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## ARTICLE



# Decision-making in imminent extreme premature births: perceived shared decision-making, parental decisional conflict and decision regret

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**OBJECTIVE:** To describe levels of perceived shared decision making (SDM), decisional conflict (DC), and decision regret (DR) in prenatal counseling by pregnant women, partners, neonatologists, and obstetricians regarding decision-making around imminent extreme premature birth in which a decision about palliative comfort care versus early intensive care had to be made.

**STUDY DESIGN:** Multicenter, cross-sectional study using surveys to determine perceived SDM at imminent extreme premature birth in parents and physicians, and to determine DC and DR in parents.

**RESULTS:** In total, 73 participants from 22 prenatal counseling sessions were included (21 pregnant women, 20 partners, 14 obstetricians, 18 neonatologists). High perceived levels of SDM were found (median 82,2), and low levels of DC (median 23,4) and DR at one month (median 12, 5).

**CONCLUSIONS:** Reported levels of self-perceived SDM in the setting of prenatal counseling in extreme prematurity were high, by both the parents and the physicians. Levels of DC and DR were low.

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## INTRODUCTION

For imminent extremely premature deliveries a gray zone, or a so-called zone of parental discretion, exists in which both palliative comfort care (PCC) and early intensive care (EIC) are treatment options. The exact borders of gestational age in this gray zone shift over time, and cross-cultural agreements on the exact borders of this zone are lacking and differ between hospitals and countries [1–5]. Even though guidelines for the management of extremely preterm deliveries differ worldwide, a broad consensus exists about shared decision making (SDM) as the preferred approach for deciding between PCC and EIC [6–9].

Although positive effects of SDM have been described [10–13], professionals may not always know what SDM is and how to perform SDM [14]. Furthermore, studies using standardized scenarios show that professionals fail to perform essential elements of SDM, such as deliberation with parents and the elicitation of parental values [15–18]. Little is known about the actual application of SDM in the field of prenatal counseling for imminent extremely premature deliveries by obstetric and neonatal professionals. More insight may help to understand and improve further implementation of SDM. Therefore, our primary objective is to describe the levels of perceived SDM, decisional conflict (DC) and decision regret (DR) in prenatal counseling conversations by pregnant woman, their partners, neonatologists and obstetricians regarding decision-making around imminent extreme premature birth. Our secondary

objectives were to explore whether individuals within the same conversation agreed on the level of SDM, to explore whether SDM, DC and DR were correlated and to explore whether SDM, DC, and DR scores differed among the different decisions made.

## METHODS

### Study design and setting

The 2010 Dutch national guideline on perinatal practice in extreme premature deliveries describes 24<sup>+0/7</sup> weeks gestational age (GA) as the lower limit at which EIC can be offered to parents [19]. Although the Dutch treatment guideline received criticism [20–23] and is currently being revised, national consensus exists on SDM as the preferred approach for decision making at 24<sup>+0/7</sup>–24<sup>+6/7</sup> weeks GA [9].

This study is a multicenter, cross-sectional study using surveys to determine perceived SDM at imminent extreme premature birth, in parents<sup>1</sup> (pregnant woman and partner) and physicians (obstetricians and neonatologists), and to determine DC and DR in parents. Three Dutch academic, tertiary perinatal care hospitals participated in this study (out of total of nine in the Netherlands). In all these centers, health care professionals are familiar with providing both EIC and PCC; no separate perinatal palliative care teams are in place.

<sup>1</sup>We will further refer to the pregnant woman and partner as ‘parents’

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## Study population

Pregnant women needing prenatal counseling at 23<sup>+0/7</sup>–24<sup>+6/7</sup> GA for imminent spontaneous extreme premature birth were included. Other inclusion criteria were maternal age >18 years, and sufficient knowledge of Dutch language. Exclusion criteria were a multiple pregnancy, known fetal congenital anomalies from ultrasound scans and iatrogenic preterm deliveries. Partners of the pregnant women and the neonatologist and obstetrician performing the prenatal counseling were also asked to participate.

Between June 2017 and May 2018 eligible parents and their doctors were approached after prenatal counseling had taken place. Informed consent was signed after both written and verbal information about the study. This study was conducted according to the principles of the Declaration of Helsinki. Formal exemption from Institutional Review Board approval by the Medical Research Ethics Committee of the University Medical Center In Utrecht (reference number 18-400) was received, as the Committee confirmed that the Dutch Medical Research Involving Human Subjects Act did not apply to this study—which was locally confirmed in the other two centers.

