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Patients' experiences with using PROM and PREM in routine perinatal care in the Netherlands: a mixed methods study

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Keywords:	OBSTETRICS, QUALITATIVE RESEARCH, PRIMARY CARE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Patients' experiences with using PROM and PREM in routine perinatal care in the Netherlands: a mixed methods study

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ABSTRACT

Objective

To gain insight into the experiences of patients with completing and discussing patient reported outcome measures (PROM) and patient reported experience measures (PREM), and tailoring their care based on their outcomes.

Design, setting, participants and method

A mixed-methods study was performed in seven obstetric care networks in the Netherlands that implemented a set of patient-centred outcome measures for pregnancy and childbirth (PCB set), published by the International Consortium for Health Outcomes Measurement. All women receiving the PROM and PREM questionnaires as part of their routine perinatal care, received an invitation for this study, including an anonymous survey (n=460) and a phone interview (n=16) regarding their experiences.

Results

More than half of the survey participants (n=255) felt the need to discuss the outcomes of PROM and PREM with their care professionals. The time spent on completing the questionnaires and the comprehensiveness of the questions was scored ‘good’ by most of the survey participants. From the interviews and free text survey answers, four main themes were identified: content of the PROM and PREM questionnaires, application of the outcomes of PROM and PREM in perinatal care, discussing PREM, and data capture tool. Important facilitators included awareness of health status in pregnancy and postpartum, receiving personalised care based on their outcomes and the relevance of discussing PREM six months postpartum. Barriers were found in insufficient information about the goal of PROM and PREM for individual care, technical problems in data capture tools and discrepancy between the questionnaire topics and the care pathway.

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Conclusions

This study showed that patients found the PCB set an acceptable and useful instrument for symptom detection and personalised care up until six months postpartum. This patient evaluation of the PCB set has several implications for practice regarding the questionnaire content, role of care professionals and congruity with care pathways.

Key words:

Value-based healthcare

Obstetrics

Perinatal care

Patient-reported outcome measures

Shared decision making

Qualitative research

Quantitative research

Mixed methods

Article Summary

- This study had a prospective design and was incorporated in an implementation project as part of routine perinatal care.
- As a result of the embedding in an implementation project, we were able to combine the results of a large sample size of survey participants with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results.
- These are the first experiences from patient perspective regarding completing and discussing PROMs and PREMs during routine perinatal care.

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- A limitation of this study was the unequal representation of time points for PROM and PREM collection in our interview sample, due to the nature of the implementation project.

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INTRODUCTION

Healthcare systems are increasingly focusing on creating value for patients.[1] Therefore, patient-reported outcome measures and experience measures (PROM and PREM) are progressively used to guide individual patient care, in quality improvement, and for research purposes. In routine care, patients complete PROM and PREM via standardised disease specific questionnaires, between visits to care professionals. Care professionals receive notifications about alarm symptoms, such as pain or functional complaints and can review longitudinal PROM and PREM reports over time. This way, symptoms and impairments are more likely to be detected, creating an opportunity to personalise care based on individual needs.[2] In chronic care settings, this approach has been shown to improve shared decision making, patient-clinician relationship and health outcomes.[3, 4]

In perinatal care, important outcomes expressing quality of life and social participation can be detained from PROM and PREM, such as maternal depression, incontinence, and birth experience. PROM and PREM may differ greatly and may be independent of provider-reported outcomes, describing far-reaching effects on patients' lives.[5, 6] Additionally, PROM and PREM may highlight important outcomes from the patient perspective that remained hidden when collecting provider-reported outcomes only. Therefore, implementation of standardised PROM and PREM, including the adaptation of individual care pathways based on individual outcomes, is essential to further personalize and improve quality of perinatal care from the patient perspective. The International Consortium for Health Outcomes Measurement (ICHOM) provided a set of patient-centred outcome measures for pregnancy and childbirth (PCB Set) for perinatal care containing both provider-reported and patient-reported outcomes.[7] Prior research in the Netherlands found this set to be acceptable and feasible for implementation by all important stakeholders including patients.[8, 9] However, little is known regarding the patients' experiences with completing the PROM and PREM and receiving care based on their individual outcomes as part of routine perinatal care.

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In the Netherlands, a nationwide implementation project was initiated to facilitate shared decision making by implementing the PROM and PREM of the PCB Set in regular perinatal care. To achieve successful implementation, identifying unanticipated influences, facilitators and barriers among the users during the early implementation process of PROM and PREM is crucial.[10] Our pre-implementation research identified patients as important users next to perinatal care professionals.[8, 9] Insights into first patients' experiences with receiving personalised care based on their individual PROM and PREM during pregnancy, childbirth and the postpartum period will enhance and improve further implementation of PROM and PREM as part of routine perinatal care. Therefore, alongside the nationwide implementation project, we conducted a mixed methods study to gain insight into the experiences of patients with completing and discussing PROM and PREM, and tailoring their care based on their outcomes in a routine perinatal care setting.

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METHODS

Design

Mixed-method prospective cohort study to gain insight in patients' experiences with using the PROM and PREM of the ICHOM PCB set for perinatal care in clinical practice among patients.

Setting

This study was conducted in seven obstetric care networks (OCNs) participating in a nationwide implementation project of the ICHOM PCB Set in the Netherlands. Data collection was performed from March 2020 up until September 2021. The PROM and PREM were sent to the participants at five time points during their pregnancy or postpartum period. In these periods, different care professionals may have been responsible for the participants' health (see Figure 1). Care professionals were trained in interpreting results of PROM and PREM, and in discussing them. They discussed the results of the PROM and PREM during the visit directly after the five time points, including the time point at six months postpartum. Implementation plans differed among the different OCNs; OCNs collected PROM and PREM during at least one time point, this was not necessarily time point 1.

Patient and Public Involvement statement

Simultaneously with the implementation of the PCB set, this study was conducted to gain insight into patients' experiences with completing and discussing PROM and PREM. In this study, we sent out a survey and conducted interviews with patients. The study was designed in close collaboration with care professionals. The questionnaires used to collect the PROMs and PREMs were tested for comprehensiveness among four women with low health literacy skills supported by Pharos, a national centre of expertise in decreasing health inequities.[11] Small language adaptations were made based on this test.

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Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.

The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points.[7]

Participants

As our study was conducted within a large implementation project of the PCB set, all patients who received PROM and PREM questionnaires as part of their routine perinatal care in one of the participating OCNs were eligible for this study. Patients received an information leaflet regarding the purpose of the PROM and PREM before filling out their first questionnaire. At the end of each questionnaire, patients were invited to participate in this study by filling out a short evaluation survey and by a telephone interview regarding their experiences with completing and discussing the PROM and PREM.

Inclusion criteria were:

- patients completed at least one questionnaire of the PCB set;
- patients were 16 years or older during the first data collection time point;
- patients gave their informed consent to use their answers for research.

Data collection

The researchers composed a short evaluation survey (Supplementary Table 1). This anonymous survey was offered to participants via a digital link after completing their PROM and PREM. One OCN collected this evaluation survey on paper. Answers to this survey were not visible to care professionals. At the end of this evaluation survey, participants were asked to provide their telephone number for an in-depth evaluation interview by phone. First, all participants who provided their telephone number were approached for a semi-structured interview by one of the researchers (see for topic list Table 1). Further on, purposive sampling was performed, e.g., selecting participants that had filled out PROM and PREM at time points 3, 4, and 5, and women who gave

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specific answers in the evaluation survey. Additionally, care professionals were asked to actively recruit women with decreased health literacy skills for an interview by the researchers. Data collection was ended as soon as thematic saturation was accomplished (see Data analysis). All interviews were audio-recorded and transcribed verbatim.

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Table 1 Topic list used for the interviews

Topics	Sub topics
Course pregnancy/childbirth	General Health / Experiences pregnancy
Time spent on completing PROM and PREM - experiences	Experiences completing PROM and PREM Experience on time spend Motivation for completion of PROM and PREM Reasons for (not) completing PROM and PREM in the future Time point 1 & 2: thoughts regarding completing PROM and PREM multiple times during pregnancy and after childbirth Time point 3-5: experiences with completing PROM and PREM after childbirth up until 6 months postpartum
Comprehensiveness PROM and PREM	Understanding PROM and PREM: language used, reason why PROM and PREM were asked, information provision Social desirability PREM regarding experiences with care providers: completing and discussing
Discussing PROM and PREM with care professionals	Experiences regarding discussing PROM and PREM Adverse outcomes of PROM and PREM Taboo topics Bond with care professional Unexpected outcomes Resistance regarding discussing PROM and PREM Advantages and gains of discussing PROM and PREM
Improvements and suggestions	Results of evaluation survey Previously completed PROM and PREM Important topics
Preferred care provider	Time point Outcomes that are discussed
Shared decision making	Care pathway – participant's influence Discussing wishes and fears regarding pregnancy and childbirth Patient – care professional relationship

PROM: patient reported outcome measures. PREM: patient reported experience measures

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Data analysis

The quantitative data from the evaluation survey was analysed using descriptive statistics with SPSS version 25 (IBM Corp., Armonk, N.Y., USA). Free text answers were analysed with thematic analysis supported by Microsoft Excel (version 16). The transcriptions from the interviews were checked for accuracy with the original audiotapes by LL. The software program Atlas.ti 9 was used to support thematic inductive content analysis.[12] LL and SK independently coded the transcripts to create a set of preliminary codes and compared the codes to reach consensus. To detect emerging themes, matching codes were merged, and links between codes were explored. An overview of themes and subthemes for patients' experiences with completing and discussing PROM and PREM was constructed. This overview was combined and compared with the free text answer analysis of the open-ended questions from the survey into an integrated overview. The integrated overview was discussed with AD, ML and MB and subthemes were identified as facilitators and barriers. Reporting followed the Standards for Reporting Qualitative Research (SRQR).[13]

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RESULTS

Survey

460 Participants filled out the patient evaluation survey from a total of 1318 women who completed at least one PROM and PREM questionnaire. Descriptive statistics of the survey are shown in Supplementary Table 2 and Supplementary Figure 1a-d. Regarding the time spent on completing the questionnaires, 87% of participants indicated this as ‘good’. The comprehensiveness of the questions was indicated as ‘good’ by most participants (78%). The need to discuss the outcomes of the questionnaires with the care professional differed: of the participants 39% answered ‘not really’, and 35% ‘a little’, and 20% ‘yes’. Of the participants that wanted to discuss the outcomes, the majority preferred their obstetric care professional for this. The answers from the open-ended questions are to be discussed below.

Interviews

26 participants provided their telephone number for the interview, none of these participants had completed PROM and PREM during time point 3 (maternity week). 16 interviews were conducted. We interviewed two participants that completed PROM and PREM during time point 1 and 4, nine during time point 2, and three during time point 5. Participants’ average age was 34 years [29-39 years] and the majority was higher educated (14 of 16), i.e., completed an education at a university or university of applied sciences. Four participants received perinatal care for the first time; they were pregnant of or had given birth to their first child. Six participants received perinatal care by a community midwife, five by a gynaecologist in the hospital, and five had shared care by both community midwives and gynaecologists.

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Themes

From the open-ended questions and interviews the identified facilitators and barriers were allocated to four overarching themes (see Table 2): 1. Content of the PROM and PREM, 2. Application of the outcomes of PROM and PREM in perinatal care, 3. Discussing PREM, and 4. Data capture tool. These themes including facilitators and barriers are described below in detail, with illustrative quotes.

1. *Content of PROM and PREM questionnaires*

Most participants found the language of the PROM and PREM clear and understood the questions. Participants felt that the PROM and PREM covered most important topics and were of a good length. Most participants emphasised the importance of PROM and PREM addressing taboo topics, such as incontinence, depression, and pain with intercourse. In the interviews, participants shared that completing PROM and PREM on these topics created awareness about their current health status and potential problems during pregnancy, childbirth and first months postpartum (see Quote 1).

Quote 1 Awareness of taboo topics:

[Complete PROM/PREM to prepare for their next visit] "I assume [advantages] for both parties: for yourself because you think about everything, also things you wouldn't consider at first. And I expect it [capturing PROM and PREM] would be helpful for a care professional as well, because he can ask further than just the topics a patient brings up at that moment." (T4)

However, the language of some questions was too difficult, especially for lower educated women, and several PROMs were not specific in timing or location of physical complaints. This led to different interpretations of the questions. Regarding the content of the PREM, participants

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experienced discrepancy between the timing of the questions and the care received. For example, at time point 2, options for pain management during childbirth had often not been discussed yet, thus participants answered negative to the PREM addressing this. Another issue mentioned by the interview participants regarding in relation to PREM, was that they often received care from multiple care professionals. They stated that they had to average their experiences when completing the PREM. Several participants reported that they missed the answer option "I don't know (yet)" or "not applicable" in some questions, and the possibility to explain their answers. Also, participants missed the possibility in the questionnaires to point out important outcomes. This topic was expanded during the interviews; participants wanted to be able to indicate outcomes important to discuss during the following visit (see Quote 2).

> *Quote 2 No opportunity to explain answers or pointing out important topics [Opportunity for explanation during completion of PROM and PREM] "You should have a choice: whether you want to discuss it [your answers] or not, whether you want to be referred or not. […] You could put it [an open text field] at the end of the questionnaire: ' If you want consultation on this, if you have a top 3 or top 5 or something of the things that were just asked, what are the topics you would like to discuss with your midwife?'"* (T2)

Although most important topics were covered in the PROM and PREM, some participants stated that there was too little attention for prevalent physical problems. They missed questions concerning pelvic pain and haemorrhoids, especially at time point 2. Lastly, the timing of one specific topic was debated by several participants: the PROM breastfeeding. At time point 2, this topic was experienced as too early since most women did not know whether they intended to breastfeed and

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could not properly answer the full questionnaire about self-efficacy. At time point 4, participants indicated it felt too late to discuss problems with breastfeeding.

2. Application of the outcomes of PROM and PREM in perinatal care

Most participants indicated that filling out PROM and PREM helped them in preparing their next visit to their obstetric care professional. They stated that thinking about the topics addressed by the questionnaires made them know better what to expect from and to discuss in the following visit. Interview participants also pointed out that the use of PROM and PREM led to discussion of topics that previously were no part of the conversation with their care professional. Some participants indicated that they were unaware of some topics being pregnancy related, such as psychological problems. Furthermore, some participants from the interviews said that they felt their care was personalised based on their individual outcomes, for example extra attention, information, or a referral for specialised care (see Quote 3 and Quote 4).

> *Quote 3 Care is personalised based on individual outcomes*
>
> *"Then she [the care professional that discussed her outcomes with her] said she could refer me to a clinic for pelvic problems if I wanted to. […] I thought that was very good. They directly did a follow-up and offered me sort of an option like 'you could this'."* (T5)

> *Quote 4 Care is personalised based on individual outcomes*
>
> *[her PROM answers indicated depressive symptoms] "Well… personally I think I, and they too [care professionals], gave some extra attention to my mental health."* (T2)

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At time point 5, one participant from the interviews felt relieved that her care professional paid attention to her incontinence and psychological problems. She felt that otherwise she would not have had any care professional to discuss these issues with.

Despite the availability of an information leaflet and their care professionals' explanation, many participants had misunderstood the aim of the project. They thought it was a research project and that their answers were used for research purposes only. This indicates that the information about the purpose of PROM and PREM for individual care was insufficient, which posed a major barrier to complete questionnaires multiple times (see Quote 5).

Quote 5 Insufficient information on the aim personalised care based on PROM and PREM

"It was not clear to me why it [PROM and PREM] was asked. And I also can't remember that it [PROM and PREM questionnaires] included an introduction text or something like that… maybe that was included you know… but for me it was not clear what they wanted to do with that information [her answers]" (T2)

Furthermore, some participants stated it was uncertain when the outcomes of their questionnaire would be discussed with them; not all participants had their outcomes discussed during the first visit after completing the PROM and PREM. One participant said that her outcomes were never discussed with her. Several participants mentioned that completing PROM and PREM gave them the feeling of 'impersonalised care', as if care professionals tried to avoid the conversation about these topics. Other interview participants felt unsure about how the outcomes of the PROM and PREM would impact the quality of care of their individual care pathway. For example, when filling out negative experiences regarding one specific care professional, they preferred to receive care from another care professional because of their negative experience. Some participants, from both the survey and

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the interviews, felt that discontinuity in care professionals posed a barrier to discuss the outcomes. They did not feel at ease discussing outcomes with a care professional they had never met before (see Quote 6). Interview participants also did not always know which care professional was responsible for their outcomes.

Quote 6 Discontinuity of care professional

"Nothing really popped up [from her answers to the questionnaires], but if that would have been the case than I think it is harder to discuss some topics with a person [care professional] that I have never met. Especially because some of these topics are sensitive and vulnerable." (T1)

3. Discussing PREM

Participants stated that the PREM were an important facilitator for them to complete the PROM and PREM. They stressed that they found it very important that care professionals had insight in patients' experiences with the provided care. Additionally, participants from the interviews thought that the insight in individual PREM may lead to improved quality of individual care. Especially participants that completed PREM at time point 5 stated that the PREM were important to complete and to discuss, because it helped them to process the pregnancy and postpartum period (see Quote 7).

