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# Dutch Ethics Support and Patient Participation: Current Practices, Aspirations, Obstacles, and Suggestions from a National Survey

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## Abstract

Patient involvement in clinical ethics support services (CESS) is increasingly recognized as important, yet global practices vary widely and comprehensive theoretical or empirical studies are scarce. Limited evidence from Europe suggests that patient participation in CESS (hereafter referred to as PP) differs by region and type of service, ranging from being entirely absent to patients acting as full dialogue partners. In contrast, North America appears to have more uniform adoption of PP. Although there are indications that PP is growing in Europe, no concrete data confirm this trend. This study aimed to gain an in-depth understanding of Dutch practices and attitudes toward PP, exploring both practical experiences and normative perspectives of respondents. A national survey targeting Dutch CESS staff was developed, consisting of 25 questions—both open and closed—covering four main areas: (1) the objectives of CESS, (2) current practices of PP, (3) ideas and ideals regarding PP, and (4) barriers to PP. Four key findings emerged: (1) PP in Dutch CESS is not yet routine; (2) perspectives on PP are closely linked to the perceived goals of ethics support; (3) hesitations or perceived obstacles to PP were generally practical rather than principled; and (4) most respondents view PP positively but emphasize the need for additional training, practical guidance, and hands-on experience. There are several normative arguments supporting PP. Nonetheless, it remains relatively uncommon and far from standard in Dutch CESS. Respondents expressed few principled objections; instead, limited PP appears connected to how CESS goals are understood, often focusing primarily on supporting healthcare professionals. Training and practical guidance were identified as crucial for building competence and experience for both CESS staff and healthcare providers.

**Keywords:** Netherlands, Patient participation, Clinical ethics, Survey, Moral case deliberation, Ethics consultation

## Introduction

Patient involvement in clinical ethics support services (CESS) has increasingly been recognized as a significant issue [1–5]. While patients are often the focus of CESS activities, they have not consistently participated as active contributors in these discussions. The question of if and how patient participation in CESS (hereafter abbreviated as PP) should be implemented is especially relevant for services directly related to patient care, which constitutes a central task of CESS [1, 6]. Despite its acknowledged importance [7], PP has been rarely explored in depth, and comprehensive theoretical or empirical investigations are lacking. One of the few studies addressing PP appeared in a special issue of Clinical Ethics [7], which revealed substantial variability in European practices. In Europe, PP is not uniformly endorsed, if at all, and its implementation differs by region [8] and type of CESS. Participation ranges from being entirely absent, to patients merely being informed, to patients serving as full conversational partners. For example, PP is uncommon in the UK [9], relatively frequent in Paris [8], and in Norway it varies depending on the institution and case type, with other European countries showing similar variability [8, 10, 11]. In Dutch moral counseling—which can be considered a form of CESS, providing individualized support for moral and

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existential concerns through pastoral care—patient participation is standard [12].

This variability in Europe contrasts with the United States, where PP appears largely standard. Fox *et al.* (2007) reported that 73–93% of US CESS services involved patients [13], a trend confirmed by more recent studies [14]. In the US context, PP is often viewed as essential, under the premise that all stakeholders involved in a patient case should participate in deliberations, which is believed to support reflection and promote morally appropriate care [15]. While some differences in attitudes toward PP may be linked to distinctions between single-ethicist consultations and ethics committee consultations, recent literature indicates that PP remains a debated issue in Europe regardless of CESS type [16].

Arguments for and against PP have been identified [9, 10, 17]. Objections include practical challenges, such as patient contact being "too difficult or impractical," or the perception that "other mechanisms already exist" and that CESS interventions primarily support clinicians [9]. Theoretical concerns include potential harm to the patient-physician relationship or increased distrust [18]. In contrast, reasons supporting PP include promoting procedural and epistemic justice [19], incorporating multiple perspectives [18], addressing hierarchical imbalances [10], reducing professional bias, enhancing deliberation on fundamental issues [10], and fostering autonomy while avoiding paternalism [9].

As PP gradually gains attention in Europe [7, 9], we developed a national survey targeting Dutch CESS staff. Given the wide variability in European prevalence and practices of PP [20–22], we aimed to explore its implementation in the Netherlands, including normative perceptions. Key questions included: What does PP look like in Dutch CESS? At what stage should patients be involved, if at all? And to what extent should direct participation occur? These questions were informed by experiences in the US, where PP appears largely settled, and by the broader global emphasis on patient involvement in healthcare.

Our study focused specifically on CESS contexts rather than general patient participation. We aimed to provide an integrated understanding of current practices, underlying ideas and ideals, and the challenges surrounding PP in the Netherlands. The survey explored both habitual practices and attitudes toward PP, including practical and normative viewpoints. Additionally, we examined barriers and facilitators of PP. Normatively, we started from the position that PP is desirable in most CESS situations, reflecting principles of participatory, procedural, and epistemic justice, while remaining open to critical perspectives and arguments against patient involvement.