## Design and data collection

After joint counseling by (ideally) both the obstetrician and neonatologist, parents were both asked to fill out the following questionnaires: a SDM questionnaire (SDM-Q-9) [24] and DC questionnaire [25]. After one and six months they were approached by e-mail and asked to both fill out the DR questionnaire [26], (up to) two reminders were sent. All instruments can be found in Table 1. The caregivers (neonatologist and obstetrician) were asked to fill out the SDM questionnaire (SDM-Q-9-DOC) after counseling [27]. The following background characteristics were collected from the electronic file: age of the mother, GA at time of counseling, parity, marital status, GA at birth, stillborn or born alive and the decision made (PCC or EIC).

The 9 item SDM questionnaires are self-report instruments measuring the process of SDM as perceived by the patient [24] and the physician [27]. Validated Dutch versions for patients (SDM-Q-9-NL) and physicians (SDM-Q-DOC-NL) were used [28]. Both the SDM-Q-9 and SDM-Q-DOC consisted of nine statements to be rated on a six-point scale from “completely disagree” (0 points) to “completely agree” (5 points). Conform user manuals, all items were summed up, up to two missing items were imputed using the mean of the other items. No total scores were calculated when more than two items were missing. The raw score was multiplied by 20/9 to provide a transformed score ranging from 0 (lowest possible level of SDM) to 100 (highest extent of SDM) [24, 27].

The DC questionnaire measures “personal perceptions of a) uncertainty in choosing options; b) modifiable factors contribution to uncertainty and c) effective decision making” [25, 29]. The Dutch translation [30] of the traditional 16-item, statement format of the DC scale was used, with 5 response categories from “strongly disagree” (0 points) to “strongly agree” (4 points). Conform user manual, scores were summed, divided by 16 and multiplied by 25 to provide transformed scores ranging from 0 (no DC) to 100 (extremely high DC). Subscores for uncertainty (items 10, 11, 12), feeling informed (items 1, 2, 3), values clarity (items 4, 5, 6), support (items 7, 8, 9) and effective decision (items 13, 14, 15, 16) were also computed on a 0 to 100 scale.

The DR questionnaire measures “distress or remorse after a (healthcare) decision” [26, 31]. It is used at a point in time when the respondent can reflect on the effects of a decision. The translated Dutch version was used [32]. Five items could be rated on a five-point scale from “strongly agree” (1 point) to “strongly disagree” (5 points). Conform user manual, item 2 and 4 were reversed coded; each item was subtracted by 1 and multiplied by 25. For the final score, items were summed and averaged, reaching scores from 0 (no regret) to 100 (high regret).

## Data analysis

Statistical analyses were conducted using IBM SPSS Statistics version 25.0 (IBM Corporation, New York, USA). Descriptive measures (medians, and interquartile ranges (IQR)) were performed for the SDM-Q-9, SDM-Q-doc, DC and DR questionnaires. Reliability of the questionnaires was checked with Cronbach's alpha. To explore accordance between individuals within one counseling session on the perceived levels of SDM, DC and DR, single measures, two-way consistency random effects intra class correlation coefficients (ICC) were used [33]. Spearman rho's correlation coefficient was used to determine correlations between SDM, DC and

DR. Finally, to determine whether scores on SDM, DC and DR differed between the decision made (EIC versus PCC), Mann–Whitney *U* test was used.

## RESULTS

### Demographics

A total of 73 participants from 22 prenatal counseling sessions were included (21 pregnant woman, 20 partners, 14 obstetricians, and 18 neonatologists). Diagnoses were for example (immature) preterm rupture of membranes, premature contractions, and antenatal hemorrhage. Demographics can be found in Table 2. In the majority (82%) of the cases EIC was chosen and in 18% PCC. In 14% of the cases, the woman actually delivered at 24 weeks GA.

### Shared decision making

Median total SDM score (IQR) for all participants ( $n = 73$ ) was 82,2 (75,6–87,8), subgroup scores can be found in Table 3 and Fig. 1. Highest scoring SDM items (see Table 1) were item #1 for physicians and item #6 for parents. Lowest scoring SDM item was item #2 for physicians and item #8 for parents. In this present study, Cronbach's alpha for the total SDM score was 0,848 (parents, SDM-Q-9) and 0,725 (physicians, SDM-Q-doc).

