KCE REPORT 350

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE FOR PRETERM NEWBORNS IN NEONATAL CARE

KCE REPORT 350
HEALTH SERVICES RESEARCH

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE FOR PRETERM NEWBORNS IN NEONATAL CARE

JENS DETOLLENAERE, NADIA BENAHMED, ELENA COSTA, WENDY CHRISTIAENS, CARL DEVOS, KOEN VAN DEN HEEDE

2022 www.kce.fgov.be

COLOPHON

Title:	Infant- and family-centred developmental care for preterm newborns in neonatal care
Authors:	Jens Detollenaere (KCE), Nadia Benahmed (KCE), Elena Costa (KCE), Wendy Christiaens (KCE), Carl Devos (KCE), Koen Van den Heede (KCE)
Information specialist:	Nicolas Fairon (KCE)
Project facilitator:	Els Van Bruystegem (KCE)
Senior supervisor:	Koen Van den Heede (KCE)
Reviewers:	Irina Cleemput (KCE), Marijke Eyssen (KCE), Laurence Kohn (KCE), Isabelle Savoye (KCE)
External experts and stakeholders:	Hervé Avalosse (ANMC – Alliance Nationale des Mutualités Chrétiennes), Nele Baeck (VBS – Verbond der Belgische Beroepsverenigingen van Artsen-Specialisten, pediatrie), Joelle Belpaire (AVIQ – Agence pour une Vie de Qualité), Mieke Caelen (NVKVV – Nationaal Verbond van Katholieke Vlaamse Verpleegkundigen en Vroedvrouwen – Werkgroep kinderverpleegkundigen), Benoît Colin (INAMI – RIZIV – Institut National d'Assurance Maladie-Invalidité – Rijksinstituut voor Ziekte- en Invaliditeitsverzekering), Murielle Conradt (UPsfB – Union Professionnelle des Sages-femmes Belges), Chantal de Boevere (RUZB – Raad van de Universitaire Ziekenhuizen van België), Kris De Coen (UZ Gent – Universitair Ziekenhuis Gent), Hilde De Nutte (Zorgnet-Icuro), Katrin De Winter (NVKVV – Werkgroep kinderverpleegkundigen), Frederic Debève (Cliniques Universitaires Saint-Luc, UCLouvain – Université Catholique Louvain), Paul D'Otreppe (ABDH – Association Belge des Directeurs d'Hôpitaux), Delphine Druart (CHU St Pierre, Bruxelles), Laurence Grevesse (SPF Santé Publique – FOD Volksgezondheid), Yves Hennequin (Centre Hospitalier Régional Haute Senne Soignies, Erasme), Aline Hotterbeex (UNESSA – UNion En Soins de SAnté), Jean-Charles Houzeau (COCOF – Commission communautaire française), Emilie Huet (HUB – Hôpital Universitaire de Bruxelles, Erasme), Els Janssens (Landsbond der Christelijke Mutualiteiten), Kelly Janssens (FOD Gezondheid – SPF Santé Publique, UZ Leuven – Universitair Ziekenhuis), Abdel Kanfaoui (ABSYM – Association Belge des Syndicats Médicaux), Philippe Lejeune (Santhea), Pierre Maton (Groupe santé CHC), Samuel Meert (AISPN – Association des Infirmiers Spécialisés en Pédiatrie et Néonatologie), Murielle Mendez (Kaleido Ostbelgien), Julien Mergen (GBPF – Groupement Belge des Pédiatres de langue Française), Kristina Mreyen (Patienten Rat und Treff), Gunnar Naulaers (VVK – Vlaamse Vereniging Kindergeneeskunde, UZ Leuven), Anne Niset (AFSFC – Association Francophone des Sages-Femmes Catholiques), Sarah Paquet (Ministerium der Deutschprachigen Gemeinschaft), Geert Peuskens (Vlaams Agentschap Zorg en Gezondheid), Fiammetta Piersigilli (Cliniques Universitaires Saint-Luc), Marie-Jeanne Schoofs (Kind & Gezin – Opgroeien), Bojoura Schouten (VVOC – Vlaamse Vereniging voor Couveusekinderen), Inge Tency (Odisee Hogeschool), Marie-Rose Van Hoestenberghe (ZOL – Ziekenhuis Oost-Limburg), Gauthier Vandeleene (ANMC – Alliance Nationale des Mutualités Chrétiennes), Inge Vanherreweghe (CHU St. Pieter, Brussel), Virginie

	Verdin (SPF SPSCAE – FOD VVVL – SPF Santé Publique, Sécurité de la Chaîne Alimentaire et Environnement - FOD Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu), Bénédicte Vos (Solidaris)
External validators:	Anne Debeer (UZ Leuven), Janet Mattsson (RKH – Röda Korsets Högskola, Sweden), Sophie Thunus (UCLouvain)
Acknowledgements:	We would like to thank Stina Klemming and Siri Lilliesköld (Karolinska University Hospital, Stockholm, Sweden), Sabine Réthoré (Centre Hospitalier de Valenciennes, France), Maria Lopez Maestro (12 de Octubre Hospital, Madrid, Spain), Monique Oude Reimer-van Kilsdonk (Sophia's Children Hospital, Rotterdam, the Netherlands) and Natascia Bertoncelli (Azienda Ospedaliera – Universitaria di Modena, Italy) for their support in the description of the organisation of the best practices. In addition, we would like to thank all the parents of preterm newborns, midwives, nurses, neonatologists and paediatricians who participated in the interviews or focus groups. We very much appreciate the time and effort they invested for sharing their stories.
Reported interests:	All experts and stakeholders consulted within this report were selected because of their involvement in the topic of infant- and family-centred developmental neonatal care. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report.
Layout:	Joyce Grijseels

Disclaimer:

- **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings.**
- **They did not co-author the scientific report and did not necessarily agree with its content.**
- **Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators.**
- **The validators did not co-author the scientific report and did not necessarily all three agree with its content.**
- **Finally, this report has been approved by common assent by the Executive Board. Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**

Publication date:	22 March 2022
Domain:	Health Services Research (HSR)
MeSH:	Premature Infant, Preterm Birth, Neonatal Intensive Care, Family Centered Nursing

NLM Classification: WY 157.3
Language: English
Format: Adobe® PDF™ (A4)
Legal depot: D/2022/10.273/09
ISSN: 2466-6459
Copyright: KCE reports are published under a “by/nc/nd” Creative Commons Licence
http://kce.fgov.be/content/about-copyrights-for-kce-publications.

How to refer to this document?

Detollenaere J, Benahmed N, Costa E, Christiaens W, Devos C, Van den Heede K. Infant- and family-centred developmental care for preterm newborns in neonatal care. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2022. KCE Reports 350. D/2022/10.273/09.

This document is available on the website of the Belgian Health Care Knowledge Centre.

TABLE OF CONTENTS

1 INTRODUCTION AND BACKGROUND 12

1.1 IMPORTANCE OF ATTACHMENT BUILDING BETWEEN PARENTS AND NEWBORN 12

1.2 WHAT DO INTERNATIONAL CHARTERS AND STANDARDS RECOMMEND? 13

1.2.1 Convention on the Rights of the Child 13

1.2.2 European Association for Children in Hospital 13

1.2.3 European Standards of Care for Newborn Health 14

1.3 DEFINITIONS AND TERMINOLOGY 16

1.3.1 Definition of infant- and family-centred developmental care (IFCDC) 16

1.3.2 IFCDC delivery: related concepts and models 17

1.4 RESEARCH QUESTIONS AND METHODS 22

1.5 SCOPE 23

2 ORGANISATION OF NEONATAL CARE IN BELGIUM 23

2.1 LOCAL NEONATAL CARE FUNCTION (N* FUNCTION) AND N* WARD 24

2.1.1 Definition 24

2.1.2 Licensing standards regarding staffing 24

2.1.3 Architectural and functional licensing standards 25

2.1.4 Current supply 25

2.2 NEONATAL INTENSIVE CARE SERVICE (NIC SERVICE) 26

2.2.1 Definition 26

2.2.2 Licensing standards regarding staffing 26

2.2.3 Architectural and functional licensing standards 26

2.2.4 Programming standards and minimum activity standards 27

2.2.5 Current supply 27
2.3 REGIONAL PERINATAL CARE FUNCTION (P* FUNCTION) 27
2.3.1 Definition 27
2.3.1 Licensing standards regarding staffing 27
2.3.2 Architectural and functional licensing standards 28
2.3.3 Current supply 28
2.4 SUMMARY OF THE CURRENT ORGANISATION OF NEONATAL CARE 29
2.5 REVENUE SOURCES OF HOSPITALS 30
2.6 MEASURES FOR PARENTS 30
2.6.1 Maternity leave 30
2.6.2 Paternity/coparent leave 31
2.6.3 Medical assistance leave 32
2.6.4 Rooming-in 32
3 PROFILE OF HOSPITALISED PRETERM NEWBORNS 33
3.1 KEY POINTS 33
3.2 INTRODUCTION 33
3.3 METHODS 34
3.3.1 Administrative databases 34
3.4 RESULTS DATA ANALYSIS 34
3.5 IMPACT OF COVID-19 45
4 INTERVENTIONS TO PROVIDE NEONATAL INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE: A SYSTEMATIC REVIEW IN HIGH INCOME COUNTRIES 46
4.1 KEY POINTS 46
4.2 INTRODUCTION 46

4.3 METHODS....47
4.4 RESULTS....48
4.4.1 Characteristics of the included trials....50
4.4.2 Interventions....59
4.5 CONCLUSION....81
5 PARENTS' PERSPECTIVES ON FACILITATORS AND BARRIERS OF IFCDC....82
5.1 INTRODUCTION....82
5.2 METHODS....82
5.2.1 Design....82
5.2.2 Sampling and selection....82
5.2.3 Data collection tools....83
5.2.4 Data analysis....84
5.2.5 Ethical committee approval....84
5.3 RESULTS....84
5.3.1 Characteristics of the participants....84
5.3.2 Advantages of anticipating preterm birth....87
5.3.3 Difficulties for mothers of a preterm baby during maternity stay....89
5.3.4 Difficulties for fathers of a preterm baby....91
5.3.5 Informational, emotional and instrumental support help parents cope with the distress of having a preterm newborn....93
5.3.6 Partnership between parents and neonatal staff is built on their availability and support....96
5.3.7 Active involvement is much appreciated but not yet perfect....97
5.3.8 Parents suffered the most from being separated from their child....101
5.3.9 Challenges and opportunities regarding (breast)feeding and skin-to-skin care....109

5.3.10 Improvements suggested by parents 118
5.3.11 Conclusion and discussion 122
6 HEALTHCARE PROFESSIONALS' EVALUATION OF IFCDC 124
6.1 KEY POINTS 124
6.2 METHODS 125
6.2.1 Online focus groups 125
6.2.2 Sampling and selection 127
6.2.3 Data collection and analysis 128
6.3 RESULTS 128
6.3.1 The importance of infant- and family-centred developmental care (IFCDC) 128
6.3.2 Core principles of IFCDC 129
6.3.3 Description of IFCDC in practice 132
6.3.4 Conditions to put IFCDC successfully in practice 141
6.4 KEY POINTS AND SUGGESTED SOLUTIONS 167
7 IFCDC IMPLEMENTATION IN EUROPEAN BEST PRACTICES 170
7.1 KEY POINTS 170
7.2 METHODS 171
7.3 KAROLINSKA UNIVERSITY HOSPITAL, STOCKHOLM, SWEDEN 171
7.3.1 Neonatal care in Sweden 171
7.3.2 Karolinska University Hospital 172
7.4 CENTRE HOSPITALIER DE VALENCIENNES, VALENCIENNES, FRANCE 175
7.4.1 Neonatal care in France 175
7.4.2 Centre Hospitalier Valenciennes 176
7.5 HOSPITAL 12 DE OCTUBRE, MADRID, SPAIN 179

7.5.1 Neonatal care in Spain....179
7.5.2 Hospital Universitario 12 de Octubre....179
7.6 SOPHIA'S CHILDREN'S HOSPITAL, ERASMUS MEDICAL CENTRE, ROTTERDAM, NETHERLANDS....182
7.6.1 Neonatal care in the Netherlands....182
7.6.2 Sophia's Children's Hospital....182
7.7 DISCUSSION AND CONCLUSION....184

LIST OF FIGURES

Figure 1 – Topics of the European Standards of Care for Newborn Health 14
Figure 2 – Flower diagram of the main elements of infant and family-centred developmental care 17
Figure 3 – Categories of preterm birth 23
Figure 4 – Underlying dependencies between perinatal services 24
Figure 5 – Number of stays for preterm newborns by hospital site (2016-2018, n=116) 37
Figure 6 – Flow chart of the study selection process 49
Figure 7 – Risk of bias graph: review authors' judgement about each risk of bias item presented as percentages across all included studies 50
Figure 8 – Selection matrix for interviews with parents of preterm newborns 83
Figure 9 – Completion of the selection matrix 85
Figure 10 – Geographical distribution of the respondent's place of residence 86
Figure 11 – What helped parents to cope with their newborn's stay at a neonatal ward? 123
Figure 12 – Distribution of the focus groups 126
Figure 13 – Conditions facilitating the implementation of IFCDC using the CFIR 142
Figure 14 – Geographical distribution of the neonatal wards of Karolinska University Hospital 172

LIST OF TABLES

Table 1 – Research questions and methods 22
Table 2 – Summary of the current organisation of neonatal care in Belgium....29
Table 3 – Proportion of stays with a neonatal bed type (N* or NIC) for term and preterm newborns (2016-2018) 35
Table 4 – Newborn stays by gestational age categories (2016-2018) 35
Table 5 – Type of stay by hospital admission year for preterm newborns (2016-2018) 36
Table 6 – Number of stays by category of stay 37
Table 7 – Characteristics of preterm newborns without stay in a neonatal care ward per year of first admission (2016-2018) 39
Table 8 – Characteristics of preterm newborns staying in a neonatal care ward per type of bed type (2016-2018) 41
Table 9 – Length of stay for preterm newborns staying in a neonatal care ward (2016-2018)....43
Table 10 – Destination after hospital discharge for preterm newborns staying in a neonatal care ward (2016-2018) 44
Table 11 – Number of stays for preterm newborn by category of stay (2016-2018)....45
Table 12 – Inclusion and exclusion criteria....47
Table 13 – Study characteristics of the included publications....51
Table 14 – Interventions focusing on skin-to-skin and kangaroo care 61
Table 15 – Massage and ATVV intervention 63
Table 16 – NIDCAP 65
Table 17 – Mother-infant transaction program 66
Table 18 – Family nurture intervention 68
Table 19 – CUES program 69
Table 20 – H-HOPE program 70
Table 21 – COPE program 71

Table 22 – Psychological interventions 73
Table 23 – Family integrated care 74
Table 24 – Music therapy 76
Table 25 – Video interaction guidance 77
Table 26 – Other family-centred interventions....80
Table 27 – Inclusion and exclusion criteria....82
Table 28 – Characteristics of the participants 86
Table 29 – Characteristics of the participants of the focus groups....127
Table 30 – Conditions facilitating the implementation of IFCDC 143
Table 31 – Unmet financial needs and suggestions for improvement by the participants 151
Table 32 – Criteria for individual rooms....159
Table 33 – Summary of countries' characteristics....186

LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AISP	Association des Infirmiers Spécialisés en Pédiatrie et en Néonatologie
APIB	Assessment of the Preterm Infant Behaviour
APR-DRG	All Patient Refined Diagnosis Related Groups
ATVV	Audio, Tactile, Visual, Vestibular intervention
BFHI	Baby Friendly Hospital Initiative
BFM	Budget Financial Means
BNBAS	Brazelton Neonatal Behavioral Assessment Scale
BTP	Baby Triple P
BVN – GBN	Belgian Society of Neonatology – Belgische Vereniging voor Neonatologie – Groupement Belge de Néonatologie
BVK – SBP	Belgische Vereniging voor Kindergeneeskunde – Société Belge de Pédiatre
CEpiP	Centre d'Épidémiologie Périnatale
CFIR	Consolidated Framework for Implementation Research
CH	Centre Hospitalier
CHU	Centre Hospitalier Universitaire
CLE	Compréhension du langage de l'enfant
COPE	Creating Opportunities for Parent Empowerment
COVID-19	Coronavirus Disease 2019
CPAP	Continuous Positive Airway Pressure
CRC	Convention on the Rights of the Child
EACH	European Association for Children in Hospital
ECMO	Extracorporeal Membrane Oxygenation
EED	Expected delivery date

EFCNI	European Foundation for the Care of Newborn Infants
ES	Effect size
FIC	Family Integrated Care
FINE	Family and Infant Neurodevelopmental Education
GBPF	Groupement Belge des Pédiatres de Langue Française
GLANCE	Global Alliance for Newborn Care
GNI	Gross National Income
H-HOPE	Hospital to Home: Optimising the Infant's Environment
HJA – ADH	Hospitalisation de jour anonyme – Anonieme dag hospitalisatie
HR	Hazard ratio
IFCDC	Infant- and family-centred developmental care
IHAB	Initiative Hôpital Ami des Bébés
INAMI – RIZIV	Institut National D'Assurance Maladie-Invalidité - Rijksinstituut voor Ziekte- en Invaliditeitsverzekering
IQR	Interquartile range
KMC	Kangaroo Mother Care
LOS	Length of stay
NBAS	Neonatal Behavioural Assessment Scale
NIDCAP	Newborn Individualized Developmental Care and Assessment Program
PAM	Pacifier-activated music player
PBIP	Parent Baby Interaction Programme
PICOTS	Population, Intervention, Comparison, Outcome, Time, Setting
PMI	Protection Maternelle et Infantile
RCT	Randomised controlled trial

RD	Royal Decree
RHM - MZG	Résumé hospitalier minimum – Minimale ziekenhuisgegevens
RoB2	Risk of Bias 2 tool
SD	Standard deviation
SHA – AZV	Séjour hospitalier anonyme – Anoniem ziekenhuisverblijf
SIDAV	Service d'Intervention à Domicile de l'Arrondissement de Valenciennes
SOFFI	Supporting Oral Feeding in Fragile Infants
SOI	Severity of Illness
SPE	Studiecentrum voor Perinatale Epidemiologie
SSC	Skin-to-skin contact
TCT	Technische Cel voor de verwerking van de gegevens met betrekking tot de ziekenhuizen – Cellule Technique de traitement de données relatives aux hôpitaux
TOP	Transmural developmental support for very preterm in infants and their parents
TRT	Triadic parent-infant Relationship Therapy
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
VIG	Video interaction guidance
VINZ	Vlaamse Intensieve Neonatale Zorgen
VVK	Vlaamse Vereniging voor Kindergeneeskunde
WHO	World Health Organization

SCIENTIFIC REPORT

1 INTRODUCTION AND BACKGROUND

This report will focus on infant-and family-centred developmental care (IFCDC) for preterm newborn infants hospitalised in neonatal wards. Every year, an estimated 15 million newborns worldwide are born too early, equalling 1 in 10 babies.[1] In Belgium, approximately 8% of the births are preterm (< 37 weeks of pregnancy)[a]. Furthermore, approximately 12% of the newborns in Belgian are hospitalised in neonatal intensive care units (NICU) or local neonatal wards (N*)[b].[2-4] Hospital length of stay (LOS) for preterm newborns roughly corresponds the number of days needed to reach the age of term[c].[2-4] Depending on the level of prematurity and/or comorbidities, this neonatal hospitalisation can last up to several months. Mothers are often discharged before the newborn when they are hospitalised in a N* ward or NICU. This requires an adapted care (model) approach since it is of utmost importance to avoid parent-newborn separation to the largest extent as possible.

1.1 Importance of attachment building between parents and newborn

Separation early in life between newborns and parents can have a significant impact on the child's development later in life.[5-7] This is supported by the concept of "attachment", which is defined as *"a deep and enduring emotional link between two human beings, that makes us search and find a sense of comfort and security"*.[6] This bond is especially crucial in the first years of life.

[a] In 2020, 8.6% of the births in Wallonia were preterm (i.e. < 37 weeks of pregnancy), 8.0% in Brussels and 8.1% in Flanders.

[b] In 2020, 9.6% of the births in Wallonia were hospitalised in a NICU or N* unit (3.7% and 5.9% respectively), 9.9% in Brussels (5.2% and 4.7% respectively), and 14.2% in Flanders (4.3% and 10.0% respectively).

[c] In 2020, average LOS in neonatal care in Flanders was 98.9 days for preterm newborn infants born before 28 weeks of pregnancy, 49.4 days for those born between 28-31 weeks of pregnancy and 18.6 days for those born between 32-36 weeks of pregnancy. Average LOS for preterm newborn infants is not available for Wallonia and Brussels.

The attachment theory, developed by Bowlby[8] in the '50s, focuses on the building of a bond by the child and the environmental factors contributing to the feeling of security.[9] According to Bowlby and Ainsworth[5], attachment with the primary caregiver develops during the first 18 months of the child's life, starting with instinctual behaviours like crying and clinging. These behaviours are quickly directed to one or a few caregivers in particular, and by 7 or 8 months old, children usually start protesting against the caregiver(s) leaving and grieve for their absence. Once children reach the toddler stage, they begin forming an internal working model of their attachment relationships. This internal working model provides the framework for the child's beliefs about their own selfworth and how much they can depend on others to meet their needs.[10]

During the last 30 years, the evidence on attachment building has become one of the most productive areas of research in developmental psychology. Difficulties in attachment building may lead to psychiatric illness and medical morbidity.[11, 12] Babies are biologically programmed to look for the physical proximity of an adult that responds to the baby's need for protection. However, the quality of his/her attachment varies according to the responses of the environment. Therefore, it is imperative that these responses are adequate, leading to the ability of the baby to use attachment as a safety and secure base.[13, 14] Furthermore, the concept of caregiving is a reciprocal motivational system between child and parents: parents give proximity and comfort in response to the attachment needs of the baby.

One of the best ways to support parenting and promote the baby's development is thus to minimise parent-newborn separation at birth and increase the quality of the parental responsivity. Early separation is harmful to both newborn infants and their parents since it disrupts the biological and emotional bonding.[15, 16] Separation between parents and newborn infants has short- and long-term consequences. These act as a stressor with effects on the physical and mental health of both the newborn infant and family and may interfere with breastfeeding[17], and alter the bonding and attachment process.[18]

1.2 What do international charters and standards recommend?

1.2.1 Convention on the Rights of the Child

Article 7 of the United Nations (UN) Convention on the Rights of the Child (CRC)[19] states that *"The child […] shall have the right to […] be cared for by his or her parents"* and article 9 stipulates that *"States Parties shall ensure a child shall not be separated from his or her parents against their will, […]"*.

1.2.2 European Association for Children in Hospital

The 10 principles of the European Association for Children in Hospital (EACH) charter[20] relate in many aspects to the rights of the child as stipulated in the UN CRC. However, the EACH charter is more tailored to the rights of children in the healthcare setting in the European context (while the CRC is more generic on the global level). Several Belgian children hospitals clearly endorse this charter on their website.

Regarding parent-child separation, the EACH charter states that *"hospitalised children have the right to have their parents or parent substitute with them at all times during their stay".* This entails all departments or services in which a child can be hospitalised: neonatal or paediatric intensive care wards, accident and emergency departments, isolation rooms, medical imaging rooms, recovery rooms, maternity services, ambulant transport services, or other healthcare settings in or outside of hospitals. This right is already deeply embedded in paediatric departments in Belgium (i.e. rooming-in possibility). However, it is not yet fully established for newborns hospitalised in Belgian neonatal departments.

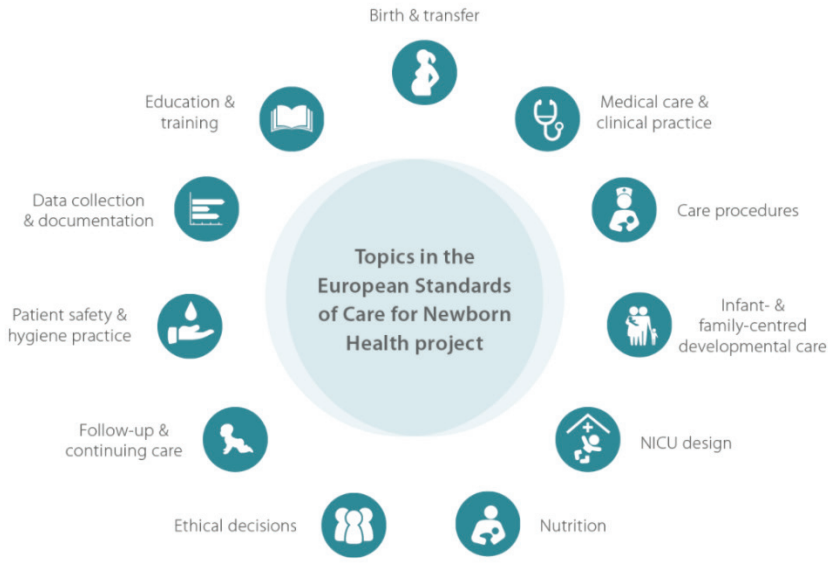
In addition, the third article of the EACH charter encourages parents to stay with their child and take part in the care by recommending policy makers and hospitals to provide parents with the required facilities, without additional costs and loss of income.[20]

1.2.3 *European Standards of Care for Newborn Health*

The European Standards of Care for Newborn Health were initiated by the European Foundation for the Care of Newborn Infants (EFCNI). It is an interdisciplinary European collaboration that develops standards of care for key topics in newborn health. The project brought together representatives of different healthcare professions, parent representatives and selected industry specialists, from more than 30 countries in 2018. A revision of the standards is currently going on and scheduled for publication in 2023. The focus of the project is the treatment and care of preterm and ill newborn babies in hospitals and as they grow up.

To address the complexity of the wide range of topics in neonatal care, the standards were divided into 11 areas (Figure 1). Although the aim of all these standards is to provide individualised high-quality care to the newborn adapted to his/her developmental level, below we will mainly focus on the standards that are especially related to infant- and family-centred developmental care (IFCDC) for the parent-newborn dyad.

Figure 1 – Topics of the European Standards of Care for Newborn Health



Source: European Foundation for the Care of Newborn Infants (EFCNI)[21]

1. **Birth and transfer:** parents must receive complete and accurate personalised information and support during pregnancy and childbirth in order to achieve efficient, optimal and respectful collaboration.[22]
2. **Care procedures:** the World Health Organization (WHO) recommends that newborn infants receive colostrum (i.e. milk rich in white cells and antibodies, protein, minerals and vitamins that are secreted in the first 2-3 days after delivery).[23] In addition, the EFCNI standards recommend that newborn infants are exclusively fed with human milk during their hospital stay and mothers should be supported to exclusively breastfeed after discharge.[24]

3. **Infant- and family-centred developmental care:** in collaboration with the parents an individual case management plan for each newborn infant should be established. This individual case management plan enables to plan and coordinate investigations and procedures, ensures acquisition of needed parental competencies prior to discharge and to plan follow-up and continuing care.[25] Therefore, it is paramount to tailor care to the family's socioeconomic, mental health, and spiritual needs.[26] Furthermore, to facilitate communication with and providing emotional support to parents, healthcare professionals need to receive counselling and clinical supervision on a regular basis.[27] In addition, to ensure IFCDC competence among all hospital-based partners (e.g. healthcare professionals, hospital and ward leadership or other staff working or visiting the neonatal ward) formal education and recurrent training needs to be organised.[28]

   The hospital environment may be challenging for the infant and their parents. The period of hospitalisation is critical, since the sensory experiences can impact neurodevelopment through many factors including synaptogenesis, synapses elimination and epigenetic factors.[29-32] As maternal stimuli are particularly salient for newborn infants, the hospital environment poses also a risk of sensory deprivation of biologically meaningful inputs for the infant.[33] Therefore, the hospital sensory environment needs to be adjusted to the infants' sensory expectancies and perceptual competencies.[34] Following birth, the newborn is exposed to a high amount of environmental noise. This environmental noise negatively impacts newborn's sleep.[35] Sleep is an important contributor to brain development during early infancy and sleep deprivation in a poorly managed acoustic environment may have a negative long-term impact on cognitive, psychomotor and behavioural development.[36] It is, therefore, important to provide a managed acoustic environment that reduces stress and discomfort for newborn infants.[37]

   Infants in neonatal intensive care wards are usually physically and emotionally separated from their parents, making it difficult for the parents to assume this expected role of caregiver.[38] Parents should be stimulated to be members of the caregiving team and, with individualised support, assume the primary role in the provision of care of their infant, and be active partners in decision-making processes.[39] For this reason, parents (and substitutes designated by the parents) are recommended to have continuous access and be able to remain with the infant 24/7.[40] The fostering of early bonding between parents and their newborn infant should also be pursued through strategies that promote early contact for the parent-infant dyad.[41] Bonding may be sustained using different strategies, including educational and informational support[42], fostering of physical contact through skin-to-skin contact, and promotion of emotional interaction.[43-45] These strategies are opportunities for parents to learn to understand their infant's behaviour and to respond to them appropriately, encouraging the feeling that the infant "belongs" to them.[46, 47] Lastly, skin-to-skin care (SSC) supports infant physiology and transition to extra-uterine life and clinical stabilisation.[48-50] It acts through multimodal mother-infant sensory interaction and offers an environment that elicits hormonal and epigenetic processes. Early SSC provides the opportunity for early bonding between the newborn infant and a safe and supportive caregiver; it is therefore of particular importance for very preterm infants, considering their recognised challenges in establishing future secure attachment.[51]

4. **NICU design:** family-centred care may be achieved independently from the design of the NICU. Neonatal care should, therefore, be optimised by utilising key design elements to promote the family as primary caregivers throughout the hospital stay.[52] In addition, it is imperative that the physical environment facilitates parent-infant closeness and SSC is considered in NICU planning.[53] NICU design should support safety and healing through unrestricted parental presence, use of sensory supportive material and optimal working facilities, promoting close collaboration between families and staff in caring for the ill infant.[54]

5. **Ethical decisions:** in most high-resource settings, newborn infants born alive have full legal status regardless of gestation or size at birth, and legally all actions should be motivated by the child's "best interests". Deliberations about limiting life support should be taken in partnership with the parents and be based on shared decision-making between parents and healthcare team taking into account the best interest of the infant and family in the context of the clinical situation and legal frameworks.[55] These decisions need to respect the rights of children,

parents, and families as far as feasible. The values behind any decisions that may compromise those rights are transparent.[56] This places an ethical duty on healthcare professionals to protect the integrity, dignity, and comfort of the infants and their family, as well as supporting the autonomy of parents in their execution of parental custody. However, in order to do so, healthcare professionals need to understand the condition of the newborn infant, values, and preferences of the parents. Parents need to fully understand the prognosis and care choices for their infant and should receive support in the decision-making process. Therefore, parents and healthcare professionals have to share all relevant information such as the conditions, prognosis, and choices for care of the infant, as well as the social situation, values, and preferences of parents.[57]

6. **Education and training:** in addition to the recommendations on IFCDC education for healthcare professionals and leadership (see above), it is also important to facilitate education, training, and support in specific skills to parents in order to become confident caregivers throughout the neonatal stay and post-discharge.[58]
7. **Follow-up and continuing care:** it is important to support families of preterm newborns following discharge from the hospital to ensure continuity and avoid unnecessary hospitalisation. Families need to receive a comprehensive discharge management plan to facilitate transition from the hospital to home.[59]

Box 1 — Campaign "Zero separation. Together for better care! Keep preterm and sick babies close to their parents"

In 2020, the Global Alliance for Newborn Care (GLANCE) (global initiative founded and coordinated by EFCNI) developed a long-term campaign to support parents of hospitalised newborns and healthcare professionals in neonatal care wards with the aim to enable infant- and family-centred developmental care in line with Coronavirus Disease 2019 (COVID-19) precautions. The campaign's goal is to raise awareness for the benefits of zero separation of preterm and sick babies and their parents in NICU in times of a pandemic. It provides healthcare organisations and professionals with possibilities to follow a zero-separation approach in neonatal wards while maintaining precautions and high standards of hygiene.[60]

1.3 Definitions and terminology

1.3.1 Definition of infant- and family-centred developmental care (IFCDC)

According to the Institute for Patient- and Family-Centered Care's definition:

"Patient- and family-centred care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships between and among consumers and health providers. Patient- and family-centred practitioners recognise the vital role that families play in ensuring the health and wellbeing of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental supports are integral components of health care. They promote the health and wellbeing of individuals and families and restore dignity and control to them. Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions".[61, 62]

In addition, EFCNI defines infant and family-centred developmental care (IFCDC) as *"a descriptive term that entails the framework of newborn care incorporating theories and concepts of parent-newborn interaction, parental involvement, neurodevelopmental and neurobehavioral care, breastfeeding promotion, environmental adaptation and change of hospital systems"*.[63]

Therefore, according to EFCNI, IFCDC should:

- be based on sensitive care relying on infant behavioural communication and cues, giving the newborn a voice[64, 65];
- be beneficial for brain growth[66];
- support parental wellbeing and the infant's development through parent engagement[67-71];
- and tailor the NICU environment and hospital system as a whole to the needs of the infant and family.[72]

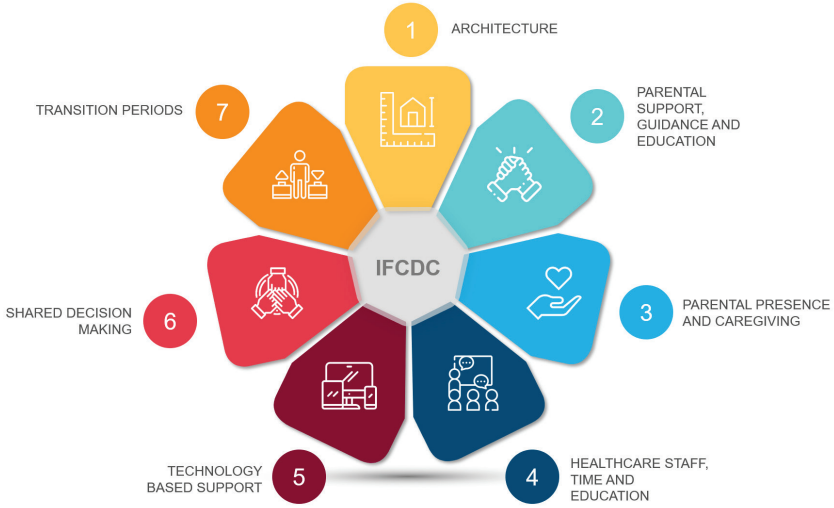
Strategies to support IFCDC are built on the unity of the newborn infant, parents and siblings as a family. This can be accomplished by continuous family access, integration in all provided care, early bonding methods, shared decision making, parental involvement as the primary caregivers, early and continuous SSC between parents and the newborn infant and promotion of breastfeeding.[43, 73] In addition, it is important to protect the newborn infant from deleterious environmental stimuli and provide them with positive sensory stimulation from parents or other significant caregivers.[74] Furthermore, sufficient support (in terms of mental health, spiritual services, or individual case management) should be available for all families. Last, trained healthcare professionals who receive counselling and regular clinical supervision in communication with parents and providing emotional support to them is a major prerequisite for successful IFCDC implementation.[71, 75, 76]

1.3.2 IFCDC delivery: related concepts and models

The existing body of literature contains a wide variety of terms, methods or theories to deliver IFCDC. However, some of these terms or methods are used interchangeably and are probably in some conditions overlapping, demonstrating the complexity and versatility of IFCDC as a multifaceted concept. The distinction or overlap between these terms and methods is not always clearly stated in the literature. In order to clarify the main elements to deliver IFCDC, we performed a concept mapping. The goal of this concept mapping is to clarify the fundamental elements in IFCDC and their relationships to laymen. The details of the method of this concept mapping can be consulted in Appendix 1.

Based on the concept mapping, we created a flower diagram that summarises the main operationalisation elements for IFCDC (Figure 2).

Figure 2 – Flower diagram of the main elements of infant and family-centred developmental care



The concept mapping is visualised as a flower to highlight the importance that all concepts stem from a general centre: the preterm infant(s) and their family (i.e. parents, siblings or other family members and friends). Important to note is that there is not necessarily a hierarchical relationship between the different main elements (the petals), but that they are all interconnected, mutually reinforcing and blending into what is defined as a philosophical approach and set of principles to guide the delivery of neonatal healthcare (rather than a list of all possible interventions).[77]

We identified the following main operationalisation elements, in what follows, we will explain these elements one by one:

1. Architecture

The physical environment in which the infant, family and healthcare professionals are placed plays a primordial role in enabling IFCDC, the design of the neonatal wards has evolved over time to accommodate the central role that families play in the care for the newborn and the individualisation of the environment for each newborn.[78] Standards for newborn intensive care unit (ICU) design are published and updated regularly.[79] The latest edition of these standards dates back from 2019 in the United States[80], in Europe[81] and includes, among other things, recommendations for ward configuration and location within the hospital, design of the reception, presence of appropriate signage, safety, security and space requirements.

There are recommendations for the presence of single-family rooms to allow the ability to provide "individualised and private environments for each baby and family" and "[rooms] are designed taking into account family integrity and privacy".[26] Couplet care rooms, in which the postpartum mother and her child can be cared for in the same physical space, avoid separation. The presence of family support spaces is also recommended, this includes a family lounge area (which should also be suitable for older siblings) and a family education area. There should be transition rooms to provide families with an "intermediate space between the highly medicalised environment of the NICU and the home[79], if this cannot be achieved via single-family rooms and/or couplet care rooms.

It is also important to provide adequate stimuli in the sensory environment of infants, families and staff. For this reason, recommendations for lighting and acoustic environment are included in the standards. Recommendations for staff-support space are included, to "meet personal, professional and administrative needs".[79]

2. Parental support, guidance and education

Parents going through the experience of having their infant hospitalised in the neonatal ward need support to cope with the experience and also in order to be emotionally, cognitively and physically able to parent their infant [77]; therefore, psychosocial and psychoeducational support is considered to be an important part of neonatal care.[26, 82] Psychosocial support includes the availability of neonatal care givers and mental healthcare professionals in the neonatal ward but also peer-to-peer support, provided by 'veteran' volunteer parents (parents who have had the experience of a child in the neonatal ward) that offer shared experiences of their infant's hospitalisation.[83] Involvement of the close environment of the family (like friends or extended family) adds an important pillar of support.

Parental guidance and education on how to read their infant's cues and respond appropriately, is a fundamental part of developmental care. Examples of developmental care are NIDCAP (see description below) and Creating Opportunities for Parent Empowerment (COPE). COPE is an educational-behavioural intervention programme for parents[42] that provides parents with educational information and parent/child activities in a phased sequence from early days following admission until weeks after discharge, helping parents to identify their infants' developmental cues and milestones and to know what to expect.[84]

Educational interventions which are tailored and individualised to the parents or carried out according to a set curriculum by the healthcare staff form an important part of the Family Integrated Care (FIC) model.[85] In the FIC model, parents are included as a vital part of the neonatal ward team, learning how to provide the biggest possible share of care while healthcare staff assumes the role of educators and coaches.[86]

Sibling support, via the organisation of sibling support activities, in order to promote sibling attachment and decrease sibling anxiety.[87]

The educational messages delivered by the healthcare professionals may be reinforced by the presence of educational material for parents, such as pamphlets or videos. Communication technology may also be used for support or educational purposes (see below).

Parents and caregivers should be allowed to give feedback and evaluate the support received in order to gauge and enhance its quality.[26]

3. Parental presence and caregiving

Parental presence is central for the development of the infant, as inputs provided by the parent(s) cannot be replicated by others[88]; therefore, it should be the aim to provide parents' presence 24h a day and to provide facilities for parents and family members (or significant others) to stay with the infant without interruption in, or adjacent to the neonatal ward.[40]

Parents can be encouraged to provide routine care for their newborn like diapering, bathing, clothing and feeding. Breastfeeding is identified as the optimal method for infant feeding.[78, 89] Breastfeeding promotion can be achieved via maternal support and the presence of lactation consultants.[90]

Box 1 – Baby-Friendly Hospital Initiative

The Baby-Friendly Hospital Initiative (BFHI) is a global effort to implement practices that protect and promote breastfeeding. The initiative was launched by WHO and the United Nations International Children's Emergency Fund (UNICEF) in 1991, following the Innocenti Declaration of 1990. The initiative is a global effort to implement practices that protect and promote breastfeeding.[91]

Since the launch of the BFHI plan by the FOD – SPF in 2005, 30 Belgian hospitals have been awarded the "Baby-Friendly Hospital" certificate after an training contract of 4 years.[92]

Developmentally supportive interventions should be based on the synactive theory of individualised developmental care (IDC) which is a caring approach that is based on each infant's individual cues and their responses to care.[93] A preterm baby is adapted to live in the environment of the uterus, their brain being immature and premature extra-uterine sensory experience may cause alteration in their development.[94] As a consequence, stimuli provided during hospitalisation should be responsive to the infant's competencies.[95]

Developmental care practices require minimising parent-infant separation, aiming to a zero separation policy, and include, but are not limited to: skin-to-skin contact (SSC), positioning or holding, adjustments of the care environment (e.g. light and sound) and provision of other positive sensory stimuli like the parents' voice via reading or singing.

Immediate SSC is the placing of the naked baby prone on the parent's bare chest at birth and early skin-to-skin contact begins within the first day and should continue until the end of the first successful breastfeeding.[96] It acts through multimodal parent-infant sensory interaction and offers an environment that elicits hormonal and epigenetic processes, also supporting the initiation of breastfeeding. On the other hand, separation of the parent and infant after birth may induce harmful stress hormone responses that potentially lead to poorer resilience.[97] Early SSC provides the opportunity for early bonding between the infant and a safe and supportive caregiver. It is therefore of particular importance for very preterm infants considering their recognised challenges in establishing future secure attachment. SSC promotes sleep cycling, necessary for the development of the brain.[98] According to the EFCNI standards, short-term benefits of early SSC are improved physiological transition to extra-uterine life[50, 99], improved early physiological stability[48, 49], increased breastfeeding rates[49], improved growth[48], facilitated parental sensitisation to their infant's needs and cues[100], improved maternal empowerment and self-efficacy[101] and improved paternal empowerment. In the long term, early SCC leads to increased breastfeeding rates beyond infant period[48, 49], improved parent-infant bonding and mental health[102, 103], improved immunity, decreased readmissions[104], reduced prematurity related morbidity in adulthood[105], improved neurodevelopmental outcome[103, 106], improved social behaviour in early adulthood[107] and reduced parental stress.[108]

Developmentally supportive methods are sometimes formalised into complex models of care. One of these models is kangaroo mother care (KMC), which refers to the positioning of the naked newborn chest-to-chest and skin-to-skin with one of the parents.[109] It was initiated in the 70s in Colombia to compensate for the unavailability of unreliability of incubators. This method includes early continuous and prolonged SSC (as far as the

parent-newborn dyad can tolerate it) and exclusive or nearly exclusive breastfeeding and attempt to early discharge from the hospital, regardless of weight or gestational age.[109] However, the last two components are less frequently identified as part of kangaroo care.[110] Kangaroo care has been reported to be associated with several positive physical and mental effects for both the preterm newborn as the mothers (e.g. reduced mortality, severe infection/sepsis rates or increased breastfeeding rates).[48, 111]

The most frequently used model of IDC in developed countries is the Newborn Individualised Developmental Care and Assessment Program (NIDCAP).[65] NIDCAP is a comprehensive care program for the NICU, developed by Als et al.[112] The core of the programme is that care should be developmentally supportive and individualised to the newborn's goals and level of stability. Healthcare professionals educate parents and take care for the newborn in collaboration. This can be achieved by direct observation of the newborn within their environment in the intensive care setting. Using a detailed observational tool, often referred to as the NIDCAP observation, the newborn's behaviours can be interpreted as steady and relaxed or as representing stress or discomfort. By observing and interpreting behaviours of newborns within their environment and as reactions to care they receive, developmental care plans that best support the newborns' overall goals and efforts at self-regulation can be developed. According to the literature, NIDCAP is associated with better cognitive, mental, psychomotor and language development up to 18 months of age, reduced LOS of the preterm newborn and lower hospital costs.[67, 113-117]

Box 2 – NIDCAP, FINE and CLE in Belgium

There are currently two recognised NIDCAP training centres in Belgium: UZ Leuven (UZ Leuven NIDCAP training centre) and CHU Saint-Pierre (Brussels NIDCAP training centre in St. Pierre). Currently, NIDCAP training is only offered to healthcare professionals working in a NICU. Most of the hospitals with a NICU have started NIDCAP training for (part of) their employees.

Healthcare professionals working at a neonatal ward can also follow a training in Family and Infant Neurodevelopmental Education (FINE). FINE is based on the framework of NIDCAP and provides a comprehensive overview of the theoretical, practical and scientific aspects of developmental care and provides insights to the healthcare professional to reflect on the own practices and how they impact the family and their child. The Brussels NIDCAP Centre has also developed and intermediate developmental care training program: "Compréhension du langage de l'enfant (CLE)". CLE is also based on the NIDCAP framework and has been followed by healthcare professionals working in several neonatal wards.

In combination with the BFHI training contracts, FOD – SPF also offers a training contract to hospitals in the context of developmental care.

Within the framework of FIC (see above), the role of the parents as caregivers extends to being involved in all possible aspects of their infant's care, including delivering parts of the medical care.

4. Healthcare staff, time and education

Safe and effective caregiving is dependent on appropriate training of the healthcare professionals both from a clinical care point of view and from a developmental care point of view.[118] As far as developmental care is concerned, in "Individualised developmental care for babies and parents in the NICU: Evidence-based best practice guidelines recommendations", a strong recommendation is made for healthcare professionals to require "extensive education and support to implement developmentally supportive caregiving".[89] Learning from qualified experts how to understand and respond to infants is essential to put in practice developmental care.[89]

Training in developmental care requires considerable investment from both the individual trainee and the institution. The average length of the training process for NIDCAP from introductory lecture to certification takes 12 months, depending on availability of the trainee.[65] Putting a neonatal professional through NIDCAP training costs thousands of euros. Training in positive communication is necessary to improve parents/staff communication in the ward.

IFCDC models imply a shift in the quantity and quality of time devoted by healthcare staff in supporting the infant and the family, which needs to be

acknowledged by the leadership with adequate time and supplies and supported by governmental decisions.[93]

5. Technology based support

Electronic technology can be used to contribute to the family-centred environment in the neonatal ward.[119] A variety of communication means such as web cameras, videoconferencing or text messages can be used to enhance communication or interaction between the neonatal ward team, parents, or infants, education of parents, or a combination of both.[119, 120] Videoconferencing technology can be used both for viewing the infant by parents who cannot be physically present, by grandparents or siblings who do not have the possibility to visit[121] or by healthcare professionals to monitor the infant once it has been discharged home.[122] Mobile applications and web platforms can be used for communication but also for educational purposes, permitting mobile access to pertinent information related to the infant's health.[119]

6. Shared decision-making

Creating the appropriate environment and opportunities for the family to communicate and collaborate with healthcare staff in the neonatal ward enables them to become part of the decision-making process, sharing all relevant information including prognosis and choice for care for the infant.[78, 123] A possible strategy to include parents in clinical decision-making is permitting their participation in clinical rounds.[124]

When zones of ambiguity arise in a premature infant treatment, where benefits of keeping or withdrawing treatment are not clear-cut, shared decision making is the ethically preferred approach, where the health practitioners elicit values and preferences from the parents and then connect them to the possibilities at hand, instead of paternalistically making decisions for them or leaving complete autonomy to them.[125]

Shared decision-making on a macro- and meso-level requires parents' representatives to be consulted as stakeholders by leadership and management when policy and institutional decisions are made regarding the organisation of neonatal care.

7. Transition periods

Special attention should be paid to the sensitive times when infant and their family transit from one care setting to another. During the antenatal period, it is important for women with a high-risk pregnancy to have access to counselling from a multidisciplinary staff (neonatal and obstetric teams), psychological support and the opportunity to visit the neonatal ward prior to the delivery.[126, 127]

The transfer of pregnant women or preterm infants between wards of specialist care needs to be done in a timely manner to avoid separation.[127] Therefore in-utero transfer is to be prioritised and zero separation should be the aim during intra and inter institution transfer.

Transition to home for hospitalised preterm infants requires technical skills, factual knowledge, emotional solidity and confidence of parents.[128] Support and education should be accessible even after the infant's discharge. Discharge preparation includes involving the parents in the process of discharge planning.[129] Discharge classes and educational material are employed to facilitate this process[130], so are the use of web-based or mobile apps.[131] Support of both formal (professionals) and informal (peers, family and friends) support is important during this transition period.[132]

Home care provided by staff affiliated with the neonatal ward may make discharge easier and smoother, ensuring continuity of care and making hospital stays shorter.[25] A structured follow-up programme is necessary in order to timely detect potential long term sequelae.[133]

1.4 Research questions and methods

The results of this report should assist public authorities, hospital sector and healthcare professionals in setting priorities and making strategic decisions regarding the implementation of IFCDC in Belgian neonatal care. The general aim covers the following research questions:

1. How is neonatal care for parents and newborns in NIC and N* wards currently organised in Belgium?
2. What is the profile of preterm newborns hospitalised in NIC and/or N* wards in Belgium?
3. What are interventions to promote IFCDC for hospitalised preterm newborns in high-income countries? What is the effect of these identified IFCDC interventions on several parental and newborn outcomes (including medical and other outcomes)?
4. What are the strengths (facilitators) and weaknesses (barriers) in the organisation and funding of neonatal care for preterm newborns (and their parents) in Belgium in the context of IFCDC?
5. What lessons can be learned from international good practices regarding IFCDC?

Different research methods were used during this project to answer the research questions. The main steps and research methods in general are summarised in Table 1. Each research method is described in detail in the respective chapter.

Table 1 – Research questions and methods

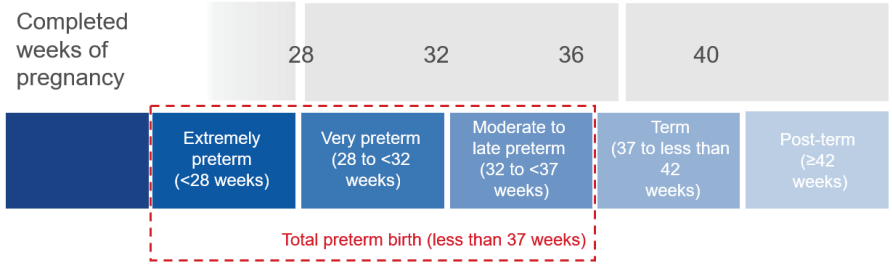
Research question	Methods	Chapter
1. How is neonatal care for parents and newborns in NIC and N* wards currently organised in Belgium?	Document review	Chapter 2
2. What is the profile of preterm newborns hospitalised in NIC and/or N* wards in Belgium?	Quantitative analysis of administrative data from SPF	Chapter 3
3. What are possible interventions to promote IFCDC for hospitalised preterm newborns in high-income countries? What is the effect of these identified IFCDC interventions on several parental and newborn outcomes (including medical and other outcomes)?	Systematic literature review	Chapter 4
4. What are the strengths (facilitators) and weaknesses (barriers) in the organisation and funding of neonatal care for preterm newborns (and their parents) in Belgium in the context of IFCDC?	Qualitative analysis of interviews with parents	Chapter 5
	Qualitative analysis of focus groups with healthcare professionals	Chapter 6
5. What lessons can be learned from international good practices regarding IFCDC?	Document review Expert consultation	Chapter 7

1.5 Scope

The target population, on which all these research objectives focus, will be preterm newborns. Preterm birth is defined as babies born alive before 37 weeks of pregnancy are completed.[1] There are sub-categories of preterm birth, based on gestational age:

- Extremely preterm: newborns born before 28 completed weeks of gestation;
- Very preterm: newborns born between 28 and before 32 completed weeks of gestation;
- Moderate to late preterm: newborns born between 32 and before 37 completed weeks of gestation.

Figure 3 – Categories of preterm birth



Source: authors' own reproduction based on World Health Organization (2018)[1]

2 ORGANISATION OF NEONATAL CARE IN BELGIUM

The information provided in this chapter is substantially based on the description of the Belgian maternity care in KCE report 323, which has been published in 2019.[134] For more details regarding the perinatal organisation, we refer the reader to this report.

Care provided in Belgian hospitals is organised in services, functions, departments and care programmes (Box 2). The neonatal intensive care (NIC) ward is a hospital service, while the local neonatal care (N*) ward is a hospital function.[135, 136] Care for children, aged from 0 to 14 years, is organised based on the care programme for children.[137] However, care provided in NIC- or N* wards is not part of this care programme but is regulated by specific legislations for the NIC service and N* function. Figure 4 illustrates the underlying inter-dependencies between the NIC service and the N* function and other (perinatal) services.

Box 2 — Organisation of hospital care activity

Hospital service: each hospital includes several care services (e.g. maternity, surgery, paediatrics). Beds in these services are identified by an index (letter(s) possibly followed by a number).

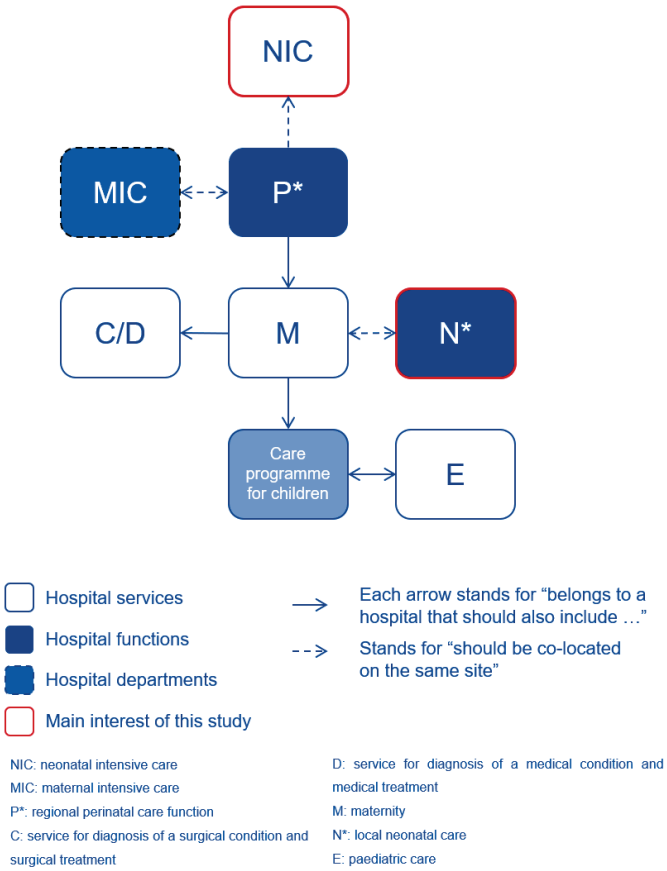
The notion of a **hospital ward** ("afdeling" – "section") is not properly defined in the law, but in general a ward is part of a service.

A **hospital function** aims to provide transversal care across services and departments.

A **care programme** is designed as an organisational framework allowing to implement care pathways.

Source: Crommelynck et al. (2013)[138]

Figure 4 – Underlying dependencies between perinatal services



Source: authors' own reproduction based on Lefèvre et al.[134]
Note: The Royal Decree (RD) of 2 April 2014 which regulates the care programme for children has been rescinded in December 2016.[139] *Therefore, care for children is currently organised by the previous RD of 13 July 2006.*[140] *This previous RD states that each care programme for children should have at least 15 paediatric beds (or E-beds), making the link between paediatric services (E) and the care programme for children bidirectional.*

2.1 Local neonatal care function (N* function) and N* ward

2.1.1 Definition

Every hospital with a maternity service is obliged to have an N* function. Each N* function is responsible for providing regular neonatal care in the room of the mother including phototherapy if the neonate's condition allows or requires it. In addition, every N* function must have an N* ward, which is exclusively meant for the supervision, treatment and care of newborns with specific adjustment problems that require specialised, non-intensive, neonatal care.

2.1.2 Licensing standards regarding staffing

Medical staff

The head of the N* function should be a licensed medical specialist in paediatrics, experienced in neonatology and is responsible for the functioning and the medical and scientific level of care offered by the N* function. The head of the N* function can be the head of the paediatrics service of the hospital and has to work exclusively for the hospital in which (s)he is the head of the N* function. At least 8/10 of his/her time is spent on hospitalised patients and on consultations in the hospital. Together with the head of the maternity service, the head of the N* function defines procedures for the collaboration between both disciplines. A detailed description of the role and responsibilities of the head of the N* function are described in articles 6 to 13 of the RD of 20 August 1996.[141]

The head of the N* function elaborates, in cooperation with the head of the maternity service, conditions for neonate transfer to intensive neonatology (NIC service see below) or retransfer from NIC services to N* function. The conditions are described in the formal and written collaboration agreement that must be concluded with at least one NIC service. The head of the N* function elaborates, in cooperation with the head nurse of N* function and the hospital hygiene committee, the access conditions to the newborns' room to allow the compliance with the hygiene and sterilisation rules and the modalities for newborn transportation inside and outside of the hospital.

A licensed medical specialist in paediatrics experienced in neonatology must be available 24/7 in the maternity and in the N* ward. The paediatrician examining the newborn after the delivery records the evaluation (including Apgar score and biochemical data) and potential treatment of the neonate and notes of all important conversations with the parents in the medical file of the newborn. Daily instructions regarding care have to be recorded in the medical file.

Nursing staff

The head nurse of the N* function is a paediatric nurse or midwife (bachelor's degree) experienced in neonatology. It can be the same person who is head midwife at the maternity service or head nurse at the paediatrics service of the hospital. The head nurse is responsible for the nursing activities and the nursing scientific level of care offered by the N* function. The head nurse of the N* function ensures the compliance with the rules regarding the access to the newborn's room, asepsis rules for care providers and visitors and is responsible to take measures in case of endemic infections.

The head nurse of the N* function is also responsible for the nursing file of the neonate and the reception of parents. Finally, the head nurse of the N* function, in collaboration with head physician of the N* function, develops the procedures for health education with regard to the care of a first born.

Six full-time equivalents of paediatric nurses or midwifes experienced in neonatology must be available in each N* ward. Supervision of the newborns hospitalised in the N* ward may not be combined with the supervision of the patients in delivery- and/or maternity ward or supervision of patients staying outside the maternity ward.

Parents must be involved as soon as possible and progressively in the care for their newborn. Parents have the right to visit their newborn all day long without limitation in duration. At night, the hospital can impose a prior authorisation of the nurse in charge. In case of perinatal death, particular attention must be paid to adequate care of the parents.

2.1.3 Architectural and functional licensing standards

Architectural standards

The N* ward is located within or adjacent to a licensed maternity service. There must be sufficient places (incubators and other facilities) to admit neonates needing specialised care, also at peak times, with the necessary space around each place to allow parents and caregivers to have direct contact with the newborn. In addition, hygienic facilities must be available, and the temperature must be 25°C at minimum.

Functional standards

Minimum equipment available in an N* ward includes a mechanical ventilator for short time ventilation, a cardiopulmonary monitor, an intravenous pump, a pulse oximeter, an oximeter, an oxygen hood, a radiant warmer and an air/oxygen mixer. Oxygen, compressed air and mucus extractor must be available in every treatment room. Furthermore, oxygen concentration and saturation, temperature, cardio-pulmonary activities and neurologic aspects must be continuously monitored. Lab and image results should be available in a minimal delay. Radiologic procedures, including ultrasound, must be able to be carried out in the N* ward.

2.1.4 Current supply

Currently 102 local neonatal care functions are available in Belgium (April 2021) from which 58 are located in Flanders, 33 in Wallonia and 11 in Brussels.[d]

[d] Centre Hospitalier Reine Astrid (Malmedy) has an N* function through association with CHR de la Citadelle (Liège).

2.2 Neonatal intensive care service (NIC service)

2.2.1 Definition

A NIC service is exclusively intended for newborns who are in a life-threatening or special condition. Newborns may stay at a NIC service until they have sufficiently recovered to be able to be transferred back to the referring hospital or service without any risks.

If the function of local neonatal care (N* function) is integrated in the NIC service, both must be clearly distinguishable from each other and intensive care must be reserved for the licensed NIC beds.

2.2.2 Licensing standards regarding staffing

Medical staff

The head of the service is a licensed medical specialist in paediatrics experienced in neonatology, whose hospital activity is exclusively for the hospital where (s)he is head of the service NIC service. (S)he has to take all possible measures to guarantee the continuity of care for the newborn. A licensed medical specialist in paediatrics experienced in neonatology or a medical specialist in paediatrics in training with a least two years of post-graduate education, has to be on duty 24/7. In this last case, the concerned NIC service must be part of the trainee's internship and (s)he must be familiar with urgent treatments and neonatal resuscitation. In addition, a medical specialist from the same discipline has to be on call 24/7.

Per five licenced NIC beds the NIC service must dispose of a full-time equivalent medical specialist in paediatrics experienced in neonatology. The head of the service has to work full-time and exclusively in the concerned NIC service. Other medical staff has to work at least 3/4 time and exclusively in the concerned NIC service.

Nursing, caring and other staff

The head nurse is a graduated nurse (bachelor's degree), preferably a graduated paediatric nurse or midwife experienced in neonatology. The head nurse is responsible for the nursing activities of the NIC service. The head nurse of the NIC service ensures the respect of the rules regarding the access to the newborn's room, asepsis rules for care providers and visitors and is responsible to take measures in case of endemic infections. The head nurse of the NIC service is also responsible for the nursing file of the neonate and the reception of parents.

Per licensed NIC bed, the service must dispose of 2.5 full-time equivalents graduated, preferably paediatric nurses and/or midwives, of whom at least 60% experienced in neonatology.

At least one full-time equivalent administrative worker has to be deployed in the service. A sufficient number of maintenance personnel must be available to allow a daily cleaning of the service, also during weekends and public holidays.

From the first admission day in the NIC service, parents receive a leaflet with, among others, the visiting rules. They must be involved as soon as possible and progressively in the care for their newborn. Parents have the right to visit their newborn all day long without limitation in duration. At night, the hospital may decide to impose a prior authorisation of the nurse in charge. In case of perinatal death, particular attention must be paid to adequate care of the parents.

2.2.3 Architectural and functional licensing standards

Architectural standards

A NIC service must have at least 15 beds and contains the following premises, which as a whole are clearly distinguishable: hygienic facilities, one or more rooms intended for intensive care including incubators and/or beds and a room with two sections for isolation. Other, more technical premises that must be available are an examination room, an office for doctors, a room for the nursing staff, clean and dirty utility rooms and a milk kitchen. The milk kitchen should have two rooms: one for the cleaning of the bottles and the other for milk preparation after the bottles have been sterilised. The milk kitchen has to fulfil the same conditions as the milk kitchen in the maternity service and can be shared with the maternity service. The technical premises can be located outside the NIC service.

Functional standards

Oxygen, compressed air and mucus extractor must be available at each NIC bed. The necessary equipment for cardiopulmonary resuscitation and long-term ventilation, for administering long-term parenteral nutrition, for performing minor surgery and devices to analyse the pH and blood gas and glucometer must be available in each NIC service. Lab and image results must be available in a minimal delay. NIC services must have mobile devices for X-ray and ultrasounds. Observations made by physicians, nurses or paramedics and daily instructions regarding care have to be recorded in the medical file. Furthermore, NIC services must have an ambulance for the transportation of newborns with incubator, resuscitation and monitoring devices. The transportation must occur immediately after a call with a physician trained in resuscitation. Finally, the NIC service is responsible of the standard follow-up organisation of high-risk newborns (gestational age < 32 weeks or a birth weight < 1 500 g).

2.2.4 *Programming standards and minimum activity standards*

The national programming standard, also determined by the RD of 21 March 1997[142], is 6 NIC beds[e] per 1 000 births. The NIC service must have a minimum of 15 beds.[143]

A NIC service has to fulfil at least three of the following activity standards[144]:

- each year at least 50 newborns with a birthweight of less than 1 500 grams are admitted annually;
- each year at least 20% of the admissions per year relate to intra[f]- or extrauterine transfers;
- each year, newborns in need of intensive care from at least 5 000 deliveries are treated through collaboration agreements with M services and N* functions;
- each year at least 50% of transferred NIC patients are returned back to the referring institution.

2.2.5 *Current supply*

In April 2021, there were 19 NIC services in Belgium (7 in Flanders, 6 in Brussels and 6 in Wallonia) including a total of 380 beds (148 in Flanders, 123 in Wallonia and 109 in Brussels).

2.3 Regional perinatal care function (P* function)

2.3.1 *Definition*

The regional perinatal care function (P* function) consists of a licensed department for high-risk pregnancies (MIC department) and a licensed service of neonatal intensive care (NIC service), on the same hospital site. Hospitals with a P* function act as a reference centre that has to make collaboration agreements with hospitals with an M/N* function. Together, these hospitals must have at least 5 000 deliveries per year.[145]

A hospital with a MIC department must have a P* function. In addition, a P* function can only be established can only be awarded if the hospital meets the following conditions: a genetic consult, a radiology service, a laboratory (24/7), a ward for prenatal monitoring and diagnosis (24/7 for a list of investigations) and a social service. The hospital must also have the following functions: cardiovascular diseases, pulmonology, nephrology, ophthalmology, pathological anatomy, neurology. Finally, the hospital or hospital group to which the hospital belongs must have an emergency department and an intensive care ward.

[e] In the RD of 21 March 1977 NIC beds are called N-beds. The notation changed on 1 January 1997 by the RD of 20 August 1996.[142]

[f] Intra-uterine transfers refer to the transfer of parturient from one hospital to another for a delivery in close proximity of a NIC service.

2.3.1 Licensing standards regarding staffing

Two medical specialists are in charge of the P* function: the head of the maternity service and the head of the NIC service. They coordinate the P* function and define procedures for the optimal treatment of mother and child. More details can be found in article 5 of the RD of 20 August 1996.[145]

2.3.2 Architectural and functional licensing standards

Architectural standards

The NIC service and MIC department must be located on the same hospital site.

Functional standards

No functional standards are defined for the P* function.

2.3.3 Current supply

In August 2021, there were 19 hospitals with a P* function in Belgium (7 in Flanders, 6 in Brussels and 6 in Wallonia), as well as 2 hospitals with associated P* function (1 in Flanders and 1 in Brussels)[g].

[g] In Flanders, this is AZ Sint-Lucas (Brugge) which is associated with AZ Sint-Jan (Brugge). AZ Sint-Lucas has M beds, but no NIC beds. In Brussels, this is Hôpital Universitaire Des Enfants Reine Fabiola – Universitair KinderZiekenhuis Koningin Fabiola (HUDERF – UKZKF) which is associated with Centre Hospitalier Universitaire (CHU) Brugmann. HUDERF has NIC beds but not M beds.

2.4 Summary of the current organisation of neonatal care

Table 2 – Summary of the current organisation of neonatal care in Belgium

	N* function/N* ward	NIC service	P* function
Purpose	N* function: normal neonatal care N* ward: supervision, treatment and care of newborns with specific adjustment problems that require specialised, non-intensive, neonatal care	Newborns who are in life-threatening or with special disease conditions Back transfer to the referring hospital to continue the treatment after stabilisation of the risk	Reference centre gathering MIC department and NIC service for high-risk pregnancies and newborns
Location	N* function: in the mother's room of the mother N* ward is located within or adjacent to a licensed maternity service.	Adjacent to a licensed maternity service. If the function of local neonatal care (N* function) is integrated in the NIC service, both must be clearly distinguishable from each other	On the same hospital site
Staffing	A licensed medical specialist in paediatrics experienced in neonatology must be available 24/7 in the maternity and in the N* ward. Six FTE of paediatric nurses or midwifes experienced in neonatology/N* ward.	A full-time equivalent medical specialist in paediatrics experienced in neonatology/5 licensed NIC beds 2.5 FTE graduated, preferably paediatric nurses and/or midwives, of whom at least 60% experienced in neonatology/1 licensed NIC bed	Physician: the head of the maternity service and the head of the NIC service
Current supply			
Belgium	102	19 (380 beds)	19
Flanders	58	7 (148 beds)	7
Wallonia	33	6 (123 beds)	6
Brussels	11	6 (109 beds)	6

2.5 Revenue sources of hospitals

The Budget of Financial Means (BFM) is the budget of hospitals and is a close-ended national budget which is fixed annually and allocated to hospitals according to a large set of criteria and parameters. The largest part of the BFM is the B2-part, which covers clinical services of nursing and care staff and the majority of the medical products. The allocation of B2, is based on the so-called "justified activities", which focuses on pathology-weighted LOS.

The process to determine the justified activities starts first by calculating the national average LOS per All Patient Refined Diagnosis Related Groups (APR-DRG) and Severity of Illness (SOI). Afterwards, the actual number of justified activities per hospital (expressed in justified patient-days) is calculated by multiplying the national LOS per APR-DRG-SOI with the case-mix of that particular hospital. Per department or group of departments, the number of justified activities is multiplied by 365 and the "normative occupancy rate" to calculate the number of justified beds. For N* wards and for NIC services this normative occupancy rate is 75%.[146]

The national B2-budget is allocated to individual hospitals by dividing it by the total number of B2-points "earned" by all hospitals. This gives the monetary value of one B2-point. Basic points are granted to finance nursing and caring staff. These points are based on the number of justified beds. The surgical ward is taken as reference with one point corresponding to one justified bed. For NIC wards, 6.25 points correspond to one bed. Additional points are granted for the N* function (next to those received for maternity wards): 15 points for a maternity service with less than 1 000 deliveries per year. The difference in the number of points per ward type corresponds to different "financing standards" in the respective wards. Financing standards are expressed as the number of FTE per number of beds i.e. 2.5 FTEs per NIC bed. On top of the B2-part, hospitals receive additional budgets for extra staff, for example through collective labour agreements or for floating pools.

In addition, hospitals receive part of the revenues of the specialist physicians working in that particular hospital to cover part of the costs related to their medical activities. Most specialist physicians are paid on a fee-for-service basis. Health insurance pays for medical and paramedical services based on a fee schedule or nomenclature, which lists about 10 000 unique covered services, their payment rates or tariffs and reimbursement.

2.6 Measures for parents

2.6.1 Maternity leave

An employee who is about to give birth is entitled to fifteen weeks maternity leave. If a multiple birth is expected, the maternity leave is in principle seventeen weeks, but can be extended to nineteen weeks. The maternity leave is composed of two periods: (i) the prenatal leave or maternity leave and (ii) the postnatal leave or maternity rest. Under no circumstances may the employee perform work during the seven-day period preceding the expected delivery date (EDD) and during the nine weeks which in principle begin on the day of delivery. The remaining weeks can be taken either before or after delivery. In case of stillbirth, maternity leave is granted on condition that the pregnancy has lasted at least one hundred and eighty days from conception onwards. For self-employed pregnant women, maternity leave is composed of a mandatory period (three weeks) and a discretionary period (nine weeks for a single birth and ten weeks for multiple births).

During maternity leave, the employee receives maternity allowance through her health insurance fund, which is entirely covered by the sickness- and invalidity insurance (maternity insurance). Therefore, the employer does not have to pay wages during maternity leave.

Prenatal leave

Prenatal leave can start at the earliest from the sixth week (the eighth week for multiple-pregnancy) before the EDD ("optional leave"). The employee must provide her employer with a medical certificate mentioning the EDD at least seven weeks (nine weeks for multiple-pregnancy) before the EDD. If the delivery takes place after this date, the prenatal leave is extended until the actual delivery date. From the seventh day before the EDD, the pregnant employee may no longer work and the employer may no longer put her to work ("compulsory rest"). If the employee gives birth before the EDD, seven minus the number of days until the EDD, are lost.

From 2020 onwards (Law of 4 June 2020 modifying the art. 39 of Labour Act of 16 March 1971 – MB/SB 18 June 2020), absence between the 6th and the 2nd week before delivery for the reasons described below are considered as work periods:

- temporary unemployment due to force majeure;
- economic unemployment of employees;
- work incapacity due to illness or an accident;
- complete temporary withdrawal of work for maternity protection reasons.

Postnatal leave or maternity rest

The postnatal leave is compulsory for at least nine weeks. From the day of delivery, the employee may not work for a period of nine weeks. If the employee has still been working on the day of the delivery, the period of nine weeks postnatal leave starts the day after the birth. This compulsory maternity rest can be supplemented by the optional prenatal leave that was not taken before the delivery, which is a maximum of five weeks (a maximum of seven weeks in case of multiple births). More specifically, the part of the optional leave that has not been taken before childbirth can be carried forward to the end of the compulsory postnatal period of nine weeks.

Breastfeeding breaks

There is no federal legislation that regulated breastfeeding leave for mothers. However, there are agreements for paid breastfeeding leave for employees working in some companies or sectors. The duration of this paid breastfeeding leave depends on those agreements.

Employees who breastfeed their infant have the legal right to breastfeeding breaks during working hours in order to feed her infant with breast milk or to collect milk. This right may be exercised up to nine months after the birth of the newborn. The breastfeeding break may last for half an hour. Employees working ≥4 hours/day are entitled to one break. Employees working ≥7.5 hours/day are entitled to two breaks (can be taken in one or two periods.

Protection against dismissal by the employer

From the moment the employer becomes aware of the pregnancy, a period of special protection against dismissal begins and the employer cannot terminate the employment contract because of the pregnancy. The protection against dismissal, however, is not total. Employees can still be fired for serious professional misconduct, economic or technical reasons, or reasons related to the employee's behaviour. In case of dismissal, the employer must be able to show that the decision is not related to the pregnancy. This protection applies until one month after the last day of the postnatal leave (including extensions).

In case of hospitalisation of the newborn

In case of a delivery occurring more than seven days before the EDD, the mandatory prenatal one-week leave before delivery is lost. However, the article 39 of Labour Act of 16 March 1971, provides extra days for postnatal leave if the newborn(s) is (are) hospitalised during more than 7 days after the delivery. The postnatal leave equals the days during which the newborn is hospitalised after those first seven days. Nevertheless, it is capped at a maximum of 24 weeks (including extensions).

2.6.2 Paternity/coparent leave

Paternity/birth leave

In the regulation on birth leave, every employee, regardless of the working regime in which he is employed (full-time or part-time), has the right to be absent from work for 10 days in connection with the birth of a child of which the parentage has been established. They do not necessarily have to be taken all at once but can be spread over the four-month period following birth, as the employee chooses. The day of birth is the first day of that four-month period. During the first three days of the leave, the employee keeps his full salary at the expense of his employer. To be entitled to this pay, the employee must inform the employer of the birth in advance. If this is not possible, the worker must inform the employer as soon as possible. During the following days of the paternity leave, the employee does not receive any salary, but is granted an allowance through the health insurance.

From 1 January 2021 onwards, the number of days of childbirth leave will increase gradually up until 20 days in 2023. This increase will take place in two stages: from 1 January 2021 the entitlement will be increased to 15 days for births occurring after that date and from 1 January 2023 an additional 5 days will be granted. The birth leave will then amount to 20 days for the births that take place from 1 January 2023 onwards. In the event of multiple births, the same number of days of paternity leave is granted as for a single birth.

From 20 May 2011, the coparent, i.e. the employee who has no legal relationship of descent with the child of his/her partner is also entitled – under certain conditions – to birth leave when the partner gives birth. The following conditions must be met in order to be entitled to birth leave as a coparent:

- the child can only have a legal parental relationship with the mother. If there is also a legal parental relationship with a father, then there is only a right to paternity leave on the father's behalf and the coparent does not benefit from birth leave.
- the coparent has to be (i) either married to the person to whom the legal parent-child relationship is established, (ii) either legally cohabiting with the person to whom the legal parent-child relationship is established and with whom the child has his/her main residence, (iii) either has lived together with the person with whom the child has his/her main residence for an uninterrupted period of three years prior to the birth.

In case of hospitalisation of the newborn

There is no extension of the paternity/birth leave for fathers or coparents.

2.6.3 *Medical assistance leave*

The medical assistance leave is a thematic leave that allows employees in some sectors to temporarily suspend working duties in order to provide assistance to a family member or relative suffering from a serious illness. This leave can either be taken by means of a complete interruption of the work activities (regardless of work schedule), half-time partial interruption (work schedule at least equivalent to ¾ of full-time job) or 1/5 partial interruption (only for full time work schedules). The periods of complete interruption obtained in the context of medical assistance may or may not be extended consecutively up to a maximum of 12 months (24 months for partial interruption).

This leave for medical assistance can also be taken by first line blood relatives (and relatives by marriage) during the hospitalisation of a minor. In this case, working duties can be completely suspended for one week (renewable for another week). The medical assistance leave to a hospitalised minor only exists in the form of a complete interruption of working duties, partial interruptions are not possible.

2.6.4 *Rooming-in*

Rooming-in is the stay of an accompanying parent in the room during hospitalisation of a child. As mentioned by the EACH charter “each hospitalised child should have the right to have their parents or parent substitute with them at all times during their stay”.[20]

Rooming-in charges are hospital-dependent, no minimum or maximum amounts have been set. Costs related to this rooming-in are not reimbursed by RIZIV – INAMI. Nevertheless, some additional hospitalisation insurances refund a certain amount.

3 PROFILE OF HOSPITALISED PRETERM NEWBORNS

3.1 Key points

- **Between 2016 and 2018, Belgium has 19 hospital sites with a NICU, 107 hospital sites with a maternity ward, and 122 hospital sites had at least one delivery.**
- **Preterm births represented 9.35% of all birth between 2016 and 2018.**
- **Among preterm births, 6.95% were dead; seven out of 10 were stillborn.**
- **When compared to preterm newborns without stay in a neonatal care ward, preterm newborns with stay in a neonatal care ward are characterised by a lower rate of delivery induction (15.08% vs 18.31%), a higher C-section rate (48.13% vs 28.11%), a higher proportion of newborns with an Apgar score < 7 (8.52% vs 5.86%), a higher proportion of extremely prematurity (5.06% vs 4.26%) and a much higher rate of newborns with a low birthweight (< 2 500 g, 67.57% vs 22.20%)**
- **When compared to preterm newborns with a stay in a non-intensive care ward, preterm newborns with a stay in an intensive care ward are characterised by a higher proportion of extremely prematurity (10.68% vs 0.53%), a higher proportion of extremely low birth weight (0.35% vs 11.58%), a higher proportion of newborns with an Apgar score < 7 (4.80% vs 13.13%), a higher length of stay (24 vs 28 vs 10 days, respectively in NIC, NIC and N* and N* beds).**
- **After a stay in a neonatal ward, 89.28% of the preterm newborns were discharged. The death rate is 1.73% in neonatal wards. However, this rate increased with the level of care intensity. During their first year of life, several stays are recorded in a small proportion of preterm newborns admitted in neonatal wards (6.27%). However, the majority of these stays are part of the same care episode (i.e. without discharge at home between stays).**
- **In 2020 during the COVID-19 period, a decrease of birth rate has been observed when compared to the previous year (higher than the trend over the last years), as well as a decrease of admissions in neonatal care; this decrease was higher than the expected one due the decrease of births observed.**

3.2 Introduction

To give an overview of the Belgian situation regarding preterm newborns[h] hospitalised in neonatal wards, TCT (Technische Cel voor de verwerking van de gegevens met betrekking tot de ziekenhuizen – Cellule Technique de traitement de données relatives aux hôpitaux) data have been analysed. A summary of the latest reports published by the Centre d'Épidémiologie Périnatale (CEpiP) and the Studiecentrum voor Perinatale Epidemiologie (SPE) has been added as complementary information.

