

EVERY PREMIE  
SCALE



# NURTURING CARE FOR SMALL AND SICK NEWBORNS: EVIDENCE REVIEW AND COUNTRY CASE STUDIES

August 2019



## Funding

This study was made possible by the generous support of the American people through the United States Agency for International Development (USAID), under the terms of the Cooperative Agreements AID-OAA-A-14-00049 and AID-OAA-A-14-00028. The contents are the responsibility of the authors and do not necessarily reflect the views of USAID or the United States Government.

## Authors

- Karen New, RN, RM, PhD, Neonatal Nurse Healthcare Consultant
- Amialya Durairaj, MSc, Health Writing Consultant, Little Octopus LLC
- Judith Robb-McCord, MAAS, MPH, Senior Director, Every Preemie-SCALE/Project Concern International (PCI)
- Neena Khadka, MBBS, DCH, MA, MPH, Newborn Team Lead, Maternal Child Survival Program/Save the Children

## Expert Advisory Group

- Bernadette Daelmans, MD, Coordinator, Policy, Planning and Programmes, Department of Maternal, Newborn, Child and Adolescent Health (MCA), WHO
- Anne Detjen, MD, Health Specialist, integrated service delivery (iCCM/IMCI), childhood tuberculosis, UNICEF
- Tedbabe Degefie Hailegebriel, MD, Senior Adviser, Maternal and Newborn Health, UNICEF
- Lily Kak, PhD, Senior Advisor for Global Partnerships and Newborn Health, USAID/Washington, Bureau for Global Health
- Ornella Lincetto, MD, MPH, Maternal, Newborn, Child and Adolescent Health (MCA), WHO

## Expert Reviewers

- Anne-Marie Bergh, PhD, senior researcher at the South African Medical Research Council Maternal and Infant Health Care Strategies Research Unit, University of Pretoria, South Africa
- Nils Bergman, MD, Karolinska Institute, Public Health Physician
- Joy Voyles Browne, PhD, UC Denver
- Marsha Campbell-Yeo, PhD, NP, Dalhousie University
- Shoo K. Lee, MBBS, PhD, FRCPC, Scientific Director, Institute of Human Development, Child & Youth Health, Canadian Institutes of Health Research; Professor of Paediatrics, Obstetrics & Gynecology, and Public Health, University of Toronto; Paediatrician-in-Chief, Mount Sinai Hospital
- James A. Litch, MD, Executive Director, Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and Technical Lead for Evidence and Knowledge Sharing, Every Preemie—SCALE/GAPPS
- Arti Maria, MD, Department of Pediatrics, Dr. Ram Manohar Lohia Hospital, New Delhi, India
- Silke Mader, Executive Director, European Foundation for the Care of Newborn Infants (EFCNI)
- Sushma Nangia, MD, Director Professor and Head at the Department of Neonatology, Lady Hardinge Medical College, New Delhi, India.

- Karel O'Brien, MD, Department of Paediatrics, Mount Sinai Hospital, Sinai Health System and University of Toronto
- Giorgio Tamburlini, MD, Internal Public Health Expert, Paediatrician/Neonataologist, WHO Senior Consultant
- Aisha Yousafzai, PhD, Associate Professor of Global Health; Department of Global Health and Population; Harvard T.H. Chan School of Public Health

## Acknowledgements

The authors sincerely appreciate the critical guidance of the expert advisory and expert review teams. Their wisdom and experience were crucial in the shaping of this document. The authors also want to recognize the project management work of Chelsea Dunning, Senior Program Officer at Every Preemie-SCALE/ Project Concern International (PCI).

Finally, the authors wish to acknowledge the champions for nurturing care practices in Nepal, Rwanda, Sweden, the Philippines, the United States of America, Colombia, and India for their expertise and willingness to participate in the country case study exercise:

### *Nepal*

Professor Dr. Ramesh Kant Adhikari, Professor of Pediatrics, former Dean of the Institute of Medicine, Tribhuvan University Teaching Hospital. Director of Medical Education, Postgraduate Program, KIST Medical College (Recently retired)

Professor Dr. Sudha Basnet, Professor of Pediatrics, Institute of Medicine, Tribhuvan University Teaching Hospital

Dr. Kalpana Upadhyay Subedi: Head of Department, Chief Consultant Pediatrician, Neonatal Unit, Maternity Hospital

Dr. Nisha Jyoti Shrestha: Chief Consultant Pediatrician, Neonatal Unit, Maternity Hospital, Kathmandu

Ms. Mithu Karki, Sister-in-charge, Neonatal Unit, Maternity Hospital

Dr. Pankaj Ray. Senior Consultant Pediatrician, Kanti Children's Hospital

Dr. Deepeshwara Nepal, Senior Consultant Pediatrician, Kanti Children's Hospital

Ms. Rama Adhikari, Hospital Nursing Supervisor, Kanti Children's Hospital

Mr. Deepak Jha, Senior Public Health Officer, Family Welfare Division, Department of Health Services, Ministry of Health and Population

### *Rwanda*

Dr. Edgar Kalimba, Acting Chief Executive Officer and Pediatrician, King Faisal Hospital

Dr. Assumpta Mwali Kayinamura, Senior RMNCH Specialist, USAID Ingobyi Activity, IntraHealth International

Dr. Muthu Maharajan, Chief of Health, UNICEF Rwanda

Dr. Lisine Tuyisenge, General Secretary, Rwanda Pediatric Association

Dr. Felix Sayinzoga, Division Manager, Maternal, Child and Community Health Division, Rwanda Biomedical Center, Ministry of Health

### *Sweden*

Dr. Bjorn Westrup, MD, PhD, Senior Neonatologist and Co-Director of the Karolinska NIDCAP Training & Research Center; Karolinska University Hospital, Department of Women's and Children's Health, Nurture Science Program, Karolinska Institutet, Stockholm Sweden

### *The Philippines*

Dr. Anthony Calibo, MD, DPPS, Officer-in-charge Division Chief and Medical Specialist IV, National Newborn Care and IYCF Program Manager, Children's Health Development Division, Disease Prevention and Control Bureau, Department of Health

Dr. Socorro De Leon-Mendoza, M.D., President, Kangaroo Mother Care Foundation Phil., Inc., and President, Federation of Asia and Oceania Perinatal Societies (FAOPS)

Dr. Ma Lourdes Imperial, Medical Specialist Level III, Chair of Department of Newborn Medicine, Dr. Jose Fabella Memorial Hospital  
Dr. Maria Esterlita Uy, Philippines Society of Newborn Medicine  
Dr. Yolanda E. Oliveros, Office of Health, USAID, Philippines  
Dr. Maria Luisa de Villa-Manlapaz, Staff Neonatologist, St. Luke's Medical Center – Quezon City and St. Luke's Medical Center Bonifacio Global City. Past Chairman, Department of Pediatrics, St. Luke's Medical Center-Quezon City

### *The United States of America*

Dr. Billie Lou Short, Division Chief Neonatology, Children's National Hospital, Professor of Pediatrics at The George Washington University School of Medicine  
Dr. Marian E. Williams, PhD, Associate Professor of Clinical Pediatrics and Psychology, Keck School of Medicine, University of Southern California and Children's Hospital Los Angeles  
Dr. Sunah (Susan) Hwang, MD, MPH, PhD, Assistant Professor, Pediatrics-Neonatology, School of Medicine, University of Colorado, Anschutz Medical Campus

### *Colombia*

Dr. Nathalie Charpak, Pediatrician and Researcher, PMCI Hospital Universitario San Ignacio; Director, Kangaroo Foundation  
Dr. Javier Guillermo Diaz Amaya, Pediatrician; Consultant in Child Health and Development, Life Course Group, Office of Promotion and Prevention, Ministry of Health and Social Protection (MOHSP)  
Dr. Clarita Galvis, Neonatologist, Hospital Militar Central  
Dr. Oscar Hincapie, Neonatologist, Hospital Militar Central  
Dr. Eugenia Espinosa, Pediatric Neurologist, Hospital Militar Central  
Dr. Roberto Chaskel, Child Psychiatrist, Hospital Militar Central

### *India*

Professor Dr. Sushma Nangia, Director and Health of Department of Neonatology, Lady Hardinge Medical College and Kalawati Saran Children's Hospital; Co-Convener, National Collaborative Center for FBNC, MoHFW, GOI; Convener, Vatsalya-Matri Amrit Kosh: National Human Milk Bank  
Professor Dr. Arun Singh, Senior Advisor, National Health Systems Resource Center, National Institute of Health and Family Welfare Campus  
Professor Dr. Arti Maria, Professor and Head, Department of Neonatology; PGIMER and Associate Dr. Ram Manohar Lohia Hospital; ISQua Expert; Nominated member ISRHML  
Dr. Nagaratna, Early Interventionist, Department of Neonatology, PGIMER & Associate Dr. Ram Manohar Lohia Hospital  
Dr. Ajay Khera, Public Health Specialist, Deputy Commissioner (Child & Adolescent Health), Ministry of Health & Family Welfare  
Dr. Harish Kumar, Pediatrician, Project Director, IPE GLOBAL  
Professor Ashok K. Deorari, Head, Department of Pediatrics, President National Neonatology Forum of India – 2020, In-charge WHO Collaborating Center for Newborn Training and Research; Chairman Skill Center; Lead for QI in SEARO; All India Institute of Medical Sciences, New Delhi  
Professor Dr. Harish Chellani, Head of Department of Pediatrics, Vardhaman Mahavir Medical College and Safdurjung Hospital

## Glossary

TERM	DEFINITION AND USAGE IN THIS EVIDENCE SUMMARY
<b>Toddler</b>	A child between the ages of 1 to 3 years.
<b>Developmentally supportive care</b>	Care of an infant to support positive growth and development, while allowing stabilization of physiologic and behavioral functioning. (National Association of Neonatal Nurses, 2000).
<b>Family-centered care</b>	An approach to care delivery that promotes a mutually beneficial partnership among mothers, families and health-care providers to support health-care planning, delivery and evaluation. The principles of family-centered care include: dignity and respect; information sharing; participation; and collaboration.
<b>Infant</b>	A child between the age of 29 days and 1 year.
<b>Inpatient care</b>	Care of a newborn in a hospital.
<b>Low birth weight (also LBW)</b>	A newborn who weighs less than 2,500 grams (up to and including 2,499 grams) regardless of gestational age.
<b>Neonate</b>	An infant who is in the first 28 days after birth (also see Newborn).
<b>Newborn</b>	The colloquial term for an infant (neonate) who is in the first 28 days after birth.
<b>Nurturing care</b>	An environment created by caregivers. It ensures children's good health and nutrition, protects them from threats, and gives them opportunities for early learning, through interaction that are emotionally supportive and responsive. (World Health Organization, 2018).
<b>Parents/Family</b>	Refers to a newborn's parents, legal guardians, primary caregivers and family members. They are in a unique position to ensure nurturing care and, in the case of mothers, breastfeeding.
<b>Post-discharge care</b>	Care given to a newborn at home post-discharge from an inpatient facility for up to 3 years of age (Nurturing care for early childhood development framework states most critical period is from 0-3).
<b>Sick newborn</b>	A newborn who requires medical care.
<b>Small for gestational age (also SGA)</b>	A newborn whose birth weight is below the 10th percentile for gestational age, compared with a gender-specific reference population. An SGA newborn may be preterm or full-term.
<b>Small newborn</b>	A newborn who is preterm and/or low birth weight, or small for gestational age.
<b>Small and sick newborn</b>	A newborn who is born preterm, small for gestational age, has an illness or suffers from a birth complication, and requires hospitalization during the neonatal period.

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## Introduction

In 2018, WHO, UNICEF, the World Bank Group, and other partners launched *Nurturing Care for Early Childhood Development: A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential* at the 71<sup>st</sup> World Health Assembly. The new Nurturing Care Framework draws on state-of-the-art evidence regarding early childhood development to guide the design of effective policies and services to ensure that parents and caregivers are providing nurturing care for babies. This document describes a whole-of-government and whole-of-society framework and action plan for supporting early childhood development from conception to age three.

Nurturing care is defined as “a stable environment that is sensitive to children’s health and nutritional needs, with protection from threats, opportunities for early learning, and interactions that are responsive, emotionally supportive, and developmentally stimulating”. (3)(p91) *The Nurturing Care for Early Childhood Development: A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential* **pertains to all newborns, infants and children from zero to three years, and** sets out five components of nurturing care: good health, adequate nutrition, responsive caregiving, opportunities for early learning, and security and safety. (2) Interventions and services for each of the five components need to be implemented to ensure children reach their full potential.

This evidence synthesis intends to provide the evidence base for developing implementation interventions that will enable environments for nurturing care. The Nurturing Care framework document (Table 1, p18 and 19) outlines laws and policies for creating enabling environments and lists services and interventions for each of the five components, while the logic model (p33) details inputs, outputs, outcomes, and impact. (2) To achieve nurturing care, health professionals and families need time and resources; facilitated by environments of capable caregivers, empowered communities, supportive services, and enabling policies. (2)

*The Nurturing Care for Early Childhood Development: A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential* document outlines the background around nurturing care and early childhood development, discussing the science, the economics, and the threats to early childhood development. A nurturing intra- and extra-uterine environment is required to provide stimulation for normal healthy brain development. Neurosensory development (touch, smell, taste, hearing and vision) begins in-utero (4) and enables the developing child to learn from their surroundings. (2) The newborn period is critical for early learning. For newborns born sick or small it is even more important as several of the senses may only be beginning to develop outside of the in-utero environment. These vulnerable newborns are at risk of neurodevelopmental delay without early, age-appropriate, neuroprotective interactions. Health professional, caregiver, and family interactions within care facilities and post-discharge at home are important for both short- and long-term outcomes. (2)

Most newborns can survive and thrive, provided they have access to quality health care – including access to appropriate inpatient care. Each year, 30 million small and sick newborns worldwide require care in a hospital. Of these, 8-10 million need intensive care to survive and thrive. (6) WHO defines the quality of care for newborns as the degree to which newborn

health services increase the likelihood of timely, appropriate care for the purpose of achieving desired outcomes that are consistent with current professional knowledge and take into account the preferences and aspirations of women and families.(7)

The quality of care framework highlights two components of care: the quality of the provision of care; and the quality of care as experienced by women, newborns, and families. Good-quality services use evidence-based best practices, are well-organized, accessible and adequately resourced; are safe, efficient timely and people-centered(7); and ensure optimal clinical, developmental and social outcomes for small and sick newborns. Within the clinical environment, it is also imperative that clinicians do no harm to newborns who are receiving more advanced clinical care including, for example, supplemental oxygen. Disabilities in this population can be prevented or mitigated with good-quality, developmentally-supportive care. As more small and sick newborns survive due to increased access to inpatient care, countries may experience higher rates of disability due to compromised quality of care.(6)

Close attention should be paid to delivering good-quality, developmentally supportive care to all newborns, including those living with their mothers in prisons; those who have medical and developmental needs that cannot be met by their families; and newborns in humanitarian settings(5), and the more vulnerable small and sick newborn. Given the unique needs of small and sick newborns, this evidence synthesis focuses on this particularly vulnerable population during inpatient care and subsequent post-discharge care. It is important to highlight that while the focus on small and sick newborns is a global priority across high-, middle- and low-income countries, vulnerability is most acute in low- and middle-income countries where health systems face many challenges.

It is acknowledged that there are many factors that need to be considered in the context of nurturing care. These include but are not limited to interventions encompassing preconception and care throughout pregnancy, maternal nutrition and health, maternal mental health, care of health workers, social protection and social support of families, community groups and faith communities, provision of safe water and sanitation and good hygiene practices. While each of these are important and need to be addressed to optimize outcomes, investigating the evidence around these interventions is outside the scope of this evidence synthesis.

### *Project Background*

Led by WHO, a group of global partners (including UNICEF, USAID, Every Premie—SCALE and the USAID-funded Maternal and Child Survival Program [MCSP]) convened to develop an evidence synthesis document. This report aims to summarize the evidence and best practices on nurturing care approaches for small and sick newborns focusing on core elements of developmentally supportive care, which is disease-independent but vital to promoting healthy growth and well-being.

This report is the fruit of that collaboration. The document is arranged in three sections:

- **Evidence Synthesis:** An updated evidence review of the core elements of developmentally supportive, family-centered, and nurturing care from existing evidence synthesis documents, peer-reviewed journals, as well as grey literature;

- **Country Case Studies:** Implementation experience from seven selected countries representing high-, middle- and low-income settings collected through interviews with key informants;
- **Gap analysis:** A gap analysis based on evidence review and implementation experience to inform future research.

Building on the Nurturing Care Framework, the authors have proposed a logic model (Figure 1, page 16) to conceptualize the evidence synthesis including the search strategy, interventions, outputs, and effective coverage measures.

## Evidence Synthesis

This evidence synthesis provides a summary of the available evidence from reviews published between 2014 and 2019 and does not contain specific actions that should be taken. This synthesis also contains specific country contexts, values, preferences and resources sourced from the grey literature specific to the countries selected for the country case studies.

### Synthesis Scope

It is acknowledged that nurturing care pertains to and is encouraged for every newborn, infant and child. While many of the interventions included in this synthesis can be applied to all newborns, the parameters for this evidence synthesis were small and sick newborns, in-patient, and post-discharge. Interventions include:

- Skin-to-skin/kangaroo care
- Nutrition (breastmilk feeding and breastfeeding)
- Sensory environment
- Stress and pain
- Supportive positioning
- Protecting and promoting sleep
- Protecting skin
- Age-appropriate stimulation and interactions
- Partnering with parents/families
- Follow-up and screening specifically in relation to neurodevelopment
- Laws and policies

Small and sick newborns for this review refers to a newborn who is born preterm, small for gestational age, has an illness, or suffers from a birth complication, and requires hospitalization during the neonatal period.

This evidence synthesis parameters did not include:

- Early childhood development programs/literature
- Feeding frequency
- Nutrition supplements
- Malnutrition
- Rights of the newborn
- Healthy well term newborns
- Toxic stress
- Zero separation
- Care of health workers
- Provision of safe water and sanitation and good hygiene practices
- Preconception and care throughout pregnancy
- Maternal nutrition, health and mental health
- Social protection and social support of families

## Summary

### *Peer-Reviewed Literature*

A search for published peer-reviewed reviews was conducted for each of the interventions between February and April 2019. The reviews were any type of review (e.g., systematic, literature, narrative), either quantitative or qualitative, in which methods were clearly articulated and involved searching two or more databases. The search terms were kept broad to minimize not finding pertinent reviews. A total of 4,147 publications were scanned by title and abstract, resulting in 578 references downloaded into a reference library. Following removal of duplicate references, 230 full text publications were scanned, resulting in 142 reviews potentially eligible for inclusion. Reviews published between 2010 and 2019 were included in the search strategy. Given the large number of reviews and the need to identify the most up to date evidence, reviews for inclusion in this synthesis were further restricted to those published between 2014 and 2019. Reviews which were published between 2010 and 2014 were considered if they added to the current body of evidence. Where reviews have reported multiple outcomes, the outcomes have been reported under the respective intervention. As Kangaroo Mother Care is considered a package of interventions, the component which was the focus of the review has been included under the respective intervention. For example, if the review focused on the skin-to-skin component of the kangaroo mother care package, then the review was included under skin-to-skin. Likewise, for reviews in which the components of exclusive breastfeeding, early discharge or follow-up care were reported, these have been reported under the respective intervention.

The majority of the individual studies included in the reviews have been conducted in high- or middle-income countries, with a small number in low-income countries. Overall the preterm populations are described by gestational age and/or weight (<2500 grams), few are described as small and/or sick. Most outcomes are reported on inpatient populations, with limited post-discharge reported outcomes, with the majority of studies report on short- (immediate to three months) to intermediate- (up to two years) term neurodevelopmental outcomes. Cerebral palsy, deafness, blindness and cognitive delay, with scores of <2 standard deviations below the mean for age can be identified in the first two to three years, however neurobehavioral and emotional problems tend not to evolve until around school age. (1) In this systematic search, review authors report that few studies report on long-term neurodevelopmental outcomes beyond two years of age.

### *Grey Literature*

Laws and policies have been identified as an intervention for this evidence synthesis as *enabling policies* are a critical component to enabling environments for nurturing care.(2) The grey literature sought to identify laws and policies (inclusive of acts, guidelines, laws, policies, procedures, protocols, reports, and standards) to support nurturing environments for small and sick newborns, in countries selected for the country case studies. Countries with centers of excellence representing low-, middle-, and high-income were put forward for consideration by steering group members and then selected by consensus of the steering group. The final selected countries included: Colombia, India, Nepal, Philippines, Rwanda, Sweden, and the United States (Children's National Hospital, Washington DC; Children's

Hospital Los Angeles, California; School of Medicine, University of Colorado, Anschutz Medical Campus, Aurora, Colorado).

The number and types of documents sourced via a search of country specific government and non-government websites varied. These results do not reflect that documents do not exist, just that they are not available publicly. This is evidenced by the number of local and national documents that were provided by interviewees for the country case studies and have been included in the country case studies section. The types of documents located included action plans, clinical standards, operational guidelines, policies, reports, reviews, strategy documents and white papers. The earlier documents from low-and-middle income countries tended to focus on newborn care generally, while the later documents have a greater focus on small and sick newborns and early childhood development. This was more evident in the documents from India and Rwanda. Documents obtained for the high-income countries of Sweden and the United States were produced by professional associations.

### *Synthesis Questions*

1. What are the best practices to support developmentally supportive and family-centered care to promote nurturing care and early childhood development for small and sick newborns in-facility and post-discharge?
2. What mechanisms (e.g., policies) exist in specific countries to facilitate developmentally supportive and family-centered care for small and sick newborns?

### *Overview of the Synthesis Process*

The evidence synthesis process includes two parts.

- Part one: evidence from reviews of the peer-reviewed literature
- Part two: a search of grey literature limited to government and non-government websites in those countries participating in the country case studies.

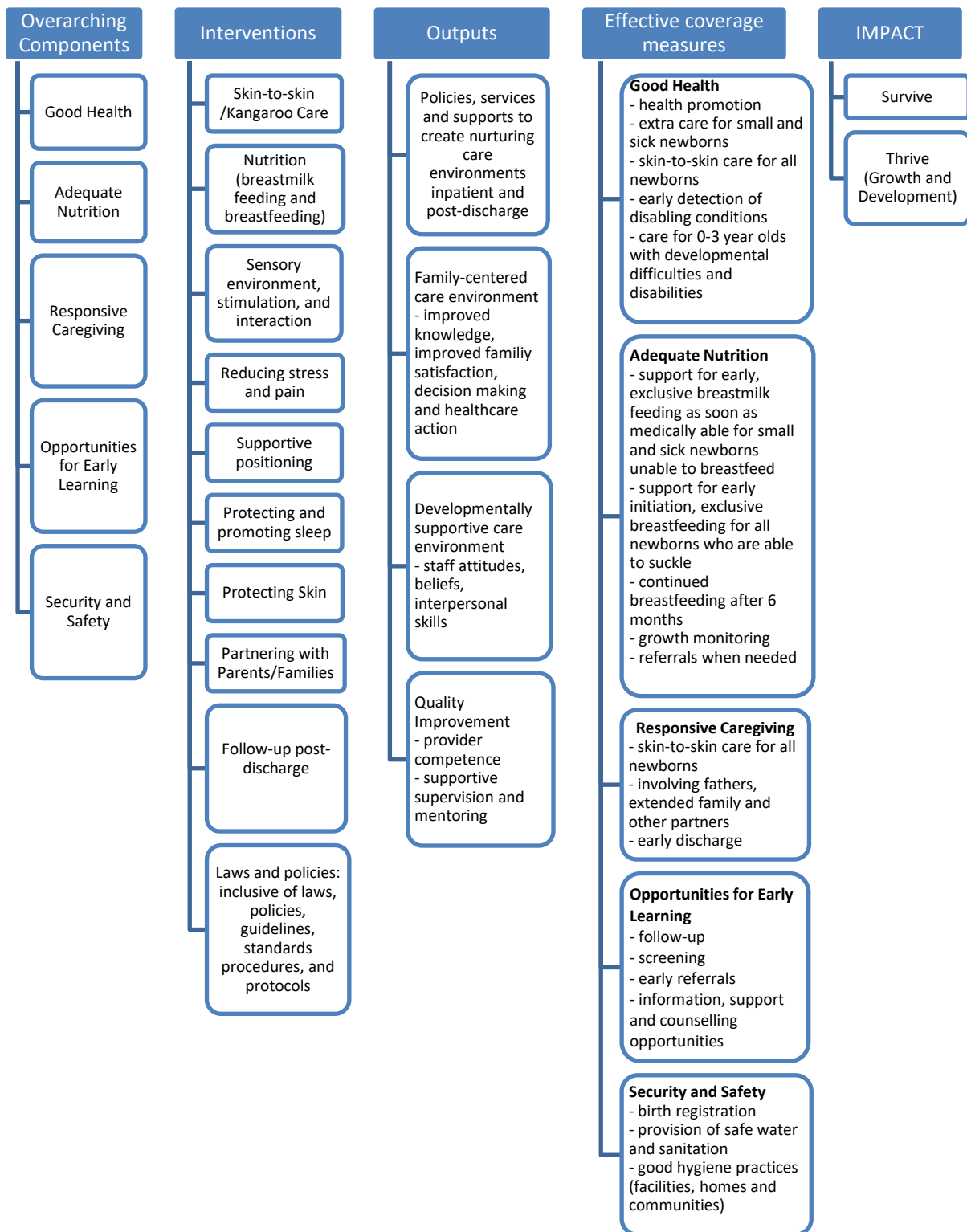
The peer-reviewed literature sought evidence from reviews on interventions of family-centered, developmentally supportive care for in-facility small and sick newborns and post-discharge care at the community level. The interventions for this evidence synthesis, were agreed upon by consensus of the steering group for this project. The findings from a grey literature search and case studies from high-, middle-, and low-income countries identified acts, guidelines, laws, policies, procedures, protocols, reports, and standards which support the concepts of nurturing care. Key organizational websites that develop or inform evidence-based guidelines (e.g., the American Academy of Pediatrics) were also searched.

### *Logic Model*

A logic model (Figure 1) was developed as a framework to conceptualize the evidence synthesis including the search strategy, interventions, outputs and effective coverage measures. The pillars of the logic model are not to be interpreted as individual, stand alone, as many of the interventions apply to several of the components of nurturing care and there is an inter-relatedness between the interventions. Additionally, the interventions are not ordered by importance but loosely aligned with the organization of the five components of nurturing care.

The logic model has the five components of nurturing care as the overarching framework, then the individual interventions directed at developmentally supportive care and a family-centered approach to care; potential outputs, and effective coverage measures. The effective coverage measures are proposed for each of the five components of nurturing care that may be used to operationalize the nurturing care framework logic model outlined in the Nurturing Care for early childhood development document (2, p33). Facilitators/enablers and barriers identified within reviews are included for consideration and grouped under service readiness, health worker readiness/competence, parent/family engagement and post-discharge care.

Figure 1: Logic Model for the Evidence Syntheses



**Facilitators and barriers:**

- Service Readiness
- Health worker readiness/competence
- Parent/Family Engagement
- Post-discharge care



## Methods

### *Review of Reviews*

To address the synthesis questions, a review of reviews was undertaken for this evidence synthesis of the core neurodevelopmental interventions to assist in timely mapping of the most current available evidence. No attempt was made to rank the interventions.

The search was guided by the question, “What is the most recent information available from reviews on interventions for developmentally supportive, family-centered, nurturing care for small and sick newborns”? Databases searched included CINAHL (EBSCOHost), Cochrane Library (CDSR), Pubmed, Scopus, Web of Science. PROSPERO – the International prospective register of systematic reviews was checked to ensure no published reviews were missed.

- Filters: Human, English language, ‘Systematic review’ or ‘review’ as database allows, 2010 – 2019
- Search Terms: “newborn\*”, “neonate\*”, “infant\*”, “developmental care”, “neuroprotective care”, “early childhood development”, “age-appropriate care”, “family-centered care”, “nurturing care”, “kangaroo care”, “skin-to-skin”, “parental interaction”, “massage” “pain”, “positioning”, “sleep development”, “sleep deprivation”, “skin care”, “sensory environment”, “stress”, “nutrition”, “human milk”, “malnutrition.”

Boolean operators OR, AND, NOT were applied.

### *Inclusion Criteria*

- Review (e.g., systematic, literature, narrative) in which methods are clearly articulated and more than one database searched
- Small and/or sick newborns (inclusive of the definitions in the glossary)
- Inpatient care for small and/or sick newborns
- Post-discharge care of small and/or sick newborns up until the age of three years related to developmentally supportive, family-centered, nurturing care
- Describing any intervention of developmentally supportive, family-centered, nurturing care as identified in interventions in Figure 1
- Describing any intervention of developmentally supportive, family-centered, nurturing care as identified in mediators in Figure 1
- Intended for health professionals or parents in high-, low-, or middle-income countries

### *Exclusion Criteria*

- Not related to small and/or sick newborns (inclusive of the definitions in the glossary)
- Not in the context of inpatient care
- Post-discharge care for small and/or sick who are now children older than three years of age
- Specific congenital anomaly care
- Describing any intervention of developmentally supportive, family-centered, nurturing care for children older than three years of age not born small and/or sick

- Biomedical neuroprotective interventions (e.g., hypothermia, pharmacological treatment)

### *Screening and Selection Process*

Reviews were initially screened for relevance by title and abstract and those potentially eligible, the references were downloaded into Zotero. Duplicates were removed and then the full text was obtained and attached to the respective record in Zotero. Reviews were then screened and those eligible were included in the annotated bibliography.

### *Annotated Bibliography and Synthesis of Results*

The annotated bibliography includes a brief descriptive and evaluative paragraph, outlining relevance, accuracy and quality of the sources cited including the following:

- Who did the study and who was studied?
- When was it done and over what time period?
- Where were the studies conducted – county/region/setting?
- Why was the work done and what issues were addressed including consideration of the usefulness and/or limitations?
- What were the results and conclusions?

The results are summarized by intervention in line with the logic model for the evidence synthesis. Under each intervention, key findings, usefulness and limitations of the evidence are summarized. The annotated bibliography identifies the intervention, the component(s) of the nurturing framework where it most relates, the source and the annotation.

### *Limitations*

Evidence for the specified developmental care interventions for this evidence synthesis was sought from reviews. For many of the interventions, reviews have been undertaken. For several interventions the evidence from reviews is limited and there may be a need to review additional sources when making recommendations for the nurturing care framework. Individual studies may need to be considered. The scope of the review was broad - from high- to low-income countries and involved a wide range of interventions. It is acknowledged that the interventions are complex and involve additional components which have not been covered in this evidence synthesis. For example, nutrition for small and sick newborns in high-income countries involves the use of parenteral nutrition while low-income countries may require other means of supplementation. Malnutrition is also a component not covered in this evidence synthesis.

### **Grey Literature**

The search strategies included searching targeted websites, Google search engines, and consultations with content experts specific to the countries included in the case study exercise. Key word search terms included: newborn, neonate, infant, preterm, early childhood development, nurturing care, developmental care, home care, guidelines, policies, standards of care. The combination of terms differed depending on the search function of

each website. The search function was used if the website had a basic or advanced search function, otherwise the webpages were hand searched.

### *Inclusion Criteria*

- Published by a government, nongovernmental organization (NGO), peak body, special interest group in the countries selected for country case studies
- Selected country (national) and/or state-based laws and policies (inclusive of standards, guidelines, protocols, reports) published within the last 10 years
- Most current version of the document
- Available in English
- Primarily pertains to small and/or sick newborns (inclusive of the definitions in the glossary)
- Inpatient care for small and/or sick newborns
- Post-discharge care of small and/or sick newborns up until the age of three years related to developmentally supportive, family-centered, nurturing care
- Describing any intervention of developmentally supportive, family-centered, nurturing care as identified in interventions in Figure 1
- Describing any intervention of developmentally supportive, family-centered, nurturing care as identified in facilitators and barriers in Figure 1

### *Exclusion Criteria*

- Unable to ascertain who published the document
- Document in draft or summary version or has been replaced with another document
- Not related to small and/or sick newborns (inclusive of the definitions in the glossary)
- Describing any intervention of developmentally supportive, family-centered, nurturing care for children older than 3 years of age not born small and/or sick
- Not in the context of in-patient care
- Post-discharge care for small and/or sick who are now children older than three years of age

### *Screening and Selection Process*

Websites (URL and title/source) screened were entered onto an excel spreadsheet. Documents located were initially screened by using the find function and searching for key words as outlined in the key word search terms. Those documents which featured key words were downloaded into a file labelled by country.

### *Annotated Bibliography and Synthesis of Results*

The annotated bibliography of country specific documents are in appendix II. The annotated bibliography identifies the document year and type, document title and source, annotation, and reviewer comments. Synthesis of results by country are included under the intervention of laws and policies.

Documents supplied by participants are included in the country case studies section.

## Limitations

The grey literature sources were limited to those countries involved in the country case studies. There may be a need to review other guidelines from other countries and also expert consensus where there is limited evidence from reviews.

## Results

### *Skin-to-Skin/Kangaroo Care*

The terms skin-to-skin, kangaroo care (KC), and kangaroo mother care (KMC) are used interchangeably within the literature. The WHO defines the components of KMC as (1) early, continuous, and prolonged skin-to-skin contact between the newborn and mother; (2) exclusive breastfeeding; (3) early discharge from a health facility, and (4) close follow-up at home.(8) In the context of this evidence synthesis KMC is regarded as a strategy comprised of several interventions; as such the individual components of KMC are reported individually under the interventions of skin-to-skin, nutrition (breastmilk feeding), follow-up, and screening. Additionally, the use of the term kangaroo care in this document implies skin-to-skin and/or the use of the kangaroo position for skin-to-skin contact.

*Summary of key findings:* Most research investigating outcomes of KMC have studied and reported only on the skin-to-skin component, making it difficult to assess the effects of the package of the intervention.(9,10) While the evidence for the package of KMC is limited, the evidence of the effectiveness of a number of the individual components is strong. The skin-to-skin and exclusive breastfeeding components confer benefit on mortality and a number of morbidities such as hypothermia and infection. (9,11) While there are added benefits for the mother-infant dyad in undertaking skin-to-skin immediately after birth (e.g., breastfeeding), skin-to-skin confers benefit to infants (e.g., thermoregulation, behavior regulation) when fathers and other non-maternal people provide skin-to-skin.(12,13) Fathers also report positive outcomes from being involved in skin-to-skin, which include feeling more in control, greater involvement in their infant's care, exhibiting more caring behaviors, decreased anxiety levels.(14) The benefits of skin-to-skin for preterm newborns of different gestational age and weight groups continue to be examined and confer benefit for breastfeeding rates, weight gain, physiological, and behavioral regulation.(15) Results for growth and breastfeeding outcomes previously reported for low birth weight infants are also seen in very low birth weight infants (<1500 grams) who receive skin-to-skin.(15) Several more recent reviews with a significant number of individual trials, conducted in multiple regions of the world, continue to highlight barriers to the implementation of skin-to-skin and the additional components of KMC.(16,17)

*Usefulness:* Studies have been undertaken in a variety of settings ranging from tertiary intensive care units to KMC wards and the evidence for skin-to-skin care is strong. Skin-to-skin has positive and protective effects, particularly in low birth weight newborns, including mortality reduction, prevention of sepsis, hypothermia and hypoglycemia, reduced hospital readmission, exclusive breastfeeding, and improved biophysiological parameters.(9,11) Involving fathers in skin-to-skin confers benefits for the whole family. Consideration to cultural and religious factors and clear communication regarding the benefits may enhance involvement of fathers early and for prolonged periods.(14)

*Limitations:* The timing and duration of skin-to-skin may or may not be reported in studies and when it is the contact time varies substantially from as little as 2 hours up to 21 hours per day. In studies involving fathers there were diverse methodologies used for the individual studies, different geographical and cultural settings. Half of the studies were conducted in Sweden, with significant positive paternal leave conditions and policies.(14) While several studies reported neurocognitive outcomes, different scales and endpoints have been used and thus summary data could not be reported(9) nor longer-term improvements in neurodevelopmental outcomes have been demonstrated. (11)

### *Nutrition (Breastmilk Feeding and Breastfeeding)*

In the context of this evidence synthesis the term nutrition is used in keeping with the terminology of the nurturing care framework. Nutrition refers to breast milk feeding and breastfeeding and supplementary feeding post-discharge.

