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# A MODEL FOR PATIENT ENGAGEMENT INTEGRATION IN PERINATAL eHEALTH DEVELOPMENT AND QUALITY ASSURANCE

Jennifer Auxier

TURUN YLIOPISTON JULKAISUJA – ANNALES UNIVERSITATIS TURKUENSIS
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## University of Turku

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*To Ben Auxier,*
*My energy is continually renewed*
*for my own engagement because of our partnership*

UNIVERSITY OF TURKU
Faculty of Medicine
Department of Nursing Science
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JENNIFER NICOLE AUXIER: A Model for Patient Engagement Integration in Perinatal eHealth Development and Quality Assurance
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## ABSTRACT

The aim of this study was to construct a model for patient engagement integration in perinatal eHealth development and quality assurance. The model was developed in four phases. The first three phases produced evidence for the development of a model. In the final phase, a qualitative interpretive synthesis was conducted using grounded theory to articulate a patient engagement model composed of three steps.

The first phase was a scoping review aimed at describing the nature and range of patient engagement from the perspective of access, personalization, commitment, and therapeutic alliance within perinatal eHealth. A narrative synthesis was used to describe findings. Phase two consisted of two studies exploring engagement practices of pregnant users during their use of a self-monitoring health promotion eHealth system. A descriptive comparative analysis was completed to understand user engagement patterns based on physical use of the wearable device. A mixed-methods convergence evaluation was conducted to understand the process of accessing the health promotion eHealth system. In phase three a process evaluation tool for parent participation and collaboration (in the neonatal intensive care unit) was developed and psychometrically tested.

For the interpretive synthesis, articles from the first three phases of this study were purposively sampled. A deductive codebook was developed using Donabedian's model, and an adapted version of Lewin's Action Research Cycle. Donabedian's model consists of quality assurance through the examination of structure, process, and outcomes. Lewin's Action Research Cycle informs iterative steps in development and implementation of health systems. Phase four resulted in a model for patient engagement integration in perinatal eHealth development and quality assurance. Three steps of the model were identified as being: Person-centered Perinatal eHealth program mapping; Process evaluation through monitoring of patient engagement processes; and Co-creation of perinatal eHealth programs through real-life testing of perinatal eHealth systems.

KEYWORDS: eHealth, Implementation, Perinatal Care, Patient Engagement

TURUN YLIOPISTO
Lääketieteellinen tiedekunta
Hoitotieteen laitos
Hoitotiede
JENNIFER AUXIER: Malli potilaan osallistumisesta perinataaliajan sähköisen terveydenhuollon kehittämiseen ja laadunvarmistukseen
Väitöskirja, 176 s.
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## ABSTRAKTI

Tutkimuksen tavoitteena oli kehittää malli ohjaamaan potilaan osallistumista perinataaliajan sähköisen terveydenhuollon kehittämiseen ja laadunvarmistukseen. Malli kehitettiin neljässä vaiheessa. Kolmessa ensimmäisessä vaiheessa tuotettiin tutkimusnäyttöä kehittämisen tueksi. Viimeisessä vaiheessa laadullisen tulkitsevan synteesin avulla muodostettiin potilaan sitoutumisen malli.

Ensimmäisessä vaiheessa tehtiin kartoittava kirjallisuuskatsaus, joka kuvasi potilaiden sähköiseen terveydenhuoltoon osallistumisen tavat ja laajuuden saatavuuden, yksilöllisyyden, sitoutumisen ja terapeuttisen hoitosuhteen näkökulmasta. Aineisto analysoitiin teorialähtöisellä sisällönanalyysillä ja tulokset kuvattiin narratiivisen synteesin avulla. Toinen vaihe muodostui kahdesta tutkimuksesta, jotka tarkastelivat itsemonitorointisysteemin avulla raskaana olevien henkilöiden osallistumistapoja terveydenedistämiseen. Tutkimuksissa odottajat käyttivät itsemonitorointisysteemiä. Osallistumistapoja analysoitiin puettavan laitteen käyttöajan pohjalta tehtyjen vertailevien analyysien avulla. Monimenetelmällisessä tutkimuksessa muodostettiin analyysin pohjalta ymmärrys itsemonitorointisysteemin saatavuuteen liittyvästä prosessista. Kolmannessa vaiheessa kehitettiin ja psykometrisesti testattiin prosessievaluaatiomittari arvioimaan vanhempien osallistumista ja yhteistyötä henkilökunnan kanssa vastasyntyneiden teho-osastolla.

Viimeisen vaiheen tulkitsevaa synteesiä varten valittiin tarkoituksenmukaisia artikkeleita. Donabedianin terveydenhuollon laadunvarmistuksen malli ja Lewinin muokatun toimintatutkimuksen syklin pohjalta muodostettiin teorialähtöinen analyysirunko. Neljännen vaiheen tuloksena muodostettiin malli potilaan osallistumisesta perinataaliajan sähköisen terveydenhuollon kehittämiseen ja laadunvarmistukseen. Malli kostuu kolmesta askeleesta: Yksilökeskeisen sähköisen terveydenhuollon kartoitus, potilaan osallistumisprosessin monitorointiin perustuva prosessievaluaatio ja perinataaliajan sähköisen terveydenhuollon yhteiskehittäminen kliinisessä todellisuudessa.

AVAINSANAT: sähköinen terveydenhuolto, käyttöönotto, perinataaliajan hoito, potilaan osallistuminen

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# Abbreviations

| | |
|---|---|
| AMICA | fAMily Integrated CAre in the neonatal ward-study |
| App | Application |
| DM | Decision making |
| EMA | Ecological Momentary Assessment |
| FCC | Family-centered Care |
| FIcare | Family Integrated Care |
| ICT | Information and Communication Technology |
| IPP | Index of Parent Participation of a hospitalized child |
| MEC-U | Medical Research Ethics Committees United |
| NICU | Neonatal Intensive Care Units |
| PE | Patient Engagement |
| PPI | Patient and Public Involvement approach |
| PPM | Parent Partnered Models |
| RMSSD | Root Mean Square of successive differences |
| SMS | Short message service |
| SOL | Sleep onset latency |
| TST | Total Sleep Time |
| WASO | Wake after sleep onset |
| WCC | Woman-centered Care |
| WHO | World Health Organization |

# List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Auxier, J.N., Bender, M., Hakojärvi, H.R., Axelin, A.M. Patient Engagement Practice within Perinatal eHealth Service: A scoping review. *Nursing Open,* 2023, 1-14

II Auxier, J.N., Asgari Mehrabadi, M., Rahmani, A.M., Axelin, A.M.A Descriptive Comparative Pilot Study: Association between use of a self-monitoring device and sleep and stress outcomes in pregnancy. Computers, Informatics, Nursing, 2022, 10-1097

III Auxier, J.N., Savolainen, K., Bender, M., Rahmani A.M., Sarhaddi, F., Azimi, I., Axelin, A.M. Exploring access as a process of adaptation in a self-monitoring perinatal eHealth system: Mixed-method study from a sociomaterial perspective. JMIR Formative Research, 2023, p.e44385

IV van Veenendaal, N.R., Auxier, J.N., van der Schoor, S.R., Franck, L.S., Stelwagen, M.A., de Groof, F., van Goudoever, J.B., Eekhout, I.E., de Vet, H.C., Axelin, A. and van Kempen, A.A. Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. *Plos one*, 2021; 16(6), p.1-18

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# 1 Introduction

The process of implementing eHealth in perinatal care should account for the irreplaceable role of pregnant persons and their families as participants in their care. When care programs are designed appreciating persons as unique and composite members of the care teams perinatal care users feel confidence and reassurance in receiving services and adverse outcomes for both parents and infants can be ameliorated (Ahlqvist-Björkroth et al., 2017; de Mooij et al., 2018; Franck & O'Brien, 2019; van Veenendaal et al., 2020). Recent research has illustrated that perinatal eHealth use is impacting perinatal users' perceptions of the delivery of their care. Some users have felt more connected to care services on a daily basis and like having the chance to lead the processes of their care by sending photos, requesting video calls, or viewing videos to train themselves in breastfeeding techniques as needed (Danbjørg et al., 2015; Jefferson et al., 2019; Shorey et al., 2018). While patient participation in healthcare has been associated with greater patient safety the optimal pace and approach for transferring care activities to patients using eHealth should be personalized and flexible (Danbjørg et al., 2015; Gibson et al., 2021; Platonos et al., 2018; Schwappach, 2010). Patient engagement in eHealth programs has the potential to stimulate users emotionally and cognitively to becoming committed toward maintenance of family wellness and self-care activities (Isetta et al., 2013; Rhoads et al., 2017). The quality of the provider-patient interactions and the maintenance of mutual trust between providers and patients remains a vital component when integrating eHealth into perinatal care systems (Gibson et al., 2021; O'Brien et al., 2013).

The structure of perinatal care is transforming and integrating new care processes that include interactions between the users and eHealth systems. Care processes occurring within perinatal eHealth influence a dynamic flow between stability and change due to the various new interactions occurring during the adoption and adaptation of new technologies (Jarzabkowski, 2004; Oudshoorn, 2011). The new insights gained through self-monitoring by perinatal eHealth users can be channeled into better optimization of lifestyle patterns for health promotion of pregnant persons and their unborn babies (Lupton, 2017; Niela-Vilén et al., 2021). Perinatal health users can also prepare for clinic visits or remote video calls differently with the help of on-demand evidenced based perinatal information and personal data (Auxier et al., 2022; de Mooij et al., 2018). New technologies have always made it necessary for care users and providers to adapt, in these cases it has often been challenging to assure quality in practice during dynamic transformations with the use of new technologies (Aarhus et al., 2009; Grönvall & Verdezoto, 2013; Mol, 2009). Perinatal eHealth is one form of ‘e-Scaped’ medicine. ‘E-Scaped’ medicine was described by Nettleton as a new frame to view medical cosmology post the emergence of information and communication technologies (ICT) (Nettleton, 2004). Not since the early 1800s (with the advent of increased medical technologies and expertise moving care from home to hospital) has such a shift in location of healthcare been experienced around the world as is now occurring with the implementation of eHealth. In the new structure of care the enactors of care processes have changed dramatically. The type of responsibility patients feel for their own care has perhaps increased. Prior to wider eHealth use pregnant persons would only be able to access reliable blood pressure readings and weights from clinic or hospital settings. Now it is possible to impact perinatal patients’ feelings of control and empowerment by giving them access to blood pressure self-monitoring technologies that can function to automatically send health data to a server through Bluetooth technology directly to their care providers in real time (Hirshberg et al., 2018; Rhoads et al., 2017). New parents can perform health assessments on their infants in the comfort of their own homes, send pictures to the providers to follow-up on transition to life at home after a neonatal intensive care (NICU) unit admission (Danbjorg et al., 2015). Now that the perinatal care has ‘e-scaped’ how is quality of care defined, how can we best develop perinatal eHealth to meet the needs and demands of perinatal patients?

As novel eHealth strategies (i.e., self-monitoring, remote communication, and serious gaming, etc.) are already being employed, concerns about the possibility of losing an awareness of who is responsible for doing the caring work has emerged (Oudshoorn, 2011 p.4). While perinatal eHealth is being tested for feasibility, usability and effectiveness on clinical outcomes, the investigation into what processes of patient engagement are impacting effective and sustainable development and use of these programs has not been extensively studied (Auxier et al., 2023a; Barello et al., 2016). Examining perinatal eHealth that integrates patient engagement is useful in deconstructing the interactions and dynamic processes occurring in ‘e-scaped’ perinatal care. The next step is to understand the link between patient engagement and essential concepts of family-and woman-centered care. The definition of patient engagement outlines four attributes, and represents both processes and behaviors: personalization, access, commitment, and therapeutic alliance (Higgins et al., 2017). Woman- and family-centered care contain core components of respect for personhood, patient involvement, collaboration, self-care and self-management during the perinatal periods (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019). Some of the elements of woman-and family-centered care can be mapped to the attributes of patient engagement (See Figure 1). Perinatal practitioners, and care organizations have been struggling in recent years to develop sustained practice of woman and family-centered care (Fontein-Kuipers, Boele, et al., 2016; Stelwagen et al., 2020; Thomson et al., 2013). Much attention has been placed on measuring effectiveness and efficacy of perinatal services, or medical and individual health behavior outcomes, such as adherence to breastfeeding, cessation of smoking, and optimal management of hypertension and gestational weight gain during pregnancy (Abroms et al., 2017; Baruth et al., 2019; Choi et al., 2015; Herbec et al., 2014; Hirshberg et al., 2018; Jefferson et al., 2019; Niela-Vilén et al., 2016). While the evaluation of these outcomes is essential for maintaining and evaluating safety and health states in perinatal programs, the evaluation of patient engagement practices and processes (i.e., family-and woman-centered care) is just as vital for assessing quality.

With the global integration of eHealth into the perinatal care programs researchers have an opportunity to apply careful focus toward patient engagement attributes as they are related to woman and family-centered care. Examining the complexity and emergent properties of perinatal eHealth characterized by the integration of patient engagement provides a platform for identifying important interactions in practice that foster a flexible design, implementation, and quality assurance of woman and family-centered care. A patient engagement model that focuses on patient involvement and inclusion in design, implementation, and evaluation of perinatal eHealth is needed.

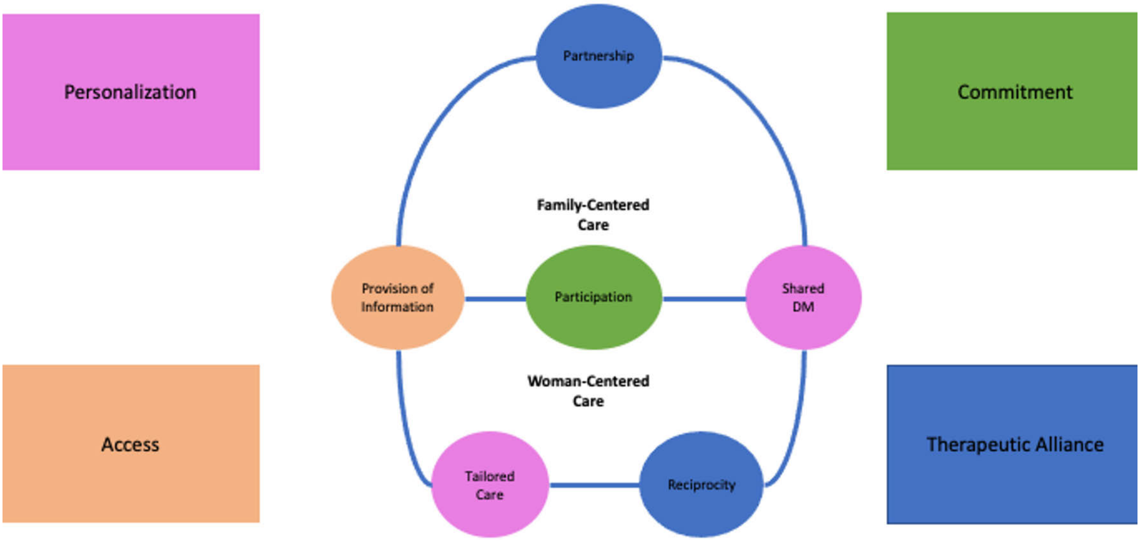


**Figure 1.** Mapping Woman-and Family-Centered Care elements to the attributes of Patient Engagement: Concepts adapted from definitions of patient engagement (Higgins et al., 2017),woman-centered care (Fontein-Kuipers et al., 2018), family-centered care(Franck & O'Brien, 2019).

# 2 Background

## 2.1 Woman- and Family-centered care practices the context of ‘e-scaped’ care

Throughout history disruptions to the location of maternal and new-born care have occurred due to technological progress. Progress in the use and availability of technology necessitated the deliberate reconceptualization of care in many instances, from the introduction of safe caesarean sections in hospital in the middle of the 19th century (Moore & de Costa, 2003) to the use of intensive care treatments for neonates in the early and mid-20th century (Gooding et al., 2011). The disruptions to location of care in these two instances had implications for woman-and family-centered care. Between 1940 and 1969 the United States experienced a drastic increase of births occurring in hospitals, moving care from the domestic arenas into expert spaces (Gooding et al., 2011). By the end of the 20th century families no longer had the same sense of personal responsibility for their own health states and survivorship of their newborns because of the new expectations of medical technology. Although the theory of woman-and family-centered care was not commonly articulated until later in the 20th century the impact of using new medical technologies to support survivorship and wellness in pregnancy and birth shifted attention from domestic concerns, values and preferences to the rules and risk adverse situations of medical processes. In our current day we are providing care again in domestic contexts and the impact of this shift must now be articulated. One example of how the shift in use of online and eHealth modalities in perinatal care has an impact already in practice is the occurring tension between health users’ desires to seek other perspectives online and resistance sometimes experienced by doctors in allowing online information into their patient interactions (Song et al., 2012). Examining technological and human processes is needed to preserve the expert influence that medical advances gave us in the 19th and 20th centuries while supporting the consideration of health users’ concerns, values, and preferences. Technology is already being used and having an impact on how new and expectant parents view their roles and responsibilities in pregnancy, birth, and childrearing (Johnson, 2014; Song et al., 2012).

Another reconceptualization of health care occurred in the 1970s as ‘patient as consumer’ became the focus for some health activist movements (Mold, 2010). The consumerist approach to health systems and policy is present in society now paired with the growing use and familiarity of wearable devices for fitness and health data tracking, smartphones with access to health media content on the go, and video conferencing which allows healthcare interactions to occur in the comfort of a patient’s own home (Lupton, 2020). Clinicians, patients, and health researchers stand at a critical point in the revolution of health systems and practices pertaining to person-centered care as it relates to transformations of care structure. Nettleton (2004) conceptualized the new health system structure as the new socio-technological interactions occurring between persons, organizations and technology, so named, ‘E-Scaped Medicine’. There is no guarantee that with the shift of technology use in perinatal care that parenting, and motherhood will not be touched or influenced as strongly by the biomedical models of health, growth, development, and parental role acquisition (Song et al., 2012). Many health users still lean heavily on the expert knowledge and structures of medical models of perinatal care and use the online resources to confirm the notions already present within the medical model and normative childbearing (Song et al., 2012). A road to a so-called ‘technological empowerment’ is more nuanced and complex than simply shifting location of practice and access to personal health data.

Designing quality care systems that are person-centered and promote engaged patients presents challenges in the face of changing care localities with the use of new technologies. Socio-technological system design methods have emerged as an approach to design thinking that consider human, social, organizational, and technical factors (Baxter & Sommerville, 2011). The concept of socio-technical systems comes from organizational sciences and refers to the existence of interactions occurring between persons and technology within society (Baxter & Sommerville, 2011; Lupton, 2013). Currently developments in information and communication technologies are impacting more than just the physical world we live in but our worldviews and practices (Nettleton, 2004). For perinatal practitioners, these changes in thinking and practicing have already been influenced greatly by socio-technological factors over decades. For example, with the introduction of advanced fetal monitoring devices and pharmaceutical methods for induction of labor practitioners and health organizations began using more risk-avoidance clinical practices (Tew, 1986). For patients and some practitioners these socio-technological factors were paired with a growing dissatisfaction with medical models used within maternity and neonatal care as little evidence had been produced to support their growing popularity (Tew, 1986). In the mid to late 20th century perinatal medical practices were reflecting a perceived disregard for parent’s preferences and need for skill building in caring for their newborns as well as limited regard for pregnant persons and women's choices for natural births in many upper to middle class countries.

Considering, a decades long push to see perinatal care models move toward more person-centered approaches two models of care have emerged, woman- and family-centered care (Fontein-Kuipers et al., 2018; Shields et al., 2006). Professional care experts and patient groups alike support woman- and family-centered care and the use of eHealth modalities within perinatal care systems. Explicit definitions and examinations of person-centered perinatal eHealth practices are lacking. While many definitions of woman-and family-centered care exist a conceptualization of the structure of practice is still lacking. Without a clear understanding of the perinatal structure of practice practitioners, researchers, and users of programs are inhibited to design person-centered perinatal eHealth programs. A conceptual structure constitutes the frame of reference from which all questions can be posed, and answers offered (Jewson, 1976), this is currently missing in the context of perinatal eHealth.

In this study two concepts and person-centered care models were be brought together to construct a frame by which to systematically examine the nature, practices, structure, and processes of person-centered perinatal eHealth. The concepts are: (1) Patient Engagement (Higgins et al., 2017), and (2) The World Health Organization (WHO) Person Centered Digital Health Interventions (World Health Organization, 2018). The two models are: Woman- and Family-centered care. Both woman- and family-centered care became popular in the late 20th century in response to a discomfort and limited evidence to support provider-driven models of perinatal care (Mold, 2010; Tew, 1986). Subsequently studies examining the provision of woman- and family-centered care reveal that if personalization of care is lacking quality of care and patient confidence decreases (Auxier, 2017; Platonos et al., 2018). eHealth usage and popularity have impacted the socio-technological environments of perinatal care structures. Perinatal eHealth practices are bringing new opportunities for tailoring care and bringing more control of care processes into the hands of perinatal health users (Danbjorg et al., 2015; de Mooij et al., 2018; Garfield et al., 2016; Rhoads et al., 2017). However, little is known about how to best examine the integration of Patient Engagement attributes into eHealth structures during design and quality assessment.

## 2.2 Patient Engagement and Quality Assurance of eHealth Programs

Patient engagement has been described as a behavior influenced by cognitive, and emotional factors (Kelders et al., 2020). Kelders and colleagues (2020) note that the process of engagement seems to be articulated in various contexts as a state of being involved in an object, artifact, or activity that often leads to a positive outcome. Further, researchers have noted that in order to capture the object of study (patient engagement) we must be clear about our definitions and ensure we have understood the shape that this concept is taking within a particular domain of practice (Higgins et al., 2017; Kelders et al., 2020).

In their concept analysis of patient engagement Higgins and colleagues (2017) defined this concept as both a "process and [a] behavior [that] is shaped by the relationship between the patient and provider and the environment in which healthcare delivery takes place". Four attributes were identified in this concept analysis that allow for the deconstruction of patient engagement into manageable components for study (Higgins et al., 2017). The four attributes of patient engagement that provide conceptual components for inquiry are: (1) access, (2) personalization, (3) commitment, and (4) therapeutic alliance (Higgins et al., 2017). Access refers to the ability of the patient to obtain all health resources required to experience high quality and appropriate care (Higgins et al., 2017). Personalization assures that the interventions conform to the unique circumstances of the patient (Higgins et al., 2017). Commitment is the cognitive and emotional factors that empower the patient to exploit health resources and therapeutic alliance represents the elements of the patient-provider relationship that impact engagement in care (Higgins et al., 2017) (See Table 1).

Researchers who have explored the concept of patient engagement have pointed to the complexity of examining the effects of patient engagement on clinical outcomes and safety. In Schawappach's (2010) systematic review investigating the effects of patient engagement on quality and safe care health behaviors he concluded that the effectiveness of patient engagement to improve quality and safety of care may be effective if initiatives for improvement are based on patient perspectives, promote complex behavioral change of staff, and if implementation is performed along with efforts to promote cultural and normative change in health care institutions (Schwappach, 2010). These recommendations suggest that integrating patient engagement into health systems is complex and requires that researchers and clinicians look at quality assurance from a variety of perspectives.

**Table 1.** Definition of Patient Engagement and Attributes.

| | |
|---|---|
| Patient Engagement | Is a process and behavior and is shaped by the relationship between the patient and provider and the environment in which healthcare delivery takes place. |
| Attributes | |
| Personalization | Assures that the interventions conform as closely as possible to the unique desires and circumstances of the patient. This includes efforts at shared decision making and tailoring information and resources to the patient's level of receptivity based on interests, capabilities, and life circumstances. |
| Access | Refers to the ability of the patient to obtain information, guidance, and tools to secure consistent, high quality appropriate care. This includes patient functional literacy as well as institutional resources adapted to the patient's geographical location, cultural background, and socioeconomic level. |
| Commitment | Pertains to the cognitive and emotional factors that empower the patient to exploit health resources available. Commitment is demonstrated by the patient efforts over time and is more inclusive than simple motivation that may waiver according to changing circumstances. It is driven by intrinsic cognitive or emotional forces that may be stimulated through social support, intellectual resources, or any means that encourages behavior change that leads to practices that improve the patient's status. |
| Therapeutic Alliance | Incorporates elements of the patient-provider relationship including quality of the clinical interaction, communication, empathy, or mutual understanding. |

(Adapted from Higgins et al., 2017)

Examining quality of care is further challenged in high and middle income countries under current conditions and national mandates for increased practice of person-centered care (Gibson et al., 2012; Millenson & Macri, 2012). Person-centered care depicts concepts important for integrating patient engagement. Assessing the sustained quality of person-centered care and patient engagement practices remains challenging. Perinatal eHealth practices have not been examined using clear definitions of person-centered care and patient engagement. Implementation and quality evaluation of person-centered eHealth programs begins with the definition of patient engagement and a clear understanding of person-centered digital health interventions (DHI), as defined by the WHO (World Health Organization, 2018). The WHO classifications of person-centered DHI contain four categories of patient activities described here as all activities intended to support a person's own health self-management (World Health Organization, 2018). These four categories lay the foreground for person-centred perinatal eHealth and are: (1) Targeted client communication; (2) client to client communication; (3) personal health tracking; and (4) on-demand information services. Perinatal eHealth structures should support person-centered (Woman-and Family-centered care) processes. For this reason, the WHO DHI person-centered categories should be used as a guide to parse out eHealth modalities that are currently in use and support elements of patient engagement.

Donabedian (2002) defines three approaches to examining quality assurance of health services. Structure, process, and outcome are described by Donabedian as the domains in which information can be gathered to assess the level of quality assurance (Donabedian, 2002, p.46). Quality assurance in perinatal eHealth should be assessed based on the level of safety and quality of medical treatments as well as the sustainment of woman-and family-centered care. Structure encompasses material and human resources, and organizational characteristics (Donabedian, 2002, p.46). Process is defined as the activities that will construct health care delivery, i.e., treatments, patient education and the like (Donabedian, 2002, p.46). Outcomes are the changes that have occurred (wanted or unwanted) resulting from the receival of care delivery (Donabedian, 2002, p.46). These domains can be viewed as having mechanistic elements to guide our understandings of artifacts, objects, material, human resources, and organizational characteristics as they encounter one another, and interactions result in processes of action for health service delivery. The functional components of eHealth systems have been identified as useful artifacts producing cost-effective service and highly engaged patients throughout many health care sectors around the world (Oudshoorn, 2011). eHealth systems can be conceptualized as interacting objects that are conducting meaningful activities inside care contexts, such as, motivating patients with games and appealing visual and tailored platforms, supporting improvements in health literacy, and connecting patients to their health providers with synchronous and asynchronous communication modalities (Abbass-Dick et al., 2017; Baron et al., 2018; Danbjorg et al., 2015; Moraes Carrilho et al., 2019). These interactions can be abstracted for further observation through the lens of socio-materiality and socio-technical approach to system development (Baxter & Sommerville, 2011; Orlikowski & Scott, 2008a).

This study examined best practices for development and quality assurance of person-centered perinatal eHealth. The jumping off point of examination begins with the above aforementioned definitions of patient engagement (Higgins et al., 2017), the WHO, here so named, person-centered digital health intervention categories (World Health Organization, 2018), Donabedian’s Structure-Process-Outcome model, an adapted version of the Action Research Cycle (Oberschmidt et al., 2022; Williamson et al., 2011) and socio-materiality conceptions of eHealth care delivery (Orlikowski & Scott, 2008a). Not only is the use of person-centered perinatal eHealth relocating the structure of health care practice but the eHealth modalities in use are transforming the care processes and redefining behaviors and roles of patients and care providers. If the complexity and flexibility of person-centered perinatal eHealth is to be maintained as an important structure of personalized health care, we must deconstruct the processes emerging in 'e-scaped' perinatal eHealth to plan and design for technology's mediating effects on person-centered care interactions.

## 2.3 Perinatal Person-centered Care and Patient Engagement

### 2.3.1 Woman-Centered Care

Woman-centered care (WCC) has been used to describe the ideal delivery of perinatal care occurring during childbirth exclusively, across pregnancy and childbirth, and in the context of midwife-led perinatal care (Fontein-Kuipers et al., 2018; Maputle & Donavon, 2013). Woman-centered care is described as a philosophy that guides practice traditions and objectives (Fontein-Kuipers et al., 2018). Two important objectives of WCC are to positively influence the perinatal care user experiences and the health of the pregnant person and their unborn infants (Fontein-Kuipers et al., 2018; Maputle & Donavon, 2013). Changes from the provider-driven approach for maternity and childbirth care to a more neo-liberal approach to healthcare service influenced a greater attention to patient led care models (e.g., woman-centered care). The implementation and consistent practicing of WCC has been lacking due to midwife attitudes, structural support and a concrete definition of the approach around the world (Fontein-Kuipers, Boele, et al., 2016; Foureur et al., 2009).

The personalization of maternity and childbirth is manifested in processes for tailoring care and provision of information according to the capacity and circumstances of each individual pregnant person (Fontein-Kuipers et al., 2018). Personalization of maternity care has been hindered due to busy caseloads of midwifes and obstetricians, slow uptake of positive attitudes toward woman-centered practices as more than a 'trend' in perinatal care (Fontein-Kuipers, Boele, et al., 2016; Kennedy et al., 2020). Shared decision-making is also paramount in the delivery of maternity and childbirth care. Many tools exist to aid in decision-making and to increase personalization in maternity and childbirth experiences, however evidence from a relevant scoping review recommends that decision aids must yet be paired with processes of value clarification, discovery of preference and good communication between perinatal providers and patients (Kennedy et al., 2020).

There are varying definitions for woman-centered care, relaying on context and objectives for building a definition of this model of care (Leap, 2009). For the purposes of this study a definition identified by Fontein-Kuipers (2018), Woman-centered care 2.0 was used to guide the exploration into person-centered perinatal eHealth (See Table 2). This definition provides a conceptual background to aid in the examination of collaborative, reciprocal, and tailored perinatal practices during pregnancy and after birth.

The definition of Woman-centered care used for the theoretical development of this study is the definition developed by Fontein-Kuipers and colleagues (2018):

> "…a philosophy and a consciously chosen tool for the care management of the childbearing woman, where the collaborative relationship between the woman - as an individual human being -and the midwife – as an individual and professional – is shaped through co-humanity and interaction; recognizing and respecting one another's respective fields of expertise. Woman-centered care has a dual and equal focus on the woman's individual experience, meaning and manageability of childbearing and childbirth, as well as on health and wellbeing of mother and child. Woman-centered care has a reciprocal character but fluctuates in equality and locus of control." (Fontein-Kuipers et al., 2018, p.8)

### 2.3.2 Family-centered Care

After the birth of the infant the physical bodies of mother and infant change irreversibly, as do the relationship, and interactions between the dyad. A new and important stage begins, and all the energy placed into providing quality person-centered care to the mother during pregnancy and labor now expands in a tangible way toward the entire family. Prior to the late 20th century infants were never separated from their mothers after birth because it was normal for the management of birth and post-partum care to occur in the home (Gooding et al., 2011). After the major technological changes emerged at the turn of the 20th century birth, post-partum, and neonatal care occurred under supervision of hospital based perinatal caregivers. The increased presence of medical experts during labor and birth resulted in the separation of infants from their parents becoming common place. The awareness of the family is an integral factor for providing personalized and safe care to neonates in hospital and community contexts has grown in popularity since the end of World War II (Jolley & Shields, 2009).

Family-centered care (FCC) as a nursing practice has incorporated the following three perspectives: (1) Appreciates the family as a context in which the neonate experiences health or illness (Shelton et al., 1987); (2) that the family as a whole and not just the neonate is the target of all care treatments (Shields et al., 2006); and (3) that the family functions as a system in which each person within the family impacts the state of the whole (Bell, 2009). Key concepts embedded in FCC are said to be "partnership, collaboration, participation, and communication" (Segaric & Hall, 2005, p. 213). Despite having theoretical and conceptual foundations for discussing the role and impact of families on the care of children and the neonates, best practices, and care processes for achieving social and psychological wellbeing of the family during the perinatal period have not been consistently or rigorously identified. Further, the evaluation of FCC in practice settings is not being conducted with consistency.

Like the above-mentioned model of WCC there is no universal definition or practice norms for FCC globally. The varying contexts of care (e.g., acute or community) and the age of the child have impacted the construction of definitions, core components of the care models, and the designing and evaluation of FCC practices. For the purposes of this study Sheilds and colleagues' definition that highlights care recipients as not only the child but the entire family, will be used. The concepts of importance within FCC are "partnership, collaboration, participation, and communication" (Segaric & Hall, 2005, p.213)

The definition of Family-centered care used for the theoretical development of this study is the definition developed by Shields and colleagues (2006):

> "A way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients." (Shields et al., 2006, p.1318)

### 2.3.3 Perinatal eHealth use

A review of the literature was conducted for the purposes of phase I of this study. A description of some of these findings is covered in this section to illustrate the current perinatal eHealth use and practices related to patient engagement. The use of modalities and treatments varies across perinatal eHealth programs (Figure 2). Providers using the systems with women and families are interdisciplinary and cover a variety of health and wellness domains of practice. Providers include dieticians, physical activity coaches (Baruth et al., 2019; Davis et al., 2018), Family integrated care and co-parenting experts (Abbass-Dick et al., 2017; Platonos et al., 2018), smoking and alcohol consumption cessation experts (Harris & Reynolds, 2015; Herbec et al., 2014; van der Wulp et al., 2014), midwives, nurses, and doctors (Baron et al., 2018; Danbjørg et al., 2015; Frize et al., 2013). Danbjørg and colleagues (2015) developed an Application (App) intervention in Denmark to support parents being discharged early (at 24 hours after birth) from hospital which include on-demand informational resources and connectivity with nurses at the hospital. Abbass-Dick and colleagues (2017) make use of a web module that supports parents in building skill in co-parenting toward accomplishment of breastfeeding goals, the program was developed by co-parenting experts and the tailored feedback component was designed by experts in breastfeeding and co-parenting.

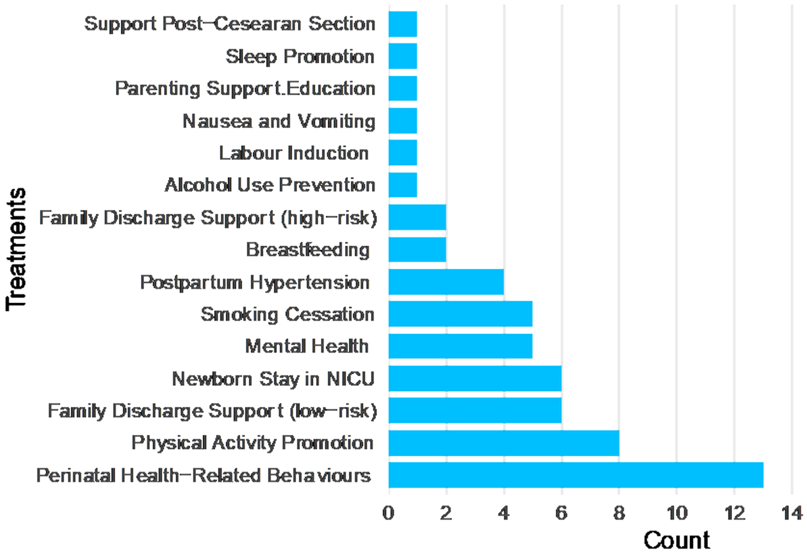


**Figure 2.** Treatments being delivered with eHealth modalities (Adapted from Original publication I).

Maternity eHealth objectives cover early recognition of non-medical and acute problems during pregnancy, management of medical needs related to gestational diabetes, hypertension, mental health, and cessation of smoking and alcohol consumption in pregnancy. Maternity eHealth programs mention core concepts of WCC i.e., provision of information, participation, shared decision-making, tailored care, and reciprocity. Pregnant persons and women experience a chance to access information and resources consistently through push notifications, tailored reminders toward healthy activities, and remote communication with care providers on-demand. The use of home self-monitoring support pregnant persons and women to follow treatment and prevention plans. Clinicians in The Netherlands, the United Kingdom, and the United States developed smoking and alcohol consumption eHealth goal setting programs (Abroms et al., 2017; Harris & Reynolds, 2015; Herbec et al., 2014; Naughton et al., 2013; Valencia et al., 2020; van der Wulp et al., 2014). The goal setting features include a combination of tailored feedback, on-demand evidenced based information and resources to support the overall goal of stopping the use of substances that can be harmful for their unborn babies. Self-monitoring, digital log keeping, ecological momentary assessment (EMA), and modalities are in use to support the reporting and management of mental health disturbances during pregnancy (Doherty et al., 2019a; Fontein-Kuipers, Boele, et al., 2016; Hantsoo et al., 2018; Muuraiskangas et al., 2016).

Neonatal eHealth objectives are namely focused on collaboration and sharing of information between new parents and medical professionals during a neonatal hospital stay or transitioning to home after birth. The central elements of family-centered perinatal eHealth programs were referenced throughout various studies i.e., partnership, provision of information, participation, and shared decision-making.

In using eHealth programs parents have the chance to access evidenced based and consistent resources while they adjust to their new or changed roles as parents. Parents have been receiving coaching for providing care to vulnerable newborns who experienced an admission to the NICU (Bower et al., 2005; Franck et al., 2019; Frize et al., 2011; Gibson et al., 2021; Globus et al., 2016; Platonos et al., 2018), and for initiation and sustainment of breastfeeding (Abbass-Dick et al., 2017; Jefferson et al., 2019). Parents and healthcare providers interact with each other to provide safe and effective care with the help of eHealth systems that support shared decision-making through the access of personalized and real-time information about the progress of NICU treatments, and health states of newborns in hospital and at home.

### 2.3.3.1 Personalization

Personalization is represented within perinatal eHealth through the enactment of user centered design and woman and family centered care approaches. Perinatal eHealth practice includes the provision of personal care experiences that are tailored, on-demand and consider women and families preferences, attitude toward eHealth, needs, values and diversity. Higgins and colleagues (2017) outline that a failure to accommodate the patients' circumstances and unique characteristics in relation to their receival of health services would inhibit patient engagement, all included studies for phase I of this study depict consistent use of personalization within perinatal eHealth care delivery.

Current perinatal eHealth programs are designed with diversity of users considered. As seen in a program, Neonatal tele-homecare, developed in part to guide parents at any level of eHealth literacy toward evidenced based, on demand information about their infant's health (Garne et al., 2016). The consideration of diversity supports the provision of woman and family centered care is central to perinatal eHealth programs that are characterized by the integration of patient engagement. Making use of tailored and on-demand strategies made all the difference for pregnant women and families, as described by two different groups of researchers studying neonatal care and pregnancy health promotion. Neonatal eHealth supported parents to settle into their own home environments without being confronted with the relational or power tensions that sometime appear during an

NICU stay (Holm et al., 2019). In a pregnancy health promotion program, the OB Nest program, the professional caregivers commented that the measurements that perinatal health users were collecting at home gave a sense of normalcy and expertise from the side of the perinatal health users that was not present before the eHealth modality of self-monitoring was introduced (de Mooij et al., 2018).

Feasibility was favorable for many of the interventions reviewed here, parents and pregnant women found the eHealth modalities useful and recruitment in some cases was very effective indicating the high interest in use and satisfaction with the service (Isetta et al., 2013). One of the parents who participated in a program developed in Sweden felt that the home visits could completely be replaced by video calls. During the interviews, the families belonging to the intervention group commented that they would like a format in which some home visits would be replaced with Skype calls (Gund et al., 2013). Pregnant women also expressed how the use of eHealth offered them a personal and quality care experience, they felt less burdened when including perinatal care into their daily lives and saw benefit in accessing and participating in their care during remote electronic fetal monitoring during an induction and when performing self-monitoring for hypertension during the postpartum periods (Janssen et al., 2021; O'Brien et al., 2013; Payakachat et al., 2020).

### 2.3.3.2 Access

New and expectant parents have access to resources and educational information, and personal medical data about themselves and their infants through the existence of eHealth systems. Access to resources and information provides insight to new and expectant parents about their families' central wellness needs and treatments. Parents have opportunities to build confidence and motivation through the on-demand availability of resources and information.

Many programs provide access to on-demand educational resources, this supports new and expectant parents to have confidence and comfort with the use of systems as described by Danbjørg and colleagues about their eHealth early discharge support program in Sweden "Parents stated that it was beneficial to be able to watch the videos at a time that suited them" (2015). Further, Baruth and colleagues described that providing many options for communication allows for pregnant persons and women to follow their preferences when using a health and activity promotion program, SELF and Exercise is Medicine Program (Baruth et al., 2019).

Perinatal health users were able to obtain resources and information that was suited for their unique needs as a health user group. This was seen in programs that supported peer support in the form of moderated online communities and allowing new parents to receive breastfeeding support in the form of discrete Apps that they could use in real-life circumstances without feeling an added burden of always needing to receive coaching at times that were outside of their normal life patterns and flows (de Mooij et al., 2018; Jefferson et al., 2019).

Access was enacted using novel eHealth modalities and through the interactions between perinatal health users, the providers, and the systems. In using novel eHealth modalities new possibilities for practice and provision of service were realized. For example, women now labor at home during low-risk induction (O'Brien et al., 2013), pictures of infected umbilical cords, critically high blood pressure values, and unsafe food consumption can be sent through Short Message Service (SMS), and automated push notifications to providers for optimal health monitoring (Boe Danbjørg et al., 2014; Hirshberg et al., 2018; Wierckx et al., 2014).

#### 2.3.3.3 Commitment

Commitment is established and maintained when perinatal health users seek greater understanding and awareness of their health status and care needs, and when they are willing to take steps on their own or in collaboration with others to achieve their health goals (Higgins et al., 2017). Commitment is represented through the integration of behavior change theories in the development of maternity eHealth programs. Among programs reviewed 14 different measures were used to evaluate behavior change. Researchers of a Mental Health monitoring program, BrightSelf state the that the consideration of factors contributing to ongoing commitment to mental health self-reporting eHealth systems is critical from the start development and design of programs (Doherty et al., 2019b).