[h] 99.76% of the stays of infants (year than one year old) admitted at hospital are 28 days of age or younger.

3.3 Methods

3.3.1 Administrative databases

Data registration has been mandatory for hospitals since 1991 in Belgium. Diagnosis, procedure codes, length of stay (LOS), hospital ward, along with patient characteristics such as gender, year of birth or postal code of residence are collected for each stay. The TCT data contain two datasets that have been coupled (the key being the patient ID) to have billing and medical data for each hospital stay:

- SHA – AZV (séjour hospitalier anonyme – anoniem ziekenhuisverblijf) and HJA – ADH (hospitalisation de jour anonyme – anonieme dag hospitalisatie) are hospital billing data collected by sickness funds (overnight stays for the former and day-care stays for the latter), which are then transferred to INAMI – RIZIV; data collected are grouped into categories, e.g. pharmaceuticals, medical imaging, fees linked to the nomenclature of health services (nomenclature des prestations de santé – nomenclatuur van de geneeskundige verstrekkingen);
- RHM – MZG (résumé hospitalier minimum – minimale ziekenhuisgegevens) are medical data related to a hospital stay; they are collected by hospitals and contain length of stay, procedures, diagnoses and patient characteristics.

The coupling percentage is over 95% for SHA – AZV data. The KCE has access to these linked data[i]. For the present study, infants (aged under one year) with a hospital stay in 2016, 2017 and 2018 have been selected. Analyses have been carried out with SAS 9.4.

3.4 Results data analysis

3.4.1.1 Hospital stays of less than one-year-old children

Over the 2016-2018 period, 366 525 hospital stays of infants (aged under one year) have been recorded in MZG – RHM database (98.80% of classic stays an 1.20% of day-care stays) spread over 122 hospital sites: **107 had beds with M bed type** (maternity ward) and **19 had beds with NIC bed type** (neonatal intensive care ward, NICU)[j]. Most of the newborns were born in the hospital where they stayed (99.1%), the rest were born in another hospital (0.8%) or elsewhere (0.1%). When the birth occurred at hospital, labour induction was carried out for 26.16% of the deliveries and Caesarean section was carried out for 21.52% of the deliveries.

- Reason of admission and destination after discharge

Among the hospitalised children younger than 1 year, 99.07% were admitted from birth. The others were admitted after discharge because of planned admissions (0.56%), urgent admissions (0.29%) or readmissions (0.06%). After the hospital stay, the vast majority of the infants went home (97.03%). A small percentage of hospitalised children were transferred to another hospital (1.87%) or to another place or unknown (0.35%). Less than one percent of hospitalised children aged less than 1 year died during the hospital stay (0.75%).

A small proportion (3.34%) of these stays were admitted in a neonatal ward (N* or NIC bed type), see Table 3.

---

[i] Law of 29 April 1996 containing social provisions, MB/BS 30 April 1996.

[j] Due to hospital mergers, some maternity wards have been closed, one has its agreement number changed in the course of the period, i.e. is represented as two different sites. More information in KCE report 323: Organisation of maternity services in Belgium (2019).[134]

Table 3 – Proportion of stays with a neonatal bed type (N* or NIC) for term and preterm newborns (2016-2018)[k]

Type of stay	Year of hospital admission							
	2016		2017		2018		2016-2018	
	n	%	n	%	n	%	n	%
Stays with N*/NIC bed type	4 301	3.47%	4 061	3.34%	3 863	3.20%	12 225	3.34%
Stays without N*/NIC bed type	119 729	96.53%	117 627	96.66%	116 944	96.80%	354 300	96.66%
Total	124 030	100.00%	121 688	100.00%	120 807	100.00%	366 525	100.00%

Among the hospitalised children aged less than 1 year, 9.35% of the stay concerned preterm newborns. Most of them were moderate or late preterm (7.64%). Less than 2% of the admission of children aged less than 1 year were preterm babies with a gestational age under 32 weeks (see Table 4).

Table 4 – Newborn stays by gestational age categories (2016-2018)[k]

Gestational age category	Year of hospital admission							
	2016		2017		2018		2016-2018	
	n	%	n	%	n	%	n	%
Extremely preterm (< 28 weeks)	842	0.68%	803	0.66%	753	0.62%	2 398	0.66%
Very preterm (28-31 weeks)	1 200	0.97%	1 155	0.95%	1 277	1.06%	3 632	0.99%
Moderate to late preterm (32-36 weeks)	9 316	7.53%	9 387	7.73%	9 243	7.67%	27 946	7.64%
Term (>= 37 weeks)	112 349	90.76%	109 993	90.59%	109 242	90.60%	331 584	90.65%
Unknown	86	0.07%	87	0.07%	55	0.05%	228	0.06%
Total	123 793	100.00%	121 425	100.00%	120 570	100.00%	365 788[l]	100.00%

[k] A small number of stays (n=1503) concerns infants born in 2015.

[l] No data over the newborn at birth were available for 737 stays.

3.4.1.2 Hospital stays in preterm newborns

In this chapter, we will focus on hospital stays of preterm newborns (n=34 204 for the 2016-2018 period): term newborns are excluded below unless noticed.

Type of stay

Inpatient stays for preterm newborns accounted for 96.08% of the stays, while day-care accounted for 3.92% (Table 5).

Table 5 – Type of stay by hospital admission year for preterm newborns (2016-2018)[m]

Type of stay	Year of hospital admission							
	2016		2017		2018		2016-2018	
	n	%	n	%	n	%	n	%
Inpatient	10 992	96.05%	10 969	95.95%	10 902	96.24%	32 863	96.08%
Day-care	452	3.95%	463	4.05%	426	3.76%	1 341	3.92%
Total	11 444	100.00%	11 432	100.00%	11 328	100.00%	34 204	100.00%

Type of bed

Hospital stays for preterm newborns have been divided in 4 categories:

- no N*/NIC bed type: no part of any hospital stay was in a neonatal ward,
- N* bed type: the newborn stayed at least some time in a non-intensive neonatal care ward, but not in a NICU,
- NIC bed type: the newborn stayed at least some time in a NICU, but not in a non-intensive neonatal care ward, and
- NIC and N* bed types (the newborn spent some time both in a NICU and in a non-intensive neonatal care ward).

During the observation period, 31 820 preterm newborns were hospitalised during 34 204 hospital stays. This means that 6.97% of stays concerned preterm newborns with at least a previous stay. Table 6 shows the distribution of stays by category of stay. Approximately, 7 out of 10 preterm newborns were admitted to a neonatal ward (71.57%). Among preterm newborns admitted to a neonatal ward, 4 out of 10 needed intensive neonatal care (41.33%): 3 out 10 stayed in an intensive neonatal bed only (26.51%) and 1 out of 10 stay both in intensive and non-intensive neonatal bed (14.82%).

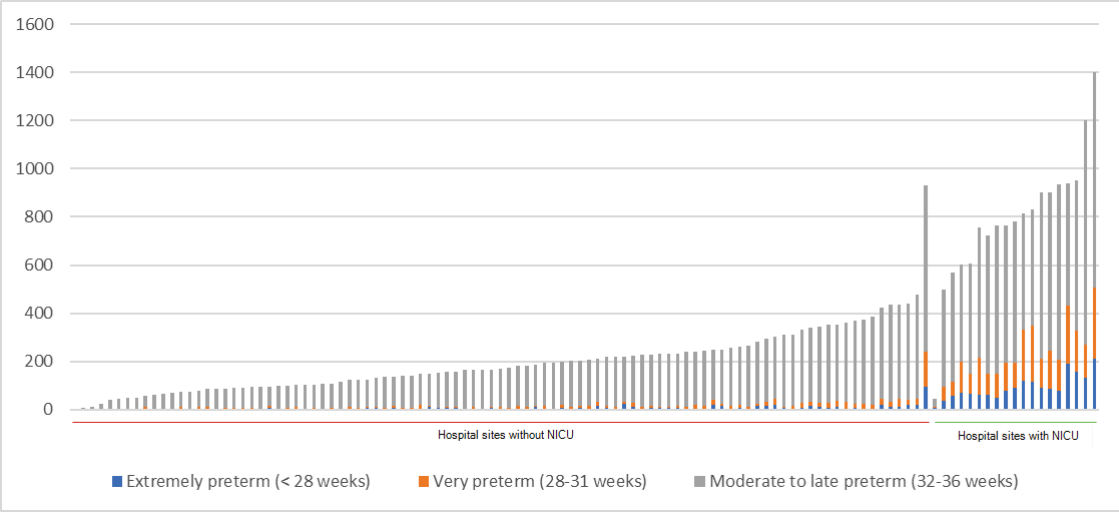
[m] 434 newborns were born in 2015.

Table 6 – Number of stays by category of stay

Category of stay (n=preterm newborn stays)	2016		2017		2018		2016-2018	
	n	%	n	%	n	%	n	%
No N* nor NIC bed type during stay(s)	3 284	28.70%	3 280	28.69%	3 161	27.90%	9 725	28.43%
N* bed type (no NIC) during stay(s)	4 863	42.49%	4 766	41.69%	4 733	41.78%	14 362	41.99%
NIC bed type (no N*) during stay(s)	2 142	18.72%	2 148	18.79%	2 199	19.41%	6 489	18.97%
NIC and N* bed types during stay(s)	1 155	10.09%	1 238	10.83%	1 235	10.90%	3 628	10.61%
Total	11 444	100.00%	11 432	100.00%	11 328	100.00%	34 204	100.00%

The number of stays per hospital site by gestational age category has been represented in Figure 5: hospital sites without NICU are shown on the left side (n=97), and the hospital sites with NICU are shown on the right side (n=19).

Figure 5 – Number of stays for preterm newborns by hospital site (2016-2018, n=116)[n]



[n] Two hospital sites changed from recognition number over the period: data have been merged for those two sites.

Outcomes of preterm births

Among hospital stays for premature delivery between 2016 and 2018 (n=31 820), 6.95% of the babies were dead (n=2 212). Among those, 72.92% were stillborn (n=1 613) while the others die after their admission (n=599, 27.08%). More than half of stillbirths (53.01%) occurred before reaching the gestational age of 28 weeks. The median number of weeks at stillbirth was 27 (IQR=9)[o]. The median weight of stillborn babies was 940 g (IQR=1 098 g).

Among the live births, 91.12% of newborns were discharged at home after their hospital stay and 7.60% were transferred to another hospital or another ward.[p]

Hospital stays for live preterm birth is described in the section below.

3.4.1.3 Hospital stays in live preterm birth

Preterm newborns without stay in a neonatal care ward

Among the live preterm newborns (n=30 207), 26.09 % were not admitted in a neonatal ward (n=7 882). The median length of these newborns was of 4 days (IQR=1 day). These stays concerned the care episode linked to birth, except for 6 stays that were observed in 8 to 14-days old newborns and 5 stays observed in 15 to 28-days old newborns.

More than nine of out ten (91.91%) of them are moderate to late preterm newborns (see Table 7). The deliveries were characterised by an induction rate of 18.31% and a C-section rate of 28.11%. Approximately three quarters (77.38%) of these newborns have a normal birth weight (≥ 2500 g). Nine out 10 preterm newborns without neonatal stay (94.14%) had an Apgar score at 5 minutes greater than or equal to 7 and 3.42% had a score under 4 (see Table 7).

The death rate among preterm newborns without stay in neonatal care ward was 2.70% during the observation period. Approximately 9 out of 10 (89.43%) were discharged at home and 7.50%[q] were transferred to another hospital.[r]

[o] IQR: interquartile range

[p] Destination of the remaining 1.28% is unknown.

[q] 3.91% in an academic hospital and 3.59% in a non-academic hospital.

[r] The remaining 0.37% went somewhere else (prison, boarding school, …) or their destination was unknown.

Table 7 – Characteristics of preterm newborns without stay in a neonatal care ward per year of first admission (2016-2018)

Prematurity	2016		2017		2018		2016-2018	
	n	%	n	%	n	%	n	%
Extremely preterm (< 28 weeks)	152	5.67%	95	3.57%	89	3.50%	336	4.26%
Very preterm (28-31 weeks)	85	3.17%	62	2.33%	89	3.50%	236	2.99%
Moderate to late preterm (32-36 weeks)	2 421	90.34%	2 472	92.90%	2 351	92.52%	7 244	91.91%
Unknown	22	0.82%	32	1.20%	12	0.47%	66	0.84%
Total	2 680	100.00%	2 661	100.00%	2 541	100.00%	7 882	100.00%
Birth weight category[s]	**2016**		**2017**		**2018**		**2016-2018**	
	n	%	n	%	n	%	n	%
Extremely low birth weight (< 1000 g)	84	3.14%	85	3.20%	80	3.15%	249	3.16%
Very low birth weight (< 1500 g)	63	2.36%	44	1.66%	50	1.97%	157	2.00%
Low birth weight (< 2500 g)	421	15.74%	462	17.40%	491	19.34%	1 374	17.46%
Normal birth weight (>= 2500 g)	2 107	78.77%	2 064	77.74%	1 918	75.54%	6 089	77.38%
Total	2 675	100.00%	2 655	100.00%	2 539	100.00%	7 869	100.00%
Frequency missing = 13								
Apgar score after 5 minutes	**2016**		**2017**		**2018**		**2016-2018**	
	n	%	n	%	n	%	n	%
0-3	102	3.82%	88	3.32%	79	3.12%	269	3.42%
4-6	57	2.13%	65	2.45%	69	2.72%	191	2.43%
7-10	2 512	94.05%	2 498	94.23%	2 385	94.16%	7 395	94.14%
Total	2 671	100.00%	2 651	100.00%	2 533	100.00%	7 855	100.00%
Frequency missing = 27								

[s] Categories were made according to Cutland et al.147. Cutland CL, Lakcritz EM, Mallett-Moore T, Bardají A, Chandrasekaran R, Lahariya C, et al. Case definition and guidelines for data collection, analysis, and presentation of maternal immunization safety data. Vaccine. 2017;4(35(48 Pt A)):6492-500, 147. Ibid.

Preterm newborns with a stay in a neonatal ward

Preterm newborns who had a least a part of their stay in a neonatal ward (n=22 325 for 2016-2018) have been separated into 3 categories:

1. At least a part of the stay in a N* bed type (non-intensive neonatal care ward) and no NIC bed type (NICU) (n=12 356), they will be referred as “newborns with non-intensive neonatal care”;
2. At least a part of the stay in a NIC bed type and no N* bed type (n=4 979), referred as “newborns with intensive neonatal care”;
3. At least a part in the stay in a N* bed type and another part of the stay in a NIC bed type (n=4 990), referred as “newborns with intensive and non-intensive care”.

Two thirds (65.34%) of newborns with non-intensive neonatal care were admitted in a N* bed type immediately[t]; 81.87% of newborns with intensive neonatal care were admitted in a NICU (NIC bed type) as first ward of admission; 90.61% of newborns with intensive and non-intensive care were admitted in a neonatal care ward (NIC bed type or N* bed type) as first ward: 41.24% were first admitted in a non-intensive neonatal care ward and 49.37% were first admitted in an intensive neonatal care ward.

The age at hospital admission of the newborns for these stays were as follows:

For newborns with a stay in a N* bed type, 99.60% of them where aged between 0 and 7 days, 0.22% were aged between 8 and 14 days, 0.18% were aged between 15 and 28 days, and 0.01% were aged over 28 days;

For newborns with a stay in a NIC bed type, 98.04% of them where aged between 0 and 7 days, 0.63% were aged between 8 and 14 days, 0.63% were aged between 15 and 28 days, and 0.69% were aged over 28 days;

For newborns with a stay in a NIC bed type as well as a N* bed type, 81.23% of them where aged between 0 and 7 days, 9.18% were aged between 8 and 14 days, 8.24% were aged between 15 and 28 days, and 1.34% were aged over 28 days.

- Characteristics of the delivery and intensity level of neonatal care

When compared to deliveries of preterm newborns without stay in a neonatal care ward, we observed a lower induction rate in deliveries of preterm newborns with stay in a neonatal care ward (15.08% vs 18.31%, respectively with and without stay in neonatal care ward). In contrast, a much higher C-section rate in observed in preterm newborns with stay in neonatal care ward (48.13% vs 28.11%, respectively with and without stay in neonatal care ward).

Among preterm newborns with a stay in a (intensive or non-intensive) neonatal care ward, 4 out 10 (40.38% or n=1 351) of deliveries with inducted labour needed intensive neonatal care: 21.00% in a non-intensive neonatal ward and 19.39% in a NICU. C-section was recorded for 39.65% of the newborns with non-intensive prenatal care, 60.76% of newborns with intensive prenatal care dans 56.55% of newborns with both non-intensive and intensive neonatal care (see Table 8).

Among preterm newborns with stay in neonatal care ward, 8.52% had an Apgar score less than 7. The proportion varied according to the type of bed occupied during the stay in neonatal ward (4.80%, 14.67% and 11.59%, respectively when only N* bed, when only NICU bed and when both n* and NICU beds were occupied).

- Gestational age and intensity level of neonatal care

In the group of preterm newborns admitted in neonatal ward, 83.59% were moderate to late preterm (had a gestational age of 32-36 weeks), 10.91% were very preterm (28-31 weeks) and 5.06% were extremely preterm (< 28 weeks).

The vast majority of extremely preterm newborns (94.25%) needed intensive neonatal care. Among those (n=1 065), 29.11% were also admitted in a non-

[t] Both labour and delivery wards have been excluded for calculations in this paragraph.

intensive neonatal ward. The proportion of very preterm newborns that needed intensive neonatal care is comparable to that observed in the extremely preterm newborns (94.87%). However, a larger proportion was also admitted in a non-intensive neonatal ward (49.07%). In contrast, only 35.11% of preterm newborns aged 32-36 weeks were admitted in a NICU and more than half of them passed through a non-intensive ward (53.97%).

- Birth weight and intensity level of neonatal care

In the group of preterm newborns admitted in neonatal ward, 32.43% of them had a normal birth weight (≥ 2 500 g) while 67.57% of the newborns weighted less than 2 500 g, divided into: 52.96% of low birth weight (1500 g to 2499 g), 9.24% of very low birth weight (1000 g to 1499 g) and 5.36% of low birth weight (< 1000 g).

As shown for the gestational age, the lower the newborns birth weight, the more intensive care they need. Indeed, we observed that 96.41% of extremely low birth weight newborns were admitted in NICU while 92.68%, 43.46%, and 24.31% were admitted in NICU respectively with very low, low and normal birth weight. The same trend is not observed for stays including no intensive neonatal care ward (31.37%, 46.97%, 57.48% and 44.06% respectively for extremely low, very low, low and normal birth weight).

Table 8 – Characteristics of preterm newborns staying in a neonatal care ward per type of bed type (2016-2018)

Prematurity	N* bed		NIC bed		NIC and N* beds		Total in neonatal wards	
	n	%	n	%	n	%	n	%
Extremely preterm (< 28 weeks)	65	0.53%	755	15.16%	310	6.21%	1 130	5.06%
Very preterm (28-31 weeks)	125	1.01%	1 177	23.64%	1 134	22.73%	2 436	10.91%
Moderate to late preterm (32-36 weeks)	12 110	98.01%	3 016	60.57%	3 536	70.86%	18 662	83.59%
Unknown	56	0.45%	31	0.62%	10	0.20%	97	0.43%
Total	12 356	100.00%	4 979	100.00%	4 990	100.00%	22 325	100.00%
Birth weight category	**N* bed**		**NIC bed**		**NIC and N* beds**		**Total in neonatal wards**	
	n	%	n	%	n	%	n	%
Extremely low birth weight (< 1000 g)	43	0.35%	792	15.92%	362	7.26%	1 197	5.36%
Very low birth weight ([1000 g, 1499 g])	151	1.22%	1 014	20.39%	898	18.00%	2 063	9.24%
Low birth weight ([1500 g, 2499 g])	6 682	54.09%	2 184	43.91%	2 953	59.20%	11 819	52.96%
Normal birth weight (≥ 2500 g)	5 477	44.34%	984	19.78%	775	15.54%	7 236	32.43%
Total	12 353	100.00%	4 974	100.00%	4 988	100.00%	22 315	100.00%
Frequency missing = 10								
Apgar score after 5 minutes	**N* bed**		**NIC bed**		**NIC and N* beds**		**Total in neonatal wards**	

	n	%	n	%	n	%	n	%
0-3	126	1.02%	186	3.74%	79	1.60%	391	1.76%
4-6	465	3.77%	543	10.93%	495	10.00%	1 503	6.76%
7-10	11 727	95.20%	4 241	85.33%	4 377	88.41%	20 345	91.48%
Total	12 318	100.00%	4 970	100.00%	4 951	100.00%	22 239	100.00%

Frequency missing = 86

Type of delivery	N* bed		NIC bed		NIC and N* beds		Total in neonatal wards	
	n	%	n	%	n	%	n	%
Vaginal delivery	7 449	60.47%	1 951	39.26%	2 176	43.95%	11 576	52.05%
Caesarean section	4 884	39.65%	3 020	60.76%	2 800	56.55%	10 704	48.13%
Unknown	23	0.19%	8	0.16%	14	0.28%	45	0.20%
Total	12 356	100.31%	4 979	100.18%	4 990	100.79%	22 325	100.39%

Labour induction	N* bed		NIC bed		NIC and N* beds		Total in neonatal wards	
	n	%	n	%	n	%	n	%
Yes	1 999	16.23%	650	13.08%	704	14.22%	3 353	15.08%
No	10 214	82.92%	4 241	85.33%	3 982	80.43%	18 437	82.90%
Unknown	143	1.16%	88	1.77%	304	6.14%	535	2.41%
Total	12 356	100.31%	4 979	100.18%	4 990	100.79%	22 325	100.39%

- Length of stay and intensity level of neonatal care

When intensive neonatal care is used, the length of stay was longer than when non-intensive care was used alone. It seems that the combination of intensive and non-intensive neonatal stay increased the total duration of the hospital stay (see Table 9).

Table 9 – Length of stay for preterm newborns staying in a neonatal care ward (2016-2018)

Type of bed type	n	Median	IQR
N* bed	12 356	10.00	12.00
NIC bed	4 979	24.00	35.00
NIC and N*	4 990	28.00	24.00
Total	22 325	15.00	20.00

IQR: interquartile range

- Destination after discharge and intensity level of neonatal care

The destinations after the stay(s) are presented in Table 10. Nine out of 10 preterm newborns (89.28%) were discharged at home after a stay in neonatal care ward. However, this proportion is lower when the stays included only NICU (75.86%) in comparison with those including non-intensive care (93.76% and 91.59%, respectively for N* bed only and NIC and N* beds).

After a stay in neonatal care ward, 7.22% of the preterm newborns were transferred to another hospital and 0.08% to another ward in the same hospital. The transfer rate is approximately three times higher when the stay occurred only in NICU in comparison with stays occurring exclusively or partially in non-intensive care ward (16.05%, 5.59%, and 4.50%, respectively in NICU, in both NICU and N* ward and in N* ward only).

Finally, we observed that the death rate increased with the degree of intensity of the stay. While the death rate is low when only non-intensive neonatal care was used (0.04%), it increased when non-intensive care was combined with intensive care (1.20%). The death rate is 5 time more important in the group of preterm newborns receiving only care in NICU compared to those combining care in N* and NICU (see Table 10).

Table 10 – Destination after hospital discharge for preterm newborns staying in a neonatal care ward (2016-2018)

Destination after discharge	N* bed		NIC bed		NIC and N* beds		Total in neonatal wards	
	n	%	n	%	n	%	n	%
Home	11 585	93.76%	3 777	75.86%	4 569	91.56%	19 931	89.28%
Academic hospital transfer	334	2.70%	73	1.47%	29	0.58%	436	1.95%
Non-academic hospital transfer	222	1.80%	704	14.14%	250	5.01%	1 176	5.27%
Transfer other ward in same hospital	10	0.08%	22	0.44%	13	0.26%	45	0.20%
Deceased	5	0.04%	321	6.45%	60	1.20%	386	1.73%
Other*	160	1.29%	81	1.63%	63	1.26%	304	1.36%
Unknown	40	0.32%	1	0.02%	6	0.12%	47	0.21%
Total	12 356	100.00%	4 979	100.00%	4 990	100.00%	22 325	100.00%

** Which can be to another institution, prison, residential school, a long hospital stay [over 6 months]*

3.4.1.4 Number of stays during the first year of life

In the database, the number of stays was counted during the preterm newborns' first year of life according to the care intensity they received after the delivery (no neonatal care, non-intensive neonatal care, intensive neonatal care, or a combination of both non-intensive and intensive neonatal care). As shown in Table 11, only one hospital stay is observed in 93.73% of live preterm births. This means that the majority of the preterm newborns were not transfer or readmitted during their first year of life. This percentage is particularly high when no neonatal care was needed after birth or when only non-intensive neonatal care was needed (respectively 100% and 99.49%). However, a slight decrease is observed in the proportion preterm newborns with one stay when the baby received only intensive neonatal care after birth (96.16%). In contrast, several stays were observed in more than a third of preterm newborns needing a mix of non-intensive and intensive care after birth (34.73%).

When focusing on preterm newborns with several stay (n= 1 986), half of them (50.86%) were born by C-section. The majority of them (67.93%) were born at a gestational age between 32 and 36 weeks. Very preterm and extremely preterm newborns represented respectively 26.33% and 3.22% of the preterm newborns with several stays.[u]

Stays for these preterm newborns with more than one represented 4 370 stays during the observation period. When analysing the trajectory of preterm newborns with several stays, most of the stays after the first one (n=2384) were transfers (n=2 072 or 86.91%). This implies that 87.66% of the preterm newborns with multiple stays had only one care episode (i.e. without home discharge between the stays).

[u] 50 (2.52%) had an unknown gestational age.

Table 11 – Number of stays for preterm newborn by category of stay (2016-2018)

Category of stay	no NIC/N* bed		N* bed		NIC bed		NIC and N* beds		Total	
Number of stays	n	%	n	%	n	%	n	%	n	%
1	9 457	100.00%	12 328	99.49%	4 792	96.19%	3 257	65.27%	29 834	93.76%
2	0	0.00%	54	0.44%	157	3.15%	1 399	28.04%	1 610	5.06%
3	0	0.00%	9	0.07%	32	0.64%	315	6.31%	356	1.12%
4	0	0.00%	0	0.00%	0	0.00%	18	0.36%	18	0.06%
5	0	0.00%	0	0.00%	1	0.02%	1	0.02%	2	0.01%
Total	9 457	100.00%	12 391	100.00%	4 982	100.00%	4 990	100.00%	31 820	100.00%

3.5 Impact of COVID-19

Since the data analysis only covers the period 2016-2018, we could not gather information about the Coronavirus Disease 2019 (COVID-19) in our RHM – MZG analysis. Regional perinatal study centres (CEpiP and SPE) have added a chapter on COVID-19 in their 2020 perinatal health reports.[2-4] Some results are described below.

Year 2020 has been divided according to the measures taken by the government (lockdown, reopening…) which had an influence on hospital activity in 2020:

- weeks 1 to 11: pre-COVID-19 period
- weeks 12 to 18: lockdown (from 16 March to 3 May)
- weeks 19 to 26: reopening (from 4 May to 28 June)
- weeks 27 to 40: summer (from 29 June to 4 October)
- weeks 41 to 52: phases 1 and 2 (from 5 October to 27 December)
- weeks 12 to 52: COVID-19 period (from 16 March to 27 December)

In Flanders, the number of births decreased by 2.39% in 2020 compared to 2019, meaning twice the mean of the annual decrease observed during the period 2011 - 2019 (1.20%). In comparison, the number of births in Wallonia-Brussels (the two regions have been pooled for the analysis) decreased by 3.72% in 2020 compared to 2019, it is almost 4 times the annual decrease observed during the period 2015 - 2019 (0.97%).

During the COVID-19 period (from 16 March to 27 December 2020), the proportion of singleton preterm newborns has decreased by 8.9% compared to 2019 in Brussels-Wallonia, and by 6,0% in Flanders. The decrease was more pronounced at the end of the year 2020 (phases 1 and 2, from 5 October to 27 December 2020): -18.2% in Wallonia-Brussels and -9.1% in Flanders (compared to the same period in 2019).

Concurrently, the proportion of babies with low birth weight (1500 g to 2499 g) has decreased for the COVID-19 period in 2020 compared to 2019: -8.5% in Wallonia-Brussels and -11.6% in Flanders.

The number of admissions in N* wards and NICU has also decreased in 2020 compared to 2019: there has been -7.9% less admissions for the COVID-19 period in 2020 (weeks 12 to 52, singletons alive) and -4.5% in Flanders. The decrease is more important in the lockdown period: -15.7% in Wallonia-Brussels and -9.7% in Flanders[v].

[v] UZ Brussels figures are included in Flanders as well as in Brussels.

4 INTERVENTIONS TO PROVIDE NEONATAL INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE: A SYSTEMATIC REVIEW IN HIGH INCOME COUNTRIES

4.1 Key points

- **This review summarises the results of 59 RCTs describing 24 neonatal infant- and family-centred developmental interventions (IFCDC) in 15 high income countries: ranging from interventions focusing on skin-to-skin care (SSC) (including different operationalisations of SSC and kangaroo care), massage and the Audio, Tactile, Visual, Vestibular (ATVV) intervention, Newborn Individualized Developmental Care and Assessment Program (NIDCAP), mother-infant transaction program, family nurture intervention, CUES program, Hospital to Home: Optimising the Infant's Environment (H-HOPE) program, Creating Opportunities for Parent Empowerment (COPE) program, psychological interventions (such as early preventive attachment-oriented psychotherapy and Triadic parent-infant Relationship Therapy [TRT]), family integrated care, music therapy, Video Interaction Guidance (VIG) and a wide range of individual interventions (among which a telemedicine program, co-bedding of multiple-gestation newborns, Assessment of the Preterm Infant Behaviour [APIB], Parent Baby Interaction Programme [PBIP], free parking for parents of hospitalised newborns, Baby Triple P [BTP], parent participation improvement program, financial support for parents and virtual family-centred rounds).**
- **The wide variety in interventions demonstrates the complexity of the multifaceted concept of IFCDC. The identified interventions incorporate one or more of the dimensions described in the concept mapping.**
- **Most RCTs found mixed effects on the studied outcomes. Nevertheless, important to note is that no major significant negative effects were found. This review suggests some benefit to support IFCDC for preterm newborns in neonatal wards, however, it has not the power to recommend one comprehensive IFCDC model.**
- **The lack of strong evidence can mainly be explained by the low methodological quality of the included RCTs in the systematic literature review. Therefore, rigorous research on the short- and long-term effectiveness of IFCDC should be conducted in the future.**

4.2 Introduction

There is a large body of knowledge supporting IFCDC at neonatal departments as a method to facilitate parent-newborn bonding. The role of an immediate and sustained parent-newborn contact after birth is essential in the process of attachment and caregiving. IFCDC increases the interaction between parent and newborns (shown by an increase of oxytocin release for the mothers[148], better attention and sensitivity to the newborn's signals[149], ...). However, skin to skin contact after birth also has many benefits for the baby, among which: maintenance of the temperature in the first hours of life[49, 150, 151], warming of the hypothermic child[152], better implementation of breastfeeding[49, 153], stabilization of the vegetative functions[154], reduced length-of-stay[155], better mental wellbeing[155], etc. It is therefore recommended by several organisations and guidelines (such as Global Alliance for Newborn Care [GLANCE] or the European Foundation for the Care of Newborn Infants [EFCNI]) as essential to minimise separation at birth between the newborn and (one of the) parents.

The literature describes a wide variety of concepts that can serve as possible interventions in IFCDC and interventions to increase parent-newborn bonding. However, these concepts are often used interchangeably and are probably overlapping in some conditions. Therefore, we aim to answer the following research questions in current chapter:

1. What are possible interventions to promote IFCDC for hospitalised preterm newborns in high-income countries?
2. What is the effect of these identified IFCDC interventions on several parental and newborn outcomes (including medical and other outcomes)?

4.3 Methods

These research questions will be answered by conducting a systematic review of the peer-reviewed literature. Primary studies and previous systematic literature reviews were identified by means of a systematic literature search in four bibliographic databases. These databases were searched in the first week of July 2021 with the following restrictions: language (English, French and Dutch), date limits (from 2000-current). Table 12 summarises the applied in- and exclusion criteria by means of the PICOTS (Population, Intervention, Comparison, Outcome, Time, Setting) model.

A search strategy was developed for Medline (Ovid SP) by the KCE information specialist, including the validated neonatal search filter developed by the Cochrane Neonatal Review Group and the validated search filter for RCTs and quasi RCTs.[156] The search strategy was subsequently adapted for Embase and the Cochrane Library. For more details regarding the search strategy and number of hits, we refer the reader to Appendix 2.1.

4.3.1.1 Assessment of risk of bias in included trials

We assessed the methodological risk of bias in the included studies using the Cochrane Collaboration Risk of Bias 2 (RoB2) tool.[156] One author (JD) assessed the risk of bias and was checked by a second author (KV).

Table 12 – Inclusion and exclusion criteria

	Inclusion	Exclusion
P	Preterm newborns (born <37 weeks after gestation or weighing less then 2500g)[157]	Newborns born at term (≥ 37 weeks of gestation) which need (no) care
I	Methods/interventions to promote IFCDC in neonatal in-hospital care	Interventions in ambulatory care or regular maternity care
C	Control group received standard neonatal care	
O	**Primary outcome:** parent-newborn attachment (measured by a validated tool), parent-newborn interaction (measured by a validated tool), length of stay (LOS) of mother (on medical ground and to avoid non-separation), LOS of newborn, hospital readmission rate after discharge newborn, mental wellbeing, in terms of depression, stress and anxiety (measured by a validated tool), satisfaction **Secondary outcome:** exclusive breastfeeding at discharge or at 40 to 41 weeks' postmenstrual age and at one to three and at six to twelve months follow-up, any breastfeeding at discharge or at 40 to 41 weeks' postmenstrual age and at one to two, three, six and twelve months follow-up, duration of breastfeeding, onset of breastfeeding, neurodevelopmental impairment, psychomotor development (measured by a validated tool), adverse events, costs of care	
T	Literature published between 2000-today	Publications before 2000

S	Randomised controlled trials (RCTs) conducted in high-income countries[w]	All other study-designs	

In order to select the most relevant outcomes for this systematic literature review, a small survey has been conducted among several professional and patients' organisations[x] in June 2020. This survey and the results can be consulted in Appendix 2.2.

Bibliographic results were exported and deduplicated to the Rayyan QRCI tool[158] for screening. Titles and abstracts of potentially relevant references were screened by one reviewer (JD), who also reviewed full texts of eligible papers. Afterwards, the reference list of each selected publication was screened for additional eligible publications (i.e. backward citation). Uncertainty was resolved by discussion with the other members of the research team. A structured form guided data extraction of study characteristics such as time frame, number of intervention and control group and the results for each outcome.

4.4 Results

The identified publications (N = 6 223) from the search in the four databases were merged and duplicates were removed. Titles and abstracts of the remaining 4 579 publications were screened for eligibility (of which 4 418 were excluded). In the second screening round, the full text of the 161 remaining publications was assessed. This resulted in a preliminary selection of 83 publications, of which 49 were primary studies and 34 were systematic literature reviews[y] or meta-analyses.[115, 119, 159-180] These systematic literature reviews or meta-analyses were excluded from our selection, because they did not exclusively include publications that met our inclusion criteria. However, we hand-searched their references for additional relevant primary studies. This hand search resulted in ten additional relevant publications, leading to a final selection of 59 primary studies.

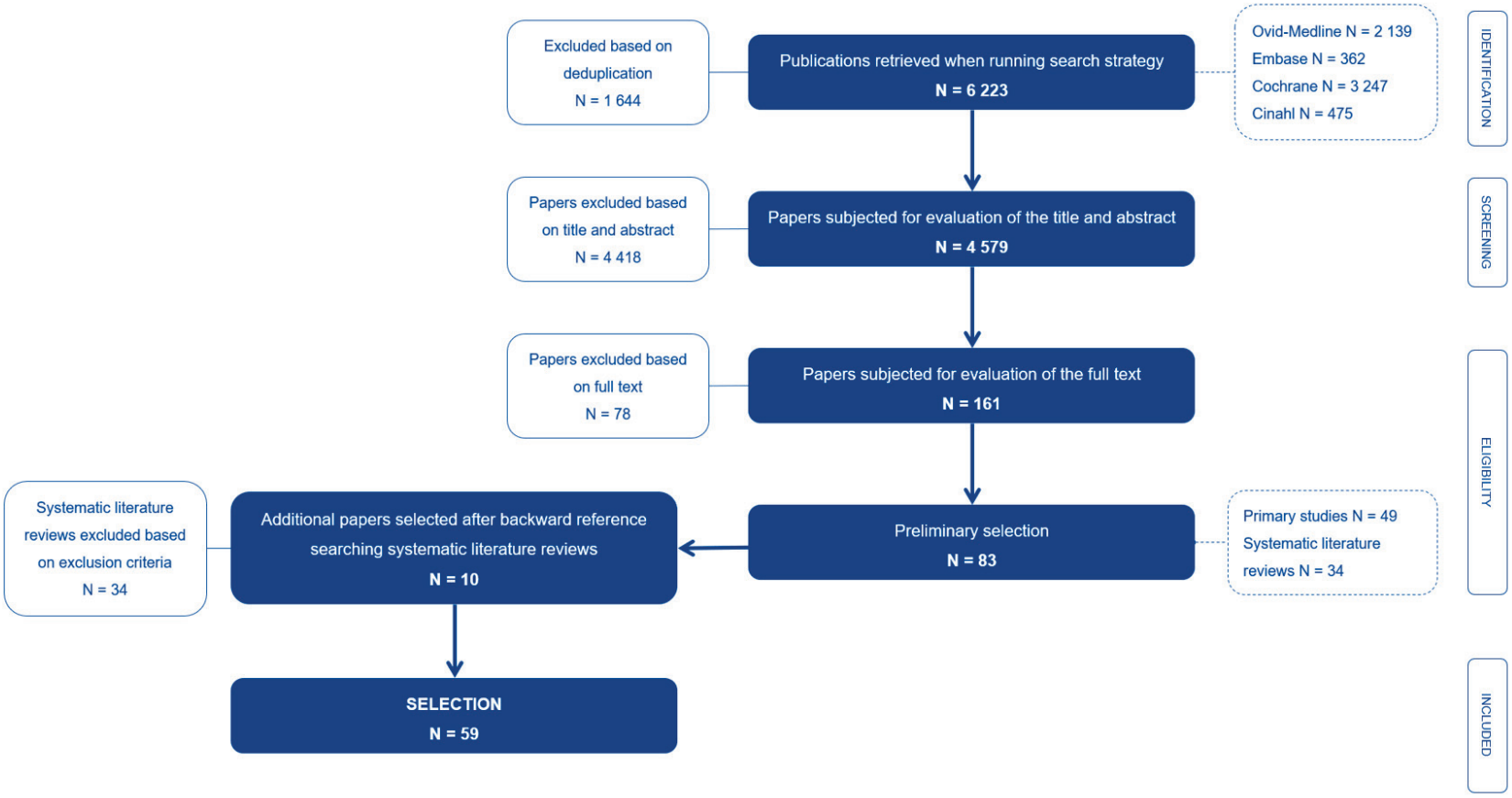
The screening process is summarised in the flow chart presented in Figure 6.

[w] The Worldbank defines the economy of a country as "high-income" when the Gross National Income (GNI) per capita is $ 12 696 or more. According to this definition, the following countries are considered high-income countries (on 26 July 2021): Andorra, Antigua and Barbuda, Aruba, Australia, Austria, the Bahamas, Bahrain, Barbados, Belgium, Bermuda, British Virgin Islands, Brunai Darussalam, Canada, Cayman Islands, Channel Islands, Chile, Croatia, Curacao, Cyprus, Czech Republic, Denmark, Estonia, Faroe Islands, Finland, France, French Polynesia, Germany, Gibraltar, Greece, Greenland, Guam, Hong Kong Special Administrative Region (China), Hungary, Iceland, Ireland, Isle of Man, Israel, Italy, Japan, Republic of Korea, Kuwait, Latvia, Liechtenstein, Lithuania, Luxembourg, Macao Special Administration Region (China), Malta, Monaco, Nauru, Netherlands, New Calondia, New Zealand, Northern Mariana Islands, Norway, Oman, Palau, Poland, Portugal, Puerto Rico, Qatar, San Marino, Saudi Arabia, Seychelles, Singapore, Sint Maarten (Dutch part), Slovak Republic, Slovenia, Spain, St. Kitts and Nevis, St. Martin (French part), Sweden, Switzerland, Trinidad and Tobago, Turks and Caicos Islands, United Arab Emirates, United Kingdom, United States, Uruguay, Virgin Islands (U.S.).

[x] The survey has been send out to the presidents or contact persons of the Belgian Society of Neonatology (Belgische Vereniging voor Neonatologie, Groupement Belge de Néonatologie; BVN – GBN), College van Geneesheren voor de Moeder en Kind, Association des Infirmiers Spécialisés en Pédiatrie et en Néonatologie (AISPN), Vlaamse Intensieve Neonatale Zorgen (vzw VINZ), Vlaamse Vereniging voor Ouders en Pasgeborenen, Association de Parents d'Enfants Prématurés (NéoNid), Vlaamse Vereniging voor Kindergeneeskunde (VVK vzw), Belgische Vereniging voor Kindergeneeskunde – Société Belge de Pédiatre (BVK – SBP), Groupement Belge des Pédiatres de Langue Française (GBPF), and SPF Public Health.

[y] Four of these systematic literature reviews were Cochrane Library reviews. For each of these, only the most recent update of the review was included.

Figure 6 – Flow chart of the study selection process



4.4.1 Characteristics of the included trials

The 59 selected RCTs described 24 interventions to provide IFCDC. Most of the trials were conducted in the USA (n=24), others were conducted in Sweden (n=4), Israel (n=4), Norway (n=2), Australia (n=3), the Netherlands (n=2), Canada (n=4), Germany (n=4), the United Kingdom (n=2), Italy (n=1), France (n=1), South Korea (n=1), Turkey (n=1) and Ireland (n=1). One RCT was conducted in multiple countries (i.e. Australia, Canada and New Zealand). Most of the interventions were studied in the NICU and there was a huge variation in prematurity definition in terms of gestational weeks or based on weights. The majority of the trials recruited small samples (only 23 trials randomised more than 100 dyads). More information on the study characteristics of the included publications can be consulted in Table 13.

4.4.1.1 Risk of bias in the included trials

The included studies were assessed using the following five key criteria: randomisation process, deviations from intended interventions, missing outcome data, measurement of the outcome and selection of the reported result. Seventeen of the included studies were evaluated to be subjected to a high risk of bias, while nine trials reported a low risk of bias (Figure 7). However, the design of the majority of the included trials could not be assessed adequately and was therefore labelled as “some concerns”. It should be noted that none of the studies met all the methodological quality criteria of the ROB2 tool.

A detailed overview of the assessment of the risk of bias across all domains is provided in Appendix 3.2.

Figure 7 – Risk of bias graph: review authors' judgement about each risk of bias item presented as percentages across all included studies

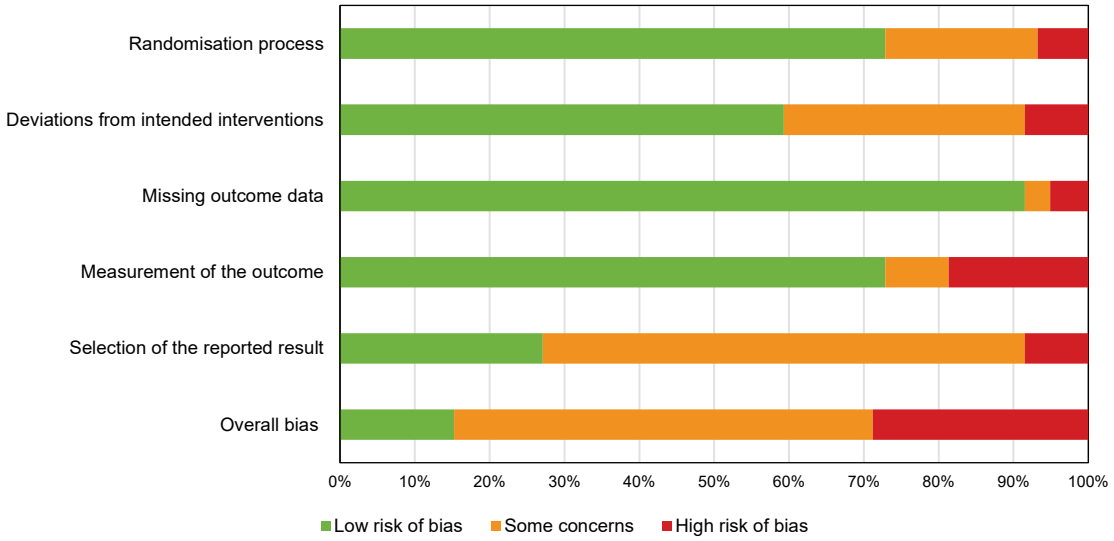


Table 13 – Study characteristics of the included publications

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
1	Gray et al. (2000)[181]	RCT	USA	Access to Baby CareLink telemedicine application vs. standard care	1 NICU	≤ 1250 gr of birthweight	November 1997 – April 1999	26	30	High
2	Roberts et al. (2000)[182]	RCT	AUS	Kangaroo mother care (SSC) vs. standard cuddling care (through clothing)	1 NICU 1 nursery	> 30 weeks of gestational age	NA	16	14	Some concerns
3	Westrup et al. (2000)[183]	RCT	SWE	NIDCAP vs. standard care	1 NICU	< 32 weeks of gestational age	September 1994 – April 1997	12	13	Some concerns
4	Melnyk et al. (2001)[184]	RCT	USA	COPE program vs. audiotaped information	1 NICU (level III)	26 – 36 weeks of gestational age	NA	20	22	High
5	Feldman et al. (2002)[185]	RCT	ISR	Kangaroo mother care vs. standard care	2 neonatal nurseries (level III)	NA (mean gestational age was 30.65 weeks)	NA	73	73	Low
6	White-Traut et al. (2002)[186]	RCT	USA	ATVV intervention vs. standard care	1 NICU (level III)	23 – 26 weeks of gestational age	NA	14	11	Some concerns
7	Fowler Byers et al. (2003)[187]	RCT	USA	Co-bedding of multiple-gestation newborns vs. single-bedding	1 NICU (level II and level III)	NA (mean gestational age was 29 weeks)	NA	16	21	High
8	Als et al. (2003)[67]	RCT	USA	Individualised developmental care vs. standard care	3 NICUs (level III)	≤ 28 weeks of gestational age	April 1990 – June 1992	45	47	Some concerns
9	Birsch et al. (2003)[188]	RCT	DEU	Early preventive attachment-oriented psychotherapeutic	1 NICU	≤ 1500 gr of birthweight	November 1994 –	43	44	Some concerns

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
				program vs. standard care	1 maternity ward		November 1997			
10	Feldman et al. (2003)[189]	RCT	ISR	Kangaroo mother care vs. standard care	2 neonatal nurseries (level III)	NA (mean gestational age was 30.65 weeks)	NA	73	73	Low
11	Browne et al. (2005)[18]	RCT	USA	Demonstration and interaction, according to the systematic administration of the Assessment of the Preterm Infant Behaviour (APIB) (group 1), education (group 2), control (group 3)	1 NICU	≤ 36 weeks of gestational age	NA	Group 1: 28 Group 2: 31	25	Low
12	Feijó et al. (2006)[190]	RCT	USA	Performing newborn massage vs. observing newborn massage	1 NICU	< 37 weeks of gestational age	NA	20	20	Some concerns
13	Kaaresen et al. (2006)[191]	RCT	NOR	Mother-infant transaction program vs. standard care	1 NICU (level III)	< 2000 gr of birthweight	March 1999 – August 2002	71	69	Some concerns
14	Melnyk et al. (2006)[42]	RCT	USA	COPE intervention vs. information regarding hospital services and policies	2 NICUs	26 – 34 weeks of gestational age	September 2001 – October 2004	138	109	High
15	Miles et al. (2006)[192]	Pragmatic controlled trial	GBR	SSC (20 minutes once daily, for 4 weeks) vs. standard care	2 NICUs	< 32 weeks of gestational age	NA	46	32	Some concerns
16	Glazebrook et al. (2007)[193]	Cluster RCT	GBR	Parent Baby Interaction Program vs. standard care	6 NICUs	< 32 weeks of gestational age	July 2002 – January 2003	112	121	High

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
17	Kleberg et al. (2007)[194]	RCT	SWE	NIDCAP vs. standard care	1 NICU (level III)	< 32 weeks of gestational age	NA	10	10	Some concerns
18	Van der Pal et al. (2007)†[195]	RCT	NLD	Developmental care vs. standard care	1 NICU (level III)	< 32 weeks of gestational age	April 2000 – May 2002	67	66	Some concerns
				NIDCAP vs. standard care	1 NICU (level III)	< 32 weeks of gestational age	July 2002 – August 2004	75	75	Some concerns
19	Chiu et al. (2009)[196]	RCT	USA	Early SSC vs. standard care	2 NICUs	32 – < 37 weeks of gestational age	1997 – 2000	42	34	Some concerns
20	Newnham et al. (2009)[197]	RCT	AUS	Mother-infant transaction program vs. standard care	1 NICU	< 37 weeks gestational age	2001 - 2002	35	33	Some concerns
21	Peters et al. (2009)[198]	Cluster RCT	CAN	NIDCAP vs. standard care	1 NICU	≤ 32 weeks of gestational age (500 - 1250 gr)	September 1999 – September 2004	51	50	Some concerns
22	Örtenstrandt et al. (2010)[73]	RCT	SWE	Family ward (at least 1 of the parents was with the newborn, 24 hours during the entire hospital stay)	2 NICUs (level II)	< 37 weeks of gestational age	September 2006 – October 2008	177	168	Some concerns
23	Zelkowitz et al. (2011)[199]	RCT	CAN	Cues program vs. standard care	2 NICUs	< 1500 gr of birthweight	August 2006 – May 2009	46	50	Low
24	Feeley et al. (2012)[200]									Low
25	Ravn et al. (2011)[201]	RCT	NOR		1 NICU (level III)	≥ 30 weeks and < 36	January 2005 –	42	41	Some concerns

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
26	Ravn et al. (2012)[202]			Mother-infant transaction program vs. standard care		weeks of gestational age	December 2006	29	32	Some concerns
27	Ravn et al. (2012)[203]							46	47	Some concerns
28	Schlez et al. (2011)[204]	Cross-over RCT	ISR	Kangaroo mother care combined with live harp music therapy vs. kangaroo mother care only	1 NICU	32 – 37 weeks gestational age	October 2008 – January 2008	52	52	Some concerns
29	Holditch-Davis et al. (2013)[205]	RCT	USA	Massage with ATVV (group 1), kangaroo care (group 2) vs. education about equipment needed at home (control group)	4 NICUs	1750 grams birth weight	NA	Group 1: 66 Group 2: 68	73	Some concerns
30	Matricardi et al. (2013)[206]	RCT	ITA	Joint observation method and newborn massage vs. standard care	1 NICU	< 32 weeks of gestational age	February 2010 – September 2011	21	21	High
31	Welch et al. (2013)[207]	RCT	USA	Family nurture intervention vs. standard care	1 NICU (level IV)	26 – 35 weeks of gestational age	June 2012 – September 2012	67	67	High
32	White-Traut et al. (2013)[208]	RCT	USA	H-HOPE intervention vs. parent education program	2 NICUs (level II and level III)	29 – 34 weeks of gestational age	NA	66	76	Some concerns
33	Arnon et al. (2014)[209]	Cross-over RCT	ISR	Kangaroo mother care combined with live maternal singing vs. kangaroo mother care only	1 NICU	32 – 36 weeks of gestational age	October 2011 – April 2012	43	43	Some concerns

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
34	Chorna et al. (2014)[210]	RCT	USA	Pacifier-activated music player (PAM) during non-nutritive sucking vs. standard care	1 NICU	34 – 36 weeks of gestational age	April 2012 – May 2013	46	48	Low
35	Holditch-Davis et al. (2014)[211]	RCT	USA	Massage with ATVV (group 1), kangaroo care (group 2) vs. education about equipment needed at home (control group)	4 NICUs	NA (< 1750 g)	NA	Group 1: 78 Group 2: 78	81	Some concerns
36	Cong et al. (2015)[212]	Cross-over RCT	USA	Maternal SSC vs. paternal SSC	1 NICU (level IV)	30 0/7 – 34 6/7 weeks of gestational age	NA	26	19	High
37	Mörelius et al. (2015)[43]	RCT	SWE	Continuous SSC vs. standard care	2 NICUs (level II and level III)	32 – 36 weeks of gestational age	April 2008 – April 2012	23	19	Some concerns
38	Hoffenkamp et al. (2015)[213]	RCT	NLD	Hospital-based video interaction guidance vs. standard care	2 NICUs 7 maternity wards	25 – 37 weeks of gestational age	September 2009 – September 2012	75	75	Some concerns
39	Samra et al. (2015)[214]	RCT	USA	SSC (3 times per week, at 50 minutes per session) throughout NICU stay vs. blanket holding	1 NICU (level III)	34 – 36 6/7 weeks of gestational age	March 2013 – January 2014	19	11	Low
40	White-Traut et al. (2015)[215]	RCT	USA	H-HOPE intervention vs. parent education program	2 NICUs (level II and level III)	29 – 34 weeks of gestational age	NA	88	94	Low

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
41	Castel et al. (2016)[216]	RCT	FRA	Triadic parent-infant Relationship Therapy (TRT) vs. standard care	1 neonatal department	28 – 35 6/7 weeks of gestational age	July 2006 – September 2008	32	33	High
42	Northrup et al. (2016)[217]	RCT	USA	Free parking vouchers during NICU stay vs. paid parking	1 NICU	≤ 1000 grams birth weight	November 2007 – February 2011	72	66	Some concerns
43	Welch et al. (2016)[218]	RCT	USA	Family nurture intervention vs. standard care	1 NICU (level IV)	26 – 34 weeks of gestational age	January 2009 – June 2012	59	56	Some concerns
44	Evans et al. (2017)[219]	RCT	AUS	Baby Triple P intervention vs. standard care	2 NICUs	< 32 weeks of gestational age	February 2012 – July 2013	61	59	Some concerns
45	Beebe et al. (2018)[220]	RCT	USA	Family nurture intervention vs. standard care	1 NICU (level IV)	26 – 34 weeks of gestational age	NA	39	32	High
46	O'Brien et al. (2018)[17]	Cluster RCT	CAN AUS NZL	Family-integrated care vs. standard care	1 NICU (level III)	≤ 33 weeks of gestational age	April 2013 – August 2015	895	891	Some concerns
47	Ranger et al. (2018)[221]	Cross-over RCT	DEU	Live harp music vs. standard care (no music)	2 NICUs (level II)	26 – 35 weeks of gestational age	July – October 2013	38	38	High
48	Vittner et al. (2018)[222]	Cross-over RCT	USA	SSC mother vs. SSC father	3 NICUs	30 – 34 weeks of gestational age	3 days (year NA)	28	28	Some concerns
49	Heo et al. (2019)[223]	RCT	KOR	Parent participation improvement program vs. Standard care	1 NICU	< 37 weeks of gestational age	February – August 2017	33	33	High

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
50	Andrews et al. (2020)[224]	RCT	USA	Financial support during newborn's hospitalisation	2 NICUs	30 – 36 weeks of gestational age	January 2017 – June 2018	25	21	Some concerns
51	Benzies et al. (2020)[225]	Cluster RCT	CAN	Alberta family integrated care vs. standard care	10 NICUs (level II)	32 – 35 weeks of gestational age	15 December 2015 – 26 July 2018	353	365	High
52	Church et al. (2020)[226]	Cluster RCT	CAN	Family integrated care vs. standard care	14 NICUs	< 33 weeks of gestational age	NA	123	62	High
53	Coşkun et al. (2020)[227]	RCT	TUR	Kangaroo mother care vs. standard care	2 NICUs	27–36 weeks of gestational age	December 2017 – October 2018	42	38	Some concerns
54	Mehler et al. (2020)[228]	RCT	DEU	Delivery room SSC (60 minutes) vs. visual contact (5 minutes)	1 NICU (level III)	25 – 32 weeks of gestational age	October 2013 – July 2015	44	43	Low
55	Sahlen Hemler et al. (2020)[229]	RCT	SWE	Continuous vs. intermittent SSC	2 NICUs (level II and III)	32 0/7 – 35 6/7 weeks of gestational age	April 2008 – April 2012	17	14	Some concerns
56	Corrigan et al. (2021)[230]	RCT	USA	Music therapy vs. standard care	1 NICU	NA (34.8 mean gestational age intervention group and 34.5 in control)	NA	43	54	High

Nr.	Author (year)	Study design	Country	Intervention	Setting*	Level of prematurity	Time frame	Sample size		Overall risk of bias
								Intervention	Control	
57	Menke et al. (2021)[231]	RCT[z]	DEU	Interactive live-improvised music therapy vs. standard care	1 NICU (level II)	≤ 30 weeks of gestational age	June 2016 – December 2016	24	26	Some concerns
58	Rosenthal et al. (2021)[232]	RCT[z]	USA	Virtual family-centred rounds vs. standard care	1 NICU level (IV)	NA (35.6 mean gestational age intervention group and 34.7 in control)	1 March 2020 – 31 August 2020	74	36	Some concerns
59	Twohig et al. (2021)[233]	RCT	IRL	Hospital-based video interaction guidance vs. standard care	1 NICU (level III)	< 32 weeks of gestational age	NA	29	32	Some concerns

** Not all settings were described as elaborately in the selected publications. We give as much detail as possible (e.g. number or type of department or level).*
† There were also two related publications[234, 235] found during the search strategy, describing only part of the results. While Van der Pal et al. (2007)[195] described them all. We, therefore, opted to only include this last publication.
SSC: skin-to-skin contact, NIDCAP: Newborn Individualized Developmental Care and Assessment Program, ATVV: Audio, Tactile, Visual, Vestibular intervention

[z] This particular study was a pilot in preparation of a randomised controlled trial with a larger sample size.

4.4.2 Interventions

Disclaimer

For each intervention the results per outcome are presented in a table by means of symbols. Effect sizes and significance levels (if available) are described in the text and in the evidence tables in Appendix 2.3. Furthermore, the measuring instrument used per outcome in each publication can also be consulted in these evidence tables. In this chapter, the term "significant" means "statistically significant" (as reported by the included publication).

The outcomes length of stay (LOS) of the mother, hospital readmission rate (both primary outcomes) and the incidence of adverse events (secondary outcome) were also part of the analysis. However, none of the selected trials did study these outcomes. They were, therefore, not included in the tables of this section to enhance readability

4.4.2.1 Interventions focusing on skin-to-skin contact

Skin-to-skin contact (SSC)

Six of the included publications studied the effect of skin-to-skin care on several outcomes.[43, 192, 196, 214, 228, 229] However, there was a wide variety in operationalisations of skin-to-skin care, ranging from continuous or intermittent skin-to-skin care throughout the hospitalisation to skin-to-skin care limited to the delivery room. This wide variety and studied outcomes make it difficult to generalise and compare the results for this particular intervention. For this reason, we will describe the results for each publication individually.

- Miles et al.[192] found no significant effect of skin-to-skin care (minimum twenty minutes, once daily, for four weeks) on mother-newborn attachment one year post-term (mean score (SD) intervention group 21.51 (2.30) vs. mean control group (2.60), p = not significant). In addition, there was also no significant difference in stress, depression or anxiety between mothers of preterm newborns at four months or one year post-term in the intervention and control group.
- Chiu et al.[196] measured the effect of SSC on mother-infant interaction with the Nursing Child Assessment Satellite Training Program (NCAST) Feeding and Teaching Scales: one scale can be used with newborns from birth to one year and the other from birth to three years. A higher score on both scales indicated an interaction that is richer in positive affect, sensitivity, synchronicity, vocalisation and reciprocity. Mothers and their preterm newborns were videotaped and a researcher scored their interaction. The two scales were rated at six, twelve and eighteen months (only the second scale). Both scales showed no significant effect of SSC on mother-newborn interaction at six, twelve and eighteen months.
- Cong et al.[212] compared the anxiety levels of mothers and fathers pre-, during- and post-SSC. Maternal anxiety levels were significantly decreased from baseline (24.31) to during SSC (5.85) and then returned to the baseline levels of anxiety in post-SSC (23.3, p = 0.01). Paternal anxiety levels were significantly decreased from baseline (19.98) to during SSC (5.80) and then increased post-SSC (9.8, p = 0.01).
- Mörelius et al.[43] compared continuous skin-to-skin care (starting in the delivery room and continuoing almost 24 hours a day with the parents alternating until hospital discharge) with standard care (separated from each other in the maternity ward and transferred to the NICU, but with the possibility to provide skin-to-skin care during visits). The authors found no significant difference in parental stress and depression between groups. All infants in the continuous skin-to-skin group were breastfeeding partly or exclusively at discharge, while this was 84.2% in the control group (no significant difference). This non-significant trend was also found one and four months post-partum (94.4% in the intervention group vs. 73.7% in the control group; 76.5% in the intervention group vs. 53.3% in the control group respectively).
- In the study of Samra et al.[214] the effect of SCC on stress perception between mothers who provided SCC (min. 50 minutes, three times/week) vs. blanket holding. Comparison of stress scores showed no significant differences between groups (mean 2.34 pre-intervention SCC vs. mean 2.94 pre-intervention blanket holding, mean 2.55 post-

intervention SSC vs. mean 2.78 post-intervention blanket holding). However, a positive correlation was observed between the stress score and the number of SSC hours (r = 0.58, p = 0.001), mothers who held their newborns a great number of hours in SSC also reported higher levels of stress. There was also no significant difference between NICU LOS of the newborn between intervention and control group (mean 13.7 days vs. mean 12.1 days respectively, p = 0.53).

- Vittner et al.[222] conducted a randomised crossover study in which mother-father-newborn triads were randomly assigned to one of the two study sequences: (i) SSC with the mother on day 1 and SSC with the father on day 2 and (ii) SSC with the father on day 1 and SSC with the mother on day 2. Regarding parent-newborn interaction, the majority of the mothers (67%) scored moderately responsive, with only 7% scoring in the low responsive group and 26% scoring as highly responsive. The fathers also scored as predominately moderately responsive (58%), with 16% scoring in the low responsiveness group and 26% scoring as highly responsive. The authors calculated no statistical difference for this outcome. Maternal and paternal anxiety scores were significantly lower during SSC (p < 0.001 and p < .003 respectively), compared to pre- and post-SSC.
- Mehler et al.[228] investigated the effect of sixty minutes of delivery room SSC (intervention group) compared with five minutes visual contact (control group) on mother-newborn interaction, bonding, maternal depression and stress at six months' corrected age. The overall rate of positive interaction between mother and newborn was significantly higher in the intervention group compared to the control group (OR 0.98, 95% CI 0.7 – 1.0). In addition, there was a significant higher rate of maternal depressive symptoms on the 3rd day of life (OR 0.2, 95% CI 0.1 – 0.6, p = 0.003) and a poorer quality of bonding (assessed at six months' corrected age) in the control group (OR 1.1, 95% CI 1.0 – 1.3, p = 0.031). No difference was found between groups regarding parental stress (OR 1.0, 95% CI 1.0 – 1.1, p = 0.559) and depression symptoms at discharge (OR 1, 95% 0.4 – 2.5, p = 1) and six month's corrected age (OR 0.5, 95% CI 0.1 – 2.8, p = 0.672) and exclusive breastfeeding rates at discharge (OR 2.8, 95% CI 0.9 – 8.2, p = 0.072).
- Sahlen Hemler et al.[229] compared the interaction between preterm newborns and their mothers after continuous (beginning in the delivery room and continuing for almost 24 hours a day until discharge) vs. intermittent (parents had the opportunity to practice SSC as much as they liked) SSC. Continuous SSC from birth to discharge was not superior to intermittent SSC concerning mother-newborn interaction at four months' corrected age. However, mean time in SSC was also high in the intermittent group (i.e. between 5.27 and 6.96 hours per day). No statistical difference in postnatal depressive symptoms was found between the two groups (mean score (SD) continuous SSC 4.2 (3.3) vs. intermittent SSC 3.9 (3.7)).

Kangaroo care

Kangaroo care is a variant of skin-to-skin contact and refers to the positioning of the naked newborn chest-to-chest and skin-to-skin with one of the parents. SSC is offered as far as the parent-newborn dyad can tolerate it. The other two components of kangaroo care are frequent and exclusive or nearly exclusive breastfeeding and attempts to early discharge from the hospital, regardless of weight or gestational age. However, the last two components are less frequently identified as part of kangaroo care.[110] It was initiated in the 70s in Colombia to compensate for the unavailability of unreliability of incubators.

One of the included publications studied the effect of kangaroo mother care (compared to conventional cuddling care through clothing) on LOS of the newborn, mental wellbeing (operationalised by stress) and the duration of breastfeeding.[182] Concerning LOS, the newborns receiving kangaroo care spent an average of 48 days (standard deviation [SD] 28) in the hospital; while their counterparts receiving conventional cuddling care spent an average of 46 days (SD 19). The Parent Stress Scale-NICU scores were not significantly different between the two groups. For the duration of breastfeeding, ten newborns receiving kangaroo care and eleven newborns receiving conventional cuddling care were breastfeeding at discharge, with nine and six newborns breastfeeding at six weeks respectively, seven and five babies breastfeeding at three months respectively and four from each group breastfeeding at six months. The authors conclude that although

kangaroo care was not superior to conventional cuddling care, neither was it inferior.

Feldman et al.[185, 189] studied the effect of kangaroo care on the interaction with mother and father. Results suggest that following kangaroo contact early in life, later interactions between mothers and infants as well as between fathers and infants were characterized by higher sensitivity, lower intrusiveness, higher parent-infant reciprocity and lower infant negative emotionality. Similarly, the family's later relational style was more cohesive and less intrusive. There was no significant effect of kangaroo care on stress levels.

Last, Coşkun et al.[227] found a significant reduction in stress levels among Turkish mothers who could not breastfeed following the implementation of kangaroo mother care (before intervention (SD): kangaroo mother care 2.94 (0.65) and standard care 2.90 (0.38) vs. post intervention (SD): kangaroo mother care 1.86 (0.57) and standard care 2.81 (0.49), $p < 0.001$).

Table 14 – Interventions focusing on skin-to-skin and kangaroo care

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
SSC										
Miles et al. (2006)	=			=	=	=				
Chiu et al. (2009)		=								
Cong et al. (2015)					-					
Mörelius et al. (2015)				=		=		=		
Samra et al. (2015)			=	=						
Vittner et al. (2018)	+				-					
Mehler et al. (2020)	+	+		=		=		=		
Sahlen Hemler et al. (2020)		=				=				
Kangaroo care										
Roberts et al. (2000)			=	=				=		
Feldman et al. (2002)		+								
Feldman et al. (2003)		+		=						
Coşkun et al. (2020)				-						

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

Based on these results, we can conclude that there is low level of evidence supporting the effect of SSC and kangaroo care on parent-newborn interaction, LOS of the newborn, parental mental wellbeing and breastfeeding.

4.4.2.2 Massage and auditory, tactile, visual and vestibular (ATVV) intervention

Massage

Massage of the hospitalised newborn by (one of) the parents is described as intervention in two selected publications. In the study of Feijó et al.[190], mothers whose preterm newborn were about to be discharged from NICU were assigned to two groups: (i) a group conducting the massage themselves and (ii) a group observing their preterm newborn receiving massage. Both groups showed a decrease in depressed mood among mothers ($F = 13.51$, $p < 0.001$). In addition, mothers who conducted the preterm infant massage themselves reported decreased anxiety ($F = 10.36$, $p < 0.01$).

Matricardi et al.[206] studied the effect of joint observation and preterm infant massage on parental stress levels (vs. standard care). At discharge, intervention group parents showed significantly lower levels of stress than those of the standard care group ($p \leq 0.001$). Overall, mothers reported higher stress levels compared to the fathers ($p = 0.05$). The intervention was effective in reducing the stress-role alteration in mothers ($p < 0.05$), but not in fathers.

ATVV intervention

The ATVV intervention is a type of massage that involves moderate stroking (tactile), eye contact (visual), talking to (auditory) and rocking (vestibular) the newborn.[186, 205, 211]

White-Traut et al.[186] studied the effect of the ATVV intervention on LOS of the newborn and breastfeeding progression. Newborns receiving the ATVV intervention were discharged at a mean of 36.5 weeks, or 1.6 weeks earlier than those receiving standard care (38.2 weeks, $p = 0.04$). Nine of the study group infants were discharged during the third week of the study, while none of the control group infants were discharged until the fourth week. In addition, control group newborns averaged sixteen days to progress from gavage-only to complete nipple feeding while ATVV-newborns averaged twelve days. A repeated-measures ANOVA revealed significant differences between groups for the proportion of nipple-intake over the first ten days of the ATVV intervention, with the ATVV newborns progressing faster to complete nipple feeding than control group.

In two separate publications, Holditch et al.[205, 211] compared the effectiveness of the ATVV intervention (group 1) and kangaroo mother care (group 2) with a control group receiving education about equipment needed at home (group 3). The mothers in all three groups were satisfied with the intervention (mean scores of 3.3 or higher on a five-point scale).[205] Concerning interaction at two and six months, mothers who performed the ATVV intervention or combined it with kangaroo mother care had higher interaction scores than mothers who engaged in neither (ATVV only 2.51, $p < 0.05$; both 2.62, $p < 0.05$).[211] Interaction scores were also higher for mothers who only performed kangaroo mother care, but this was not significant (1.86, $p = 0.07$). Mothers in the three groups did not differ on depressive symptoms, state anxiety, post-traumatic stress symptoms, or parenting stress.[211] Time and time-squared effects indicated that depressive symptoms, state anxiety and post-traumatic stress symptoms decreased over time and the rate of decrease slowed over time. Parenting stress was measured at only three time points so only the linear effect of time was examined and showed a decrease over time.

Although only studied by one trial, the ATVV intervention significantly lowers LOS of the newborn and increases breastfeeding rates. The results for the other outcomes are more heterogeneous.

Table 15 – Massage and ATVV intervention

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Massage										
Feijó et al. (2006)					-	-				
Matricardi et al. (2013)				=						
ATVV										
White-Traut et al. (2002)			+					+		
Holditch-Davis et al. (2013)							=			
Holditch-Davis et al. (2014)		=		=	=	=				

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.3 *Newborn Individualized Developmental Care and Assessment Program (NIDCAP)*

NIDCAP is a comprehensive care program for the NICU, developed by Als et al.[67] The core of the program is that care should be developmentally supportive and individualised to the newborn's goals and level of stability. It seeks to support the family and health care professionals who care for these newborns. This can be achieved by direct observation of the newborn within their environment in the intensive care setting. Using a detailed observational tool, often referred to as the NIDCAP observation, the newborn's behaviours can be interpreted as steady and relaxed or as representing stress or discomfort. By observing and interpreting behaviours of newborns within their environment and as reactions to care they receive, developmental care plans that best support the newborns' overall goals and efforts at self-regulation can be developed.

Five publications in this systematic review studied the effect of NIDCAP on a variety of outcomes.[67, 183, 194, 195, 198]

Kleberg et al.[194] found that NIDCAP mothers felt significantly closer to their infants compared to mothers receiving conventional care (median score NIDCAP group: 4 vs. conventional group: 3.5, p = 0.022). Concerning LOS of the newborn, two studies described a significant reduction in the number of days a newborn was hospitalised.[67, 183, 198] For example, Peters et al.[198] observed that the median LOS was significantly reduced from 74 days for NIDCAP newborns (compared to 84 days for the standard care group, p = 0.003). The estimated hazard ratio (HR) was 1.83 (95% CI: 1.24 – 2.72). When other important factors such as gestational age and days of ventilation before randomization were considered, LOS was still significantly reduced for NIDCAP infants (HR 1.65, 95% CI: 1.05 – 2.59). Westrup et al.[183] found no significant reduction between newborns receiving NIDCAP and newborns in the control group (LOS: 38.3 days vs. 41.0 days respectively, significance level not reported).

The results on mental wellbeing of parents after the NIDCAP intervention were more heterogeneous. While Als et al.[67] reported significantly less stress for mothers included in the NIDCAP group (p = 0.41), Van der Pal et al.[195] found no significant differences on parental stress. Furthermore, mothers in the NIDCAP group of Kleberg et al.[194] experienced a significant higher level of anxiety compared to the mothers in the conventional care group (median score NIDCAP group: 3.2 vs. conventional group: 2.5, p = 0.033).

Regarding neuro-developmental impairment, the NIDCAP group in the study of Als et al.[67] was significantly better modulated in terms of autonomic and motor system regulation, had better self-regulation and required less facilitation/support. Peters et al.[198] found no statistically significant difference in psychomotor developmental index scores (mean score NIDCAP (SD): 85.1 (15.4); mean score control (SD): 81.1 (15.3); mean difference: 3.95, 95% CI: 2.78 – 10.69, p = 0.246).

Last, newborns receiving NIDCAP had significantly lower total hospital charges compared to the control group ($ 157 vs. $ 181 in hospital $ 1, 314 vs. $ 395 in hospital 2, $ 203 vs. $ 187 in hospital 3; p ≤ 0,001).[67]

Table 16 – NIDCAP

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Westrup et al. (2000)			=							
Als et al. (2003)			+	-						+
Kleberg et al. (2007)		+			+					
Van der Pal et al. (2007)				=						
Peters et al. (2009)			+						=	

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.4 Mother-infant transaction program

The mother-infant transaction program has been developed by Rauh et al.[236] in 1990 and has been slightly modified in the studies we included for the current systematic literature review. It is an early intervention program which has been designed to improve developmental and mental outcomes of preterm newborns and their parents by enhancing the quality of interaction between mother and newborn. The initial program consists of 11 sessions, carried out by trained NICU nurses. The aim of the program is to help parents appreciate their infant's unique characteristics, temperament and developmental potential, acquaint the parents with the newborn's functioning and guide them in being more sensitive and responsive to their psychological and social cues, especially those signalling stimulus overload.[203]

Following the early-intervention program, Kaaresen et al.[191] found a significant difference in attachment between parents and newborns (at both six and twelve months post-intervention). For example, the mean difference on the attachment subscale of the Parenting Stress Index between mothers in the intervention group and control group twelve months post-intervention was 1.7 (95% CI 0.7 – 2.6, ≤0.02) and for fathers 1.6 (95% CI 0.5 – 2.7, p = 0.004). In addition, a significant reduction in parental stress among both mothers and fathers in the intervention group was observed. The mean difference in total stress of mothers and fathers in the intervention group and control group twelve months post-intervention was 13.7 (95% CI 1.6 – 25.9, p = 0.03) and 14.8 (95% CI 2.1 – 27.6, p = 0.02) respectively.

The effect of the program on parent-newborn interaction was studied by Newnham et al.[197] Mothers in the intervention group were more responsive than control mothers (mean score intervention group (SD) = 1.97 (0.08) vs. control group = 1.64 (0.45), $p < 0.05$) and intervention infants were significantly more attentive than control infants (mean score (SD): intervention group = 1.03 (0.10) vs. control group = 0.59 (0.54), $p < 0.012$). There was more mother-newborn reciprocity/synchrony at three months (mean score (SD): intervention group = 0.29 (0.09) vs. control group = 0.23 (0.11), $p < 0.012$) and more mutual attention at six months in the intervention group compared with control dyads (mean score (SD): intervention group = 0.45 (0.08) vs. control group = 0.24 (0.13), $p < 0.012$). Furthermore, Newnham et al.[197] found significant higher stress levels among mothers in the control group compared to intervention mothers (mean score difference: 3.25, $p < 0.012$). There were no significant mean differences in depression scores between mothers in the intervention and control group.

The effect of the mother-infant transaction program on several outcomes was studied in three separate papers of Ravn et al.[201-203] First, the results showed a significant difference in postpartum depression one month after discharge between mothers in the intervention group and those in the control group (mean score intervention group (SD) = 8.3 (5.1) vs. control group = 10.9 (6.7), $p = 0.04$).[203] A significant decrease in depression scores was found in both preterm groups from one to twelve months. There were no significant group-differences in favour of the intervention group in maternal stress scores at six and twelve months. For fathers, there were no significant differences found in total stress scores between intervention and control group at six and twelve months.[202] In addition, a positive effect was found on social interaction between newborns and their mothers at twelve months. Intervention mother scored higher on maternal sensitivity/responsiveness than mothers in the control group ($p = 0.05$).[201] Last, significantly more mothers in the intervention group were breastfeeding their infants at nine months ($p = 0.02$) and this tendency was also found at twelve months (however not significant).[203]

Table 17 – Mother-infant transaction program

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Kaaresen et al. (2006)	+			-						
Newnham et al. (2009)		+		-		=				
Ravn et al. (2011)		+								
Ravn et al. (2012)				=						
Ravn et al. (2012)				=		-		+		

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.5 *Family nurture intervention*

The family nurture intervention is a dyadic intervention comprising repeated calming activities during a newborn's NICU hospitalisation. The intervention is based on the hypotheses that adverse consequences of prolonged separation of mother and preterm newborn can be ameliorated with calming activities. These activities occur during calming sessions facilitated by nurture specialists (i.e. former NICU nurses trained in implementing the family nurture procedures). Calming sessions engaged the mother and newborn reciprocally in physical, sensory and emotional experiences. The calming procedures were as follows:

- **Scent cloth exchange:** mothers were instructed to exchange cotton cloths with their baby on a daily basis. The mother's scent cloth was worn close to her skin overnight and was replaced with the one in the newborn's incubator.
- **Calming touch:** mothers were shown how to calm their newborn using firm sustained touch. While engaging in calming touch, the nurture specialist prompted the mother to communicate her thoughts and emotions to the baby in her native language. During this activity, the mother was encouraged to seek and maintain eye contact with the baby as much as possible.
- **Holding:** when newborn's could be taken out of the incubator, the nurture specialists assisted the mother to engage in skin-to-skin or clothed calming sessions. Holding sessions were facilitated at least four times per week, however, mothers were encouraged to engage in calming techniques in all of their visits.

