VALUE BASED PERINATAL CARE

women at the centre of learning healthcare networks

ALIES DEPLA

Value based perinatal care

women at the centre of learning healthcare networks

Anne Louise Depla

Value Based Perinatal Care
Women at the centre of learning healthcare networks.
Thesis, Utrecht University, with a summary in Dutch

Author:	Anne Louise Depla
Cover design:	Leonie van der Molen
Lay-out:	Publiss | www.publiss.nl
Print:	Ridderprint | www.ridderprint.nl
ISBN:	978-94-6483-010-1

The author gratefully acknowledges financial support for the printing of this thesis by ZonMW.

Value based perinatal care

women at the centre of learning healthcare networks

Waardegedreven geboortezorg

vrouwen in het middelpunt van lerende zorgnetwerken

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de
Universiteit Utrecht
op gezag van de
rector magnificus, prof. dr. H.R.B.M. Kummeling,
ingevolge het besluit van het college voor promoties
in het openbaar te verdedigen op

donderdag 11 mei 2023 des ochtends te 10.15 uur

door

Anne Louise Depla

geboren op 6 juli 1992
te Utrecht

Promotoren:
Prof. dr. M.N. Bekker
Prof. dr. A. Franx

Copromotor:
Dr. M. Lamain – de Ruiter

Beoordelingscommissie:
Prof. dr. M.A.A.J. van den Bosch
Prof. dr. M.A. Grootenhuis
Prof. dr. A. de Jonge
Prof. dr. H.A.H. Kaasjager
Prof. dr. F.E. Scheepers

CONTENTS

1

CHAPTER 1

Introduction

FROM VOLUME TO VALUE

Current healthcare landscape demands a different way of care organization. With fragmented services, payment for volume and focus on disease, healthcare systems worldwide drive costs, disparities in outcomes and unwarranted practice variation – while collaboration and prevention are hindered.[1] In many countries, financial sustainability and workforce capacity of the healthcare system pose major public challenges, both exposed vulnerable by the COVID pandemic already today.[2,3] Anticipating on these illnesses, a transition from volume to value has been strived for since the 90s.[4–6]

VALUE BASED HEALTHCARE

The value-based healthcare (VBHC) theory, introduced in 2006 by Porter and Teisberg, offers a strategy to guide the transformation from volume to value.[7,8] At the base of their theory lays a straightforward quotation that aims to align all actors in healthcare systems towards the same goal. Value in care is defined as “outcomes in terms of patients’ health status divided by the costs spend to reach them”.[9] The strategy encompasses six components assumed mutually reinforcing towards a value-driven system: 1. organize into integrated practice units, 2. measure outcomes and costs per patient, 3. move to bundled payment for care cycles, 4. integrate care delivery across separate facilities, 5. expand excellent services across geography, 6. build an enabling information technology platform.

Over the past decade, VBHC has had an immense uptake in healthcare systems worldwide with certain fields leading the way such as oncology, chronic conditions and surgery in hospitals, mental care and primary care settings.[10–12] Fifteen years of VBHC has shown its use in practice to be challenging and heterogenous due to both the theory itself (ambiguity of the concept of value, its multifaced components) and different interpretations of its meaning (stakeholders’ frame of reference, level of understanding).[13,14] This heterogeneity combined with critique for a too narrow and economic approach of value applied to healthcare, has led to various interpretations and suggested adaptations to the theory.[13,15]

Overall, two elements of VBHC have been embraced widely to support making the right choices in today’s healthcare systems:[16,17] 1) create insight in results of care that matter to patients and 2) organize care services, evaluation and continuous improvement around patients instead of providers. Also in the Netherlands, these elements form the compass for healthcare policy the coming years, as presented in the framework ‘Appropriate Care’ recently launched by the Ministry of Health.[18] Despite challenging and heterogenous implementation in practice, value-based healthcare has thus created renewed emphasis on integrated care organization and enforced the development and uptake of tools that measure results of care directly at patients.

Patient reported outcome and experience measures

Results of care that matter to patients include not only clinical outcomes of disease and recovery, but also patients' wellbeing and experiences with care measured directly at patients. Patient reported outcome measures (PROM) are instruments, often structured questionnaires, allowing patients to report their health status in general or on specific domains (e.g., mental health, physical functioning).[19] Whereas patient reported experience measures (PREM) capture experiences with different aspects of the care process (e.g., communication, autonomy). In the shift from volume to value, PROM and PREM have been adopted to guide clinical decisions, drive quality improvement and inform research.[20–23] To standardize outcomes measurement in and around patients, international collaboration has been sought to define domains and timelines for measurement per condition or patient group, and develop validated questionnaires to measure health status and experiences with care.[24,25]

Insight in patient-reported results besides clinical outcomes, can contribute to value-based care at multiple levels:

i. Use individual outcomes in clinic: screening and monitoring of symptoms, broader informed shared decision-making.
ii. Evaluate group outcomes: data analysis to learn and improve with care professionals providing care for patients with a certain condition or disease.
iii. Benchmark group outcomes: detect unwarranted variation, find best practices, incentivize value at system-level (quality registry, outcomes transparency, payment models).

Individual PROM/PREM use (i.e., questionnaires are completed between care visits and reviewed with a provider) can improve patient engagement, shared decision-making, detection of unrecognized symptoms and even clinical health outcomes.[26,27] Still, clinical application of PROM/PREM is limited because of the complexity of integrating them in routine care.[28] Continuous quality improvement based on evaluation of group outcomes suits the movement towards learning healthcare systems: using clinically generated data in a continuous cycle of data, analysis and improvement in practice.[29,30] At this moment, PROM outcomes are underrepresented in improvement efforts in practice, while they could add patients' perspective on created value.[31] Recommended by the EOCD in 2017, system-level PROM/PREM have been adopted in national registries for quality evaluation,[32] whereas outcome transparency or even payment based on PROM/PREM has been limited due to ambiguous definition of value, distrust in insurers, and validity of measures.[33]

PERINATAL CARE

To improve value of perinatal care, the relevance for integration of care services is already recognized, and patient-reported outcomes measurement reflects a large unemployed potential.[34]

Perinatal care concerns a relatively young, healthy population and impacts lifelong health of mother and baby. As pregnancy and childbirth are worldwide drivers of morbidity and costs, and large practice variation exists, numerous quality indicators for perinatal care are available. Until now these indicators are mainly focused on structure and process measures, such as prenatal care utilization or caesarean section rate, and to a lesser extent on clinical outcomes like postpartum hemorrhage.[35,36] While important parameters of medical performance, these clinical indicators do not reflect women's wellbeing and postpartum recovery on physical and mental health domains. Ultimately, women's wellbeing in pregnancy and recovery after childbirth in these domains are crucial to be able to care for their new-born and regain their function again, whether it is at home or at work.[37]

In the Netherlands, with approximately 180.000 births per year, healthcare costs are amongst the highest of Western countries, while perinatal health outcomes have been amongst the lowest of Europe in 2004. Traditionally, Dutch perinatal care organization has been unique for the two-tier system with primary care midwives as gatekeepers to specialist care with their own professional autonomy and financial arrangements. After better coordination of services was agreed on as a direction towards better perinatal health outcomes a decade ago, a more integrated organization of care has been pursued like in many other countries.[38,39] In practice, integrated care delivery asks interprofessional as well as interorganizational collaboration to bridge different visions, autonomous facilities, and separate resources: which is now being realized in obstetric care networks (OCN) to various degrees.[40] Along this movement towards better collaboration, clinical outcomes have improved while further value could be gained via substitution of care (i.e., same care at lower costs) and better communication between providers and towards patients.[41,42] To evaluate and improve impact of perinatal care delivery further, insight in outcomes information is needed not only in terms of clinical indicators, but also from patients' perspective over the full care trajectory.

Currently, patient-reported measurements are not structurally integrated in perinatal care. Although their interest and use has grown, most PROM/PREM in this field are assessed anonymously for research purposes or for quality improvement per organization.[43] At patient level, individual PROM/PREM could help to screen, detect and intervene when a woman's wellbeing in pregnancy or recovery postpartum differs from expected. For example, mental health problems as depression and anxiety are often not recognized in time, and breastfeeding confidence could be screened for already during pregnancy.[44,45] As perinatal care is delivered across facilities and professions, group level outcomes would preferably evaluate the complete care trajectory from patients' perspective instead of fragmented per provider. Yet consensus is lacking on how to measure all aspects of health and recovery after childbirth.[46,47]

Patient-centred outcome set for pregnancy and childbirth

In 2016, the ICHOM (International Consortium for Health Outcomes Measurement) published a patient-centred outcome set for pregnancy and childbirth (PCB set).[48] The PCB set consists of PROM, PREM, and clinical outcome definitions in twelve domains: from mortality to breastfeeding and birth experience, selected by an international panel of professionals from all disciplines and patients advocates. For each patient-reported domain, a PROM/PREM questionnaire is proposed with a timeline for measurements at two moments in pregnancy and three postpartum, until six months postpartum. This way, the set's patient-reported data can enhance patient-centred improvement of perinatal care not only by capturing patients' health status more complete, but also across the whole trajectory of pregnancy, childbirth, and postpartum recovery despite of care transitions.[49]

To assess their potential for personalized care, the PROM/PREM questionnaires and their timing across pregnancy and postpartum period need to be evaluated, as well as how to embed them in the interdisciplinary perinatal care trajectory in a way they can contribute to clinical decision-making. At group level, patient-centred cyclic learning and improving with these outcomes requires effective collaboration across the borders of professions and organizations, data infrastructures, and network-broad learning strategies for quality improvement. Despite the development of implementation strategies and frameworks in other settings, sustainable PROM/PREM use at both levels has proven challenging and calls for a better understanding of real-life challenges and complexity of local practices.[28,50]

OUTLINE OF THIS THESIS

The VBHC strategy provides vision and theory to guide healthcare systems to their aim: integrated care around patients, continuously improving based on outcomes that matter to patients. Yet the how-question of this transformation process is largely unanswered in current practice, especially in an integrated care context. Perinatal care is a field already in a journey towards integrated care, where the potential of patient-reported data for value-based care has to be explored yet.[34,51]

This thesis' overarching aim is to investigate how PROM/PREM can be embedded in obstetric care networks and explore how they can advance the journey towards value-based perinatal care. Using the PCB set, we investigated:

- the implementation of PROM/PREM in perinatal care (**Part I**)
- their application in both individual care and quality improvement (**Part II**)

Approach

To address the complex implementation of PROM/PREM in the context of care networks, we used implementation science theories to clarify multilevel barriers, facilitators, and outcomes in different phases of the process, as well as an action research approach to guide both processes of implementation and inquiry. Action research employs a cyclic design of study activities (i.e., plan and execute actions, data generation, reflection, adjustment of subsequent actions) that involve both researchers and all stakeholders taking part in the practice change.[52] Its iterative, participatory design is particularly useful to implement a complex intervention that needs adjustment to local context; as detailed data are generated on both the implementation activities (what it involved) and change mechanisms (how it worked) in the local context, whilst contributing to the change and/or learning process in practice at the same time.

The work presented in this thesis has been conducted along two projects, initiated after translation of the PCB set's patient-reported domains and applicability to the Dutch context in 2018.[53] First, the Dutch PCB set development coincided the launch of the ministry program 'Outcome based healthcare 2018-2022', leading to the ***BUZZ project*** (Dutch abbreviation of 'discussing outcomes of pregnancy with the pregnant woman').[54] In this implementation pilot, seven OCN across the Netherlands incorporated the PCB set in clinic with the aim to guide individual care over the entire care trajectory and enable shared decision-making with outcomes information. Secondly, along the national PROM/PREM implementation efforts in the BUZZ project a call for continuous learning in practice with local networks led to the ***USER study*** (Dutch acronym for 'outcomes-driven perinatal care'). The USER study, an action research project carried out in three regionally connected OCN consecutively, used a participatory and iterative design to investigate and facilitate the PROM/PREM implementation process, and develop a learning strategy for quality improvement with group-level outcome data.

Part I - Implementation process of PROM and PREM in perinatal care

In **Part I** we investigated the implementation process of PROM/PREM in perinatal care. First, a pre-implementation analysis was performed in **Chapter 2** to get insight in facilitators and barriers amongst all stakeholders in OCN. In **Chapter 3**, a feasibility study was performed to provide insights in acceptability, usability and preferences of both women and obstetric care professionals using the questionnaires. As part of the USER study, **Chapter 4** aimed to evaluate implementation outcomes of PROM/PREM implementation for individual care and quality improvement as well as underlying implementation processes to explain those outcomes.

Part II - The use of PROM and PREM in individual care and for network-level quality improvement

Part II of this thesis explores how PROM/PREM can be used in perinatal care to 1) provide personalized care with individual results and 2) continuously learn from group data as care network. In **Chapter 5**, overall PROM/PREM results from the BUZZ project were analysed to report compliance with the questionnaires, reference scores per domain throughout pregnancy and postpartum and clinical usability of threshold values. **Chapter 6** evaluated patients' experiences and preferences with using their individual PROM/PREM results for personalized care. Furthermore, **Chapter 7** describes the development of a network-broad learning strategy to improve with outcomes data and evaluates collaboration factors needed for joint learning across professional and organizational borders.

Finally, **Chapter 8** explores the journey towards value-based perinatal care based on the work presented in this thesis and related literature.

REFERENCES

1. Institute of Medicine (US) Committee on Quality of Health Care in America Washington (DC). Crossing the Quality Chasm: A New Health System for the 21st Century. In: National Academies Press (US); 2001. doi:10.17226/10027
2. Wetenschappelijk Raad voor het Regeringsbeleid [Scientific Council for Government Policy]. *Kiezen Voor Houdbare Zorg. Mensen, Middelen En Maatschappelijk Draagvlak [Choosing Sustainable Care]*.; 2021. https://english.wrr.nl/publications/reports/2022/05/03/sustainable-healthcare-a-matter-of-choice.-people-resources-and-public-support.
3. Blumenthal D, Fowler EJ, Abrams M, Collins S r. Covid-19 - Implications for the Health Care System. *N Engl J Med*. 2011;362(5):567-571.
4. Alsever RN, Ritchey T, Lima NP. Developing a hospital report card to demonstrate value in healthcare. *J Heal Qual*. 1995;17(1):19–25.
5. Beveridge RN. Creating value-focused healthcare delivery systems: Part three--Core competencies. *J Oncol Manag*. 1997;6(6):16-23.
6. Ohldin A, Mims A. The search for value in health care: a review of the National Committee for quality assurance efforts. *J Natl Med Assoc*. 2002;94(5):344-350.
7. Porter ME, Teisberg EO. *Redefining Health Care: Creating Value-Based Competition on Results.* Harvard Business Press; 2006.
8. Kaplan RS, Porter ME. The Big Idea: How to Solve the Cost Crisis in Health Care. *Harv Bus Rev*. 2011.
9. Porter ME. What Is Value in Health Care? *N Engl J Med*. 2010;363(26):2477-2481. doi:10.1056/NEJMp1002530
10. Kokko P. Improving the value of healthcare systems using the Triple Aim framework: A systematic literature review. *Health Policy (New York)*. 2022;126(4):302-309. doi:10.1016/j.healthpol.2022.02.005
11. Shah A. Value-based healthcare: A global assessment. *Econ Intell Unit Find Methodol*. 2016:1-31. http://vbhcglobalassessment.eiu.com/wp-content/uploads/sites/27/2016/09/EIU_Medtronic_Findings-and-Methodology.pdf.
12. NHS England. NHS RightCare and the shift to value-based healthcare. 2017:1-7. https://www.england.nhs.uk/wp-content/uploads/2017/02/board-papers-090217-item-6-nhs-rightcare.pdf.
13. Steinmann G, Van De Bovenkamp H, De Bont A, Delnoij D. Redefining value: a discourse analysis on value-based health care. *BMC Health Serv Res*. 2020;20(1):1-13. doi:10.1186/s12913-020-05614-7
14. Fredriksson JJ, Ebbevi D, Savage C. Pseudo-understanding: An analysis of the dilution of value in healthcare. *BMJ Qual Saf*. 2015;24(7):451-457. doi:10.1136/bmjqs-2014-003803
15. Groenewoud AS, Westert GP, Kremer JAM. Value based competition in health care's ethical drawbacks and the need for a values-driven approach. *BMC Health Serv Res*. 2019;19(1):1-6. doi:10.1186/s12913-019-4081-6
16. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health and costs. The remaining barriers to integrated care are not technical; they are political. *Heal Aff*. 2008;27:759–69.
17. Coulter A. Measuring what matters to patients. *BMJ*. 2017;356:1-2.
18. Ministery for Popultation Health Wellbeing and Sport. *Kamerbrief Kader Passende Zorg*.; 2022:1-5.
19. US Department of Heath and Human Services FDA Center for Drug Evaluation and Research. Guidance for industry: Patient-reported outcome measures: Use in medical product development to support labeling claims: Draft guidance. *Health Qual Life Outcomes*. 2006;4:1-20. doi:10.1186/1477-7525-4-79

20. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of Patient-Reported Outcomes in Routine Medical Care. In: *American Society of Clinical Oncology Educational Book*. American Society of Clinical Oncology; 2018:122-134. doi:10.1200/edbk_200383
21. Bastemeijer CM, Boosman H, Ewijk H Van, Voogt L, Hazelzet JA. Patient experiences : a systematic review of quality improvement interventions in a hospital setting. *Patient Relat Outcome Meas*. 2019;10:157-169. doi:10.2147/PROM.S201737
22. Wicklund I. Assessment of patient-reported outcomes in clinical trials: the example of health-related quality of life. *Fundam Clin Pharmacol*. 2004;18(3). doi:https://doi.org/10.1111/j.1472-8206.2004.00234.x
23. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Qual Saf*. 2014;23(6):508-518.
24. The International Society for Quality of Life Research (ISOQOL). https://www.isoqol.org/who-we-are/. Published 1994.
25. International Consortium of Health Outcomes Measurement (ICHOM). Patient-centered outcome measures. https://www.ichom.org/patient-centered-outcome-measures/.
26. Basch E, Deal AM, Kris MG, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol*. 2016;34(6):557-565.
27. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? a realist synthesis. *J Patient-Reported Outcomes*. 2018;2(1). doi:10.1186/s41687-018-0061-6
28. Stover AM, Haverman L, van Oers HA, et al. Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in routine care settings. *Qual Life Res*. 2021;30(11):3015-3033. doi:10.1007/s11136-020-02564-9
29. Menear M, Blanchette MA, Demers-Payette O, Roy D. A framework for value-creating learning health systems. *Heal Res Policy Syst*. 2019;17(1):1-13. doi:10.1186/s12961-019-0477-3
30. Franklin P, Chenok K, Lavalee D, Love R. Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System. *EGEMS (Wash DC)*. 2017;5(1):17.
31. Kampstra NA, Zipfel N, Nat PB Van Der, Westert GP, Wees PJ Van Der, Groenewoud AS. Health outcomes measurement and organizational readiness support quality improvement : a systematic review. 2018;9:1-14.
32. Ernstsson O, Janssen MF, Heintz E. Collection and use of EQ-5D for follow-up, decision-making, and quality improvement in health care - the case of the Swedish National Quality Registries. *J Patient-Reported Outcomes*. 2020;4(1). doi:10.1186/s41687-020-00231-8
33. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. *Heal Serv Deliv Res*. 2017;5(2):1-280. doi:10.3310/hsdr05020
34. Sudhof L, Shah NT. In pursuit of value-based maternity care. *Obstet Gynecol*. 2019;133(3):541-551. doi:10.1097/AOG.0000000000003113
35. Cellissen E, Franx A, Roes KCB. Use of quality indicators by obstetric caregivers in the Netherlands: A descriptive study. *Eur J Obstet Gynecol Reprod Biol*. 2017;211:177-181.
36. Mann S, Pratt S, Gluck P, et al. Assessing Quality in Obstetrical Care : *Jt Comm J Qual Patient Saf*. 2006;32(9):497-505.

37. Sultan P, Carvalho B. Postpartum recovery: what does it take to get back to a baseline? *Curr Opin Obs Gynecol*. 2021;33(2):86-93.
38. Struijs JN, Hargreaves DS. Turning a crisis into a policy opportunity: lessons learned so far and next steps in the Dutch early years strategy. *Lancet Child Adolesc Heal*. 2019;3(2):66-68. doi:10.1016/S2352-4642(18)30384-5
39. D'haenens F, Rompaey B Van, Swinnen E, Dilles T, Beeckman K. The effects of continuity of care on the health of mother and child in the postnatal period: a systematic review. 2019;30(4):749-760. doi:10.1093/eurpub/ckz082
40. De Inspectie voor de Gezondheidszorg. *Thematisch Toezicht Geboortezorg: Afsluitend Onderzoek Naar de Invoering van de Normen van 'Een Goed Begin' De Stand van Zaken in de Verloskundige Samenwerkingsverbanden in Nederland*.; 2016.
41. T. van Ark (Dutch Minister of Health Welfare and Sport). *Kamerbrief Stand van Zaken Geboortezorg 2020. [Letter to Parliament about Status of Perinatal Care 2020]*.; 2021. https://www.rijksoverheid.nl/documenten/kamerstukken/2020/12/07/kamerbrief-over-stand-van-zaken-geboortezorg-2020-aanbevelingen-voor-de-toekomst.
42. Baas CI, Erwich JJHM, Wiegers TA, de Cock TP, Hutton EK. Women's Suggestions for Improving Midwifery Care in The Netherlands. *Birth*. 2015;42(4):369-378. doi:10.1111/birt.12185
43. Thompson JF, Roberts CL, Ellwood DA. Emotional and physical health outcomes after significant primary post-partum haemorrhage (PPH): A multicentre cohort study. *Aust New Zeal J Obstet Gynaecol*. 2011;51(4):365-371. doi:10.1111/j.1479-828X.2011.01317.x
44. Browne PD, Bossenbroek R, Kluft A, Van Tetering EMA, De Weerth C. Prenatal Anxiety and Depression: Treatment Uptake, Barriers, and Facilitators in Midwifery Care. *J Women's Heal*. 2021;30(8):1116-1126. doi:10.1089/jwh.2019.8198
45. Martin CR, Hollins Martin CJ, Burduli E, Barbosa-Leiker C, Donovan-Batson C, Fleming SE. The Birth Satisfaction Scale–Revised (BSS-R): should the subscale scores or the total score be used? *J Reprod Infant Psychol*. 2018;36(5):530-535. doi:10.1080/02646838.2018.1490498
46. Dickinson F, McCauley M, Smith H, Van Den Broek N. Patient reported outcome measures for use in pregnancy and childbirth: A systematic review. *BMC Pregnancy Childbirth*. 2019;19(1):1-8. doi:10.1186/s12884-019-2318-3
47. Sultan P, Sharawi N, Blake L, et al. Use of Patient-Reported Outcome Measures to Assess Outpatient Postpartum Recovery: A Systematic Review. *JAMA Netw open*. 2021;4(5):e2111600. doi:10.1001/jamanetworkopen.2021.11600
48. ICHOM. *Pregnancy & Childbirth: Data Collection Reference Guide*.; 2016. https://connect.ichom.org/patient-centered-outcome-measures/pregnancy-and-childbirth/.
49. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
50. Greenhalgh J. Understanding the complexities of collecting and using PRO data in a primary care context. *BMJ Qual Saf*. 2021:bmjqs-2021-013315. doi:10.1136/bmjqs-2021-013315
51. Chen A, Väyrynen K, Schmidt A, et al. The impact of implementing patient-reported measures in routine maternity care: a systematic review. *Acta Obstet Gynecol Scand*. 2022;(May):1-13. doi:10.1111/aogs.14446
52. Lieshout F van, Jacobs G, Cardiff S. *Actieonderzoek: Principes Voor Verandering in Zorg En Welzijn [Action Research: Principles for Change in Health and Welfare].* Koninklijke Van Gorcum BV; 2017.

53. Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. *Patient Educ Couns*. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022

54. Dutch Ministry of Healthcare Welfare and Sport. *Ontwikkeling Uitkomstgerichte Zorg 2018-2022 [Outcome Based Healthcare 2018-2022].*; 2018. https://www.government.nl/topics/quality-of-healthcare/information-on-the-quality-of-care.

PART I

Implementation of PROM and PREM in perinatal care

2

CHAPTER 2

Implementation of a standard outcome set in perinatal care: a qualitative analysis of barriers and facilitators from all stakeholder perspectives

Anne L. Depla, Neeltje M. Crombag,
Arie Franx, Mireille N. Bekker

BMC Health Serv Res. 2021 Feb 2;21(1):113

ABSTRACT

Background To improve their quality, healthcare systems are increasingly focused on value delivered to patients. For perinatal care, the International Consortium for Health Outcomes Measurement (ICHOM) proposed a patient-centred outcome set with both clinical and patient-reported measures for pregnancy and childbirth (PCB set). This study aimed to identify factors that affect the implementation of the PCB set at the pre-implementation stage, using the consolidated framework for implementation research (CFIR).

Methods In this qualitative study, we conducted semi-structured interviews amongst a purposive sample of key stakeholders within an obstetric care network (OCN): 1) patients, 2) perinatal care professionals involved in the full cycle of perinatal care, and 3) policy makers, including hospital managers, administrative staff and health care insurers. While the CFIR guided data capture and structuring, thematic analysis revealed overarching themes that best reflected the barriers and facilitators from different stakeholder perspectives. Within these overarching themes, the CFIR constructs were maintained.

Results Interviews were conducted with 6 patients, 16 professionals and 5 policy makers. Thematic analysis supported by the CFIR framework identified four main themes: the instrument and its implementation process, use in individual patient care, use in quality improvement, and the context of the OCN. Important barriers included professional workload, data reliability, and interprofessional and interorganizational collaboration. Potential facilitators were the PCB set's direct value in individual care, interprofessional feedback and education, and aligning with existing systems. Prominent variations between stakeholder groups included the expected patient burden, the level of use, transparency of outcomes and the degree of integrated care.

Conclusions This study clarified critical factors that affect successful implementation of the PCB set in perinatal care. Practice recommendations, suggested at multiple levels, can enable structural patient-centred care improvement and may unite stakeholders towards integrated birth care.

BACKGROUND

Worldwide, healthcare systems are shifting towards more value driven care.[1] After the era of evidence based medicine, healthcare stakeholders are aligning their goals in “learning health systems” that continuously measure and improve the value of care from the patients’ perspective.[2–4] In this journey, routine outcome collection from patients has become essential and empowers patients to take an active role in their care, e.g. via symptom detection and broader informed care decisions.[3,5,6] Therefore, patient-reported outcome measures (PROM) and experiences measures (PREM) – tools that assess patients’ perceived health status and their experience with received care – are progressively being used for clinical practice, research and quality improvement.[7–9]

For perinatal care, numerous quality indicators are available, as pregnancy and childbirth are worldwide drivers of morbidity and costs, and large practice variation exists. Until now these indicators mainly focused on structure and process measures, such as prenatal care utilization or caesarean section rate, and to a lesser extent on clinical outcomes like postpartum haemorrhage. While important parameters of medical performance, these indicators do not directly reflect all outcomes that matter to pregnant women – for example urine incontinence or mother-child bonding. They also often lack an improvement incentive for clinicians.[10]

The International Consortium for Health Outcomes measurement (ICHOM) developed, through international collaborations among patients, clinicians and researchers, a more complete outcome set for Pregnancy and Childbirth (PCB).[11] This set consists of standardized clinical metrics, PROMs and PREMs, addressing outcomes that matter to pregnant women and their child.[12] With five measurement moments throughout pregnancy until 6 months postpartum, it considers quality of care from the patients’ perspective, regardless of barriers between different care professionals and organizations involved in perinatal care. Potential benefits of such standard outcome sets can emerge at several levels. In individual patient care, structural PROM collection has shown to significantly improve patient-provider communication, detection of unrecognized symptoms and even clinical health outcomes.[13,14] At organization level, data on both clinical and patient-reported outcomes have been shown to support informed decision-making and empower providers to improve care.[4] Ultimately, international standardization of outcome measures enables benchmarking, reduces practice variation and creates learning health systems on the impacts that matter to patients.

Although the potential benefits of the PCB outcome set are recognized by key stakeholders in perinatal care, knowledge and instruments are lacking for its implementation in clinical practice, especially the collection and use of its PROMs and PREMs.[15] Some patient-reported measures of the PCB outcome set were recently collected in perinatal studies, but were used anonymously for quality improvement or research goals only.[16,17] Other care settings in which common barriers and facilitators to implement PROMs have been identified have been limited to chronic or planned care – such as cancer care and surgery.[18,19] These settings differ considerably from perinatal care, which affects a relatively healthy population at start of care, and within which multiple care organizations combine planned and acute care in a short time period. In most studies the challenges and success factors for PROM implementation have mainly been studied from the clinician perspective. Yet, patients and policy makers have been shown relevant stakeholders for the successful implementation of PROMs as well, in particular in network settings.[18,20,21]

This qualitative study aims to identify impeding and enabling factors affecting the implementation of the PCB outcome set in perinatal care. In this pre-implementation analysis, we explored variations in stakeholder perspectives by interviewing care professionals, patients and policy makers. This will generate knowledge of the contributing factors and different incentives from each stakeholder perspective, facilitating the development of more effective implementation strategies.

METHODS

Study design

For this pre-implementation analysis, a qualitative study was performed to explore barriers and enablers to implement the PCB outcome set in perinatal care, and to elaborate perspectives of key stakeholders. Semi-structured interviews were conducted to enable the interviewees to share their own perspectives and attitudes towards the topics of interest.[22] Data collection, analysis and interpretation were guided by the Consolidated Framework for Implementation Research (CFIR), a framework of standardized constructs developed by meta-analysis of theory-based models from several disciplines and proven to support the implementation process.[20] It comprises 39 constructs, organized across 5 major domains (Table 1). The framework is widely used in implementation research and applies to each phase of implementation.[23] Prior to implementation, it supports identification of multi-level factors that can affect future implementation.[24]

Table 1. CFIR domains and constructs, with aligning study entities

Domain (aligning study entity)	**Construct**
Intervention Characteristics (of the PCB outcome set)	- Intervention Source - Evidence Strength and Quality - Relative Advantage - Adaptability - Trialability - Complexity - Design Quality - Cost
Inner Setting (OCN practices)	- Structural Characteristics - Networks and Communications - Culture - Implementation Climate - Readiness for Implementation
Outer Setting (Dutch perinatal care)	- Patient Needs and Resources - Cosmopolitanism - Peer Pressure - External Policy and Incentives
Characteristics of Individuals (OCN stakeholders)	- Knowledge and Beliefs about the Intervention - Self-efficacy - Individual Stage of Change - Individual Identification with Organization - Other Personal Attributes
Process (aspects of implementing, delivering and evaluating the PCB outcome set)	- Planning - Engaging - Executing - Reflecting and Evaluating

PCB pregnancy and childbirth; *OCN* obstetric care network.

Intervention background: the ICHOM Pregnancy & Childbirth standard set

The PCB outcome set was composed by ICHOM, which aims to develop standard outcome sets for each particular disease or condition from patients' perspective. The PCB outcome set, developed through a Delphi procedure with international experts and patient involvement, consists of one third clinical outcomes and two thirds PROMs and PREMs.[12] The clinical metrics are collected 6 weeks postpartum; the patient-reported items are assessed with questionnaires at five moments proposed by ICHOM (2 during pregnancy and 3 postpartum; from 28 weeks of gestation until 6 weeks postpartum).[11] The information could be used at several levels: at individual patient level as part of usual care, aggregated data to measure and improve care performance and externally for benchmarking, quality reporting or value-based payment.

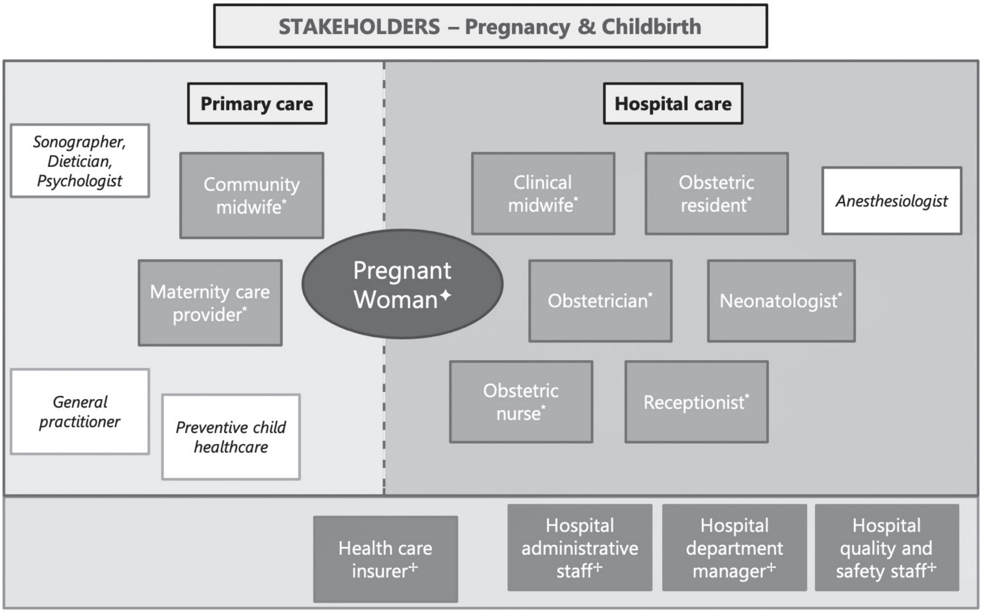
Setting

This study was carried out from May to August 2017 in the obstetric care network (OCN) around the Wilhelmina Children's Hospital in Utrecht, the Netherlands. Dutch perinatal care is organized in a distinct two-tier system, providing primary care through midwives for low-risk pregnancies and secondary/tertiary care through obstetricians in the hospital for high-risk pregnancies. Primary care midwives act as gatekeeper to specialist care and have their own professional autonomy, responsibilities and financial arrangements. They collaborate with their secondary/tertiary referring partners in an Obstetric Care Network (OCN). Over the last decade, a more integrated obstetric care system (a collaboration of community care midwives and hospital employed obstetric professionals in one care pathway) has been advised by the Ministry of Health and is partly being realized within OCNs.[25,26] The OCN in this study consists of a tertiary hospital, 6 community midwifery practices and multiple maternity care assistance organizations. In the setting of an OCN, all aspects relevant for implementation could be explored, as the instruments' purpose is to address perinatal care performance over the whole pregnancy and postpartum period.

Participants

All stakeholders involved with perinatal care in this OCN were systematically identified, according to a framework for stakeholder mapping in health research.[27] After defining stakeholder categories for perinatal care, both directly and indirectly involved stakeholders were mapped and feedback of expert informants was collected. During the interviews, this map was validated via snowballing sampling – i.e., new stakeholders arising from earlier interviews, until no relevant new stakeholders came up. (Figure 1) Key stakeholders comprised three main groups: patients, care professionals and policy makers. A purposive sample of patients was selected, including both pregnant and postpartum women, both nulliparous and multiparous, whether in primary or hospital care. Patients had to be 18 years old and able to speak Dutch. Professionals and policy makers were included based on their role in the OCN. Participants were included until saturation was reached. We anticipated six patients were needed and aimed to include two of each type of care professional or policy maker. Prior to each interview, participants received standardized background information about the study topic and verbal informed consent was obtained. None of the stakeholders received compensation for participation. Ethical approval for this study was granted by the University of Utrecht Ethics Committee.

Figure 1. Stakeholder map



‘Filled’ boxes = key stakeholders (interviewed), ‘white’ boxes = stakeholders with minor involvement (not interviewed). Stakeholder groups: ✦Group 1: patients; *Group 2: care professionals; +Group 3: policy makers.

Data collection

A semi-structured topic list was composed that covered current quality improvement initiatives, levels of using the PCB outcome set, and determinants of change (see Additional file 1). To guide complete data collection, this list was supported by an overview of the CFIR constructs and a selection of CFIR guide questions. For each CFIR domain, the aligning entity in this study is provided in Table 1. The interviews were conducted face-to-face at a location convenient to the interviewee and audio recorded after permission. All interviews were conducted by the first author, a researcher trained in interviewing and qualitative analysis. Every interview was transcribed verbatim using Amberscript software. After checking for accuracy by the researchers, the transcriptions were coded and stripped of personal identifying data.

Analysis

Data analysis started directly after the first interview, using a combined deductive and inductive approach along the Qualitative Analysis Guide of Leuven (QUAGOL).[28] This method, characterized by its iterative process and team approach, consists of two parts with five steps each: part one aims to create a conceptual understanding of the research data as a whole, part two is the actual coding process. In this study, the researchers read the transcripts and discussed first impressions, thoughts and initial codes. Then, the researchers identified themes in the transcripts, organized them along the CFIR framework and analysed differences between stakeholder groups. During this process, additional codes emerged to develop a thematic framework that better reflected the language and reflections of participants. Although the CFIR framework was identified as the a priori framework, our thematic analysis revealed four overarching themes best reflecting the topics our participants described. Within those overarching themes, we retained the CFIR constructs to maintain their in-depth value. The analysis process was executed with two authors (AD and NC) and supervised by a third author (MB). Constant movement between the various stages of the process was required as new data and themes emerged, resulting in interaction between each part of the analysis. The process was continued until saturation was reached. *NVIVO software (V.11.2.2)* facilitated data management, organization and analysis. Also, *Microsoft Excel (2010)* was used to organize constructs and compare stakeholder groups. Reporting followed the consolidated criteria for reporting qualitative research (COREQ).[29]

RESULTS

At 27 interviews, saturation was reached: 6 with patients, 16 with care professionals and 5 with policy makers involved in the OCN (Table 2). In this paper, interviewees are referred to as PT (patient), HCP or CCP (hospital-employed or community care professional) and PM (policy maker). Thematic analysis revealed four main themes: A) instrument and process factors, B) use in clinical practice, C) use aggregate outcomes for quality improvement, and D) context of the OCN. Although initially organizing along the CFIR framework, thematic analysis indicated significant overlap between the domains. As the complexity of the intervention and implementation context made it difficult to separate key findings by domain, the overarching themes found appeared most appropriate to describe our findings. The CFIR constructs identified within these themes are listed in Table 3. Each theme showed a variation in stakeholder perspectives; Table 4 provides an overview of the factors with prominent similarities *or* differences between stakeholder groups. A difference in perspective either meant a stakeholder group did not mention a barrier or facilitator, or they had another view (or focus).

Table 2. Number and function of individuals interviewed

Interview Subjects		Description
Community care professionals (CCP)		
community midwife	2	provides perinatal care for low-risk pregnancy, delivery and postpartum care at home (also after discharge from the hospital)
maternity care provider	2	nurse that assists community midwife with at home deliveries and provides maternity care at home (also after discharge the form hospital)
Hospital-employed care professionals (HCP)		
clinical midwife	2	all provide perinatal care to medium/high risk pregnancies and deliveries in the hospital
obstetrician	2	
obstetric resident	2	
obstetric nurse	2	
neonatologist	2	
receptionist	2	
Policy makers (PM)		
hospital department manager	1	head of obstetric department
manager quality and safety	1	quality manager of the hospital
administrative staff	2	financial and clinical registration
healthcare insurer	1	largest regional insurer
Patients (PT)	6	currently in perinatal care, equally representing: - pregnant and postpartum (within 6 weeks) - primiparous and multiparous - receiving hospital or community care, or both

Theme A: instrument and process factors

All stakeholders appreciated, the PCB set combines clinical and patient-reported measures, covering most relevant aspects across the course of pregnancy. The set's international, interdisciplinary development was considered to support uptake amongst care providers. Whilst policy makers were most keen about (inter)national uniformity, professionals noticed this can also hinder adaptation to a local context. To some, the instrument was still abstract and thought of as research, resulting in a passive attitude towards implementation. Professionals with basic understanding believed it can improve care and expressed willingness to start, emphasizing clear goals and instructions. Others demanded proof of efficacy first, for instance a pilot with quick feedback.

> Thus, I do very much see the added value of this outcome set, not only to steer medical outcomes, but also experiences and… identify complaints women have by using it. HCP2

> …I'm not going to try a new system... before it has been validated in a clinic. HCP3

Table 3. CFIR domains and constructs per theme; barriers and facilitators

Theme	**Subthemes** (facilitators and barriers)	**CFIR elements identified** (*domains*; constructs)
Instrument and process factors	Enabling: complete set; international consensus; instructions; effect proof; feedback professionals; patient engagement; combine registrations; interdisciplinary; leadership; IT-system Impeding: international consensus; effectivity; abstract; patient burden; resistance to change; professionals' workload; lack of prioritizing; privacy; IT-system; costs	*Intervention characteristics:* intervention source, evidence strength, relative advantage, trialability, complexity, costs *Outer setting:* patient needs and resources, peer pressure *Inner setting:* implementation climate, readiness for implementation *Individual characteristics:* knowledge and beliefs, individual stage of change *Process:* planning, engaging
Use in individual patient care	Enabling: patients' benefits; time gain individual reaction; more unity Impeding: PREM misinterpretation; professionals' responsibility	*Intervention characteristics:* relative advantage, complexity *Outer setting:* patient needs and resources *Inner setting:* implementation climate, readiness for implementation *Individual characteristics:* self-efficacy
Use in quality improvement	Enabling: measures reflect goals; less fragmentation; motivation; improve quality; learn from benchmark; external policy Impeding: data reliability; current QI; perceived influence; measures too general; transparency; scepticism PREMs	*Intervention characteristics:* relative advantage, complexity, cost *Outer setting:* patient needs and resources, external policy *Inner setting:* culture, implementation climate *Individual characteristics:* knowledge and beliefs about the intervention
Context of OCN	Enabling: local collaboration; trust; communication structures; more unity; integrated care Impeding: collaboration structure; financial incentives; interdisciplinary relations	*Intervention characteristics:* relative advantage, complexity, cost *Inner setting:* structural characteristic, networks and communication, culture, implementation climate *Individual characteristics:* individual identification with organization

OCN obstetric care network; *QI* quality improvement; *T5* measurement moment at six months postpartum.

For patients, both professionals and policy makers feared the questionnaire burden would be too high, especially for those with low socio-economic status. However, patients stated their willingness to complete five questionnaires of 5-15 minutes each. One patient anticipated circumstances around pregnancy, like postnatal depression, which might impede filling out the questionnaires. Similar strategies to engage patients were mentioned by professionals and patients: clear counselling about the purposes (both individual care and quality improvement), a personal approach, easy (digital) completion process and incorporation into usual care.

> …one must be careful with the burden in time and intensity of questions you ask patients. CCP2
>
> …I don’t think patients would complete four or five questionnaires. HCP3
>
> I don’t think it’s all that many questions, I mean... you don’t have to think about it for long. So that does not seem burdensome to me and a great good […] I would just make it obligatory. Yes, simply: fill in this list before your appointment, and if things are highlighted which we can discuss, we will do that. PT3
>
> But if I feel like how I felt after my first child, I don’t know whether I would be happy to do that (fill out a questionnaire). If I feel good, I am fine, I feel like it, I will do it. But back then, I really felt bad. PT1

At the same time, all participants raised concerns whether professionals have sufficient time to interpret and discuss individual answers, as well as to analyse data for quality improvement. Professionals’ workload and registration burden were underlined as already high, with a perceived lack of feedback and priorities in current improvement initiatives. Merging with existing systems and clinical processes was considered essential. All stakeholders identified an IT system with real-time data and guaranteed privacy as preconditions for implementation, but complex and costly to arrange in an OCN.

> …because of the current workload you really see that... people don’t feel like it, people are tired… little leeway is left… people just keep their heads above water... HCP8
>
> Well, as I said earlier, there are so many improvement projects going on: if this will be added again… those initiatives are all fantastic, but it seems a proliferation of… everything is called out like ‘this should be better, that should better, that can be better’ then I think ‘well, someone has to set priorities’… HCP2

Table 4. Stakeholder perspectives

	Patients	**Care professionals**	**Policy makers**
Barriers	= professionals' workload	= professionals' workload, lack of prioritizing	= professionals' workload, lack of prioritizing
	▲ privacy: assumed	= privacy: issue	= privacy: issue
	▲ patient burden: low, yet pregnancy circumstances	= patient burden: to many questions and time points	= patient burden: to many questions and time points
		= collaboration inter-disciplinary: financial incentives, different professional views, no joint responsibility	= collaboration inter-disciplinary: financial incentives, goals of hospital vs. OCN, no joint responsibility
	= IT system	= IT system	= IT system
		= data quality, costs	= data quality, costs
		▲ effectivity: has to be proven first	
Facilitators	= complete set of outcomes, time points	= complete set of outcomes, time points	= complete set of outcomes, time points
	= first use for individual care (raise issues easier, recognition) or QI (better care for other women)	= first use for individual care (better patient care) or QI (improve interdisciplinary collaboration)	▲ first use for QI, also for external quality reporting
	= patient engaging factors	= patient engaging factors	
	▲ transparency not needed; quality assumed	= transparency of outcomes to patients	= transparency of outcomes to patients
	= discuss PROM/PREM answers in clinic, clear to patients what is done with answers	= discuss PROM/PREM answers in clinic, feedback of aggregate outcomes to professionals	= discuss PROM/PREM answers in clinic, feedback of aggregate outcomes to professionals
	▲ more unity in provided care	▲ step towards more integrated care, more unity in provided care	▲ integrated care organization and imbursement

= = similar perspective; ▲ = different perspective; *OCN* obstetric care network; *QI* quality improvement.

Theme B: use in individual patient care

All stakeholders recognized opportunities to detect symptoms earlier, to recognize individual issues and to adapt care accordingly. For patients and professionals, the standard questionnaires could make certain subjects – such as depression or incontinence, easier to raise. Provided before a visit, patient's answers might enable professionals to gain time by focusing on the problems raised. Patients could become more aware of their health status and better prepared to pregnancy-related issues. Even more, patients valued comparing their health status to that of other women, feeling more recognized. With aggregated data on clinical and patient-reported measures, participants thought patients could make better-informed decisions. These benefits could empower women in their care process and increase their autonomy.

> Some things you just don't discuss so quickly… huh, that it's still a bit of a taboo, to discuss or say or ask… depression in particular. PT5
>
> I had that (depression) after my first child and... I was not heard, even though I indicated it. So, the moment you report it here (questionnaire)… it's easier for providers to recognize. PT1
>
> …that I don't have to deepen out that part of the anamnesis further… so it becomes easier to get to the core, indeed, of what it is about in those patients. HCP6

Regarding their PREM answers, patients worried about misinterpretation and wanted an opportunity to explain them. That way, they felt potential issues can be raised and dealt with earlier. Moreover, few patients proposed that all moments should include PREMs.

> ...I would let that (PREMs) return particularly at the first and third moment as well. Because I noticed with the maternity care assistant at home: who actually asked every day like 'are you satisfied, are there things I can do differently?'…that also gave space… if you are dissatisfied or if there are questions, to then still discuss that. PT3
>
> …in perinatal care, and in other patient care as well: although you may not have done something optimally, if you find out with such a questionnaire and can reflect upon it and let a patient tell her story, she can still leave the hospital with a good feeling. So, I think you can use that, thus, on an individual level. HCP5

Providing individual patient's answers to professionals and ensuring (re)action upon them was considered mandatory by all stakeholders. Yet, they also raised an obstacle in professional responsibility: it might be unclear which professional should interpret and act on answers, especially six months postpartum, when perinatal care has ended. However, all stakeholders expected increased collaboration and unity, as the questionnaires become a mutual responsibility of professionals across the network.

> …because that does seem important to me, that you just also talk about it with a care professional, that it doesn't linger. PT3
>
> …the attunement between those... the midwifes have their image, and the gynaecologists have their image, and… one does not really prepare you for the other… expectation management can be improved... I think something like this (PCB set) can help with that. PT2

Theme C: use aggregate outcomes for quality improvement

Compared to current indicators, professionals saw their efforts better reflected in the PCB set's outcomes, increasing their motivation for registration and improvement initiatives. Those initiatives were expected to become less fragmented when approached from the patients' perspective across the OCN, eventually leading to the most appropriate care. The purpose of quality improvement also increased patients' motivation to complete questionnaires. For this use, obtaining reliable data was considered crucial, yet challenging due to selection bias and missing data, and requiring investments in IT and data management staff. To prevent increased registration and patient burden, several interviewees advocated dropping existing quality registrations. At the same time, some professionals would refuse to replace well-preforming intradisciplinary registrations, and policy makers noticed the external accountability of several performance measures.

> …objective and subjective patient experience is a very important factor that we, I think, have taken aboard too little to date. HCP2
>
> …actually, in particular also that group with a low SES (socio-economic status) or people with language problems, I would want to take along, […] and those are still the weaker groups that are very difficult to reach. CCP1

Nonetheless, professionals felt they have only a slight influence on (a part of) the PCB set's domains and feared its outcomes are too general to lead care improvements, as they are assessed across provider organizations and lack process measures. However, most stakeholders believed insight into these outcomes would create awareness and identify areas for improvement. As an improvement strategy, professionals proposed joint education on specific domains, also creating more incentive for data collection. Additionally, they thought training in discussing taboo subjects would support them.

> …what I'm a bit worried about… [is] that the outcomes are too general, too generic, to make them applicable for specific patient groups. HCP3

For further improvement, every stakeholder group valued that the instrument enables benchmarking to learn from other regions. Still, some professionals feared unfair data and increased competition between providers. Other professionals and policy makers advocated public transparency to create incentive for improvement. However, patients stated they wouldn't choose their care provider based on these outcomes and, furthermore, worried their data would be shared with healthcare insurers. If used for external performance reporting, some in each stakeholder group mentioned scepticism about PREMs becoming equally as important as clinical outcomes.

> …I think one should be careful with a kind of patient-snitch, so to speak, say marketing in healthcare… I'm not an advocate of that… and this (PCB set) can also facilitate that a bit. CCP2

> …well, when you ask for advice it's just: ask around, see which ones are near you, check the website. I think if you do a full comparative study of all possibilities and outcomes... you will go completely crazy. PT3

Theme D: context of the Obstetric Collaborative Network

All stakeholder groups emphasized, because of the joint responsibility for pregnancy and childbirth as a whole, implementation across the OCN. All the same, the OCN was considered a complex context, as multiple organizations collaborate with no joint juridical entity. Consequently, professionals and policy makers noticed issues with data ownership, allocation of costs, patient flow in and out of the network and various medical record systems. Furthermore, they pointed out that different incentives exist between OCN and hospital, whilst community midwives are autonomous as well. When joint financial rewards are lacking, it was argued that joint improvement cycles remain restricted.

> …as long as community practices maintain their own financial autonomy, you always have... uh, other interests at play. Not only your quality interest, but also financial interest... So, introducing the PCB set will improve quality to some extent, but on very relevant points... other interests are greater… HCP3

Whereas trust was identified key for joint outcome improvement, professionals perceived a barrier in interdisciplinary relationships within the OCN. Despite a decade of collaboration, professionals' views on pregnancy and childbirth still differ, resulting in different care policies and lack of trust. Most professionals felt partly related to the OCN, depending on who they worked with in daily practice, and still identified closest with their organization or professional group. Policy makers, most hospital employed, perceived their few OCN tasks as inconvenient or complex. They recognized interprofessional collaboration barriers but lacked incentive or tools for change. At the same time, some collaboration was seen as performing very well – bringing local collaboration and more interdisciplinary equality and trust – for example joint audits and knowing each other personally and professionally, and the multiple communication systems established across the OCN to reach each professional group.