### Decisional conflict

Median DC total score (IQR) for all parents ( $n = 39$ ) was 23,4 (25,6–28,1)—scores can be found in Fig. 2 and Table 3. Subscore ‘uncertainty’ reached the highest score (median 33,3) and subscore ‘support’ reached the lowest score (median 16,7). A total of 21 parents (54%) had a DC score of <25, associated with implementing decisions. A total of two parents (5%) had a DC score of >37, 5 indicating decision delay or being unsure. In this present study, Cronbach's alpha for the total DC score was 0,941.

### Decision regret

Median DR score (IQR) for all parents ( $n = 20$ ) after one month was 12,5 (0–28,8), scores can be found in Fig. 2 and Table 3. Only two parents (one pregnant woman and her partner) filled out DR after six months. In this present study, Cronbach's alpha for the total DR score was 0,659.

All mean and median scores per question (SDM, DC, and DR) can be found in the Online Supplementary Table 1.

### Secondary objectives: explorations of the correlation on the level of SDM, on the correlation between SDM and DC, DR scores, and on the influence of the decision made

In this sample, no conclusion on the correlation on the level of SDM could be determined (see Online Supplementary - Accordance on the level of SDM).

SDM-q-9 score was negatively correlated to DC score, but this negative correlation reached significance for the partners only: Spearman rho's correlation coefficient ( $r$ ) was  $-0,392$  ( $p = 0,087$ ) for pregnant women and  $-0,569$  ( $p = 0,011$ ) for partners. No significant correlations for parents SDM versus DR could be found, nor for DC versus DR.

A higher DC score was found for PCC group (DC score median 28,1 (IQR 26,6–32,8)), than for the EIC group (DC score median 21,1, (IQR 15,6–27,7),  $p = 0,027$  Mann–Whitney *U*). No significant differences on SDM-q-9, SDM-q-doc and DR score (1 month) were found when scores were compared between treatment options chosen (PCC or EIC).

## DISCUSSION

This study showed high perceived levels of SDM, and low levels of DC and DR in prenatal counseling sessions in imminent extreme premature delivery in which a decision about PCC versus EIC had

**Table 1.** Used instruments – questions.

<b>T = 0, immediately after counseling</b>		
	<b>SDM-Q-9 (patients)</b>	<b>SDM-Q-doc (physicians)</b>
1	My doctor made clear that a decision needs to be made.	I made clear to my patient that a decision needs to be made
2	My doctor wanted to know exactly how I want to be involved in making the decision	I wanted to know exactly from my patient how he/she wants to be involved in making the decision
3	My doctor told me that there are different options for treating my medical condition	I told my patient that there are different options for treating their child*
4	My doctor precisely explained the advantages and disadvantages of the treatment options	I precisely explained the advantages and disadvantages of the treatment options to my patient
5	My doctor helped me understand all the information	I helped my patient understand all the information
6	My doctor asked me which treatment option I prefer	I asked my patient which treatment option he/she prefers.
7	My doctor and I thoroughly weighed the different treatment options	My patient and I thoroughly weighed the different treatment options
8	My doctor and I selected a treatment option together	My patient and I selected a treatment option together
9	My doctor and I reached an agreement on how to proceed	My patient and I reached an agreement on how to proceed

(\* *Their child instead of his/her condition in original SDM-Q-doc*)

#### **T = 0, immediately after counseling**

<b>Decisional conflict (DC) questionnaire</b>	
1	I know which options are available to me
2	I know the benefits of each option
3	I know the risks and side effects of each option
4	I am clear about which benefits matter most to me
5	I am clear about which risks and side effects matter most
6	I am clear about which is more important to me (the benefits or the risks and side effects)
7	I have enough support from others to make a choice
8	I am choosing without pressure from others
9	I have enough advice to make a choice
10	I am clear about the best choice for me
11	I feel sure about what to choose
12	The decision is easy for me to make
13	I feel I have made an informed choice
14	My decision shows what is important to me
15	I expect to stick with my decision
16	I am satisfied with my decision

#### **T = 1 month and t = 6 months**

<b>Decision regret (DR) questionnaire</b>	
1	It was the right decision
2	I regret the choice that was made
3	I would go for the same choice if I had to it over again
4	The choice did me a lot of harm
5	The decision was a wise one

to be made. A low DC score seems to be related to a high parent SDM score, and DC seemed to be higher for parents in the PCC group than the EIC group.