Furthermore, the nurture specialists encouraged mothers to feed, change and bath their newborns. Fathers were also encouraged to engage in these activities. Specific procedures used during the family nurture intervention are described in Welch et al.[237]

The family nurture intervention does not seem to have a significant effect on LOS of the newborn. According to Welch et al.[207], the mean LOS for newborns in the intervention group (i.e. receiving the family nurture intervention) was 47.4 days (SD 27.4) vs. 50.8 days for the control group (receiving standard care) (SD 45.5). Although mean LOS was 3.4 days shorter in the intervention group, median LOS was 4 days longer in the intervention group (median LOS in days: intervention group = 40, 95% CI 30 – 50 vs. control group = 36, 95% CI 29 – 43) with no significant difference between the groups (p = 0.687).

Furthermore, the family nurture invention has the potential to diminish maternal depressive and anxiety symptoms.[218] For example, mean state anxiety scores were significantly lower in mothers attributed to the family nurture intervention at four months corrected-age in comparison to the mean score in control group (p = 0.004); whereas at baseline, neither the current state nor the more stable trait anxiety scores differed by group. In the control group, 28.6% of the mothers were recorded as attempting to breastfeed at least once as compared to 37.5% of the intervention mothers (p = 0.32). Moreover, there was no significant main effect the rate of breastfeeding.

Last, mothers in the family nurture intervention showed more touch and calmer touch patterns than those in the control group receiving standard care.[220] In maternal touch interactive contingency, when infants looked at their mothers, mothers in the intervention group were more likely to respond with a positive touch.

Table 18 – Family nurture intervention

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Welch et al. (2013)			=							
Welch et al. (2016)					-	-		=		
Beebe et al. (2018)		+								

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, parental mental wellbeing and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, parental mental wellbeing and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.6 CUES program

The CUES program is a six-session intervention for mothers of a preterm newborn hospitalised in the NICU.[199, 200] The program was designed to teach mothers to recognise signs of their anxiety or distress, to use various strategies to alleviate this distress, read their newborn's communication cues and respond sensitively to these cues and distress. In the first two sessions, mothers learned about strategies to reduce anxious feelings. The remaining four sessions were focused on the recognition and interpretation of a newborn's interaction cues and how to respond sensitively. The first five sessions took place in the NICU at a frequency of one or two sessions per week. The last session took place at home after discharge.

Two publications in our systematic literature review studied the effectiveness of the CUES program.[199, 200]

In both studies there was no difference in mother-newborn interaction, mental wellbeing and satisfaction between dyads subjected to the CUES program and the control counterparts. For example, Zelkowitz et al.[199] found a mean interaction score for dyads in the CUES program of 2.8 (SD 1.0) vs. mean interaction score for the control group of 2.8 (SD 1.0, p = 0.71). In addition, the LOS of newborns in the CUES program did not differ from those in the control group in both studies (e.g. mean days (SD): CUES program = 78.8 (41.7) vs. control group = 78.5 (36.5), p = 0.97).[199]

Table 19 – CUES program

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Zelkowitz et al. (2011)		=	=	=	=	=	+			
Feeley et al. (2012)		=	=		=	=				

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.7 Hospital to Home: Optimising the Infant's Environment (H-HOPE) program

The H-HOPE program is an integrated intervention consisting of two components: (i) the infant-directed component and (ii) the mother-directed component. The infant-directed component included twice-daily infant stimulation with ten minutes of ATVV stimuli. The stimuli were presented in a gradual progression and in the following sequence: auditory only, followed by auditory and tactile, with visual added as the newborn became alert. The mother-directed component of H-HOPE consisted of maternal education and social support through individualised participatory guidance. The program was provided by the research team during two in-hospital visits.

Dyads exposed to the H-HOPE programs were more likely to have high responsiveness during play-moments (67.6% vs. 58.1% of the control group).[208] After adjustment for maternal and infant characteristics, H-HOPE dyads had marginally higher scores during feeding on overall mother-infant interaction ($\beta = 2.03$, $p = 0.06$). In the adjusted analysis, H-HOPE dyads had statistically significant increased odds of high vs. low mutual responsiveness during play (OR = 2.37, 95% CI 0.97 – 5.80). Furthermore, in a more recent publication, LOS did not differ between newborns in the H-HOPE group and the control group (mean days (SD): intervention group = 21.3 (10.4), control group = 21.4 (12.5)).[215]

Table 20 – H-HOPE program

	PRIMARY OUTCOMES						SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents: Stress	Mental wellbeing parents: Anxiety	Mental wellbeing parents: Depression	Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
White-Traut et al. (2013)		+								
White-Traut et al. (2015)			=							

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.8 Creating Opportunities for Parent Empowerment (COPE) program

The COPE program is a four-phase educational behavioural intervention program at the NICU.[42] Each phase provides parents with information on:

- the appearance and behavioural characteristics of premature newborns (infant-behaviour information) and how parents can participate in their newborns' care, meet their infants' needs, enhance quality of interaction and facilitate their newborn's development (parent-role information) and,
- activities that assist parents in implementing the experimental information.

To achieve widespread diffusion without intensive staff training and time through person-to-person interventions, the intervention was audiotaped and written information along with prescribed activities so that it could be easily reproduced and administered to all parents of preterm infants in NICUs at low cost.

- **Phase I** (two to four days after the newborns' admission to the NICU): consisted of audiotaped infant-behaviour and parent-role information. In addition, parents were given their first set of parenting activities to complete that consisted of identifying the special characteristics of their infant and keeping a record of their milestones in the NICU.
- **Phase II** (two to four days after the first intervention): consisted of audiotaped and written information that reinforced critical content of the initial audiotape and provided supplemental information on premature newborns' behaviors and development. Additional suggestions regarding how parents could participate in their infants' care and enhance their development were provided. The activities in this phase consisted of identifying the special characteristics of their preterm infants and recognizing their infants' stress cues as well as cues that signal readiness for interaction.
- **Phase III** (one to four days before discharge): consisted of developmentally appropriate audiotaped information, including specific details about newborn states and the best times for interaction as well as parent-role information about how to smooth the transition from hospital to home and how to continue to foster a positive parent-infant relationship. Parent activities during phase III included continuing to assist parents in recognizing their infants' cues and helping parents to recognize strategies to assist their infants when stressed.

- **Phase IV** (one week after infant discharge): audiotaped and written information contained anticipatory guidance specific to preterm-newborn development, suggestions for fostering a positive parent-infant relationship and specific activities for parents to perform to foster their infants' cognitive development.

According to the pilot study of Melnyk et al.[184], mothers in the COPE group reported significantly less stress compared to mothers receiving standard care. There were no statistically significant differences between the study groups on maternal state anxiety, overall negative mood state and depression during and following hospitalisation. However, there were small to medium positive effects (borderline significant) for the COPE program on: maternal state anxiety at the Phase II and Phase III interventions and maternal depression at the Phase II and Phase IV interventions. There was no significant difference in mother-newborn interaction between intervention and control group. There also were no significant differences between the length of time in days that the COPE and comparison infants were home before the 3 months' corrected age data collection visit (mean LOS days (SD): intervention group = 134.5 (19.9) vs. control group = 132.8 (20.1)) and the 6 months' corrected age data collection visit (mean LOS days (SD): intervention group = 232.5 (22.7) vs. control group = 230.5 (28.6)).

In their more recent study, Melnyk et al.[42] found a significant reduction in 3.8 days for the LOS of the newborns in the intervention group than for those in the control group (mean LOS days (SD): intervention group = 31.86 (22.54), 95% CI 29.32 – 34.41 vs. control group = 35.63 (26.85), 95% CI 32.80 – 38.46). In addition, the total hospital LOS, including days spent in transfer hospitals, was 3.9 days shorter for newborns in the COPE group (mean LOS days (SD): intervention group = 35.29 days (22.40), 95% CI 33.06 – 37.52 vs. control group = 39.19 days (27.00), 95% CI 36.69 – 41.69). In addition, mothers in the COPE program reported also significantly less overall parental stress in the NICU than did mothers in the control group and specifically related to their general NICU stress, their infants' behaviours and staff behaviours. There were no differences between the groups on fathers' reports of stress in the NICU. In addition, both mothers' and fathers' state anxiety and depressive symptoms decreased over time, without significant COPE- and control group differences identified.

Table 21 – COPE program

	PRIMARY OUTCOMES						SECONDARY OUTCOMES			
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Melnyk et al. (2001)		=	=	-	=	=				
Melnyk et al. (2006)			+	=	=	=				

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.9 Psychological interventions

Early preventive attachment-oriented psychotherapeutic program

The early preventive attachment-oriented psychotherapeutic program is a parent-oriented intervention consisting of supportive group psychotherapy, attachment-oriented focal individual psychotherapy, a home visit and video-based sensitivity training.

In the study of Birsch et al.[188], 77.8% of the preterm newborns in the control group showed a secure attachment classification, 8.3% were insecurely avoidant and 13.9% insecurely ambivalent attached. In the intervention group only 59.4% of the premature newborns were securely attached, whereas a higher percentage than in the control group was insecurely avoidant (31.3%) and a lesser percentage of 9.4% was insecurely ambivalent attached. The group differences in the results between control and intervention group did not reach a statistical significance.

Although subjects were randomly assigned to the control and the intervention group, the data of the neurological development of the newborns at 14 months (corrected for prematurity) revealed a significant difference in the two groups ($p = 0.009$) with more newborns being neurologically impaired in the intervention group (23.7% healthy vs. 76.3% impaired) than in the control group (54.1% healthy vs. 45.9% impaired). This difference is reflected in the significant ($p = 0.049$) correspondence of neurological development and attachment development of the newborns in the control group, revealing that newborns with secure mother-newborn attachment showed a high percentage of neurologically healthy development (64.3%). Whereas those with insecure attachment were predominantly neurologically impaired (75%).

Triadic parent-infant Relationship Therapy (TRT)

TRT is program consisting of 22 sessions, including two home visits per month (for four months), up until a corrected age of 18 months.[216] TRT is based on the attachment theory was therapeutic interventions were organised in three stages:

- Facilitation of the parent-infant interactions to enhance emotional sharing with the triad mother-father-infant and mental health for both parents.
- Promotion of the understanding of infant development to reduced parental stress and strengthen parents' appropriate perceptions regarding their infant's behaviour.
- Promotion of the parent-infant triadic relationship to foster the infant's cognitive, motor, socioemotional and behavioural development.

Castel et al.[216] studied the effect of TRT on parental stress levels, parental depression and neurodevelopmental impairment of the newborns. They found a significant reduction of parental stress levels and depressive symptoms in favour of the intervention group. In addition, at 18 months' corrected age, children in the intervention group showed significant higher developmental quotients than the preterm control infants.

Table 22 – Psychological interventions

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Birsch et al. (2003)	=								-	
Castel et al. (2016)				-		-			-	

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.10 Family integrated care

The implementation of family integrated care is focused on four pillars: (i) a parental educational program, bedside parental coaching, parental involvement in medical rounds, training of staff about the importance of family involvement and tools to coach and support parents and psychosocial support for parents including peer-to-peer and professional support.[17]

In one publication, the effect of family-integrated care on LOS of the newborn, parental stress and breastfeeding was studied.[17] By implementing family-integrated care in the NICU, parents are enabled to become primary caregivers in the NICU. This implementation was organised following the four pillars of family-integrated care: (i) a parental education program, (ii) parental coaching at the bedside and parental involvement in medical rounds, (iii) staff training on importance of family involvement and (iv) psychosocial support including peer-to-peer and professional support for parents throughout the NICU stay. There was no significant difference in mean LOS of the newborn (50 days for the family-integrated care group vs. 48 days for the standard care group, p = 0.19). Furthermore, parents in the family-integrated care group reported less stress and anxiety compared to the control group (mean stress scores (SD): intervention group = 2.3 (0.8) vs. standard care group = 2.5 (0.8), p < 0.001; mean anxiety scores (SD): intervention group = 70.8 (20.1) vs. standard care group = 74.2 (19.9), p = 0.005). Concerning breastfeeding, the rate of high-frequency breastmilk feeds (> six times a day) at discharge home was higher in the family-integrated care group than in the standard care group (70% vs. 63% respectively, p = 0.016).

Benzies et al.[225] adapted the family-integrated care model for their study in Alberta (Canada) and evaluated the effects of this new Alberta family integrated care model in terms of LOS of the newborn, readmission rate, type of feeding and several maternal psychological distress outcomes (i.e. stress, anxiety and depression).

Alberta family integrated care has three main components:

- Relational communication: based on family systems theory and uses circular pattern diagrams and questioning practices to negotiate parent and health care providers roles as parents gain confidence in providing care.
- Parent education: based on adult learning and self-efficacy theories and included a parent education pathway, individual bedside teaching, group parent education sessions and the use of a app.
- Parent support: based on stress and coping theory and included postpartum despression screening and referrals to insure mtoher receive timely psychological support. Family mentors, parents who had experience with a preterm infant in the NICU, provided also peer-to-

peer support. In addition, parents in the intervention group received a free parking pass.

The results showed a significant reduction in newborn LOS, the LOS was 2.55 days shorter (95% CI -4.44 – -0.66, p = 0.02) for the infants in the intervention group than for their control counterparts. Type of feeding, readmission rate and maternal psychological distress outcomes were not significantly different between groups.

Church et al.[226] compared the impact of family-integrated care in 7 family integrated wards and 7 non-family integrated wards in terms of parent-newborn interaction and stress levels of the parents. According to their results, family integrated care increased the parent-newborn interaction and reduced parental stress.

Table 23 – Family integrated care

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
O'Brien et al. (2018)			=	-	-			+		
Benzies et al. (2020)[aa]			-	=	=	=		=		
Church et al. (2020)		+		-						

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

[aa] Benzies et al. (2020) studied also the effect of Alberta FICare™ on the readmission rate of newborns. Readmission rates were similar in proportions of infants in the intervention and control group. Because only one publication studied this outcome we excluded it from all tables of this chapter.

4.4.2.11 Music therapy

Two publications studied the effect of kangaroo mother care combined with live harp music therapy or maternal singing.[204, 209] Both studies demonstrated a significant reduction in maternal anxiety between intervention and control mother-infant dyads. For instance, kangaroo mother care combined with live harp music therapy has a significant beneficial effect on maternal anxiety state (before intervention (SD): KC only 53 (11.3) and KC combined with music therapy (SD): 55.3 (9.2); after intervention (SD): 46.8 (10) vs. 27.7 (7.1), respectively, $p < 0.01$).[204] Furthermore, compared with kangaroo mother care alone, kangaroo care with maternal singing showed to have a significant beneficial effect on maternal anxiety (mean score before kangaroo mother care only (SD): 56.2 (10.8); mean score after kangaroo mother care only (SD): 42.8 (8), $p = 0.09$ vs. mean score before kangaroo mother care with singing (SD): 50.6 (12.3); mean score after kangaroo mother care with singing (SD): 26.4 (8.2), $p = 0.04$). The mean difference in the State-Trait Anxiety Inventory score between pre-intervention to post-intervention was also significantly higher in the intervention group compared to the control group (mean difference intervention group (SD): 12.8 (2.3) vs. mean difference control group (SD): 23.7 (5.4), $p = 0.03$).[209]

Ranger et al.[221] studied the impact of exclusive live harp music (not in combination with kangaroo care) on maternal anxiety. They found that mothers reported less anxiety after listening to the music intervention than beforehand ($p = 0.01$). The interactive live music therapy studied by Menke et al.[231] showed a significant reduction in stress and anxiety levels for mothers and fathers but no significant reduction of the LOS of the infant ($p = 0.072$).

Chorna et al.[210] found no significant reduction of the use a pacifier-activated music player (PAM) playing the mother's voice during non-nutritive sucking on LOS of the newborn (mean LOS in days: intervention 41 vs. control 50, $p = 0.07$).

Last, the use of music therapy in the study of Corrigan et al.[230] showed no statistical significant differences in maternal-newborn bonding after one week between intervention and control group (mean score music therapy (SD): 0.64 (1.6) vs. mean score standard care (SD): 0.57 (1.5), $p = 0.60$).

Table 24 – Music therapy

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Schlez et al. (2011)					+					
Arnon et al. (2014)					+					
Chorna et al. (2014)			=							
Ranger et al. (2018)					+					
Corrigan et al. (2021)	=									
Menke et al. (2021)			=	-	-	=[bb]				

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.12 Video interaction guidance (VIG)

VIG is a short-term, behaviourally focused video-feedback intervention that guides parents to reflect on their interactions with their newborn and is performed by certified professionals who work by a standardised protocol when (i) video recording parent-infant interaction, (ii) editing recordings and (iii) reviewing the edited recordings with the parents.

The video recordings (of approximately fifteen minutes duration) are made during daily moments of caregiving (e.g. bathing, changing diapers, or feeding). Recordings are subsequently edited by the VIG professional, who selects fragments of the newborn's contact initiatives and parents' positive responses to these initiatives. Parents are invited to review these moments and discuss them with the VIG professional. VIG consisted of three review sessions during the first week of birth.

The results of the study of Hoffenkamp et al.[213] demonstrated a significant positive effect on parent-newborn bonding among fathers. There was no significant effect of VIG on maternal reported bonding problems. Yet, the outcome on paternal bonding problems were significantly different between the intervention and control group (mean difference one-month post-intervention: -0.71, 95% CI -2.23 – 0.80, p = 0.36, mean difference six-month post-intervention: 0.49, 95% CI -0.74 – 1.71, p = 0.44). Fathers who received VIG reported fewer difficulties in parent-newborn bonding one-month post-intervention (mean difference: -2.10, 95% CI -4.05 – -0.13, p = 0.04) as well as six-month post-intervention (mean difference: -2.08, 95% CI -3.88 – -

[bb] The numbers showed a decrease in depression symptoms in parents pre- and post-intervention. However, the authors did not calculate significance levels.

0.28, p = 0.02). Twohig et al.[233] did not find a significant difference in maternal interaction between intervention and control group (p = 0.90).

With respect to attachment representations, the differences between the groups did not reach significance in mothers (mean difference one-month post-intervention: 0.56, 95% CI -0.61 – 1.75, p = 0.35) or in fathers (mean difference one-month post-intervention: 1.18, 95% CI -0.18 – 2.54, p = 0.09). Last, the effects of VIG on maternal and parental stress responses and psychological wellbeing reached no significance. After one week and one month, there were no statistically significant differences between the intervention and control group on maternal and paternal NICU-related stress, infant-related worries, distress, or infant separation anxiety.

Table 25 – Video interaction guidance

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Hoffenkamp et al. (2015)	=	+		=	=	=				
Twohig et al. (2021)		=								

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.4.2.13 Other

Baby CareLink

Baby CareLink is a telemedicine program with the main goal to enhance interactions between families, NICU staff and other health care providers in the community. The Baby CareLink system could be accessed by the family from their home computer and incorporated a video conferencing module. It allowed virtual visits and distance learning during the infant's hospitalisation as well as virtual house calls and remote monitoring after discharge.

The LOS of the newborn did not differ between the Baby CareLink telemedicine group and the control group (mean LOS (SD): telemedicine group = 68.5 days (28.3) vs. control group = 70.6 days (35.6), mean difference -2.1 days, p ≤ 0.05). Furthermore, for the outcome of family satisfaction, Gray et al.[181] reported that the Baby CareLink usage was associated with significant improvements in family satisfaction. Results on family satisfaction were not described elaborately, therefore we were not able to calculate effect sizes.

Co-bedding of premature multiple gestation newborns

Fowler Byers et al.[187] compared the effects of co-bedding of premature multiple-gestation newborns with those of single-bedding in terms of attachment, anxiety and satisfaction. Co-bedded infants received care using the institution's co-bedding care protocol. This protocol addresses identifying infant, equipment and line/wire; consistent positioning of the newborns; clustering of care; recording all the care provided to one infant before providing care to the second infant; staff handwashing before and

after caring for each infant; temperature monitoring; and having criteria for infant separation. However, there was no statistically significant difference in parental anxiety, attachment, nor satisfaction.

Assessment of the Preterm Infant Behaviour (APIB): guided interaction and education

The APIB is an extension and refinement of the Brazelton Neonatal Behavioral Assessment Scale (BNBAS) and provides a framework for the systematic observation of the premature newborn's behavioural response to increasing levels of environmental stimuli, manipulation and social interaction.

Browne et al.[18] studied the effect of this intervention by assigning mother-newborn dyads into three groups. Group 1 participated in a demonstration of newborn reflexes, attention, motor skills and sleep-awake states. Group 2 received educational materials and group 3 (control group) participated in an informal discussion. A significant treatment effect on parent-newborn interaction was found ($p < 0.05$), with scores for the control group significantly higher, indicating lower relationship quality, than scores for the intervention groups. The results revealed significant difference in stress levels across treatment groups. Subscale analyses revealed a marginally significant difference between groups ($p = 0.056$) which indicated that mothers in the control group perceived more stress parenting their baby one-month discharge, than mothers in group 1 and 2.

Parent Baby Interaction Programme (PBIP)

The PBIP is a supportive, educational intervention delivered by research nurses in the NICU.[193] It aims to enhance parents' observation of their newborn and sensitivity to cues through a series of activities which follow the progression of care from incubator to home. Components of PBIP can classified in four topics: tactile (e.g. stroking the newborn), discussion (e.g. newborn development), verbal (e.g. greeting the newborn) and observation (e.g. identifying different states). It also incorporates several principles of developmental care, such as use of incubator covers to shield newborns.

However, research showed no measurable effects on mother-infant interaction, short-term infant neurobehavioral functioning, or parental stress.[193] For example, high levels of parental stress (scores above the 85th centile) were found among 25.3% of the mothers in the intervention group and 19.4% mothers in the control group, compared with the expected 15% in the normative population.

Family-centred unit in NICU

Örtenstrandt et al.[73] conducted a RCT comparing LOS of premature newborns randomly assigned to family-centred wards or standard care wards in two NICUs (both level II). Each family-centred ward had a four-bed intensive care room, with staff continuously present. There were separate rooms for each family, including beds for both parents, a private bathroom, bed for the newborn and equipment for supplementary oxygen and telemetric wireless monitoring. At least one of the parents was expected to be present 24/7 during the entire hospital stay. The parents of the newborns randomised to the standard care ward were advised to be with their baby as much as possible. The results showed a statistically significant total LOS reduction of 5.3 days (mean days (95% CI): family-centred unit = 27.4 days (95% CI 23.2 – 31.7), standard NICU = 32.8 days (29.6 – 35.9), $p = 0.05$).

Free parking for parents of hospitalised newborns

Northrup et al.[217] hypothesized that free parking for parents of these children may deter visitation rates. Therefore, they studied the effect of free parking on LOS, parental involvement and satisfaction. Parents in the free parking-group received seven parking vouchers at a time (value: $ 10/each), control group received no parking vouchers and had to pay ≥ $ 10 per visit. The results showed no significantly decrease in LOS (mean LOS (SD): free parking group = 89 (37) vs. control group = 102 (66), $p = 0.22$) after the implementation of free parking vouchers. There was also no significant difference in the number of visitation days, parental involvement, breastfeeding rates and satisfaction. Post-hoc analyses found that high-income parents with a car and less children visited more their newborns in the NICU.

Parenting intervention Baby Triple P (BTP)

BTP consisted of hospital and community-based content delivered by BTP trained facilitators. Families received four two-hour in-hospital sessions while there newborn was hospitalised in the NICU.[219]

- Session 1: focused on survival skills and included information including parenting traps, understanding emotions, expectations about becoming a parent, acceptance and coping skills.
- Session 2: focused on parenting support and gave the parents insights on parenting traps, becoming a family, staying happy in current relationship, communication skills, social support and allocation of family chores.
- Session 3: was attributed to positive parenting. Parents received information on the aspects of positive parenting, creating a safe environment for the infant, newborn's behaviour and development, recording the newborn's behaviour and developing a positive relationship with the infant.
- Session 4: was centralised around responses to the newborn and included information on how parents could teach their newborn new skills and behaviours, develop a flexible routine, the newborn's sleep and how to promote safe sleeping.

Evans et al.[219] studied the effect of the BTP parenting intervention on the mother's attachment to her infant at six weeks' and twelve months' corrected age. The results showed that at six weeks' corrected age, no significant differences were found between the mothers who received the BTP group (intervention group) and mother who received standard care (control group) (effect size = -0.09, 95% CI -2.40 – 4.09, p = 0.610). At twelve months' corrected age, the control group scored significantly higher for self-reported maternal attachment compared to the mothers in the intervention group (effect size = -0.43, 95% CI -5.61 – 0.45, p = 0.021).

Parent participation improvement program

Heo et al.[223] developed a parent participation improvement program and tested the effect on parent-newborn attachment through a RCT conducted in South Korea. The parent participant improvement program was a two-week program consisting of three stages:

- Individualised interaction stage: during this stage, the parents identified the factors that impeded their parenting experience in the NICU and assessed individual requests for participation.
- Preparticipation stage: this stage was conducted three times (50-60 minutes), according to the educational and practical contents. This stage provided parents with information on selected topics based on the interviews from the first stage and practical exercises were provided to enhance the technical aspects of actual parent participation.
- Active participation stage: during this stage parents (both mothers and fathers) engaged in nursing care a total of six times. Parental participation took place during the regular handling time for preterm newborns.

Compared to the control group, both mothers and fathers in the intervention group reported significantly higher scores on the Maternal Attachment Inventory Scale (effect size intervention group (SD) mothers: 0.25 (0.02) vs. control group 0.11 (0.01), $p < 0.001$; and effect size intervention group (SD) fathers: 0.33 (0.03) vs. control group 0.07 (0.02), $p < 0.001$).

Financial support for mother of hospitalised newborns

In the study of Andrews et al.[224] Medicaid-eligible mothers received financial support (up to three weekly financial transfers of $ 200) while their preterm newborns were in the NICU. Mother receiving the financial support were 1.85 times as likely to practice SSC (95% CI 1.25 – 2.75), 1.23 times as likely to visit the NICU (95% CI 1.02 – 1.49) and 1.36 times likely to provide breastfeeding (95% CI 1.10 – 1.69) on any given day compared to the control group (who did not receive the financial transfers). There was no statistically significant difference in observed

LOS between the intervention and control group (-1.66, 95% CI -6.54 – 3.21).

Virtual family-centred rounds

Rosenthal et al.[232] conducted a pilot study to test the implementation of virtual family-centred rounds with parents of neonates hospitalised in NICU. Once the medical team was at the bedside, the research assistant called the parents using Zoom® to establish the real-time, bidirectional audio and visual connection. The virtual rounds proceeded in usual fashion with a neonatologist, neonatal fellow, 2 paediatric residents, charge nurse, bedside nurse, pharmacist, dietician, a social worker. Following the pilot study, there was a significant reduction in newborn LOS (0.62, 95% CI 0.50 – 0.75) and increase in exclusive breastfeeding (20.0, 95% CI 3.1 – 37.0) in favour of the intervention group. No significant difference was found for any breastmilk feedings between groups (9.9, 95% CI -7.6 – 27.4).

Table 26 – Other family-centred interventions

	PRIMARY OUTCOMES							SECONDARY OUTCOMES		
	Parent-newborn attachment	Parent-newborn interaction	LOS newborn	Mental wellbeing parents			Parent satisfaction	Breastfeeding	Neuro-developmental impairment	Costs of care
				Stress	Anxiety	Depression				
Gray et al. (2000)			=				+			
Fowler Byers et al. (2003)	=				=		=			
Browne et al. (2005)		+		-						
Glazebrook et al. (2007)		=		=					=	
Örtenstrandt et al. (2010)			+							
Northrup et al. (2016)			=				=	=		
Evans et al. (2017)	-									
Heo et al. (2019)	+									
Andrews et al. (2020)		+	=					+		
Rosenthal et al. (2021)			+					=		

+ refers to a significant positive effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding increases; LOS of the newborn, neurodevelopmental impairment and costs of care decreases)
= refers to a unchanged or mixed effect of the intervention
- refers to a significant negative effect of the intervention (parent-newborn attachment and interaction, stress, depression, anxiety and satisfaction, breastfeeding decreases; LOS of the newborn, neurodevelopmental impairment and costs of care increases)

4.5 Conclusion

This review summarises the results of 59 RCTs describing 24 neonatal IFCDC interventions: ranging from interventions focusing on SSC (including different operationalisations of SSC and kangaroo care), massage and the ATVV intervention, NIDCAP, mother-infant transaction program, family nurture intervention, CUES program, H-HOPE program, COPE program, psychological interventions (such as early preventive attachment-oriented psychotherapy and TRT), family integrated care, music therapy, VIG and a wide range of individual interventions (among which a telemedicine program, co-bedding of multiple-gestation newborns, APIB, PBIP, free parking for parents of hospitalised newborns, BTP, parent participation improvement program, financial support for parents and virtual family-centred rounds).

These different operationalisations and interventions demonstrate the complexity of IFCDC. It is a multifaceted concept which is usually implemented as a model incorporating some aspects, but not all. The identified interventions incorporate one or more of the dimensions described in the concept mapping (see section 1.3.2). The interventions themselves were very different from one another, making it difficult to generalise or combine the results for an estimate of overall effectiveness. In addition, the used tools and instruments to measure the impact on the outcomes is quite heterogenous across studies.

Most RCTs found mixed effects on the studied outcomes. Nevertheless, important to note is that no major significant negative effects were found. This review suggests some benefit to support IFCDC for preterm newborns in neonatal wards, however, it has not the power to recommend one comprehensive IFCDC model. These results are in line with those from a recent literature review that studied family engagement interventions in adult, neonatal and paediatric ICUs (not limited to RCTs only).[238]

This limited level of evidence of IFCDC can be explained by the weak methodological quality of the selected RCTs. As highlighted in several recent Cochrane Library reviews[48, 49, 115, 239], there continues to be a lack of high-quality quantitative research about the effects of IFCDC. Most of the included RCTs recruited small samples (only 23 trials randomised more than 100 dyads). For instances, trials in which a significant effect on one of the outcomes was found, had usually recruited a small sample of participants or in other cases the clinical relevance of the effect was questionable. Therefore, we recommend further rigorous research on the short- and long-term effectiveness of IFCDC as a model of care delivery.

Important for the interpretation of the results is that this review was limited to high-income countries only. This decision was made to increase the relevance of the results for the Belgian context.

We included pilot RCTs to add a rich description of neonatal IFCDC interventions. During our screening process, we came across several recent protocols of RCTs which were relevant for inclusion in this review. However, these RCTs have not yet published any results, which is why they were excluded during the screening process.[113, 240-247]

Furthermore, IFCDC interventions in the ambulatory setting were also excluded from this review because the scope of this report focuses on intramural neonatal care. We agree that IFCDC does not end at the discharge of the preterm newborn. We recommend future systematic reviews to investigate the short- and long-term effects of these ambulatory IFCDC interventions.

5 PARENTS' PERSPECTIVES ON FACILITATORS AND BARRIERS OF IFCDC

5.1 Introduction

In this study, the identification of facilitators and barriers to implement infant- and family-centred developmental care (IFCDC) is based on a multimodal approach combining data collection from professionals and parents of preterm newborns. The professional perspective is described in the next chapter. This chapter aims to identify the facilitators and barriers experienced by the parents. Therefore, all statements and quotes used to illustrate answers are the points of view and experiences of the interviewees.

5.2 Methods

5.2.1 Design

To retrieve the parents' perspectives regarding IFCDC in Belgian neonatal wards, a qualitative approach was conducted. In-depth face-to-face semi-structured interviews have been carried out by a native French-speaking researcher (NB) and a native Dutch-speaking researcher (JD). Due to the corona measures in place at the time, interviews were organised online using the videoconferencing software Zoom®. Interviews were scheduled between mid-April and the first week of May 2021.

5.2.2 Sampling and selection

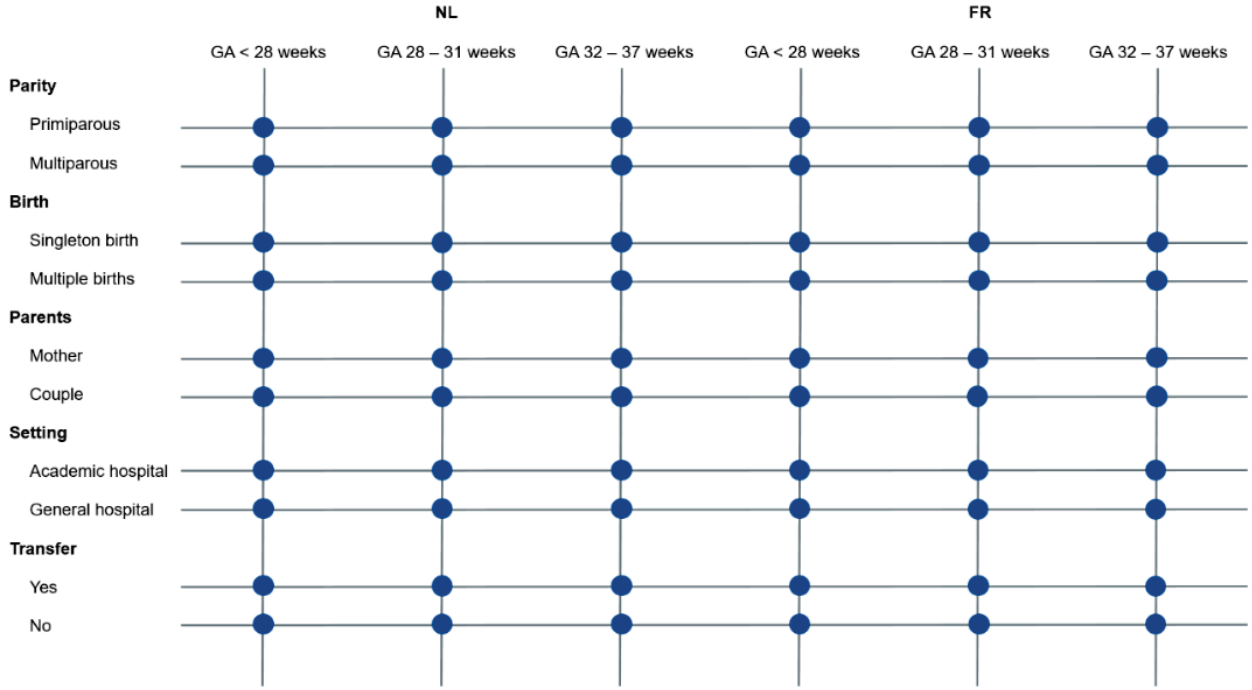
An open call was launched to recruit parents who had a preterm newborn that was hospitalised in a Belgian neonatal ward. The open call was sent to the KCE mailing list, several Belgian parent organisations for preterm newborns and was shared on social media. Candidates could apply via a structured application form on the KCE website. The form included information about the newborn (i.e. gestational age and single of multiple births), the hospitalisations (i.e. stay hospital(s), duration between discharge and interview, transfer from one hospital to another) and about the parents (i.e. age, parity and postal code).

The applied in- and exclusion criteria are presented in Table 27. The sampling aims to capture the variation in the parents' perspectives, according to their demographic characteristics (such as place of residence or parity) and several admission-related characteristics (such as setting hospital or transfer). A predefined selection matrix was used to structure the selection process (Figure 8).

Table 27 – Inclusion and exclusion criteria

	Criteria
Inclusion	Parents with a preterm newborn who were discharged alive (between 1 month and 1-year post-discharge) after neonatal hospitalisation. Parents aged ≥ 18 years Dutch or French speaking parents Hospitalisation in a Belgian hospital
Exclusion	Parents of preterm newborns who deceased during the hospital stay or shortly after hospital discharge. Parents of term newborns in need of surgery or newborns admitted to N*/NIC because of non-medical issues. Discharge > 1 year ago Parents of preterm newborns who are not yet discharged The hospitalisation was in a foreign hospital

Figure 8 – Selection matrix for interviews with parents of preterm newborns



5.2.3 Data collection tools

5.2.3.1 Interview guide

The researchers developed a questionnaire with open questions and additional sub-questions to guide the interview (see Appendix 4). Publications on qualitative research among parents of preterm newborns that were generated by the search strategy of the systematic literature review of Chapter 4 (but that were included because they did not meet the inclusion criteria of design, i.e. no RCTs) were used for the development of the interview guide. The first draft of the interview guide was piloted with a couple who did not fulfil the inclusion criteria (infant was discharged more than one year before the interview). During the pilot test, the formulation of questions and the flow of questions were tested. In addition, both interviewers attended one interview of the other to align the interview method.

5.2.3.2 *Informed consent*

The informed consent stated that the interview would be recorded and transcribed verbatim. Tapes of the interviews would be destroyed after the research project was finalised. In addition, participants were guaranteed that transcripts would only serve the data analysis within the research project. Quotes in the final report would be anonymised to protect the identity of the participants, as well as the healthcare professionals or organisations they mentioned.

Before the interview, interviewees received a mail with a video link explaining the informed consent. Afterward, interviewees received the actual informed consent which could be signed digitally (also co-signed by the interviewer). At the start of each interview, the interviewers explained orally the informed consent to the interviewee(s) and responded to possible additional questions. Participants were also informed about the possibility to stop participation at any moment without any disadvantages.

5.2.4 *Data analysis*

The interviews were audio-recorded. Following the interview, the audio files were transcribed verbatim by a subcontractor. The transcripts were imported to the qualitative data analysis software package NVivo® (version 1.5) to facilitate coding and analysis of the data. All the French-speaking and Dutch-speaking transcripts of interviews were coded by two native-speaking researchers (JD and NB) using codes drafted in English.

We performed a qualitative thematic inductive analysis on the transcripts of the interviews. The smallest textual unit of analysis was ‘a sentence’ being the minimal coding unit: the codes were organised and grouped to obtain the main categories of analysis. Through the analysis, several meetings with the research team were organised to discuss the results and their interpretation.

5.2.5 *Ethical committee approval*

Before starting the interviews, the research protocol, including the interview guide, was submitted to and approved by the ethical committee of the Hôpital Erasme – ULB (P2020/422/B4062020000174).

5.3 Results

5.3.1 *Characteristics of the participants*

A total of 25 interviews were conducted: 13 interviews in Dutch and 12 in French. The newborns whose parents were interviewed were cared for in 22 different hospitals including 7 academic hospitals. The Dutch-speaking newborns were cared for in 12 different hospitals including 4 academic hospitals, while the French-speaking ones were cared for in 10 hospitals including 3 academic hospitals. The selection matrix was nearly completed for the Dutch-speaking interviews, except for multiple births among preterm births born < 28 weeks gestational age. For the French-speaking interviews in Wallonia and Brussels, we could not recruit multiparous parents of preterm newborns born < 28 weeks gestational age. Also, we have no parents of newborns born between 28 – 31 weeks gestational age who had been hospitalised in an academic hospital and no parents of newborns born between 32 – 37 weeks gestational age who had been transferred.

A detailed overview of the characteristics of the participants can be consulted in Table 28.

Figure 9 – Completion of the selection matrix

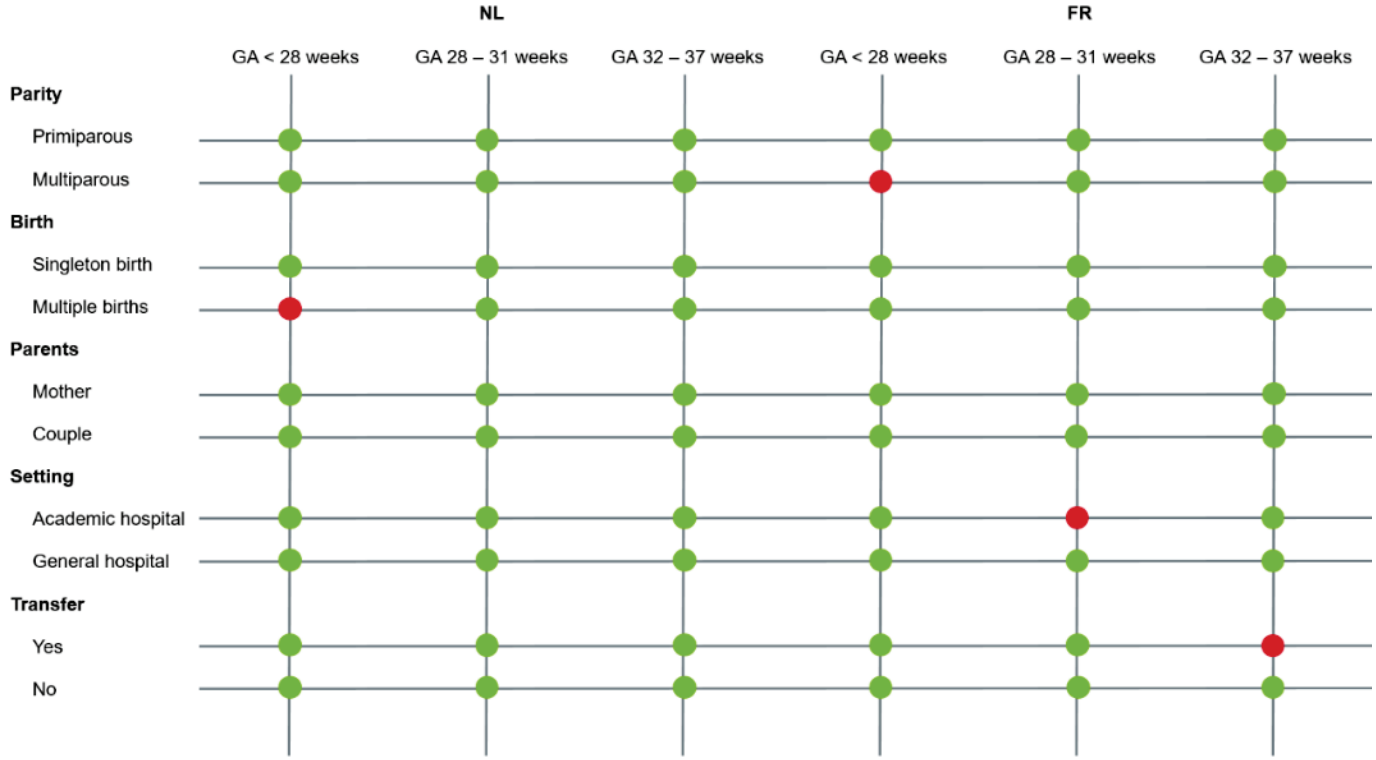
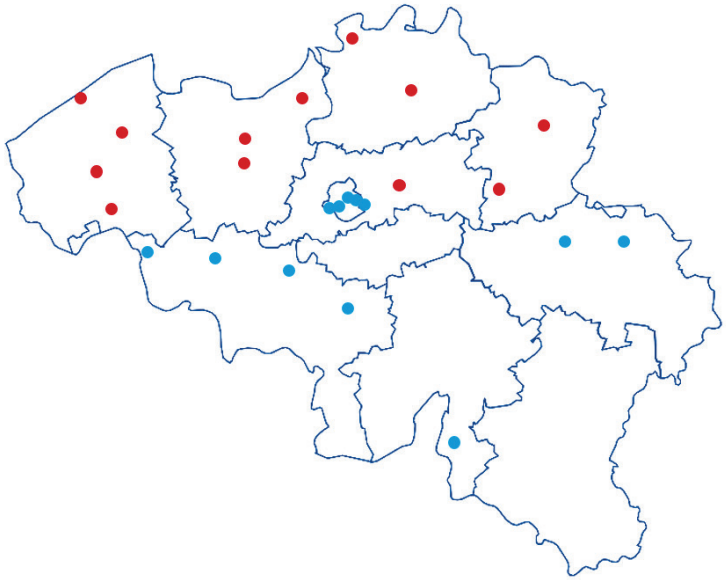


Table 28 – Characteristics of the participants

	Flanders (n)	Wallonia and Brussel (n)
Gestational age		
GA < 28 weeks	4	3
GA 28 – 31 weeks	5	3
GA 32 – 37 weeks	4	6
Parity		
Primiparous	7	6
Multiparous	6	6
Birth		
Singleton birth	10	10
Multiple birth	3	2
Parents		
Mother	6	4
Couple	7	8
Setting		
Academic hospital	7	5
General hospital	6	7
Transfer		
Yes	4	2
No	9	10
TOTAL	13	12

Figure 10 shows that respondents were scattered over Belgium. However, two Walloon provinces were not represented in the sample: Walloon Brabant and Luxembourg.

Figure 10 – Geographical distribution of the respondent's place of residence



In what follows we present what worked or did not work for parents of a preterm baby when looking back to their stay at the maternity ward and neonatal ward. We tried to link these findings explicitly with the key principles of IFCDC, such as starting early, partnership between parents and neonatal staff, and avoiding separation between parents and child.

5.3.2 Advantages of anticipating preterm birth

Key points

- **Anticipation of preterm birth during pregnancy allows parents to make informed decisions about the choice of the hospital to give birth the planning of the newborn's care and treatment (e.g. surgery), and the setting of personal limits of therapeutical relentlessness according to the gestational age reached.**
- **An antenatal visit to the neonatology service helps parents to prepare for neonatal intensive care. It makes neonatal intensive care more tangible, it helps to develop realistic expectations, and to create relationships of trust with the neonatal staff.**
- **The anticipation of preterm birth allows future parents to get an answer to their questions about the pregnancy, the neonate's health condition and chances of survival.**

Anticipation of a preterm birth is one of the key ideas of IFCDC. Interviewees confirmed in several ways its positive impact on their experience with neonatal care.

The anticipation of a preterm birth allows parents to make informed decisions

The anticipation of a preterm birth allows parents to **choose the hospital** according to the gestational age, the availability of a NICU or its characteristics (e.g. availability of individual rooms), contacts with neonatal staff or the surgery needs of their baby. However, a prerequisite is that parents receive enough information about the risk of preterm delivery to allow them to **compare all the alternatives** and to choose the most relevant hospital in function of the gestational age of their baby.

> *« C'est nous qui avons décidé. Comme je disais, franchement c'est le gynécologue à ce moment-là qui nous a vraiment accompagnés et qui a pris contact lui-même avec les chirurgiens pour organiser les rendez-vous. Et donc on a pu discuter avec les chirurgiens de H2 et de H3. Pour voir un peu quelles méthodes de chirurgie ils utilisaient, etc. Et donc j'avoue que on s'est surtout basé pour choisir, sur le contact qu'on avait eu avec les deux équipes. […] Sur les méthodes utilisées, ben ça ils utilisaient les mêmes méthodes. Et sur la proximité. Parce que du coup, on s'est dit : « On habite à [lieu] », H2 c'est à six, sept minutes en voiture, de chez nous donc … on a quand même fait ce choix aussi pour des facilités d'organisation quoi. […] Ils nous ont laissé nous-mêmes acteurs [de notre choix], et ça c'est chouette. » (Mother, GA 32 to 37 weeks)*

> *« Bon, parce que maintenant on comprend qu'on ne sait toujours pas, mais je veux dire on n'a pas été confrontés au choix. Simplement peut-être parce que le premier hôpital donc l'hôpital 1, lui dans sa tête avant 24 semaines ce n'est même pas la peine, on laisse tomber. Et donc mais c'est, c'est la moindre des choses de devoir le dire. Qui plus est, qui plus est à chaque fois qu'elle a été aux urgences, nous on habite en plein milieu entre l'hôpital 1 et l'hôpital 2 [...] Donc qui plus est c'est le jour où elle est née, moi j'ai pris, on a pris la décision d'aller à l'hôpital 1 parce qu'on ne nous a pas dit qu'on ne savait pas prendre la petite en charge. Autrement, qu'est-ce qu'on aurait fait, on aurait été directement…Et tous les risques qui ont été pris, donc elle s'était fait 100 kilomètres en ambulance à […] deux heures de vie alors que si elle avait été prise en charge à l'hôpital 2, ça, donc ce sont toutes des, des informations qu'entre guillemets je trouve inacceptable de la part. » (Father, GA less than 28 weeks)*

> *"Want dan hadden we eigenlijk gevraagd om naar het [ziekenhuis] te mogen, omdat ik, allez een goede vriendin van mij is vroedvrouw, maar niet in [ziekenhuis]. Dus ik vroeg, allez ik had haar opgebeld en gevraagd wat moet ik kiezen? Wat is, allez ik weet niet wat ik moet doen. En dan zei die, ga naar het [ziekenhuis] want daar hebben ze ook kind-ouder-kamers voor als die toch zou komen. Dan hebben ze naar het [ziekenhuis] gebeld, en daar kregen we toen de boodschap van nee, die mag niet naar hier komen, het is hier, het was heel hectisch toen met corona." (Mother, GA 32 to 37 weeks)*

An antenatal visit to the neonatal ward helps parents to prepare for neonatal intensive care

An antenatal visit to the neonatal ward or an antenatal contact with a neonatologist or a paediatrician helps parents expecting a preterm delivery **to make neonatal intensive care more tangible**. The visit allows parents to visualise the environment in which their child will be cared for, the different degrees of medicalisation, and the related length of stay. The NICU visit also allows parents to build **realistic expectations** about a preterm compared to a full-term baby. Finally, the visit helps to reduce the parents' anxiety by **creating a trust relationship** with the neonatal staff. In the contact with the neonatal staff humanity was very much appreciated. The supporting effect of the antenatal visit is also observed in parents who had a previous experience with a preterm baby.

> *"Ze hebben dat, ja eigenlijk zelfs al voor de bevalling gevraagd. Want ja, met dat we dan wisten van dat de kans redelijk groot was dat ik te vroeg zou bevallen, zijn we tijdens de zwangerschap toen dat we opgenomen waren op week 26 al ne keer op de neonatologie geweest. En hebben ze ons een rondleiding gegeven. Dus dan wist je eigenlijk al wat dat we konden verwachten. Allez ja, je weet dat natuurlijk nooit helemaal, maar dan heb je toch al een beetje een beeld. Het is op zich wel heel fijn." (Mother, GA 28 to 31 weeks)*

> *« Quand j'étais au MIC, on nous avait proposé pour visiter la néonat. […] on a visité le service avec une des infirmières-chefs […] elle nous a présenté tous les types de chambres qui existaient. […] Ça c'était vraiment bien de pouvoir visiter le service avant. Même si moi mes yeux étaient embrumés de larmes, […] parce que ça rendait les choses beaucoup plus concrètes quoi. Euh on était un peu euh… Quand on était au MIC, donc on était dans notre petit euh cocon où les sage-femmes n'arrêtaient pas de dire que ça allait quand même bien se passer, etc. Et euh… On était vraiment dans notre petit cocon quoi. Et voir les lits, les couveuses, etc., je trouve que ça rendait les choses beaucoup plus concrètes et que on se rendait beaucoup plus compte que ça allait être notre réalité pour plusieurs mois quoi. On savait déjà que ça allait durer longtemps. » (Mother, GA 32 to 37 weeks)*

> *« **Papa :** Et qu'elle [le spécialiste en néonatologie] soit venue pour nous expliquer un peu comment ça allait se passer un peu car on était un peu dans le brouillard, voilà on s'est dit : « OK, il y a des gens qui vont prendre en charge la suite quoi. **Maman :** Ce qu'elle nous expliquait était très rationnel. Elle nous expliquait bien les étapes, comment ça allait se passer. Et en même temps il y avait beaucoup d'humanité je trouve, alors que le moment était critique et qu'elle avait sans doute mille choses à faire. Enfin moi j'ai vraiment un souvenir de m'être dit quand elle est sortie de la pièce : « OK je sais que je peux lui faire confiance quoi. » Je me rappelle que c'est un moment très humain bizarrement. » (Parents, GA less than 28 weeks)*

> *« Non, c'était terrible. […] Aucune envie de revivre ça, à la base. […] Ils m'avaient dit : « Allez voir, allez poser vos questions. » Et ça, c'est vrai que ça m'a quand même rassurée avant d'y retourner. Voilà. Mais le premier c'était pas du tout prévu. […] Je savais pas du tout le parcours qui nous attendait. Ici, j'avais des appréhensions parce que je connaissais le parcours qui allait nous attendre, mais je savais ce que c'était, donc c'était moins terrifiant à ce niveau-là. » (Mother, GA 32 to 37 weeks with a previous preterm baby)*

During the antenatal period, parents have a lot of questions about the pregnancy and the neonate's chances of survival

For the parents the antenatal period is a time of intense reflection about the chance to continue the pregnancy until the limit of viability, their baby's chances of survival, or their wishes related to therapeutic obstinacy after the baby's birth. Antenatal discussion with a neonatologist helps parents to cope with their concerns and to continue the pregnancy more serenely.

> *« Après la césarienne […] je me suis dit : « Oh, on dirait un bébé, ça va quoi. » Et c'est vraiment quelque chose qui m'a un peu soulagé. En fait je pense que je me projetais dans ses chances de survie parce que la néonatologue était passée une heure avant la césarienne pour répondre un peu à nos questions, et elle avait commencé par le préambule directement en nous disant : « voilà,*

la question que vous attendez immédiatement c'est les chances de survie », elle nous avait dit : « 80-20 ». Quatre-vingts chances de survie, 20 % de... Voilà que ça se passe mal. Et donc moi le voir comme ça je me suis dit : « OK donc euh bon j'en- je ne sais pas ce qui va se passer mais... Mais il ressemble à un bébé quoi. » (Father, GA less than 28 weeks)

"Ja, nee, dat heb ik niet verteld. In de twee dagen voor de geboorte hebben we ook twee gesprekken gehad, dus één op het verloskwartier met de neonatoloog en dan de dag erna, of twee dagen daarna nog eens om opnieuw die kansen en zo een keer te horen van ja, hoe dat de situatie ervoor stond. Want wij waren wel echt in twijfel van oké, gaan we hiermee door of ja, wat moeten we doen? We, we wisten het niet. En die twijfel was er eigenlijk tot aan de bevalling, waarop dat de artsen dan eigenlijk voor ons beslist hebben om het nodige te doen. Eh waar dat we nu wel heel blij mee zijn." (Mother, GA less than 28 weeks)

« Concrètement lorsque j'étais à l'unité des grossesses à haut risque, en ayant cette image des jumeaux du fils de mon beau-père et de ce par quoi ils sont passés, où là en fait, alors je me permets de le dire parce qu'à l'époque je l'ai vécu mais de loin, il y a eu un acharnement thérapeutique des équipes avec je pense quatre ou cinq réanimations, remise sous tube machin qui ont probablement grillé des petits neurones et induit certains handicaps, voilà. Donc après avoir vécu aussi tout le parcours de [nom d'un enfant décédé] voilà c'était en cancérologie, c'était encore autre chose, mon mari et moi on a tenu à rencontrer les médecins de néonat. […] En fait on l'a fait alors que j'étais toujours alitée, et avant la naissance des bébés en disant voilà notre parcours. On a choqué le médecin en question, après on est revenu discuter avec. Je voyais l'infirmière qui comprenait tout à fait, parce qu'ils étaient venus à plusieurs. Lui il était choqué, il est revenu discuter avec et cetera. On a dit clairement : « voilà, si à un moment donné vous êtes à un stade où il faut intervenir, on refuse l'acharnement thérapeutique ». Et pour nous c'est important de mettre quand même des balises, par rapport à un handicap très, très lourd pour l'enfant et le suivi derrière. Donc on l'a dit clairement. » (Mother of twins, GA 28 to 31 weeks)

5.3.3 Difficulties for mothers of a preterm baby during maternity stay

Key points

- **Interviewed mothers reported a strong feeling of guilt towards their baby because they gave birth too early.**
- **Some mothers of preterm babies felt treated as a patient, not as a mother at the maternity ward. These mothers also felt they got less attention from the maternity staff in comparison to the other mothers (e.g. longer waiting times).**
- **Mothers also felt hurt if the staff did not inquire about the child's condition.**

Interviewed mothers evaluated their maternity stay in function of how it facilitated or impeded their presence at the neonatal service. From the data a heterogenous image emerged with mothers making use of their maternity stay in different ways. For some mothers the maternity ward was mainly a place to sleep. If they were not sleeping, they spend their time next to their baby in the neonatal service. For others, often mothers who needed more care (e.g. after a caesarean section) their maternity stay was not only a way to facilitate being with their preterm newborn, but also to be cared for themselves. In the latter case, some mothers reported a lot of flexibility from the maternity staff (e.g. by coming to the neonatal service to take care of the mother, smooth communication between maternity and neonatal staff), others said they had to divide their time between the maternity ward and the neonatal service and experienced pressure from both sides. This was felt as highly uncomfortable and a barrier to their involvement in the care of their newborn. In what follows we give an overview of the difficulties mothers reported regarding their maternity stay.

Mothers felt guilty about giving birth too early

Many mothers reported a strong feeling of guilt towards their baby because they gave birth too early. This guilt feeling influenced the way they took care of their child. They wanted to be strongly involved. They wanted to prove being a good mother and were sensitive to things that threatened or ignored their identity as a mother (e.g. when the maternity staff did not inquire about their child's condition).

> *"En toen heb ik heel veel geweend van, dat is hier mijn schuld. Waarom heb ik niet stilgezeten? Waarom heb ik niet geluisterd? [...] En mijn vriend heeft me toen wel goed opgevangen, gezegd van ja 'dat is uw schuld niet." (Mother, GA 32 to 37 weeks)*

> *"Zoals dat ik daarstraks zei hè, dat wij IVF hebben gedaan, was dat voor mij psychologisch wel een belangrijke dat ik, ik wou echt borstvoeding geven om voor mijn eigen te kunnen bewijzen van zie eens, ik kan dat wel. Ik kon niet zwanger worden, ik kon niet zwanger blijven, dus ik wou echt nog wel borstvoeding kunnen geven, omdat ik mij ook schuldig voelde door het feit dat ik dan zo vroeg was bevallen." (Mother, GA less than 28 weeks)*

> *« Par contre, le sentiment qui m'est resté, c'est que je m'en voulais. Je me dis mais qu'est-ce que j'ai fait de mal ? Qu'est-ce que je n'ai pas bien fait pour qu'il soit là ? Donc en fait, c'était plus, je m'en voulais, je crois que je lui ai demandé plein de fois "je m'excuse", "pardon". » (Mother, GA 32 to 37 weeks)*

Mothers found it difficult to cope with the presence of other babies at the maternity ward

The presence of other babies at the maternity ward was difficult to cope with for mothers with a preterm baby. However, maternity staff was attentive to this feeling. Mothers of a preterm birth are commonly separated from the other mothers, to mitigate the confrontation.

> *« On avait mis en salle de réveil une maman qui était avec son bébé en train d'allaiter. Et euh… Je faisais que pleurer. Je faisais que pleurer. J'étais méga-jalouse et euh… J'avais la maman qui était à côté avec son bébé et moi mon bébé bah… Non, je n'ai même pas pu l'avoir sur moi euh rien du tout donc euh… C'est difficile. » (Mother, GA 28 to 31 weeks)*

Some mothers of a preterm baby felt they were treated as a patient, rather than a mother at the maternity ward

In maternity wards mothers with preterm babies differ from mothers with a term baby by the fact that they are separated from their newborn who stays at the neonatal ward. They felt being a mother and treated like a mother when being with their child at the neonatal ward, but not so at the maternity ward. The interviewed mothers gave us insights in the dynamics at the maternity ward that ignored their identity as a mother, as if the absence of a baby in their room made their transition to motherhood incomplete.

Mothers of a preterm baby can be kept separate from the mothers with a term baby. This might be done by simply giving them a room at the end of the corridor. Also, mothers of preterm babies were sometimes grouped in a common room.

> *« […] Voilà, ils font en sorte sans nous le dire … C'est un peu implicite, mais ils nous mettent tout au fond de la maternité où il n'y a pas vraiment d'autres bébés. [rires] Parce que ce n'est pas commun d'être dans une chambre de maternité sans bébé, quoi. […] on a passé très peu de temps du côté maternité en fait. Pour être honnête. On allait juste là pour récupérer les plateaux-repas et dormir un petit peu la nuit quoi. Mais sinon, la plupart du temps on était du côté de la néonat. » (Mother, GA 32 to 37 weeks)*

Interviewed mothers said that they were treated differently in comparison to the other mothers and that mothers of a term baby got priority of the staff. They felt they got **less attention of the staff** or had to **wait for a long time** when they asked for help. In addition, if **staff did not inquire about the child**'s condition or mothers did get the opportunity to talk about their child, they felt their identity as a mother was ignored. As a result, mothers felt treated like a patient rather than a mother.

> *"Ik persoonlijk vond ik dat die ondersteuning op materniteit beter kan, want als, de mama's die dat er lagen met een kind, die gingen altijd voor op mij. Er, er is, is één verpleegster geweest die dat*

gevraagd heeft van, hoe gaat het met uw kind? Terwijl, ook al was ik daar, ik was wel bevallen en ik had wel een kind. Dus ge kunt ook, ook al ligt dat kind niet naast mij, ge kunt daar wel naar vragen. Eh ik wil daar ook graag over vertellen. Dat had allemaal mee geholpen in het feit van, ik voel mij mama. Terwijl eh ik ben, ik, ik ben daar altijd behandeld als patiënt op de materniteit en nooit als mama, terwijl dat ik wel mama was." (Mother, GA less than 28 weeks)

Mothers who had a caesarean section were **dependent on the maternity staff** to help them move between the maternity ward and the neonatal service, as they could not walk. They reported long waiting times until the staff found the time to transport them to the neonatal ward.

"Ja. Die eerste dagen moest ik dan gebracht worden. Dan moest ik eh ik weet niet hoe lang wachten totdat ze eens een verpleegster gevraagd hadden om mij te brengen. Dan moest ik al bijna smeken van ja, wilt ge alstublieft iemand, iemand tien, hè want dat was zelfs geen tien minuten hè, want als ze dat lift pakken, mij in die kamer zetten, dat moest zelfs niet hè, want aan de deur pakte een verpleegster van de Neo dat over hè. Eh dus het was gewoon mij deur uit rollen van, van de materniteit, in de lift zetten en de lift uit rollen hè. Dat was het hè. En dan moest je echt een paar keren bellen van ja, mag ik alsjeblieft, wanneer zou er iemand tijd hebben om..." (Mother, GA less than 28 weeks)

IFCDC might not yet percolate into the maternity ward as mothers were not consistently supported in being with their child and take up care tasks in function of the rhythm of the baby and their own possibilities, both during their stay and after discharge from the maternity ward.

« Le matin mais ça a été assez difficile à organiser parce que je vais dire comme le papa n'était pas à côté de moi, il fallait trouver une infirmière qui soit libre, qui accepte de me descendre parce que je n'étais pas encore capable de marcher, enfin qui m'accepte de descendre en fauteuil à l'étage en dessous où était le centre néonat. […] Et à côté de ça, j'ai un peu ressenti, mais ça même surtout le séjour en maternité, d'être un peu, je ne vais pas dire négligée, je ne le dirais pas comme ça, mais de pas être une maman comme les autres. » (Mother, GA 32 to 37 weeks)

5.3.4 Difficulties for fathers of a preterm baby

Key points

- **Fathers of preterm babies reported that the system is not ready, nor equipped to host them, hence made it difficult for them to fulfil their role as a father.**
- **In addition, fathers' early return to work exposed them to a high degree of work-family imbalance during the hospitalisation of their child. The role conflict leads to exhaustion and prevents them from taking up their parental role.**

Fathers felt they were counteracted in fulfilling their role as a father

Our first observation is that mothers and fathers, even if they wanted to be on equal footing, are de facto pushed in a different position. In the striving to keep parents and child(ren) together, the focus is mostly on mother and child. Fathers remain on the second plan, as a kind of back-up if the mother is not capable of being present (e.g. immediately after a caesarean section). This bias towards the mother is both logical and understandable from a biological perspective: i.e. mothers are the ones that give birth and can breastfeed the child. They have a kind of reproductive advantage over fathers that stands in contrast with the current societal norm and ethical principle of equality between men and women. In the interviews fathers told us about how they wanted to fulfil their role as a father and how the system prevents them from doing so.

"En dat ik denk: waarom moet altijd een moeder, ook al is het corona, maar dat alleen dragen voor het kind? En dat vond ik heel fijn op neonato dat dat daar niet bestond. Dat dat moeder en vader dat zijn twee gelijke personen en jullie blijven bij jullie kind zoveel als ge wilt." (Mother, GA 28 to 31 weeks)

In the interviews fathers said that they were tolerated, but not supported to be present near their child. The infrastructure of the neonatal ward is often not equipped for two parents. For example, there is only one chair or one single bed foreseen. Fathers said they experienced **the system as not ready**, nor equipped to host them.

> *« Moi j'étais un peu l'électron libre, on n'est pas prévus, on n'est pas prévus dans le système, clairement, en tant que, que papa euh [soupir], oui on peut. On tolère ta présence. […] Voilà, on tolère ma présence. Maintenant pour dormir, ben c'est déjà pas mal qu'il y ait un fauteuil lit, ce n'est pas ça. Bon, si c'est une hospitalisation prolongée, clairement je n'aurais pas voulu continuer encore des semaines là-dedans, je ne dormais vraiment pas bien. […] Mais je comprends aussi. Je ne suis pas du tout le [plus important], ce n'est pas moi l'élément important en même temps. La maman et la fille ne manquaient de rien. […] sur un plan personnel […] je n'avais pas un sentiment d'exclusion ou de troisième roue, ou de, pas du tout. [soupir] mais l'infrastructure, le système n'est clairement pas prévu pour nourrir et loger le papa dans ces conditions-là, c'est sûr. » (Father, GA 32 to 37 weeks)*

> *« **Maman :** […] au début, on nous avait dit il n'y a que la maman qui peut rester tout le temps et le papa vient juste en accompagnant, et en fait ça nous avait fait vraiment beaucoup de mal parce que [papa] a mis complètement sa carrière professionnelle entre parenthèses pour qu'on soit sur un pied d'égalité à ce moment-là. Et en fait, tout ce qu'on avait vécu à deux tout le temps- on a eu la chance de pouvoir vivre tout ça à deux euh là pour la première fois on nous disait : « Bah voilà, le papa, il passe au second plan. » Alors qu'on essaye d'être un couple, […] on part du principe que voilà il y a une égalité. Et là pour la première fois bah on retournait dans un système où c'est la maman qui doit…*

> ***Papa :** Où on m'expliquait que moi je n'avais plus trop ma place et ça a été très très difficile pour moi. Et d'un autre côté [prénom de la maman] angoissait énormément de se dire : « Je vais me retrouver coincée dans une chambre… » […] Vingt-quatre heures sur 24 en voyant mon mari que deux heures par jour sans pouvoir sortir pendant, on ne sait combien de temps à l'époque. » (Parents, GA less than 28 weeks)*

> *« Ik voelde mij dom eigenlijk op die moment. Want dat is juist denk ik de ronde van Frankrijk of zo dat aan het afspelen was. Toen dacht ik, allez nu ben ik juist vader geworden maar ja ge zit daar helemaal alleen, dus ge kunt nog niks, ge weet nog niks. Ge weet ook niet wanneer dat ge haar moogt gaan bekijken. Hoe goed dat ze het doet, of hoe dat ze het niet doet. Ge weet niks van uw vrouw. En toen dacht ik, nu moet ik hier toch niet als een stommerik naar de koers beginnen kijken. Maar ik denk dat ik het na anderhalf uur wel heb gedaan, dat ik dan toch die tv heb opgezet." (Father, GA 28 to 31 weeks)*

In addition, **paternity leave** is much shorter than maternity leave.[cc] If fathers of preterm babies must return to work before the baby is discharged this situation exposes them to a high degree of work-family imbalance during the hospitalisation of their child, as they must combine work with managing the household, caring for siblings, and commuting between home and the neonatal ward. It leads to exhaustion and prevents them from being involved in the daily care for their preterm newborn, or stated differently, from taking up their parental role. At the same time, mothers felt alone in taking care of the newborn. Fathers also reported long term (mental) health consequences after an intensive period of trying to balance work and family life during the hospitalization of their preterm baby.

> *"Awel maar mijn voordeel is dat ik eh eigenlijk een doctoraat aan het doen ben en dat dat vrij flexibel is. En ik kon wel mijn tijd wel zelf heel goed indelen. Ik kon dat zelf bepalen. Eh maar ik heb dat wel een beetje onderschat. Ik dacht dat dat allemaal*

[cc] In Belgium paternity leave is 15 days since 01/01/2021. For more information on parental leaves, see section 2.6.

combineerbaar was, maar dan heb ik wel eh, vanaf wanneer was het? In december bijvoorbeeld, zelfs als [naam kind] al thuis was, heb ik toch efkes moeten stoppen met werken, omdat dat niet meer ging. Ik zat er mentaal een beetje door. Dus eh ik ben dan efkes op ziekteverlof geweest, omdat ik het eh eigenlijk te lang geprobeerd heb om, om het wel te doen en dat was me te veel van het goede." (Father, GA less than 28 weeks)

« Ce qui lui a le plus pesé, c'est de se dire qu'il avait juste ses 10 jours de paternité et puis bon voilà quoi. Une énorme fatigue euh… Autant mentale que physique. Parce que ben devoir gérer, d'aller au travail, de venir à la néonat, parfois de se dire : « Ben malheureusement, je suis tellement fatigué, aujourd'hui, je ne sais pas aller voir ma fille. » (Mother of twins, GA 32 to 37 weeks)

5.3.5 Informational, emotional and instrumental support help parents cope with the distress of having a preterm newborn

The current organisation of neonatal wards seemed to meet parents' need to be informed about the care for and the evolution of their newborns. It helps them to cope with distress. Communication was reported to be clear, transparent, friendly, progressive, supportive, and tailored to parents' needs. The communication between the neonatal staff and parents continued during the night or after the newborn's discharge. Neonatal staff also played an important role in the translation of information in lay language.

« J'ai eu l'impression en fait que on nous a tellement tout expliqué au fur et à mesure, que ça a déjà écarté beaucoup de peurs. Euh, donc il restait le stress, l'inquiétude, etc. On a eu énormément d'empathie à ce niveau-là, de la part de tout le service. Donc les gens demandaient comment ça allait, etc. Et on avait l'impression qu'à chaque petite avancée, c'était toute la néonat qui se réjouissait quoi. Il y avait un peu cet effet de pas se sentir seul, se sentir soutenu. Et on a eu énormément enfin d'explications de la part de l'infirmière, des médecins. » (Father, GA 32 to 37 weeks)

"Heel correct, heel, we mochten ook dag en nacht bellen. We deden dat dan ook. Eh als wij thuis waren en we wilden weten hoe dat ze gedronken hadden of hoe dat ze geslapen hadden, dan belden we ook. Dat was nooit geen probleem, nooit. Raar eh, ze hebben daar nooit raar gedaan." (Mother of twins, GA 32 to 37 weeks)

"Ik vond dat niet altijd even, en dan hielp het wel dat de verpleegsters er waren, dat die dat een beetje konden nuanceren of duidelijker konden toelichten." (Mother, GA 28 to 31 weeks)

A NICU is a highly technical environment. The noise of the alarms contributed to parents' distress. Parents wanted to understand the alarms and screens surrounding their newborn. Understanding the 'language' of the medical devices helped parents to cope with the stress caused by the alarms.

"In het begin, begin ook echt vreselijk hè. Dat gepiep. Zo die alarmkes. Zeker als het van uw eigen baby is natuurlijk, maar evenzeer bij de andere baby's vond ik het ook altijd eng. Maar eh dat, dat vond ik ook eh, dat is ook wel zoiets, ja, traumatisch is een heel groot woord, maar dat gaat wel altijd bijblijven." (Mother, GA 28 to 31 weeks)

*« **Papa :** Mais alors que moi j'ai été dans la technicité tout de suite. […] Et j'ai vraiment posé beaucoup de questions techniques en demandant : « Et cet appareil-là ? Et cet appareil-là ? Et cet appareil-là ? Et cet appareil-là ? Et machin ?» Et les infirmières répondaient, ouais avec plaisir. Ouais elles rigolaient d'ailleurs que je sois aussi et j'ai très vite compris… Je n'ai pas compris, mais je savais à quoi ça correspondait et puis au fur et à mesure on a vraiment appuyé le sujet au fur et à mesure parce qu'en plus on était une très bonne équipe je trouve, dans le sens où en fait … […] « Tu as compris ça ? » On débriefait. À chaque fois que quelqu'un nous disait un truc on débriefait après en disant ça et… **Maman :** Et si on n'avait pas la même version on redemandait des explications… » (Parents, GA less than 28 weeks)*

"Ja dat was, in het begin is dat heel impressionant hè, allemaal dingen dat je niet kent en al die alarmen en, maar ze hebben daar ook wel, wij hadden een heel goede verpleger de eerste dagen die enorm zijn tijd genomen heeft om alles uit te leggen. En eigenlijk

zelfs na weken was er nog altijd, allez het is niet dat je en rare blik krijgt als je iets vroeg. Dus op dat vlak, allez dat is ja, dat is wel indrukwekkend maar wel allez, ze deden zeker de moeite om alles uit te leggen en om dat toegankelijk te maken. Ja." (Mother, GA less than 28 weeks)

"En ja, ik weet niet dat dat bij elke ouder zo is, maar ik vond dat wel fijn om daar genoeg uitleg over te krijgen over wat dat dan allemaal betekende. Dat stelde mij ergens gerust dat ik dat mee kon volgen." (Mother of twins, GA 28 to 31 weeks)

Note that apart from informational support, parents also mentioned the need for other types of support, such as emotional, and instrumental (i.e. administrative and financial) support.

Emotional support was needed throughout the baby's stay at neonatal ward, e.g. at admission, during breastfeeding, in case of bad news, and at discharge. Emotional support was provided by the neonatal staff, as well as psychologists, family, friends and other parents. Psychologists however were often not part of the neonatal ward and therefore less available than nurses. In addition, they work during office hours only, which means they were not always available when needed. Family and friends were important providers of emotional and practical support (e.g. preparation of meals, picking up older children from school). Other parents of preterm babies were also an important source of social support and understanding as they went through the same experience. Parents exchanged information and encouraged each other during hospitalisation. Some developed close friendships and stayed in contact even after hospitalisation.

"Ja. Wij zijn daar wel, allee ik toch, super positief over de manier waarop dat wij daar opgevangen zijn. Eh als wij info vroegen dan kregen we het. Eh als je een schouderklop nodig had dan voelden ze het al en gaven ze [verpleegsters en arts] het al voordat ge er zo eh achter vroeg, dus dat is wel iets die super belangrijk geweest is het traject." (Mother, GA less than 28 weeks)

"Goh, we hebben heel vaak met de psychologen moeten babbelen van het ziekenhuis omdat het, ja, heel onwerkelijk was. We hadden nooit verwacht dat dat ging gebeuren dat wij, allee, een prematuurtje gingen krijgen aangezien ons dochter veel te laat kwam. … En ja, allee, het was wel heel, heel, heel zwaar. Maar we werden ook wel heel goed ondersteund, dat wel. Door iedereen, niet alleen de psychologen eigenlijk. Iedereen." (Mother, GA less than 28 weeks)

"Ik denk dat wij wel heel veel steun ervaren hebben van onze dichte omgeving. En ik ben daar eigenlijk wel in positieve zin dan echt van verschoten hoe goed dat sommige mensen wel zich konden inleven. Eh en sommige zeiden echt wel de juiste dingen vond ik." (Mother, GA less than 28 weeks)

"En we hebben daar ook een andere tweeling leren kennen waar dat we ondertussen ook nog altijd contact mee hebben. Eh dus het is toch mooi omdat je het kan delen. Je kan die ervaring van Neonatologie kan je niet delen met familie, als ze dat niet meemaken. De, het verdriet of het plezier, de vreugde eh dat je meemaakt op Neonatologie kan je enkel maar delen met de mensen die het ook meemaken. Want enkel zij begrijpen dat. Eh je kan je dat, ik kan dat niet uitleggen hoe dat dat is aan iemand, om je kind daar weer te moeten achterlaten. Maar wel aan de mensen die het ook meemaken." (Mother of twins, GA 32 to 37 weeks)

« Le fait de, le fait d'avoir une salle commune, ça avait des avantages aussi parce que du coup ça permettait de créer des liens avec les autres mamans. Et donc on pouvait parler entre mamans de comment allaient les bébés et de s'encourager les unes les autres, et ça franchement c'était, c'était précieux. »
(Mother of twins, GA 32 to 37 weeks)

Instrumental support consisted of administrative, financial assistance and childcare. Interviewees reported that the baby's stay at a neonatal ward brings an **administrative burden** (e.g. application for paternity leave, advancement of medical expenses). More importantly, parents said they were not in a state capable of taking the necessary steps. The emotional distress of a preterm birth should not be underestimated. Especially parents who did not anticipate a preterm birth, would benefit administrative support.

« Quand j'étais en néonat on a une dame de l'ONE, une assistante sociale de l'ONE qui passait. […] Elle nous expliquait notamment toutes les démarches qu'on pouvait faire pour avoir l'allocation familiale majorée, la reconnaissance de handicap euh tout ça. Et donc après, elle nous avait dit qu'on pouvait voir ça avec l'assistante sociale de la mutuelle. Et donc ici l'assistante sociale de la mutuelle s'occupe de mon dossier. » (Mother, GA 28 to 31 weeks)

« Au début c'est un petit peu dans le vape, enfin on ne sait pas comment remplir les documents, par rapport aux factures, par rapport les congés maternité. Je suis allée à la mutuelle, j'avais pris un rendez-vous et là ils m'ont tout expliqué un petit peu mais bon après il fallait se débrouiller toute seule. Et donc à ce moment-là, ben on se débrouille et on fait une fois, deux fois et puis on… On commence à comprendre comment ça fonctionne. […] Au début c'est compliqué- enfin pas compliqué, … C'est ne pas savoir mais après avec le temps on le fait, on trouve des petits moments. […] Il faut savoir un petit peu quel document il faut prendre, où il faut s'adresser et tout ça. Mais, voilà ce n'est pas compliqué, mais il faut le faire c'est tout, il faut prendre un peu le temps. […] Grâce à la petite famille qui m'entoure c'est faisable. » (Mother, GA less than 28 weeks)

*« **Papa :** Même le congé paternité et cetera, c'est nous qui l'avons cherché. Quand on l'a cherché ben il était trop tard, on avait dépassé le délai de quatre jours. **Maman :** On n'a pas eu d'infos euh. […] On n'est pas bien dans le cadre dans ce genre de situation. **Papa :** Je pense qu'ils n'ont pas, même pas les infos eux-mêmes. **Maman :** Pour moi il faudrait quelqu'un qui intervienne et qui prenne les choses en main peut-être en disant "voilà, donnez-moi les papiers, je vais faire les démarches pour vous". Parce que clairement on n'est pas les premières semaines, les premiers jours, on n'est pas capable de faire les démarches. Je les ai faites à la limite même pour l'assurance et de toute façon je les ai faites trop tard. Du coup, on s'est retrouvés dans des soucis par rapport à ça : on doit avancer l'argent, l'assurance nous rembourse après et cetera, alors que le système aurait pu être inverse, parce que on n'est pas en état de faire les démarches. Oui, on aurait besoin de quelqu'un qui dise "allez, donnez-moi, c'est quoi votre mutuelle, je vais appeler, je vais faire moi, je vais", ça nous soulagerait. **Papa :** Surtout qu'on n'est pas préparés, dans notre cas à nous on n'était pas préparés à se retrouver face à cette situation-là. » (Parents, GA less than 28 weeks)*

Interviewees also mentioned the **financial burden** that is caused by a preterm birth. Additional costs were e.g. medical costs, costs of an ambulance, travel costs, reduced income due to fewer working hours, parking costs etc. Parents noted that some hospitals try to reduce costs such as the cost of rooming-in or parking. Parents welcomed this kind of financial support.