*Summary of key findings:* Breastfeeding supports optimal nutrition, however, challenges to this for small infants include mother-infant separation, and motor and physiological immaturity.(18) Early exposure to breastmilk confers benefit to preterm infants. Evidence is emerging that human milk has a positive impact on preterm infants' neurodevelopmental outcomes not only in the shorter-term but in the longer-term right through to adulthood. Studies undertaken in South Asia, predominantly India and Bangladesh, but not specific to small and sick newborns, demonstrate that a multi-prong approach is needed both for interventions and across environments to improve breastfeeding practices.(18) These include education, counselling, community mobilization and mass media campaigns, delivered across multiple environments such as health, community and home/family.(18)

In regard to community-based supplementary feeding, there is limited evidence that energy and protein supplements to pregnant women may reduce the risk of small-for-gestational age infants.(19) In children under five years of age, supplementary feeding did not have an impact on growth, but a small impact was seen for children under two years of age. Critical aspects related to outcomes include the social environment at home, sanitation and access to clean water.(19)

*Usefulness:* Evidence suggests that exposing preterm infants to breastfeeds before 30 weeks enhances physiological stability when breast-fed from 27-28 weeks and achieves exclusive breastfeeding more quickly.(20) Consideration of the standards and criteria outlined in the *Baby-Friendly Hospital Initiative for Neonatal Wards* (Neo-BFHI) document may be useful to neonatal units caring for small and sick newborns in setting goals to assist in improving breastfeeding practices.(21)

Targeting education and mass media campaigns to the local context and involving the wider community can enhance breastfeeding practices.(18) Likewise, although not specific to the small and sick newborn post-discharge, providing educational messages about introducing semi-solid foods at appropriate age stages via leaflet, counselling, teaching sessions, and practical demonstrations improved the duration of exclusive breastfeeding, hygiene practices, and a reduction in the introduction of foods before 6-months of age by 12%.(22)

*Limitations:* The majority of studies investigating community-based supplementary feeding report on short term outcomes with longer-term outcomes such as quality of life and costs of supplementary feeding programs are under-reported.

### *Sensory Environment, Stimulation, and Interaction*

For small and sick newborns in hospital environments, sensory stimulation can be excessive because of environmental noise and light, and has been associated with poorer neurodevelopmental outcomes. (23,24) Moreover, it has been demonstrated that low-stimulation is also detrimental to the development of very preterm infants.(23) There is a need for positive sensory exposures (e.g., language exposure) for brain circuitry stimulation and that stimulation during social interaction time needs to be of adequate intensity, time, and regularity for brain development. Excessive and/or inappropriately timed stimulation should be avoided.

*Summary of key findings:* The sensory environment can provide both negative (20,24–26) and positive (23,27–29) sensory stimulation. The impact of interventions on neurodevelopmental long-term outcomes for preterm newborns is currently limited, as individual studies included in reviews show mixed results, with some demonstrating improved outcomes while others do not. There are significant differences in the sensory exposures, dosages, timing and outcome measures, making it difficult to combine studies and to determine appropriate sensory exposure. Additionally, many of the interventions are implemented over short periods of time and inconsistently and thus, if undertaken consistently over greater lengths of time, improvements may occur. (23) While the evidence is limited, there is some evidence on improved short-term outcomes such as improved sleep and physiological stability. Similarly providing appropriate light and noise to reduce infant stress, improve autonomic stability and sleep may have a positive impact on neurodevelopment. Cycled lighting is important for induction of circadian rhythm and it is thought that near darkness reflects the lighting conditions in utero (though not identical) until birth. Cycled lighting may promote sleep (see protecting and promoting sleep). While exposure to high levels of sound are known to be detrimental, so is exposure to low levels of language. However, what is not known is the optimal level of exposure for optimal neurodevelopmental outcomes. (23,24) A Cochrane systematic review published in 2015, looked at sound reduction management for preterm and low birth weight infants. (26) This review includes only one high-quality study meeting the inclusion criteria and the results showed a trend for better weight gain at 34 weeks gestation, a significant difference in mental developmental at 18-22 months corrected age (favoring the earplug group), but this was not seen for psychomotor development index. Of note, is that the included study was conducted over 16 years ago and due to technology improvements, increased knowledge and changes in practice, the intervention in this study (silicone earplugs verses no earplugs) may no longer show the same benefits.

Developmental care programs are numerous and contain many interventions or combinations of interventions, which makes comparisons and determining which intervention may be effective difficult. In the review by Burke(27) there was no developmental care program which performed significantly better than another. However, providing gentle touch and containment while interacting with infants are simple, cost-effective interventions that can be implemented to promote developmentally supportive care.(30)

Outcomes from music intervention are mixed with some studies reporting differences, while others report no differences in outcomes of physiological stability, behavioral states (e.g., sleep, distress, interaction, motor activity, etc.), pain scores, length of hospital stay, long term effects on feeding skills, language, and overall development at 5 to 75 months corrected age. (23,31) Of the 25 studies which reported on physiological and behavioral measures around a quarter showed positive effects on physiological parameters and sleep states. Two studies reported long-term outcomes which showed decreased readmission over the first-year post-discharge and improved overall development at five months. Positive outcomes for mothers included reduced anxiety and stress, improved breastmilk supply, and increased responsiveness and sensitivity. Few studies involved family-centered interventions.(31)

Positive touch including providing containment, light touch, or massage confer benefit. Containment and light touch confer additional benefits other than appropriate sensory stimulation, such as contributing to positive interactions between parents and their infants (eye contact, engaging vocally). Individual massage studies have reported improved physiologic measures, however, a meta-analysis could not be undertaken due to various units of measure.(29) Minor or no adverse events related to touch were reported by three studies. While meta-analysis could not be performed for maternal outcomes, positive outcomes were noted in two studies, including higher maternal self-efficacy scores.(27)

*Usefulness:* In the clinical context, the focus should be on interactions and activities that promote maternal/parent-infant contact and reduce stress for families while in hospital and post-discharge.(32) Age-appropriate positive sensory exposures based on current available evidence combined with expert clinical opinion can aid in guiding important early parent-infant interaction to optimize outcomes for both infants and parents. Pineda and colleagues (23) mapped sensory interventions to postmenstrual age, based on the available data and evidence from the included studies in the review, which is likely to be useful in making recommendations in operationalizing the nurturing care framework.

Cycled lighting appears safe and confers some short-term benefits (shorter length of stay) but may not promote physiological stability, and there is limited research on longer-term neurodevelopment following discharge. With cycled lighting, while no clear conclusion can be drawn, there are positive trends for better outcomes. The ability to cycle lighting in low resource settings may be challenging and will be dependent on resources such as window blinds, cot covers and ability to dim central lighting. Reducing noise appears to confer benefit in enhancing quiet sleep states and physiologically stability. Parent education and involvement are important but more so ensuring that parents understand the information and that they have the ability (resources/needs etc.) to provide the intervention. Early intervention, as simple and low cost as holding/touching, and parent involvement are important for positive neurodevelopmental outcomes. While massage confers benefit regarding growth, effect on short and long-term neurological outcomes has not been established.

*Limitations:* There is variability in the timing of when interventions commenced (inpatient vs. post-discharge), delivery of the intervention (clinic vs. home), who delivered the intervention, focus of the intervention (infant outcomes or parent-infant), inclusion criteria, dosage, and length of follow-up.(23,33) There are a limited number of studies reporting outcomes to school age and longer.(33)

## *Reducing Stress and Pain*

*Summary of key findings:* Assessment and management of pain is considered a developmental care intervention as exposure to repeated painful procedures in early life can lead to alteration in later pain perception, hyperactivity of the peripheral and central nervous system, alterations in optimal brain development and brain plasticity and impaired cognition, behavior and emotional regulation. There is some evidence that preterm infants who had painful procedures during inpatient care, display hypersensitivity to pain at school age and older and lower motor and intellectual developmental indices at 18 months related to painful procedures experienced as inpatients.(20)

Assessment and management of pain is still poorly undertaken with reports that pain management (pharmacological or non-pharmacological) is only undertaken about 50% of the time for painful procedures in neonatal units.(20) The non-verbal nature of infants and young children increase their vulnerability.

Non-pharmacological interventions such as skin-to-skin contact and sweet tasting solutions are the most effective interventions in reducing pain associated with minor painful procedures such as heel lancing and intramuscular injections. Skin-to-skin commenced 30 minutes prior to a heel lance or intramuscular injection is effective in reducing pain in preterm newborns.(34) Additionally touch/massage, non-nutritive sucking, environmental modification, swaddling/facilitated tucking, or a combination of facilitated tucking with non-nutritive sucking are effective in reducing immediate pain and distress in inpatient preterm newborns.(34)

There have been more than 74 studies involving the use of sucrose in preterm and term infants undergoing minor painful procedures. There is high quality evidence for the beneficial effect of 24% sucrose with non-nutritive sucking or given orally prior to heel lance, venipuncture, and intramuscular injections(35)

*Usefulness:* Skin-to-skin confers benefit over sweet solution in preterm newborns. Skin-to-skin undertaken with any provider confers benefit. Of 24 non-pharmacologic interventions reviewed, those conferring benefit in reducing pain immediately after a procedure (most common heel lance/stick) include touch/massage, non-nutritive sucking, environmental modification, swaddling/facilitated tucking. A combination of sucking with sucrose and facilitated tucking with non-nutritive sucking was effective for needle pain.(37) There are a number of clinical practice guidelines that could not be included in this evidence synthesis that could be drawn upon where there is a lack of reviews available. This includes the clinical practice guidelines from Taddio et al (2015) which includes strong recommendations for infants and children up to three years.

*Limitations:* The Cochrane systematic review on breastfeeding or breastmilk for procedural pain in neonates stated that there were no studies involving premature infants and the use of supplemental milk for reducing pain have been undertaken. This review was last updated in 2012 and therefore this statement may be outdated. (36) Variability in study designs and outcome measures means only a small number of the studies could be compared, or results combined.(34)



## *Supportive Positioning*

*Summary of key findings:* It is thought that newborn position can enhance neurodevelopment by promoting physiological stability and sleep, stimuli integration, and reducing stress thus enhancing brain development. Positioning and containment increase self-regulation behaviors in preterm infants.(30) Additionally, positioning interventions that promote stability and reduce stress may have an impact on the cortex development in preterm infants and should be encouraged. Positioning small and sick newborns in a prone position may confer some short-term respiratory benefits but prone positioning should only be undertaken where newborn respirations can be monitored. Additionally, parents require education that prone positioning should not be undertaken at home due to associated increased risk of sudden infant death syndrome.(30)

*Usefulness:* Positioning not only has short- and long-term benefits for development but also for cognitive function. Considerations for positioning need to include preventing positional deformities caused by stretching or shortening of ligaments, tendons or muscles and postural asymmetries, caused by poor positioning. Recommendations include using available materials/tools such as blanket rolls/positioning devices to position the preterm infant so that the neck is slightly flexed, the head and neck are well aligned with the rest of the body, the arms and legs flexed towards the midline, the posture is symmetrical and the spine slightly flexed.(20)

*Limitations:* Effects of positioning on short- or long-term neurodevelopmental outcomes are lacking.

## *Protecting and Promoting Sleep*

*Summary of key findings:* Clustering of care (e.g., diaper change, eye care, repositioning of monitoring device leads) is the only intervention that has been linked to protecting sleep.(38) Studies suggest theoretically that clustering of care provides longer uninterrupted sleep periods, reducing physiological stress, and allowing for the completion of sleep cycles that are beneficial for neurodevelopment. Cycled lighting, non-nutritive sucking, prone sleeping position, rocking, and sucrose are reported to promote sleep. However, caution is needed with the use of a number of these interventions and consideration given to the setting and resource context. Non-nutritive sucking (with use of a pacifier) is unlikely to be suitable for low-income countries. Prone sleeping position should only be undertaken when an inpatient and continuous monitoring is available as per Sudden Infant Death Syndrome recommendations. Sucrose has been shown to be effective for pain relief, but evidence of longer-term outcomes is unknown and the efficacy of sucrose to promote sleep in small and sick newborns is lacking, as are longer-term neurodevelopmental outcomes.(38)

*Usefulness:* Clustering of care and procedures is recommended to ensure complete sleep cycles and reduce stress-induced physiological instability. No recommendations given on the frequency or timing of the clustering of care.(20)

*Limitations:* Measurements for sleep were diverse between studies, with subjective and objective assessments or assessment methods not described.(38)

## *Protecting Skin*

*Summary of key findings:* Assessment of newborn skin should be undertaken regularly and is important to ensuring good skin care. Recognition of risk factors such as lower gestational age, lower birth weight, and the use of medical devices are the most common causes of neonatal skin injuries.(39) Being aware of risk factors assists in the prevention of, and early identification and treatment of skin injuries. The most recent Cochrane systematic review (28) which analyzed data by high- and middle-to-low income countries reports that the current evidence does not support the use of emollients for reducing invasive infection or mortality in preterm infants in inpatient settings in any country defined by high-, middle-, or low-income.

*Usefulness:* The evidence in the literature shows conflicting results in regard to the impact on skin barrier function and the acid mantle.(28) It is recognized that there are unique cultural and traditional skin care practices in low-resource settings and some evidence of the impact of topical emollients, predominantly oils on preterm infant skin.(40) Sunflower oil is high in linoleic acid and has been recommended for use on newborn skin. Conversely other vegetable oils, such as olive oil, are high in oleic acid and are not recommended for newborn skin.(41)

*Limitations:* Unknown effect of emollient use in community settings. Neurodevelopment and longer-term outcomes have not been assessed. Limited information on which emollients are the most effective.

### *Partnering with Parents/Families*

*Summary of key findings:* There are many models of care and many individual interventions within these models that aim to increase engagement between parents, healthcare professionals, and institutions. Key aspects of family-centered care (FCC) include communication, collaboration, respect, and flexible, culturally competent and responsive caregiving. Engaging parents early with good communication, education, participation in care giving and decision-making benefits short term outcomes for newborns such as breastfeeding, growth, readiness for discharge, distress, and stress; and for parents: reduced stress, increased confidence and positive parent-infant interactions.(20,42–44) Additionally, providing education and information to parents on environmental modulation, age-appropriate interaction activities, transition home preparation, and post-discharge support may confer positive longer-term benefits.

*Usefulness:* Segers et al(42) review focused on interventions for parents of neonates/infants and not neonates themselves; this review provides useful information regarding involving parents in care. Collaborating with parents, improved communication and involvement in decision-making results in improved outcomes for both parents and neonates. These interventions can be applied across all neonatal care units in all countries. One of the studies included in the review by Segers et al (42), conducted in Pakistan and in a pediatric unit, found that families were significantly more satisfied regarding involvement, decision making and communication (use of simple language by clinicians). These aspects are useful to the neonatal unit context.

*Limitations:* Engagement in family-centered care for positive outcomes requires several considerations: sufficient resources, adequate staff training, as well as support from hospital

managers and health policy makers. Long term follow-up and associated benefits are lacking in studies. Not all reviews specified the newborn population other than when newborns were those cared for in a neonatal unit. It is assumed newborns in a neonatal unit were small and/or sick newborns.

### *Follow-up Post-Discharge*

It is acknowledged that all infants deemed 'high-risk' due to medical and/or developmental problems should receive follow-up. The evidence from systematic reviews on how, when, and why are limited. However, guidelines exist and are tailored for the specific country, state, and/or local context. For this evidence synthesis following-up has been limited to reviews on aspects of neurodevelopmental care and associated areas such as hearing and vision. This evidence synthesis does not report on cardiac or surgical follow-up. Systematic reviews exist on the practice of cooling for hypoxic ischemic encephalopathy and the positive outcomes on neuroprotection, but these reviews do not provide recommendations for follow-up care.(45)

*Summary of key findings:* Follow-up care for preterm and sick newborns ("high-risk infants") is needed due to the risk of a broad spectrum of medical and developmental problems post-discharge. Most high-income countries have established clinics and/or intervention programs for high-risk infants and there is evidence that early intervention has a significant effect on cognitive outcomes and a small effect on motor outcomes assessed up to three years of age. (33) Evidence on outcomes for preterm infants visited at home is mixed and/or many studies do not report follow-up or outcomes are reported for short-term follow-up.(46) Additionally compliance with follow-up visits has been reported in respect to newborn hearing screening.(47) Recommendations to improve and/or maintain high levels of attendance at follow-up include having a stringent tracking system, good communication with parents and education/information for parents on importance of follow-up in relation to short and long-term implications on childhood development.

*Usefulness:* Early recognition, early intervention and follow-up interventions improve cognitive and motor outcomes up until three years of age. Guidelines, standards, and consensus statements provide direction for policy development and the European standards for newborn care provide indicator outputs for meeting standards.(48)

*Limitations:* Limited recommendations from reviews on the timing, number of visits, and minimal length of follow-up.

### *Laws and Policies*

The publicly available documents sourced from government and non-government websites for each of the countries involved in the country case studies are presented in Appendix II. A summary for each country is presented below.

*Colombia:* Several documents were able to be retrieved from a search of websites, a report on early childhood development, and an overview of a policy and strategy document (Zero to Forever). The overview was available in English; however, the full document and complimentary materials were only available in Spanish. Following contact with a content expert, a series of kangaroo care evidence-based clinical practice guidelines were obtained,

however, as these documents were in draft they were not eligible for inclusion in the evidence synthesis but are noted within the country case study.

**India:** The six documents initially located via internet searching, consist of reports, white papers, policy, action plan, and operational guidelines. Few of the documents specifically focus on sick and small newborns, although a report highlights the establishment of special newborn care units to provide care for sick newborns (*Care of small and sick newborns in special newborn care units (SNCUs) of India. Two-year report April 2013 – March 2015*). A number of additional documents appeared available but required login permission to access.

Following consultation with contact experts, additional documents were sourced. These include National and Operational guidelines produced by the National Health Mission, Ministry of Health and Family Welfare, Government of India. Operational guidelines are available for family participatory care (FPC) for improving newborn health (2017), and Home-based care for young child (see Annex II for details) and Strengthening of health and nutrition through home visits (2018). The latter document is directed towards all infants and children, with no additional care or follow-up outlined for those born small or sick. While the former document outlines involvement of state and district managers (policy makers and resource allocators), training for healthcare providers (including addressing attitudes), creating FPC environments, and information and education for parents to be involved in care. The schedule of home visits for small and sick newborns post-discharge from a special care baby unit, includes a visit within the first 24 hours of being home and then routine follow-up for all newborns/infants to 12 months of age.

**Nepal:** The eight documents, published between 2013 and 2018, consist of national health policies, national strategies, reports, implementation and action plans, clinical standards and a protocol. Most of the documents have been produced by the Government of Nepal or in partnership with external organizations such as UNICEF. The older documents made no direct reference to small and sick newborns, while the more recent documents discuss newborns and actions, including intensive care units for newborns, referral systems for newborns and early detection of developmental delays among high-risk newborns (*Country Programme Action Plan 2018-2022*). The most recent document from March 2018 was a report on the *Evaluation of the National Early Childhood Development Program 2004-2015* and reports that programs have been implemented for sick newborn care management and presents data for all newborns, not specifically for small and sick newborns. This document highlights that the National Newborn Care Package is currently being revised.

**Philippines:** Similar to other countries, the Philippines operationalized the Every Newborn Action Plan, and furthermore an Action plan for healthy newborn infants in the Western Pacific Region (2014-2020) was developed. National strategic frameworks 2017-2030, health objectives 2017-2022 and first 1,000 days law outline strategies and actions for health of infants, children and across the life course, however, none of these documents refer specifically to small and sick newborns. Additionally, a review produced by the WHO regional office for South-East Asia sets out components of the health system in the Philippines, and while maternal and newborn status is reported, there is no reference to small and sick newborns or nurturing care.

*Rwanda:* Six documents produced between 2011 and 2018 were retrieved from government and non-government websites. The majority of these documents focused on early childhood development, actions needed and/or the evaluation following implementation of early childhood development interventions. Another of the documents was the *Neonatology clinical treatment guidelines* produced to standardize neonatal care nationally. These guidelines included very specific guidance on who and how soon high-risk, preterm, and low-birth weight infants should be seen at follow-up and should be assessed. While there was reference to a national KMC guideline, this could not be sourced via a search of the internet and related government websites of the Rwanda Ministry of Health. However, an evaluation report of KMC services from 2012 outlined challenges to implementation and practice and the need for ongoing support and education in facilities. However, that report is now six years old and the current situation may have changed.

*Sweden:* No national or local laws and policies were identified by a search of key government and hospital websites. A content expert in Sweden advised that the *European Standards of Care for Newborn Health* (48) guides newborn care in Sweden. The standards have 11 broad topic areas with each topic area outlining the target group (e.g., preterm infants with risk factors), the user group, a statement of the standard, rationale, benefits, components, grading of the evidence, and an indicator for meeting the standard (e.g., patient information sheet, guideline, training documentation). The following standards are presented in arrangement with the interventions in the logic model, although some standards overlap and are grouped accordingly.

The standard, *very early and continuous skin-to-skin contact*, promotes the initiation of skin-to-skin contact between mother or father, as early and as continuously as possible. The many benefits of skin-to-skin are clearly documented along with rationales for why separation should be avoided and why skin-to-skin needs to be achieved. Additionally, the standard emphasizes the importance of ensuring that health workers are competent and skilled in facilitating skin-to-skin contact.

The *promotion of breastfeeding standard* advocates that in-patient newborns are exclusively fed breast milk and post-discharge mothers are supported to exclusively breastfeed. Components of the standard include providing information to parents/families and ensuring health workers undertake training to be able to guide and support successful breastfeeding practices.

Within the topic area *infant- & family-centered care*, numerous practice standards are presented: *supportive sensory environment* and *management of the acoustic environment* highlight the need to manage the hospital sensory environment to support a nurturing environment and thus reduce the negative impact on development. Short-term benefits include improved comfort and sleep and enhanced environment for infants, parents and health workers. Improved language development is seen as a long-term benefit. *Parental involvement* and *family support services* addresses parents as members of the caregiving team, partners in decision-making and that socioeconomic, mental health, and spiritual needs are supported. Short- and long-term benefits examples include: reduced length of hospital stay and stress for parents, increased breastfeeding rates and improved weight gain, increased satisfaction with communication and understanding and involvement in pain

management, reduced risk of maternal depression and improved long-term outcomes from skin-to-skin contact, improved child behavior, and long-term cognitive development.

The topic area care procedures address standards for: support during painful procedures and pain assessment, and taking blood samples; positioning support and comfort, protecting sleep, skin care of hospitalized infants and nappy/diaper change, and/or supporting the infant during hygiene procedures. The respective standard stresses the importance of: ensuring appropriate attention to assessment and treatment of pain and discomfort; providing individualized supportive positioning for brain, skeletal and muscular development; sleep for brain development and developmental outcomes with benefits such as improved growth, neuronal development, behavioral organization and temperature regulation; protecting skin integrity in reducing risk for nosocomial infections and preventing skin injury from mechanical forces of friction, pressure, shear and stripping are integral to maintaining skin integrity; and age-appropriate stimulation and interactions, in this instance in relation to providing personal care such as washing or bathing. The method and schedule for washing or bathing should be cue-based and individualized. Integral components of the standards include education for parents and training for staff and the use of assessment tools where applicable (e.g., pain/skin integrity).

The standards pertaining to the topic area, follow-up & continuing care covers assessment of visual function, cognitive development, communication, speech and language, coordination and integration of care after discharge home, hearing screening, meeting special needs at school, mental health, motor and neurological follow-up assessment, post-discharge responsive parenting programs and transition from hospital to home. These standards highlight that all high-risk infants need targeted structured follow-up and emphasize the care and treatment required post- hospital discharge. Long-term benefits to follow-up include early diagnosis promotes timely interventions, improved decision making for schooling, learning support and academic outcome, improved parent-infant interaction, improved social integration and quality of life, and reduced social burden and costs.

*United States of America:* A search of the individual websites of the hospitals and schools of medicine participating in the country case studies, did not reveal any documents fitting the criteria for this evidence synthesis. The following table of documents are those produced by national professional associations in the United States that may potentially guide practice documents. The largest number of guidelines and policy statement documents located have been produced for or by the American Academy of Pediatrics. *The American Academy of Pediatrics Guidelines for Perinatal Care* (49) provides guidance on specific requirements of follow-up care for high-risk newborns which include monitoring of growth, development, nutrition requirements; early detection of delayed developmental progress and early intervention, parent education and referral to community resources. Additionally, the American Academy of Pediatrics produces policy statements and clinical reports, published in addition to the perinatal guidelines. These are summarized in Appendix II.

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) and the National Association of Neonatal Nurses (NANN) websites advertise a number of evidence-based guidelines, however, these are available in full to members only or for purchase and therefore have not been annotated in this evidence synthesis. The Neonatal Skin Care evidence-based clinical practice guideline(50) produced by AWHONN provides

recommendations and rationale for 13 topic areas such as skin assessment, bathing, umbilical care, and parent education. Recommendations based on the best available evidence present considerations for preterm infants and newborns in low-resource settings born in health facilities or community settings. The guideline includes skin assessment tools that would be relevant to health workers in all settings.

### *Facilitators and Barriers*

A number of reviews have been undertaken pertaining to facilitators and barriers to the implementation of a specific intervention (e.g., kangaroo care), while other reviews explored facilitators and barriers within the discussion section of the reviews. The facilitators and barriers have been grouped around service readiness, health worker readiness/competence, parent/family engagement and post-discharge care and may potentially influence enabling environments for nurturing care. This is not an exhaustive list of facilitators and barriers. Consideration of facilitators and barriers is integral in developing strategic actions and practical strategies to address issues such as resourcing, sociocultural practices and experiential issues in operationalizing the nurturing care framework. Solutions may be simple such as providing training and information for families and staff to improve awareness; to more complex solutions to address workforce issues (staff shortages/workload).

Facilitators (10,14,16,17,51)

#### *Parent/family engagement*

- Being encouraged to be involved in care activities while newborn was an inpatient
- Having family help, support and encouragement with doing skin-skin and household responsibilities.

Barriers (10,14,16,17,51)

#### *Service readiness*

- During a two-year period from 2015 to 2017 there were an additional 16 papers published around the area of skin-to-skin/KC implementation, with the barriers identified in the 2017 review(16) very similar to those identified in the earlier review by Seidman and colleagues.(17)
  - The environment can act as a barrier, such as crowdedness, noisiness, lack of privacy, uncomfortable beds, and a lack of food and supplies.
  - Lack of facility policies
  - Inadequate and under-resources health systems, human resources and the environment

#### *Health worker readiness/competence*

- Health workers' attitude – unsupportive, loud, uncaring, negative impressions and interactions
- Lack of explanation on the benefits and assistance or instruction from health workers
- Lack of time for health workers to assist or provide education

#### *Parent/family engagement*

- Postpartum pain preventing skin-to-skin

- Limited buy-in from parents and families
- Lack of awareness among parents, families and communities
- Beliefs around handling/touching umbilical cord and other traditional newborn practices
- Financial barriers for mothers/parents to visit while their newborn is still an inpatient
- Sociocultural issues around having a preterm newborn
- Stigma associated with having a preterm newborn
- Breastfeeding and breastmilk feeding - uncomfortableness with baby and physically in doing skin-to-skin, responsibility for household chores and lack of motivation
- Cultural norms and expectations of roles of fathers
- Fathers attitudes on the parenting role

#### *Post-discharge care*

- Perceived cost costing/reduced hospital bills due to early discharge
- Perceived lack of support from the parent's families and communities
- Financial barrier of returning to the hospital for follow-up



## Evidence Synthesis Summary

- In the clinical context, the focus should be on interactions and activities that promote maternal/parent-infant contact and reduce stress for families while in hospital and post-discharge. (23,32)
- Age-appropriate positive sensory exposures based on current available evidence combined with expert clinical opinion can aid in guiding important early parent-infant interaction to optimize outcomes for both infants and parents.(23)
- Regarding developmental care interventions there is variability in the timing of when interventions commenced (inpatient vs. post-discharge), delivery of the intervention (clinic vs. home), who delivered the intervention, focus of the intervention (infant outcomes or parent-infant), inclusion criteria, dosage, and length of follow-up.(33, 67) This has limited studies being able to be combine, in particular for sensory exposures. A guideline outlining the type, dose, timing, and frequency needs to be established based on current evidence and expert clinical opinion.
- The majority of the individual studies included in the reviews have been conducted in high- or middle-income countries, with a small number in low-income countries. Most outcomes are reported on inpatient populations, with limited post-discharge reported outcomes, with the majority of studies reporting on short- (immediate to three months) to intermediate- (up to two years) term neurodevelopmental outcomes.
- The number and types of documents sourced via a search of country specific government and non-government websites varied. These results do not reflect that documents do not exist, just that they are not available publicly. The earlier documents from low-and-middle income countries tended to focus on newborn care generally, while the later documents have a greater focus on small and sick newborns and early childhood development.
- Reported barriers to the implementation and ongoing delivery of interventions remain constant and are related to resourcing (infrastructure and human), sociocultural practices, lack of training of health workers and a lack of information for families. Ongoing training of health workers and improved information for families is needed. (10, 14, 16, 51)

## Country Case Study: Nepal

### *After boosting newborn survival, healthcare leaders move towards nurturing care*

Nepal has seen a vast improvement in the newborn mortality rate in the recent past. In 2011, there were 33 deaths per 1,000 live births; by 2016, the country reduced this number to 21 deaths per 1,000 live births.<sup>(52)</sup> While participants acknowledged that the survival rates had improved due to the rapid advances in technology, some reported concern about the unknown long-term outcomes of at-risk newborns who have been discharged from their facilities. This uneasiness has led to a growing awareness that more can be done to support small and sick newborn well-being during hospitalization and post-discharge.

Participants reported that a dearth of robust follow-up care after discharge was a missed opportunity to help small and sick newborns thrive. Continuing care post-discharge will enable clinicians to screen at-risk newborns for potential disability while garnering relevant data that can be employed for continuous quality improvement. This growing awareness is reflected in the *Country Programme Action Plan 2018-2022*, where UNICEF and the Government of Nepal prioritize the early identification, referral, and care collaboration for newborns at risk of disability and developmental delays.<sup>(53)</sup>

While the *Nepal Every Newborn Action Plan* (NENAP) provides guidance on some specific elements of nurturing care (such as KMC for small newborns, early exclusive breastfeeding, and skin-to-skin after birth), more comprehensive recommendations for other elements of nurturing care (e.g., partnering with parents, enabling sensory environment, reducing stress and pain, protecting and promoting sleep, protecting skin, post-discharge care) would improve future policies and action.

### *Methodology*

Nine high-level senior clinicians, academics, and government public health officials from five different organizations in Nepal were interviewed. Each participant was asked a standard set of questions with additional follow-up questions when clarification was needed. All answers were transcribed into English and analyzed for themes.

Among the respondents were eight clinicians from tertiary care facilities included KIST Medical College, Tribhuvan University Teaching Hospital, Maternity Hospital, and Kanti

#### Country Demographics: Nepal

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 21 Total: 11,842
Infant Deaths <sup>1</sup>	Per 1,000 live births: 28 Total: 15,808
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 34 Total: 19,189
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	5.3%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	18%

<sup>1</sup> UNICEF. 2019. Country Profiles. Retrieved June 20, 2019 from: <https://data.unicef.org/country/npl>

<sup>2</sup> Chawanpaiboon S, Vogel JP, Moller AB, et al. Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. *Lancet Glob Health*. 2018;7(1):e37–e46.

<sup>3</sup> The World Bank. 2011. Data: Low -birthweight babies (% of births). Retrieved June 19, 2019 from: <https://data.worldbank.org/indicator/SH.STA.BRTW.ZS>

Children’s Hospital. A public health official from the Ministry of Health and Population also participated.

### *Facilitators and Barriers of Nurturing Care*

Below is a brief discussion of the facilitators and barriers for nurturing care arranged by each intervention in the logic model (see page 16).

#### *Laws and Policies*

Published in 2016, the *Nepal Every Newborn Action Plan* (NENAP) has been the guiding policy document for newborn care for the past three years. The inpatient care of small and sick newborns is an essential part of the NENAP.

Training packages were developed to meet NENAP objectives. The training materials emphasize some of the features of nurturing care including skin-to-skin, early and exclusive breastfeeding, and KMC. However, the other interventions that comprise developmentally supportive care are not included in this educational content.

“Our policies have been driven by numbers of deaths and causes of death. Nepal has made some progress and more babies are surviving. However, we do not know if the babies that avoided death are thriving.”

—*Practicing Policy Advisor*

The *Nepal Health Sector Strategy implementation Plan 2016-2021* articulates plans to establish more intensive newborn care and special newborn care units throughout the health system, as well as to create a transport and referral system for high-risk deliveries.(54) Currently, there is a policy supporting the provision of free inpatient and follow-up care. (55)

Participants said that medical and nursing schools do not include information about developmentally supportive care for small and sick newborns. Also, they cited a lack of continuing educational opportunities for clinicians to expand their understanding and skills in providing nurturing care. In one facility, expatriate nurses from the United States provided supportive on-the-job mentoring on elements of nurturing care. The participants were unable to recall any Nepali professional associations that championed the best practices although one participant stated that advocacy from these institutions had the potential to influence policy.

Several participants pointed out that the current policies do not provide any directions for developmental follow-up care so that providers can understand how at-risk newborns were doing post-discharge.

Despite these challenges, some participants reported that they were making efforts to provide nurturing care to the best of their knowledge despite the lack of national policies, training, or formal education.

#### *A note on temperature regulation*

The temperature in the intensive newborn care units is mostly maintained through a central air-conditioning system. For preterm and low birth weight newborns, radiant warmers and incubators are available until they can regulate their temperature. Small and sick newborns are placed in incubators where humidity can be controlled and monitored. Also, skin-to-skin care is promoted in intensive newborn care and special newborn care units.

#### *Skin-to-Skin and Kangaroo Care*

The NENAP includes KMC as an intervention and participants well understood its benefits. There may, however, be a limited understanding of all four components of KMC, as defined by the WHO. Participants often used the phrase KMC to refer to a standalone skin-to-skin practice (without the other elements that comprise KMC).