In SDM, clinicians and patients make decisions together using the best available evidence [10]. The perception of SDM in neonatal end-of-life decisions was shown to be associated with lower grief scores compared to paternalistic or informed decision-making [11]. A higher level of self-reported SDM in neonatal intensive care decisions was related to lower DR [12]. Furthermore, higher decisional quality in prenatal resuscitation decisions seems to be associated with better mental health outcomes three

months after delivery [13]. However, no measured levels of (perceived) SDM in actual prenatal counseling conversations in extreme prematurity have been described so far. Although we found high levels of perceived SDM, it is unsure whether perceptions of SDM would match with an observation of SDM [34]—in other clinical settings a much higher level of perceived SDM versus observed levels of SDM have been described [35, 36]. It has been suggested that (high) levels may also reflect feelings and views about the patient-clinician relationship [35–37].

Median DC was in the lower range (median 23,4) in this sample, however still 5% of the parents showed a high level of conflict.

**Table 2.** Demographics.

	<b>N (total = 22 counseling sessions)</b>	<b>% (of all counseling sessions)</b>
<b>Para</b>		
Nulliparous	10	45%
Multiparous	12	55%
<b>GA during counseling</b>		
23 <sup>+0/7</sup> t/m 23 <sup>+6/7</sup>	8	36%
24 <sup>+0/7</sup> t/m 24 <sup>+6/7</sup>	14	64%
<b>GA at time of birth</b>		
24 <sup>+0/7</sup> t/m 24 <sup>+6/7</sup>	3	14%
25 <sup>+0/7</sup> t/m 31 <sup>+6/7</sup>	12	55%
32 <sup>+0/7</sup> – above	7	32%
<b>Marital status</b>		
Relationship/not living together	2	9%
Relationship/living together	9	41%
Married	11	50%
<b>Live birth<sup>a</sup></b>		
Yes	19	86%
No	1	5%
Unknown	2	9%
<b>Treatment decision made<sup>b</sup></b>		
Palliative comfort care	4	18%
Early intensive care	18	82%
	<b>Median (IQR)</b>	
Age (pregnant woman)	32 (27,6–34,1)	

<sup>a</sup>(for  $n = 2$  the patient file stated that the pregnant woman was transferred to another hospital at  $> 32$  GA but there was no information in the file on the infant's condition at birth).

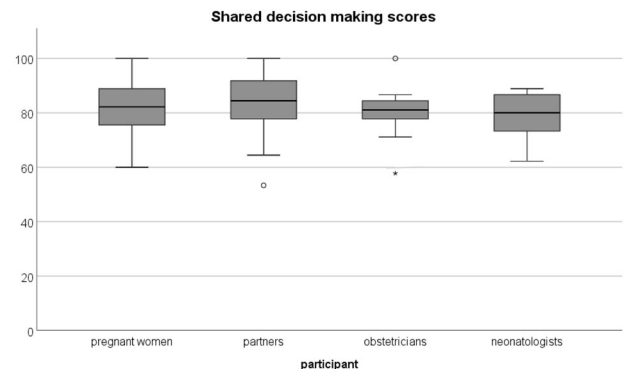
<sup>b</sup>1: at time of counseling, i.e., in one palliative comfort care case redirection to early intensive care was anticipated after 48 h for corticosteroids. 2: in some cases early intensive care was chosen but the neonatologist explicitly mentioned to exclude circulatory resuscitation; i.e., not to administer epinephrine nor to apply heart massage when adequate ventilation would fail.