> …an enormous translation has been made in uniformity of interdisciplinary protocols [...] there is still some improvement possible, because in the end the clinical point of view always prevails in my opinion... and I don't always think that is justified... CCP2

> …that (integrated care) is very much stimulated by the government, but it certainly felt like a kind of forced collaboration… especially among the gynaecologists and midwives, who struggled very much with ‘how you do that’? And that is often on financial grounds, I noticed. HCP9
>
> I think we all want to, but also don’t always say so… I guess many things are thought, but not everything is spoken out. CCP3
>
> …the collaboration with the hospital, there is always something above it: who has the power here? PM1

Despite structural and cultural barriers, all stakeholders acknowledged the potential of the PCB set to strengthen interdisciplinary collaboration within the OCN by shared responsibility for outcomes. Patients expected it might improve interprofessional collaboration and continuity in care policy and advice. A health care insurer suggested eventually merging to one organization, to overcome structural and financial barriers and make future value-based payments possible. This, it was argued, would provide improvement incentives, truly arranged from the patients’ perspective. Though professionals considered this too soon, they saw the PCB set as a positive step towards more integrated care.

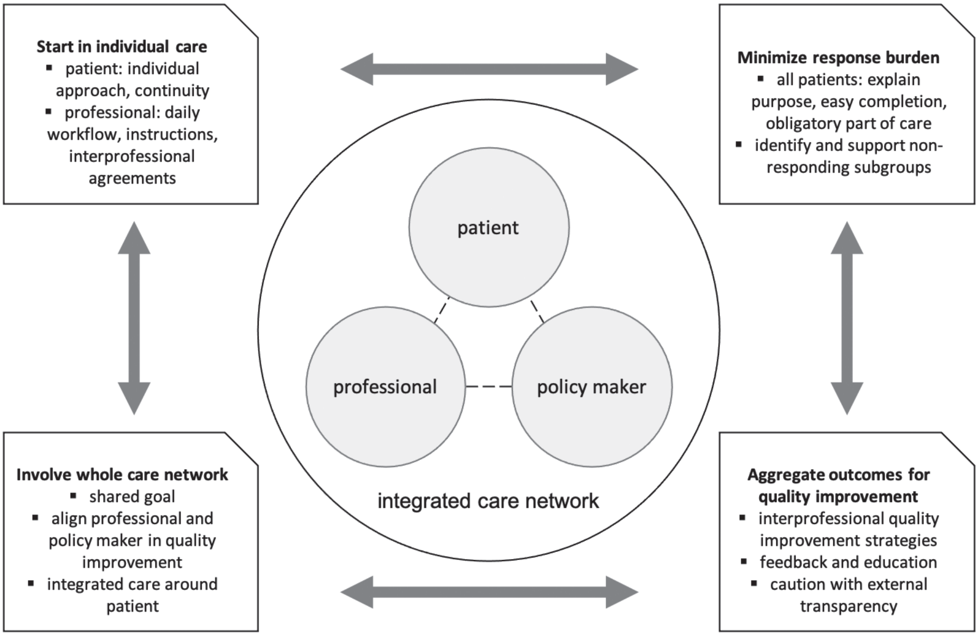
> I think you want the best outcomes together… in that way you will also go to an integrated organization faster, because you really have to do it together. CCP3
>
> …for that (bundled payment) the OCN actually has to be an organization instead of a collaboration… and because you also have a joint, eh, contract then… they also feel jointly responsible. PM5

DISCUSSION

This pre-implementation analysis systematically explored factors affecting successful implementation of the use of the PCB outcome set in perinatal care. Supported by the CFIR framework, a complete overview of interrelated constructs was identified across four main themes: instrument and process, use in clinical practice, use for quality improvement and the context of the OCN. Important barriers included local adaptability, feared patient burden, privacy, professionals’ workload and responsibilities, limited influence on outcomes, data reliability and transparency, financial incentives, collaboration structure and cultural differences. At the same time, it offered the completeness and relevance of the PCB sets’ outcomes, direct value to individual care, possibilities for professional education and feedback, patient engagement, integration into the clinical workflow, IT-systems and interprofessional shared goals. Here, we further elaborate stakeholders' perspectives and factors unique for this setting and can make recommendations based on our findings (Figure 2).

Despite professionals and policy makers raising patient burden as a substantial barrier, patients considered the questionnaires' length and frequency appropriate. Studied in other settings, patients also seem to perceive the response burden of completing many PROMs as minimal, especially when their answers are used to guide clinical care.[30,31] Still, non-response and partial completion often hinder the adoption and sustainability of PROMs.[18] In recent studies, perceived response burden and completion rates have been shown to correlate with health status, cognitive function, treatment factors and demographic characteristics.[30,32] Hence, rather than the length or subjects of a questionnaire, patient characteristics and circumstances were predictive for PROM completion. In perinatal care, these factors could include pregnancy related illnesses, low literacy and socio-demographic background.[33] With future implementation, efforts should be made to identify and understand non-responding patient groups or pregnancy circumstances, in order to tailor strategies to support them – for example, with in-clinic assistance, questionnaire translations or an interview setting (Figure 2). For all patients, response burden can be minimized by discussing outcomes individually to let women feel their story matters.

Figure 2. Recommendations for practice



Across all stakeholder groups, using individual answers to guide patient care was believed to engage both patient and professional. This way, having PROMs' value directly visible in clinical practice, was also considered an important facilitator in previous implementation research.[18,34] However, to date individual use of PREMs has been limited, because of the fear to yield socially desirable answers as a result of the dependency relation between patient and professional.[15,35] Interestingly, our patients emphasized the opportunity to explain PREM answers face-to-face and, furthermore, felt supported to raise negative experiences if they become part of clinical routine. These women might have become accustomed to daily individual experience evaluations with maternity care assistance. Therefore, discussion of PREMs individually might be optional, providing women a choice whether to show their answers to their provider or only use them anonymously for quality improvement. At the same time, this use in clinic requires clear instructions and easy data access for professionals, embedded in daily workflow (Figure 2). Furthermore, care pathways and actions following the outcomes should be agreed on interprofessionally to ensure continuity of care and follow-up of patients' answers throughout the network, for instance with a principal care provider.

When using aggregate outcomes for quality improvement, public transparency was debated by our participants and could have bidirectional impact on implementation. Whilst some professionals feared competition and fragmentation, public reporting was seen by others as stimulating improvement at the organization level, In line with a review on how performance data can improve care.[36] According to some, however, this information would not be used by patients to choose providers, as they mainly rely on relatives' experiences, something affirmed by patients both in our study and in other papers.[37] Like patients in other settings, women did value aggregate outcomes to compare themselves to others and make treatment decisions.[38] Thus, the value of public reporting is questionable for choosing a provider, whereas its effect on quality of care seems bidirectional. Transparency can create tension for improvement on a managerial level, as well as unintended competition and fragmentation of care networks. In a slowly growing interprofessional collaboration, public reporting should therefore not be prioritized, as it could impede continuity and quality of care. Aside from this, the value of aggregate outcomes was recognized as a way to gain insight and awareness of patient-reported outcomes and to identify multidisciplinary opportunities for improvement. This stakeholder motivation advocates starting with regular feedback to all disciplines involved, with interprofessional education around domains of the PCB set (Figure 2). Such a strategy would be supported by a review of facilitators in quality improvement using outcome indicators, although to date, PROMs have been rarely incorporated in structural improvement strategies.[39]

While stakeholders all favoured implementing the PCB set across the OCN, important structural and cultural organization barriers arose within this complex context, crossing the boundaries of public health, community care and hospital care. Notably, these organizational aspects have been given little attention in other studies on PROM implementation, mostly conducted within organizations.[18] In integrated care networks, similar factors have been shown to affect interprofessional and interorganizational collaboration for a long time, not only in the Netherlands but also in perinatal care systems elsewhere.[40–42] Barriers like financial autonomy and limited trust could be addressed with interdisciplinary education or efforts to increase mutual acquaintance, yet are unlikely to be solved completely with any implementation strategy in the near future.[41,42] Nonetheless, with the PCB set providing a more patient-centred approach, barriers could be reduced in future as shared responsibility for outcomes provides opportunities to unite towards integrated care.[42] Therefore, involving the whole integrated care network needs to be the focus, aligning professional and managerial incentives around the patient's perspective (Figure 2). Though policy makers seemed to adopt interprofessional attitudes, it could be their role in particular to bridge differences and provide leadership from the OCN. Fragmentation could decrease as the implementation of the PCB set enables measurement of a joint goal, supporting the journey towards integrated value driven care.

Strengths and limitations

Although women were randomly selected from a varied population and included up to saturation, caution is always needed regarding the generalizability of qualitative methods. Patients should actively participate in further implementation evaluation. To obtain a complete view on patients' needs and beliefs, purposive sampling of patients with both favourable and unfavourable PROM or PREM results would be of added value. Unfortunately, this was not possible in our pre-implementation study as the questionnaires had not been filled out by patients yet. While combined methods may have added to the generalizability, the semi-structured interviews provided us with an in-depth understanding of the various perspectives.[22] At this stage of implementation, it was most valuable to gain deeper understanding of participants' motives and beliefs, rather than quantitative results.

A strength of this study was that stakeholders were identified systematically, reflecting the views of different professionals and policy makers as well as patients. Including patients was crucial, since in successful implementation, they have been shown to be equally important stakeholders. Aligning the incentives of professionals and policy makers has been reported crucial but is also often lacking.[43] Furthermore, the CFIR framework supported complete assessment of what is needed to implement changes in the context of perinatal care. Thereby, we extended the frameworks' use to an integrated network setting, including care providers collaborating over a whole cycle of care; this is momentous in the current transformation to value driven healthcare.[21]

Conclusions

Before implementing the PCB outcome set, this qualitative study explored contributing factors and different incentives from each stakeholder perspective. This allows for both addressing barriers early and tailoring implementation strategies to the unique context of perinatal care. As our findings indicate, implementing the PCB set can be valuable to all stakeholders in perinatal care, providing an opportunity to improve individual patient care and to unite providers towards more integrated care around their patient. Implementation could start in clinical practice and involve the whole care network in quality improvement strategies. Future research should monitor this implementation process, inquiring into both interprofessional collaboration and the effects on patient outcomes.

REFERENCES

1. Sudhof L, Shah NT. In pursuit of value-based maternity care. *Obstet Gynecol*. 2019;133(3):541-551. doi:10.1097/AOG.0000000000003113
2. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346(7896):f167. doi:10.1136/bmj.f167
3. Foley T, Fairmichael F. *The Potential of Learning Health Care Systems*. Newcastle: Learning Healthcare Project; 2015. http://www.learninghealthcareproject.org/LHS_Report_2015.pdf.
4. Franklin P, Chenok K, Lavalee D, Love R. Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System. *EGEMS (Wash DC)*. 2017;5(1):17.
5. Basch E. Harnessing Patients' Voices to Improve Clinical Care. *N Engl J Med*. 2017;376(2):105-108. doi:10.1056/NEJMp1615714
6. McAllister M, Dearing A. Patient reported outcomes and patient empowerment in clinical genetics services. *Clin Genet*. 2015;88(2):114-121. doi:10.1111/cge.12520
7. Deshpande P, Sudeepthi Bl, Rajan S, Abdul Nazir C. Patient-reported outcomes: A new era in clinical research. *Perspect Clin Res*. 2011;2(4):137. doi:10.4103/2229-3485.86879
8. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. *Heal Serv Deliv Res*. 2017;5(2):1-280. doi:10.3310/hsdr05020
9. Groeneveld IF, Goossens PH, van Meijeren-Pont W, et al. Value-Based Stroke Rehabilitation: Feasibility and Results of Patient-Reported Outcome Measures in the First Year After Stroke. *J Stroke Cerebrovasc Dis*. 2019;28(2):499-512. doi:10.1016/j.jstrokecerebrovasdis.2018.10.033
10. Cellissen E, Franx A, Roes KCB. Use of quality indicators by obstetric caregivers in the Netherlands: A descriptive study. *Eur J Obstet Gynecol Reprod Biol*. 2017;211:177-181. doi:10.1016/j.ejogrb.2017.02.016
11. ICHOM. *Pregnancy & Childbirth: Data Collection Reference Guide*.; 2016. https://connect.ichom.org/patient-centered-outcome-measures/pregnancy-and-childbirth/.
12. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
13. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res*. 2013;13:211. doi:10.1186/1472-6963-13-211
14. Basch E, Deal AM, Dueck AC, et al. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA*. 2017;318(2):197-198. doi:10.1001/jama.2017.7156
15. Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. *Patient Educ Couns*. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022
16. Al-Shammari I, Roa L, Yorlets RR, et al. Implementation of an international standardized set of outcome indicators in pregnancy and childbirth in Kenya: Utilizing mobile technology to collect patient-reported outcomes. *PLoS One*. 2019;14(10):e0222978. doi:10.1371/journal.pone.0222978
17. Slavin V, Gamble J, Creedy DK, Fenwick J, Pallant J. Measuring physical and mental health during pregnancy and postpartum in an Australian childbearing population - Validation of the PROMIS Global Short Form. *BMC Pregnancy Childbirth*. 2019;19(1):1-19. doi:10.1186/s12884-019-2546-6

18. Foster A, Croot L, Brazier J, Harris J, O’cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient-Reported Outcomes*. 2018;2:46. doi:10.1186/s41687-018-0072-3
19. Biber J, Ose D, Reese J, et al. Patient reported outcomes – experiences with implementation in a University Health Care setting. *J Patient-Reported Outcomes*. 2018;2:34. doi:10.1186/s41687-018-0059-0
20. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implement Sci*. 2009;4:50. doi:10.1186/1748-5908-4-50
21. Nuño-Solinís R. Advancing towards value-based integrated care for individuals and populations. *Int J Integr Care*. 2019;19(4):8, 1-3. doi:10.5334/ijic.5450
22. Boeije H. *Analysis in Qualitative Research*. (SAGE Publications, ed.).; 2010.
23. Kirk MA, Kelley C, Yankey N, Birken SA, Abadie B, Damschroder L. A systematic review of the use of the Consolidated Framework for Implementation Research. *Implement Sci*. 2016;11:72. doi:10.1186/s13012-016-0437-z
24. Warner G, Lawson B, Sampalli T, Burge F, Gibson R, Wood S. Applying the consolidated framework for implementation research to identify barriers affecting implementation of an online frailty tool into primary health care: A qualitative study. *BMC Health Serv Res*. 2018;18:395. doi:10.1186/s12913-018-3163-1
25. Stuurgroep Zwangerschap en Geboorte. *A Good Start, Safe Birth Care (In Dutch: Een Goed Begin, Veilige Zorg Rond Zwangerschap En Geboorte)*. Utrecht; 2009. Advies Stuurgroep zwangerschap en geboorte.
26. Boesveld IC, Bruijnzeels MA, Hitzert M, et al. Typology of birth centres in the Netherlands using the Rainbow model of integrated care: Results of the Dutch Birth Centre Study. *BMC Health Serv Res*. 2017;17:426. doi:10.1186/s12913-017-2350-9
27. Schiller C, Winters M, Hanson HM, Ashe MC. A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. *BMC Public Health*. 2013;13:428. doi:10.1186/1471-2458-13-428
28. Dierckx de Casterle B, Gastmans C, Bryon E, Denier Y. QUAGOL: A guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360-371. doi:10.1016/j.ijnurstu.2011.09.012
29. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*. 2007;19(6):349-357. doi:10.1093/intqhc/mzm042
30. Atkinson TM, Schwartz CE, Goldstein L, et al. Perceptions of Response Burden Associated with Completion of Patient-Reported Outcome Assessments in Oncology. *Value Heal*. 2019;22(2):225-230. doi:10.1016/j.jval.2018.07.875
31. Ackerman IN, Cavka B, Lippa J, Bucknill A. The feasibility of implementing the ICHOM Standard Set for Hip and Knee Osteoarthritis: a mixed-methods evaluation in public and private hospital settings. *J Patient-Reported Outcomes*. 2018;2:32. doi:10.1186/s41687-018-0062-5
32. Parrish JM, Jenkins NW, Patel D V., et al. Demographic and Perioperative Factors Associated With Patient-reported Outcomes Measurement Information System (PROMIS) Survey Completion. *Clin Spine Surg*. 2020;33(10):E519-E524. doi:10.1097/BSD.0000000000000998
33. Scheerhagen M, van Stel HF, Tholhuijsen DJC, Birnie E, Franx A, Bonsel GJ. Applicability of the ReproQ client experiences questionnaire for quality improvement in maternity care. *PeerJ*. 2016;2016(7). doi:10.7717/peerj.2092

34. Barr PJ, Berry SA, Gozansky WS, et al. No date for the PROM: the association between patient-reported health events and clinical coding in primary care. *J Patient-Reported Outcomes*. 2020;4:17. doi:10.1186/s41687-020-0183-5

35. Lagha E, Noble A, Smith A, Denvir MA, Leslie SJ. Patient reported experience measures (PREMs) in chronic heart failure. *J R Coll Physicians Edinb*. 2013;42(4):301-305. doi:10.4997/JRCPE.2012.404

36. Fung CH, Lim YW, Mattke S, Damberg C, Shekelle PG. Systematic review: The evidence that publishing patient care performance data improves quality of care. *Ann Intern Med*. 2008;148(2):111-123. doi:10.7326/0003-4819-148-2-200801150-00006

37. Dixon A, Robertson R, Bal R. The experience of implementing choice at point of referral: A comparison of the Netherlands and England. *Heal Econ Policy Law*. 2010;5(3):295-317. doi:10.1017/S1744133110000058

38. Coulter A. Do patients want a choice and does it work? *BMJ*. 2010;341(7780):973-975. doi:http://www.jstor.org/stable/20800353

39. Kampstra NA, Zipfel N, Van Der Nat PB, Westert GP, Van Der Wees PJ, Groenewoud AS. Health outcomes measurement and organizational readiness support quality improvement: A systematic review. *BMC Health Serv Res*. 2018;18:1005. doi:10.1186/s12913-018-3828-9

40. Van Der Lee N, Driessen EW, Scheele F. How the past influences interprofessional collaboration between obstetricians and midwives in the Netherlands: Findings from a secondary analysis. *J Interprof Care*. 2016;30(1):71-76. doi:10.3109/13561820.2015.1064876

41. Cronie D, Rijnders M, Jans S, Verhoeven CJ, de Vries R. How good is collaboration between maternity service providers in the Netherlands? *J Multidiscip Healthc*. 2019;12:21-30. doi:10.2147/JMDH.S179811

42. D'Amour D, Goulet L, Labadie JF, Martín-Rodriguez LS, Pineault R. A model and typology of collaboration between professionals in healthcare organizations. *BMC Health Serv Res*. 2008;8:118. doi:10.1186/1472-6963-8-188

43. Pannick S, Sevdalis N, Athanasiou T. Beyond clinical engagement: a pragmatic model for quality improvement interventions, aligning clinical and managerial priorities. *BMJ Qual Saf*. 2016;25:716-725. doi:10.1136/bmjqs-2015-004453

SUPPLEMENT

Additional file 1. Topic list semi-structured interviews

Prior to the interview, participants received standardized background information about the PCB set, its development and purpose.

Part 1: Knowledge and current situation

- Current quality improvement policies (registrations, audits, protocols)
- Knowledge of the PCB set (purpose, content, source)

Main question: what do you know about quality improvement in perinatal care?
Main goal: insight in understanding of PCB set and quality improvement, insight in current situation

Part 2: Levels of using the PCB set outcomes

- Added value of the PCB set at:
    - Patient level
    - Organization or OCN-level
    - Benchmarking of several institutions or regions
- Level of preference of stakeholder

Main question: How do you think the PCB set can contribute to better quality of birth care?
Main goal: how does ICHOM fit in current quality improvement; preference for type of use; intrinsic motivation, personal goals, incentives for change

Part 3: Determinants of change

- Barriers
- Facilitators
- Other stakeholders involved
- Responsibilities and role of stakeholder
- Incentives stakeholder
- Patient (interest, burden)
- Overall opinion on the proposed intervention

Main questions:
- What do you think is necessary for a successful implementation of a quality cycle based on the PCB set?

- What bottlenecks do you see for this implementation? Which factors can promote implementation?
- How do you feel about the intervention?

Main goal: bottlenecks and facilitators for the intervention, new stakeholders, drivers and role of stakeholder, Overall opinion on the proposed intervention

3

CHAPTER 3

A feasibility study of implementing a patient-centered outcome set for pregnancy and childbirth

Anne L. Depla, Hiske E. Ernst-Smelt, Marjolein Poels,
Neeltje M. Crombag, Arie Franx, Mireille N. Bekker

Health Sci Rep. 2020 Jun 26;3(3):e168

ABSTRACT

Background Patient-reported outcome and experience measures (PROM and PREM) can facilitate shared-decision making and hold potential to improve healthcare quality. However, their adoption in perinatal care is still limited. The International Consortium Health Outcome Measures (ICHOM) developed a Pregnancy and Childbirth (PCB) outcome set, including PROM and PREM questionnaires. We studied the feasibility to use these PROMs/PREMs in Dutch perinatal care, addressing both women’s and professionals’ perspective.

Methods Patients and professionals in primary and hospital care participated. Women under care at one of five timepoints for PROM/PREM collection of the PCB set (2 during pregnancy, 3 postpartum), were e-mailed a questionnaire and discussed their answers with their obstetric professional the next regular visit. Compliance was recorded. After discussing the PROMs/PREMs, usability and experience were assessed with separate surveys amongst women and professionals.

Results Of 26 women approached, 21 completed and discussed their PROM/PREM questionnaire. Mean questionnaire completion rate was 97%. Average reported time completing the questionnaires was 10 minutes; most women (90%) stated this was acceptable. Women preferred completing questionnaires digitally and discuss their answers with an obstetric professional rather than other care professionals, also six months postpartum. Over half of women agreed PROMs/PREMs supported shared-decision making (58%), ability to raise issues (60%) and patient-clinician relationship (52%). Six professionals participated: two obstetricians, two clinical midwives and two community midwives. Most professionals experienced sufficient time to discuss the responses, except at six months postpartum. They knew what items to discuss but did not always feel responsible to act upon them. Professionals agreed PROMs/PREMs supported symptom detection and personalized care.

Conclusions Patients and obstetric professionals consider the PCB set a feasible instrument for PROM/PREM assessment, with good compliance, acceptability and usability. Important determinants of successful implementation are a well-equipped ICT-tool, agreements regarding professionals’ responsibilities and how outcomes are discussed or acted upon.

INTRODUCTION

Routine collection and use of patient-reported outcome measures (PROM) enables focusing on patients' perspective of wellbeing, in both clinical practice and in healthcare quality improvement.[1,2] In individual patient care, structural PROM collection and use can improve patient-clinician communication, detection of unrecognized symptoms and even clinical health outcomes.[3,4] In the past decade, the use of PROMs has therefore rapidly grown in orthopaedics, oncology and chronic care settings, but their adoption is still limited in clinical practice of perinatal care.[5–7] Even though in this setting, PROMs could add considerable value to patient care and quality improvement, as its general population consists of relatively healthy women at low risk for mortality or severe morbidity, and multiple professional organizations combine planned and acute care in a short time period.[8,9]

The International Consortium of Health Outcome Measures (ICHOM) published a standard outcome set for Pregnancy and Childbirth (PCB), which has recently been translated to Dutch and validated in the Netherlands.[10–12] This standard set comprises clinical outcomes, patient-reported outcome measures (PROM) and patient-reported experience measures (PREM), assessed with a questionnaire regarding health status and experiences with care at five different timepoints in pregnancy and the postpartum period. By collecting and using this information in clinical practice, women gain insight in relevant outcomes for themselves and their child. This way, women can be empowered to effectively communicate their health status and make better informed decisions about their care.[4,13] At the same time, care professionals value patient-reported measures when they are useful for the clinical process, as they can become more aware of patients' issues and are enabled to more patient-centred discussion and action.[4,14]

Multiple governments have initiated national programs to stimulate the incorporation of PROMs and PREMs in their healthcare system.[15–17] In the Netherlands, the Ministry of Healthcare mandates the implementation of patient-reported measurements throughout the healthcare system, supported by clinician and patient organizations.[18] The primary step of this implementation is incorporation in clinical practice, whereas secondary use for quality improvement and quality benchmarking are subsequent steps in the transition to value-based healthcare. However, to date, knowledge and experience to collect and use PROMs or PREMs routinely in perinatal care are lacking, and little is known about time investment and response burden of the PCB outcome set for both women and obstetric care professionals.[7,9] At this moment, unfamiliarity and uncertainty seem to hinder the implementation of its patient-reported measures in perinatal clinical practice.[11]

Therefore, the aim of this study was to assess the feasibility of implementing the PCB outcome set, by piloting the process of collecting its PROM and PREM questionnaires and discuss the responses as part of usual care (i.e., the pilot intervention). Barriers and facilitators to use the PROMs and PREMs in routine perinatal care were evaluated with surveys. We expected this study to provide insights in acceptability, compliance, usability and preferences of both women and obstetric care professionals using the questionnaires.

METHODS

Within a three-month pilot, a cross-sectional feasibility study was performed to collect data regarding compliance, usability and experiences when using the PROM and PREM questionnaires of the PCB outcome set in clinical practice. For this pilot intervention, women receiving perinatal care were asked to complete one questionnaire and discuss their answers with their obstetric care professional during the next regular visit. After discussing the PROMs and PREMs in clinic, both woman and obstetric care professionals were sent an evaluation survey regarding usability and experience.

Setting

From March 2019 to June 2019, this study was carried out in the perinatal care network of the Wilhelmina Children's Hospital (WKZ) in the Netherlands. Dutch perinatal care is organized in a two-tiered system, with community midwives providing care to low risk patients, while obstetricians in hospitals provide care to medium and high-risk patients. Community midwives refer patients to hospital care if complications arise and cooperate in an Obstetric Collaborative Network (OCN) with their referring partners. The WKZ is a secondary and tertiary referral centre, collaborating in an OCN with six community midwifery practices.

Participants

Patients: women receiving perinatal care were recruited at each of the five proposed timepoints to capture data for the PCB outcome set. ICHOM recommends the following timepoints to assess the PROM/PREM domains using standard questionnaires:

- **T1:** 1st trimester	(gestational age between 8 and 16 weeks)
- **T2:** early 3rd trimester	(gestational age between 28 and 32 weeks)
- **T3:** at birth	(±3 days postpartum)
- **T4:** first postnatal check-up	(between 5 and 6 weeks postpartum)
- **T5:** 6 months after birth	(between 22 and 26 weeks postpartum)

For this pilot study, women were asked for only one of these timepoints, because the complete timeline of measurements is spread over 12 months. To assess the feasibility of each timepoint, a sample of five women per timepoint was aimed, including both nulliparous and multiparous women at each timepoint. Women had to be able to read Dutch language.

Professionals: a sample of obstetric care professionals was selected from all care settings in the OCN: obstetricians, clinical midwives (hospital employed), and community midwives. Each professional was asked to assess and discuss one PROM/PREM questionnaire of each timepoint (T1 – T5) with different women as part of usual care.

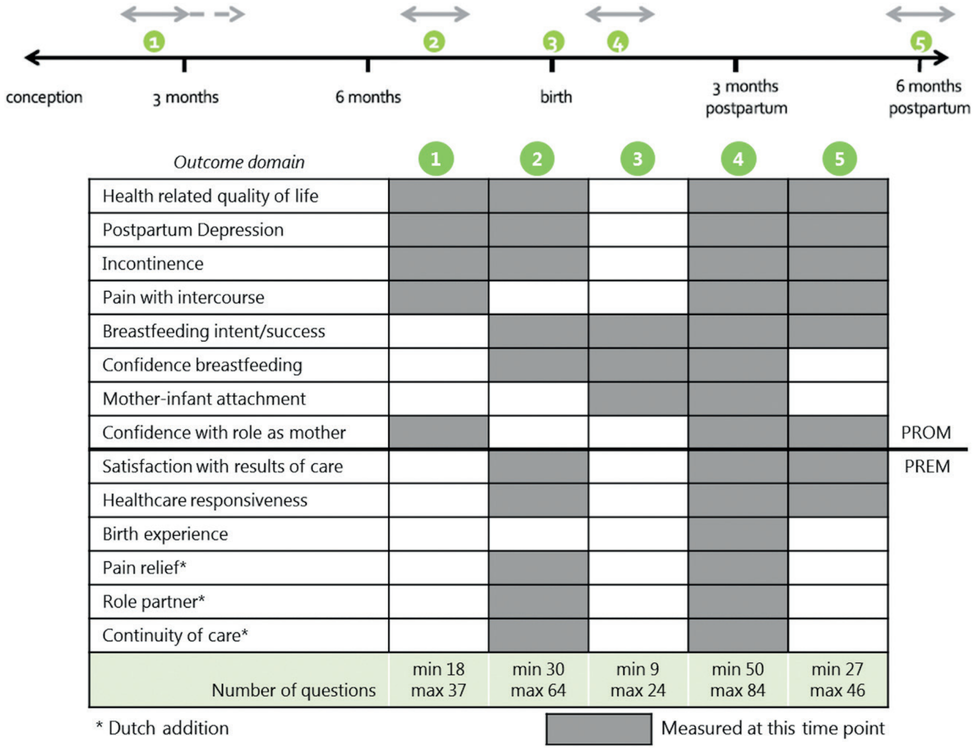
Pilot intervention: ICHOM Pregnancy and Childbirth outcome set

ICHOM aims to create standard sets of outcomes that matter to patients for each particular disease or condition, including both clinical metrics and PROMs/PREMs. The development and content of their standard set for Pregnancy and Childbirth are described by Nijagal et al.[10,12] During recent translation and validation of this PCB outcome set, a few PREMs were added to adjust to the Dutch context.[11] The PROMs and PREMs comprise 14 domains, measured at five timepoints described above (Figure 1). Each domain has its own measurement instrument(s) – in this case questionnaire (Appendix A). Questions that aim for screening were embedded in several domains: if a woman is not at risk, certain questions are ruled out. That way, the number of questions per timepoint differs per woman (Figure 1), and the burden of filling out many questions is reduced.

In this pilot, the PROM and PREM questionnaires of the PCB outcome set are used as part of routine clinical practice. This process includes the following steps:

1. The obstetric care professional explains the purpose and process of the PROM/PREM questionnaires to his/her patient visiting at one of the five timepoints;
2. The patient fills out the PROM/PREM questionnaire suitable for that particular timepoint;
3. The obstetric care professional and patient discuss the PROMs/PREMs in the next regular visit.

Figure 1. Timeline for ICHOM patient questionnaires (adapted from Nijagal et al. [12])



Outcome domain	1	2	3	4	5	
Health related quality of life	▨	▨		▨	▨	
Postpartum Depression	▨	▨		▨	▨	
Incontinence	▨	▨		▨	▨	
Pain with intercourse	▨			▨	▨	
Breastfeeding intent/success		▨	▨	▨	▨	
Confidence breastfeeding		▨	▨	▨		
Mother-infant attachment			▨	▨		
Confidence with role as mother	▨			▨	▨	PROM
Satisfaction with results of care		▨		▨	▨	PREM
Healthcare responsiveness		▨		▨	▨	
Birth experience				▨		
Pain relief*		▨		▨		
Role partner*		▨		▨		
Continuity of care*		▨		▨		
Number of questions	min 18 max 37	min 30 max 64	min 9 max 24	min 50 max 84	min 27 max 46	

* Dutch addition

▨ Measured at this time point

PROM patient-reported outcome measure; *PREM* patient-reported experience measure.

During the pilot period, the first step of this process was combined with obtaining informed consent for the study. The PROM/PREM questionnaire was sent by e-mail and could be returned to the obstetric care professional digitally or taken to the next visit as a hardcopy. If it was not returned 48 hours prior to the following appointment, an e-mail reminder was sent. As the last timepoint (T5) falls outside routine perinatal care, the obstetric care professional scheduled an additional telephone consultation to discuss the responses to this questionnaire.

Data collection and analysis

The PROM/PREM questionnaires were retrieved from women's medical records to assess completion rates, along with several baseline characteristics. To calculate the proportion of missing responses per measurement instrument, the missing responses per instrument were divided by the number of women that were supposed to fill the instrument out. This denominator differs, as some instruments are dependent of a screening question (Appendix A), or specific for certain timepoints (Figure 1).

To evaluate usability and experiences, separate evaluation surveys were composed for both patients and obstetric care professionals, regarding barriers and facilitators to using the PROM/PREM questionnaires in daily practice (Appendix B1 and B2). Both surveys were developed through a multidisciplinary focus group discussion with all involved stakeholders. The surveys consisted of multiple-choice questions, with regular opportunities to give free comments. They were collected digitally and anonymously using LimeSurvey, an open source survey tool.[19] Women were invited for their evaluation survey directly after the visit in which they discussed their PROM/PREM questionnaire with their obstetric care professional. The obstetric care professionals received one survey at the end of the pilot period, evaluating all timepoints they had tested (with different women). Quantitative data were gathered and analysed in Microsoft Excel (version 2010) using basic descriptive statistics. The qualitative data from the open-ended survey questions were subject of a thematic analysis along the survey-themes, to enrich the qualitative survey results.

RESULTS

Participants and baseline

Twenty-six women were approached to participate in the study, five of whom did not complete the pilot intervention. Two women that dropped out were excluded from the response analysis, as they did fill out their PROM/PREM questionnaire but could not return it to their care professional due to technical (internet) problems. Three women did not fill out their questionnaire, for different reasons: questions were considered too personal (at T1), fatigue (at T1) and unknown (at T3). Thus, overall response rate was 88% (21 of 24 women). Baseline characteristics of the participating women are presented in Table 1.

Six obstetric care professionals were included: four were employed in the hospital (two obstetricians; two clinical midwives) and two worked in primary care practices (community midwives). The midwives piloted all five timepoints. The obstetricians piloted only T2, T4 and T5, as they did not have a consultation scheduled with a woman at T1 or T3 during the study period.

Table 1. Baseline characteristics patients

		Patients across all timepoints (n= 21) N	(%)	Patients per timepoint T1 (n=4)	T2 (n=5)	T3 (n=3)	T4 (n=5)	T5 (n=4)
Age (years)		32 IQR 28-34						
Ethnicity	Northern European	18	(85)					
	Mediterranean	3	(15)					
Parity	Primiparous	14	(67)	2	3	1	5	3
	Multiparous	7	(33)	2	2	2	0	1
Care setting	Primary care	9	(43)	3	2	1	2	1
	Hospital care	12	(57)	1	3	2	3	3

T1 first trimester; *T2* early third trimester; *T3* three days after birth; *T4* five weeks after birth; *T5* six months

Response and missing items

The PROM/PREM questionnaires were completed digitally by 14 of 21 women (67%) and on paper by seven cases (33%). As parts of the questionnaires are dependent on screening questions, the number of questions women had to answer differed at each timepoint (Table 2). Overall, a mean number of 34 questions had to be answered and their average completion rate was 97%. Per PROM/PREM instrument, the proportion of missing responses was 23% (3 of 13 women) for sexual function (*PROMIS-SSFAC102)*; 14% (1 of 7) for breastfeeding confidence screening (*BFCONFID)*; 12% (1 of 8) for faecal incontinence (*Wexner)*; and breastfeeding self-efficacy (*BSES-SF)* was left blank in the one case where it should have been filled out (100%). All missing responses were found in questionnaires that had been filled out on paper. In these cases, women replied with a free comment in the margins that the question was not applicable to their situation.

Evaluation surveys

All women that filled out and discussed the PROM/PREM questionnaires with their obstetric care professional also completed the evaluation survey afterwards. All obstetric care professionals returned their evaluation survey.

Patients' perspective: completing the questionnaires

Women's self-reported time to complete their PROM/PREM questionnaire was mean 10 minutes (range 2-20 minutes), shown per timepoint in Table 2. Most women stated this time-investment was acceptable: 90% rated it 'good' or 'short'. Seven women (33%) – of whom three had tested T4, two T3, one T2, and one T5 – would not be willing to complete the questionnaires at all five timepoints. Thematic analysis of open survey questions (Appendix C) indicated that these women mostly debated timepoint T3, just after birth; the other moments were percieved more acceptable. In general, women emphasized the need for a user-friendly system to complete the questionnaires digitally at home. Women repeatedly noted they would prefer to explain their answers in free text areas. Also, it was important that time frame of questions is clear.

Patients' perspective: utility in clinical care

The majority of women (76%) wanted to discuss their PROM answers with a care professional, and 81% their PREM answers (Table 2). Others would complete them for quality improvement only. Most women (86%) preferred an obstetric care professional to discuss their answers with – none of them chose their general practitioner, an obstetric nurse or a preventive child healthcare provider. Few women did not want to discuss all domains with one professional, nor want all answers transferred in case of referral to a new care professional. Their main consideration, emerging from thematic analysis (Appendix C), was that specific domains are not relevant for a new situation or professional.

Over half of women recognized that PROMs helped them prepare for the visit (50%), their ability to raise issues (60%), shared decision making (58%), quality of information and patient-clinician relation (52%) (Table 2). Other women (31-45%) were predominantly neutral about these potential benefits of discussing their answers. According to open-ended survey data (Appendix C), the value of discussing the answers might be lower if no issues emerge from the questionnaires, still women expressed motivation to fill them out for quality improvement purposes. At the same time, it was important to acknowledge that discussing certain outcomes can be perceived over-alarming, such as the mother-child binding scale addressing emotions in the first week postpartum.

Table 2. Patients' experiences & preferences

Completing questionnaires	Overall	T1	T2	T3	T4	T5
Number of questions *Mean (min-max)*	34 (9-59)	19 (17-21)	43 (31-54)	10 (9-10)	54 (51-59)	34 (27-46)
Completion rate (%) *Mean (min-max)*	97 (71-100)	100 (100-100)	94 (71-100)	97 (89-100)	98 (93-100)	99 (96-100)
Time to complete (minutes) *Mean (min-max)*	10 (2-20)	9 (5-15)	13 (7-20)	4 (2-5)	14 (10-15)	10 (10-10)
Multiple choice		N (%)				
Acceptability of time spent						
	Too long	1 (5)				
	Long	1 (5)				
	Good	17 (81)				
	Short	2 (9)				
	Too short	0 (0)				
Willing to fill out all five time points						
	Yes	14 (67)				
	No	7 (33)				
Preferred device						
	Phone/Tablet (application)	8 (38)				
	Phone/Tablet (website)	9 (43)				
	Computer (website)	8 (38)				
	On paper	2 (9)				
	Other	0 (0)				
Preferred location						
	At home	17 (81)				
	Waiting room	3 (14)				
	No preference	1 (5)				

Statements[b]	(strongly) agree	neutral	(strongly) disagree	Total N
Goal clear	16 (76)	1 (5)	4 (19)	21
Explanation understood	18 (86)	1 (5)	2 (10)	21
Flyer clear	14 (78)	4 (22)	0 (0)	18
Understood questions well	19 (90)	1 (5)	1 (5)	21
Capable to fill in all questions	14 (67)	3 (14)	4 (19)	21
Pleasant to discuss with partner	9 (45)	9 (45)	2 (10)	21

Use in clinical care	
Multiple choice	N (%)
Discuss PROM answers	
All answers	7 (33)
Only deviant answers	9 (43)
Anonymous use	5 (24)
Don’t fill in at all	0 (0)
Discuss PREM answers	
Discuss with care professional	17 (81)
Only anonymous use	3 (14)
Don’t fill in at all	0 (0)
No response	1 (5)
Preferred care professional	
Midwife	62 (13)
Gynaecologist	5 (24)
Other[a]	3 (14)
Transfer answers to new professional	
Yes	17 (81)
No	4 (19)

Statements[b]	(strongly) agree	neutral	(strongly) disagree	Total N
Pleasant to discuss with professional	14 (70)	5 (25)	1 (5)	21
Supports visit preparation	10 (50)	9 (45)	1 (5)	20
Easier to raise issues	12 (60)	7 (35)	1 (5)	20
Increased shared decision making	11 (58)	8 (42)	0 (0)	19
Better informed	13 (68)	6 (32)	0 (0)	19
Better relationship with professional	11 (52)	8 (38)	2 (10)	21

[a] Other answers: no preference (n=1), subject dependent (n=1), nobody (n=1)

[b] Statements were rated on a 5-point Likert scale. For this table, ratings are summarized into three groups. See Appendix D (figure D.1) for the full ratings.

Professionals' perspective: time investment

Time investment for obstetric care professionals was self-reported at each timepoint (Table 3). On average, discussing patient's answers took them 10 minutes (range 3-20 minutes). At two of five timepoints, the majority of professionals (50% at T1 and 75% at T5) felt they were short in time to discuss all issues raised in patient's questionnaires. Time spent on discussing the answers did not correlate with the number of questions that patients had answered. Thematic analysis showed (Appendix C), this time was more dependent on the number of issues raised. Professionals could also gain time, because it was clear in advance which subjects were important for their patient to address. To attain this advantage, they debated that insight in the answers before the visit is crucial, emphasizing the need for a well-supporting IT system. Also, to relief their time burden, support of administrative staff was proposed, for example in explaining the purpose and process of the questionnaires to patients.

Table 3. Care professionals' experiences and preferences

Time investment	Overall	T1	T2	T3	T4	T5
Explain purpose (minutes) *Mean (min-max)*	5 (1-10)	-	-	-	-	-
Discuss answers (minutes) *Mean (min-max)*	10 (3-20)	10 (7-15)	8 (3-15)	6 (3-10)	10 (5-15)	15 (10-20)
Utility per timepoint[a]	T1 (n=4)	T2 (n=4)	T3 (n=2)	T4 (n=5)	T5 (n=4)	
Knew what to discuss	N (%)	N (%)	N (%)	N (%)	N (%)	
(strongly) agree	4 (100)	3 (75)	2 (100)	5 (100)	4 (100)	
neutral	0 (0)	1 (25)	0 (0)	0 (0)	0 (0)	
(strongly) disagree	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	
Recognized deviant answers						
(strongly) agree	3 (75)	4 (100)	2 (100)	4 (80)	4 (100)	
neutral	1 (25)	0 (0)	0 (0)	1 (20)	0 (0)	
(strongly) disagree	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	
Knew what to do if deviant						
(strongly) agree	2 (50)	4 (100)	2 (100)	4 (80)	4 (100)	
neutral	1 (25)	0 (0)	0 (0)	1 (20)	0 (0)	
(strongly) disagree	1 (25)	0 (0)	0 (0)	0 (0)	0 (0)	
Felt responsible						
(strongly) agree	1 (25)	2 (50)	0 (0)	3 (60)	1 (25)	
neutral	1 (25)	0 (0)	1 (50)	0 (0)	2 (50)	
(strongly) disagree	2 (50)	2 (50)	1 (50)	2 (40)	1 (25)	

Utility overall (n=6)	(strongly) agree N (%)	neutral N (%)	(strongly) disagree N (%)
Goal clear	6 (100)	0 (0)	0 (0)
Capable of explaining the purpose	5 (83)	1 (17)	0 (0)
Usable	4 (67)	2 (33)	0 (0)
Supports signalling symptoms	6 (100)	0 (0)	0 (0)
Supports identify what matters to my patient	5 (83)	1 (17)	0 (0)
Supports appropriate care	6 (100)	0 (0)	0 (0)
Supports relationship with patient	2 (33)	3 (50)	1 (17)
Supports patient empowerment	1 (17)	4 (67)	1 (17)
Supports insight in quality of care	1 (17)	5 (83)	0 (0)
Need real-time insight answers	4 (67)	0 (0)	2 (33)
Need answers directly in EPD	2 (33)	3 (50)	1 (17)

[a] Statements were rated on a 5-point Likert scale. For this table, ratings are summarized into three groups. See Appendix D (Figure D.2 and D.3) for the full ratings.

Professionals' perspective: utility in clinical care

According to most care professionals, either a midwife or gynaecologist is the preferred professional to discuss the answers at all timepoints. Some professionals would assign T5 to the general practitioner or a nurse, reasoning this is not a regular part of perinatal care and the imbursement structure. Though, from thematic analysis also emerged (Appendix C) that assigning T5 to an obstetric care professional could be more valuable to both patients and professionals, for evaluation of health status and care given.

Preferences about how to discuss the answers with patients differed little between professionals: if a patient agrees, all of them would discuss deviating answers. In case of deviating answers, most professionals preferred to have standardized information or referral options. At each timepoint, all obstetric care professionals stated they knew what to discuss and what to do in case of deviant answers (Table 3). Yet, it varied widely among professionals whether they felt it as their responsibility to notice and discuss or act upon the responses. This theme arose in qualitative analysis as well (Appendix C), as professionals emphasized the importance of a clear structure or agreements about their responsibilities. Also, they considered it helpful to share thoughts with colleagues about how to discuss the outcomes with their patients.

Most of the professionals agreed that the PROMs supported the detection of symptoms, contributed to more appropriate care and identifying subjects that matter a patient (Table 3). Professionals rated other possible effects of PROMs rather neutral. How professionals value PROMs also appeared from thematic analysis (Appendix C), indicating better insight in subjects that are important to their patients and easier detection of psychological issues or pelvic floor problems.

DISCUSSION

In this pilot we studied the feasibility to use patient-reported outcomes and experiences in perinatal care. Utilizing the PCB sets' PROMs and PREMs as part of routine care, we found good compliance to the questionnaires, acceptability of time burden and usability in clinic. In patients' and professionals' experience, patient-reported items can be valuable to perinatal care through symptom detection, patients' ability to raise issues and more personalized care.

To the majority of participating women, the time to complete the questionnaires (mean 10 minutes) was acceptable, whilst patient burden was considered a potential barrier in advance.[20] Furthermore, most women were willing to participate at all timepoints in case of future implementation. However, as one third of the women considered the timepoint just after birth (T3) too burdensome, the added value of timepoint T3 should be evaluated concisely. Still, the response rate was 88% across all timepoints. Non-response correlated with fatigue, or, at T1, the questions were considered too personal to share with a care professional, indicating the urge to explain the questionnaires' purpose well. Although with a different purpose, another experience questionnaire in perinatal care reached a 32% response rate.[21] Compared to this questionnaire, the PCB sets' PROMs and PREMs are used to support individual care instead of care improvement only, which might explain the higher compliance. Also used directly in a clinical setting, the questionnaires of the Osteoarthritis ICHOM set were reported a 71% response rate three months post-surgery.[5] Further possible explanation for our high response rate could be the relatively young and positively engaged population in perinatal care, familiar with digital devices. However, with further implementation, compliance might decrease as this pilot was carried out with dedicated clinical staff in a purposive sample of patients.

Analysing each domain, the only high missing response rate (23%) was found for 'pain with sexual intercourse' – assessed with PROMIS-SSFAC102 at T1, T4 and T5. As most missing responses were found at T4 (six weeks postpartum), this missing rate could be explained by 20% of women not having reinitiated intercourse three months postpartum.[22] Although sexual activity is not required to be able to answer the question according to its developers,[23] these results suggest otherwise. However, this domain also addresses a relative taboo and deserves attention in further implementation.

According to participating care professionals, their time in daily clinic to discuss patients' answers was sufficient at most timepoints, except for T5 (six months postpartum) when current perinatal care and its reimbursement structure has ended. However, women in this pilot clearly preferred to discuss the results obtained at T5 with their obstetric care professional, instead of their general practitioner for example. Moreover, women and professionals did value the evaluation of health status and provided care at this timepoint, both in our pilot and at previous exploration.[11] Thus, although potentially valuable, feasibility of consultation at T5 is questionable, requiring to adapt current care pathways.

Relative advantages of discussing individual outcomes in clinical practice were experienced by both women and professionals, acknowledging it could improve insight in health status and support appropriate, personalized care. These findings correspond with a comprehensive review on how PROMs support clinician-patient communication in oncologic care.[4] Yet, PROMs' contribution to patient-clinician relationship was rated fairly neutral in our study, possibly caused by the PCB outcome set containing standardized, rather than individualized PROMs (that allow patients to select domains of most relevance to themselves), which have been assumed less supportive for building patient-clinician relationships.[4] Interestingly, women preferred to discuss both their PROM and PREM responses, whereas sharing individual PREM answers was considered a potential barrier to patients and would yield social desirable answers.[11]

Though promising benefits were recognized for use in clinical practice, our findings emphasize the need for a well-supporting IT tool in perinatal care. Firstly, filling out questionnaires was preferably done digitally at home, pertaining to a generation of women reaching their fertility years that are profound users of internet, smartphones and applications.[24] Still, subgroups with lower socio-economic status or migration backgrounds deserve attention, and might need in-clinic support. Additionally, real-time data have to be easily accessible for professionals to gain the full potential of PROMs and keep the administrative burden minimal. Furthermore, sharing responses across the care system should be facilitated, as both women and professionals argued this is essential for individual patient value in the complex birth care network. Eventually, merging patient-reported data with clinician-reported outcomes on an aggregate level will be challenging, but essential to future use of the PCB outcome set in shared decision making, quality improvement, benchmarking and value-based birth care.

To facilitate further implementation in perinatal care, agreements on responsibility and actions upon patients' answers were identified as key factors, ensuring continuity of care and follow-up. For participating professionals, what issues to discuss and how to act upon them was clear, suggesting good acceptability and usability. However, whether professionals felt it their responsibility to notice and discuss or act upon responses differed widely per timepoint. This could be related to the relatively short period of care or the moments of measurement; but might also be caused by some questionnaires concerning general topics that health care specialists are not used to incorporate in their tasks. Several solutions were raised by professionals, such as appointing a principal obstetric professional to discuss responses with and creating standard referral options for different outcomes. For the latter, thresholds for each outcome have to be established for this population at all timepoints.

Despite its small sample size, a strength of this feasibility study was to involve both women and care professionals across the perinatal care network this early in the implementation process. Thereby, this paper provides an important preliminary view of their experiences and preferences using PROMs and PREMs in routine perinatal care, which can support further implementation and engage new stakeholders. An important limitation of our study was patients completing only one of the five timepoints, as the pilot was limited to a 3-month period. Assessing all timepoints in each woman may affect perceived questionnaire burden and response rates; as women receive more questions on one hand, but on the other, become more familiar with filling out and discussing the questionnaires as care-as-usual over the course of pregnancy. Although carried out in the Dutch perinatal care setting, our findings can provide practical information for other regions planning to implement this international standard set.

The main implication for practice emerging from this pilot is the expected benefit of implementing the PCB outcome set in routine care, as women and professionals expressed the value of discussing its PROMs and PREMs individually. The added value for patients and professionals should be evaluated, with attention to specific timepoints, subjects and professionals' responsibilities. This could not only identify necessary adaptations to the PCB set, but also create tension for change in structural aspects needed to reach sustainable implementation, such as IT-systems and care pathways. At the same time, the PCB outcome set has been assessed on an aggregate level in Kenia recently.[25] Even though adapted to both Kenyan and Dutch setting, an international standard set creates future opportunities for benchmarking and improvement of the birth care system.