## Materials and Methods

### *Design and survey*

We conducted a cross-sectional survey to explore patient participation (PP) in Dutch CESS. The survey was structured around four main topics: the goals of CESS, current practices, ideas and ideals regarding PP, and barriers to participation. It included sections on respondent demographics, patient participation in CESS, family and proxy participation, and CESS practice characteristics (e.g., how CESS operates in respondents' settings). Each section combined multiple-choice questions with open-ended options for comments. While most sections used predefined answer options, questions about family and proxy participation were primarily open-ended; results from that section are reserved for a separate paper. This study focuses specifically on respondents' experiences with PP and their normative and practical views on it. Some questions allowed multiple responses, and respondents could provide additional comments, reflecting a mixed-methods approach [23]. Survey items were developed iteratively, informed by both a preliminary literature review and our practical experiences with CESS. The survey and answer options underwent a two-step refinement process: (1) peer review by five expert ethicists with backgrounds in clinical ethics, research methodology, and healthcare practice, and (2) a pilot with 10 CESS staff members, whose feedback on clarity and content informed final revisions.

### *Sampling*

Participants were recruited via four listservs and our personal network of ethics support professionals. Three listservs targeted individuals trained in ethics support, including the NEON network (Netwerk Ethiek Ondersteuning Nederland), which comprises around 300 members with diverse professional backgrounds. Invitations were posted, asking interested individuals to email their consent to participate. A single reminder was sent, and prior experience with patient-involved CESS was not required.

Eligibility was limited to individuals actively involved in ethics support services, such as MCD facilitators, ethics committee members, ethics consultants, or spiritual care providers engaged in ethics support. Individuals whose roles were limited to ethics education and who had no hands-on experience in CESS were excluded (e.g., students still in training). The study specifically focused on CESS activities addressing patient-related ethical issues, excluding cases related to human resource management or other organizational matters.

### *Data collection*

Survey responses were recorded using Castor, a secure database platform. Personal identifiers such as names or IP addresses were not collected. Respondents could optionally provide contact information in the comments section to receive updates or be re-contacted for follow-up questions; this information was stored separately from survey responses. Data were collected between December 2020 and March 2021.

### *Data measures*

The survey was structured to branch depending on respondents' prior experience with patient participation (PP). For those with PP experience, questions focused on the current state of participation, including frequency of patient involvement, who typically initiates contact, timing and degree of participation, and perceived reasons for and against PP in their clinical practice. Respondents without prior PP experience were asked a single question about why patient contact had not occurred in their setting.

Subsequent sections addressed all respondents, regardless of experience. Participants were asked about their ideas and ideals regarding PP, including when patient contact should occur (before, during, and/or after the CESS activity) and the perceived importance of such contact, measured on a Likert scale from 1 (not important) to 5 (very important). They were also asked to identify reasons for and against PP in an ideal scenario, as well as obstacles to participation that they had experienced or could anticipate. Finally, the survey inquired about the goals of case-based ethics support. Respondents were provided with 19 predefined options, categorized into four main goal domains: (1) patient-related, (2) individual healthcare professional-related, (3) team-related, and (4) organizational. Participants rated the importance of these goals using a five-point Likert scale. Demographic information on CESS staff and their practice settings was also collected.

### *Analysis*

Quantitative data from predefined survey responses were analyzed using descriptive statistics in SPSS, version 22.

#### *Qualitative analysis*

One open-ended survey question asked respondents to identify what they perceived as necessary to overcome obstacles to patient participation (PP). Responses were analyzed using the framework analysis method [24]. Two researchers (WL and ME) independently coded the data to capture emerging themes, resolving differences through discussion and consulting the entire research team. The resulting themes aligned with the paper's broader findings and are presented accordingly.

Additional open-ended responses collected under the 'further comments' sections of predefined questions mostly provided clarifications or minor remarks rather than generating new variables. Selected quotes from these responses are used to illustrate and enrich the quantitative findings.

## Results and Discussion

### *Respondents' demographics*

A total of 103 individuals requested the survey link, of whom 75 completed more than 80% of the questions, yielding a completion rate of 73% among those who expressed interest. Due to the survey being distributed across four listservs, an exact overall response rate cannot be determined. Respondent characteristics are summarized in **Table 1**.

Approximately half of the respondents worked in hospital settings, while the remainder were employed in long-term care for the elderly, facilities for individuals with cognitive disabilities, or mental health care settings. Professionally, 40% identified primarily as healthcare professionals (physicians, nurses, spiritual caregivers, social workers), 36% worked in roles such as lawyer, researcher, or policy advisor, and 24% were classified as 'other' (including coaching or teaching roles). Fourteen percent self-identified as ethicists.