The level of conflict was comparable to earlier described data in which a mean DC (in retrospect) of 28 was found [38]. Tucker Edmonds et al. recently described a DC level of 3,91 (on a scale ranging from 1 – high DC, to 4 – no DC) [13], and Moore et al. showed that using a decision-aid could lower DC from 50 (before use) to 0 (after use) [39]. The slightly higher level of decisional conflict for parents choosing PCC may (speculating) by nature be related to the associated outcome of their infant (the baby will die)–although little is known on this. A higher level of DC in the palliative care group has not been described before for this population, but groups were always small [38], and sometimes no distinction in DC scores based on the decision made was reported [13, 39]. DC for surrogate decision-makers is described to be higher in end-of-life decisions than non-end-of-life decisions in the adult ICU [40]. An aspect of great importance in perinatal palliative care decisions is communication: suboptimal communication by health care professionals could potentially influence levels of DC, and specific concerns regarding PCC communication have been described: Garten et al. identified emotional distress in perinatal PCC situations, identifying caregiver's insecurity of how to communicate with parents and how to provide emotional

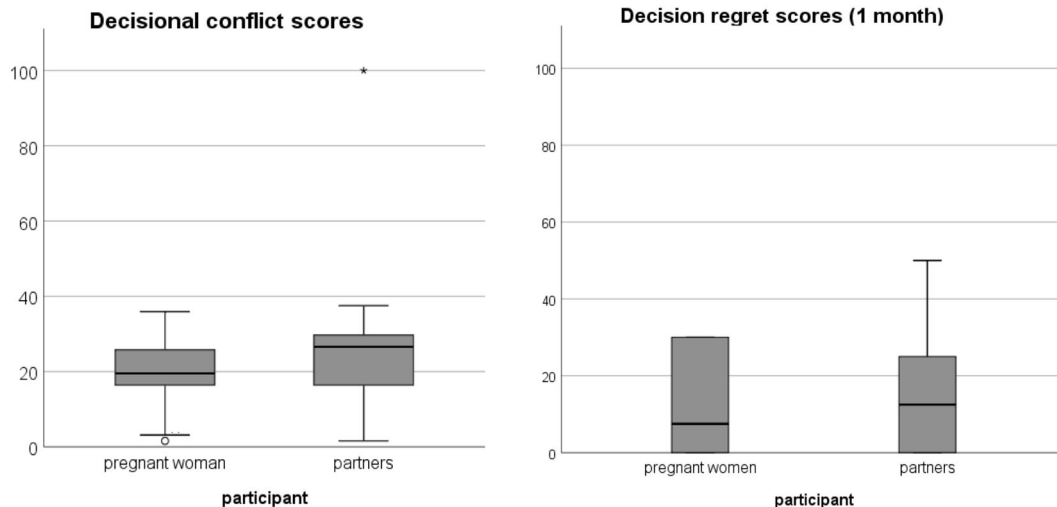
**Table 3.** Main outcomes per instrument and including subscales.

<b>Instrument (n = total participants (*))</b>	<b>Median (IQR)</b>
SDM-q-9 (n = 41)	84,4 (75,6–91,1)
Pregnant woman (n = 21)	82,2 (75,6–90,0)
Partner (n = 20)	84,4 (76,7–92,1)
SDM-q-doc (n = 32)	81,1 (73,9–86,1)
Obstetrician (n = 14)	81,1 (76,6–85,0)
Neonatologists (n = 18)	80,0 (73,3–86,7)
Decisional conflict (DC) total score (n = 39)	23,4 (25,6–28,1)
Pregnant woman (n = 20)	19,5 (16,0–26,2)
Partner (n = 19)	26,6 (15,6–29,7)
DC subscore uncertainty	33,3 (16,7–50,0)
Pregnant woman	29,2 (16,7–47,9)
Partner	33,3 (16,7–58,3)
DC subscore feeling informed	25,0 (16,7–25,0)
Pregnant woman	16,7 (16,7–25,0)
Partner	25,0 (8,3–25,0)
DC subscore values clarity	25,0 (16,7–25,0)
Pregnant woman	20,8 (2,1–33,3)
Partner	25,0 (16,7–33,3)
DC subscore support	16,7 (0–25,0)
Pregnant woman	8,3 (2,1–22,9)
Partner	16,7 (0–25,0)
DC subscore effective decision	25,0 (12,5–31,3)
Pregnant woman	25,0 (7,8–29,7)
Partner	25,0 (22,5–31,3)
Decision regret score 1 month (n = 20)	12,5 (0–28,8)
Pregnant woman (n = 10)	7,5 (0–30)
Partner (n = 10)	12,5 (0–28,8)
Decision regret score 6 months	<i>Not reported due to only two observations</i>

(\* maximum observations would always be 44 per instrument; given a total of 22 conversations potentially 44 physicians (obstetricians and neonatologists) or 44 parents (pregnant woman + partner) could fill out each instrument).