Quote 7 Discussing PREM at time point 5 important for reflection on pregnancy and childbirth

[After completing the T5 questionnaire] "The fact that she [care professional] called back, that she called back actually concerned, and just … just was talking with me and

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explained things. That has really, also in my head, enormously helped to sort things out. […] Yes, I really look back on that [childbirth and postpartum period] better now.” (T5)

Additionally, analysis of aggregate PREM results may indicate improvement topics, according to the interview participants. At the same time, a barrier was identified in overlap; some participants received PREM and other care evaluation questionnaires from their community midwives postpartum, and it caused confusion for them whether these outcomes were also sent to their midwives. Ambiguous opinions were found regarding discussing PREM individually. Some participants, who were satisfied with the care they received, indicated they would have preferred addressing negative experiences directly with their care professional, instead of via PREM (see Quote 8). In contrast to participants that had had negative experiences: they explained it felt easier to indicate this via PREM instead of discussing it face to face with their care professional.

Quote 8 Negative PREM preferably face to face

[addressing care experiences with care professional] “I believe it is fairer when they [care professionals] hear it from me personally, but I can imagine that some people don’t feel comfortable with that and prefer to leave their feedback anonymously and that eventually it will reach the care professional anyway.” (T2)

Additionally, some participants stated to feel dependent of their care professional during their care pathway, which posed a barrier to report negative experiences in the PREM.

4. *Data capture tool*

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Participants indicated that they preferred to complete PROM and PREM digitally. Completing the PROM and PREM on mobile phones or tablets was preferred by most women. However, participants pointed out technical issues as a major barrier; PROM and PREM questions and answers that were not entirely visible on a mobile phone led to incomplete or incorrect outcomes according to some women (see Quote 9).

Quote 9 Technical problems and bugs

[Completing PROM and PREM] "On my smartphone I can't see all the questions. On the iPad, some answer options disappear, so I must check three times whether my answers are completed correctly. For example, satisfaction is measured on a scale from 1 to 4. But when I go to the next page and back, it appears to be a scale from 1 to 10." (T2)

Also, some participants received PROM and PREM belonging to a different time point or received the same PROM and PREM multiple times. Furthermore, several interviewed participants stated that it was unclear which organization sent the invitation to complete the questionnaires and which care professionals had access to their answers. This made them have doubts regarding privacy (see Quote 10).

Quote 10 Privacy issues

[Completing questions regarding incontinence, mental health, physical complaints]: "And yes, those are questions of a kind that you would only complete honestly if you are completely sure that you can trust that they will end up at the right person." (T2)

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Table 1 Overarching themes and identified facilitators and barriers

Themes	Facilitators	Barriers
1. Content of PROM and PREM questionnaires	Clear language PROM and PREM covering all important topics Good length of questionnaires Awareness of taboo topics	Language of some questions too difficult Some PROM questions not specific in time or location Discrepancy questions with care path and situation Absence of answer option "I don't know (yet)" or "not applicable" No opportunity to explain answers or pointing out important outcomes Too little attention to physical problems (time point 2) (Timing of) PROM breastfeeding
2. Application of the outcomes in individual care	Better preparation for next visit/appointment Discussing topics that were not discussed before Care is personalised based on individual outcomes Discussing outcomes at Time point 5	Insufficient information on the aim personalised care based on PROM and PREM Uncertainty when outcomes are discussed Feeling of impersonalised care Unsure of impact on individual quality of care Discontinuity of care professional
3. Discussing PREMs	PREM being included in the questionnaires Insight in individual PREM improves individual quality of care Discussing PREM at Time point 5 important for reflection on pregnancy and childbirth Analysis of aggregate PREM for care improvement Completing PREM safer option in case of dissatisfaction	Receiving multiple questionnaires regarding experiences Negative PREM preferably face to face Dependency of care professional
4. Data capture tool	Completing questionnaires digitally Availability on mobile phones or tablets	Technical problems and bugs Privacy issues

PROM: patient-reported outcome measures, PREM: patient-reported experience measures

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DISCUSSION

This mixed methods study provides insight into the first experiences of patients with completing and discussing PROM and PREM at different time points during and after pregnancy as part of routine perinatal care. The evaluation survey results showed that the time spent on completing the PROM and PREM was acceptable, and their content was comprehensive. Most survey participants felt the need to discuss the outcomes. In the interviews, participants were mainly positive about discussing their individual PROM and PREM outcomes with their perinatal care professionals. Patients' barriers and facilitators to complete and discuss PROM and PREM individually were identified in four overarching themes.

Strengths and limitations

A strength of this study was the prospective design, incorporated in an implementation project as part of regular care. Its results supported further implementation of the outcome set, as they were directly translated into adaptations in the clinical project, such as IT improvements and an option to further explain an answer. Another strength was the large sample size of survey participants combined with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results. Also, the participation threshold was lowered by conducting the survey anonymously and the interviews by telephone, limiting the risk of selection bias. However, despite our efforts to minimize the risk of selection bias with as well, mostly higher educated women were included, and only Dutch speaking women could participate to the surveys. This was inevitable to some extent, as the sample was taken from an already selected population: women completing the PROM and PREM were Dutch speaking only and had a relatively good health literacy, as no support was provided with completing them. Nevertheless, this exploration of patient experiences with individual PROM and PREM was the first among women receiving perinatal care. A second limitation,

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3 27 resulting from the outline of the implementation project, was the unequal representation of time
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5 28 points for PROM and PREM collection in our interviews. Despite our strategy to ask care
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7 29 professionals to recruit participants for the interviews directly, i.e., without filling out the survey, we
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9 30 could not interview women who had completed PROM and PREM at time point 3 (maternity week).
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13 32 *Compared with literature*
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15 33 In line with findings in other disciplines, discussing PROM and PREM with care professionals as part
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17 34 of routine perinatal care was found to improve patient satisfaction and willingness to complete the
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19 35 questionnaires.[4, 14-16] Participants felt better prepared for their next visit and discussed topics
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21 36 that were not discussed before, which reconfirms results from large studies in chronic care
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23 37 settings.[16-18] At the same time, a significant part of our survey respondents did not feel the need
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25 38 to discuss their outcomes. Moreover, for some women completing the questionnaires even felt as
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27 39 impersonalized care. As the survey was offered directly after completing the PROM and PREM,
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29 40 survey participants had not yet discussed their outcomes with their care professional. These findings
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31 41 indicate that discussing outcomes are an essential part of using PROM and PREM in clinical
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33 42 practice.[4] Another explanation could be inadequate information provision, as several women
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35 43 stated that the purpose of the PROM and PREM was unclear to them. As patients' perception of this
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37 44 purpose largely depends on their care professional, care professionals may improve this by actively
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39 45 using PROM and PREM as a part of routine care. For example, by encouraging women to consider
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41 46 which outcomes they want to discuss in the next visit.
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45 48 Using individual outcomes to tailor care was an important facilitator to complete PROM and PREM
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47 49 over the course of pregnancy and postpartum. Nevertheless, two important barriers to use PROM
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49 50 and PREM individually were raised by our participants as well. First, discrepancy between the
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51 51 timelines of provided care and the PROM and PREM was pointed out. For example, a PREM
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questioning information provision on pain relief was sent to women, before care professionals addressed this topic according to standard care. Secondly, discontinuity in care professional was posed as a barrier, as discussing PROM and PREM with different care professionals lead to discomfort among participants. Discussing outcomes in the multidisciplinary setting of perinatal care may be easier if a principal care professional is allocated to every pregnant woman. A relationship of trust between care professional and patients may be a crucial facilitator completing and discussing PROM and PREM, especially for discussing taboo topics such as incontinence.[19] This may provide opportunity to improve perinatal care outcomes, as several taboo topics have been shown highly prevalent and only 15% of the affected women bring this up during a postpartum check-up.[20, 21] Additionally, although hard to accomplish by perinatal care professionals, our participants stated that evaluating their outcomes at six months postpartum with a perinatal care professional was of added value to the regular postpartum check-up. This reconfirms previously reported patient views regarding time point five of the PCB set.[8, 9] Compared to the check-up-up at six weeks postpartum, at six months postpartum most women have further recovered in multiple domains and resumed their work and social life. Hence, at this moment, the sustainability and severity of physical or mental problems can be determined and referred for, improving long-term outcomes of perinatal care.

Confirming pre-implementation studies, our participants emphasized that PREM were an important facilitator to complete the questionnaires.[8, 9] However, evidence on individual PREM use as part of clinical practice is scarce. This study revealed different opinions amongst patients: some preferred to address negative experiences face to face, some felt PREM made it easier to raise and others felt too dependent on their care professional to discuss a negative experience at all. Future research should evaluate the possible effects of offering each woman a choice whether her individual answers are visible to care professionals and discussed as part of her care.

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As shown before from a professional perspective, a good functioning data capture tool for assessment and real-life visualisation of patient reported measures is essential for successful implementation.[4, 22, 23] In our patient evaluation, technological issues of the data capture tools were also a major barrier for completing the questionnaires. Although challenging in terms of inter-organisational collaboration and IT infrastructure, this project was one of the first to attempt system wide implementation of PROM and PREM in routine perinatal care. In the transformation towards health care systems that provide patient-centred care over the full cycle of care, it is essential to use data capture tools that facilitate information exchange between all health care tiers involved with a disease or condition.

Future research and implications

To achieve personalized care based on PROM and PREM, patient engagement is essential but requires efforts at several points. For successful implementation, patients will benefit from a system-wide data capture tool, a principal care professional to discuss their outcomes with and a timeline of PROM and PREM collection that fits clinical care: matching their appointments and content of care pathways. Also, an open text field to explain answers and point out outcomes they want to discuss could empower patients to take an active role in their care. Lastly, when completing PROM and PREM, patients should be clearly informed about 1) the purpose of using their answers for personalized care and 2) the topics addressed by the questionnaires at each time point and their relation to pregnancy and childbirth. Since care professionals are crucial in providing this information and in discussing the outcomes, future research may focus on the experiences of care professionals with PROM and PREM use in perinatal care. To engage care professionals, it would be useful to evaluate training strategies, but also their perceived benefits when working with PROM and PREM. These could include direct improvement of individual care for their patients, as well as insight in the results of their efforts in terms of patient outcomes.[24]

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3 102
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6 103 *Conclusions*
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9 104 This study reported the first patient experiences with completing and discussing PROM and PREM as
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11 105 part of perinatal care. The ICHOM PCB set was found to be an acceptable and useful instrument for
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13 106 symptom detection and personalized perinatal care up until 6 months postpartum. Patients'
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15 107 reflections on these PROM and PREM allow several improvements of the content of the
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17 108 questionnaires, the role of care professionals and congruity with routine care pathways.
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Competing interests statement:

AF and ML were chair and member respectively of the ICHOM working group that developed the PCB standard outcome set. The other authors have nothing to declare.

Contribution to Authorship

LL, AD, ML, AF, HE and MB designed the study. LL and SK performed the data collection. LL and SK analysed the data under supervision of MB. All authors interpreted the data. LL and AD wrote the first version of the manuscript. All authors revised all versions of the manuscript and approved the final version.

Details of Ethics Approval

The Medical Ethics Committee Erasmus Medical Centre (MEC-2020-0129) declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known as WMO) do not apply to this study. This study was exempt from formal medical ethical assessment. Local approval of the

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regional ethical boards was obtained in each participating OCN. All participants signed written informed consent.

Data availability statement

Data are available upon reasonable request.

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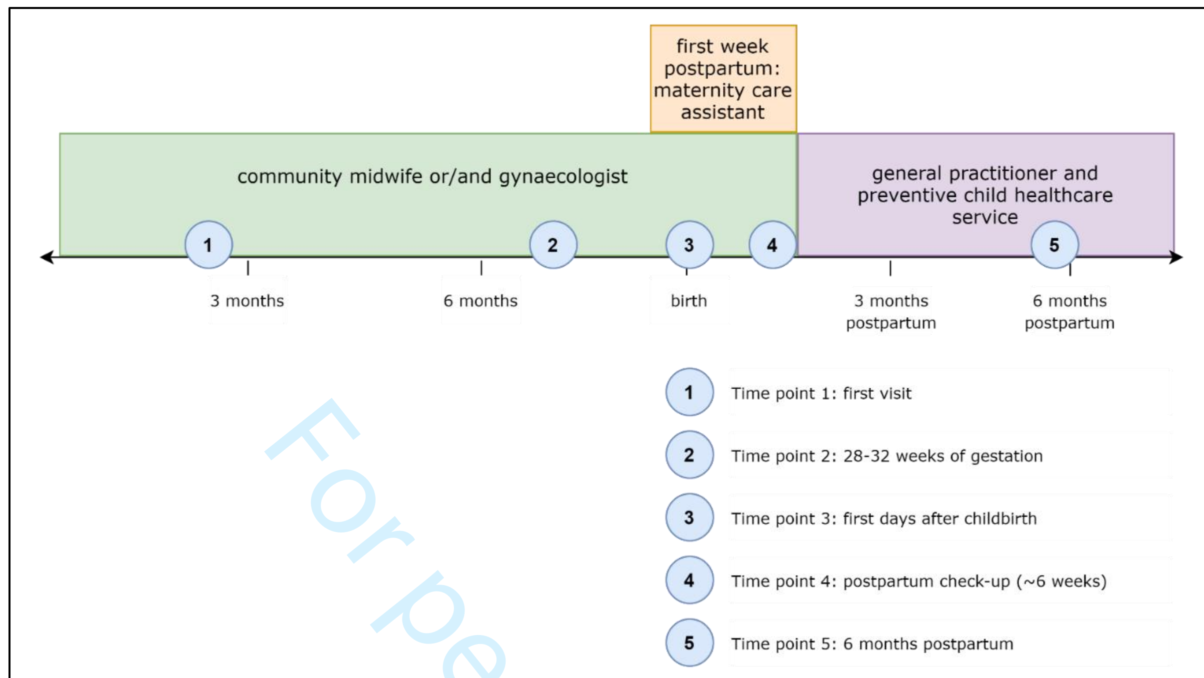

Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.

The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points. [7]

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Supplementary Table 1 Evaluation survey

Q1) I found the time needed to complete the PROM and PREM …	
	Too much
	A lot
	Good
	Short

Q2) Were you able to properly complete all PROM and PREM?	
	Yes
	No, I did not understand all questions
	No, the questions were too personal
	Other: …….

Q3) During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?		
	Yes	→ Go to question 3b
	A little	→ Go to question 3b
	Not really	→ Go to question 3c
	Not at all	→ Go to question 3c
Q3b) Who do you prefer to discuss your outcomes with?		Community midwife
		Clinical midwife
		Gynaecologist
		Maternity care assistant or nurse
		Preventive Child Healthcare services
		General practitioner
		No preference
Q3c) Can you please explain why you do not prefer to discuss your outcomes?		……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………

Q4) Do you have any remarks regarding the PROM and PREM or suggestions for improvement?
…… …… ……

Q5) Do you give permission for an evaluation by telephone in the future?	
	Yes, my telephone number is: ………………………………………………
	No

PROM: patient reported outcome measures. PREM: patient reported experience measures

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Supplementary Table 2 Survey participants per time point

Time point	n
T1	93
T2	337
T3	10
T4	9
T5	11
Total	**460**

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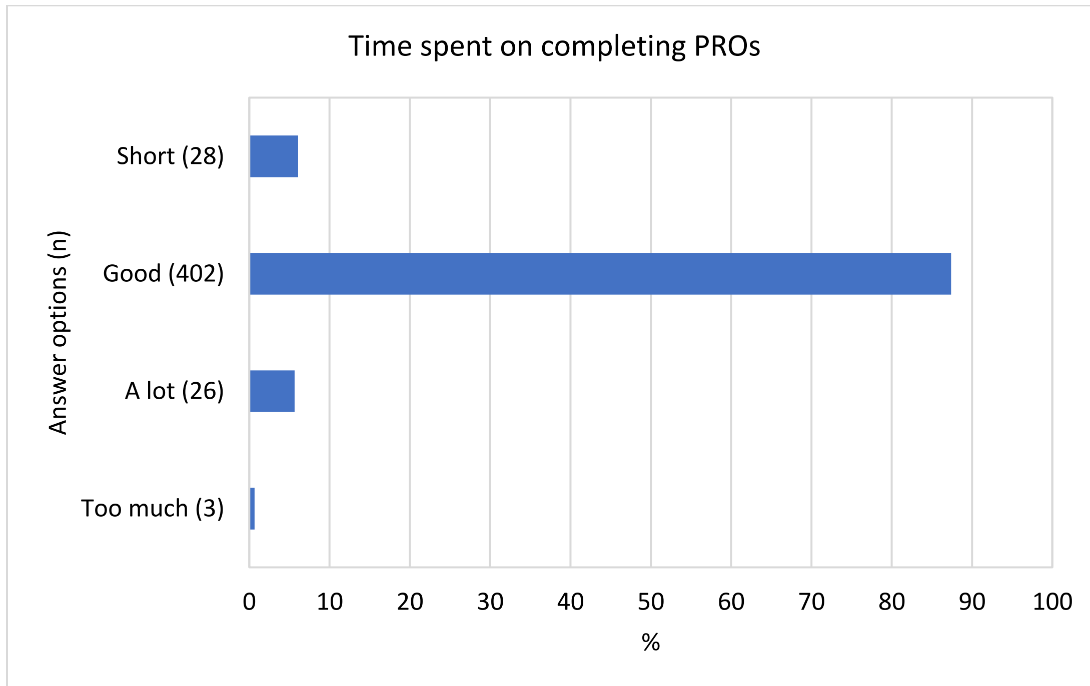
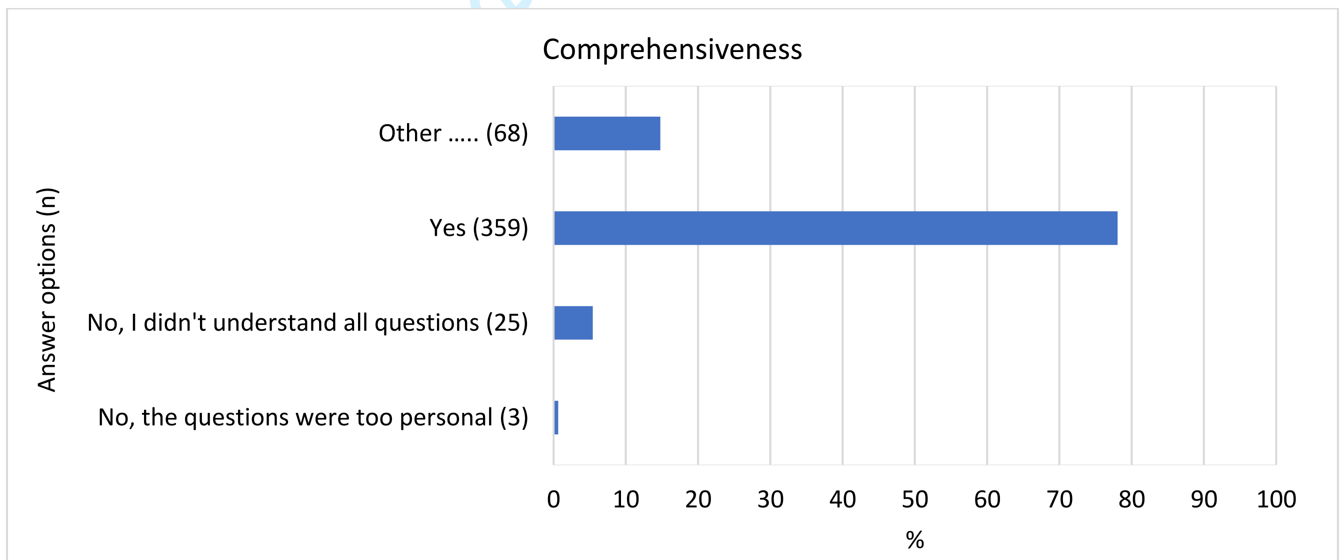