« Ben déjà pendant toute la durée du séjour en néonat, donc pendant quatre mois et demi on était à plus ou moins 2 000 kilomètres par semaine, en voiture donc ce qui fait un fameux budget carburant à la fin du mois. Et il n'y a pas d'aide pour ça donc c'est ou tu trouves une solution pour financer, ou tu ne vas pas voir ton bébé, en gros c'est ça. Sachant que ben maman se retrouve sur la mutuelle en congé maternité donc on perd un pourcentage de son salaire, et que ben dans notre cas papa est indépendant mais papa doit réduire ses horaires aussi parce qu'il doit s'occuper des autres enfants et cetera. Donc il y a aussi une perte financière, ça, c'est compliqué, oui. Et il n'y a pas d'aide qui est faite pour ça. » (Mother, GA less than 28 weeks)

« Maintenant c'est vrai que bon voilà, on est des gens prévoyants aussi. Donc on a aussi une assurance hospitalisation qui a pris tout en charge. Et c'est vrai que là, quand on reçoit la facture et qu'on regarde le montant complet, on se dit "heureusement qu'on en a une". [rires] Mais oui, c'est vrai qu'au niveau peut-être carburant et cetera, c'était bon peut-être une charge un peu plus lourde à ce moment-là. Mais à côté de ça, ben il y avait peut-être d'autres choses qu'on ne faisait pas donc voilà, un dans l'autre ça équilibrait. Au niveau du parking de l'hôpital, ben on avait droit à un pass spécial qui nous donnait accès illimité au parking pour 3 € par jour. Donc c'était un fameux gain. L'hôpital met aussi en

place des, des choses pour aider les parents. » (Mother, GA 32 to 37 weeks)

"Nu hebben wij natuurlijk wel nog afspraken in het [ziekenhuis] en daar wordt ook wel een deel van terugbetaald, maar ja je, ja, je zit wel met een hogere kost omwille van het feit dat hij meer op consultatie moet hè." (Mother, GA less than 28 weeks)

"Eh financieel hebben we het effe moeilijk gehad. Omdat we dan alle twee thuis waren. Awel, dat zou misschien een mooie steun zijn voor, van, van de staat voor mensen die zoiets meemaken. Gelijk zij, ja, zij moest blijven platliggen. Zij kon helemaal niks. Ja, en we hadden hier nog een kindje rondlopen en, en, ja, die eerste maanden met heel die problemen was ik blijven werken maar ik ging er gewoon onderdoor. Toen heb ik dan die loopbaanonderbreking genomen maar…[lacht] 700 euro, ja, daar heb ik mijn lening mee afbetaald. And that's it. [lacht] Dat is… Dan houdt het op." (Father, GA less than 28 weeks)

5.3.6 Partnership between parents and neonatal staff is built on their availability and support

Key points

- **Parents were impressed by the availability of the neonatal staff.**
- **Their availability allowed the development of a relationship based on trust, which in its turn facilitated partnership in care.**
- **Variation in how nurses carried out care tasks gave rise to parents feeling unsure about how to carry out care.**

Parents called the availability and support of the neonatal staff impressive. Neonatal staff was available to answer questions day and night and even after discharge. Parents said it allowed the development of a relationship built on trust, which was self-reinforcing as it facilitated parents to ask questions without fear of being judged. Neonatal staff and parents became partners in care and gradually parents' autonomy grew. Parents made a difference between members of the neonatal staff based on familiarity. Not with all members of the staff an equal strong relationship could be built.

« […] Enfin c'est peut-être la frustration de poser la question bête à un pédiatre. Parce que on se dit : « Bah ils n'ont pas que ça à faire. » Ou voilà. Tandis que les infirmières, elles sont tout le temps dans les parages. On les voit tout le temps, tout le temps, tout le temps donc si on posait des questions aux infirmières même les questions un peu, on va dire, bêtes, ce qu'on pense ce n'est pas grave. […] il y avait certaines infirmières, bah je n'avais pas envie de leur poser des questions. Ce n'était pas intéressant, il y avait des infirmières où je voulais absolument avoir leur avis parce qu'il y avait un lien de confiance. Donc ça c'est encore une fois un lien de confiance qui se crée en… En vivant là-bas. Euh donc on crée un lien, il n'y a rien à faire on crée un lien. » (Mother, GA less than 28 weeks)

« Ça c'est directement dès le premier jour, on nous a dit : « Vous allez participer à chaque soin lorsque que vous venez. » On a pu prendre la température, on a pu changer ses langes euh… Qu'est-ce qu'on faisait d'autre ? Ben à partir de plus ou moins un mois, on a fait son premier bain. Toujours avec beaucoup d'aide et beaucoup de câbles parce que [prénom du bébé] elle a gardé très longtemps l'oxygène donc elle ne pouvait pas rester trop longtemps sans oxygène. À chaque fois dans tous les cas, si on était là, et ou alors quand on partait, si je partais on va dire vers 16h, ben je disais qu'à 19h on revenait avec papa. Si on avait un peu de retard, ils nous attendaient parce qu'ils savaient qu'on allait venir. Après, y avait toujours des petits couacs des fois avec certaines infirmières qui n'avaient pas l'habitude par exemple, de travailler avec nous ou- ce n'était pas les infirmières habituelles on va dire. Parce que c'est important d'avoir les infirmières habituelles pour chaque enfant. Ça c'est vraiment très, très important. Et des fois, certaines qui n'ont pas voulu attendre. Ou qui ne savaient pas qu'on allait venir. » (Mother, GA less than 28 weeks)

In addition to variation in familiarity, interviewees also noticed variation in how nurses carried out care tasks, giving rise to doubts and uncertainty among parents. Also, variation in attentiveness between NICU and N* staff was mentioned (e.g. the intensity of observations).

> *"Wat dat soms wel niet altijd even evident was, was dat, ja daar loopt heel veel, daar lopen heel veel verschillende mensen rond die dat ook verschillende manieren hebben om dingen te doen. Dus dan, ja legt persoon A u iets uit, en dan ja doet persoon B het anders. En ik vond dat wel lastig, dat zo, ja ik wou dat dan allemaal heel goed doen. En te goed doen, en dan ineens is dat, ja maar, wacht. De ene heeft dat zo gedaan, en de andere zo, en dan ja dan wist ik het zo niet meer. En dat heeft zo soms wel wat voor wat lastige momenten gezorgd. Terwijl als je daar op een afstand naar kijkt, dan denk je oké goed, hè de grote lijnen zijn wel hetzelfde, en dat zijn gewoon wat verschillen in accentjes. Maar op die moment, ja kon ik dat niet zo helder zien, en heeft dat zo soms wel tot wat onzekerheid geleid." (Mother of twins, GA 28 to 31 weeks)*

> *"**Papa:** Ook minder oplettend op hoe hij ligt. Op NICU waren ze echt aan het kijken van: ah, hij heeft nu zoveel uur op die kant van het hoofdje gelegen. Nu gaan we hem op die kant leggen. En daar werd er zo minder naar gekeken eigenlijk, ja. **Mama:** Ja, en ook toen, toen zijn plakker helemaal zo tegen zijn neus… Hij kon precies niet, niet ademen. En ik, ik zei dat dan en dan zeiden ze: "Ja, maar zijn saturatie is goed dus dat is geen probleem." Terwijl, allee, toen we in de NICU lagen als we iets zeiden dan hielden ze daar altijd rekening mee en dan keken ze of… Ja, ik moest eigenlijk nooit iets zeggen want daar keken ze altijd heel goed naar hem. […] Ja, inderdaad. Ze letten daar minder op dan in de NICU. En dan moest ik echt zelf afkomen met: "Kijk, ik vind dat hij daardoor niet…". En toen, ja, toen… Als ge, als ge u boos maakt, ja, dan luisteren ze wel natuurlijk maar anders niet hè." (Parents, GA less than 28 weeks)*

5.3.7 Active involvement is much appreciated but not yet perfect

Key points

- **Parents felt stimulated to be involved in the care of their preterm baby by the continued encouragement of the neonatal staff. It helped them to overcome feelings of discomfort or fear.**
- **Parents felt either reassured or frustrated by the supervision and feedback of the neonatal staff.**
- **Preparation of the baby's discharge increases parents' autonomy.**
- **The barriers that parents withheld from being involved were 1) the variability in the supportive and encouraging attitude of the neonatal staff, 2) physical limitations, 3) the fear of doing something wrong and 4) hospital routines.**

One of the key elements in IFCDC is that professionals and parents function as partners in care. Parents are instructed early on how to take up this active role.

Appreciation and frustration about the continuous support of the neonatal staff

The continuous invitation of neonatal staff to assist them, makes parents feel useful and facilitates the development of their parenting role. Parents, especially at the start, may feel uncomfortable, redundant, or not in place. Interviewed parents talked about the neonatal staff continued encouraging them to be involved in care and in decisions, hence helping them to overcome feelings of discomfort or fear. Parents reported being invited by the neonatologist to assist to a meeting of the medical staff to be informed and to ask their questions. Calling parents not by their name but rather "mother/father of baby X" was a remarkable example of how parents experienced the staff's discourse as very stimulating.

« Je me rappelle c'était un peu compliqué pour moi de vraiment me rendre compte que je faisais partie du monde des parents quoi. On en avait parlé avec la psy elle nous avait dit : « C'est normal, vous êtes parents à mi-temps. » On rentrait chez nous et… On vivait la même vie qu'avant que je sois enceinte quoi. […] je ne me sens pas maman. Et donc dès que j'arrivais à la néonat, dès que je pouvais faire le moindre truc pour me sentir maman de [prénom du bébé] donc au début ça a commençait par ses couches quoi, on le changeait et pouvoir changer sa couche ça a été : « Han ouais, je change sa couche donc je suis la maman, c'est mon bébé et je lui change sa couche. » (Mother, GA less than 28 weeks)

« Il y a eu une évolution extrêmement rapide entre le premier moment où on l'a et on nous montre. Où on a accès à la petite dans sa chambre et on ne sait pas très bien. À un moment je me suis surpris à demander à l'infirmière "je peux la prendre ?" et l'infirmière m'a dit "mais écoutez c'est votre fille". Entre ça et quelques jours après où on était tout à fait à l'aise pour la manipuler, euh oui l'évolution est rapide et elle est assez grande. » (Father, GA 32 to 37 weeks)

« Je me souviens d'une infirmière qui nous a dit un jour : « Il ne faut pas oublier que c'est nous les intrus, et c'est vous la famille, les parents quoi. » Et moi ça m'avait vraiment aidé à me sentir à ma place. Parce qu'il y a quand même des moments où il y a trois infirmiers dans la chambre pour faire des soins et que, nous on est là et qu'on ne sait rien faire, on ne se sent pas au bon endroit quoi. Même quand on lui fait une prise de sang et qu'il y a… Cinq mains déjà, cinq ou six mains, déjà sur elle et qu'on arrive et qu'on ne sait pas- y a même plus de place pour nous pour l'accompagner. Et du coup c'est vrai que là parfois, c'est difficile. Mais il n'y a pas une fois où un infirmier n'a pas dit : « Ben venez ici, maman, mettez-vous là, etc. », ouais. Et les infirmiers nous ont toujours appelé aussi, ils ne nous ont jamais appelé par nos prénoms. Euh ça a toujours été : « Ah, maman, papa… Papa de [personne], venez un peu ici ! », etc. Et ça, ça nous a vraiment aidé à nous sentir parent aussi je trouve. » (Mother, GA 32 to 37 weeks)

« Mais ce sont les pédiatres qui nous ont proposé les deux fois de dire : « Ben voilà, est-ce que ça vous intéresserait de participer à la réunion ? Comme ça on parlera de [prénom du bébé] et vous verrez comment ça se passe et puis vous pourrez donner votre avis, parce que ça intéresse les pédiatres de l'avoir. » Et donc c'était aussi très instructif parce qu'on voit mieux que les décisions sont prises collégialement et que les avis sont challengés quoi. […] On vous informe de comment ça se passe et de ce qu'on prévoit, est-ce que vous êtes d'accord ? Et on pouvait venir avec nos questions. » (Father, GA 32 to 37 weeks)

Parents were stimulated to observe their child and were invited to report their observations in order to adapt the baby's treatment (e.g. feeding amount, medication dose) if needed.

« Et c'est ce qu'on se disait pendant toute l'hospitalisation de [prénom du bébé] ça nous a vachement aidé de se sentir impliqués … On avait l'impression d'être utiles. […] on suivait bien les recommandations de NIDCAP, on participait aux soins […] et les infirmières disaient : « C'est vous qui connaissez le mieux votre enfant, si vous avez des recommandations vous nous le dites et tout. » Et c'est vrai qu'on discutait de [[prénom du bébé] et- et on avait l'impression de faire partie de l'équipe médicale et ça vraiment ça a été très très fort quoi. » (Father, GA less than 28 weeks)

Parents felt reassured by the **presence, supervision, feedback and supportive attitude of the neonatal staff**. However, there was a **downside** too. Some parents did not feel comfortable being watched all the time. For some being supervised was not reassuring, but instead withheld them from carrying out care tasks. For others having the neonatal staff around all the time was frustrating, especially near the moment of discharge, when they felt sufficiently self-assured or skilled in managing care autonomously.

"Dan kwamen ze wel altijd na, na een halfuurtje kijken en dan zeiden ze van: "Gaan jullie beginnen aan de verzorging? Ah ja, maar nee, het is al goed gedaan." Ze kwamen wel altijd kijken of het, of het lukte of, of als ze ons bezig zagen en ze hadden tijd kwamen ze dan al eens binnen." (Mother, GA 28 to 31 weeks)

"En dan mocht ik hem loskoppelen, mocht ik al die kabeltjes uittrekken dat die monitor af lag. En mocht ik hem beginnen ontkleden en doen. Allez ze staan er wel bij te kijken, want. Het is raar, alle zo uw eigen kindje, en ge wordt zo goed in de gaten gehouden eigenlijk, ja." (Mother, GA 32 to 37 weeks)

« C'est le plus le papa du coup qui était très peu sûr de lui dans ses gestes et le fait d'avoir une infirmière qui regarde, qui est là pour superviser, c'est tout simplement, ça l'a intimidé énormément et donc il préférait ne rien faire. Il n'a quasi jamais changé le petit pendant les trois semaines. Mais il m'a dit : "C'est parce qu'on me regarde… » (Mother, GA 32 to 37 weeks)

« C'est terriblement frustrant. C'est tellement frustrant parce qu'au départ on ne peut pas faire grand-chose. Et, après les infirmières, elles sont top parce que la moindre petite chose qu'on peut faire en tant que parent, elles nous laissent faire. […] puis après plus on arrive à la fin du séjour, ben plus on a face à soi un, un bébé qui se rapproche d'un bébé à terme et donc on voudrait pouvoir gérer soi les, pas, pas nous dire quand il faut la changer, quand il faut prendre la température et cetera. Alors que ben, là y a, voilà, tant qu'on est en néonat ben y a toujours des infirmières qui sont derrière. Donc ça c'est sûr que c'est terriblement frustrant, surtout quand, peut-être quand c'est le premier on est un petit peu moins frustré de pouvoir prendre ces initiatives parce qu'on est un peu hésitants. Mais nous, ben c'était déjà la troisième, donc euh après, une fois qu'elle avait moins d'appareillage, ben j'étais tout de suite relativement plus à l'aise pour la prendre, pour la manipuler. Donc c'était quand même frustrant de toujours devoir dépendre du personnel médical. » (Mother, GA less than 28 weeks)

Preparation of the baby's discharge increases parents' autonomy

During the hospital stay, parents were surrounded by a highly accessible medical team, which could always be solicited in case of problems or questions. However, at home, parents were on their own. Preparation of the baby's discharge by rooming-in for one or a couple of nights enabled parents to care for their baby autonomously.

Parents also mentioned follow-up at home, or help to organise follow-up at home, courses in resuscitation or the use of equipment needed to monitor the baby at home. Parents stated these efforts made a big difference. They felt more at ease to go home and care themselves for their child. Also, the staff of the neonatal service emphasised being reachable by phone at any time, hence they functioned as a kind of hotline for whenever parents had any doubt or question once at home.

"En wat doet het ziekenhuis, wat bieden ze aan? Dat is een rooming-in en dat is eigenlijk de dag voordat je naar huis mag, dan zij je welkom vanaf 4 uur in de namiddag. Eh en dan blijf je eigenlijk voor de eerste keer samen met je baby op de kamer. Dus dan krijg je een kamer. Eh ze laten jou gerust, dus ze, ze komen eigenlijk niet meer helpen. Eh maar ze zijn er wel, moest er iets zijn. Eh en dat is ja, eigenlijk echt die eerste nacht een keer kennismaken voordat je naar huis gaat. En dat geeft je toch een zeker gevoel. Ik denk dat wij eh veel onzekerder zouden geweest zijn, moesten we dat niet gehad hebben." (Mother of twins, GA 32 to 37 weeks)

« D'ailleurs, quand on sort de néonat ben, c'est toujours stressant parce qu'on est entourés avec plusieurs personnes etc., et on se pose des questions : comment est-ce que ça va être ? […] Chaque jour, chaque semaine on doit demander si on peut prendre notre enfant, si on peut le changer, si on peut faire ci, si on peut faire là. À chaque fois c'est une autorisation avec un accord. Tandis que là-quand on se dit ben on va rentrer à la maison ça va être complètement différent, ça va être à nous de gérer nous-mêmes, […] c'est vraiment impressionnant alors ce qu'ils disent au début : « Voilà si vous allez voir, vous allez vous en sortir […] mais si vous avez la moindre question, vous pouvez toujours appeler. Vous pouvez toujours appeler en néonat vous connaissez le numéro. Si vous avez des questions, si maintenant voilà, vous voyez un jour que [personne] ne va pas très bien vous pouvez toujours appeler. » D'ailleurs, je n'ai pas appelé tout de suite […] je ne voulais pas… Abuser […] j'ai appelé une fois ou deux. […] j'ai appelé d'autres fois quand elle n'allait pas bien ou si je devais prendre le rendez-vous. Mais voilà, à chaque fois, ils étaient super disponibles. » (Mother, GA less than 28 weeks)

"Dat was dan ook voor ons het moeilijkste, hè want eh, wij zijn dan naar huis gegaan met nog, nog, nog extra zorgen hè. Wij zijn niet naar huis gegaan met een à terme baby die op dat moment gezond was hè. Wij zijn én met een monitor én een slaapmonitor en met maagsonde naar huis gegaan. Eh hadden, had ge ons dat een jaar geleden gezegd, dan hadden wij u vierkant uitgelachen, want wie zijn wij om een maagsonde te steken. Of, of, of om met een monitor naar huis te gaan. Maar op den duur zijt ge, zijt ge het zo beu in het ziekenhuis dat ge zegt van oké, geef die monitor maar mee hè. En geef die maag-, die, die, die sonde, kom, ik pak dat wel mee. Allee, het enigste wat dat we, allee, we hadden bijna gezegd van oké, geef die, geef die eh zuurstoffles ook maar mee hè. We, we pakken ze wel mee naar huis hè. We hebben op bepaald moment gezegd eh, we pakken ze liever nu mee op twee kilo met alle ondersteuning dan dat we naar het [ziekenhuis 3] gaan." (Mother, GA less than 28 weeks)

What withheld parents from being actively involved?

Nevertheless, parents reported **barriers** in feeling involved or taking up care tasks. First, parents reported **variability in the supportive and encouraging attitude of the neonatal staff**. In other words, not all neonatal staff was supportive to the same degree. Some parents got the impression that some members of the neonatal staff preferred doing care tasks themselves due to time constraints.

« Oui, à la fin. Elles encourageaient à l'autonomie, mais euh il y avait tous les câbles […] Les fils d'oxygène et cetera, ce n'est quand même pas si simple à… À manipuler et euh… C'est quand même bien d'être deux. […] Moi je dirais qu'il y avait une différence avec les infirmières par rapport à ça. Certaines on encourageait plus, d'autres on voyait bien que c'était… Euh que ça les dérangeait peut-être un tout petit peu. Est-ce que c'est par le surplus de travail parce que c'était quand même chaque fois un quart d'heure pour la mise en œuvre, et puis le retrait. » (Father, GA 28 to 31 weeks)

Second, mothers who were not recovered from the delivery or suffered from complications were terribly frustrated for not being able to take care of their baby and had difficulties to accept their **physical limitations**. At the same time, this situation gave fathers the opportunity to parent for two, this way compensating for the constraints of the mother.

"Het moeilijkste vond ik dat ik lichamelijk beperkt was. Dus ik was aan het herstellen van mijn, van mijn operatie en dat woog voor mij heel zwaar door. Bijvoorbeeld, hè, ik, ik wou eentje in bad steken en uiteindelijk moest ik zeggen tegen eh tegen de verpleging op Neo van kijk, je gaat moeten overpakken, want ik kan niet meer. Ik heb zeer aan mijn rug of ik heb zeer aan mijn wond of... Ik lag ook al plat van december, dus ik, qua conditie, spieren, schiet er eigenlijk niet veel niet meer van over. Nog altijd niet. Eh...Maar dat vond ik echt heel moeilijk. Eh dat je op bepaald moment echt moet luisteren naar je lichaam en beseffen van, het gaat niet. Ik moet terug naar mijn kamer, ik moet gaan rusten of ik moet terug kunnen zitten. Dat is, dat doet pijn. Zeker omdat dat gaat over uw kinderen hè. Je wilt ze in bad steken, je wilt erbij blijven, je wilt ze liefde geven en d'r flesje geven. Eh telkens dat je daar vertrekt en die deur valt toe achter je is dat weer een leegte dat je voelt." (Mother of twins, GA 32 to 37 weeks)

"Ik vanuit een ziekenhuisbed kon niet veel doen. Maar al heel snel, ik kan nu ook niet meer zeggen wanneer, maar eigenlijk al heel snel mochten wij een flesje geven in de couveuse dan. Eh ja of vroegen ze van hè, papa, wil jij de pamper verversen? Eh eigenlijk al heel snel. Want ik was, ja ze zijn zo klein dat je bang bent van ze aan te raken eigenlijk, omdat ja, maar ja dat went ook wel hè, maar in het begin was, was ik bang. [naam partner] was daar veel sneller mee weg." (Mother of twins, GA 32 to 37 weeks)

Third, some parents felt held back by **fear of doing something wrong** or hurting their baby who seemed so small and fragile. Neonatal staff then played an important role in overcoming these feelings and encouraging parents.

"En dat was oei ja, ik moet dat onder dat armke steken en heel bang voor iets verkeerd te doen. Maar dat ze ons daar heel snel al in betrokken hebben en ze vonden dat zelf ook wel heel belangrijk." (Mother, GA less than 28 weeks)

Fourth, **hospital routines** or the way care was organised had potentially a discouraging impact on parents (e.g. when imaging occurred before the appointed time in absence of the parents). In addition, not in every hospital IFCDC is developed to the same extent. In case of a transfer, parents have to get used to a different approach towards parental involvement.

"Zo, dan, we hadden dan al het badje eens gedaan in [ziekenhuis], natuurlijk. Maar dan moesten we dat ook nog eens doen in [ziekenhuis], maar dat staat allemaal anders en zo. Dus gij, allez, eigenlijk hebben die dat zelf gedaan, toen dat gij daarbij waart hè, ge zei dat hè, die namen alles uit uw handen." (Mother, GA 32 to 37 weeks)

*"**Mama:** Dan heeft [voornaam] ook eens echo moeten nemen van zijn hoofd. Dat zeiden ze dan van morgen moeten we een echo nemen van zijn hoofd. En ik vroeg, ah mag ik daar bij zijn? Ja ja ja, tuurlijk. Om twee uur zal dat, rond twee uur zal dat zijn. Ik was daar om twee uur, ik zag [voornaam] en ik zag al dat hij zo die gel dat dan op zijn hoofd hing, dus ik vroeg, van wat is die gel? Ah ja, de echo is al gebeurd. Dan denk ik oké ja goed. Dat is niet, dat was, allez ja. Waarom?*

***Papa:** Dat was gewoon niet fijn omdat ge de dag daarvoor bij wijze van spreken had afgestemd met iemand.*

***Mama:** Ja. Dat, ik dacht dat dat afgesproken was, maar dat was niet." (Parents, GA 32 to 37 weeks)*

5.3.8 Parents suffered the most from being separated from their child

Key points

- **Parents experienced the separation from their child as extremely difficult and heart-breaking, especially when the mother was discharged and had to return home without the newborn.**
- **For mothers of a preterm baby fathers were a way to keep control if they themselves were not physically able of exerting that control.**
- **The separation from their newborn made them feel a 'part-time mother' and a 'mother on call'.**
- **Mothers strongly appreciated the flexibility of the maternity staff who came over to the neonatal service to care for them (e.g. administer medication).**
- **Technological means suchs as apps, tablets, camera's could ease the pain of the separation, but could not replace being with the child.**
- **Determinants of how parents of a preterm baby experienced the access to their child were 1) physical infrastructure, 2) distance and travel time, 3) the availability of individual rooms, couplet care and a hotel function in the hospital, 4) being physically able or dependent on others, 5) the flexibility of maternity staff, 6) COVID-19 restrictions and 7) siblings.**

Non-separation of parents and children is one of the key principles of IFCDC. Although parents and child(ren) are kept together as much as possible, still every separation is one too much. Parents experienced the separation from their child as extremely difficult and heart-breaking, especially when the mother was discharged and had to return home without the newborn.

"Ja, ze hebben dat op voorhand gezegd van, het is zes nachten standaard, dus ik wist wel, dat was direct uitgerekend, dan wist je van ja vrijdag moet je naar huis en je kindje niet. En dat was voor mij, ik denk de eerste keer dat ik echt geweend heb die dag, dat ik enorm enorm ja, dat was zo, ik lag wel in een kamer op de MIC en dat was niet bij [naam baby] maar dat was wel in hetzelfde gebouw. Mijne man ging wel thuis gaan slapen, maar ik had zoiets van ja als er 's nachts iets is en ik moet of ik wil bij hem, awel ik bel een verpleegster, ze rollen mij met mijn bed tot in de neonatologie en ik kan zo lang bij hem blijven als ik maar wil. Maar ne keer dat je thuis zijt, ben je thuis, en ben je zo, ja dat was op dat vlak was dat 45 kilometer van elkaar gescheiden. En dat was mentaal wel heel heftig voor mij, dus ja, ge kunt moeilijk ja drie maanden opgenomen worden in het ziekenhuis natuurlijk, dat gaat ook niet. Dus, allez, dat zou wel gegaan zijn moest dat de mogelijkheid geweest zijn, ik ging dat wel gedaan hebben, maar allez ja, dat bestaat natuurlijk niet." (Mother, GA less than 28 weeks)

« Quand on m'a dit euh "vous retournez là comme ça aujourd'hui" euh et que ça m'a euh, là je me suis vraiment effondrée ce jour-là euh, ça a été très très dur. Surtout que bon, moi on m'avait parlé du lundi et puis j'ai l'infirmière qui arrive le dimanche matin avec son grand sourire, je ne lui en veux pas, elle arrive, elle me dit "ben vous devez être contente, vous pouvez rentrer chez vous aujourd'hui". Et là je me suis effondrée. » (Mother, GA 32 to 37 weeks)

In this chapter we describe what parents experienced to be the main barriers that kept them from being with their child and what they appreciated as helpful.

Fathers help mothers cope with being separated from their child

Mothers said to appreciate the presence of the father, especially when they themselves could not be with their child. For example, after a caesarean section they urged the father not to lose sight of the baby. They described the **father as an extension of themselves**. The father functioned as a bridge between mother and child, passing through information, which the mother needed to cope with the separation. For mothers, fathers were a way to keep control of the situation if they themselves were not physically capable of exerting that control.

« À l'accouchement, donc après l'accouchement euh, j'ai vraiment fort ressenti le fait d'envoyer le papa, c'était comme si c'était une partie de moi qui allait voir comment le petit allait. » (Mother, GA 32 to 37 weeks)

« Enfin pour l'investissement du papa et puis, de nouveau, on préfère savoir notre bébé avec nous qu'avec des mains étrangères […] Papa s'est senti impliqué, c'est lui qui a pris soin de son bébé à la naissance, et ça je crois que c'était important aussi. […] on est plus rassurée de savoir qu'il est avec son papa quoi. [...] Et donc je lui avais dit : « Tu ne le quittes pas des yeux hein, ils vont me l'échanger hein ici, tu restes avec lui où qu'il aille ! » [rires]. […] Et donc il (le papa) était quand même redescendu à un moment avec une photo me montrer le petit parce que je n'avais pas pu le voir. Ça aussi c'est terrible. […] ils (les soignants) sont allés dans une petite pièce à côté, ils l'ont nettoyé, ils ont pris ses constantes, etc., ils ont vu qu'il fallait le mettre sous respirateur, mais quand on est revenu me le montrer, sur papa, il était là, je voyais qu'il était paisible, qu'il respirait, il vivait, enfin- [silence] psychologiquement, c'est clair que ça aide. » (Mother, GA 32 to 37 weeks)

Being a 'mother on call'

Being separated from their baby felt strange and unnatural for mothers of a preterm baby. Because of the separation mothers depended on the information and feedback from the neonatal staff at the neonatal service to know how their child was doing. Our interviewees reported that the separation from their newborn made them feel a **'part-time mother'** and a **'mother on call'**. 'Part-time' because they did not feel as a mother but rather as a patient at the maternity ward and 'on call' because the neonatal staff called them when they were needed at the neonatal ward, mostly to breastfeed.

« Ce qui était bizarre c'était que du coup j'étais maman sur appel. Euh parce que on me conseillait de pas rester trop longtemps après les tétées pour pouvoir aller me reposer dans ma chambre. Donc

en fait je quittais la néonat pour aller dans ma chambre et là je n'avais plus aucune conscience de comment allaient mes bébés. Je ne savais pas s'ils étaient réveillés ou pas, je ne savais pas s'ils pleuraient ou pas, je ne savais pas s'ils avaient faim ou pas, enfin je. Et en fait ils m'appelaient, c'était les infirmières de néonat qui m'appelaient pour me dire "bon ben voilà, ils ont faim, il faut que vous veniez". Donc j'avais ce laps de trois heures où je ne dormais pas toujours parce que ben il faut aussi faire sa toilette, manger, y avait des tranches horaires et pas très facile de dormir. Euh mais pendant ce temps-là j'étais plus vraiment maman en fait, en fait j'étais une patiente dans sa chambre, ça j'ai trouvé ça très bizarre. Hum, surtout qu'il y avait des fois où je retournai en néonat et puis l'infirmière me disait "ah ils ont pas mal chouiné alors du coup je leur ai mis une tétine". "Mais il fallait m'appeler alors enfin j'aurais bien voulu être là pour leur faire un câlin". Euh mais bon je comprends, enfin voilà c'est, c'est aussi comme ça qu'ils fonctionnent et, et voilà […] Mais c'est vachement bizarre parce que les quelques jours où ils ont été en néonat j'avais l'impression d'être maman à temps partiel. J'étais une maman en néonat et puis j'étais juste une patiente quand j'étais dans ma chambre Je ne pense pas que ça m'a perturbée dans mon lien avec mes enfants, puisque j'ai un lien super fusionnel avec eux. Euh c'est juste que ça m'a semblé bizarre de pas être en permanence avec eux en fait. Euh j'avais l'impression en quelque sorte de pas être en permanence leur maman, oui enfin, j'avais l'impression de prendre des vacances de mon rôle de maman pour deux heures sur trois et je trouvais ça super bizarre. » (Mother of twins, GA 32 to 37 weeks)

Unlimited access is not as unlimited as it seems

Parents of preterm born babies expressed a **very strong desire to be with their child**. IFCDC recognises this important need and wants to facilitate parents in being together with their newborn and avoid separations. However, a lot of organisational and practical obstacles are in the way. Parents depend on hospital staff, procedures and rules to gain access to their child.

In general parents are told to have **unlimited access to their child 24/7**. They were not considered visitors and were approached as parents and partners in the care for the newborn. However, from the interviews with parents we learned that although access can theoretically be free and unlimited, in practice parents experienced impediments.

« Qu'on puisse être là, autant qu'on le souhaite et qu'on le juge nous nécessaire. Que ce soit laissé à notre propre appréciation, l'étendue de présence qu'on voulait avoir. Et puis après d'essayer plutôt de nous accompagner là-dedans. On ne nous a pas mis des barrières en disant : « Non, c'est tout, les visites c'est de 2h à 6h, et puis c'est tout. » On nous a plutôt dit : « Vous pouvez être là quand vous voulez, mais on va vous aider à ce que vous ne vous y perdiez pas quoi. ». Et donc cette approche-là était, je trouve, beaucoup plus responsabilisante et aussi beaucoup plus apte à nous faire sentir suffisamment chez nous que pour prendre notre rôle de parents. Et pas être juste des visiteurs de malades, parce que y a ça aussi qui se joue quoi c'est… On n'est pas juste là pour visiter notre fille. On est là pour prendre notre rôle de parent en main, alors que ça se passe dans des circonstances un peu bizarres quoi. » (Father, GA 32 to 37 weeks)

First, **physical infrastructure (or lack of it)**, such as doors, corridors or elevators were relevant in how parents experienced the access to their child. The fewer the physical barriers, the more parents felt facilitated. Interviewees confirmed that it helps when their room was nearby the neonatal service. Staff knew each other, communication was facilitated, and care seemed to be more fluent. The absence of barriers or distance seemed to soften the fact of not being with the child. Being in another building or at another floor was an additional stressor for mothers.

« Mais vu que ça faisait 40 jours que j'étais déjà au centre grossesse à risque, ben déménager juste pour trois jours ce n'était pas utile. Je connaissais déjà toutes mes affaires, etc. C'était aussi un stress pour moi de repartir de l'autre côté. Et surtout que je sais que là-bas, il y a des mamans avec les bébés. Et moi, je ne voulais pas aller là parce que mon bébé il n'était pas à côté de moi. Et en plus, le centre de grossesse à risque, c'est vraiment à côté de

centre néonatal. Donc c'était aussi beaucoup plus facile d'aller directement. » (Mother, GA less than 28 weeks)

« En continu entre les deux services qui sont l'un à côté de l'autre, elles se connaissaient aussi. Ce n'était peut-être pas des collègues directes, clairement ce n'est pas le même service mais il y a qu'une porte qui sépare les deux couloirs adjacents et elles étaient très bien au courant de l'une et de l'autre et de la situation. Quand on avait une requête et qu'on se trouvait ici ou là, ben elles faisaient passer le message et il y avait aucun problème. » (Father, GA 32 to 37 weeks)

« Non. Je trouve que [H1] a bien fait ça avec le fait que la « mat » et la néonat étaient au même étage, séparées par une porte. On avait cette impression d'accès, pas comme à [H2], où j'avais l'impression que je devais aller demander l'accès pour voir mon enfant, enfin voilà. Le fait que ce n'était pas au même étage […] me donnait l'impression d'avoir un bébé à part, et à part de moi. » (Mother, GA 32 to 37 weeks)

Parents also pointed to a **lack of comfort**, such as a place to put personal belongings, the lack of a family room to have a meal, the lack of a bed to sleep near the newborn, the lack of toilet facilities, shower and accommodation for sibling. These were elements that hindered parents' presence in the neonatal ward. Parents noted that comfort varied a lot between hospitals.

*« **Maman:** On aurait pu hein! J'aurai pu dormir sur l'espèce de fauteuil à côté des machines, on peut hein. Mais… **Papa :** On y est retournés la nuit, on y est retournés deux trois fois la nuit, je pense chaque fois pour porter le lait… **Maman :** […] Le service était ouvert hein, donc on pouvait y aller. Ce ne sont pas des endroits où on dort en fait hein, c'est un service de soins intensifs, il y a d'autres enfants et donc…Ah ce n'est pas prévu pour dormir non, non. » (Parents, GA 28 to 31 weeks)*

« Ben la douche, tant que j'avais la chambre d'hébergement, pour moi c'était plus facile parce que du coup j'avais la salle de bain. Sinon, dans le service non, il n'y avait pas. Y a, l'inconvénient dans, dans ce service là à [hôpital 2] c'est qu'il n'y a pas de toilettes non plus dans le service, donc il fallait à chaque fois sortir du service pour aller aux toilettes. Et euh après, il y avait la pièce des parents, une pièce mise à disposition des parents avec deux fauteuils et deux tabourets, une table, et un micro-ondes, un frigo pour les parents qui restent là toute la journée pour pouvoir manger. » (Mother, GA less than 28 weeks)

« Euh… Oui. Oui. Et mon conjoint… La première nuit il est resté. Euh… Mais alors il n'y avait pas de lit donc il avait une… Enfin, c'était sur le coin de fenêtre qu'on l'a laissé dormir. C'était un coté de fenêtre un peu plus long. » (Mother, GA 28 to 31 weeks)

"Dat is aan de inkom van waar iedereen binnen komt. En er is nul privacy. Ge hebt geen, we zaten ook aan de kast waar dat iedereen van die verpleegkundigen elke keer in moesten zijn, dus ge zit daar dan op uw gemak, want ge zijt nooit op uw gemak hè maar we zitten daar gewoon maar efkes en dan moet ge met die stoel weer, allez, u verplaatsen omdat ze in die kast moesten zijn." (Mother, GA 32 to 37 weeks)

"Goh op dat vlak vind ik het eigenlijk wel heel goed georganiseerd naar infrastructuur. Het enige maar dat is echt wel heel plaatselijk, in onze box was er dus zo'n zetel, zo'n lounge, maar voor de papa of voor de persoon die niet buidelde, wat dat meestal de papa was bij ons, is dat zo'n klapstoeltje, maar mijne man zat daar hele dagen met pijn in zijn rug van op dat stoeltje te zitten, dus dat is wel iets, een deftige stoel voor op te zitten, als je daar al die uren moet zitten vertoeven." (Mother, GA less than 28 weeks)

Second, discharge from the maternity ward was difficult to cope with, as parents had to leave their child behind. Interviewees emphasised that returning home was heart-breaking and stressful. The more **travel time**, the more difficult it became. Not being with the child, but still in hospital was experienced more comfortable and reassuring than not being with the child and at home, especially if home was distant from hospital. The fact of being in the same building within reach reduced mothers' distress.

"Ja, ze hebben dat op voorhand gezegd van, het is zes nachten standaard, dus ik wist wel, dat was direct uitgerekend, dan wist je van ja vrijdag moet je naar huis en je kindje niet. En dat was voor mij, ik denk de eerste keer dat ik echt geweend heb die dag, dat ik enorm enorm ja, dat was zo, ik lag wel in een kamer op de MIC en dat was niet bij [naam baby] maar dat was wel in hetzelfde gebouw. Mijne man ging wel thuis gaan slapen, maar ik had zoiets van ja als er 's nachts iets is en ik moet of ik wil bij hem, awel ik bel een verpleegster, ze rollen mij met mijn bed tot in de neonatologie en ik kan zo lang bij hem blijven als ik maar wil. Maar ne keer dat je thuis zijt, ben je thuis, en ben je zo, ja dat was op dat vlak was dat 45 kilometer van elkaar gescheiden. En dat was mentaal wel heel heftig voor mij, dus ja, ge kunt moeilijk ja drie maanden opgenomen worden in het ziekenhuis natuurlijk, dat gaat ook niet." (Mother, GA less than 28 weeks)

« […] Quand on m'a dit de rentrer à la maison, parce que on m'a dit que je ne pouvais rien faire pour mon bébé pour l'instant, et que je serais mieux à la maison que de rester avec lui, déjà il faut le digérer ça, c'est moyen ! D'accord ! Bon, pas de soucis, puisqu'on me le dit … […] Je me suis soumise à ce qu'on me dit, je le fais. C'est terrible de rentrer le ventre vide, sans mon bébé, enfin voilà. Je le vis comme je peux. Un matin, j'arrive à la néonat et on me dit : « Ah, c'est vraiment dommage que vous n'étiez pas là cette nuit hein, parce qu'il a bien mangé en sonde sur doigt. » [silence] Ah. [rires] « Ce n'est pas mon plaisir de rentrer le soir. Vous pensez que je fais quoi moi ? Je vais au ciné, je me tape une bouffe ? Enfin… [rires] Non, je rentre, je pleure, je dors et j'arrive, donc euh… » [rires] Voilà. Je dois avouer que psychologiquement, ils ne se rendent pas compte de l'impact que les mots peuvent avoir sur les mamans déjà quand même vachement fragiles, et fragilisées par l'expérience. » (Mother, GA 32 to 37 weeks)

Third, to enable being with the child and to overcome the impediment of distance and travel time, interviewed mothers strongly valued **individual rooms** where parents and babies can stay together 24/7. Mothers felt that in an individual room they were able to be a full mother for their child. The organisation of this type of room varied from one hospital to another. When starting immediately after the delivery, **couplet care** is provided to both mother and baby in the same room. Individual rooms are also used to prepare the baby's discharge and train parents to care autonomously for their child. In the absence of individual rooms, parents may be offered to stay somewhere in the hospital while their baby is at the neonatal service. This kind of **hotel function** is used e.g. when parents reside far from the hospital.

« Pas au début. Au début, j'étais en chambre à la maternité. Euh… Et lui était dans une chambre, parce qu'il avait dû être sous respirateur. Enfin, euh sous lunettes. Euh… Et donc les premiers quatre jours, il est resté dans cette chambre commune avec cinq autres enfants qui faisaient que gueuler, c'était terrible. Et là, quand ils m'ont dit que je devais rentrer, alors qu'ils venaient seulement de m'enlever ma sonde et que je n'étais toujours pas capable de marcher avec ma césarienne, j'ai… Exigé, de ne pas rentrer. Et le médecin- le pédiatre nous a mis en chambre à ce moment-là, à deux. Euh et que je fasse des allers-retours au sein de l'hôpital, disant que ça allait être plus simple […] Je n'allais pas conduire, je n'aurais jamais pu revenir à l'hôpital m'occuper de mon enfant dans ce cas-là ! Et c'est le pédiatre qui trouvait que mon bébé évoluait vachement bien, et qu'il était dans une chambre beaucoup trop bruyante, que si on était à deux, il allait très vite évoluer, qu'on allait très vite sortir. Et c'est lui qui a proposé directement de passer alors en chambre […] En même temps j'étais dans un tel état [rires], quand ils m'ont mis dans la chambre, j'ai pleuré tellement je me sentais soulager de pas devoir rentrer et d'arriver enfin avec mon bébé, qu'ils m'auraient mis dans un cagibi, j'aurais été contente hein ! À un moment, voilà. On était bien, on était bien. C'était silencieux, c'était euh… […] y avait pas de bruit, et […] ça j'étais aussi reconnaissante d'être seule avec mon bébé […] Mais il devrait y avoir suffisamment de chambres pour qu'une maman puisse être avec son bébé à la naissance. Si je pouvais militer pour quelque chose, c'est ça quoi. Être présent pour les soins. Être présent pour tout. Être une maman quoi. » (Mother, GA 32 to 37 weeks)

Fourth, **being dependent on others** to gain access or needing to demand the permission to access the neonatal ward was felt as a strong limitation of access to their child.

> *"Ja. Die eerste dagen moest ik dan gebracht worden. Dan moest ik eh ik weet niet hoe lang wachten totdat ze eens een verpleegster gevraagd hadden om mij te brengen. Dan moest ik al bijna smeken van ja, wilt ge alstublieft iemand, iemand tien, hè want dat was zelfs geen tien minuten hè, want als ze dat lift pakken, mij in die kamer zetten, dat moest zelfs niet hè, want aan de deur pakte een verpleegster van de Neo dat over hè. Eh dus het was gewoon mij deur uit rollen van, van de materniteit, in de lift zetten en de lift uit rollen hè. Dat was het hè. En dan moest je echt een paar keren bellen van ja, mag ik alsjeblieft, wanneer zou er iemand tijd hebben om..." (Mother, GA less than 28 weeks)*

Dependence on others is related to **being physically able** to go to or stay at the neonatal ward. Some mothers reported they were not yet recovered from the delivery and still needed care at the moment of discharge from the maternity ward. They felt discharge came too early as they were physically not ready to go home, especially after a caesarean section. Also, discharge was not always well prepared.

> *"Maar we hadden eigenlijk gehoopt voor nog wat langer te blijven, omdat mijne man direct weekend nacht had. En met mijn keizersnede ik kon wel rondlopen, maar het was allemaal, allez nog heel, ja lastig, en pijnlijk. En mijn mama is dan hier komen slapen, want anders ging het wel niet gelukt zijn. Ik kon met moeite de trap op. Mijn kolftoestel ging ik bijvoorbeeld nooit boven gekregen hebben, en meerdere keren op en af van die trap mocht ook niet. Dus op dat vlak allez, het was, ja voor mij was het eigenlijk een paar dagen te vroeg." (Mother, GA less than 28 weeks)*

> *« Ils nous avaient dit de base : une césarienne, c'est quatre jours ; et voilà quoi. Et euh… Ça a été très vite pour nous. Mais comme je vous disais, ça a été un peu compliqué quand on nous a dit qu'on n'avait pas de place en hôtellerie, et qu'on devait un peu se débrouiller […] Je me suis un peu négligée quand même après la naissance, donc on n'a rien fait du tout. » (Mother, GA 32 to 37 weeks)*

> *« La première semaine, comme j'étais toujours en congé de paternité, ben, c'est moi qui conduisais mais la deuxième semaine, c'est ma femme qui a dû conduire sa voiture donc elle avait quand même la cicatrice qui était quand même fraîche. Voilà donc je suppose que ça n'a pas dû être facile pour elle de conduire dans cet état-là quoi. C'était quand même conduire 150 km par jour quoi, donc voilà c'était... » (Father, GA 32 to 37 weeks)*

> *« Ce qui lui a le plus pesé, c'est de se dire qu'il avait juste ses 10 jours de paternité et puis bon voilà quoi. Une énorme fatigue euh… Autant bah mentale que- que- que physique. Parce que ben devoir gérer, d'aller au travail, de venir à la néonat, parfois de se dire : « Ben malheureusement, je suis tellement fatigué, aujourd'hui, je ne sais pas aller voir ma fille. » Et euh, c'est des choses qu'il n'a pas toujours bien vécues. » (Father of twins, GA 32 to 37 weeks)*

Fifth, during their stay at the maternity ward, mothers strongly appreciated the flexibility of the maternity staff. Mothers reported that maternity staff came over to the neonatal service to care for the mother (e.g. administer medication). If this flexibility was lacking, mothers felt **pressured to be in their room** at the maternity ward to be there when staff passed by. This also accounts for other services such as physiotherapy and visits of ONE/Opgroeien. If the mothers were not there, they missed out the service, treatment or dose and/or in extremis were reproached for not being in their room.

The pressure for being in their maternity room made mothers feel uncomfortable when they were with their child at the neonatal service. Mothers reported a **lack of empathy and understanding** at the maternity ward for the fact that they wanted to be with their child at the neonatal service. Care at the maternity ward seemed not always adapted to the specific needs of mothers with preterm newborns, nor facilitating parents and child(ren) to be together as much as possible.

« […] par exemple ben j'avais les injections pour les risques de phlébite, quand j'étais près de mon bébé, je n'avais pas les yeux rivés sur ma montre à me regarder "oui, est-ce qu'elle passe vers dix heures, est-ce qu'elle passe à neuf heures et demi". […] Au lieu presque je vais dire de commencer leur tournée piqûre par nous pour pouvoir être tranquille et pouvoir descendre pour nos bébés, ben on finissait par nous. Donc il y a des fois elle passait vers dix heures, dix heures trente du matin alors qu'elles commençaient peut-être leur service à huit heures. Donc une fois on peut attendre, mais en même temps on se dit, mais on attend, on attend, il y a le bébé en dessous, "j'ai envie de le voir", j'avais vraiment ce besoin, j'avais l'impression presque de l'entendre pleurer quoi c'était. Et alors euh après, quand je remontais dans la chambre, ben je voyais la seringue posée sur ma table de nuit et euh des fois je sonnais, j'attendais un quart d'heure une demi-heure avant que quelqu'un ne vienne et me dise "ben c'est pourquoi" je dis "ben je vois que ma piqûre est là". "Ah bah oui mais vous n'étiez pas là". Donc c'était presque me reprocher que je n'étais pas dans mon lit. Je dis zut quoi. […] elle aurait pu dire "voilà on prend deux minutes", il y a juste un étage et dix marches à descendre, venir faire ou demander je ne sais pas, même à une stagiaire ou quoi, qu'elle aille faire les piqûres aux mamans qui étaient en néonat quoi [rires] ça aurait été chouette aussi. Mais c'est vrai que, si j'ai vraiment un gros regret au niveau de la prise en charge, c'est au niveau de la maternité, le manque d'empathie, je vais dire le manque de soutien quand on ne se sentait pas bien quoi. » (Mother, GA 32 to 37 weeks)

"Wij maakten eigenlijk ons eigen planning op die zes dagen. Dat was ons planning en de verpleegster die kwamen dan mijn bloeddruk zelfs op de neonatologie van de materniteit gingen naar de neonatologie om daar mijn bloeddruk te meten. Dus dat was eigenlijk heel los allemaal." (Mother, GA 28 to 31 weeks)

Also, after discharge mothers had to balance between staying at home to receive postpartum care, especially in case of a caesarean section and being with their child(ren) at the neonatal ward. As a result, mothers neglected their own postpartum health in order to be with their newborn at the hospital.

« […] J'ai posé la question en demandant si ce n'était pas possible de rester plus- j'ai posé la question et clairement j'ai un médecin, bien embêté, qui m'a dit : « Écoutez on se rend bien compte que ce n'est pas l'idéal. Mais la maternité et le MIC sont full de chez full, on a besoin de place et il n'y a rien à faire quoi. » […] Ils m'ont dit : « Madame c'est la loi, on n'a pas le choix. ». […] [J'ai été prévenue] la veille. […] 'Et au bout du quatrième jour j'étais dehors à une heure et quart de l'endroit où étaient les bébés. Par contre c'est très, très, très, très dur, donc j'avais du mal à marcher, j'ai une maison pleine d'escaliers et tout. Et c'est clair que ne sachant pas comment les choses allaient évoluer après, bah mon mari gardait un maximum aussi de congés. Donc je suis rentrée à la maison je pense le dimanche. Et le lundi matin, toute seule, je prenais la voiture en abaissant mon dossier au maximum avec mes points qui étaient tout neuf etc., pour me taper une heure et quart de route, en sachant que j'essayais de tirer mon lait au maximum parce que j'étais bien consciente que lancer un allaitement dans ces conditions ce n'est vraiment pas facile du tout. Et donc je me suis tapée la route en allant là-bas. Au bout de 24 heures, mes points ont sauté. […] Beh je suis allée à la pharmacie chercher des « steri-strip », je me suis démerdée, j'ai continué- parce que quand t'as tes bébés qui… […] Euh très concrètement je savais très bien que si j'étais passée par les urgences, si j'avais sonné une infirmière, on m'aurait interdit de revenir en néonat. Donc je n'ai juste rien dit du tout, j'ai fait semblant de rien et j'ai consolidé moi-même ma plaie avec des « steri-strip », avec des pansements etc., pour pouvoir continuer à prendre la voiture et continuer à aller voir les bébés. […] Je n'étais pas prête à rentrer, mais je n'ai pas eu le choix donc euh excuse-moi tu mords sur ta chique et tu y vas. » (Mother of twins, GA 28 to 31 weeks)

« Il a fallu aussi organiser les soins à la maison avec les infirmières à domicile pour les soins, la cicatrice. Oui, ça a été, ça a été une organisation assez complexe on va dire. » (Mother, 32 to 37 weeks)

Sixth, **COVID-19 restrictions** such as access control at the entrance of the hospital were also experienced as restricting access. Although the staff of the neonatal service emphasised the unlimited access in their communication with parents, this was not how parents experienced access mainly because COVID-19 restrictions imposed constraints. For example, parents could be present only one at the time, or even only one per day and for a limited timeslot. Having to enter through the emergency department during night hours was also experienced as a barrier, as well as the staff's preference for long visits instead of several short visits. National restrictions such as the evening curfew were also very restrictive as parents could not travel between their hospital and their home during those hours.

> *"Wat dat op zich wel niet zo'n evidente was, dat was natuurlijk met corona nu wel wat specifiek, maar ja ge hebt dan, ja de neonatologie is een afdeling van hè van een heel groot ziekenhuis. Dus ja, ge moet dan ook, er waren geen bezoekers, dus ja, je moest dan ook zo u elke keer ook zo aan de ingang mee verantwoorden. Ge moest mee in de rij staan, gaan aanschuiven van de toegangscontrole, ja en dat zijn dan zo van die dingen dat ge wel eens kunt missen op die moment. Dat ik zoiets had van goh, kan hier nu hè geen ander systeem voor gevonden worden? Dat was ook wel afhankelijk van wie dat er aan de toegangscontrole stond." (Mother of twins, GA 28 to 31 weeks)*

These restrictions on access to the neonatal service made breastfeeding more difficult, reduced social support for parents and reduced the presence of parents due to external COVID-19 measures (e.g. curfew or compulsory testing after risk contact). Not allowing both parents to be present at the same time was very difficult for parents and felt as inhuman. Being alone made it more difficult to cope with the situation and with bad news. Parents who had to alternate said they only became a family when the baby came home.

> *"En dan, goh ik denk een week daarna of zo was het plots één uur per dag. Dus dat was, ja dat is. Allez de dag dat mijne man kwam, dan zit je hier thuis tegen de muur te lopen, dat is, ja. Gek worden in je hoofd hè. Je wil maar één ding, en dat is bij je kind zijn, maar je mag niet. […] We hebben echt geprobeerd er tegenin te gaan, maar het was voor de neonatologen op dat moment ook een volledig onbekende situatie, dus beetje paniek. Wat dat ze in andere NICU's wel ietswat menselijker geweest, bleven was het in [ziekenhuis] wel heel extreem. Dat neem ik ze wel nog altijd kwalijk. Maar ja, ergens weet je ook wel van ja, ze wisten ook niet wat dat ze moesten doen, maar dat is wel iets dat ik ook in de beoordeling heb doorgegeven dat dat niet echt menselijk was." (Mother, GA less than 28 weeks)*

> *« **Papa :** Puis comme- c'est votre question hein, le COVID par rapport à la prématurité et à ce qui nous est arrivé, je crois que c'est vraiment notre plus gros euh… Notre plus grande tristesse, notre plus grand problème en fait. Euh parce que le reste à la limite…*
>
> ***Maman :** Le fait qu'on ne pouvait pas être ensemble.*
>
> ***Papa :** Et le fait qu'on ne pouvait pas être ensemble.*
>
> ***Interviewer :** Ah donc vous deviez visiter votre bébé chacun votre tour ?*
>
> ***Maman :** Bah sauf les cinq jours où j'étais hospitalisée, on pouvait être tous les deux. Mais après cinq jours, une fois sortis de l'hôpital, on ne pouvait pas être en même temps, mais on ne pouvait pas non plus faire le matin quelqu'un, et l'après-midi quelqu'un. Donc ça devait être la même personne sur la journée. […] Donc pendant six semaines, on n'a jamais vu notre fille en même temps. […] » (Parents, GA 28 to 31 weeks)*

Seventh, **siblings** complicated and decreased the ability of parents to be with their newborn, especially in combination with siblings being denied access to the neonatal ward as infection control measure. Parents experienced it as very difficult to explain to their older child(ren) and felt torn between the older child(ren) at home and the newborn at the neonatal ward. Siblings were a point of discussion and negotiation between parents and staff, as parents really wanted to unite their family around the newborn and introduce the newborn to its brother(s) and/or sister(s). In addition, siblings withheld parents from making use of an individual room and stay with their newborn in hospital.

« Pas de visite autorisées. Ce qui a été le plus dur c'était par rapport au deuxième qui n'a pas pu voir sa sœur pendant huit semaines quoi. Papa : Moi je dirais que c'est vraiment ça le plus compliqué c'est que le frère ne puisse pas voir sa petite sœur et je crois que ça a des répercussions toujours maintenant, et que ça c'était vraiment le plus compliqué parce que la famille, bon ce sont des adultes, ils s'en remettront. Et même si c'est peut-être compliqué, mais le petit frère qui ne sait pas ce qui se passe, qui voit plus sa maman pendant cinq jours, qui sait qu'il a une sœur qu'il voit quand même l'angoisse dans la famille. Euh il ne sait pas encore bien parler donc pour lui c'est quand même assez compliqué de comprendre ce qui se passe. Et ça c'est pour moi la plus grosse répercussion… » (Mother, GA 28 to 31 weeks)

*"**Mama:** Goh, dat was heel zwaar om hem zo achter te laten. En dan helemaal alleen. Maar langs de andere kant hadden wij ook ons dochter die ik ook heel lang heb, allee, niet heb kunnen zien dus haar heb ik ook gemist. Dan moet ge eigenlijk tussen, ja, twee kindjes op en af. Dat is wel moeilijk, dat wel. Maar we wisten wel dat hij daar in goeie handen was dus dat maakte het toch wat draaglijker. [lacht]*

***Papa:** [lacht] Ja, ja, toch wel, ja. Het is heel raar om zo… Hij heeft het dan gehaald en, en ge zijt dan eindelijk een compleet gezin maar dan toch moet ge hem daar zo achterlaten zoveel verder van huis en dan, ja, dat doet wel pijn, ja. […] Het is gelijk mijn vrouw zegt. Ge, ge moet u eigenlijk opsplitsen in, in twee. Ge hebt ook nog een dochter thuis en ge, ge hebt hem dan. Dus dat is wel, ja, een heel fijne ervaring om hem dan te zien en hem te zien groeien en zo. En langs de andere kant hebt ge uw, ja, uw ander kind thuis. Dus eh dat is, ja, moeilijk." (Parents, GA less than 28 weeks)*

"Tenzij, ja ze hadden wel gezegd dat dat wel kon, maar dan moest ge evenzeer gewoon u erbij ook al betalen en ik denk, als zij de eerste was of de enige was dan had ik dat waarschijnlijk wel gedaan. Maar ja, met ons zoontje, het was al sowieso de hele tijd op en neer pendelen en eh dat vond hij sowieso al heel zwaar, dus eh ben ik niet eh gebleven. Maar meestal wel gewoon van 's morgens tot 's avonds en dan elke dag opnieuw hetzelfde traject." (Mother, GA 28 to 31 weeks)

Multimedia applications can ease the separation

Technological means such as apps, tablets, cameras were sometimes used and could ease the pain of the separation but could not replace being with the child.

" […] j'avoue que j'étais assez rassurée puisque les néonatologues étaient vraiment vraiment bien. […] ensuite ils m'ont emmenée en salle de réveil où je suis restée je ne pense pas très longtemps parce que les jambes commençaient déjà à bien se réveiller. La néonatologue est venue me voir en salle de réveil pour me rendre mon téléphone parce que j'avais prêté mon téléphone pour qu'ils fassent des photos. Elle m'a rendu mon téléphone avec des vidéos des bébés pour me montrer que les bébés allaient bien. Et elle m'a dit à ce moment-là que non seulement ils allaient bien mais qu'en plus ils avaient super faim et que donc il fallait que j'aille direct en néonat en remontant de salle de césar. Et donc euh je ne sais pas, donc je pense vingt minutes après, un truc comme ça, le brancardier est venu me chercher et m'a emmenée direct en néonat. Et en néonat on a fait un peau à peau et une tétée d'accueil avec les deux." (Mother of twins, GA 32-37 weeks)

"Bij [ziekenhuis] wordt dat iets of wat opgevangen omdat ze daar ne camera, ze hebben daar webcams boven die bedjes gehangen. Waardoor dat ge eigenlijk zowel contact voor ons als ge er efkes, ja gewoon op uw kamer al kijken of dat ge daar zijt. En kunt ge ook die code doorgeven aan de grootouders, want die hebben nog altijd hun kleinkind niet kunnen zien. Dus dat was dan wel één van de dinges." (Father, GA 28 – 31 weeks)

5.3.9 Challenges and opportunities regarding (breast)feeding and skin-to-skin care

Key points

- **The motivation to breastfeed was very high among mothers of preterm babies. Their motivation stemmed from their desire to give their baby the best feeding option, but also from feeling guilty about delivering prematurely.**
- **Even if completely exhausted, mothers can be unable to take the decision to stop breastfeeding. They felt like they needed the approval of their partner or the care provider to allow themselves to stop breastfeeding.**
- **Neonatal wards try to support breastfeeding and skin-to-skin care by providing separate rooms, equipment, operational support, and counselling of staff.**
- **Factors impairing the breastfeeding of a preterm baby were mothers perceiving it as not natural and complicated, lack of privacy, the lack of alignment of care between the maternity and the neonatal service, discharge from the maternity ward and return home, the** breastfeeding narrative and contradictory information.

Feeding and skin-to-skin care are examples of active parental involvement in the care for their newborn. During the interviews parents talked about how they experienced these two ways to have close contact with their baby and what happened when this contact was impossible or impaired. No contact with their baby gave parents the feeling of being useless and worthless.

> *"Sommige ouders konden dan - zoals je zo ziet op tv - dat flesje geven in de couveuses zo, of mogen hem eruit halen om te kangoeroeën, maar ik mocht dat niet in het begin. Ik mocht zijn flesje ook niet geven. Ik zat ik eigenlijk bij die couveuse voor niks eigenlijk. Mijne vriend mocht dan ook niet, allez kon ook niet blijven, we hadden nog een dochter. Dus zat ik daar helemaal alleen. Ik voelde mij wel redelijk eenzaam, en zeker als dat ik hem, ja niet mocht pakken en zo. Ik mocht ik wel altijd gaan, midden in de nacht of eender wanneer. Maar ik mocht hem niet uit de couveuse halen, ik mocht dat niet. En als ouder doet dat wel pijn […] Nooit gezegd. Ik voelde mij op dat moment ook een beetje waardeloos. Allez van wat zit ik hier eigenlijk, want ik kon even goed naar huis gaan na een 2-3 tal dagen. Maar ik ben zo lang mogelijk willen blijven voor bij hem te kunnen zijn." (Mother, GA 32 to 37 weeks)*

Parents reported how the neonatal staff tried to facilitate breastfeeding, even to the point that it became counterproductive. What accounts for breastfeeding often is also relevant for skin-to-skin care. From the interviews we identified a number of points of attention.

Feeding decisions and trust in the neonatal staff to respect parents' decisions

Breastfeeding is the preferred feeding option for preterm newborns. If parents were not yet strong believers before birth, their decision to breastfeed was motivated by:

- the advice and encouragement of professionals they met before the birth,
- the feeling of guilt for delivering prematurely,
- the conviction that breastfeeding is the best option for their baby,
- the confirmation of mothers status as a mother.

> *"Vanaf moment dat ik eigenlijk al aan de weeënremmers lag in [ziekenhuis] was dat één van de eerste vragen dat ze stelden van, wil je borstvoeding geven. En dat was iets dat ik sowieso altijd gewild heb. Dus mijn antwoord was daar heel duidelijk. Maar ze hebben wel heel snel gezegd van, dat is heel goed dat je dat doet, zeker in [naam baby] zijn geval. Stel dat we het niet kunnen trekken, dat hij vroeggeboren wordt, wat dat dan wel voor hun al duidelijk was, maar ze konden dat nog niet uitspreken waarschijnlijk. Ze benadrukten echt wel het belang van borstvoeding maar doordat ik al zo overtuigd was vooraf was het*

eigenlijk niet echt nodig om dat nog een keer." (Mother, GA less than 28 weeks)

"'Eh ja, gelijk dat ik daarstraks zei hè, dat wij IVF hebben gedaan, was dat voor mij eh psychologisch wel eh een belangrijke dat ik, eh ik wou echt borstvoeding geven om voor mijn eigen te kunnen bewijzen van zie eens, eh ik kan dat wel. Eh ik kon niet zwanger worden, ik kon niet zwanger blijven, dus ik wou echt nog wel eh borstvoeding kunnen geven, omdat ik mij ook schuldig voelde door het feit dat ik dan zo vroeg was bevallen." (Mother, GA less than 28 weeks)

« J'avais regardé même sur quelques infos par rapport à [l'allaitement pour] les enfants prématurés. Je savais très bien que c'était le meilleur pour l'enfant, c'est le lait maternel. Maintenant je n'étais pas très sûre d'avoir les quantités, tout ça. Donc je me suis dit : « Je vais essayer. Si j'y arrive, tant mieux. Si je n'y arrive pas voilà, j'aurai fait mon possible. » Après je voulais vraiment, vraiment, vraiment allaiter. » (Mother, GA less than 28 weeks)

When breastfeeding is not chosen or the production of breastmilk is insufficient, the use of human **donor milk** was offered. This can be experienced as somewhat intrusive. Once babies need larger amounts, it was difficult to maintain this feeding option as the stock of donor breastmilk is very limited.

"Toen bij [persoon 1] hebben ze wel echt gezegd van: "Borstvoeding, kijk, de overlevingskansen zijn veel groter voor prematuurtjes bij borstvoeding. Als u die keuze niet wi-… Allee, als u dat liever dat niet doet dan begrijpen wij dat maar dan zouden we toch wel voorstellen om eventueel van een donor eh melk of, of van onze melkpoule zeker de eerste dagen, weken gebruik te maken om dan over te schakelen op flesvoeding.". Maar daar vond ik het nogal redelijk, en dat kan misschien mijn gevoel zijn hè, maar nogal redelijk pusherig overkomen. Dat is zo van: oké, borstvoeding it is." (Mother with a previous preterm baby, GA 28 to 31 weeks)

*« **Maman :** Effectivement quand on a mis le biberon, on a vu qu'elle buvait tout de suite. Donc on avait essayé avant le lait d'une autre maman, mais après deux trois jours, ils ont dit "ah mais non, mais nous, on n'a plus du lait pour vous parce qu'on donne la priorité à d'autres bébés qui en ont plus besoin donc on devra faire avec le lait artificiel" […] **Papa :** Je les comprends. On ne peut pas effectivement, parce que la petite grandissait quand même donc elle avait besoin de quantités qui vont en augmentant évidemment. Le lait de banque comme ils disent, c'est un stock limité forcément, et on ne peut pas continuer ad vitam æternam dans l'espoir que l'allaitement s'enclenche. » (Parents, GA 32 to 37 weeks)*

Parents found the type of feeding – breastmilk or formula – important. It seems to be a **sensitive subject** which easily leads to misunderstandings. Parents reported reactions of the neonatal staff which they interpreted as disrespectful of their choice to breastfeed or not. Being able to **trust the neonatal staff** was an important element as parents were not continuously with their baby. Trust was especially threatened when parents felt that the neonatal staff disagreed with their decisions. Parents felt betrayed if the neonatal staff did not respect their choice or take decisions in their place. Some interviewees felt not at all supported in their decision to breastfeed and said they had to fight to make breastfeeding work. Also, the way to administer milk (e.g. bottle, probe) was subject of discussions between parents and staff about what to prioritize, the rhythm of the baby or learning the baby to drink.

"Dat was de lactatiedeskundige zelf hè. Ik snap haar zelf en ik stond zelf met mijn mond vol tanden, dat ik dacht van, we willen hier wel aan die borstvoeding werken, en dan na ene dag zegt ze al zo van, we zullen met een flesje proberen. Heb ik gewoon direct gezegd, nee we doen dat nu nog niet. We gaan eerst echt haar aan die borst krijgen." (Mother, GA 28 to 31 weeks)

"En pushen, terwijl dat ik, ja ik had er heel veel over gelezen. En ik wist dat ik daar zo lang mogelijk mee moest wacht met die flesjes, en echt eerst moest goed drinken aan de borst. En dan uiteindelijk is uitgekomen dat ze achter mijne rug flesjes hebben gegeven. Als ik er niet was. Ook al had de dokter gezegd dat het niet mocht, dat het onze wil, onze keuze was om te wachten met die flesjes, dat

we dat nog niet wouden, maar blijkbaar hebben ze achter onze rug haar toch al flesjes gegeven." (Mother, GA 28 to 31 weeks)

"En ook, moest het voor haar nadelig geweest zijn en moest het medisch nodig geweest zijn, had ik natuurlijk direct de fles gegeven, maar ze kwam bij, ze was gelukkig, ze was levendig, ze had haar pipi pampers, alles was oké. Ik kolfde genoeg, dus er was, maar toch bleven zij hameren op die flesjes. En het is jammer want ik was toen heel zwak. Ja als ge uw kind moet achterlaten drie maand zijt ge, ik had die zwangerschapsvergiftiging gedaan, ik had een keizersnede gehad, en dan moest ik… […] ik was heel moe, en op die moment moest ik dan ook nog eens zo hard strijden voor die borstvoeding. […] Er kwam eigenlijk een extra taak bij, buiten onze dochter moesten we nu ook voor die borstvoeding gaan strijden. En het werd ook voor mij veel moeilijker om haar daar achter te laten, omdat ik niet het gevoel had dat ze achter ons stonden, en dat ik de juiste steun kreeg eigenlijk. Ik kon haar daar heel moeilijk achter, ik had heel weinig, ja het vertrouwen was er niet op die moment." (Mother, GA 28 to 31 weeks)

*"**Mama:** Ja, hij kon, hij kon nog niet uhm zelfstandig alle flesjes leegdrinken. En ze moesten dan ook vaak een sondeke zetten, maagsonde. Allee, de moedermelk via de maagsonde in plaats van… Maar ik vond ook wel, en dat heb ik hun ook gezegd, dat ze hem zo naar het einde toe niet wakker maakten voor, voor zijn flesje. Ze zeiden: "Oh, hij slaapt. Laat hem maar effe slapen.". Hup, de sonde in. Ja, toen heb ik mij ook boos gemaakt.*

***Papa:** Ja, dat is de bedoeling niet.*

***Mama:** En gezegd: "Als ge, als ge dat altijd gaat doen voor u… Uhm dat hij een maand langer voor u blijft dat maakt u niet uit maar wel voor ons." En, ja. "Oh nee, dat is niet de bedoeling." Ik zeg: "Ja, waarom maakt ge hem dan niet wakker? Waarom probeert ge hem niet wakker te maken?".*

***Interviewer:** Gaven ze dan flesvoeding via de sonde omdat hij aan het slapen was?*

***Mama:** Ja, sommigen. Niet allemaal. Velen he- maakten hem wel wakker en dekten hem af zodat hij stillekes aan kouder, allee, frisser en dat hij dan wakker werd. Maar daar waren ook een paar tussen die dan echt zoals excuus gaven van: "Hij lag te slapen en ik dacht: oh, laat hem maar wat slapen, dan kan hij wat rusten." Bla bla bla. Ja, nee, dat is niet de bedoeling." (Parents, GA less than 28 weeks)*

Stopping breastfeeding is a difficult decision

The transition from breastfeeding to formula was mainly motivated by the physical and/or emotional exhaustion of the mothers. The support of a lactation consultant helps mothers to make this transition. Some mothers reported that they were unable to decide to stop breastfeeding. They needed the approval of their partner or care providers to allow themselves to stop breastfeeding.

"Op bepaald moment was ik het zo beu dat de mensen aan mijn lijf kwamen, ik had het gehad. Ik had overal pijn. Ik was zo, zo vermoeid, ik was lichamelijk uitgeput eh omdat ik een zware zwangerschap achter de rug heb, dan die keizersnede, eh dat ik gezegd heb: Het is genoeg. Ge kunt het niet meer aan. Eh ik heb dat ook aangegeven en dan zijn we overgestapt naar flesjes. Eh dus dat is heel bewust mijn eigen keuze geweest. Ik heb ook documentatie gekregen eerst van het ziekenhuis, om een keer ja in te lezen hè en nog een keer, ik heb ook raad gevraagd hè en mijn bezorgdheid kunnen uiten bij verschillende mensen. Eh maar ze zijn daar eh ja met respect mee omgegaan. Dat ik dan uiteindelijk gezegd heb van kijk, ik ga het stoppen. En dan zijn we overgegaan op flesvoeding. En ik ben nog altijd blij met mijn keuze. Ik sta daar nog altijd 100 procent achter." (Mother of twins, GA 32 to 37 weeks)

*« **Maman :** Quand je commençais à plus produire beaucoup directement elles s'en rendent compte parce qu'on apporte nos petits pots. Et donc là très vite c'est : « Oh beh dis-donc » - enfin très gentiment, ça a toujours été avec beaucoup de bienveillance mais : « On a remarqué que voilà vos quantités diminuaient et*

tout. » Et là, elle [l'infirmière] m'a vraiment bien tout expliqué, elle est venue voir comment je faisais. Elle est venue voir avec moi dans une petite cabine là. Et la conclusion c'est que tout allait bien enfin je suivais bien la méthodologie. […] En fait moi à la fin j'en avais marre de tirer mon lait et tout parce que je voyais que mes quantités devenaient de plus en plus petites. Je pense que psychologiquement je n'arrivais pas à arrêter parce que j'avais l'impression de trahir [nom du bébé]. Mais en même temps je n'en pouvais plus, et je pense que les infirmières se sont dit : « Ouais mais la maman de [nom du bébé] elle veut vraiment persévérer et il y a eu un truc- il faut l'aider pour persévérer... » Et en même temps moi j'avais juste besoin je pense que quelqu'un me dise stop. C'est pour ça je pense que [l'infirmière] a eu la bonne intuition en disant : « Écoutez maintenant faut… ***Papa :*** *Je pense qu'elle t'a vu en souffrance, et je me souviens qu'il y avait les regards qui disaient que elle- toute l'équipe savait que t'étais en souffrance à ce niveau-là et qu'il fallait que t'arrêtes et que personne n'osait te le dire parce qu'elles sentaient que c'était quelque chose d'extrêmement important pour toi quoi. » (Parents, GA less than 28 weeks)*

"Maar toch, als mama heb je het gevoel van oké, ik moet dat hier, ik moet dat hier doen en ik moet dat hier zo lang mogelijk doen. Eh en dan op een gegeven moment was er een verpleegster die zei van, ja je kan ook stoppen hè. Allee, je doet het nu al zo lang. Alles wat dat hij al gekregen heeft dat heeft hij gekregen. Eh het is belangrijk ook dat je zelf nog op je twee benen staat een keer dat hij naar huis komt. En dan had ik zoiets van, oké er heeft mij iemand gezegd dat ik mag stoppen. Ik had dat gelijk nodig. [lacht]" (Mother, GA less than 28 weeks)

Neonatal wards try to support breastfeeding with the available means

Neonatal wards try to facilitate breastfeeding as much as possible by providing privacy (e.g. by means of breastfeeding rooms, screens), the necessary equipment for milk expression, and making available neonatal staff and/or lactation consultants.

- **Allocate breastfeeding rooms to create privacy**

The proximity of the baby optimises the milk production during breastfeeding and milk expression. Privacy is thus a key element to allow the mother to be near their baby without being hindered by NICU activities or visitors. Therefore, the interviewees preferred individual neonatal rooms. When these rooms are not available, screens are used to create a 'private' space near the baby. Another solution was the allocation of separate rooms for expressing milk. However, this solution induces a separation between mother and neonate. It creates privacy at the cost of not being with the child during milk expression. Mothers experienced it to be strange to distance themselves from their baby to express milk. The organisation of expressing milk caused distress and withheld mothers from enjoying being with their baby.

« Pour ça (l'allaitement) à [hôpital 2] enfin ils sont super aussi. Il y a une pièce qui est mis à disposition des mamans avec plusieurs tire-laits et tous les biberons nécessaires pour récolter le lait. Et on avait la possibilité de prendre le tire-lait pour tirer son lait à côté du bébé. Quand elle était dans sa chambre particulière, ben voilà, on avait plus d'intimité. Quand elle était en chambre commune, on mettait un paravent de manière à ce que la maman soit en intimité mais qu'elle puisse rester à côté de son bébé pour tirer son lait malgré tout. Il y a aussi une infirmière spécialisée en lactation qui était là pour donner des conseils, si j'avais une crevasse ou quoi, je pouvais lui en parler, elle regardait, voilà. Elle m'a donné des compresses d'allaitement. Enfin, j'ai vraiment été bien entourée aussi par rapport à l'allaitement, ça oui ! » (Mother, GA less than 28 weeks)

"Ja, ja, om die, en ook soms moest ik dan als ik aan het buidelen was, moest ik hem terugleggen om te gaan kolven, maar dat voelde voor mij heel tegenstrijdig. Zat ik daar liever een uur langer te buidelen dan dat ik daar achter dat machine zat. Eh dus ja, dat, dat klopte niet. Ik moest dat gelijk overal ingepast krijgen en dat, toen dat dat weggevallen is, ben ik veel meer kunnen gaan genieten van een badje geven, een flesje geven, dan eh, dan kon ik daarvan genieten en daarvoor was dat niet. Dat was gewoon overleven en

plannen en ja, ge zit wel op uw reserves ook fysiek. Eh dus ik vond dat dat heel veel vroeg." (Mother, GA less than 28 weeks)

- **Equipment for milk expression**

The neonatal wards provide all the necessary equipment for expressing milk. Sterilisation of the equipment and storage of the milk is also taken care of. Parents appreciated this operational support.

« Le service est top parce que du coup, il faut tout stériliser à chaque fois et ça il suffit de déposer tous les sets dans le couloir et ils passent les nettoyer pour nous, les stériliser… Donc ça facilite quand même vraiment le tirage… » (Mother, GA 32 to 37 weeks)

- **Neonatal staff's support for breastfeeding and skin-to-skin care**

In addition to the operational support, the support of the neonatal staff and the lactation consultants values the mothers in their role as breastfeeding mothers. The support took different forms such as counselling, ways to use the breast milk when the baby cannot yet suckle (e.g. use of breast milk for baby care or use of devices to learn suckling), or the support of speech therapists. The absence of pressure to breastfeed and the respect of the mothers' decision not to breastfeed or to stop breastfeeding were also very much appreciated.