There is a heightened awareness of KMC as an effective package of interventions. Participants reported that their nurses made efforts to initiate a minimal level of skin-to-skin for preterm and LBW newborns while admitted in the intensive newborn care and special

newborn care units. Most in-service neonatal training materials include KMC as a nursing competency. Additionally, intermittent skin-to-skin is regularly encouraged when the mother comes to breastfeed or express breast milk in the intensive newborn care unit.

Nepal, at present, lacks national guidelines and plans for KMC. However, the NENAP includes plans for expansion of specific policy guidance as well as the development of KMC corners in tertiary facilities.(56) Dedicated KMC areas are limited due to a current lack of space.

#### *Partnering with Parents and Families*

There is a shortage of policy guidance around family visitation, family-centered care, or other components of partnering with families. Therefore, each facility has a different policy for visitation and its own practices integrating families into care.

For example, the visitation policies appear to vary by unit. Mothers consistently received the most access to their newborns to promote breast milk production. This practice was bolstered by the breastfeeding guidelines outlined in the *National Neonatal Clinical Protocol* which recommends allowing mothers to room in with their newborns 24 hours a day.(57) Fathers and other relatives' admittance was often more restricted.

The facilities offer lodging, toilets, and bathing facilities to mothers. Some facilities also offer benches and chairs for other family members. A few facilities allowed families to rent comfortable cabins in the hospital. To promote family engagement, mothers are admitted or re-admitted with their newborn and provided free stay and food. This practice limits mother/baby separation and promotes breastmilk feeding.

In one of the facility's intensive newborn care units, mothers were encouraged to breastfeed, tube feed, cup-feed, or paladai-feed their newborns. Mothers are also involved in diaper changes and nesting activities. However, the limited space in the intensive newborn care unit posed a challenge to engaging all mothers in the care of their newborns. In the special newborn care units, mothers provided the majority of the care for their newborn.

### *Nutrition (Breastmilk Feeding and Breastfeeding)*

Breast milk production is highly prioritized and encouraged throughout the facilities. Clinicians regularly counsel mothers on the importance of breastmilk feeding for their small and sick newborns. The activities described by the participants appear to be in harmony with the practices described in the *National Neonatal Clinical Protocol*.(57)

Mothers are granted unlimited access to their newborns. One participant stated that it was common for mothers to be asked to visit the facility every two hours or so to either breastfeed or express breast milk. In at least two of the facilities, there are separate areas near the intensive newborn care unit that are dedicated to lactation and feeding.

One facility reported that breast pumps are not allowed. Instead, large syringes are used to create negative pressure. There is no milk bank or refrigerator but expressed breast milk is allowed to be served at room temperature for up to six hours.

A cadre of formally qualified lactation consultants does not exist in Nepal, and therefore this role is undertaken by the nurses. When newborns are too small and sick to breastfeed, nurses allow newborns to practice non-nutritive sucking on their mother's breast. This helps mothers recognize and stimulate their newborns' sucking reflexes. In one facility, mothers are taught to stimulate sucking using gentle massage around and inside the mouth using their fingers.

Newborns are fed formula when mothers are unavailable or unable to provide breastmilk. A special preterm formula is offered where it is appropriate and available.

### *Sensory Environment, Stimulation, and Interaction*

National policies and training materials do not articulate the need for neuroprotective, developmentally supportive care regarding light, noise, and touch during interactions. Individual facilities, however, are making some efforts to increase mindfulness of newborn's sensory needs. Most participants noted that providers within the facility need to make changes in their behaviors to improve the sensory environment.

### *A Story of KMC at a Nepali facility*

"Our facility has a fully functioning KMC unit. Mothers are encouraged to practice continuous skin-to-skin and exclusive breastfeeding. Our experience is, over time, the length of skin-to-skin period increases.

Skin-to-skin begins from birth - with babies kept skin-to-skin for two hours. Intermittent skin-to-skin is practiced while in the intensive newborn care and coupled with counseling. Parents hence feel comfortable by the time they are shifted to the KMC unit and fully accept the intervention. Privacy has not been much of an issue in Nepali culture where families live together. Weight gain has been a great incentive and motivator for KMC.

Unfortunately, there is no dedicated staff. We have tried to overcome this by creating model mothers, who support their peers. Fathers and caregivers are allowed to come and help as well.

There is a checklist for KMC. Educational materials are displayed on the walls. We would have liked more staff to continue support for KMC. This has been a challenge. "

--Clinician

Participants noted a growing awareness of ensuring conducive noise and light environments for newborns in the intensive newborn care and special newborn care units. Implementing changes to reduce noise and provide cycled lighting proved to be more difficult. While there are some champions of these practices, the participants reported that behavior change has been difficult.

### *Supportive Positioning*

While there are no particular protocols or policies related to positioning, individual facilities have started to understand its usefulness. Locally available materials have been used to create nesting support. Nurses have noted newborns are more relaxed and sleep better due to the containment. In one facility, the nursing staff have learned a special type of positioning when the baby is irritable or crying. They have taught receptive mothers how to use positioning when they visit the unit.

### *Reducing Stress and Pain*

Stress and pain management is a new area of care in facilities. The limited number of nurses on each shift made it challenging to encourage evidence-based non-pharmacological pain-management practices before painful procedures.(58) Participants reported that they did not provide sucrose deliberately due to concerns about infection. In addition, participants reported that skin-to-skin or breastfeeding during routine procedures was not practiced, citing a lack of confidence among both parents and providers. There was also some concern of parents becoming aggressive if they did not understand the rationale behind a particular procedure.

In one of the facilities, a resident introduced the practice of providing two milliliters of mothers' milk before procedures. A study led by the resident doctor in the facility demonstrated that newborns were less stressed after introducing the breastmilk.

### *Protecting and Promoting Sleep*

The concept of protecting and safeguarding sleep is not well-ingrained among clinicians. Care protocols in the facility take precedence, though nurses were mindful of not disturbing newborns that are sleeping. Positioning and containment are believed to help promote sleep. Changing clinician behavior to prioritize sleep will require modifications to clinical and care protocols, including the hours of labs and medical rounds. The morning hours were particularly disruptive to the rest of newborns.

### *Protecting Skin*

There are increasing efforts to reduce any unnecessary injuries and to protect the skin of newborns. Previously, adhesive tapes, radiant warmer, electrocardiogram probes, intubation, nasal prongs, and sometimes adult probes were used, causing unintentional injury. Clinicians are trying to avoid these injuries by decreasing the number of probes on very preterm newborns and supporting nasal prongs with foam. Some facilities have had success using improved adhesive tapes (i.e., Tegaderm and Duoderm). These efforts and consciousness have helped facilities reduce both skin breakdown and suffering among newborns.

### *Follow-up Post-Discharge*

Participants reported that post-discharge follow-up care is a nascent area where there are missed opportunities to help Nepali newborns thrive. All participants recognized that small and sick newborns were at higher risk for physical, cognitive, and developmental delays or disabilities and understood that early identification or treatment, was critical.

Currently, there are no established guidelines, policies, or protocols regarding what type of post-discharge care would be most beneficial for small and sick newborns. However, *the Nepal Health Sector Strategy implementation plan 2016-2021* does recognize the need to create more thorough referral networks between newborn and child health.(55)

“There is a lot of attention to saving lives with technology - without much thought given to outcomes. Saving smaller and smaller babies are at times shown off as medals of achievements. But before we try to save the smallest and sickest heroically, we need to know how these babies are surviving: their disabilities and the parents' suffering.”

--- *Senior Clinician and Academic*

The follow-up check-ups were similar to other pediatric check-ups for typically developing children with a few exceptions. In the outpatient clinic, clinicians take anthropometric measurements and assess developmental milestones. In some cases, at-risk newborns are referred for vision or hearing tests. Other newborns with low or high muscle tone are linked to physical therapy. The early identification and treatment of disabilities has been identified as one of the government's priorities in the next several years.(55)

Follow-up is free for all newborns discharged after in-patient admissions. (55) This policy provides a facilitative environment for parents to come back to the facility if they note any issues after discharge. However, there are no social or community structures that support parents of newborns that have developmental delays. There are individual organizations that take care of children with autism or cerebral palsy. However, these services are limited and not available for all. Currently, there are no follow-up incentives, or linkages with community health workers for home visits after discharge.

## Country Case Study: Rwanda

*While implementing essential newborn care, clinicians incorporate some nurturing care practices*

Rwanda has achieved a remarkable reduction in low birth weight and preterm mortality in the past several decades.(59) With a preterm birth rate that is lower than some other high-income countries, Rwanda also touts impressive statistics on early and exclusive breastfeeding.(60) Rwanda has prioritized the creation of specialized care units for small and sick newborns, including at the district level. Despite its considerable achievements and government commitment to improving the outcomes of newborns, the majority of respondents agreed that there was a long way to go to operationalize essential newborn care practices throughout the health system. Needless to say, the softer elements of neuroprotective care in hospitals often takes a backseat to the more practical and immediate business of saving lives.

One of Rwanda’s greatest strengths is its community-based health insurance scheme (called Mutuelle de Santé) which covers the majority of newborn care costs. One participant estimated that 85-90% of the newborns in the country are covered by this compulsory insurance scheme, but the overall population coverage is likely to hover around 75%.(61) The introduction of this policy in 2008 has increased care-seeking, improved healthy behaviors, and bolstered the overall quality of the healthcare system.(62)

Recruiting and retaining a cadre of specialized neonatal providers and nurses remains a challenge as in other low- and middle-income countries.(62) For example, one participant reported that there were only two neonatologists working in the entire country. However, the improvements in quality of care are also due in part to the cultivation of new skills by the clinical staff. In addition, the introduction of quality improvement processes and mentorship programs in hospitals have helped staff innovate. As one respondent said, “facility staff members are looking at their own gaps and developing solutions.”

### Methodology

For this case study, the research team spoke with a senior-level Ministry of Health official, a hospital executive, a senior level technical specialist, a high-level administrator from UNICEF

#### Country Demographics: Rwanda

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 16.4 Total: 6,104
Infant Deaths <sup>1</sup>	Per 1,000 live births: 28.9 Total: 10,677
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 37.9 Total: 13,987
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	12%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	7%

<sup>1</sup> UNICEF. Country profiles Sweden [Internet]. New York: UNICEF; 2019 [cited 2019 June 20]. Available from: <https://data.unicef.org/country/rwa/>

<sup>2</sup> March of Dimes. Born too soon the global action plan on preterm birth. Arlington (VA): March of Dimes; 2010 [cited 2019 June 19]. Available from: <https://www.marchofdimes.org/mission/global-preterm.aspx#tabs-3>

<sup>3</sup> The World Bank. Data: Low -birthweight babies (% of births)[Internet].Washington: World Bank; 2011 [cited 2019 June 19]. Available from: <https://data.worldbank.org/indicator/SH.STA.BRTW.ZS>



Rwanda, and a representative from the Rwanda Pediatric Association. These conversations were conducted in English, transcribed, and then analyzed for overlapping themes. The results of these conversations are summarized below.

### *Facilitators and Barriers of Nurturing Care*

Described below are the facilitators and barriers for nurturing care. These factors have been arranged by the intervention in the logic model (see page 16).

### *Laws and Policies*

Rwanda has had several relevant policies to guide the country's efforts in newborn and maternal health. The policy most referenced by the respondents was the *National Neonatal Care Protocol*, which is the primary guiding document followed by the *Essential Newborn Care Reference Manual*.<sup>(63)</sup> Currently, the *National Neonatal Care Protocol* is under revision with a national neonatal working group and the new edition is expected to be published soon. Another forthcoming document is the *Reproductive, maternal, newborn, child and adolescent health policy*. Both policies are expected to emphasize KMC along with other lifesaving interventions. Having said that, the majority of specialized protocols are yet to be developed due to a lack of time, local evidence, and money. As one participant suggested: "Establishing those specialized protocols will require the support from different partners and especially some experts from other countries." One respondent said that, in their facility, the international WHO recommendations on newborn health and Essential Newborn Care guidelines were closely followed.

The Rwanda Pediatric Association and the Rwanda Midwife Association are both influential organizations. The Rwanda Pediatric Association has been heavily involved with the revision of the National Neonatal Care Protocol and engaged in the care at district hospitals. The Rwanda Midwife Association has also been involved in promoting developmental care.

The respondents agreed that there was no consistent clinician training on neuroprotective developmentally supportive care. In some hospitals, mentorship by pediatricians has helped other health care workers to expand their skills in providing nurturing support. Training on the job on these elements often occurs from visiting lecturers or by video conference. These learning opportunities are supported by the Ministry of Health.

### *Skin-to-Skin and Kangaroo Care*

Participants used the terms skin-to-skin and KMC interchangeably and noted that KMC begins from the time of birth and continues throughout hospitalization. KMC (intermittent and continuous) practices are widely accepted as a norm for small babies in Rwanda. KMC guidelines are integrated into both the *Essential Newborn Care Reference Manual* and the *National Neonatal Care Protocol*.

#### *A Note on Temperature Regulation*

Across those interviewed, the following practices are used to maintain thermoregulation of small and sick babies in the facilities: KMC (intermittent and continuous), incubators, radiant warmers, and sometimes plastic bags. In some of the highest level hospitals, skin temperature probes were used to monitor the newborn's temperature continuously. The participants reported using various methods for maintaining humidity, including using plastic wrapping, using humidified water and oxygen blenders, and closing windows.

When neonatal units were established throughout Rwanda, they included KMC units. In Rwanda, newborn units are available at the district level and higher (i.e., district hospitals, provincial hospitals, and referral hospitals), and it is at these levels where inpatient KMC units are found. According to a Ministry of Health (MOH) representative, 35 district hospitals and 10 provincials and referral hospitals have a KMC unit. "Findings from newborn audits allow to emphasize on the importance of KMC unit," added the MOH participant.

"KMC starts from the hospital, and we encourage mothers to continue at home," said one participant. Other participants reported that KMC benefited the facility because it required less nursing staff and decreased overcrowding. Also, it was noted that skin-to-skin reduced the rate of infections and promoted early discharge.

Though KMC is seen as part of the standard of care for the intensive care level, most facilities do not have rooming-in for mothers or caregivers available, which makes continuous KMC very difficult to implement. In the intensive care unit, KMC is performed next to the radiant warmer or incubator in a chair or sofa. Rooming-in is often available once the baby is discharged to the step down or KMC units.

Another challenge for KMC was a lack of ownership by some facility health providers. Many did not feel comfortable encouraging mothers of more unstable newborns to practice KMC. Some providers may feel uncomfortable with mothers practicing prolonged KMC with children on continuous positive airway pressure (CPAP) or other types of equipment. Also, a shortage of health care providers meant that staff often do not have enough time for counseling, monitoring, and support for mothers. Not all mothers can regularly practice skin-to-skin due to their own health issues, transportation barriers, or competing priorities. KMC is also meant to happen at the community level upon discharge, though the participants note that the actual implementation of this was weak.

A need for an earlier start to skin-to-skin was identified by one of the participants. "Even after the baby is born and referred to district hospital the midwives tend to focus on delivery process and mother and less on what baby needs, including KMC," said one participant. They went on to add that "91% of deliveries in the country happen at health centers, so babies needing KMC are referred to district hospitals. 60% of babies are hypothermic by the time they get to the hospital, as they are not in KMC." The participant added that the situation is improving as the facility began collecting and analyzing monitoring data that unveiled the gaps in care.

Despite the myriad of barriers to the adoption of KMC, there continue to be champions within the country that promote the practice. One of the influential groups to support KMC in country, the neonatal sub technical working group, continues to engage stakeholders as key sources of technical advice and coordination. Good collaboration between MOH partners has also promoted the widespread adoption of skin-to-skin. There was also a creation of a pilot site at Muhima Hospital that has helped facilitate the scale-up of KMC. Lastly, the ongoing training of health care providers and good follow-up of discharged babies continues to support the practice.

#### *Partnering with Parents and Families*

“Although family-centered care is part of the *National Neonatal Care Protocol*, this has really not been implemented in practice yet,” said one participant, noting that the practice was “still in stages of planning and designing.”

In all facilities, parents can visit their newborns at any time of day and night. Paternal involvement was uncommon, however. There are some restrictions on other family members and caregivers being allowed in the facilities.

Most participants expressed that parents were able to participate in care more fully when the newborn is moved to the special care or KMC unit. In these units, there is more space and beds for rooming-in which helps parents feel more comfortable to take on care of the newborn. In rare cases, mothers may be allowed to room-in next to their children in the intensive care unit. But, one participant noted that they “have to petition insurance in order to get it covered for mom's bed”.

Nurses educate parents and encourage them to participate in basic caregiving activities such as diaper changes, feeding (gavage, breast, or bottle), and sponge baths. Parents are not involved in other clinical procedures or providing medicines.

While the accommodations for parents varied from facility to facility, the participants agreed that most were inadequate. Mothers often had to find their own source of food, water, and bathing. One participant expressed that lack of clean water for mothers can negatively impact lactation, as many mothers may be dehydrated.

#### *Maternal Responses to KMC*

Participants reported that mothers were eager to provide intermittent KMC for their babies. Mothers become more enthusiastic as they are better educated on KMC and feel more comfortable providing care to their baby. Often this change coincides with the time the newborn is moved to the step down or KMC unit.

In the intensive care unit, the mothers of sick children are more hesitant to have confidence to provide KMC. There is also limited space and privacy as the intensive care is an open space. This may also influence not having as many fathers participate since the parents need to undress partially. Therefore, convincing other parents and relatives to participate in KMC is a challenge.

In the highest referral hospital in the country, a senior clinician reported that skin to skin was provided by 80-90% of mothers and at an average of four hours a day. Fathers are allowed to participate in KMC but the practice was rarer. The duration of KMC often increases in a KMC or step-down, depending on the mother's availability.

“NICU space is generally limited, and often while the baby is in the newborn care unit, parents spend time waiting in a waiting room or the KMC area. As an exception, in one neonatal unit in a District Hospital in the western side of country, the unit has a bed inside the neonatal unit, but this is rare. This hospital with beds for parents in the neonatal unit has a pediatrician who promoted the practice and they also had the luxury of some space available to make it happen.”

-- Senior Administrator

The participants reported that engaging parents can sometimes be challenging. In some instances, a newborn will need to stay an extra day in intensive care unit before moving to the special care unit because the mother is deemed not involved enough. It can be difficult for single mothers and working parents to spend significant time in the facility.

#### *Nutrition (Breastmilk Feeding and Breastfeeding)*

Specific policies around feeding small and sick babies are integrated into *the National Neonatal Care Protocol*, as well as the *Essential Newborn Care Reference Manual*. In addition, each facility generally has its own policy around feeding.

The criteria for initiating breast milk feeding for small and sick newborns vary from facility to facility. However, they share two common themes: 1) early breastfeeding initiation and 2) an emphasis on exclusive breastfeeding. Some hospitals have protocols that outline that no formula should be given unless a mother is unable to provide breastmilk.

Nurses use nasogastric tube feeding and cup feeding when newborns cannot breastfeed. Non-nutritive sucking was not common, although one respondent said it was practiced in the special care unit.

The availability of lactation consultants varied from facility to facility. The highest referral hospital in the country had two trained lactation consultants available and helped mothers of small and sick newborns starting in the maternity ward. These lactation consultants are trained in pre-service education. But more commonly, lactation advice is given by nurses that receive lactation training on the job.

The respondents expressed that there is no means to bank or share milk in Rwanda. Some hospitals may have facilitated informal exchanges (for example, a mother with excess breastmilk may donate some to another mother), but this was not practiced in every facility. Nearly all respondents mentioned that a milk bank was desirable.

Mothers can breastfeed by the bedside of the newborn but space is often limited for this. There is often a room set apart for pumping but sometimes the room may be lacking in privacy, disinfectant, and refrigeration. The majority of the facilities did not provide breast pumping equipment for mothers.

#### *Sensory Environment, Stimulation, and Interaction*

One respondent said that there were no specific policies, protocols, and guidelines that promote neuroprotective developmentally supportive environment. The other respondents felt that the *National Neonatal Care Protocol* did touch on sensory elements. However, the participants noted that either the policy itself was not specific or comprehensive enough or that it was not implemented fully in practice. Another said that new policies were forthcoming.

For managing light levels, respondents did say some efforts were underway in some of the facilities. These included use of curtains to block unnecessary light from windows, and turning off overhead lights for the most part (and just using the radiant warmer lights during procedures).

For the management of noise, none of the units included in the case study said they were monitoring noise levels. One unit had placed signs around indicating sound levels should be kept low, but alarms made it difficult to reduce noise.

Respondents said that barriers to these practices included the cost of the training, insufficient number of health providers, and the high turnover of skilled personnel.

### *Supportive Positioning*

The practices to facilitate developmental positioning vary by facility. One facility mentioned practicing midline nesting supine positioning during the first 72 hours. Other facilities used towels or linens for containment. There is some effort to check on positioning during quality initiative processes. Another participant reported that newborns were handled minimally with supine positioning being the most frequent position. There is currently no comprehensive policy that covers positioning.

### *Reducing Stress and Pain*

Stress and pain are recognized through behavioral changes and vital signs instability and taken seriously in the units. For example, one facility employs a pain assessment tool in their medical records to regularly assess the level of pain multiple times per day at set intervals. However, this practice is not universally adopted.

Some facilities allowed mothers to be present and assist with non-pharmacologic management of pain at the bedside during routine clinical procedures (i.e., IV placement). Mothers were encouraged to practice KMC, breastfeed, provide positive touch, or talk and sing to their newborns. One participant noted that it was a challenge to involve mothers in this type of care as they were often quite stressed themselves.

Other non-pharmacologic strategies used by nurses included swaddling and a reduction of stimulus. "Practicing non-pharmacological pain management has reduced the use of drugs in our unit," said one participant. "We have reduced unnecessary practices in our unit like doing only very important laboratory blood tests, thereby reducing invasive procedures causing pain and stress."

### *Barriers to breastmilk feeding*

Staffing shortages lead to lack of lactation support, and therefore, the quantity of breastmilk produced by mothers is not always enough. Many mothers are coming from far away and have limited access to food or water.

Staffing shortages also make it difficult for clinicians to fully adhere to policies and guidelines. "So what is seen in places where there is not extensive mentorship support is that not all policies are being followed properly," a participant said. They added the example that sometimes the daily fluid volume or volume of breastmilk feed was below what was recommended.

Formula is rarely provided and usually only employed in the case where mothers are ill and unable to lactate. "Being highest referral centers, we get sicker moms who themselves need to be in intensive care and can't express milk," said one participant.

“Sleep is promoted in the unit. We practice minimum handling only when required and group procedures in order to respect sleeping time. If procedures can be pushed to another time if the baby is sleeping, this does happen. In the past, this was not always the case, but a new neonatologist on the ward promotes this.

Nurses have not yet gotten into the routine of respecting structured sleep for each infant. It is a bit halfhearted still.”

-- Senior Clinician

### *Protecting and Promoting Sleep*

The respondents reported that there were some elements of protecting and promoting sleep in the national guidelines, but that it was primarily up to the hospitals to lay out their own practices and procedures. Some practices in facilities to promote sleep and rest include: reducing sound in the unit, switching off the light during the day, and promoting regular cycles of caretaking by grouping procedures that respect sleep periods. These were not consistently practiced in the units. One participant reported that often organizing and respecting sleep and caregiving cycles happens because a caregiver or clinician championed the practice, advocating for the clustering of care. However, protecting sleep remains a challenge. As one participant said about protecting sleep in their facility, “there is still a lot to do.”

### *Protecting Skin*

Skin injuries are seen in the unit, and there are no comprehensive policies on injury prevention and management. The most common causes of skin injury include: intravenous lines insertion and their tapes, nasogastric tube tape, diaper rashes, and intravenous cannulation. One participant said that some nasal CPAP devices cause septum erosions, but that this was happening less frequently than in the past. Some common practices undertaken in some of the facilities to prevent or minimize skin injuries include:

- regular monitoring of both nasogastric and intravenous lines
- removal of IV lines once no longer necessary
- Encouraging mothers to change diapers on a regular basis
- Using an umbilical catheter to minimize unnecessary lines for newborns below 1.5 kilograms or 32 weeks of gestational age
- Minimizing the taping of skin wherever possible
- Using protective tape for nasal CPAP probes

### *Follow-up Post-Discharge*

There are no clear guidelines for follow-up care, and no incentives exist for families to return after discharge. One participant said: “government services are very scarce. Most resources are church- or private-based, but they are very expensive.” Private specialized care may be viewed as superior and preferable for many families with the means to access it.

Mothers must demonstrate certain skills before being discharged to home. These skills included demonstrating the ability to properly feed/breastfeed the newborn, KMC positioning, basic caretaking tasks, as well as knowledge of danger signs, the importance of immunizations, and basic infection prevention skills such as handwashing techniques.

The participants reported that mothers were given a discharge summary sheet that includes follow-up data to return to the hospital. Only one hospital mentioned that written materials were given to the mother, including information on KMC, breastfeeding, and family planning.

When newborns are discharged to home, parents are given a date to return for their first follow-up visit. The date they are given depends on the condition of the newborn at discharge. One participant said families were asked to return within three days, whereas another participant said this timeframe was two weeks.

"Only when mothers are significantly distressed psychologically are they referred for professional help. During rounds, we see quite frequently low-grade postpartum depression, especially with mothers of preterm babies. We do get psychotherapists to come to do some sessions.

Many of the mothers refuse help, which is part of our culture. We don't show pain, instead, we say: 'Tears flow into the inside, not the outside. We cry from within.'"

-- Senior Clinician

The follow-up visits include monitoring growth and development, discussing feeding issues, taking vital signs, educating caretakers, and assessing neurodevelopment. It is not uncommon for parents to miss these appointments due to geographic or financial barriers.

Providers may also make referrals for more specialized care (e.g. auditory appointments, vision appointments, more extensive disability support). A participant noted that there was one hospital-based ophthalmologist that did specialized retinopathy of prematurity (ROP) screening prior to discharge, but to their knowledge, this is the only hospital in the country with an ophthalmologist available.

There are several centers in the country that are specialized on providing interventions for developmental delays, but not all mothers get access to that as they have to be identified and referred from the district level. For newborns with developmental delays and other disabilities, there are physical, occupational, and speech therapies available at the hospital. While some social support is available for children with disabilities, there are some much needed services such as special education that are currently lacking.

One participant said that "very few referrals are coming back to the hospital, as they probably go to pediatric doctor or don't go at all and then the chain is disconnected." Most small and sick newborn care is provided in the district hospital, while most of the post-discharge care is meant to be provided at the community level, with periodic visits to the hospitals. The *National Neonatal Care Protocol* specifies newborns are supposed to be linked to community health workers for follow-up and to motivate parents to go back to the hospital for checkup and screen for danger signs to refer. However, several participants noted that, in reality, this process was not functioning very well. Follow-up rates are not high, so many of the newborns who really need more support and services are lost in the system.

## Country Case Study: Sweden

### *Active collaboration ensures high-quality nurturing care*

The country of Sweden has one of the highest levels of care and some of the best outcomes for newborns born preterm, low birth weight, or sick.(64) This success is due in part to child-friendly policies and robust public healthcare systems.(65) Parents also have supportive parental leave policies, which are associated with lower infant mortality.(66) Parental leave enables Swedish parents to stay in the hospital with their fragile newborns. In addition, families do not have to pay out of pocket for medical care, which may help reduce the stress of having their newborn hospitalized.

The European Foundation for the Care of Newborn Infants (EFCNI) coupled with pediatric and obstetric health clinicians, have collaborated to develop *The European Standards of Care for Newborn Health*. The multi-stakeholder process (which included representatives from Sweden) ensured a widespread adoption of these guidelines, which have reinforced some of the best practices in nurturing care.

Partnership with families has helped ensure that nurturing care begins at birth and extends after discharge. One example, the concept of “couplet care” where mothers in need of medical care and their admitted newborns are treated together with zero separation on the same ward is increasingly common. It is also common for newborns to receive early discharge along with comprehensive medical follow-up care in the home environment.

### *Methodology*

For this case study, the case study team spoke with the recently retired senior clinical director of an intensive care unit at a large, urban university hospital. This hospital provided the highest level of the care in the country with three neonatal intensive care units serving 30,000 annual births with a total of 50-60 beds. The interview was conducted in English. The results of this conversation are summarized below.

#### Country Demographics: Sweden

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 2 Total: 205
Infant Deaths <sup>1</sup>	Per 1,000 live births: 2 Total: 279
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 3 Total: 342
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	5.9%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	5%

<sup>1</sup> UNICEF. Country profiles Sweden [Internet]. New York: UNICEF; 2019 [cited 2019 June 20]. Available from: <https://data.unicef.org/country/swe/>

<sup>2</sup> March of Dimes. Born too soon the global action plan on preterm birth. Arlington (VA): March of Dimes; 2010 [cited 2019 June 19]. Available from: <https://www.marchofdimes.org/mission/global-preterm.aspx#tabs-3>

<sup>3</sup> The World Bank. Data: Low -birthweight babies (% of births)[Internet].Washington: World Bank; 2011 [cited 2019 June 19]. Available from: <https://data.worldbank.org/indicator/SH.STA.BRTW.ZS>



“Providers are mostly trained in the pathology and physiology of the newborn, but they are not quite open to the psychological aspect. It is a big challenge to overcome the mind-set of providers, especially doctors, but nurses as well. They are by necessity very efficient and task oriented. Thus it is often challenging to educate and open their minds so that they also understand the importance and benefits of nurturing care.”

### *Facilitators and Barriers of Nurturing Care*

Described below are the facilitators and barriers for nurturing care. These factors have been arranged by the intervention in the logic model (see page 16).

#### *Laws and Policies*

*The European Standards of Care for Newborn Health* were developed jointly with contributions from about 220 healthcare professionals and parent representatives from more than 30 countries. (70) This effort was led by EFCNI and was launched in 2018 after a five-year collaboration process. Swedish clinicians contributed to these standards from their research and rich implementation experience and now follow the guidelines closely.

The policies include standards for birth and transfer, care procedures, data collection and documentation, education and training, ethical decisions, neonatal intensive care unit design, follow-up and continuing care, infant- and family-centered developmental care, medical and clinical practice, nutrition, patient safety, and hygiene. These policies guide all aspects of newborn care in the country.

#### *Skin-to-Skin and Kangaroo Care*

The benefits of skin-to-skin contact were well known, and in the facilities, the attending physician initiated the practice as soon as the newborn was considered stable. All four components of KMC were regularly practiced as a part of routine care throughout the facility. In the participant’s experience, daily skin-to-skin was practiced by parents a median of nine or ten hours per day.

“We have noted when the parent is present, they can buffer the physiological challenges of their babies,” the participant said. In his experience, skin-to-skin was commonly understood to support appropriate temperature maintenance, humidity, and weight gain. It was also agreed that this physical contact facilitated the attachment process.

The current guideline promoted putting stable babies above 32 weeks on immediate skin-to-skin. “In Sweden, we have more liberal criteria which is determined by the attending physician” the participant said. “Babies on mechanical ventilation, umbilical catheters, and central lines are put skin-to-skin.”

The participant noted that there was not much evidence so far on the safety or benefits of immediate skin-to-skin for babies below 33 weeks. He noted that currently a trial was

“With a few exceptions, such as parents with severe psychological problems, almost all parents are eager to take on KMC and learn very quickly. Even fathers find the experience overwhelming the first time they have their child skin-to-skin. Something happens physiologically and psychologically. I believe toxic stress is reduced and that something changes in the brain connections.”

“We have only 50-60 beds in the three NICUs at the Karolinska University Hospital and this is the only hospital in Stockholm providing the highest level of intensive care for 2.5 million population. This number of beds is low for a high-income country. One of the reasons why is that we involve parents from the start. We discharge babies early on gavage feeding and have follow-up home visits. Approximately 50% of our small and sick babies are cared for in the home rather than in intensive care or nursery.”

underway in Sweden and Norway with the aim to investigate whether immediate skin-to-skin contact during the first six hours of birth and as much possible during the first 72 hours leads to improved physiological stabilization, altered epigenetic profile, and long-term psychomotor outcomes compared to conventional management for babies 28 to 33 weeks.(68) A parallel trial is ongoing in low- and middle-income countries.

Fathers frequently share the skin-to-skin time so that the mothers are ensured sufficient rest. The staff can also recommend a “significant other” or surrogate to support skin-to-skin. The participant noted that preparing parents to be ready for skin-to-skin and care of their baby was sometimes a

challenge because some parents were initially afraid to hold their fragile newborns. The participant’s experience was that if women are supported for immediate skin-to-skin, they bond to the infant in a completely different way than if they have to wait six hours or more. However, he noted that he did not have data to support this opinion, and hence more research was needed.

Other barriers included the monitoring of the newborn on skin-to-skin and securing the airway for safe breathing. There have been incidents of suffocation, so it was essential to monitor, educate, and train care-providers and parents to secure open airways. There are no separate KMC units or rooms. Instead, parents stay in the neonatal intensive care unit. As soon as the obstetrician allows, the mother is invited to stay in the neonatal intensive care unit with their newborn. The hospital is partnering with the obstetric team to provide care to both mother and newborn as a dyad in the intensive unit (a.k.a., couplet care). The participant has demonstrated that rooming-in has helped reduce chronic lung disease of the premature newborn.(69)

Sweden’s facilities are temperature-controlled. There is no shortage of incubators, radiant warmers, and water mattresses. For very small preterm babies, the use of incubators with controlled humidity was the standard practice. The participant noted that temperature control could be challenging for newborns delivered by cesarean section. Surgeons require quite low temperatures in the operating rooms, so many do not follow WHO’s recommendations for appropriate temperatures for newborns.

### *Partnering with Parents and Families*

The hospital follows EFCNI’s *Infant and Family Centered Developmental Care* (IFCDC).(71) “The IFFCD has reduced the time of stay, hence has helped [reinforce] the system,” the participant noted. There are no visiting hours in the facility, and parents can visit anytime. There are, however, limits on the number of visitors and family members allowed.

Engaging family members in care has been a gradual process that began in the 1980s. The Stockholm neonatal family-centered care study looked at the effect on length of stay and

infant morbidity.(72) This study is still the biggest randomized control trial on family-centered care and demonstrated shortened length of stay for premature newborns by 5 days (from a mean of 32 days to 27 days). This number jumped to 10 days for the very preterm babies. The reduction was during the most acute period of illness.

Parents are involved with all the routine baby care, such as bathing and cleaning, changing diapers and sheets, and feeding the newborn (including gavage feeding). Parents do everything except for medical interventions.

There are quite a few single rooms available for families. However, at Karolinska, a single room policy is not strictly followed. Instead, in the intensive care unit, small open bay rooms house three to four newborns and lots of floor space to allow a mother's bed to be brought in and for parents to be with their newborns. Parents have access to nearby rooms to sleep. The hospital offers private rooms for parents to care for their newborns once they are stable enough to leave intensive care. These units include space for two beds and cribs as well as an attached private bathroom.

Barriers to family-centered care remain. Medical staff members are, by virtue and necessity, task-oriented. The participant notes that sometimes clinicians needed to be persuaded that family engagement will not jeopardize medical treatment.

Partnership with parents' organizations has played a valuable role in improving care. However, during the acute phase of hospitalization, most families do not have time to interact with other parents and can only get involved in advocacy after discharge.