Supplementary Figure 1a *Q1 I found the time needed to complete the PROM and PREM…*



Supplementary Figure 1b *Q2 Were you able to properly complete all PROM and PREM?*

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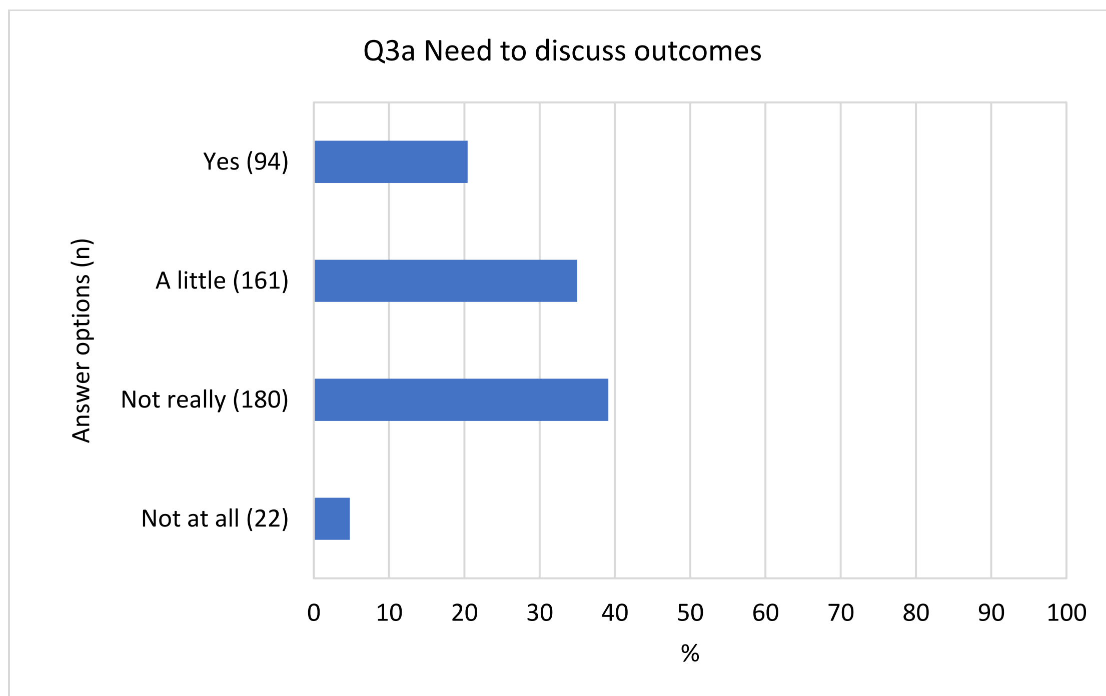
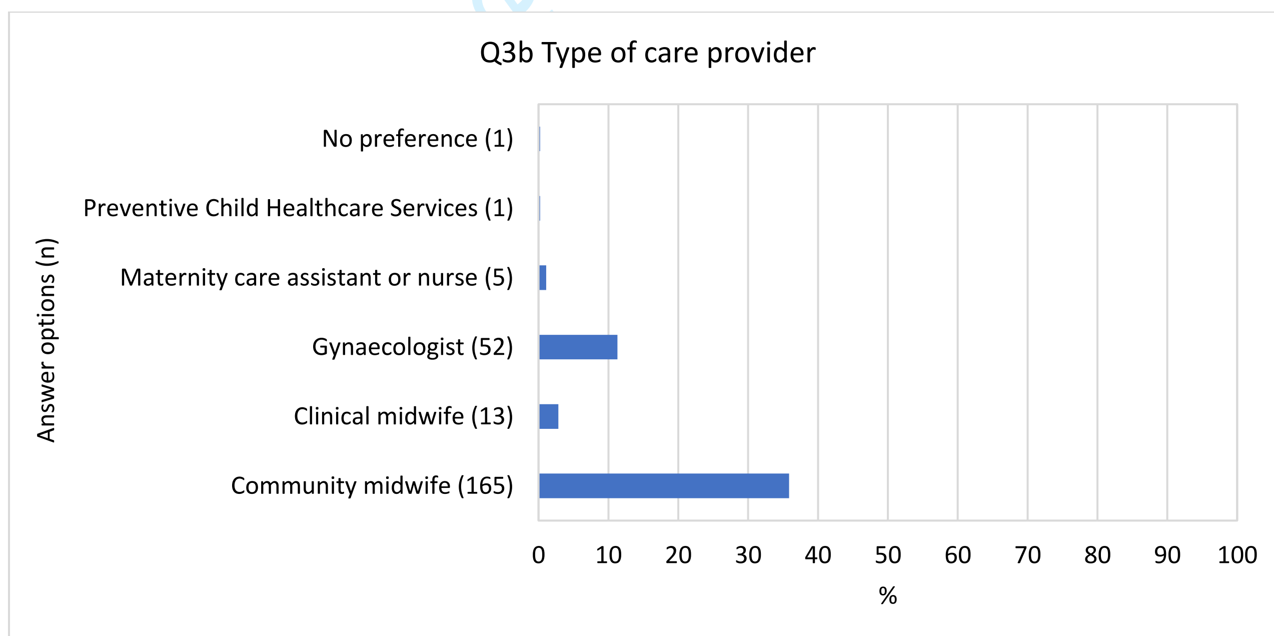


Supplementary Figure 1c *Q3 During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?*



Supplementary Figure 1d *Q3b Who do you prefer to discuss your outcomes with?*

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/ 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2-3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-5/117-126
Purpose or research question - Purpose of the study and specific objectives or questions	5/124-126

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	6, 129-130
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	10/187-199
Context - Setting/site and salient contextual factors; rationale**	7/160-166 8/176-179
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	8/159-170 8/177-184
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	25/466-471
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6/134-135 8/172-184

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Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7/176-179, 183-184
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11/213-222
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	10/188-192
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	10/187-199
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6, 129-130 10/192-193, 197-198

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-12/224-228, Table 2
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quote 1-10

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	20/342-349, 21-23/371-424
Limitations - Trustworthiness and limitations of findings	20/ 351-368

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	24/454-456
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	24/452-453

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

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Women's experiences with using patient-reported outcome and experience measures in routine perinatal care in the Netherlands: a mixed methods study

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Women's experiences with using patient-reported outcome and experience measures in routine perinatal care in the Netherlands: a mixed methods study

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ABSTRACT

Objective

To gain insight into the experiences of women with completing and discussing patient reported outcome measures (PROM) and patient reported experience measures (PREM), and tailoring their care based on their outcomes.

Methods

A mixed-methods study was performed in seven obstetric care networks in the Netherlands that implemented a set of patient-centred outcome measures for pregnancy and childbirth (PCB set), published by the International Consortium for Health Outcomes Measurement. All women receiving the PROM and PREM questionnaires as part of their routine perinatal care, received an invitation for a survey (n=460) and an interview (n=16). The results of the survey were analysed using descriptive statistics; thematic inductive content analysis was applied on the data from open text answers and the interviews.

Results

More than half of the survey participants (n=255) felt the need to discuss the outcomes of PROM and PREM with their care professionals. The time spent on completing questionnaires and the comprehensiveness of the questions was scored 'good' by most of the survey participants. From the interviews, four main themes were identified: content of the PROM and PREM questionnaires, application of these outcomes in perinatal care, discussing PREM, and data capture tool. Important facilitators included awareness of health status, receiving personalised care based on their outcomes and the relevance of discussing PREM six months postpartum. Barriers were found in insufficient information about the goal of PROM and PREM for individual care, technical problems in data capture tools and discrepancy between the questionnaire topics and the care pathway.

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Conclusions

This study showed that women found the PCB set an acceptable and useful instrument for symptom detection and personalised care up until six months postpartum. This patient evaluation of the PCB set has several implications for practice regarding the questionnaire content, role of care professionals and congruity with care pathways.

Key words:

Value-based healthcare

Obstetrics

Perinatal care

Patient-reported outcome measures

Patient-reported experience measures

Shared decision making

Qualitative research

Quantitative research

Mixed methods

Article Summary

- This study had a prospective design and was incorporated in an implementation project as part of routine perinatal care.
- As a result of the embedding in an implementation project, we were able to combine the results of a large sample size of survey participants with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results.
- These are the first experiences from patient perspective regarding completing and discussing PROMs and PREMs during routine perinatal care.

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- A limitation of this study was the unequal representation of time points for PROM and PREM collection in our interview sample, due to the nature of the implementation project.

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INTRODUCTION

Healthcare systems are increasingly focusing on creating value for patients.[1] Therefore, patient-reported outcome measures and experience measures (PROM and PREM) are progressively used to guide individual patient care, in quality improvement, and for research purposes. PROM and PREM are defined as information that is provided by patients concerning the impact of their condition, disease or treatment on their health and functioning.[2, 3] In routine care, patients complete PROM and PREM via standardised questionnaires – both generic and disease specific – between visits to care professionals. Care professionals receive notifications about alarm symptoms, such as pain or functional complaints and can review longitudinal PROM and PREM reports over time. This way, symptoms and impairments are more likely to be detected, creating an opportunity to personalise care based on individual needs.[4] In chronic care settings, this approach has been shown to improve shared decision making, patient-clinician relationship and health outcomes.[5, 6]

In perinatal care, important outcomes expressing quality of life and social participation can be detained from PROM and PREM, such as maternal depression, incontinence, and birth experience. PROM and PREM may differ greatly and may be independent of provider-reported outcomes, describing far-reaching effects on women's lives.[7, 8] Additionally, PROM and PREM may highlight important outcomes from the patient perspective that remained hidden when collecting provider-reported outcomes only. Therefore, implementation of standardised PROM and PREM, including the adaptation of individual care pathways based on individual outcomes, is essential to further personalize and improve quality of perinatal care from the patient perspective. The International Consortium for Health Outcomes Measurement (ICHOM) provided a set of patient-centred outcome measures for pregnancy and childbirth (PCB Set) for perinatal care containing both provider-reported and patient-reported outcomes.[9] Prior research in the Netherlands found this set to be acceptable and feasible for implementation by all important stakeholders including women.[10, 11]

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However, little is known regarding women's experiences with completing the PROM and PREM and receiving care based on their individual outcomes as part of routine perinatal care.

In the Netherlands, a nationwide implementation project was initiated to facilitate shared decision making by implementing the PROM and PREM of the PCB Set in regular perinatal care. To achieve successful implementation, identifying unanticipated influences, facilitators and barriers among the users during the early implementation process of PROM and PREM is crucial.[12] Our pre-implementation research identified women as important users next to perinatal care professionals.[10, 11] Insights into first women's experiences with receiving personalised care based on their individual PROM and PREM during pregnancy, childbirth and the postpartum period will enhance and improve further implementation of PROM and PREM as part of routine perinatal care. Therefore, alongside the nationwide implementation project, we conducted a mixed methods study to gain insight into the experiences of women with completing and discussing PROM and PREM, and tailoring their care based on their outcomes in a routine perinatal care setting.

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METHODS

Design

Mixed-method prospective cohort study to gain insight in women's experiences with using the PROM and PREM of the ICHOM PCB set for perinatal care in clinical practice among women receiving perinatal care.

Setting

This study was conducted in seven obstetric care networks (OCNs) participating in a nationwide implementation project of the ICHOM PCB Set in the Netherlands. Alongside the implementation project in clinic, this study was performed to evaluate women's experiences with this innovation in routine care. The implementation project aimed integration of the PCB Set into routine perinatal care, i.e. that women were invited to complete PROMs and PREMs and discuss them with their care professional as part of routine perinatal care at five time points during their pregnancy or postpartum period. At these time points, different care professionals may have been responsible for the participants' health (see **Figure 1**). Women received an information leaflet regarding the purpose of the PROM and PREM before filling out their first PROM and PREM questionnaire and could complete the questionnaires digitally at home. Care professionals were informed about the content of the PCB Set (**Figure 2**) and how to interpret the results. Training on how to discuss the outcomes was available if needed. Care professionals discussed the results of the PROM and PREM during the next regular visit directly after each time point, also at six months postpartum. Implementation plans differed among the OCNs to enhance local implementation; OCNs collected PROM and PREM during at least one time point, this was not necessarily time point 1 (see **Table 1**).

Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.
The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points.[9]

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Figure 2 Pregnancy and childbirth Set as applied in the Netherlands: domains and moments to measure (adapted from Depla et al.[13]).

The blue dots indicate the five time points for data collection during pregnancy and postpartum (see also Figure 1). The outcome domains are divided into patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Below, the number of questions of the total questionnaire (PROM and PREM) per time point is shown.

Table 1 Implementation of time points per obstetric care network

	OCN 1	OCN 2	OCN 3	OCN 4	OCN 5	OCN 6	OCN 7
Time point 1: first visit			✓	✓	✓	✓	
Time point 2: 28-32 weeks of gestation	✓	✓	✓	✓	✓	✓	
Time point 3: first days after childbirth			✓	✓	✓	✓	✓
Time point 4: postpartum check-up		✓	✓	✓	✓	✓	✓
Time point 5: 6 months postpartum					✓		✓

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Patient and Public Involvement statement

Simultaneously with the implementation of the PCB set, this study was conducted to gain insight into women's experiences with completing and discussing PROM and PREM. Both the clinical implementation project and this study were a continuation of previous projects that actively involved women as important stakeholders, resulting in changes into the Dutch PCB Set, as well as providing insight in facilitators and barriers to be addressed during the implementation of the PCB Set in routine care. In this study, we sent out a survey and conducted interviews with women. The study was designed in close collaboration with care professionals, while taking into account previous findings from surveys, interviews, and focus group interviews with women.[10, 11, 14] Also, the PROM and PREM questionnaires used in clinic were tested for comprehensiveness among four

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women with low health literacy skills supported by Pharos, a national centre of expertise in decreasing health inequities.[15] Small language adaptations were made based on this test.

Participants

As our study was conducted within a large implementation project of the PCB set, all women who received PROM and PREM questionnaires as part of their routine perinatal care in one of the participating OCNs were eligible for this study. Women were invited to participate in this study via a digital link immediately after filling out a PROM/PREM questionnaire at home. They were asked to complete a short evaluation survey and optionally participate in a telephone interview regarding their experiences with completing and discussing the PROM and PREM.

Inclusion criteria for this study were:

- women completed at least one questionnaire of the PCB set;
- women were 16 years or older during the first data collection time point;
- women gave their informed consent to use their answers for research.

Data collection

Data collection was performed from March 2020 up until September 2021. The researchers composed a short evaluation survey (Supplementary Table 1). This anonymous survey was offered to participants via a digital link directly after completing their PROM and PREM. One OCN collected this evaluation survey on paper. No case mix questions were asked to minimise response burden for women who had already completed the PROM and PREM questionnaire. Answers to this survey were not visible to care professionals. At the end of this evaluation survey, participants were asked to provide their telephone number for an in-depth evaluation interview by phone. First, all participants who provided their telephone number were approached for a semi-structured interview by one of the researchers (see for topic list **Table 2**). Further on, purposive sampling was performed, e.g., selecting women that had filled out PROM and PREM at time points 3, 4, and 5, or women who gave specific answers in the evaluation survey. Additionally, care professionals were asked to

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actively recruit women with decreased health literacy skills for an interview by the researchers. Data collection was ended as soon as thematic saturation was accomplished (see Data analysis). All interviews were audio-recorded and transcribed verbatim.