Consideration of commitment as a factor for designing perinatal eHealth systems is evident in the frequent use of reminders, transmission of relevant and manageable volumes of information to new and expectant parents. For example, Himes and colleagues describe the function of text message reminders in the Healthy Beyond Pregnancy eHealth program intended to support pregnant persons and women in adhering to post-partum care follow-up visits. They stated the importance of nudging text messages to point to important postpartum concerns that could get lost in the often-busy time of adapting to your newborn at home after delivery (Himes et al., 2017).

Specific eHealth modalities support new ways of relating and connecting with patients that spark their intrinsic cognitive and emotional characteristics, enabling them to participate and collaborate for the provision of their perinatal care. New and expectant parents are given opportunities to participate in their own wellness goals and care plans in real-time by using current technologies. These opportunities influence patients' motivations over time and give them much needed confidence for self-maintenance of wellness and management of health challenges. As seen in the

‘Home-but-not-alone’ post-partum program, wherein parents were given the opportunity to search for information, instructional videos, and even read-aloud content that they could access anytime, for example even while breastfeeding or on the go (Shorey et al., 2018).

Becoming committed was different between neonatal and maternity phases of perinatal care. Pregnant persons and women’s development of competence in making health behavior change goals does not need to involve health care provider support or interaction in the beginning. For example in programs used to aid expectant parents in cessation of smoking or drinking alcohol during pregnancy the self-reporting log and goal setting was possible without physical interaction with a health professionals (Valencia et al., 2020; van der Wulp et al., 2014; Whitemore et al., 2019). The work of becoming committed to participating in infant care after the birth is more complex and can depend on reassurances from healthcare providers that the parents are fit to care for their infant, as well as ensuring parents have physical and intellectual access to infants. Further, parents are not independent with all elements of infant care from the very beginning and require and want coaching, especially when their infant is experiencing a health challenge. Differences are present in the primary sources of this review in how eHealth modalities were used to support the element of commitment in the maternity and neonatal care interventions.

Platonos and colleagues describe that parents need to be given a chance to feel included in the complex care of their infants during an admission to the NICU and the eHealth service of an App to be used along with the Family Integrated Care (FICare) parent coaching program (Platonos et al., 2018). This program coupled with the app allowed for parents to receive learning material on-demand and on the go and could move through the program with an eye on their unique progress and coaching needs with the use of self-reporting enabled with the App (Platonos et al., 2018). Alternatively, in a program in The Netherlands developed to help pregnant women stop consuming alcohol in pregnancy, women are stimulated to work toward their health behavior goals through contact with an automated computer coach (van der Wulp et al., 2014). Pregnant women work through questionnaires to share their current state of alcohol consumption with the computer program and receive computer generated tailored advice based on their responses, the advice is intended to guide goal setting without speaking directly with their healthcare provider, keeping the process feeling anonymous for women (van der Wulp et al., 2014).

#### 2.3.3.4 Therapeutic Alliance

Therapeutic alliance sets patient engagement as a concept apart from empowerment, involvement, and self-management (Higgins et al., 2017). Perinatal eHealth systems allow for the support of a therapeutic alliance through increased connectivity between new and expectant parents and the perinatal care providers. Increased connectivity occurs through low burden synchronous and asynchronous communication characterized by remote communication, tailored and on-demand feedback and on-demand tailored information.

Connectivity is increased between health users and the perinatal care service through interactions with the eHealth systems. New and expectant parents have commented that the eHealth system is a "virtual companion" (Krishnamurti et al., 2017) partner in care (Kennelly et al., 2016; Naughton et al., 2013) and the "only person in my life who asked me how I was doing everyday" (Krishnamurti et al., 2017). Naughton and colleagues developed a delivery system for text messages that was intended to encourage and coach pregnant persons to quit smoking, they included personalized details within the messages, such as the name of the person receiving the message, this provided the sense for participants that, "someone who [them, like the message] had come from a friend" (Naughton et al., 2013). An App for tele-homecare was described by one mother as a lifeline to help when she was not physically in the NICU. The app was described as a sort of bed side alarm that one would use when in need of help (Holm et al., 2019).

Connectivity between patients and care providers was also enhanced through the sharing of data collected through self-monitoring devices, digital journaling technology, and digital logging of remote newborn assessments. This data was intended to be used during discussions about care and had potential to encourage a unified view of individual and family health status and progress toward goals and achievements in skill acquisition. This information can be accessed remotely and sent to healthcare professionals. Moraes and colleagues (2019) reported on an App used in Brazil that supported women when making birth plans to share with their health care providers. The information women shared about their birth plans was integrated into the electronic health record and was intended to be discussed during each antenatal care visit to support women toward their goals, preferences, and problem solving.

Finally, the review of these primary sources informs that perinatal eHealth developers are giving attention to the level of eHealth literacy of professionals, challenges in balancing healthcare providers' workflows supporting new activities related to eHealth modalities and these challenges remain. It is important to note that new and expectant parents have reported being more comfortable with technologies than the health providers which supports developer attention to coaching and educating the health care professionals on the benefits and functionalities of eHealth systems and how it can support collaboration and connectivity with patients.

The above description of perinatal eHealth use did not include interventions that were blended between maternity and neonatal services, and there were no programs developed to better understand perinatal eHealth systems for health promotion around management of healthy sleep patterns and stress levels which are important areas of study in pregnancy (Niela-Vilén et al., 2021).

## 2.4 Person-centered Perinatal eHealth Development and Quality Assurance

A conceptual structure is needed to clearly articulate best practices for development and quality assurance in perinatal eHealth. It is possible to arrange our understanding of person-centered perinatal eHealth as a structure that has woman-and family-centered care concepts at its core and relies on patient engagement principles for enacting person-centered core components. From this perspective the Figure 3 that follows provides a starting place in which to explore how perinatal eHealth structures and processes can be systematically identified and assessed.

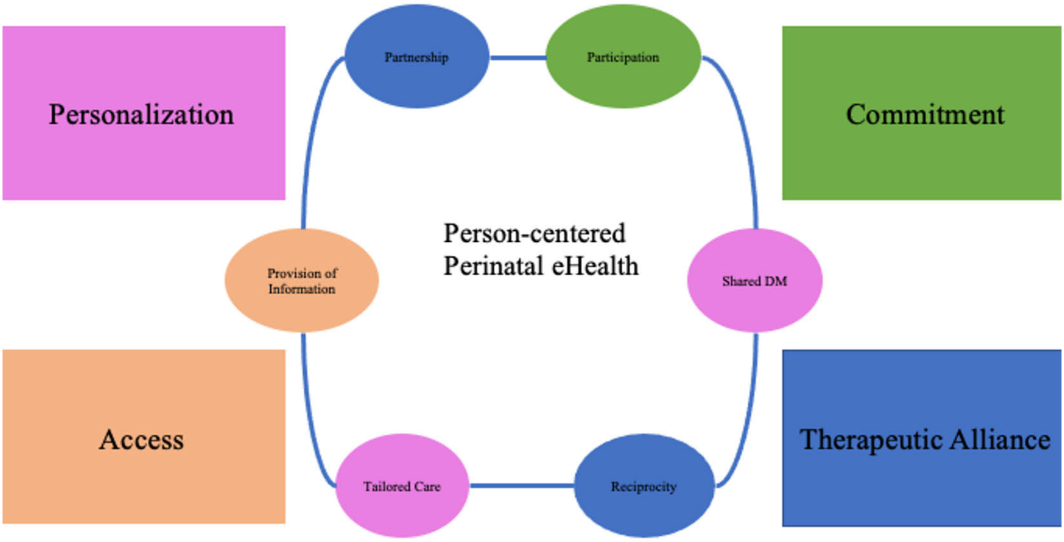


**Figure 3.** Woman- and Family-centered care is conceptualized as Person-centered Perinatal Care. The colors of concepts are mapped to the Patient Engagement attributes.

## 2.5 Justification for current study

Perinatal health organizations around the world are aiming for consistent and sustainable person-centered care practices while attempting to integrate eHealth. The existence of a guide for perinatal eHealth development and quality assurance is lacking. Person-centered philosophies represent adaptation and responsiveness as core components of practice. Personalization, access, commitment, and therapeutic alliance practices are all dependent on adapting to the needs, preferences, motivations, decisions of patients, and the development of supportive relationships with new and expectant parents. If we are to incorporate patient engagement practices that support person-centered eHealth practice, we must allow for adaptation to occur as events of care unfold in action and observe and evaluate the adaptation process. The integration of eHealth and patient engagement into perinatal care is an already emerging process. Demand for greater eHealth use has increased due to recent social-technological reforms resulting from the 2019 pandemic stay at home regulations. Although eHealth methods are gaining in popularity and use, perinatal care contexts lack standardization for development and quality assurance of eHealth programs. The perinatal care community has established strong person-centered values, strives to engage care users, and needs to consider applying standards into future development and evaluation of person-centered practices in the context of perinatal eHealth systems. In this study a model was developed through four phases to inform one systematic approach to the integration of patient engagement in the development and evaluation of perinatal eHealth systems.

# 3 Aims

The overall aim of this study was to integrate and synthesize methodologically diverse perinatal eHealth practice narratives and empirical data into a model for patient engagement integration in perinatal eHealth development and quality assurance. A model was generated through the use of pre-existing textual evidence about patient engagement practices-in-use in perinatal eHealth and the building of new evidence base for development and evaluation of perinatal eHealth from a patient engagement perspective (Dixon-Woods & NHS Health Development Agency, 2004).

This PhD work comprised four phases and four original publications. Phase I aimed at discovering the nature and range of perinatal eHealth characterized by integration of patient engagement, through a scoping review approach. Phase II aimed at examining feasible practices for developing and testing the presence of three patient engagement attributes (personalization, access, and commitment) within an antenatal eHealth self-monitoring service. Phase III aimed at the development and psychometric testing of a measure that was used in Neonatal Intensive Care Units to evaluate the processes of collaboration and participation (recursive concepts linked to therapeutic alliance and commitment) of parents with new-burns receiving family-centered care. Phase IV consisted of the conceptualization of the model for patient engagement integration in perinatal eHealth development and quality assurance.

The research questions for the study were:

1. What is the nature of perinatal eHealth as a structure of health care delivery characterized by the integration of Patient Engagement? (Phase I)

   Specific underpinning research questions:

   a. What are practices and the range of perinatal eHealth strategies that are characterized by the integration of patient engagement? (Original Publication I)

   b. Do current practices of perinatal eHealth support all attributes of Patient Engagement (i.e., Personalization; Access; Therapeutic Alliance; and Commitment)?
      (Original Publication I)

2. What forms of evaluation support the exploration of patient engagement (commitment and access) in the development and testing of an antenatal eHealth self-monitoring program? (Phase II)

   Specific underpinning research questions:

   a. What are changes overtime related to the level of behavioral engagement (commitment) and sleep quality, levels of fatigue and stress, and sleep behaviors? (Original Publication II)
   b. What are the characteristics of the process of use after pregnant users receive access to a self-monitoring eHealth system? (Original Publication III)

3. Does the CO-PARTNER measure allow for examination of the process of collaboration and participation in the context of family-centered care models and therefore serves as a valid tool for process evaluation of perinatal eHealth practices (therapeutic alliance and commitment)? (Phase III/Original Publication IV)

4. What are the steps of patient engagement integration in perinatal eHealth development and quality assurance?
   (Phase IV)

# 4 Materials and Methods

Practices explored in this study relate to the emergence of complex processes of person-centered care embedded in a perinatal eHealth structure of care. The exploration of patient engagement practices in perinatal eHealth occurred through a scoping review (Phase I). A feasibility study for an antenatal sleep and stress self-monitoring eHealth system was conducted to understand the measurability of personalization, and access and commitment within a perinatal eHealth structure (Phase II). The development and psychometric testing of a process evaluation tool for use by parents and nurses in a NICU care context was conducted to support the examination of commitment and therapeutic alliance practices in a perinatal eHealth care structure (Phase III). An interpretive synthesis was conducted to integrate methodologically diverse patient engagement and person-centered care narratives and empirical data into a model for patient engagement integration for perinatal eHealth development and quality assurance (Phase IV). The contents of this chapter include study designs, settings, participants, and ethical considerations for the conduction of the four phases of this study and their associated original publications (Tables 2-5).

In this study investigating the various effects of eHealth practices was paramount. Understanding that various effects exist concurrently and that as nursing professionals we can view our work and collaboration with health users and other health professionals as the enactment of models of practice rather than a list of right actions that should be carried out (Bender, 2018b, 2018a). My epistemological stance as a nursing researcher requires attention to the day-to-day evidence at play in the enactment of care processes and the embodiment of the self and co-creation between enactors within ever shifting health service structures. Finding knowledge in areas of complexity and shifting structures requires that we do not completely disentangle the intricacies of daily life from the field of observation (Mol, 2006). Our participants and perinatal eHealth users are adapting to the use of health systems within the context of their daily lives, while the technology and their own actions for adaption of use of these systems are embodying perinatal care processes and structures. These processes and structures provide knowledge that is workable into practice models. In this way I frame the investigations of this PhD study with a pragmatic view in mind. I align myself with the principles of 'good care' described by anthropologist Dr. Annemarie Mol. The interventions described in this study reveal qualitatively different 'good care' and 'bad care'(Mol, 2006). The 'good' and 'bad' are understood within the context and unique personalized situations of the individual and perinatal health user groups (Mol, 2006). To unravel the discrepancies of care experiences I aim toward examining the intricacies of enacted processes and existing structures of perinatal eHealth to see what can be tinkered with for desired enactment of care (Mol, 2006). The use of randomized or quasi-experimental designs for understanding the effectiveness of perinatal eHealth interventions is already common within the field of research on person-centered perinatal eHealth (Original publication I). The most common outcomes of study within the experimental designs were patient satisfaction, and healthcare utilization. In fact, if different 'good care' and 'bad care' exist in the enactment of person-centered perinatal eHealth services then a value judgement is called for. The scientific inquiry and interpretations of this PhD study are therefore, intended for pragmatic use toward an understanding of how many actors (material and social) work together in a playing field or an emergence of sorts for personalized, quality, and appropriate person-centered perinatal eHealth services. The work of this PhD study is positioned to aid in the everyday work of eHealth designers, eHealth practitioners, participants, and stakeholders in their constant 'tinkering', adjustment, and co-creation of the meaningful use of services toward 'better' care and personal health and developmental outcomes, with the continued goal of improving services.

**Table 2.** Materials and methods PHASE I.

| Design and Research Question | Setting | Sample | Data collection method | Analysis |
|---|---|---|---|---|
| **DESCRIPTION OF NATURE AND RANGE OF PERINATAL EHEALTH (PHASE I)** | | | | |
| **Scoping review**<br>**(ORIGINAL PUBLICATION I)**<br>*What is the nature and range of perinatal eHealth as a structure of health care delivery characterized by the integration of patient engagement?* | Existing literature on five databases (Web of Science, Scopus, Pubmed, Eric, and CINAHL) | 80 primary sources | Systematic literature search using keywords and MeSH terms in five relevant databases | Narrative synthesis was conducted utilizing a deductive qualitative content analysis and matrix containing four attributes of patient engagement and digital health strategy categories defined by the World Health Organization |

**Table 3.** Materials and methods PHASE II.

| **EXPLORATION OF ENGAGEMENT PRACTICES WHEN USING AN ANTINATAL SELF-MONITORING EHEALTH SYSTEM FOR SLEEP AND STRESS (PHASE II)** | | | | |
|---|---|---|---|---|
| **Feasibility Study (ORIGINAL PUBLICATIONS II & III)** | One Finnish Antenatal Clinic | 20 healthy pregnant women | | |
| *Were there any associations between pregnant persons' behavioral engagement and changes in sleep duration, and quality and levels of stress after they used the self-monitoring eHealth system?* | | | Quantitative data collection using smart wearable device | Black week analysis (t-test)<br>Kernel Density Estimate (KDE) Test<br>Mixed Linear effect models |
| *What are the characteristics of the process of use after pregnant users receive access to a self-monitoring eHealth system?* | | | Quantitative data collection using smart wearable device<br>&<br>Qualitative interviews with women | Mixed Method Convergent Evaluation study from a socio-materiality perspective |

**Table 4.** Materials and methods PHASE III.

| **DEVELOPMENT AND PSYCHOMETRIC TESTING OF A MEASURE FOR PARENTAL PARTICIPATION AND COLLABORATION IN THE NICU (PHASE III)** | | | | |
|---|---|---|---|---|
| **Development and psychometric test (ORIGINAL PUBLICATION IV)** | Two Dutch NICUs | 306 parents of infants who experienced a NICU hospitalization | Item Generation | Public and Patient Involvement approach |
| *Does the co-partner measure allow for examination of processes of collaboration and participation in the context of parent-partnered care models?* | | | Structural Validity Testing | Confirmatory Factor Analysis<br>Internal Consistency |
| | | | Construct Validity Testing | Construct validity Distinctiveness Hypothesis Testing |

**Table 5.** Materials and methods PHASE IV.

| **INTERPRETIVE SYNTHESIS OF CURRENT EVIDENCE ON THE DEVELOPMENT AND QUALITY ASSURANCE OF PERINATAL EHEALTH (PHASE IV)** | | | | |
|---|---|---|---|---|
| **Interpretive Synthesis**<br>*What are the steps for a model of patient engagement integration in perinatal eHealth development and quality assurance?* | Purposeful literature search conducted for purposes of theoretical sampling | 86 primary sources | | Qualitative meta synthesis using grounded theory |

## 4.1 Study designs, settings, samples, and data collection

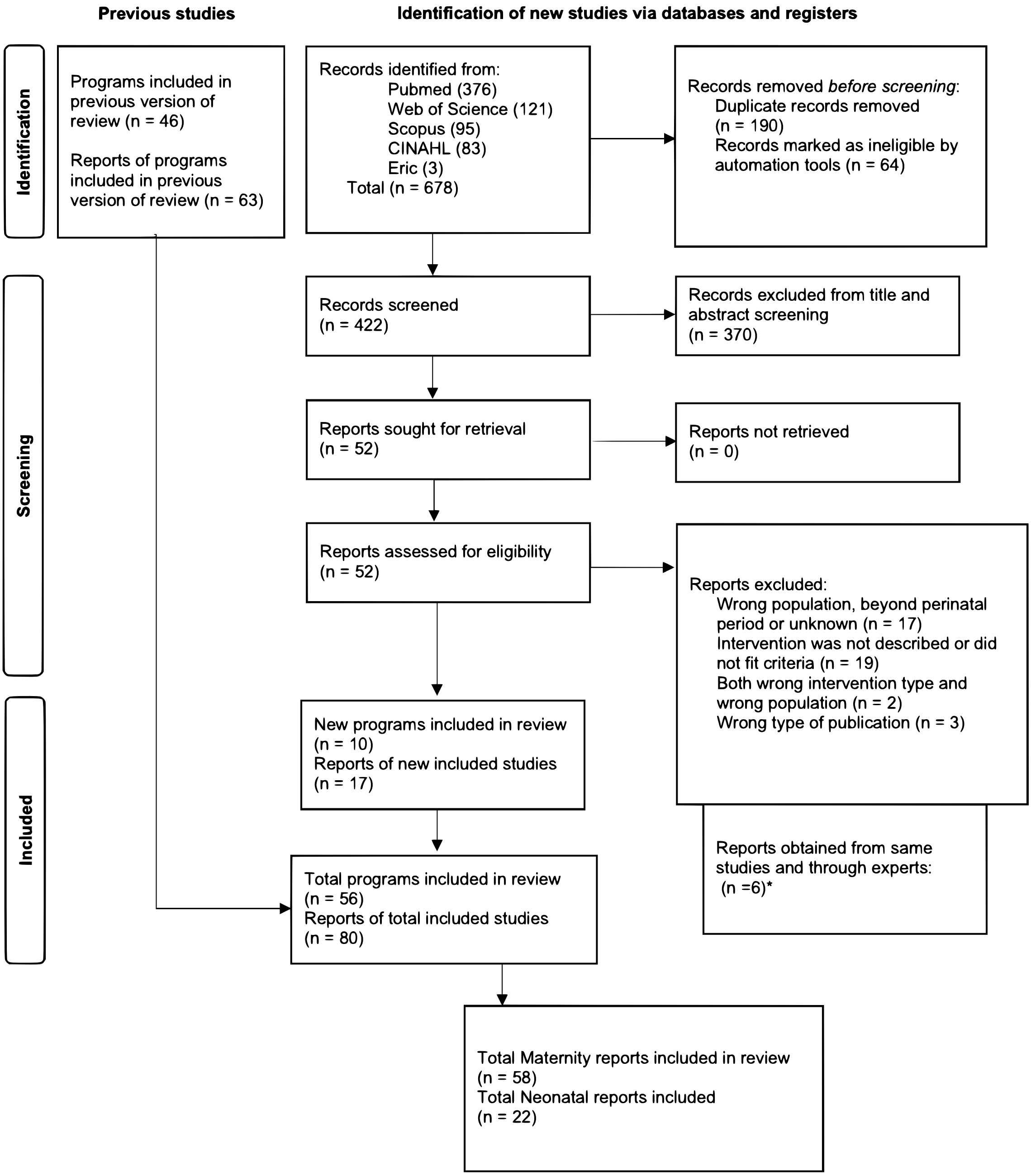
This study consisted of four phases and culminated at the final phase with an interpretive synthesis of multiple empirical studies and data sources. All study descriptions that follow are based on the study aims and research questions (Tables 2-5).

### 4.1.1 Phase I/ Original Publication I

A scoping review was suited in the case of examining perinatal eHealth practices where there was not an extensive review of the topic (Tricco et al., 2018). A systematic approach was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - extension for scoping reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). Due to the complexity of examining both maternity and neonatal sources in the context of perinatal eHealth an iterative process for data charting was used during the analysis, and synthesis phases of the study (Daudt et al., 2013). Five electronic databases (Web of Science, Scopus, Pubmed, Eric, and CINAHL) were searched on January 29, 2020, and updated the search in April 2022. An expansive list of search terms was used to incorporate perinatal care, patient engagement, as defined by Higgins and colleagues (2017) and eHealth systems and devices involved in person-centered digital interventions as described by the World Health Organization (WHO)(World Health Organization, 2018).

Studies were included that reported the design, development, and/or testing of perinatal eHealth offered to participants/target users who were pregnant persons and/or partners who had received service during pregnancy, 6 weeks after birth, and in the case of neonatal care, up to the time that the infant was 44 weeks postmenstrual age. Services would contain at least one of the four WHO patient-centered digital health intervention categories: (1) Target client communication; (2) Client to client communication; (3) Personal health tracking; and (4) On-demand Information services to health users (World Health Organization, 2018).

Data containing descriptive characteristics were extracted by two researchers (JA, & HRH). Initial descriptive data included the following categories: (1) Author, year, and country of publication, (2) Study design, (3) Aim of research, (4) Target population, (5) Setting (low- or high-risk), (6) Digital services and devices used, and (7) Patient engagement attributes. The total number of records identified through database searches, hand search of bibliographies and expert recommendation was 1555. After screening and eligibility assessments were completed 80 primary sources were included (58 maternity sources and 22 neonatal sources). See Figure 4.



* Doherty et al., 2019, Spargo et al., 2018, Triebwasser et al., 2020, & Xue Chen Ke et al., 2019 were included because they were older reports adding information about included programs. Fontein-Kuipers et al., 2016 & Franck et al., 2019 were included due to finding these studies through experts in the field.

**Figure 4.** PRISMA Flowchart of source inclusion (Adapted from Original Publication I of this study).

### 4.1.2 Phase II/ Original Publications II and III

A descriptive comparative pilot study was conducted with twenty pregnant women to examine associations between level of behavioral engagement (non-wear time), physical activity, sleep and stress metrics and patterns of eHealth use according to level of engagement. A descriptive comparative pilot was suited for the investigation of implementation and demand for using a smart-ring (worn on the finger) self-monitoring technology in a Finnish antenatal clinic (Bowen et al., 2009). A mixed methods approach was ideal for increasing understanding of both subjective and objective measures of behavioral engagement (Original publication II) and the process of women accessing perinatal eHealth system (Original publication III).

Eligible participants were pregnant persons in their first and second trimesters and were sampled using convenience sampling according to their receival of care in one antenatal clinic. Inclusion criteria consisted of pregnant persons being 18 years or older, having access to a smartphone (Android or iOS) and having good literacy in Finnish and English languages. Women were recruited during late first trimester of pregnancy or mid second trimester to allow for a nurse visit schedule to include two or more visits prior to the end of pregnancy.

During the pilot testing women wore the smart-ring and viewed their data on the ŌURA App for on average for 9.5 weeks. Women could not access the mobile App until they first connected the device to the ŌURA App (supplied by the nurse research assistant) one week after beginning their participation in the study (the first week of use is described here on as the black-out week). After this period women recorded sleep, physical activity, night-time heart rate, and heart rate variability each day as desired. Women received coaching from public health nurses and study nurse researchers when they had questions and if there were technical challenges with the battery or the Bluetooth connection. The nurse research assistant and computer engineer team supported trouble shooting for optimal use of wearable device and the ŌURA App.

Women were able to wear the smart ring on their fingers to monitor physical activity, sleep and stress metrics using a four layer Internet of Things (IoT) data collection and storage system (Sarhaddi et al., 2021). The ŌURA smart ring uses three-dimensional accelerometer, gyroscope and biomarker signals including Photoplethysmogram (PPG) and Electrocardiogram (ECG) and Bluetooth technology syncing between the wearable and ŌURA App. Six public health nurses were enrolled in the study and received the smart-rings and use of the ŌURA App at the start of the study to familiarize themselves with the use of the ŌURA self-monitoring technology. ŌURA smart ring version 2.0 was used in the pilot study. The smart-ring device has been tested and validated for the monitoring of sleep and stress outcomes including, total sleep time (TST), wake after sleep onset (WASO); and sleep onset latency (SOL).(Asgari Mehrabadi et al., 2020; Cao et al., 2021). Women who consented to take part in the study received the wearable device upon entering the study and access to the mobile App after one week of using the wearable device only (the first week of use is described here on as the black week). During the black week women were asked to wear the smart ring without viewing data and did not have access to their data during this period. Women could not access the mobile App until they first connected the device to a smartphone and App (supplied by the nurse research assistant) one week after beginning their participation in the study. After this period women would record sleep, physical activity, nighttime heart rate, and heart rate variability each day as desired.

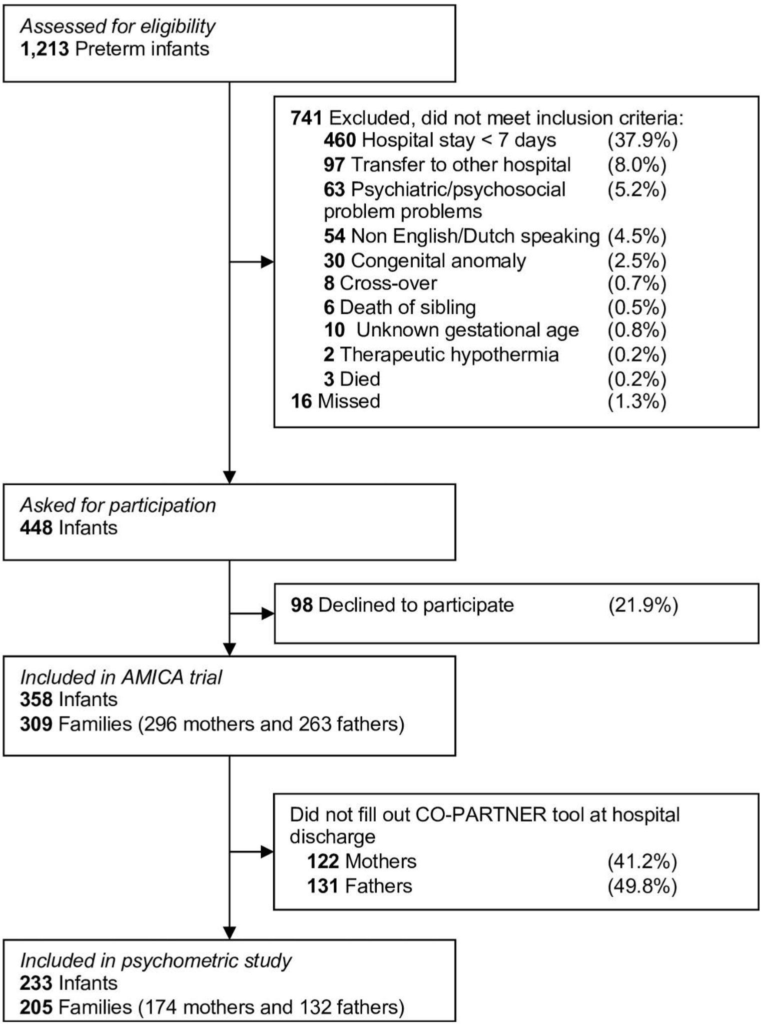
Women could wear the ring at night to record, TST, WASO, SOL, and length of time spent inside each sleep stage. At the time of this pilot recording of heart rate, heart rate variability (i.e., Root Mean Square of Successive Differences RMSSD), temperature, and respiration rate were only possible at nighttime. Women completed demographic, and health parameter survey data at baseline of the study period. A study team member met each of the pregnant women after their pilot period to have semi-structured interviews with individual women in a location of their choosing, the interviews lasted between 30-90 minutes. An interview guide was generated by three study team members, one for pregnant women based on the definitions of patient engagement (Higgins et al., 2017). Interviews were audio recorded and transcribed verbatim and raw audio and document files were digitized and stored in a secured server that were password protected. Transcribed documents were cleaned of identifying features and used for analysis by three study members who accessed the password protected files.

### 4.1.3 Phase III/ Original Publication IV

The study was aimed at developing and psychometrically testing an evaluation tool for assessing parent participation and collaboration in neonatal care. Systematic item generation was achieved through a patient and public involvement (PPI) approach (Hayes et al., 2012). The concept of parent participation and collaboration in the context of NICU was adapted from a proposed definition by Power and Franck (2008) “The activities performed by a parent/guardian for their infant in the hospital set- ting in which they share, take part, or independently act in the care of their infant across the entire hospital episode. Activities are defined as physical, psychological, or social performed by parents to improve the health and/or psychological well-being of their infant, with or without collaboration with healthcare professionals.” The measure was developed as a formative measure.

The developer of a similar tool, The Index of Parent Participation (IPP) of a hospitalized child consulted our research team on identification of applicable items from this original tool for NICU contexts (Melnyk, 1994). Items were then extracted by two researchers independently and blind from one another to make final decisions of which items to keep from the IPP tool (26 from original 36 were included). Focus groups and one-to-one interviews were then conducted with healthcare professionals and veteran parents to decide on item inclusion and scoring structure of the new tool. The final inclusion of items before psychometric testing was 34.

The response sample for the psychometric test were collected with parents of infants who participated in the larger AMICA study, and prospective non-randomized study evaluating the effect of a family integrated care model (FIcare) in a level 2 NICU in the Netherlands. Questionnaires were sent using Castor Electronic Data Capturing at admission and discharge from the level 2 NICU. In the case of families with multiple births, parents received one questionnaire per time point. Parents received two reminders if they did not fill out the questionnaire one and two weeks after the initial questionnaire was sent. All parents completed a survey package that included the CO-PARTNER items, surveys on perceived stress in the NICU (PSS-NICU), depression and anxiety (HADS), parent-self-efficacy (PMP-SE), satisfaction and empowerment (subscale on parent participation, EMPATHIC-N) and impaired parent bonding (PBQ) (See Appendix 1). Item responses from 306 parents (174 mothers and 132 partners) completed at discharge were included in the psychometric analysis (See Figure 5).



van Veenendaal, N. R., Auxier, J. N., van der Schoor, S. R., Franck, L. S., Stelwagen, M. A., De Groof, F., ... & van Kempen, A. A. (2021). Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. *Plos one*, *16*(6),e0252074. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0252074

**Figure 5.** Flow-chart of inclusion of parent sample for psychometric analysis.

### 4.1.4 Phase IV: Interpretive Synthesis

Empirical reports (purposeful sampling of literature) were combined through deductive reasoning, supported by the concept definition, and associated attributes of patient engagement, Donabedian’s framework for quality assurance, and an adapted version of the Action Research Cycle (Oberschmidt et al., 2022; Williamson et al., 2011). Interpretive synthesis through content analysis was used for a description of steps for patient engagement integration in perinatal eHealth development and qualitive assurance in the form of a model (Strauss & Corbin, 2007; Thorne et al., 2004).

Data collection was iterative and was based on the findings and interpretations gained from the first three phases of this PhD study. A progressive interpretation of the Donabedian quality assurance model, an adapted version of the Action Research Cycle (Oberschmidt et al., 2022; Williamson et al., 2011) guided data analysis. Further, existing conceptual frameworks of patient engagement, woman and family-centered care, and methodological approaches associated with interpretive synthesis supported the synthesis (Donabedian, 2002; Higgins et al., 2017; Thorne et al., 2004). The first phase of data collection included obtaining original research in the form of peer reviewed articles, and conference reports sampled through a systematic search in January 2020 (Updated in April 2022). The second phase of data collection included hand searches of bibliographies of included studies and instances of google scholar searches based on expert consultation for sources that were not identified in the original search. The original findings of sub-study I (Scoping Review) showed that little had been reported in the field about therapeutic alliance and process evaluation, two important areas of discovery. Sources in phase two were selected because they reported on therapeutic alliance and process evaluation related to person-centered perinatal services. See Table 6 for the description of source sampling.

**Table 6.** Description of source sampling for Interpretive Synthesis.

| Sampling Rationale | Number of Sources |
|---|---|
| Scoping Review (Original Publication I) | N=80 |
| Purposive Search to include more information about Therapeutic Alliance: Targeted Google search and consultation with experts | N=2<br>(Niela-Vilén et al., 2016)<br>(Wu et al., 2019; Wu et al., 2020) |
| Purposive Search to include more information about Evaluation approaches in person-centered Perinatal eHealth systems | N=3<br>(van Veenendaal et al., 2021)*<br>(Auxier et al., 2022)**<br>(Auxier et al., 2023b)** |
| Total sources | N=86 |
| Sources relevant for construction of step 1 | N=85*** |
| Sources relevant for construction of step 2 | N=86 |
| Sources relevant for construction of step 3 | N=85*** |

*Original Publication IV of this PhD study; **Original Publications II & III of this PhD study; ***Van Veenendaal et al., 2021 was not relevant for construction of the first and third steps of the model

## 4.2 Data Analysis

### 4.2.1 Phase I/ Original Publication I

A deductive content analysis was performed to examine the practices of patient engagement and features of person-centered perinatal eHealth (Kyngäs et al., 2020). Primary sources were organized according to maternity and neonatal domains; types of treatments being provided and digital devices and services in use (Petticrew & Roberts, 2006). Meaning units were identified based on a matrix of deductive concepts consisting of definitions for access, personalization, commitment, and therapeutic alliance (Graneheim & Lundman, 2004; Higgins et al., 2017). The matrix also consisted of the four WHO patient-centered digital health intervention categories and perinatal treatments that arose inductively after review of included studies (Kyngäs et al., 2020; Petticrew & Roberts, 2006; World Health Organization, 2018). Codes were developed from condensed meaning units from both maternity and neonatal services separately (Graneheim & Lundman, 2004). Subcategories were developed from harmonization of codes, some codes in maternity and neonatal services overlapped and some remained separate (Graneheim & Lundman, 2004). Finally, the latent content of the categories was formulated into two main themes (Graneheim & Lundman, 2004). A narrative synthesis was used to report findings from this scoping review.

### 4.2.2 Phase II/ Original Publication II and III

Statistical analysis was performed to obtain findings about whether the physical access and use of a self-monitoring eHealth system would impact women's sleep behaviors and sleep quality and stress outcomes.

After pre-processing of data and descriptive statistics were performed. ŌURA technology provides daily data summary for activity and sleep parameters in a structured format. Python 3.8 was used to parse these files and extract parameters of relevance to our research group. The ŌURA company reports all the sleep events, therefore we labelled the events happening during the night-time and focused only on night sleeping. In addition, the black-out week was labelled for each subject individually. Descriptive statistics (means, ranges, and distribution of values) of participant demographic and survey totals were completed using R for statistical analyses, version 3.6.1.

For the analysis of pre and post black-out week parameter changes we used a two-sided t-test. To cluster the participants into high and low engagement groups we extracted non-wear time percentage/day of the ring and looked at the normalized distributions for use in a Kernel Density Estimate (KDE) test to stratify the participants into two groups. Linear mixed effect model (LMEM) analyses were conducted to analysis between-subject, within-subject, and overall trends for specific sleep and stress parameter data. See Table 7 for list of variables collected.

**Table 7.** Sleep and Stress Parameters.

| **Variable** | **Definition** |
|---|---|
| Non-Wear Time | "A record is kept through the PPG signal detection of the smart ring indicating when the ring is being worn. Total minutes of non-wear time per day was recorded by the device and uploaded to the cloud storage through Bluetooth connection." (Auxier et al., 2022) |
| Sleep behavior (time to bed) | In this study the time that individual started sleep each night |
| Sleep Duration | "Total sleep time (TST) is a measure of duration of total sleep during the night."<br>(Auxier et al, 2022) |
| Sleep Quality | "Sleep quality was measured in our study using sleep onset latency (SOL), waking after sleep onset (WASO), and sleep efficiency." (Auxier et al., 2022) |
| Levels of Stress | "The root mean square of successive differences (RMSSD) reflects the variance in heart rate beat-to-beat and is a primary time-domain measure for estimating the vagally mediated changes reflected in heart rate variability. Lower values of RMSSD are indicative of increased impact on the para-sympathetic nervous system as a response to physiological stress exposure." (Auxier et al., 2022) |

Auxier et al., 2021 In-Pr is Original Publication II of this PhD study, see publication for references of terms used.

A mixed methods analysis was conducted using multiple methodological strategies. The interview frame was generated by three study team members for pregnant women. Deductive work was first completed with all participants' data together by nursing research assistant using the definition and attributes of Patient Engagement as defined by Higgins et al., 2017. At this point the data was split and analyzed separately using the KDE results. Data were extracted to include meaning units covering the topic of access to the self-monitoring technology only due to the central research aim of understanding the adaptation process that occurs after women received access to the digital service. Two researchers (JA and KS) reviewed meaning units independently to confirm all topics related to access were included, any disagreements were brought to a third researcher (AA), expert in qualitative research methodologies and primary investigator. Original excerpts from the interviews related to access were extracted, divided according to user group, and translated from Finnish to English by a nursing research assistant. Meaning units were interpreted into codes, and codes were clustered under sub-categories, and sub-categories were developed into main categories (Graneheim & Lundman, 2004). A final conceptual matrix was constructed using the model of socio-material semiotics after deductive and inductive development of codes and categories revealed a fit between main categories and a socio-material perspective on co-creation by users and the eHealth system (Orlikowski & Scott, 2008b; Oudshoorn, 2011; Tavory & Timmermans, 2014).

### 4.2.3 Phase III/ Original Publication IV

Psychometric testing was conducted on item responses from the 306 parents at discharge to the NICU receiving either FIcare approach or standard NICU care. Structural validity with confirmatory factor analysis (CFA), construct validity, using the Average Variance Extracted and Heterotrait-Monotrait ratio of correlations, and hypothesis testing with correlations and univariate linear regression were performed. Internal consistency was assessed with composite reliability. Data were pre-processed and missing data was managed with multiple imputations by chained equations. All statistical analysis was performed using R for statistical analysis version 3.6.1.

### 4.2.4 Phase IV/Interpretive Synthesis

Data sources were purposively chosen at the beginning of the study to ensure the inclusion of information sources that related to the current state of person-centered perinatal eHealth development and evaluation, and included more data related to therapeutic alliance and process evaluation. All studies included in phase I of this study (original publication I) were included in the sampling for phase IV. Data extraction was conducted using a deductive grounded theory approach guided by a concept matrix that had been developed through conceptual insights gained from phases I through III of this study, the Donabedian quality assurance model, and an adapted version of Lewin's Research Action Cycle (See Figure 6) (Donabedian, 2002; Oberschmidt et al., 2022). The concept matrix consisted of the definition and attributes of patient engagement (Higgins et al., 2017), taxonomy of eHealth modalities (Auxier et al., 2023a), the three principles from Donabedian's quality care evaluation model (Donabedian, 2002) and lastly the adapted version of the Action Research Cycle (Oberschmidt et al., 2022; Williamson et al., 2011). Data was charted according to study design, author, year, design development procedures (if applicable) and the identified structure, process, and outcomes of each eHealth system. The data were synthesized through an abductive phase where linkages were mapped and placed in three newly constructed recommendations referred to from here on as the steps that depict the model (Tavory & Timmermans, 2014; Thorne et al., 2004). Step 1 is comprised of a mapping of structure components of all included primary sources as they relate to the four attributes of patient engagement. Phase I of the PhD study was the source of evidence to construct step 1 (See Figure 6). Step 2 was developed through use of the available literature and the CO-Partner tool (See Phase III). The aim of the constructed vignette was to trigger discussions among important stakeholders about how best to plan process evaluation for the carrying out of person-centered perinatal eHealth services. The probable case of hospital/community in City Z was developed using evidence gathered in Phase I and Phase III (See Figure 6) and all stakeholders were included based on available evidence and expert knowledge of participatory action research methods. Step 3 was comprised of the evidence from Phase II of this PhD study (See Figure 6).