Regarding involvement in case-based ethics support, 46 respondents reported active participation. No significant associations were found between respondents' professional backgrounds and their views on PP.

### *Goals of ethics support*

**Table 2** presents respondents' perceptions of the goals of case-based ethics support. The three goals most frequently prioritized related to individual healthcare professionals and the organization, followed by team-related goals as the next most important (goals 4, 5, and 6). Patient-related goals were less frequently selected. Among patient-focused options, the most commonly noted goal was the identification of ethical issues concerning the patient that are subsequently discussed by the ethics support service. This goal ranked seventh in importance overall and was selected as significant by 30% of respondents. When asked to identify the single most important goal, only two respondents selected this patient-centered objective.

*Patient participation in ethics support: prevalence, Ideas, and Ideals*

**Tables 3 and 4** summarize the prevalence and extent of PP, as well as the most prominent ideas and ideals regarding participation in Dutch CESS. The 'ideals' data include all respondents, regardless of whether they conduct case-based consultations or other types of ethics support, and irrespective of prior PP experience.

*Prevalence, timing, and extent of patient involvement: current Practice*

Of the 75 respondents, 41 (55%) reported no direct patient contact in their ethics support role, while 34 (45%) indicated they did engage with patients. Among those with patient contact, 8 respondents reported that participation occurred most or all of the time, 12 stated patients were rarely involved, and 14 indicated that participation occurred occasionally. Nearly two-thirds (65%) of respondents performing case-based CESS noted that the patients involved had cognitive or neurological impairments, as summarized in **Table 1**.

*Timing and extent of patient involvement* *

(The asterisk (*) indicates that the data presented in this section are based on the 34 respondents who reported having direct patient contact.**)**

Regarding who typically initiates patient involvement, 21 respondents indicated that it was the healthcare professional (HCP) requesting CESS, while 16 reported that the ethics support staff usually took the initiative to contact the patient.

The degree of actual patient involvement varied widely. Eighteen respondents stated that patients were informed about the ethics support activity before the meeting, 14 indicated that patients were asked for their views on the ethical issue beforehand, and 13 reported that patients were invited to actively participate in the session. Six respondents noted that patients were only informed after the meeting had taken place.

In the open-ended responses, a few participants explained that they engaged patients through moral counseling rather than direct participation. One respondent elaborated: "I'm mostly involved to have a plain conversation with the patient… In this way it is a mediated type of patient participation."

**Table 1.** General demographics

| Characteristic | n | % | Notes |
|---|---|---|---|
| **Respondent Gender** | | | No respondents selected 'other' |
| Female | 58 | 78.4 | |
| Male | 16 | 21.6 | |
| **Profession** | | | |
| Physician | 3 | 3.9 | |
| Nurse | 6 | 7.8 | |
| Spiritual Care | 20 | 26.0 | |
| Social Worker | 2 | 2.6 | |
| Administrator | 1 | 1.3 | |
| Policy Maker | 8 | 10.4 | |
| Lawyer | 3 | 3.9 | |
| Ethicist | 11 | 14.3 | |
| Researcher | 5 | 6.5 | |
| Other | 18 | 23.4 | |
| **Work Setting** | | | Percentages exceed 100% as respondents may work in multiple settings |
| General Hospital | 15 | 19.2 | |
| Academic Hospital | 21 | 26.9 | |

| | | | |
|---|---|---|---|
| Elderly Care Organization | 13 | 16.7 | |
| Mental Health Organization | 6 | 7.7 | |
| Disability (Mental) Care | 14 | 17.9 | |
| Home Care | 2 | 2.6 | |
| Other | 17 | 21.8 | |
| **Ethics Support Role** | | | Percentages exceed 100% as respondents may hold multiple roles |
| Ethics Committee Member (not REB) | 19 | 25.0 | |
| Chief Ethics Committee Member (not REB) | 3 | 3.9 | |
| Moral Case Deliberator | 47 | 61.8 | |
| Ethics Working Group Member (not REB) | 11 | 14.5 | |
| Chief/Coordinator Ethics Working Group | 9 | 11.8 | |
| Ethics Consultant/Support | 17 | 22.4 | |
| Moral Counselor | 6 | 7.9 | |
| Other | 14 | 18.4 | |
| **Experience as Ethics Support Professional (years)** | | | 51% reported 0–5 years of experience |
| **Time per Month on Case-Based Ethics Support** | | | Over half of respondents spend 1–5 hours/month |
| **Time per Month in Ethics Support Overall** | | | 50% reported 0–5 hours/month regardless of case-based support |
| **Ethics Support Methods Used** | | | Percentages exceed 100% as multiple methods can be applied; some US methods (e.g., 4-box) were included but not selected |
| No Method | 3 | 6.4 | |
| Socratic Dialogue | 17 | 36.2 | |
| “Utrechts Stappenplan” | 4 | 8.5 | |
| Nijmegen Method | 6 | 12.8 | |
| Dilemma Method | 23 | 48.9 | |
| 7-Phase Model | 3 | 6.4 | |
| Care-Ethics Method | 5 | 10.6 | |
| Relief Method | 11 | 23.4 | |
| Mixed Method | 19 | 40.4 | |
| Other | 8 | 17.0 | |
| **Patient Impairments in Case-Based Ethics Support** | | | Percentages exceed 100% as patients may have multiple impairments |
| Mental Illness/Mental Disability | 17 | 56.7 | |
| Psychiatric Impairment | 22 | 73.3 | |
| Cognitive Disability (e.g., Dementia) | 20 | 66.7 | |
| Disorder of Consciousness | 7 | 23.3 | |

