physicians, giving the latter room for final input.*

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table1criteriasociallydisadvantaged.docx
- Table3Themesillustrativequotesedited.docx
- Appendixsessionguide.docx
- Appendixpainpointmap.docx
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