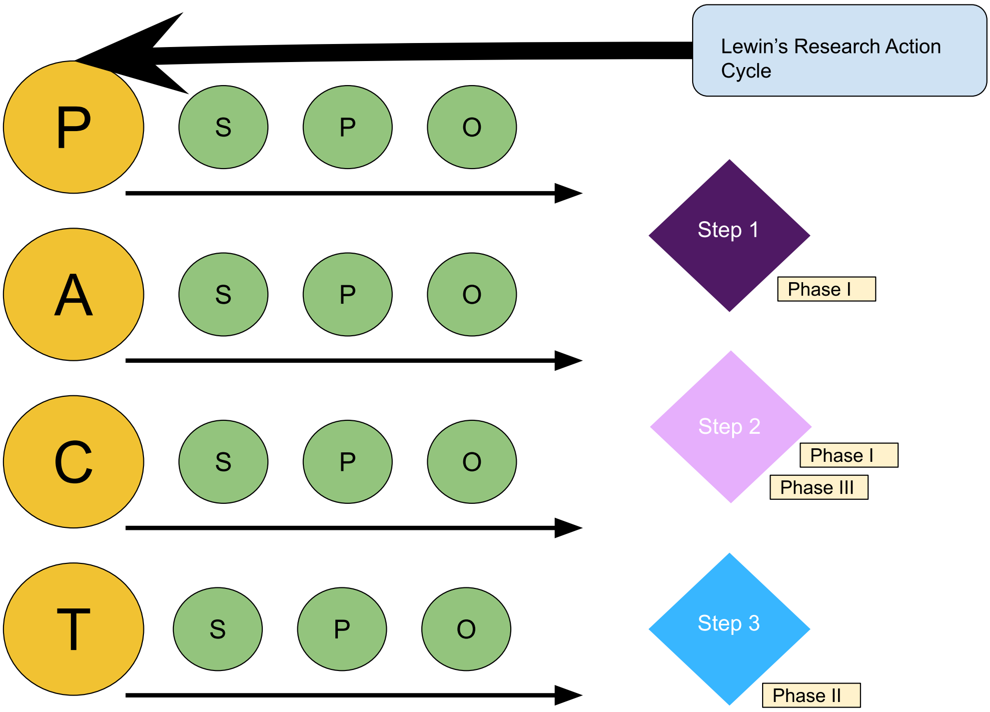


**Figure 6.** Conceptual Matrix for grounded theory of Phase IV. PACT=The four attributes of patient engagement (Higgins et al., 2017); SPO=Structure, Process, Outcome (Donabedian, 2002); Phase=Phase of PhD study.

## 4.3 Ethical Considerations

This study was conducted as a part of two larger studies. A multicenter non-randomized prospective study, the fAMily Integrated CAre in the neonatal ward (AMICA) study, was conducted in The Netherlands and examined the effects of the FICare service on infants and parents receiving care in the NICU. The AMICA study took place from May 2017 until January 2020 and received ethical approval from the medical research ethics committees united (MEC-U) in Nieuwegein, The Netherlands on December 23rd, 2016 (Trial Registry NL6175). Participants of the AMICA study gave informed consent and contributed to the development of the CO-PARTNER tool through a patient and public involvement approach upholding ethical concepts of dignity, respect, and inclusion (van Veenendaal et al., 2021). The second study was an exploratory feasibility study evaluating implementation and useability of an antenatal self-monitoring eHealth system for pregnant patients in Southwest Finland. Ethical approval was received by the Ethics Committee of the Hospital District of Southwest Finland in the winter of 2020. The study was conducted between March 2020 until August 2020.

Parents and multidisciplinary professionals who participated in the AMICA study had the opportunity to share their experiences and concerns with regards to current healthcare professional practices of parental coaching toward caring for a sick infant. A patient and public involvement (PPI) approach was used to support the inclusion of patient and veteran parent voices in a tool that would be used to support their experiences of receiving coaching and support during an admission of their newborns into the NICU.

Public Health Nurses (PHN) and pregnant persons provided informed consent prior to participation in the study and were notified that at any time they may exit the study with no negative consequences to their receival of antenatal care/job security. No paid incentives were used during the recruitment process or at any point in the study activities. The possible crowding out effect was considered as one reason for not including financial incentives, as our work is only possible with women or pregnant persons (Mellström & Johannesson, 2008; Zutlevics, 2016). We worked to balance the burden and benefit of participating in the study by offering participants free trial use of the technology during the study period. All digital information collected from participants using the self-monitoring technology was done so using pseudonym email addresses. Participants in the exploratory feasibility study were asked to participate as partners in research. PHN and pregnant persons were encouraged to use the eHealth devices as much or as little as they wished after the black-out week. In this way the participants were able to act in accordance with their rights for dignity, as they were seen as experts in their own experience and preferences in using the eHealth system.

The procedures described in the two larger studies throughout this report were carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The precepts of PPI were implemented for the conduction of transparent, and democratic research procedures (Hayes et al., 2012; Staniszewska, 2009). Involving end-users in the development and exploration of person-centered perinatal eHealth systems was critical in the ethical conduction of the two research studies.

# 5 Results

This chapter gives a summary of all results from the four phases of this study. According to the descriptive generative nature of the fourth phase of this study these research findings will be given as sub-parts of a generative whole, to address patient engagement core components that support development and quality assurance of person-centered perinatal eHealth. A model for patient engagement integration in perinatal eHealth development and quality assurance is described based on findings from a description of current patient engagement practices (Personalization, Access, Commitment, and Therapeutic Alliance) within person-centered perinatal eHealth of relevant literature (Phase I), findings related to patient engagement processes from a feasibility study in which women piloted an eHealth antenatal self-monitoring eHealth system (Commitment, Access and Personalization) (Phase II), and one example of a valid evaluation tool (CO-PARTNER) aimed at examining two processes related to patient engagement (Commitment and Therapeutic alliance) (Phase III). The final phase (Phase IV) of this study was the conduction of an Interpretive Synthesis for the identification and description of a model for the integration of patient engagement in perinatal eHealth development and quality assurance. The model consists of three steps that support the integration of patient engagement in person-centered perinatal eHealth development and quality evaluation.

## 5.1 Study Phase I-Original Publication I: The nature and range of Perinatal eHealth

According to Donabedian's model for quality evaluation structure and processes within healthcare settings make up important elements of healthcare quality (Donabedian, 2002). Examining the quality of healthcare within a given setting requires that researchers and clinicians gain a clear understanding of the structure and process components of the healthcare programs/services. Examining the structure and processes within person-centered perinatal eHealth was completed through the identification of the nature and range of person-centered perinatal eHealth. In what follows the findings of phase one of this study are presented.

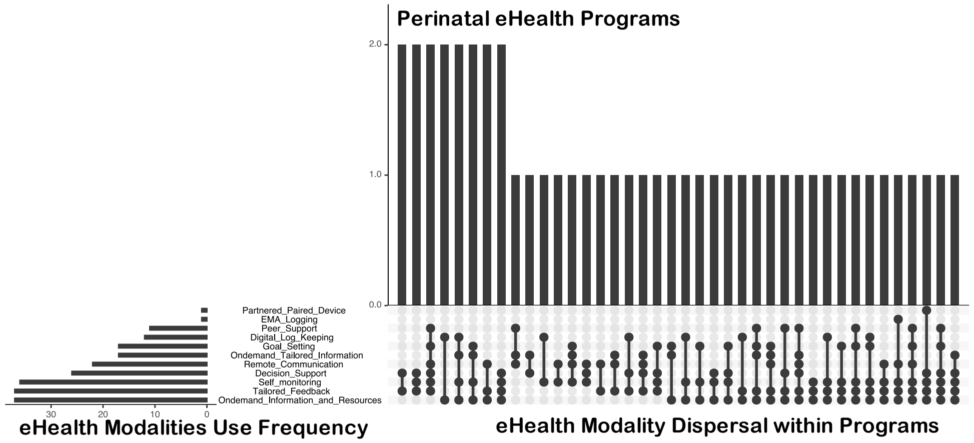


**Figure 7.** Current Dispersal of Perinatal eHealth Strategies in High- and Middle-Income Countries- Modified from Original Publication I.

A new structure of person-centered perinatal care has emerged using eHealth. Perinatal eHealth is a structure of care and practice that has the potential to re-shape perceptions of person-centered perinatal care and to bring a higher degree of holistic and personalized care into perinatal systems in middle- and high-income countries. The structure of care and practice is developing dynamically in the developed world, contains complexity in many areas of perinatal service delivery and is moving the boundaries of perinatal care beyond the historical tradition of institutions and clinical gatekeepers. The receival of perinatal eHealth services is being increasingly expected by new and expectant parents as the next generations of childbearing families are of an age of ubiquitous smartphone and electronic device use. eHealth modalities such as personal health tracking, on-demand evidenced based, tailored health information and real time health care feedback bring two previously separated localities for perinatal care practice into the same cohesive location of practice, in the home of health care users. Further, the way in which eHealth modalities are being offered is not uniform, illustrating the flexible use of eHealth. From this review it was found that 12 different eHealth modalities were in use (See Figure 7). The eHealth modalities and their definitions can be found in Appendix 3.

Fifty-six eHealth systems were described in this review, and 12 eHealth modalities were seen to be in current use across the systems. The use of eHealth modalities ranges from rarely used (n=1) modality of serious gaming, to tailored feedback being incorporated into 76.8 % (n=43) of all programs. Of the programs included in this review 30 out of the 56 are unique in the combination of eHealth modalities they offer (See Figure 7). Patient engagement practices are represented within the programs with, access and personalization being integrated into all programs, and commitment and therapeutic alliance being absent from 3 and 8 programs respectively. Further, only 53.6% (n=30) of the perinatal programs described in this review included nurses in the provision of care, program development, or research activities. All neonatal programs included nurses in provision of eHealth, and only 38.1% (n=16) of maternity programs included nurses in provision of eHealth. Fifteen percent of studies were published in nursing journals (Scimago Lab, 2021).

This is the first review to bring together perinatal eHealth programs, treatments, and modalities, with the aim of describing the range of practices for a conceptualization of the nature of person-centered perinatal eHealth. A critique of perinatal eHealth practice has been that it continues to separate maternity and neonatal programs, while some perinatal eHealth users are requesting to have more harmonized programs (Danbjørg et al., 2015). Findings from this review reveal that person-centered and patient engagement practices are being used within the current perinatal eHealth structure, however development and design of these programs lack harmonization between maternity and neonatal care, and consistency of integration of commitment and therapeutic alliance is lacking.

## 5.2 Study Phase Two-Original Publication II: Behavioral engagement group comparison for sleep and stress outcomes and behaviors

The findings from the scoping review (Phase I) informed that commitment as an attribute of patient engagement was not consistently applied within the structure and processes of person-centered perinatal eHealth. Commitment was represented most in programs described in the scoping review as behavioral commitment in the form of adherence to eHealth program use. In phase two of our study, first the characteristics of commitment were examined. Commitment was described as adherence to eHealth system use (behavioral commitment) with a descriptive comparative study involving pregnant users of a self-monitoring eHealth system.

During the development phase of an antenatal self-monitoring eHealth system our research team explored the usefulness of operationalizing commitment as the concept of behavioral engagement over time. Behavioral engagement was captured through examining use before and after having access to personal on-demand data of daily wellness patterns and through the physical wear-time of the self-monitoring smart ring (worn on the finger) device.

Previous research has been conducted to understand the adherence to behavior change interventions. Adherence as a concept must be based on an expected intended use for effect, in the context of using the eHealth self-monitoring system founded on ŌURA technology researchers in our team suggested that daily use and viewing of personal data would produce a significant change in health behaviors over the course of the study. Building on the conception that the more antenatal eHealth users engage in building self-awareness, setting their own wellness goals, and making choices toward health behaviors the more positive changes would be seen in their sleep and stress health outcomes. In what follows the findings of this stepwise investigation of behavioral commitment as one measure of patient engagement.

Twenty pregnant participants participated in the study and the group of participants were arranged according to their level of engagement. See demographic data in Table 8.

**Table 8.** Characteristics of pregnant participants according to engagement group

| | **High engagement (N=14)** | **Low engagement (N=6)** |
|---|---|---|
| Age mean (SD) | 32(2.42) | 29(3.01) |
| Average Pregnancy weeks (Baseline) | 15+4 | 15+3 |
| Able to wear device at work %(n) | 92.85(13) | 16.66(1) |
| Employed % (n) | 85.7 (12) | 100.0 (6) |
| BMI | 24.95<br>(17.43–31.64) | 26.48<br>(20.96–39.84) |
| Medical Condition* %(n) | 28.6 (4) | 50.0(3) |
| Number of children | 1 child=6<br>2 children=3<br>No children=5 | 1 child=2<br>2 children=1<br>No children=3 |
| Planned pregnancy %(n) | 85.7(12) | 100.0(6) |
| Frequency of Other App use in daily life | Daily=8<br>Weekly=5<br>Monthly=1<br>Rarely=0 | Daily=3<br>Weekly=2<br>Monthly=0<br>Rarely=1 |

### 5.2.1 Behavioral changes and health outcomes measured with t-test analysis pre and post access to smart ring application

There was no significant change in the average time to start of sleep between the black-out week recording and the rest of the study period (P=0.66). Black-out week average time to start of sleep was 23:05:24 and post black-out week the average time to start sleep was 23:12:25 (See Figure 6). Indicating that after providing women with the option of real-time viewing of personal sleep and stress data there was no difference in their behaviors related to time to start of sleep. Sleep and stress outcomes averages during the black-out week were not significantly different from the averages seen after the black-out week for all women in the study (See Figure 7 and Table 9).

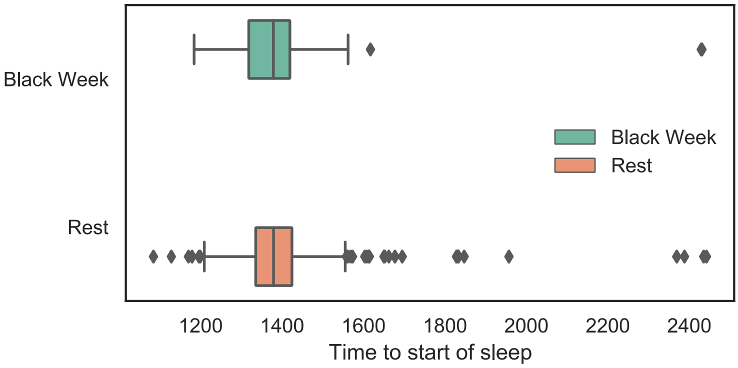


**Figure 8.** T-test of time to start of sleep boxplot (n=20; P=0.66).

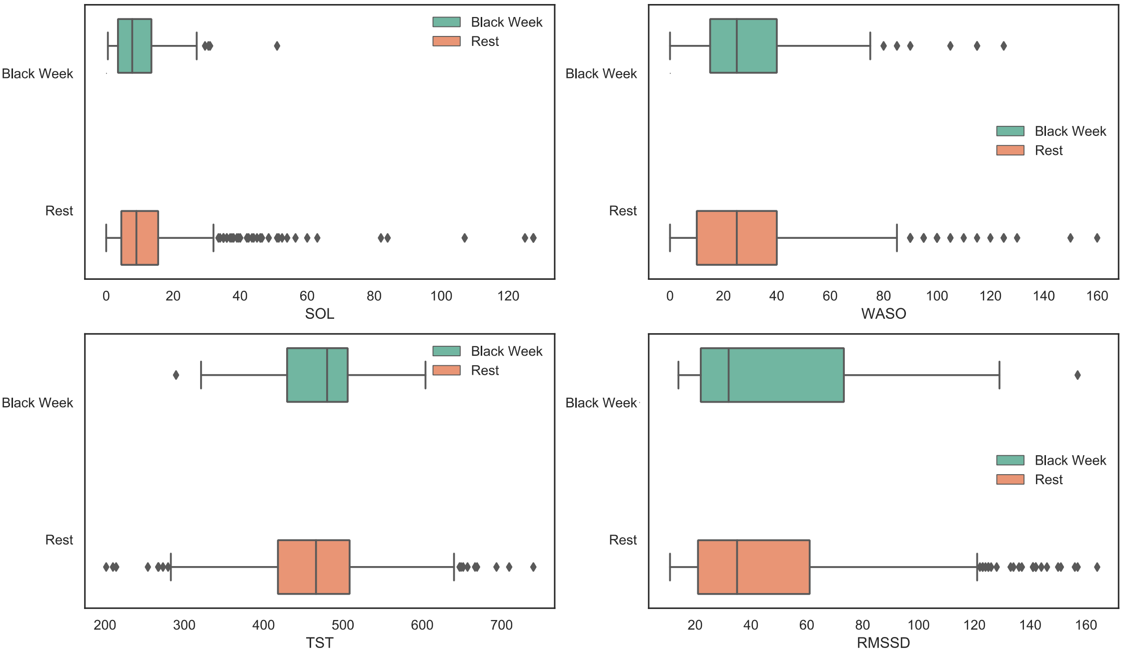


**Figure 9.** T-test of sleep and stress outcomes (n=20).

**Table 9.** T-test results for sleep and stress outcomes (n=20).

| Sleep and Stress outcomes | T-test: Average (P values) |
|---|---|
| SOL | t=-1.92; P=.054 |
| WASO | t=0.64; P=0.51 |
| TST | t=1.22; P=0.21 |
| RMSSD | t=1.37; P=0.16 |

SOL=Sleep onset latency; WASO=waking after sleep onset; TST=Total sleep time; RMSSD=Root mean square of successive differences

### 5.2.2 Engagement measured by wear time: Kernel Density Estimate (KDE) Analysis

After our findings revealed no changes over time pre and post black-out week we investigated the relationship between level of use over time with sleep duration/quality and levels of stress over time. Women were spilt into high and low engagement groups by clustering subjects with a normalized non-wear time less than 20% as high engagement group (n=14; 70%) and the rest as low engagement group (See Figure 8).

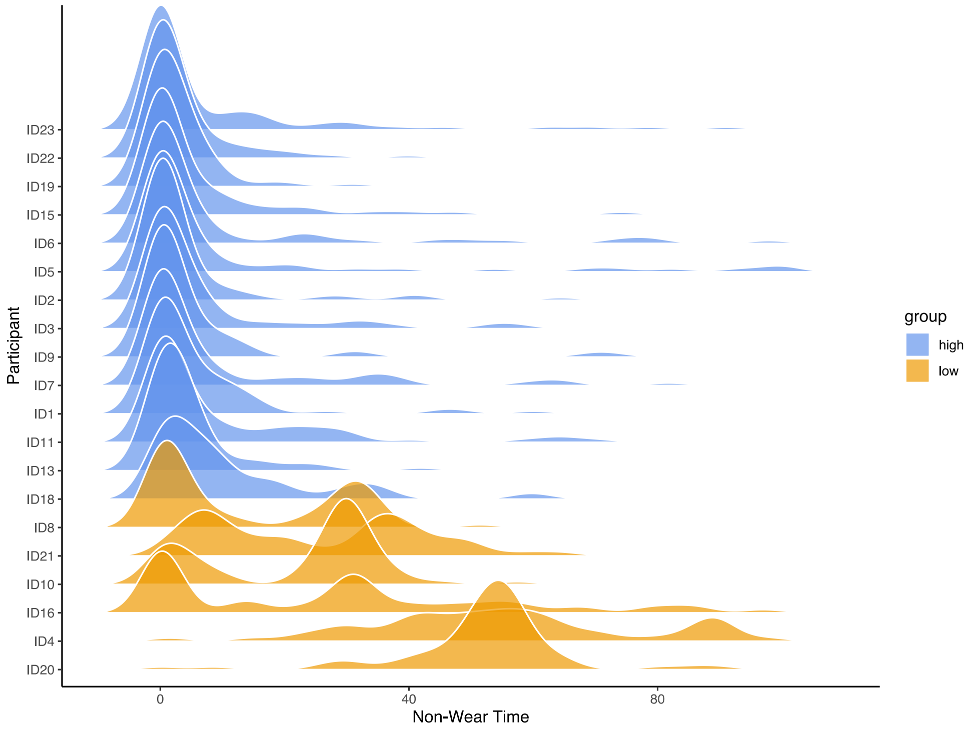


**Figure 10.** Distributions of Mean User Non-wear time (Original Publication II).

### 5.2.3 Sleep duration/quality and levels of stress over time according to engagement group: Linear mixed effect models

Total sleep time (TST) intercepts were 475.54 (P<.001; CI: 463.22-487.86) minutes (7.93 hours) per night in the high engagement group and 464.47 (P<.001; CI: 428.23-500.70) minutes (7.74 hours) per night in the low engagement group. TST slope values were -0.28 (*P*=.015; CI: -0.51-0.05) for the high engagement group and 0.03 (*P*=.889; CI: -0.35-0.40) in the low engagement group. Like the WASO comparisons both groups started at similar TST baseline values, but the low group experienced an improvement in TST over time whereas the high group showed a decrease in TST over time. The Sleep Onset Latency (SOL) intercept for the high engagement group was 11.16 minutes (P <.001; CI: 8.79-13.52) and 8.33 minutes (P<.001; CI: 4.20-12.47) for the low use group. SOL slope values were similar, 0.02 in the low group (*P*=.523; CI: -0.03-0.07) and 0.03 (*P*=.293; CI: 0.02-0.08) in high group. The groups had different baseline SOL times and the low engagement group experienced a slight increase, trending toward values above 5 minutes. Waking after sleep onset (WASO) intercept in the high engagement group was 26.26 minutes (P<.001; CI: 20.36-32.17) and 25.73 minutes (P<.001; CI: 19.06-32.41) in the low engagement group. WASO slope values were 0.03 (*P*=.554; CI: -0.07-0.13) in the high engagement group and -0.04 (*P*=.492; CI: -0.17-0.08) for the low engagement group, the groups began at a similar baseline and the low engagement group experienced a slight decrease in WASO over time. The sleep efficiency intercept in the high and low user groups were 93% (high: P<.001; CI: 0.92-0.94, low: P<.001; CI: 0.91-0.94). The groups started at the same sleep efficacy percentage at the start of the pilot and the low user group trended toward increased sleep efficiency whereas the high user group trended toward a decrease in sleep efficiency (See Figure 12).

The intercepts of the Root Mean Square of successive differences (RMSSD) were 40.35 (P<.001; CI: 28.09-52.60) in the high engagement group and 67.69 (P<.001; CI: 40.01-95.36) in the low group. RMSSD slope value of the high engagement group was -0.12 (*P*=.001; CI: -0.20- -0.05) and -0.14 (P=.023; CI: -0.25-0.02) in the low engagement group. Both groups experienced a decrease in RMSSD, an indication of normal changes over the course of pregnancy, however the high engagement group experienced a lower value of RMSSD from the start of the study than did the low user group.

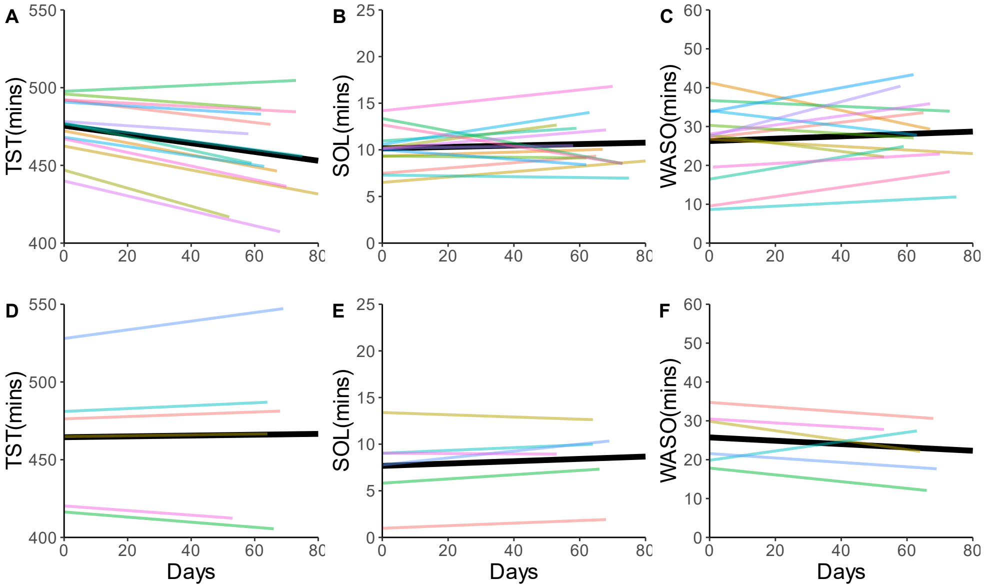


**Figure 11.** Linear Mixed Effect Models Sleep Duration and Quality (Original Publication II).

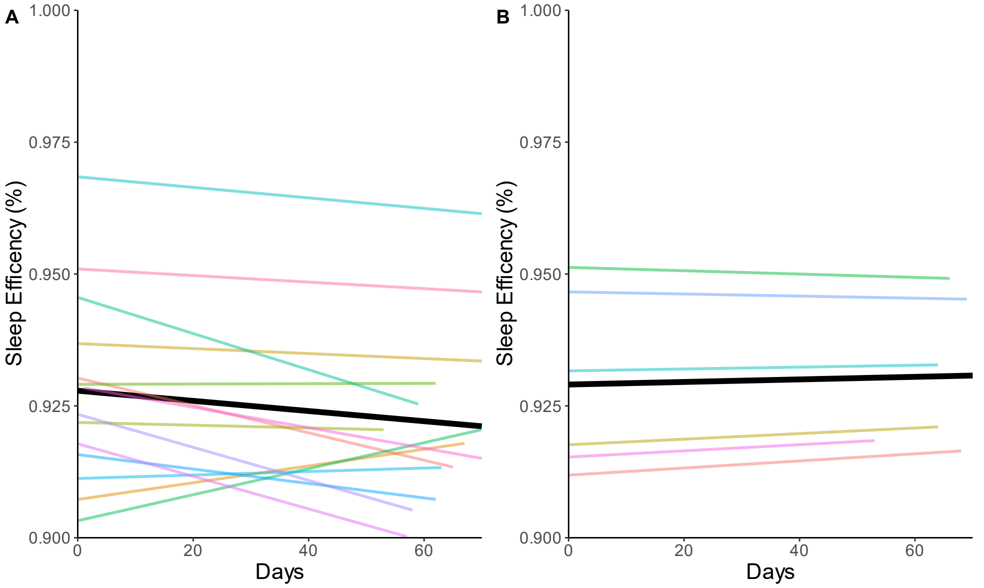


**Figure 12.** Linear Mixed Effect Models Sleep Efficiency (Original Publication II).

After pilot use of the ŌURA eHealth self-monitoring system trends for sleep duration and quality were less favorable in the high engagement group than in the low engagement group. The high engagement group experienced a greater impact on their parasympathetic nervous system from stress exposure than did the low engagement group. Both groups had positive trends in SOL.

The main findings of this study indicate that the use of behavioral engagement to understand meaningful participation in eHealth programs is lacks specificity. As other researchers have shown, meaningful participation might not always be linked to volume of participation (Kelders, 2019). Examination of perinatal eHealth users' adaptation and habituation to use is a good next direction, considering that the amount of physical use and access to viewing personal data did not reveal any benefit toward improvement in sleep and stress outcomes in pregnancy over the course of the pilot study.

## 5.3 Study Phase Two-Original Publication III: Adaptation process for the co-creation of an antenatal self-monitoring service

Findings from our first phase of this study identified that the processes of patient engagement were not often explored in studies examining person-centered perinatal eHealth systems. To build a model for integrating patient engagement as a process into perinatal eHealth more knowledge and understanding was needed relating to processes of patient engagement. We focused our work in the second step of phase two of this study in describing perinatal eHealth user perceptions of adaptive processes after receiving access to an eHealth self-monitoring system. Users described their adaptation differently based on their use threshold (high or low use). This step of phase two informed the usefulness of co-creation and the socio-material interaction perspective in identifying important processes related to patient engagement, namely, personalization, access, and commitment.

Here, a convergent mixed-method evaluation design study was conducted to understand what the adaptive and mediating activities were of women and the eHealth system during a piloting of an antenatal eHealth self-monitoring program using ŌURA 2.0 technology. Women monitored themselves either a high or low amount and they were stratified into two groups based on the distribution of mean non-wear time (See Figure 10). From the perspective of the women, their own adaptive and the mediating activities of the eHealth system enacted a process of adaptation within their antenatal care. The new self-care and antenatal interactions that developed in the real-world use of the system illustrated emerging scenarios and considerations for quality person-centered eHealth care. The main theme constructed through content analysis was a co-creation process between pregnant users' and the eHealth system for eHealth system use and design. The co-creation process encompassed two phases: (1) the adaptation phase (domains 1 and 2), and a (2) feedback phase (domains 3 and 4). Both phases can be used to design person-centered perinatal eHealth systems. Domains within each phase include: (1) Pregnant user adaptive activities, and (2) Mediation activities of the eHealth components, (3) Recommendations for improvement of personalization and accessibility, and (4) end-user training.

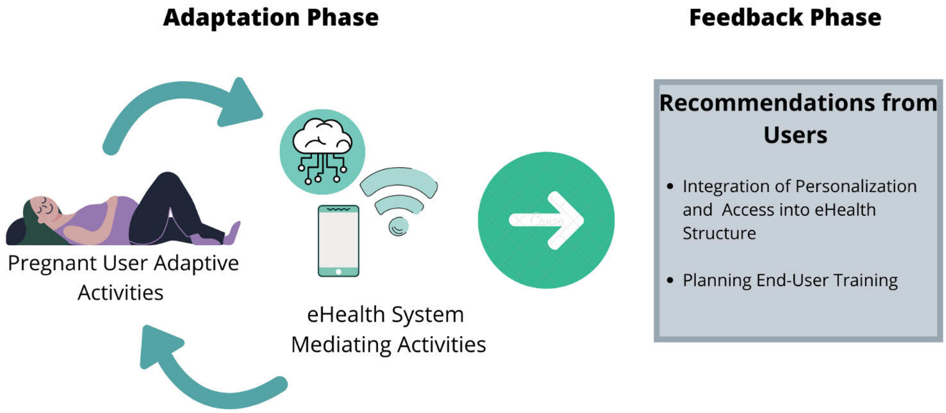


**Figure 13.** A co-creation of eHealth system usage and design.

### 5.3.1 Adaptative Phase-Domain 1: Pregnant User adaptive activities

Women in our pilot study experienced the use of the eHealth self-monitoring system in the foreground of their own habits, skills, eHealth literacy, and values. All the women enjoyed using the system, and some would recommend the use to their friends or family, many also thought the system would be useful in daily life or to be extended in use throughout the entire perinatal period. The level of physical wear-time of the smart ring device was not linked to their enjoyment, habits of goal setting, and in fact it appears that some women in the high engagement group (higher level of wear-time) became interested in becoming skilled in the recording and interpreting their data over learning how to improve exercise, sleep, or relaxation practices during pregnancy.

### 5.3.2 Adaptive Phase-Domain 2: Mediation activities of the eHealth system

The eHealth system mediated activities that stimulated women user patterns of eHealth system engagement. Women in the high user group experienced that the eHealth system’s feedback was gentle and non-judgmental toward their personal lifestyle and needs for rest. Women in the low user group did not comment on the gentle and guiding nature of the eHealth system but spoke more about the nurses’ non-judgmental way of coaching them during clinic visits. Further, the eHealth system gave feedback and tips only when women opened the wellness App to view data and sync data from self-monitoring. In this way women found that having options about what to view and when made it a bit hard to get used to using the system initially, after getting comfortable with their own use threshold they were satisfied. Nurses and women began to interact differently, mediated by the eHealth system, when they viewed data from the eHealth wellness App together.

### 5.3.3 Feedback Phase-Domain 3: Recommendations for Improvement of Personalization and Accessibility

Participants felt the system could be more personalized and accessible. Women wanted consistent expert coaching, better algorithms that were sensitive to pregnancy states and diet. Women in the high user group suggested having a self-monitoring system available through the entire perinatal period.

### 5.3.4 Improving Personalization

Women stated that some personalized features could be added to the eHealth self-monitoring system. Women in the low use group stated that the system was not suitable for their work environments, only 1 out of 6 women in this group was able to wear the ring during work. Women in this group remarked that it was not easy to keep track of their daily activity because so much of their movement occurred at work. Physical activity monitoring was not very reliable for the women in the high use group, many commented that the ring did not register certain exercises, and the recommendations from the App did not match personal bodily feelings, for example one woman stated that: “[ŌURA] should understand that you´re pregnant…I think it would be important that you could tell the application you´re pregnant and then [that] would influence…suggestions” (ID3, High use group).

Participants commented that having a choice of what type of wearable device to use would improve personalization. Not all women felt the ring style suited them. However, some women preferred the ring over the watch because they were not prompted to view the watch display throughout the day and did not become overly occupied. Women stated that their pregnancy was busy, and they were concerned at times that they would lose the ring. One woman suggested a ‘find my ring’ function so to prevent losing the wearable. Women suggested improvements in monitoring diet, including tips for eating and drinking water, options for heart rate monitoring and alerts during exercise, and monitoring important medical values and symptoms.

Some participants noted that medical treatments and investigations took priority over health promotion coaching in antenatal visits, when deemed necessary. Monitoring of women's health behaviors and the connection of these behaviors to pregnancy health states was not a perspective taken in this care context when medical concerns arose.

### 5.3.5 Improving Access

Women saw concerning recommendations from the App and became unsure if the device was recording well. One woman mentioned that it can be irritating to have worked hard to do the self-monitoring and find that the device was faulty or improperly worn preventing good recording of data (ID4). It is clear, that having a multidisciplinary team would support women to use the eHealth system to its greatest potential. A team that includes eHealth and lifestyle specialists, nurses, and primary care providers was suggested by participants.

Women in the high user group stated that an eHealth system available throughout the entire perinatal period would be ideal for supporting self-management of wellness and maintenance of health behaviors. Users think that receiving daily reminders for diet, exercise, sleep, and stress could be beneficial. Two users in the high use group mentioned that having sleep data to view during post-partum could build self-awareness when tasks feel extremely hard during the post-partum period (ID23 / ID11). Women in both groups noted that an eHealth self-monitoring system could be used to record important clinical values (e.g., blood glucose readings, and temperature). These users wanted eHealth systems to support medical and wellness monitoring within wholistic perinatal programs.

### 5.3.6 Feedback Phase-Domain 4: Recommendations for Researcher Training

Women's experiences of accessing the ŌURA technology have provided us with insight into what should be included in a training plan for researchers and research assistants for the design of of an eHealth self-monitoring system (See Table 10).

**Table 9.** Training domains for researchers and research assistants

| **Training domain** | **Design Considerations** |
|---|---|
| Technology Functionality/Use of wearables | o Find a good match of wearable for individual users (e.g., ring, watch, different sizes, multiple devices).<br>o Consider having a tracking system for finding the device if misplaced.<br>o Ensure the size of wearable is correct for accurate monitoring.<br>o Consider training care team members who can support nurses and women if there are any questions about the accuracy of data collection with devices in use. |
| Familiarity with Application | o Detailed orientation to all resources, and ongoing reminders to use tools available on applications, such as, guided meditation sessions.<br>o Orientation to the explanations about parameters give ongoing reminders to check this information.<br>o Reminders to view the daily feedback and advice. |
| Troubleshooting | o Ensure women know that troubleshooting is a common occurrence in using digital services. Give them instructions and easy ways to communicate with eHealth technical support. |
| Software updates and Operating systems | o Sometimes smartphones are not compatible with software updates. Users should know what to check for incase of incomplete software updates.<br>o The available languages and user interface might improve with software updates, prepared for improvements in this case. |
| Content of Health Promotion Counselling | o Add coaching about healthy sleep and strategies for improving sleep during antenatal care visits.<br>o Overall wellness and rest are important elements in a coaching plan for all mothers and this application is oriented toward a gentle move toward healthy lifestyle habits, the nurse can match this counselling approach and softly encourage the setting of health goals.<br>o Reviewing health parameter data is relevant to pregnant women, traditional antenatal visit patterns might overtake women’s curiosity to bring up the data if the nurse does not lead the viewing of data.<br>o Looking at data together and brainstorming about the interpretations of the data was something women enjoyed. |

## 5.4 Study Phase III-Original Publication IV: Development and psychometric testing of a Process Evaluation tool for Collaboration and Participation for NICU eHealth Systems

From phases I and II of this study it was illustrated that development and evaluation of perinatal eHealth systems would benefit from the exploration and assessment of patient engagement processes. We were able to develop and validate a tool that would record features of commitment and therapeutic alliance as a process through the assessment of participation and collaboration of parents who are caring for their newborns in the context of the NICU. In what follows the product and findings from the development and psychometric testing of the CO-PARTNER tool, in phase IV a vignette description of this tool being used in the evaluation of a theoretical NICU to Home eHealth system will be illustrated. The findings from phase III support the rationale for using such an assessment tool for monitoring processes related to patient engagement in perinatal eHealth systems.

The patient engagement model for perinatal eHealth will support new perspectives of quality assurance based on the examination of person-centered and patient engagement practices that make up the habits of perinatal care within the emerging structure of practice that is eHealth. The development and testing of a measure for capturing the process of participation and collaboration in the NICU is an example of a process measure that can be used to promote coaching between professionals and perinatal health users toward their wellness and effective self-care practices.

A 31-item tool for parent participation and collaboration in neonatal care was developed. Confirmatory Factor Analysis revealed high factor loadings of items within each domain. Internal consistency was 0.558 to 0.938. Convergent validity and discriminant validity were strong. Higher scores correlated with less parent depressive symptoms ($r = -0.141$, 95%CI -0.240; -0.029, $p = 0.0141$), less impaired parent-infant bonding ($r = -0.196$, 95%CI -0.302; -0.056, $p<0.0001$), higher parent self-efficacy ($r = 0.228$, 95%CI 0.117; 0.332, $p<0.0001$), and higher parent satisfaction ($r = 0.197$, 95%CI 0.090; 0.308, $p = 0.001$). Parents in a family integrated care model had higher scores than in standard care (beta 6.020, 95%CI 4.144; 7.895, $p<0.0001$) and mothers scored higher than fathers (beta 2.103,95%CI 0.084; 4.121, $p = 0.041$). The tool consists of 31 items within six domains with good face, content, construct, and structural validity.

Three domains within the measure specifically focus on parents' progression through newborn care task (e.g., Daily Care, Medical Care, and Closeness and Comforting the Infant). These domains are evaluated on four-point Likert type scale spanning markers for the type of participation parents were involved in during each task (22 items). The scale responses are: (1) The nurse does this; (2) I do this together with the nurse; (3) I do this independently (without the help of the nurse); and (4) This is not applicable.

The CO-PARTNER tool explicitly measures parents' participation and collaboration with professionals in neonatal care capturing their unique roles in care provision, leadership, and connection to their infant. This measure can be used for benchmarking, examining the frequency of parent participation in specific newborn care tasks, however, in the context of process evaluation in eHealth systems the progression of participation in newborn tasks and the style of each parent in reaching their intended goals will be the focus of using this tool.

## 5.5 Theoretical foundations for a Model of Patient Engagement Integration (Phase IV)

Two theoretical frames were applied in the construction of the patient engagement model. Donabedian's conceptual model for the assessment of quality care was incorporated in the second deductive phase of the analysis. Donabedian introduced the three approaches to quality assessment in his conceptual model first in 1966. The three approaches represent three dimensions of care to be considered when evaluating quality of care provision and are structure, process, and outcome (Donabedian, 2002). The second theoretical frame is adapted from Lewin's 1946 Action Research Cycle and was incorporated into the synthesis of the patient engagement model in the abductive phase of the analysis. Lewin is credited for being the first to describe the Action Research Cycle and this conceptual model has been later explained as an ideal method for changing workplace practice by putting emphasis on reflective processes that support the generation of new knowledge and understandings about the practice and quality of care (Williamson et al., 2011).

This patient engagement model is aimed to describe and provide a harmonized set of steps for practice that allows the discrete workings of perinatal patients, and eHealth functionalities to be visualized through recording and evaluating processes and outcomes that will continually build and re-design a structure of practice. The kind of service provision aimed for is one that is personalized and flexible to change while maintaining core components of the structure (person-centered perinatal care). The nature of a new perinatal system that integrates both eHealth modalities and patient engagement principles could be one that moves across a spectrum of care models dependent on the preferences, actions, participation level, interactions, and collaboration of all actors within the system. The two theoretical frames used in this study support the synthesis of a model that would allow for the examination and a practice of system in continual movement while maintaining the core components of person-centered perinatal care.

**Table 11.** Use of Theoretical Frames for development of Qualitative Deductive Matrix.

| **Theoretical Frame** | **Methods and Concepts used in Matrix** |
|---|---|
| **Step 1:** Donabedian's Quality Assurance Frame | Perinatal eHealth system Structure, Process and Outcomes (SPO) were extracted and applied within deductive matrix under these three categories according to attributes of Patient Engagement |
| **Step 2:** Adapted version of Lewin's Action Research Cycle | Final deductive steps were taken by applying the previously extracted data (according to SPO-Step 1) into a matrix composed of four steps of Action Research Cycle:<br>Diagnose and plan<br>🡇<br>Implement action strategy<br>🡇<br>Evaluate action strategy<br>🡇<br>Reflect plan again and 're-spiral' |

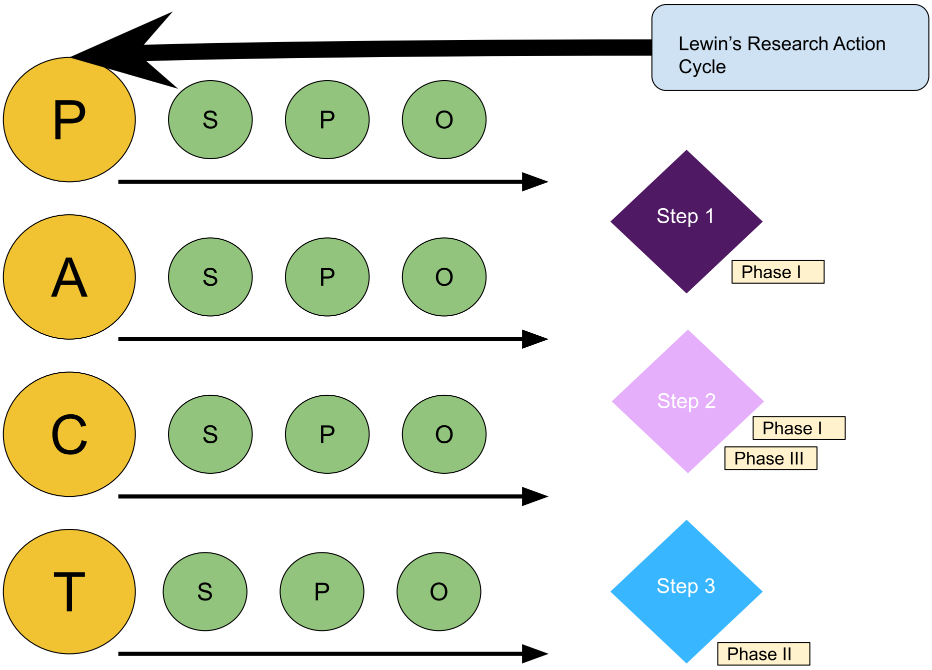


**Figure 14.** Conceptual Matrix (See also Figure 6). PACT=The four attributes of patient engagement (Higgins et al., 2017); SPO=Structure, Process, Outcome (Donabedian, 2002); Phase=Phase of PhD study.