### *Nutrition (Breastmilk Feeding and Breastfeeding)*

There are clear guidelines on breastmilk feeding that are closely followed. Each facility has a milk kitchen, with facilities for pasteurized donor human milk. There is one milk bank in Stockholm that supplies frozen milk across the city. The steady supply of breastmilk from this milk bank means that donor milk can be used throughout the hospitalization, without the need for formula. Once the donor-fed newborns are closer to discharge, and when it is needed, staff members give support also in formula feeding.

Breastmilk is often fortified for added nutrition. Staff analyze the breastmilk and tailor the fortification to the individual needs. The staff has found that the preterm mothers' milk is generally appropriate in nutritional content, but this can vary woman to woman.

Currently underway is an ambitious program to support initiation of breast milk production for mothers of preterm babies, called the colostrum kit. Mothers are given information before delivery about collecting a few milliliters of colostrum immediately after birth to give to their small babies. The results have not yet been published, but the preliminary findings are encouraging.

“The system needs to support the presence of the family in the NICU. This system needs to take care of the mother who may be in need of medical care herself. All women need monitoring after delivery. However, for the ones that give birth to small babies, the most vulnerable babies in the world, it is very common to separate the mother from the baby for at least three or four days. This is not nurturing care. Hence, a system that supports nurturing care and an appropriate NICU design that supports it is needed.”

“The greatest challenge even in high-income countries is to ensure timely expression of milk from mothers – as quickly as immediately or at least within one hour of birth and on a regular basis during the first couple of days. The crux of the problem is health workers who do not understand the importance of early expression and hence do not support and educate the mother.”

The hospital has implemented a policy of early minimal feeding; immediately providing one milliliter of milk per feed along with parenteral nutrition for the extremely sick newborns and/or all infants below 1,000 grams.

The staff members put the newborns to the nipple for non-nutritive sucking. The smell of the mother and nipple is important for the newborn, and the suckling helps increase lactation. The staff also use pacifiers and fingers to stimulate sucking reflex during gavage feeding.

Mothers can breastfeed in the intensive care unit in beds or comfortable chairs. For pumping mothers,

there are electric double pumps available. A cadre of lactation consultants exist, but they are few in number. The preference is not to have specialized lactation consultants, but to ensure that all nurses working in the newborn unit are trained to support mothers to breastfeed.

#### *Sensory Environment, Stimulation, and Interaction*

The participant reported that the hospital followed *The European Standards of Care for Newborn Health* for the acoustic and light environment. In their experience, this issue requires continuous discussions and a nurse champion to monitor sound and light. At times, sound levels were measured which provides valuable, actionable data. The participant noted that the speech sounds were the hardest to reduce.

Limiting the number of family members around the newborn in the intensive care unit is one way to reduce unnecessary stimulation. “It is important to understand that these babies are quite fragile for sensory input and a lot of people around, means a lot of noise, many activities, and the babies can actually do worse,” said the participant. He went on to add that the newborn family does not need the extended family from the very beginning, only a few people to form a mutual attachment with.

The hospital promotes positive stimulation by voice, but they tread carefully as some very small newborns get easily stressed and might even stop breathing. Clinicians guide parents from the very beginning to look at the cues of their newborn and respond and interact. Parents are asked to vocalize or sing in their mother tongue and observe the newborn’s behavioral responses.

#### *Supportive Positioning*

The unit has guidelines on developmentally supportive positioning, including information on how to position and use appropriate postural materials and strategies to prevent skeletal and muscular imbalance. Positioning is individualized to the comfort of the baby. Parents can bring their own materials for positioning, as long as it is within the guidelines of the unit. Before discharge, parents are informed and trained by health workers in individualized positioning support and comfort – all postural boundaries are removed, and infants are put to sleep in a supine position so that infants and parents become accustomed to it. Parents

learn about the safety of the supine position during sleep and the reduced risk of sudden infant death syndrome.

### *Reducing Stress and Pain*

The participant noted that they wholly followed *The European Standards of Care for Newborn Health*, with all newborns receiving optimal comfort to minimize stress and pain, supported by their parents. Compared to older children, newborns were less likely to communicate their pain and discomfort and are at higher risk for poor pain management. The staff tries to minimize stress by regular prospective observation, reading the newborn's behavioral cues of pain and discomfort.

Staff paid attention to positioning, the immediate environment, and timing of intervention and appropriate use of pain relief strategies. This includes non-pharmacological approaches such as tucking, wrapping, giving individualized supportive care, as well as the use of pacifiers and analgesics. For non-urgent procedures, they support parents to provide non-pharmacological pain relief and plan for the timing of the procedures.

### *Protecting and Promoting Sleep*

Sleep protection is a priority in the hospital. Sleep states were identified and respected to ensure the sleeping period of preterm infants is not disturbed. The participant reported that the staff encouraged and promoted a minimally invasive environment, focused on the infant's individual needs and behavioral patterns.

### *Protecting Skin*

The participant noted that *The European Standards of Care for Newborn Health* for skin care are followed in the unit.

### *Follow-up Post-Discharge*

Staff conduct hearing testing right after discharge. If they discover any potential delays, impairments, or disabilities they will refer the newborn to physical and occupational therapists. During the follow-up care, the newborns receive a neurological examination, physical therapy, and psychological testing. Follow-up care is done up to 24 months, and this continues up to five and half years for the extreme preterm newborns born earlier than 28 weeks gestational age.

Preterm newborns are discharged to the Home Care Program. In this program a neonatal nurse visits one to three times a week, depending on the child's level of acuity. When growth and full feeding is ensured the infants are referred to the community health system and to the follow-up programs described above. It is an extremely supportive, gradual discharge process. For the older 'NICU graduates,' the visits tends to be less intensive and they transition earlier into the traditional healthcare system where the community nurse takes over, as for all healthy newborns, with frequent visits during the first months and less intense contacts continuing up to school age.

Mothers' mental wellbeing is also screened and supported after delivery through the community health system postpartum follow-up.

Feeding is the most essential skill for both parents and newborns to learn before discharge. It is observed that if the parents have learned to feed in an individualized manner, they will have developed the other caregiving skills they need for the newborn to thrive.

## Country Case Study: Philippines

*The country demonstrates an impressive commitment to kangaroo mother care and breastmilk feeding*

As one of the top ten countries with the greatest number of preterm births, the Philippines has invested enormous resources in protecting the survival of its smallest citizens.<sup>(72)</sup> There is perhaps no greater evidence of this commitment than the Philippine Health Insurance Corporation, or PhilHealth, a government-owned and controlled corporation attached to the Department of Health. A Newborn Care Benefit Package was developed in 2006, with subsequent enhancements in 2011 and 2018 (PHIC circular O11-2011 and 2018-0021, respectively). This health insurance benefit package provides emergency and essential maternal and newborn care, with free premiums for the most impoverished families. In the past year, the coverage was extended to include a benefit package for infants under 32 weeks of gestational age and with birth weights less than 2,500 grams: PhilHealth Z Benefit Package for Preterm and Small Newborns. The Enhanced Newborn Care Package is available in both public and private facilities that are accredited by the government. The Z Benefit Package, on the other hand, is targeted to be made universally available to public facilities that will be contracted by PhilHealth.

While many private facilities provide high-quality care, they may be more expensive for families and are less likely to follow government guidelines. The interviewed participant from the private facility reported that their hospital had followed the guidelines and had been certified as a KMC Center of Excellence and Training from the Department of Health.

The government standards around KMC and breastmilk feeding were particularly rigorous. Therefore, it was unsurprising that the respondents were committed to and well-versed in supporting both interventions. This focus has led to positive momentum in many areas of nurturing care. However, some of the other components of nurturing care were less appreciated.

The facilities featured had their share of barriers to providing nurturing care. Overcrowding, especially in the neonatal intensive care units, was typical and affected the staff's ability to

### Country Demographics: Philippines

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 13.6 Total: 32,836
Infant Deaths <sup>1</sup>	Per 1,000 live births: 22.2 Total: 53,300
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 28.1 Total: 67,158
Preterm birth rate (babies born <37 weeks): <sup>2</sup>	13%
Low birth weight rate (babies born <2,500g): <sup>3</sup>	20.1%

<sup>1</sup> UNICEF. February 2018. Neonatal mortality data [Internet]. New York: UNICEF, 2018 Feb [cited 2019 June 21]. Available from: <https://data.unicef.org/topic/child-survival/neonatal-mortality/>

<sup>2</sup> Chawanpaiboon S, Vogel JP, Moller AB, et al. Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. *Lancet Glob Health*. 2019 Jan;7(1):e37–e46.

<sup>3</sup> UNICEF. May 2019. Low birth weight estimates [Internet]. New York: UNICEF, 2019 May [cited 2019 June 21]. Available from: <https://data.unicef.org/topic/nutrition/low-birthweight/>

engage parents in caregiving. In addition, a lack of human resources for health made adequate staffing a challenge.

### *Methodology*

For this case study, the research team spoke with six individuals which included multiple clinicians, a policy maker, a Vice-President of a professional association, and a leader of the KMC Foundation. Interviews were conducted in English and transcribed. The text was analyzed for key themes.

### *Facilitators and Barriers of Nurturing Care*

Below is a brief discussion of the facilitators and barriers for nurturing care. These have been arranged by each intervention in the logic model (see page 16).

### *Laws and Policies*

After a successful 1999 pilot program, (73) one of the urban tertiary maternity hospitals initiated and established KMC as the standard of practice through institutional policy. Four years later, the practice was adopted for low birth weight newborns by all city primary health care facilities of the Manila Health Department.

In 2008, a neonatal sepsis outbreak in a local government hospital triggered the political will to focus on improving practices of care for newborns throughout the country. The government led a comprehensive investigation of newborn care practices. The investigatory team noted that many of the evidence-based WHO protocols for newborns were not in practice. This analysis led to a decision to transform care for newborns in the Philippines.

To kick off this transformation, the Secretary of Health signed an administrative order in 2009 to adopt the *Essential Intrapartum and Newborn Care (EINC)* as the national policy. This comprehensive policy also included KMC in the care for small babies. As the first national guiding document, it led to many practice changes in maternal and newborn care facilities.

The KMC Foundation Philippines, Inc. has worked with interested hospitals to operationalize the comprehensive and programmatic implementation of KMC, including the *EINC* policies. This step helped to guide the standards of care on KMC in the facilities that endorsed it and was used to conduct facility assessments during post-training visits.

Building on this foundational work in KMC, the Department of Health spearheaded the capacity building modules for providing holistic care for small and sick newborns in 2014, in partnership with the foundation and other non-government organizations and development partners. This was turned into a training of trainers which was scaled up to sub-national government hospitals a few months later.

The Department of Health is currently drafting a policy called *Quality of care for small babies addressing prematurity and low birth weight*. This policy will cover the continuum of care from essential newborn care to specialized care for small and sick babies. This policy is expected to be signed in late 2019 and will officially guide all health facilities on the implementation of care. The new quality of care policy will mandate that every facility taking care of preterm and low birth weight newborn infants, aside from a neonatal intensive care

unit, should have a separate space for KMC within the next three years. It will also include a developmental assessment component after discharge so that newborns are tracked and early interventions are made available to those who need it. This policy will include implementing rules and regulations.

The participants acknowledged the KMC Foundation as a significant partner for improving and strengthening KMC services. There are 21 centers of excellence for KMC in the country that cascade training to regional, provincial and district hospitals. This has led to training in 171 hospitals of the 1,223 hospitals in the country that have intensive care units. The Department of Health ensures the quality of implementation, training, and supportive supervision. The KMC Foundation volunteers to provide re-accreditation support every three years.

The Philippine Society of Newborn Medicine was also noted to be an influencer for care changes. The Society developed capacity building materials on newborn resuscitation, called Neonatal Resuscitation Philippines Plus (NRPh+), that included the elements on early essential newborn care at delivery before advanced resuscitation is required. The Philippine Pediatric Society has officially endorsed this module for the training of doctors and nurses handling newborns.

In November 2018, Republic Act No. 11148 called the Kalusugan at Nutrisyon ng Mag-Nanay Act (translated as “health and nutrition of mother and child”) was passed, scaling up health and nutrition for the first 1,000 days. This law goes beyond the mere provision of maternal and newborn services and includes responsive caregiving, early stimulation, and developmental assessment components so that discharged newborns are tracked and early interventions are available. President Rodrigo Roa Duterte signed this law in 2018.

### *Skin-to-Skin and Kangaroo Care*

Skin-to-skin and KMC are widely practiced and supported by both national guidelines and the influential KMC Foundation. The two terms are often used interchangeably; at times participants referred to “KMC” without including all four components as defined by WHO.

Intermittent skin-to-skin is initiated in the intensive care unit once the newborn is stable and continued in the special newborn care units. Parents are encouraged to stay on as long as they can to provide the care, and fathers are encouraged to practice skin-to-skin as well. Some participants even noted that newborns receiving oxygen with a nasal cannula or who are ventilated and intubated are also placed on skin-to-skin care. A few select hospitals have KMC units. Space has been an issue, but neonatal intensive care units have tried as much as possible to place comfortable reclining chairs near the newborn's cot. Skin-to-skin is also practiced in the breastfeeding room next to intensive care units. Hospital gowns are given to mothers for privacy.

The participants reported that nearly all parents accept KMC for their babies in the hospital. Some find it challenging when they have other priorities, such as the care of other siblings. KMC facilities provide parents with KMC booklets that record prenatal to postnatal information for mothers and their newborns. Post-discharge, however, parents noted that KMC was a challenge to maintain.



The Department of Health adopted the KMC Foundation's core training modules and expanded further to reflect multi-professional and multidisciplinary approach on the care for small babies. It has sponsored its roll-out training throughout the country's government hospitals. Educational content on prevention of complications of prematurity and low birth weight, early intrapartum and neonatal care for the preterm and small newborn, breastfeeding, and basic neonatal resuscitation were later added and the training was rebranded to the Care for Small Babies seminar-workshop for trainers and program implementers.

The KMC Foundation set up a system for supportive supervision following the training, which has been adopted and now led by the Department of Health. Facilities are graded after each

### The Role of Supportive Supervision in Furthering KMC

"A facilitator for quality KMC in the Philippines has been the program of supportive supervision undertaken by the trainers after the training. Such support ensures what has been learnt is actually what is happening, and it helps the facility team ensure that they are doing the right thing. The trainers also support the first rollout of training in the facility. The future supportive supervision visits focus on four main areas:

- Administrative organization
- Training of staff
- Service provision
- Routine audit and clinical or implementation research initiated

The facilities are graded each time. It can take between 6 and 18 months to attain full KMC accreditation status. Once accredited, they have the privilege to teach other hospitals and become a training center.

The leadership matters in this process. The director is important to keep the team motivated."

-- KMC Foundation representative

supervisory visit until they attain full KMC status and are accredited. Numerous hospitals have been certified as KMC centers through this process. Facilities have to be reaccredited every three years, and the KMC certification is a requirement for hospitals to get reimbursed for the care of low birth weight infants.

KMC is bolstered by the PhilHealth Newborn Care Benefit package, which requires that hospitals provide KMC services, preferably in a KMC unit, to be reimbursed.

In the KMC units, there is significant thought towards providing positive stimulation for newborns. There are efforts to support parents by allowing them to slowly tube feed while doing skin-in-skin. Parents are encouraged to sing and speak to their newborns. In at least one facility, the KMC protocol includes infant massage.

Despite the widespread support and enabling environment, obstacles to widespread implementation of KMC remain. For example, a lack of nurses can make it challenging to support KMC. Some doctors and nurses resist KMC, believing that incubators are better for temperature regulation or that it is too much additional work to implement. Participants reported that it is not as difficult to implement KMC in private hospitals where

the practitioners have more autonomy. However, not all private facilities follow national guidance for KMC, and it is usually left to the individual practitioners' prerogative. Finally, another hindering factor is a lack of community support for the continuation of KMC, when a low birth weight newborn is discharged early.

### *Partnering with Parents and Families*

Other than KMC, there are no specific policies to encourage providers to partner with family members. A lack of space is the primary barrier that restricts parents from staying longer and getting involved in caregiving activities. The intensive care units are crowded, and sometimes there is not enough space around the newborn's bed for caregiving activities. One participant reported that the infrastructure would need to change before family engagement can be made possible. Participants said that private sector intensive care units were more likely to include parents in the care which may be because of the availability of space or perhaps because of the requirements of international certifications.

There is a 24/7 visiting policy for mothers in both the government and private facilities. The visitation policy for fathers is more permissive in the private facilities and restricted to regular visiting hours in the government facilities due to overcrowding of the intensive care units. In some intensive care units, fathers and other caregivers are not allowed to visit at all. Often, siblings and other family members are not permitted to visit. There is a hesitation on the part of doctors and infectious disease specialists to have a less restrictive policy. In one facility, family members are allowed one visit when the newborn is admitted where they can view the newborn from a transparent glass window. In some cases, only one person is allowed to be with the newborn at a given time.

Nurses mentor mothers on the care of their newborns during admission in the intensive care unit, and mothers are engaged in skin-to-skin and breastfeeding activities. However, participants said that including parents in routine care activities such as diaper change, monitoring, sponge bathing, or tube feeding was inconsistent.

In the public facilities, mothers providing KMC receive a bed and have access to all of the amenities in the hospital. The KMC Foundation has worked with the hospital leaders of select facilities to set aside temporary rooms for sleep and food of mothers where they can stay until their newborns are ready to room-in.

In one facility, mothers have a bed, food, and daily change of gown provided for as long as the newborn is an inpatient. This service is limited only to mothers, who cannot go home without the permission of the legal department of the hospital. In the private hospital, families could pay to stay in condominiums around the hospital during their newborn's treatment in the intensive care unit until the newborn is ready for transfer to a private room with the parents.

One participant mentioned that the *Quality of care for small babies addressing prematurity and low birth weight* document underway included guidelines about engaging with family members in the care of their inpatient newborns. This draft includes a visitation policy, as well as support for breastfeeding, KMC, and skin-to-skin.

The participants reported that clinicians had many opportunities to educate parents about the care of their newborns. For high-risk pregnancies, obstetricians refer families to the neonatologist during pregnancy to communicate the possible management and outcomes.

The family meetings with the neonatologists continue once the newborn is admitted into the intensive care unit. Parental education in hospitals varied. While some facilities did not have any formal education activities, others offered regular formal talks for mothers on a variety of topics.

#### *Nutrition (Breastmilk Feeding and Breastfeeding)*

Human breastmilk feeding is well-supported by both policy and practice. For example, the Philippines passed three major laws to support breastfeeding since 1986. The rules are followed by all government hospitals and in the majority of private hospitals.

To further support lactation, the *Expanded Breastfeeding Promotion Act* of 2009 (Republic Act 10028) includes lactation stations in the workplace. It also mandates employers provide lactating mothers with a minimum of a 40-minute break per eight hours of work. Lastly, the maternity leave has been extended to 105 days to ensure the continuation of successful breastfeeding. At present, the *Kalusugan at Nutrition ng Mag-Nanay Act* of 2018 (Republic Act 11148) mandates the availability of human milk pasteurizers for strategic level two and level three facilities with neonatal intensive care units. This law was created to ensure breastmilk supply for small newborns born preterm and small within the facilities, throughout the service delivery networks, and during emergencies and disasters.

The Philippines also has a Human Milk Bank Association that is working on scaling-up milk banks. Currently, there are 22 human milk banks in the country. According to the participants, supply is not an issue for government hospitals that house these milk banks. Mothers were open to using donor milk. When milk bank supplies were unavailable, there were sometimes informal arrangements made to connect mothers with other lactating mothers.

In both government and private hospitals operating intensive care units, all nurses and doctors are mandated to take on a 20-hour Integrated Essential Maternal and Newborn Care, and Lactation Management Training (EMNC-LMT) Course that includes counseling and lactation support. While there is a cadre of lactation nurses in one of the facilities, for the majority of hospitals, lactation support is considered everyone's responsibility.

Feeding begins as soon as it is safe for the newborn. Total parenteral nutrition (TPN) is available in the large private hospitals. Otherwise, the use of TPN is rare and usually only provided in cases of very small babies (less than 1,000 grams) or contraindications such as surgical conditions and congenital anomalies. In cases where the newborn is unable to suckle well or gets tired, breastfeeding is supplemented with expressed breast milk provided by cup

“Mothers continue to stay in the postpartum ward for the duration of their babies’ hospitalization to ensure a continuous supply of breastmilk for the admitted babies. When these babies are stable enough to be transferred out of the intensive care unit and roomed-in, then both mother and baby are transferred to the KMC Ward where continuous KMC is performed until baby is deemed ready for discharge.

The presence of the mothers allow them to be partners in the care of the premature baby, and reduces the incidence of these babies being abandoned or not being visited for long stretches.”

-- Senior Clinician, Government Hospital

or dropper. Non-nutritive sucking at the breast is practiced on a case to case basis, depending on the clinician’s judgment.

As the newborn grows, they are supplemented with minerals and vitamins during the follow-up treatment. A preterm formula is used at times by some private hospitals when there is no donor milk available or added to the breastmilk to help the newborn grow faster. These practices are prohibited in government hospitals.

In some facilities, electric breast pumps are provided with separate rooms for expression. Mothers sometimes bring their personal pumps to hospitals.

Additionally, the Mother-Baby Friendly Hospital Initiative (MBFHI) accreditation is required every three years. All health workers caring for mothers and newborns are mandated to take the 20-hour integrated EMNC-LMT course as part of this process.

While the policies and practices promoting breastmilk feeding are strong in the country, there is little policing or oversight. One participant noted that they had heard of cases where newborns are prescribed mixed feedings by doctors, particularly in privately run, community-based hospitals and birthing facilities.

#### *Sensory Environment, Stimulation, and Interaction*

While none of the national policies specifically describe a supportive sensory environment for inpatient newborns, individual clinicians are sensitive to protecting their patients from noise and sound. One participant mentioned that providers sometimes write individualized orders for simple practices such as covering an incubator at certain times of the day to block out light.

“We have not been able to prioritize care along these lines, though we are aware of its importance for the developmental outcomes of babies in our care. The NICU is very well lighted and the unit is busy, with people and equipment noises at high levels.”

– Clinician, tertiary level

All of the clinicians interviewed reported that more efforts are needed to improve noise and sound levels in the units. The voices of the health providers cause the highest sound volumes, adding to the noise created by equipment in the units. “Nurses want the alarms to be loud,” said one provider at a private facility.

Multiple participants advocated for a national policy or consensus statement to create an enabling environment in both government and private facilities. One participant talked about an opportunity to promote motor sensory stimulation and early literacy through book reading, singing, and humming. In at least one facility, mothers were encouraged to hold the newborns for sensory stimulation and sing and talk to them.

#### *Supportive Positioning*

Nesting is routinely practiced in all intensive care units. Nurses are adept at positioning, using blankets and linen rolls to create shapes that match the size of the newborn. The position is changed periodically, and newborns are placed prone position to aid breathing. In step down units, where babies do not need frequent monitoring, newborns are swaddled. One participant mentioned that linen rolls were used to prevent accidental extubation for ventilated newborns.

### *Reducing Stress and Pain*

Participants reported that healthcare staff recognized stress and pain in newborns. Most nurses were noted to hold and touch their patients to soothe them during routine procedures.

In the government facility, there was no formal protocol to manage stress and pain. Sucrose was not used, which may have been due to a fear of infection risk or concern that it might interfere with breastfeeding. Breastfeeding and skin-to-skin positions were noted to help calm the newborns and mothers were often asked to assist during procedures.

The participant of the private facility noted having the newborn's pain profile monitored on an hourly basis, and the newborn sedated when required, using appropriate drugs. Individual clinicians may choose to provide surface anesthesia for IV insertions. During procedures, parents are asked to stay outside, and the nurse usually tries to comfort the newborn by cradling and swaddling.

### *Protecting and Promoting Sleep*

Participants said that guarding newborn sleep was a challenge in both the private and public sector because care protocols created unavoidable interruptions. The sheer number of newborns in the intensive care unit of the government hospital made it difficult to provide individualized care that considered the sleep needs of the newborns. There was, however, an effort to try to give the smallest newborns a less noisy and dim environment at the end of the room that would promote sleep. The participants reported that nurses regularly turned off the light in the night to facilitate slumber.

### *Protecting Skin*

Participants reported that skin injuries were common. This was an area of concern in the public hospitals where the ratio of nurses and patients made it difficult to protect the skin. Frequent injuries were caused by extravasations, from adhesives, the pressure of the mittens and socks, burns from the pulse oximeters, and nasal prongs. Practices to limit these injuries in the private facility included use of hydrocolloid dressing to secure devices on the newborn, regular monitoring of IV sites, change of the newborn's position and prongs, and the use of hydrocolloid plaster to form a protective barrier for the nose.

### *Follow-up Post-Discharge*

Although there is no official national guide that instructs specific follow-up actions for small and sick newborns discharged from the facility, there are efforts to highlight this vital care aspect in upcoming national initiatives. For example, the soon-to-be-published *Quality of care for small babies addressing prematurity and low birth weight* policy on caring for small babies will emphasize post-discharge care.

"We are aware of the stress that babies are subject to in the NICU. However, we have no formal program to manage their stress."

--Clinician, tertiary level

Also, a national holistic package campaign aligned with the immunization program will include job aids on post-discharge care from weeks 1, 6, 10, 14 and will consist of anthropometry, feeding practices, and parent education on early stimulation. This national benefits package will also include expanded newborn metabolic screening; hearing screening as supported by the hearing screening

law; and testing for retinopathy of prematurity (ROP) (although laser treatment is unlikely to be offered).

The National Program on the Prevention of Blindness also includes ROP screening. There is also the PhilHealth Z Benefit Package for Children with Disabilities and provides support for hearing, sight, mobility, and developmental delays. The training curriculum on small baby care also instructs on referring the newborn for further evaluation as needed.

“Parents undergo a short course [to] learn about infant CPR. The course includes a video which we show and then practice on a mannequin. We do not discharge unless the mother is breastfeeding well. We leave the mother and baby by themselves for one or two days to help transition from hospital to home.”

– Clinician, Private facility

For facilities practicing KMC, there is a standard protocol on the follow-up of small babies. However, getting parents to come for monitoring has been a challenge, and the rate of failure has been documented. There were efforts to get social workers to do home visits, but success has varied between region and province. Community engagement and community follow-up support from the local government units may be essential to strengthen this component of care.

Follow-up care is extended to one to two years in accordance with the American Academy of Pediatrics guidance. During the follow-up visit, anthropometric measurement, physical wellness checks, nutritional counseling, immunization, and screening tests (i.e. eye, development, and hearing) are conducted. In the private facilities, neonatologists have access to services of a developmental pediatrician and rehabilitation programs where they can refer patients for follow-up. They routinely test all newborns for congenital disorders, including cardiac issues, and refer diagnosed newborns to the appropriate facility.

Participants noted that their facilities were trying to ensure that mothers were confident in taking care of their small and sick newborns before discharge. Participants reported using a KMC booklet that captures the newborn's progress from the time of delivery, throughout the course in the hospital, to the post-discharge period up to one year of age. Newborns will be discharged with one to three follow-up appointments per week in the beginning, which are reduced as the infant grows. Efforts are being made to ensure that health workers are fully trained in supporting KMC at home.

Children requiring more specialized care are referred to developmental or medical specialists. Families, however, do not receive any incentives to support compliance with follow-up activities. One tertiary facility occasionally text-messaged or conducted home visits for very small newborns whose parents did not bring them for follow-up. This practice, however, was not routine due to an inconsistent availability of social services.

## Country Case Study: The United States of America

### *Family-centered care paves the way for a renewed interest in infant mental health*

While the US has some of the highest acuity care facilities in the developed world, its prematurity (74) and newborn mortality (75) rates are higher than other developed nations. Access to high-quality health care can be a challenge for marginalized populations, the underinsured, or people living in rural places.<sup>(75)</sup> All newborns will receive medical treatment regardless of a parent's ability to pay. However, the amount billed to the parent may be significant depending on the quality of the parent's private or public insurance coverage. Some parents without insurance are responsible for paying out of pocket for all services, which can be a high burden.

There are other social factors that influence a vulnerable newborn's wellbeing and development. For example, in many states, there is no guarantee of paid parental leave and few government protections for families that are caring for sick newborns. This means that many parents of very low birth weight newborns may have to make the difficult choice of using their parental leave for the hospitalization period or working throughout the hospitalization and being less engaged in care. Another barrier is that fragile newborns born very preterm or with medical complexity (e.g. congenital heart defects) may be transferred to large urban centers which can be hundreds of miles away from the parents. The separation can pose challenges in engaging families in care as well as facilitating the attachment between parent and newborn.

Despite these barriers, along with European countries, the United States has historically been one of the leaders in both implementation and research around family-centered care practices.<sup>(76)</sup> Additionally, in some of the large urban hospitals, led by institutions such as Children's Hospital Los Angeles, there is a greater shift towards thinking about the psychological wellbeing of newborns and a desire to mitigate the harms of hospitalization on early child development.

### *Methodology*

For this case study, the research team spoke with two neonatologists and a clinical psychologist that specializes in mental health for infants. All participants were from urban,

#### Country Demographics: USA

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 3.6 Total: 14,839
Infant Deaths <sup>1</sup>	Per 1,000 live births: 5.7 Total: 22,943
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 6.6 Total: 26,867
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	12.03%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	8%

<sup>1</sup> UNICEF. Country profiles USA [Internet]. New York: UNICEF; 2019 [cited 2019 June 20]. Available from: <https://data.unicef.org/country/usa/>

<sup>2</sup> March of Dimes. Born too soon the global action plan on preterm birth. Arlington (VA): March of Dimes; 2010 [cited 2019 June 19]. Available from: <https://www.marchofdimes.org/mission/global-preterm.aspx#tabs-3>

<sup>3</sup> The World Bank. Data: Low -birthweight babies (% of births)[Internet]. Washington: World Bank; 2011 [cited 2019 June 19]. Available from: <https://data.worldbank.org/indicator/SH.STA.BRTW.ZS>

high acuity hospitals serving the sickest newborns in California, Washington DC, and Colorado. The results of these conversations are summarized below.

#### *The Role of Family Advisory Councils*

All three of the facilities have a Family Advisory Council which comprises of family members of children or former patients that have been treated at the hospital. The council members meet regularly to improve the hospital experience for patients and families, ensuring they are treated with respect and compassion throughout their hospitalization.

#### *Facilitators and Barriers of Nurturing Care*

Described below are the facilitators and barriers for nurturing care. These factors have been arranged by the intervention in the logic model (see page 16).

#### *Laws and Policies*

The American Academy of Pediatrics has a protocol on neonatal care that outlines how neonatal intensive care units should be set up and the services that should be provided by levels of care. These guidelines are not a regulation but a suggestion. According to one participant, “we follow and try to meet those recommendations, but also go beyond it to provide quality and improved care in our units.”

Also influential are the federal early intervention programs which are available in every state under different names. Program staff endeavor to detect potential developmental delays and disabilities at an early stage so that services can be provided.

The participants cited the National Perinatal Association, ZERO TO THREE, and the World Association of Infant Mental Health as organizational leaders in promoting nurturing care practices in the United States.

#### *Skin-to-Skin and Kangaroo Care*

KMC and skin-to-skin are in regular practice in the units. The term “Kangaroo Care” seems to be generally preferred over “Kangaroo Mother Care” to reflect the encouragement of fathers to participate. Both terms are used interchangeably for skin-to-skin care. Other family members are encouraged to hold the swaddled newborn.

For the most part, the initiation of skin-to-skin is guided by individual clinician judgment. While some facilities have specific protocols, others do not. Therefore, there is a lot of variability on the type of newborns that receive Kangaroo Care (KC).

Some nurses and physicians believe that there should be no restrictions even when newborns are on high-frequency ventilators or umbilical catheters. Other clinicians may be less willing to take the risk to accidentally extubate or pull a line. “If we can come up with a consensus within each unit that would help with doing skin-to-skin,” said one participant.

Skin-to-skin is well understood to improve oxygenation, vital signs, weight gain, sleep, milk production, and breastfeeding duration. The participants also mentioned that KC was known to decrease risk of neonatal sepsis, hypoglycemia, and hypothermia. Also reported by the participants were the emotional benefits of KC such as facilitating attachment. “In our anecdotal experience, babies tend to be more stable physiologically on skin-to-skin and show fewer signs of stress,” reported a participant.



There are no separate wards for skin-to-skin. Most rooms are private, and mothers can practice skin-to-skin by the bedside. The intensive care units offer reclining chairs that are more comfortable for parents to use when practicing skin-to-skin. Skin-to-skin is also practiced in an end of life care setting.

### *Partnering with Parents and Families*

The United States facilities are open 24 hours a day for parents. There are some restrictions for siblings, especially during the flu/respiratory syncytial virus (RSV) winter season. Policies for other family visitors vary by facility. There are chairs in the rooms for parents to sleep on. Most of the country's major children's hospitals have Ronald McDonald Houses nearby for families to stay for a low or no cost.

A parent-provider partnership begins from the start. "Once the baby is born, no matter how sick the baby is, we involve the mother and father in some aspect of care," said one of the participants. Nurses encourage new parents of fragile newborns to hold their hands or speak to them to facilitate bonding. "Once admitted the bedside nurses do a lot of bonding with the moms," a participant said, adding that, "If a primary nurse then tells the mother that their baby recognizes their voice and smell, the nurse can be really impactful in engaging families."

As the newborn becomes more stable, parents are taught to change diapers and participate in routine care such as weighing, taking temperatures, changing diapers, weighing diapers,

"We try our best to do skin-to-skin while the baby is in the NICU, but there are some barriers. For the preterm babies we care for, their mothers are usually sicker and could be having preeclampsia or other complications and so cannot be in the NICU for a very long period of time. For those that can, we try to optimize skin-to-skin, but it depends on the baby's acuity. For instance, we do put ventilated babies that are stable on skin-to-skin. However, for babies that are on high-frequency ventilation, ionotropic support, or have central line catheters, it may not be the safest."

-- Senior Clinician

### *A note on temperature regulation*

At one of the facilities, a nursing practice guideline provides thermoregulation guidance to be followed up for all neonates in critical care. Axillary temperature is checked manually every three to four hours, even if the skin temperature is displayed on the warmer and incubator. Probes are used for continuous temperature monitoring. Incubators are preferred for use over radiant heaters for any infant below 1,800 grams. Relative humidity is practiced for infants less than 1,200 grams or younger than 32 weeks gestational age. For the extremely small newborns (i.e. born at 24 weeks gestation) humidity is maintained at 80-85% administered through the isolettes. Detailed instructions exist for weaning relative humidity off for preterm infants. For late preterm infants, skin-to-skin is the preferred temperature regulation method.

and providing sponge baths. This involvement in caregiving helps prepare parents for discharge. Occupational and speech therapists meet with parents to help train them to feed their newborns by mouth. The physical therapists work with the family on various developmentally supportive therapies during the day, so that mothers and fathers can continue in the home environment. "We wouldn't have the families do the medical procedures," reported a

participant. “Outside of that, I would love to have families take on as much as they would like to do.”

There are challenges to engaging parents in the care of the newborn. For example, at least one of the facilities did not have clear guidelines for family engagement, although a participant said that they were currently under development. The level of participation a family can provide varies.

Some of the more experienced nurses are more used to doing all of the care themselves. However, according to a participant: “there is growing recognition that we need to get these families to be ready for discharge and so allowing them to start taking care will make them confident to take care of their babies at home.”