In conclusion, both women and obstetric care professionals consider the PCB set as a feasible instrument for PROM and PREM assessment with good compliance, acceptability and usability, with the promise to improve perinatal care. Important determinants for successful clinical implementation are a well-equipped supporting IT tool, agreements regarding responsibilities of different professionals and guidance in how outcomes are discussed or acted upon. Timing of the T5 questionnaire is an important barrier for implementation in current practice. Future research should focus on implementation, identify barriers and facilitators to improve integration in clinical practice, and evaluate the effect on shared decision making, patient empowerment and clinical outcomes.

REFERENCES

1. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res*. 2013;13:211. doi:10.1186/1472-6963-13-211
2. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346(7896):f167. doi:10.1136/bmj.f167
3. Basch E, Deal AM, Kris MG, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol*. 2016;34(6):557-565. doi:10.1200/JCO.2015.63.0830
4. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? a realist synthesis. *J Patient-Reported Outcomes*. 2018;2(1). doi:10.1186/s41687-018-0061-6
5. Ackerman IN, Cavka B, Lippa J, Bucknill A. The feasibility of implementing the ICHOM Standard Set for Hip and Knee Osteoarthritis: a mixed-methods evaluation in public and private hospital settings. *J Patient-Reported Outcomes*. 2018;2:32. doi:10.1186/s41687-018-0062-5
6. Foster A, Croot L, Brazier J, Harris J, O'cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient-Reported Outcomes*. 2018;2:46. doi:10.1186/s41687-018-0072-3
7. Boulkedid R, Alberti C, Sibony O. Quality indicator development and implementation in maternity units. *Best Pract Res Clin Obstet Gynaecol*. 2013;27(4):609-619. doi:10.1016/j.bpobgyn.2013.04.001
8. American College of Obstetricians and Gynecologists. Value-Based Payments in Obstetrics and Gynecology. ACOG Committee Opnion No. 744. *Obs Gynecol*. 2018;132:e53-9.
9. Mahmud A, Morris E, Johnson S, Ismail KM. Developing core patient-reported outcomes in maternity: PRO-Maternity. *BJOG*. 2014;121:15-19.
10. ICHOM. *Pregnancy & Childbirth: Data Collection Reference Guide*.; 2016. https://connect.ichom.org/patient-centered-outcome-measures/pregnancy-and-childbirth/.
11. Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. *Patient Educ Couns*. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022
12. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
13. McAllister M, Dearing A. Patient reported outcomes and patient empowerment in clinical genetics services. *Clin Genet*. 2015;88(2):114-121. doi:10.1111/cge.12520
14. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Qual Saf*. 2014;23(6):508-518. doi:10.1136/bmjqs-2013-002524 BMJ
15. Devlin NJ, Appleby J, Buxton M, Vallance-owen A. Getting the most out of proms: putting health outcomes at the heart of NHS decision-making. 2010.
16. Alonso J, Bartlett SJ, Rose M, et al. The case for an international patient-reported outcomes measurement information system (PROMIS®) initiative. *Health Qual Life Outcomes*. 2013;11(1):1-5. doi:10.1186/1477-7525-11-210
17. Coulter A. Measuring what matters to patients. *BMJ*. 2017;356:1-2. doi:10.1136/bmj.j816
18. Dutch Ministry of Healthcare Welfare and Sport. *Outcome-Based Healthcare 2018-2022*.; 2018. https://www.government.nl/documents/reports/2018/07/02/outcome-based-healthcare-2018-2022.

19. Schmitz C. LimeSurvey: An Open Source Survey Tool. LimeSurvey Project Hamburg, Germany. 2012. http://www.limesurvey.org.
20. Atkinson TM, Schwartz CE, Goldstein L, et al. Perceptions of Response Burden Associated with Completion of Patient-Reported Outcome Assessments in Oncology. *Value Heal*. 2019;22(2):225-230. doi:10.1016/j.jval.2018.07.875
21. Scheerhagen M, van Stel HF, Tholhuijsen DJC, Birnie E, Franx A, Bonsel GJ. Applicability of the ReproQ client experiences questionnaire for quality improvement in maternity care. *PeerJ*. 2016;2016(7). doi:10.7717/peerj.2092
22. López-Lapeyrere C, Serna-Gómez N, Hernández-López AB, Pérez-García MF, Tejeda-Esteban A, Solís-Muñoz M. The development and validation of a new postpartum sexual function and dyspareunia assessment tool: The Carol Scale. *Midwifery*. 2018;58(November 2017):27-36. doi:10.1016/j.midw.2017.11.008
23. PROMIS initiative. PROMIS Sexual Function and Satisfaction Manual. 2018. http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Sexual_Function_and_Satisfaction_Measures_User_Manual_v1.0_and_v2.0.pdf.
24. Van Den Heuvel JFM, Groenhof TK, Veerbeek JHW, et al. eHealth as the next-generation perinatal care: An overview of the literature. *J Med Internet Res*. 2018;20(6):e202. doi:http://www.jmir.org/2018/6/e202
25. Al-Shammari I, Roa L, Yorlets RR, et al. Implementation of an international standardized set of outcome indicators in pregnancy and childbirth in Kenya: Utilizing mobile technology to collect patient-reported outcomes. *PLoS One*. 2019;14(10):e0222978. doi:10.1371/journal.pone.0222978

SUPPLEMENT

Appendix A: Measurement tools per patient reported ICHOM domain

PROM/PREM domain	Measurement type	Measurement instrument
Health related quality of life	Measured through	PROMIS-10 Global Health[1]
Postpartum depression	Screened through Optionally measured with	Patient health questionnaire-2 (PHQ-2)[2] Edinburgh Depression Scale (EPDS)[3]
Incontinence	Screened through Optionally measured with	ICHOM questionnaire (INCONSCREEN) Urinary incontinence short form (ICIQ-SF) and / or Wexner score[4,5]
Pain during intercourse		PROMIS-SFFAC102[6]
Breastfeeding confidence	Screened through Optionally measured with	ICHOM question (BFCONFID) Breastfeeding Self-Efficacy Scale: short form (BSES-SF)[7]
Mother-infant bonding	Measured through	Mother-to-infant bonding scale (MIBS)[8]
Birth experience	Measured through	Birth Satisfaction Scale-Revised (BSS-R)[9]
Breastfeeding intent and success	Measured through	ICHOM questions (BFINTENT and BFSUCCESS)
Confidence with role as mother	Measured through	ICHOM questions (ROLECONFID)
Satisfaction with results of care	Measured through	ICHOM questions (CARESAT)
Healthcare responsiveness	Measured through	ICHOM questions (HCR) and 4 Dutch added questions
Pain relief; Partner role; Continuity of care	Measured through	Dutch added questions

ICHOM International Consortium for Health Outcomes Measurement.

---

1 Hays RD, Bjorner JB, Revicki DA, Spritzer KL, Cella D. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Qual Life Res*. 2009;18(7):873-880.

2 Kroenke K, Spitzer RL, Williams JBW. The patient health questionnaire-2: Validity of a two-item depression screener. *Med Care*. 2003;41(11):1284-1292.

3 Bergink V, Kooistra L, Lambregtse-van den Berg MP, et al. Validation of the Edinburgh Depression Scale during pregnancy. *J Psychosom Res*. 2011;70(4):385-389.

4 De Oliveira C, Seleme M, Cansi PF, et al. Urinary incontinence in pregnant women and its relation with socio-demographic variables and quality of life. *Rev Assoc Med Bras*. 2013;59(5):460-466.

5 Parés D, Martinez-Franco E, Lorente N, Viguer J, Lopez-Negre JL, Mendez JR. Prevalence of fecal incontinence in women during pregnancy: A large cross-sectional study. *Dis Colon Rectum*. 2015;58(11):1098-1103.

6 Weinfurt KP, Lin L, Bruner DW, et al. Development and Initial Validation of the PROMIS® Sexual Function and Satisfaction Measures Version 2.0. *J Sex Med*. 2015;12(9):1961-1974.

7 Dennis C. The Breastfeeding Self-Efficacy Scale: Psychometric Assessment of the Short Form. *J Obstet Gynecol Neonatal Nurs*. 2003;32(6):734-744.

8 Taylor A, Atkins R, Kumar R, Adams D, Glover V. A new mother-to-infant bonding scale: Links with early maternal mood. *Arch Womens Ment Health*. 2005;8(1):45-51.

9 Fleming SE, Donovan-Batson C, Burduli E, Barbosa-Leiker C, Hollins Martin CJ, Martin CR. Birth Satisfaction Scale/Birth Satisfaction Scale-Revised (BSS/BSS-R): A large scale United States planned home birth and birth centre survey. *Midwifery*. 2016;41:9-15.

Appendix B1: Evaluation survey - patients

<u>Section A: baseline</u>

1. Which care professional did you discuss the questionnaire with?
   community midwife – clinical midwife – gynecologic resident – gynecologist – other

2. At which moment did you complete the questionnaire?
   1st trimester – 3rd trimester – 3 days after birth – 5 weeks after birth – 6 months after birth

<u>Section B: completing the questionnaires</u>

3. How much time did you spent on completing the questionnaire?
   [number] minutes

4. The time I spent completing the questionnaires was:
   too long – long – good – short – too short

5. Assume your care professional would send you a questionnaire about your health and experiences with care: [explain 5 time points]. We expect that completing it takes maximum 15 minutes per questionnaire, depending on the number of questions. Would you be willing to complete a questionnaire at all these moments?
   yes – no, because: [open field]

6. How would you prefer to complete the questions?
   phone/tablet (application) - phone/tablet (website) - computer (website) – on paper – other: [open field]

7. Where would you prefer to complete the questions?
   at home – in the waiting room – other [open field]

8. I completed the questionnaires:
   alone – with my partner – with someone else: [open field]

9. Did you need help with completing the questionnaires?
   yes – no

b. <u>If "yes":</u> If yes, of whom did you need help? *[open field]*

10. Do you have any remarks about completing the questionnaires?
    [open field]

Section C: statements about the questionnaires

11. The purpose of the questionnaires was clear to me.
    totally agree – agree – neutral – disagree – totally disagree
12. I understood the explanation of my care provider about the purpose of the questionnaires.
    totally agree – agree – neutral – disagree – totally disagree
13. The information folder was clear.
    totally agree – agree – neutral – disagree – totally disagree
14. I understood the questions well.
    totally agree – agree – neutral – disagree – totally disagree
15. I could fill out all questions.
    totally agree – agree – neutral – disagree – totally disagree
16. I it is pleasant to discuss the questions with my partner.
    totally agree – agree – neutral – disagree – totally disagree
17. Do you have any remarks about the questionnaires or the information folder?
    [open field]

Section D: your answers

18. Which care provider would you prefer to discuss your answers with?
    midwife – gynecologist – obstetric nurse – general practitioner – preventive child healthcare provider – other: [open field]
19. It was pleasant to discuss my answers with my care provider.
    totally agree – agree – neutral – disagree – totally disagree
20. Completing the questionnaires and the conversation about them with my care provider supported in:
    a. The preparation for the conversation with my care provider.
       totally agree – agree – neutral – disagree – totally disagree
    b. Raising my issues more easily.
       totally agree – agree – neutral – disagree – totally disagree
    c. The feeling that I take part in decisions about my care.
       totally agree – agree – neutral – disagree – totally disagree

   d. The information that I received about my pregnancy and postpartum period.
      totally agree – agree – neutral – disagree – totally disagree
   e. A better relationship with my care provider.
      totally agree – agree – neutral – disagree – totally disagree

21. Completing the questionnaires and the conversation about them supported me in something else: *[open field]*

22. Part of the questions considered how you (and your child) are doing.
    What has your preference regarding discussing your answers to these questions?
    discuss all my answers –
    discuss only my answers that are different from a group of similar women –
    I don't want to discuss them; they may be used anonymously for improving quality of care –
    I don't want to complete questions about how I am doing

23. Part of the questions considered your experiences with the care given and the care providers. What has your preference regarding discussing your answers to these questions?
    my care provider can see my answers about my experiences, so we can talk about this –
    my experiences with care & care providers are used only anonymously to improve quality of care –
    I don't want to complete questions about my experiences

24. If change of care provider occurs, for example in case of reference to the hospital or transition to maternity care: do you prefer your new care provider to see your answers?
    yes – yes, but [open field] – no, because [open field]

25. Do you have any remarks about discussing and using your answers?
    [open field]

Appendix B2: Evaluation survey - obstetric care professionals

Section A: baseline

1. Which type of care professional applies to you?
   community midwife – clinical midwife – gynecologic resident – gynecologist – other
2. At which timepoints did you pilot the questionnaires?
   1st trimester – 3rd trimester – 3 days after birth – 5 weeks after birth – 6 months after birth

Section B: overall experience with questionnaires

These questions are about your experience in general, so for all timepoints.

3. How much time did you spent (on average) explaining the goal of the questionnaires to your patient?
   [number] minutes
4. Please indicate how much you agree with the following statements:
   a. The purpose of the questionnaires was clear to me.
      totally agree – agree – neutral – disagree – totally disagree
   b. I could explain the purpose of the questionnaires well to my patient.
      totally agree – agree – neutral – disagree – totally disagree
   c. The use of the questionnaires in clinical practice is simple.
      totally agree – agree – neutral – disagree – totally disagree
5. Do you need support when using the questionnaires?
   yes - no

b. In case “yes”: If yes, with what / form whom? *[open field]*

6. The questionnaires supported the following purposes:
   a. Signaling symptoms
      totally agree – agree – neutral – disagree – totally disagree
   b. More insight in what is important to my patient
      totally agree – agree – neutral – disagree – totally disagree
   c. Delivering appropriate care to my patient
      totally agree – agree – neutral – disagree – totally disagree
   d. A better relationship with my patient
      totally agree – agree – neutral – disagree – totally disagree

   e. Empowering my patient her care
      totally agree – agree – neutral – disagree – totally disagree
   f. Insight in the quality of care in our obstetric care network
      totally agree – agree – neutral – disagree – totally disagree

7. Space for any remarks about the questionnaires in general, or explanation of your answers (for example differences between timepoints):
   [free field]

<u>Section C: experiences per time point</u>

This section is offered for each timepoint tested; dependent on the answer to question 2

8. How much time did you spent on the conversation about the answers of your patient?
   [number] minutes

9. Do you have sufficient time in daily practice to discuss the answers of your patient?
   yes – no

10. Did you spend time on other things than explanation or conversation, because of the questionnaire? (For example, a referral or extra registration)
    yes – no

b. <u>In case "yes":</u> If yes, how much time and on what? *[free field]*

11. Did you create extra time in the visit due to the completed questionnaire?
    yes – no

b. <u>In case "yes":</u> If yes, how much time and due to what? *[free field]*

12. Please indicate how much you agree with the following statements:

    a. I knew what I wanted to discuss about the answers of my patient.
       totally agree – agree – neutral – disagree – totally disagree
    b. I knew when the answers of my patient deviated from normal.
       totally agree – agree – neutral – disagree – totally disagree
    c. I knew what I had to do in case of deviant answers; which subsequent actions I could do.
       totally agree – agree – neutral – disagree – totally disagree
    d. I felt responsible for the answers of my patient.
       totally agree – agree – neutral – disagree – totally disagree

13. Space for any remarks about the questionnaires at [*one specific timepoint*]:
    [free field]

Section D: overall experience with discussing the answers

These questions are about your experience in general, so for all timepoints.

14. I want to be able to see the answers before the conversation with my patient.
    totally agree – agree – neutral – disagree – totally disagree
15. I want to be able to see the answers directly in my electronic patient system.
    totally agree – agree – neutral – disagree – totally disagree
16. To which extent do you think the answers should be discussed?
    always – only deviant answers – only if my patient wants to – other: [free field]
17. In case of deviant answers, I need most:
    a care pathway or protocol – standard referral opportunities – standard information to provide to my patient – nothing, I can solve it with my patient – other: [free field]
18. Which care professional should discuss the answers with the patient? Fill out the professional you feel is most appropriate to discuss the answers at each timepoint.

a.	T1 – first trimester:	*[free field]*
b.	T2 – third trimester:	*[free field]*
c.	T3 – 3 days after birth:	*[free field]*
d.	T4 – 5 weeks after birth:	*[free field]*
e.	T5 – 6 months after birth:	*[free field]*

19. Space for any remarks about discussing the answers:
    [free field]

Appendix C: Thematic analysis of open-survey questions

	Themes	Subthemes
Patients	Completing questionnaires	T3 barrier
		User-friendly IT tool
		Explain answers
		Time frame of questions
	Utility in clinical care	Preferred professional per domain
		Value in discussing issues
		Over-alarming
Professionals	Time investment	Time depends on issues raised
		Answers prior to visit (gain in time)
		Focus on important subjects (gain in time)
		Support from administrative staff
	Utility in clinical care	T5 barrier, yet valuable
		Responsibility
		How to discuss answers
		Value of PROM (symptom detection, important subjects)

Patients' perspectives: illustrative quotes

Subtheme T3: "At all moments, except for the maternity week probably, at that moment you really have something else on your mind" (*patient at T4, asked for reason not 5 moments*)

Subtheme preferred professional: "Depending on which question it is. If it is about breastfeeding or about mental condition, it does make a difference with whom you want to discuss something." (*patient at T2, asked for preferred professional to discuss answers)*

Subtheme value: "Good initiative!" (*patient at T4*, *free comment*)

Subtheme value: "I don't know if it had a lot of added value to the conversation, but maybe that's because my answers were relatively normal. For other women it can be nice as support, I would mainly fill it out for care improvement" *(patient at T4, free comment)*

Subtheme over-alarming: "[describes the MIBS questionnaire] …the fact that the care professional responds to this immediately makes it as if you should not feel this or if you are different from others. I felt no further need to discuss this." *(patient at T3, free comment)*

Professionals' perspectives: illustrative quotes

Subtheme focus: "I had more time for the things that were important to my patient, more focused on specific questions & advice" *(obstetrician, free comment)*

Subtheme T5: "This is an extra consultation, usually no time is scheduled for this. In specific cases, especially in case of pathology, it is good to evaluate together a little later" *(obstetrician, about T5)*

Subtheme value of PROM: "I was a bit skeptical in the beginning, but if you get the questionnaire prior to the visit, you still get a deeper insight into what is going on with the client." *(clinical midwife, free comment)*

Subtheme value of PROM: "Reference to pelvic floor specialist now clearly emerged, could have been missed if not thoroughly questioned for" *(obstetrician about T4)*

Subtheme responsibility "Another important point is when you are responsible for the patient's answers. I would like more structure or agreements about this." *(obstetrician, free comment)*

T1 1st trimester; *T2* 3rd trimester; *T3* days after birth; *T4* 5 weeks after birth; *T5* 6 months after birth.

Appendix D: Complete rating of survey statements (5-point Likert)

Figure D.1: patients' experiences

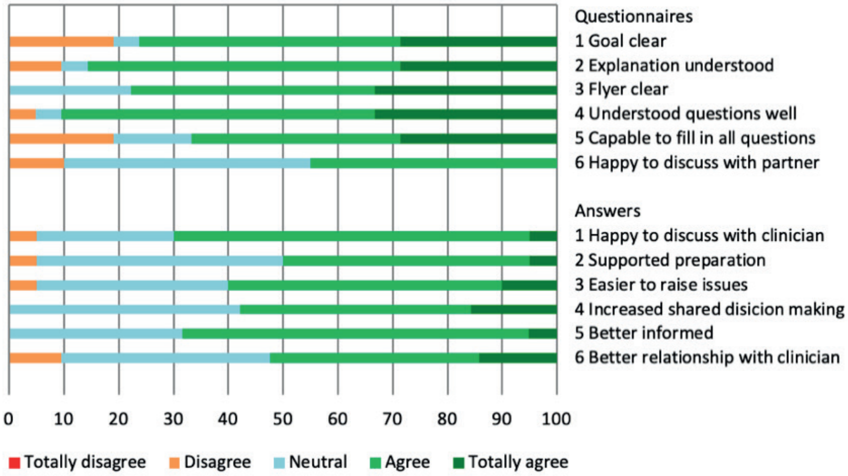


Figure D.2: care professionals' experiences (overall)

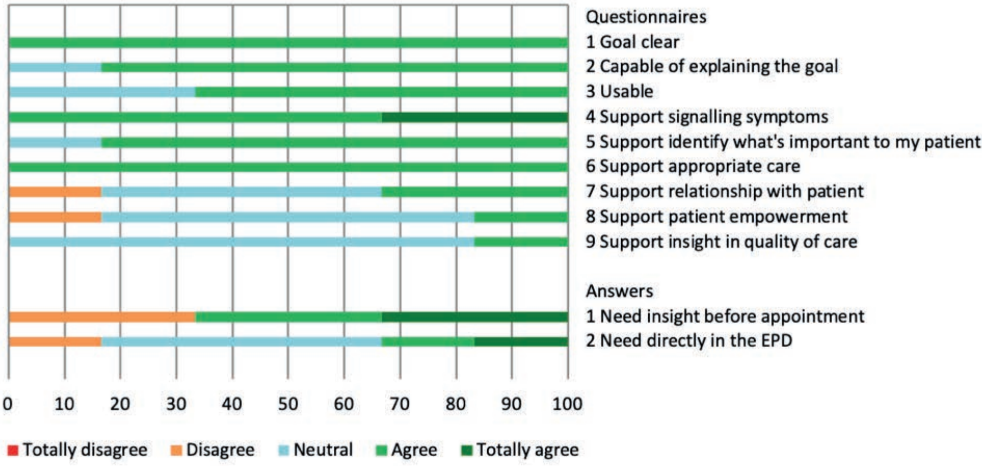
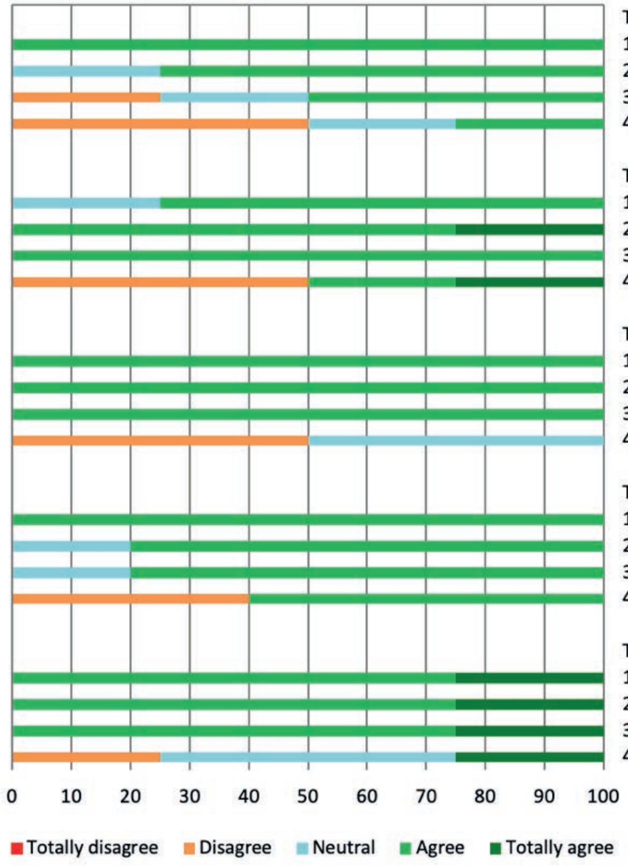


Figure D.3: care professionals' experiences (per timepoint)



4

CHAPTER 4

PROMs and PREMs in routine perinatal care: mixed methods evaluation of their implementation into integrated obstetric care networks

Anne L. Depla, Bettine Pluut, Marije Lamain-de Ruiter,
Anna W. Kersten, Inge M. Evers, Arie Franx, Mireille N. Bekker

J of Patient Rep Outcomes. 2023 Mar 9;7(26):1-15

ABSTRACT

Background In the transition towards value-based healthcare, patient-reported outcome and experience measures (PROM and PREM) are recommended by international collaborations and government programs to guide clinical practice and quality improvement. For many conditions, using PROM/PREM over the complete continuum of care requires implementation across care organizations and disciplines. Along PROM/PREM implementation in obstetric care networks (OCN), we aimed to evaluate implementation outcomes and the processes influencing these outcomes in the complex context of care networks across the continuum of perinatal care.

Methods Three OCN in the Netherlands implemented PROM/PREM in routine practice, using an internationally developed outcomes set with care professionals and patient advocates. Their aim was to use PROM/PREM results individually to guide patient-specific care decisions and at group-level to improve quality of care. The implementation process was designed following the principles of action research: iteratively planning implementation, action, data generation and reflection to refine subsequent actions, involving both researchers and care professionals. During the one-year implementation period in each OCN, implementation outcomes and processes were evaluated in this mixed-methods study. Data generation (including observation, surveys and focus groups) and analysis were guided by two theoretical implementation frameworks: the Normalization Process Theory and Proctor’s taxonomy for implementation outcomes. Qualitative findings were supplemented with survey data to solidify findings in a broader group of care professionals.

Results Care professionals in OCN found the use of PROM/PREM acceptable and appropriate, recognized their benefits and felt facilitated in their patient-centred goals and vision. However, feasibility for daily practice was low, mainly due to IT issues and time constraints. Hence PROM/PREM implementation did not sustain, but strategies for future PROM/PREM implementation were formulated in all OCN. Processes contributing positively to implementation outcomes were internalization (understand the value) and initiation (driven by key-participants), whereas challenges in relational integration (maintain confidence) and reconfiguration (refine activities) affected implementation negatively.

Conclusion Although implementation did not sustain, network-broad PROM/PREM use in clinic and quality improvement matched professionals’ motivation. This study provides recommendations to implement PROM/PREM meaningfully in practice in ways that support professionals in their drive towards patient-centred care. In order for PROM/PREM to fulfil their potential for value-based healthcare, our work highlights the need for sustainable IT infrastructures, as well as an iterative approach to refine their complex implementation into local contexts.

BACKGROUND

In the past decade, the discourse of value-based healthcare (VBHC) has had an immense uptake in healthcare.[1] At system level, healthcare systems strive to use patients' well-being to evaluate care performance for full treatment cycles for a condition.[2] At patient level, professionals aim to organize integrated care around a health condition and make personal values prescriptive to guide treatment decisions.[3] In the development towards VBHC, patient-reported outcomes and experiences measures (PROM and PREM) have been embraced to generate data about what matters to patients and drive patient-centred quality improvement (QI).[4] Therefore, the capture and use of PROM/PREM has been encouraged in many healthcare settings by international collaborations and government programs.[5,6] Nevertheless, PROM/PREM implementation remains challenging, especially in network settings like perinatal care.[7,8]

PROM/PREM implementation has been considerably studied with an implementation science approach, identifying common influencing factors such as technology and clinical leadership.[9,10] Different challenges have been described dependent on the purpose of PROM/PREM implementation. For example, a challenge for individual-level use includes fitting PROM collection to appointment schedules, while at group-level motivating care professionals for (external) QI appears more challenging.[8,9] Yet these implementation factors have been explored in single organization settings or primary care predominantly,[11,12] whereas the majority of health conditions require interdisciplinary and interorganizational collaboration across healthcare tiers to provide the full continuum of care.[13,14] As for pregnancy and childbirth, where care professionals collaborate both interdisciplinary (e.g., obstetrics, neonatology) and interorganizational (e.g., hospitals, midwife practices, youth care) to provide acute and long-term care with in-hospital, outpatient and community-based care and support. Thus, to contribute to patient- and family-centred care, PROM/PREM in perinatal care would ideally be implemented across care networks, to cover patients' whole care trajectory in individual-level use and involve all stakeholders in group-level use for QI. Yet, implementation in network context prompts other challenges, like engaging diverse stakeholders, aligning incentives and resources, and building common infrastructures.[4,15] Evaluations of individual-level PROM/PREM implementation in network context are scarce, but needed to advance our understanding of practice challenges, contextual factors, and mechanisms through which implementation strategies work across organizations.[10,16]

For perinatal care, until recently, no consensus on PROM/PREM had been formed to evaluate its patient outcomes.[17] Yet, in 2016, a set of standardized patient-centred outcomes measures for pregnancy and childbirth (PCB set) was developed internationally with perinatal care professionals and patient advocates.[17,18] This set includes PROM/PREM from beginning of pregnancy until six months postpartum. Over the last years, the PCB set has been adopted internationally and implementation efforts have been started worldwide, of which most are in research context.[19–21] Potential factors influencing PCB set adoption in practice have been explored in pre-implementation analyses, indicating all stakeholders recognized the relevance and potential benefits of PROM/PREM.[8,22] At the same time, stakeholders acknowledged important efforts yet to be made, e.g., embedding PROM/PREM into service processes or informing care professionals and patients about their purpose.

Recently, the patient-reported measures of the PCB set were implemented in three obstetric care networks (OCN) in the Netherlands, that aimed to use these PROM/PREM for two levels of VHBC: individual scores to guide patient-specific care decisions and group-level results in to improve quality of care. This implementation process was designed following the principles of action research to enhance practice change and, concurrently, gain knowledge about PROM/PREM implementation in the context of care networks. Guided by theoretical frameworks for implementation, this study aimed to evaluate 1) the outcomes of PROM/PREM implementation in obstetric care networks and 2) the implementation processes that influence these outcomes to increase our understanding of this complex implementation, its practice challenges, and underlying change mechanisms.

METHODS

Design

This mixed-methods study was conducted between December 2019 and June 2022 as part of an action research project aimed at PROM/PREM implementation in clinical practice and QI processes of OCN. Action research aims to both change practice and develop knowledge about that change via a cyclic design of action, data generation and reflection, while involving all stakeholders in research and practice change.[23] Action research is particularly useful to implement a complex intervention that needs adjustment to the local context, as detailed data are generated on both the implementation activities (what it involved) and change mechanisms (how it worked). This way, the outcomes achieved can be explained for, increasing the transferability of findings.[24] To understand the change mechanisms underlying the complex implementation of PROM/PREM, the use of multilevel implementation frameworks and theories has been recommended by scoping literature.[10,25] To evaluate PROM/PREM implementation in the context of care networks, this study combinedly used

Proctor's taxonomy for implementation outcomes,[26] and the Normalization Process Theory (NPT).[27] Proctor's taxonomy describes the outcomes of different stages in implementation, whereas the NPT describes implementation processes in terms of what care professionals (don't) do to embed a new way of working in routine practice and is distinct in proposing mechanisms for sustained uptake. Proctor and NPT guided the collection and analysis of both qualitative and quantitative data within the mixed-methods design, increasing both the depth and transferability of our findings.

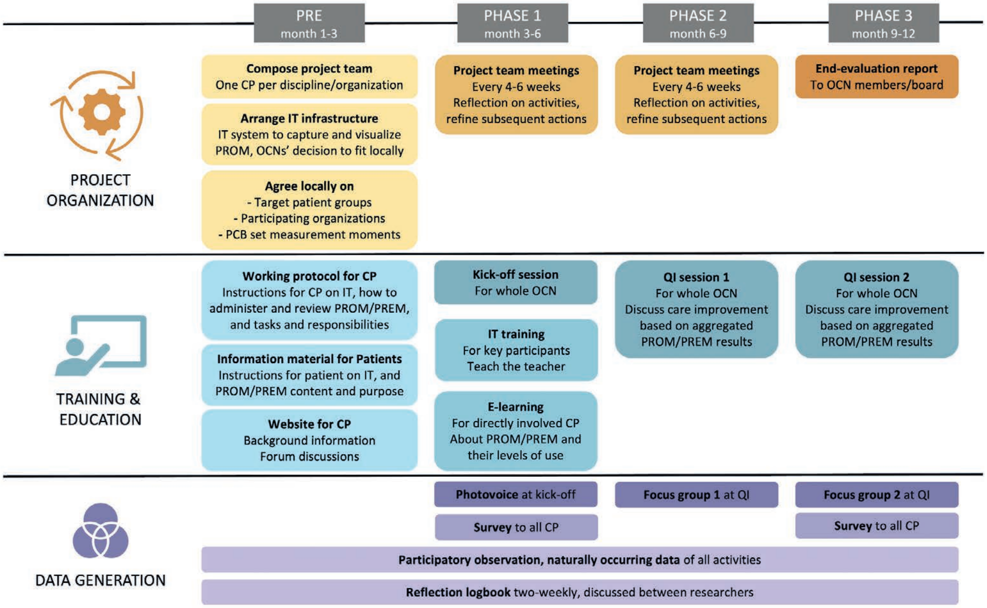
Setting and participants

Dutch perinatal care is provided interdisciplinary from two healthcare tiers: primary care by community midwives and maternity care organizations; and secondary/tertiary care by hospital employed care professionals. Hospitals, regional community midwife practices and maternity care organizations increasingly cooperate in OCN to provide continuity of care across pregnancy, childbirth and puerperium. In 2019, PROM/PREM implementation was initiated from a regional collaborative between ten OCN in the middle of the Netherlands, of which three OCN participated. In each OCN, the hospital and 2-4 midwifery practices implemented individual-level PROM/PREM in clinic. All other professionals working in the OCN (e.g., from other midwifery practices, maternity care organizations, youth care) could join network-broad QI with group-level outcomes. Each OCN had an interdisciplinary team in charge of implementation (including, at least one obstetrician, clinical midwife, and community midwife from each participating midwifery practice), of which one was appointed project leader. In this study, participants were defined as 1) professionals *directly* involved in implementation: project team members (key participants) or obstetricians/midwives using individual-level PROM/PREM, and 2) *indirectly* involved professionals: from other OCN-organizations or discipline, such as nurses. Patients were involved in implementation as they completed PROM/PREM for routine care but did not actively participate in this evaluation study. As patients had participated in our pre-implementation analysis and feasibility pilot,[8,28] their needs were incorporated in the initial implementation strategy.

Action research project

The PROM/PREM implemented in this project were those proposed in the PCB set: questionnaires at two moments during pregnancy (T1: first trimester, T2: early third trimester) and three postpartum (T3: maternity week, T4: 6 weeks postpartum, T5: 6 months postpartum). The PCB set was developed internationally and subsequently translated to the Dutch setting, both phases involving all stakeholders, including care professionals and patients.[18,29] An overview of the PCB set's patient-reported domains and timeline for completion is provided in Supplementary Figure S1. The set's PROM/PREM were implemented for two purposes. First, individual-level PROM/PREM were implemented in clinic: reviewing N=1 scores with patients during a regular care contact after completing a questionnaire. The timeline of collection, workflow, and follow-up services (including scoring and alert values) were organized as described in a national pilot project.[30] Second, the same PROM/PREM outcomes would be used at group-level in network-broad QI sessions. Despite the complexity of combining these purposes, findings in our pre-implementation research amongst care professionals, patients and other stakeholders in perinatal care suggested both goals could also reinforce each other.[8] Direct usability in clinical practice could, for instance, motivate care professionals and patients to comply, thereby generating data for group-level use (and vice-versa). Likewise, other previous findings from our pre-implementation analysis and feasibility pilot,[8,28] were used to design the initial implementation strategy. Important elements for individual-level use included visual alerts to support care professionals in interpreting the answers and offering patients a choice whether their care professional had insight in their individual PREM answers. During the action research project, this initial implementation strategy (Figure 1) was continuously refined guided by action research principles in iterative cycles of planning and executing implementation activities, data generation, and reflection on these data to refine subsequent activities. These cycles were conducted jointly by researchers and care professionals. The researchers developed the baseline strategy for project organization and education (e.g. identified possible IT-systems, developed an e-learning and kick-off meeting), provided materials and support for its execution (e.g. patient information folder, for working protocol for care professionals), and facilitated data generation for its refinement (e.g. organized focus groups, sent out the survey). The project teams designed and coordinated local implementation (e.g. adapt instruction material to local workflow, chose the IT system that best fitted local needs and resources) and participated in data generation and reflections (e.g. survey results were discussed in project team meetings, participation in focus groups). Three OCN started implementation sequentially to be able to learn from previous experiences, exchanged via the researchers and directly between care professionals from different OCN. After the one-year implementation period, project teams reported their experiences to their OCN and advised future steps in an end-evaluation.

Figure 1. Timeline of implementation and data generation activities



PROM patient-reported outcome measure; *PREM* patient-reported experience measure; *QI* quality improvement; *OCN* obstetric care network; *CP* care professional; *VBHC* value-based healthcare.

Outcome measures

First, implementation outcomes were assessed using Proctor's taxonomy of implementation outcomes. Inspired by the translation to PROM/PREM specific implementation outcomes by Stover et al,[10] implementation outcomes and the indicators to assess them were defined for this study's context (Table 1). These indicators were evaluated with survey items of the Measurement Instrument for Determinants of Innovations (MIDI), via administrative data and embedded in qualitative methods such as observation checklists. The MIDI was developed to identify factors influencing the use of an implemented intervention by measuring determinants in innovation, user, organization and socio-political context.[31] As recommended by its developers, a selection of items was made based on relevance for our context. Second, implementation processes were evaluated along the NPT, which describes four core mechanisms towards normalization. These mechanisms and their subconstructs were measured trough the validated Normalization Measurement Development (NoMAD) instrument,[32,33] and were included in the survey and qualitative methods (Supplementary Table S1). The complete survey administered to care professionals consisted of validated NoMAD and MIDI items, completed with three extra questions (about education used, knowledge level, needs in implementation) based on our feasibility pilot and PROM/PREM specific implementation literature.[28,34] All survey questions and details about scoring are provided in Supplementary Table S2.

Table 1. Implementation outcomes and their assessment

Implementation outcome	Definition	Indicators	Assessment methods
Acceptability	Perception among CP that the PROM/PREM are agreeable, palatable, or satisfactory	Expected relative advantage Expected reporting ease/comprehensible PROM/PREM and IT system	Qualitative[a] Observations[b] Survey (MIDI 8 and 15; Extra 3)
Adoption	Initial decision to implement the PROM/PREM	Participating hospitals and midwifery practices Representativeness of those clinics; reason to participate	Administrative data Observation
Appropriateness	Perceived fit, relevance, or compatibility of the PROM/PREM for **a)** midwifery practices, hospitals, CP, pregnant women, and **b)** their goal to guide personal care and quality improvement	PROM/PREM fit patient (level, language, condition, font size) PROM/PREM fit professional (visualized, easy access, decision support) PROM/PREM fit culture and values (leadership support) PROM/PREM fit goals: helpful to discuss symptoms / improve care	Qualitative Observations Survey (MIDI 9, 12, 26)
Feasibility	Extent to which PROM/PREM can be successfully used or carried out within the OCN, midwifery practice, hospital	IT: technical issues, adaptability to visualize PROM/PREM meaningful Usability for patients (access, timing) Usability for professional (time efficiency; capable; support)	Survey (MIDI 13 and 16; Extra 1) Qualitative Observations
Fidelity	Degree to which PROM/PREM were implemented as described originally	Consistency of administering PROM/PREM Professionals reviewing PROM/PREM results with patients How and why local adaptations (time points, patient groups)	Observations Administrative data
Implementation cost	Cost impact of the effort to implement PROM/PREM	Technology costs Personnel and time	Administrative data Observations; Qualitative
Penetration	Integration of PROM/PREM in OCN, midwifery practices and hospitals	Targeted patient groups Professionals: involved (or knowledge), training attendance	Survey (MIDI 18 and 28; Extra 2) Observations; Qualitative
Sustainability	Extent to which the PROM/PREM are maintained within an OCN, midwifery practice or hospital	Normalization / routinized (carry on; with what?) Stakeholder perceptions	Administrative data Observations; Qualitative

[a] Qualitative methods: indicators were embedded in coding schemes of all qualitative data (i.e., open-ended survey answers, transcriptions, observation reports, reflection logbook, naturally occurring documents). [b] Observations: performed along a checklist with these indicators while participating in implementation activities (i.e., project team meetings, kick-off sessions, QI sessions and two-weekly reflection logbook). *OCN* obstetric care network; *CP* care professional; *PROM* patient-reported outcome measures; *PREM* patient-reported experience measures; *IT* information technology; *MIDI* Measurement Instrument for Determinants of Innovations.

Data generation

A timeline of data generation along is provided in Figure 1. For quantitative data, the survey was sent to all OCN care professionals at the start and end of implementation by e-mail. Care professionals indirectly involved in implementation were led to a short version. Demographics were collected on profession and working experience. This way, the survey explored implementation processes in a broad group of care professionals, which was used to solidify qualitative findings and to guide reflection on the implementation process and needs with participants during qualitative methods. Qualitative data were generated through focus group discussions, observations, reflections and naturally occurring data. At each kick-off session, group discussion was organized using photovoice (i.e. a method to empower all participants to share their perspectives),[35] of which notes were taken for the observation report. Along the QI sessions, traditional focus group discussions were led by two researchers (AD, AK) along statements about implementation based on outcome indicators and NPT subconstructs (Supplementary Table S3). For each focus group, a selection of these statements was made to address specific gaps in data generation emerging from collective iterative reflections and quantitative results from the survey. After informed consent, focus groups were recorded and transcribed ad verbatim. During the whole implementation, two researchers (AD, ML) conducted participative observations in all meetings and kept a reflection logbook, both structured along the theoretical frameworks. Considered as naturally occurring data,[36] all documents emerging during the implementation process were gathered (e.g., meeting reports), containing administrative data too (e.g., IT system data on costs, professionals with account).

Data analysis

Quantitative survey data were analysed in R version 4.0.2.[37] Mean scores were calculated for items consisting of multiple statements and multiple items measuring a subconstruct. Frequencies of responses to items were visualized in stacked-bar diagrams to gain insights in the diversity of opinions. All qualitative data (i.e., open-ended survey answers, transcriptions, observation reports, reflection logbook, documents) were thematically analysed in Microsoft Excel version 16.61 conform QUAGOL guidelines, combining a deductive and inductive approach.[38] The researchers assigned codes from the conceptual frameworks (Proctor and NPT) as well as open codes describing themes within their concepts. At start, three researchers (AD, BP, ML) coded three documents independently, and discussed the resulting codes to develop a mature coding scheme. Data were then analysed by AD until saturation was reached, after which four researchers (AD, ML, BP, MB) reviewed and discussed the codes to establish final interpretations. Quantitative and qualitative data were then triangulated by exploring (dis) agreements and silences between both datasets. This was conducted by a single researcher (AD) identifying items and subconstructs in the quantitative dataset demonstrating particularly high or low survey scores, to compare these against qualitative themes and discuss that among the research team. In this process, quantitative data were used to solidify quantitative findings in a broader group of professionals and over time.

RESULTS

Overall, 159 surveys were returned, of which 63 (39%) in phase one and 97 (61%) in phase three. Five focus groups were held with, in total, 78 care professionals attending QI sessions. Other data (from observations, reflections, documents) were generated along 39 project team meetings, 3 kick-off sessions, 5 QI sessions, and the logbook. Participants' characteristics for the survey and focus groups are presented in Table 2. Of survey respondents, 62% (99/159) was directly involved in implementation (i.e., project team member or using individual-level PROM/PREM). Mean survey scores were largely in agreement with qualitative themes, thus strengthening each other, and are together presented per theoretical framework below. Full response frequencies per survey item are provided in Supplementary Figure S2.

Table 2. Baseline characteristics survey and focus group participants

Characteristic		Survey, N=159	Focus groups, N=79
Profession			
	community midwife	64 (40%)	39 (49%)
	hospital midwife	27 (17%)	14 (18%)
	obstetrician/gynaecologist	17 (11%)	10 (13%)
	obstetric resident	11 (7%)	9 (11%)
	obstetric nurse	21 (13%)	4 (5%)
	maternity care	13 (8%)	2 (3%)
	neonatologist/paediatrician	2 (1.3%)	0
	youth care professional	1 (0.6%)	1 (1%)
	other[a]	3 (2%)	-
OCN region			
	OCN 1	55 (35%)	11 (14%)[b]
	OCN 2	46 (29%)	34 (43%)
	OCN 3	58 (36%)	34 (43%)

[a] Managers, n=2. Missing, n=1.

[b] In OCN 1, just one focus group was held so a community midwife was interviewed here in phase 3 (month 9-12 of implementation). *OCN* obstetric care network.

Implementation outcomes

Below, Proctor's outcomes as defined in Table 1 are provided along our most important findings.

Motivations and objectives

At the start, potential benefits of PROM/PREM were recognized by most care professionals, contributing to acceptability and adoption. Care professionals expected that individual-level PROM/PREM would assist them in recognizing symptoms and identifying topics important to their patient and empower patients to prepare visits and raise issues. Moreover, care professionals expressed enthusiasm for using group-level PROM/PREM for patient-centred quality improvement. Patients' opinions were care professionals' main motivation to comply and 54% (46/85) of survey respondents expected their cooperation, whereas 11% (9/85) did not.

Experienced benefits

According to care professionals, system-wide PROM/PREM capture and use facilitated their patient-centred goals and vision, expressing good appropriateness. In consultations, several care professionals felt supported by PROM/PREM results to identify and discuss patients' issues, sometimes leading to richer conversations and/or appropriate referrals. From the group-level PROM/PREM data in QI sessions, care professionals gained valuable insights and directions for improvement in their patients' wellbeing and experiences, which contributed to their work pleasure. In practice, the PROM/PREM content was considered appropriate for most of their patients, except for non-Dutch speaking women and those with low health literacy, who care professionals hesitated to invite for that reason. Also, some adaptations to PROM/PREM content were suggested, such as open answer options to enable personalized care even more.

Experienced barriers

Whilst most care professionals strongly favoured integration in their electronic health record (EHR), the locally explored IT options either could not function across different EHRs, or their costs to realize that were too high. Hence, in each OCN, an affordable start-up IT system without EHR integration was chosen, that promised automated data capture, visualization for care professionals, network communication and privacy. This IT system enabled PROM/PREM adoption in all participating practices per OCN but became the main barrier for acceptability, feasibility, and further implementation. Care professionals did not consider it to be user-friendly (complicated access, frequent issues and bugs, poor overview, not visible whether responses had been discussed and unable to connect PROM/PREM measurements to visits) and felt increasingly frustrated by the IT supplier's slow pace, and sometimes inability, to solve issues. Although their patients often appeared willing to complete PROM/PREM, IT was considered a major barrier for patients too, due to poor accessibility and bugs, leading to privacy concerns too. Other patient barriers mentioned were a lack of motivation or time (especially postpartum) and misunderstanding of the purpose.

Additionally, the high time investment for care professionals negatively influenced acceptability (44% of care professionals (60/135) expected it would take too much time), appropriateness (for their high current workload) and feasibility (of workflow integration). Factors contributing to a high time investment in practice included the administrative burden of the non-integrated IT system, instructing patients, reviewing PROM/PREM results, and learning a new skill.

Costs

The IT systems' costs and care professionals' time investment (i.e., project team efforts and using PROM/PREM in practice) were the main drivers for implementation costs. In two of three OCN, these costs demanded external funding (used for the IT system and project leader allocation); the third OCN could finance them from a joint reimbursement structure.

Fidelity and penetration

The process of creating an account for the external IT system, inviting patients, and discussing individual PROM/PREM responses required continuous support from project teams and action researchers to reach fidelity and penetration in participating practices. At start, project teams decided to begin with a selection of patient groups, measurement moments (all selected T1–T4) and care professionals. Eventually, most targeted care professionals created an IT system account, but only few actively invited patients: others often missed eligible patients due to time constraints and low exposure resulting from the patient group selection. Half of the invited patients created an account and completed PROM/PREM; postpartum response rates were lower. Based on experiences shared in project team meetings, almost all completed PROM/PREM were discussed in the next visit, except in case of IT bugs or care transitions in the maternity week (T3). Regarding group-level PROM/PREM use, five QI sessions were carried out during the pilot periods. Reflecting good fidelity, local care professionals actively participated in preparation, presentation, and elaboration of these sessions, which were attended by an average of 17 (range 11-25) care professionals representing all participating disciplines. Unlike in-clinic PROM/PREM use, QI sessions extended penetration to care professionals without direct involvement in implementation.

Sustainability

Except for one community midwifery practice that sustainably integrated PROM/PROM, routine PROM/PREM administration was stopped in all OCN after the one-year implementation period. However, all OCN intended to continue the QI sessions with data available in the OCN and, after EHR integration, reinitiate PROM/PREM capture and use. After the decision to stop, the second QI session in one OCN was not conducted, because the project team expected it would be of more benefit to a future restart.

Implementation process

The complete NPT framework analysis is listed in Table 3 with supportive qualitative and quantitative data (mean survey scores on a 5-point Likert scale) per subconstruct. Per core mechanism, subconstructs contributing most to (un)successful implementation outcomes are elaborated on below. Overall, main processes contributing to implementation positively were *internalization* (understand value) and *initiation* (drive by key-participants), whereas *relational integration* (maintain confidence) and *reconfiguration* (attempts to redefine) affected implementation negatively.

Coherence: sense-making

As terminology like PROM/PREM and VBHC often appeared abstract at the start, hearing experiences directly from participants of earlier regions helped to gain understanding of practical aspects. This was arranged both across and within OCN enhancing *differentiation* and *individual specification*. Care professionals early recognizing the potential benefits of PROM/PREM contributed to *internalization* and willingness for implementation. The ability to incorporate patients’ voice in QI appeared their main driver, so they were enthused by the QI sessions. Although some experienced that individual-level PROM/PREM supported time-efficiency and personalized care by discussing important rather than all topics, care professionals felt they needed more exposure to these benefits for sustained *internalization*.