## 5.6 Phase IV-Model for integration of Patient Engagement

Interpretation of all included studies' components were made with the use of the Donabedian quality assurance model. Structure of perinatal eHealth systems was depicted in step one of the model through our mapping of eHealth modalities to specific patient engagement attributes (Access, Personalization, Commitment, and Therapeutic Alliance). Processes of perinatal eHealth systems were interpreted and made relevant through the deconstruction of patient engagement as a process throughout all the included studies. In the second and third steps of this model process was depicted first (step 2) as necessary for examination of co-creation of meaningful eHealth use and design (Commitment, Access, and Personalization) and secondly (step 3) as a vignette form for the illustration of process evaluation using a newly designed measure for participation and collaboration (Commitment and Therapeutic Alliance) in the use of a theoretical eHealth NICU system. The model for patient engagement integration into perinatal eHealth includes therefore three steps: (1) Person-centered perinatal eHealth modality mapping; (2) Process evaluation through monitoring of person-centered and patient engagement processes; and (3) Co-creation of perinatal eHealth systems through real-life flexible access to perinatal eHealth modalities. The following sections of this report describe the three steps in detail (Figure 15).

**Figure 15.** Model for Patient Engagement Integration in Perinatal eHealth.

### 5.6.1 Step One: Person-centered Perinatal eHealth modality mapping

The first step of the model provides a start point for development and planning of meaningful perinatal eHealth systems that will support person-centered perinatal care provision. The WHO recommends using a shared language for the development and classification of digital and mobile technologies used to support health system challenges. While the classification of digital health interventions (DHI) developed by the WHO exists, a taxonomy and template for mapping person-centered health system challenges and DHIs is not explicitly highlighted. eHealth modalities and their descriptions have been constructed from the work of Phase I of this study. The 12 eHealth modalities in use in perinatal eHealth systems (digital health interventions) can be linked to health system challenges. Perinatal health system challenges are linked to limited or non-sustained practice of the perinatal care core values of partnership, participation, provision of information, shared decision-making, reciprocity, and tailored care (See Figure 16). A process of mapping perinatal health system challenges and eHealth modalities is lacking in the current design and development research in this field.

Here, a taxonomy and mapping template of person-centered perinatal eHealth modalities was interpreted through the perspective of structure (Donabedian, 2002). This taxonomy as the step in the model provides design logic for the integration of patient engagement attributes into the structure of perinatal eHealth systems. A taxonomy could support identification of perinatal person-centered health system challenges (WHO, 2018) and inform explicit design decisions.

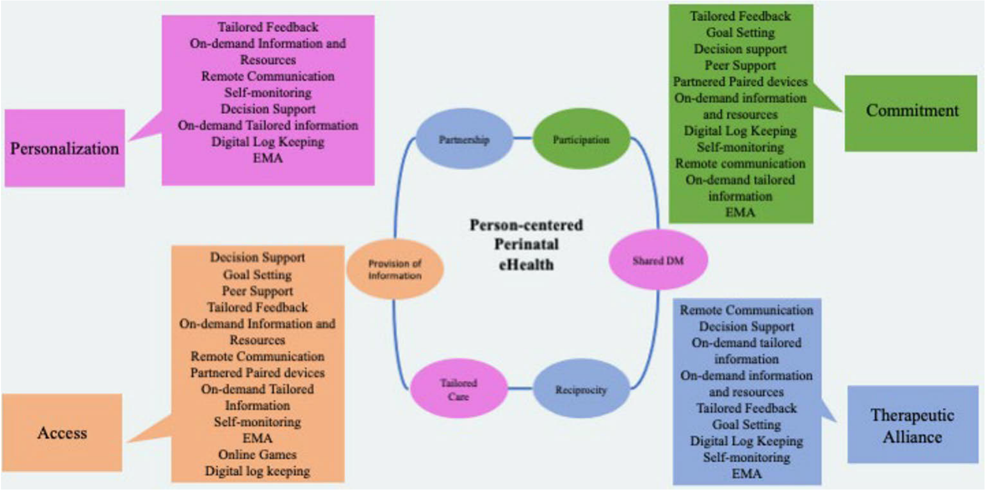


**Figure 16.** eHealth modalities linked Patient Engagement Practices.

When developing a perinatal eHealth system design concept relevant literature should be consulted, and the expertise of stakeholders should be solicited (Jefferson et al., 2019). From these investigations and consultations, a clear description of the perinatal health system challenges should be made at the outset to guide developers and stakeholder advisory panels in their discussions about possible designs (See Figure 17). This step to design planning can guide the development of a clear conception of patient engagement elements to be integrated according to the deficiencies (health system challenges) that have been identified by developers and stakeholders.

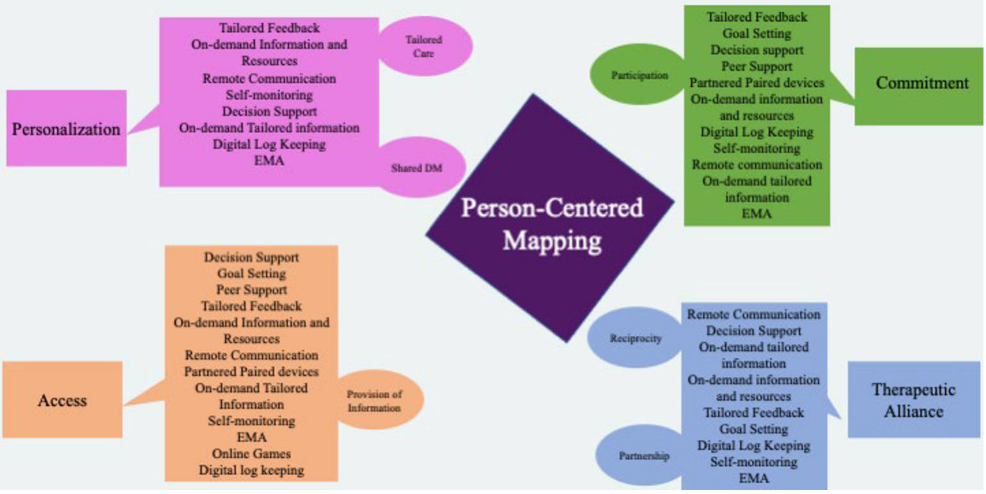


**Figure 17.** Phase one-Person-centered Mapping.

### 5.6.2 Step Two: Process evaluation through monitoring of patient engagement processes (Vignette description)

Process evaluation of eHealth systems is important because within often well-intentioned organizational structures the enactment of person-centered perinatal care processes does not always come to fruition. As seen in the findings from Phase II of this study processes that occur during use and adaptation to use are complex and require examination of nuanced practices of eHealth users. Here, step two-vignette description illustrates a possible process evaluation structure, and associated workflow. The vignette includes three predetermined responses from hypothetical experts in the field of perinatal care, and perinatal care recipients (Wilks, 2004). This vignette is intended to be used in future participatory action research to elicit stakeholder views and preferences for a similar person-centered eHealth in the form of focus group or individual interviews (Wilks, 2004). The vignette can be developed after the first step (Perinatal Person-centered Mapping) is complete.

Researchers active in using process evaluations have been doing so in health system implementation to support decisions with theoretical bases for design concept structure, intervention aims, and improvement of patient experiences (Moore et al., 2015). In the review of current perinatal eHealth programs conducted in Phase I of this study it was noted that a small percentage of studies incorporated methods for evaluating processes within their program evaluations (See Figure 18). There is a need to shift current research aims toward the discovery of processes within person-centered perinatal eHealth programs. However, the reporting and examination of process evaluation methods remains minimal. A theoretical perinatal eHealth program is described that makes explicit use of process evaluation in a vignette that can be used in future studies for the possible examination of process evaluation within perinatal eHealth development.

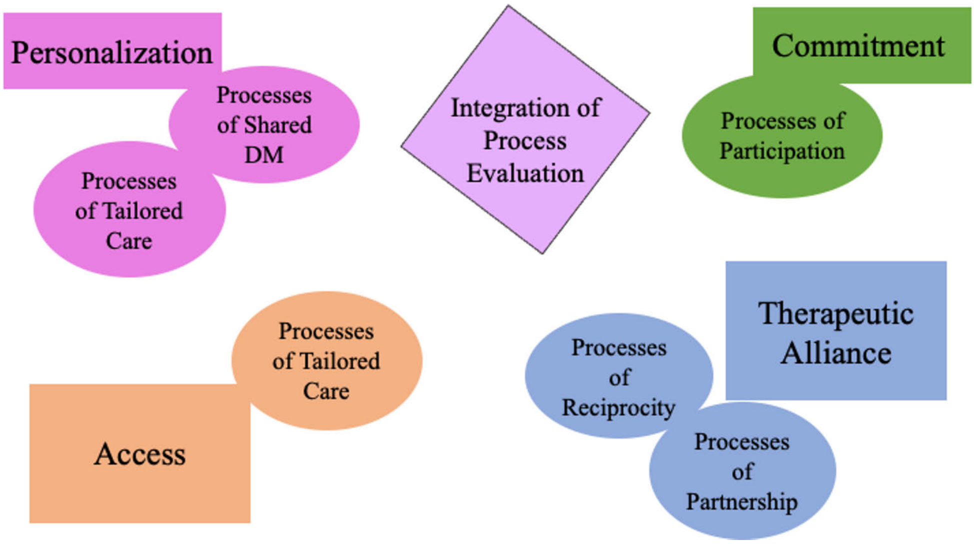


**Figure 18.** Phase Two-Integration of Process Evaluation: Processes available for evaluation linked to Patient Engagement.

### 5.6.2.1 CO-PARTNER eHealth program for care of newborns by parents in NICU and transition to home

In what follows, a description of an hypothetical eHealth program for use by clinicians specialized in neonatal care and parental coaching and parents of newborns who have been admitted to the NICU after traumatic birth or illness in a fictional city, so named, City Z. This vignette description includes information about the structure, and processes that important for the quality of this eHealth program. The attributes of patient engagement as described by Higgins and colleagues and the core values of person-centered perinatal care (See Figure 2) provide the core components of the CO-PARTNER program. The hospital organization in City Z values woman-and family centered-care through explicit mention of these care approaches in their core value statements. City Z hospital has a committee in charge of monitoring policy development and revisions that support person-centered care approaches and practices. The hypothetical CO-PARTNER eHealth program was developed in collaboration between organizational leaders in City Z hospital's NICU and homecare nurses working to visit and support parents going home after NICU admission in City Z. The theoretical CO-PARTNER eHealth program was designed in response to reports of low satisfaction in care gathered in a routine quality survey. Specifically:

- Feelings of parents in not receiving personalized care
- Parents stating often that they did not have enough access to important information about their newborns during the NICU stays
- Parents often felt unprepared to go home with their newborns after they had been discharged from City Z hospital NICU-they wanted more resources available at home and more practice in the hospital prior to going home with their newborns

Further investigation was conducted using qualitative approaches to understand what factors were perceived by parents as influencing their feelings of readiness to transition from NICU to home with their newborns in City Z. The findings from this research revealed that parents felt lack of partnership and reciprocity between them and the nurses in the NICU in City Z and lacked these feelings with the City Z homecare nurses delivering care and monitoring in the community after discharge to home. As well, according to parents tailored care and information receival was missing because the resources available for them during the NICU stay and after discharge included a decade old handbook for families returning home with newborns after discharge from the NICU. They tried to google information on their own, but this caused frustration, and confusion with a large amount of conflicting and concerning information found through their searching. Based on findings from the survey, qualitative study and expert knowledge of work processes occurring within City Z NICU/homecare programs the organizational leaders and clinical/nursing experts interpreted that parents had little opportunity to participate in care processes during NICU stays and struggled in competency and comfort when going home with newborns newly discharged from the NICU.

#### 5.6.2.2 Structure of CO-PARTNER program

The CO-PARTNER program includes five eHealth modalities aimed at supporting the reported concerns with quality related to lack of provision of information, partnership and reciprocity between parents and clinical staff, and low participation and confidence in care of newborns. The four eHealth modalities align with the four attributes of patient engagement (See Figure 17) and are:

- Remote communication
- On-demand digital information and Resources
- On-demand tailored feedback (all feedback is available to look at on-demand using a viewing history function)
- Digital log keeping
- Tailored feedback

The CO-PARTNER eHealth program includes an App parents can download on either iOS or Android phones. The CO-PARTNER to home App is only available in City Z hospital and community district. The App is useable with mobile devices and has a cloud and administration layer that professionals can interact with. The App includes a professional communication section which allows parent to chat and make appointments with health care providers (in person or via video calls). The parents can chat with the homecare nurses or NICU City Z hospital nurses depending on need. There is an evidenced based (developed by perinatal health professionals from City Z hospital/community district) library and searchable database that includes information and videos that parents can use anytime. Parents complete a personal profile when starting up with the App at the time of admission of their new-born to the NICU. They apply their delivery date, gestational age of their new-born and special treatments the new-born is receiving (with help from the nursing and medical staff). All data entered in the profile is linked into an automated message system that will notify parents of important milestones, send tips about how to build skill and confidence in specific tasks based on personal profile information and updates about new-born treatments that nurses, and medical staff provide. Parents will have use of the CO-PARTNER digital log to first learn what tasks are possible for them to complete during the NICU stay and the nurses will show parents how to complete the CO-PARTNER tool (one for both parents is possible) as an orientation to the App and the NICU care experience. Parents will then be asked to complete the CO-PARTNER tool (process evaluation and participation measure) twice weekly, and to review progress with nurses once weekly. Parents will be prompted to complete CO-PARTNER logs twice weekly and once prompted to have a discussion with their nurse in the NICU. Prior to being discharged nurses will have a discussion with parents to make a shared decision about whether parents will continue to use the digital log after returning home.

#### 5.6.2.3 Processes of CO-PARTNER program

The eHealth modalities used in the CO-PARTNER eHealth NICU to home program in theoretical City Z are used to mediate and support patient engagement processes. Personalization processes are enabled using tailored feedback (tailored messages about milestones and tips for how to improve confidence and skill) and through use of chat functions that parents can use 24/7 at the times that work best for them. Personalization is also supported through the tracking of participation and collaboration through digital log keeping with the use of the CO-PARTNER tool. Access processes are supported through the eHealth modality of on-demand digital information and resources, remote communication, and updates within their family profile available anytime (up to date information about their newborn's treatments and progress). Commitment process might be supported with the nurse coaching element of this program in combination with the CO-PARTNER digital log keeping. Commitment could be evaluated over time looking at the progress of parents toward higher levels of participation using the frequency of independent participation in new-born care activities. Therapeutic Alliance processes are supported using asynchronous and synchronous remote communication with professionals, tailored feedback (on-demand and push notifications).

#### 5.6.2.4 Process Evaluation using the CO-PARTNER tool

City Z hospital and community district developed a plan to evaluate the process of participation and collaboration between parents and nurses. They implemented an evaluation plan that consisted of audits of the completion of the CO-PARTNER digital log keeping, and the patterns of use. Nurses were asked to record in the CO-PARTNER App if the weekly meeting occurred and what the goal of coaching for parents was said to be at each visit and if parents had any feedback or preferences for the style and delivery of coaching toward their learning goals. All data collected for the process evaluation was anonymized and use and process data were summarized and interpreted by the quality managers from City Z hospital and community and shared with higher level leadership in monthly meetings.

#### 5.6.2.5 Predetermined responses of stakeholders

The CO-PARTNER program design was pitched to stakeholders in the community of City Z and the following responses were elicited. The following stakeholders are fictional, and the inclusion of the stakeholder groups was decided based on relevant literature regarding common practices of stakeholder inclusion (Oberschmidt et al., 2022):

Veteran Parent-mother of two children, two years prior her new-born was born at 27 weeks' gestation and remained in the NICU in City Z hospital for two months:

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> *I believe in as parents we should be active in the care of a new-born who is staying in an NICU. From my experience, in the beginning you are just so shocked with everything that has happened. You wanted the birth and first days as a parent to go differently, like you had expected! I think the eHealth program, CO-PARTNER from NICU to home seems like a very intense program for parents, the nurses I spent time with when my last baby was in the NICU did not have much time to explain things to me…*

> *I am not sure how they would be finding time to give me coaching and orientation to the eHealth program at first I would need a lot of help to begin logging my activities, and learning about the care of my new-born.*

Neontologist has been working for 10 years in City Z NICU

> *I want to know how the parents are coping with the care and processes involved in the NICU treatments. Sometimes I think it is hard to find time to really sit with parents and find out how they are doing with all the new tasks and stress involved when their newborns are staying in the NICU. I think the CO-PARTNER eHealth program might offer me insight into parents' experience and progress. However, I do not have time to review digital logs and assess the process of parents and I do not know who will be responsible for summarizing the digital logs through the weeks of the newborns' stay in the NICU. I need someone skillful and concise to explain to me how parents have been doing....*

Nurse has worked in City Z NICU for 10 years

> *I have been curious about baby friendly hospitals and parent partnered models of practice for a long time now. I think our NICU does a good job of listening to parents and tailored approaches and we are flexible to help parents feel welcome in our unit. I do not know how to quantify or explain that 'hidden' work that we do to include parents in the care of their newborn daily. I think the CO-PARTNER tool could help use to be able to assess the model of care the NICU nurses strive to carry out.*

Community homecare Nurse has worked in City Z for 27 years as a family nurse making home visits to parents returning home from hospital

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> *I hear so much about process from this program! I know the process between the parents and babies, we go through the journey together. I hear that with this new program I will be expected to record our process…and the parents will record their process?? We just do it, like we always have. We have a new member of the family at home with the parents and they learn how to blend into a whole new family. I am not sure how this eHealth will help the process, is that the intention of the program? I don't want to be looking at a screen instead of at the families, I already spend too much time recording the care then I want to. Not sure about this program really…. most of the time we have a good process with each other at home with the new babies!*

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### 5.6.3 Step Three: Co-creation of perinatal eHealth systems through real-life flexible access to perinatal eHealth modalities

The co-creation of perinatal eHealth systems can be experienced between eHealth users and the technology itself. The perinatal eHealth user carries out activities during their adaptation/habit formation in using perinatal eHealth systems and the technology itself performs a mediation function, together a pattern of use will be determined. As first seen in Phase II of this study a socio-materiality perspective supports the examination of user-technology interactions (Orlikowski & Scott, 2008a), these interactions inform the types of processes that occur between the perinatal eHealth user (through adaptive activities/habit formation) and the mediating activities conducted by the technology in the co-creation of new eHealth systems. From the purposive literature sample, the elements of co-creation through real-life use of perinatal eHealth systems were readily seen, in what follows a narrative description of step three, the co-creation phases: (1) the adaptive phase (described through socio-materiality perspectives) and (2) the iterative feedback phase (described as receiving feedback after use for the refinement and development of eHealth system structures and end-user training).

The adaptation of perinatal eHealth users to the use of eHealth systems is an important area of investigation. In Phase II of this study it was discovered that investigation of the process of adaptation can help to unravel important person-technology interactions that make up the new understandings and functions present in the emerging eHealth systems (e-scaped care). Placing importance on the user process also illuminated areas where patient engagement structures could be improved upon. Here, using an Interpretive Synthesis analysis we examine the processes of adaptation related to the four attributes of patient engagement (Access, Personalization, Commitment, and Therapeutic Alliance) and subsequent recommendations from users on how the eHealth systems could be improved according to structures of patient engagement (See Figure 17).

Perinatal eHealth user adaptive activities were related to their personal preferences, attitudes about technology, and level of motivation for improving or maintaining their health during pregnancy or after the birth of their newborns. The mediating activities of technologies manifested throughout eHealth systems (Purposive sample of n=59 programs) provided new meaningful ways in seeing technology as a partner in perinatal care processes. Co-designing of perinatal eHealth systems was reported as a priority to development in 19 of included programs (32.2%). Although, this was a theme from the available reports there are many programs that are not using or not reporting patient and public involvement approaches to design. When co-designing was included, it was important to receive feedback that would be used in subsequent phases of eHealth system development.

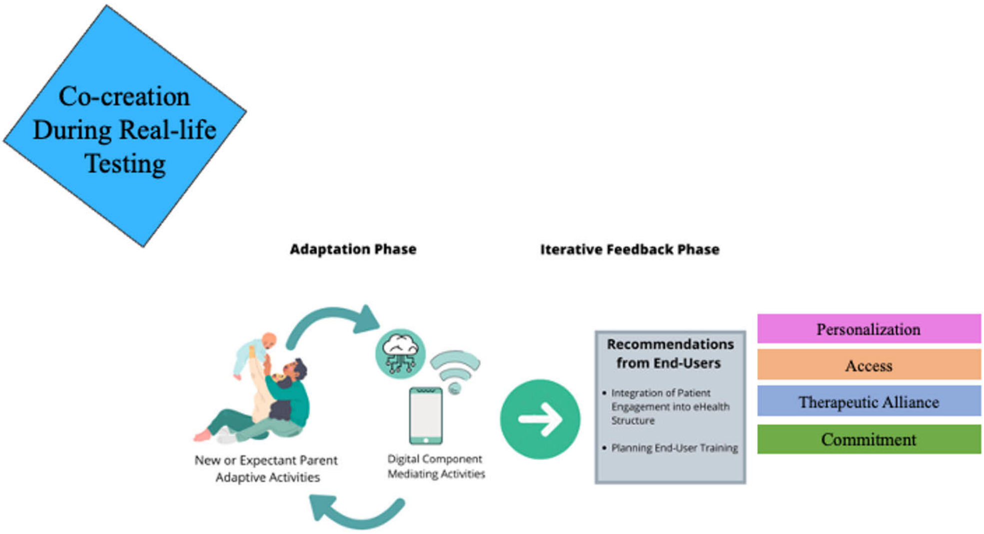

**Figure 19.** Phase three-Co-creation During Real-life Testing.

### 5.6.3.1 Co-creation-Adaptive phase: Access

Having access to eHealth modalities supported the emergence of use patterns and habits across a broad range of perinatal eHealth systems. New and expectant parents adapted to new ways for participating and leading their own care using eHealth modalities, such as, self-monitoring, digital log keeping and remote communication. New care processes emerged with access to eHealth modalities due to the flexible and ubiquitous presence of technology in perinatal health users' daily lives. The access to eHealth modalities resulted in perinatal health users adapting to new use patterns based on their personal preferences, needs, values, and attitudes. The access to eHealth modalities also resulted in a mediating effect of the technology on the ability of perinatal health users to obtain information, guidance and tools needed to receive consistent and quality perinatal care (Higgins et al., 2017).

Perinatal health users' were given access to platforms that allowed for them to seek advice 24/7 via chat functions and were given the option to request video calls with their nurses outside of the normally scheduled clinic visits (Baron et al., 2018; Cramer et al., 2018; de Mooij et al., 2018; Jefferson et al., 2019; Ridgeway et al., 2015). In one program developed in New Zealand perinatal health users were instructed to view and reconfirm information provided by nursing staff about their newborns who had been admitted to the NICU (Gibson et al., 2021).

New activities for management and maintenance of wellness emerged with the newfound access to eHealth self-monitoring, goal setting, decision-making, EMA, digital log keeping, tailored feedback, and partnered paired devices. Reporting activities of daily living (i.e., physical activity, sleep, and rest/mindfulness moments, and diet) gave perinatal health users a chance to record, report and interpret their own daily patterns, the eHealth mediated this new role of perinatal health users within their care processes. Programs are being used that support parents in monitoring their newborns during transition from the NICU to home environments, the technology mediates that new-born wellness assessments can be carried out by parents and this information shared with care providers (Garfield et al., 2016; Holm et al., 2019; Isetta et al., 2013; Strand AS et al., 2021). This change in care processes gives parents a chance to support their newborns from a parental and a medical perspective.

Perinatal health users were able to disclose sensitive medical and lifestyle data in a way that gave them a sense of control over the data being viewed, shared, and interpreted. The eHealth modalities of self-monitoring, EMA and digital logging mediated a meaningful disclosure of sensitive/possibly stigmatizing information in treatment contexts of smoking cessation, alcohol consumption, and mental health interventions (Abroms et al., 2017; Doherty et al., 2019a, 2019a; Fontein-Kuipers, Ausems, et al., 2016; Hantsoo et al., 2018; Harris & Reynolds, 2015; Herbec et al., 2014; Muuraiskangas et al., 2016; Naughton et al., 2013; Valencia et al., 2020; van der Wulp et al., 2014).

Personal preferences, values, attitudes, and needs were seen as important factors in the adaptation of perinatal health users to use eHealth systems once they had received access to the various modalities (See Appendix 3 for all modalities included in the literature). Perinatal health users voiced their perception that nurses in the NICU or maternity units were obviously busy carrying out important tasks and that they preferred therefore to search some questions on their own. In this way perinatal health users were happy to use on-demand evidenced based information/search platforms provided by the health organizations. Perinatal eHealth users valued the access to informational logs and journals/data trends, and tailored feedback on their mobile phones. The mobile phone was always with them and in this way, they could make important notes to themselves in between visits, record their blood pressure, diet, mood, or sleep and stress patterns and have all the information at the ready during visits or remote communication with their health care professionals. Finally, perinatal health users stated that researching and gathering information was vital for their meaningful participation in their own care processes and having a flexible trusted service through on-demand evidence-based information and resources or on-demand tailored feedback supported this need and made the use of eHealth systems appealing for perinatal health users.

#### 5.6.3.2 Co-creation-Adaptive phase: Personalization

Personalization as a process occurring during interactions between perinatal health users and technology is conceptualized in marker 2 of co-creation as a type of becoming and discovery for health users in their roles within the newly ‘e-scaped’ personal care context and perinatal care journeys. The studies included in this Interpretive Synthesis capture the structure and outcomes related to personalization and few contain information about personalization as a process. What we know about this process that occurs between health users and the eHealth modalities is that personalization is desired and reacted to by perinatal health users. They like the flexible use of services, the fact that they can play a role in collection and sharing of their own health and wellness data, and had the sense of being supported through tailored feedback and timely sharing of information and knowledge through new eHealth systems (Banerjee A & Mansfield A, 2020; Danbjorg et al., 2015; Hirshberg et al., 2018; Holm et al., 2019; Peahl et al., 2020; Platonos et al., 2018; Rhoads et al., 2017). Studies included in this Interpretive Synthesis highlight that perinatal health users were placed as important members of a team with their various autonomous roles and tasks (i.e., monitoring newborns at home, self-monitoring fetal movements and heartrates at home during induction of labor), little was examined about the nuances of how health users experience an adaptation into their new roles. Of note the important role of shared-decision makers was of high importance for new and expectant parents when they were recipients of medical services during their perinatal periods (i.e., hypertension in pregnancy and new-born admission to the NICU). eHealth modalities such as tailored feedback, on-demand information and resources, on-demand feedback, remote communication supported perinatal health users to participate in shared-decision activities, less was examined in the included studies about the nuanced experiences of adaptation of perinatal health users becoming more involved in decision making through the mediation of eHealth modalities.

### 5.6.3.3 Co-creation-Adaptive phase: Commitment

The new activities that emerged from the access to eHealth systems (adaptation and mediating effects of the technologies) laid the groundwork for new care processes that appear to have a relationship with increased commitment over time toward health promotion and management by perinatal health users. A plethora of processes thought to stimulate higher participation in care and the use of eHealth systems were seen in the literature included in this Interpretive Synthesis and represent mediating effects of the technology on commitment. In some studies, the factors related to behavioral, emotional, and cognitive commitment were examined through behavioral change theories (See Appendix 1). Some mediating effects included, higher frequency of interactions between users and the health service through tailored feedback, automated updates, being involved more in care processes and having a chance to collaborate with care providers in a more flexible and relevant way, having the possibility to accesses relevant information anytime users wanted.

Effective communication (improved through eHealth modalities) was said to support participation and adherence to treatments during pregnancy in two specific cases related to blood pressure monitoring and treatment in pregnancy and in perinatal mental health screening and prevention (Doherty et al., 2018; Rhoads et al., 2017). Other programs asserted the connection between being involved in problem solving toward goal setting and decision support (through the use of new eHealth modalities) and long term commitment to health prevention and promotion during perinatal periods (in treatment contexts of general postpartum health promotion, breastfeeding support, weight management, smoking cessation, and alcohol consumption) (Abroms et al., 2017; Choi et al., 2015; Demment et al., 2014; Halili et al., 2018; Hawkins et al., 2019; Herbec et al., 2014; Herring et al., 2019; Soltani et al., 2015; van der Wulp et al., 2014; Whitemore et al., 2019; Wierckx et al., 2014; Willcox et al., 2015).

The process of commitment within perinatal eHealth involves greater and relevant connectivity between perinatal health users and their health resources. Viewing and having the possibility to interpret data trends with health professionals in more flexible and accessible forms was an example of greater connectivity and was made possible by the mediating effects of eHealth modalities of self-monitoring, digital logging, EMA, tailored feedback and remote communication (de Mooij et al., 2018; Herring et al., 2019; Marko et al., 2016; Wierckx et al., 2014). The possibility to access health information and resources in new ways that lessened burdens previously felt by perinatal health users occurred in instances where ongoing connected care was applied through 24/7 remote communication availability and possibility for video calls, tailored feedback and motivational messages were sent directly to health users'' mobile phones, and when wearable devices were used for self-monitoring that required low maintenance/upkeep and fit the lifestyle of perinatal health users (e.g., could be worn underwater and in the work place). Finally, safety alerts to contact medical professionals and online peer support connectivity (through tailored feedback, peer support, and remote communication) that span care resources aligned with urgent and non-urgent care needs(Abroms et al., 2017; Davis et al., 2018; Herring et al., 2019; Hirshberg et al., 2018; Jefferson et al., 2019; Krishnamurti et al., 2017; Ridgeway et al., 2015; Tobah et al., 2019; Tommasone et al., 2016; Wierckx et al., 2014; Willcox et al., 2015; Wu et al., 2019). These features of connectivity were combined in only one eHealth program included in this Interpretive Synthesis (Wierckx et al., 2014).

#### 5.6.3.4 Co-creation-Adaptive phase: Therapeutic Alliance

The processes involved in professional and client interactions with the use of eHealth modalities changes how eHealth user roles are given meaning. eHealth became a partner in care through mediating activities, and access to data through self-monitoring and remote communication modalities influenced the power balances between health users and professionals.

The new collaboration practices that were mediated by the eHealth modalities included remote sharing of data, photos, and assessments by new and expectant parents with health care professionals. In one program developed in Denmark nurses acknowledged the parents' observations more readily as these systems of sharing information became normalized (Holm et al., 2019). This change in recognition of parental input in some cases led to increased feelings of respect between the two parties (Holm et al., 2019). New practices related to building care plans and carrying out activities of informed consent for medical procedures using remote data sharing and communication modalities supported reciprocity and partnership between both parties (Bower et al., 2005; Garne Holm et al., 2017).

eHealth modalities such as remote communication, on-demand information and resources, self-monitoring, and online peer support enabled perinatal health users to contribute and use information and resources in new ways (i.e., requesting video chat visits, searching information within trusted and mediated online spaces, and recording and reporting health parameter data). These new processes effectively changed the location of information and resources supporting new types of participation. In some instances it was noted that staff adapted to the use of eHealth modalities, trusting the process through use and seeing the benefit of performing their therapeutic work with the use of eHealth (Gund et al., 2013). During the use of an eHealth system, Care@Distance, to support parents transitioning to home with newborns who were born premature Swedish homecare nurses commented that they liked the flexible process of remaining connected to their homecare health users even when they did not have time for a home visit each day (Gund et al., 2013). Perinatal health users also built trust with the system over the adaptation to use. In one example of a program in use in The Netherlands sharing information with the 'app' allowed health users to feel like they could keep their providers up to date between physical visits without burdening nursing staff with the communication (Wierckx et al., 2014).

Finally, the eHealth modality of remote communication in the form of video conferencing allowed for a chance to build relationships through sharing information and asking for coaching in tasks such as breastfeeding or receiving emotional support in the form of early perinatal visits to discuss non-acute matters without having to make a face-to-face meeting. These mediating effects of the eHealth modality allowed perinatal health users to feel they could connect with providers in the comfort of their own homes, giving them a familiar place to process information and reflect on perinatal topics in spaces they could identify with (Jefferson et al., 2019; Tobah et al., 2019).

#### 5.6.3.5 Co-creation-Iterative feedback phase

Iterative feedback and cyclic design of systems was a core component in studies that focused on designing systems with the user perspective in focus. Feedback was gathered and was specific to context and attitudes present within the workplace and with client stakeholders (Abbass-Dick et al., 2017; Bower et al., 2005; Danbjorg et al., 2015; Franck et al., 2019; Garne Holm et al., 2017; Ke et al., 2019; Shorey et al., 2016, 2018). Training programs and toolkits are being prepared and seen as valuable the early stages of implementation of perinatal eHealth designs. These programs addressed attitude, skill level of users/professionals and integration of coaching and therapeutic relationships within the training programs. In some cases, was apparent that a training plan for nursing/clinical staff should include topics related to personal attitude toward use of eHealth and be sensitive to possible low eHealth competency levels of these staff (Danbjørg et al., 2015; Gund et al., 2013). There was a paradoxical theme of workload and burden on staff reported as feedback for future design of perinatal eHealth systems throughout the included literature. Whereas some researchers reported that very training would be needed for nurses and health users working with the eHealth system (Isetta et al., 2013) clinicians and health users noted the increased burden or saw potential for increased burden on them with the use and maintenance of the eHealth systems in Phase IIa of this study.

# 6 Discussion

Before this study was conducted patient engagement development and quality assurance in perinatal eHealth had been examined in fragments. Here, we have performed an examination of patient engagement practices from the perspective of structure of eHealth, processes, integration of process evaluation, and processes of human-technology interaction. Much work had been conducted that described patient engagement as an outcome along with health related and economical outcomes. What was missing in the previous span of literature was the expression of explicit linkages between structure (Nature and range of perinatal eHealth characterized by patient engagement practices; Phase I), illustrations of human-technology interactions that lead to patient engagement processes during the co-creation of eHealth use patterns (Phase II), and the articulation of a possible method for examining processes of patient engagement in perinatal eHealth systems (Phase III). To provide perinatal eHealth designers and users with a stronger evidence base toward the sustainment of person-centered practices in the light of new and emerging eHealth systems this study's overall aim was to construct a model to guide integration of patient engagement into the design and evaluation of perinatal eHealth. The study included four phases and combined qualitative and quantitative methods (See Tables 2-5). The study first, described the nature of person-centered perinatal eHealth programs, explored the usefulness of prototype testing in real-life use of such a program for maintenance of wellbeing during pregnancy, and developed a process evaluation tool that is useable within eHealth systems serving users in the NICU. The first three phases informed the bases for an Interpretive Synthesis (Phase IV) of evidence toward a construction of the model (three steps).

This discussion section presents the interpretations of the main findings of the four phases of this study. A discussion of research and clinical impact have been made, as well as an interpretation of our trustworthiness, validity, and reliability assessments, and limitations of the studies.

## 6.1 Phase I: Scoping Review

The scoping review characterized the range and nature of perinatal person-centered care. The decision to focus the review on the developed world was made to support the deepening of practitioners and perinatal eHealth developers' knowledge of perinatal person-centered eHealth processes influenced by a burgeoning neo-liberal ideal of healthcare receival. Perinatal eHealth processes and structure still limit the interplay between maternity and neonatal services (See original publication I). Perinatal eHealth research often depicts positive impacts and perceptions of the use of perinatal eHealth, with any negative perspectives emerging from healthcare providers and less often from perinatal health users (Baruth et al., 2019; Ke et al., 2019; Wierckx et al., 2014). Perspectives about burden of perinatal eHealth use and threshold for effective personal eHealth use was not covered at length. The importance of designing perinatal person-centered eHealth systems with tensions of use in mind was covered in only one primary source (Doherty et al., 2020). Some research has found that perinatal health users do favor personal contact with healthcare providers over other eHealth communication modalities which supports the use of blended perinatal care services (McAra-Couper et al., 2020). Blended services are a combination use of eHealth modalities and more traditional face-to-face meetings and other analog methods of healthcare delivery.

This review was conducted to support the description of the nature and range of perinatal eHealth characterized by use of perinatal person-centered care processes and structure. Other reviews have been conducted in recent years to assess the new generation of perinatal care, and to look more broadly at eHealth practices and technology worldwide(da Fonseca et al., 2021; van den Heuvel et al., 2018). From these reviews insight was gained about what kinds of eHealth solutions are in current use around the world for perinatal practice and more broadly across all health domains(da Fonseca et al., 2021; van den Heuvel et al., 2018). Our review offers a closer inspection of eHealth processes and structures influenced by the actualization of patient engagement in the context of person-centered perinatal care.

The scoping review has highlighted that perinatal eHealth developers are giving attention to the level of eHealth literacy of professionals, challenges in balancing healthcare providers' workflows supporting new activities related to eHealth processes. It is also clear that these concerns remain a barrier to fully implementing on-demand patient-centered perinatal eHealth programs, as was seen in two reports describing the development and evaluation of the C-care app, an eHealth program to support pre-and post-operative care for caesarean sections (Ke et al., 2019, 2021). Within these reports a disconnect was seen between patient preferences and health care professional willingness to integrate eHealth modalities that would support greater access to information and communication. Perinatal eHealth patient stakeholders requested a direct line to professional caregivers as one eHealth modality within the C-care app program, and this was not implemented due to requests by anesthesiologists not to include because of lack of clarity on legal and privacy issues related to data sharing (Ke et al., 2019). It is also apparent from our review that patient users of the new eHealth modalities are identifying with and have an affinity with the eHealth processes. This emergence of perinatal health users' growing attachment to eHealth processes could support developer attention to coaching and educating the health care professionals on the benefits and functionalities of perinatal eHealth functionalities and how they can support collaboration and connectivity with patients (Boe Danbjørg et al., 2014; Niela-Vilén et al., 2016). The current evolution in the types of technologies being used in perinatal programs are not so much unlike past changes to technology in practice. The seemingly new concerns about the shifts in power, re-identification of roles and asking the questions of 'who is doing the caring?' and 'where is the care happening?' have been considered in the past (Oudshoorn, 2011). As other health and social scientists have noted, preparing for healthcare program innovation should begin with the perspectives of the healthcare program receivers and practitioners and uphold humanistic values and practices that ultimately support transparency, dignity, safety, and wellness (Doherty et al., 2020; Franck et al., 2019; Staniszewska, 2009).

While this scoping review provides a novel entry point for discussing and appreciating perinatal eHealth, the nature of terminology usage in the available publications is inconsistent and we suspect some sources have been missed due to the complexity of language and variety of professionals working in the field. This work is limited as a scoping review and the level of evidence cannot be evaluated as such, data extraction was focused on elements of program development and description and any data collected from the findings sections of articles occurred in qualitative studies that described the processes occurring within the eHealth programs. Credibility was sought through careful consideration of suitable meaning units that were founded in the definitions of patient engagement attributes and WHO digital service person-centered categories (Graneheim & Lundman, 2004; Higgins et al., 2017; World Health Organization, 2019). Transferability can be evaluated through our clear descriptions of the practice structure context and presentation of findings (Graneheim & Lundman, 2004).

## 6.2 Phase II: Feasibility Study

The feasibility study conducted in Phase II of this study was comprised of two parts (original publications II and III). The differences between two user groups were examined through a descriptive comparative study and a mixed methods exploration into the adaptation of use process through a socio-materiality perspective. The women in the high user group experienced higher impact from stress on their parasympathetic nervous system over time during the pilot period than did the women using the device to a lesser amount. Factors related to daily patterns of living (e.g., physical activity, amount of time at work, and life stresses) could have influenced the groups differently. Women in the high user group expressed having greater focus on their performance of self-monitoring skills (recording and interpreting readings). The concern that burdening healthcare users with greater responsibilities in respect to their care could impact poorly on the users' levels of stress. Research about self-monitoring users living with multiple sclerosis found that it was important for them to have an expert coach who supported them in their technical use of the eHealth service (Wendrich et al., 2019).

Important notions related to the concept of embodiment of the self can be useful in interpreting findings from Phase II of this study. Embodiment of the self as in the production of ones' own norms and values for their own health and quality of life are being impacted by self-monitoring practices in society (Lupton, 2017). To enact the self and experience the process of embodiment perinatal eHealth users might experience a sense of wanting to optimize their potential health and that of their unborn baby and in this way seek out access to eHealth services. Whereas, others might experience the self-monitoring processes of perinatal eHealth as burdensome and something they are being pressured into by new sociality and politics of current healthcare delivery norms and values (Lupton, 2017). Further, potential demands for performance of perinatal eHealth users might arise from the tacit understandings of the responsibility of anyone participating in a Quantified Self (QS) lifestyle, (e.g., optimization of health and wellness, self-quantification as a mission in life) (Ruckenstein & Pantzar, 2017). Embodied negotiations, practices and experiences of pregnant persons has been studied in the global south regarding experiences in low-middle income countries (Bagalkot et al., 2022). However, this perspective has been less explored in the developed world. It is important to bring more attention toward how the structure of perinatal eHealth services, such as self-monitoring might impact women and pregnant person's experiences of navigating and negotiating perinatal journeys (Bagalkot et al., 2022).

Our feasibility study points to the argument that personalization of eHealth engagement thresholds for effective use could be an important area of study because the user groups in our study did not differ in their opinions of the usefulness of the self-monitoring program, however, they noted different aspects of the eHealth program as beneficial based on values, and preferences for use. For example, some women in the low user group found that looking at their daily lifestyle and stress patterns with public health nurses during visits was valuable in bringing up topics they might not otherwise have mentioned in a regular visit. This group of women might enjoy the use of self-monitoring and digital log keeping as an eHealth modality instead of self-monitoring paired with goal setting for example. Women in the high engagement group thought that it was interesting to view their own lifestyle habits and see how they changed based on circumstances (i.e., visiting a cottage in summer vacation compared to being home during the pandemic lock-down period), this group might find it beneficial to use self-monitoring as an eHealth modality in times when they need medical treatment (i.e., monitoring blood sugar readings or blood pressure during pregnancy). Other health researchers have examined eHealth personalization through the perspective of meaningful threshold for use in The Netherlands, and found that developing programs that are suited to the type of eHealth modalities care recipients are interested in shows promise as a meaningful direction forward for the development and sustainment of eHealth design and implementation (Kelders, 2019).