“There are barriers both at the social level and the hospital level that impedes parents’ engagement in the care of their babies. I think that for families that do not speak English or families are not as extroverted are less likely to be offered opportunities to be engaged in the care process. In addition, a family’s income and resources can definitely affect the parent’s engagement. Can they be there by the bedside providing care or do they have to work; or do they have other children that they have to take care of? There is some bias and discrimination that providers have towards families. We tend to be more warm towards families that are more like us.”

*-- Senior Clinician*

Many of the facilities have individual rooms which have distinct advantages and disadvantages over their open bay rooms (where multiple patients are housed in one large area). “The advantage is the parents can stay there and have the space for food and other amenities,” said one participant. “But the barriers include lack of interaction with other parents and makes the single rooms very isolating.”

Social workers have an important role to play in facilitating family-centered care. “We have terrific social workers who support the families to take away some of the social barriers (e.g. travel costs, parking fees, free meals for families at the bedside during the day). They provide some practical solutions for under-resourced families,” said a participant. Social workers are also tasked with screening and assessing parental stress. They are trained to provide some support, but they refer the parents with more acute emotional distress to outside psychological help.

One participant mentioned that their facility was working to develop a bundle of interventions that can improve parental engagement starting during the prenatal period. For example, if a mother happens to be hospitalized in preterm labor with some medical complication, the clinicians will meet with her to set expectations on what the intensive care unit will be like. This has helped parents become a vital part of the healthcare team early on.

Another facility makes an active effort to bring parents of hospitalized children together for emotional support. A family specialist leads social and learning events which help parents get to know each other, including one occasion for fathers. When there is a newborn with complications who may need to undergo a procedure, the staff make an effort to match them with another family who went through a similar experience.

The increasing awareness of the need to provide family-centered care has led to the development of online, blended, and in-person educational programs for staff members that discuss family engagement. The Gravens Conference, popular for nurses, provides a forum for dialogue about the environment of care for high-risk newborns. Still, the participants reported that there were little formal curricula that discuss family-centered care or nurturing care in the neonatal intensive care environment.

#### *An Infant Mental Health Program at Children's Hospital Los Angeles*

"The focus of our program is on the parent-child relationship, the core foundation of our early childhood mental health program. It begins before birth for the sickest of the babies (those with a genetic syndrome or anomalies detected before birth). Once referred, a psychotherapist works with pregnant women and families, providing support from the very beginning to begin bonding and cope with stress. Infant mental health specialists provide services in the hospital and after-discharge home visiting services, including follow-up in high risk clinics. This provides a continuum of care.

In addition, mental health services are available for high risk families, referred from the community at large and other areas of the hospital, and includes families dealing with trauma and stress, parental mental health issues, depression, those facing substance abuse, intergenerational trauma, and immigration stresses. The transition to parenting may already be hard for these families so adding a medical emergency contributes another layer of stress.

The focus on the psychological side is the infant-parent care component, so that the key window for interventions are not missed for helping with bonding and attachment. We focus on the parent-infant relationship-- how they interact with each other and how that provides neuroprotection for the babies. We work to find ways to support that even in a medically intense environment. We have adapted the child parent psychotherapy model for the NICU environment.

Every family is assigned a social worker, trained to identify the psychological needs of the family. They are skilled at an assessment of family conditions and can assess for financial needs or any other resources they need. They identify families who may need the additional interventions provided by our infant mental health specialists. We can provide therapy for up to one year (or more if needed), home visits, and individualized counseling on reading and responding to a newborn's cues. Each family also receives the brochure on "having a baby in the hospital" which describes the experience that families go through, the stress, indicates resources available and how they can access the services if they need them. Every family in the NICU can receive our program in a dose-specific intervention that is tailored to family needs."

-- *Clinical Psychologist*

#### *Nutrition (Breastmilk Feeding and Breastfeeding)*

Feeding of small and sick newborns is a high priority in the United States. Mother's breast milk is the feeding of choice and begins during tube feeding. There is a cadre of lactation consultants, and many nurses are trained to provide lactating mothers with support and counseling early on. Due to the acuity of patients served, it is expected that breastfeeding

may take time to initiate. However, refrigerators and electric breast pumps are available in the facilities, and mothers are encouraged to express and refrigerate their milk.

If a mother's breast milk is unavailable, pasteurized donor human milk can be provided to infants who meet the facility's criteria.<sup>1</sup> Donor milk is available on a limited basis because it is expensive and the cost is not commonly covered by insurance. The hospital will pay for a limited supply upfront, knowing it is the next best thing to mothers' milk. This is provided to newborns when their mother's milk does not come in, later switching to formula.

One of the facilities had a milk analyzer which provides information on the lipid content of mother's or donor milk. Milk analysis is initiated when newborns are not gaining weight as expected. Breastmilk is sometimes supplemented with formula to ensure adequate growth.

Preterm newborns who do not meet the criteria and do not have breastmilk from their mothers are given premature formula that is high in protein. Dieticians are involved in the management of formula as newborns transition into different formulas as they grow.

Feeding guidelines were available at the facilities. For example, at Children's National Hospital in Washington DC, the goal is to initiate feeds within 24 hours of admission and preferably no later than 24 to 48 hours of life to prevent gut atrophy, facilitate gastrointestinal maturation, and shorten time to full feeds.

Occupational therapists work with newborns early on to help induce suckling reflex. Cue-based feeding is used to assess newborn readiness. Oral feeding cues include sucking on a pacifier, fingers, or feeding tube; rooting reflex; hand to mouth behaviors; mouthing movements; and inability to settle after a diaper change. Non-nutritive sucking is practiced where babies are put on mothers' dry breasts.

### *Sensory Environment, Stimulation, and Interaction*

The United States facilities were thoughtful and cautious about maintaining a sensory environment that was neuroprotective. Some facilities have clear protocols in place, while others do not. The *Nursing Practice Guideline* document at Children's National provides

### *Barriers to Breastmilk Feeding*

While there is a great deal of support for lactation in most hospitals, rates of exclusive breastfeeding in the US remain lower than those of other highly developed nations. Many factors can influence breastmilk feeding in the US. A few of these include:

- Recovering mothers may have difficulty establishing a supply
- Lack of parental leave
- Work that does not support pumping
- Cultural reasons
- A lack of family support
- Critically ill newborns may be separated from their mothers after birth

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<sup>1</sup> One unit's criteria for use of donor milk: infants below 1,500 grams or less than 30 weeks gestation or for newborns with history of necrotizing enterocolitis, abdominal wall defects, bowel resection, or short bowel syndrome.

### *Protecting Light at Children's National*

The unit maintains low lighting whenever possible for neonates less than 32 weeks of gestational age or less than 1,500 grams. It is standard practice to cover the eyes of such newborns during periods of bright light. Those that are less than 30 weeks of gestational age have an incubator cover to reduce lighting. However, periods of low lighting are provided during the day. Care is taken not to assess pupil reactions for babies under 30 weeks of gestational age.

For babies between 33 and 35 weeks or for those newborns weighing more than 1,500 grams, low lighting is maintained during sleep times and if on incubators, covers are weaned off so that newborns become more accustomed to the light.

For babies at 35 weeks of gestational age or for those born full term, the development of a circadian rhythm is encouraged by increasing room light during the day and decreasing during the night. Bright sunlight is avoided.

detailed guidance on environmental and sensory stimulation, noise, and neonatal development.

Noise is kept to a minimum in the intensive care unit setting. Private rooms make it easier to manage the sound and light levels. Cell phone use is discouraged at the bedside to avoid unnecessary noise.

### *Supportive Positioning*

Care is taken to position newborns in a developmentally supportive way that reflects what is appropriate for gestational age and level of acuity. There are a plethora of positioning devices used, including different swaddles, the bendy bumpers, gel pillows, sheepskin, nesting, blankets, and foam supports. To promote head shape and reduce pressure points, one participant reports that gel packs are placed under newborns' heads. Nurses rotate the opposite ends of the beds twice weekly to promote alternate visual stimulation and to prevent torticollis. Swaddling is used to calm irritable newborns, to promote sleep, and to protect medical devices. Older newborns are put in a prone position during periods of wakefulness to support their core development.

### *Reducing Stress and Pain*

Clinicians in the US facilities recognize pain and stress in newborns and try to mitigate negative experiences using both pharmacological and non-pharmacological means. For example, pacifiers are one non-pharmacological measure commonly used to comfort a newborn. Providers prescribe medications for more invasive procedures, surgeries, and during the post-operative period.

### *Protecting and Promoting Sleep*

Protecting sleep in the neonatal intensive care unit can be challenging, as care requirements occur every three hours in the intensive care unit. The participants reported making a concerted effort to try to avoid intervening outside of the care period unless the newborn was critically ill. Therefore, nurses and respiratory therapists tend to cluster all of the interventions around the care period. Once they have finished providing care, they cover the newborn's isolette and allow the newborn for rest in between.

### *Protecting Skin*

The participants reported that great care is made to avoid skin injury, although it can happen in spite of diligent efforts. Nurses regularly screen for any signs of infiltration on IV site or

burns, which can happen on IV calcium lines. Necrosis on arterial lines occurs, although it is rare. Injuries due to nasal prongs have started declining. Respiratory therapists are very vigilant and check a few times a day for an early sign of skin breakdown for CPAP and oxygen cannulas. If that happens, one participant mentioned that the respiratory therapist would quickly switch to a mask to allow the skin to heal.

### *Follow-up Post-Discharge*

Most preterm newborns are discharged close to term age, but discharge criteria are based on several factors. There is no specific discharge weight, but one participant said that they try to get the newborn to a minimum weight of 1,800 grams before they go home. The newborns must be temperature stable and be able to tolerate the bed flat for safe sleeping. Most newborns are sent home breast or bottle feeding. One participant noted that sending newborns home on nasogastric tube feedings was dangerous. Gastrostomy tubes are placed when deemed medically necessary.

Every facility has a similar set of criteria to be checked off before discharge. In the United States, it is common to test a newborn in their car seat for 90 minutes to verify that they can maintain their oxygen saturation. In Colorado, where the altitude is high, oxygen-dependent newborns are also put on a 'room air challenge' to ensure that they will not desaturate if their cannula is removed. It is not uncommon for very preterm newborns to be sent home with supplemental oxygen. They are followed up by primary care providers or pulmonologists.

Initial hearing and vision screenings occur while a newborn is an inpatient. If ROP is detected, the newborns will be treated or linked with an ophthalmologist for follow-up care.

Caregivers are educated on care and equipment use, as appropriate. They are encouraged to learn their newborn's likes and dislikes and have information on safe sleep. In one facility, families receive a brochure that describes the "Preemie Pathway" and introduces them to the Child Development Program.

Most of the premature newborns come to the neurodevelopmental follow-up clinic within the first month. Then they have appointments scheduled every four to eight months that attend to neurodevelopmental issues. The medical needs are met in different specialized clinics. The number of appointments can be overwhelming for parents, which is why one participant said: "we are trying to combine some of the clinics because parents have to go to several different clinics and we want to make it more convenient for them to attend them." Children born preterm are typically followed up to two years. If they still have needs after that, they transition to clinics for older children.

The urban centers also have complex care clinics for children with lots of needs (e.g. tracheostomy, gastrostomy tube). Social workers and case managers work with the families that require complex management post-discharge and lack insurance coverage. They advocate on the family's behalf to get them nursing support, whenever possible. The level of support varies by the comprehensiveness of the insurance benefit and whether the child qualifies for Medicaid coverage.

The priority in preparation for discharge is to support the parents in feeling ready and engaged with their babies. During the discharge process, parents choose a pediatrician, and a formal handover is made. The hospital staff create a discharge summary and usually make a phone call to the pediatrician to ensure the continuation of care. The initial visit is usually recommended within the first three days after discharge.

"I recognize and appreciate the joy of parenting babies with developmental delays and the awareness of their each having unique potential. But when parents are new to this role, it becomes harder for them to adjust. Our goal when we work with such parents as they are getting ready to take their babies homes is to help them feel supported and connected to their baby, whatever their child's developmental outcome will be. We make them aware that they are not on their own and that there is a network of support."

-- *Clinical Psychologist*

The hospital staff will make a referral to early intervention services for any at-risk newborns. Early intervention programs are available nationally and administrated by the state. Every state has its own eligibility criteria for the use of the service. While eligibility criteria vary, any child could be referred and evaluated. The early intervention assessors will go to the child's home and assess and determine the need for therapy, which will continue to age three. Therapists provide care up to three times per week, as needed.

## Country Case Study: Colombia

### *The home of KMC continues to champion nurturing care*

Colombia is the birthplace of KMC, as the practice was created and developed in 1978 by a team of pediatricians in the Instituto Materno Infantil in Bogotá.<sup>(78)</sup> KMC continues to be the dominant method of care provision in the country where both evidence and support have been building for decades. The government and clinician buy-in of KMC and related nurturing care activities have fostered an enabling environment for parent partnership. This has allowed Colombian providers to remain leaders in nurturing care in Latin America and throughout the world.

In the last few years, newer components of nurturing care have been adopted in policies, protocols, and practice. Often, these efforts are incorporated into the standard KMC practices, giving each practice a slightly different flavor than other countries. Partnership with parents is integral with KMC, which provides a solid foundation for nurturing care to be continued into the home environment.

### *Methodology*

For this case study, the research team spoke with and received written inputs from six Colombian champions for newborn care including neonatologists, a pediatric neurologist, a child psychiatrist, researchers, a representative from the Kangaroo Foundation, and a government policymaker. The interviews were conducted in English, and the written Spanish responses were translated into English. The participants' responses are summarized below.

### *Facilitators and Barriers of Nurturing Care*

Described below are the facilitators and barriers for nurturing care. These factors have been arranged by the intervention in the logic model (see page 16).

#### Country Demographics: Colombia

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 8 Total: 5,850
Infant deaths <sup>1</sup>	Per 1,000 live births: 12.7 Total: 9,297
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 14.7 Total: 10,841
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	8.84%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	10%

<sup>1</sup> UNICEF. Country profiles Columbia [Internet]. New York: UNICEF; 2019 [cited 2019 June 20]. Available from: <https://data.unicef.org/country/col/>

<sup>2</sup> March of Dimes. Born too soon the global action plan on preterm birth. Arlington (VA): March of Dimes; 2010 [cited 2019 June 19]. Available from: <https://www.marchofdimes.org/mission/global-preterm.aspx#tabs-3>

<sup>3</sup> The World Bank. Data: Low -birthweight babies (% of births)[Internet]. Washington: World Bank; 2011 [cited 2019 June 19]. Available from: <https://data.worldbank.org/indicator/SH.STA.BRTW.ZS>



“The review of evidence and scientific findings is fundamental. However, it is necessary to incorporate the research findings into public policy, to achieve an adequate transfer of knowledge between science and the reality of clinical care.”

-- Ministry of Health and Social Protection representative

### *Laws and Policies*

The Ministry of Health and Social Protection, in collaboration with the World Food Program and the Kangaroo Foundation, published the first KMC policies called *Lineamientos Técnicos para la Implementación de Programas Canguro en Colombia* (“Technical Guidelines for the Implementation of KMC Programs in Colombia”) in 2010. In 2014, multiple partners including the Kangaroo Foundation, various universities, and the Ministry of Health and Social Protection collaborated to write the *Guía de Práctica Clínica del Recién Nacido Prematuro* (“Clinical practice guidelines for the management of premature

infants”). These guidelines include aspects of developmentally supportive care for newborns in inpatient care, starting from the delivery room. Three years later, the Ministry of Health and Social Protection published the *Actualización de los Lineamientos Técnicos para la implementación de Programas Madre Canguro en Colombia, con énfasis en la nutrición del neonato prematuro o de bajo peso al nacer* (“Update of the Technical Guidelines for the Implementation of Kangaroo Mother Programs in Colombia, with emphasis on nutrition for premature or low birth weight newborns”).

The Kangaroo Foundation has a significant presence in Colombia and been working in the research and diffusion of KMC since 1989. The Foundation has a remarkable partnership with the Ministry of Health and Social Protection to move the nurturing care agenda forward in Colombia. For example, the Kangaroo Foundation was asked by the Ministry of Health and Social Protection to draft the first and the last technical guidelines on KMC and management of premature infants. Since 2006, the Kangaroo Foundation also organizes a national workshop with the Ministry of Health and Social Protection every two years.

There are many national professional organizations in Colombia which have been instrumental in paving the way for the care of small and sick newborns. These include the Colombian Pediatric Society (SCP), the Colombian Academy of Pediatrics and Child Care (ACPP), the Neonatal Colombian Association (ASCONI) as well as various universities such as the Universidad Nacional de Colombia, the Pontifical Xavierian University, and the Universidad de Antioquia. The Kangaroo Foundation and other KMC champions in the country are well linked into international networks such as the International KMC network (INK) and KMC Acceleration Partnership (KAP). Since its creation 20 years ago, and with the support of many international non-governmental organizations, the Kangaroo Foundation trained more than 70 teams from 35 developing countries in KMC practices.

### *Skin-to-Skin and Kangaroo Care*

KMC is widely practiced and accepted in neonatal units of first, second, or third level care complexity hospitals. Currently, Colombia has 53 hospitals with KMC programs distributed in 35 regions of the country, the vast majority of these in public hospitals. The participants reported practicing all four components of KMC, as defined by WHO.

To bolster the KMC program, the Ministry of Health and Social Protection developed the technical guidelines mentioned above, translated as “Update of the Technical Guidelines for the Implementation of Kangaroo Mother Programs in Colombia, with emphasis on nutrition for premature or low birth weight newborns”. The Resolution 3280 of 2018 established the obligation to provide the KMC program to all preterm or low birth weight infants throughout the country when a newborn is considered stable, per hospital protocol.

“Skin-to-skin is practiced every time that is possible. The more contact the newborn has with his parents, the better. One challenge has been when the mother is not available, often when she is in recuperation. To overcome this, we encourage fathers to the initial contact skin-to-skin initially in the NICU.”

-- *Clinician at a Military Hospital*

Intermittent skin-to-skin is initiated in neonatal units once a newborn meets facility protocol for stability and age. For example, in the military hospital, newborns less than 30 weeks are required to be in an incubator. In the university hospital, stability is defined as when a newborn can be touched and transported to the mother’s chest without any changes in vital signs. One participant reported that they have tried to initiate skin-to-skin when infants are intubated or have an umbilical catheter.

To determine if a newborn is stable enough to initiate KMC, health workers try short sessions. The time in KMC is increased as the newborn’s condition remains stable. In the two large hospitals included in this case study, KMC is practiced at the side of the crib or incubator. Screens or curtains provide some privacy if needed. Wraps are often used to keep newborns in place.

There are no separate KMC wards, as Colombian clinicians prefer to incorporate KMC throughout the inpatient experience. Parents have chairs to sit in next to the newborn's crib or incubator, but the comfort and functionality of the chair differ by the facility. At one hospital, the average time spent in KMC for stable newborns was reported as 10 hours.

Newborns are discharged home in the KMC position as soon as they are stable and the staff feels parents can handle the care at home.(78) Ambulatory KMC is provided with strict follow-up to 40 weeks of gestational age. High-risk newborns are followed-up to one year of corrected age.

One barrier to KMC includes transportation costs for parents to come back and forth to the hospital. Additionally, there has been some initial resistance from health care workers, although it has decreased significantly with time and practice. From a country perspective, respondents reported that it was challenging to ensure KMC program coverage to all facilities for all small and premature newborns. One participant stated that it often took some time to convince parents to try KMC because they perceived their newborn as too fragile to touch. However, the participants found that most parents came to appreciate KMC with encouragement and experience.

The weather can become quite cold in mountainous regions of Colombia, such as in Bogotá, so regulation of temperature for newborns in neonatal units is often needed. Staff initiate skin-to-skin or use incubators based on the gestational age and condition of the newborn.

The temperatures of newborns are monitored continuously using a peripheral skin probe placed near the liver. When they are in incubators, the heat and humidity is regulated automatically. Staff members are taught about the importance of maintaining a neutral thermal environment. Emphasis is also placed on ensuring the operability of the incubators, with health officials making regular visits to the intensive care units to verify the status of the equipment. Nurses are also taught to check every change of shift to ensure the incubators are functioning. "Wherever you go in Bogotá, you will see the rule of maintenance put up on the incubators so that all providers and parents are aware and follow it," reported one participant.

### *Partnering with Parents and Families*

Colombian respondents reported having an "open NICU" which meant that there were no restrictions to visiting hours in neonatal units. This practice has developed organically and not through a specific protocol. The promotion of open neonatal units was carried out through a particular work process in a public-private partnership within the framework of *De Cero a Siempre* ("From Zero to Forever") in 2016.(79)

"When a mother can stay 10 or 12 hours in the unit, she learns to do everything on her own. The goal of the nurse who is working with her is to ensure the mother is confident to take care of her baby at home. The mother opens the incubator, takes her baby, and puts on skin-to-skin or feeds. There are no activities they are not involved with. Mothers stay during the visit and participate in all of the procedures. When both the mother and baby are deemed well enough, the dyad is ready to be discharged home with an adequate follow-up in a kangaroo mother care program."

-- KMC Foundation representative

All respondents noted the importance of partnering with parents during hospitalization. Upon admission, nurses mentor mothers on the care and ways they can assist while in the intensive care unit. Parents are instructed and shown how to follow strict infection prevention procedures. Parents are encouraged to participate from the earliest days of the admission with essential caregiving responsibilities (diaper changes, feedings, etc.).

Once the newborn is stable, parents can actively participate more with KMC. While the university hospital respondent noted that parents are involved with all procedures, the military hospital respondents reported that parents were not involved with clinical procedures.

There are no national policies that specify the provision of lodging, bathing, or food facilities for mothers, fathers, and caregivers of hospitalized

newborns. Sleeping quarters, food, water, and bathroom options vary widely across the various KMC programs in the country. Some facilities have nearby free or low-cost shelters while other hospitals offer sleeping dormitories. Other facilities will have social workers who will work with families who cannot afford transport money or have other barriers to visiting. "Sometimes, we need to help families with costs of transportation," said one participant. In one of the hospitals, the Ronald McDonald House charity offers services to parents in the hospital. The participants from the military hospital included in this case study reports giving three free meals to breastfeeding mothers, but this does not seem to be the norm.

Colombia has both private and public health insurance. One respondent said that the KMC program in Colombia is free of charge for parents and that the health system in Colombia works with public and private insurances so that the cost for the care of the infant is low. The obligatory health plan published by the Ministry of Health and Social Protection includes coverage for newborn care. “The structure of a KMC program unit make the care of a kangaroo patient cost-effective in relation with the traditional minimal care in hospital,” said one participant.

Across participants, it seems that helping families of small and sick newborns is supported. Families often have access to social workers and psychological services. In the military hospital, parents have access to psychiatric support. Group support sessions are held for parents, grandparents, and siblings while the newborn is inpatient, and are also part of the ambulatory KMC programs. Parents can get individual support in these sessions as well as collective support from other families that have gone through similar experiences. In addition, parents have access to psychological and psychiatric help. This support is especially critical when the new parents require “help to understand the critical situation of their newborn and sometimes accompanying in the process of death,” said one participant.

#### *Nutrition (Breastmilk Feeding and Breastfeeding)*

The participants were well-versed in the policies to support the promotion of breastmilk feeding. The protocols that guide practice around breastmilk feeding and breastfeeding small and sick newborns include the *Ten-Year Plan for Breastfeeding (2010-2020)*, Mother and Baby Friendly Hospital Initiative Protocols, and the *Guía de Práctica Clínica del Recién Nacido Prematuro* (“Clinical practice guidelines for the management of premature infants”), among others. These guidelines have been incorporated into the country's *National Development Plan 2010-2014* and *The National Development Plan (NDP) 2018-2022*.

“The review of evidence and scientific findings is fundamental. However, it is necessary to incorporate the research findings into public policy, to achieve an adequate transfer of knowledge between science and the reality of clinical care.”

-- *Ministry of Health and Social Protection representative*

There are at least 15 milk banks in Colombia, but only one of the facilities included in this case study had a milk bank onsite. This limits the availability of donor breastmilk. In March 2019, an update on the *Guidelines for Human Milk Banks* was published.

Feeding is started as early as possible. Breastmilk from the newborn's mother (whether from breastfeeding, syringes, or tube feeding) is the preferred option. Donor milk is the second choice, followed by formula. Since milk banks are not available in most hospitals, formula is used when breastmilk is not available. Breastmilk may also be fortified if the newborn is not growing. Preterm formula is used where appropriate.

In newborns weighing less than 1,500 grams who cannot tolerate full enteral feeding, staff members provide both total parenteral feeding and breastmilk. Trophic feeding (use of colostrum drop by drop) is started in the first 48 hours if the newborn is stable.

Non-nutritive sucking at the mother's breast is widely practiced, starting at 30 to 32 weeks gestational age. This may continue beyond 32 weeks of gestational age if the newborn is still fed through an oral or nasal tube and is not ready for complete sucking feeding.

"We do not have a milk bank, so we only provide the mother's breastmilk. But we are able to attain 78% exclusive breastmilk feeding, at discharge from the neonatal unit.

We begin with drops of colostrum. We call it trophic nutrition, use of the colostrum drop by drop even when the baby is on parenteral feeding

We monitor growth using Fenton's growth charts before term and WHO growth curves after 40 weeks of gestational age up to one or two years of corrected age. For babies that are not growing 15 grams per kilos every day, we fortify the milk with calcium, phosphorus, etc."

-- KMC Foundation representative

The participants reported that breastfeeding and pumping typically take place in the chair next to the newborn's cot or incubator. However, the majority of hospitals have a separate room for breastmilk expression that is a bit more comfortable and private. "The challenge is for the extraction room to be open 24 hours a day," one respondent noted, adding that "you have to keep reminding mothers the importance of feeding newborns with mother's milk, and there must be a counselor present to facilitate mother's extraction."

All nurses provide lactation support, but there are also some specially-trained lactation nurses available in some facilities. Services vary by facility, but participants mentioned other facilitators in interviews. These included staffing the breastmilk extraction room with nurses, hosting a "breastmilk group" in the institution during the day to help mothers and promote breastfeeding, and breastfeeding consultations for high-risk cases.

As breastfeeding is the second component of the KMC method, the same nurse responsible for the positioning of the premature newborn in kangaroo

position is responsible for the initiation of the breastfeeding as soon as possible. The nurse is also in charge of the mother-newborn dyad while both are still in the delivery room or in the KMC ward.

### *Sensory Environment, Stimulation, and Interaction*

The *Guía de Práctica Clínica del Recién Nacido Prematuro* ("Clinical practice guidelines for the management of premature infants") outlines the protocol for light and sound management in the neonatal intensive care unit. To manage sound levels, one participant noted that the intensive care units use a sound meter that show sound levels when they reach 60 decibels or above. This has helped reduce noise. One challenge has been to reduce the noise of the alarms. However, staff are aware and try to keep their voices low. Windows and incubators are covered with washable covers at specific intervals to maintain darkness.

### *Supportive Positioning*

Nurses practice nesting in intensive care units, either through commercial positioning aides or cotton sheets. Newborns are gently repositioned on an hourly basis. The supine position was most frequently used. However, if a prone position is needed to support breathing, nurses take care to keep the shoulder rounded and hips in a flexed position.

Nurses teach families how to position newborns, and positioning is checked on a routine basis throughout the day. The participants also noted that the lycra band to maintain the baby in kangaroo position was an important source of positioning.

### *Reducing Stress and Pain*

All of the respondents reported that stress, pain, and discomfort were taken very seriously in their facilities. For example, the respondent from the military hospital reported using the Neonatal Infant Acute Pain Assessment Scale (NIAPAS) to assess pain three times a day, and the CRIES scale in the first 72 hours after a procedure. For painful procedures, the military hospital uses a classification that helps them to identify the severity of the pain; and thus to be able to plan non-pharmacologic and pharmacologic intervention before the procedure.

Two clinicians interviewed said common non-pharmacologic ways to minimize stress during procedures was to do them when the newborn was in KMC positioning, in their parent's arms, or while breastfeeding. Sucrose was mentioned as another non-pharmacological intervention by the military hospital respondents, but not the participant from the government hospital.

“We are very alert on recognizing cues of babies in pain and stress. Painful procedures are done in kangaroo position with parents involved. If the mother is not there in the unit, we even have two nurses support. One holds and contains the baby, while the other draws the sample.

Providers have to change our mindset to think mothers cannot tolerate seeing their babies in pain. The mother feels good that she is doing something for a baby to decrease the pain.”

-- KMC Foundation representative

### *Protecting and Promoting Sleep*

The importance of sleep is well understood, but participants reported that there were challenges in protecting prolonged periods of rest. Nurses try to align caregiving cycles and sleep cycles, but there was a recognition that this can be hard to coordinate across all staff members. Unnecessary interventions are avoided at night, whenever possible. Nurses teach parents how to use KMC and massage to promote sleep. Parents were also instructed to decrease light and sound.

### *Protecting Skin*

Participants reported very little information about skin protection. One participant mentioned that skin injury was not an issue in their facility. For the military hospital, nurses do a skin assessment each shift to assess for skin breakdown and use prevention strategies to minimize or eliminate friction.

### *Follow-up Post-Discharge*

Parents or other caregivers are trained during their inpatient stay to ensure their competence in taking care of their small and sick newborn in the home environment. Caregivers are offered written materials to aid them in caring for their newborns at home, as well as materials about the outpatient KMC program. Parents are given a phone number to call in case they have questions once they reach home. “We aim for a short hospitalization,” said one respondent, noting that a mother’s ability to breastfeed and to carry her newborn in kangaroo position at home was the primary discharge criteria.

On average, newborns stay in the unit for 10 to 14 days according to gestational age at birth. Newborns are not discharged on tube feeding; if feeding support is needed it is provided by syringe. The other criteria for discharge is growth targets, which are usually not achieved until 32 weeks gestational age. Some newborns are sent home with oxygen, the cost of which is covered by insurance.

When it is determined that a newborn can be discharged, they are looped into the KMC ambulatory care program and given the date for a first outpatient follow-up appointment. Daily kangaroo follow-up is done until the child is thriving well, then weekly up to 40 weeks of gestational age and when the baby reaches 2,500 grams. The policy outlines that newborns should then be followed-up until two years of age, though some facilities follow-up for only one year. The military hospital respondent explained that they also arrange access to a variety of other referrals/exams at the time of discharge, such as occupational therapy, neurology, ophthalmology, audiology, etc. However, this access is currently only available to families with military insurance.

The first follow-up visit is 24 to 48 hours after discharge, and this initial visit is more extensive than other follow-up sessions. The mother is asked to attend with the father or another caregiver. Registered nurses specialized in feeding and KMC, paediatricians, and other specialists (such as social workers or psychologists) lead the sessions. Each child is assessed individually, and each family receives personalized recommendations. At the same time, the entire group is taught about KMC procedures and benefits. This methodology facilitates a collective learning process and connection with other families experiencing the same difficulties. The commitment to attend the daily consultations at the beginning of the outpatient KMC Program can be demanding on parents. However, it provides continuity of care as the structure is similar to the daily visits they did when the child was hospitalized, which creates a link between the hospital and home care.

In the ambulatory KMC program, an ophthalmologic screening is performed when a newborn reaches 32-33 weeks of gestational age to detect ROP. A full audiological screening occurs at 40 weeks of gestational age. During the first year of follow-up, the clinicians try to identify any deviations to a normal neurological or psychomotor development and refer them to early intervention services. All these activities are part of the early child development components woven into the national KMC program and guidelines. The KMC program offers a unique opportunity for Colombia's fragile infants to have a high-risk follow-up.

There are special centers where children with detected disabilities can be followed-up. Children with disabilities or those with developmental problems have the right to rehabilitation support, psychosocial support, and various related resources. In this case there is intersectoral coordination, especially with the education sector, the protection sector, and the social welfare sector. Children with disabilities or those with development problems have the right to education, and for this, educational institutions must make the necessary adjustments to ensure the long-term inclusion of children in educational settings. Parents are informed about these resources by different means and through the various responsible institutions.

### *Challenges and incentives for follow-up care*

Many parents experience difficulties with the logistics and costs of transportation required to make it for follow-up visits. Some facilities will call mothers who do not show for follow-up, as phone connectivity is functional even in remote places.

Home visits may be scheduled if the newborn is less than 40 weeks gestational age and has not been seen at a follow-up appointment, but this is rare. Resolution 3280 passed in 2018 calls for dedicated home visits for small and sick newborns following discharge. However, the implementation of this policy has not begun.

Some social workers can give transport cost incentives to needy families. Incentives for follow-up for families are usually provided to the More Families in Action Program, which is a money transfer program aimed at the most socioeconomically vulnerable families.



## Country Case Study: India

*This country makes tremendous strides in delivering evidence-based nurturing care*

Once the home of some of the bleakest neonatal statistics, in the past few decades India has made incredible strides to invest in sick and small newborns' survival.<sup>(80)</sup> The Government of India has made newborn health a priority and championed policies that foster an enabling environment for nurturing care. For example, the government has invested in a rapid scale-up of special newborn care units during the past decade. While this change has been a relatively rapid one, the transition towards nurturing care in India began decades before.

Components of nurturing care became an integral component of inpatient newborn care at the All India Institute of Medical Sciences (AIIMS) when the institute began collaboration with the University of Pennsylvania, Philadelphia in 1991. In 2000, an International Rotary exchange program with the University of Calgary continued this work. Another high-level partnership was fostered in 2016 between Lady Hardinge Medical College, Kalawati Saran Children's Hospital, and the Oslo University Hospital, Norway. Supported by the Norway India Partnership Initiative (NIPI) and the Ministry of Health and Family Welfare, this bilateral exchange program of doctors and nurses revolutionized care in the newborn units of the hospital. The Norwegian nurses spent six months to a year and Indian doctors and nurses spent three to six months at partnering institutions as part of the exchange program. This collaboration led to the establishment of the human milk bank at Lady Hardinge Medical College and Kalawati Saran Children's Hospital.

Even as early as 2011, the special newborn care unit guidelines in India have noted the importance of having the mother's bed next to the newborn to make family-centered care feasible. For example, around the time of the Asia launch of Essential Care for Every Baby in 2015, a 12-bed small newborn ward was created at Lady Hardinge Medical College. This ward housed all vaginally-born stable babies with birth weights between 1,500 and 2,000 grams and their mothers who provided KMC and assisted feeding with expressed breastmilk. In 2017, Safdarjang Hospital demonstrated the feasibility of keeping the mother with their sick and small newborn 24 hours a day, 7 days a week through the establishment of a mother-neonatal intensive care unit (M-NICU). The Government of India approved this initiative and sent directives to include beds for mothers in special care units. While policies are available to guide the care of small and sick newborns, widespread implementation in a vast, multifaceted country remains challenging.

### Country Demographics: India

Neonatal deaths <sup>1</sup>	Per 1,000 live births: 24 Total: 604,700
Infant Deaths <sup>1</sup>	Per 1,000 live births: 32 Total: 802,000
Under 5 deaths <sup>1</sup>	Per 1,000 live births: 39.4 Total: 989,200
Preterm birth rate (babies born <37 weeks) <sup>2</sup>	13.6%
Low birth weight rate (babies born <2,500g) <sup>3</sup>	28%

<sup>1</sup> UN Interagency Group for Child Mortality Estimation (IGME). Levels and trends in child mortality 2017. Available from: <http://www.childmortality.org>

<sup>2</sup> Chawanpaiboon S, Vogel JP, Moller AB, et al. Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. *Lancet Glob Health*. 2019 Jan;7(1):e37–e46.