**Table 2.** Goals of ethics support

| Goal Category | Specific Goal | n | % |
|---|---|---|---|
| **Healthcare Professional–Related** | Enhance moral and reflective skills and knowledge/understanding for individual HCPs | 49 | 74.2 |
| **Organization-Related** | Improve the reflective climate within the organization | 39 | 59.1 |
| **Healthcare Professional–Related** | Strengthen moral resilience for individual HCPs | 30 | 45.5 |
| **Team-Related** | Provide a space to discuss moral distress, doubts, or other ethical hesitations | 29 | 43.9 |
| **Patient-Related** | Identify existing ethical issues concerning the patient that are subsequently discussed by the ethics support service | 20 | 30.3 |

**Table 3.** Prevalence of Patient Participation and Extent of Involvement

| Characteristic | n | % |
|---|---|---|
| **Direct Patient Contact** | | |
| No | 41 | 54.7 |
| Yes | 34 | 45.3 |
| **Engagement in Case-Based Ethics Support** | | |
| No | 12 | 20.7 |
| Yes | 46 | 79.3 |
| **Frequency of Direct Patient Involvement** | | |
| Never | 3 | 8.8 |
| Hardly ever (1–10%) | 9 | 26.5 |
| Sometimes (10–40%) | 14 | 41.2 |
| Most of the time (40–80%) | 5 | 14.7 |
| Nearly always (80–99%) | 1 | 2.9 |
| Always (100%) | 2 | 5.9 |
| **Forms of Patient Involvement in Ethics Support** | | |
| Patient informed about ethics support activity prior to the meeting | 18 | 60.0 |
| Patient asked for their perspective on the ethical issue before the meeting | 14 | 46.7 |
| Patient asked for consent to discuss case without attending | 11 | 36.7 |
| Patient invited to actively participate in CESS session | 13 | 43.3 |
| Patient informed about ethics support activity after the meeting | 6 | 20.0 |
| Other forms of involvement | 8 | 26.7 |

**Table 4.** Prominent ideas around patient participation in the netherlands

| Aspect | Specific Item | n | % | Notes |
|---|---|---|---|---|
| **Disadvantages of Patient Participation Experienced in Practice** | | | | Percentages exceed 100% as respondents could select multiple options |
| Reduced openness as providers might be less candid in discussions | 16 | 48.5 | | |
| No disadvantages experienced | 11 | 33.3 | | |
| Meetings become more complex due to additional perspectives | 6 | 18.2 | | |
| Reduced openness as patient requires more attention during discussions | 5 | 15.2 | | |
| **Advantages of Patient Participation Experienced in Practice** | | | | Percentages exceed 100% as respondents could select multiple options |
| Enhances quality of decisions (decision content) | 24 | 72.7 | | |
| Improves healthcare provider understanding of the patient perspective | 23 | 69.7 | | |
| Amplifies the patient’s voice and perspective | 22 | 66.7 | | |
| Strengthens collaboration among stakeholders | 17 | 51.5 | | |
| **Most Important Reasons Supporting Patient Participation** | | | | Max 2 choices; percentages exceed 100% |

| | | | |
|---|---|---|---|
| Allows determination of what constitutes 'good care' through the patient's perspective | 32 | 45.1 | |
| Empowers or ensures the patient's perspective is heard | 31 | 43.7 | |
| Facilitates shared decision-making | 27 | 38.0 | |
| Enhances collaborative practices | 18 | 25.4 | |
| Upholds democratic principles and equality | 16 | 22.5 | |
| **Most Valid Reasons Against Patient Participation** | | | Max 2 choices; percentages exceed 100% |
| Reduces openness and free discussion | 41 | 57.7 | |
| Ethics support primarily aims to develop HCPs' moral competencies | 22 | 31.0 | |
| May negatively affect patient-provider trust | 15 | 21.1 | |
| Potentially harmful for the patient | 14 | 19.7 | |
| **Reasons for Absence of Patient Participation in Practice** | | | Max 3 choices; percentages exceed 100% |
| PP is uncommon in the respondent's ethics support practice | 19 | 46.3 | |
| Focus on improving HCPs' moral competencies | 16 | 39.0 | |
| PP reduces openness and free expression of HCPs | 11 | 26.8 | |