The feasibility study includes a small sample size, however, the number of observations that were incorporated into the analysis was high in volume. This is not a controlled study; the results are not generalizable, and more controlled interventions would be necessary to design any effectiveness studies. The study findings also highlight the need to better define the concept of behavioral engagement and to challenge our assumptions regarding the impact behavioral engagement has in the context of technological perinatal care processes.

The feedback we received from women for design of an eHealth self-monitoring program was detailed and could be used in future designing of a perinatal self-monitoring wellness eHealth programs in the same context. Two reviews describing holistic and best practices of design and implementation of person-centered eHealth recommend that eHealth systems can be designed with techniques available for combining randomized control trials with action research, using a holistic framework for design based on participatory development, persuasive design techniques, and business modeling (Oberschmidt et al., 2022; van Gemert-Pijnen et al., 2011) . These reviews gathered literature from eHealth use generally and did not have a focus on perinatal eHealth systems, but a holistic framework and other best practices can be combined with the use of the model developed in our study to further improve and expand the use of person-centered perinatal services. Further, the co-creation process that occurred between women from both groups and the technology has implications for design and evaluation of perinatal self-monitoring eHealth systems. Researchers and clinicians can observe the interactions that occur once access to eHealth systems is given in real-life contexts. Our feasibility study illustrates the usefulness of eHealth modalities as process evaluation tools, self-monitoring to explore processes of perinatal care receival (as in our use of self-monitoring to provide insight on behavioral engagement). Other researchers should consider the use of EMA and digital log keeping as other sources for process evaluation modalities.

The study was limited in the group of users, they were self-selecting in using wearable devices during pregnancy, all women were moderately to highly educated and wanted to use wearable devices. In this way our findings reflect personal preferences, habits, and values of women who like to use wearable devices and are educated. More research should be conducted with pregnant persons and women experiencing a variety of different life circumstances and who have various levels of education. Knowing the reasons for use patterns can inform designs that do not overburden or under stimulate users, but more user groups should be included in future investigation of use processes from a socio-materiality perspective.

## 6.3 Phase III: Development and Psychometric Testing of Process Evaluation Tool

The CO-PARTNER tool was developed to examine elements of parent participation, including, time spent with the infant, closeness with infant, and collaboration and competencies in daily care activities that have not been incorporated into the same tool before (van Veenendaal et al., 2021). This new measure incorporates collaborative features explicitly and incorporates the process of collaboration between parents and healthcare professionals that is aligned with the constructs of perinatal person-centered care. A main strength of this tool development was the close collaboration with parents, ensuring face and content validity.

This process evaluation tool can be used to support quality improvement by health organizations, practitioners, and care specialists working within various NICU settings when perinatal eHealth is being delivered. There is a possibility of using this tool for benchmarking purposes. All items included in the CO-PARTNER tool can be completed by parents and as advocated by representatives from the WHO this should be fully supported by healthcare professionals (European Foundation for Care of Newborn Infants (EFCNI), 2018; WHO, 2019). This process evaluation tool is the first know that can support parents in providing actionable quantitative data on the level of parent participation in care. Lower scores suggest more tasks performed solely by healthcare professionals and could inform practices through parental monitoring of their own access to care processes using eHealth modalities.

In the context of eHealth use in clinical practice we envision that there is no summing of total scores, as the measure is intended to be an examination for understanding of each parent's and professionals' unique styles of participation and collaboration. The tool can help identify gaps in eHealth coaching processes to support working together toward individualized strategies for improving parent participation. The evaluation tool can be used in eHealth programs to evaluate new care processes and coaching methods that occur with the introduction of eHealth modalities and the integration of patient engagement in NICU care to home. The measure has been in use to capture perinatal person-centered care processes in-hospital care of newborns in Amsterdam, The Netherlands (van Veenendaal et al., 2022). The evaluation tool can be used in eHealth programs to evaluate new care processes and coaching methods that occur with the introduction of eHealth modalities and the integration of patient engagement in NICU care to home.

## 6.4 Phase IV: Interpretive Synthesis of a Model

The model for patient engagement integration in perinatal eHealth is novel. The steps can give researchers and developers a path forward for using person-centered perinatal eHealth development and quality assurance approaches based on theoretical foundations of patient engagement. E-scaped care, as described by Nettleton (2004) positions researchers, clinicians, and society in the position to create new processes within our medical/care journeys. The model proposed here, can help us harness ‘existing processes of transformation’ (Nettleton, 2004; p.674). The interactions that perinatal health users have with eHealth could have an impact on how they relate and think about the role of their perinatal health professionals. For example, with new access to information and their own powerful roles as health care recipients coming into focus some perinatal eHealth users might resist the connection with their health care professionals (Nettleton, 2004). If a path is taken that pulls attention along the entire eHealth development and quality assurance journey toward core components of person-centered perinatal eHealth and patient engagement it would be possible to undergo the transformations with a consistent eye on our person-centered perinatal core values. Step one encourages a focus on mapping our eHealth programs based on eHealth modalities that have been shown to support personalization, access, commitment, and therapeutic alliance (Section 5.6.1). Step two illustrates a need to apply questions throughout the process of use and keep stakeholder and perinatal eHealth users’ preferences, attitudes, and values in sight throughout development and quality assurance through methods of process evaluation (Section 5.6.2). The importance of supporting stakeholders in their participation in eHealth design, development and evaluation requires more attention, this was not covered in detail through this PhD study and methods have been recommend for broad eHealth development and implementation (Oberschmidt et al., 2022). Step three supports a re-thinking about planning interventions from the perspective of real-life testing and co-creation with a focus on patient engagement attributes and human-technology interaction theory (Section 5.6.3). The model constructed in this PhD study is a top-level model and researchers and more research should be conducted to see which action research processes are well suited to the design and improvement of person-centered perinatal eHealth. Oberschmidt and colleagues have identified best practices for Action Research in eHealth design and implementation (Oberschmidt et al., 2022). Further, participatory design approaches have been supported in the designing of eHealth programs as they offer a cooperative experiential approach that would suite health research contexts (Clemensen et al., 2007). Perinatal contexts are lacking incorporation of these approaches. Three categories of best practices were identified by Oberschmidt and colleagues and they are, Process features, Stakeholders and relationships, and Context and environment (Oberschmidt et al., 2022). More research can be conducted to find best practices around the same three categories named by Oberschmidt and colleagues for person-centered perinatal eHealth using the Model for Patient Engagement Integration in Perinatal eHealth Development and Quality Assurance (See Section 5.6) as a top-level guide to practicing.

### 6.4.1 Step One: Person-centered Perinatal eHealth modality mapping

A scoping review conducted for this study revealed that out of 56 different Perinatal eHealth programs 53.6 % (n=30) programs had unique combinations of eHealth modalities built into the structure of the program. The other 26 programs' combinations of eHealth modalities were repeated each only once. The reasons for deciding on each eHealth modality (and combination) has not been reported using a discreet person-centered mapping. However, the programs described from our purposive sample of literature (86 studies) did report the ways in which eHealth modalities supported processes of personalization, access, commitment, and therapeutic alliance to various amounts. We were then able to map meaningful use of eHealth modalities to patient engagement attributes (Figure 17). Most studies in the interpretive synthesis (n=86) report that eHealth in general has important benefits for society, health, and improving engagement of health users but do not explain the unique reason for using eHealth modalities. More work should be completed to understand the mediating factors of eHealth modalities on the processes related to personalization, access, commitment, and therapeutic alliance. By mapping eHealth modalities to specific health system challenges mediating factors can be monitored.

Person-centered Mapping is a tool for developing and sharing a clear vision of specific person-centered perinatal eHealth programs. It is important to receive relevant feedback from stakeholders that can impact the choices for when and how to implement eHealth modalities. Until now a taxonomy and mapping template was missing.

### 6.4.2 Step Two: Process evaluation through monitoring of patient engagement processes

Step two in this model depicts a usable vignette for stakeholder design and gives researchers, clinicians, and patient stakeholders a chance to imagine one way of working together in the process evaluation stages of project implementation. This was a novel addition to the perinatal nursing eHealth field. The processes of patient engagement found in the literature relevant to person-centered perinatal eHealth have in some cases been operationalized and have been used for clear process evaluations less often. Access was operationalized as a mediator rather than as a process for obtaining eHealth modalities/resources and support, and as a concept for capturing fulfilment of intended use volumes (adherence), and frequency of use/logging into systems. The presence of personalization was mostly understood through proxy measures of satisfaction, having informational needs met, and perceptions of flexibility of the program. Commitment was captured through behavioral change theories, as adherence, participation over time, and the typology of participation (evaluation of participation characteristics). Therapeutic Alliance was understood through theoretical model (Fontein-Kuipers, Ausems, et al., 2016), and amount of interactions between healthcare professionals and perinatal users.

Patient engagement practices that make up the processes of person-centered care should be further developed into process measures. The process measures can be used together between perinatal eHealth users and professional care givers, and should be built into new eHealth modalities, such as, digital log keeping and EMA to build better data sets for quality assurance and perinatal practice process evaluations. This study and the development of a model provide a beginning to reframing our investigation of perinatal eHealth programs not only from the perspective of effectiveness toward improvement of health outcomes but in evaluating our actual person-centered care practices. Researchers and policy makers have struggled to innovate eHealth systems due to insufficient reimbursement and legislation that support the use of eHealth systems (Chaudhry et al., 2006). With the model constructed through this Interpretive Synthesis perinatal researchers and clinicians can express concrete reasons for beginning and continuing their travel along person-centered perinatal eHealth system development and quality assurance journeys. As one group of eHealth researchers described in the 2000s, when we travel toward effective design and implementation of eHealth systems, we can think of our work toward our goals using the metaphor of ‘The Land of Oz’. We begin the journey along the yellow brick road, and we eventually want to arrive home (a sustainable, and manageable person-centered eHealth system), but just like in Dorothy’s story our home has been uprooted-as in our care context can be understood as ‘e-scaped’ care-we are looking for a home that will be found in a new location (Dansky et al., 2006). We need to gather all the help from many stakeholders and keep our focus on patient engagement throughout our entire journey. Unlike the case for Dorothy our journey will never fully end, and we will continue with iterative steps along this path to support adaptation along the way.

### 6.4.3 Step Three: Co-creation of perinatal eHealth systems through real-life flexible access to perinatal eHealth modalities

Step three illustrates the various eHealth processes/interactions that occur related to patient engagement. Co-creation illustrates that development toward meaningful, sustainable, and manageable use of eHealth systems will involve a close look at attitudes, values, and habits of users. Researchers exploring eHealth have noted that the immediate impact of eHealth systems on health outcomes is virtually unknown (van Gemert-Pijnen et al., 2011). We recommend that one of the many reasons for this is a lack of basic understandings for how eHealth systems are emerging, what kinds of new meanings they are mediating in practice, and how do eHealth users choose and experience their interactions within the systems.

It has been difficult to reach desired adoption of eHealth technologies in many contexts due to the complexity of the interventions, the need for sound process evaluation/monitoring of quality, and the lack of coordination and communication between many stakeholders (Dansky et al., 2006; Moore et al., 2015; van Gemert-Pijnen et al., 2011). Examining co-creation from a socio-material perspective supports designing systems with the concrete aim of co-creating technological systems with all possible stakeholders. The socio-materiality perspective and a close look at attitudes, values, and habits of eHealth users have been suggested by sociologists and health scientists for nearly a quarter of a decade (Dansky et al., 2006; Nettleton, 2004; van Gemert-Pijnen et al., 2011), and until now, in the area of perinatal eHealth, we have been lacking a practice model that supports examination of vital interactions, contextual factors, and user feedback related to attributes of patient engagement/person-centered perinatal care.

The evidence to support the construction of step three encompasses mainly eHealth users who are interested in and value the use of eHealth and technology in their daily lives. Applying knowledge about the process of adaptation to eHealth systems will be continually limited if researchers do not also investigate the process of helping those who are resistant to using eHealth systems (i.e., counselling on choice for use of eHealth services, and providing education to support eHealth literacy). There should be future research dedicated to those within the population who prefer to opt out of eHealth services, as there is no evidence currently available on this topic with the study of perinatal eHealth.

Some work has been done to understand how disadvantaged or hard to reach groups might be motivated to use perinatal eHealth (Cramer et al., 2018; Doherty et al., 2019a). As research reveals those with extreme disturbances to their health might benefit greatly by the simple act of making their issues know and applying small changes that have a great impact on the health outcomes (i.e., stopping or limiting smoking or drinking alcohol during pregnancy) (van der Wulp et al., 2014; Whitemore et al., 2019). Doherty and colleagues found in a study using an EMA mood tracking perinatal App that women within ethnic minorities were less likely to install the mobile App but once they did install the App there was no difference in level of engagement with the system according to ethnic groups (Doherty et al., 2019a).

## 6.5 Research Implications of using the Model: Responsive and Adaptive Practice

Jarzabkowski (2004) provides insight into the problem of recursive practice, they state that recursive practices will provide structure and boundaries for those providing service but limits the adaptability and responsiveness of health care delivery. Perinatal care has emerged as a health service directed toward the integration of persons' engagement in their own care (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019). The support of new and expectant parents enacts autonomy in care settings such as laboring rooms, antenatal clinics, and neonatal intensive care units is stated as the central focus of woman centered and parent-partnered care models (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019). While terminologies related to patient engagement (i.e., Involvement, participation, collaboration, activation, and empowerment) are consistently present within the relevant literature about perinatal care (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019) a clear interpretation of the concept of engagement as it is shaped by the practices of woman and parent-partnered care models is lacking. Rather than conceptualizing patient engagement within perinatal eHealth as an outcome to be measured once care delivery has occurred it can be conceptualized as a part of the structure and processes of care.

Each attribute of patient engagement can be understood as a component of the structure, processes of care, and outcomes (Donabedian, 2004) of perinatal eHealth. Conditions and actions come together for the promotion of personalized and appropriate perinatal care receival and optimal perinatal outcomes. Perinatal eHealth care providers bring together a unique grouping of disciplines, the expertise, and a dynamic potential for innovation in care are ever present. Further, new, and expectant parents bring their own expertise into the practice of perinatal care, which has become much richer with the use of eHealth modalities. The precepts of person-centered perinatal care are intended to harness the expertise of health users and professionals for the co-creation of positive and optimal care experiences and health maintenance. If we remain closed off to examining the processes and structures of health service, we miss an opportunity to evaluate the usefulness of eHealth systems as adaptive tools for increasing user engagement and person-centered care. The model described in this study supports a focused look at how patient engagement can be consistently integrated into design and implementation to the aim of adapting and applying recursive practices that together support person-centered perinatal eHealth.

# 7 Conclusion

The work of this Interpretive Synthesis and associated study phases have furthered our ability to capture what we thought was familiar, ubiquitous technology use, and perinatal systems in middle and high income countries and frame these elements of societal situations/ health care practice into a new construction that guides re-framing of development and quality assurance (Thorne et al., 2004). In this study three steps of a model were constructed for the integration of patient engagement into perinatal eHealth: (1) Person-centered Perinatal eHealth modality mapping; (2) Process evaluation through monitoring of patient engagement processes; (3) Co-creation of perinatal eHealth systems through real-life flexible access to perinatal eHealth modalities. Due to the popularity of eHealth use and the measurement of patient engagement more work should be done to develop perinatal eHealth in the direction of person-centered perinatal care models. This study recommends that understanding the best fit of eHealth modalities will support the integration of patient engagement into perinatal eHealth systems. Further, planning and developing more process measures that capture patient engagement attributes will help researchers and developers understand their progress toward benchmarks of patient engagement and person-centered care. Finally, testing eHealth systems in real-life contexts will allow for more personalization and interpretation of the adaptation process of integrating eHealth modalities into perinatal care services.

This study revealed that with the use of eHealth in maternity and neonatal care providers can co-create and enact the practices associated with patient engagement through three steps of the patient engagement model of perinatal eHealth. In eHealth structures of care responsibility for the maintenance of wellness can be in the hands of expectant mothers, their families, and the healthcare providers. Perinatal eHealth structures are being tested and implemented and in this way patient engagement has the potential to become normalized within these care networks. The next step is to explain our design, development, and quality assurance work concretely and through the explicit mention of patient engagement structures and processes. The model can aid in the description of explicit patient engagement elements when explaining design plans to investors, insurance companies and legislators in perinatal preventative and acute care provision.

Perinatal eHealth is facilitating the earlier traditions of perinatal care by offering education, coaching on new skills for parents, and support for healthy lifestyles in pregnancy, and promoting utilizing medical services when required. Pregnant users and family members can obtain the resources, information, guidance, and tools for their perinatal care in a free-living context. What is then transformed is their capacity to participate in their own perinatal care journeys. This has shown to affect the level of client confidence, feelings of normalcy during pregnancy and early parenting experiences, and changes the activities required by professional caregivers during the perinatal periods from ‘doing for’ health users to facilitating perinatal service. Health organizations, researchers, and clinicians are aiming to promote patient engagement of perinatal health users through access to digital programs, apps, and wearable devices for self-monitoring procedures, what is needed now, is a sustained focus on developing and monitoring quality with an eye on explicit patient engagement elements, this has the potential to support the innovation and sustainment of wholistic perinatal eHealth systems.

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# Appendix

**Appendix 1.** Description of measures used in hypothesis testing of CO-PARTNER tool (Original publication IV).

## Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is used to screen for anxiety and depression. The HADS is made up of two 7-item scales, for anxiety and depression respectively. The two scales score between 0-21. (1)

## PMP-SE

The Perceived (Maternal) Parenting Self-Efficacy (PMP-SE) tool is used to measure perceived parental self-confidence during their care of their infant who has been admitted to the Neonatal Ward. (2) The internal consistency reliability of the PMP-SE is 0.91, external/test-retest reliability is 0.96. A total of four subscales of parenting are included and are: “Care taking procedures”; “Evoking behavior(s)”; “Reading behavior(s) or signaling”; and “Situational beliefs”. Items are rated in a four-point Likert scale ranging from ‘strongly disagree’ (score 1) to ‘strongly agree’ (score 4). Low scores on the PMP-SE indicate low parental self-efficacy.

## EMPATHIC-N

EMpowerment of PArents in THe Intensive Care - Neonatology questionnaire (EMPATHIC-N) measures parental satisfaction. (3) This questionnaire was developed and tested in a single center in the Netherlands. The EMPATHIC-N consists of five domains: Information; Care and Treatment; Parental Participation; Organization; and Professional Attitude.

## PBQ

The Postpartum Bonding Questionnaire (PBQ) is a screening instrument for the detection of bonding problems in obstetric and primary care services. (4) The PBQ is a 25- item scale that illustrates a parent’s feelings or attitudes towards their baby. The screen instrument is scored on a 6-point Likert type scale ranging from always (score=0) to never (score=5). Low scores indicate good bonding. The PBQ has four subscales: rejection and anger; anxiety about care; and risk of abuse.

## PSS-NICU

The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS-NICU) is a scale used to measure parental perceptions of stressors associated with hospitalization of their child. (5) The PSS-NICU measures parents' perceptions of stressors arising from the physical and emotional environment. It has a minimum score of 46, and a maximum score of 230. Previous internal consistencies have been 0.89 - 0.94.

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2. Barnes CR, Adamson-Macedo EN. Perceived Maternal Parenting Self-Efficacy (PMP S-E) tool: Development and validation with mothers of hospitalized preterm neonates. J Adv Nurs. 2007;60: 550–560. doi:10.1111/j.1365-2648.2007.04445.x
3. Latour JM, Duivenvoorden HJ, Hazelzet JA, Van Goudoever JB. Development and validation of a neonatal intensive care parent satisfaction instrument. Pediatr Crit Care Med. 2012;13: 554–559. doi:10.1097/PCC.0b013e318238b80a
4. Brockington IF, Fraser C, Wilson D. The Postpartum Bonding Questionnaire: A validation. Arch Womens Ment Health. 2006;9: 233–242. doi:10.1007/s00737-006-0132-1
5. Miles MS, Funk S, Carlson J. Parental Stressor Scale: Neonatal Intensive Care Unit. Nurs Res. 1993;42: 148–152.

**Appendix 2.** Table of behavioral change theory use (Adapted from Original Publication I supplementary file):

| | Kennelly et al. (2016),(2018) | Krishnamurti et al. (2017) | Himes et al. (2017) | Willcox et al. (2015), (2017) | Soltani et al. (2015)<br>Hawkins et al. (2019) | Demment et al. (2014) | Carrilho et al. (2019) | van der Wulp et al. (2014) | Davis et al. (2018) | Herbec et al. (2014) | Ledford et al. (2015), (2017) | Abroms et al. (2017)<br>Baruth et al. (2019)<br>Choi et al. (2015)<br>Herring et al. (2019)<br>Naughton et al. (2012),(2013),(2017)<br>Whitemore et al. (2019) | Harris et al. (2015) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Behaviour Change Wheel | X | | | | | | | | | | | | |
| Behaviour Decision Research Paradigm | | X | | | | | | | | | | | |
| Behavioural Economics | | | X | | | | | | | | | | |
| CALO-RE Taxonomy of Behaviour Change | | | | X | | | | | | | | | |
| Control theory and lifestyle interventions[1] | | | | | X | | | | | | | | |
| Fishbein And Yzer's Integrative Model of Behavior Prediction | | | | | | X | | | | | | | |
| Human Centered Design Approach | | | | | | | X | | | | | | |
| I-Change Model | | | | | | | | X | | | | | |
| Information-Motivation-Behavioural-Skills-Approach | | | | | | | | | X | | | | |
| PRIME theory of motivation and addiction | | | | | | | | | | X | | | |
| Self-determination Theory | | | | | | | | | | | X | | |
| Social Cognitive Theory | | | | | | | | | | | | X | |
| Stages of Change Ladder | | | | | | | | | | | | | X |

**Appendix 3.** Perinatal eHealth modality definitions.

| eHealth Modality | Definition |
|---|---|
| Tailored Feedback | Information purposefully developed through the collection and synthesis of personalized pregnancy/infant age progression, health status, and circumstantial data (i.e., unique personal profiles). The information output is feedback for health users. |
| On-demand Tailored Information | Information outputs developed through the eHealth modality of 'Tailored Feedback' is made available 24/7 to health users (i.e., SMS messages, health progress trends with tips for improvement, weblinks to videos, games, or pdf articles with personally relevant evidence). |
| On-demand Information & Resources | Information and resources are mainly made available through use of Apps. The information is available 24/7 through search functions, and resources can include videos, instructions about assessing or reporting health record data, or requesting to contact health professional. |
| Self-monitoring | The access to remote health data tracking using a wearable device. The self-monitoring systems also include a link to sharing the collected data in real-time to healthcare professionals using Bluetooth connectivity and a secure cloud server. |
| Remote Communication | Asynchronous or synchronous communication that is used in between clinic visits. Devices such as smartphones, tablets, laptops, or desktop computers are used in a variety of ways to maintain communication and connectivity between perinatal health users and their health providers |
| Online Games | Serious games used for promoting perinatal education and competency acquisition. |
| Partnered Paired Devices | Applications or wearable devices that function to inform members of the family in real-time of trends in the pregnant parent's health and symptoms (i.e., nausea and vomiting symptoms). |
| EMA Logging | Ecological Momentary Assessment is a modality that functions to monitor perinatal client's thoughts, behavior, and experiences in their daily lives close to or in real-time.* |
| Digital Log Keeping | The collection of information and notations that a perinatal client makes for themselves that links to their personal health profile, is searchable 24/7 and can be stored and accessed through a smartphone or other digital device. |
| Decision Support | A feature in an eHealth system that allows for data, personal health, and circumstantial content to be used to build recommendations for health decision-making. The information is viewable and often shared in real-time with perinatal healthcare providers to support the process of shared decision making. |
| Goal Setting | A feature in an eHealth system that allows for data, personal health, and circumstantial content to be used to develop useful personal goals or gives the opportunity for the individual client to interpret their health habits and status toward personal goals. They should be able to record their goals within the eHealth system also in the form of 'Digital Log Keeping'. |
| Peer Support | Asynchronous or synchronous communication with perinatal client peers or veteran parents. This is made possible through mediated social chats/forms or through a special contact feature within eHealth systems that links perinatal health users directly with other health users or veteran parents who wish to be of support. |

*https://www.gov.uk/guidance/ecological-momentary-assessment

# Original Publications

**Auxier, J., Bender, M, Hakojärvi, H, & Axelin, A. (2023)**
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SCOPING REVIEW

# Patient engagement practice within perinatal eHealth: A scoping review

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## Abstract

**Background:** There is a gap in knowledge about how perinatal eHealth programs function to support autonomy for new and expectant parents from pursuing wellness goals.

**Objectives:** To examine patient engagement (access, personalization, commitment and therapeutic alliance) within the practice of perinatal eHealth.

**Design:** Scoping review.

**Methods:** Five databases were searched in January 2020 and updated in April 2022. Reports were vetted by three researchers and included if they documented maternity/neonatal programs and utilized World Health Organization (WHO) person-centred digital health intervention (DHI) categories. Data were charted using a deductive matrix containing WHO DHI categories and patient engagement attributes. A narrative synthesis was conducted utilizing qualitative content analysis. Preferred Reporting Items for Systematic Reviews and Meta-Analyses 'extension for scoping reviews' guidelines were followed for reporting.

**Results:** Twelve eHealth modalities were found across 80 included articles. The analysis yielded two conceptual insights: (1) The nature of perinatal eHealth programs: (1) emergence of a complex structure of practice and (2) practising patient engagement within perinatal eHealth.

**Conclusion:** Results will be used to operationalize a model of patient engagement within perinatal eHealth.

KEYWORDS
implementation, perinatal care, technology

## 1 | INTRODUCTION

Perinatal periods are a time when new and expectant parents should receive support towards health-related behaviours, health prevention and coaching to maintain wellness and closeness with infants (Hantsoo et al., 2018; Hawkins et al., 2019; He et al., 2021; Marko et al., 2016). Intensive, frequent, quality health behaviour coaching and counselling of new parents is important during perinatal periods to promote patient engagement and positive perinatal outcomes (Danbjørg et al., 2014; de Mooij et al., 2018; Himes et al., 2017;

Kennelly et al., 2016). Perinatal patients perceive care as satisfactory when it is personalized and supports health engagement (Labrie et al., 2021; Phillippi et al., 2016).

eHealth perinatal care that focuses on involving patients has the potential to improve quality of care (van den Heuvel et al., 2018). New models of perinatal care are emerging that show promise for benefiting perinatal patients, these aim to improve participation and collaboration between families and professional care providers (de Mooij et al., 2018; Nelson & Holschuh, 2021). Few studies have investigated how eHealth programs support parents to engage throughout the entire perinatal continuum. Perinatal care has been historically fragmented between services for maternity and neonatal care, which has limited parents' ease in engaging (Molenaar et al., 2018). Integrated eHealth systems might support the harmonization between maternity and neonatal care programs, which might be the bridge that leads to more patient participation. Examining patient engagement practices within perinatal eHealth could illuminate ways for integration of programs that are engaging, personalized and less fragmented between maternity and neonatal care.

In 2015, the World Bank Group, the United States Agency for International Development (USAID) and the World Health Organization (WHO) strongly recommended the 'use of the digital revolution to scale up health interventions and engage civil society' (World Health Organization, 2018). Patient engagement is a bedrock philosophy for healthcare policy and practice in the United States of America (USA) and the United Kingdom (UK) (Gibson et al., 2012; Millenson & Macri, 2012). Financial incentives and support are being offered for care systems that demonstrate practices of patient engagement in the USA and UK (Gibson et al., 2012; Millenson & Macri, 2012). Patient engagement integration into health policy has been discussed in the last decade; however, the operationalization, mention of a clear definition and monitoring of patient engagement as a structure, process and outcome lack consistency (van den Heuvel et al., 2018).

## 2 | BACKGROUND

### 2.1 | Principles of perinatal patient engagement

The principles of woman- and family-centred care are central to perinatal care, consider the individual parent and aim for interactions between health providers and individuals that promote collaboration and shared decision-making (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019). Patient Engagement is conceptually linked to woman- and family-centred care. The practices associated with patient engagement cannot be captured within a single measure or indicator (Barello et al., 2016; Higgins et al., 2017; Kelders, van Zyl, & Ludden, 2020). Higgins et al. (2017) proposed that the meaning of patient engagement deserved scrutiny, and other researchers pose that patient engagement is multifactorial and works through structures, processes and behaviours (Higgins et al., 2017; Kelders, Kip, & Greeff, 2020). In a concept analysis, patient engagement was defined as both a 'process and behaviour [that] is shaped by the relationship between the patient and provider and the environment in which healthcare delivery takes place' (Higgins et al., 2017). Four attributes of patient engagement provide conceptual components for inquiry: (1) access, (2) personalization, (3) commitment and (4) therapeutic alliance (Higgins et al., 2017). Access refers to the ability of the patient to obtain all health resources required to experience high-quality and appropriate care (Higgins et al., 2017). Personalization assures that the interventions conform to the unique circumstances of the patient (Higgins et al., 2017). Commitment is the cognitive and emotional factors that empower the patient to exploit health resources and therapeutic alliance represents the elements of the patient–provider relationship that impact engagement in care (Higgins et al., 2017).

### 2.2 | Examination of person-centred perinatal eHealth practices

Perinatal eHealth programs have not been examined using clear definitions of person-centred and patient engagement practices. Implementation of eHealth interventions in perinatal practice should begin with the definition of patient engagement and a clear understanding of person-centred digital health interventions (DHI), as defined by the WHO (World Health Organization, 2018). WHO classifications of person-centred DHI contain four categories of patient activities intended to support their health self-management (World Health Organization, 2018). These four categories lay the foreground for person-centred perinatal eHealth and are as follows: (1) Targeted client communication; (2) client-to-client communication; (3) personal health tracking and (4) on-demand information services.

If integrating patient engagement into perinatal eHealth is to meet or exceed the promise as a novel system that supports current values of person-centred perinatal practice, research needs to be conducted to examine the nature of perinatal eHealth, and how the attributes of patient engagement are being practised within programs. Here, this scoping review identifies the nature and range of person-centred perinatal eHealth and illustrates how the attributes of patient engagement are practised within these programs. The research question guiding this review was: What is the nature and range of perinatal eHealth practice characterized by integration of the four WHO person-centred DHI categories and patient engagement attributes?

## 3 | METHOD

### 3.1 | Design

A scoping review was suited for mapping person-centred perinatal eHealth due to the complexity of this topic (Tricco et al., 2018). Considering the complexity and interdisciplinary nature of the perinatal eHealth practice we utilized an iterative process for data charting, analysis and synthesis recommended by Daudt et al. (2013) and endorsed by Pham et al. (2014). The aim of this scoping review was to develop an understanding of the nature and range of perinatal eHealth and identify gaps in the research to inform practice, policymaking and future research (Daudt et al., 2013). A systematic approach for this scoping review was further guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—extension for scoping review (PRISMA-ScR) guidelines (Tricco et al., 2018).

## 3.2 | Search strategy

Five electronic databases (Web of Science, Scopus, PubMed, Eric and Cumulative Index to Nursing and Allied Health Literature) were searched in January 2020 and again on April 26th, 2022, to include all studies up to the end of 2021. We used an expansive list of search terms to incorporate person-centred perinatal eHealth programs. See Table 1 for a list of general search terms and keywords. All citations were exported into RefWorks and Rayyan citation software for storage, screening and management (Ouzzani et al., 2016).

## 3.3 | Study selection

All reports included were published in English, had abstracts available, and no date limitations were set for the in original search. Studies were included that reported on person-centred perinatal eHealth programs, target users were new or expectant parents, programs were delivered during pregnancy, 6–8 weeks after birth (puerperium) and in the case of neonatal care, from birth up to the time a neonate receives care in neonatal or public health services (commonly near 44 weeks postmenstrual age). Puerperium has been defined as 6 weeks after birth (Aisien, 2021); however, inconsistencies in reporting this period occur and often range from 6 to 8 weeks after birth. All programs would contain at least one of the four WHO patient-centred DHI categories (World Health Organization, 2018). Studies were not included if the technology was meant to be used without a two-way interaction between health providers and clients; the eHealth system was using only outdated forms of telehealth (i.e. follow-up telehealth phone calls, paging or faxing) or the system was used solely for diagnostic screening.

TABLE 1 Search keywords.

| Keywords for search |
|---|
| Expectant Mothers, pregnancy, parent, family, partner, father |
| AND |
| Patient Engagement, Personalization, Decision Making, tailored care, tailoring information, tailoring resources, individual preferences, access to information, access to resources, access to guidance, healthcare availability, health service access, functional literacy, health literacy, commitment, patient commitment, motivation, patient-provider relationship, therapeutic alliance, communication, empathy, mutual understanding, trust, therapeutic relationship |
| AND |
| Randomized Controlled Trial, group, feasibility, acceptability, exploratory, mixed-method, Quasi-Experimental Studies, non-randomized controlled trial, qualitative studies |
| AND |
| Handheld, mobile, Computers, ipad, iphone, smartphone, cell phone, wireless, mHealth, Telemedicine, mobile health, eHealth, Wearable, application, External Fetal Monitoring, remote monitoring |
| AND |
| maternal care, antepartum, prenatal, perinatal, postnatal, neonatal, postpartum |

## 3.4 | Data charting

Descriptive characteristics of all included studies were charted by two researchers (J.A. & H.H.). Descriptive data included:

(1) Author, year and country, (2) Study design, (3) Aim, (4) Target population and setting, (5) Program structure/devices, (6) WHO DHI categories, (7) Engagement evaluation and (8) eHealth modalities. Deductive and inductive content were charted according to codebook.

## 3.5 | Data analysis

Content analysis was performed for examining perinatal eHealth programs. Our initial codebook consisted of deductive codes related to access, personalization, commitment and therapeutic alliance and the four WHO DHI person-centred categories (Higgins et al., 2017; Kyngäs et al., 2020a; World Health Organization, 2018). We ensured validity of our codebook development by separating maternity and neonatal studies, ensuring careful organization and separation of inductive meaning units that came from maternity and neonatal programs. eHealth modalities and perinatal treatments were inductively identified and defined through careful examination of data about the eHealth programs' structure and device use (Kyngäs et al., 2020b). Treatment and eHealth modality categories were added to the codebook after consultation with first, third and fourth authors (Kyngäs et al., 2020b). Next meaning units were identified based on a matrix of deductive and inductive concepts (Graneheim & Lundman, 2004). The first author extracted meaning units and suggested associated codes, these were reviewed by the last author for clarity and consistency of coding. Codes were developed from condensed meaning units from maternity and neonatal services separately (Graneheim & Lundman, 2004). Subcategories were developed from harmonization of codes, some codes in maternity and neonatal services overlapped and some remained unique (Graneheim & Lundman, 2004). The latent content of categories was formulated into two main themes (Graneheim & Lundman, 2004). Agreements about interpretations of the latent content were made in consultation between the first, second and fourth authors. The decisions stemming from these consultations support the fit of the evidence to the final interpretations of latent content (Tavory & Timmermans, 2014, pp. 105–106).

## 3.6 | Ethics

This study did not require ethical approval or client consent.

# 4 | RESULTS

## 4.1 | Study selection

First and third authors reviewed 1555 titles and abstracts independently. Full-text review for screening was performed in 257 sources due to abstract inconsistency. The fourth author and a research assistant provided support when agreement was not reached, and 80 sources were selected for review (Maternity $n=58$, Neonatal $n=22$; See Figure 1; Page et al., 2021).

## 4.2 | Study characteristics

Thirty-nine maternity programs and 17 neonatal programs were included in this review ($n=56$). See Table S1 for charted data. Programs were delivered mainly in North America, the United Kingdom and Europe (See Table 2). Twelve eHealth modalities (See Figure 2) and 15 different treatments (Figure 3) were used in the programs. Programs integrated one to four of the WHO DHI person-centred categories (Table S1). Healthcare providers included nurses, midwives, primary and special practice doctors, as well as public health, breastfeeding and co-parenting experts, dieticians, lifestyle coaches and community health workers. In 53.6% ($n=30$) of perinatal programs nurses were involved in provision of care, program development or research activities. All neonatal programs integrated nurses in provision of care, alternatively maternity programs reported nurses' work in 16 out of 42 programs (38.1%). Fifteen percent of the studies were published in recognized nursing journals (Scimago Lab, 2021).

## 4.3 | The nature of perinatal eHealth programs: Emergence of a complex structure of practice

Perinatal eHealth programs make up a structure of practice that developed through new interactions and processes mediated by eHealth modalities. The design and implementation of perinatal eHealth programs are emerging as the availability of new eHealth systems (i.e. applications and machine learning-based tailored feedback), and ubiquitous devices (i.e. smartphones and wearables) increases. The current generation of new families identifies with perinatal eHealth (Danbjørg et al., 2015; Gund et al., 2013; Herring et al., 2019; Soltani et al., 2015). The modality combinations and use within programs are complex, used for a broad range of person-centred care goals (See Figure 2). All programs are divided according to maternity or neonatal contexts (See Figure 3).

Programs for supporting parents at home in the care of their infants were found to be easy to use, relevant and understandable to users (Abbass-Dick et al., 2017; Danbjørg et al., 2015). In one case, using an early discharge digital support for parents, a father was showing nurses how to use the technology and his partner stated, 'my boyfriend is technical, so it was [basically] him showing the nurses how it worked' (Danbjørg et al., 2014). Pregnant women expressed comfort in using devices and applications that they could take with them anywhere, to receive information anytime (Himes et al., 2017; Wierckx et al., 2014). Users expressed wanting to use the programs beyond the study periods and wished for more harmonized systems throughout the entire perinatal period (Krishnamurti et al., 2017; Shorey et al., 2018). Most programs across both maternity and neonatal contexts were focused on a single care objective.

## 4.4 | Practising patient engagement within perinatal eHealth

Unique practices related to each attribute of patient engagement are summarized in Table 3 and described below in a more detailed narrative synthesis. Access and personalization were integrated into each program, whereas commitment and therapeutic alliance were absent from 3 and 8 programs respectively (See Supplementary Material S4: Table S3).

### 4.4.1 | Access

Access is practised in programs through the provision of eHealth modalities that support new opportunities for new or expectant parents to participate in self-care, health promotion and illness prevention. eHealth modalities mediate new interactions that support the access to appropriate care and potentiate support for increased knowledge, skill and capacity for self-management of pregnant persons' and families' wellness and development.

eHealth programs aimed to give access to on-demand health information and resources, communication and tailored feedback intended to support families in building confidence, familiarity, knowledge and awareness in health promotion and illness prevention activities (Banerjee et al., 2020; Baron et al., 2018; Cramer et al., 2018; Doherty et al., 2019; Fontein-Kuipers et al., 2016; Shorey et al., 2018; Spargo & Vries, 2018; Strand et al., 2021; Wierckx et al., 2014). Patients had more convenient communication experiences with their health professionals, timely information through feedback and self-monitoring modalities, and could lead content and timing of communication (Dalton et al., 2018; Doherty et al., 2019; Herring et al., 2019; Holm et al., 2019). Medical and non-medical issues were brought to the forefront of the maternity patients' minds through access to information and communication (Carrilho et al., 2019; de Mooij et al., 2018; Himes et al., 2017; Krishnamurti et al., 2017; O'Brien et al., 2013; Soltani et al., 2015). Parents had opportunities to be involved in the care of their infants in new ways through access to NICU automated updates through

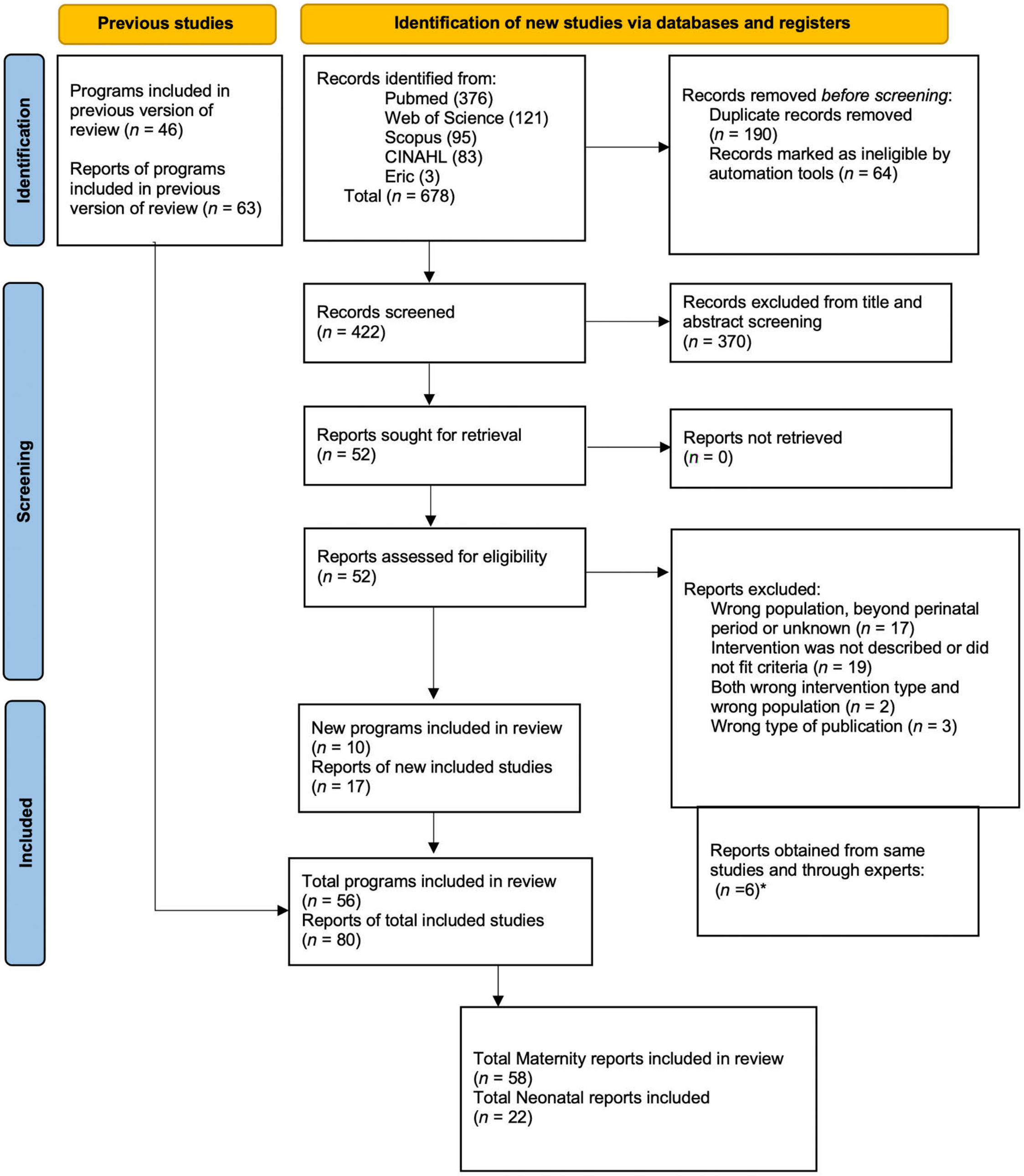


FIGURE 1 PRISMA 2020 flow diagram for updated systematic reviews.

short message service (SMS) (Globus et al., 2016), and infant care and collaboration training using education and coaching applications (Banerjee et al., 2020; Platonos et al., 2018). Women and their families received new access to the care team from remote locations which supported timely appropriate care, in many cases from the comfort of their own homes (Doherty et al., 2020; Garne et al., 2016; Gund et al., 2013; Holm et al., 2019; Payakachat et al., 2020; Shorey et al., 2018; Strand et al., 2021; Triebwasser et al., 2020).