« Et je trouve qu'ils étaient vraiment super encourageants. Les premiers jours quand on arrive avec 20 malheureux millilitres là … Qu'on a eu du mal à avoir, ils sont là : « Ah ouais, c'est génial ! Franchement félicitations ! », je trouve qu'ils ont toujours été super encourageants par rapport à ça. Et du coup c'était chouette parce que, ben même si [nom du bébé] pouvait pas boire, ils arrivaient quand même à utiliser le lait avec des parades. Donc on mettait genre un peu de lait sur un coton-tige et on lui faisait des soins de bouche avec ça. Et puis c'est mon lait qu'on mettait dans son petit tuyau pour la nourrir. Je trouve quand même assez valorisant, et valorisé par les infirmières quoi. Elles n'arrêtaient pas de dire que c'était incroyable ce qu'on faisait et elles mettaient tout en place en tout cas pour qu'on puisse le faire. Il y avait une conseillère en lactation qui a toujours respecté mes choix, etc., je trouve et qui m'a vraiment accompagnée dans ce que je voulais. » (Mother, GA 32 to 37 weeks)

« Parce qu'au tout début, pour la mise au sein, on a le dispositif le DAL au sein, l'infirmière nous aide, allez pendant quand même 30 à 45 minutes. […] il y en a eu une ou deux infirmières on voyait qu'elles étaient plus de l'ancienne école où finalement, donc le DAL, le dispositif d'aide à la lactation, donc ça, on a besoin d'aide pour ce genre de dispositif … Il y en avait, on voyait que [rires] : "Oh ça va encore prendre 30 minutes, rien que pour être juste là à tenir la seringue …" Donc la seringue était reliée à un petit tuyau qui était mis dans une téterelle au niveau de- de mon mamelon et… Mais la majorité des infirmières, c'est leur mission, c'est qu'on arrive à lui faire prendre le sein et … Et elles ont utilisé, elles ont réfléchi à des méthodes. C'était très chouette, … C'était très chouette. Mais je pense qu'il y a une [qui n'était pas de la même] génération. [rires] Voilà, c'est une observation. [rires] » (Father, GA 32 to 37 weeks)

"Op N bij de voedingsmomenten ook van de logopediste, omdat zij dan, hè ze hebben dan met het flesje leren drinken, zo volgens de EFS methode, en dan is de logopediste ook een heel stukje komen helpen." (Mother, GA 28 to 31 weeks)*

« Ils ont posé la question : « Est-ce que vous avez choisi, si vous allez allaiter ou pas ? » Une fois que j'avais dit que je voulais- j'ai dit : « Ça y est, je veux essayer d'allaiter. » Ils m'ont dit qu'ils étaient contents. Ils m'ont dit : « On est vite contents ici. Vous allez allaiter, on est contents. Vous ne voulez pas allaiter, on est contents. » Ils essaient de rester neutre » (Mother, GA less than 28 weeks)

The support of neonatal staff **also applied to skin-to-skin care**. This support took several forms such as creating privacy or a quiet place, explaining the medical interest to perform skin-to-skin contact, allowing skin-to-skin contacts on parents' demand, or the use of techniques to make skin-to-skin contact possible for early preterm babies.

"Maar ze hebben er wel alles aan gedaan. Eh [kind 2] die zolang in zijn couveuse lag en die er niet uit kon, eh ze kunnen die couveuse kunnen ze eigenlijk die bak waar dat ze, of die plaat waar dat ze op liggen, kunnen ze eigenlijk uittrekken. En dan eh konden ze de couveuse laten zakken tot op de hoogte van mijn rolstoel en kon ik daar mooi onder zitten en dan lag hij zo gezegd op mijn schoot, maar dan wel op eh allee, half in zijn couveuse. Dus op die manier moesten we het eigenlijk doen. Zeker in het begin. Maar dan ja, met tijd eh mochten ze er alle twee uit en gingen ze naar een bedje en dat was eigenlijk gelijk als dat je dat thuis zou doen, behalve dat ze nog de sonde hebben en dat ze nog een eh een probe hebben voor de zuurstof eh te meten." (Mother of twins, GA 32 to 37 weeks)

« Oui, ça je dois dire « merci » pour ça. Il n'y avait vraiment pas de soucis à ce qu'ils amènent mon lit et fassent de la place et tout pour que je puisse dormir avec lui là-bas. […] [le contact peau à peau est très positif] Psychologiquement, pour le lien, pour tout. Au moment où je pouvais enfin quitter ma chambre, j'arrivais à m'enfuir de- de ces rendez-vous médicaux, je pouvais le prendre. […] on arrivait à chaque fois tout le monde- tout le personnel- je vous dis, même en pleine nuit, j'arrivais à 22 h, 23 h pour qu'on me le mette ; et parfois à 4 h, 5 h, euh je disais : « Ben voilà, maintenant je ne sais pas, y a trop de bruit ou… Ou je vais quand même aller un peu mieux dormir dans ma chambre…", eh ben il n'y a pas de soucis, j'appelais, on venait me le reprendre, on le mettait dans son petit lit et on me ramenait dans ma chambre, donc euh… tout le personnel là a été très très à l'écoute et je n'ai pas eu l'impression de déranger. […] » (Mother, GA 32 to 37 weeks)

Factors impairing breastfeeding or skin-to-skin care

In the interviews we identified several factors impairing the breastfeeding of a preterm baby. While some factors were directly linked to the prematurity of the neonate or inherent to the milk extraction process, some of the factors were linked to the organisation of care.

- **Breastfeeding a preterm baby was felt to be not natural and complicated**

Mothers experienced the breastfeeding of their preterm baby as not natural because of the mechanical milk extraction with a pump. Mothers felt that they missed the beautiful aspects of breastfeeding such as the contact with the baby, watching the baby drink or bonding with the baby. Besides the mechanical dimension, the lack of solicitation of the baby to be breastfed induces an artificial rhythm. Mothers found it very complicated to breastfeed a preterm baby: the start-up is done manually, after that a pump is used, all attributes must always be sterilised, the milk must be preserved and transported in certain conditions (e.g. temperature), mothers must get up at night to extract milk, milk extraction is often done in absence of the baby, milk extraction must be planned in between other activities, such as skin-to-skin cuddling, baby care, postpartum care, travel time to the hospital, care for siblings etc. Distress and exhaustion often lead to quitting breastfeeding. Neonatal wards invest a lot in supporting and encouraging breastfeeding mothers in order to make breastfeeding succeed.

« Moi, d'office je savais que je voulais allaiter mon bébé parce que j'avais allaité les deux premiers et donc elle, je voulais l'allaiter aussi. Après, la crainte en accouchant à 24 semaines, c'est "est-ce que c'est possible d'allaiter un bébé qui est né si tôt ? Comment ça se passe et cetera ?". Donc là, c'est sûr que c'est compliqué. Quand on se plaint que c'est compliqué d'allaiter un bébé à terme, on ne sait pas à quel point c'est compliqué d'allaiter un grand préma […]. Au départ évidemment elle, elle ne savait pas téter donc j'ai dû tirer mon lait. Il a fallu mettre en place l'allaitement de manière manuelle au départ et puis après avec un tire-lait. Et alors ce qu'il se passait, c'est que moi je tirais mon lait, je le mettais dans des petits récipients que je donnais en néonat et, tout le temps où elle était nourrie par sonde, c'était toujours avec mon lait. Et donc elle a commencé à téter plus ou moins trois mois après sa naissance. Donc pendant trois mois il a fallu vraiment faire tout le temps ça. » (Mother, GA less than 28 weeks)

« Ben, y a rien de naturel. C'est un bébé médicalisé, il n'y a rien de naturel. Ce n'est pas comme on nous le décrit avant, la beauté de

cette naissance où il va naître, on va vous le mettre sur vous, il va aller chercher son sein pour la tétée de bienvenue, ah ça va être génial : ben non ! Nous on n'a rien de tout ça. Et cet allaitement qui est censé être naturel, est mécanique, donc on… L'allaitement du premier jour, ça avait été les deux premières semaines, est mécanique parce tirage de lait constant, on n'a jamais ce contact avec l'enfant. Quand on rentre en plus chez soi, qu'on doit tirer son lait la nuit, alors que ce n'est pas le bébé qui demande, et que t'es juste crevée, t'as juste envie de dormir. […] On est tellement fatiguée, et on n'a pas l'enfant avec nous, que ce côté mécanique de l'allaitement, ce n'est pas gai. Ce n'est pas la joie de la mise au sein, il n'y a pas la beauté de l'enfant qui tète, c'est une machine, donc non, ça c'est vraiment dommage.' (Mother, GA 32 to 37 weeks)

- **The lack of privacy**

In open bay wards or shared rooms, the presence of the other babies' families created a strong sense of **discomfort and lack of privacy** during breastfeeding or milk expression (e.g. due to the presence of other babies' fathers) and skin-to-skin care.

« Alors, dans certains moments, parce que tu as le torse nu donc voilà. Euh tu as les papas qui passent. » (Mother of twins, GA 28 to 31 weeks)

« Et c'est ça qui a un peu posé problème dans la chambre avec les deux autres bébés. C'est que moi, je venais énormément, des fois, je passais toutes mes journées là-bas. Je tirais mon lait parce que je l'allaite. Il y avait dans les deux autres bébés. Une famille d'origine marocaine à qui ça déplaisait que je montre mes seins pour tirer mon lait. » (Mother, GA 28 to 31 weeks)

"Eh ja dat was niet altijd makkelijk, omdat je, ja je zit dan natuurlijk niet in het midden van de zaal en je, en je bloot lijf hè, ja dat is niet zo hè. Eh dus eh zolang dat ik in het ziekenhuis lag, met een ziekenhuisbed, was dat gemakkelijk, omdat ik neerlag en eh dan legde ik een deken op mij. Eh maar dat werd dan een beetje moeilijker hè. Zeker dat, dat echt, dat huid-op-huidcontact, dat is dan een beetje achterwege gebleven." (Mother of twins, GA 32 to 37 weeks)

- **Availability and alignment of neonatal and maternity staff**

Care in the maternity ward is not always adapted to the needs of mothers with a preterm baby. For example, mothers of a term baby being prioritised for lactation counselling because their preterm baby was not waiting to be fed, or the non-separation of mother and child being hampered by locating the counselling activities of the lactation consultant in the maternity ward instead of at the neonatal service. Hence mothers have to be in the maternity ward to receive breastfeeding counselling, while their baby is at the neonatal service. If the maternity ward and neonatal service are at a distance from each other, it becomes even more difficult to walk back and forth between the two, especially when just given birth.

"Ge merkte dat ook hè van, als ik een vraag had voor borstvoeding of te kolven, ja, ik moest maar wachten, want mijn kind moest niet eten en andere kinderen moesten wel eten. Dat is ook letterlijk gezegd. Ik zeg ja, ik moet wel eten maken voor mijn kind en mijn kind heeft dat absoluut nodig om te kunnen groeien. Ook al at die nog niet zoveel gelijk dat ik kon afkolven." (Mother, GA less than 28 weeks)

"Want allez ik wou ook heel graag proberen voor borstvoeding te geven. Dus, wat dat ook echt een verhaal is. Dat is heel absurd. Ik weet niet of het het UZ van [stad] kent van, maar de afdeling waar ge dan, de materniteit is dat, waar dat ge verblijft, dat is echt twee kilometer van de NICU hè. En ik heb echt drie uur na de bevalling gestapt, dat is echt, allez dat zou geen enkel net bevallen mama moeten doen, want, allez dat kunt ge toch niet verklaren dat ge daar met dat, allez dat is echt, met dat nettegaas onderbroekske en dan ligt daar zo een maandverband in van tien ton dik, en ge hebt zoveel pijn, en dat ge dan gewoon daar te voet naartoe moet. En dan zeiden die ook van, het eerste advies dat ik kreeg over borstvoeding was, slaapt gij maar eerst een nachtje door dan kunt ge al bekomen. Maar als er iets is dat ge niet moet doen, is het dat. En dat was heel raar, want ge krijgt op materniteit dat te horen, en dan ga je naar beneden, en dan wilt ge ook die vraag stellen van,

hoe kan ik hier nu, allez of ik wil dat heel graag geven. Hoe moet dat nu verder? En dan zeggen die wel wat info, maar ge merkt dat die er echt niet zo veel over weten. Dus dan zeggen ze, vraag het aan uw vroedvrouw. Maar uw vroedvrouw zit twee kilometer, allez dat voelde als twee kilometer. Ja dat is niet hè, maar die zat veel te ver." (Mother, GA 32 to 37 weeks)

For skin-to-skin care also parents needed the neonatal staff to help them with taking the baby in and out of the incubator. Parents worried about disturbing the neonatal staff's workflow.

"En dan, ja als we dan wouden stoppen, dan belden wij. En dan kwam er iemand. De ene keer was dat wat sneller als de andere keer, dus dat was zo wat zien. Dat was zo niet altijd even praktisch. Zeker zo in het begin vond ik dat heel lastig, want ja ge zijt afhankelijk van anderen op die moment. Ja ze waren ook nog veel te klein om ze zelf weg te leggen. En als ge dan belt, en ja soms, allez meestal was dat wel, allez op een korte termijn. Maar soms moest je toch, ja wat langer wachten. Maar als ge dan zelf bijvoorbeeld ja een fysiek ongemak hebt of zo, ja dan is dat niet altijd zo handig." (Mother of twins, GA 28 to 31 weeks)

"Maar het begin vond ik soms wat moeilijk. Om ja, sommigen kent ge dan wel al wat meer en dan durf je al eens te vragen van, hé, eh mag ik ze op mij hebben? Maar ja, sommigen zijn ook zo druk bezig. En dan durfde ik ook niet altijd meteen van, hé eh, hallo, ik ben hier ook. Mag ik...? Terwijl dat, ja, ge wilt dat natuurlijk wel. Maar ze hebben niet, niet alleen maar [naam baby] hè. Ze hebben nog baby's. Ze hebben ook in één keer ja urgente dingen, want hoe vaak je daar piepers, ja dat..." (Mother, GA 28 to 31 weeks)

- **The discharge from the maternity ward and return home**

Once outside of the hospital, mothers have to manage the milk expression, milk storage, and milk transportation from home to the hospital, sometimes during long journeys. The management of siblings, the imperatives of daily and professional life add to the challenge of breastfeeding a baby at a distance.

« Ah c'est… Faut se le prendre et avec toute la fatigue, en sachant que depuis deux mois, je faisais l'aller-retour. En tirant mon lait, c'est-à-dire quand j'étais à la maison toutes les trois heures : je buvais, et je tirais mon lait avec l'appareil électrique, j'avais apporté les bibis dans la glacière etc. Je faisais la route, fallait chercher, aider les grandes [sœurs], etc., donc… Dans un contexte entre deux heures et demie, trois heures de voiture par jour. Les bébés, se lever la nuit pour tirer le lait, la fatigue post-accouchement. Et c'était mon adjointe qui gérait le département infirmier, avec qui j'avais des backgrounds par téléphone ou en « visio » une fois par semaine, où j'avais quand même des petits suivis par rapport à mon boulot à l'hôpital. Je ne lâchais pas complètement mes équipes, donc c'était très, très, très fatigant et très dur. » (Mother of twins, GA 28 to 31 weeks)

- **The breastfeeding narrative and contradictory information**

During breastfeeding education and counselling professionals create great expectations regarding breastfeeding. The dominant narrative emphasises that breastfeeding is the best feeding option, especially for preterm babies as it increases their chances of survival. This seems to put a lot of pressure on mothers' shoulders. When breastfeeding does not work out well mothers experienced a sense of failure, guilt and frustration. In addition, contradictory information of different professionals is very confusing for mothers who are already anxious and distressed about the prematurity of their baby.

*« **Maman** : Tandis qu'au début, on te dit "mais ça va aller, ne vous inquiétez pas" comme si tu n'es pas capable de raisonner. Et après à un certain moment on arrive à trois pour "mais vous savez madame, il faut accepter mais si vous voulez on vous envoie un psychologue parce que vous n'avez pas le lait". Mais et c'est vous qui m'avez dit [que ça allait vernir], et […] l'infirmière est arrivée avec ce biberon de lait artificiel, moi je me suis mise à pleurer comme s'ils étaient en train de l'égorger parce qu'ils m'avaient tellement passé cette idée qu'il fallait absolument allaiter […] quand j'ai vu, enfin en plus c'était par l'infirmière que je n'aimais pas qui me traitait […] mal, qu'elle prenait ma fille, qu'elle lui mettait ce biberon, je disais "non, non, je veux pas", […] Mais c'était un peu*

eux qui m'avaient passé cette idée. Moi, avant d'accoucher, je pensais que bon, des fois ça marche des fois ça ne marche pas, on essaie de faire au mieux. Donc oui, la sensation que j'ai à la fin de cette expérience c'est négatif, mais bon peut-être j'ai pris un peu trop sur moi, peut-être on aurait dû s'entendre d'une autre façon. ***Papa :*** *Ce qu'il faut retenir de toute cette histoire, c'est que la façon dont ils ont géré cette situation de l'allaitement dans la finalité a fait en sorte que [prénom de la maman] s'est sentie coupable et frustrée du résultat alors ça ne devrait pas être le cas. » (Parents, GA 32 to 37 weeks)*

« Ah, oui. J'ai été très perturbée à un moment parce qu'il y a eu beaucoup de discours qui semblaient être antagonistes les uns avec les autres. J'ai même fini par noter. C'était un peu fou. […] Ils ont considéré qu'il faisait parfois des coliques et donc on nous dit : […]"Mais il ne faut pas lui donner trop souvent le sein parce que ça va stimuler les coliques." "Oui mais en même temps il va avoir des poussées de croissance et donc s'il demande plus le sein, il faut lui donner." Finalement, moi, j'étais persuadée qu'il y avait du reflux plus que des coliques. A ce moment-là on nous dit : "Ah mais alors si c'est le reflux, il faut vraiment essayer de maintenir un écart suffisant entre deux tétées." Mais encore à côté de ça on nous disait : "Attention la glycémie, attention…" Enfin, c'était à se tirer les cheveux, là. » (Mother, GA 32 to 37 weeks)

5.3.10 Improvements suggested by parents

Key points

Parents suggested the following improvements of neonatal care:

- **The generalisation of family rooms, couplet rooms and IFCDC in neonatal wards**
- **A hotel function for all parents living far away from the hospital**
- **Simplified administrative procedures**
- **Longer maternity stay for mothers with a preterm baby**
- **Longer parental leave for parents with a preterm baby**
- **Harmonisation of breastfeeding support**
- **Additional support for parents with siblings**

Generalisation of family rooms

The generalisation of family rooms could stimulate the development of peer support networks between parents and compensate for the lack of space in the open bay neonatal wards. Family rooms are decompression chambers where parents can relax, do activities with siblings or engage in professional activities.

"Ja in het ziekenhuis, als je in het ziekenhuis zijt, zijt ge in het ziekenhuis. En ge kunt wel uw laptop meenemen bijvoorbeeld, of je kunt wel een boek lezen, maar de mogelijkheid van dingen dat ge daar kunt doen is ook wel beperkt. Dus ja misschien dat dat ook nog wel zoiets is van goh, als er daar, er was ook wel een ouderkamer waar dat ge dan kon gaan zitten bijvoorbeeld." (Father of twins, GA 28 to 31 weeks)

« C'est, ce n'est pas toujours possible. Maintenant c'est vrai que, allez, le fait que comme quand, dans les hérissons, tu avais la petite cuisine où on pouvait justement se retrouver entre parents et discuter à ce moment-là en, en mangeant un bout. Mais ça c'est vrai que ça c'est quelque chose qui pourrait être, je veux dire, étendu à, un peu plus quoi. […] Mais je trouve qu'il faut aussi, voilà, favoriser justement les liens entre les parents, en tout cas ceux qui le souhaitent, faut qu'il y ait, pas forcément le forcer parce que y a des gens qui n'ont peut-être pas envie de ça mais euh voilà, je trouve que ça permet justement d'échanger un peu son vécu, je l'ai déjà dit plusieurs fois, mais de se rassurer de son courage et d'échanger des fois les bons plans. » (Mother, GA 32 to 37 weeks)

A hotel function for all parents living far away from the hospital

While individual and/or couplet rooms were preferred by parents, they proposed to have at least a hotel function for parents living far away from the hospital to decrease exhaustion and financial burden of travels.

> *« Les transports ne sont pas remboursés donc une maman qui en plus voilà elle- tu sentais que- enfin voilà elle nous expliquait que financièrement c'était un peu compliqué pour elle et toutes ses économies étaient parties dans les transports pour venir à la néonat voir son enfant quoi. Donc ça c'est vrai que c'est des choses qui font réfléchir et que tu te dis bon voilà- tu te dis : « Bon bah on avait de la chance d'avoir juste une bagnole en fait. » (Mother, GA less than 28 weeks)*

Generalisation of individual and couplet rooms in neonatal wards

More than individual rooms, parents recommended couplet rooms. Couplet rooms allowed parents (both mother and father) to be with their baby, day and night. According to the parents, it helped them to take charge of their role as parents by, for example, taking over some of the care tasks from nurses. However, this form of accommodation should not be imposed on parents. The specific situations of each family should be taken into account (e.g. giving priority access to these rooms to parents of very preterm babies, understanding mothers who do not want to use these rooms because they want to leave the hospital after a long MIC stay, etc.). Individual rooms allowed parents to have more privacy and involve the siblings in the care for the baby.

> *"Ja, nee, zoals ik al zei uhm die aparte kamertjes. […]. Dus ik vind dat wel een minimum van een ziekenhuis dat het daar dan in investeert. Want ik denk dat het een echte investering is. Dat die misschien iets of wat steun of label of ik weet niet wat moeten krijgen. Of ondersteund om de werken te doen. Dat ge als ouder ook die mogelijkheid krijgt 24/7 er zijn. Ja, dan moet ge op een zetel slapen. Dat is uw eigen keuze dan. Dan denk ik: ja, er mag wel een switch zijn meer naar Scandinavische normen dan naar, naar wat prioritair is in dat, in dat aspect. En ik denk dat beide partijen op termijn er baat bij kunnen hebben want ouders kunnen zaken overnemen van verpleegkundigen. […] En hospitalisatieduur kan mijn inziens wel verkort worden door kinderen die meer op hun gemak zijn. En verpleegkundigen die meer op hun gemak zijn want ze moeten niet meer bijvoorbeeld met kinderen zitten spelen bij wijze van spreken. Dat kunnen de ouders doen. Dus ik vind voor zo'n dingen standaard moeten worden." (Mother, GA 28 to 31 weeks)*

> *"Ik zou echt dolgelukkig zijn, want elk verhaal van een vroeggeboorte is volgens mij heel, allez kan wel echt pijnlijk zijn. Maar dat gescheiden zijn van elkaar, gewoon dat, zo echt, allez dat zou toch normaal moeten zijn dat ge bij uw kindje kunt blijven, dacht en nacht. Of toch de keuze moet kunnen hebben. Dat zou naar mijn gevoel heel ons verhaal anders inkleuren. Als ik er maar bij kon zijn, dan had ik wel het gevoel gehad dat ik mama was. En dat is maar gekomen als die thuis is gekomen en dan nog." (Mother, GA 32 to 37 weeks)*

> *« J'ai cru comprendre que les chambres mère-enfant étaient un peu exceptionnelles. Euh… Je pense que le développer plus serait chouette. Pas systématiquement parce que j'ai compris aussi que par exemple les mères longtemps hospitalisées qui finissaient par accoucher donc prématurément, euh souvent n'avaient plus envie de rester hospitalisées. Et les mères avec un- déjà des premiers enfants, je crois qu'elles ne sont pas forcément friandes de rester. Ou alors de les organiser différemment. C'est-à-dire- parce qu'en fait quand on nous dit : "Vous avez une chambre mère-enfant", il faut quand même l'utiliser entre guillemets. Euh donc faut pas venir dormir seulement deux nuits sur la semaine. Or peut-être que des mamans avec déjà d'autres enfants, peut-être que ça elles aimeraient bien. Donc ces chambres-là, les développer. En tout cas développer cette opportunité. » (Mother, GA 32 to 37 weeks)*

Simplified administrative procedures

Administrative procedures need to be finalised within a specific time frame, while it is particularly difficult for parents to initiate administrative procedures when the survival of the neonates is unsure. It would be more comfortable for parents of preterm babies to have more time to settle down administration.

> *« **Maman :** Même, même pour tout ce qui est démarches hein, on ne tient pas compte, voilà, on a les mêmes délais que les autres parents alors que ben on, enfin voilà. Moi je l'ai inscrite à la mutuelle mais vraiment au tout dernier délai parce que je n'étais pas sure qu'elle allait survivre et que moi je voulais, enfin pour moi ce n'était pas possible de me projeter, de faire les démarches en sachant pas si quelques jours après je ne devais pas faire les démarches, inverses et la désinscrire de partout en disant "mon enfant est morte", quoi. S'inscrire à la commune, plein de choses, on a été vraiment au bout du délai mais il n'y a pas de délai supplémentaire accordé alors que c'est des situations qui sont très particulières. On parle d'un enfant qui est entre la vie et la mort et des parents qui sont dans un état euh, on ne peut même pas décrire. **Papa :** Ou du moins si on ne sait pas nous aider sur le moment et cetera, il faudrait que d'office les délais soient prolongés. […] Oui, doublés ou triplés ou adaptés. Je ne sais pas mais c'est certain qu'on devrait le faire en sorte. On ne doit pas pouvoir, dans notre cas à nous, on devait faire les démarches pendant qu'elle était encore hospitalisée. » (Parents, GA less than 28 weeks)*

Longer maternity stay for mothers with a preterm baby

Parents suggested a longer maternity stay for mothers with a preterm birth, because the recovery of the mother is more complicated when she is discharged and needs to go back and forth between home and the hospital every day.

> *« Très- très concrètement par rapport à la maternité, le fait de donner une certaine souplesse au niveau de la durée de séjour euh… Voilà je pense que ces fameux quatre jours obligatoires au niveau des césariennes, qu'il y ait ou qu'il n'y ait pas des bébés en néonat, euh… C'est- ça c'est du costaud quoi et c'est- c'est le pire moment au niveau de la chute hormonale, au niveau de la montée de lait et cetera, c'est le pire moment pour faire sortir le- les mères [séparées] […] de leurs bébés, clairement. […] je pense qu'effectivement ce n'est pas possible [de garder des mamans plusieurs mois en néonat], mais au moins le temps que la maman ait la possibilité entre guillemets de tenir sur ces deux jambes. » (Mother of twins, GA 28 to 31 weeks)*

> *« D'office il devrait y avoir quelque chose, vous passez en néonat, ben votre séjour de maternité ce n'est pas quatre jours, c'est autant de jours. S'il y a une pathologie, c'est autant de jours, il devrait y avoir quelque chose, un tableau, les nomenclatures devraient être établies, ça c'est clair, ce n'est pas. […] En fonction des pathologies ou ou du temps que le bébé passe en en néonatologie quoi. » (Father, GA less than 28 weeks)*

Longer parental leave for parents with a preterm baby

Parents suggest that paternity leave should be extended when the baby needs hospital care. They also suggest that parental leave should be adapted to the baby's care needs at the moment of discharge. This is especially needed in case the baby still requires a lot of care from his parents after discharge and cannot be cared for in a childcare facility.

> *"Dus, dus eh er wordt heel hard in het ziekenhuis en, en daar rond eh gedacht aan de baby en aan de mama, maar de papa's worden eigenlijk, die vallen echt wel uit de boot. Eh en dan vooral als ge in, in, in zo'n traject zit. Eh dan wil ik het n-, allee, een gewone bevalling, ben ik heel blij dat ze daar het recht hebben opgebouwd naar twintig dagen, maar ook hier is eigenlijk twintig dagen nogal, nogal weinig." (Mother, GA less than 28 weeks)*

> *« J'aurais dû reprendre le travail alors qu'au final ma fille n'a pas 3 mois d'âge corrigé. [silence] À part l'allaiter, elle ne mange rien d'autre. Et elle a des soucis d'immunité, neutropénie sévère, elle a une grande anémie. Donc, ici, elle est suivie par la cheffe hématologue de [lieu]. Qui m'a dit que : « Non, il fallait absolument*

continuer l'allaitement maternel, le plus longtemps possible, pour essayer qu'elle ait un petit peu mes défenses immunitaires à moi. » Plus une allergie aux protéines de lait de vache chez elle, donc si on doit prendre un lait artificiel ben… Ça ne va pas être facile non plus. Et euh donc voilà, puis cinq mois, elle est tellement petite, j'ai encore plein de rendez-vous médicaux parce qu'aucune crèche, aucune accueillante n'acceptera un bébé dans ces conditions. Et- autant dire que ça ne fait pas longtemps non plus qu'on a retiré le monitoring portable hein, elle est sortie de néonat avec un monitoring. Ben voilà- donc il n'y a personne qui veut la garder dans ces conditions. Euh les médecins voilà- si la seule affirmative que j'ai eu, c'est de me mettre sous certificat médical. En ayant mon employeur qui ne l'accepte pas et qui m'a déjà dit qu'il ne me paierait pas. C'est pénible. […] Ben, oui, parce que je pense qu'il faudrait tenir en compte l'âge corrigé de bébé dans ces congés- autant pour les mamans que pour les papas parce que… Voilà, mon compagnon le vit très mal par exemple de ne pas pouvoir aller à un seul rendez-vous médicaux avec la petite. » (Mother, GA 28 to 31 weeks)

Harmonisation of breastfeeding support

Parents suggest that harmonising the discourse around breastfeeding allows mothers to support breastfeeding without the pressure of conflicting advice or the feeling of being judged. They also recommend that the presence of lactation consultants is generalised in all neonatal wards.

*« **Papa :** Cette histoire d'allaitement et la pression qu'ils mettent sur la maman, voilà, ça c'est un problème. […] Mais il faut être honnête aussi, quand à chaque fois qu'il est venu nous en parler, c'est peut-être ça aussi le problème, c'est que voilà, on parle du sujet et de toutes les possibilités [et ce n'était] pas très structuré, de "voilà, aujourd'hui, c'est ça le, voilà ce qu'on pourrait faire", "ah oui ben écoutez oui, ce que vous dites, oui, c'est une possibilité aussi". […] cette communication se fait dans sa globalité n'est pas extrêmement précise, euh et focus. **Maman :** Et puis ce côté jugement […] de certaines infirmières qui suivent certaines formations. **Papa :** Ça ne devait pas vraiment, j'ai l'impression que l'approche de l'hôpital, globale est assez claire, sans ambiguïté. Mais le reste est quand même assez subjectif d'une infirmière à l'autre. […] Et il y a des conseils qui sont donnés par certains membres de personnel, enfin infirmier, qui sont différents d'une infirmière à l'autre. » (Parents, GA 32 to 37 weeks)*

"Uhm dat ze al in de NICU al, denk ik, wat meer uhm bezig zijn met, met de borstvoeding en de flesjes vind ik. Want nu zijn we ineens overgeplaatst naar de N en daar begon het dan echt zo de fles en de borstvoeding. Ze zijn wel, allee… Ze hebben ons wel geholpen, dat wel. […] Allee, dat was fijn. En, en daar waren dan meer lactatiedeskundigen… die u daarbij konden helpen want daardoor heeft hem langer moeten blijven in het ziekenhuis." (Mother, GA less than 28 weeks)*

Generalisation of the NIDCAP approach

Parents suggested generalising the NIDCAP approach because it is very supportive in the development of parenthood and the development of their child.

*« **Papa :** Ah oui, tout à fait moi- poursuivre et implémenter le NIDCAP partout c'est… Des soins personnalisés à l'enfant, de l'observation de l'enfant pour- extérieur par rapport aux soins pour améliorer la situation, l'intégration des parents, le kangourou tout ça c'est… Ouais c'est fantastique ça. **Maman :** Ça nous a permis de se sentir parents en fait à un moment donné, d'avoir l'impression d'être actif, acteur du truc. » (Parents, GA less than 28 weeks)*

Additional support for parents with siblings

The parents suggested that childcare solutions should be put in place for the siblings. These could take several forms: childcare at home, in childcare centres, or at hospital. During this care the siblings should be offered psychological support. Flemish parents also mentioned maternity assistance (Kraamhulp) could be useful to support the family even if the baby is still in hospital.

« Ah on devrait mettre quelque chose en place, obligé. Parce que c'est ce que je dis, tout le monde n'a peut-être pas cette chance-là, on devrait pouvoir avoir soit des familles d'accueil ou des trucs comme ça, je veux dire, que ça soit. Ou des centres d'accueil. De la même façon qu'on accueille le nouveau prématuré, on devrait pouvoir accueillir les, la fratrie, parce qu'ils ont probablement aussi besoin d'être rassurés, pourquoi maman n'est pas là, pourquoi bébé il était dans le ventre de maman, maintenant il est plus là. Pourquoi est-ce que papa je le vois qu'en coup de vent et y a, y a tout ça. » (Father, GA less than 28 weeks)

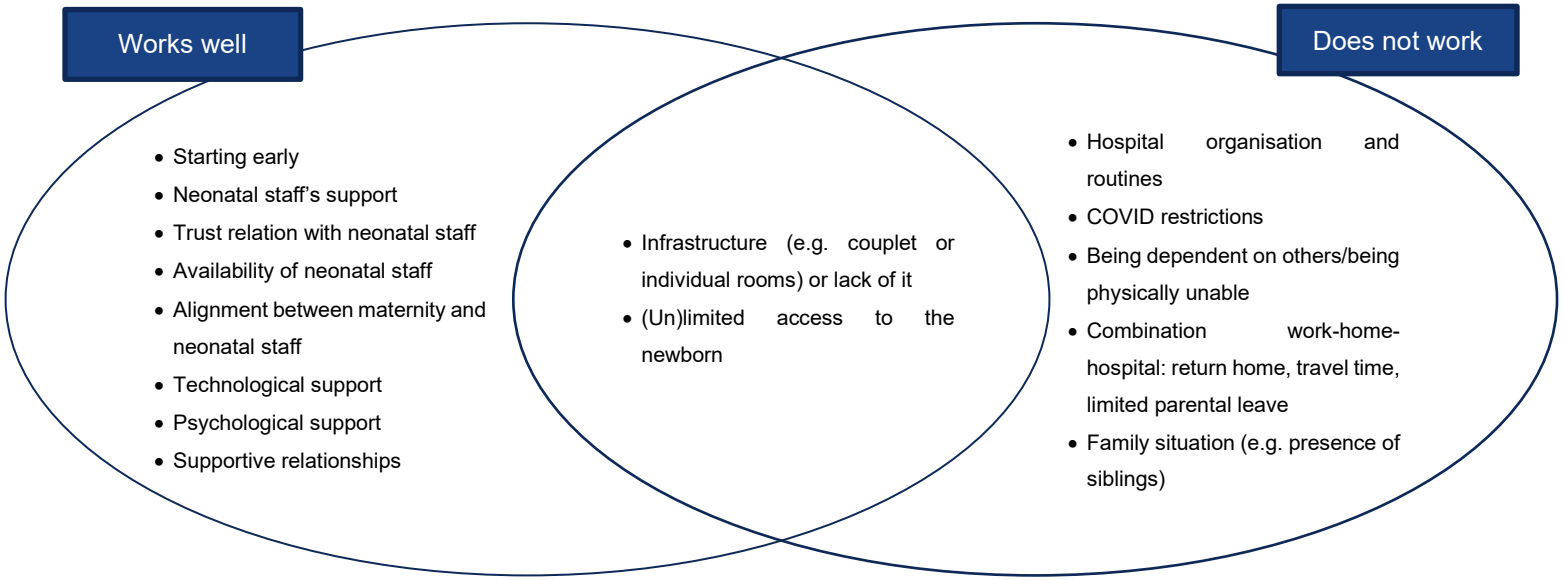
5.3.11 Conclusion and discussion

To gather information on parents' perspectives on neonatal care we conducted 25 interviews with parents who reported on their experiences with 22 neonatal wards. The sample is well balanced in terms of language, gestational age, parity, twin pregnancies, type of hospital, and the need for a transfer between hospitals. However, geographically the sample of the French speaking parents is mostly concentrated in Brussels and near the linguistic border. Luxemburg, Brabant Wallon and a large part of Namur were not represented. In 15 interviews fathers were involved.

The interviews covered the advantages of anticipating preterm birth, gender specific difficulties for mothers and fathers, the importance of different types of social support, the conditions to build a partnership between parents and neonatal staff, the meaning of active involvement and separation, challenges and opportunities regarding (breast)feeding and skin-to-skin care and parent's suggestions for improvements of neonatal care.

Throughout these topics we identified what helped parents cope with their newborns' stay at a neonatal ward (see Figure 11). Facilitators were starting early with IFCDC, the neonatal staff's support and availability, a trust relationship with the neonatal staff, alignment between maternity and neonatal staff, the use of technological support (e.g. apps, tablets, camera's), psychological support and supportive relationships (e.g. with peers, family members, friends, but also hospital staff). Barriers were the rigidity of the hospital organization and routines, the combination work-home-hospital due to the early discharge of the mother, the subsequent travel time between the home and the neonatal service, and the limited paternity leave, COVID-19 restrictions, dependency on others and physical capabilities and the family situation, mostly the presence of siblings. Factors which had both a facilitating and hampering impact were infrastructure (e.g. individual rooms) or lack of it and the (un)limited access to the newborn.

Figure 11 – What helped parents to cope with their newborn's stay at a neonatal ward?



We close this chapter by a number of limitations of the parents' interviewing round. First, parents have been recruited by means of social media in French or Dutch. This introduced a selection bias excluding parents speaking another language or parents who do not use social media. In addition, we do not have information on the affiliation with parent organisations or socioeconomic status, which could also have led to a selection bias. The use of a videoconferencing application can have contributed to a selection bias. However, due to the COVID-19 pandemic at the time of the interviewing, there was no alternative. This bring us at the second limitation: the COVID-19 pandemic could not be denied during the interviews. COVID-19 imposed severe restrictions for parents which means that some topics such as accessibility can be overestimated in comparison to before the COVID-19 pandemic. Also, during COVID-19 waves less babies were admitted to neonatal wards, which may also have influenced parents' experiences. Third, the sample of parents did not contain parents living in the province of Luxembourg, while it overrepresented parents living in Brussels Capital region. Fourth, based on parents' interviews we cannot differentiate the findings between N* and NIC wards.

Despite these limitations we could identify what worked or did not work for parents of a preterm baby when looking back to their stay at the maternity ward and neonatal ward. We linked these do and don'ts with the key principles of IFCDC, such as starting early, partnership between parents and neonatal staff, and avoiding separation between parents and child.

6 HEALTHCARE PROFESSIONALS' EVALUATION OF IFCDC

6.1 Key points

- **Although IFCDC is scientifically grounded, it is not universally implemented as the standard of care.**
- **We identified the following core principles of IFCDC: the whole family, including siblings, is involved in taking care of the newborn; parents actively carrry out care tasks together with professionals; parents and child are kept together as much as possible; care tasks are carried out in function of the rhythm of the baby, taking into account the possibilities and bearing capacity of the parents; complete transparency of information towards parents; IFCDC starts before birth and IFCDC continues after discharge.**
- **The conditions to put IFCDC successfully in practice are neonatal wards having adequate resources (i.e. finances, staff and infrastructure) available, neonatal wards being supported by their hospital administrators to create the right implementation climate (i.e. installing a learning climate, making IFCDC a relative priority), staff having access to knowledge and information and IFCDC being compatible with existing workflow. Conditions external to the hospital or neonatal service, such as peer pressure, policy, knowing patient needs and being part of a network of external organisations, can also contribute to the implementation of IFCDC.**
- **Adequate staffing and infrastructure is essential in the implementation of IFCDC. Lack of resources, especially lack of staff, was the main barrier to successfully implement IFCDC. Transfers of infants between N* and NIC wards are affected by hospitals' financial interests.**
- **The neonatal landscape needs a profound change to enable all neonatal wards to implement and develop IFCDC.**

- **Leadership engagement from hospital administrators is a prerequisite to the implementation of IFCDC. Leadership engagement is closely linked to the available resources. Both leadership engagement and available resources determine the access to knowledge and information of the neonatal staff, the learning climate, the relative priority and readiness for implementation of IFCDC.**
- **IFCDC is facilitated by compatible workflows, not only within the same hospital, but also between collaborating hospitals. If existing workflows are too much under pressure (mostly because of time pressure or lack of staff), IFCDC is abandonned.**
- **Peer hospitals push to get on the same footing regarding the implementation of IFCDC. In case of a referral, it is expected that the family gets the same quality of care in the receiving services as is the case in the referring service.**
- **IFCDC is also stimulated when *patient/parent needs*, and the ways to meet those needs, are known and considered important by the neonatal service and the hospital by extension.**
- **Parents need additional support such as adapted parental leave, an affordable hotel function in hospital, and sibling day-care to be available for their newborn(s) at neonatal service.**

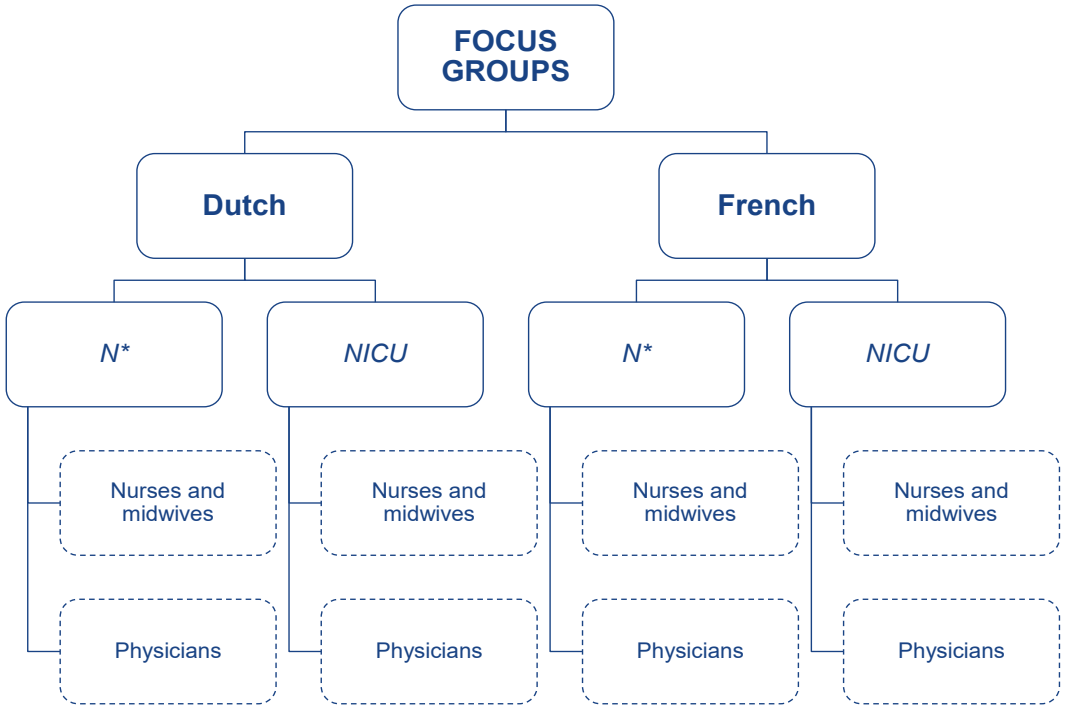
6.2 Methods

6.2.1 Online focus groups

In order to collect data on perspectives of healthcare professionals on IFCDC in neonatal care, we organised eight online focus groups. Focus groups are group semi-structured interviews used for the purpose of information gathering focused on a specific subject.[248] Focus groups allow interaction between participants, which means rich data can be generated in a short time. From the group dynamic, topics can emerge that otherwise might be unobservable. As focus groups allow interaction among participants, the group dynamics can bring about insights in ways individual interviews may not be able to do. The interaction between participants may result in more in-depth information and elicit a broader range of perspectives related to the carefully designed questions.

Focus groups for this study were stratified according to language (i.e. two French focus groups and two Dutch focus groups), professional group (i.e. nurses and midwives versus physicians), and ward of employment (i.e. N* or NIC ward). Figure 12 visualises the distribution of the different focus groups. Moderation of the focus groups has been carried out by two native French-speaking researchers (NB was moderator and EC was observer) for the French speaking groups and two native Dutch-speaking researchers (WC was moderator and JD was observer) for the Dutch speaking groups. In both groups, the researcher who conducted the interviews with parents of preterm newborns was present (either as a moderator or as an observer). Due to the COVID-19 measures in place at the time, focus groups were organised online using the videoconferencing software Zoom®. Focus groups were scheduled between 31 May and 20 June 2021. The focus groups lasted between 114 to 171 minutes. All focus group interviews have been transcribed verbatim.

Figure 12 – Distribution of the focus groups



6.2.2 *Sampling and selection*

An open call was launched to recruit healthcare professionals working in a Belgian neonatal ward. The open call was sent to the KCE mailing list, several Belgian professional organisations for healthcare professionals working in neonatal care and was shared on social media. Candidates could apply via a structured application form on the KCE website. The application form requested the following information: name, hospital and ward of employment, job title and the availabilities for the focus group per professional group (i.e. two possible dates per professional group).

Participants were selected based on their availability (for each professional group the date available for most candidates was chosen) and in view of assembling the most diverse group possible (in terms of location and hospital type).

Finally, 40 healthcare professionals participated in the online focus groups. The sample consisted of a heterogeneous group regarding gender, professional group, hospital type, and ward of employment. Location of the hospitals was not that fairly distributed. We noticed that some hospitals were overrepresented, while for some provinces we had no participants (i.e. Luxemburg and Walloon Brabant). Table 29 provides an overview of the main characteristics of the participants

Table 29 – Characteristics of the participants of the focus groups

	Dutch focus groups (n = 24)						French focus groups (n = 16)					
	Nurses and midwives			Physicians			Nurses and midwives			Physicians		
	*N**	*NIC*	*N* and NIC*	*N**	*NIC*	*N* and NIC*	*N**	*NIC*	*N* and NIC*	*N**	*NIC*	*N* and NIC*
Gender												
Male	-	2	-	2	1	1	-	-	-	-	1	2
Female	7	3	2	3	2	1	2	3	2	3	3	-
Hospital type												
General hospital	7	3	2	5	2	1	1	2	-	2	3	2
University hospital	-	2	-	-	1	1	1	1	2	1	1	-
Location of the hospital												
Antwerp	2	2	-	1	1	1	-	-	-	-	-	-
East-Flanders	1	2	2	1	1	-	-	-	-	-	-	-
Flemish-Brabant	-	-	-	1	1	1	-	-	-	-	-	-
Limburg	1	-	-	-	-	-	-	-	-	-	-	-
West-Flanders	3	1	-	2	-	-	-	-	-	-	-	-
Hainaut	-	-	-	-	-	-	1	-	-	-	-	1
Liège	-	-	-	-	-	-	-	1	-	-	-	1
Luxemburg	-	-	-	-	-	-	-	-	-	-	-	-

Namur	-	-	-	-	-	-	1	-	-	1	2	-
Walloon Brabant	-	-	-	-	-	-	-	-	-	-	-	-
Brussels Capital Region	-	-	-	-	-	-	-	2	2	2	2	-

6.2.3 *Data collection and analysis*

The focus groups were moderated by means of a semi-structured interview guide, which can be consulted in Appendix 5. During the focus group, topics and statements were visualised by the observer using post-it's on a Miro® board. All participants could see this so that they were able to give feedback if statements were not in line with their message or not noted correctly.

Transcripts have been coded in NVivo© by two KCE researchers (WC and NB) in their respective language. After the coding of one interview in each language, code trees have been compared and discussed. After coding all data, clustering of both Dutch and French codes was performed by one researcher. The result was an overarching node tree including both the Dutch and French data. An inductive thematic analysis has been performed. Nodes have been clustered together in several themes. Subsequent analytic steps (e.g. explorative query's in NVivo©) and drafting of the report were done by one researcher. We added quotes (in the mother-tongue of the participant) to the text. The text stands on its own, quotes are only added as an illustration of the finding. Note that the characteristics between brackets refer to the focus group, not the individual participant.

6.3 Results

6.3.1 *The importance of infant- and family-centred developmental care (IFCDC)*

6.3.1.1 *Societal importance of a good start in life*

We would like to start this chapter with the call of our interviewees for more societal recognition of the importance of neonatal care. Throughout our data collection round, they emphasised that an investment in the start of life, has lifelong positive returns, at the individual, but also at the societal level.

> *"Als je aan de basis alles goed doet opstarten hebt je voor de rest van uw leven daar voordeel van." (Physician, N*)*

> *"Ik denk dat je als maatschappij moet nadenken over wat belangrijk is. Het belang van een goeie zorg voor kinderen en pasgeborenen lijkt niet genoeg benadrukt." (Physician, N*)*

6.3.1.2 *Although IFCDC is scientifically grounded, it is not universally accepted as the standard of care*

The interviewees stated that the scientific knowledge base about the merits of IFCDC is sufficiently developed and convincing. Nevertheless, believers have to fight to put IFCDC in practice even in hospitals that are, at least on paper, in favour of IFCDC. Convincing professionals about the merits and importance of IFCDC seems to be a never-ending effort. However, in the focus groups the general belief was that IFCDC should not be questioned and be a universal self-evident practice.

"Dus het stadium van eh werkt dit allemaal wel en eh klopt het wel allemaal wat men vertelt, dat is eigenlijk al gepasseerd. Ik denk dat men voldoende wetenschappelijke evidentie heeft en voldoende erkenning heeft vanuit verschillende, ook vanuit politieke organen, dat de gezinsgerichte zorg, dat dat standard of care moet worden of moet zijn in de toekomst." (Physician, NICU)

« Moi aussi je crois que je reste convaincue du bien fondé et je me bats pour ça. Mais je me rends compte que dans les équipes, même si sur papier on est pour le bien fondé. Dans la réalité, dans la pratique y a régulièrement des tensions, parce que c'est vrai qu'on est obligés de composer. On ne peut pas faire comme on voulait." (Physician, NICU)

"Ontwikkelingsgerichte zorg heeft, als ge het puur wetenschappelijk bekijkt, eh harde eindpunten die ver in de toekomst liggen. En die zijn altijd multifactorieel (…) en dat is heel moeilijk hard te maken met RCT's. (…) Dus je moet de mensen de basis waarop dat allemaal gebaseerd is blijven duidelijk maken. Want het is niet evident om het te accepteren. Ik denk dat dat een permanente opdracht is." (Physician, NICU)

"Op de pediatrie is dat gewoon algemene praktijk. Daar is er geen discussie meer over dat er een ouder bij zijn kind blijft. Dat is een vanzelfsprekendheid. Maar het onderscheid wordt gemaakt op basis van of het kind ouder is of jonger dan 28 dagen. Is een kind ouder dan 28 dagen (…) dan komt het op de pediatrie terecht en gaat het eigenlijk sowieso in een ouder-kind kamer terechtkomen. Is het kind jonger dan 28 dagen dan komt het op de neonatologie terecht in veel gevallen. En daar is het een ander verhaal. Dus eigenlijk wordt er gewerkt met twee maten en twee gewichten voor kinderen ouder en jonger dan 28 dagen." (Nurse/midwife, NICU)

6.3.2 Core principles of IFCDC

From the accounts of the professionals, it was clear that IFCDC is associated with several core principles. However, professionals differ in the principles they consider essential for IFCDC. In what follows we describe the principles we could identify in general terms. In the next section (see 6.3.3) we will go into more detail and address how the principles are put in practice.

- **The whole family, including siblings, is involved in taking care of the newborn**

  Among the interviewees there is a willingness to broaden this involvement to the extended family, with for example grandparents as important sources of social support for the parents. However, this is currently mostly limited to intentions for the future as it is not yet implemented everywhere to the same extend.

  "Dus voor mij is eigenlijk uiteindelijk de gezinsgerichte neonatale zorg het betrekken van gans het gezin, al dan niet met brusjes, en hen effectief van eigenlijk al bijna prenataal tot postnataal meer en meer aanwezig te hebben in het ziekenhuis." (Physician, N)*

  "Dat er situaties zijn waarbij je inderdaad wel het hele gezin of opa's en oma's toe wil laten om het gezin verder te ondersteunen, omdat die daar natuurlijk ook wel een rol in spelen." (Physician, NICU)

  « On permet aussi à la fratrie de rentrer tout le temps en néonat et donc ça, ça accentue aussi fort je trouve les soins centrés sur la famille. » (Nurse/midwife, NICU)

  « Je pense que les parents sont aussi conscients que leur présence auprès de leur bébé est importante. Et les papas sont beaucoup plus impliqués, au jour d'aujourd'hui que y a 20 ans. Et ils veulent aussi faire partie de cette famille. Donc la parentalité, ce n'est pas que la maman, c'est aussi le papa. Et puis après, y a la fratrie, bien sûr donc… Oui, on a encore du chemin. » (Physician, N)*

- **Parents actively carry out care tasks together with professionals**

  One of the key elements in IFCDC seems to be sharing care tasks between professionals and parents. Parents are early instructed on how to take up the role of partners in care.

  > *« Ils sont maintenant convaincu de vraiment inclure les parents dans les soins et ils même apprendre les parents de faire les soins avec eux pour que les soins sont toujours fait à quatre mains. Et les parents, tous au début apprennent comment ils peuvent soutenir le bébé pour les différents soins. » (Physician, NICU)*

  > *"En dan komt het erop aan dat we geleidelijk aan de ouders willen introduceren in het een deel overnemen van de zorg voor hun kind, waarbij dat we moeten proberen rekening te houden met het draagvlak van de ouders." (Physician, NICU)*

- **Parents and child are kept together as much as possible**

  Another important element is that professionals organise care in such a way that parents and child can stay together. The emphasis seems to lay on mother and child, although partners are often mentioned too. This also implies that parents get the opportunity to be with their infant 24/7. In other words, parents are no longer perceived as visitors, but as part of the team.

  > *"Het samenhouden van het gezin en toch zeker de moeder en het kind samen, dat is één van de belangrijkere zaken". (Physician, NICU)*

  > *"Waarbij dat de ouders actief betrokken worden in de zorg bij ons. We hebben geen bezoekuren. Ouders worden niet gezien als bezoek. Ze mogen 24 uur op 24 binnen." (Nurse/midwife, NICU)*

  > *« Donc tout ça, on essaie de mettre en œuvre le plus tôt possible la présence des parents, des deux parents, est possible 24 heures sur 24 et les parents peuvent toujours rester dormir même si c'est des soins très intensifs. » (Nurse/midwife, NICU)*

- **Care tasks are carried out in function of the rhythm of the baby, taking into account the possibilities and bearing capacity of the parents**

  IFCDC is organised in function of the rhythm of the baby, meaning that for example the baby is not woken up for examinations or feeding. Parents are instructed how to recognise and interpret signals of their newborn. In addition, the availability and capabilities of parents are taken into account. This means that IFCDC is not a uniform package but is customised to parents' and newborns' needs and capacities.

  > *« Je dirais que c'est essayer de changer de paradigme. Quand j'ai commencé, ben c'était tout au médecin et c'était le médecin qui mettait un peu le rythme à la fois pour les- pour les soins ou- ou suivre les enfants. Et aussi bien au niveau infirmier avec des heures très précises. Et je dirais que ben voilà on a constaté que c'est important plutôt de suivre le rythme du bébé. Et donc y a toute une modification (…) pour centrer tout ce que l'on fait à l'enfant, que ce soit les soins, l'alimentation, le bain, enfin tous les soins qu'on peut lui apporter au niveau de son suivi, plutôt le suivi basé sur son rythme à lui. » (Physician, N*)*

  > *"Dat eigenlijk de ouders dermate worden betrokken in het herkennen van hun kind, in de zorgverlening van hun kind. En dit eigenlijk onbeperkt. Ik bedoel daarmee (…) op het ritme van het kind en wanneer ook de ouders kunnen komen." (Nurse/midwife, NICU)*

  > *"En dan komt het erop aan dat we geleidelijk aan de ouders willen introduceren in het een deel overnemen van de zorg voor hun kind, waarbij dat we moeten proberen rekening te houden met het draagvlak van de ouders. Draagvlak op gebied van wat kunnen zij aan qua zorg, maar ook bijvoorbeeld op gebied van taal." (Physician, NICU)*

  > *"Dat zijn ook wel zaken die maken dat je eigenlijk geen eenduidige omschrijving kunt hebben van familiegerichte zorg. Bij sommigen kun je daar heel ver in gaan en bij anderen moet je aan het beginstadium eigenlijk een beetje blijven hangen. Het finale doel in*

feite is de ouders zodanig vertrouwd te maken met de zorg voor hun baby dat zij op een bepaald ogenblik aangeven dat ze klaar zijn om die zorg over te nemen in de thuissituatie. En ook dat is heel dynamisch hè, dat is afhankelijk van gezin tot gezin." (Physician, NICU)

- **Complete transparency of information towards parents**

  Communication and transparency of information facilitate IFCDC, in a sense that they are a precondition to parental involvement. Information transfer is organised in different ways and at different levels, depending on the way a neonatal service is organised and, on the parents' wishes. For example, in some neonatal wards parents can participate in the neonatologists' tour through the ward, but this is not yet the case everywhere.

  « Partager en toute transparence, tous les éléments médicaux concernant leur enfant. Vraiment favoriser le partage de manière prolongée. » (Physician, NICU)

  « Donc en fait dans nos pratiques quotidiennes, tous les jours, les pédiatres voient les enfants et en général à ce moment-là ils voient les parents au pied du lit des enfants. Puis après deux trois jours, souvent ils leur proposent alors, tous les jours on a un tour médical où se réunissent tous les médecins, et les infirmières à tour de rôle vont prendre les infos pour les bébés dont elles s'occupent, et alors à ce moment-là on emmène le parent. » (Nurse/midwife, NICU)

  "Maar ik heb het gevoel dat wij daarin een beetje moeten compenseren, omdat we de continue aanwezigheid niet altijd kunnen garanderen, proberen wij daar toch dagelijks oudergesprekken te hebben met patiënten, zeker de eerste dagen als de mama er nog, of de papa er nog altijd zijn in het materniteitsgebeuren. En anders proberen wij toch continu eigenlijk feedback te geven. Niet alleen via de verpleging maar ook via de artsen." (Physician, NICU)

- **IFCDC starts before birth**

  In case risk factors for preterm birth are present, parents are already introduced to neonatal care during pregnancy. To familiarise them with the neonatal service, they get for example a guided visit through the neonatal ward.

  "Ik denk ook dat het gesprek vaak ook al voorafgaand aan de bevalling begint. Ouders, zwangeren met risicofactoren, al eens te spreken persoonlijk op de MIC waarbij ouders al uitleg krijgen van wat ze staat te wachten, zodat ze daar een klein beetje op kunnen anticiperen. Ze uitnodigen op diensten, een keer met de verpleegkundige een toer over de zaal te kunnen doen, zodat ze al iets van voorbereiding hebben." (Physician, NICU)

  « Je pense que chez nous on utilise déjà très bien le « Family Integrated Care ». Et ça commence déjà en anténatal. On explique toujours aux parents en binôme avec une infirmière et un néonatologue, comment ça va se dérouler dans notre service. » (Physician, NICU)

- **IFCDC continues after discharge**

  IFCDC is potentially stretched out over a long period of time as it ideally starts before birth and continues after discharge. Interviewees plead for the continuation of care and support at home by a midwife or nurse doing home visits, as well as a regular contact with the neonatal staff, by phone or through consultations.

  "Die familiegerichte zorg (…) dat begint niet bij de muur van het ziekenhuis en dat stopt niet bij de muur van het ziekenhuis. Dat gaat breder. En misschien was de bedoeling van jullie van te spreken over een kamer moeder met (…) een verpleegster die af en toe een keer komt kijken. Maar dat is niet waar hè. Dat gaat veel verder dan dat." (Physician, N)*

  "Dus ik denk ook na het ontslag uit het ziekenhuis moeten we zorgen dat de zorg thuis gecontinueerd kan worden, zodat iedereen de standaard zorg krijgt, iedereen een vroedvrouw aan

huis kan hebben, en dat de opvolging op de pediatrie financieel haalbaar." (Physician, NICU)

6.3.3 Description of IFCDC in practice

In this section we will describe how the core principles of IFCDC are put in practice by the professionals we have interviewed. We will present the core principles described above to structure the section.

- **The whole family, including siblings, is involved in the care for the newborn**
  - Parents' presence at the neonatal ward

In general parents can stay with their newborn day and night, i.e. 24/7. They are not considered as visitors, hence not bound by visiting hours. Several initiatives are taken to facilitate the contact with their newborn. Neonatal wards are usually characterised with little personal space (often only have an armchair in between the incubators), little or no privacy and a lot of noise (e.g. alarms), hence are not a comfortable environment for parents.

Some hospitals organise a hotel function for parents in order to let them stay overnight. This might be in the ward, external but close to the ward, somewhere in the hospital or even outside, but close to the hospital. In addition to facilitate parents taking up care tasks for their newborn, there are several other reasons to let parents stay overnight: e.g. facilitating feeding, avoid transport, to be nearby if the newborn is in a critical condition.

Other hospitals invest in rooming-in possibilities, i.e. a room for parents and newborn. Again, several modalities are possible in terms of how long parents can stay in the room, where it is located, and the medical condition or gestational age of the newborn. Reasons to use individual rooms are to prepare discharge, to start breastfeeding, to let parents familiarise with their child and grow self-confidence.

> *"Ik denk dat overal een beetje hetzelfde verloopt hetgeen dat, als ik het zo hoor, men meestal inventief is vlak voor ontslag dat men die rooming-in aanbiedt. Maar idealiter, allee, wij streven er nu naar om zo'n koalakamers effectief te creëren om van bij het begin maar dan eigenlijk een selectie te doen van bepaalde indicaties. Niet de grootste prematuren maar degene die zo net 35, 36 weken zijn waar dat je van weet dat het maximaal een week zal duren bij wijze van spreken om die op zo'n koalakamers meteen moeder en kind samen op te nemen. Maar dat vergt heel veel goodwill van heel veel mensen en personeel hè. Dat is een moeilijk organiseerbaar iets." (Physician, N*)*

Individual rooms stimulate parents to be present near their child. They feel more at ease. It also facilitates other family members to take over from parents if they need a break, so that the baby is never left alone.

> *« Moi je dirais que de manière générale, ben parce que donc moi j'ai travaillé à [organisation] avant et là on avait une salle commune. Et je pense que c'est euh la présence des parents c'est euh, le fait qu'ils puissent avoir une salle rien que pour eux. Ça permet vraiment donc aux parents d'être beaucoup beaucoup plus présents. Je trouve qu'on a des parents qui sont encore plus présents qu'avant parce que ben ils sont chez eux, qu'ils sont, enfin dans la salle précédente c'était vraiment, ils avaient juste un fauteuil où ils pouvaient s'installer, tandis que là, ben ils peuvent un peu circuler dans la pièce, ils ont un lit, ils ont un fauteuil, ils peuvent amener des affaires à eux et donc du coup, voilà, ça leur permet vraiment d'être plus présents auprès de leurs enfants. » (Nurse/midwife, NICU)*

> *« Dans les chambres kangourou on essaie vraiment qu'il y ait une présence d'un parent en permanence. Donc il arrive parfois quand les séjours sont longs que les mamans ont besoin un peu de souffler. Mais même si parfois elle veut aller au restaurant, imaginons avec le papa pour vraiment souffler, on essaye toujours qu'il y ait un, une personne de la famille, ça peut être la mamie ou la marraine pour que le bébé ne soit jamais tout seul. » (Nurse/midwife, N*)*

As nor the hotel-function, nor the rooming-in is part of the hospital financing, the staff is obliged to find creative solutions, both practical and financially to make them happen. In some hospitals the hospital management agreed to offer rooming-in at a very low price or even for free in specific situations. Others discharge mothers of preterm babies from the maternity ward to

readmit them elsewhere. For newborns who need only a short stay at the neonatal ward, the mother is sometimes kept a few days longer at the maternity ward, but this needs the agreement of gynaecologists and a stay at the maternity ward that exceeds 72h, is financially disadvantageous for the hospital. Focus group participants suspected that if the biggest hurdles, i.e. financing and staffing, are resolved, the adequate infrastructure will follow.

> *"Dus dat is volledig ten koste van de ouders. Ofwel krijgen ze natuurlijk geen hotelkosten. Dus dat is geen plateau om te eten. Maar eigenlijk officieel dan ook geen lakens om in te slapen. Dus dat is ook een probleem hè. Dus die koalakamers we proberen die te organiseren maar we stoten toch continu tegen heuvels vanuit de directie." (Physician, N*)*

> *"En naar uhm rooming-in zoals wij dat s- vaak, graag zouden hebben dat is heel beperkt in wat ge kunt aanbieden, hoe dat ge dat moet organiseren, hoe dat ge dat moet financieren. Ik noem dat amateuristisch een beetje. Het is er wel maar het kan niet goed uitgebouwd worden omdat gewoon die infrastructuur er niet is." (Physician, N*)*

> *"Als wij bijvoorbeeld rooming-in willen doen, wij proberen dat vooral te doen voor het ontslag, zodanig dat ouders één of twee nachten en dagen met hun baby in een aparte kamer kunnen ja het volledige zorg opnemen onder supervisie van onze verpleegkundigen en artsen. Dan moeten wij eigenlijk een kamer gaan stelen bij wijze van spreken op onze observatieafdeling eh van de gynaecologe. Hangen we dus eigenlijk ook een beetje af van de goodwill van de gynaecologe." (Physician, NICU)*

> *"Ik ben overtuigd dat als er een financiering is voor hotelfunctie en personeel dat die architectuur plotseling geen groot probleem meer gaat zijn." (Physician, N*)*

Part of being creative is also the use of multimedia applications allowing remote contact. Although remote contact cannot replace physical presence, in some circumstances (e.g. in case the mother is COVID-19 positive) there is no alternative. Remote contact can also be useful for siblings or other family members to be able to see the newborn. In any case the online applications should not withhold parents from visiting their child. According to the focus group participants, online applications should remain an additional facility, not a replacement of physical presence. The focus group participants mentioned several ways for parents to keep contact with their newborn at a distance: the use of iPads, camera's allowing continuous streaming, and the NeoParent App (Box 3). Although positive experiences were reported, the two last options have been discontinued because of financial reasons.

> *"Het is wel belangrijk denk ik dat die systemen dienen als extra inderdaad, zoals voor broers en zussen in de COVID-tijd, maar moeten wel oppassen dat de mensen blijven komen naar hun kinderen. De bedoeling is natuurlijk dat ze zoveel mogelijk bij hun baby zijn en dat dit alleen maar een add-on is, maar zeker absoluut geen vervanging van eh bezoek, want eh het is het bezoek en het samenzijn met de baby die eh waar de studies aantonen dat het een groot verschil maakt in de toekomstige ontwikkeling. En daar zijn geen studies van camerabeelden die de ontwikkeling later bevorderen." (Physician, NICU)*

> *"We hebben geen camera's omwille van dezelfde hinderpalen. Dus voornamelijk financieel. […] Maar we hebben dan wel meegedaan aan een project […] over de NeoParent App waarmee ouders kunnen communiceren met de verpleegkundigen, waar foto's kunnen geüpload worden die zij dan thuis kunnen bekijken wanneer ze niet bij hun baby kunnen zijn, die ze kunnen delen met wie ze willen, waar een dagboekje in staat, waar heel wat uitleg in staat. […] Dat is niet hetzelfde als een camera ter plaatse te hebben, maar dat is wel een deel van de oplossing om dat contact met het gezin te behouden wanneer de ouders fysiek niet aanwezig kunnen zijn op de dienst. En daar hebben we eigenlijk wel behoorlijk goede ervaringen mee gehad." (Physician, NICU)*

> *"Want op zich vind ik de webcams eigenlijk een ultieme poging om aan gezinsgerichte zorg te doen. Zeker in centra zoals het onze, waar de architectuur het niet mogelijk maakt om vierentwintig op vierentwintig uur aanwezig te zijn. En ik denk dat dat nu door de*

COVID-situatie ook nog veel duidelijker geworden is, waar ook bezoekregelingen van grootouders, broertjes en zusjes ook wat onder druk is komen staan door de veiligheidsvoorschriften van het ziekenhuis en in dat opzicht zouden die camera's natuurlijk ook een tegemoetkoming kunnen zijn. Maar, dus de grootste barrière is vooral financieel en praktisch." (Physician, NICU)

Box 3 – NeoParent application

The NeoParent application is developed by Odissee University College between 2018 and 2021. This mobile application aims to support parents of newborn hospitalised in the NICU ward by providing personalised information, optimising communication between parents and healthcare professionals and stimulating parent participation. Some of the features of the application are a diary function in which both parents and healthcare professionals can post messages or milestones, practical information about the hospital and plan visits, a webcam function, dictionary function with medical terms, weight and height trends, tips for parents (in terms of selfcare, administration, etc.) and a photo gallery in which both parents and healthcare professionals can upload photos. The application has been piloted in four Belgian hospitals and is now managed by MoChi.[249]

- Access for other family members, including siblings

Although parents are very much welcomed by means of almost unlimited access to the neonatal ward, be it in some hospitals, access for siblings or other family members is restricted. Policy regarding visits of siblings seems to vary between hospitals, but mostly their access to the ward is (very) limited, especially in winter in function of infection prevention.

"Maar brusjes bijvoorbeeld, ja, dat is bijna niet mogelijk, zeker niet in de winter, om die binnen te laten." (Physician, N)*

« On essaie de moduler un petit peu l'allée et venue des enfants. Mais c'est sûr que ou on leur laisse deux plages horaires ou ils peuvent venir en fin de journée. » (Nurse/midwife, N)*

« En fait pour le moment la fratrie peut encore venir chez nous. On les intègre. […] Souvent ils ne restent quand même pas très longtemps […] Ou sinon quand c'est dans les chambres, c'est vrai qu'ils peuvent facilement faire le bain avec les parents rester un petit euh. On ne fait pas d'action particulière pour les inclure. Ils sont les bienvenus. Parfois on les guide un peu, mais sinon c'est les parents qui gèrent la fratrie. » (Nurse/midwife, N)*

The limited access is somewhat compensated by other initiatives to involve siblings such as continuous streaming, video calls, a play corner, gadgets (e.g. picture books, goodie bag), pictures of the newborn, etc. A remarkable initiative was the organisation of educative sibling support workshops explaining what it means to have a sister or brother at the neonatology ward, and which at the same time unburdens the parents.

« Les ateliers permettent aussi aux enfants de s'exprimer par rapport à la maladie de leur petit frère de leur petit- de leur petite sœur. Mais aussi que les parents soient entre guillemets déchargés de la responsabilité de leur petit pendant cet après-midi-là. » (Physician, NICU)

"Wij hebben ook nog een dienst in het ziekenhuis, […]. Eigenlijk kunnen broertjes of zusjes op woensdagnamiddag naar daar en dat is eigenlijk een psychologe die hen dan begeleidt en vaak is het zo dat broertjes of zusjes niet zo goed begrijpen […] hoe dat de zorg hier is en hoe dat alles verloopt en zo […]. Zij heeft dan boekjes liggen, van alles eigenlijk van activiteiten die zij dan doen. […] Ouders mogen kiezen of dat de broertjes en zusjes daarnaartoe gaan of niet, maar dat is ook wel een groot succes." (Nurse/midwife, N)*

- Nursing activities in function of parents availability

The presence of siblings is one of the most important barriers hampering parents' presence at the neonatology ward. Nursing activities are as much as possible adapted to parents' availability. However, parents are asked to take into account the rhythm of the newborn too, hence to come when the baby is awake.

« On essaye de communiquer un maximum avec les parents pour savoir quand est-ce qu'ils viennent, à quelle heure ils sont disponibles pour qu'on sache si on doit les attendre pour les soins. […] on a un petit tableau de communication où les parents sont amenés à noter tous les jours si jamais ils ne restent pas dormir parce qu'en effet ils ont un grand, dire "je serai présent pour tout à l'heure, merci de m'attendre pour les soins" ou "aujourd'hui j'aimerais bien faire un bain" et on veille à avoir des infirmières qui sont réparties avec le même nombre par shift donc on est continuellement le nombre. C'est-à-dire que du coup ben on n'a pas plus de raison de faire le bain le matin que le faire l'après-midi ou le faire la nuit, ça c'est vraiment en, en fonction du timing des parents, on va essayer de s'adapter un maximum à ce dont ils ont besoin. » (Nurse/midwife, NICU)

« Donc les parents sont les bienvenus 24 heures sur 24. Il y a juste qu'on leur explique bien quand les bébés sont encore rythmés par exemple s'ils doivent manger toutes les trois heures, d'essayer d'être présents au moment un petit peu même à l'avance pour être là quand le bébé est éveillé. Donc ils peuvent venir 24 heures sur 24 mais on leur explique dès le départ que, le bébé dort, ben il dort hein. On ne le réveille pas parce que papa et maman sont là, on ne va pas le sortir de son sommeil, oui sinon ils sont les bienvenus oui. » (Nurse/midwife, N)*

- Parents' participation

Parents are, as much as possible, involved in the care for their child, and even more generally involved in the care policy of the ward. Regarding their own child this is mostly done by means of bedside briefings. More general parental input is gathered through surveys, focus groups, parents' advisory boards, and follow-up consultations.

"Waar wij ook wel op inzetten, is de mogelijkheid om ouders mee te laten participeren in zowel het beleid in de zorg op de afdeling door enquêtes op te sturen of door ze te laten deelnemen aan focusgesprekken om op die manier de ouders te laten meedenken, meewerken aan de werking van onze dienst in het ziekenhuis. Maar ook door aan bedside briefing te doen kunnen zij meebeslissen in de zorg voor hun kind. Door het feit dat ze bij hun kindje kunnen blijven en zij kennen hun kind beter dan wie dan ook kennen, hoe het reageert, hoe zijn kleur is, hoe het zich gedraagt en eigenlijk geven we hen de mogelijkheid om mee te briefen en hun mening door te geven aan de arts, dus dat het niet alleen van ons uit komt, maar ook vanuit de ouders, dat zij mee kunnen nadenken over de zorg van hun kind." (Nurse/midwife, N)*

"Wij hebben daarvoor een ouder adviesraad opgericht. Dat zijn ouders van ex-prematuren die na hun verblijf op neonatologie hun ervaringen meenemen om zo een aantal zaken te veranderen, te verbeteren, ouders te ondersteunen, maar daar krijgen wij toch ook wel redelijk veel feedback van. En hoe het voor ouders aangenamer zou zijn om op onze afdeling te verblijven." (Physician, NICU)

"Ook wel de raadplegingen. We zien de kinderen meestal nog terug na twee maanden en vier maanden, zeker degenen die prematuur zijn of met afwijkingen, waar ook nog wel veel informatie van ouders komt, waar je ook kunt bevragen van, hoe is het nu eigenlijk geweest op de diensten? Zijn er zaken die die stoorden of die minder goed gingen? Dus ook daar is wel een soort van feedback mogelijkheid." (Physician, NICU)

- **Parents actively carry out care tasks together with professionals**
  - Parents as partner in care

The staff educates parents to enable them to participate in the care for their newborn. Initially this takes additional time. However, once parents know what to do and how, they somewhat unburden the staff. Parents and healthcare professionals then work together as a team. Healthcare professionals nevertheless admit that it is difficult to relinquish care tasks. Also staffing is crucial. If staffing falls short in numbers, parents' education stops, and the service falls back in old routines.

"De volgende stap is dat we benoemen family integrated care, waarbij de ouders meer en meer worden betrokken in de zorg en waar ge dan, ja als ik met vier handen moet werken bijvoorbeeld of

troosten bij procedures, dat de ouders worden mee ingezet. En waardoor ge dan toch soms als ouders goed meewerken ook een deel van de belasting voor verpleegkundigen een beetje kunt verminderen. Dus het kan ook een positief punt zijn op dat gebied van de organisatie. Maar dat is wel een moeilijke stap. We zijn daar ook al een tijdje mee bezig, maar verpleegkundigen staan niet graag zorg af aan ouders." (Physician, NICU)

"Vroeger waren wij als, als zorgverlener waren wij eigenlijk de, de hoofdzorgverlener van de baby, terwijl dat, dat we dat nu eigenlijk de ouders zijn ook zorgverlener van de baby en wij staan er als verpleegkundigen eigenlijk naast om hun te begeleiden, maar jammer genoeg verdwijnt dat soms toch weer volledig op de achtergrond, gewoon omdat wij die zorgen niet kunnen bieden door het gebrek aan personeel en dat is heel jammer, denk ik." (Nurse/midwife, N)*

Parents vary in the degree to which they are involved in the care for their newborn, as they differ in capabilities and bearing capacity. Hence, parents' involvement in care tasks is determined on the one hand by the organisational capacity of the service (i.e. availability of staff) which fluctuates in time and the readiness of staff to relinquish tasks, and on the other hand parents' characteristics (e.g. availability, capabilities, the time they spend with their baby, language barriers, etc.).

« Il y a des parents pour qui c'est évident de rester et de passer énormément de temps. Il y a des parents qui ont des difficultés à rester, on l'a dit, pour des raisons sociales ou d'organisation générale. Mais il faut quand même penser aussi qu'il y a parfois des parents, et là il faut l'aide des psys *évidemment, mais y a des parents pour qui c'est… presque intolérable de rester tout le temps près du bébé. Et ça il faut aussi pouvoir mettre le doigt dessus et il faut le comprendre et ne pas les culpabiliser hein donc. Tout ça n'est pas si simple. » (Physician, NICU)*

"En dan komt het erop aan dat we geleidelijk aan de ouders willen introduceren in het een deel overnemen van de zorg voor hun kind, waarbij dat we moeten proberen rekening te houden met het draagvlak van de ouders. Draagvlak op gebied van wat kunnen zij aan qua zorg, maar ook bijvoorbeeld op gebied van taal. Je moet de dingen goed kunnen uitleggen om ouders goed te kunnen betrekken in de zorg." (Physician, NICU)

- Care "à quatre mains"

Parents are invited and stimulated to be involved in the care for their newborn, to assist the staff and grow self-confidence in taking care of their baby. This is done at their own pace, as not all parents feel comfortable in doing so. This is a learning process that is started as soon as possible. However, they can take their time to get familiar with the care tasks and procedures.