*Importance and ideals of patient participation (PP)*

Opinions regarding the significance of patient participation in ethics support varied. Among the 75 respondents, 37% considered PP to be important, while 57% felt that its relevance depended on the specific ethical dilemma. One comment reflecting this conditional view stated: “It depends on the situation or setting,” and another clarified the absence of patients by noting: “Sometimes the ethical issue is something within the team…”

*Timing and extent of patient involvement*^

(Our use of the ^ symbol indicates that the data presented under this section are based on responses from all 75 participants)

Perspectives differed regarding when and to what degree patients should be involved. The strongest consensus was on the importance of informing patients about what to expect and their role in ethics support meetings (mean score 3.81 on a 1–5 Likert scale). Respondents also largely agreed on notifying patients about the ethics support process in advance (3.79) and asking for their input on the moral issue being discussed (3.79). There was less agreement on the value of updating patients about the meeting's outcome afterward (3.30) or inviting them to participate (3.21). Seeking patient consent to discuss their case scored even lower (3.17), while the least favored practice was merely informing the patient post hoc that a meeting had occurred (2.89). One respondent explained the hesitation: “Informing the patient [that a CESS activity about him/her took place] afterwards could create bad feelings for the patient.” Nevertheless, respondents also recognized the necessity of post-meeting communication: “If the patient does not participate, then, certainly, they would have to be informed afterwards.”

*Reasons for patient participation (PP)*

We presented our respondents with a set of predefined reasons for why patient participation in CESS should be feasible. Respondents, regardless of whether they had personal experience with PP, could select multiple options, so total agreement exceeded 100%. Illustrative examples from respondents' open comments are included.

*Reasons for PP: 'current status' and practice**

When asked about their own experiences with PP in CESS, respondents cited the following main reasons for its value. The most frequently mentioned reason was that PP enhances the quality of decision-making, with 73% highlighting that it improves the content of decisions. The second most cited reason was that it fosters a better understanding of the patient and their perspectives (70%). Third, hearing the patient's voice and viewpoint was considered important (67%), and fourth, PP was reported to improve collaboration among all parties involved, including the patient (52%).

### *Reasons for PP: normative ideas and ideals^*

Drawing on literature and a pilot study, we offered respondents ten potential normative reasons for PP, alongside an option to provide additional open comments. The top five selected reasons were: (1) creating a space to define what constitutes 'good care' (45%); (2) empowering or ensuring the patient's perspective is heard (44%); (3) facilitating shared decision-making (38%); (4) enhancing the overall quality of care (28%); and (5) promoting collaborative practices (25%). Interestingly, reasons related to (social) justice, such as adherence to democratic principles or equality, were less frequently endorsed (23%), ranking sixth among the ten options.

Three further reasons emerged from the comment section, offering additional viewpoints. These included statements such as: "enhances understanding and empathy for the client's personal journey and struggles" and "respects the care relationship by involving the patient."

### *Reasons and explanations against PP*

Respondents provided a range of explanations, justifications, and barriers for not including patients in CESS, selected from several pre-defined options.

### *Current practice*

Among the 41 respondents who did not engage directly with patients in their ethics support role, 46% indicated that patient participation was rare in their practice. Some elaborated in the comments, pointing to unsupportive institutional policies and the prevailing organizational culture. Additionally, 39% emphasized that the primary purpose of ethics support sessions was to enhance healthcare providers' (HCPs') moral competencies. A further 27% suggested that involving patients could hinder open discussion among HCPs.

### *Ideas and ideals^*

Two major concerns consistently appeared among respondents regarding patient participation. The most frequently cited worry, noted by 29% of respondents (41 individuals), was that including patients might limit HCPs' openness in discussions. The second concern, expressed by 16% (22 respondents), was that the central aim of ethics support sessions should remain the development of HCPs' moral competencies. Additional reasons against patient involvement included potential harm to the patient or strain on the patient-provider relationship, ranking third and fourth (10% and 11%, respectively).

Open comments reinforced and clarified these concerns. Several remarks reflected anxiety that patient participation could reduce candid discussion and shift the focus away from HCP development, for instance: "In our case, moral case deliberation is the moment for deepening HCPs' moral issues for the HCPs." Other comments highlighted potential risks to patients, such as "too much tension [for the client]," "patient is psychotic," "creates co-responsibility for the patient," "could be experienced as a tribunal," and "risks causing ambiguity for the patient regarding the HCP's responsibilities and their own role in ethical matters… especially if the professional lacks sufficient moral skills."