Table 3. Framework analysis for the NPT subconstructs with supportive data

NPT mechanisms and subconstructs	Framework analysis	Illustrative quotes and observations
Coherence "Sense-making work as individuals and collective"		
Differentiation	- Most CP able to differentiate PROM[a] from normal work. - Terminology (ICHOM, VBHC, PROM) made it abstract. - Helped by previous experiences, kick-off session, e-learning.	PTM1, OCN 3, HM/PL(OCN2): [preparing kick-off session, PL of OCN2 attends PTM to help] *"I would present the practical aspect of discussing PROM answers, along an example case. Otherwise, it remains quite abstract with the ICHOM circle and value-based healthcare."*
Communal specification	- Shared vision amongst kick-off and QI session participants: goal is patient centred care and collaboration for better outcomes. - Varied per OCN if staff had aligned project goals and whether their goal was clear to CP in clinic. - Easier in OCN with a more mature organization structure.	PTM18, OCN1, report: [after doubts in previous meeting] *"Looking back, participation of X (the hospital) and X (a midwifery practice) in this project has surely been discussed and decided upon in the OCN. They would start with the PROM and evaluate whether it's feasible to move up with the whole OCN and would report that to the OCN."*
Individual specification	- Most CP comprehended individual tasks, supported by the protocol, IT training and key participants. - PROM often interpreted as research: both CP and patients.	PTM18, OCN1, observation: *"She (CM), and the other project team members, have always interpreted the PROM as research and informed patients that way too. […] Now, she informs her patients clearer that PROM completion is for their own care and, thereby, in their own good. She states that she gets more responses and has to 'go after it' less. That is also really motivating for themselves (CM + her colleague)."*
Internalization	- Most CP constructed potential value of PROM at start. - Helped further by e-learning, kick-off session and previous experiences. - Not all CP aware of ownership to use group-level PROM for QI.	QI1, OCN3, mentimeter: [after introduction video: what attracts you in the video?] (Attending CP) *"Honest answers, ability to raise issues, more fulfilment of work, elaboration of a person, customized care, patient at the centre, being seen, prepared for situation, personal attention."*
Cognitive participation "Relational work to build and sustain a community of practice around the intervention"		
Initiation *Mean survey score[b]: 3.82*	- Project leader and team members initiated with training and support. These key-participants felt facilitated by one-year implementation period (felt as 'try out') and by the action research project providing materials, support and earlier regions experiences. - Still, for some CP, it felt the PROM appeared without explanation. - Towards end: key-participants stopped motivating their peers, feeling they asked too much effort whilst IT issues were unresolved.	Kick-off, OCN2, observation: *PL takes charge in the presentation, including general information and vision why the project is carried out. […] The project team members are clearly the early adopters / key-participants, also clear for the other CP attending this kick-off session. The project team members have completed the e-learning and the IT training already {before this kick-off session)."*

NPT mechanisms and subconstructs	**Framework analysis**	**Illustrative quotes and observations**
Enrolment *Mean survey score: 3.84*	- Most CP open to working with PROM, some wanted to await results. - Sceptic/hesitant about technology, time investment, patient burden. - Helped by education/training, but continuous attention and support in practice more important regarding low training attendance. - Impaired by little real-life contact (COVID-19 pandemic). - Harder in larger organizations with distant leadership.	*Kick-off, OCN2, observation: [question attitude towards PROM]: Most CP answer positive, few neutral, no negative. CPs answering positive share they have a better understanding of what is expected from them. They praise the project team for their good preparations and hard work. CP answered neutral because of worries about IT, workload, and uncertainty about the exact time investment.”*
Legitimation *Mean survey score: 3.48*	- Most midwives and obstetricians considered PROM a legitimate part of their role (except T5). Others felt not in need of PROM to discuss the topics these PROM address: felt as check / registration burden. - CP without active involvement invited to QI sessions (i.e., obstetric nurses, preventive youth care, non-participating CM) had to attend before understanding their valid contribution.	Interview, OCN1, CM: *“It somewhat has been brought, in my experience, like “well this is really the tool to provide personal care”. […] In my opinion, I already provide very personal care and all freedom for women to feel the opportunity to raise their personal items. [...] And yes, then we [CP] get the next check off list on our plates.”*
Activation *Mean survey score: 3.69*	- Over time, IT issues for both CP and their patients created resistance. - Most CP stopped working with PROM because too much effort and time (mainly IT, see feasibility) for little gain (low PROM exposure). - Key-participants and OCN boards continued to support the potential of PROM for VBHC and looked for alternatives to embed them.	Focus group, OCN2, multiple CP: “*(CM3) yes but the question… the content of the project: that was something we fully supported. Well, I’ll speak for myself, I fully supported that. Only how the IT system… that was where it got stuck on for me. (CM2) well, for everybody here (OB) also for our patients”*
Collective action “Operational work to enact a set of practices”		
Interactional workability *Mean survey score: 2.91*	- Protocol and experiences form earlier regions helped. Still, hard to integrate PROM in clinical routine (IT issues, time). - Different experiences of CP how long the PROM took to discuss, but existing workload was already high, with little time to learn new skills. - CP needed more exposure to build routine. Yet local project teams hesitant with expansion because of time investment and IT struggles.	Evaluation report, OCN2, CM: *“However, the usability [of the IT system] causes irritation, both in midwives as well as patients. Our patients complain about leaving personal data, the barrier to log-in and recurrent reminders even if they already completed the PROM. For midwives, integrating PROM in their consultations remained difficult, having to log-in to an external system is a barrier.”*

NPT mechanisms and subconstructs	Framework analysis	Illustrative quotes and observations
Relational integration *Mean survey score: 3.71*	- PROM were mostly an individual task in clinic, highest workload CM. - Group-level PROM results led to conversations about improvement opportunities in the OCN, motivating CPs' implementation efforts and contributing positively to working culture and pleasure. - Trust in the innovation was negatively affected by bad functioning IT system, privacy questions and PROM content or timing.	PTM18, OCN1, report: *"She (HM) also states that she feels all negative emotions about the use of the IT system also affect CP's receptivity for the idea of value-base care."* Evaluation report, OCN2, HM/PL: "*A hindering factor for CP was the uncertainty whether questionnaires were sent out. Sometimes they would not be sent out at all, and it wasn't clear to the CP whether this was due to the IT system or a problem in patient's registration."*
Skill set workability *Mean survey score: 3.41*	- Most CP felt skilled to use PROM in clinic and for QI. CP negative on self-efficacy, CP needed more time, administrative staff, open answer options to the PROM, and better IT and data-analysis. - Allocating administrative tasks was difficult because of the external IT system (e.g., manual tasks: enter delivery date, invite patients).	PTM8, OCN1, PL: *"After birth, date of delivery has to be entered in the IT system directly to send out the postpartum questionnaires on time. The project team suggests allocating this task to the secretary. They should be contacted to discuss their possibilities."*
Contextual integration *Mean survey score: 3.44*	- CP felt PROM need to be integrated in their EHRs, but also easy to share across organizations, but at this point impossible. - Resources (for project leader, IT, data analysis), external incentives (policy guidelines) and accreditation for learning were helpful. - Resources and leadership support varied, dependent on collaboration (and reimbursement) structure of OCNs and size of individual practices.	Evaluation report, OCN3, CM: "*Working in a system accessible across practices is nice! It is a pity we have to log-in to an external system first, and that this system isn't connected to you own EHR. That would make it way easier to use as it [external system] costs a lot of extra time."* PTM16, OCN2, OB: *"This [decision to stop at end of project] represents two points very clearly: the need for one EHR and the fact that we have had many start-up problems in this project"*
Reflexive monitoring "Appraisal work to assess and understand the ways that the innovation affects them and others"		
Systemization	- Response rates and practice experiences with input from colleagues (directly and from survey), discussed in project team and QI sessions. - Some CP discussed (negative) experiences amongst each other, without sharing with the project leaders. - Some CP indicated they did not receive feedback on project results or adaptations and felt unheard in their struggle to integrate in workflow. - Each team planned an evaluation report to their OCN at 12 months.	PTM7, OCN2, report: (PL) *"The project team questions whether we generate enough patients with the current selection in patient groups. […] In case of little patients filling out PROM, there is a large change we forget to discuss completed PROMs. The decision is to start with the current patient groups, then evaluate whether we see enough patients, and if needed per January expand with diabetes gravidarum patients."*

NPT mechanisms and subconstructs	Framework analysis	Illustrative quotes and observations
Communal appraisal	- CP's and patient's experiences were leading in evaluating PROM value. - Overall, the value of PROM for daily practice and QI were seen but did not way the extra workload due to IT issues and the burden of an external system.	Evaluation report, OCN3, CM: "*As midwifery practice, we perceived that the use of PROM could lead to women preparing more consciously for a visit. As CP, we experienced that we sometimes gained more information in visits with PROM than without. Hence, topics like pain, urine and stool problems were discussed more often.*"
Individual appraisal	- Many CP appreciated value of group-level PROM results for QI. - Appraisal for individual-level PROM was various across CP: in general, more valuable to hospital CP than community midwives. - PROM were considered unsuitable for women with low health literacy/non-Dutch speaking, whom CP believed would most benefit.	Evaluation report, OCN3, CM/PL: "*The QI sessions were inspiring and binding for our OCN and really led to positive action points for the OCN. Many of the attending CP reported afterwards to be enthusiast about using this method*."
Reconfiguration	- Learning from practice experiences and other regions, adaptations were made in close collaboration with the IT system. - Appeared hard to improve IT functionality, allocate administrative tasks and PROM content/timing. - At the end, conditions for future restart were formulated in evaluation reports to their OCN management.	PTM7, OCN3, OB: *"I had expected that it [the IT system] would be more developed, the technique works quite difficult. This whole meeting was about IT, it's disturbing it can't be tackled now. It has to be easy, and at the moment, I don't experience it that way. X (PL) and X (OBR) are constantly on top of it: that really takes an excessive amount of time."*

[a] PROM includes PROM and PREM in this table. [b] Rated on a 5-point Likert scale: a higher score indicates a more positive attitude. *PROM,* patient-reported outcome measures. *PREM*, patient-reported experience measures. *CP* care professional; *VBHC* value-based healthcare; *ICHOM* International consortium of health outcome measurement (developer of PCB set); *OCN* obstetric care network; *IT* information technology; *QI* quality improvement; *T5* time point 5 for measurement of patient-reported domains of the PCB set (6 months postpartum); *PTM* project team meeting; *CM* community midwife; *HM* hospital midwife; *OB* obstetrician/gynaecologist; *OBR* obstetrics/gynaecology resident; *PL* project leader (of local implementation team).

Cognitive participation: relational work

Formally appointed local project leaders mainly drove *initiation*, particularly if this was a clinician from a participating practice with OCN management support (both in resources and vision). Project team members representing each participating practice and discipline could engage colleagues, reflect on practical challenges, and establish possible solutions. *Initiation* by key-participants was facilitated by action researchers' activities (e.g., share experiences and materials, participate in identifying and solving issues, practical support) and by the one-year implementation period, making them feel able to try PROM/PREM without being 'stuck' to them. Whether local key-participants drove *initiation* or relied on the action researcher, depended on the level of ownership felt by local project teams. In-clinic support from key-participants and action researchers was most important for *enrolment* of other care professionals, since training reached a minority: 22% (22/99) of survey respondents had used support or training. *Enrolment* was harder in large practices, as care professionals felt less influence on the decision (or had little knowledge of the reasons) to participate. Care professionals differed in their feeling of PROM/PREM being a *legitimate* part of their role, which could be supported by positive practice experiences or those of colleagues. Additionally, *enrolment and legitimation* appeared to improve by the QI sessions, where valuable interprofessional conversations led to concrete improvement actions. However, care professionals' positive expectations and involvement decreased over time by enduring IT issues and low exposure to benefits. At the end, (key) participants kept support for the potentials of PROM/PREM for VBHC and formulated future strategies for sustainable *activation*.

Collective action: operational work

Discussed in 92% of project team meetings (36/39), feasibility issues dominated the implementation process and impaired workflow integration (i.e., *interactional workability)*. Key-participants' and action researchers' time and efforts mainly went into getting the IT system working and supporting users (care professionals and patients) in operational work. Project teams experienced a vicious circle of poor-usable IT and not building up workflow routine: their attempts to increase routine, like expanding patient groups, were withheld by IT issues and concurrent time investment. The IT system affected participants' confidence in the innovation (i.e., *relational integration*), especially the inability to improve or solve issues in time. Also, reliability of PROM/PREM results was questioned, because care professionals experienced varying clinical relevance of alerts, inappropriate timing, unsuitable answer options and, at group-level, numbers were too small. Most care professionals expressed confidence about discussing PROM/PREM, but the challenging part of *skill set workability* was allocating all tasks appropriately, for example ensuring that individual-level PROM/PREM were discussed across participating practices. To solve this, allocating a principal care provider to discuss PROM/PREM was opted by care professionals, both to keep overview of which responses had been discussed, as to gain most value from that conversation in a trusted relationship.

Reflexive monitoring: appraisal work

Facilitated by action researchers, project teams continuously reflected on (*systemization*) and tried to refine (*reconfiguration)* processes to improve implementation, like standard phrases to report PROM/PREM conversations to decrease administration burden. *Reconfiguration* was easier for smaller practices, such as temporarily collect T3 (maternity week) on paper to increase response rates. However, limited adaptability was experienced for several reasons: IT suppliers' inability to improve, time constraints and the PCB set's international origin. Key-participants' evaluation reports stated *reconfigurations* needed for future restart and sustained implementation. For individual use, PROM/PREM should be easily accessible for patients and professionals, with EHR-integration across the network. For QI with group-level data, essential aspects were data analysis and visualization (provided by the researchers during the action research project) and linking PROM/PREM to clinical outcomes.

DISCUSSION

In this mixed-method evaluation of PROM/PREM implementation in the context of care networks, the use of PROM/PREM was found to be acceptable and appropriate but not feasible in daily practice, mainly due to IT issues and time constraints. Hence PROM/PREM implementation did not sustain, but their potentials for VBHC fitted professionals' motivation and strategies for their future adoption were formulated in all OCN. In line with previous evidence,[10,11] our findings affirm the value of individual-level PROM/PREM for clinical care perceived by professionals and emphasize the need for workflow integration. Based on participants' and researchers' reflections on the re-adjusted, co-created implementation strategy, recommendations for PROM/PREM implementation across care networks were formulated in end-evaluations and summarized in Table 4. To embed these recommendations, an iterative approach is key to adjust to local context.

Table 4. Recommendations for PROM/PREM implementation across care networks

Aspect	Recommendations
PROM/PREM content	Individualize questionnaires: text field to elaborate on answers given
	Local adaptations to complement clinical workflow
	Ongoing PCB set governance based on implementation experiences in international collaboration.
Training and support	Implementation support available in clinic
	Allocation of administrative staff
	PROM/PREM expert and clinical leader to drive implementation
	Learning directly from experiences in other regions
	Continuously inform CP and patient of primary purpose
Network collaboration	Case manager to discuss PROM/PREM for continuity across providers
	Infrastructure for data exchange across different providers/EHRs
	Connective leadership to focus innovations
IT and resources	PROM/PREM access integrated in EHR (CP and patient)
	Sustainable funding for network collaboration to develop/arrange data exchange across different providers
	External incentives (policy guidelines and protocols; time and accreditation for learning)

CP care professional; *PCB set* pregnancy and childbirth outcome set; *PROM* patient-reported outcome measures; PREM patient-reported experience measures; *EHR* electronic health record.

Despite tailoring the strategy to our pre-implementation analysis amongst patients and care professionals and further adaption of implementation activities during each action research cycle,[8,28] the feasibility of integrating PROM in practice was lower than expected, largely explainable by poor usability of the IT system chosen at start. Of the numerous PROM/PREM capture systems developed in the past years, most were designed for single centre settings or group-level, anonymous use only.[11,39,40] Besides healthcare systems with a shared EHR,[41] successful system-wide PROM collection with direct visualization for individual-level use in clinic has proven challenging to realize and was only recently described and developed in a Welsh national program.[42] To support PROM/PREM implementation and network collaboration for patient-centred care, there is a need for PROM/PREM integration into EHRs and, moreover, infrastructures for cross-EHR data exchange.[43] Structural financial support for their development and governance should be explored, as most network collaborations are temporarily funded which undermines adoption, feasibility, and sustainability.[4,11,44]

Previous PROM/PREM implementation strategies, both at the individual and group level, often emphasize the selection of PROMs and the challenge of involving care professionals.[5,11,45] Although we acknowledge their importance, most care professionals in our study already demonstrated a positive attitude towards PROM/PREM at start, reflected in good coherence and cognitive participation and consistent with previous findings.[22,41] They were keen to learn from previous experiences and motivated by the prospective of patient-centred QI with group-level PROM/PREM, which fuelled their efforts for individual-level implementation as well. In current healthcare landscape with professional shortage and high turnover, care professionals' work pleasure might be one of the most valuable benefits of PROM/PREM.[46,47] Despite feasibility challenges and IT issues, key participants' threshold to adopt such complex implementation was lowered by the iterative approach that gave space to 'try out' and adapt to local context, which has enabled them to get acquainted with PROM/PREM and their potential for VBHC. Concurrently, other care professionals felt demotivated and overruled by management when unaware of the reasons to participate in such implementation and driving their workload even higher. So new initiatives should be carefully selected and coordinated across care networks, where an iterative approach to implementation can provide space for early adopters' energy, sharing practice experiences to engage others, and fine-tuning to local context.

The integrated care context affected implementation not only by challenges in IT infrastructure, fragmented leadership and allocation of costs, but also in consistency of discussing individual-level PROM/PREM results across care transitions. To ensure that individual-level results were discussed, care professionals opted to allocate a principal care provider, arguing that a conversation about the topics would gain most value in a trusted relationship, similar to a solution to improve continuity of perinatal care in general.[48] However, these issues arising from network-broad implementation are lacking in current PROM/PREM implementation frameworks and strategies.[9,10] Further research within real-life projects should identify and address barriers and enablers for innovation across organizational boundaries. That way, innovations can improve value of care for individuals and overall care performance from patients' perspective.

Reflecting on the action researchers' role, many similarities were seen with the facilitator role described by Roberts in the iPHARIS framework.[49] Similar to their findings, our action researcher was a crucial enabler for implementation, providing an external view with expert knowledge to identify and solve emerging issues in practice, especially in collaboration with the local project leader. Additionally, participating in all regions resulted in overview, expertise and sharing previous lessons in new regions. However, the tension between guidance in problem solving and doing the work to fit local workflow was present in our projects as well: in some regions, the PROM/PREM workflow never became completely independent of the action researcher. Across OCN, the level of implementation ownership of the project teams varied, which could partly be explained by existing collaboration mechanisms and integrated reimbursement in some OCN.

As called for in recent literature,[10,16] this study substantially contributes to the understanding of care professionals' real-life experiences and challenges for PROM/PREM implementation, specifically addressing the integrated care context in a realistic range of collaborating organizations. In the mixed-methods design, consistency in data from different sources and methods strengthened our findings. Also, our data collection and analyses were supported by widely used implementation science theories and their validated instruments. The iterative, participatory action research approach enabled in-depth understanding of implementation activities, processes and outcomes, which contributes to the transferability of findings. An important limitation of our study was that we did not invite patients to the evaluation of the implementation process and outcomes, except indirectly via care professionals. We did explore patients' experiences with individual-level use in another study along a national pilot with the PCB set,[50] while the current project focused on the (organizational challenges of) implementation. In next action cycles, patients should be certainly involved. Here, special attention should go to women with low health-literacy and language barriers, who are prone to be neglected by PROM/PREM, to prevent existing health inequities becoming even larger.[51] Besides providing digital support and translating questionnaires, solutions to involve these women should be sought outside the idea of questionnaire completion. In thinking of solutions, research methods should be embraced that centralize patients and local opportunities (e.g. linkage to primary care, community-based solutions).[52,53] Another limitation of our study is that the IT system used appeared such a major barrier to implementation, that other factors might have been undervalued. Selection bias of both early adopter OCN and professionals is likely to have enhanced a positive attitude towards PROM/PREM. We attempted to reach professionals broader by inviting the whole OCN for QI sessions and the survey, which had a short version for indirectly involved professionals. Lastly, the COVID-19 outbreak has probably influenced care professionals' willingness and ability to adopt a new way of working, affected implementation planning (e.g., paused, postponed) and restricted study activities to online contacts with minimal field work.

Conclusions

Although implementation did not sustain, network-broad PROM/PREM use in clinic and for QI matched professionals' motivation for patient-centred care. This study provides recommendations to implement PROM/PREM meaningfully in practice, in ways they support professionals in their drive towards patient-centred care by efficient, person-centred assessment of patients' wellbeing. For PROM/PREM to fulfil their potential for VBHC, our work highlights the need for sustainably funded technology infrastructures that communicate across healthcare tiers, as well as an iterative approach to refine their complex implementation to local contexts.

REFERENCES

1. Groenewoud AS, Westert GP, Kremer JAM. Value based competition in health care's ethical drawbacks and the need for a values-driven approach. *BMC Health Serv Res*. 2019;19(1):1-6. doi:10.1186/s12913-019-4081-6
2. Zorginstituut Nederland. Meer patiëntregie door meer uitkomstinformatie in 2022. 2018:Available from: https://www.zorginstituutnederland.
3. Steinmann G, Van De Bovenkamp H, De Bont A, Delnoij D. Redefining value: a discourse analysis on value-based health care. *BMC Health Serv Res*. 2020;20(1):1-13. doi:10.1186/s12913-020-05614-7
4. Austin E, LeRouge C, Hartzler AL, Segal C, Lavallee DC. Capturing the patient voice: implementing patient-reported outcomes across the health system. *Qual Life Res*. 2020;29(2):347-355. doi:10.1007/s11136-019-02320-8
5. NHS England. *National Patient Reported Outcome Measures (PROMS) Programme Guidance*. Leeds; 2017. https://www.england.nhs.uk/wp-content/uploads/2017/09/proms-programme-guidance.pdf.
6. Alonso J, Bartlett SJ, Rose M, et al. The case for an international patient-reported outcomes measurement information system (PROMIS®) initiative. *Health Qual Life Outcomes*. 2013;11(1):1-5. doi:10.1186/1477-7525-11-210
7. Greenhalgh J. Understanding the complexities of collecting and using PRO data in a primary care context. *BMJ Qual Saf*. 2021:bmjqs-2021-013315. doi:10.1136/bmjqs-2021-013315
8. Depla AL, Crombag NM, Franx A, Bekker MN. Implementation of a standard outcome set in perinatal care: a qualitative analysis of barriers and facilitators from all stakeholder perspectives. *BMC Health Serv Res*. 2021;21(1):1-13. doi:10.1186/s12913-021-06121-z
9. Foster A, Croot L, Brazier J, Harris J, O'cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient-Reported Outcomes*. 2018;2:46. doi:10.1186/s41687-018-0072-3
10. Stover AM, Haverman L, van Oers HA, et al. Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in routine care settings. *Qual Life Res*. 2021;30(11):3015-3033. doi:10.1007/s11136-020-02564-9
11. Gelkopf M, Mazor Y, Roe D. A systematic review of patient-reported outcome measurement (PROM) and provider assessment in mental health: Goals, implementation, setting, measurement characteristics and barriers. *Int J Qual Heal Care*. 2021;33(1). doi:10.1093/intqhc/mzz133
12. Biber J, Ose D, Reese J, et al. Patient reported outcomes – experiences with implementation in a University Health Care setting. *J Patient-Reported Outcomes*. 2018;2:34. doi:10.1186/s41687-018-0059-0
13. Van Kemenade E, De Kuiper M, Booij M, Minkman M. How Different Quality Paradigms Undermine a Shared Value Base for Integrated Care: The Need for Collective Reflexivity. *Int J Integr Care*. 2022;22(1):1-6. doi:10.5334/ijic.5935
14. Pascucci D, Sassano M, Nurchis MC, et al. Impact of interprofessional collaboration on chronic disease management: Findings from a systematic review of clinical trial and meta-analysis. *Health Policy (New York)*. 2021;125(2):191-202. doi:10.1016/j.healthpol.2020.12.006
15. D'Amour D, Goulet L, Labadie JF, Martín-Rodriguez LS, Pineault R. A model and typology of collaboration between professionals in healthcare organizations. *BMC Health Serv Res*. 2008;8:118. doi:10.1186/1472-6963-8-188

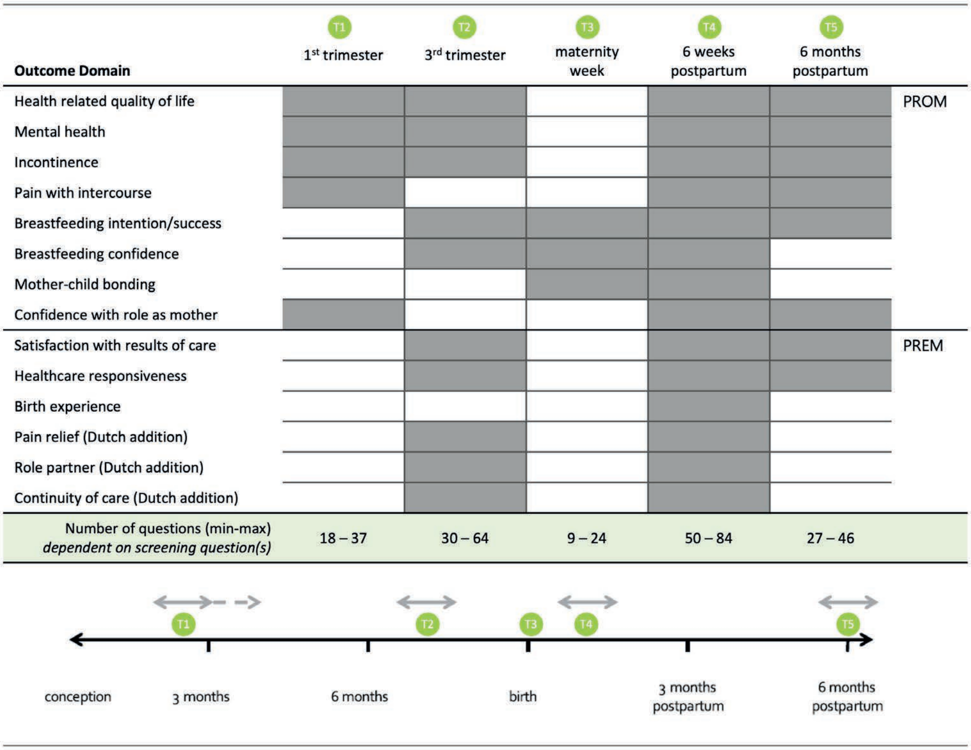
16. Wolff AC, Dresselhuis A, Hejazi S, et al. Healthcare provider characteristics that influence the implementation of individual-level patient-centered outcome measure (PROM) and patient-reported experience measure (PREM) data across practice settings: a protocol for a mixed methods systematic revie. *Syst Rev*. 2021;10(1):1-12. doi:10.1186/s13643-021-01725-2
17. Sudhof L, Shah NT. In pursuit of value-based maternity care. *Obstet Gynecol*. 2019;133(3):541-551. doi:10.1097/AOG.0000000000003113
18. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
19. Al-Shammari I, Roa L, Yorlets RR, et al. Implementation of an international standardized set of outcome indicators in pregnancy and childbirth in Kenya: Utilizing mobile technology to collect patient-reported outcomes. *PLoS One*. 2019;14(10):e0222978. doi:10.1371/journal.pone.0222978
20. Chen A. Introducing Patient Reported Measures (PRMs) Into Finnish Public Maternity Service : A Study on Professionals ' Views. *BMC Health Serv Res*. 2021;21:645. doi:10.1186/s12913-021-06658-z
21. Slavin V, Gamble J, Creedy DK, Fenwick J, Pallant J. Measuring physical and mental health during pregnancy and postpartum in an Australian childbearing population - Validation of the PROMIS Global Short Form. *BMC Pregnancy Childbirth*. 2019;19(1):1-19. doi:10.1186/s12884-019-2546-6
22. Chen A, Väyrynen K, Leskelä RL, et al. A qualitative study on professionals' attitudes and views towards the introduction of patient reported measures into public maternity care pathway. *BMC Health Serv Res*. 2021;21(1):1-15. doi:10.1186/s12913-021-06658-z
23. Lieshout F van, Jacobs G, Cardiff S. *Actieonderzoek: Principes Voor Verandering in Zorg En Welzijn [Action Research: Principles for Change in Health and Welfare]*. Koninklijke Van Gorcum BV; 2017.
24. Dixon-Woods M, Bosk CL, Aveling EL, Goeschel CA, Pronovost PJ. Explaining Michigan: Developing an Ex post theory of a quality improvement program. *Milbank Q*. 2011;89(2):167-205. doi:10.1111/j.1468-0009.2011.00625.x
25. May CR, Cummings A, Girling M, et al. Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions : a systematic review. *Implement Sci*. 2018;13(1):1-42. doi:10.1186/s13012-018-0758-1 RESEARCH
26. Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Heal Ment Heal Serv Res*. 2011;38(2):65-76. doi:10.1007/s10488-010-0319-7
27. May CR, Mair F, Finch T, et al. Development of a theory of implementation and integration: Normalization Process Theory. *Implement Sci*. 2009;4(1):1-9. doi:10.1186/1748-5908-4-29
28. Depla AL, Ernst-Smelt HE, Poels M, Crombag NM, Franx A, Bekker MN. A feasibility study of implementing a patient-centered outcome set for pregnancy and childbirth. *Heal Sci Reports*. 2020;3(3). doi:10.1002/hsr2.168
29. Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. *Patient Educ Couns*. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022
30. Depla AL, Ruiter ML, Laureij LT, et al. Patient-Reported Outcome and Experience Measures in Perinatal Care to Guide Clinical Practice: Prospective Observational Study. *J Med Internet Res*. 2022;24(7):e37725. doi:10.2196/37725
31. Fleuren MAH, Paulussen TGWM, Dommelen P, Buuren S Van. Towards a measurement instrument for determinants of innovations. *Int J Qual Heal Care*. 2014;26(5):501-510. doi:10.1093/intqhc/mzu060

32. Finch TL, Girling M, May CR, et al. NoMAD: Implementation measure based on Normalization Process Theory. [Measurement instrument]. http://www.normalizationprocess.org. Published 2015.
33. Finch TL, Girling M, May CR, et al. Improving the normalization of complex interventions: Part 2 - validation of the NoMAD instrument for assessing implementation work based on normalization process theory (NPT). *BMC Med Res Methodol*. 2018;18(1):1-13. doi:10.1186/s12874-018-0590-y
34. Joeris A, Knoll C, Kalampoki V, Blumenthal A, Gaskell G. Patient-reported outcome measurements in clinical routine of trauma, spine and craniomaxillofacial surgeons: Between expectations and reality: A survey among 1212 surgeons. *BMJ Open*. 2018;8(6):1-11. doi:10.1136/bmjopen-2017-020629
35. Budig K, Diez J, Conde P, Sastre M, Hernán M, Franco M. Photovoice and empowerment: Evaluating the transformative potential of a participatory action research project. *BMC Public Health*. 2018;18(1):1-9. doi:10.1186/s12889-018-5335-7
36. Kiyimba N, Lester JN, O'Reilly M. *Using Naturally Occurring Data in Qualitative Health Research*.; 2019. doi:10.1007/978-3-319-94839-3
37. R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing. 2020. https://www.r-project.org/.
38. Dierckx de Casterle B, Gastmans C, Bryon E, Denier Y. QUAGOL: A guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360-371. doi:10.1016/j.ijnurstu.2011.09.012
39. van Oers HA, Teela L, Schepers SA, Grootenhuis MA, Haverman L. A retrospective assessment of the KLIK PROM portal implementation using the Consolidated Framework for Implementation Research (CFIR). *Qual Life Res*. 2021;30(11):3049-3061. doi:10.1007/s11136-020-02586-3
40. Amini M, Oemrawsingh A, Verweij LM, et al. Facilitators and barriers for implementing patient-reported outcome measures in clinical care: An academic center's initial experience. *Health Policy (New York)*. 2021;125(9):1247-1255. doi:10.1016/j.healthpol.2021.07.001
41. Mou D, Horn DM, Heng M, et al. Primary care physician's (PCP) perceived value of patient-reported outcomes (PROs) in clinical practice: A mixed methods study. *BMJ Qual Saf*. 2021:221-229. doi:10.1136/bmjqs-2020-012206
42. Withers K, Palmer R, Lewis S, Carolan-Rees G. First steps in PROMs and PREMs collection in Wales as part of the prudent and value-based healthcare agenda. *Qual Life Res*. 2021;30(11):3157-3170. doi:10.1007/s11136-020-02711-2
43. PCORI. *Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records*.; 2017. http://dx.doi.org/10.1016/j.jclinepi.2013.04.005%0Ahttp://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records.
44. Ahmed S, Zidarov D, Eilayyan O, Visca R. Prospective application of implementation science theories and frameworks to inform use of PROMs in routine clinical care within an integrated pain network. *Qual Life Res*. 2021;30(11):3035-3047. doi:10.1007/s11136-020-02600-8
45. van der Wees PJ, Verkerk EW, Verbiest MEA, et al. Development of a framework with tools to support the selection and implementation of patient-reported outcome measures. *J Patient-Reported Outcomes*. 2019;3(1). doi:10.1186/s41687-019-0171-9
46. Feijen-de Jong EI, van der Voort-Pauw N, Nieuwschepen-Ensing EG, Kool L. Intentions to leave and actual turnover of community midwives in the Netherlands: A mixed method study exploring the reasons why. *Women and Birth*. 2022;(February). doi:10.1016/j.wombi.2022.02.004
47. Lefebvre G, Honey L, Hines K, et al. Implementing Obstetrics Quality Improvement, Driven by Medico-legal Risk, is Associated With Improved Workplace Culture. *J Obstet Gynaecol Canada*. 2020;42(1):38-47.e5. doi:10.1016/j.jogc.2019.05.011

48. Dharni N, Essex H, Bryant MJ, et al. The key components of a successful model of midwifery-led continuity of carer, without continuity at birth: findings from a qualitative implementation evaluation. *BMC Pregnancy Childbirth*. 2021;21(1):1-11. doi:10.1186/s12884-021-03671-2
49. Roberts NA, Janda M, Stover AM, Alexander KE, Wyld D, Mudge A. The utility of the implementation science framework "Integrated Promoting Action on Research Implementation in Health Services" (i-PARIHS) and the facilitator role for introducing patient-reported outcome measures (PROMs) in a medical oncology outpatient. *Qual Life Res*. 2021;30(11):3063-3071. doi:10.1007/s11136-020-02669-1
50. Laureij LT, Depla AL, Kariman SS, et al. Women's experiences with using patient-reported outcome and experience measures in routine perinatal care in the Netherlands: a mixed methods study. *BMJ Open*. 2023;(In Press).
51. Calvert MJ, Rivera SC, Retzer A, et al. Patient reported outcome assessment must be inclusive and equitable. *Nat Med*. 2022;28(6):1110-1127. doi:10.1038/s41591-022-01836-w
52. Nijagal MA, Patel D, Lyles C, et al. Using human centered design to identify opportunities for reducing inequities in perinatal care. *BMC Health Serv Res*. 2021;21(1):1-15. doi:10.1186/s12913-021-06609-8
53. McCloskey L, Bernstein J, The Bridging the Chasm Collaborative, et al. Bridging the Chasm between Pregnancy and Health over the Life Course: A National Agenda for Research and Action. *Women's Heal Issues*. 2021;31(3):204-218. doi:10.1016/j.whi.2021.01.002

SUPPLEMENT

Figure S1. Pregnancy and Childbirth outcome set: patient-reported domains and timeline of their measurement



Outcome Domain	T1 1st trimester	T2 3rd trimester	T3 maternity week	T4 6 weeks postpartum	T5 6 months postpartum	
Health related quality of life	▨	▨		▨	▨	PROM
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 adapted from Nijagal et al.[1] The original outcomes set has been translated to the Dutch language and setting by Laureij et al.[2] For a full description of measurement instruments and scoring systems per domain, refer to Depla et al.[3] *PROM* patient-reported outcome measure; *PREM* patient-reported experience measure; *T1* time point 1; *T2* time point 2; *T3* time point 3; *T4* time point 4; *T5* time point 5.

---

[1] Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. BMC Health Serv Res. 2018;18(1):953. doi:10.1186/s12913-018-3732-3

[2] Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. Patient Educ Couns. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022

[3] Depla AL, Ruiter ML de, Laureij LT, et al. Patient-Reported Outcome and Experience Measures in Perinatal Care to Guide Clinical Practice : Prospective Observational Study Corresponding Author : J Med Internet Res. 2022;24(7):e37725. doi:10.2196/37725

Table S1. Normalization Process Theory (NPT): mechanisms, subconstructs and assessment

Mechanism	**Subconstruct**	**Definition**	**Assessment methods in this study**
Coherence (sense making)	Differentiation	Participants see how (the set of new practices)[a] differs from usual ways of working	observation[b], qualitative methods[c]
	Communal specification	Staff in this organization have a shared understanding of the purpose of (the set of new practices)	observation, qualitative methods
	Individual specification	Participants understand how (the set of new practices) affects the nature of my own work	observation, qualitative methods
	Internalization	Participants construct the potential value of (the set of new practices) for my work	observation, qualitative methods
Cognitive participation (relational work)	Initiation	Key people are driving (the set of new practices) forward and get others involved	survey[d], observation, qualitative methods
	Enrolment	Participants (re)organize themselves to contribute to the work involved in (the set of new practices)	survey, observation, qualitative methods
	Legitimation	Participants believe it's right to be involved in (the set of new practices) and that they can make a valid contribution to it	survey, observation, qualitative methods
	Activation	Participants continue to support (the set of new practices)	survey, observation, qualitative methods
Collective action (operational work)	Interactional workability	Participants execute the tasks of the (the set of new practices) and integrate them into their existing work	survey, observation, qualitative methods
	Relational integration	Participants build accountability and maintain confidence in each other as they use (the set of new practices)	survey, observation, qualitative methods
	Skill set workability	The work of (the set of new practices) is allocated to the right persons who receive sufficient training	survey, observation, qualitative methods
	Contextual integration	The work of (the set of new practices) is adequately supported by management and resources	survey, observation, qualitative methods
Reflexive monitoring (appraisal work)	Systemization	Participants have access to information about the effects of (the set of new practices)	observation, qualitative methods
	Communal appraisal	Participants collectively agree that (the set of new practices) is worthwhile	observation, qualitative methods
	Individual appraisal	Participants individually value the effects that (the set of new practices) has had on their work	observation, qualitative methods
	Reconfiguration	Participants modify their work with (the set of new practices) based on their appraisal of the (the set of new practices)	observation, qualitative methods

[a] The set of new practices*:* in this project defined as the use of PROM/PREM in individual care and quality improvement [b] Observations*:* performed along a checklist with NPT subconstructs while participating in implementation activities (i.e., project team meetings, kick-off sessions, QI sessions and two-weekly reflection logbook). [c] Qualitative methods: NPT subconstructs were embedded in coding schemes of all qualitative data (i.e., open-ended survey answers, transcriptions, observation reports, reflection logbook, and naturally occurring documents) [d] Survey: measured with the validated NoMAD (Normalization MeAsure Development) instrument.

Table S2. Full statements of survey administered to care professionals to evaluate the implementation of the PCB set including the NoMAD (a), MIDI (b), and extra evaluation (c).

(a)	**Baseline**		
No.	**Topic**	**Survey A/B**[a]	**Item**
B1	Region	Both	In which OCN do you work?
B2	Professional role	Both	What is your profession within your OCN?
B3	Working experience	Both	How many years of experience do you have *a) in this profession; b) in this OCN?*
B4[b]	Implementation role	Both	What is your role in the implementation of [the intervention]?
B5	Start	A	Has implementation of [the intervention] started in you OCN yet?
B6[c]	Use	A	Are you using [the intervention] yourself?
(b)	**NoMAD**[d]		
No.	**Subconstruct**	**Survey A/B**	**Item**
CP1	Initiation	Both	There are key people who drive [the intervention] forward and get others involved
CP2	Legitimation	Both	I believe that participating in [the intervention] is a legitimate part of my role
CP3	Enrolment	Both	I'm open to working with colleagues in new ways to use [the intervention]
CP4	Activation	A	I will continue to support [the intervention]
CA1	Interactional workability	A	I can easily integrate [the intervention] into my existing work
CA2[e]	Relational integration 1	A	[The intervention] disrupts working relationships
CA3	Relational integration 2	Both	I have confidence in other people's ability to use [the intervention]
CA4[c]	Skill set workability 1	A	Work is assigned to those with skills appropriate to [the intervention]
CA5	Skill set workability 2	A	Sufficient training is provided to enable staff to implement [the intervention]
CA6	Contextual integration 1	A	Sufficient resources are available to support [the intervention]
CA7	Contextual integration 2	A	Management adequately supports [the intervention]
GN1[c,f]	Past normality	A	When you use [the intervention], how familiar does it feel?
GN2[c,f]	Current normality	A	Do you feel [the intervention] is currently a normal part of your work?
GN3[f]	Future normality	A	Do you feel [the intervention] will become a normal part of your work?
(c)	**MIDI**		
No.	**Subconstruct**	**Survey A/B**	**Item**
U8[g,h]	Personal benefit/ drawback	Both	[The innovation] contributes to *recognize symptoms and changes in them / insight in what matters to my patient / set priorities for the conversation / the shared decision-making process / the relationship with my patient / insight in the results of care I deliver / quality improvement of care pathways in the OCN / allocate who provides which care in the OCN* ‡ Possible drawbacks of [the innovation]: *I have too little information, knowledge, or experience to use it / it takes too much time in my daily work / I don't believe it benefits perinatal care / completing the questionnaires is too burdensome for my patients / the costs are too high for the OCN or my organization / data from the questionnaires are subjective, thus unreliable*

U9[g,h]	Outcome expectations	Both	My patient will … *have a lower threshold to raise issues* / *be better prepared to her care trajectory / be empowered in her care trajectory / have more insight in relevant outcomes of care and choice information / receive more personalized care that fits what matters to her / other outcome expectations*[i]
U12	Client cooperation	A	Clients will generally cooperate if I use [the innovation].
U13	Social support	A	I can count on adequate assistance from my colleagues if I need it to use [the innovation].
U15[h]	Subjective norm: motivation to comply	A	When it comes to working in accordance with [the innovation], to what extent do you comply with the opinions of *your direct colleagues / your local OCN / your regional obstetric collaboration / pregnant women / the national obstetric care collaboration*?
U16[h]	Self-efficacy	A	Should you wish to do so, do you think you can *interpret answers to the PCB set questionnaires and discuss them with pregnant women / act appropriately on answers to the PCB set questionnaires if needed / improve the quality of care in the OCN with group-level data from the PCB set questionnaires?*
O26	Unsettled organization	A	Are there, in addition to the implementation of [the innovation], any other changes in the organization affecting the implementation of the innovation now or in the foreseeable future (reorganization, merger, cuts, staffing changes, other innovations)?
O28	Performance feedback	B	In my organization, feedback is regularly provided about progress with the implementation of [the innovation].
(d)	**Extra evaluation**		
No.	**Topic**	**Survey A/B**	**Item**
E1[i]	Extra evaluation	A	What do you need to become able to do this?[j]
E2[k]	Extra evaluation	A	Which supportive materials do / did you use when working with [the innovation]?
E3	Extra evaluation	A	Which aspects are important to embed [the innovation] in your daily work? Please indicate to what extent the following aspects are important to you: *Ease of use / Costs (capture and governance) / Time efficiency / Dashboard per client (compare over time and with group level results) / Embed in existent IT systems (EHR etc.) / Reliability or clinical relevance of answers / Adjustment to current registries / Other aspects*[i]
E4[b]	Extra evaluation	Both	To what extent do you know about the [intervention]?

Statements were measured on a 5-point Likert scale of 1 (strongly disagree) to 5 (strongly disagree).

[a] Based on their answer to question B4, respondents were led to survey A or B: Survey A for participants with direct involvement in implementation (i.e., participation in the implementation team or using the PROM in practice). Survey B for participants with indirect involvement in implementation.

[b] Multiple choice.

[c] Optional: only asked if implementation had started (baseline question B5).

[d] The additional response option of the NoMAD instrument to indicate if a statement was applicable was not included.

[e] Conversed for analysis since this was a negative statement.

[f] Measured on a 0 (not at all) to 10 (completely) visual analogue scale.

[g] Researchers had to state (U8) concrete expected benefits/drawbacks for the user and (U9) intended objectives of the innovation.

[h] All phrases in italic that are separated by a dash were questioned in separate statements and averaged to provide a single subconstruct score for analysis.

[i] Open-ended.

[j] Optional: dependent of U16 (self-efficacy), only asked in case of negative answer to a specific task.

[k] Checkboxes with dichotomous scale (‘yes’/’no’).

No. abbreviated construct name plus item number; *NoMAD* Normalization MeAsure Development instrument; *B* baseline; *GN* global normalization; *CP* cognitive participation; *CA* collective action; *MIDI* Measurement Instrument for Determinants of Innovations; *U* user; *O* organization; *E* extra evaluation; *[The innovation]* capture and use of the PCB set’s questionnaires; *OCN* obstetric care network.

Table S3. Topic guide (statements) for focus groups in care professionals attending QI sessions

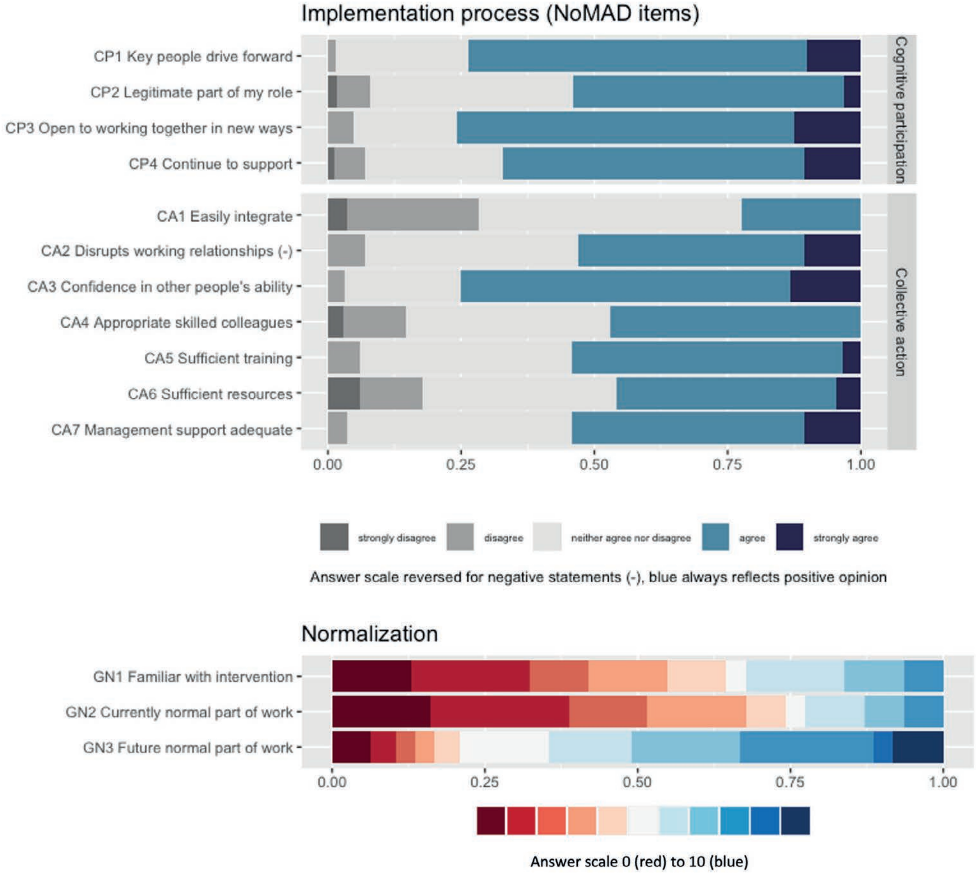
Statement	**Focus group #**
[The innovation] has more added value for patient and care professionals in the consultation room, than for learning and improving as OCN.	1,2[a]
A good accessible IT system for the questionnaires would certainly have led to successful implementation.	2
As OCN, we learn and improve already with outcome information (enough).	1
We will continue these learning and improvement sessions (QI session): if not with PROM/PREM-data, then with other data available about our OCN (e.g., from the national registration).	2
Learning and improving always comes on top of our normal/daily work.	1,2
Midwives and obstetricians are the most important stakeholders for learning and improving in an OCN.	1,2
As OCN, we are able to carry out joint improvement actions.	1,2

Participants could ‘vote’ yes/no to the statements to facilitate discussion about the statements. [a] Focus group 1 was held in phase 2 (month 6-9) and focus group 2 in phase 3 (month 9-12).

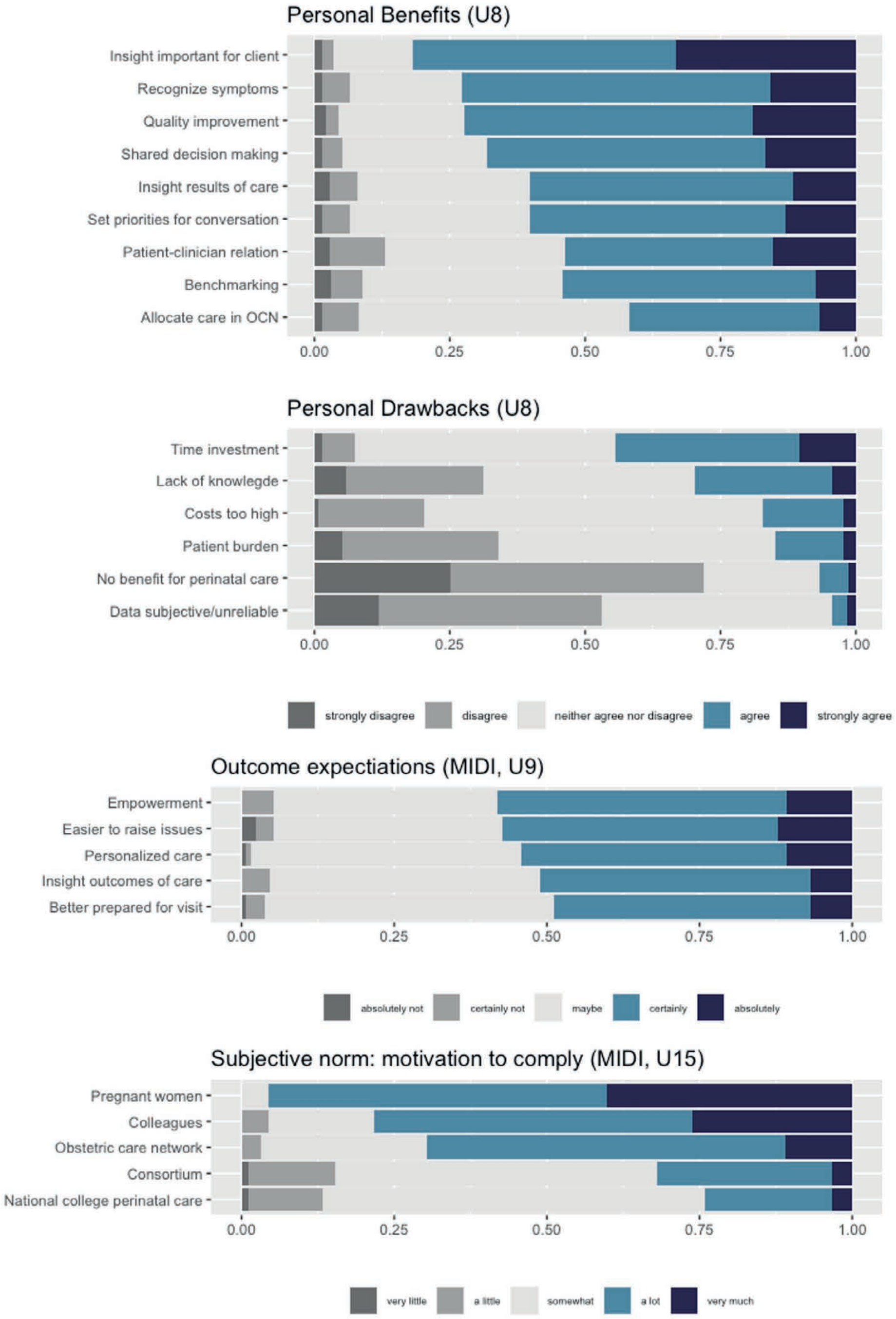
[The innovation] capture and use of the PCB set’s questionnaires; *OCN* obstetric care network; *QI* quality improvement.