« On va évidemment essayer d'intégrer au maximum les parents dans les soins, assez rapidement les rendre acteurs au niveau des soins, donc changer un Pampers dès qu'ils se sentent capables sans jamais évidemment obliger parce que c'est vrai pour certains parents, c'est assez vite impressionnant pour eux de, voilà, avec tous les câbles et compagnie, de devoir changer un Pampers c'est, il y a certains parents qui vont le faire plus tard mais, voilà, soutenir le bébé, ça on essaie de faire. De toute façon les soins à quatre mains, dans un premier temps avec la collègue et une fois que les parents ont vu et se sentent capables eh ben on les invite vraiment à mettre leurs mains au plus vite près de leur enfant. » (Nurse/midwife, NICU)

« C'est très chouette que les infirmiers d'ici, ils ont fait le changement vers le « Family Integrated Care », déjà il y a plusieurs années. Et alors, ils ont maintenant convaincu de vraiment inclure les parents dans les soins et ils ont même appris aux les parents à faire les soins avec eux pour que le soin soient toujours fait à quatre mains. Au début les parents ont tous appris soutenir leur bébé pendant les différents soins. » (Physician, NICU)

- **Parents and child are kept together as much as possible**
  - Non-separation starts in the delivery room

Keeping the family together evidently starts in the delivery room. Unless the mother's/baby's health is at risk, staff can perform drying, assessments and assignment of Apgar scores while the baby is on the mother's chest. One focus group participant even described a procedure for reanimating the newborn on the mother's belly, or just next to her, with an intact umbilical cord, to involve her in the first care for her child. According to the focus group participants, the procedure is well-explained beforehand to prevent parents to be traumatised.

> *« On a écrit un système pour accueillir vraiment le bébé sur le ventre de la maman carrément, bon à part quand c'est une césarienne mais donc c'est en cas d'accouchement par voie basse. Et donc là on fait, donc là aussi ça dépend un peu de, ben du bébé si jamais il nécessite juste un petit peu de ventilation. Mais donc on, on met directement la CPAP sur le ventre de la maman et donc on essaie de faire les, tous les soins d'accueil sur le ventre de la maman. Et donc voilà, ça c'est vraiment une question un petit peu d'observation clinique du bébé évidemment parce que si jamais on voit que le bébé ne va pas bien, on va d'office du coup considérer la réanimation sur la table mais si le bébé va bien, on va faire carrément la réanimation sur le ventre en mettant déjà sa CPAP sur le ventre. » (Nurse/midwife, NICU)*

> *« Nous au niveau de la prise en charge, enfin ce qui aide au niveau de l'intégration des parents dans les soins, ben en commençant par la naissance, en fait nous on a le système LifeStart. C'est une table à cordon intact qu'on a depuis l'été dernier. Euh du coup c'est vrai que ça, ça aide au niveau que ce soit à césarienne ou voie basse on peut l'utiliser. Et donc ça permet pendant les césariennes aux mamans de d'avoir la réa qui se fait près d'elles et donc tout se fait à côté d'elles. Au début on avait d'abord fait avec, pour le temps que toute l'équipe s'adapte et même notre néonatologue, on avait fait avec des bébés qui étaient moins prématurés, des 34 semaines, des 36 semaines. Et ici on, on fait de plus en plus, même avec des 24 semaines ou des hernies diaphragmatiques où là l'intérêt du cordon intact enfin et même, enfin c'est pertinent au niveau médical. Et donc ben ça permet aux parents du coup d'assister à la naissance, de voir le bébé et cetera. » (Nurse/midwife, NICU)*

After birth, conform IFCDC principles, the newborn is kept together with the mother. In some hospitals, it is possible to transport mother and baby together from the delivery room to the neonatal care ward in case the baby needs special care. If not possible, the baby is transferred to the neonatal care ward together with the coparent, and the mother follows as soon as possible. In the meantime, the coparent and baby are installed for SSC.

> *"Sinds een tijdje, een jaar of twee, denk ik, doen we ook gentle opnames op N*. […] Wij proberen nu elk kindje dat opgenomen wordt op neonatologie huid op huid te laten liggen bij zijn mama na de geboorte en dan met zijn mama en papa samen naar hier te komen, dus niet meer in de couveuse te leggen maar huid op huid met de mama naar de neonatale gebracht te worden." (Nurse/midwife, N*)*

> *« On essaie un maximum évidemment dans la mesure du possible de promouvoir le peau-à-peau immédiat donc c'est-à-dire qu'un bébé qui ne nécessite pas de soins intensifs directement, on peut, à 34 semaines par exemple aller dans, sur le ventre de sa maman pendant allez, 20 minutes une demi-heure sans trop de difficultés. Un bébé qui aura besoin d'une assistance ventilatoire et ben on attendra que la maman ait terminé ses soins et que nous on ait terminé de stabiliser le bébé pour l'installer en peau-à-peau. Mais on essaie je pense dans 80 % des cas de mettre le bébé directement en peau-à-peau à la naissance. Et ça on se rend compte que c'est très très bénéfique de manière générale pour intégrer dans un premier temps la maman. Et puis le papa évidemment si la maman ne peut pas pour des raisons médicales prendre son bébé directement en peau-à-peau parce qu'elle doit aller aux soins intensifs, mais où là on le proposera au papa. » (Nurse/midwife, NICU)*

The feasibility of keeping the family together depends mostly on availability of staff and adequacy of infrastructure. To promote non-separation, infrastructure often needs an upgrade. Among the participants, some were in the process of adaptation, others already finalised it.

> *"Wij trachten ook zo veel mogelijk onze ouders en kind zo weinig mogelijk te scheiden natuurlijk op als de sectio doorgaat op het operatiekwartier, dan hebben wij geen vroedvrouw die daar continu kan toezichthouden op dat baby'tje. Dus is het eigenlijk de bedoeling dat de huid op huid ook niet onderbroken wordt en dat die met de papa mee komt op neonatologie en om daar te skinnen. Dus wij hebben een aparte corner daarvoor. Maar mama komt dan wel achteraf na de keizersnede wel tot bij de baby dan. (Nurse/midwife, N*)*

> *« Donc nous à [organisation], on a fait le choix effectivement d'avoir que des chambres seules. […] On a eu la chance de construire un nouvel hôpital y a trois ans, et donc la direction nous a soutenu, mais on a - je crois - multiplié notre surface par six, ou quelque chose comme ça, donc c'est vrai que ça demande un investissement au niveau de la direction et un financement important. » (Physician, NICU)*

- Non-separation and couplet care

In mother-newborn couplet care the ill or preterm born infant and the mother, needing medical care of her own, are cared for together, preferably from the birth of the baby to its discharge. From our focus group data this zero separation of mother and child seems quite challenging within the Belgian neonatal landscape. Some focus group participants confirmed that in some specific, not too complex, situations couplet care is put in place. But this is far from common practice.

> *« Le maître-mot dans la rédaction du projet médical c'était : ne pas séparer la mère et l'enfant. Et donc on se retrouve aussi dans une structure où on peut accueillir à tout endroit du service finalement, la mère en même temps que son enfant. Mais on est confrontés aux mêmes difficultés, effectivement, qui ont diverses origines, mais en tout cas, faire en sorte que la mère reste d'emblée à côté de son enfant. Disons quand l'enfant a besoin de soins extrêmement intensifs, ou qu'il est extrêmement prématuré, ça reste compliqué. Par contre on a une unité qui est en fait un mixte de post-partum et de soins à l'enfant, où on commence à accueillir des enfants qui ont besoin de soins spécifiques et ça on peut le faire dès la naissance maintenant. Des enfants qui ont besoin d'une perfusion ou d'une sonde gastrique, pour l'instant pas encore d'un support respiratoire, l'idée c'est d'y arriver… Ben voilà, au fur et à mesure je dirais de la prise de possession des lieux et de la possibilité d'étendre les choses. Et dans un second temps alors l'idée, c'est effectivement de pouvoir soigner et la mère, et l'enfant. Même quand l'enfant est dans une situation je dirais critique. Ou plus préoccupante. Pour l'instant, on y va pas à pas. » (Physician, NICU)*

To realise non-separation, collaboration between the maternity ward and the neonatal ward is essential, but at this stage non-separation is rather a goal than a reality. It was mentioned to be a "bricolage" or making the best of it with the means available. For example, the mother may be transferred to the neonatal ward when discharged from the maternity ward.

> *« Aujourd'hui, il y a déjà une collaboration puisqu'on essaie voilà, de séparer le moins possible. Et donc dans des situations, par exemple, d'antibiothérapie, ou des choses comme ça, avec un bébé qui est bien, on va de plus en plus dire les premières heures où l'enfant est chez nous, ou le premier jour pour pouvoir voir un peu comme il tolère, et puis il va remonter à la maternité, il viendra juste pour avoir sa dose d'antibiotique dans le service. Mais ce sont les infirmières de néonat qui régulièrement montent à la maternité, et suivent le bébé, en collaboration avec la sage-femme de la maternité. Donc y a déjà des choses qui se mettent en place pour améliorer la collaboration entre les sage-femmes et les infirmières de néonat. Donc on fait un peu du bricolage. » (Physician, NICU)*

> *« Dans les chambres qui sont appelés ou koala ou kangourou suivant les hôpitaux, ben là c'est comme vous avez expliqué là tout de suite. Les sage-femmes s'occupent de la maman, les infirmières pédiatriques plutôt du bébé, mais vu les sorties précoces des*

mamans maintenant qu'ils sortent à J2, de plus en plus on s'occupe très très vite des des mamans. Et elles sont complètement intégrées au soin du bébé mais nous aussi on s'occupe un peu d'elles puisqu'elles sont plus prises en charge alors par les sage-femmes. » (Nurse/midwife, NICU)

- **Care tasks are carried out in function of the rhythm of the baby and taking into account the possibilities and bearing capacity of the parents**

IFCDC considers the rhythm of the baby and parents' availability. In our data we found examples of caring tasks such as feeding and bathing. Staff awaits parents to be present and the baby to be awake. Precondition to respect the rhythm of the baby is the recognition of the baby's body language. The more parents are present, the more they get to know their baby's language and recognise his/her needs. Rooming-in is a big advantage in this matter. Staff educates parents in the recognition of bodily signs of their baby.

"Bij ons op de afdeling […] zetten we fel in op voeding op vraag en het leren kennen van de signalen van het kind naar de ouders toe. Waar dat we inderdaad vroeger standaard voedingsuren hadden, waarbij ouders tussen voedingsuren toekwamen en eigenlijk nog niet helemaal goed de signalen van hun kind kenden, kunnen we nu inzetten op die rooming-in, op die aanwezigheid van die ouders zo veel mogelijk en daar eigenlijk richting naar huis of in de evolutie, ontwikkeling van hun kind toch ouders veel meer klaarstomen en zelfzekerheid geven in de zorgen naar hun kind toe." (Nurse/midwife, N)*

« Ce qu'on essaie de faire, on a eu il y a quelques années une partie de l'équipe, on a eu la petite formation clé pour apprendre à comprendre le langage de l'enfant. Et donc avec ça on essaye vraiment que les parents apprennent à connaître vraiment ce que leurs bébés peuvent déjà leur communiquer. Et on essaie vraiment par rapport à ça de les guider dans le rôle de parents et dans les soins qu'ils peuvent faire, vraiment en essayant qu'ils aient le plus confiance en eux. Parce que c'est eux en définitive qui connaissent le mieux leur bébé. » (Nurse/midwife, N)*

- **Complete transparency of information towards parents**
  - Communication with parents

Having a fixed point of contact among paediatricians and nurses or not, seems to depend on the intensity of care and the size of the service. At small services, staff knows each baby, is involved in and informed about the care of each baby, which makes them all eligible to communicate with parents. Bigger services tend to allocate a responsible neonatologist and nurse to each baby, who is in charge of communication with the parents, at least at crucial moments (e.g. discharge) or when important decisions must be taken.

"Wij dat proberen te organiseren met een vast aanspreekpunt zowel bij de artsen als verpleegkundigen. Voornamelijk bij de artsen. Dat merk je wel dat dat een, een zekere geruststelling geeft aan de ouders dat ze altijd dezelfde persoon kunnen aanspreken. Want we werken met een ploeg van acht van negen kinderartsen. Maar als ze alle dagen een andere kinderarts zien is dat ook geen oplossing. Dus we proberen dat ook altijd als er beslissingen moeten genomen worden of verdere stappen moeten ondernomen worden dat altijd diezelfde persoon ook het beleid uitstippelt en met de ouders bespreekt. Dus ik denk dat dat een goede start." (Physician, N)*

"Ik moet wel zeggen, de minder lange liggers hebben bij ons wel geen echte vaste, vast aanspreekpunt maar proberen wij als team wel zo dusdanig elkaar op de hoogte te houden, met meerderen aanwezig te zijn dagelijks bij de briefing, zodat we eigenlijk wel alle patiënten en ouders een beetje proberen te kennen." (Physician, NICU)

"Ja, bij ons is het eigenlijk ook een beetje zo dat wij met vaste gespreksartsen werken voor zeer intensieve kinderen en de kinderen die geboren worden na een zwangerschapsduur onder de 28 weken. Voor de minder intensieve en, en de kinderen die bij ons op de N komen, wat ook een groot aandeel is bij onze kinderen, is er niet echt een vaste gespreksarts en wordt er een beetje gekeken naar de afhankelijkheid van hoe is de beschikbaarheid*

van de ouders en de artsen op die moment waarbij dat ze afspraken kunnen maken en dan wel zien welke artsen dat er vrij zijn." (Physician, NICU)

- Communication between parents or peer support

Some participants talked about initiatives to stimulate peer support relationships among parents. Some wards have a recreational area where parents can meet while drinking a cup of coffee, others created support groups, e.g. for breastfeeding. One participant noted that although a shared room has many disadvantages, the advantage is that parents meet, get into contact and support each other. Mother-child rooms keep parents inside and more isolated from one another. A solution to this drawback is rooms for two mother-child dyads or common rooms such as a kitchen. Rooms for two mother-child dyads are a compromise between enough privacy and still the opportunity to benefit from peer support. Also, parents may feel lonely in an individual room without any contact with other parents.

« Dans la nouvelle architecture, prévu une salle qu'on voulait une salle commune, une salle de vie où la fratrie peut venir jouer, où les parents, ou coparents, venir boire une tasse de café, ou se poser une peu en dehors de la chambre. Parce que quand le séjour se prolonge, C'est parfois nécessaire de pouvoir un petit peu changer d'atmosphère. […] Mais finalement, elles restent beaucoup dans leur chambre. Voilà, je sais qu'il y a des services où les mamans sont invitées à venir prendre le petit déjeuner, même avec le bébé encore au Kangourou, ensemble, et à pouvoir échanger un petit peu à cette occasion-là. » (Physician, N)*

« Après, nous ce qu'on a aussi c'est que dans nos trois chambres, en fait on a deux chambres : on a une chambre à un lit, et une chambre à deux lits. Et donc c'est vrai que dans la chambre à deux lits, ben quand y a deux mamans avec- bon en général, c'est des bébés qui vont bien, qui sont sortis d'affaire et qui doivent surtout attendre de grossir, ou sous antibiotiques, qui vont bien, etc. Et donc c'est vrai que souvent il y a une émulation entre les deux mamans, donc ça peut être assez chouette, donc c'est un petit compromis entre les deux parfois, d'avoir ça. » (Physician, N)*

« Mais parfois j'entends, elles sont un peu seules dans ces chambres quand elles sont toutes seules. Quand vous êtes au bout du couloir et qu'il n'y a pas beaucoup, beaucoup de passage, c'est un peu de solitude quoi. » (Nurse/midwife, N)*

- **IFCDC starts before birth and continues after discharge**

During the focus groups it was estimated that introducing the neonatal ward and its functioning during pregnancy is beneficiary for the parents. This is done by means of information leaflets, a guided tour at the neonatal ward, a video etc.

"Ik denk ook dat het gesprek vaak ook al vooraf aan de bevalling begint. Zwangeren met risicofactoren te spreken persoonlijk op de MIC waarbij ouders al uitleg krijgen van wat ze staat te wachten, zodat ze daar een klein beetje op kunnen anticiperen. Hen uitnodigen op dienst, een keer met de verpleegkundige een toer over de zaal kunnen doen, zodat ze al iets van voorbereiding hebben." (Physician, NICU)

« Moi je pense que pour implémenter, le fait de rencontrer les parents en anténatal, ça facilite toujours- enfin les rencontres. Et les brochures quand même on explique le fonctionnement du service et nous on a une capsule vidéo où ils voient vraiment l'ensemble du pôle mère-enfant, comment on fonctionne. Et je pense que le fait de voir aussi sur des images que les parents sont présents, que les parents portent les bébés, ben je pense que ça les aide aussi. » (Physician, NICU)

IFCDC also pays attention to the preparation of discharge and what happens after discharge. First, discharge should be announced timely, and parents should be invited to learn how to take care of their child at home. This is often done by letting them room-in overnight. If the baby needs complicated care at home, all professionals involved are gathered to discuss the organisation of care at home.

After discharge follow-up is organised in different ways: hospital midwives doing home visits, staff from the neonatal ward giving parents a phone call to inform whether everything goes well, or follow-up consultations with the neonatologist.

> *"Ik denk ook met de ouderparticipatie van nu dat wij ook wel merken dat kindjes sneller niet per se maar met meer zorgen naar huis gaan. Wij hebben nu meer kindjes die met zuurstof naar huis gaan, die met sondevoeding naar huis gaan. En dat is ook omdat ouders meer betrokken worden tijdens het verloop. En dan op het einde wordt het ook altijd op tijd aangekondigd, worden die technieken aangeleerd. Niet het plaatsen van een sonde maar wel het aanhangen van de sondevoeding. De ouders komen dan in de rooming-in inslapen één nacht of meerdere nachten zodat wij nog kunnen helpen bij het opstarten. Dan wordt er alles geregeld van materiaal door de firma, als thuisverpleging. Dan gaat dat vooral over kindjes die dat langer verblijven natuurlijk. Maar er zijn ook zorgen die dat een langere tijd nodig zijn om aan ouders aan te leren." (Nurse/midwife, NICU)*

> *"Daarnaast hebben wij ook een aantal vroedvrouwen die deeltijds bij ons werken en deeltijds ook de postnatale zorg op zich nemen. Dus het voordeel daarvan is dat zij de mama's al kennen vanuit het ziekenhuis en nadien daar ook kunnen thuis bij hen…" (Nurse/midwife, N*)*

> *"Dat we na drie dagen ofwel een week later de ouders zelf ons opbellen om te vragen of alles goed gaat. Dat er geen specifieke vragen zijn want die vragen kunnen altijd pas later opkomen. Dus dat proberen we op die manier op te lossen. En ouders zijn daar zeer gedreven mee en hebben ook zo niet het gevoel dat ze zo onmiddellijk zich alleen gelaten voelen eens dat ze thuis zijn bijvoorbeeld." (Nurse/midwife, NICU)*

6.3.4 Conditions to put IFCDC successfully in practice

So far, we gave a description of the core IFCDC principles and how these are put in practice. In the next section we will describe the conditions that need to be fulfilled to facilitate IFCDC.

The themes that emerged inductively from the data have been matched with the conditions specified by the Consolidated Framework for Implementation Research (CFIR)[250] as a guiding principle, more specifically the inner and outer setting constructs of the CFIR (Box 4). We did not use the CFIR constructs to code our data but looked post hoc for convergence between the CFIR and the themes emerging from our inductive coding strategy. We have also put the constructs in relationship to each other (see Figure 13), hence constructing a model with the potential to explain the conditions necessary to successfully implement IFCDC. In the data we identified all four outer setting conditions and nine out of fourteen inner setting conditions. Figure 13 presents the constructs that were identified in the data, Table 30 explains each construct.

Box 4 – Consolidated Framework for Implementation Research (CFIR)

In the domain of health services research, many implementation theories have been published to help effective implementation. The CFIR synthesizes constructs provided by 19 implementation theories into a unified typology.[250] The synthesis of Greenhalgh et al.[251] of nearly 500 publications was taken as a point of departure. The researchers applied a snowball sampling to identify new articles through in implementation literature. The CFIR is a meta-theory including constructs from existing theories without depicting interrelationships or specific hypotheses. It provides a list of constructs to promote theory development and insight in what works where. The constructs can be used to guide diagnostic assessments of implementation, evaluate implementation progress, and help explain findings in multiple contexts.[252] For a complete overview of the CFIR we refer to www.cfirguide.org.

Figure 13 – Conditions facilitating the implementation of IFCDC using the CFIR

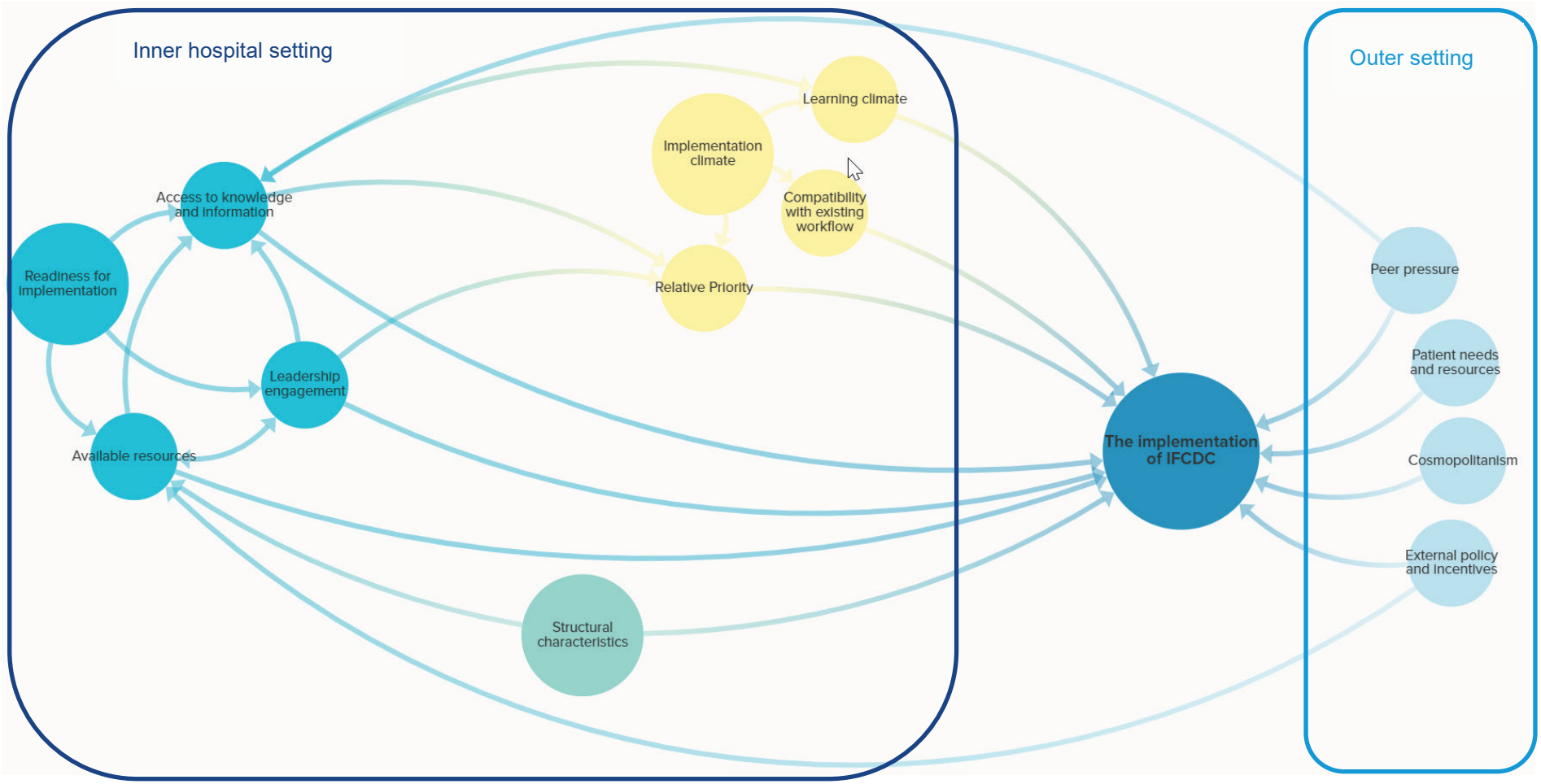


Table 30 – Conditions facilitating the implementation of IFCDC

INNER HOSPITAL SETTING	
Structural characteristics	The social architecture, age, maturity, and size of an organisation.
Implementation climate	The absorptive capacity for change, shared receptivity of involved individuals to an intervention, and the extent to which use of that intervention will be rewarded, supported, and expected within their organization.
• **Compatibility**	The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems.
• **Relative priority**	Individuals' shared perception of the importance of the implementation within the organisation.
• **Learning climate**	A climate in which: a) leaders express their own fallibility and need for team members' assistance and input; b) team members feel that they are essential, valued, and knowledgeable partners in the change process; c) individuals feel psychologically safe to try new methods; and d) there is sufficient time and space for reflective thinking and evaluation.
Readiness for implementation	Tangible and immediate indicators of organisational commitment to its decision to implement an intervention.
• **Leadership engagement**	Commitment, involvement, and accountability of leaders and managers with the implementation.
• **Available resources**	The level of resources dedicated for implementation and on-going operations, including money, training, education, physical space, and time.
• **Access to knowledge & information**	Ease of access to digestible information and knowledge about the intervention and how to incorporate it into work tasks.
OUTER SETTING	
Peer pressure	Mimetic or competitive pressure to implement an intervention; typically, because most or other key peer or competing organisations have already implemented or are in a bid for a competitive edge.
Patient needs & resources	The extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization.
Cosmopolitanism	The degree to which an organization is networked with other external organizations
External policy & incentives	A broad construct that includes external strategies to spread interventions, including policy and regulations (governmental or other central entity), external mandates, recommendations and guidelines, pay-for-performance, collaboratives, and public or benchmark reporting.

Source: https://cfirguide.org/constructs/ (02/12/2021)

For the implementation of IFCDC we identified thirteen interacting conditions that match with the CFIR, nine referring to the inner hospital setting, four to the outer setting. In Figure 13 we visualised the mutual relationships as we understood them from the data. This means that other relationships (arrows) plausible on theoretical or other grounds, are not presented in Figure 13.

Figure 13 is characterized by two parts: conditions of the inner hospital setting and conditions of the outer setting facilitating the implementation of IFCDC. When absent these conditions act as a barrier. We start our description with the inner hospital conditions and move towards the outer conditions.

Structural characteristics of the neonatal ward and the hosting hospital set the scene and are the entrance point to start the reading of Figure 13. Based on these characteristics' *resources* are attributed to neonatal wards. *Resources* are threefold: financing, staffing and infrastructure. Hospital directors manage the deployment of resources; hence *leadership engagement* is crucial. Neonatal wards need the commitment of managers to be able to implement IFCDC (e.g. permission of training, decisions of infrastructure adaptations or hiring additional staff). Both *available resources* and *leadership engagement* determine *the access to knowledge and information* of the neonatal staff, the *learning climate*, the *relative priority* and *readiness for implementation*. In other words, neonatal wards need hospital managers who allow staff to be trained in IFCDC, hence support a *learning climate*, which consists of sufficient time for learning and reflective activities. The hospital managements attitude also contributes to individuals' perception of the importance of IFCDC for the organization (*relative priority)*. *Compatibility* or how IFCDC fits with the existing workflows also facilitates the *readiness for implementation*. If existing workflows are too much under pressure (mostly because of time pressure or lack of staff), IFCDC disappears in the background.

Peer pressure is the first outer condition. It is situated in the fact that neonatal wards expect IFCDC in other neonatal wards. For example, in case of a referral, it is expected that the family gets the same quality of care in the receiving services as is the case in the referring service. Some NIC wards organize trainings and symposia for neonatal wards of other hospitals (in the same locality) to build a similar way of working in both referring and receiving services. This way neonatal wards in the same network (c*osmopolitanism*) can help each other move forward with IFCDC. IFCDC is also stimulated when *patient/parent needs*, and the ways to meet those needs, are known and considered important by the neonatal service and the hospital by extension. Finally, *external policy and incentives* bring the circle to a close, as these conditions are closely linked to the *available resources* in the inner hospital setting.

In the following chapter we will describe the facilitating conditions, referring to the CFIR were relevant (words in italic), develop the logic described in the previous paragraph further, present the threats or difficulties related to each facilitator and potential solutions to overcome these difficulties (if these were mentioned by the focus group participants).

6.3.4.1 Structural characteristics – Type of ward, admission criteria, capacity and competences

For neonatal wards we identified *structural characteristics* which, according to interviewees, interfere with other facilitating conditions, such as *available resources*.

From the focus group interviews we learned that **admission criteria** vary between neonatal wards. Especially N* services seem to vary largely between low care, medium care and post-intensive care. From the focus group data, a rough **typology of N* services** seems to emerge: some N* services, probably the N* services of hospitals with a low number of deliveries, are little developed. This means the hospital does not invest much in the N* service, skills and competences of the staff are limited to low care activities and capacity is kept low. They have a low threshold to refer newborns to another neonatal service. Other N* services, probably the N* services of hospitals with a high number of deliveries, are capable to perform medium and post-intensive care activities. When they refer to a NIC ward they expect a back-referral once the newborn no longer needs intensive care.

> *"Er zijn ook geen gelijke criteria voor de ziekenhuizen. Bij ons is opname, d'office opname is een kind onder de twee kilo drie en onder de 36 weken. Gewoon het feit van daar twee kilo vijf van te maken en daar 37 weken van te maken, wat dat volgens mij bij veel ziekenhuizen gebeurt, is dat een enorme impact." (Physician, N*)*

"Het is heel leuk dat die heel wat pathologie ook bij ons willen houden, ze mogen vanaf 32 weken bij ons bevallen, want er zijn er ook wel geregeld die toch vroeger bij ons bevallen natuurlijk […]. Maar men houdt ook nogal best heel wat baby'tjes bij ons, wat van de ene kant heel leuk is, want de mensen op de neo vinden het ook plezant om die te verzorgen, maar anderzijds, natuurlijk geeft dat toch wel een enorme werkdruk, hè. […] Ja, welke pathologie hoort er nog bij een N en welke moet eigenlijk in principe doorgestuurd worden naar de NIC?' Uhm, ja, want ja, eigenlijk op een N* heb je daar dan eigenlijk niet meer echt de bestaffing voor, hè." (Physician, N*)*

"Andere ziekenhuizen gaan met 1.000 bevallingen, met 998 bevallingen gaan verder, hebben kinderen met infuus, hebben kinderen die zwaardere zorg nodig hebben, kinderen met eh met eh antibiotica en dergelijke, kinderen met longlines die intensiever zijn, kinderen met een, met CPAP, die houden die allemaal. Die hebben evenveel personeel. Dit klopt ergens niet." (Physician, N)*

6.3.4.2 Available resources – Introduction

'Available resources' were emphasised by the focus group participants and are crucial in interfering with the other facilitators. Since N* and NIC wards are financed in a different way (see section 2.5), they not surprisingly face different challenges. Therefore, where relevant, we will differentiate between N* and NIC wards.

Available resources are threefold: financing, staffing, and infrastructure.

6.3.4.3 Available resources - Financing of neonatal wards and its unintended consequences

Financing of neonatal wards is complicated by the fact that N* and NIC wards are financed in different ways. For the technical description we refer to Chapter 2 (see section 2.5). Here we will focus on the '**unintended consequences' of financing** on the one hand and **unmet needs of neonatal wards** on the other hand.

N* wards are financed a rato of the number of deliveries exceeding 1000 per year or not. Hence an N* of a hospital with 400 deliveries gets as many means as an N* of a hospital with 999 deliveries. The group of hospitals with less than 1000 deliveries is however a very heterogenous group in terms of admission criteria and expertise, hence the complexity of care they offer. Every N* determines its own admission criteria. Put in another way, which newborns they take care of themselves and which newborns are referred to a NICU. This is often expressed in gestational age of the newborn as a proxy for the complexity of care. A lower gestational age implying more complex care.

"Wij zijn eigenlijk ook een N-functie. Het aantal bedden bij ons ligt eigenlijk ook niet echt vast. Het is niet dat wij ook voor verantwoorde bedden vind ik dat eigenlijk ook altijd een heel moeilijke berekening, omdat ge als N*-functie afhangt van uw aantal bevallingen en dat ge niet van vaste posities kunt spreken, een vast aantal bedden. Ik vind ook dat de zorgzwaarte op N*-diensten ook ruimschoots onderschat wordt. Een beetje afhankelijk hoe groot uw materniteit is in uw ziekenhuis en het aantal geboortes. Wij hebben toch een grote materniteit van 1.300 à 1.400 bevallingen, waardoor we toch ook wel wat kinderen op neonatologie hebben. Wij hebben allemaal kinderartsen die graag neonatologie doen, waardoor wij ook CPAP, Optiflow, heel uitzonderlijk ook navelkatheters, etc. plaatsen. Er zijn zeker N*-diensten waar de activiteit zich wat beperkt tot een paar couveuses of een verwarmd bedje. Dat is een bedje waar dat je in uw ziekenhuis voor kiest en met welke arts dat je bestaft bent. Maar N*-diensten worden vaak over één kam geschoren en er wordt niet altijd een verschil gemaakt naar de zorgzwaarte op die diensten, laat staan dat daar een financiering voor in de plaats gesteld wordt." (Physician, N*)*

"Ik denk dat daar inderdaad het, het grote probleem zit hè. De verschillen tussen de neonatologie en het feit dat dat allemaal gelijk gefinancierd wordt. En degene die meer willen doen en meer presteren er eigenlijk niet voor gehonoreerd worden." (Physician, N)*

This financing system of N* services has been called **out-dated** during the focus group interviews and has several **perverse consequences**.

> *"En dan heb je de financiering van de N*-functies die volgens mij eh compleet achterhaald is, waar men nog altijd financiert op basis van het aantal bevallingen in het ziekenhuis, terwijl er toch heel wat N* zijn die patiëntjes overnemen in de context van intra-uteriene verwijzingen, waar ze nooit de bevalling van gehad hebben, maar wel de zorg moeten overnemen en daar dus eigenlijk geen structurele financiering van personeel is voorzien. En ik denk dat daar nog grootste hervorming zou moeten doorgevoerd worden, dat men dat herbekijkt en dat men de N*-functies gaat financieren in functie van het werk dat ze verzetten en niet van het aantal bevallingen dat er in de ziekenhuizen heeft plaatsgevonden." (Physician, NICU)*

First, focus group participants described that in hospitals with few deliveries, staff intended for the N* function is working at other services instead because they have very few newborns who need specialised neonatal care. The hospital does not invest in the N* service (including building expertise and skills to run the N* ward). By consequence, newborns are easily transferred to the neonatal service of another hospital. This results in a kind of **"ghost N* service"**.

> *"Maar er zijn zeker ziekenhuizen waar personeel elders ingezet wordt en waar elke zorg die meer is dan een fles, ik overdrijf misschien ietske maar toch niet veel hoor, dat, elke handeling meer dan een fles geven daarvoor is op een NICU." (Physician, N*)*

> *"Je hebt ook de kleine materniteiten in België, die allemaal een N*-functie hebben, waar je ook overal minstens één verpleegkundige moet hebben die, zoals al vermeld is, dan vaak op de materniteit wordt ingezet, niet alleen om financiële redenen, maar ook omdat er op de N*-functie geen enkele baby ligt." (Physician, NICU)*

Second, **intra-uterine referrals** although good clinical practice are disadvantageous in terms of N* financing. Because this delivery is performed in another hospital it is not counted in the number of deliveries of the referring hospital. Hence if the newborn is referred back to the referring hospital, the latter is not financed for this newborn.

> *"Ik denk dan voornamelijk dus aan de intra-uteriene verwijzingen. Als op dit ogenblik een gynaecoloog beslist van een zwangere door te sturen naar een tertiair centrum dan doet hij aan goede geneeskunde, maar wordt daar financieel door afgestraft omdat hij zijn patiënten en bevallingen en dergelijke afstaat. En het ziekenhuis dat ziekenhuis wordt ook nog eens financieel afgestraft, omdat het een bevalling minder heeft, dus minder financiering krijgt om de N*-functie te entoureren. Maar dat kind dat dan geboren wordt in het tertiair centrum wordt nadien wel teruggestuurd, om daar dagen of nog weken verzorgd te worden. Dus moest men een eh honorering voorzien voor gynaecologen die patiënten doorsturen, die dus aan goede geneeskunde doen, dat dat ook beloond kan worden, en moest men in de financiering van de N*-functie deze gemiste bevallingen virtueel meetellen omdat het kind later wel zal terugkomen om verzorgd te worden, dan zou dat daar lokaal ook al wat meer mogelijkheden creëren om handen aan bed te hebben en mensen eh te kunnen opleiden voor gezinsgerichte zorg." (Physician, NICU)*

Third, neonatal care that could be performed in an N* ward seems to shift more frequently to intensive neonatal care wards. In other words, there seems to be a kind of **inflation of medium care**.

> *"En het feit dat het ziekenhuis daar financieel aan verliest aan goeie pasgeborenenzorg maakt sommige ziekenhuizen… En ik heb er echt bewijzen van. De artsen forceren van kinderen die op N* zouden kunnen liggen toch door te verwijzen naar de neo-, intensieve zorg waar de kostprijs toch een 1.000 euro per dag is." (Physician, N*)*

Fourth, in hospitals with both an N* and NIC ward, the **N* ward seems to function as a kind of buffer** for the occupancy of the NIC ward. In other words, transfers from N* to NIC and back are function of the occupancy of the NIC ward. This may result in elective transfers to NIC: if occupancy is low, newborns are less likely to be referred back to the N* ward, if occupancy of the NIC is high, newborns are more likely to be transferred to the N* ward.

"Uiteindelijk de kunst van goede neonatale zorg te kunnen leveren in sommige ziekenhuizen erop achteruitgaat omdat meer medium care ook al verschuift naar neonatale. Enfin, grote neonatale zorg. En dat vind ik soms spijtig. Zeker ik zie bij ons de wisselwerking want wij hebben in het ziekenhuis én een neonatale NICU én een N. En de N* wordt eigenlijk gevoed naar believen van de bezetting op de NICU. Dus als de NICU weinig bezet is gaan we ook weinig doorverwijzingen hebben. En als het sterk bezet is dan krijgen we eigenlijk de kinderen pas door." (Physician, N*)*

"Bij ons in [ziekenhuis] is het nog meer pervers want ik ben ook naar de directie gestapt en die zeggen: "Ja, maar als ge daar intensievere zorg wilt geven, we hebben een intensieve dus transfereert uw kinderen van de N naar de intensieve. En dat brengt veel beter op. Dat zit beter in de budget financiële middelen. Ze krijgen hogere severity indexen en betere financiering. Dus dat is het antwoord die je krijgt. En als je niet eh financieel gepoeld zijn met de neonatologen dan is dat eigenlijk een eh een gewoon een doorschuifluik en zij worden daar beter van en wij moeten maar verder ploeteren met de, met de beperkte middelen. Dus ik denk dat dat toch een, een aandachtspunt vergt absoluut." (Physician, N*)*

By consequence **collaboration between N* and NIC wards** may be hampered and become more of a competition. Interviewees especially criticize NIC wards for not backreferring newborns to the N* ward and keeping them until discharge instead.

"Wij zijn een N die wel CPAP'en, wel infusen, wel eh navelkatheters, longline allemaal doen. Parenterale voeding, wij kunnen dat. (…) Wij krijgen daar gewoon de centen niet voor om dat te organiseren. En dat vind ik, ja, dat (…) op een bepaald moment is de zorg niet meer voor een NICU en moet dat terug naar een N* gaan. Dat vind ik. En die liggen daar soms echt tot, bijna tot op hun ontslag op een NICU. Ik kan mij niet inbeelden dat alle kinderen tot ontslag op een NICU-waardig zijn. De meesten kunnen terug naar hun N*. En dat is een vraag die gewoon niet gesteld wordt. Dan denk ik… I-ik weet dat het in, in X [ziekenhuis] en in Y [ziekenhuis] heel anders georganiseerd wordt, dat de samenwerking veel beter is. Bij ons is dat al een strijd van 25 jaar. Eens dat ge een patiënt verwijst krijgt ge die bijna nooit terug. (…) Wij krijgen ze terug als hun bezetting te hoog is en dan vooral de "ambetanten" moet ik zeggen. Degenen waar dat ze niet goed mee kunnen babbelen die mogen dan terug bij ons komen. Maar gewoon het feit dat zij de ce-, de mogelijkheid hebben om dat uit te bouwen en wij niet de middelen krijgen dat is iets dat tegen mijn borst stuit. Dat is niet eerlijk. Wij zouden ook moeten kunnen een mooie gezinsgerichte neonatale zorg geven en daar de middelen voor hebben. Personeel, infrastructuur, eh wat dat er nodig is om dat te doen." (Physician, N*)*

"Wij hebben eigenlijk ferm onder ons voeten gekregen van het universitair ziekenhuis omdat wij vanaf 30 weken wilden opvangen. … Eh wij hebben heel sterk eh… Maar… Met heel sterke aandrang is gezegd dat wij de grens op 32 weken moesten brengen en liefst zelfs 34 weken. … Omdat zij, ja, zij hebben een aantal verwijzingen nodig, interne en externe verwijzingen nodig. Ze hebben een aantal bevallingen onder de 32 weken nodig om, om erkenning te houden. Maar zo, ja… Ge wilt wel welwillend zijn voor uw NICU maar zij moeten ook welwillend zijn voor ons. En voorlopig is dat altijd eenrichtingsverkeer. Uhm ja, en dat is, dat is, dat is enerverend hè dat." (Physician, NICU)

From the perspective of N* services, NIC wards keep newborns unnecessarily long, often even until they return home, hence skipping medium/low care at an N* service. The other way round, the lack of skills in low care contributes to referring newborns needing medium care that should be feasible at an N*, to NIC wards.

"Maar als ge dat wil zeker zijn vraag dat een keer aan de universitaire ziekenhuizen die kinderen willen terugsturen wat de criteria zijn om terug te sturen. Bij sommigen zijn de criteria voor terug te sturen niet alleen, ze hebben toch geen longline meer maar ze hebben toch geen infuus meer. Of zelfs in sommige gevallen: ze hebben toch geen sondevoeding meer. Dat is een zeer kwalijke evolutie die uiteindelijk, allee, dat ik juist ook gezegd heb, heel veel geld kost." (Physician, N)*

*"Onze ervaring hier [regio] is dat niet iedere N*afdeling de competenties heeft om zelf de zorg aan te kunnen. Bijvoorbeeld er zijn hier wel N*afdelingen waarbij dat je probleemloos een kind met een centrale diepe katheter kan naartoe sturen maar er zijn ook ziekenhuizen bij die dat totaal niet aankunnen of omdat ze gewoonweg geen ervaring hebben ook. Dat is één. En twee, want dat is daarjuist ook al aangekaart, ja, soms worden die mensen daar ook ingezet om op materniteit of verloskwartier te gaan werken, is daar ook geen continue bewaking op die N* afdeling dus dat zorgt er ook voor dat je beperkt zit in soms het tijdig kunnen doorverwijzen van patiënten." (Nurse/midwife, NIC)*

"En dat vind ik, ja, dat, dat zou bijna wetmatig moeten zijn dat, dat op een bepaald moment is de zorg niet meer voor een NICU en moet dat terug naar een N gaan. Dat vind ik. En die liggen daar soms echt tot, bijna tot op hun ontslag op een NICU. Ik kan mij niet inbeelden dat alle kinderen tot ontslag op een NICU, NICU-waardig zijn. De meesten kunnen terug naar hun N*." (Physician, N*)*

"Dat, doordat niet meer dagdagelijks te doen dat je ook eigenlijk onrechtstreeks bijna geduwd wordt in het toch terug doorverwijzen naar andere centra." (Physician, N)*

From the focus group data, it becomes clear that **the decision to refer a newborn back** to the referring N* does not only depend on the health condition of the child. Many other structural and organisational conditions must be fulfilled. Focus group participants reported that back-referring is hampered if the N* service of the referring hospital lacks competences or continuous surveillance.

In addition to lack of skills, focus group participants also mentioned lack of capacity at N* services as a factor hampering back-referring to an N* service. It was assumed that N* services are not eager to take back newborns, because of inadequate hospital financing and high insurance fees.

"Waar wij heel vaak tegenaan lopen bij ons op de afdeling is capaciteitsprobleem. Capaciteitsprobleem ten gevolge van verwijzers die overvol liggen, van verwijzers die bepaalde zorg niet goed eh niet uitvoeren om het zo te noemen. Eh uhm waar dat zij ook met de capaciteitsprobleem zitten, waar dat ze ook onvoldoende bestaft zijn om bijvoorbeeld extra N of extra low care neonato te gaan verzorgen. Dus eigenlijk lopen wij heel vaak aan tegen capaciteitsproblemen." (Nurse/midwife, NIC)*

"Want ook daar lopen we heel vaak tegen problemen aan dat verwijzers weinig zin hebben om patiënten terugnemen, terug te nemen. Gewoon omwille van het feit dat dat verlieslatend is voor de dienst naar materiaal, naar personeel. En dat genereert geen inkomsten. Dat is dus het probleem waardoor dat je misschien overconsumptie hebt van dure, intensieve neonatale zorgbedden." (Nurse/midwife, NICU)

"We hebben in [ziekenhuis] zeker ziekenhuizen die bereid zouden zijn van de rol op te nemen van post-intensive care high care neonatologieafdeling, omdat zij de knowhow wel in huis hebben en eh dankzij de inzet van de directies eh ook al eh wat hoger niveau van zorgen, zoals eh CPAP, zoals het gebruik van centrale lijnen en dergelijke eh willen toepassen. De hinderpaal daar is dan vaak financiering hè, bijvoorbeeld langdurige CPAP wordt niet gefinancierd in die N-functies. Dat zou moeten kunnen. En ook verzekeringsmatig, eh als je zulke invasieve technieken gaat toepassen, moet je ook een verzekering hebben die eh dergelijke toediening van zorg mee dekt en dat kost ook geld. En dat speelt mee een rol waarom sommige ziekenhuizen wel die richting willen uitgaan en andere ziekenhuizen niet. Ik denk, als men dat zou kunnen aanpakken en de profilering zou kunnen doen van zulke ziekenhuizen, dan is het haalbaar om die twee niveaus te gaan creëren. Waarom gebeurt dat nu niet? Omdat dat financiële repercussies heeft." (Physician, NICU)*

Moreover, an N* service cannot be separated from the hospital that hosts it. Its functioning is influenced by not only management decisions, but also other hospital functions such as pharmacy (e.g. availability of parenteral feeding during the weekend). Hence, a certain degree of *compatibility* is needed, a fit between the functioning of the N* service (admission criteria, capacity, skills of staff etc.) and existing workflows and hospital wide systems.

"Wij hebben concreet dezelfde ervaringen gehad. Wij hebben ook al een aantal ziekenhuizen opgeleid om bijvoorbeeld centra-patiënten met centrale katheters te kunnen terugnemen. Verpleegkundigen, artsen, de dienst was daar zeer enthousiast om dat te doen maar dan is het de apotheek in dat ziekenhuis die dan aangeeft: ja, en wij gaan in het weekend geen parenterale voeding aanleveren. Dus dan zit je daar op vast. Dus het is eigenlijk het volledige ziekenhuis die eigenlijk in zijn filosofie moet mee zijn in dat verhaal om die patiënten ook die terugverwezen worden maximale zorg te kunnen geven."

In conclusion, these observations suggest an **evolution towards more newborns in high care**. It is clear from the data that *structural characteristics* of neonatal wards and of the hospitals they are part of, determine referring and back-referring practices. A certain constellation of *structural characteristics* is needed to create an environment of good clinical referring practice and cooperative relationships between neonatal wards. From the data we conclude that this constellation is complicated and not present everywhere. If the right conditions are not fulfilled, **newborns may be unnecessarily referred to or stay unnecessarily long at high care**. The financing of N* function plays a crucial role and might induce suboptimal transferring of newborns, hence creating suboptimal care and higher healthcare expenditures.

How do these observations on the consequences of neonatal financing translate into consequences for IFCDC?

Focus group participants asserted that N* services are financed less than NICU, while the same IFCDC is expected

"Gezinsgerichte ondersteuning en, en NIDCAP te verwachten van de N-diensten, dat ze meegaan in dat verhaal, maar ze krijgen de middelen niet zoals dat een eh een, een NICU-afdeling uhm dat krijgt, dus ja, dat zijn twee maten en twee gewichten natuurlijk, hè." (Nurse/midwife, N*)*

N* services and NIC wards with collaborative relationships enable each other to offer IFCDC, by sharing experiences, knowledge and skills. For example, an NIC ward can organise a training for the N* services geographically nearby. Neonatal wards find it important that they function following the same (IFCDC) principles, make the same agreements with parents, use the same material etc, in order to soften the transition between services in case of a (back)referral.

"En in samenwerking met X geven we ook externe opleidingen op gebied van NIDCAP in de regio [ziekenhuis] om het principe ook, de transitie eigenlijk van die NIDCAP-zorg van de neonatale intensive care naar de N-functie, wanneer onze baby's worden terugverwezen naar de ziekenhuizen van herkomst, van die eigenlijk gewoon door te geven, zodanig dat dat niet stopt wanneer de baby's onze dienst verlaten." (Physician, NICU)*

"Je hebt één manier om te maken dat de mensen mij vertrouwen in het perifeer ziekenhuis is hetgeen wat wij al sinds een jaar of twintig doen, […], dat is maken dat zoveel mogelijk samenwerking is met het universitair ziekenhuis waar dat we naartoe verwijzen en dan ook de materialen gelijk zijn. Bijvoorbeeld ge ligt in een universitair ziekenhuis, ge komt bij ons terecht. Wat verandert er? In feite enkel de verpleging verandert. De types van couveuses zijn dezelfde. De intraveneuze voeding is hetzelfde. De antibiotica uhm therapie is dezelfde. Er wordt niet in één keer van alles veranderd. Moogt ge uit de couveuse in een universitair ziekenhuis dan is dat bij ons ook zo. Dat geeft ook vertrouwen. Mensen schrikken altijd wat als ze, als ze komen naar een perifeer ziekenhuis, hoe groot dat het ook is. Maar als er behalve de verpleging die meer tijd voor hen kan nemen dan op een universitair ziekenhuis, als er behalve dat niks verandert dan loopt dat vlot." (Physician, N)*

"Wat ook belangrijk is, denk ik, is dat we ervoor zorgen dat ook ons verwijzers, de andere ziekenhuizen mee op dezelfde lijn krijgen. Ik denk dat dat ook heel belangrijk is. Want bij ons in het ziekenhuis gaat meer dan de helft van onze patiënten terug naar een verwijzend centrum. Meer dan de helft van ons opgenomen patiënten gewoon omwille van het feit dat we een derdelijnscentrum zijn en waarbij dat we eigenlijk zelfs geen pediaters hebben bij ons in het ziekenhuis die gewone consulten doen. Dus dat betekent dat al die patiënten die bij ons op de afdeling liggen gaan opgevolgd worden in een ander centrum. De

meesten toch. En dan is het belangrijk dat je uw verwijzers mee hebt in uw verhaal zodat die dezelfde lijn proberen aan te houden zoals dat wij die aanhouden om ervoor te zorgen dat de ouders niet geconfronteerd worden met verschillen in beleid." (Nurse/midwife, NICU)

Nevertheless, focus group participants working at N* services reported that N* services have **insufficient financial means to train all staff** in IFCDC. In addition, they have **insufficient staff to carry out IFCDC** as this is more time consuming than standard care. This situation leads to frustration because of staff shortage, they cannot permanently offer care according to the IFCDC principles they were taught, and which are expected by (back-) referring neonatal wards.

"Wij hebben daar niet onze equipe neonatologie mee kunnen opleiden, laat staan, we een aantal vroedvrouwen of mensen die op de materniteit werken, dus dat is ook een beetje de frustratie van een N-dienst, dat wij uiteraard ook graag die visies volgen, maar dat we daar zeker niet de financiële en de praktische modaliteiten voor hebben. En dat vind ik wel een beetje moeilijk op een N*-dienst." (Physician, N*)*

"Dus personeel dat je moet vrijmaken om de opleiding te volgen en dan de toepassing aan bed is veel tijdrovender dan dat men zich zou kunnen inbeelden, omdat je de zorg van de patiënt wordt anders hè. Denk aan de vier-handen-zorg wat bijvoorbeeld niet het geval is. Dat intensifieert de entourage van een patiënt. Dus dat slorpt personeel op. En dan wat ook al aangehaald is, dat je uiteindelijk dat type van zorg ook moet aanleren aan de verwijzers die de zorg overnemen. En dat is al aangehaald, op de N-functies is dat niet evident om daar ook al de mensen op te leiden en daar voldoende handen aan bed te hebben om dat te blijven toepassen zoals op de NICU's." (Physician, NICU)*

*"Dus eh daarom waren wij op zich wel heel eh content dat uiteindelijk ook de N*ren de kans gekregen hebben om mee te doen aan die FINE. Ook weliswaar met een beperkt budget waardoor dat ge een deel van uw personeel wel kunt opleiden en dat de bedoeling was dat ze mekaar gingen kruisbestuiven op de afdeling zelf. Maar omgekeerd dat ge ook wel merkt dat ge daar geen, niet voldoende personeel voor hebt. Dus men kan dat allemaal heel mooi uitleggen van ge moet zo en zo met twee verpleegkundigen uw kind verzorgen. Maar als ge maar twee verpleegkundigen hebt en er liggen daar tien of elf kinderen kunnen ze niet ieder kind met twee gaan verzorgen." (Physician, N*)*

« Ça permet que- eux viennent aussi nous former, ou nous aider dans ces domaines-là. Ou faire des protocoles aussi. On se passe beaucoup, évidemment, on ne peut pas adapter tous leurs protocoles, parce que ce n'est pas la même chose. Mais en tout cas clairement, quand on veut voir des choses on peut clairement se baser sur leurs protocoles qui sont déjà faits, et de manière assez rigoureuse, donc ça nous fait gagner du temps … Par rapport à ça. Donc … Oui, cette collaboration est importante. » (Physician, N)*

Financing is also based on technical acts, which are less common in N* services compared to NIC wards and contributes to the unequal financing of N* and NICU.

« Les grands N sont très bien je pense, très bien financés, parce que tout ce qui est technique euh les premiers jours euh d'intubation, de ventilation- enfin voilà, toutes ces techniques-là sont très bien financées. Mais dans les « petit N », on est moins intervenants- alors ceux qui sont un peu plus intervenants, comme- comme des centres comme nous, avec des "CPAP", on est financés. Mais quand on a juste des enfants qui doivent apprendre à boire, et donc ils sont juste avec un temps de présence, éventuellement parfois une petite perfusion pendant un jour ou deux, ben ça ne rapporte rien. [silence] En fait. » (Physician, N)*

Financing should take into account that IFCDC has other prerequisites than standard care. It is more time consuming, hence demands more staff.

« X : que souvent les efforts qu'on fait pour essayer d'avoir des soins de qualité ou- ou pour passer du temps auprès des familles sont en aucun cas récompensés sur le plan financier. On l'est si on met des voies centrales, qu'on intube euh et qu'on fait voilà,

beaucoup de soins aigus, mais- mais- ce n'est pas toujours ça qui est gage de qualité en tout cas pour certains patients.

I : Donc il faudrait un financement d'un acte d'intégration des parents dans les soins par exemple, c'est plutôt ça que vous voyez ?

X : Oui, sans doute quelque chose qui se rajouterait euh à un financement existant pour- ben oui pour la présence euh d- des psychologues dans le service, mais ça je pense que c'est présent ; pour la présence d- d- des infirmières en lactation ; pour le- la réalisation de réunions au sein de l'équipe euh voilà, oui. » (Physician, NICU)

"Zoals nu ook voor de lactatiekundige het geval is, zorg dat er een nomenclatuurnummer komt voor de mensen die de inspanning doen voor de gezinsgerichte zorg aan bed." (Physician, NICU)

"Dus als die activiteiten zouden gehonoreerd worden dan zouden we denk ik al een stap in de goede richting gaan om dan toch meer handen aan bed te hebben, wat op dit ogenblik ook nog een nijpend probleem is bij de gezinsgeoriënteerde zorg." (Physician, NICU)

Focus group participants made several suggestions regarding unmet financial needs of neonatal wards (Table 31).

Table 31 – Unmet financial needs and suggestions for improvement by the participants

Unmet financial needs identified in the data	Quote
Financing of the mother's stay is lacking	*« Qu'on ne centre pas du tout sur le bébé, mais on centre tout sur la maman. Et sur la pathologie de la maman, et actuellement pas sur celle du bébé. Et voilà, les mamans elles peuvent rester un certain nombre de jours en fonction d'elles, mais pas de leur bébé. Et donc ça pose des problèmes de financement pour libérer euh de l'espace pour ces chambres euh… Qui ne sont pas payées, en fait le bébé va payer sa chambre mais pas la maman. Et donc ça, ça pose des problèmes. » (Physician, N*)* *"Omdat ik ook van het principe ben en zo heb ik het ook aan de directie uitgelegd: op pediatrie wordt ge bijna scheef aangekeken als ge niet bij uw kind blijft maar op materniteit of op neonatologie als ge vers bevallen zijt vliegt ge bij wijze van spreken na twee dagen buiten. Dus dat moet eh eigenlijk wel mogelijk om, om, om ook bij uw kind te blijven eh, eh in het ziekenhuis." (Physician, N*)*
Lack of financing for lactation counselling by other professionals then midwives	*« Oui, excusez-moi. Moi je voulais rebondir sur la consultante en lactation. Parce que vous parliez, je suis tout à fait d'accord avec [personne] qu'elles font un travail formidable, et de nouveau, c'est un travail qui n'est absolument pas financé hein. Donc les consultantes en lactation, sage-femmes qui font des consultations en dehors de l'hôpital, elles peuvent tarifer les choses. Mais dans nos unités, on a des consultantes en lactation qui sont des infirmières pédiatriques, ou qui sont sage-femmes aussi, mais qui travaillent à l'intérieur de l'hôpital. Et en tout cas, chez nous on n'a pas trouvé la possibilité de valoriser. Donc encore une fois, on fait énormément de choses pour soutenir l'allaitement, pour soutenir les familles, mais sans financement. (…) Effectivement, à partir du moment en tout cas où on a au moins une sage-femme dans l'équipe… Et qu'elle s'oriente [silence] vers l'allaitement, alors il y a une possibilité de financement qui existe, mais c'est un peu particulier effectivement que ce soutien à l'allaitement ne puisse pas être étendu à d'autres professions, nommément effectivement les infirmières pédiatriques, voire même il y a aussi des médecins qui font des formations de- de soutien à l'allaitement, et pour la cause ils ne sont pas forcément valorisés pour ça. » (Physician, NICU)*
Lack of financing for psychological care	*« Et- surtout sur le plan psychologique […] : l'importance d'avoir un psychologue pour justement centrer sur la famille, par rapport même quand il n'y a pas de problèmes dans la famille, le fait que euh l'enfant soit malade et donc soit hospitalisé, alors que ça doit être un évènement heureux et- et y a des complications, euh donc effectivement, je pense qu'il n'y a pas un grand financement des*

	psychologues non plus par rapport à ça. Et ils sont- et encore moins des pédopsychiatres, et alors ça c'est vraiment important qu'ils puissent être présents. » (Physician, N)*
Lack of financing for multidisciplinarity	*« On l'a un peu évoqué, mais c'est toujours dans le côté- dans le- par rapport aux financements, mais c'est la pluridisciplinarité hein. Il faut que- dans nos équipes doivent être vraiment pluridisciplinaires. Il faut euh des- des infirmières, des spécia- des- des expertes en lactation, des médecins, des psychologues, des kinés, des assistants sociaux, enfin je veux dire- voilà, il faut- il faut être- la pluridis- pluridisciplinarité n'est- et- et le temps de rencontre pluridisciplinaire n'est pris en évidence- voilà, ça c'est de nouveau- enfin toujours parti du financement, mais voilà, que ce soit dans ce domaine de la néonat, ou dans d'autres euh… Les moments où c'est pluridisciplinaire c'est- ce- ce temps-là qui doit être un temps- qui est quand même un temps important, un temps de rencontre important pour pouvoir parler chaque situation n'est pas pris en compte. » (Physician, N*)*
Lack of financing for NIDCAP observations	*« Oui, et encore de financement. Soyons clairs. De financement, y a aucun financement, on fait une observation NIDCAP, ben il faut que la direction soit d'accord de libérer une infirmière qui travaille et de payer cette infirmière pour faire ça. Il y a aucun retour. Il n'y a pas de code, il n'y a rien. » (Physican, NICU)* *"En uiteraard, family-centred care is in NIDCAP is family-centred care een heel belangrijk deel van NIDCAP. Maar ik denk dat we in Vlaanderen daar wel goed aan het eh evolueren zijn. Ik denk dat we daar in het rapport, maar dat zal dan straks komen, dat we daar misschien toch ook betere financiering voor moeten voorzien, want dat is een enorme investering voor verpleegkundigen en artsen om een goed NIDCAP-consult te geven, maar op dit moment staat daar niks tegenover. Dus ik denk zoals ook nu voor advies, lactatieadvies een nummer bestaat, gaan we misschien ook voor NIDCAP-advies in de toekomst een financiering moeten voorzien, zodat eh de diensten het ook effectief kunnen uitvoeren, omdat het anders op de tijd die de verpleegkundige daarin steekt, is heel groot." (Physician, NICU)*
More staff needed	*"Want uiteindelijk willen zij voor elk personeelslid dat ze inzetten, zien wat dat het opbrengt. Eh dat is de taak van een directie waarschijnlijk. Onze taak is van eh de personeelsleden in te zetten om de kwaliteit van de zorg te verbeteren. Maar je kunt de twee van elkaar niet loskoppelen. Dus als die activiteiten zouden gehonoreerd worden dan zouden we denk ik al een stap in de goede richting gaan om dan toch meer handen aan bed te hebben, wat op dit ogenblik ook nog een nijpend probleem is bij de gezins- eh georiënteerde zorg." (Physician, NICU)*
Lack of financing for training of staff and parents	*"Ja ik denk behalve het opleiden van uw, van het personeel waar we grote stappen aan het zetten zijn, is het toch belangrijk om de ouders en de verple-, mensen die mee voor het kind gaan zorgen, ook op te leiden. En ook daar steekt ge veel tijd in. Hè als ge eh opleidingsadvies wilt geven aan, of informatiesessies wilt geven aan ouders rond ontwikkelingsgerichte zorg dan is dat ook zeer tijdsintensief, allee of, en gebeurt dat ook vaak na de uren." (Physician, NICU)*

6.3.4.4 *Available resources – Staffing is a conditio sine qua non for the implementation of IFCDC*

Staffing is a conditio sine qua non in the implementation of IFCDC. From the focus groups it is clear that **IFCDC takes more time**. It is by far more efficient to perform care themselves than to learn parents how to carry out the task.

> *"Het is gewoon een evolutie en het vraagt meer inzet van personeel om ouders dat allemaal aan te leren en om ouders veel zelf te laten doen. Het is veel minder tijdrovend en als wij zelf alle zorgen zouden doen. Dat is gewoon zo en dat is een evolutie die we de laatste tien jaar, denk ik, dat dat een ongelofelijke evolutie is en een absoluut heel positieve evolutie, maar jammer genoeg volgt de personeelbestaffing daarin niet. Dat is jammer." (Nurse/midwife, N*)*

Participants call the current situation schizophrenic because at the one hand the importance of IFCDC is recognised, trainings are followed, awareness is created, but at the other hand **staffing remains insufficient**. Participants report that IFCDC is dropped when work pressure peaks. In other words, staff may be educated to provide IFCDC, adequate infrastructure can be foreseen, but if staffing is insufficient, it is all in vain.

> *"Vroeger waren wij als zorgverlener eigenlijk de hoofdzorgverlener van de baby, terwijl dat nu eigenlijk de ouders ook zorgverlener van de baby zijn en wij staan er als verpleegkundigen eigenlijk naast om hun te begeleiden, maar jammer genoeg verdwijnt dat soms toch weer volledig op de achtergrond, gewoon omdat wij die zorgen niet kunnen bieden door het gebrek aan personeel en dat is heel jammer, denk ik." (Nurse/midwife, N*)*

> *"Dus eigenlijk is het soms een beetje schizofreen en wordt er enerzijds wel geïnvesteerd in opleidingen zoals die FINE, in infrastructuur, maar anderzijds blijft het personeelsbestand een beetje achter." (Nurse/midwife, N*)*

> *« Et puis parfois un peu le côté frustrant quand on a fait les formations, des choses qu'on n'a pas le temps matériel de mettre en place parce que faire les observations, parce que mettre en place ça ben il faut dégager du temps et de l'énergie. Et puis je crois qu'aussi dans les barrières, une des choses qui reste c'est qu'il faut longtemps des habitudes qui sont bien ancrées. Ça c'est parfois un travail de titan parce qu'on a l'impression d'avoir changé un petit quelque chose, et puis très vite on re-rentre, parce que oui, parce qu'il manque du monde, parce qu'il manque de certaines structures on re-rentre très vite dans certains vices antérieurs et on est reparti et il faut tout recommencer à zéro. » (Physician, NICU)*

This creates **frustration**. The staff gets the feeling of being unable of doing their job well. Quality of care is under pressure, as well as the staff's professional wellbeing.

> *"En dat heeft ook te maken met het feit zoals vroeger werd aangehaald ook dat we soms te weinig tijd hebben om, ja, om de mensen goed te ondersteunen waarbij dat we soms naar huis gaan met soms een, een slecht gevoel van, ja, dat je de ouders niet toch hebt alles kunnen geven of, bespreken wat dat je eigenlijk wou doen door de werkdruk vooral." (Nurse/midwife, NICU)*

> *"Ik wil graag hier eh bij aansluiten, bij die bestaffing en bij het onvoorspelbaar karakter. Ook wij zitten met het probleem dat wij één vroedvrouw hebben voor acht bedden. Wanneer het heel rustig is, hebben wij heel veel tijd voor de mensen en kunnen wij heel fel inzetten op die gezinsgerichte zorg, maar als het druk is, dan schiet die zorg er volledig aan over en dat is iets wat heel fel in contrast gaat met het gevoel van elke verpleegkundige, denk ik, en vroedvrouw, waar dat wij op een neonatale heel graag daarop willen inzetten, maar dat dat heel frustrerend is dat we gewoon door eh de aantal mensen, collega's, medewerkers dat we hebben, dat we dat eigenlijk heel vaak niet kunnen doen." (Nurse/midwife, N*)*

> *"Als je dan toevallig verantwoordelijkheid hebt voor verschillende patiënten, ja, en het is als ik X hoor zeggen voor zeven patiënten, ja, dat is enorm zwaar hè. Dan stel ik me soms ook de vraag van: op welke manier kan je dan nog kwalitatieve zorg bieden die veilig is? En dat vind ik wel een serieuze bezorgdheid." (Nurse/midwife, NICU)*

Reasons for understaffing are multiple. First, there seems to be a systemic lack of staff because of **outdated staffing norms**. Participants stated that the current staffing norm is no longer adequate, as it dates back from before there was any IFCDC. The participants stressed the urgent need for a new staffing norm that takes into account the current quality of care standards, including IFCDC.

> *"De norm is uitgeschreven in 1996. Het KB van 1996 die de neonatale zorg beschrijft. Op het moment dat er nog geen sprake was van vier handen zorg, om onder andere family-centred care ook toe te passen om ouders zoveel mogelijk te betrekken. Het is niet omwille van het feit dat ouders primaire zorgverstrekker zijn dat je daarom uw personeelsnorm kunt laten zakken. Integendeel. Dus ik denk dat er nog, dat het sneller gaat om het kind zelf te wassen dan dat je begeleiding geeft aan de ouders om die te verzorgen. En ik denk dat de nieuwe zorginzichten rond NIDCAP en dergelijke meer eigenlijk toch wel een andere norm, ja, vereisen." (Nurse/midwife, NICU)*

> *« Donc nous avons un beaucoup plus petit centre, voilà parce que comme je disais on accueillait maximum six ou sept bébés, ben parfois on en a qu'un ou deux. Et on a des donc pour cette possibilité-là- enfin pas la possibilité d'avoir- donc y a toujours une infirmière, malheureusement parfois y en a qu'une aussi pour six ou sept bébés, donc ça c'est parfois très compliqué. Parce qu'avec le nombre de sage-femmes ou d'infirmières qui sont prévues pour la maternité et la salle d'accouchement, vu que les lits néonataux ne sont pas comptés vraiment et d'ailleurs c'est pour ça qu'on s'adapte en fonction- d'ailleurs, ce n'est pas- y a pas de normes en fait je pense sur les lits néonataux. » (Physician, N*)*

> *« Prise en charge euh d'un, d'un nombre de bébés incroyable. Et c'est c'est difficile parce que vous courrez comme une poule sans tête quoi entre les pompes qui sonnent, la perf à repiquer les prises de sang. Et puis il y en a un qui ne va pas bien et en fait ça vous occupe et puis tout le reste doit, doit tourner. Donc c'est très compliqué une fois qu'il y a quelqu'un d'absent. À un moment donné bon ben on donne, on donne, on donne et puis les gens disent "non, stop", non, c'est, c'est catastrophique. Alors lier à l'occupation des lits c'est bien mais il y a d'autres critères qui doivent rentrer dedans, le taux d'occupation des lits ou l'intensivité, il y a tout ce côté ben de, prise en charge des parents, de NIDCAP, qui prend aussi du temps. Ça c'est des choses auxquelles on ne fait pas tellement attention. Bien évidemment s'il y a des échelles dans le nouveau truc clé là ben ça va peut-être [rires] faire avancer ces choses, mais voilà. Il faut d'autres critères pour staffer des soins intensifs des services néonataux." (Nurse/midwife, N*)*

Second, the shortage of staff is exacerbated by **lengthy absences** (e.g. sickness leave, maternity leave) not being replaced. Hence the service has to keep running with less staff.

> *"Toch een vrij groot aantal mensen die ziek zijn dikwijls. Ja, de rest moet dat opvangen. Ook regelmatig zwangere collega's. En dat wordt niet ingevuld hè. Dus ge moet ge moet het dan doen met de mensen die er zijn. Niet dat ge dan kunt beroep doen op andere diensten. Integendeel, wij zijn zelf moeten gaan helpen op de COVID-diensten. Dus [lacht], ja. En dan zit ge zelf eigenlijk, ja, een beetje met uw handen in uw haren." (Nurse/midwife, NICU)*

In addition to understaffing, neonatal wards have to adapt to a **fluctuating workload**. Participants mentioned a variation between no babies at all and more than ten. This seems to be especially problematic for (small) N* services.

Participants mentioned several ways to cope with the fluctuating number of admitted newborns and the care intensity they need. At **quiet moments** some hospitals ask staff to go home and return if the workload increases. They have to absorb overtime or take up leave. In other hospitals, staff is transferred to other services. This demands a lot of flexibility.

> *"Het is echt, het is echt wel, ja, wisselend, ongeveer meestal rond de zes à acht prematuren, zitten een aantal keer uitschieters bij van boven de tien, maar het zijn ook sommige dagen dat er maar drie liggen. […] Maar ze verwachten enorme flexibiliteit dan ook van de collega's, dus als er bijvoorbeeld maar drie kindjes liggen, moeten ze naar huis. Zijn er plots opnames, moeten ze terugkeren.*

Dus ja, ik vind dat wel moeilijk om zo veel flexibiliteit te verwachten van de collega's ook." (Nurse/midwife, N)*

"Als het wat kalmer is op de dienst, dat we of A onze hulp gaan geven op een andere afdeling die hoge zorgzwaarte scoren, maar als het dan ook rustig is en er is geen hulp niet meer in het ziekenhuis nodig, dat ze of met referentiewerk bezig zijn of overuren terugpakken of eventueel verlof pakken." (Nurse/midwife, N)*

At peak times, additional staff not on duty can be called or staff from less busy services is requested to help out. To enable the switching of personnel between services, hospital-wide monitoring systems are put in place. If assistance is needed for several days, hospitals dispose of a mobile team that can be asked to join the staff at the neonatal service until the workload decreases. The mobile team however does not necessarily have the same skills and routines, which may limit their contribution. A final option is to call on volunteers, mostly consisting of retired staff.

"Er is een zorgzwaarteschaal die wij in het hele ziekenhuis invullen, dus als het heel rustig is op de afdeling en je hebt sowieso tijd om te gaan helpen, scoren wij 1 of groen, en 2 is: we kunnen gaan helpen, maar dan moeten we wel eventjes afspreken op bepaalde tijdstippen bijvoorbeeld. 3 is van: ja, ik heb geen hulp nodig. Maar ik kan er ook geen geven en een 4 scoor je als je echt met je handen in het haar zit en je hebt hulp nodig van een andere afdeling. Dus iedere afdeling in het ziekenhuis vult die schaal naar eigen behoren in en dan moet je gaan kijken, op een bepaald uur moet je gaan kijken: zijn er afdelingen die hulp nodig hebben? En je kunt er gaan geven? Ja, dan behoor je ook die afdeling te gaan helpen. En ja, die hulp werkt ook natuurlijk in de andere richting, als wij extra handen nodig hebben." (Nurse/midwife, N)*

"En als dat dan heel druk is, wij hebben ook wel een mobiele equipe, maar die zijn daar totaal niet voor opgeleid. Dus die gaan dan gaan helpen op materniteit, waardoor dat ons collega van materniteit soms kan inspringen, maar als dat daar dan ook druk is, is dat ook niet mogelijk. Dus wij moeten dan ook rekenen op flexibiliteit, op vroedvrouwen van buitenaf, die dan extra komen werken." (Nurse/midwife, N)*

"Als het nu echt heel, heel, heel druk is en we zien, dat is vaak voor een aantal dagen. Oké, we gaan hier een aantal dagen tegemoet waarbij we eigenlijk geen extra ruimte hebben, dan durven we ook wel in ons eigen team een oproep te doen en, ja, de verpleegkundigen of vroedvrouwen bij ons op de afdeling, ja, die werken daar ook eigenlijk met hart en ziel, dus die gaan daar ook wel extra komen, hoor, om toch wel die zorgen te kunnen verlenen die dat we eigenlijk allemaal zo graag daar met hart en vuur voor werken." (Nurse/midwife, N)*

"Er is al een paar keer sprake geweest ook over bijscholing rond vrijwilligers. Eh, dat kan over kleine zaken gaan, want dat gaat inderdaad niet over eh zorgen aanleren waar dat wij allemaal voor hebben, zijn opgeleid of hebben gestudeerd, maar die dan toch wel een aantal kleinere taken kunnen uitvoeren, waardoor dat wij wel meer tijd hebben voor onze eigen taken. […] onze collega's die met pensioen gaan, die altijd mee neonato hebben gedaan. […] Die mensen zijn wel een stuk opgeleid, die kunnen daar wel een stukje in ondersteunen. Dat hoeft zeker geen wildvreemde te zijn, maar dat kan naar mijns inziens wel." (Nurse/midwife, N)*

To objectify staff shortage, services may perform **workload measurements**. This is usually not done permanently, but sample-wise during a limited time period. Participants mentioned the Triple N score as an example of a validated workload measurement for neonatal intensive care wards. Some use the workload measurement to convince hospital management that more staff is needed and to show that the number of admitted babies is not an accurate proxy of workload. Workload is mostly determined by the intensity of care the newborns need.

"Wij passen de Triple N-score toe. Dat is een gevalideerde werklastmeting voor neonatale intensive care units. En wij vergelijken dat dan met de verdeling van de verantwoorde bedden en eigenlijk moet ik wel zeggen dat dat behoorlijk goed overeenkomt. De verantwoorde bedden krijg je natuurlijk maar twee jaar later, maar als we dan de workload volgens de Triple N-

score van die periode nemen dan lijkt dat wel goed te kloppen. Nu de Triple N-score is een relatief ruwe score met een beperkt aantal groepen en we zijn wel aan het uitkijken om over te schakelen naar meer gedetailleerde werklast meetinstrumenten voor neonatale intensive care units, om die te gaan toepassen, omdat ik vind dat dat belangrijke en objectieve parameters zijn waar je op een veel eerlijker manier een zorgzwaarte kunt meten. Beter dan gewoon het aantal opnames te tellen, andere parameters te gebruiken die eigenlijk niet veel te maken hebben met werklast maar meer met aantallen patiënten, die niet altijd representatief zijn voor werklast." (Physician, NICU)

"Maar dat wordt echt wel nagekeken, hè, of dat je als het hier rustig is, en zeker op onze afdeling, iedereen zal dat herkennen, zitten ze met een vergrootglas te kijken. Wat zijn ze daar aan het doen eh, ja? En het is niet het aantal kindjes wat ze moeten tellen, hè. […] Ze moeten kijken naar de zorgzwaarte, hè. We kunnen met zes kinderen meer werk hebben dan met tien kinderen die stabiel zijn en het goed doen." (Nurse/midwife, N)*

Staffing is a matter of staffing norms, hence hospital financing, but at the same time hospital management has some manoeuvring space to allocate support to neonatal wards. The degree of *leadership engagement*, or the alignment and spirit of partnership between clinical professionals and administrators within a hospital, differs between hospitals. Some participants said they could convince hospital management of the importance of having enough staff at the neonatal service, other report a daily battle with hospital management about staffing.

« Voilà on a aussi quelques infirmières qui sont certifiées NIDCAP, maintenant de nouveau, comme nous sommes en nombre- en sous-effectif au niveau infirmier, ben voilà, c'est parfois compliqué de pouvoir détacher ces infirmières-là vraiment des soins, pour avoir des vrais bilans NIDCAP au quotidien. Donc elles peuvent le faire de temps en temps, mais malheureusement pas assez régulièrement à notre goût, mais voilà, c'est vraiment une question de staff infirmier. Et c'est une bataille permanente avec la direction. » (Physician, NICU)

The lack of staff has **consequences** in several ways. The following consequences have been reported during the focus groups. Support groups and workshops for parents and siblings cannot be organised, mother and baby cannot be kept together after birth, and trainings cannot be followed or must be postponed (see paragraph 6.3.4.6.

« Et quand j'entends tous les groupes et les ateliers, j'ai une grosse demande et de, des groupes de travail dans mon unité aussi de mettre ça en pratique mais pour le moment je suis sous-staffé et on n'a malheureusement pas le temps de libérer ces infirmières pour mettre ça en pratique. Des groupes de fratrie et des ateliers pour les parents et la consultante de lactation pour faire encore plus pour les parents, des informations de, du soutien, c'est un peu compliqué pour le moment. » (Nurse/midwife, NICU)

"Het scheiden van moeder en kind hangt niet alleen van uw NICU af, maar ook van de goodwill van de vroedvrouwen en de mogelijkheid om ook zorg van de vroedvrouwen op uw diensten te hebben, of vroedvrouwen die na de bevalling mee willen komen om de mama in het oog te houden. Dat situeert zich niet alleen op de neonatologie, maar dat situeert zich ook voor mij op de verloskamer, waar ge toch ook tegen wel barrières aanloopt. Zeker als ge naar moeder-kindscheiding wilt inzetten en eigenlijk de baby zo lang mogelijk bij de mama wil laten, dat ge daar ook wel wat tegen barrières aanloopt. Praktisch soms, maar ook vaak ja onderbestaffing van uw verloskamer. […] En dat eerste uur is dat inderdaad wel belangrijk, dus je zit heel snel praktisch ook met een scheiding die niet alleen infrastructuursgewijs is, maar ook door onderbestaffing op andere diensten, allee, dus, dus door uw verloskamer hè. Omdat de vroedvrouwen ook niet altijd mee kunnen." (Physician, NICU)

In conclusion, the focus group participants indicated that **neonatal wards lack staff, the staffing norms are inadequate to provide IFCDC to each newborn and his/her family**. Although most healthcare professionals involved in neonatal care seem to be convinced about the benefits of IFCDC and are willing to invest time and energy in adhering to its principles, the actual implementation depends on the workload. If the workload is too high relative to the available staff, IFCDC moves to the background. Services try

to maximise IFCDC with available means. A lot of flexibility, creativity and a high level of bricolage are reported by professionals. With bricolage IFCDC is brought in accordance with the available means, such as staffing and infrastructure.