<sup>3</sup> UNICEF. State of the world's children 2017. Geneva: UNICEF; 2017.

The Government of India is making remarkable efforts to improve the quality of care for newborns both during their inpatient stay and after discharge using quality improvement methodology.(81) India will continue to demonstrate to other low- and middle-income countries on how high-quality, neurodevelopmental support can be operationalized within a resource-constrained setting.

### *Methodology*

For this case study, seven high-level senior clinicians, policymakers, public health specialists, and policy advisors from different organizations in India were interviewed. Each participant was asked a standard set of questions with additional follow-up questions when clarification was needed. Interviews were mostly conducted in English with some Hindi interspersed. The Hindi responses were translated into English before all of the data were analyzed for themes.

### *Facilitators and Barriers of Nurturing Care*

Discussed below are the facilitators and barriers for nurturing care. These have been arranged by each intervention in the logic model utilized for the evidence synthesis (please see page 16).

#### *Laws and Policies*

The political will to improve newborn survival in India has led to rapid progress.(82) More recently, the Government of India has turned its attention to including the provision of nurturing care in policy documents. This government buy-in, in combination with the demonstrated successes of individual facilities, has led to a rapid translation into national policies and guidelines. A key example is the 2011 publication of the *Facility Based Newborn Care Operational Guide*, an initiative to operationalize the standardized inpatient care of neonates.(83) Before this policy, only medical schools (250 in the whole country) had any neonatal beds and facility for inpatient care. This policy articulated that success required a mother's touch and presence to augment neonatal care. Family Participatory Care guidelines (also known as family-centered care) were endorsed by the government as the national guideline for all Special Newborn Care Units (SNCUs) in the country. Prior to that, the Government of India had already endorsed the KMC and low birth weight feeding guidelines that build off in-country experience of implementing this practice in several hospitals in the country. The current Facility Based Newborn Care training modules have KMC and feeding of LBW as integral clinical practices for doctors and nurses.

“The needs of the newborns are thought to be as small as their size. There is also inadequate awareness that mother is an integral part of the care and she needs to be pampered if you want to provide care for her newborn. Hence advocacy is needed. The WHO has to create standards that speaks loud and clear that these are not luxury items, but the basic minimum of acceptable standards of care for small and sick newborns.”

-- Clinician, Tertiary Level

Many more policy documents about the components of nurturing care are currently underway. For example, the M-NICU, tested for feasibility, is now a directive for all SNCUs in the country and a toolkit will be developed to guide its implementation. Similarly, a 2018 publication in *Indian Pediatrics* that demonstrated the feasibility of supporting skin-to-skin after a cesarean section has been used to develop directives that were communicated to all

states in the country.(84) Guidelines will soon be released to facilitate the implementation of this practice.

The curriculum of medical and nursing schools and continuing education does not prepare clinicians to include nurturing care as the foundation of care for all small and sick newborns. This has created a barrier, for it is more challenging to unlearn what has been taught in the formative learning years. However, recently, a midwifery-training program was developed and plans are moving ahead for a specialized one-year nursing education program for inpatient newborns. Both offer opportunities for integrating nurturing care for small and sick newborn care as the foundation for strengthening medicalized care in facilities. The recently updated intensive care units protocols used at AIIMS include all elements of nurturing care and have been used to train physicians and nurses in the facility. This course and all associated tools are available for interactive learning through the establishment of blended e-learning using the latest pedagogy and mentoring.

Professional associations have not prioritized nurturing care as an integral element of standards of care. Instead, India has individual champions who have transformed care in their facilities. Their efforts have been bolstered by organizational partners and exchange programs. According to one participant, each newborn is now treated as a human being that can feel and respond to care. Now, the written protocols of the facility reflect this new approach. Similarly, the Government of India, with support from projects such as NIPI and the USAID-supported VRIDDHI project, is scaling Family Participatory Care throughout the country.

At the national level, the government and WHO have initiated discussions on early childhood development, and there is a potential for inclusion of nurturing care for small and sick newborns. So far, individual facilities have created this revolution in care. It will, however, take some time for the concepts and practices to reach the mainstream.

“Nurses and residents are very aware that KMC is medication and treatment and not to be done just casually. Nurses maintain records of hours of skin-to-skin and feeding in each shift. The sister-in-charge of every shift begins the duty by asking how many hours of skin-to-skin and how much of mothers’ milk is provided.”

---- Clinician, tertiary level

#### *Skin-to-Skin and Kangaroo Care*

KMC is a well-established norm of both intensive and special newborn care. Its importance is reflected in its inclusion in the national guidelines and policy documents.(85) Participants often used the phrase KMC to refer to a standalone skin-to-skin practice (without the four other elements that comprise KMC). These terms were commonly used interchangeably throughout the interviews.

There have been innovative delivery mechanisms tested in India, foremost among them being the M-NICU at Safdarjang Hospital. These new wards have been designed to include beds for mothers to encourage them to provide skin-to-skin as early and

as long as possible. In the M-NICU, KMC begins at admission for some of the sickest babies. As a component of critical care, 70 to 80% of their most acute newborns are cared for skin-to-skin for up to 18 hours a day, without the use of radiant warmer. The obstetricians in the hospital follow the mother’s care as they engage in the care of their small and sick babies.

The M-NICU is also creating bridges between neonatologists and obstetricians as well. The clinician leading the M-NICU at Safdarjang hospital emphasized, “with mother in the M-NICU, separate KMC wards will become redundant and will harmonize several interventions such as KMC, family-centered care.”

In one facility, a participant reported that skin-to-skin is initiated starting in the neonatal intensive care unit even when newborns are hooked up to CPAP, IV lines, or oxygen. In the same facility, clinicians have made a concerted effort to engage other family members such as fathers and grandmothers. A participant noted that “when grandmothers are engaged, other family members also accept the practice more easily and support the care in the intensive care unit.” This clinician reported that family members are encouraged by the weight gain and positive feedback by providers. The facility shows a KMC video and other educational materials so that family members can understand KMC’s benefits. “KMC is now a culture in our unit, and everyone does it,” says the clinician. This facility also ensures that mothers continue to provide KMC post-discharge at home as most preterm babies are discharged in India much earlier than in high-income countries.(86)

“Family centered-care is the overall underlying intervention, which is the foundation for all elements of nurturing care. It has to be first established before any aspect of nurturing care is initiated during inpatient care of small and sick newborns.”

-- Clinician, tertiary level

The same tertiary hospital has established a new unit just adjacent to the delivery room for stable small babies and mothers. With parents involved in care, according to this participant, the skin-to-skin practice expanded to 8 to 10 hours a day. While the data still needs to be analyzed, preliminary results suggest that infection rates have gone down, and newborns are discharged earlier.

“These are high-risk babies. The touch of the mother is needed for them since they are in pain and stress. The emotional bonding makes the babies secure which helps them recover very fast. So how is it possible to provide this care without having a facility that accommodates the mother? We can do without a few incubators in the unit, but we cannot do without the mother being at the side of the baby. This is the only way we can ensure the baby thrives and grows into a good citizen for the country.”

---- Clinician, tertiary level

#### *Partnering with Parents and Families*

Participants from all of the four tertiary hospitals noted that mothers and fathers are now integral partners in the care of the newborn in the neonatal intensive care unit. All four facilities have liberal visitation hours, with mothers being allowed to visit at any time. In almost all of the facilities, mothers enter freely every two hours for breastmilk feeding. Mothers are also encouraged to come at night for feedings.

Other female relatives, such as grandmothers, are also allowed to support and visit. Fathers are still not as commonly engaged in the care of their babies, but more and more of them are participating. In one of the facilities, the fathers' entry was limited to visiting hours, due to security worries.

There was initial resistance from health providers, including concerns of privacy. However, the champions of this approach, helped in part by nurses visiting from exchange programs, have

led to the change in culture. Participants reported that after health providers saw positive outcomes and became more confident in their skills, they have accepted parents as partners in care.

Two of the facilities noted a hospital policy that provides free services for mothers, and they are given beds to stay for as long as the newborn is inpatient. Beds come with all other facilities provided by the hospital, including food. However, at some hospitals, such facilities are available only for a short period for mothers who deliver in the hospital and are not available for other mothers. After much persistence, food and toilet facilities have been provided to mothers in the units. Beds and bathing facilities are still not available in every hospital.

All of the participants noted that there was adequate space for one member of the family to sit and stand next to the newborn's cot in the intensive care unit. Chairs provided are comfortable and suitable for skin-to-skin care.

While in intensive care, mothers, fathers, and caregivers are taught to engage in care. For example, parents clean, change diapers, practice skin-to-skin, feed, and provide positive stimulation. Family members also monitor for any injuries and help position their newborn. Mothers and family members quickly become empowered enough to share their experience with newer mothers and mentor them on skills needed to take care of their newborns in the unit. Lastly, family members are encouraged to be active and informed decision-making partners. In one facility, where family-centered care was tested, focus group discussions are frequently held with parents to discuss systematic issues and come up with solutions jointly. One participant reported that frequent focus group discussions between parents, nurses, residents, and faculty have become an essential feedback mechanism for management.

According to some of the clinicians interviewed, family-centered care and provision of nurturing care have broken many barriers between nurses and doctors. Senior nurses are now leaders who orient new doctors and nurses on family-centered care practices.

The Government of India has endorsed Family Participatory Care as the protocol for all care, and the guidelines are approved for country-wide implementation. This practice is defined as follows: "Family participatory care is based on the understanding that the family is the child's primary source of strength and support and their participation in the care of child admitted to hospital is important in decision making and long-term care."(87) While the country has done well in endorsing innovative policies, a lack of human resources, inadequate infrastructure, and the size of the country pose challenges to widespread adoption.(88) The national government continues to extend support to the state government to facilitate quality of implementation.

#### *Nutrition (Breastmilk Feeding and Breastfeeding)*

While the healthcare community has a full understanding and acceptance of the benefits of feeding human milk to small and sick newborns, the country's rate of early initiation of breastmilk feeding is low, at 42%.(89) This has been attributed to increasing rates of cesarean sections (8.5%) and a large number of low birth weight newborns that were not being breastfed shortly after birth.(89) Significant efforts are planned to improve this situation.

For example, in August 2016, the government of India launched the Mothers' Absolute Affection (MAA) program with support from UNICEF. MAA is an intensified program to enhance optimal breastfeeding practices, including early initiation of breastfeeding within one hour of birth. Among other activities, the program builds the capacity of health workers to support mothers initiate early breastfeeding, with emphasis on mothers recovering from a cesarean section. The Dr. Ram Manohar Lohia hospital in New Delhi has demonstrated successful early initiation of breastfeeding of newborns delivered by cesarean section.

The Government of India has created guidelines that will support the implementation of the MAA program. Comprehensive lactation management centers (CLMCs) are being established across the country that would support the feeding of small babies by encouraging the expression of breastmilk for newborns who are unable to suck. India has lactation management guidelines in facilities which are currently being integrated into the *Facility Based Newborn Care Operational Guidelines*.<sup>(90)</sup> One of the tertiary care centers has established a CLMC with support from Norwegian experts. This has been designated as the 'Centre of excellence' for teaching, training and mentoring for CLMC establishments across the country.

Participants of the tertiary facilities noted that it is standard practice to counsel parents on the benefits of breastmilk feeding but they acknowledged that mothers of sick and small newborns have barriers to lactation. For example, it was exhausting for mothers to provide skin-to-skin for hours a day and move in and out of the intensive care unit every two hours to express their breastmilk. Additionally, a separation between mothers and newborns after birth can make it difficult for women to establish enough supply to ensure successful breastfeeding outcomes. For newborns that have arrived by cesarean, the early initiation of lactation within one hour of delivery is often missed, which can make successful lactation more difficult later. One of the centers has initiated breast pumping in post-cesarean mothers in the post-operative ward so that their newborn received their mother's milk and colostrum.

Participants mentioned several initiatives that were designed to address these challenges. One facility's intensive care unit provides additional lactation counseling and breast pumps. All of the hospitals had space created next to the intensive care unit for mothers to have privacy while expressing their breastmilk. Some of the hospitals trained staff in the KMC units, post-operative delivery wards, and intensive care unit on how to best support lactation right after birth. In one hospital, an NGO had funded two dedicated lactation support staff.

One hospital has initiated a state-of-the-art human milk bank that ensures availability of human breastmilk for all babies in inpatient care, noting that in their facility, "early exclusive breastmilk feeding is the norm." In this facility, staff members pasteurize the milk. Human milk banks have not been established nation-wide, but other facilities in the area do use the milk bank's services when needed.

Small and sick newborns are provided with oral stimulation to support a later transition to breastfeeding. Non-nutritive sucking on mothers' drained breast, oral-motor stimulation, and use of fingers to stimulate the early onset of sucking reflex to initiate a smooth and rapid transition to full feeding on the breast was a regular practice in the tertiary hospitals.

### *Educating parents on age-appropriate stimulation*

Participants reported that teaching parents about how to respond to their newborns' cues was a regular practice in India. For example, one of the participants said: "we teach mothers how to respond to cues given and calm the baby when the baby is stressed." This education can be especially impactful since a preterm newborn may offer different cues than a full-term sibling, which can make bonding and feeding more difficult.

There was also some thought to providing positive stimulation and sensory input to newborns.

Mothers are taught to use visual sensory stimulation cards and talk to their newborns. Family members were encouraged to hold the newborn as much as possible.

Some facilities regularly provide education and counseling for parents both in the facility and after discharge. One participant noted that this education seemed to improve parental decision-making.

### *Sensory Environment, Stimulation, and Interaction*

Awareness of the effect of sound and light on the newborn's development is a more recent understanding. One participant noted that the concept of "dim and dimmer" is followed in intensive care units. At night, low lights and blankets over incubators are used. Some participants noted applying eye bands used during phototherapy to reduce light for preterm babies under radiant warmers and earplugs to mask the sound.

Sound was more challenging to control, but participants reported that staff were making efforts to reduce unnecessary noise. Deliberate efforts have been made to decrease the level of sound of alarms, restrict the use of mobile phones, and move discussions away from the bedside. Mothers were also educated and made aware of the detrimental effects of excess sound, which made both providers and families' more conscious about reducing noise. Some of the hospitals had devices that regularly measured sound levels.

One clinician spoke about being particularly sensitive to smell for newborns, arguing that it is another good reason not to separate the newborn from its mother: "Out of the primary sensations that the sick newborn brain conceives, the smell is the most important. The smell of the mother's milk is recognized – bringing mother closer stimulates the parasympathetic system," this participant reported. "Taking the mother away stimulates the sympathetic system and stress."

### *Supportive Positioning*

Positioning for neurodevelopmental care is a well-known, accepted, and experienced care practice among the clinicians interviewed. All four of the tertiary level facilities were practicing supportive

positioning and using locally appropriate materials to create an intrauterine position for the newborn.

In one facility, mothers were educated on the importance of correct positioning for their newborns' developmental outcomes and engage them in taking on this aspect of care. "Positioning is done by mothers," reported the clinician, adding that "we have found that they love taking care of their baby by keeping them in correct positions and by changing them from time to time."

During each shift, nurses record maintenance and periodic changes in position in patient care record sheets. For the most part, the newborn was kept supine or side-lying, but newborns were placed prone when they had difficulty oxygenating.

One participant reported that initially there was some resistance that positioning and containing newborns in warmers could make them too hot or could interfere with routine monitoring of vital signs. However, an assessment of time spent on these activities convinced the providers that the practice was beneficial and would not take additional time. Since then, supportive positioning has become an “integral care component,” according to one of the clinicians interviewed.

### *Reducing Stress and Pain*

Participants noted that in previous years there was a general lack of recognition that newborns felt stress and pain. There is, however, a growing awareness that neonates could feel pain and, therefore, should be better protected for their neurodevelopment. In one facility, Norwegian nurses had introduced the idea of pain management to the staff. Since then, this facility’s staff began appreciating that their actions are stressing the newborn and have been more careful to avoid triggering stress and pain, except for when needed. One participant mentioned that they were particularly conscious of not making newborns cry by trying to pick up on cues of stress ahead of time.

More recently, providers have begun teaching mothers how to recognize stress as well as measures to be taken to calm the newborn. There are differing approaches to employing parents to help mitigate stress to newborns during procedures. For example, some invited mothers and/or fathers to stay and hold their babies and had a very positive experience of their participation. “As much as possible, parents are allowed to hold their newborns, keep them in skin-to-skin care, and breastfeed during any painful procedures,” one participant said, noting that nurses held the newborns when parents were not available. Other facilities routinely asked mothers to provide breastmilk and then requested they leave the room before any procedure is undertaken.

The COMFORTneo Scale is used to assess babies in one facility; especially those at risk for stress.<sup>(91)</sup> However, the participant cited inadequate human resources as the most significant impediment in undertaking such assessments.

Pharmacologic measures, sucrose, and pacifiers are not generally used for pain management. Participants reported using non-pharmacologic strategies to reduce pain and stress such as holding the newborn, using supportive positioning and containment, practicing skin-to-skin, and breastfeeding.

### *Protecting and Promoting Sleep*

There was overall awareness of the importance of safeguarding sleep for improved developmental outcomes and a clear understanding of the role of sleep in both brain growth and weight gain. Sound and light management were two strategies used to facilitate sleep for small and sick newborns. Participants reported that the clustering of care was a common practice. By bundling activities at the same time (e.g. examining the newborn, taking temperature, providing medicines, feeding, sampling, cleaning, change diapers), newborns



were disturbed less often. However, the participants felt that there needs to be someone in the unit that can advocate on behalf of their patients for rest.

The participants reported that it was not always practical to let the newborn sleep if it is time for a feed, which can happen every two hours. This reality meant that it was challenging to support longer sleep periods. The clinicians interviewed thought that more strategizing was required to promote more extended periods of productive rest for inpatient newborns.

### *Protecting Skin*

Injuries have decreased immensely with improved equipment and procedures. For example, Tegaderm and Argyl nasal prongs have reduced adhesive and CPAP prong injuries. The practice of providing cushions near the nasal bridge also can minimize damage.

Another facility has decreased IV site extravasation by monitoring sites every hour. One participant noted that protocols of IV fluids have been changing for better practices such as the use of Venflon, decrease in the use of IV fluids, change in the protocol of IV calcium for all babies, and starting up minimal enteral nutrition early on. One facility reported many small and sick babies (80%) received only enteral nutrition and no intravenous line and no intravenous fluid or alimentation. This practice has tremendously reduced skin breach, infections, and other morbidities of the preterm neonates.

The participants also noted that the engagement of mothers in intensive care units helped both identify and prevent injuries.

### *Follow-up Post-Discharge*

Special attention is paid to discharge education and follow-up care. Parental readiness and confidence were noted as critical drivers for patient discharge. The participants reported that Family Participatory Care practices had taught parents valuable caregiving skills that translated into the home environment. By the time of discharge, parents had already learned how to wash hands, how to interact with their newborns while breastfeeding, and how to change diapers.

Regular counseling sessions during the inpatient stay also ensure that parents are knowledgeable of their newborn's issues and future needs. Facilities have prioritized and tried to ensure that mothers and family members are well versed on danger signs for timely care-seeking. One way to reinforce learning is the Mother Child Protection (MCP) booklet of the Ministry of Health and Family Welfare and the Ministry of Women and Child Development. The booklet is given to parents before discharge, and includes information on care ranging from antenatal through postnatal periods, as well as information on danger signs for illness and developmental delays, vaccination schedules, developmental milestones, and hygiene. The booklets include pictures and visual elements to make it easy to understand.

During the inpatient stay, newborns are screened for ROP and hearing impairment. Improved practices in the intensive care unit, however, have decreased the incidence of both disabilities.

Before discharge, providers do their best to ensure mothers are competent in breastfeeding their newborns. At times, however, newborns have had to be discharged on expressed

### *How one facility follows newborns at highest risk*

“For babies with very high risk, we provide individualized care on managing tone, visual stimulation, and overall developmental support. We have an Early Interventionist on our team.

We have jointly developed a high-risk follow-up framework – a high-risk baby gets a unique identity during stay in the facility. These babies are prioritized for follow-up; phone calls are made if they miss a visit. These babies are followed up for nutrition/growth, medical issues, neurodevelopment (including screenings for vision, hearing, and speech) and immunizations.

Early interventions are done, starting from the time they are in the facility. Babies with any high-risk sign receive individualized early interventions that are integrated into activities of daily life. Babies are followed up to three years of age.”

--- Clinician, tertiary level

breastmilk, because of the sheer pressure of overcrowding. The Government of India recently published the *Home based care for young child (HBYC) Strengthening of health and nutrition through home visits: Operational Guidelines* which calls for children in the early stages of life to be monitored for growth and feeding practices.(92)

Hospitals have their preferred frequency and timing of follow-up. At one hospital, parents are asked to bring back newborns for the first follow-up after 48 hours of discharge, and the focus on this visit is to ensure the newborn is adjusted to the home environment and has not lost weight. The next follow-ups occur after two weeks, and so on, depending on the size and progress of the newborn. After that, the child is seen on their immunization schedule. While providers advise that newborns be closely followed until age two, a majority will fall off at 15 months when their vaccinations are completed. This is often the case when parents feel that their child is growing well in relation to their peers.

In the first few follow-up visits emphasis is on ensuring adequate feeding, anthropometry (i.e., weight, length, and head circumference), immunizations, and a development assessment. For the latter, the Trivandrum development-screening test (TDST) is administered. If a delay is discovered, the child is referred to the Department of Physical Medicine and Rehabilitation for a complete development assessment using the Development Assessment Scale for Indian Infants (DASII). Appropriate occupational therapy is initiated to achieve a normal tone to ensure the full potential for growth and development.

Lastly, India has a complete screening program through the district early intervention centers (DEIC) that screens all children, from birth to 18 years of age. The program is new and has not been fully implemented in every state due to a shortage of human resources and equipment.

The DEIC screens for the ‘4Ds’: defect, developmental delays, deficiencies, and diseases. Efforts are now underway to link all small and sick newborns with these early district intervention centers. Parents are also being informed about the services available at the DEIC during their newborn’s inpatient visit. If a developmental delay is observed, the centers provide occupational therapy.

In spite of the practical challenges in service delivery, the range of offerings is ambitious. The Government also provides free transportation, free diagnostics, and free treatment or medications, including surgery, for children up to one year of age. Some states have extended these services to five years of age.

## Country Case Studies: A Summary

Seven countries were selected to review nurturing care practices throughout the globe. Two countries were considered low-income (Nepal and Rwanda), three were middle-income (Colombia, India, and the Philippines) and two were high-income (Sweden and the United States).

Nearly all the participants interviewed were familiar with neurodevelopmental supportive care interventions and the rationale behind them. Their ability to implement these practices varied tremendously, due in part to a lack of human capital, resources, infrastructure within facilities, family involvement, and supportive policies. In high-income settings where there was adequate staffing and equipment, nurturing care practices were more highly prioritized.

Often, clinicians were forced to put nurturing care on the back burner and prioritize life-saving care. There was an awareness that, at times, long term developmental outcomes were compromised in favor of short-term survival. Despite these challenges and substantial differences in resources among the countries, there were many instances where low- and middle-income countries found creative ways to weave nurturing care practices into everyday clinical operations. The creativity and resourcefulness of LMIC clinicians in fostering neuroprotective care, even when elements of essential newborn care had not been fully implemented, was laudable.

### *Facilitators and Barriers of Nurturing Care*

Summarized below are the interventions and some of the highlights from the participant interviews.

#### *Laws and Policies*

There was a substantial role of national laws in the ability for parents to care for their newborns. The standout was Sweden where health care is universally covered and generous parental leave policies enable caregivers to participate more fully during the hospitalization and in the home environment.

More recently, the government of the Philippines has expanded its government-owned and controlled insurance (called the Philippine Health Insurance Corporation or PhilHealth) to include a benefit package for small and sick newborns.

Clinical protocols were also critical to ensuring high-quality care. Overall, the participants were highly knowledgeable about the national/regional policies (or lack thereof) that guided their practice. For example, the participants from Nepal were guided very closely by their national policy document, the *Nepal Every Newborn Action Plan*.

#### *Skin-to-Skin and Kangaroo Care*

Skin-to-skin care was perhaps the most practiced of the interventions throughout all seven countries. Colombia had the longest history and perhaps the most rigorous policies and practices around skin-to-skin. This was perhaps the only place where all four components of KMC, as defined by WHO, were routinely employed. One near-universal challenge that many participants reported was difficulties in supporting the continued KMC after discharge, perhaps due to a lack of community or family support for the parents. Another common

barrier to KMC was a lack of clear criteria for what type of stability would guide the initiation of skin-to-skin.

### *Partnering with Parents and Families*

A growing awareness of the importance of providing family-centered care was universal, although the strategies for engaging families varied by context. For example, India is in the process of rolling out its much-recognized Family Participatory Care program which engaged mothers in care in their specialized newborn care units (SNCUs). A randomized control trial of this intervention showed increases in the rates of exclusive breastfeeding without a higher incidence of infection.(93) In the United States, the advocacy of Family Advisory Councils has been an instrumental facilitator of family engagement. More recently, a new focus on infant mental health in the United States recognizes the psychological vulnerability of both newborns and their parents and attempts to promote attachment.

### *Breastmilk and Breastmilk Feeding*

Breastmilk was highly prioritized by all participants, although resources did not always allow for its promotion. A cadre of lactation consultants were available in many of the countries, but their presence was not needed in others. Nurses were trained to provide lactation support to mothers in all countries, with the understanding that supporting breastmilk feeding was everyone's responsibility. Milk banks were becoming increasingly important sources of nutrition for vulnerable newborns, most notably in the Philippines and Colombia.

### *Sensory Environment, Stimulation, and Interaction*

Nearly all of the participants reported challenges in ensuring a protective environment for newborns. Most facilities kept the lights as dim as possible, in some cases covering isolettes or windows to block light. Minimizing sound however, was more of a challenge. The alarms and sounds of speech were difficult to reduce. A few of the facilities had measured noise regularly, but the majority had felt that there was more to be done to make the sensory environment more neuroprotective. Perhaps the most robust policies to protect newborn's environment was at one large urban facility in the United States where specific light and sound protocols were detailed by gestational age.

### *Supportive Positioning*

Participants reported that supportive positioning was practiced in almost all of the countries profiled. In Nepal, mothers are engaged in positioning using locally-available materials. In Sweden, the supine position is used for sleep and as an educational experience to teach parents about safe sleep practices for infants.

### *Reducing Stress and Pain*

Every participant interviewed recognized that newborns were capable of feeling stress and pain. In Rwanda, mothers were engaged in nurturing care activities (e.g. KMC, breastfeeding, and holding) during routine procedures to minimize the newborn's stress. Colombia also routinely involved parents in similar activities during procedures. In one military hospital, clinicians also employed the Neonatal Infant Acute Pain Assessment Scale (NIAPAS) pain scale to assess pain three times a day.

### *Protecting and Promoting Sleep*

Perhaps the single greatest challenge of all facilities was supporting periods of rest among newborns. All participants appeared to be aware of its importance, but disturbing newborns' rest often seemed unavoidable.

### *Protecting Skin*

Preventing skin injuries was difficult in many of the facilities, regardless of the income level of the country. The participants in India reported seeing enormous improvements in the past few years due to an hourly monitoring of IV sites. Participants noted that another benefit of engaging parents in care was that injuries were identified and addressed more quickly.

### *Follow-Up and Screening*

The follow-up and screening procedures reported by the country representatives were probably the most variable of the nurturing care intervention. In this area, it is perhaps not surprising that the vulnerable newborns in the higher-income countries had a more significant advantage. Newborns in the United States and Sweden were able to provide a greater range of early child development services by highly specialized professionals for a longer period (i.e. up to five years for the extremely premature in Sweden). The middle-income countries were also recognizing the importance of early screening and follow-up care and implementing programs to ensure that at-risk newborns did not fall through the cracks of the system. Regardless of the income of the setting, however, engaging parents in this ongoing care proved to be challenging, especially for more marginalized populations.

## Gap Analysis

As discussed previously, the literature reviewed for this report was limited in scope, concerning itself with primarily grey literature reviews of specific nurturing care practices and contexts. Based on this review of the evidence and implementation experience, future exploration would benefit from looking at the areas briefly discussed below.

### *Follow-up Systems*

In the current literature, little is known about post-discharge care, particularly in low- and middle-income contexts. Follow-up care may be under-resourced (e.g. due to a lack of specialized staffing) or underutilized due to several family barriers (e.g. transportation, needing to work, or lack of money). One evident barrier is the lack of community engagement around nurturing services that support small and sick newborns as well as their mothers post-discharge. Another identified challenge is a lack of information and communication for parents regarding follow-up. More could be uncovered about what parents think about follow-up care and where there needs to be more education.

For countries that do offer comprehensive follow-up programs, there is a dearth of data around families who return and those who are lost to follow-up. Additionally, the reasons for drop out of follow-up care are not well-monitored or studied, which may mean that vulnerable families may fall through the cracks of the system.

### *Implementation Science*

While implementation research about various nurturing care interventions exist, too often, the research focuses on high-income countries. More experimentation will need to be undertaken in middle- and low-income countries to see how these practices can be adapted to different contexts. As these countries generate their own evidence, they will be better positioned to advocate for the policy changes and investments they need.

### *Dosage of Interventions*

Even when an intervention is studied in multiple contexts, it may be difficult to compare due to a lack of consistent practices or dosage level. The dosage and timing of interventions vary tremendously, not to mention the types of outcomes that are measured and the timing of the follow-up measurements. This can make it difficult for researchers to understand what interventions work and when they are likely to be most efficacious.

### *Enabling Policies and Environment*

Currently, there are no systematic reporting measures that look at enabling policies and environmental factors and their effects on a newborns' development. More could be discovered about factors that enable nurturing care (e.g. generous parental leave policies) and inhibit it (e.g. a lack of community engagement) beyond anecdotal evidence.

### *Family Engagement*

While family-centered care is rapidly gaining acceptance throughout much of the world, what specific interventions and practices define it are less understood. Additionally, more needs to be learned about how to support healthcare workers by promoting positive behaviors and

countering staff resistance. While there has been much discussion about this in a high-income context, there is less in low-and middle-income countries. Similarly, more needs to be understood about how to motivate and enable parents to spend significant time with their fragile newborns in the hospital.

With the invention of the M-NICU, more facilities are collaborating across disciplines to treat mothers and newborns as a pair. More information is needed about how to best treat the dyad in tandem. For example, there is currently little evidence about how treating a mother's health and mental wellbeing can help prepare her to engage in care in the hospital and home environments. How can perinatal collaboration facilitate nurturing care? Additionally, there is a need for standardized indicators to test and validate so that researchers measure and monitor this new type of care.

### *Skin-to-Skin/KMC*

While skin-to-skin is a well-researched intervention, little is known about the other components of KMC, particularly around early discharge and follow-up. Additionally, while the implementation science of KMC has been studied extensively, the ideal next steps to build momentum remains unclear.

### *Long-Term Outcomes*

There is currently limited data on longer-term follow-up and measuring results. Most studies report outcomes to the 12-month period. To justify more investments in nurturing care in the future, more needs to be understood about how nurturing care practices in the newborn period can affect early childhood development up to school age.



## Annex I: Annotated bibliography for peer-reviewed literature

Skin-to-skin/Kangaroo Care			
Focus of the review	Nurturing care component/s	Source	Annotation
Kangaroo Mother Care compared to conventional care	Component 1: Good health and 3: responsive caregiving	Conde-Agudelo A, Díaz-Rossello J. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. <i>Cochrane Database Syst Rev</i> [Internet]. 2016 Aug 23;(8). Available from: <a href="http://dx.doi.org/10.1002/14651858.CD002771.pub4">http://dx.doi.org/10.1002/14651858.CD002771.pub4</a> (11)	This Cochrane systematic review was last updated in 2016 when three new studies were found, however the conclusions remained unchanged. The review question was whether KMC reduces morbidity and mortality in low birth weight infants in comparison to conventional care once infants are stabilized. In this review there were 21 studies included, involving 3,042 infants of which 16 studies were conducted in low-or middle-income countries. Of the four components to KMC, all of the studies included skin-to-skin and encouraged breastfeeding. Mean or median duration of skin-to-skin varied from less than 2 hours (six studies) to equal to or greater than 20 hours (3 studies). Only one study conducted in 1997 reported on early discharge, while an additional eight studies reported on criteria for discharge. Plans for follow-up of infants was reported in 13 studies with the most common plan being weekly until 40 weeks' postmenstrual age and then monthly until three to six months of age or corrected age. Two studies reported follow-up to 12 months of age/corrected age. At the time of discharge around 40 – 41 weeks postmenstrual age, KMC was associated with a significant reduction in the risk of mortality and morbidities such as infection/sepsis and hypothermia. Similar results were reported at latest follow-up. Additionally, KMC was associated with increased overall growth. Timing of onset of KMC did not appear to influence morbidity and mortality outcomes, but early-onset was associated with reduction in length of hospital stay. While the quality of the evidence was low, no statistical differences were found for psychomotor development at 12 months corrected age.
Assessment of how studies define and report the 4 components of kangaroo mother care	Component 1: Good health and 3: responsive caregiving	Chan GJ, Valsangkar B, Kajeepeeta S, Boundy EO, Wall S. What is kangaroo mother care? Systematic review of the literature. <i>J Glob Health</i> . 2016 Jun;6(1):1–9.	This systematic review is the second paper reporting outcomes of KMC studies (see Boundy et al, 2016). This paper describes the definitions of KMC and the presence of absence of KMC components. Ten databases, with no language restrictions were searched with a date range of 1960 and 2014. A search was also undertaken for program reports and program implementation data. Of 1035 studies screened, 299 met the inclusion criteria and included in the review, and of these 71% (n=211) provided a definition of KMC. Of the included studies 45% were conducted between 2010-2014, 48% involved less than 50 participants, 28% were randomized controlled trials, the majority conducted in the Americas (38%), followed by Europe (21%) and then Africa (15%). The majority of participants were late preterm (19%) or very preterm (17%), however 35% of studies did not report gestational age. The individual components of KMC varied, with 50% including skin-to-skin only. For the additional components 16% included skin-to-skin and breastfeeding (exclusive or near exclusive), 12% skin-to-skin and follow-up post-discharge and 7% included early discharge. The authors report that skin-to-skin time and criteria were not well described.