### 4.4.2 | Personalization

User-centred program design practices supported personalization. eHealth practices included the provision of personal care experiences that were founded on woman-and family-centred approaches. Personalization practices encompass tailored, on-demand, flexible programs and consider new and expectant parents' preferences, needs, values and diversity.

TABLE 2 Included studies' context and characteristics.

| Study characteristics (*N* = 80) | Number of studies % (*N*) |
|---|---|
| Continent | |
| Asia | 2.5 (2) |
| Australia/New Zealand | 7.5 (6) |
| United Kingdom | 18.7 (15) |
| Europe | 17.5 (14) |
| North America | 52.5 (42) |
| South America | 1.2 (1) |
| Study design | |
| Qualitative Exploratory | 18.75 (15) |
| User-Centred/Design Research | 13.75 (11) |
| Participatory Action Research/Implementation | 10.0 (8) |
| Conference and other Reports of Development | 7.5 (6) |
| Randomized control trial | 50.0 (40)[a] |
| Nursing journal publications | |
| Maternity (*N* = 58) | 10.3 (6) |
| Neonatal (*N* = 22) | 27.3 (6) |
| Characteristics of eHealth programs (*N* = 56) | |
| Perinatal setting | |
| Maternity | 75.0 (42) |
| Neonatal | 25.0 (14) |
| Nurse involvement in perinatal eHealth | |
| Maternity *N* = 42 | 38.1 (16) |
| Neonatal *N* = 14 | 100.0 (14) |

[a] Eight of which were protocol reports; Two of which were mixed methods.

Programs were very often designed using a participatory design (PD), or user-centred design model. Involving key stakeholders (e.g. professional, informal caregivers and patients) in the design of eHealth programs was seen to encourage engagement and sustainable uptake of perinatal programs (Danbjørg et al., 2015; Payakachat et al., 2020; Strand et al., 2021). One research team in Canada developed a way of recording interactions with the C-Care application throughout real-time testing and modified the program during testing to accommodate higher interaction with the system (Ke et al., 2021). Functions included automated text messages personalized to the individual's unique circumstances, which supported core woman-and family-centred concepts such as reciprocity, tailored care and shared decision-making (Danbjørg et al., 2015; Doherty et al., 2020). Users expressed that having understandable, individualized, relevant and timely information met their support needs during pregnancy, labouring at home and in early days at home with their infants (de Mooij et al., 2018; Frize et al., 2013; Gibson et al., 2021; O'Brien et al., 2013; Ridgeway et al., 2015; Willcox et al., 2015; Yee et al., 2021). One woman described that she felt a personal care experience while using remote foetal monitoring system at home, because nurses could see what was happening on their own monitors and coordinate with her at a distance (O'Brien et al., 2013). While parents using an Application to support early discharge home after birth found that staying home and getting timely answers to their questions using remote communication had a positive impact on their affinity within the family (Danbjørg et al., 2015).

### 4.4.3 | Commitment

Commitment is practised in programs through integration of behavioural change and self-efficacy theories during the development and design (See Supplement Material S3: Table S2). eHealth modalities mediated new opportunities for patients to become meaningfully

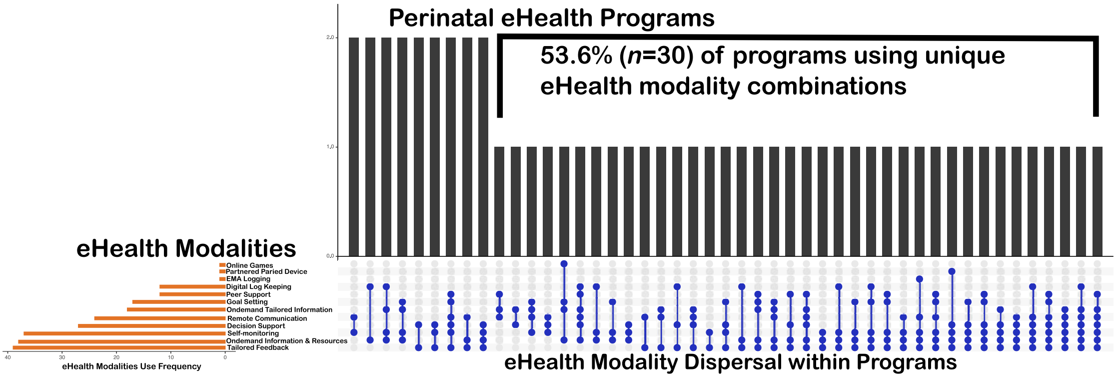
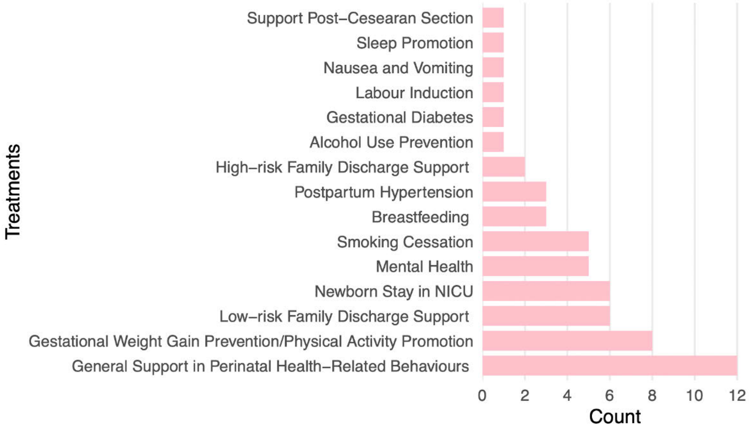


FIGURE 2 Perinatal eHealth programs and modalities.

FIGURE 3 Treatments within Perinatal eHealth programs.



involved in their own care processes. Commitment was also practised through the supporting of new ways to coach and connect with patients. Lastly, new interactions mediated by eHealth modalities supported new processes of becoming committed to self and newborn care.

Perinatal eHealth programs change the face of connectivity and coaching for new or expectant parents. Tailored alerts and information sharing directed to the personal handheld devices of patients changes their capacity to interact as members of the care teams (Choi et al., 2015; Danbjørg et al., 2015; Davis et al., 2018; Frize et al., 2013; Herring et al., 2019). eHealth patients have a chance to view information and their own personal health data and trends on demand (Abbass-Dick et al., 2017; Isetta et al., 2013; Valencia et al., 2020; van der Wulp et al., 2014). These opportunities are mediated by eHealth modalities such as tailored feedback, decision-making supports, digital log keeping and self-monitoring. Perinatal patients can participate in shared decision-making with new confidence and receive contact and coaching when and where they would like it (Danbjørg et al., 2015; de Mooij et al., 2018). Meaningful involvement in perinatal care processes was a motivating factor for many perinatal patients. They could look at their own personal trends, record and report their findings (i.e. for newborn assessment or pregnancy weight gain or blood pressures) and support care decisions and goal setting with their professional care givers (Davis et al., 2018; Dougall et al., 2020; Garfield et al., 2016; Isetta et al., 2013; Rhoads et al., 2017).

Perinatal patients experienced becoming committed for self and newborn care enabled through new interactions mediated by eHealth modalities. Maternity programs supported motivation for behaviour changes through interactive tools, and feedback, as was seen in Doherty and colleagues 'ideas machine' a feedback system that used user input about preferences and experiences to deliver tailored tips for achieving goals for mental wellness in the moment (Doherty et al., 2019). Parents of newborns were able to become committed to learning and practising their new roles when just returning from hospital with access to on-demand information and resources that were provided in many formats, instructional videos, links to go deeper on topics, and pages they could 'favourite' for reading later (Danbjørg et al., 2015; Garfield et al., 2016; Isetta et al., 2013; Shorey et al., 2018; Strand et al., 2021).

### 4.4.4 | Therapeutic alliance

Perinatal eHealth practices that integrate therapeutic alliance encompass new provider–patient interactions, and eHealth-driven emotional and lifesaving supportive activities. eHealth components are seen as partners in care, and the fostering of teamwork through remote communication are important features from the patients' perspective. Therapeutic alliance is supported through consideration for the integration of eHealth modalities into workflows, and eHealth policies.

Therapeutic alliance is practised through considering policy and physical infrastructure and staff attitudes, and capacity to use eHealth modalities as guiding factors for successful implementation of new eHealth practices (Banerjee et al., 2020; Baruth et al., 2019; Bower et al., 2005; Dalton et al., 2018; Danbjørg et al., 2015; Doherty et al., 2020; Frize et al., 2013; Globus et al., 2016; Herring et al., 2019; Jefferson et al., 2019; Strand et al., 2021; Triebwasser et al., 2020; Wierckx et al., 2014). Self-monitoring and sharing of data to aid in collaborative clinical interpretations and decision-making emerged as new patient–provider interactive processes. Some perinatal patients used data to guide conversations, and other times clinicians were triggered through the automated systems to contact patients because of concerning data or events (i.e. abnormal blood pressure readings or mental health alerts) (Hantsoo et al., 2018; Krishnamurti et al., 2017; O'Brien et al., 2013; Rhoads et al., 2017; Strand et al., 2021). Self-monitoring and remote communication modalities mediated lifesaving and emotional support provision by professional caregivers at a distance (Doherty et al., 2020; Holm et al., 2019; Jefferson et al., 2019; Ledford et al., 2017; Marko et al., 2016; Rhoads et al., 2017; Strand et al., 2021). Perinatal eHealth patients explained that they felt companionship with some eHealth

**TABLE 3** Novel practices of patient engagement within eHealth: Categories and sub-categories from content analysis.

| **Patient engagement categories** | **Subcategories of practices of patient engagement within eHealth % (*N*) of programs** | | | |
|---|---|---|---|---|
| **Access**<br>Receival of resources, guidance and tools. Adaptability of services for personalized access.[a] | Maternity<br>100 (39) | • Access has the potential to support increasing health knowledge, skill and management of care needs with new eHealth modalities **56.4 (23)**<br>• Access supports new opportunities for participation **94.9 (37)**<br>• Access to eHealth allows for receiving appropriate care through new care interactions **89.7 (35)** | Neonatal<br>100 (17) | • Access gives opportunities for support for increasing health knowledge, skill and confidence building with new eHealth modalities **70.6 (12)**<br>• Parents get to practise new ways of caring for self and newborns by having access to eHealth **70.6 (12)**<br>• Access to eHealth program modalities allows for more opportunities for appropriate care **41.2 (7)** |
| **Personalization**<br>Provision of unique and tailored services that align with clients' life circumstances and diversity.[a] | Maternity<br>100 (39) | • Designed systems consider the diversity and preferences of target users **61.5 (24)**<br>• The individual perinatal eHealth user is considered throughout healthcare journey **43.6 (17)**<br>• Perinatal eHealth users receive a personal care experience **43.6 (17)** | Neonatal<br>100 (17) | • Designed systems consider the diversity of target users **76.5 (13)**<br>• The individual family is considered throughout healthcare journey **58.8 (10)**<br>• Parents experience personal eHealth care interactions **58.8 (10)** |
| **Commitment**<br>Harnessing cognitive and emotional factors that empower clients to exploit health resources available. Commitment is demonstrated by client efforts over time and is more inclusive than simple motivation that may waiver according to changing circumstances.[a] | Maternity<br>94.9 (37) | • Commitment examined through behaviour theories of change **56.4 (22)**<br>• New ways of becoming committed were stimulated through new eHealth care interactions **59.0 (23)**<br>• eHealth supported coaching and connectivity in new ways **74.4 (29)**<br>• Meaningful involvement is a demonstration of commitment and was enabled in new ways with the use of digital health **56.4 (22)** | Neonatal<br>94.1 (16) | • Commitment examined through behaviour and self-efficacy theories **5.9 (1)**<br>• New ways of Becoming committed were stimulated through new eHealth care interactions **52.9 (9)**<br>• eHealth supported coaching and connectivity in new ways **58.8 (10)**<br>• eHealth mediates new opportunities for parents to become meaningfully involved in the care processes of their infants **17.6 (3)** |
| **Therapeutic Alliance**<br>Incorporates elements of the client-provider relationship including quality of the clinical interaction, communication, empathy, or mutual understanding.[a] | Maternity<br>82.1 (32) | • Professional caregivers and patients interact in new ways with the use of eHealth modalities **46.2 (18)**<br>• Some eHealth functionalities are seen as 'partners in care' **76.5 (13)**<br>• Emotional and lifesaving support can be received using eHealth modalities **58.8 (10)**<br>• Integration of eHealth modalities into current practice structure has potential to support sustainability of programs (ensure capacity for eHealth practice is supported) **41.0 (16)**<br>• Perinatal eHealth users want to have communication and perform teamwork with professional caregivers using eHealth modalities, but this was not used in the program due to objections from providers **2.6 (1)** | Neonatal<br>94.1 (16) | • Professional caregivers and patients interact in new ways with the use of eHealth modalities **64.7 (11)**<br>• Some eHealth functionalities are seen as 'partners in care' **29.4 (5)**<br>• Emotional and lifesaving support can be received using eHealth modalities **23.5 (4)**<br>• Integration of eHealth modalities into current practice structure has potential to support sustainability of programs (ensure capacity for eHealth practice is supported; involve the perspectives for sustainability from care staff to ensure possibility for 'buy in') **64.7 (11)**<br>• Perinatal eHealth users want to have communication and perform teamwork with professional caregivers using eHealth modalities, but this was not used in the program due to objections from providers **5.9 (1)** |

[a] Higgins, T., Larson, E., & Schnall, R. (2017). Unraveling the meaning of patient engagement: A concept analysis. *Patient Education and Counseling*, *100*(1), 30–36. https://doi.org/10.1016/j.pec.2016.09.002.

components, with one women saying that the eHealth program was the 'only person in [her] life who asked…how [she] was doing everyday' (Krishnamurti et al., 2017). Interactions between perinatal patients and the eHealth modalities provided new forms of support to supplement face-to-face visits (Banerjee et al., 2020; Danbjørg et al., 2015; Doherty et al., 2020; Herbec et al., 2014; Himes et al., 2017; Hirshberg et al., 2018; Holm et al., 2019; Ledford et al., 2017; Shorey et al., 2018; Soltani et al., 2015; Strand et al., 2021; van der Wulp et al., 2014; Yee et al., 2021).

# 5 | DISCUSSION

## 5.1 | Principal results

This is the first review to bring together perinatal eHealth programs, treatments and modalities, with the aim of describing the range of practices and conceptualizing the nature of perinatal person-centred eHealth. Perinatal eHealth programs in the developed world make up a structure of practice that contains person-centred eHealth modalities and separates care between maternity and neonatal practices. Nursing leadership might be lacking in the structure development and process evaluation of perinatal eHealth due to the high percentage of studies and programs that are not reporting on nursing expertise. Access and personalization are being practised in all perinatal eHealth programs, and commitment and therapeutic alliance are lacking in a 19.6% ($n=11$) of all programs. Findings from this review reveal that person-centred and patient engagement practices are being used within the current structure; however, development and design of these programs lack harmonization between maternity and neonatal care, and consistency of commitment and therapeutic alliance practices.

## 5.2 | The nature of perinatal eHealth programs

A summary of the programs captured in this scoping review illustrates that perinatal eHealth is being provided across various perinatal treatments; from health promotion and symptom management in pregnancy, to parental skill development in caring for, breastfeeding and monitoring infants and supporting parental-infant closeness (See Figure 3). No programs have harmonized maternity and neonatal treatments across the continuum of the perinatal period into a single eHealth program. A structure of siloed care has been persistent in perinatal care programs internationally due to the growing complexity and specialization of services (Liu, 2016; Molenaar et al., 2020). Uncoordinated services have led to low engagement by families (Molenaar et al., 2018). Research has revealed that new and expectant parents desire an expanded integrated service that supports easy navigation and a smoother continuity of care throughout their perinatal journeys (Abbass-Dick et al., 2017; Danbjørg et al., 2015; Garne Holm et al., 2017; Himes et al., 2017; Liu, 2016; Wierckx et al., 2014). Our findings reveal that although eHealth programs could provide a system for harmonizing maternity and neonatal care programs this potential has not yet been harnessed.

A lot has been learned about how to integrate numerous eHealth modalities into routine and common perinatal care processes (i.e. management and monitoring of gestational diabetes and hypertension; and supporting parent participation in the care of a sick neonate). Programs included in this review have innovated clinical care practices to include eHealth modalities with the aim of improving patient satisfaction, health and clinical outcomes. The WHO recommends clearly articulating how technology will address specific person-centred health system problems, such as poor patient experience and delayed provision of care (World Health Organization, 2018). Therefore, the WHO person-centred digital health interventions being implemented by each perinatal eHealth program in this review could be more clearly identified by researchers in the future to support better understanding of the usefulness of eHealth innovation towards solving person-centred health system challenges. In combination with this nursing-led research about perinatal eHealth practice and program development should be considered. Exemplary nursing leadership has been found to positively impact on structural outcomes for quality care, supports common visions and goals for care among staff and promotes effective information sharing (Cook & Leathard, 2004; Kiwanuka et al., 2021; Sfantou et al., 2017).

## 5.3 | Practising patient engagement within perinatal eHealth

### 5.3.1 | Access

Access has been identified as a precondition for patient engagement (Kelders, van Zyl, & Ludden, 2020) and as a metric that should be considered when examining the presence of patient engagement within eHealth programs (Barello et al., 2016). Our review expands on this by illustrating that practices of access provide opportunities for developing partnerships at a distance and allow for new participation in perinatal care processes. Pregnant persons and families can integrate perinatal practices into their daily lives. New access can lead to care approaches that connect providers with patients in their natural settings. This has provided relief to parents who find it hard to make the trips to medical offices, and balances power dynamics as providers are assessing families in their own home environments through video conferencing (Lieu et al., 2021). Pregnant persons monitor their own goals for health-related behaviours without waiting to have important assessments and collation of lifestyle pattern data during antenatal clinic visits (Naughton et al., 2013; van der Wulp et al., 2014). Research about self-monitoring has suggested that self-care activities might introduce increased burden related to worry and stress (Auxier et al., 2023; Mol, 2018, p.19). Further study should be conducted on the nature of care processes occurring at home from a variety of perspectives and user groups. Perinatal eHealth practitioners should also consider tailoring the level of access provided and the amount of engagement that suites each client when using eHealth programs.

### 5.3.2 | Personalization

In this review, eHealth modalities were mechanized for personalization practices, and user-centred design of programs contributed to the integration of personalization from a development perspective. Past literature shows that perinatal services do not always support women and families' expectations for personalized care (Auxier, 2017; Platonos et al., 2018). This scoping review reveals that eHealth modalities mediate new personal care experiences. By using eHealth modalities purposefully for the sustainment of person-centred care, and the tailoring of care journeys to unique patients some of the persistent challenges with enabling person-centred care might be combated. Patient involvement was common in programs from this review and in line with the best practice recommendation of ensuring stakeholder involvement in eHealth program design (Oberschmidt et al., 2022).

### 5.3.3 | Commitment

Our findings reveal that consistency in the use of process measures to guide evaluation of commitment and participation within perinatal eHealth programs is lacking. Process evaluation, also described as process monitoring by the WHO is needed for collecting and analysing data to understand how well our programs are meeting the aims of care (World Health Organization, 2016). Commitment can be measured through behaviour and cognition, as seen in Kelders, Kip, and Greeff (2020) measure, Twente Engagement with Ehealth Technologies Scale (TWEETS). Neonatal eHealth person-centred practices that support commitment can be evaluated by using a newly developed process evaluation measure, the CO-PARTNER tool (van Veenendaal et al., 2021). More process measures could be developed in the future to guide the monitoring of perinatal eHealth user engagement and care processes related to commitment as these are not being consistently reported in the scientific literature. This scoping review highlights the potential to monitor behavioural engagement and participation over time using digital log keeping and ecological momentary assessment modalities.

### 5.3.4 | Therapeutic alliance

Therapeutic alliance sets patient engagement as a concept apart from others such as empowerment, and involvement (Higgins et al., 2017). While there has been a plethora of knowledge accumulated about collaboration and connectedness between perinatal care providers and their clients, very little is known about how therapeutic alliance is enacted within perinatal eHealth programs. Our findings illustrated that in 12.5% of programs therapeutic alliance practices were not reported. Current research shows that increased connectivity can aid in collaboration and continuity of perinatal care and our review highlights which functionalities help to enact these practices. More purposeful inquiry into this attribute of patient engagement would support deeper understandings of the nuanced interactions between patients, providers and eHealth modalities. All care begins with building trust, this is being investigated in relation to face-to-face perinatal practice (Korstjens, 2021; Wreesmann et al., 2021); however, researchers and clinicians need to appreciate the importance of investigating how trust is built with eHealth systems as a partner-in-care. Person-centred eHealth modalities are helping to bring relevant, personal and timely resources, information, and support to perinatal clients and help to provide safer transition from hospital to home. In the wake of a revolution in perinatal practice, providers need to be supported to interact with eHealth systems in ways that enhance and support the co-creation of therapeutic alliances.

## 5.4 | Implications for nursing research and practice

This review demonstrates a synthesis of knowledge from many disciplines. From this, we have a diversity of perspectives that provides a shared understanding of the range and nature of perinatal eHealth. However, nursing inquiry and practice are scarce in the literature related to maternity eHealth practice, neonatal literature has integrated nursing expertise and inquiry to a larger extent. Although multidisciplinary work is of high importance, nursing knowledge and inquiry are lacking in the research and development of services overall. Health Science literature indicates that nursing and midwifery inquiry is integral to the development, implementation and evaluation of eHealth resource use in perinatal services (Richardson et al., 2018). More collaborative research should be conducted that combines user design theory with nursing science perspectives.

Findings from our review illustrate that eHealth modalities support women and families towards accessible, and personalized health service, eHealth modalities should be paired with relational nursing approaches (Korstjens, 2021; Stelwagen et al., 2020). Commitment and therapeutic alliance integration within perinatal eHealth fulfils perinatal nursing practice goals of woman- and family-centred care; parent–infant closeness and health-related behaviour promotion in pregnancy (Fontein-Kuipers et al., 2018; Franck & O'Brien, 2019; van den Heuvel et al., 2018). In this review, we recommend prioritizing defining and implementing commitment and therapeutic alliance interventions within perinatal eHealth as this will support more clarity for nursing practitioners working towards evidence-based practices (EBP).

## 5.5 | Limitations and strengths

While this scoping review provides a new entry point in which to discuss and appreciate perinatal eHealth, the nature of terminology usage in the available publications is inconsistent and we suspect some sources have been missed due to the complexity and interdisciplinary nature of the literature. Key terms were not used to capture pregnancy experiences of person's not identifying as women, (i.e. trans, trans/masculine and non-binary and transgender). Future reviews discussing perinatal care should include this group, to better identify the level of their involvement in perinatal eHealth evaluation. Further, this work is limited in its form as a scoping review and the level of evidence cannot be evaluated as such. We attended to credibility through careful consideration of suitable meaning units that were based on definitions of patient engagement attributes and WHO digital service person-centred categories (Graneheim & Lundman, 2004). Transferability can be judged through our clear descriptions of the practice structure context and presentation of findings (Graneheim & Lundman, 2004). We suggest avenues for perinatal eHealth implementation, clinical practice and policy considerations and future research based on descriptions of the nature and range of perinatal eHealth and current knowledge gaps.

## 6 | CONCLUSIONS

Perinatal eHealth is emerging as a complex and potentially harmonized practice, the next generations of new families demand access to personalized, relevant, stimulating, integrated and connected perinatal care. To date, current evaluations of perinatal eHealth programs have been mainly focused on satisfaction of care, feasibility and medical-based patient outcomes. Process evaluation and purposeful eHealth program development should be carried out more commonly in the future and can incorporate more nursing perspectives. Based on the findings from this review, access and personalization are being practised in all included programs, but therapeutic alliance and commitment can be reported more often. The integration of all attributes is important for embedding core values of person-centred perinatal care into practice. The next steps stemming from this review are to conduct an interpretive synthesis to inform a patient engagement model for perinatal eHealth development and quality assurance.

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## CONFLICT OF INTEREST STATEMENT

We have no conflicts of interest to disclose.

## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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**Auxier, J., Asgari Mehrabadi, M., Rahmani, A., & Axelin A. (2022)**
**A Descriptive Comparative Pilot Study: Associating Between Use of Self-monitoring Device and Sleep and Stress Outcomes in Pregnancy.**
Computers, Informatics, Nursing

# II

# A Descriptive Comparative Pilot Study: Association Between Use of a Self-monitoring Device and Sleep and Stress Outcomes in Pregnancy

Jennifer Auxier, MSN, Milad Asgari Mehrabadi, MSc, Amir M. Rahmani, PhD, MBA, Anna Axelin, PhD

Pregnancy is a challenging time for maintaining quality sleep and managing stress. Digital self-monitoring technologies are popular because of assumed increased patient engagement leading to an impact on health outcomes. However, the actual association between wear time of such devices and improved sleep/stress outcomes remains untested. Here, a descriptive comparative pilot study of 20 pregnant women was conducted to examine associations between wear time (behavioral engagement) of self-monitoring devices and sleep/stress pregnancy outcomes. Women used a ring fitted to their finger to monitor sleep/stress data, with access to a self-monitoring program for an average of 9½ weeks. Based on wear time, participants were split into two engagement groups. Using a linear mixed-effects model, the high engagement group showed higher levels of stress and a negative trend in sleep duration and quality. The low engagement group showed positive changes in sleep duration, and quality and experienced below-normal sleep onset latency at the start of the pilot but trended toward normal levels. Engagement according to device wear time was not associated with improved outcomes. Further research should aim to understand how engagement with self-monitoring technologies impacts sleep/stress outcomes in pregnancy.

**KEY WORDS:** Behavioral changes, Pregnancy, Self-care, Sleep, Wearable sensors

Pregnancy is a time of physical and emotional changes. Many pregnant persons experience pain, discomfort, and bodily changes that have been linked to sleep disturbances that can increase the prenatal experience of stress.[1,2] Sleep disturbances are common during pregnancy because of hormonal and physiological changes and manifest as insomnia or sleep fragmentation.[3,4] Antenatal stress and sleep disturbances have been linked to increased likelihood of preterm birth.[5,6] Sleep disturbances have also been associated with incidence of stillbirth and growth and weight restrictions.[6] Because of a low frequency of contact visits during the early antenatal period, nonmedical concerns such as sleep disturbances and stress in early pregnancy have been historically left out of antenatal care.[2] It is now possible to monitor sleep quality and mental health states linked to stress during pregnancy using eHealth modalities.[7–10] A self-monitoring technology that provides insights into actual sleep patterns and stress responses could support pregnant persons toward building a greater bodily awareness in between antenatal clinic visits.[11,12]

If pregnant persons are given access to sleep and stress data collected using three-dimensional accelerometer, gyroscope, and biomarker signals including photoplethysmogram (PPG) and electrocardiogram through wearable recording devices and Bluetooth technology, they might be able to engage in lifestyle self-monitoring that stimulates their commitment to manage their sleep disturbances and levels of stress. Increasing pregnant persons' commitment (behavioral engagement)[13] over time might influence the quality of care.[14]

Pregnant persons use eHealth modalities to remind them about important issues during pregnancy when so much is already on their minds.[15] Self-monitoring technology is being used by persons living with chronic conditions such as diabetes and multiple sclerosis in order to motivate and support behavioral engagement in self-care.[16,17] These eHealth users experienced greater condition awareness and benefited from setting goals toward health behaviors.[16,17] The use of self-monitoring technologies has raised some concerns about user overburden due to feelings of needing to perform after viewing their personal data and experiences of decision fatigue related to access and choice of self-monitoring devices.[17–19] Participation in self-care could be enhanced with the use of wearable devices and viewing of personal data;

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however, associations between behavioral engagement and health outcomes are not well understood.

It is common for pregnant persons to experience sleep disturbances during pregnancy, and the effects of such disruptions to normal rest and sleep have been shown to be positively correlated with fatigue, childbirth fear, and anxiety.[20] Although sleep and stress are important clinical problems, we know that personalized antenatal health promotion coaching for sleep and stress is often difficult because of the common inaccuracy of visit self-reports of stress, mental health states, and sleep quality.[21,22] This results in an assessment gap at the time of clinic visits. In the past decade, self-monitoring of personal health data has made it possible to monitor sleep duration and quality, and the levels of stress during pregnancy in between visits.[12,23] Although the assessment gap can be lessened with the use of these technologies, little is understood about the impact technological interventions of self-monitoring might have on behavioral engagement in self-care and subsequent quality of care and health outcomes. Previous studies investigating perinatal technological sleep self-monitoring have not investigated the association between behavioral engagement and health outcomes using multiple week collection of PPG signal sleep and stress parameters.[24,25]

### Self-monitoring and the Engaged User

Technological self-monitoring care processes are often aimed at motivating users to become engaged in their own self-care.[26–28] Having access to wearable devices and personal sleep and stress data makes it possible for pregnant persons and healthcare providers to assess health without a greater use of health service resources related to in-person clinic visits.[2,29] Although self-monitoring technology is gaining popularity in perinatal care in high- to middle-income countries, the associations between behavioral engagement in wearing devices and stress and sleep outcomes remain unclear. Studies examining the effectiveness of self-monitoring in pregnancy have revealed conflicting results; more should be investigated on the impact of self-monitoring activities on improved health outcomes.[8,9,30,31]

Wearable device monitoring and viewing personal data have shown to be highly effective and reliable for use in daily life of users and for research purposes.[11,23,32] Self-monitoring modalities support the collection of data about stress levels, sleep duration, and quality.[12,23] Changes over time can also be examined related to pregnant users' behavioral engagement of wearing devices (eg, wear time). The objective of this pilot study was to observe any associations between pregnant persons' behavioral engagement and changes in sleep duration, and quality and levels of stress. Behavioral engagement was measured using amount of wear time of the smart ring device (worn on the finger).

## METHODS

The pilot study investigated the implementation and demand of using a smart ring self-monitoring technology in a Finnish antenatal clinic.[33] This study is one phase of a larger feasibility study examining engagement by pregnant persons in a perinatal eHealth program using self-monitoring and goal setting for physical activity, stress, and sleep in collaboration with their public health nurses. In the present pilot report, implementation and demand were examined by comparing the user groups according to their level of behavioral engagement (ie, wear time) and their trends in sleep duration and quality and levels of stress over the course of the pilot period.[33]

### Study Participants and Setting

Pregnant persons receiving care at one antenatal clinic in Southwest Finland were sampled using convenience sampling.[34] Participants were enrolled in the study between March and August 2020 during their first or early second trimesters. Inclusion criteria included being 18 years or older, having access to a smartphone (Android or iOS), and having good literacy in Finnish and English languages. Six public health nurses were enrolled in the larger feasibility study; they received the smart rings and use of the wellness Web and smartphone applications (apps) at the start of the study to familiarize themselves with the use of the self-monitoring technology. Public health nurses agreed to participate in the larger feasibility study to act as testers and supports for the pregnant persons who used the self-monitoring and goal setting eHealth program. Participants were recruited during late first trimester of pregnancy or early to mid-second trimester to allow for a nurse visit schedule to include two or more visits prior to the end of the larger feasibility study.

### Pilot Use of Ōura Technology

Pregnant persons who consented to take part in the study received the wearable ring to be worn on their finger and access to the smartphone and Web ŌURA apps through Bluetooth pairing and anonymized user logins. The ŌURA technology is a commercially available wearable device to be worn on the finger. Version 2.0 was used in this study and was able to monitor sleep and stress data. The stress levels were interpreted from the recording of heart rate variability during sleep. All nighttime recordings can be uploaded to the smartphone and Web apps through a Bluetooth connection each day. Users could access the Web app to view more details on their data trends and download their own data if they wished. The smartphone app provided daily tips and feedback about best practices for maintaining low stress levels and sleep duration and quality. As a part of the larger feasibility study, pregnant participants were instructed to wear the ring as much as possible every day in ways that best suited them. They were instructed also to discuss use of the smart ring and apps, self-monitoring, and goal setting for physical activity, stress, and sleep with their public health nurse over the course of the study.

## Data Collection

Participants piloted the self-monitoring program for, on average, 9.5 weeks. The smart ring device has been tested and validated for the monitoring of sleep and heart rate variability data.[11,32,35] Participants in our study recorded daily sleep and stress data whenever they wore the smart ring. Participants completed demographic, use and availability of technology, and health parameter survey data at baseline of the study period. Participants were informed that if the smart ring was uncomfortable or not recording well or the battery did not last between normal charging periods they had to contact the nurse researcher for assistance. The data were uploaded with Bluetooth pairing to the ŌURA cloud service supported by a data sharing and storing system provided through the ŌURA company.

### *Nonwear Time*

A record is kept through the PPG signal detection of the smart ring indicating when the ring is being worn. Total minutes of nonwear time per day was recorded by the device and uploaded to the cloud storage through Bluetooth connection.

### *Sleep Duration and Quality*

Total sleep time (TST) is a measure of duration of total sleep during the night.[4] Sleep quality was measured in our study using sleep onset latency (SOL), waking after sleep onset (WASO), and sleep efficiency. Sleep onset latency is the time it takes to move from a fully wakeful state to a sleep state determined by polysomnography.[36] The ŌURA ring 2.0 has been validated to measure this parameter using PPG signal and hand movement indicators (eg, accelerometer).[11] Sleep onset latency is commonly experienced as equal to or less than 20 minutes.[36] Waking after sleep onset was recorded in the length of time spent awake after sleep onset; this indicated how much sleep disturbance is experienced according to disrupted TST.[4] Sleep efficiency was calculated by dividing TST by the sum of TST, SOL, and WASO.

### *Levels of Stress*

The root mean square of successive differences (RMSSD) reflects the variance in heart rate beat-to-beat and is a primary time-domain measure for estimating the vagally mediated changes reflected in heart rate variability.[37] Lower values of RMSSD are indicative of increased impact on the parasympathetic nervous system as a response to physiological stress exposure.[38]

## Statistical Analysis

### *Data Preprocessing*

ŌURA smart ring provides the daily data summary for sleep and stress parameters in a structured format. We utilized Python 3.8 to parse these files and extract parameters we were interested in. Because ŌURA reports all the sleep events, we labeled the ones happening during nighttime and focused only on night sleep.

Descriptive statistics (means, ranges, and distribution of values) of participants demographic and questionnaire totals were organized and prepared for analysis using R for statistical analyses (version 3.6.1; R Core Team, Vienna, Austria).

### *Kernel Density Estimate Analysis*

To cluster our subjects into high and low engagement groups, we extracted the nonwear time of the smart ring and looked at the normalized distributions and observed two groups of users based on the characteristics of the distributions. We leveraged kernel density estimation on the nonwear time to estimate such normalized distributions. Kernel density estimation is a useful nonparametric tool to estimate the distributions and helps to distinguish different clusters of data.[39]

### *Linear Mixed-Effects Model Analysis*

To model the characteristics of the participants, a hierarchical linear mixed model was exploited for each of the high and low engagement groups (Supplemental Digital Content 1, http://links.lww.com/CIN/A201). Using this model, we were able to analyze the between-subject, within-subject, and overall trends. The single within-subject independent variable was the time (day), and the health outcomes related to sleep duration and quality and levels of stress were the dependent variables in this study.

## Ethics

Ethical approval was obtained by the ethics committee of the Hospital District of Southwest Finland prior to the start of the study (approval ID: ETMK Dnro: 1/1801/2020). Pregnant persons and public health nurses provided informed consent before participation in the larger feasibility study.

# FINDINGS

Six public health nurses and 20 pregnant women agreed to participate in the larger feasibility study. Finnish pregnant women joined the study during their first or early second trimesters. All women had low risk pregnancies at the start of the study, with one participant requiring bed rest later in the study period. Eighteen (90%) of the women were employed, and seven (35%) of the women experienced chronic illnesses outside of pregnancy.

Seventy percent of women in the study stated that their pregnancies negatively impacted their sleep quality (71.4%; n = 10 of high engagement group; 66.6%; n = 4 of low engagement group). All participants stated that they had an unlimited smartphone data plan to use in the study. We experienced some technical difficulties regarding appropriate smart ring sizes and faulty batteries; however, women received fast technical service and new smart rings within 24 hours of their reported concerns (Supplemental Digital Content 2, http://links.lww.com/CIN/A202).

## Engagement Measured by Wear Time: Kernel Density Estimate Analysis

Women were spilt into high and low engagement group by clustering subjects with a normalized nonwear time less than 20% as high engagement group (n = 14; 70%) and the rest as low engagement group. Distributions according to participants can be seen in Figure 1. See Table 1 for background data according to user groups.

## Sleep Duration and Quality Changes Over Time According to Engagement Groups

Total sleep time intercepts were 475.54 minutes ($P < .001$; confidence interval [CI], 463.22–487.86 minutes [7.93 hours]) per night in the high engagement group and 464.47 minutes ($P < .001$; CI, 428.23-500.70 minutes [7.74 hours]) per night in the low engagement group. The TST slope values were −0.28 ($P = .015$; CI, −0.51 to 0.05) in the high engagement group and 0.03 ($P = .889$; CI, −0.35 to 0.40) in the low engagement group. Like the WASO comparisons, both groups started at similar TST baseline values, but the low group experienced an improvement in TST over time, whereas the high group showed a decrease in TST over time (Figure 2).

The SOL intercept for the high engagement group was 11.16 minutes ($P < .001$; CI, 8.79–13.52 minutes) and 8.33 minutes ($P < .001$; CI, 4.20–12.47 minutes) for the low use group. The SOL slope values were similar, 0.02 in the low group ($P = .523$; CI, −0.03 to 0.07) and 0.03 ($P = .293$; CI, 0.02–0.08) in high group. The groups had different baseline SOL times, and the low engagement group experienced a slight increase, trending toward values above 5 minutes. The WASO intercept in the high engagement group was 26.26 minutes ($P < .001$; CI, 20.36–32.17 minutes) and 25.73 minutes ($P < .001$; CI, 19.06–32.41 minutes) in the low engagement group. The WASO slope values were 0.03 ($P = .554$; CI, −0.07 to 0.13) in the high engagement group and −0.04 ($P = .492$; CI, −0.17 to 0.08) in the low engagement group; the groups began at a similar baseline, and the low engagement group experienced a slight decrease in WASO over time. The sleep efficiency intercepts in the high and low user groups were 93% (high: $P < .001$; CI, 0.92–0.94, low: $P < .001$; CI, 0.91–0.94). The groups started at the same sleep efficacy percentage at the start of the pilot, and the low user group trended toward increased sleep efficiency, whereas the

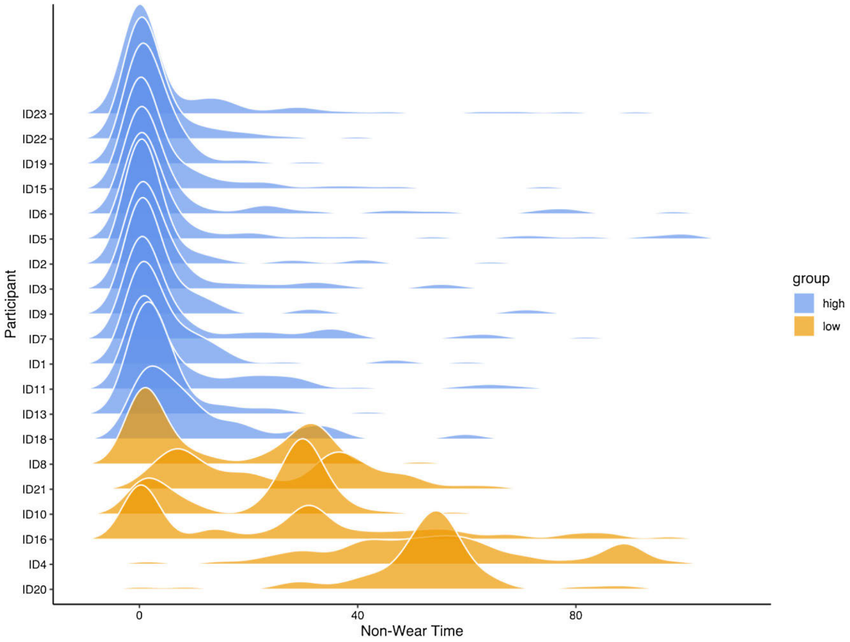

**FIGURE 1.** Distributions of user nonwear time. Values represent normalized values of nonwear time.

## Table 1. Baseline Characteristics of Participating Pregnant Women According to Engagement Group

| | High Engagement (n = 14) | Low Engagement (n = 6) |
|---|---|---|
| Age, mean (SD), year | 32 (2.42) | 29 (3.01) |
| Average pregnancy weeks (baseline) | 15 + 4 | 15 + 3 |
| Able to wear device at work,[a] % (n) | 92.85 (13) | 16.66 (1) |
| Employed, % (n) | 85.7 (12) | 100.0 (6) |
| Body mass index, mean (SD), kg/$m^2$ | 24.95 (17.43–31.64) | 26.48 (20.96–39.84) |
| Nonwear time average, % | 7.13 | 32.49 |
| Medical condition,[b] % (n) | 28.6 (4) | 50.0(3) |
| No. of children | One child = 6<br>Two children = 3<br>No children = 5 | One child = 2<br>Two children = 1<br>No children = 3 |
| Planned pregnancy, % (n) | 85.7 (12) | 100.0 (6) |
| Frequency of other app use in daily life | Daily = 8<br>Weekly = 5<br>Monthly = 1<br>Rarely = 0 | Daily = 3<br>Weekly = 2<br>Monthly = 0<br>Rarely = 1 |
| EPDS scores (baseline) | 4.57 (2.90)<br>Range, 1–12 | 3.50 (3.08)<br>Range, 0–8 |
| Perceived stress (baseline) | 37.14 (5.14)<br>Range, 29–44 | 37.67 (7.66)<br>Range, 27–46 |
| PRAQ-R (baseline) | 5.57 (0.85)<br>Range, 4–7 | 5.67 (0.52)<br>Range, 5–6 |
| Sense of coherence (baseline) | 72.64 (5.62)<br>Range, 62–81 | 77.00 (4.73)<br>Range, 71–84 |

Abbreviations: EPDS, Edinburgh Postnatal Depression Scale; PRAQ-R, Pregnancy-related Anxiety Questionnaire-Revised.