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Table 2 Topic list used for the interviews

Topics	Sub topics
Course pregnancy/childbirth	General Health / Experiences pregnancy
Time spent on completing PROM and PREM - experiences	Experiences completing PROM and PREM Experience on time spend Motivation for completion of PROM and PREM Reasons for (not) completing PROM and PREM in the future Time point 1 & 2: thoughts regarding completing PROM and PREM multiple times during pregnancy and after childbirth Time point 3-5: experiences with completing PROM and PREM after childbirth up until 6 months postpartum
Comprehensiveness PROM and PREM	Understanding PROM and PREM: language used, reason why PROM and PREM were asked, information provision Social desirability PREM regarding experiences with care providers: completing and discussing
Discussing PROM and PREM with care professionals	Experiences regarding discussing PROM and PREM Adverse outcomes of PROM and PREM Taboo topics Bond with care professional Unexpected outcomes Resistance regarding discussing PROM and PREM Advantages and gains of discussing PROM and PREM
Improvements and suggestions	Results of evaluation survey Previously completed PROM and PREM Important topics
Preferred care provider	Time point Outcomes that are discussed
Shared decision making	Care pathway – participant's influence Discussing wishes and fears regarding pregnancy and childbirth Patient – care professional relationship

PROM: patient reported outcome measures. PREM: patient reported experience measures

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Data analysis

The quantitative data from the evaluation survey were analysed using descriptive statistics with SPSS version 25 (IBM Corp., Armonk, N.Y., USA). Free text answers were analysed with thematic analysis supported by Microsoft Excel (version 16). The transcriptions from the interviews were checked for accuracy with the original audiotapes by LL. The software program Atlas.ti 9 was used to support thematic inductive content analysis.[16] LL and SK independently coded the transcripts to create a set of preliminary codes and compared the codes to reach consensus. To detect emerging themes, we merged matching codes, and explored links between codes. An overview was constructed of themes and subthemes for women's experiences with completing and discussing PROM and PREM. This overview was compared with the free text answer analysis of the open-ended questions from the survey and combined into an integrated overview. The integrated overview was discussed with AD, ML and MB and subthemes were identified as facilitators and barriers. Reporting followed the Standards for Reporting Qualitative Research (SRQR).[17]

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RESULTS

Survey

460 Participants (35%) filled out the patient evaluation survey from a total of 1318 women who completed at least one PROM and PREM questionnaire. Descriptive statistics of the survey are shown in Supplementary Table 2 and Supplementary Figure 1a-d. Regarding the time spent on completing the questionnaires, 87% of participants indicated this as 'good'. The comprehensiveness of the questions was indicated as 'good' by most participants (78%). The need to discuss the outcomes of the questionnaires with the care professional differed: of the participants 39% answered 'not really', and 35% 'a little', and 20% 'yes'. Of the participants that wanted to discuss the outcomes, the majority preferred their obstetric care professional for this. The answers from the open-ended questions are to be discussed below.

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Interviews

26 participants provided their telephone number for the interview, none of these participants had completed PROM and PREM during time point 3 (maternity week). 16 interviews were conducted. We interviewed two participants that completed PROM and PREM during time point 1 and 4, nine during time point 2, and three during time point 5. The average age of participants was 34 years [29-39 years] and the majority were higher educated (14 of 16), i.e., completed an education at a university or university of applied sciences. Four participants received perinatal care for the first time; they were pregnant for the first time or had given birth to their first child. Six participants had received perinatal care by a community midwife, five by a gynaecologist in the hospital, and five by both community midwives and gynaecologists.

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Themes

The facilitators and barriers identified from the open-ended questions and interviews were allocated to four overarching themes (see Table 3): 1. Content of the PROM and PREM, 2. Application of the outcomes of PROM and PREM in perinatal care, 3. Discussing PREM, and 4. Data capture tool. These themes including facilitators and barriers are described below in detail, with illustrative quotes.

1. Content of PROM and PREM questionnaires

Most participants found the language of the PROM and PREM clear and understood the questions. Participants felt that the PROM and PREM covered most important topics and were of a good length. Most participants emphasised the importance of PROM and PREM addressing taboo topics, such as incontinence, depression, and pain with intercourse. In the interviews, participants shared that completing PROM and PREM on these topics created awareness about their current health status and potential problems during pregnancy, childbirth and first months postpartum (see Quote 1).

Quote 1 Awareness of taboo topics:

[Complete PROM/PREM to prepare for their next visit] "I assume [advantages] for both parties: for yourself because you think about everything, also things you wouldn't consider at first. And I expect it [capturing PROM and PREM] would be helpful for a care professional as well, because he can ask further than just the topics a patient brings up at that moment." (T4)

However, the language of some questions was too difficult, especially for lower educated women, and several PROMs were not specific in timing or location of physical complaints. This led to different interpretations of the questions. Regarding the content of the PREM, participants

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experienced discrepancy between the timing of the questions and the care received. For example, at time point 2, options for pain management during childbirth had often not been discussed yet, thus participants answered negative to the PREM addressing this. Another issue mentioned by the interview participants in relation to PREM, was that they often received care from multiple care professionals. They stated that they had to average their experiences when completing the PREM. Several participants reported that they missed the answer option "I don't know (yet)" or "not applicable" in some questions, and the possibility to explain their answers. Also, participants missed the possibility in the questionnaires to point out important outcomes. This topic was expanded during the interviews; participants wanted to be able to indicate outcomes important to discuss during the following visit (see Quote 2).

> *Quote 2 No opportunity to explain answers or pointing out important topics [Opportunity for explanation during completion of PROM and PREM] "You should have a choice: whether you want to discuss it [your answers] or not, whether you want to be referred or not. […] You could put it [an open text field] at the end of the questionnaire: 'If you want consultation on this, if you have a top 3 or top 5 or something of the things that were just asked, what are the topics you would like to discuss with your midwife?'"* (T2)

Although most important topics were covered in the PROM and PREM, some participants stated that there was too little attention for prevalent physical problems. They missed questions concerning pelvic pain and haemorrhoids, especially at time point 2. Lastly, the timing of one specific topic was debated by several participants: the PROM breastfeeding. At time point 2, this topic was experienced as too early since most women did not know whether they intended to breastfeed and

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could not properly answer the full questionnaire about self-efficacy. At time point 4, participants indicated it felt too late to discuss problems with breastfeeding.

2. Application of the outcomes of PROM and PREM in perinatal care

Most participants indicated that filling out PROM and PREM helped them in preparing their next visit to their obstetric care professional. They stated that thinking about the topics addressed by the questionnaires made them know better what to expect from and to discuss in the following visit. Interview participants also pointed out that the use of PROM and PREM led to discussion of topics that previously were no part of the conversation with their care professional. Some participants indicated that they were unaware of some topics being pregnancy related, such as psychological problems. Furthermore, some participants from the interviews said that they felt their care was personalised based on their individual outcomes, for example extra attention, information, or a referral for specialised care (see Quote 3 and Quote 4).

Quote 3 Care is personalised based on individual outcomes

“Then she [the care professional that discussed her outcomes with her] said she could refer me to a clinic for pelvic problems if I wanted to. […] I thought that was very good. They directly did a follow-up and offered me sort of an option like ‘you could this’.” (T5)

Quote 4 Care is personalised based on individual outcomes

[her PROM answers indicated depressive symptoms] “Well… personally I think I, and they too [care professionals], gave some extra attention to my mental health.” (T2)

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At time point 5, one participant from the interviews felt relieved that her care professional paid attention to her incontinence and psychological problems. She felt that otherwise she would not have had any care professional to discuss these issues with.

Despite the availability of an information leaflet and their care professionals' explanation, many participants had misunderstood the aim of the project. They thought it was a research project and that their answers would be used for research purposes only. This indicates that the information about the purpose of PROM and PREM for individual care was insufficient, which posed a major barrier to complete questionnaires multiple times (see Quote 5).

Quote 5 Insufficient information on the aim personalised care based on PROM and PREM

"It was not clear to me why it [PROM and PREM] was asked. And I also can't remember that it [PROM and PREM questionnaires] included an introduction text or something like that… maybe that was included you know… but for me it was not clear what they wanted to do with that information [her answers]" (T2)

Furthermore, some participants stated it was uncertain when the outcomes of their questionnaire would be discussed with them; not all participants had their outcomes discussed during the first visit after completing the PROM and PREM. One participant said that her outcomes had never been discussed with her. Several participants mentioned that completing PROM and PREM gave them the feeling of 'impersonalised care', as if care professionals tried to avoid the conversation about these topics. Other interview participants felt unsure about how the outcomes of the PROM and PREM would impact the quality of care of their individual care pathway. For example, when filling out negative experiences regarding one specific care professional, they preferred to receive care from another care professional because of their negative experience. Some participants, from both the

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survey and the interviews, felt that discontinuity in care professionals posed a barrier to discuss the outcomes. They did not feel at ease discussing outcomes with a care professional they had never met before (see Quote 6). Interview participants also did not always know which care professional was responsible for their outcomes.

Quote 6 Discontinuity of care professional

"Nothing really popped up [from her answers to the questionnaires], but if that would have been the case than I think it is harder to discuss some topics with a person [care professional] that I have never met. Especially because some of these topics are sensitive and vulnerable." (T1)

3. Discussing PREM

Participants stated that the PREM were an important facilitator for them to complete the PROM and PREM. They stressed that they found it very important that care professionals in general have insight in patients' experiences with their provided care. Additionally, participants from the interviews thought that the insight in individual PREM may lead to improved quality of individual care. Especially participants that had completed PREM at time point 5 stated that the PREM were important to complete and to discuss, because it helped them to process the pregnancy and postpartum period (see Quote 7).

Quote 7 Discussing PREM at time point 5 important for reflection on pregnancy and childbirth

[After completing the T5 questionnaire] "The fact that she [care professional] called back, that she called back actually concerned, and just … just was talking with me and

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explained things. That has really, also in my head, enormously helped to sort things out. […] Yes, I really look back on that [childbirth and postpartum period] better now." (T5)

Additionally, analysis of aggregate PREM results may indicate improvement topics, according to the interview participants. At the same time, a barrier was identified in overlap; some participants received PREM and other evaluation questionnaires from their community midwives postpartum, and it was unclear for them whether these outcomes were also sent to their midwives. Ambiguous opinions were found regarding discussing PREM individually. Some participants, who were satisfied with the care they received, indicated they would have preferred addressing negative experiences directly with their care professional, instead of via PREM (see Quote 8). In contrast to participants that had had negative experiences: they explained it felt easier to indicate this via PREM instead of discussing it face to face with their care professional.

Quote 8 Negative PREM preferably face to face

[addressing care experiences with care professional] "I believe it is fairer when they [care professionals] hear it from me personally, but I can imagine that some people don't feel comfortable with that and prefer to leave their feedback anonymously and that eventually it will reach the care professional anyway." (T2)

Additionally, some participants stated to feel dependent of their care professional during their care pathway, which posed a barrier to report negative experiences in the PREM.

4. Data capture tool

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Participants indicated that they preferred to complete PROM and PREM digitally. Completing the PROM and PREM on mobile phones or tablets was preferred by most women. However, participants pointed out technical issues as a major barrier; PROM and PREM questions and answers that were not entirely visible on a mobile phone led to incomplete or incorrect outcomes according to some women (see Quote 9).

Quote 9 Technical problems and bugs

[Completing PROM and PREM] "On my smartphone I can't see all the questions. On the iPad, some answer options disappear, so I must check three times whether my answers are completed correctly. For example, satisfaction is measured on a scale from 1 to 4. But when I go to the next page and back, it appears to be a scale from 1 to 10." (T2)

Also, some participants received PROM and PREM belonging to a different time point or received the same PROM and PREM multiple times. Furthermore, several interviewed participants stated that it was unclear which organization sent the invitation to complete the questionnaires and which care professionals had access to their answers. This made them have doubts regarding privacy (see Quote 10).

Quote 10 Privacy issues

[Completing questions regarding incontinence, mental health, physical complaints]: "And yes, those are questions of a kind that you would only complete honestly if you are completely sure that you can trust that they will end up at the right person." (T2)

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1 **Table 3 Overarching themes and identified facilitators and barriers**

Themes	Facilitators	Barriers
1. Content of PROM and PREM questionnaires	Clear language PROM and PREM covering all important topics Good length of questionnaires Awareness of taboo topics	Language of some questions too difficult Some PROM questions not specific in time or location Discrepancy questions with care path and situation Absence of answer option "I don't know (yet)" or “not applicable” No opportunity to explain answers or pointing out important outcomes Too little attention to physical problems (time point 2) (Timing of) PROM breastfeeding
2. Application of the outcomes in individual care	Better preparation for next visit/appointment Discussing topics that were not discussed before Care is personalised based on individual outcomes Discussing outcomes at Time point 5	Insufficient information on the aim personalised care based on PROM and PREM Uncertainty when outcomes are discussed Feeling of impersonalised care Unsure of impact on individual quality of care Discontinuity of care professional
3. Discussing PREMs	PREM being included in the questionnaires Insight in individual PREM improves individual quality of care Discussing PREM at Time point 5 important for reflection on pregnancy and childbirth Analysis of aggregate PREM for care improvement Completing PREM safer option in case of dissatisfaction	Receiving multiple questionnaires regarding experiences Negative PREM preferably face to face Dependency of care professional
4. Data capture tool	Completing questionnaires digitally Availability on mobile phones or tablets	Technical problems and bugs Privacy issues

2 *PROM: patient-reported outcome measures, PREM: patient-reported experience measures*

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DISCUSSION

This mixed methods study provides insight into the first experiences of women with completing and discussing PROM and PREM at different time points during and after pregnancy as part of routine perinatal care. The evaluation survey results showed that the time spent on completing the PROM and PREM was acceptable, and their content was comprehensive. Most survey participants felt the need to discuss the outcomes. In the interviews, participants were mainly positive about discussing their individual PROM and PREM outcomes with their perinatal care professionals. Women's barriers and facilitators to complete and discuss PROM and PREM individually were identified in four overarching themes.

Strengths and limitations

A strength of this study was the prospective design, incorporated in an implementation project as part of regular care. Its results supported further implementation of the outcome set, as they were directly translated into adaptations in the clinical project, such as IT improvements and an option to further explain an answer. Accordingly, by providing PROMs and PREMs throughout pregnancy and the postpartum period, women can become aware of what high-quality care encompasses, and of complications or symptoms that can occur. This awareness can empower women and support them to adjust their care pathway to their individual preferences and values. Another strength was the large sample size of survey participants combined with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results. Also, the participation threshold was lowered by conducting the survey anonymously and the interviews by telephone, limiting the risk of selection bias. However, despite our efforts to minimise the risk of selection bias with purposive sampling as well, mostly higher educated women were included, and only Dutch speaking women could participate to the surveys. This was inevitable to some extent, as the sample

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was taken from an already selected population: women completing the PROM and PREM were Dutch speaking only and had a relatively good health literacy, as no support was provided with completing them. This limitation should be taken into account when interpreting our findings and stresses the importance of future efforts to engage all women when implementing PROM and PREM to prevent further health inequities. Nevertheless, this exploration of patient experiences with individual PROM and PREM was the first among women receiving perinatal care. A second limitation, resulting from the outline of the implementation project, was the unequal representation of time points for PROM and PREM collection in our interviews. Despite our strategy to ask care professionals to recruit participants for the interviews directly, i.e., without filling out the survey, we could not interview women who had completed PROM and PREM at time point 3 (maternity week).

Compared with literature

In line with findings in other disciplines, discussing PROM and PREM with care professionals as part of routine perinatal care was found to improve patient satisfaction and willingness to complete the questionnaires.[6, 18-20] Participants felt better prepared for their next visit and discussed topics that were not discussed before, which reconfirms results from large studies in chronic care settings.[20-22] At the same time, a significant part of our survey respondents did not feel the need to discuss their outcomes. Moreover, for some women completing the questionnaires even felt as impersonalized care. As the survey was offered directly after completing the PROM and PREM, survey participants had not yet discussed their outcomes with their care professional. These findings indicate that discussing outcomes are an essential part of using PROM and PREM in clinical practice.[6] Another explanation could be inadequate information provision, as several women stated that the purpose of the PROM and PREM was unclear to them. As women's perception of this purpose largely depends on their care professional, care professionals may improve this by actively

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using PROM and PREM as a part of routine care. For example, by encouraging women to consider which outcomes they want to discuss in the next visit.