Figure S2. Stacked-bar graphs of survey outcomes

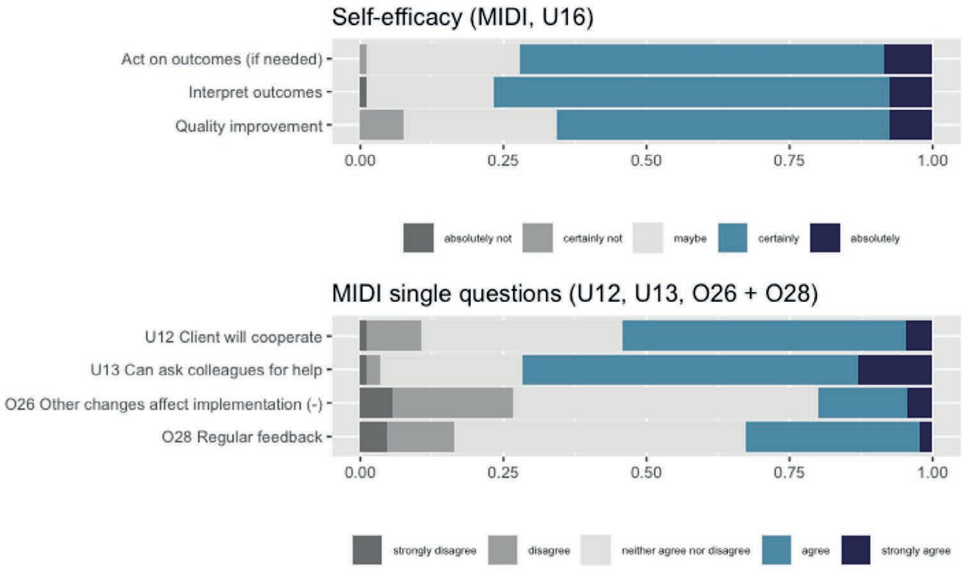
Supplementary Figure 2a. NoMAD items



Supplementary Figure 2b. MIDI items

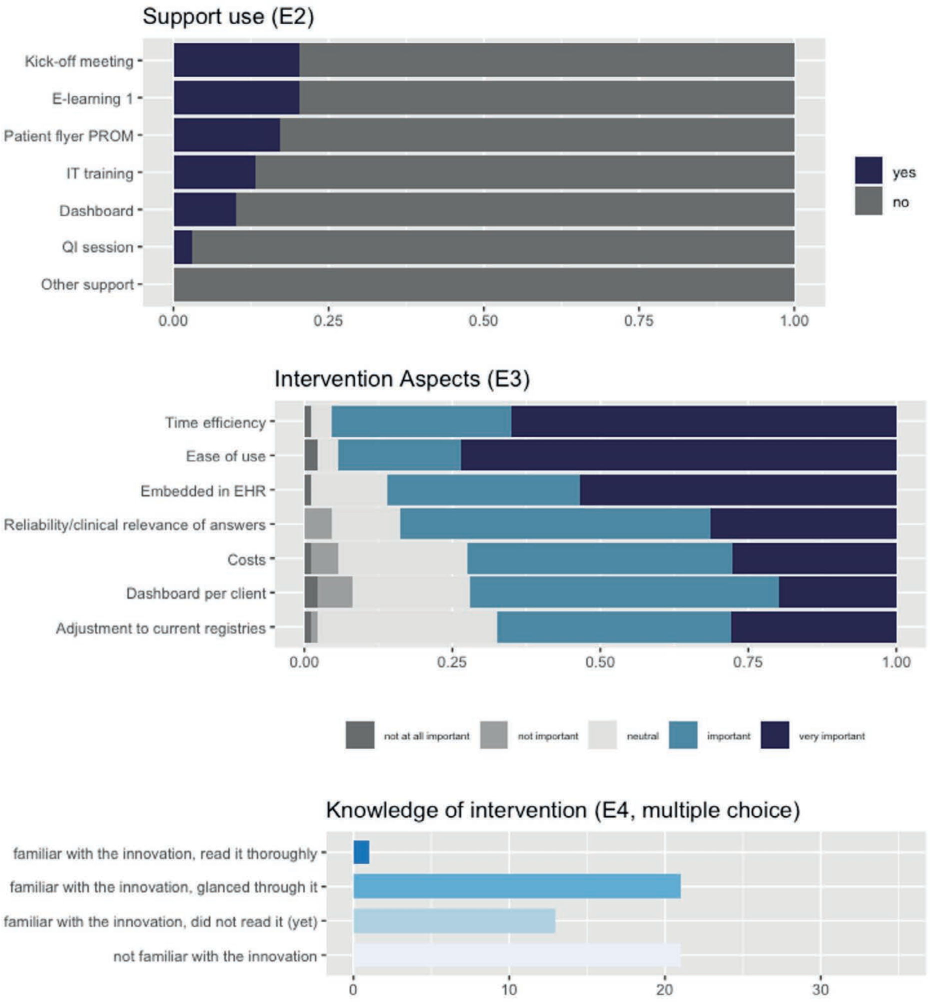


Continued: *Supplementary Figure 2b.* MIDI items



Answer scale reversed for negative statements (-), blue always reflects positive opinion

Supplementary Figure 2c. EXTRA Questions



PART II

Using PROM and PREM in daily practice and for quality improvement in care networks

5

CHAPTER 5

Patient-reported outcome and experience measures in perinatal care to guide clinical practice: prospective observational study

Anne L. Depla, Marije Lamain-de Ruiter, Lyzette T. Laureij,
Hiske E. Ernst-Smelt, Jan A. Hazelzet, Arie Franx, Mireille N. Bekker;
on behalf of the BUZZ project team

J Med Internet Res. 2022 Jul 5;24(7):e37725

ABSTRACT

Background The International Consortium for Health Outcomes Measurement has published a set of patient-centred outcome measures for pregnancy and childbirth (PCB set), including patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). To establish value-based pregnancy and childbirth care, the PCB set was implemented in the Netherlands, using the outcomes on the patient level for shared decision-making and on an aggregated level for quality improvement.

Objective This study aimed to report first outcomes, experiences, and practice insights of implementing the PCB set in clinical practice.

Methods In total, 7 obstetric care networks across the Netherlands, each consisting of 1 or 2 hospitals and multiple community midwifery practices (ranging in number from 2 to 18), implemented the PROM and PREM domains of the PCB set as part of clinical routine. This observational study included all women participating in the clinical project. PROMs and PREMs were assessed with questionnaires at 5 time points: 2 during pregnancy and 3 postpartum. Clinical threshold values (alerts) supported care professionals interpreting the answers, indicating possibly alarming outcomes per domain. Data collection took place from February 2020 to September 2021. Data analysis included missing (pattern) analysis, sum scores, alert rates, and sensitivity analysis.

Results In total, 1923 questionnaires were collected across the 5 time points: 816 (42.43%) at T1 (first trimester), 793 (41.23%) at T2 (early third trimester), 125 (6.5%) at T3 (maternity week), 170 (8.84%) at T4 (6 weeks postpartum), and 19 (1%) at T5 (6 months postpartum). Of these, 84% (1615/1923) were filled out completely. Missing items per domain ranged from 0% to 13%, with the highest missing rates for depression, pain with intercourse, and experience with pain relief at birth. No notable missing patterns were found. For the PROM domains, relatively high alert rates were found both in pregnancy and postpartum for incontinence (469/1798, 26.08%), pain with intercourse (229/1005, 22.79%), breastfeeding self-efficacy (175/765, 22.88%), and mother-child bonding (122/288, 42.36%). Regarding the PREM domains, the highest alert rates were found for birth experience (37/170, 21.76%), shared decision-making (101/982, 10.29%), and discussing pain relief ante partum (310/793, 39.09%). Some domains showed very little clinical variation, for example, role of the mother and satisfaction with care.

Conclusions The PCB set is a useful tool to assess patient-reported outcomes and experiences that need to be addressed over the whole course of pregnancy and childbirth. Our results provide opportunities to improve and personalize perinatal care. Furthermore, we could propose several recommendations regarding methods and timeline of measurements based on our findings. This study supports the implementation of the PCB set in clinical practice, thereby advancing the transformation toward patient-centred, value-based healthcare for pregnancy and childbirth.

INTRODUCTION

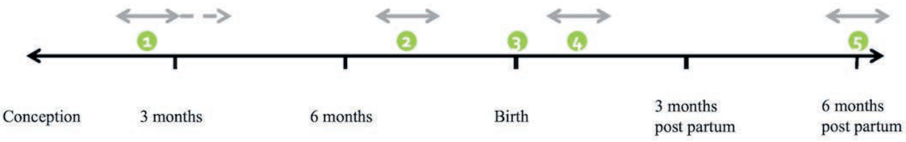
Background

Currently, healthcare systems are moving toward high-value care, adapted to each individual patient.[1,2] These healthcare systems prioritize patients' health goals in care decisions and quality improvement, above processes and clinical parameters. The transformation into a patient-centred, value-driven system is dependent on access to data that capture what matters most to patients.[3–5] Patient-reported outcome measures (PROMs) and patient-reported experience measures (PROMs) provide standardized assessment of patients' health status or experience with healthcare directly from the patient.[6] Integrated into routine care, these measures can facilitate patient provider communication, improve patients' experiences, and enhance detection and management of their health status.[7–9] When aggregated, PROMs and PREMs foster inclusion of patients' perspective in continuous quality improvement, along with clinical measures that are already being captured for quality performance.[10]

Just as in other disciplines, perinatal care may benefit from systematic PROM and PREM assessment to enhance quality of care. Moreover, patient-reported outcomes of perinatal care, such as depression or incontinence, may have serious long-term consequences for the health of the mother and child and might currently be undervalued. The interest in, and use of, PROMs and PREMs has grown in perinatal care, but most PROMs and PREMs in this field are assessed anonymously for quality improvement or research purposes only,[11] whereas if integrated in clinical care on an individual level, could provide perinatal care givers an opportunity to detect symptoms and adapt care appropriately, as well as encourage patients to think, and speak, about their current well-being and experiences.[12] Nevertheless, clinical integration of PROMs and PREMs has many challenges such as selecting relevant topics, valid assessment instruments, measurement moments and threshold values that require action.[3,13,14]

The International Consortium for Health Outcomes Measurement (ICHOM) has published a core set of patient-centred outcome measures for pregnancy and childbirth (PCB set), proposing standardized measures of clinical outcomes as well as patient outcomes and experiences over the full cycle of care.[15] For its patient-reported domains, the PCB set includes measurement instruments (i.e., questionnaires) and a timeline for assessment: at 5 time points throughout pregnancy and postpartum until 6 months after birth (Figure 1).[16] Recently, the feasibility and acceptability of the PCB set were studied in clinic and its patient-reported domains collected for research purposes.[17–19] In addition, some of its measurement instruments were evaluated for validity and reliability in a maternity population.[20–22] However, little is known regarding compliance with the PROM and PREM questionnaires of the PCB set and the clinical performance of threshold values that require action throughout pregnancy and the postpartum period.

Figure 1. Pregnancy and childbirth outcome set: patient-reported domains and moments to measure (adapted from Nijagal et al.[16])



Outcome domain	①	②	③	④	⑤	
Health-related quality of life	■	■		■	■	
Postpartum depression	■	■		■	■	
Incontinence	■	■		■	■	
Pain with intercourse	■			■	■	
Breastfeeding intent or success		■	■	■	■	
Confidence breastfeeding		■	■	■		
Mother-infant attachment			■	■		
Confidence with role as mother	■			■	■	PROM
Satisfaction with results of care		■		■	■	PREM
Health care responsiveness		■		■	■	
Birth experience				■		
Pain relief (Dutch addition)		■		■		
Role partner (Dutch addition)		■		■		
Continuity of care (Dutch addition)		■		■		
Number of questions	Minimum 18 Maximum 37	Minimum 30 Maximum 64	Minimum 9 Maximum 24	Minimum 50 Maximum 84	Minimum 27 Maximum 46	

■ Measured at this time point

PREM patient-reported experience measure; *PROM* patient-reported outcome measure.

Study rationale

In an implementation project across the Netherlands, 7 regions incorporated the PCB set in clinic over the full cycle of perinatal care with all care professionals involved. In the journey toward value-based perinatal care, the primary goal was to discuss individual PROMs and PREMs as part of regular care and use them for shared decision-making to personalize care accordingly (level 1 of value-based healthcare). Furthermore, aggregated PROM and PREM results could be used for patient-centred quality improvement (level 2 of value-based healthcare). During the project, we closely monitored first experiences and practice insights of the regions' incorporation of patient-reported measures into routine perinatal care at an individual level. This study aimed to report compliance with the PROM and PREM questionnaires, the outcomes per domain throughout pregnancy and postpartum, and the clinical use of threshold values. Our findings can support clinical implementation of value-based healthcare with the PCB set, accelerate the transformation toward personalized care, and contribute to governance of the PCB set to retain its international comparability.

METHODS

Study design

An observational study was conducted to report and gain insight into PROMs and PREMs as part of clinical routine for personalized perinatal care. This paper is written following the Strengthening the Reporting of Observational Studies in Epidemiology checklist.[23]

Setting

This study was carried out as part of a project involving the implementation of the PCB set in Dutch perinatal care called the BUZZ project (Dutch abbreviation of Discuss Outcomes of Pregnancy with the Pregnant Woman). In total, 7 regions across the Netherlands joined forces to implement the PROM and PREM domains of the PCB set in routine clinical practice. The implementation was supported by Zorginstituut Nederland and coincided with a nationwide ministry program to enhance value-based healthcare and shared decision-making.[24] Each participating region consisted of 1 or 2 hospitals and 2 to 18 community midwifery practices (Table 1) collaborating in local obstetric care networks (OCNs; refer to Textbox 1 for an explanation of Dutch perinatal care organization). Data were collected from February 2020 to September 2021.

Table 1. Implementation strategy per obstetric care network

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7
Time point 1: first trimester			✓	✓	✓	✓	
Time point 2: early third trimester	✓	✓	✓	✓	✓	✓	
Time point 3: maternity week			✓	✓	✓	✓	✓
Time point 4: 6 weeks postpartum		✓	✓	✓	✓	✓	✓
Time point 5: 6 months postpartum			[a]		✓		✓
Collection	Stand-alone data capture tool	EHR[b]	EHR	Stand-alone data capture tool	Stand-alone data capture tool	Stand-alone data capture tool	Paper
Hospitals	1	1	1	1	1	1	2
Community midwifery practices	3	2	13	2	2	9	18
Patient group	All	All	All	Women in vulnerable situations	Diabetes or history of CS [c]	GBS+[d]	Induction with AROM[e] by CM[f]

[a] Planned to implement at the end of the project period;

[b] *EHR* electronic health record;

[c] *CS* caesarean section;

[d] *GBS+* urine sample Group B streptococcus in pregnancy;

[e] *AROM* artificial rupture of membranes;

[f] *CM* community midwife

Textbox 1. Organization of Dutch perinatal care

Dutch perinatal care is organized in a 2-tier system. Community midwives provide primary care for low-risk pregnancies and act as gatekeepers to specialist care. These midwives have their own professional autonomy, responsibilities, and financial arrangements. For medium- to high-risk pregnancies, hospital-employed obstetric care professionals provide secondary or tertiary specialist care. Of all women receiving perinatal care, up to 70% visit both healthcare tiers.[25] Over the last decade a more integrated obstetric care system has been advised by the ministry of health, which is partly being realized by collaboration of both tiers in obstetric care networks.

Participants

Women receiving perinatal care at a participating organization were invited to complete PROM and PREM questionnaires as part of usual care. Women who additionally gave informed consent to use their answers for research were included in this study. Informed consent was obtained in the PROM and PREM questionnaire itself. As this study aimed to report outcomes of the PCB set as is, we report the results of all PROM and PREM questionnaires collected within the project period; no target size was predetermined.

Implementation in clinical practice

The primary purpose of the BUZZ project was to use PROM and PREM questionnaires to guide individual perinatal care. Pregnant and postpartum women were invited to fill out questionnaires as part of routine care and their obstetric care professional discussed the answers in their next regular visit. The BUZZ project was explicitly organized within OCNs to ensure continuity of care over the full cycle of care for pregnancy and childbirth. The project team of each OCN made local decisions to enhance implementation in their practice on several key points (Table 1):

- Mode of administering questionnaires: some sites could capture questionnaires through their electronic health record (EHR), others used a stand-alone data capture tool, and 1 site used paper questionnaires (whatever at that moment was considered the most optimal to use the responses in their clinical setting).

- Population and time points: most sites chose to start small by either selecting a few time points for PROM and PREM assessment or a specific patient group.

- Site-specific adaptations: some sites made minor adaptations to the questionnaire content. For example, 1 site dismissed the screening questions for depression and used the full questionnaire in all women.

Outcome measures

The PCB set's PROM and PREM domains were captured as proposed by ICHOM with questionnaires at 5 time points during pregnancy and postpartum (Figure 1).[16] Each domain is assessed with its own measurement instrument, consisting of one or more questions (Multimedia Appendix 1). At every time point only relevant domains are assessed. In some domains, one or more screening questions can either rule in or rule out further questions for that domain. To fit Dutch perinatal care, a few domains have been added to the original PCB set (Figure 1).[17] Before implementation, the translated Dutch questionnaires were tested among 4 women with low health literacy by the Dutch centre of expertise on health disparities (Pharos). Minor adaptations were carried out where possible; questionnaires already validated in Dutch were not adapted. For each measurement instrument a clinical threshold value (alert) was defined according to existing literature or, if not available, determined by the multidisciplinary national BUZZ project team, informed by expert opinion (Multimedia Appendix 1). The alerts supported care professionals interpreting the answers, indicating worrisome outcomes through a color-coded dashboard (or calculated by hand in case of paper questionnaires). As clinical data could not yet be merged (digitally), a few casemix variables were collected through the questionnaires: age, gravidity, parity, postal code, and ethnicity.

Data analysis

Only the data of women who gave informed consent were uploaded by project leaders to a central and highly secure digital research environment. Data merging and analysis was performed on this secured server using R software (version 4.0.2; The R Foundation for Statistical Computing).[26] Duplicate and blank questionnaires resulting from technical problems were removed. In addition, questionnaires with only the first item filled out, requesting informed consent or social support, were excluded because we could not determine whether this resulted from a technical problem. A new option to answer a question was added by 1 site (i.e., *not applicable*): these answers have been considered missing in analysis because they were not included in the national (validated) scoring systems. Secondary analysis of these data was considered, but the numbers were too small. Questions that were answered unintentionally, for example, a full depression questionnaire filled out despite having scored a negative screening, were removed. The casemix variables gravidity and parity are reported as state in current pregnancy: if parity and gravidity were equal, parity was corrected to gravidity–1. Completion rates were calculated per question and per measurement instrument. If applicable, sum scores were calculated according to a predefined scoring system. Missing items were excluded from this calculation; therefore, sum scores with one or more missing items are lower by definition. Alerts were calculated according to the thresholds provided in Multimedia Appendix 1. In an additional sensitivity analysis of domains with multiple questions, results with >25% missing items were removed, and their mean sum scores and alert rates were compared with the complete analysis.

Ethics

The Medical Ethics Review Committee of the Erasmus Medical Centre (MEC-2020-0129) declared that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study. Therefore, it was exempt from formal medical ethics assessment. For each site, local approval was obtained from the regional ethics board.

RESULTS

Overall

In total, 1923 unique questionnaires were collected, most of them during pregnancy (Table 2). The median moments of completion corresponded well with the proposed time points (Figure 1). Some T2 and T4 questionnaires were completed earlier than the proposed window, whereas a few T1 questionnaires were filled out too late. The questionnaires were filled out by 1318 individual women, of whom 838 (63.58%) completed 1 questionnaire and the remaining 480 (36.41%) completed up to 4 questionnaires. Their baseline characteristics are presented in Table 3. Sum scores and alerts per domain and time point are presented in Tables 4 and 5. Multimedia Appendix 2 contains figures that show each domain's scores and alerts.

Table 2. Moment of completing questionnaires (N = 1923)

Time point	**Questionnaires completed, n (%)**	**Moment of questionnaire completion, median (range)**
First trimester (T1)	816 (42.43)	15 (9-27)[a]
Early third trimester (T2)	793 (41.24)	28 (23-37)[a]
Maternity week[b] (T3)	125 (6.5)	5 (4-5)[c]
Postpartum, 6 weeks[b] (T4)	170 (8.84)	3 (0-12)[d]
Postpartum, 6 months (T5)	19 (1)	27 (22-30)[d]

[a] Moment occurred in weeks of pregnancy.

[b] The exact moment of completion was missing for *maternity week* and *6 weeks postpartum* for 123 and 127 questionnaires, respectively. Because of the information technology system setup, we do know that *maternity week* questionnaires were completed mostly between 1 and 3 weeks postpartum and *6 weeks postpartum* questionnaires between 3 and 5 weeks postpartum.

[c] Moment occurred in days postpartum.

[d] Moment occurred in weeks postpartum.

Table 3. Participant characteristics (N=1318)

Characteristics	Values
Age (yrs), median (range); missing n=77	32 (17-46)
Parity, n (%); missing n=330	
Nulliparous	360 (36.43)
Multiparous	628 (63.56)
Ethnicity, n (%); missing n=143	
Western	1057 (89.96)
Other	118 (10.04)

Table 4. Outcomes per patient-reported outcome measure domain.

Domain and subdomain	Time point	Value, n (%)	Score, median (range)	Alerts, n (%)	Missing[a], n (%)
Social support	All	1092 (56.79)	3 (0-3)	44 (4.06)	7 (0.64)
Quality of life					
	All	1798 (93.5)	37 (7-50)	21 (1.17)	1 (0.06)
	T1[b]	816 (45.38)	38 (7-50)	6 (0.74)	0 (0)
	T2[c]	793 (44.1)	37 (7-50)	12 (1.52)	1 (0.13)
	T4[d]	170 (9.45)	38 (14-49)	2 (1.18)	0 (0)
	T5[e]	19 (1.06)	37 (19-46)	1 (5.26)	0 (0)
Mental health					
Screen depression					
	All	1756 (91.32)	0 (0-6)	61 (3.52)	25 (1.42)
	T1	798 (45.44)	0 (0-6)	33 (4.19)	10 (1.25)
	T2	776 (44.19)	0 (0-5)	22 (2.85)	5 (0.64)
	T4	163 (9.28)	0 (0-5)	5 (3.27)	10 (6.13)
	T5	19 (1.08)	0 (0-4)	1 (5.26)	0 (0)
Full depression[f]					
	All	103 (5.36)	10 (0-25)	47 (52.22)	13 (12.62)
	T1	51 (49.51)	11 (0-23)	27 (52.94)	0 (0)
	T2	39 (37.86)	7 (0-25)	13 (44.83)	10 (25.64)
	T4	12 (11.65)	12 (3-25)	6 (66.67)	3 (25)
	T5	1 (0.97)	N/A[g]	1 (100)	0 (0)
Incontinence and dyspareunia					
Screen, urine					
	All	1798 (93.5)	—[h]	469 (26.91)	55 (3.06)
	T1	816 (45.38)	—	150 (20.15)	22 (2.7)
	T2	793 (44.1)	—	266 (34.64)	25 (3.15)
	T4	170 (9.45)	—	45 (27.78)	8 (4.7)
	T5	19 (1.06)	—	8 (42.1)	0 (0)
Screen, stool					
	All	1798 (93.5)	—	15 (0.86)	57 (3.17)
	T1	816 (45.38)	—	3 (0.38)	23 (2.82)
	T2	793 (44.1)	—	6 (0.78)	26 (3.28)
	T4	170 (9.45)	—	6 (3.70)	8 (4.71)
	T5	19 (1.06)	—	0 (0)	0 (0)
Screen, flatus					
	All	1798 (93.5)	—	388 (22.26)	55 (3.06)
	T1	816 (45.38)	—	149 (18.77)	22 (2.7)
	T2	793 (44.1)	—	190 (24.74)	25 (3.15)
	T4	170 (9.45)	—	44 (27.16)	8 (4.71)
	T5	19 (1.06)	—	5 (26.32)	0 (0)
Full urine[f]					
	All	469 (24.39)	6 (0-18)	185 (39.45)	0 (0)

Domain and subdomain	Time point	Value, n (%)	Score, median (range)	Alerts, n (%)	Missing[a], n (%)
	T1	150 (31.98)	6 (0-15)	62 (41.33)	0 (0)
	T2	266 (56.72)	5 (1-18)	100 (37.59)	0 (0)
	T4	45 (9.59)	6 (1-15)	19 (42.22)	0 (0)
	T5	8 (1.71)	7 (3-12)	4 (50)	0 (0)
Full stool and flatus[f]					
	All	394 (20.49)	3 (0-17)	385 (97.96)	1 (0.25)
	T1	151 (38.32)	3 (0-10)	147 (98)	1 (0.66)
	T2	193 (48.98)	3 (0-14)	190 (98.45)	0 (0)
	T4	45 (11.42)	3 (0-17)	43 (95.56)	0 (0)
	T5	5 (1.27)	2 (2-3)	5 (100)	0 (0)
Pain with intercourse					
	All	1005 (52.26)	0 (0-5)	229 (24.65)	76 (7.56)
	T1	816 (81.19)	0 (0-5)	161 (20.72)	39 (4.78)
	T4	170 (16.91)	1 (0-5)	59 (44.36)	37 (21.76)
	T5	19 (1.89)	0 (0-5)	9 (47.37)	0 (0)
Breastfeeding					
Breastfeeding intention	All (T2)	793 (41.24)	—	172 (22.4)[i]	25 (3.15)
Breastfeeding success					
	All	314 (39.6)	—	116 (39.46)[j]	20 (6.37)
	T3[k]	125 (39.81)	—	45 (36)[j]	0 (0)
	T4	170 (54.14)	—	61 (40.67)[j]	20 (11.76)
	T5	19 (6.05)	—	10 (52.63)[j]	0 (0)
Screen, breastfeeding confidence[f]					
	All	765 (39.78)	4 (1-5)	175 (23)	4 (0.52)
	T2	596 (77.91)	4 (1-5)	150 (25.25)	2 (0.34)
	T3	80 (10.46)	4 (2-5)	13 (16.46)	1 (1.25)
	T4	89 (11.63)	4 (1-5)	12 (13.64)	1 (1.12)
Full breastfeeding self-efficacy[f]					
	All	175 (9.1)	40 (4-64)	124 (72.94)	5 (2.86)
	T2	150 (85.71)	41 (14-64)	104 (71.23)	4 (2.67)
	T3	13 (7.43)	36 (12-54)	11 (84.62)	0 (0)
	T4	12 (6.86)	27 (4-52)	9 (81.82)	1 (8.33)
Role transition					
Mother-child bonding					
	All	288 (14.98)	2 (0-11)	122 (44.85)	16 (5.56)
	T3	125 (43.4)	2 (0-8)	56 (45.9)	3 (2.4)
	T4	163 (56.6)	2 (0-11)	66 (44)	13 (7.98)
Role as mother					
	All	1005 (52.26)	4 (1-5)	3 (0.31)	40 (3.98)
	T1	816 (81.19)	4 (2-5)	1 (0.13)	26 (3.19)
	T4	170 (16.91)	5 (2-5)	1 (0.64)	14 (8.24)
	T5	19 (1.89)	5 (1-5)	1 (5.26)	0 (0)

[a] Completely missing.

[b] T1: first trimester.

[c] T2: early third trimester.

[d] T4: 6 weeks postpartum.

[e] T5: 6 months postpartum.

[f] Optional subdomain, dependent on screening question or questions.

[g] N/A: not applicable.

[h] Answer options were yes or no; therefore, there are no median and range values.

[i] Alert means no intention to breastfeed.

[j] Alert means feeding baby only formula.

[k] T3: maternity week.

Table 5. Outcomes per patient-reported experience measure domain.

Domains and subdomains	Time point	Value, n (%)	Score, median (range)	Alerts, n (%)	Missing[a], n (%)
Satisfaction with care					
	All	982 (51.07)	3 (1-4)	4 (0.43)	58 (5.91)
	T2[b]	793 (80.75)	3 (1-4)	4 (0.53)	45 (5.67)
	T4[c]	170 (17.31)	4 (2-4)	0 (0)	13 (7.64)
	T5[d]	19 (1.93)	3 (2-4)	0 (0)	0 (0)
Healthcare responsiveness and shared decision-making					
	All	982 (51.07)	16 (2-16)	101 (10.67)	35 (3.56)
	T2	793 (80.75)	16 (2-16)	82 (10.72)	28 (3.53)
	T4	170 (17.31)	16 (2-16)	17 (10.43)	7 (4.12)
	T5	19 (1.93)	14 (4-16)	2 (10.53)	0 (0)
Birth experience	All (T4)	170 (8.84)	30 (8-40)	37 (23.27)	11 (6.47)
Pain relief					
Information ante partum	All (T2)	793 (41.24)	1 (0-2)	310 (41.33)	43 (5.42)
Experience at birth	All (T4)	170 (8.84)	3 (1-4)	4 (2.65)	19 (11.18)
Partner role					
During pregnancy	All (T2)	793 (41.24)	3 (0-5)	56 (7.35)	31 (3.91)
At birth	All (T4)	170 (8.84)	4 (0-5)	1 (0.66)	18 (10.59)
Continuity of care					
	All	963 (50.08)	11 (4-12)	55 (6.08)	58 (6.02)
	T2	793 (82.35)	11 (4-12)	49 (6.54)	44 (5.55)
	T4	170 (17.65)	11 (4-12)	6 (3.85)	14 (8.24)

[a] Completely missing.

[b] T2: early third trimester.

[c] T4: 6 weeks postpartum.

[d] T5: 6 months postpartum

PROM per domain

Social support

Of the 1092 women who were asked the social support question, administered at the first time point in pregnancy that each site had implemented, 44 (4.03%) scored an alert, meaning that they had 1 or no person near them to count on in time of difficulty. A comparison of T1 and T2 showed a slightly higher alert rate at T2 (17/25, 6.8%) than at T1 (26/815, 3.19%).

Quality of life

The quality-of-health domain, assessed with the Patient-Reported Outcomes Measurement Information System–Global Health Short Form, had few alerts at all time points. The alerts were based on the sum score; no alerts came from a high pain score. In additional analysis, calculation of sub scores for mental and physical health showed no variation across time points.

Mental health

In 3.52% (61/1731) of the women completing the 2-item depression screening (Patient Health Questionnaire-2 [PHQ-2]) an alert was scored, without variations over time. Women with an alert on the PHQ-2 filled out the full depression questionnaire (i.e., Edinburgh Postnatal Depression Scale-10 [EPDS-10]). As 1 region dismissed the PHQ-2 screening questions, 29 women filled out the EPDS-10 directly. The EPDS-10 exceeded the clinical threshold in 52% (47/90) of the women, meaning that 2.67% (47/1760) of the women in the whole population screened positive for depression. The numbers with regard to the EPDS-10 results were too small to allow for interpreting variations over time.

Incontinence and dyspareunia

The screening question for urine and flatus incontinence was positive in 1 of 4 women. This proportion was lower at T1 than at the other time points. Screening for stool incontinence was positive in 0.86% (15/1741) of the cases, mostly at T4 (6/162, 3.7%). The full questionnaires in case of a positive incontinence screening resulted in alert rates of 39.4% (185/469) on urine incontinence (International Consultation on Incontinence Questionnaire, Short Form) and 97.96% (385/393) on flatus or stool incontinence or both (Wexner scale). Women who screened positive for flatus incontinence but not to stool incontinence scored lower on the Wexner scale (median 3; range 0-11) than women who screened positive for stool incontinence with or without flatus incontinence (median 6; range 1-17). In 24.7% (229/929) of the women, an alert was scored on dyspareunia, with a lower alert rate at T1 than at the other time points.

Breastfeeding

During pregnancy, 77.6% (596/768) of the women intended to breastfeed their baby. After giving birth, 64% (80/125) of the women indicated that they would breastfeed their baby (fully or combined with formula) in the first week postpartum, which decreased over time: 59% (89/150) at 6 weeks and 47% (9/19) at 6 months postpartum. Of the 761 women who were breastfeeding (T3 or T4) or intended to (T2), 175 (23%) scored an alert on the screening question for confidence in breastfeeding. This alert rate was higher during pregnancy than during the postpartum period. After a positive screening question, the full breastfeeding self-efficacy questionnaire (i.e., Breastfeeding Self-Efficacy Scale-10) gave an alert in 72.9% (124/170) of the cases.

Role transition

The mother-child bonding questionnaire (Mother-to-Infant Bonding Scale) had a median score of 2 (range 0-11) and 44.9% (122/272) alert values. No difference was seen over time. The single question about confidence in the role as mother scored almost no alerts, and the median score was equal to the maximum score.

PREM per domain

Individual insight to PREM

Before answering PREM questionnaires at T2 (early third trimester), the women could choose whether to give their care professional direct insight into their answers because the answers could affect the dependent relationship with their care professional. The answer to this question was not reported by all participating sites. We received data of 175 women, of whom 26 (14.9%) did not agree to share the answers of their PREM questionnaire directly with their caregiver.

Satisfaction with care

This single-question domain, filled out by 924 women, scored almost no alerts, and the median score was 3 out of 4 (range 1-4).

Healthcare responsiveness and shared decision making

Total scores were high, with a median of 16 (range 2-16) without variation over time. Still, the alert rate for this domain was 10.7% (101/947), based on a negative answer to one or more questions. Of the 101 women scoring an alert, 59 (58.4%) answered in the negative to just 1 of 8 questions. The alerts per question provided insight into direction for improvement, such as information provision about care decisions.

Birth experience

Assessed with the 10-item Birth Satisfaction Scale, Revised, at T4, this domain gave an alert in 23.3% (37/159) of the women and had a median total score of 30 (range 8-40). The Birth Satisfaction Scale, Revised, subscales scored a median of 11 (range 2-16) for stress, 14 (range 4-16) for quality of care, and 5 (range 0-8) for women’s attributes. Comparing women with and without an alert on the sum score, the subscales stress and women’s attributes decreased by 50%, whereas the subscale quality of care decreased by 21%.

Pain relief

During pregnancy, at T2, 41.3% (310/750) of the women indicated that the options for pain relief had not been discussed with their care professional yet. Postpartum, most women were satisfied with the options for pain relief that were offered during childbirth.

Partner role

Women were asked whether care professionals had engaged their partner enough in their care. This was insufficient for 7.4% (56/762) of the women during pregnancy and for 0.7% (1/152) during labour.

Continuity of care

In total, 6.1% (55/905) of the women answered in the negative to one or more questions about continuity of care, with a median score of 11 (range 4-12). This domain had a slightly higher alert rate in pregnancy than during the postpartum period. In 96% (53/55) of the alerts, the women scored only 1 of the 3 questions negatively. Most alerts resulted from a negative answer to the question about knowing who their principal care provider was. In 23.5% (213/905) of the cases, the women had received perinatal care from just 1 care professional. Excluding these, the overall alert rate was 7.9% (55/692) and the median score 10 (range 4-12).

Adherence to the questionnaires

Overall, 84% (1615/1923) of the questionnaires were filled out completely. Per domain, the percentage of completely missing answers ranged between 0% and 13%, as presented in Tables 4 and 5. Certain domains were skipped more often, such as the EPDS-10 (depression) and the Patient-Reported Outcomes Measurement Information System–Sexual Function and Satisfaction (PROMIS-SFFAC102; pain with intercourse). Missing rates per question are listed in Multimedia Appendix 3 and ranged from 0% to 16%. Evaluated per question, no remarkable missing patterns were found that could not be explained by site-specific adaptations to the questions. In Multimedia Appendix 4, missing patterns per domain are visualized. In additional sensitivity analysis of domains with multiple questions, sum scores and alert rates did not significantly change after ruling out the questionnaires with >25% missing items. Here, we chose to report the complete case analysis, best reflecting clinical use, because these results were not ruled out from individual reports to care professionals.

DISCUSSION

Findings and recommendations

This study reports the results of an innovation in perinatal care in the Netherlands: implementation of ICHOM's PROM and PREM domains for pregnancy and childbirth to guide individual patient care in 7 OCNs. The large cohort resulting from this project showed good adherence to the questionnaires. In several domains, such as incontinence and breastfeeding, the high alert rates revealed opportunities to improve and personalize perinatal care for individual women on outcomes that matter to them. In addition, our results indicate that some measurement instruments and their timing as proposed by ICHOM are less suitable for clinical use. On the basis of these findings, we present several recommendations regarding the methods and timelines of PROM and PREM assessment in clinical practice.

Overall, adherence to the questionnaires was good, similar to PROM adherence when used for routine oncologic care.[7] High missing rates per instrument could be explained by technical issues, site-specific adaptation to the questionnaires, or questions addressing a relatively taboo subject, such as those included in the EPDS-10 and PROMIS-SFFAC102 (depression and pain with intercourse, respectively). In pre-implementation tests, the PROMIS-SFFAC102 question also seemed difficult to understand despite language adjustments. Adapting the answer options might help, or an alternative instrument should be selected. Although they may be imperfect, the questions on these taboo subjects were answered by most women. Especially, these taboo subjects create more awareness at both patient and care professional levels, thereby increasing the likelihood of problems being recognized and addressed in clinic.

Median moments of completion corresponded well with the timeline of data collection as proposed by ICHOM. In contrast to the provider expectations described by Chen et al,[27] the questionnaire administered shortly after childbirth (T3) resulted in a large group of respondents in this study who completed them mostly within 2 weeks postpartum. At this point, there is an excellent opportunity to improve breastfeeding outcomes and mother-child bonding. As final maternal check-up with an obstetric care professional is at 6 weeks postpartum in the Netherlands, the questionnaire at 6 months postpartum (T5) is practically difficult to arrange for care providers. As a result, most OCNs chose to skip T5 to enhance feasibility; thus, few questionnaires were collected. Although practically challenging, patient views on this timing should be considered because this moment previously has been shown to be valuable to reflect on long-term recovery after pregnancy and childbirth.[17,28]

Our findings in the mental health domain indicate that the first instrument of the 2-step screening (PHQ-2) is missing an unacceptable proportion of women at risk for depression, in line with the findings of Slavin et al.[21] The prevalence of perinatal depression has been reported at a rate of 7% to 20% during pregnancy and up to 22% in the first year postpartum.[29] In our cohort, the prevalence of depressive symptoms was only 2.7% over the whole period of pregnancy and childbirth up until 6 months postpartum. As the main purpose in clinical care is to identify women at high risk for depression, we strongly recommend removing the PHQ-2 and screening all women for depressive complaints with the EPDS-10, despite an increased response burden. The EPDS-10 has been thoroughly validated and has been shown to be acceptable to women in pregnancy and postpartum.[30,31] Furthermore, 2 PREM domains showed striking results. Women answered almost always in the positive to the PREM satisfaction with results of care, despite multiple PROM alerts suggesting that their results were not as positive. This might be explained by women expecting incontinence to be a normal result of pregnancy and childbirth. Either way, this single question did not differentiate between women who were satisfied and those who were unsatisfied with their care and does not add value to shared decision-making or quality improvement. The PREM on information provision about pain relief options gave unexpected high alerts: 41.3% (310/750) of the care professionals had not discussed this yet with their patient. This might indicate that the timing of the assessment does not fit clinical practice because the T2 questionnaire was completed at 28 weeks of pregnancy on average and regular pathways plan to discuss pain relief later. Overall, each domain in need of adjustment based on our results is listed in Textbox 2, along with proposed adaptations to enhance their use in clinical practice.

Textbox 2. Proposed adaptations to PCB set content

- **Mental health:** Remove Patient Health Questionnaire-2 and use only the Edinburgh Postnatal Depression Scale-10 to screen depressive symptoms because current 2-step screening rules out too many women at risk for perinatal depression.

- **Incontinence:** Use the first question of the International Consultation on Incontinence Questionnaire, Short Form, and first 3 questions of the Wexner scale as screening questions because they ask the same questions as the current screening questions. The current screening questions create an unnecessary response burden and have led to inconsequential answers.

- **Pain with intercourse:** Adjust the answer options or replace the instrument considering its relatively high missing rate and signs that the question is hard to understand.

- **Role as mother:** Replace with another instrument because this single question does not differentiate between women who were confident and those who were insecure in their role as mother. As patients proposed this subject originally, it should be maintained in the pregnancy and childbirth set.[16]

- **Satisfaction with care:** Remove or replace with another instrument because this question does not differentiate between women who were satisfied and those who were unsatisfied with their care or provide insight into the direction for improvements.

- **Pain relief:** Measurement at T2 (early third trimester) is often too early because most perinatal care professionals discuss pain relief options later in the care path. We recommend involving patients to determine the optimal timing in pregnancy to discuss options for pain relief during childbirth.

- **Social support:** Ask it at each time point because women's social networks can change throughout pregnancy and postpartum. This domain was originally designed as a casemix factor but is used in clinical practice also as an outcome to act upon.

- **Before asking questions about patient experiences:** Ask the woman whether her answers to the patient-reported experience measure questions may be made visible to her care professional individually because women are in a dependent relationship with their care professionals.

In several domains, high alert rates revealed opportunities to adapt care accordingly and improve individual outcomes. For example, a high prevalence of incontinence and pain with intercourse was found over the course of pregnancy, as expected from previous research on these topics.[32] Breastfeeding success rates were low, which corresponds to provider reported breastfeeding numbers in the Netherlands from 2018.[33] Strikingly, many alerts were scored on breastfeeding confidence and self-efficacy during pregnancy. This provides important opportunities for all perinatal care professionals involved to improve breastfeeding outcomes. At the same time, threshold values for alerts on several instruments must be evaluated for clinical use to determine whether women scoring an alert want help and whether clinicians have the instruments to provide this help. For example, the threshold for the Mother-to-Infant Bonding Scale was set quite low based on the literature,[34,35] resulting in many alerts on mother-child bonding. At this moment, it is unknown whether women want their care professional to address these alerts, and clinical guidelines on when and how to act are lacking.[36] However, in perinatal care too, structural PROM monitoring did create openings for dialogue between patients and care professionals to personalize and improve care on these themes.[2]

Regarding experience domains, 85.1% (149/175) of the women in this study agreed to making their individual answers to PREMs visible to their care professionals, but the remaining 14.9% (26/175) disagreed. These numbers both affirm the acceptability of individual PREM use and underline the importance of providing women an opportunity to choose, considering their dependent relationship with care professionals. In general, evaluating results of all women, the sum scores of the PREM instruments often did not differentiate very much, but separate answers gave valuable information about directions for improvement. For example, most alerts in the domains continuity and healthcare responsiveness resulted from negative answers to specific items: about knowing their principal care professional and information provision, respectively. In birth experience, the PREM with the highest alert rate, the subscales most affected in women with an alert on the sum score were stress and women's attributes. Until now, the literature on individual PREM use to guide clinical practice has been scarce because anonymous use is mostly advocated, for quality improvement only.[17,37]

Strengths and limitations

To our knowledge, this project was one of the first experiences with incorporating the complete PCB set into clinical practice to guide individual perinatal care. Although it was challenging, each participating site collaborated with a multidisciplinary transmural team of care professionals (part of an OCN) for implementation to ensure continuity of care over the whole cycle of care in a patient-centred approach. For this study, we have performed thorough additional analyses such as sensitivity analysis and appraisal of the use of screening questions, leading to practice implications for several domains. The sample size was large, and our results reflect the true clinical use of all patient-reported domains in the PCB set in various settings across the Netherlands. Nevertheless, because of this practical and local approach, non-responders were not registered; therefore, we cannot report any response rates. In addition, variation over time in our results should be interpreted with caution because of different numbers of results per time point—especially, the numbers at 6 months postpartum were too small to enable drawing any conclusions. Another limitation was the absence of questionnaire translations, restricting the participants to Dutch-speaking women only. Moreover, because no resources were available to support completion of the questionnaires, women with low (digital) health literacy are likely to be underrepresented, although women with language barriers or low health literacy probably have higher prevalence of pregnancy-related issues and thus greater opportunities to improve their outcomes.[38] This reveals an important concern regarding the transformation to value-based care: it could worsen existing health inequities even further. Therefore, efforts should be made to standardize the questionnaires to facilitate translation into multiple languages. Furthermore, when implementing PROMs and PREMs as part of value-based care, all stakeholders involved should be well informed about their purpose and supported with multiple solutions to embed the PCB set structurally in clinic; for example, through group consultations.[39]

Implications for practice

On the basis of the first efforts to incorporate the PCB set into clinical practice, we have proposed several adaptations to its content and structure to better fit routine perinatal care (Textbox 2). At the same time, international governance of the PCB set is essential to maintain comparability for care improvement purposes. In addition, although we tested their clinical usefulness, further validation is needed of all the measurement instruments and their clinical thresholds during pregnancy and postpartum, which has been started successfully in another cohort.[20–22] Although the numbers per region could not be compared because of differences in pilot setup (e.g., patient group selection), data capture was more feasible when PROMs could be embedded in their own EHR. When used in performance management, PROM and PREM results would preferably be merged with clinical outcomes, ideally through the EHR. Although beyond our main scope, merging patient-reported data with clinical outcomes from EHRs was explored in this project. In concordance with previous findings,[40] this seemed very challenging, depending on the software systems available. This study focused on the content of the PCB set; future work should investigate other factors influencing implementation in the patient, care professional, and organization contexts.[41]

Conclusions

This study shows that the PCB set is a useful tool to capture and discuss patient-reported outcomes and experiences that need attention during pregnancy, childbirth, and postpartum. These are promising findings in the journey toward patient-centred, personalized, and value-based perinatal care. In the future, merging patient-reported data with clinical outcomes and casemix factors would be even more valuable to improve quality of healthcare both at an individual level and an aggregated level.

SUPPLEMENT

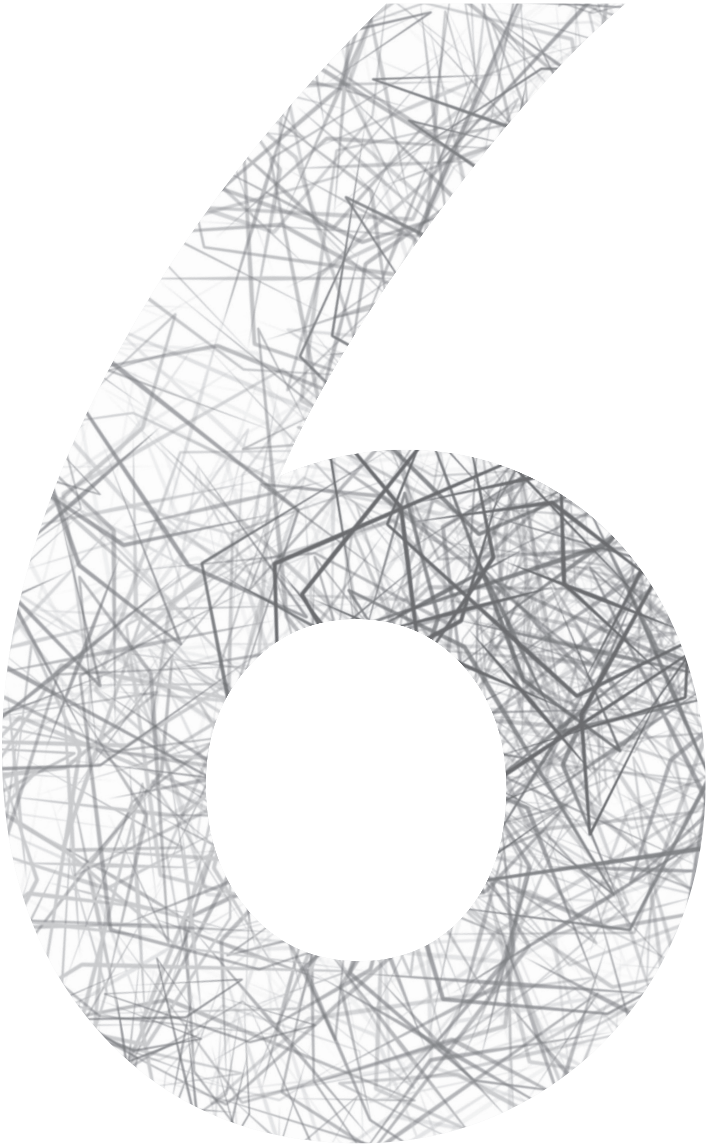
Multimedia appendices are available online (doi:10.2196/37725).

REFERENCES

1. Steinmann G, Van De Bovenkamp H, De Bont A, Delnoij D. Redefining value: a discourse analysis on value-based health care. *BMC Health Serv Res*. 2020;20(1):1-13. doi:10.1186/s12913-020-05614-7
2. Gray M, Gray J, Howick J. Personalised healthcare and population healthcare. *J R Soc Med*. 2018;111(2):51-56. doi:10.1177/0141076817732523
3. Austin E, LeRouge C, Hartzler AL, Segal C, Lavallee DC. Capturing the patient voice: implementing patient-reported outcomes across the health system. *Qual Life Res*. 2020;29(2):347-355. doi:10.1007/s11136-019-02320-8
4. Damman OC, Jani A, de Jong BA, et al. The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients. *J Eval Clin Pract*. 2020;26(2):524-540. doi:10.1111/jep.13321
5. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346(7896):f167. doi:10.1136/bmj.f167
6. National Quality Forum. Patient-reported outcomes. https://www.qualityforum.org/Patient-Reported_Outcomes.aspx. Published 2018. Accessed December 23, 2021.
7. van Egdom LSE, Oemrawsingh A, Verweij LM, et al. Implementing Patient-Reported Outcome Measures in Clinical Breast Cancer Care: A Systematic Review. *Value Heal*. 2019;22(10):1197-1226. doi:10.1016/j.jval.2019.04.1927
8. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of Patient-Reported Outcomes in Routine Medical Care. In: *American Society of Clinical Oncology Educational Book*. American Society of Clinical Oncology; 2018:122-134. doi:10.1200/edbk_200383
9. McAllister M, Dearing A. Patient reported outcomes and patient empowerment in clinical genetics services. *Clin Genet*. 2015;88(2):114-121. doi:10.1111/cge.12520
10. Basch E. Harnessing Patients' Voices to Improve Clinical Care. *N Engl J Med*. 2017;376(2):105-108. doi:10.1056/NEJMp1615714
11. Scheerhagen M, van Stel HF, Tholhuijsen DJC, Birnie E, Franx A, Bonsel GJ. Applicability of the ReproQ client experiences questionnaire for quality improvement in maternity care. *PeerJ*. 2016;2016(7). doi:10.7717/peerj.2092
12. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? a realist synthesis. *J Patient-Reported Outcomes*. 2018;2(1). doi:10.1186/s41687-018-0061-6
13. Foster A, Croot L, Brazier J, Harris J, O'cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient-Reported Outcomes*. 2018;2:46. doi:10.1186/s41687-018-0072-3
14. Nordan L, Blanchfield L, Niazi S, et al. Implementing electronic patient-reported outcomes measurements: Challenges and success factors. *BMJ Qual Saf*. 2018;27(10):852-856. doi:10.1136/bmjqs-2018-008426
15. ICHOM. *Pregnancy & Childbirth: Data Collection Reference Guide*.; 2016. https://connect.ichom.org/patient-centered-outcome-measures/pregnancy-and-childbirth/.

16. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
17. Laureij LT, Been J V., Lugtenberg M, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. *Patient Educ Couns*. 2020;103(3):642-651. doi:10.1016/j.pec.2019.09.022
18. Al-Shammari I, Roa L, Yorlets RR, et al. Implementation of an international standardized set of outcome indicators in pregnancy and childbirth in Kenya: Utilizing mobile technology to collect patient-reported outcomes. *PLoS One*. 2019;14(10):e0222978. doi:10.1371/journal.pone.0222978
19. Depla AL, Ernst-Smelt HE, Poels M, Crombag NM, Franx A, Bekker MN. A feasibility study of implementing a patient-centered outcome set for pregnancy and childbirth. *Heal Sci Reports*. 2020;3(3). doi:10.1002/hsr2.168
20. Slavin V, Creedy DK, Gamble J. Single Item Measure of Social Supports: Evaluation of construct validity during pregnancy. *J Affect Disord*. 2020;272(April):91-97. doi:10.1016/j.jad.2020.03.109
21. Slavin V, Creedy DK, Gamble J. Comparison of screening accuracy of the Patient Health Questionnaire-2 using two case-identification methods during pregnancy and postpartum. *BMC Pregnancy Childbirth*. 2020;20(1):1-15. doi:10.1186/s12884-020-02891-2
22. Slavin V, Gamble J, Creedy DK, Fenwick J, Pallant J. Measuring physical and mental health during pregnancy and postpartum in an Australian childbearing population - Validation of the PROMIS Global Short Form. *BMC Pregnancy Childbirth*. 2019;19(1):1-19. doi:10.1186/s12884-019-2546-6
23. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: Guidelines for reporting observational studies. *Int J Surg*. 2014;12(12):1495-1499. doi:10.1016/j.ijsu.2014.07.013
24. Dutch Ministry of Healthcare Welfare and Sport. *Outcome-Based Healthcare 2018-2022*.; 2018. https://www.government.nl/documents/reports/2018/07/02/outcome-based-healthcare-2018-2022.
25. Perined. *Perinatale Zorg in Nederland Anno 2020: Duiding Door Landelijke Perinatale Audit En Registratie*. Utrecht; 2021. https://assets.perined.nl/docs/3d6a2b46-aa8a-417e-a55e-de0184fe2078.pdf.
26. R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing. 2020. https://www.r-project.org/.
27. Chen A. Introducing Patient Reported Measures (PRMs) Into Finnish Public Maternity Service : A Study on Professionals ' Views. *BMC Health Serv Res*. 2021;21:645. doi:10.1186/s12913-021-06658-z
28. Depla AL, Crombag NM, Franx A, Bekker MN. Implementation of a standard outcome set in perinatal care: a qualitative analysis of barriers and facilitators from all stakeholder perspectives. *BMC Health Serv Res*. 2021;21(1):1-13. doi:10.1186/s12913-021-06121-z
29. Littlewood E, Ali S, Dyson L, et al. Identifying perinatal depression with case-finding instruments: a mixed-methods study (BaBY PaNDA – Born and Bred in Yorkshire PeriNatal Depression Diagnostic Accuracy). *Heal Serv Deliv Res*. 2018;6(6):1-210. doi:10.3310/hsdr06060
30. Hewitt CE, Gilbody SM, Brealey S, et al. Methods to identify postnatal depression in primary care: An integrated evidence synthesis and value of information analysis. *Health Technol Assess (Rockv)*. 2009;13(36). doi:10.3310/hta13360
31. Bergink V, Kooistra L, Lambregtse-van den Berg MP, et al. Validation of the Edinburgh Depression Scale during pregnancy. *J Psychosom Res*. 2011;70(4):385-389. doi:10.1016/j.jpsychores.2010.07.008
32. Brincat C, Crosby E, McLeod A, Fenner DE. Experiences during the first four years of a postpartum perineal clinic in the USA. *Int J Gynecol Obstet*. 2015;128(1):68-71. doi:10.1016/j.ijgo.2014.07.026

33. Engelse O, van Dommelen P. Peiling Melkvoeding 2018. *NCJ/TNO*. 2018:15. https://assets.ncj.nl/docs/4353efb6-135e-4ef4-8afb-a1b6f772995c.pdf.
34. Bienfait M, Maury M, Haquet A, et al. Pertinence of the self-report mother-to-infant bonding scale in the neonatal unit of a maternity ward. *Early Hum Dev*. 2011;87(4):281-287. doi:10.1016/j.earlhumdev.2011.01.031
35. Yoshida K, Yamashita H, Conroy S, Marks M, Kumar C. A Japanese version of mother-to-infant bonding scale: Factor structure, longitudinal changes and links with maternal mood during the early postnatal period in Japanese mothers. *Arch Womens Ment Health*. 2012;15(5):343-352. doi:10.1007/s00737-012-0291-1
36. Woodhouse SS, Scott JR, Hepworth AD, Cassidy J. Secure Base Provision: A New Approach to Examining Links Between Maternal Caregiving and Infant Attachment. *Child Dev*. 2020;91(1):e249-e265. doi:10.1111/cdev.13224
37. Lagha E, Noble A, Smith A, Denvir MA, Leslie SJ. Patient reported experience measures (PREMs) in chronic heart failure. *J R Coll Physicians Edinb*. 2013;42(4):301-305. doi:10.4997/JRCPE.2012.404
38. Vos AA, Denktaş S, Borsboom GJJM, Bonsel GJ, Steegers EAP. Differences in perinatal morbidity and mortality on the neighbourhood level in Dutch municipalities: A population based cohort study. *BMC Pregnancy Childbirth*. 2015;15(1):1-9. doi:10.1186/s12884-015-0628-7
39. Carter EB, Mazzoni SE. A paradigm shift to address racial inequities in perinatal healthcare. *Am J Obstet Gynecol*. 2021;224(4):359-361. doi:10.1016/j.ajog.2020.11.040
40. Aerts H, Kalra D, Sáez C, et al. Quality of hospital electronic health record (EHR) data based on the international consortium for health outcomes measurement (ICHOM) in heart failure: Pilot data quality assessment study. *JMIR Med Informatics*. 2021;9(8):1-14. doi:10.2196/27842
41. Roberts NA, Alexander K, Wyld D, Janda M. Factors in randomized controlled trials reported to impact the implementation of patient-reported outcome measures into routine care: Protocol for a systematic review. *JMIR Res Protoc*. 2019;8(11). doi:10.2196/14579


6

CHAPTER 6

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

Lyzette T. Laureij, Anne L. Depla, Shariva S. Kariman,
Marije Lamain-de Ruiter, Hiske E. Ernst-Smelt,
Jan Hazelzet, Arie Franx, Mireille N. Bekker;
on behalf of the BUZZ project team

BMJ Open. 2023 Mar 10;13:e064452

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.

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.

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] 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.

METHODS

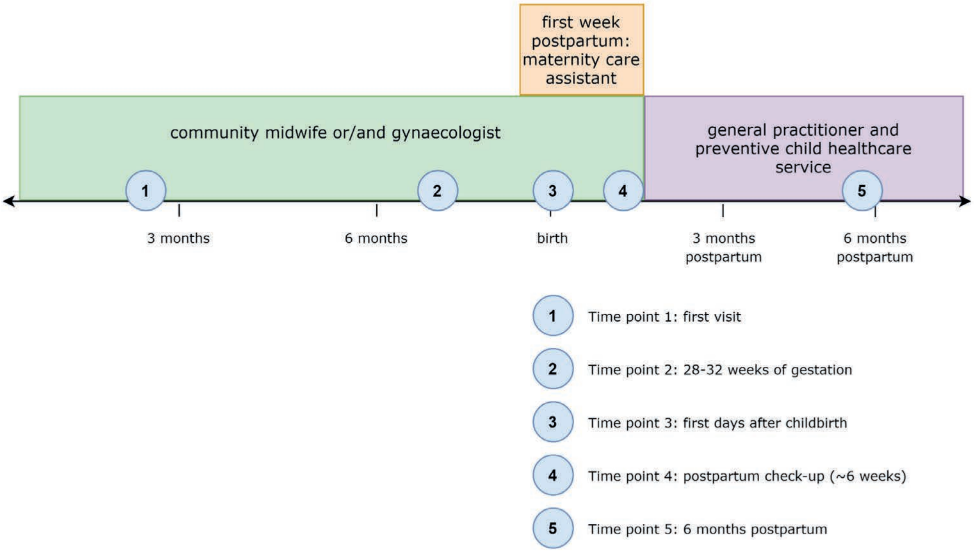
Design

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

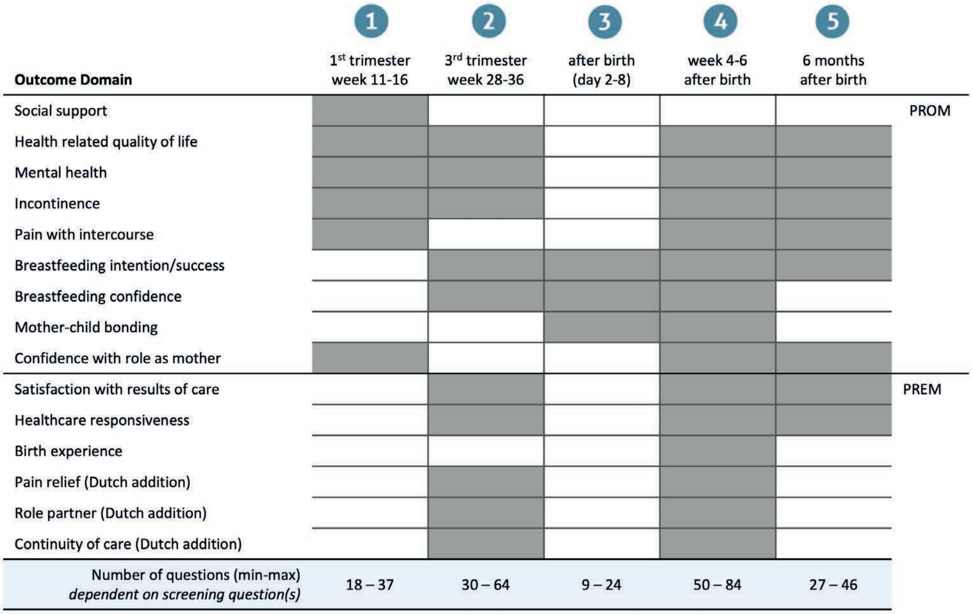
This study was conducted in seven obstetric care networks (OCNs) participating in a nationwide implementation project of the ICHOM PCB Set in the Netherlands. Alongside the implementation project in clinic, this study was performed to evaluate women's experiences with this innovation in routine care. 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] *PREM* patient-reported experience measure; *PROM* patient-reported outcome measure.

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



Outcome Domain	① 1st trimester week 11-16	② 3rd trimester week 28-36	③ after birth (day 2-8)	④ week 4-6 after birth	⑤ 6 months after birth	
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	

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					✓		✓

OCN obstetric care network.

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 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 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 the Data analysis section). All interviews were audio-recorded and transcribed verbatim.

Table 2. Topic list used for the interviews

Topics	Subtopics
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 points 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.

Data analysis

The quantitative data from the evaluation survey were analysed using descriptive statistics with SPSS V.25 (IBM). Free text answers were analysed with thematic analysis supported by Microsoft Excel (V.16). The transcriptions from the interviews were checked for accuracy with the original audiotapes by LL. The software program Atlas.ti V.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.[17]

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

Twenty-six participants provided their telephone number for the interview, none of these participants had completed PROM and PREM during time point 3 (maternity week). Sixteen 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.

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.

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 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.

Table 3. Overarching themes and identified facilitators and barriers

Themes	Facilitators	Barriers
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
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
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
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.

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 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.

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)

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 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)*

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 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.

Data capture tool

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)

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 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. 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 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] Second, 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 5 of the PCB set.[10,11] Compared with the check-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.[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

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 content of the questionnaires, the role of care professionals and congruity with routine care pathways.

REFERENCES

1. Porter ME, Teisberg EO. Redefining health care: creating value-based competition on results: Harvard Business Press; 2006.
2. Gliklich RE, Dreyer NA, Leavy MB, editors. Registries for Evaluating Patient Outcomes: A User's Guide [Internet]. 3rd edition. Rockville (MD): Agency for Healthcare Research and Quality (US); 2014 Apr. Available from: https://www.ncbi.nlm.nih.gov/books/NBK208616/
3. US Department of Heath and Human Services FDA Center for Drug Evaluation and Research. Guidance for industry: Patient-reported outcome measures: Use in medical product development to support labeling claims: Draft guidance. *Health Qual Life Outcomes*. 2006;4:1-20. doi:10.1186/1477-7525-4-79
4. Basch E. Patient-reported outcomes—harnessing patients' voices to improve clinical care. New England Journal of Medicine. 2017;376(2):105-8.
5. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of patient-reported outcomes in routine medical care. American Society of Clinical Oncology Educational Book. 2018;38:122-34.
6. van Egdom LSE, Oemrawsingh A, Verweij LM, Lingsma HF, Koppert LB, Verhoef C, et al. Implementing patient-reported outcome measures in clinical breast cancer care: a systematic review. Value in Health. 2019;22(10):1197-226.
7. Martin CJH, Martin CR. Development and psychometric properties of the Birth Satisfaction Scale-Revised (BSS-R). Midwifery. 2014;30(6):610-9.
8. Mason L, Glenn S, Walton I, Appleton C. The experience of stress incontinence after childbirth. Birth. 1999;26(3):164-71.
9. Nijagal MA, Wissig S, Stowell C, Olson E, Amer-Wahlin I, Bonsel G, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. BMC Health Serv Res. 2018;18(1):953.
10. Depla AL, Ernst-Smelt HE, Poels M, Crombag NM, Franx A, Bekker MN. A feasibility study of implementing a patient-centered outcome set for pregnancy and childbirth. Health Sci Rep. 2020;3(3):e168.
11. Laureij LT, Been JV, Lugtenberg M, Ernst-Smelt HE, Franx A, Hazelzet JA, et al. Exploring the applicability of the pregnancy and childbirth outcome set: A mixed methods study. Patient Educ Couns. 2019.
12. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009;4:50.
13. Depla AL, Lamain-de Ruiter M, Laureij LT, Ernst-Smelt HE, Hazelzet JA, Franx A, et al. Patient-Reported Outcome and Experience Measures in Perinatal Care to Guide Clinical Practice: Prospective Observational Study. Journal of Medical Internet Research. 2022;24(7):e37725.
14. Depla AL, Crombag NM, Franx A, Bekker MN. Implementation of a standard outcome set in perinatal care: a qualitative analysis of barriers and facilitators from all stakeholder perspectives. BMC Health Serv Res. 2021;21(1):113.
15. Pharos. Pharos 2022 [Available from: https://www.pharos.nl/.
16. Green J, Thorogood N. Qualitative methods for health research: Sage; 2018.
17. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-51.
18. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC health services research. 2013;13(1):1-24.

19. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. Jama. 2017;318(2):197-8.
20. Lapin BR, Honomichl R, Thompson N, Rose S, Abelson A, Deal C, et al. Patient-reported experience with patient-reported outcome measures in adult patients seen in rheumatology clinics. Qual Life Res. 2021;30(4):1073-82.
21. Lapin B, Udeh B, Bautista JF, Katzan IL. Patient experience with patient-reported outcome measures in neurologic practice. Neurology. 2018;91(12):e1135-e51.
22. van der Horst C. Personalized Health Care for Orofacial Cleft Patients. In: van Weert N, Hazelzet J, editors. Personalized Specialty Care: Value-Based Healthcare Frontrunners from the Netherlands. Cham: Springer International Publishing; 2021. p. 41-7.
23. Oemrawsingh A, Hazelzet J, Koppert L. The State of Patient-Centered Breast Cancer Care: An Academic Center's Experience and Perspective. Personalized Specialty Care: Springer; 2021. p. 127-35.
24. Schütze S, Hohlfeld B, Friedl TWP, Otto S, Kraft K, Hancke K, et al. Fishing for (in) continence: long-term follow-up of women with OASIS-still a taboo. Archives of Gynecology and Obstetrics. 2021;303(4):987-97.
25. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. Journal of patient-reported outcomes. 2018;2(1):1-16.
26. Arora J, Haj M. Implementing ICHOM's standard sets of outcomes: cleft lip and palate at Erasmus University Medical Centre in the Netherlands. International Consortium for Hea lth Outcomes Measurement (ICHOM), London. 2016.

SUPPLEMENT

Supplementary Table 1. Evaluation survey

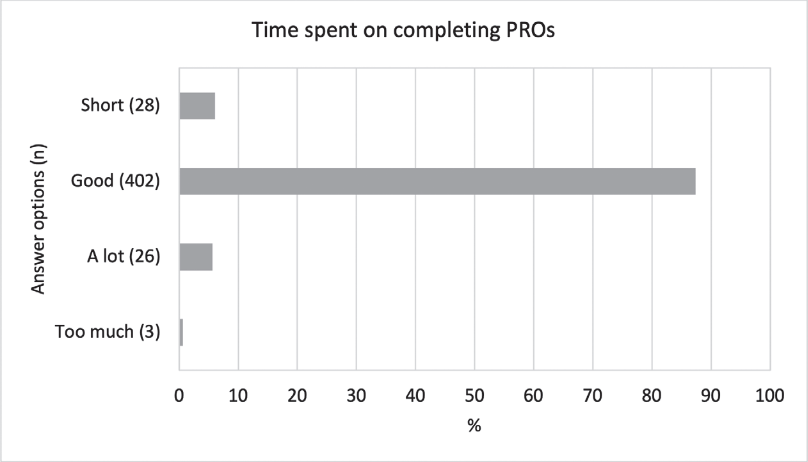
Q1) I found the time needed to complete the PROM and PREM …		
	Too much	
	A lot	
	Good	
	Short	
Q2) Were you able to properly complete all PROM and PREM?		
	Yes	
	No, I did not understand all questions	
	No, the questions were too personal	
	Other: …….	
Q3) During the next visit, you will discuss the 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

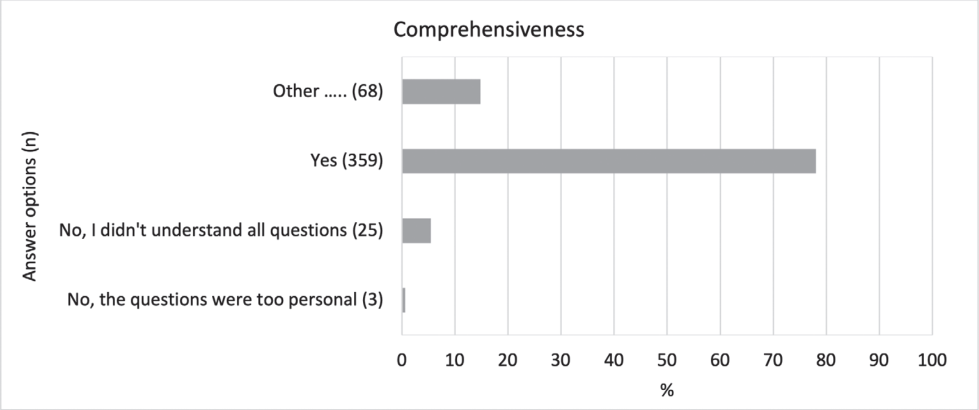
Supplementary Table 2. Survey participants per time point

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

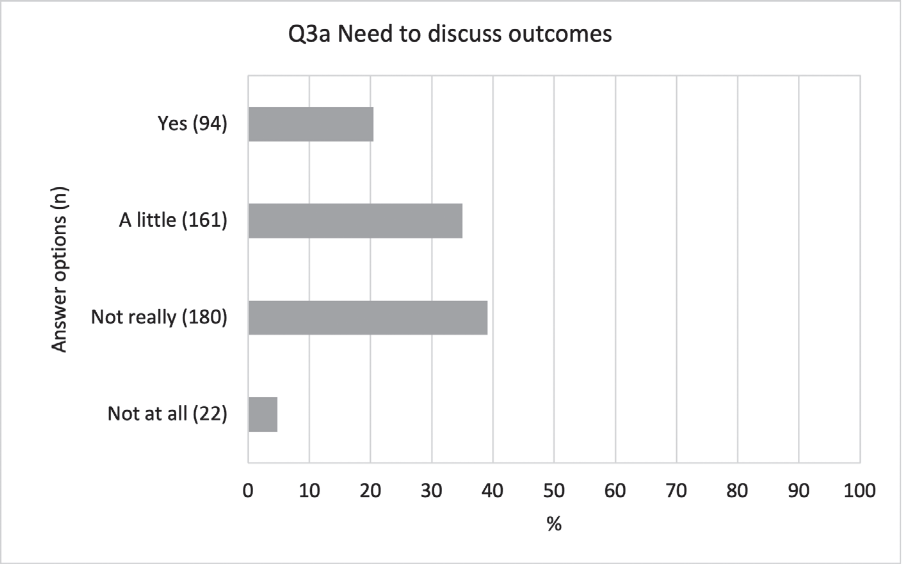
Supplementary Figure 1a. *Q1 I found the time needed to complete the PROM and PREM…*



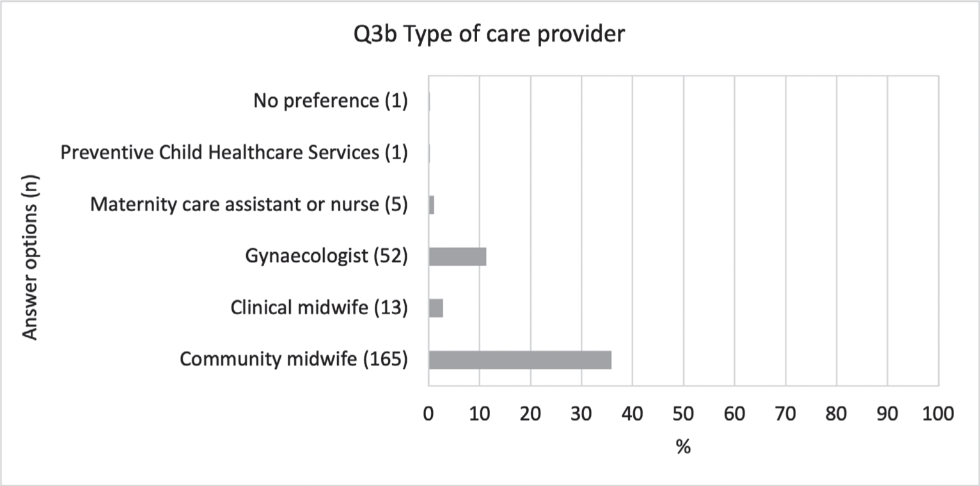
Supplementary Figure 1b. *Q2 Were you able to properly complete all PROM and PREM?*



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?*



7

CHAPTER 7

Quality improvement with outcome data in integrated obstetric care networks: evaluating collaboration and learning across organizational boundaries with an action research approach

Anne L. Depla, Anna W. Kersten, Marije Lamain-de Ruiter,
Marielle Jambroes, Arie Franx, Inge M. Evers,
Bettine Pluut, Mireille N. Bekker

Manuscript submitted (at International Journal of Integrated care)

ABSTRACT

Introduction Patient-reported outcome and experience measures (PROM and PREM) are used to guide individual care and quality improvement (QI). QI with patient-reported data is preferably organized around patients, which is challenging across organisations. We aimed to investigate network-broad learning for QI with outcome data.

Methods In three obstetric care networks using individual-level PROM/PREM, a learning strategy for cyclic QI based on aggregated outcome data was developed, implemented and evaluated. The strategy included clinical, patient-reported and professional-reported data; together translated into cases for interprofessional discussion. This study's data generation (including focus groups, surveys, observations) and analysis were guided by a theoretical model for network collaboration.

Results The learning sessions identified opportunities and actions to improve quality and continuity of perinatal care. Professionals valued the data (especially patient-reported) combined with in-dept interprofessional discussion. Main challenges were professionals' time constraints, data infrastructure, and embedding improvement actions. Network-readiness for QI depended on trustful collaboration through connectivity and consensual leadership. Joint QI required information exchange and support including time and resources.

Conclusions Current fragmented healthcare organization poses barriers for network-broad QI with outcome data, but also offers opportunities for learning strategies. Furthermore, joint learning could improve collaboration to catalyse the journey towards integrated, value-based care.

INTRODUCTION

The value-based healthcare strategy has shaped the development of healthcare systems towards a more person-centered and value-driven approach.[1,2] Defining value as outcomes for patients related to costs to deliver them, has aligned stakeholders to optimize value for patients.[3] Key-components currently adopted from this strategy include that professionals collaborate to organize care around patients' needs and continuously measure outcomes that matter to those patients, such as functional status and quality of life.[4,5] Patient-reported outcomes and experience measures (respectively, PROM and PREM) are structured questionnaires that allow patients to report their health status and experiences with care.[6] In addition to clinical outcomes registry, PROM/PREM capture is therefore increasingly embedded in care systems to enable value-driven care at both the patient level: by discussing outcomes in clinical encounter to guide care decisions, and the population or patient group level: by evaluating aggregated outcomes for continuous quality improvement (QI).[7–9]

Although potentially promising, QI with aggregated PROM data of patient groups has been rarely described in the literature.[10] In value-based care research, examples of multidisciplinary QI with other outcomes data have been gathered: strategies included benchmarking, plan-do-study-act cycle, dashboards, and internal statistical analysis.[10–12] One of the main lessons from these projects, mostly conducted within organisations or single-provider networks, was that organisational readiness is needed for such an approach.[4,11,13] For many conditions, like frail elderly or pregnancy and childbirth, interorganizational collaboration in QI is needed to involve all professionals responsible for the outcomes of care.[14] In other words, patient-centred QI implies data collection, learning and innovating in integrated care networks, but what is needed to ensure network-readiness? Growing knowledge on network collaboration has emerged from many systems in transition to integrated care, including in perinatal care.[15–17] These transitions and accompanying research have offered valuable insights into collaboration processes across organizational boundaries and exposed barriers to be addressed at interprofessional level and at system level.[16,18,19] However, conditions and (learning) strategies for network-broad QI with outcome data are yet to be investigated.

This knowledge gap applies to present-day Dutch perinatal care as well (Textbox 1), where collaboration in obstetric care networks (OCN) has increasingly integrated care around patients. Although structural QI with patient-centred outcome data is considered an essential part of integrated care in their Care Standard as well, many OCN still struggle in practice to organize access to reliable data, joint learning strategies and follow-up of improvement actions.[20,21] In an implementation project guided by action research, three OCN aimed to both implement PROM/PREM assessment at individual level to guide patient care and use their aggregated data in network-broad QI cycles. Along PROM/PREM implementation in practice, this study focused on learning strategies for QI with outcome data in integrated care networks. Our aims were to 1) develop, implement and evaluate a learning strategy for patient-centred QI with outcome data in obstetric care networks and 2) explore and facilitate network collaboration factors that enable joint learning across organisational boundaries.

Textbox 1 Dutch perinatal care system

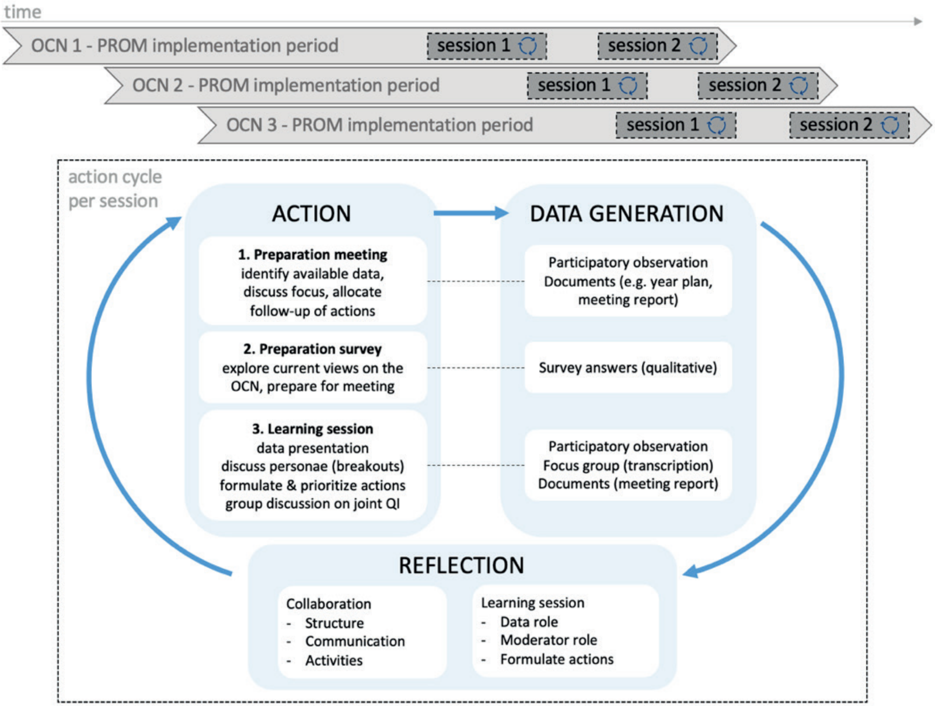
Dutch perinatal care is provided multidisciplinary from two healthcare tiers: primary care by community midwives and maternity care organizations; and secondary/tertiary care by hospital employed care professionals. After this system became under pressure by relatively poor outcomes in 2004, care integration from all providers across the perinatal care continuum was considered one of the solutions to improve care continuity, perinatal health outcomes and even lifelong health of mother and child.[22,23] This potential solution was adopted by the Dutch government and the main parties within the sector.[20,24] Since then, hospitals, regional community midwife practices, maternity care and preventive child health organizations increasingly cooperate in local obstetric care networks (OCN) that aim to deliver high standard integrated care.[21]

METHODS

Design and framework

A qualitative observational study was conducted to investigate network-broad learning with outcome data. This study was embedded in an implementation project with the aim to implement PROM/PREM in routine practice of OCN, for which implementation analysis is described elsewhere,[25] and subsequently in network-broad QI cycles based on aggregated results. A PROM/PREM set for perinatal care was used that was developed internationally, and tested recently in a national pilot.[26,27] The implementation process was guided by the principles of action research, an approach both to investigate practice change, whilst at the same time facilitating that change with researchers and participants collectively contributing to both aims.[28] This enables a broad understanding of complex practice changes and is done in a cyclic design of planning, action, data generation and reflection on data to plan subsequent actions. In this study, researchers and care professionals iteratively developed, implemented, reflected on, and adapted a learning strategy for QI with aggregated outcome data, concurrently gaining understanding of the complex conditions needed to learn and improve as care network. Each learning session corresponded with an action research cycle: to enable learning from previous cycles, the implementation project started in each OCN consecutively (Figure 1). As underlying theory, D'Amour and colleagues' model for collaboration was used to determine the intensity of collaboration and link it to the ability to learn and improve as network.[29] Their model, consisting of four dimensions covering ten indicators, addresses both interprofessional and interorganisational collaboration and provides a typology to assess intensity of collaboration via three levels per indicator (Table 1). This study was conducted between September 2019 and June 2022.

Figure 1. Study design: timeline and action research cycles per learning session



OCN obstetric care network; *PROM* patient-reported outcome measure; *Implementation period* was 12 months in each OCN.

Table 1. Indicators for collaboration (based on the model and typology of D'Amour 2008)

Core construct	Indicator	Description
Shared goals and vision	Shared Goals	The extent to which common goals have been formed and are supported by all collaborating partners.
	Client-centred orientation vs. other allegiances	The existence of asymmetric interests among partners and whether these are being expressed and negotiated.
Internalization	Mutual acquaintanceship	The presence of social conditions through which professionals get to know each other personally and professionally and create a sense of belonging to a group.
	Trust	Whether trust or uncertainty exists in each other's competencies and ability to assume responsibilities, and whether this is grounded by previous experiences.
Governance	Centrality	Explicit and active involvement of central authorities with a well-defined strategic and political role to foster consensus and improve collaboration.
	Leadership	Type of leadership and balance of power in the collaboration: emergent or position-related, ad-hoc decisions or complete policy and shared or monopolistic.
	Support for innovation	The extent to which the organization draws on expertise needed to support complementary learning processes.
	Connectivity	Connection between parties through venues to discuss problems, find consensus and constructing bonds.
Formalization	Formalization tools	The degree of consensual agreements about roles and responsibilities: whether these are jointly defined and respected by all parties.
	Information exchange	The existence and appropriate use of an information infrastructure that meets care professionals' needs for rapid, complete exchanges of information.

Setting and participants

The implementation project in which this study was embedded, was initiated from a consortium of all OCN in the middle of the Netherlands ('Geboortezorg Consortium Midden Nederland', GCMN). The current Dutch perinatal care system is explicated in Textbox 1. The project was carried out in three OCN, of which the hospital and several midwifery practices implemented PROM/PREM in their practice. In this study, regarding the learning strategy with aggregate outcomes, all care professionals working in these OCN could participate. Three levels of professionals' participation could thus be defined: care professionals in the local project team (key participants), care professionals actively working with individual PROM/PREM results in practice (midwives and gynaecologists of practices participating in practice implementation), and other care professionals only joining the learning sessions with aggregated data (from non-participating practices or from other disciplines, e.g., maternity care assistants, nurses).

Learning strategy

The purpose of the learning strategy was to support the OCN in setting up cyclical improvement of quality of care based on outcome data of their patient population. Its development was based on the IPEC (Interprofessional Education Collaborative) framework and a previous municipality project. Of the four core competencies of the IPEC framework required for interprofessional collaborative practice, the focus of the learning strategy was on competences in 'Teamwork and Teambased practice' (defined as *"Apply relationship-building values and the principles of team dynamics to perform effectively in different team roles to deliver and evaluate patient-centred care"*).[30] The municipality project provided three years of experience in developing a learning strategy in which population data is used as basis to improve interprofessional collaboration between primary care, social care, and the municipality. The experiences from this project were translated to the OCN setting.

The learning strategy consisted of three parts, which were reflected upon and adapted if needed in each action research cycle (Figure 1):

1. Preparation meeting: a one-hour meeting with a key-participant from each discipline to 1) prepare a session that matches current OCN goals and QI activities, and 2) engage key participants in session preparation to support embedding future improvement actions and sustainable learning cycles (even after the project). We aimed to discuss preliminary PROM/PREM results, identify additional data sources, choose important themes emerging from the data, adjust the preparation survey and session-invitation to local needs, and find possible follow-up structures for improvement actions formulated in the upcoming session.
2. Preparation survey: the goal was to 1) let participants think of the goal, topics, and expectations of the session beforehand, and 2) provide data for the session about the view of the professionals on current problems/challenges in their population.
3. Learning session: a three-hour session with five activities 1) icebreaking: exchange experience with using PROM/PREM on a patient level, 2) data presentation, 3) small, interprofessional group discussions about main themes from data along recognizable cases, 4) plenary discussion to share, choose and prioritize concrete improvement actions, 5) focus group discussion to reflect on collaboration conditions and needs for QI as network. Two sessions were planned per OCN: around 6-9 months and 9-12 months into the one-year implementation period.

The sessions were based on three types of data: clinical data, PROM/PREM data and care professional-reported data (via the preparation survey). Together, these data were used to create a shared understanding of the most important problems/challenges in the OCN's population. These challenges were translated into individual, fictive personae reflecting recognizable cases in practice. Personae were discussed in interdisciplinary groups of 4-8 care professionals along a standard question format addressing positive and negative aspects of care for this persona. We aimed to achieve diversity in attending professional roles (i.e., minimum: a gynaecologist and midwife per persona, and a nurse, maternity care assistant and neonatologist per session). After re-joining again, each group summarized their conversation and concrete improvement actions were set, prioritized and allocated with all attendants. As final part of joint learning, the focus group offered space for collective reflections on collaboration conditions for QI as network and identify (local) needs for sustainable QI cycles. A session was summarized in a written document and a factsheet, to share the results across the OCN. Three researchers moderated the sessions together with the local project leader (a care professional).

Data generation

A combination of qualitative methods was used to collect individual views of and generate group discussions with care professionals directly, as well as indirect via observations and documents (Figure 1):

- Qualitative survey: the preparation survey for participants to the learning sessions was used (Supplementary Table 1). It consisted of six open-ended questions and took 5-15 minutes to complete. Via a digital link, it was sent out with the session-invitation. Professionals who applied for the session received a reminder week beforehand.

- Focus group discussions: with care professionals attending the learning sessions who gave verbal informed consent. The topic guide based on D'Amour's model concerned collaboration factors, current network-broad learning and conditions for outcome-based QI. One researcher (AD or AK) moderated the focus groups. Notes were taken by a second researcher and discussed afterwards (AK, AD and ML). Focus groups were transcribed ad verbatim.

- Participatory observation: three researchers (AD, AK, ML) performed participatory observations at the preparation meetings and learning sessions, supervised by a senior action researcher (BP). Notes were taken about network collaboration, roles of and interaction between professionals (and researchers), and elements of the learning sessions. Afterwards, the researchers reflected upon the notes and saved them in a logbook.

- Documents: written documents regarding OCN collaboration and learning process (e.g., vision document, year plan, meeting reports) were saved for analysis.

Data analysis and reflection

During the study period, researchers and participants iteratively developed and executed learning activities, generated data on their experiences and reflected on those data, which shaped the learning strategy and subsequent data generation. For example, reflections in dialogues between researchers and participants were used to adapt the topic guide for focus group discussion to address collaboration aspects important in context and time. A structured reflection journal was kept and discussed every two weeks to strengthen this process. Eventually, data from all sources were merged and thematically analysed by two researchers (AD, AK) conform QUAGOL guidelines, using a combined deductive and inductive approach.[31] Guided by D'Amour's model, this process included the following steps: data familiarization, initial coding (two documents by both researchers), discuss differences to reach consensus and develop a mature coding scheme, further coding of all data, summarize main themes per document, charting and mapping all coded fragments, and interpretation. We used Microsoft Word for coding and Microsoft Excel (version 16.64) for mapping and analysis.[32]

RESULTS

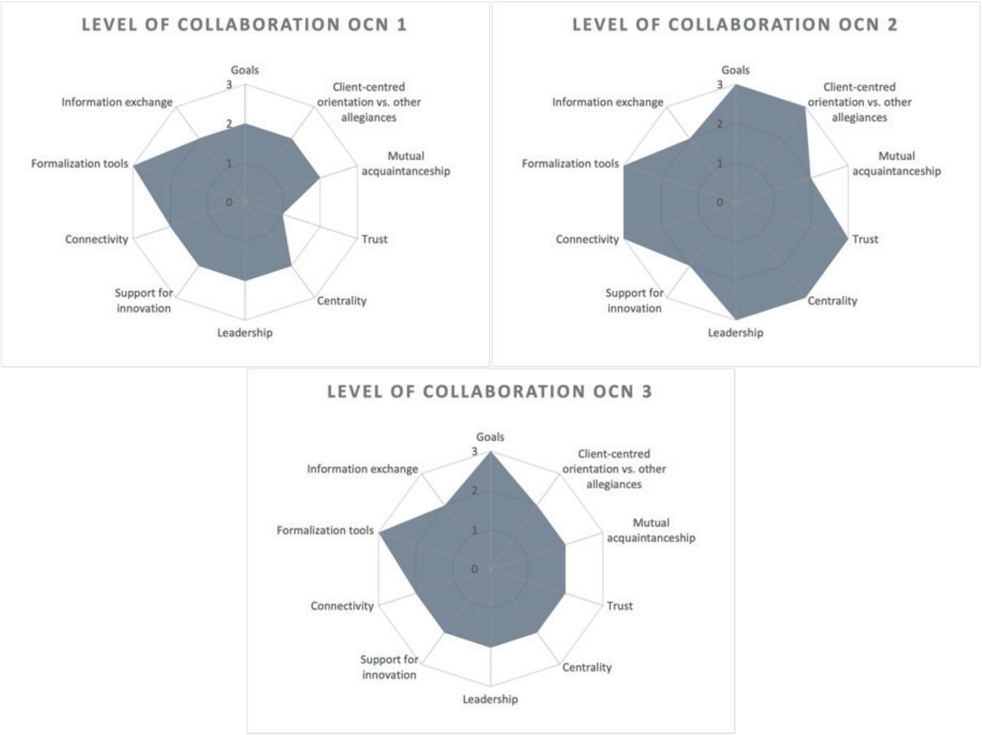
Across the three OCN, five learning sessions were organized, four of which took place online because of the COVID pandemic. One OCN organized only one of two indented sessions: after stopping PROM/PREM capture after the one-year implementation period mainly because of IT issues, this OCN wanted to invest first in solving IT issues and improving collaboration before putting their time and efforts in a second session. On average 17 professionals attended the sessions, representing four to six different disciplines and four to seven organizations (Table 2). The preparation meeting before each session was attended by mean four care professionals (range 2-8). In total 60 preparation surveys were returned. Five focus groups were held, one in each session, with a total of 78 care professionals participating. Overall collaboration levels across the study period varied per OCN (Figure 2), of which intermediate assessments were used to prepare meetings and reflected on with participants. After merging all data sources, thematic analysis resulted in an overall evaluation of the learning strategy and collaboration factors affecting network-board learning.

Table 2. Characteristics of learning sessions

	Session 1	Session 2	Session 3	Session 4	Session 5	Total	Total unique
Region	OCN1	OCN2	OCN2	OCN3	OCN3		
Location	online	online	live	online	online		
Participants	16	25	11	16	19	87	70
community midwife	9	11	5	8	10	43	33
hospital midwife	1	6	3	3	2	15	12
obstetrician/gynaecologist	2	2	2	2	4	12	9
obstetric resident		6		1	2	9	9
youth care professional	1					1	1
obstetric nurse			1	2	1	4	3
maternity care	2					2	2
neonatologist/paediatrician	1					1	1

OCN obstetric care network.

Figure 2. Collaboration levels of participating OCN



These Kiviat graphs map the collaboration per OCN: a score of 1 to 3 is assigned to each of the 10 indicators depending on the level of achievement of the indicator in the OCN.[29] *OCN* obstetric care network.

Learning strategy evaluation

Iterative reflection and adaption of the learning strategy with researchers and care professionals resulted in main challenges and successful elements, for which illustrative quotes are listed in Textbox 2.

Textbox 2. Supportive quotes learning strategy evaluation

<u>Successful elements of strategy</u>	
Interdisciplinary discussion	**Q1** Clinical midwife OCN2, focus group – "*It [the subgroup discussion] is very small and compact, everyone brings their expertise from their own profession. I also think that it goes very harmonious. And as a result, such follow-up visit [improvement actions], that it arises in both groups: that wouldn't emerge in a regular meeting."*
Interdisciplinary discussion and data insight	**Q2** Clinical midwife OCN3, focus group *"In the past, we did look regularly at clinical data and actions were taken. [..] But then, I agree with [a gynecologist], in a meeting like this one, where you can also discuss data more in-dept and concrete with each other [..] then I think you will be able to realize improvements and adjustments much better together."*
<u>Challenges for learning strategy</u>	
Follow up of actions	**Q3** Gynecologist OCN3, observation of preparation meeting *"GYN states they were still habituating in the first session and must seek as OCN who picks up the actions. The actions of first session have been submitted to the OCN board but have remained there."*
Engage all disciplines	**Q4** Clinical midwife OCN2, focus group *"The intention is that we will involve nurses and the maternity caregivers much more in the OCN, and inform them much more about what it all means and what topics are at stake. And that they also have input on that."*

Successful elements included insight in (patient-reported) data, interprofessional discussion along personae, plenary prioritizing, and joint reflection.

- Professionals in all OCN were enthused by the insight in *data directly from their patients*. Clinical data about their network had been presented before, and sometimes discussed for quality performance as well, but the combination with patient-reported data provided a more complete view of their patients' wellbeing and experiences (e.g., breastfeeding, shared decision making). Session participants emphasized that data presentation should be short and concise and highlight both positive and negative outcomes.

- *The translation of data into personae* reflecting most important challenges was praised in participants' reflections and enabled a conversation about the provided care for that persona in all observations, while limiting the discussion about the quality of the data themselves (e.g., casemix factors, representativeness). Also, reflected in the sessions' output, professionals were in the lead which part of the persona was most important, i.e. the main challenge they encountered in practice for this persona.

- Session participants agreed on the value of *interprofessional discussion* in small subgroups about improvement opportunities in practice. Based on survey answers and focus group opinions, these discussions were most valuable if a diverse range of professionals joined and shared various perspectives. Regardless of the exact topic, participants in subgroups were observed to share expertise, find consensus, and use each other's qualities or initiatives.

- After subgroup discussions, *the plenary conversation* was found essential to prioritize and allocate improvement actions to individuals or existent working groups, which required time and active moderation. Sometimes, multiple subgroups (i.e., that had discussed different personae) shared similar improvement actions here, which gave participants a feeling of consensus and urgency.

- Iterative *joint reflection* on sessions and local collaboration*,* both in the preparation meeting and collective focus group, was noted to enhance professionals' ownership over the QI process and adjust it to contextual factors and priorities. In the preparation meeting, key participants incorporated current OCN goals in the preparation survey, discussed how to engage all disciplines, and set priorities and goals for the session. Also, specific collaboration themes that arose in preparation meetings could be incorporated in focus group statements, which helped to create collective discussion and form consensus on these collaboration themes.

Elements that posed challenges included care professionals' time constraints, data infrastructure, engagement of all disciplines, and formulating actions and their follow-up.

- *Professionals' time constraints* were one of the main reasons for absence, interrupted meetings or partial attendance, partly due to the acute nature and irregular hours of perinatal care. Although they felt learning is part of their normal job, all participants conformed that preparing and attending network-level learning or QI always came on top of regular working hours. Besides demanding patient care, some focus group participants emphasized that personal priorities and the OCN culture influenced available time and efforts for collaboration and joint QI as well.

- *Data infrastructure.* In all OCN, participants and researchers experienced difficulties to gain valid, real-time data. Network-broad clinical data were often outdated or unreliable due to registration issues. Moreover, little PROM/PREM data were available due to IT challenges that persisted during the implementation projects and couldn't be merged directly with clinical data. Also, data preparation (access available sources, analyse, visualise) took much time and had to be conducted largely by the researchers. In the OCN with a quality manager, this process was easier and resulted in more valuable data.

- *Follow-up of improvement actions* differed in success per session, and joint reflections pointed out two aspects: OCN collaboration structure and nature of improvement actions. A clear and active collaboration structure to set priorities and divide responsibilities was considered helpful to allocate the actions directly to the right persons or existing working groups. Researchers noticed that a confined range of improvement actions came up (e.g. practical, direct actions, education), and that a broader action repertoire could enhance finding suitable and effective solutions.

- Several participants noted that *engaging professionals* not working with PROM/PREM in practice had added value but was harder. Moreover, existing gaps between professions or organisations were considered difficult to bridge. In several focus groups, participants expressed a need to increase involvement of nurses and maternity care in their OCN. If attending a session, often a manager came, who could contribute less to a persona discussion because of little practice experience.

Based on reflections, improvements made to the sessions in general included a more concise data presentation, a longer plenary end to prioritize and allocate actions, a list of possible action levels to broaden the range of thinking, and adjustments to the persona format to navigate the subgroup discussion better. After the first two sessions (online), the topic guide for focus group discussion was transformed by the researchers into statements to provoke discussion and engagement of all participants. In the next sessions, these statements could be adapted easier to collaboration topics important in local context and time, based on reflection in dialogue between researchers and care professionals.

Collaboration factors affecting joint learning

Thematic analysis of collaboration in the networks and the influence on the ability to learn and improve as network was summarized in Table 3 along the indicators of D'Amour. Below we elaborate on the indicators that contributed mostly to the ability to learn and improve as a network, for which illustrative quotes are listed in Textbox 3.

Textbox 3. Supportive quotes collaboration factors affecting joint learning

Baseline collaboration needed	
Collaboration baseline	**Q5** Clinical midwife OCN1, focus group *“I think it’s until you have your act together as OCN that it will be fun to look at those outcome data together.”*
Trust and other allegiances	**Q6** Obstetric resident, OCN2, preparation survey (item 6: when is the session successful for you?) *“If we work together on outcomes without restrictions in trust or finances/autonomy: ‘what is best for the pregnant woman?’”*
Connectivity vs leadership	**Q7** Gynaecologist OCN3, focus group – “*I also think that what she said [statement of clinical midwife] is a somewhat broader endorsed dissatisfaction. That, with the implementation of the new [leadership] structure, too much goes via mandate or too much goes via a limited number of people. That the joint meetings [in the past] really added something.”*
Conditions for joint learning	
Information exchange	**Q8** Obstetric resident OCN3, preparation survey (item 2: what do you need as professional to address these themes?) – *“A joint EPD, this also ensures more efficiency and less chance of errors, because then we don’t have to retype anything.”*
Support for innovation: joint reimbursement	**Q9** Gynaecologist OCN2, focus group – *“But we can buy that time by being an integrated care organization: by having a quality officer, having secretarial support, having a manager. We buy off all kinds of things, so to speak, so that we have time for learning and improving”*

Before learning and improving together, a collaboration based on *trust* was explicitly stated essential in focus groups and survey answers and reached most noticeably through *connectivity* and *leadership*. In the sessions, professionals unanimously agreed that *trust* was the base of collaboration, including respect for divergent opinions or visions and acknowledgement for different qualities per profession. Although all OCN expressed a shared patient-centred goal and vision formalized in their plans, professionals described variation in the extent to which *connectivity* was present to discuss differences (in opinions, visions, other allegiances), find consensus, and share commitments to reach those goals. If connectivity decreased, or was confined to a small number of professionals, increased fragmentation was described and observed on several collaboration aspects, such as goals, formalization tools and decision-making. Arising from joint reflections in group discussions and observations, collective *leadership* that invested actively in broad *connectivity* and gave regular feedback could improve *trust* in collaboration on all these aspects, whereas ad-hoc and fragmented decisions could even cause distrust. For example, top-down decisions made in a single organization surprised care professionals in (other) practice(s) and were less likely to be accepted by professionals in practice, both affecting the level of trust negatively.

When a base for collaboration was present in an OCN, their ability to learn and improve together was influenced mostly by *information exchange*, *support for innovation*, and *centrality*. Current *information exchange* posed a barrier in all OCN: each of them searched better access to aggregated data – especially patient-reported data. An integrated approach to innovation was believed most valuable for patients. Yet important barriers classified in *support for innovation* were time constraints for care professionals and, along that, financial support for joint innovation (e.g., participation in working groups, performing leadership roles, data analysis and visualisation). Most tasks were thus performed voluntarily, making these efforts vulnerable to professionals' individual motivation and priorities for QI. In OCN2, a quality manager and administrative support could be allocated from their joint reimbursement structure, which supported them significantly in joint QI. When the strategic and political roles within an OCN (*centrality*) were clear to all professionals and carried out actively, new initiatives were easier to allocate and follow-up.