### *Obstacles and requirements for enabling PP^*

We asked respondents to identify potential obstacles to facilitating patient participation (PP). Among the pre-defined options, practical issues were most frequently highlighted. The primary concern cited was a patient's inability to participate, for instance due to unconsciousness or limited decision-making capacity (49 respondents, 20% of all answers). Other commonly noted barriers included reduced openness among healthcare providers (46 respondents, 19%), resistance from surrogates (38 respondents, 16%), and limitations in the ethics support person's skills (27 respondents, 11%).

In the open comment section, we explored what would be needed to overcome these barriers. Analysis revealed distinct requirements for different stakeholders. For ethics support personnel, respondents emphasized the importance of targeted training, such as instruction in group management and facilitating group discussions, as well as a proactive approach to promoting PP among healthcare providers. This proactive role was seen as part of their core responsibilities rather than something to be addressed only if prompted by HCPs.

For HCPs, respondents highlighted the need for education and guidance on the value of PP in CESS and strategies to mitigate potential risks or obstacles, aiming to reduce their reluctance or "cold feet." Alternative approaches to patient involvement were also suggested, such as interacting with patients before or after CESS sessions, which could help ease HCPs' concerns.

Organizational changes were deemed necessary to support wider adoption of PP in CESS, including cultivating a culture that endorses patient involvement and establishing a "safe" environment for all participants in ethics support activities. Several respondents recommended starting with pilot initiatives to gradually implement PP. Finally, respondents noted the importance of patients' and proxies' cognitive and emotional capacity, as well as their willingness and commitment to participate, as critical factors for successful engagement.

In this study, we explored the perspectives of ethics support professionals regarding patient participation (PP) in the Netherlands, examining both practical experiences and normative views. The responses revealed a wide range of insights, showing that arguments for PP from other CESS contexts could not be directly applied to the Dutch setting. Our findings are particularly meaningful when considered alongside broader questions about the goals of CESS, as these goals appeared to shape practices and perceptions, including beliefs, ideals, and challenges related to PP. Four key observations emerged: (1) PP in Dutch CESS is far from routine; (2) perceptions of PP are closely linked to the objectives of ethics support; (3) hesitations, fears, and perceived barriers to PP are context-dependent rather than absolute; and (4) PP can be a beneficial opportunity that requires additional training and practical guidance. These results have normative implications and highlight avenues for further research.

### *Patient participation in dutch CESS: not yet routine*

The literature frames PP as a continuum, ranging from patients being informed before or after a CESS session, consulted at various stages, involved in meetings, contributing to guideline development, or even serving as full co-decision-makers [25]. Similarly, potential forms of PP in CESS have been described along a comparable spectrum [26], including: (a) informing patients about the referral; (b) allowing patients to communicate directly with ethics support prior to deliberation; (c) sharing the outcomes or recommendations from CESS with the patient; and (d) providing patients the opportunity to speak with a CESS member after deliberations when conflicts arise between clinician and patient values.

Our data indicate that active patient involvement in CESS—where patients participate directly in the ethics support process—is relatively rare in the Netherlands. Fewer than half of the respondents reported engaging directly with patients, and only a minority of services consistently informed patients about ongoing CESS activities. This contrasts sharply with practices in the United States [13, 14], where patient involvement is more systematically implemented. While previous authors, such as Ballentine and Gray, have highlighted the surprising lack of patient engagement in CESS given commitments to patient-centered care, our Dutch respondents tended to view PP as potentially valuable depending on the situation, rather than as an absolute requirement.

### *Views on PP are closely linked to the goals of ethics support, which do not necessarily Include Patient Participation*

In the Netherlands, the main emphasis of CESS appears to be on supporting healthcare providers (HCPs) rather than directly supporting patients, which may help explain why PP is not widely practiced. Respondents consistently highlighted the development of HCPs' moral reasoning skills as both a central ideal and a core element of their experience with CESS. This focus aligns with the predominant form of ethics support in the Netherlands, moral case deliberation (MCD), where a primary aim is to enhance HCPs' moral reflexivity and competence [21, 27].

Although MCD ultimately seeks to improve the quality of care for all stakeholders, its literature does not explicitly prioritize the patient's perspective. Instead, one of its key objectives is fostering a "joint process of moral learning" [28]. While this collaborative approach is defensible from dialogical and hermeneutic ethical perspectives, it may undervalue the unique contribution of the patient's viewpoint.