Using individual outcomes to tailor care was an important facilitator to complete PROM and PREM over the course of pregnancy and postpartum. Nevertheless, two important barriers to use PROM and PREM individually were raised by our participants as well. First, discrepancy between the timelines of provided care and the PROM and PREM was pointed out. For example, a PREM questioning information provision on pain relief was sent to women, before care professionals addressed this topic according to standard care. Synchronising the time points of the PCB set with routine perinatal care pathways may solve this barrier. Based on compliance to the PROM and PREM and results of the PROM and PREM, concrete recommendations to adapt the PCB set's content and timeline have been suggested in a recent publication, and are in accordance with women's experiences found in this study. [13] Secondly, discontinuity in care professional was posed as a barrier, as discussing PROM and PREM with different care professionals lead to discomfort among participants. Discussing outcomes in the multidisciplinary setting of perinatal care may be easier if a principal care professional is allocated to every pregnant woman. A relationship of trust between care professional and patients may be a crucial facilitator for completing and discussing PROM and PREM, especially when discussing taboo topics such as incontinence.[23] This may provide opportunity to improve perinatal care outcomes, as several taboo topics have been shown highly prevalent and only 15% of the affected women bring them up during a postpartum check-up.[13, 24] Additionally, although hard to accomplish by perinatal care professionals, our participants stated that evaluating their outcomes at six months postpartum with a perinatal care professional was of added value to the regular postpartum check-up. This reconfirms previously reported patient views regarding time point five of the PCB set.[10, 11] Compared to the check-up at six weeks postpartum, at six months postpartum most women have further recovered in multiple domains and resumed

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their work and social life. Hence, at this moment, the sustainability and severity of physical or mental problems can be determined and referred for, improving long-term outcomes of perinatal care.

Confirming pre-implementation studies, our participants emphasized that PREM were an important facilitator to complete the questionnaires.[10, 11] However, evidence on individual PREM use as part of clinical practice is scarce. This study revealed different opinions amongst women: some preferred to address negative experiences face to face, some felt PREM made it easier to raise and others felt too dependent on their care professional to discuss a negative experience at all. Future research should evaluate the possible effects of offering each woman a choice whether her individual answers are visible to care professionals and discussed as part of her care.

As shown before from a professional perspective, a good functioning data capture tool for assessment and real-life visualisation of patient reported measures is essential for successful implementation.[6, 25, 26] In our patient evaluation, technological issues of the data capture tools were also a major barrier for completing the questionnaires. Although challenging in terms of inter-organisational collaboration and IT infrastructure, this project was one of the first to attempt system wide implementation of PROM and PREM as a standard part of individual perinatal care to guide individual care and personalised care pathways. In the transformation towards health care systems that provide patient-centred care over the full cycle of care, it is essential to use data capture tools that facilitate information exchange between all health care tiers involved with a disease or condition.

Future research and implications

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To achieve personalized care based on PROM and PREM, patient engagement is essential but requires efforts at several points. For successful implementation, women will benefit from a system-wide data capture tool, a principal care professional to discuss their outcomes with and a timeline of PROM and PREM collection that fits clinical care: matching their appointments and content of care pathways. Also, an open text field to explain answers and point out outcomes they want to discuss could empower women to take an active role in their care. Lastly, when completing PROM and PREM, women should be clearly informed about 1) the purpose of using their answers for personalized care and 2) the topics addressed by the questionnaires at each time point and their relation to pregnancy and childbirth. Since care professionals are crucial in providing this information and in discussing the outcomes, future research may focus on the experiences of care professionals with PROM and PREM use in perinatal care. To engage care professionals, it would be useful to evaluate training strategies, but also their perceived benefits when working with PROM and PREM. These could include direct improvement of individual care for their patients, as well as insight in the results of their efforts in terms of patient outcomes.[14]

Conclusions

This study reported the first patient experiences with completing and discussing PROM and PREM as part of perinatal care. The ICHOM PCB set was found to be an acceptable and useful instrument for symptom detection and personalized perinatal care up until 6 months postpartum. Women's reflections on these PROM and PREM allow several improvements of the content of the questionnaires, the role of care professionals and congruity with routine care pathways.

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Competing interests statement:

AF and ML were chair and member respectively of the ICHOM working group that developed the PCB standard outcome set. The other authors have nothing to declare.

Contributorship statement:

AF, HE, JH, and MB led the overall implementation project in practice and established its funding. Collaborators of the BUZZ team led local implementation and recruited study participants. This study was designed by LL, AD, and MLdR under supervision of AF, HE and MB. LL and SK performed the interviews for data collection and analysed the data under supervision of MB. LL, AD, and MB interpreted the data. LL and AD wrote the first version of the manuscript and made adaptations after feedback of the other authors under supervision of MB. MB, AF, JH, HE, MLdR, SK, and the BUZZ team reviewed the manuscript and approved the final version. MB is the guarantor for the final product.

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Details of Ethics Approval

The Medical Ethics Committee Erasmus Medical Centre (MEC-2020-0129) declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known as WMO) do not apply to this study. This study was exempt from formal medical ethical assessment. Local approval of the regional ethical boards was obtained in each participating OCN. All participants signed written informed consent.

Data availability statement

Data are available upon reasonable request.

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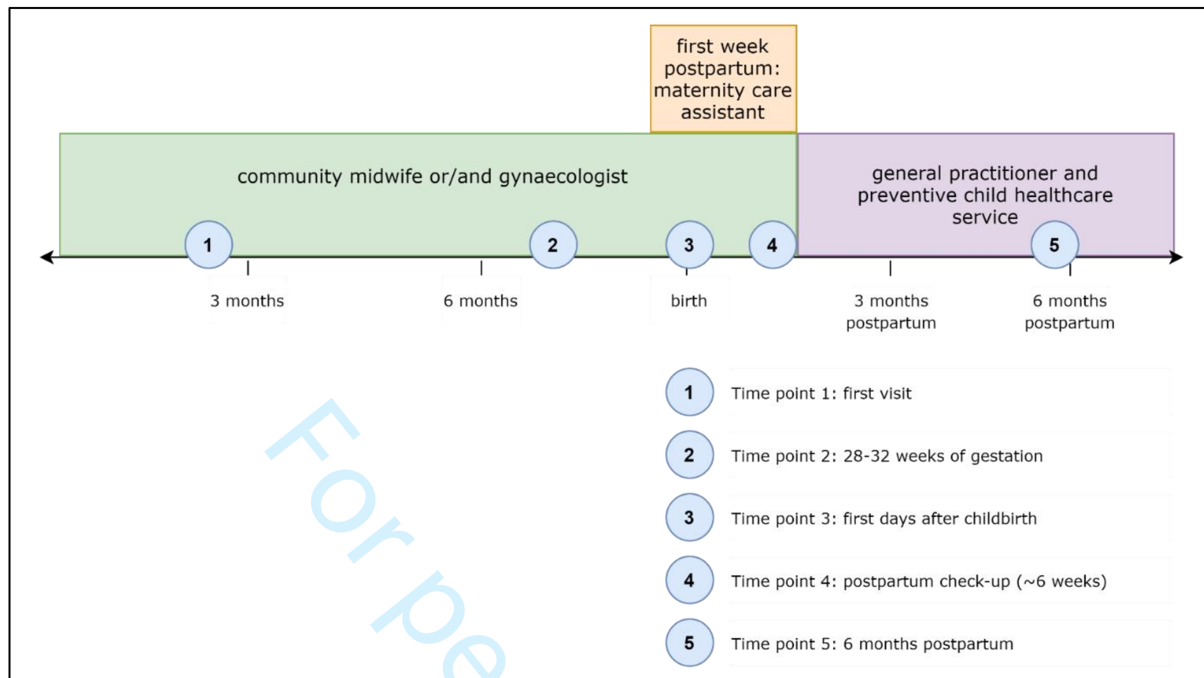

Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.

The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points. [7]

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Outcome Domain	1 1st trimester First visit	2 3rd trimester 28-32 weeks of gestation	3 after birth (first days)	4 Postpartum check-up (~6 weeks postpartum)	5 6 months postpartum	
Social support	■					PROM
Health related quality of life	■	■		■	■	
Mental health	■	■		■	■	
Incontinence	■	■		■	■	
Pain with intercourse	■			■	■	
Breastfeeding intention/success		■	■	■	■	
Breastfeeding confidence		■	■	■		
Mother-child bonding			■	■		
Confidence with role as mother	■			■	■	
Satisfaction with results of care		■		■	■	PREM
Healthcare responsiveness		■		■	■	
Birth experience				■		
Pain relief (Dutch addition)		■		■		
Role partner (Dutch addition)		■		■		
Continuity of care (Dutch addition)		■		■		
Number of questions (min-max) *dependent on screening question(s)*	18 – 37	30 – 64	9 – 24	50 – 84	27 – 46	

Figure 2 Pregnancy and childbirth Set as applied in the Netherlands: domains and moments to measure (adapted from Depla et al.[13]).

The blue dots indicate the five time points for data collection during pregnancy and postpartum (see also Figure 1). The outcome domains are divided into patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Below, the number of questions of the total questionnaire (PROM and PREM) per time point is shown.

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Supplementary Table 1 Evaluation survey

Q1) I found the time needed to complete the PROM and PREM …	
	Too much
	A lot
	Good
	Short

Q2) Were you able to properly complete all PROM and PREM?	
	Yes
	No, I did not understand all questions
	No, the questions were too personal
	Other: …….

Q3) During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?		
	Yes	→ Go to question 3b
	A little	→ Go to question 3b
	Not really	→ Go to question 3c
	Not at all	→ Go to question 3c
Q3b) Who do you prefer to discuss your outcomes with?		Community midwife
		Clinical midwife
		Gynaecologist
		Maternity care assistant or nurse
		Preventive Child Healthcare services
		General practitioner
		No preference
Q3c) Can you please explain why you do not prefer to discuss your outcomes?		……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………

Q4) Do you have any remarks regarding the PROM and PREM or suggestions for improvement?
……… ……… ………

Q5) Do you give permission for an evaluation by telephone in the future?	
	Yes, my telephone number is: ……………………………………………
	No

PROM: patient reported outcome measures. PREM: patient reported experience measures

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Supplementary Table 2 Survey participants per time point

Time point	n
T1	93
T2	337
T3	10
T4	9
T5	11
Total	**460**

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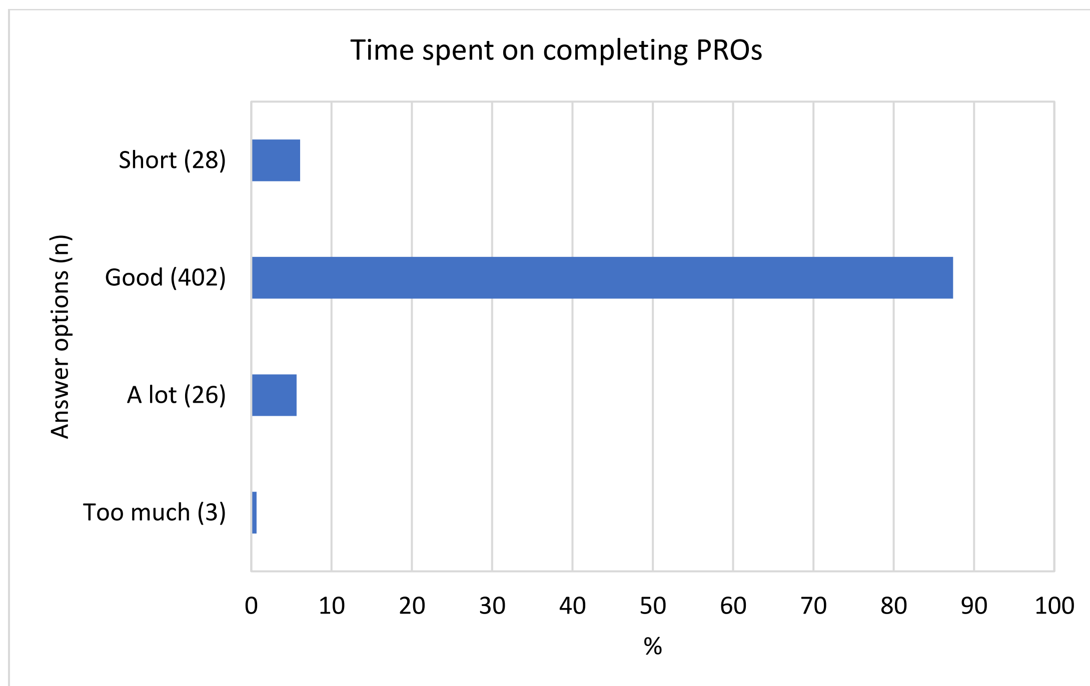
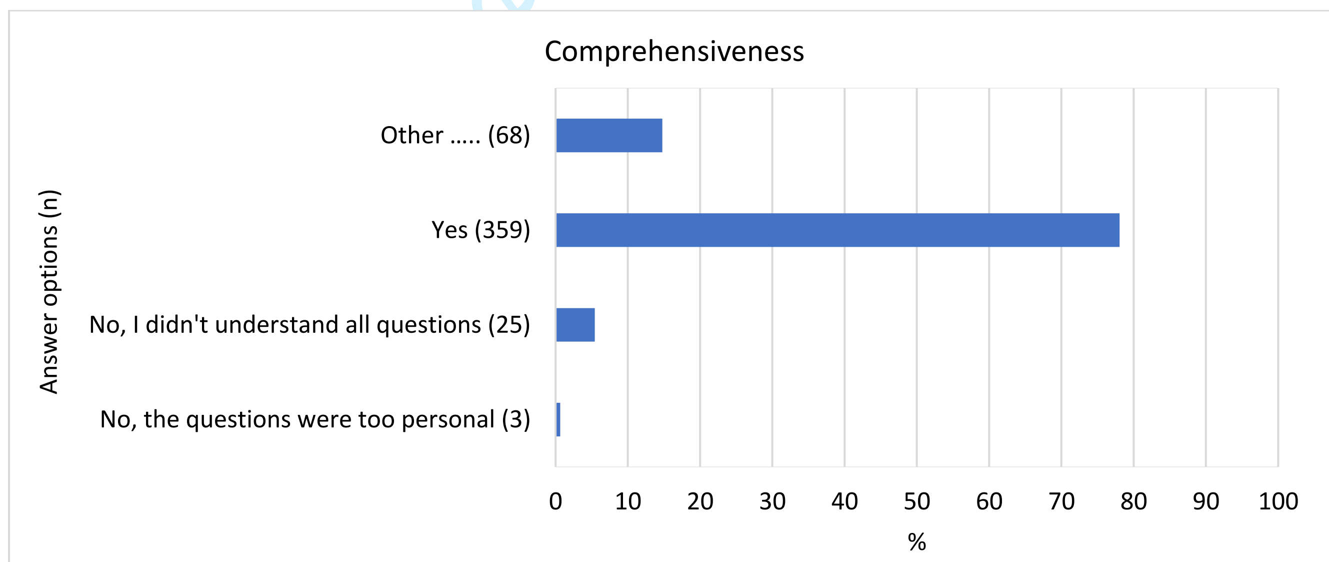


Supplementary Figure 1a *Q1 I found the time needed to complete the PROM and PREM…*



Supplementary Figure 1b *Q2 Were you able to properly complete all PROM and PREM?*

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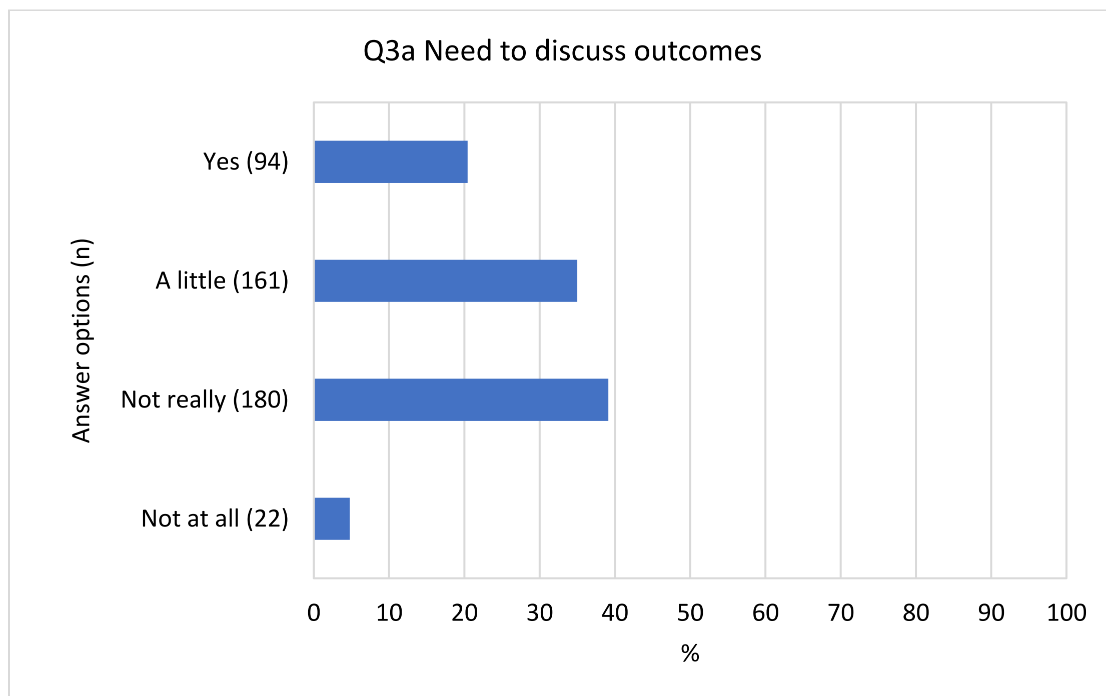
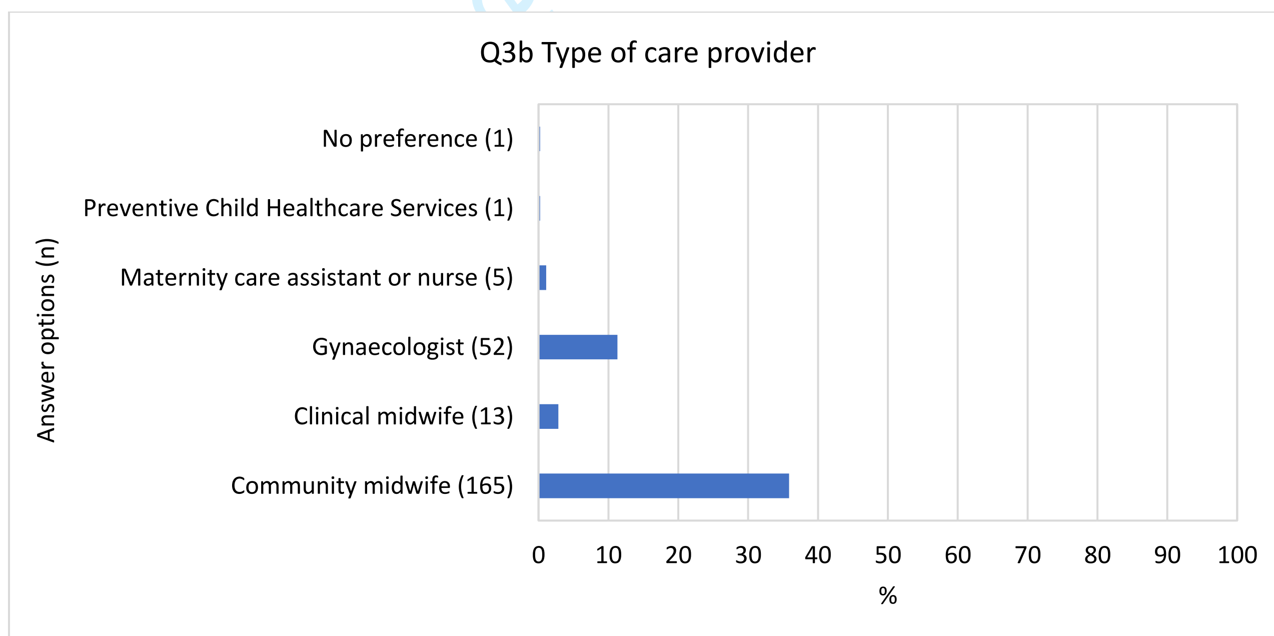