Table 3. Framework analysis of network collaboration and learning along D'Amour model

Indicators of collaboration	**Thematic analysis** (Summary with subthemes in bold)
Shared goals	All OCN had a shared patient-centred goal: best possible outcomes and continuity of care. **Year plans** to reach their goal were formalized in OCNs to various extent, and in each organisation (e.g., a hospital) separately. This could lead to **fragmentation**, dependent on the network's governance. For learning, shared goals were important, but should be **concise and focused** (not too many or too broad).
Client-centred orientation vs. other allegiances	All OCN **centred patients** in their vision, but it differed to what extent **other allegiances** overruled that (e.g., professional autonomy, financial structures). Also, professionals had **divergent views** on what benefits patients most. All OCN wished to involve **patient views** in learning/improving, especially when selecting or evaluating new initiatives, but struggled to do so (see information exchange).
Mutual acquaintanceship	In all OCN, professionals stated that knowing each other and meeting regularly were of greatest importance for good collaboration. When feeling part of the OCN was **limited to a few key participants**, the network was depended on the same people who were very motivated but needed broader engagement for results. Participants identified **stakeholders** needed for learning as all professionals involved in care and patients themselves. Yet in all OCN, engaging **nurses and maternity care assistants** in network activities was challenging. Knowing what occurs in the OCN and experiencing their valid contribution could help them become more involved.
Trust	Care professionals stressed trust as most important, the **base**, for collaboration and joint learning/improving. Important for trust were **respect** for divergent opinions and **acknowledgement** for qualities across disciplines. All OCN had built some level of trust from fragile to grounded, but differed in whether that was **maintained** over time, and how broadly it was **shared** across professionals. Trust was determinative for working pleasure/atmosphere perceived by care professionals and was mostly influenced by the level of connectivity and mutual acquaintanceship.

Indicators of collaboration	**Thematic analysis** (Summary with subthemes in bold)
Centrality	Centrality was not often chosen or stated by care professionals as important factor, but indirectly they mentioned that improvement initiatives should **not overlap**, and **consensus** and **clarity** existed on goals and plans of the OCN. In OCN with an inactive central body (for several reasons, see leadership), initiatives were **fragmented** and proceeded slow as it was harder to **allocate actions**.
Leadership	Leadership varied across the OCNs and noticeably influenced the ability to learn and innovate together. If leadership patterns were observed more **fragmented** across organizations, ad-hoc decisions and **unclarity** where decisions should be made often resulted in **top-down** decisions eventually – which were then less likely to be accepted by professionals in practice. Leadership **structures** were still developing, and professionals noted that its changes affected their connectivity and mutual acquaintanceship.
Support for innovation	OCNs experienced little support not necessarily in a lack of expertise, but in **time** (workload, priorities) and **resources** (data availability and analysis, digital support). In two OCNs the working group for quality improvement was inactive or even absent. In OCN2 it was stated they 'bought time for innovation' to some extent by allocating administrative support and a quality manager for the OCN, possible via a **joint reimbursement** structure. Care professionals indicated that learning and QI felt as a **normal part** of their professional role. On a personal level, they **learn and improve every day** during work, but network level learning or QI always comes **on top of their normal job**, often in late hours as patient care comes first. For care professionals, learning/improving was stated to be **easier within organisations than in a network** (challenging to engage all stakeholders) but they expect most **value** for patients from a network approach.
Connectivity	Connectivity was highly important for collaboration and innovation, both from professional's views as from observations. First, regular venues for discussion were essential to **form consensus or accept differences** in vision and **make use of each other's expertise**. Second, connectivity in the way that professionals knew from each other **what they were working on** and what their **level of commitment** was. Both contributed positively to trust between OCN professionals, their sense of belonging (mutual acquaintanceship) and ability to work simultaneously instead of fragmented.
Formalization tools	All OCN experienced positive results from their joint formalization tools (e.g., joint protocols, shared care pathways, standard collaboration partners). In the past years, this has been their **primary focus** to improve quality and **continuity** of care. While many survey respondents expressed a need for more formalization, others emphasized that attention should remain for **patient's values and individual choices** in care paths. In QI, formalization was considered and observed as a tool to embed actions in practice.
Information exchange	As almost all organisations worked in different EHRs, each OCN faced problems with information exchange (i.e., e-mail, fax, on paper) and mandated a **shared or connected EHR** to enable easier communication in practice and better access to aggregated data for learning and QI. **Reliable data** were stated essential for QI and learning but are hard to access or require much effort. Moreover, patient-reported data are not accessible at network level at all (except during the implementation period), making it difficult to **involve patient** views in learning and QI.

OCN obstetric care network; *EHR* electronic health record; *AR* action research; *QI* Quality Improvement.

DISCUSSION

In three OCN using PROM/PREM for individual care, a network-broad learning strategy was developed with the aim to set up cyclic QI with aggregated data of their population using clinical, patient-reported and professional reported data. Guided by an action research approach, the learning strategy was implemented, evaluated and adapted simultaneously to gaining knowledge of network collaboration conditions that enable joint learning. In all OCNs, the learning strategy created a venue for in-dept interprofessional discussion and helped to identify improvement opportunities for quality and continuity of care across the perinatal care continuum. Main challenges were professionals' time constraints, follow-up of improvement actions and data accessibility. The significant differences found in network collaboration affected their ability to activate joint learning and improvement cycles. First, readiness of a network to learn together depended on a baseline collaboration with trust, reached most noticeably through connectivity and consensual leadership. Second, sustainable joint learning and improvement cycles required information exchange and support for innovation in terms of time, data, and resources.

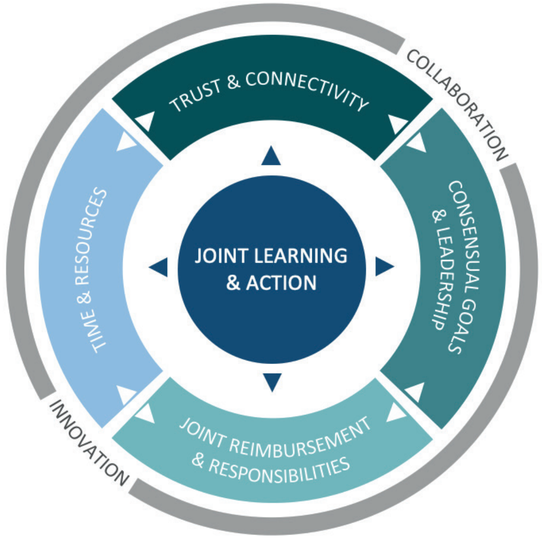
In line with literature, collaboration was only possible when grounded trust was present, thus fundamental for joint learning too.[29,33] Trust between maternity care professionals is an area of tension historically, originating from several factors including professional autonomy, financial incentives, and divergent paradigms on the physiology of pregnancy and birth.[34,35] In our project, these tensions emerged as well to some extent in all OCNs striving for integrated care, but important variations in trust were found between OCN (e.g., the degree of trust, how broadly shared, at practice level and/or at managerial level). A crucial factor for whether OCN had built and maintained trust appeared the level of connectivity to discuss issues, form consensus, and build mutual accountability in relations. Here, an important role for leadership emerged to foster connectivity, participatory decision-making, and clear communication about decisions to, subsequently, build trust. Networks with collective, consensual leadership expressed more connectivity compared to top-down power relations or fragmented leadership patterns. This resonates with previous reflections on leadership and power dynamics in integrated care, that state a need to reflect on power as dispersed and negotiated throughout the network and its actors, instead of power as bidimensional; and a need for collective leadership to build trust, distribute accountability, power, and funding across organisational boundaries.[36,37] Thus, to build and maintain trust throughout the journey towards integrated care, connectivity built in daily practice between professionals must be supported by leaders, who have the time, resources, and drive to organize common ground to manage conflict and form consensual decisions on a continuous basis.

A main barrier for collaboration and joint learning across the networks was a lack of time, and underneath that, the resources to make time. Although mentioned as external factors influencing collaboration, resources and financial constraints were not included as internal collaboration indicators by D'Amour.[29] In contrast to our findings, where internal structures in network governance (i.e., joint reimbursement agreements) affected the availability of time and resources for collaboration and were interconnected with trust and shared goals as well. For instance, the level of trust and shared goals influences the decision to become an integrated organisation with a juridical entity for joint reimbursement agreements, which, in turn, creates opportunities to further collaboration with shared resources and responsibilities, decreasing other allegiances than client-centeredness. Therefore, time, resources and financial agreements reflect collaboration and should be considered when evaluating and improving network collaboration as part of governance. Still, as emphasized by others as well,[16,17] external system-level changes are required that address the structural barriers for collaboration to enable possibilities for joint reimbursement agreements in networks that feel ready.

In the learning strategy, the outcome data feedback was valued as it helped to identify opportunities to improve care and stimulated care professionals in their willingness for QI. At the same time, the available data for the sessions were far from optimal and their gathering and analysis (especially patient-reported; organized temporarily during the implementation projects) took much time and efforts. Noticeably, the learning strategy facilitated a shift from a discussion about data (quality) towards content of care by translating main themes emerging from the data into personae. Even with better-quality data, this strategy might help to focus on content of care, as case-mix factors and validity (i.e., whether the data truly measure value of care) will always be subject for discussion to some extent. Another benefit of this data-to-case strategy was that professionals were in the lead of important aspects of care that needed change for a persona. As such a strategy depends on professionals' capability to observe, interpret and reflect broadly on possible solutions to produce effective actions, future (action) research could explore how knowledge on learning to learn could benefit the VBHC strategy.[38] Empowerment of professionals in learning can contribute to workforce development, working culture and their ownership of QI initiatives.[39,40] Thereby supporting to rebalance the reinforcing relation between bottom-up initiatives and top-down directives needed to implement integrated care.[41] Although the data-to-case strategy provided short-term opportunities for joint learning, sustainable resources for (patient-reported) data capture are needed to empower professionals further in QI, such as digital questionnaire tools and infrastructures to merge clinical and patient-reported data across providers.

In short, the venue for discussion created in the sessions was more important than the data themselves and, although not directly measured, presumably contributed positively to connectivity and trust – especially if some of that was already present. So, not only collaboration factors affected the ability to learn together but, reversed, learning activities seemed to influence collaboration: creating a cyclic effect between collaboration and innovation visualized in Figure 3. A similar effect was described in a study of multidisciplinary teams, stating that joint actions – more than vision or strategy – have the potential to catalyse integrated care.[42] A challenge for collaboration and learning encountered in our project was how to engage all disciplines needed and, if engaged, a broader group than just key stakeholders. Nurses and maternity care, for example, were considered important stakeholders but were less connected to the OCN in general. Our findings do provide a direction for improvement via joint learning and action.

Figure 3. Joint learning in relation to collaboration and innovation in care networks



Strengths and Limitations

The use of D'Amour's typology strengthened our analyses and understanding of collaboration mechanisms and the way they influence joint learning. The combination of focus groups, open-ended surveys, observations enabled data triangulation from multiple sources and various perspectives. Findings were further verified by the interaction between professionals and researchers. Still caution is needed with generalizability, as researchers and participants were focused on applying the findings and improving the strategy to the local context. The usability and future sustainability of the learning strategy was enhanced by care professionals' participation in actions and reflections on the needs for collaboration and learning. When implementing the strategy in other settings, this adaptive and reflexive design should be adopted as well to match local needs. With three different network settings participating consecutively, the iterative action research process contributed to improve the sessions in general, reach data saturation in research activities, and adapt to the exceptional circumstances during the covid pandemic. Still, the COVID-19 pandemic has influenced our findings not only because online contact limited interprofessional interaction in group discussions, but also because other joint activities were on a lower level and professionals' workload was extra high. Although unfortunate in terms of data to evaluate and improve the strategy, one session not being carried out provided insight in the conditions needed to carry out collective learning at the same time. Ideally, patients would have participated in the learning strategy too, but this was chosen not to organize as PROM/PREM data were already used.

Practice implications

The lessons learned in this study have both short- and long-term implications for the journey towards patient-centred integrated care improvement. Short time implications for learning strategies for QI with outcome data are 1) combine available data sources and use them pragmatically (e.g., personae, question format) to generate meaningful discussions; 2) work in an iterative design to adjust to local collaboration and existent QI processes; 3) invite all disciplines and organizations as multidisciplinary discussions could improve the value of learning sessions and the connectivity across the network; 4) embed new learning strategies in policies (e.g., Standard of Care, training, accreditation) with sufficient support, to reduce the burden of QI initiatives on professionals and create short-term external incentive. Long term implications for network collaboration and learning include 1) invest in network-broad data infrastructures including patient-reported data;[43,44] 2) explore joint reimbursement structures to enable sustainable joint learning and follow-up of actions; 3) create sustainable, collective leadership structures that foster connectivity.

Conclusions

Before integrated care and joint quality improvement based on (patient-reported) data will become normal practice, important challenges exist in current fragmented healthcare organization on system-level, data-level and professional-level. Despite those barriers, this study exposed ways to organize collective learning for QI in present practice. Network-broad learning and improvement based on outcome data has the potential to improve continuity of care, working pleasure, and eventually patient outcomes and experiences. This action research project resulted in a learning strategy for QI in perinatal care networks, adapted to care professionals needs and, with a cyclic and participatory approach, transferable to other integrated care networks as well. Our analysis of network collaboration contributes to the understanding of complex processes towards integrated care with patient-centred care improvement, translated into concrete implications for practice.

REFERENCES

1. Groenewoud AS, Westert GP, Kremer JAM. Value based competition in health care's ethical drawbacks and the need for a values-driven approach. *BMC Health Serv Res*. 2019;19(1):1-6. doi:10.1186/s12913-019-4081-6
2. Kokko P. Improving the value of healthcare systems using the Triple Aim framework: A systematic literature review. *Health Policy (New York)*. 2022;126(4):302-309. doi:10.1016/j.healthpol.2022.02.005
3. Porter ME. What Is Value in Health Care? *N Engl J Med*. 2010;363(26):2477-2481. doi:10.1056/NEJMp1002530
4. Staalduinen DJ Van, Bekerom P Van Den, Groeneveld S, Kidanemariam M, Stiggelbout AM, Van Den Akker-Van Marle ME. The implementation of value-based healthcare : a scoping review. *BMC Health Serv Res*. 2022:1-8. doi:10.1186/s12913-022-07489-2
5. Steinmann G, Delnoij D, Van De Bovenkamp H, Groote R, Ahaus K. Expert consensus on moving towards a value-based healthcare system in the Netherlands: A Delphi study. *BMJ Open*. 2021;11(4). doi:10.1136/bmjopen-2020-043367
6. US Department of Heath and Human Services FDA Center for Drug Evaluation and Research. Guidance for industry: Patient-reported outcome measures: Use in medical product development to support labeling claims: Draft guidance. *Health Qual Life Outcomes*. 2006;4:1-20. doi:10.1186/1477-7525-4-79
7. NHS England. *National Patient Reported Outcome Measures (PROMS) Programme Guidance*. Leeds; 2017. https://www.england.nhs.uk/wp-content/uploads/2017/09/proms-programme-guidance.pdf.
8. Dutch Ministry of Healthcare Welfare and Sport. *Ontwikkeling Uitkomstgerichte Zorg 2018-2022 [Outcome Based Healthcare 2018-2022].*; 2018. https://www.government.nl/topics/quality-of-healthcare/information-on-the-quality-of-care.
9. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. *Heal Serv Deliv Res*. 2017;5(2):1-280. doi:10.3310/hsdr05020
10. Dorr MC, van Hof KS, Jelsma JGM, et al. Quality improvements of healthcare trajectories by learning from aggregated patient-reported outcomes: a mixed-methods systematic literature review. *Heal Res Policy Syst*. 2022;20(1):1-13. doi:10.1186/s12961-022-00893-4
11. Kampstra NA, Zipfel N, Van Der Nat PB, Westert GP, Van Der Wees PJ, Groenewoud AS. Health outcomes measurement and organizational readiness support quality improvement: A systematic review. *BMC Health Serv Res*. 2018;18:1005. doi:10.1186/s12913-018-3828-9
12. Bastemeijer CM, Boosman H, Ewijk H Van, Voogt L, Hazelzet JA. Patient experiences : a systematic review of quality improvement interventions in a hospital setting. *Patient Relat Outcome Meas*. 2019;10:157-169. doi:10.2147/PROM.S201737
13. Heijsters FACJ, Breda FGF Van, Nassau F Van, Steen MKJ Van Der. A pragmatic approach for implementation of value - based healthcare in Amsterdam UMC , the Netherlands. *BMC Health Serv Res*. 2022;1:1-11. doi:10.1186/s12913-022-07919-1
14. Bally ELS, Grieken A Van, Ye L, et al. ' Value - based methodology for person - centred , integrated care supported by Information and Communication Technologies ' (ValueCare) for older people in Europe : study protocol for a pre - post controlled trial. 2022:1-12. doi:10.1186/s12877-022-03333-8
15. Barimani M, Care PH, Sciences C, Hylander I, Sciences C, Stockholm M. Linkage in the chain of care : a grounded theory of professional cooperation between antenatal care , postpartum care and child health care. 2008;8(December). doi:10.5334/ijic.254

16. Munro S, Project MA, Kornelsen J, Grzybowski S. Models of maternity care in rural environments : Barriers and attributes of interprofessional collaboration with midwives. *Midwifery*. 2013;29(6):646-652. doi:10.1016/j.midw.2012.06.004
17. Psaila K, Schmied V, Fowler C, Kruske S. Interprofessional collaboration at transition of care : perspectives of child and family health nurses and midwives. doi:10.1111/jocn.12635
18. Bångsbo A, Dunér A, Lidén EVA. Barriers for Collaboration : What Matters for an Integrated Care Programme ? 2022;22(2):1-10. doi:10.5334/ijic.6005
19. Saint-pierre C, Herskovic V, Sepúlveda M. Multidisciplinary collaboration in primary care : a systematic review. 2018;35(2):132-141. doi:10.1093/fampra/cmx085
20. T. van Ark (Dutch Minister of Health Welfare and Sport). *Kamerbrief Stand van Zaken Geboortezorg 2020. [Letter to Parliament about Status of Perinatal Care 2020]*.; 2021. https://www.rijksoverheid.nl/documenten/kamerstukken/2020/12/07/kamerbrief-over-stand-van-zaken-geboortezorg-2020-aanbevelingen-voor-de-toekomst.
21. College Perinatale Zorg. *Zorgstandaard Integrale Geboortezorg [Standard of Integrated Birth Care]*.; 2020. https://www.kennisnetgeboortezorg.nl/zorgstandaard/.
22. Rodríguez C, Des Rivières-Pigeon C. A literature review on integrated perinatal care. *Int J Integr Care*. 2007;7(3). doi:10.5334/ijic.202
23. D'haenens F, Rompaey B Van, Swinnen E, Dilles T, Beeckman K. The effects of continuity of care on the health of mother and child in the postnatal period: a systematic review. 2019;30(4):749-760. doi:10.1093/eurpub/ckz082
24. College Perinatale Zorg. *De Agenda van de Geboortezorgpartijen [The Agenda of the Perinatal Care Parties]*.; 2018. https://www.kennisnetgeboortezorg.nl/wp-content/uploads/2019/06/Agenda_Geboortezorg_tot_.pdf. Accessed August 18, 2022.
25. Depla AL, Pluut B, Lamain-de Ruiter M, et al. PROMs and PREMs in routine perinatal care: mixed methods evaluation of their implementation into integrated obstetric care networks. J of Patient Rep Outcomes. 2023 Mar 9;7(26):1-15.
26. Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3
27. Depla AL, Ruiter ML, Laureij LT, et al. Patient-Reported Outcome and Experience Measures in Perinatal Care to Guide Clinical Practice : Prospective Observational Study Corresponding Author : *J Med Internet Res*. 2022;24(7):e37725. doi:10.2196/37725
28. Lieshout F van, Jacobs G, Cardiff S. *Actieonderzoek: Principes Voor Verandering in Zorg En Welzijn [Action Research: Principles for Change in Health and Welfare]*. Koninklijke Van Gorcum BV; 2017.
29. D'Amour D, Goulet L, Labadie JF, Martín-Rodriguez LS, Pineault R. A model and typology of collaboration between professionals in healthcare organizations. *BMC Health Serv Res*. 2008;8:118. doi:10.1186/1472-6963-8-188
30. Interprofessional Education Collaborative. Core Competencies for Interprofessional Collaborative Practice: 2016 Update. *Washington, DC Interprofessional Educ Collab*. 2016. https://ipec.memberclicks.net/assets/2016-Update.pdf.
31. Dierckx de Casterle B, Gastmans C, Bryon E, Denier Y. QUAGOL: A guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360-371. doi:10.1016/j.ijnurstu.2011.09.012
32. Ose SO. Using Excel and Word to Structure Qualitative Data. *J Appl Soc Sci*. 2016;10(2):147-162. doi:10.1177/1936724416664948
33. Vangen S, Huxham C. Nurturing Collaborative Relations: Building Trust in Interorganizational Collaboration. 2003. doi:doi.org/10.1177/0021886303039001001

34. Cronie D, Rijnders M, Jans S, Verhoeven CJ, de Vries R. How good is collaboration between maternity service providers in the Netherlands? *J Multidiscip Healthc*. 2019;12:21-30. doi:10.2147/JMDH.S179811
35. Van Der Lee N, Driessen EW, Scheele F. How the past influences interprofessional collaboration between obstetricians and midwives in the Netherlands: Findings from a secondary analysis. *J Interprof Care*. 2016;30(1):71-76. doi:10.3109/13561820.2015.1064876
36. Rensburg AJ Van, Rau A, Fourie P, Bracke P. Power and Integrated Health Care : Shifting from Governance to Governmentality. 2016;16(3):1-11. doi:http://dx.doi.org/10.5334/ijic.2480
37. Sibbald S, Hall R, Gutberg J, Wodchis W. A Multi-Method Case Study of Collective Leadership in System Reform. *Int J Integr Care*. 2022;22(S2):207. doi:10.5334/ijic.icic21280
38. Robert W Putnam. Double-loop learning. In: Coughlin D, Brydon-Miller M, eds. *The Sage Encyclopedia of Action Research*. Sage Press; 2014. doi:10.4135/9781446294406
39. Lefebvre G, Honey L, Hines K, et al. Implementing Obstetrics Quality Improvement, Driven by Medico-legal Risk, is Associated With Improved Workplace Culture. *J Obstet Gynaecol Canada*. 2020;42(1):38-47.e5. doi:10.1016/j.jogc.2019.05.011
40. Barraclough F, Smith-merry J, Stein V. Workforce Development in Integrated Care : A Scoping Review. 2021;21(4):1-14. doi:10.5334/ijic.6004
41. Behrendt K. Factors in implementing integrated care … a duty to collaborate ? 2021;(April):1-4. doi:10.1136/ihj-2019-000025
42. Barimani M, Hylander I. Joint action between child health care nurses and midwives leads to continuity of care for expectant and new mothers. 2012;2631. doi:10.3402/qhw.v7i0.18183
43. Meyer I. Data matters - no service integration without data integration: a transnational learning exercise. *Int J Integr Care*. 21(S1):28. doi:doi.org/10.5334/ijic.ICIC20545
44. Schulte T, Bohnet-Joschko S. How can Big Data Analytics Support People-Centred and Integrated Health Services: A Scoping Review. *Int J Integr Care*. 2022;22(0):23. doi:10.5334/ijic.5543

SUPPLEMENT

Supplementary Table 1. Preparation survey for learning sessions

Introduction:

All attendants of the learning sessions are asked to complete these preparation questions. For you as preparation to the session and for us to organize a valuable session fitted to your OCN and patient population

Baseline:

For which organisation do you work?
What is your function?

Survey:

1. In the learning session we will work on the current goals in the OCN [adapted per session and region]. Which of these themes should we address as OCN first?
2. What do you need as professional to address these themes?
3. Do you miss any issues/themes that we could improve as OCN? For example, specific patient groups, outcomes, or experiences.
4. According to you, which activities (initiatives/agreements/collaboration) in the OCN have yielded most value (client/patient; care professional; financially)?
5. What should we stop doing?
6. When is the session successful for you?

All questions had open ended answer fields. In each preparation meeting, the items of this survey were discussed with key participants in the OCN and adapted to fit the regions' current goals for quality improvement. *OCN* obstetric care network.

8

CHAPTER 8

General discussion

TOWARDS VALUE BASED PERINATAL CARE

In the transition from volume to value, this thesis shows the complexity of implementing PROM/PREM in perinatal care and exposed their potential for value-based healthcare (VBHC) at individual and group level. Our findings highlight the challenges for workflow integration and data infrastructures in an integrated care setting, while the use of PROM/PREM was facilitated by their match with professionals' intrinsic motivation for patient-centred care and involvement of all stakeholders in iterative reflection on implementation, collaboration and improvement. In light of the current literature and developments in the healthcare landscape, we reflect on implications of our work for PROM/PREM use and further directions in the journey towards value-based perinatal care.

VBHC with PROM/PREM as tool for personalized perinatal care on the 1:1 level

To explore how PROM/PREM can contribute to value-based perinatal care when using them in individual care contacts, we first elaborate on the usability of PROM/PREM for personalized decision-making, the relevance and timing of patient-reported domains in pregnancy and postpartum recovery, and their workflow integration across the interorganizational trajectory.

Value of individual PROM/PREM

In the operationalization of VBHC, shared decision-making (SDM) has been considered one of the key-components and could add a personal dimension to the strategy.[1] Providing insight in outcomes information for a condition, both clinical outcomes and patient-reported wellbeing or experiences can facilitate well-informed decision making.[2]

Like in other settings, the importance of individual use of outcome information, including for SDM, was recognized across perinatal care stakeholders as well (**Chapter 2**). In practice, individual-level PROM/PREM in perinatal care helped to recognize issues in psychosomatic wellbeing earlier and women described receiving personalized care based on their results (**Chapter 4 and 6**). Although considered a potential barrier yielding social response bias, discussing individual PREM was valued by many women and providers (**Chapter 3 and 6**). The relative importance of women's experiences with care for quality and outcomes of perinatal care might explain this finding.[3] Based on women's varying opinions, we recommend offering women a choice whether to discuss their PREM and evaluate this in further implementation. Individual PROM/PREM can thus serve as a tool to create awareness in both patients and professionals facilitating the conversation about these topics, but this opportunity depends on professionals' attitude toward PROM/PREM and how they introduce them to patients. When experienced as extra workload or accountability on their performance, professionals won't adopt them and women, without knowing the correct goal, can even experience un-personalized care due to the standardizing questionnaires (**Chapter 6**).

Apart from increased awareness and broader insight of patients' wellbeing, discussing individual PROM/PREM in itself did not lead to SDM as no specific choices are addressed and aggregated information about outcomes of treatment options is not available yet.[2] To incorporate PROM/PREM in the 'option talk' of SDM, for example integrating them in decision aids or show patients-like-me in specific situations, reliable reference data are needed with proper access and accompanying analyses.

Until then, individual PROM/PREM can contribute to personalized care by creating awareness. Discussing them should start with asking an open question 'what outcome is most important to you?', instead of focusing on alerts that will never capture all nuances and individual values. To put this in practice, clear communication about the rationale for PROM/PREM is needed continually to inform professionals and patients collection, but also training in the SDM process in general and in which way PROM/PREM can support that.[4,5] When patients and professionals experience the value of PROM/PREM for guiding individual care, more outcomes and experiences can be generated for reliable group data to be incorporated in SDM in the future.[6]

Domains and timing of PROM/PREM

In this thesis, the outcomes set for pregnancy and childbirth (PCB set) as proposed by the International Consortium of Health Outcomes Measurement provided the base for PROM/PREM measurements across the perinatal care continuum from pregnancy up to six months postpartum. Its domains were found to be appropriate in terms of topics and time burden for patients and care professionals (**Chapter 3 and 6**). Because their timing around care transitions, the moments in the maternity week and at six months postpartum posed organizational challenges but were regarded valuable by women and their providers as well. By detecting impartial recovery or unprocessed experiences with care, especially the moment six months postpartum showed large potential clinical value to be further investigated (**Chapter 6**), while solutions for its timing beyond current perinatal care paths could be sought in more integrated collaboration with general practitioners or Youth Care - locally adjusted.[7] In **Chapter 5**, the instruments that assess the domains appeared not always suitable or their timing did not fit well with care pathways. Moreover, some were not validated for the population or timing (e.g., during pregnancy, six weeks postpartum), or clinically relevant thresholds were lacking.

This lack of valid instruments for perinatal care is in line with the conclusions of a systematic review by Sultan et al, which searched for a multidimensional PROM that captures at least 3 domains – of 13 domains identified in their previous literature evaluation – for postpartum recovery.[8,9] Therefore, development of a new instrument was proposed after identifying all domains and specific items that matter to patients.[10] Although endorsing the call for valid instruments that capture women's multidimensional recovery after childbirth, PROM (and PREM)[3] domains for perinatal care seem largely clear, as the PROM domains of the PCB set correspond almost completely to those found in their systematic review of the literature.[9] Moreover, these domains appeared to cover most important topics for women, who only missed common physical complaints as pelvic pain (**Chapter 6**). Yet for several of these domains, valid instruments are lacking to assess them. Still, developing a new multidimensional instrument should be given careful consideration first, as many instruments are already available for each of the individual domains. For instance, valid instruments exist for pelvic function and complaints that are being used extensively in individual practice and performance measurement.[11,12] Using existing instruments and validate them for screening at several measurement moments along the course of pregnancy and postpartum recovery as performed by Slavin and colleagues,[13,14] could minimize fragmentation, extra development work and overlap in instruments. In addition, adaptive and disease specific instruments (e.g., for pregnancy diabetes, surgical recovery) could be added for more personalized care after iterative evaluation in practice. Yet regarding the growing diversity of treatments, morbidities, and cultural values, it might be most effective to simplify measurements by focusing on common (unifying) outcomes and values.

Integration in practice

Innovation is always accompanied by a certain degree of resistance, and it takes time and education for professionals and patients to look upon PROM/PREM information as laboratory results that can guide care from patients' perspective. For integration beyond adoption, key elements to smooth the innovation barrier for PROM/PREM are time efficiency for both patient and provider (e.g., easy access, clear visualization) and congruent timing between collection and clinical pathways (**Chapter 5**). When available in clinic that way, PROM/PREM information can actually empower patients and support professionals to provide appropriate care fitted to individual needs.[15,16]

Accessible PROM/PREM information over the full cycle of perinatal care warrants digital applications to capture them, linkage with electronic health records (EHRs), and data exchange across care providers. Although many applications exist for questionnaire completion, these applications, the (variety of) EHRs, and the national perinatal care registry were far from ready to support network-broad use at the time of initiating the projects described in this thesis (**Chapter 4**). Examples from other conditions or countries for network-broad PROM/PREM capture are often carried out in single organization networks or facilitate use for quality performance only: the data are limitedly available for consultations in clinic. Possible approaches to collect PROM/PREM nationally across providers have been shown in most recent projects, which realized data accessibility at both aggregated and individual level to some extent.[17,18] Still, these system-wide projects are challenged by connecting to local EHRs and therefore confronted with a large administrative burden to send out PROM and standalone clinical portals to view individual results as well. With the great variety of EHR across hospitals and midwifery practices in the Netherlands, PROM/PREM capture across the perinatal care trajectory could be realized in a few large hospital EHRs combined with an external tool for smaller EHRs. Most importantly, current data-connection initiatives in obstetric care networks should incorporate PROM/PREM and include them in the national perinatal registry of clinical outcomes as well.

But then, as in all digital innovations, women in vulnerable situations and/or with language barriers are prone to be neglected whereas the opportunities to improve their care outcomes are rather bigger.[19,20] Therefore, an important concern about using PROM/PREM is existing health inequalities becoming even larger. Besides providing digital support and translating the questionnaires, solutions to involve these women in the benefits of PROM/PREM should be sought outside the idea of questionnaire completion. For example in group consultations, where their awareness of the topics addressed by PROM/PREM can be improved by contact with other women that completed the questionnaires and thematic discussion organized by professionals.[21] In thinking of solutions, research methods should be embraced that centralize patients and local opportunities (e.g. linkage to primary care, community-based solutions).[22,23] In this search, equity rather than equality should be the guiding principle.

VBHC with PROM/PREM as tool for learning in integrated care systems

Besides personalized care in individual contacts, the second goal of PROM/PREM capture was to organize continuous patient-centred quality improvement (QI). That is, patient-centred not only by structurally capturing patients' health status more complete, but also addressing the whole trajectory of pregnancy, childbirth, and postpartum recovery despite of care transitions.

Value of aggregated PROM/PREM in QI

Ideally, healthcare would continuously learn from clinically generated data, as described in learning healthcare systems and increasingly enabled by big data.[24,25] To centre patients in this continuous process, VBHC implies not only capturing patients' health status more complete by combining patient-reported with clinical data, but also an integrated approach to address a full cycle of care despite of care transitions or professions.[26] Although often perceived as abstract in theory; in practice, this patient-centred continuous learning matched the intrinsic motivation of perinatal care professionals (**Chapter 2, 4 and 7**). Many professionals recognized the value of QI across the borders of professions/organizations and were motivated for QI by insight in data that reflect their patients' whole wellbeing and function trough pregnancy and postpartum recovery. Insight in PROM/PREM across the care trajectory could therefore contribute to care professionals' involvement in QI, align different professions, and enhance workplace culture across care networks.[27,28] Despite adoption of the principles and starting change, we found that the current perinatal care system is not adequately equipped yet for continuous patient-centred learning and improving with outcomes since data are fragmented, PROM/PREM capture across networks is challenging (**Chapter 4**), and first experiences on how to use PROM data for QI is only emerging now.[29] Still, elements that facilitated QI with outcomes were identified in how we use data and in network collaboration (**Chapter 4 and 7**); both further discussed here.

Role of data in quality improvement

In current fragmented healthcare system, unlocking the potential of data generated in routine care for quality improvement requires making long-term efforts and using short-term opportunities simultaneously. In addition to the efforts needed for patient-reported data capture, patient-centred learning with routine care data requires well-formulated research questions, real time appropriate data to answer them – including analyses and bias reduction techniques – and meaningful visualization of results.[30,31] Also, privacy and legalization agreements are essential to realize (digital) data exchange and make routine data available for learning,[32] particularly when organized across organizations. Provided by the Netherland's Perinatal Care Registry (PeriNed), a network-broad dashboard with aggregated clinical data is available with benchmark opportunities to national average scores, yet perinatal care professionals in practice struggle to get the right data into the registry and get reliable, timely data out of it (**Chapter 1 and 6**). In conclusion, learning from data (both patient-reported as well as clinician-registered) takes huge efforts and entails expertise, time, and resources for analysis, merging and visualizing. As such, huge efforts and resources go into registering and interpreting data, while it often results in a discussion about data credibility and casemix factors rather than on how to use these for learning and QI.

In current literature, the strategies reported for QI based on outcome data include audit and feedback, benchmarking, PDSA cycles, and statistical analyses.[29,33,34] Various effects of these strategies have been found on PREM and clinical outcomes, whereas PROMs are entering the QI field later and effects have not yet been shown or measured. In this thesis, only small samples of patient-reported data were obtained, primarily to guide individual care: while clinical value of PROM/PREM increases their uptake, it does affect usability for QI.[35] While imperfect, these patient-reported data (combined pragmatically with available clinical data, case-mix factors, and professionals' views) were still valuable for QI as starting point to create awareness of most the important issues and motivation for change (**Chapter 7**). Distancing the data from the discussion between professionals via personae (cases) enabled a shift from discussing the data (quality) towards reflection on the content of the care they provide together, which facilitated both innovation and collaboration.

Thus, long term investments should advance the establishment of a comprehensive data infrastructure (i.e., link EHRs, connect to patient-reported questionnaires and devices, data experts). Although important steps are being made, current policy programs facilitating data exchange between EHRs seem not to focus on integrated care delivery sufficiently.[36] Meanwhile, currently available data sources could be used pragmatically and closer to professionals to facilitate patient-centred QI today. When stakeholders and their values become involved in QI, the whole narrative about the achieved value is reflected on instead of just the data.[37]

Collaboration and learning in integrated networks

Although a better data infrastructure and effective learning methods can drive QI, well-established network collaboration was found imperative to continuous outcome improvement with providers over the full cycle of care. A decade after starting the journey towards an integrated system in Dutch perinatal care, large differences in collaboration levels per obstetric care network (**Chapter 7**) indicate the challenges that are faced when organizing care and learning around patients.[38,39] The importance of connectivity and leadership for trustful collaboration was signified in **Chapter 7**, in which a cyclic relation between joint learning and collaboration was found to catalyse the change towards integrated care. Our findings on network collaboration and innovation correlate to an evaluation of healthcare policies towards integrated care that emphasized two dichotomous tensions for change: top-down versus bottom-up direction of change, and intrinsic versus external incentives.[37] In both these tensions, the two sides of their spectrum are argued to reinforce each other for successful change - described by others as managing in the middle,[40] but need (re)balancing.

First regarding direction of change, an overemphasis on top-down policy directives demanding the change seems present in Dutch perinatal care as well, while less focus exists on empowering professionals in local clinical leadership, learning and collaboration. For instance, the QI strategy in **Chapter 7** would benefit from professionals better equipped with how to learn broader than first order learning: analysing not only actions and results, but also reflecting on underlying values.[41] If strengthened, local (clinical) leadership could work synergistically with stable governance and top-down programs that measure and spread impact of integrated care. Second regarding incentives for change, this balance could be straightened by, rather than applying extensive external financial or regulatory incentives, removing financial disincentives for collaboration to create more space for professionals' intrinsic motivation to collaborate and improve.

To remove disincentives for collaboration, network-level reimbursement has been widely assumed as a solution to improve quality of perinatal care through shared accountability and flexible use of resources for coordination of care delivery and innovation.[42,43] As described in **Chapter 7**, the OCN with (partial) joint reimbursement had more opportunities to support connectivity, data insight and learning across professions and organizations. Although reimbursement innovation created opportunities for collaboration, we suspect that joint payment agreements (and with that, sharing financial risk) are more likely to *result* from well-established collaboration rather than its cause. Today's literature on network-level payment models shows, besides the relevance of risk mitigation strategies, moderate effects on network performance that remain to be proven in perinatal care.[42,44] Until now, these studies of alternative payment models for maternity care have been largely made in the US context, but recent policy in the Netherlands offers perspectives.[45] In regions that feel ready for it, these system-level changes could help exploring different options (such as pay-for-performance, shared savings, bundled-payment), while being aware of the effects on professional autonomy and equality of interprofessional relations.[44,46,47] Along these experiments, extensive evaluation should take place to monitor (un)intended effects, identify blind spots, and assess whether space for internal incentives is created. In such evaluations, insight in PROM/PREM can aid to focus on outcomes for patients and thereby aid to align stakeholders in perinatal care.

Bridge the gap: knowledge versus change in practice

In this thesis, implementation science and action research were used to advance practice change and to gain a deep understanding of how to implement and embed PROM/PREM in daily consultation and learning practices, in contrast to more traditional science approaches that aim for universal truth finding. Where implementation science aims to generate universal knowledge by measuring implementation outcomes and comparing effectiveness of strategies, action research intends to gain detailed understandings of local change mechanisms whilst at the same time advancing practice change with participants.[48] Originating from the social sciences, action research has gained interest in healthcare, merely adopted in nursing and education until now.[49]

Implementation science helped us to inform the design of local strategies by gaining valuable insights about implementation outcomes and factors (Part I). When put to work in practice, shifting from barriers and initial adoption to reconfigurations and sustained implementation appeared challenging and time-consuming. An inability for sustained use of QI initiatives in healthcare has been highlighted in implementing telemedicine as well,[50] and may partly be explained by a poor understanding of what exactly comprises the complex intervention (not only the technical aspects, but also the social practices surrounding them) that contributed to the effect or the change in the original setting.[51,52] Action research could help to translate general knowledge on implementation barriers and facilitators to "actionable knowledge" about PROM/PREM implementation and sustained use, by generating detailed data on activities, the interaction between complex interventions and underlying change mechanisms in the local context in which it is implemented.[53,54]

In the USER study (**Chapter 4 and 7**), both the research team and participating care professionals needed time to gain un understanding of what an action research approach entails, particularly grasping the meaning of they themselves being an active participant in a change process. This puzzle, in contrast to the clear roles of investigators in strict GCP-guidelines for research, led to a unclarity in ownership of implementation and study activities. Also, action research is ideally initiated by professionals experiencing a problem in practice but the decision to start PROM/PREM implementations were merely made by management, and the PCB set left little space for reconfiguration given its international nature. Similar to other action research projects in healthcare,[49] these challenges indicate that, for action research to benefit healthcare, future work could focus on education strategies for both researchers, participants and management, specifically when conducting action research projects in settings with little experience.

At the same time, a benefit of the action research approach was that it empowered professionals to gain experience with using PROM/PREM for individual care and QI. The cyclic design enabled project teams to start despite shortfalls in outcomes measures and IT infrastructure, adapt to actual struggles in practice, and share their experiences with others. This underlines the importance of ownership amongst care professionals in healthcare innovation – organized by iterative reflection on and refinement to adapt the intervention to local context and, vice versa, to increase professionals' knowledge and skills in change work – so that complex interventions can be made effective and spread beyond early adopters.[55] Similarly, other complex problems of contemporary healthcare systems could benefit from this cyclic approach close to practice. While most medical research is focused on knowledge questions within specific disease or sectors, many challenges (and their possible solutions) today lay in fragmented organization of care and inefficient use of resources, resulting in shortage of staff and capacity.[56] Issues like inadequate IT infrastructure, workforce shortage, inequity, and sustainability, call for a fusion of change and inquiry, and often require more context-specific solutions than traditional research offers. With the Dutch integrated care agreement (IZA) advocating local solutions to complex challenges and large funding agencies specifically calling for action research,[57] the need to support care professionals and organizations in such an approach is urgent.

Future perspectives: value driven perinatal care

Value based healthcare

The vast uptake of the VBHC strategy signifies its ability to align all stakeholders, yet its adoption in practice is heterogeneous and its economic approach of value to is argued inapplicable to healthcare, raising important infringements upon medical ethical principles.[58] After adopting elements of VBHC in perinatal care, we recognize both sides and reflect on the heterogeneity in practice and the definition of value before stating further implications.

First, large heterogeneity in VBHC uptake has been argued unwanted and adopting all elements together was emphasized for successful implementation.[59] However, starting small and using elements of the strategy as inspiration for change is probably more powerful in practice, each contributing a piece to the shift from volume to value.[1,60] In this case, the risk of pseudo innovation should be considered:[61] a variety of research projects and policy programs presenting a part or a different interpretation as innovative solution, while ultimately sharing similar purposes along the Quadruple Aim (i.e., improve population health outcomes, patient experiences, and employee wellbeing, while reducing costs).[62] Rather than catalysing each other, competition of these initiatives can cause tension between policies and confusion for professionals in practice: eventually inhibiting the change. On balance, the shift to value could benefit from small steps in practice using VBHC elements as inspiration for change,[63] while at system-level comprehensive, unifying, and long-term policy is needed.

Second, a stricter definition of value has been called for to further VBHC implementation. Yet eventually, as encountered in perinatal care, the definition of value achieved by a system largely depends on the *values* of its stakeholders.[58,64] As argued in integrated care transitions, this bidirectional relationship between value and values should be considered when transforming from volume- to value-driven care.[37] Otherwise, VBHC as practice runs the same risk as how evidence-based medicine (EBM) developed into guidelines based on collective evidence with strict governance. Of the originally described EBM pillars, EBM development in practice has been predominantly focused on the evidence pillar in a collective form, whereas the patient values pillar has been underdeveloped.[65] The resulting care system has been described as impersonalized, even comparing hospitals as factories where care pathways resemble assembly lines.[66,67] So despite the original attempt of EBM, the use of patient values in decision-making is still limited, illustrated by recent research indicating that professionals appear unconsciously incompetent in SDM.[68] In practice, such approach to value (i.e., defined by values) means less focus on perfect data for competition, public reporting, performance payments, or patients choosing a provider based on public outcomes reporting.[69] Instead, it implies more focus on personal values in individual care decisions and QI initiatives by enabling relevant stakeholders (i.e., patients, care professionals, communities) to interpret outcomes and make well-informed choices based on their values within available resources. Hence, focus on personal values does not mean neglecting urgent capacity and cost issues of healthcare systems.[70] But rather than extensive top-down regulation of value, their solutions should be sought in making the right choices by providing relevant stakeholders the data they need, remove financial disincentives for their collaboration, and strengthening their reflexive capacities and culture.

Future implications

As value is determined by personal values, patients must be actively involved in the interpretation of PROM/PREM data to make their values leading in both clinic and QI. So besides user-friendly E-Health tools connected across providers, information for patients and professionals on the rationale of PROM/PREM capture is crucial and should emphasize the monitoring of health status and patient empowerment to meet their personal values as primary goals. Future implementation processes involving patients should focus iterative co-design: how to ensure personal values are discussed, where in a SDM process PROM/PREM are most meaningful, and what is needed to embed those aspects in professionals' (communication) training and patient information material.

For care professionals, value-based working seems to match their intrinsic motivation and has the potential to improve working culture and pleasure (e.g., teamwork, see value achieved by their work), but can easily create a feeling of extra workload and performance check at the same time (**Chapter 4 and 7**). Therefore, professionals working with PROM/PREM need information about their rationale, training in individual-level communication about results, easy access to data, the time, space and capacity to learn, and support to collaborate around their patients. Future (action) research could evaluate how knowledge about learning to learn could contribute to the VBHC strategy by strengthening professionals' capacities to reflect on data, distinguish levels of improvement, and formulate powerful actions for change*.* Such empowerment of professionals can advance the goal of a resilient workforce: added as fourth aim in the Quadruple Aim framework, quickly adopted in hospitals and policies, and even more emphasized by the pandemic demonstrating that healthcare systems in developed countries are more severely constrained by their staffing rather than costs.[71,72]

At the system level, quality governance is slowly moving from regulation of EBM-guideline adherence, towards continuous outcomes measurement per condition combined with joint improvement and collective learning.[73] In this change, focusing on defining outcomes to capture achieved value has created comprehensive discussions about disease-specific outcomes with subsequent fragmentation. A simplification of measurements (i.e., focus on common, unifying outcomes) would minimize both efforts and fragmentation in a way that corresponds with current core set for generic PROMs of the Dutch outcome-driven care program,[74] and can contribute to benchmark opportunities as well. Above making PROM/PREM a control mechanism for value, data should be seen as a catalyser to learn as a professional and to improve quality as a network, using professionals' intrinsic motivation. System-level changes must therefore remove disincentives for network collaboration and reward joint reflexivity, learning and improvement. Moreover, infrastructure to merge fragmented data sources should be invested in, so stakeholders have access to the data they need.

Regarding future research, it has not been within the scope of this thesis to validate questionnaires and their clinical thresholds, nor assess the effects of PROM/PREM use on patient outcomes: important research efforts still to be made for their routine use in perinatal care.[75,76] Along those efforts, results of implementation studies can inform the design of local implementation strategies, which then need to be put to work on the basis of adaptive learning in practice. Multilevel endorsement (in research funding, education, policy) of iterative, participatory action research approaches can empower professionals in their journey towards value-based care and other challenges facing healthcare today.

Concluding remarks

Our current healthcare landscape requires difficult choices to spend available resources and workforce on (personal) value for patients and resilience in professionals. In potential helpful to centralize patients in these choices at individual and system level, the use of PROM/PREM asks a lot from data and technology, but also changes the way we approach our research questions, learning processes and governance of care. For PROM/PREM to fulfil their potential for value-based perinatal care, this thesis sheds light on the ways they could add value, current challenges to implement them in practice, and both short- and long-term directions for their use. To embed PROM/PREM in a meaningful way, value-based perinatal care should focus on collaboration between stakeholders needed (independent of professions or tiers), iterative learning (small steps, understanding change together), the picture of patients as a whole, and be aware of value versus values.

REFERENCES

1. Steinmann G, Delnoij D, Van De Bovenkamp H, Groote R, Ahaus K. Expert consensus on moving towards a value-based healthcare system in the Netherlands: A Delphi study. *BMJ Open*. 2021;11(4). doi:10.1136/bmjopen-2020-043367
2. Damman OC, Jani A, de Jong BA, et al. The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients. *J Eval Clin Pract*. 2020;26(2):524-540. doi:10.1111/jep.13321
3. Vogels-Broeke M, de Vries PR, Nieuwenhuijze M. Validating a framework of women's experience of the perinatal period; a scoping review. *Midwifery*. 2021;92:102866. doi:10.1016/j.midw.2020.102866
4. Skovlund PC, Ravn S, Seibaek L, Thaysen HV, Lomborg K, Nielsen BK. The development of PROmunication: a training-tool for clinicians using patient-reported outcomes to promote patient-centred communication in clinical cancer settings. *J Patient-Reported Outcomes*. 2020;4(1). doi:10.1186/s41687-020-0174-6
5. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Qual Life Res*. 2015;24(7):1707-1718. doi:10.1007/s11136-014-0903-5
6. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Qual Saf*. 2014;23(6):508-518.
7. College Perinatale Zorg. *Samenwerking Tussen Kraamzorg En Eerstelijns Verloskundigen En de Jeugdgezondheidszorg*.; 2021. https://www.kennisnetgeboortezorg.nl/wp-content/uploads/2021/12/Samenwerking-tussenkraamzorg-en-eerstelijns-verloskundigen-en-de-jeugdgezondheidszorg-23122021.pdf.
8. Sultan P, Sharawi N, Blake L, et al. Use of Patient-Reported Outcome Measures to Assess Outpatient Postpartum Recovery: A Systematic Review. *JAMA Netw open*. 2021;4(5):e2111600. doi:10.1001/jamanetworkopen.2021.11600
9. Sultan P, Sadana N, Sharawi N, et al. Evaluation of Domains of Patient-Reported Outcome Measures for Recovery after Childbirth: A Scoping and Systematic Review. *JAMA Netw Open*. 2020;3(5):1-12. doi:10.1001/jamanetworkopen.2020.5540
10. Landau R. Deconstructing Current Postpartum Recovery Research - The Need to Contextualize Patient-Reported Outcome Measures. *JAMA Netw Open*. 2021;4(5):2021-2023. doi:10.1001/jamanetworkopen.2021.11689
11. Kamińska A, Futyma K, Romanek-Piva K, Streit-Ciećkiewicz D, Rechberger T. Sexual function specific questionnaires as a useful tool in management of urogynecological patients – Review. *Eur J Obstet Gynecol Reprod Biol*. 2019;234:126-130. doi:10.1016/j.ejogrb.2019.01.015
12. De Oliveira C, Seleme M, Cansi PF, et al. Urinary incontinence in pregnant women and its relation with socio-demographic variables and quality of life. *Rev Assoc Med Bras*. 2013;59(5):460-466.
13. Slavin V, Creedy DK, Gamble J. Comparison of screening accuracy of the Patient Health Questionnaire-2 using two case-identification methods during pregnancy and postpartum. *BMC Pregnancy Childbirth*. 2020;20(1):1-15. doi:10.1186/s12884-020-02891-2
14. Slavin V, Gamble J, Creedy DK, Fenwick J, Pallant J. Measuring physical and mental health during pregnancy and postpartum in an Australian childbearing population - Validation of the PROMIS Global Short Form. *BMC Pregnancy Childbirth*. 2019;19(1):1-19. doi:10.1186/s12884-019-2546-6
15. Barr PJ, Berry SA, Gozansky WS, et al. No date for the PROM: the association between patient-reported health events and clinical coding in primary care. *J Patient-Reported Outcomes*. 2020;4:17.