Patient-centered goals were generally rated lower by respondents when considering the objectives of CESS. Aims such as enhancing patient care through ethics support, improving patient experiences, or resolving conflicts between patients and HCPs were infrequently endorsed, despite being common themes in the broader literature. In contrast, U.S.-based ethics support often places greater emphasis on patient-related goals, including patient empowerment and mediating conflicts between HCPs and patients, which are regular responsibilities of ethics consultants [29]. The reasons why such patient-focused goals are less prominent in Dutch CESS remain unclear and are not addressed by our data.

The prioritization of HCP learning over patient-related goals is not unique to the Netherlands. In other countries where CESS originally developed as HCP committees, ethics support systems were primarily aimed at assisting providers, and patient participation was not always incorporated [1, 8, 16, 30, 31]. In contexts where committees were primarily advisory, such as in the U.S., PP was not generally considered necessary, particularly regarding policy or educational functions [29]. Additionally, historical, cultural, and healthcare system factors have been suggested to explain why certain countries emphasize either HCPs or patients in their ethics support practices [8, 9, 32].

Patient participation (PP) in ethics support systems has evolved over time in certain countries, notably the U.S., France (Paris), and Norway. In these contexts, questions regarding the objectives of clinical ethics services (CES) and the prerequisites for PP emerged in response to the authoritative role of ethics committees and uncertainties about the functions of different services [1], particularly in the U.S. setting. The notion that patient consent was necessary for discussing a case heightened the emphasis on PP, as patients were perceived to have a stake in such meetings and could potentially object. Current developments in Norway appear to follow a similar rationale [33]. Moreover, as ethics consultations increasingly involved conflicts, patient input became more critical. Consequently, the perspective on PP shifted from viewing consultation solely as a physician-driven need to recognizing that patient contributions could balance or complement the values of providers or institutions, even if this raised concerns about privacy and autonomy. In the U.S., practical guidelines endorsed PP in CESS as early as 2000 [34].

Although our Dutch respondents prioritized HCPs, this does not diminish the role of patients in CESS. The moral case deliberation (MCD) model, even when HCP-focused, is ultimately oriented toward promoting high-quality patient care. Patients are indirectly engaged: for instance, in the dilemma method of MCD, the values and norms of patients and their families are explicitly considered by professionals during ethical reflection on what constitutes good care [35]. Enhancing HCPs' competencies and moral reflexivity through MCD equips providers to deliver better care and be more attuned to the values of patients and families [36]. Nevertheless, even with this indirect involvement, the broader ethical question remains: why should patients not have the opportunity to participate directly in CESS, whether before, during, or after the ethics support activity?

### *Hesitations, barriers, and fears do not automatically preclude PP*

The concerns expressed by respondents about patient participation (PP) mostly reflected practical challenges, echoing issues reported in other European contexts. Commonly mentioned obstacles included patients' limited decision-making ability or objections from proxies, which have previously been cited as reasons for caution in implementing PP [11]. Respondents also worried that involving patients could reduce candor in CESS discussions or interfere with full transparency, a concern similarly noted in France and Norway [8, 11]. Some hesitations appeared to reflect nervousness or "cold feet," while others pointed to external factors, such as reluctant HCPs initiating the consultation. A smaller subset raised principled objections, fearing harm to patients or perceiving the process as resembling a "tribunal." Yet, these issues are not uniquely Dutch. Hackler observes that patients or families may feel intimidated entering a room of professionals, regardless of the committee's intentions [37]; Neitzke emphasizes possible harm in situations with prognostic uncertainty [10]; and Magelssen describes participation as potentially burdensome for patients [11].

Despite these apprehensions, such barriers do not necessitate abandoning PP. Experiences in other contexts show that concerns over decision-making capacity or proxy objections have not prevented patient involvement [38]. Fears about transparency, openness, or harm are empirical and can be addressed through procedural adjustments, and delays in developing HCP skills are largely tied to the goals of moral case deliberation (MCD) rather than principled objections. Consequently, these concerns alone do not justify excluding patients. As Finder notes, understanding the precise details of a case is essential to fully appreciate the ethical considerations at stake [35], and Magelssen highlights the continued importance of stakeholder participation despite potential difficulties [11]. Practical measures, such as involving only a single consultant rather than a full committee, can further reduce fears that the process might feel like a tribunal.

### *PP as a constructive opportunity with guidance needs*

Although active PP remains limited in Dutch CESS, many respondents saw it as a potentially valuable addition, provided that ethics support professionals receive proper training and guidance. They emphasized that PP can bring new insights, uncover overlooked information, and highlight ethical issues that might otherwise remain unrecognized [29]. While respondents did not explicitly discuss the "framing problem," where professional perspectives can bias ethical interpretation [39], they implicitly recognized its relevance by stressing the importance of capturing and including the patient's viewpoint in deliberations [40].