Supplementary Figure 1c *Q3 During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?*



Supplementary Figure 1d *Q3b Who do you prefer to discuss your outcomes with?*

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/ 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2-3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-5/117-126
Purpose or research question - Purpose of the study and specific objectives or questions	5/124-126

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	6, 129-130
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	10/187-199
Context - Setting/site and salient contextual factors; rationale**	7/160-166 8/176-179
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	8/159-170 8/177-184
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	25/466-471
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6/134-135 8/172-184

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Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7/176-179, 183-184
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11/213-222
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	10/188-192
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	10/187-199
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6, 129-130 10/192-193, 197-198

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-12/224-228, Table 2
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quote 1-10

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	20/342-349, 21-23/371-424
Limitations - Trustworthiness and limitations of findings	20/ 351-368

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	24/454-456
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	24/452-453

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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BMJ Open

Women's experiences with using patient-reported outcome and experience measures in routine perinatal care in the Netherlands: a mixed methods study

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Secondary Subject Heading:	Qualitative research, Health services research
Keywords:	OBSTETRICS, QUALITATIVE RESEARCH, PRIMARY CARE

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Women's experiences with using patient-reported outcome and experience measures in routine perinatal care in the Netherlands: a mixed methods study

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Shortened running title: Patient experiences using PROMs and PREMs in perinatal care

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Appendices: 3

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ABSTRACT

Objectives

To gain insight into the experiences of women with completing and discussing patient reported outcome measures (PROM) and patient reported experience measures (PREM), and tailoring their care based on their outcomes.

Design

A mixed-methods prospective cohort study.

Setting

Seven obstetric care networks in the Netherlands that implemented a set of patient-centred outcome measures for pregnancy and childbirth (PCB set), published by the International Consortium for Health Outcomes Measurement.

Participants

All women receiving the PROM and PREM questionnaires as part of their routine perinatal care, received an invitation for a survey (n=460) and an interview (n=16). The results of the survey were analysed using descriptive statistics; thematic inductive content analysis was applied on the data from open text answers and the interviews.

Results

More than half of the survey participants (n=255) felt the need to discuss the outcomes of PROM and PREM with their care professionals. The time spent on completing questionnaires and the comprehensiveness of the questions was scored 'good' by most of the survey participants. From the interviews, four main themes were identified: content of the PROM and PREM questionnaires,

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application of these outcomes in perinatal care, discussing PREM, and data capture tool. Important facilitators included awareness of health status, receiving personalised care based on their outcomes and the relevance of discussing PREM six months postpartum. Barriers were found in insufficient information about the goal of PROM and PREM for individual care, technical problems in data capture tools and discrepancy between the questionnaire topics and the care pathway.

Conclusions

This study showed that women found the PCB set an acceptable and useful instrument for symptom detection and personalised care up until six months postpartum. This patient evaluation of the PCB set has several implications for practice regarding the questionnaire content, role of care professionals and congruity with care pathways.

Key words:

Value-based healthcare

Obstetrics

Perinatal care

Patient-reported outcome measures

Patient-reported experience measures

Shared decision making

Qualitative research

Quantitative research

Mixed methods

Strengths and limitations of this study

- This study had a prospective design and was incorporated in an implementation project as part of routine perinatal care.

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- As a result of the embedding in an implementation project, we were able to combine the results of a large sample size of survey participants with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results.
- These are the first experiences from patient perspective regarding completing and discussing PROMs and PREMs during routine perinatal care.
- A limitation of this study was the unequal representation of time points for PROM and PREM collection in our interview sample, due to the nature of the implementation project.
- The evaluation survey had a response rate of 35%, which creates a risk for non-response bias that should be considered when interpreting our results.

INTRODUCTION

Healthcare systems are increasingly focusing on creating value for patients.[1] Therefore, patient-reported outcome measures and experience measures (PROM and PREM) are progressively used to guide individual patient care, in quality improvement, and for research purposes. PROM and PREM are defined as information that is provided by patients concerning the impact of their condition, disease or treatment on their health and functioning.[2, 3] In routine care, patients complete PROM and PREM via standardised questionnaires – both generic and disease specific – between visits to care professionals. Care professionals receive notifications about alarm symptoms, such as pain or functional complaints and can review longitudinal PROM and PREM reports over time. This way, symptoms and impairments are more likely to be detected, creating an opportunity to personalise care based on individual needs.[4] In chronic care settings, this approach has been shown to improve shared decision making, patient-clinician relationship and health outcomes.[5, 6]

In perinatal care, important outcomes expressing quality of life and social participation can be detained from PROM and PREM, such as maternal depression, incontinence, and birth experience. PROM and PREM may differ greatly and may be independent of provider-reported outcomes, describing far-reaching effects on women's lives.[7, 8] Additionally, PROM and PREM may highlight

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important outcomes from the patient perspective that remained hidden when collecting provider-reported outcomes only. Therefore, implementation of standardised PROM and PREM, including the adaptation of individual care pathways based on individual outcomes, is essential to further personalize and improve quality of perinatal care from the patient perspective. The International Consortium for Health Outcomes Measurement (ICHOM) provided a set of patient-centred outcome measures for pregnancy and childbirth (PCB Set) for perinatal care containing both provider-reported and patient-reported outcomes.[9] Prior research in the Netherlands found this set to be acceptable and feasible for implementation by all important stakeholders including women.[10, 11] However, little is known regarding women's experiences with completing the PROM and PREM and receiving care based on their individual outcomes as part of routine perinatal care.

In the Netherlands, a nationwide implementation project was initiated to facilitate shared decision making by implementing the PROM and PREM of the PCB Set in regular perinatal care. To achieve successful implementation, identifying unanticipated influences, facilitators and barriers among the users during the early implementation process of PROM and PREM is crucial.[12] Our pre-implementation research identified women as important users next to perinatal care professionals.[10, 11] Insights into first women's experiences with receiving personalised care based on their individual PROM and PREM during pregnancy, childbirth and the postpartum period will enhance and improve further implementation of PROM and PREM as part of routine perinatal care. Therefore, alongside the nationwide implementation project, we conducted a mixed methods study to gain insight into the experiences of women with completing and discussing PROM and PREM, and tailoring their care based on their outcomes in a routine perinatal care setting.

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METHODS

Design

Mixed-method prospective cohort study to gain insight in women's experiences with using the PROM and PREM of the ICHOM PCB set for perinatal care in clinical practice among women receiving perinatal care.

Setting

This study was conducted in seven obstetric care networks (OCNs) participating in a nationwide implementation project of the ICHOM PCB Set in the Netherlands. Alongside the implementation project in clinic, this study was performed to evaluate women's experiences with this innovation in routine care. The implementation project aimed integration of the PCB Set into routine perinatal care, i.e. that women were invited to complete PROMs and PREMs and discuss them with their care professional as part of routine perinatal care at five time points during their pregnancy or postpartum period. At these time points, different care professionals may have been responsible for the participants' health (see **Figure 1**). Women received an information leaflet regarding the purpose of the PROM and PREM before filling out their first PROM and PREM questionnaire and could complete the questionnaires digitally at home. Care professionals were informed about the content of the PCB Set (**Figure 2**) and how to interpret the results. Training on how to discuss the outcomes was available if needed. Care professionals discussed the results of the PROM and PREM during the next regular visit directly after each time point, also at six months postpartum. Implementation plans differed among the OCNs to enhance local implementation; OCNs collected PROM and PREM during at least one time point, this was not necessarily time point 1 (see **Table 1**).

Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.
The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points.[9]

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Figure 2 Pregnancy and childbirth Set as applied in the Netherlands: domains and moments to measure (adapted from Depla et al.[13]).

The blue dots indicate the five time points for data collection during pregnancy and postpartum (see also Figure 1). The outcome domains are divided into patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Below, the number of questions of the total questionnaire (PROM and PREM) per time point is shown.

Table 1 Implementation of time points per obstetric care network

	OCN 1	OCN 2	OCN 3	OCN 4	OCN 5	OCN 6	OCN 7
Time point 1: first visit			✓	✓	✓	✓	
Time point 2: 28-32 weeks of gestation	✓	✓	✓	✓	✓	✓	
Time point 3: first days after childbirth			✓	✓	✓	✓	✓
Time point 4: postpartum check-up		✓	✓	✓	✓	✓	✓
Time point 5: 6 months postpartum					✓		✓

Patient and Public Involvement statement

Simultaneously with the implementation of the PCB set, this study was conducted to gain insight into women's experiences with completing and discussing PROM and PREM. Both the clinical implementation project and this study were a continuation of previous projects that actively involved women as important stakeholders, resulting in changes into the Dutch PCB Set, as well as providing insight in facilitators and barriers to be addressed during the implementation of the PCB Set in routine care. In this study, we sent out a survey and conducted interviews with women. The study was designed in close collaboration with care professionals, while taking into account previous findings from surveys, interviews, and focus group interviews with women.[10, 11, 14] Also, the PROM and PREM questionnaires used in clinic were tested for comprehensiveness among four

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women with low health literacy skills supported by Pharos, a national centre of expertise in decreasing health inequities.[15] Small language adaptations were made based on this test.

Participants

As our study was conducted within a large implementation project of the PCB set, all women who received PROM and PREM questionnaires as part of their routine perinatal care in one of the participating OCNs were eligible for this study. Women were invited to participate in this study via a digital link immediately after filling out a PROM/PREM questionnaire at home. They were asked to complete a short evaluation survey and optionally participate in a telephone interview regarding their experiences with completing and discussing the PROM and PREM.

Inclusion criteria for this study were:

- women completed at least one questionnaire of the PCB set;
- women were 16 years or older during the first data collection time point;
- women gave their informed consent to use their answers for research.

Data collection

Data collection was performed from March 2020 up until September 2021. The researchers composed a short evaluation survey (Supplementary Table 1). This anonymous survey was offered to participants via a digital link directly after completing their PROM and PREM. One OCN collected this evaluation survey on paper. No case mix questions were asked to minimise response burden for women who had already completed the PROM and PREM questionnaire. Answers to this survey were not visible to care professionals. At the end of this evaluation survey, participants were asked to provide their telephone number for an in-depth evaluation interview by phone. First, all participants who provided their telephone number were approached for a semi-structured interview by one of the researchers (see for topic list **Table 2**). Further on, purposive sampling was performed, e.g., selecting women that had filled out PROM and PREM at time points 3, 4, and 5, or women who gave specific answers in the evaluation survey. Additionally, care professionals were asked to

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actively recruit women with decreased health literacy skills for an interview by the researchers. Data collection was ended as soon as thematic saturation was accomplished (see Data analysis). All interviews were audio-recorded and transcribed verbatim.

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3 214 **Table 2 Topic list used for the interviews**

Topics	Sub topics
Course pregnancy/childbirth	General Health / Experiences pregnancy
Time spent on completing PROM and PREM - experiences	Experiences completing PROM and PREM Experience on time spend Motivation for completion of PROM and PREM Reasons for (not) completing PROM and PREM in the future Time point 1 & 2: thoughts regarding completing PROM and PREM multiple times during pregnancy and after childbirth Time point 3-5: experiences with completing PROM and PREM after childbirth up until 6 months postpartum
Comprehensiveness PROM and PREM	Understanding PROM and PREM: language used, reason why PROM and PREM were asked, information provision Social desirability PREM regarding experiences with care providers: completing and discussing
Discussing PROM and PREM with care professionals	Experiences regarding discussing PROM and PREM Adverse outcomes of PROM and PREM Taboo topics Bond with care professional Unexpected outcomes Resistance regarding discussing PROM and PREM Advantages and gains of discussing PROM and PREM
Improvements and suggestions	Results of evaluation survey Previously completed PROM and PREM Important topics
Preferred care provider	Time point Outcomes that are discussed
Shared decision making	Care pathway – participant's influence Discussing wishes and fears regarding pregnancy and childbirth Patient – care professional relationship

215 *PROM: patient reported outcome measures. PREM: patient reported experience measures*

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3 216 Data analysis
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6 217 The quantitative data from the evaluation survey were analysed using descriptive statistics with SPSS
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8 218 version 25 (IBM Corp., Armonk, N.Y., USA). Free text answers were analysed with thematic analysis
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10 219 supported by Microsoft Excel (version 16). The transcriptions from the interviews were checked for
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12 220 accuracy with the original audiotapes by LL. The software program Atlas.ti 9 was used to support
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14 221 thematic inductive content analysis.[16] LL and SK independently coded the transcripts to create a
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16 222 set of preliminary codes and compared the codes to reach consensus. To detect emerging themes,
17
18 223 we merged matching codes, and explored links between codes. An overview was constructed of
19
20 224 themes and subthemes for women's experiences with completing and discussing PROM and PREM.
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22 225 This overview was compared with the free text answer analysis of the open-ended questions from
23
24 226 the survey and combined into an integrated overview. The integrated overview was discussed with
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26 227 AD, ML and MB and subthemes were identified as facilitators and barriers. Reporting followed the
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28 228 Standards for Reporting Qualitative Research (SRQR).[17]
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RESULTS

Survey

460 Participants (35%) filled out the patient evaluation survey from a total of 1318 women who completed at least one PROM and PREM questionnaire. Descriptive statistics of the survey are shown in Supplementary Table 2 and Supplementary Figure 1a-d. Regarding the time spent on completing the questionnaires, 87% of participants indicated this as ‘good’. The comprehensiveness of the questions was indicated as ‘good’ by most participants (78%). The need to discuss the outcomes of the questionnaires with the care professional differed: of the participants 39% answered ‘not really’, and 35% ‘a little’, and 20% ‘yes’. Of the participants that wanted to discuss the outcomes, the majority preferred their obstetric care professional for this. The answers from the open-ended questions are to be discussed below.

Interviews

26 participants provided their telephone number for the interview, none of these participants had completed PROM and PREM during time point 3 (maternity week). 16 interviews were conducted. We interviewed two participants that completed PROM and PREM during time point 1 and 4, nine during time point 2, and three during time point 5. The average age of participants was 34 years [29-39 years] and the majority were higher educated (14 of 16), i.e., completed an education at a university or university of applied sciences. Four participants received perinatal care for the first time; they were pregnant for the first time or had given birth to their first child. Six participants had received perinatal care by a community midwife, five by a gynaecologist in the hospital, and five by both community midwives and gynaecologists.