**Fig. 1 Shared decision making (SDM).** Scores on the SDM-Q-9- (patients) and SDM-Q-doc (physicians), on the perceived process of SDM. Range from 0 (lowest possible level of SDM) to 100 (highest extent of SDM).



**Fig. 2** Decisional conflict and decision regret. Left: scores on the DC questionnaire, ranging from 0 (no DC) to 100 (extremely high DC). Right: scores on the DR questionnaire, ranging from 0 (no regret) to 100 (high regret).

support [41]. Furthermore, parents described the importance of presenting both options (EIC & PCC) equally: “there is no wrong or right decision” [42] and also the way PCC is explained has proven to be important [43, 44].

Taking the low response rate into consideration, DR was low (median 12,5) at 1 month. Previously reported numbers of DR for prenatal decision-making in extreme prematurity were even lower, both 0 (years later) [38] and 8,36 (after 3 months) have been reported [13].

SDM is argued to comprise the following: 1: acknowledging a decision has to be made, 2: talking about options and their pros and cons, 3: deliberation on patients’ needs and preferences, or so-called value clarification, and 4: decision-making itself (made by the patient, together, or deferred to the physician—according to patients’ preferences) and its follow-up [45]. Although median reported levels of SDM were high, and median levels of DC and DR were in the lower range, there may still be room for improvement for at least some of the counseling sessions, or on specific, lower scoring aspects. An example is to (better) explore how parents want to be involved in making the decision—a lower scoring item on the SDM-q-doc questionnaire. Previous reports showed various parental preferences regarding the extent of involvement in decision-making—so this exploration is needed [42, 46, 47]. Strategies to improve SDM have been suggested to be useful in the setting of prenatal counseling in extreme prematurity, such as decision-aids, handbooks and value eliciting methods [39, 48–50]. It is unclear to what extent these supportive tools can be used in other settings since cross-cultural differences have been described extensively [3, 51–53]. Furthermore, training may also help physicians to increase their SDM performance, since the level of SDM can be physician-specific [16, 35, 54].

This study shows valuable insights into the perceptions of SDM in the setting of prenatal counseling in extreme prematurity. Strengths are the combined measurement of SDM by both physicians and parents, the prospective data collection and the multi-center data collection. Limitations of this study are the relative small sample size—although incidence of extreme premature birth is also relatively rare, and the low response rate for the DR questionnaires. A qualitative component (open text or interviews could have enriched the results. Results of our secondary aims were exploratory since the sample size is probably underpowered to exclude correlations, relations and differences between groups. For example, we could not demonstrate a significant correlation on the level of SDM between the participants (patients versus physicians) within conversations (online supplementary). However, it has been

suggested before that parents and physicians can have a completely different view of the conversation [55, 56]. The Dutch setting makes it unclear to what extent results can be generalized internationally [57]. Future studies may also want to include an observation of SDM, and future efforts into developing culturally-sensitive decision support tools are underway.

## CONCLUSION

Reported levels of self-perceived SDM in the setting of prenatal counseling in extreme prematurity were high, by both the parents and the physicians. Levels of DC and DR were in the lower range. Continued attention to improve SDM and to lower DC is of great importance.

## DATA AVAILABILITY

The dataset is available upon reasonable request through the corresponding author.

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#### AUTHOR CONTRIBUTIONS

RG, JFMH, MB, and MH designed and planned the study. JFMH, MB, MH, and ELH did the data collection. RG did the data analysis, JFMH and JHH assisted with data analysis. RG took the lead in writing the manuscript, together with JFMH. MB and MH supervised data collection and analysis. All authors provided critical feedback and helped shape the research, analysis, and manuscript.

## ETHICS APPROVAL

This study was conducted according to the principles of the Declaration of Helsinki. Formal exempt from Institutional Review Board approval by the Medical Research Ethics Committee of the University Medical Center In Utrecht (reference number 18-400) was received, as the Committee confirmed that the Dutch Medical Research Involving Human Subjects Act did not apply to this study—which was locally confirmed in the other two centers. Participants signed informed consent after both written and verbal information about the study.

## COMPETING INTERESTS

The authors declare no competing interests.

## ADDITIONAL INFORMATION

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