[a] Women were unable to wear the ring on their fingers for health and safety reasons during working hours.

[b] Medical conditions included: migraines; asthma; hypothyroidism; ulcerative colitis; & endometriosis.

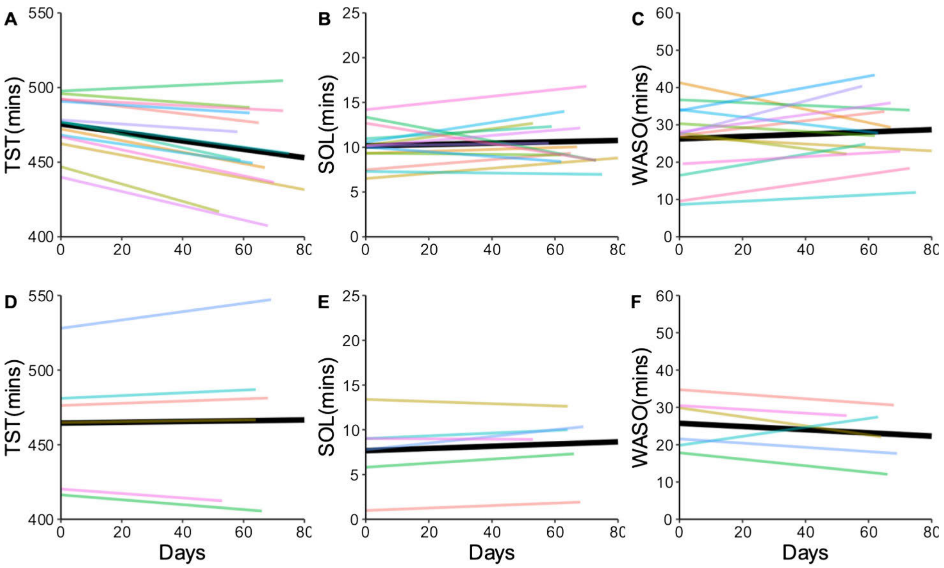

**FIGURE 2.** Linear mixed-effects model of sleep duration and quality. A, B, and C are the high group models; D, E, and F are the low group models.

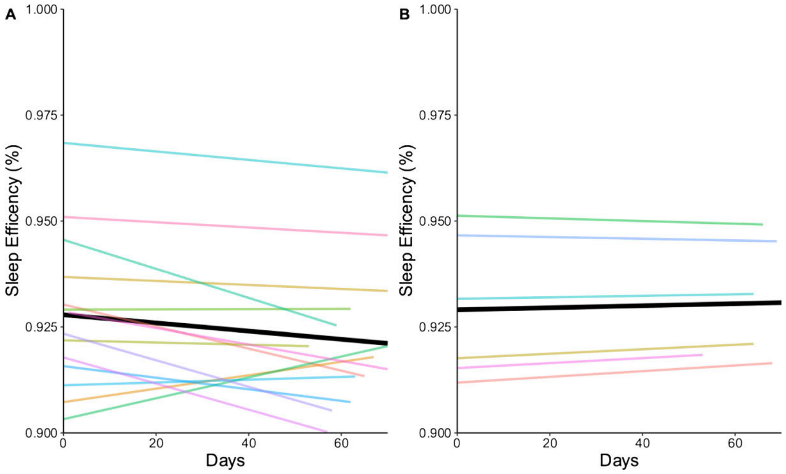

FIGURE 3. Linear mixed-effects model of sleep efficiency. A = high group model; B = low group model.

high user group trended toward a decrease in sleep efficiency (Figure 3).

### Stress Levels Changes Over Time According to Engagement Group

The intercepts of the RMSSD were 40.35 ($P < .001$; CI, 28.09–52.60) in the high engagement group and 67.69 ($P < .001$; CI, 40.01–95.36) in the low group. The RMSSD slope values were −0.12 ($P = .001$; CI, −0.20 to −0.05) in the high engagement group and −0.14 ($P = .023$; CI, −0.25 to 0.02) in the low engagement group. Both groups experienced a decrease in RMSSD, an indication of normal changes over the course of pregnancy; however, the high engagement group experienced a lower value of RMSSD from the start of the study than did the low user group (Figure 4).

## DISCUSSION

### Main Findings

The study findings reveal that 70% of the women in our study were highly engaged in wearing the smart ring on their fingers for the duration of the pilot. Trends for sleep duration and quality were less favorable in the high engagement group than in the low engagement group. The high engagement group experienced a greater impact on their parasympathetic nervous system from stress exposure than did the low engagement group. Both groups had positive trends in SOL.

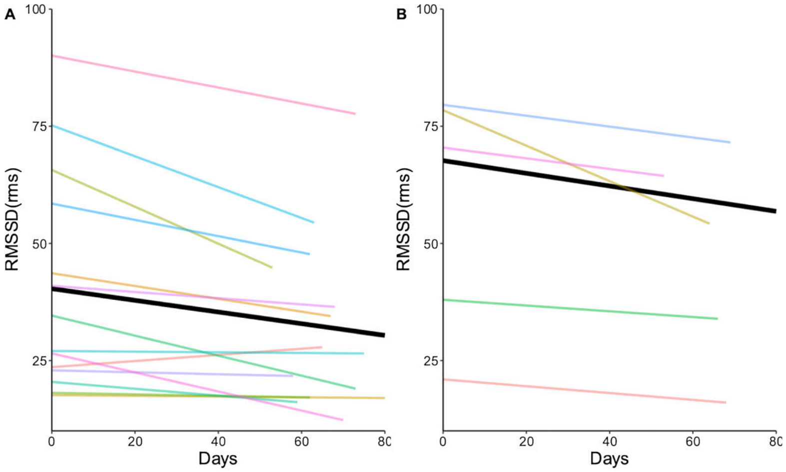

FIGURE 4. Linear mixed-effects model of RMSSD. A = high group model; B = low group model. Abbreviation: rms, root mean square.

The demand for wearing a smart ring that monitors sleep and stress data was high in our pilot user group. Most users (80%; n = 16) missed less than 15% of data recording during the night, resulting a low level of missingness in our data set (Supplemental Digital Content 2, http://links.lww.com/CIN/A202). In our study, participants in the low engagement group experienced a barrier to wear the ring due to restrictions at work (not being able to wear rings during working hours). The demand for using eHealth programs has been shown in other pilot studies evaluating eHealth technologies. In Lima, Peru, researchers saw a similar percentage of physical use of their self-monitoring program for sleep and physical activity in a group of 20 women (65%; n = 13).[7] The demand for eHealth integration into perinatal care has been noted in the contexts of labor and early discharge of infants and mothers from hospital.[29,40]

Second trimester is the period in which the sleep duration and quality are generally improved from the first trimester and generally worsen as the trimester ends.[4] Our study findings reveal expected trends for both TST and WASO during the second trimester. We noted that the high engagement group trended toward the normal decline in TST as the second trimester progressed, and the low engagement group maintained a consistent duration of sleep throughout the pilot phase. A greater proportion of women in the high engagement group (64.28%) had one or more children than in the low engagement group (50.00%). Perhaps the group with more children will have experienced increased daily work related to childcare and perhaps experienced disrupted sleep due to needing to care for small children in the nighttime periods.

The women in the high engagement group also experienced higher impact from stress on their parasympathetic nervous system during the pilot period than did the women in the low engagement group. Factors related to daily patterns of living (eg, physical activity, amount of time at work, and life stresses) could have influenced the groups differently. Perhaps the group who performed more self-monitoring with the smart ring device experienced stress from the responsibility of knowing that they were recording correctly and not forgetting to wear and charge the ring effectively. The concern that burdening healthcare users with greater responsibilities in respect to their care could impact poorly on the users' levels of stress due to feelings of needing to perform, low health and eHealth literacy levels, and incompatibility between the digital service and the preferences of the individual.[16,17,19] Self-monitoring users living with multiple sclerosis found that an important component of a technological self-monitoring program would be to have expert coaching and support for using this service related to the practical matters of self-monitoring technology and that the data collected should be integrated into the development of personalized treatment plans.[17]

## Implications for Future Research

Women in the high engagement group experienced higher sleep quality levels than did the low user group, based on SOL trends. Causes of sleep disturbances are varied, and for pregnant women in our study, their lives were impacted by a global pandemic with first lockdown orders starting on March 12, 2020. Another cohort of pregnant Finnish women participated in a cohort study examining sleep and physical activity patterns during the pandemic lockdown, and it was noted that the coping capacity of these women to maintain appropriate levels of stress and restful sleep habits (waking up later in the morning) might have been connected to a change in lifestyle habits due to the lockdown measures and the strong social supports available to Finnish nationals.[12] Further research should focus on testing technological self-monitoring of sleep and stress in pregnancy with other population groups who experience different socioeconomic circumstances, diverse life experiences, and varying levels of behavioral engagement in the technological programs.

Our study demonstrates the usefulness of collecting large data sets from a valid home monitoring device. Although other studies have used valid sleep parameter data to understand sleep disturbances in pregnancy, these studies either have relied on short-term data collection in clinical settings or have used actigraphy monitoring paired with self-report of sleep.[24,25] One recent pilot randomized controlled trial used a Shine 2 device to monitor sleep patterns at home for 12 weeks in 12 pregnant women randomized to sleep education and digital self-monitoring compared with a group of 12 pregnant women who only received sleep education.[30] This study showed no significant differences between the groups on sleep questionnaire results; however, the study did not report on sleep parameter data measured with the Shine 2 device. Patient-reported outcome measures have their limitations and benefit from being paired with real-time sleep parameter recordings to understand validity of testing, which our study was able to provide.

The validation of the ŌURA sleep monitoring was explained to participants in our study. Women used the wearable device at high or low levels. Women's moderate to high willingness to use the smart ring to monitor sleep was dependent on how they felt about the trustworthiness of wearable data being collected during our study. Other studies have used sleep monitoring devices but have not reported the level of wear time throughout the study periods.[25,30] By implementing this pilot study with less controls on when and for how long women would wear the smart ring, we could examine how much women would choose to or be able to use the smart device. Studies completed about engagement in self-monitoring have been conducted using smart bands and have studied physical activity and prevention of gestational weight gain.[30,41] As well, because some of these studies implemented pay incentives to use the wearable device, this may have impacted participants' willingness to use the devices[41]; we provided no financial incentives to participants in our study. Our participants had free use of the device and mobile app and access to their data during the study period, which might have an impact on their desire to use the service on a trial basis.

The behavioral engagement examined in this pilot study was not consistently associated with positive sleep and stress outcomes. One reason for this could be related to the fact that optimal use of devices is not best thought of as a linear progression to higher and higher use, as some healthcare theorists have suggested.[19,42] Rather, personalization and giving choice of how and when to use eHealth programs have been thought to lead to better outcomes and patient satisfaction in a perinatal care context.[2,43,44] However, current research has yet to test the association of personalized eHealth programs in pregnancy and health outcomes directly. This an area of research that should be undertaken in the future.

### Implications for Nursing Practice

Tailoring the care processes toward individual pregnant users is critical for the practicing of woman-centered care. It is possible that the promise of access to data will lead to higher levels of digital engagement; however, emotional responses to seeing the trends of one's personal lifestyle habits might influence feelings of shame for underperforming or undue worry about the state of their unborn child in a case that they do not practice healthy enough habits.[45,46] Each perinatal client can be guided to use the eHealth programs to the optimal level that suits their needs, preferences, and capacity to manage their own health promotional care.

Many studies have compared digital self-monitoring with regular health promotion interventions in pregnancy and concluded no significant difference between user groups' behavioral change activities and health outcomes.[30,31] Health anthropologist Annemarie Mol states in *The Logic of Care* that "What characterizes good care is a calm, persistent but forgiving effort to improve the situation of a [client] or to keep this [condition] from deteriorating."[19] In light of what good care might be defined as care providers and eHealth developers should consider, low and high engagement in eHealth programs might lead to positive outcomes as long as the care process includes collaboration with perinatal care providers.

## LIMITATIONS

This study includes a small sample size; however, the numbers of observations we incorporated into the statistical analysis were high in volume. This is not a controlled study; the results are not generalizable, and more controlled interventions would be necessary to design any effectiveness studies. The descriptive comparative findings of this study highlight the need to better define the concept of behavioral engagement and to challenge our assumptions regarding the impact behavioral engagement has in the context of technological perinatal care processes. Our study is limited in the potential to see impacts on outcomes related to behavioral engagement as the women used the service during the second trimester and there are generally fewer disruptions to sleep during this period. We did observe women at a time when they were likely to experience sleep disruptions and high levels of stress due to other factors such as childrearing of their older children and due to the timing of the pilot, during a lockdown period related to the global SARS-CoV-2 pandemic.

## CONCLUSION

The use of self-monitoring technology allowed pregnant users, public health nurses, and health researchers to view and store sleep (duration and quality) and stress data in real time. Women in the high engagement group did not experience an improvement in sleep duration or quality compared with the women in the low engagement group, whereas women in the low group did experience higher scores in RMSSD and saw a less dramatic drop in their RMSSD value, an indication of less stress response. These findings may explain that personalization of self-monitoring strategies and meaningful, trusting interactions with health coaches play equally important roles in supporting pregnant persons and women toward health promotion activities as do initiatives to support increased behavioral engagement in self-monitoring.

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**Auxier, J., Savolainen, K., Bender, M., Rahmani, A., Sarhaddi, F.,**
**Azimi I., & Axelin, A. (2023)**
**Exploring access as a process of adaptation in a self-monitoring perinatal eHealth system: Mixed-method study from a sociomaterial perspective.**
JMIR Formative Research

# III

Original Paper

# Exploring Access as a Process of Adaptation in a Self-Monitoring Perinatal eHealth System: Mixed Methods Study From a Sociomaterial Perspective

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## Abstract

**Background:** The development and quality assurance of perinatal eHealth self-monitoring systems is an upcoming area of inquiry in health science. Building patient engagement into eHealth development as a core component has potential to guide process evaluation. Access, 1 attribute of patient engagement, is the focus of study here. Access to eHealth self-monitoring programs has the potential to influence pregnancy health and wellness outcomes. Little is known about how pregnant users' ability to obtain resources is influenced by their own adaptive activities and the mediating activities of eHealth systems during the process of real-world testing of these systems.

**Objective:** Here, we examine the patient engagement process of access occurring during the adaptation of eHealth self-monitoring use from a sociomaterial perspective.

**Methods:** In this mixed methods convergent evaluation design, we interviewed women about perceptions of the adaptation process of using an eHealth self-monitoring system. Deductive analysis was conducted guided by the definition of access as an attribute of patient engagement. After initial qualitative and quantitative data collection and analysis, participants were spilt based on their level of use of the eHealth system (physical wear time of self-monitoring device). Content analysis was then conducted according to user group, using a conceptual matrix developed from ontological perspectives of sociomateriality.

**Results:** Pregnant users' adaptive activities and the mediation activities of the eHealth system represent a cocreation process that resulted in user group–specific characteristics of accessing and using the system. The high- and low-use groups experienced different personal adaptation and eHealth mediation during this process of cocreation. Differences were noted between high- and low-use groups, with the high-use group giving attention to developing skills in recording and interpreting data and the low-use group discussing the manual adding of activities to the system and how the system worked best for them when they used it in their mother tongue.

**Conclusions:** A cocreation process between pregnant users and the eHealth system was identified, illustrating access as a useful core component of perinatal eHealth self-monitoring systems. Researchers and clinicians can observe reasons for why pregnant users access eHealth systems in unique ways based on their personal preferences, habits, and values. Mediation activities of the eHealth system and the different user adaptive activities represent a cocreation process between the users and the eHealth system that is necessary for the personalization of perinatal eHealth systems.

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**KEYWORDS**

patient engagement; eHealth; pregnancy; motivation; pregnant; maternal; cocreation; participatory; codesign; use pattern; usage; self-monitor; sociomaterial

# Introduction

## Background

Pregnancy is a time when persons and women think about their own health as it relates to their unborn child and sometimes use this period to form new health-related habits [1]. eHealth resources are becoming a common source of support for health care users. The use of eHealth resources has been associated with individual motivations for improving health and lifestyle [2], improving health literacy [2], and having enough time and choice to use the resources tailored to their personal lifestyle and circumstances [3]. Although we understand the circumstances in which pregnant persons and women are likely to use resources when access is given to them, knowledge about how their choice of use leads them to being able to obtain the needed resources and support required for the maintenance of health and healthy lifestyles during pregnancy has been less studied. Exploring user behaviors that impact habituation or meaningful use of eHealth self-monitoring systems could provide insights into why certain individuals use devices more than others and whether the use is connected to appropriate receival of health resources.

The provision of accessible eHealth is a global concern. Access can be facilitated by designing systems that are easy to use, are convenient, and negate travel to clinic or hospital settings [4]. Barriers to supporting accessible eHealth systems are improperly matched technology, low eHealth literacy, and a lack of financial or structural resources supporting eHealth systems [4]. Access to eHealth during pregnancy has been associated with increased engagement in self-management tasks and antenatal clinic visits, and satisfaction with care [5-7]. What is less understood are the processes under which pregnant persons and women become accustomed to using eHealth resources and discover their patterns of use for meaningful engagement.

Higgins et al [8] define patient engagement as a behavior and a process within health care. Patient engagement is a multifaceted concept with 4 attributes: personalization, therapeutic alliance, commitment, and access [8]. Access is defined as “…the ability of [individuals] to obtain information, guidance, and tools to secure consistent, high quality, [and] appropriate care” [8]. Access has been mainly studied from the perspective of adherence and the frequency of use rather than from a process perspective. Exploring the interactions and impact of the interrelated processes that occur once access to eHealth is given could inform nuances of appropriate care/support receival. Perinatal eHealth feasibility studies conducted in United States and the Netherlands have illustrated that trusting interactions between health providers and clients are a component of appropriate antenatal care, as well as the presence of a shared understanding of current health states of pregnant users and their care providers [9,10]. eHealth self-monitoring is being applied in the United Kingdom to support trusting relationships and foster honest reporting of health states [11]. Less is known about pregnant persons’ personal motivations for engaging in self-monitoring when eHealth is made accessible to them. With the availability of an eHealth self-monitoring system, it is expected that users choose eHealth features that they grow to identify with [12]. Little is known about perinatal user-eHealth interactions and technological mediations that occur during real-world testing of eHealth self-monitoring during pregnancy.

With the use of an available smart-ring and wellness app, ŌURA, pregnant users can track their total sleep time and sleep cycles, resting heart rate and variability, daily activity levels, and physical wear time of the device [13]. ŌURA provides an opportunity to view personal health data, health status alerts (eg, not enough total sleep), and recommendations for level of physical activity based on the previous night’s sleep and day’s activity levels. Users can set goals with the support of tailored feedback and health data trends.

## Objective

The objective of this study was to examine the processes occurring during the adapting of eHealth self-monitoring use, with a focus on the technology-pregnant user interactions. To that end, our research question was developed using the sociomaterial perspective and became, What are the characteristics of the process of use after pregnant users receive access to an eHealth self-monitoring system?

# Methods

## Study Design

A mixed methods convergent evaluation design was conducted, whereby data were collected at parallel time points and brought together during the analysis step of the study [14]. Participants collected use data (according to wear time) throughout the pilot testing of the self-monitoring system and participated in semistructured exit interviews. The full data set was examined for elements related to the process of accessing the eHealth self-monitoring system. See Table 1 for stages of data convergence.

**Table 1.** Concepts under study and convergence of data sources.

| Method | Concept under study | Convergence of data |
|---|---|---|
| Qualitative: semistructured interviews with pregnant users about their perceptions of access | Access as a process attribute of patient engagement: "…the ability of [individuals] to obtain information, guidance, and tools to secure consistent, high quality, appropriate care" [8]. | • Interview data related to access of eHealth self-monitoring system modalities<br>• After group stratification, analysis to identify pregnant users and eHealth system mediating activities according to user group |
| Quantitative: distribution of nonwear time of pregnant users recorded with the ŌURA wearable ring that pregnant users wore throughout the pilot use of the self-monitoring wellness eHealth system | Wear time measurement and group stratification allowed us to examine differences in the level of use. | • User groups identified through the kernel density estimate test [15] |

The sociomaterial perspective was used as a theoretical frame of this study. This perspective proposes that an interconnectedness exists between technology, work, and organizations [16]. This perspective supports the nonhierarchical relationship between technology and humans, wherein both humans and technology play a role in the creation of social and societal processes [16]. This nonhierarchical relationship between objects and humans can also be understood through an ontology of mutually dependent ensembles, as described by Orlikowski and Scott [16]. The pervasive presence of a new technology is not only meaningful at specified events or processes within a health program but also provides mediation and emergence of patterns of accessing services during program delivery [16]. Activities of pregnant users will be mediated by new technologies, and the accessibility of these systems may be understood through the eHealth mediation activities and the responsiveness of the pregnant persons during their engagement with the systems. The sociomaterial perspective supports examining pregnant users' activities after their newly acquired access to an eHealth lifestyle self-monitoring system.

## Setting and Participants

In total, 20 pregnant women in their second trimester were sampled, using convenience sampling, to take part in the pilot use of an eHealth self-monitoring system [17]. Two perinatal clinics in Raisio and Rusko and their public health nurses (PHNs) were willing to participate in the pilot use of the ŌURA smart ring and wellness app. The 2 public clinics represent 2 separate but financially linked health service organizations. Inclusion criteria were pregnant users being 18 years of age or older, in the second trimester of pregnancy, having access to a smartphone (Android or iOS), and understanding Finnish and English languages. Pregnant users were recruited from early antenatal visits during their second trimester by the PHNs. Refer to Auxier et al [18] for details regarding recruitment and informed consent.

## Pilot Testing of the eHealth Self-Monitoring System

The ŌURA ring is a commercial smart ring that collects heart rate and variability, sleep, body temperature, respiratory rate, and physical activity data. Previous studies with nonpregnant persons indicated the reliability of self-monitoring with ŌURA, including heart rate and variability, sleep, and physical activity [19-21]. The ring is small, lightweight, and easy to use for long-term monitoring. It has up to 1-week battery life and sends the collected data via a Bluetooth connection to a mobile app and cloud server (iOS and Android). The ŌURA app comprises a main panel that presents the user's daily sleep, activity, and a proprietary readiness score. Users can view their daily and weekly trends on the mobile app and are able to download personal data and view monthly and yearly trends from a web app on a desktop or laptop computer. The collected data can be visualized on smartphones and computers. The data were collected and stored using anonymous usernames. Data are computed for activity, sleep, and readiness scores based on previous data. Personalized feedback, recommendations, and goal adjustments to balance the activity and rest are then provided by the app on demand and in real time. Women wore the ŌURA ring and used the wellness app to track and view their wellness data for an average of 9.5 weeks, with women having 2-4 visits with PHNs over the course of the study. The PHNs were trained to provide their normal wellness coaching during visits but could use the personal data that women had available from the wellness app to inform their regular perinatal coaching if they saw an opportunity to do so. The PHNs were given an ŌURA ring and shown how to use the app for themselves and could contact the research nurse assistant at any time for questions or comments regarding the use of the smart ring device, app, or coaching of women during perinatal visits.

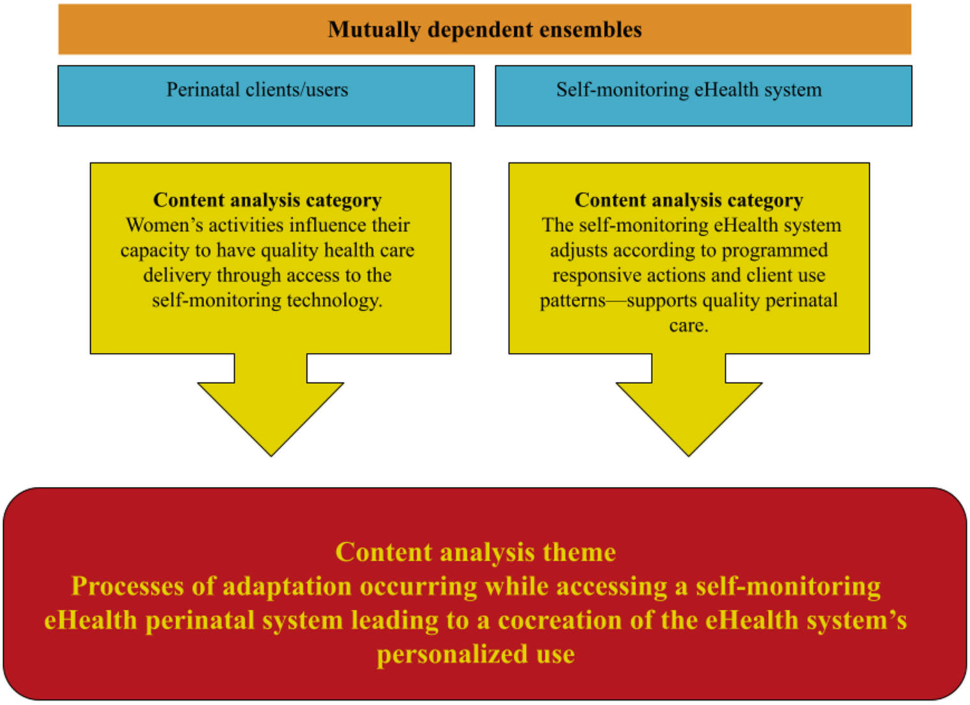
## Semistructured Interviews

The interview guide was generated by the first, second, and last authors based on the constructs of patient engagement. The second author met each of the pregnant women at the end of the pilot at a location of their choice where they could participate in 1-on-1 semistructured interviews. Interviews were audio-recorded and transcribed verbatim, and all raw audio and document files were digitized and stored in secure password-protected files. Typed transcripts were cleaned of identifying information prior to analysis.

## Data Analysis

The study was conducted guided by a content analysis deductive approach using the definition of access and statistical user group stratification. All qualitative data were collected and analyzed deductively to identify processes related to access prior to group stratification. Participants were stratified according to the distribution of individual means of nonwear time of the smart ring. See further details of stratification reported previously [18]. Convergence of data sources was then conducted by organizing qualitative data according to user group. A final conceptual matrix was constructed using a model of sociomaterial interactions in which the technology in use and the social processes are not seen as separated from each other but part of complex interactive processes (see Figure 1) [16]. This matrix was used once the deductive and inductive development of codes and categories revealed a fit between the main domains and a sociomaterial perspective [16,22,23]. A description of the quantitative concept (wear time) and qualitative concept (access as a process) can be seen in Table 1.

**Figure 1.** Conceptual matrix using mutually dependent ensembles from the sociomaterial perspective.


Mutually dependent ensembles

Perinatal clients/users

Self-monitoring eHealth system

**Content analysis category**
Women's activities influence their capacity to have quality health care delivery through access to the self-monitoring technology.

**Content analysis category**
The self-monitoring eHealth system adjusts according to programmed responsive actions and client use patterns—supports quality perinatal care.

**Content analysis theme**
**Processes of adaptation occurring while accessing a self-monitoring eHealth perinatal system leading to a cocreation of the eHealth system's personalized use**

### Ethical Considerations

This study was accepted by the Ethics Committee of the Hospital District of Southwest Finland (approval ID: ETMK Dnro: 1/1801/2020). Each participant provided written informed consent before participation in the study and was aware that they could exit the study at any time.

## Results

### Participants

In total, 20 pregnant women monitored themselves in either a high (n=14, 70%) or a low (n=6, 30%) amount (Table 2) based on the kernel density estimate conducted in our previous study [18]. Women described that the eHealth system's mediating activities and their own adaptive activities of self-monitoring enacted a process of cocreation for eHealth system use. The new interactions that developed in the real-world use of this eHealth system illustrated emerging scenarios and considerations for the receival of appropriate resources. The main theme was the cocreation of eHealth self-monitoring system usage. The eHealth system usage was attained through (1) adaptive activities of the pregnant user and (2) mediation activities of the system. These activities varied in some cases based on user group (see Table 3).

**Table 2.** Baseline characteristics according to group.

| Characteristics | High-use group (n=14) | Low-use group (n=6) |
|---|---|---|
| Age (years), mean (SD) | 32 (2.42) | 29 (3.01) |
| Average gestation (days), mean (SD) | 108.86 (12.59) | 107.50 (6.66) |
| Wearing device at work, n (%) | 13 (93) | 1 (17) |
| Daily nonwear time (minutes/day), mean (SD) | 7.13 (15.35) | 32.49 (23.99) |
| BMI, mean (SD; range) | 24.95 (3.49; 17.43-31.64) | 26.48 (6.92; 20.96-39.84) |
| **Number of children, n (%)** | | |
| 1 | 6 (43) | 2 (33) |
| 2 | 3 (21) | 1 (17) |
| 0 | 5 (36) | 3 (50) |
| **Frequency of other mobile app use in daily life, n (%)** | | |
| Daily | 8 (57) | 3 (50) |
| Weekly | 5 (36) | 2 (33) |
| Monthly | 1 (7) | 0 |
| Rarely | 0 | 1 (17) |
| **Baseline health survey scores** | | |
| EPDS[a] score, mean (SD; range) | 4.57 (2.90; 1-12) | 3.50 (3.08; 0-8) |
| Perceived stress, mean (SD; range) | 37.14 (5.14; 29-44) | 37.67 (7.66; 27-46) |
| PRAQ-R[b], mean (SD; range) | 5.57 (0.85; 4-7) | 5.67 (0.52; 5-6) |
| SOC-13[c], mean (SD; range) | 72.64 (5.62; 62-81) | 77.00 (4.73; 71-84) |

[a] EPDS: Edinburgh Postnatal Depression Scale.

[b] PRAQ-R: Pregnancy-Related Anxiety Questionnaire –Revised

[c] SOC-13: 13-item Sense of Coherence scale.

**Table 3.** Characteristics of adaptive and mediating activities according to user group.

| User group | Both groups | High-use only | Low-use only |
|---|---|---|---|
| Adaptive activities of pregnant users | • Use related to self-awareness<br>• Practical matters of reviewing tips and feedback<br>• Use related to comfort and preference, and knowledge | Practical matters of recording daily data | • Added their own activities when the eHealth system did not record certain exercises automatically<br>• Preferred to use the system in their mother tongue (Finnish) |
| Mediating activities of eHealth system | • Flexible and responsive tips and information<br>• New opportunities for participation | Gentle and guiding nature of eHealth advice | • Mentioned that nursing guidance and advice were kind and nonjudgmental |

## Cocreation of eHealth System Usage Between Pregnant Users and Technology

### *Pregnant User Adaptive Activities*

Participants described a process of adapting after receiving access to the eHealth self-monitoring system. The process incorporated personal choices to use the system, depending on eHealth literacy, comfort with the technology, and interest in eHealth, as a tool for health promotion. Participants expressed that personal self-awareness, perceptions of trusting their own bodies, and participation in goal setting activities emerged as important elements of using the eHealth system. Women in the high-use group found themselves becoming focused on the practical skills of monitoring and interpreting data. Unlike the low-use group, this active focus and concentration on maintaining good self-monitoring techniques made it difficult for them to use the data initially in relevant ways for their own health promotion. Women in the low-use group were instead concerned about whether they could incorporate this device into their daily lives, for example, remembering where they put the ring after washing their hands, and whether they would have to remember to manually add their exercises into the app.

### *Use Related to Self-Awareness*

Participants began looking at their daily activity and sleep pattern data using the app. Women refer to bodily self-awareness as critical to adapting to the daily viewing of personal health data. Some women continued to be interested in seeing the daily sleep and activity patterns and told the researcher that they liked becoming aware of their own daily habits. Multiple women in the high-use group stated that they never knew they slept poorly before using the service and that after learning this, they gave themselves permission to rest more. One woman commented that she was really trusting the data from the app:

> *…Somehow it's also nice to know that maybe my own feeling isn't always in line with the data. I somehow trust the app and what it says [about my sleep].* [Participant 2]

Women's personal preferences, attitudes, and past life experience contributed to their impressions of self-monitoring. Some participants identified as having good self-awareness prior to practicing self-monitoring and felt that listening to their own bodily rhythms was crucial. One woman in the low-use group commented on her experience with physical activity recommendations:

> *I think the weirdest part was that I don't feel I exercise a lot, but still [the app] may announce that you have exercised a lot yesterday, so today it's good for you to take it easy…there might be many days when it announced that you haven't recovered yesterday so take it easy…[but]…I haven't done anything heavy. Other than cycled [to work].* [Participant 10]

The system was not responsive to the bodily changes unique to pregnancy, and some women gave little weight to the interpretations from the app because of this. Many women in the high-use group discussed that they had confidence in their own body rhythms and health habits and felt that the App was used for reassurance, that things were as well as they felt them to be. Some participants also noted that this system would be well suited to persons with some health challenges but maybe not needed for someone like them.

### *Practical Matters of Recording Daily Data: High-Use Group*

Some women in the high-use group became distracted with the practical matters of self-monitoring and interpreting data, and in this way, a focus on simple ways of improving activity or sleep quality was not a priority. These women expressed that they were focused on becoming technically skilled at recording their daily data and understanding the functionality of the system. They wondered what to do if the system was making the wrong recordings or wrong conclusions about daily patterns. For example, 1 woman noticed that the system gave a tip that eating before going to bed could prevent her higher resting heart rate at the start of sleep on an evening that she was fasting. The woman was concerned about how to proceed with the wrong messaging.

### *Practical Matters of Reviewing Tips and Feedback*

The app was only available in English at the beginning of the feasibility study; however, some women received access to the Finnish version of the app during their use. Women in the low-use group mentioned that this update supported them to identify more with the feedback. The women who found the use of their mother tongue helpful stated that they could internalize the feedback better and that this added clarity to the messages given by the app. One woman mentioned that she explored the definitions and educational sections of the app in greater detail:

> *I started to use maybe more [information from the app] when the upgrade of the Finnish version came. When the app became Finnish, I was able to look all the different things because some of the [English words] were so specialized.* [Participant 10]

The app suggests goals for women to make based on their behavior patterns. Multiple participants expressed that after regularly viewing their personal data on activity, sleep, and recovery, they took on an interested passive observer role. They found the patterns interesting to watch and found no reason to make use of the goal-setting function, as 1 woman explained:

> *I have been a good sleeper always and even after a night shift…[Since using the smart ring] it has been nice to look at it [sleep patterns].* [Participant 21]

One woman (high-use group) felt her health behaviors were not changeable in anyway because she was pregnant. She thought it was good to just monitor what naturally happened due environmental or other contextual changes in life:

> *I've thought I would buy some smart watch or so, but then after pregnancy, not now when sleeping poorly and exercising so little. But still, it's interesting to observe the data because it really got better during the summer.* [Participant 6]

Some participants described times where they made changes to their habits in daily life because of the tips from the app. Women cited changes made to sedentary time, frequency of restful moments, not eating snacks close to going to sleep, and considering new stress management strategies.

### *Use Related to Comfort, Preference, and Knowledge*

When the data recordings were not in agreement with women's own bodily perceptions or knowledge of events, they often referred less to the app for information. One woman explained her habit of examining the recovery score from the app over time:

> *At first, I checked that state of readiness, but I'm not sure, because I feel it's not reflecting my real feeling. Sometimes it said the readiness was at its highest and I felt that no, not today.* [Participant 3]

Some women in the low-use group manually added physical activities when they knew the ring would not record correctly. Many women were not interested or engaged in using the physical activity features of the system as they felt the advice and recordings were not in agreement with their own goals (expressed as either too much asked of them or too little).

Many women in the high-use group had past experiences with self-monitoring equipment. This led some to compare devices, and some used this previous familiarity in self-monitoring to get the best out of the service through paired use with other devices. Some women expressed that they struggled to always wear this ring because the size and style appears to be best suited to men or it was too big and sometimes caught on items or their children during handling.

### Mediation Activities of the eHealth System

The eHealth system presented new health resources in combination with women’s activities. Nurses and women developed new patterns of interacting due to access to data that was collected in between clinic visits. With the help of their PHNs, perinatal clients developed a personal understanding of the possible links between their health behaviors and their health states in a way that was not possible before having access to on-demand data.

#### *Gentle and Guiding Nature of eHealth Advice: High-Use Group*

Women in the high-use group expressed that the app was not mean or rude in its recommendations and tips and that having access to health behavior data gave them and their PHNs insight into the connection between health behavior and stress management. ŌURA reminds its users about balancing activity and rest and explains how this could improve overall stress outcomes through use of its proprietary recovery score reports. Women in the high-use group noted that whether the recordings are accurate or not, interfacing with the system provided an opportunity for interpreting overall progress on matters such as stress, sleep, and physical activity with nurses. One woman articulated this when asked whether the eHealth system would fit into maternity clinic care:

> *Well, why not…Like on very many things connected also to health, body functioning, and other, I think it would fit very well.* [Participant 18]

Women in the low-use group did not express a perception of the eHealth system as being a guide or a gentle service for them; they did, however, discuss that looking at the data with the nurses during the clinic visits was an enjoyable and nice experience for them because the nurses used the system to discuss things that were not acute. Further, women mentioned that the nurses did not use a judgmental tone when discussing the personal data in the clinic.

#### *Flexible and Responsive Tips and Information*

The app was responsive in some respects to women’s daily patterns and available on demand. This provided women with an opportunity to view data according to their interest and energy levels at any given time. The information was categorized into sleep, stress, and physical activity separately, and women could look up information about each topic. Women suggested that this structure allowed for them to participate in health promotion activities when and how they wanted. Some women stated that the high volume of options made it a bit hard to get used to using the system initially, and after getting comfortable with their own use threshold, they were satisfied. Some women thought it was interesting to view data as questions in their life arose; in 1 case, a woman and her partner were wondering about sleep latency and were able to answer their questions with the system right away.

#### *eHealth Provided New Opportunities for Participation*

Participants mentioned that they had new and interesting experiences during their clinic visits with the nurse because of using the system. Women gained new accountability in their care team because they could contribute to the care planning with self-monitoring data. These data provided more information about daily life contexts and could be used in the interpretations of health states of the women. Further, the women and nurses had experiences of looking at the same data and working out interpretations together. Viewing data together also gave some women an opportunity to share their emotional struggles that related to the patterns that they might otherwise not have. Some women took the lead; in 1 case, the woman showed the nurse the data on her phone because the nurse could not log on to her computer system.

## Discussion

### Principal Findings

Our study revealed that pregnant users participated in the cocreation of the use of an eHealth self-monitoring system through the presence of adaptive (the women) and mediating (the eHealth system) activities. What is novel in our study is the use of a sociomaterial perspective and the exploration of the influences of different behavioral engagement levels (physical wear time of the device) in the development of the meaningful use of an eHealth system. Identifying and defining the activities of both perinatal users (high- and low-use groups) and the eHealth system itself illuminated interactions and processes that inform designs based on our user groups’ skills, habits, and values.

A recent review noted that of 12 different emerging perinatal eHealth modalities, self-monitoring was the third-most prevalent in use in the developed world [24]. A common reason for providing access to eHealth self-monitoring systems was to promote the movement of perinatal service away from the clinic into the home environments of clients [25-28]. Researchers report that by moving care from the clinic spaces back into the homes of perinatal clients, care inequities and power imbalances between providers and clients could be ameliorated [26,29]. Self-monitoring is trending with the expressed goal of improving patient engagement and perinatal health outcomes; however, there is limited examination of the meaningful use of eHealth systems [24,30]. Not all high use was related to meaningful use for the pregnant users in our study. Some women used the system a lot but did not see the need to develop goals related to their lifestyle, while others did not consistently record their activities and sleep but found discussions with PHNs about incidences of poor sleep useful for managing their well-being during pregnancy.

What is lacking in many studies on evaluating perinatal self-monitoring systems is a clear definition and examination of patient engagement and associated health outcomes [24]. A descriptive comparative analysis conducted as part of our larger feasibility study revealed the limitations of only examining the physical use of self-monitoring technology [18]. The process characteristics will be missed if we do not look beyond physical use as an indicator of engagement [18]. Here, women cocreated their use patterns aided by the mediation of the eHealth system. Use patterns were cocreated based on personal preferences and attitudes about technology and the adaptive qualities of the eHealth system to pregnant users' circumstances. For example, in some cases, the system aided in their receipt of appropriate resources in the form of tailored feedback (ie, notes about relaxing a little during the day because of poor sleep).