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3 253 Themes
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5 254 The facilitators and barriers identified from the open-ended questions and interviews were allocated
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7 255 to four overarching themes (see Table 3): 1. Content of the PROM and PREM, 2. Application of the
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9 256 outcomes of PROM and PREM in perinatal care, 3. Discussing PREM, and 4. Data capture tool. These
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11 257 themes including facilitators and barriers are described below in detail, with illustrative quotes.
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15 258
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18 259 *1. Content of PROM and PREM questionnaires*
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21 260 Most participants found the language of the PROM and PREM clear and understood the questions.
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23 261 Participants felt that the PROM and PREM covered most important topics and were of a good length.
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25 262 Most participants emphasised the importance of PROM and PREM addressing taboo topics, such as
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27 263 incontinence, depression, and pain with intercourse. In the interviews, participants shared that
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29 264 completing PROM and PREM on these topics created awareness about their current health status
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31 265 and potential problems during pregnancy, childbirth and first months postpartum (see Quote 1).
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35 266
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38 267 *Quote 1 Awareness of taboo topics:*
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40 *[Complete PROM/PREM to prepare for their next visit] "I assume [advantages] for*
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42 *both parties: for yourself because you think about everything, also things you*
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44 *wouldn't consider at first. And I expect it [capturing PROM and PREM] would be*
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46 *helpful for a care professional as well, because he can ask further than just the*
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48 *topics a patient brings up at that moment."* (T4)
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54 269 However, the language of some questions was too difficult, especially for lower educated women,
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56 270 and several PROMs were not specific in timing or location of physical complaints. This led to
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58 271 different interpretations of the questions. Regarding the content of the PREM, participants
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experienced discrepancy between the timing of the questions and the care received. For example, at time point 2, options for pain management during childbirth had often not been discussed yet, thus participants answered negative to the PREM addressing this. Another issue mentioned by the interview participants in relation to PREM, was that they often received care from multiple care professionals. They stated that they had to average their experiences when completing the PREM. Several participants reported that they missed the answer option "I don't know (yet)" or "not applicable" in some questions, and the possibility to explain their answers. Also, participants missed the possibility in the questionnaires to point out important outcomes. This topic was expanded during the interviews; participants wanted to be able to indicate outcomes important to discuss during the following visit (see Quote 2).

> *Quote 2 No opportunity to explain answers or pointing out important topics [Opportunity for explanation during completion of PROM and PREM] "You should have a choice: whether you want to discuss it [your answers] or not, whether you want to be referred or not. […] You could put it [an open text field] at the end of the questionnaire: 'If you want consultation on this, if you have a top 3 or top 5 or something of the things that were just asked, what are the topics you would like to discuss with your midwife?'"* (T2)

Although most important topics were covered in the PROM and PREM, some participants stated that there was too little attention for prevalent physical problems. They missed questions concerning pelvic pain and haemorrhoids, especially at time point 2. Lastly, the timing of one specific topic was debated by several participants: the PROM breastfeeding. At time point 2, this topic was experienced as too early since most women did not know whether they intended to breastfeed and

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could not properly answer the full questionnaire about self-efficacy. At time point 4, participants indicated it felt too late to discuss problems with breastfeeding.

2. Application of the outcomes of PROM and PREM in perinatal care

Most participants indicated that filling out PROM and PREM helped them in preparing their next visit to their obstetric care professional. They stated that thinking about the topics addressed by the questionnaires made them know better what to expect from and to discuss in the following visit. Interview participants also pointed out that the use of PROM and PREM led to discussion of topics that previously were no part of the conversation with their care professional. Some participants indicated that they were unaware of some topics being pregnancy related, such as psychological problems. Furthermore, some participants from the interviews said that they felt their care was personalised based on their individual outcomes, for example extra attention, information, or a referral for specialised care (see Quote 3 and Quote 4).

> *Quote 3 Care is personalised based on individual outcomes*
>
> *"Then she [the care professional that discussed her outcomes with her] said she could refer me to a clinic for pelvic problems if I wanted to. […] I thought that was very good. They directly did a follow-up and offered me sort of an option like 'you could this'."* (T5)

> *Quote 4 Care is personalised based on individual outcomes*
>
> *[her PROM answers indicated depressive symptoms] "Well… personally I think I, and they too [care professionals], gave some extra attention to my mental health."* (T2)

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3 304 At time point 5, one participant from the interviews felt relieved that her care professional paid
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5 305 attention to her incontinence and psychological problems. She felt that otherwise she would not
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8 306 have had any care professional to discuss these issues with.
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10 307 Despite the availability of an information leaflet and their care professionals' explanation, many
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12 308 participants had misunderstood the aim of the project. They thought it was a research project and
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14 309 that their answers would be used for research purposes only. This indicates that the information
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16
17 310 about the purpose of PROM and PREM for individual care was insufficient, which posed a major
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19 311 barrier to complete questionnaires multiple times (see Quote 5).
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25 *Quote 5 Insufficient information on the aim personalised care based on PROM and*
26
27 *PREM*
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29 *"It was not clear to me why it [PROM and PREM] was asked. And I also can't*
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31
32 *remember that it [PROM and PREM questionnaires] included an introduction text*
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34 *or something like that… maybe that was included you know… but for me it was not*
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36 *clear what they wanted to do with that information [her answers]"* (T2)
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41 314 Furthermore, some participants stated it was uncertain when the outcomes of their questionnaire
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43 315 would be discussed with them; not all participants had their outcomes discussed during the first visit
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45 316 after completing the PROM and PREM. One participant said that her outcomes had never been
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47 317 discussed with her. Several participants mentioned that completing PROM and PREM gave them the
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50 318 feeling of 'impersonalised care', as if care professionals tried to avoid the conversation about these
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52 319 topics. Other interview participants felt unsure about how the outcomes of the PROM and PREM
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54 320 would impact the quality of care of their individual care pathway. For example, when filling out
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56 321 negative experiences regarding one specific care professional, they preferred to receive care from
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58 322 another care professional because of their negative experience. Some participants, from both the
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survey and the interviews, felt that discontinuity in care professionals posed a barrier to discuss the outcomes. They did not feel at ease discussing outcomes with a care professional they had never met before (see Quote 6). Interview participants also did not always know which care professional was responsible for their outcomes.

Quote 6 Discontinuity of care professional

“Nothing really popped up [from her answers to the questionnaires], but if that would have been the case than I think it is harder to discuss some topics with a person [care professional] that I have never met. Especially because some of these topics are sensitive and vulnerable.” (T1)

3. Discussing PREM

Participants stated that the PREM were an important facilitator for them to complete the PROM and PREM. They stressed that they found it very important that care professionals in general have insight in patients’ experiences with their provided care. Additionally, participants from the interviews thought that the insight in individual PREM may lead to improved quality of individual care. Especially participants that had completed PREM at time point 5 stated that the PREM were important to complete and to discuss, because it helped them to process the pregnancy and postpartum period (see Quote 7).

Quote 7 Discussing PREM at time point 5 important for reflection on pregnancy and childbirth

[After completing the T5 questionnaire] “The fact that she [care professional] called back, that she called back actually concerned, and just … just was talking with me and

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3 *explained things. That has really, also in my head, enormously helped to sort things out.*
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6 *[…] Yes, I really look back on that [childbirth and postpartum period] better now." (T5)*
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11 339 Additionally, analysis of aggregate PREM results may indicate improvement topics, according to the
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13 340 interview participants. At the same time, a barrier was identified in overlap; some participants
14
15 341 received PREM and other evaluation questionnaires from their community midwives postpartum,
16
17 342 and it was unclear for them whether these outcomes were also sent to their midwives. Ambiguous
18
19 343 opinions were found regarding discussing PREM individually. Some participants, who were satisfied
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21 344 with the care they received, indicated they would have preferred addressing negative experiences
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23 345 directly with their care professional, instead of via PREM (see Quote 8). In contrast to participants
24
25 346 that had had negative experiences: they explained it felt easier to indicate this via PREM instead of
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27 347 discussing it face to face with their care professional.
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31 348
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33
34 *Quote 8 Negative PREM preferably face to face*
35
36 *[addressing care experiences with care professional] "I believe it is fairer when*
37
38 *they [care professionals] hear it from me personally, but I can imagine that some*
39
40 *people don't feel comfortable with that and prefer to leave their feedback*
41
42 *anonymously and that eventually it will reach the care professional anyway." (T2)*
43
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45 349
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48 350 Additionally, some participants stated to feel dependent of their care professional during their care
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50 351 pathway, which posed a barrier to report negative experiences in the PREM.
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56 353 *4. Data capture tool*
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Participants indicated that they preferred to complete PROM and PREM digitally. Completing the PROM and PREM on mobile phones or tablets was preferred by most women. However, participants pointed out technical issues as a major barrier; PROM and PREM questions and answers that were not entirely visible on a mobile phone led to incomplete or incorrect outcomes according to some women (see Quote 9).

Quote 9 Technical problems and bugs

[Completing PROM and PREM] "On my smartphone I can't see all the questions. On the iPad, some answer options disappear, so I must check three times whether my answers are completed correctly. For example, satisfaction is measured on a scale from 1 to 4. But when I go to the next page and back, it appears to be a scale from 1 to 10." (T2)

Also, some participants received PROM and PREM belonging to a different time point or received the same PROM and PREM multiple times. Furthermore, several interviewed participants stated that it was unclear which organization sent the invitation to complete the questionnaires and which care professionals had access to their answers. This made them have doubts regarding privacy (see Quote 10).

Quote 10 Privacy issues

[Completing questions regarding incontinence, mental health, physical complaints]: "And yes, those are questions of a kind that you would only complete honestly if you are completely sure that you can trust that they will end up at the right person." (T2)

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368 **Table 3 Overarching themes and identified facilitators and barriers**

Themes	Facilitators	Barriers
1. Content of PROM and PREM questionnaires	Clear language PROM and PREM covering all important topics Good length of questionnaires Awareness of taboo topics	Language of some questions too difficult Some PROM questions not specific in time or location Discrepancy questions with care path and situation Absence of answer option "I don't know (yet)" or "not applicable" No opportunity to explain answers or pointing out important outcomes Too little attention to physical problems (time point 2) (Timing of) PROM breastfeeding
2. Application of the outcomes in individual care	Better preparation for next visit/appointment Discussing topics that were not discussed before Care is personalised based on individual outcomes Discussing outcomes at Time point 5	Insufficient information on the aim personalised care based on PROM and PREM Uncertainty when outcomes are discussed Feeling of impersonalised care Unsure of impact on individual quality of care Discontinuity of care professional
3. Discussing PREMs	PREM being included in the questionnaires Insight in individual PREM improves individual quality of care Discussing PREM at Time point 5 important for reflection on pregnancy and childbirth Analysis of aggregate PREM for care improvement Completing PREM safer option in case of dissatisfaction	Receiving multiple questionnaires regarding experiences Negative PREM preferably face to face Dependency of care professional
4. Data capture tool	Completing questionnaires digitally Availability on mobile phones or tablets	Technical problems and bugs Privacy issues

369 *PROM: patient-reported outcome measures, PREM: patient-reported experience measures*

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DISCUSSION

This mixed methods study provides insight into the first experiences of women with completing and discussing PROM and PREM at different time points during and after pregnancy as part of routine perinatal care. The evaluation survey results showed that the time spent on completing the PROM and PREM was acceptable, and their content was comprehensive. Most survey participants felt the need to discuss the outcomes. In the interviews, participants were mainly positive about discussing their individual PROM and PREM outcomes with their perinatal care professionals. Women's barriers and facilitators to complete and discuss PROM and PREM individually were identified in four overarching themes.

Strengths and limitations

A strength of this study was the prospective design, incorporated in an implementation project as part of regular care. Its results supported further implementation of the outcome set, as they were directly translated into adaptations in the clinical project, such as IT improvements and an option to further explain an answer. Accordingly, by providing PROMs and PREMs throughout pregnancy and the postpartum period, women can become aware of what high-quality care encompasses, and of complications or symptoms that can occur. This awareness can empower women and support them to adjust their care pathway to their individual preferences and values. Another strength was the large sample size of survey participants combined with semi-structured interviews to explore survey answers in-depth, which increased the generalizability of our results. Also, the participation threshold was lowered by conducting the survey anonymously and the interviews by telephone, limiting the risk of selection bias. However, the survey response rate of 35% does create a risk for non-response bias. Despite our efforts to minimise the risk of selection bias with purposive sampling, mostly higher educated women were included, and only Dutch speaking women could participate to

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3 394 the surveys. This was inevitable to some extent, as the sample was taken from an already selected
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5 395 population: women completing the PROM and PREM were Dutch speaking only and had a relatively
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7 396 good health literacy, as no support was provided with completing them. This limitation should be
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9 397 taken into account when interpreting our findings and stresses the importance of future efforts to
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11 398 engage all women when implementing PROM and PREM to prevent further health inequities.
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13 399 Nevertheless, this exploration of patient experiences with individual PROM and PREM was the first
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15 400 among women receiving perinatal care. A second limitation, resulting from the outline of the
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17 401 implementation project, was the unequal representation of time points for PROM and PREM
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19 402 collection in our interviews. Despite our strategy to ask care professionals to recruit participants for
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21 403 the interviews directly, i.e., without filling out the survey, we could not interview women who had
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23 404 completed PROM and PREM at time point 3 (maternity week).
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27 406 *Compared with literature*
28
29 407 In line with findings in other disciplines, discussing PROM and PREM with care professionals as part
30
31 408 of routine perinatal care was found to improve patient satisfaction and willingness to complete the
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33 409 questionnaires.[6, 18-20] Participants felt better prepared for their next visit and discussed topics
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35 410 that were not discussed before, which reconfirms results from large studies in chronic care
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37 411 settings.[20-22] At the same time, a significant part of our survey respondents did not feel the need
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39 412 to discuss their outcomes. Moreover, for some women completing the questionnaires even felt as
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41 413 impersonalized care. As the survey was offered directly after completing the PROM and PREM,
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43 414 survey participants had not yet discussed their outcomes with their care professional. These findings
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45 415 indicate that discussing outcomes are an essential part of using PROM and PREM in clinical
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47 416 practice.[6] Another explanation could be inadequate information provision, as several women
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49 417 stated that the purpose of the PROM and PREM was unclear to them. As women's perception of this
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51 418 purpose largely depends on their care professional, care professionals may improve this by actively
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using PROM and PREM as a part of routine care. For example, by encouraging women to consider which outcomes they want to discuss in the next visit.

Using individual outcomes to tailor care was an important facilitator to complete PROM and PREM over the course of pregnancy and postpartum. Nevertheless, two important barriers to use PROM and PREM individually were raised by our participants as well. First, discrepancy between the timelines of provided care and the PROM and PREM was pointed out. For example, a PREM questioning information provision on pain relief was sent to women, before care professionals addressed this topic according to standard care. Synchronising the time points of the PCB set with routine perinatal care pathways may solve this barrier. Based on compliance to the PROM and PREM and results of the PROM and PREM, concrete recommendations to adapt the PCB set's content and timeline have been suggested in a recent publication, and are in accordance with women's experiences found in this study. [13] Secondly, discontinuity in care professional was posed as a barrier, as discussing PROM and PREM with different care professionals lead to discomfort among participants. Discussing outcomes in the multidisciplinary setting of perinatal care may be easier if a principal care professional is allocated to every pregnant woman. A relationship of trust between care professional and patients may be a crucial facilitator for completing and discussing PROM and PREM, especially when discussing taboo topics such as incontinence.[23] This may provide opportunity to improve perinatal care outcomes, as several taboo topics have been shown highly prevalent and only 15% of the affected women bring them up during a postpartum check-up.[13, 24] Additionally, although hard to accomplish by perinatal care professionals, our participants stated that evaluating their outcomes at six months postpartum with a perinatal care professional was of added value to the regular postpartum check-up. This reconfirms previously reported patient views regarding time point five of the PCB set.[10, 11] Compared to the check-up at six weeks postpartum, at six months postpartum most women have further recovered in multiple domains and resumed

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their work and social life. Hence, at this moment, the sustainability and severity of physical or mental problems can be determined and referred for, improving long-term outcomes of perinatal care.

Confirming pre-implementation studies, our participants emphasized that PREM were an important facilitator to complete the questionnaires.[10, 11] However, evidence on individual PREM use as part of clinical practice is scarce. This study revealed different opinions amongst women: some preferred to address negative experiences face to face, some felt PREM made it easier to raise and others felt too dependent on their care professional to discuss a negative experience at all. Future research should evaluate the possible effects of offering each woman a choice whether her individual answers are visible to care professionals and discussed as part of her care.

As shown before from a professional perspective, a good functioning data capture tool for assessment and real-life visualisation of patient reported measures is essential for successful implementation.[6, 25, 26] In our patient evaluation, technological issues of the data capture tools were also a major barrier for completing the questionnaires. Although challenging in terms of inter-organisational collaboration and IT infrastructure, this project was one of the first to attempt system wide implementation of PROM and PREM as a standard part of individual perinatal care to guide individual care and personalised care pathways. In the transformation towards health care systems that provide patient-centred care over the full cycle of care, it is essential to use data capture tools that facilitate information exchange between all health care tiers involved with a disease or condition.

Future research and implications

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To achieve personalized care based on PROM and PREM, patient engagement is essential but requires efforts at several points. For successful implementation, women will benefit from a system-wide data capture tool, a principal care professional to discuss their outcomes with and a timeline of PROM and PREM collection that fits clinical care: matching their appointments and content of care pathways. Also, an open text field to explain answers and point out outcomes they want to discuss could empower women to take an active role in their care. Lastly, when completing PROM and PREM, women should be clearly informed about 1) the purpose of using their answers for personalized care and 2) the topics addressed by the questionnaires at each time point and their relation to pregnancy and childbirth. Since care professionals are crucial in providing this information and in discussing the outcomes, future research may focus on the experiences of care professionals with PROM and PREM use in perinatal care. To engage care professionals, it would be useful to evaluate training strategies, but also their perceived benefits when working with PROM and PREM. These could include direct improvement of individual care for their patients, as well as insight in the results of their efforts in terms of patient outcomes.[14] These practice implications resulting from women's reflections on individual level PROM and PREM use can advance structural integration of women's perspective in clinical care. Although clinical integration can enable group level use, further research is still needed to explore how PROM and PREM can contribute to embed patients' perspective in research and management decisions as well.