> *« On ne l'a pas abordé mais voilà, moi j'y connais un peu moins bien, mais tout le côté "supporting" par nos directions, et puis après, au-dessus, par le ministère de la Santé. Parce que tout ça, s'il y avait des financements un peu meilleurs en termes de personnels, pour avoir des équipes pluridisciplinaires qui soient vraiment centrés dans les soins de développement, ça nécessite beaucoup d'argent. Ça aiderait. Et donc chacun d'entre nous essaie de faire au mieux avec ce qu'il a. On bricole tous avec nos équipes pour essayer de- de tout optimaliser, mais c'est clair que le financement il n'est pas là, hein. » (Physician, N*)*

Solutions can be found in adequate staffing norms based on care intensity (not the number of admitted infants) and *leadership engagement* within hospitals creating a climate of partnership and shared *relative priority*.

6.3.4.5 Available resources – Infrastructure is insufficiently adapted to IFCDC

From the focus groups with professionals working at N* and NIC wards, we learned that the **hospital infrastructure is often inadequate** to provide IFCDC.

> *"De meeste couveuses zijn gebouwd in de jaren waar dat er geen sprake was van ouders bij de zorg te betrekken. En zelfs onze couveuse die relatief nieuw is, en dan spreek ik over tien jaar, is wat breder gebouwd en daar kan, met moeite een ligzetel of een slaapbedje geïnstalleerd worden. Maar zo luxueus ingericht is het toch niet. Dus ik denk dat dat daar toch wel een mentaliteitswissel is dat die zorg toch breder moet gegarandeerd worden." (Physician, N*)*

> *"En dat je dan ook vierentwintig uur op vierentwintig bezoekmogelijkheid hebt van ouders bij het kind ofwel idealer wijze natuurlijk verblijf van de ouders bij het kind, maar dat is architectonisch in de meeste ziekenhuizen ook nog niet echt mogelijk." (Physician, NICU)*

Focus group participants mentioned unisono that **neonatal wards lack space** to fully implement IFCDC. Especially rooming-in of parents is highly limited by the often-outdated inadequate infrastructure, hence remains limited because of a lack of surface in general, and lack of available individual rooms in particular.

> *"En naar rooming-in zoals wij dat graag zouden hebben dat is heel beperkt in wat ge kunt aanbieden, hoe dat ge dat moet organiseren, hoe dat ge dat moet financieren. Dat blijft altijd zo maar… Ja, dat is zo… [lacht] Ik noem dat amateuristisch een beetje. Het is er wel maar het kan niet goed uitgebouwd worden omdat gewoon die infrastructuur er niet is." (Physician, N*)*

> *"Momenteel hebben wij eigenlijk één rooming-in kamer. Spijtig dat het maar één kamer maar dat is natuurlijk, ja, de infrastructuur die, die dat niet toelaat. Dus wij hebben één kamer waarin dat ouders met hun kind kunnen overnachten. Maar dus, ja, spijtig genoeg hebben we er niet meer. En het is lastig want soms willen, ja, mensen echt wel bij hun kind bij blijven. Dat is spijtig, ja. Dus het is echt infrastructuur, architectuur dat het dan moeilijk maakt." (Nurse/midwife, NICU)*

> *« On a une architecture qui ne nous permet pas d'avoir des chambres « maman-bébé » dès le NIC, donc forcément ça ce sont des freins quand même importants. » (Physician, NICU)*

Nevertheless, the participants estimate that the **size of the neonatal wards** is an extremely important precondition to deliver not only IFCDC, but also high standards of quality of care in general. As an illustration, participants mentioned the level of noise in a room shared by several infants providing discomfort for both the infants, the parents and the staff.

> *« Et puis encore dans les salles encore de l'intensif mais au lieu d'avoir je veux dire un, deux, trois, quatre, cinq, six, sept bébés dans une pièce, on n'en a plus que quatre. Donc au niveau du bruit, c'est tout à fait différent. Au niveau de l'espace, c'est complètement différent. On sait bien que quand il y est, entretemps avec le COVID*

ça c'était assez flagrant quand il y avait moins de bébés, il y avait moins de bruit et ils grossissaient nettement mieux. Donc l'espace, c'est quelque chose excessivement important. » (Nurse/midwife, N)*

Larger neonatal wards offer more comfort for all actors involved. For parents this is about privacy and the comfort of being able to sit or lay down next to their infant. For staff being able to carry out the principles of IFCDC (e.g. four hands care, feeling comfortable in talking to parents).

"A: Het enige probleem is uhm, ja, we hebben ook nog een deels open afdeling en daar is het delicaat als je aan bedside briefing doet. […]

B: Ja. Ja, bij ons is dat ook het probleem, dat het een grote open afdeling is en dat iedereen dan in feite alles hoort. We zijn ook aan het zoeken naar een oplossing daarvoor." (Nurse/midwife, N)*

« S'il n'y a pas beaucoup de place déjà pour sortir un bébé d'une couveuse, ben parfois on est un peu, pas très à l'aise et je pense que voilà, avec les fils, on l'est encore moins. Parfois on est, pour discuter d'un allaitement, ben parfois on a bien besoin d'espace pour pouvoir tourner autour de la maman pour savoir vraiment. Et puis pour pouvoir discuter, je trouve que même quand on parle de l'allaitement, quand on parle de, du cas propre du bébé, je trouve que tout le monde, le reste des parents n'a pas besoin de ça, de connaitre toute l'histoire de l'enfant et ça n'aide pas la maman à se confier s'il y a un souci ou si elle a une angoisse, enfin. Là y en a qui n'ont, qui n'ont pas de tracas et ça ne les dérange pas que tout le circuit soit au courant. Mais voilà, je trouve qu'enfin ce n'est pas, en tout cas moi ça me dérange de parler d'un bébé alors que les autres mamans euh un petit peu à côté. » (Nurse/midwife, N)*

In addition to the size of the neonatal ward, the **availability of individual rooms** providing parents the possibility to stay overnight close to their baby, facilitates IFCDC.

« On a la chance d'avoir mis sur pied une unité "kangourou" dans notre centre hospitalier, y a quelques années, et ça permet vraiment d'appliquer ces préoccupations de soins centrés sur la famille de façon beaucoup plus aiguë. » (Physician, N)*

"Het probleem van beschikbare kamers, als je ouders een, een paar dagen of, of een nacht of twee wil laten in-roomen, is het niet alleen bij de N-functies, want we hebben daar bij ons op de NICU in [ziekenhuis] ook een zeer hoge nood aan en weinig beschikbaarheid. Wij hebben één kamertje ouder-en-kind op de dienst zelf en dat gebruiken we dan meestal voor de hele complexe ontslagen. Kinderen die met zuurstof of met sondevoeding naar huis gaan of voor een overlijden. En dan heb je inderdaad ook bij de gynaecologen één of twee kamers waar we moeten naar vragen, die voorlopig bijvoorbeeld niet beschikbaar zijn omwille van verbouwingen. En dan is er nog ergens in de pediatrie een kamer en op de oncologie, maar dat is nogal een grote afstand van de neonatologie. Dus ik denk dat een belangrijk onderdeel van gezinsgerichte neonatologie is zorgen dat je het aanbod van zulke kamers voor de ouders echt voldoende hebt en dat je mensen niet moet teleurstellen, in de kou moet laten staan of een paar honderd meter over de campus moet laten stappen vooraleer ze bij hun kind zijn. Ik denk dat dat een heel belangrijk onderdeel is, zorgen voor de mogelijkheid om te overnachten, zo dicht mogelijk bij de baby's." (Physician, NICU)*

In the worst case, infrastructure does not allow parents to stay overnight with their child, in the best-case rooming-in is possible but only for a very limited number of children and/or a limited number of nights. This means the staff has to choose which family benefits most from an individual room. As the individual rooms are scarce, they are only offered for a limited number of nights, mostly one or two nights before discharge to give parents the possibility to familiarise with their child and learn what it takes to take care of the child 24/7.

« On voit vraiment la différence, enfin tout, enfin toutes nos chambres mère-enfant sont tout le temps prises parce que du coup c'est vrai qu'on n'en a pas pour tous les patients et dès qu'il y en a une de libre, on a toujours des demandes. Et c'est vrai que, par contre chez nous, comme on n'a pas des chambres mère-enfant pour tout le monde, ben on favorise plutôt les chambres mère-

enfant pour les patients qui sont moins intensivement. » (Nurse/midwife, NICU)

Staff imposes criteria to determine which parent-child dyad qualifies for an individual room. Organisation and access criteria of individual rooms are multiple but focus group participants mostly cite the same criteria.

« Donc y a chaque fois sage-femme et infirmière pédiatrique dans le service, ça c'est quand même une chance d'avoir cette double-permanence. Et donc en fait, les bébés qui répondent à certains critères, à la fois de terme et de stabilité de paramètres médicaux, peuvent aller dans une chambre kangourou pour faire donc un séjour continu avec la maman. Les parents, le papa est le bienvenu aussi. Il est logé également dans la chambre. » (Physician, N)*

We listed the criteria that have been mentioned during the focus groups in Table 32, however this is certainly not meant to be an exhaustive list. We differentiated between child-related and mother-related characteristics. Individual rooms are more likely to be proposed to the parents of children who do not or no longer need intensive care; hence the child is doing sufficiently well. The child only needs a short stay, or he/she is ready for discharge. The mother should also be in a sufficiently well health condition and she must be discharged from maternity. Mothers with breastfeeding or psycho-social problems are often prioritised. Finally, preparing parents for discharge was an often-cited reason to offer an individual room.

Table 32 – Criteria for individual rooms

Criterion	Quote
Child-related criterion	
The child does not/no longer need intensive care	*« On a des chambres maman-bébé, mais plutôt pour les enfants qui sont passés en N* en fait, qui n'ont plus besoin de soins intensifs » (Physician, NICU)*
The child is doing sufficiently well	*"Ben c'est vraiment des critères enfin globaux, il faut que le, que l'enfant soit stable donc qu'il ait pas le système respi, d'aide respiratoire, qu'il n'ait pas de voie centrale, qu'il soit en tout cas au tout début hors couveuse." (Nurse/midwife, N*)* *« Donc y a chaque fois euh sage-femme et infirmière pédiatrique dans le service, ça c'est quand même une chance d'avoir cette double-permanence. Et euh donc en fait, les bébés qui répondent à certains critères, euh à la fois de terme et de stabilité euh de paramètres médicaux, peuvent aller dans- dans une chambre kangourou pour faire donc un séjour continu avec la maman. Les- les parents, le papa est le bienvenu aussi. Il est logé également dans la chambre. » (Physician, N*)*
Rather short stay	*"Na de COVID-periode is het wel de bedoeling van hier op de afdeling die rooming-in kamer te bouwen waarbij dat er ook couveuses zouden kunnen geplaatst worden en dan zou bijvoorbeeld de bedoeling ook kunnen zijn van later prematuren bijvoorbeeld vanaf 35 of zo, waarvan je weet dat die kinderen het heel goed stellen en dat die ontslag termijn niet zo lang zal duren, van ouders daar al onmiddellijk in te betrekken ook en op te nemen nadat ze op de materniteit of op de MIC-afdeling zijn opgenomen." (Nurse/midwife, NICU)* *« Quand c'est plus long, je ne sais pas comment ça se passe à [organisation], mais les bébés qui restent deux, trois semaines, je pense qu'on aura du mal à garder nos mamans tout ce temps-là. » (Physician, N*)*
The child is ready for discharge	*« Quand c'est chez, c'est des séjours jours plus longs et qu'il y a une chambre qui est disponible, on essaie que la maman vienne passer deux, trois nuits avec son bébé pour vraiment s'habituer, pour voir si l'allaitement se passe bien à la demande, vraiment pour pouvoir profiter de l'éveil au maximum du bébé. » (Nurse/midwife, N*)*

Mother-related criterion	
The mother is doing sufficiently well	*« Si la santé du bébé et de la maman le permettent. » (Physician, N*)*
The mother must be discharged from maternity	*« Ah c'est une fois qu'elles sont sorties, qu'elles de, de la maternité, quelles peuvent avoir accès à ces chambres mère-enfant. » (Nurse/midwife, N*)*
In case of psycho-social problems	*« Et alors, je voulais juste rajouter que nous on a encore une autre utilisation de ces chambres "kangourou", c'est dans les situations psychosociales un peu compliquées, qu'on va définir en anténatal. Soit des mamans qui peuvent avoir des troubles psychiques… Et y en a je dois dire de plus en plus, ou avec des consommations de toxiques u- ou autres. Donc dans des situations psychosociales complexes, on utilise les chambres pour les mettre très vite- enfin tout de suite, si on peut, en contact en permanence avec leur bébé. » (Physician, N*)*
In case of breastfeeding problems	*« On leur propose en fin d'hospitalisation pour améliorer en tout cas ou s'il y a des problèmes de, de, d'allaitement pour l'améliorer. » (Nurse/midwife, N*)*
To prepare discharge	*"Wij hebben een, een, een mogelijkheid tot rooming-in. Maar dat is beperkt tot een paar dagen net voordat ze naar huis gaan." (Physician, N*)* *« Et avant de partir, elle fait quelques jours avec le bébé où elle prend en, l'entièreté des soins en charge avant la sortie pour euh, souvent on s'est rendu compte que lorsqu'on a un groupe qui s'occupe de visiter les enfants très prématurés en, à la maison, et on s'est rendu compte que les parents sont un petit peu perdus quand ils rentrent à la maison, surtout s'ils n'ont pas pu rester 24 heures sur 24. Donc on leur propose de rester les derniers jours pour 24 heures sur 24 en tout cas cette chambre mère-enfant de façon à faire tous les soins, donner tous les médicaments de façon à ce qu'ils rentrent de manière un peu plus sereine à la maison. » (Nurse/midwife, N*)*

Notwithstanding the advantages, individual rooms are also challenging for the staff, especially in terms of surveillance. When the healthcare professionals are with the parents and newborn in an individual room, they cannot at the same time keep an eye on the infants in the shared room who are doing less well. A central monitor does not solve this issue completely. In addition, infants cannot be left alone in a room when parents are absent. Individual rooms with glass or with two doors was mentioned as a potential solution. One door then opens onto the nursing post, and can be left open, especially when parents are not present, allowing the staff to keep a close look on the infant. Also, individual rooms mean more staff is needed, as the staff can only observe one infant at the time. Finally for parents, individual rooms can be more lonely, as contact with other parents is less frequent.

« Mais par contre, quand elles sont occupées avec ces mamans-là, elles n'ont pas d'œil du tout sur les autres, qui sont eux dans la salle commune et qui sont moins bien. Et ça c'est parfois effectivement assez compliqué. Et ça demande probablement du personnel supplémentaire d'avoir toutes les chambres individuelles au niveau des bébés. » (Physician, N)*

« On a beau avoir le moniteur, ça ne nous dit comment le bébé est installé, si enfin on n'a pas envie tout le temps de rentrer dans la chambre. Et par la suite, ben quand c'est des bébés un peu plus intensifs, et si les parents ne sont pas là et que nous on est dans la salle, ben le bébé a un recrache pendant qu'on est occupé au cinq, ben on l'entend et on, on va pouvoir agir avant que le monitoring ne nous interpelle. Et ça parfois, enfin, je ne sais pas comment on va pouvoir, on va voir dans toutes les thèses du

personnel s'il n'y a pas des idées parce que cette surveillance, ce regard, on ne peut pas, on ne peut pas tout fermer et laisser un bébé tout seul dans une, dans une pièce, voilà, en étant parfois toute seule dans le service, je, je ne conçois pas qu'on n'ait pas un œil sur les bébés quoi. » (Nurse/midwife, N)*

Lack of space does not only translate in a lack of individual rooms, but also means a lack of space for:

- Stocking material

  « On a une grande salle, on a huit bébés les uns à côté des autres. Quand y a un décès, qui se passe ben le service est comme pétrifié pendant 24 heures, parce que pour les autres parents ils ont partagé. Alors y a des grands avantages par contre pour les soins intégrés- pour les familles intégrées, parce que y a un échange de parents quand y a des grandes salles. Et donc y a quand même un, comment dirais-je, l'aide par les pairs. Où y a des échanges : « Ben oui, mon bébé il a fait ça, mais tu verras, ça va aller mieux. » Mais on a n'a pas d'endroit pour stocker le matériel non plus. Quand on manque de mètres carrés, c'est vraiment dans tous les domaines. Vraiment dans tous les domaines. D''espace pour accueillir les parents- ils n'ont pas de toilettes dans le service. Donc ils sont obligés de quitter le service pour aller aux toilettes. Nous on n'a pas de supérette. On a ben la cafétéria de l'hôpital, mais qui est fermée le dimanche, donc c'est… C'est tout un tas de choses… C'est tout un tas de choses, où je pense qu'effectivement… on est loin du service de nos rêves. [rires] En résumé. » (Physician, NICU)

- A recovery room in the neonatal ward

  « A : C'était nos chambres mère-enfant chez nous et voilà, et notre petite salle de réveil qu'on, qu'on a pour les césariennes quand les mamans ne sont plus euh séparées de leur bébé et de leurs maris surtout aussi euh voilà.

  Interviewer : Donc directement après la césarienne, avant d'entrer donc dans le service, elles ont une salle de réveil.

  A : Oui. Ils sont quand même monitorés le bébé pour la sat, et la maman la tension, la sat pendant une, une petite heure, on fait des premiers soins aussi dans cette petite salle de réveil où il fait bien chaud, on a créé une bonne ambiance dans cette, c'est, c'est une chambre qui a été aménagée en salle de réveil. Et après on soigne la maman et après ils retournent en chambre.

  Interviewer : Et donc là, alors ils retournent ensemble.

  A : Oui. C'est ça. Mais ils sont, ils restent tout le temps ensemble dans cette petite salle de réveil oui. » (Nurse/midwife, N)*

- A room for siblings and/or a parental lounge

  "Bezoekuren zijn niet beperkt. Maar brusjes bijvoorbeeld, ja, dat is bijna niet mogelijk, zeker niet in de winter, om die binnen te laten. Onze neonato is daar niet groot genoeg voor." (Physician, N)*

  « Mais on a aussi un petit espace, enfin un petit espace réduit pour les frères et sœurs où il y a quelques jeux, deux, trois, enfin une poupée, pour faire des dessins. Donc parfois ça permet d'un peu sortir, on laisse le, le bébé avec le papa dans la chambre et la maman passe un peu de temps avec l'aîné. Mais sur surtout quand les mamans ne sont pas hospitalisées et qu'elles sont à la maison, la même chose quand ça favorise qu'elles restent plus longtemps, elles ont juste à les faire réchauffer leur plat ou à s'asseoir un peu parce que dans le service, on ne mange pas donc elles n'ont pas d'autre choix que d'aller dans cette petite pièce là si elles veulent se restaurer » (Nurse/midwife, N)*

In addition to the lack of space and facilities to implement IFCDC, it was mentioned during the focus groups that **infrastructure always lacks behind evolutions in neonatal care**. Changing infrastructure takes time, while new evolutions in neonatal care come fast. Infrastructure cannot keep up the pace.

"Ik wou daarbij aansluiten. Het gaat allemaal zo snel, verandert eh heel snel en dan tegen dat je infrastructuur is aangepast, is er weer iets nieuws en dat kan het ziekenhuis niet echt volgen, denk ik ook,

om dat weer snel aan te passen als die infrastructuur, denk ik dan." (Nurse/midwife, N)*

Also, a **need for architectural norms** or guidelines about how a neonatal ward should look like, was identified.

« Des normes architecturales financées, où on prend en compte aussi, parce qu'on n'en a pas parlé mais bon, y a aussi le bruit, y a aussi la lumière, y a aussi tout l'environnement. Comme on l'a dit, il faut une place pour les parents devant la chambre ; probablement une place en dehors de la chambre. Il faut réfléchir à la famille au sens large. Il faut des cuisines, il faut des salles de détente, enfin bon voilà. Donc dans le monde idéal, oui, ce serait bien que tout le monde ait- qu'on discute de ce que c'est qu'un centre néonatal idéal et puis qu'on puisse le construire. Et l'entretenir. » (Physician, NICU)

Finally, it was mentioned that with an increasing size, neonatal wards face **increasing fixed costs**, (e.g. cleaning). As already mentioned, when individual rooms are introduced or are replacing a shared room, more staff is needed.

« Et puis y a le financement au sens plus large hein, comme on l'a dit hein. Ce sont des mètres carrés, donc il faut- il faut financer les mètres carrés, il faut les nettoyer. Moi je vous dis chez nous ça a été un problème énorme. On augmente le service, et puis on n'augmente pas le service nettoyage enfin- mais tout ça, ça a des coûts, ce sont des répercussions évidemment. Et la direction ne pense pas toujours non plus à toutes les conséquences, vous voyez ? » (Physician, NICU)

6.3.4.6 Access to knowledge and information – Training staff is crucial but far from evident

One of the consequences of staff shortage is the **difficulty to free staff for trainings**. Participants reported cancelled trainings because of high workload. Nonetheless, trainings are said to be crucial as the stock of knowledge relative to neonatal care is evolving rapidly. Furthermore, **trainings in IFCDC (e.g. FINE, NIDCAP) are expensive and time consuming**, hence demand a big investment of hospitals and staff. Finally, **training one staff member is not sufficient**, because putting IFCDC in practice demands a drastic change in work attitude and processes. One trained professional cannot evoke such a change.

"Ik denk dat iedereen, ieder van ons wel ervaart wat dat drukke momenten kan inhouden, welke weerslag dat dat heeft op de ploeg ook. Maar ik zou dat ook iets willen verder trekken want dan wordt er verwacht van bijscholingen te volgen of te organiseren. En bijvoorbeeld ook dat we simulatieoefeningen organiseren of zo. Maar het gebeurt wel soms. Dat is heel jammer dat je omwille van, van de werkdruk en door beperkt zorgpersoneel dat je daardoor nevenactiviteiten die toch ook heel belangrijk zijn dat je die soms moet afzeggen of annuleren. En dat vind ik ook wel een barrière. Want uiteindelijk neonatale zorg is iets wat dat altijd heel snel evolueert ook. Maar als je dan goed wil bijzijn met de hedendaagse tendensen dan zijn die bijscholingen zeker noodzakelijk. En dat kan je niet beperken tot één bijscholing per jaar bijvoorbeeld. Wat nu in de realiteit wel zo is. Of sommigen kunnen het gewoonweg niet volgen, dus dat ze geen bijscholing per jaar volgen." (Nurse/midwife, NICU)

« Je pense que on manque énormément de temps de formation parce que, en tout cas chez nous, on a droit seulement à, il y a 15 heures de formation par an qui est reconnu, et voilà, ça je pense que ce n'est vraiment pas suffisant, on a 15 heures qui sont reconnues et même pas entièrement payées parce qu'on n'a droit qu'à un financement de 50 € par formation donc en tout cas chez nous ce n'est pas très incitant à la formation. Toutes les formations doivent se faire si jamais on a envie de se former en plus c'est personnel. » (Nurse/midwife, NICU)

« Et qu'en plus c'est des formations qu'il ne faut pas faire seul, parce que si on est seul on se retrouve seul devant mur. Donc il faut pouvoir les faire à plusieurs pour pouvoir créer un noyau qui permet d'intégrer des changements. » (Physician, NICU)

« Oui, enfin que la- si les formations en tout cas aux soins de développement devenaient un petit peu plus accessibles en tout

cas, parce que c'est ça, former une infirmière, c'est 25 000 euros par- je pense hein, à ma connaissance on est quand même dans […] ces eaux-là, pour une infirmière. Plus le temps de son détachement, donc c'est quand même un budget qui est non-négligeable. » (Physician, NICU)

« Et voilà, c'est vrai que c'est des formations qui sont relativement lourdes aussi, qui demandent un gros investissement personnel aussi des équipes soignantes. Et parfois c'est difficile même de trouver des candidates qui veulent s'investir, parce que je trouve que ce sont des formations, on l'a dit tout à l'heure, qui sont lourdes. » (Physician, NICU)

The importance of trainings in IFCDC cannot be underestimated. Participants witnessed that **training has the potential to induce a service-wide change in approach**: a change in staffs' attitude towards IFCDC, a change in workflow, and a revision of work processes.

"We hebben ook effectief mensen die de FINE, alle vroedvrouwen hebben de FINE 1 gevolgd, van materniteit ook, neonato, en werkgroepen inderdaad de FINE 2, maar wij zien ook een enorme evolutie eigenlijk in het verzorgen van de baby's vooral effectief, hè, het hanteren, het goed positioneren, hè, dus steeds inderdaad proberen naar een middenlijn te werken. Het is vooral bij de badjes, bij de bloedafnames en we laten ook de ouders effectief ook steeds meehelpen, hè, ook zelfs bij maagsonden plaatsen, dus eigenlijk bij heel veel zaken betrekken we effectief ook de ouders en we zien ook dat dat voor de baby's ook een goed comfort geeft, dat die inderdaad ook goed mee kunnen vasthouden en zo. En wij merken effectief dat dat een heel andere neonato geworden is dan enkele jaren geleden, hè, ook qua huilen en comfortzorg zo. We werken dat de baby's zich duidelijk veel comfortabeler voelen." (Nurse/midwife, N)*

"Ik denk een mentaliteitswijziging die er dan toch gebeurt in het team zelf. Ik denk dat wij een paar jaar geleden als team toch ook wel heel weigerachtig misschien stonden naar ontwikkelingsgerichte zorg, […] het gaat ons meer werk bezorgen en weet ik wat. Maar natuurlijk met heel dat FINE-gebeuren, waar dat dan toch ook verschillende verpleegkundigen referentieverpleegkundigen eigenlijk in zijn en die toch meer het team trekken, dat we daar toch wel een mooie evolutie in zien, dus ja, volharding in het team dan een team dat ook gewoon groeit, dat heeft tijd nodig en dat dat toch wel ook heel positief is, gelijk het nu geëvolueerd is eigenlijk. Dat is mooi om te zien, omdat we als team ook wel echt gegroeid zijn." (Nurse/midwife, N)*

« J'ajouterai c'est dans la même lignée que la formation, mais je pense le NIDCAP est un facilitateur. Le fait d'avoir des experts au sein de l'équipe et de leur déléguer du temps hors des soins pour réfléchir, penser, revoir le processus de soins et comment les soins sont organisés autour du patient et sa famille. Parce que parfois on est tellement le nez dans le guidon que on n'a pas l'occasion d'y réfléchir. » (Physician, NICU)

Some services take the initiative to share their knowledge and skills regarding IFCDC by organising trainings for own personnel or staff from neighbouring hospitals. This kind of initiatives aim, for example, at streamlining the way of working in NICU and N* services. In case of referrals and back-referrals between services, it is beneficial for parents and newborns if services share the same work processes.

"En daar worden ook op regelmatige basis interne opleidingen georganiseerd die gevolgd worden door de mensen die zorg doen op neonatologie, maar die ook toegankelijk is voor mensen die werken op materniteiten, op onze materniteit dan. En in samenwerking met [ziekenhuis] geven we ook externe opleidingen op gebied van NIDCAP in de regio [stad] om het principe ook, de transitie eigenlijk van die NIDCAP-zorg van de neonatale intensive care naar de N-functie, wanneer onze baby's worden terugverwezen naar de ziekenhuizen van herkomst, van die eigenlijk gewoon door te geven, zodanig dat dat niet stopt wanneer de baby's onze dienst verlaten." (Physician, NICU)*

6.3.4.7 *Leadership engagement – Support of hospital management*

We briefly addressed *leadership engagement* under subheading (see 6.3.4.4) 'It's all about staffing'. *Leadership engagement* refers to the alignment between clinical professionals and administrators within a hospital. From the focus groups it was clear that **neonatal wards cannot all count on a solid partnership between staff and hospital management**.

> *"Bij ons in het ziekenhuis is dat eigenlijk een beetje moeilijk, omdat ik wel voel dat het soms echt een strijd is om het belang van de neonatologie ook te duiden [….] wat het niet altijd simpel maakt, ook voor mij, ik moet ook altijd bij de zorgmanagers zowat, ja, onszelf promoten en dat vind ik wel, allé, ik vind dat wel moeilijk, omdat ik ook wel het belang er wel van inzie en ik denk dat we al enorme progressie gemaakt hebben de laatste tien jaren, dat wij echt wel op alles ook willen inzetten, maar ook meer en meer krijgen wij toch de druk van bovenaf van: 'Ja, jullie moeten met minder personeel werken en als het kalmer is op jullie dienst, dan moeten jullie even met minder zijn.' Maar, allé, ze kijken ook wel enorm altijd naar het aantal kindjes dat bij ons op de dienst ligt, terwijl dat de zorgzwaarte daar minder van belang speelt […], maar je voelt bij ons dat het nog niet, ja, dat er nog niet 100 procent, ja, begrepen wordt precies." (Nurse/Midwife, N*)*

> *« Voilà on a aussi quelques infirmières qui sont certifiées NIDCAP, maintenant de nouveau, comme nous sommes en nombre- en sous-effectif au niveau infirmier, ben voilà, c'est parfois compliqué de pouvoir détacher ces infirmières-là vraiment des soins, pour avoir des vrais bilans NIDCAP au quotidien. Donc elles peuvent le faire de temps en temps, mais malheureusement pas assez régulièrement à notre goût, mais voilà, c'est vraiment une question de- de staff infirmier. Et c'est une bataille permanente avec la direction. » (Physician, NICU)*

The support of hospital management is especially relevant in function of investment in staffing and infrastructure. Focus group participants mentioned that the low care neonatal wards (N*) do not bring profit to a hospital but are rather loss-making. The hospital financing was said to be disadvantageous for neonatal wards. Hospitals have to invest own means, without being compensated for that, to IFCDC at their neonatal service, as this demands additional staffing and a specific infrastructure. In case new hospitals are build, neonatal wards have to convince hospital management to invest in square meters for neonatal care. The theme of infrastructure is further elaborated in section 6.3.4.5.

> *"Ik denk dat dat je je management of je directie moet mee hebben. Dat is een hele belangrijke blok eh, dat ze je middelen en de mogelijkheden geven om hieraan te werken, dat je de mogelijkheden hebt architecturaal om kamers te voorzien, dat je de mensen hebt die je kunt inzetten […]. Je moet de mensen op opleiding mogen sturen. Uhm, ja, je moet de middelen krijgen om zaken aan te kopen rond NIDCAP of rond het comfortabel installeren van de kinderen. Dus ja, voor ons is dat een hele belangrijke en ik voel dat onze directie daar, ja, 300 procent achterstaat, wat maakt dat je die mogelijkheden krijgt om, om zulke zaken uit de grond te stampen." (Nurse/midwife, N*)*

> *"Zeker wij als artsen zijn wel van het principe onze herberg is altijd open dus ze zijn bij ons altijd welkom. Hè zolang dat het praktisch mogelijk is. Niet dat we daar tegenstribbelingen krijgen vanuit directie maar toch, ja, dat is een soort service dat ge biedt dat eigenlijk geen geld oplevert natuurlijk hè. We zijn wel in gesprek gegaan ondertussen ook met de directie en gevraagd ook om die family-centred care en ook wat meer privacy en wat is het allemaal te kunnen creëren. Maar dat vraagt van uw directie een zekere toegeving financieel. En nu met corona is dat allemaal een beetje op de lange baan gezet geweest. Dus het komt er eigenlijk op neer dat we allemaal wel willen maar dat we een beetje het budget missen en het personeel missen om te doen wat dat we zouden willen doen." (Physician, N*)*

> *"Er moet daar ergens een andere financiering voor komen, zeker naar de ziekenhuizen toe. Niet meer naar de artsen maar de ziekenhuizen want de ziekenhuizen die steken dat, die waar dat het goed gewerkt wordt dat er minder kosten zijn op de NICU, die steken daaraan toe. En soms kun je dat forceren bij je ziekenhuis*

maar soms kun je dat niet forceren of niet meer forceren." (Physician, N)*

"Alhoewel dat we hard werken […] betekenen wij niks voor de directie. Wij brengen niet op, wij kosten alleen maar. En daar moet er duidelijk iets aan veranderen. Een pasgeborene kost, dat kost personeel. Ge hebt daar extra personeel voor nodig. […] Wij hebben niks te bieden aan de directie. Behalve we hebben veel te bieden aan de ouders, veel te bieden aan de pasgeborenen, geven goeie zorg, we doen fantastisch werk. […] Maar voor directie zijn wij niks waard." (Physician, N)*

« Nous on a récemment eu une petite projet, un projet peau-à-peau après la césarienne, ça a pris quand même un an et demi. J'ai vraiment invité à chaque fois la direction là-dedans, parce que oui, il faut un peu plus de personnel quand même, on, le jour qu'on a des césariennes. C'est plus important qu'on a les médecins, mais aussi la direction avec nous. Et bon, ça suit son cours facilement, je trouve, allez, ça va. » (Nurse/midwife, N)*

« Maintenant voilà, d'avoir l'aide de sa propre institution, ça serait quand même aussi parfois quelque chose de positif. C'est vrai quand j'entends tous mes collègues qui ont eu la chance, et la joie, d'avoir un grand service - enfin pas tous n'ont gagné donc - comme nous on a effectivement le projet d'avoir un nouveau centre, mais c'est une bataille au quotidien. C'est pouvoir gagner quasi mètre par mètre, en essayant de justifier. Enfin moi j'ai l'impression que pour nos gestionnaires d'hôpitaux c'est … Un bébé, c'est un petit bébé, il a besoin d'une petite couveuse, de petits médecins… Je ne sais pas. [rires] » (Physician, NICU)

6.3.4.8 Peer pressure, cosmopolitanism, patient/parent needs and external policy

Under this subheading we turn to the outer conditions facilitating IFCDC. Peer pressure and cosmopolitanism are both linked to the impact of peer neonatal wards in other hospitals, how they collaborate or compete for available means to implement IFCDC. In case of a referral, it is expected that the family gets the same quality of care in the receiving service as is the case in the referring service. Some NIC wards organize trainings and symposia for neonatal wards of other hospitals (in the same locality) to build a similar way of working in both referring and receiving services.

> *"En in samenwerking met [ziekenhuis] geven we ook externe opleidingen op gebied van NIDCAP in de regio [stad] om het principe ook, de transitie eigenlijk van die NIDCAP-zorg van de neonatale intensive care naar de N*-functie, wanneer onze baby's worden terugverwezen naar de ziekenhuizen van herkomst, van die eigenlijk gewoon door te geven, zodanig dat dat niet stopt wanneer de baby's onze dienst verlaten." (Physician, NICU)*

This way neonatal wards in the same network can help each other move forward with IFCDC. During one of the focus group interviews participants even raised the idea of purchasing cameras in group to lower the price. This is another example of the benefits induced by *cosmopolitanism*, or the degree a neonatal service is networked with other organisations.

> *"Die vragen inderdaad een prijs die ook binnen ons budget niet past, omdat aan te schaffen, maar misschien is het wel een heel goed idee om de handen in elkaar te slaan en als een groep met dat bedrijf te gaan spreken en niet als individuele NICU's of N*-functies." (Physician, NICU)*

This project may even contribute to further developing the cosmopolitanism of the participating neonatal wards, as also the idea to create a kind of N* reflection group emerged during one of the focus group interviews.

> *"Eigenlijk vind ik het wel leuk om ook andere collega N*diensten te horen en eens te zien en hun mening te horen en hun ideeën te horen [lacht]. Het is misschien een idee om, gelijk de NICU eens een keer een groep samen te stellen en op regelmatige basis eens*

samen te komen, hoe het, hoe het, ja, hoe het gaat bij ons, bij u, om ideeën uit te wisselen. Zou dat geen idee zijn?" (Nurse/midwife, N)*

IFCDC is also stimulated when *patient needs*, and the ways to meet those needs, are known and considered important by the neonatal service and the hospital by extension. In the case of neonatal care patient needs are broadened to parent needs. Focus group participants told us about parent advisory boards installed to learn from parents' feedback.

"Wij hebben daarvoor ook een ouder adviesraad opgericht. Dat zijn ouders van ex-prematuren die na hun verblijf op neonatologie hun ervaringen meenemen om zo ja een aantal zaken te veranderen, te verbeteren, ouders te ondersteunen, maar daar krijgen wij toch ook wel redelijk veel feedback van. En hoe het voor ouders aangenamer zou zijn om op onze afdeling te verblijven." (Physician, NICU)

Finally, *external policy and incentives* are closely linked to the available resources in the inner hospital setting.

6.3.4.9 *Impact of the COVID-19 pandemic on IFCDC*

COVID-19 was not a severe threat to the health of preterm newborns. Still precautions have been taken to prevent infections. Isolation boxes have been installed for infected families. In the most extreme cases infected parents were separated from their infant after delivery, which led to heart-breaking situations. Staff tried to soften the separation through remote contact by means of iPads.

« Maintenant, le COVID n'a pas été que positif pour les mamans qui étaient réellement COVID, hein. Donc c'est les mamans qui étaient, qui devaient être isolées […] Mais y avait un choix à faire de la part du papa : donc soit papa restait avec maman, et alors c'était, du moment où il rentrait il ne sortait plus jusque quand tout le monde sortait, […] Ou il décidait : non, y a la fratrie, je reste à l'accouchement, mais dès que l'accouchement est fini, je pars et je ne vois plus ma femme et mon bébé jusqu'à ce qu'ils rentrent à la maison, donc y a quand même eu des coupures hein. Ça n'a pas été qu'un ciel bleu. On n'a pas eu beaucoup mamans qui ont été séparés, mais on a eu des mamans en soins intensifs, et donc on a eu quelques bébés isolés chez nous. Là ils étaient isolés, isolés. Ça n'a pas été fréquent. » (Physician, N)*

"Mama's die dat op COVID lagen en daar vanuit de problematiek van de mama te vroeg zijn bevallen. Dat zijn hartverscheurende situaties hè. Dat zijn mama's die dat hun kind een lange periode niet zien, waar dat de papa dan ook positief is. Dus kindjes die daar echt totaal geen bezoek kregen. Dus ja, dan skypen en op die manier ouders toch een beetje proberen te betrekken maar, ja, dat gaat zo helemaal tegen de natuur in hè. Dat was niet evident." (Nurse/midwife, NICU)

Also, in reaction to the COVID-19 pandemic neonatal wards severely restricted visitors. The severity of the restrictions varied between hospitals, but in general parents could continue to visit their newborn without restrictions in time, but other family members, including siblings were no longer allowed. The most severe ward (represented in our focus groups) allowed only one parent at the same time.

« C'est clair que les visites ben en chambre privée, le papa pouvait rester ; en chambre commune, pas beaucoup. Les fratries pouvaient pas du tout venir, donc quand ils viennent deux ou trois-ils restent deux à trois semaines, et qu'il y a deux enfants qui ne peuvent pas venir, c'était assez compliqué. Alors nous on a demandé énormément à la direction de faire des efforts, parce que c'était assez inhumain là-dessus. » (Physician, N)*

"We hebben ons beleid gaandeweg wel wat aangepast op vraag van de ouders, maar initieel hadden wij eh dat er alsmaar één van de twee ouders aanwezig mocht zijn. Wel continu, dus vierentwintig op vierentwintig, mocht er iemand zijn, maar wel altijd apart. Uit bevraging is daar wel gebleken dat ze het daar wel moeilijk mee hadden. Dat ze eigenlijk nooit samen als gezin aanwezig konden zijn. We zitten natuurlijk in een open ruimte, waarbij er niet zo heel veel plaats is tussen de couveuses, dus het was eigenlijk om het aantal mensen op de afdeling te beperken dat we dat hadden ingesteld. Maar wij zijn dan overgegaan naar een

systeem waarbij dat ze een soort van tijdslot konden reserveren, dat een bepaalde periode toch de twee ouders tezamen aanwezig konden zijn." (Physician, NICU)

Although the restrictions on visitors were difficult to bear for parents, they also had some positive consequences: parents were more focussed on the baby, had more time to spend with the baby, breastfeeding went more smoothly, and parents, babies and staff were more relax. These unanticipated positive consequences incited a rethinking of the wards policy towards visitors.

« C'était compliqué pour certains parents, mais autour du bébé lui-même, c'était par contre magnifique, parce que ben les parents n'avaient rien d'autre à faire que de s'occuper de ce bébé. Les allaitements ont été beaucoup mieux. Les infirmières étaient plus posées, parce qu'il n'y a pas les visites. » (Physician, NICU)

"Het toelaten van minder bezoek is niet altijd negatief geweest bij ons. Voor de COVID hadden wij twee keer per dag een half uurtje bezoekuur. […] Ze mochten per kindje met vier mensen binnen. En soms gaf dat echt een overrompeling op onze afdeling. Wij zien nu dat dat, ja, nu dat we dat niet meer doen, dat onze neonaatjes eigenlijk toch wel rustiger zijn, dat wij minder alarmpjes soms hebben en ook dat ouders ook wel rustiger zijn als ze zich niet nog moeten bekommeren om het bezoek dat ze eigenlijk ook nog moeten entertainen. Nu kunnen ze zich bezighouden met hun kindje en zich daar echt volledig op richten." (Nurse/midwife, N)*

"Ik denk dat we de bezoekregeling, gelijk het vroeger was toch zeker gaan herbekijken." (Nurse/midwife, N)*

Despite a decreased number of admissions during COVID-19 waves, staff reported a higher workload. Wards had to function with a minimal staffing, because part of the staff was claimed to work at COVID-19 wards. In addition, staff had to be exempted for the care of infected infants. Precautions such as protective clothing and adapted workflows also increased the workload.

"Ik denk dat dat automatisch de zorgzwaarte verhoogt eigenlijk. Hier was ook de afspraak op het ziekenhuis als er een COVID-patiënt werd opgenomen of in, zelfs in de pre-COVID zone dat er maar één verpleegkundige mocht bijgesteld worden. Maar als je dan al met een minimumbezetting moet werken waarvan dat je daar nog één iemand aan kwijt bent dat verhoogt automatisch ook de druk bij de anderen." (Nurse/midwife, NICU)

Other reported difficulties caused by the COVID-19 pandemic were staff feeling unsafe because of many parents in one room, lack of interpreters hampering communication with foreign parents, the efforts to involve siblings were cancelled (e.g. cases with gadgets), trainings and meetings were postponed and the impact of face masks and other protective clothing on infants.

In sum, the COVID-19 pandemic has both positive and negative consequences, but in general IFCDC came under pressure. Principles such as non-separation, involvement of the whole family, including siblings, were difficult to reconcile with all precaution measures, while taking care of newborns in function of their rhythm seems to be facilitated by banning visitors.

6.4 Key points and suggested solutions

From this chapter we learn that although there is a consensus about the desirability and benefits of IFCDC, it is not systemically supported. Hence the current implementation initiatives are hospital-specific and depend on the enthusiasm and goodwill of the hospital staff and management.

We identified a number of preconditions for a successful implementation of IFCDC at the organisational or hospital level. Here we summarize them and link them to solutions participants suggested during the focus group interviews.

Adequate staffing and infrastructure are essential in the implementation of IFCDC

Lack of resources was the main barrier cited by the focus group participants, especially lack of staff to implement the principles of IFCDC. As IFCDC is more labour intensive, more staff is needed to get the work done. In case of a too high workload, IFCDC can no longer be provided, and staff

returns to standard care. In addition, infrastructure was said to be inadequate or not adapted to IFCDC. Neonatal wards have too little space, too few individual rooms, and often lack a family or leisure room.

In addition, participants reported that **transfers of infants between N* and NIC wards are affected by hospitals' financial interests**. Referrals and back referrals impact hospital financing and physicians' remuneration. This means some referrals and back referrals do not happen, because of financial interests. If infants are kept longer than medically necessary in an expensive intensive care bed, this leads to suboptimal care and a waste of public means.

A profound change in the neonatal landscape is needed to further develop IFCDC

According to the focus group participants **the neonatal landscape needs a profound change** to enable all neonatal wards to implement and develop IFCDC, besides other objectives.

> *"Ik zou eerder streven naar een grondige hertekening van de perinatale zorg in België, zowel op niveau van intensieve zorg als niet-intensieve zorg en een veel efficiënter verdeling van de financiële en de personele middelen proberen te bereiken." (Physician, NICU)*

To this end a reform of the hospital financing for N* services needs revision, the admission criteria of every neonatal service should be explicit, transparent and subscribe in a national reprogramming of neonatal care services. In this reprogramming there is a need for medium care.

> *"Wij hebben al reeds gepleit naar een herechelonering van de neonatale zorg waarbij dat je tertiaire zorg hebt waarbij dat je eigenlijk, ja, ook een soort intermediaire neonatologie creëert waar dat die, die patiënten, ik zeg nu maar bijvoorbeeld, die, die nog wat eh parenterale voeding nodig hebben, die nog zuurstof nodig hebben. Die dikwijls te veel zorgen nog nodig hebben om in een low care setting verzorgd te worden. Maar die eigenlijk te goed zijn om echt die intensieve care of die intensive care unit zoals bij ons voor een deel verzorgd worden. Eigenlijk een soort ja, tussenechelonering met een aangepast financieringsmodel. Want ook daar lopen we heel vaak tegen problemen aan dat verwijzers weinig zin hebben om patiënten terugnemen, terug te nemen. Gewoon omwille van het feit dat dat verlieslatend is voor de dienst naar materiaal, naar personeel. En dat genereert geen inkomsten. Dat is dus het probleem waardoor dat je misschien overconsumptie hebt van dure, intensieve neonatale zorgbedden." (Nurse/midwife, NICU)*

In addition, referrals and back referrals should not impact hospital financing, nor physicians' remuneration, to get a correct attribution of infants to the most adequate level of care.

> *"Maar dat vraagt een volledige hertekening van het perinatale landschap, waarbij men ook de financiering van de geneeskunde moet, of van de perinatale geneeskunde moet gaan herbekijken, zodanig dat verwijzingspatronen geen impact hebben op inkomsten van artsen of inkomsten van ziekenhuizen, maar dat die in tegendeel gehonoreerd worden wanneer ze op correcte wijze patiënten doorverwijzen naar de diensten waar ze nodig zijn. Dus ik denk dat het meer neerkomt op een herverdeling van financiële en personele middelen en niet op een uitbreiding van financiële en personele middelen." (Physician, NICU)*

Leadership engagement from hospital administrators accelerates the implementation of IFCDC

Leadership engagement is closely linked to the *available resources*. For hospital managers it is obviously more convenient to take a supportive stance towards the neonatal service if resources are available and if the functioning of the neonatal service has no financial disadvantages for the hospital. Throughout the focus group interviews it was evident that the support of hospital management is essential in the implementation of IFCDC. For example, to get time and means to train staff in IFCDC, to adapt infrastructure, etc.

Leadership engagement is a prerequisite for the organisation's *readiness for implementation* of IFCDC, IFCDC's *relative priority* and the creation of a *learning climate* in the hospital. Individuals' shared perception of the importance of IFCDC within the hospital as well as organizational commitment to the implementation of IFCDC are largely determined by the *available resources* and *leadership engagement*. If the latter are absent this results in discouraged staff who feels like fighting its own management. Especially if staff has *access to knowledge and information* about IFCDC and is trained in IFCDC while the conditions to implement IFCDC are barely met, staff gets frustrated.

Participants did not come up with other solutions to augment *leadership engagement*, than foreseeing adequate hospital financing and an adequate distribution of means.

IFCDC is facilitated by compatible workflows, not only within the same hospital, but also between collaborating hospitals

Compatibility or how IFCDC fits with the existing workflows also facilitates the implementation of IFCDC. If existing workflows are too much under pressure in the execution of IFCDC mostly because of time pressure or lack of staff, IFCDC disappears in the background.

Focus group participants also talked about the benefits of harmonisation of IFCDC work processes between N* and NIC wards to create seamless transitions between N* and NIC. Parents know what to expect if care is organised in the same way across wards. Harmonisation is reached through dialogue, sharing protocols and experiences. Some NIC wards organize trainings and symposia for neonatal wards of other hospitals (in the same locality) to build a similar way of working in both referring and receiving services.

Peer hospitals push to get on the same footing

Peer pressure is defined as a competitive pressure to implement IFCDC. It is situated in the fact that neonatal wards expect the same degree of IFCDC in other neonatal wards to which infants are referred. The development of IFCDC in a neonatal ward functions as a kind of quality-of-care indicator. In case of a referral, it is expected that the family gets the same quality of care in the receiving neonatal service.

Parents need additional support to be available for their newborn

So far, we focused on conditions at the organizational level. However, during the focus group interviews we also gathered ideas about the individual family level. Suggestions have been done to facilitate parents to be present at the neonatal service and take op the care for their newborn.

- To have an affordable hotel function in hospital

  « On a obtenu ça il y a quelques années, que les parents ne payent rien. Donc soit ils sont en chambre mère-enfant et ils sont, la maman est accompagnante et elle n'a aucun frais, soit elle est dans une chambre avec un lit d'appoint à côté d'un bébé en réa. Et alors elle dispose une chambre quelques étages plus bas où elle a aussi une douche, une toilette, un lit, où elle peut aller manger, mais les repas ne sont pas compris mais toute l'hôtellerie est gratuite en fait. Et c'est vrai que ça, ça a vraiment changé la donne parce qu'avant ça, il y a des gens qui ne restaient pas parce qu'ils ne savaient pas payer. » (Nurse/midwife, NICU)

- To adapt paternity and parental leave

  « Il faudrait aménager le congé hein de paternité, particulièrement si on a un bébé en néonat. » (Nurse/midwife, N)*

  « C'est de nouveau les populations les plus précaires alors qui en souffrent, parce que nous on a souvent des papas qui disent "mais moi si je ne vais pas travailler, je vais perdre mon boulot, même avec un certificat", c'est vrai. » (Nurse/midwife, NICU)

- To provide support at home to allow parent to be available

  « Quand il y a d'autres enfants, pendant l'école c'est facile de rester, et puis après il faut rentrer, il faut faire à souper, il faut faire les devoirs, enfin bon, il faut tout organiser. Et donc là si on parle d'un point de vue vraiment beaucoup plus large, il y a probablement toute une série d'aides qui pourraient être amenées à la famille en dehors de l'hôpital, mais qui aideraient vraiment la famille. Et qui

aideraient je crois euh l'enfant aussi, qui est chez nous. » (Physician, NICU)

- To create a sibling day-care system in the hospital

  « Je trouve, je trouve que parfois le papa il est là avec les enfants et il ne reste pas longtemps parce que c'est difficile. Alors que s'il y avait quelqu'un qui pouvait les surveiller, ben voilà, un espace récréatif entre guillemets pour les frères et sœurs pour être surveillés. Une sorte de garderie ou peut-être juste le mercredi après-midi comme ça le papa sait quand même venir. » (Nurse/midwife, N)*

7 IFCDC IMPLEMENTATION IN EUROPEAN BEST PRACTICES

7.1 Key points

- **We investigated four centres in Europe that were considered "best practices" by Belgian experts.**
- **Access to the neonatal ward 24/7 is granted in all four wards for parents and siblings. In addition, there are supporting interventions in place for both parents and siblings.**
- **The space of all four wards has been reorganised in recent years to accommodate parents as much as possible.**
- **Couplet care is difficult to implement and not all centres offer it.**
- **The implementation of NIDCAP is limited by available resources. Training programs for staff are mainly offered via the FINE 1 and FINE 2 programs. NIDCAP training is taken up less frequently due to its cost and length.**
- **Flexibility and creativity are used in all centres to optimise newborn care.**
- **Families in precarious situations face the most barriers to be present in the neonatal ward.**

7.2 Methods

The international comparison is based on semi-structured interviews of key informants in four European centres. We selected the centres to be included in our international comparison of best practices by consulting several professional and patients' organisations in Belgium[dd]. Four centres were selected: Karolinska University Hospital in Stockholm (Sweden), Centre Hospitalier Valenciennes (France), Sophia's Children Hospital in Rotterdam (Netherlands) and 12 de Octubre Hospital in Madrid (Spain). The centres were selected based on their long experience of offering IFCDC, their implication in national and international research, and their transformative influence in their region and beyond.

A topic guide for the interviews was also developed with the collaboration of the same experts in neonatology, a pilot interview was performed with the Policlinico di Modena (Italy), and the topic guide was subsequently adapted. The topic guide contained questions about general aspects of neonatal care in the country where the centre was located, and then about architectural characteristics, parent's access and role in the ward, staffing of the ward and their education in IFCDC, and how transition periods are organized in the various wards.

After each interview, the interviewees reviewed the text relating to their centre to assure accuracy.

7.3 Karolinska University Hospital, Stockholm, Sweden

7.3.1 Neonatal care in Sweden

Sweden has around 115 000-120 000 deliveries per year. There were 113 077 babies born in Sweden in 2020, with a prematurity rate of 7%. Among these babies, 6 502 were born preterm before 37 weeks gestational age, 991 before 32 weeks, and 366 before 28 weeks.

Neonatal care is organised into four levels: level 1 is the care provided in the maternity ward (for instance care provided to stable late preterm newborns, mild hypoglycaemia, uncomplicated jaundice). Level 2 wards provide care to babies born after 28 weeks of pregnancy which do not require intensive treatment such as ventilation or hypothermia treatment (when a level 2 ward is geographically close to regional centres that provide level 3 care, it may be limited to treating babies born above 32 weeks). Level 3 wards care for babies born before 28 weeks of pregnancy, provide hypothermia treatment, invasive ventilatory support, and specific surgery (e.g. heart surgery, neurosurgery, retinopathy of prematurity- ROP- surgery, depending on the centre). Level 4 provides Extracorporeal Membrane Oxygenation (ECMO).

The country has 37 neonatal wards of which 21 are level 3 and 4, for a total of 438 recognised beds, of which 132 beds are designated for level 3-4. Because of lack of staff (mainly a shortage of nurses), not all these beds are open and available.

Parental leave in Sweden consists of 390 days, allocated to the parents for each child, paid 250 to 1012 SEK per day, depending on the parents' salary (10 SEK ≈ 1 EUR), besides the 390 days, there is an additional 90 days that can be taken by all parents paid 180 SEK/day. Parental leave can be taken by either one of the parents, but 90 days are reserved for each parent. This parental leave must be taken before the child turns 8 years old. The first 10

[dd] The list of best practices has been send out to the presidents or contact persons of the Belgian Society of Neonatology (Belgische Vereniging voor Neonatologie, Groupement Belge de Néonatologie; BVN – GBN), College van Geneesheren voor de Moeder en Kind, Association des Infirmiers Spécialisés en Pédiatrie et en Néonatologie (AISPN), Vlaamse Intensieve Neonatale Zorgen (vzw VINZ), Vlaamse Vereniging voor Ouders en Pasgeborenen, Association de Parents d'Enfants Prématurés (NéoNid), Vlaamse Vereniging voor Kindergeneeskunde (VVK vzw), Belgische Vereniging voor Kindergeneeskunde – Société Belge de Pédiatre (BVK – SBP), Groupement Belge des Pédiatres de Langue Française (GBPF), and SPF Public Health.

days of parental leave can be taken by both parents at the same time, this is called “temporary leave in connection with a child’s birth or adoption” and must be taken before the child is 60 days old. When a child is sick, one parent can stay at home with the child or at the hospital up to 60 days/year per child, for children aged 0 to 11 year. If a child is born before 32 weeks of pregnancy and/or has a severe life-threatening condition, the social insurance agency (Försäkringskassan), allows both parents to be off work for an unlimited time, according to certification provided by a medical doctor, paid 250 to 1012 SEK per day according to the parents’ salary.[253]

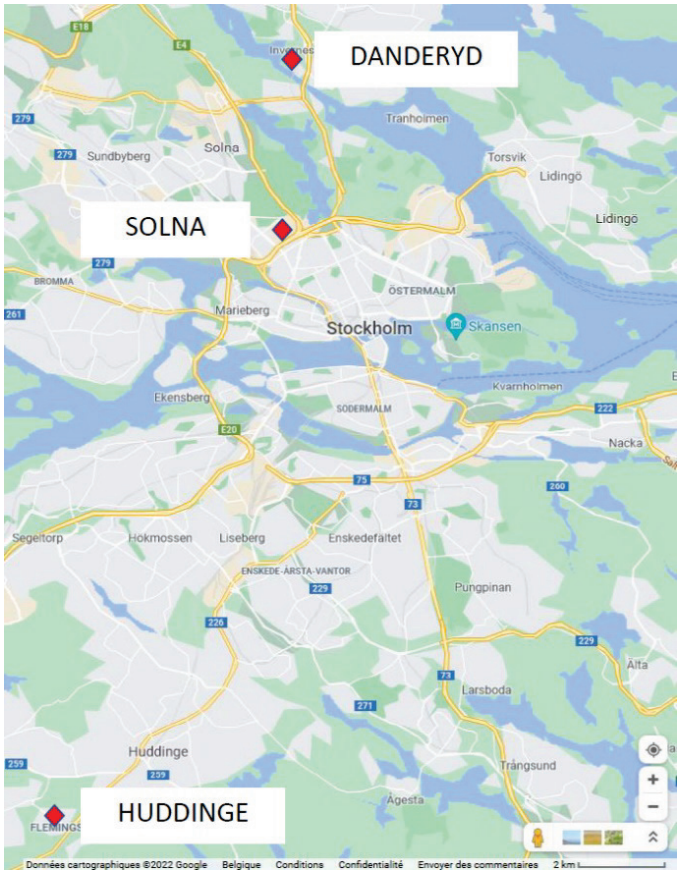
The National Board of Health and Welfare (Socialstyrelsen) issued in 2021 a set of “recommendations for the support of parents” that include the practice of “zero separation” between mother and baby at birth, early skin-to-skin care, and support for parents to learn how to interpret their infant’s behaviour.[254]

7.3.2 Karolinska University Hospital

7.3.2.1 General information

Karolinska University Hospital has three neonatal wards (one level 2, one level 3, and one level 4 ward) distributed in three different municipalities in greater Stockholm (Figure 14). In total there are 72 beds, but because of a shortage of nurses, not all these beds are open and available. The level 2 ward is located in Danderyd (18 beds), the level 3 ward is located in Huddinge (16 beds), the level 4 ward is located in Solna (12 beds). In addition, a total of 46 home care beds is attached to these wards. Infants and their families are frequently transferred between wards one or several times. This is both related to the level of care needed, but sometimes also to lack of beds.

Figure 14 – Geographical distribution of the neonatal wards of Karolinska University Hospital



Overall, the neonatal wards of Karolinska University Hospital account for 2 700 admissions per year. Of these admissions, the level 2 ward at Danderyd has almost 915 admissions per year, the level 3 at Huddinge 915 admissions per year, and the level 4 ward at Solna 440 admissions per year. Preterm infants represent 17-18% of all admissions.

The organisation of neonatal care at Karolinska University Hospital does not always include the possibility of scaling up or -down care within the same ward; if a baby needs lower or higher care, he/she will often be transferred to the most appropriate ward. Centralizing the most critical cases has resulted in an increase in the level of care, but sometimes it is also a source of frustration for families who need to be transferred. As far as home care beds are concerned, babies are eligible for home care when they reached cardio-respiratory and thermal stability and do not need 24/7 observation. In practice, infants meeting these eligibility criteria are frequently older than 34 corrected weeks, although there is no formal fixed eligibility criterion for gestational age. They may still be on gavage feeding (nasogastric tube feeding with a syringe). Home care is provided by experienced neonatal nurses, who perform home visits 2-3 times a week. Babies needing a higher level of care (e.g. still needing oxygen) may be cared for in advanced home care, with check-ups scheduled more often and nursing and medical staff available 24/7. The eligibility for home care is assessed on an individual basis and babies are taken out of home care when they can be fed orally, are stable without oxygen or other medical need. This is for preterm infants often at or passed corrected term age. For term infants, home care is used for phototherapy and infants with more complicated medical needs like Down syndrome, Prader-Willi syndrome, and other neurological difficulties.

The introduction of NIDCAP at Karolinska University Hospital dates from the end of the nineties and in 2003 the first couplet-care ward was built. In 2003, midwives were employed at the NICU (levels 3 and 4) to care for newly delivered mothers. The most common organisation now is for midwives and obstetricians at the maternity ward come to the NICU to care for and do rounds for the admitted mothers to infants in the NICU. Couplet care is not available in a consistent way and not for the more sick and unstable mothers. A written policy in IFCDC exists since 2010. All wards (levels 2, 3 and 4) adhere to the principles of IFCDC.

7.3.2.2 Architecture

In the last 10 years all wards have undergone major renovations: the level 2 ward (Danderyd) in 2003 and 2009 (two floors), the level 3 ward (Huddinge) in 2011 and level 4 ward (Solna) in 2016. The renovations in the level 2 ward resulted in all rooms being suitable for couplet care, with two smaller open bay areas for in total of 8 beds, the possibility of adjusting lighting, and plastic carpet on the floor to absorb sound. A wireless system was installed for long-distance surveillance of children, so the screen in the room can be switched off and the wireless relays the alarm to the nurse's beeper. Similar changes have been done in the level 3 and 4 wards: parents' rooms have been introduced for parents whose children are critically ill and need care in the open bay area. Family rooms are installed for when they can leave the open bay. At the level 4 ward the "open bay" area is organized as 4 bed spaces as a leaf clover divided by walls. More globally, there has been a rethinking of space employment, so that parents are better incorporated in the ward, for example, having enough space for a comfortable recliner seat besides the ICU beds. All neonatal wards are built to be able to provide couplet care, but the practice of couplet care has been implemented discontinuously because of organisational barriers and difficulties in a satisfactory model of employment of midwives in the neonatal ward.

7.3.2.3 Parental presence and caregiving

Parents are encouraged to stay in the ward 24/7. There are no visiting hours or restrictions for visits. Parents have a code to access the neonatal ward and can walk in and out themselves. While the mother is hospitalised in the maternity ward, the father can sleep in the mother's room for an out-of-pocket fee (250 SEK) per night and parents have unrestricted access to the neonatal ward. If the baby's need for special care is limited (i.e. cardio-respiratory stability, temperature stability, oral feeding, being older than 34 corrected age or having a weight above 1800 grams), they can be cared for in the maternity ward. The mother's stay in the maternity ward can last in most cases from 6 hours to 6 days, depending on the mode of delivery and complications. Once the mother is discharged from the maternity ward, all parents have either a small room adjacent to the open bay area or a family room and can invite visitors (maximum 2-3 visitors per visit). There is a common area for families that is equipped with a small kitchen. Parents

sleeping in the ward only get breakfast but must provide the other meals themselves. Families have to pay for parking (30 SEK per hour). There is no laundry service for parents available. There are no structured activities for siblings of hospitalised babies, but staff sometimes try to integrate the siblings. Siblings have access in the ward to a reading book and a colouring book[255] that has been made by the parent of a former patient of the neonatal ward.

Other interventions routinely implemented in the framework of IFCDC include adjustments of the lighting and sound, environmental protection of the incubator (e.g. incubator covers and covers for cots), support for developmental positioning, pain and stress evaluation and treatment, and SSC. The full extent of NIDCAP intervention is not implemented routinely.

Care aims at minimising the separation between baby and parent(s) and includes parent(s) from the very start, each parent is supported, guided and informed based on their needs and abilities. They participate in the medical aspect of their child's care but are most often not present when more invasive procedures like intubation or central line positioning are carried out, or when imaging exams are performed. This is because these procedures are also learning situations for new staff members, and staff may feel uncomfortable.

When families are in the family room, parents can sometimes, but not consistently, fully participate in clinical rounds. When the baby is in the open bay area, the participation in clinical rounds may still happen in the level 2 and 3 wards, and mostly does not happen in level 4. This is linked to architectural barriers, the open bay area does not permit the needed confidentiality, the sound level risks going up higher than advisable during rounds including parents and skin-to-skin sessions may be interrupted. In the family rooms, parent participation depends on who is in charge. Most often there is a short informative meeting between the physician in charge and the parents every day.

7.3.2.4 Staffing

Nurse staffing in level 3 and 4 wards consists of a nurse and a nurse assistant for every two babies, in the level 2 ward there is one nurse and one nurse assistant (plus occasionally another nurse or one nurse assistant) for every 4 babies. For babies in the family rooms there are one nurse and one nurse assistant for 5 to 6 families.

Physician staffing in levels 3 and 4 consists of 3 to 4 physicians per ward (3 neonatologists and a resident paediatrician), in the level 2 ward there are 3 physicians per ward (2 neonatologists and one resident paediatrician).

Social workers, psychologists and physiotherapists are allied professionals in the neonatal ward. The social workers, although not employed by the neonatal ward, work exclusively for the neonatal ward. These social workers mainly focus on parental support. There is a team of psychologists (employed by the paediatric hospital) who work in the neonatal ward on problems of attachment. Physiotherapists are called for specific problems (e.g. Prader-Willi or Angelman syndrome, Down syndrome).

Staff is offered the Family and Infant Neurodevelopmental Education programme (FINE) tier 1 and 2. The FINE 1 programme is offered through seminars and lectures and not in a two-days classroom-based course as it is classically organised. Among the total of 450 employees of the neonatal ward (this includes administrative staff as well) 169 have done FINE 2, 1 out of 44 physicians is certified with FINE 2. There are 10 certified NIDCAP professionals.

7.3.2.5 Financing of family stay

The organisation of parental leave in Sweden makes it relatively easy for parents to be able to afford to be at their child's side during the neonatal stay. Nonetheless, benefits apply only to people who have been working in Sweden for at least 6 months and it is not uncommon that the benefit is limited to 180 SEK per day. Therefore, the second parent may return to work to have sufficient financial means. Families may be eligible for extra support from social security if in need of further financial assistance.

7.3.2.6 *Transition periods*

If a stay in the neonatal ward can be anticipated, a neonatologist meets the pregnant woman and her partner to explain what to expect. Visual support like a presentation on a tablet is sometimes used. When possible, a visit to the neonatal ward is planned.

Transition to home support is incorporated in the care that is given routinely, especially when the child is cared for in the family rooms. Homecare nurses provide a lot of information on how to handle the baby, breastfeeding, brain development, olfactory stimulation. A web page in the Karolinska university hospital web site has been established [256] that provides information and films on different topics, for example how to bathe a preterm baby, how to put on a sling, information about certain diseases like pulmonary hypertension or acute respiratory distress syndrome. The information is available in 23 different languages.

7.4 Centre Hospitalier de Valenciennes, Valenciennes, France

7.4.1 *Neonatal care in France*

France had 740 000 babies born in 2020, with a prematurity rate of 7%.

Neonatal care is organised in four levels. Criteria for care in the different levels may vary slightly between and within different regions, roughly level 1 is care given at the maternity ward to stable late preterm babies or babies with mild jaundice, level 2a is the neonatology current care ward, babies can be admitted starting 33-34 weeks of pregnancy and/or 1500 g provided they are stable on a respiratory level, they are babies requiring simple care, they may be on peripheral perfusion and on enteral feeding. 2b is the intensive care ward, for babies from 30 weeks of pregnancy and/or 1000 g that may need a central perfusion line, of cardio-respiratory surveillance and/or Continuous Positive Airway Pressure (CPAP). Level 3 is the neonatal resuscitation ward for babies in vital distress, weighing less than 1000 g, needing interventions like invasive ventilation and hypothermia. National standards for staffing prescribe that there should be one healthcare practitioner for every 2 babies in level 3, one for every 3 babies in level 2b and one for every 6 babies in level 2a.

In 2014, continental France had 536 maternities, of which 49% offer only level 1 care, 23% offer level 1 and 2a care, 16% offer level 1, 2a and 2b care and 12% offer the full extent of neonatal care from level 1 to 3.[257] Maternal leave in France consists of 6 weeks before and 10 weeks after the expected delivery date, and it is paid 100% of the mother's salary. Maternity leave increases with parity starting from the third child and is longer for twins and higher-order multiples. If a mother delivers prematurely, her maternity leave is going to end 10 weeks after her expected delivery date, regardless of the actual delivery date. Since the summer of 2021, the mother's partners have 28 days of paternity leave, if the baby is hospitalised at birth, they can add the length of the hospitalisation to their leave for a maximum of 30 days of hospitalisation. In order to prolong the time mothers can be with their babies, an extra 4 weeks can be added to the maternity leave if it is considered that the postpartum was pathological; this concerns the mother and not the baby, but postpartum depression linked to the baby's prematurity is a valid justification. In some regions, prematurity justifies a daily parental presence allowance.[258] There is the possibility of requesting a parental leave after the maternity leave, but compensation is less favourable.

In France, there are currently no governmental recommendations for IFCDC but the "Societé Française de Néonatologie ", via the GREEN (Groupe de Réflexion et d'Évaluation de l'Environnement des Nouveau-nés) issued good clinical practices on this subject.[259]

7.4.2 Centre Hospitalier Valenciennes

7.4.2.1 General information

Centre Hospitalier (CH) Valenciennes offers the full range of neonatal care (levels 1 to 3). There are 10 level 3 beds, 6 level 2b beds and 14 level 2a beds with 6 beds located in the maternity ward. The centre has 3 500 deliveries per year. The ward admits 31 babies per year below 28 weeks of pregnancy, 42 between 28 and 32 weeks of pregnancy and 273 between 32 and 37 weeks of pregnancy.

CH Valenciennes integrates NIDCAP in their neonatal care since 2005, the date in which the ward moved to a new location and underwent major architectural adaptations. In 2011, they obtained the Initiative Hôpital Ami des Bébés (IHAB) label.[260] The hospital is a certified NIDCAP centre since 2016. A written philosophy of care charter is available from 2011, the latest version dates from 2014 ("Philosophie des soins, Charte du service sur le soutien apporté aux familles" - philosophy of care - ward's charter on the support given to families).

7.4.2.2 Architecture

Before 2005, the ward was a traditionally structured ward around a long corridor. This structure did not facilitate parents' presence and, therefore, parents were not often with their newborn. In 2005, the ward moved to a new location and was completely redesigned, the previous lack of parents' presence in the ward led to an underestimation of the needs for parents' accommodation. The ward is set at the same level as the delivery ward and the maternity ward. The level 3/2b beds are organised in four single rooms and three open bay rooms. The level 2a beds are divided into 10 beds within the neonatal ward (four couplet care rooms, two individual rooms and one open bay room with up to four babies), eight beds in the kangaroo ward (couplet care rooms that are physically in the maternity ward but adjacent to the neonatal ward, for babies that are born after 33 weeks of pregnancy and weigh ≥1500 g) and six koala ward beds (regular rooming-in beds in the maternity ward for milder cases such as stable late preterms born after 35-36 weeks, babies with orally corrected hypoglycaemia or in need of phototherapy or antibiotics). There is certain flexibility on the number of available beds, for instance the number of koala beds can be expanded (there have already been 14 koala beds at one time). In recent years, the level 2b/3 mean activity is on average 100%.

In level 2b/3, there are two rooms to accommodate parents overnight, and besides there are also two family lounge rooms that can accommodate parents if needed.

The building of a new ward has been approved, so it is currently not possible to intervene with the major remodelling of the ward. The planning phase of the new ward is not yet underway.

Rooms are equipped with reclinable window blinds to adapt lighting to the baby's activity, and ear-shaped noise-sensors light alarms that become green, yellow or red according to noise intensity, allowing for noise modulation. There are no sound-making alarms in the babies' rooms, the alarms are relayed to the nursing staff. Folding screens are installed in common rooms to protect privacy. For every bed, there is enough space to accommodate one reclinable armchair, sometimes two. Some of the armchairs can be converted into beds.

7.4.2.3 Parental presence and caregiving

Parents have access to the ward 24/7. There is badge access only during the night. In the level 2b/3 wards, there are no mother-infant rooms, so one of the strategies for enabling the parents' presence is to extend the mother's hospitalisation as long as possible. In France, the allowed length of postpartum hospitalisation is up to 21 days for mothers who delivered by caesarean section and 11 days for mothers who delivered by vaginal delivery, there is an arrangement with the department of obstetrics to prolong hospitalisation of mothers of babies hospitalised in the 2b/3 ward as much as it is allowed. Those stays end up not being cost-effective for the maternity ward, and they counterbalance it by having shorter stays for healthy mothers and babies when possible. While the mother is hospitalised, her partner can stay in the maternity ward but has to pay for meals. When mothers are no longer hospitalised, parents of babies in 2b/3 wards can sign up to sleep in one of the dedicated parent's rooms. If multiple parents request a room, they will have to agree to go in turns as there are only two rooms available. There is a high degree of creativity in creating

accommodation for parents. They are welcome to sleep in the two parents' lounge rooms, or the convertible armchairs next to the baby's bed. There is a kitchen dedicated to parents in the ward and there are extra meals from the maternity ward that are requested to give to families of babies in the neonatal ward. Parking is free and parents are given a badge. There is no laundry service available.

Siblings also have unrestricted access to the neonatal ward, depending on the hospitalised baby's health. A psychologist can be asked to talk to siblings, and they are given books that explain what it means to have a baby sibling hospitalised in the neonatal ward.[261, 262] Siblings are encouraged to interact with the baby and sometimes have had the opportunity to practice SSC. On Wednesdays (days when there is no school in France), volunteers from the association "Les Blouses Roses" ("The Pink Coats") organise activities for siblings of all ages. The service of home intervention of Valenciennes (Service d'Intervention à Domicile de l'Arrondissement de Valenciennes [SIDAV]) provides a service of babysitting for siblings of babies hospitalised in the neonatal ward, with a price proportional to the family's income. Every person that is valued as a support to the parents may have access to the ward (extended family or friends). A maximum of two people per family are allowed at the same time, always in the presence of at least one parent and respecting the needs of the baby and of other babies that may be hospitalised in the same room, so these visits require a minimum of planning.

The ward is NIDCAP certified, parents are involved in their baby's care from the very start. When possible, a meeting with the paediatrician is planned before birth and explanations are given on how the ward is organised, breastfeeding, skin-to-skin and NIDCAP. Parents can have access to a psychologist and a lactation consultant. At birth the baby has first contact with the mother (if possible, skin-to-skin), and if the conditions permit, the baby is transferred to the neonatal ward in skin-to-skin with the father. Manual expression of colostrum is initiated antenatally if possible, in the early postpartum period fathers are tasked with giving the colostrum to the newborn. There is early contact with a neonatologist after birth, the neonatologist that is present at birth is going to be the case manager for the baby until the end of hospitalisation, and in post hospitalisation follow-up. The parents meet the lactation consultant and the NIDCAP referent, the message is reinforced via brochures.[263] Parents of former neonatal ward babies are a further resource for the support of parents, via the association "SOS Prema".[264] The psychologist supports both the parents and the baby, a child psychiatrist can be called in case there are signs of attachment disorders. The social worker helps the parents carry out administrative procedures.

Parents participate in acts where they can have a support role, they support their babies during invasive procedures like a central line positioning or a lumbar puncture, if they wish to do so, but their presence during acts like intubation is less encouraged. Clinical rounds at the ward are not carried out at a specific time of the day, but when it is time to provide care to the baby they are examined, and a briefing is done with the parents.

7.4.2.4 Staffing

Nurse staffing in the 3/2b ward (10 beds in level 3 and 6 in level 2b) consists of five paediatric nurses (plus one extra paediatric nurse during the day), one paediatric nurse coordinator, a referent nurse for NIDCAP, and one lactation consultant. Physician staffing is one neonatologist plus one or two resident paediatricians.

For level 2a in the 14 beds that compose the current care neonatal ward and the kangaroo rooms, the nursing staff consists of two paediatric nurses and one assistant paediatric nurse, physician staffing is one neonatologist and one resident paediatrician. For the six koala beds, there is one paediatric nurse, one assistant paediatric nurse (that can be deployed in the koala beds if needed) and one neonatologist (the one that looks after all babies in the maternity ward). There are two extra neonatologists in the ward, should they be needed.

Apart from nursing and physician staff, the ward has a full-time psychologist, and a child psychiatrist is available a half-day per week (they can also be called upon if needed). There is a social worker that serves the whole paediatrics department. Community physiotherapists come to the ward to accompany parents in the period before and after discharge. Midwives from the maternity ward look after healthy babies, and may move to the neonatal ward, should a mother need care that can be performed at the bedside of

her baby. There are two lactation consultants: a midwife in the maternity ward and a paediatric nurse in the neonatal ward.

A significant proportion of staff is NIDCAP certified: two of eight neonatologists, and 5 of 66 nurses with two more in course of certification (three of whom have the title of "NIDCAP referent" and perform NIDCAP observations in the ward, one is training as a NIDCAP trainer), four staff members have a Supporting Oral Feeding in Fragile Infants (SOFFI) certification.[265] In the ward, NIDCAP observations are carried out every day, so all staff is aware of the technique and most of them have a good level of knowledge in developmental care. There are courses carried out by NIDCAP certified personnel at the school for paediatric nurses and assistant paediatric nurses. Trainees have days dedicated to shadow for one day the lactation consultant and one day the NIDCAP referent nurse. Newcomers get theoretical introductions and are invited to participate in the opening conference of the first available NIDCAP training cycle. Physicians receive a theoretical course on KMC, SSC, NIDCAP and breastfeeding. There are no major barriers in accessing the department's training budget to finance training, it is more challenging to manage the staff when some people are off for training, but it needs to be done.

7.4.2.5 Financing of family stay

No out-of-pocket costs are billed to the parents during their stay. The SIDAV provides help with the babysitting of older siblings. Families in need may resort to financial help for transportation via the Protection Maternelle et Infantile (PMI) service of the region. The healthcare personnel are particularly supportive with families with social and financial disadvantages, midwives in the maternity ward are in contact with personnel of the neonatal ward to detect and assess the situation of disadvantage of a family and intervene accordingly. The neonatal ward achieves a consistent presence of both parents without major issues, especially since the paternity leave of 28 days was established.