16. van Muilekom MM, Luijten MAJ, van Oers HA, et al. From statistics to clinics: the visual feedback of PROMIS® CATs. *J Patient-Reported Outcomes*. 2021;5(1). doi:10.1186/s41687-021-00324-y
17. Withers K, Palmer R, Lewis S, Carolan-Rees G. First steps in PROMs and PREMs collection in Wales as part of the prudent and value-based healthcare agenda. *Qual Life Res*. 2021;30(11):3157-3170. doi:10.1007/s11136-020-02711-2
18. Ernstsson O, Janssen MF, Heintz E. Collection and use of EQ-5D for follow-up, decision-making, and quality improvement in health care - the case of the Swedish National Quality Registries. *J Patient-Reported Outcomes*. 2020;4(1). doi:10.1186/s41687-020-00231-8
19. Ukoha EP, Davis K, Yinger M, et al. Ensuring Equitable Implementation of Telemedicine in Perinatal Care. *Obstet Gynecol*. 2021;137(3):487-492. doi:10.1097/AOG.0000000000004276
20. Vos AA, Denktaş S, Borsboom GJJM, Bonsel GJ, Steegers EAP. Differences in perinatal morbidity and mortality on the neighbourhood level in Dutch municipalities: A population based cohort study. *BMC Pregnancy Childbirth*. 2015;15(1):1-9. doi:10.1186/s12884-015-0628-7
21. Carter EB, Mazzoni SE. A paradigm shift to address racial inequities in perinatal healthcare. *Am J Obstet Gynecol*. 2021;224(4):359-361. doi:10.1016/j.ajog.2020.11.040
22. Nijagal MA, Patel D, Lyles C, et al. Using human centered design to identify opportunities for reducing inequities in perinatal care. *BMC Health Serv Res*. 2021;21(1):1-15. doi:10.1186/s12913-021-06609-8
23. McCloskey L, Bernstein J, The Bridging the Chasm Collaborative, et al. Bridging the Chasm between Pregnancy and Health over the Life Course: A National Agenda for Research and Action. *Women's Heal Issues*. 2021;31(3):204-218. doi:10.1016/j.whi.2021.01.002
24. Foley T, Fairmichael F. *The Potential of Learning Health Care Systems*. Newcastle: Learning Healthcare Project; 2015. http://www.learninghealthcareproject.org/LHS_Report_2015.pdf.
25. Schulte T, Bohnet-Joschko S. How can Big Data Analytics Support People-Centred and Integrated Health Services: A Scoping Review. *Int J Integr Care*. 2022;22(0):23. doi:10.5334/ijic.5543
26. Porter ME. What Is Value in Health Care? *N Engl J Med*. 2010;363(26):2477-2481. doi:10.1056/NEJMp1002530
27. Nielsen PE, Goldman MB, Mann S, et al. Effects of teamwork training on adverse outcomes and process of care in labor and delivery: a randomized controlled trial. *Obstet Gynecol*. 2007;109(1):48-55.
28. Lefebvre G, Honey L, Hines K, et al. Implementing Obstetrics Quality Improvement, Driven by Medico-legal Risk, is Associated With Improved Workplace Culture. *J Obstet Gynaecol Canada*. 2020;42(1):38-47.e5. doi:10.1016/j.jogc.2019.05.011
29. Dorr MC, van Hof KS, Jelsma JGM, et al. Quality improvements of healthcare trajectories by learning from aggregated patient-reported outcomes: a mixed-methods systematic literature review. *Heal Res Policy Syst*. 2022;20(1):1-13. doi:10.1186/s12961-022-00893-4
30. Casey JD, Courtright KR, Rice TW, Semler MW. What can a learning healthcare system teach us about improving outcomes? *Curr Opin Crit Care*. 2021;27(5):527-536. doi:10.1097/MCC.0000000000000857
31. Menear M, Blanchette MA, Demers-Payette O, Roy D. A framework for value-creating learning health systems. *Heal Res Policy Syst*. 2019;17(1):1-13. doi:10.1186/s12961-019-0477-3
32. Groenhof TKJ, Mostert M, Lea NC, et al. How traditional informed consent impairs inclusivity in a learning healthcare system: lessons learned from the Utrecht Cardiovascular Cohort. *J Clin Epidemiol*. 2022;article in.

33. Kampstra NA, Zipfel N, Nat PB Van Der, Westert GP, Wees PJ Van Der, Groenewoud AS. Health outcomes measurement and organizational readiness support quality improvement : a systematic review. 2018;9:1-14.
34. Bastemeijer CM, Boosman H, Ewijk H Van, Voogt L, Hazelzet JA. Patient experiences : a systematic review of quality improvement interventions in a hospital setting. *Patient Relat Outcome Meas*. 2019;10:157-169. doi:10.2147/PROM.S201737
35. Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. *Heal Serv Deliv Res*. 2017;5(2):1-280. doi:10.3310/hsdr05020
36. College Perinatale Zorg: Werkgroep indicatoren integrale geboortezorg. *Brief: Stopzetten Deelname Integrale Geboortezorg Als Onderdeel van Het Programma Uitkomstgerichte Zorg*.; 2022. https://www.kennisnetgeboortezorg.nl/wp-content/uploads/2022/09/Brief-FMS-programma-uitkomstgerichte-Zorg-aug-2022.pdf.
37. Behrendt K. Factors in implementing integrated care … a duty to collaborate ? 2021;(April):1-4. doi:10.1136/ihj-2019-000025
38. De Inspectie voor de Gezondheidszorg. *Thematisch Toezicht Geboortezorg: Afsluitend Onderzoek Naar de Invoering van de Normen van ‘Een Goed Begin’ De Stand van Zaken in de Verloskundige Samenwerkingsverbanden in Nederland*.; 2016.
39. Cronie D, Rijnders M, Jans S, Verhoeven CJ, de Vries R. How good is collaboration between maternity service providers in the Netherlands? *J Multidiscip Healthc*. 2019;12:21-30. doi:10.2147/JMDH.S179811
40. Bohmer R. The Hard Work of Health Care Transformation. *N Engl J Med*. 2016;375(8):709-711.
41. Tosey P, Visser M, Saunders MNK. The origins and conceptualizations of “triple-loop” learning: A critical review. *Manag Learn*. 2012;43(3):291-307. doi:10.1177/1350507611426239
42. Reindersma T, Sülz S, Ahaus K, Fabbricotti I. The Effect of Network-Level Payment Models on Care Network Performance: A Scoping Review of the Empirical Literature. *Int J Integr Care*. 2022;22(1):1-61. doi:10.5334/ijic.6002
43. Dutch Ministry of Healthcare Welfare and Sport. *Evaluatie van de Oprichting van Geboortezorgorganisaties En de Invoering van Integrale Bekostiging van Geboortezorg*.; 2015. https://www.rivm.nl/documenten/evaluatie-van-oprichting-van-geboortezorgorganisaties-en-invoering-van-integrale.
44. De Vries EF, Scheefhals ZTM, Bruin-Kooistra M De, Baan CA, Struijs JN. A scoping review of alternative payment models in maternity care: Insights in key design elements and effects on health and spending. *Int J Integr Care*. 2021;21(2):1-16. doi:10.5334/ijic.5535
45. Kuipers E. Voorhangbrief - Passende bekostiging voor integrale geboortezorg. *Minist Popul Heal Welf Sport*. 2022.
46. Vries E de, Scheefhals Z, Exel J van, Struijs J. *Systematische Studie Naar de Verschillende Opvattingen Rondom Bekostigingshervorming in de Geboortezorg - RIVM Adviesrapport*.; 2022. https://www.rivm.nl/publicaties/systematische-studie-naar-verschillende-opvattingen-rondom-bekostigingshervorming-in.
47. Perdok H, Jans S, Verhoeven C, et al. Opinions of maternity care professionals and other stakeholders about integration of maternity care: A qualitative study in the Netherlands. *BMC Pregnancy Childbirth*. 2016;16(1). doi:10.1186/s12884-016-0975-z
48. Lieshout F van, Jacobs G, Cardiff S. *Actieonderzoek: Principes Voor Verandering in Zorg En Welzijn [Action Research: Principles for Change in Health and Welfare]*. Koninklijke Van Gorcum BV; 2017.

49. Cordeiro L, Soares CB. Action research in the healthcare field: a scoping review. *JBI Database Syst Rev Implement Reports*. 2018;16(4):1003-1047. doi:10.11124/JBISRIR-2016-003200
50. Greenhalgh T, Wherton J, Papoutsi C, et al. Beyond adoption: A new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *J Med Internet Res*. 2017;19(11). doi:10.2196/jmir.8775
51. Dixon-Woods M, Bosk CL, Aveling EL, Goeschel CA, Pronovost PJ. Explaining Michigan: Developing an Ex post theory of a quality improvement program. *Milbank Q*. 2011;89(2):167-205. doi:10.1111/j.1468-0009.2011.00625.x
52. Abimbola S, Patel B, Peiris D, et al. The NASSS framework for ex post theorisation of technology-supported change in healthcare: Worked example of the TORPEDO programme. *BMC Med*. 2019;17(1):1-17. doi:10.1186/s12916-019-1463-x
53. Casey M, Coghlan D, Carroll Á, Stokes D, Roberts K, Hynes G. Application of action research in the field of healthcare: a scoping review protocol. *HRB Open Res*. 2021;4:46. doi:10.12688/hrbopenres.13276.2
54. Bradbury H, Lifvergren S. Action research healthcare: Focus on patients, improve quality, drive down costs. *Healthc Manag Forum*. 2016;29(6):269-274. doi:10.1177/0840470416658905
55. Rogers EM. *Diffusion of Innovations*. 5th editio. New York: New York Press; 2003.
56. Kuipers E, Helder C, Ooijen M van. *Kamerbrief Aanbieding Integraal Zorgakkoord: Samen Werken Aan Gezonde Zorg*.; 2022. https://www.rijksoverheid.nl/documenten/kamerstukken/2022/09/16/kamerbrief-aanbieding-integraal-zorgakkoord-samen-werken-aan-gezonde-zorg.
57. Actiz, De Nederlandse GGZ, Federatie Medisch Specialisten, et al. *Integraal Zorg Akkoord Samen Werken Aan Gezonde Zorg [Integrated Care Agreement]*.; 2022. https://www.rijksoverheid.nl/documenten/rapporten/2022/09/16/integraal-zorgakkoord-samen-werken-aan-gezonde-zorg.
58. Groenewoud AS, Westert GP, Kremer JAM. Value based competition in health care's ethical drawbacks and the need for a values-driven approach. *BMC Health Serv Res*. 2019;19(1):1-6. doi:10.1186/s12913-019-4081-6
59. Staalduinen DJ Van, Bekerom P Van Den, Groeneveld S, Kidanemariam M, Stiggelbout AM, Van Den Akker-Van Marle ME. The implementation of value-based healthcare : a scoping review. *BMC Health Serv Res*. 2022:1-8. doi:10.1186/s12913-022-07489-2
60. Nilsson K, Bååthe F, Erichsen Andersson A, Sandoff M. Value-based healthcare as a trigger for improvement initiatives. *Leadersh Heal Serv*. 2017;30(4):364-377. doi:10.1108/LHS-09-2016-0045
61. Walshe K. Pseudoinnovation: The development and spread of healthcare quality improvement methodologies. *Int J Qual Heal Care*. 2009;21(3):153-159. doi:10.1093/intqhc/mzp012
62. Bodenheimer T, Sinsky C. From triple to Quadruple Aim: Care of the patient requires care of the provider. *Ann Fam Med*. 2014;12(6):573-576. doi:10.1370/afm.1713
63. LINNEAN. Linnean Model "Sneller meer waarde voor de patient" ["Faster more value for patients"]. https://www.linnean.nl/home-linnean-model/linnean-model/default.aspx. Accessed September 30, 2022.
64. Lewis S. Value-based healthcare-meeting the evolving needs of our population. *Aust Heal Rev*. 2019;43(5):485. doi:10.1071/AHv43n5_ED
65. Kelly MP, Heath I, Howick J, Greenhalgh T. The importance of values in evidence-based medicine. *BMC Med Ethics*. 2015;16(1):1-8. doi:10.1186/s12910-015-0063-3
66. Yuill C, McCourt C, Cheyne H, Leister N. Women's experiences of decision-making and informed choice about pregnancy and birth care: A systematic review and meta-synthesis of qualitative research. *BMC Pregnancy Childbirth*. 2020;20(1):1-21. doi:10.1186/s12884-020-03023-6

67. Cullen A. *Deny, Dismiss, Dehumanise*. Uitgeverij van Brug; 2019.

68. Driever EM, Stiggelbout AM, Brand PLP. Do consultants do what they say they do? Observational study of the extent to which clinicians involve their patients in the decision-making process. *BMJ Open*. 2022;12(1):1-6. doi:10.1136/bmjopen-2021-056471

69. Anderson M, Pitchforth E, Owen AV, Mossialos E, Millner P, Fistein J. Misconceiving patient reported outcome measures (PROMs) as primarily a reporting requirement rather than a quality improvement tool : perceptions of independent healthcare sector stakeholders in the UK. *J Patient-Reported Outcomes*. 2022. doi:10.1186/s41687-022-00511-5

70. Wetenschappelijk Raad voor het Regeringsbeleid [Scientific Council for Government Policy]. *Kiezen Voor Houdbare Zorg. Mensen, Middelen En Maatschappelijk Draagvlak [Choosing Sustainable Care]*.; 2021. https://english.wrr.nl/publications/reports/2022/05/03/sustainable-healthcare-a-matter-of-choice.-people-resources-and-public-support.

71. Lapaine M. Embracing the Quadruple Aim: One hospital’s experience. *Healthc Manag Forum*. 2021;34(1):26-28. doi:10.1177/0840470420942791

72. Haldane V, De Foo C, Abdalla SM, et al. Health systems resilience in managing the COVID-19 pandemic: lessons from 28 countries. *Nat Med*. 2021;27(6):964-980. doi:10.1038/s41591-021-01381-y

73. Nederlandse Vereniging voor Obstetrie & Gynaecologie (NVOG). *Visiedocument NVOG “Kwaliteit Is Samen Leren” [Visiondocument Dutch Society for Gynaecology “Quality Is Learning Together.”*; 2021. https://www.nvog.nl/wp-content/uploads/2021/11/Visiedocument-‘Kwaliteit-is-samen-leren-2021.pdf.

74. Programma Uitkomstgerichte Zorg. Adviesrapport set Generieke PRO(M)s. https://platformuitkomstgerichtezorg.nl/aan+de+slag/documenten/handlerdownloadfiles.ashx?idnv=2148205. Published 2022.

75. Chen A, Väyrynen K, Schmidt A, et al. The impact of implementing patient-reported measures in routine maternity care: a systematic review. *Acta Obstet Gynecol Scand*. 2022;(May):1-13. doi:10.1111/aogs.14446

76. Haverman L, Van Oers HA, Van Muilekom MM, Grootenhuis MA. Options for the Interpretation of and Recommendations for Acting on Different PROMs in Daily Clinical Practice Using KLIK. *Med Care*. 2019;57(5):S52-S58. doi:10.1097/MLR.0000000000001061


9

CHAPTER 9

Addenda

Summary

Nederlandse samenvatting (Dutch summary)

List of publications

About the author

Dankwoord (Acknowledgements)

SUMMARY

Healthcare systems are increasingly challenged by financial sustainability and workforce capacity, leading to a shift from volume to value. The value-based healthcare (VBHC) strategy provides vision and theory to guide healthcare systems to their aim by 1) creating insight in results of care that matter to patients and 2) organizing care services, evaluation and continuous improvement around patients instead of providers. In this development, patient-reported outcome and experience measures (PROM and PREM) have been embraced to capture results of care directly from patients, which can contribute to value-based care at multiple levels. Yet the how-question of this transformation process is largely unanswered in current practice, especially in an integrated care context (**Chapter 1**). Perinatal care is a field already in a journey towards integrated care, where the potential of patient-reported data for value-based care must be explored yet. Using an internationally developed patient-centred outcomes set for pregnancy and childbirth (PCB set), this thesis' overarching aim was to investigate how PROM/PREM can be embedded in obstetric care networks and explore how they can advance the journey towards value-based perinatal care.

In **Part I**, we investigated the implementation of PROM/PREM in perinatal care.

In **Chapter 2** semi-structured interviews were conducted with keys stakeholders (i.e., six patients, 16 professionals and five policy makers) in the pre-implementation stage. Along the consolidated framework for implementation research (CFIR) this study clarified critical factors that affect successful implementation of the PCB set in obstetric care networks (OCN). Most important barriers (professional workload, data reliability, interprofessional and interorganizational collaboration) and potential facilitators (direct value of PROM/PREM in individual care, interprofessional feedback and education, embedding data capture in existing systems) were translated to multilevel recommendations for implementation of PROM/PREM in an integrated care context.

Chapter 3 reports a feasibility study of using the PROM/PREM in routine perinatal care, i.e., discussing individual results in regular consultations. Usability, preferences and experiences were explored in 21 patients and six professionals for the five timepoints for PROM/PREM collection of the PCB set (two during pregnancy, three postpartum). Patients rated the time spent on completing the questionnaires acceptable. They preferred to complete questionnaires digitally and discuss their answers with an obstetric professional rather than other care professionals, also at the last timepoint six months postpartum. Professionals experienced sufficient time to discuss the responses, except at six months postpartum as it falls outside of current perinatal care paths. Most patients and professionals felt that the PROM/PREM

facilitated symptom detection and personalized care. Professionals needed a well-equipped IT-tool and agreements regarding their responsibilities to discuss or act upon outcomes.

Findings of both the pre-implementation analysis and the feasibility study shaped the strategy that provided the basis for PROM/PREM implementation in three OCN, which was further refined by an iterative action research approach. In **Chapter 4** we describe the mixed-methods evaluation of these implementation projects' outcomes and underlying change processes leading to those outcomes, specifically addressing the context of care networks. Two theoretical implementation frameworks guided iterative data generation (including observation, surveys and focus groups) and analysis to gain an in-dept understanding of activities that contributed to (un)successful change. The use of PROM/PREM was found to be acceptable and appropriate, as professionals recognized the benefits of network-broad PROM/PREM use and felt facilitated in their intrinsic patient-centred motivation. However, feasibly in daily practice was low, mainly due to IT issues and time constraints. Hence implementation did not sustain, but strategies for future adoption were formulated in all OCN. Based on participants' and researchers' reflections on the re-adjusted, co-created implementation strategy, recommendations for PROM/PREM implementation across care networks were formulated. Our findings highlighted the need for sustainable IT infrastructures that enable data exchange across healthcare tiers, as well as an iterative approach to refine the complex implementation of PROM/PREM into local (network) contexts.

In **Part II** of this thesis, we explored the application of PROM/PREM at two levels: individual care and quality improvement.

The studies reported in **Chapter 5** and **Chapter 6** were conducted along a national pilot integrating the PCB set's PROM/PREM at individual level in clinical practice of seven OCN.

Chapter 5 reports the PROM/PREM outcomes of all women who had participated in the national pilot. In total, 1923 questionnaires were collected across the five time points, of which 84% was filled out completely. We found several PROM and PREM domains with relatively high alert rates (clinical threshold values indicating possibly alarming outcomes for professionals) providing opportunities for personalized care both in pregnancy and postpartum. For example, high alert rates for a PROM and PREM domain respectively, were 23% (175/765) for breastfeeding self-efficacy and 10% (101/982) for shared decision making. Some questionnaires needed adaptations for clinical use, as they showed very little clinical variation (mother-child binding) or did not fit clinical care pathways (PREM on pain relief antepartum was administered too early). Overall, we could propose adaptations to the PCB set regarding methods and timeline of measurements based on our findings.

In **Chapter 6,** a mixed methods study investigated women's experiences with completing the questionnaires and discussing individual results as part of regular care. Results of 460 anonymous surveys and 16 phone interviews showed that women perceived benefits of PROM/PREM by an increased awareness of their health status in pregnancy and postpartum and receiving personalized care based on their outcomes. Also, women stressed the relevance of discussing PREM six months postpartum. At the same time, important barriers for women using PROM/PREM included in insufficient information about the rationale of PROM/PREM for individual care, IT issues and discrepancy between the questionnaire topics and the care pathway.

In **Chapter 7**, a qualitative observational study was conducted to investigate network-broad learning with outcome data. Guided by an action research approach, a learning strategy was developed, implemented, and evaluated simultaneously to gaining knowledge of network collaboration conditions that enable joint learning. The strategy included clinical, patient-reported, and professional-reported data; together translated into cases for interprofessional discussion. We found that, despite professionals' time constraints and limited data accessibility, the learning strategy created a venue for in-dept interprofessional discussion and helped to identify improvement opportunities for quality and continuity of perinatal care. Iterative joint reflection on sessions and local collaboration, both in the preparation meeting and collective focus group, was noted to enhance professionals' ownership over the QI process and adjust it to contextual factors and priorities. Along significant differences in network collaboration found, readiness of a network to learn together was shown to depend most on a basis of collaboration with trust, reached through connectivity and consensual leadership. The reinforcing relation between collaboration and innovation identified, provides a direction to advance integrated care via joint learning and action. Eventually, this study resulted in a learning strategy for QI in perinatal care networks adapted to care professionals needs and, with the cyclic and participatory approach, transferable to other integrated care networks as well.

To conclude, the findings of this thesis were discussed along related literature in **Chapter 8** to define its implications for future steps in the journey towards value-based perinatal care. Besides considerations for the application of PROM/PREM in daily consultations and learning, we reflected on how various research methods and our approach to value in general can advance that journey.

NEDERLANDSE SAMENVATTING

De houdbaarheid van zorgstelsels wordt in toenemende mate uitgedaagd door financiële en personele capaciteit, wat heeft geleid tot een verschuiving van volume naar waarde van zorg. De waardegedreven zorg strategie biedt een visie en een theorie voor doelgerichte zorgstelsels door 1) inzicht te creëren in uitkomsten van zorg die er toe doen voor patiënten en 2) de organisatie van zorgverlening, zorgevaluatie en continue verbetering in te richten rondom patiënten (in plaats van rondom zorgverleners). In het licht van deze ontwikkeling zijn patiënt gerapporteerde uitkomstmaten (PROM) en ervaringsmaten (PREM) omarmd om de resultaten van zorg rechtstreeks bij de patiënt te meten, meestal via vragenlijsten. Inzicht in PROM/PREM kan bijdragen aan waardegedreven zorgverlening op meerdere niveaus. Toch is het tot nu toe onduidelijk gebleven hoe deze transitie naar waardegedreven zorg te maken, met name in de context van zorgnetwerken (**hoofdstuk 1**). Hoewel geboortezorg een gebied is dat al op weg is naar integrale zorg, moet het gebruik van patiëntgerapporteerde gegevens voor waardegedreven zorgverlening nog worden verkend. Gebruikmakend van een internationaal ontwikkelde patiëntgerichte uitkomstenset voor zwangerschap en geboorte (Z&G set), was het overkoepelende doel van dit proefschrift om te onderzoeken hoe PROM/PREM kunnen worden ingebed in geboortezorgnetwerken en hoe ze de verschuiving naar waardegedreven geboortezorg kunnen bevorderen.

In het eerste deel van dit proefschrift hebben we de implementatie van PROM/PREM in de geboortezorg onderzocht.

In **hoofdstuk 2** werden semigestructureerde interviews gehouden in de pre-implementatiefase met de belangrijkste belanghebbenden, d.w.z. zes patiënten, 16 zorgverleners en vijf beleidsmakers. Langs een geconsolideerd raamwerk voor implementatieonderzoek verduidelijkte deze studie kritische factoren die een succesvolle implementatie van de Z&G set in geboortezorgnetwerken beïnvloeden. De belangrijkste barrières (professionele werkdruk, databetrouwbaarheid, interprofessionele en interorganisatorische samenwerking) en potentiële facilitators (directe waarde van PROM/PREM in individuele zorg, interprofessionele feedback en educatie, inbedden van data-verzameling in bestaande systemen) werden vertaald naar aanbevelingen op meerdere levels voor de implementatie van PROM/PREM in een integrale zorgcontext.

Hoofdstuk 3 beschrijft een haalbaarheidsstudie naar het gebruik van de PROM/PREM in reguliere geboortezorg: het invullen van de vragenlijsten en het bespreken van individuele resultaten in reguliere consulten. Bruikbaarheid, voorkeuren en ervaringen werden onderzocht in 21 patiënten en zes zorgverleners op de vijf meetmomenten voor PROM/PREM van de Z&G set (twee tijdens de zwangerschap, drie na de bevalling). Patiënten beoordeelden de tijd die ze aan het invullen van de vragenlijsten besteedden als acceptabel. Zij hadden een voorkeur voor het digitaal invullen van de vragenlijsten. Ook bespraken ze hun antwoorden liever met een verloskundig zorgverlener dan met andere zorgverleners, inclusief het laatste meetmoment een half jaar na de bevalling. Zorgverleners gaven aan voldoende tijd te hebben om de antwoorden te bespreken, behalve een half jaar na de bevalling omdat dit moment buiten de huidige geboortezorgpaden valt. De meeste patiënten en zorgverleners waren van mening dat de PROM/PREM hielpen bij het signaleren van symptomen en gepersonaliseerde zorg. Zorgverleners hadden behoefte aan goed werkende IT-tools en afspraken over hun verantwoordelijkheden om resultaten te bespreken en ernaar te handelen.

Met de bevindingen uit zowel de pre-implementatieanalyse als de haalbaarheidsstudie werd de basis strategie gevormd voor PROM/PREM-implementatie in drie geboortezorgnetwerken. Deze strategie werd vervolgens verder verfijnd in een iteratieve aanpak gebaseerd op actieonderzoek principes (participatief, iteratief, reflexief en context-gericht). Met de mixed-methode studie in **hoofdstuk 4** evalueerden we de uitkomsten van deze implementatieprojecten, evenals de onderliggende veranderingsprocessen die tot deze uitkomsten hebben geleid. Daarbij gingen we specifiek in op de context van integrale zorgnetwerken. Geleid door twee theoretische kaders voor implementatie, verkregen we via iteratieve gegevensgeneratie (via observaties, enquêtes en focusgroepen) en analyse een diepgaand inzicht in activiteiten die hebben bijgedragen aan (on)succesvolle verandering. Het gebruik van PROM/PREM werd acceptabel en passend bevonden, daar zorgverleners de voordelen zagen van netwerk breed PROM/PREM-gebruik. Bovendien voelden zij zich gesteund in hun intrinsieke patiëntgerichte motivatie. De haalbaarheid in de dagelijkse praktijk bleek echter laag, voornamelijk vanwege IT-problemen en tijdsdruk. De implementatie hield daarom geen stand, maar strategieën voor toekomstige adoptie werden in alle deelnemende geboortezorgnetwerken geformuleerd. Op basis van reflecties van de deelnemende zorgverleners en onderzoekers op de herijkte, gezamenlijk gecreëerde implementatiestrategie werden aanbevelingen voor PROM/PREM-implementatie in zorgnetwerken geformuleerd. Onze bevindingen benadrukten de behoefte aan duurzame IT-infrastructuren die gegevensuitwisseling tussen zorgdomeinen mogelijk maken, evenals de noodzaak voor een iteratieve benadering om de complexe implementatie van PROM/PREM aan te passen aan de lokale (netwerk) context.

In het tweede deel van dit proefschrift hebben we de toepassing van PROM/PREM verkend op twee niveaus: in de individuele zorg en voor kwaliteitsverbetering.

De studies die in **hoofdstuk 5** en **hoofdstuk 6** worden beschreven, zijn uitgevoerd tijdens een landelijke pilot waarin de PROM/PREM van de Z&G set op individueel patiënt niveau in de klinische praktijk van zeven geboortezorgnetwerken werd geïntegreerd.

Hoofdstuk 5 rapporteert de PROM/PREM uitkomsten van alle vrouwen die hebben deelgenomen aan de landelijke pilot. Op de vijf meetmomenten gezamenlijk werden 1923 vragenlijsten verzameld, waarvan 84% volledig was ingevuld. We vonden relatief hoge percentages alarmscores (klinische drempelwaarden die mogelijk alarmerende uitkomsten voor zorgverleners aangeven) voor verschillende PROM- en PREM-domeinen, wat mogelijkheden biedt voor gepersonaliseerde zorg zowel tijdens de zwangerschap als na de bevalling. Voorbeelden van hoge percentages alarmscores voor respectievelijk een PROM- en PREM-domein waren 23% (175/765) voor borstvoeding zelfredzaamheid en 10% (101/982) voor gezamenlijke besluitvorming. Sommige vragenlijsten hebben aanpassingen nodig om ze klinisch te gebruiken, omdat ze weinig klinische variatie vertoonden (moeder-kindbinding) of niet pasten in klinische zorgpaden (de PREM over pijnbestrijding antepartum werd te vroeg uitgevraagd). Uiteindelijk konden we op basis van onze bevindingen aanpassingen aan de Z&G set voorstellen met betrekking tot de methoden en tijdlijn van de metingen.

In **hoofdstuk 6** onderzochten we de ervaringen van vrouwen met het invullen van de vragenlijsten en het bespreken van individuele resultaten als onderdeel van de reguliere zorg via een mixed-methode studie. De resultaten van 460 anonieme enquêtes en 16 telefonische interviews lieten zien dat vrouwen voordelen van PROM/PREM ervoeren: een groter bewustzijn van hun gezondheidstoestand tijdens de zwangerschap en na de bevalling, en het krijgen van gepersonaliseerde zorg naar aanleiding van hun antwoorden. Ook benadrukten vrouwen de relevantie van het bespreken van PREM een half jaar na de bevalling. Tegelijkertijd waren er belangrijke barrières voor vrouwen bij het gebruik van PROM/PREM: ontoereikende informatie over de bedoeling van de PROM/PREM in individuele zorg, IT-problemen en discrepantie tussen de vragenlijst onderwerpen en het zorgtraject.

In **hoofdstuk 7** werd een kwalitatieve observationele studie uitgevoerd om netwerk-breed leren met uitkomstdata te onderzoeken. Geleid door de principes van actieonderzoek werd een leerstrategie gelijktijdig ontwikkeld, geïmplementeerd en geëvalueerd om kennis te verwerven over condities in netwerksamenwerking die gezamenlijk leren mogelijk maken. In de leerstrategie werden klinische gegevens, door de patiënt gerapporteerde uitkomsten en door zorgverleners gerapporteerde informatie gebruikt. Het beeld uit deze data werd vertaald naar casuïstiek voor interprofessioneel overleg. Ondanks de tijdsdruk van zorgverleners en de beperkte toegankelijkheid tot data, zagen we dat de leerstrategie ruimte creëerde voor diepgaande interprofessionele discussies en hielp bij het identificeren van verbetermogelijkheden voor de kwaliteit en continuïteit van geboortezorg. De iteratieve, gezamenlijke reflectie op de sessies en de lokale samenwerking, zowel in de voorbereidingsbijeenkomst als in de collectieve focusgroep, vergrootte het eigenaarschap van zorgverleners over het kwaliteitsverbetering proces en maakte aanpassing aan contextuele factoren en prioriteiten mogelijk. In de significante verschillen in netwerk samenwerking die werden gevonden, bleek de gereedheid van zorgnetwerken om samen te leren het meest afhankelijk van vertrouwen. Dit werd met name bereikt door connectiviteit en consensueel leiderschap. De gevonden versterkende relatie tussen samenwerking en innovatie biedt een richting om integrale zorg verder te brengen via gezamenlijk leren en handelen. Uiteindelijk resulteerde deze studie in een leerstrategie voor kwaliteitsverbetering in geboortezorgnetwerken aangepast aan de behoeften van zorgverleners en, met de cyclische en participatieve benadering, ook bruikbaar in andere integrale zorgnetwerken.

In **hoofdstuk 8** werden de bevindingen van dit proefschrift besproken aan de hand van verwante literatuur om de implicaties ervan te definiëren voor toekomstige stappen in de reis naar waardegedreven geboortezorg. Naast overwegingen voor het gebruik van PROM/PREM in de spreekkamer en gezamenlijk leren, reflecteerden we hier op de manier waarop verschillende onderzoeksmethoden en onze benadering van het begrip waarde de reis kunnen bevorderen.

LIST OF PUBLICATIONS

A feasibility study of implementing a patient-centered outcome set for pregnancy and childbirth
Depla AL, Ernst-Smelt HE, Poels M, Crombag NM, Franx A, Bekker MN
Health Sci Rep. 2020 Jun 26;3(3):e168.

Implementation of a standard outcome set in perinatal care: a qualitative analysis of barriers and facilitators from all stakeholder perspectives
Depla AL, Crombag NM, Franx A, Bekker MN
BMC Health Serv Res. 2021 Feb 2;21(1):113.

Patient-Reported Outcome and Experience Measures in Perinatal Care to Guide Clinical Practice: Prospective Observational Study
Depla AL, Lamain-de Ruiter M, Laureij LT, Ernst-Smelt HE, Hazelzet JA, Franx A, Bekker MN; BUZZ Team
J Med Internet Res. 2022 Jul 5;24(7):e37725.

Women’s experiences with using PROM and PREM in routine perinatal care in the Netherlands: a mixed methods study
Laureij LT, **Depla AL**, Kariman SS, Lamain-de Ruiter M, Ernst-Smelt HE, Hazelzet JA, Franx A, Bekker MN; BUZZ Team
BMJ Open. 2023 Mar 10;13:e064452.

PROM and PREM in routine perinatal care: mixed methods evaluation of their implementation into integrated obstetric care networks
Depla AL, Pluut B, Lamain-de Ruiter M, Kersten AW, Evers IM, Franx A, Bekker MN
J of Patient Rep Outcomes. 2023 Mar 9;7(26):1-15.

Quality improvement with outcomes data in integrated obstetric care networks: evaluating collaboration and learning across organizational boundaries
Depla AL, Kersten AW, Lamain-de Ruiter M, Jambroes M, Franx A, Evers IM, Pluut B, Bekker MN
Submitted at Int J of Integrated Care (under review)

Werken met uitkomsten in de geboortezorg. Hoofdstuk in: Gepersonaliseerde medische zorg, innovatieve zorg afgestemd op persoonlijke behoeften, voorkeuren en waarden
Depla AL, Laureij LT en Ernst-Smelt HE
NFU-consortium Kwaliteit van Zorg. Editors: van Weert N, Hazelzet J (2020)

Effect of maternal diabetes on fetal heart function on echocardiography: systematic review and meta-analysis
Depla AL and De Wit L, Steenhuis TJ, Slieker MG, Voormolen DN, Scheffer PG, De Heus R, Van Rijn BB, Bekker MN
Ultrasound Obstet Gynecol. 2021 Apr;57(4):539-550.

Polyhydramnios in isolated oral cleft pregnancies: incidence and outcome in a retrospective study
Depla AL, Breugem CC, van der Horst CM, de Heus R, van den Boogaard MH, Maas SM, Pajkrt E, Bekker MN
Prenat Diagn. 2017 Feb;37(2):162-167.

Treatment and prognostic factors of radiation-associated angiosarcoma (RAAS) after primary breastcancer: a systematic review
Depla AL, Scharloo-Karels CH, de Jong MAA, Oldenborg S, Kolff MW, Oei SB, van Coevorden F, van Rhoon GC, Baartman EA, Scholten RJ, Crezee J, van Tienhoven G
European J of Cancer. 2014 Jul;50(10):1779-1788.

ABOUT THE AUTHOR

Alies Depla was born on July 6th, 1992, in Utrecht, the Netherlands, as second child of Toke and Maurits. She grew up with her two brothers in Utrecht and followed her secondary education at the Christelijk Gymnasium Utrecht, like her older brother and their grandfather. From 2010-2016 she studied medicine at the University of Amsterdam / AMC. During her study she stayed based in Utrecht for her other passion: playing water polo for UZSC in the national league. Her interest in obstetrics and gynaecology was sparked during clinical rotations in the Academic Medical Centre in Amsterdam and grew further in clinical electives in the Wilhelmina Children's Hospital (WKZ) and Diakonessenhuis Utrecht. As a medical student, she started her scientific carrier in research internships in the field of radiotherapy (supervision dr. Tienhoven, AMC) and prenatal care (supervision prof. Bekker, UMCU), both resulting in a publication in an international peer-reviewed journal. During her clinical rotations, she was wondered by the organisation of care and motivated for quality improvement, leading to an elective internship on value-based healthcare at the Obstetrics department of the WKZ (supervision dr. Koenen and prof. dr. Franx). After obtaining her medical degree in 2016, Alies returned to the Diakonessenhuis as resident (not in training) and fertility doctor at the department of Gynaecology and Obstetrics. She started her doctoral research a year later by combining her clinical work in the Diakonessenhuis with research at the Obstetrics department of the WKZ, which she could continue full-time from 2018-2022. Under the supervision of prof. dr. Franx and prof. dr. Bekker, this research led to the work presented here. In February 2023, Alies started her specialty training as a resident in obstetrics and gynaecology at the Gelre Ziekenhuis in Apeldoorn (supervision dr. Paarlberg). Alies currently lives in Utrecht with her partner Richard and their two sons Joah and Faas.

DANKWOORD

Het is af! Zonder team geen resultaat, zo ook niet dit proefschrift. De afgelopen jaren hebben ontzettend veel mensen bewust of onbewust hieraan bijgedragen, die wil ik hier graag bedanken.

Allereerst dank aan alle vrouwen en zorgverleners die belangeloos deelnamen aan het onderzoek in dit proefschrift. Zonder jullie vertrouwen en inzet was dit werk er niet geweest.

Prof. dr. Bekker, Mireille. Toen jij net in Utrecht kwam, mocht ik mijn eerste stappen als onderzoeker bij je zetten, met succes. Uiteindelijk viel de afronding van dit proefschrift bijna gelijk met jouw oratie; je commitment aan mijn traject kende geen grenzen. Altijd een overvolle agenda, maar jouw onuitputtelijke energie en ambitie maakten dat ik altijd op je kon rekenen als het erom ging. Ik heb diep respect voor hoe je alles combineert: extreem goed prioriteren, de juiste mensen op de juiste plek zetten en openhartig je doelen nastreven. Een voorrecht dat ik dat bij je mocht afkijken. Bedankt voor je ruimte, vertrouwen en je gave om altijd kansen te zien.

Prof. dr. Franx, Arie. Jij hebt me geïnspireerd voor het werk in dit proefschrift en zorgde ervoor dat ik kon starten. Ik voelde me gesteund vanaf moment dat ik bij je binnen liep tot op de dag van vandaag. Dank voor je oprechte aandacht en het vertrouwen dat je me gaf ondanks de fysieke afstand. Jouw inhoudelijke expertise en kritische blik bleven mijn stukken altijd naar een hoger niveau tillen. Ik heb heel veel plezier gehad van je perspectief en visie op het vak, ik verwacht nog veel langer.

Dr. Lamain-de Ruijter, Marije. Voor het eerst ben je copromotor, ook al was dat misschien niet helemaal de bedoeling. Origineel verving je me ‘‘alleen’’ in mijn hoognodige verlof: ik had me geen andere of betere vervanger kunnen voorstellen. Je kritische kijk op de samenwerking in de geboortezorg, prettige levenshouding én hoogwaardige onderzoeksvaardigheden maakte je de dagelijks begeleider die ik zo nodig had. Toch nog even sparren, je R-skills delen, en ruimte voor ventileren maakte je zowel op professioneel als persoonlijk vlak een groot plezier om mee samen te werken.

Dr. Pluut, beste Bettine. Hoewel je niet op de tweede pagina van dit proefschrift staat, had je een essentiële rol in de laatste fase van mijn traject: toen het allemaal ineens op z’n pootjes terecht kwam. Wat heb ik, en collega’s om mij heen, veel van jou geleerd over actieonderzoek, leerprocessen en reflectie. Ontzettend stoer en knap hoe jij je bedrijf runt op zo’n eigen en oprechte manier. Dank voor je aandacht en enorme inzet voor mijn traject en mij als persoon.

Graag wil ik de leden van de beoordelingscommissie, te weten prof. dr. Scheepers, prof. dr. Grootenhuis, prof. dr. Kaasjager, prof. dr. van den Bosch en prof. dr. de Jonge, bedanken voor de tijd en moeite die u in het beoordelen van mijn proefschrift heeft gestoken.

Dr. Koenen, Steven, dank voor je visie en enthousiasme die me en inspireerden tot op weg hielpen bij dit proefschrift. Jouw “alle begin is moeilijk” heeft me nog jaren op de been gehouden. Dr. Schaap, Timme, jij stond voor me klaar toen mijn team even uiteen viel, veel dank daarvoor.

Dr. Dilaver, Gönül, vanaf onze eerste kennismaking voelde ik me bij je thuis en daarna stond je altijd voor me klaar. Ik waardeer jouw warme, krachtige persoonlijkheid en inspirerende manier van werken. De gesprekken met jou wisten me steeds op te warmen om verder te gaan.

Graag dank ik alle medeauteurs. Dr. Crombag, Neeltje, jij maakte me wegwijs in het kwalitatieve onderzoek en was altijd bereikbaar als ik er even niet uit kwam. Alle leden van het BUZZ team, dank voor de gedeelde visie en de effort die ieder van jullie daarin gestoken heeft met alle hobbels die erbij kwamen kijken. Prof. dr. Hazelzet, Jan, en Hiske, jullie waren met Arie de motor achter het BUZZ project, dank voor de kansen die jullie me daarmee boden en de prettige samenwerking in de praktijk en wetenschap. Lyzette, we deelden een vergelijkbaar onderwerp en uitdagend traject, ik ben blij dat wij (op afstand) altijd konden samenwerken op de inhoud en zo twee papers hebben neergezet. Dr. Poels, Marjolein, jouw begeleiding bij het binnenhalen en opstarten van de USER studie waren essentieel na het wegvallen van Dr. van der Stel, Henk. Aan de kartrekkers van de USER studie, Inge, Valerie, Ieke, Simone en alle projectteamleden: jullie waren, net als ik aanvankelijk, niet geheel zeker waar je aan begon met actieonderzoek. Wel deelden we hetzelfde doel en gelukkig waren jullie zo moedig om mee te doen: dank voor jullie vertrouwen en keiharde inzet. Collega’s van het Julius centrum en onderwijsomgeving, het was ontzettend leerzaam om van onze ideeën met jullie daadwerkelijk onderwijs te maken. Dr. Jambroes, Marielle, je scherpe blik brachten zowel het onderwijs en de papers naar een hoger niveau. Anna, wat een plezier om samen te werken met jouw frisse en kundige blik. Onze verschillende achtergronden gaven de mix die nodig was voor geslaagde leer- en verbetersessies; gelukkig mochten we het uiteindelijk toch één keer live doen.

Erica, Marieke, Barbara, Els, Christina, jullie werk was goud waard. Zonder jullie hulp, geduld en doorzettingsvermogen met onmogelijke agenda’s, was het nooit tot een boek gekomen.

Dan mijn oud Diak collega’s: wat een voorrecht om bij jullie mijn eerste stappen in het vak te zetten en jullie in de eerste fase van mijn promotie als basis te hebben. Dr. Schuitemaker en Dr. Vogelvang, Nico en Tatjana, veel dank voor de kansen en het vertrouwen dat ik van jullie kreeg als jonge dokter. Jet en alle dames van de fertiliteit, ik vond het prachtig om deel uit te maken van jullie team en de mooie zorg die jullie leveren. Een ochtend ‘fert’ voelde altijd als een warm bad. Aan Jan, Lyzette, Eline, Roosmarijn, Yvonne, Martijn, Emiel, Annelien, Blanka, Mirte, Nick, Laura, Kevin, Anneke, Marissa, Evelien, Jolijn: wat een feest was het met jullie als assistenten groep, op skireis, in de kroeg en op cursus in Londen. Het zegt genoeg dat bijna iedereen na vijf jaar nog steeds geen afscheid heeft genomen van onze app-groep. Speciaal dank aan Dr. Veerbeek, Jan, voor je vertrouwen en blijvende support wanneer ik het nodig had, je bent een inspirerend voorbeeld! Dr. Brouwers, Laura, in werk was je mijn ‘voorganger’ waarmee ik duidelijk grote voetstappen te vullen had, tegelijk echt een maatje in triatlon, borrels, en inmiddels ook moederschap. Ik kijk ernaar uit om weer samen te werken met je ad-rem humor, sportiviteit en liefde voor het vak! Evelien, het was instant plezier met jou op de werk- of dansvloer, op de piste of met Bert & Ernie: eigenlijk alle dingen waar het echt om gaat in het leven.

Lieve oud-collega’s, onderzoekers, Hans, Leon, Laura, Katrien, Fieke, Veronique, Chryselle, Doortje, Doortje, Daphne, en natuurlijk alle AZU-onderzoekers. Onderlinge verbinding is broodnodig in een PhD traject: dank voor alle koffie-momentjes, maandaglunches, borrels en strijdvaardigheid. Chryselle, wij deelden onze sportieve passie, en kwamen op de fiets tot de conclusie ‘wij zijn best wel hetzelfde’. Chris en Joline, aan ‘de andere kant’ maar toch een warme klik! Chris, jouw enthousiasme sleepte je me zelfs door een 16km-lange 10km hardlopen. Joline, wat een plezier om nu naast je in de kliniek te staan! Katrien, dank voor het delen van je enthousiasme voor de wetenschap en lekker eten. Leon, heel blij dat ons harde werk goed terecht is gekomen in jouw boek, ik geniet van jouw humor en gave om alles ‘rooskleurig’ in te zien. Hans, jij lijkt de rust zelve terwijl je keihard werkt, wat een plezier om jouw collega te zijn en samen ons eerste (en enige) kunstwerk te fabriceren. Aan alle ‘nieuwe’ PhD-ers (Ilse, Anna, Ellis, Mette, Shinta, Lotte, Shariva, Eline, Jacintha, Odette, Margriet): dank voor jullie enthousiasme, ik heb alle vertrouwen in jullie en verwacht jullie snel weer als collega!

Zonder ontladen en opladen buiten werk was er geen proefschrift. Ladies (& René) van Dames 3 en andere UZ’ers, bij jullie kan ik altijd thuiskomen in de chloorlucht of het clubhuis, even stoom afblazen: dat is een groot goed dat ik blijf koesteren. Kiki, achter jouw soms intimiderende vastberadenheid gaat een warme persoonlijkheid schuil die klaar staat voor ieder die het ’t hardst nodig heeft. Sonja, het is een groot plezier om bij & met jou te mogen klagen, vooràl bij een goed glas wijn en heerlijk eten (bij voorkeur Pecorino ei). Leo, speciaal dank voor je maaltijd service en natuurlijk de prachtige omslag!!

Lieve old-school, ook al neemt ieder een ander pad en verliezen we elkaar regelmatig uit het oog, het voelt direct weer als vanouds bij life-events of een goeie borrel. Ik ben trots op ieder van jullie en dankbaar voor alles wat we samen delen na 18 (!) jaar vriendschap. Lieve Emma, vanzelfsprekend mijn paranimf. Na ons profielwerkstuk samen te schrijven (ik typte het uit, jij corrigeerde d/t-fouten) kozen we ieder een eigen weg naar hetzelfde eindpunt: arts en ons (eigen) proefschrift op dezelfde dag af. Altijd vastberaden, eigen en integer: je bent een prachtig mens en ik ben gezegend met zo'n trouwe vriendin. Ik bewonder je wetenschappelijk talent en ben trots dat ik straks eerst naast jou mag staan.

Fons en Sytse, een soort extra opa's voor de jongens, maar stiekem ook voor ons. Wat een bonus om altijd te kunnen rekenen op jullie interesse en/of lasagne (of gehakballen) als we het nodig hebben. Natuurlijk dank voor de prachtige werfkelder als ultieme werkplek voor de laatste loodjes van dit boek.

Lieve Stijn, grote broer. Ook al zijn we soms fysiek lang uit elkaar, we delen stiekem veel gedachten, (sport)ambities en valkuilen, en hebben maar een paar woorden nodig om elkaar te begrijpen. Het geluk dat je vond bij Renske en kleine Ted is besmettelijk, fijn om jullie nu zo dichtbij te hebben. Lieve Gust, groot klein broertje, nu suikeroom én straks advocaat! Jouw relativeringsvermogen en hulp op afroep zijn goud waard. Je rust en humor zijn een verademing: ik kan me geen betere paranimf wensen. Lieve oma Wies, jouw onverzettelijkheid en zelfstandigheid zijn een immens voorbeeld. Bovendien gaf jij me, met opa, een vanzelfsprekend vertrouwen dat ik voor altijd bij me houd.

Lieve pap en mam, wat ben ik een geluksvogel met jullie als uitvalsbasis. Dat was onmisbaar voor dit boek, maar ook al daarvóór en nu weer. Lieve Maurits, jouw liefde en zorgzaamheid zijn grenzeloos. Je rol als opa staat je uiteraard met glans en was onmisbaar voor de laatste fase van dit boek. Lieve Toke, jij inspireert me (onbewust) om buiten de gebaande paden te denken, je eigen visie te bepalen en mensen te verbinden. Niet zomaar stuitte ik geheel toevallig op de netwerk samenwerking in "jouw" wijkteams. Hoewel je me al jong zelfstandigheid bijbracht (o.a. vergeten op het schoolplein), kan ik bovenal altijd naar je terug als ik het even niet meer weet.

Lieve Joah en Faas, jullie zijn een stel boeven om te besluiten dat jullie de wereld met z'n tweeën tegelijk onveilig kwamen maken. En wat ben ik jullie daar dankbaar voor: ik voel intens geluk elke dag met jullie. Soms kom ik in armen te kort (zeker in jullie ogen), maar nooit in liefde voor elk van jullie.

Lieve Richard, wat ben ik trots op jou. Al 12,5 jaar hou je het met me vol, waarvan je er dit proefschrift 5 jaar bij kreeg. Dat volbrengen, moet je topsportmentaliteit zijn (ik twijfel dan ook niet aan Parijs 2024). Ik ben je oneindig dankbaar voor je rust, ontwapenende humor, heerlijke kookkunsten, grenzeloze vaderschap en al het andere waarmee je er voor me bent. Er is veel wat ik niet weet, maar ik kan altijd terugvallen op de liefde en het thuis dat ik bij jou heb gevonden.