Conclusions

This study reported the first patient experiences with completing and discussing PROM and PREM as part of perinatal care. The ICHOM PCB set was found to be an acceptable and useful instrument for symptom detection and personalized perinatal care up until 6 months postpartum. Women's reflections on these PROM and PREM allow several practice implications to improve the questionnaire content, the role of care professionals and congruity with routine care pathways.

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Competing interests statement:

AF and ML were chair and member respectively of the ICHOM working group that developed the PCB standard outcome set. The other authors have nothing to declare.

Contributorship statement:

AF, HE, JH, and MB led the overall implementation project in practice and established its funding. Collaborators of the BUZZ team led local implementation and recruited study participants. This study was designed by LL, AD, and MLdR under supervision of AF, HE and MB. LL and SK performed the interviews for data collection and analysed the data under supervision of MB. LL, AD, and MB interpreted the data. LL and AD wrote the first version of the manuscript and made adaptations after feedback of the other authors under supervision of MB. MB, AF, JH, HE, MLdR, SK, and the BUZZ team reviewed the manuscript and approved the final version. MB is the guarantor for the final product.

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Details of Ethics Approval

The Medical Ethics Committee Erasmus Medical Centre (MEC-2020-0129) declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known as WMO) do not apply to this study. This study was exempt from formal medical ethical assessment. Local approval of the regional ethical boards was obtained in each participating OCN. All participants signed written informed consent.

Data availability statement

Data are available upon reasonable request.

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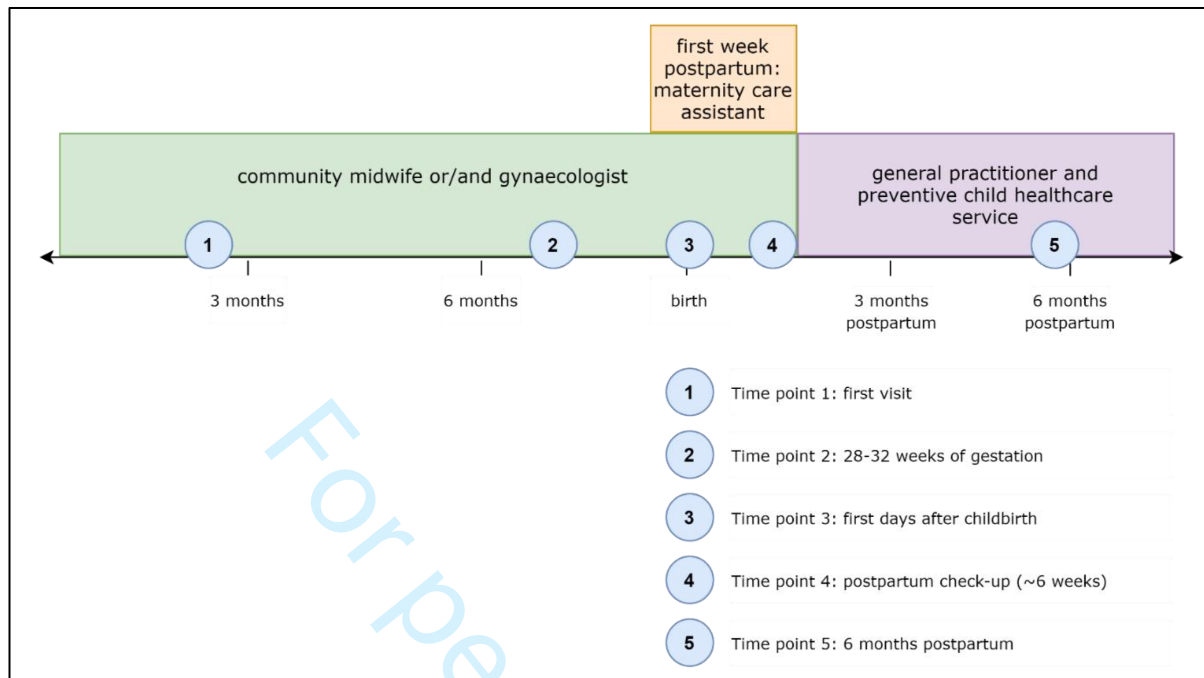

Figure 1 Time points for data collection (PROM and PREM) and involvement of different care professionals, according to current practice in the Netherlands.

The blue dots indicate the five time points for data collection during pregnancy and postpartum. Above the timeline, the involved care professionals are shown. In this project, the outcomes of the PROMs and PREMs were discussed with an obstetric care professional during all time points. [7]

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Outcome Domain	1 1st trimester First visit	2 3rd trimester 28-32 weeks of gestation	3 after birth (first days)	4 Postpartum check-up (~6 weeks postpartum)	5 6 months postpartum	
Social support						PROM
Health related quality of life						
Mental health						
Incontinence						
Pain with intercourse						
Breastfeeding intention/success						
Breastfeeding confidence						
Mother-child bonding						
Confidence with role as mother						
Satisfaction with results of care						PREM
Healthcare responsiveness						
Birth experience						
Pain relief (Dutch addition)						
Role partner (Dutch addition)						
Continuity of care (Dutch addition)						
Number of questions (min-max) *dependent on screening question(s)*	18 – 37	30 – 64	9 – 24	50 – 84	27 – 46	

Figure 2 Pregnancy and childbirth Set as applied in the Netherlands: domains and moments to measure (adapted from Depla et al.[13]).

The blue dots indicate the five time points for data collection during pregnancy and postpartum (see also Figure 1). The outcome domains are divided into patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Below, the number of questions of the total questionnaire (PROM and PREM) per time point is shown.

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Supplementary Table 1 Evaluation survey

Q1) I found the time needed to complete the PROM and PREM …	
	Too much
	A lot
	Good
	Short

Q2) Were you able to properly complete all PROM and PREM?	
	Yes
	No, I did not understand all questions
	No, the questions were too personal
	Other: …….

Q3) During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?		
	Yes	→ Go to question 3b
	A little	→ Go to question 3b
	Not really	→ Go to question 3c
	Not at all	→ Go to question 3c

Q3b) Who do you prefer to discuss your outcomes with?		
		Community midwife
		Clinical midwife
		Gynaecologist
		Maternity care assistant or nurse
		Preventive Child Healthcare services
		General practitioner
		No preference
Q3c) Can you please explain why you do not prefer to discuss your outcomes?	……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………	

Q4) Do you have any remarks regarding the PROM and PREM or suggestions for improvement?
……… ……… ………

Q5) Do you give permission for an evaluation by telephone in the future?	
	Yes, my telephone number is: ………………………………………………
	No

PROM: patient reported outcome measures. PREM: patient reported experience measures

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Supplementary Table 2 Survey participants per time point

Time point	n
T1	93
T2	337
T3	10
T4	9
T5	11
Total	**460**

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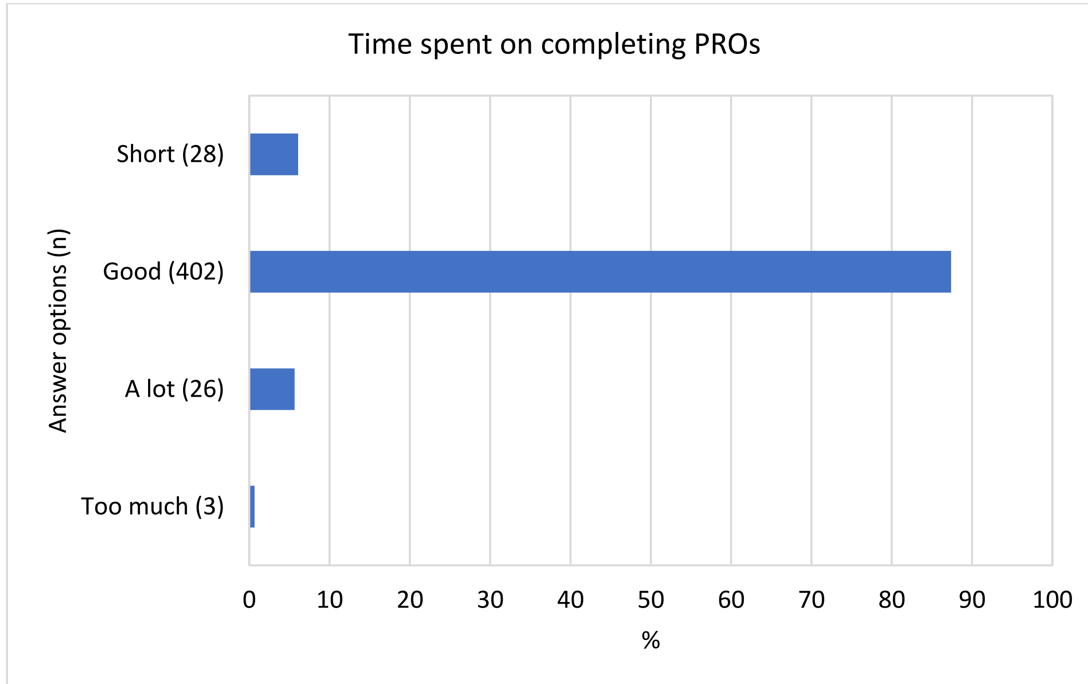
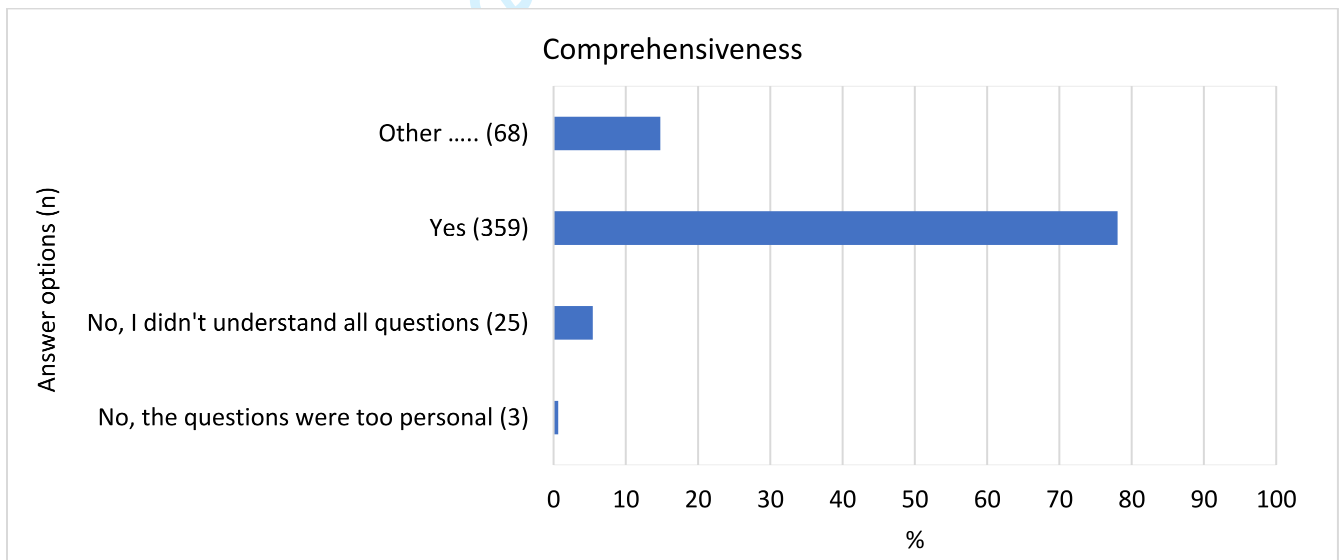


Supplementary Figure 1a *Q1 I found the time needed to complete the PROM and PREM…*



Supplementary Figure 1b *Q2 Were you able to properly complete all PROM and PREM?*

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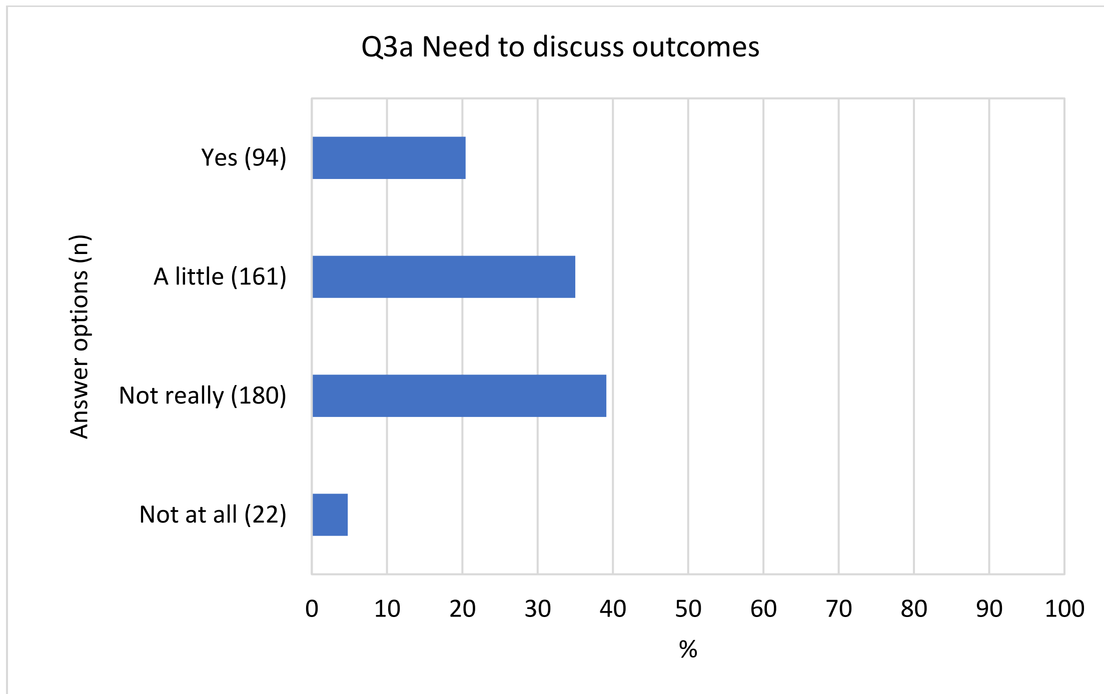
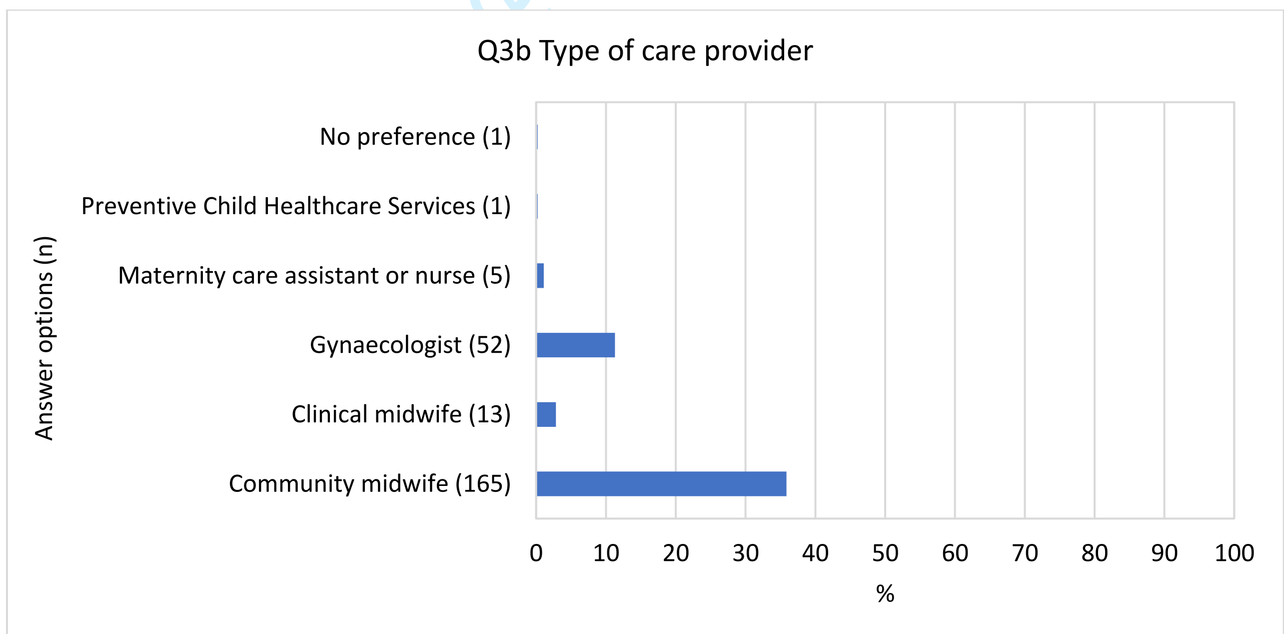


Supplementary Figure 1c *Q3 During the next visit, you will discuss the outcomes of the PROM and PREM with you care provider. Do you feel the need to discuss the outcomes?*



Supplementary Figure 1d *Q3b Who do you prefer to discuss your outcomes with?*

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/ 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2-3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-5/117-126
Purpose or research question - Purpose of the study and specific objectives or questions	5/124-126

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	6, 129-130
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	10/187-199
Context - Setting/site and salient contextual factors; rationale**	7/160-166 8/176-179
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	8/159-170 8/177-184
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	25/466-471
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6/134-135 8/172-184

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Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7/176-179, 183-184
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11/213-222
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	10/188-192
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	10/187-199
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6, 129-130 10/192-193, 197-198

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-12/224-228, Table 2
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quote 1-10

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	20/342-349, 21-23/371-424
Limitations - Trustworthiness and limitations of findings	20/ 351-368

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	24/454-456
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	24/452-453

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

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