7.4.2.6 Transition periods

Contact with the parents is sought after as early as possible, antenatal preparation for at-risk families is important to stress how fundamental their presence is at their baby's side. The neonatologist present at the moment of birth becomes the case manager for the family and assures continuity of care, they follow up the child until 5 years of age within the framework of vulnerable newborns follow-up. As parents are implicated in their baby's care from the very start, they become every day more autonomous. For babies hospitalised in level 3/2b, a big step is the moment of transfer to level 2a: at that stage, there is a meeting to evaluate with the parents their level of autonomy. After hospital-to-home discharge, the family is referred to the PMI service, a PMI paediatric nurse visits the family at home regularly after discharge (one or more times a week according to needs). The lactation consultant can be reached by phone and by appointment or walk-in consultation. A physiotherapist guides the parents concerning motor development. Before discharge, parents are provided with booklets concerning their return to home, where are listed all coordinates of professionals they may need to contact. Parents can easily reach out to the neonatal ward by phone after discharge.

7.5 Hospital 12 de Octubre, Madrid, Spain

7.5.1 Neonatal care in Spain

Spain had 370 000 babies born in 2019, with a prematurity rate of 7%. Neonatal care is organised into three levels (level I, level II, level III), with two sublevels (IIa and IIb) for level II (intermediate care) and three sublevels (IIIa, IIIb, IIIc) for level III (intensive care).

The care criteria for the different levels were published in 2012 and have not significantly changed since then.[266] Level I is the maternity ward level; it can admit healthy newborns at term and stable late preterm at 35-37weeks. It is required to have a nurse-to-neonate ratio of one nurse every 8-10 neonates. Level IIa admits babies over 32 weeks and weighing more than 1500 g. It provides short-term CPAP, but it cannot support mechanic ventilation or arterial catheter placement. The nurse-to-neonate ratio is one nurse every four to five neonates. Level IIb provides the same care as level IIa but in addition, may provide short-term ventilation (<24h) or non-invasive respiratory assistance. Nursing requirements are one nurse every three babies. Level IIIa admits babies of more than 28 weeks and weighing over 1000 g, besides care offered in level IIb it provides mechanic ventilation. Level IIIb admits neonates of all gestational ages and all weights. Besides the care offered in level IIIa it provides High frequency Oscillatory Ventilation with nitric oxide and general paediatric surgery. Level IIIc admits neonates of all gestational ages and all weights. Besides care provided on level IIIb it offers ECMO and specialised paediatric surgery according to the centre's specialty. Levels IIIb/c need to have at least 150 entries per year, of which at least 25 of neonates weighing less than 1500g and at least 40 mechanic invasive ventilations. Nursing requirements are one nurse for every two newborns in intensive care, one nurse per newborn in high technology intensive care (for example hypothermia, peritoneal dialysis), and two nurses for every newborn in very high technology intensive care (for example ECMO).

In 2018, Spain had 78 level III and 76 level II neonatal wards.[267] Maternity leave consists of 16 weeks from the moment of birth, plus 2 extra weeks if twins. If the baby needs to be hospitalised, the length of the hospitalisation is added to the maternity leave up to a maximum of 13 weeks. Since 2018, fathers have the right to 5 weeks of paid paternity leave. There is a bill that may pass in parliament, and may be enforced in 2022, raising paternity leave to 16 weeks, with a two-week period where parents must stay at home at the same time, and 14 weeks that may be taken together or separately within the first year of the baby's life. There is a breastfeeding leave of one hour per day until the child is 9 months. If the child is preterm, the 9 months of breastfeeding leave start from the day of the expected delivery date.

In Spain, there are no national or regional IFCDC recommendations.

7.5.2 Hospital Universitario 12 de Octubre

7.5.2.1 General information

Hospital 12 de Octubre is a level IIIc centre and thus offers the full range of neonatal care (levels I to IIIc). The neonatology ward has 21 beds in intermediate care, and 21 beds in intensive care. It serves a relatively underprivileged area in the south of Madrid.

The centre had 4 040 deliveries in 2019, in that same year 1 297 babies were admitted in the neonatal ward, of which 49 below 28 weeks of pregnancy, 49 between 28 and 31 weeks of pregnancy, 394 between 32 and 37 weeks of pregnancy.

Developmental care has been a part of the philosophy of the centre for many years, with a steady and progressive transformation of the general approach. A pivotal moment in the evolution of the centre's philosophy was the visit from Nathalie Charpak in 2004. The centre is a NIDCAP training centre since 2007.

7.5.2.2 *Architecture*

The ward was recently rebuilt, and the new ward was inaugurated at the beginning of 2020. Before that, the ward used to have open bay rooms with poor spaces, without even the possibility to put a chair between beds. After the renovation the ward acquired space, giving up the doctors' office space and getting space from the adjacent dermatology ward. The intensive care beds are now organised in 11 family rooms (with two "twins" rooms) and 2 common rooms of four beds each. In the family rooms, there is a bed and one comfortable armchair, there is no bathroom in the family rooms, but bathroom space is provided in the ward. The intermediate care beds are now organised in three rooms with seven beds each, besides every bed there is a convertible armchair. Two "pre-discharge" rooms were already present in the ward. Oxygen outlets have been added in order to transform to regular hospitalisation beds if needed. There is a common room for parents with a kitchen. The building of a completely new hospital is planned for the near future. In the plans of the new hospital, there will be more family rooms, even for intermediate care babies. However, probably not all beds will be placed in family rooms because in some cases families cannot be consistently present. This could entail the risk of sensory under stimulation of the babies. The delivery ward, maternity ward and neonatal ward will be put on the same floor, which is currently not the case since the maternity ward is on another floor.

7.5.2.3 *Parental presence and caregiving*

Access is permitted 24/7, mothers can access the neonatal ward from their room at any time during hospitalisation. Couplet care is unavailable due to lack of space and the fact that the maternity ward and the neonatal ward are on different floors. In the new hospital there is hope to implement couplet care. Parents are given the codes to the electronic doors at the moment of their child's birth. When the mother is hospitalised, she sleeps at the hospital, when she is discharged parents can spend the night have either in the family room or in a convertible armchair that is available besides the baby's bed. It is current for parents to stay and sleep even if they only have the armchair available. The first time a sibling visits, the visit is prepared with the parents, one professional will be dedicated to the sibling to explain everything they see and hear in the ward. After the first visit, siblings have unrestricted access, if families have no other resources, siblings can be around while the mothers take care of the sick baby. Small tables with chairs for drawing are available in the family room, but there are no specific organized activities dedicated to siblings. Families in the family rooms get three meals a day at no extra cost, the other families can cook in the common kitchen. There is a 20-30% discount on parking fees. There is no laundry service.

Parents are involved as early as possible in the care of their newborn. Pregnant women with high-risk pregnancies have a meeting with a "perinatal group" (obstetrician, neonatologist and other specialists depending on the team plus psychologist and/or psychiatrist) to receive a first round of information. They usually also visit the neonatal ward. SSC is practiced as much as possible in the delivery/operating room, but it is seldom done when babies are less than 28 weeks of gestational age and/or weigh less than 1000g. Parents are given key information on developmental care via an information checklist that is followed perinatally. The ward has a program that is called "care for me" organised in 14 areas that provides mirrored information for both professionals and families to support families being autonomous in the care of the baby (for instance information is given on diapering, bathing, KMC, infection control, positioning and neurobehavior). Each baby has both a developmental care referent (that coordinates the delivery of information on developmental care) and a clinical care referent, that is responsible for the baby from admission to discharge. If the parents choose, they may assist all medical procedures including invasive procedures. Parents participate in clinical rounds if they want to and are in any case consulted by the clinical care referent, since they are those who best know their baby. If there is an important decision to make, parents are always consulted. If parents have difficulties to be present in the ward, they can designate a caregiver, that will be treated in par as a parent in the neonatal ward. There are psychosocial rounds every week where medical staff presents the families to social assistants, psychologists and child psychiatrists and plan psychosocial interventions if needed. Visits from non-caregivers are allowed ten minutes a day, maximum of two people per baby. Grandparents are allowed during the weekends.

7.5.2.4 Staffing

Staff consists of neonatologists, paediatric nurses, auxiliary nurses, speech therapists, physical therapists, psychologists, child psychiatrists and social assistants. Nursing staffing respects the national standards, with one nurse every two babies and one auxiliary nurse every four babies in the intensive care ward and one nurse every five babies and one auxiliary nurse every five babies in intermediate care. A doctor is the clinical referent to three to four babies in intensive care and intermediate care.

Speech therapists, physical therapists and psychologists are shared with the paediatric department but can be called upon when needed. The child psychiatrist is dedicated to perinatal care. Five social assistants work mainly with the neonatal ward, they approach each family to talk about available resources and may be involved if further psychosocial interventions are needed.

Seventy percent of the staff is trained in FINE 1, three doctors and two nurses recently completed FINE 2 training. There are plans to extend the training also to social workers and radiologists. Thirteen staffers are trained in NIDCAP. Two doctors and two nurses are lactation consultants. Before starting to train staffers in FINE 1, other locally developed courses in developmental care were available. Staffers from the ward are sometimes contracted to go and train other centres in developmental care, they try to make it as affordable as possible.

7.5.2.5 Financing of family stay

Apart from parental leave, a sick child leave is available for a list of 123 conditions, which include prematurity. If the family comes from outside the region to receive care in Madrid, there is financial aid to support them. What is generally observed is that families where parents have a regular job and are entitled to parental leave, they are present in the ward. Parents in precarious situations are not or less present in the ward, hence the need to designate another caregiver to be present with the baby if the parents have the financial need to keep working or take care of other siblings.

7.5.2.6 Transition periods

Pregnant women with high-risk pregnancies have a meeting with a “perinatal group” (obstetrician, neonatologist and other specialist depending on the team plus psychologist and/or psychiatrist) to receive a first round of information about the stay in the neonatology, and they usually also visit the neonatal ward. Parents are encouraged to look after their babies autonomously during their stay and before they are sent home, there are two pre-discharge rooms where parents can see what it means to be alone with the baby. There is an early discharge program in place, where babies are discharged home, but nurses visit the family the day after discharge and are regularly in touch with the family for the following two weeks. The contact with the nurses is individualised according to the needs of the family and includes communication via text message. After the two weeks, there is a follow-up appointment at the hospital, and then the family is referred to primary care.

7.6 Sophia's Children's Hospital, Erasmus Medical Centre, Rotterdam, Netherlands

7.6.1 Neonatal care in the Netherlands

In 2020 the Netherlands registered 163 840 births, with a prematurity rate of 7%. Neonatal care is divided into three levels: medium care (level I), high care (level II), intensive care (level III) and specialised intensive care (level IV). Level IV and Level III is targeted to children that weigh less than 1200 g, if born in the maternity of the intensive care centre, or less than 1500 g if born in a peripheral hospital, and children who need vital function assistance, for instance invasive ventilation, or other intensive treatment like therapeutic hypothermia, in level IV there is also the possibility of having highly specialised treatments like ECMO and neonatal surgery. In level II there are children weighing more than 1200 g or 1500 g (depending on the ward of birth), and above 32 weeks of pregnancy who need help with some vital functions but not at an intensive care level (for example CPAP or non-invasive ventilation). Level I is for late preterm children, who do not need support with vital functions, and do not need continuous monitoring, receiving treatments like intravenous antibiotics for necrotising enterocolitis. There are 9 level III/ IV wards in the Netherlands, and these wards operate within a network of centres that organises transfers on a geographical basis. The limits between levels I, II and III are slightly different depending on the amount of experience of the centre.

Maternity leave consists of 16 weeks at 100% of the previous salary (20 weeks for twins), of which 4 weeks need to be taken before the expected delivery date. The father or coparent has a five-day leave, paid 70% of the previous salary. If a baby is born prematurely at a gestational age below 32 weeks, 10 more weeks are added to the maternity leave at 100% of the previous salary. There are plans to expand these leaves. Beyond maternity and paternity leaves, there are parental leaves, these cover a period of 26 weeks until the child is eight years old, they are not paid. In 2022, a bill to extend maternity and paternity leave is going to be enforced guaranteeing all parents nine weeks of paid leave.[268]

In the Netherlands there are no written guidelines about IFCDC, every centre applies IFCDC within its capacity. Access to the neonatal ward 24/7 is available in almost every centre.

7.6.2 Sophia's Children's Hospital

7.6.2.1 General information

Sophia's children hospital is a level IV centre. It became a NIDCAP training centre in 2004, values of patient-centredness are explicitly stated in the vision of the hospital but there is no specific written mention of IFCDC in the neonatal ward. The neonatal ward includes 32 beds organised in four open bay rooms, most beds are occupied by infants requiring level III care, that are then transferred to peripheral hospital when not anymore in need of intensive care, but occasionally all range of neonatal care can be offered. In 2020 there were 93 babies admitted at less than 28 weeks, 174 between 28 and 31 weeks, 190 between 32 and 36 weeks.

7.6.2.2 Architecture

The neonatal ward is situated on the third floor of the hospital, on a different floor from the maternity ward that is placed on the fourth floor. The ward was partially renovated in June 2021. Infant's beds are organised in four open bay rooms, three rooms with eight beds and one room with six beds. Beside each bed, there is a place for a very comfortable reclining chair (also for a bed for mothers in the immediate postpartum period) and curtains can be drawn to provide privacy. Materials used in the construction of rooms muffle sound, and individual lighting is installed for each bed. There are three isolation rooms, that are used for babies who need isolating for infectious reasons but can also be used for babies who are particularly sensitive or restless or have sleep problems. The number of beds can fluctuate according to demand and the number of nurses available. There is one quiet room where families can go if a child is approaching the end of life and find privacy and a soothing environment. Clinical rounds are not made at the child's bedside, but in a room nearby, to avoid activity in the children's room. There is a common room for parents, where they can relax, eat and receive visitors and where siblings can spend time with one of the parents. On the floor there are several places where parents can get hot beverages for free.

Families can lodge in a house provided by the Ronald McDonald children's fund[ee] (i.e. Ronald Mc Donald house[269]) that is right next to the hospital, and a "Ronald McDonald living room" dedicated to siblings. There is the intention to change the architecture in the near future, but plans are not yet being developed. Ideally there will be smaller rooms and a mixture of individual and common rooms, to adequately stimulate babies even when parents are not present, and spaces will be adapted for the implementation of couplet care.

7.6.2.3 Parental presence and caregiving

The neonatal ward is open 24/7, parents are always welcome, they are provided with a badge and can independently access the ward. All parents are given information also on what to expect during the stay in the neonatal ward on an individualised basis, they receive a booklet called "taking care of your baby in the neonatal ward", and they are involved in weekly training/ information sessions held over lunch time which are provided by healthcare staff and veteran parents. Lunch is offered by the ward during these sessions. The content of the sessions is centred on how to be involved in daily care, the impact of being a parent in the NICU, the importance of KMC and in general of IFCDC, some sessions are frontal seminars, and some are open discussions. Every other week the session is led by psychosocial staff. Parents are involved in caregiving; they comfort the baby when the nurses provide care and are never required to step away during procedures and are involved in clinical rounds. Parents can spend the night in the reclining chair next to the baby's bed, but there is no official space for parents to sleep in the ward. Families can lodge in the nearby Ronald McDonald house, that is available to all parents of children hospitalised in Sophia's children's hospital. In this accommodation there is space for parents and siblings to stay overnight, families have to pay a fee of 15 euros per night per room. This fee is covered by some health insurances, sometimes in the basic plan and sometimes in the advanced plan. Occasionally there might be not enough places but most of the times room availability is not an issue. Siblings are welcome in the "Ronald McDonald living room" that is present in the hospital, where they can play, eat and where volunteers organise activities for siblings of all hospitalised children. There is no couplet care available in the ward, but for babies who only need phototherapy or intravenous antibiotics or gavage feeding, care is provided in the maternity ward. NIDCAP observations are routinely performed to all babies born with a gestational age below 27 weeks, and on demand for all other babies if requested by nurses, psychologists, doctors or parents. Every family has a nurse practitioner that is responsible for developmental care and that guides the family in that aspect and a "first responsible nurse" that is the clinical case manager for the family. At 6 weeks of hospitalisation, there is a planned conversation between the family and the staff, centred on the health of the baby but on the wellbeing of the family and which steps can be implemented to improve the family's experience.

7.6.2.4 Staffing

The staffing in the ward consists in neonatal nurses, trainee neonatal nurses, care assistants, nurse practitioners, neonatologists resident paediatricians, speech therapists and physiotherapists. Among the staff there are 6 NIDCAP certified professionals (of whom 2 are NIDCAP trainers). One NIDCAP professional is present everyday Monday to Friday. A psychosocial team, consisting of psychologists, social workers, spiritual caregivers and a child life therapist, supports the parents and the neonatal nursing and medical staff. The number of personnel available per bed depends on the health status of the babies, a very ill baby will require a 1:1 care. A care assistant is present in every room during the day and the evening , in order to comfort the babies when parents are not present. There is a nurse practitioner, doctor in Trainee and a neonatologist per ward/room during the day. In the evening and night; 1 doctor in trainee and a neonatologist for 4 wards. For transportation and emergency there is an extra neonatologist on call. There is a weekly psychosocial multidisciplinary round led by the psychologists with social workers, nurses, doctors and NIDCAP professionals. During this weekly round, the psychosocial wellbeing of the baby and their family is discussed from a holistic point of

[ee] This is also available in Belgium: https://www.kinderfonds.be/nl

view and referrals are made for support from the psychosocial team. The psychologists and social workers are attached to the obstetric ward and neonatal wards exclusively. The psychologists look after the babies and their families but also after the medical and nursing staff. They moderate debriefing sessions and audit of cases. The spiritual caregivers and child life professional are shared with the rest of the hospital. Especially in sensitive moments such as end of life of the new-born, the child life professional supports parents in the communication with siblings The psychosocial team consists of religious and culturally diverse professionals. Physiotherapists and speech therapists come to consult the babies in the ward if needed.

7.6.2.5 Financing of family stay

The stay of the mother is financed via maternity leave, the lodging in the Ronald McDonald house is sometimes covered by health insurance plans, if it is not the case social workers can inquire whether some other form of public funding is available for parents who cannot afford the lodging fee. Fathers have only five days of paternity leave, so their presence in the neonatal ward is limited to before/after their working hours. Some time off can be negotiated with the employer but only as a private arrangement, if needed with the aid of a social worker that may be in contact with the employer to explain the case and write a letter on behalf of the parents.

7.6.2.6 Transition periods

In pregnancy at high risk of prematurity, antenatal preparations are offered to the parents, if the birth may occur between 24 and 26 weeks there is a counselling session that occurs between the parents and the healthcare staff about their will to get active treatment for their extremely preterm new-born. If possible, the parents are given a tour of the neonatal ward.

Most infants that are discharged from the neonatal ward are sent to a non-academic hospital in the region, only occasionally are they discharged home. During the discharge process to the hospital, parents are encouraged to go and visit the place in advance. Alongside the medical report explaining the clinical situation of the baby, the parents write a report where they describe the baby and its behaviour, and their level of autonomy. After the transfer a nurse checks in with the family to make sure that the transfer is going smoothly.

For the babies that are discharged home, the first responsible nurse prepares them to what to expect once discharged, and families can spend 24-48 hours in a room with “home-like” conditions to test their autonomy. There is a specific post discharge responsive parenting program available in the Netherlands for very preterm babies called “Transmural developmental support for very preterm in infants and their parents” (TOP).[270] In this program paediatric physiotherapists support and coach parents in their interaction with the children up to 1 year of corrected age. Twelve one-hour visits are scheduled at the family’s home, and additional professional figures can be called upon if needed.

7.7 Discussion and conclusion

We reported the example of four neonatal centres, selected by experts’ opinion on based on their experience with IFCDC and their transformative impact on a local, national and international level.

A summary of the main characteristics of the four countries’ neonatal care and parental leave regulation can be consulted in Table 33. All countries have the same proportion of prematurity. The density of NICU is 1.8 per 10 000 births in Sweden, XX births in France, 2.1 per 10 000 births in Spain, and 0.61 per 10 000 births in the Netherlands.

Except for Sweden, maternity leave is significantly higher than the coparent’s leave, but all countries are in the process of extending paternity leave or have recently extended it. The extent of parental leave for both parents in Sweden makes it particularly easy for parents to be beside their hospitalised children, on the other hand, the five-days paternity leave in the Netherlands means that the coparent’s presence is prevalently outside working hours.

A common point in all four wards is the accessibility of the ward to parents 24/7. Access codes or badges are provided to parents to have an autonomous access to their child. In all cases unrestricted access is also extended to siblings and special attention is given to the siblings’ wellbeing, which includes availability to psychological support, adapted involvement

during their visits, and interventions aimed to help parents caring for other children. Examples of this support are the babysitting help provided by local authorities in Valenciennes (SIDAV) and the volunteer's work in the centres of Rotterdam and Valenciennes organising activities for siblings of hospitalized children.

All neonatal centres have undergone recent renovations to diminish barriers to the parent's presence, space is of the utmost importance and care is taken to have enough space beside the child's bed to have at least a comfortable armchair where parents can do KMC and, if needed, spend the night. All centres have spaces that allow parents' accommodation within the ward or in its vicinities.

Couplet care seems one of the most difficult interventions to implement, as it requires close collaboration between the neonatal ward and the obstetrics department. The implementation is particularly challenging when the maternity ward and the neonatal ward are not physically adjacent, like when they are on separate floors.

Parents are guided through their stay in most centres by appointed referent of developmental care, that may or may not be the same person that is the clinical case manager of the child. In all centres, parents are encouraged to participate in care (e.g. breastfeeding, daily care), to be present for procedures and to participate in clinical rounds. Various strategies of parents' support are implemented: all centres can count on the support of social works and psychologists. For example in Rotterdam, weekly seminars for parents and veteran parents are part of the support network.

All centres implement NIDCAP, but its routine use is limited by the availability of resources. A big emphasis is put on the education of the medical and non-medical staff in developmental care, all centres have some of their staff certified in NIDCAP, but mostly staff follows shorter developmental care programs such as FINE 1 and FINE 2. In some cases, the FINE program is offered to staff that does not belong directly to the neonatal ward such as radiologists and obstetricians.

A certain degree of flexibility and creativity is displayed to optimise care for the newborns. For instance, in Valenciennes, in collaboration with the obstetrics department, the mother's stay is prolonged as much as possible. In Madrid, when parents are not available, they can designate a "carer" to be present by the child in their place. In Rotterdam, fathers are helped by the hospital's social assistants in arranging leave of absence from work.

Families in precarious situations, such as immigrant families, face some of the highest barriers to be present in the neonatal ward, due mainly to difficulties to meet their financial needs.

All centres offer pregnant women in a high-risk pregnancy a meeting with the neonatal team and, when possible, a tour of the neonatal ward. Information about the transition to home is incorporated in routine care in all centres, sometimes pre-discharge rooms are available to test the family autonomy before their discharge. In Stockholm, part of the neonatal beds are home care beds, so the child is already cared for in their home environment. In Rotterdam (and generally in the Netherlands) there is a program in developmental care for very preterm babies until one year of age, led by physiotherapists that are informally called "NIDCAP at home".

In all these wards, the IFCDC philosophy of care is shared by most staff and management, and personnel goes to great lengths to implement IFCDC as fully as possible.

Table 33 – Summary of countries' characteristics

	Sweden	France	Spain	Netherlands
Number of deliveries per year	113 077 in 2020	740 000 in 2020	370 000 in 2019	163 840 in 2020
Prematurity rate	7%	7%	7%	7%
Levels of neonatal care	Level 1: care provided at the maternity ward Level 2: babies born after 28 weeks that do not require intensive treatment Level 3: babies born before 28 weeks and all babies requiring intensive care Level 4: babies requiring highly specialized intensive care (e.g. ECMO)	Level 1: care provided at the maternity ward Level 2a: Current neonatal care. Stable babies above 33 weeks and/or 1500 g Level 2b: High care. Babies above 30 weeks and/or 1000 g. Non-invasive breathing assistance. Level 3 Intensive care. Babies below 1000g, babies in vital distress	Level 1: care provided at the maternity ward Level 2a: babies above 32 weeks weighing more than 1500 g. No invasive ventilation Level 2b: as level 2a, adding invasive ventilation of <24h Level 3a: babies above 28 weeks and above 1000g, mechanic ventilation Level 3b: all gestational ages, all weights. Same care as level 3a plus HFOV and paediatric surgery Level 3c: same care as level 3b plus ECMO and specialised paediatric surgery	Level 1, medium care: late preterm children who do not need continuous monitoring Level 2: high care, children above 32 weeks and 1200g (if born at a level 3 maternity) or 1500 g (if born at a level 2 maternity) who need s help with vital functions (CPAPA High flow) but no intensive caret Level 3: intensive care, children below 1200g (if born in a level 3 facility) or below 1500g (if born in a level 2 facility). Babies who need vital function assistance as mechanic ventilation or cooling Level 4: the same care as level 3 plus neonatal surgery and ECMO
Number of NICUs	Level 3-4: 21 wards	Level 3: approximately 64 wards	Level 3: 78 wards	Level 3-4: 9 wards
Maternity leave	A total of 480 days to be shared with the coparent. 90 days are reserved for the mother	6 weeks before and 10 weeks after the expected delivery date	16 weeks	4 weeks before the expected delivery date and 12 weeks after
Paternity (or coparent) leave	A total of 480 days to be shared with the coparent. 90 days are reserved for the father (or coparent)	28 days	5 weeks	5 days

REFERENCES

1. World Health Organization. Preterm birth. Geneve: World Health Organization; 2018.
2. Devlieger R, Goemaes R, Laubach M. Perinatale activiteiten in Vlaanderen 2020. Brussels: Studiecentrum voor Perinatale Epidemiologie (SPE); 2021.
3. Leroy C, Van Leeuw V. Santé périnatale en Wallonie – Année 2020. Brussels: Centre d'Épidémiologie Périnatale; 2021.
4. Van Leeuw V, Leroy C. Santé périnatale en Région bruxelloise – Année 2020. Brussels: Centre d'Épidémiologie Périnatale; 2021.
5. Ainsworth MDS. The development of infant-mother attachment. In: Caldwell BM, Recciuti HN, editors. Review of Child Development Research. Chicago: University of Chicago Press; 1973. p. 41-93.
6. Bowlby J. Attachment and loss. New York: Basic Books; 1969.
7. Klaus MH, Kennell JH. Parent-infant bonding. St. Louis: Mosby; 1982.
8. Bowlby J. The nature of the child's tie to his mother. International Journal of Psycho-Analysis. 1958;39(5):350-73.
9. Guedeney N, Lamas C, Bekhechi V, Mintz A, Guédeney A. Développement du processus d'attachement entre un bébé et sa mère. Arch Pediatri. 2008;15:S12-9.
10. Kennedy JH, Kennedy CE. Attachment theory: implications for school psychology. Psychology in the Schools. 2004;41(2):247-59.
11. Chambers J. The neurobiology of attachment: from infancy to clinical outcomes. Psychodyn Psychiatry. 2017;45(4):542-63.
12. National Institute for Health and Care Excellence. Children's attachment: attachment in children and young people who are adopted from care, in care, or at high risk of going into care. London: NICE; 2015.
13. Guédeney N, Beckechi V, Mintz A, Saive A. L'implication des parents en néonatologie et le processus de caregiving. Devenir. 2012;24:9-34.

14. Guédeney N, Morales-Huet M, Roabouam C, Jeammet P. Apports de la théorie de l'attachement aux traitements conjoint parents-bébés. A propos de la construction du cadre et du niveau possible des interprétations. In: L'attachement, de la théorie à la clinique. Toulouse: ERES; 2007. p. 61-72.

15. Latva R, Lehtonen L, Salmelin RK, Tamminen T. Visiting less than every day: a marker for later behavioral problems in Finnish preterm infants. Arch Pediatr Adolesc Med. 2004;158(12):1153-7.

16. Franck LS, Spencer C. Parent visiting and participation in infant caregiving activities in a neonatal unit. Birth Berkely Calif. 2003;30(1):31-5.

17. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health. 2018;2(4):245-54.

18. Browne JV, Talmi A. Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. J Pediatr Psychol. 2005;30(8):667-77.

19. United Nations. Convention on the Rights of the Child. 1989.

20. European Association for Children in Hospital. EACH charter. 2016.

21. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health [Web page].2018 [cited 18 November 2021]. Available from: https://newborn-health-standards.org/

22. Schlembach D, Simeoni U, Nagy Bonnard L, Bernloehr A, Cetin I, Gent M, et al. European Standards of Care for Newborn Health: Collaboration with parents in ante- and perinatal care. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

23. World Health Organization. Infant and young child feeding: model chapter for textbooks for medical students and allied health professionals. Geneva: World Health Organization; 2009.

24. Frauenhelder O, Oude-Reimer M, Camba F, Ceccatelli M, Hankes-Drielsma I, Jørgensen E, et al. European Standards of Care for Newborn Health: Promotion of breastfeeding. European Foundation for the Care of Newborn Infants (EFNCI); 2018.

25. Damhuis G, König K, Westrup B, Kuhn P, Daly M, Bertoncelli N, et al. European Standards of Care for Newborn Health: Case management and transition to home. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

26. Westrup B, Kuhn P, Daly M, Guerra P, Bertoncelli N, Damhuis G, et al. European Standards of Care for Newborn Health: Family support services. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

27. Ahlqvist-Björkroth S, Westrup B, Kuhn P, Bertoncelli N, Caballero S, Montirosso R. European Standards of Care for Newborn Health: Clinical consultation and supervision for healthcare professionals on supporting families. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

28. Warren I, Westrup B, Kuhn P, Guerra P, Ahlqvist-Björkroth S, Bertoncelli N, et al. European Standards of Care for Newborn Health: Education and training for infant- and family-centred developmental care (IFCDC). European Foundation for the Care of Newborn Infants (EFCNI); 2018.

29. Kundsen EI. Sensitive periods in the development of the brain and behavior. J Cogn Neurosci. 2004;16(8):1412-25.

30. Kappeler L, Meaney MJ. Epigenetics and parental effects. Bioessays. 2010;32(9):818-27.

31. Montirosso R, Provenzi L. Implications of epigenetics and stress regulation on research and developmental care of preterm infants. J Obstet Gynecol Neonatal Nurs. 2015;44(2):174-82.

32. Dubois J, Dehaene-Lambertz G, Kulikova S, Poupon C, Hüppi P, Hertz-Pannier L. The early development of brain white matter: a review of imaging studies in fetuses, newborns and infants. Neuroscience. 2014;276:48-71.

33. Als H, Duffy FH, McAnulty G, Rivkin MJ, Vajapeyam S, Mulkern RV. Early experience alters brain function and structure. Pediatrics. 2004;113(4):846-57.

34. Kuhn P, Westrup B, Bertoncelli N, Filippa M, Hüppi P, Warren I. European Standards of Care for Newborn Health: Supportive sensory environment. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

35. Kuhn P, Zores C, Langlet C, Escande B, Astruc D, Dufour A. Moderate acoustic changes can disrupt the sleep of very preterm infants in their incubators. Acta Paediatr. 2013;102(10):949-58.

36. Ednick M, Cohen AP, McPhail GL, Beebe D, Simakajornboon N, Amin RS. A review of the effects of sleep during the first year of life on cognitive, psychomotor, and temperament development. Sleep. 2009;32(11):1449-58.

37. Sizun J, Hallberg B, Moen A, Bambang Oetomo S, Druart D, Ferrari F, et al. European Standards of Care for Newborn Health: Management of the acoustic environment. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

38. Feldman R, Eidelman AI. Maternal postpartum behavior and the emergence of infant-mother and infant-father synchrony in preterm and full-term infants: the role of neonatal vagal tone. Dev Psychobiol. 2007;49(3):290-302.

39. Pallás-Alonso CR, Westrup B, Kuhn P, Daly M, Guerra P. European Standards of Care for Newborn Health: Parental involvement. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

40. Westrup B, Kuhn P, Daly M, Guerra P, Ahlqvist-Björkroth S, Bertoncelli N, et al. European Standards of Care for Newborn Health: Family access. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

41. Montirosso R, Westrup B, Kuhn P, Ahlqvist-Björkroth S, Bertoncelli N, Lilliesköld S. European Standards of Care for Newborn Health: Support for parental-infant bonding. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

42. Melnyk BM, Feinstein NF, Alpert-Gillis L, Fairbanks E, Crean HF, Sinkin RA, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. Pediatrics. 2006;118(5):e1414-e27.

43. Mörelius E, Ortenstrand A, Theodorsson E, Frostell A. A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding. Early Hum Dev. 2015;91(1):63-70.

44. Provenzi L, Santoro E. The lived experience of fathers of preterm infants in the Neonatal Intensive Care Unit: a systematic review of qualitative studies. J Clin Nurs. 2015;24(13-14):1784-94.

45. Welch MG, Myers MM, Grieve PG, Isler JR, Fifer WP, Sahni R, et al. Electroencephalographic activity of preterm infants is increased by Family Nurture Intervention: a randomized controlled trial in the NICU. Clin Neurophysiol. 2014;125(4):675-84.

46. Gathwala G, Singh B, Balhara B. KMC facilitates mother baby attachment in low birth weight infants. Indian J Pediatr. 2008;75(1):43-7.

47. Feeley N, Waitzer E, Sherrard K, Boisvert L, Zelkowitz P. Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. J Clin Nurs. 2013;22(3-4):521-30.

48. Conde-Agudelo A, Diaz-Rossello JL. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. Cochrane Database Syst Rev. 2016(8).

49. Moore E, Anderson G, Bergman N, Dowswell T. Early skin-to-skin contact for mothers and their healthy newborn infants. Cochrane Database Syst Rev. 2012;18(3).

50. Bergman NJ, Linley L, Fawcus S. Randomized controlled trial of skin-to-skin contact from birth versus conventional incubator for physiological stabilization in 1200- to 2199-gram newborns. Acta Paediatr. 2004;93(6):779-85.

51. Bergman NJ, Westrup B, Kuhn P, Daly M, Bertoncelli N, Caballero S, et al. European Standards of Care for Newborn Health: Very early and continuous skin-to-skin contact. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

52. Moen A, Hallberg B, Mader S, Ewald U, Sizun J, White R. European Standards of Care for Newborn Health: Core principles of NICU design to promote family-centred care. European Foundation for the Care of the Newborn Infants (EFCNI); 2018.

53. Moen A, Hallberg B, Bambang Oetomo S, Ewald U, Fröst P, Ferrari F, et al. European Standards of Care for Newborn Health: Facilitation of skin-to-skin care and parental involvement through the physical environment. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

54. Moen A, Hallberg B, Fröst P, White R, Sizun J, Bambang Oetomo S, et al. European Standards of Care for Newborn Health: General layout of the unit. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

55. Greisen G, Latour JM, Verhaest Y, Alfonso E, Bucher HU, Caeymaey L, et al. European Standards of Care for Newborn Health: Decisions of withholding or withdrawing life support. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

56. Greisen G, Latour JM, Verhaest Y, Alfonso E, Bucher HU, Caeymaey L, et al. European Standards of Care for Newborn Health: Rights of infants, parents, and families in difficult decisions. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

57. Latour JM, Greisen G, Verhaest Y, Alfonso E, Bucher HU, Caeymaey L, et al. European Standards of Care for Newborn Health: Communication in ethically complex decisions. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

58. Johnston L, van den Hoogen A, Roehr CC, Gözen D, Kühn T, Mannix T, et al. European Standards of Care for Newborn Health: Education programme supporting parents and families. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

59. Hüning BM, Härtel C, Wolke D, van Wassenaer-Leemhuis A. European Standards of Care for Newborn Health: Transition from hospital to home. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

60. Global Alliance for Newborn Care (GLANCE). Zero separation. Together for better care! Keep preterm and sick babies close to their parents [Web page]. European Foundation for the Care of Newborn Infants (EFCNI);2020 [cited 1 December 2021]. Available from: https://www.glance-network.org/covid-19/campaign/

61. Institute for Patient- and Family-Centered Care (IPFCC). What is patient- and family-centered care [Web page].McLean (Virginia): Institute for Patient- and Family-Centered Care (IPFCC);2021 [cited 14 January 2022]. Available from: https://www.ipfcc.org/about/pfcc.html

62. Johnson BD, Abraham MR. Partnering with patients, residents, and families: a resource for leaders of hospitals, ambulatory care settings, and long-term care communities. Bethesda, MD: Institute for Patient- and Family-Centered Care; 2012.

63. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: infant- and family-centred developmental care. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

64. Als H. A synactive model of neonatal behavioral organization. Phys Occup Ther Pediatr. 1986;6(3-4):3-63.

65. NIDCAP Federation International. Program guide: Newborn Individualized Developmental Care and Assessment Program

(NIDCAP) - an education and training program for health care professionals. 2015.

66. Als H, Duffy FH, McAnulty G, Butler SC, Lightbody L, Kosta S, et al. NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction. J Perinatol. 2012;32(10):797-803.

67. Als H, Gilkerson L, Duffy FH, McAnulty GB, Buehler DM, Vandenberg K, et al. A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting, and caregiving effects. J Dev Behav Pediatr. 2003;24(6):399-408.

68. McAnulty G, Duffy FH, Kosta S, Weisenfeld NI, Warfield SK, Butler SC, et al. School age effects of the Newborn Individualized Developmental Care and Assessment Program for medically low-risk preterm Infants: preliminary findings. J Clin Neonatol. 2012;1(4):184-94.

69. Roué JM, Kuhn P, Lopez Maestra M, Maastrup RA, Mitanchez D, Westrup B. Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit. Arch Dis Child Fetal Neonatal Ed. 2017;102(4):F364-8.

70. Westrup B. Family-Centered Developmentally Supportive Care. Neoreviews. 2014;15(8):e325-35.

71. Gilkerson L, Als H. Role of reflective process in the implementation of developmentally supportive care in the newborn intensive care nursery. Infants Young Child. 1995;20(8).

72. Smith K, Buehler DM, Als H. NIDCAP Nursery Certification Program (NNCP): Nursery Assessment Manual. Boston: NIDCAP Federation International; 2011.

73. Ortenstrand A, Westrup B, Brostrom EB, Sarman I, Akerstrom S, Brune T, et al. The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity. Pediatrics. 2010;125(2):e278-85.

74. Caskey M, Stephens B, Tucker R, Vohr B. Adult Talk in the NICU With Preterm Infants and Developmental Outcomes. Pediatrics. 2014;133(3):e578-84.

75. Hall SL, Phillips R, Hynan MT. Transforming NICU care to provide comprehensive family support. Newborn Infant Nurs Rev. 2016;16(2):69-73.

76. Hyrkäs K, Appelqvist-Schmidlechner K, Haataja L. Efficacy of clinical supervision: influence on job satisfaction, burnout and quality of care. J Adv Nurs. 2006;55(4):521-35.

77. Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. Birth Defects Res. 2019;111(15):1044-59.

78. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. In: Saunders WB, editor. Seminars in perinatology; 2011. p. 20-8.

79. White RD, Smith JA, Shepley MM, Committe to Establish Recommended Standards for Newborn ICU Design. Recommended standards for newborn ICU design, eighth edition. J Perinatol. 2013;33(1):S2-16.

80. Consensus Committee on Recommended Design Standards for Advanced Neonatal Care. Recommended standards for newborn ICU design. Clearwater Beach, Florida: Ninth Consensus Conference on Newborn ICU Design; 2019.

81. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: NICU design. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

82. Hynan MT, Hall SL. Psychosocial program standards for NICU parents. J Perinatol. 2015;35(1):S1-4.

83. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. J Perinatol. 2015;35(1):S9-13.

84. COPE for HOPE Inc. COPE for HOPE®: evidence-based, family-centered, cost-reducing NICU and PICU programs [Web page].New York: COPE for HOPE Inc.;2015 [cited 27 September 2021]. Available from: http://copeforhope.com/index.php

85. Family Ingrated Care™. FICare™: Family Integrated Care [Web page].2020 [cited 10 October 2021]. Available from: http://familyintegratedcare.com/

86. O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy and Childbirth. 2013;13:S12.

87. Doll-Speck L, Miller B, Rohrs K. Sibling education: implementing a program for the NICU. Neonatal Netw NN. 1993;12(4):49-52.

88. Darcy Mahony A, White RD, Velasquez A, Barrett TS, Clarck RH, Ahmad KA. Impact of restrictions on parental presence in neonatal intensive care units related to coronavirus disease 2019. J Perinatol. 2020;40:36-46.

89. Griffiths N, Spence K, Loughran-Fowlds A, Westrup B. Individualised developmental care for babies and parents in the NICU: evidence-based best practice guideline recommendations. Early Hum Dev. 2019;139:104840.

90. Herber-Jonat S, Koletzko B, Fewtrell MS, Embleton ND, van Goudoever JB, Gruszfeld D, et al. European Standards of Care for Newborn Health: Family education and training on infant feeding in the unit and after discharge. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

91. Willumsen J. Implementation of the Baby-Friendly Hospital Initiative. Geneva: World Health Organization; 2013.

92. SPF Health Food Chain Safety and Environment. BFHI & Ontwikkelingsgerichte zorg. BECare Magazine. 2021;15.

93. Macho P. Individualized developmental care in the NICU: a concept analysis. Adv Neonatal Care. 2017;17(3):162-74.

94. Tierney AL, Nelson CA. Brain development and the role of experience in the early years. Zero Three. 2009;30(2):9-13.

95. Glorieux I, Montjaux N, Casper C. NIDCAP®(Programme Néonatal Individualisé d'Évaluation et de Soins de Développement): définition, aspects pratiques, données publiées. Arch Pediatr. 2009;16:827-9.

96. Widstrom AM, Lilja G, Aaltomaa-Michalias P, Dahllof A, Lintula M, Nissen E. Newborn behaviour to locate the breast when skin-to-skin: a possible method for enabling early self-regulation. Acta Paediatr. 2011;100:79-85.

97. Charney DS. Psychobiological mechanisms of resilience and vulnerability: implications for successful adaptation to extreme stress. Am J Psychiatry. 2004;161(2):195-216.

98. Peirano PD. Sleep in brain development. Biol Res. 2007;40(4):471-8.

99. Chi Luong K, Long Nguyen T, Huynh Thi DH, Carrara HPO, Bergman N. Newly born low birthweight infants stabilise better in skin-to-skin contact than when separated from their mothers: a randomised controlled trial. Acta Paediatr. 2016;105(4):1812-8.

100. Bigelow AE, Littlejohn M, Bergman N, McDonald C. The relation between early mother-infant skin-to-skin contact and later maternal sensitivity in South African mothers of low birth weight infants. Infant Ment Health J. 2010;31(3):358-77.

101. Aghdas K, Talat K, Sepideh B. Effect of immediate and continuous mother-infant skin-to-skin contact on breastfeeding self-efficacy of primiparous women: a randomised control trial. Women Birth J Aust Coll Midwives. 2014;27(1):37-40.

102. Tessier R, Cristo MB, Velez S, Giron M, Nadeau L, Figueroa de Calume Z, et al. Kangaroo Mother Care: a method for protecting high-risk low-birth-weight and premature infants against developmental delay. Infant Behav Dev. 2003;26(3):384-97.

103. Feldman R, Rosenthal Z, Eidelman AI. Maternal-preterm skin-to-skin contact enhances child physiologic organization and cognitive control across the first 10 years of life. Biol Psychiatry. 2014;75(1):56-64.

104. Lawn JE, Mwansa-Kambafwile J, Horta BL, Barros FC, Cousens S. "Kangaroo mother care" to prevent neonatal deaths due to preterm birth complications. Int J Epidemiol. 2010;39(1):144-54.

105. Hochberg Z, Feil R, Constancia M, Fraga M, Junien C, Carel JC, et al. Child health, developmental plasticity, and epigenetic programming. Endocr Rev. 2011;32(2):159-224.

106. Felman R, Rosenthal Z, Eidelman AI. Maternal-preterm skin-to-skin contact enhances child physiologic organization and cognitive control across the first 10 years of life. Biol Psychiatry. 2014;75(1):56-64.

107. Charpak N, Tessier R, Ruiz JG, Hernandez JT, Uriza F, Villegas J, et al. Twenty-year follow-up of kangaroo mother care versus traditional care. Pediatrics. 2017;139.

108. Atzil S, Hendler T, Feldman R. Specifying the neurobiological basis of human attachment: brain, hormones, and behavior in synchronous and intrusive mothers. Neuropsychopharmacology. 2011;36(13):2603-15.

109. World Health Organization. Kangaroo mother care: a practical guide. Geneva: World Health Organization; 2003.

110. Chan GJ, Valsangkar B, Kajeepeta S, Boundy EO, Wall S. What is kangaroo mother care? Systematic review of the literature. J Global Health. 2016;6(1).

111. Charpak N, Montealegre-Pomar A, Bohorquez A. Systematic review and meta analysis suggest that the duration of kangaroo mother care has a direct impact on neonatal growth. Acta Paediatr. 2021;110(1):45-59.

112. Als H, McAnulty G. The newborn individualized developmental care and assessment program (NIDCAP) with kangaroo mother care (KMC): comprehensive care for preterm infants. Curr Womens Health Rev. 2011;7(3):288-301.

113. Aita M, Héon M, Lavallée A, de Clifford-Faugère G, Altit G, Le May S, et al. Nurturing and quiet intervention (NeuroN-QI) on preterm infants' neurodevelopment and maternal stress and anxiety: a pilot randomized clinical trial protocol. J Adv Nurs. 2021;77(7):3192-203.

114. Soleimani F, Azari N, Ghiasvand H, Shahrokhi A, Rahmani N, Fatollahierad S. Do NICU developmental care improve cognitive and motor outcomes for preterm infants? A systematic review and meta-analysis. BMC Pediatr. 2020;20(1):67.

115. Symington A, Pinelli J. Developmental care for promoting development and preventing morbidity in preterm infants. Cochrane Database Syst Rev. 2006(2):CD001814.

116. Ohlsson A, Jacobs SE. NIDCAP: a systematic review and meta-analyses of randomized controlled trials. Pediatrics. 2013;131(3):e881-93.

117. Aita M, Stremler R, Feeley N, Lavallée A, De Clifford-Faugère G. Effectiveness of interventions during NICU hospitalization on the neurodevelopment of preterm infants: a systematic review protocol. Systematic Reviews. 2017;6:225-9.

118. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: education and training. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

119. Dol J, Richardson B, Tomblin Murphy G, Aston M, McMillan D, Campbell-Yeo M. Impact of mobile health (mHealth) interventions during the perinatal period for mothers in low- and middle-income countries: a systematic review. JBI Database System Rev Implement Rep. 2019;17(8):1634-67.

120. Epstein EG, Arechiga J, Dancy M, Simon J, Wilson D, Alhulsen JL. Integrative review of technology to support communication with parents of infants in the NICU. J Obstet Gynecol Neonatal Nurs. 2017;46(3):357-66.

121. Epstein EG, Sherman J, Blackman A, Sinkin RA. Testing the feasibility of Skype and FaceTime updates with parents in the Neonatal Intensive Care Unit. Am J Crit Care. 2015;24(4):290-6.

122. Gund A, Sjöqvist BA, Wigert H, Hentz E, Lindecrantz K, Bry K. A randomized controlled study about the use of eHealth in the home health care of premature infants. BMC Med Inform Decis Mak. 2013;9(13):22.

123. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: ethical decisions. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

124. Abdel-Latif ME, Boswell D, Broom M, Smith J, Davis D. Parental presence on neonatal intensive care unit clinical bedside rounds: randomised trial and focus group discussion. Arch Dis Child Fetal Neonatal Ed. 2015;100(3):F203-9.

125. Lantos JD. Ethical problems in decision making in the neonatal ICU. N Engl J Med. 2018;379(19):1851-60.

126. Gaucher N, Nadeau L, Barbier A, Janvier A, Payot A. Personalized antenatal consultations for preterm labor: responding to mothers' expectations. J Pediatr. 2016;178(130-134):e7.

127. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: birth and transfer. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

128. Smith VC, Hwang SS, Dukhovny D, Young S, Pursley D. Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: connecting the dots. J Perinatol Off J Calif Perinat Assoc. 2013;33(6):415-21.

129. Sneath N. Discharge teaching in the NICU: are parents prepared? An integrative review of parents' perceptions. Neonatal Netw. 2009;28(4):237-46.

130. Schlittenhart JM, Smart D, Miller K, Severtson B. Preparing parents for NICU discharge: an evidence-based teaching tool. Nurs Womens Health. 2011;15(6):484-94.

131. Garfield CF, Seok Lee Y, Nam Kim H, Rutsohn J, Yasmin Kahn J, Mustanski B, et al. Supporting parents of premature infants transitioning from the NICU to home: a pilot randomized control trial of a smartphone application. Internet Interv. 2016;4(2):131-7.

132. Coopman L, Tency I. Sleutelmomenten en noden van ouders met een kind op de neonatologie. Tijdschrift voor Vroedvrouwen. 2020;26(2):96-103.

133. European Foundation for the Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health: follow-up and continuing care. European Foundation for the Care of Newborn Infants (EFCNI); 2018.

134. Lefèvre M, Bouckaert N, Camberlin C, Devriese S, Pincé H, de Meester C, et al. Organisation of maternity services in Belgium. Brussels: Belgian Health Care Knowledge Centre (KCE); 2019. Health Services Research (HSR)

135. Koninklijk besluit van 20 augustus 1996 houdende vaststelling van de normen waaraan een functie van lokale neonatale zorg (N*-functie) moet voldoen om te worden erkend - Arrêté royal du 20 août 1996 fixant les normes auxquelles une fonction de soins néonatals locaux (fonction N*) doit satisfaire pour être agréée. B.S. 01/10/1996.

136. Koninklijk van 21 maart 1977 besluit tot vaststelling van de criteria die van toepassing zijn voor de programmatie van verschillende soorten ziekenhuisdiensten - Arrêté royal du 21 mars 1977 fixant les critères qui sont d'application pour la programmation des différents types de services hospitaliers. B.S. 30/04/1977.

137. de Salaberry J, Hait V, Thornton K, Bolton M, Abrams M, Shivananda S, et al. Journey to mother baby care: implementation of a combined care/couplet model in a level 2 neonatal intensive care unit. Birth Defects Res. 2019(111):1060-72.

138. Crommelynck A, Degraeve K, Lefèbvre D. L'organisation et le financement des hôpitaux. Fiche-info. Supplément à MCInformations n° 253 [Web page].2013 [cited 29 June 2020]. Available from: https://www.mc.be/media/mc-informations_253_fiche-info-hopitaux_tcm49-28968.pdf

139. Koninklijk besluit van 2 april 2014 houdende vaststelling van de normen waaraan het zorgprogramma voor kinderen moet voldoen om erkend te worden - Arrêté royal du 2 avril 2014 fixant les normes auxquelles un programme de soins pour enfants doit répondre pour être agréé. B.S. 18/04/2014.

140. Koninklijk besluit van 13 juli 2006 houdende vaststelling van de normen waaraan het zorgprogramma voor kinderen moet voldoen om erkend te worden en tot wijziging van het koninklijk besluit van 25 november 1997 houdende vaststelling van de normen waaraan de functie "chirurgische daghospitalisatie" moet voldoen om te worden erkend. B.S. 16 augustus 2006.

141. Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, et al. Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. BMC Pediatr. 2013;13(18).

142. Wigert H, Berg M, Hellström AL. Parental presence when their child is in neonatal intensive care. Scand J Caring Sci. 2009;24(1):139-46.

143. Koninklijk besluit van 20 augustus 1996 tot wijziging van het koninklijk besluit van 23 oktober 1964 tot bepaling van de normen die door de ziekenhuizen en hun diensten moeten worden nageleefd. B.S. 1 oktober 1996.

144. Brockman V. Implementing the mother-baby model of nursing care using models and quality improvement tools. Nurs Women Health. 2016;19(6):490-503.

145. Grubbs L, Cottrell BH. Nurses' attitude and concerns about couplet care. Nurs Manag. 1996;27(1):54-6.

146. Van de Voorde C, Van den Heede K, Beguin C, Bouckaert N, Camberlin C, de Bekker P, et al. Required hospital capacity in 2025 and criteria for rationalisation of complex cancer surgery, radiotherapy and maternity services. Brussels: Belgian Health Care Knowledge Centre (KCE); 2017. Health Services Research (HSR)

147. Cutland CL, Lakcritz EM, Mallett-Moore T, Bardají A, Chandrasekaran R, Lahariya C, et al. Case definition and guidelines for data collection, analysis, and presentation of maternal immunization safety data. Vaccine. 2017;4(35(48 Pt A)):6492-500.

148. Lvoff N, Lvoff V, Klaus M. Effect of the baby-friendly initiative on infant abandonment in a Russian hospital. Arch Pediatr Adolesc Med. 2000;154(5):474-7.

149. Bystrova K, Ivanova V, Edhborg M, Matthiesen A, Ransjö-Arvidson A, Mulhamedrakhimov R, et al. Early contact versus separation: effects on mother-infant interaction one year later. Birth. 2009;36(2):97-109.

150. Bystrova K, Widström AM, Matthiesen A, Ransjö-Arvidson A, Welles-Nyström B, Wassberg C, et al. Skin-to-skin contact may reduce negative consequences of "the stress of being born": a study on temperature in newborn infants, subjected to different ward routines in St. Petersburg. Acta Paediatr. 2003;92(3):320-6.

151. Christensson K, Siles C, Moreno L, Belaustequi A, De La Fuente P, Lagercrantz H, et al. Temperature, metabolic adaptation and crying in healthy full-term newborns cared for skin-to-skin or in a co. Acta Paediatr. 1992;81(6-7):488-93.

152. Christensson K, Bhat G, Amadi B, Eriksson B, Höjer B. Randomised study of skin-to-skin versus incubator care for rewarming low-risk hypothermic neonates. Lancet. 1998;352(9134):1115.

153. Jaafar SH, Ho JJ, Lee KS. Rooming-in for new mother and infant versus separate care for increasing the duration of breastfeeding. Cochrane Database Syst Rev. 2016;26(8).

154. Bergman N, Linley L, Fawcus S. Randomised controlled trial of skin-to-skin contact from birth versus conventional incubator for

physiological stabilisation in 1200-to 2199-gram newborns. Acta Paediatr. 2004;93(6):779-85.

155. Peters KL, Rosychuk RJ, Hendson L, Coté JJ, McPherson C, Tyebkhan JM. Improvement of short-and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial. Pediatrics. 2009;124(4):1009-20.

156. Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, et al. Cochrane Handbook for Systematic Reviews of Interventions. 2nd Edition. Chichester (UK): John Wiley & Sons; 2019.

157. Blencowe H, Cousens S, Oestergaard MZ, Chou D, Molle AB, Narwal R, et al. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. Lancet. 2012;379(9832):2162-72.

158. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan: a web and mobile app for systematic reviews. Systematic reviews. 2016;5(210).

159. Athanasopoulou E, Fox JR. Effects of kangaroo mother care on maternal mood and interaction patterns between parents and their preterm, low birth weight infants: a systematic review. Infant Ment Health J. 2014;35(3):245-62.

160. Boundy EO, Dastjerdi R, Spiegelman D, Fawzi WW, Missmer SA, Lieberman E, et al. Kangaroo mother care and neonatal outcomes: a meta-analysis. Pediatrics. 2016;137(1).

161. Conde-Agudelo A, Diaz-Rossello JL. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. Cochrane Database Syst Rev. 2016(8):CD002771.

162. Ding X, Zhu L, Zhang R, Wang L, Wang TT, Latour JM. Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: a systematic review and meta-analysis of randomised controlled trials. Aust Crit Care. 2019;32(1):63-75.

163. Evans T, Whittingham K, Sanders M, Colditz P, Boyd RN. Are parenting interventions effective in improving the relationship between mothers and their preterm infants? Infant Behav Dev. 2014;37(2):131-54.

164. Jafari M, Farajzadeh F, Asgharlu Z, Derakhshani N, Asl YP. Effect of kangaroo mother care on hospital management indicators: a systematic review and meta-analysis of randomized controlled trials. J Educ Health Promot. 2019;8:96.

165. Legendre V, Burtner PA, Martinez KL, Crowe TK. The evolving practice of developmental care in the neonatal unit: a systematic review. Physical & Occupational Therapy in Pediatrics. 2011;31(3):315-38.

166. McGregor J, Casey J. Enhancing parent-infant bonding using kangaroo care: a structured review. Evidence Based Midwifery. 2012;10(2):50-6.

167. Mirghafourvand M, Ouladsahebmadarek E, Hosseini MB, Heidarabadi S, Asghari-Jafarabadi M, Hasanpour S. The effect of creating opportunities for parent empowerment program on parent's mental health: a systematic review. Iran J Pediatr. 2017;27(2).

168. O'Callaghan N, Dee A, Philip RK. Evidence-based design for neonatal units: a systematic review. Matern Health Neonatol Perinatol. 2019;5:6.

169. Puthussery S, Chutiyami M, Tseng PC, Kilby L, Kapadia J. Effectiveness of early intervention programs for parents of preterm infants: a meta-review of systematic reviews. BMC Pediatr. 2018;18(1):223.

170. Sabnis A, Fojo S, Nayak SS, Lopez E, Tarn DM, Zeltzer L. Reducing parental trauma and stress in neonatal intensive care: systematic review and meta-analysis of hospital interventions. J Perinatol. 2019;39(3):375-86.

171. Sakonidou S, Andrzejewska I, Webbe J, Modi N, Bell D, Gale C. Interventions to improve quantitative measures of parent

satisfaction in neonatal care: a systematic review. BMJ Paediatr Open. 2020;4(1):e000613.

172. Scime NV, Gavarkovs AG, Chaput KH. The effect of skin-to-skin care on postpartum depression among mothers of preterm or low birthweight infants: a systematic review and meta-analysis. J Affect Disord. 2019;253:376-84.

173. Segers E, Ockhuijsen H, Baarendse P, van Eerden I, van den Hoogen A. The impact of family centred care interventions in a neonatal or paediatric intensive care unit on parents' satisfaction and length of stay: a systematic review. Intensive Crit Care Nurs. 2019;50:63-70.

174. Servel AC, Rideau Batista Novais A. [Single-family rooms for neonatal intensive care units impacts on preterm newborns, families, and health-care staff. A systematic literature review]. Arch Pediatr. 2016;23(9):921-6.

175. Shahheidari M, Homer C. Impact of the design of neonatal intensive care units on neonates, staff, and families: a systematic literature review. J Perinat Neonatal Nurs. 2012;26(3):260-6.

176. Tan K, Lai NM. Telemedicine for the support of parents of high-risk newborn infants. Cochrane Database Syst Rev. 2012(6):CD006818.

177. van Veenendaal NR, van Kempen A, Franck LS, O'Brien K, Limpens J, van der Lee JH, et al. Hospitalising preterm infants in single family rooms versus open bay units: a systematic review and meta-analysis of impact on parents. EClinicalMedicine. 2020;23:100388.

178. Wallin L, Eriksson M. Newborn Individual Development Care and Assessment Program (NIDCAP): a systematic review of the literature. Worldviews Evid Based Nurs. 2009;6(2):54-69.

179. Yu X, Zhang J. Family-centred care for hospitalized preterm infants: a systematic review and meta-analysis. Int J Nurs Pract. 2019;25(3):e12705.

180. Zhang X, Kurtz M, Lee SY, Liu H. Early Intervention for Preterm Infants and Their Mothers: A Systematic Review. J Perinat Neonatal Nurs. 2014;18:18.

181. Gray JE, Safran C, Davis RB, Pompilio-Weitzner G, Stewart JE, Zaccagnini L, et al. Baby CareLink: using the internet and telemedicine to improve care for high-risk infants. Pediatrics. 2000;106(6):1318-24.

182. Roberts KL, Paynter C, McEwan B. A comparison of kangaroo mother care and conventional cuddling care. Neonatal Netw. 2000;19(4):31-5.

183. Westrup B, Kleberg A, von Eichwald K, Stjernqvist K, Lagercrantz H. A randomized, controlled trial to evaluate the effects of the newborn individualized developmental care and assessment program in a Swedish setting. Pediatrics. 2000;105(1 Pt 1):66-72.

184. Melnyk BM, Alpert-Gillis L, Feinstein NF, Fairbanks E, Schultz-Czarniak J, Hust D, et al. Improving cognitive development of low-birth-weight premature infants with the COPE program: a pilot study of the benefit of early NICU intervention with mothers. Res Nurs Health. 2001;24(5):373-89.

185. Feldman R, Eidelman AI, Sirota L, Weller A. Comparison of skin-to-skin (kangaroo) and traditional care: parenting outcomes and preterm infant development. Pediatrics. 2002;110(1):16-26.

186. White-Traut R, Nelson MN, Silvestri JM, Vasan U, Littau S, Meleedy-Rey P, et al. Effect of auditory, tactile, visual, and vestibular intervention on length of stay, alertness, and feeding progression in preterm infants. Dev Med Child Neurol. 2002;44:91-7.

187. Fowler Byers JF, Yovaish W, Lowman LB, Francis JD. Co-bedding versus single-bedding premature multiple-gestation infants in incubators. J Obstet Gynecol Neonatal Nurs. 2003;32(3):340-7.

188. Brisch KH, Bechinger D, Betzler S, Heinemann H. Early preventive attachment-oriented psychotherapeutic intervention program with parents of a very low birthweight premature infant: results of

attachment and neurological development. Attach Hum Dev. 2003;5(2):120-35.

189. Feldman R, Weller A, Sirota L, Eidelman AI. Testing a family intervention hypothesis: the contribution of mother-infant skin-to-skin contact (kangaroo care) to family interaction, proximity, and touch. J Fam Psychol. 2003;17(1):94.

190. Feijó L, Hernandez-Reif M, Field T, Burns W, Valley-Gray S, Simco E. Mothers' depressed mood and anxiety levels are reduced after massaging their preterm infants. Infant Behav Dev. 2006;29:476-80.

191. Kaaresen PI, Ronning JA, Ulvund SE, Dahl LB. A randomized, controlled trial of the effectiveness of an early-intervention program in reducing parenting stress after preterm birth. Pediatrics. 2006;118(1):e9-19.

192. Miles R, Cowan F, Glover V, Stevenson J, Modi N. A controlled trial of skin-to-skin contact in extremely preterm infants. Early Hum Dev. 2006;82(7):447-55.

193. Glazebrook C, Marlow N, Israel C, Croudace T, Johnson S, White IR, et al. Randomised trial of a parenting intervention during neonatal intensive care. Arch Dis Child Fetal Neonatal Ed. 2007;92(6):F438-43.

194. Kleberg A, Hellstrom-Westas L, Widstrom AM. Mothers' perception of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared to conventional care. Early Hum Dev. 2007;83(6):403-11.

195. van der Pal SM, Maguire CM, le Cessie S, Wit JM, Walther FJ, Bruil J. Parental experiences during the first period at the neonatal unit after two developmental care interventions. Acta Paediatr. 2007;96(11):1611-6.

196. Chiu SH, Anderson GC. Effect of early skin-to-skin contact on mother-preterm infant interaction through 18 months: randomized controlled trial. Int J Nurs Stud. 2009;46(9):1168-80.

197. Newnham CA, Milgrom J, Skouteris H. Effectiveness of a modified Mother-Infant Transaction Program on outcomes for preterm infants from 3 to 24 months of age. Infant Behav Dev. 2009;32(1):17-26.

198. Peters KL, Rosychuk RJ, Hendson L, Cote JJ, McPherson C, Tyebkhan JM. Improvement of short- and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial. Pediatrics. 2009;124(4):1009-20.

199. Zelkowitz P, Feely, Shrier I, Stremler R, Westreich R, Dunkley D, et al. The Cues and Care Randomized Controlled Trial of a neonatal intensive care unit intervention: effects on maternal psychological distress and mother-infant interaction. J Dev Behav Pediatr. 2011;32(5):591-9.

200. Feeley N, Zelkowitz P, Shrier I, Stremler R, Westreich R, Dunkley D, et al. Follow-up of the Cues and Care Trial. J Early Interv. 2012;34(2):65-81.

201. Ravn IH, Smith L, Lindemann R, Smeby NA, Kyno NM, Bunch EH, et al. Effect of early intervention on social interaction between mothers and preterm infants at 12 months of age: a randomized controlled trial. Infant Behav Dev. 2011;34(2):215-25.

202. Ravn IH, Lindemann R, Smeby NA, Bunch EH, Sandvik L, Smith L. Stress in fathers of moderately and late preterm infants: a randomised controlled trial. Early Child Dev Care. 2012;182(5):537-52.

203. Ravn IH, Smith L, Smeby NA, Kynoe NM, Sandvik L, Bunch EH, et al. Effects of early mother-infant intervention on outcomes in mothers and moderately and late preterm infants at age 1 year: a randomized controlled trial. Infant Behav Dev. 2012;35(1):36-47.

204. Schlez A, Litmanovitz I, Bauer S, Dolfin T, Regev R, Arnon S. Combining kangaroo care and live harp music therapy in the neonatal intensive care unit setting. Isr Med Assoc J. 2011;13(6):354.

205. Holditch-Davis D, White-Traut R, Levy J, Williams KL, Ryan D, Vonderheid S. Maternal satisfaction with administering infant

interventions in the neonatal intensive care unit. J Obstet Gynecol Neonatal Nurs. 2013;42(6):641-54.

206. Matricadi S, Agostino R, Fedeli C, Montirosso R. Mothers are not fathers: differences between parents in the reduction of stress levels after a parental intervention in a NICU. Acta Paediatr. 2012;102:8-14.

207. Welch MG, Hofer MA, Stark RI, Andrews HF, Austin J, Glickstein SB, et al. Randomized controlled trial of Family Nurture Intervention in the NICU: assessments of length of stay, feasibility and safety. BMC Pediatr. 2013;13:148.

208. White-Traut R, Norr KF, Fabiyi C, Rankin KM, Li Z, Liu L. Mother-infant interaction improves with a developmental intervention for mother-preterm infant dyads. Infant Behav Dev. 2013;36(4):694-706.

209. Arnon S, Diamant C, Bauer S, Regev R, Sirota G, Litmanovitz I. Maternal singing during kangaroo care led to autonomic stability in preterm infants and reduced maternal anxiety. Acta Paediatr. 2014;103(10):1039-44.

210. Chorna OD, Slaughter JC, Wang L, Stark AR, Maitre NL. A pacifier-activated music player with mother's voice improves oral feeding in preterm infants. Pediatrics. 2014;133(3):462-8.

211. Holditch-Davis D, White-Traut RC, Levy JA, O'Shea TM, Geraldo V, David RJ. Maternally administered interventions for preterm infants in the NICU: effects on maternal psychological distress and mother-infant relationship. Infant Behav Dev. 2014;37(4):695-710.

212. Cong X, Ludington-Hoe SM, Hussain N, Cusson RM, Walsh S, Vazquez V, et al. Parental oxytocin responses during skin-to-skin contact in pre-term infants. Early Human Dev. 2015;91(7):401-6.

213. Hoffenkamp HN, Tooten A, Hall RA, Braeken J, Eliens MP, Vingerhoets AJ, et al. Effectiveness of hospital-based video interaction guidance on parental interactive behavior, bonding, and stress after preterm birth: a randomized controlled trial. J Consult Clin Psychol. 2015;83(2):416-29.

214. Samra HA, Dutcher J, McGrath JM, Foster M, Klein L, Djira G, et al. Effect of skin-to-skin holding on stress in mothers of late-preterm infants: a randomized controlled trial. Adv Neonatal Care. 2015;15(5):354-64.

215. White-Traut RC, Rankin KM, Yoder JC, Liu L, Vasa R, Geraldo V, et al. Influence of H-HOPE intervention for premature infants on growth, feeding progression and length of stay during initial hospitalization. J Perinatol. 2015;35(8):636-41.

216. Castel S, Creveuil C, Beunard A, Blaizot X, Proia N, Guillois B. Effects of an intervention program on maternal and paternal parenting stress after preterm birth: a randomized trial. Early Hum Dev. 2016;103(17-25).

217. Northrup TF, Evans PW, Lillie ML, Tyson JE. A free parking trial to increase visitation and improve extremely low birth weight infant outcomes. J Perinatol. 2016;36(12):1112-5.

218. Welch MG, Halperin MS, Austin J, Stark RI, Hofer MA, Hane AA, et al. Depression and anxiety symptoms of mothers of preterm infants are decreased at 4 months corrected age with Family Nurture Intervention in the NICU. Arch Womens Ment Health. 2016;19(1):51-61.

219. Evans T, Boyd R, Colditz P, Sanders M, Whittingham K. Mother-very preterm infant relationship quality: RCT of Baby Triple P. J Child Fam Stud. 2017;26(1):284-95.

220. Beebe B, Myers MM, Lee SH, Lange A, Ewing J, Rubinchik N, et al. Family nurture intervention for preterm infants facilitates positive mother-infant face-to-face engagement at 4 months. Dev Psychol. 2018;54(11):2016-31.

221. Ranger A, Helmert E, Bott TS, Ostermann T, Als H, Bassler D, et al. Physiological and emotional effects of pentatonic live music played for preterm neonates and their mothers in the newborn intensive care unit: a randomized controlled trial. Complement Ther Med. 2018;41(240):246.

222. Vittner D, McGrath JM, Robinson J, Lawhon G, Cusson RM, Eisenfeld L, et al. Increase in oxytocin from skin-to-skin contact enhances development of parent–infant relationship. Biol Res Nurs. 2018;20(1):54-62.

223. Heo YJ, Oh WO. The effectiveness of a parent participation improvement program for parents on partnership, attachment infant growth in a neonatal intensive care unit: a randomized controlled trial. Int J Nurs Stud. 2019;95:19-27.

224. Andrews KG, Martin MW, Shenberger E, Pereira S, Fink G, McConnell M. Financial support to Medicaid-eligible mothers increases caregiving for preterm infants. Matern Child Health J. 2020;24(5):587-600.

225. Benzies KM, Aziz K, Shah V, Faris P, Isaranuwatchai W, Scotland J, et al. Effectiveness of Alberta Family Integrated Care on infant length of stay in level II neonatal intensive care units: a cluster randomized controlled trial. BMC Pediatr. 2020;20(1):1-11.

226. Church PT, Grunau RE, Mirea L, Petrie J, Soraisham AS, Synnes A, et al. Family Integrated Care (FICare): positive impact on behavioural outcomes at 18 month. Early Human Dev. 2020;151(105196).

227. Coşkun D, Günay U. The effects of kangaroo care applied by Turkish mothers who have premature babies and cannot breastfeed on their stress levels and amount of milk production. J Pediatr Nurs. 2020;50(e26-e32).

228. Mehler K, Hucklenbruch-Rother E, Trautmann-Villalba P, Becker I, Roth B, Kribs A. Delivery room skin-to-skin contact for preterm infants - a randomized clinical trial. Acta Paediatr. 2020;109(3):518-26.

229. Sahlen Helmer C, Birberg Thornberg U, Frostell A, Ortenstrand A, Morelius E. A randomized trial of continuous versus intermittent skin-to-skin contact after premature birth and the effects on mother-infant interaction. Adv Neonatal Care. 2020;20(3):E48-E56.

230. Corrigan M, Keeler J, Miller H, Naylor C, Diaz A. Music therapy and family-integrated care in the NICU: using heartbeat-music interventions to promote mother-infant bonding. Adv Neonatal Care. 2021:1-11.

231. Menke BM, Hass J, Diener C, Pöschl J. Family-centered music therapy—empowering premature infants and their primary caregivers through music: results of a pilot study. PloS One. 2021;16(5):e0250071.

232. Rosenthal JL, Sauers-Ford HS, Williams J, Ranu J, Tancredi DJ, Hoffman KR. Virtual family-centered rounds in the neonatal intensive care unit: a randomized controlled pilot trial. Acad Pediatr. 2021.

233. Twohig A, Murphy JF, McCarthy A, Segurado R, Underdown A, Smyke A, et al. The preterm infant–parent programme for attachment—PIPPA study: a randomised controlled trial. Pediatr Res. 2021:1-8.

234. van der Pal SM, Maguire CM, Bruil J, Le Cessie S, van Zwieten P, Veen S. Very pre-term infants' behavior at 1 and 2 years of age and parental stress following basic developmental care. Br J Dev Psychol. 2008;126:103-15.

235. van der Pal SM, Maguire CM, Le Cessie S, Veen S, Wit JM, Walther FJ, et al. Parental stres and child behavior and temperament in the first year after the newborn individualised developmental care and assessment program. J Early Interv. 2008;30(2):102-15.

236. Rauh V, Nurcombe B, Achenbach T, Howell C. The mother-infant transaction program. The content and implication of an intervention for the mothers of low-birthweight infants. Clin Perinatol. 1990;17(1):31-45.

237. Welch MG, Hofer M, Brunelli SA, Stark RI, Andrews H, Austin J, et al. Family nurture intervention (FNI): methods and treatment protocol of a randomized controlled trial in the NICU. BMC Pediatr. 2012;12(1):1-17.

238. McAndrew N, Jerofke-Owen T, Fortney CA, Costa DK, Hetland BH, Guttormson J, et al. Systematic review of family engagement interventions in neonatal, paediatric, and adult ICUs. Nurs Crit Care. 2020.

239. Shields L, Zhou H, Pratt J, Taylor M, Hunter J, Pascoe E. Family-centred care for hospitalised children aged 0-12 years. Cochrane Database Syst Rev. 2012(10).

240. Schneider J, Borghini A, Morisod Harari M, Faure N, Tenthorey C, Le Berre A, et al. Joint observation in NICU (JOIN): study protocol of a clinical randomised controlled trial examining an early intervention during preterm care. BMJ Open. 2019;9(e026484).

241. Scholten N, Bretthauer S, Eilermann K, Hagemeier A, Hellmich M, Hoffmann J, et al. The effects of webcams on German neonatal intensive care units - study protocol of a randomised crossover trial (Neo-CamCare). BMC Health Serv Res. 2021;21(456).

242. Tiryaki Ö. Effect of family integrated care on the discharge of parents with premature babies in the neonatal intensive care unit. US National Library of Medicine; 2020.

243. Dykstra C, Kuper-Sasse M. Evaluating parent engagement, attachment, stress, and satisfaction with remote rounding in the NICU. US National Library of Medicine; 2020.

244. AdventHealth. Mother's recorded voice for preterm infants. US National Libary of Medicine; 2020.

245. Landry MA. Mindful kangaroo care: mindfulness intervention for mothers during skin-to-skin care. US National Library of Medicine; 2021.

246. Shorey S. Effectiveness of 'Supportive Parenting App' on parental and newborn outcomes. US National Library of Medicine; 2021.

247. López NC, Gualdron LV. Effect of kangaroo baby massage on mother-infant interaction at home (KBM). US National Library of Medicine; 2021.

248. Kohn L, Christiaens W. The use of qualitative research methods in KCE studies. Brussels: Belgian Health Care Knowledge Centre (KCE); 2012. Method KCE Report 187C

249. NeoParent. NeoParent-app [Web page]. Odisee Hogeschool;2021 [cited 14 December 2021]. Available from: https://neoparent.be/neoparent-app/

250. Fernandez ME, Walker TJ, Weiner BJ, Calo WA, Liang S, Risendal B, et al. Developing measures to assess constructs from the Inner Setting domain of the Consolidated Framework for Implementation Research. Implement Sci. 2018;13(52).

251. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q. 2004;82:581-629.

252. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009;4(50).

253. European Commission. Sweden - Parental benefits and benefits related to childbirth [Web page].2021 [cited 1 December 2021]. Available from: https://ec.europa.eu/social/main.jsp?catId=1130&intPageId=4808&langId=en

254. Socialstyrelsen. Vårdkedjan för barn som behöver neonatalvård och deras familjer – Nationella rekommendationer till beslutsfattare och stöd till personal. 2021.

255. Karlsson A. Otto and the machines [Web page].2021 [cited 1 December 2021]. Available from: https://www.ottoandthemachines.com/en/

256. Karolinska University Hospital.2021 [cited 12 November 2021]. Available from: https://www.karolinska.se/for-patienter/graviditet-och-forlossning/sjuka-nyfodda-barn/neonatal-care

257. Haute Autorité de Santé (HAS). Qualité et sécurité des soins dans le secteur de naissance [Web page].2014 [cited 20 November 2021]. Available from: https://www.has-sante.fr/plugins/ModuleXitiKLEE/types/FileDocument/doXiti.jsp?id=c_1732384

258. Caisse d'Allocations Familiales (CAF). L'allocation journalière de présence parentale (Ajpp) [Web page].2022 [cited 15 October 2021]. Available from: https://www.caf.fr/allocataires/droits-et-prestations/s-informer-sur-les-aides/petite-enfance/l-allocation-journaliere-de-presence-parentale-ajpp

259. Société Française de Néonatologie. Recommandations [Web page].2021 [cited 20 November 2021]. Available from: https://www.societe-francaise-neonatalogie.com/recommandations

260. Initiative Hôpital ami des bébés (IHAB). Un label de l'OMS et de l'UNICEF: le nouveau-né et sa famille au cœur du système de soins [Web page].2022 [cited 14 January 2022]. Available from: https://www.i-hab.fr/

261. Association SPARADRAP. Le petit frère de Lili est né mais il n'est pas à la maison [Web page].2013 [cited 20 November 2021]. Available from: https://www.sparadrap.org/boutique/produit/guide-le-petit-frere-de-lili-est-ne-mais-il-nest-pas-la-maison

262. Pardou A, Merveille C, Goffin J. Né trop tôt. Mijade; 2011.

263. Association SPARADRAP. Pour les parents [Web page].2021 [cited 10 October 2021]. Available from: https://www.sparadrap.org/parents/documents-pour-les-familles/pour-les-parents

264. SOS Préma. Accueil [Web page].2021 [cited 10 October 2021]. Available from: https://www.sosprema.com/page/173781-accueil

265. Feeding FUNdamentals. SOFFI Trainings [Web page].2021 [cited 10 October 2021]. Available from: https://www.feedingfundamentals.com/soffi-trainings

266. Rite Gracia S, Fernandez Lorenzo JR, Echaniz Urcelay I, Botet Mussons F, Herranz Carrillo G, Moreno Hernando J, et al. [Health care levels and minimum recommendations for neonatal care]. An Pediatr (Barc). 2013;79(1):51 e1- e11.

267. Pallas-Alonso CR, Loureiro B, De la Cruz Bertolo J, Garcia P, Ginovart G, Jimenez A, et al. Spanish survey on follow-up programmes for children born very preterm. Acta Paediatr. 2019;108(6):1042-8.

268. Oyster Team. How does parental leave in the Netherlands work? [Web page].2021 [cited 12 October 2021]. Available from: https://www.oysterhr.com/library/parental-leave-in-the-netherlands

269. EGM Architecten. Ronald McDonald Sophia House [Web page].2021 [cited 2 October 2021]. Available from: https://www.egm.nl/en/architects/projects/ronald-mcdonald-sophia-house/64

270. Jeukens-Visser M, Koldewijn K, van Wassenaer-Leemhuis AG, Flierman M, Nollet F, Wolf MJ. Development and nationwide implementation of a postdischarge responsive parenting intervention program for very preterm born children: The TOP program. Infant Ment Health J. 2021;42(3):423-37.