Participants experienced a process of adapting in the use of the system, and they were able to obtain benefits from the self-monitoring program with low or high amounts of engagement, depending on their preferences or life circumstances. Experts in the field of eHealth design have pointed to the impact personal habits, routines, and life skills can have on one's choice and patterns of the use of eHealth technologies [31]. What is yet to be deeply explored is how these variations can support personalized effective "dosing" of engagement in eHealth system use, and many studies report under the notion that "the more the use, the better" [32]. A study was conducted to evaluate the feasibility of building unique profiles within an eHealth system created by researchers using The Incredible Intervention Machine (TIIM) to understand the impact of personalization based on the client's intended use and engagement in the intervention [33]. Directions toward conceptualizing our programs through the threshold for intended use have been supported by other researchers; in a systematic review of eHealth evaluations, authors highlighted that historically, pharmaceutical influence supports the concept of intended use and this spills over into general health program development fields [32]. The assumption that eHealth users should reach a standard level of intended use for effectiveness to be achieved was then perpetuated in the field. In our study, it is apparent that users found individual effective thresholds of use. The unique experiences of receiving support, encouragement, and coaching toward health lifestyle habits that are tailored specifically for each perinatal patient can have lasting positive impacts on health promotion and self-care regardless of a specific eHealth program dose.

Women in the high-use group suggested using the service beyond pregnancy during the postpartum period, and all women in our study said they had an affinity with using technology in their lives as information support. This indicates that the adapting process described in the findings of our study is unique to pregnant women who find technology beneficial to some degree and choose their own intended usage in order to match the technology to their own goals. Experts in eHealth user engagement have suggested designing programs, keeping in mind the dose-response relationship rather than the adherence-response relationship, that is, "the more use, the better" [32]. Our study illustrates that in populations and contexts where pregnant persons are open to interacting with eHealth at some level, it is possible to identify user-specific intended usage.

## Limitations

This study was conducted to understand the feasibility and useability of an eHealth self-monitoring system examined through a pilot use of the system. The sample was small, and the eHealth modalities of ŌURA ring 3.0 have changed to incorporate new functionalities that the women in our study would have liked to see at the time of our pilot use in spring/summer 2020. The findings of this study do not inform the effectiveness or efficacy of such an eHealth system but do inform on strategies and the research directions to take in the future development of personalized eHealth self-monitoring systems. We were not able to note any clear link between the demographics of our participants and their level of use. The ability to wear the smart device at work might have played a role in the low-use group; however, our study took place when there was a governmental stay-at-home order and some of the participants were taking vacation time during the period of the study. We recommend that future research be conducted with a larger group and a specific focus on links between demographic variables and use patterns, habits, and values. Further, our study was limited in examining real-time reactions of our participants to the app's automatic cues and tips given in real time and on demand. For our chosen system, this was not possible, and we recommend that to learn about real-time adapting to behavior change in the future, researchers integrate a way to monitor this type of real-time response to automatic behavioral prompts.

## Conclusion

This feasibility study highlights the value of examining the processes of adapting in the pilot use of a perinatal eHealth self-monitoring system. Women in our study had varying levels of use and cocreated their eHealth system use along with the technology mediation. Mediating activities conducted by technology play an important role in the restructuring of perinatal care programs and have potential for improving personalization and accessibility of antenatal resources. The exploration of the meaningful use of eHealth systems is recommended as pregnant users' ability to obtain appropriate health resources depending not only on having systems accessible to them but also on their own use patterns that are based on personal preferences, values, and habits.

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## Data Availability

The participants of this study did not provide written informed consent for their data to be shared publicly, so due to the sensitive nature of the research, supporting data are not available. Qualitative data from this study are not available in raw form; however, the codebook and coding details can be shared upon request.

## Conflicts of Interest

None declared.

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## Abbreviations

**PHN:** public health nurse

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RESEARCH ARTICLE

# Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care

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## Abstract

### Background

Active parent participation in neonatal care and collaboration between parents and professionals during infant hospitalization in the neonatal intensive care unit (NICU) is beneficial for infants and their parents. A tool is needed to support parents and to study the effects and implementation of parent-partnered models of neonatal care.

### Methods

We developed and psychometrically evaluated a tool measuring active parent participation and collaboration in neonatal care within six domains: *Daily Care*, *Medical Care*, *Acquiring Information*, *Parent Advocacy*, *Time Spent with Infant* and *Closeness and Comforting the Infant*. Items were generated in focus group discussions and in-depth interviews with professionals and parents. The tool was completed at NICU-discharge by 306 parents (174 mothers and 132 fathers) of preterm infants. Subsequently, we studied structural validity with confirmatory factor analysis (CFA), construct validity, using the Average Variance Extracted and Heterotrait-Monotrait ratio of correlations, and hypothesis testing with correlations and univariate linear regression. For internal consistency we calculated composite reliability (CR). We performed multiple imputations by chained equations for missing data.

### Results

A 31 item tool for parent participation and collaboration in neonatal care was developed. CFA revealed high factor loadings of items within each domain. Internal consistency was 0.558 to 0.938. Convergent validity and discriminant validity were strong. Higher scores correlated with less parent depressive symptoms (r = -0.141, 95%CI -0.240; -0.029, p = 0.0141), less

there are legal and ethical restrictions on sharing these data publicly due to the data containing sensitive and identifiable information. The data set contains information like birthweight and gestational age of infants and information on parents - information that could be used to link and identify individuals, in relation with the information that the study was conducted in Amsterdam, the Netherlands. Above, sensitive information includes data on depression, anxiety, and stress in parents. In the informed consents signed by the parents and guardians of the infants of this study and granted by the regional committee for medical ethics in Nieuwegein, The Netherlands, guardians were not asked about data sharing. Researchers interested in the data may contact the Privacy protection officer in OLVG (fg@olvg.nl) and the ethics committee that approved the study (info@mec-u.nl) and provide the reference: NL ABR 56691.

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impaired parent-infant bonding (r = -0.196, 95%CI -0.302; -0.056, p<0.0001), higher parent self-efficacy (r = 0.228, 95%CI 0.117; 0.332, p<0.0001), and higher parent satisfaction (r = 0.197, 95%CI 0.090; 0.308, p = 0.001). Parents in a family integrated care model had higher scores than in standard care (beta 6.020, 95%CI 4.144; 7.895, p<0.0001) and mothers scored higher than fathers (beta 2.103,95%CI 0.084; 4.121, p = 0.041).

## Conclusion

The CO-PARTNER tool explicitly measures parents' participation and collaboration with professionals in neonatal care incorporating their unique roles in care provision, leadership, and connection to their infant. The tool consists of 31 items within six domains with good face, content, construct and structural validity.

## Introduction

Active parent participation in neonatal care during infant hospitalization in the neonatal intensive care unit (NICU) can ameliorate adverse outcomes for infants and their parents [1–7]. Through parent participation in neonatal care, parents can be a central part of the NICU care team, gain confidence in taking care of their infant, and prepare themselves for discharge [8, 9]. Although the NICU has been incorporating parent involvement practices for decades, attention directed toward parent-partnered models fidelity and implementation through the examination of active parent participation and integration into care teams is currently lacking [2].

Several tools have been developed and used to assess parent participation in the pediatric care setting [10–12]. In the neonatal setting, studies have mainly focused on constructs related to parent participation [13] such as the passive construct of (time) being present in the NICU or holding the infant [14–17], and healthcare professional recordings of parent competencies and activities [17, 18]. Other tools have focused on aspects such as feeling guided or supported by healthcare professionals [19] or constructs related to maternal knowledge, confidence, expectations and social support within infant care engagement and risk evaluation [13, 20–22].

However, all aforementioned tools lack the assessment of parent active participation, and the inherent collaborative partnerships and processes that are currently changing the NICU environment from healthcare-led to parent-led infant care [2]. Most tools have also not included fathers from initial development. It is important to have validated tools to measure levels of parent participation and collaboration in the NICU to tailor care practices in real-time, to be able to assess parent-partnered care models such as family integrated care (FICare) [2, 3]. Above all, a broader measure is needed, that is not only centred around risk-evaluation but can also be used in a strengths-based approach to promote parent active participation in care and achieve better outcomes for infants and their parents.

In this study we developed and psychometrically evaluated the CO-PARTNER tool measuring parent participation and inherent collaboration with healthcare professionals in neonatal care during NICU hospitalization.

## Methods

This psychometric study was conducted before and during a multicentre non-randomized prospective study on the effects of FICare on infants and their parents in a NICU level 2 context in the Netherlands [23], including a group of parents and infants who experienced family integrated care (FICare) in single family room units and a group who experienced standard care in open bay units (the AMICA study, see S1 Appendix of S1 File for details on FICare and standard care in the different participating units). In the AMICA study, preterm infants admitted for at least 7 days to one of the participating wards and their parents were included. The primary outcome in the AMICA study was the effect of FICare in single family rooms on neurodevelopment of preterm infants. In the AMICA study, outcomes in parents (mothers and fathers separately) were also included as secondary outcomes in the short and longer term [23]. We excluded families if mothers or fathers had severe psychosocial problems (for instance acute psychiatric illness or if a family was under supervision of social services etc.), if death of a sibling occurred or if a congenital or metabolic syndrome was present in the infant.

Before conduct of the AMICA study, we considered parent active participation as a possible mediator in the pathway between the FICare-setting and improved health outcomes (for mothers, fathers and infants). However, as no validated measure of parent participation existed, we decided to conduct the generation, validation and psychometric evaluation of the CO-PARTNER tool before and during the AMICA study. We first included parents and healthcare professionals in the item generation phase using purposive sampling in May 2016-April 2017. For the validation and psychometric evaluation, we included parents who participated in the AMICA study and who filled out the CO-PARTNER tool at hospital discharge of their infant. Recruitment of the AMICA study took place May 2017-January 2020. The medical ethical review board of MEC-U in Nieuwegein, The Netherlands, approved the study and all parents provided written informed consent. The work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The AMICA trial was registered on the 23rd of December 2016 in the Netherlands Trial Registry NL6175 [23].

We used the quality checklist developed for the reporting of health-related-patient reported outcomes [24] for this study. The primary outcomes for this study were content validity, structural validity, and construct validity of the CO-PARTNER tool.

## Description of the construct to be measured

We adapted the definition as proposed by Power and Franck for parent participation, including the unique roles parents have during infant NICU stay and the process of collaboration with staff for developing capacity to perform activities independently [25]. Parent participation is defined as "The activities performed by a parent/guardian for their infant in the hospital setting in which they share, take part or independently act in the care of their infant across the entire hospital episode. Activities are defined as physical, psychological, or social performed by parents to improve the health and/or psychological well-being of their infant, with or without collaboration with healthcare professionals." We developed a formative measure to the concept of parent participation.

## Content validity

The Index of Parent Participation (IPP, developed for paediatric care) [11] questionnaire was used as a starting point as many of the 36 items could be completed by parents during infant hospitalization in the NICU.

**Item generation.** Two researchers (NvV and SvdS) independently and blind from each other extracted relevant items from the IPP [11] for the NICU setting. We simultaneously consulted the original author of the IPP on which items of the 36 in the original IPP could be applied to a NICU care context (see acknowledgments). This resulted in 26 items to be included in the item generation phase. Focus groups, one-on-one interviews and scoring of the instrument was performed with a purposive sample of six healthcare professionals and forty-five parents. Healthcare professionals included a speech therapist experienced in FICare and nurses and midwives who either worked at the FICare or the standard care unit, with a large range in working experience (8 to 30 years in profession). Parents (mothers or fathers >18 years of age) had a preterm infant (born at a gestational age between 24 weeks—36 6/7 weeks), were at the time experiencing or had experienced a NICU stay in the previous 2 years, and had experience in either a standard or FICare unit participating in the AMICA trial. Parents and professionals were approached by independent researchers. Specifically for parents, the researchers were not involved in the care of their infants. Participants were asked to identify (additional) items on parent participation. Above, we investigated their views on content of items, how response options to items should be presented and on the rightful inclusion of the 26 items from the original IPP in the first version of the tool [26]. Participants were asked to score items (during generation from the original IPP, focus groups or one-on-one interviews) as; (1) relevant or not relevant in light of parent participation in the NICU; (2) if the items needed a yes/no response, or if the items had to be scored on a scale and were intended to examine a collaborative process in care towards being able to perform activities independently ('the nurse does this', 'the nurse and I do this together' and 'I do this independently'). Inclusion of participants ended after no new items were identified and consensus was reached on item responses.

The research team, healthcare professionals and parent consultants identified a total of 88 relevant items that could be considered meaningful to the concept of parent participation and the process of collaboration in the NICU context. Two neonatologists, a researcher specialized in parent empowerment, and one neonatal nurse (see acknowledgments), independently and blind from each other, scored the items as to their applicability to the concept of parent participation and collaboration in the NICU. If at least 3 out of 4 experts rated the item as relevant, it was included in the CO-PARTNER tool. A total number of 34 items were generated during the item generation phase but three items were dropped during the analysis phase (see Structural validity) resulting in a total of 31 items included.

**Conceptualizing six domains.** After item generation research members consulted together on concept use, and current state in the literature [2, 5, 27]. Language considerations are described in the S2 Appendix of S1 File. The research team identified the definition of parent participation to be multidimensional and items were applied to each domain based on informal consensus in an empirical and iterative process.

The six domains are based upon essential parent participation, collaboration and role within the NICU context: (1) *Daily Care*; (2) *Medical Care*; (3) *Acquiring Information*; (4) *Parent Advocacy*; (5) *Time Spent with Infant*; and (6) *Closeness and Comforting the Infant* (See Table 1).

## Data collection

The tool was evaluated by fathers and mothers of infants enrolled in the AMICA study, a prospective non-randomized study evaluating the effect of a family integrated care model in level 2 NICUs in the Netherlands (see S3 Appendix of S1 File for an elaborate description of the neonatal population and caregiving practices in the Netherlands). Questionnaires were sent using Castor Electronic Data Capturing [28] at admission and at discharge from the level 2 NICU. In the case of families with multiple births, fathers and mothers received 1 questionnaire per time point. Parents received 2 reminders if they did not fill out the questionnaire (1

**Table 1. CO-PARTNER tool.**

| Activity | Response |
|---|---|
| **Domain 1. Daily Care** | |
| 1. Bath my child/clean my child with a washcloth. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 2. Change my child's diaper. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 3. Feed my child (breast or bottle). | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 4. Change my child's clothing. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 5. Get my child out of the incubator/cradle. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 6. Give my child medication. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 7. Weigh my child. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 8. Keep track of output (urination and defecation) of my child | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 9. Measure the temperature of my child. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 10. Keep track of my child's weight. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 11. Keep track of drinking and my child's feeds. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| **Domain 2. Medical Care** | |

(*Continued*)

**Table 1.** (Continued)

| Activity | Response |
|---|---|
| 12. Give tube feeding to my child. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 13. Look at my child's monitor and handling accordingly (e.g. stimulating during a bradycardia). | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 14. Regulate the visiting of others to my child. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 15. Participate in the daily rounds with the doctor. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| **Domain 3. Acquiring Information** | |
| 16. Did you ask healthcare professionals information on the health of your child? | ○ Yes<br>○ No |
| 17. Did you ask the healthcare professionals for information about your child for times when you were not present? | ○ Yes<br>○ No |
| 18. Did you talk with another parent about your experiences? | ○ Yes<br>○ No |
| **Domain 4. Parent Advocacy** | |
| 19. I stood up for my child; I told somebody to do something in the care of my child. | ○ Yes<br>○ No |
| 20. I stood up for my child; I told somebody NOT to do something in the care of my child; I gave boundaries | ○ Yes<br>○ No |
| 21. I gave an explanation on the daily routines of my child to a healthcare professional. | ○ Yes<br>○ No |
| **Domain 5. Time Spent with Infant** | |
| 22. On average, how many hours were you present in the hospital with your child? | Number of hours per day: |
| 23. On average, how many hours a day do you have contact with your child? | Number of hours per day: |
| 24. On average, how many hours were you really close with your child? | Number of hours per day: |
| **Domain 6. Closeness and Comforting the Infant** | |
| 25. Hold/rock/cuddle my child. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 26. Comfort my child whenever he/she needs it. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 27. Kangaroo care / skin to skin contact. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |

(*Continued*)

**Table 1.** (Continued)

| Activity | Response |
|---|---|
| 28. Be together with my child, be close with my child (intimate time). | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 29. Be together with my child (be present). | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 30. Soothe my child during a painful procedure (for instance drawing blood). | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |
| 31. Recognize my child's signals. | ○ The nurse does this<br>○ I do this together with the nurse<br>○ I do this independently (without the help of the nurse)<br>○ This is not applicable |

Domains 1 and 2 consist of 11 and 4 items, respectively, and measure the nature of parent participation in activities of daily care and medical care. The degree of collaboration between parents and healthcare professionals is indicated by the response options. These items are measured on a 3-point scale (e.g. I do this myself/independently; I do this together with the nurse; or The nurse does this) or scored as "This was not applicable". The following three items measure *Acquiring Information* and the next three items measure the nature of *Parent Advocacy* activities while caring for their child in the NICU. Questions are answered either yes or no. Three questions pertain to the amount of *Time Spent with Infant* in the NICU. This domain represents the mean time over the hospital stay that parents reported to be present and felt close with their child per day in hours. Seven items pertain to *Closeness and Comforting the Infant*, and include activities such as comforting the infant during painful procedures and kangaroo care, and the process of collaboration with staff is visible through the response options.

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and 2 weeks after the initial questionnaire was sent). All parents completed a survey package that included the tool and additionally, surveys on perceived stress in the NICU (PSS-NICU) [29], depression and anxiety [30] (HADS), parent-self-efficacy (PMP-SE) [31], satisfaction and empowerment (subscale on parent participation, EMPATHIC-N) [32], and impaired parent-infant bonding (PBQ) [33] (see S4 Appendix of S1 File for details on the characteristics of the questionnaires).

## Statistical analyses

**Sample size calculation.** We performed a sample size calculation for the AMICA study for the primary outcome of neurodevelopment in preterm infants at 2 years of age corrected for prematurity (See S5 Appendix of S1 File for details on the sample size calculation [23]). We included sufficient parents for our psychometric analyses, as we had 10 participant responses per item [34].

**Dealing with non-applicable responses and missing data.** We used the proposed guidance as explained by Sterne *et al.* [35] for missing data and applied the multivariate imputation by chained equations (mice) procedure with parcel summary scores to missing data at the item level [36]. Imputed datasets were used for further analyses [37], including confirmatory factor analysis (CFA) and construct validity [38]. We performed sensitivity analyses for data considered missing if participants did not fill out a question, or if items were scored as "this was non-applicable". For all datasets we performed 10 imputations and 50 iterations to obtain imputed datasets (see S6 Appendix of S1 File for variables included in the missing data model). Convergence was checked graphically with stripplots for Domain 1, 2, 3, 4 and 6, and convergence plots for Domain 5. Pooled estimates for further analyses were derived applying Rubin's Rules [39, 40].

**Structural validity.** *Confirmatory factor analysis*. Confirmatory factor analysis was done on imputed datasets using structural equation modelling. We used diagonally weighted least squares (DWLS). The DWLS approach uses the weighted least squares (WLS) estimator with polychoric correlations as input to create the asymptotic covariance matrix [41]. We calculated the following fit measures: comparative fit index (CFI), Tucker-Lewis index (TLI), Root Mean Square Error of Approximation (RMSEA) and the (Standardized) Root Mean Square Residual (SRMR) [42].

*Internal consistency*. We calculated composite reliability (CR) for each domain to assess internal consistency, as the CR is calculated from factor loadings and acknowledges the possibility of heterogeneous item-construct relations and estimates true score variance from the factor loadings resulting in more precision for multilevel confirmatory factor analyses than the commonly used Cronbach's alpha [43]. Desirable values for CR are between 0.6 and 0.9 [44].

**Construct validity.** *Distinctiveness between domains*. We analyzed construct validity by using the Average Variance Extracted and Heterotrait-Monotrait criterion [44]. First, we determined the Average Variance Extracted (AVE) which informs how closely each domain is related based on the item characteristics within each domain, the AVE should be greater than 0.05 to be acceptable [44]. To examine the distinctiveness between domains we performed Heterotrait-Monotrait (HTMT), a new method that measures a ratio of correlation [44]. The HTMT method has emerged as a discriminant validity method that has been shown to achieve higher sensitivity and specificity (99% and 97%) than the commonly used cross-loadings and Fornell-Lacker methods [44]. We set our threshold for the HTMT analysis at 0.85 [44].

*Total scoring*. Total scores per domain were obtained by summing scores for hypothesis testing. For Domain 1, 2 and 6 we calculated 0 for 'The nurse does this', 1 for 'The nurse and I do this together' and 2 for 'I do this independently' (minimum scores 0 to 22, 8 and 14 respectively), indicating the positive inherent relationship between participation and collaboration. We performed sensitivity analyses on non-applicable items, either transforming them to 0 (no participation in this item) indicating that parents did not participate or did not experience an item or to missing before multiple imputation (and thus rendering a 0,1, or 2 value after multiple imputation). For domain 3 and 4 'yes' was scored as 1, and 'no' as 0 (minimum scores 0 to maximum 3). For the domain Time Spent with Infant (3 items) we performed sensitivity analyses including the items as scored originally (minutes or hours of relevant items) or as quartiles (minimum 0 maximum 12). Quartiles were calculated in imputed datasets. A total participation score was obtained by summing all domain scores. Minimum total scores were 0 and maximum 62.

*Hypotheses testing*. We calculated Pearson correlation coefficients (rho) and associations for hypothesis testing. We set up 5 hypotheses. A priori, we hypothesized (Hypothesis 1) that the total score would have a negative correlation with parent well-being outcomes such as depression and anxiety, of -0.3 to -0.5, meaning that if parents were depressed or anxious, they would demonstrate lower active parent participation. Contrarily, Hypothesis 2 was that the total score would have a positive correlation with self-efficacy and satisfaction and empowerment, of +0.3 to +0.5. We used univariate linear regression analysis to compare groups and test for associations. We stated that (Hypothesis 3) the CO-PARTNER-tool would be able to discriminate between high and low parent presence (Domain 5) and participation (total score) within the trial on the effect of FICare in SFR on parent and infant outcomes [23]. Also, we anticipated (Hypothesis 4) that mothers would be more present (Domain 5) than fathers, as fathers in the Netherlands had on average 2–5 days of paternity leave, and resume to work quickly after birth during conduct of the study [45]. The last hypothesis (Hypothesis 5) was that parents who were more present (Domain 5), would participate more in daily care (Domain 1).

### Statistical packages and software

We used R for statistical analyses (version 3.6.1) [46] for missing data analysis the 'mice'-package [47], for confirmatory factor analysis the 'lavaan'-package and 'semTools'-package [48, 49]. For all tests, a *p*-value of less than 0.05 was considered statistically significant.

## Results

During the conduct of the AMICA study, 1213 preterm infants were assessed for eligibility. In total, 309 families were included, with 358 infants, 296 mothers and 263 fathers (Fig 1). One hundred and seventy-four out of 296 included mothers and 132 out 263 included fathers (response rates 58.8% and 50.2% respectively) filled out the questionnaire on parent participation and collaboration at NICU discharge of their infant and were included in this psychometric study (see S7 Appendix of S1 File on parent responses to the CO-PARTNER tool). There were 233 infants within 205 families. The median gestational age of their infants was $33^{+3}$ weeks, and parents filled out the CO-PARTNER tool at a median postmenstrual age of their infants of $37^{+1}$ weeks. Baseline characteristics of the sample are outlined in Table 2.

*Structural validity*. Three items were removed, and included items highly correlated with each other ("Keep track of defecation of my child" and "Keep track of urination of my child", transformed into "Keep track of output (urination and defecation) of my child") and two items were deemed redundant in the analysis phase by the author group ("Walking a small round with my child if it is permitted" and "On average, how many minutes did you perform skin-to-skin per day?"). A total of 31 items were used in CFA. The fit parameters demonstrated good to moderate fit, CFI and TLI were 0.923 and 0.914, respectively, RMSEA 0.030 (90%CI: 0.021; 0.037), and SRMR (0.129). Factor loadings for domains are described in Table 3. Sensitivity analyses for missing data, revealed that model fit was better without transforming the non-applicable items to missing (see S8 Appendix of S1 File for sensitivity analyses). The overall model fit increased if the domain *Time Spent with Infant (Domain 5)* was scored with quartiles.

The domains *Acquiring Information* (Domain 3) and *Parent Advocacy* (Domain 4) were initially included and evaluated as one domain (Advocacy). CFA revealed low factor loadings of *Acquiring Information* items to the overall domain of Advocacy. Post-hoc, better loadings were achieved when items were within the domain of *Acquiring Information*.

Factor loadings were 0.508 or higher in *Daily* Care (*Domain 1*, range 0.508–1.003). Within *Medical Care (Domain 2)* factor loadings ranged between 0.399 and 0.591. *Acquiring Information* (*Domain 3)* and *Parent Advocacy* (*Domain 4*) had overall good representation and items within the domain on *Time Spent with Infant (Domain 5)* loaded all above 0.7. The *Closeness and Comforting the Infant* domain showed overall factor loadings equal to or above 0.65, three items were low (between 0.487–0.566). The three lower items were, "Soothe my child during a painful procedure (for instance drawing blood)"; "Skin to skin contact"; and "Comfort my child whenever he/she needs it". CR scores were strong in *Daily Care* (Domain 1, CR: 0.934), *Acquiring Information* (Domain 3, CR: 0.745), *Parent Advocacy* (Domain 4, CR: 0.855); *Time Spent with Infant* (Domain 5, CR:0.839) and *Closeness and Comforting the Infant* (Domain 6, CR: 0.871). CR within participation in *Medical Care* showed results just outside desirable ranges (Domain 2, CR: 0.558, see S9 Appendix of S1 File for CR scores).

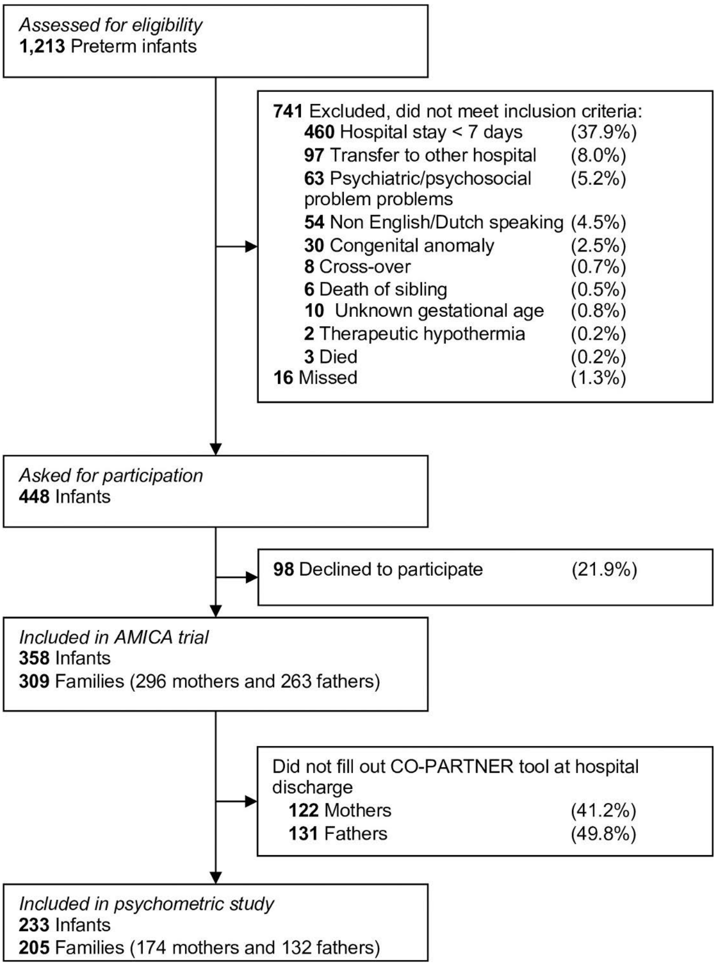

**Fig 1. Flow diagram of study.**

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*Construct validity*. The Average Variance Extracted and HTMT demonstrated strong construct validity and distinctiveness of domains (see S10 Appendix of S1 File for construct validity and distinctiveness outcomes). The direction of correlation between total and domain scores met our prespecified hypotheses (Fig 2 and S11 Appendix of S1 File for outcomes of hypotheses testing). Negative correlations were present between total and domain scores on the CO-PARTNER tool with depression and impaired parent-infant bonding (Hypothesis 1). No correlations were found between the CO-PARTNER tool and parent NICU stress (total and domain scores). We found positive correlations for total and domain scores between parent participation and parent self-efficacy and parent satisfaction and empowerment (Hypothesis 2).

**Table 2. Baseline characteristics of the sample.**

| | Included (n = 306 parents) | Missing (n (%)) |
|---|---|---|
| Mothers (n (%)) | 174 (56.9) | 0 |
| Admitted to FICare setting (n, (%)) | 157 (51.3) | 0 |
| Gestational age of infant at birth (weeks$^{+days}$, median (IQR), range (min- max)) | $33^{+3}$, $(31^{+0}–34^{+6})$, $(24^{+5}–36^{+6})$ | 0 |
| Postmenstrual age of infant at discharge to home (weeks$^{+days}$, median (IQR)) | $37^{+1}$ $(36^{+4}–38^{+0})$ | 0 |
| Age (years, mean (SD)) | 34.4 (4.7) | 7 (2.3) |
| Higher education level (n, (%)) | 273 (89.2) | 14 (4.6) |
| Employed (n, (%)) | 259 (84.6) | 14 (4.6) |
| Work hours per week (mean (SD)) | 38 (7.4) | 2 (0.7) |
| Identifies with Dutch background (n, (%)) | 270 (88.2) | 9 (2.9) |
| Attended FICare sessions (n, (%)) | 64/157 (40.8) | 27 (8.8) |
| Supported by child psychologist during NICU stay (n, (%)) | 73 (23.9) | 42 (13.7) |
| Intends to raise child with partner (n, (%)) | 277 (90.5) | 15 (4.9) |
| Single parent (n, (%)) | 8 (2.6) | 15 (4.9) |
| First child upbringing (n, (%)) | 209 (68.3) | 13 (4.2) |
| Level of experienced stress during pregnancy (scale 1–5) (mean (SD)) | 2.2 (1.2) | 9 (2.9) |
| Level of experienced stress during birth (scale 1–5) (mean (SD)) | 2.8 (1.3) | 12 (3.9) |
| Anxiety and depression score at discharge (median, IQR) | 7 (4–12) | 23 (7.5) |
| Self-efficacy score at discharge (mean, SD) | 63 (8.9) | 29 (9.5) |
| Parent NICU stress score at discharge (total, mean (SD)) | 47.0 (23.6) | 23 (7.5) |
| Impaired parent-infant bonding score at discharge (median, IQR)) | 8 (4–13) | 13 (4.2) |
| Parent participation in EMPATHIC-N score (median, IQR) | 5.6 (5.1–6.0) | 10 (3.3) |

n: number, FICare: family integrated care, NICU: neonatal intensive care unit, SD: standard deviation.

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We confirmed our Hypothesis 3 that parents in the FICare group participated more, they had significantly higher total CO-PARTNER total scores (beta 6.020, 95%CI 4.144; 7.895, $p<0.0001$). Also, parents in FICare had higher subdomain scores than parents in the standard care group (including *time being present*, Domain 5), except for Domain 3 (*Acquiring Information*, see S11 Appendix of S1 File). Likewise (Hypothesis 4), mothers had higher CO-PARTNER scores than fathers (beta 2.103, 95%CI 0.084; 4.121, $p = 0.041$). Overall, parents who were present more (*Domain 5)* participated more in daily care (Hypothesis 5, *Domain 1*, beta 0.390, 95%CI +0.240; + 0.540, $p<0.0001$, see S11 Appendix of S1 File for outcomes of hypothesis testing).

## Discussion

To our knowledge, this is the first study to perform rigorous instrument development and psychometric testing methodology to develop a measure of parent participation and inherent collaboration with healthcare staff in neonatal care. The six domains of this tool explicitly measure parents' participation and collaboration with care providers in their unique roles in care provision, leadership, and connection to their infant.

The psychometric evaluation demonstrated good content, construct and structural validity of the CO-PARTNER tool to the construct of parent participation in neonatal care. Overall, it was able to measure our pre-specified hypotheses. However, the factor loadings within Domain 2 (*Medical Care)* were not as desirable as we had hypothesized beforehand. This

**Table 3. Factor loadings after confirmatory factor analysis.**

| Domain | Factor loading | Standard Error |
|---|---|---|
| Domain 1. Daily Care | | |
| 1. Bath my child/clean my child with a washcloth. | 0.508 | 0.058 |
| 2. Change my child's diaper. | 1.003 | 0.046 |
| 3. Feed my child (breast or bottle). | 0.681 | 0.068 |
| 4. Change my child's clothing. | 0.862 | 0.061 |
| 5. Get my child out of the incubator/cradle. | 0.640 | 0.084 |
| 6. Give my child medication. | 0.714 | 0.044 |
| 7. Weigh my child. | 0.652 | 0.043 |
| 8. Keeping track of output (urination and defecation) of my child | 0.775 | 0.033 |
| 9. Measure the temperature of my child. | 0.777 | 0.040 |
| 10. Keep track of my child's weight. | 0.775 | 0.033 |
| 11. Keep track of drinking and my child's feeds. | 0.790 | 0.031 |
| Domain 2. Medical Care | | |
| 12. Give tube feeding to my child. | 0.537 | 0.071 |
| 13. Look at my child's monitor and handling accordingly (e.g. stimulating during a bradycardia). | 0.424 | 0.079 |
| 14. Regulate the visiting of others to my child. | 0.591 | 0.093 |
| 15. Participate in the daily rounds with the doctor. | 0.399 | 0.072 |
| Domain 3. Acquiring Information | | |
| 16. Did you ask health care professionals information on the health of your child? | 0.84 | 0.198 |
| 17. Did you ask the healthcare professionals for information about your child for times when you were not present? | 0.584 | 0.167 |
| 18. Did you talk with another parent about your experiences? | 0.671 | 0.117 |
| Domain 4. Parent Advocacy | | |
| 19. I stood up for my child; I told somebody to do something in the care of my child. | 0.775 | 0.071 |
| 20. I stood up for my child; I told somebody NOT to do something in the care of my child; I gave boundaries | 0.747 | 0.064 |
| 21. I gave an explanation on the daily routines of my child to a healthcare professional. | 0.913 | 0.070 |
| Domain 5. Time Spent with Infant | | |
| 22. On average, how many hours per day were you present in the hospital with your child? | 0.946 | 0.122 |
| 23. On average, how many hours per day do you have contact with your child? | 0.98 | 0.128 |
| 24. On average, how many hours per day were you really close with your child? | 0.799 | 0.132 |
| Domain 6. Closeness and Comforting the Infant | | |
| 25. Hold/rock/cuddle my child. | 0.943 | 0.057 |
| 26. Comfort my child whenever he/she needs it. | 0.511 | 0.102 |
| 27. Kangaroo care / skin to skin contact. | 0.487 | 0.066 |
| 28. Be together with my child, be close with my child. (intimate time). | 0.566 | 0.095 |
| 29. Be together with my child (be present). | 0.995 | 0.048 |
| 30. Soothe my child during a painful procedure (for instance drawing blood). | 0.653 | 0.055 |
| 31. Recognize my child's signals. | 0.665 | 0.064 |

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domain represents areas of care that are associated with hospital unit specific tasks and might contain items that parents were not familiar with (yet), insufficiently coached into, or in which nurses were not comfortable supporting parents in. There might also be individual preferences or variations to what extent parents want to participate in medical care. Parent participation in medical care is rapidly evolving and a new area of neonatal care that needs to be further

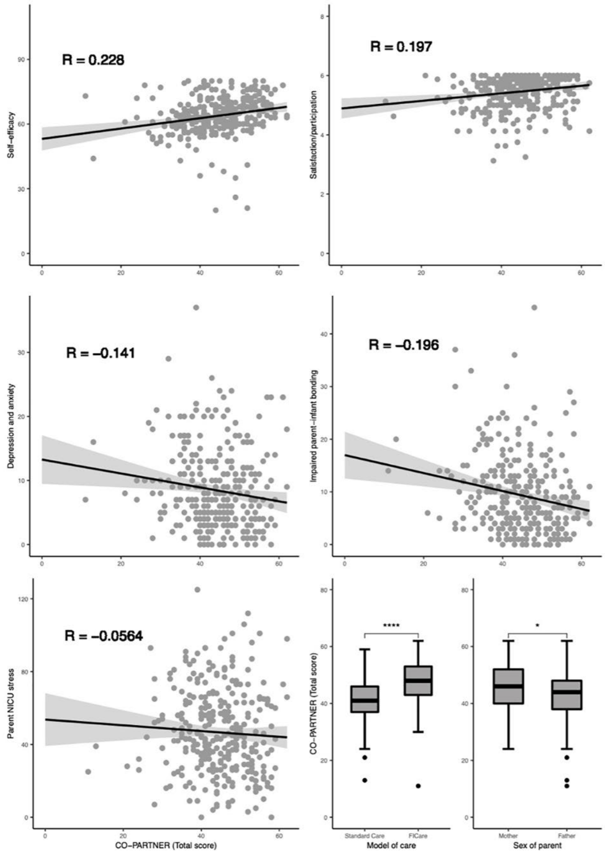

**Fig 2. Results of hypothesis testing.** Scatterplot and boxplot values are shown from the first imputed dataset. Correlation coefficients and significance are pooled outcomes from all imputed datasets. r: correlation coefficient (Pearson's rho).

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explored. Specifically, the item on daily rounds should be studied more carefully as parents' desired role could be different from their actual role, possibly explaining the low factor loading within that domain [8]. Nevertheless, from a FICare perspective, parent active participation in daily rounding is key and therefore should be incorporated in the tool. Equally, the closeness and comforting items were loading satisfactory but not excellent. These questions have been formed with a collaborative component (in the item generation phase) when in fact the collaboration between parents and healthcare professionals might not be a relevant component for these items.

The CO-PARTNER tool encompasses elements of parent participation such as time spent with the infant, closeness with infant, collaboration and competencies in daily care activities that have been previously measured separately [14–18]. The CO-PARTNER tool included fathers from initial conception, which provided insight into their specific needs and support to feel comfortable and competent in caring for their baby. In contrast to previous tools, our newly developed tool incorporates collaborative features explicitly describing and incorporating the process of collaboration between parents and healthcare professionals within daily and medical care and decision-making for hospitalized neonates, in alignment with the construct to be measured [2]. Above, one of the main strengths is, that the tool was developed in close collaboration with parents, ensuring face and content validity. The tool was also acceptable and feasible for parents to fill out, with an average missingness in items of 2.3%, with 4 items >5% missingness and a maximum of 8.9%.

The findings from this study should be considered in light of its limitations. First, the CO-PARTNER tool is unable to distinguish between different kinds of collaboration, as that would increase the data collection burden. However, collaboration details can be explored within the context of trusting relationships between nurses and families. Together they could view results of the CO-PARTNER tool and consider the parent development towards performing activities independently as an examination of their collaborative processes during NICU hospitalization of their infant. Second, learning is not explicitly assessed with the tool. For instance (learning how to) feed a preterm or sick neonate can be technically challenging and parents develop skills over time [50]. The answer option "the nurse and I do this together" can be seen as a proxy for a learning scale, eventually resulting in parents feeling competent to do this independently. As the level of learning is different from the level of collaboration the tool is unable to measure learning processes directly. Another limitation is that the directions of correlations between the total participation score met our pre-specified hypotheses but were not strong. This could be due to the fact that the constructs for which we assessed the correlation were different. The correlation between depression and participation is expected to be much weaker than the correlation of the scores of the CO-PARTNER tool with another patient participation instrument, but this was not assessed within this study as no such tool was available. Within this psychometric study, we did not adjust for clustering within families but included fathers and mothers as separate individuals. Therefore, the possibility of non-independence of a couple's responses cannot be ruled out [51] and should be explored in future studies. Also, parents who completed the tool were highly educated, and therefore future studies should include a more diverse sample of mixed levels of educated parents to validate our results.

The CO-PARTNER tool can be used to support quality improvement by health organizations, practitioners, and care specialists working within various NICU settings and with different models of (parent-partnered) care. This tool could potentially be used for benchmarking across and comparing settings. All items included in the CO-PARTNER tool can be performed by parents and this should be fully supported by units, as is advocated by parent representatives and the WHO [52, 53]. With CO-PARTNER scores parents can provide actionable quantitative data on the level of parent participation in care, with lower scores suggesting more tasks performed solely by healthcare professionals without participation of parents. Equally, the CO-PARTNER tool can potentially enable comparison of parent-partnered care practices and to study (health) outcomes in infants and their parents through, for instance, mediation analysis [54].

For clinical practice we envision that there is no summing of total scores, as the measure is intended to be a guide in understanding each parent's unique style of caring and participation and identify gaps in the culture of the unit. One could consider adding open-ended free-text questions to allow participants to explain some difficulties in their own words. However, for research and benchmarking between units total scoring can be meaningful; measuring parent participation in total or within subdomains can inform if interventions are needed to ameliorate family care practices. By measuring parent participation, researchers and parents can identify which collaborative practices are occurring in the NICU, which items are deemed not applicable by the parents, and subsequently work together to develop individualized strategies for improving parent participation rather than simply reporting quantity and types of tasks completed by parents.

Future research should focus on use of the tool in different settings (for instance in level 3 units), different countries, different intercultural contexts (for instance immigration, language or lower levels of education) and different resource settings (for instance in units relying on care delivery by families out of necessity), and with parents of infants with a wider range of diagnoses to determine if further adaptation is needed to account for context. It would also be interesting to evaluate the inter-rater-reliability between perspectives of parents and nurses on the items in this tool, which could enable an assessment of nurses' ability to collaborate with parents and enable parents' participation and tailor education programs further if deemed insufficient for parents or healthcare professionals. Likewise, the CO-PARTNER tool could be studied to evaluate progress within parents (beginning and end of hospital stay) or to evaluate changes in parent participation and collaboration after implementation of education programs for parents and healthcare professionals. Above, analyses of non-applicable items and their meanings related to unit culture could be studied further, preferably in mixed-method research understanding qualitative features of hospital care culture.

## Conclusions

The CO-PARTNER tool is able to assess parent participation and the collaborative process between parents and healthcare professionals in the NICU for research and in care. The CO-PARTNER tool, developed on the basis of participation theory and with parent engagement design methods, can reignite health organizations' motivation toward researching, monitoring and implementing parent-delivered and parent support interventions in the NICU. The tool could serve as a standard measurement for parent-partnered interventions in the neonatal care unit.

## Supporting information

**S1 File.**
(DOCX)

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