Skin-to-skin component of kangaroo mother care and a neonatal outcome	Component 1: Good health and 3: responsive caregiving	Boundy EO, Dastjerdi R, Spiegelman D, Fawzi WW, Missmer SA, Lieberman E, et al. Kangaroo Mother Care and Neonatal Outcomes: A Meta-analysis. <i>Pediatrics</i> . 2016 Jan 1;137(1):e20152238. (9)	This systematic review and meta-analysis included a summary of observational studies and randomized controlled trials published in any language up until April 2014. An extensive list of databases was searched as was grey literature. Quality assessment was undertaken for all studies. Studies of KMC included in this review included studies with the component of skin-to-skin and any neonatal outcome. Studies without a comparison group were excluded. Studies were not limited by birth weight or gestational age. Of 1,035 studies screened, 124 were included, most of which were published post-2000. Most studies were conducted in healthcare facilities in middle- or high-income countries. KMC compared to conventional care in low birth weight newborns demonstrated lower mortality, decreased risk of sepsis, hypothermia, hypoglycemia and hospital readmission; and increased exclusive breastfeeding. Biophysiological parameters were also improved.
Skin-to-skin on growth and breastfeeding rates	Component 2: adequate nutrition and 3: responsive caregiving	Sharma, D., Farahbakhsh, N., Sharma, S., Sharma, P., & Sharma, A. (2019). Role of kangaroo mother care in growth and breastfeeding rates in very low birth weight (VLBW) neonates: a systematic review. <i>Journal of Maternal-Fetal and Neonatal Medicine</i> , 32(1), 129–142. <a href="https://doi.org/10.1080/14767058.2017.1304535">https://doi.org/10.1080/14767058.2017.1304535</a> (15)	This recent systematic review looked at growth and breastfeeding outcomes for newborns of very low birth weight, who received skin-to-skin for a period of time each day compared to conventional care (usually incubator and no encouragement of skin-to-skin). Duration of skin-to-skin varied from ‘as much as possible’ to minimum of 3 hours per day. Thirteen studies were included in this review which included randomized controlled trials, other study designs such as retrospective chart reviews, involving newborns with birth weight less than 1,500 grams, high risk preterm infants and low birth weight infants of less than 2000g. All the studies were conducted in high – or middle-income countries. Data specific to very low birth weight infants analyzed separately. Significantly better growth and breastfeeding rates were seen in the skin-to-skin groups.
Barriers and enablers of skin-to-skin/kangaroo care	Component 3: responsive caregiving	Smith ER, Bergelson I, Constantian S, Valsangkar B, Chan GJ. Barriers and enablers of health system adoption of kangaroo mother care: a systematic review of caregiver perspectives. <i>BMC Pediatr</i> . 2017 Jan 25;17(1):35(16)	This focus of this systematic review was barriers and enablers of KMC and skin-to-skin from the family perspective, based on the experience of caregivers and health providers, drawing on qualitative research. Of the 98 studies eligible for inclusion 33% were conducted in the America’s, 27% in Africa, 16% in Europe and the remainder in multiple regions. Four themes were identified: ‘buy in and bonding’ (lack of awareness), ‘social support’ (needing assistance from others), ‘sufficient time to do KC’ and ‘medical concerns about mother and/or infant.’ Additional barriers included adherence to traditional newborn practices, stigma around preterm birth and gender roles. Financing (lack of money for families to visit hospital post maternal discharge) and service delivery (lack of resources, privacy, space) were also barriers.
Barriers and enablers of skin-to-skin/kangaroo care	Component 3: responsive caregiving	Seidman G, Unnikrishnan S, Kenny E, Myslinski S, Cairns-Smith S, Mulligan B, et al. (2015). (n.d.). Barriers and Enablers of Kangaroo Mother Care Practice: A Systematic Review. <i>PLoS ONE</i> , 10(5), 10(5): e0125643.	This systematic review was undertaken to identify experiences and barriers to implementation of skin-to-skin. A total of 103 eligible papers were reviewed and the frequency in which individual barriers and enablers were mentioned across studies was counted. Barriers were grouped into three different categories: resourcing, experiential and sociocultural. The studies were conducted either in high, middle or low-income countries. Four of the top five barriers were resource-related, and low awareness of skin-to-skin was in the top five barriers for all countries, but was the top barrier identified in low-and middle-

		<a href="https://doi.org/10.1371/journal.pone.0125643">https://doi.org/10.1371/journal.pone.0125643</a> . (17)	income countries. The top five enablers were ranked similarly for high, middle- or low-income country settings and included 'mother-infant attachment,' 'feelings of confidence/empowerment' and 'ease of practice/preference over traditional care,' 'support from family, friends and other mother.'
Paternal involvement in skin-to-skin	Component 3: Responsive caregiving	Shorey, S., He Hong-Gu, & Morelius, E. (2016). Skin-to-skin contact by fathers and the impact on infant and paternal outcomes: an integrative review. <i>Midwifery</i> , 40, 207–217. <a href="https://doi.org/10.1016/j.midw.2016.07.007">https://doi.org/10.1016/j.midw.2016.07.007</a> (14)	This review searched for studies across four databases in which the intervention was skin-to-skin by fathers and outcomes were reported for newborns and/or fathers. Both quantitative and qualitative research designs were eligible, and the results included 10 quantitative and two qualitative studies, of which 10 were undertaken in high-income countries and two in middle-income countries of India and Colombia. A number of the studies involved mother-father-infant triads, with only father and infant outcomes reported in this review. This review included studies involving both preterm and term infants and in the description of studies table KMC and skin-to-skin appear to be used interchangeably, with timing of and length of time not always indicated or described in the original study. Of the 12 studies, nine involved preterm infants, which report early and/or later outcomes up to 18 months corrected age. The findings included: father's feeling in control, greater involvement in their infant's care, had higher sensitivity scores, exhibited more caring behaviors, decreased experiences of spouse relationship problems, decreased anxiety levels, engaged more vocally, particularly with male infants.
Parental experiences of skin-to-skin (qualitative)	Component 3: Responsive caregiving	Anderzen-Carlsson, A., Carvalho Lamy, Z., & Eriksson, M. (2014). Parental experiences of providing skin-to-skin care to their newborn infant - Part 1: A qualitative systematic review. <i>International Journal of Qualitative Studies on Health &amp; Well-Being</i> , 9, 1–22. <a href="https://doi.org/10.3402/qhw.v9.24906">https://doi.org/10.3402/qhw.v9.24906</a> (12) and Anderzen-Carlsson, A., Lamy, Z. C., Tingvall, M., & Eriksson, M. (2014). Parental experiences of providing skin-to-skin care to their newborn infant - Part 2: A qualitative meta-synthesis. <i>International Journal of Qualitative Studies on Health &amp; Well-Being</i> , 9, 1–20. <a href="https://doi.org/10.3402/qhw.v9.24907">https://doi.org/10.3402/qhw.v9.24907</a> (13)	These two papers from the same author group describe the experiences of mothers and fathers in engaging in skin-to-skin with their preterm, low-birth weight or term newborn/s. A total of 29 qualitative studies were included and the authors extracted data relating to parental experiences and themes developed. All but one of the nine studies were conducted in high- or middle-income countries. Part 2 sought to synthesize and interpret the qualitative research findings on parental experiences. The authors report that skin-to-skin can be both 'restorative' as well as 'energy-draining.' A supportive environment is an enabler, while obstacles in the environment act as a barrier and skin-to-skin becomes 'energy draining.' The majority of the studies were with parents of preterm or low birth weight newborns.

Nutrition			
Focus of the review	Nurturing care component/s	Source	Annotation
Early breastfeeding exposure	Component 2: Adequate nutrition	Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., & Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal of Neonatal Nursing</i> , 25(1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane systematic review on this subject has not been updated since 2006, around five core measures: ‘protected sleep,’ ‘assessment and management of pain,’ ‘developmentally supportive activities of daily living,’ ‘family-centered care’ and the ‘healing environment.’ Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – ‘optimized infant-driven feeding.’
Educational interventions	Component 2: Adequate nutrition and 3: Responsive caregiving	Arikpo D, Edet ES, Chibuzor MT, Odey F, Caldwell DM. Educational interventions for improving primary caregiver complementary feeding practices for children aged 24 months and under. <i>Cochrane Database of Systematic Reviews</i> 2018, Issue 5. Art. No.: CD011768. DOI: 10.1002/14651858.CD011768.pub2. (22)	This Cochrane systematic review published in 2018, sought to assess the effectiveness of education interventions for improving weaning feeding practices and how this related to health and growth outcomes in infants. Poor complementary feeding practices can contribute to malnutrition, poor growth and poor neurodevelopment in infants and children. This review included only randomized controlled trials involving caregivers of infants aged 4-24 months. Of the 23 studies included in the review, 19 were community-based and the majority (n=13) were cluster-randomized trials. Educational interventions included messages about introducing semi-solid foods at appropriate age stages and distributed via leaflet, counselling, teaching sessions and practical demonstrations. In the community-based studies, education improved the duration of exclusive breastfeeding. Overall there was improvement in hygiene practices and the introduction of foods before 6-months of age was reduced by 12%. There is limited evidence for improved growth outcomes. The studies were conducted across high-, middle and low-income countries. The studies were not specifically focused on post small and sick newborns.
Implementation environments and type of interventions.	Component 2: Adequate nutrition	Benedict RK, Craig HC, Torlesse H, Stoltzfus RJ. Effectiveness of programmes and interventions to support optimal breastfeeding among children 0–23 months, South Asia: A scoping review. <i>Maternal and Child Nutrition</i> [Internet]. 2018;14. Available	This scoping review sought to summarize evidence from peer-reviewed and program evaluation literature on intervention to improve breastfeeding rates in five South Asian countries. For studies and program evaluations to be included, the interventions/evaluations must have been undertaken in one of the five countries: Afghanistan, Bangladesh, India, Nepal or Pakistan and published in English. Of the 31 studies included the majority were from India (n=14), then Bangladesh (n=11), followed by Pakistan (n=4) and Nepal (n=2). No eligible studies were undertaken in Afghanistan. Studies and evaluations were explored by implementation environment and the type of intervention (education, counselling, media). While results of individual education and counselling by health workers at home improves breastfeeding rates and duration, further benefits were gained with community mobilization. More community-level interventions are needed

		<p>from:  <a href="https://www.scopus.com/inward/record.uri?eid=2-s2.0-85057528888&amp;doi=10.1111%2fmcn.12697&amp;partnerID=40&amp;md5=50b2fc7f4154cbfb6ab0121abd24896a">https://www.scopus.com/inward/record.uri?eid=2-s2.0-85057528888&amp;doi=10.1111%2fmcn.12697&amp;partnerID=40&amp;md5=50b2fc7f4154cbfb6ab0121abd24896a</a> (18)</p>	<p>to maximize benefits to breastfeeding rates and duration. Skin-to-skin and KMC during inpatient stay provides opportunities to impact on early initiation of breastfeeding. The authors report that for those studies or programs which did not report an impact on breastfeeding practices there was inadequate or irregular frequency and/or duration of support from health workers. The key message was that a multi-prong approach is needed for improving breastfeeding practices which include: education, counseling, community mobilization, mass media campaigns, delivered across multiple environments such as health, community, and home/family. Did not report on the population of newborns within the studies (e.g., age and weight of newborns).</p>
<p>Community-based supplementary feeding</p>	<p>Component 2: Adequate nutrition; 3: Responsive caregiving and 5: Security and safety</p>	<p>Visser J, McLachlan MH, Maayan N, Garner P. Community-based supplementary feeding for food insecure, vulnerable and malnourished populations – an overview of systematic reviews. Cochrane Database of Systematic Reviews 2018, Issue 11. Art. No.: CD010578. DOI: 10.1002/14651858.CD010578.pub2. (19)</p>	<p>This Cochrane overview of systematic reviews was last updated in 2018, with the search undertaken in 2017, evaluated community-based supplementary feeding in vulnerable, malnourished populations. This overview includes seven Cochrane systematic reviews, across populations, three of which were focused on infants and young children from birth to five years, disadvantaged infants and children from three months to five years and children with moderate acute malnutrition. The authors conclude that given the current evidence base, the effects of supplementary food are modest and limited mortality evidence. Additionally, longer term outcomes including quality of life and cost effectiveness are not systematically reported. However, the shorter-term outcomes include that energy and protein supplements to pregnant women may reduce the risk of small-for-gestational age infants. In children under five years of age, supplementary feeding did not have an impact on growth, but a small impact was seen for children under two years of age. The authors suggest that the critical aspects related to outcomes include the social environment at home, sanitation and access to clean water.</p>
<p>Guiding principles and steps for breastfeeding for neonatal wards</p>	<p>Component 2: Adequate nutrition</p>	<p>Nyqvist K, Maastrup R, Hansen M, Haggkvist A, Hannula L, Ezeonodo A, et al. Neo - BFHI. The Baby-Friendly Hospital Initiative for Neonatal Wards. Core document with recommended standards and criteria. Nordic and Quebec Working Group; 2015. (21)</p>	<p>This document is an extension of the WHO/UNICEF Baby-Friendly Hospital Initiative (BFHI) to neonatal wards, writing by an international group of health professionals. This document is directed at initiation and maintenance of breastmilk production for those infants born small (preterm) and sick, who are unable to breastfeed. This ensures that they are still able to receive breastmilk and when can breastfeed, mothers' milk supply will be established. The three guiding principles are around staff attitudes, the health facility environment and the health care system. The 10 steps to successful breastfeeding include: having a policy; education and training of staff; educating mothers on expression, maintenance and importance of breastmilk supply; encouraging skin-to-skin; show mothers of small and sick newborns how to express and establish early breastfeeding as soon as stability allows; exclusive breastmilk feeds only; keep mothers and newborns together 24 hours a day; encourage demand breastfeeding; use alternatives to bottle feeding; prepare parents for continued breastfeeding after hospital discharge. While the standards and criteria outlined within this document may be more likely achievable in their entirety in high-income countries, many are achievable in low- and middle-income countries. For example, addressing staff attitudes, having a breastfeeding policy, open visiting policy, facilitating skin-to-skin and KMC by providing information to parents/families.</p>

Sensory Environment			
Focus of the review	Nurturing care component/s	Source	Annotation
Sensory experiences on infant development and parental outcomes: tactile, auditory, visual, kinesthetic, gustatory/olfactory, multimodal.	Component 3: Responsive caregiving	Pineda R, Guth R, Herring A, Reynolds L, Oberle S, Smith J. Enhancing sensory experiences for very preterm infants in the NICU: an integrative review. <i>J Perinatol.</i> 2017 Apr;37(4):323–32. (23)	This integrative review was undertaken on sensory-based interventions to improve outcomes for preterm infants and their parents. Studies were limited to sensory-based interventions delivered to preterm infants ≤ 32 weeks in a neonatal unit and did not focus on reduction of external stimuli, pain or NIDCAP interventions. A total of 88 articles describing tactile, auditory, visual, kinesthetic, gustatory/olfactory, or multimodal interventions were included in this review. Tactile sensory interventions included gentle human touch, massage, and kangaroo care. While benefits are seen, outcomes related to physiological and developmental outcomes are mixed, with some studies demonstrating benefit and others no benefit. No differences were seen in infant social interaction, memory, developmental outcomes at 1-year, or IQ at 5 and 10 years. Auditory interventions included music/singing recorded or live. Neurobehavior and developmental outcomes at 3 and 6 months were reported as better in those infants who had been exposed to maternal voice. Visual interventions were limited to cycled lighting, with no studies investigating the effects using objects or people. No differences were seen in neurobehavior with cycled lighting. Kinesthetic involved physical therapy and no studies assessed neurodevelopmental outcomes. Gustatory and olfactory interventions involved the use of breast milk/mother's scent and no studies reported on infant development or maternal mental health outcomes. Multimodal interventions included a combination of auditory, tactile, vestibular, and visual. Results are mixed with some studies reporting improved infant and maternal outcomes and others showing on difference. Due to the heterogeneity of interventions it is difficult to combine studies to determine appropriate sensory exposures. The evidence is limited on long-term outcomes from sensory interventions.
Gentle touch, eye-contact, verbal communication during interactions	Component 3: Responsive caregiving	King, C., & Norton, D. (2017). Does therapeutic positioning of preterm infants impact upon optimal health outcomes? A literature review. <i>Journal of Neonatal Nursing</i> , 23(5), 218–222. <a href="https://doi.org/10.1016/j.jnn.2017.03.004">https://doi.org/10.1016/j.jnn.2017.03.004</a> (30)	This literature review examined published literature from 2009 – 2015, including reviews, guidelines, and legislation regarding neonatal care of premature infants. The studies included in this review were undertaken in high – to middle-income countries and were either randomized controlled trials or cohort studies. The authors of this review identified three themes emerging from the studies regarding the effect of therapeutic positioning on neurodevelopment and stress response, sleep state and physiological stability. Several studies have shown that providing gentle touch and containment aid infants to self-regulate, whilst rapid or rough/inappropriate handling causes stress and distress to the infant. Thus, there is a positive correlation between therapeutic handling and decreased stress behaviors in preterm infants.

<p>Multiple developmental care interventions including holding/touch (massage) - inpatient and post-discharge outcomes</p>	<p>Component 3: Responsive caregiving and 4: Opportunities for early learning</p>	<p>Burke, S. (2018). Systematic review of developmental care interventions in the neonatal intensive care unit since 2006. <i>Journal of Child Health Care</i>, 22(2), 269–286. <a href="https://doi.org/10.1177/1367493517753085">https://doi.org/10.1177/1367493517753085</a> (27)</p>	<p>This systematic review was undertaken by a single author and includes studies published between 2008 – 2016 in which developmental care was the intervention and neurodevelopment were an outcome of interest. Interventions were initiated when preterm infants were inpatients and outcomes measured over time up to 9 years of age. Many of the studies were conducted in high income countries with one conducted in the middle-income country of Lebanon. Most participants were less than 32 weeks gestation, low or very low birth weight and one study of small for gestational age preterm infants. Interventions were multiple and diverse (10 from 19 studies), so the author used the coding system by Benzies et al (2013) to organize the interventions into parent support, parent education and therapeutic child support. NIDCAP was the most commonly studied intervention and three studies assessed the Family Nurture Intervention (FNI). The effects were mixed, but positive effects were observed for language, motor and cognitive development up to 18 months and IQ up to 5 years. Behavioral observation results were most significant up to 12 months of age but were nonsignificant at two and three years of age. Kangaroo care and massage as interventions resulted in significant findings. The author concluding that infant holding, and touch are key components for successful interventions. There was no clear developmental care program which performed significantly better than another in this review.</p>
<p>Early developmental intervention programs</p>	<p>Component 3: Responsive caregiving and 4: opportunities for early learning</p>	<p>Spittle, A., Orton, J., Anderson, P., Boyd, R., &amp; Doyle, L. (2015). Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. <i>Cochrane Database of Systematic Reviews</i>, (11). <a href="https://doi.org/10.1002/14651858.CD005495.pub4">https://doi.org/10.1002/14651858.CD005495.pub4</a> (33)</p>	<p>This Cochrane Systematic Review, last updated in 2015, includes a total of 25 trials involving preterm infants who received post-discharge early developmental interventions and followed-up from infancy (0-3 years) through until adulthood. The intervention program was commenced within 12 months of birth and had to have a post-discharge component. Most of the trials, had published a number of times as they followed participants up over time, reporting cognitive and motor outcomes. Most studies included participants less than 37 weeks or birth weight less than 2,500 grams and 12 of the 25 trials were randomized controlled trials, the remainder quasi or cluster randomized trials. The review has not reported on country of origin for the trials. Meta-analysis showed improved cognitive outcomes at infancy and preschool age (0-3 years) but not sustained at school age. Motor outcomes showed significant effect at infancy only for the early developmental intervention group, although the effect was small.</p>
<p>Light and noise</p>	<p>Component 3: Responsive caregiving</p>	<p>Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., &amp; Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal</i></p>	<p>This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane Systematic review on this subject has not been updated since 2006, around five core measures: ‘protected sleep,’ ‘assessment and management of pain,’ ‘developmentally supportive activities of daily living,’ ‘family-centered care’ and the ‘healing environment.’ Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – ‘optimized infant-driven feeding.’ Study countries were not reported in the review. After the review by Morag and Ohlsson (2016 - see below), two randomized controlled trials published in 2017, suggest that neither cycled lighting or near dark lighting has an influence on increasing physiological stability or</p>

		<i>of Neonatal Nursing</i> , 25(1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	decreasing motor activity level, nor does cycled lighting impact on length of hospital stay or neurodevelopment following discharge. Since the update of the Cochrane systematic review in 2015 (Almadhoob & Ohlsson - see below), several studies have been published. A randomized cross-over trial showed that preterm infants wearing earmuffs spent more time in quiet sleep state and were physiologically more stable (Khalesi et al, 2017)
Light	Component 3: Responsive caregiving	Morag, I., & Ohlsson, A. (2016). Cycled light in the intensive care unit for preterm and low birth weight infants. <i>Cochrane Database of Systematic Reviews</i> , (8) <a href="https://doi.org/10.1002/14651858.CD006982.pub4">https://doi.org/10.1002/14651858.CD006982.pub4</a> (25)	This Cochrane systematic review undertaken by Morag and Ohlsson, use the standard search strategy of the Cochrane Neonatal Review Group, at look at the effectiveness and safety of cycled lighting for preterm infants born before 32 weeks, at 32 weeks and from 36 weeks and small for gestational age compared to continuous bright light, near darkness or irregularly dimmed light. Updated in 2016, an additional study was eligible which strengthened the findings that cycled lighting shortens length of hospital stay compared to continuous bright light. For all outcomes the quality of the evidence was low, mainly due to lack of blinding and small sample size. Growth at 3- and 6-months corrected age was intended to be reported upon, but no studies have reported at these time points, although 1 study reported no difference in weight at 4 months between cycled light and near darkness. All studies were conducted in high- or middle-income countries.
Noise	Component 3: Responsive caregiving	Almadhoob A, & Ohlsson A. (2015). Sound reduction management in the neonatal intensive care unit for preterm or very low birth weight infants. <i>Cochrane Database of Systematic Reviews</i> , (1), <a href="https://doi.org/10.1002/14651858.CD010333.pub2">https://doi.org/10.1002/14651858.CD010333.pub2</a> (26)	This Cochrane systematic review was undertaken to look at the effects of sound on growth and long-term neurodevelopmental outcomes of preterm newborns less than 32 weeks gestation or less than 1,500 grams birth weight. Only one study of high quality, conducted in the US in 2002-3, enrolled 34 newborns to have earplugs or no earplugs. There was a trend for better weight gain at 34 weeks gestation, however at 18-22 months corrected age there was a significant difference in mental developmental index favoring the earplug group, but this was not seen for psychomotor development index.
Touch (effect of oils and massage)	Component 1: Good health	Cleminson, J., & Mcguire, W. (2016). Topical emollient for preventing infection in preterm infants. <i>Cochrane Database of Systematic Reviews</i> , 2016(1). <a href="https://doi.org/10.1002/14651858.CD001150.pub3">https://doi.org/10.1002/14651858.CD001150.pub3</a> (28)	This Cochrane Systematic Review, updated in 2016, includes analysis of randomized or quasi-randomized trials by low and middle income and high-income countries. The main objective was to assess the effect of emollients in reducing infection, other morbidity and mortality in preterm infants. However, outcomes for growth are reported in addition to the above (see skin intervention). In the 11 trials that plant or vegetable oils were used, infants massaged with vegetable oil had a higher rate of weight gain (2.55 g/kg/day), linear growth and head growth than infants that received routine skin care.



Touch (Massage)	Component 3: Responsive caregiving	Kurdahi Badr, L., Abdallah, B., & Kahale, L. (2015). A Meta-Analysis of PRETERM INFANT MASSAGE: An Ancient Practice With Contemporary Applications. <i>MCN: The American Journal of Maternal Child Nursing</i> , 40(6), 344–358. <a href="https://doi.org/10.1097/NMC.000000000000177">https://doi.org/10.1097/NMC.000000000000177</a> (29)	This team of academics and researchers from the US and Lebanon searched for studies published from 2000 – 2014, pertaining to medically stable preterm and low birth weight inpatient newborns and massage. No studies prior to 2000 were included due to an earlier Cochrane systematic review (Vickers et al, 2004). Seven electronic databases were searched and the PRISMA guidelines used to guide the search. Of the 34 eligible studies, 30 were randomized controlled trials, 1 a pilot study and 3 quasi-experimental, conducted in high – or middle-income countries. Five meta-analyses were able to be performed but only a modest daily weight gain of 0.53g/day favored the massage group as did mental development (7.89 points) but not motor development. Weight at discharge, length of stay, caloric intake crossed the line of no effect.
Maternal interaction	Component 3: Responsive caregiving and 4: opportunities for early learning	Korja, R., Latva, R., & Lehtonen, L. (2012). The effects of preterm birth on mother-infant interaction and attachment during the infant’s first two years. <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 91(2), 164–173. <a href="https://doi.org/10.1111/j.1600-0412.2011.01304.x">https://doi.org/10.1111/j.1600-0412.2011.01304.x</a> (32)	The systematic review was undertaken by authors who work in Departments of Child Psychiatry and/or Pediatrics within hospitals and universities in Turkey and Finland. Electronic searches were undertaken of 3 electronic databases (unknown dates) pertaining to preterm or low birth weight newborns and maternal interaction. Studies eligible for inclusion had a comparison full-term control group. Infant attachment was studied between 10-18 months post corrected age. A total of 29 studies were included and three areas systematically reviewed: maternal attachment representations, mother-infant interaction and infant attachment. Differences in maternal-infant behavior and preterm infant’s interaction behavior exist more so in the first six months of life. But mothers and their preterm infants are not at higher risk of insecure attachment than full-term infant – mother dyads. Study country not reported. Only included studies that used an Internationally known structured methods to evaluate maternal attachment representation. No qualitative studies included.
Delivery of live or recorded music	Component 3: Responsive caregiving and 4: opportunities for early learning	Palazzi, A., Nunes, C. C., & Piccinini, C. A. (2018). Music therapy and musical stimulation in the context of prematurity: A narrative literature review from 2010-2015. <i>Journal of Clinical Nursing</i> , 27(1–2), e1–e20.	The authors looked at music therapy (MT) and music stimulation (MS) as interventions carried out by music therapists (as part of MT) and other care providers including parents (as part of MS). Outcomes included physiological stability, behavioral states (e.g., sleep, distress, interaction, motor activity), pain scores, length of hospital stay, long term effects on feeding skills, language and overall development at 5 to 75 months corrected age. Of the 30 included studies, all were conducted in high- or middle-income countries. Outcomes were reported for the infant and/or the mother. Overall MT and MS were reported to have a tendency for positive results. Of the 25 studies which reported on physiological and behavioral measures around a quarter showed positive effects on physiological parameters and sleep states. Two studies reported long- term outcomes which showed decreased readmission over the first-year post-discharge, improved overall development at 5 months. Positive outcomes for mothers included reduced anxiety and stress, improved breastmilk supply and increased

<https://doi.org/10.1111/jocn.13893> (31)

responsiveness and sensitivity. Wide variety in the type of music (lullabies, classical, raga), duration of intervention, how the music was delivered (via headphones or no headphones).

Reducing Stress and Pain			
Focus of the review	Nurturing care component/s	Source	Annotation
Pain management	Component 3: Responsive caregiving	Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., & Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal of Neonatal Nursing</i> , 25(1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane Systematic review on this subject has not been updated since 2006, around five core measures: ‘protected sleep,’ ‘assessment and management of pain,’ ‘developmentally supportive activities of daily living,’ ‘family-centered care’ and the ‘healing environment.’ Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – ‘optimized infant-driven feeding.’ Study countries were not reported in the review.
Skin-to-skin	Component 1: Good health and 3: Responsive caregiving	Johnston, C., Campbell-Yeo, M., Disher, T., Benoit, B., Fernandes, A., Streiner, D., Zee, R. (2017). Skin-to-skin care for procedural pain in neonates. <i>Cochrane Database of Systematic Reviews</i> , (2). <a href="https://doi.org/10.1002/14651858.CD008435.pub3">https://doi.org/10.1002/14651858.CD008435.pub3</a> (34)	This is the second update of this Cochrane systematic review by the same team of nursing academic's and clinicians based mostly in Canada. The primary intent of this review was to determine the effect of skin-to-skin for inpatient painful procedures, conducted by health professionals, and whether the duration or who provided skin-to-skin reduced pain. A further six studies were included in this update, which now includes data from a total of 25 studies, of which 18 involve preterm newborns. All of the studies were conducted in high- or middle-income countries, most involved heel lance or intramuscular injections and most compared skin-to-skin with no skin-to-skin. Overall behavioral indicators and composite pain scores were reduced, more so when the mother provided skin-to-skin. However, pain was reduced when fathers and non-maternally related women provided skin-to-skin compared to no skin-to-skin. For preterm infants, outcomes favored skin-to-skin care over sweet taste (glucose).
24 non-pharmacological interventions (excluding skin-to-skin and music)	Component 1: Good health and 3: Responsive caregiving	Pillai Riddell, R., Racine, N., Gennis, H., Turcotte, K., Uman, L., Horton, R., Lisi, D. (2015). Non-pharmacological management of infant and young child procedural pain.	This Cochrane systematic review, whilst published in 2015, was declared stable in July 2017, as no new studies were found, and the conclusions remain unchanged. The review team are based at Canadian Universities and Hospitals. All studies were undertaken in high- or middle-income countries and the population of interest were newborns, and children from birth to three years of age. The review looked at 24 non-pharmacological management interventions other than Kangaroo Care and music and results were analyzed for preterm and term newborns and infants from one month to three years. On the available evidence from 29 studies involving inpatient preterm newborns, interventions effective in reducing pain immediately after a procedure include:

		<p><i>Cochrane Database of Systematic Reviews</i>, (12). <a href="https://doi.org/10.1002/14651858.CD006275.pub3">https://doi.org/10.1002/14651858.CD006275.pub3</a> (37)</p>	<p>touch/massage, non-nutritive sucking, environmental modification, swaddling/facilitated tucking. A combination of sucking with sucrose and facilitated tucking with non-nutritive sucking was effective for needle pain.</p>
Sucrose	Component 1: Good health and 3: Responsive caregiving	<p>Stevens, B., Yamada, J., Ohlsson, A., Haliburton, S., &amp; Shorkey, A. (2016). Sucrose for analgesia in newborn infants undergoing painful procedures. <i>Cochrane Database of Systematic Reviews</i>, (7). <a href="https://doi.org/10.1002/14651858.CD001069.pub5">https://doi.org/10.1002/14651858.CD001069.pub5</a> (35)</p>	<p>In 2016 this Cochrane systematic review update included an additional 20 randomized controlled trials bringing the total to 74, enrolling 7,049 newborns undergoing a minor painful procedure. The included studies have been conducted in 22 countries; 21 high – or middle income and one low-income (Nepal). In this review comparisons were undertaken for different concentrations of sucrose and control interventions for both term and preterm infants and for neurodevelopmental outcomes. For preterm infants there is high quality evidence for the beneficial effect of 24% sucrose with non-nutritive sucking (pacifier dipped in sucrose) or 0.5 ml of sucrose given orally prior to heel lance, and 2 mls prior to venipuncture and intramuscular injections. Sucrose is not effective in reducing circumcision pain. No serious side-effects have been reported.</p>

Supportive Positioning			
Focus of the review	Nurturing care component/s	Source	Annotation
<b>To prevent overstretching of muscles and ligaments, promote flexion and physiological stability and sleep</b>	Component 3: Responsive caregiving	Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., & Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal of Neonatal Nursing</i> , 25(1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane Systematic review on this subject has not been updated since 2006, around five core measures: ‘protected sleep,’ ‘assessment and management of pain,’ ‘developmentally supportive activities of daily living,’ ‘family-centered care’ and the ‘healing environment.’ Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – ‘optimized infant-driven feeding.’ Study country not reported.
<b>Positioning to enhance neurodevelopment, sleep state and physiological stability</b>	Component 3: Responsive caregiving	King, C., & Norton, D. (2017). Does therapeutic positioning of preterm infants impact upon optimal health outcomes? A literature review. <i>Journal of Neonatal Nursing</i> , 23(5), 218–222. <a href="https://doi.org/10.1016/j.jnn.2017.03.004">https://doi.org/10.1016/j.jnn.2017.03.004</a> (30)	This literature review examined published literature from 2009 – 2015, including reviews, guidelines and legislation regarding neonatal care of premature infants. The studies included in this review were undertaken in high – to middle-income countries and were either randomized controlled trials or cohort studies. The authors of this review identified three themes emerging from the studies regarding the effect of therapeutic positioning on neurodevelopment and stress response, sleep state and physiological stability. Several studies have shown that postural support during care giving activities like changing a diaper, reduces stress and provides physiological stability. A number of studies have explored prone versus supine positioning on sleep states and stress behaviors. These studies have found that preterm infants placed in a prone position are better able to self-regulate their behavior, are less stressed, have improved quality sleep states. The evidence for prone versus supine sleeping to support physiological stability is mixed. Prone positioning for respiratory stability in self-breathing preterm infants does not appear to confer benefit but does so for ventilated preterm infants. Prone positioning can occur under conditions in which infants can be safely monitored but infants should be sleeping supine when not monitored and in preparation for discharge to reduce the risk of sudden infant death syndrome.

Protecting and Promoting Sleep			
Focus of the review	Nurturing care component/s	Source	Annotation
<b>Clustering of care to protect sleep</b>	Component 3: Responsive caregiving	Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., & Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal of Neonatal Nursing</i> , 25(1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane systematic review on this subject has not been updated since 2006, around five core measures: ‘protected sleep,’ ‘assessment and management of pain,’ ‘developmentally supportive activities of daily living,’ ‘family-centered care’ and the ‘healing environment.’ Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – ‘optimized infant-driven feeding.’
<b>Non-pharmacological interventions to promote sleep</b>	Component 3: Responsive caregiving	Liao, J.-H., Hu, R.-F., Su, L.-J., Wang, S., Xu, Q., Qian, X.-F., & He, H.-G. (2018). Nonpharmacological Interventions for Sleep Promotion on Preterm Infants in Neonatal Intensive Care Unit: A Systematic Review. <i>Worldviews on Evidence-Based Nursing</i> , 15(5), 386–393. <a href="https://doi.org/10.1111/wvn.12315">https://doi.org/10.1111/wvn.12315</a> (38)	This review team searched seven databases for randomized trials which reported on nonpharmacological interventions to promote sleep in inpatient preterm infants. Total sleep time (TST), active sleep (AS) and quiet sleep (QS) were across reported. Nonpharmacological interventions included cobedding, newborn individualized developmental care and assessment program (NIDCAP), remolding mattresses, cycled lighting, music, touch, non-nutritive sucking, rocking, oral sucrose, and family nurturing. The authors state the measurements for sleep were diverse, with subjective and objective assessments which resulted in not being able to pool results for each intervention. Outcomes for pooled studies: cobedding and NIDCAP were not effective in promoting sleep; remolding mattresses promoted total sleep time and active sleep but not quiet sleep; cycled lighting promoted greater total sleep time. Outcomes for interventions in which studies could not be pooled: music intervention and touch were mixed, some studies reported promotion of sleep, others did not; non-nutritive sucking, and prone sleep position conferred increased sleep time, rocking and/or sucrose increased quiet sleep. Family nurturing study reported on interaction and development of the infants’ nervous system but not sleep results per se.