Some respondents offered constructive suggestions on how to address barriers to patient participation (PP). One approach was to involve patients indirectly, through proxies, representatives, or patient-board members, creating a "hybrid" form of participation that could reduce concerns about potential harm. In addition, participants emphasized the importance of providing CESS staff with targeted training and concrete guidelines to ensure PP is conducted safely, transparently, and effectively.

Although we did not explicitly ask respondents to justify their recommendations, several suggestions mirror practices already adopted in other CESS systems. For instance, training in communication and conflict resolution is available to ethics consultants in some countries, sometimes with formal certification [41]. In the U.S., ethics consultations often occur in smaller groups or are conducted by individual consultants [35], which can lessen the intimidation patients might feel. Smaller consultation formats also foster transparency, minimize the feeling of a tribunal, and enable all participants to contribute equally, consistent with dialogical approaches [11].

### *Normative implications and directions for future research*

Our study began from the premise that PP is important both for democratic and epistemic reasons. Accordingly, the findings raise several normative considerations that could be explored in future theoretical or empirical research. Given the generally positive attitudes toward PP reported by our respondents, we highlight a few areas for further investigation.

One notable observation was that democratic ideals, rights, or equality concerns did not appear as primary motivations for PP among our respondents. In the literature, such arguments are often central, emphasizing patients' right to an "equal voice" and equal opportunity to participate, especially for vulnerable or minority groups [25, 42, 43]. In contrast, Dutch CESS does not yet appear to explicitly frame PP in these terms or as a mechanism to equalize moral dialogue, an issue that warrants further investigation.

Our analysis also suggests three questions meriting further exploration. First, since Dutch CESS primarily responds to HCP requests, is there a gap in addressing patient needs? In the U.S., patients are often treated as equal partners and receive ethics-related education; this raises the question of how, or whether, patients are "educated" within the Dutch system while HCPs are trained to develop their moral competencies. Second, regarding the proposal of patient board members as a hybrid form of representation, it is worth asking whether such representation is sufficient and, if so, who qualifies as an appropriate representative. Third, trust emerged as a rationale for PP in our survey. This prompts the question of how ethics support systems can effectively foster trust in healthcare and among HCPs, and whether promoting trust should serve as a justification for patient involvement in CESS.

### *Limitations and strengths*

Our findings provide a unique perspective on the goals of CESS in relation to the practice, ideas, and ideals of patient participation (PP) in the Netherlands, but they should be interpreted with certain limitations in mind. First, because we did not compare data on PP with information on family or proxy involvement, it is possible that respondents who reported no direct patient participation were in fact involving families or proxies as alternatives. Second, a substantial portion of our respondents worked with patients experiencing cognitive, mental, or psychiatric impairments; this context may influence their hesitations regarding PP, suggesting a need for further research on how professional work context shapes ideas and ideals about patient involvement.

Third, when cross-analyzing responses, it was unclear whether participants reported patient contact in terms of their broader professional role (e.g., as HCPs) or specifically within their tasks as ethics support personnel, as requested in the survey introduction. This ambiguity may have affected the reported prevalence of PP. Finally, the fact that respondents self-identified as contributors to ethics support practice may also have influenced the data. While this study offers valuable insights into the goals and nature of PP, it does not provide guidance on how PP in CESS should be implemented or promoted in the Dutch context. Addressing these practical aspects will require dedicated investigation, which we plan to pursue in future research.

## Conclusion

Our findings indicate that questions regarding patient participation (PP) in clinical ethics support services

(CESS) are complex and do not yield simple answers. By integrating data on prevalence, respondents' beliefs and ideals, perceived obstacles and needs, as well as the intended goals of CESS, our study provides a distinctive perspective. The results suggest that discussions about PP are closely linked to underlying views on the objectives of ethics support practices, and that arguments supporting PP cannot be universally applied across countries or regions, given differences in both understanding and goals of CESS. In the Netherlands, respondents indicated that the primary aim of CESS is to enhance healthcare professionals' moral competencies, which may explain the limited implementation of PP. Consequently, determining whether and to what extent PP should be incorporated into Dutch CESS is not straightforward. Among the various forms of PP described in the literature [8, 17], only a few are currently practiced in the Dutch context, meaning that advancing PP would require substantial adjustments, primarily due to practical concerns rather than principled objections. Respondents generally favored increasing PP to amplify the patient's voice and proposed strategies to overcome perceived barriers, including addressing potential objections from healthcare professionals through clearer guidelines on the nature and scope of PP. Following their recommendations, pilot studies and further research on PP appear warranted. Sharing national experiences of best practices and identifying learning needs could help determine the feasibility and alignment of PP with safe, high-quality healthcare. Potential initiatives could involve training CESS staff and exploring opportunities for PP before, during, or after ethics consultations. Ultimately, given that CESS discussions can influence moral decisions in patient care, we argue that staff should adopt PP as a foundational principle.

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