Protecting Skin			
Focus of the review	Nurturing care component/s	Source	Annotation
Risk factors for skin injuries	Component 1: Good health	August DL, New K, Ray RA, Kandasamy Y. Frequency, location and risk factors of neonatal skin injuries from mechanical forces of pressure, friction, shear and stripping: A systematic literature review. <i>Journal of Neonatal Nursing</i> . 2018;24(4):173–80. (39)	This systematic review undertaken by a team of neonatal health professionals looked at frequency, location and risk factors for neonatal skin injuries. Both term and preterm skin is thin, fragile and easily injured, providing entry for infection. Additionally, the more premature the infant, the greater the water and heat loss through the skin. Neonatal skin injuries may occur from pressure or friction related to the use of medical devices and stripping from the removal of adhesives such as tape to securing devices. After screening, 21 studies were included in the review and reported frequency of injuries between 9-43%. Included studies were conducted in high-and middle-income countries, involving predominantly late preterm newborns. Assessment of potential risk-factors for a neonate can inform prevention and management.
Emollient therapy for reducing invasive infection and mortality	Component 1: Good health	Cleminson, J., & Mcguire, W. (2016). Topical emollient for preventing infection in preterm infants. <i>Cochrane Database of Systematic Reviews</i> , 2016(1). <a href="https://doi.org/10.1002/14651858.CD001150.pub3">https://doi.org/10.1002/14651858.CD001150.pub3</a> (28)	This Cochrane systematic review, updated in 2016, includes analysis of randomized or quasi-randomized trials by low and middle income and high-income countries, for the effect of emollients in reducing infection, other morbidity and mortality in preterm infants. The eight trials conducted in high-income countries using topical ointments or creams, involved mostly very preterm infants did not show a difference in the incidence of invasive infection or mortality. Nine trials undertaken in low- or middle-income countries based in inpatient settings did not show evidence of a difference in the incidence of invasive infection or mortality.
Emollient therapy	Component 1: Good health	Salam, R. A., Das, J. K., Darmstadt, G. L., & Bhutta, Z. A. (2013). Emollient therapy for preterm newborn infants - Evidence from the developing world. <i>BMC Public Health</i> , 13(SUPPL.3). <a href="https://doi.org/10.1186/1471-2458-13-S3-S31">https://doi.org/10.1186/1471-2458-13-S3-S31</a> (41)	This systematic review searched to identify published and unpublished clinical trials, up to December 2012, describing the effectiveness of emollient therapy in inpatient preterm newborns. Emollients used in the included studies were sunflower, coconut, soybean or mineral oil. All studies (seven published and one unpublished) were conducted in middle-income countries and enrolled preterm less than 37 weeks gestation. Gestation age determination was reported in four studies and in the remaining three studies, weight (as less than 2,000 grams) was reported with or without gestation age reported as 37 weeks or less. The most commonly used oil in the studies (5 out of 7) was Sunflower Oil 3-4 times a day (10-12 mls/kg/day). The results indicated that topical emollient therapy reduced neonatal mortality and hospital acquired infections (based on three studies) and was associated with an increase in weight and daily weight gain (based on four studies). The authors report using hospital acquired infection as a proxy for neonatal mortality and suggest that emollient therapy can reduce neonatal infection related mortality.

Partnering with parents/families			
Focus of the review	Nurturing care component/s	Source	Annotation
Family-centered Care, Policy development and decision-making	Component 3: Responsive caregiving	Segers, E., Ockhuijsen, H., Baarendse, P., van Eerden, I., & van den Hoogen, A. (2019). 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. <i>Intensive and Critical Care Nursing, 50</i> , 63–70. <a href="https://doi.org/10.1016/j.iccn.2018.08.008">https://doi.org/10.1016/j.iccn.2018.08.008</a> (42)	This systematic review undertaken by a team of clinicians, academics and researchers from the Netherlands, looked at the impact of family-centered care (FCC) interventions on parents' satisfaction and length of stay who infants were admitted to neonatal or pediatric units. Four databases were searched up until October 2017 and papers written in Dutch, English, French and German were reviewed and included if eligible and multiple study designs were included. Of the 17 included studies, 13 were conducted in neonatal units. Details regarding the age and/or weight of newborns included in the neonatal populations were not given, nor were the country settings, apart from one study which was conducted in Pakistan (pediatric patients). From all the studies, the FCC interventions were grouped into one of two groups: interventions that improve parental participation and involved the newborn individualized care and assessment program (all neonatal studies) and the other included parents being involved in policy development, cot side rounds and decision-making. The studies involving parents of infants in neonatal units provided strong evidence that collaboration with parents and increased involvement in care reduces length of stay.
Involvement of parents/families in care, communication, collaborative partnerships	Component 3: Responsive caregiving	Lavallée, A., De Clifford-Faugère, G., Garcia, C., Fernandez Oviedo, A. N., Héon, M., & Aita, M. (2019). Part 1: Narrative overview of developmental care interventions for the preterm newborn. <i>Journal of Neonatal Nursing, 25</i> (1), 3–8. <a href="https://doi.org/10.1016/j.jnn.2018.08.008">https://doi.org/10.1016/j.jnn.2018.08.008</a> (20)	This narrative overview undertaken by a Canadian academic and research team, looked at the evidence of effectiveness of developmental care interventions on short and long-term outcomes and neurodevelopment in preterm infants. This review was seeking the latest evidence, since the Cochrane Systematic review on this subject has not been updated since 2006, around five core measures: 'protected sleep,' 'assessment and management of pain,' 'developmentally supportive activities of daily living,' 'family-centered care' and the 'healing environment.' Five electronic databases were searched, and a narrative synthesis of findings presented, adding a sixth core measure – 'optimized infant-driven feeding.' Study country not reported. Thorough literature search methods used but not systematic methods.
Parent engagement as a component of Family-centered Care	Component 3: Responsive caregiving	Yu, X., & Zhang, J. (2018). Family-centred care for hospitalized preterm infants: A systematic review and meta-analysis. <i>International Journal of Nursing Practice, e12705</i> . <a href="https://doi.org/10.1111/ijn.12705">https://doi.org/10.1111/ijn.12705</a> (43)	This recently published systematic review assessed the effects of family-centered care (FCC), versus standard neonatal care, on hospitalized preterm infants less than 37 weeks gestation on the outcomes of hospital length of stay, morbidity, feeding, growth, and neurobehavioral performance. A total of four randomized controlled trials undertaken in high- or middle-income countries were included in this review. A scoring system for family centeredness was used to determine inclusion of studies. Studies which did not score a moderate degree (26/50) of family centeredness were excluded. One study was published in 2006 and the remaining three between 2010-2017. While the intervention components for each of the four studies were different, all had a key parent engagement/involvement component. Despite differences in the overall components, those receiving FCC had a shortened length of stay in both the NICU and total hospital stay of nearly 5 days. Overall, FCC did not influence infant morbidities. Only one



			<p>study reported on feeding and growth, which showed infants in the FCC group achieved full enteral feeding earlier and had a greater daily weight gain between 36-40 weeks. But this weight difference was not sustained by term age. Only one study assessed neurobehavioral performance at 40 weeks, which showed infants in the FCC group had better tone and motor patterns and total neurobehavioral performance. Longer-term benefits were not studied.</p>
<p>Experiences and needs of parents of preterm and sick newborns</p>	<p>Component 3: Responsive caregiving</p>	<p>Ballantyne M, Orava T, Bernardo S, McPherson AC, Church P, Fehlings D. Parents' early healthcare transition experiences with preterm and acutely ill infants: a scoping review. Child Care Health Dev. 2017 Nov;43(6):783–96. (44)</p>	<p>This scoping review conducted in Canada synthesized evidence on the experiences and needs of parents of preterm and sick newborns following birth. These experiences and needs focused on transition within and between hospitals/care facilities. A total of 90 studies and 11 articles were included in the synthesis, which represented 435 parents. The key themes identified were parent distress, parenting at a distance, sources of stress and sources of support. Lack of communication, being informed and involved in the decision-making were major sources of stress. While supports included regular engagement with health professionals; being informed on future transition/plans for transfer of infant; family, and friends.</p>

Follow-up			
Focus of the review	Nurturing care component/s	Source	Annotation
Follow-up in newborn hearing screening	Component 1: Good health and 4: Opportunities for early learning	Ravi R, Gunjawate DR, Yerraguntla K, Lewis LE, Driscoll C, Rajashekhar B. Follow-up in newborn hearing screening – A systematic review. <i>Int J Pediatr Otorhinolaryngol.</i> 2016 Nov 1;90:29–36. (47)	This systematic review undertaken by a team of academics from India and Australia to look at loss to follow-up rates for newborn hearing screening, reasons and strategies to reduce loss to follow-up (LTF) rates. A systematic search of seven databases, with a date range of 2005- 2015, in English language for studies examining loss-to follow-up for hearing screening was undertaken. A total of 53 studies were included in this review, conducted in low- (n=2), low-middle (n=8), upper-middle- (n=18) and high-income (n=25) countries. Study designs varied: prospective, retrospective, observational, cohort and surveys. The percentage of LTF was similar for single center and multi-center studies (median of 20% and 22% respectively). Factors contributing to successful follow-up included: multidisciplinary dedicated teams; well-educated and knowledgeable professionals on risks and early intervention services, with good communication skills; systematic training programs; stringent tracking system, and parent/family awareness and education. Factors contributing to LTF included: lack or inadequate parent/family knowledge of the need/importance, distance and work constraints. Just under half of the studies 22/53 discussed measures to increase follow-up. The most commonly reported strategy was having an adequate data management system. Only four studies discussed increasing parental education.
Follow-up component as reported in studies of kangaroo mother care	Component 1: Good health and 4: Opportunities for early learning	Chan GJ, Valsangkar B, Kajeepeta S, Boundy EO, Wall S. What is kangaroo mother care? Systematic review of the literature. <i>Journal of Global Health.</i> 2016 Jun;6(1):1–9. (10)	This systematic review describes the definitions of KMC and reports on the four components as described in studies on KMC. Ten databases, with no language restrictions were searched with a date range of 1960 and 2014. A search was also undertaken for program reports and program implementation data. Of 1,035 studies screened, 299 met the inclusion criteria and included in the review. Just 20% (n=61) of the included studies described post-discharge follow-up in facilities, at home or a combination of in facilities and homes. The majority of individual studies included in the review reported follow-up to 12 months, with very few following up post this period; and follow-up compliance was rarely reported.
Early developmental programmes post-hospital discharge	Component 4: Opportunities for early learning	Spittle A, Orton J, Anderson P, Boyd R, Doyle L. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. <i>Cochrane Database Syst Rev.</i> 2015(11). (33)	This Cochrane systematic review last updated in 2015 examined post-discharge early developmental intervention programs for preterm infants at risk in comparison to standard medical follow-up. This review reported outcomes at four time points, but only 0 to less than 3-year time point is included in this annotation. Of the 25 included studies, 16 contained data for the 0 to less than 3-year time point. There is evidence that early intervention programs have a significant impact on cognitive outcomes and a small effect on motor outcomes up to 3-years. This effect was not seen by school age (3-5 years). Those interventions that had a greater effect focused on the parent-infant relationship and infant development.

Home visiting	Component 1: Good health and 4: Opportunities for early learning	Goyal NK, Teeters A, Ammerman RT. Home visiting and outcomes of preterm infants: A systematic review. Pediatrics. 2013;132(3):502– 16. (46)	This systematic review examined home based, preventive services for preterm and/or low birth weight infants at medical or social risk. The search was conducted up to November 2012, single home visit interventions were excluded as were studies involving children with chronic conditions. A total of 17 studies, involving 2,983 infants were included in this review. From the studies the authors of the review report outcomes under five general domains: infant development, morbidity and health care utilization, abuse and neglect, parent-infant interaction and growth and development. The program interventions varied by provider (nurse or infant development specialist), frequency and duration of visits and additional interventions. The evidence on outcomes was limited and some studies reporting positive results and others showing no difference. The authors concluded that home visiting promotes improved parent-infant interaction but additional studies are needed for impact and cost benefit.
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Laws and Policies – tabled for each case study country in Appendix II

## Annex II: Annotated bibliography for grey literature

### Colombia

Document year & type	Document title and Source	Annotation	Comment
2013 Report	Early Childhood Development (ECD). SABER Country Report. Produced by The World Bank.	<p>This report was prepared by the World Bank using the SABER-ECD framework which collects, analyses and disseminates comprehensive information on ECD policies. The analysis includes early learning, nutrition, health, social and child protection policies and interventions for children 0-5 years old. The report highlights three core policy goals which include establishing an enabling environment, implementing widely and monitoring and assuring quality. The document sets out policies and interventions across sectors including healthcare, nutrition, early learning, social protection and child protection. The following are policies/guidelines/documents that guide the sectors in Colombia:</p> <ul style="list-style-type: none"> <li>• Healthcare: Constitution</li> <li>• Nutrition: 10 Year breastfeeding plan 2010-2020</li> <li>• Early learning: Zero to Forever strategy</li> <li>• Social protection: Law No 1532</li> <li>• Child protection: Decrees/Laws.</li> </ul>	This document provides details on current and future actions around early learning and the associated documents (mostly in Spanish – e.g., Ruta Integral). The document also contains examples from other countries including Sweden and what lessons can be applied to Colombia.

### India

Document year & type	Document title and Source	Annotation	Comment
2018/19 Report	Annual report 2017-18. Chapter 4 – Child Health Program.  Government of India.	The annual report produced by the Department of Health and Family Welfare, covers many areas within health. Chapter 4 reports on Child Health aspects from neonatal to under 5. Regarding newborn health, the report details the newborn mortality rate, strategic interventions outlined in the India Newborn Action Plan (see separate overview), and interventions related to nutrition; pneumonia and diarrhea; defects, diseases, delays and deficiencies, and immunization. For this review nutrition strategies include promotion of exclusive breastfeeding to 6 months. To address developmental delays, strategies include, expanding the reach of mobile health teams to improve child health screening and early intervention services for children and establishment of district early intervention centers.	The introduction of the chapter highlights the strategy/policy or mission which relates to the goals for child health.
2018 Training white paper	Induction training program for nurses.	The document outlines the importance of training and upskilling of nursing staff. The training program is broad, inclusive of adult, pediatric, maternity and newborn care. It is directed at newly recruited nurses.	Not specifically focused on care of the small and sick newborn

	Government of India.	The training includes an introduction to hospital/institutional guidelines and protocols. There is a training component on the importance of breastfeeding, kangaroo mothers and human milk banking.	
2018 Operational guidelines	Home based care for young child. Strengthening of health and nutrition through home visits. Operational guidelines. Government of India	This document presents data on the nutrition state of play within India currently and the changes over time. The document discusses the importance of home care visits in the promotion of nutrition, nurturing care and early childhood development. The home care program is being extended into the second year of life. The guideline outlines the tasks and interventions to be promoted during home visits. Furthermore, the document articulates actions required National, State and district levels. Nine child health and nutrition indicators will be monitored and evaluated, which include feeding, vaccines, growth monitoring but no neurodevelopmental delay indicators.	Pertains to all newborns with no additional care or follow-up for those born small and sick.
2017 Operational guidelines	Family participatory care for improving newborn health. Operational guidelines for planning and implementation. Government of India.	This document outlines the context of small and sick newborns in India and the need for post-discharge follow-up care. The document defines Family participatory care (FPC) “is based on the understanding that the family is the child’s primary source of strength and support and their participation in the care of child admitted to hospital is important in decision making and long-term care” (p2). The purpose of the document is for all stakeholders involved in the process of planning and delivering newborn care. The document outlines involvement of state and district managers (policy makers and resource allocators), training for healthcare providers (including addressing attitudes), creating FPC environments, and information and education for parents to be involved in FPC. Three facility-based indicators are outlined (implementation of FPC, training sessions held and number of families participating).	Small and sick newborns should be scheduled to receive a home visit within 24 hours and then routine follow-up as for all newborns/infants to 12 months of age.
2017 Policy	National Health Policy. Government of India.	The policy highlights the National Health Programme for Child and Adolescent Health which endorses improved home-based and facility-based management of sick newborns.	The document refers to sick newborn once. No reference to small, preterm, kangaroo care, developmental care, nurturing care.
2016 Report	Care of Small and sick newborns in special newborn care units (SNCUs) of India. Two-year report April 2013 –	This report outlines the establishment of Special Newborn Care Units to provide care for sick newborns. Data presented in this report was collated from individual units at a State level and then submitted for this national report. The report provides comprehensive details on National admission and mortality profiles of newborns. Prematurity was the main cause for mortality and 75% of newborns who died were of low birth weight. Individual State profiles are then presented. National and state-based key findings and actions for way forward are presented. Way forward points (related to care of small and sick newborns) include	No data presented on aspects of Family-centered developmentally supportive care.

	<p>March 2015. Gov of India</p>	<ul style="list-style-type: none"> <li>• States need to establish SNCUs in districts (especially high priority districts) that do not have such units and make alternative arrangements for care of small and sick newborns till operationalization of such units.</li> <li>• Adequacy of nursing personnel is essential for providing quality newborn care at the SNCUs. Efforts should be made to strengthen this through recruitment and retention.</li> <li>• Outborn admissions had higher incidence of sepsis and adverse outcomes compared to inborn admissions. About 20% of the outborns were referred from the community. It is important to strengthen community level interventions for early identification of sick newborns and their timely referral to SNCUs.</li> <li>• There is an emerging need to implement package of interventions at the health facility for management of preterm newborns. This includes use of antenatal corticosteroids during preterm labor, managing preterm delivery, timely support for respiratory distress using CPAP if needed, provision of KMC, and appropriate follow-up.</li> </ul>	
<p>2014 Action Plan</p>	<p>India Newborn Action Plan. Government of India.</p>	<p>This action plan was developed in response to the Global Every Newborn Action Plan, with targeted strategies to address newborn deaths and stillbirths. The document has six interventions packages of which three are immediate newborn care, care of small and sick newborns and care beyond newborn survival. For each package, interventions and priority actions are indicated. The priority actions relevant to this review for inpatient care includes: Implementing standardized clinical protocols for essential newborn care, dissemination of guidelines at all levels of facilities, monitor training quality and scale up operational guidelines. Specific interventions include KMC. For post-discharge care priority actions included screening for developmental delays, mobile health teams, establish early intervention centers, facility-based follow-up of small and sick newborns, 12-month follow-up in the community for all sick/high-risk newborns discharged from a neonatal care unit.</p>	<p>A bottleneck assessment and actions are included in the document. This includes lack of synchronization of information in various guidelines, lack of staff training and mentoring, lack of equipment and supplies, limited guideline dissemination, poor awareness of community services.</p>
<p>2014 Operational Guidelines</p>	<p>Kangaroo Mother Care and optimal feeding of low birth weight infants. For programme managers and service providers. Government of India.</p>	<p>This document defined KMC as two components (skin-to-skin contact and exclusive breastfeeding) and that KMC is for stable low-birth weight (LBW) infants. Whereas skin-to-skin is for all newborns immediately after delivery. The purpose of the guideline is to present the evidence around KMC and feeding of LBW infants and how to operationalize. The document discusses feeding, including amount of feeds, supplementation, feeding progression and weight gain. The action plan for implementation and scale-up includes involving the respective professional bodies of neonatologists, neonatal nurses and obstetrician-gynecologists; colleges and teaching institutes across National, State, and District levels.</p>	<p>A detailed document providing guidance on how to undertake and implement KMC and feeding practices.</p>

## Nepal

Document year & type	Document title and Source	Annotation	Comment
March 2018 Report	Evaluation of the National Early Childhood Development Program. Final Report. Oxford Policy Management and UNICEF.	This document reports on Nepal's National Early Childhood Development (ECD) Program 2004-2015 with the focus on five sectors – education, health, nutrition, WASH, and protection. The report aimed to identify potential ways of enhancing coordination between ministries, demonstrate linkages between early childhood education and other interventions of ECD and identify gaps between policy and implementation. Presents data around newborns regarding immunizations, postnatal follow-up/check; for all newborns and not specifically for small and sick newborns.	Identifies that programs have been implemented for sick newborn care management. This document mentions that the National Newborn Care Package is currently being revised.
February 2018 Action Plan	Country Programme Action Plan 2018-2022. The Government of Nepal and UNICEF	<p>This document articulates co-operation between the Government of Nepal and UNICEF to continue to address children's rights and disparities in levels of achievements and access to resources. Programme priorities include improved and equitable access to high-quality child-friendly services, improved care practices, protective and safe environments and better policies and resource allocation for children. The country program has six components and are guided by country policies, plans and acts.</p> <ul style="list-style-type: none"> <li>• Health: guided by National Health Policy 2014 and Nepal Health Sector Strategy 2016-2021</li> <li>• Nutrition: Multi-sector Nutrition Plan II (MSNP 2018-2022)</li> <li>• Education: School sector development plan (2016-2022)</li> <li>• WASH: WASH sector development plan (2016-2030)</li> <li>• Child protection: Children's Act</li> <li>• Safety and Security: Fourteenth Three-Year National Plan (2016-2019) and National Framework on Social Protection (in draft)</li> </ul> <p>The document articulates further the support UNICEF will offer regarding early childhood development and disability.</p>	Discusses newborns and actions. These include intensive care units for newborns, referral systems for newborns, early detection of developmental delays among high-risk newborns.
2018 Strategy document	Nepal – WHO Country Cooperation Strategy (CCS) 2018-2022. WHO Nepal and the Government of Nepal	This document is informed by the National Health Policy 2014 and the Nepal Health Sector Strategy 2015 – 2020. The four strategic priorities include advancing universal health coverage, effective delivery of priority public health programs, health security and engagements for improved health outcomes. Focus areas for newborns include implementing newborn and birth defects surveillance, development of a capacity-building package for facility-based integrated management of neonatal and childhood illnesses and development of guidelines, protocols and training package for ECD.	Newly developed strategy and therefore a work in progress.

2017 Clinical Standards for care of preterm infants at the hospital level	Profile of preterm and low birth weight prevention care. Produced by Every Premie Scale	This fact sheet presents an overview of preterm birth and at low birth weight worldwide and the statistics for Nepal on the number of babies born too soon and under 5 mortality rate. The fact sheet reports that delivery facilities with space designated for KMC is 91%, there is formal education in neonatal care, there is a policy for kangaroo care, and a national clinical standard for kangaroo mother care.	Unable to locate either the policy or national clinical standard via the internet.
June 2016 Protocol	National Neonatal Clinical Protocol. Government of Nepal.	This document addresses assessment and treatment of sick and at-risk newborns with emphasis on physiological management such as temperature, airway and breathing on presenting newborns to a health facility. The document addresses feeding, sepsis, management of seizures.	This document does not discuss interventions/components for nurturing care.
April 2016 Report	Promoting KMC in selected hospitals of Nepal through the training and provision of a baby wrap. Jhpiego Nepal.	The preamble of the document highlights that while KMC guidelines are included in current training packages, KMC is not widely practiced or promoted. The report presents an overview and results of a study undertaken in Nepal at the request of the Government – to test a KMC wrap – prior to incorporating it into the National KMC policy. Result was that the provision of a wrap enhanced KMC practice at facility and community level.	This project developed a competency-based training package
2016 Action Plan	Nepal's Every Newborn Action Plan. Produced by Ministry of Health, Government of Nepal.	This document sets out targets and milestones for improving newborn health and prevent stillbirth by 2035. The document sets out care around birth and care of the sick and small newborns – identifying kangaroo mother care as a component. Key outputs and actions for care of the sick and small newborn involves: <ul style="list-style-type: none"> <li>• Developing and enforcing national guidelines, standards and clinical protocols – KMC and inpatient care</li> <li>• Developing training packages</li> <li>• Expand use of chlorhexidine cord care</li> </ul>	Have not located National documents.
2016 Implementation plan	Nepal Health Sector Strategy implementation plan 2016-2021. Government of Nepal.	This document outlines how the Nepal Health Sector Strategy (see below) will be translated into action. The 9 goals mentioned in earlier document will be measured through 29 outcome level indicators. Indicators relevant to this review include % of children under 5 years who are stunted, and disability adjusted life years lost due to neonatal non-communicable and injuries. For the delivery of quality health services and quality assurance systems – development of guidelines/protocols are needed. The Child Health Division responsible for children under 5 years old will be responsible for developing program components around immunization, integrated management of childhood illness (includes newborn care, management of sick neonates, malnutrition, detection and management of disability among children) and national nutrition program.	Outputs and key interventions include establishing neonatal care services, KMC units in all hospitals over a 3-year period.



## Philippines

Document year & type	Document title and Source	Annotation	Comment
2018 Review	The Philippines health system review. Produced by World Health Organization, regional office for South-East Asia.	This review is an all health system review and not just maternal and newborn health areas. These areas are mentioned in this document (e.g., the diploma of midwifery program covers care of the newborn) but no reference to small and sick newborn, premature or nursery. Indicates that neonatal mortality rate reduction target is not likely to be met.	Not specific for small and sick newborns
July 2018 Law	First 1000 days law. Philippines Government.	First 1,000 days bill signed into law in the Philippines. The State has committed funds to scaling up nutrition intervention programs and address malnutrition of infants and young children 0-2 years old in a whole of Government approach. Objectives of this act also include creating a policy environment conducive to nutrition improvement, integrate responsive caregiving and early stimulation in a safe and protective environment. Review and incorporate scale up of nutrition into the following documents: The National Plan on Nutrition, the Early Childhood Care and Development Intervention packages, the Philippine Development Plan, the National Plan of Action for Children, the regional development plans and local government units' investment plans for health and nutrition. The bill outlines in general objectives for program implementation and components. <a href="https://www.officialgazette.gov.ph/downloads/2018/11nov/20181129-RA-11148-RRD.pdf">https://www.officialgazette.gov.ph/downloads/2018/11nov/20181129-RA-11148-RRD.pdf</a>	The bill is less than 12 months old. Have not been able to locate supporting documents that operationalize the objectives of this bill.
2018 Strategy document	National Objectives for Health 2017-2022. Department of Health, Philippines.	The document is a general overview of the health system and governing structures. A summary of selected maternal and newborn health outcomes are presented. The three strategic goals are better health outcomes, more responsive health system and more equitable healthcare financing. Indicators include reducing low birth weight infants.	No specific actions regarding small and sick newborns, nurturing care, early childhood development.
November 2018. Administrative order.	Strategic Framework for the implementation of the expanded newborn screening program 2017-2030. Department of Health.	The aims of the National Comprehensive Newborn Screening System is to ensure that babies are born healthy and that each child reaches his/her full potential with the right opportunities and accessible resources. The administrative order sets the aims for the framework and policy direction and guidance for parties involved in the implementation of this program. The order has set targets to be achieved by 2030.	Outlines strategies for achieving the aims. Pertinent to all newborns.

2014 Action plan	Early Essential Newborn Care Action Plan in 2014	Every Newborn 'Spotlight on the Philippines' mentions that the Philippines developed an 'Early Essential Newborn Care Action Plan 2014.' However unable to be located on the internet. In addition, WHO Western Pacific office launched First Embrace in Manila, in 2015. Also, in 2014 an 'Action plan for healthy newborn infants in the Western Pacific Region (2014-2020)' was launched. This document specifically focusses on addressing preterm and low birth weight neonates, but actions are for all 'member states' and not country specific.	The document is specific for actions required, but these are not operationalized by individual member states.
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## Rwanda

Document year & type	Document title and Source	Annotation	Comment
2018 Report	Transforming the lives of children in Rwanda: investing in family and community-centred services. United Nations Children's Fund (UNICEF), Kigali, Rwanda	This document in the endline evaluation summary report of the ECD and Family Programme, 2015-2017. This report builds on the earlier baseline report - see Early Childhood Development and Family Services baseline evaluation summary below). Multiple interventions were implemented in 10 centers, which included a communications strategy, training of religious leaders and community members, production and distribution of children's books, training for ECD caregivers, as well as a mentoring and supervision program and home-based ECD services were implemented. The overall findings were a positive impact, particularly at a community level.	
2015 Report	Early childhood development and family services. Baseline evaluation in 20 sites in Rwanda. United Nations Children's Fund (UNICEF), Kigali, Rwanda	In operationalizing the early childhood development policy, the first early childhood development and family center was opened in 2013, with an additional nine centers opening in 2014. This report was the baseline assessment of the impact of the center's and the programs including the health and well-being of young children and families. The data presented in the report is specific for two age groups, 0-11 months and 24-35 months, in specific sites. The assessment focused on many aspects under broader areas of: core family care practices and the physical environment. For assessment of child development, the tools, <i>The Ages and Stages questionnaire version 3 (ASQ-3)</i> and <i>the Ages and Stages Social-Emotional Questionnaire (ASQ:SE)</i> were used as these tools have previously been used in low-resource settings. Overall conclusions and recommendations: home environments are an important factor in ECD, lack of education of primary caregivers, food availability and malnutrition are issues that need addressing to improve ECD.	
2012 Guideline	Neonatology clinical treatment guidelines. Ministry of Health, Republic of Rwanda	The document outlines guidelines and policies for newborn care in Rwanda, including care of the preterm and low-birth weight infant. In relation to the interventions within this review – this document discusses pain management, discharge, and follow-up. Follow-up criteria clearly articulated and covers small and sick infants, and those with congenital anomalies. Recommended follow-up occurs within 2 weeks. The section on prematurity and	

		low birth weight indicates that all infants less than 2 kilograms be followed-up within a week post-discharge. This section outlines kangaroo care for LBW infants.	
2012 Report	Evaluation of Kangaroo Mother Care services in Rwanda. Produced by a collaboration of partners from Rwanda and South Africa.	The document mentions a National KMC guideline, but this was not locatable via the internet and from the Ministry of Health website. This document evaluated 7 district hospitals who had implemented KMC. Each of the components of KMC were evaluated and each hospital was scored based on stages of implementation. The scoring was out of a total of 30 points. The average score was 18, indicating that there was evidence of integration of KMC into routine practice. The report highlights barriers to KMC which included: no posters or information about KMC, no education around KMC in antenatal classes, no records of actual practice (data based on perceptions of staff), no written evidence of plans for training of staff in KMC.	
2011 Protocol	Neonatal protocols. Ministry of Health. Republic of Rwanda.	This document was produced to provide national standardization of neonatal care in Rwanda. This document contains many sections now contained in the 2012 guidelines document and would appear to be superseded by the guideline document.	
2011 White Paper	Early childhood development policy. Ministry of Education, Republic of Rwanda.	The document acknowledges the need for nurturing and support of children from parents/guardians and caregivers. This policy provides a framework in which to address the development of young children in a holistic and integrated approach. The document outlines a continuum of development including pregnancy until birth, birth to 3-years and onwards up until 8-years. The document outlines regional and international contexts for ECD, frameworks for ECD, goals, policies to support ECD along with specific objectives and actions.	A comprehensive document which outlines anticipated approaches to help meet the objectives and targets of Vision 2020.

## Sweden

Document year & type	Document title and Source	Annotation	Comment
2018 Standards	European Standards for newborn care. Available at <a href="https://newborn-health-standards.org/">https://newborn-health-standards.org/</a>	The European Standards for newborn care project was initiated and coordinated by the European Foundation for Care of Newborn Infants. The standards are defined into 11 broad areas in which a topic expert groups developed the standards for individual topic areas. The topic expert groups consisted of healthcare professionals, parent representatives and industry specialists. The focus of the standards was preterm and ill newborn care and treatment as in-patients and post-discharge. The evidence-based standards provide a rationale, outline the benefits to care and treatment and recommend components/indicators required to meet the standard.	

2015 Guideline	The baby-friendly hospital initiative for neonatal wards (Neo-BFHI). Core document with recommended standards and criteria. Nyqvist K, Maastrup R, Hansen M, Haggkvist A, Hannula L, Ezeonodo A, et al. Neo - BFHI.	This document is an extension of the WHO/UNICEF Baby-Friendly Hospital Initiative (BFHI) to neonatal wards, writing by an international group of health professionals. This document is directed at initiation and maintenance of breastmilk production for those infants born small (preterm) and sick, who are unable to breastfeed. This ensures that they are still able to receive breastmilk and when can breastfeed, mothers' milk supply will be established. The three guiding principles are around staff attitudes, the health facility environment and the health care system. The 10 steps to successful breastfeeding include: having a policy; education and training of staff; educating mothers on expression, maintenance and importance of breastmilk supply; encouraging skin-to-skin; show mothers of small and sick newborns how to express and establish early breastfeeding as soon as stability allows; exclusive breastmilk feeds only; keep mothers and newborns together 24hours a day; encourage demand breastfeeding; use alternatives to bottle feeding; prepare parents for continued breastfeeding after hospital discharge. While the standards and criteria outlined within this document may be more likely achievable in their entirety in high-income countries, many are achievable in low- and middle-income countries. For example, addressing staff attitudes, having a breastfeeding policy, open visiting policy, facilitating skin-to-skin and KMC by providing information to parents/families.	
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## United States of America

Document year & type	Document title and Source	Annotation	Comment
2018 Guideline	Neonatal Skin Care. Evidenced-based clinical practice guideline. 4 <sup>th</sup> Edition. Produced by the Association of Women's health, obstetric and neonatal nurses (AWHONN).	The guideline was developed by member experts from AWHONN, the National Association of Neonatal Nurses, and International Neonatal Nurses. The guideline provides recommendations for neonatal skin care based on the best available evidence for neonates of all gestational ages, for inpatient, community and post-discharge settings and in low and high resource settings. The guideline covers 13 topic areas including parent education.	
2018 Policy statement	Screening examination of premature infants for retinopathy of prematurity (ROP). American Academy of Pediatrics	This statement provides recommendations for screening of infants in the United States: birth weight of equal to or less than 1,500 grams, gestational age of 30 weeks or less. At risk-infants up to 2,000 grams and older than 30 weeks should also be screened for ROP. The standard provides recommendations for the timing of examinations, treatment and follow-up.	
2017 Guideline	Guidelines for perinatal care. American Academy of	This 8 <sup>th</sup> Edition of the guidelines was published in 2017 and are produced in a book format. The guidelines provide recommendations from pre-pregnancy care, to the care of high-risk infants	

	Pediatrics and the American College of Obstetricians and Gynecologists	including hospital discharge and follow-up care. The associations note that the recommendations provide a framework to guide individual institutions in developing a local guideline. Guidance for follow-up care for high-risk newborns includes monitoring of growth, development, nutrition requirements; early detection of delayed developmental progress and early intervention, parent education, and referral to community resources.	
2016 Policy statement	Prevention and management of procedural pain in the Neonate: an update. American Academy of Pediatrics	This policy statement provides an overview of pain assessment tools for neonates, including their use in the preterm population, and outline those tools which have been validated. The statement summarizes nonpharmacological and pharmacological treatment strategies, and topical anesthetic agents. Recommendations include: institutions should have a written evidence-based guideline for pain assessment and management, a pain assessment tool should be used routinely, implementation of nonpharmacological strategies for all painful procedures and ongoing training of healthcare professionals.	
2015 Clinical report	Skin-to-skin care for term and preterm infants in the neonatal ICU. American Academy of Pediatrics	This clinical report is directed towards resource-rich countries in which skin-to-skin is offered for shorter periods of time and to less stable, technology-supported neonates. The benefits and risks are outlined and implications for clinical practice include: encouraging both parents to provide skin-to-skin care, need for unit specific guidelines and protocols and infant safety is maintained with correct positioning and monitoring.	
2013 Guideline	Multidisciplinary guidelines for the care of late preterm infants. A collaborative project facilitated by the National Perinatal Association.	The guideline was developed for this sub-group population of preterm infants following a review of available existing guidelines as there was an identified need for a multidisciplinary, consensus and evidence-based set of guidelines to increase uniformity. The guideline consists of four sections including in-patient and post-discharge care and follow-up. Within each section recommendations are made for the healthcare care and education of families.	Evidence-based and consensus statements to aide in the development of a local policies taking into consideration individual state-based requirements.

## Annex III: For Further Reading

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